

“What am I waiting for?”

Receiving a timely diagnosis is crucial to doing well with inflammatory arthritis in the short- and long-term; in fact, a patient’s future mobility may depend on it. (The three most common types of inflammatory arthritis are rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis.) Numerous studies have shown that a class of arthritis medications called disease-modifying anti-rheumatic drugs (also known as “DMARDs”), can help to prevent joint damage if taken within the first three months of disease onset.

In this issue:

In this month’s issue of JointHealthTM monthly, we explore issues related to timely treatment for arthritis.

- **“What am I waiting for?”** Reasons why people delay seeking appropriate timely treatment
- **Access denied:** Barriers to appropriate timely treatment
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Arthritis Consumer Experts (ACE)

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JointHealth Monthly is available in print and online in English and français.



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Unfortunately, many people do not seek the advice of a doctor when they first experience the hallmark symptoms of inflammatory arthritis. Symptoms include morning stiffness lasting more than an hour, joint pain and swelling, fatigue, and decreased range of motion in the joints.

Until recently, doctors and scientists have known relatively little about the factors that influence people’s decisions to use health services or seek treatments to manage their illness—a process called ‘help-seeking’. This area of research is important because studies have indicated that when people with inflammatory

“... when people ... are treated early ... their health outcomes are dramatically improved.”

arthritis are treated early in their disease process, their health outcomes are dramatically improved.

Unfortunately, rather than seeking help promptly, some people may decide to see a health professional only when the pain and swelling become severe and debilitating; when their lives are disrupted and they are prevented from doing the things they normally do. Tragically, by then the disease may have progressed beyond the early stage, and joint damage may have already occurred.

In a recent pilot study by Dr. Linda Li titled “Early Rheumatoid Arthritis Help-Seeking Experience”, researchers from University of British Columbia and Arthritis Research Centre of Canada found that the help-seeking process for people in the early stages of rheumatoid arthritis may be influenced by a number of different factors. These include the severity of

the symptoms, the person’s own beliefs about the cause of the pain, difficulty in getting time off work, how much support they receive from their family and access to other resources, such as educational information.

Some common themes arising from discussions with patients who participated in this pilot study include:

- the tendency to downplay early symptoms as ‘just normal aches and pains’, and work around them in day-to-day life, before individuals decide to see a family doctor,
- for those who have seen a family doctor, the tremendous challenges to manage symptoms while waiting to see a rheumatologist,
- the importance of the relationships with their health care providers, and
- the ‘hard work’ required to find a medication that worked for them.

Researchers involved in the study believe that understanding people’s experience during the earliest stage of rheumatoid arthritis in the context of their daily lives can help to develop ways that will shorten the delays in help-seeking and in receiving medical care.

Using the pilot study results, the research team from the University of British Columbia and Arthritis Research Centre has begun a large and comprehensive project to examine the factors that influence help-seeking in early rheumatoid arthritis. This will involve interviewing people seen by rheumatologists, family doctors and/or other health professionals, and conducting a national survey to capture other factors that are related to seeing a doctor early for joint symptoms. This work is funded by the Canadian Institutes of Health Research.

For more information, about this upcoming project, visit: http://www.arthritisresearch.ca/_page/10155271.4108.0.7083234.2009762.aspx

For more information about the Arthritis Research Centre of Canada please visit their website at: www.arthritisresearch.ca



It is a story that is all too familiar to people who live with arthritis—the story of treatment delayed or denied until it is too late to prevent crippling joint damage. The reasons vary, but the outcome remains the same; damage and disability that could have been prevented becomes a reality, and a person who could have lived a happier, more productive life is left with damaged joints, decreased mobility, and chronic pain.

Research has proved that starting aggressive treatment for inflammatory arthritis within the first three months of disease onset is the best way to prevent irreversible joint damage. This is in contrast to the conservative approach once thought to be the most sensible treatment plan for inflammatory arthritis. We now know that there is a small window of time, at the outset of the disease process, when proper treatment can actually prevent joint damage.

