

Dear CFSAC Members:

Chronic fatigue syndrome (CFS) has devastated my life both physically and mentally for twenty-five years. It took thirteen years to find a doctor who could make the diagnosis. CFS has been unimaginably debilitating and life-altering. My energy level has fluctuated between 5-15% of my normal level. There is always the extreme fatigue, post-exertional malaise if too much energy is used, burning and aching muscles, and neurological problems, including difficulties, in processing new information. Employment is not an option, and there is never sufficient energy to engage in social activities. Even light housework is a struggle. It is often difficult for healthy-individuals who have normal energy levels to understand the life-robbing aspects of CFS and the personal suffering of patients and their families.

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

1. It is crucial that the CDC adopt a more precise case definition of CFS. It was concerning when the number of estimated CFS patients in this country jumped from about a million to up to four million with the adoption of the Empirical Definition. Using the broader definition further muddies the CFS waters.
2. Serious research holds the key to understanding CFS. The research focus must be biomedical, not psychosocial. Rigorous scientific effort must be directed toward studying the etiology, pathophysiology, possible biomarkers, and treatments for CFS.
3. Government databases on CFS should be shared with other researchers; academics, health agencies, and physicians both nationally and internationally. Collaboration with outside sources is to be encouraged as it would likely accelerate the understanding of this illness.
4. CFS is an under-funded illness. Precious CFS dollars must be judiciously spent. There should be a careful accounting of expenditures with periodic audits.
5. Progress reviews of CFS programs should be completed every two or three years by objective CFS experts from outside the agency.
6. Many doctors are poorly prepared to diagnose and treat CFS patients. As a result, many CFS patients receive inadequate treatment. We must find ways to better train medical students, physicians, and other health care professionals regarding this difficult illness.
7. Regional Centers of Excellence specializing in research and treatment of CFS would be of great benefit to the CFS community and should be established.
8. The term "Chronic Fatigue Syndrome" was an unfortunate choice as it trivializes the illness. We must work toward a more adequate name for this illness.

9. The general public is beginning to have some understanding that CFS is associated with fatigue and tiredness, which is chronic. However, most persons do not comprehend the seriousness and complexity of this illness, which affects various systems of the body. More education is needed.

Through an accelerated research program leading to better ways to diagnose and treat this complex illness and additional effort put forth to better train doctors and educate the general public, the quality of life for CFS patients would be greatly improved. I thank everyone who is working toward this end.

Sincerely,

Faith Wong
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