

Dystonia Coalition Projects



This study is being conducted at

**Toronto Western
Hospital**

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What is dystonia?

Dystonia is a disorder involving excessive involuntary contraction of muscles with repetitive and patterned movements.

What is the Dystonia Coalition?

The Dystonia Coalition is an international collaboration of medical researchers and patient advocacy groups with a mission to advance the pace of research in the dystonias to find better treatments and a cure.

What is the purpose of this research?

This research includes four related projects each having different but overlapping goals;

- Learn about how dystonia may progress over time and what causes dystonia
- Develop tools to measure the severity of symptoms objectively
- Create a collection of blood samples for analysis
- Develop an app to monitor symptom severity

Who can participate?

- You must be diagnosed with one of the following isolated dystonias:
 1. Focal dystonia, including:
 - a) Blepharospasm (Eyes)
 - b) Oromandibular (Jaw and/ or tongue dystonia)
 - c) Laryngeal dystonia/Spasmodic dysphonia(Larynx)
 - d) Cervical dystonia/Spasmodic torticollis (Neck)
 - e) Limb dystonia/Writer's cramp/Musician's dystonia (Arms, hands, legs, feet)
 2. Segmental or multifocal dystonia (More than one body region)
 3. Generalized dystonia (Trunk and other body region/s)
 4. Hemi-dystonia (One side of the body)
- Your last injection of botulinum toxin should be at least 2 months prior to study visit (or your symptoms should be noticeable).

What is expected of the participants?

- Answer questions about medical and family history and current state of mind
- Have a neurological exam that will be video recorded
- Donate a blood sample
- Consider coming back every so often for follow-ups
- Consider spending about 1 hour during each study visit

Where can you learn more about joining this research?

- Contact your doctor
- Contact the coordinator