

PA Tourette Syndrome Alliance Testimony
For May 18, 2017

We are here to testify on behalf of the PA Tourette Syndrome Alliance (PA-TSA) as a family affected by Tourette Syndrome. We wish to engage your help in restoring funding for PA-TSA's Tourette Syndrome (TS) support services in the 2017-2018 state budget and to share our concerns regarding how the HHS Unification Proposal may affect small grant programs under the Department of Health.

The PA Tourette Syndrome Alliance is the only statewide nonprofit organization serving and representing over 3,000 individuals with Tourette Syndrome and their family members. Their services of information, education, camp/social support, and disability advocacy in schools, colleges and employment have a tremendous impact on the lives of children and adults with TS. Since the 1990's, Tourette Syndrome has been a line item in the State Budget under the PA Department of Health. The services provided by this \$150,000 state grant are invaluable for families; important to schools and the medical community; and beneficial to the general public. Without these services, many children and families would struggle to find effective treatment and proper diagnosis. Many students would not receive the proper accommodations, IEP or support to succeed in school. Many teachers would not know how to help their students and may discipline them for symptoms of their disability.

Our concern with the proposed HHS unification is that this grant, and many other disease category grants, will be lost in the bureaucracy of such a large agency. PA-TSA has dutifully reduced our operating expenses while increasing our services and impact in the lives of Pennsylvanians and within the health and education state systems. Through our dedication and determination we have cut our costs using creativity and ingenuity in our small non-profit and the results have been fruitful for Pennsylvania. We feel it would be unfair for organizations such as ours to be potentially punished for our perseverance during a financial crisis in our economy and our state. We urge our PA legislators, to take the time and concern, to ensure that many individuals and families are not forgotten.

Over the years, this comparatively tiny state grant contract of only \$150,000 has enabled PA-TSA to work with schools, agencies and healthcare professionals across the state to help thousands of Pennsylvanians with TS become productive, educated, and gainfully employed taxpayers. Loss of this contract will leave these families, especially those newly diagnosed, completely on their own to understand this confusing disorder, navigate through the maze of public prejudice and misconceptions, and to fight for appropriate accommodations for their student within our public education system.

This funding is extremely important and has had an immeasurable impact on Pennsylvania. If these services and supports are eliminated there will be undoubtedly additional dollars spent on restrictive school placements and at times, unnecessary residential placements of children with TS. We do not know how much money PA-TSA services have saved school districts over the years (*because training teachers and helping develop supportive Individual Education Plans (IEP) saves schools time and money*), or how much increased income tax revenue these services have generated within the Commonwealth (*because Pennsylvanians who have been helped by PA-TSA's services have become more productive citizens, require fewer support services, and pay more in income taxes than they would if they were less educated or less skilled.*) What we do know is that when a child with TS receives the appropriate services, is supported, understood and properly accommodated, almost all of them can be successful in regular education and go on to become successful and productive adults.

Tourette Syndrome is an extremely complex, inherited, neurological disorder characterized by involuntary, rapid and frequent movements and vocalizations. These symptoms can range from simple eye blinking, throat clearing and facial movements to more severe such as barking, using profanity or making inappropriate sounds. TS typically manifests in children between the ages of 5 and 18 and co-occurs with other disorders such as ADD/ADHD, OCD (Obsessive-Compulsive Disorder) and Learning Disabilities. Tourette Syndrome and its complex spectrum of disorders are frequently misunderstood, and pose great challenges to those with TS who are struggling to succeed in school, in the workplace and in society.

Funding for Tourette Syndrome has truly made a difference in the lives of many children and families and to their schools. These are services that would not exist if the PA Tourette Syndrome Alliance did not provide them. Pennsylvania cannot afford to discontinue this grant and terminate these services. If the proposed HHS Unification is passed, we implore you to remember these important disease category grants including the line item for Tourette Syndrome. We ask that you make a permanent place for these disease category grants within that new agency.