



# 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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### MESSAGE FROM OBRI

Thank you for participating in the Ontario Best Practices Research Initiative (OBRI)! We've had a busy year and are excited to update you on our latest research activities and outcomes.

We just returned from the Canadian Rheumatology Association (CRA) Annual Scientific meeting in Quebec City where we presented research outcomes from 13 arthritis studies! Quebec City was beautiful (and very cold), but we had a fabulous and productive meeting with other rheumatologists, allied health professionals, and researchers from across Canada.

In 2014 we presented our research at two international Scientific Meetings – the American College of Rheumatology (ACR) Annual Meeting in Boston, and the European League against Rheumatism (EULAR) Annual meeting in Paris. We also hosted three Patient Sessions, launched a newsletter for participating rheumatologists, and hosted our first Annual OBRI Research Day.

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](http://www.obri.ca). We'd love to hear from you!



### NEWS AND HIGHLIGHTS

#### OBRI is Expanding to include Spondyloarthritis (SpA)

Until now, the OBRI study has been focused on patients with Rheumatoid Arthritis (RA). Starting in 2015, OBRI is expanding to include another set of inflammatory arthritis diseases called Spondyloarthritis or SpA for short. SpA includes Ankylosing Spondylitis (AS), Psoriatic Arthritis (PsA), Arthritis associated with Inflammatory Bowel Disease, Reactive Arthritis (ReA), Juvenile Idiopathic Arthritis that is Enthesitis Related (JIA-ERA) and Undifferentiated Spondyloarthritis (USpA). Researchers will be looking at the different gene markers that they believe to be associated with these diseases and determining the disease characteristics that result from each. They will check whether the original diagnosis made by the rheumatologist matches with current understandings of these diseases. Researchers will study disease activity, physical disability, quality of life, and employment productivity in these patients.

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.

## Cathie Hofstetter, Chair – OBRI Patient Advisory Committee



I was diagnosed with RA at the age of 36, unbelievably 23 years ago. I thought my life had ended, but fortunately, I had a fabulous family doctor who got me in to see a great rheumatologist fairly quickly.

Since my diagnosis, I've been through all the conventional 'front line' medications, several anti-inflammatories and a few biologics. It's been a bumpy road – my disease appears to be quite stubborn, but not as stubborn as I am! I've had a good outcome so far, and my RA has opened up a new and fascinating world for me in the arthritis community.

I feel compelled to give back, and want to ensure a smoother journey for the next person diagnosed. Naturally, I jumped at the opportunity to be part of OBRI about 8 or 9 years ago, when Dr. Claire Bombardier called.

Through work with the Arthritis Society, the Canadian Arthritis Network and Patient Partners in Arthritis, I have met and made friends with fabulous, committed, and empowered people who live with arthritis every day. I also work with the Ontario Rheumatology Association 'Models of Care' committee, and the OMERACT worker productivity special interest group. In my real life, I own and operate a small fence contracting company in Toronto.

Twenty-three years later, thanks to the discoveries being made in arthritis research every day, I'm still going strong!!

*We'd like to congratulate Cathie Hofstetter on her **2014 Qualman-Davies Arthritis Consumer Community Leadership Award!** Ms. Hofstetter has over 17 years of experience advocating for patients through the promotion of more effective policies and treatments for arthritis; the communication of patient needs; and the facilitation of patient involvement in arthritis research and decision-making. Her commitment to action for improved quality of care in arthritis is truly inspirational.*

## NEWS AND HIGHLIGHTS

### Linking OBRI to the Provincial Health Databases

OBRI researchers are now able to access data in the Provincial Health database (e.g., OHIP billing codes) to gather more detailed information about OBRI patient well-being. This lets researchers study healthcare usage patterns of patients and clinicians and also study the safety and effectiveness of the various drugs for patients. This enhanced dataset will be very powerful as researchers work to learn more about our disease.

### Studying Pregnancy and Arthritis

A group of Rheumatologists who are interested in pregnancy and arthritis have formed a small research group that will operate as part of the OBRI study. They are currently developing and testing new tools for data collection. Data will be linked to administrative databases to better understand pregnancy and RA.

### 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: people who were diagnosed as children and followed in their care as adults.

## DID YOU KNOW? A Look at Subsequent Entry Biologics (S.E.B.'s)

By: Cathie Hofstetter, OBRI Patient Advisory Committee

You may have heard about a new treatment option coming to market for forms of inflammatory arthritis (such as rheumatoid arthritis, psoriatic arthritis and ankylosing spondylitis) called Subsequent Entry Biologics (S.E.B.'s), also referred to as Biosimilars.

Biologic therapies contain very complex molecules made from living organisms. They have changed the face of rheumatology care in Canada and around the world. As the patents on these innovator or brand name drugs begin to expire, S.E.B.'s are being developed to replace them. While they are similar to the innovator product, it is important to know that they are not the same. S.E.B.'s are not generic versions of the brand name product.

