



Plotting the future of arthritis research in Canada: A community-based approach

Legacy: noun, leg-a-cy

According to Merriam-Webster's online dictionary, legacy is defined as follows:

- 1. a gift by will especially of money or other personal property: bequest*
- 2. something transmitted by or received from an ancestor or predecessor or from the past*
<the legacy of the ancient philosophers>

THAT DICTIONARY DEFINITION of legacy is a kissing cousin to the one used by the Networks of Centres of Excellence (NCE) to describe what happens to a network when its funding period ends. A network's legacy is perceived to be the programs and principles that carry on after a network closes.

Back in 1998 when the Canadian Arthritis Network (CAN) was formed, its management knew that 14-years in the future government funding would terminate. CAN has always had a deadline hanging over it and that deadline is shockingly close: March 31, 2012.

"CAN is too special an organization to fade away to nothing," says **Dr. Claire Bombardier**, Co-Scientific Director,



Left to right – ACAP members Dr. Elizabeth Badley, ACREU, and Lynn Moore, The Arthritis Society

Canadian Arthritis Network. "We have a good plan in place to ensure that CAN's successes will continue to influence the arthritis research community and we are hopeful that the community that CAN has built and fostered will remain active and continue to embody CAN's values and goals."

After much self-assessment, and discussion and consultation with CAN members, stakeholders and partners, CAN's management has identified the best elements of CAN to live on and has developed a Legacy Strategy that relies on the arthritis community to bring it to fruition.

In keeping with CAN's vision of a world free of arthritis and its mission to maximize its R&D partnerships with stakeholders to create and disseminate findings that will improve the quality of life of people with arthritis, decrease the economic disease burden, promote the growth of the economy and cure arthritis, CAN has two overall goals to attain if it is successful in obtaining additional funding from the NCE for the years 2012 to 2014. These supplementary funds are expressly designed to support networks that can demonstrate that their knowledge translation and exchange (KTE) activities will continue to provide

Continued on page 2

Contents

2. Message from the Co-Scientific Directors
3. Helping vulnerable members of society
5. Tipping the balance for treating chronic inflammation
6. Test driving the new conference formula
8. CAN and CAPRI host 2010 ASC

Plotting the future

Continued from page 1

benefit to Canada's economic and social development. CAN's goals are as follows:

Goal #1: Implement a National Framework to reduce the burden of arthritis

The *National Framework for Improving Pan-Canadian Co-operation and Co-ordination for Arthritis* (the National Framework) is being developed by CAN and its partners at the Alliance for the Canadian Arthritis Program (ACAP). CAN is a founding and principal member of this alliance and it is invested in supporting the National Framework due to the tremendous positive influence it could have on the lives of those living with arthritis. The document aims to increase awareness about the impact and burden of arthritis in Canada and to offer solutions to improve how people with arthritis are diagnosed and treated.

Objective #1: Partner and support the development of the National Framework
CAN will provide leadership, expertise, knowledge and resources to the working groups developing the National Framework.

Objective #2: Synthesis and dissemination of strategically important areas of research
Working with its partners within ACAP, CAN will commission up to six syntheses in crucial areas such as early diagnosis, early treatment, obesity and physical activity, and then seek publication opportunities.

Goal #2: Sustain network strengths in developing Highly Qualified Personnel (HQP), creating lasting research efficiencies and facilitating networking and research strategy creation

Not wanting to lose CAN's greatest successes – its research and training programs, knowledge transfer activities, and workshops and conferences designed to foster networking and strategic priority setting – CAN has been seeking

partners to adopt these programs and initiatives. CAN intends to transition its most successful programs and processes to partners who will maintain and sustain them for the benefit of the arthritis community.

Objective #1: Integrate aspects of CAN's Training and Career Development program, including its philosophy and operational expertise, to The Arthritis Society
At this time, The Arthritis Society has agreed to work with CAN to adapt the training program for adoption into The Society's operations. The Society has been a partner in the training program since it was formed and CAN is delighted that The Society is willing to administer the program indefinitely. In February 2011, The Society announced its commitment to the newly named **The Arthritis Society/CAN Training Program** with a further donation of \$1 million to support programming through to March 2014.

