THE NATIONAL TOURETTE SYNDROME ASSOCIATION DESIGNATES 10 “CENTERS OF EXCELLENCE” AT U.S. MEDICAL CENTERS AND INSTITUTIONS

Leading Tourette and Tic Disorder Non-profit Takes National Action to Improve Care, Research and Education for those Living with the Disorder

(September 23, 2014 – New York, NY) – The national Tourette Syndrome Association today announced the designation of 10 “Tourette Syndrome Association Centers of Excellence” at premier healthcare facilities, research centers and academic institutions located across the United States. Some Centers of Excellence will be awarded up to $50,000 per year for three years in an effort to improve or build high-level care for individuals living with the disorder. Among the 10 Tourette Syndrome Association Centers of Excellence, are a consortium of individual Centers located within a single state and a network of participating institutions located across several regional states, which will collaborate extensively to meet the many needs of the Tourette Syndrome community.

For people coping with Tourette Syndrome or other Tic Disorders today, there are inconsistencies in the level of care they receive. The national Tourette Syndrome Association Centers of Excellence (CofE) designation and funding will help to facilitate the development of high-quality, interdisciplinary and multidisciplinary care approaches for the field. Designated centers will also seek to advance research, improve understanding and build awareness of the conditions among patients, care providers and the general public.

“The designation of Tourette Syndrome Association Centers of Excellence in communities across the country, particularly in underserved areas, is crucial to our mission,” said Annetta Hewko, President of the Tourette Syndrome Association. “Today, there is no standard model of care for Tourette’s or Tic Disorders. Our aim is to partner with the Centers of Excellence to set these standards and increase access to informed, evidence-based treatment, compassionate care and guidance. We are genuinely excited to launch this initiative. It can significantly impact our mission to serve to all people affected by Tourette’s and Tic Disorders.”

“The newly designated Centers will be the catalysts for cutting-edge scientific and clinical research aimed at decreasing diagnostic variability, deciphering the cause(s) and improving treatment of both tic and non-tic features. The Centers will also lead the way in training the next generation of experts in TS and Tic Disorders,” said Dr. Kevin St.P. McNaught, the Tourette Syndrome Association’s Vice President for Medical and Scientific Programs.

The CofE program will lead the way for heightened awareness and understanding of Tourette Syndrome and related conditions among community physicians, allied health professionals, patients, families and the general public.

About Tourette Syndrome and Tics
Tourette Syndrome is part of a spectrum of hereditary, childhood-onset, neurodevelopmental conditions referred to as Tic Disorders. These conditions affect both children and adults, causing them to make sudden, uncontrollable movements and/or sounds called tics (e.g. head bobbing, arm jerking, shoulder shrugging and grunting). Non-tic features, such as obsessive compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD) and learning difficulties, often develop in affected individuals. Symptoms in Tic Disorders can range from mild to severe and, in some cases, can be self-injurious, debilitating and markedly reduce quality of life. While some treatments are available for people with TS and other Tic Disorders, approaches to care are inconsistent, medications are often ineffective and there is no cure.
It is increasingly being recognized that Tic Disorders occur more frequently than previously thought. Prevalence studies show that up to 1 in 100 children in the U.S. have TS or another Tic Disorder. This significant burden of people with tics in our population underscores the importance of the CoE program, and the continuing need for increased research and more education among professionals and the general public.

The 10 designated TSA Centers of Excellence are hosted by the following institutions:

1. Baylor College of Medicine (Houston, TX); Texas A&M University, College Station, TX
2. Children’s Mercy Hospital, Kansas City, MO
3. Emory University School of Medicine, Atlanta; GA; Medical University of South Carolina, Charleston, SC; University of Alabama at Birmingham, Birmingham, AL; University of Florida, Gainesville, FL; University of South Florida Morsani College of Medicine, St. Petersburg, FL
4. Icahn School of Medicine at Mount Sinai, New York, NY; North Shore/Long Island Jewish Hospital, Manhasset, NY; University of Rochester Medical Center, Rochester, NY; Weill Cornell Medical College, New York, NY
5. Johns Hopkins University School of Medicine, Baltimore, MD
6. Massachusetts General Hospital, Boston, MA
7. Atlantic Neuroscience Institute, Summit, NJ; New Jersey Center for TS, Somerville, NJ; Rutgers University, Piscataway, NJ
8. University of California, Los Angeles, Los Angeles, CA
9. University of Utah, Salt Lake City, UT
10. Yale Child Study Center, New Haven, CT

About the national Tourette Syndrome Association

Founded in 1972, the national Tourette Syndrome Association (TSA) is the only national, voluntary health organization serving the Tourette Syndrome community. The TSA has a three-pronged mission to identify the cause of, control the effects of, and to find a cure for Tourette Syndrome through education, research and service. The TSA directs a network of 32 Chapters and more than 55 support groups across the country. For more information on TS, call 1-888-4-TOURET, visit http://tsa-usa.org, and on Facebook and Twitter.

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