

# 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.

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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

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.

In fact, many of you ask us if you should keep participating in your telephone interviews if you are feeling well. Having you participate while feeling well is exactly the information we are interested in hearing- so that we can communicate and advocate for continued access to treatments and therapies on your behalf to payers and regulators!

2017 has been a busy and successful year – today, our cohort includes more than 3,500 patients and 71 rheumatologists from across Ontario. We have presented research and generated insights at various international and national scientific meetings, hosted our 10<sup>th</sup> patient information session, reported on our SpA pilot initiative, and formed new linkages with our pediatric colleagues. We also hosted our 4<sup>th</sup> Annual Scientific Meeting for rheumatologists, researchers, and stakeholders, and worked closely with our Patient Advisory Committee and Clinical Advisory Committee to engage patients, exchange expertise, and advance our research initiatives.

2018 is shaping up to be just as busy – we look forward to celebrating our 10-year anniversary and keeping you in the loop on our latest activities and upcoming events. For more information on OBRI, please contact us, attend a patient session in person or online, or visit our website: [www.obri.ca](http://www.obri.ca). We would love to hear from you!

Thank you to all of our patients participating in OBRI. A special thank you to those patients who are completing their 10 years in the study! With your contributions, we can continue to create new and important insights for patients, prescribers and payers.

*Claire Bombardier, Principle Investigator, OBRI*

## Investigator Profile – Dr. Carter Thorne



**Dr. Carter Thorne** is on the Consultant Staff at Southlake Regional Health Centre in Newmarket, Ontario, Chief of the Division of

Rheumatology and Director of The Arthritis Program; the latter is a unique Inter-Professional care program established to optimize outcomes for people who have arthritis and other rheumatic disorders.

Dr. Thorne is sought for his expertise in developing Outcome Based Clinical Programs, not only in Arthritis Care, but also Shared Care in a Comprehensive Musculoskeletal Program. He was a member of the Steering Committee of CARE, a European based project, addressing and identifying best practices in ‘non-pharmacologic management of arthritis’.

Dr. Thorne is Past-President of the Canadian Rheumatology Association (2012-2014) and Past Secretary Treasurer (1996-2004). He is a founding member of the Ontario Rheumatology Association and Past-President (2008-10). He is Past Secretary-Treasurer of PANLAR. He is active in Clinical Research as Principal Investigator with The Arthritis Program Research Group Inc. As part of a strategic interest in identifying ‘Best Practices’, he has established an Early Arthritis Clinic, collaborating with a national initiative (CATCH-of which he is a member of the Scientific Advisory Committee and Operations Director), and an Osteoporosis Intervention Clinic.

Dr. Thorne has been actively involved as an OBRI investigator since its inception and is a member of the Clinical Advisory Committee. The OBRI would like to acknowledge Dr. Thorne as the highest recruiting investigator in OBRI. Thank you Dr. Thorne!!

## NEWS AND HIGHLIGHTS

We’ve had a busy and exciting year at OBRI – we presented research at a number of International and Canadian Scientific meetings including the American College of Rheumatology (ACR) meeting in San Diego, the Canadian Rheumatology Association (CRA) meeting in Ottawa, the International Conference of Pharmacoepidemiology (IPCE) in Montreal and at several meetings focused on Real World Data. We also held our 4th OBRI Scientific Meeting in Toronto and hosted our 10th Patient Information Session in Brampton offering, for the first time, the opportunity to join the session remotely from the comfort of your own home.

We are excited to announce that Dr. Vandana Ahluwalia published OBRI findings in the September 2017 issue of Clinical Rheumatology. The article is titled: Predictors of patient decision to discontinue anti-rheumatic medication in patients with rheumatoid arthritis: results from the Ontario Best Practices Research Initiative. (For more information, see Research Update.)

We are delighted to expand our investigator team and welcome the following 16 investigators: Dr. Mary Bell, Dr. Gregory Choy, Dr. Shirley Chow, Dr. Emily McKeown and Dr. Sharron Sandhu from Sunnybrook; Dr Antonio Cabral, Dr. Sybel Aydin, Dr. Nataliya Milman and Dr. Ines Midzic from the Ottawa General; Dr. Julie Brophy and Dr. Rafat Farawi from Guelph Cambridge area; and Dr. Raman Rai, Dr. Suneet Sekhon, and Dr. Ola Wierzbicki from Hamilton.



### Building data centres for Ontario specialists

Physicians, regardless of their practice, are encouraged to document and report on outcomes and quality of care they provide to their patients. Rheumatologists in Ontario have been participating voluntarily for 10 years in the OBRI so that collective health data can be used for research and the evaluation of treatments in the real world. It is no surprise that other speciality groups are excited and interested in the OBRI and the value and services it offers. In an effort to support the collection of comparative long-term clinical outcomes for their patients and the medications they take, specialists including dermatologists and gastroenterologists are now collaborating with the OBRI to create their respective data centres.



