

Research

The Canadian Arthritis Network: Working towards a world free of arthritis

In this May issue of JointHealth™ monthly, we offer readers an overview of the Canadian Arthritis Network (CAN)—an organization which is on the leading edge of innovation in the world of arthritis research.

Research is the root of hope for millions of Canadians living with arthritis. Through research innovation, groundbreaking treatments have been developed for arthritis, occupational and physical therapy have taken great strides, models of healthcare delivery have been improved, and people living with arthritis and medical professionals better understand the over 100 different types of arthritis disease.

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



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The organization

Founded in 1998 by the federally funded Networks of Centres of Excellence, the CAN is a national and international leader in the way arthritis research is done; instead of individual researchers working in isolation, the CAN brings together researchers and other professionals and stakeholders from a wide variety of disciplines. This is an approach to research that has been pioneered by the CAN. As Scientific Director and CEO Dr. John Esdaile says, "CAN has always been about thinking the unthinkable".

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The CAN brings together over 155 of Canada's leading arthritis researchers and clinicians, from 43 different universities, institutions and other organizations (both public and private) to develop teams of highly qualified experts. These teams comprise a wide variety of experts, like basic scientists, clinical researchers, people with arthritis, social scientists, and bioengineers, among others. These teams partner with industry and government, further expanding their resources and areas of expertise.

One of the most exciting and innovative aspects of the CAN's work is the role that people with arthritis (or "consumers") play in the research. Consumers are fully involved in every

"CAN has reduced the isolation experienced by many researchers by networking likeminded scientists and concentrating on specific goals, such as early diagnosis and aggressive treatment of osteoarthritis and other musculoskeletal diseases. CAN's innovative involvement of consumers in the research process has had profound results for both people with arthritis and scientists by building mutual respect and confidence."

Senator Pat Carney,
member, Canadian Arthritis Network
Consumer Advisory Council

aspect of the CAN's workings, from collaborators and co-investigators on research projects, to deciding which projects will be funded by the CAN. This is a critically important part of what makes the CAN a unique and valuable organization to Canada. Far too often, consumers — the experts at living with disease — are left without a voice in research decision-making. At the CAN, people with arthritis take an active role in guiding the organization at all points in the research process.

The contributions of people with arthritis involved in the organization's governance have been meaningful and plentiful: They have developed a national model for involving the public in health research; identified key unmet needs of people with arthritis and ensured that these needs were addressed by CAN's research program, and shared these and other experiences at international arthritis research meetings.

The research

The Canadian Arthritis Network provides funding to its members through three distinct research programs. These are:

Strategic Research Initiatives, which focus

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Canadian Arthritis Network *continued*

on unmet areas of research and knowledge along the clinical spectrum of prevention, early diagnosis and intervention and healing. Current research areas identified for funding include: Osteoarthritis, Inflammatory Joint Disease (like rheumatoid arthritis and ankylosing spondylitis), and Bioengineering for the Restoration of Joint Function (like improved joint prostheses).

To develop these areas of primary research, the CAN held high-level "brainstorming" sessions with key arthritis stakeholders groups, including people with arthritis, researchers, industry representatives, government, health policy makers and doctors.

Strategic Research Initiatives Development Grants, which fund preliminary research projects needed to establish a base for developing larger research projects.

Spotlight on psoriatic arthritis

There are over 100 different types of arthritis affecting approximately 4 million Canadians. Psoriatic arthritis is linked to the skin disease, psoriasis, which causes a scaly-type rash usually occurring on the elbows, knees, and scalp. Psoriasis is considered a significant risk factor for developing psoriatic arthritis – up to 30% of people diagnosed with psoriasis go on to develop psoriatic arthritis.

Psoriatic arthritis is a form of inflammatory arthritis which causes swelling and pain in and around joints, as well as a scaly rash on the skin. Joints most commonly affected are the fingers, wrists, toes, knees, shoulders, elbows, and ankles.

In addition to joints and skin, psoriatic arthritis affects the tendons and ligaments around the joints. This causes swelling, not just of joints, but of surrounding tissue as well. Psoriatic arthritis can also affect the spine – a form of the disease called psoriatic spondylitis.

Psoriatic arthritis affects men and women in equal numbers, and like many forms of inflammatory arthritis, it tends to strike people in the prime of their lives; most commonly, people are diagnosed between the ages of 20 and 50.

Diagnosis of psoriatic arthritis

If you suffer from psoriasis, it is important to remember that you are at an increased risk for developing psoriatic arthritis; speak with your doctor immediately if you develop any of the warning symptoms of psoriatic arthritis.

Psoriatic arthritis has several "hallmark" symptoms, which are often present at the onset of disease. These include:

- Pain and swelling in the joints, tendons,

Discovery Advancement Program, which supports research into areas about which there is currently very little known. These projects are generally considered "high risk" as they often focus on concepts or principles which have not yet been proved through previous research; this type of research program can be very exciting and have the potential to lead to "breakthrough" discoveries.

