

Testimony of Mikayla Minnig on behalf of the Arthritis Foundation
Submitted to the House Committee on Appropriations
Subcommittee on Labor, Health & Human Services, Education, and Related Agencies
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My name is Mikayla Minnig, and I live in Downey, California. I am here today on behalf of the nearly 300,000 kids like myself who have juvenile arthritis. I am 10 years old and in the 5th grade. I was diagnosed with pauciarticular juvenile rheumatoid arthritis when I was just 3 years old. Pauciarticular means it affects four or fewer joints and usually large joints. For me, it affects my left knee and ankle. I also am at high risk for eye inflammation and must have them checked often so I don't become blind, which could happen. It all began when I felt a lot of pain and swelling in my neck. I couldn't walk or run like the other kids, and I couldn't turn my head.

For ten months I went to lots of different doctors to figure out what was wrong with me. Some of these doctors told my parents I must have bad growing pains or must be faking the pain and tears. Finally, we were sent to a pediatric rheumatologist—a doctor who treats kids like me with juvenile arthritis. Dr. Starr said I had arthritis. My parents were surprised. They didn't know, like most people, that kids got arthritis. In fact, most people don't know that juvenile arthritis is one of the most common childhood diseases in the United States.

People are surprised when I tell them that I have arthritis because I don't look very different than other kids. But unlike other kids, I take a cancer drug every week plus daily medication to control my arthritis, and it helps me try and lead a normal kid-life. I have met other kids through the Arthritis Foundation who are not as lucky as me. The drugs don't work for them, and they end up in a wheelchair or have to have their joints replaced. In fact, juvenile arthritis is the leading cause of disability in kids. I also am lucky to be able to see a doctor who understands and can treat my disease. Kids in 9 states don't even have a single specialist to see them.

I am here today to ask Congress to focus more attention on kids like me with arthritis. Research is the key to a cure. Research has led to newer drugs that help kids stay out of wheelchairs, but these drugs can have really bad side effects. We need a cure! Right now, the government spends \$9.8 million at the National Institutes of Health for juvenile arthritis research. That sounds like a lot of money to me but when you think of the nearly 300,000 kids that works out to be just about \$32 per child.

There is a group of pediatric rheumatologists who are working together to study and treat children with arthritis, but they need your help. With more funding and attention from Congress, more research studies can move forward to help find a cure. The Arthritis Foundation supports, at least, a doubling of juvenile arthritis research over the next few years. Also, the NIH should spend more money training future doctors. Kids around the country are diagnosed too late to prevent damage – please help change this. I hope one day when I tell people I got arthritis at age 3, and they say “but kids don't get arthritis” I can tell them “you are right – not any more – because research has found a cure”.

Juvenile arthritis is the leading cause of acquired disability in children and is the sixth most common childhood disease (following asthma, congenital heart disease, cerebral palsy, diabetes and epilepsy). Sustaining the field of pediatric rheumatology is essential to the care of the 294,000 children under the age of 18 living with a form of juvenile arthritis. Children who are diagnosed with juvenile arthritis will live with this chronic and potentially disabling disease for their entire life. Therefore, it is imperative that children are diagnosed quickly and treated with the most effective treatment protocols known for their particular disease.

The Childhood Arthritis and Rheumatology Research Alliance (CARRA) is a national organization of pediatric rheumatologists who have joined together to answer critical clinical research questions. CARRA has created a multi-center network of pediatric rheumatology research centers across North America that is working together on clinical investigations. Such collaboration increases the number of children who participate in studies and reduces the research time it takes to reach valuable conclusions.

Similar research networks have dramatically advanced the treatment currently available for both childhood cancer and cystic fibrosis. Children with cancer who are treated in a participating center with network protocols now have a much greater chance of disease-free survival, compared to children treated outside the network with non-network protocols. This dramatic improvement in treatment is a direct result of careful clinical studies and trials within the collaborative research organization. The pediatric oncology networks were started 30 years ago with the goal of developing and refining treatment protocols for children with cancer in the U.S. Currently over 90% of all children with cancer in the U.S. are enrolled in a Children's Oncology Group (COG) protocol. As a result, the standard-of-care for pediatric oncology patients has been critically and comprehensively evaluated and standardized, leading directly to better outcomes with improved survival and decreased treatment morbidity. CARRA's overall goal is that by 2012 there will be a protocol for every child with a rheumatic disease to participate in. Through participation in research and conducting investigations of these diseases, we will be able to significantly improve the standard-of-care for all children with rheumatic diseases in the future.

Pediatric rheumatology is one of the smallest pediatric subspecialties with only 195 pediatric rheumatologists actively practicing in the United States. Over 95% of all pediatric rheumatologists practice in academic medical centers; however, more than one-third of U.S. medical schools do not have any pediatric rheumatology program. Over a third of pediatric rheumatologists are in single-person divisions, resulting in significant isolation. Further, there is a significant manpower deficit in pediatric rheumatology such that only one-third of all children with rheumatic diseases are cared for by a pediatric rheumatologist, and the estimated number of pediatric rheumatologists required to provide optimal care is almost twice the current number. All these factors result in lack of access to state-of-the-art subspecialty care and the opportunities for participation in research protocols for children with rheumatic diseases. One of the goals of the pediatric rheumatology research network is to offer participation in research protocols for patients of community physicians in areas where there are no pediatric rheumatologists.

The Arthritis Foundation has given substantial financial support to the development of the Childhood Arthritis and Rheumatology Research Alliance (CARRA). **However, in addition, NIH has a unique opportunity to leverage its public research funds through CARRA's**

capabilities, and the Arthritis Foundation urges Congress to express support for a national network of cooperating clinical centers for the care and study of children with arthritis.

