Robert Miller

05/10/2010 Testimony to CFSAC

Committee Chair, Members, Dr. Jones and staff Thank you all.

My name is Robert Miller and I'm a CFS/ME patient. I 've been ill for over 20 years now.

I'd like to thank the Assistant Secretary of Health Dr. Koh for attending our meeting, it's the first time in over four years of my attending in which we've had the Secretary of Health or the Assistant Secretary attend and I hope that Dr. Koh will follow CFS/ME and CFSAC closely as prior administrations have failed to give this patient population of 1 to 4 MILLION people the medical concern that we deserve .

I also want to thank the Secretary of Health for undoing the neglect we faced from the CDC, by removing Dr. Reeves from the CFS program. It's the first real step our government has taken to validate my illness. I welcome Dr. Unger, and at the same time I expect the CDC to aggressively make up for the 20 years of lost time. We do NOT need more head counting.

We have a moment to seize , so be bold and fund real research. Dedicate $100 million in NIH grants to CFS researchers who have given up on federal funding due to neglect, help expand the exciting private research that's propelled the current XMRV discovery and my hope,Which is what we should be discussing here today.

You have miles to go before we patients say that our government takes CFS seriously. I was set to attend in person today, but my health prevented me. I had to move back to Reno last year, from the D.C. area to be treated by one of the very few doctors who truly knows this illness, Dr. Daniel Peterson, and to the only facility where I could return to Ampligen, A drug which has been Stone-Walled by the FDA for over 20 years. Again I ask, how is it that Ampligen has been Safe enough for patients to self-pay and use for 15 plus years, but the FDA is still asking for research on Lab rats??? That's insane. The FDA should be coordinating clinical trials for this serious illness, but it has chosen to be in the way, just like the CDC was.

As for the request from April 1 2010 re: In-put for The Charter. The problem has not been the Charter, as Clearly CFSAC has been doing their part by sending well studied recommendations to the Secretary's office. CFSAC must remain as Two day meetings Twice a year to be productive and an extension for some members is key in keeping CFSAC moving forward as Dr. Snell has suggested.

The only way CFSAC can function properly is If They Get A Response and Action from The Secretary, Otherwise, they are rendered invalid. So I suggest in the Charter that it state the Secretary will respond to all CFSAC recommendations, directly or through the Assistant Secretary. Confirm the recommendations or deny them, but there must be a response to CFSAC from the Secretary of Health. Our lives and families depend on it!

Thank you, Robert Miller