

## **RESEARCH STUDY**

### **Title of research: Disclosure of Parkinson's disease diagnosis within the workplace, Phase II**

#### **Why is this research important?**

Parkinson's disease (PD) has a significant impact on an individual's ability to maintain employment. Cessation of employment is an important issue for people living with Parkinson's, particularly for those with young-onset Parkinson's disease (YOPD) as they are often diagnosed during their most productive working years and are at risk of financial instability and loss of self-worth.

Parkinson Society Canada is interested in learning about the issues around disclosing a diagnosis of Parkinson's to direct future education and advocacy efforts that will support people living with Parkinson's.

#### **What is the purpose of this study?**

The purpose of this study is to expand on previous research (Phase I) conducted in January 2011 in central Ontario which investigated workplace disclosure choices (disclosure versus non-disclosure, timing of disclosure events, and reasons for disclosure decisions) among employed people living with Parkinson's.

From the research conducted in Phase I, 90% of participants reported that they had disclosed their diagnosis to an employer and at least one co-worker. More than half reported that they had disclosed to their employer within 3 months of being diagnosed with PD. The most common reason for disclosing was that symptoms had become obvious or had disrupted job productivity and this necessitated an explanation. Less than half the respondents had disclosed for the purpose of accessing accommodation.

The main limitation of the data from Phase I was the small sample size which made a quantitative analysis difficult. There were no significant associations found between disclosure habits and various demographic, health, and job characteristics. A larger sample size would increase the power of analyses and potentially enable the identification of such associations.

The purpose of Phase II is to expand the sample size to other communities across Canada.

#### **Who is eligible to participate in the study?**

Both men and women are eligible to participate; participants must be 18 years and older; and the study seeks English and French-speaking participants. Volunteers should meet the following criteria:

1. Were clinically diagnosed with Parkinson's disease in 2005 or later.
2. Were engaged in (paid) employment (part-time or full-time) at the time of diagnosis (participants do not need to be employed currently).
3. Were not self-employed at the time of diagnosis.

### **What is required of the participants?**

Participants must provide informed consent prior to beginning the study. Participants will be required to complete a one-time telephone questionnaire. The questionnaire typically takes about 30 minutes to complete. The questionnaire is divided into several sections: 'basic demographics', 'health and disease status', 'occupational characteristics' and 'disclosure and accommodation'. The survey makes use of previously validated scales (including the Schwab and England Activities of Daily Living Scale, Karasek's Job Demands Scale, Caplan's Social Support Scale, and The Bristol Stress and Health at Work Study Occupational Stress Scale) as well as newly developed questions.

### **How large is the study?**

The study is seeking 40 volunteers across Canada. Recruitment will occur through Parkinson Society Canada and its regional partners using websites, support groups (YOPD), and newsletters. The interviews will take place June-December 2011. Results will be shared with all participants and Parkinson Societies.

### **What are the ethical considerations?**

Before participating in the study, volunteers are encouraged to enquire about the process of ethics approval, as well as their rights as a participant.

As in Phase I of the study, supervisors are Dr. Connie Marras, Movement Disorders Centre at the Toronto Western Hospital, and Debbie Davis, CEO Parkinson Society Central Northern and Ontario Region.

### **Who should I contact for more information?**

If you are interested in participating in this research, please contact Debbie Davis, PSCNO, 1-800-565-3000 ext. 3373, [debbie.davis@parkinson.ca](mailto:debbie.davis@parkinson.ca); or Barbara Snelgrove, PSC, 1-800-565-3000 ext. 3381, [barbara.snelgrove@parkinson.ca](mailto:barbara.snelgrove@parkinson.ca).