



We are the GBS/CIDP Foundation International

The GBS/CIDP Foundation International is an organization of more than 30,000 people diagnosed with or recovered from Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and variants: Miller Fisher syndrome, multifocal motor neuropathy (MMN), multifocal acquired demyelinating sensory and motor neuropathy (MADSAM), and acute motor axonal neuropathy (AMAN).

Mission Statement

To improve the quality of life for individuals and families worldwide affected by GBS, CIDP and variants by:

- Providing a network for all patients, their caregivers and families so that GBS or CIDP patients can depend on the Foundation for support and reliable, up-to-date information.
- Providing public and professional educational programs worldwide designed to heighten awareness and improve the understanding and treatment of GBS, CIDP and variants.
- Expanding the Foundation's role in sponsoring research and engaging in patient advocacy.

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Guillain-Barré Syndrome (GBS)

Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

Support
Education
Research
Advocacy

Working for a future when no one afflicted with Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP) or variants suffers alone and every patient has a full recovery.



ESTELLE AND ROBERT BENSON began the Foundation in 1980 as a self-funded group with a few volunteers to help others deal with these devastating conditions. Since then, their grass roots efforts have grown to become an international organization with over 175 chapters in more than 30 countries.

What is GBS?

GBS is a rare disorder in which the body's immune system attacks the peripheral nerves. It occurs in only one or two people per 100,000.

GBS develops rapidly, starting with weakness and abnormal sensations in the hands and feet and progressing to paralysis within days to weeks. The paralysis often extends to the arms, face, even the breathing muscles – forcing some patients to rely on ventilators.

Treatment focuses on supporting patients during paralysis, reducing the condition's severity and speeding recovery.

Newly diagnosed patients often are hospitalized and placed in intensive care to monitor bodily functions and provide needed support for paralysis.

High-dose intravenous immunoglobulin therapy (IVIG) can block the effects and production of harmful antibodies. Another treatment, plasmapheresis – or plasma exchange- is used to cleanse the blood of the antibodies that attack the nerves.

Each treatment is equally effective and can dramatically speed a patient's recovery. In most cases, GBS is temporary, with more than 85% of patients recovering.

What is CIDP?

CIDP is caused by the immune system attacking peripheral nerves. The major symptom of CIDP is mounting weakness which progresses over more than 2 months, often accompanied by sensations such as tingling and numbness. Symptoms usually are less severe than in GBS. For most patients, the disease is chronically progressive, while in others, symptoms recur intermittently.

The number of new cases of CIDP each year is estimated at 1.5 to 8.5 people per million and, because of the chronic nature of the disease, may affect up to 40,000 patients in the U.S. at any one time. This disorder can affect children and adults of any age.

CIDP patients rarely need intensive care. They often benefit from corticosteroids or immunosuppressive treatments including IVIG and plasma exchange. If they do not respond well to these primary treatments, patients can be given other immunosuppressive drugs. A neurologist will prescribe the appropriate course of treatment.

Foundation Support Services

Personal Visits

The Foundation can arrange for members to visit patients suffering from GBS or CIDP to provide experienced insight and hope.

Publications

The Foundation produces a range of publications - brochures on GBS, CIDP, Miller Fisher Syndrome, and Multifocal Motor Neuropathy (MMN); an Overview for the Layperson; a quarterly newsletter; and handbooks for caregivers, children and teenagers.

Community Education

Most people have never heard of GBS or CIDP. Even many medical professionals are unfamiliar with these disorders. The Foundation is working to change this, through regional meetings and symposia.

Physician Referrals

The Foundation can direct patients to neuromuscular specialists with experience in the diagnosis and treatment of GBS, CIDP and variants.

Centers of Excellence

The Foundation recently initiated a Centers of Excellence program in the USA and Europe to help patients obtain early and correct diagnosis and treatment from specialists in designated medical facilities. Check the website for locations.

Ongoing Research

The Foundation funds research into the causes and treatment of GBS, CIDP and variants, and has established a fellowship in neuromuscular neurology.

Advocacy

The Foundation engages in patient advocacy at federal and state levels, and with third party insurers, to promote access to early diagnosis and affordable treatment.

Visit our website at www.gbs-cidp.org to:

- Locate the nearest support group chapter.
- Access educational materials.
- Access contact information for Centers of Excellence.
- Connect with other patients and caregivers through discussion forums.
- Keep up-to-date on research programs and patient trials.

Ron J.Deshaires/Treasured Events of Charlotte



Members deeply understand the needs of patients and

caregivers and reach out with helpful support.

www.gbs-cidp.org

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