There are a number of concerns with these new therapies, such as what they will cost, whether the pharmacist will be able to substitute an S.E.B. for the brand name biologic, how they will be labelled, how public and private payers (i.e., Trillium Drug Plan in Ontario or private insurance plans) will view these new arrivals, and what insurers will be willing to cover in terms of cost.

There are many good resources for information on S.E.B.'s. We encourage you to visit the following websites regularly for updates on how these questions and concerns are being addressed. Also, don't forget to ask your rheumatologist about S.E.B.'s!

#### For more information:

The Arthritis Society has a video and position paper on S.E.B.'s:  
<http://www.arthritis.ca/page.aspx?pid=7775>

The Canadian Arthritis Patient Alliance (CAPA) has a position paper and videos:  
<http://www.arthritispatient.ca/projects/subsequent-entry-biologics/>

Arthritis Consumer Experts' (ACE) provides a background on S.E.B.'s and recommendations on regulation and Public Drug Formulary reimbursement:  
<http://jointhealth.org/programs-jhmonthly-view.cfm?id=104&locale=en-CA>

To receive up to date news and information, subscribe to [www.jointhealth.org](http://www.jointhealth.org), follow CAPA on their website [www.arthritispatient.ca](http://www.arthritispatient.ca) or facebook page, and keep up to date with news from The Arthritis Society at [www.arthritis.ca](http://www.arthritis.ca).

## Patient Advisory Committee (PAC)

The OBRI PAC is a volunteer-led committee comprised of patient representatives. Its role is to represent and communicate patient perspectives to OBRI staff, investigators and stakeholders; and motivate and engage patients through education, knowledge transfer, and ongoing communication.

This year's accomplishments include:

- The development of plain-language summaries to communicate research findings to patients
- The compilation of information on medications to facilitate patient awareness of RA treatment options
- The co-facilitation of OBRI patient sessions to communicate OBRI research activities and identify patient research priorities
- The production of an annual patient newsletter
- The creation of terms of reference and guiding principle documents

## OBRI Student Researchers

In 2014 OBRI hosted four summer students – Jessica Gosio, Kangping Cui, Nancy Guo, and Thomas McKeown. With hard work and guidance from the OBRI team, each student completed an independent research project using OBRI clinical data.

Jessica explored the generalizability of the OBRI-RA cohort compared to the Ontario population; Kangping examined the prevalence and characteristics of cardiovascular diseases in the OBRI-RA clinical cohort; Nancy focused on disease activity in moderate RA patients treated with DMARDs or biologics; and Thomas explored the characteristics, medication use, and disease activity of RA patients treated in community vs. academic settings.

Research results were presented by each student at the Toronto General Research Institute Annual Research Day in October 2014. Kangping and Thomas also presented their research at the American College of Rheumatology Annual Meeting in Boston. We'd like to thank all students for their hard work and dedication!

## RESEARCH UPDATE

The OBRI is a clinical registry focused on improving quality of care and health outcomes for patients living with rheumatoid arthritis (RA) in Ontario. Through the collection of data on arthritis therapies, clinical practices, and health care utilization, the OBRI is working to monitor the long-term safety and effectiveness of RA treatment options for patients with the goal of improving patient health outcomes. Here is an update on some of the questions we are working on!

### Study Results: Use of Disease Measurement Tools and Treat-to-Target Strategies in RA Patients

By: Kuriya B, Jacob B, Widdifield J, Li X, Bombardier C.

Treat to Target (T2T) is an effective RA treatment strategy that emphasizes remission as the main goal of treatment. Remission means complete or close to complete reduction of RA symptoms. T2T requires that Rheumatologists treat their patients with the goal of achieving remission in as short a time period as possible. It is carried out by customizing and delivering therapies specific to remission treatment goals (e.g. prevention of joint damage, fatigue and pain management). Rheumatologists regularly measure RA disease activity by using multiple proven tools such as lab work (e.g. inflammatory markers), observational data (e.g. number of swollen/tender joints) and questionnaires (e.g. patient self-assessment). As part of the T2T strategy, the results of these measures can be compared to pre-set goals and used to make decisions on treatment changes. An important part of T2T is open communication between doctor and patient regarding treatment options and their potential risks and benefits.

OBRI is currently studying RA treatments and outcomes by reviewing data from 59 Rheumatologists across Ontario that was collected during 3,000 patient visits. The aim is to determine which disease activity measurement tools Rheumatologists use most often, which are most effective, and whether Rheumatologists are following T2T recommendations. The impact of the T2T approach will also be studied. Results of this study will be discussed with Rheumatologists and patients to examine enablers and barriers to the regular use of the T2T strategy. This will help increase our understanding of Ontario Rheumatology practices and how best to support T2T in daily care.

### Study Results: Adherence to RA Medication

By: Cesta A, Li X, Couto S, Jacob B, Bombardier C.

