

Here are a list of things that I urge you to take action on. My name is Sarah Goodwin, I have been disabled by "CFS" for almost three years at this point. I was a healthy and active overachiever with a lot of plans for the future until I came down with a virus and my entire life caved in around me and took all that away. My career and educational goals have all been put on hold as I am barely able to care for myself at this point. I had just graduated college when I got this disease, I am now 25 years old.

The CDC empiric definition is irreparably flawed and must be immediately and permanently discarded. Why is the CDC still using this definition when even the NIH finds it to be inaccurate and refuses to use it for research? Outside studies have shown that it leaves out the sickest patients, but picks up people who do not actually have what is traditionally medically defined as "CFS". Any research undertaken by the CDC using this definition will be a useless waste of taxpayer funds, not to mention will do more to confuse the body of science than to advance it. No further funding should be given to CDC if this definition is to be employed. How does CDC expect to conduct a truly scientific assessment of research by other groups, for instance recent findings on XMRV, if they insist on using an unscientific definition that all other research bodies refuse to employ?

CBT and GET are not cures for this disease and it is dangerous for government researchers to suggest that they are. GET has been proven in study after study to make a far higher percentage of patients worse than to improve, regardless of what type of person is overseeing the treatment. If GET were a drug it would be taken off the market, so why would anyone in a position of authority advocate it? Pacing and energy conservation has sound science behind it, but are all but ignored by the CDC researchers. Why is William Reeves, who is billed as a virologist on payroll of the Emory University Psychiatry department? Does this not present a conflict of interest? I cannot overemphasize that I feel we are on a slippery slope here as much of the current research into this physical disease is being overseen by the Emory University Psychiatry department through the CDC. This is not where answers are going to be found and it is a tragic and negligent waste of taxpayer money to suggest otherwise. By the CDC's own admission this is a physical disease. Why are they consulting so many psychiatrists? If Peter White, a UK psychiatrist is used as an external reviewer of the CDC programs, he should not be consulted about the programs regularly. CDC should be forced to sever all ties with Peter White and bring in consultants and reviewers of a broader range of scientific views, they should be required to have biological knowledge of this disease, how else will a cure, treatment or prevention ever come about? We need to get the psychiatrists out of this physical disease so they can spend their time helping people who truly and desperately need their help- those with actual psychiatric diseases.

If the CDC is not willing to participate in finding a CURE for this disease than their funding should be zeroed out and given to an agency or group that will. The entire investigative team that is working on CDC CFS projects needs to be let go and a team of researchers who will actually help find a cure brought in. At this point how many chances are you willing to give them? Secretary Sebelius must make this a priority and do

whatever it takes to get a research team who is more interested in science than organizational politics, saving face and psychologizing physical diseases. Higher ups within the organization need to be taken to task and made aware that the time for foot dragging, stalling and dishonest research is past. This is not a problem that starts and ends with William Reeves and his employees, the administration of the CDC needs to know in no uncertain terms that this type of waste cannot be tolerated. This is a call that is coming from all major organizations that deal with CFS, yet it has been continuously ignored. The time to act is now. We cannot waste the money we have on research projects that are not geared towards finding a cure. There have been undeniably scandalous problems with the CDC's CFS programs for over 25 years and I cannot help but think that if things had been different in all of these years I, and others more recently affected, might never have come down with this disease or would have had a cure immediately. Our lives would not be on hold while we are waiting for effective treatments and answers. The time for second third and fourth chances was over a long time ago.

A GAO investigation is needed immediately into contracts with Emory University while CDC officials are benefiting financially from this partnership, in a glaring conflict of interest. as well as into work done by ABT associates contractors, who appear to have been paid for work never completed, and work not done at all as it was contracted. Perhaps a congressional investigation would be more appropriate. At this point though, taxpayer funding is being carelessly squandered on research that brings us no closer to health.

Why hasn't the CDC responded to critiques of it's program and five year plan that have come from researchers and organizations? How can a plan be comprehensive if you take the word of four people (the external review team) and ignore the concerns of tens of thousands? If the CDC is not willing to take any suggestions from researchers with far more knowledge than patients like me, why should they they be conducting research at all? The five year plan needs to be restarted from scratch with genuine input from all concerned parties.

If the CDC team is replaced with researchers who are willing to conduct research into the physical nature of this disease and are using a definition that is in line with what all other agencies and groups are using, then their funding must be drastically increased to make up for the lost time and missteps of the previous team. If this cannot happen, disband the CDC program altogether and give their funds to the NIH CFS programs. In the meantime, either way, funding for this disease at the NIH needs to be very dramatically increased to put it in line with other chronic disabling diseases and to make up for so much time that has been lost. Especially given the recent XMRV findings, research must be stepped up greatly so that momentum is not lost and time and money are no longer wasted.

Where are doctors supposed to find accurate information for their patients if they cannot get it from the CDC? How are medical schools supposed to teach new doctors about this disease? I think lack of information along with dissemination of inaccurate information in the medical community is the biggest treatment obstacle we as patients are facing. How

can this be rectified?

It should not be forgotten that we are in desperate need of a new, far more accurate, name for this disease. It is no fun to get laughed at or dismissed for having a debilitating disease. I am sure that a large part of the misunderstandings and misconceptions that we all must face from the medical community and society at large are due to what the title "chronic fatigue syndrome" implies.

Please do what you can to speed up passage of the ICD 10 codes in Congress. This is something that will be useful and important to the medical community as a whole.

How long must we continue to waste away and wait for something to change? It is all well and good for you to pass recommendations that seem to address what we are all saying, but until your recommendations have clout and are acted upon by the leaders of the DHHS they will continue to be meaningless. I say that with a great amount of appreciation and respect for the work you are doing, yet it seems that people and organizations must come before you to address the same problems and concerns year after year. How do you plan to carry out your suggestions and maintain your relevance? Is there some sort of governing body that would be effective in addition to this advisory committee? Is there a way you could help to organize a standing committee in both houses of congress to help our needs be addressed throughout the legislative process and to authoritatively deal with problems that we face with government agencies such as the Social Security Administration and the CDC? You need help to accomplish the goals that you wish to achieve. Tell us exactly what kind of help you need to make your recommendations a reality and I am sure the patient community and associated organizations will do what they can to try to push for the resources and authority that you need. We appreciate all of your efforts sincerely and want you to have all of the tools you need for success.

Thank you for the opportunity to submit this testimony and thank you for working on our behalf to solve the institutional problems and obstacles that we are all facing.

Sarah Goodwin