

June 29, 2020

Chairwoman Anna Eshoo
Subcommittee on Health
House Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

Ranking Member Michael Burgess
Subcommittee on Health
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Dear Chairwoman Eshoo and Ranking Member Burgess—

The Tourette Association of America would like to thank you for holding the hearing titled “High Anxiety and Stress: Legislation to Improve Mental Health During Crisis.” Mental health is an important topic in normal times and even more so during the current COVID-19 pandemic. We thought it would be helpful to share a little background on Tourette Syndrome and Tic Disorders and the impact this pandemic is having on those living with these conditions and their parents, families or caregivers.

Tourette Syndrome is one type of Tic Disorder. Tics are involuntary, repetitive movements and vocalizations. They are the primary symptoms of a group of childhood-onset neurological conditions known collectively as Tic Disorders and individually as Tourette Syndrome (TS), Persistent (Chronic) Motor or Vocal Tic Disorder, and Provisional Tic Disorder. Onset of symptoms begins in childhood. Tics wax and wane over time and for some, symptoms can remain severe into adulthood causing lifelong impairment.

86% of people with TS have at least one additional co-occurring condition that is mental, behavioral or developmental (ADHD, Obsessive Compulsive Disorder, Anxiety, Depression, Oppositional Defiance Disorder, Learning Disability, etc.) <https://www.cdc.gov/ncbddd/tourette/data.html> . Data suggests that 1/100 school aged children have Tourette Syndrome or another Tic Disorder, that equates to approximately 1 million Americans living with TS or another Tic Disorder <https://tourette.org/spectrum-tourette-syndrome-tic-disorders-consensus-scientific-advisors-tourette-association-america/>. According to the CDC, data suggests 50% of children with Tourette Syndrome are not diagnosed <https://www.cdc.gov/ncbddd/tourette/data.html> .

Since COVID-19 hit, we have been hearing the following from patients:

- tics are worse for many due to social isolation, lack of movement or exercise and a lack of structured or no school/work
- increase in symptoms of comorbidities (anxiety, OCD, depression, rage, oppositional defiance, etc.)
- difficulties with executive functioning interfere with doing schoolwork at home
- emotional outbursts have increased due to increased stress and isolation and its taking a toll on the individual with TS, as well as families
- most students are having difficulty completing schoolwork virtually and families are prioritizing social/emotional well-being over assignment completion
- patients with coughing tics feel anxiety and are experiencing negative interactions with people in their communities when in public (we developed a printable “I have TS” card specific to tics that could be mistaken for COVID-19 symptoms which can be shown to explain their TS)

Here is what people with TS, parents/family, schools, physicians and others have been requesting from TAA:

- families are reaching out for IEP (individualized education plans) and 504 plan support - meetings with schools and parents are still happening virtually
- schools/districts are reaching out for virtual presentations and team meetings to help them better serve students with TS-as parents have to work and teach their children at home, work/life balance has become difficult to manage and they need easily accessible resources
- parents are serving double duty as educators in the home and are seeking advice/support n how to best teach a child who has complex education needs due to their TS
- support for individuals on how to manage their TS better during work/school from home
- support for siblings because families are spending so much time/energy with sibling with TS

Telehealth is critically important during these times and both physicians and families have reached out expressing the need to ensure there is insurance coverage and medical license reciprocity for out of state patients for telehealth now and post COVID-19. Due to a lack of specialists for TS, patients often drive or fly for hours and even sometimes across multiple state lines to see their doctor. Doctors can better serve patients better when they can see their tics happen in their natural environment which does not always occur in an office setting. Ensuring doctors and patients will be able to continue telehealth and its reimbursement, when determined by doctor and patient care delivered by telehealth is a positive method for them, is critically important.

In our 2018 Impact Survey of people with TS, the survey showed that of the ~1,000 respondents, adults living with TS and parents/caregivers responding on behalf of a child, 51% of adults and 32% of children have contemplated suicide or self-harm. This is an alarming statistic that underscores the need for more suicide prevention research and resources, particularly for those with chronic conditions. <https://tourette.org/research-medical/impact-survey/>

These experiences and requests underscore the importance of the Centers of Disease Control and Prevention's (CDC) Tourette Syndrome Public Health Education and Research Program as well as the continued FY2021 funding of the enacted level of \$2 million for the CDC TS Program. The program funds essential educational materials, webinars, workshops, trainings for physicians, teachers, educators, patients, caregivers and the public at large. COVID-19 has increased the needs of the TS population and for these resources, as described above. Ensuring the program's continued funding is critically important to the approximate 1 million people living with TS and other Tic Disorders in the United States.

Thank you again for holding this important hearing. We appreciate the opportunity to provide insight on the experiences of those in the Tourette Syndrome and Tic Disorders community during this COVID-19 pandemic.

Sincerely,



Diana Felner
Vice President, Public Policy

