

Speaker Series Summary Episode 3: How To Be Your Own Advocate

Overview

In this episode of our Speaker Series, we dive into conversations that patient should have with their doctor from three MMN patients, Pam Stoikopoulos, Richard Sparry, and Clive Phillips.

Summary

<p>Pam Stoikopoulos</p>	<p>Pam experienced MMN for about 7 year at a slow progression until finally she had enough. She was on a neurology waitlist for 7 months and then was misdiagnosed while being pregnant. She describes her experience as being pushy and persistent until she was finally put on IVIg to overcome her “pirate foot”.</p> <hr/> <p>Here are some words of advice from Pam:</p> <ul style="list-style-type: none"> • Latch on to the people who are there for you so that there are more people who can advocate for you • Keep your cool and go in it with a positive mindset • Accept the Vulnerability • Doctors are taught to hear for hoofs and find horses not zebras, so speak up and do your research
<p>Richard Sparry</p>	<p>Richard experienced MMN for about 18 months because he was “positively persistent and and pleasantly pushy”. He was misdiagnosed with ALS and traveled state to state, eventually going to the Mayo Clinic where he was diagnosed with MMN and put on IVIg.</p> <hr/> <p>Here are some words of advice from Richard:</p> <ul style="list-style-type: none"> • Never take no for an answer • Ask all the question, even in remission to understand the what the future could hold • It takes a team effort

<p style="text-align: center;">Clive Phillips</p>	<p>Clive experienced MMN for 7 years because he ignored his symptoms. He is not a naturally pushy person from being in the military and was taught to push through pain. He talks about avoiding symptoms, not talking about them, and not having a “princess mentality”. Eventually, he was convinced by his family to go to the doctor and seek treatment.</p> <hr/> <p>Here are some words of advice from Clive:</p> <ul style="list-style-type: none"> • Listen to your family and your body • Most doctors like the weird case and enjoy trying to figure out issues • Ask why test are being performed • Get to know everyone you come across and make them like you because if you are nice, they will be nice back • Do not overthink how much time it will take for a doctor to get back to you, just ask • Ask your doctor: “what are you trying to understand or look for” • There is nothing wrong with saying “ I read this _____ and _____” because it will be easy for you to make conversations with your doctor
<p style="text-align: center;">Questions for the Speaker</p>	<p>Was there a time where you had an uncomfortable conversation?</p> <ul style="list-style-type: none"> • Pam: She knew more than her doctor on subcutaneous infusion and her doctor became defensive about not taking it because of his protocol. So, she persisted and was able to receive subcutaneous. • Clive: He wishes he had more uncomfortable conversations about things that seemed small. • Richard: He had more frustrating conversations that did not have value with some neurologist, who did not know much about MMN. <p>What is one piece of advise for other MMN patients (in 6 words)?</p> <ul style="list-style-type: none"> • Pam: Take notes and ask questions • Clive: Be prepared and know your symptoms • Richard: Do not take no for an answer

Relevant Resources

Website Information: [What is MMN?](#)
[Centers for Excellence](#)
[Questions to ask your doctor!](#)