Research is also showing that many people with arthritis in Canada are not receiving the best treatment possible. In one recent study, Dr. Diane Lacaille found that only 43 percent of the people diagnosed with rheumatoid arthritis in British Columbia received disease modifying anti-rheumatic drugs (DMARDs), a class of medications considered “essential” to preventing joint damage and controlling disease in the early going.

As well, Dr. Lacaille’s research tells us that access to a rheumatologist meant that people

Barriers to appropriate timely treatment

were much more likely to receive appropriate treatment—76% of people diagnosed with rheumatoid arthritis and treated by a rheumatologist did, as opposed to just 10% who were treated solely by their general practitioner. This statistic is particularly alarming given there are almost four and a half million people with arthritis and fewer than 270 rheumatologists to treat them.

In another study, Tavares et al found that

“Eighty seven percent of the delay occurred before referral to a rheumatologist.”

only about 1/3 of those people who did get to see a rheumatologist were started on treatment within 6 months of the onset of symptoms; only 13% were able to receive those treatments within 3 months of symptoms beginning. Current guidelines recommend that treatments should be started within 6 months, with 3 months begin the ideal “window of opportunity”. Eighty seven percent of the delay occurred before referral to a rheumatologist.

For the more than 600,000 people in Canada who live with some form of inflammatory arthritis (mostly rheumatoid arthritis), this study proves what many of them already knew: treatments that are proved effective do exist, but they are not getting them in time.

Recently, the Division of Rheumatology at Dalhousie University reported wait times to see a rheumatologist of almost 6 weeks for urgent cases, and more than 40 weeks for “semi-urgent” cases.

At ACE, we hear story after story about people who spent months or even years desperately trying to get a diagnosis. We know of people who have been forced to travel long distances within their province, or even out of the country, to gain access to a rheumatologist. For people who are unable to take these drastic measures, the best treatments may be simply out of reach. The statistics reported in this article are evidence that a new arthritis model of care is desperately needed in Canada. ❧

Osteoarthritis and optimal body weight

Osteoarthritis can cause serious pain and disability.

Though medication treatments are more limited for osteoarthritis than for inflammatory types of the disease, a healthy diet and exercise program can be one of the most important components of a treatment plan for osteoarthritis.

Research shows that being overweight – by possibly even 10 to 20 pounds – is clearly linked to the development or progression of osteoarthritis. This may be because load-bearing joints are overstressed when they are supporting more weight. In any case, losing weight and / or maintaining optimal body weight can help to prevent, or treat, osteoarthritis. The

sooner that a person can achieve and maintain ideal body weight, the more likely that further joint damage can be minimized.

Many people find it difficult to get started on an exercise program because of their pain. In this case, many doctors recommend taking a pain reliever (such as acetaminophen or Tylenol®) about 30 minutes prior to starting exercise. Depending on a person’s joint complaint, using ice or heat, according to one’s preference, is a non-medicinal treatment that may be effective at helping people with osteoarthritis exercise effectively - and with enjoyment. ❧

Sam's story

For many people who are diagnosed with arthritis, access to early, aggressive treatment is the single most important factor in preventing permanent, crippling joint damage. Sam Hayduk, age 4, is one of those people.

Sam's parents noticed a rash on his face, which they believed to be related to the stress of starting pre-school in the winter of 2006. Doctors made several diagnoses, including Fifth's disease and eczema. When the rash didn't clear up, a dermatologist diagnosed psoriasis and prescribed cortisone cream.

The rash still didn't improve, and finally, after several months, the dermatologist began to suspect that Sam had Juvenile Dermatomyositis (JDMS), a childhood rheumatic autoimmune disease. At the same time, Sam's condition began to deteriorate quickly. Suddenly, he was unable to climb stairs or run more than a couple of paces. His breathing was laboured, and he had a terrifying episode where he was unable to swallow.

