Facing the Waitlist: Visual Grammars of Organ Donation and Transplantation

Dissertation

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By

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Abstract

*Facing the Waitlist: Visual Grammars of Organ Donation and Transplantation* situates and explores how models of organ procurement and allocation (MOPAs) function within the U.S.—from the official, State-sanctioned United Network for Organ Sharing, to websites like MatchingDonors.com, to social networking sites—and how their functioning produces effects on individuals. In particular, *Facing the Waitlist* interrogates how MOPAs manage patient and donor identity information in accordance with specific logics, or structural rules, that seem to inform potential donors’ willingness to donate and transplant patients’ medical outcomes. This project also suggests that the management of identity information might be altered to increase positive health outcomes for those suffering organ failure. Ultimately, *Facing the Waitlist* makes contributions of two types. The first is methodological: it develops a methodology for examining MOPAs informed by affect, biopolitics, and cultural studies methodologies. The project’s second contribution is more material: it suggests a new model of organ procurement and allocation.
Dedication

For Gerald Rubenstein (1944 – 2007)
I miss you. Every day.
Acknowledgments

I spent half of my time writing this dissertation quietly hidden away in the “half of a windowless closet” that was my graduate reading carrel, on the most basement level of OSU’s Music and Dance Library. The other half was spent in a carrel on the second most basement level of the Gallagher Law Library, University of Washington. Although there was not enough room in either of those spaces for another person (and few could have even found me in those libraries if they had tried), the writing and completion of this project was far from a solitary affair: the dissertation process not only involves the writer, but also the people who, for some reason or another, elect to tough-out the journey with the writer as well. That I should finish this dissertation with those nearest and dearest to me still near and dear to me speaks volumes about them, their kindness, patience, and generosity and little about me. I am grateful that I have such amazing and patient people in my life.

First, there is my advisor. Maurice Stevens recruited me, brought me into the department, and always keep me within sight as I moved through my course work, exams, and this dissertation while I traveled between Ohio, Vermont, and Washington. Maurice was somehow always about eight months ahead of me in my thinking about
the project, and he remained the patient and watchful mentor allowing me to work and feel my own way to that place. In his most sly and polite way, Maurice never failed to ask, “So, Rachel, tell me again, what is it that you do?” as a way of guiding me ever forward with this project and with my life.

Philip Armstrong and David Horn rounded out my dissertation committee. Philip has always known how to bring the “tough love.” It is a character trait of his I greatly respect, and it is one for which I am most grateful. Philip’s careful reading and critical editorial eye never failed to challenge my thinking and pushed me reach greater clarity with aspects of the project and in how I was conveying them to my readers. I can only hope that I’ve done him proud and best for my readers. David Horn’s two terms as department chair and year’s recovery meant that he came to know me far later than Maurice and Philip. Having never even had me in a class, David signed onto this project and working with me though he had no first hand knowledge that this was something I could pull off. David’s very vocal support of this project and me has been quite humbling. Such support and enthusiasm drove me to do all that I could to make this project achieve all that he saw within it.

Though he may have moved on from Comparative Studies and across the pond to the Center for Death and Society, John Troyer’s one-year in our department and continued friendship has had a lasting and profound impact upon my work. John offered his early and enthusiastic support of this project and me. His continued support
and chats via Skype helped me transform some early thoughts about the Alder Hey Children’s Hospital scandal and organs, identity, and affect into this.

The guidance and support that Maurice, Philip, David, and John provided me is an indicator of the intellectual and personal generosity of all those who constitute the Department of Comparative Studies. I am especially grateful for the resourcefulness and kindnesses of those who oversee all in our department: Marge Lynd, Wen Tsai, and Lori Wilson. Marge, Wen, and Lori were instrumental in helping me navigate my way through the Ph.D. program. And I could not have submitted this project from afar without Lori’s help. Thank you, Lori.

Beyond providing a smart and supportive community in which to complete this work, the Department of Comparative Studies also facilitated it by directly funding my travel to many conferences and my participation in the 2010 Futures of American Studies Institute at Dartmouth College. Likewise, The Ohio State University has provided invaluable financial support throughout my graduate career—a Post-Prospectus Research Fellowship that fostered the development of this project and two Graduate Research Small Grants that enabled me to gain invaluable feedback from a variety of generous interlocutors. The Bread Loaf School of English and Middlebury College generously supported me intellectually and financially through the completion of my M.A. and beyond by providing multiple financial awards. Finally, the Program in the Comparative History of Ideas (CHID) supported the revision and completion of this work by giving me access to many resources at the University of Washington.
I have benefitted immensely from the attention and expertise of professional guides near and far who were kind enough to respond to an email or phone call from a virtual stranger. Michele Goodwin was magnanimous with her insights and advice as I worked to refine the proposal for this project. Kelly Edwards took great care in getting to know me and my project and helped me create an intellectual home-away-from-home for myself in Seattle. Philip Thurtle provided me with that intellectual home and office space as I worked on my revisions and the completion of the project. Benjamin Wilfond generously welcomed me into the Treuman Katz Center for Pediatric Bioethics Fellows Seminar and has helped me to plan out what comes next.

Such an embarrassment of professional riches is matched by a similar abundance of riches in my personal life; I count myself very lucky to have good friends who have not only humored my complaining and minor freak-outs but have also and buoyed me up along the up and propelled me forward with my work. Ruth Miller is a remarkable friend in every way, and she has been my steadfast ally, confidant, and supplier of all things chocolate throughout. Chris Knapp always knew when I needed a break and always had some car, bike, or house project to help me take my mind off of the dissertation for a bit. David Glynn, thankfully, was always on the other side of a gchat screen when I needed a breather. Damon Berry and Marvin Brown, my big and little brothers of Comparative Studies, shared not only their time and lent their eyes to drafts of various sections project but also their unshakable faith in me and my work. Amy Gregg has been an equally and overwhelmingly generous friend throughout this
process. Rebecca Adelman has been on this journey with me longer than either one of us actually knew—she is not only an amazingly supportive colleague but also a wonderful friend.

Finally, Christopher Morris. From our first day of college to now, I never imagined that it would be you by my side through the completion of this project and throughout life—my friend, my partner, my husband.
Vita

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Introduction

Death. Of all the possible things in life, death is the one great certainty. From the vegan marathoner to the fast-food consuming couch potato, death is inescapable; death does not discriminate. For a concept so seemingly binary—one is either living or dead—there are multiple legal as well as medical definitions of death, various personal views on what it means to be alive versus what it means to be dead, and ontologies of death that differ both geographically and culturally the world over. Though there may not be a singular way of understanding death, death, for most, is not a welcomed state; rather, it is that which is to be staved off or avoided. In writing about his own mortality, after undergoing his second heart transplant, philosopher Jean-Luc Nancy wondered, “why, and how is there no longer for us—we of the ‘developed countries’ of the year 2000—a ‘right’ [juste] time to die (scarcely before the age of eighty; and will not this age continue to increase)?”

1 Because there is no longer a right time to die in the biomedical-technological culture of the 21st century, the intense pressure to prolong life, cure disease, and increase one’s quality of life has created an environment in which all

biomedical interventions, including organ transplantation, have become a basic
expectation of medical care.

This project, *Facing the Waitlist: Visual Grammars of Organ Donation and
Transplantation* enters into the ongoing conversations about organ donation and
transplant practices in the U.S. at a critical moment. Fueled by the tension between
inevitable death and continued living through biotechnological interventions, the U.S.’s
United Network for Organ Sharing (UNOS) organ transplant waitlist has surpassed
110,000 candidates.² And this list grows daily. Everyday, 93 individuals are removed
from the organ transplant waitlist, but by each day’s end, approximately 150 new
candidates are added. In late 2009, when I was working on the first draft of the
proposal for this project, the list stood at 105,000,³ by the time I submit and defend this
project in the spring of 2012, the list of those awaiting organs for transplant will near
115,000.⁴ Although each day 93 transplant candidates are removed from the waitlist,
not all of those 93 are removed because they’ve received a long-awaited organ—19 are
removed because they died before an organ became available. Still, the waitlist
continues to grow, and so does the rate at which it grows. As both the list itself and the
rate at which it grows increase, so too does the desperation of those seeking organs to
stave off death and/or increase the quality of their remaining lives.

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² 112,673 as of 21 November 2011.
³ 105,221 as of 28 November 2009.
⁴ 114,434 as of 22 May 2012.
With the demand for organs further increasingly outstripping the supply, more and more individuals in the U.S. are looking beyond UNOS to gain organs. Within the U.S., UNOS is responsible for more than maintaining the organ transplant waitlists: UNOS is the State-sanctioned, private, non-profit, government-contract organization that manages the whole organ transplant program. However, it is not the only way to go about getting an organ—other models of organ procurement and allocation do exist within the U.S.

Models of Organ Procurement and Allocation or MOPAs is the term that I use throughout this project to refer to sites that facilitate organ donation, organ matching, and organ transplantation. I use the term MOPA because the term currently used to describe institutions that facilitate organ sharing, Organ Procurement Organizations or OPOs is no longer an accurate term or way to think about how the landscape of tissue exchange is being managed, directed, or shaped in the U.S. MOPA, the term I have developed and deploy here, encompasses organizations, systems, individual and/or group campaigns, and governed as well as ungoverned sites of tissue exchange. MOPAs are models, not (only) institutional organizations that facilitate tissue exchange.

The intense pressure to prolong life, cure disease, and increase one’s quality of life combined with the fear, desperation, and distrust of the current organ transplant system in the U.S. means that more and more individuals are turning away from UNOS and toward non-State-sanctioned MOPAs. Some are transforming spaces like billboards, Facebook pages, profiles on MatchingDonors.com, and YouTube videos into
MOPAs in order to find organs for themselves and/or loved ones. Still other individuals have come together to propose new, federal MOPAs to encourage organ donation and facilitate more transplants, such as sanctioned transplant tourism, paying for donors’ funerals, and paying for organs. All of these new and proposed MOPAs are focused upon gaining more organs for those on the transplant waitlists. Gaining organs for those in need is critical, but the fact that it is one piece of the larger puzzle of relations suggests that MOPAs should be examined for their other functions and purposes as well.

As many individuals hold the expectation that bio-medical-technology will prolong life, cure disease, and increase quality of life, then perhaps the focus of new MOPAs or rethinking current MOPAs should be on improving the health outcomes for transplant candidates. A piece of improving the health outcomes for transplant candidates is, yes, gaining more organs, but there are other equally critical parts. In shifting the focus from obtaining organs to enhancing beneficial health outcomes, three sites of intervention (rather than the one) are illuminated: (1) increasing potential organ donors’ willingness to donate, (2) gaining more organs for transplantation, and (3) increasing the positive post-operative outcomes for transplant patients.

In organ transplantation, certainly part of the successful health outcomes of transplant recipients and the success of the organ transplant system has to do with medicine. Another part of it has to do with how people feel—how potential donors, families of deceased potential donors, and transplant candidates feel about the organ
transplant system itself; and how organ transplant recipients feel about the organs they’ve received. Given the intense pressure to find organs, to be alive, to have a better quality of life, feelings about organs or the organ transplant system often get pushed to the side in favor of the more critical, pressing, and urgent need to save a life. But feelings matter, too. If individuals feel the transplant system is unjust, they will often refuse to register as donors or donate their organs; if the family of a potential organ donor feels like the physicians and nurses may not try as hard to save their loved one’s life if they know that he or she is an organ donor, they may refuse to disclose the individual’s donor status; if a transplant recipient feels uneasy about his or her newly transplanted organ, the recipient’s body may reject the organ regardless of how perfect a biological match the donor and recipient may be. The ways that people feel about organ transplantation have a lot to do with the ways that MOPAs function.

Much has been written about our current transplant system in the U.S., and much has been written about how the new and proposed MOPAs in the U.S. function or would function if implemented. But there is a gap when it comes to understanding how their functioning affects individuals, which, in turn, affects the overall transplant system. This project represents a way in which I have sought to illuminate that knowledge gap.

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5 By individuals, I mean potential donors, donors, donor families, transplant candidates, and transplant recipients.
While largely overlooked in the analysis of MOPAs, the area of donor and patient identity information management is in critical need of exploration because organ recipients and live donors experience tissue exchange as highly personal—as though some part of the donor’s ‘self’ or ‘person’ is transmitted along with the organ.\(^6\) This project works to illuminate the governing grammars, the logics, or structural rules that underpin these MOPAs’ identity management practices as they seem to inform potential donors’ willingness to donate and have a bearing on transplant patients’ medical outcomes. Understanding the logics of how MOPAs function with respect to identity information reveals not only how their practices operate on individuals, but also how a new model of organ procurement and allocation can be constructed that will improve the health outcomes of transplant patients and decrease the number of transplant candidates who die daily as they linger on the waitlist by (1) increasing potential donors’ willingness to donate, (2) gaining more organs for transplantation, and (3) increasing the positive post-operative health outcomes for transplant patients.

My approach to this project is by necessity interdisciplinary, but it is not a simple or procedural interdisciplinary approach; it is not a borrowing of constructs, methods, or theories from a diverse set of disciplines or fields of inquiry; it is not a bricolage. Rather, in assembling this project I have sought out the points of contact, the spaces of overlap, the instances in which knowledges from different fields seem to almost graze one

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another. Each of the methods, constructs, or concepts that gets brought together here is essential to this project; remove one and the thrust of this project is lost. This is an interdisciplinary, cultural studies project that engages theoretical constructs as well as disciplinary knowledges and concepts from cultural studies, American Studies, science and technology studies, visual culture, bioethics, and psychoanalysis. My work here not only makes contributions to these fields, but it also serves as an example of how yoking together disparate knowledges can yield approaches, suggestions, or interventions that the fields in isolation or siloed disciplines may not.

**Key Concepts**
What follows in this section is an overview of the key concepts that I use throughout this project. By establishing and defining the concepts that I use upfront—theoretical constructs, fields of inquiry, modes of analysis, practical workings, terms with disciplinary-specific legacies—I hope to bridge the diverse discourses this project engages. Furthermore, through this initial groundwork, I hope to lay bare the different facets of the foundation upon which this interdisciplinary project is built.

**Affect**
I understand affect as an intangible biological component of emotions and feelings.

Affect is a response of the central nervous system (CNS) to various stimuli. It is through affect that stimuli enter consciousness. Affect is pre-social, whereas feeling and emotion are social—i.e. feeling and emotion are what result from the processing of affect. Feeling follows affect as an individual’s conscious and pre-conscious experience
of affect. Emotion follows affect as an individual draws upon social and cultural ideologies and personal history in interpreting the affect.

As affect is a CNS response, affect is something that is always present; it exists in state of potential. Affect is intangible but it is real, and the effects of affect are material and tangible.

Affect has been shown to produce effects more surely and swiftly than deliberate interventions. For example, at the height of the dotcom boom, the briefcase belonging to Alan Greenspan, then Chairman of the Federal Reserve, became a highly visible and suddenly affect motivating or affective object. The “briefcase theory,” as it was dubbed by the media, held that the size of Greenspan’s briefcase, especially on the mornings of his meetings with the Federal Open Market Committee, was an indicator of whether he would be raising or lowering the interest rates. Greenspan’s briefcase, images of it captured by news cameras as he walked to his office on those mornings and played for all on CNN and MSNBC, motivated affect such that trading was effected well before the Federal Open Market Committee meetings got underway.

Like the briefcase, organs motivate affect—they too are affective objects. However, because organs are objects that are for the most part unseen, their affective potential is often tied to representations of the identity of the organ donor or the organ recipient—such representations or the conspicuous lack thereof are the stimuli that trigger CNS responses. In this project, I pay particular attention to the potentially

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7 Greenspan, Age of Turbulence, 197-198, 227, 276.
affective components of MOPAs as related to the management of identity information, especially the visual components.

Ultimately, affect is an important aspect of this project in terms of how I consider that MOPAs function, in terms of their effectiveness. If affect is able to produce an effect—a shift in the stock market—more swiftly and surely than economic policy changes, then it would seem important to consider not only how MOPAs function, but that the ways in which they operate, specifically the ways in which they manage identity information, motivates affect and stirs emotions for potential organ donors, donor families, and organ recipients and effects the organ transplant system. And furthermore, a MOPA grounded in affect might prove highly effective in terms of gaining organs for transplantation, perhaps more so than new, formal institutional policies or regulations.

**Visual Culture**

I consider visual culture, in the broadest of senses, to be the combination of both physiological as well as cultural processes that render artifacts and objects within the visual landscape comprehensible. The rods and cones that capture light enable one to see, physically, but it is through culture that one comes to discern visual objects and interpret what they “mean.” Visual culture is preeminently an American movement that emerged in the 1990s.⁸ Visual culture emerged in Western culture in the mid-20th

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century as the dominant media shifted to visual from oral or textual. Visual culture studies is a dynamic field because the relationship between the visual object and the culture in which visual culture is rooted operates in both directions: just as culture shapes how visual objects are understood, visual objects also shape cultural processes.

In this project I turn to visual culture when analyzing MOPAs for two reasons. First, identity information on organ donors and/or organ transplant candidates and/or recipients allows these individuals to appear, to become visible to varying degrees. With some MOPAs the individuals appear in a very literal way, they are visible to the eye as represented in pictures and other images. With other MOPAs the individuals come to appear in the mind’s eye given descriptions and pieces of information—age, gender, region of the country. Second, in the absence of direct personal experience with organ donation or transplantation, most people gain information about organ donation processes and organ transplant surgeries through visual media, namely television.

**Biopolitics**

Biopolitics is the calculated management and regulation of bodies vis-à-vis the State. The biopolitical State is concerned with regularizing biological processes at the level of “man-as-species” rather than “man-as-body” or “man-as-individual.” In this way, issues raised by biology become a part of political processes and political processes become a part of biology.

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10 Morgan et al., “Entertainment (Mis)Education,” 143.
The concept of biopolitics or biopower, which was first articulated by Michel Foucault in the 1970s, emerged in Europe during the latter half of the 18th century. According to Foucault, biopolitics’ “first objects of knowledge” were the statistical ways in which the population was being measured: the State sought to understand the rates of births and deaths, the longevity of a population, the rate at which a population reproduced, the fertility of a population, and more. Understanding these statistical measurements and recognizing the attendant political and economic issues opened up new sites of control for the State, new ways of targeting and regulating the whole of the population.

Biopolitics as it was first observed as exercising power is still present, though in ways in the U.S. and in the 21st century that are slightly different from how Foucault first discussed their emergence. At present, in the U.S., biopower is not directly concentrated with the State; rather, biopower flows through institutions that more directly and specifically regulate the customs, habits, health, well-being, and reproduction of the population. Additionally, biopower is not necessarily used to regulate the U.S. population as a whole but often subgroups or subpopulations. As an example, one of the most prominent biopolitical institutions in the U.S. is the National Institutes of Health (NIH). The NIH has an annual budget of more than 30 million

12 Ibid.
13 Ibid.
dollars. In making decisions to fund certain research projects and not others or grant different levels of funding—for example, greater funding for cancer research and treatment than diabetes research and treatment—the NIH privileges certain knowledges and seeks to save or improve the lives of a certain demographic of its population rather than another—in this specific comparison, middle class and white rather than poor and black.

UNOS, the dominant, State-sanctioned MOPA in the U.S., is the institution that regulates life and death for transplant candidates at the macro or man-as-species level. That regulation takes place through the ethical principles it articulates and advances, the donor guidelines it establishes, the formulas it devises that guide organ allocation, and the procedures all UNOS regional life centers must follow to determine which patients in need of organs are suitable candidates for transplantation. In the context of organ failure, organ donation, and organ transplantation, patients, donors, and donor families must deal with institutions (hospitals, UNOS, local organ centers), laws, and even the State rather than individuals or individual bodies.

Biopolitics is a key concept in this project because for someone suffering organ failure, the decisions over what can and should be done do not rest with the individual, his or her doctor, or family members alone. An individual suffering organ failure must deal with para-State institutions that determine whether or not his or her body is fit and

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14 National Institutes of Health. “NIH Budget.”
15 National Institutes of Health. “Estimates of Funding.”
'worthy’ enough to even get on the government mandated and regulated organ transplant waitlist and, if eligible, then where on the waitlist he or she will fall.

Biopolitics is also a key concept in this project because for someone who wishes to be an organ donor, the individual (whether alive or dead) cannot simply give someone else his or her organ. Institutions and regulations are involved in the management bodies, and they become even more pronounced when the body is (or may become) disaggregated into parts as in the case of organ donation.

**Organ Donation and Transplantation**
Because this project is concerned with the donation and transplantation of organs, it is important to have a grasp of the processes involved in donating or receiving an organ in the U.S. today. Anyone of any age in the U.S. can be an organ donor. Organs can be donated either after one has died—if viable—or while one is alive.

**Cadaveric Organ Donation**
The whole organs from a single deceased donor may be used to save up to eight lives and improve the lives of an additional 50 people through tissue donation, but not all who die are suitable organ donors. Organ donors are screened for diseases and lifestyle/risk factors are also considered. A potential cadaveric organ donor or dead donor needs to die in a way that meets the criteria for the legal definition of death and also die in a way that keeps the organs alive. This is to say that one must meet the criteria for brain death, but not cardiopulmonary death. Accepting both brain death and cardiopulmonary death as two different means of recognizing death does not imply that

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17 Like corneas, heart values, skin, bone, musculoskeletal tissue, and cardiovascular tissue.
there are two forms of biological death, only that there are two forms of recognition.\footnote{18}{G. Miller, “Determination of Death,” 119.}

Brain death is defined as the irreversible cessation of whole brain function, which would be followed by the cessation of cardiopulmonary function in the absence of medical interventions. An individual is declared brain dead after repeated testing determines that there is an absence of electrical activity in the brain, no blood flow to the brain, and no brain function. Without brain activity, the rest of the body is unable to survive. While the individual is dead, the ventilator, a medical intervention initially intended to help heal the body and brain now preserves the organs and tissue of the deceased donor, but the ventilator also makes the individual appear as though he or she is still ‘alive.’ The individual remains warm to the touch as oxygenated blood circulates throughout the body; his or her countenance and pallor do not change; and the chest rises and falls like it did when the person could still breathe on his or her own. The ventilator sustains or mimics cardiopulmonary function to keep the organs functioning in the brain-dead donor. If consent to donate is given, while the potential donor undergoes testing, tissue matching through UNOS takes place, and the recipients to whom the donated organs will be allocated are located.

In order to donate organs after death, one can register to be an organ donor when applying for or renewing a driver’s license, record one’s wishes in advanced directives or a living will, and/or by make the wish known to family members. This latter piece is important because even though consent from one’s next of kin is not legally
required if an individual has registered with the state’s donor registry, hospitals do
discuss donation with family members before recovering organs. Even if an individual
has registered as an organ donor, should the family object, hospitals thus far have not
made it a policy to harvest the organs of registered donors over the objections of the
next of kin.19

Despite the fact that 95% of people in the U.S. support organ donation, there
remains a critical shortage of organs: only 40% of those who support organ donation are
registered organ donors. Still, being a registered organ donor does not ensure that after
death all registered organ donors’ organs will be harvested and allocated to those listed
on the transplant waitlists. According to bioethicist Arthur Caplan, only about one in
1000 deaths leads to viable organs for transplantation.20 Because an organ donor needs
to die in a way that meets the criteria for the legal definition of death while dying in a
way that keeps the organs alive, “even in an ideal world in which all brain-dead
potential donors became actual donors and the demand for organs remained constant
rather than increasing, the supply of organs from brain-dead donors could not meet the
needs of all the patients on waiting lists.”21

Living Organ Donation

19 The most recent research on this has been done in the U.K. where approximately 1 in 10
families of dead patients on the organ donor register still refuse to allow them to become
donors.
20 J. Goodwin, “Shortage of Transplant Organs.”
Organs can also be harvested from living donors. One can elect to become a *living donor* and donate certain organs at any point while one is alive. As a living donor one can donate a kidney, a segment of the liver, a lobe of one’s lung, a portion of the pancreas, and/or a part of the intestine. Blood, bone marrow, and plasma are tissues that can also be donated while one is alive. Living donors most often donate organs to related family members or to someone with whom they have emotional relationship (spouse, close friend, etc.). Because the potential donor is alive, he or she has the ability to direct the donation of his or her organ(s) to a designated recipient. The direct donation enables an intended recipient to receive a specifically donated organ and bypass the waitlist. This means that whether the intended recipient is #1 on the waitlist or #912, the specific organ from the specific living donor will be allocated to the intended, designated recipient. A direct donation allows one to bypass the waitlist but not the whole of the UNOS transplant system. Even with a direct donation a local transplant center is involved and it oversees and coordinates the whole process.

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22 So long as one is determined by organ transplant coordinators to be both physically and mentally fit.

23 Only under a very specific and rare set of instances may one donate their heart while still living. A domino transplant makes some heart-lung recipients living heart donors. When a patient receives a heart-lung transplant from a deceased donor, his or her healthy heart may be donated to another individual waiting for a heart transplant. This procedure is performed when physicians determine that the deceased donor lungs will function best if they are used in conjunction with the deceased donor heart or if the patient has cystic fibrosis (CF). With CF patients, both lungs need to be replaced and in a technical sense it is an easier operation to replace the heart and lungs at the same time. As the patient’s native heart is usually still healthy it can be transplanted into someone else on the transplant waitlist who is in need of a heart.
While it is rare, there are some living donors who elect to donate organs to unknown recipients. In these instances, UNOS protocols for organ allocation are followed—the organ goes to the highest ranked, best match on the waitlist.

**Donation After Cardiac Death**

In very specific and rare circumstances, organs can be recovered from patients who do not fully meet the criteria for brain death. If a physician has determined that a patient has no chance of survival and the next of kin have decided to withdraw life support, the option of Donation After Cardiac Death (DCD) or becoming a *DCD donor* may be broached with the family. As a potential DCD donor, the patient is moved to an operating room that is prepared for organ recovery where life support is then withdrawn. A surgical team will then wait up to an hour for the patient’s heart to stop beating. After the patient’s heart stops beating—i.e. cardiopulmonary function ceases—death is declared. At this point the organ recovery team waits a designated amount of time following the cessation of cardiopulmonary function before starting organ recovery—depending upon the institution and age of the patient the amount of time ranges from 75 seconds to 5 minutes.\(^\text{24}\) The lungs, liver, pancreas and kidneys often can be recovered from a DCD donor. The allocation of these organs is managed by UNOS, just as it is with non-DCD cadaveric organ donors. If, however, the potential DCD donor’s heart does not stop beating within an hour of life support being withdrawn,

\(^{24}\) Souter, “Donation After Cardiac Death.”
organs are not harvested and the patient is returned to the intensive care unit for reassessment and continued monitoring.

Organ Transplant Candidate
An individual who is suffering organ failure and whose doctors feel may benefit from undergoing an organ transplant is referred by his or her specialist to a transplant center. The transplant center evaluates the potential candidate’s medical factors and psychosocial factors: medical tests are run, the individual’s mental and physical health are considered, his or her social support system is discussed, and the financial/insurance situation is reviewed. If the transplant center determines that the individual will be a good transplant candidate and accepts him or her into the system, his or her medical profile is then added to UNOS’ organ transplant waitlist. Not all who suffer organ failure will become organ transplant candidates.25

Organ Transplant Waitlist
At the time of being added to the list, the transplant candidate is not placed on a ranked list. Rather, the transplant candidate’s information is kept in a constantly updated, computerized database—UNet. When a deceased organ donor is identified (or an altruistic living donor who elects to donate an organ to an unknown recipient), a transplant coordinator accesses UNet. After entering the donor’s medico-institutional data into the system, a “match run” is performed: the computer system runs each

25 Access to the waiting list remains a great concern for patients suffering organ failure and OPTN/UNOS. OPTN/UNOS acknowledges that listing practices and requirements may vary considerably among transplant centers and from one organ type to another. OPTN/UNOS also acknowledges that geographic factors as well as socioeconomic challenges may have an impact upon referrals to transplant centers. OPTN/UNOS Ethics Committee, “Ethical Principles.” Michele Goodwin and Dr. Clive O. Callender refer to this concept as “green screening.”
patient in the waitlist database against the donor’s characteristics. UNet then generates a ranked list of candidates for each available organ in ranked order according to the specific policies for each organ.

**Organ Matching**
The match for each transplant candidate is unique. At a minimum, when a donor organ becomes available, it must be matched with the blood type, tissue type and physical size of the transplant candidate. The relative geographies of the organ donor and transplant candidate are also factors in determining a match because once the organs are removed from the donor (i.e. harvested) there is a finite window of time in which they will remain viable.

For a transplant candidate whose blood type is A-positive, for example, his or her body can only accept an organ from a donor whose own blood type is either A or O.

When blood is typed, a sample will only belong to one of four major blood groups based upon the antigen present on the blood cell’s surface (A, B, AB, or O).\(^{26}\) In addition to matching for blood type, the candidate and donor’s tissue must typed to test for compatibility. Even if a transplant candidate and donor are matched for blood type, if the transplant candidate has high levels of antibodies that are incompatible with the donor organ, this is deemed a positive cross-match and the transplant candidate cannot receive the donor’s organ because it would be rejected.

\(^{26}\) See http://en.wikipedia.org/wiki/Blood_type (accessed November 19, 2009) for more information on the details of blood typing and blood system groups. The International Society of Blood Transfusion recognizes a total of 30 human blood group systems.
The organ donor and transplant candidate must also be a physical match in terms of comparable body size. Someone who is 5’7” and 125 lbs. would not be well served by an organ coming from a four-year-old donor. The same 5’7”, 125 lbs. transplant candidate would also not be well served by an organ coming from someone who was 6’7” and 250 lbs. At a foot taller and twice the weight of the transplant candidate, there is a good chance the donor organ would not even be able to fit into the transplant candidate’s body without compromising his or her other organs.

Once a transplant candidate is selected and contacted, once all testing is complete, and once the transplant candidate and his or her transplant team have discussed the organ offer, surgery is scheduled and the transplant takes place or the candidate passes on the organ and it is offered to the next appropriate transplant candidate on the match list.
Constraints

*Facing the Waitlist* exists within the global landscape of bio-medical-technological advances; it exists alongside histories and emerging stories of organ transplants taking place in all corners of the world; and it exists amid an ever-changing, global backdrop of different national and governmental policies/biopolitics concerning the health, bodies,
and mortality of citizenry. Still, as with all projects, bounds must be demarcated, a scale of operations must be selected. For this project I have limited my focus to organ procurement and transplantation practices of MOPAs in the U.S. and to organ donations and organ transplant surgeries that are a part of legal organ sharing practices.

Because the U.S. leads the world in organ transplant surgeries—both in sheer volume of transplants performed each year and in biotechnological innovations related to the field—I have chosen to limit my focus to the U.S. Thus, Facing the Waitlist is almost exclusively a project about organ donation and transplantation practices in the U.S. in the 20\(^{th}\) and 21\(^{st}\) centuries. My discussion of identity management practices of MOPAs, as well as the ideas about community, social relationships, identity, rights, race and ethnicity, healthcare, and biopolitics that I place in conversation with one another must be understood within this specific context.

Within this project on organ donation and transplantation there is a dimension that may be seen as being conspicuously absent from such a project that takes the U.S. as its focus: religion. Freedom of religion was a central tenet in the establishment of the U.S. colonies, for the colonies were settled by individuals who held deeply religious beliefs and had faced religious persecution; individuals who had crossed the Atlantic to practice their religion, share their beliefs, and express their faith freely. Within the U.S., where more than 30 different religions are practiced today, organized belief and worship are widespread ideological influences. Religion influences, among other things, the ways individuals—those of different ethnic groups, communities, races, and
religions—consider their bodies. In the U.S., religious beliefs and values play into the ways in which individuals view their own bodily and mental health, engage in discourses of the body, and (as is germane to this project) consider organ donation and transplantation. For many individuals, religious teachings and beliefs come into play when deciding whether or not to register as an organ donor, whether or not one is willing to consent to the donation of a loved one’s organs, whether or not to accept an organ (even if it is the only medical intervention that will prolong life). Given that the U.S. is a secular state and that there are a myriad of religious perspectives throughout the U.S., a discussion of religion and organ donation and transplantation is beyond the scope of this project and is absent from the body of this dissertation. In the appendices I have included statements UNOS has collected from officials of approximately 30 different religions practiced in the U.S. Appendix A provides a gloss of the positions and statements of various religions with regard to organ and tissue donation and transplantation.

*Facing the Waitlist* as a project is exclusively concerned with legal organ procurement and allocation practices within the U.S. That is, this project focuses upon tissue exchanges between cadaveric donors or living donors and recipients in which no parties involved “acquire, receive, or otherwise transfer any human organ for valuable consideration.”

