

Spring 2016

Parents of children with arthritis-related diseases: An examination of knowledge of and participation in select support programs and services offered by the Arthritis Foundation

Margo B. Deihl
James Madison University

Follow this and additional works at: <https://commons.lib.jmu.edu/honors201019>

 Part of the [Health Services Research Commons](#), and the [Immune System Diseases Commons](#)

Recommended Citation

Deihl, Margo B., "Parents of children with arthritis-related diseases: An examination of knowledge of and participation in select support programs and services offered by the Arthritis Foundation" (2016). *Senior Honors Projects, 2010-current*. 241.
<https://commons.lib.jmu.edu/honors201019/241>

This Thesis is brought to you for free and open access by the Honors College at JMU Scholarly Commons. It has been accepted for inclusion in Senior Honors Projects, 2010-current by an authorized administrator of JMU Scholarly Commons. For more information, please contact dc_admin@jmu.edu.

Parents of children with arthritis-related diseases: An examination of knowledge of and participation in select support programs and services offered by the Arthritis Foundation

An Honors Program Project Presented to
the Faculty of the Undergraduate
College of Health and Behavioral Studies
James Madison University

by Margo Breanna Deihl

May 2016

Accepted by the faculty of the Department of Health Sciences, James Madison University, in partial fulfillment of the requirements for the Honors Program.

FACULTY COMMITTEE:

HONORS PROGRAM APPROVAL:

Project Advisor: Debra L. Sutton, Ph.D.
Associate Professor, Health Sciences

Bradley R. Newcomer, Ph.D.,
Director, Honors Program

Reader: Audrey J. Burnett, Ph.D.
Associate Professor, Health Sciences

Reader: Timothy M. LaPira, Ph.D.
Associate Professor, Political Science

PUBLIC PRESENTATION

This work is accepted for presentation, in part or in full, at James Madison University on April 15, 2016.

Table of Contents

| | |
|--|----|
| Acknowledgements | 3 |
| Abstract | 4 |
| Introduction | 5 |
| Review of Literature | 7 |
| Methodology | 15 |
| Results | 18 |
| Discussion and Conclusions | 31 |
| References | 37 |
| Appendix A – Consent to Participate in Research | 39 |
| Appendix B – Parent Survey | 41 |
| Appendix C – Additional Data to Benefit the Arthritis Foundation | 45 |

Acknowledgements

First, I would like to express my sincere appreciation to my advisor, Dr. Debra Sutton, for having an incredible vision for this research and encouraging me to follow my passion. Without her advice and direction, this project as well as other opportunities would not have been possible. Her time and extraordinary efforts dedicated to this project are deeply appreciated.

I would also like to thank my committee members, Dr. Timothy LaPira and Dr. Audrey Burnett, for their assistance with data analysis and editing. I am very thankful for their patience and time throughout the duration of the research.

In addition, I would like to thank Health Sciences and Nursing librarian Carolyn Schubert for assisting me in my research and the formatting of my Honors project. This project would not have been possible without her expertise.

I would like to thank Philip Harris for his help in creating a survey format that could be used online. Without his help, I would not have been able to collect data necessary for this project and for the Arthritis Foundation at large.

Lastly, I would like to thank the many parents who willingly gave of their time to complete my survey. I am moved by the way that you shared about your lives and I could not have completed this project without your input.

Abstract

The purpose of this pilot study was to identify the knowledge of and participation in select Arthritis Foundation support programs and services among parents of children with arthritis-related diseases. Parents attending the 2014 Juvenile Arthritis National Conference in Keystone, Colorado completed an online survey that asked about their knowledge of and participation in these programs. The data collected for the study was quantitative and qualitative. Respondents were given the opportunity to add comments to some survey items, and these items were analyzed by grouping them according to common themes. Results indicated that the parents were more knowledgeable about the Juvenile Arthritis National Conference and other fundraisers compared to knowledge of the Advocacy Summit and regional Arthritis Foundation programs. The parents had the highest level of participation in the Juvenile Arthritis National Conference and Walk to Cure Arthritis and the lowest participation in the Advocacy Summit and regional Arthritis Foundation programs. These two programs were the least known among parents. Despite high participation, retention of first-time attendees across all programs was low. This pilot study supports the idea that a study of this nature can be done by the Arthritis Foundation on a larger scale because of the helpful feedback that it can provide to the organization.

Introduction

Significance of the Study

The Arthritis Foundation is the largest nonprofit organization that serves those affected by the over 100 types of arthritis-related diseases (“About Us,” 2014). The national organization offers many support programs and services designed to provide information about arthritis, create networking opportunities, and improve quality of life of those affected by the disease. Parents of children with arthritis-related diseases have many opportunities in which to involve themselves with the Foundation, and these opportunities include fundraising events, local family events sponsored by the local Arthritis Foundation offices, as well as national conferences. It is valuable for the Arthritis Foundation to know the degree to which parents of children with arthritis-related diseases are knowledgeable about current programs offered and if the parents have participated in those programs. The parents of children who have an arthritis-related disease can benefit from valuable resources through programs and outreach efforts provided by an organization such as the Arthritis Foundation, whose mission is to “exist to conquer arthritis,” (“Mission and Vision,” 2015). It is through these programs that parents and families are offered information, provided opportunities to network, and develop support systems.

Therefore, the purpose of this pilot study is to identify the knowledge of and participation in select Arthritis Foundation support programs and services among parents of children with arthritis-related diseases. This study is unique since the national Arthritis Foundation has not conducted a study of this nature.

Research Questions

This study aims to address the following questions:

1. How knowledgeable are parents of children with arthritis-related diseases about select Arthritis Foundation programs and services?
2. How often do parents of children with arthritis-related diseases participate in select Arthritis Foundation programs and services?
3. Are there differences in the demographics among parents of children with arthritis-related diseases and knowledge of select Arthritis Foundation programs and services?
4. Are there differences in the demographics among parents of children with arthritis-related diseases and participation in select Arthritis Foundation programs and services?

Limitations of the Study

Parents of children with arthritis-related diseases supplied the data for the study. The parents who were willing to participate in the survey were already familiar with the Arthritis Foundation since the participants were attendees of the 2014 Juvenile Arthritis National Conference. Parents of children with arthritis-related diseases who have not been informed about Arthritis Foundation programs were not included in the study since this study used a convenience sample to complete the survey.

Review of Literature

Background on Juvenile Arthritis

Juvenile arthritis (JA) is a form of arthritis, among others, that is the focus of many programs within the Arthritis Foundation. According to the National Institute of Arthritis and Musculoskeletal and Skin Diseases, juvenile arthritis is an umbrella term used to describe arthritis in children (NIAMS, 2009). Arthritis is an autoimmune disorder that has an unknown cause. There are many other forms of arthritis that impact juveniles, such as scleroderma, lupus, and polyarticular arthritis, all of which have no cure. Of the approximately 50 million Americans who suffer from an arthritis-related disease, 300,000 are children. Juvenile arthritis is characterized by pain, swelling, and redness at the joints, all of which impact a child's quality of life (NIAMS, 2009). Whether it is through funding, research, advocating for health care policies, or providing health education materials, the Arthritis Foundation is dedicated to creating a partnership with parents to provide empowering programs, information, and services (Arthritis Foundation, 2014).

