

# Marly's Story

## *The Importance of Advocacy for CFS*

by Marly Silverman

**C**hronic fatigue syndrome has many names, one of which is as a neuroendocrine-immune disorder, simply termed CFS/ME. As a patient diagnosed with CFS/ME and fibromyalgia (FM), I quickly came to the realization that advocacy would play an important role in my life. Without someone willing to stand up for an adequate and better quality of life for those with disabilities meant that I would merely be a survivor, not having the ability to thrive and succeed. I decided that someone had to be me.



I had the opportunity to meet Rebecca Artman, (my CFS-ME/FM twin), who shared a very similar vision of what needed to be accomplished so that individuals diagnosed with these disorders could fare better in their communities. July 2002 marked the official founding of P.A.N.D.O.R.A. (Patient Alliance for Neuroendocrine-Immune Disorders Organization for Research and Advocacy). As representatives of P.A.N.D.O.R.A., Rebecca and I have walked the halls of Capitol Hill, sharing with our congressional representatives the hurdles that people with CFS/ME experience daily. We lack research in the scientific field; accessibility to basic social services; qualified medical care and treatment; and lastly, denial of benefits by the private, corporate and governmental disability systems for our illness. The threat of these inadequacies could result in individuals even dying from untreated or poorly treated complications of CFS/ME.

As P.A.N.D.O.R.A. evolved, so did our participation in the advocacy movement, leading us to one of the most amazing recent events in the history of CFS—the *8th International Association for Chronic Fatigue Syndrome (IACFS) Conference*, a significant scientific and educational event, which was held January 10-14, 2007 in Fort Lauderdale, Florida. We sincerely believe that without the vision of Dr. Nancy Klimas, president of the IACFS, and the dedication of the conference planning committee, this event would not be as successful as it was! Leading researchers from 21 countries—Australia, Belgium, Denmark, Canada, England, France, Iceland, Ireland, Japan, Korea, Latvia, Mexico, New Zealand, Norway, Portugal, Scotland, Spain, Sweden, Switzerland, The Netherlands, and the United States gathered to exchange and share research on CFS/ME, FM and related illnesses. The 700 individuals—patients, caregivers, scientific researchers from all corners of the globe—as well as officials from the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH) attended. Specialty laboratories for CFS, Lyme disease, fibromyalgia, HHV-6, Epstein Barr virus; pharmaceutical and nutraceutical companies, non-profit organizations and advocacy groups met at this great event. Many signed up as exhibitors and donors (including To Your Health, Inc.).

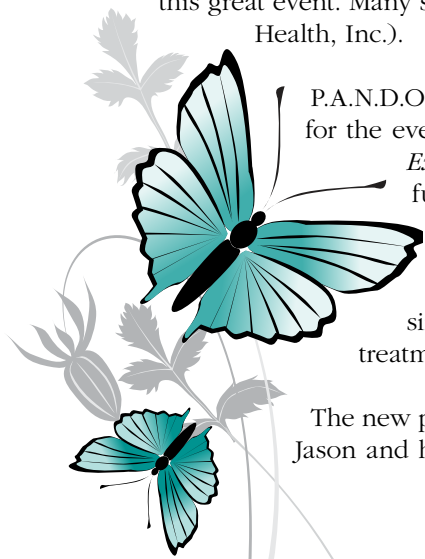
*“Ground breaking scientific announcements from studies were made in the area of brain/neurological functions, fatigue, sleep and much more. They offer new hope for CFS patients since the lack of a reliable marker has made diagnosis difficult and thus limited options for treatment.”*

P.A.N.D.O.R.A. and the CDC were the two major sponsors, with P.A.N.D.O.R.A. the local host organization for the event. We were extremely proud to the many attendees who participated in the 2007 *Advocates Extraordinaire!*© Advocacy & Leadership Training to become advocates themselves and/or further their training.

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The new proposed Pediatric Case Definition for ME/CFS for children over the age of 12, developed by Dr. Jason and his research team of international experts focuses on “children who have clinically evaluated,

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## Marly's Story *continued*

unexplained, persistent or relapsing chronic fatigue that persists or recurs for at least three months that is not the result of ongoing exertion is not substantially alleviated by rest, and results in substantial reduction in previous levels of educational, social, and personal activities". Parents with children and teenagers diagnosed with CFS now have an additional advocacy tool and P.A.N.D.O.R.A. will continue to follow this matter closely in the future.

During the conference, a side meeting composed of renowned CFS/FM scientific researchers and physicians renewed efforts for a name change for CFS to become ME and transition the name to ME/CFS. For some advocates ME stands for myalgic encephalomyelitis (brain inflammation) and for others myalgic encephalopathy (brain damage). Both are associated with muscle pain. However, without increased CFS research funding to unlock the medical mystery of chronic fatigue syndrome and a dynamic advocacy movement fighting for an official name change, the ultimate goal of finding a cure will remain difficult.

If you're interested in becoming an advocate or want more detailed information on the conference, visit P.A.N.D.O.R.A.'s website at [www.pandoranet.info](http://www.pandoranet.info).



*In the fall of 1998, Marly (Marla) Silverman was diagnosed with chronic fatigue syndrome and fibromyalgia. Her personal health struggles with these illnesses made her realize the need for a well organized patient advocacy effort, which led her to found P.A.N.D.O.R.A., a 501 C3 charitable organization in July 1, 2002. P.A.N.D.O.R.A.'s mission is to pro-actively participate in finding a cure for CFS, FMS and related illnesses. Rebecca Artman was recently appointed to serve in the CCFS Advisory Committee under the supervision of the U.S. Secretary of Health, Michael Leavitt, from the Department of Health and Human Services. She now serves as an advisor on P.A.N.D.O.R.A.'s board.*

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