

# 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 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](http://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.

We've had a busy and exciting year at OBRI – we surpassed 3,000 patients in our RA clinical cohort, expanded our registry to include SpA, presented research at a number of International and Canadian Scientific meetings including the European League Against Rheumatism (EULAR) meeting in Rome, American College of Rheumatology (ACR) meeting in San Francisco, and Canadian Rheumatology Association (CRA) meeting in Lake Louise. We also held our 2<sup>nd</sup> Annual OBRI Research Day, and hosted Patient Information Sessions in Barrie, Hamilton, and Sault Ste Marie.

So far 2016 is shaping up to be just as busy – we look forward to keeping you in the loop on our latest activities and upcoming events. For more information on OBRI, please don't hesitate to contact us, attend a patient session in your area, or visit our website: [www.obri.ca](http://www.obri.ca). We'd love to hear from you!



### NEWS AND HIGHLIGHTS

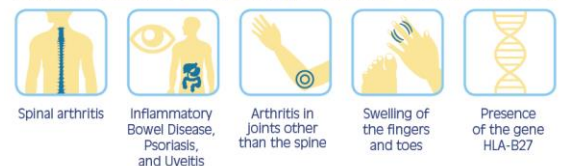
#### Cohort Expansion to include SpA!

The OBRI clinical cohort was expanded this year to include Spondyloarthritis (SpA). This initiative is a 2-year pilot project led by Dr. Vinod Chandran, rheumatologist at Toronto Western Hospital. SpA describes a group of inflammatory arthritis diseases with common features, including inflammation of the spine and other joints, and swelling in sites where ligaments and tendons attach.

To date we have over 150 patients enrolled from 11 rheumatology sites. Data will be used to monitor treatment patterns, determine the long-term value of different SpA treatments, provide insight

into treatment patterns and classification of disease, and help us inform policy makers on how to improve access to treatment and funding. We're excited about this expansion and look forward to growing our SpA cohort in 2016!

#### Characteristics of Spondyloarthritis (SpA) includes:



## Introducing Dr. Mohammad Movahedi



We'd like to introduce Dr. Mohammad Movahedi - our newest member of the OBRI research team! His role includes analyzing data, developing and

answering OBRI research questions, and communicating research outcomes through the development of abstracts, posters, and publications.

Previously, Dr. Movahedi worked as a researcher at the University of Leeds, UK where he managed and analyzed data for a large randomized trial exploring the preventive effect of aspirin on risk of colorectal cancer. He also worked as a researcher at the University of Manchester, UK investigating steroid safety in patients with RA using Clinical Practice Research Datalink (CPRD), a database of anonymized UK primary care electronic medical records. Dr. Movahedi has many years of research experience, with publications in high-impact scientific journals, presentations at national and international conferences, and 5 years of teaching experience as an assistant professor of Epidemiology at the Beheshti University in Iran. He also currently serves as a reviewer for a number of peer-reviewed journals.

Dr. Movahedi holds a PhD in Clinical Epidemiology from University of Leeds, UK, and a Medical Degree (MD) from Tehran University, Iran. We are very pleased to welcome him to OBRI!

### 3 new OBRI interviewers!

We'd like to welcome 3 new interviewers to the OBRI team! Lynda Linderman, Lisa Guerin, and Gail Walker recently joined OBRI to collect data from patients enrolled in the OBRI RA and SpA clinical cohorts. Telephone interviews with patients are used to collect data on medication use, comorbidities, quality of life, socio-economic status, social support networks, work productivity, and functional ability.

Each OBRI interviewer is trained then assigned patients whom they will interview for as long as they remain in the study. We'd like to welcome our newest interviewers to the team and know they look forward to speaking with you.



## RESEARCH UPDATE

### OBRI RA Clinical Cohort Update

OBRI was founded in 2005 to improve the treatment and outcomes of Ontarians living with RA through cooperative efforts of patients, researchers, rheumatologists and allied health professionals.

Data collected is used to monitor the long-term safety and efficacy of RA treatments, provide insight into rheumatology treatment patterns, identify gaps and barriers to care, and inform policy makers on how to improve access to treatment funding.

Today, 64 rheumatologists participate in OBRI and over 3,000 patients with RA are enrolled in the OBRI clinical registry. These patients volunteer their time and clinical data to help us deepen our understanding of arthritis care and disease management through clinical research. Below you will find a summary of some of our research findings. To learn more about our other studies, visit our website: [www.obri.ca](http://www.obri.ca).

