

What's new at OBRI

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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.



RESEARCH INITIATIVE

Shaping the Future of Arthritis Care

MESSAGE TO ALL INVESTIGATORS

This past year brought important changes to the OBRI platform – the implementation of data sharing and the reduction of telephone interviews.

- i. Data Sharing: There is increased awareness and need for Real World Data (RWD). In the past year, OBRI has been approached by several groups to collaborate on Canada-wide projects. To meet this growing demand to share RWD, OBRI will ask all patients to consent to data sharing. All sites will be provided with a data sharing addendum that will be added to the Patient Information Packages. Patients already enrolled in OBRI will be asked to agree to the data sharing addendum by their interviewer or via written communication.
- ii. Telephone interviews: Due to financial constraints, telephone interviews have been suspended at the 5-year mark. Patients were notified of this decision by either letter/email or a telephone call from OBRI. The communication to the patient clearly states that no changes are being made to the collection of physician data. However, we have heard from a number of sites that some patients think they have been withdrawn from OBRI. This is not the case. Please continue to submit your OBRI study forms unless you have received a withdrawal notification from OBRI.
- iii. Health Assessment Question (HAQ): For sites using the HAQ in-office, OBRI is requesting that a copy of the completed HAQ be submitted with the OBRI assessment forms.

We thank you for your continued support and we look forward to exciting new collaborations and opportunities in 2019!

OBRI WORKING COMMITTEES

Clinical Advisory Committee (CAC)

The CAC was formed in 2015 to serve as an oversight committee and provide expert advice, as needed, on matters relating to OBRI internal operations.

The committee provides strategic leadership for communications and interactions with external stakeholders

Committee members include:

- Dr. Vandana Ahluwalia
- Dr. Claire Bombardier
- Dr. Vinod Chandran
- Dr. Edward Keystone
- Dr. Arthur Lau
- Dr. Janet Pope
- Dr. Carter Thorne
- Catherine Hofstetter

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.

Committee members include:

- Catherine Hofstetter, Chair
- David Baker
- Jennifer Boyle
- Maureen Forbes
- Lynda Linderman
- Gerald Major
- Erinn McQueen
- Denis Morrice



SPECIAL PROJECTS

OBRI is pleased to share the exciting and innovative projects that we will focus on in the coming months.

Data Sharing: The momentum to create a structure for collaboration of registries across Canada has sparked the following initiatives:

- Rhumadata: OBRI is pleased to collaborate with the Quebec rheumatoid arthritis registry, Rhumadata, under the leadership of Dr. Denis Choquette. The initial project will be to replicate a recent Rhumadata tofacitinib study using OBRI data.
- <u>Pan-Canadian Rheumatoid Arthritis (RA) Initiative</u>: This Canadian collaboration will use data from multiple registries to answer specific research questions.
 Preliminary discussions were held this past October.



CONTINUING PROFESSIONAL DEVELOPMENT

A friendly reminder to our investigators that participating as an OBRI Investigator is a performance assessment activity as defined by the Maintenance of Certification (MOC) Program of the Royal College of Physicians and Surgeons of Canada. Performance assessments are included under Section 3 of the MOC Program. Investigators who collect and complete the OBRI data collection tools, attend and reflect on their individualized OBRI reports for self-improvement may record up to 25 hours for this program.



UPCOMING EVENTS

- 6th Annual OBRI Conference Friday, May 3, 2019 (Toronto)
- 2019 Patient Session: TBC

Have questions? Want to provide feedback?

Don't hesitate to contact us!

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