GBS | CIDP Foundation International

Speaker Series Summary Episode 16: Living Well with MMN #MMNAwarenessMonth

Overview

In honor of MMN Awareness Month, we talked with Dr. Tom Harbo, a neurologist, Pam Stoikopoulos, an MMN patient, Chrissie Jenkins, a Licensed Social Worker and a member of our Board of Directors, and Richard Sperry, a MMN patients and the Foundation's Chief Strategy Officer.

Summary

How would you describe MMN and how is it different from ALS?	Dr. Harbo: • MMN is "an ultra rare disorder" affecting 1 out of 100,000 people. ◦ More common for men • The onset of symptoms begin between the ages of 35 to 45, but can start at 20 years old. • Purely motor with some sensory and cognitive impairments • MMN is often Misdiagnosed with common neurological disorders like ALS • MMN is treatable, unlike ALS

What were your biggest challenges when receiving a diagnosis?	Pam
	• The average time to diagnosis is 6 years and it took Pam 7 years to receive a diagnosis.
	• Started with a twitchy finger and eventually she could not curl that finger. She also noticed her typing was impacted.
	• Started limping while she was pregnant at 40
	• Tried osteoplasty and acupuncture, but it did not help
	• A podiatrist eventually noticed that one of her legs was very thin compared to the other leg. This made the podiatrist recommend a neurological consult.
	• Saw 3 neurologists before receiving a proper diagnosis
	  ◦ The third neurologist dismissed her self-diagnosis of MMN, because she did not have the anti-GM1 antibody.
	  ◦ So, she kept pushing her neurologist to receive IVIg. When she tried IVIg, she first got really sick, and then started to see results.

What are the biggest emotional and social challenges for MMN patients?	Chrissie • A major challenge can be “coming to terms” or the initial and ongoing adjustment to accepting one’s diagnosis and prognosis • This happens differently for every patient at their new normal • Anxiety and Depression are very common • Patients say: “it feels like I’ve been hijacked and being held hostage” What advice would you give a patient, who is trying to balance treatment, a career, familial responsibilities, etc? • Be gentle with yourself. • Everyday will look different with your capacity to do things. • Be mindful when you feel like you are struggling. • Get counseling support. • Talk to patient volunteers at the Foundation It is ok to be stoic and still go through the 5 stages of grief (denial, anger, bargaining, depression, and acceptance). Therapy can make a lasting difference!
What does treatment look like for an MMN patient?	Dr. Harbo • Typical treatment for MMN is immunoglobulin (Ig), given intravenously or subcutaneously. • Plasma Exchange and steroids are not beneficial for MMN. • Some patients feel a decline in their baseline, even when they use IVIg. • There are ongoing trials for MMN and clinical trials in the US, Europe, Denmark, and most of the world. • Treatment options for MMN are still currently limited. Pam • Started with IVIg, and then tried SCIg, but did not see the same results, so she went back to IVIg. • Hydration, and specifically Hydrolyte helped reduce side effects of Ig • Her first few infusions made her nauseous and gave her headaches, so her neurologist reduce the rate of infusion. • In Ontario, the standard rate is 200ml per hour, but her rate was reduced to 150ml per hour and now she is at 180 ml per hour ◦ The different between 200ml to 180ml makes a big difference for Pam and does not experience headaches at 180ml. • As a personal preference for her schedule and lifestyle, Pam enjoys her two-day infusion treatment every 3 weeks. She explains that, for her, it is very calming and similar to a spa treatment.

Are there new treatments and therapies in progress?	Companies are targeting Anti-complement treatments. ◦ Complements are proteins in the blood, part of the immune system, that clean bacteria. ▪ In MMN, they damage the body's nerves, so blocking them will theoretically reduce damage to nerve cells. ◦ Researchers are looking into less invasive administrations of IVIg. ◦ What are the side effects of complement Inhibitors? ▪ There is a concern that patients could get a bacterial infection. ▪ Trials typically require vaccination against bacteria that could put patients at risk. ▪ Some compounds only block antibodies that hurt nerves, so bad complements may still be active in the body.
Is there evidence that Rituximab is effective for MMN patients?	Dr. Harbo • Currently, we have not seen any studies testing Rituximab's effectiveness for MMN patients • There is a percentage of MMN patients who do not respond well to IVIg. ◦ In this case, some neurologists may consider Rituximab. ◦ Note: Rituximab is not a magical treatment of CIDP either. ◦ Rituximab is not toxic as other immunosuppressant drugs. • Cyclophosphamide has also been tried, but is very toxic because it is an old fashioned chemotherapy.
What advice do you have for patients, caregivers and care partners?	Chrissie • Trust and good support is important. • If you don't feel comfortable, seen, or heard, you need to change the people in your team. • Advocate for yourself. • Care givers are unsung heroes, and need to make sure that they are also taking care of themselves as well. • Open, honest, and vulnerable communication is needed for caregivers to succeed. • Do not give up on trying to find the right place for care. • Finding the right members of your care team is important. • Nurses are the core of the team; they often know patients more than their own family members do. • Caregiving is hard because the responsibilities of daily life do not go away.

How far are we from a biomarker for MMN?	Dr. Harbo • Mentioned he is not optimistic for a simple biomarker for MMN. • We are dependent on patient reports, clinical examination, objective measures of grip strength and muscle strength, but these measures are not always effective. • We have some helpful tests for diagnosis, including ganglioside antibody testing and electro-physiological exams. ◦ Neurofilament light chain as a biomarker is only effective when the disease is very active. • There is work on testing through peripheral nerves, but it is not an effective biomarker.
Are there specific attributes, levels of functions, or anything definitive that can indicate the progress of treatment?	Dr. Harbo • Every patient is different because every patient has different nerves. • Manual Muscle test are good indicators. ◦ Handwriting, cramping when walking, or drop foot after walking 10 meters versus 50 meters (30 feet versus 150 feet)
What advice would you give to a newly diagnosed patient?	Pam • The reality is that no one knows what is going to happen. This can be a dark cloud, making days different and sometimes really hard. • Diagnosis was a relief for Pam and she kept repeating: “I am lucky, I should do what I can”. • Found satisfaction in volunteering and participating in support groups. • Some days, the mental state will impact the physical state. • If you notice a drop off after infusion, record it and tell your physician. Chrissie • The only guarantee in life is that everything changes. • You will become stronger with a new sense of meaning and purpose. • Endurance and perseverance will be a gift you can give to other people. • Be comfortable with the unknown. ◦ Our human nature is to know and understand everything. • This disease is unpredictable, so every morning is an opportunity to try again.

What advice would you give to a newly diagnosed patient? (Continu.)	Dr. Harbo • Accept that this is a chronic disorder. • Look at the possibilities and not its limitations. • Find a team in the hospital that you trust. ◦ They are important when receiving treatment, correct information, and understanding your options. • This period is about what feels best for you. • If you go through a period where you are getting weaker, the medical team is extremely important to adjusting your treatment. • Exercise is important.

Have you seen any evidence that Hizentra and Hyqvia are effective for MMN patients?	Dr. Harbo
	• In Denmark, both are seen as equal.
	  ◦ Hizentra is only immunoglobulin.
	  ◦ Hyqvia is a mix of hyaluronidase and immunoglobulin.
	  ▪ You can receive higher doses at faster rates.
	• Every patient is different so if one does not work, try the other.

Relevant Resources

Centers of Excellence

Treatments and Access Portal

Questions to Ask Your Provider