



IN THE LOOP



Keeping OBRI patients informed

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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

Collaboration was the key word for the OBRI in 2019. Thank you to all OBRI participants who consented to data sharing – an essential component to these exciting OBRI collaborations listed below:

1. OBRI is pleased to announce our collaboration with Rhumadata, a Quebec rheumatoid arthritis (RA) registry. For the first time in Canadian RA research, individual data from two registries will be combined to create a new dataset, essentially doubling the size for both registries. The first project will compare Tofacitinib (Xeljanz®) use to other biologics in RA patients.
2. After years of working independently, Canadian rheumatoid arthritis (RA) researchers have joined together and are looking to answer questions using a larger, merged, national data set. Some of this research will look at the uptake of biosimilar medications in Canada for patients with RA and other diseases such as dermatology and gastroenterology. This larger data set will also be used to look at practice patterns and to update the Canadian treatment guidelines for rheumatoid arthritis.
3. OBRI is looking beyond rheumatoid arthritis and is creating partnerships with other disease groups such as psoriatic arthritis and gastroenterology. We offer more than a decade of experience collecting and analyzing real world data.

Updates on these and other projects are available on the OBRI website (www.obri.ca).

OBRI Clinical Advisory Committee Profile: Dr. Sibel Aydin



Dr. Sibel Aydin is the newest member of the OBRI Clinical Advisory Committee. Dr. Aydin is an OBRI investigator and practices Rheumatology at the Riverside Campus of the Ottawa Hospital. In 2019, she was appointed Director of Research at the Arthritis Center, University of Ottawa.

Originally trained in Istanbul, Turkey, Dr. Aydin received a fellowship in imaging inflammatory arthritis at the University of Leeds. In Turkey, she established a clinical registry for patients with Psoriatic Arthritis (PsA) entitled The Psoriatic Arthritis Registry of Turkey.

Her main research interest is the identification of true inflammation, accurate assessment of radiographic involvement in inflammatory arthritis and predictive factors in the development of inflammatory arthritis in psoriasis.

Expansion to Psoriatic Arthritis

Over the last decade, the OBRI has developed a sophisticated platform to study therapeutics in rheumatology, including rheumatoid arthritis and spondyloarthritis. We are happy to announce that the OBRI will be collaborating with Dr. Sibel Aydin on a new province-wide community based Psoriatic Arthritis (PsA) registry. Dr. Aydin has been working closely with the OBRI team over the past year to develop the OBRI PsA registry. Data collection is set to begin this summer.

Psoriatic arthritis is a type of inflammatory arthritis that affects people with psoriasis, a skin condition characterized by itchy red scaly patches. Many patients have psoriasis before the joints are affected. Unlike rheumatoid arthritis (RA), PsA affects males and females at the same rate (RA is more common in females). Like RA, early diagnosis is key to control the disease and prevent joint damage. Read more about PsA on The Arthritis Society website (<https://arthritis.ca>).

RESEARCH UPDATE

STUDY RESULTS: Do Patients Differ in Their Assessment of Rheumatoid Arthritis Disease Symptoms Compared with Their Doctors?*

By Pooneh Akhavan, Mohammad Movahedi, Claire Bombardier

Rheumatoid Arthritis (RA) is a chronic disease that requires regular follow-ups. Doctors' make treatment decisions based on their assessment of disease status, a process which takes into consideration physical examination (tender and swollen joint counts), lab test findings, and patient responses to standardized questionnaires. Patients' assessment of their disease severity is based on these and other factors such as pain, fatigue, and level of disability. Both patients' and doctors' assessment of disease status changes over time.

The OBRI investigators looked at the patients' and doctors' assessment of disease status in early RA patients joining OBRI and 1 year later. The difference between patients' scores of disease symptoms and doctors' scores of disease activity were compared and the factors affecting these scores were examined.

There was a significant difference between the patients' and doctors' assessment in approximately 25% of the early RA patients joining OBRI. In most cases, the patients' score was higher than the physicians' score. One year later, the difference remained but was smaller. A closer look at the patients who scored themselves higher than the physicians at entry into OBRI showed that these patients had more fatigue, disability, pain, tender joints, and comorbidities. The patients who scored higher 1 year later had higher pain scores.

Doctors should consider this finding when making treatment decisions.

**Factors affecting the discrepancy between patient and physician global assessment of disease activity in patients with early rheumatoid arthritis over time. EULAR Annual Scientific Meeting, Madrid, ESP. June 12-15, 2019 (Poster Presentation)*

OBRI Patient Advisory Committee Profile: Maureen Forbes



Encouraged by her rheumatologist to participate in the Ontario Best Practices Research Initiative (OBRI), Maureen has recently completed 5 years of phone data gathering interviews with OBRI.

