

Testimony

Kathryn Stephens

Dear Committee Members, President Barack Obama, Sec. Kathleen Sebelius, DHHS, and Director Collins, NIH, and Senate HELP Committee

CRIMES AND DIMES

The NIH and CDC have willfully and criminally ignored their mandates and over 5,000 scientific studies of patients with CFS, which was originally M.E. (Myalgic Encephalomyelitis), which they intentionally mis-named in order to cover-up sporadic outbreaks of ME. This was done for at least two reasons: First, CFS/ME arose as HIV/AIDS was killing people and the CDC could not mentally manage a parallel infectious disease that the public would learn about and demand answers. The CDC had the mental problem, not us patients. Secondly, the CDC also knew how disabling ME could be, making more people eligible for medical care and disability benefits along with the burgeoning list of HIV/AIDS patients. Their disregard of our care must have been sanctioned by very powerful, higher echelon government agencies (NIH?, DHHS?); I don't believe they could have done this without it.

These inhumane violations of our civil right to disability benefits, appropriate testing and treatment trials has meant 30 years of possibly criminal neglect of the American people. They have violated their own mandates to research and define CFS in a scientific and responsible manner.

Now Reeves has been transferred...so what!? He is still publishing garbage based on his erroneous, misleading "Empirical Definition" on almost a weekly basis, and getting away with it. Who are the scientific, clinical peer-reviewers of the psychobabble he gets away with; what are their inherent interests in perpetuating the myths of child abuse, psychological problems and lack of neurological and immune system symptoms in this devastating disease?

NIH Director Collins assured patients at the recent XMRV conference of Sept. 8-9, 2010, that "we are on track. Things will happen." He said NIAID is setting up multi-centered clinical trials. The Question of the Day is: Based on WHAT DEFINITION? The CDC's depressed or wrongly diagnosed GA cohort, selected by random phone calls? The Canadian Consensus on ME/CFS? The 194 Fukuda definition? Only one is acceptable: The Canadian Consensus.

At the same meeting, Dr. Gottesman, Dep. Dir., Intra-Mural Research, NIH, said there will be more funding and more publications, explaining there was a "lack of concrete scientific, clinical and medical findings and published papers" does he SELECT OUT the 5,000 CFS publications, or is he just as ignorant as the CDC's scientists? Is he also blind or willfully ignorant? He was clueless out the patient's abhorrence of Strauss and Fauci's past actions towards us, so he obviously has never read Hilary Johnson's "Osler's Web", either. This brilliant history

of the CFS criminal saga should be required reading for everyone from President Obama, to Secretary Sebelius, Director Collins, Director Friedan(CDC) and whomever gets the new post as head of the CDC's CFS research program, before any more damage is done to us.

Gottesman did say that the "Alter/Lo publication will change everything for our illness." Maybe we could start by getting the dentists and psychiatrists now on the CFS research grants team replaced immediately. Dr. Peterson was at this meeting, and informed Dr. Gottesman that the major researchers of CFS are not getting funding. The patients in attendance there stated the research grants process for CFS is flawed and needed fixing. There are four research teams that I know of that could be funded immediately: Dr. Nancy Klimas, Dr. Ila Singh, Dr. Paul Cheney and the Whittemore Peterson Institute. The PANDORA organization needs funding for the already approved New Jersey Center of Excellence. It's needs to be built at once, with clinical trials for treatment of the myriad diseases of the NeuroEndocrineImmune spectrum, including CFS, FM, GWI, Autism, atypical MS, among others. Then we need at least six or more, so patients don't have to kill themselves just getting to one for evaluation and treatments.

DIMES have been spend of CFS, or should I say misspent? We demand the NIH release at least \$100M over the next YEAR, to forward the research into the third Retrovirus found to infect mankind. XMRV/MLVs may not be the primary cause, but retroviruses have not been found to be benign and its association with CFS is no longer in doubt, no matter where it came from, no matter that not everyone positive for it is not (yet) sick.

The CDC has spent about \$3 per patient per year on CFS. This is unconscionable for a disease far more prevalent than MS, for one, and just as disabling to certain patients as HIV in their last few months of life.

The dimes need to be exchanged for dollars now...lots of them!

The crimes against humanity must stop. Real science, real research, real clinical trials, and real treatments must begin. Start with the XMRV positive patients, and retest often those sick but testing negative. Just click on "Start"!CLINICAL TRIALS NOW!

Remove the CDC from all CFS related programs; they must be at the NIH's NAIAD division, immediately.

Strong measures must be taken to protect the nation's blood supply; not questions eliciting whether a patient feels 'unwell' at the time.

Let's trade CRIMES for TRUST
Let's trade DIMES for DOLLARS

Let's do it together. NOW IS THE TIME.

From: We Three in One Home; All with CFS/ME Kathryn Stephens Mary L
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NO TEST=NO HELP=NO HOPE
Ask me.

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