Continued on page 3

Message from the Co-Scientific Directors

LEGACY IS VERY MUCH ON OUR MINDS with the recent application to the Networks of Centres of Excellence (NCE) for \$500,000 to carry out legacy activities from April 2012 to March 2014. We are hopeful that our strong plan, coupled with The Arthritis Society's February 2011 announcement that it will continue to fund the training of Canadian PhD students, postdoctoral fellows and network scholars through to 2014, and its commitment to take over the training program in 2014, will tip the NCE's decision in our favour. If you haven't already, you can read about our Legacy Strategy on the cover of this issue. (The Arthritis Society's news release is available on CAN's Media page at www.arthritisnetwork.ca).

First RIPP

CAN's Rapid Impact Platform Program (RIPP) was launched in 2010 to fund activities "today" that will have an impact on arthritis researchers in the future. We are already seeing the impact of this funding program through a landmark initiative that took place February 4-5, 2011, in Montreal, Quebec.

The platform, entitled "Administrative Data in Rheumatic Disease Research and Surveillance," was funded to develop recommendations and definitions to improve the use of administrative information for these purposes. The workshop was led by **Drs. Sasha Bernatsky** (McGill University), **Diane Lacaille** (University of British Columbia) and **Lisa Lix**

(University of Saskatchewan), and moderated by **Dr. John Hanly** (Dalhousie University). Forty-five participants from across the country, together with international experts, met to develop consensus recommendations for the use of administrative data for research on, and tracking of, rheumatic diseases.

This initiative is the first of its kind and will bring Canadian researchers to the forefront internationally. It is certain that the recommendations will be of use in future years by researchers, government agencies and health policy planners, thus contributing to CAN's legacy. CAN is proud to have partnered with the Public Health Agency of Canada (Center for Chronic Disease Prevention and Control, Chronic Disease Surveillance Division) in funding this novel and worthwhile initiative. The recommendations are being finalized and dissemination is expected to start later in 2011.

Sincerely,

Claire Bombardier

Monique Gignac



CAN has established programs, processes and principles that can continue to benefit the arthritis community and CAN's researchers have developed a wealth of knowledge and expertise that is ripe for mobilization.

Objective #2: Introduce research efficiencies by investing in platforms that make existing research expertise and know-how more readily accessible

Through the Platform Program, launched in December 2009, CAN will support opportunities to develop expertise, and standardized tools and operating procedures.

Objective #3: Transfer key CAN programs to partners

CAN is in discussions with The Arthritis Society and the Canadian Rheumatology Association who are both expanding their research funding efforts and may want to harness CAN's expertise in these areas.

After 14 years of existence, CAN has established programs, processes and principles that can continue to benefit the arthritis community and CAN's researchers have developed a wealth of knowledge and expertise that is ripe for mobilization. Everyone involved with CAN would prefer not to see it end, but the real tragedy will be if the Network is unsuccessful at transitioning its programs and supporting the implementation of the National Framework. CAN will learn in July 2011 whether it is successful in obtaining management funds from the NCE. Fingers crossed!

This is a brief overview of CAN's Legacy Strategy. To see the full strategy, please write to can@arthritisnetwork.ca. ■

Helping vulnerable members of society

Despite their small numbers, Canadian researchers involved in pediatric rheumatology are leaders in the international arena of Juvenile Idiopathic Arthritis (JIA) research. With Juvenile Arthritis Awareness Month just behind us (March) it seems like an appropriate time to conduct a JIA "research roundup" to see what the Canadian Arthritis Network's (CAN) funded researchers have been up to.

CAN'S FORAY INTO JIA research began in 2006 with a \$1.7 million commitment to fund **Dr. Alan Rosenberg**, of the University of Saskatchewan, and his multi-disciplinary, multi-institutional research team investigating the interaction of genes, environment and lifestyle early in the disease which, they theorized, could help predict JIA outcomes such as joint damage and diminished quality of life. CAN contributed funding in partnership with The Arthritis Society and the Canadian Institutes of Health Research's Institutes of Musculoskeletal Health and Arthritis and Infection and Immunity, and various academic, government and not-for-profit research organizations.

