

# Taking Part in Medical Research at the Morton & Gloria Shulman Movement Disorders Clinic

**For patients and families**



Read this information to learn:

- Why we do medical research
- How taking part can help
- About research studies
- Who to contact if you have any questions



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## **The Edmond J. Safra Program in Parkinson's Disease and The Morton & Gloria Shulman Movement Disorders Clinic**

Medical research helps us find new ways to treat and care for patients at our centre. Research helps us learn information about movement disorders that can improve how we provide care to our patients now and in the future.

We may ask you to take part in a research study at our centre. Taking part in a research study could involve:

- filling out a questionnaire or survey
- trying a new medicine, medical device, or treatment (including surgery)
- taking part in genetic testing

Some of the research is done with the University of Toronto, Baycrest (a health centre that focuses on aging and brain health), and other hospitals or universities.

### **Do I have to take part if I'm asked?**

No. It is your choice whether or not you want to participate. Choosing to take part in a research study is a very important personal decision. We will continue to give you excellent care no matter what you decide.

### **How can taking part in a research study help?**

Taking part can help you become more active in your health. Taking part in research studies can help you and other people with movement disorders.

You may be asked to use research treatments that are not yet available to everyone. You and others may benefit in the future from this research. Information from research studies may improve our knowledge of how to treat, prevent and diagnose your disorder.

## **Who can take part in a research study?**

Every research study has rules or guidelines about who can participate. Whether or not we ask you to take part will depend on things like:

- your age
- whether you are male or female
- the type of disorder you have
- the treatments or medicines you are currently taking or you have already tried
- other medical conditions you may have

Before we ask you to join a research study, we want to make sure you are a good fit so we can keep you safe.

## **What should I know before deciding to join a research study?**

You should know as much as possible about the research study that we ask you to join. Please ask any questions about it that you may have. We want you to understand fully what will happen before you agree to participate.

Here are some questions to ask your doctor at the Movement Disorders Clinic:

- What kind of study is this?
- Why is it being done?
- How will this research affect me? For example:
  - How long is the study?
  - How many visits will I have to make?
- What are the benefits and risks?
- What are the other available treatment options?
- Who should I contact if I have any questions or concerns?

Talking about taking part in a research study with your family, friends and your family doctor can help you decide.

**Important:** Taking part in a research study may not have any direct benefit to you.

## **What is informed consent?**

Informed consent means you learn the important information about a research study before you decide to participate. It also means that we will continue to give you information during the study. A consent form is a piece of paper that you sign which tells us you agree to take part in a research study.

The consent form will include the following information about the study:

- the purpose
- how long it will take
- what we already know about the treatment
- the possible risks and benefits of taking part (based on what we know about the treatment)
- how many visits you will have to make and what you will do during each visit (for example: checking your blood pressure, doing blood work)
- what medicines (including herbal and supplements) that you can or can't take while taking part
- what other treatments are available besides the trial treatment
- no cost to take part in the study
- who is responsible for costs if you need extra care as a result of participating
- your identity (privacy) will be protected
- you are agreeing to take part
- you can leave the study at any time and still receive proper treatment
- who to contact if you have questions at any time during the study
- who to contact in case of an emergency during the study

## **Who is on the research team?**

The research team may include:

- doctors
- nurses
- research assistants and coordinators
- other health care professionals from our clinic, the hospital, or a university

**Remember:** You are also a very important member of this team.

## **Who should I speak to about taking part in a research study?**

If you want to take part in research, tell your doctor or the research team. Ask them about future research studies that may be suitable for you.

**Once you have signed the Movement Disorders Clinic general access consent form, only the staff at the Movement Disorders Clinic can check to see if you can take part in a specific research study.**

Only our staff can review your chart and contact you. If you have not signed a consent form, and you are interested in research, let your doctor know.

## Useful websites

### Health Canada

Website: [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

### The Michael J. Fox Foundation for Parkinson's Research – Fox Trial Finder

Website: <http://foxtrialfinder.michaeljfox.org>

### Parkinson's Foundation

Website: [www.parkinson.org](http://www.parkinson.org)

### National Institutes of Health – NIH Clinical Research Trials and You

Website: [www.nih.gov/health/clinicaltrials](http://www.nih.gov/health/clinicaltrials)

### Center Watch

Website: [www.centerwatch.com](http://www.centerwatch.com)

### ClinicalTrials.gov

Website: <http://clinicaltrials.gov>

### Dystonia Medical Research Foundation

Website: [www.dystonia-foundation.org](http://www.dystonia-foundation.org)



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