

The following is the testimony given by Marly McKibben to the Chronic Fatigue Syndrome Advisory Committee on March 22nd in Washington DC.

Dear Members of the CFSAC:

I am grateful to be able to travel to Washington DC and speak to you on behalf of P.A.N.D.O.R.A., Inc. – Patient Alliance for Neuroendocrineimmune Disorders Organization for Research and Advocacy I am also honored to be able to speak on behalf of the following groups:

- The Chronic Fatigue Syndrome & Fibromyalgia Empowerment Group at Memorial Hospital West, Pembroke Pines, Florida;
- The Chronic Fatigue Syndrome & Fibromyalgia Empowerment Group at Temple Shalom, Pompano Beach, Florida
- The Chronic Fatigue Syndrome & Fibromyalgia Empowerment Group –Clay County, Florida
- The Miami Coral Gables CFS/CFIDS Fibromyalgia Support Group, Miami, Florida
- “The Non Group” in Broward County

I am bringing, good wishes and sincere gratitude from the south Florida Neuroendocrineimmune Disorders community. I hope to be able to effectively convey the concerns people with Neuroendocrineimmune Disorders have as they battle such an insidious illness.

First, let me say, I am sincerely optimistic about the CFSAC commitment to accomplish the tasks assigned. I sincerely believe this committee has in mind the well being of all Chronic Fatigue Syndrome patients. I also know the committee will be facing many

difficult issues. The road to a final consensus and the creation of national policies for Neuroendocrine-immune Disorders will be a bumpy one.

As a patient advocate, I am here, with some guarded concern from my physicians and at perhaps at a serious cost to my health. I did it, because I know how crucial the work of the *CFSAC IS TO THE NEUROENDOCRINEIMMUNE DISORDERS COMMUNITY*, and as such to me as well.

The items I am presenting, you may have heard before, but it is important to repeat them because if you hear the same message again and again, it will be loud and clear. I respectfully ask this committee for a future feedback related to these issues.

They are as follows:

1) PROCEED IN CHANGING THE NAME OF CFS. Chronic Fatigue Syndrome is not a good “brand” name. Simply put, there are many health conditions afflicting mankind in which, you will find “chronic fatigue” described as one of their major symptoms.

I am using the term “brand”, merely because I believe “branding” this condition with the name “Chronic Fatigue Syndrome” is incorrect. It is misleading and confusing. “Branding is a well-known practice in the business and marketing world. It is the way to send a message, to be recognized by the masses or by the targeted audience when one mentions a product, a concept or a service.

The term Chronic Fatigue Syndrome does a poor job in describing the illness. It does a poor job in inspiring respect and credibility towards the patients. It does not truly reflect the overall symptomology of the syndrome either. Subjectively, it does not even promote the impetus to find a cure, simply because the main

symptom described by the condition is a symptom that everyone in this country, will at one time or another experience. Let's face it, we are "tired and fatigued nation". But for a CFS person to hear someone say "Well I am tired and fatigued too, I must have CFS", it does not ring true and it trivializes the condition.

It is disturbing because of overall lack of knowledge about CFS and the lack of a "good brand name" in this country, patients are being inflicted with the "collateral side effects"- a term the majority of the members of this committee are quite familiar with and therefore are aware of the implications.

If you don't do something to correct the situation, you will be seen as willingly allowing this situation to go on.

Current research is showing that CFS is a condition that affects the neurological, endocrinological and the immune systems. You have enough current research to support a name change. P.A.N.D.O.R.A. requests you not to abandon the Name Change Work Group to a dusty file cabinet.

There are many issues I have seen over the years be discussed at CFS support groups meetings, chat rooms and at patient conferences. I have also seen important issues addressed by national and local CFS/CFIDS organizations, which are extremely important, but the NAME CHANGE ISSUE IS THE NUMBER ONE ISSUE every patient wants to have addressed by the committee. Please address it immediately.

The caliber of your committee is superb. I trust and sincerely believe the CFSAC is made up of individuals who are highly qualified to come up with a viable national solution. Please do not fall into the trap that tackling the issue of the name change requires additional time and additional research. In the contrary, P.A.N.D.O.R.A. believes by "branding" CFS with a more suitable

name it will easily cause research to increase, and ultimately a cure to be found.

P.A.N.D.O.R.A. also believes that if you don't do it NOW, you will disenfranchise the entire Neuroendocrineimmune Disorder/CFS community from your efforts. Although not listed on the mission description of the CFSAC, I can safely say one of your "collateral duties" is to energize and unify this community. One sure way to do it is by working on a name change. If you are able to accomplish such task, the establishment of national guidelines and national policy will be very successful indeed.