Since then, CAN has funded a number of research projects and initiatives to help treat the one out of every 1,000 Canadian babies, toddlers and children up to the age of 16 diagnosed with this chronic, disabling condition that significantly impacts a child's quality of life. Summaries of these research projects follow.



JIA researchers work for kids like Sarah, age 12, of Stouffville, ON.

Rae Yeung

Hospital for Sick Children
Understanding Childhood Arthritis Network (UCAN): Towards a harmonized approach to the conduct of research in childhood arthritis worldwide

UCAN enjoys an unprecedented level of international collaboration in childhood arthritis research and is the only network to unite all the major international organizations involved in childhood arthritis research, which together represent over 50 countries and 300 sites. UCAN is an international resource for bench to bedside research in childhood arthritis. Its unique focus is building standardized international research platforms to support rapid translation of basic science findings to improve clinical care. UCAN will provide the opportunity for affected children all over the world to participate in high quality translational research through the creation of standardized research platforms.

Continued on page 4

Helping vulnerable members

Continued from page 3

Heinrike Schmeling

Alberta Children's Hospital

Pharmacogenetics of juvenile idiopathic arthritis: A genome wide association study on the efficacy and toxicity of methotrexate therapy

Methotrexate is the most commonly used immunosuppressive medication for children with chronic arthritis. This research focuses on identifying key gene variants that predict response to methotrexate and treatment-related toxicity. An international partnership of expert physicians and researchers in childhood arthritis was established. Children's arthritis and response to methotrexate therapy will be carefully characterized. The child's genetic make-up will be determined from saliva samples and correlated with treatment response and side effects. The results of the study will enable physicians to optimize childhood arthritis therapy and prevent medication side effects by tailoring medications towards the individual genetic make-up.

Sasha Bernatsky

McGill University

Administrative Database Research in Rheumatic Diseases: Pediatric Populations

The research team is focused on examining the prevalence of specific inflammatory rheumatic diseases

(systemic autoimmune rheumatic disorders (SARD)), using administrative data. The aim is to build on previous work to estimate SARD prevalence in Canadian children. It is well-established that inflammatory rheumatic diseases have a debilitating impact on many Canadians. SARDs, though considered relatively uncommon, are an important part of this burden, since they are often severe and even life-threatening. Existing population-based information on SARD prevalence in Canada is lacking, particularly for children. This project will fill important knowledge gaps and help optimize strategies to improve outcomes in rheumatic disease.

Johannes Roth

Children's Hospital of Eastern Ontario

The effect of whole body vibration therapy on muscle function and joint loading in children with juvenile idiopathic arthritis

Many children suffering from juvenile arthritis encounter permanent joint damage. Both the direct effects of inflammation as well as mechanical factors might be responsible. Recent research has shown that impaired muscle function leading to an alteration of joint loading can induce significant joint damage. In juvenile arthritis, reduced muscle function and abnormal gait are found in a high percentage of patients. In addition to optimal medical treatment of the disease, it is therefore most important to restore normal muscle

function in order to protect the joints of these children. A novel therapeutic approach, whole body vibration, has been shown to improve muscle function very efficiently. This project is going to evaluate whether whole body vibration will significantly improve muscle function and joint biomechanics in patients suffering from juvenile arthritis.

Brian Feldman and Jennifer Stinson

Hospital for Sick Children

Development of an internet-based psycho-educational program for school-age children with arthritis and their parents – Phase 1

In school-age children, activities to manage JIA are shared by the child and family. Improved symptom management and coping early on could help prevent worsening of the disease and symptoms. Therefore, it is important to develop programs to make it easier for children and parents to manage their disease. This study will determine the information needs of children with JIA and their parents to develop an internet-based program of JIA education, strategies to manage symptoms and social support to reduce symptoms and ultimately improve quality of life.

