

August 11, 2004

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Dr. Gerberding:

I commend the CDC on the recent study highlighting the tremendous economic loss to the nation caused by the disease, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Dr. Reeves and his team did an excellent job of bringing this part of the suffering & loss of this disease to the attention of the CDC and the public.

To get desperately needed traction in useful research on the serious physiological abnormalities in this disease, we now need to turn our focus on:

1. **Adoption of the 2003 Canadian Consensus Criteria for M.E./CFS, especially the “Clinical Working Case Definition” and “Diagnostic Protocol”** (definitive set of criteria by respected, international experts from the US, Canada, and Belgium); see the following web site: <http://www.cfids-cab.org/MESA/ccpccd.pdf> (cardiac abnormalities should also be included)
2. **A name change back to the original Myalgic Encephalomyelitis** M.E. has been classified by the WHO since 1969 as a neurological disease (G93.3 in ICD-10 currently in use worldwide, and ICD-9-CM 323.9 in US), and is easily substantiated as a neurological disease by abnormal SPECT or PET brain scans that become even more abnormal after exercise. The US needs to adopt the WHO ICD-10 neurological classification of ME/CFS. "Chronic fatigue" needs to be removed.

Adoption of this Clinical Case Working Definition & the name change (with the appropriate G93.3 ICD code for the ICD-10 with neurological classification) would accomplish 4 things:

1. Correct the CDC mistake in 1988 when they chose a trivial name and ICD code for a disease which already had been in the ICD with useful diagnostic criteria for 21 years (the arbitrary selection of the name Chronic Fatigue Syndrome was also an unscientific procedure – naming a disease after one symptom, especially detrimental in a multi-systemic disease such as M.E.); the CDC did not take into account the very abnormal tests that were done on patients at that time, and instead passed things off as psychosomatic (substantiated from book, Osler's Web)
2. Open the way for patients to be appropriately treated for a very grave disease with potentially deadly complications. After 21 years of bringing this serious situation to the attention of the CDC, there is still no appropriate treatment protocol for this disease, and in contrast, there is danger in inappropriate psychiatric-oriented or exercise-oriented treatments that can further deteriorate the quality of life. See Drs. Vance Spence & Neil Abbott from MERGE (M.E. Research Group for Education & Support, <http://www.mererearch.org.uk/>) for a better understanding and why such treatments are likely to be ineffective.
3. Discontinue the discrimination in both medical and public settings that makes patients denigrated or objects of disbelief & keeps many patients from receiving even the inadequate symptomatic treatment currently available. See Dr. Leonard Jason's attribution study – 2002 (attached) These show that on a practical clinical level, patients are treated with care and seriousness if the name Myalgic Encephalopathy is used, in contrast to the trivializing and lackadaisical treatment rendered for the name Chronic Fatigue Syndrome.

4. Energize and build interest in the medical research community, creating motivation by the study of a serious **physiological** disease with definitive criteria.

In direct contrast to the dominant medical community and public mind-set, Dr. Vance Spence, a medical doctor who suffers from M.E., has notably stated in the foreword to the book, "Shattered":

"Only scientific research into the causes and treatment of M.E. can prevent experiences like those described in this book. Comparatively little biomedical research has been done due, in part, to the economics of medical research funding. In addition, M.E. has been subsumed by the all inclusive, heterogeneous diagnostic construct termed chronic fatigue syndrome (CFS). For most M.E. patients, the CFS term is insulting – akin to tuberculosis being renamed chronic cough syndrome – as it focuses on one symptom, "fatigue", which is the hallmark of a range of illnesses with different underlying physiological causes. Nevertheless, the construction of the CFS label has resulted in a disproportionate allocation of funding towards psychosocial models of the illness. It has been left to a small minority of pioneer researchers – funded by smaller charities to identify the physiological causes of M.E. and try to find a cure."

Dr. David Bell, expert in both pediatric & adult and ME/CFS opened the most recent CFSAC meeting by reading this quote from same Foreword: "I can think of no other illness where such a powerful schism exists between those who suffer from it and those whose responsibility is to care for them."