Workshops and Conferences

One of the most vital tools for researchers, stakeholders, and consumers to share ideas and information is to meet regularly.

Each year, the CAN holds an annual scientific conference that brings together network investigators, consumers, members of the public, government and international experts to learn about and discuss the work of CAN.

In addition to yearly conferences, the CAN

and ligaments fingers and toes, causing the appearance of "sausage fingers"

- Fingernails becoming detached from the nail bed or develop small pin hole sized dents (called "pitting") on the surface
 - Reduced range of motion
 - Morning stiffness, lasting more than one hour
- Often, doctors are able to tentatively diagnose psoriatic arthritis if a patient has several red, swollen fingers or toes along with a case of psoriasis. If symptoms include finger- or toenails lifting or "pitting", a more solid diagnosis can be made. It is important to remember, though, that the symptoms of psoriatic arthritis often mimic other forms of arthritis, including gout and rheumatoid arthritis. For this reason, doctors often confirm a diagnosis of psoriatic arthritis by running blood tests to rule out other forms of arthritis.

While there is no known cause of psoriatic arthritis, research has proved that heredity plays a role; children with parents who have psoriatic arthritis are up to three times more likely to develop it. For this reason, be sure to tell your doctor about any family history of psoriasis or psoriatic arthritis if you suspect you may have the disease.

Treatment of psoriatic arthritis

If your doctor believes you may have psoriatic arthritis, you will usually be referred to a rheumatologist—a specialist in the treatment of arthritis. Rheumatologists have many years of extra training on top of their regular medical schooling, and are experts at diagnosing and treating all forms of arthritis, including psoriatic arthritis.

Once your rheumatologist has diagnosed psoriatic arthritis, there are effective treatments available to help you manage the symptoms and minimize joint damage. While there is no known cure for psoriatic arthritis, treatments are available, and your rheumatologist is the best person to discuss these with and formulate a treatment plan to address all aspects of psoriatic arthritis.

also holds a series of workshops on specific research topics. Typically, these are two-day meetings which bring together a range of stakeholders, from scientists to people living with arthritis, to discuss and identify areas of unmet need in arthritis research and to discuss the progress and challenges of current research conducted by the CAN.

Several of the workshops held to date produced position papers outlining key research priorities and research goals. For example, the Pain and Arthritis Workshop produced a consumer written white paper outlining research issues specifically relevant to people living with arthritis, not just those areas of interest to researchers (which often differ from people living with the disease). To learn more about these papers, visit the CAN website at www.arthritisnetwork.ca ↵

There are five major groups of medications which are used to treat psoriatic arthritis. These are:

- Non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (for example Advil® or Motrin IB®), naproxen (or Naprosyn®), diclofenac (or Voltaren® and Arthrotec®)
- COX-2 inhibitors, such as celecoxib (Celebrex®) or lumiracoxib (Prexige®)
- Corticosteroids, such as prednisone
- Disease-modifying anti-rheumatic drugs (DMARDs) such as methotrexate, sulfasalazine, leflunomide (Arava®), hydroxychloroquine and azathioprine
- Biologic response modifiers (or "biologics"), including adalimumab (Humira®), etanercept (Enbrel®), and infliximab (Remicade®), all of which have been approved in Canada and the United States for use in treating psoriatic arthritis.

These medications can work alone or, most often, in combination to reduce the pain and other symptoms associated with psoriatic arthritis. As well, a medication called alefacept (Amevive®) is available for treatment of the skin symptoms associated with the disease.

To treat and protect your skin, you can use a humidifier in your home to prevent dryness. As well, unscented lotions and creams can protect and soothe your skin. Avoid any strong perfumes or dyes in skin lotion, as these can aggravate psoriasis. If the psoriasis is not well controlled by simple measures, consultation with a skin specialist (or "dermatologist") is needed. In some people, better control of the skin disease can result in better control of the arthritis aspect, too.

As with any form of arthritis, maintaining a healthy lifestyle is also a critical part of any psoriatic arthritis treatment plan. Poor diet, lack of exercise, and high levels of stress may make disease activity worse, so healthy eating, appropriate levels of aerobic and strengthening exercise, and relaxation are highly recommended. ↵

Advocacy

The Consumer Advisory Council of the CAN

From its beginnings, the CAN recognized the importance of involving people with arthritis in research decision-making. Along with being the first National Centre of Excellence to receive a disease-specific grant, it was the first one to include consumers (people living with arthritis) in their decision-making.