Arthritis-related diseases in children require timely medical attention as well as parents who are able to assist with the many challenges presented by the disease. In order to effectively treat the arthritis-related disease, a child may be on a rigorous medication and therapy regimen that the parent will need to monitor. A past study on parents of children with a disability noted that, "parents [as informal caregivers] provide long-term care that often requires extraordinary physical, emotional, social, and financial resources," (Murphy, Christian, Caplin, & Young, 2005, p. 180). Murphy et al (2005) mentioned that parents are responsible for the physical care of the child as well as "coordinating their child's multifaceted medical, educational, and

developmental interventions while balancing competing family needs,” (pp. 180-181).

Furthermore, it is important to the wellbeing of the child and the family as a whole to have parents who are informed of programs available to assist in the family’s needs, such as social and educational support programs.

Background on the Parent Population

Parents of children with arthritis-related diseases experience “changes of life routines [that] are necessary in order to provide for the child’s care, which have been found to have significant effects on family functioning,” (Heiman, 2002, p.160). Heiman (2002) also notes that “the difficulties encountered by parents coping with a child with a disability and their familial relationships have been cited as a source of anxiety, overprotection, and rigidity,” (p. 160). According to Heiman (2002), after families discover that a child within the family has a disability, the family will either “adapt flexibility” or have more of an “ineffective reaction” where the family does not become “mobilized into effective action,” (p. 160). The Arthritis Foundation offers programs that specifically target the needs of these families, from information sessions at a national conference to mobilizing communities to become aware of the prevalence of arthritis. However, if parents are not knowledgeable of other programs offered by the Foundation that could provide needed support, the feelings of anxiety and fear have the potential to continue.

Parents of children with arthritis-related diseases require a great amount of support and it is key for the parents to have access to programs and resources that will improve the quality of life of their child. A study by the Association of British Paediatric Nurses agreed that program development is a necessity for children, specifically those with juvenile idiopathic arthritis, and

their parents in order to “jointly manage” the effects of the arthritis-related disease (Stinson, et al., 2012, p. 25). The Arthritis Foundation currently has many programs that aim to meet the needs of children suffering with arthritis-related diseases as well as the needs of their parents. Current programs include the Juvenile Arthritis National Conference, Jingle Bell Run, Walk to Cure Arthritis, JA Camps, regional Arthritis Foundation programs, and the Advocacy Summit to name a few (“Programs and Resources for Better Living,” 2014). Some programs are focused on educating and empowering individuals through presentations and specific experiences, such as the conference and camps. However, the fundraisers, such as the Jingle Bell Run and Arthritis Walk, also build relationships and spread awareness of arthritis by rallying the community around those impacted by the disease. These fundraisers not only provide financial support to groundbreaking research in the field, but also provide networking opportunities to connect with others in the same community who are affected by arthritis. The aforementioned programs are the programs that seem to be most advertised by the Arthritis Foundation in relation to arthritis-related diseases in juveniles, and each of the six program types are listed on the Kids Get Arthritis Too website (2015). This website is a resource specifically formulated for parents of children with arthritis-related diseases as well as pages for children and teens.

Background on the Arthritis Foundation

The Arthritis Foundation is the largest nonprofit organization that serves those affected by the over 100 types of arthritis-related diseases (“About Us,” 2014). The Foundation began in 1948 and today is the “largest nonprofit contributor” to arthritis research in the world. The Foundation has ten regional organizations, which consist of local offices within the region, regional boards, and two national offices in Washington D.C. and Atlanta, GA (“National Leadership Team,” n.d.).

The Arthritis Foundation has investigated the needs of parents in the daily lives of their children, but has not specifically looked at parent knowledge of and participation in specific support programs and services. Parents have many opportunities to become involved with the Foundation, and these opportunities range from community fundraising events to local family events to national conferences. The following six programs provided by the Arthritis Foundation address the educational, social, and fundraising aspects of support programs and services offered to parents of children with arthritis-related diseases.

The Juvenile Arthritis National Conference is an annual nationwide conference that has been hosted by the Arthritis Foundation for thirty-five years with the aim of educating, connecting, informing, and equipping attendees with resources for improved management of arthritis-related diseases. This event is focused on arthritis-related diseases in children, and activities are provided for all family members during the conference. There are typically more than a thousand attendees from across the country participating in this event. The Arthritis Foundation is not the only nonprofit organization that implements a national conference as a means of informing and equipping the attendees. The National Autism Association has created the National Autism Conference where, in a similar fashion, individuals affected by autism are welcome to participate in a time of learning and engaging with others (“National Autism Conference,” 2014). A national conference for families affected by a chronic illness, specifically relating to arthritis-related diseases, is very important for networking, finding support, and gathering breakthrough knowledge on related topics. These conferences allow parents to speak with others who have children affected by similar conditions. It is through relationships formed at these conferences that parents can discover medications that are working for another child

with a similar condition, the doctors who have been most helpful to others, as well as discover other available opportunities and resources.

The Walk to Cure Arthritis is an annual fundraising event hosted by Arthritis Foundation offices and volunteers from across the United States with the goal of raising money for research and increasing community awareness of all arthritis-related diseases. This walk event parallels the efforts by the March of Dimes Foundation, which hosts the March of Dimes walk. Both of these walks raise money for research relating to the respective cause, and the March of Dimes walk has specifically been credited with much of the research that has advanced in the area of newborn screening (Howse, et al., 2006, p. 280). It is through such fundraising events that a community is mobilized to make a difference on behalf of community members who are personally connected to a specific cause.

The Jingle Bell Run, like the Walk to Cure Arthritis, is an event with the goals of fundraising and building community. A similar event to the Jingle Bell Run is presented by the American Lung Association as the Lung Force Run/Walk (“Walk and Run Events,” 2014). While both of these events seem to be a positive force for change for their respective causes, neither have significant publications documenting their “critical role” in funding research.

The Walk to Cure Arthritis and the Jingle Bell Run/Walk are important programs for parents for many reasons. These events are centered on fundraising and rallying a community around a cause that impacts community members. It is through these Arthritis Foundation programs that parents have the opportunity to gain support from friends and family members while telling the story of the challenges their children face. The walk events raise money for research dedicated to finding new treatments, which can impact the quality of life of the parents

as well as their children with arthritis-related diseases. Overall, the parents can spread awareness about the cause as well as raise funds to help not only their own children, but also all children and adults with arthritis-related diseases.

The Arthritis Foundation Advocacy Summit is an annual event where families impacted by arthritis-related diseases may become trained to advocate for legislation that is centered on arthritis-related government funding. This event is a multi-day effort to speak with Congressional staff about the issues relating to arthritis that impact a family on a day-to-day basis. The goal is to achieve changes in legislation to benefit future research and medications for arthritis-related diseases. The attention that has been directed to arthritis at the Congressional level has been in large part due to the efforts of the Arthritis Foundation (White & Waterman, 2012, p. 92). The Arthritis Foundation Advocacy Summit is similar to the Children's Congress sponsored by the Juvenile Diabetes Research Foundation ("JDRF 2015 Children's Congress Application Site Remains Opened," 2014). The Children's Congress event is held every two years and has a similar goal to the Arthritis Foundation Advocacy Summit in that it allows the participants to "leave Children's Congress as empowered advocates to use their voices for the change that will improve their lives and the lives of all people affected by T1D."

