

PATRICIA A. BRYANT

EXECUTIVE DIRECTOR, GBS/CIDP FOUNDATION INTERNATIONAL

AFTER A DIVERSE CAREER OF HELPING OTHERS and a frighteningly unexpected bout with Guillain-Barré Syndrome (GBS), Pat Bryant embraces the challenge of leading an international foundation, taking the reins from the group's matriarch, Estelle Benson, and using her personal and professional experience to guide the organization forward.

Tell us about your personal experience with Guillain-Barré Syndrome.

Life's journey is full of twists, turns and surprises. Who would have thought being diagnosed with a rare, paralyzing, frightening peripheral neurological disease would be the path to my present position as executive director of the GBS/CIDP Foundation International.

Part of that journey began when I awoke on a Saturday morning in late January of 2003 and discovered that while I wanted to walk, my legs were not cooperating. I couldn't feel my feet and found I was unable to lift myself out of the chair where I had taken a moment to rest. I tried to walk down a few steps and my knees buckled. I chalked my weakness up to the fact that I was in bed for most of the previous week as a result of what was thought to be a virus. During that week, I had difficulty swallowing, had severe bouts of diarrhea and experienced severe back pains. I phoned my doctor to tell him of my weakness and numbness in my legs and hands. He urged me to go back to bed and rest. By this time, I could feel the paralysis ascending my body and could even feel it internally. The next morning, I was unable to walk without assistance, my back pains worsened and I was frightened beyond belief. Knowing that something serious was happening, I went to the emergency room (ER). The ER doctor who treated me suspected a heart problem and admitted me. The fact that I couldn't walk, had no feeling in my hands, couldn't swallow, and had no feeling in my bowels, etc. did not seem to be taken seriously. The next morning, I was sent home and was told to see my internist.

My friends literally had to drag me around because I could not stand or walk on my own. One of them rented a walker, so that I could at least balance myself. The following two weeks found me being shuffled from doctor to doctor, hospital to hospital for tests—magnetic resonance imaging (MRI), electromyography (EMG)—and still no definitive diagnosis. A physiatrist that I was referred to was the first doctor to check my reflexes. Of course, there were none. With each passing day I became weaker and more frightened. It seemed as if no one was listening to ALL of my symptoms and no one was able to connect the dots!

After two weeks, my body finally gave out completely, and I had to be taken by ambulance back to the hospital where I was first seen and discharged. Two doctors in the emergency room



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finally listened and told me that they believed I had Guillain-Barré Syndrome.

From the time of the onset of symptoms to the time I was diagnosed, I had not slept. I was emotionally and physically drained and thought that I was going to die. Even with a diagnosis, no one explained what was happening to me, nor my prognosis. Once admitted to the hospital, I began a five day regimen of intravenous immune globulin (IVIG). My swallowing difficulties continued, and I proceeded to quickly lose 35 lbs. I couldn't walk, had no use of my arms and hands, was

extremely weak and had to depend on others for everything. Being an independent person, this was most difficult. I was convinced that I never walk again or be able to return to my normal lifestyle.

Hope finally came when a friend learned of my situation and phoned me in the hospital to tell me he knew of two men who had had GBS. They gave me a call and hearing them share their experiences with GBS and their words of encouragement gave me, for the first time since the nightmare began, a feeling of hope and encouragement. I could literally feel the anxiety leaving my body. While I realized that the road back from GBS was going to be long and meant five steps forward and three steps backwards, patience, a positive attitude and humor kept me focused and enabled me to take one day at a time.

During my first week in rehabilitation, one of the men with GBS who had called me was able to visit. Just seeing him walk through the door was the best medicine I could have been given. This person had experienced firsthand what I was going through and was standing in front of me sharing his story. There was a light at the end of the tunnel. What a blessing! I took each day in stride, working at my physical and occupational therapy, always trying to keep a very positive attitude. I firmly believed that this was happening to me for a reason. Little did I know that it would dramatically change the course of my life!

What led you to your new role as executive director of the GBS/CIDP Foundation International?

