Natural History of Primary 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 the years

Who are the eligible participants?
- You must be at least 18 years old
- You must be diagnosed with one of the following primary 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 Dystonia
  3. Generalized Dystonia
  4. Hemi-Dystonia
- Your symptoms must have started in the past 5 years
- Your last injection of botulinum toxin should be at least 2 months prior to study visit and you must not have evidence of a secondary cause for dystonia

What is expected of the participants?
- Answer some questionnaires about medical and family history and current state of mind
- Have a neurological exam that will be videotaped
- Donate about 4 Tablespoons of blood
- Commit to coming back for the same exam once a year for five 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.
Biorepository for Primary 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 the causes for dystonia.

Who are the eligible participants?
- You must be at least 18 years old.
- You must be diagnosed with one of the following primary dystonias:
  1. Focal dystonia, including:
     a. Cranial dystonia/Meige Syndrome (including blepharospasm)
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  3. Generalized Dystonia
  4. Hemi-Dystonia
- Your last injection of botulinum toxin should be at least 2 months prior to study visit and you must not have evidence of a secondary cause for dystonia.

What is expected of the participants?
- Answer some questionnaires about medical and family history.
- Have a neurological exam that will be videotaped.
- Donate about 4 Tablespoons of blood.

How much time does it take to participate in the study?
The study visit takes about 45 minutes.

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.

Approved 3/8/13 AL EP

Dystonia 1/22/13