



**2023**

# **ANNUAL REPORT**

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# Highlights of 2023

The Canadian Open Parkinson Network (C-OPN) hit several milestones throughout the year. Notably, a total of **1717 participants** are currently enrolled, from which we have collected thousands of data points and over 600 blood samples. Broken down, this includes:

- **1511 participants with Parkinson's disease (PD)**
- **73 participants with Atypical Parkinsonism**
- **122 volunteer controls**

With respect to the latter, select C-OPN sites across Canada have begun recruiting healthy controls to further meet researchers' needs.

C-OPN currently has **303 members**, including both national and international researchers, clinicians, and student trainees.

The Researcher Spotlight series, highlighting C-OPN members and the exciting research they are conducting utilizing C-OPN resources, has continued to be showcased across our social media platforms. This series was developed to give back to C-OPN participants looking to better understand the impact of their research involvement. To date, **25+ research** projects have leveraged C-OPN resources, and these projects will continue to be showcased throughout 2024. To get a better understanding of these research projects and the C-OPN resources they are utilizing, check out the **[Current C-OPN Projects list](#)**.

C-OPN's continued collaboration with the Global Genetics Program (GP2), a resource program of the Aligning Science Across Parkinson's initiative, has begun to yield genomic data. To date, we have sent 367 DNA samples from C-OPN participants for genome-wide association study (GWAS) analysis, in addition to 127 DNA samples from C-OPN participants with early onset or a familial history of PD (monogenic hub) for full genome sequencing. This data will soon be available to C-OPN members through controlled access. To learn more about GP2 and C-OPN, check out the **[Cohort Dashboard](#)**.

For all data inquiries, please email Guillaume Penouilh [data@copn-rpco.ca](mailto:data@copn-rpco.ca)

## List of Publications Utilizing C-OPN Resources

1. de Rus Jacquet, Aurelie, et al. "Clinical perception and management of Parkinson's disease during the COVID-19 pandemic: A Canadian experience." *Parkinsonism & Related Disorders* 91 (2021): 66-76.
2. Su, Zi H., et al. "Parkinson's disease deficits in time perception to auditory as well as visual stimuli—A large online study." *Frontiers in Neuroscience* 16 (2022): 995438.
3. McVittie, James H., et al. "Stacked survival models for residual lifetime data." *BMC Med Res Methodol* 22, 10 (2022). <https://doi.org/10.1186/s12874-021-01496-3>



# What's New?



## Sites

There are currently 10 C-OPN sites: University of British Columbia (Vancouver, BC); University of Alberta (Edmonton, AB); University of Calgary (Calgary, AB); University of Toronto (Toronto, ON); Western University (London, ON); University of Ottawa (Ottawa, ON); McGill University (Montreal, QC); University of Montreal (Montreal, QC); Laval University (Quebec, QC); and Clinique Neuro-Lévis (Lévis, QC). Importantly, 2 additional sites will be launched in the coming months: University of Sherbrooke (Sherbrooke, QC); and Dalhousie University (Halifax, NS).

## Task Forces

During the C-OPN Retreat in May 2023, 4 different Task Forces were created to propel the needs and priorities of the Network forward. Each Task Force consists of a chair, and a mixture of clinicians, researchers, trainees, and community representatives.

**Diversity Task Force** (chair, Dr. A. Jon Stoessl): The central objective of this initiative is to promote greater diversity within the C-OPN cohort.

**Technology Task Force** (chair, Dr. Martin McKeown): The overarching goal of this initiative is to harness the potential of technology for the purpose of improving recruitment and engagement strategies, as well as access to care within Canada.

**Resilience Task Force** (chair, Dr. Silke Appel-Cresswell): The primary goal of this initiative is to comprehensively capture the various factors that play a pivotal role in influencing resilience among individuals facing the challenges of living with PD.

**Funding Task Force** (chairs, Dr. Michael Schlossmacher and Bob de Wit [Parkinson Community Advisor]): The primary goal of this endeavour is to secure the financial sustainability of C-OPN.

Each of the 4 Task Forces will work both independently and collaboratively to achieve common goals and make significant strides in the Canadian Parkinson's research landscape. If you are interested in joining one of the above-mentioned Task Forces, please email: [national.manager@copn-rpco.ca](mailto:national.manager@copn-rpco.ca)





