



IN THE LOOP



Keeping OBRI patients informed

March 2017 | Vol.5

The Ontario Best Practices Research Initiative was developed to improve the treatment and outcomes of Ontarians living with Rheumatoid Arthritis and Spondyloarthritis through the cooperative efforts of patients, researchers, rheumatologists and allied health care professionals.

CONTACT US

OBRI@uhnres.utoronto.ca

Office: 1.866.213.5463

Fax: 1.888.757.6506

www.obri.ca

The information contained in this newsletter is not medical advice. The Ontario Best Practices Research Initiative offers evidence-based information and support to help you better understand your Rheumatoid Arthritis. Always seek the expert advice of your rheumatologist or other health care professional before making changes or additions to your treatment plan.



MESSAGE FROM OBRI

Thank you for participating in the Ontario Best Practices Research Initiative (OBRI)! Your involvement helps us monitor the long term safety and efficacy of medical treatments for Rheumatoid Arthritis (RA) and Spondyloarthritis (SpA) to improve arthritis care and management for patients in Ontario.

Enrollment continues to grow! We now have 3380 patients participating in OBRI-RA and 339 patients in the SpA pilot. As a patient participating in the OBRI, you are making an important contribution to the future of arthritis care and management. For more information on the OBRI, please don't hesitate to contact us, attend a patient session in your area, or visit our website: www.obri.ca. We'd love to hear from you!



NEWS AND HIGHLIGHTS

2016 was a busy year for OBRI - data was presented at the Canadian Rheumatology Association (CRA) meeting in Lake Louise, Alberta; the annual European League Against Rheumatism (EULAR) meeting in London, England; and the American College of Rheumatology (ACR) Annual meeting in Washington, DC. We hosted our 3rd Annual Research Day and Patient Information Sessions in Toronto and London.

The OBRI launched another pilot project in 2016 – the extraction of data from the Electronic Medical Records (EMRs) of participating OBRI rheumatologists. This pilot project is focused on automating the seamless extraction of clinical data from the EMR with the goal of eliminating paper data collection forms. The OBRI is also working to develop a platform to monitor the long-term safety, efficacy and economic benefits of the biosimilars now entering our health-care system.

We are excited to announce that Jennifer Boyle, member of the OBRI Patient Advisory Committee and Dr. Claire Bombardier, OBRI lead investigator, both received prestigious awards for their work! In addition, Dr. Carter Thorne, OBRI Investigator and Clinical Advisory Committee Member, was awarded the distinction of Master by the American College of Rheumatology at the annual meeting – a true honour!

Congratulations to Jennifer Boyle of the OBRI-Patient Advisory Committee!

We'd like to congratulate Jennifer Boyle, member of the OBRI Patient Advisory Committee, on her Ontario Medal of Good Citizenship!



The award, presented by the Honourable Elizabeth Dowdeswell, Lieutenant Governor of Ontario, in Toronto on December 1st, was awarded to Jennifer for her volunteer work and contributions to improved quality of life in the community and province.

Jennifer is an arthritis patient advocate and volunteer for numerous arthritis-related research and educational programs. She has been involved in the Patient Partner in Arthritis program since 2000 and is a health mentor in the Inter-professional Education Program for the University of Toronto, Faculty of Medicine.

As a patient advocate, Jennifer is a member of the OBRI Patient Advisory Committee (PAC) and the Psoriatic Arthritis Research Program at the Toronto Western Hospital. As a person living with psoriatic arthritis, she brings an invaluable patient perspective to the research teams and organizations she collaborates with. She has been a research volunteer for The Arthritis Society since 2008 and was awarded the 2013 Ontario Volunteer Impact Award for her work in research, education, and knowledge translation.

Since being diagnosed with psoriatic arthritis over two decades ago, Jennifer has been an advocate for arthritis education, research, and the inclusion of patients in arthritis research. We are very excited to see Jennifer receive the Ontario Medal of Good Citizenship in recognition of her hard work and dedication!

The importance of long-term data

Clinical data from registries is crucial to determining treatment effectiveness- how medications work in the real world. All stakeholders need to know the benefits and harms before deciding which treatments will improve the quality of life of Canadians. To determine treatment safety and effectiveness, we need information from all patients, both those doing well and those who aren't. Missing information distorts the real view.

The Cochrane Collaboration is an international organization that compiles systematic reviews of treatment benefits and harms. In a nutshell, it assembles all the research available on a particular topic and prepares summaries of what we know and what we don't know about the effects of interventions. Our summaries pull together all the evidence from the many data sources including primary research studies (such as randomized controlled trials) and data from registries such as the OBRI. Randomized controlled trials usually enroll patients without any other health conditions and are conducted over a short limited time period in ideal circumstances. These results need to be placed in a real world context; this is where the OBRI comes in. In the OBRI, clinical information is collected regularly from all registered patients who reflect the full spectrum of disease. This provides information on the benefits and harms over a much longer period and tells us how patients manage in different contexts (eg., access if living rural vs. urban) and with co-existing medical conditions, such as cardiovascular disease, depression and diabetes. This comprehensive dataset provides essential information not only for future patients and their doctors and families, but is crucial for policymakers when advocating for access and funding of medications.

