

IN THE KNOW

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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RESEARCH CORNER

The OBRI continues to make the dissemination of research outcomes a focal priority. In 2014, we attended and contributed to important scientific meetings including the European League Against Rheumatism (EULAR) where we presented 4 poster presentations, as well as the American College of Rheumatology (ACR) where we presented 5 poster presentations and 2 oral presentations. Stay tuned for new updates at the 2015 Canadian Rheumatology Association (CRA) meeting. For more information about our research portfolio, please visit our website: www.obri.ca



COHORT PERFORMANCE AND INVESTIGATOR NEWS

New Additions
 The OBRI is pleased to welcome the following new investigators in 2014: *Dr. Derek Haaland* from Barrie, *Dr. Arthur Lau* from Hamilton, and *Dr. Maggie Larche* from Hamilton. Today, 61 rheumatologists participate in the OBRI research platform from community and/or academic settings.

Cohort Performance Update (Nov 9th 2014)

Patients referred to OBRI	3,243
Patients consented	2,768 (85.4%)
1. Patients consented to ICES* linkage	2,743 (99.1%)
2. Patients consented to interview data	2,657 (96.0%)
3. Patients consented to physician data	2,757 (99.6%)
6.5 Follow-up years	82 (2.5%)
Patient withdrawal	172 (5.3%)
Patient lost to follow-up	43 (1.3%)

*Institute for Clinical and Evaluative Sciences (ICES)

OBRI Student Researchers

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

Nancy focused on the proportion of RA patients with moderate disease activity that progressed or went into remission at 6 months; Jessica explored the generalizability of the OBRI RA cohort compared to the Ontario population; Thomas explored the characteristics, medication use, and disease activity of RA patients treated in community versus academic rheumatology settings; and Kangping examined the prevalence and characteristics of cardiovascular diseases in the OBRI RA clinical cohort.

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



INTERNAL OPERATIONS

New members of the OBRI internal head office team!



Laura Fullerton joined the OBRI team in March 2014 as a Research Associate. She holds a M.Sc. in Community Health from Memorial University, and a B.A. in International Development from the University of Guelph. As a Research Associate, Laura works to develop and answer OBRI research questions, communicate research results, manage study literature, and develop knowledge translation

materials. Before joining the OBRI team, Laura completed a thesis on the implementation of the WHO/UNICEF Baby-Friendly Initiative in St. John's, NL, and conducted research on dengue fever with the United Nations University Institute for Water, Environment and Health.



Mark Tatangelo is a PhD student at the University of Toronto in the Institute of Health Policy Management and Evaluation. His research focuses on conducting economic analyses of RA medications using large clinical cohort data linked with administrative data to inform optimal care delivery for RA patients. His research interests include trend and

utilization patterns for high-cost drugs, population-level economic analysis, and the use of novel applied statistical methods for observational research. Mark currently holds peer reviewed grants from the Canadian Institute for Health Research (CIHR), The Arthritis Society (TAS), and the Ontario Drug Policy Research Network (ODPRN).

OBRI WORKING COMMITTEES

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 accomplishments include:

- The production of an annual patient newsletter to keep patients informed about OBRI research, news, and events
- 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 creation of terms of reference and guiding principle documents

Clinical Cohort Advisory Committee

Over the last few years, OBRI has received an influx of research questions from its stakeholder groups. In an effort to support growing research demands, a new working group comprised of OBRI rheumatologists has been established to lead and manage the completion of research questions from the clinical cohort. We are pleased to share that *Dr. Vandana Ahluwalia, Dr. Ed Keystone, Dr. Janet Pope* and *Dr. Carter Thorne* will be leading the newly created OBRI Clinical Cohort Advisory Committee. Stay tuned for more information!

Research Highlight



Kangping Cui is a second-year medical student at the University of Toronto with research interests in inflammatory arthritis, cardiovascular disease, and epidemiology. She joined OBRI as a summer student in June 2014 to conduct a study on the characteristics and medication-use of RA patients with and without cardiovascular disease in the OBRI clinical cohort.

Her research found that patients with cardiovascular disease (16.2%) were more frequently treated with glucocorticoids (34.9% vs. 28.3%, $p < 0.05$) than with NSAIDs (29.9% vs. 49.3%, $p < 0.05$), and had higher RA disease activity and lower functional status than patients without cardiovascular disease.

As part of her school curriculum, Kangping is currently using OBRI data to explore the effects of socio-demographic factors on treatment responses in RA patients. This research will highlight the effects of various social factors on RA outcomes. Kangping has research experience in the field of cancer pharmacology, vision sciences, and clinical trials, and holds an H.B.Sc. in Biomedical Toxicology from the University of Toronto.



ONGOING SPECIAL PROJECTS

OBRI SpA

Led by its principal investigator Dr. Vinod Chandran, 11 community rheumatologists will soon be recruiting patients into the OBRI clinical SpA cohort – *Dr. Henry Aaverns, Dr. Vandana Ahluwalia, Dr. Bill Bensen, Dr. Patricia Ciaschini, Dr. Andrew Chow, Dr. Sanjay Dixit, Dr. Arthur Karasik, Dr. Imtiaz Khan, Dr. Arthur Lau, Dr. Munisha Mulgund and Dr. Carter Thorne*. The objectives of the initiative include cataloguing the clinical phenotype of SpA patients seen in routine practice, comparing the treating rheumatologist diagnosis with current classification criteria, and determining: disease activity, damage and impairment of physical function, quality of life, and worker productivity.

ICES Linkage: Clinical RA cohort to administrative data

Baseline primary clinical data has now been linked for patients who were enrolled in OBRI and completed an interview and rheumatologist assessment ($n=1841$) within 60 days as of July 15, 2013. As a result of linking OBRI clinical data with ICES administrative data, a powerful dataset now exists for researchers using patient-level analysis of drug safety, efficacy, clinical practice patterns, and health care resource use. This unique dataset will allow for the validation of co-morbid conditions and medications in administrative data.

Pregnancy focus

Rheumatologists in Ontario with an interest in collecting pregnancy-related outcomes for their RA patients have come together to establish a small working group including: *Dr. Bindee Kuriya, Dr. Carl Laskin, Dr. Dharni Mahendira, Dr. Viktoria Pavlova, Dr. Sharron Sandhu and Dr. Carter Thorne*. New data collection tools are being developed and field tested. OBRI infrastructure will be leveraged to provide resources and data management support. Clinical data collected will be linked to administrative databases including the Better Outcomes Registry Network (BORN) to assess the impact of RA and pregnancy on health care services.

Linkage with Paediatrics

Collaborative efforts are ongoing with our pediatric rheumatology team. A newly created Childhood Arthritis New Medication users Registry (CANMR) has been established at the Hospital for Sick Children. As patients transition from pediatric to adult rheumatology care, they will also be transitioned to the OBRI. This collaboration will establish the first pediatric-adult clinical arthritis cohort within North America.

Stay tuned for new updates!

Spring 2014 Patient Sessions

OBRI held three patient sessions in the spring of 2014 to personally engage 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. In each session, patients had an opportunity to ask questions, and 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 in Barrie, Hamilton and Sault Ste. Marie.

2014 Qualman-Davies Award Recipient



Congratulations to Ms. Cathie Hofstetter, recipient of the 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. She is a member of the Consumer Advisory Council of the Canadian Arthritis Network (CAN) and Canadian Arthritis Patient Alliance, acts as Chair for the OBRI Patient Advisory Committee, and serves with the OMERACT Worker Productivity Group and CAN Research Development Committee. Ms. Hofstetter has also served on the Board of Directors for The Arthritis Society and has chaired the Ontario Arthritis Advocacy Committee. Her commitment to patient needs and action for improved quality of care in arthritis is truly inspirational.



LEADING THROUGH e-TECHNOLOGY

Since its inception, OBRI investigators have been collecting clinical data on the use of paper-based data collection forms. With the arrival of electronic medical record (EMR) platforms, data collection and data sharing has taken on a new meaning for health care professionals. Until recently, many of the EMR platforms available in Ontario had very little customization to meet the needs of rheumatologists. Through the efforts of the ORA EMR committee, rheumatology-specific tools have been developed and fully embedded within rheumatologists' EMR platforms, including QHR, OSCAR, and Telus.

Of particular interest has been the initial integration of e-OBRI data collections forms. These have allowed data to be collected from physician EMRs and transmitted directly to the OBRI methods center.

The next phase of work involves the creation of a web-based forms library to house clinician, patient, research, and administrative forms that can be readily accessed by the EMR user. The forms library will allow for the collection of structured data within EMRs, and the seamless data extraction out of EMRs in real time.

With the push towards big data, and the overwhelming interest by various stakeholders to access it, physicians are now left wondering who can help them navigate this process. There is a need to create capacity and a model that supports data governance, data stewardship, and how these translate at the practice-level for physicians. **The OBRI is leading this effort and will provide reporting requirements for rheumatology EMR users!**

UPCOMING EVENTS

OBRI Annual Research Day

April 24th, 2015 (Toronto)

There will be an investigator-led session during this meeting. Come and learn about your clinical practice and how you compare to the provincial cohort!

2015 Patient Sessions:

May 2nd, 2015 (Barrie)

May 9th, 2015 (Hamilton)

May 30th, 2015 (Sault Ste. Marie)



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

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