

# Family and Consumer Advocacy to Congress: from Stigma to Stability for Borderline Personality Disorder

American Psychiatric Association  
May 21, 2009

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# Disclosure

- The presenter serves as:
  - Congressional Liaison, National Education Alliance for Borderline Personality Disorder (NEA-BPD)
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  - President, Northern Virginia affiliate, National Alliance on Mental Illness (NAMI)
- The views herein are not necessarily those of any organization with which the presenter is affiliated. The presenter has no relevant commercial relationships with commercial interests.

# Dan Badal, M.D., 1912-2006, Cleveland, Ohio (presenter's uncle-in-law and encourager)

“I have learned to increase the contact with the suicidal patient and his or her family after starting a new medication ... I describe this method in the new, upcoming edition of my book *Treatment of Depression and Related Moods—A Manual for Psychotherapists*.”

*Psychiatric News*, Letter, Aug. 5, 2005, vol. 40, no. 15, p. 36



# Nada Stotland, M.D., APA President

## On Diagnosing BPD

“Borderline personality disorder . . . not only causes personal distress for patients and their loved ones but can also cause considerable consternation in the medical care setting . . . Making the diagnosis can help the primary care clinician to understand how the patient experiences the world . . . This understanding allows the clinician to support colleagues and ancillary staff, avoid confrontations, and better address the patient's real health care needs.”

*Primary Care Update for OB/GYNs*, vol. 5, issue 2, 1998

# Selected Highlights in BPD History

1938

- name “borderline personality disorder”

1960s – 1970s

- structural shift: from border of schizophrenia to border of mood disorder
- Specialized psychotherapy emerging: TFP, DBT

1980

- DSM III – official diagnosis

# Highlights

2001

- APA Treatment Guideline
  - “this diagnosis is often incorrectly diagnosed or underdiagnosed in clinical practice”

2002

- Congressional Report, S. Rep. 107-216. TARA.
  - “[F]ailure to recognize and adequately treat BPD can have devastating consequences ... The Committee urges the NIMH to expand its research on this disease.”

# Highlights

2003

- Family Connections©, NEA-BPD, family education
  - high burden on families
  - information, skills (DBT based), support network
  - [www.neabpd.org](http://www.neabpd.org)

2005

- APA Treatment Guideline Watch
  - “BPD is a condition that can be effectively treated by a combination of psychotherapy and symptom-targeted pharmacotherapy.”

# Highlights

2006

- NAMI: BPD named as “priority population”
  - BPD Expert Focus Group – school curricula, Congressional advocacy

2007

- FOIA: NIMH annual funding in millions
  - BPD - \$6. Bipolar - \$101. Schizophrenia - \$335.
- Congressional BPD Briefing
  - consumer, family member and Robert Friedel, M.D.
- Congressional Study Request

# Highlights

2008

- NIH intramural study – 5.9% lifetime prevalence
- Congress names May as “Borderline Personality Disorder Awareness Month”
  - House Resolution 1005, passed 414-0, 4/1/08
  - Resolution and Awareness Kit at [www.neabpd.org](http://www.neabpd.org)

# House Resolution 1005 - sets May as BPD Awareness Month

- “official recognition of BPD is relatively new, and diagnosing it is often impeded by lack of awareness and frequent co-occurrence with other conditions”
- BPD is “a leading cause of suicide” and “is inheritable and is exacerbated by environmental factors”
- “it is essential to increase awareness of BPD among people suffering from this disorder, their families, mental health professionals, and the general public by promoting education, research, funding, early detection, and effective treatments”

# Highlights

2008

- Congressional BPD Reception with APA
  - Presenters John Gunderson, M.D., Wayne Goodman, M.D. (NIMH), and others
  - Advocacy Awards to US Representatives (bipartisan)
- Congressional Letter to NIMH
- Proposal for BPD Track at 2009 APA Conference

# Proposal for BPD Track at APA

“The failure to be informed about the diagnosis and to use well-validated and effective treatments is responsible for the continuing perception of these patients as hateful, treatment resistant, and chronic . . . The United States Congress has recognized this injustice and moved quickly and unanimously to pass a resolution . . . but this is a resolution that must first be observed within our professions . . . ”

Ken Silk, M.D., NAMI Exemplary Psychiatrist

# Highlights

2009

- Time Magazine article
  - “Borderline individuals are the psychological equivalent of third-degree-burn patients. They simply have, so to speak, no emotional skin,” quoting Dr. Marsha Linehan
- NAMI call-in with Dr. Marsha Linehan
  - NAMI BPD Expert Focus Group was “transforming”
  - Host Ken Duckworth, M.D. said NAMI ‘determined’ about BPD
- US Representative Rosa DeLauro opens NEA-BPD Conference at Yale

# Highlights

2009

- NEA-BPD call-in with Robert Friedel, M.D.
  - “sea change” akin to schizophrenia, bipolar 20 years ago
- APA Convention with BPD Track
- NAMI Convention - Dr. Marsha Linehan Keynote

# Future for Borderline Personality Disorder

## APA

- DSM-V? Axis I or II? Name? 2001 Treatment Guideline update?
- Leadership role with 2009 Conference

# Future for Borderline Personality Disorder

## Mental health professionals

- Disseminate specialized “psychotherapy and symptom-targeted pharmacotherapy” in schools and to clinicians, per 2005 APA Guideline Watch?
- make and say the diagnosis?
- treat per 2005 APA Guideline Watch?
- refer family to family education?

# Future for Borderline Personality Disorder

## Federal Government

- NIMH
- SAMHSA
- CDC

## State Governments

## Local Governments

# Closing Word - Ken Silk, M.D., NAMI Exemplary Psychiatrist

Recalling how persons shunned mention of cancer 50 years ago, he strives for a different type of era for BPD - an era when a patient can more easily say to a professional:

*“I have BPD. What can I do about it?”*

# NEA-BPD Resources

- [www.borderlinepersonalitydisorder.com](http://www.borderlinepersonalitydisorder.com) or [neabpd.org](http://neabpd.org)  
Resource Library: free access to 90 audio and 50 video tapes of conferences on BPD and Call-Ins since 2004. Articles from the current issue of the *American Journal of Personality Disorders*.
- [www.bpdforum.com](http://www.bpdforum.com)  
An online research community forum for researchers and clinicians that focuses on borderline personality disorder and its co-occurring disorders. On-line Editorials for open dialogue and discussion in collaboration with the *Journal of Personality Disorders* and Guildford Press.