



WOMEN IN GOVERNMENT

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Rheumatoid Arthritis

Policy Matters

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CHRONIC CONDITIONS AND THE AFFORDABLE CARE ACT

By Representative Kelly Skidmore, Florida House of Representatives, 90th District



As a member of the Florida Legislature, an employee of the Arthritis Foundation, and a person with juvenile rheumatoid arthritis, I have often been asked over the years to describe what it is like to live with the chronic and painful condition of arthritis. The question never fails to remind me of a childhood revelation I had when I was very young and my older sister knelt down in front of me to tie my unraveling shoelace. It

was as if for the first time I noticed the ease at which she bent and moved from standing to kneeling in one effortless motion, something I had never been able to do. I considered this for a moment and then I asked her to explain to me what it felt like to not have arthritis. For both of us, the question is difficult to answer and the condition difficult to describe.

From personal experience and from being an advocate, I know that for children and adults coping with the challenges of arthritis and other chronic autoimmune diseases, life can be filled with scheduling doctors' visits, avoiding hospital stays, managing varying levels of pain, dealing with isolation and ridicule, worrying about side effects of prescribed medication and a host of insurance related rules, regulations and exclusions that can often dictate a patient's course of treatment. From the perspective of a legislator, I know that the decisions we make and the laws we pass directly impact the ability of physicians to provide access to care, the ability of patients to choose their doctor, the regulatory environment in which insurance companies must operate, and the public health policies that will guide services and programs for people with chronic disease.

All of these moving parts actually come together in the federal health care reform law. For people with arthritis, the elimination of annual and lifetime caps on insurance lifts an enormous burden. For example, at age 33, I had already had both knees replaced, lost partial use of both arms, no longer had a right shoulder joint, was a candidate to have both ankles fused, and lost all vision in one eye. It is not hard to

imagine that lifetime caps for people with a debilitating disease can be exceeded at an early age, and that annual caps can be met within weeks of a new year. Also included in the health care reform law is the elimination of exclusion provisions for pre-existing conditions. This is also an incredibly important provision for people with lifelong conditions, and allows them to be eligible for coverage without interruption through employment changes and changes in insurance. The third element of the bill that is helpful, especially to those with juvenile onset, is the ability for parents to keep their children on the family plan until they reach age 26. The reality is that it does take longer for young people with disabilities to complete school and become independent. This provision provides an appropriate and critical "bridge" of insurance coverage that will keep patients on a consistent course of treatment that prevents flares and deterioration.

Research and development of treatment is the last piece of the puzzle, and although it is not specifically a part of the health care reform law, it is an essential part of the Arthritis Prevention, Control and Cure Act that the U.S. House of Representatives passed just last month. The treatments of the future are likely to allow the next generation of juvenile arthritis patients the unique ability to know what it is like to *not* have arthritis. ■



DEMOGRAPHIC VARIABLES AND WORK DISABILITY

By Dana Chesla, Graduate Fellow

The primary factors affecting work disability in people with rheumatoid arthritis (RA) are not the physical factors or symptoms that most people would assume. Rather, recent analysis of 15 reports points to demographic variables - age, sex, level of education, and socioeconomic status - as the major contributors to work disability. The long believed notion that work disability can be explained by physiological variables such as limited range of joint motion, radiographic damage, and/or laboratory tests, is turning out to be less important than demographic variables, a report by researchers Tuulikki Sokka and Theodore Pincus says.

The researchers summarized 15 studies and identified specific markers associated with work disability and people with rheumatoid arthritis. High age was significantly associated with work disability status in 11 out of the 13 studies reporting a statistically significant connection. Low formal education was another important marker for work disability status with 9 of the 13 studies (69%) showing a correlation. The physicality of an occupation is also a significant variable in work disability. The researchers did not provide a specific reason for these correlations, but it is plausible that a lower level of education may lead an individual to a more labor intensive occupation. Overall, there appears substantial consensus in the 15 studies that age, formal education level, and occupation are significantly associated with work disability.

What can be done to reduce the risk of work disability in people with rheumatoid arthritis? Several studies indicate that long term outcomes of RA can be improved with early and aggressive therapy with conventional disease modifying anti-rheumatic drugs. The problem lies in the fact that many people are already experiencing RA-related disabilities before being officially diagnosed. The lag time between symptoms and diagnosis creates a substantial barrier in avoiding long term disability.

Furthermore, the study points out, prolonged unemployment can lead to the development of an “unemployed” identity, and the burden of diagnosis of a chronic disease may lead to psychological distress. Depression is a common comorbidity for those suffering with rheumatoid arthritis. Therefore, consultation with a social worker, physical therapist, occupational therapist, or a psychologist may also be of value in early diagnosed cases of RA in order

to prevent work disability related to psychological distress. This, of course, can only occur after primary diagnosis from a doctor.