Patient data from the OBRI was used to look at why patients may or may not take their medications as prescribed by their doctor. Data was collected on the reasons that both doctors and patients reported for patients not taking medications as prescribed. The reasons were then categorized by frequency under each of the five factors the World Health Organization identifies for patients not taking medications as prescribed: personal reasons (41%), health care system (24%), treatment plan (18%), health status, including health conditions in addition to RA (6%), social and economic status (4%).

Characteristics of study patients starting from their time of enrolment into OBRI were also factored in. It was determined that patients who did not take medications as prescribed were younger and had higher income and education than those who did take medications as prescribed. There were no significant differences between patients who did or did not take their medications based on how long they had had RA, whether they smoked, had private health insurance, had other health conditions or experienced varying levels of pain and functional ability.

Some reasons that patients reported for not taking medications as prescribed were: personal assessment of their treatment needs, concerns about side effects, and forgetting to take medications. Thirty-three percent of OBRI patients reported not taking their medications at times of lower disease activity. These study results suggest that patients stop taking medications when they are feeling better.

## OBRI Patient Sessions

OBRI held three patient sessions in the spring of 2014 to engage personally with patients enrolled in the OBRI clinical cohort. At each session, OBRI provided an update on research activities, and patients shared their experiences, concerns, and challenges with RA. Patients also provided feedback to OBRI on how research questions could be updated to better reflect their needs and priorities.

Patients who attended had an opportunity to ask questions, meet OBRI interviewers, OBRI staff, other patients with RA, and members of the OBRI Patient Advisory Committee. Sessions were held in Newmarket, Mississauga, and Bowmanville.

Three patient sessions are scheduled for 2015. We hope you can join us!

## 2<sup>nd</sup> Annual OBRI Research Day

This scientific meeting brings together OBRI investigators, researchers, industry partners, research coordinators, interviewers, patient advocates and patients from across Ontario. This year we would like to invite OBRI participants to attend the afternoon sessions which include presentations of ongoing OBRI research.

**Space is limited - see insert for details.**

## UPCOMING EVENTS

### OBRI Annual Research Day

- April 24<sup>th</sup>, 2015 (Toronto)

### 2015 Patient Sessions:

- May 2<sup>nd</sup>, 2015 (Barrie)
- May 9<sup>th</sup>, 2015 (Hamilton)
- May 30<sup>th</sup>, 2015 (Sault Ste. Marie)

*Come meet the OBRI and learn about our latest research activities and outcomes!*

OBRI is funded by peer-reviewed grants from CIHR, MOHLTC, CAN and unrestricted grants from: Abbvie, Amgen, Bristol Myers Squibb, Celgene, Janssen, Pfizer, Roche, Sanofi, & UCB.

## HIGHLIGHT – MODELS OF CARE FOR ARTHRITIS

Health care systems around the world and within every medical discipline are undergoing transformations to cope with medical needs and rising healthcare costs. The Ontario Rheumatology Association (ORA) believes a fundamental shift in arthritis care is needed to address current issues such as: rising incidence and prevalence rates of arthritis, growing economic burden of disease, human resources shortages, long wait times for patients with early inflammatory conditions, and variations in quality of care and health outcomes.

The Arthritis Alliance of Canada (AAC) has created a pan-Canadian report to raise awareness for arthritis, champion improvements in models of arthritis care, and promote research focused on the prevention, self-management, and efficiency of arthritis care. With a well-defined national framework, provinces are working together to develop and implement local strategies that align with AAC principles. In Ontario, a Models of Care working committee has been created to build a platform to improve efficiencies within our health care system and enhance health outcomes for patients.

The work of this committee includes:

- a) Developing guiding principles for a new rheumatology model in Ontario
  - A platform that supports a patient-centered continuum of care
  - A coordinated triage mechanism to identify patients and their respective care path so care is delivered to the right patient at the right time
  - An integrated multi-disciplinary practice unit that delivers care for patients from time of diagnosis and throughout the course of the disease
  - Medical Management using Electronic Medical Records (EMRs) that integrate clinical guidelines into daily practice
  - A Patient Self-Management platform involving portable patient education tools to increase disease awareness and improve adherence to treatments
  - A commitment to tracking health outcomes through EMRs linked to OBRI
- b) Identifying provincial priorities:
  1. Facilitating patient identification/diagnosis
  2. Improving access to specialists
  3. Optimizing medical management
  4. Working in a shared care environment
  5. Helping patients through self-management
  6. Monitoring health and system measures

While there is no single model of care that can be applied to inflammatory arthritis, the proposed framework describes key elements that must be included to support better care and outcomes. It considers the mix of health care providers needed and their specialized scopes of practice. The proposed approach is meant to provide sufficient flexibility so it can function at the local or regional level.



*Have questions? Want to provide feedback?*

*Don't hesitate to contact us!*

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