

Dear CFSAC Members:

I have had CFS for 25 years and am an 18-year survivor of bilateral breast cancer. To date, the CFS has been far more devastating and disabling than the cancer.

Recently, our 32 year-old daughter was diagnosed with early stage breast cancer. Certainly, it was a blow to her and our family to discover she had a cancer in her body which could kill her. But I kept thinking. It could have been worse. She could have been diagnosed with a full-blown case of life-altering CFS, which could have affected her for the rest of her life. That would have been a fate worse than death for our high-energy, adventuresome, life-loving, and hard-working daughter.

I mention the above because CFS is considered a "lesser" illness than breast cancer. Breast cancer certainly can kill you and CFS does not normally lead to death. But based on my experience with the two illnesses, I would choose for my daughter to take her chances with breast cancer rather than have to endure CFS.

As a long-time patient, I submit the following recommendations:

1. It is crucial that the CDC adopt a more precise case definition of CFS. Using the broader definition further muddies the CFS waters.
2. The research focus must be biomedical, not psychosocial. Rigorous scientific effort must be directed toward studying the etiology, pathophysiology, possible biomarkers, and medical treatments for CFS. Money should not be spent on Graded Exercise and Behavioral Cognitive Therapies.
3. Government databases on CFS should be shared with other researchers, academics, health agencies, and physicians both nationally and internationally. Collaboration with outside sources would accelerate the understanding of this illness.
4. CFS is an under-funded illness. Limited CFS dollars must be judiciously spent. There should be a careful accounting of expenditures with periodic audits, and the findings made available to the public.
5. Progress reviews of CFS programs should be completed every two years by objective CFS experts from outside the CDC. Evaluation results should be made available to the public.
6. Many doctors are poorly prepared to diagnose and treat CFS patients. As a result, many CFS patients receive inadequate treatment. There must be better ways to train health care professionals and those in training regarding CFS.
7. Regional Centers specializing in research and treatment of CFS should be established.
8. Efforts to educate the public about CFS should be continued.

9. Concerning the 2009-2010 International Workshops on CFS sponsored by the CDC::

- A. Names of those attending the workshops should be posted online in advance of the workshops.
- B. CFS groups such as CFSAC, The CFIDS Association of America, and The IACFS/ME should be allowed to help select participants.
- C. Workshops should be web cast and workshop transcripts posted online.

Thank you for permitting members of the ME/CFS community to submit comments.

Sincerely,

Anonymous