



## Calling for participants for The Parkinson's Victoria Research Registry

**The research registry is an exciting, collaborative project between the Howard Florey Institute and Parkinson's Victoria to establish a registry of people with Parkinson's who have been very carefully assessed and who are willing to participate in research. The registry will be a rich resource of information to improve our understanding of the condition and as a further resource for improving treatment and symptom control.**

### **What would happen if I participated?**

- A detailed history would be compiled of your experience of Parkinson's, based on an assessment at St Vincent's Hospital (Melbourne). The assessment, which will take approximately 1 hour, will include a range of tests to assess severity and signs/symptoms of the condition. It may also include videotaping, scans and a history of medications.
- Blood would be taken for genetic testing and other blood tests.
- You would be asked to participate in various research trials.

### **How often would I have to participate?**

- An examination would take place on entry and then every three years.
- You will be invited to participate in various research studies (with various time frames). (This may occur as frequently as several times a year.) You choose which ones you wish to participate in. (The reason for joining the register is to be readily identified as being suitable to participate in research studies, however this is not a binding obligation.)

**Am I eligible?** You are eligible if you meet the following criteria:

#### **People with Parkinson's group - OPTION (1)**

1. Do you have Parkinson's? While the examination will go over this information in detail, we are looking to register people with Parkinson's (disease) proper and not one of its related "cousins" (such as Multiple System Atrophy or Progressive Supranuclear Palsy (PSP)). If you are not sure, ask your neurologist. (It is advised that you gain your neurologist's approval before you participate in the registry.)

2. Are you able to get to St Vincent's hospital to have a 1- 1½ hour examination every 3 years?

3. Will you be able to participate in research programs? For example, if you come from the country will it be realistic for you to make the trip down to Melbourne?

**If you answer say "yes" to questions 1 AND 2 AND 3, then you may be eligible to participate.**

#### **Control group - OPTION (2)**

The registry also requires "control" subjects (those who do not have Parkinson's or a 'cousin' condition) and we need approximately equal numbers of people of the same age and gender as those with Parkinson's.

### **How do I indicate my interest in participating in option (1) or (2)?**

Email [gmahoney@parkinsons-vic.org.au](mailto:gmahoney@parkinsons-vic.org.au) or send a letter expressing your interest to: Parkinson's Victoria Research Registry, 20 Kingston Rd Cheltenham 3192.

Please ensure you include your contact details (name, phone number/s and address), and the year you began taking Parkinson's medications (if you are newly diagnosed and haven't started medications, please state that). Your expression of interest will then be passed on to the project team at the Howard Florey Institute who will be in contact with you to follow up.