



PPTA Interview: Lisa Butler, Executive Director of the GBS|CIDP Foundation International

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The GBS|CIDP Foundation International is the preeminent global non-profit organization supporting individuals and their families affected by Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related syndromes such as multifocal motor neuropathy (MMN) through a commitment to support, education, research, and advocacy.

Q Can you tell me about the GBS|CIDP Foundation and the work you do?

We were founded 35 years ago by Estelle Benson. Her husband, Bob Benson, was diagnosed with GBS and when she went to look for information and support services for this rare condition, nothing existed. She vowed that she would do something about this. The foundation was started in her living room outside of Philadelphia, Pennsylvania. Estelle Benson approached the University of Pennsylvania and Dr. Arthur Asbury responded with his resident, Dr. David Cornblath, and it blossomed from there. Now we serve 35,000 members and have opened our doors to other autoimmune neurologic disorders such as CIDP, MMN, and others.

From the very beginning, the foundation wasn't founded to look for a cure—it was founded to provide support. We've been true to that mission from the beginning. We strive to provide access to early and accurate diagnosis, appropriate and affordable treatment, and knowledgeable support



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services. The four mission pillars that guide us are: support, education and awareness, research, and advocacy. Every decision we make is based on these four pillars. We are very fortunate to have support from the pharmaceutical industry. We also have an incredible global medical advisory board with some of the world's top neuromuscular neurologists who guide our science and research. We have an amazing board of directors and are fortunate that we are never lacking for volunteers. People are always stepping forward and wanting to give back. We have over 200 volunteers worldwide who provide support. They are available for patient visits, they organize local chapter support group meetings, they hold walk events, and they engage in advocacy from the grass roots up to Capitol Hill.

Q What is Guillain-Barré syndrome?

Guillain-Barré syndrome (GBS) is an inflammatory disorder of the peripheral nerves. GBS is characterized by the rapid onset of numbness, weakness, and often paralysis of the legs, arms, breathing muscles, and face. It is a rare condition affecting 1-2 people per 100,000. Typically, in GBS, the treatment protocol is plasmapheresis or intravenous immunoglobulin (IVIG).

Q What is Chronic Inflammatory Demyelinating Polyneuropathy?

Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) is a rare disorder of the peripheral nerves characterized by gradually increasing sensory loss and weakness associated with loss of reflexes. CIDP is a chronic form of GBS. Patients need infusion therapy every four to six weeks. Most commonly CIDP patients are treated with IVIG, which is the only approved treatment for CIDP.

Q How did you get involved in the GBS|CIDP Foundation International?

In 1990, my father-in-law was diagnosed with GBS. My family had never heard of it and couldn't pronounce it. He survived and made a very good recovery. He was treated at the University of Pennsylvania and the physicians there put my mother-in-law in touch with Estelle Benson.

Ten years later, our son started displaying some issues with his gait. We thought there was some similarity to my father-in-law's symptoms but had no idea that children could get GBS. He was indeed diagnosed with a serious case of GBS and was treated with IVIG and eventually made a pretty full recovery. When my son was diagnosed, my mother-in-law reached out again to Estelle and the Foundation for information and support. The Foundation sent us literature and when my son relapsed they put us in touch with a parent volunteer who helped to put our son's neurologist in touch with a pediatric neurologist who specialized in GBS in order to help determine the best course of treatment.

As soon as my son recovered, both he and I started volunteering for the Foundation and eventually took over as the parent liaison for children who were diagnosed. I started working full time with the Foundation three years ago, helping with the volunteer program. I next started working in marketing and development. When the Executive Director stepped down about a year ago, I was fortunate to step into the role. I am honored and humbled that I spend my days helping other people—there is nothing more fulfilling. The biggest impact we provide is connection and community in a world where people feel isolated and alone.

Q What has been your greatest challenge?

I think our biggest challenge is awareness, on many levels, with physicians, emergency room staff, and the general public. People have issues with not being able to obtain early diagnoses and therefore do not receive early treatment, which can affect their outcomes.

I think the hardest day is when you talk with patients and you don't have an immediate answer for their concern or situation. That, very often, deals with financial or access to care issues. Continually reevaluating the programming we're providing and making sure we are answering the patient's needs—that's a challenge but that is our mission.

Q What are the greatest strengths of the Foundation?

Providing that sense of community and connection for patients and making them feel a part of something. Often, people come to one of our events and it is the first time they've met other people who have had a similar journey and it can be a very emotional and powerful moment. Knowing that we are providing these connections is incredibly fulfilling. We provide a place where everyone can belong.

Also, our doctors are so collaborative. The Chairman of our Global Medical Advisory Board, Dr. Kenneth Gorson at St. Elizabeth's in Boston, Massachusetts and our Vice Chairman, Dr. Bart Jacobs, at Erasmus University in the Netherlands represent this group of world's finest in the field of neuromuscular neurology. It is incredible how they've devoted themselves to these conditions.

Q What are the Foundations priorities?

We have never swayed from our mission. We are solidly focused on our mission. We need to be constantly responding to new challenges that our patients face. For example, dealing with the impact of the Zika virus that can cause GBS. Puerto Rico has been significantly impacted with Zika-related GBS and the Foundation has partnered with the Centers for Disease Control and Prevention (CDC) to host a large chapter meeting where past GBS patients will attend and be a resource for newly diagnosed GBS patients. The CDC will participate and talk about how they will support these patients. Our medical advisory board published an article in the *New England Journal of Medicine* about the Zika virus and its association with GBS. We've talked with our industry partners about donating IVIG to Central and South America where there is a real need for therapies.

Our newest mission is advocacy and we've done a lot of work both on Capitol Hill and at the grass roots level to reach out to members of Congress. On the occasion of our 35th anniversary, we honored Congressman John

Garamendi (D-CA), who has a family connection to GBS. Congressman Garamendi has been an incredible leader for us.

GBS has also been named as an eligible condition with the Peer Reviewed Medical Research Program, a U.S. Department of Defense program. The Foundation was able to establish the connection between the deployment of service members and the increased exposure to triggers of GBS. This opens up a lot of research avenues and is a very exciting development.

Q What motivates you day to day?

We receive 75-100 inquiries weekly. The knowledge that we can help that many people is incredibly motivating. Being able to provide the resources and community for people who have questions and who are looking for other people who have had a similar path is very fulfilling.

We have had some of our "walk and Rolls" where people have literally taken their first steps. People will come to a walk in their wheelchair and during the walk will get out of their wheelchair and take their first steps. It is so moving and exciting to see their journey and their success.

Q What does the future hold for the Foundation?

What I see for the future is that we move forward without forgetting where we've been. We should never forget our beginnings in Estelle Benson's living room and remain committed to our mission to provide support, education, awareness, research, and advocacy.

We don't presume to have all of the answers but we strive to be the connector to the best resource for our patient community. As we have grown and flourished over the past thirty-five years, we look forward to ensuring our legacy by strategically planning for the future needs of our patients. ●