

ARTHRITIS ALLIANCE OF CANADA

MEDIA RELEASE

For immediate release

PATIENTS FRONT AND CENTER AT ARTHRITIS ALLIANCE OF CANADA'S FIRST ANNUAL RESEARCH CONFERENCE AND SYMPOSIUM

Hundreds of patients and experts meet to shape future of arthritis research in Canada

Ottawa (November 20, 2013)

Hundreds of patients and experts will gather in Ottawa this week at the Arthritis Alliance of Canada's inaugural Conference and Research Symposium to discuss the latest advances and the future of arthritis research in Canada. The three-day event features participation from across the country, including medical and allied health professionals, patient advocates, government representatives and non-profit health organizations.

"This precedent-setting event is a unique opportunity to bring together all stakeholders in the Canadian arthritis community," says Alliance Chair **Janet Yale**. "Canada is a world leader in research into arthritis and chronic pain. The work being done at this event 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."

Participants will examine the state of research, learn about exciting research discoveries, network with colleagues in the research community, government and industry, and help define priorities for arthritis research under the Canadian Institutes of Health Research (CIHR)'s Strategy on Patient Oriented Research (SPOR).

Patients are in the spotlight during the three-day conference, both as presenters and moderators, sharing their perspectives to help bring the patient experience to the forefront in the midst of the program's intensive workshops.

Nathalie Courtois knows first-hand the importance of having patient voices represented when important health issues and policies are being discussed. After living for over two decades with a baffling array of health concerns, the Canada Post mail carrier from Roxboro, Quebec finally had her illness diagnosed as ankylosing spondylitis, an autoimmune disease and a form of arthritis that affects the spine.

Recently, the diagnosis of Courtois' illness has been further refined to NOMID syndrome, an even rarer form of inflammatory auto-immune disease. She is responding well to treatment with a new biologic, helping her resume something resembling a normal life.

"I'm living proof of the benefits of research, but also the importance of sharing expertise and improving diagnostic capabilities," says Courtois. "Unfortunately, too many doctors are unaware of or unable to diagnose complex and genetic-related conditions whose symptoms are too intricate to easily identify. Doctors need to be more alert when patients do not respond to treatments, and must find a better way to properly diagnose rare diseases."

Research indicates that, on average, it takes ten years for a woman in Canada with ankylosing spondylitis to receive a diagnosis. Courtois praises the conference as a venue to transfer specialized knowledge among experts, and to give patients input into reform of our health care system. “We need to keep the focus on the patient experience, on improving the quality of health care services provided to Canadians.”

Friday evening, Honorary Chair **Laureen Harper** hosts the ‘Arthritis and the Arts’ Gala, which features a variety of artistic expressions by people living with arthritis. Among them is **Dallas Hayes-Sparks**, an 18-year-old opera singer from Calgary who is currently pursuing a performance degree at the University of British Columbia despite living with rheumatoid arthritis, lupus, and class VI membranous nephritis.

“We’re so pleased to have Mrs. Harper involved given her commitment to the performing arts,” says Yale. “This gala reminds us that our work allows those living with arthritis to pursue their passions and not to be defined or limited by their disease.”

Other highlights on the conference agenda include:

- **Dr. Stefan Lohmander**, an internationally recognized expert in sports science and clinical biomechanics from the University of Lund in Sweden, will explore achievements, gaps and opportunities in the current state of osteoarthritis research.
- **Dr. Hani El-Gabalawy**, a renowned rheumatologist from the University of Manitoba, will discuss his studies of a susceptible First Nations population to explore what happens before the onset of rheumatoid arthritis.
- Friday’s Economic Club of Canada luncheon on health care reform, featuring **Jeffrey Simpson** of The Globe and Mail, **Dr. Deborah Marshall** from the University of Calgary, and **Dr. Adalsteinn Brown** from the University of Toronto. The discussion will be moderated by **Don Newman**, former broadcaster and now Chair of the Advisory Board at CANADA 2020 and Sr. Strategic Advisor, Bluesky Strategy Group.
- A developmental workshop for Arthritis Society and Canadian Arthritis Network research trainees. This program supports investigators in the early stages of their career development, providing professional and skills training to enhance their present and future studies into arthritis, its impacts and its solutions.

Janet Yale, Natalie Courtois, Dallas Hayes-Sparks, Dr. Stefan Lohmander, and Dr. Hani El-Gabalawy will all be available for comment during the conference.

To learn more about the conference and symposium, visit <http://www.arthritisalliance.ca/conference/>.

About the Arthritis Alliance of Canada

The Arthritis Alliance of Canada is a coalition of over 35 organizations representing patient groups, arthritis consumer organizations, professional organizations, not-for-profits, government, industry and researchers. The Alliance’s goal is to improve the lives of Canadians with arthritis. While each member organization continues its own work, the Alliance provides a central focus for national arthritis-related initiatives. For more information, please visit the Arthritis Alliance of Canada website at <http://www.arthritisalliance.ca/home/index.php>

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For more information about this conference or the Arthritis Alliance, please contact:

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BACKGROUND

Attention Media: Janet Yale, Natalie Courtois, Dr. Stefan Lohmander, Dr. Hani El-Gabalawy and Dallas Hayes-Sparks will all be available for comment during the conference.

