

Taking Part in Medical Research at the Edmond J. Safra Program in Parkinson's Disease and The Morton & Gloria Shulman Movement Disorders Clinic



Read this information to learn:

- why we do medical research
- how taking part can help
- about clinical trials
- who to contact if you have any questions



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 research at our centre. Medical research that asks patients to take part is called a **clinical trial**. Taking part in a clinical trial 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 the aging and brain health), Tanz Centre for Research for Neurodegenerative Diseases, 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 take part. Choosing to take part in a clinical trial 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 clinical trial help?

Taking part can help you become more active in your health care. Taking part in clinical trials 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 clinical trials may improve our knowledge of how to treat, prevent and diagnose your disorder.

Who can take part in a clinical trial?

Every clinical trial has rules or guidelines about who can take part. 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 clinical trial, 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 clinical trial?

You should know as much as possible about the clinical trial we ask you to join. Please feel comfortable asking lots of questions about it. We want you to understand fully what will happen before you agree to take part.



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

- What kind of trial is this?
- Why it is 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 trial with your family, friends and your family doctor can help you decide.

Important: Taking part in a clinical trial may not have any direct benefit to you.

What is informed consent?

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

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

- 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
- there is no cost to take part in the trial
- who is responsible for costs if you need extra care as a result of taking part
- your identity (privacy) will be protected
- you are agreeing to take part
- you can leave the trial at any time and still receive proper treatment
- who to contact if you have questions at any time during the trial
- who to contact in case of an emergency during the trial

Who is on the clinical trials team?

The clinical trial 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 clinical trial?

If you want to take part in research, tell your doctor or the clinical research team. Ask them about future clinical trials 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 clinical trial.

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

Who can I contact if I have any questions?

If you have any general questions about clinical trials you can call Julie So at 416 603 5800 ext. 2569, or speak to your doctor or any member of our research team.

Useful websites about clinical trials:

Research at UHN

Website: www.uhn.ca/research

Health Canada

Website: www.hc-sc.gc.ca

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

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

Parkinson's Disease Foundation

Website: www.parkinson.org

National Institutes of Health – NIH Clinical Research Trials and You

Website: www.nih.gov/health/clinicaltrials

Center Watch

Website: www.centerwatch.com

ClinicalTrials.gov

Website: <http://clinicaltrials.gov>

Dystonia Medical Research Foundation

Website: www.dystonia-foundation.org



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