What is Guillain-Barré Syndrome (GBS)

Guillain-Barré (Ghee-YAN Bah-RAY) Syndrome, also called acute idiopathic polyneuritis and Landry’s ascending paralysis, is an inflammatory disorder of the peripheral nerves, those outside the brain and spinal cord. It is characterized by the rapid onset of weakness and often, paralysis of the legs, arms, breathing muscles and face. Abnormal sensations often accompany the weakness.

Many patients require an intensive care unit during the early course of their illness, especially if support of breathing with a machine is required or if swallowing is involved. Although most people recover, this can take months, and some may have long-term disabilities of varying degrees. Mortality rate is less than 5 percent. GBS can develop in any person at any age, regardless of gender.

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MISSION STATEMENT

We improve the quality of life for individuals and families affected by GBS, CIDP and related conditions. Our unwavering commitment to the patients we serve is built on four pillars: support, education, research, advocacy.

• We support patients by nurturing a global network of volunteers, healthcare professionals, researchers and industry partners to provide them with critical, timely, and accurate information.
• We educate doctors, clinicians, patients and caregivers to increase awareness and understanding;
• We fund research through grants, establishing fellowships and other appropriate avenues to identify the causes of and discover treatments;
• We advocate at the federal, state, and grassroots levels to educate policymakers and help them make informed decisions that benefit our patient community.

MORE INFORMATION

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Non-profit 501(c)(3)
WHAT CAUSES GBS?

The cause is unknown. We do know that about 50% of cases occur shortly after a microbial infection (viral or bacterial), some as simple and common as the flu or food poisoning. Some theories suggest an autoimmune trigger, in which the patient’s defense system of antibodies and white blood cells are called into action against the body, damaging myelin (nerve covering or insulation), leading to numbness and weakness.

HOW IS GBS DIAGNOSED?

Quite often, a patient’s symptoms and physical exam are sufficient to indicate the diagnosis. The rapid onset of (ascending) weakness, frequently accompanied by abnormal sensations that affect both sides of the body similarly is common.

Loss of deep tendon reflexes, such as the knee jerk, are often found. To confirm the diagnosis, a lumbar puncture to find elevated fluid protein and electrical tests of nerve and muscle function may be performed.

HOW IS GBS TREATED?

GBS in its early stages is unpredictable, so except in very mild cases, most newly diagnosed patients are hospitalized. Usually, a new case of GBS is admitted to ICU (Intensive Care) to monitor breathing and other body functions until the disease is stabilized. Plasma exchange (a blood “cleansing” procedure) and high dose intravenous immune globulins are often helpful to shorten the course of GBS. The acute phase of GBS typically varies in length from a few days to months, with over 90% of patients moving into the rehabilitative phase within four weeks. Patient care involves the coordinated efforts of a team such as a neurologist, physiatrist (rehabilitation physician), internist, family physician, physical therapist, occupational therapist, social worker, nurse, and psychologist or psychiatrist. Some patients require speech therapy if speech muscles have been affected.

THE GBS|CIDP FOUNDATION INTERNATIONAL

The organization was founded in 1980 by Estelle and Robert Benson to help others deal with this frightening and potentially catastrophic disorder from which recovery may not always be complete. The Foundation has over 182 chapters in the North America, Europe, the near and middle East, Africa, Australia, New Zealand and The Netherlands.

Its goals are to support you, the GBS patient and family. The Foundation is proud to have on its medical advisory board some of the world’s leading experts on GBS, as well as physicians who themselves have had the disorder.

NEED HELP?

If you have GBS or know someone who does and would like assistance or information, contact the Foundation. If you would like to form a local support group chapter or learn of local physicians who are familiar with GBS, contact us. If you are a health care professional and would like our literature or emotional support for your patients, feel free to contact us. We are here to serve you.

SERVICES AVAILABLE

• Centers of Excellence
• Visits to patients by recovered persons
• Comprehensive information booklets for all stages of GBS|CIDP
• Patient assistance by local and worldwide chapters
• Social Media channels to connect
• Physicians referrals experienced in GBS
• Quarterly newsletters
• Research funding
• Patient advocacy & ways to get involved
• International educational symposia for the medical community and general public
• Online Resources. Visit our web site: www.gbs-cidp.org

JOIN THE GBS|CIDP PATIENT REGISTRY.
SHARE YOUR EXPERIENCE, AND PLAY A CRITICAL ROLE IN A BETTER TOMORROW FOR PATIENTS EVERYWHERE...
HTTPS://GBS-CIDP.IAMRARE.ORG/

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