PARENT AND PATIENT TREATMENT PREFERENCES IN JUVENILE IDIOPATHIC ARTHRITIS (JIA)

By

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DEDICATION

To my parents Jorge Montealegre and Blanca Cecilia Sanchez, my brother

Jorge A. Montealegre, friends and mentors
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## LIST OF ABBREVIATIONS

<table>
<thead>
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<th>Full Form</th>
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<tr>
<td>ANA</td>
<td>Antinuclear Antibody</td>
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<td>BCMH</td>
<td>The Bureau for Children with Medical Handicaps</td>
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<td>CCP</td>
<td>Anti-cyclic Citrullinated Peptide antibodies</td>
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<td>CHAQ</td>
<td>Childhood Health Assessment Questionnaire</td>
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<td>CWRU</td>
<td>Case Western Reserve University</td>
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<td>DAS</td>
<td>Disease Activity Score</td>
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<td>DMARDs</td>
<td>Disease Modifying Anti-Rheumatic Drugs</td>
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<td>ERA</td>
<td>Enthesitis-Related Arthritis</td>
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<td>IAJI</td>
<td>Intra-Articular Joint Injections</td>
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<td>ILAR</td>
<td>International League of Associations for Rheumatology</td>
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<td>IRB</td>
<td>Institutional Review Board</td>
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<td>JIA</td>
<td>Juvenile Idiopathic Arthritis</td>
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<td>NSAIDs</td>
<td>Non Steroidal Anti-Inflammatory Drugs</td>
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<td>Oligoarticular JIA</td>
<td>Oligoarticular Juvenile Idiopathic Arthritis</td>
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<td>Pedi-TiPS</td>
<td>Pediatric Trust in Physician Scale</td>
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<td>Polyarticular JIA</td>
<td>Polyarticular Juvenile Idiopathic Arthritis</td>
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<td>RA</td>
<td>Rheumatoid Arthritis</td>
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<td>RF</td>
<td>Rheumatoid Factor</td>
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<tr>
<td>SES</td>
<td>Socioeconomic Status</td>
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<tr>
<td>SoJIA</td>
<td>Systemic Onset Juvenile Idiopathic Arthritis</td>
</tr>
<tr>
<td>TNF</td>
<td>Tumor Necrosis Factor</td>
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Parent and Patient Treatment Preferences in Juvenile Idiopathic Arthritis (JIA)

Abstract

By

GINA ALEXANDRA MONTEALEGRE SANCHEZ

OBJECTIVE: Understand the factors that influence parent’s decision-making and to investigate whether the tendency for non-aggressive medical treatment seen in minority adult patients is also present in parents of pediatric patients with JIA.

METHODS: Using a multicenter cross sectional survey, families of patients with an established diagnosis of JIA were invited to participate.

RESULTS: When families were asked to rank their considerations prior to initiating medical treatment for JIA, medications safety ranked as the most important. Pediatric rheumatologist and nurse practitioners were considered by parents and patients to be the most reliable and important source of information. Tendency toward more aggressive options was associated with having BCMH or a child with SoJIA or polyarticular JIA. Medicaid families were more likely to prefer a less aggressive treatment and have children with higher CHAQ.

CONCLUSION: First study to evaluate the dynamics of medication decision-making in families of children with JIA.
INTRODUCTION

Health disparities have been documented in patients with rheumatoid arthritis (RA) and other rheumatic diseases (1,2). Minority patients with RA have been shown to have poorer health outcomes, including greater disability, pain scores and worse global health when compared with their non-minority counterparts (3). The reasons for these disparities are unclear but may include genetic, socioeconomic, cultural factors, lack of trust in physicians and/or the health care system. Constantinescu et al, suggested the possibility that patient treatment preferences may account for racial disparities in the use of medical interventions, where black patients preferred less aggressive treatment compared to whites with similar disease (4). Similar behaviors have also been described in black patients with moderate to severe osteoarthritis, who were less willing to consider total joint arthroplasty compared to whites (5,6).

Ethnic disparities in treatment preferences for arthritis and musculoskeletal conditions are recognized in adults but little research has been conducted in pediatrics.

The objective of this thesis is to review the available data of disparities in treatment preferences for RA and develop a model that could serve to identify similar disparities in patients with juvenile idiopathic arthritis (JIA).
BACKGROUND

Treatment preferences in rheumatoid arthritis:

Rheumatoid arthritis (RA) is a chronic, systemic disease characterized by inflammation of the joints. The treatment goal in RA is to prevent or control joint damage and decrease pain (7). Medication continues to be the dominant therapy for patients with RA. Recent advances in this area have provided patients and physicians with new options for treatment; new biologics and disease-modifying antirheumatic drugs (DMARDs) have demonstrated efficacy and are being widely used. Novel therapeutic regimens have not only increased the options for treatment but have also increased the concerns about side effects and patients’ out-of-pocket expenses.

Racial and socio-demographic disparities in treatment preferences have been identified among patients with RA. Suarez-Almozor and colleges (8), described a cohort of 285 patients with RA who were seen at two different clinics in Texas, both operated by physicians from the same institution. The authors evaluated the time of initiation of DMARDs from onset of disease until therapy was prescribed. The differences between the two clinics (private vs. public) were outstanding. Non-white patients were more likely to be seen at the public clinic 83% vs. only 13% of non-white patients at the private clinic. Patients with RA for less than 10 years seen at the public clinic had a median time to initiation of DMARDs of 6 years versus 1.5 years in the private clinic. The difference was more apparent when the group was subdivided by races; non-whites had a median time of
initiation of DMARDs of 7 years compared with 1 year to their counterpart group. In this cohort, ethnicity persisted as a significant independent predictor for DMARDs initiation, after adjusting for other variables (8).

The Consortium of Rheumatology Researchers of North America (CORRONA) (9) reported similar results with a prospective registry that was used to evaluate the extent to which race, ethnicity, education, type of insurance and disease activity influenced RA patients receiving tumor necrosis factor (TNF) alpha inhibitors. Hispanics with RA, 7% of the total sample, were less likely to receive TNF-alpha inhibitors compared to whites, OR 0.76 (0.61-0.95) after adjusting for type of insurance.

Berrios-Rivera (10) and colleagues presented an abstract with 44051 RA patients, who were analyzed in the context of their first time to use any biologic therapy approved in the United States. African American patients were less likely to have used biologic therapy, OR 0.54 (0.48-0.61) compared to the other groups. Patients with an income greater than $ 60000/yr had an increased odds of having used biologic therapy compared to patients with an income less than $ 20000/yr. This cohort study also suggested that the number of first time users of biologic therapy decreases as age increases. Results were not statistically significant until patients reached 60 years of age. Risk aversion for side effects by older patients could explain some of these differences. The concept of risk aversion may vary between race and ethnicity as discussed later. Fraenkel L et al (11)
presented the option to receive treatment with DMARDs (methotrexate, gold, leflunomide) vs. a biologic treatment (etanercept) to a group of 120 white RA patients. After evaluating medication related side effects, effectiveness and cost, older white RA patients preferred a biologic over other treatment options. The only variable that was associated with decreased preference for biologic treatment was an increase in co-pay for the treatment to thirty dollars. It was suggested that this population might prefer drugs with short-term risks and uncertain long-term safety, rather than those with a greater number of established risks. An important limitation for this study was the exclusion of minorities; all patients were white and well educated.

There are other factors associated with delay in initiation of treatment. Hernandez-Garcia and colleagues in Spain found that the lag time between onset of symptoms and first visit with the rheumatologist was the most critical independent factor of time to initiation of DMARDs therapy (12).

It is evident that racial and socio-demographic disparities exist in the use of DMARDs and biologics. One important question is where are these disparities arising? Are these differences a real representation of patient treatment preferences? Or are these differences a reflection of imbalances in the health care system that is leading to health disparities? (13). Constantinescu and colleagues (14) found that African American patients have a greater risk aversion than whites. In the African American population 52% had more risk aversion
compared to whites, in whom it was only 12%. It was suggested by the authors that African American patients attach greater importance to the risk of toxicity, in this specific case the theoretical increased risk of cancer related to treatment, and less importance to the likelihood of benefit. Results suggested that African Americans were more likely to have an increased risk aversion with an OR 8.4 (3.1-23.1) and preferred less aggressive treatment (only methotrexate) greater than aggressive treatment (anti-TNF-α plus methotrexate) when compared to white patients with RA (4).

Patient choices are driven by the extent to which they value each particular outcome, such as the possibility to improve their health status versus avoiding adverse consequences (15). These decisions are also influenced by the patient’s own beliefs as well as historical roots as described by Barton and Katz (16). Patient preference for less treatment may represent “cultural aversion for gains” (17) as a result of racial and sex discrimination. Historically, black patients did not have access to traditional medical care, leading this community to frequently turn to home remedies, prayer or the advice outside the medical community before seeking traditional medical care; therefore, developing mistrust and lower expectations from the health care system. The origin for these disparities could also come from imbalances in the health care system (13). One example is the underrepresentation of minority physicians in the United States (US). Blacks and Hispanics account for less than 10% of all US physicians while they represent more than 20% of all patients.
In general, black and Hispanic patients report worse physician communication than white patients. Johnson and colleagues found that physicians were more verbally dominant and less patient-centered in their approach to black patients \(^{(18)}\). Physicians talked 43\% more to black patients than white patients. White patients tend to receive more information when talking with their physicians. One interesting study, published by Fry and his group, reviewed information from 404 patients taking NSAIDs and found that black patients reported that they were less likely to be informed about gastrointestinal side effects (38\% vs. 52\%, \(p=0.001\)) and were recommended to take medications to reduce gastrointestinal risk (30\% vs. 50\%, \(p=0.001\)) less than whites \(^{(19)}\).

Disparities in communication about medication cost have also been reported. Beard et al \(^{(20)}\) interviewed and collected questionnaires from 193 patients with RA. Medication changes happened in 50\% of all visits, but medication cost was discussed in only 34\% of those visits. The odds of discussing cost were higher when patients were white OR 2.82 or reported middle income OR 1.98. Non-white patients had less active behavior during medical visits and physicians were less participatory and less likely to engage them.

In summary there is evidence of racial disparities in treatment preferences for RA. Blacks and Hispanics have a tendency to receive less intensive treatment, but it is still unclear if the origins of these differences are fixed traits, inherent to individuals or whether they have been acquired over a lifetime by a range of
experiences and limitations. Patient preference for less intensive treatment may in fact represent that interventions are unavailable, unaffordable, thought to be ineffective or unduly risky \(^{(15)}\). Most of the studies reviewed are retrospective or cross-sectional making it difficult to establish a cause and effect relationship.

**APPLICABILITY TO PEDIATRIC RHEUMATOLOGY**

Juvenile idiopathic arthritis (JIA) is the most common chronic rheumatic disease of childhood and an important cause of short-term and long-term disability. Prevalence has been reported to be 16 to 150 per 100,000 \(^{(21)}\). In order to obtain disease remission, preserve range of motion, muscle strength and have normal growth and psychological development, patients and families with JIA are confronted with increasingly complex treatment choices. Choices that involve weighing benefits, side effects, risk and financial cost. If patient treatment preferences are linked to both inherent and acquired behaviors, it is not surprising to think that these behaviors and methods of making decisions are also passed on through generations.

