

Testimony

Sarah Goodwin

My name is Sarah Goodwin, I have been disabled by "CFS" for over four years at this point. I was a healthy and active high achiever 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 27 years old. I live every day facing the reality that this part of my life and all the goals I set for myself may be put on hold permanently. I would like to remind you that the written, telephone, and in person testimony you receive is representative of the needs and demands of thousands of patients who are too ill to manage even this. I was forced to use previous testimony to this committee as a starting point for this testimony, because I was too ill to start from scratch and very little has changed.

While the recent research into XMRV and other MLV's is very exciting for researchers and the patient community, it has not changed much yet. In the event current research does not reveal a new era in neuro immune disease treatment, I hope at the least XMRV and MLV's have grabbed attention of researchers and made them curious enough about this disease that the field will be reinvigorated and the search for a cure will continue. I remain hopeful that these new discoveries are the breakthrough we have all been waiting for, but I cannot help but worry that interest in researching this disease will collapse if it does not pan out. There are many issues that still must be dealt with, regardless of how this research turns out.

- We still live with the preposterous name “chronic fatigue syndrome” as a label for our complex disease that leaves 1 in 4 of its sufferers bed-ridden or home bound or even paralyzed and tube fed. We cannot tell people what disease we have, out of concern of getting laughed at for being unlucky enough to have an incurable, sometimes deadly disease that just happens to have a terribly demeaning name derived from one of it's more minor symptoms. Few understand or believe us, even with a lengthy explanation. Concrete steps must be taken by authorities to implement a new, more medically appropriate name, or to revert to the original name for CFS, Myalgic Encephalomyelitis (ME). ME has been classified as neurological disease by the World Health Organization since 1969, and in a recent talk, Harvard Medical School professor, Dr Anthony Komaroff thought ME was indeed a more accurate name than CFS.

- There are literally a handful of knowledgeable doctors in the United States for a patient base of at least 1 million. No proven treatment options exists, and there is no cure. In the US, if a patient wants any chance to stop the progression of their neurological disease, they often have no choice but to travel thousands of miles to private doctors with no guaranteed outcome. If they cannot find a way to afford this or borrow money they may never be able to repay, and are by default halted in their tracks. Insurance can claim that any treatment or test for CFS is experimental and deny access to this treatment as long as the the CDC continues to claim there are “no tests” and “no treatments”, without making any honest effort to find tests or treatments that are effective.
- Our public and private disability claims are still being unjustly denied, or delayed for an unnecessarily long series of appeals. Until our government begins treating this disease as seriously as it deserves to be treated, this injustice will undoubtedly continue.
- Medical schools are still not adequately training doctors to diagnose, never mind treat us. Medical schools do not even have the staff capable of accomplishing this. In this environment- even understanding and accepting what this disease actually is is impossible. Please refer to Dr. Kenneth Freidman's recent presentation at the NIH state of the knowledge workshop on ME/CFS. Medical schools in the US and other countries remain a hostile place for some researchers who are interested in studying this disease. What hope do we have that interest in this field of study will ever grow, or that new doctors will be trained, when researchers and doctors are facing such blatant institutional discrimination? How will this be rectified? The primary symptoms of CFS and ME are: Permanent muscle weakness and exhaustion, Chronic Pain, Cardiac and breathing problems, Autonomic Nervous System Dysfunction, Neurological symptoms (convulsions, numbness, blurred vision, loss of coordination, cognitive impariment etc). With the label of 'CFS' we are offered a management strategy of exercise and behavioral therapy, along with treating minor symptoms- according to the CDC guidelines. We patients know that innovation is not going to come from the CDC, it is going to come from private researchers and it is extremely disheartening to hear they are being blacklisted by their institutions. Experts in CFS are scarce, and many are nearing retirement age. Will there be any government efforts to encourage medical students to consider this field, or to provide them with texts or instructors that can give them accurate information on their future patients? At the very least, will there be any effort to prevent discrimination against researchers for their activities involving CFS?
- We have no government- sponsored centers of excellence to look to when we

need treatment This is a critical failing in disease management and one that the CFSAC has been pushing for many years. How can we make this happen? Why must we keep going over this year after year only to see it never actually happen? There are government sponsored centers for other diseases that they could be easily modeled after, and the shortage of physicians available to treat this disease is currently staggering and inexcusable.

- William Reeves may be gone from the CDC, but the flawed research definition and the faulty research done with that flawed cohort remain. All of the researchers selected and hired by Reeves are still at the CDC conducting the same kinds of studies with the same erroneous research definition. How can we fix this problem? Or rather, how does the CDC intend to fix it? Elizabeth Unger, who despite voluminous and vocal patient opposition has been appointed head of the CDC CFS research program, asserts that this definition is fundamentally sound and so is the research conducted under this definition. The majority of CFS researchers, including those in other sections of DHHS- disagree with her. Continued research using this definition is a colossal waste of money, and only serves to set the science back further. A definition of this disease that insists upon post exertional malaise as a hallmark symptom, such as the Canadian Consensus Criteria- created by an international group of researchers, must be adopted. As long as research is being conducted on a heterogenous population that is not comprised entirely of what most specialists would call CFS patients, we are doing nothing but wasting taxpayer money and time that we don't have.

