



This study is being conducted at

**Toronto Western
Hospital**

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Dystonia Coalition Projects

Patient Centered Outcome

What is the Dystonia Coalition Patient Centered Outcome Project (PCO)?

Researchers have developed an app that will help understand patient responses to botulinum toxin injections.

What is the purpose of this research?

The purpose of the study is to find out how participants with dystonia respond to receiving the standard of care treatment (Botox) injections.

Who can participate?

- You must be diagnosed with one of the following Focal dystonias:
 - a) Blepharospasm (Eyes)
 - b) Cervical dystonia/Spasmodic torticollis (Neck)
- Your last injection of botulinum toxin should be at least 2 months prior to study visit (or your symptoms should be noticeable).
- Willing to come to the hospital for study visits
- Ability to use a smartphone and app
- Had at least 5-6 prior treatment cycles before entering the study

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 study coordinator