



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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# Diagnostic and Rating Tools for Blepharospasm

#### What is Blepharospasm?

A focal dystonia involving involuntary contraction of the muscles around the eye, leading to involuntary eye closure.

#### What is the purpose of the study?

To develop the best way to measure the symptoms and impact of blepharospasm

#### Who are the eligible participants?

- All participants must be 18 years of age or older
- There are 3 different groups of people in this study
  - o People with blepharospasm
  - People with other facial or eye disorders, like hemifacial spasm, facial tics, psychogenic facial disorders, apraxia, and ptosis due to weakness.
     These problems may be a part of Bell's palsy, myasthenia gravis or Progressive Supranuclear Palsy
  - o People with no facial or eye problems or other neurological complaints
- There are a few other criteria for being in the study. If you are interested in learning more, let your doctor or a study coordinator know and they will give you more information.

#### 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 video recorded

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

The study visit takes up to 1.5 hours.

### 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.