Patrick McGrath with Jennifer Stinson

IWK Health Centre

Development and usability and feasibility testing of a web-based self-management intervention for adolescents with arthritis

While activities to manage JIA are shared by the child and family, adolescents are expected to assume a greater role in disease management. Greater self-management early on could help prevent worsening of the disease and symptoms. Therefore, it is important to develop interventions to assist adolescents to manage their disease. This study will develop and evaluate the usability and feasibility of the "Teens Taking Charge: Managing Arthritis On-line" web-based intervention of self-management, information, and social support to improve quality of life of adolescents with arthritis. ■



Tipping the balance for treating chronic inflammation

CAN funds antibody research in launch of Commercial Development Grant Program

By Brian Bobechko, Director of Research and Development

IN THE CONTEXT OF ARTHRITIS, inflammation usually has a negative connotation for its role as a long-term (or chronic) destructive process. In fact, inflammation also involves healing, and short-term (or acute) inflammation is a vital, positive part of the immune response that provides protection against infection. Unfortunately, rheumatologists currently face a balancing act when fighting chronic inflammation, as they try not to disrupt normal acute inflammation needed for healing. Existing anti-inflammatory drugs, including tumor necrosis factor-alpha (TNF-alpha) inhibitors, don't discriminate acute from chronic inflammation, and while they manage chronic inflammation – they only work in 30-50 per cent of the population – the associated risk of infection is among a number of serious potential side effects.

Important discovery

This inflammation balance is where **Dr. Philippe Tessier**, Professor in the Department of Medical Biology at Laval University in Quebec City, is an expert. For the past ten years, Dr. Tessier and his research team have been studying a new family of cytokines (proteins that move between cells to modulate their respective biological activities), focusing in particular on three members called S100A8, S100A9, and S100A12. These proteins are involved in part of the inflammation process when immune cells (neutrophils in particular, which are a type of white blood cell) are recruited to the site of inflammation (an arthritic joint for example). The key to Dr. Tessier's technology is the discovery that the balance of S100A8 and S100A9 matters for acute inflammation and only S100A9 is essential for chronic inflammation.

In 2006, Dr. Tessier received a CAN Discovery Advancement Program grant to test the role of S100A8 and S100A9

in rheumatoid arthritis. When Dr. Tessier's team used an antibody to prevent S100A9 from performing its normal biological role, animal models of chronic inflammatory diseases – including rheumatoid arthritis, gouty arthritis and Crohn's disease – showed improvements that were comparable to the gold standard anti-inflammatory TNF-alpha inhibitor. Meanwhile, mice that don't have S100A9 are still healthy and able to mount a normal response to "good" inflammation of the acute type. Dr. Tessier's discovery means that chronic inflammation can be treated while acute inflammation is allowed to run its course.

InflammatoRx

The next balancing trick is to get Dr. Tessier's discovery out of the lab and into the clinic. Dr. Tessier is proving adept at this as well. In 2009, with the support of SOVAR s.e.c., a Quebec-based start-up incubator, he founded InflammatoRx to commercialize his discovery. With acting CEO **Caroline Fortier**, InflammatoRx and CAN are working closely on commercialization and R&D for Dr. Tessier's technology.

Potential investors and commercial partners have indicated that proof-of-concept, with an antibody suitable for use in humans, will be the tipping point to consider this an investment ready pre-clinical technology. But finding development money for converting lab tools into clinically relevant treatments is not easy and competition is severe.

To ensure that commercially interesting Canadian arthritis research has an opportunity to reach the marketplace and benefit people living with arthritis, CAN launched the Commercial Development Grant Program (CDGP) award in January 2011 as a new component in CAN's R&D Program. The CDGP creates a mechanism to fund research and



Dr. Philippe Tessier

development of promising technologies that have the potential to become products and services.

CAN's Business Development and Commercialization Committee (BDCC) recognized the potential of Dr. Tessier's technology and the rigor of his commercial development approach and recommended it for a \$40,000 award to fund the work of developing an antibody suitable for use in humans. Now that funding has been granted, the antibody should be ready for testing by the middle of 2011.