From the day it was funded, people with arthritis were invited to join the CAN and provide the vision for ensuring meaningful consumer involvement. This led to the creation of the Consumer Advisory Council (CAC) within the CAN in February 2000. The CAC is a standing committee of the CAN, created to ensure that CAN's policies, strategic initiatives and research are relevant to people living with arthritis (CAN, 2003: 32).

Consumer Advisory Council members are volunteers living with different types of arthritis, from juvenile idiopathic arthritis and rheumatoid arthritis to osteoarthritis. They represent different ages, professional backgrounds and skill sets, and

levels of volunteer leadership experience. What they have in common is personal experience living with arthritis and a strong desire to make the research process and results as relevant to the lives of people living with arthritis as possible. Importantly, they have a keen interest in arthritis research and are informed about the issues facing them and their community at large.

The CAC participates in decision-making at each level of CAN, including the board of directors, training awards review panel, theme meetings and projects, core facilities, and the scientific and medical advisory committee (CAN, 2003: 4). Two CAC members sit on each committee within the CAN, including: the Research Management Committee, the Scientific and Medical Advisory Committee, and the Training & Education Committee. They are there to ensure that their valuable disease perspectives and views on research priorities are represented.

In addition to the participation of CAC members in the CAN's work, five other arthritis

consumer groups in Canada are directly involved, too. Their participation helps to ensure that the CAC connects with the larger arthritis consumer community across Canada. Representatives from these groups are considered "Allied Members" of the CAC and they fully participate in their decision-making processes. As well, Allied Members make sure that information about CAN's research and new knowledge generated from it gets out to their memberships – members of the public living with arthritis. The CAC's Allied Member groups are:

- Arthritis Consumer Experts (ACE)
- Canadian Arthritis Patients Alliance (CAPA)
- Childrens' Arthritis Foundation (CAF)
- Consumer Advisory Board of the Arthritis Research Centre of Canada (ARC-CAB)
- Patient Partners in Arthritis

For more information about the CAC, visit their website at http://www.arthritisnetwork.ca/consumer_advisory_council/cac_index.asp

The future of the Canadian Arthritis Network

It is critical that the Canadian Arthritis Network continue to survive and thrive in order to achieve their vision of "A world free of arthritis" and address the impact of the disease on those who live with it. Yet the future of the CAN is in jeopardy as their federal funding from the Networks of Centres of Excellence ends in 2012.

Over 4 million Canadians have arthritis disease and this costs the government approximately \$18 billion per year. Despite arthritis representing the largest financial burden on Canada's health care system, research in this area is severely under-funded when compared to other disease areas:

2005-2006 Canadian Institutes of Health Research* funding levels by disease area:

Arthritis	\$2.4 million (2004-2005)
Diabetes	\$5.5 million
HIV/AIDS	\$22 million
Cancer	\$118 million

with tools for excellent treatment, and leads to innovation in disease prevention and management. This can be seen in the significant increases in survival rates for people living with several types of cancer, as well as with HIV/AIDS. In addition, the number of people getting some types of cancer is dropping, but the same cannot be said about arthritis.

The number of people getting most types of arthritis is rising, the best non-drug and drug treatments are not covered by provincial health care systems (or one has to fight from their hospital bed to get them), and public awareness about what "arthritis" really means and does to one's body is alarmingly low. Few know that arthritis acts in the body very similarly to cancer. Even fewer know that a number of types of arthritis can kill, just like cancer and HIV/AIDS. But keeping the researchers in CAN going will help to change that—just like the well-funded cancer and HIV/AIDS researchers have for people living with those terrible diseases.

The CAN represents one of the most innovative and important arthritis research centres in Canada, providing a forum to bring together experts from different disciplines as well as people living with arthritis to ensure that the research emerging from CAN is relevant and

innovative. If CAN is not able to continue, \$2.5 million dollars of research funding will be lost and Canada's ability to effectively address the burden of arthritis will be even more severely limited than it already is given its current funding levels.

If you want to help Arthritis Consumer Experts and other arthritis organizations fighting to ensure that arthritis research receives its fair share of Canada's health research budget, join with us in telling the federal government that the CAN is a valued, critically important organization in the fight for "a world without arthritis".

Please take the time to send a letter or email to the Federal Minister of Health, your own Member of Parliament ("MP"), and your provincial Member of the Legislative Assembly ("MLA") or Member of the Provincial Parliament ("MPP") outlining why you think arthritis research funding should increase to equal that of cancer or HIV/AIDS. Mailing and email addresses for your federal MP can be found at www.parl.gc.ca. For mailing and emailing addresses for your MLA or MPP, visit your provincial government web site or call their toll free number listed under the government section in your phone book.

Together, our collective voice is strong and we must make sure it is heard by our representatives in government. <

Research is vitally important; it provides doctors and other health care professionals

*Canadian Institutes of Health Research.
<http://www.cihr-irsc.gc.ca>. Accessed March 2007

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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