The Advocacy Summit is a unique experience for parents of children with arthritis-related diseases. The parents as well as the children have the opportunity to share their personal stories with Congressional representatives who can make a difference on their behalf. The children and parents both offer Congressional representatives a unique perspective of what it means to live with an arthritis-related disease every day. These events can also create meaningful networking opportunities between families as well as between family and Congressman. These relationships are ways in which parents and children can increase

awareness for the cause as well as ask leaders for their help in improving the lives of those with arthritis-related diseases.

Lastly, the Arthritis Foundation JA Camps are annual camps held across the United States specifically for juveniles who have arthritis-related diseases. On the website of the American College of Rheumatology, summer camps are mentioned as a means for those with juvenile arthritis and their respective families to connect and find support (“Arthritis in Children,” 2013). This camp experience is much like Camp Ronald McDonald for Good Times, sponsored by the Ronald McDonald House Charities. This camp and the JA camps provide an environment that is “fun” and “positive” (“Camp Ronald McDonald for Good Times,” 2014). The JA camps provide ways for children suffering from arthritis-related diseases to build relationships and connect with other families sharing the same battle. These camps provide opportunities for not only the parents to network with other parents, but also for the children with arthritis-related diseases to form a network of support and friendship. At some camps, parents and families may also participate (“Juvenile Arthritis Camp,” n.d.). These relationships with other children are important for the health of the child and are ways to help the children know that they are not alone in the struggles associated with living with an arthritis-related disease. The family as a whole can benefit from these relationships as it has the potential to create an uplifting experience for children with arthritis-related diseases.

Many Arthritis Foundation programs are similar to those provided by other health-related nonprofit organizations. A potential reason for a lack of published articles on the Arthritis Foundation programs may be due to a lack of research conducted on the programs and the outcomes of participation. Also, a study of this nature has not been done in order to analyze the

knowledge of and participation in support programs by parents of children with arthritis-related diseases.

Methodology

This section addresses the purpose for the site that was selected to obtain participants, the research design, and the method for collecting the data in order to answer the four research questions.

Site Selection

The participants for the study were parents of children with arthritis-related diseases who were attending the 2014 Juvenile Arthritis National Conference in Keystone, Colorado. This site was chosen since the attendees were parents who could provide insight about their participation in and knowledge of the six Arthritis Foundation support programs and services studied in this research. The parents in attendance were from various parts of the United States and have been directly impacted by the Arthritis Foundation to varying levels, which are reflected in this study. The diversity in location of these parents was beneficial in studying the participation in and knowledge of programs at different regions of the country. This conference was attended by over 1500 people, which made it feasible to gather participants for the study.

Research Design

The JMU Institutional Review Board approved this study (protocol #15-0415) in the spring of 2015. After IRB approval of the study, an email was sent to voluntary participants that included a link to an online survey. Approximately 70 parents of a child (or children) with arthritis-related diseases received an email to participate. Participants were selected based on their attendance at the July 2014 Juvenile Arthritis National Conference in Keystone, Colorado. The Arthritis Foundation provided access to the email addresses of parents in attendance that voluntarily expressed interest in the study. The survey was distributed via an email link to one

parent per household at the beginning of March 2015 and the parents had approximately one week to complete the survey. Each survey participant was provided with a consent form prior to proceeding with the survey. The participants also received a follow-up reminder email in order to encourage more responses. The participants were not compensated for their time.

Instrumentation

The instrument used for this study was an anonymous online pilot survey developed through research software. A portion of the survey included questions regarding demographic information of the parents. This demographic information included the following: parent relationship to the child, age of the parent, number of children in the family, ethnicity, region of residence, highest level of degree completed, form of arthritis-related disease of each child in the family, and helpfulness of a select group of resources. This information was included so that the Arthritis Foundation could become familiar with the parent population of the pilot study and, knowing this information, evaluate the parent participation in and knowledge of the selected programs.

The survey also documented the parents' knowledge of and participation in select Arthritis Foundation programs and services. The parents' knowledge was represented by a Likert scale consisting of options ranging from "no knowledge" to "very knowledgeable." The parents were able to pick one response representing their knowledge for each individual program. The parents' participation was represented by a numeric scale, consisting of options ranging from "0 times" to "10+ times." Parents were able to pick one response representing their level of participation for each individual program. The Likert scale used for the knowledge

questions allowed for parents to provide a simple rating that combined varying levels of knowledge into one variable.

At the end of the survey, two free-response questions were included. These questions asked how each family had been impacted by arthritis-related diseases and if the Arthritis Foundation could be providing further support that had not been previously available. This allowed for the parents to supply information about personal experiences with arthritis-related diseases within the family. These questions also provided feedback for the Arthritis Foundation in regards to other ways in which the organization could assist parents.

Data Analysis

After the data collection was complete, the data was placed into tables corresponding to region and survey question. The data was also placed into tables that displayed the mean responses from the parents. These tables were used to analyze the knowledge of and participation in the programs being studied. The data from knowledge and participation for each region was also placed in tables where the values could be compared between regions.

Results

For this pilot study, frequencies and descriptive statistics were used to analyze research questions #1 and #2. A cross-tab comparison was used to evaluate possible correlations between knowledge and demographic variables (question #3) and participation and demographic variables (question #4). Aggregate-level data was reported for the quantitative data, and a thematic analysis was performed on free-response questions.

The survey was completed by 35 parents, 91% of which were mothers, 6% fathers, and 3% other (Table 1). Most of the respondents fell into the age range of 35-44 years old (Table 2). The average number of children in the family of the respondents was between two and three children, with 37% of respondents answering for both age options. The ethnicity of the respondents was 82% white, 15% Hispanic or Latino, and 3% black (Table 3). The survey respondents resided in all Arthritis Foundation regions in the United States except the Northeast Region (Table 4). The three regions with the most respondents were the Pacific (24%), Heartland (21%), and Great West regions (12%). The two most common levels of education among the respondents were “some college credit, no degree” (31%) and “bachelor’s degree” (29%).

Table 1. Parent distribution of respondents.

| Relationship | Respondents | % of Sample |
|---------------|-------------|-------------|
| Mother | 31 | 91% |
| Father | 2 | 6% |
| Other | 1 | 3% |

Table 2. Age distribution of respondents.

| Age Bracket (years old) | Respondents | % of Sample |
|-------------------------|-------------|-------------|
| 25-34 | 4 | 12% |
| 35-44 | 16 | 47% |
| 45-54 | 9 | 26% |
| 55-64 | 5 | 15% |
| 64+ | 0 | 0% |
| Total | 34 | 100% |

Table 3. Ethnic identification of respondents.

| Ethnic Identification | Respondents | % of Sample |
|--|-------------|-------------|
| American Indian or Alaskan Native | 0 | 0% |
| Asian or Pacific Islander | 0 | 0% |
| Black or African American (not Hispanic) | 1 | 3% |
| Hispanic or Latino | 5 | 15% |
| White or Caucasian (not Hispanic) | 27 | 82% |
| Other | 0 | 0% |
| Total | 33 | 100% |

Table 4. Number of respondents by region.

| Region | Respondents | % of Sample |
|-----------------|-------------|-------------|
| Florida Chapter | 3 | 9% |
| Great Lakes | 2 | 6% |
| Great West | 4 | 12% |
| Heartland | 7 | 21% |
| Mid-Atlantic | 2 | 6% |
| New England | 1 | 3% |
| Northeast | 0 | 0% |
| Pacific | 8 | 24% |
| South Central | 3 | 9% |
| Southeast | 2 | 6% |
| Upper Midwest | 2 | 6% |
| Total | 34 | 100% |

When asked about the arthritis-related disease of the children of the respondents, the two main responses were “Juvenile Idiopathic Arthritis” (30 responses) and “Fibromyalgia” (5 responses), seen in Table 5.