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Although I have greatly winnowed my focus within this discussion of MOPAs to illuminate how the affects generated by the identity management practices of MOPAs have effects upon the transplant system as a whole in the U.S., it is my hope and belief that some of what I raise here may have implications in further conversations or use beyond the explicit bounds I have drawn.

**Overview of the Chapters**

This dissertation is divided into three chapters. Each chapter is organized around one particular grammar that emerges from the constellation of particular MOPA practices. The chapters themselves are organized into three parts: Part I of each chapter details the mechanics of the MOPAs’ identity information management practices; Part II situates the identity information management practices and the MOPAs themselves within the broader cultural and theoretical contexts; Part III discusses the affects the MOPAs’ identity management practices motivate as well as how those affect the whole of the transplant system. In this project, my focus is on analyzing the ways in which various MOPAs manage donor and patient identity information to explore how MOPA practices affect how people feel about donating or receiving organs and effect the larger transplant system. These MOPAs, however, don’t exist in a vacuum, nor do they operate in simple response to one another. I have organized my research, analysis, findings, and discussion into three distinct chapters, each with three parts, but it is important that the project be viewed as a whole because the practices I observe and
address are not isolated—they exist within culture and act in concert with one another and upon one another.

The first chapter engages with MOPAs that function by erasure. MOPAs that erase manage patient and donor identity information by removing ‘person’ from ‘patient,’ separating out the patient or donor’s socio-political identity (race, class, gender, age, ethnicity, education, family, religion, etc.) from his or her medico-institutional identity (diagnosis, health history, lab results, etc.). Erasing practices—promulgated by organizations like UNOS—are meant to ensure the equitable allocation of organs based upon standardized, established institutional criteria. MOPAs that are dominated by the logic of erasure strip the socio-political identity, in particular the socially salient features of individual identity, from patients and donors—names are converted into numbers, age into points, and race/ethnicity a box that gets checked; the rest is ignored. What remains, the medico-institutional ‘self’ proves efficient for medical institutions and organizational structures and also supports efforts to inhibit discriminatory patterns that might shape organ donation or allocation.

The second chapter takes up MOPAs that function by inscription. MOPAs that inscribe manage patient and donor identity information by marking those who are experiencing organ-failure as people first and patients or donors second. Inscribing practices—carried out by MatchingDonors.com, users of Facebook and Twitter, and via personal blogs, flyers, and other media and social media—highlight one’s socio-political identity while marginalizing the medico-institutional identity. MOPAs that inscribe take
medical need as a given; thus the features of one’s socio-political identity function as the criteria by which organ allocation is determined.

The third chapter examines MOPAs that function by re-inscription. MOPAs that re-inscribe manage patient and donor identity information by highlighting a limited amount of socio-political identity information and overlaying it onto the medico-institutional identity that is produced and privileged by State-sanctioned MOPAs. Re-inscribing practices—implemented by Lifesharers.org—are meant to ensure the equitable allocation of organs within a group of people that choose to be identified by their shared socio-political identity trait(s). Re-inscribing practices privilege key features of socio-political identity information while also relying upon medico-institutional identity information for the efficient management of organ allocation to those who display the shared socio-political identity feature(s). Re-inscription plays upon ideas about shared community and affiliation rooted in the highlighted socio-political identity information to encourage organ donation.

As consumers of the U.S.’s bio-medical-industrial complex hold fast to the expectation that bio-medical-technology will prolong life, cure disease, and increase quality of life, I conclude this project with a discussion of designing a MOPA, one that in its design focuses upon improving health outcomes for transplant candidates. In suggesting such a MOPA, I draw upon the strengths of each of the different identity management schemes I lay out in the chapters on erasure, inscription, and re-inscription. Ultimately, I suggest a MOPA that is imbricated in the complexities of
concepts like citizenship, race, and ethnicity that are particular to the U.S. It is a MOPA that draws upon the attendant social salient features of identity to motivate affect in hopes of increasing potential organ donors’ willingness to donate, gaining more organs for transplantation, and increasing the positive-post operative outcomes for transplant patients.

The interdisciplinary approach I have taken with this project, that I have taken to discerning the logics of MOPAs has helped me to produce a dissertation that is as much about processes in constructing and articulating a method of analysis as it is about suggesting a definitive intervention. I strike this balance because in the doing of interdisciplinary, cultural studies work, the choice of research practices depend upon the questions that are asked, and those questions depend upon the cultural, social, historical, and geographic contexts. Recognizing the circumscribed or situated nature of this work also means I recognize that any definitive or proscriptive interventions I suggest are temporal. The careful attention to analysis and processes is what will allow for the translation of the work done in this project between and across contexts. Thus, this project may be located and situated, but it is not limited.

Ultimately, cultural studies projects are often marked by timeliness and urgency: our objects of study are finite, the theoretical constructs we employ are ever-shifting, and the intellectual work we produce—in the words of cultural studies scholars Grossberg, Nelson and Treicher—“...is, by itself, incomplete unless it enters back into

the world of cultural and political power struggle, unless it responds to the challenges of history.”29 Facing the Waitlist: Visual Grammars of Organ Donation and Transplantation is no exception.

29 Ibid., 6.
Chapter 1: MOPAs that Erase

Until now, I had thought of my heart and lungs as having come from an anonymous stranger, an unknown young man whom I hadn’t thought much about. But when this dream was over, something had changed. I woke up knowing—really knowing—that Tim L. was my donor and that some parts of his spirit and personality were now in me.

I was eager to verify this information. But how? The transplant program at Yale-New Haven Hospital, where I received my new heart and lungs, observed a strict code of confidentiality. The hospital officials maintained an ironclad rule that the donor’s identity could never be revealed to the recipient. The same was true in reverse: the donor’s family could never be told exactly who had received the various organs they had made available. Strictly speaking, I wasn’t even supposed to know what little I did: that my donor was an eighteen-year-old boy, that he lived in Maine, and that he died on a motorcycle. I had heard these things from a nurse shortly after the operation.

The day after the dream, I called Gail Eddy, the transplant coordinator at Yale-New Haven, who had been enormously helpful to me before, during and after the operation. I knew that Gail couldn’t tell me who my donor was, but perhaps she would be willing to confirm the name of Tim L. from my dream. Assuming, of course, my information was correct.

…

“No, no, you can’t know that,” Gail finally said. “I’m not supposed to discuss this with you. Please, Claire, let it go. Even if you can succeed in tracking down the family, you’d just be opening a can of worms.”

“What do you mean?”

“You can never predict how the donor’s family will respond. People in these situations have all kinds of unexpected reactions. If you’re curious about the donor, I don’t blame
you; I’d be curious too. But please let it go. This whole topic is too emotional and too volatile.”

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On May 29, 1988, Claire Sylvia was the first patient in New England to undergo a simultaneous heart/lung transplant at New Haven’s Yale University Hospital. Just 17 hours prior to the phone call that informed Claire Sylvia a match had been found, the Yale-New Haven transplant program received permission from the state of Connecticut to officially open. Thus, just 17 hours prior to finding a match, Claire Sylvia had been added to the UNOS organ transplant candidate waitlist. For someone who is in need of an organ or for someone who upon death donates his or her organs, in being interpolated into the organ transplant system in the U.S. by being added to the UNOS transplant waitlist, as Claire was, or having one’s information added to DonorNet, as the young motorcycle driver from Maine would have had he died today, both transplant candidate and organ donor are erased.

This first chapter is concerned with MOPAs that erase—in particular, the United Network for Organ Sharing (UNOS). The chapter is divided into three parts. Part I focuses upon how erasure happens, the mechanisms behind donor and patient identity information management that separate out the socio-political identity of an organ donor or transplant candidate from the medico-institutional one. Part II situates the erasing practices by locating the MOPAs that erase within social, cultural, and historical

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30 Sylvia, Change of Heart, 6-7.
contexts and theoretical constructs that have informed their practices. Part III discusses how the practices of erasure affect donors and donor families as well as organ transplant candidates/recipients and discusses how the ways they experience affect effect the overall organ transplant system in the U.S.

**Part I: The Mechanics of Erasure**
This first part of the chapter defines erasing practices. It identifies UNOS as the primary MOPA of this identity management practice and details how its principles for the ethical and equitable allocation of organs have translated into practices that erase. Part I lays out the mechanisms of erasure: UNOS’ ethical principles for organ allocation, the construction of organ allocation formulas and use of organ allocation scores, and UNet and DonorNet.

*Erasure Defined*
MOPAs that erase manage patient and donor identity information by removing “person” from “patient,” separating out the patient or donor’s socio-political identity (race, class, gender, age, ethnicity, education, family, religion, etc.) from his or her medico-institutional identity (diagnosis, health history, lab results, etc.). Erasing practices are meant to ensure the equitable allocation of organs based upon standardized, established institutional criteria. MOPAs that are dominated by the logic of erasure strip the socio-political identity, in particular the socially salient features of individual identity, from patients and donors—names are converted into numbers, age into points, and race/ethnicity a box that gets checked; the rest is ignored. What remains, the
medico-institutional ‘self’ proves efficient for medical institutions and organizational structures and also supports efforts to inhibit discriminatory patterns that might shape organ donation or allocation.

The United Network for Organ Sharing (UNOS)
For those who undergo evaluation at an organ transplant center in the U.S. and are placed on UNOS’ organ transplant waitlist, the need for a new organ becomes a given—the transplant candidates who are added to the list have one or more organs that are failing and will soon die without a transplant. The need for a new organ may be a given, but because organs are a discrete, limited resource that come from the bodies of dead and living donors, a system has been put in place to guarantee, among other things, the equitable allocation of organs. For UNOS, the equitable allocation of organs is achieved via erasure.

In 1984 Congress passed the National Organ Transplantation Act (NOTA), P.L. 98-507. In its mandate for the establishment of the Task Force on Organ Procurement and Transplantation and formation of a unified transplant network to be operated by a private, non-profit organization under federal contract—the Organ Procurement and Transplant Network (OPTN)—congress specifically expressed concern for “equitable access by patients to organ transplantation and for assuring the equitable allocation of donated organs among transplant centers and among patients medically qualified for an organ transplant.”

In September of 1986, UNOS was awarded the initial contract to

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administer the OPTN. UNOS has been the only organization to administer the OPTN for now more than 25 years and through multiple successive contract renewals.

For UNOS, considering and reconsidering what the equitable allocation of organs looks like has meant asking and re-asking a number of questions as life-sustaining technologies for those suffering organ failure have advanced and continue to advance:

How long can a candidate survive without a transplant? What organ will produce the best medical outcome for a candidate—the one most closely matched or the first available? How many years of life might a candidate have left after his or her organ transplant? For how long may a candidate be kept alive by other medico-technological means (i.e. dialysis, a left ventricular assist device [LVAD], supplementary oxygen, etc.)? What is the candidate’s quality of life as he or she awaits transplantation? All of these questions and more have helped to shape and inform the ethical principles that guide organ allocation for the ever-growing list of patients in need of organs.

Ethical Principles for the Allocation of Organs
The principles that guide the equitable allocation of organ via organ allocation formulas come out of a general framework articulated by OPTN and UNOS for the ethical allocation of organs and the ethical operation of the organ transplant system. According to OPTN/UNOS, “the ethics of allocating human organs for transplantation is a specific application of ethical norms to social practices. The principles involved are essentially the same as those that apply to other areas of human conduct.”

In 2010, the

32 OPTN/UNOS, “Ethical Principles.”
OPTN/UNOS Ethics Committee detailed three principles of primary importance that they felt have long been used in determining the allocation of human organs: utility, justice, and autonomy.\(^\text{33}\)

The principle of utility, according to OPTN/UNOS, refers to “[maximizing] the expected net amount of overall good, while minimizing harm, thereby incorporating the principle of beneficence (do good) and the principle of non-maleficence (do no harm).”\(^\text{34}\) The goods and harms are, however, not limited to what some might deem ‘medical goods,’ for OPTN/UNOS consider factors like patient survival, graft survival, quality of life, availability of alternative treatments, and age in the application of the principle of utility.\(^\text{35}\) Although factors beyond ‘medical goods’ are considered, social aspects of utility, or ‘social worth’ criteria are not factors that are considered in the principle of utility—i.e., the particular social usefulness of an individual in determining organ allocation or variations in transplant outcomes among social groups as a basis for predicting individual outcomes in determining organ allocation.\(^\text{36}\)

The principle of justice, according to OPTN/UNOS, refers to “fairness in distribution of the benefits and burdens of an organ procurement and allocation program.”\(^\text{37}\) Thus, OPTN/UNOS is concerned not only with the “aggregate amount of medical good that is produced, but also with the way in which that good is distributed

\(^{33}\) Ibid.  
\(^{34}\) Ibid.  
\(^{35}\) Ibid.  
\(^{36}\) Ibid.  
\(^{37}\) Ibid.
among potential beneficiaries."  

Giving all potential transplant candidates a fair chance at an organ means that allocation policies complicate utility and maximizing the net amount of overall good as OPTN/UNOS also considers factors like medical urgency, likelihood of finding a suitable organ in the future, waiting time, first vs. repeat transplants, and age in the application of the principle of justice. 

The principle of autonomy, according to OPTN/UNOS, holds that “actions or practices tend to be right insofar as they respect or reflect the exercise of self-determination.”  

Thus, factors like the right to refuse an organ, free exchanges among autonomous individuals, allocation by directed donation, transparency of processes and allocation rules to enable stakeholders to make an informed decision are considered in the application of the principle of autonomy.

These three principles provide a framework for organ allocation practices and donor and patient identity management, and they are used in the construction of organ allocation formulas that are meant to ensure the ethical and equitable allocation of organs. The principles OPTN/UNOS have detailed and I outline here do, however, come into conflict with one another. The principles of justice and autonomy come into conflict with utility as often times there are morally justifiable reasons for allocating organs in a manner that will not do as much aggregate medical good as possible. But the construction and use of organ allocation formulas means that such conflicts need
not be resolved on a case-by-case basis. However, in that organ allocation formulas are constructed around objective, medical criteria, it would seem that such formulas guide the allocation of organs in accordance with principle of utility rather than the principles of justice or autonomy. Emphasizing the use of medically objective criteria in the allocation of organs and organ allocation formulas erases.

*UNOS and UNet Organ Allocation*
What has emerged and have been revised over time are formulas for each organ that UNOS uses to compute organ allocation scores. These scores determine patient priority for receiving an organ transplant once a donor organ that matches a transplant candidate’s blood type, size, and geographic region becomes available. These algorithms and scores that are meant to ensure the equitable allocation of organs based upon medically objective criteria, however, are what erase; they are what divide socio-political identity from medico-institutional identity.

Erasure is accomplished through UNOS’ management of donor and patient identity information. Since 1999, this management has taken place through UNet. UNet is an online database system that collects, stores, analyzes, and publishes all OPTN data related to the organ transplant waitlist, organ matching, and organ transplant surgeries.\(^42\) The database contains data on every organ donation and “transplant event” that has taken place in the U.S. since October 1, 1987.\(^43\) UNet serves as a type of institutional record keeping or historical database, and it is also used each day to

\(^{42}\) Organ Procurement and Transplantation Network, “About Data.”

\(^{43}\) Ibid.
register patients for transplants, match donated organs with transplant candidates, and manage health data on all patients before and after their transplants. UNet is used by all of the organ transplant centers in the U.S., all of UNOS’ regional organ procurement organizations in the U.S., and all of the tissue typing laboratories in the U.S. connected with transplant programs.

Each time someone performs a match run in UNet, an organ allocation formula is used to run each patient in the waitlist database against the donor’s characteristics. The ranked list of candidates that the match run generates is a result of the organ allocation score that is computed for each transplant candidate. As each organ is different, the relative health or sickness of each transplant candidate is measured by different means: thus, the allocation formulas for each organ are different. In what follows I detail the organ allocation formulas and computation of organ allocation scores for two organs—the lungs and the liver. I also detail the information collected on organ donors, for those data are critical to the computation of organ allocation scores as the scores are based upon the match runs given each new donor entered into UNet.

**Lung Transplant Candidates and Lung Allocation Scores (LAS)**

Claire Sylvia suffered from primary pulmonary hypertension (PPH)—a terminal condition that narrows blood vessels in the lungs, and forces the heart to pump harder than is in the accepted, normal range to move blood through the vessels; over time, the right side of the heart becomes enlarged and not enough blood flows to the lungs to pick up oxygen. There is no known cure for PPH, and for some like Claire a heart-lung transplant
is often the only chance to escape certain death from the condition. In 1988, Claire was one of four heart-lung transplant candidates in her region; today there are 60 heart-lung transplant candidates, 3,137 heart transplant candidates, and 1,692 lung transplant candidates listed on UNOS’ nationwide organ transplant waitlist.

In 1988, two years after UNOS began managing the U.S. transplant system, lungs were allocated on a first-come-first-served basis (again, after taking into consideration the blood type, size, and geographic region). The thought behind this allocation practice at the time was that if someone met the medical criteria for being placed upon the waitlist, the longer the patient was waiting on the list, the more critical the health situation would become and the more desperate he or she would be for an organ. In 2005, lung allocation policies and practices changed. Now, the allocation of donor lungs to a matching transplant candidate is based upon the candidate’s Lung Allocation Score (LAS). Figure 2 shows the LAS Calculator available on the OPTN website; Table 1 explains the data fields in the unseen dropdown menus of the LAS calculator.

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45 Based on OPTN data as of January 27th, 2012.
### Figure 2. Lung Allocation Score (LAS) Calculator from the OPTN website

The Lung Allocation Score (LAS) Calculator is used to determine the priority for lung transplantation among candidates. The score is calculated based on various factors, including age, functional status, and medical history. The calculator is accessible on the OPTN (Organ Procurement and Transplantation Network) website, and the score produced by the LAS Calculator is for informational use only.

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<th>Input Description</th>
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<tbody>
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<tr>
<td>Height (cm)</td>
<td>(cm)</td>
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<td>Weight (lbs)</td>
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<td>Amount (L/min)</td>
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<tr>
<td>Percent Predicted FVC (%)</td>
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<tr>
<td>Pulmonary Artery Systolic Pressure</td>
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<td>Pulmonary Capillary Wedge Mean</td>
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<td>Current PCO₂</td>
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<td>Highest PCO₂</td>
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<tr>
<td>Lowest PCO₂</td>
<td>(mm Hg)</td>
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<tr>
<td>Change in PCO₂</td>
<td>(%)</td>
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<tr>
<td>Serum Creatinine</td>
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The calculator output provides the LAS score, which is used to prioritize candidates for lung transplantation based on their medical condition and other relevant factors.
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<tbody>
<tr>
<td>Height Weight</td>
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<td>Body Mass Index- BMI is a ratio of a person’s weight to height that, when interpreted with other medical test results, helps to evaluate health status.</td>
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<td>Lung Diagnosis</td>
<td></td>
<td>Diagnosis- Research has shown that urgency among people needing a lung transplant and success following a lung transplant vary among people with different lung diseases. Therefore, for every lung transplant candidate, diagnosis factors into the calculation of the lung allocation score.</td>
</tr>
<tr>
<td>Functional Status</td>
<td></td>
<td>Functional status- A way to measure the effects that lung disease may have on a person’s ability to perform routine daily tasks.</td>
</tr>
<tr>
<td>Diabetes</td>
<td>Dependency Unknown</td>
<td>Diabetes- Diabetes may be a predictor of health status in some people with lung disease.</td>
</tr>
<tr>
<td>Assisted Ventilation</td>
<td>BiPap CPAP Continuous Mechanical Intermittent Mechanical No Assisted Ventilation</td>
<td>Assisted ventilation- The use of a ventilator to assist breathing may be a measure of disease severity and may affect success after a transplant.</td>
</tr>
<tr>
<td>Requires Supplemental O₂</td>
<td>At Rest With Exercise Only Not Needed Amount: _______L/min _______%</td>
<td>Oxygen at rest- This is the amount of oxygen needed at rest to maintain adequate oxygen levels in the blood. People with severe lung disease may need additional oxygen.</td>
</tr>
<tr>
<td>Percent Predicted FVC</td>
<td></td>
<td>Forced Vital Capacity- This is a lung function test that measures the maximum amount of air you can breathe out after you breathe in as deeply as possible. This amount may be lower in patients with lung disease.</td>
</tr>
<tr>
<td>Pulmonary Artery Systolic Pressure Mean Pulmonary Artery Pressure</td>
<td>mm Hg mm Hg</td>
<td>Pulmonary Artery Pressure- This is the pressure the heart must generate to pump blood through the lungs. This pressure may be high in some people with serious lung disease.</td>
</tr>
<tr>
<td>Pulmonary Capillary Wedge Mean</td>
<td>mm Hg</td>
<td>Pulmonary Capillary Wedge Pressure- The pressure that blood returning to the heart from the lungs must overcome. This pressure can become increased when the heart is not pumping effectively.</td>
</tr>
<tr>
<td>Current PCO₂</td>
<td>mm Hg</td>
<td>PCO₂- The candidate’s current PCO₂ and change in PCO₂ are both considered in the lung allocation score calculation. A blood gas test is performed to measure the amount of CO₂ in the blood. When the lung’s ability to exchange oxygen and CO₂ becomes impaired, the PCO₂ level may become increased.</td>
</tr>
<tr>
<td>Highest PCO₂</td>
<td>mm Hg</td>
<td></td>
</tr>
<tr>
<td>Lowest PCO₂</td>
<td>mm Hg</td>
<td></td>
</tr>
<tr>
<td>Change in PCO₂</td>
<td>mm Hg</td>
<td></td>
</tr>
<tr>
<td>Six Minute Walk Distance</td>
<td>feet</td>
<td>6-minute walk distance- In the 6-minute walk test, transplant candidates are asked to walk as far as they can in 6 minutes. The distance walked is a measure of functional status.</td>
</tr>
<tr>
<td>Serum Creatinine</td>
<td>mg/dl</td>
<td>Serum Creatinine- Serum creatinine levels are a measure of kidney function. High creatinine levels reflect impaired kidney function, sometimes associated with severe lung disease.</td>
</tr>
</tbody>
</table>

Table 1. Lung Allocation Score (LAS) Calculator Expanded/Explained
The score, which results from computing the inputted values/information from various pieces of medical data “represents an estimate of the severity of each candidate’s illness and his or her chance of success following a lung transplant.” A score of 0 indicates that the lung transplant candidate is less ill, while the maximum score of 100 indicates that the candidate is gravely ill. The LAS score is calculated from each candidate’s lab values, test results, and disease diagnosis that are inputted into UNet.

Liver Transplant Candidates and the Model for End-Stage Liver Disease (MELD)
The Model for End-Stage Liver Disease or MELD score calculator was implemented in 2002. The MELD score is used to determine liver allocation for adult transplant patients (> 12-years-of-age) while the Pediatric End-Stage Liver Disease or PELD score calculator is used for patients under 12-years-of-age. Figure 3 shows the PELD Calculator available on the OPTN website. Figure 4 shows the MELD Calculator available on the OPTN website.

48 Ibid.
The score which results from computing the inputted data from various lab test-results reflects how urgently a patient needs a liver transplant in the next three months: a minimum score of 6 indicates that the transplant candidate is less ill, while a maximum
score of 40 indicates that the candidate is gravely ill. The MELD score indicates the degree of the candidate’s health or illness based upon how effectively the liver excretes bile—the patient’s bilirubin level; the liver’s ability to make blood-clotting factors—the patient’s INR; and the measurement of kidney function—the patient’s serum creatinine level.

Organ Donors and DonorNet
DonorNet is an integrated part of UNet. It is the donor side of the network. Organ procurement coordinators input donor information and consent forms, blood-typing and serology results, and digital images of the donor’s x-rays and even images of the organs; video files of donor EGKs, angiograms, and bronchoscopies can also be uploaded to the donor’s file. The information inputted into DonorNet is used for UNet’s organ matching purposes. While some pieces of data that are collected are markers of socio-political identity (drug use, alcohol use, smoking, etc.), the manner in which it gets inputted and handled by UNet, it is through such processes that the organ donor is erased. Figure 5 shows the fields into which information from a potential heart donor is entered.

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49 California Pacific Medical Center, “MELD and the Waiting List.”
51 “DonorNet.”
Figure 5. UCLA’s Organ Transplant Information System (OTIS) — Heart Donor Information Screen. OTIS is fully integrated with UNet/DonorNet.

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I have detailed the processes involved in arriving at organ allocation scores for two organs to give a sense of what is prioritized in organ allocation and, ultimately, in
determining who lives.\textsuperscript{52} Looking at a transplant candidate’s organ allocation score number, his INR value, or her six-minute walk distance, one may be hard-pressed to see a person behind those values. Looking at a donor’s serology results, blood type, or EKG, one may be hard-pressed to see a person behind those pieces of data. In the computation of any transplant candidate’s place on the waitlist in a given match run, the individual in the hospital bed or the consult room becomes nothing more than a set of data points in a system. The emphasis upon the data, the measurable, objective medical criteria, allows for the organ rather than person to be the focus. Such focus upon the data and the data combinations that result in the best match between donor and candidate—in a mathematical sense—is about maximizing the use-value of the donated organ and finding the most suitable host-body in greatest need with the greatest likelihood of success, given the data. By focusing solely upon the allocation score, the transplant candidate’s PCO\textsubscript{2} level (mm/Hg), or the organ donor’s cardiac index (L/min/sq.m), the socio-political identities of both donor and transplant candidate are erased.

Understanding how UNOS operates with respect to the management of donor and patient identity information is critical because the manner in which it manages such information motivates affect. The affect motivated by UNOS’ identity management practices effects current transplant candidates, potential organ donors, and the family

\textsuperscript{52}There are calculators for kidney, heart, intestine, pancreas, and multi-organ allocation as well, but they are not readily available online.
members of potential organ donors. And, ultimately, the affect motivated by the identity management practice of erasure effects the sustainability of the transplant system in the U.S.

**Part II: Situating MOPAs that Erase — Cultural and Theoretical Contexts**

Because the identity management practices that MOPAs use seem to have some bearing on potential organ donors’ willingness to donate and have an impact upon the medical outcomes of organ transplant recipients, it is important to understand not only how they manage identity information but also why a particular identity management practice was implemented in the overall construction of the MOPA. Part II of this chapter situates UNOS to bring into relief some of what has informed its erasing practices.

UNOS as a MOPA has two distinct moments of instantiation. UNOS was awarded the contract to administer the OPTN in September of 1986, but UNOS was first formed in 1968 as the South-Eastern Organ Procurement Foundation (SEOPF). Because of how the organization is located historically, its identity management practices need to be understood as not only being informed by what was transpiring in the U.S. in the 1980s but also by what was transpiring in the U.S. in the late 1960s and early 1970s as well—developments in lifesaving technologies and practices for managing the allocation of scarce resources, the civil rights movement, the medical institution’s continued exploitation of minority and economically disadvantaged populations, the emergence of
medication to manage organ rejection, an explosion in demand for organ transplants, and the rise of unregulated organ solicitations.

The First Successful Organ Transplant — The Herrick Brothers
30 years before UNOS incorporated, Drs. Joseph Murray and John Harrison performed the first successful solid organ transplant at Boston, Massachusetts’s Peter Bent Brigham Hospital, on December 23rd 1954. Many previous attempts at kidney transplant operations had failed, but this one was successful in large part because Drs. Murray and Harrison transplanted a kidney from one twin brother into the other. As monozygotic or identical twins, Ronald and Richard Herrick’s blood types, Human Leukocyte Antigens (HLAs), and genetic profiles were identical. In transplanting a kidney from Ronald into Richard, Richard’s body would not detect the transplanted kidney from his twin brother as something biologically ‘other,’ which greatly increased the chances that his body would accept it. The operation was successful, the transplanted kidney functioned well, both brothers fully recovered from their respective surgeries, and Richard lived for an additional eight years. In this first successful transplant operation, the surgery was successful because both donor and recipient were genetically, identically matched as only monozygotic twins can be; thus, there really could be no identity management practices imposed by the medical institution.

53 California Transplant Donor Network, History.
54 Shapiro, “Transplant Pioneers.”
55 Ibid.
Before 1954, there had been other attempts at organ transplants. The first kidney transplant operation was performed in 1936; ultimately, however, it was unsuccessful. In 1952, two years before the Herrick brothers’ transplant took place, what initially looked as though it would be the first successful kidney transplant was performed by surgeons who harvested a kidney from a mother who was killed in a traffic accident and transplanted it into her son. Initially, the kidney functioned well, but 22 days after the transplant surgery, the organ was rejected.

56 Medical University of South Carolina, *Timeline*.
57 Ibid.
58 Ibid.
After 1954 many more successful organ transplant procedures were performed in the United States on identical twins.⁵⁹ In 1959, the first transplant between dizygotic twins or fraternal twins was performed.⁶⁰ Eventually, some doctors went on to perform transplants between patients and related, living family members who were willing to be live organ donors and between patients and related and unrelated cadaveric organ donors, with mixed success.⁶¹ Because organ transplant operations were still experimental and uncommon, physicians and hospitals dealt with each transplant patient and organ donor on a case-by-case basis.

By the time transplant medicine advanced to the point that organs from donors could be transplanted into unrelated patients and the need for a regulatory body or mechanism like UNOS was apparent, models for allocating other scarce, life-saving medical resources had been developed and could be drawn upon. In looking at the models of allocation of scarce resources that informed UNOS’ management of organs and patients, I am looking at situations where the shortage of a resource was a given and the resource was a biological material or a substitute for a biological material. I am looking at what I’ve termed proto-MOPAs, for the identity management practices used in determining the allocation of these scarce resources shaped UNOS’ erasing practices.

⁶⁰ Souter, “Donation After Cardiac Death.”
⁶¹ Holtkamp, *Wrapped in Mourning*, 2. In 1962 the first cadaveric organ transplant was performed. Souter, “Donation After Cardiac Death.”
Identity Management Practices of Proto-MOPAs

The Life and Death Committee
In the 1960s, the Life and Death Committee,\textsuperscript{62} officially known as The Admissions and Policies Committee of the Seattle Artificial Kidney Center at Swedish Hospital and also known as the “God Committee,” did for patients seeking access to the first artificial kidney machines what UNOS and its organ matching computer system UNet do for patients in need of organ transplants today. First convened in the summer of 1961, the brainchild of Dr. James Haviland, the chairman of the King County Medical Society,\textsuperscript{63} the Life and Death Committee was organized to evaluate kidney patients to determine who would determine who would live or who would die—who would gain access to the life-saving, blood-filtering technology of the artificial kidney (a forerunner of the dialysis machine) and who would more quickly succumb to renal failure.

While the Life and Death Committee did what UNOS does for patients today, the committee members’ means of determining patient priority for access to the artificial kidney machine units was completely different from how patient priority or ranking on the UNOS organ transplant waitlists is currently determined. Instead of UNet organ allocation formulas, and organ allocation scores, the allocation of the artificial kidney machines units was left up to the judgment of a lawyer, a minister, a banker, a

\textsuperscript{62} In some texts, including Shana Alexander’s article, you will see the committee referred to as the “Life or Death Committee” (emphasis mine). As most texts seem to refer to it as the “Life and Death Committee,” this dissertation shall use that naming convention.

housewife, an official of state government, a labor leader, and a surgeon—seven “high-minded, good-hearted citizens, much like the patients themselves, who were selected as a microcosm of society-at-large.” This deliberately constructed microcosm, advised by two physicians, was charged with selecting who of the patient-applicants would receive the new, experimental treatment for end-stage kidney disease and who would not. However, this deliberately constructed microcosm of society really wasn’t one at all. While “it was envisaged as representing a broad socioeconomic spectrum of the Seattle community, in hope that this would mitigate any bias in favor of candidates with certain social backgrounds or occupations,” that vision was not realized. The members of the committee were decidedly upper-middle class and white, and the majority was male.

In addition to having a committee that was not representative of Washington state’s community, the committee’s duties were further complicated by potential social and ideological differences as the decisions they were to make about the candidates were not based upon objective medical criteria. For the committee members, “each month they received a pile of charts about persons with end-stage-renal disease. A

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65 Ibid.
66 This deliberately constructed microcosm of society really wasn’t one at all. “It was envisaged as representing a broad socioeconomic spectrum of the Seattle community, in hope that this would mitigate any bias in favor of candidates with certain social backgrounds or occupations.” Fox and Swazey, Courage to Fail, 230. But that did not turn out to be the case. The committee members were decidedly upper-middle class, white, and the majority was male.
68 Fox and Swazey, Courage to Fail, 230.
prior medical evaluation had rated them all medically suitable for dialysis. The committee’s task was to select one or two out of a dozen or so to take the available spots,”⁶⁹ but the patient files that reached the Life and Death Committee consisted of only those who had been deemed both medically and mentally fit for treatment by a panel of physicians.⁷⁰ Still, how, in the earliest days of the Seattle Artificial Kidney Center at Swedish Hospital, such medical and mental fitness and the degree of patient illness were assessed and whether or not such assessments were uniform for all patients remains for the most part unknown. All that the committee members knew of the patient-applicant’s medico-institutional identity was that the individual had been deemed fit for treatment and would otherwise soon die without access to one of the artificial kidney machines. Thus, “with no moral or ethical guidelines save their own individual consciences, […]”⁷¹ the Life and Death Committee was left to develop its own criteria for patient selection as well as its own guidelines for how the committee would operate. Ultimately, this was a committee that focused upon assessing each patient-applicant based upon his or her socio-political identity and how that identity fit with (or did not) the ideologies held by the white, upper-middle class, and mostly male committee members.

