



Institute of Musculoskeletal Health and Arthritis Newsletter: Summer 2014

IMHA - *On the Move!*

A Message from the Scientific Director



Summer greetings! I hope yours is going well.

Gairdner Award

The arthritis research community was thrilled to find out that [Sir Ravinder Maini](#) and [Sir Marc Feldmann](#) of the United Kingdom were the recipients of this year's prestigious [Gairdner Award](#) for their discovery and clinical development of tumour necrosis factor inhibitors as treatments for rheumatoid arthritis.

Not only has this discovery revolutionized the treatment of rheumatoid arthritis, but also of other chronic inflammatory diseases such as ankylosing spondylitis, juvenile idiopathic arthritis, Crohn's Disease, and psoriasis, just to name a few. This discovery has further launched an entirely new era of highly effective targeted biologic therapies that have literally changed the lives of millions of people worldwide who are affected by these devastating inflammatory diseases. These recipients are truly worthy of this great honour which will be celebrated at a [gala dinner](#) the evening of October 30, 2014 in Toronto.

In further recognition of the award recipients, IMHA has worked with the [Arthritis Alliance of Canada](#) and the [Gairdner Foundation](#) to plan a state-of-the-art symposium the next day on October 31 featuring talks by the recipients, and by a number of prominent national and international researchers in the area of inflammation. The symposium will describe new research directions and opportunities that will have a major impact on patients with inflammatory diseases.

IMHA Symposium & Strategic Plan Launch

IMHA is delighted to also use the auspicious Gairdner event as a launching point for its 2014-2018 Strategic Plan which will be introduced to the stakeholder communities on October 30, immediately prior to the Gairdner Award dinner. Together, we hope these events will be inspirational and will help bring inflammation research and knowledge translation to the forefront of medical science.

Signature Initiatives

While plans for rolling out initiatives around IMHA's new 2014-2018 Strategic Plan are underway, the Institute has

been increasingly involved in CIHR's [Signature Initiatives](#). In July, the nine successful teams in CIHR's [Inflammation in Chronic Disease Signature Initiative](#) were selected and informed. A public announcement by the Minister's office is imminent. IMHA has served as the co-lead for this initiative, and is delighted to see its stakeholder communities well represented in the successful teams. In future newsletters, we will feature profiles and interviews with members of these teams to highlight the very important work being done on inflammation. The Institute is also a co-lead on the [Pathways to Health Equity for Aboriginal Peoples Signature Initiative](#), leading the Oral Health exemplar.

Funding Opportunities

Please note that CIHR is still [accepting applications](#) for Component 1, Phase 2 of the Signature Initiative Pathways to Health Equity for Aboriginal Peoples. Full applications are due October 15th, 2014.

More general funding opportunities from CIHR have recently been announced with upcoming fall deadlines. Please visit the [CIHR Funding Opportunities page](#) for current grant listings.

Featured Researcher

In this issue of IMHA on the Move! we are pleased to profile the work of [Dr. Lawrence Korngut](#), who is leading the development of a [Canadian Neuromuscular Disease Network](#) to promote advances in clinical care, research and education in the field of neuromuscular disease. This Network and the Advancement of Burn Care Network, which we featured in [an interview with Dr. Sarvesh Logsetty in June](#), are recipients of the two Network Catalyst Grants awarded by CIHR-IMHA in 2014. Congratulations to the teams of these two projects!

Please submit any questions or comments to IMHA@cihr-irsc.gc.ca and follow me on Twitter [@HaniElGabalawy](#).

Sincerely,

Hani El-Gabalawy MD FRCPC

Scientific Director

CIHR Institute of Musculoskeletal Health and Arthritis

Funding Opportunities and Research News

For information on current funding opportunities, please visit [IMHA's Funding Opportunities](#) online.

IMHA Funding Opportunities

Pathways to Health Equity for Aboriginal Peoples: Implementation Research Team Grants - Component 1

[Pathways to Health Equity for Aboriginal Peoples](#) (Pathways) is a [CIHR Signature Initiative](#) with an overall goal to develop a better understanding of how to design, implement and scale up population health interventions that will improve First Nations, Inuit and Métis health in four exemplar areas: Suicide Prevention, Diabetes/Obesity, Tuberculosis, and Oral Health.

Note: CIHR will be launching a separate Funding Opportunity for Component 2 applications across the exemplar areas at a later date. A Component 3 Funding Opportunity is planned for a later date.

Phase 2 – Full Application:

- Application deadline: **October 15, 2014**
- Notice of Decision: **January 30, 2015**
- Funding start date: **February 1, 2015**

Research News

KT Tools - This summer, the Institute of Health Services and Policy Research (IHSPR) hosted a Policy Round on Knowledge Translation Tools: The Evidence-Informed Healthcare Renewal Portal (aka: [EIHR Portal](#)). The Portal is a continuously updated repository of policy-relevant documents that address 'healthcare renewal' in Canada. Managed by the [McMaster Health Forum](#) and CIHR, the Portal is useful for health system policymakers, and stakeholders including analysts, researchers, and members of the media by helping them to:

- Identify existing documents on various Canadian healthcare renewal topics or priority areas;
- Search by categories (keywords, publication date, topics);
- Access links to use-friendly summaries and full-text reports (if applicable and freely available).