It is my hypothesis that the same tendencies for treatment decisions seen in adults is also present in the care of children. Are the parents of pediatric minority patients with JIA and their families less likely to consider aggressive treatment compared to non-minority parents and patients with the same condition? And if that is the case, can we identify which factors influence parent decision-making regarding their children with JIA? The long-term implications of confirming my hypothesis is that physician awareness of the dynamics behind this decision has
the potential to improve patients and families’ understanding, satisfaction and confidence with medical care but may require an intervention besides just reporting the findings of this study.
METHODS

Design and setting

The research protocol was reviewed and approved by Human Use committees at three institutions affiliated with Case Western Reserve University; Rainbow Babies and Children’s Hospital, the Cleveland Clinic Foundation and MetroHealth Medical Center. We conducted a multicenter, cross-sectional prospective study. Parents with children between the ages of 1 to 17 with a definite diagnosis of JIA by the International League of Associations for Rheumatology (ILAR) (22) seen in 10 pediatric rheumatology clinics were asked to participate. After signing informed consent and assent, questionnaires were completed by one parent or legal guardian, patients if older than 13 years of age and physician or nurse practitioner evaluating the patient. Subjects not well enough to complete the questionnaire or with physical or mental disabilities that would affect the individual’s ability to understand the informed consent or the study questionnaire were excluded from the study.

Questionnaire

To evaluate the factors that influence patient and parent’s decision-making, three questionnaires (parent, patient and physician questionnaires) were developed after extensive literature review and with the help of Joseph J Sudano and Adam Perzynski. The parent questionnaire was evaluated for clarity and comprehension in a convenience sample of three secretaries in the pediatric department.
Each instrument assessed the following variables:

- **Parent questionnaire:**
  - Demographics (parent and patient): Age, gender, race, education, income, number of miles driven to see a pediatric rheumatologist, type of patient’s health insurance and medical history of other chronic conditions.
  - Medical literacy: It was assessed by the item, “*How confident are you filling out medical forms by yourself?*” This was formatted as a 5-point Likert scale (extremely, quiet a bit, somewhat, a little bit and not at all).
  - Social support: Current marital status, family member with a rheumatologic condition, source of disease knowledge, and options available for treatment. Parents were asked to rank the most helpful source of information about their child’s arthritis by the item, “*Please identify which of the following sources you found more helpful regarding information about your child’s arthritis and about treatment options for your child’s arthritis.*” Parents were given the following sources of information: “child’s physician or nurse practitioner,” “friends and family,” “someone else diagnosed with a rheumatic disease,” “internet, radio or television,” “Arthritis Foundation, American College of Rheumatology, American Academy of Pediatrics.” They were asked to rank the choices from 1 (most helpful) to 5 (least helpful).
  - Disease related factors: Type of disease, duration, presence of uveitis, severity at time of diagnosis, and at the time questionnaire was completed. A visual analog scale from 0 to 10 was used as a tool to measure for disease activity.
- Medication related factors: History of current and previous medications was collected, including history of side effects. Time to initiation (in months) of NSAIDs, systemic steroids, IAJI, DMARDs, and biologics after initial diagnosis. Parents were also asked to rank their considerations from the most to least important about medication safety, efficacy, side effects, years on the market, physician’s experience with the product, physician’s personal preference, method of administration, dosing, frequency, cost (out-of-pocket) and available patient support programs at the time of initiation of treatment (23).

- Childhood Health Assessment Questionnaire (CHAQ): An adapted form of the Stanford Health Assessment questionnaire, validated for use in children ages 1-19 years, was used. The CHAQ evaluates two different indices, disability and discomfort. The disability index assess function by eight different domains (dressing, grooming, arising, eating, walking, hygiene, reach, grip and ability to perform activities) in which each functional area has at least one question that is relevant to children of all ages. Discomfort indices assess the presence of pain from 0-10 cm using a visual analogue scale and parent global assessment of arthritis (24). The CHAQ has been demonstrated to have excellent internal reliability with a high coefficient of reliability and consistency (Cronbach’s alpha of 0.94).

- Physician Trust: Using a modified version of the Trust in Physician Scale, an instrument initially developed and tested on men with diabetes treated at the VA Medical Center in North Carolina and recently validated in adult patients with rheumatic diseases (Cronbach’s alpha of 0.87), physician trust was
assessed (25). Eleven original questions were modified to change the type of physician evaluated, and parents of patients were asked about “my child’s doctor” instead of “my doctor.” The 11 items in the Trust in Physician Scale were scored on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). A summary measure of trust was obtained by taking the unweighted mean of the response to the 11 questions and transforming that value to a 0 - 100 scale. Higher scores reflect greater trust.

- Future treatment preferences: Parent future medical treatment preferences were assessed by the question “In the future, if you have another child diagnosed with arthritis in either less than or more than or equal to five joints, which would be your preferred treatment?”

- Patient questionnaire:
  - Disease knowledge was evaluated by the two items “What kind of arthritis have you been diagnosed with?” and “Have you been diagnosed with eye inflammation or uveitis?”
  - Social support: Patients were asked to rank the most helpful source of information about their arthritis by the item “Please identify which of the following sources you found more helpful regarding information about your child’s arthritis and about treatment options for your arthritis.” Patients were given the following sources of information: “physician or nurse practitioner,” “friends and family,” “someone else diagnosed with a rheumatic disease,” “internet, radio or television,” “Arthritis foundation, American College of
Rheumatology or American Academy of Pediatrics” and asked to rank them from 1 (most helpful) to 5 (least helpful).

- Role in treatment decision-making: Using the same questionnaire utilized by the investigator Clara Lin, MD in the pilot study “Attitudes toward the Human Papiloma Virus (HPV) vaccine (Gardiasil®) among the pediatric population with rheumatologic disorder,” subjects older than 13 were asked about how involved they were in regards to their medical care by the item “Who makes decisions about your medical care?”

- Physician questionnaire (completed by physician or nurse practitioner):
  - Physician global assessment of disease activity was assessed using a 0 (not active) to 10 (very active) scale.
  - Physicians or nurse practitioners recorded the number of active joints on physical exam at the time the questionnaire was completed.
  - Patient diagnosis was recorded.

- Chart review: For disease classification patient antibody status was collected via chart review. Antinuclear antibody (ANA), rheumatoid factor (RF), anti-cyclic citrullinated peptide (CCP) antibodies and HLA B27 were collected.
Database
De-identified completed questionnaires were entered into REDCap (Research Electronic Data Capture), a secure web-based application to build and manage online databases. REDCap is supported and approved by the three Case Western Reserve University affiliated institutions. A total of 143 questionnaires were entered into the database that consisted of 143 observations and 171 variables. De-identified data was transferred to R for statistical analysis.

Institutional Review Board approval (IRB):
The research protocol was reviewed and approved by each institution’s IRB. A facilitated IRB process was not available at the time of initial submission but has since been instituted. The time frame for approval ranged from 7 to 90 days.

Table 6.

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<td>MetroHealth Medical Center IRB</td>
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STATISTICAL ANALYSIS

Descriptive analysis
Analysis of the data for descriptive purposes and secondary post hoc analysis was done using the statistical software R (version 2.9.1). The database was available as a set of comma separated version (csv.) files and consisted of 143 observations and 171 variables. Two observations were excluded from the analyses, the first one because the parent signed the informed consent and left with the questionnaires (there was no information available to be entered into the database), and the second observation was not included because it was considered a double entry by the principal investigator. In the final analysis, the database consisted of 141 observations and 171 variables. Personal identifiers (http://privacyruleandresearch.nih.gov/research_repositories.asp) were removed from the database, including patient 5-digit zip code and date when services were provided (i.e. dates were laboratory data was collected). To calculate number of miles driven by the patient, a Google maps (http://maps.google.com/) tool was used. The distance was calculated as the number of miles between the patient’s house and one of the main pediatric rheumatology centers were the patient could have received a IV infusion if indicated, University Hospitals, Rainbow Babies and Children’s Hospital (Zip code 44106), Main campus Cleveland Clinic (Zip code 44195) and MetroHealth Medical Center (Zip code 44109). Results of descriptive analysis are shown in table 1 and will be discussed later.
**Comparative analysis:**

Secondary analysis was used to evaluate factors that may influence parent’s decision-making regarding treatment of their children with oligoarticular juvenile idiopathic arthritis (arthritis in less than 4 joints) and treatment of children with polyarticular disease (arthritis in equal to or more than 5 joints), groups were divided into those parents who preferred less aggressive treatment vs. more aggressive treatment. Results of this analysis are shown in table 2 and will be discussed in the next chapter. A third analysis included identification of differences among subjects based on time of initiation of treatment (DMARDs vs. biologics) after initial diagnosis, groups were divided by patients receiving treatment within 6 months of diagnosis vs. patients receiving treatment beyond 6 months after diagnosis. The Wilcoxon rank sum test, t-test and Fisher’s exact test were used for group comparisons, p value <0.05 was considered to be statistically significant. A final analysis was performed to evaluate the presence of health disparities in the treatment of JIA; database was analyzed by type of insurance using chi-square test and Kruskal-Wallis test.

Only 132 observations were available at the time of this analysis. Data from MetroHealth Medical Center will be obtained after the data use agreement with the National Institute of Health (NIH) is approved by MetroHealth Medical Center.
RESULTS

To date, 152 eligible patients have been invited to participate. Of these, 141 subjects (93%) completed the questionnaire. At the time of this analysis only data from 132 subjects was available.

In a descriptive analysis, 82% of the questionnaires were completed by the mothers with a mean age of 40 years, 92% of the parents were Caucasian, 81% married, 54% reported having at least a college degree, 49% had a household income greater than $75000, and 70% were considered to have good health literacy. Most of the children were white (89%) and female (77%), with a mean age of 10 years. All patients had medical insurance, 66% private insurance, 18% Medicaid and 16% any insurance plus BCMH\(^1\). Only 20% of families reported having a first-degree relative with an underlying rheumatologic condition, rheumatoid arthritis (RA) being the most common one. In our patient population, 26% reported having a second comorbidity.

Persistent oligoarticular JIA (34%) was the most frequent subtype of JIA, followed by RF negative polyarticular JIA (29%), extended oligoarticular JIA (11%), ERA (10%), SoJIA (8%) and RF positive polyarticular JIA (5%). Parent global disease activity score at diagnosis was 7 (3-10), compared to a mean disease activity score of 3 (0-8) at the time the questionnaire was completed. This value differed from the physician’s global assessment of disease activity only 1.65 (0-7) at the time of enrollment in the study. In regard to disease knowledge, there was a significant correlation among physicians, parents and

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\(^1\) The Bureau for Children with Medical Handicaps (BCMH) is a health care program in the Ohio Department of Health that links families of children with special health care needs to a network of quality providers and helps families to obtain payment for the services their children need.
patients in diagnosis or subtype of JIA (70%), but not in the frequency of uveitis, reported by 20% of the parents versus 12% of patients.

When families were asked to rank their considerations prior to initiating medical treatment for JIA, medication safety ranked as the most important, followed by efficacy, associated side effects, and physician’s experience with the treatment. Years on the market, physician personal preference, co-pay (out-of-pocket expenses), method of administration, frequency, and availability of patient support programs were respectively ranked lower.

Pediatric rheumatologists and nurse practitioners were considered by parents and patients to be the most reliable and important source for information about arthritis (91% vs. 83%), and options for medical treatment (91% vs. 89%); results correlated with a physician trust score of 85 (range 0-100). The second most useful source of information for parents was the media, compared to patients who ranked second as friends, family or someone else with a rheumatologic disease.

