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From: Linda Ferris

Sent: Wednesday, May 20, 2009 11:00 PM

To: OS OPHS CFSAC (HHS/OPHS)

Subject: FW: [CO-CURE] ACT: Goals submitted for CFSAC meeting May 27-28, 2009

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Here are the goals I have sent in as my testimony to the CFSAC meeting. There is no way I can physically or financially attend the meeting. I am using a friend's statements and comments because my cognitive has seen better days and I just turned 60. Please include these goals into the minutes:

1. End the current CDC program on CFS and burn the questionnaires.
2. Return to the goals expressed in the 1994 Fukuda study: Focus on identifying subgroups using objective biomarkers.
3. Abandon the psycho-social approach to focus on biomedical answers. Quit

hiring British psychiatrists (who use a completely psychiatric definition) as consultants to CDC for CFS.[Linda Ferris] This is a complete waste of our time and our money and we do not appreciate the CDC going there. Why aren't 4000+ scientific studies enough to point you (the CDC) in the correct direction?

4. Make public the testing and treatment that those of us who are paying cash can get, so that others have a chance at diagnosis and treatment. The easiest way to begin would be to adopt the Canadian Consensus Definition and Protocol for ME/CFS.

See <<http://www.mefmaction.net/Portals/0/docs//ME-Overview.pdf>>.

5. Ask for equitable funding for our disease. The U.S. spends less than \$10 a year per patient, far below the amounts for cancer, AIDS, and heart disease.[Linda Ferris] So with paltry SSD checks, we are barely making ends meet and will soon be living under bridges. So many patients with Medicare are treated with absolutely no respect and are blatantly shown the impatience by the physicians who still believe that we are all without gray matter. These same physicians who do find something questionable, do not pursue the condition or they send them to other Dr's who know nothing about the subject matter that the patient was referred to. It is truly a disgrace to the profession that is supposed "first, do no harm." When an M.D. yawns and shows no interest in a patient but gets reimbursed by Medicare, they openly show their ignorance and arrogance which is very humiliating. MS was once made fun of. Why is that disease any different from what we have and try to live as normal people can and do but we are the "walking dead." To be so sick and to be so humiliated is unjust and indefensible.

6. Adopt the WHO diagnostic criteria and recognition of Myalgic Encephalomyelitis (M.E.) in neurology. Share this information with neurologists! [Linda Ferris] Teach this to our new physicians as they start on the road of being helpful or being rich. One MPH instructor told us that we are not patients but clients. Sad, but true.

7. HHV-6 encephalitis, intended to describe an adult condition, now has its

own ICD-9-CM code, 049.8. Perhaps you could share that with physicians.

See:

<<http://www.cdc.gov/nchs/data/icd9/agendam06.pdf>> [Linda Ferris] Especially when Dr.'s have no interest in the subject because there is so much controversy, thanks to the CDC doing nothing for 20 years.

8. Please take note of the report that a group of us prepared for the Obama-Biden transition team, "HCCD Report Delaware 19711." It is available on the HealthCare.gov website:

<[http://healthreform.gov/communityreports/delaware/delaware\\_19711.html](http://healthreform.gov/communityreports/delaware/delaware_19711.html)>

[Linda

Ferris] If you really want to help a tremendous number of American citizens and taxpayers, there is excellent information to be found here. Use it for our benefit; not to collect dust on a shelf or add to the trash can.

9. Most important of all, CDC should quit trying to re-invent the wheel.

Establish Centers of Excellence and fund those that already exist. The Whittemore-Peterson Institute is a perfect model of research complementing care. Dr. Nancy Klimas will be re-establishing a clinic for similar purposes in Miami this summer. That would be two. How many centers do patients with

cancer get? Remember, there are one million of us. [Linda Ferris] And that may be on the lower end of the count. We have been ignored, harassed, embarrassed and told that there is nothing wrong with us but no one can get out of bed in the morning feeling refreshed. It is more like being just run over by an 18 wheeler. This is not a life. It is an existence. We have been asking for the truth and help for 20 years now and the disease goes back much further than that. The last budget that I read for the CDC was a disgraceful amount of money that was basically wasted when we live like paupers. If you can't or won't do the job that is needed to be done, get out and waste precious time and money on somebody or something other than us.

Linda C. Ferris with a lot of help from a friend!