Within a week of the tentative diagnosis, blood tests confirmed that Sam had JDMS. Less than a week later, he was admitted to hospital, started treatments, and almost immediately began to feel better. His muscles regained strength, a bit at a time, and his fatigue gradually began to lift.

Today, it is amazing to see how far Sam has come over the past seven months. He is responding well to his treatments and has regained full strength. While it is difficult as a parent to give children powerful medicines and then worry about possible side effects, Sam's parents believe that they are very lucky to have access to appropriate treatments; prior to treatments being used today, 1/3 of children with JDMS died and 1/3 were left severely handicapped.

In August 2007, Sam and his mother ran a 5K race together. Here, Sam's mother Kat describes the run.

"Five months after beginning treatments, Sam asks me if he can run a 5K race with me. My husband and I think "why not?" The doctors have told us to follow Sam's lead when it comes to exercise—not to push him but to let him do what he's comfortable with. I picture a long, slow race with many stops—maybe finishing, maybe not.



This is how it goes: At the beginning of the race, Sam runs with a huge smile and the utmost enthusiasm. Not far from the start we hit a big hill and I tell Sam that we can walk up the hill if he wants to. "My muscles are strong" he says.

We pass the 2K mark and he's still running. Then there's a long, slow hill for about half a kilometer. As we run up it, I keep saying, "Sam, this is a big hill. Tell me if you want to walk a little while." He says "No, my muscles are strong". I hear him mumbling to himself about how his muscles used to hurt but now they are strong and he can keep running because of the computer in his leg. I realize he's talking about the timing chip around his ankle and laugh.

We reach the ½ way water station, stop for a quick drink, and just keep going. Around 4K in, he grabs my hand and I suddenly realize that he is going to run the whole race.

As we approach the finish I say to Sam, "Do you want to go across the finish by yourself or together with mommy?" "Together" he says. And that's what we did. We crossed the line together right into the arms of his dad who looks at me with shock and I say "he ran the whole way... honestly... he literally ran the whole way".

We know that if Sam hadn't been able to access early, aggressive treatment for JDMS, he probably wouldn't be walking unassisted. We are so grateful that we live in a place where we had access to the best physicians, including dermatologists and pediatric rheumatologists. We know that if we lived somewhere else—even in a more rural location here in BC—we might not have been so lucky."

Way to go, Sam.

It is safe to say that most people in Canada have no idea that a child of four can be struck down with a life-threatening form of arthritis. The next time someone tells you that arthritis is something old people get, tell them about Sam.

For more information about juvenile dermatomyositis, see the spotlight in this issue or visit: www.curejm.com

Spotlight on juvenile dermatomyositis

We are always happy to present information requested by our readers, and are excited to be receiving requests for spotlight features on different types of arthritis. Please contact us at info@arthritisconsumerexperts.org if you would like us to profile a specific type of arthritis.

Juvenile dermatomyositis (JDMS) is an inflammatory autoimmune disease affecting approximately three in one million children.

Autoimmune diseases generally occur when the body's immune system begins to malfunction and attack healthy tissue in various parts of the body, causing inflammation and damage. In dermatomyositis, muscle and skin are attacked by inflammation, but the joints, lungs, heart, and intestinal tract can also be affected.

Juvenile dermatomyositis affects girls and boys in equal numbers, and the average age of onset is seven years. While it has no known cure, it is treatable.

The cause of juvenile dermatomyositis remains unknown, although some researchers believe it may be a combination of an inherited susceptibility and an external trigger, such as exposure to excessive sunlight.

Diagnosis of juvenile dermatomyositis

Juvenile dermatomyositis is one type of a much larger disease category called "myositis" (translated, it means "inflammation of the muscle"); approximately 85% of diagnosed myositis is juvenile dermatomyositis. Other kinds of the disease are juvenile polymyositis (JPM) and overlap myositis, which occurs when a child has more than one autoimmune disease, including myositis.