Table 5. Form of arthritis per child in the family of the respondent.

| <i>Form of Arthritis Per Child</i> | | | | | | | |
|--|----------------|----------------|----------------|----------------|----------------|------------------------|-------------|
| Type of Arthritis | Child 1 | Child 2 | Child 3 | Child 4 | Child 5 | Total Responses | Mean |
| Juvenile Idiopathic Arthritis | 23 | 1 | 4 | 4 | 0 | 30 | 1.5 |
| Juvenile Dermatomyositis | 1 | 1 | 0 | 0 | 0 | 2 | 1.5 |
| Juvenile Lupus | 1 | 0 | 0 | 1 | 0 | 2 | 2.5 |
| Juvenile Scleroderma | 1 | 0 | 0 | 0 | 0 | 1 | 1.0 |
| Kawasaki Disease | 1 | 0 | 0 | 0 | 1 | 2 | 3.0 |
| Mixed Connective Tissue Disease | 1 | 1 | 0 | 0 | 0 | 2 | 1.5 |
| Fibromyalgia | 2 | 2 | 1 | 0 | 0 | 5 | 1.8 |

The respondents were also asked about the current resources that had been most helpful to them in relation to the arthritis-related diseases of their children. (Table 6). The most helpful resource was the “Kids Get Arthritis Too” Website, followed by physicians. The resources that were used the least by parents were counselors and nurses at the children’s schools.

Table 6. Assessment of resources used by respondents ranked by helpfulness; from parent perspective.

| Helpfulness of Current Resources | | | | | | |
|---|----------------------|--------------------|-------------------------|---------------------|------------------------|-------------|
| Question | Have Not Used | Not Helpful | Somewhat Helpful | Very Helpful | Total Responses | Mean |
| Arthritis Foundation Website | 2 | 2 | 11 | 17 | 32 | 3.3 |
| "Kids Get Arthritis Too Website | 2 | 0 | 8 | 22 | 32 | 3.6 |
| Physican(s) | 2 | 0 | 11 | 19 | 32 | 3.5 |
| Nurse at your child's school | 11 | 14 | 5 | 2 | 32 | 1.9 |
| Counselor at your child's school | 13 | 14 | 5 | 0 | 32 | 1.8 |
| Teacher at your child's school | 8 | 15 | 6 | 3 | 32 | 2.1 |

The parents were then asked about their knowledge of specific Arthritis Foundation support programs and services. The percentage of each knowledge category (Very Knowledgeable to No Knowledge) chosen by parents for the respective programs is seen in Table 7. The percentage of each participation category (0 Times to 10+ Times) chosen by parents for the respective programs is seen in Table 8. The eleven regional categories were recoded into four numbers (1-4) (Table 9) and the four knowledge categories were recoded into four numbers (1-4) (Table 10) for analysis purposes. There were no statistically significant differences between parent demographic variables and knowledge of and participation in select Arthritis Foundation programs and services (all $p > 0.05$). The cross-tabulation of regional location and parent participation in the support programs and services had a p-value of 0.551 (Table 25). The cross-tabulation of regional location and parent knowledge of the support programs and services had a p-value of 0.248 (Table 17).

Table 7. A summary of the mean knowledge of six Arthritis Foundation programs and services expressed as a percentage that includes all respondents.

| Support Program | Very Knowledgeable | Knowledgeable | Somewhat Knowledgeable | No Knowledge | Respondents |
|---|---------------------------|----------------------|-------------------------------|---------------------|--------------------|
| Juvenile Arthritis National Conference | 77.1% | 17.1% | 5.7% | 0% | 34 |
| Walk to Cure Arthritis | 51.4% | 28.6% | 20.0% | 0% | 34 |
| Jingle Bell Run | 42.9% | 23.5% | 32.4% | 0% | 34 |
| Regional Arthritis Foundation Programs | 38.2% | 14.7% | 35.3% | 11.8% | 34 |
| Advocacy Summit | 20.6% | 20.6% | 44.1% | 14.7% | 34 |
| Juvenile Arthritis Camps | 41.2% | 23.5% | 32.4% | 2.9% | 34 |

Table 8. A summary of the mean participation of six Arthritis Foundation programs and services expressed as a percentage that includes all respondents.

| Support Program | 0 Times | 1-3 Times | 4-6 Times | 7-9 Times | 10+ Times | Respondents |
|---|----------------|------------------|------------------|------------------|------------------|--------------------|
| Juvenile Arthritis National Conference | 0% | 85.3% | 8.8% | 5.9% | 0% | 34 |
| Walk to Cure Arthritis | 26.5% | 50.0% | 11.8% | 11.8% | 0% | 34 |
| Jingle Bell Run | 54.5% | 42.4% | 3.0% | 0% | 0% | 33 |
| Regional Arthritis Foundation Programs | 54.5% | 15.2% | 9.0% | 0% | 21.2% | 33 |
| Advocacy Summit | 93.8% | 3.1% | 3.1% | 0% | 0% | 32 |
| Juvenile Arthritis Camps | 41.2% | 50.0% | 5.9% | 0% | 2.9% | 34 |

Table 9. Regions recoded from 11 subdivisions to 4 numbers.

| Recoded Region Number | Region Grouping | Regions Included |
|------------------------------|------------------------|--|
| 1 | Northeast | New England, Northeast |
| 2 | Southeast | Florida, Mid-Atlantic, Southeast |
| 3 | Midwest | Great Lakes, Heartland, South Central, Upper Midwest |
| 4 | Great West | Great West, Pacific |

Table 10. Knowledge levels recoded from 4 descriptive subdivisions to 4 numbers.

| Knowledge Level Recoding | Knowledge on Survey |
|---------------------------------|----------------------------|
| 1 | No Knowledge |
| 2 | Somewhat Knowledgeable |
| 3 | Knowledgeable |
| 4 | Very Knowledgeable |

The knowledge and participation levels in the six Arthritis Foundation programs and services are divided by region in Tables 11-16 for knowledge and Tables 19-24 for participation. Tables 18 and 26 show the mean knowledge and participation levels chosen by the four regions.