To be sure, InflammatoRx is a long way from having a commercial success story, with many expensive safety and regulatory hurdles still ahead. The hope is that CAN's modest investment and commercialization guidance and expertise will help to ensure that InflammatoRx is able to attract the big investments that it will need to push Dr. Tessier's discovery into the clinic, for the benefit of patients. In its own way, CAN is trying to help tip the balance. ■

Test driving the new conference formula

The 2010 Annual Scientific Conference (ASC) kept all the popular features of previous conferences while introducing a new one: a partnership model that could take the ASC beyond the end of Networks of Centres of Excellence (NCE) funding in 2012.

FOR ANYONE WHO REGULARLY attends the Canadian Arthritis Network's (CAN) ASC, 2010 was fairly unchanged:

- large group of delegates (250) comprised of investigators, trainees, consumers, industry, government and invited speakers;
- nearly 100 poster abstracts submitted with winners chosen in four categories;
- interesting program (more on that later);
- many awards and frivolity (sorry, what happens at the ASC stays at the ASC); and,
- thought-provoking presentations to inspire ideas and collaborations.

Where the 2010 ASC differed from previous conferences was the addition of a partner, CAPRI (Canadian Alliance of Pediatric Rheumatology Investigators), as a co-host. While pediatric rheumatologists have always been welcome, and attended, CAN's annual conferences, this was the first year that the two groups joined forces and offered two meetings for the price of one.

The partnership offered a variety of operational, financial and strategic benefits for the partners and attractive advantages for delegates through access to a larger group of arthritis stakeholders to network with.

"The combined meeting allowed a greater exposure of CAPRI and its activities to the Canadian rheumatology research and consumer community and productive networking opportunities with CAN researchers," explains **Dr. Kiem Oen**, Chair, CAPRI, Annual Meeting and Workshops Committee. "Furthermore, it allowed CAPRI members who were not previously associated with CAN an opportunity to attend the ASC. CAPRI members found



ASC industry delegates review the day's program

the combined meeting valuable and look forward to even greater integration with CAN during the 2011 meeting."

Dr. Claire Bombardier, Co-Scientific Director of the Canadian Arthritis Network, concurred and had this to add: "There were many benefits in partnering with CAPRI in a joint arthritis conference. In addition to the travel time saved by attending consecutive conferences and the enhanced networking opportunities, this format was a strategic decision to boost revenues and test a model that

could potentially keep the ASC viable once the Network shuts down. As we hoped, industry sponsorship grew this year."

In terms of improvements for next year, a priority for Dr. Bombardier and the program committee is to achieve more collaboration and integration between the meetings.

The Scientific Program

In keeping with the inclusive nature of the ASC, symposia themes were

wide-ranging and covered broad topics:

- Joint Pain Across the Lifespan
- Patient Oriented Research – Outcomes that Matter
- CAN Highlights
- Stem Cell and Regenerative Medicine: Hype, Hope and Help for those with Joint Disease

In addition to the plenary sessions, CAN also offered workshops that corresponded with the themes listed above (the exception being “CAN Highlights” as that symposium simply showcased some of the notable work currently being funded by the Network.) The workshops provided delegates an opportunity to delve deeper into the topics and brainstorm action items for the future.

Workshop details

The purpose of the **Pain** workshop was to seek feedback on the feasibility of establishing a pain network in Canada. Delegates in the room were in agreement that this would be a valuable addition to the research community and it should not focus on specific types of pain or pain resulting from specific sources. They also wanted the issue of how pain causes disability and the topic of prevention to be a focus of the research. A letter of intent was submitted to the Networks of Centres of Excellence program, but CAN has learned that the application for a pain network was unsuccessful.

