



## tourette syndrome association, inc.

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September 28, 2007

Michael J. Astrue  
Commissioner of Social Security  
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### **Re: Advance Notice of Proposed Rulemaking (ANPRM), 72 Fed. Reg. 41649 (July 31, 2007).**

Dear Commissioner:

Thank you for the opportunity to provide recommendations about the standards to use for compassionate allowances and the opportunity to present our view concerning the eligibility screening process.

The Tourette Syndrome Association (TSA) is pleased to submit these comments on behalf of its members in response to Federal Register's Advance Notice of Proposed Rulemaking (ANPRM) on Compassionate Allowances for screening disability determinations, 72 Fed Reg. 41649 (July 31, 2007).

The 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 Tourette Syndrome. As you may know, Tourette Syndrome (TS) is an inherited, neurological disorder, characterized by involuntary movements and sounds that are known as tics. The disorder is often accompanied by Attention Deficit (Hyperactivity) Disorder and/or Obsessive-Compulsive Disorder. There is no known cure for TS.

We agree with SSA's initiative to provide people who have both medically determinable impairments and are unable to work, with a quick and deliberate process for determining eligibility for public services by SSA.

Further, we appreciate that SSA's current eligibility criteria for compassionate allowance already includes several screening methods that expedite the access for some claimants. We strongly urge the consideration of additional provisions that would recognize and cover the serious disabilities incurred by some patients with Tourette Syndrome (TS). TS is a neurological disorder causing significant health impairments among the more severely affected. In our view, clearly this condition should be recognized officially as a disability under Compassionate Allowance.

It follows that we are now strongly recommending that eligibility for services and accommodations should be based on a medically knowledgeable assessment of an individual's symptoms that clearly compromise his/her ability to participate in the normal activities of daily life. For those with severe, disabling TS motor tics as well as inappropriate, prominent vocal symptoms, the quality of their lives can only be described as non-existent. Some of the most disabling factors that make it veritably impossible to cope with TS symptoms include self-mutilating behaviors, isolation, and employment discrimination due to public stigmatization.

These very troubling symptoms are just a few examples of the most disabling outcomes that result from this complex disorder. Therefore, we recommend that a comprehensive document be developed that would provide specific guidelines for determination of patient eligibility. Furthermore, we suggest that SSA determine disability based on a case by case basis. These would include, but would not be limited to: diagnosis, symptom severity and impairment, as well as, quality of life impact.

The TSA sponsors a multi-disciplinary, national Medical Advisory Board whose members (16) guide and advises our Association on all matters of patient care. Collectively, these physicians have treated over 15,000 TS patients; we urge the SSA to use the expertise of our Medical Advisory Board and consult with these expert clinicians on the development of objective medically evidentiary requirements for TS eligibility.

Finally, the TSA has informally surveyed key physicians known to us who are responsible for TS clinics in several regions of the country. This survey indicates that even for those who eventually did receive approval for SSA benefits and services, the process was unacceptably lengthy with patients having to pursue an endless appeals process. It is our sincere hope that the SSA will consider our views and make every effort to effectively address this significant burden placed on the most disabled and vulnerable TS citizens among us.

**Recommendation Summary:**

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.

Again, thank you for the opportunity to comment on the Compassionate Allowances and the eligibility screening process. In addition, at this time, the TSA is requesting an opportunity to testify at SSA's first quarterly hearing on Compassionate Allowances for rare diseases that will be held in Washington, DC on December 4, 2007. We look forward to hearing from your office about the hearings. If you have any questions, please contact me at 718-224-2999 ext. 224 or [judit.ungar@tsa-usa.org](mailto:judit.ungar@tsa-usa.org).

Sincerely,

Judit Ungar,  
President