The word "mysterious" is wrongly associated with ME despite a wealth of definitive scientific markers of abnormalities, which leads to confusion and poor medical care for patients:

- Abnormal brain SPECT & PET scans (Dr. Byron Hyde, The Clinical and Scientific Basis of Myalgic Encephalomyelitis/CFS)
- MRI findings consistent with organic brain syndrome--focal demyelination and/or edema typically in the subcortical areas (Dr. Anthony Komaroff)
- Disregulated HPA axis (Dr. Mark Demitrack, Dr. Anthony Komaroff)
- Disregulated antiviral pathway (Dr. Robert Suhadolnik)
- Cardiac abnormalities from viral invasion into the heart (Dr. Martin Lerner)
- Left-ventricular dysfunction following exertion and orthostatic stress (Dr. Arnold Peckerman)
- Cardiomyopathy, liver failure, pancreatic cancer, brain tumors & renal disease reported after 40 years of research in Enteroviral and Toxin Mediated Myalgic Encephalomyelitis/CFS and Other Organ Pathologies (Dr. John Richardson)
- Mitochondrial encephalopathy (Dr. Paul Cheney & Dr. Shungu, using Magnetic Resonance Spectroscopy)
- Abnormal capillary flow due to high percentage of flat red blood cells instead of normal discoid shaped red blood cells (Dr. Les Simpson, rheologist from New Zealand)
- High percentage of patients with a viral load (HHV-6, EBV, cytomegalovirus) and/or Mycoplasma bacteria (Dr. Ablashi, Dr. Constance Knox, Dr. Carrigan, Dr. Nicholson)
- Low circulating blood volume (Dr. David Bell, Lyndonville, New York)
- Abnormal bicycle ergometry test with gas analysis indicating immediate movement to anaerobic threshold in M.E./CFIDS patients (Dr. Paul Cheney, who uses this test for his disability reports)
- Cardiomyopathy due to myofibers of virus (EBV or CMV) lodged in the heart (Dr. Martin Lerner)
- Head-up tilt test with haemodynamic instability (Dr. J. E. Naschitz)
- Abnormal T-helper 1/T-helper 2 Function Panel (Dr. Paul Cheney)
- Very low Natural Killer Cell Function by Lymphocyte Enumeration (Dr. Paul Cheney)
- Prolonged vasodilatory effect of acetylcholine in the microvasculature of M.E. patients (Dr. Vance Spence)
- Positive testing for Ciguatera Toxin Epitope (Dr. Yoshitsugi Hokama, Hawaii)

Finally, I request in your educational efforts that you discontinue the idea of "branding" the name CFS into the public mind, and instead reestablish the truth that Myalgic Encephalomyelitis is primarily a neurological disease (AM Ramsay, ME and Post Viral Fatigue States, 1988, Chapter 3 'The endemic form of the disease'--The clinical features of myalgic encephalomyelitis). Also, in regard to educational materials, we urgently need an updated education package which would include the problems faced by those with long-term ME/CFS and by homebound disabled patients. The current education package (like most research and materials) suggests patients stop exercise when they feel more fatigue; it does not teach doctors that all symptoms can worsen both during and after exercise/activity, not just the symptom fatigue, but also pain, complex Orthostatic Intolerance symptoms with abnormalities in blood pressure and heart rate, dizziness, cardiac and respiratory problems and visual problems.

In addition, the material does not mention those of us whose worst symptoms include dizziness. It assumes we all have the waxing/waning type illness but many of us have progressive illness and have been sick for a long time (Only 4-8% of patients with M.E. recover fully). All that is left out of education material. I would request you to instruct Dr. Reeves to include other patient (or consumer) representatives in CDC CFS committees or activities & in any discussion of research projects, and to immediately adopt the Canadian Consensus Criteria, a very useful document for the case definition which would save valuable time for the CDC instead of the CDC trying to design another flawed case definition.

