



### How It All Started

In early 1997, I was stung by an African Bee during a business trip to Brazil, and had an anaphylactic reaction. Midyear, I had a long bout with bronchitis and later suffered a car accident

leaving a client's office. The following year, I remember struggling to accomplish simple tasks—functioning in a fog. I remember parking my car at the office garage and later could not remember where I had parked it. How could it be?

I would fall asleep at the wheel while driving on the expressway. I would drive and not remember where I was heading, stopping on the highway feeling lost. I would look at the traffic lights not knowing if the color meant I should stop or go. (Later I found out I was suffering from a cognitive impairment typically found in Neuroendocrine-immune Disorder patients)

I ached all over. Long hours of night sleep would not prevent me from waking up feeling unrestored. I experienced unrelenting, debilitating fatigue, the kind that normal rest would not help. Sore throats, low-grade fevers and cold sores in my mouth were the norm. I had yeast infections and suffered from irritable bowel syndrome. I experienced unexplained, painful nauseating headaches that at onset would require me to lie down or rush to vomit. I was now at my all-time lowest weight—99 lbs. on a 5'5" frame!

### Searching for Answers

As an AVP—International Financial Consultant, representing a bank in Brazil and Portugal, I traveled 9 to 10 times during the year. Because of my physical condition, eventually my employer questioned my performance and told me...“It's only stress from such a demanding job. It's all in your head. Learn to relax”. Unfortunately, reading self-help books didn't help. My increased exercise routine, only worsened my symptoms.

I remember asking myself, “Why am I so tired all the time? Why do I hurt so much?” Consulting with my family physician and other physicians didn't provide any answers. Meanwhile, my uncle, a respected physician in Brazil, had a long heart-to-heart conversation with me. He suggested I discuss and ask about chronic fatigue syndrome (CFS) with my doctors.

### The Diagnosis

My family physician confirmed CFS, also known as chronic fatigue immune dysfunction syndrome (CFIDS), myalgic encephalomyelitis (ME). He told me that [it] affects more Americans

than Multiple Sclerosis (MS), AIDS or lung cancer. I was very fortunate to become a patient of Dr. Nancy Klimas, Medical Director of the CFS Center at the University of Miami/VA Hospital in Miami, Florida. I was also referred to Dr. Maria Gutierrez, a rheumatologist, to make sure I didn't have an unusual rheumatological condition. She diagnosed me with Fibromyalgia, (FMS) as my symptoms met the criteria set by the American College of Rheumatology 1990 classification.

### Getting Better

During the months following my diagnosis, I felt an overwhelming feeling of despair and abandonment. Here I was at the peak of my professional career, at age 43, going home on long-term disability. My employer decided not to accommodate an employee with a highly misunderstood condition. Senior management said it would create legal precedents. Human Resources Department stated that I had no choice in the matter.

It was confusing going through the disability maze. Strange forms had to be filled out and completed. Here I was a college-educated woman, with an above average intelligence, experiencing difficulty in completing insurance forms. My ERISA insurance company forced me to file for Social Security Disability and Workman's Compensation. Shortly after I was approved for Social Security Disability benefits and after they received their financial offset, they quickly denied me future benefits. They didn't understand what it was to have an invisible illness.

The medical testing continued by CFS and FMS specialists. Brain MRI's came back abnormal with large still unexplained white lesions. A cervical MRI showed herniated disks caused by the car accident. Glucose intolerance test diagnosed reactive hypoglycemia partially explaining the sense of confusion I felt. Blood tests proved positive for the Epstein-Bar virus. Some of the answers produced even more questions. I was so incredibly frustrated.



## **From Surviving to Thriving**

Then I realized that I needed to face these challenges using my business skills and experience. I created a concept I coined, "The Business of Getting Better". I became the CEO of my enterprise setting up an agenda consisting of five phases and naming each phase...the Business of the Medical, the Financial, the Mental, the Spiritual and the Emotional.

Creativity flowed as I worked on these goals. Seeing my personal need for a support group, I co-founded the CFS/FMS Empowerment Group with Dawn Broksch from Memorial Hospital West. I very quickly realized that there were very few people aware of the plight CFS and FMS patients endure. I went to Capitol Hill to lobby for awareness. I took my voice to the media. I told my story to anyone willing to listen. Like a business I established credibility, and my physicians became my business partners.

I lovingly embraced the illness and no longer felt like a victim of circumstances. Surrounded by darkness, only true family and friends remained. Courageously, I left a long-term toxic relationship behind. Soon after, I fell in love with Stephen, a kind gentle man who helped me build a butterfly garden. I nourished my soul and my spirituality. Surrounded by beauty, I practiced gratitude and aggressive rest. Choosing to be happy made me a survivor!

## **A New Organization**

Soon, I discovered my soul had a constant need for nourishment. I supplied it by founding P.A.N.D.O.R.A., Inc.—Patient Alliance for Neuroendocrineimmune Disorders Organization for Research & Advocacy, a not for profit 501c-3 organization to address issues of persons with Neuroendocrineimmune Disorders (PwNEIDs).

One restless night as I fell in the arms of Morpheus, the Greek god of dreams, I dreamed of Pandora. Curiosity prompted Pandora to open the jar her husband Epimetheus had, releasing all the ailments the world. When one says, "You are opening a Pandora's box", it's meant to express the situation of facing a challenge without solutions or facing a set of never ending problems. I saw it differently. When I opened my box, it was magical because I found hope, which Pandora according to the legend, left behind inside the box.

Hope is paramount if I am to become a "master thriver". A good plan is fundamental in creating a soothing environment for PwNEIDs. It is the very first step to encourage and lead PwNEIDs towards a thriving productive life. It's the legacy I hope to leave for others. 🍷

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Rheumatology Association Criteria for diagnosing  
Fibromyalgia at [www.myalgia.com](http://www.myalgia.com) or  
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CFIDS Association of America Inc. at  
[www.cfids.org](http://www.cfids.org).