#### Study Results: Contributions of Social Determinants of Health on Treatment Responses in Rheumatoid Arthritis Patients

**Authors:** Kangping Cui, Claire Bombardier, George A. Tomlinson, and OBRI Investigators

Using data from OBRI, this study looked at the impact of social and economic factors on the achievement of remission in RA. Factors explored included age, sex, social and economic status, health behaviors, social support, and living conditions. The association between these factors and remission was evaluated using logistic regression analyses, and controlling for clinical factors such as RA duration, RA medications, disease activity and functional ability. At 6 months, higher neighbourhood income and private insurance were associated with disease remission. At 1-year follow up, living with someone, living in a rural community, and smoking were associated with remission. Socioeconomic factors appear to have an effect on remission at 6 months. Health behavior and living environment appear to be associated with remission at 12 months. Different social determinants may affect treatment response and disease outcome at different time points and this study highlights the complexity in studying social determinants of health.

#### Study Results: Patient Priorities in RA Research: An Exploration of Perspectives from those Enrolled in a Canadian RA Clinical Cohort

**Authors:** Fullerton L, Cesta A, Hofstetter C, Bombardier C, and OBRI Investigators

RA patients enrolled in OBRI were invited to participate in 1 of 3 patient sessions held in 2014. In each session, small group discussions were facilitated by a moderator. Patients were asked to discuss their priorities for RA research, identify gaps they felt were present in OBRI data collection, and complete a questionnaire on their use of social media. In total, 48 RA patients participated in a facilitated discussion. Four research priorities were identified:

1. A need for qualitative research focused on patient experiences with RA including: journeys to diagnosis, symptoms, treatment side effects and challenges/concerns
2. A need to research patient satisfaction with rheumatology care including: accessibility, communication, and disease management
3. A need for OBRI research questions addressing patient social support networks, strategies for coping with flares, diet and exercise, and the use of alternative therapies
4. A need for more information from rheumatologists on medication risks and side effects

Although the majority of patients reported using social media, only 54% preferred to receive research related communication through email. This study identified patient preferred communication methods and the need to expand OBRI data collection methods to include more experience based information.



## DID YOU KNOW?

The MedsCheck program is one of many professional services offered by Ontario community pharmacists. It consists of a one-on-one interview between a pharmacist and a patient to review the patients' medications. It is designed to encourage patients to better understand their medication therapy, and to ensure they can experience benefit from their medications by taking them correctly. Any patient with a valid Ontario Health Card who is currently taking a minimum of 3 prescription medications for a chronic condition is eligible to receive a MedsCheck.

During your MedsCheck appointment with your pharmacist, you will be able to review your prescriptions, along with any over-the-counter and alternative medications (including vitamin supplements) that you are taking and how they may be interacting with or affecting each other. At the end of your private one-on-one discussion with the pharmacist, you will receive:

- A complete and accurate medication list (including over the counter medications, vitamins, and natural health products) of all the medications you are taking
- Information about how you should take your medications to make sure they are most effective and helpful
- Suggestions for managing medication side effects
- Support to help avoid and/or manage drug interactions you may experience.

The MedsCheck program is a great way to learn more about your medications and how to better manage your condition and medication side effects. If you haven't already done so, book a MedsCheck appointment with your local pharmacist today!



## HIGHLIGHT – Arthritis Patient Charter

Have you seen it? Have you read it? An updated Arthritis Patient Charter is now available! The charter highlights an arthritis patient's rights and responsibilities associated with their arthritis and care. This Charter is a grassroots culmination, led by the Canadian Arthritis Patient Alliance (CAPA) with input, support, and participation from all Canadian arthritis stakeholders, including founding support from the Ontario Rheumatology Association. The Charter is also a reflection of the changing landscape of the arthritis community and the healthcare system. It emphasizes the strong and committed relationship of patients and their healthcare providers. Look for the Charter in your rheumatologist's office or visit it on line at: <http://arthritispatient.ca/projects/arthritis-patient-charter/>

### Nancy Roper, OBRI Patient Advisory Committee Member



My name is Nancy and I'm 51 years old. I've had RA since I was 39, and thanks to excellent care and drugs, am almost 100% able-bodied and able to live a full and active life. Here is my arthritis story:

At New Years the year I was 39, I was tobogganing with my nephews at the cottage and each time we went inside, I felt like I had pulled a muscle: except it was a different muscle each time and they were adding up! Within 3 days, I could barely walk and my hands were pretty much useless. Each day a different joint would be added to the

picture and I'd have to figure out how to do my day to day activities without it. The next stretch of my life was scary as we tried to come up with a diagnosis. Clearly something was seriously wrong, but we took several wrong turns in the diagnosis phase so I was in limbo for much longer than necessary. I started pondering the songs for my funeral and saying my good-byes.