Because some symptoms of dermatomyositis are similar to those of other diseases and because it is rare, it can be difficult for physicians to make the diagnosis. Often, the characteristic skin rashes are first misdiagnosed as eczema or psoriasis. Muscle pain can be mistaken for growing pains or overuse, and weakness can be confused with

laziness or sleepiness.

There are several hallmark symptoms of juvenile dermatomyositis, often present at the time of diagnosis. These warning signs include:

- Rash—including red face rash, scaly patches on arms and legs, and hardened patches on fingers at the knuckles
- Weakness
- Muscle pain
- Fever
- Fatigue
- Difficulty swallowing
- Joint pain and swelling

For more than 50% of children diagnosed with juvenile dermatomyositis, rash is the first sign of the disease. For children with juvenile polymyositis, rashes are less common, and muscle pain and weakness are the most common first signs.

Doctors may order several different types of tests in order to confirm a tentative diagnosis of juvenile dermatomyositis. These may include

- Blood tests
- Urine analysis
- Muscle imaging tests, including magnetic resonance imaging (MRI), ultrasound scan, and computed tomography (CT) scan
- Muscle biopsy
- Electromyography, a test in which a small needle is placed into the muscle, electrically stimulating the muscle, and measuring the response.

Treatment for juvenile dermatomyositis

While there is no cure for juvenile dermatomyositis, treatment advances are allowing more children to live normal lives. Before the use of corticosteroid treatments (also called steroids or prednisone) for juvenile dermatomyositis, one third of children would die from the disease, one third would be severely disabled, and one third would achieve spontaneous remission. Today, the majority of children with the disease who receive treatment recover completely.

Once a diagnosis of juvenile dermatomyositis has been made, the child will usually be referred to a pediatric rheumatologist—a doctor who specializes in treating childhood arthritis diseases. Rheumatologists have at least five years of extra training in addition to regular medical school, and are the best people to treat arthritis diseases. Other specialists usually involved in treating a child with juvenile dermatomyositis include dermatologists, to

treat the skin problems associated with the disease.

A well-rounded treatment plan for juvenile dermatomyositis includes medication, education, physiotherapy and occupational therapy, and a healthy diet.

The medications most commonly used to treat the inflammation in juvenile dermatomyositis are oral or IV steroids, like prednisone, which work to slow down the immune system and decrease inflammation. Methotrexate, another medication used to decrease inflammation, is often also used in combination with prednisone.

Another medication, hydroxychloroquine (Plaquenil®), can be used to control the severe rash sometimes present in juvenile dermatomyositis. As well, intravenous immunoglobulin, a drug prepared from human blood, appears to be of benefit in treating severe skin involvement.

Many parents of children with juvenile dermatomyositis note that giving strong medications in the high doses often necessary is one of the most difficult parts of coping with the disease. This is why education is such a critical part of a treatment plan for juvenile dermatomyositis. Like many inflammatory arthritis diseases, early aggressive treatment is vitally important. Parents who have received all of the necessary information are much more likely to be able to help create and implement a well-rounded, effective treatment plan. Children who are treated quickly and effectively have the very best chance of recovering fully.

Physiotherapy and occupational therapy can help to prevent muscle tightening and damage in the early stages of treatment. After the disease is controlled, physiotherapy may be helpful in regaining strength and range of motion. In almost all cases, children are encouraged to return to their regular physical activities as soon as they are able.

Sunscreen is recommended for children with juvenile dermatomyositis, as the rash can become more active with sun exposure. Sunscreen with SPF 21 or higher is usually recommended.

