GBS|CIDP Foundation International

Speaker Series Summary Episode #27: GBS and CIDP 101

Overview

Join us for a refresher in the basics for GBS and CIDP; we will cover the diagnosis, treatment, and long-term outcomes for both conditions through a conversation with Dr. Ken Gorson, a former chair of the Foundation's Global Medical Advisory Board.

Summary

Introduction	Dr. Kenneth Gorson is a Professor of Neurology at Tufts University School of Medicine. With decades of experience in the diagnosis and management of conditions such as Guillain-Barré syndrome and Chronic Inflammatory Demyelinating Polyneuropathy, Dr. Gorson is widely recognized for his contributions to patient care, clinical research, and medical education. He previously served as Chair of the Global Medical Advisory Board for the GBS|CIDP Foundation International, where he helped guide clinical and scientific priorities to improve outcomes for patients worldwide.

What is Guillain-Barré Syndrome (GBS)?	GBS is a rare autoimmune disease (1–2 per 100,000) typically triggered by an infection. The immune system mistakenly attacks the myelin (nerve lining), disrupting nerve signals and causing rapidly progressive weakness, numbness, and sometimes paralysis.
What symptoms do patients with GBS experience?	• Rapidly progressing weakness (days to weeks) • Difficulty walking, climbing stairs, or using hands • Numbness, tingling, and nerve pain • In severe cases, paralysis and breathing difficulty (up to 1/3 of patients require ventilator support)
What is the difference between weakness and paralysis in GBS?	It is a matter of severity. Weakness allows some movement, while paralysis means complete inability to move muscles.
How is GBS diagnosed?	• Primarily a clinical diagnosis (history + physical exam) • Supported by: -EMG/nerve conduction studies -Lumbar puncture to examine the spinal fluid (elevated protein, no inflammation)

How long does it take to diagnose GBS?	Typically 1–3 days in ideal settings, but delays are common due to the rarity and evolving symptoms.
How is GBS treated?	• IVIG (intravenous immunoglobulin) – 5-day course • Plasma exchange (plasmapheresis) • Both are equally effective and used once (not repeated routinely)
Do treatments reverse GBS symptoms?	Yes. Most patients recover over time, even without treatment, but treatment reduces complications and speeds recovery.
What is the typical recovery from GBS?	• ~80% of patients regain independent function • Many people have residual symptoms (fatigue, pain, weakness) • ~20% of patients may have long-term disability

How are long-term residual symptoms managed?	• Symptom-based treatment (e.g., neuropathic pain medications) • Physical and occupational therapy • Not treated with IVIG or plasma exchange • Patients should continue to see a neurologist, espeically if new symptoms appear to determine if they are related to GBS or something else.
Can GBS recur?	Rarely (<5%). GBS is generally a **one-time illness**.
What research is happening in GBS?	• New therapies targeting the immune system (e.g., complement inhibitors) • Promising trial results showing faster recovery
What is Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)?	CIDP is a **chronic autoimmune nerve disorder** with similar symptoms to GBS but progresses slowly over weeks to months.
How is CIDP different from GBS?	• GBS: acute, rapid onset • CIDP: chronic, slow progression • CIDP requires long-term management
Are there triggers for CIDP like GBS?	No clear triggers are typically identified.

How is CIDP diagnosed?	• Clinical evaluation • EMG/nerve conduction studies • Lumbar puncture to look at the spinal fluid (elevated protein)
Why is CIDP diagnosis often delayed?	Symptoms progress slowly and can mimic many other conditions; diagnosis may take up to a year or longer.
How is CIDP treated?	• Intravenous Immunoglobulin - known as IVIG (ongoing, every 3–4 weeks) • Corticosteroids (e.g., prednisone) • Plasma exchange • Subcutaneous immunoglobulin- known as SubQ or SCIG • Newer therapies tarting the immune system (e.g., efgartigimod) • Ongoing clinical trials with potential new therapies
Is CIDP treatment lifelong?	Not always. The goal is to: • Stabilize the patient • Then attempt to wean off treatment if possible • Minimize long-term disability and maximize independent function
What happens if CIDP is untreated?	Progressive nerve damage can lead to permanent disability.
What if a patient does not respond to treatment?	• Reevaluate the diagnosis • Ensure proper dosing according to the CIDP treatment guidelines • Switch therapies if needed

Can GBS turn into CIDP?	Rarely. Consider CIDP if: • Symptoms persist beyond 8 weeks • There are multiple relapses • New symptoms develop after initial recovery
What is the role of physical therapy/occupational therapy in CIDP?	Essential for maintaining function, mobility, and quality of life.
What research is happening in CIDP?	• 7+ active clinical trials • Focus on monoclonal antibodies and complement inhibition • New targeted immune therapies under investigation
Final takeaways!	• GBS = **acute, one-time illness** • CIDP = **chronic, treatable condition** • Early diagnosis and proper treatment are critical • Residual symptoms require **ongoing management, not immune therapy** • Research is rapidly advancing, offering new hope

Relevant Resources

Centers of Excellence: https://www.gbs-cidp.org/support/centers-of-excellence/

Doctor to Doctor Consult: https://www.gbs-cidp.org/doctor-to-doctor/

Find our Awardee's Research Here: https://pubmed.ncbi.nlm.nih.gov/

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