



Holiday greetings!

Wishing you
Joint Health in 2014



Now entering our 14th year of working diligently on behalf of Canadians with arthritis, their families, friends, and communities, ACE continued in 2013 to empower consumers/patients and help them take control of their disease. As one of Canada's leading arthritis advocacy organizations providing evidence-based informational programs and innovative wellness tools, ACE was a popular "go to" source in the past 12 months of education to consumers, healthcare professionals, and government.

Highlights of our achievements in 2013 include:

- ▶ Representing arthritis consumers and serving as the social media hub at major conferences, such as the Canadian Rheumatology Association Annual General Meeting and the 21st Annual Rural and Remote Medicine Course "Sea To Sea To Sea."
- ▶ Engaging consumers, raising the profile of arthritis, and sharing arthritis research news through the Arthritis Broadcast Network.
- ▶ Launching a three-year partnership with Shoppers Drug Mart and the Arthritis Research Centre of Canada, as part of the National Arthritis Awareness Program.
- ▶ Improving arthritis awareness among government and opposition officials to generate policy changes that will positively affect people living with arthritis.
- ▶ Growing ACE's reach through JointHealthTM surveys, monthlies, expresses, website, and social media.
- ▶ Working with other patient groups through the Arthritis Alliance of Canada and the "National Arthritis Framework."
- ▶ Hosting and/or participating in public lectures.

Arthritis Community
Unites in
Nation's Capital



Our 2014 work plan is innovative and ambitious. With the engagement of Canadians, volunteers, subscribers and staff, ACE will continue providing evidence-based education, information and advocacy leadership and training on arthritis prevention, detection/screening, treatment and research.

For 13 years, ACE has led the Canadian arthritis community by developing and executing strategic advocacy programs, which have resulted in improving access to arthritis treatment and care across Canada, and most importantly, empowered tens of thousands of Canadians living with arthritis to seek better health outcomes for themselves and their families. But we could not have done it without you. Thank you for being a part of changing arthritis. We hope that we will have your continued interest and support in 2014.

With kind regards,

Cheryl Koehn
President and founder, Arthritis Consumer Experts



The Arthritis Alliance of Canada (AAC) holds its first Conference and Research Symposium.

Scientists, advocates, healthcare providers, policy makers, and arthritis community members from all over Canada recently united in Ottawa for the Arthritis Alliance of Canada's inaugural Conference and Research Symposium. There was no more fitting a place than the nation's capital for the AAC to come together and advance the work of the arthritis community. They met during the city's typically crisp and snowy November to share advances in arthritis research and to brainstorm ideas for the direction of future research and programs to improve the lives of Canadians living with arthritis.

Highlights of the event included a welcoming address by the parliamentary secretary to the Minister of Health, a keynote speech by the president of the Canadian Institutes of Health Research (CIHR), a healthcare reform expert panel, four research sessions, and a gala evening featuring musical performers living with arthritis.

Opening the symposium, Janet Yale, the Alliance Chair and President of The Arthritis Society, said the conference was "a unique opportunity to bring together all stakeholders in the Canadian arthritis community" and that the work done there "will lay out the roadmap for future research priorities designed to advance our understanding of arthritis—what causes it, how to diagnose and treat it, how to care for those living with it, and ultimately how to prevent and cure it."

In her welcoming speech, Member of Parliament and Parliamentary Secretary to the Minister of Health, Eve Adams said, "if we are to make a difference in the lives of patients, we need to hear from them. We need to know the challenges they face in order to properly align research priorities and health services. And we need to put the research into action. That takes commitment and collaboration—principles that the Arthritis Alliance and its members have clearly adopted and put into practice." To that end, during the opening ceremony, Cheryl Koehn spotlighted the symposium's patient participation, both as presenters and moderators, sharing their perspectives to help bring the consumer experience to the forefront between the program's intensive workshops.

Participants learned about exciting new research discoveries, networked with colleagues in the research community, government and industry, and helped define priorities for arthritis research under the Canadian Institutes of Health Research (CIHR)'s Strategy on Patient Oriented Research (SPOR). SPOR is a program based on partnerships

with stakeholders that focuses on ensuring that decision makers and policy makers are involved early in discussions. Policy issues play an important role in helping understand the context for research and the necessary research response.

The keynote speaker, Dr. Alain Beaudet, President of the CIHR, said that the CIHR is committed to two equally important tasks: supporting knowledge creation (research) and supporting knowledge translation (spreading information) towards better health outcomes and care. Three elements are critical to achieving those tasks. They are:



Dr. Alain Beaudet

1. Putting the consumers of healthcare first when evaluating research priorities and determining how to apply research findings.
2. Involving those who will be using the knowledge that the CIHR's investments have or will have generated, namely, decision makers and caregivers.
3. Building strong partnerships to tap into the expertise and networks of partners. As an example, Dr. Beaudet noted the innovative collaboration between the researchers, the private sector and consumers that resulted in a unique three-year partnership between Shoppers Drug Mart/Pharmaprix, Arthritis Consumer Experts, and the Arthritis Research Centre of Canada.

