

243 Glen Avenue  
Dumont, NJ 07628  
May 11, 2007

Dear Members of the CFSAC,

I am a nurse and have had CFS for over seven years. I, like so many other PWC, was subject to insult and accusations during a diagnostic process that, for me, lasted 16 months. Of the ten specialists that I saw, only two actually demonstrated any knowledge of CFS. The remaining eight either dismissed my symptoms or said it was "depression." I became involved with the local support group and subsequently, the NJCFSA in hope that others might find answers.

I was excited about the Awareness Campaign and crushed when it was delayed. It was gratifying when the campaign finally began, but I am somewhat dismayed by the coverage. I have seen a few print ads and a few short spots on local TV, but certainly not the campaign that I had envisioned. I think that I, unrealistically, hoped that CFS would be on everyone's lips and it would no longer be the illness physicians do not want to handle.

The campaign uses the statement "Get diagnosed. Get treated." As someone who actively searches for CFS treating physicians (personally and as a member of the NJCFSA Board of Trustees), I can report that without a blitz of education for physicians, many people can be neither diagnosed nor treated. I still do not have a physician treating my CFS.

In 2002, the University of Medicine and Dentistry of NJ, along with the Academy of Medicine of NJ and the NJ Department of Health and Senior Services, produced *A Consensus Manual for the Primary Care and Management of Chronic Fatigue Syndrome*. This outstanding manual drew upon the expertise of many of the leaders in the field of CFS. It has been translated into Japanese, yet it is becoming obsolete in the US, because the original supply has been exhausted. Thanks to the dedication of the original authors, the manual has been updated and the state of Vermont has adopted it for use in their state. We need to have it adopted as the manual for the entire US. Furthermore, it needs to be updated regularly - perhaps every two years - to keep current with new research results. We need the CFSAC to help secure funding to insure that this valuable educational tool will be available to physicians across the nation.

We need to reach out to physicians, explaining to them the serious nature of this illness. Presently, it is often the patient who identifies the illness and then searches for a physician to make a diagnosis. A sick person should be able to have CFS identified, just as other illnesses are. I am asking the CFSAC to initiate and/or oversee an aggressive medial educational program.

I implore the CFSAC to consider establishing CFS treatment centers and to encourage treating physicians to accept insurance. CFS patients are often unemployed. They cannot afford to see doctors who do not accept insurance, and cannot pay the high fees charged by some of those who do treat the disease. A portion of these centers need to be in suburban areas, because large metropolitan medical centers are not always accessible to a person too ill to make the trip to a

city. Patients could make suggestions for locations they would find accessible. These sites should be located near major highways and crossroads with nearby lodging facilities.

There need to be incentives for practicing physicians and nurses to take continuing medical/nursing education credits in the area of CFS. I am asking you to encourage CME providers to include CFS in their program offerings.

CFS must be a part of every medical and nursing education program. In an effort to encourage awareness of CFS, the NJCFSA has instituted a modest scholarship available to NJ medical school students. It is believed to be the first CFS-focused scholarship in the United States. I am asking the CFSAC to explore ways to institute nationally available medical student scholarships that foster interest in CFS.

Volunteers, most of whom have CFS, are willing to expend precious energy to increase awareness, often making themselves sicker in the process. We cannot do it alone. I respectfully request that you consider my comments as possible areas of interest for the CFSAC to address.

Thank you.

Sincerely,

Patricia LaRosa, RN, MSN  
NJ Chronic Fatigue Syndrome Association, Inc.  
Vice President  
Co-leader Bergen County CFS-FM Support Group  
pat@larosas.net