

IN THE LOOP



Keeping OBRI patients informed

April 2019 | Volume 7

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

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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

The past year has brought new and exciting opportunities for OBRI. As a result of the Canada-wide momentum to create collaborations between researchers focused on rheumatoid arthritis, OBRI has been asked to share anonymized data with other RA researchers. Data sharing is only possible with the permission of each OBRI participant. Since data sharing was not part of the original OBRI study protocol/consent, OBRI participants will be contacted and asked to sign an additional data sharing consent. Please take a moment to sign and return the consent to OBRI.

The patient reported outcomes collected during the interviews are extremely valuable to OBRI. Due to financial constraints, at this time we have temporarily suspended patient interviews at the 5-year mark. Patients who had been enrolled in OBRI for more than 5 years received a letter/email or telephone call from OBRI explaining this decision. Physician data will continue as per usual. We would like to take this opportunity to thank all OBRI participants for your time and dedication!



OBRI at a GLANCE

Cohort Performance Update (January 11, 2019)

Patients referred to OBRI	4463
Patients consented	3802
1. Physician data	3770
2. Interview data	3619
3. ICES* linkage	3795
Patient withdrawal	307
Patient lost to follow-up	179

*Institute for Clinical Evaluative Sciences (ICES)

Trailblazing Women in Arthritis

On International Women’s Day on March 7, 2019, Dr. Claire Bombardier (OBRI principal investigator) was recognized by The Arthritis Society (TAS) as one of Canada’s Leading Women in Arthritis.

Dr. Bombardier is the inaugural recipient of a lifetime achievement award and the Arthritis Society’s Gala honouree. Her reputation is recognized on an international level for her achievements in the field of rheumatology.

In addition to being the OBRI Principal Investigator, she is also a Senior Scientist at the Toronto Research Institute and former Co-Scientific Director at the Canadian Arthritis Network.

Catherine Hofstetter, Chair of the OBRI Patient Advisory Committee, was also recognized during the Gala honouring the Canadian trailblazing women who have made an impact on arthritis research and care.



Dr. Claire Bombardier with Janet Yale, Arthritis Society (Canada) President & CEO. Photo courtesy of The Arthritis Society.

Medical Cannabis & Rheumatoid Arthritis

By Gerald Major, Member of the OBRI Patient Advisory Committee

The Canadian Rheumatology Association (CRA) released a position statement on Medical Cannabis on January 15th, 2019. The full statement is available on the CRA website:

<https://rheum.ca/resources/publications/canadian-rheumatology-association-cra-position-statement-on-medical-cannabis-use-in-rheumatic-disease/>

How does this impact me as a patient?

As an early adopter of medical cannabis, I lived through the pre-legalization and pre-position statement era. I experienced disease at 14 years old and pain became my worst symptom. I turned to cannabis as a treatment option but there was little support at the time.

Not everyone has been an early adopter; in fact, many are new to this treatment option. There is a recent shift in the patient population to the elderly. Some, but not all, patients experience relief when using medical cannabis. It is import for those taking it to be under the care of a physician who is closely monitoring you.

The CRA’s position statement is very detailed. While some may feel they haven’t gone far enough to promote its use, I’m of the opinion that they did given their comfort level and experience with research. As stated in the **Overarching principles for medical cannabis in rheumatology patients**, “Rheumatologists must endeavor to maintain an empathetic therapeutic relationship with their patients, avoid personal biases, and ensure harm reduction for both patients and society.”

The CRA has created a starting point for a patient/physician medical cannabis conversation by:

- Acknowledging that “Medical cannabis may provide symptom relief for some patients with rheumatic diseases”.
- Identifying the need for more research and indicating that they will follow the research.
- Remaining cautious with a new medication, as they should.
- Asking their membership to acknowledge the topic and by providing very detailed descriptions for their membership including:
 - **Table 1. Contraindications and cautions for medical cannabis use**
 - **Table 2. When considering a trial of medical cannabis, the following should be addressed by the prescribing physician.**
- Recognizing the patient need for support and communication with respect to this treatment option.

If this is something you believe can help, continue to advocate for yourself. I call this progress and, as a patient, I appreciate the support.

OBRI PATIENT ADVISORY COMMITTEE PROFILE – ERINN MCQUEEN



Erinn is a new member to the OBRI Patient Advisory Committee. Although new to the committee, Erinn has been involved with OBRI as a patient for the past several years, being a part of the phone data gathering process. Erinn has been inspired by some current and past members of the committee, and when she was asked to be a part of the team, she accepted enthusiastically.

Erinn has lived with Rheumatoid Arthritis for almost 20 years, being diagnosed at the age of 21. During this time, she has been involved with several organizations, including The Arthritis Society, Patient Partners and the Arthritis Research Foundation.

Erinn has had many opportunities to speak to various groups, including potential fundraising donors, pharmaceutical companies, fellow patients, etc.

