

Testimony  
To the  
Labor-HHS-Education Subcommittee  
Committee on Appropriations  
U.S. House of Representatives

In Support of  
FY 2012 Funding  
For NIMH and SAMHSA

By  
Helen S.  
Individual Suffering  
From  
Borderline Personality Disorder

And

Beth and Rob Elliott in New York,  
Diane and Jim Hall in Texas,  
And  
Other Concerned Parents  
Of  
Individuals Suffering  
From  
Borderline Personality Disorder

April 15, 2011

## **Introduction**

On April 1, 2008, the U.S. House of Representatives unanimously passed House Resolution 1005 supporting the month of May as Borderline Personality Disorder Awareness Month. The resolution stated that “despite its prevalence, enormous public health costs, and the devastating toll it takes on individuals, families, and communities [borderline personality disorder] only recently has begun to command the attention it requires.”

Borderline personality disorder (BPD) is the most maligned, misunderstood and misdiagnosed of all the major mental disorders. It is serious and often life-threatening, characterized by severe emotional pain and extreme emotional and behavioral dysregulation and expressed by impulsivity (such as reckless driving, risky sex, wild spending), extraordinary negative emotion (such as anger, shame,), chaotic relationships, deep-seated fear of abandonment, and difficulties maintaining a stable and accepting sense of self. Suicidality, self-harm (such as cutting), and substance abuse are highly prevalent.

Although not as well known as bipolar disorder or schizophrenia, borderline personality disorder is estimated to be far more prevalent than either, afflicting up to 18 million people. The human suffering and economic costs are high. Here are some statistics presented at a Congressional Briefing sponsored by the National Education Alliance for Borderline Personality Disorder (NEA-BPD) and the National Alliance on Mental Illness (NAMI) on May 19, 2010:

- 10% of adults with this disorder take their own lives;
- 33% of youth who commit suicide have features of this disorder;
- 20% of psychiatric hospital patients and more than 10% of outpatients suffer from BPD;
- 17% of prison inmates suffer from its symptoms;
- 50% of individuals with the disorder are severely impaired in their ability to support themselves economically.

In addition, there is the collateral damage suffered by the families of these individuals in terms not only of emotional pain, but also decreased productivity, the cost of health care, and disruption of normal family life; and communities bear the burden of increasingly greater demands on schools, mental and health care facilities, the criminal justice system, and public assistance.

Borderline personality disorder was regarded as untreatable for many years, but today treatments have been developed that are effective for many individuals. At the same time, diagnosis remains difficult, appropriate treatments are not widely available, and stigma and ignorance remain major obstacles to their implementation. There is still much work to be done to address the human suffering, lost potential, and major mental health and public policy issues of this disorder.

**Testimony of Helen S.  
To the House Labor-HHS-Education Subcommittee  
Committee of Appropriations**

**April 15, 2011**

Chairman Rehberg and Members of the Subcommittee, I am grateful for the opportunity to provide written testimony to the Subcommittee. My name is Helen and I suffer from borderline personality disorder.

People ask me what it's like to have borderline personality disorder. Words and language fail. But there's a photograph from the Viet Nam war...it's a little girl running down a dirt road straight into the camera. She is naked, her clothes burned away by napalm. Her little face is contorted with agony and terror. She is screaming. Several people off to the side of the road are not even interested. She's utterly alone. I call her the "Burning Girl." This is what a borderline feels like inside.

My medical history is roughly the length of Beowulf, but here are some numbers: 3 hospitalizations; 30 consecutive years of individual therapy; \$1.3 million in treatment costs (all cash, no reimbursements); and \$2 million in lost salary and benefits; 52 medications over 29 consecutive years – currently 8 medications; 4 diagnoses – bipolar, anorexia/bulimia, post-traumatic stress disorder, and borderline.

The diagnosis of borderline came last. I want you to know it is a mongrel diagnosis because of the shame, stigma, and contempt. Nowhere is it more pernicious than with mental health professionals. Worst is the invalidation, as if overnight I'd turned into a mad dog. Self-injury, suicide and extreme dissociation can be lurid, repellant and seemingly intractable, but I'm not a mad dog. No person wants to use these methods. As Proust said, "To kindness and knowledge we make promises. But pain we obey." So cutting has its own perverse logic and beneficence. It's a form of communication, a language written on the body. It says "This is how much pain I feel."

Here's how government funding has significantly helped me recover. First, through NIMH support of the National Education Alliance for Borderline Personality Disorder – a grassroots movement of professionals – with the essential inclusion of borderlines and their families - who are disproving the conventional ignorance of the illness. Second, funding of Dialectical Behavior Therapy (DBT) through NIMH. In conjunction with individual therapy, DBT provides pragmatic methods, dozens of skills to regulate emotions, negotiate relationships, and execute strategies for life and work. Third, NIMH leadership in validating BPD as a national concern.

