

## **A New Research Partnership**

This summer brought an exciting new opportunity for partnerships in the search for better solutions for patients with blepharospasm. After 18 months of planning, the Office of Rare Diseases and the National Institutes of Neurological Disorders and Stroke at the National Institutes of Health agreed to fund a large cooperative effort called the *Dystonia Coalition*. This effort brings together 34 clinical sites in America and abroad to cooperate on studies of patients with uncommon conditions. Most importantly, the mission of the *Dystonia Coalition* is to encourage clinical and translational research devoted to focal dystonias. Specifically it will address blepharospasm and craniofacial dystonias, cervical dystonia, spasmodic dysphonia, and limb dystonias.

The *Dystonia Coalition* has begun several projects already, after a competitive review of several promising proposals. BEBRF has agreed to partner with the *Dystonia Coalition* in the funding of one that is particularly promising for blepharospasm. This project will be led by Dr. Giovanni DeFazio from the University of Bari in Italy. Dr. DeFazio has had a special interest in blepharospasm for many years, and was part of the early planning for the *Dystonia Coalition*. Dr. DeFazio has proposed the development of a clinical rating scale that will be used worldwide to help in the diagnosis and measurement of severity of patients with blepharospasm. His project will bring together experts in blepharospasm, experts in other types of focal dystonia, and experts in development of rating scales. The goal is to develop and test a scale for the future. This type of scale is essential for rigorous testing of any new treatments that may come along, and is likely to be critically important as we move forward with promising new treatments.