Fifty-nine percent of patients older than 13 years of age reported being involved in the medication decision-making process, versus 36% in whom decision was made by their parents, and 5% exclusively by their physicians. In our cohort, 98% of parents recorded that NSAIDs were part of the treatment for their children with JIA, 81% have used DMARDs, 58% IAJI, 57% biologics, 50% systemic steroids and 22% herbal medicines. The most common DMARD used was methotrexate 93%, followed by sulfasalazine 10%. Among biologics, etanercept (61%) was the most commonly used, followed by adalimumab 33%, abatacept 25%, infliximab
19% and anakinra 11%. Time of initiation varied; NSAIDs, DMARDs, IAJI, biologics and systemic steroids were initiated respectively in 97%, 55%, 38%, 19% and 66% of patients within 3 months of diagnosis. Use of IAJI and biologics increased over time to 62% and 81%, respectively. Medication related side effects were reported by 55% of the parents, DMARDs were the most frequently medication associated with side effects, followed by biologics, systemic steroids, NSAIDs and IAJI. Parent future treatment preferences to treat children with oligoarticular JIA and polyarticular JIA varied but there was a tendency towards the inclusion of biologics in our population.

In a post-hoc analysis factors associated with tendency toward more aggressive options to treat children with JIA were having BCMH as a secondary type of insurance and to be a parent of a child with SoJIA or polyarticular JIA. Sixty-five percent of parents of children with BCMH preferred the used of DMARDs + biologics over IAJI as the ideal treatment for oligoarticular JIA, versus 42% of parents of patients with private insurance and 26% with Medicaid (p=0.02). Similar decisions were seen when parents were asked how to treat polyarticular disease; 57% of parents of children with BCMH preferred DMARDs + biologics over DMARDs only, followed by 28% of parents of patients with private insurance and 22% with Medicaid (p=0.022). Families with Medicaid were also most likely to use alternative medicine. Higher parent global disease activity score and number of active joints at diagnosis were associated with DMARDs + biologics as a preferred type of treatment for patients with Oligoarticular JIA versus IAJI only (p<0.05).
Analysis by type of insurance showed clear differences in the distribution of demographics among the study population. Medicaid and BCMH subgroups represented the majority of minorities (17% and 14% versus 2% in the private insurance group, p=0.023), parents with less than a high school degree (17% and 24% versus 0% in the private insurance group, p=0.001), families with an annual income less than $50000 (91% and 58% versus 14% in the private insurance group, p<0.001), and the majority of single or divorced parents (50% and 30% versus 8% in the private insurance group, p<0.001). Despite these remarkable differences, the children with Medicaid or BCMH were the more likely to have biologics initiated within 6 months of diagnosis when compared with children with private insurance (p=0.004). As previously described by Brunner (26) and colleges, Children with Medicaid and BCMH status were associated with higher mean CHAQ scores than those with private health insurance (0.459 and 0.34 versus 0.217; p=0.031); there was no difference in the distribution of subtypes JIA.

Time of initiation of DMARDs and biologics were found to be associated with subtype of JIA. Children with psoriatic arthritis and ERA were more likely to have DMARDs initiated within 6 months of diagnosis, compared to children with SoJIA who were more likely to be started on biologics. Polyarticular JIA was associated with initiation of DMARDs and biologics within 6 months of disease.

Analysis by institution showed that initiation of biologic treatment maybe related to the population seen. Physicians in one of the two centers were more likely to offer biologic therapy to their patients, compared to the other institution (68%
versus 45%, p=0.015). Further analysis demonstrated this difference maybe related to the distribution of disease between the two centers; patients with SoJIA (9% vs. 6%) and polyarticular disease (41% vs. 27%) were more frequently seen at the institution where biologics were more regularly offered (p=0.05); in contrast to the other institution who had more patients with oligoarticular disease, and ERA.

Physician role in medical decision-making was also different by institution. At the center with a higher physician trust (p=>0.05), patients did not report the physician as the leading person during the process of medical decision-making (p<0.001). It was reported as a conjoin decision between patients and families.
DISCUSSION

Juvenile idiopathic arthritis is the most common chronic rheumatic disease of childhood, despite its frequency in all pediatric rheumatology clinics, it takes a multicenter team work to build a database with significant numbers that can be useful for clinical research. In a combined effort between three CWRU affiliated institutions, we were able to build a database with over 140 patients within 8 months. Our database resembles the general demographics of children with JIA; most of the patients were white and females. The under-representation of minorities in our cohort, only 6% of the total population, limited the power to assess the impact of race. The analysis of the data collected is the first one to reveal:

1. The value given by families of children with JIA to different treatment characteristics such as safety, efficacy, and side effects. This study endorses the findings seen in adults with RA\(^{(23)}\), in whom medication safety overcomes efficacy and presence of side effects. All other factors such as physician’s experience, personal preference, co-pay, method of administration, frequency and availability of support programs were not as important.

2. The role of physicians and nurse practitioners as disease educators, being the most reliable source of disease information and for treatment options.

3. The important role teenagers with JIA play in their medical decision-making.

Two outcomes that to our knowledge have not been document in families of children with JIA.
4. The use of The Pediatric Trust in Physician Scale (Pedi-TiPS) in families of children with JIA. Pedi-TiPS, a modified version of the Trust in Physician Scale, had similar properties to the original instrument (Cronbach’s alpha of 0.84) in a cohort of parents of children evaluated in pediatric specialty clinics and primary care (27). To our knowledge, we are the first ones to measure parent’s trust in their child’s physician in an outpatient pediatric rheumatology setting.

5. To document a tendency of Medicaid families for less aggressive treatment options in JIA compared to families of children with private insurance or BCMH. That maybe associated with a higher CHAQ previously described by Brunner and colleagues (26).

Even though this is the first study to evaluate parent medical treatment preferences for JIA, the design of the study lacks the ability to evaluate treatment preferences in naïve families, as the majority of our population had established diagnosis of JIA. Future treatment preferences observed in this study were likely to be biased by their own exposure. The study design did not allow us to evaluate a causal relationship. For example, is the option for less aggressive treatment preferred by Medicaid families associated with higher CHAQ, or is this score a reflection of the dynamics of having a chronic condition in the setting of a low SES? Those questions that could only be answered in a prospective study. Pedi-TiPS validation and association to treatment preferences is also of interest and will be the objective of future data analysis.
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Table 1</td>
</tr>
<tr>
<td>2.</td>
<td>Table 2</td>
</tr>
<tr>
<td>3.</td>
<td>Table 3</td>
</tr>
<tr>
<td>4.</td>
<td>Table 4</td>
</tr>
<tr>
<td>5.</td>
<td>Table 5</td>
</tr>
<tr>
<td>6.</td>
<td>Parent questionnaire</td>
</tr>
<tr>
<td>7.</td>
<td>Patient questionnaire</td>
</tr>
<tr>
<td>8.</td>
<td>Physician questionnaire</td>
</tr>
<tr>
<td>9.</td>
<td>CHAQ questionnaire</td>
</tr>
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**TABLE 1**  
**DESCRIPTIVE ANALYSIS**

<table>
<thead>
<tr>
<th><strong>PARENTAL DEMOGRAPHICS</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean Age</strong> (years)</td>
<td>40 (29-49)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>17%</td>
</tr>
<tr>
<td>Female</td>
<td>83%</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>5%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>2%</td>
</tr>
<tr>
<td>Latino or Hispanic</td>
<td>2%</td>
</tr>
<tr>
<td>Native Hawaiian or Pacific Islander</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>92%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Mexican</td>
<td>1%</td>
</tr>
<tr>
<td>Puerto Rican</td>
<td>2%</td>
</tr>
<tr>
<td>Cuban</td>
<td>2%</td>
</tr>
<tr>
<td>Non Applicable, Non Latino</td>
<td>67%</td>
</tr>
<tr>
<td>Other</td>
<td>30%</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>3%</td>
</tr>
<tr>
<td>Some high school</td>
<td>4%</td>
</tr>
<tr>
<td>High school (GED)</td>
<td>12%</td>
</tr>
<tr>
<td>Some college</td>
<td>27%</td>
</tr>
<tr>
<td>College degree</td>
<td>40%</td>
</tr>
<tr>
<td>Graduate / Professional degree</td>
<td>14%</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>8%</td>
</tr>
<tr>
<td>Married or living with a partner</td>
<td>81%</td>
</tr>
<tr>
<td>Divorced</td>
<td>11%</td>
</tr>
<tr>
<td><strong>Family income</strong></td>
<td></td>
</tr>
<tr>
<td>Less than 10 000</td>
<td>3%</td>
</tr>
<tr>
<td>10 000 – 14 999</td>
<td>2%</td>
</tr>
<tr>
<td>15 000 – 19 999</td>
<td>4%</td>
</tr>
<tr>
<td>20 000 – 24 999</td>
<td>6%</td>
</tr>
<tr>
<td>25 000 – 29 999</td>
<td>3%</td>
</tr>
<tr>
<td>30 000 – 49 999</td>
<td>16%</td>
</tr>
<tr>
<td>50 000 – 74 999</td>
<td>13%</td>
</tr>
<tr>
<td>75 000 – 99 999</td>
<td>21%</td>
</tr>
<tr>
<td>Over 100 000</td>
<td>28%</td>
</tr>
<tr>
<td>Unknown</td>
<td>3%</td>
</tr>
<tr>
<td><strong>Relation with patient</strong></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>82%</td>
</tr>
<tr>
<td>Father</td>
<td>17%</td>
</tr>
<tr>
<td>Legal guardian</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Medical literacy</strong></td>
<td></td>
</tr>
<tr>
<td>Extremely</td>
<td>70%</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>22%</td>
</tr>
<tr>
<td>Somewhat</td>
<td>6%</td>
</tr>
<tr>
<td>A little bit</td>
<td>1%</td>
</tr>
<tr>
<td>Not at all</td>
<td>1%</td>
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</table>

*It is hard for me to pay for my child’s health coverage*
<table>
<thead>
<tr>
<th>Agreement Level</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Totally agree</td>
<td>9%</td>
</tr>
<tr>
<td>Agree</td>
<td>16%</td>
</tr>
<tr>
<td>Neutral</td>
<td>22%</td>
</tr>
<tr>
<td>Disagree</td>
<td>24%</td>
</tr>
<tr>
<td>Totally disagree</td>
<td>28%</td>
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</table>

<table>
<thead>
<tr>
<th>CHILD INFORMATION</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age (years)</td>
<td>10 (3-17)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>23%</td>
</tr>
<tr>
<td>Female</td>
<td>77%</td>
</tr>
<tr>
<td>Distance from home (miles)</td>
<td>33.54 (8-85)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>5%</td>
</tr>
<tr>
<td>Asian</td>
<td>1%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>5%</td>
</tr>
<tr>
<td>Latino or Hispanic</td>
<td>2%</td>
</tr>
<tr>
<td>Native Hawaiian or Pacific Islander</td>
<td>2%</td>
</tr>
<tr>
<td>White</td>
<td>89%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Mexican</td>
<td>1%</td>
</tr>
<tr>
<td>Puerto Rican</td>
<td>4%</td>
</tr>
<tr>
<td>Cuban</td>
<td>1%</td>
</tr>
<tr>
<td>Non Applicable, Non Latino</td>
<td>63%</td>
</tr>
<tr>
<td>Other</td>
<td>31%</td>
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<tr>
<td>Health coverage</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>100%</td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td></td>
</tr>
<tr>
<td>Type of insurance</td>
<td></td>
</tr>
<tr>
<td>Only Medicaid</td>
<td>18%</td>
</tr>
<tr>
<td>Only Private insurance</td>
<td>66%</td>
</tr>
<tr>
<td>Any insurance +BCMHC</td>
<td>16%</td>
</tr>
<tr>
<td>First degree relative with rheumatologic disease</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>20%</td>
</tr>
<tr>
<td>No</td>
<td>80%</td>
</tr>
<tr>
<td>If yes, which disease? (n &gt;&gt; than 27)</td>
<td></td>
</tr>
<tr>
<td>Juvenile dermatomyositis</td>
<td>6</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td></td>
</tr>
<tr>
<td>Juvenile Idiopathic Arthritis</td>
<td>7</td>
</tr>
<tr>
<td>Mixed connective tissue disease</td>
<td>2</td>
</tr>
<tr>
<td>Rheumatoid Arthritis</td>
<td>11</td>
</tr>
<tr>
<td>Sarcoidosis</td>
<td>1</td>
</tr>
<tr>
<td>Systemic sclerosis</td>
<td></td>
</tr>
<tr>
<td>SLE</td>
<td>2</td>
</tr>
<tr>
<td>Vasculitis</td>
<td>1</td>
</tr>
<tr>
<td>Unknown</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
<tr>
<td>History of another chronic disease</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>26%</td>
</tr>
<tr>
<td>No</td>
<td>74%</td>
</tr>
<tr>
<td>If yes, which disease? (n &gt;&gt; than 39)</td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>17</td>
</tr>
<tr>
<td>Heart disease</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2</td>
</tr>
<tr>
<td>IBD</td>
<td>Kidney disease</td>
</tr>
<tr>
<td>-----</td>
<td>----------------</td>
</tr>
<tr>
<td></td>
<td>4</td>
</tr>
</tbody>
</table>