Table 11. Knowledge level chosen by parents from each region regarding the Juvenile Arthritis National Conference.

| Knowledge Level: <i>Juvenile Arthritis National Conference</i> | | | | | |
|---|----------|----------|----------|----------|--------------|
| Recoded Region | 1 | 2 | 3 | 4 | Total |
| 1 | 0 | 0 | 0 | 1 | 1 |
| 2 | 0 | 0 | 2 | 6 | 8 |
| 3 | 0 | 2 | 2 | 10 | 14 |
| 4 | 0 | 0 | 2 | 10 | 12 |
| Total | 0 | 2 | 6 | 27 | 35 |

Table 12. Knowledge level chosen by parents from each region regarding the Walk to Cure Arthritis.

| Knowledge Level: <i>Walk to Cure Arthritis</i> | | | | | |
|---|----------|----------|----------|----------|--------------|
| Recoded Region | 1 | 2 | 3 | 4 | Total |
| 1 | 0 | 0 | 0 | 1 | 1 |
| 2 | 0 | 1 | 4 | 3 | 8 |
| 3 | 0 | 2 | 3 | 9 | 14 |
| 4 | 0 | 3 | 4 | 5 | 12 |
| Total | 0 | 6 | 11 | 18 | 35 |

Table 13. Knowledge level chosen by parents from each region regarding the Jingle Bell Run.

| Knowledge Level: <i>Jingle Bell Run</i> | | | | | |
|--|----------|----------|----------|----------|--------------|
| Recoded Region | 1 | 2 | 3 | 4 | Total |
| 1 | 0 | 0 | 0 | 1 | 1 |
| 2 | 0 | 3 | 2 | 2 | 7 |
| 3 | 0 | 2 | 4 | 8 | 14 |
| 4 | 0 | 6 | 2 | 4 | 12 |
| Total | 0 | 11 | 8 | 15 | 34 |

Table 14. Knowledge level chosen by parents from each region regarding regional programs.

| Knowledge Level: <i>Regional Programs</i> | | | | | |
|--|----------|----------|----------|----------|--------------|
| Recoded Region | 1 | 2 | 3 | 4 | Total |
| 1 | 0 | 0 | 0 | 1 | 1 |
| 2 | 0 | 4 | 0 | 3 | 7 |
| 3 | 2 | 3 | 5 | 4 | 14 |
| 4 | 2 | 5 | 0 | 5 | 12 |
| Total | 4 | 12 | 5 | 13 | 34 |

Table 15. Knowledge level chosen by parents from each region regarding the Advocacy Summit.

| Knowledge Level: <i>Advocacy Summit</i> | | | | | |
|--|----------|----------|----------|----------|--------------|
| Recoded Region | 1 | 2 | 3 | 4 | Total |
| 1 | 0 | 0 | 0 | 1 | 1 |
| 2 | 0 | 4 | 2 | 1 | 7 |
| 3 | 3 | 3 | 5 | 3 | 14 |
| 4 | 2 | 8 | 0 | 2 | 12 |
| Total | 5 | 15 | 7 | 7 | 34 |

Table 16. Knowledge level chosen by parents from each region regarding JA Camps.

| Knowledge Level: <i>JA Camps</i> | | | | | |
|---|----------|----------|----------|----------|--------------|
| Recoded Region | 1 | 2 | 3 | 4 | Total |
| 1 | 0 | 0 | 0 | 1 | 1 |
| 2 | 1 | 2 | 3 | 1 | 7 |
| 3 | 0 | 3 | 3 | 8 | 14 |
| 4 | 0 | 6 | 2 | 4 | 12 |
| Total | 1 | 11 | 8 | 14 | 34 |

Table 17. Key statistics for knowledge of selected programs over 4 regions.

| Statistics Overview: <i>Knowledge</i> | | | | |
|--|---------------------------|----------------|----------------|----------------|
| Mean | Standard Deviation | Minimum | Maximum | p-value |
| 3.1 | 0.6 | 1.7 | 4 | 0.248 |

Table 18. Mean knowledge levels for each region.

| Means by Region: Knowledge | | | |
|-----------------------------------|-------------|---------------------------|------------------|
| Recorded Region | Mean | Standard Deviation | Frequency |
| 1 | 4 | 0 | 1 |
| 2 | 3.0 | 0.4 | 8 |
| 3 | 3.2 | 0.7 | 14 |
| 4 | 2.9 | 0.6 | 12 |
| Total | 3.1 | 0.6 | 35 |

Table 19. Participation level chosen by parents from each region regarding the Juvenile Arthritis National Conference.

| Participation Level: Juvenile Arthritis National Conference | | | | | |
|--|----------------|------------------|------------------|--------------------|--------------|
| Recorded Region | 0 Times | 1-3 Times | 4-7 Times | 8-10+ Times | Total |
| 1 | 0 | 0 | 0 | 1 | 1 |
| 2 | 0 | 8 | 0 | 0 | 8 |
| 3 | 0 | 13 | 0 | 1 | 14 |
| 4 | 0 | 9 | 3 | 0 | 12 |
| Total | 0 | 30 | 3 | 2 | 35 |

Table 20. Participation level chosen by parents from each region regarding the Walk to Cure Arthritis.

| Participation Level: Walk to Cure Arthritis | | | | | |
|--|----------------|------------------|------------------|--------------------|--------------|
| Recorded Region | 0 Times | 1-3 Times | 4-7 Times | 8-10+ Times | Total |
| 1 | 0 | 0 | 0 | 1 | 1 |
| 2 | 2 | 5 | 2 | 0 | 9 |
| 3 | 5 | 5 | 1 | 2 | 13 |
| 4 | 2 | 8 | 2 | 0 | 12 |
| Total | 9 | 18 | 5 | 3 | 35 |

Table 21. Participation level chosen by parents from each region regarding the Jingle Bell Run.

| Participation Level: <i>Jingle Bell Run</i> | | | | | |
|--|----------------|------------------|------------------|--------------------|--------------|
| Recoded Region | 0 Times | 1-3 Times | 4-7 Times | 8-10+ Times | Total |
| 1 | 0 | 1 | 0 | 0 | 1 |
| 2 | 5 | 3 | 0 | 0 | 8 |
| 3 | 5 | 8 | 0 | 0 | 13 |
| 4 | 9 | 2 | 1 | 0 | 12 |
| Total | 19 | 14 | 1 | 0 | 34 |

Table 22. Participation level chosen by parents from each region regarding regional programs.

| Participation Level: <i>Regional Programs</i> | | | | | |
|--|----------------|------------------|------------------|--------------------|--------------|
| Recoded Region | 0 Times | 1-3 Times | 4-7 Times | 8-10+ Times | Total |
| 1 | 0 | 0 | 0 | 1 | 1 |
| 2 | 5 | 0 | 1 | 2 | 8 |
| 3 | 9 | 2 | 1 | 1 | 13 |
| 4 | 5 | 3 | 1 | 3 | 12 |
| Total | 19 | 5 | 3 | 7 | 34 |

Table 23. Participation level chosen by parents from each region regarding the Advocacy Summit

| Participation Level: <i>Advocacy Summit</i> | | | | | |
|--|----------------|------------------|------------------|--------------------|--------------|
| Recoded Region | 0 Times | 1-3 Times | 4-7 Times | 8-10+ Times | Total |
| 1 | 1 | 0 | 0 | 0 | 1 |
| 2 | 7 | 1 | 0 | 0 | 8 |
| 3 | 12 | 1 | 0 | 0 | 13 |
| 4 | 11 | 0 | 0 | 0 | 11 |
| Total | 31 | 2 | 0 | 0 | 33 |

Table 24. Participation level chosen by parents from each region regarding JA Camps.

| Participation Level: <i>JA Camps</i> | | | | | |
|---|----------------|------------------|------------------|--------------------|--------------|
| Recorded Region | 0 Times | 1-3 Times | 4-7 Times | 8-10+ Times | Total |
| 1 | 0 | 1 | 0 | 0 | 1 |
| 2 | 4 | 3 | 1 | 0 | 8 |
| 3 | 5 | 9 | 0 | 0 | 14 |
| 4 | 6 | 4 | 1 | 1 | 12 |
| Total | 15 | 17 | 2 | 1 | 35 |

Table 25. Key statistics for participation in selected programs over 4 regions.

| Statistics Overview: <i>Participation</i> | | | | |
|--|---------------------------|----------------|----------------|----------------|
| Mean | Standard Deviation | Minimum | Maximum | p-value |
| 1.6 | 1.5 | 0.2 | 6.2 | 0.551 |

Table 26. Mean participation levels for each region.

| Means by Region: <i>Participation</i> | | | |
|--|-------------|---------------------------|------------------|
| Recorded Region | Mean | Standard Deviation | Frequency |
| 1 | 5.5 | 0 | 1 |
| 2 | 1.4 | 1.1 | 8 |
| 3 | 1.4 | 1.0 | 14 |
| 4 | 1.8 | 1.9 | 12 |
| Total | 1.6 | 1.5 | 35 |

The respondents were given two free response questions regarding the impact of arthritis on their personal lives as well as how the Arthritis Foundation could provide more support to the parent population. The themes were analyzed and summarized in Tables 27 and 28.