On behalf of P.A.N.D.O.R.A, I request you give top priority to the name change issue. Much effort and work was put by the Name Change Work Group. You can't discard their work. As a CFS person I am putting my trust and my confidence you will get this issue accomplished in no time.

2) Since the CFSAC is chartered to look into "(2) current and proposed diagnosis and treatment methods for chronic fatigue syndrome (3) development and implementations of program to inform the public, health care professionals, and the biomedical, academic, and research communities about chronic fatigue syndrome advances" I believe it is imperative you assign a specific medical code under an umbrella which does not allow any misunderstanding about CFS. Current relevant research shows CFS is neither a psychiatric condition, nor a psychological one. There should be no further discussion about this outdated, only hypothetical and by now quite "unscientific" thought. The CFSAC armed with current scientific, medical and clinical research has to move forward, strongly, loudly and courageously, to put an end to this travesty.

I was recently told by Ms. Rebecca Artman, chairperson of P.A.N.D.O.R.A.'s Legislative and Advocacy Committee, that

presently “there is no specific medical code or medical billing code” to be used when one is diagnosed with CFS. It is quite difficult if not impossible to acquire medical treatment. A solid example is the fact insurance companies (health, disability & long term) have the “excuse” of not providing accessibility to treatment and pay for disability benefits because according to them “*the condition does not exist*”.

But it gets worse. It leads to the automatic lumping of CFS with mental and psychiatric disorders and its exclusion on most of the disability policies issued in this country. But it does not end here. Currently ERISA employer long-term disability and private disability insurance policies are either completely excluding Chronic Fatigue Syndrome (Fibromyalgia as well) or by providing only the typical two (2) year window of benefits. If a claimant has this type of policy, the insurance companies will nonetheless deny the benefits anyway, making it financially counterproductive and less attractive to hire an attorney to fight for your rights. And the saga continues. Take for example the CFS person who might be able to re-join the work force - if that individual suffers a serious disabling relapse, he or she will not be covered because of a “pre-existing condition” clause.

Persons with Neuroendocrine-immune Disorders are then blatantly discriminated. It doesn't matter if they had paid their premiums on time. It does not matter if these benefits are part of an employer list of available benefits. The reality is when the benefits are needed the most – they are painfully denied.

Currently, the disability insurance companies are listing CFS in their policies as a “self reporting illness” implying the patient is the one in charge of such diagnosis. If the CFSAC truly accomplishes its mandates, these hurdles will no longer be encountered.

3) We request you provide us with a clear public accounting of the monies the NIH has spent on CFS research over the last 10 years and an explanation for the sharp decline in funds for the last 3 years. We have yet to see a clear report on such spending.

4) P.A.N.D.O.R.A. further asks you to form a subcommittee in order to develop policies to increase CFIDS research efforts. P.A.N.D.O.R.A would like this committee to prioritize the methods they advise for increasing the funding.

5) P.A.N.D.O.R.A. also requests you provide the CFS community with alternative ways to communicate with you. Look into bringing some of your committee meetings to major cities in the U.S. One sure way to stay in touch with the Neuroendocrineimmune Disorders community is to attend and share your message actively at the many patient/medical conferences, which occur from time to time in many areas of the country.

The CFSAC needs to do a better job in reaching out to the national and local organizations, which have a stake in your accomplishments. They may not be equal in their agenda and representation, but nonetheless most of these organizations have great impact in their geographic areas. It would be important to develop strong liaison and partnerships with them. I challenge you, as the sole governmental body created specifically for CFS matters, to generate a strong influence on the office of the Secretary of Health by addressing all of these matters. If you accept this challenge, you will unequivocally have P.A.N.D.O.R.A.'s support and appreciation.

I conclude this presentation by sincerely thanking you for the opportunity to speak on behalf of P.A.N.D.O.R.A. I invite the committee members and in particular those who live in South Florida to join P.A.N.D.O.R.A. in promoting Awareness Day for

CFS, FMS, GWS and MCS by attending our 4th Annual conference “Inspiring Hope Through Awareness” on May 14, 2004 at the Pompano Beach Civic Center, Pompano Beach, (Broward County) Florida.). P.A.N.D.O.R.A looks forward to working with you in many of the issues pertaining to the Neuroendocrineimmune Disorders community. Thank you.

Marly (Marla) C. McKibben

Founder

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