Over this time of living with RA, there have been many ups and downs, and learning experiences that will not be forgotten. Erinn appreciates the opportunity to spread awareness about RA and in particular how RA affects young women, and very much looks forward to be a part of the PAC for OBRI.



NEWS AND HIGHLIGHTS

We are excited to announce that OBRI data has been accepted for 4 publications in 2018. We also attended and contributed to important scientific meetings including the Canadian Rheumatology Association (CRA) in February where we presented 4 posters and at the European League Against Rheumatism meeting (EULAR) in June where we presented 4 posters. October found the OBRI at both the American College of Rheumatology (ACR) with 5 poster presentations and the Canadian Association for Population Therapeutics with 3 poster presentations. For more information about our research, please visit our website: www.obri.ca.

RESEARCH UPDATE

Study Results: Is high disease activity in early rheumatoid arthritis related to depression?

Bindee Kuriya, Raman Joshi, Mohammad Movahedi, Emmanouil Rampakakis, John S. Sampalis, Claire Bombardier, and Ontario Best Practices Research Initiative Investigators

Depression in early rheumatoid arthritis is a common health concern for patients participating in the Ontario Best Practices Research Initiative. Active RA symptoms (high disease activity) were found to be related to depression and its persistence over time. The risk of depression seems particularly increased in women with active disease. Future studies in early rheumatoid arthritis are needed to determine if there is a “window of opportunity” to control disease activity to reduce the occurrence of mental health outcomes, such as depression.

Study Results: Are dangers to your heart also bad for your rheumatoid arthritis?

Kangping Cui, Mohammed Movahedi, C. Bombardier and B. Kuriya on behalf of the OBRI Investigators

Rheumatoid arthritis has been shown to increase your chances of having cardiovascular disease (disease of the heart and/or blood vessels). High blood pressure, abnormal lipid amounts (e.g. triglycerides, cholesterol, fat phospholipids) in the blood, diabetes and smoking are all risk factors for heart disease. OBRI investigators asked the question: Do these dangers to your cardiovascular health influence your rheumatoid arthritis outcomes? The study found that heart disease risk factors, even in the absence of heart disease, were related to active rheumatoid arthritis symptoms (high disease activity) and disability. Further study will examine how much each of these cardiovascular risk factors contributes to your arthritis outcomes.

USEFUL TIPS AND RESOURCES

Opening jars can be challenging. To make the task easier, use something to help you get a firm grip:

- wear rubber gloves
- use a rubber tourniquet
- use a wide rubber band
- use a silicon pad

RESOURCES FOR PEOPLE LIVING WITH ARTHRITIS:

Canadian Arthritis Patient Alliance

www.arthritispatient.ca

Joint Health

www.jointhehealth.org

Rheuminfo

www.rheuminfo.com

The Arthritis Society

www.arthritis.ca

Canadian Spondylitis Association

<http://www.spondylitis.ca/>

Arthritis Research Canada

<https://www.arthritisresearch.ca/>

DAILY SMILE

(submitted by an OBRI patient)

I had a follow up appointment for my hip replacement with the surgeon. As I sat in triage, I analyzed the X-ray of my hip that was in front of me on the computer monitor. I “discovered” some unqualified spots in the area of my tailbone. I became concerned.

After my examination by the surgeon, he asked me if I had any questions. I felt comfortable to ask “yes, I’m wondering what those spots are on my X-ray?” (Thinking I knew that there was something up for sure.)

He politely responded, “That is gas”.

Please submit your humorous anecdotes to OBRI at

OBRI@uhnres.utoronto.ca

CAREGIVER PERSPECTIVE (by David Barker)

The Language of Caregiving

There are many words we can use and be aware of as caregivers. Four words come to mind. First is “advocating.” I don’t think I have ever had to use this word with the wonderful rheumatologists that care for my wife, but there have been times in other medical and social interactions (even those with family and friends) when a second voice seemed to bring a little more attention and understanding from the listeners. Second is “helping/serving.” Perhaps it is taking a second plate to the buffet, finding a chair with arms, opening a can or jar, or a myriad of other things that make life easier. It’s even better if we don’t have to be asked. Third is “informed.” As the options for treatment become more numerous and complex, an informed caregiver can help in decision-making and navigating the treatment options. The final is “listening.” This is the hardest for me. To sit still long enough to listen to the stories, frustrations, and small victories helps us enter the world of the arthritic patient, and gives value and dignity to the one we are journeying with. It gives us an opportunity to tell our stories as well which engages us to life and realities together.



UPCOMING EVENTS

6th OBRI Annual Conference: **May 3, 2019**

Sandman Signature Hotel, Toronto Airport

55 Reading Court

Toronto, ON M9W 7K7

If you are interested, agenda and registration details will be available on the website or call OBRI.

2019 Patient Sessions: **TBA**



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***Have questions? Want to provide feedback?
Don't hesitate to contact us!***