GBS|CIDP Foundation International

Speaker Series Summary Episode 26#:Ask The Experts: MMN Awareness Month Special

Overview

In recognition of February as MMN Awareness Month, join us for an MMN Ask the Experts webinar focused on Multifocal Motor Neuropathy (MMN). This session will provide an overview of MMN, including diagnosis, treatment options, and emerging research.

Featured speakers include Dr. Chafic Karam, neurologist and member of the Foundation's Global Medical Advisory Board, and Richard Sperry, MMN patient advocate, the Foundation's Chief Strategy Officer, and widely known as "Mr. MMN." Live Audience Q&A included.

Summary

Introduction	**Moderator — Richard Sperry** **Richard serves as the GBS|CIDP Foundation International's Chief Strategy Officer, and he also brings something equally important to this space — lived experience as someone personally impacted by MMN.** **Richard leads much of the Foundation's strategic work around education, research partnerships, and patient advocacy, but at his core, he is deeply committed to building community and making sure patients feel seen, heard, and supported. He understands firsthand the challenges of diagnosis, treatment, and day-to-day living with MMN, which is why he's so passionate about creating opportunities like today's conversation — connecting patients directly with experts and with one another.**

	Featured Speaker — Dr. Chafic Karam **Dr. Chafic Karam, Professor of Neurology at the University of Pennsylvania and a valued member of the GBS|CIDP Foundation International's Global Medical Advisory Board. Dr. Karam is a highly respected neuromuscular specialist with deep expertise in MMN, GBS, CIDP and other immune-mediated neuropathies. Beyond his clinical and research accomplishments, he is known for his compassionate approach to care and his long-standing commitment to the patient community. He has been a trusted partner to the Foundation for many years, generously sharing his time, knowledge, and guidance to help improve outcomes and quality of life for people living with GBS, CIDP and MMN.**
Why does MMN often take so long to diagnose?	**MMN is rare, so clinicians naturally think of more common conditions first. There's also no single definitive test for MMN. Diagnosis relies on a combination of:** • **Clinical exam** • **Nerve conduction studies (especially looking for conduction block)** • **Blood work (including GM1 antibodies)** • **Response to treatment** **Conduction block isn't always easy to find and sometimes requires targeted testing beyond routine EMGs. Anti-GM1 antibodies are helpful when positive—but they're only present in about ~50% of cases and aren't fully specific. Ultimately, diagnosis depends on putting the whole picture together.**
Can patients advocate for earlier diagnosis or treatment?	**Yes. Patients are encouraged to speak up, ask questions, and request further evaluation if things don't feel right. A 3-month IVIG treatment trial is considered reasonable when MMN is suspected—even if conduction block isn't clearly seen—because most people with MMN will show objective improvement if the diagnosis is correct.** **Improvement should be measured objectively (grip strength, muscle testing, function), not just "feeling better".**

How is MMN differentiated from ALS or CIDP?	• ***ALS***: **Usually shows upper motor neuron signs (brain/spinal cord involvement like brisk reflexes or upgoing toes). MMN does not. MMN is also treatable; ALS currently is not.** • ***CIDP***: **Typically involves sensory symptoms (numbness, tingling, pain). *MMN* is primarily motor. CIDP weakness tends to be more symmetric and generalized, while MMN is multifocal and asymmetric.** **If someone appears to have a "pure lower motor neuron" picture, a trial of IVIG is often done to rule out MMN before concluding ALS.**
What are GM1 antibodies, and how useful are they?	**GM1 antibodies (usually IgM) can support an MMN diagnosis, but:** • **Only ~50% of MMN patients test positive** • **They can also appear in ALS or CIDP** • **A negative test does not rule out MMN** **They're one supportive piece—not a standalone diagnostic answer. Patients with abnormal immunofixation results should also be evaluated by hematology.**
Are there biomarkers for MMN yet?	**Not currently. Diagnosis still depends on clinical features, nerve studies, lab work, and treatment response. Research is ongoing, especially as pharmaceutical trials expand.**
What should patients realistically expect from IVIG?	• **IVIG is currently the standard and only proven treatment for MMN** • **Most patients improve in strength and function** • **Earlier treatment leads to better outcomes** • **Lack of response should prompt re-evaluation of the diagnosis** **If IVIG works, it's usually continued long-term. If it doesn't, options become much more limited.**
How can patients track whether IVIG is working?	• **Grip dynamometers (for hand strength)** • **Functional measures (lifting objects, daily tasks)** • **Physical therapy assessments (therapists often have objective strength-measuring tools)** **Physical therapy referrals are strongly encouraged for structured tracking without having to buy expensive equipment.**

Does regular IVIG "calm" the disease over time?	**IVIG works by suppressing harmful immune activity. While MMN doesn't go away, consistent treatment helps control immune attack on nerves. Some patients can stretch dosing intervals; others need more frequent or higher doses. Individual response varies widely.**
Can IVIG dosing be adjusted? Is higher dosing safe long-term?	• **Typical approach: 2 g/kg loading → ~1 g/kg every 3–4 weeks** • **Many patients need higher or more frequent dosing** • **Some eventually require 2 g/kg every 2–3 weeks** **There's no accumulation of IVIG in the body over time, and faster infusion rates increase clot risk. The goal is always to find the lowest effective dose that maintains function.**
Why do some patients worsen despite ongoing IVIG?	**Unfortunately, some patients gradually lose responsiveness over time and require dose escalation or shorter intervals. This is recognized in MMN and isn't uncommon.**
What about rituximab?	**Clinical trials haven't shown consistent benefit. Some individuals respond, many don't. It's generally reserved for people who cannot tolerate IVIG or have contraindications.**

What is subcutaneous immunoglobulin (SCIG), and who is it for?	**SCIG delivers immunoglobulin under the skin instead of through veins. Reasons patients switch:** • **Poor vein access** • **IVIG side effects (headache/nausea)** • **Travel or scheduling convenience** **It's off-label for MMN in the U.S., meaning it has not received specific FDA approval for MMN even though it contains the same type of immunoglobulin as IVIG. However, it is commonly prescribed by neuromuscular specialists in clinical practice, particularly when long-term IV access becomes difficult, and insurance coverage may require additional documentation or prior authorization.**
What new treatments are coming?	**Very promising therapies are in late-stage trials targeting the complement system—a key driver of nerve damage in MMN.** **These drugs:** • **May work faster than IVIG (infusions under ~1 hour)** • **Are being compared head-to-head with IVIG** • **Could become available within the next few years** **Early data suggest they may help even some IVIG non-responders.**
Final Takeaways	• **MMN diagnosis is complex and relies on clinical judgment + testing + treatment response** • **A 3-month IVIG trial is appropriate when MMN is suspected** • **Objective measures (grip strength, PT testing, function) matter more than subjective feeling** • **IVIG works for most—but dosing and intervals must be individualized** • **Loss of IVIG effectiveness over time does happen** • **SCIG is a practical option when veins or side effects become limiting** • **Rituximab is not standard care** • **Complement-blocking therapies are the most exciting near-term advances** • **Earlier treatment = better outcomes** • **The goal is always: maximum function with the lowest effective dose**

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/

Visit our Research Portal Here: https://www.gbs-cidp.org/research-portal/