



PATIENT ALLIANCE FOR NEUROENDOCRINEIMMUNE DISORDERS
P-A-N-D-O-R-A
ORGANIZATION FOR RESEARCH AND ADVOCACY *inc.*

**PATIENT ALLIANCE FOR NEUROENDOCRINEIMMUNE DISORDERS ORGANIZATION
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DSM-5 Task Force
American Psychiatric Association
1000 Wilson Boulevard
Suite 1825
Arlington, VA 22209

Members of the DSM-5 Task Force,

We would like to provide our input to an open request for input on proposed changes to the fifth revision of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM).

P.A.N.D.O.R.A. is deeply concerned by the American Psychiatric Association's potential reclassification which not only may include CFS as a somatoform disorder in DSM-5, but also Fibromyalgia (FM), toxic encephalopathy or multiple chemical sensitivity (MCS), chronic Lyme disease (CLD) and Gulf War Illness (GWI). These illnesses are under the scientific umbrella concept of Neuroendocrine Immune Disorders (NEIDs) embraced by our organization.

Researchers at the National Institutes of Health (NIH), National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the Centers for Disease Control and Prevention (CDC), Department of Defense (DOD), and have all documented the physiological and pathophysiological underpinnings of CFS, FM, CLD and GWI. The CDC, under the leadership of Julie Gerberding, launched a multi-million-dollar campaign within the past few years to underscore that CFS is a multi-system disorder, which can and should be treated as such. NIAMS has provided funding for FM and over the years so has DOD under the GWI umbrella, which was last year finally acknowledged by the U.S. Government as a serious medical illness affecting our Gulf War veterans.

Based upon the numerous, peer-reviewed studies that have linked CFS to infection and multiple organ systems abnormalities, classifying CFS, as a Complex Somatic Symptom Disorder (CSSD) seems unreasonable and unwarranted. The same applies for FM and chronic Lyme disease. According to your web site CSSD is described as:

...The hallmark of this disorder is disproportionate or maladaptive response to somatic symptoms or concerns. Patients typically experience distress and a high level of functional impairment. In severe cases, they may adopt a sick role. Sometimes the symptoms accompany diagnosed general medical disorders or psychiatric disorders, and sometimes the disorder occurs alone. There may be a high level of health care utilization, which rarely alleviates the

patient's concerns. From the clinician's point of view, many of these patients seem unresponsive to therapies, and new interventions or therapies may only exacerbate the presenting symptoms or lead to new side effects and complications. Some patients feel that their medical assessment and treatment have been inadequate.

Patients with this diagnosis typically have multiple, current, somatic symptoms that are distressing; rarely, they may have only one severe symptom. The symptoms may or may not be associated with a known medical condition. Symptoms may be specific (such as localized pain) or relatively non-specific (e.g. fatigue or multiple symptoms). The symptoms sometimes represent normal bodily sensations (e.g., orthostatic dizziness), or discomfort that does not generally signify serious disease (e.g., bad taste in one's mouth) or are incompatible with known pathophysiology (e.g. seeing double with one eye closed). Such patients often manifest a poorer health-related quality of life than patients with other medical disorders and comparable symptoms.

Patients with this diagnosis tend to have heightened levels of health-related anxiety and a low threshold for alarm about the presence of illness. They appraise their bodily symptoms as particularly threatening, harmful, or troublesome and have a tendency to assume the worst about their health. They believe in the medical seriousness of their symptoms despite evidence to the contrary. Health concerns are diffuse and may assume a central role in their lives, becoming a feature of their identity, a way of responding to stressful events, a topic of interpersonal communication, or a basis for interpersonal relationships.

To meet criteria for CSSD, criteria A, B, and C are necessary.

A. Somatic symptoms:

Multiple somatic symptoms that are distressing, or one severe symptom

B. Misattributions, excessive concern or preoccupation with symptoms and illness: At least two of the following are required to meet this criterion:

- (1) High level of health-related anxiety.
- (2) Normal bodily symptoms are viewed as threatening and harmful
- (3) A tendency to assume the worst about their health (catastrophizing).
- (4) Belief in the medical seriousness of their symptoms despite evidence to the contrary.
- (5) Health concerns assume a central role in their lives

C. Chronicity: Although any one symptom may not be continuously present, the state of being symptomatic is chronic and persistent (at least 6 months).

The following optional specifiers may be applied to a diagnosis of CSSD where one of the following dominates the clinical presentation:

XXX.1 Multiplicity of somatic complaints (previously, somatization disorder)

XXX.2 High health anxiety (previously, hypochondriasis) {If patients present solely with health-related anxiety in the absence of somatic symptoms, they may be more appropriately diagnosed as having an anxiety disorder.} *

XXX.3 Pain disorder. This classification is reserved for individuals presenting predominantly with pain complaints who also have many of the features described under criterion B. Patients with other presentations of pain may better fit other psychiatric diagnoses such as major depression or adjustment disorder.