### Linking with Young Patients as they Transition to Adult Care

OBRI is working with the Pediatric Rheumatology Team at the Hospital for Sick Children. As children transition from pediatric to adult rheumatology care, they will be invited to join the OBRI study. This collaboration will give OBRI a unique group of patients: those diagnosed as children and followed in their care as adults.



### Awards

We extend congratulations to the following OBRI collaborators:

- **Dr. Vandana Ahluwalia** for receiving the William Osler Health System Physician Philanthropy Leadership Award. Co-Chair of the Holi Gala committee, under her guidance, this event has grown over 50 per cent in the last two years.
- **Dr. Vinod Chandran** for receiving the CRA Young Investigator Award in March 2017. This award is a competitive, national award aimed at providing, “recognition of a young Canadian investigator who has contributed significant, original research in rheumatology.” Dr. Chandran leads the OBRI SpA initiative.
- **Mark Tatangelo**, PhD candidate working with the OBRI, for winning the 2017 Ted Goldberg Award. This award, given by the Institute for Health Policy Management and Evaluation for academic excellence and promise, is the highest achievement for a PhD candidate.

## Patient Perspective – September 2017 Patient Information Session

*A conversation with Maureen Forbes - who attended the session remotely from the comfort of her home.*

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

This was my 2<sup>nd</sup> OBRI Patient session. I'm always interested in hearing from Dr. Bombardier and her colleagues with respect to new drugs and treatments that are available or in development; what they have learned to date from the data collected by patients like me; and about the new research in progress. It is so wonderful to hear these professional and dedicated doctors talk about their work, research, and patients. I always come away having learned something new.

### What did you learn?

I'm excited to hear that new biologics are in development, especially in pill form. I was especially interested to learn about the link between RA and cardiovascular disease.

### What was the major highlight for you?

Dr. Bombardier - I so respect this woman for her work and dedication to this disease. Her updates are always positive and I come away feeling as though there are doctors/researchers out there who take this disease seriously and are working hard to find a cure. We are so lucky to have OBRI - it is extremely important to have this organization dedicated to inflammatory diseases.

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

As a life-long learner, I can't even come up with a reason why someone with this disease would not be interested in attending. Knowledge is power - understanding your disease and looking for ways that will make day to day life easier is so important!

**Hope you can join us on June 2<sup>nd</sup>  
(see details in Upcoming Events)**

## RESEARCH UPDATE

### Predictors of patient decision to discontinue anti-rheumatic medication in patients with rheumatoid arthritis: results from the Ontario Best Practices Research Initiative

Vandana Ahluwalia, E. Rampakakis, M. Movahedi, A. Cesta, X. Li, J.S. Sampalis, C. Bombardier and OBRI Investigators

Using data from OBRI, this study looked at the relationship between various social, demographic, health insurance and disease-related factors and non-adherence to rheumatoid arthritis (RA) medications. Non-adherence was defined as the patient's decision to discontinue their RA medication(s). This is important because other studies have shown that patients with chronic illnesses, including rheumatoid arthritis, have less benefit from drugs when compared to patients participating in clinical trials. Researchers believe this reduced benefit may be partly related to patient adherence to their prescribed medications. OBRI patients who were married, rheumatoid factor positive (RF+), and reported having other diseases or disorders were less likely to discontinue their RA medications. Patients who were prescribed several RA medications and those rated as having higher disease activity by their rheumatologist were more likely to discontinue their RA medications.

The non-adherence rate to any RA medication was 23%. Patients were more likely to discontinue NSAIDs (non-steroidal anti-inflammatory drugs) compared to other RA medications. The non-adherence rate to csDMARDs (conventional synthetic disease modifying anti-rheumatic drugs) and bDMARDs (biologic disease modifying anti-rheumatologic drugs) was 9.4%. Patients reporting greater disability were less likely to discontinue DMARDs/csDMARDs. These results will be helpful in developing support programs to help patients adhere to their prescribed medications and in the choice of treatment regimens for each patient.

## UPCOMING EVENTS

### OBRI Annual Conference: **Friday, May 11, 2018 (9am-5pm)**

Hilton Garden Inn - Toronto Airport (3311 Caroga Drive, Mississauga, ON)

Please register in advance for the meeting:

- by telephone: 1-866-213-5463
- by email: [OBRI@uhnres.utoronto.ca](mailto:OBRI@uhnres.utoronto.ca)
- online: <http://www.obri.ca/5th-annual-obri-conference-may-11-2018-registration-form-patients/>

### 2018 Patient Session: **Saturday, June 2, 2018 (9<sup>30</sup>am-12<sup>30</sup>pm)**

Patients will have an opportunity to learn about the latest OBRI research, meet the OBRI team, ask questions and connect with others living with arthritis.