Pharmacy Partnership for Patients

In September, ACE, the Arthritis Research Centre of Canada (ARC) and Shoppers Drug Mart/Pharmaprix ("Shoppers") partnered to improve the lives of individuals and families living with arthritis. Pharmacists at more than 1,200 Shoppers stores across Canada can now provide valuable and easily accessible information and tools on arthritis prevention, detection and screening, treatment, and research information. During his keynote address at the AAC conference and research symposium, Dr. Alain Beaudet said of the partnership, "It is a powerful example of how we can improve the lives of people living with chronic diseases. It illustrates the kind of collaboration that is necessary to move research from idea to action."

Research highlights of the AAC conference included:



Dr. Stefan Lohmander, an internationally recognized expert in sports science and clinical biomechanics from the University of Lund in Sweden, discussed achievements, gaps and opportunities in osteoarthritis research.



Dr. Hani El-Gabalawy, a renowned rheumatologist from the University of Manitoba, discussed his studies of Cree/Ojibway First Nations, who are disproportionately more susceptible to rheumatoid arthritis than the general population, to learn how to detect the disease earlier. The goal is to reduce the impact of RA through early detection, and possibly to prevent the disease completely.



Dr. Gillian Hawker, a rheumatologist and Professor of Medicine and Health Policy at the University of Toronto, discussed the relationship between osteoarthritis and other chronic conditions, such as heart disease, obesity, and diabetes. The conclusion of her study was that rather than treating OA as a single disease, the strategy should be to consider all of its associated diseases as well. In particular, chronic disease management and prevention should be focused on improving patients' mobility.

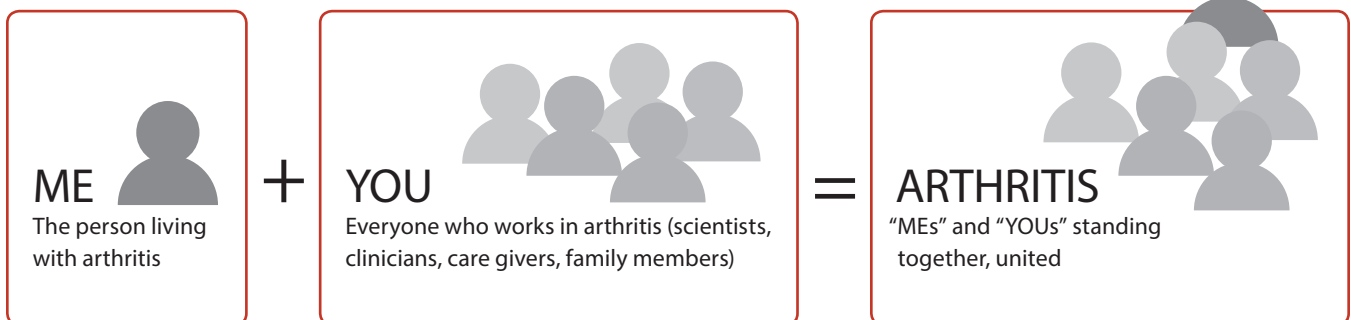


Dr. Jason MacDougall, an associate professor in the Department of Pharmacology at Dalhousie University, explored the preclinical and clinical evidence for a neuropathic component to arthritis pain. Neuropathic pain occurs when damaged nerve fibres send incorrect messages to other pain centres. Understanding the source of arthritis pain will, possibly, one day lead to new treatments that can help alleviate chronic pain and restore joint function.

"Me, You and Arthritis"

Patients were in the spotlight during the three-day conference, both as presenters and as moderators, sharing their perspectives through a series of consumer presentations entitled "Me, You and Arthritis." They were unapologetic and straight-from-the-hip accounts of living with juvenile idiopathic arthritis, or with newly diagnosed or long-term rheumatoid arthritis and osteoarthritis.

In an incredible show of solidarity, ARTHRITIS (everyone attending the event) would stand whenever a consumer/patient came to the podium to speak or moderate a scientific session alongside their scientific peer.





About the “Arthritis and the Arts” Gala



Murielle Bruneau, Dallas Hayes-Sparks, Laureen Harper and Janet Yale

Mrs. Laureen Harper, the wife of Prime Minister Stephen Harper, was the Honorary Chair for the “Arthritis and the Arts” gala evening during the conference. Featured at the Gala were performances by artists living with arthritis, including Dallas Hayes-Sparks and Murielle Bruneau, and artwork by the Peoples of the Longhouse, Brad Henry and Christina Moore.

Dallas Hayes-Sparks, Soprano, aged eighteen, was the youngest performer at the gala. Originally from Calgary, Alberta, she is now in her first year of studying opera performance at the University of British Columbia, but she began seriously pursuing her singing career at the age of twelve. That year, she received second place at the Alberta Provincial Music Festival. A year later Dallas was diagnosed with rheumatoid arthritis, lupus, and class VI membranous nephritis. Since her diagnoses, she has entered vocal competitions every year, placing first over twenty-five times.