As estimated and communicated to you by the IACFS/ME: Over the past 25 years, 2,000 peer-reviewed CFS studies have been published. The data support a multifactorial condition characterized by disturbances in HPA function, upregulated antiviral pathways in the immune system, and genetic abnormalities. Unlike clinical anxiety and depression, psychotropics are generally ineffective for CFS and standard medical advice to exercise and rest or resume

activities often lead to symptom worsening. In contrast to clinical depression, motivation is much less affected in CFS and the desire to be active remains intact.

In the past, the absence of a documentable, medical explanation has relegated other illnesses to a psychiatric diagnosis. Illnesses given psychiatric diagnoses out of ignorance are later given more accurate, medical diagnoses with additional scientific research. Surely, you do not wish to demean the field of psychiatry by repeating the errors of psychiatry's past.

P.A.N.D.O.R.A. is further concerned that the reclassification of CFS and potentially the other illnesses that our organizations embraces under the umbrella of Neuroendocrineimmune Disorders, as a somatoform disorder in the DSM-5 will result in decreased care of these medically ill patients. The CDC's Chronic Fatigue Syndrome educational programs for physicians explicitly suggest the management of CFS by primary care physicians with the suggestion of a psychiatric consult if the patient manifests appropriate symptoms. The same applies for the other NEIDs by the various medical specialists and researchers.

The reclassification of CFS, FM, CLD and GWI, as a somatoform disorder in the DSM-5 will create confusion for many practitioners. It will demean these illnesses, and the willingness of some practitioners to treat it. Moreover, the suggested listing of CFS, FM and other NEIDs, as a somatoform disorder may impact the ability of these patients to receive reimbursement of their treatment costs, as well as being afforded disability benefits coverage, resulting in a loss of treatment and benefits, and quality of life.

We have witnessed in England this "cookie cutter" approach as they attempt to place ME (which is the other name for CFS in Europe), as a psychiatric condition. This approach has been chosen by the government and supported by insurance companies because it is considerably less expensive for them to treat ME-CFS patients under this controversial approach. For the sake of cost, the UK government decided with the support of misdirected and allegedly ME-CFS researchers who are psychiatrists, pushing for the Cognitive Behavior Therapy (CBT) in mental health centers alleging that CBT would "cure" individuals with CFS-ME (who oddly have been giving the same criteria rationale as the one suggested under CSSD for the purpose of DSM-5) as well as referring patient to another controversial program of physical reconditioning titled GET (graded exercise therapy). Patients who are referred to these therapies and who fall under the Canadian definition for ME-CFS suffer devastating results and the hardship is cruel for them and to their families.

In the U.S. this approach has been applied for children with CFS-ME. Our organization last year spearheaded with other 23 non-profit and patient advocacy groups the return of a young male teenager suffering with CFS and other related illnesses, who was taken from his loving family by the Buncombe County Department of Social Services (BCDSS). This allegedly well intended social services agency officials charged the mother originally with Munchausen Syndrome By Proxy now commonly know as Factitious Disorder by Proxy (FDP). Once the case went through the court system, the charges against the mother changed to parents "failure to provide a mental health care provider to the minor child", then to "failure to provide medical care to the minor child" to finally after 9 and half months later, upon the return of the child to his loving family, the parents were charged with "failure to provide the care of a primary physician to a minor child." This happened because primary physicians in the Buncombe County and in 16 other contiguous mountain area counties in the state of North Carolina have not been educated on any of the NEIDs our organization embraces. The same applies to pediatricians in North Carolina. According to the board of physicians who are currently overseeing the Mountain Area

Health Education Center- (MAHEC) programs, and quoted by a MAHEC official “In general, they feel the diagnosis and treatment of CFS is a gray area”. You can certainly understand that you will be contributing to this widespread misunderstanding, which remains in existence despite the substantial amount (thousands) of scientific research papers on CFS and other NEIDs, demonstrating viral and bacterial, and microplasma infections, HPA axis dysregulation, adrenal insufficiency, brain inflammation and neurological findings, brain and CNS dysfunction in patients with NEIDs.

P.A.N.D.O.R.A. is committed to improving the health care and the lives of patients with chronic fatigue syndrome, fibromyalgia, chronic Lyme disease, environmental illness and Gulf War illness. Therefore, we view the suggested inclusion of CFS, as well as the potential inclusion of any other similar multi-symptomatic chronic illnesses that we embrace in our mission, in the DSM-5 as a somatoform disorder under the CSSD category, as inevitably creating additional harm to individuals suffering with these illnesses. We ask that you abandon this proposal of the creation of CSSD and or the inclusion of NEIDS.

Like many other patient advocacy organizations, which have already provided their input to you, we do not see the utility value of creating CSSD as a means to compartmentalize complex multi-symptoms chronic illnesses as a psychiatric condition and much less in “one fits all” approach. Once again we ask you that you abandon this proposal within DSM-5. Thank you for your attention.

Sincerely yours,

Marly Coutinho Silverman

Founder

P.A.N.D.O.R.A. & NeuroEndocrinImmune (NEI) Center™

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