



## tourette syndrome association, inc.

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May 28, 2009

Internal Revenue Service  
U.S. Department of the Treasury

Employee Benefits Security Administration  
U.S. Department of Labor

Centers for Medicare & Medicaid Services  
U.S. Department of Health and Human Services

VIA EMAIL: [E-OHPSCA.EBSA@dol.gov](mailto:E-OHPSCA.EBSA@dol.gov)

**Re: Request for Information Regarding the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (published in 74 Fed. Reg. 19155 et seq.)**

The national Tourette Syndrome Association (TSA) is pleased to provide comments on the proposed rulemaking process on the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA). As the only national voluntary non-profit membership organization dedicated to identifying the cause, treatment, and finding the cure for TS, it should be noted that the passage of this law has been a prime legislative objective for the TSA.

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

For historical reasons TS has been classified as a mental health disorder in the reference lists used by health maintenance organizations and health insurers. This is so despite the fact that TS is an inherited, neurobehavioral disorder. Both neurologists and psychiatrists treat the disorder, using the same medications.

As a result of the arbitrary classification of TS in the mental health category, many people with TS have been denied or greatly limited in receiving reimbursement for expenses of treatment relating to hospital stays, office visits, and medications. We support the Congressional intent behind MHPAEA to remove any limits on mental health benefits that are different from limits on other medical and surgical benefits.

Furthermore, as a member of the Mental Health Liaison Group (MHLG), we emphasize the following recommendations:

1. Clarify the distinction between mental health and medical/surgical in regard to limits in a benefit package and cost-sharing requirements. It is necessary to explain these terms in order to ensure that any limits on mental health services are appropriately given the overall coverage (including limits and financial obligations of the insured) in a particular plan.

2. A more direct process is necessary to assist with identifying whether State or Federal Mental Health Parity law is stronger and when state laws are to be preempted. It is particularly important to provide clarity on how States should interact with the new federal law.
3. Since there is no provision in MHPAEA that allows for special considerations for small entities, we agree that all entities that are subject to MHPAEA should be required to comply with the law.
4. To assure Parity, when a service is denied, a clear explanation of why this particular service was not considered appropriate at this time for the individual should be required.
5. In reference to the cost impact of MHPAEA, the TSA has found for its members, access to mental health professionals as an “outpatient” would certainly be less expensive than frequent out of network hospitalization for mental health specialists. Therefore, the need to enforce regulations to provide timely and appropriate mental health services is critical in addressing the cost impact. This would also eliminate the disparities that currently exist between the coverage for mental illness and physical illness.

Thank you for the opportunity to provide these comments on behalf of all individuals with TS. We look forward to receiving more information about the process ahead. I can be reached directly at 718-224-2999 Ext. 224 or you may contact Elridge Proctor, VP of Public Policy in Washington, DC at 202-408-7009 or [elridge.proctor@tsa-usa.org](mailto:elridge.proctor@tsa-usa.org).

Sincerely,

A handwritten signature in black ink that reads "Judit Ungar". The signature is written in a cursive, slightly slanted style.

Judit Ungar  
President