The **Patient-Oriented Research** workshop was structured to review the current state of research (in its “adolescence”), identify gaps and challenges in measuring these outcomes (outcome measures need to be personalized, not only standardized, to be meaningful; and, hard outcomes are favoured over self-reported outcomes but both are valuable) and determine whether delegates want to develop a plan to drive an agenda for patient-oriented outcomes research that could be adopted by CAN’s partners (yes!). Delegates to the workshop would like to see the development of a strategic plan and more discussion on this topic to take place at the 2011 ASC. They also endorsed partnerships between CAN, OMERACT and The Cochrane Collaboration.

The jumping off point for the **Stem Cell** workshop was to discuss

what the vision of a future group might be and to draft a preliminary mission statement: *“To create longer lasting biological joint replacements and regenerative therapies – resulting in practical clinical translation – through a multi-sector, multidisciplinary research approach between researchers, scientists, industry and consumers.”* Delegates were enthusiastic about making advances in stem cell and regenerative medicine research and determined the best approach would be to create a supportive environment for this research to take place. In the next 12 months, they hope to organize a consensus conference; define priorities and champions (academic, political, economic, consumer); create an advocacy group; and, create a business case.

Workshop reports were produced

that are available for downloading at www.arthritisnetwork.ca (see Workshop button on homepage).

2011 ASC

The plan for the 2011 ASC is ambitious. CAPRI will again be a partner, but so will CaNIOS (Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus) and CSRG (Canadian Scleroderma Research Group). The partners expect registration may reach 500 and no doubt the needs of four hosts and many hundreds of delegates at two locations (the Quebec City Convention Centre and the Hilton Québec) will test the resilience, patience and planning skills of the CAN staff, but they’re looking forward to the challenge. ■

SAVE THE DATE

**2011 ASC
QUEBEC CITY
OCTOBER 27-29**

**Canadian Arthritis Network
2011 Annual Scientific Conference**

Bridging Gaps in Arthritis Knowledge with CaNIOS, CAPRI, and CSRG

The Canadian Arthritis Network (CAN) is hosting its 2011 Annual Scientific Conference (ASC) in partnership with the Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS), the Canadian Alliance for Pediatric Rheumatology Investigators (CAPRI) and the Canadian Scleroderma Research Group (CSRG) to offer an enriched arthritis conference experience that will benefit and welcome all stakeholders in the arthritis community.

The conference will showcase a broad spectrum of arthritis research and themes may include the following:

- Successes in Arthritis Research
- The Challenges and Controversies
- The Future of Arthritis in Canada and Training its Leaders

Registration will be available summer 2011. Visit www.arthritisnetwork.ca

To discuss sponsorship, please contact Johnathan Riley at jriley@mtsinaï.on.ca
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CANADIAN ARTHRITIS NETWORK | LE RÉSEAU CANADIEN DE L'ARTHRITE | Member of the Networks of Centres of Excellence

CAN and CAPRI host 2010 ASC

October 28-30, Hilton Lac-Leamy, Gatineau, Quebec



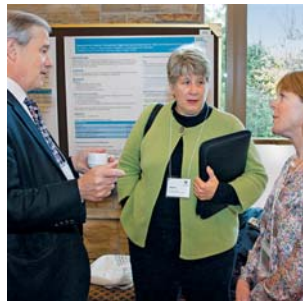
David Griller, SECOR



Dr. Claire Bombardier is interviewed by CTV News



Dr. Andrea Best, Abbott



Drs. Cy Frank, Aileen Davis and Gillian Hawker



Ruben Tavares



Left to right – Marie-Eve Veilleux, Lynn Cooper, Louise Bergeron and Simone Hughes



CAPRI members



Sadia Ladhani

More ASC photos can be found through a link on the homepage of the CAN website.



CANADIAN ARTHRITIS NETWORK | LE RÉSEAU CANADIEN DE L'ARTHRITE

Today's arthritis research :: Tomorrow's cure

The Canadian Arthritis Network (CAN) is funded by the Networks of Centres of Excellence program (www.nce.gc.ca). CAN's vision is "a world free of arthritis" and it seeks to link Canada's leading researchers with partners who will help translate knowledge and innovations to improve the quality of life of people with arthritis, decrease the personal, societal and economic burden of the disease and promote the growth of the Canadian economy.

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