Thank you for considering the requests that I have made. The patient community has waited decades for the above-mentioned actions to be taken. **We need serious attention – now – in these areas.**

Upon becoming completely disabled in 1998, I went to the Center for Special Immunology in Irvine, California, which treats people with M.E./CFS as well as AIDS patients. The personnel there said that people with M.E./CFIDS are much sicker and less functional than AIDS patients. Yet there is the abysmal discrepancy in treatment and research efforts in these two diseases.

Sincerely,

Steven Du Pre

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Attachment: Jason Attributional Study

What's in a name? Plenty, when the subject is Chronic Fatigue Syndrome (CFS), according to DePaul University psychology professor Leonard Jason, whose recent study suggests that a name change would result in the much-maligned illness being taken more seriously.

An international debate on the issue weighs whether or not CFS's weak moniker has hampered efforts to gain recognition and government support. Jason was joined by Sigita Plioplys, M.D., a psychiatry resident affiliated with the University of Illinois at Chicago and a research team from DePaul, which set out to determine if doctors' perceptions of the disease would change if the name were changed.

The team found that when groups of medical trainees reviewed case studies of CFS patients that featured three different names for the disease, their perceptions did change depending on the name the illness was

given. The names used in the study were: CFS, Florence Nightingale Disease (FN), named for the public health nurse who served during the Crimean War and was believed to have suffered from chronic fatigue; and Myalgic Encephalopathy (ME), the medically based term used to describe the condition.

More than 100 Chicago medical students and residents responded to questions pertaining to prognosis, correct diagnosis, illness cause and appropriate treatment. When asked to assess the likelihood that the patient would improve within two years, 42 percent of the medical trainees assessing the Florence Nightingale name, and a similar 41 percent of trainees evaluating the CFS name responded that it was likely or very likely that the patient would improve. However, only 16 percent of the students and residents who thought the condition was called Myalgic Encephalopathy felt it was likely or very likely that the patient would improve. This finding suggests that the doctors perceived the ME label as being indicative of a more chronic and debilitating illness as compared to the labels CFS and FN, Jason said.

When asked what factors were most likely responsible for the person's illness, a greater proportion of medical trainees in the ME group attributed the illness to medical causes (39 percent) as compared with trainees in the FN (30 percent) and CFS (22 percent) groups.

"If you have a more medical-sounding name it does seem to change perceptions of the illness," said Jason. "This study provides a much-needed methodology for helping to change the name, and a way to go about it in a scientific, systematic way."

According to Jason, a more biological-sounding name for CFS will be beneficial because people tend to interact in a more sympathetic way when an illness has a name that communicates medical and scientific legitimacy. Also, the perception that CFS is a trivial illness has negatively affected government funding and support services. Jason indicated that more research and studies are needed to erase this myth.

Jason has conducted numerous studies on the prevalence of CFS and has written a book about the condition. Other study team members were Renee A. Taylor, a project director affiliated with DePaul's psychology department; Jennifer Shlaes, a graduate student of psychology at DePaul, and Zuzanna Stepanek, a volunteer research assistant and recent graduate of DePaul's bachelor's degree program in psychology.

The study, "Evaluating Attributions for an Illness based upon the Name: Chronic Fatigue Syndrome, Myalgic Encephalopathy and Florence Nightingale Disease," was reported in the July/August 1999 issue of the "Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) Chronicle."

The findings of the study have bolstered Jason's confidence that CFS will have a new name in the future. "In the next year or two, a new name will come," said Jason. "A consensus is needed on what to change it to, and the scientific community will have to make that decision."

CFS is a chronic condition with symptoms that are severe, but often difficult to detect upon physical examination. They include fatigue, headaches and insomnia. For years the condition went un- or misdiagnosed because physicians weren't able to differentiate between common fatigue and CFS. Dr. Jason can be reached at 773/325-2018 for more information.

Also published here: Am J Community Psychol. 2002 Feb;30(1):133-48

Evaluating attributions for an illness based upon the name: chronic fatigue syndrome, myalgic encephalopathy and Florence Nightingale disease.

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