For more information about the EIHR Portal, please see the [brochure here](#) or learn more from the info session [YouTube recording here](#).

Media Webinar – On June 26, 2014, CIHR – IMHA hosted a Media Training Webinar to provide IMHA's community stakeholders with information on how to respond to and prepare for interview requests from different formats of journalistic media including television, radio, print, and online or social media. The session was recorded and can be [accessed here](#) for those who were unable to attend.



CIHR Funding Opportunities

CIHR has announced new Funding Opportunities for general awards including Clinician-Scientist and New Investigator Salary and Training awards, Fellowships, Operating Grants, and Travel awards. Please visit the [CIHR Funding Opportunities webpage](#) for a full listing.

Partner Corner

Canadian Dental Association



NOHAP Report Available

At the end of June, [The Canadian Dental Association \(CDA\)](#) released the National Oral Health Action Plan Consensus Report, which arose out of the Symposium hosted by the CDA February 27, 2014. Priority areas identified for future collaboration included a common position on community water fluoridation; oral health standards for residents in long-term care facilities; and oral health education programs for children and parents. [Please contact the CDA](#) for a copy of the NOHAP Report.

Arthritis Consumer Experts

Best Arthritis Strategies and Practice in the Workplace

Arthritis Consumer Experts is still inviting applications from Canadian companies to



evaluate their best arthritis strategies and practices in the workplace. To participate, please visit the website for [Canada's Best Workplaces for Employees Living With Arthritis Program](#).



Arthritis in Film

Rheumatoid arthritis is rarely the subject of major films starring academy award-winning actors but [Words and Pictures](#) starring Clive Owen and Juliette Binoche is an iconoclast in that sense. Binoche's character is an artist challenged by advancing RA, an autoimmune disease with symptoms of inflammation and resulting pain. Arthritis Consumer Experts founder, Cheryl Koehn, was called upon to assist Ms. Binoche in preparing for the role and to review the script for comment on the accuracy of the characterization of someone suffering from RA.

Featured Researcher

In April, IMHA was pleased to award Network Catalyst Grants to two research teams: one for the Advancement of Burn Care Network (ABCN) headed by Dr. Sarvesh Logsetty (featured in our [June Newsletter](#)) and one for the Canadian Neuromuscular Disease (CAN-NMD) Network led by Dr. Lawrence Korngut. This month we feature Dr. Korngut and the CAN-NMD Network.

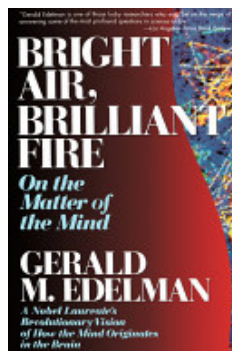
NETWORK PROFILE: The CIHR-IMHA Network Catalyst Grant awarded to Dr. Korngut and his team will help them to develop a [Canadian Neuromuscular Disease \(CAN-NMD\) Network](#) to promote advances in clinical care, research and education in the field of neuromuscular disease. No such organization yet exists in Canada to bring together specialists, scientists, and care providers, to work in partnership with national patient advocacy groups such as [Muscular Dystrophy Canada](#).



PI PROFILE: Dr. Lawrence Korngut is an Assistant Professor in the Department of Clinical Neurosciences at The University of Calgary, and a neuromuscular neurologist interested in clinical translational research, registries, and epidemiology. His research includes clinical trials of new therapies for neuromuscular conditions and he is National Principal Investigator of the [Canadian Neuromuscular Disease Registry](#). He recently led the development of the

Canadian Neurological Registry Best Practice Guidelines, which culminated in the formation of the [Canadian Registry Network](#). Dr. Korngut kindly answered some questions about his work and motivation behind it for IMHA's newsletter.

THE INTERVIEW: "I want to be a neuromuscular neurologist when I grow up," were not likely his exact words, but after reading Nobel laureate [Gerald Edelman's](#) book [Bright Air, Brilliant Fire](#) as a child, the seed was planted in young Lawrence's brain. A grown-up Dr. Korngut recalls how Edelman's work caught his attention with its proposal that "we were at the beginning of the greatest revolution in human history, namely the neuroscientific revolution which would lead us to an understanding of how the brain works."



Further inspired in his post-secondary medical studies by such mentors as neurologist Dr. Warren Blume, neurosurgeon Dr. John Girvin, and award-winning researcher Dr. Michael Strong at the University of Western Ontario, Dr. Korngut pursued a neuromuscular fellowship with Dr. Douglas Zochodne at the University of Calgary. There, he learned about translating bench research findings into human clinical trials. "The excitement of being the first to try a new potential treatment in human subjects," he said, "and realizing that I could co-ordinate collaboration between experts with very different skill sets resulted in a clear sense that clinical translational research would be my focus."