**Diagnosis (reported by parent)**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oligoarticular JIA</td>
<td>32%</td>
</tr>
<tr>
<td>Polyarticular JIA</td>
<td>37%</td>
</tr>
<tr>
<td>Systemic onset JIA</td>
<td>10%</td>
</tr>
<tr>
<td>Psoriatic arthritis</td>
<td>4%</td>
</tr>
<tr>
<td>Enthesitis related arthritis (ERA)</td>
<td>8%</td>
</tr>
<tr>
<td>Undifferentiated</td>
<td>3%</td>
</tr>
<tr>
<td>Not sure</td>
<td>6%</td>
</tr>
</tbody>
</table>

**Year of diagnosis**

<table>
<thead>
<tr>
<th>Year</th>
<th>Percentage</th>
</tr>
</thead>
</table>

**Time between diagnosis and first visit to pediatric rheumatology**

<table>
<thead>
<tr>
<th>Time</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1 year</td>
<td>96%</td>
</tr>
<tr>
<td>1-2 years</td>
<td>3%</td>
</tr>
<tr>
<td>&gt;3 years</td>
<td>1%</td>
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</tbody>
</table>

**Uveitis (reported by parent)**

<table>
<thead>
<tr>
<th>Uveitis</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>20%</td>
</tr>
<tr>
<td>No</td>
<td>80%</td>
</tr>
<tr>
<td>Unknown</td>
<td></td>
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</tbody>
</table>

**PARENT SOURCE OF INFORMATION**

**Most helpful source of information about arthritis**

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician &amp; nurse practitioner</td>
<td>91%</td>
</tr>
<tr>
<td>Friends &amp; family</td>
<td>2%</td>
</tr>
<tr>
<td>Someone else diagnosed with a rheumatologic disease</td>
<td>2%</td>
</tr>
<tr>
<td>Media (internet / radio / TV)</td>
<td>4%</td>
</tr>
<tr>
<td>Arthritis Foundation / American College of Rheumatology / American Academy of Pediatrics</td>
<td>2%</td>
</tr>
</tbody>
</table>

**Least helpful source of information about arthritis**

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician &amp; nurse practitioner</td>
<td>1%</td>
</tr>
<tr>
<td>Friends &amp; family</td>
<td>29%</td>
</tr>
<tr>
<td>Someone else diagnosed with a rheumatologic disease</td>
<td>23%</td>
</tr>
<tr>
<td>Media (internet / radio / TV)</td>
<td>29%</td>
</tr>
<tr>
<td>Arthritis Foundation / American College of Rheumatology / American Academy of Pediatrics</td>
<td>18%</td>
</tr>
</tbody>
</table>

**Most helpful source of information about treatment options**

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician &amp; nurse practitioner</td>
<td>91%</td>
</tr>
<tr>
<td>Friends &amp; family</td>
<td>3%</td>
</tr>
<tr>
<td>Someone else diagnosed with a rheumatologic disease</td>
<td>1%</td>
</tr>
<tr>
<td>Media (internet / radio / TV)</td>
<td>3%</td>
</tr>
<tr>
<td>Arthritis Foundation / American College of Rheumatology / American Academy of Pediatrics</td>
<td>3%</td>
</tr>
</tbody>
</table>

**Least helpful source of information about treatment options**

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician &amp; nurse practitioner</td>
<td>1%</td>
</tr>
<tr>
<td>Friends &amp; family</td>
<td>33%</td>
</tr>
<tr>
<td>Someone else diagnosed with a rheumatologic disease</td>
<td>26%</td>
</tr>
<tr>
<td>Media (internet / radio / TV)</td>
<td>23%</td>
</tr>
<tr>
<td>Arthritis Foundation / American College of Rheumatology / American Academy of Pediatrics</td>
<td>17%</td>
</tr>
</tbody>
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**Disease activity at diagnosis**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>(3-10)</td>
</tr>
</tbody>
</table>

**Disease activity today**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>(0-8)</td>
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</tbody>
</table>

**IMPORTANT FACTORS WHEN MAKING A DECISION**

**Efficacy**
<table>
<thead>
<tr>
<th>Category</th>
<th>Totally important</th>
<th>Important</th>
<th>Neutral</th>
<th>Not important</th>
<th>Totally not important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safety</td>
<td>87%</td>
<td>11%</td>
<td>2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Side effects</td>
<td>64%</td>
<td>33%</td>
<td>4%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years on the market</td>
<td>33%</td>
<td>42%</td>
<td>22%</td>
<td>3%</td>
<td>1%</td>
</tr>
<tr>
<td>MD experience with treatment</td>
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<td>33%</td>
<td>6%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MD personal preference</td>
<td>33%</td>
<td>51%</td>
<td>16%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Method of administration</td>
<td>20%</td>
<td>42%</td>
<td>25%</td>
<td>9%</td>
<td>3%</td>
</tr>
<tr>
<td>Frequency</td>
<td>20%</td>
<td>36%</td>
<td>30%</td>
<td>11%</td>
<td>2%</td>
</tr>
<tr>
<td>Co-pay</td>
<td>27%</td>
<td>23%</td>
<td>28%</td>
<td>14%</td>
<td>9%</td>
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<tr>
<td>Presence of patient support programs</td>
<td>10%</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Importance</td>
<td>26%</td>
<td>46%</td>
<td>14%</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>---------------------</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
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</tr>
</tbody>
</table>

**MEDICATIONS**

**Ever used**

<table>
<thead>
<tr>
<th>Medication</th>
<th>Current</th>
<th>Prior</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Herbal &amp; non-vitamin supplements (n=122)</td>
<td>7%</td>
<td>14%</td>
<td>72%</td>
</tr>
<tr>
<td>NSAIDs (n=133)</td>
<td>43%</td>
<td>55%</td>
<td>3%</td>
</tr>
<tr>
<td>Systemic steroids (n=130)</td>
<td>11%</td>
<td>39%</td>
<td>48%</td>
</tr>
<tr>
<td>IAJI (n=127)</td>
<td>4%</td>
<td>54%</td>
<td>39%</td>
</tr>
<tr>
<td>DMARDs / non biologic modulators (n=133)</td>
<td>58%</td>
<td>23%</td>
<td>20%</td>
</tr>
<tr>
<td>Biologics</td>
<td>40%</td>
<td>17%</td>
<td>46%</td>
</tr>
</tbody>
</table>

**Time of initiation**

<table>
<thead>
<tr>
<th>Medication</th>
<th>Within 3 months</th>
<th>Within 6 months</th>
<th>Within 12 months</th>
<th>After 1 year</th>
<th>Option never offered</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSAIDs</td>
<td>95%</td>
<td>1%</td>
<td>2%</td>
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<td>2%</td>
</tr>
<tr>
<td>Systemic steroids</td>
<td>36%</td>
<td>7%</td>
<td>2%</td>
<td>10%</td>
<td>45%</td>
</tr>
<tr>
<td>IAJI</td>
<td>25%</td>
<td>11%</td>
<td>14%</td>
<td>15%</td>
<td>34%</td>
</tr>
<tr>
<td>DMARDs / non biologic modulators</td>
<td>46%</td>
<td>19%</td>
<td>8%</td>
<td>11%</td>
<td>16%</td>
</tr>
<tr>
<td>Biologics</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------</td>
<td>----------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within 3 months</td>
<td>10%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within 6 months</td>
<td>6%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within 12 months</td>
<td>12%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>After 1 year</td>
<td>27%</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Option never offered</td>
<td>44%</td>
<td></td>
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</tr>
</tbody>
</table>

**Future treatment preferences**

**Oligoarthritis (< 4 joints)**
- No answer or not sure: 30%
- Alternative medicine: 3%
- Alternative medicine +/- NSAIDs +/- IAJI: 23%
- Alternative medicine +/- NSAIDs +/- IAJI +/- DMARDs: 19%
- Alternative medicine +/- NSAIDs +/- IAJI +/- DMARDs +/- biologic: 25%

**Polyarthritis (> 4 joints)**
- No answer or not sure: 38%
- Alternative medicine: 1%
- Alternative medicine +/- NSAIDs +/- IAJI: 7%
- Alternative medicine +/- NSAIDs +/- IAJI +/- DMARDs: 23%
- Alternative medicine +/- NSAIDs +/- IAJI +/- DMARDs +/- biologic: 32%

**Side effects**

**Any side effects?**
- Yes: 55%
- No: 45%

**If yes, to which? Reported by side effects events**

**N=73**

**NSAIDs**
- Yes: 23%
- No: 77%

**Systemic steroids**
- Yes: 27%
- No: 73%

**IAJI**
- Yes: 11%
- No: 89%

**DMARDs / non biologic modulators**
- Yes: 66%
- No: 34%

**Biologics**
- Yes: 36%
- No: 64%

**PHYSICIAN TRUST SCORE**
- 85 (63-100)

**CHAQ**
- 0.28 (0-1.37)

**PATIENT QUESTIONNAIRE n=53**

**PATIENT SOURCE OF INFORMATION**

**Most helpful source of information about arthritis**
- Physician & nurse practitioner: 83%
- Friends & family: 10%
- Someone else diagnosed with a rheumatologic disease: 4%
- Media (internet / radio/ TV): 2%
- Arthritis Foundation / American College of Rheumatology / American Academy of Pediatrics: 2%

**Least helpful source of information about arthritis**
- Physician & nurse practitioner: 16%
- Friends & family: 10%
<table>
<thead>
<tr>
<th>Medical Decision Making</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>My parents make all the decisions</td>
<td>15%</td>
</tr>
<tr>
<td>My parents make most of the decisions</td>
<td>21%</td>
</tr>
<tr>
<td>I make all the decisions</td>
<td>2%</td>
</tr>
<tr>
<td>I make most of the decisions</td>
<td>2%</td>
</tr>
<tr>
<td>My physician makes all the decisions</td>
<td>2%</td>
</tr>
<tr>
<td>My physician makes most of the decisions</td>
<td>4%</td>
</tr>
<tr>
<td>My parents and I equally contribute to make the decision together</td>
<td>55%</td>
</tr>
</tbody>
</table>

### Diagnosis

- **Oligoarticular JIA**: 21%
- **Polyarticular JIA**: 33%
- **Systemic onset JIA**: 4%
- **Psoriatic arthritis**: 4%
- **Enthesitis related arthritis (ERA)**: 10%
- **Undifferentiated**: 10%
- **Not sure**: 19%

### History of uveitis

- **Yes**: 12%
- **No**: 88%
- **Unknown**: 