The study concludes that substantial delays are often seen in the diagnosis of RA in the community and therefore, improvement of work disability outcomes in RA may depend as much on the education of physicians as on new drugs. It is clear that work disability results from a combination of many factors, including disease diagnosis and progression, physiological symptoms, and demographic variables.

Social and public policy also influences the way in which employers respond to people on work disability and that can directly impact the fates of RA patients in the workplace. The Task Force Recommendations put forth by Women in Government’s Board of Directors outlines key steps state legislators can take to reduce the burden of rheumatoid arthritis. The Board emphasized that states should promote education and awareness about the disease. Specifically, states should develop outreach programs in collaboration with their Departments of Health to improve education about rheumatoid arthritis, early detection, and treatment services. State legislators should develop community collaborations among advocacy stakeholders and create printed materials, conduct health fairs, and work with the media. In addition to finding other opportunities to educate the public, a good way for legislators to raise community awareness is to support awareness resolutions for National Arthritis Month.

To address the problem of work place disability, states should support continued employment of persons with rheumatoid arthritis by supporting workplace accommodations and the Americans with Disabilities Act. Policymakers should support increased funding for vocational rehabilitation and counseling programs to expand services for individuals with rheumatoid arthritis and other chronic diseases. State governments have the opportunity to develop a more effective education and outreach plan for RA as well as other chronic conditions in order to counteract the trends of late diagnosis and the effects of demographic variables. ■



THE FRUSTRATION OF DIAGNOSIS

By Representative Kim Rosen, Maine House of Representatives, 40th District



Representative Kim Rosen (Bucksport, Maine) is currently serving her third term in the Maine House of Representatives. She was diagnosed with rheumatoid arthritis in 2009.

My biggest frustration with rheumatoid arthritis (RA) was getting diagnosed. As is often the case, it took over a year to get my diagnosis. The pain started in my foot and after a few months, migrated to both knees. After months of pain and many visits to my primary care doctor, I was told that my reported pain was much worse than any injury they could find. To specialists, I described every detail of my intense pain, even the electric shocks I felt when I exhaled.

The pain was in my hips, wrist, and shoulder, and at this point I was told by my primary care physician to try yoga. The thought was laughable. The pain was so constant and severe that I couldn't even get down on the floor, I could barely walk, I couldn't open a jar, and I couldn't sleep. Exercise, even therapeutic yoga, was impossible.

After countless doctors' appointments, MRIs, and X-Rays, the process got the best of me and I had a meltdown. Perhaps because I was sobbing, my primary care physician finally referred me to a RA specialist. Wasting no time, I called immediately and even though rheumatologists are scarce in Maine, I was able to see the doctor the same day. As soon as he saw my swollen wrist and thumb, he immediately tested me for rheumatoid arthritis. Even though I now had a diagnosis, my

problems did not end there. Unfortunately I have had severe allergic reactions to the most common drugs given for RA. I have insurance and was able to work through these issues, but I can't help but wonder how someone without insurance would handle this situation.

Since then, I have spoken to many women about ways I, as a state legislator, can reduce the barriers to diagnosis and treatment. One woman shared with me her struggle with RA. After years with the disease, her prescribed medications were no longer effective in controlling her symptoms. Her doctor put her on a new medication which worked beautifully for three months, until her insurance stopped coverage on the medication. The lack of medication coverage is a common barrier for people with RA, and I am working hard to change this policy. Another woman pointed out that there are no public year round pools in her town, making water therapy impossible.

So what do we need in Maine and throughout the country? We need incentives to train and attract more rheumatologists, as well as education and awareness campaigns about the importance of early diagnosis for the public. Once someone has been diagnosed there should be information available on exercise regimens, food choices, and treatment options. My job now, as a state legislator, is to help as many people as I can through education and awareness. I am so lucky to have Women In Government as a resource to get this message out. As frightening as it is to be told you have RA, it is a relief to start the process of getting it under control. Thank you WIG for getting the message of RA out to many people; I know it will make a big difference. ■

RHEUMATOID ARTHRITIS TOWN HALL MEETINGS

Nationwide, eleven legislators will be hosting a town hall about rheumatoid arthritis, an event organized by Women In Government, the Arthritis Foundation, and state legislators. It is an excellent opportunity to connect with constituents and spread information about this disease. ■

Alabama	Representative Laura Hall
Arkansas	Representative Ann Clemmer
Colorado	Senator Evie Hudak
Connecticut	Representative DebraLee Hovey
Georgia	Senator Nan Orrock
Hawaii	Representative Barbara Marumoto
Indiana	Representative Terri Austin
Iowa	Representative Renee Schulte
Kentucky	Representative Joni Jenkins
North Carolina	Representative Katie Dorsett
North Dakota	Representative Kathy Hawken



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Women In Government
1319 F Street, NW
Suite 710
Washington, DC 20004



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