

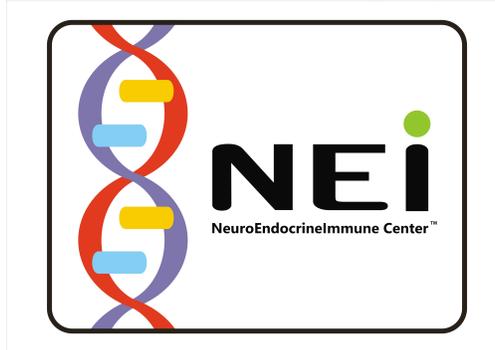


PATIENT ALLIANCE FOR NEUROENDOCRINEIMMUNE DISORDERS ORGANIZATION
FOR RESEARCH AND ADVOCACY - 501 c 3 - ID # 550795076

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TESTIMONY TO THE CFSAC MEETING OCT 29-30, 2009

Marly Silverman, Founder, P.A.N.D.O.R.A

*In Memoriam of Rachel Bray, a CFS patient, who left us on February 21, 2009, age 47,
from Scurry, Texas*

October 28, 2009

Dear Distinguished Members of the CFSAC,

I want to speak to you today about the 3 R's and it is not related to schoolwork and the tools that children need to succeed, but it is just as important. I want to speak about Reconciliation, Restore, and Resolve.

Reconciliation is needed in our overall community. For far too long the CFS-ME community has been embroiled in an unwanted and undesirable dissention with the CDC and other government agencies regarding the overall approach used for CFS-ME. This anger and frustration on both sides have obfuscated the real issues. I have witnessed contentions, misguided, inflammatory and obnoxious positions from both sides. While I can say that the anger from the patient advocacy community has been empowering, uplifting and quite necessary, I don't know how to justify what drives the other side of the aisle.

It is now upon us a new era of amazing scientific technology and knowledge that 10-15-20-30 years ago would simply be written-off as science fiction. The members of this committee are well-versed participants of this "Brave New World". There is no turning the clock back. The recent scientific discoveries regarding CFS are the lifeline that we have been waiting for a long time. It is a gift! We understand extremely well the potential ramifications if we don't too embrace the possibilities.

As we look to the past, to the present, and to the future of CFS-ME research, we have witnessed it "going down with the tubes", being marginalized, and worse yet, as it currently is, not given the monetary incentives necessary to gather and accomplish significant results compared to other illnesses. We all realize that the current scientific research studies are patient-driven. It is no wonder that the CDC, NIH, and DHHS, as well as other government health agencies will have no choice, but to deal with the real anger that all stakeholders in the CFS-ME community experience. It is unfortunate that the government does not realize we are all on this together.

The second R is for Restore or Repair. I see it as to restore the lack of trust of the patient advocacy community towards the CDC, the NIH, the DHHS and our government. The lack of trust from the major stakeholders, in the patient advocacy community, is fueled by the lack of transparency, action and results. Where did we go wrong here? When did it happen?

CFS historians go back to the early beginnings during the Incline Village, Nevada outbreak. They point out to the CDC's handling of such outbreak as well as the one in the state of New York. While I have been told that the name choice for CFS was well intended, and I don't question that with malignant fervor. However, for patients the emotional, physical, financial and professional beatings are not getting any better. In fact, it cannot be hidden that the name of CFS carries a connotation not found in other major illnesses.

I speak of experience. I am a CFS patient. The two major CFS-ME outbreaks I mentioned were long before I fell ill. But they have certainly affected my life. Then, I was living life to its fullest and the world was mine to see, enjoy and conquer professionally and personally. It was in 1997 when I fell ill after an African Brazilian bee bite that almost killed me, followed by a viral infection that lasted more than 8 months, followed by a hit-and-run car accident. I never recovered from the viral infection. The car accident made it even worse. It was the beginning of a scary personal journey. I never quite pictured seeing me turning CFS patient, disabled, patient advocate, finally leading me to develop PANDORA. That was not part of my plan.

But the important point to drive home is that it does not matter to patients who started this mistrust. We need to put it behind us. It belongs in the past. But before we do, we need to talk about it. We need reconciliation. As I stand here in this room. I can feel the tense energy. It is not healthy. It is the 800 lb gorilla in the room that everyone pretends is not there, and hopes to avoid. He is staring at us, not only making us uncomfortable but also threatening us, menacing the relationship that

should exist between citizens, researchers in the CFS-ME field inside and outside of with our government.

Now with the recent scientific findings of the XMRV virus and its correlation to CFS-ME, and as well to prostate cancer, the prime opportunity to repair the wrongs that were committed a while back are here. We can all learn from our mistakes! We must all be open to the possibilities that this discovery is an exciting piece of information that needs to be aggressively and assertively investigated by the CDC and other members of the overall scientific community. As a patient, I no longer want to hear that "science takes time". This paradigm no longer applies to a "brave new world". I don't want to hear from CDC officials that they "will not probably be able to reproduce" the finding from the Whittemore Peterson Institute.

The CDC and the other governmental agencies represented in this committee need to approach this opportunity (I understand), with guarded optimism, but not sheer skepticism. We don't want the CDC to repeat the same mistake that it did years ago back in 1991, when another virus was also discovered by Drs. Elaine de Freitas, David Bell and Paul Cheney. According to CFS historians the CDC did not use its body of scientific resources to move that forward. Was it lack of funding? Or was it simply lack of strong will and or perceived attitudes and biased towards the patient population? Was it simply lack of knowledge of the new science?

Here is the opportunity for our government to right a wrong of many years ago. We want the CDC and other health government agencies, to view the latest scientific findings of the XMRV virus, as an opportunity, as a bridge to what is yet to come for the fascinating field of CFS-ME research.

Which then leads me to the third R, which is Resolve. We want to see a strong resolve from our government in getting the job done. It is time for change in the CDC. It is time for the leadership at one of the most prestigious health agencies in the world to do its job in a fashion that is truly state-of-the-art cutting edge by 21st century standards on CFS-ME. It is incumbent on the CDC to aggressively address CFS scientific research. We have all been playing this game for way too long - at least a quarter of century in the U.S. For reasons that many, including myself, in our community of suffering clearly do not understand is why has the CDC and other health agencies been so slow to elucidate the physiology and pathogenesis of CFS?

I am sick and tired (punt intended) of finger pointing as well as of long-winded tiring excuses from government health agencies officials. P.A.N.D.O.R.A.'s mission is geared to more than anything else to be part of the solution. I am sure other research and patient advocacy organizations feel the same way. It is time for the CDC and other government health agencies to actively work towards the same goals, with the same speed, tenacity, courageous, and more importantly resolve that we find in the patient community and in the dedicated researchers outside of the CDC, and outside of our government, so my generation and the ones behind me, can have the opportunity to regain their health and lead productive lives.

Lastly, we are also in the middle of flu pandemic. Is the CDC keeping tabs of the folks who are getting very sick after a bout with the flu? Whether they are progressing to CFS?

I am delivering to you a petition created by Tom Kindlon, a CFS patient advocate colleague. His petition addresses the problems created by the current empirical CFS definition used by the CDC. As of yesterday, there were 1, 893 signatures in this petition. The comments are an eye-opening account of the diversity found within the patient community. It could be a tool for potential CFS research.

I look forward to the presentation of the 5 year CFS-CDC draft proposal with great anticipation, but for now I will say it again: It is time for change. Together, we need to be One Voice, One Community, and One Cause.

Thank you!

**Marly Silverman
Founder, P.A.N.D.O.R.A.
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