

OS OPHS CFSAC (HHS/OPHS)I

From: Margaret Lauritson-Lada
 Sent: Thursday, April 16, 2009 4:56 PM
 To: OS OPHS CFSAC (HHS/OPHS)
 Subject: CFS.ME & CDC -and WHO

QUESTIONS:

WHAT AM I SUPPOSED TO DO IN THE AMERICAN MEDICAL SYSTEM IF I HAVE AN ENGLISH DISEASE?

MYALGIC ENCEPHALOMYELITIS (ME): IS A UK NAMED DISEASE FOR WHICH I HAVE FOUND NO AMERICAN PARALLEL, A DISEASE THAT MOST CLOSELY RESEMBLES WHAT I HAD I HAVE FOR THE LAST 20-25 YEARS. CDC'S WEBSITE SIMPLY REFERS "ME" INQUIRIES TO CFS, WHICH IS A SYNDROME NOT A DISEASE, THEN FAILS TO INCORPORATE "ME" INTO THE CFS INFORMATION. THE WORLD HEALTH ORGANIZATION HAS YET ANOTHER DISEASE/SYNDROME DEFINITION.

PLEASE STUDY MYALGIC ENCEPHALOMYELITIS AND COLLABORATE WITH OTHER GLOBAL INITIATIVES. YOU ARE MISSING A VERY/REAL AND SEVERE DISEASE. IT'S NOT A SLEEP DISORDER OR "FATIGUE" SYNDROME. IF YOU EVER HAD IT, YOU'D HAVE NO DOUBT ABOUT THAT.

SHARING BLOOD AND ORGANS: What's CDC's position on the safety of blood and organ donations by people with CFS/ME?

- I've had this disease for almost two decades. No medical person has ever suggested I cease or banned me from donating blood. I stopped doing it on my own. Would you want my blood in your body or your child's body? It's okay for it to be there, in someone else's body, as far as I know. Is it possible I got the disease from a blood transfusion I received shortly before I became very ill?
- I forgot about being an organ donor via my driver's license. I just realized I was still an organ donor when I got my new license, so I changed that as well.
- **HAS CDC DONE RESEARCH ON THIS? IS IT SAFE FOR ME TO GIVE BLOOD? DO YOU HAVE RULES AND REGULATIONS IN PLACE REGARDING BLOOD AND ORGAN DONATIONS? HAVE DOCTORS, PATIENTS BEEN INFORMED/EDUCATED?**

CDC RESEARCH ON AND DESIGNATION OF CFS/ME: From the CDC website, I see:

CFS is under "WOMEN'S HEALTH". What's that all about? Doesn't seem to make any sense at all.

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-Men get the disease. Keith Jarrett and Blake Edwards are two prominent men who have suffered a severe form of the disease for years if not decades. Did they have a "WOMAN'S HEALTH" problem all those years? -Children get the disease, but CDC didn't file CFS under PEDIATRIC HEALTH. Is it true, some CFS children are diagnosed as Munchausen's by proxy?

-If you studied the demographics of the sickest of the sick, the ME types, you might get a gender and age neutral outcome. Again, remember Munchausen's by proxy types of situations might undercount the number of children with the disease.

-Isn't there a more appropriate designation or specialty to place CFS/ME? There has to be.

Research: I see that research dollars are spent on some things that makes little sense to me and not on other things that make a lot of sense.

-Psychiatric/psycho-social/behavior health: Anyone who's had *ME/CSF* would know how useless, wasteful and inappropriate this research is. Why is money being spent on it at all? I don't think any rational person, let alone a scientific person, could accept or even entertain a theory that *ME/CFS* outbreaks in Lyndonville, NY or Incline Village, NY (or Punta Gorda, Iceland, Great Britain, or any other *ME/CFS* epidemic centers) resulted from the simultaneously resurfacing of multiple sexual abuse cases confined in one small town, hospital or nunnery. That's incredulous, ridiculous. Please stop spending your meager research dollars on psychiatric/psycho-social/behavioral health things, most of all early childhood sexual abuse trauma. That "flavor of the month" psycho-topic, which was attached to almost every ailment, has come and gone.

-Cluster Studies: I got excited to see what CDC had discovered from Incline Village and Lyndonville and other international studies. I'm disappointed.

-A few summaries of cluster studies are presented on CDC's site, two published in a Psychiatric Journal. Again, how did psychiatry get into the game and at such a high level and oddly heading up "cluster studies"?

-There is no mention of Lyndonville, Punta Gorda, Iceland, Great Britain and other places where the disease appeared as in an epidemic manner. It's global, Why aren't we working hand in hand with the rest of the world and taking advantage of every other country's research work?

International Collaboration or lack there of

-The work done in the UK is so relevant to my situation; so in sync with my experience; and the disease they describe is so on target. Yet, in America, I get stuck in the gate,

because America, CDC, refers ME to the CDC CFS site where it simply disappears and ceases to exist. They are so far ahead of the USA, and we ME suffers are the losers. Essentially, I'm an American with an English disease. How can that be rectified?

Thank you for your time, Margaret Lauritson-Lada