



tourette syndrome association, inc.

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October 15, 2008

Michael J. Astrue
Commissioner of Social Security
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Dear Commissioner Astrue:

We submitted comments to the Social Security Department on behalf of the national Tourette Syndrome Association (TSA) in response to the Federal Register's Advance Notice of Proposed Rulemaking (ANPRM) on Compassionate Allowances for screening disability determinations, 72 Fed Reg. 41649 (July 31, 2007).

Our Board Member, Nancy Thomas Baker presented our views during the testimony-Hearing on the Compassionate Allowance for Rare Diseases, Office of the Commissioner on December 5, 2007.

As a follow up to that hearing, we would like to submit to you our findings on the Social Security Benefits application process for those with Tourette Syndrome (TS) and provide your staff with some suggestions on how to process claims for individuals with TS.

The Social Security Administration determines disability benefits based on functional impairments. For TS patients, who have very severe and physical tics that have impaired their ability to work, communicate, or socialize with other people; they are eligible to apply for social security benefits. Under current circumstances, people with TS do not receive a timely or deliberative eligibility decision by SSA. For those who have received approval for SSA benefits and services, the process was unacceptably lengthy with patients having to pursue an endless appeals process. We believe increase knowledge about Tourette Syndrome and its effects on some individuals will result in a much faster and deliberate process for determining eligibility for public services by SSA. At this point, a deeper perspective on Tourette Syndrome would be helpful.

Gilles de la Tourette Syndrome (Tourette Syndrome or TS) is a neurological disorder characterized by involuntary movements and sounds known as tics. These involuntary tics may also be complicated; involving the entire body, such as kicking, stamping and jerking. More severe cases involve jumping, touching, smelling, twirling about, and self-injurious actions that may permanently damage parts of the body. The symptoms of TS vary from person to person and range from very mild to severe. Nearly all cases of TS are accompanied by co-morbid disorders; such as Attention Deficit (Hyperactivity) Disorder and/or Obsessive-Compulsive Disorder.

The Tourette Syndrome Association (TSA) is the only national voluntary non-profit membership organization dedicated to identifying the cause, finding the cure and improving the quality of life for individuals with TS. The TSA believes Tourette Syndrome, as a neurological disorder, causes significant health impairments among the more severely affected and therefore recommends that TS be recognized officially as an eligible disorder under the category of neurological disorders to receive social security disability benefits.

In accounting the experiences of TS applicants for Social Security Disability benefits, the widely shared view is that the process is too long, complicated, and the SSA is unaware of the potential severity of the disorder. TS has no markers or tests that could quickly produce medical evidence of disability and therefore do not fall under most of SSA's expedited processes of claims. A majority of TS applicants are referred by the State Agency to have special examinations, as stated in the Social Security Administration's Publication #05-10029 (Jan 2006).

Many of the TS members throughout the application process are finding themselves having to prove severity of TS solely on the diagnosis of the disorder rather than the effects of the disorder. For example, one patient's tics were neck spasms and after 50 years, his spinal column began to choke his spinal cord, threatening to result in paralysis.

Some TS applicants have reported to the TSA that the special examinations arranged by the SSA have been with physicians that were not completely aware of TS or how to diagnosis it. During these visits one applicant described it as a "car wash" process where the procedure last only 15 minutes and the patients were in and out. This sentiment is overwhelmingly shared with many of the applicants who feel that the 15 minutes given to them by the SSA to prove their disabilities to a medical professional is simply not enough time. Some applicants have stated that often their TS is suppressed during these examinations and therefore a fair judgment cannot be made.

Beyond the interviewing process, many of our applicants also face trouble on the issue of evidentiary documents and requirements. This is baffling since many applicants have accumulated large amounts of documents and reports from various physicians and medical experts as they pursued diagnosis and sought effective treatment over the years. Despite providing substantial documentation of diagnosis and detailed medical history, many of our applicants are still denied disability benefits. One mother had submitted a collection of nearly 10 years of evaluations from psychiatrists and therapists yet was denied benefits for her 19 year old son who is incapable of telling time, naming all the months in a year, count change, and drive. As many cases of TS are accompanied by co-morbid disorders, her son has both TS and Obsessive Compulsive Disorder.