Diet is also an important component of treatment for any disease, and this is especially true for one requiring steroid treatment. Children with juvenile dermatomyositis should eat a diet low in sodium and high in calcium, to help prevent the brittle bones that are a potential side-effect of steroid treatment. ◀

Arthritis Consumer Experts

A preview of 2008

Arthritis Consumer Experts is constantly striving to best to meet the needs of our community. We believe that people with arthritis deserve evidence-based information upon which to base treatment decisions. We believe that every person with arthritis should have access to the best, most appropriate treatment and care for their disease. We believe that people with arthritis are the true experts and moral authorities on the disease, and that the “voices of arthritis” need to be heard by government.

We received very enthusiastic feedback this past year that our service performance met or exceeded our members, subscribers, and readers expectations. We are thrilled to be able to continue our work providing evidence-based education and information, advocacy leadership and training, to people with arthritis in 2008.

Here are some of the things we have planned in the first half of next year:

- **More JointHealth™ podcasts** will be made available soon. Topics will include ankylosing spondylitis, the cost-effectiveness of treating arthritis, and financial planning for people with arthritis
- **JointHealth™ monthly** will continue to provide evidence-

based information to help people with arthritis take control of their disease. As well, we will continue to provide “special editions” on issues relevant to people with arthritis

- We will continue to alert our members and subscribers to “**breaking news**” about arthritis with JointHealth™ express
- Since we believe that people with arthritis are experts in the disease we will continue our **JointHealth™ survey program**, and provide reports on the surveys we have done so far
- **New this year**, we will be adding another innovative program, JointHealth™ **Web Workshops**, in addition to JointHealth™ podcasts, JointHealth™ monthly, JointHealth™ arthritis medications guide, and JointHealth™ express. WebWorkshops will deliver video programs with top experts on arthritis right to the inboxes of our subscribers.

The upcoming year promises to be an exciting one at Arthritis Consumer Experts. Please tell us what you think—if there is something you would like to see covered in JointHealth™ monthly or podcasts, if you have found something from ACE to be particularly inspiring, or if you have suggestions about how we can better serve your needs, we want to hear from you. Write to us at info@arthritisconsumerexperts.org.

Arthritis Consumer Experts

Who we are

Arthritis Consumer Experts (ACE) provides research-based education, advocacy training, advocacy leadership and information to Canadians with arthritis. We help empower people living with all forms of arthritis to take control of their disease and to take action in health care and research decision making. ACE activities are guided by its members and led by people with arthritis, leading medical professionals and the ACE Advisory Board. To learn more about ACE, visit

www.arthritisconsumerexperts.org

Guiding principles and acknowledgement

Guiding Principles

Health care is a human right. Those in health care, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the

influence of any specific constituency and a practical necessity. Any profit from our activities is re-invested in our core programs for Canadians with arthritis.

To completely insulate the agenda, the activities and the judgments of our organization from those of organizations supporting our work, we put forth our abiding principles:

- ACE only requests unrestricted grants from private and public organizations to support its core program.
- ACE employees do not receive equity interest or personal “in-kind” support of any kind from any health-related organization.
- ACE discloses all funding sources in all its activities.
- ACE identifies the source of all materials or documents used.
- ACE develops positions on health policy, products or services in collaboration with arthritis consumers, the academic community and health care providers and government free from concern or constraint of other organizations.
- ACE employees do not engage in any personal social activities with supporters.
- ACE does not promote any “brand”, product or program on any of its materials or its web site, or during any of its educational programs or activities.

Thanks

ACE thanks the Arthritis Research Centre of Canada (ARC) for its scientific review of JointHealth™.



Acknowledgement

Over the past 12 months, ACE received unrestricted grants-in-aid from: Abbott Laboratories Ltd., Amgen Canada / Wyeth Pharmaceuticals, Arthritis Research Centre of Canada, AstraZeneca Canada Inc., Bristol-Myers Squibb Canada, GlaxoSmithKline, Hoffman-La Roche Canada Ltd., Merck Frosst Canada, Pfizer Canada and Schering Canada.

ACE thanks these private and public organizations.

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