Patients and their involvement in research are also a primary focus, which is why he spends much time in the clinic. "That connection with patients and their diseases drive my research program," he explained. "The sense of duty to impact my patients' future beyond what we are capable of in the clinic is striking as a result of the minimal impact we can make on survival in diseases like certain forms of muscular dystrophy and ALS. At the same time, most of our research ideas come directly from observations we have made in the clinic."

Connecting patients to the research community empowers them, he said, by giving them access to "cutting edge research opportunities regardless of where they live. Neuromuscular diseases are rare diseases and partnership with the patient community is the only way forward in the process of developing and testing potential treatments." As researchers, he said, "Our role as the clinical translational research community is to ensure that our clinical trials are properly designed to ensure safety and minimize the risk of error in estimating the true effects of the compound."

That is where the need for a network comes in. Though patients living with neuromuscular diseases have diverse needs, common themes exist, but support for patients is varied from province to province. "We hope that the establishment of standards of care will help provide more equity for patients across different provinces," said Dr. Korngut. "Access to clinical expertise, equipment, and respiratory care vary and through the formation of the Canadian Neuromuscular Disease Network we expect to impact these issues and improve care across Canada."

Dr. Korngut first noticed a need for a network when trying to recruit subjects for a study. It took a very long time to find only a few patients who met the criteria. "I was concerned that we would not be capable of recruiting sufficient numbers of patients into clinical trials," he said. "At the same time we were approached by the [Marigold Foundation](#) (Calgary, Alberta) who were keen to develop a national neuromuscular registry and had already made a lot of progress."

FACTS ABOUT ... The Canadian Neuromuscular Disease Registry (CNDR):

- Involves over 40 investigators at 10 academic institutions in 8 provinces across Canada.
- Currently houses data on over 2,000 patients from 12 of the 13 provinces and territories.

Continued on page 4...

The Canadian Neuromuscular Disease Registry (CNDR), now housed at the University of Calgary, is a clinic-based registry where trained personnel collect data from patients during clinic visits and from clinic charts. One aspect of conducting a registry in this manner is keeping the data consistent. "For example," said Dr. Korngut, "on every patient with Duchenne muscular dystrophy we request a Forced Vital Capacity data point. This means that every patient with [the disease] must undergo a pulmonary function test as part of their clinical care. In this way, the registry directly impacts the consistency of clinical care across the country."

The registry is also directly helping to increase clinical research opportunities and make recruitment for them more cost efficient. "We are hopeful that one day this will directly impact therapeutic treatments available to patients and their long-term prognoses," said Korngut.

The [CAN-NMD Network](#) will build further on the CNDR's capacity to connect researchers, clinicians, allied health professionals, primary care physicians and patients. "We expect that this closer collaboration will make Canada a world-leader in neuromuscular translational research," he said.

FAMOUS LAST WORDS: "Never before has Canada seen such collaboration and a broad community of patients and care providers coming together for a single initiative within neuromuscular disease. The collaborative environment created by the registry contributed to creating willingness to move to the next level and launch the Canadian Neuromuscular Disease Network and the registry's strong research and clinical infrastructure will make the Network's collaborations effective." - *Dr. Lawrence Korngut*



An informative video on the new Canadian Neuromuscular Disease Network

Meetings of Interest

[American Society for Bone & Mineral Research](#)
September 12-15, 2014 Houston, TX

[Scleroderma Society of Canada Conference](#)
September 18-20, 2014 Winnipeg, MB

[Cochrane Collaboration Colloquium](#)
September 21-26, 2014 Hyderabad, India

[Work Disability International Conference](#)
September 29-October 1, 2014 Toronto, ON

[Quebec Rheumatology Association](#)
October 23-25, 2014 Quebec, QC

[American Osteopathic Academy of Orthopedics
2014 Annual Meeting](#)
October 23-25, 2014 Rancho Palos Verdes, CA

[Arthritis Alliance of Canada 2nd Annual Conference
and Research Symposium](#)
October 30 – November 1, 2014 Toronto, ON

[American College of Rheumatology Annual Meeting](#)
November 14-19, 2014 Boston, MA

Share your news with the IMHA community

Do you have a story that has helped sustain health and enhance quality of life by eradicating the pain, suffering and disability caused by arthritis, musculoskeletal, oral and skin conditions? Are you planning an event that might be of interest to the IMHA community? Is your organization launching a funding opportunity? IMHA would like to celebrate our partners' and stakeholders' success stories, events, and funding opportunities in our monthly newsletter. Please make your submissions to IMHA@cihr-irsc.gc.ca. We look forward to sharing your information with the IMHA community!

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