

# **TASMAN**

## **An International study on different Movement Disorders**

### **Information Letter for Patients**

Dear Sir/Madam,

We kindly ask for your participation in the TASMAN-study, an international medical scientific study on patients with movement disorders.

For permission or refusal, information on our part and careful consideration on your part are needed. For this reason, you have received this information letter. Take your time to read this carefully. Before you make a decision, it is important that you have some knowledge about the research project itself. Please read this letter carefully and discuss this research project with your partner, friends or family. Participation is completely voluntary. If you still have questions after reading the information provided, you can always contact one of the researchers named at the end of this information letter.

#### **Background and aim of the research.**

Movement disorders come in many different forms. Sometimes movements increase (e.g., tremulous movements, jerks) and sometimes decrease/become limited (e.g., stiffness or slowness). When you see a neurologist, they will ask you several questions about your symptoms and will ask you to perform different movement tests. Based on these findings, it is sometimes possible to make a diagnosis after the first visit. However, there are often still doubts after the first evaluation, and it can take quite a while before a definite diagnosis is established.

The current research aims to investigate whether certain patient factors might help to differentiate between several types of movement disorders. To do this, patients complete a questionnaire prior to their visit to the neurologist. After their visit to the neurology clinic, the diagnosis made by the neurologist will be evaluated. We already know that certain factors are associated with movement disorders, but their ability to predict and differentiate between different conditions has never been investigated in this way before.

This research will be conducted in Australia and in the Netherlands. To participate, you do not have to make an additional trip to the hospital as the questionnaire is completed online. If you have read the information and want to participate, please go to:

**<http://redcap.link/tasman-australia>**

You will first be asked for permission to participate and then the questionnaire will start automatically.

# **TASMAN**

## **An International study on different Movement Disorders**

### **How will this study be executed?**

#### *Questionnaire*

The survey consists of a questionnaire about your symptoms. This will take approximately 15 minutes. The questionnaire is not only about your movement problems but will also include questions about your so-called 'patient features' (e.g., medical history, additional symptoms, general health). To avoid bias, it is important you complete the survey prior to your visit to the neurologist. Your neurologist will not know if you have taken part in the study or not and does not have access to your answers.

#### *Request of information*

After the outpatient visit, we ask the neurologist to fill in a short questionnaire about the diagnosis they have made and why they have made it. We also ask whether additional research is being carried out and which treatment has or has not been started. In addition, the researchers themselves will check your medical file after a few months to see whether the diagnosis has changed. For this data the same applies as for all other data that you have entered yourself and is collected in this research, see the heading "Privacy".

### **What are possible advantages and disadvantages of participation?**

Participation will not give you a direct advantage. The information that will be obtained from this research will possibly contribute to a faster and more accurate diagnosis in movement disorder patients in the future. A disadvantage of this research is that the questionnaire takes some time to complete.

### **What happens if you do not wish to participate in this research?**

It is your own decision to participate in this research project. Participation is voluntary. If you do not want to participate, you do not have to do or to sign anything. You also do not have to tell us why you do not want to participate. You will receive the same treatment as normal. If you do wish to participate, you are able to change your mind and leave the project at any point.

### **Privacy**

Only a few other people are able to look into your data. These individuals/agencies are, for example: employees of the research team, members of the Medical Ethics Committee and the Inspection for Health care. All research data will be handled according to the Dutch Data Protection Act ('Wet Bescherming Persoonsgegevens'). All research data that is collected during this research will be assigned a code number. This is to make sure that your personal data will not be used in research documentation. Furthermore, it is not possible to retain personal data from a possible future publication of research results. Only the researcher who holds the key to the code knows who the person behind the code number is.

# **TASMAN**

## **An International study on different Movement Disorders**

After closure of the research, your medical data will be kept for up to 15 years. It is possible that we will use research data for research that is not defined in this protocol but is in line with this research.

### **Has this study been approved by the Medical Ethics Committee?**

Since the TASMAN study only contains an online questionnaire with very few risks, the Medical Ethics Committee has assessed that the content of this study does not need to be inspected according to the WMO (Medical Scientific Research with humans Act). We do, of course, work according to the Medical Ethical guidelines.

### **Is there anything else you would like to know?**

For more information or any questions about the TASMAN study, please email:  
t.j.lagrand@umcg.nl

### **Informed consent**

If you decide to participate in this research, we kindly ask you to go to:

**<http://redcap.link/tasman-australia>**

You will first be asked for permission to participate and then the questionnaire will start automatically.

Kind regards,

Drs. Tjerk Lagrand, neurologist

On behalf of the international research team,

Dr. A. Lehn, neurologist movement disorders, Princess Alexandra Hospital, Brisbane

Drs. C. Lugtenberg, neurologist in training, UMCG, Groningen

Dr. J.M. Gelauff, neurologist in training, Free University, Amsterdam

Prof. Dr. M.A.J. de Koning-Tijssen, neurologist movement disorders, UMCG, Groningen