



A Florida-based nonprofit supporting neuroendocrine-immune disorders, P.A.N.D.O.R.A. was founded in 2002 by PWC Marla McKibben, pictured here with organization president Stephen Silverman during the fourth annual Neuroendocrine Disorders Conference. In addition to sponsoring this conference and many empowerment groups, P.A.N.D.O.R.A. addresses the everyday issues affecting people who are diagnosed with CFIDS and FM.

This author drew on her spiritual courage and business acumen to develop a **five-pronged business plan** to manage her illness and bring joy back into her life.

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From Survivor to Thriver

Full 1998 was the bittersweet mark of a new beginning for me. That's when I finally received two correct diagnoses—CFIDS and fibromyalgia. After experiencing a litany of severe debilitating symptoms and enduring 13 months of visits to various specialists, my primary physician confirmed the CFIDS diagnosis that my uncle, a respected doctor in Brazil, had suspected all along. A month later, a rheumatologist also diagnosed me with fibromyalgia.

I felt relieved knowing I was not a hypochondriac and that it wasn't "all in my head" as the disability insurance company later suggested. But, ironically, they were close. I did have white lesions on my brain, which joined other physical biomarkers (EBV, sleep disorder, hypoglycemia, neurally mediated hypotension) to create a medical puzzle. After seeing the critically acclaimed documentary *I Remember Me*, written and directed by PWC Kim Snyder, I realized my lesions were the same type described in her film, prompting me to "hire" a special team of neurologists.

Recognizing that I now had a set of

unpredictable limitations brought me to tears. I cried for the life I left behind and for fear of the unknown. But I had spiritual courage, and I knew I needed to figure out a way to face the future. So I drew on my professional skills, devised a five-tiered business plan exclusively dedicated to tackling this illness and appointed myself CEO of the enterprise. The Business of Getting Better™ focuses on medical, financial, mental health, and social and emotional wellness.

1. Set the agenda

I began by identifying the few things that I knew were still in my control. Listing short- and long-term goals and objectives, I outlined and identified necessary areas of focus. I visualized where I would be in one month, three months, six months and even years down the road. I wrote a personal mission statement committing myself to doing everything possible toward a pathway to wellness.

I adopted a multidisciplinary approach that includes my body, mind and soul in the healing process. The next step toward success was to surround myself with physicians—

“business partners” who would embrace my concept.

2. The business of medical help and treatment

This phase began with the personal task of identifying medical personnel and required treatments. I “hired” and later “fired” many doctors whom I recognized were going to be a hindrance to the business of getting better.

Fortunately, my business partners now include renowned CFIDS specialist and researcher Dr. Nancy Klimas, medical director of the CFS Center at the University of Miami/VA Hospital, and noted rheumatologist Dr. Steven Croft of Arthritis Associates of South Florida. My family physician, Dr. Walter Flesner, is also quite knowledgeable about CFIDS and FM and has an integrative approach to treatment.

My treatment includes periodical visits to an endocrinologist and an ophthalmologist, and to ensure my sexual vitality, I visit a gynecologist. I’ve also seen a sleep disorder physician. Stretching and aqua therapy remain my favorite exercises, but water aerobics can cause serious relapses. On my good days I play brainteaser games and walk with my dog, Patches, whenever possible. I practice aggressive rest on the bad days when I’m homebound.

3. The business of financial health

Although I tried, I wasn’t able to return to work, severely impacting my financial situation. I attempted to make sound decisions, but it was difficult because cognitive impairments prevented me from making the right decisions within reasonable or required time frames. Somehow I survived this dark period of financial losses.

Having previously worked as a financial consultant, I knew it was important to get a handle on finan-

cial concerns. I contacted colleagues in the areas of law, investment and family planning. Their guidance allowed me to protect my assets and to understand the disability insurance contracts of my employers and Social Security, as well as my private disability insurance. I was able to avoid some of the pitfalls of facing such a life-altering event by giving myself some financial cushioning.

I’ve shared my personal experience with many groups, and I feel good when I can help someone navigate the disability and medical insurance systems.

4. The business of mental health

Short-term memory, inability to concentrate, panic attacks caused by reactive hypoglycemia, irritability caused by unrefreshing sleep, debilitating fatigue, losses of employment and social status, and abandonment by loved ones would no doubt shake anyone’s foundation.

To deal with these issues, I hired an excellent psychologist and business partner. He reinforced the concepts I had outlined in my business plan, held me back when I exerted myself, pushed me forward when I got stuck in self-pity and embraced the genuine desire I had to move on with my life while remaining true to my inner essence.

5. The business of emotional and spiritual health

How do you fix Humpty Dumpty when you can’t even find all the pieces? How do you mend the broken heart caused by all the devastating losses CFIDS brings? It wasn’t fair, when things had been going so well financially and professionally before illness struck.

Although my son, Lawrence, gave me a great deal of support, by 2000 I recognized I needed a broader support group to help me

work through the anger and other emotions that are so much a part of chronic illnesses like CFIDS and FM.

I teamed up with Dawn Broksch of Memorial West Hospital to successfully cofound the CFS/FM Empowerment Group. We don’t call the gatherings support group meetings because we want to use a word that fulfills our mission to feel validated, to gain knowledge, to take action based on that knowledge and to feel empowered. I am sincerely amazed at how much I learn at the meetings and how much I share with others.

Two years later, I founded P.A.N.D.O.R.A. (Patient Alliance for Neuroendocrine-immune Disorders Organization for Research and Advocacy Inc.), a nonprofit organization that addresses the issues of people with neuroendocrine-immune disorders. During this journey, I found my best friend and the love of my life—Stephen Silverman. Currently the president of P.A.N.D.O.R.A., Stephen is very supportive of my efforts to find a cure for CFIDS and related illnesses. He is my rock, and he keeps me balanced. ■

Marla McKibben, a former financial consultant and fraud investigator, is founder of P.A.N.D.O.R.A. and creator of the Business of Getting Better, a five-tiered plan she uses to live with chronic illness. She hopes to eventually write a book based on the plan, which she currently uses to generate discussion during group seminars. She can be contacted via e-mail at beat-cfsfms@bellsouth.net. For more information about P.A.N.D.O.R.A., visit www.pandoranet.info.