Explicit guidelines stated by the committee for how they would conduct their operations were few—the committee member’s names were to be kept strictly

⁷¹ Ibid.
anonymous, and, “at their second session, they decided they did not want to know the names of the patients either.”

Eventually, once the Artificial Kidney Center was open, located in the basement of the nurses’ residence next to the hospital, the committee found itself meeting in a room just down the hall from the room in which patients were undergoing treatment. Given the committee members’ proximity to the patients, an unspoken, guiding principle emerged: the committee members would have no interaction with patients. As Shana Alexander recounted in “They Decide Who Lives, Who Dies: Medical Miracle and a Moral Burden of a Small Committee,” her 1962 Life magazine exposé of the group,

Figure 7. Image of the "Life and Death Committee" from Life, 1962

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72 Ibid.
73 Ibid.
74 Illman, “Pioneers in Kidney Dialysis.”
“neither the patients nor the committee wish[ed] any such confrontation. Their relationship [was] far too intimate for casual informality.” Maintaining a distance from the patients enabled the committee to do its job; just as the committee itself and the deciding powers that rested with it enabled the physicians to do their job. The Life and Death Committee was tasked with selecting patients to receive the life-saving, blood-filtering treatments, but it was also functioned to “protect those in charge of the Center from pressure to take a given patient.” Moreover, so argued legal scholars David Sanders and Jesse Dukeminier in a 1968 article for the *UCLA Law Review*, it may be even more objectionable for the decision to be made by physicians. The physician owes to his patient a high degree of fidelity and care for his welfare. Disciplined by this duty, the medical profession has built up an enormous reservoir of public trust. When physicians select who is to live and who is to die without reference to any medical criteria, this trust may dissipate.

Thus, ultimately, “[the committee’s] authority was final and irrevocable.”

Developing criteria for patient selection was daunting, yet necessary because the pool of applicants was vast. The development of painstakingly thorough patient selection criteria was also called for as the committee did not feel that it could ethically support a lottery system or a system of accepting patients on a first-come, first-served basis. Dr. Belding Scribner, the physician-researcher whose design of the Teflon shunt made sustained use of the artificial kidney possible, and Dr. Harold Davidson, a National

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76 Ibid., 108-110.
77 J.S. Murray et al., “A Community Hemodialysis Center,” 316.
78 Sanders and Dukeminier, “Medical Advance,” 379.
79 Illman, “Pioneers in Kidney Dialysis.”
Institutes of Health (NIH) peer-reviewer who supported allocating research funds for the project, defended the patient-applicant selection criteria the committee ultimately put forth, arguing that “the first-come-first-served technique is inadequate because it may allow the thief, prostitute, or other social undesirables to be treated while excluding a working man or woman with family, merely because the application of the former antedated that of the latter’.”\textsuperscript{81} Regardless of the personal scrutiny the patient-applicants would face on top of a determination of medical/physical fitness for the treatments, kidney patients from all over the country wanted to be the first to have their lives saved (really, extended) by being hooked up to one of the new artificial kidney machines for 12-hour intervals twice a week. Upon the Center’s opening only three applicants could be selected,\textsuperscript{82} as the artificial kidney trial run through the center was intended for five patients and two pre-existed the committee’s formation and the Center’s existence (an additional five patients would be added by the end of 1962 to bring the facility’s care capacity to 10).\textsuperscript{83}

In an effort to begin to narrow the field of possible artificial kidney trial candidates, the committee determined that they would only consider patient-applicants

\textsuperscript{82} Fox and Swazey, \textit{Courage to Fail}, 231.
\textsuperscript{83} Alexander, “They Decide Who Lives,” 104; Satel and Hippen, “When Altruism,” 166: “In its first thirteen months, the committee considered thirty candidates; of the seventeen that were medically suitable, ten were chosen for treatment and seven died”; Quinn notes that the original dimensions of the Center called for a maximum outpatient capacity of nine patients. Quinn, “Who’s Worth Saving,” 10.
who were residents of the state of Washington. The committee justified this decision based upon the fact that state-funded institutions, like the University of Washington Medical School and the University Hospital, had supported the research to develop the artificial kidney technology. The committee reasoned that “the people whose taxes had paid for the research should be its first beneficiaries.” Additionally, at the recommendation of the two physicians who first gathered the committee, committee members decided they would consider neither patient-applicants over 45 years-of-age nor children. The age criteria had much to do with the heightened probability of medical complications for the older patient-applicants and a fear that the treatment procedures and processes themselves might traumatize young patient-applicants. After the age range and geographic parameter aspects of the selection criteria were determined in the first and second meetings, respectively, the committee members drafted a list of factors and conditions they would consider in the selection process:

- age and sex of patient; marital status and number of dependents;
- income; net worth; emotional stability, with particular regard to the patient’s capacity to accept the treatment; educational background;
- nature of occupation, past performance and future potential; and names of people who could serve as references.

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85 Ibid. No specific age range seems to have been associated with the term “children.” According to the recollections of committee member Rev. John B. Darrah the age guidelines for treatment of 18-45 had been agreed upon, which were later extended in both directions. Darrah, “The Committee,” 791.
In addition to these items, other factors like church attendance,\textsuperscript{87} a record of “public service,”\textsuperscript{88} employer attitude,\textsuperscript{89} whether or not the individual’s death would result in his or her family becoming a burden on society,\textsuperscript{90} and even, perhaps, the surviving spouse’s chances at remarriage were also considered.\textsuperscript{91} At one point during the discussion of patient selection criteria, a committee member suggested that perhaps they should not “consider anyone with a ‘criminal or prison record’.”\textsuperscript{92} Other committee members objected to this proposed criteria, as, according to the recollections of one committee member, “we were not primarily interested in the past, but rather the present and prospect for the future.”\textsuperscript{93} Ultimately, all of the factors that the Life and Death Committee opted to consider were ones that measured a patient-applicant’s social worth—his or her socio-political identity—against the dominant socio-cultural ideologies held by the committee members at the time.

Whether the committee intended or not, their patient-applicant selections did reflect biases. Sanders and Dukeminier highlighted these biases in what has become a rather infamous castigation of the Life and Death Committee:

> The magazines paint a disturbing picture of the bourgeoisie sparing the bourgeoisie, of the Seattle Committee measuring persons in accordance with its own middle-class suburban value system: boy scouts, Sunday school, Red Cross. This rules out creative nonconformists, who rub the

\textsuperscript{87} Ibid., 110.
\textsuperscript{88} Sanders and Dukeminier, “Medical Advance,” 377.
\textsuperscript{89} Murray et al., 316.
\textsuperscript{90} Ibid.
\textsuperscript{91} Sanders and Dukeminier, “Medical Advance,” 377.
\textsuperscript{92} Darrah, “The Committee,” 791.
\textsuperscript{93} Ibid.
bourgeoisie the wrong way but who historically have contributed so much to the making of America. The Pacific Northwest is no place for a Henry David Thoreau with bad kidneys.94

The committee had a very narrow definition of ‘contribution to society,’ and it was also one that was not made public.

UNOS’ erasing practices, in as much as they emerge from the cultural climate of the 1960s and 1980s and the previous practices of other MOPAs and proto-MOPAs are also a response to the Life and Death Committee’s use of social worth, social aspects of utility, or socio-political identity criteria in determining who would gain access to the artificial kidneys. As noted above, the Life and Death Committee drew sharp criticism for their practices. Given the polarization the committee produced and the social and political repercussions, UNOS could not afford (neither socially, politically, nor fiscally) to operate as they did. The OPTN/UNOS principle of utility explicitly excludes consideration of the social usefulness of individuals in organ allocation because, as the OPTN/UNOS Ethical Committee outlines, “considering one person more useful to society than another, based on prevailing social values, may be a matter of opinion or good fortune in the random distribution of natural and socially cultivated talents and abilities. [And] [w]e add insult to injury when we withhold the benefits of transplantation from those who may not be as likely to benefit society as those more fortunately endowed.”95

The exclusion of socio-political identity information in the calculation of organ allocation

94 Sanders and Dukeminier, “Medical Advance,” 378.
95 OPTN/UNOS, “Ethical Principles.”
scores prevents the allocation of organs only to those whom the dominant ideology of society suggests might benefit culture more at one period of time or another.

_Civil Rights_
Sanders and Dukeminier decried the actions of the Life and Death Committee, arguing that the committee was comprised of the bourgeoisie who worked to spare the bourgeoisie, that the committee members were advancing their own middle-class value system and other middle-class individuals, and that the committee sparred patients who were like themselves while those who were not were left to die. ⁹⁶ In saving those like themselves, it is very likely that those who gained access to the artificial kidney machines throughout the 1960s and 1970s were white and middle class. This is also likely, given the committee’s use of social worth criteria, for the committee members’ ideological foundations were formed as they came of age in the first part of the 20th century during which segregation was still legal.

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⁹⁶ Sanders and Dukeminier, “Medical Advance,” 378.
The Supreme Court had declared segregation unconstitutional in their *Brown v. Board of Education* ruling seven years before the Life and Death Committee first met. Yet, in 1961, men and women of different races were still not being seen or treated as equals among one another as a singular “man-as-species” (and certainly they aren’t today). On June 11, 1963, John F. Kennedy spoke to the American public of American citizens’ rights to political and social freedom and equality in his weekly radio and television address. His address and message to his “fellow citizens” was prompted by the events of that and the previous day: on June 10, 1963, President Kennedy federalized the Alabama
National Guard in order to force the University of Alabama to admit “two clearly qualified young Alabama residents who happened to have been born Negro”; their enrollment was being blocked by Alabama’s governor, George C. Wallace, as he, personally, (flanked by armed state troops) stood in the doorway of Foster Auditorium to prevent their entrance. This incident prompted Kennedy to call for broad, sweeping legal and social measures to end discrimination, segregation, and unequal treatment beyond those measures won in Brown. “Next week,” Kennedy promised to his radio and television audiences, “I shall ask the Congress of the United States to act, to make a commitment it has not fully made in this century to the proposition that race has no place in American life or law.”

Kennedy’s proposition, as it was codified and posthumously written into law with the July 2, 1964 passing of the Civil Rights Act, made it unlawful to discriminate against any persons based upon their race, color, religion, sex, or national origin. While the legislation specified the contexts of schools, housing, employment, public establishments (hotels, restaurants, retail stores, etc.), and public, government-run and funded facilities or agencies, its affects upon the culture and climate of the country were, over time, far reaching. More significantly, the passage of the civil rights legislation and enactment of antidiscrimination laws signaled that a shift in the dominant socio-cultural ideologies had been taking place in some parts of the U.S.

97 Kennedy, “On Civil Rights.”
Furthermore, the continued enforcement of the Civil Rights Act further aided in reshaping socio-cultural ideologies within America and beyond.

Two things come out of this that help us to understand both the legal and cultural contexts out of which UNOS arose. First, the Civil Rights Act of 1964 both reflected and reinforced the ideological changes that were taking place in the U.S., as culturally, the U.S. was simultaneously moving and being prodded towards antidiscrimination. Second, the Civil Rights Act of 1964 prevented discrimination from being written into all future laws, acts, regulations, and policies. Thus, it is out of a social and political climate greatly shaped by civil rights legislation, as well as biopolitics, that organ procurement and allocation practices were enacted and, ultimately, the act providing for a nationwide Organ Procurement and Transplant Network, run by UNOS, was born. UNOS’ commitment to antidiscrimination is supported by its erasing practices; although that does not mean that erasing practices ensure justice.

*Cyclosporine*

The field of organ transplantation changed dramatically in 1983 when the FDA approved cyclosporine, a drug that aided in transplantation by suppressing an organ recipient’s immune system.\(^{100}\) Suppressing a transplant recipient’s immune system is a necessary step after organ transplantation because the patient’s white blood cells do not recognize the new organ as ‘self’—the transplant recipient’s body sees the new organ as ‘other’ and attempt to destroy it. This is what a healthy immune system is supposed to

\(^{100}\) Fox and Swazey, *Spare Parts*, 4.
do; knowing how to recognize ‘self’ from ‘other’ and mobilizing an immune response is how the body fights off a cold or an infection, an invading body, or pathogen.

The advent of cyclosporine and its widespread use in transplantation—becoming “a drug that was ‘almost universally given to transplant recipients’ alone or in combination with other immunosuppressive agents”101—meant that what at the time had been the greatest barrier to successful organ transplantation—rejection—had been overcome.102 Because cyclosporine was approved for commercial use, organ sharing between genetically unrelated individuals was now possible. Seemingly overnight, the number of patients considered suitable candidates for organ transplantation increased fivefold.103 Cyclosporine completely altered the landscape of transplant medicine as it “...played a preeminent role [in] moving organ transplantation ‘from an experimental operation to an accepted mode of treatment for many end-stage heart, lung, liver, and

101 Ibid.
102 As presented in the Hearings Before the Subcommittee on Investigations and Oversight of the House Committee on Science and Technology, 98th Cong., 1st Sess. 145 (1983):
“At the University of Pittsburgh, one of the first transplant centers in the United States to use cyclosporine, the survival rate for kidney transplant patients rose from 50% to 80% when the hospital began to use cyclosporine in 1980 and subsequently increased to 90% in 1981. The survival rate for nonrenal transplant patients also increased dramatically. When hospitals began using cyclosporine in liver transplants, the one-year survival rate doubled to approximately 65-70%. At Stanford University, the Shumway Heart Transplant Team reported that with the use of cyclosporine, 80% of heart transplant recipients survive two years or longer. Before the introduction of cyclosporine, only 20% of heart transplant recipients survived one year or more.” rpt. in Denise, “Regulating the Sale,” 1037.
103 United Network for Organ Sharing, “UNOS Celebrates 25th Anniversary.”
renal diseases.” Cyclosporine meant that bodies themselves were no longer able to discriminate on the basis of difference.

Cyclosporine caused a significant shift in the climate and culture of transplant medicine. Because of the drug’s success, “the number of people listed for transplantation quickly shot from about 2,000 nationwide to more than 10,000.” In 1983, the NIH proclaimed liver transplants therapeutic, an act which further opened the flood of potential transplant patients for all organs. A significant advancement in biomedical technology had made it possible for 8,000 people, for whom biology had made an organ transplant an impossibility to suddenly see an organ transplant as a possibility. Cyclosporine not only meant more transplant candidates, but also the need for more organs. The rapid increase in the demand created a need for the greater management of organs and also the management of organ donor and transplant patient identity information as transplants between unrelated donors and recipients were now possible given how effective cyclosporine was at mitigating organ rejection.

_Early MOPAs_
In 1983 there were roughly 120 independent, nonprofit MOPAs coordinating donations “throughout the country, representing both state and federal government involvement and some private sector interests.” These independent MOPAs were regulated neither at the state nor federal level, thus hospitals, regions, and physicians had to

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104 Ballantyne et al., 53 rpt. in Fox and Swazey, _Spare Parts_, 4.
105 Ibid.
106 Blank, _Rationing Medicine_, 49.
107 Denise, “Regulating the Sale,” 1018.
enact their own organ procurement and allocation policies and identity management practices as a result of the sudden boom in organ demand due to the new-found transplant successes with cyclosporine. The pool of agencies involved in organ procurement and allocation was not only unregulated but also poorly coordinated, and many found trying to work with multiple, independent agencies operating with different protocols and principles problematic.

In 1983, the Subcommittee on Investigations and Oversight of the House Committee on Science and Technology held hearings on the Procurement and Allocation of Human Organs for Transplantation. Bioethicist Arthur Caplan was called upon to testify before the committee about the state of the transplant system in the U.S. In his testimony, Caplan stated that the ‘system,’ which was made up of 120 or so different MOPAs involved “‘too many private agencies, organizations and groups [engaged] in inefficient and redundant activities.’”\(^{108}\) Furthermore, the House Committee on Energy and Commerce went so far as to say that the low donation and transplantation rates resulted “primarily from the poor organization of the nation’s procurement efforts.”\(^{109}\) Keith Mueller, a professor of public health and health policy management, in reviewing Congressional responses to changes in biotechnology, found that the coordination of procurement and allocation efforts was so poor “during the early 1980s, some agencies


\(^{109}\) Denise, “Regulating the Sale,” 1018.
were actually disposing of unused organs, while other regions of the country suffered a shortage.”

As there were no nationwide, standardized, codified, or government-sanctioned models of organ procurement or allocation until the mid-1980s, there were many questions that physicians, hospitals, and agencies faced on their own and had to answer for themselves and their patients. Each unit found itself in a position that required it to draw up regulations, but regulations that only applied at a single site. Each had to ask and answer a myriad of questions: How should organ allocation be handled? Should a first-come-first-served protocol be used, or should organ allocation be based upon patient need? If need, then how should a hospital determine, measure, or rank need? Was it okay to approach the family of someone who might die while in the hospital to see if the next of kin might be willing to donate their loved one’s organs? Could someone in need of an organ for transplantation buy an organ? Could a potential transplant candidate pay another person to be a live donor?

Because the questions and answers varied site to site and in many cases even in a single hospital policies were not clearly defined, some patients and patient families tried to use the lack of clarity and inconsistencies to their own advantage. In an attempt to gain organs for transplant, some transplant candidates and their family members did what they could to publicize their own need and highlight the socio-political identity characteristics of their ill loved one to gain organs. Other transplant candidates and

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their family members sought to take advantage of the low socio-political and economic standing of people in the third world and pay them to be live organ donors. These early MOPAs that emerged (they are, in fact, models of organ procurement and allocation) because cyclosporine’s success suddenly made organ transplantation possible for thousands of patients prompted the formation of the Task Force on Organ Procurement and Transplantation and further shaped UNOS’ erasing practices once it was selected to administer the OPTN.

“Save that Little Girl”
On July 23, 1983 the shortage of organ donors was given national attention when President Ronald Reagan made an appeal in his weekly, national radio address for Ashley Bailey.\textsuperscript{111} Ashley Bailey was an 11-month-old girl from Texas who was in need of a liver transplant. Reagan explained, “Right now, somewhere in America, there may be a pair of stunned and grief-stricken parents whose own baby has died in an accident or is sadly near death. I know if these parents were aware they could make it possible for Ashley to live, they would have no hesitation in saying, 'Save that little girl'.”\textsuperscript{112} In addition to his plea for an organ to save the life of young Ashley Bailey, Reagan pled for an organ to save White House electrician Stuart Thomas’s young daughter Candi, and went on to address the overall issues of organ transplants and the organ shortages:
Reagan said,

\begin{flushleft} \textsuperscript{111} Reagan, “Radio Address to the Nation.” \\ \textsuperscript{112} Ibid. \end{flushleft}
America has faced shortage in the past of everything from nylons during World War II to oil in the 1970's. But modern medical science has provided us with a new shortage—a shortage of living organs: livers, hearts, lungs, eyes, kidneys. I urge all Americans to fill out donor cards, little cards you carry in your wallet or purse that, in the event of your death, offer the hope of life to others.\textsuperscript{113}

Reagan’s plea was a type of MOPA, one that was effective as, among other things, it was deeply affecting. A week later, in his July 30, 1983 radio address to the nation, Reagan reported “over 5,000 calls were received from people in 47 States. Many callers asked for donor cards so they could help others even after they're gone.”\textsuperscript{114} Reagan also shared the status of one of the young patients he had specifically mentioned in his previous week’s broadcast as well as others his national appeal had helped: “Six liver transplants have already taken place. Six children, including Candi Thomas, one of the little girls I mentioned last week, have been given a new lease on life. And two people have received cornea transplants. They were given the gift of sight by one of our neighbors who heard about a chance to help.”\textsuperscript{115}

Reagan’s two radio addresses brought attention to the severe organ shortage and successfully encouraged many to register as organ donors. Paul Taylor, transplant coordinator for the University of Colorado Health Sciences Center, observed: “I have been in the transplant game for 21 years and there have never, ever, seen three donors from one place in one week.”\textsuperscript{116} Still, Reagan’s appeals to the American audience were

\textsuperscript{113} Ibid.
\textsuperscript{114} Ibid.
\textsuperscript{115} Ibid.
\textsuperscript{116} Associated Press, “Six Children Get New Livers.”
neither enough to save Ashley Bailey nor the thousands of other patients for whom cyclosporine had recently made organ transplantation a life-saving option.¹¹⁷

“...And For the Low, Low Price of $5000...” In September 1983,¹¹⁸ just a few months after President Reagan made his plea to the nation to save Ashley Bailey and other patients in desperate need of organ transplants, Dr. H. Barry Jacobs¹¹⁹ founded International Kidney Exchange, Inc.¹²⁰ While President Reagan fostered a MOPA that appealed to the nation in hopes of growing the donor pool, Jacobs, desiring the same ends, endeavored to find a different means of stemming the organ shortage. Reagan and Barry’s strategies were rather different. In developing a business model for the Virginia-based International Kidney Exchange, Inc., Dr. H. Barry Jacobs relied upon the capitalist ideology that underpinned much of America in the “greed is good” 1980s. In effect, what Dr. Jacobs had done with the founding of the International Kidney Exchange, Inc. was form organ brokerage company: “Jacobs intended to solicit healthy individuals to sell one of their kidneys at their chosen price.

¹¹⁷ Ashley Bailey died 11 November 1983 as “no liver donor was found to match her small size and blood and tissues types.” Unfortunately for this young patient, so explained chief of surgery Dr. John Majarian, “‘the irony of the situation is that on this very day we’re going to be doing a transplant on a child just about the size of Ashley Bailey. A donor is available today – the day of her death. So that’s really quite sad.’” Associated Press, "Girl Dies," 2.
¹¹⁸ Denise, "Regulating the Sale," 1016.
¹¹⁹ According Jeff Rowes, an attorney for the Institute for Justice, H. Barry Jacobs was “a Virginia doctor who’d lost his medical license after a mail-fraud conviction in 1977.” Rowes, “IJ's Bone Marrow Case: History of NOTA.”
¹²⁰ I have also seen Dr. Jacob’s company referred to in print as the International Kidney Exchange Ltd. In this project, however, I defer to the authority of Renée C. Fox and Judith P. Swazey.
[And] a person needing a transplant would pay for the cost of the kidney plus $2000 to $5000 for Jacobs' services.”\textsuperscript{121}

However, before he could solicit donors, Dr. Jacobs needed to line up “clients” (i.e. patients suffering renal failure) and doctors willing to work with his company. In September 1983 Jacobs wrote to 7500 hospitals, inviting them to participate in his organ brokerage firm.\textsuperscript{122} In a September 19, 1983 article in The Washington Post, staff writer Margaret Engle reported, “several of the nation’s 7500 hospital he contacted by letter... have expressed interest in removing kidneys of the healthy donors Jacobs plans to solicit.”\textsuperscript{123} Thus, through Jacob’s company, participating hospitals would be able to buy and sell human kidneys in national and international markets.\textsuperscript{124} According to scholars Renée C. Fox and Judith P. Swazey in their book \textit{Spare Parts: Organ Replacement in American Society}, the International Kidney Exchange, Inc. intended to “[commission] kidneys from persons living in the Third World or in disadvantaged circumstances in the United States for whatever price would induce them to sell their organs, and then negotiate their acquisition for a fee, by Americans who could afford to purchase them.”\textsuperscript{125}

\textsuperscript{121} Denise, "Regulating the Sale,” 1016.
\textsuperscript{122} Fox and Swazey, \textit{Spare Parts}, 65.
\textsuperscript{124} Fox and Swazey, \textit{Spare Parts}, 65.
\textsuperscript{125} Ibid.
Dr. Jacobs’s proposal to broker kidney sales from live donors was completely legal when he first incorporated the International Kidney Exchange.\footnote{Denise, “Regulating the Sale,” 1016.} His practices, however, were deemed “‘immoral and unethical’ by The National Kidney Foundation, the Transplantation Society, the American Society of Transplant Physicians, and the American Society of Transplant Surgeons.”\footnote{Fox and Swazey, \textit{Spare Parts}, 65.} Once the U.S. Surgeon General C. Everett Koop learned about the proposed International Kidney Exchange, Inc. from the FDA in July of 1983, he counseled Jacobs against the commercial venture even though there were no federal regulations that prohibited such practices at the time. However, six months after Jacobs’ company was incorporated, Virginia passed legislation prohibiting the sale of organs,\footnote{Denise, “Regulating the Sale,” 1016.} and within little more than a year congress passed a federal law prohibiting the sale of human organs.\footnote{NOTA was signed into law on October 19\textsuperscript{th} 1984.}

\textit{Establishing a Nationwide MOPA — The National Organ Transplant Act of 1984} 

The congressional hearings that resulted in the National Organ Transplant Act (NOTA) were a result of Reagan’s, Jacobs’, and many other group and individual practices to bring attention to the severe organ shortage and gain more organ donors. Al Gore, then a congressman from Tennessee, was instrumental in making organ transplantation “a federal policy concern through congressional… action”\footnote{Mueller, “The National Transplant Act of 1984,” 347.} as he brought the issue to the attention of investigative committees and subcommittees. In hearings before the
Committee on Labor and Human Resources, the Subcommittee on Health and the Environment, the Committee on Energy and Commerce, the Subcommittee on Investigations and Oversight, and the Committee on Science and Technology, congressmen were confronted with and considered the ethical as well as administrative issues associated with organ transplantation.\footnote{Ibid., 349-350, 356. 

Of great concern in the hearings were the manners in which some were going about getting organs and how available organs from cadaveric donors were being allocated—i.e. concern over the models of organ procurement and allocation that were spreading throughout the U.S. Reagan’s radio address and Jacob’s proposal were examples of the lengths to which individuals were willing to go when in need of an organ. But not just a general need—their own personal need.

Many were troubled by the media-abetted crowdsourcing of organs. In his testimony before the Subcommittee on Investigations and Oversight, Robert Veatch, a professor of medical ethics at Georgetown University, condemned the desperate situation of organ transplantation in the U.S.: “As a society, [...] I believe we should be ashamed that these people are forced to use ad hoc techniques, personal charisma and persuasion to obtain organs for their families.... It is unfair to those who lack the power or access to those means of getting organs.”\footnote{Ibid., 349-350, 356. 
Hearings Before the Subcommittee on Investigations and Oversight, Committee on Science and Technology, W.S. House (July 29, 1983) National Organ Transplant Act. Washington, DC: U.S. Government Printing Office: 339 rpt. in Ibid. 349.} Veatch’s comment about these organ procurement and allocation practices encapsulated the concerns many held about the
growing medical-media trend. The stories in the news, the lack of institutional oversight, and the lack of information about what organ donor registration meant and how organs were allocated meant that individuals were registering to become donors to donate their organs not to all those in need but to the child or a child like the one mentioned in the President’s radio address, the sibling featured in a local newspaper story, or because of a family member’s plea covered in primetime.

Many were also troubled by Dr. H. Barry Jacobs’ International Kidney Exchange and the proposed payments for organs scheme. Of the proposed commodification of organs, U.S. Representative Al Gore said, “‘Putting organs on a market basis is abhorrent to our system of values [...] It seems to be something inconsistent with our view of humanity... Prostitution is illegal for reasons that are similar. So is slavery.’”133 Gore’s comment about these organ procurement and allocation practices encapsulated the concerns many held about the commodification of the body, the ways in which paid donors would be treated, and what might happen to those in need of transplants who could not pay the market rate for an organ. The incorporation of the International Kidney Exchange alienated many, but it also illuminated how desperate the need for organs had become.

The hearings revealed the need for nationwide MOPA that could ensure the equitable allocation of organs, a MOPA that could uniformly assess and rank medical need, and a MOPA that would make organ transplantation a possible solution for all

those in medical need. From the various testimonies given in the committee and subcommittee hearings, it became apparent that federal government involvement was needed to provide, at minimum, assistance in ensuring “an adequate supply of organs” as well as to coordinate the procurement and distribution of organs.\(^\text{134}\)

UNOS and UNOS’ policies were shaped by National Organ Transplant Act (NOTA), P.L. 98-507, which was signed into law by President Reagan on October 19th, 1984. But the organization that we know UNOS—the United Network for Organ Sharing—was first incorporated in 1975 as SEOPF—South-Eastern Organ Procurement Foundation. SEOPF’s practices, as the first institutionalized MOPA, had a significant bearing on UNOS’ practices when it became the first organization to oversee the procurement and allocation of organs nationwide.

**SEOPF**

In 1975, having grown out of the Southeastern Regional Organ Procurement Program (SEROPP), “one of seven original organ procurement programs funded by the federal government in 1969,”\(^\text{135}\) the South-Eastern Organ Procurement Foundation (SEOPF) was incorporated.\(^\text{136}\) SEOPF was a “membership and scientific organization for transplant professionals”\(^\text{137}\) that functioned as a site of exchange for surgeons who were pioneers

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\(^{135}\) Louisiana State University Health Sciences Center, “Transplantation Contributions.”


\(^{137}\) United Network For Organ Sharing, “Timeline of Key Events.”
in the field of organ transplantation and transplant centers throughout the mid-Atlantic and Southern regions of the United States.\textsuperscript{138}

At the first meeting of the newly incorporated SEOPF, Gene A. Pierce, later the founder and first executive director of UNOS, put forth the idea of establishing a “Kidney Center with the purpose of increasing kidney-sharing, assisting in organ transport and providing general assistance to the procurement coordinators”\textsuperscript{139} as more and more hospitals were opening transplant centers. Pierce’s idea, much to his surprise, was met with great resistance by SEOPF’s executive board: “One surgeon on the board said that in the kidney distribution process, ‘doctors need to talk with doctors’,\textsuperscript{140} which seemed to reveal how new, unknown, and tenuous organ sharing happened to be. Despite the lack of support Pierce found from members of the executive board, he felt his idea for a centralized institution to aid in kidney sharing had merit and would be of great benefit to the growing community of transplant centers. So Pierce, independent of SEOPF, went in search of funds to establish his Kidney Center. Two years later, having secured funds for a two-year trial of a centralized kidney placement institution from the American Kidney Fund (AKF), and accepting the edict that no SEOPF funds would be used for running, staffing, or maintaining the Center, SEOPF’s executive board approved the institutionalization of Pierce’s Kidney Center and its mission to

\textsuperscript{138} Ibid., “UNOS Celebrates 25th Anniversary.”
\textsuperscript{139} Pierce, “A ‘Profound Idea’,” 24.
\textsuperscript{140} Ibid.
increase the efficiency of organ distribution.\textsuperscript{141} SEOPF’s Kidney Center opened in 1982 and it became the foundation for larger developments in organ procurement and allocation practices, for once “SEOPF rolled out its first extra-renal organ-matching center ... the Kidney Center became known as the Organ Center,”\textsuperscript{142} and later, “UNOS was molded, shaped, and largely directed by SEOPF.”\textsuperscript{143}

SEOPF served as more than just the institutional template off of which UNOS was based: UNOS’ name, the beginnings of its matching practices, and its technology came from SEOPF initiatives as well. In order to carry out matching donated organs with transplant patients and prevent waste, SEOPF recognized early on that organs would have to be shared between hospitals and regions and that computer technology would play a significant part in their efforts.\textsuperscript{144} As more and more transplant centers across the U.S. wanted their patients to have a chance at receiving an organ from a nationwide pool,\textsuperscript{145} more and more sophisticated computers and programming were needed to manage all of the information. SEOPF moved their computers in-house and worked with developers to create a specific computer program to help provide round-the-clock

\textsuperscript{141} Ibid. SEOPF, however, did allot the Kidney Center space for operations as they were first based out of a conference room in SEOPF’s headquarters in Richmond, Virginia.
\textsuperscript{142} Ibid., 25.
\textsuperscript{143} McDonald, \textit{SEOPF: Accomplishments}, 2.
\textsuperscript{144} Ibid., 5.
\textsuperscript{145} Ibid., 7.
assistance in placing time-sensitive organ offers.\textsuperscript{146} The computer program was named the United Network for Organ Sharing.