Table 27. Thematic analysis of the impact of arthritis; from the parent perspective.

| Impact of Arthritis | |
|----------------------------|--|
| Common Themes: | <i>Mentally</i> ; thinking of the future impact of medicines and disease, managing schedules |
| | <i>Emotionally</i> ; struggle of giving the medicines, seeing child in pain |
| | <i>Financially</i> ; parents dealing with endless bills |
| | <i>Physically</i> ; parents suffering from stress |
| | <i>Relationally</i> ; marriages challenged, less time with family |
| | <i>Socially</i> ; parents have less interaction with friends, hard to help others understand |
| | <i>Education Interrupted</i> ; move to homeschooling, lack of school understanding |
| | <i>Professionally</i> ; quitting jobs or missing work for caregiving |
| | <i>Siblings</i> : non-arthritis siblings are neglected |
| | <i>Mobility Challenged</i> ; modify vacations |
| | <i>Proximity</i> ; need to live close to medical facilities |
| | <i>Attitude</i> ; choosing positivity and living day by day |
| | <i>Time</i> ; appointments, talking with insurance companies and schools, giving medicine |

Table 28. Thematic analysis of needed support from the Arthritis Foundation aside from current efforts; from the parent perspective.

| What the AF Could Do to Support Parents | |
|--|---|
| Common Themes: | <i>Inform</i> ; make parents aware of JA news and opportunities |
| | <i>Motivate and Inspire</i> ; keep parents positive and uplifted |
| | <i>Proximity</i> ; have events closer to home |
| | <i>Presence in Doctor's Offices</i> ; resources readily available at time of diagnosis |
| | <i>Knowledgeable Doctors</i> ; rheumatologists should know about AF resources |
| | <i>School Resources</i> ; information on JA to give to schools |
| | <i>Age-Specific Forums</i> ; provide opportunities for all ages to engage with others |
| | <i>Navigation Help</i> ; assist parents in navigating insurance, schools, and finding local support |
| | <i>Local Support</i> ; facilitate local support groups in the community |
| | <i>Diverse Support</i> ; ensure that all types of arthritis are effectively reached |

Lastly, the parents were given a free response question asking how the Arthritis Foundation already supports the parent population and in what ways. The themes from the responses were analyzed and summarized in Table 29.

Table 29. Thematic analysis of current Arthritis Foundation areas of support; from the parent perspective.

| How the AF Already Supports Parents | |
|--|--|
| Common Themes: | <i>Local Chapters</i> ; presence in the community |
| | <i>Emails</i> ; email updates sent out |
| | <i>Current Support Programs</i> ; JA Conference and other programs are effective |
| | <i>Presence</i> ; continue to be available when parents need to call for information and support |
| | <i>Continue Current Efforts</i> ; genuine caring, research efforts, finding ways to make life easier |

Discussion and Conclusion

Discussion

Parents of children with arthritis-related diseases are affected in many ways by the diagnoses of their children. Arthritis is a complicated condition that takes on many forms and not only affects the individual diagnosed with arthritis, but the parents and other family members also coping with the condition. The Arthritis Foundation offers many support programs and services that assist parents and families in managing life with the many forms of the disease. The parents of children with an arthritis-related disease that participated in this pilot study identified their knowledge of and participation in six of these Arthritis Foundation support programs.

Parents were most knowledgeable about the Juvenile Arthritis National Conference (Table 7). This result was expected since the list of study participants was obtained at the conference. The second program that parents were most knowledgeable about was the Walk to Cure Arthritis, which is the most popular Arthritis Foundation fundraising event and resulted in 100% of parents having some level of knowledge about the Walk. The third program that parents had the most knowledge of was the Jingle Bell Run, another fundraising event. Again, 100% of the parents in the study had some level of knowledge about the Jingle Bell Run. The three programs and services that parents were the least knowledgeable about were regional Arthritis Foundation programs (11.8% of parents with no knowledge), Advocacy Summit (14.7% of parents with no knowledge), and JA Camps (2.9% of parents with no knowledge), with the Advocacy Summit having the largest number of parents without knowledge of the program

(Table 7). This result could be due to more advertising efforts being dedicated to the fundraisers in contrast to the support programs, such as the Advocacy Summit.

Parents in the study had a high rate of participation in the Juvenile Arthritis Conference, with 85.3% participating 1-3 times, 8.8% participating 4-6 times, and 5.9% participating 7-9 times (Table 8). However, this program did not have a high retention rate in comparison to the regional Arthritis Foundation programs, with 15.2% of parents participating 1-3 times, 9.1% 4-6 times, and 21.2% participating 10+ times. Although the regional programs had the highest overall retention rate, 54.5% of parents had never participated in regional programs. This could be due to a lack of knowledge, considering that only 38.2% of parents in the study were “very knowledgeable” about the regional programs. The Advocacy Summit was the program with the lowest amount of participation, with 93.8% of the parents having never attended the program. However, only 14.7% of the parents had no knowledge of the program. This could be attributed to the distance parents would be expected to travel to Washington D.C., the price of attending the program, or potentially a lack of interest in the legislative work of the Arthritis Foundation. Approximately half of the parents surveyed had not participated in either a JA Camp or a Jingle Bell Run. Overall, parents had participated more in the Walk and Juvenile Arthritis National Conference and had participated the least in the Advocacy Summit. However, this result did not appear to be due to a lack of knowledge of the programs.

When the participation and knowledge levels were cross-tabulated with the four regions of the United States (Tables 19-24 and 11-16), there was no significant connection between a region and higher or lower participation or knowledge of a program. This lack of significance (Tables 17 and 25), shown by p-values greater than 0.05, was due to a small sample size of 35 parents. However, the results of this pilot study indicate how a study of this nature may be

conducted on a larger scale for the Arthritis Foundation. The average knowledge across the four regions for all programs was 3.1 (Table 18) and average participation was 1.6 (Table 26).

The parents highlighted some main themes in regards to how arthritis affects them (Table 27), including mentally, physically, emotionally, financially, socially, relationally, professionally, and others. A few parents mentioned the need to remove their child from school in order to homeschool due to arthritis. Others mentioned how their child's diagnosis had caused marital stress and one parent had to quit his/her job in order to focus on the wellness of his/her child. Another parent noted that he/she had to forego advancing his/her career in order to care for the child with an arthritis-related disease. Parents commented about how the children in their families without a form of arthritis were neglected since the child with arthritis received time and attention due to illness.