### PHYSICIAN QUESTIONNAIRE

#### Patient diagnosis

- **Oligoarticular JIA**: 44%
- **Polyarticular JIA**: 36%
- **Systemic onset JIA**: 8%
- **Psoriatic arthritis**: 2%
- **Enthesitis related arthritis (ERA)**: 10%

#### JIA diagnosis

- **Persistent Oligoarticular JIA**: 34%
- **Extended Oligoarticular JIA**: 11%
- **RF (+) Polyarticular JIA**: 5%
- **RF (-) Polyarticular JIA**: 29%
- **Systemic onset JIA**: 8%
- **Psoriatic arthritis**: 2%
- **Enthesitis related arthritis (ERA)**: 10%

**Disease activity score**: 1.65 (0-7)

**Number of active joints on physical exam**: 1.5 (0-8)
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<tr>
<th>Diagnostic correlation</th>
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<tr>
<td>Both parent &amp; child</td>
<td>70%</td>
</tr>
<tr>
<td>Only parent or child</td>
<td>6%</td>
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<tr>
<td>Does not correlate at all</td>
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<table>
<thead>
<tr>
<th>CHART REVIEW</th>
<th></th>
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<tbody>
<tr>
<td>Active joint count at diagnosis</td>
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<tr>
<td>NSAIDs</td>
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</tr>
<tr>
<td>Current</td>
<td>28%</td>
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<tr>
<td>Prior</td>
<td>72%</td>
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<tr>
<td>Never</td>
<td>5%</td>
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<td>Systemic steroids</td>
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<td>Current</td>
<td>7%</td>
</tr>
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<td>Prior</td>
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<td>61%</td>
</tr>
<tr>
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</tr>
<tr>
<td>Current</td>
<td>1%</td>
</tr>
<tr>
<td>Prior</td>
<td>58%</td>
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<td>38%</td>
</tr>
<tr>
<td>DMARDs / non biologic modulators</td>
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<td>Prior</td>
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<td>Never</td>
<td>18%</td>
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<td>Current</td>
<td>42%</td>
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<tr>
<td>Prior</td>
<td>27%</td>
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<tr>
<td>Never</td>
<td>49%</td>
</tr>
<tr>
<td>* 144 , n greater than 124. Extra patients given by patients who have received more than one biologic.</td>
<td></td>
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<tr>
<td>Ibuprofen</td>
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<td>Current</td>
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<td>Prior</td>
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<td>66%</td>
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<td>Naproxen</td>
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<td>Current</td>
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<td>Prior</td>
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<td>Celebrex</td>
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<tr>
<td>Prior</td>
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<td>86%</td>
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<td>Prior</td>
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<tr>
<td>Never</td>
<td>97%</td>
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</tr>
<tr>
<td>Prior</td>
<td></td>
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<td>Never</td>
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<tr>
<td>Azathioprine</td>
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<td>Drug</td>
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</tr>
<tr>
<td>Methotrexate</td>
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<tr>
<td>Hydroxychloroquine</td>
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<tr>
<td>Sulfasalazine</td>
<td>4%</td>
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<tr>
<td>Cyclophosphamide</td>
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<tr>
<td>Anakinra</td>
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<tr>
<td>Etanercept</td>
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<tr>
<td>Adalimumab</td>
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<tr>
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<tr>
<td>Infliximab</td>
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<td>Rilonacept</td>
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<tr>
<td>Rituximab</td>
<td>1%</td>
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<td>Tocilizumab</td>
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**LABORATORY RESULTS**

<table>
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<tr>
<th>Test</th>
<th>Positive</th>
<th>Negative</th>
<th>Unknown</th>
</tr>
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<tbody>
<tr>
<td>ANA</td>
<td>54%</td>
<td>38%</td>
<td>8%</td>
</tr>
<tr>
<td>RF</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Positive</td>
<td>Negative</td>
<td>Unknown</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>----------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>8%</td>
<td>71%</td>
<td>22%</td>
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<table>
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<tr>
<th><strong>HLA B27</strong></th>
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<tbody>
<tr>
<td>Positive</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>Negative</td>
<td>36%</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>59%</td>
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</tr>
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</table>

<table>
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<tr>
<th><strong>CCP</strong></th>
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</thead>
<tbody>
<tr>
<td>Positive</td>
<td>7%</td>
<td></td>
</tr>
<tr>
<td>Negative</td>
<td>36%</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>57%</td>
<td></td>
</tr>
</tbody>
</table>
TABLE 2
FUTURE TREATMENT PREFERENCES

<table>
<thead>
<tr>
<th>Future treatment preferences</th>
<th>Oligoarticular JIA</th>
<th>Polyarticular JIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>IAJI</td>
<td>DMARD +/- Biologics</td>
<td>P value</td>
</tr>
<tr>
<td>N=30</td>
<td>N=58</td>
<td>0.965</td>
</tr>
</tbody>
</table>

PARENTAL DEMOGRAPHICS

| Median Age (years) | 40 (30-49) | 40 (28-54) | 0.775 | 41 (31-53) | 40 (28-50) | 0.409 | 0.59 |

| Gender | Male | 20% | 17% | 15% | 24% | 0.704 | 0.385 |
|        | Female | 80% | 83% | 85% | 76% |

| Race | American Indian or Alaska Native | 3% | 7% | 5% | 7% |
|      | Asian | 2% | 5% |
|      | Black or African American | 3% | 7% | 5% | 7% |
|      | Latino or Hispanic | 3% | 7% | 5% | 7% |

| Pacific Islander | 3% | 7% | 5% | 7% |
| White | 3% | 7% | 5% | 7% |
| Other | 3% | 7% | 5% | 7% |

| Education | 3% | 7% | 5% | 7% |
| Less than high school | 5% | 7% | 5% | 7% |
| Some high school | 13% | 14% | 13% | 17% |
| High school (GED) | 33% | 26% | 23% | 31% |
| Some college | 37% | 41% | 41% | 38% |
| College degree | 17% | 10% | 15% | 10% |
| Graduate / Professional degree | 0.727 | 0.900 |

| Marital status | 7% | 7% | 5% | 7% |
| Never married | 90% | 80% | 89% | 74% |
| Married or living with a partner | 3% | 13% | 5% | 15% |

| Divorced | 3% | 13% | 5% | 15% |
| Family income | 4% | 7% | 5% | 7% |
| Less than 10 000 | 4% | 7% | 5% | 7% |
| 10 000 – 14 999 | 4% | 7% | 5% | 7% |
| 15 000 – 19 999 | 4% | 7% | 5% | 7% |
| 20 000 – 24 999 | 4% | 7% | 5% | 7% |
| 25 000 – 29 999 | 4% | 7% | 5% | 7% |
| 30 000 – 49 999 | 4% | 7% | 5% | 7% |
| 50 000 – 74 999 | 4% | 7% | 5% | 7% |
| 75 000 – 99 999 | 4% | 7% | 5% | 7% |
| Over 100 000 | 4% | 7% | 5% | 7% |
| Unknown | 4% | 7% | 5% | 7% |

| Relation with patient | Mother | 76% | 84% | 82% | 79% |
| Father | 24% | 16% | 18% | 21% |

| Medical literacy | 60% | 79% | 69% | 79% |

43
<table>
<thead>
<tr>
<th>Response</th>
<th>33%</th>
<th>14%</th>
<th>26%</th>
<th>12%</th>
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</thead>
<tbody>
<tr>
<td>Extremely</td>
<td>7%</td>
<td>5%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Quite a bit</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little bit</td>
<td>2%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td></td>
<td></td>
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<table>
<thead>
<tr>
<th>It is hard for me to pay for my child’s health coverage</th>
<th>0.288</th>
<th>0.478</th>
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<tr>
<td>Totally agree</td>
<td>3%</td>
<td>9%</td>
</tr>
<tr>
<td>Agree</td>
<td>3%</td>
<td>16%</td>
</tr>
<tr>
<td>Neutral</td>
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<td>19%</td>
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<tr>
<td>Disagree</td>
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<td>21%</td>
</tr>
<tr>
<td>Totally disagree</td>
<td>33%</td>
<td>35%</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>CHILD INFORMATION</th>
<th>Median Age (years)</th>
<th>11 (2-17)</th>
<th>10 (3-17)</th>
<th>0.975</th>
<th>12 (3-19)</th>
<th>10 (2-17)</th>
<th>0.992</th>
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<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>20%</td>
<td>19%</td>
<td>21%</td>
<td>21%</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>81%</td>
<td></td>
<td>79%</td>
<td>79%</td>
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<tr>
<td>Race</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>American Indian or</td>
<td>3%</td>
<td>9%</td>
<td>5%</td>
<td>10%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alaska Native</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Asian</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>87%</td>
<td>88%</td>
<td>56%</td>
<td>90%</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Latino or Hispanic</td>
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<td>3%</td>
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</tr>
<tr>
<td>Native Hawaiian or</td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Pacific Island</td>
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</tr>
<tr>
<td>White</td>
<td>10%</td>
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<td>Type of insurance</td>
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</tr>
<tr>
<td>Only Medicaid</td>
<td>11%</td>
<td>14%</td>
<td>13%</td>
<td>12%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Only Private insurance</td>
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<td>63%</td>
<td>79%</td>
<td>59%</td>
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<tr>
<td>Any insurance +BCMH</td>
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<td>8%</td>
<td>29%</td>
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<tr>
<td>First degree relative with rheumatologic disease</td>
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<tr>
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TIME TO INITIATION OF TREATMENT

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**PARENT DEMOGRAPHICS**

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**Gender**

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<tr>
<td>Gender</td>
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<td>83%</td>
<td>19%</td>
<td>81%</td>
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**Race**

| American Indian or Alaska Native | 5% | 2% | 10% | 4% |
| Asian                           | 4% | 86% | 4% | 31% |
| Black or African American       | 4% | 86% | 4% | 31% |
| Latino or Hispanic              | 14% | 86% | 4% | 31% |
| Native Hawaiian or Pacific Islander | 14% | 86% | 4% | 31% |
| White                          | 90% | 96% | 86% | 92% |
| Other                          | 1% | 96% | 2% | 92% |

**Education**

| Less than high school | 2% | 6% | 5% | 4% |
| Some high school      | 5% | 5% | 5% | 5% |
| High school (GED)     | 14% | 5% | 4% | 4% |
| Some college          | 25% | 25% | 4% | 4% |
| College degree        | 42% | 42% | 25% | 25% |
| Graduate / Professional degree | 42% | 42% | 25% | 25% |

**Marital Status**

| Never married | 7% | 10% | 12% |
| Married or living with a partner | 78% | 80% | 73% |
| Divorced      | 15% | 10% | 15% |

