

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

**This study is being
conducted at**

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Natural History & Biospecimen Repository for Dystonia

What is dystonia?

A disorder involving excessive involuntary contraction of muscles with repetitive and patterned movements

What is the purpose of the study?

To learn more about how dystonia may progress over time and what causes dystonia

Who are the eligible participants?

- You must be at least 18 years old
- You must be diagnosed with one of the following isolated dystonias:
 1. Focal dystonia, including:
 - a) Cranial dystonia/Meige Syndrome (including blepharospasm)
 - b) Jaw or tongue dystonia
 - c) Laryngeal dystonia (including spasmodic dysphonia) with diagnosis confirmed by nasolaryngoscopy
 - d) Cervical dystonia (spasmodic torticollis)
 - e) Limb dystonia (including writer's cramp and musician's dystonia)
 2. Segmental or Multifocal Dystonia
 3. Generalized Dystonia
 4. Hemi-Dystonia
- Or, you could be diagnosed with myoclonus dystonia or dopa-responsive dystonia
- Your last injection of botulinum toxin should be at least 2 months prior to study visit and your dystonia must not be part of another disorder

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 about 4 Tablespoons of blood
- Consider committing to come back every 1, 2, 3, or 4 years

How much time does it take to participate in the study?

Each study visit takes about 1 hour.

Where can you learn more about joining this study?

- Contact your local coordinator
- Contact the Coordinating Center's Coordinator
- www.rarediseasesnetwork.org/dystonia

There is no compensation for participating in this study.