Of the 120 independent, nonprofit OPOs coordinating donations throughout the U.S., SEOPF was the only one of its kind. It was, according to transplant pioneer John C. McDonald, “the only organization in this country to address the issues of how the profession could deliver the service of transplantation to the population at large.”\textsuperscript{147}

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In the creation of the nationwide Organ Procurement and Transplantation Network (OPTN), we see how the cultural contexts and previous practices of MOPAs and proto-MOPAs intersect to produce UNOS and the policies by which it operates. As cyclosporine improved immunosuppression, organ transplant surgeries shifted from being seen as experimental to being understood as therapeutic, biotechnological interventions. The sudden explosion of the list of people for whom organ transplantation was now an option drew attention to the absence of nationwide organ procurement and allocation policies. Various independent MOPAs and individuals attempted to fill both the supply and policy gaps, but biopolitics or a call for the exercise of biopower prevailed. In becoming a biopolitical institution to manage the OPTN, UNOS was influenced and shaped by the broader U.S. culture as well as previous

\textsuperscript{146} United Network for Organ Sharing, “UNOS Celebrates 25th Anniversary”; United Network For Organ Sharing, “Timeline of Key Events.”

\textsuperscript{147} McDonald, \textit{SEOPF: Accomplishments}, 8.
situations in which patients were not treated fairly or equitably and organs were being wasted.

Transplant surgeries rely upon the altruism of organ donors. Potential donors will not register as donors and transplant surgeries will not take place if potential donors do not have confidence in the transplant system. Erasing practices were adopted by UNOS to ensure the fair and equitable allocation of organs and to inhibit discriminatory practices, the history of which has long plagued the institution of medicine in the U.S. The development and use of organ allocation formulas and computerized matching through UNet erase; such erasure also protects doctors and transplant teams as they help to ensure complete support of each transplant candidate. On the one hand it would seem that erasing practices support justice within the transplant system; on the other hand, that has not proven true because the practice of erasing socio-political identity information has created a transplant system that alienates potential donors and places racial and ethnic minorities at a disadvantage in the allocation of organs.

Part III: Affects/Effects of Erasure
According to Fox and Swazey, in the early years of organ transplant procedures, transplant teams revealed identity information of cadaveric donors, their recipients, and their families, and gave details about each others’ backgrounds and lives.148 This information was shared not for use in organ matching or the selection of recipients—as the Life and Death Committee had done in determining which patient-candidates would

148 Fox and Swazey, Spare Parts, 37.
gain access to the artificial kidney machines—but the identity information was shared with transplant recipients and the family members of deceased donors because “physicians believed that these intimate participants in the acts of giving and receiving that transplantation entails were entitled to such knowledge.”

As more transplants were performed and transplant teams had more encounters with transplant recipients and donor families, they were discomforted by what they observed: “recipients, their kin, and donor families personified cadaver organs.” Because of these interactions the policy of anonymity was adopted. Overtime that policy of anonymity trickled up from hospital to regional transplant center and into the structure and functioning of UNOS’ identity management practices.

UNOS is a MOPA that erases. The formulas it uses in allocating organs are meant to ensure the equitable allocation of organs based upon medical data, but these formulas also erase. The specific data fields established for gathering information on deceased potential organ donors for purposes of determining the suitability of the donor and matching also erase. And finally, UNOS’ policies regarding the disclosure of donor and recipient information erase. Functioning by erasure is thought to be something that protects donors, transplant candidates, transplant recipients, and the institution itself. The limiting of information is meant to be protective, but it seems that UNOS’ identity management practices extend beyond its donors and patients to itself,

\[149\] Ibid.
\[150\] Ibid.
for many do not know how it operates. The limiting of information does not support improving the health outcomes of transplant candidates for it compromises organ donors’ willingness to donate and the organization’s ability to gain more organs for transplants; it also compromises the post-operative recovery of many transplant patients. Part III looks at the types of feelings that result from the affect motivated by erasing practices. In particular, this part examines how the practices of erasure affect organ transplant recipients as well as organ donors/donor families and discusses how these experiences effect the overall transplant system.

**Transplant Recipients**

For organ transplant recipients, the organs they receive are material objects with material effects—pumping blood, taking in oxygen, filtering out bodily wastes, etc. Yet these autonomous organs are also affective objects, for “donor kin and recipients share the understanding that the transplanted organs, as donor fragments, carry with them some sense of their former selves, and this persists in the bodies of recipients.” The identity management practices of erasure promulgated by UNOS complicates the recovery process for many transplant patients by suppressing knowledge of the donor’s former self, a part of which resides within the transplant recipient.

In terms of each organ there is some sort of excess—not an excessive fleshiness or an excess number of nephrons, but an excess of affect that perpetually escapes the form in which it might be captured or reside that causes transplant recipients like Claire

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151 Sharp, *Strange Harvest*, 190.
Sylvia to think about an organ as more than just a mechanically or organically functioning material object aiding in the circulation of other materials within the body. UNOS as well as many transplant professionals would prefer that transplant recipients think of their newly transplanted organs in purely mechanical or organic ways—

“Transplant recipients are encouraged to depersonalize their new organs and speak of them in terms that can sometimes even approximate car repair.” The oft proffered analogy given is that the body is like a car and whatever failing organ is like a clogged fuel filter or no longer functioning alternator; replace the fuel filter or the alternator and it is still the same car, it just runs better. But the excess—within, beside, surrounding—the organ is immaterial, and its escape is that which contributes to the sense of singularity of the organ—after her transplant Claire remains Claire; she just has a new heart from Tim L.

This excess means that an organ is not only ontologically charged but also affectively charged. For it is in the affect produced by excess, or in that which escapes the organ, that identity may lie, indelibly linking organ and subject. Organ transplantation is a medical process, but it is also, as anthropologist Leslie A. Sharp frames it, a “sociomedical process.” The in-body changes transplant recipients experience are not just medical or biological but social as well, for they involve the

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152 Sharp, Strange Harvest, 14.
154 Sharp, Strange Harvest, 4.
identity of the donor which is bound up in the organ and the identity of the transplant recipient. The changes in material composition of the self affects the transplant recipient as he or she struggles to understand his or her post-operative hybridity, his or her relationship to the donor organ, and perhaps his or her relationship to the deceased or anonymous living donor. Sharp explains, “[organ transplant] recipients do in fact imagine a donor’s identity in all sorts of ways and frequently integrate this unknown Other as an intrinsic part of their subjective sense of self.”

The lack of information transplant recipients receive about the donor because of UNOS’ erasing practices often makes that integration all the more challenging. The integration of a new organ is critical to the organ transplant process, for, according to Nicolas Rose, “...we are increasingly coming to relate to ourselves as somatic individuals, that is to say as beings whose individuality is in part at least grounded within our fleshly, corporeal existence, and who experience, articulate, judge, and act upon ourselves in part in the language of biomedicine.” The language of biomedicine, of the process of organ transplantation and recovery was one thing for Claire; however, the experience itself—the change to her corporeal self with the implantation of an organ from a donor much of whose socio-political identity had been erased—threw her somatic and psychological self into question.

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155 Ibid., 5.
After her heart-lung transplant Claire Sylvia struggled to understand who she was. Up until her surgery she had been ill, and much of her life revolved around that illness. The illness and her own failing organs were a part of who she was—“your illness may not be pleasant, but at least it’s yours. It’s familiar, and you know how to cope with it,”¹⁵⁷ she explained. While Claire did not miss her old heart or lungs or her old illness, the changes involved not only in getting used to not being ill but also getting used to living with someone else’s heart and lungs were deeply unsettling.¹⁵⁸ Claire had been a dancer, a passion and profession for her that involved a deep awareness of her body; after her transplant she struggled to understand her post-operative-self as

...now, certain parts of that body—big, major, important parts—had been taken away and replaced with somebody else’s. What did that mean? What was this ‘else’? And how did he, or it, fit into me? I had always known who I was, but who was I now? I had been ripped in two and sewn back up, but something was different. ... But that new, reconstructed person just wasn't me.”¹⁵⁹

Claire struggled not only intellectually and philosophically with reconciling her new post-transplant-self, but also with the emotional and physical feelings the transplant stirred for her. Reflecting upon that first week after receiving her transplant, Claire explained, “I knew only that the very center of my being was not fully mine, that it functioned and pulsated with its own rhythm, and a sense of separateness and independence. I didn’t understand what was happening to me—but whatever, it was I found it enormously

¹⁵⁷ Sylvia, Change of Heart, 97.
¹⁵⁸ Ibid.
¹⁵⁹ Ibid., 91-92.
upsetting.” The physical feeling that the heart was separate, not physically integrated into her in the way that her old one was could be explained: Claire’s doctor explained that to fit the new heart into her chest cavity he had to position it further back than the old one. But her feeling that it was somehow independent of her and that her center was no longer her own was compounded by her changes in tastes and preferences that seemed to come along with the new heart and lungs, changes she could not make sense of given the erasing practices supported by Yale-New Haven Hospital.

On the third day after her transplant, Claire was interviewed by two reporters who had come to write a story about the first heart-lung transplant in New England. At the end of the interview one reporter asked, “‘Claire, now that you've had this miracle, what do you want more than anything else?’” Without thinking much about it, Claire responded, “‘Actually,’ … ‘I'm dying for a beer right now.’” Her own response completely perplexed her and made her all the more curious about her donor:

As soon as those words came out of my mouth, I wished I could pull them back in. I was mortified that I had answered this sincere question with such a flippant response. I was also surprised because I didn't even like beer. At least I never had before. But the craving I felt at that moment was specifically for the taste of beer. For some bizarre reason, I was convinced that nothing else in the world would quench my thirst.

The unexplainable craving for a beer piqued Claire’s curiosity about her new organs and their donor. The craving also further complicated her own understanding of herself.

160 Ibid., 92.
161 Ibid., 89.
162 Ibid.
163 Ibid., 89-90.
For Claire, the idea that “maybe the donor of my new organs, this young man from Maine, had been a beer drinker” made her wonder if the “heart had reached me with its own set of tastes and preferences?” Such thoughts and questions were deeply unsettling for Claire; the affect motivated by the presence of the new heart and lungs sent her into a deep depression. Depression can complicated the post-operative health outcomes of transplant patients—patients’ psychological health effects their physiological health, and the body does not recover as readily. Depression also leads to non-compliance. Patients who are depressed may stop taking their anti-rejection medications.

Beth Israel Deaconess Medical Center’s Transplant Institute in conjunction with more than $3 million in funding from the NIH and HHRS has taken steps to treating not only the medical but also the psychological complications associated with organ failure and transplantation. Depression is a critical piece of this because it has an impact upon a transplant recipient’s long-term recovery from the surgery. Though Claire was depressed, troubled, and struggled for years to understand her post-transplant self, medically, her recovery was successful: Claire lived for an additional 21 years after her transplant; she died in 2009 at the age of 69.

How people feel about their organs during recovery, as a result of the affect that those organs motivate, often becomes more profound when that which is transplanted

164 Ibid., 90.
165 Beth Israel Deaconess Medical Center, “Behavioral Health Research.”
166 Ibid.
167 Ruzicka, “Claire Sylvia, 69.”
can be seen—when limbs and appendages are transplanted rather than just internal organs. In 2006, Chinese surgeons performed the first ever penis transplant. Earlier that year the patient had been in an accident that damaged his penis beyond repair; the 1cm left of the organ was not enough to allow for urination or intercourse. Although doctors had previously performed surgeries in which they reattached a penis to the man from whom it had been damaged in an accident or attack, this was the first time a ‘donor penis’ was successfully transplanted.

After 15 hours of surgery and 10 days of recovery, tests revealed that the transplant was a success—the blood supply to the organ was more than adequate to sustain the transplanted penis and the man was able to urinate normally. Physiologically, the 44-year-old patient with a penis from a brain dead man half his age was fine. Psychologically, he was suffering. Two weeks after the successful transplant, the surgeons who performed the initial surgery removed the penis: “‘Because of a severe psychological problem of the recipient and his wife, the transplanted penis regretfully had to be cut off.’” The affective intensity of the donor penis did not compromise the transplant as after its removal, “an examination of the organ showed no signs of it being rejected by the body,” but it certainly compromised the transplant recipient’s post-operative health and wellbeing.

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168 See Waldby and Mitchell, *Tissue Economies*.
169 Sample, “Man Rejects,” 3.
170 Ibid.
171 Ibid.
In 1998 Clint Hallam was the first man to receive a hand transplant. Two years later Hallam asked the surgical team that performed the transplant to remove the hand. Hallam asked to have the hand removed because, among other reasons, he claimed “he had become ‘mentally detached’ from it.”\(^{172}\) Hallam further explained that “his body and mind had said ‘enough is enough’ and the hand should be amputated.”\(^{173}\) The mental detachment Hallam had from his transplanted hand contributed to the chronic rejection he was experiencing. Eventually it even led him to discontinuing his anti-rejection medications. Ceasing to take those medications put his health in jeopardy and forced his surgeons to amputate the hand.

For transplant recipients like Claire Sylvia, Clint Hallam, and the man who underwent the penis transplant, striving for better health outcomes for transplant candidates really does mean taking into consideration more than just the bios.

Considering affect and the effects affect produces as a result of MOPAs identity management practices help us to achieve this as

\[\text{[i]n the analysis of the body, affect allows more than an analysis of discourses, meaning systems, and the social construction of the body; it also allows for an analysis of the dynamism of the body’s matter, such that the body is thought as a center of action and reaction, a site of energy flows and changes in intensity.}\] \(^{174}\)

Looking at the body as Elizabeth Wissinger suggests above, as the center of dynamism, dynamism is complicated when transplant recipients know little about the energy that is

\(^{172}\) Ibid.
\(^{173}\) “Transplanted Hand Amputated.”
brought into their bodies with the transplanted organs from unknown donors. By
framing successful MOPAs as those that promote better health outcomes for transplant
patients, restricting information that may allow a transplant recipient to better integrate
the new organ presents an impediment for some to achieving those positive medial
outcomes.

*Organ Donors*
Unless one is in need of an organ transplant, becomes a living donor, or donates the
organs of a loved one, most individuals do not have a good understanding of how UNOS
functions or how organ donation and organ allocation work. The erasing practices
promulgated by UNOS compromise the health outcomes of transplant candidates as
they contributes to a climate of non- or mis-information that often decreases potential
organ donors’ wiliness to donate or outright discourages organ donation.

The erasing practices and culture of anonymity that has suffused UNOS has, in
part, created a knowledge gap for potential donors. For those who otherwise have no
direct personal experience with organ donation or transplantation, they receive their
information about these processes through the media. The media has done no
favors for the organ transplant system in the U.S. as, according to research done by
Susan Morgan et al., “inaccurate and negative portrayals of organ donation and
transplantation are surprisingly common on TV and feed the public’s fears about the

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175 Morgan et al., “Entertainment (Mis)Education,” 143.
From 2004 to 2005, Morgan et al. conducted an exhaustive study of all of the television shows during that period that had organ donation storylines or subplots. Morgan et al. concluded that save for a few notable exceptions, organ donation was consistently framed in negative terms in all TV shows. The negative portrayals of donation and transplantation practices by the media are deeply problematic as “organ transfer is especially vulnerable because it must always struggle against public perceptions that this highly specialized branch of medicine preys on the bodies of dying patients.” Such negative perceptions are incredibly problematic for a system that depends upon the altruism of deceased donors and donor families. Erasure practices do little to counter the negative portrayals.

The negative portrayals of organ donation and transplantation on TV shows are especially problematic when people don’t have competing sources of information. As the primary source of information about organ donation and transplant practices for most people is the media, this proves to be an issue “because most people cannot test the accuracy of fictional portrayals against personal experience with organ donation and transplantation.” The medium compounds the situation, according to Sara Pace Jones, chairwoman of Donate Life America: “Some fears are perpetuated by dramatic television shows that, because they have to tell a complete story in an hour or less,

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176 O’Reilly, “Campaign Targets TV’s.”
177 Morgan et al., “Entertainment (Mis)Education,” 143.
178 Sharp, Strange Harvest, 26.
179 Morgan et al., “Entertainment (Mis)Education,” 143.
180 O’Reilly, “Campaign Targets TV’s.”
don’t have time to show the accurate and entire process of donation’.  

The lack of other sources of information about transplant practices, about donors, and transplant candidates means that many people who develop opinions about transplantation as a result of what they see on television report, “story-consistent beliefs and evaluations, regardless of whether a narrative was labeled as fact or fiction.”

The misrepresentation of organ procurement procedures and the treatment of organ donors in potent dramas is deeply problematic not only because viewers may develop “story-consistent beliefs,” but also because the media’s influence viewers’ judgment actually has lasting effects: regardless of whether or not the claims presented are true or false, the messages taken away from experiencing fictional narratives are actually integrated into real-world knowledge. Thus, the more that audiences view TV shows that depict doctors letting patients die just to harvest their organs, or a poor person in need of an organ being passed over in favor of a rich politician, or women from the third world being flown into the U.S. to have their kidneys harvested in a warehouse, the less likely that viewers are to donate. Erasure further complicates how people feel about organ donation because of the mystery it creates around what happens if you are a donor, how the body is treated during donation, how organs are allocation to transplant candidates, etc. The media has filled the void that erasing practices have helped to create with its own fantastical stories.

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181 Pope, “Reluctant Organ Donor.”
183 Ibid. referencing work done by Brock, Green, and Appel and Richter on information acceptance and narrative.
The integration of negative media narratives surrounding organ donation into real-world knowledge helps to explain why 95 percent of the 2000 people surveyed by Gallup in 2005 reported that they strongly supported organ donation, but less than half actually agreed to donate the organs of a loved one after death. A 2009 survey of 5100 people conducted by Donate Life America revealed that only 38% of licensed drivers were registered organ donors.184 People remain reluctant to donate because they “still harbor fears about what organ donation really means.”185 The survey revealed “50 percent of respondents [were] concerned that doctors [would] not try as hard to save them if they are known to be an organ donor. 44 percent believe there is a black market in which people can buy or sell organs or tissue. 57 percent question whether or not a person can recover from brain death.”186 Additional research has shown that “a considerable number of people who refuse to donate their organs believe that the actual distribution of organs at present is unjust.”187 The fears that many hold about the transplant system are often created and perpetuated by the media: the 2005 Gallup poll also revealed that 43 percent of those surveyed listed television shows and films as an “important source of information” about organ donation.188

Tenaya Wallace, the director of the Donate Life Hollywood campaign, has been especially critical of media portrayals of organ donation and organ transplant surgeries.

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184 Pope, “Reluctant Organ Donor.”
185 Ibid.
186 Ibid.
188 O’Reilly, “Campaign Targets TV’s.”
Wallace has observed that the media has been and continues to be allowed to treat the
depiction of organ donation and transplantation very differently from how it treats and
depicts other medical diseases, procedures, or treatments. And, for whatever reason,
such differences in treatment have been tolerated. Wallace argues, “‘If there were a
storyline about someone who contracted HIV from a toilet seat, there would be an
uproar, [...]. By presenting that inaccuracy, you would be creating a public health crisis.
It’s the same thing with organ donation’. 

Yet, when it comes to inaccurate
depictions of organ procurement and transplantation practices that contribute to 19
deaths per day, the inaccurate portrayals are allowed to continue and are not
considered as contributing to a public health crisis.

Television narratives fill the information void created and supported by UNOS’
erasing practices. When this is coupled with the current system of organ donor
registration in the U.S., it makes the translation of fears and mis-information into not
becoming an organ donor very easy—an individual does not have to do anything. This is
a perfect storm scenario for a public health crisis in the U.S. where the intense pressure
to prolong life, cure disease, and increase people’s quality of life has created the
expectation that organ transplantation is a treatment option while the media
discourages many from registering to be donors or to donate the organs of a deceased
loved one. By failing to submit forms to an organ donor registry, not checking YES on the
organ donor box when at the DMV, or neglecting to inform family members, an

189 Ibid.
individual easily avoids becoming a potential donor. In this instance, one can protect one’s self by doing absolutely nothing. It is becoming a donor that actually requires effort.

_The Organ Transplant System in the U.S._

Erasure practices, which are accomplished through UNOS’ management of donor and patient identity information, support the three principles of primary importance that UNOS adheres to in the allocation of human organs: utility, justice, and autonomy. Erasure is meant to ensure the equitable allocation of organs by separating the patient or donor’s socio-political identity from his or her medico-institutional identity. While erasing practices do, in fact, create a medico-institutional ‘self’ that proves efficient for medical institutions to manage, the practices compromise the transplant system for they neither increase the positive post-operative health outcomes for transplant patients nor do they increase potential donors’ willingness to donate. UNOS’ erasing practices have greatly contributed to the fear desperation and distrust of the transplant system in the U.S. As the desperation for organs has grown MOPAs that function by inscription have begun to contend with UNOS and its erasing practices.
Chapter 2: MOPAs that Inscrib

MatchingDonors.com

Figure 9. Gail Tomas and Paul Wagner

Desperately Needs Your Help to Live
I am a vital 65 year old grandmother who loves her family more than life itself. I neither look nor feel my age and if it wasn't for my kidney problem, I believe that I would have at least 20 more years to live a productive life. When I was a child, they didn't have antibiotics, so my kidneys had to overwork in order to rid my body of infection. This ended up causing one of my kidneys to stop functioning; it became really small. With only one good kidney functioning most of my adult life, I got type 2 diabetes in my late 40s. When I found out about the diabetes, it was suggested to me to get a nephrologist. I have been placed on the national kidney waiting lists, but I was told that it will take over three years to find me a kidney, and my chances of surviving dialysis are not very good. My only chances of surviving are going to be given to me by the grace of God and the grace of an amazingly kind and generous person who wants to help me. I hope and pray every night that there is someone out there who wants to help me see my grandchildren grow and to fulfill the rest of the life that I know was meant for me to live.
The gift of an organ donation is the most precious there is on this earth. I would be eternally grateful to someone who can answer my prayers.\textsuperscript{190}

\textit{Crowdsourcing Organs}

Figure 10. Facebook Group — Amit Gupta Needs You

\textsuperscript{190} PRWeb. “Philadelphia Woman Receives Kidney Transplant.”
Two weeks ago I got a call from my doctor, who I’d gone to see the day before because I’d been feeling worn out and was losing weight, and wasn’t sure why. He was brief: “Amit, you’ve got Acute Leukemia. You need to enter treatment right away.”

I was terrified. I packed a backpack full of clothes, went to the hospital as he’d instructed, and had transfusions through the night to allow me to take a flight home at 7am the next day. I Googled acute leukemia as I lay in my hospital bed, learning that if it hadn’t been caught, I’d have died within weeks.

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I have a couple more months of chemo to go, then the next step is a bone marrow transplant. As Jay and Tony describe below, minorities are severely underrepresented in the bone marrow pool, and I need help.

A few ways to help:

1. **If you’re South Asian**, get a free test by mail. You rub your cheeks with a cotton swab and mail it back. It’s easy.
2. **If you’re in NYC**, you can go to this event my friends are putting on.
3. **If you know any South Asians** (*India, Pakistan, Bangladesh, Nepal, Bhutan, Maldives, or Sri Lanka*), please point ’em to the links above.

*UPDATE 1* Organize a donor drive near you (the most helpful thing you could possibly do!) email 100kcheeks@gmail.com. They’ll send you kits, flyers, tell you what to say, and make the whole process easy cheesy.

*UPDATE 2* Want to get a free test, but not in the US. Here’s a list of international donor registries that are globally searchable.

jayparkinsonmd:

My friend Amit Gupta founded my favorite photography site Photojojo. A few weeks ago, he was diagnosed with leukemia. Amit is one of the nicest, most genuine, most creative people you could ever meet. Prior to founding the awesome Photojojo, he also co-founded Jelly in 2006 in NYC, a coworking community, that’s now spread to 60 cities across the world and helped spark the coworking revolution. It looks like Amit will need a bone marrow transplant quite soon. We can help him with that.

tony b:

Unlike blood transfusions, finding a genetic match for bone marrow that his body will accept is no easy task. The national bone marrow registry
has 9.5 million records on file, yet the chances of someone from South Asian descent of finding a match are only 1 in 20,000.

This is where we come in. We’re going to destroy those odds.

How? By finding and registering as many people of South Asian descent as we possibly can.

Tests are easy— a simple swab of the cheek. If you’re a match, the donation involves an outpatient procedure. It’s not fun, but it’s not dangerous either. And doing it could save a life.

We are encouraging anyone of South Asian descent to take a test to see if you’re a match.

You can get a free test by mail, or, if you’re in New York, you can join us Friday, October 14th for a special party to rally support.

We’ll have test kits on hand at the party, as well as music, booze, and maybe even a photo booth. It will, for the first time, combine a House 2.0-style party with a New Work City-style party, and if you’ve ever been to either, you know they are always something special.

Please spread the word and please do everything you can to help Amit beat leukemia. He’s a superstar.

Much thanks to Tony and pals for organizing this event, and EVERYONE who’s been tweeting and reblogging.

Please help get the word out any way you can. My life quite literally depends on it.¹⁹¹

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For Gail Tomas and Amit Gupta, none of their family members were matches. Gail Tomas was uncomfortable asking any of her friends if any one of them might be a match for her blood type, let alone if one of them might be willing to donate a kidney to her.

¹⁹¹ Gupta, Amit Gupta Likes You! October 6, 2011.
Tomas’ daughter knew that the UNOS kidney transplant waitlist was long and that her mother did not have the estimated more-than-three-years to wait for a transplant from a cadaveric donor through UNOS, so she signed her up with MatchingDonors.com.\textsuperscript{192} Amit Gupta knew that his ethnic background as an Indian-American meant that finding anyone whose HLA markers matched his own would be nearly impossible—about 1 in 20,000.\textsuperscript{193} The deep level of compatibility that is required for a bone marrow transplant coupled with the fact that South-Asians and other minorities are dramatically under represented in the bone marrow registries meant that his chance of having a match in the National Bone Marrow Donor Registry was slim to none,\textsuperscript{194} so Amit Gupta and his friends turned to Facebook, Twitter, and their own personal websites. In writing narratives of themselves and their lives, detailing their conditions, and sharing photos of themselves, Gail Tomas and Amit Gupta began their searches for organs via MOPAs that operate by inscription.

This second chapter is concerned with MOPAs that inscribe—in particular, MatchingDonors.com and via crowdsourcing through the media and social media websites. The chapter is divided into three parts. Part I focuses upon how in the functioning of various MOPAs inscription happens, the mechanisms behind donor and patient identity information management that promotes and privileges the use of socio-political identity information in facilitating organ matches. Part II situates the inscribing

\textsuperscript{193} Dailey and Danzico, “Amit Gupta and the Social Media.”
\textsuperscript{194} Ibid.
practices by locating the MOPAs that inscribe within cultural and theoretical constructs that have informed their practices. Part III, discusses how the practices of inscription affect donors as well as organ transplant candidates/recipients and discusses how these experience effect the overall organ transplant system in the U.S.

Part I: The Mechanics of Inscript
This first part of the chapter defines inscribing practices. It identifies MatchingDonors.com and crowdsourcing via the media and social media websites as the primary MOPAs of this identity management practice. Part I provides different examples of how MOPAs of inscription operate and lays out how these MOPAs function.

Inscription Defined
Inscription orders a set of practices that mark those who are experiencing organ-failure as people first and patients second. Inscribing practices—carried out by MatchingDonors.com and via crowdsourcing through the media and social media websites—highlight one’s socio-political identity while marginalizing the medico-institutional identity. MOPAs that inscribe take medical need as a given; thus one’s socio-political identity factors function as the criteria by which organ allocation is determined. More specifically, organs are donated to a specific patient based upon his or her individual characteristics rather than greatest medical need, urgency, or chance of successful outcome. Inscribing practices work to make visible, to varying degrees, the socially salient features of a patient’s identity—image, name, affiliations, etc.—while
minimizing the factors that constitute his or her medico-institutional identity—illness, organ-failure, and degree of need, etc.

MatchingDonors.com
One day Paul Wagner was reading a New York Times article by Sally Satel in which she discussed her search for a kidney donor. In the article Satel described a website called MatchingDonors.com. Wagner clicked on the link and entered “Philadelphia” into the search bar—this is how Paul Wagner came across Gail Tomas profile with the headline “Desperately Needs Your Help to Live.” That evening Wagner went home and shared what he had learned and the plan he had formed with his partner: “Aaron, there’s this lady I read about that’s going to die if she doesn’t get a new kidney and I’ve decided to give one to her.”

Launched in 2004, MatchingDonors.com is a website that facilitates organ sharing between those in need of organs and live organ donors. The mission of this U.S. based organization is to give those in need of organs “an active way to search for a live organ donor.” As an organization, it focuses upon increasing the number of

198 I deliberately use the phrase “those in need of organs” because not all of the individuals who solicit organs through MatchingDonors.com are registered organ transplant candidates. While they may be experiencing organ failure they may not be listed on the UNOS organ transplant waitlist for a variety of reasons.
199 MatchingDonors.com, “About MatchingDonors.com.”
transplant surgeries and [improving] awareness of live organ donation.”

Its aim is to match patients in need of organs with altruistic individuals who are willing to give a kidney, a lobe of their liver, a segment of intestine, bone marrow, a portion of a lung, etc. Currently there are 530 MatchingDonors.com patient-members in need of organs who have posted profiles to the site and 10,613 potential live organ donors who’ve resisted with the site. Potential live donors may search patient profiles on the website, read their stories, see pictures, and learn about what qualities those in need of organs are looking for in a donor. There is no hierarchy or scoring of patients on the Matching Donors website and MatchingDonors.com does not actually do any matching or active pairing of patient-members and donor-members: it is simply a website where people willing to be live organ donors may encounter or search for patients in need of organs; it is a site where those in need of organs can search the profiles of people who have registered as potential living donors. Donors are able to establish their own criteria for judging potential recipients as the site gives them complete freedom in choosing to whom they would like to donate their organs.

Individuals looking for live organ donors register as a patient-members with MatchingDonors.com. Registration requires that patients provide basic contact information, the type of organ needed, and blood type.

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200 Ibid. MatchingDonors.com is a U.S. based organization, with a growing global reach: patients in need of organs in Australia, the UK, and Canada have posted profiles to the site.

201 These figures are of March 14, 2012, 11:50am.
Optional information includes the contact information for a patient-member’s physician and transplant coordinator.
Finally, the patient-member is asked to provide a brief personal description of his or her self and his or her situation as well as a longer narrative. Photographs can also be posted to the patient-member’s profile.
The personal biography and pictures are what inscribe, they are used to create interest
in the patient-member and his or her life story—“When patients provide their biography
and open up personally, the potential for live donors to respond is
increased.”

Figures 14 and 15 are two examples of patient profiles that have been
posted to the MatchingDonors.com website.

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202 Canton Citizen. “State Recognizes Lifesaving Work.”
Figure 14. MatchingDonors.com Patient Profile — Searching for a Kidney

Description of Patient Situation
The organ needed by my mom is a kidney. She is in a really tough situation at this point in her life. My mom has always suffered from kidney disease. It started as early as when she was at the age of 23, she is now age 44. She is married and has 2 daughters. She first started with the chronic kidney infections, constant hospitalizations in her country of birth which is Bosnia and Herzegovina. My mom felt the constant pain at an early age, but it finally caught up with her in the year 1995 right after the war in Bosnia ended. She had her right kidney removed by Norwegian surgeons during the war in Bosnia. The physicians felt that it was due to the war suffering as she was tormented by the war criminals. She has also lost 8 members of her immediate family that she still to this day does not know anything about, dead or alive, or even what happened to them. Even after the war ended, and her right kidney removal, she was constantly hospitalized. We have seen doctors in Bosnia, and Luxembourg, where we moved to right before America in the hopes of finding peace, and to better the lives of our family. She was going for her kidney check-ups, and in the mean time she got more ill with other health issues. She suffers from back pain, post war trauma, high blood pressure, rheumatoid arthritis, high cholesterol. We moved to the United States in 2000 because we had to leave Luxembourg due to full capacity of refugees at the time, so we were asked to choose between going back to Bosnia where the condition was still bad due to the war, or start a new life in America, we knew that moving to America was a better choice because mom needs better care. My mom has endured so much in her life that even since our move here, she was always in the care of physicans. It recently became worse, that the doctors told her they have to put her on dialysis, as the left kidney no longer functioned properly. We have tried family members and noone is moms match or they are not able to donate due to age, kidney stones, etc. So, our family is in the need of a potential kidney donor, my mom is going through a lot at such a young age, we never thought that she would have to live such a hard life. I want her to be able to live the rest of her life happy and pain free.
Figure 15. MatchingDonors.com Patient Profile – Searching for a Liver.

