



OBRI

ONTARIO
BEST PRACTICES
RESEARCH INITIATIVE

Shaping the Future of Arthritis Care

Keeping OBRI patients informed

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The Ontario Best Practices Research Initiative (OBRI) 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 OUR PATIENT ADVISORS

Thank you for your participation in the Ontario Best Practices Research Initiative (OBRI). Patients are an integral part of OBRI research. You may not realize, however, just how vital patient participation is to the initiative. Patients are the ones who help OBRI by allowing information to be collected from their doctor and by participating in interviews. The OBRI uses this information to explore ways to improve delivery of arthritis care to patients, and to assess the safety and effectiveness of rheumatoid arthritis treatments.

In fact, patients are part and parcel of every aspect of OBRI and have been since the very beginning. While the OBRI was still a vision, one of the first calls by the lead investigators developing the project was to the Canadian Arthritis Patient Alliance (CAPA).

As the OBRI study protocol was developed, and the ethics requirements were met, several patients were at the table, lending their perspectives on living with inflammatory arthritis. Once the OBRI was launched, patients have remained involved, contributing as needed. Recently, a Consumer (Patient) Advisory Committee was created to look at ways to give back to the patients involved in the research.

We are delighted to invite you to our first OBRI Patient Information Session in Toronto on (Saturday October 5th, 2013). Come to meet the OBRI team, including the interviewers you have been speaking with by telephone since you started in the program, as well as the rheumatologists involved in the project. Allow us to thank you personally for your valuable contributions to the OBRI and learn how the information you provide is making a positive difference for people with rheumatoid arthritis.

Sincerely,
Cathy Hofstetter*
Anne Lyddiatt*
Jennifer Boyle*
Christine Fyfe*

* Consumer (Patient) Advisory Committee, patient members

OBRI PARTNERS

The OBRI is currently working with:

- The Best Medicines Coalition (BMC) a broad-based alliance of organizations and individuals with a shared vision of equitable and consistent access for all Canadians to safe, effective and good quality drugs which improve patient outcomes. The BMC ensures patient involvement in government recommendations on common drug renewals, it ensures patients are involved in provincial drug approvals and addresses drug shortage issues.
www.bestmedicines.ca
- The Arthritis Society
www.arthritis.ca
- The Ontario Rheumatology Association (ORA)
www.ontariorheum.ca
- The Canadian Rheumatology Association (CRA)
www.rheum.ca
- Canadian Arthritis Patient Alliance (CAPA)
www.arthritispatient.ca
- Institute of Clinical Evaluative Sciences (ICES)
www.ices.on.ca
- Canadian Spondylitis Association (CSA)
www.spondylitis.ca



NEWS AND HIGHLIGHTS

Originally created as the Ontario Biologics Research Initiative (OBRI), was founded in 2005, through the cooperative efforts of patients, researchers, rheumatologists and payers to improve the treatment and outcomes of Ontarians living with RA. The OBRI continues to focus on safety, efficacy and sustainability of rheumatic medications, and has evolved into an important research platform dedicated to supporting health planning and clinical practice monitoring. With this added scope of focus, the OBRI renamed and established itself as the Ontario Best Practices Research Initiative (OBRI).

Today close to 60 Ontario rheumatologists and 3000 patients living with RA participate in the OBRI. The operational team at the OBRI is comprised of biostatisticians, project and data managers, research coordinators, and interviewers all dedicated to gathering high quality data for the improvement of patient health care outcomes.

The OBRI has three important working committees. The Consumer Advisory Committee (CAC) ensures that the patient's needs are well represented in the OBRI platform. The Planning and Review Board (PRB) is a senior oversight committee that provides ongoing leadership. The Research Operations Committee (ROC) is led by clinician researchers who explore research areas of interest using OBRI data. Most importantly, all the OBRI committees have patient representation.

The OBRI has a unique and novel working relationship with the Institute of Clinical Evaluative Sciences (ICES), which collects information from various health services in Ontario. Through this linkage the OBRI can learn the long term effects of medications on health care utilization.



UPCOMING EVENTS

Events for patients:

- **1st OBRI Patient Information Session**
Location: Toronto Western Hospital Main Auditorium
Date: **Saturday October 5th, 2013** (10am-12pm)
** This is the first of many regional patient sessions*
- 2013 Arthritis Alliance of Canada Conference and Research Symposium, Westin Ottawa, November 21-23, 2013
- The Arthritis Society offers - programs and services to help people with arthritis to live well. Including a Toronto public forum on Pain Management, Sept. 17. Visit www.arthritis.ca/on/events for a full calendar of event listing in Ontario. To learn more about The Arthritis Society, please visit the website.

Introducing Jennifer Boyle, Consumer Advisory Committee, member

Jennifer went to a physician when she was a teenager and was told then that the hand pain she was having was “just growing pains”. She gave up playing the violin because of the pain it caused (and not just because she was a terrible musician). Two years later, she was diagnosed with rheumatoid arthritis. After developing a skin rash, her diagnosis was changed to psoriatic arthritis. She has now lived with arthritis for 23 years.

Her diagnosis started her journey in the field of arthritis research. She earned her Ph.D. degree in cartilage tissue engineering at the University of Toronto. Unfortunately, Jennifer has battled a rare medical condition for several years now. It has meant starting over for her but undaunted, she remains active in the arthritis community. She is a volunteer with the Arthritis Society, and recently was awarded a 2013 Volunteer Impact Award (The Arthritis Society, Ontario Division). Jennifer is a volunteer with the Patient Partners in Arthritis program at the Toronto site and is an integral part of the Consumer Advisory Committee with OBRI. Her experience and knowledge have been a powerful aid in facilitating the projects undertaken by OBRI. She loves to paint and donates paintings to charity fundraising events. Jennifer and her adorable cat, Bailey, live in Toronto.



UPCOMING EVENTS

Events for rheumatologists (at which OBRI data will be presented):

- OBRI Investigator / Coordinator Meeting, Toronto, Ontario; October 17, 2013
- OBRI Planning and Review Board Meeting, Toronto, Ontario; October 17, 2013
- American College of Rheumatology Annual Meeting, San Diego, USA; October 25-30, 2013
- Canadian Rheumatology Association Annual Scientific Meeting, Whistler, British Columbia February 26-March 1, 2014



DID YOU KNOW?

- 60% of OBRI participants have been enrolled in the study beyond 1.5 years
- 25% of participants have completed their 3 year interviews
- 10 OBRI interviewers connect daily with participants to collect patient reported outcomes and experiences
- All OBRI working committees have a patient representative
- The OBRI has representation from the Ontario Ministry of Health and Long-Term Care
- The OBRI is pro-actively working with drug insurance companies to educate decision makers on the value rheumatic medications can offer in terms of quality of life and work productivity
- Drug payment criteria can be viewed at http://www.health.gov.on.ca/en/pro/programs/drugs/pdf/frequently_requested_drugs.pdf.
If you do not use a computer, please consult your physician

Consumer Advisory Committee (CAC)

On behalf of people with arthritis, the CAC contributes to improve the relevance and accessibility of OBRI's work. It is comprised of a diverse membership representing a wide range of arthritis and professional experience, ages and cultures.

Mandate

To provide a voice for, and give back to, OBRI patients by providing information on how OBRI is progressing and influencing care for patients with rheumatoid arthritis based on the data being collected.

Have a question? Want to provide feedback?

Don't hesitate to contact us:

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