Let's be frank – I can make this testimony because I'm white, overeducated, and English is my first language. But I represent so many people who can't: my friend Linda, a middle-aged blind woman with a dysfunctional seeing-eye dog, who didn't miss a day of DBT group in eight months; and Sherri, a young African-American who worked in a subway toll booth; she had two small children, two top teeth missing, and too many abusive boyfriends. One day she just disappeared. I wish you could see the striving, the will to connect and contribute, and the lost potential. I know firsthand how many could be saved with more research and education.

You, all of you, have the greatest power to lead the battle against borderline personality disorder, to reverse the inhumane negligence of human beings capable of recovery. Please

don't throw us away. There is so much work to be done. Think of 18 million Americans – burning. Please include us in the world in which mental illnesses are prevented and cured. We belong there. We borderlines have the capacity and will to reside in that world. Thank you.

**Testimony of Concerned Parents of Individuals Suffering from Borderline  
Personality Disorder  
To the House Labor-HHS-Education Subcommittee  
Committee of Appropriations  
April 15, 2011**

Chairman Rehberg and Members of the Subcommittee, thank you on behalf of ourselves and our loved ones, for giving us this opportunity to present this testimony.

Every parent watches their child grow up with great hopes and dreams of a happy and healthy future. The cruel irony of this disorder is that it most often becomes evident in our children just as they are on the cusp of adulthood. As parents, we are mystified when they become increasingly angry, volatile and self-destructive. We consult a series of experts and doctors about their behavior, often for years, without finding answers or relief. College savings go for treatment and medications; our hopes and dreams change into the daily reality of coping with repeated mental, physical, social, and familial crises. Our children are no longer progressing towards a functional and gratifying adulthood. Our management of a now disrupted family life itself gives way to greater and greater micro-focus and support for the less and less functional adult child, while they themselves may turn to cutting or substance abuse to relieve excruciating emotional pain. This pain, along with anger and impulsivity may lead some to commit criminal acts or engage in violent or risky behavior. An alarming number turn to suicide as their only way out.

If we are lucky, our search may lead us to the proper diagnosis, access to effective therapy, and gradual improvements. Although there are no medications specific for the disorder, there are some prescriptions that can help to manage symptoms. The good news is that with proper treatment, sufferers can experience remission of symptoms and be able to resume their navigation toward a functional adult life. However, remission is not the same as recovery and the path from remission to recovery remains largely uncharted.

Several organizations have been at the forefront of creating a brighter future for our loved ones. One of those is **The National Education Alliance for Borderline Personality Disorder** (NEA-BPD). Formed in 2001, NEA-BPD is a non-profit organization staffed by volunteer consumers, family members, and professionals. NEA-BPD seeks to advance the borderline personality disorder agenda by raising public awareness of borderline, providing education, and promoting research about borderline personality disorder through a variety of programs. For example, with partial funding from a grant from the **National Institute of Mental Health** (NIMH), NEA-BPD has hosted over 30 conferences worldwide, featuring internationally recognized borderline researchers and scientists and attended by professionals, family members, and consumers alike.

Realizing that it was of utmost importance to increase awareness and educate people across the Nation about this devastating and highly stigmatized mental disorder afflicting nearly 18

million Americans, NEA-BPD has turned to Congress for its help and support. **Two Congressional Luncheon Briefings on Borderline Personality Disorder** were held in May 2007 and 2010. The first Briefing was Co-Hosted by Representative Nita Lowey (D-NY) and former Representative Tom Davis (R-VA). The second Briefing was Co-Hosted by Representatives Frank Wolf (R-VA) and Chris Van Hollen (D-MD). The Director of **National Alliance on Mental Illness** (NAMI), the Director of **NIMH**, and the President-elect of the **American Psychiatric Association** gave presentations at this Briefing.

**The Committee on Appropriations of the U.S. House of Representatives** (House Report 111-220) requested a report from **the National Institute of Mental Health** regarding its plans to enhance its programs for borderline personality disorder. NIMH submitted a report to Congress in May 2010 entitled “Congressional Appropriations Committee Report on Borderline Personality Disorder” to the Committees on Appropriations of the U.S. House of Representatives and the Senate. NIMH’s report stated that the collective efforts from maximizing NIMH-sponsored research will, in turn, lead to improved diagnosis, prevention and interventions for borderline personality disorder.

The Committee on Appropriations also requested a report from the **Substance Abuse and Mental Health Services Administration** (SAMHSA) about its plans to expand its programs and services regarding borderline personality disorder. SAMHSA submitted a report to Congress in July 2010 entitled “Report to Congress on Borderline Personality Disorder” to the Committees on Appropriations of the U.S. House of Representatives and the Senate. SAMHSA’s report stated that they are committed to providing a full range of prevention, promotion and treatment services to individuals with borderline, their families, and the communities in which they live.

As evidenced in these reports, NIMH and SAMHSA place a high priority on addressing borderline personality disorder and the needs of individuals afflicted with it. **As parents who are speaking for so many families that grapple with BPD, we urge you to provide full funding for the FY 2012 budget requests of both NIMH and SAMHSA, in order that their work might continue undiminished in the fight to reduce the human and economic toll of this disorder.** Thank you.