According to the parents surveyed, the main way the Arthritis Foundation could offer more support to them would be through a heightened presence in doctor's offices. Arthritis Foundation information could be located in the offices of doctors who would be diagnosing arthritis (rheumatologists) so that the support would be readily available upon diagnosis. Some parents wrote that it took a while after the diagnosis before the family even heard about the Juvenile Arthritis National Conferences. Overall, this parent population was mainly concerned with awareness of Arthritis Foundation programs and services within medical offices and the availability of those resources when being diagnosed. In addition, parents commented that the Arthritis Foundation should continue its current efforts, including the Juvenile Arthritis National Conferences and email updates to parents. The parents were appreciative of the work of local Arthritis Foundation chapters within their respective regions. They seemed to appreciate current Arthritis Foundation efforts, but also recognized the need for faster connections between the time

of diagnosis and being informed of the Arthritis Foundation and its support programs and services.

Conclusion

Overall, there was no statistically significant connection between region of the United States and participation in and knowledge of Arthritis Foundation support programs and services. However, if the sample of parents had been larger, there would have been the possibility for statistically significant results. This information is useful for the Arthritis Foundation since it provides feedback on current programs as well as parent engagement in different regions of the U.S. The information from the survey provides an overview of the ways that parents feel most affected by arthritis as well as their needs aside from what the Arthritis Foundation currently offers.

The next step would be to make the necessary adjustments to the survey and research design and launch the survey on a larger scale with more parent participants in order to gather more information on knowledge and participation. The parents in this study were most knowledgeable about the Juvenile Arthritis National Conference and least knowledgeable about the Advocacy Summit and regional programs. The parents also participated the most in the Juvenile Arthritis National Conference and Walk to Cure Arthritis, while the Advocacy Summit and regional programs had the lowest amount of participation. Although the programs chosen for the analysis of participation and knowledge were the more well-known programs and services offered by the Arthritis Foundation, there are many other programs that could be included in a larger study. Also, with a larger study, the Arthritis Foundation could ask more detailed questions about the parents' experiences with the programs and services. These

questions could ask about information gained from the programs and likelihood of participating in the program again, which could help with increasing retention rates.

The larger study could focus on other populations engaged with the Arthritis Foundation, such as young adults and older generations. These two populations would be able to provide unique feedback about the support needed from the Arthritis Foundation when it comes to the different needs of the young and old. Along with adding different age groups to the larger study, the survey could ask more detailed demographic questions in order to focus outreach efforts in the local communities before making changes on a national scale. If local Arthritis Foundation offices within each region have access to constituent feedback on needs for programs and services, then engagement with the organization could first increase in the area closest to the constituents. After focusing on the community and regional level first, the Arthritis Foundation will be able to see that regional programs are positive primary connections to the organization and the first way for individuals to become more involved with the Foundation as a whole. When implementing need-based changes on the local level, the Arthritis Foundation will begin to see program retention rates increase because of a connection founded in one's own community.

The large group of participants should include young adults, parents, and older adults with varying degrees of knowledge of and participation in Arthritis Foundation programs and services. The Arthritis Foundation could use a volunteer or advocate database as a participant pool, which would provide the contact information of people of all ages and all involvement levels. It is through this random sample that participation in and knowledge of programs would be more diverse.

The pilot study gives the Arthritis Foundation confidence knowing that the organization has constituents who are willing to participate in studies regarding its programs and services. Based on involvement with the current study, the Arthritis Foundation will be able to easily gain interest among advocates and volunteers for the new study since the study will ultimately benefit those who participate. The Arthritis Foundation has created many beneficial programs and services that are addressing different needs of the parents of children with arthritis-related diseases. However, a larger study could provide beneficial feedback from other age groups and engagement levels. It is through this larger study that the Arthritis Foundation will be able to engage individuals beginning at the community and regional level and increase retention and involvement in their programs.

References

- About Us. (2014, January 1). Retrieved April 17, 2014.
- Abramson, L. (2013, May 1). Arthritis in Children. Retrieved November 21, 2014.
- Arthritis in Children. (2013). Retrieved November 21, 2014.
- Camp Ronald McDonald for Good Times. (2014, January 1). Retrieved November 21, 2014.
- Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities, 14*(2), 159-171.
- Howse, J. L., Weiss, M., & Green, N. S. (2006, December 20). Critical role of the march of dimes in the expansion of newborn screening. *Mental Retardation and Developmental Disabilities Research Reviews, 12*(4), 280-287. doi:10.1002/mrdd.20129
- “JDRF 2015 Children’s Congress application site remains open.” Juvenile Diabetes Research Foundation, 2014. Web. 21 November 2014.
- "Juvenile Arthritis." *Disease Center*. Arthritis Foundation, n.d. Web. Retrieved May 2014.
- “Juvenile Arthritis Camp.” Arthritis Foundation, n.d. Web. Retrieved January 9, 2016.
- Kids Get Arthritis Too. (2015, January 1). Retrieved March 22, 2015.
- Murphy, N.A., Christian, B., Caplin, D.A., Young, P.C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child: Care, Health, and Development, 33*(2), 180-187. doi: 10.1111/j.1365-2214.2006.00644.x
- “National Autism Conference.” National Autism Association, 2014. Web. 21 November 2014.

“National Leadership Team.” Arthritis Foundation, n.d. Web. Retrieved January 13, 2016.

"Programs and Resources for Better Living." Arthritis Foundation, 2014. Web. 26 May 2014.

Stinson, J. N., Feldman, B. M., Duffy, C. M., Huber, A. M., Tucker, L. B., McGrath, P. J., Vijenthira, A. (2012). Jointly managing arthritis: Information needs of children with juvenile idiopathic arthritis (JIA) and their parents. *Journal of Child Health Care: For Professionals Working with Children in the Hospital and Community*, 16(2), 124-140. doi:10.1177/1367493511430679

“Walk and Run Events.” American Lung Association, 2014. Web. 21 November 2014.

“What is Juvenile Arthritis? Fast Facts: An Easy-to-Read Series of Publications for the Public.”

National Institute of Arthritis and Musculoskeletal and Skin Diseases, May 2009. Web. 7 November 2014.

White, Patience H., Waterman, Mary. (2012). Making osteoporosis a public health priority: several initiatives are placing this chronic illness on the national agenda. *Orthopaedic Nursing*, 31(2), 92-97. doi: 10.1097/NOR.0b013e31824fcd8f

Appendix A

Consent to Participate in Research

Identification of Investigator & Purpose of Study

You are being asked to participate in a research study conducted by Margo Deihl, a student from James Madison University. The purpose of this study is to identify the knowledge of and participation in support programs and services offered by the Arthritis Foundation to one constituent group: parental caregivers of children with arthritis-related diseases.

Research Procedures

Should you decide to participate in this research study, you will be asked to sign this consent form once all of your questions regarding the study have been answered to your satisfaction. This study consists of a survey administered online. The survey includes questions requesting information on your knowledge of, participation in, and change in quality of life (if any) due to the Arthritis Foundation's support programs and services. The survey contains questions with a rating scale, single-choice, and open-ended questions.

Time Required

Participation in this study will require approximately ten to twenty minutes of your time.

Risks

The investigator does not perceive more than minimal risks from your involvement.

Benefits

There are no direct benefits to the participant. Potential benefits of your participation in this study will include a valuable contribution of information to the Arthritis Foundation.