Description & Requirements

Description of Patient Situation

Hi, my name is Chanel and I have Hep C. I am desperately seeking someone who is willing and able to help me as a donor. You see I have three grandchildren of whom I love to see grow and prosper. As you would. I love them dearly and don’t know. I had a sister that passed with the same illness and I learned a lot from being there with her when she passed. I know how much I miss her as she was just a great older sister. She got me interested in God and the more spiritual side of life that I never really understood. I owe her a lot for that, and more to God for his being there for me when I needed him and he still is! I was once very active as well, I go to the gym everyday and worked the eve. Shift taking my youngest granddaughter everywhere, running jumping and playing with her all the time. I love children! And you’d thought she was mine as much as I had her. My middle granddaughter was also raised by me. She’s a very good girl today, and smart. She worked her own way through college by working up to 5 pt jobs a week. How she did it was through the grace of God because there was no way she could have done it alone. Well those days are over now. Seems I don’t have strength enough to do much these days anymore, my youngest grandchild has changed towards me, as I think she senses that there’s something wrong. She’s special needs that being one of the reasons she is so special to me. Although this makes me sad I try to do what I can for her anyway, but she does not respond the same as she used to. Maybe with God’s blessing I can have my operation and get some of my energy back so she’ll love me in the same way again. I miss all the things we used to do so much. I miss her too. It seems sometimes that I’m just waiting to die, and I’m not ready yet so if someone out there could find it within their heart to help me I would be most grateful, all one has to do is put themselves in my shoes for just one day, to know what I mean. Thank you for listening and may God bless. Bye.

Requirements the Potential Donor must have to be a compatible match.

From what I’m told by the Drs., NO drinking of alcoholic beverages, NO street drugs. NO smoking, (cigarettes, marijuana, cocaine etc.) Oh… and by the way… a liver can be ANY color. Red yellow orange or blue, cause I could not ask if it was for you!

Nice To Have Attributes of the Donor

This is up to the donor. Would be nice but it’s up to you.

Required Medical Condition of the Donor

Not sick themselves, and again I stress that the donor please be free of any kind of recreational drugs. And of course have a compatible blood type.

Required Citizenship of the Donor

United States

Organ Needed

Liver

Is the Patient willing to travel to Donor?

Yes

Earliest Date Patient Can Accept Organ

19-Nov-11

No, Patient unable to travel
Crowdsourcing Organs
People turn to a variety of sites to crowdsource organs. Unlike MatchingDonors.com where there is a specific website, a membership for both those seeking organs and potential live donors, forms to fill out, and categories of information to address and share, people who crowdsource organs may share whatever information they find relevant in whatever spaces they have access to that might gain them an organ. What follows are three examples of ways that people have used media and social media as MOPAs of inscription to crowdsource organs.

Amit Gupta Needs You!
In September 2011, Amit Gupta, the founder of Photojojo (a social media site for photography that publishes a twice weekly newsletter about photograph tips, DIY projects, and photo gear) was diagnosed with acute leukemia. His only hope for survival was a bone marrow transplant. Amit Gupta drew upon his own immediate network of friends in the technology and start-up industries in Silicon Valley to crowdsource a bone marrow donor match through social media networks (Facebook, Twitter, Tumblr, Photojojo Forums, and YouTube), news outlets, a dedicated website—amitguptaneedsyou.com, and a Facebook community page. Gupta’s friends, his friends’ friends, and eventually total strangers shared, “Liked,” and Retweeted his story as well as information about how people could get tested to see if they might be a match.

203 Gupta, Amit Gupta Needs You!
On January 18th 2012, Amit Gupta posted to both his Tumblr account and Twitter feed that a match had been found and he was headed to Boston to start the transplant process.\(^{204}\)

**Can You Help Save Sarah?**
Sarah Dickman’s parents, Lori and Joe added their daughter’s name to UNOS’ transplant waitlist when they learned that neither one of them happened to be a match for her and that she would need a kidney from someone else.\(^{205}\) Sarah suffered from juvenile

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\(^{204}\) Gupta, “Many of You Have Asked.”

\(^{205}\) Associated Press, “Stranger Donates Kidney to 8-Year-Old Girl.”
nephronophthisis, a genetic condition. In September 2007, Lori and Joe also printed up flyers and circulated them around Sarah’s elementary school.

Figure 17. Sarah Dickman and the flyer her parents circulated around her elementary school.

Laura Bolan, whose children attended the same elementary school as Sarah, saw one of the flyers in the school and it was “more than [she] could take.” Bolan as well as another individual contacted the Dickman family and offered to be tested to see if they might be matches for Sarah. Bolan was the better match. Sarah Dickman and Laura Bolan underwent surgery in February 2008, just five months after Sarah’s parents had circulated the flyer with their daughter’s picture and story.

\[^{206}\text{Ibid.}\]

\[^{207}\text{Ibid.}\]
I Need A Liver. Please Help Save My Life!
In 2004, Todd Krampitz was a 32-year-old newlywed who had been recently diagnosed with liver cancer. Krampitz was in need of a liver. Krampitz was in need of a liver, but he was told that his chances of receiving one were not good: Krampitz was neither sick enough to be a priority case, nor well enough to survive the years-long wait for an organ. At the time of his diagnosis Todd Krampitz’s cancer had reached the terminal stage.\(^{208}\) Thus even if he survived the years-long wait on the transplant waitlist for an organ, his condition was so advanced that it was unlikely a transplant would work for him.\(^{209}\) Krampitz, however, wanted a liver—he wanted to gain even the slimmest of chances of living or at least prolonging his life.

Even though a transplant was unlikely, and it was unlikely that a transplant could save him, Krampitz’s doctors placed him on the UNOS’ organ transplant candidate waitlist. Krampitz, however, went ahead and employed “advertising strategies such as billboards, television commercials, websites, and a toll-free hotline to solicit [an organ].”\(^{210}\) Additionally, Krampitz and his new bride also took to the national morning news program circuit as well the one’s local to them in Texas to share their story with audiences far and wide.

\(^{208}\) Crean, “Billboard Plea.”
\(^{209}\) “Commentary - Krampitz' Media Blitz.”
\(^{210}\) Zink et al., “Examining the Potential,” 7.
Todd Krampitz received an organ after only a single week of intense publicity. 211 A family in a neighboring state directed the donation of a liver from their recently deceased loved one to Krampitz. 212

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I have provided examples of different MOPAs of inscription to give a sense of how inscription happens, what types of information people share and how people share it. The information that transplant candidates inscribe on social media sites, flyers, billboards, and list on website profiles highlight their socio-political identity qualities in order to attract attention and gain organs. People in need of organs share their

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211 “Commentary - Krampitz' Media Blitz.”
212 Ibid.
personal stories, post pictures, and circulate their information as widely as possible or as they are comfortable. The stories and photos make the individuals and their own need the focus. MOPAs of inscription turn the consumers of media and social media into allocation committees—each individual using his or her own personal ideologies to evaluate the social worth of the individuals using MOPAs of inscription to gain organs. The organ transplant candidates who work to gain organs through MOPAs of inscription do not share information about their medical tests or data that would indicate how healthy or ill they happen to be, from a medically objective standpoint —i.e. their true degree of medical need. In focusing upon crafting and publicizing their personal stories in hopes of making a connection, the socio-political identity of the person seeking an organ gets inscribed.

Understanding how MOPAs like MatchingDonors.com and sites of crowdsourcing operate with respect to the management of donor and patient identity information is critical because the circulation of that information generates affect. The affect the identity management practices generate or motivate effect current transplant candidates (both those who are trying to gain organs through MOPAs of inscription and those who have been listed by their local transplant center on the UNOS transplant waitlist), potential live organ donors, and the family members of potential deceased organ donors. Furthermore, the affects motivated by the identity management practice of inscription effects the larger transplant system in the U.S.
Part II: Situating MOPAs that Inscribe — Cultural and Theoretical Contexts

Because the identity management practices that MOPAs use seem to have some bearing on potential organ donors’ willingness to donate and have an impact upon the health outcomes of transplant recipients, it is important to understand not only how MOPAs of inscription manage identity information, but also why that identity management practice was implemented by the various MOPAs that function by inscription. Part II of this chapter situates the MOPAs that inscribe—MatchingDonors.com and the various media and social media sites of crowdsourcing organs—to bring into relief some of what has informed their particular identity management practices.

MOPAs of inscription became institutionalized and routinized in specific sites in the first decade of the 21st century. The identity management practices of MOPAs that inscribe were informed by the medico-cultural shift that took place around organ transplant surgeries, the desperate situation created by the critical organ shortage, the use of extended criteria donors for transplants, and the principle of autonomy.

Shift from an Accepted to an Expected Method of Treatment and the Organ Shortage

In 2009, the Centers for Disease Control and Prevention (CDC) released their latest figures on life expectancy for Americans. These figures bear out Jean-Luc Nancy’s statement: there no longer is, for those of us in “developed countries,” a “right” time to die—at least not before the age of 80.213 Based upon a survey of 90% of the death certificates issued in the U.S. in 2007, women, the CDC reports, have a life expectancy of

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80.4 years and men have a life expectancy of 75.3 years. The term itself that the CDC uses—“life-expectancy”—both informs and betrays a particular mindset: individuals presume they will achieve such an age, that they are entitled to that length of life. It also reveals a set of expectations about modern medicine in the U.S.: it suggests that individuals have come to count on “biotechnological solutions to human health problems” to achieve the expected lifetime. Though there may be fears and unknowns about the process of organ transplantation, such expectations of modern medicine have been extended to organs and organ transplantation as well, as, according to Sharp, “the intense desire to prolong life and cure disease has spawned ... an ever-increasing national list of patients for whom transplantation is deemed a basic medical right.” Sharp employs the same diction as Nancy—both use the term “right.” For Americans, Frenchmen, and others of the “developed nations,” there is neither a “right” time to die, nor will such individuals tolerate being denied their “right” to an organ.

Because of ideas about “life-expectancy,” the feeling there no longer is a “right” time to die, and the notion that organ transplantation has been “deemed a basic medical right,” “the transfer of human parts between disparate bodies [has become] conceived of as a natural progression within medicine.” But for as much as organ transplantation has been naturalized as a medical therapy and is in great demand, it is a therapy for which the therapeutic devices, human organs, are in short supply.

\[214\] Xu et al., 3.
\[216\] Ibid., 17.
\[217\] Ibid., 23.
The organ supply is the final arbiter in all transplant surgeries. The present stakes of the difference between the supply of organs and the demand for organs, however, are very different than they were 30 years ago. Chapter 1 discussed cyclosporine and its role “in moving organ transplantation ‘from an experimental operation to an accepted mode of treatment...’”\(^{218}\) and the heightened demand for organs it created. Since 1983, the continued and increasingly rapid shift towards organ transfer as a natural progression of medical advancement to helping all people reach 80 years of age and beyond has created an even greater demand for organs than the arrival of cyclosporine did. Since that time, organ transplantation has gone from an ‘accepted’ method of treatment to an ‘expected’ one.

The field of organ transplantation technology has grown, and expectations have grown—both have created an increase in demand for transplant surgeries and organs, and both have contributed to the critical shortage of organs. On June 3rd 2003, Dr. Robert M. Sade, Professor of Surgery at the Medical University of South Carolina, testified before the Congressional Subcommittee on Oversight and Investigations on behalf of the American Medical Association (AMA) about the serious nature of the organ shortage.\(^{219}\) According to Sade’s testimony, between 1990 and 2000 the annually compounded rate of increase in the number of individuals in need of organs added to the waitlists averaged 14.1\% per year, while the rate of the increase of donors only

\(^{218}\) Ballantyne et al., 53 rpt. in Fox and Swazey, Spare Parts, 4.
\(^{219}\) Sade, “Assessing Initiatives.”
averaged 2.9% per year.\textsuperscript{220} This critical organ shortage has contributed to the climate of desperation that emerged around organ transplantation in the early years of the 21\textsuperscript{st} century in the U.S. In her 2006 book \textit{Strange Harvest}, Leslie Sharp noted, “For more than a decade I have watched how proposals designed to enhance donation have shifted from casual, what-if scenarios to a pronounced level of alarm and even desperation. Thus although concerns over supply and demand have always pervaded transplantation, the intensity of organ scarcity anxiety is new.”\textsuperscript{221} Patients too began to internalize the fear and desperation perpetuated by the critical nature of the organ shortage. After three years of waiting on the kidney transplant waitlist, transplant candidate Mike Molinaro said, "The UNOS [waitlist] to me is a dying list. You are waiting to die."\textsuperscript{222}

The shift to how organ transplantation is viewed now—an expected method of treatment—has created transplant waitlists that are tens of thousands of people long. Depending upon one’s region, a transplant candidate in need of a kidney, for example, can expect to wait between one and six years for an organ. Such long lists, the critical shortage of organs, and the growth in online networks and social media are what have given rise to MOPAs of inscription. People have become more and more willing to share personal details of their lives in hopes that they can be freed from their wait and be given an organ.

\begin{footnotes}
\textsuperscript{220} Ibid.
\textsuperscript{221} Sharp, \textit{Strange Harvest}, 17.
\textsuperscript{222} Alfano, “The Ultimate Gift Found Online.”
\end{footnotes}
Extended Criteria Donors
The critical nature of the organ shortage has pushed doctors into rethinking the types of organs they will accept as transplantable. Because of the severe shortage of organs and the ever-growing waitlist, more and more doctors are considering organs from donors whose organs would have been deemed unacceptable 20-years ago. While transplant medicine has evolved over the past 30-years, it still involves suppressing the immune system of an individual, which in-and-of-itself opens the recipient to greater health risks. Even in the best of circumstances and with the healthiest and best matched organ, the use of immunosuppressants means “a transplant marks the beginning of yet another sort of chronic condition that can extend to the end of one’s life.”

In the 1980s, when organ transplantation was still far from an expected therapy, [the organ] donors were almost all young, between 15 and 45. (In the 80's, few transplant surgeons would take a 50-year-old organ.) They were of average weight, with no history of diabetes, cancer, infectious disease, imprisonment, high blood pressure, cigarette-smoking habits, tattoos (which have been associated with blood-borne illnesses) or unsafe sexual behaviors. The chosen organs … ‘were pristine.’

Additionally, that was at a time when, according to Dr. Nicholas Tinley, “If a patient had to wait a few weeks for a kidney, that seemed long.” Such short wait times and donors are of a bygone era, and those “pristine” organs and their donors have become “an idealized social medical category.”

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224 Reynolds, “Will Any Organ Do?”
225 Ibid.
In discussing the individuals from whom organs are being harvested today, Dr. Goran Klintmalm explained to New York Times writer Gretchen Reynolds, “’What people have to understand is that donors now, except for the 75-year-olds who die of intracranial bleeds, are not part of the church choir.... The ones who die are the ones you don't want your daughter or your son to socialize with. They drink. They drive too fast. They use crack cocaine. They get caught up in drive-bys.’”\[^{227}\] Klintmalm’s language paints a rather dramatic picture of extended criteria organ donors, a worst-case scenario. Klintmalm’s language is also highly coded—driving too fast is attributed to young men (at least car insurance premiums indicate as much); crack cocaine (rather than just cocaine) implies a lower socio-economic or class standing, and crack is also racially coded (mostly Black users); and drive-bys signal the same—and although the coding itself is factually wrong (more women then men donate, with respect to the percent of the population they make up Blacks and Whites donate equally, and those who are more financially stable are more likely to donate than those who are less) what Klintmalm is trying to express about the organs is correct.

Organs are now considered from those who fit “extended criteria,” or are considered to be “marginal donors.” Such organs come from people who have led high-risk lives by engaging in prostitution and drug use, for example\[^{228}\] (although, interestingly, drug use alone will still disqualify someone from being able to donate

\[^{227}\] Reynolds, “Will Any Organ Do?”
\[^{228}\] Beth Israel Deaconess Medical Center, “Where Does.”
blood); donors who are known to have Hepatitis C or B\textsuperscript{229}; and donors of advanced age (over 50 or 60 years-of-age is considered advanced).\textsuperscript{230} Depending upon the organ, other more organ-specific and relevant factors are considered. For example, lungs: the question it is no longer did the potential donor smoke or not; instead, it is for how long had the lung donor smoked. Over the last 20 years, the organ shortage has grown so dire that “surgeons started accepting lungs from people who had smoked, sometimes for decades.”\textsuperscript{231}

The critical organ shortage has created a conflict between doctors who understand the reality of the organ shortage and patients who desperately want organs. The OPTN addressed the conflict in its 2003 annual report: “The need to more aggressively utilize available organs for the candidate population as a whole competes with the expectation of each individual.”\textsuperscript{232} It seems that patient desires and those of their physicians are at a bit of an impasse due to the organ shortage with doctors often favoring accepting and transplanting more and more organs from marginal donors. Patients who are made aware of the marginal status of the organs “are thus faced with a lethal trade-off between severe disability or death from organ failure, and the long-

\textsuperscript{229} Ibid.
\textsuperscript{230} Beth Israel Deaconess Medical Center, “Where Does”; Botha, “Extended Donor Criteria.” Although a 93 year-old liver from a deceased donor was transplanted into a patient by a team of Canadian physicians, and physicians at NYU transplanted a liver from an 80 year-old donor. Renyolds, “Will Any Organ Do?”
\textsuperscript{231} Reynolds, “Will Any Organ Do?”
\textsuperscript{232} Ibid.
term consequences of infections stemming from flesh acquired from anonymous
diseased, organ donors.”²³³

Because of the organ shortage, the culture of erasure that permeates UNOS, and
organ transplant teams’ strict adherence to policies of anonymity, many transplant
patients are not made aware of the fact that they are receiving extended criteria donor
organs. The identities (of organs? of donors?) rarely come to light because of erasing
practices. However, erasing practices when exercised upon marginal criteria donors
would seem to explicitly violate the principle of autonomy that UNOS feels is critical in
supporting ethical organ allocation practices. In an informal survey of transplant
surgeons at a major conference in 2003, about half of the physicians said that they
always tell their patients if they will be implanting a marginal organ while the other half
reported that they do not.²³⁴ The reasons transplant surgeons give for not sharing the
status of the organ with the patient are many.

Some doctors, according to Sheldon Zink, a medical anthropologist at the
University of Pennsylvania, feel that empowering a patient with such information may
result in a decision tantamount to discrimination. Zink says,

‘I would question anyone's motivation in refusing an organ from a drug
user....They aren't responding to clinical information, because the
available clinical data’—the anecdotal reports from doctors—‘indicates
that organs from crack-cocaine users are fine, in general. So they must be
responding to preconceptions about that person's lifestyle. That's only

²³³ Sharp, Strange Harvest, 65.
²³⁴ Reynolds, “Will Any Organ Do?”
one small step from declining an organ because the donor is black or Hispanic.\textsuperscript{235}

Zink logic supports UNOS’ erasing practices. However, it does seem that refusing an organ due to the immutable characteristics of a donor is very different from refusing an organ due to a donor’s lifestyle choices. Such choices—the use of illegal, street drugs, as in Zink’s example—reflect upon how the donor has treated his or her own body and potentially how he or she valued (or did not) his or her physical well-being.

Physicians also gave other reasons for not telling patients into whom they had implanted extended criteria donor organs. Their reasons reflect a number of cultural and professional anxieties. Some surgeons refrain from sharing donor information as they are concerned about potential medical malpractice lawsuits— i.e. better to say nothing than reveal that an organ may not be “pristine,” have your judgment proven right, and be sued for it.\textsuperscript{236} Others say nothing because they are concerned about the patient’s recovery, believing that a patient will recover better if he or she is not worried about the health of the organ—\textsuperscript{237} this is an argument that would seem to support the total erasure of donor identity information but also an acknowledgement that organs are affective objects that do produce material effects. Finally, even other physicians acknowledge that almost all organs that are being transplanted today are marginal organs or from extended criteria donors.\textsuperscript{238}

\textsuperscript{235} Ibid. \\
\textsuperscript{236} Ibid. \\
\textsuperscript{237} Ibid. \\
\textsuperscript{238} Ibid.
In February 2002, patient Vincent Liew received a kidney. At the time of the transplant surgery no one who was a part of the transplant team or the organ recovery team knew that the Liew's donor should have been classified as an extended criteria donor or that she should not have been accepted as a donor at all. Liew had been on the kidney transplant waitlist for five years, during which time he endured thrice-weekly dialysis sessions as diabetes had “ravaged [his] kidneys.”\textsuperscript{239} Seven months after the successful transplant surgery and his recovery Vincent Liew was dead. Vincent Lew died from uterine cancer.\textsuperscript{240}

Sandra Cabrera, Vincent Liew’s kidney donor, had died from a stroke and subsequent intracranial hemorrhage.\textsuperscript{241} According to Cabrera’s friends and family, neither she nor those surrounding her suspected or had any knowledge that the 50-year-old woman had uterine cancer.\textsuperscript{242} It was not until days after her death and her family's donation of her organs that, during autopsy, medical examiners found signs of Cabrera’s cancer. It was still two months before Dr. Thomas Diflo, Liew’s doctor, learned that the kidney he transplanted into Liew came from a woman who had cancer. Diflo, like many of the doctors Zink surveyed, did not tell Liew that the kidney he received came from a donor who had cancer\textsuperscript{243}—whether he initially kept the information from Liew so as not to hinder his patient’s recover process or in an attempt

\textsuperscript{239} Peltz, “Man Dies.” Zambito, “Queen’s Man Vincent Liew.”\textsuperscript{240} Peltz, “Man Dies.”\textsuperscript{241} Feeney, Nelson, and Siemaszko, “Tragic Story.”\textsuperscript{242} Ibid.\textsuperscript{243} Zambito, “Queen’s Man Vincent Liew”
to avoid suit is unknown. Yet even when Liew was not recovering well from the transplant, even when his was pain was worsening, Diflo did not tell his patient of the marginal nature of his organ. According to Vincent Liew’s widow, Kimberly Liew, “‘they made up a lot of excuses…. They told us the kidney [was] not adapting to his body. They didn’t tell me he had cancer’.” Eventually Diflo told Liew that his kidney had come from a woman who had cancer and suggested that the safest course of action—even accounting for the fact that Liew’s chances of developing the cancer were slim, less than 1% given his lack of female reproductive organs—would be to remove the organ.

Tests on Liew’s kidney from May 2002 to August 2002 found no indication of cancer in the organ. Liew’s pain, however, continued to worsen and he asked Diflo to remove the kidney. Upon opening Liew to remove the organ, tumors were readily apparent. Within a month Liew was dead. According to his widow, “[Vincent Liew’s] autopsy attributed his death to cancer that derived from the transplant and had genetically female cells.” Furthermore, a cancer expert concluded that Liew did, in fact, die from uterine cancer. Liew’s case is an unfortunate example of how the “search for new sources of transplantable organs has thus reintroduced procedures that now threaten the humanity of dying patients, adding to their discomfort and suffering

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244 Ibid.
245 Ibid.
246 Peltz, “Man Dies.”
247 Ibid.
248 Ibid.
249 Ibid.
and even potentially, accelerating their deaths.\textsuperscript{250} Liew’s case is also an unfortunate example of erasure’s double-edge: erasure may have allowed Liew to recover from surgery well, without worrying about the health of his organ, but erasure may also have been what cost him his life.

The development of MOPAs of inscription can be seen, primarily, as a response to the extreme organ shortage. But stories like Liew’s have also supported the growth of MOPAs of inscription. By sharing their own personal stories transplant candidates in need of organs hope to connect with potential donors and encourage them to direct their organs to them. Transplant candidates also hope that in the process of sharing their stories with potential donors they will learn about the potential donor, too, and the medical and social history of the organ to ensure not only a transplant but also the best possible one for them. Because Gail Tomas sought out her organ through a MOPA of inscription, she had an opportunity to get to know her donor, Paul Wagner, and in doing so, she learned from Paul that he had been a smoker. Gail Tomas was able to make an informed decision about whether or not to accept the proffered organ because the donor volunteered minor, although relevant health information. While receiving a kidney from a smoker certainly does not compare to what it might mean to receive lungs from a former smoker, smoking greatly increase the risky of chronic kidney

\textsuperscript{250} Sharp, \textit{Strange Harvest}, 72.
disease.\textsuperscript{251} The MOPA of inscription made it possible for Gail Tomas to make a better informed decision about the organ than if it had been offered to her via UNOS.

\textit{Directed Donations and Living Organ Donation}

MOPAs of inscription have been able to grow over the past decade because so long as no valuable consideration is given for a donated organ, MOPAs of inscription do not violate NOTA and they are supported by the Uniform Anatomical Gift Act (UAGA). The UAGA allows for gifts of organs to be made to a specified recipient or without specifying a recipient. Anatomical gifts or organ donations of the latter kind are what support the UNOS transplant system. The former are known as directed donations—these anatomical gifts are given to a specific, named person, and they are what have supported the emergence and growth of MOPAs of inscription.

It is challenging to coordinate the direct donation of one’s own organs upon death to a designated recipient in accordance with MOPAs of inscription while dying. Family members of a deceased potential donor are better able to coordinate direct donations—this is how Todd Krampitz received a liver from a deceased donor in Florida—but direct donations require foreknowledge and planning. Direct donations of these types—from cadaveric donors to unknown, unrelated recipients as a result of MOPAs of inscription—are rare. Coordinating a direct donation as living donor is comparatively easy. MatchingDonors.com, for example, is a MOPA that specifically

\textsuperscript{251} U.S. Department of Health and Human Services, “National Kidney & Urologic Diseases Information Clearinghouse (NKUDIC).”
targets living donors; crowdsourcing targets living donors and the families of deceased potential donors.

Within the U.S. living donations have been on the rise. Currently, more than one-third of all kidneys that are transplanted in the U.S. come from living donors.²⁵²

Figure 19. Kidney Transplants by Donor Type from OPTN

Most who choose to become living organ donors, direct their donation of an organ to a spouse, family member, or close friend. Transplant candidates like Sarah Dickman, Gail Tomas, and Todd Krampitz who can receive organs from deceased donors as well as living donors and whose family members aren’t suitable matches are able to turn to MOPAs of inscription because the UAGA allows for direct donations.

²⁵² Timothy F. Murray asserts that “the number of kidneys coming from living donors exceeds the kidneys coming from the dead” in his 2006 article “Would My Story Get Me a Kidney?” published in the Hastings Center Report.
Autonomy
In actively searching for an organ through MatchingDonors.com or using the media or social media websites to crowdsourse an organ, transplant candidates are furthering MOPAs of inscription by drawing upon and appealing to the concept of autonomy. MOPAs of inscription support the autonomous actions of transplant candidates as well as the autonomous actions of potential donors. The concept of autonomy, or what Professor of Ethics and Bioethics Guido Pennings refers to as the “autonomy principle” is central to the workings of MatchingDonors.com and transplant candidates’ use of media and social media websites to crowdsourse organs as it “implies that a person has the right to make important decisions about his or her own life. This includes the right to make one’s own life plans and the right to do what he or she thinks is right.” 253

Transplant candidates are asserting their own autonomy from UNOS’ biopower as they participate in MOPAs of inscription as these MOPAs allow them to regain some control over the process, their lives, and their health.

Additionally, for transplant candidates, MOPAs of inscription support their autonomy and reassertion of self in the process of trying to gain an organ but also in giving them more information about the socio-political and medico-institutional identity of the willing, potential donors. The reassertion of self through a MOPA of inscription is not just about one’s psychological health, as was discussed with MOPAs of erasure, but also one’s physical health given the medico-cultural shifts that have taken place around

transplantation that have increased the demand for organs and resulted in the use of more organs from extended criteria donors and more fatalities. Understanding some aspect of the organ donor besides his or her blood type, gender, and where he or she lived or died, means having better grounds for making a choice as whether or not to accept a proffered organ if one becomes available—not only for psychological reasons, but also for health reasons.

MOPAs of inscription also support the autonomy of potential organ donors. According to Pennings, “The importance attached to informed consent (even in countries with a ‘presumed consent’ policy) shows that the decision to donate is seen as a part of the person’s autonomy. It can be argued that also the point to whom one donates is a matter of the individual’s decisional authority.” The autonomy principle undergirds the U.S. transplant system as a whole—i.e. the right to make decisions regarding the donation of one’s own organs while alive or after death—but it is central to the functioning of MOPAs that inscribe. A potential donor’s autonomy and assertion of individual identity transpires through and is facilitated by inscribing practices—i.e. making the decision as to whom one wants to donate an organ based upon the identity characteristics of various transplant candidates. In this way, the organs become material representations of a donor’s identity and agency—the choices a donor makes

\[^{254}\text{Ibid.}\]
and otherwise made in his or her lifetime, about the beliefs he or she holds, and about who that individual is in relation to the rest of society.

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With the growth of MOPAs of inscription we see how the shift in culture around life, living, and quality of life coupled with the regularization of transplant surgeries as medical therapies has created a severe shortage of organs for an exponentially increasing waitlist of people who expect this therapy. The critical organ shortage coupled with the proliferation of, ease of use, and reach of media and social media has allowed transplant candidates to elide UNOS’ biopower and assert their own autonomy while appealing to the autonomy of potential live donors/the families of deceased potential donors to gain organs for themselves.

Organ transplant surgeries require organs from dead or living donors. Transplant candidates who are placed on the UNOS organ transplant waitlists often face incredibly long waits for organs, and many fear that they won’t survive long enough to receive an organ through UNOS. The individuals who seek out donors and organizations that facilitate transplants based upon inscribing practices argue that they engage in such practices because MOPAs that inscribe make available organs to which transplant candidates might not otherwise have access—due to either their standing on the waitlist, their geographic location, or just the overall lack of organs available for transplantation. To gain those organs, to get people who encounter their profile on a website or hear of their plight through the media to consider donating an organ to a
stranger, transplant candidates must lay bare the socio-political features of their identity they feel are most compelling.

**Part III: Affects/Effects of Inscription**

Arranging to receive an organ via direct donation through a MOPA of inscription is often the surest and quickest path to receiving an organ. Such transplants help save lives. But donations and transplantations that result from MOPAs of inscription are often filled with many emotional complications. The affects motivated by MOPAs of inscription sometimes result in those who are initially willing to be living donors not donating or transplant candidates who’ve used MOPAs of inscription to seek out donors sometimes refusing an organ. “Near-transplant experiences” from donors that have been reached through MOPAs of inscription and which fall through for some (non-medical) reason or another are often the result of what Fox and Swazey call the “tyranny of the gift”—the overwhelming and disquieting sense that such an exchange between donor and patient would “[bind] them to one another in a mutually fettering way”\(^\text{255}\) for the rest of their lives. All transplant recipients may experience feelings associated with the “tyranny of the gift,” to some degree or another; for those who gain organs via MOPAs of inscription such feelings are often heightened because the organs are donated to a specific patient based upon his or her characteristics from a specific, most often living donor. The transplants that take place as a result of organs gained through MOPAs of inscription create complex, in-body sociomedical relationships that the recipients must

\(^{255}\) Fox and Swazey, *Spare Parts*, 40.
reconcile; often, they also create complex social relationship between the recipient and the live donor or the deceased donor’s family members that all parties must reconcile.

The identity management practices of the MOPAs of inscription—what and how transplant candidates share information about themselves to gain organs—have a significant bearing on those relationships. Part III looks at the types of feelings that result from the affect generated by inscribing practices. In particular, this part examines how the practices of inscription affect organ transplant recipients as well as organ donors and discusses how these experiences effect the overall transplant system.

Transplant Recipients

For transplant recipients who’ve receive an organ after sharing information about themselves and their need through MatchingDonors.com or media and social media sites, the new organ carries with it a sense of the donor’s self which now resides within them. This was true for those who received organs via MOPAs of erasure, but because MOPAs of inscription rely on direct donation, recipients often know a great deal about their donors. The sense of experiencing an in-body “other” is often even greater, but oftentimes it is less alienating.

In October 2008, kidney transplant patient Kris Randall received a kidney from Melissa Stephens. Stephens contacted Randall after finding his profile on MatchingDonors.com—his was the second profile she read of the ones on the site that matched her blood type and geographical restrictions. Since he received the organ Stephens donated to him Randall wakes up each day and says, “Hi Melissa, how are
The in-body sociomedical relationship is positive one for him: “It’s like having my best friend right near me. As far as I’m concerned it’s still hers. I just like to say, ‘How you doin’? Everything good? You want something to drink?”

For some transplant recipients who search for and receive an organ through a MOPA of inscription, there is an additional onus or burden on them because they were chosen. Someone who read their profile, heard their story on the news, saw the Retweet chose them specifically and not someone else; there was something about them or their story that compelled a stranger to donate an organ to them. For kidney transplant recipient Sally Satel, she was uncomfortable with what it would mean to receive a kidney from someone who directed an organ to her:

I ruminated constantly about what it would mean to be related to someone “by organ.” Would my future donor assume a proprietary interest in how I lived my life, since she had made it possible? Would she make sure I was taking proper care of “our” kidney or lord her sacrifice over me? Or would I hold it over my own head, constantly questioning whether I might have said or done anything that could offend or disappoint my donor, anything that might be taken as ingratitude? How could a relationship breathe under such stifling conditions? It was exhausting to think about; I wanted no part of a debtor-creditor relationship. I didn’t want a gift, I wanted a kidney.

