

## Testimony

### Marly Silverman

Dear Distinguished Members of the CFS Advisory Committee,

I once again thank you for the opportunity to address this committee of behalf of PANDORA. My testimony today is in honor of all who have died while suffering with great despair from this NeuroEndocrineImmune Disease and I will remain in mourning- wearing black as I make my presentation, until we see progressive results from our government.

For some of you whom may not know me, I am the founder of P.A.N.D.O.R.A., a small grass roots charitable organization dedicated to restoring quality of life for individuals with ME/CFS and other NeuroEndocrineImmune diseases. While our budget has averaged less than \$50K in the past 3 years, our outreach programs are of national and international scope.

The message PANDORA would like to share with you today is:

We are no longer invisible.

Nós não somos mais invisíveis.

Ya no somos invisibles.

Nous ne sommes plus invisible.

Nou pa envizib.

Non siamo più invisibili.

Wir sind nicht länger unsichtbar.

We zijn niet langer onzichtbaar.

I apologize if my pronunciation is not good for some of the languages spoken here. Yes, there is sense of urgency in what I say. There is also a sense of anger and defiance represented here. No matter what language I

speaking, the message I want to convey is: **We are no longer invisible.** This is a message that is resonating loud and clear across our community and I am here reminding you of this fact.

PANDORA urges you to continue to pursue and recommend a comprehensive and prioritized approach by the Department of Health and Human Services through the NIH, CDC, AHRQ, HRSA, and other agencies, for substantial, aggressive, assertive, generous and coordinated funding that will advance the current science body of knowledge for ME/CFS.

As Dr. Baraniuk suggested at the April 8, 2011, State of the Knowledge (SOK) of the Science of ME-CFS Workshop Meeting – “We need a Manhattan Project”. Our director of Public Policy – Dr. Kenneth Friedman, has suggested similar approaches through his essay “Fish or War” and more recently as he shared at the SOK meeting, on his “Elephants in the Room” presentation.

Both suggestions are pro-active approaches and after all these years that I have been coming here and providing personal testimonies as well as on behalf of PANDORA, I cannot shake that nagging feeling of “déjà-vu”.

As far as the NIH – While PANDORA appreciates Dr. Dennis Mangan efforts in getting the State of the Knowledge (SOK) of the Science of ME-CFS Workshop Meeting, the April 7-8, 2011, in place and we hope this is just the first of many more similar future meetings. It was painfully obvious that the theme that rung loudly at the SOK was – LACK OF FUNDING. No wonder because without any money, without any funding - the catching up to the science that already exists in so many other diseases and are required to create scientific breakthroughs are not in place for ME/CFS. We all know that funding matters to the ME/CFS patient, researchers, medical providers and to the family members of individuals with ME/CFS. Yet our health government still lacks in the commitment that is required to move the knowledge of the science of ME/CFS.

I am wearing a button today that reads “I am worth more than \$3.64”. The button reflects the annual amount current spent by the NIH on each ME/CFS patient. We are grateful to Mrs. Pat Fero, who was one of the patient representatives at the SOK meeting and shared this eye opening information in her presentation. We also express to Mary Schweitzer for her presentation about the damaging policies by the CDC and the challenges that have

prevented this patient community from thriving and living normal lives.

The DHHS/NIH/CDC policies, approaches to research and funding allocations for ME/CFS over the last thirty years have been woefully inadequate especially in comparison to other less devastating or less common diseases. The economic impact of ME/CFS, based upon the combined estimate of lost productivity, the cost of tertiary care, and wages lost to disability, annually is a staggering \$23 Billion dollars per year. Sources: NIH, NIAMS, CDC, Leonard Jason *et. al* (DePaul University).

We ask that this committee places its powers and strongly recommend that the NIH use their mighty resources to **immediately pursue** and **implement initiatives** that will implement research and clinical trials in “centers of excellence” or “collaborative research networks” for ME/CFS.

The NIH must catch up with the science and technology advances that were reported at their own ‘ME/CFS State of the Knowledge Conference’ held in April of 2011. These advances demonstrated the very real possibility of breakthroughs in the science of a ME/CFS that will follow when funding is provided.

The "budget restraint" or "no money in the budget" approach has been responsible for the "state of the knowledge of the science" of ME/CFS as we know it. The approach of "not having money in the budget" has been an approach we patients have endured for the past 30 years, even at a time of great prosperity in the U.S. and during a time when Congress increased overall budgeting for the NIH in at least 23% from previous years.

As far as the CDC:

We ask you that you require from the CDC the immediate take-down of its web site pages where they are stating that ME is not CFS and that they are two distinct separate diseases. We also ask the same be done for the pages where they advise primary physicians the steps they should take on medical tests and diagnostic tools as well as potential medical treatments. The pages information are confusing, troublesome and If I can add a personal insight, it is an emotional beating having to read the type of information that is currently on the CDC pages. These pages are a travesty. Our organization backed by ME/CFS researchers’ positions, believe that the CDC past , current and future approaches have not worked and are not working. It is time for a change!

The information contained in the CDC web site is confusing to the scientific community and even more so to the patients. It does not contribute to patient's quality of life. Quite contrary, it perpetuates the "psychobabble" that hurts patients and their families. ME/CFS is real. ME/CFS is brutal. The direction that the CDC is now taking is unacceptable and problematic. We once again share with you that patients, scientists and other ME/CFS experts have expressed that the CDC overall approach is resulting in a "waste of time and effort"

PANDORA expresses similar observations. PANDORA feels that these resources should be applied more effectively by investigating the biological and complex physiology that ME/CFS brings to the table. Simply put, stop wasting taxpayer's money. ME/CFS is not a mental health condition as the CDC is suggesting it.

While we look forward to meeting on May 26 with Dr. Beth Unger and her team, we nonetheless would like the CFSAC to be more assertive with these issues and require more of the CDC CFS program.

There are many issues that we have concerns in which this committee needs to attend and to address in the months ahead:

- Name definition and criteria – Pediatrics and Adult ME/CFS definitions
- ICD-10 (WHO) and ICD-10-CM
- APA-DSM
- Follow up on the SOK meeting potentiality

The needs of the ME/CFS community are large, complex, and time-consuming but they are not unreachable. It will take commitment, compassion, passion, purpose, innovation, creativity and mostly important – FUNDING – FUNDING – FUNDING.

This must be your focus. This is our focus.

Thank you for the opportunity to address you today. Thank you for all that you do.

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