While new treatment options are available, we are still working to improve the quality of life for Americans living with arthritis, and ultimately finding a cure. Research funded by the National Institutes of Health and the Arthritis Foundation has produced a revolutionary class of biological therapies that alleviate painful inflammation and prevent disability. While these advances have changed the lives of Americans living with arthritis significantly, there is still no cure for the disease and its prevalence and impact continues to grow.

The Arthritis Foundation firmly believes research holds the key to tomorrow's advances and provides hope for a future free from arthritis pain. From its inception in 1948, a core mission of the Arthritis Foundation is to raise funds each year to support peer-reviewed research. As the largest non-profit contributor to arthritis research, the Arthritis Foundation fills a vital role in the big picture of arthritis research. Our research program complements government and industry-based arthritis research by focusing on training new investigators and pursuing innovative strategies for preventing, controlling and curing arthritis. To date, the Arthritis Foundation has funded more than 2,200 researchers with more than \$380 million in grants. By supporting researchers in the early stages of their careers, the Arthritis Foundation makes important initial discoveries possible that lead to ultimate breakthrough results. However, even with this commitment every year grants that rate "stellar" in our peer review process go unfunded. These are potential cures without the funding to be realized.

An increased public investment in biomedical research holds the real promise of improving the lives of millions of Americans with arthritis. This investment will reduce the burden of arthritis on the U.S. economy with less missed work days, disability payments, and expensive surgical interventions. To illustrate this point, less than 50% of working age adults with rheumatoid arthritis are still employed 10 years after disease onset. Nearly 2/3 of people diagnosed with arthritis are *under* the age of 65. 992,100 hospitalizations and 44 million outpatient visits annually are due to arthritis.

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases, the training of basic and clinical scientists to carry out this research, and the dissemination of information on research progress in these diseases. Research opportunities at NIAMS are being curtailed due to the stagnating and in some cases declining numbers of new grants being awarded for specific diseases. The training of new investigators has unnecessarily slowed down and contributed to a crisis in the research community where new investigators have begun to leave biomedical research careers in pursuit of other more successful endeavors.

The Arthritis Foundation is dedicated to finding a cure for arthritis. However, the investment in NIH research is absolutely crucial to realize this dream. With continued and increased investment in research, the Arthritis Foundation believes a cure is on the horizon. **The Arthritis Foundation urges Congress to increase funding and provide \$500 million for arthritis research over the next five years to continue to fuel innovation and discoveries that could put an end to the pain of arthritis.**

The medical and societal impact of arthritis in the United States is staggering. Arthritis costs the economy **\$128 billion**, which was equivalent to 1.2% of the U.S. gross domestic product in 2003. These costs include \$81 billion in direct costs for expenses like physician visits and surgical interventions, and \$47 billion in indirect costs for missed work days. Arthritis is the most common cause of disability in the United States, and nearly one-third of adults with arthritis experience work limitations.

The Arthritis Foundation strongly believes that in order to prevent or delay arthritis from impacting people and to mitigate the effects of arthritis that an investment both from the private and public sector must be made today. Research shows that the pain and disability of arthritis *can* be decreased through early diagnosis and appropriate management, including evidence based self-management activities such as weight control and physical activity. The Arthritis Foundation's Self-Help Program, a group education program has been proven to reduce arthritis pain by 20% and physician visits by 40%. These interventions are recognized by the Centers for Disease Control and Prevention to reduce health care expenditures. The Arthritis Foundation offers and partners with other organizations to offer the Self-Help Program, and an Aquatic Program, and an Exercise Program as part of our Life Improvement Series. Each of these programs is proven to reduce pain and physician visits, decrease stiffness and increase function.

The public sector investment at the federal government level entails the Centers for Disease Control and Prevention's arthritis program. In early 1998, the Arthritis Foundation joined forces with the CDC to develop the National Arthritis Action Plan – an innovative public health strategy. Among the goals are improving the scientific information base on arthritis, increasing awareness that arthritis is a national health problem, and encouraging more individuals with arthritis to seek early intervention and treatment to reduce pain and disability. Due to the Subcommittee's support and leadership, the CDC was provided with \$10 million in Fiscal Year 1999 to begin to make this vision a reality. More than ten years later, the CDC's arthritis program has not kept pace and in fact, has seen a decline in funding from just a few years ago. For Fiscal Year 2009, the arthritis program was funded at \$13.2 million.

Approximately half of the CDC's arthritis program funding was distributed through a competitive grant process to 12 state health departments. These state health departments in partnership with other state organizations have successfully used CDC funding to increase public awareness of the burden of arthritis and increase the availability of interventions that have been proven to improve the quality of life and health care of people with arthritis. Last year, twenty-eight additional states submitted grants and were approved, but unfunded due to limited funding. The CDC estimates 67 million or 25% of the adult population will have arthritis by 2030. More than 57% of adults with heart disease and more than 52% of adults with diabetes also have arthritis. Arthritis limits the ability of people to effectively manage other chronic diseases. It is time to make a significant investment now to sustain and improve the reach of these proven interventions.

The Arthritis Foundation strongly recommends Congress appropriate \$23 million in Fiscal Year 2010 for CDC's arthritis program, which is equivalent to 50 cents per person with arthritis. This is a \$10 million increase from Fiscal Year 2009, which will ensure that qualified, participating states can continue the vital work of lessening the burden of arthritis on Americans and the American work force.

The Arthritis Foundation greatly appreciates the opportunity to submit testimony in support of increased funding for arthritis research at the National Institutes of Health and arthritis public health initiatives at the Centers for Disease Control and Prevention, which are aimed at improving the lives of 46 million adults and 294,000 children living daily with arthritis in the United States.