Fortunately, I am an IT specialist and worked from home most of the time, spending my days talking to customers around the world via telephone and email to design their computer backup solutions. This allowed me to keep working, although the days were short since every task took so much longer due to the pain and disability, plus I was sleeping a lot and spending a lot of time at medical appointments.

Every evening I jumped on the internet, looking up all sorts of horrible illnesses. I'll never forget the day the penny dropped. Both my maternal grandmother and paternal grandfather had had very severe Rheumatoid Arthritis. A quick trip to the Arthritis Society website confirmed my hypothesis. What a help to finally have a name for the illness and a list of symptoms to watch for!

It was the year of the SARs epidemic so it took several months to see a rheumatologist. However, the doctor I saw was FANTASTIC and I've enjoyed wonderful medical care ever since. I was back on my feet shortly after I met my new doctor and we overcame a flare 2 years later. Touch wood, all has been well ever since.

Although I was initially terrified about what the future would hold, it has turned out to be excellent so far. I've met many people whom I really enjoy and would not have met if I'd never become ill. I've also had the opportunity to get involved in the medical community as a volunteer, both on the OBRI Patient Advisory Committee and in the Patient Partners in Arthritis program where we volunteer at the medical school. This has fulfilled a passion for medicine that I had overlooked when I chose my career. Better still, the resume that I built via volunteering allowed me to jump to a new career working on the IBM Watson computer - the one that won Jeopardy in 2011. So now I spend my days working with Watson to help doctors and drug companies match patients to clinical trials.

I pray that medical science can find a cure for arthritis in my lifetime – I'm incredibly curious to know what causes this disease!

## Patient Perspective – 2015 Patient Sessions

A conversation with Joyce Kellough

### Why did you want to attend a patient session/ what motivated you to attend?

I have a nursing background so have always had an interest in medical research, especially if it happens to focus on RA. I've been enrolled in OBRI since 2010, and felt attending a session was an opportunity to learn more about the study and its main objectives.

### What did you learn?

The really interesting thing I learned was that clinical trials conducted by drug companies have very definite parameters when choosing study participants. When the drug is put on the market, it reaches a much broader section of the population, many of whom have other medical conditions besides just RA. Thus unexpected problems and side effects occur on a population-level that were not originally observed in the drug trial. Clinical cohorts like OBRI allow researchers to monitor the true safety and effectiveness of drugs on a population level over time.

### What was the major highlight for you?

A major highlight was having an opportunity to listen to the expertise of other Rheumatologists, learn of their involvement in research, and their endeavors to help improve the treatment and outcomes of people living with RA, not just their own patients.

### Why should patients attend a session in their area?

OBRI Patient Sessions give an overview of the research going on and the many professionals working to improve treatment and care for those with RA. Attending a session will give you an opportunity to realize how many other people are affected in similar ways. It's an opportunity to learn! It's an opportunity to gain better understanding of the disease. I hope to attend one of the sessions being held in 2016!



## 2016 Patient Information Sessions

Mark your calendars – we're holding two OBRI patient information sessions this Spring and would love to see you there! Our sessions will be held on:

- Saturday May 14<sup>th</sup> in Toronto, ON
- Saturday June 4<sup>th</sup> in London, ON

Anyone enrolled in the OBRI clinical cohort is invited to attend – family and friends are welcome too!

Sessions will begin with a presentation from Dr. Bombardier, Principal Investigator of OBRI, and will be followed with time for discussion/questions and a presentation by local Rheumatologist. Dr. Edward Keystone will present at our session in Toronto, and Dr. Janet Pope at our session in London.

At each session patients will have an opportunity to ask questions, provide feedback, and meet OBRI interviewers, OBRI staff, other patients with RA, and members of the OBRI Patient Advisory Committee.

Patient feedback from our 2015 sessions:

*"The team of presenters and organizers were enthusiastic, knowledgeable, and informative."*

*"I have a better understanding of OBRI, a better understanding of the types of arthritis and medications for RA."*

*"The program provides a great opportunity to meet with people in this field – the presentations were very informative"*

Come to learn how your involvement in OBRI is contributing to the future of arthritis care and management in Ontario! We'd like to meet you, and hope to see you there!

## UPCOMING EVENTS

### OBRI Annual Research Day

Friday May 6<sup>th</sup> 2016 (Toronto, ON)

### 2016 Patient Sessions:

Saturday May 14<sup>th</sup>, 2016, 10am-12pm (Toronto, ON)

Saturday June 4<sup>th</sup>, 2016, 10am-12pm (London, ON)



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

[OBRI@uhnres.utoronto.ca](mailto:OBRI@uhnres.utoronto.ca)