Janet Yale

Chair, The Arthritis Alliance of Canada, Toronto, ON

Janet Yale joined The Arthritis Society as president and CEO in June 2012. An accomplished senior executive, Janet served as executive vice president at TELUS from 2003 to 2010 and as president and CEO of the Canadian Cable Television Association from 1999 to 2003. Janet has also held senior leadership positions at AT&T Canada, the CRTC and the Consumer's Association of Canada.

Janet's true passion is in the not-for-profit sector and she currently serves as chair of the Arthritis Alliance of Canada as well as on the Boards of the Ontario Trillium Foundation, CARE Canada and the Ottawa Art Gallery.

Janet is a recipient of the Queen Elizabeth II Diamond and Golden Jubilee Medals. She was named "Woman of the Year 2001" by Canadian Women in Communications, "Businesswoman of the Year" (2005) by the Women's Business Network and was inducted into the Women's Executive Network Hall of Fame after being named one of "Canada's Most Powerful Women - Top 100" for three consecutive years. In 2008, Janet was awarded the United Way Community Builder Award for Volunteer of the Year. Janet holds an LLB from the University of Toronto and a MA (Econ) from McGill University.

Natalie Courtois

Patient Advocate, Roxboro, QC

Nathalie Courtois worked for Canada Post as a letter carrier for 21 years. After having suffering for more than 20 years from intense and severe joint pain, she was finally diagnosed at age 41 with ankylosing spondylitis. Soon after her diagnostic, she began to use a biologic medication, which enabled her to deal with her pain at a tolerable level. Many other symptoms continued to flare up including chronic urticaria, optic nerve damage and many others.

Nathalie Courtois has been doing a lot of advocacy and volunteer work to raise awareness for auto inflammatory arthritis over the years. She was involved with the My Health My Future project as well as being a weekly blogger in 2012-13 for the ABN Network Organization. She also participated in numerous conferences to promote awareness on arthritis. In September 2013 she was diagnosed with NOMID syndrome, an extremely rare autoimmune inflammatory disease.

Today Nathalie wants to get involved in rare diseases / precocious diagnostics to try changing the orphan drug policy in Canada so more patients will get approval of needed drugs for their condition.

Dallas Hayes-Sparks

Soprano Soloist and Patient Representative

Dallas Hayes-Sparks is an 18 year old from Calgary, Alberta. She is currently in her first year studying opera performance at the University of British Columbia. Dallas began pursuing her singing career seriously at the age of 12, with her first singing competition resulting in Dallas receiving first place in every competition she entered, as well as a Provincial Nomination, in which she placed second at the Alberta Provincial Music Festival.

A year later Dallas was diagnosed with rheumatoid arthritis, lupus, and class VI membranous nephritis. Despite her illness she has entered vocal competitions every year, placing first over 25 times, as well as receiving provincial nominations five out of six competitive years. At the age of 16, Dallas was asked to audition for the 2012 American High School Honors Performance Series choir and sang in New York at Carnegie Hall. Dallas has been section leader of her high school choir, as well as teacher's assistant to two younger choirs. She was an integral part of her school choir for two consecutive competition wins in which she performed a prominent solo.

In September of 2013 Dallas moved to Vancouver, British Columbia to begin secondary level opera training. Since her diagnoses 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 key, and she is determined not to let her illness take away any of her dreams.

Dr. Stefan Lohmander

Professor, Department of Orthopaedics, Lund University, Lund, Sweden

Stefan Lohmander, MD, PhD, is senior professor at the Department of Orthopedics at Lund University, Sweden, and professor at the Institute of Sports Science and Clinical Biomechanics, and the Department of Orthopedics and Traumatology, University of Southern Denmark, Odense. He received his training and degrees at the Karolinska Institute, Stockholm, Sweden.

After serving as a visiting scientist at the NIH in Bethesda USA, he moved to Lund University. His research focuses on basic and clinical aspects of osteoarthritis. He has published over 300 scientific papers, receiving over 13,000 citations with an h-factor of 63.

Dr. Lohmander is the editor-in-chief of 'Osteoarthritis and Cartilage' and past president of the Osteoarthritis Research Society International. He has received the OARSI Award for Clinical OA Research, the ORS Steindler Award for significant international contributions to the understanding of musculoskeletal disease and injury, the Marshall Schiff Award from the American College of Rheumatology for 'research in the interface between rheumatology and orthopedics in musculoskeletal medicine', and the Bone and Joint Decade 2000-2010 Award for Research in Osteoarthritis.

Dr. Hani El-Gabalawy

Scientific Director, CIHR Institute of Musculoskeletal Health and Arthritis, Winnipeg MB

Dr. El-Gabalawy, an internationally recognized rheumatologist, is Professor of Medicine and Immunology, and senior clinician scientist at the University of Manitoba. He also holds the Endowed Rheumatology Research Chair at that institution. He holds a medical degree from the University of Calgary and has completed postdoctoral fellowships in internal medicine and rheumatology at McGill University.

Dr. El-Gabalawy has published landmark studies on synovial biology, the pathogenesis of early arthritis, and has recently established a unique First Nations cohort to study gene-environment interactions in the pre-clinical phase of arthritis. He has served on several committees and has held key leadership positions in The Arthritis Society, the Canadian Arthritis Network, and the Royal College of Physicians and Surgeons of Canada.

Over the span of his career, Dr. El-Gabalawy has published more than 100 peer reviewed papers, as well as multiple book chapters and editorials. He has received academic awards and recognitions including an NIH Bench to Bedside Award, fellowship in the Canadian Academy of Health Sciences, and a Queen Elizabeth II Diamond Jubilee Award for service to the arthritis community.