Diagnosed 6 years ago with rheumatoid arthritis, Maureen has had both hips replaced and continues to deal with the highs and lows of the disease.

After 34+ years with the Ontario Public Service, retirement has provided Maureen with the opportunity to learn more about this disease and share information informally with other RA patients.

Maureen is currently a member of the Foundation Board for Big Brothers Big Sisters of Halton and Hamilton and is a former chair of the Association Board for Big Brothers Big Sisters of Hamilton and Burlington.

Married with 2 adult children, Maureen enjoys the support of her family and friends. She joined the OBRI Patient Advisory Committee in early 2019.

CAREGIVER PERSPECTIVE

David Barker, OBRI Patient Advisory Committee Member

Every July the most famous bicycle race in the world happens in France and Belgium, the Tour de France. As I watch it, a word keeps being repeated—domestique”. Yes, it means “servant,” but it refers to anything but something menial in the Tour. It’s a word of prestige, respect, and necessity. Domestiques are carefully chosen and, without them, the team cannot be successful.

In many ways, caregivers function in the same valued and important role. Sometimes a domestique rides out in front creating a draft for the other riders on the team. A caregiver often goes ahead to make things easier, or even possible, for the person being cared for. Sometimes a domestique is sent to chase down a break-away group that is creating a threat to the success of the team. A caregiver sometimes is called on to advocate for their patient when circumstances and decisions (or lack of decisions) create a threat to the patient’s well-being. A major task of the domestique is to get food and water for the team from the team car and then distribute the supplies to team-members as the peloton is racing forward. Often a caregiver is tasked with ensuring that the necessities of life and well-being are provided as life moves along

An important feature of domestiques is that they are an integral part of the team. They are part of the conversations and strategy discussions on how to best proceed. A caregiver is very much part of the team and needs to be part of the conversations with doctors, therapists, and others so that strategies for treatment and care are well thought out and implemented as a team moving forward together.

To be a domestique in the Tour de France is a high calling and honour. To function as a caregiver in a similar way for a spouse, parent, grandparent, child, friend, neighbour, or colleague is of the same high calling and honour.

David is married to Lorraine who was diagnosed with rheumatoid arthritis when she was 17 years old. Lorraine and David have just celebrated their 45th wedding anniversary.



NEWS AND HIGHLIGHTS

We are excited to announce that OBRI data was accepted for 5 publications in 2019. 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 2 poster presentations. For more information about our research, please visit our website: www.obri.ca.

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/>

RESOURCES FOR CAREGIVERS

Ontario Caregiver Association,
<https://ontariocaregiver.ca>.

DAILY SMILE

(submitted by an OBRI patient)

Several years ago, when I was first dealing with my diagnosis and also dealing with not playing varsity soccer anymore, one of the university football players saw me limping. He asked what had happened.

I struggled for a few moments as I wasn't keen on sharing my whole story at that point. So I blurted out, "I sprained my ankles."

He questioned, "Both of them?!?" I confidently answered, "Yes."

I have since found an efficient and honest way to answer such inquiries!

Please submit your humorous anecdotes to OBRI at

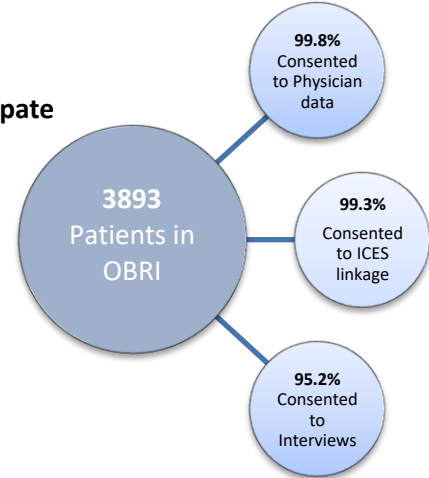
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OBRI at a GLANCE

What's in our Data?	
# Patient Interviews conducted by OBRI	45,607
# Physician Visits submitted to OBRI	43,342

How do patients participate in OBRI?



UPCOMING EVENTS

7th OBRI Annual Conference: May 8, 2020

St. Paul's Bloor Street, 277 Bloor Street East (Bloor at Jarvis)
 For more information, the agenda and registration details will be available on the website or call the OBRI. You are welcome to bring a guest (all attendees must register).

Online registration available [here](#).

Download the [agenda](#).



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