**Anna Bendas**



**Guillaume Penouilh**

## New Personnel

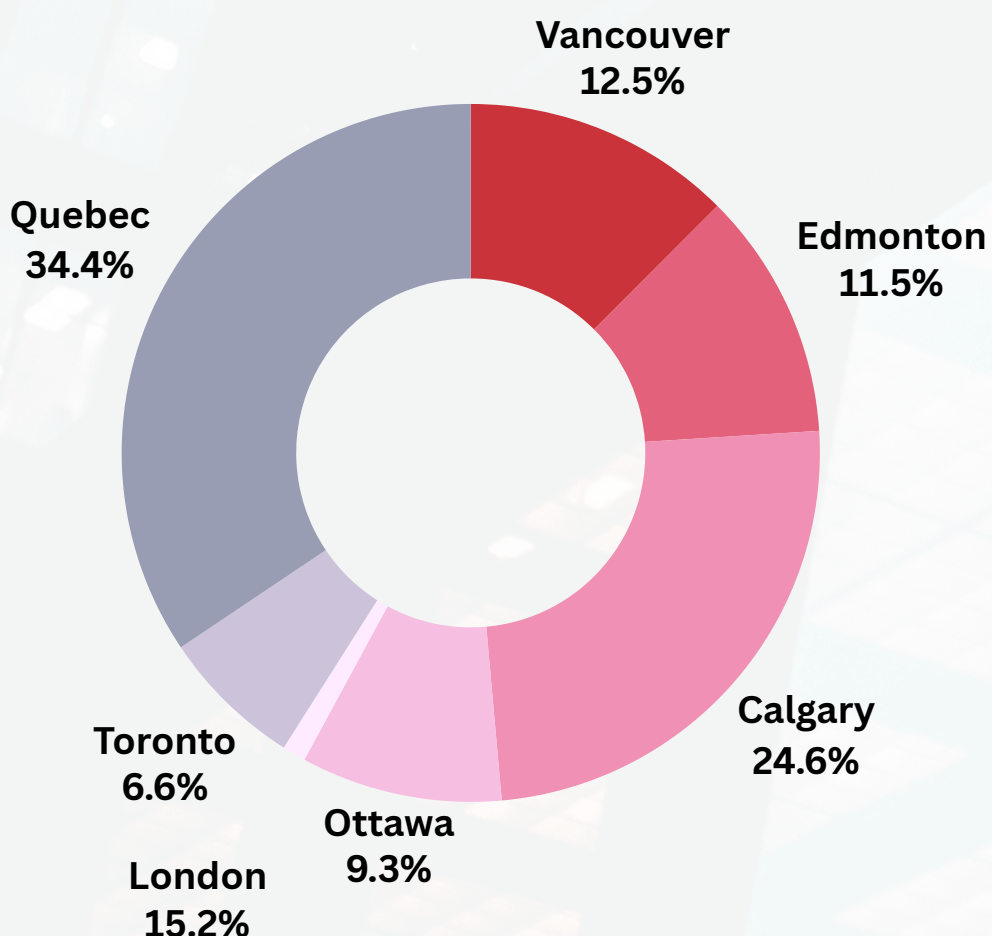
It is our pleasure to introduce two new personnel who are now working with C-OPN.

**Anna Bendas** is acting as the **National Manager** of C-OPN. Anna Bendas holds a Master of Science degree in Management from HEC Montréal University. She has extensive experience in coordinating clinical research projects. Her primary interests focus on impactful leadership, creative project management, strategic consulting and innovative knowledge transfer methodologies.

**Guillaume Penouilh** is acting as the **Data Monitor** of C-OPN. Guillaume holds a DEC in IT Business, specializing in systems operation. He has extensive experience in IT project management, having spent several years working for major corporations. His main focus is on methods such as ITIL and tools like JIRA. He is a specialist in continuous improvement and user support.

## Key Demographics

### Site distribution



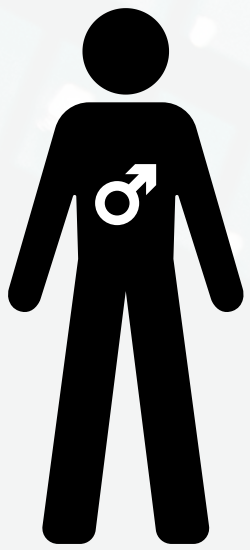
### Number of blood samples collected to date

<b>DNA</b>	991
<b>Serum</b>	832
<b>PBMCs</b>	674

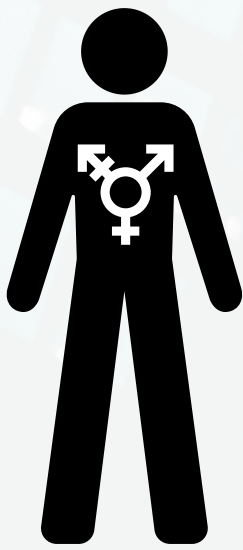


# Key Demographics (cont...)

## Gender



n=965  
(61%)



n=2  
(0.1%)



n=608  
(39%)

## Age

32yrs



98yrs

Median: 67 yrs

Mean: 66.1 yrs

## Ethnicity

91% White or French Canadian

## Education

Average 11.1 yrs



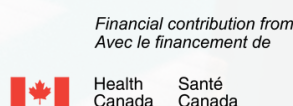
## Goals for 2024

With a successful infrastructure in place, C-OPN is well positioned to work towards the next steps of having a more active role in accelerating PD research, enhancing our understanding and paving the way for innovation. We expect to achieve the following goals during 2024:

- Submission of first C-OPN PD cohort manuscript for publication (in preparation)
- Launch of Sherbrooke site (led by Dr. Karina Lebel)
- Launch of Halifax site (led by Dr. Kerrie Schoffer)
- Continue to expand C-OPN participant recruitment across the country
- Establish plan for remote recruitment of new participants

## Acknowledgements

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For any questions, please do not  
hesitate to reach out to  
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