At the age of sixteen, Dallas was asked to audition for the 2012 American High School Honors Performance Series choir and sang in New York at Carnegie Hall. In addition to singing, Dallas also plays piano, and has placed first in competitions four times. As well, she plays tenor saxophone and has even tutored her own group of beginner saxophonists. In September of 2013, Dallas moved to

Vancouver, British Columbia to begin secondary level opera training. With the help of her physicians, she has been able to control her illness and pursue her dream of becoming an opera singer. Dallas believes that prayer and perseverance are critical. She will not let this illness take away any of her dreams. Dallas has always worked hard to succeed and will continue to do so in the future.

Murielle Bruneau, Double Bassist, lives with rheumatoid arthritis, has been a member of the National Arts Centre (NAC) Orchestra since 1989 and has performed as solo double bass with the Orchestra on many occasions.

She has appeared as soloist and chamber musician at numerous festivals in Europe and North America and was solo bass of the McGill Chamber Orchestra and the Montreal chamber ensemble La Pieta with whom she made six recordings.

Learn more about Murielle Bruneau: <http://nac-cna.ca/orchestra/musicians/murielle-bruneau>

About the Arthritis Alliance of Canada

The Arthritis Alliance of Canada, formerly the Alliance for the Canadian Arthritis Program (ACAP), was formed in 2002. Its goal is to improve the lives of Canadians with arthritis. With more than 35 member organizations, the Arthritis Alliance brings together arthritis healthcare professionals, researchers, funding agencies, governments, voluntary sector agencies, industry and, most importantly, representatives from arthritis consumer organizations from across Canada.

While each member organization continues its own work, the Alliance provides a central focus for national arthritis-related initiatives.

Peoples of the Longhouse: Christina Moore, Brad Henry

Christina Moore is a painter and art educator who is passionate about art, culture and education. She holds degrees in both Visual Arts and Education from the University of Ottawa. She has lived in the Ottawa area for the last 25 years, but was born in Wainwright, Alberta, “home of the Buffalo,” and comes from Huron-Wendat, French, English and Irish ancestry.

Her interest in exploring and celebrating her First Nation ancestry through art led her to start working in collaboration with Tlingit artist Brad Henry. As urban First Nation people they work together to find a middle ground between traditional ways and the contemporary world.

Brad Henry is a firefighter turned artist, also living with arthritis, who moved to the nation’s capital from Vancouver twenty years ago. Born in Whitehorse, Yukon, he comes from Tlingit and Vun Tut Gwitch’in



roots. He has been creating art using traditional Pacific Northwest Coast design elements for almost 15 years. He notes that “these traditional design elements are as old as the hills and it is an honour to use them in our art.” Both the visual and musical art he creates focuses on sharing his cultural beliefs and traditions with others.

The art the pair create together explore traditional design elements, unique colour combinations, and are strongly rooted in First Nation teachings.

Learn more about the Peoples of the Longhouse: <http://peoplesofthelonghouse.wordpress.com/>



*Ms. Eve Adams,
Parliamentary Secretary
to the Minister of Health*

The Canadian Institutes of Health Research’s Institute of Musculoskeletal Health and Arthritis (CIHR-IMHA) recently awarded the Bone and Joint Canada (BJC) the 2013 CIHR-IMHA Knowledge Translation Award. Ms. Eve Adams, Member of Parliament for Mississauga-Brampton South and Parliamentary Secretary to the Minister of Health, presented the award at the opening reception of the Arthritis Alliance of Canada’s Conference and Research Symposium.

“On behalf of our Government, I congratulate Bone and Joint Canada for receiving this important honour,” said Parliamentary Secretary Adams. “Your leadership has improved both the care and management of musculoskeletal conditions and enhanced the quality of life of many Canadians.”

Bone and Joint Canada was formed in 2002 to represent Canada in the International Bone and Joint Decade launched by the World Health Organization in 2000 as a global partnership to reduce the impact of musculoskeletal health

conditions. BJC received the award in recognition of its outstanding contribution over the last ten years in engaging stakeholders, building research capacity, sharing best practices, and developing and implementing national models of care for hip and knee replacement and hip fracture.

“We are pleased to recognize the outstanding work of Bone and Joint Canada with this award,” said Dr. Hani El-Gabalawy, Scientific Director of CIHR-IMHA, “They are an important partner and have contributed greatly in moving research into action and fostering the development of young researchers in the field of musculoskeletal health.”

The CIHR-IMHA Knowledge Translation Award honours and supports exemplary knowledge translation efforts and activities of an exceptional individual, team or organization that has made an outstanding contribution to increasing the application of research findings, improving the health of Canadians, health services and products or strengthening the healthcare system.

About 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 healthcare 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.joinhealth.org

Guiding Principles

Healthcare is a human right. Those in healthcare, 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 healthcare 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 website, 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™.



Arthritis Research Centre of Canada
Arthrite-recherche Canada

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