This is why your continued engagement as patients in the OBRI, throughout your disease journey, is so critical to the value of the database. At the Cochrane Collaboration, we value the contribution of all patients and caregivers and a number of OBRI patients also contribute actively to our ongoing work.

The Cochrane Musculoskeletal Group

For more information about Cochrane, please visit <http://crowd.cochrane.org/index.html>

RESEARCH UPDATE

Title: The effect of triage assessments on identifying inflammatory arthritis and reducing rheumatology wait times in Ontario

Authors: Ahluwalia V, Bombardier C, Brooks S, Bell M, Cesta A, Fullerton L, Karasik A, Kendzerska T, Sweezie, Widdifield J.

Abstract: Many patients in Ontario experience long wait times to see a rheumatologist after their family doctor refers them. For those with inflammatory arthritis, waiting months to receive treatment may result in unnecessary joint damage. The average wait time from referral to rheumatologist in Ontario is 122 days. Specially trained Extended Role Providers (ERPs) can be used in rheumatology settings to assess patients on waiting lists, identify those with inflammatory arthritis, and ensure they are seen within a timely manner. This research explored the impact of integrating ERPs into rheumatology clinics. Six rheumatology sites participated in this research, and 177 patients on rheumatology waiting lists received a joint assessment from an ERP to determine their urgency. Of those prioritized by the ERP, the average wait time from doctor's referral to rheumatologist's first visit was 37 days. Rheumatologists suspected inflammatory arthritis or connective tissue disease in 58 of the 71 who were prioritized. Of those who were not prioritized, the average wait time for doctor's referral to first rheumatology appointment was 100 days, however these patients also benefited as they received education on exercise and joint protection. This research demonstrates that ERP joint assessments in rheumatology clinics can significantly reduce wait times to rheumatology care for those with inflammatory disease. This model of care has the potential to improve access to rheumatology care and reduce joint damage for those with inflammatory arthritis.

Anne Lyddiatt, OBRI Patient Advisory Committee (PAC) Member

My RA started about 30 years ago. I had difficulty getting started in the morning, and walking for the first hour or so was difficult. I had 3 small children, was working full-time, and had an active social life, so I thought being tired was a way of life - didn't everyone in my situation feel tired? When I eventually had to go down the stairs on my backside, I knew there was a problem. I saw my GP and he thought it might be RA. I knew a rheumatologist at the time, so called and described what was going on - in my mind this was to rule out RA - not to diagnose it! He saw me right away and started me on meds. Soon after, I was on gold injections. They worked like a charm, and for about 7 years I carried on with life as usual until I developed gold poisoning. I was off work for quite some time and on a lot of prednisone. Once things settled, I started on MTX which worked for a few years until biologics became available.

I wasn't overly affected by my diagnosis in the early years. It was later when the biologics weren't effective, that I felt the impact. That was also a time when I started what seemed like a never-ending round of orthopaedic surgeries. I eventually had to stop working, and felt like I had lost part of my identity. This had a huge impact on my family, which ended up leading to a divorce. While the RA was an underlying factor, it was more my reaction to the changes taking place and feeling a lack of control over my life, that led to this outcome. After the 3 failed biologics, my rheumatologist and I agreed to see how I managed without them. I've been fortunate - my disease settled and I manage flares with a prednisone pulse.

I became involved with The Arthritis Society (TAS) shortly after I was diagnosed and, when I was no longer working, I also became active in Patient Partners, the Cochrane MSK group and OMERACT. Over the years as more arthritis-related groups formed, I joined them.

It's absolutely essential that long-term data is captured so rheumatologists, industry and payers, can assess the impact over long periods of time and study patterns to promote optimal prescribing. I hope those enrolled in OBRI realize this importance and the great contribution they are making for patients now and in the future.

Medication Access: The Changing Landscape

The availability of prescription drugs has changed rapidly in the past 20 years. Today, there are thousands of medications available for the treatment of diseases and conditions that only a few decades ago were never thought possible. Although this is very promising for patients, many medications are expensive and are not covered by provincial health plans or private insurers.

Recently, the high cost of specialty drugs (including biologics) has set off alarm bells for employers and insurance companies. In 2015, specialty medications made up only 2.1% of all claims, but accounted for 29.9% of total drug spending.⁽¹⁾ In an effort to control rising costs, insurance companies have introduced changes to their plans, such as deductibles, increases in co-pays, and the introduction of maximum allowable drug costs (upper limit their plan will pay). Restrictions have also appeared through the use of insurance case managers, and prior authorization systems – these are more of a cost management tool for payers than a health benefit tool for patients.

