C-OPN NEWSLETTER
RPCO INFOLETTRE

WINTER 2026 **Together, the Future is Open for Parkinson's Research** **Vol.3**

C-OPN DATA AT WORK:

"Ethnic and Gender Disparities in Access to Deep Brain Stimulation Surgery for Parkinson's Disease"

Authors: Ba, F., Poonja, S., Torabi, P., Yen, K., Daud Shah, B., Noyes, E., Dimapilis, G., Corrick, S., Sankar, T., Rajput, A., Monchi, O., Vitali, A.M., Salami, B., Shetty, A. and Miyasaki, J.M

This study examines disparities in access to deep brain stimulation (DBS), an effective and cost-efficient treatment for Parkinson's disease (PD) that improves motor function and quality of life. Despite its known benefits and availability within Canada's large, publicly funded healthcare system, DBS remains underused, particularly among women and racialized populations, raising concerns about inequitable care.

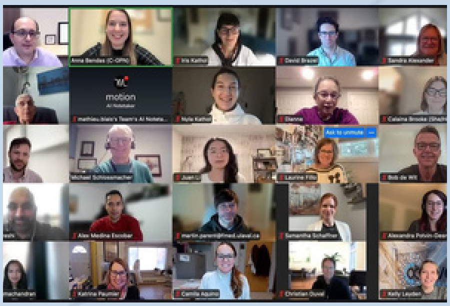
Using data from two Canadian academic centers and from the Canadian Open Parkinson Network (C-OPN) registry, the researchers analyzed who gets referred for and who ultimately receives DBS.

They found clear demographic patterns: most of the patients undergoing DBS were White, male, highly educated, and married. Although referral rates roughly reflected the known higher prevalence of PD in men, men were significantly more likely than women to proceed to surgery. Similarly, racialized groups were markedly underrepresented compared to their proportion in the general population. In contrast, factors like income and rural versus urban residence did not appear to limit access, suggesting that disparities are not purely financial or geographic.

This study highlights multiple possible contributors to these observed inequities. These include potential provider biases, such as underestimating symptoms in certain groups, differences in patient communication or health literacy, cultural attitudes toward illness and surgery, and mistrust of the healthcare system overall among racialized communities. Women, in particular, may delay seeking treatment or decline DBS due to risk concerns, caregiving responsibilities, or differences in how symptoms are perceived and expressed. Higher education and having a spouse or caregiver may also improve access by enabling stronger self-advocacy and support through the complex treatment process.

Overall, the findings show that inequities in DBS access persist even in a universal healthcare system. The authors conclude that addressing these disparities will require better understanding of referral pathways, increased education for both providers and patients, and culturally sensitive, system-level interventions to ensure equitable access to advanced PD therapies like DBS.

Community Snapshots:



A screenshot from C-OPN's 5th annual General Assembly. Thank you to everyone who participated, and to our incredible presenters!

C-OPN PCAC member Barbara was featured on CBC News discussing the importance of dance for people diagnosed with Parkinson's!

C-OPN Quick Stats:

2563
Participants

460
Research Members

11
Sites

108
Projects

C-OPN NEWSLETTER
RPCO INFOLETTRE

WINTER 2026 Together, the Future is Open for Parkinson's Research **Vol.3**

C-OPN DATA AT WORK:

Standardizing the QPN imaging dataset

Researchers: Dr. Nikhil Parag Bhagwat, Dr. Jean-Baptiste Poline, and Team

Use this portal link to explore the data for yourself!: **query.neurobagel.org**

This incredible project focused on standardizing a large, complex Parkinson's disease dataset from the Quebec Parkinson Network (QPN) for research use. Previously fragmented and not easily accessible, the data were cleaned, standardized, and organized over two years, covering more than 270 participants and including brain scans as well as extensive clinical and cognitive measures. The team also ensured privacy, developed tools to explore the data, and created systems that allow researchers to easily access and use it. This work has transformed this dataset into a powerful resource now contributing to national and international collaborations through networks like C-OPN and beyond. By connecting QPN data with other research datasets, researchers can work more efficiently and generate stronger, more reliable insights into how Parkinson's develops and progresses.

As Dr. Nikhil Bhagwat noted, this effort highlights the importance of research infrastructure. He described the data as an iceberg—only a small visible portion is accessible, while much more remains hidden. Proper infrastructure for data, including data cleaning, standardization, and sharing systems, is what reveals the full value of the data and enables it to drive meaningful research to improve patient outcomes.

My Journey with Parkinson's: A Testimony

Serge Boily is not only a valued member of the C-OPN Parkinson Community Advisory Committee (PCAC), but also a Parkinson's advocate, research participant, and co-founder of Victimes des Pesticides du Québec, raising awareness and supporting others.

VICTIMES DES
PESTICIDES
DU QUÉBEC

"I live with Parkinson's disease. When I received my diagnosis, I felt shock, confusion, and a deep sense of injustice. The tremors, the slowness, the fatigue—but above all, the uncertainty. I kept asking myself: why me? How would my life change? Every daily gesture became a reminder that something profound had shifted.

The real turning point came one evening as I watched the documentary "When Pesticides Make Us Sick," broadcast on the program Découverte on Radio-Canada. Listening to the testimonies and scientific explanations, I felt something shift inside me. Everything aligned—my professional background, my exposure to pesticides, my diagnosis. It was no longer a disease that happened by chance. It was possibly the result of years of exposure. That moment was overwhelming. I felt anger, but also deep determination.

I realized I was not alone. Other workers were living the same reality, often in silence, struggling to have the link between their illness and their professional exposure recognized. Isolation, complex administrative procedures, and lack of recognition added to the burden.

It was in this spirit that I helped found Victims of Pesticides of Quebec. Our organization informs, supports, and advocates for individuals affected by pesticide exposure. We assist workers and their families in understanding their rights and work toward recognition of the health impacts of pesticides, particularly in connection with neurodegenerative diseases such as Parkinson's disease.

Alongside my advocacy work, I have been deeply involved in scientific research. Over the past six years, I have participated in approximately 25 to 30 research projects related to Parkinson's disease. I am involved as a patient partner, collaborator, and active participant, convinced that lived experience must contribute directly to advancing knowledge. For me, research represents hope.

Despite the daily challenges imposed by the disease, I continue to move forward. What began as a personal trial has become a collective mission: transforming pain into action, injustice into mobilization, and vulnerability into strength."