Satel understood that receiving an organ meant opening herself up to a very foreign type of relationship with another individual specifically because she was seeking an organ through a MOPA of inscription. The in-body, sociomedical relationship between

256 MacFarquhar, “The Kindest Cut,” 47.
257 Ibid.
258 Satel, “Desperately Seeking a Kidney.”
herself and the organ was nowhere near as daunting for Satel as the social relationship that would exist between herself and the donor. And it was a type of relationship she did not want. Still, it was a relationship Satel would learn to suffer because, for her, being alive and off dialysis was more important.

Organ Donors
Each example of a MOPA of inscription I’ve provided in this chapter, from MatchingDonors.com to crowdsourcing organs through the media and social media sites, involves an identity management practice that includes both a narrative and a visual component, namely images. Affect is the central nervous system’s response to stimuli and it is what the MOPAs of inscription seem to motivate in attempting to gain organs for transplantation.

Narratives and images are particularly powerful stimuli. Research in communications has demonstrated that people are particularly attuned to narrative as “learning, culture, and social relations all revolve around storytelling.” Narrative is also a particularly powerful stimulus that motivates affect because, “the very structure of the brain appears to be organized in a way that makes stories easily processed and remembered.” As too is the visual. In his work on affect, Brian Massumi is very attentive to the relationship between affect and the visual suggesting a theory of “image-based power: images as the conveyors of forces of emergence, as vehicles for

existential potentialization and transfer.” The images that transplant candidates choose to display as well as the narratives they compose motivate these forces of emergence—forces which are critical to engaging potential organ donors and gaining organs as the allocation of organs via MOPAs of inscription are rooted in how people feel about/for the person in need.

The image he encountered on the Matching Donors’ website stirred affect for Paul Wagner, producing overwhelming feelings such that he was motivated to donate an organ to Gail Tomas:

The first patient he saw was Gail Tomas. He enlarged her photograph on his screen so that he could examine every detail. She was sitting on stairs in what appeared to be her living room. She was a woman of mixed race in her late sixties. He stared at her, searching for clues to her personality in her hair style and how she wore makeup. He inspected the stairs behind her, trying to see how clean they were. Almost immediately, he felt that she was the one. He knew that his blood and her blood would match and that he would donate a kidney to her. There was no question of backing out: having seen her picture, he felt himself to be already involved. It was like seeing a car crash—if he didn’t help, he thought, he would cheapen himself.

Wagner never considered Tomas’s ranking on the UNOS waitlist nor did he ever know it; he employed no medical criteria in evaluating Tomas’s need. Instead, what motivated Wagner to donate was the affect stirred by the image of Tomas sitting on her stairs, for, according to Eve Kosofsky Sedgwick in her book Touching Feeling, “motivation itself, […]

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261 Massumi, Parables, 43.
is the business of the affect system.”\textsuperscript{263} Affect, according to Lauren Berlant, is also that which “helps to bind individuals to one another in the larger social-scape.”\textsuperscript{264} Thus, a powerful relationship was formed through this affecting image used in a MOPA of inscription—a relationship powerful enough that it motivated Wagner to donate an organ to a woman he had never met before.

Because affect is more general, more diffuse, synesthetic,\textsuperscript{265} and autonomous,\textsuperscript{266} (but it achieves its autonomy not through closure but, rather, openness),\textsuperscript{267} as well as that which remains “unactualized, inseparable from but unassimilable to any particular, functionally anchored perspective,”\textsuperscript{268} the resulting feelings and emotions that come from processing affect are not the same for everyone. If that were the case, then all who saw the image Tomas’ displayed on her profile would have volunteered to donate.

Individuals who want to direct an organ to someone they are not related or to someone with whom they have no relationship (and have only encountered because of a MOPA of inscription) are often met with great skepticism and some are turned away. Paul Wagner’s transplant surgeon “wasn’t sure that he was willing to do the surgery—he was concerned that it might be a violation of his Hippocratic oath to operate on a

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\textsuperscript{263} Sedgwick, \textit{Touching Feeling}, 18.
\textsuperscript{264} Berlant, \textit{Female Complaint}, x-xi.
\textsuperscript{265} Massumi, \textit{Parables}, 35.
\textsuperscript{266} Ibid.
\textsuperscript{267} Ibid.
\textsuperscript{268} Ibid.
healthy person who wasn’t even related to the recipient.” Ultimately, Wagner’s own narrative of how he came to find Tomas and how he decided he wanted to donate a kidney to her stirred affect in the transplant surgeon such that by the end of Wagner’s story the surgeon was in tears and willing to perform the operation.270

The affect motivated by the narrative and image components of these MOPAs of inscription is of great interest to me in terms of how it affects the transplant recipients, and how donating an organ as a result of a MOPA of inscription affects the donors. This relationship is key to this project because, according Michael Hammond, “the strongest and most meaningful social bonds are based on intense affective arousal and people seek to construct social worlds facilitating this arousal”271

For live donors who direct their organs to specific individuals, the relationship that gets formed because of the intense affective arousal of the transplant is often complicated. For Paul Wagner, upon meeting Tomas for the first time he had trouble discerning what emotions he should allow himself to experience.272 After meeting her, “he was also worried that he’d done a bad thing by allowing himself to meet Tomas at all. It made him feel guilty. Did it diminish the value of his deed to accept her gratitude?”273 For him, the relationship became more complicated after he donated the organ and was recovering because of how others responded to what he felt was a good

270 Ibid.
273 Ibid.

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deed. While still in the hospital after his surgery, Paul Wagner received a phone call: “A woman on the other end, who had heard about him on the local news, told him that she hoped his remaining kidney would fail quickly and kill him because her husband had been next in line to receive a kidney and he, Wagner, had given his to someone else.” Wagner felt awful and struggled to reconcile how he felt about what he had done and what others were feeling.

For some donors, much of how they feel and how they feel about the recipient rests with the success or failure of the surgery. Friends and family members may reject the donor and their ‘good deed’ if the transplant recipient dies or if the recipient’s body rejects the organ. Donors internalize these poor medical and surgical outcomes as their own failings, feeling that in trying to do something good, they instead did great harm.

For Melissa Stephens, after she donated her kidney to Kris Randall she did not hear from him again. His complete disappearance after he received her kidney devastated her. Stephens had gotten caught up in the mystique of the man she chose as the recipient of her organ. Eventually, after she blogged about the experience, Randall reached out to her and thanked her. She, however, was not convinced that he was grateful. Months later Randall emailed her some photographs of him on a trip—a trip she felt she had made possible for him because of the organ she gave him. But the correspondence upset her even more than his silence: “I get this email from him that’s...

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274 Ibid.
275 Ibid.
276 Ibid., 46.
like, “Just got back form St. Maarten!” … So I was like, that asshole went to St. Maarten—the pictures are of him hanging on the beach, holding a drink, sunbathing—and he couldn’t even pick up the phone to be like, I’m doing well, thank you? Now I wish I had kept my donation anonymous, because, fine, he gets the kidney, he goes to St. Maarten, has a good time, and I don’t ever have to know about it. I guess it’s like if somebody’s cheating on you do you want to know or do you not want to know? It’s the same feeling.’”

The Organ Transplant System in the U.S.
Inscribing practices, which are accomplished through MatchingDonors.com and the various media and social media sites individuals use to crowdsource organs, motivate affect in ways that effects the transplant system in the U.S. Some feel that people who gain organs though MOPAs of inscription are helping the transplant system, that they are promoting better health outcomes for transplant candidates, and that they are encouraging more people to be live donors or register to donate by brining attention to the desperate organ shortage as inscribing practices put faces, names, and stories to the issue. Other’s feel that the MOPAs of inscription are completely unethical and do harm not only to the many patients on transplant waitlists when an organ is directed to a specific individual who is then able to “jump the list,” but also to the integrity of the whole transplant system in the U.S.  

277 Ibid.
In 1982, Charlie Fiske’s daughter Jamie was 11-months old and in need of a liver. For a period of time Fiske was the face of organ transplantation in America as his “dramatic plea to the American Academy of Pediatrics' 1982 annual meeting for a liver for his infant daughter Jamie was televised nationally.” But the climate around organ donation and transplantation at the time of Fiske’s plea in 1982 and Reagan’s public plea in 1983 was quite different from the current one—there was no state-sanctioned organ procurement and allocation system, there was no nationwide waitlist, no NOTA, no OPTN, no UNOS and Fiske and Reagan were not paying for ad time, paying for toll-free numbers, paying for domain names, or the cost of photocopies.

Even in 1982, Fiske was uncomfortable with the lengths to which he had to go in pleading his case for free media attention to gain an organ for his daughter. Fiske felt “people like him ‘should not have to turn to the media’ in each individual case.” Despite the consternation raised today by the media blitzes, the ads on Craigslist seeking organs, and the proliferation of Facebook pages of people seeking donors, no action has been taken: “The transplant community recognize[s] the consequences and dangers of permitting organ solicitation. However, [...] there [has been] no action taken by the medical community to prevent similar situations from occurring.”

Transplant surgeon Dr. Douglas Hanto understands that MOPAs of inscription appeal to the autonomy of potential donors, re-instill a sense of autonomy in transplant

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280 Ibid.
candidates, and may serve to encourage people to donate, but he also believes that “...justice and utility demand a balance between the donor, who claims autonomy, and the rights of all patients on the waiting list. If a donor’s choice interferes with justice and utility, it should neither be considered a fair application of autonomy nor be allowed.”

Todd Krampitz’s death after receiving an organ directed to him, which transplant surgeons knew would not save him because the cancer ravaging his body would ultimately claim his life in a few months, is an example of how, according to Hanto, the organ donor’s and the transplant candidate’s autonomy violated utility. For Hanto, the fact that many people aren’t able to craft compelling stories, can’t afford to post a profile on MatchingDonors.com, or are unable to gain access to the internet are just some of the ways in which he believes that MOPAs of inscription violate justice.

Hanto also believes that the use of inscribing practices to crowdsource organs may result in “a net decrease in the number of living organ donors because fewer family members might be approached.” Hanto’s statement implies that the individuals who receive organs from non related donors as a result of MOPAs of inscription who might have been able to receive an organ from a family member or friend are somehow taking organs away from others on the transplant waitlist who are not using MOPAs of inscription to gain organs. A 2002 study conducted Dr. Aaron Spital does support Hanto’s statement, to an extent.

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283 Ibid., 1064.
284 Ibid., 1065.
Spital conducted two telephone surveys of adults in the U.S. about “the general acceptability of allowing altruistic strangers to direct donations, the willingness to donate a kidney to a stranger, and the impact of permitting directed donation on willingness to give.”²⁸⁵ Each survey had more than one thousand participants.²⁸⁶ Across both surveys, Spital found that a quarter of survey respondents said they would be willing to donate a kidney to a stranger for free. And that 93 percent of those respondents who were willing to donate a kidney to a stranger for free were still willing to donate even if they could not direct their donation to a specific person.²⁸⁷ Spital’s study does support Hanto’s belief that MOPAs of inscription and directed donations from altruistic strangers may result in a fewer net live organ donations.

If we are to follow Hanto’s argument, MOPAs of inscription may not enhance the beneficial health outcomes for transplant candidates as they may result in a net decrease in the number of organs for transplantation, but they may also decrease the positive-post operative outcomes for transplant patients who receive organs from family members or people with whom they have close emotional relationships because of the degree to which organs are affectively charged and the sociomedical in-body relationships that result from transplantation. Sally Satel recounted the experiences of a “son who refused a kidney from an over bearing mother, telling his surgeon, ‘She’s devoured enough of me already’ [and a] young man who chose to remain on dialysis

²⁸⁶ Ibid.
²⁸⁷ Ibid.
rather than accept a kidney from his long-term girlfriend lest he be forced to reciprocate by marrying her.”

Transplants between family members tend to “bind the donor and recipient together, sometimes with love, sometimes with guilt, or gratitude, or a feeling of physical union due to the presence of the organ in the other’s body. The strength of these new bonds could weaken other bonds and leave families strained and disoriented.”

The psychological affects of transplants between individuals who are related or have close emotional relationships may result in poor physiological outcomes for those patients.

While Spital’s research may support Hanto’s feeling that MOPAs of inscription have an overall net negative effect on the transplant system, he neglects to consider that MOPAs of inscription are what circulate information about the critical organ shortage and the great need for people to register as donors or consider becoming a living donor. While the donation of a liver to Todd Krampitz was, from a purely medical stand point, ethically questionable, “some believe that Krampitz helped contribute to organ donation records in 2004 by stimulating conversation and “putting a face” on the dire need for donated organs.”

MOPAs of inscription highlight the needs of a single person, but oftentimes the whole transplant system and other patients on the waitlists benefit.

MOPAs of inscription not only help the transplant system in the U.S. by drawing

288 Satel, “Desperately Seeking a Kidney.”
290 Robeznieks, “Man Who Got Transplant.”
attention to the need for organs, but they also aid in other ways. MOPAs of inscription have also helped to increased the positive post-operative outcomes for transplant patients by creating new spaces for transplant patients to connect with one another and support one another:

Some patients, [...], say [crowdsourcing via the media and social media websites] can have benefits to people other than the one needing a donation. Krampitz inspired New York City truck driver Sonny Velez to develop his own Web site. Velez didn’t receive a liver through the Web site, but his wife said the site introduced him to a support group that helped his recovery after he received a liver through traditional channels in November 2004.291

Beyond gaining organs, MOPAs of inscription have further helped to normalize transplantation as medical therapy. Still, 19 people a day die due to the extreme shortage of organs. The continued shortage and every-growing waitlists, and mounting desperation of transplant candidates has also prompted MOPAs that function by re-inscription—MOPAs that challenge both those that function by erasure and inscription.

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291 Robeznieks, “Man Who Got Transplant.”
Chapter 3: MOPAs that Re-Inscribe

**LIFESHARERS DONOR CARD** (Carry with your driver’s license)

Name: ________________________________

In the hope that I may help others, I hereby make this anatomical gift, if medically acceptable, to take effect upon my death. The words and marks below indicate my desire. I give: any needed organ for the purpose of transplantation or therapy. Limitations or special wishes: For purposes of transplantation and therapy, it is my express wish that my organs be donated first to members of the LifeSharers network, unless no LifeSharers member is a suitable match. For each part of my body donated, I designate as donee that LifeSharers member who is the most suitable match as defined by the criteria in use by LifeSharers at the time of my death. I retain the right to donate my organs to members of my family. For names of LifeSharers members who need my organs call 1-888-ORGAN88 or 1-888-674-2688

Signed by the donor and the following witnesses in the presence of each other:

<table>
<thead>
<tr>
<th>Signature of the Donor</th>
<th>Date of Birth</th>
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<th>City/State</th>
<th>Date Signed</th>
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Witness:____________________________________

Witness:____________________________________

TO NEXT-OF-KIN AND MEDICAL PERSONNEL: Please get the names of LifeSharers members who need my organs by calling 1-888-ORGAN88 or 1-888-674-2688. Please tell transplant personnel I wish to donate my organs to these individuals.

This is a legal document under the Uniform Anatomical Gift Act and similar laws.

Figure 20. LifeSharers Organ Donor Card
Brett Jortland, 31, of Bethesda, remembers the first time he signed on to donate his organs to some unknown person needing a new kidney, heart or lung. He was just 17 years old and signing the paperwork for his first driver’s license.

“I checked off that box saying I’d donate my organs,” he said. “I remember thinking, I’m not taking this stuff with me.”

Years later, he remains committed to that ideal, but with one important caveat: He wants his organs to go to a fellow organ donor and not just any name that comes up on a waiting list.

So like some [15,000] others across the country, he joined LifeSharers, a nonprofit organ donor network that enables its members to have “first dibs” on the organs of fellow members.

“Ultimately, it just makes sense to do it this way,” said Jortland,… “If you’re not willing to give an organ, you should not be the first in line to receive an organ.”

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Sasha Albertini, an IT worker in Houston, joined LifeSharers in 2004, thinking it the right thing to do.

“I’m not one of those people who’s terribly attached to my body after I no longer need it,” she says. “I still have good stuff, and, frankly, I would hate to see it go to waste.”

She has since lost a kidney to a massive infection. Now she takes comfort in her slightly better odds of receiving a transplant if the other one goes. She calls the network “a leg up.”

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Brett Jordland and Sasha Albertini were already registered organ donors, but the idea of giving people who were already registered as organ donors preferential treatment in the allocation of organs made sense to them. For Albertini, who later went on to

292 Vaughn, “Network Gives Donors ‘First Dibs’.”
293 Giglio, “Houstonians (And Others).”
develop a kidney infection and lose one of her kidneys, her convictions about her
decision to join LifeSharers grew even stronger—should her one remaining kidney fail
she might receive an organ sooner because of the agreement between herself and the
15,000 LifeSharers that they will give their organs to other LifeShares first. By
registering with LifeSharers.org, Brett Jordland and Sasha Albertini became a part of a
MOPA that operates by re-inscription.

This third chapter is concerned with MOPAs that re-inscribe—in particular,
LifeSharers.org. This chapter is divided into three parts. Part I focuses on how re-
inscription happens, the mechanisms behind donor and patient identity information
management practices that highlight select pieces of socio-political identity information
and overlays those onto medico-institutional identity information. Part II situates the
re-inscribing practices by locating the MOPAs that re-inscribe within the cultural
contexts and theoretical constructs that have informed and support their practices. Part
III engages with how the practices of re-inscription affect organ donors/donor families
as well as organ transplant candidates/recipients and discusses how the ways they
experience affect effect the overall organ transplant system in the U.S.

Part I: The Mechanics of Re-Inscription
This first part of the chapter defines re-inscribing practices. It identifies LifeSharers.com
as the primary MOPA of this identity management practices. Part I addresses the
mechanisms of re-inscription: LifeSharers’ operating principles, membership, and the
duties of the future potential deceased donor/donor’s family members.
Re-Inscription Defined
MOPAs that re-inscribe manage patient and donor identity information by highlighting a limited amount of socio-political identity information and overlaying it onto the medico-institutional identity that is produced and privileged by State-sanctioned MOPAs. Re-inscribing practices—implemented by Lifesharers.org—are meant to ensure the equitable allocation of organs among a group of people who choose to be identified by their shared, singular socio-political identity trait. Re-inscribing practices privilege particular pieces of socio-political identity information while also relying upon medico-institutional identity information for the efficient management of organ allocation to those who also choose to highlight the shared socio-political identity features. Re-inscription plays upon ideas about shared community and affiliation rooted in the highlighted socio-political identity information to encourage organ donation.

LifeSharers.org
Founded in 2002, LifeSharers is a membership organization in the U.S. that facilitates organ sharing between its members. Those who join the organization pledge that upon their death they will offer their organs first to other LifeSharers members, provided that a member who is in need of an organ is a suitable match, before allowing their organs to be offered to other individuals on the nationwide organ transplant waitlists. LifeSharers’ mission is “to end the shortage of donated human organs for transplant operations.” Its members say that they are working to stem the organ shortage by

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295 LifeSharers, “Welcome to LifeSharers.”
creating “an incentive to donate, by directing the donation of our organs first to others who have promised to donate theirs.” As of February 2012, the organization had 14,984 registered members; 113 of these LifeSharers members are also in need of organs and have been placed on the UNOS organ transplant waitlists—103 of the 113 LifeSharers-transplant-candidates “have qualified for preferred access to the organs of fellow LifeSharers members.”

Individuals who hope to support organ donation by pledging to donate their organs upon their death to other organ donors register with LifeShares.org. Registration requires accepting the agreement set forth by the organization and creating a membership ID and password—see Figures 21 and 22. Registration is free. Anyone of any age can become a LifeSharers member (parents may enroll children who are not of consenting age) regardless of health or pre-existing medical condition.

296 Ibid.
297 Undis, “LifeSharers Member Newsletter, March 2012.”
298 LifeSharers, “FAQ.”
299 Ibid.
Join Here

As a member of LifeSharers you will receive:

- A LifeSharers donor card - You should sign your card, get it signed by the person who you want to be notified in case of a medical emergency, and carry it with you.
- A letter to send to your doctors - You should send this letter to each of your doctors to inform them about your wish to donate your organs and to ask them to refer other patients to LifeSharers.
- A letter to send to your family - You should send this letter to family members to make sure they're aware of your wish to donate your organs and to suggest they consider joining LifeSharers.
- Language for including in your durable power of attorney for healthcare - You can include this language so that your healthcare proxy will know about your organ donation preferences.

LIFESHARERS MEMBERSHIP AGREEMENT

To join LifeSharers, you must accept the following LifeSharers membership agreement:

As a member of LifeSharers, I agree to donate my organs upon my death. It is my express wish that my organs be donated first to members of the LifeSharers network, unless no LifeSharers member is a suitable match. For each organ of my body donated, I designate as donee that LifeSharers member who is the most suitable match as defined by the criteria in use by LifeSharers at the time of my death. I retain the right to donate my organs to members of my family.
I understand that:

- LifeSharers is a non-profit organization.
- LifeSharers is not a licensed organ procurement organization.
- LifeSharers does not guarantee that organs will be available to LifeSharers members or from LifeSharers members.
- LifeSharers members are not eligible for preferred access to organs from other LifeSharers members until they have been a member for 180 days.

I agree to not hold LifeSharers, its directors, advisors, management, staff, agents, servants, and assigns liable in the event I do or do not receive any organ that becomes available from another LifeSharers member, and further to pay any and all fees, costs, judgments, including attorneys' fees, incurred in any lawsuit or legal proceeding I may bring in connection herewith.

☐ I accept this agreement
☐ No thank you

Select Your MemberID and Password

Select a MemberID (3-20 characters)

Select a password (6-10 characters; your password cannot be the same as your MemberID)

Retype your password

Submit  Reset

Figure 22. LifeSharers.org Membership Registration, Part 2
The LifeSharers membership/donor card, and, per the card’s notation, carrying it with one’s driver’s license, is what re-inscribes. The card highlights a piece of a potential organ donor’s socio-political identity information—his or her membership as a LifeSharer, supporting “Organs for Organ Donors” (the organization’s motto)—and this piece of socio-political identity information is used in allocating the organ donor’s/LifeSharer’s organs: evaluating the UNOS match run and selecting recipients from the match run, regardless of allocation score, who are also LifeSharers members.

**Principles for the Allocation of Organs**
LifeSharers is rooted in a proposed “advanced-directive organ registry” organ donation/allocation scheme that was outlined by Irvin Kleinman and Frederick Lowy in a 1992 article, “Ethical Considerations in Living Organ Donation and New Approach—An Advance-Directive Organ Registry.” The Advance Directive Organ Registry was developed as an “incentive-based organ registry”\(^{300}\) to encourage deceased donations: all adults, age 18 and older, would be encouraged to voluntarily register an advance directive regarding organ donation; those who agreed to “permit all usable organs to be taken at the time of death would receive priority for organs generated by the program, should a transplant become necessary when there is a shortage of organs”,\(^{301}\) those who did not agree to donate could register at a future date, but “a delay before obtaining priority to receive organs from the registry (perhaps equivalent to the initial

\(^{300}\) Kleinman and Lowy, “Ethical Considerations in Living Organ Donation,” 1486.

\(^{301}\) Ibid.
delay in joining) might be necessary.”

Kleinman and Lowy’s organ donation/allocation scheme for increasing the availability of cadaveric organs and greater ethical equanimity in the allocation of organs, off of which the LifeSharers membership program is based, was guided by the principles of autonomy, justice and beneficence. These same principles underpin LifeSharers’ allocation of organs via re-inscription:

Autonomy is served by the voluntary registration of an advance directive that will likely be honored. The welfare of those who need transplants is served by increasing the supply of cadaveric donor organs, while the welfare of their family members is advanced by reducing the need for living organ donation, with its potential risks as well as ethical and psychological conflicts. Justice is also served when more persons who need transplants get them.

These three principles provide a framework for LifeSharers organ allocation practices and their donor and patient identity information management practice of re-inscription to “advance the public good by participating in the responsibility for organ donation,” as the organization believes “organ donors deserve special consideration in organ allocation because without organ donors there would be no organs to allocate.”

LifeSharers and UNOS Organ Allocation

Individuals in need of organs who have already been evaluated and approved by a transplant center and placed on the UNOS transplant candidate waistlist who hope to

302 Ibid.
303 Ibid., 1487.
304 Ibid.
305 Ibid.
306 LifeSharers, “FAQ.”
gain organs from a deceased donor sooner by also pledging to give their organs to other organ donors must register with LifeSharers.org first and then notify the organization via email that they are a transplant candidate on the UNOS waitlist at a regional transplant center. A transplant candidate must be a LifeSharers member for 180 days before organs from other LifeSharers will be directed to the candidate.

As a MOPA of re-inscription, LifeSharers operates parallel to UNOS—its own list of members has no bearing on UNOS’ transplant candidate waitlists, organ allocation formulas, or match runs. Furthermore, LifeSharers participates neither in organ matching nor in the physical procurement or allocation of organs. The LifeSharers membership card and next of kin are the vehicles through which re-inscription take place.

If a LifeSharers member dies in manner that allows for the donation of his or her organs, the LifeSharers donor is treated just as any other individual who has consented to donate his or her organs after death. The individual’s information is entered into DonorNet/UNet and organ matching is carried out. However, because LifeSharers members agree to donate their various organs, upon their death, to transplant candidates who are both highest ranked on the match run and also LifeSharers, the organization relies upon the LifeSharer’s next of kin to call the organization and get a list

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307 LifeSharers, “FAQ.”
308 Ibid. The waiting period instituted by LifeSharers encourages individuals to become members when they are healthy, and it is meant to discourage individuals from waiting to join only when they find out they are in need of an organ.
309 LifeSharers, “FAQ.”
of the names of fellow LifeSharers members who are organ transplant candidates. The deceased member-donor’s family members must present the transplant coordinator with the LifeSharers Donor Card and/or durable power of attorney documents and the list of names of LifeSharers members who are also registered with UNOS as transplant candidates so that each of the member-donor’s organs will be directed first to the highest ranking qualified LifeSharers member on the match run of the UNOS transplant candidate waitlist. If no suitable matches within the LifeSharers’ membership organization are found (i.e. blood type, size, relative geography, HLA markers aren’t compatible), then the organs will be offered as they normally would to transplant candidates listed on the match run. If the organs are declined by fellow LifeSharers-transplant-candidates and/or their transplant teams, then the organs will be offered to the transplant candidates with the highest organ allocation scores from the match run.

A transplant candidate on the UNOS waitlist who is also LifeSharers member may receive an organ from a deceased organ donor who is a fellow member of LifeSharers or from a deceased organ donor who is not. The LifeSharers-transplant-candidate’s medical team will evaluate an organ-offer from a LifeSharers-donor in the same way that all organ offers for that candidate are evaluated. Should a LifeSharers-transplant-candidate receive an organ, he or she may never know if the organ donor was a LifeSharers member or not due to UNOS’ erasing practices.

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I have detailed the principles that have helped to inform the LifeSharers organization and how it functions, the process of becoming a LifeSharers member, and how organs from LifeSharers members are procured and allocated to give a sense as to how this MOPA of re-inscription functions. LifeSharers is a MOPA of re-inscription operating in parallel with UNOS, a MOPA of erasure; its members prioritize the socio-political identity trait of “being an organ donor” in the allocation of their organs upon death. In overlaying the list of LifeSharers-transplant-candidates onto the list of transplant candidates and their organ allocation scores generated by a match run, a single aspect of the socio-political identities of both organ donor and organ transplant candidate are re-inscribed back onto the donor and patient.

**Part II: Situating MOPAS that Re-Inscribe — Cultural and Theoretical Contexts**

Because the identity management practices that MOPAs use seem to have some bearing on potential organ donors’ willingness to donate and have an impact upon the health outcomes of transplant recipients, it is important to understand not only how MOPAs of re-inscription manage identity information, but also why that identity management practice was implemented. Part II of this chapter situates LifeSharers to bring into relief some of what has informed and supported its re-inscribing practices.

LifeSharers.org was founded around the same time that MatchingDonors.com was founded. The same intense anxiety around the organ scarcity and the same appeal to the principle of organ donors’ autonomy that supported the emergence of MatchingDonors.com and sites of crowdsourcing contributed to the emergence of
LifeSharers.org. However, LifeSharers’ identity management practices greatly differ from those of MOPAs of inscription. LifeSharers’ re-inscribing practices were shaped by the controversies and revisions to organ allocation policies that stemmed from the case of a deceased KKK sympathizer’s family members stipulating how they wished his organs allocated, informed by the UAGA’s support of directed donation, and encouraged by physicians who refused to transplant organs from living organ donors who had been solicited.

*Controversies in Organ Allocation*

On July 4, 1990, 24-year-old Marine reservist Thomas Simons was shot multiple times and killed as he reached into his car for his wallet in what amounted to a $5 robbery. Simons was declared brain dead after being driven from the scene in Bradenton, Florida’s Waterfront Park to a nearby hospital by his girlfriend, who had also been shot. After being approached by a Florida LifeLink transplant coordinator, Simons’ parents agreed to the donation of their son’s organs, but they requested that their son’s organs only be given to white transplant candidates. Although Simons’ parents denied that there son was a Ku Klux Klan member, the police found three Ku Klux Klan cards in Simons’ wallet, family members barred fellow Marine Corps members who were Black from attending Simons’ funeral, and a white supremacist group erected a memorial to Simons where he had been shot in honor of their “‘fallen brother’.”

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311 Ibid., 8A.
While “LifeLink officials did their best to explain that tissue matching made it likely that Thomas Simons’ organs would go to whites anyway, whether there was a stipulation or not,” they still accepted the organs with the explicit racial conditions Simons’ family attached to the donation—“...the consent form ... shows Simons’ father agreeing to donation of organs ‘to white recipients only’.” In 1990, the organ transplant waitlist stood at 33,000 people; LifeLink of Florida agreed to this conditional donation of Thomas Simons organs because it did not want the organs to go to waste.

Four years later when the murder case went to trial, the gunman’s defense attorney shared the details of the conditional organ donation to argue “racially charged circumstances” in a motion to move the trial to a different location. Ultimately, the information about the racial stipulations attached to the organ donation attracted more attention than the murder trial itself. The U.S. Office of Civil Rights weighed in on LifeLink’s decision stating that allocating organs to a specific race did, in fact, violate the Federal Civil Rights Act of 1964 which bars discrimination based on race, color, or national origin. Bioethicist Arthur Caplan voiced his opposition to LifeLink’s actions, arguing that accepting conditional organ donations or such stipulations attached to a

312 Testerman, “Should Organ Donors Get a Say In Who Receives Their Organs?” 8A.
313 Ibid.
315 Testerman, “Should Organ Donors Get a Say In Who Receives Their Organs?” 1A.
316 Ibid.
317 Associated Press, “‘Organ Donation Agency Agrees to Racial Stipulations,” 1B.
donation is “‘a terrible practice’ that would ‘throw the whole system into turmoil’.”  

The Simons case led UNOS to adopt an advisory declaring that the “‘donation of organs in a manner which discriminates for or against a class of people based on race, national origin, religion, gender, or similar characteristics is unethical and may not ethically be accepted by UNOS members or transplant professionals’.” This statement was adopted by UNOS’ Board of Directors in November 1994, amended in June 1996, and reaffirmed in April 1999. However, Clive O. Callender, a prominent Black transplant surgeon, said at the time of the Simons case “he would prefer the flexibility to accept organs whatever the stipulations if it meant saving lives.” The transplant system in the U.S. is a delicate one. If the general public does not support the ethical values that are used in evaluating organ donations/allocations, donation rates fall.

UNOS’ policy against donations to groups of people is meant to protect against judgments about the social worth of people based on discriminatory, invidious views of race, religion, ethnicity, gender, etc. LifeSharers’ re-inscribing practices, though the organization is not re-inscribing “protected class” identity information back onto the UNOS organ transplant waitlists, does challenge the policy the Simons’ case prompted in

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318 Testerman, “Should Organ Donors Get a Say In Who Receives Their Organs?” 1A.
320 Murphy and Veatch, “Members First,” 59.
321 Testerman, “Should Organ Donors Get a Say In Who Receives Their Organs?” 1A.
322 Murphy and Veatch, “Members First,” 50.
an effort to gain more organs for transplantation (for fellow organ donors).\textsuperscript{323} While the manner in which LifeSharers functions does not meant that organs from LifeSharers will only be given to fellow LifeSharers members or discarded if no suitable LifeSharers-transplant-candidate is found, it does create a “class of people that gets special consideration in organ allocation” over others by re-inscribing a specific socio-political identity trait back onto the UNOS transplant waitlist.

