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Committee Chair and members, Thank you for allowing me to give my testimony today.

My name is Robert Miller and I am a CFS/ME patient. I have remained ill for over 20 years, due largely to the complete Failure of the CDC to do its part for this patient population.

CDC stands for Centers for Disease Control and Prevention, of which it has done neither, Control nor Prevent this life destroying illness. I am for the most part Chained to my home due to CFS/ME and dependent upon my wife and twin 8 yr. old sons.

I put my trust and faith in the CDC to move CFS/ME research forward in a timely manner, much in the way the NIH had done for my deceased sisters who were born with cancer over 45 years ago, and my elder brother who died from testicular cancer after a 9 yr battle. All of them took part in cutting edge research and treatments, my sisters in the 1960's at Sloan Memorial Hospital, a true "Center for Excellence" my brother at Baptist Hospital in Miami. Those cutting edge treatments benefited my sisters, as well as the thousands of children who came after them, and it gave my brother 9 years of life allowing him to see his daughter graduate.

I believe I am doing my part to further the science of CFS. I have given blood, muscle tissue, spinal fluid and a lymphnode to further along research in CFS/ME. I have volunteered in two FDA approved drug trials to test treatments.

With all due respect to this committee, and I am humbled by your dedication to help us all with CFS/ME, I believe it's time to make very substantial, "life changing" recommendations to the new Secretary of Health, for the million patients like me who have faced the same stonewalling by our federal agencies for 25 years.

First: You will hear at today about the CDC's "CFS Strategic Research plan". I will tell you what I told the cdc at their April meeting: No matter how much money is allocated to this program, it will fail until the head of this program is changed. We need to attack this illness with a New Attitude and a New Commitment, We need to do what is best for the CFS/ME community and Replace Dr. Reeves as the head of this program.

I am appalled by Dr. Reeves lack of Urgency and leadership, not just this year, but for years past. I have attended CFSAC meetings in which Dr. Reeves does not have the respect nor decency to stay and listen to the testimony of CFS/ME patients, who have scarified much financially and suffered physically to attend to give a 5 minute testimony.

When it's time for public comments Dr. Reeves Runs out of the meeting.

Recently I attended the 2009 IACFS conference in Reno, NV, where top researchers, doctors and patients from all across the globe gathered to present, share and listen to the latest science and research on CFS/ME. Dr. Reeves was not there.

How can this happen? How can the head of this program NOT attend one of the most important conferences being presented? How can he Not be presenting? This is total failure. We need the CDC to have a CFS Program Leader that can think out of the box the way the CDC was forced to do with HIV and that leader needs to be dynamic and energetic with a sense of urgency matching the needs of our GFS/ME community.

Second: Funding must be a top priority at the federal agencies. Leadership has changed. New leaders who actually believe in science have a mandate to make change, but they need you -the only federal board of experts on CFS/ME -to call for bold investments quickly. We need you to make the following recommendations to the new Secretary of Health:

- The Secretary require its agencies to budget \$100 million in the first 2 years of the new administration to CFS research,
- and within that, NIH be required to fund 500/0 of the grant~ proposals submitted to their institutes, until they reach a~ meaningful funding level~
- that CDC be required to provide access to it's vast store of data to all CFS researchers and Clinicians world wide
- that the FDA approve Ampligen, the one and only drug to complete Phase 11I FDA approved trials which has shown efficacy and safety. After more than Ten years of late stage study, yesterday the FDA once again stalled the approval due to Quote:" the delay was attributed by the Agency to certain staff

scheduling changes which might (or might not) delay the report.

- FDA be required to solicit applications for treatment of CFS

Lastly, That the Secretary call for federally funded Centers for Excellence devoted to CFS/ME. There is such a center being built as we speak, with private and state funding. Federal funding would slingshot this Center into results for us all with CFS/ME. It is The Whittemore Peterson Institute for Neuroimmune Disease in Reno, Nevada.

We would not be able to say today that we can cure or treat many cancers without centers like Sloan Kettering and the National Cancer Institute. The CFS/ME community will not be able to celebrate diagnostic markers, treatments or patients returning to work without sophisticated Centers of Excellence which merge clinical and scientific research to discover what ails us.

We're investing billions in our country's infrastructure, including science. We could save billions, as much as \$20 billion annually, if we seize this moment to devote real funding to the science of CFS/ME, and we could return to productivity and back to work.

I still have hope to change the course of this illness, in fact I demand it, but we need our federal agencies' full support. We are doing all we can, Advocating, Donating, Lobbying and Volunteering, but we need you our Panel of Experts to guide the Secretary of Health.

Thank you!