**Family Income**

| Less than 10 000 | 4% | 5% | 6% |
| 10 000 – 14 999 | 2% | 5% | 2% |
| 15 000 – 19 999 | 6% | 5% | 6% |
| 20 000 – 24 999 | 4% | 6% | 4% |
| 25 000 – 29 999 | 12% | 21% | 10% | 12% |
| 30 000 – 49 999 | 14% | 8% | 10% | 10% |
| 50 000 – 74 999 | 20% | 21% | 30% | 15% |
| 75 000 – 99 999 | 27% | 33% | 25% | 31% |
| Over 100 000     | 4% | 4% | 4% |
| Unknown          | 4% | 4% | 4% |
| How difficult is to pay for my child's health coverage | | | | |  |
| --- | --- | --- | --- | --- |
| | Totally agree | Agree | Neutral | Disagree | Totally disagree |
| | 13% | 12% | 27% | 22% | 27% |
| | 4% | 29% | 12% | 25% | 29% |
| | 5% | 20% | 25% | 20% | 30% |
| | 12% | 18% | 20% | 27% | 22% |
| | 0.185 | 0.185 | 0.879 |  |

| CHILD INFORMATION | | | | |  |
| --- | --- | --- | --- | --- |
| Median Age (years) | 12 (3-17) | 11(3-17) | 0.318 | 12 | 11 |
| Gender | Male | Female | 1 | 14% | 27% |
| | 24% | 76% | 21% | 86% | 73% |
| Race | American Indian or Alaska Native | Asian | Black or African American | Latino or Hispanic | Native Hawaiian or Pacific Islander |
| | | | 6% | 1% | 2% |
| | | | 8% | 14% | 6% |
| | | | 14% | 86% | 92% |
| Type of insurance | Only Medicaid | Only Private insurance | Any insurance +BCMH |
| | 18% | 64% | 18% |
| | 8% | 75% | 17% |
| | 25% | 40% | 35% |
| | 16% | 61% | 22% |
| | 0.546 | 0.546 | 0.245 |
| First degree relative with rheumatologic disease | Yes | No | 1 | 19% | 27% |
| | 23% | 77% | 21% | 81% | 73% |
| History of another chronic disease | Yes | No | 1 | 40% | 22% |
| | 28% | 72% | 29% | 71% |
| | 40% | 60% | 22% | 78% |
| Time between diagnosis and first visit to pediatric rheumatology | < 1 year | 1-2 years | >3 years |
| | 95% | 4% | 1% |
| | 96% | 4% | 2% |
| | 91% | 6% | 2% |
| | 0.383 | 0.221 | 0.31 |
| DISEASE RELATED FACTORS | | | | |  |
| Uveitis (reported by parent) | Yes | No | Unknown | 0.577 | 0.739 |
| | 17 | 27% | 73% | 15% | 85% |
| | 3% | 22% | 78% |
| Mean disease activity at diagnosis | 7.5 | 7 | 0.383 | 8 | 0.179 |
| Mean active joint count at dx | 5 | 3 | 0.221 | 9 | 0.06 |
| QUALITY OF LIFE | | | | |  |
| Mean CHAQ score | 0.278 | 0.353 | 0.584 | 0.434 | 0.31 | 0.366 |
## MEDICATION RELATED FACTORS

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<th>58%</th>
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<th>58%</th>
<th>0.080</th>
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<td>8%</td>
<td>21%</td>
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<td>Alternative medicine +/- NSAIDs +/- IAJI +/- DMARDs</td>
<td>22%</td>
<td>35%</td>
<td>14%</td>
<td></td>
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</tr>
<tr>
<td>Alternative medicine +/- NSAIDs +/- IAJI +/- DMARDs +/- Biologics</td>
<td>22%</td>
<td>28%</td>
<td>57%</td>
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<tr>
<td><strong>TIME OF TREATMENT INITIATION after diagnosis</strong></td>
<td></td>
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<tr>
<td><strong>NSAIDs</strong></td>
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</tr>
<tr>
<td>&lt; 6 months</td>
<td>86%</td>
<td>98%</td>
<td>95%</td>
<td><strong>0.245</strong></td>
<td></td>
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</tr>
<tr>
<td>&gt; 6 months</td>
<td>9%</td>
<td>1%</td>
<td>5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never offered</td>
<td>5%</td>
<td>1%</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Steroids</strong></td>
<td></td>
<td></td>
<td></td>
<td><strong>0.086</strong></td>
<td></td>
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</tr>
<tr>
<td>&lt; 6 months</td>
<td>48%</td>
<td>40%</td>
<td>52%</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 6 months</td>
<td>10%</td>
<td>10%</td>
<td>29%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never offered</td>
<td>43%</td>
<td>51%</td>
<td>19%</td>
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<tr>
<td><strong>IAJI</strong></td>
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<td><strong>0.016</strong></td>
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<tr>
<td>&lt; 6 months</td>
<td>55%</td>
<td>37%</td>
<td>5%</td>
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</tr>
<tr>
<td>&gt; 6 months</td>
<td>27%</td>
<td>27%</td>
<td>47%</td>
<td></td>
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</tr>
<tr>
<td>Never offered</td>
<td>18%</td>
<td>36%</td>
<td>47%</td>
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<tr>
<td><strong>DMARDs</strong></td>
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<td></td>
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</tr>
<tr>
<td>&lt; 6 months</td>
<td>68%</td>
<td>63%</td>
<td>75%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 6 months</td>
<td>9%</td>
<td>21%</td>
<td>20%</td>
<td></td>
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</tr>
<tr>
<td>Never offered</td>
<td>23%</td>
<td>15%</td>
<td>5%</td>
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<tr>
<td><strong>Biologics</strong></td>
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<td></td>
<td></td>
<td><strong>0.004</strong></td>
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<td></td>
</tr>
<tr>
<td>&lt; 6 months</td>
<td>24%</td>
<td>10%</td>
<td>35%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 6 months</td>
<td>38%</td>
<td>38%</td>
<td>55%</td>
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</tr>
<tr>
<td>Never offered</td>
<td>38%</td>
<td>52%</td>
<td>10%</td>
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<tr>
<td><strong>PARENT DEMOGRAPHICS</strong></td>
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<tr>
<td><strong>Median Age</strong> (years)</td>
<td>39 (30-54)</td>
<td>41 (30-54)</td>
<td>39 (28-45)</td>
<td>0.076</td>
<td></td>
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</tr>
<tr>
<td>------------------------</td>
<td>-----------</td>
<td>-----------</td>
<td>-----------</td>
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</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td>0.25</td>
<td></td>
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</tr>
<tr>
<td>Male</td>
<td>27%</td>
<td>13 (15%)</td>
<td>2 (10%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>73%</td>
<td>72 (85%)</td>
<td>19 (90%)</td>
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</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
<td>0.023</td>
<td></td>
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<tr>
<td>American Indian or</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alaska Native</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or African</td>
<td>13%</td>
<td></td>
<td>3 (14%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>American</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Latino or Hispanic</td>
<td>4%</td>
<td>2 (2%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Native Hawaiian or</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pacific Islander</td>
<td>78%</td>
<td>81 (96%)</td>
<td>18 (86%)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>4%</td>
<td>1 (1%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Education</strong></td>
<td>13%</td>
<td>1 (5%)</td>
<td></td>
<td>0.0001</td>
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</tr>
<tr>
<td>Less than high school</td>
<td>4%</td>
<td>8 (9%)</td>
<td>4 (19%)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Some high school</td>
<td>13%</td>
<td>23 (27%)</td>
<td>3 (14%)</td>
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<td></td>
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</tr>
<tr>
<td>High school (GED)</td>
<td>39%</td>
<td>41 (48%)</td>
<td>7 (33%)</td>
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</tr>
<tr>
<td>Some college</td>
<td>17%</td>
<td>13 (15%)</td>
<td>2 (10%)</td>
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<td></td>
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</tr>
<tr>
<td>College degree</td>
<td>13%</td>
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</tr>
<tr>
<td>Graduate / Professional</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>degree</td>
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</tr>
<tr>
<td><strong>Marital status</strong></td>
<td>23%</td>
<td>1 (1%)</td>
<td>4 (20%)</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>50%</td>
<td>76 (92%)</td>
<td>14 (70%)</td>
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</tr>
<tr>
<td>Married or living with a partner</td>
<td>27%</td>
<td>6 (7%)</td>
<td>2 (10%)</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
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<tr>
<td>Divorced</td>
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</tr>
<tr>
<td><strong>Family income</strong></td>
<td>19%</td>
<td></td>
<td></td>
<td>0.334</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 10 000</td>
<td>14%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 000 – 14 999</td>
<td>5%</td>
<td>1 (1%)</td>
<td>3 (14%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 000 – 19 999</td>
<td>24%</td>
<td>1 (1%)</td>
<td>1 (5%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20 000 – 24 999</td>
<td>29%</td>
<td>2 (2%)</td>
<td>2 (10%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25 000 – 29 999</td>
<td>29%</td>
<td>8 (10%)</td>
<td>6 (29%)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>30 000 – 49 999</td>
<td>39%</td>
<td>11 (13%)</td>
<td>4 (19%)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>50 000 – 74 999</td>
<td>13%</td>
<td>23 (28%)</td>
<td>4 (19%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>75 000 – 99 999</td>
<td>5%</td>
<td>34 (41%)</td>
<td>1 (5%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Over 100 000</td>
<td>5%</td>
<td>3 (4%)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Relation with patient</strong></td>
<td>68%</td>
<td>70 (83%)</td>
<td>19 (90%)</td>
<td>0.334</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>27%</td>
<td>13 (15%)</td>
<td>2 (10%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>5%</td>
<td>1 (1%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legal guardian</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Medical literacy</strong></td>
<td>61%</td>
<td>65 (76%)</td>
<td>12 (57%)</td>
<td>0.018</td>
<td></td>
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</tr>
<tr>
<td>Extremely</td>
<td>22%</td>
<td>18 (21%)</td>
<td>5 (24%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quite a bit</td>
<td>9%</td>
<td>2 (2%)</td>
<td>4 (19%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat</td>
<td>4%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little bit</td>
<td>4%</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Not at all</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>It is hard for me to pay for my child’s health coverage</strong></td>
<td></td>
<td></td>
<td></td>
<td>0.628</td>
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</tr>
<tr>
<td>Totally agree</td>
<td>13%</td>
<td>7 (8%)</td>
<td>2 (10%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td>17%</td>
<td>12 (14%)</td>
<td>4 (19%)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Neutral</td>
<td>26%</td>
<td>17 (20%)</td>
<td>6 (29%)</td>
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</tr>
<tr>
<td>Disagree</td>
<td>9%</td>
<td>23 (27%)</td>
<td>6 (29%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Totally disagree</td>
<td>35%</td>
<td>26 (31%)</td>
<td>3 (14%)</td>
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</tr>
<tr>
<td>Miles from home (median)</td>
<td>27(6-65)</td>
<td>21(8-79)</td>
<td>43 (9-100)</td>
<td>0.175</td>
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</tr>
<tr>
<td>-------------------------</td>
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<td>----------</td>
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<tr>
<td><strong>CHILD INFORMATION</strong></td>
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<tr>
<td>Median Age (years)</td>
<td>13 (2-16)</td>
<td>10 (3-17)</td>
<td>11 (3-16)</td>
<td>0.505</td>
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<tr>
<td><strong>Gender</strong></td>
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<td>0.259</td>
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<tr>
<td>Male</td>
<td>26%</td>
<td>21%</td>
<td>29%</td>
<td></td>
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</tr>
<tr>
<td>Female</td>
<td>74%</td>
<td>79%</td>
<td>71%</td>
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</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
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<td>0.096</td>
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</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>13%</td>
<td>1%</td>
<td>14%</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Asian</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or African</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>American</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Latino or Hispanic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Native Hawaiian or</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pacific Islander</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>78%</td>
<td>93%</td>
<td>86%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>9%</td>
<td>2%</td>
<td></td>
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<td></td>
</tr>
<tr>
<td><strong>First degree relative with rheumatologic disease</strong></td>
<td></td>
<td></td>
<td></td>
<td>0.308</td>
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</tr>
<tr>
<td>Yes</td>
<td>17%</td>
<td>19%</td>
<td>33%</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>83%</td>
<td>81%</td>
<td>67%</td>
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</tr>
<tr>
<td><strong>History of another chronic disease</strong></td>
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<td></td>
<td>0.179</td>
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</tr>
<tr>
<td>Yes</td>
<td>14%</td>
<td>25%</td>
<td>38%</td>
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</tr>
<tr>
<td>No</td>
<td>86%</td>
<td>75%</td>
<td>62%</td>
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</tr>
<tr>
<td><strong>Time between diagnosis and first visit to pediatric rheumatology</strong></td>
<td></td>
<td></td>
<td></td>
<td>0.068</td>
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<tr>
<td>&lt; 1 year</td>
<td>95%</td>
<td>98%</td>
<td>89%</td>
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</tr>
<tr>
<td>1-2 years</td>
<td>5%</td>
<td>2%</td>
<td>11%</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>&gt;3 years</td>
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<tr>
<td><strong>DISEASE RELATED FACTORS</strong></td>
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</tr>
<tr>
<td>Uveitis (reported by parent)</td>
<td>14%</td>
<td>24%</td>
<td>15%</td>
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</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td>0.502</td>
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<tr>
<td>No</td>
<td>86%</td>
<td>76%</td>
<td>85%</td>
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</tr>
<tr>
<td>Unknown</td>
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<tr>
<td><strong>Mean disease activity at diagnosis</strong></td>
<td>7</td>
<td>7</td>
<td>8</td>
<td>0.040</td>
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<tr>
<td><strong>Median active joint count at dx</strong></td>
<td>2 (1-37)</td>
<td>2 (0-12)</td>
<td>3 (1-9)</td>
<td>0.192</td>
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<tr>
<td><strong>QUALITY OF LIFE</strong></td>
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**ANALYSIS BY INSTITUTION**