TS applicants must overcome the burden of proving disability without the support of medical proof and examinations explicitly revealing disability. As a member of the National Organization for Rare Diseases/Disorders (NORD), we support the suggestion that SSA create a generic form for physicians with questions on disability. This questionnaire can almost serve as the "objective medical evidence" for case reviewers.

The TSA recommends the following:

1. Expand the SSA list of impairments to include Tourette Syndrome (TS);
2. Base eligibility criteria on both diagnoses and the severity of symptoms;
3. Broaden the definition of medical evidentiary requirements;
4. Add observation to the final screening process.

Furthermore to reiterate, we wish to provide our answers to NORD's questionnaire requesting medically related information sought by the SSA on functional impairment, criteria determination and disability.

1) Are there any generally accepted functional scores or scales of progression that medical professionals rely upon in determining functional impairment?

The survey questions included in the accepted functional scales are for the most part, not relevant to the symptoms and other manifestations of several neurological disorders including Tourette Syndrome (TS). That said, it should be strongly emphasized that patients with TS do indeed experience functional impairment.

Typically, TS is characterized by involuntary movements and sounds known as tics. These tics can be extremely complex and debilitating. They can involve the entire body, such as kicking, stamping and jerking or repeated movements that causes self-injury. Other examples of movements experienced by those with severe cases include; jumping, touching, smelling, twirling about, and repetitive violent neck jerks and mouth biting, which often results in permanent damage to various body-parts.

The symptoms of TS vary greatly from person to person. The frequency, intensity, and body location range from very mild to severe. It is important to note that with almost all cases of TS the condition is accompanied by additional and often disabling co-morbid disorders such as Attention Deficit Hyperactivity Disorder and/or Obsessive-Compulsive Disorder.

This overview should clarify why we believe there are no generally accepted functional scores or scales to adequately measure the functional impairment endured by some people with TS.

2) Are there any generally accepted clinical tests (including genetic or other bio-markers) which can be relied upon to diagnose a disorder or to determine a patient's stage of disease or level of functional impairment?

Unfortunately there are no accepted diagnostic tests that are available when there is a suspicion that someone has TS. Confirmed diagnoses are accomplished exclusively by expert observation and augmented by the information gleaned from a comprehensive and thorough family history.

As already stated, when those symptoms are severe, secondary problems occur (even surgery or paralysis in extreme cases), and these medical difficulties are clearly impairing and can negatively affect functioning. In sum, currently there are no bio-markers or other medical tests that can aid in the confirmation of stage or presence of this disorder.

This situation causes many applicants with TS the difficulty of having to prove their eligibility based on a testable, confirmed diagnosis, with little, or no, consideration being given to the effects of dealing with TS (Symptomatology) symptoms.

3) Given the natural history of the disorder generally, is there a certain age (or time since onset) at which the person's functional impairments typically become severe?

In terms of 'disease stage' it should be noted that, typically, symptom onset occurs between the ages of 8 to 11 years old. Data from studies seem to indicate that for some people, symptoms peak in severity during the teen years. However, for many adults the severity of their symptoms persists throughout their lives. It is these groups of people with TS who most need social security benefits and assistance.

As for prevalence, the estimates from epidemiological studies vary greatly and data published range from 1 in 1,000 to 1 in 5,000. Thus, it is believed that the number of people with TS in the United States is estimated at 200,000.

In conclusion, the TSA recognizes difficulties in even the basic functions for all individuals with TS due to activities derived from tic severity, co-morbid disorders, and effects of the stigma associated with the disorder. To ensure that vulnerable citizens with Tourette Syndrome receive a quick and deliberate process when applying for public services by SSA, We suggests that the Social Security Department (SSA) determine disability based on a case by case basis that would include, but would not be limited to: diagnosis, symptom severity and impairment, as well as, quality of life impact.

On behalf of our members, we thank you for the opportunity to provide our views and recommendation concerning social security benefits for people with Tourette Syndrome. We look forward to hearing from your office about this issue. If you have any questions, please contact me at 718-224-2999 ext. 224, email judit.ungar@tsa-usa.org, or contact my public policy office at 202-408-7009 or mail to elridge.proctor@tsa-usa.org.

Sincerely,

Judit Ungar,
President
National Tourette Syndrome Association, Inc.

cc: Diane Braunstein