

Speaker Series Summary Episode 1: What is Multifocal Motor Neuropathy?

Overview

In this episode of our Speaker Series, we discuss what MMN is with Dr. Michal Vytopil from Beth Israel Lahey Health and Brenda Perales, an MMN patient and volunteer, who share their expertise on the clinical course, diagnosis and progression of MMN, and available treatments and resources for patients.

Summary

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| <p>Under- standing MMN</p> | <p>What is MMN? Multifocal Motor Neuropathy is an inflammatory autoimmune condition attacking components of the peripheral nervous system. It affects the body in different patches and part of the body asymmetrically. MMN only affects the fibers going into the muscles so it is not life threatening like ALS. Some may experience weakness in ones hands, tingling, and painlessness. Although, ALS is often confused with MMN, ALS is more deadly, fatal, has no cure, has a 3-5 year life expectancy, and most of all it deals with motor nerves such as swallowing. There is not a specific diagnostic test available to identity MMN, yet doctor use the process of elimination with other test such as EMGs, Spinal Taps, and MRIs.</p> |
| <p>Treatments for MMN</p> | <p>What is Intravenous Immunoglobulin (IVIg)? IVIg is the only approved initial therapy for patients with MMN and about 70-90% of patients respond well to IVIG. IVIG is a block product of immunoglobulin pulled from thousands of plasma donors filled with antibodies. Every patient is different, so results may not be visible for weeks to months. Unfortunately, plasma exchange and steroids are not effective in treating MMN.</p> <p>What do treatment infusions look like? There are two phases of treatment which is the initial treatment and maintenance treatments. Typically patients start with 2-5 infusions in a row and then slow down to about 5 infusions a month or even once every 3 week. Initial treatments will primarily involve IVIG while the maintenance treatments can include both IVIG and subcutaneous infusion.</p> |

Treatments for MMN

What is Subcutaneous Infusion? (SCIg)

Subcutaneous infusion differs from IVIg because it is self-administered under the skin whereas IVIg is administered intravenously through one's vein. Subcutaneous infusion is administered in smaller amounts more frequently than IVIg. Subcutaneous infusion has 30% less symptoms than IVIg because IVIg is administered in larger doses. Doctors will start patients off with a 1-to-1 ratio of subcutaneous infusions where they are given the same amount of immunoglobulin as they took with IVIg. Eventually, a patient will find their best amount of dose and its frequency with time, but it still a hard adjustment. In some cases, patients can relapse after taking subcutaneous infusion or may not respond to subcutaneous infusion at all. Above all, a patient must respond well to IVIg before they can transition to subcutaneous infusion.

What do long-term treatments look like?

Subcutaneous infusion can offer stability and independence from the doctors office, yet IVIG is different. The responsiveness of IVIG may decrease over time with the development of axon loss. Essentially, the body can repair myelin, or the proteins wrapped around nerves but not the wiring of nerves. Even if there is a relapse, the disease never comes back fully and will never affect major muscles like breathing or spread to critical muscles. Yet, patients can experience fixed weakness due to the loss of axons over time. Lastly, about 20% of MMN patients go into remission, where their condition is stable and do not need to receive anymore treatment.

Brenda Perales' Story

Brenda's Diagnosis Journey

In 2010, Brenda started tripping a lot and having muscle cramps until she broke her leg walking down some bleachers. After her physical therapist noticed that her ankle was the rotating incorrectly, her experiences with limping, cramps, and losing sensation in her left foot, she went to a neurologist in 2013. Her MRI did not show signs of MMN so she was misdiagnosed with ALS. She was about to start ALS medication when her neurologist decided to perform a genetics test. She went to John Hopkins Medical Center and was diagnosed with MMN. Then she started IVIG treatments and it became fully clear that she had MMN.

Brenda Perales' Story

Brenda's Treatment Journey

Brenda started off with IVIg for two year and would get flu-like symptoms for each treatment. She explained that she felt down and tired after each infusion. So, her doctor slowed the rate of infusion until she decided to try subcutaneous. During the transition, she explains that she felt weaker and weaker after the first dose. So she took IVIg and increased her subcutaneous dose until she was finally stable with subcutaneous. Now, she says she is stronger than ever with more independence and has found her "sweet spot" dose at 35 milligrams.

Brenda's encouraging words: "It is ok to be frustrated but don't stay there, find different ways to do the things you love"

What should patients ask their doctor?

- Are you sure this is what I have?
- Where do you think I would be or should be in (blank) amount of years?
 - Will I still be on IVIg?
- What are some other alternatives to IVIg?
- Do I need to increase my dose?
- If I feel better overtime will my dose increase or decrease?

Relevant Resources

Website Information: [What is MMN?](#)

Speaker Series Episode: [What is MMN?](#)

[Centers for Excellence](#)

*Special thanks to Dr. Michal Vytopil, MD, PHD - Beth Israel Lahey Health