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<td></td>
</tr>
<tr>
<td>ROLE IN MEDICATION-DECISION MAKING</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>My parents make the decisions</td>
<td>45%</td>
<td>28%</td>
<td></td>
</tr>
<tr>
<td>My physician makes the decision</td>
<td>11%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I make most of the decisions</td>
<td>7%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>My parents and I equally contribute to make the decision together</td>
<td>37%</td>
<td>68%</td>
<td></td>
</tr>
<tr>
<td>DISEASE RELATED FACTORS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Uveitis (reported by parent)</td>
<td>21%</td>
<td>19%</td>
<td>0.824</td>
</tr>
<tr>
<td>Yes</td>
<td>79%</td>
<td>81%</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Unknown</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median disease activity at diagnosis</td>
<td>8 (3-10)</td>
<td>8 (3-10)</td>
<td>0.848</td>
</tr>
<tr>
<td>Median active joint count at diagnosis</td>
<td>1 (0-8)</td>
<td>2 (1-23)</td>
<td>0.040</td>
</tr>
<tr>
<td>QUALITY OF LIFE</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHAQ (median)</td>
<td>0 (0-0.86)</td>
<td>0 (0-1.4)</td>
<td>0.328</td>
</tr>
<tr>
<td>MD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PHYSICIAN TRUST SCORE (Median)</td>
<td>90 (68-100)</td>
<td>97 (62-100)</td>
<td>0.061</td>
</tr>
<tr>
<td>JIA diagnosis (MD)</td>
<td></td>
<td></td>
<td>0.055</td>
</tr>
<tr>
<td>SoJIA</td>
<td>6%</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>Persistent OligoJIA</td>
<td>42%</td>
<td>27%</td>
<td></td>
</tr>
<tr>
<td>Extended OligoJIA</td>
<td>6%</td>
<td>15%</td>
<td></td>
</tr>
<tr>
<td>RF (+) PolyJIA</td>
<td>6%</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>RF (-) PolyJIA</td>
<td>21%</td>
<td>36%</td>
<td></td>
</tr>
<tr>
<td>Psoriatic arthritis</td>
<td>2%</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>ERA</td>
<td>16%</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>Global disease activity score</td>
<td>2 (0-7)</td>
<td>1.134</td>
<td>0.002</td>
</tr>
<tr>
<td>Diagnosis correlation</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>With parent and patient</td>
<td>70%</td>
<td>70%</td>
<td></td>
</tr>
<tr>
<td>Only parent or patient</td>
<td>6%</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>Do not correlate</td>
<td>24%</td>
<td>25%</td>
<td></td>
</tr>
<tr>
<td>TREATMENT PREFERENCES</td>
<td></td>
<td></td>
<td>0.101</td>
</tr>
<tr>
<td>Oligoarticular JIA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No answer / not sure</td>
<td>24%</td>
<td>35%</td>
<td></td>
</tr>
<tr>
<td>Alternative medicine</td>
<td></td>
<td></td>
<td>6%</td>
</tr>
<tr>
<td>Alternative medicine +/- NSAIDs +/- IAJI</td>
<td>27%</td>
<td>19%</td>
<td></td>
</tr>
<tr>
<td>Alternative medicine +/- NSAIDs +/- IAJI +/- DMARDs +/- Biologics</td>
<td>48%</td>
<td>41%</td>
<td></td>
</tr>
<tr>
<td>Polyarticular JIA</td>
<td>41%</td>
<td>35%</td>
<td>0.837</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-----</td>
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</tr>
<tr>
<td>No answer / not sure</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alternative medicine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alternative medicine +/- NSAIDs +/- IAJI +/- DMARDs</td>
<td>29%</td>
<td>30%</td>
<td></td>
</tr>
<tr>
<td>Alternative medicine +/- NSAIDs +/- IAJI +/- DMARDs +/ - Biologics</td>
<td>30%</td>
<td>33%</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TIME OF TREATMENT INITIATION after diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSAIDs</td>
</tr>
<tr>
<td>&lt; 6 months</td>
</tr>
<tr>
<td>&gt; 6 months</td>
</tr>
<tr>
<td>Never offered</td>
</tr>
<tr>
<td>IAJI</td>
</tr>
<tr>
<td>&lt; 6 months</td>
</tr>
<tr>
<td>&gt; 6 months</td>
</tr>
<tr>
<td>Never offered</td>
</tr>
<tr>
<td>DMARDs</td>
</tr>
<tr>
<td>&lt; 6 months</td>
</tr>
<tr>
<td>&gt; 6 months</td>
</tr>
<tr>
<td>Never offered</td>
</tr>
<tr>
<td>Biologics</td>
</tr>
<tr>
<td>&lt; 6 months</td>
</tr>
<tr>
<td>&gt; 6 months</td>
</tr>
<tr>
<td>Never offered</td>
</tr>
</tbody>
</table>
PATIENT PREFERENCES IN PEDIATRIC RHEUMATOLOGY
PARENT QUESTIONNAIRE

Please complete the following information about YOUR SELF

Age ___ ___ years

Gender:  ☐ Male  ☐ Female

Which of the following best describes your racial or ethnic background? You can choose more than one category.

☐ American Indian or Alaska Native  ☐ Native Hawaiian or Pacific Island
☐ Asian  ☐ White
☐ Black or African American  ☐ Other (write in) _______________
☐ Latino or Hispanic

Which of the following best describes your ethnic background? You can choose more than one category.

☐ Mexican  ☐ Non Applicable, Non Latino
☐ Puerto Rican  ☐ Other (write in) _______________
☐ Cuban

What is the highest degree of education you have completed?

☐ Less than high school
☐ Some high school
☐ High school (GED)
☐ Some college
☐ College degree
☐ Graduate / professional degree

Marital status:  ☐ Never married  ☐ Married or living with a partner  ☐ Divorced

Please select the category that is closest to your total household income in the past year for all family members, including any money from work, interest, and dividends.

☐ less than 10,000  ☐ 25,000 - 29,999  ☐ Over 100,000
☐ 10,000 - 14,999  ☐ 30,000 - 49,999  ☐ Unknown
☐ 15,000 - 19,999  ☐ 50,000 - 74,999
☐ 20,000 - 24,999  ☐ 75,000 - 99,999

What is your relationship to the patient?

☐ Mother  ☐ Father  ☐ Legal guardian

How confident are you filling out medical forms by yourself?

☐ Extremely  ☐ quite a bit  ☐ somewhat  ☐ a little bit  ☐ not at all

Please complete the following information about YOUR CHILD

Age: ___ ___ years

Gender:  ☐ Male  ☐ Female  

Zip Code of residence: _____ _____ _____ _____
Which of the following best describes your child’s race or ethnic background? (You can choose more than one).

- American Indian or Alaska Native
- Native Hawaiian or Pacific Islander
- Asian
- White
- Black or African American
- Other (write in) ______________
- Latino or Hispanic

Which of the following best describes your child’s family background? (You can choose more than one).

- Mexican
- Non Applicable, Non Latino
- Puerto Rican
- Other (write in) ______________
- Cuban

Does your child have health coverage?

- Yes
- No
- Unknown

If Yes, What type of health coverage does your child have?

- Medicaid or Medicare
- Private insurance
- Self pay
- HMO (Health Maintenance Organization)
- No insurance
- BCMH (Bureau for Children with Medical Handicaps)

Have you, your child’s other parent or one of your child’s siblings, ever been diagnosed with a rheumatologic disease?

- Yes
- No

If YES, please specify which disease

- Dermatomyositis
- Rheumatoid Arthritis
- Vasculitis
- Fibromyalgia
- Sarcoidosis
- Unknown
- Juvenile Idiopathic Arthritis (JIA)
- Systemic sclerosis
- Other __________
- Mixed Connective tissue disease
- Systemic Lupus Erythematosus

Has your child ever been diagnosed with a chronic medical condition other than arthritis that requires the use of frequent medications?

- Yes
- No

If YES, please specify which disease

- Asthma
- Diabetes
- Kidney disease
- Heart disease
- Inflammatory bowel disease
- Seizure
- Other _______

Please answer the following questions regarding YOUR CHILD’S ARTHRITIS

What type of arthritis has your child been diagnosed with?

- Oligo arthritis (arthritis in LESS than 4 joints)
- Poly arthritis (arthritis in MORE than 4 joints)
- Systemic arthritis (arthritis, fever, skin rash, swollen glands and organ involvement)
- Psoriatic arthritis (arthritis and psoriasis)
- Spondyloarthropathy, ankylosing spondylitis, arthritis related to inflammatory bowel disease (Enthesitis Related Arthritis, also called seronegative arthritis)
- Other kind of arthritis (Undifferentiated)
- Not sure

When was your child diagnosed with arthritis? ______ ______ ______ Year
When was your child first seen by a pediatric rheumatologist? ___ ___ ___ ___ Year

Has your child been diagnosed with eye inflammation or uveitis?
 Yes   No   Unknown

Please identify which of the following sources you found helpful regarding information about your child's arthritis. Please order them from the most helpful (1) to the least helpful (5).

____  My child's physician/nurse
____  My friends and family
____  Someone else diagnosed with a rheumatologic disease
____  Internet / Radio / Television
____  Arthritis Foundation / American College of Rheumatology / American Academy of Pediatrics

Please circle the number that best describes, how severe in your opinion was your child's arthritis at the time of the INITIAL DIAGNOSIS.

Not severe  1  2  3  4  5  6  7  8  9  Very severe

Please circle the number that best describes, how severe in your opinion your child's arthritis is TODAY.

Not severe  1  2  3  4  5  6  7  8  9  Very severe

Please answer the following questions regarding YOUR CHILD'S MEDICATIONS.

Please identify which of the following sources you found more helpful regarding information about treatment options for your child's arthritis. Please order them from the most helpful (1) to the least helpful (5).

____  My child's physician/nurse
____  My friends and family
____  Someone else diagnosed with a rheumatologic disease
____  Internet / Radio / Television
____  Arthritis Foundation / American College of Rheumatology / American Academy of Pediatrics

When you are choosing a treatment for your child's arthritis, please evaluate how important are the following factors?

