



## **Bjorn Moller Research Repository Participant Information**

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The Pacific Parkinson's Research Centre is excited for the fall 2024 launch of the '**Bjorn Moller Research Repository**' (BMRR), thanks to the support of the Moller family and **Pacific Parkinson's Research Institute**.

**Purpose:** To establish a biorepository for storage of biological samples and clinical/demographic data from individuals diagnosed with Parkinson's disease and other movement disorders (ataxia, essential tremor, etc.) as well as individuals who have not been diagnosed with Parkinson's disease. These samples will be available to scientists at the UBC Pacific Parkinson's Research Centre with ethics-approved projects to study the causes of and interventions for movement disorders.

**Impact:** Typically, participant recruitment and biosample collection are repeated each time a new research study begins, and leftover biosamples cannot be repurposed. Establishing the BMRR will allow participants to consent for use of their biosamples and associated data for future studies, enhancing the efficiency of clinical research, permitting analysis with future technologies, and increasing reproducibility of findings.

**Estimated commitment:** Participants will be provided with fecal and urine sample collection kits which can be used to collect biosamples at home. Participation also requires two in-person visits at UBC (18 months apart) for blood collection, plus completion of online surveys.

**Procedures required:** A total of 35 mL of blood (7 teaspoons) will be collected at each in-person visit.

### **Who can participate in the BMRR?**

You may be able to participate in the BMRR if:

- You are 19 years of age or older
- You either have a diagnosis of a movement related disorder (i.e. Parkinson's Disease, ataxia, dystonia, multiple system atrophy, progressive supranuclear palsy, myoclonus, tremor), or no known neurological symptoms (i.e. healthy control)
- Sufficient command of English to understand any questionnaires



### Data collected for the BMRR

If you participate in this biorepository, you will be provided with:

- Optional questionnaires concerning your past medical history (including any diagnosed movement disorders, your symptoms, family history of neurological disorders, gastrointestinal conditions)
- Optional questionnaires regarding diet, quality of life, sleep, neuropsychiatric symptoms, and social history

If you choose to complete the questionnaires online, a secure link to complete these will be emailed to you. Otherwise, you may complete the questionnaires in hard copy and mail them to the study coordinator. All questionnaire results will be de-identified. Data will be retained indefinitely unless you withdraw from the study.

### Samples collected for the BMRR

If you agree to be part of the BMRR, you will have the option to provide a variety of samples:

- Urine sample collected at home, prior to your study visit
- Fecal specimens collected at home, prior to your study visit
- 35 mL (7 teaspoons) of blood collected at your in-person visit at UBC

All biospecimens will be de-identified. Biospecimens will be kept indefinitely unless the sample integrity has been compromised or you withdraw from the study.

### Who will have access?

Only researchers from the UBC Pacific Parkinson's Research Centre will be eligible to access the BMRR. Researchers must obtain approval from the BMRR science committee (comprised of the Principal Investigator and Co-Investigators) in order to access samples and data.

### How will my taking part in this study be kept confidential?

No information or records that disclose your identity will be published without your consent, nor will any information or records that disclose your identity be removed or released without your consent unless required by law. You will be assigned a unique study number as a participant in this study, which will not include any personal information. Only this number will be used on any research-related information collected about you during this study.

### What will the study cost me?

All research-related procedures that you will receive during your participation in this study will be provided at no cost to you.

### Questions

For more information, please contact [bjorn.moller.repository@ubc.ca](mailto:bjorn.moller.repository@ubc.ca) or call 604-822-3177 (Mondays, Tuesdays, and Thursdays during business hours).

**Note: This document is not a consent form.** When you register as a BMRR participant, an official consent form will be provided, and you will have the opportunity to discuss with a study team member prior to signing.