In my earlier professions, I always focused on improving the quality of life for others. For 20 years, I taught and was a school administrator. Then I worked for Catholic Charities to develop educational, job

training and health care programs for juvenile offenders. I also was an investor relations professional and, during that time, became hospice volunteer providing patient care. As part of hospice's speaker's bureau, I gave lectures on end-of-life issues and palliative care.

Having GBS led me directly to the Foundation. When recovering and when I had regained enough strength in my hands to wheel myself to a computer, I searched the Internet for "Guillain-Barré Syndrome." I had many questions about this disease and needed answers. Those answers came when I discovered the GBS/CIDP Foundation International. Immediately I registered and was sent a wonderful package of information that contained a directory of national and international chapters. I made arrangements to meet with the liaison for Nassau County, New York. After experiencing what a contact and a visit from a former GBS patient had done for me, I wanted to be able to give that same hope and support to others. I became a liaison for the Foundation and then took over as regional director for New York and New Jersey. In 2006, I became a member of the Board of Directors, and in May of 2009 assumed the position of executive director.

On a personal note, as a result of having GBS, my life made a 180 degree turn. It also was the catalyst that propelled me onto the dance floor. While I was struggling with the possibility that I could not and may not walk again, I thought of the times I wanted to take ballroom dance lessons, but kept putting it off. When I regained the use of my legs, I took myself to Arthur Murray and signed up for lessons. I was hooked, and since 2004 I have been dancing, competing and winning!

What are the Foundation's key priorities this year?

The Foundation's key priorities for 2010 are to continue to expand awareness of GBS, chronic inflammatory demyelinating polyneuropathy (CIDP) and variants, so that anyone afflicted will receive early diagnosis and dependable treatment. To this end, our medical advisory board is developing criteria in order to designate Centers of Excellence around the country. This will be a tremendous help to patients who need neurologists and neuromuscular specialists. Our organization will continue to be the catalyst for connecting people with similar experiences. We also will be redesigning and expanding our website. Our 11th International Symposium will be held November 5 to 7 in King of Prussia, Pennsylvania with attendees coming from as far away as New Zealand. Our organization continues to fund cutting edge research into these rare diseases. And, we are working to ensure that the needs of

patients with rare diseases are addressed and that the current coverage and reimbursement policies of Medicare, Medicaid and third party insurers support the treatment and rehabilitation needs of our patients.

Tell us about your chief public policy goals?

To ensure that people afflicted with GBS, neuromuscular variants, and CIDP and their families have an active and strong voice in the nation's capital and state capitals across the country. Through awareness, education and outreach the Foundation and its members effectively promote the interests and concerns of the Foundation directly to our nation's elected officials.

I believe strongly in the importance of developing and successfully executing effective public policy/advocacy programs focused on research, early diagnosis and treatment; expert, unencumbered healthcare and care giver support; and access to affordable health insurance coverage.

The true strength of our Foundation efforts has and will continue to derive its strength from an international network of chapters and people who in some way are connected to these rare diseases. Individuals that can tell their stories and demonstrate why much more can and will done.

There is enormous dedication and commitment by our board of directors, medical advisory board, our national headquarters' team, volunteers, donors, fellow patient advocate groups and industry friends that continues to support our efforts in a professional and generous sign of faith.



Above: Estelle Benson (pictured left) established the Foundation 12 years ago. Today, she remains a guiding force in its mission.

Below: The Foundation's headquarters are located in Narberth, PA, just outside of Philadelphia, and is staffed by: (from left) Camille Yee, Shawn Coats, Paricia A. Bryant and Cheryl Cloutman.



Please share any final thoughts about your work and the Foundation's mission.

Since the Foundation was started in 1988 by Estelle Benson, it has never wavered from its mission to improve the quality of life for individuals and families worldwide. When Estelle's husband, Robert, was diagnosed with GBS, little was known about the disease and there were no support groups or organizations in existence to help people cope with treatment issues and the physical and emotional problems that patients and caregivers experience when faced with a rare disease. Estelle took on the challenge. Under her outstanding leadership, a small group of eight people around a dining room table grew into 174 chapters in 22 countries with more than 30,000 members. I am honored to be following in her footsteps!

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