How well it works?
 Totally important   Important   Neutral   Not important   Totally not important

How safe it is?
 Totally important   Important   Neutral   Not important   Totally not important

Associated side effects
- **Years on the market**
  - Totally important
  - Important
  - Neutral
  - Not important
  - Totally not important

- **Physician’s experience with treatment**
  - Totally important
  - Important
  - Neutral
  - Not important
  - Totally not important

- **Physician’s personal preference**
  - Totally important
  - Important
  - Neutral
  - Not important
  - Totally not important

- **Method of administration (by mouth vs. injection)**
  - Totally important
  - Important
  - Neutral
  - Not important
  - Totally not important

- **How often it is taken**
  - Totally important
  - Important
  - Neutral
  - Not important
  - Totally not important

- **Out of pocket expenses**
  - Totally important
  - Important
  - Neutral
  - Not important
  - Totally not important

- **Presence of patient support programs**
  - Totally important
  - Important
  - Neutral
  - Not important
  - Totally not important

Please mark all the medications your child has ever used for arthritis:

<table>
<thead>
<tr>
<th>Medications</th>
<th>Current</th>
<th>Prior use</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Herbal and non-vitamin supplements</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ibuprofen, Naproxen, Motrin, Advil, Celebrex, Meloxicam</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nonsteroidal anti-inflammatory drugs (NSAID) /COX 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prednisone, prednisolone, medrol</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systemic oral corticosteroids</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Joint injection</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intra-articular corticosteroids</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMARDS disease modifying antirheumatic drugs and non-biologic immune modulators</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cyclosporin A, Cellcept (Mycophenylate Mofetil)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Imuran (Azathioprine), Methotrexate (Trexall), Plaquenil (Hydroxychloroquine)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sulfasalazine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biologics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anakinra (Kineret), Enbrel (Etanercept), Humira (Adalimumab), Ocrenica (Abatacept), Remicade (Infliximab), Rilonacepf (Arcalyst), Rituximab (Rituxan), Tocilizumab (Actemra)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Has your child experienced any side effects from the medicines used to treat his / her arthritis?

- Yes
- No

If you answer YES, Please mark which group of medicines had been associated with side effects:

<table>
<thead>
<tr>
<th>Medications</th>
<th>Presence of side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prednisone, prednisolone, Medrol</td>
<td></td>
</tr>
</tbody>
</table>
Please mark after the diagnosis of arthritis was made how soon were the following group of medicines started

<table>
<thead>
<tr>
<th>Category</th>
<th>Within 3 months</th>
<th>Within 6 months</th>
<th>Within 12 months</th>
<th>After 1 year</th>
<th>Option never offered</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Joint injection</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intra-articular corticosteroids</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>DMARDS disease modifying antirheumatic drugs and non-biologic immune modulators</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cyclosporin A, Cellcept</strong> (Mycophenylate Mofetil)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Imuran</strong> (Azathioprine), <strong>Methotrexate</strong> (Trexall)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Plaquenil</strong> (Hydroxychloroquine)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sulfasalazine</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Biologics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Anakinra</strong> (Kineret), <strong>Enbrel</strong> (Etanercept), <strong>Humira</strong> (Adalimumab), <strong>Orencia</strong> (Abatacept), <strong>Remicade</strong> (Infliximab), <strong>Rilonacept</strong> (Arcalyst), <strong>Rituximab</strong> (Rituxan), <strong>Tocilizumab</strong> (Actemra)</td>
<td></td>
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<td></td>
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<td><strong>Prednisone, prednisolone, Medrol</strong></td>
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<tr>
<td>Systemic oral corticosteroids</td>
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<td></td>
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<td></td>
<td></td>
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<tr>
<td><strong>Ibuprofen, Naproxen, Motrin, Advil, Celebrex, Meloxicam</strong></td>
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</tr>
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<td>Nonsteroidal anti-inflammatory drugs (NSAID) / COX 2</td>
<td></td>
<td></td>
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<td></td>
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<td>Systemic oral corticosteroids</td>
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</tr>
</tbody>
</table>
In the future, If you have another child diagnosed with arthritis in LESS than or equal than four joints, which would be your preferred treatment?

- No treatment
- Alternative Medicine
- Ibuprofen, Naproxen, Motrin, Advil (Nonsteroidal anti-inflammatory drugs)
- Joint injection
- Methotrexate (DMARDs disease modifying antirheumatic drugs)
- Enbrel, Humira, Kineret, Remicade, Rituxan (biologics)
- Not sure

If you have another child diagnosed with arthritis in MORE than four joints, which would be your preferred treatment?

- No treatment
- Alternative Medicine
- Ibuprofen, Naproxen, Motrin, Advil (Nonsteroidal anti-inflammatory drugs)
- Joint injection
- Methotrexate (DMARDs disease modifying antirheumatic drugs)
- Enbrel, Humira, Kineret, Remicade, Rituxan (biologics)
- Not sure

Thinking about your child’s arthritis doctor, please answer the following questions.

I doubt that my child’s doctor really cares about my child as a person.

- Totally Agree
- Agree
- Neutral
- Disagree
- Totally Disagree

My child’s doctor is usually considerate of my child’s needs and puts them first.

- Totally Agree
- Agree
- Neutral
- Disagree
- Totally Disagree

I trust my child’s doctor so much that I always try to follow his / her advice.

- Totally Agree
- Agree
- Neutral
- Disagree
- Totally Disagree

If my child’s doctor tells me something is so, then it must be true.

- Totally Agree
- Agree
- Neutral
- Disagree
- Totally Disagree

I sometimes distrust my child doctor’s opinion and would like a second one.

- Totally Agree
- Agree
- Neutral
- Disagree
- Totally Disagree

I trust my child doctor’s judgment about my child’s medical care.

- Totally Agree
- Agree
- Neutral
- Disagree
- Totally Disagree

I feel my child’s doctor does not do everything he / she should do for my child’s medical care.

- Totally Agree
- Agree
- Neutral
- Disagree
- Totally Disagree

I trust my child’s doctor to put my child’s medical needs above all other considerations when treating his / her medical problems.

- Totally Agree
- Agree
- Neutral
- Disagree
- Totally Disagree

My child’s doctor is a real expert in taking care of medical problems like childhood arthritis.

- Totally Agree
- Agree
- Neutral
- Disagree
- Totally Disagree

I trust my child’s doctor to tell me if a mistake was done about my child’s treatment.

- Totally Agree
- Agree
- Neutral
- Disagree
- Totally Disagree

I sometimes worry that my child’s doctor may not keep the information we discuss totally private.
PATIENT PREFERENCES IN PEDIATRIC RHEUMATOLOGY

PHYSICIAN QUESTIONNAIRE

Physician diagnosis:
- Oligo JIA
- Poly JIA
- Systemic JIA
- Psoriatic JIA
- Enthesitis Related Arthritis
- Undifferentiated
- Not sure

Please circle the number that best describes, how severe in your opinion is your patient overall disease activity

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not active</td>
<td>Very active</td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Please write the total number of active joints your patient had today on physical exam: ____
## Patient Preferences in Pediatric Rheumatology

### Chart Review

**Current Medications:**

<table>
<thead>
<tr>
<th></th>
<th>Current</th>
<th>Prior Use</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Herbal and non-vitamin supplements</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ibuprofen, Naproxen, Motrin, Advil, Celebrex, Meloxicam</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prednisone, prednisolone, medrol</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systemic oral corticosteroids</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Joint injection</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intra-articular corticosteroids</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMARDS disease modifying antirheumatic drugs and non-biologic immune modulators</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cyclosporin A, CellCept</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Imuran (Azathioprine)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Methotrexate (Trexall)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plaquenil (Hydroxychloroquine)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sulfasalazine</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Biologics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anakinra (Kineret), Enbrel (Elainercept), Humira (Adalimumab), Ocrenica (Abatacept), Remicade (Infliximab), Rilonacect (Arcalyst), Rituximab (Rituaxan)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tocilizumab (Actemra)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Most recent ESR:** ______

**Date:** ______ / ______

**Most recent CRP:** ______

**Date:** ______ / ______

**Most recent PLT count:** ______,000

**Date:** ______ / ______

**Total of active joints at diagnosis:** ______

**Positive ANA**

- Yes
- No
- Unknown

**Positive IgM RF**

- Yes
- No
- Unknown

**Positive HLA B27**

- Yes
- No
- Unknown

**Positive CCP**

- Yes
- No
- Unknown
PATIENT PREFERENCES IN PEDIATRIC RHEUMATOLOGY
PATIENT QUESTIONNAIRE

Please identify which of the following sources you found more helpful regarding information about your arthritis. Please order them from the most helpful (1) to the least helpful (5).

- My physician/nurse
- My friends and family
- Someone else diagnosed with a rheumatologic disease
- Internet / Radio / Television
- Arthritis Foundation / American College of Rheumatology / American Academy of Pediatrics

Please identify which of the following sources you found more helpful regarding information about treatment options for your arthritis. Please order them from the most helpful (1) to the least helpful (5).

- My physician/nurse
- My friends and family
- Someone else diagnosed with a rheumatologic disease
- Internet / Radio / Television
- Arthritis Foundation / American College of Rheumatology / American Academy of Pediatrics

Who makes decisions about your medical care?

- My parents make all the decisions
- My parents make most of the decisions
- I make all the decisions
- I make most of the decisions
- My physician makes all the decisions
- My physician makes most of the decisions
- My parents and I equally contribute to make the decision together

What kind of arthritis have you been diagnosed with?

- Oligo arthritis (arthritis in LESS than 4 joints)
- Poly arthritis (arthritis in MORE than 4 joints)
- Systemic arthritis (arthritis, fever, skin rash, swollen glands and organ involvement)
- Psoriatic arthritis (arthritis and psoriasis)
- Spondyloarthropathy, ankylosing spondylitis, arthritis related to inflammatory bowel disease (Enthesitis Related Arthritis)
- Other kind of arthritis (undifferentiated)
- Not sure

Have you been diagnosed with eye inflammation or uveitis?

- Yes
- No
- Unknown
We are interested in learning how your child’s illness affects his/her ability to function in daily life. Please feel free to add any comments on the back of this page. In the following questions, please tick the one response which best describes his/her usual activities OVER THE PAST WEEK. ONLY NOTE THOSE DIFFICULTIES OR LIMITATIONS WHICH ARE DUE TO ILLNESS. If most children at your child’s age are not expected to do a certain activity, please mark it as ‘not applicable’. For example, if your child has difficulty in doing a certain activity or is unable to do it because he/she is too young, but not because he/she is RESTRICTED BY ILLNESS, please mark it as ‘not applicable’.

**DRESSING & PERSONAL CARE**
Is your child able to:
- Dress, including tying shoelaces and doing buttons?
- Shampoo his/her hair? _ _ _ _ _
- Remove socks? _ _ _ _ _
- Cut fingernails? _ _ _ _ _

**GETTING UP**
Is your child able to:
- Stand up from a low chair or floor? _ _ _ _ _
- Get in and out of bed? _ _ _ _ _

**EATING**
Is your child able to:
- Cut his/her own meat? _ _ _ _ _
- Lift a cup or glass to mouth? _ _ _ _ _
- Open a new cereal box? _ _ _ _ _

**WALKING**
Is your child able to:
- Walk outside on flat ground? _ _ _ _ _
- Climb up five steps? _ _ _ _ _

* Please tick any AIDS or DEVICES that your child usually uses for any of the above activities:
  - Devices used for dressing __
    (button hook, zip pull, long-handled shoe horn, etc.)
  - Walking stick __
  - Walking frame __ Built up pencil or special utensils __
  - Crutches __ Special or built up chair __
  - Wheelchair __ Other ________________________ _

* Please tick any categories for which your child usually needs help from another person BECAUSE OF PAIN OR ILLNESS:
  - Dressing and personal care __ Eating __ Getting up __ Walking __
BIBLIOGRAPHY


