What is Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)?

Chronic Inflammatory Demyelinating Polyneuropathyis a rare disorder of the peripheral nerves characterized by gradually increasing sensory loss and weakness associated with loss of reflexes.

While GBS and CIDP share many features, one that separates them is the onset: in GBS the onset to maximum weakness occurs in under 30 days and in most people in under 14 days, while in CIDP the sensory loss and weakness progress beyond those times. The incidence of new cases of CIDP is about 1-4 per million people but as the disease can be present in any one person for a long time, the prevalence may be as high as 9 per 100,000.

Like GBS, CIDP is caused by damage to the covering of the nerves, called myelin. It can start at any age and is more frequent in men than women. Unlike GBS, the active phase of CIDP is not limited to less than a month. Although in about 1/3rd of patients the disease can go into a stage of remission where no immune treatments are needed, most with CIDP experience slow progression or relapses over years or more. Left untreated, 30% of CIDP patients will progress to wheelchair dependence. Early recognition and proper treatment can avoid a significant amount of disability.

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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CIDP

Chronic Inflammatory Demyelinating Polyneuropathy

SUPPORT EDUCATION RESEARCH ADVOCACY

Working for a future where every person affected by GBS, CIDP, MMN or a related variant, will have access to early and accurate diagnosis, appropriate treatment and knowledgeable support services.

WHAT CAUSES CIDP?

Current theory holds that the body's immune system, which normally protects itself, perceives myelin as foreign and attacks it. Myelin is an important part of the peripheral nervous system. It wraps around the nerve axon (the long, wire-like part of a nerve cell) much like insulation around an electrical wire. The nerves extend from the spinal cord to the rest of the body, stimulating muscle contraction and transmitting sensory information back to the nervous system from receptors in the skin and joints. This insulation (myelin) allows electrical impulses to efficiently travel along the nerve axon. When myelin is damaged or removed, these electrical impulses are slowed or lost, and messages transmitted from the brain are disrupted and may never make it to their final destination. What causes this process is not yet clear.

HOW IS CIDP DIAGNOSED?

Diagnosis of CIDP is based on the symptoms of the patient:

- Symptoms such as loss of sensation (numbness), abnormal sensation (tingling and pain), loss of reflexes, and weakness (difficulty walking, foot drop)
- Tests such as nerve conduction and EMG (usually showing a demyelinating neuropathy), spinal fluid analysis (usually showing elevated protein with normal cell count), blood and urine tests (to rule out other disorders that may cause neuropathy and to look for unusual proteins)

HOW IS CIDP TREATED

There are three standard or first line treatments in CIDP:

- **Corticosteroids** (Prednisone, Prednisolone) are similar to naturally occurring anti-inflammatory hormones made by the body, and can be used as an initial treatment. Corticosteroids often improve strength, are conveniently taken by mouth, and are inexpensive. Side effects however can limit long-term use.
- **High dose Intravenous Immune Globulins** (IVIG) is the only drug that has FDA, Canadian, and European approval for treatment of CIDP. IVIG contains naturally occurring antibodies obtained from healthy volunteers. IVIG is given through a vein over the course of several hours. Newer preparations of higher concentrations that can be given under the skin (subcutaneous) are currently being tested in controlled trials in CIDP patients.
- **Plasma Exchange (PE), or Plasmapheresis** (PLEX), is a process by which some of the patient's blood is removed and the blood cells returned without the liquid plasma portion of the patient's blood. It may work by removing harmful antibodies contained in the plasma.
- **Subcuteaneous Immune Globulins** (SCIg) SCIg is commonly used in patients with immunodeficiency. SCIg is administered by patients themselves at home. Infusions are generally given in the fat under the skin in the stomach or thighs. It is approved by the FDA in the US for treatment in CIDP.

There are a large number of so-called second line drugs used to treat CIDP. These are used when the above standard treatments fail, cause significant side-effects, or the clinical response is not optimal. These drugs are largely not tested in randomized controlled trials, but their use is supported by case series from the medical literature.

There are a number of so-called third line treatments, usually chemotherapy drugs, but these should be given only in selected circumstances and by those with extensive experience in their use.

There are also ongoing research studies (see www.clinicaltrials.gov)

Centers of Excellence

Treatment of CIDP is an art. An experienced doctor is more likely to have good outcomes than someone treating their first case as is true throughout medicine. That is why we have set up the Centers of Excellence program. If treated early, most CIDP patients respond well to therapy that can limit the damage to peripheral nerves and contribute to improved function and quality of life and at times can cure the disorder altogether. Please visit gbs-cidp.org/support/centers-of-excellence for more information.

Although CIDP can affect children and adults of any age, the peak period of life during which patients typically develop this disorder is between 50 to 60 years of age. It is more common in men than women.

NEED HELP?

If you have GBS or CIDP 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 or CIDP, 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**