Testimony by Robert D. Miller

October 13th, 2010

CFSCA

Good Day, Mr. Chairman and committee members. I am Robert Miller and I want to thank you for listening to me today.
I am here to present patient requests and concerns we delivered to Deputy Director Dr. Gottesman of the NIH on September 7th, 2010.

First: We are particularly grateful for the work of Dr. Lo and Dr. Alter for their XMRV publication in PNAS.

I have attended this committee for several years now and given my story. I have had CFS for over 25 years, which is the time it has taken the NIH to get to this point of confirming the XMRV link to CFS. And still, we are only at the beginning of understanding a retroviral role in our illness.

INTROS: Next

1. Trust Building: The PNAS paper was critical in confirming the Science study last fall which identified a retroviral association with CFS. But the fact that it almost wasn't published, that it took an outcry from patients and scientists some I suspect sitting here today, and that the NIH almost let the CDC prevail again, after 25 years of failed CDC studies, is frightening to us patients.

    a. Even with the first XMRV conference sponsored by NIH on Sept. 7th, the researchers that found the XMRV association in CFS were not going to be invited to speak until patients protested.

    b. So, a group of patients presented this petition (XMRV: Allow Science to Progress) to the NIH, even though it was after the study was published, because the 1016 patients who signed this petition(http://health.change.org/petitions/view/xmrv_allow_science_to_progress) , and many more viewing us today want the NIH to know we are watching the NIH's commitment to scientific progress in CFS very closely, and that NIH/HHS has to build up some trust as our federal health agency in this patient population.

    c. We delivered a second petition(http://apps.facebook.com/causes/petitions/409) from P.A.N.D.O.R.A. (PATIENT ALLIANCE FOR NEUROENDOCRINEIMMUNE DISORDERS ORGANIZATION FOR RESEARCH AND ADVOCACY) with nearly 1600 signatures requesting a

meeting with Secretary Sebelius to address the lack of funding for CFS/ME, and related illnesses.

2. Funding.
3. On funding, As all on this committee know all to well, NIH's record of funding CFS research is near zero. Less than $2 per CFS patient per year and that is being very kind. So patients ask this committee to give Secretary Sebelius a specific request to allocate at least $100 million dollars over the next two years to researching CFS, especially the family of retroviruses that have now been identified.

    a. I've heard years of excuses at these CFSAC meetings from NIH representatives that not enough fundable proposals make it through their process. We know that right now they have a stimulus budget. We Say "Build it and They will come". There is a huge opportunity right now to attract hundreds maybe thousands of proposals on this illness, and you our representatives need to be aggressive about requesting the funding. That means changing the "Norm" we must change a useless process and expedite the way proposals get reviewed (Reviewers on the Panel) and studies get funded in CFS, just like they did with AIDS. The CDC's failure and 25 plus years of foot dragging are over and NIH/HHS must make up for that time. My time and every patient who has been "Chained" down by this illness Deserves and Expects an Accelerated Renewed Process to begin Today!

    b. There are many lessons from the AIDS epidemic that were published and presented by NIH. [shown in the report]. One lesson is that funding early saves money in the future and certainly could prevent the spread of a debilitating virus. The book that gives an account of the politics behind HIV in America "And the Band Played On" describes Dr. Don Francis then at the CDC, was turned down for $33 million in funding when he was desperately trying to prevent the spread of AIDS in 1985. That lack of early funding for HIV prevention cost the U.S. government $$$ Billions of Dollars later while addressing the HIV/AIDS epidemic, which we are still fighting today.

4. We would not be here if the privately funded Whittemore Peterson Institute had not identified the connection between XMRV in cancer and the immune problems (RNASE L defect) in CFS patients. They had to know CFS patient histories to figure that out. That is why it is Key to have doctors like Dr. Daniel Peterson, Dr. Nancy Klimas, Dr. Antony Komaroff and others here working with NIH researchers. We need CFS Centers of Excellence funded by NIH – as recommended by this CFSAC committee for years.

The WPI should be funded as our very first one, and you need to request for other Centers in major cities to happen Now.

4. NIH and FDA need to drive a clinical trial process for treatments with the end goal of making safe and accessible treatments available as soon as possible. We are already experiencing the AIDS-effect of patients self-medicating with very serious medications, such as antivirals and antiretrovirals, because many of us are so desperately sick and there are no alternatives for CFS patients - none.

a. I have told you prior of my participation in the only clinical trial approved by the FDA for CFS, the Ampligen (AMP-516 and AMP-511) study. I was on it 10 years ago, And I improved, the data showed efficacy and if it were not safe then please Dr.Cavaille explain how it has been available to "Paying" patients for over years, but still the FDA denies approval. After living in the DC area for 5 years, I had to up-root and move my family (Wife and 10-year old twin sons) back to Reno, so that I could access Ampligen again, but yet To This day, I am still one of only a few patients with access to Ampligen. There is no excuse that there is only one trial in one city in the whole country to access the only treatment available. NIH needs to seed this process quickly, so patients have faith that FDA trials will bring them relief. The alternative is chaos like the early days of AIDS.

5. Lastly, children with CFS is a very troubling issue. Many recommendations have been made by this CFSAC to address the obstacles to real pediatric care and coordination with educators and law enforcement. Children with CFS have to be part of the science. The PNAS study also compels us to worry about passing this living torture on to our children and spouses, and to worry whether every childhood cold will trigger what I have. What would you do if it were your child? We need Action on all these issues Now.

While I am angry that it has taken decades to get here, I Still have Hope, Because, We are sitting here today, just after the First XMRV Conference and because the NIH has confirmed a breakthrough. Your perseverance and Backbone can help give us our lives and "Break These Chains".

Thank you for allowing me to speak here today,

Robert Miller.