



# 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](http://www.rarediseasesnetwork.org/dystonia)

There is no compensation for participating in this study.



Approved  
3/8/13/AL/EP

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**

**Virginia Commonwealth  
University**

**by:**

**Dr. Claudia Testa  
Dr. Leslie Cloud  
Dr. Mark Barron  
Dr. Scott Voda**

**Coordinator:  
Ginger Norris  
Phone: 804-828-3747  
vwnorris@vcu.edu**

**Central Coordinating Center  
Washington University  
at St. Louis  
PI: Joel Perlmutter, MD  
Coordinator: Ling Yan, PhD  
Phone: 314-362-7148  
[yanling@npg.wustl.edu](mailto:yanling@npg.wustl.edu)**

This consortium (Dystonia Coalition) is a part of NIH Rare Diseases Clinical Research Network (RDCRN). Funding has been provided by 1U54NS065701.



# 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)
    - 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 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](http://www.rarediseasesnetwork.org/dystonia)

There is no compensation for participating in this study.

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

Virginia Commonwealth University

by:

Dr. Claudia Testa  
Dr. Leslie Cloud  
Dr. Mark Barron  
Dr. Scott Voda

Coordinator:  
Ginger Norris  
Phone: 804-828-3747  
[vwnorris@vcu.edu](mailto:vwnorris@vcu.edu)

Central Coordinating Center  
Washington University  
at St. Louis

PI: Joel Perlmutter, MD  
Coordinator: Ling Yan, PhD  
Phone: 314-362-7148  
[yanling@npg.wustl.edu](mailto:yanling@npg.wustl.edu)

This consortium (Dystonia Coalition) is a part of NIH Rare Diseases Clinical Research Network (RDCRN). Funding has been provided by 1U54NS065701.

