

From: kathryn stephens [mailto:kathrynstep1@webtv.net] Sent: Friday, May 22, 2009 2:29 PM
To: OS OPHS CFSAC (HHSjOPHS)
Cc: kathrynstep1@webtv.net Subject: Written Remarks to CFSAC, per your Instructions and Offer to Print and Disseminate

My name is Kathryn Stephens. I come here today with hope, but also with trepidation, because this Committee has been worthless since it's inception.

I have a List of "WHYs" today:

WHY has no one questioned the CDCs (erroneo,us) demographics, which are based on their (equally wrong), research criteria?

WHY do you and the CDC ignore the Canadian Criteria, and/or the WHO's diagnostic code of 93.3; (REAL CFS, according to the 1994 criteria in the U.S." is M.E., a Neurological condition.)

WHY have so many Committee members (since its inception) been so uninformed, so ignorant of the more than 3500 studies that have shown serious abnormalities in so many PWCS? Why do you exist?

WHY has the International Association for CFS/ME correctly changed their focus to ME, while you have not? Are you part of the CDC's further denying and obscuring of the reality of CFS? Do you support their "international focus"; (meaning, the UK'S NICE guidelines?) Are you even aware of those?

WHY has the CDC slyly been trying to copy the UK's NICE guidelines, which make this a psychosocial illness, and which proscribe CST and GET, when so many competent, published studies have shown that most of us are exercise intolerant?

William Reeves must GO, and NOW, before MORE irreparable, possible malpractice, harm has been done.

WHY, as a perfect example of how behind the research and understanding of ME/CFS you and your "Related Federal Sites" are, is this allowed?:

The AHRQ website is indicative of the problems inherent in the CDC's hiding the true facts of this terrible disease:

Their website is dated Sept., 2001!

. (and apologetically makes this)

STATEMENT: "This evidence report has not been updated within the past five years..." Can you believe this? WHY?

It goes on to say, " the validity of one case definition over another is not well established" (and) " there are NO clear biologic markers...." (and) "NO effective treatments specific to CFS have been identified."

These nine year old statements are STILL true today. How can that possibly happen? What does the CDC ever investigate that is replicable and valid? What has this Committee accomplished for our sick and dying PWCs?

The site then have the audacity to

CONCLUDE: "...although several therapies have been studied, potential benefits, as well as harms, of most...are not well established" (and) "behavioral therapies that emphasize increasing activity levels may improve quality of life and function in some with CFS." Most dedicated researchers know these are damaging statements.

(The nine studies they reviewed did not have any patients who were too sick to be included, and it was known, EVEN THEN, that it is not FATIGUE that is the problem, but neurological damage and RECOVERY from aerobic activities.)

If "CFS" has no scientific basis, as the CDC claims, WHY should there even be a CFS department at the CDC -which now includes traumatized children, depr'essives, fatigue from dozens of causes, and only god knows how many other inclusions.

This current program must go, and Mr. Reeves should be allowed to move on to his new, competing interests at Emory.

LASTLY, and finally, WHY do I think this comment may be in vain, that you will allow this horrible disease to be a psychosocial illness? Maybe because of past performances of this Committee? Maybe a class action lawsuit or a Congressional Inquiry will help you understand how serious we are about ACTION NOW!

I will thank you when and if informed and constructive action takes place towards the concerns we (collectively) will have expressed here today and tomorrow.

We will ALL.: be thankful then.

Breathe in...hold.,,exhale...relax, be at peace..