Attendance options:

1. Join Dr. Bombardier and the OBRI team in person at Toronto General Hospital, 200 Elizabeth Street, EN1-430 (near the Eaton elevators)
2. Join the meeting remotely from your computer, tablet or smartphone: <https://global.gotomeeting.com/join/614640765> (Access Code: 614-640-765). (If this is your first GoToMeeting, please run a quick system check before the meeting: <https://link.gotomeeting.com/system-check>)

Please register in advance for the meeting and feel free to bring a guest. You may register:

- by telephone: 1-866-213-5463
- by email: [OBRI@uhnres.utoronto.ca](mailto:OBRI@uhnres.utoronto.ca)
- online: <http://www.obri.ca/obri-patient-information-session-registration-form-2018/>

## Gerald Major, OBRI Patient Advisory Committee (PAC) Member



Gerald was very active as a child and, while playing hockey at the age of 14, he

noticed his knees were feeling loose. He started wrapping them with tensor bandages and so began his journey into Spondyloarthritis. It took about 7 years to his diagnosis of Ankylosing Spondylitis – with Psoriatic Arthritis and Psoriasis added years later.

Like many people, Gerald has been on a journey through arthritis and now volunteers his time to help support others who live with arthritis. “We as a community have an opportunity and an obligation to share our experiences in hope that it helps others through their journey.”

Gerald is the current President of the Canadian Spondylitis Association (CSA), serves on the board of directors for the Arthritis Alliance of Canada (AAC) and the Best Medicine Coalition (BMC), and co-chairs the patient advisory board for Canadians for Fair Access to Medical Marijuana (CFAMM).

Gerald feels that his involvement with OBRI and the CSA allows him to stay connected with those people living with inflammatory arthritis, while his other volunteer activities allow him to transfer those conversations into influencing policy on their behalf. “This is the best way I believe I can contribute to others living with arthritis.”

Gerald, his wife Anna and daughter Tessa are huge supporters of improved patient outcomes.

## Reflections of a Long-term Caregiver

She was diagnosed when she was seventeen; we were married in our early twenties, and have now been married for over forty years. RA has been our constant companion on the journey. As a caregiver, these are a few of the things I think about. First, while as caregivers we do not experience the physical pain, we inevitably feel the psychological pain, the social pain, and even the spiritual pain. This means a need for care for the caregiver. Second, while there are challenges, there is often great gain—a deeper understanding and compassion for those who suffer, and added patience in taking the time to move at another person’s pace. As caregivers we serve as advocates helping navigate through the health care system and participating in the conversations with physicians, therapists, and other professionals who are part of the circle of care. A life with an RA patient is a shared life – and we all need to increase our awareness about what that shared life means.

David Barker  
Kitchener, Ontario

## Interviews: Collecting Patient Reported Outcome Measures

Part of what makes the OBRI unique is our ongoing collection of patient reported outcome measures through structured telephone interviews with patients. Patient reported data is collected on a regular basis to document disease activity, quality of life, comorbidity, socioeconomic status, functional ability, and work productivity. These interviews, combined with physician-reported data and administrative data, provide us with a holistic picture of the RA care landscape in Ontario.

Thank you to our dedicated team of interviewers for their ongoing role in ensuring patient data is collected in a standardized manner.

## We’d like to thank the OBRI Investigators!

**Thank you to the dedicated rheumatologists who have contributed to OBRI over the past decade:** Drs. Vandana Ahluwalia, Zareen Ahmad, Pooneh Akhavan, Lori Albert, Catherine Alderdice, Michael Aubrey, Sibel Aydin, Sanjeeta Bajaj, Mary Bell, Bill Bensen, Sankalp Bhavsar, Raja Bobba, Claire Bombardier, Arthur Bookman, Antonio Cabral, Simon Carette, Raj Carmona, Andrew Chow, Shirley Chow, Gregory Choy, Patricia Ciaschini, Alf Cividino, Dana Cohen, Sanjay Dixit, Derek Haaland, Brian Hanna, Nigil Haroon, Jackie Hochman, Anna Jaroszynska, Sindhu Johnson, Raman Joshi, Allan Kagal, Arthur Karasik, Jacob Karsh, Ed Keystone, Nader Khalidi, Bindee Kuriya, Maggie Larche, Arthur Lau, Nicole LeRiche, Felix Leung, Frances Leung, Dharini, Mahendira, Mark Matsos, Heather McDonald-Blumer, Emily McKeown, Ines Midzic, Nataliya Milman, Shikha Mittoo, Ami Mody, Angela Montgomery, Manisha Mulgund, Edward Ng, Tripti Papneja, Viktoria Pavlova, Louise Perlin, Janet Pope, Jane Purvis, Raman Rai, Gina Rohekar, Sherri Rohekar, Thanu Ruban, Nooshin Samadi, Sharron Sandhu, Saeed Shaikh, Ali Shickh, Rachel Shupak, Doug Smith, Elaine Soucy, Jonathan Stein, Andy Thompson, Carter Thorne, Sharon Wilkinson

***Have questions? Want to provide feedback?***

***Contact us!***

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