



**OBRI**  
ONTARIO  
BEST PRACTICES  
RESEARCH INITIATIVE  
*Shaping the Future of Arthritis Care*

## Keeping OBRI patients informed

January 2021 | Volume 9

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.

### CONTACT US

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

Office: 1.866.213.5463

Fax: 1.888.757.6506

[www.obri.ca](http://www.obri.ca)

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 THE OBRI

2020 presented unprecedented challenges to the OBRI and the world. The COVID-19 pandemic forced us to change our daily practices and become innovative in our personal and professional lives. For many, life became virtual – from medical appointments, meetings and congresses, family visits, to grocery shopping. The OBRI team was fortunate to continue working uninterrupted with the technology provided by the University Health Network (location of our main office) and the year has been a productive one.

The interviewer questionnaires have been updated to collect important and timely data on COVID-19. A new vaccination questionnaire has been developed which we expect will raise awareness of the recommended vaccinations for RA patients, as well as identify any barriers preventing patients from receiving the recommended vaccinations. In addition, existing questionnaires have been updated to newer versions.

In May, we hosted our first virtual annual conference for a record number of attendees. The meeting featured a session on Big Data and the Rheumatologist, with the panel members each presenting a different perspective on the topic. The meeting also included poster presentations of OBRI's latest research and updated on the OBRI cohort.

At the end of the year, we hosted the Psoriatic Arthritis investigator meeting and we look forward to enrolling patients in 2021.

The start of new year always brings with it the hope of better times. Our best wishes for a safe, happy and healthy year!

## OBRI Clinical Advisory Committee Profile: Dr. Manisha Mulgund

Dr. Manisha Mulgund is a graduate of the McMaster University



Rheumatology program. She works as a community rheumatologist in Hamilton, ON at the West Mountain Medical Center. Her special interest lies in early inflammatory arthritis. She strives to provide timely access to care for patients with inflammatory arthritis and dedicates much of her time to making innovative improvements in the field of patient care. With the inspiration and support of her patients, Manisha has developed a free, patient-centric app named "Arthritis + Patient". She hopes to facilitate self-management and improve outcomes for patients with inflammatory arthritis. Her vision statement includes- Respect, Educate, Empower, Improve.

She has been part of the Ontario Telemedicine Network (OTN) eConsult specialist group since its early days. To her honour and delight, she has recently become a Peer Leader with OntarioMD. She is Electronic Medical Records (EMR) peer leader for OSCAR EMR users and member of the informatics committee with the Ontario Rheumatology association and regularly engages with the Diversity and Inclusion Committee at the Canadian Rheumatology Association. Manisha is actively involved in clinical trials and studies and has also been involved as an Ontario Best Practises Research Initiatives (OBRI) investigator.



## Patient + Arthritis App

Dr. Manisha Mulgund thought that there should be a better way for her patients to keep track of their symptoms and their medications and she decided to do something about it. She got busy and developed the **Arthritis + Patient** app.

This app, available for both iPhone and Android, is an easy to use portal for any inflammatory arthritis (IA) patient (RA, AS or PsA) to help track and manage their disease. There is a profile where you can enter all of your own information (please note that you can use any number for your patient ID), diagnosis, medical and surgical history, lifestyle components, and medications. It has a symptom journal complete with a camera to photograph swollen joints (for example) and it has a speech-to-text feature for note taking. There is a Functional Assessment feature (HAQ), General Assessment (16 questions with a visual scale for each) and a Homunculus where you can mark in painful or swollen joints, and this can be kept in the records section which you can print off and take to your appointment with you. To help you learn more about your disease, there is a section for arthritis information which contains a basic written and audio overview, complete with pictures, for each type of IA.

The best part is it is **FREE** to download from the App store or Google Play or on your phone so you can carry it with you to the doctor's office. The only thing that Dr. Mulgund asks in return is that you fill out the survey that is also on the app so she can continue to develop new features to make this an indispensable aid to all inflammatory arthritis patients! Please be sure to do that, she really values your input!



## NEWS AND HIGHLIGHTS

We are excited to announce that 3 OBRI papers were accepted for publication in 2020. We also virtually attended and contributed to important scientific meetings including the Canadian Rheumatology Association (CRA) in February where we presented 5 posters; the Canadian Association for Population Therapeutics meeting in October with 2 oral presentations and 1 poster presentation; and in November at the American College of Rheumatology (ACR) with 1 oral presentation and 4 poster presentations.

For more information about our research, please visit our website: [www.obri.ca](http://www.obri.ca).

## OBRI Patient Advisory Committee Profile: Denis Morrice



Well, here we are in the middle of COVID-19 and at 77 with Osteoporosis and Osteoarthritis, I have just retired from the Ontario Rheumatology Association (the most progressive and patient focused medical association in Canada – just saying). I plan to continue my volunteer work with OBRI, the Best Medicines Coalition, Pharmaceutical Advertising Advisory Board and Health Canada’s Multi-Service Stakeholder Steering Committee on Drug Shortages.

To support OBRI, I will continue to draw on my experience as CEO of the Canadian Hearing Society, CEO of The Arthritis Society of Canada, and the boards of the Arthritis Networks of Centres of Excellence, Institute of Musculoskeletal Health and Arthritis along with having been the Canadian Ambassador to the International Bone and Joint Decade.

Things don’t just happen – people make them happen. So for patients and patient groups in this arena we clearly state: “Nothing About Us Without Us”.