Is the CDC still contracting out research into this physical disease to the Emory University psychiatry department? Does the CDC intend to update it's five year plan based on new information? How does the CDC plan on funding the goals laid out in this plan, when we are not very far into their timeline and already they have not been able to meet the goals they have laid out for themselves?

- Our doctors are still receiving this inaccurate research with the seal of approval of the CDC, and as a result, we are still suffering the consequences of the CDC's past research. Where should we be sending our primary care doctors for information if they cannot trust the CDC? Why is the CDC program being conducted in such a way that patients themselves must bear the burden of educating their primary care doctors with research sponsored by the NIH and private entities?

- We remain shocked and dismayed that the NIH budget is still directing exponentially more resources to health issues such as erectile dysfunction than it is

to this chronic, disabling disease, especially when we see what the funding levels of diseases with similar disability levels and prevalence rates are. We are getting less than 2 dollars per patient per year, is that what my life is worth to the federal government? NIH, you should be ashamed of yourselves! You could increase the CFS research budget 10 times over and it still would not match the funds going to solve other complex, disabling and potentially deadly diseases like Parkinson's and MS. It has been argued that until recently there was not enough proof that this was indeed a disabling condition with a physical cause, but thousands upon thousands of published papers dating back to the mid 80's say otherwise. It is not our fault as patients that this research was ignored and in some cases buried or dishonestly refuted by government officials and scientists. Patients could only watch with dismay as we were told money from the economic stimulus package would be available for additional research funds at the NIH, only to see (to the best of my knowledge) none of it earmarked for CFS research. Now, we will surely be told there is no money for any new projects due to budget cuts. Well, cut some of the funding for diseases that already have cures and move it into funding for CFS research. There is no good excuse for not doing this.

- We deserve better than what we are getting, and we have deserved better for an inexcusably long time. I have only been sick for 4 years. I cannot help but wonder: if the government had treated this as the serious, disabling and life destroying disease that it is when they first started dealing with it, would I have ever gotten sick? (Would I have known how to prevent it?) If I had still gotten this disease would there be a cure or at least effective treatment ready and waiting for me?
- This disease deserves an unprecedented increase in funding across all relevant agencies to make up for lost time. We cannot just have funding levels similar to those of other chronic disabling diseases, we need funding to make up for being unforgivably ignored by government research funding mechanisms for the past 25 years. The committees approving these grants need to be comprised of scientists and doctors who have a concrete understanding of CFS, instead of including dentists and psychologists who have no idea what they are looking at. There is no excuse for the grant approval rates for research into this condition, and the time for excuses passed long ago. If that means going above and beyond the normal review process, as was done when HIV was first taken seriously by the government, then so be it. We need real research into finding a cause and finding a cure. We need research that employs accurate definitions of this disease. We need research grounded in the fact that this is a severe, life altering physical disease, and not based on the specious supposition that this is some sort of post-modern character flaw, or an artifact of supposed childhood abuse. If, after all this back and forth,

CFS turns out to be a communicable disease caused by a retrovirus, the blood will be on the hands of the DHHS, NIH and CDC, not on the hands of patients who have been unwittingly spreading a retrovirus throughout the population for decades.

So, the time to act is now. This committee is more essential now than it ever has been, we are not out of the woods yet and we will not be for some time. Due to our disability and marginalization from society and the medical system, we are unable to consistently advocate for ourselves. Due to the laughable nature of the name “chronic fatigue syndrome” we are still politically untouchable and invisible. When it comes to representation of our interests in Congress and to government agencies, we remain as disenfranchised as ever. I went to school for political science and social science, and I thought I knew a lot about how government worked, and when to trust the government and when not to. I wasn’t in any way naïve, I didn’t always agree with actions the government had taken, but at the end of the day I was still proud to be an American. Getting this disease has taught me more about my federal government than I ever could have learned in school, and getting this disease has made me more ashamed of our government than I ever would have thought possible only a few years ago. If you had asked me then if I thought that contracting a disease could change how I felt, I probably would have laughed. It will take more than token gestures to regain the trust that I, and so many others, have lost in our government.

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. I sincerely urge every member of this committee to reach out to every legislative contact you may have and impress upon them how urgent this situation is, and how many of their constituents are affected. We too can write to our representatives, but there is an urgent need to have what we are saying backed up by experts, be they government officials or not. 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.