\textit{Direct vs. Directed Organ Donation}  
Just as MOPAs of inscription are supported by the autonomy principle in that they appeal to the autonomous actions of potential organ donors so too do MOPAs of re-inscription. As a living donor who has been engaged through a MOPA of inscription, the donor retains rights over his or her body and can donate an organ to a recipient of his or her choosing. As a deceased donor, engaged through either a MOPA of inscription or re-inscription, the donor’s ability to give an organ to a specific individual is legally authorized by the Uniform Anatomical Gift Act (UAGA). These donations from deceased donors to specified individuals are referred to as \textit{directed donations}. According to OPTN, a “directed donation is a request made by a donor or donor family to transplant a specific recipient.”\textsuperscript{324} LifeSharers only supports organ sharing from deceased organ donors, sharing the organs from deceased LifeSharers members with other LifeSharers members who are also transplant candidates.

\textsuperscript{323} According to Wikipedia, the characteristics of race, color, religion, national origin, age, sex, familial status, disability, veteran and genetic information are considered “Protected Classes” and persons cannot be discriminated against based on these characteristics.  
\textsuperscript{324} OPTN, “OPTN Information Regarding Deceased Directed Donation.”
Guido Pennings, in his article “Directed Organ Donation: Discrimination or Autonomy?” examines the category of “directed organ donations” from cadaveric donors and usefully sub-divides the category further as he differentiates between directed organ donations and direct organ donations. According to Pennigns, “A ‘directed’ donation is a procedure in which donors or their family members direct the organs to a group of recipients that are determined by the presence or absence of a particular characteristic. This procedure must be distinguished from the ‘direct’ donation in which the organs are given to a specific person.”

Following Pennings, MOPAs of inscription are supported by direct donations—a living donor or the family members of a deceased organ donor request that an organ be given to a specific person, whereas MOPAs of re-inscription are supported by directed donations—a deceased donor or the family members of a deceased donor request that all of the donor’s organs be given to individuals belonging to a group sharing a particular socio-political identity trait.

Directed donations on the basis of non-medical criteria are not legal—in part, because of the Simons’ case. LifeSharers is still able to operate as a MOPA of re-inscription, privileging the socio-political identity trait of ‘organ donor’ and re-inscribing that information back onto the UNOS organ transplant waitlists, because of the language of the membership agreement: “For each organ of my body donated, I

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325 Pennings, “Directed Organ Donation,” 41. From here on in, I shall follow Penning’s naming conventions in differentiating between direct and directed donations.
designate as donee that LifeSharers member who is the most suitable match as defined by the criteria in use by LifeSharers at the time of my death.”

The language the LifeSharers organization uses tries to shift its donation from being directed to direct so as not to violate the UAGA and UNOS’ policies. UNOS, however, does not support the manner in which LifeSharers operates. In the November 2003 OPTN/UNOS Board of Directors Meeting, the board “declined to endorse the operating principles of the LifeSharers organization.”

A LifeSharers-organ-donor’s ability to direct the donation of his or her organs by re-inscribing the socio-political identity feature of ‘organ donor’ back onto the organ transplant waitlists and UNOS match run is not only tied to the donor’s next of kin and the phone call to LifeSharers but also to transplant professionals. Although LifeSharers does violate the OPTN/UNOS’ advisory—declaring directed donations to particular groups unacceptable—it counts upon the professionalism of transplant coordinators:

“The role of transplant professionals is to ensure that any donor offer is handled properly and that the safety and interests of the donor and donor family are protected. This is true in the rare instance of directed donation as well as the commonplace, non-directed allocation of organs to transplant candidates.”

Additionally, LifeSharers is able to leverage the continued organ shortage so that its member’s organs will be

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326 LifeSharers, “FAQ.”
327 OPTN/UNOS, “Executive Summary of the Minutes.”
328 OPTN, “OPTN Information Regarding Deceased Directed Donation.”
accepted and allocated in accordance with the organization’s/donor’s directed donation directives.

Opposition to Direct Donations Through MOPAs of Inscription
According to OPTN, at least 100 deceased donor transplants each year have occurred through direct donations. In most cases, the deceased donor or donor’s family directs only one organ to a specific recipient—generally, the recipient is someone the donor knew; the donor’s other organs are allocated in accordance with the OPTN/UNOS organ allocation policies. Since it was founded in 2004, MatchingDonors.com has facilitated more than 100 live-donor transplants through direct organ donations; crowdsourcing through the media and social media networks has facilitated hundreds if not thousands more direct donations. These, of course, are a result of the MOPAs of inscription—the highlighting of socio-political identity traits of a known or unknown transplant candidate and the direct donation of an organ to a particular candidate based upon his or her socio-political identity characteristics rather than medical need/a transplant candidate’s medico-institutional identity.

The opposition to discriminatory organ allocation practices in the Simons case brought attention to direct donations and an organ donor’s ability to direct the donation of his or her organs to individuals upon death. Direct donations from living and deceased donors have supported the growth of MOPAs of inscription. However, opposition to MOPAs of inscription and opposition to direct donations to unrelated

329 Ibid.
recipients have served to encourage the growth of MOPAs of re-inscription and paths to directed donations to groups.

There are many physicians and ethicists who oppose MOPAs of inscription. As the head of the ethics committee of the American Society of Transplant Surgeons in 2004, Dr. Hanto asked the members of the society to “boycott privately arranged transplants.” Additionally, NATCO, The Organization of Transplant Professionals does not support MOPAs of inscription and the direct donation transplant surgeries that result. In a position statement on organ solicitation currently under review, NATCO argues

[Direct] donation was never intended to facilitate inequitable, unjust, or discriminatory allocation of organs. These policies were intended to allow families some control over the organs of their loved one so that they could potentially help someone else close to them. However, because of the currently unrestricted nature of directed donation, abuses are possible. [...] NATCO proposes that under no circumstance will solicitation for organs from either living or deceased donors be permitted. Commercial solicitation is especially reprehensible and should be stopped.331

Hospitals have also instituted polices that discourage transplant candidates from seeking organs through MOPAs of inscription and direct organ donations from unknown, unrelated donors—“A survey of 132 U.S. kidney transplant centers published in the October 2007 American Journal of Transplantation found that only 30% were

330 Satel, “An Internet Lifeline.”
willing to accept donors who were publicly solicited.”

Because of explicit hospital policies or the attitudes of transplant surgeons, transplant candidates must often seek out transplant centers that are willing to support them and their donors.

There are also transplant candidates who oppose MOPAs of inscription. Some transplant candidates feel that MOPAs of inscription are unfair because not all candidates have amazing, touching stories, not all make for great poster-boys or poster-girls for their disease, not all candidates want to share deep, personal information about themselves to convince someone to donate an organ to them. As one physician explained, “I had a patient who viewed herself as an unattractive black woman,’ [...]. ‘She told our psychologist, “If I put my profile on MatchingDonors.com, why would anyone want to donate to me?”’

For those who oppose MOPAs of inscription because they believe that such MOPAs encourage donations only to the beautiful, rich, successful, or famous people in need of organs, MOPAs of re-inscription, depending upon the identity trait that gets re-inscribed, eliminate the “beauty contest” aspect that is sometimes attributed to MOPAs of inscription.

Between questions about fairness, equitability, and the ethics of MOPAs of inscription, MOPAs of re-inscription, like LifeSharers, have acted as a middle ground, for they aim to encourage organ donations, do not seek organs from living donors, and

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332 O’Reilly, “Public Pleas for Organs.”
333 Ibid.
respect the much of UNOS’ biopolitical functioning.

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In the emergence and growth of LifeSharers, we see how policies around directed organ donations, controversies due to organ allocations that put organs before civil rights, and donors’ desires for greater autonomy produced this organization. As the anxiety around the organ scarcity reached a new level of intensity, transplant candidates sought out other means of gaining organs for themselves. More and more, organ donors sought ways of exercising their autonomy and directing the donations of their organs—this was easily accomplished while alive, but it was more challenging after death. While transplant candidates had some success in gaining organs for transplantation through MOPAs of inscription, finding donors who were willing to be live donors and direct the donation of their organs to them, many physicians and hospitals did not support such practices. LifeSharers, a free membership organization open to all regardless of health or age emerged and grew as a site that supports the autonomy of donors even after their death. LifeSharers links potential donors and patients based upon a shared identity quality—they are individuals who support donating their organs after their death. This MOPA of re-inscription joins the MOPAs of inscription and the MOPA of erasure and completes the landscape of organ sharing practices that has developed in the U.S. over the last nearly 60 years of transplant history.
Part III: Affects/Effects of Re-Inscription
LifeSharers is a MOPA that functions by re-inscription. Its identity management practices are intended to encourage organ donor registration and organ donation by highlighting a particular aspect of their members’ socio-political identity and using that to “create a class of people that gets special consideration in organ allocation.” Part III looks at the types of feelings that result from the affect motivated by re-inscribing practices. In particular, this part examines how the practices of re-inscription affect organ transplant recipients as well as organ donors/donor families and discusses how these experiences effect the overall transplant system.

Transplant Recipients
The goal of LifeSharers is to improve an individual’s odds of receiving an organ should one ever need a transplant: “If you ever need an organ for a transplant operation, chances are you will die before you get one. You can improve your odds by joining LifeSharers. Membership is free.” Yet as a MOPA, it has in no way met its stated goal. LifeSharers is a completely ineffective MOPA. None of the LifeSharers-transplant-candidates have received organs from fellow LifeSharers in the organization’s 10-year history. To date, none of its members have died in a manner that allowed for the recovery of their organs. Thus, no LifeSharers have become organ donors.

Because LifeSharers has facilitated no transplant surgeries, the types of feelings that result from the affect motivated by being transplanted with the organ of a fellow

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335 LifeSharers, “FAQ.”
336 LifeSharers, “Welcome to LifeSharers.”
337 LifeSharers, “FAQ.”
LifeSharer are unknown. Furthermore, what the effects on a transplant
candidate/recipient of the affect motivated by the MOPA’s re-inscribing identity
management practices might be are also unknown. Finally, because LifeSharers, a
MOPA of re-inscription and operates in concert with UNOS, a MOPA of erasure, if the
donor’s identity information—that he or she was a LifeSharer—does not get re-
inscribed back onto the organ and shared with the recipient, then there will be no way
of knowing if the affect motivated by the organ transplanted as a result of a MOPA of
re-inscription will increase the positive post-operative outcomes of a transplant patient
or not. Because of how this particular MOPA of re-inscription functions, a LifeSharers-
transplant-recipient may or may not even know that his or her donor had been a
LifeSharer.

Many people in need of organs see some sort of inherent logic to the manner in
which LifeSharers operates: giving organs first to organ donors should, ultimately, create
more organ donors, which should, in the end, save more lives. Yet, there is no evidence
that this MOPA has saved any lives. As less than one percent of deaths result in organs
that are viable for transplantation, literally millions of people would need to register as
both organ donors and LifeSharers (and, also, die) for the organization to even begin to
have enough organs to distribute to its members who are in need of organs and on
transplant waitlists.
Organ Donors
One of LifeSharers’ aims is to increase the number or organ donors in the U.S. by creating an incentive to donate organs through directing the donations of LifeSharers members’ organ first to other LifeSharers. According to the organization, LifeSharers-member-donors respond, in part, to this incentive:

Seventy five percent said they joined because they want organs to go to other organ donors. Seventy one percent said they joined because they wanted to create an incentive for non-donors to become donors, and 65 percent said they joined because they want to increase their chances of getting a transplant if they need one. Five percent said they joined for other reasons. 338

LifeSharers’ member Tim Harker falls into the other five percent. Harker became a LifeSharers member because, as he explained, “‘I’m a conservative and I’m never happy when a bureaucracy [like the DHHS] runs things in my life,’ [...]. ‘The notion I can have some say, make some decisions, even in a situation like [organ donation] is important to me.’” 339 While there are some who have registered as LifeSharers, like Harker because it does support the autonomy principle, there are many more who joined because it does incentivize donation. Members John and Kimberly Wisniewski “joined not so much for our own needs, but because we know we are giving priority in utilizing our donated organs to others who are willing to give. What a wonderful way to encourage all people to donate, which is the ultimate goal here.” 340 In this respect, LifeSharers has met it goal: in a March 2009 presentation at The Ethics of Organ Transplantation conference,

338 Wright, “Two Transplant Lists.”
339 Vaughn, “Network Gives Donors ‘First Dibs’.”
340 LifeSharers, “People.”
LifeSharers’ Executive Director David J. Undis cited internal polling data that revealed 20% of LifeSharers members were not already registered organ donors when they joined the organization.\(^{341}\)

Although LifeSharers has met its goal of encouraging more people to donate, it has made little impact. I would suggest that LifeSharers’ ineffectiveness has, in part, to do with the fact that its practice of identity information management does not lend itself to the motivation of affect. Affect involves both an individual’s body and the mind—\(^{342}\) “the mind’s power to think corresponds to its receptivity to external ideas; and the body’s power to act corresponds to its sensitivity to other bodies.”\(^{343}\) As a MOPA of re-inscription, LifeSharers makes very little in the way of identity information known or visible other than that one’s fellow members, the one’s to whom one intends to donate are also organ donors. This singular piece of identity information does not generate much of an external idea for the mind to respond to and the lack of visibility of other members—what does an organ donor look like?—does not give the body another body to respond to. The limiting of an individual’s capacity to be affected, limits a person’s power to act.\(^{344}\)

The Organ Transplant System in the U.S.
The practice of re-inscription as it is carried out by the LifeSharers organization makes minimal inroads towards enhancing beneficial health outcomes for transplant patients.

\(^{341}\) Undis, “Donated Cadaveric Organ Should Be Allocated First to Registered Organ Donors.”
\(^{342}\) Hardt, “Foreword: What Affects Are Good For,” ix.
\(^{343}\) Ibid., x.
\(^{344}\) Ibid.
Because no organs have been recovered from LifeSharers members and no organs from LifeSharers members have been transplanted into LifeSharers-transplant-candidates, the post-operative outcomes for transplant patients who receive organs from a MOPA of re-inscription is unknown. Internal data from the organization indicates that it has increased potential organ donors’ willingness to donate, but since no organs have been recovered from LifeSharers-members, no additional organs have been gained through this MOPA of re-inscription. Finally, any gains to the organ donor pool that LifeSharers has facilitated are minimal: as of March 2012, LifeSharers had nearly 15,000 registered donor members; in of October 2011, the U.S. organ donor registry registered its 100 millionth donor.\textsuperscript{345}

\textsuperscript{345} Donate Life America, “Donate Life American Announces 100 Millionth.”
Conclusion

With multiple models of organ procurement and allocation in the U.S. operating simultaneously, constituting our current transplant system (and in this project I’ve only addressed the legal MOPAs), each day, there are still 19 people on the transplant waitlists who die awaiting organs. Given these deaths and the projected rate at which such deaths will increase, in developing this project I sough out a new way to approach the ongoing conversations about organ donation and transplant practices in the U.S. because current, existing approaches have not yielded new understandings or innovative interventions in a system that fails thousands each year.

In this project, instead of focusing on gaining more organs for transplant patients, I have focused on enhancing health outcomes for transplant patients; instead of focusing upon the organs, I have focused upon how the MOPAs manage the identities of the organ donors, organ transplant candidates, and organ transplant recipients; instead of focusing solely on how MOPAs function, I have focused upon how their functioning affects people. I have reframed the well-worn issues in the discussions of organ donation and transplantation practices by taking an interdisciplinary, cultural studies approach to the current MOPAs that dominate the landscape of tissue exchange.
My method of analyzing the current MOPAs that dominate the landscape of tissue exchange was prompted by the work of other scholars whose research has shown organ transplant recipients, live donors, and families of deceased donors experience tissue exchange as highly personal—as though some part of a donor’s self or person gets transmitted along with the organ. Given the very personal nature of organ transplantation—having the tissue and cells of one person incorporated into the body of another—examining the identity management practices of current MOPAs opened up a new avenue for assessing how their functioning motivates affect which effects potential organ donors’ wiliness to donate, the number of organs that are available for transplantation, and the post-operative health outcomes for transplant patients. This examination of the identity management practices of current MOPAs in the U.S. has not only yielded a better understanding of our existing MOPAs and how the affects their identity management practices motivate effect the transplant system in the U.S., but it has also provided another avenue for intervention.

In concluding this project I am using this space to put forward a thought experiment, to suggest the construction of a new MOPA that draws upon the strengths of what I’ve identified as the identity management practices of current MOPAs. The body of the project has been about constructing and deploying a method of analysis; this conclusion is about imagining a type of intervention such that the ideas garnered
from the analysis “enter back into the world of cultural and political power struggles,”

to generate further conversations, new ideas, new methods of analysis, and new, innovative interventions that may enhance beneficial health outcomes for transplant patients and decrease the number of transplant patients who die each day as they await organs that may never come.

This new MOPA would be a MOPA that respects UNOS’ erasing practices in terms of its organ allocation formulas and policies on anonymity, but one that recognizes how UNOS’ practices fail to motivate donation and disadvantage minorities; it would be a MOPA that draws upon the successes of MOPAs of inscription and their use of images and narrative to gain organs for individual transplant patients, but it would also be one that recognizes the associated risks and costs of such personal exposure to the individuals seeking organs and the potential harms to other transplant candidates on the waitlists; and it would be a MOPAs that uses group affiliation and the power of an imagined community that underpins LifeSharers’ re-inscribing practices, but it would also be one that recognizes the powerful connection of the social and the biological that LifeSharers’ highlighted, uniting identity trait does not. In this thought experiment I am suggesting a MOPA that re-inscribes the socially salient features of racial and ethnic identity back onto the UNOS organ transplant waitlists in the hopes of motivating affect to (1) increase potential organ donors’ willingness to donate to people of their own racial or ethnic community, (2) to gain more organs for all transplant

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patients, and (3) to facilitate better organ matches between donors/ recipients of similar racial/ethnic/geographic background to increases the positive post-operative health outcomes for all transplant patients.

I am suggesting this MOPA of re-inscription that is imbricated in the complexities of race and ethnicity in the particular context of the history and culture of the U.S. I turn to race and ethnicity because they reflect deeply confounded social, cultural, and biological factors that often become significant in the face of tissue exchange. I suggesting re-inscribing the socially salient features of race and ethnicity back onto the UNOS transplant waitlists as such re-inscription plays off of the “projects of biological citizenship in the nineteenth and twentieth century,” that Nikolas Rose explains, “produced citizens who understood their nationality, allegiances, and distinctions at least in part, in biological terms.” According to Rose, biological citizens

...linked themselves to their fellow citizens and distinguished themselves from others, noncitizens, partly in biological terms. These biological senses of identification and affiliation made certain kinds of ethical demands possible: demands on oneself; on one’s kin; community, society; on those who exercised authority.

The intense pressure of the bio-medical-technological culture of the 21st century, to prolong life, cure disease, and increase one’s quality of life further develops these same biological citizens. If, as Rose suggests, individuals have come to understand their own selves and their own links to particular communities through biology, and that the

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347 Rose, *Life Itself*, 133.
348 Ibid.
349 Ibid.
biological connection to communities makes “ethical demands possible,” then Rose’s work on biological citizenship would seem to connect to Lauren Berlant’s work on national sentimentality which suggests that affect is part of what makes the construction of biologically rooted communities of affiliation possible, for it is affect that helps bind individuals together in the larger social-scape. In re-inscribing the socially salient features of identity, of race, ethnicity, and/or nation of origin back onto the UNOS transplant waitlist I am attempting to construct a MOPA that motivates affect, that connects biological citizens and compels them to “make live.”

In reframing the current crisis in organ transplantation as being about enhancing beneficial health outcomes for transplant patients rather than gaining more organs for transplant patients, I am focusing on re-inscribing the socio-political identity traits of race and ethnicity because there are aspects of these identity categories that are socially salient, that are connected to appearance, that tap into the visual and narrative and motivate affect to (hopefully) encourage registration and donation, and there are aspects of race, ethnicity, and/or nation of origin that are biological, which support better organ matching and better post-operative outcomes. In what follows of this conclusion, I address the biological aspects and social aspects that underpin this thought experiment, this possible new MOPA of re-inscription.

350 Berlant, Female Complaint, x-xi.
Biological and Racial/Ethnic Factors in Organ Donation and Transplantation

I am working through a MOPA that would re-inscribe race, ethnicity, and or/nation of origin back onto the UNOS transplant waitlists as another route to intervening in the current transplant system in the U.S, to enhancing the beneficial health outcomes of transplant patients, because our current transplant system is not only underserving its patients it is underserving them unequally: minority organ transplant candidates in the U.S., in particular, Black Americans, are dying at rates far higher than those of other groups. While most, including myself, would argue that transplant candidates overall health outcomes should not be tied to racial or ethnic identity—that a phenotypically based social construct has no place in the discussion of biomedicine—there is a body of research which shows that even after reviewing “the dismal history of race thinking and racialized eugenics [it was] nonetheless concluded that even when other variables were controlled, contemporary research had shown that there were differences in disease prevalence associated with race.”\textsuperscript{351} In this section, I work through how a MOPA that re-inscribes the socially salient features of racial or ethnic identity back onto the UNOS transplant waitlist may help to enhance the overall beneficial health outcomes of transplant patients for using race and ethnicity may facilitate better matches between donors and patients to increase positive post-operative health outcomes.

\textsuperscript{351} Rose, \textit{Life Itself}, 159. More specifically, they write: “Studies show that even after controlling access to health care, bias in treatment, and social class, there are still disparities in disease morbidity and mortality.” Kittles and Weiss, “Race, Ancestry, and Genes,” 53. One example they provide to articulate their finding is the disparity observed in rates of prostate cancer in the U.S.: “Prostate cancer rates in the United States are one of the most pronounced with the incidence and mortality races for African Americans being 1.5-2.0 times that of European-American men.” Kittles and Weiss, “Race, Ancestry, and Genes,” 53.
Black Americans are disproportionately afflicted with conditions that put them at risk for organ failure and organ transplantation, like diabetes and high blood pressure.\textsuperscript{352} Currently, Black Americans comprise about 13% of the total U.S. population,\textsuperscript{353} and as of March 16, 2012 they accounted for 29.3% of the 113,416 organ transplant candidates on the combined waitlists.\textsuperscript{354} Currently, White Americans comprise about 80% of the total U.S. population,\textsuperscript{355} and as of March 16, 2012 they accounted for 44.6% of the total number of organ transplant candidates on the combined waitlists.\textsuperscript{356}

\begin{figure}[h]
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\includegraphics[width=\textwidth]{figure23}
\caption{OPTN Data on Organ Transplant Candidate Waitlist by Ethnicity}
\end{figure}

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\textsuperscript{352} U.S. Department of Health and Human Services, “Organ Donation and African Americans.”
\textsuperscript{353} U.S. Census Bureau, “State and Country Quick Facts.”
\textsuperscript{354} U.S. Department of Health and Human Services, “Organ Donation and African Americans.”
\textsuperscript{355} U.S. Census Bureau, “State and Country Quick Facts.”
\textsuperscript{356} U.S. Department of Health and Human Services, “Organ Donation and African Americans.”
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The 29.3% is a figure that by all estimates could and should be higher; however, “green screening practices” often mean that many Black Americans who will or do need transplants never end up on the waitlists. The table below provides additional historical data that shows the percentage of Black Americans in need of organs on the waitlists and the increase over the recent 10-year span.

![Table: Characteristics of Waiting List Patients at End of Year, 2000 to 2009](chart)

Figure 24. OPTN/SRTR Data on the Transplant Waitlist by Race

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357 “There is what Dr. Clive Callender, director of the transplant center at Howard University here, calls ‘the green screen.’ A new liver can cost as much as $250,000, and most hospitals want evidence of insurance up front. Racial minorities, who are less likely than whites to have medical coverage, are thus less likely to receive a referral for transplant surgery, Dr. Callender said.” Stolberg, “Ideas & Trends: The Unlisted.” According to Michele Goodwin, “Commentators suggest that gaps in the organ referral process provide room for pernicious forms of rationing to occur.” Goodwin, Black Markets, 86. And, “Commentators allege that equitable distribution of organs has been impeded by the equivalent of racial profiling. They argue that social valuing overwhelms the organ referral process, influencing whether Blacks and Latinos are provided entrée to the transplantation allocation process.” Goodwin, Black Markets. 90. Additionally, the 2011 figures I’ve cited are consistent with earlier figures. On December 15, 2007 the transplant waitlist stood at 98,117 people, Blacks comprised 28% of those waiting organ transplants. Goodwin and Gewerts, “Rethinking Colorblind State Action,” 258.
While Black Americans may make up approximately 29% of the transplant patients on the organ transplant waitlists, they only receive about 20% of the organs.\textsuperscript{358} White Americans, make up approximately 45% of the transplant patients on the waitlists, yet they receive about 60% of the organs.

\begin{figure}
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\includegraphics[width=\textwidth]{fig25.png}
\caption{OPTN Data on Organ Transplantation by Race}
\end{figure}

Not all transplant candidates make it to surgery and receive an organ. For White Americans, 31% were removed from the waitlists in 2009 because they died or experienced conditions that would ensure death (deemed medically unsuitable, too sick to transplant, refused the transplant, etc.); for African Americans, 39% were removed.

\textsuperscript{358} This is an increase from the 1990s when Black Americans received about 15-17% of the organs while White Americans received about 70-73% of the organs.
from the waitlists in 2009 because they died or experienced conditions that would ensure death (deemed medically unsuitable, too sick to transplant, refused the transplant, etc.).\textsuperscript{359} Often this is because Black Americans wait longer than all other groups for organs—especially for kidneys. In 2005, for example, the median waiting time for kidneys—the organ in highest demand by Black Americans—was 809 days for Whites while it was 1968 days for Blacks.\textsuperscript{360}

Blacks often wait longer and receive fewer organs because in assessing whether or not a donor kidney is a good match for a transplant candidate, doctors look not only at blood type and size but also at six specific HLA antigens. Matching for these protein markers on the surface of the organ’s cells has shown to improve medical outcomes for patients. In calculating kidney allocation scores the number of matched versus mismatched antigens is a part of the kidney allocation formula.\textsuperscript{361} A 6:6 match is ideal. While an organ can be transplanted from a donor into a transplant patient if there is a less than perfect match, with every mismatch the chances of organ rejection increase. It is in this antigen matching that race becomes an issue: for Black Americans, due to the great heterogeneity of their DNA, there is very little chance of finding a 6:6 antigen match.

\textsuperscript{359} Organ Procurement and Transplantation Network, \textit{Data}.
\textsuperscript{360} Organ Procurement and Transplantation Network and Scientific Registry of Transplant Recipients, “Table 5.2: Time to Transplant, 2002 to 2009.”
\textsuperscript{361} The formulas for kidney allocation are currently under going review and significant revisions. HLA matching remains a part of the proposed revisions.
With the arrival of genetic sequencing, we have been able to determine, quantitatively, that the DNA sequences of any two people will always be 99.9% identical.\textsuperscript{362} Saying that all people are 99% the same or that genome mapping has also allowed us to see that genomic differences within racial or ethnic groups substantially exceed the differences across groups,\textsuperscript{363} however, is misleading:

Genome mapping led to the conclusion that while the three billion base pairs that make up the DNA sequence of any two randomly selected individuals will be 99.9 percent identical, there are many variations at the Single Nucleotide Polymorphism level where, say, a T is substituted for a C. On average, it was claimed, one letter in 1000 differed between two individuals—which made a total of many million variations between them (estimates of the number ranged from 6 million to 15 million). It began to be argued that these SNP differences between individuals were very significant, notably in relation to susceptibility to particular disease and treatability by specific drugs. Most significantly, it appeared that these differences occur with different frequencies in different populations, and might hold the key to the long recognized differences in disease susceptibility.\textsuperscript{364}

As individuals, on the genetic level, we both are and are not a lot alike, regardless of race, ethnic background, or nation of origin. But the ways in which we are genetically different and similar occur in rather predictable fashions. Because our HLA antigens are tied to our parents, to our ancestors, to geography, etc., better transplant matches and better post-operative outcomes might be tied to the different frequencies of genome differences in different racial and ethnic populations.

\textsuperscript{362} Rose, \textit{Life Itself}, 168.
\textsuperscript{363} Kittles and Weiss, “Race, Ancestry, and Genes,” 35.
\textsuperscript{364} Rose, \textit{Life Itself}, 168.
For those transplant candidates who make it to surgery and receive an organ, Black Americans experience organ rejection at rates higher than their White counterpart-patients. The rates of graft survival (the transplanted organ is still functioning) for kidney transplant recipients who’ve received organs from deceased non-extended criteria donors show disparities at the one-year, five-year, and ten-year marks. The one-year graft survival rate for Whites who have undergone kidney transplantation is 93.5%; for Blacks it is 91% (2.5 percentage point difference). The graft survival rate decreases overall at five-year and ten-year measures, but the gap in survival rates between Whites and Blacks grows as well. Five-years post-transplant the graft survival rate for White American kidney recipients is 74.8%, while the graft survival rate for Black American kidney recipients is 66.3% (8.5 percentage point difference). At ten-years post-transplant the graft survival rate for White American kidney recipients is 49.1%, while the graft survival rate for Black American kidney recipients is 37.1% (12 percentage point difference).

Finally, for those transplant candidates who make it to surgery and receive an organ, Black Americans also die at rates far higher than their White counterpart-patients. For example, those who received heart transplants, the one-year survival rate for Whites who have undergone heart transplantation is 87.6%; for Blacks it is 86.2%

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365 Organ Procurement and Transplantation Network and Scientific Registry of Transplant Recipients, “Table 5.8a Adjusted Graft Survival, Deceased Donor non-ECD Kidney Transplants.”
366 Ibid.
367 Ibid.
368 The survival rate decreases overall at three-year and five-year measures, but the gap in survival rates grows as well. Three-years post transplant 79.7% of White heart recipients are still alive, while only 73.1% of Black heart recipients are still alive (6.6 percentage point difference). 369 At five years, 73.3% of White heart transplant recipients are still alive as compared to 64.0% of Blacks (9.3 percentage point difference). 370

In 1977, 23-years before the Human Genome Project first began uncovering the sequence of DNA base-pairs, the first article to openly address and question racial, ethnic, and geographic difference as a factor in transplant outcomes was published in Transplant Proc. 371 Since then, researchers have returned to the question of race to explain what so far seem to be otherwise unexplainable differences in patient outcomes. In 2004, Dr. Charles Modlin, a top kidney transplant surgeon and director of the Minority Men’s Health Center at the Cleveland Clinic Foundation, explained to Kevin Chappell, now Senior Editor at Ebony magazine, “‘when it comes to transplantation, genetic makeup plays a critical role in matching a person with an organ. Black’s immune

368 Ibid.
369 Organ Procurement and Transplantation Network, Data.
370 Ibid.
371 Dr. John C. McDonald names Opelz, Mickey, and Terasaki 1977 paper “Influence of Race on Kidney Transplant Survival” as having been the first to report results that “Kidney transplants are less successful in blacks.” McDonald makes this claim in a lecture and comments entitled “Issues Related to Race in Transplantation” which he delivered at the Conference on Patient Selection Criteria in Organ Transplantation: The Critical Questions, held in Dearborn, Michigan on March 14, 1989.
systems react differently than Whites’. From Mondin’s statement and other similar claims from transplant physicians and researchers, many have concluded that Blacks experience fewer post-operative complications when they receive organs from Blacks.

In October 2008, Jayme E. Locke et al. published a study in the *Journal of the American Society of Nephrology* reporting on a 13-year study focusing upon race and D.C.D. (donation after cardiac death) kidneys. Locke et al. found that “among black recipients of kidneys obtained after cardiac death, those who received kidneys from black donors had better long-term graft and patient survival than those who received kidneys from white donors.”

While Black Americans have been the focus of much research in area of race in transplant outcomes (because of the disproportionately high rate of renal disease in Blacks), some studies have shown that matching for race or ethnicity, that is matching for single-nucleotide polymorphism (SNP) variation, has been seen to produce better medical outcomes in a variety of racial and ethnic populations.

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372 Chappell, “Life Goes On,” 88. African Americans may be highly sensitive to antigens either because of the complexity of their HLA profile or environmental factors: Dr. Michael Dreis, administrator in the HRSA, Office of Special Programs, Division of Transplantation, suggests that “Blacks have been exposed to more foreign antigens and at a higher rate than have Whites, thereby causing the development of antibodies that fight off foreign antigens.” Be it biologically linked or environmentally linked, Dreis still seems to be tying rates of organ rejection to race. Goodwin, *Black Markets*, 99.


