

Chronic Fatigue Syndrome Education in the United States

Testimony for the Chronic Fatigue Syndrome Advisory Committee

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Good morning!

My name is Kenneth Friedman and I am a medical school professor.

I have been asked by the IACFS/ME to comment upon the status of Chronic Fatigue Syndrome education in the United States.

Comments on The Academic, Medical School Environment

The Director of the Office of Ethics and Compliance of my employer has informed me that my off-campus activities related to CFS which include: testifying **before** this Committee, serving **on** this Committee, providing continuing medical education courses, establishing medical student scholarships and assisting with healthcare legislation are **not** part of my responsibilities as a University Professor. I am told that I will be punished with a penalty as severe as termination of my employment for these activities.

I am not a unique target. Colleague Ben Natelson has left the same school. A different medical school has refused to permit access to their medical students to discuss CFS or inform them of a medical student scholarship. A statewide health care provider, with no physician capable of managing CFS patients refuses to permit a CFS training session for their physicians. The failure of the CDC to convince the medical-academic establishment of the legitimacy of CFS, and the urgent need for its treatment, has created this environment.

Comments on Medical Student Education

High ranking officials of medical education have testified before this Committee that they are powerless to control the curriculum of medical schools, and cannot mandate the inclusion of Chronic Fatigue Syndrome in the medical school curriculum.

Were the CDC to mandate the reporting of CFS to the Federal Government, as it does for other illnesses, the National Board of Medical Examiners would have no choice but to put CFS questions on the National Boards. If CFS questions were to appear on National

Board licensure examinations, medical schools would have no choice but to include CFS in their curriculum.

I have appeared before this body on **two** separate occasions arguing for the use of existing **student** programs within **both** the NIH and the CDC to rotate medical students through NIH and CDC laboratories. I have pleaded for dialogue and feedback on **any** of my proposals. I have heard **nothing**.

The only mechanism for medical student education for CFS is the medical student scholarship programs run by patient advocate organizations. We now have programs running in three states. **How many scholarship programs must be mounted by state patient advocate groups before the CDC mounts a single, national medical student program?**

Comments on Continuing Medical Education for Physicians

To my knowledge, the CDC's on-line continuing medical education CFS course is the only involvement of the federal government in healthcare provider education. Does the CDC honestly believe that sitting in front of a computer screen for a few hours will make a physician capable of diagnosing and treating CFS?

From the CFS Community's perspective, what is the impact of the on-line course on diagnosis and treatment of CFS? From Vermont CFIDS: there is no increase in the number of physicians who diagnose or treat CFS in this state. From NJCFSA: the number of requests for physician referrals to our helpline has not diminished.

Comments on Chronic Fatigue Syndrome Educational Materials

In my opinion, all federal and private sector literature concerning Chronic Fatigue Syndrome is out of date. There is no established mechanism for updating health care provider literature. Of the available literature, the most authoritative and accepted source of information on Chronic Fatigue Syndrome is a physician's diagnosis and treatment manual **not** produced by the Centers for Disease Control, **not** produced by the National Institutes of Health, but produced by the New Jersey Chronic Fatigue Syndrome Association: the *Consensus Manual for the Primary Care and Management of Chronic Fatigue Syndrome*. I ask that this Committee recommend to the U.S. Secretary of Health that a national diagnosis and treatment manual for CFS be created, that a panel be formed to write this manual, that the Department of Health and Human Services underwrite the expense of producing and distributing this manual.

With regard to the recent, CDC "Spark Awareness" Campaign and the accompanying "Physicians' Toolkit," not one patient in the State of Vermont ever saw the patient's pamphlet. An incredible waste of money!

Conclusions

The only on-going educational programs for medical students and physicians that involve human contact come from patient advocate groups.

Patient advocate groups are the current source of educational materials for CFS. They rely on the assistance of academicians. If academicians are threatened with termination of employment for participating in Chronic Fatigue Syndrome education, there will be no educational programs.

I beg you to consider the magnitude of this problem.

I beg you to undertake a course of remedial action.

Thank-you!