Confidentiality

The results of this research will be presented to the National Arthritis Foundation Board of Directors for dissemination as needed. In addition, research results may be published within journals and/or presented at conferences in related fields. Finally, the research results may also be presented in other media (e.g. JMU website). The results of this study will be coded in a way that your identity will not be attached to the final form of the study. The primary researcher retains the right to use and publish non-identifiable data. While individual responses are kept confidential, aggregate data will be presented representing averages or generalizations about the responses as a whole. All data will be stored in a secure location accessible only to the

researcher. Upon completion of the study, all survey information and any additional notes will be destroyed.

Participation & Withdrawal

Your participation is entirely voluntary. You are free to choose not to participate. Should you choose to participate, you can withdraw at any time without consequences of any kind.

Questions about the study

If you have questions or concerns during the time of your participation in this study or after its completion, or you would like to receive a copy of the final cumulative results of this study, please contact:

Researcher's Name: Margo Deihl
Department: Health Sciences
James Madison University
Email Address: deihlmb@dukes.jmu.edu
Telephone: (540) 419-8487

Questions about Your Rights as a Research Subject

Dr. David Cockley
Chair, Institutional Review Board
James Madison University
(540) 568-2834
cocklede@jmu.edu

Giving of Consent

I have read this consent form and I understand what is being requested of me as a participant in this study. I freely consent to participate. I have been given satisfactory answers to my questions. The investigator provided me with a copy of this form. I certify that I am at least 18 years of age.

Appendix B

Parent Survey

The purpose of this study is to identify the knowledge of and participation in selected Arthritis Foundation support programs and services among parents of children with arthritis-related diseases. Thank you for participating in this survey. Please record your responses to the following questions.

1. **What is your relationship to the child?**
 - a. Mother
 - b. Father
 - c. Other

2. **What is your age?**
 - a. 25-34 years old
 - b. 35-44 years old
 - c. 45-54 years old
 - d. 55-64 years old
 - e. 65+ years old

3. **How many children do you have in your family?**
 - a. 1
 - b. 2
 - c. 3
 - d. 4
 - e. 5 or more

4. **How do you describe yourself?**
 - a. American Indian or Alaskan Native
 - b. Asian or Pacific Islander
 - c. Black or African American – not Hispanic
 - d. Hispanic or Latino
 - e. White or Caucasian – not Hispanic
 - f. Other

5. **In which region do you live?**
 - a. **Florida Chapter** (Florida)
 - b. **Great Lakes Region** (Kentucky, Michigan, Ohio, Western Pennsylvania, West Virginia)
 - c. **Great West Region** (Alaska, Northern California, Colorado, Idaho, Montana, Oregon, Utah, Washington, Wyoming)
 - d. **Heartland Region** (Illinois, Indiana, Iowa, Kansas, Missouri, Nebraska)
 - e. **Mid-Atlantic Region** (North Carolina, South Carolina, Virginia, Maryland, Delaware)
 - f. **New England Region** (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont)
 - g. **Northeast Region** (New Jersey, New York, Eastern Pennsylvania)
 - h. **Pacific Region** (Arizona, Southern California, Hawaii, Nevada)

- i. **South Central Region** (Oklahoma, New Mexico, Texas)
- j. **Southeast Region** (Alabama, Arkansas, Georgia, Louisiana, Mississippi, Tennessee)
- k. **Upper Midwest Region** (Minnesota, North Dakota, South Dakota, Wisconsin)

6. What is the highest degree or level of school you have completed? *If currently enrolled, highest degree received.*

- a. Some high school, no diploma
- b. High school graduate, diploma or the equivalent (for example: GED)
- c. Some college credit, no degree
- d. Trade/technical/vocational training
- e. Associate degree
- f. Bachelor's degree
- g. Master's degree
- h. Professional degree
- i. Doctorate degree

| Please check the form of arthritis-related disease each child in your family has. | | Child 1 | Child 2 | Child 3 | Child 4 |
|---|---------------------------------|---------|---------|---------|---------|
| 1 | Juvenile Idiopathic Arthritis | | | | |
| 2 | Juvenile Dermatomyositis | | | | |
| 3 | Juvenile Lupus | | | | |
| 4 | Juvenile Scleroderma | | | | |
| 5 | Kawasaki Disease | | | | |
| 6 | Mixed Connective Tissue Disease | | | | |
| 7 | Fibromyalgia | | | | |

Please add any additional arthritis-related diseases your child or children may have that are not included in the table above.

| Please check how helpful the following resources have been in providing you with information about Juvenile Arthritis or arthritis-related diseases. | Have Not Used | Not Helpful | Somewhat Helpful | Very Helpful |
|--|---------------|-------------|------------------|--------------|
| | | | | |

| | | | | | |
|---|----------------------------------|--|--|--|--|
| 1 | Arthritis Foundation website | | | | |
| 2 | "Kids Get Arthritis Too" website | | | | |
| 3 | Physician(s) | | | | |
| 4 | Nurse at your child's school | | | | |
| 5 | Counselor at your child's school | | | | |
| 6 | Teacher at your child's school | | | | |

| Please check your level of knowledge about the following Arthritis Foundation support programs or services. | | No Knowledge | Somewhat Knowledgeable | Knowledgeable | Very Knowledgeable |
|---|--|--------------|------------------------|---------------|--------------------|
| 1 | Juvenile Arthritis National Conference | | | | |
| 2 | Walk to Cure Arthritis | | | | |
| 3 | Jingle Bell Run | | | | |
| 4 | Regional Arthritis Foundation Programs | | | | |
| 5 | Advocacy Summit | | | | |
| 6 | Juvenile Arthritis Camps | | | | |

Please add any additional resources that have been helpful in providing you with information about juvenile arthritis or arthritis-related diseases that not listed in the above table.

Please add any additional Arthritis Foundation support programs or services that you are knowledgeable about that are not included in the above table.

| Please check the number of times that you have participated in the following Arthritis Foundation programs or services. | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10+ |
|---|--|---|---|---|---|---|---|---|---|---|---|-----|
| 1 | Juvenile Arthritis National Conference | | | | | | | | | | | |
| 2 | Walk to Cure Arthritis | | | | | | | | | | | |
| 3 | Jingle Bell Run | | | | | | | | | | | |
| 4 | Regional Arthritis Foundation Programs | | | | | | | | | | | |
| 5 | Advocacy Summit | | | | | | | | | | | |
| 6 | Juvenile Arthritis Camps | | | | | | | | | | | |

Please add any additional Arthritis Foundation support programs or services that you are knowledgeable about but are not included in the table above.

Please briefly answer the following questions:

In what ways has your family been impacted by arthritis-related diseases?

Is there anything that the Arthritis Foundation could be doing to further assist you as a parental caregiver of a child with an arthritis-related disease?

Appendix C

Additional Data to Benefit the Arthritis Foundation

Table 30. Knowledge of additional Arthritis Foundation support programs not mentioned in the survey.

| Knowledge of Additional AF Support Programs | |
|--|---|
| Free Response: | support groups |
| | annual Arthritis Introspective National Gathering Conference Program |
| | online resources for ordering pamphlets for school |
| | Kids Get Arthritis Too |
| | JA Power Pack Program |
| | JA Toolkits |

Table 31. Arthritis-related diseases not listed as options for selection on the survey.

| Arthritis-Related Diseases Not Mentioned in Survey | |
|---|---------------------------------|
| Free Response: | Uveitis |
| | TRAPS |
| | Granulomatosis with Polyangitis |
| | Iritis |
| | Psoriatic Arthritis |
| | Gerds/Pfappa |