374 Currently, much work is being done with the Hispanic population in South Texas to encourage organ donation because of the hurdles many transplant candidates face awaiting organs from donors whose genetic make-up and blood type match their own. Aguilar, “Organ Donations Lag” A27A.
In 2009 the *Saudi Journal of Kidney Diseases and Transplantation* published a study by Lakshmi Kiran Chelluria, Adavi Vasantha, and Kamaraju S. Ratnakar in which they put forth their finding that “graft survival was better among North and South Indian patients than in East Indian patients.”\(^{375}\) While such results still require further investigation, the researchers recognize that such outcomes may have something to do with the country’s racial distribution; they explain: “India, with its vast racial distribution, has a need to look into the ethnic variation and its impact on allograft survival.”\(^{376}\) And in October of 2009 Dr. Anita Patel, a transplant nephrologist at Henry Ford Hospital Transplant Institute, presented work at the American Society of Nephrology’s Annual Meeting and Scientific Exposition which revealed, by regression analysis, that in the U.S., “non-black recipients who received a kidney from black donors had a significant lower survival rate compared to those who received a kidney from a non-black donor [...] after adjusting for all known variables.”\(^{377}\) Dr. Patel drew these conclusions after studying more than 158,000 organ recipients between 1995 and 2008.\(^{378}\) Earlier in 2009, Dr. Patel presented similar study. However, in the earlier one she was looking at race and the effect on survival of the transplanted kidney in different donor/recipient pairs (i.e. the life or death of the organ itself, not the patient).\(^{379}\) Here, too, she was also looking at whether the organ was a D.C.D kidney or a D.B.D. (donation

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\(^{375}\) Chelluria, “Impact of Ethnicity,” 998.

\(^{376}\) Ibid., 995.

\(^{377}\) Seyrig, “Donor Race.”

\(^{378}\) Ibid.

\(^{379}\) Ibid.
after brain death) kidney. Still within this study, Dr. Patel found an increased risk in
the organ’s failure in non-black recipients of D.C.D black donor kidneys—the risk of
organ failure in increased two-fold.

I am working through this thought experiment, a MOPA of re-inscription in which
the socially salient features of race, ethnicity, and/or nation of origin are re-inscribed
back onto the UNOS waitlist because race and ethnicity are tied to both social and
biological factors. While engaging with race in medicine is akin to touching the third-rail
in healthcare, geneticists Rick Kittles and Kenneth Weiss beleive “...the fact that humans
have generally been a slow-traveling, slow-reproducing but globally distributed species
whose variation is related to geographic location provides a sufficient element of truth
to reinforce the idea that whatever they are, race captures something that is real, even
in everyday experience.” What Kittles and Weiss advance would seem to suggest that
the biological factors of race may not just be genetic; the biological factors of race may
be socially linked with race, too.

In November 2009, NPR’s Brenda Wilson talked with Dr. Courtney Lynch, a
physician at The Ohio State University about a report from the National Center for
Health Statistics on infant mortality. The 2009 report ranked the U.S. 30th in the world
in terms of its infant mortality rate; this represents a significant change as in the 1960’s

\[\text{Ibid.}\]
\[\text{Ibid.}\]
\[\text{Kittles and Weiss, “Race, Ancestry, and Genes,” 57.}\]
the U.S. ranked 12th. While the rise in U.S. infant mortality rates over the past 50 years is in and of itself worth significant exploration, some of the specific research that examined race in relation to risk of preterm delivery seems to point to what some are calling epigenetic race-linked medical factors—epigenetic meaning ‘above the genome.’ According to Lynch, “a black woman [in the United States] who is a physician and is well-educated actually has a higher risk of preterm delivery than the least well-educated white woman.” Lynch believes that race alone is the distinguishing factor in this health disparity and many others, but she does not link the disparity in infant mortality rates between Black and White women in the U.S. to genetic difference. Instead, Lynch roots the difference in racism: “It makes some folks uncomfortable and, you know, it's sort of tough to drill down. Those of us who have been working in this field have really been trying to figure out what it is. But we think that it is something related to the physiologic effects of experiencing lifelong racism.” The shift from race to the experiences of racism move issues like infant mortality and graft survival simultaneously into the social and the biological as how others respond to an individual’s socially salient features—or even how someone responded to an individual’s grandmother’s socially salient features—may shape his or her health.

At its most basic, studying the epigenome means looking at changes in gene activity that do not involve altering the genetic code but still get passed down to at least

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383 Wilson, “Infant Mortality.”
384 Ibid.
385 Ibid.
one successive generation. This is to say that not only do racial or ethnic phenotypic differences point to more significant genetic variation across races or ethnicities, but also that the physiological and psychological effects of racism can be inherited, thus these, too, are linked to racial and ethnic identity.

As transplant candidates’ racial or ethnic identity—be it genetically linked or otherwise—seems to have some bearing on their access to organs, the amount of time they will wait for an organ, and post-transplant health outcomes, race and ethnicity play an unseen role in organ transplantation in the U.S. for the transplant system is dominated by a MOPA of erasure. While race or racial/ethnic categories are often used as a stand-in for geography or a surrogate for genetic factors in many areas of biomedical research, the legacies of racism in the U.S. and the physiological effects of racism trouble the ways in which we may be currently matching donors and transplant patients. Because there are not only 19 transplant candidates who die each day while awaiting organs, but also because there are so many patients who experience organ rejection and/or die in the years following their transplant surgeries, I have focused on enhancing the overall health outcomes for transplant patients. A MOPA of re-inscription rooted in the socially salient features of race and ethnicity furthers this aim as it would encourage better post-operative outcomes for transplant patients by supporting organ donors who wish to donate an organ to someone of their own racial/ethnic/geographic background.
Just as race and ethnicity have both biological and social components, so too does organ transplantation. Tissue exchange would be a part of what Brian S. Turner describes as “our bodily maintenance [that] creates social bonds, expresses social relations and reaffirms or denies them.” MOPAs are in many ways what act as the gatekeepers to the social aspects of transplantation. Given that tissue exchange cannot only create social bonds but also reaffirm them or deny them, I could have suggested that this thought experiment for the construction of a new MOPA be rooted in aspects of identity far less charged or potentially fracturing than race and ethnicity. I could have suggested waitlists upon which alumni-networks or political affiliations were re-inscribed. While such aspects of individuals’ socio-political identity may be affective, they are only social and not biological. In the previous section I addressed the biological factors that have led me to suggest a new MOPA of re-inscription, for re-inscribing the socially salient features of racial and ethnic identity back onto the UNOS waitlists might ensure better matching and better post-operative health outcomes for transplant patients; in this section I am working through the ways that such re-inscribing practices might support improving the overall health outcomes for transplant patients by increasing potential organ donors willingness to donate and gaining more organs by tapping into the social, cultural, or community aspects of biological citizenship via affect.

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Because MOPA’s identity management practices have some bearing on organ donor’s willingness to donate, perhaps the current crisis of the organ supply for all transplant patients, minorities especially, is not with the supply side of the organ equation (that of donors or available organs), but the demand side, or, rather, how the demand side fashions itself or is fashioned. The contrast between UNOS, the MOPA of erasure and the MOPAs of inscription reveals that in stripping the transplant waitlists of all markers of personhood it seems that such erasure removes that which motivates people to donate, those things that make transplant candidates people too and make others remember that the transplant waitlists aren’t just lists like the grocery list or list of things to do, but people make up those lists—it is the human element which taps into the humanity of others. Even the current MOPA of re-inscription, LifeSharers removes too much of donors’ and transplant candidates’ socio-political identity traits, for the small number of members suggests that a potential registrant or potential donor has trouble connecting with those in need of organs if all that is known is a transplant candidate is also an organ donor. One cannot envision what that piece of information looks like, how it is embodied, for this as a potentially shared identity trait does not lend itself to visibility or open up a space for connection or community.

MOPAs of inscription have been effective in terms of gaining organs for many individuals who go outside UNOS to find organs because inscribing practices or types of information that most often get inscribed stir affect. Yet, because “anxieties surrounding organ scarcity, [have rendered] professionals especially reluctant to
instigate new policies that could further threaten the all too fragile trust the lay public
invests in their highly specialized medical realm.\textsuperscript{387} reconnecting individual transplant
candidates’ images and stories with their location on the waitlist risks too much for all
involved. However, because these same “professionals dedicatedly guard the
anonymity of cadaveric organ donors and in turn respect the privacy of transplant
recipients who, they feel, need not learn too much of their organs’ origins”\textsuperscript{388} re-
inscribing the socially salient features of racial or ethnic identity back onto the
transplant waitlists and allowing individuals to donate organs to their own communities
of affiliation may stir affect such that individuals previously unwilling or uninterested in
donating organs register as donors while all involved remain protected.

Re-inscribing the socially salient features of racial and ethnic identity back onto the
UNOS organ transplant waitlists means constructing images, visual representations
of communities, of biocitizens—making White, Black, Hispanic, Asian, American
Indian/Alaska Native, Pacific Islander, and Multi-racial transplant candidates appear
from out of the otherwise invisible list.\textsuperscript{389} I am focusing upon images and
representations of appearance, aspects of the surface of an individual’s body that are
the socially salient because the “idea behind producing an affective image is to transmit

\textsuperscript{387} Sharp, \textit{Strange Harvest}, 161.
\textsuperscript{388} Ibid.
\textsuperscript{389} These are the racial/ethnic categories (along with Unknown) that the OPTN and UNOS track. The SRTR only reports on White, African American, Other/Multi-race, Asian, Hispanic/Latino, and Unknown.
a ‘force of potential’.”\textsuperscript{390} Re-connecting the visual and identity to the organ transplant waitlists may help to create this potential and gain organs because of how the visual and the social are connected. In his essay “Showing Seeing,” W.T.J. Mitchell explains, “It is not just that we see the way we do because we are social animals, but also that our social arrangements take the forms they do because we are seeing animals.”\textsuperscript{391} In this thought experiment I am focus upon re-inscribing the socially salient features of race and ethnicity back onto the UNOS transplant waitlist because social arrangements between individuals are connected to appearances, because our understandings of ourselves and others as biocitizens are connected to appearances.

While thus far there are no MOPAs that function explicitly in the manner I am exploring here in this thought experiment, the socially salient features of race and ethnicity have been considered in other areas of donation and transplantation besides managing donor and patient identity information and the waitlists.

In the mid-1990s race, ethnicity, religion, and profession were criteria taken into consideration in both the hiring practices of one organ procurement organization (OPO) and in who they would send to council families about donating the organs of a loved one who had recently been declared brain dead. Leslie Sharp who conducted extensive ethnographic work within hospitals and OPOs in the 1990’s summarized the practices of this single and highly controversial East Coast OPO; she writes:

\textsuperscript{390} Wissinger, “Always on Display,” 244.
\textsuperscript{391} Mitchell, “Showing Seeing,” 92.
This OPO is based in a large and ethnically diverse city, and in the mid-1990s the director hired a team of counselors who represented an eclectic range of professions, religions, and ethnicities. This hiring practice was based on the premise that it would facilitate the rapid establishment of rapport with families whose backgrounds overlapped with those of individual counselors. Such an approach was nevertheless highly controversial within this OPO and beyond because of a dominant assumption in the realm of organ transfer that all patients or bodies are equal beneath the surgeon’s knife.  

The hiring and counseling practices that take race and ethnicity into account have little to do with the body that will be going beneath the knife. Instead, it is initially about appearance and its connection to social relations with the aim of facilitating a rapport with a potential donor’s next of kin. It is about first impressions and finding the person whose first impression on a family that has lost a loved one is the least objectionable, at minimum, or, ideally, most comforting for “the presentation of appearances in everyday life is not merely a matter of the external surfaces of the self, for appearances are also connected to identity.” Appearance in Sharp’s OPO example reveals that appearance is standing in for shared background or identity characteristics. She further explains,  

...if it was known in advance that a potential donor was, say, Latina, the team’s director would make every effort to assign a family counselor fluent in Spanish and, preferably, also of Latin American descent. Similarly, an Orthodox rabbi, who often agreed to be on call, would respond to requests to meet with Jewish families of a range of levels of observance; and an African American woman, who has worked previously as a Pentecostal minister within a storefront church, was regularly matched with inner-city African American and Caribbean families.  

392 Sharp, Strange Harvest, 55.  
393 Post, Prejudicial Appearances, 3.  
394 Sharp, Strange Harvest, 55.
For groups that are uneasy with the medical profession and for those who are weary of
the transplant system because most of their information about organ donation,
harvesting, and transplantation has come from television, that initial impression of the
transplant coordinator matters greatly. No matter what that initial impression is
important, but it is critical if the goal of ensuring better health outcomes for transplant
patients can in part be met by increasing next of kin’s willingness to donate and gaining
organs for transplantation for all transplant candidates.

The successes of MOPAs of inscription have shown how affective/effective the
use of images of the individuals in need of can be. Yet, I am proposing re-inscribing the
socially salient features of racial and ethnic identity back onto the transplant waitlists
because even the imagined recognizable appearance of someone of a shared
background can be affecting to the extent that it motivates someone to donate.

For 56-year-old David Koster, his decision to become a live organ donor had as
much to do with the kidney’s intended recipient as anything else. Yet, Koster did not
know and had not seen the specific man who would be receiving his kidney. All that
Koster knew was that the man to whom he would be giving his kidney was also an
Orthodox Jew.395 In an interview with the Jewish Daily Forward Koster explained,
“People are interested in helping their own first, and then helping others.”396 Koster’s
decision and rationale is rooted in Talmudic law. Rabbi Elliot Dorff explains,

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395 Siegel, “Live Donation.”
396 Ibid.
Specifically, the Talmud asserts that one needs to preserve one’s own life first and then worry about one’s own family, then one’s own Jewish community, then the rest of the Jewish community, and then the rest of humanity. Given the way Jews were treated historically by non-Jews, it is remarkable that the Talmud requires us to give to the poor among non-Jews too ‘for the sake of peace,’ but one is supposed to worry about one’s family and community first.\(^{397}\)

Individuals’ priorities vary, but for many Orthodox Jews the pull of one’s religious and ethnic community identity or affiliation is significant, so much so that as of 2005 a transplant surgeon at Montefiore Medical Center in New York, the university hospital for the Albert Einstein College of Medicine, reported that of the 100 to 120 transplant surgeries he was performing each year, “five to 10 of which involve[d] Jews helping Jewish strangers.”\(^{398}\) Koster’s decision to donate his kidney to a fellow Orthodox Jew is unlike the case of Todd Krampitz that I laid out in the second chapter, although affect produced by appearance played a role in both.

The family in Florida that ultimately chose to donate the liver of their deceased loved one knew, in the visual sense, who would be receiving that organ. Similarly, Koster could see, in his mind’s eye, his organ’s intended recipient. Knowing that the recipient was an Orthodox Jew, like himself, Koster could construct an image of this man—the kidney recipient would probably dress in all black or navy; he would have a beard; when out in public he would probably be wearing a dark hat; ultimately, Koster’s recipient would look much like himself or the man standing next to him in his temple.

\(^{397}\) Ibid.  
\(^{398}\) Ibid.
Between 2002 and 2004, Michele Goodwin set out to gain greater insight into Black Americans’ reluctance to donate organs. On the whole, the need for organs is great, but the need within the Black community for organs, specifically kidneys, is significantly greater. While Black Americans make up about 13% of the total U.S. population, they account for 29% of the total number of individuals on organ transplant waitlists. The reluctance to donate organs is understandable given the centuries of abhorrent treatment and experimentation at the hands of the American medical system. So even though UNOS is a MOPA of erasure, whose organ sharing practices are rooted in the principles of utility, justice, and autonomy, many Black Americans lack confidence in the altruistic model and formulaic matching.

Goodwin’s survey of 588 Black Americans in Chicago revealed that 36% were registered organ donors. When these same 588 participants were asked if they would be willing to donate their organs if they knew that the recipient would be Black, over 58% answered affirmatively. Goodwin’s data here reveal that the donating one’s organs after death was not by-and-large opposed by the members of the Black community she surveyed—in fact, her data reveal that only 10% of survey participants completely opposed organ donation. Rather, she explains, “Blacks were more willing to donate

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399 U.S. Census Bureau, “State and Country Quick Facts.”
401 Goodwin, Black Markets, 48.
402 Ibid.
when they believed African Americans would be treated equitably in both the procurement and allocation process.”

While such practices of re-inscription that would support a transplant system in which Blacks were able to donate organs other to Blacks could be seen as promoting discriminatory practices—practices that both UNOS and the U.S. Office of Civil Rights abjure—there are others, like Guido Pennings who argue that re-inscribing the socially salient features of racial and ethnic identity back onto the UNOS transplant waitlists would be an act of redistributive justice and not discrimination. Pennings suggests, “one could argue that the direction of black organs to black people is a form of positive discrimination that compensates for the built-in-bias [of the current system]. Black donors who want to allocate their organs to black people could appeal to the principle of justice.” While achieving equanimity and fairness within MOPA processes does not absolutely call for moving to a MOPA of re-inscription, the visibility, affect, and feeling that one might be contributing to one’s community and affirm one’s biocitizenship may increase individuals’ willingness to donate as Goodwin’s assertion that “...those suspicious of the American transplant system lack the confidence and motivation to participate in the current altruistic regime as donors, but it is possible other systems might prove more attractive to them.” Furthermore, re-inscription may prove more attractive than even other proposed MOPAs because “ironically, many [Blacks] felt that

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403 Ibid.
404 Pennings, “Directed Organ Donation,” 43-44.
405 Goodwin, Black Markets, 83.
even with mandatory donation, such would not resolve the organ crisis for [Black] Americans. They were not convinced that [Black] Americans would be the beneficiaries of organs even with such a system.”

So, for Blacks, knowing, in a very general sense because of the re-inscription of the socially salient feature of race and ethnicity back onto UNOS’ transplant waitlists, to whom their organs would be going might aid in mitigating the organ shortage not just for Black Americans but for all groups and individuals in the U.S.

The degree to which an appearance may be affecting may have to do with what it is that we are seeing when we glimpse someone else’s face because the social factors of race may be biologically linked as well. In researching prosopagnosia, more commonly known as “face blindness,” Oliver Sacks discovered something interesting about the brain’s or eye’s relationship to seeing appearances. In reviewing the work of Olivier Pascalis et al. for his 2010 *New Yorker* article “Face Blind,” Sacks explained,

In humans, some ability to recognize faces is present at birth or soon after. By six months, [...], babies are able to recognize a broad variety of individual faces, including those of other species (in this study, pictures of monkeys were used). By nine months, though, the babies had become less adept at recognizing the monkey faces unless they had received continuing exposure to them. As early as three months, infants are learning to narrow their model of ‘faces’ to those they are frequently exposed to. The implications of this work for humans are profound. To a Chinese baby brought up in his own ethnic environment, Caucasian faces may all, relatively speaking, ‘look the same,’ and vice versa.407

Thus, according to Sacks and Pascalis, throughout life appearances will affect individuals

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406 Ibid., 131.
differently based upon the faces or appearances to which they were exposed when young. While the example that Sacks gives and Pascalis’s research focus upon infancy, the window during which one learns how to see an appearance extends a bit further: Sacks explains, “it seems that there is an innate and presumably genetically determined ability to recognize faces, and this capacity gets focused in the first year or two, so that we become especially good at recognizing the sorts of faces we are likely to encounter.”\(^{408}\) This idea, that our ‘face cells,’ our ‘appearance seeing cells’ are already present at birth and require experience to develop\(^{409}\) and also have a limited time frame in which they can be maximally developed, further supports re-inscribing the socially salient features of racial or ethnic appearance onto transplant waitlists given that how individuals see faces and how people respond socially and emotionally is biologically rooted in appearance and identity and trained when people are young.

A MOPA of re-inscription based upon the socially salient features of racial and ethnic identity differs from MOPAs that inscribe. The former play off of group affiliation, or the affective power of the faces that one can most clearly recognize and with which one may more readily connect. The latter single out individuals. A MOPA that operates by re-inscribing the social salient features of racial and ethnic identity back into UNOS’ transplant waitlists is a MOPA that might contribute to enhancing beneficial health outcomes for transplant patients because of the affective and

\(^{408}\) Ibid.
\(^{409}\) Ibid.
potentially effective powers in the seeing of appearances. Sacks disentangles the complicated set of emotions and processes around seeing appearances; he explains: “Above all, the recognition of faces depends not only on the ability to parse the visual aspects of a face—its particular features and their over-all configuration—and compare them with others but also on the ability to summon the memories, experiences, and feelings associated with that face.” It is in the summoning of memories that affect moves into feeling which has a bearing upon peoples’ willingness to donate. The memories that get summoned might be about that particular face or similar faces, which is to say that the recognition of faces and the way in which appearances are both socially and biologically situated functions on the individual level as well as the group level.

In thinking about how the recognition of faces is connected to not just one’s understanding of features, but also the emotions and experiences connected with such faces, if we go back to the example Sack’s gives earlier, the Chinese baby brought up in his own ethnic environment might feel more drawn to donate to other Chinese individuals rather than the current faceless mass populating organ transplant waitlists because no affective response can be stirred. This same Chinese baby brought up in his own ethnic environment be more affected by other Chinese faces than Caucasian faces attached to an organ transplant waitlist because there is a legitimate, biological reason why all Caucasian ‘look the same’ to him and, as such, may stir little affect. A MOPA of

\[\text{Ibid.}\]
re-inscription could allow for the re-mapping of affective relations back onto the organ transplant waitlists; sometimes it might reflect racial affiliations, sometimes ethnic, but such a MOPA would always reflect or make apparent patterns of community imagined through affect.

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There are, no doubt, many dangers that could come with re-inscribing the socially salient features of race and ethnicity back onto the organ transplant waitlists because of the history of violence done by uses of appearance and violence resulting from affects generated by appearances. Examining identity management practices to see how they affect organ donors, donor families, transplant candidates, and transplant recipients and effect the transplant system is one thing. Using identity management practices to try to work with affect to (1) increase potential donors’ willingness to donate, (2) gain more organs for transplantation, and (3) increase the positive post-operative health outcomes for transplant patients is something else entirely because to work with affect “is to work with something volatile and difficult to control.” Nevertheless, the greater understanding that may result from working through how MOPA’s identity management practices stir affect in different ways may prove incredibly beneficial because to work with affect is to work with something that spurs on motivation as “motivation itself, [...], is the business of the affect system.”

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411 Wissinger, “Always on Display,” 238.
412 Sedgwick, Touching Feeling, 18.
On June 3rd 2003, Dr. Robert M. Sade testified, on behalf on the American Medical Association (AMA) before Congress in a hearing on “Assessing Initiatives to Increase Organ Donations.” In his testimony, Sade cited past initiatives to increase organ donation—“vigorous” educational campaigns directed at donors, efforts directed at health professionals to encourage them to talk to their patients about donation, legislatively mandating that next of kin of a newly deceased individual be presented with the choice to donate.\textsuperscript{413} But such initiatives, and even the further expansion of the initiatives in collaboration with OPTN, Sade noted, had yet to yield an increase in cadaveric organ donations.\textsuperscript{414} While Sade suggested to Congress that such initiatives remain funded, he stated, “the AMA supports innovative approaches that are informed by a more comprehensive understanding of what motivates and what hinders individuals’ decision to donate.”\textsuperscript{415}

This project has examined how the identity management practices used by different MOPAs either motivate or hinder a potential organ donor’s decision to donate. However, this project has viewed initiatives to increase organ donation as just one piece of a larger puzzle of relations within the organ transplant system. Sade called for a more comprehensive understanding of what motivate and what hinders individuals’ decision donate; this project has articulated a more comprehensive approach to the

\textsuperscript{413} Sade, “Assessing Initiatives,” 52.  
\textsuperscript{414} Ibid.  
\textsuperscript{415} Ibid.
organ transplant system in the U.S. by shifting the focus from obtaining organs to enhancing beneficial health outcomes for all transplant patients.


Appendix A: Adult Lung Transplant Registration Worksheet
Adult Liver Transplant Candidate Registration Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 02/29/2012

Note: These worksheets are provided to function as a guide to what data will be required in the online TIED ® application. Currently in the worksheet, a red asterisk is displayed by fields that are required, independent of what other data may be provided. Based on data provided through the online TIED ® application, additional fields that are dependent on responses provided in these required fields may become required as well. However, since those fields are not required in every case, they are not marked with a red asterisk.

Provider Information
Recipient Center:

Candidate Information
Organ Registered:
Date of Listing or Add:

Last Name:* First Name:* M:\

Previous Surname:

SSN: Gender:* Male Female

HIC: DOB:

State of Permanent Residence:* Permanent ZIP Code:*

Is Patient waiting in permanent ZIP code: YES NO UNK

Ethnicity/Race:* (select all origins that apply)
American Indian or Alaska Native
- American Indian
- Eskimo
- Aleutian
- Alaska Indian
- American Indian or Alaska Native: Other
- American Indian or Alaska Native: Not Specified/Unknown
Black or African American
- African American
- African (Continental)
- West Indian
- Haitian
- Black or African American: Other

Asian
- Asian Indian/Indian Sub-Continent
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Asian: Other
- Asian: Not Specified/Unknown

Hispanic/Latino
- Mexican
- Puerto Rican (Mainland)
- Puerto Rican (Island)
- Cuban
- Hispanic/Latino: Other
Black or African American: Not Specified/Unknown

Hispanic/Latino: Not Specified/Unknown

Native Hawaiian or Other Pacific Islander
  - Native Hawaiian
  - Guamanian or Chamorro
  - Samoan
  - Native Hawaiian or Other Pacific Islander: Other
  - Native Hawaiian or Other Pacific Islander: Not Specified/Unknown

White
  - European Descent
  - Arab or Middle Eastern
  - North African (non-Black)
  - White: Other
  - White: Not Specified/Unknown

Citizenship:
  - U.S. CITIZEN
  - RESIDENT ALIEN
  - NON-RESIDENT ALIEN, Year Entered US

Year of Entry to the U.S.

Highest Education Level:
  - NONE
  - GRADE SCHOOL (0-8)
  - HIGH SCHOOL (9-12) or GED
  - ATTENDED COLLEGE/TECHNICAL SCHOOL
  - ASSOCIATE/BACHELOR DEGREE
  - POST-COLLEGE GRADUATE DEGREE
  - N/A (< 5 YRS OLD)
  - UNKNOWN

Medical Condition at time of listing:
  - IN INTENSIVE CARE UNIT
  - HOSPITALIZED NOT IN ICU
  - NOT HOSPITALIZED

Patient on Life Support:
  - YES
  - NO
    - Extra Corporeal Membrane Oxygenation
    - Intra Aortic Balloon Pump
    - Prostacyclin Infusion
    - Prostacyclin Inhalation
    - Inhaled NO
### Ventilator
- Ventilator
- Other Mechanism, Specify

### Functional Status

<table>
<thead>
<tr>
<th>Option</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Limitations</td>
<td></td>
</tr>
<tr>
<td>Limited Mobility</td>
<td></td>
</tr>
</tbody>
</table>

### Physical Capacity

<table>
<thead>
<tr>
<th>Option</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wheelchair bound or more limited</td>
<td></td>
</tr>
<tr>
<td>Not Applicable (&lt;1 year old or hospitalized)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td></td>
</tr>
</tbody>
</table>

### Working for income

<table>
<thead>
<tr>
<th>Option</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>Working Full Time</td>
</tr>
<tr>
<td>NO</td>
<td>Working Part Time due to Demands of Treatment</td>
</tr>
<tr>
<td>UNK</td>
<td>Working Part Time due to Disability</td>
</tr>
<tr>
<td></td>
<td>Working Part Time due to Insurance Conflict</td>
</tr>
<tr>
<td></td>
<td>Working Part Time due to Inability to Find Full Time Work</td>
</tr>
<tr>
<td></td>
<td>Working Part Time due to Patient Choice</td>
</tr>
<tr>
<td></td>
<td>Working Part Time Reason Unknown</td>
</tr>
<tr>
<td></td>
<td>Working, Part Time vs. Full Time Unknown</td>
</tr>
</tbody>
</table>

### Academic Progress

<table>
<thead>
<tr>
<th>Option</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within One Grade Level of Peers</td>
<td></td>
</tr>
<tr>
<td>Delayed Grade Level</td>
<td></td>
</tr>
<tr>
<td>Special Education</td>
<td></td>
</tr>
<tr>
<td>Not Applicable &lt;5 years old/ High School graduate or GED</td>
<td></td>
</tr>
<tr>
<td>Status Unknown</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Option</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Full academic load</td>
</tr>
<tr>
<td></td>
<td>Reduced academic load</td>
</tr>
</tbody>
</table>
Academic Activity Level:
- Unable to participate in academics due to disease or condition
- Not Applicable < 5 years old/ High School graduate or GED
- Status Unknown

Previous Transplants:

<table>
<thead>
<tr>
<th>Organ</th>
<th>Date</th>
<th>Graft Fail Date</th>
</tr>
</thead>
</table>

The three most recent transplants are listed here. Please contact the UNet Help Desk to confirm more than three previous transplants by calling 800-978-4334 or by emailing unethelpdesk@unos.org.

Previous Pancreas Islet Infusion:
- YES
- NO
- UNK

Source of Payment:
Primary: Specify:
Secondary: Specify:

Clinical Information: AT LISTING
Height: ft in. cm ST=
Weight: lbs kg ST=
BMI: kg/m²

ABO Blood Group:

Primary Diagnosis: Specify:

General Medical Factors:
- No
- Type I
- Type II
- Type Other
- Type Unknown
- Diabetes Status Unknown

Diabetes:
- No dialysis
| **Dialysis:** | | | | | |
| --- | --- | --- | --- | --- |
| Hemodialysis | Peritoneal Dialysis | Dialysis Status Unknown | Dialysis-Unknown Type was performed |
| **Peptic Ulcer:** | | | | | |
| No | Yes, active within the last year | Yes, not active within the last year | Unknown |
| **Angina:** | | | | | |
| No | Yes, and documented Coronary Artery Disease | Yes, with no documented Coronary Artery Disease | Yes, but Coronary Artery Disease unknown | Status Unknown |
| **Drug Treated Systemic Hypertension:** | | | | |
| **Symptomatic Cerebrovascular Disease:** | | | | |
| **Symptomatic Peripheral Vascular Disease:** | | | | |
| **Any previous Malignancy:** | | | | |
| Yes | No | Unknown |
| **Specify Type:** | | | | |
| Skin Melanoma | Skin Non-Melanoma | CNS Tumor | Genitourinary |
| Breast | Thyroid | Tongue/Throat/Larynx | Lung |
Leukemia/Lymphoma

Liver

Other, specify

Specify:

Most Recent Serum Creatinine: __________ mg/dl ST= __________

Total Serum Albumin: __________ g/dl ST= __________

**Lung Medical Factors**

**Pulmonary Status:**

<table>
<thead>
<tr>
<th>Test</th>
<th>%predicted</th>
<th>ST=</th>
<th>YES</th>
<th>NO</th>
<th>UNK</th>
</tr>
</thead>
<tbody>
<tr>
<td>FVC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FeV1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>pCO2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FeV1(L)/FVC(L)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

O2 Requirement at Rest: __________ L/min ST= __________

IV Treated Pulmonary Sepsis Episode >= 2 in last 12 months: YES NO UNK

Corticosteroid Dependency >= 5mg/day: YES NO UNK

Six minute walk distance: __________ # of feet

Pan-Resistant Bacterial Lung Infection: YES NO UNK

Infection Requiring IV Drug Therapy within 2/wks prior to listing: YES NO UNK

**Heart/Lung Medical Factors:**

**Most Recent Hemodynamics:**

<table>
<thead>
<tr>
<th>Test</th>
<th>mm/Hg</th>
<th>ST=</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>PA (sys)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PA (dia)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PA (mean)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PCW (mean)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CO L/min</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Inotropes/Vasodilators:

ST= __________ YES NO
**History of Cigarette Use:**
- **YES**
- **NO**
- 0-10
- 11-20
- 21-30

If Yes, Check # pack years:
- 31-40
- 41-50
- >50
- Unknown pack years

**Duration of Abstinence:**
- 0-2 months
- 3-12 months
- 13-24 months
- 25-36 months
- 37-48 months
- 49-60 months
- >60 months
- Continues To Smoke
- Unknown duration

**Other Tobacco Use:**
- **YES**
- **NO**
- **UNK**

**Prior Cardiac Surgery (non-transplant):**
- **YES**
- **NO**
- **UNK**

- CABG
- Valve Replacement/Repair
- Congenital
- Left Ventricular Remodeling
- Other, specify

Specify:

**Prior Lung Surgery (non-transplant):**
- **YES**
- **NO**
- **UNK**
If yes, check all that apply:

- Pneumoreduction
- Pneumothorax Surgery-Nodule
- Pneumothorax Decortication
- Lobectomy
- Pneumonectomy
- Left Thoracotomy
- Right Thoracotomy
- Other, specify

Specify: