

# 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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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

### Oct 5, 2013 Patient Information Session – Summary

On Saturday, October 5<sup>th</sup>, 2013, the OBRI held its inaugural patient day at Toronto Western Hospital. Attendees included 24 patients from Toronto and surrounding areas, as well as 2 members of the Consumer Advisory Committee, 2 investigators, the OBRI team, and 8 of the OBRI interviewers who work with the patients on a regular basis.

Dr. Claire Bombardier, principal investigator for the OBRI, introduced the agenda for the day, and explained what led her to choose a career in Rheumatology, and why OBRI was so very important, both to the patients and to the OBRI team.

Dr. Viktoria Pavlova gave a talk on the OBRI, how research is done, what is done with the information that is gathered and how it is improving the care of patients with rheumatoid arthritis.

Following this, the patients and the OBRI team split into two groups to discuss various aspects of the program and the interview process. There was discussion on what was working well for all; what could be added that would be helpful; any components they didn't like or understand and any problematic areas. During discussions the patients expressed an overwhelming desire to know more about the OBRI research.

The day was very successful and the patients left with a better understanding of the initiative of which they are a part.

Sincerely,  
Cathy Hofstetter, Anne Lyddiatt, Jennifer Boyle, Christine Fyfe and  
Michael Mallinson

Consumer (Patient) Advisory Committee, patient members



Drawing by a young family member of an OBRI participant during the OBRI Patient Information Session

**Introducing: Michael Mallinson, Consumer Advisory Committee, member**

Late one evening in the summer of 1981, I stepped out of a taxi in front of my house after coming home from work, and I couldn't move! I was frozen in the middle of the road! The muscles in my legs were so knotted from pain and inflammation that I spent the next two agonizing weeks in bed. So started my long and painful road to diagnosis.

Over the next ten years, I visited doctors, chiropractors, rheumatologists and physiotherapists, all without relief or diagnosis. There were times I couldn't walk, lift up my little children or even carry a laundry basket. I suffered fatigue and depression. I slept sitting upright for three years because it was too painful to lie down.

Finally, I complained to a chiropractor that his treatments did no good for me whatsoever. He thought about it, and then wrote a note to my family physician suggesting I had ankylosing spondylitis. I had never heard of it. The diagnosis was confirmed by x-ray and a test for the HLA-B27 gene.

Looking for information, I turned to The Arthritis Society and was put in touch with the Ontario Spondylitis Association (OSA). I immediately understood then that I was not alone and that my journey with AS was not unusual.

I joined the OSA, became a board member and eventually president. When the Canadian Spondylitis Association (CSA) was formed, I was elected its first president.

Why did and do I volunteer so much of my time to the OSA and CSA, something that I am able to do more so now that I am retired from a 35 years banking career? It's because my ten years from onset to diagnosis of AS were so miserable that I did not want anyone else to have to go through the same thing.

My ambition is to touch everyone in Canada with Spondyloarthritis so they know they are not alone and to raise awareness of these diseases so that both health care providers and sufferers can get a much earlier diagnosis and proper treatment than I did.



**MESSAGE FROM AN OBRI PATIENT**

**Oct 5, 2013 Patient Session - An Attendee's Perspective**

Although I've had arthritis for more than a decade, I'm a new addition to the OBRI study as of June 2013. Hence the inaugural Patient Day in October was timed perfectly to introduce me to the study. The event was fabulous and I wish it had lasted all day. I loved meeting all the players, especially my own interviewer, Lindsey Tashlin. It was really interesting to hear how the twists of fate had led Dr. Bombardier to her career as a researcher and how OBRI evolved. Dr. Pavlova did a great job explaining the OBRI study and some of their findings to date. Her passion for her career and her patients was contagious and heartwarming. I am in awe of the number of papers and presentations that have come out of OBRI already, and the benefit they are providing to patients.

The other key part of the day was meeting the other patients. I came away with two new friends from the patients I met, and only wish we'd had more time to meet others too. Kudos to the OBRI team for putting on such an outstanding event, and thank you for taking it to the participants elsewhere in the province in the coming years.

**Nancy Roper** - New Consumer Advisory Committee member



**DID YOU KNOW?**

**Inflammatory Arthritis Medications Commonly Reported by OBRI Patients**

There are many different types of inflammatory arthritis such as rheumatoid arthritis (RA), ankylosing spondylitis (AS), psoriatic arthritis (PsA), etc. The table below lists some of the medications commonly prescribed by Canadian Rheumatologists for the treatment and management of inflammatory arthritis. Some medications, such as non-steroidal anti-inflammatory drugs (NSAIDs) and some steroids, are used to treat disease symptoms and are generally fast acting. Other medications, such as disease modifying anti-rheumatic drugs (DMARDs) and biologic response modifiers, have slower acting response times and can change the course of, or even halt, the disease. Routes of administration (how it is taken) and some brand (common) names are listed below.

**Table 1. Inflammatory Arthritis Medications Commonly Reported by OBRI Patients**

<b>OVER-THE-COUNTER</b> (oral)	<ul style="list-style-type: none"> <li>Acetaminophen (Tylenol); Acetylsalicylic acid (Aspirin); Ibuprofen (Motrin, Advil); Naproxen (Naprosyn, Aleve)</li> </ul>
<b>NSAIDs &amp; COXIBs</b> (oral)	<ul style="list-style-type: none"> <li>Diclofenac (Voltaren); Arthrotec; Celecoxib (Celebrex); Indomethacin (Indocid); Meloxicam (Mobicox)</li> </ul>
<b>DMARDs</b> (oral, injection)	<ul style="list-style-type: none"> <li>Azathioprine (Imuran); Gold/sodium aurothiomalate (Myochrysine); Hydroxychloroquine (Plaquenil); Leflunomide (Arava); Methotrexate; Sulfasalazine (Salazopyrin)</li> </ul>
<b>BIOLOGICS</b> (injection, infusion)	<ul style="list-style-type: none"> <li>Abatacept (Orencia); Adalimumab (Humira); Anakinra (Kineret); Belimumab (Benlysta); Certolizumab pegol (Cimzia); Etanercept (Enbrel); Golimumab (Simponi); Infliximab (Remicade); Rituximab (Rituxan); Tocilizumab (Actemra)</li> </ul>
<b>STEROIDS</b> (oral, injection & infusion)	<ul style="list-style-type: none"> <li>Cortisone; Prednisone (Deltazone); Methylprednisolone (Solumedrol, Depomedrol); Hydrocortisone; Dexamethasone; Bethamethasone (Celestone)</li> </ul>

**OBRI Investigator Spotlight:  
Dr. Viktoria Pavlova, Rheumatologist**

Dear OBRI participant,  
I am delighted to write to you and express my sincere appreciation for your willingness to share your personal stories and dedicate your time to the OBRI. Through your contributions we enhance our knowledge of Rheumatoid Arthritis. I am one of 59 rheumatologists who participate in this important research. I truly believe in the importance of a Rheumatoid Arthritis (RA) registry such as OBRI.

OBRI is a combined effort of patients like you, rheumatologists, and researchers that allows us to learn more about RA in the real world setting. The registry allows us to better understand the course of RA (which has changed over the last decade), how disease severity may differ between patients and how patients respond differently to the therapies available. This knowledge allows us to treat RA patients more effectively and improve the quality of care we provide to our patients, while advocating for new investigation methods and treatment options to payers and policy makers.

The OBRI is about every patient who lives with RA. We want to know whether you have severe or mild disease, whether or not you have damage to your joints, how you function at work and home and how you respond to anti-rheumatic therapy. Based on your input and the data collected, we share back progress reports on how your disease is progressing and how you are responding to overall treatments.

Soon after I graduated from my Rheumatology Fellowship at McMaster University, I joined the OBRI. During my residency training, I was surprised that the general public had little awareness of arthritis. There were misconceptions as to who can get arthritis and how to recognize early symptoms of inflammatory arthritis in general practice. With the research from the OBRI we are making a difference.

Thank you for supporting RA research. Your contribution is priceless and will make a tremendous difference in our understanding and management.

Dr. Viktoria Pavlova, MD, FRCPC  
Assistant Clinical Professor,  
McMaster University, Department of Medicine,  
Division of Rheumatology



## NEWS AND HIGHLIGHTS

### OBRI Research Results & Outcomes of Studies

The OBRI mission is to gather evidence to create best practices to improve outcomes for people with rheumatoid arthritis. Currently the OBRI has 2541 patients in the registry, who have agreed to volunteer their time and clinical data to help achieve this. The data is collected on their therapies and disease activity through the 59 participating rheumatologists (investigators). To ensure that patients are kept informed on the latest research findings, the OBRI will provide summaries for some of the patient-centred studies (abstracts) that have been submitted to the relevant rheumatology conferences and meetings, in their newsletters and on the OBRI website ([www.obri.ca](http://www.obri.ca)).

#### Study Results: Cigarette Smoking & Disease Activity in RA Patients

Smoking is a known risk factor for developing RA. However, the effect of smoking on RA disease activity is not clear. To determine the effects of smoking on disease activity a study was conducted based on OBRI patients who provided a smoking status at the time of enrollment (baseline): never smoker, past smoker and current smoker. Numerous factors such as patient's demographics, treatments, and blood work (rheumatoid factor (RF) and general markers of inflammation) were compared according to smoking habits. Disease activity measures were estimated using statistical analysis after adjusting for the differences in age, sex and RF.

Out of a total of 2090 patients with an average age of 57.3 years, 77% were females), 343 were current smokers, 812 past smokers and 935 had never smoked. It was determined that 76.7% of current smokers were RF positive as compared to 70.9% of past smokers and 64.5% of never smokers. Once the data was adjusted to account for differences due to age, sex and RF, it was determined that current smokers also had a significantly higher (on average) number of tender joints and swollen joints and higher scores on other common disease activity measures. Analysis showed no significance for more DMARDs than biologics being used at baseline in smokers.

These study results indicate that amongst RA patients, smokers have worse disease activity outcome measures than non-smokers.

#### Study Results: Use of MEDSCHECK program among RA patients

MedsCheck is an OHIP covered service designed to help patients understand and manage their medications. The program allows patients taking three or more prescription medications for a chronic condition to schedule a one-to-one meeting with their community pharmacist.

733 of 2081 OBRI patients were identified as suffering from three or more chronic medical conditions (at baseline). Of those, 105 patients were contacted by telephone for a survey to determine their use of MedsCheck. The average age of the patients was 62.4, 69% were female and their disease activity was determined (on average) to be moderate. Thirty two percent of interviewed patients had participated in MedsCheck and of those 88% reported the meeting to have taken 15-30 min. Of the interviewed patients 41% reported to have found the review to be extremely effective (10 on a 1-10 effectiveness scale) in addressing their medical concerns and 79% reported no interest in a program solely focused on reviewing arthritis medications.

These study results indicate that the Ontario MedsCheck program is underutilized and because a good proportion of patients found it useful, there is a need to increase awareness of it.



## OBRI PARTNERS

The OBRI is currently working with:

- The Best Medicines Coalition (BMC) is 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](http://www.bestmedicines.ca)
- The Arthritis Society  
[www.arthritis.ca](http://www.arthritis.ca)
- The Ontario Rheumatology Association (ORA)  
[www.ontariorheum.ca](http://www.ontariorheum.ca)
- The Canadian Rheumatology Association (CRA)  
[www.rheum.ca](http://www.rheum.ca)
- Canadian Arthritis Patient Alliance (CAPA)  
[www.arthritispatient.ca](http://www.arthritispatient.ca)
- Institute of Clinical Evaluative Sciences (ICES)  
[www.ices.on.ca](http://www.ices.on.ca)
- Canadian Spondylitis Association (CSA)  
[www.spondylitis.ca](http://www.spondylitis.ca)



## UPCOMING EVENTS

**Events for Patients:**

- **OBRI Patient Information Sessions** (see insert for details)
  - Saturday May 3, 2014 - *Newmarket*
  - Saturday May 31, 2014 - *Mississauga*
  - Saturday June 7, 2014 - *Bowmanville*
- Patient Forum on Ankylosing Spondylitis hosted by the Spondyloarthritis Research Consortium of Canada (SPARCC) and the Canadian Spondylitis Association (CSA) at Toronto Western Hospital at 6:30 pm on March 27, 2014  
<http://www.sparcc.ca/>
- "Prescription For Education" for inflammatory arthritis (RA, PsA, IBD, AS, Gout and Lupus) on May 2, 2014 from 9:00 am - 3:30 pm. Located at St. Michael's Hospital with satellite sites available across Ontario. Video access available. Sponsored by The Arthritis Society. For more information please contact Sofia at 416-864-5295
- The Arthritis Society's Walk to Fight Arthritis being held in 25 cities across Canada on Sunday, June 8, 2014. Visit website for more details <http://walktofightarthritis.ca/>
  - \* The Arthritis Society offers many weekly events for patients. Please visit The Arthritis Society website to find an event/program near you ([www.arthritis.ca](http://www.arthritis.ca))

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

- OBRI Research Day Friday April 11, 2014 (Toronto, ON)
- Ontario Rheumatology Association (ORA) 13<sup>th</sup> Annual General Meeting - May 23-25, 2014 (Muskoka, ON)
- European League Against Rheumatism (EULAR) Annual Scientific Conference - June 11-14, 2014 (Paris, France)

**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:

[OBRI@uhnres.utoronto.ca](mailto:OBRI@uhnres.utoronto.ca)