

Global Dystonia Registry

The Benign Essential Blepharospasm Research Foundation is proud to be part of a two-year effort to develop and implement the first-ever patient registry devoted to focal dystonias. The Registry is designed to collect data on persons affected by a focal dystonia(s), including blepharospasm, to assist in future research efforts and clinical trials.

This collaboration is between dystonia patient organizations, including the BEBRF and the research leaders of the Dystonia Coalition, to develop and offer this self-reporting patient registry to the dystonia community. "The registry is a fantastic new opportunity for the dystonia community worldwide. It will be extremely valuable for fostering better communication between people who are affected by dystonia and researchers who are trying to learn more about dystonia," said Dr. H. Jinnah, the principal investigator for the Dystonia Coalition.

Although the focal dystonias, which includes blepharospasm, have many different manifestations, most experts believe they share a common pathogenesis or mechanism that causes the disorder. The common causes may be a similar gene defect, similar lifetime experiences, or both. Collecting information from different patient populations may help us identify the common features that they may share. This Registry complements the current scope of research for the Dystonia Coalition, a National Institutes of Health supported clinical research effort.

We anticipate that it will take 10 to 15 minutes to complete the survey. However, you may log out at any time and your answers will be saved. **Please know your responses will remain confidential.** Your participation is completely voluntary but we hope you will consider registering today!

Thank you so much....
Mary Lou Thompson, Pres.



The Global
Dystonia Registry

Sign Up Today at:
www.globaldystoniaregistry.org

Thank you for your support of our BEBRF/blepharospasm community!

Benign Essential Blepharospasm Research Foundation

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