Speaker Series Summary Episode 23: A Conversation With A Neuromuscular Nurse

Overview

Behind every treatment plan is a nurse who will listen, support, and walk beside patients through each stage of their journey. In this webinar, Hannah Smith, a neuromuscular nurse at Northern Care Alliance NHS Foundation in London, United Kingdom with experience in administering IVIG, SCIG, and other immunotherapy treatments, will share what it's really like to care for people living with GBS, CIDP, and MMN. She will offer an honest look at what patients can expect, from the first signs and diagnosis to recovery and beyond. We will discuss how nurses help bridge the gap between patients and the healthcare system, offering not just medical care, but compassion, reassurance, and understanding when it's needed most.

Summary

Introduction	**Hannah is a Highly Specialist Neuromuscular Nurse at the Salford Care Organisation Northern Care Alliance NHS Foundation Trust, located in In London, United Kingdom.**
What are the key differences between IVIG and SCIG treatments?	• **IVIG (intravenous) is administered through a vein by medical staff, while SCIG (subcutaneous) is self-administered into fatty tissue—typically through the stomach or thighs.** • **IVIG is usually every four weeks; SCIG is more frequent (weekly or twice weekly).** • **SCIG offers greater independence, fewer side effects, and more flexibility, though some prefer hospital-based IVIG for social or safety reasons.**

What are common side effects of IVIG and SCIG, and how can they be managed?	• SCIG: Local redness, itching, or bumps—often relieved by slowing infusion rates. • IVIG: Headaches, fatigue, or skin rashes—managed with hydration, slower infusions, paracetamol, or antihistamines. • Hydration before and after treatment helps prevent headaches.
Is SCIG less effective than IVIG?	Generally no. About half of patients respond equally well, though some need to return to IVIG. SCIG may maintain steadier symptom control because doses are more frequent.
Can patients switch between IVIG and SCIG for travel?	Occasionally, yes. It depends on the healthcare system and provider approval. This is a personalized healthcare decision that should be discussed thoroughly with the doctor.
How long does it take to determine the right dosage and schedule?	Usually about a year of adjustments. Dosing is gradually reduced or spaced out once stability is achieved.
What’s the purpose of saline flushes before IVIG?	To ensure the IV line works properly and to provide extra hydration, which helps reduce side effects.

What are options for patients who don’t respond to IVIG?	Options include immunosuppressants (mycophenolate, rituximab, cyclophosphamide) or newer therapies as they become available.
What should patients do if symptoms worsen between treatments?	Contact their nurse or provider. Causes for symptoms temporarily worsening might include illness, vaccines, or infection. Adjustments to treatment or short steroid courses may help.
What is the nurse’s role in care coordination?	Nurses often prescribe and monitor immunoglobulin, coordinate with infusion centers or home care, ensure medication delivery, and assess progress every 3–6 months.
What’s involved in switching from IVIG to SCIG?	A dose of IVIG is given a week before starting SCIG to maintain antibody levels. Patients receive hands-on training (either in clinic or at home) until they feel comfortable self-administering.
How do symptoms of GBS, CIDP, and MMN differ?	• GBS: Rapid onset (within 4 weeks), treated once with rehabilitation. • CIDP/MMN: Gradual, chronic onset with ongoing treatment needs.

How can someone tell if it’s a relapse or progression?	Relapse symptoms appear suddenly and worsen rapidly; gradual changes may be normal progression or aging.
When should patients seek urgent/emergency care?	Breathing or swallowing difficulty, or new bowel/bladder issues—these are not typical and require immediate attention.
Is remission possible?	Yes, but unpredictable. The only way to confirm remission is by safely pausing treatment under supervision.
What lifestyle changes can help manage symptoms?	• Stay active—resistance training helps maintain strength. • Prioritize sleep, nutrition, and hydration. • Schedule vaccines mid-cycle between infusions to avoid symptom flare-ups; consult with your doctor. • Manage comorbidities like diabetes, which can influence nerve health.
Can alcohol be consumed?	In moderation, yes—but avoid drinking near infusion days to prevent dehydration-related side effects. Also, pay attention to how alcohol makes you/your symptoms feel the next day.

How can patients manage neuropathic pain?	Medications (amitriptyline, duloxetine, gabapentin), topical creams (capsaicin or menthol), or referral to pain specialists. Heat/cold therapy can also help.
How can patients cope with the emotional impact of a chronic condition?	Access counseling or cognitive behavioral therapy if available, and connect with peer support organizations (like the GBS|CIDP Foundation International or GAIN UK).
How can patients best communicate with their healthcare team?	• Write down questions before appointments. • Bring a companion for note-taking. • Track infusion dates, side effects, and symptom changes. • Use a treatment diary or grip-strength tracker if possible. • Always ask questions—there are no “stupid” ones.
Final Take aways	• Stay hydrated. • Keep moving. • Take ownership of your care—track symptoms, ask questions, and seek support. • Don’t hesitate to request resources like physiotherapy or nutrition counseling. • Advocate for yourself—asking is the first step to access.

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/