Introductory Leaflet

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Study: Parkinson's and Movement Disorders Families Project (PFP)
Chief Investigator: Professor Huw Morris

Parkinson's and Movement Disorders Families Project: genes, research, me and my family

Why is research important?

One person in every 500 has Parkinson's and around 127,000 people are living with the condition in the UK. The prevalence of other movement disorders vary, for example it is estimated that one person in 900 is affected by dystonia in the UK, whereas essential tremor is estimated to be 20 times more prevalent than Parkinson's. Treatments are available that can improve or maintain someone's quality of life, but we would like to develop treatments that can be used at a much earlier stage in the development of the disorder. These could slow down or even halt the progression of the condition.

Why are you interested in people who have a family history of these conditions?

For most people who develop Parkinson's and other movement disorders there is no clear underlying cause. We are particularly interested in the minority of people diagnosed with Parkinson's or another movement disorder who experienced onset of their condition on or before the age of 45, and/or have other relatives affected by the condition. We think that variation in inherited material (genes) can sometimes cause the condition, and this may run in families. This opens the door to a range of studies on the effects of gene variation at a nerve cell and brain level, which we hope will lead to new targeted treatments.

We already know that rare gene variants can cause Parkinson's and some other movement disorders. Some of these are inherited in what is called an 'autosomal dominant' way i.e. each child of a person with this type of gene change has a 50% chance of inheriting it. However, we also know that not everyone who carries the gene change will go on to develop the disease. Some people appear to be protected against developing the disease and we would like to understand this better. Other variants, particularly important in early onset Parkinson's, are "recessive", and in this form of inheritance there is a very low risk to parents and children.

How are you following this up?

We are looking closely at the genetic make-up of people affected by movement disorders in comparison to the general population in order to find out more about which gene changes can cause these conditions. It is particularly useful to study both affected and unaffected relatives.

How can I join in?

We are interested in making contact with people with Parkinson's or a movement disorder, particularly if they have a family history of a movement disorder and /or they have early onset disease (starting on or before the age of 45).

What will joining in mean for me?

We will ask for your permission (consent) to collect and store blood samples and have your details stored securely on our research database. We will ask you to contact other family members (parents and brothers/sisters) if possible, to see if they would be happy to donate samples as well. We will give you detailed information about the study to read in your own time.

Will I find out if I have a Parkinson's/movement disorder causing gene change?

This is a research project and will not be generating genetic results for clinical use. If you would like to find out more about this we can discuss further NHS blood tests with you and your main consultant and/or at the research centre. If you like, we can also let you know if we have developed new tests based on your family's samples.

I'm related to someone who has Parkinson's/movement disorder – why are researchers interested in me and does this mean I'll develop the disease?

No - being invited to take part as an unaffected relative does not mean that you have the gene change or that you are going to develop Parkinson's or another movement disorder. However depending on how you are related to that individual, you may be at a higher risk of developing the condition and we are happy to discuss this with you.

If you would like to find out more about this we will arrange for you to have the appropriate NHS counselling and advice through the neurogenetics clinic at the National Hospital or in liaison with your local genetic/neurological services.

It is important to understand that taking part in research as a relative of someone who has a disease caused by a gene change does not mean that any results will be passed on to you. It is not a way to find out about your risk of disease, but we hope this will help us to understand these conditions better.

What next?

This leaflet is designed to only give a broad outline of these conditions, the part played by gene changes and the role of research in progressing advances in treatments. We realize that reading this leaflet may lead to more questions.

If you would like to talk about the information in this leaflet in more detail then please contact

PFP Study Coordinator

Tel: 020 8016 8174

Email: ion.pdresearch@ucl.ac.uk

If you are happy to be contacted and to find out more about our research studies then please complete and return the “permission to contact” slip attached.

Thank you.