## CAREGIVER PERSPECTIVE

David Barker, OBRI Patient Advisory Committee Member

### “Put Your Own Mask on First”: Caregiving in Times of a Pandemic

In September 2020, the Ontario Caregiver Organization stated the following:

Across Ontario, there are 3.3 million caregivers—ordinary people, including children and youth, caring for family members, partners, friends and neighbours, who have physical and/or mental health challenges. These caregivers deliver roughly three-quarters of all patient care, including personal, emotional and often medical care. Caregivers are the single most valuable resource to our health care system, our communities and our society at large.

In our times of a pandemic, this number is not going down anytime soon. The result will be increased liabilities of compassion fatigue, physical exhaustion, neglect of those needing care, personnel shortages, and generally increased burdens on both caregivers and those for whom we care.

There are several means by which to mitigate some of this, but the one thing I would point out in this brief article comes from what we have all heard in the pre-take-off safety reviews of every flight we’ve ever been on: “Put your own mask on first.”

In other words, we are talking about *self-care*. Self-care is less of a right than it is a responsibility. We owe it to those for whom we care. Here are several suggestions that I have found helpful. First, simply retreating into a state of mental or emotional oblivion (binging on Netflix?) is not helpful. We rarely come out the other end in an improved state. Second, get outdoors. Somehow being surrounded by nature, or even an excursion around the block a few times, helps refresh and regenerate. Third, sleep, nutrition, diet. All three are necessary to sustain ourselves as caregivers. Fourth, engage with people outside our care-circle—a friend, a mentor, a spiritual director. Conversation, laughter, and even a few tears (in a context where we are receiving as much as giving) can rejuvenate in surprising ways. Finally, connect with support groups. For example, I have found that the Ontario Caregiver Organization (<https://ontariocaregiver.ca>) or the Ontario Caregiver Coalition (<https://ontariocaregivercoalition>) are great resources for help, hints, and encouragement.

If “caregivers are the single most valuable resource to our health care system, our communities and our society at large” is true (and we have no reason to believe that isn’t), then yes, we need to put our own masks on first if our efforts are going to be strong and sustainable.

*David is married to Lorraine, who was diagnosed with rheumatoid arthritis when she was 17 years old. Lorraine and David have just celebrated their 46th wedding anniversary.*

## RESOURCES FOR PEOPLE LIVING WITH ARTHRITIS:

Canadian Arthritis Patient Alliance

[www.arthritispatient.ca](http://www.arthritispatient.ca)

Joint Health

[www.jointhealth.org](http://www.jointhealth.org)

Rheuminfo

[www.rheuminfo.com](http://www.rheuminfo.com)

The Arthritis Society

[www.arthritis.ca](http://www.arthritis.ca)

Canadian Spondylitis Association

<http://www.spondylitis.ca/>

Arthritis Research Canada

<https://www.arthritisresearch.ca/>

## RESOURCES FOR CAREGIVERS

Ontario Caregiver Association,

<https://ontariocaregiver.ca>.

## DAILY SMILE

**Medical experts were asked if it is time to ease the COVID lockdown:**

Allergists were in favour of scratching it, but Dermatologists advised not to make any rash moves.

Gastroenterologists had a sort of a gut feeling about it, but Neurologists thought the government had a lot of nerve.

Obstetricians felt certain everyone was labouring under a misconception, while

Ophthalmologists considered the idea short-sighted.

Many Pathologists yelled, "Over my dead body!" while Paediatricians said, "Oh, grow up!"

Psychiatrists thought the whole idea was madness, while Radiologists could see right through it.

Surgeons decided to wash their hands of the whole thing and pharmacists claimed it would be a bitter pill to swallow.

Plastic Surgeons opined that this proposal would "put a whole new face on the matter."

## RESEARCH UPDATE

**STUDY RESULTS: Frailty and risk of osteoporotic fractures in patients with rheumatoid arthritis: Data from the Ontario Biologics Research Initiative**

Guowei Li, Maoshui Chen, Xiuying Li, Angela Cesta, Arthur Lau, Lehana Thaban, Jonathan D. Adachi, Junzhang Tian, Claire Bombardier

Frailty is defined as the state of being **weak in health or body** due to loss of reserves (such as energy, physical ability, cognition, health).

The relationship between frailty and risk of poor health outcomes in patients with rheumatoid arthritis (RA) remains unclear. Data from the Ontario Best Practices Research Initiative (OBRI), a clinical registry of patients with RA, were used to explore the relationship between frailty and fracture (bone breakage) risk in patients with RA.

The primary result investigators measured was the number of years to the first osteoporotic fracture (bone breakage due to bone loss) that led to a hospitalization or emergency room visit. Frailty was measured by an index (called Rockwood type frailty index) measuring 32 health related limits to one's social, psychological, and physical functioning.

The study participants (total= 2923) were an average age of 58 years old and 78% of the patients were female. Participants were followed by OBRI for an average of almost 4 years and during this time there were 125 (4.3%) fractures reported. RA patients with a fracture showed higher levels of frailty compared to patients without fractures.

In summary, the study demonstrates that higher frailty levels are significantly related to increased risk of fractures in patients with RA. Measuring the frailty of RA patients may aid in fracture risk assessment, management and decision making.



## UPCOMING EVENTS

Please check the OBRI website for 2021 events.

[www.obri.ca](http://www.obri.ca)



## CONTACT US

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

Telephone: 1.866.213.5463

### OBRI Interviewers:

Lynda Linderman	905.235.5019
Andrea McClintock	416.588.5522
Colleen Perrin	416.778.4640
Sharon Zwarych	289.660.0201

*Have questions? Want to provide feedback?*

*Don't hesitate to contact us!*