The World Health Organization recommends the provision of universal drug coverage in every developed country with a universal health care system. The National Forum on Health stated back in 1997 that access to medication is just as important as access to doctors and hospitals. Despite this, Canada remains the only country in the world with a universal healthcare system and no universal drug coverage.

Currently, about 47% of Canadians are covered by government programs; about 43% by private insurers, and about 10% live without drug coverage. Although there are calls for a national Pharmacare program in Canada – a system that supports universal drug coverage that is publicly managed and evidence based- such a program does not yet exist. This leaves many without the medication they need, or living in fear of losing access to their medication.

The need for real world clinical data to accurately demonstrate the efficacy and safety of drugs has never been more important – especially for specialty drugs and biologics. As a participant in OBRI, you provide valuable data that can be used to inform the decision-making of government and private payers to ensure that the right drugs are given to the right patients.

1. Stettin, G. & Henderson, R. Express Scripts 2015 Drug Trend Report. 15EME32857. <https://lab.express-scripts.com/lab/drug-trend-report>. Accessed Dec 5, 2016.

OBRI Principal Investigator Dr. Claire Bombardier Awarded Distinguished Clinician Scholar Award!

This November, OBRI's Principal Investigator, Dr. Claire Bombardier, was awarded the Distinguished Clinician Scholar Award from the American College of Rheumatology (ACR)!

The award, presented to Dr. Bombardier at the ACR Annual Scientific Meeting in Washington, D.C. on Nov. 12th, was given in recognition of her contributions to medicine, education, and clinical scholarship.



OBRI Investigator Dr. Carter Thorne ACR Master Award Winner!

Dr. Carter Thorne was designated a Master of the American College of Rheumatology at the ACR Annual Meeting in Washington, DC. This designation was given in recognition of his outstanding contribution to the field of rheumatology. Congratulations Dr. Thorne!



Patient Perspective

We invite you and a family member to join us at the OBRI Patient Session on **Saturday, September 30, 2017**.

The feedback below was provided by OBRI participants and family members who attended the 2016 sessions. Thank you to all who attended.

General comments about the Patient Session:

“These seminars are good – helps patient understand more about the disease & what’s being done & how we can help”.

“Thanks so much to all who made this possible – way beyond my wildest expectations.”

“2 wonderful speakers: information presented/provided in layman’s language.”

“Sense of hope & confidence in practitioner’s care.”

“I would be happy to be part of the care-giver aspect of research and conversations! (Spouse of OBRI participant)

“First time here – so was impressed with all facets. (Family member of OBRI participant)”

Has your participation in OBRI had a personal impact on you?

“Gives me hope - STILL - after having RA for 45 years!!”

“Making my condition real and a good reason to keep treatment!”

Role of the Caregiver

It is very difficult to watch someone you care deeply about struggle to live with the debilitating pain and overwhelming fatigue of inflammatory arthritis. You are anxious to help and support, but don’t know where to begin. The role of caregiver is a complex, ever changing process. While care-giving in and of itself is not stressful, the always changing landscape of an evolving and shrinking health care system combined with the challenges to access needed care, medications and modalities such as physiotherapy can test the strength, fortitude and finances of most caregivers. Living with a chronic disease is a lifetime journey. Some organizations such as the Alzheimer Society focus a great deal on the role of caregiver due to the populations they represent, but other chronic diseases such as arthritis put less focus on the caregiver as they usually have a community of very strong and vocal patients. However, in the beginning of our disease / diagnosis most people feel very vulnerable and frightened. Adjustments must be made to our lives, families, workplaces and our vision of self and the future. For a strong independent person the diagnosis of inflammatory arthritis can impact physical independence and lead to less emotional independence and decreased self-esteem. For many, even the strongest marriage / partnership can be threatened by the loss of intimacy; sudden physical, emotional and financial dependence; and social isolation. What can the caregiver do?? Learn about inflammatory arthritis so you understand what is happening - remember the disease is not always visible. Offer physical and emotional support and help with the activities of daily living. Inflammatory arthritis can be very episodic in nature so the person living with it will have good and bad days, often in the same week. Being supportive and giving care when needed is not easy – you have to take care of yourself as well!!

Research studies on chronic disease and care-giving continue to be an important focus. In the future, we hope to initiate research on this topic with the OBRI researchers and cohort. Stay tuned!



UPCOMING EVENTS

OBRI Annual Research Day

Friday May 12th, 2017 (Toronto, ON)

2017 Patient Session:

Saturday September 30, 2017 **(location to be announced)**

Please check our website for updated information @ www.obri.ca or ask your interviewer for more details.

Have questions? Want to provide feedback?

Don’t hesitate to contact us!

OBRI@uhnres.utoronto.ca