

Transcript Details

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A Real-World CIDP Patient Journey: Perspectives From a Neuromuscular Specialist

Announcer:

You're listening to ReachMD. This medical industry feature, titled "A Real-World CIDP Patient Journey with VYVGART Hytrulo®: Perspectives from a Neuromuscular Specialist" is sponsored by argenx. This program features an actor portrayal based on a real patient's experiences and treatment decisions drawn from their physician's clinical judgment and medical expertise. Here is Dr. Shiv Bhadola.

Dr. Bhadola:

Hi, I'm Dr. Shiv Bhadola, and I'm a neurologist with expertise in neuromuscular medicine. In my practice treating patients with neuromuscular disease, I see those who have issues with their nerves and muscles, and I commonly treat a condition called chronic inflammatory demyelinating polyneuropathy, or CIDP. In my practice, I have dozens of patients with CIDP, and I see the wide breadth of disability that these patients can have. It's important for us to consider where patients are when they come to us in our practice, and where they want to go with treatment.

Today, I want to introduce my patient David and share my experience working together with David to treat his case of CIDP including how we approached shared decision-making when we first met and how we continue to do so to this day to treat his CIDP. Along the way in this video, we'll walk through key moments during David's journey from the onset of his symptoms and the path to diagnosis to how we made treatment decisions together and how those treatments have impacted his daily life.

I met David a little more than 2 years ago. He's now 54 and lives a couple hours away from my clinic.

When David first came to me, I took the time to listen to him, to hear him talk about his experience with CIDP and his medical history.

It's important for us to give an ear to our patients and understand where they're coming from so we can guide them to where they want to go.

Patient VO:

Before my CIDP symptoms started, I had a job that I really enjoyed. I worked in a factory as a traffic coordinator and forklift operator for a furniture store. It was hands-on work, and I liked that it kept me active and busy. Outside of work, I spent a lot of my free time outdoors flying drones. Then, in 2023, things started to change.

At first, I noticed I started having a foot drop. It kept getting worse, and over time I started losing my balance more often. I was also having trouble climbing stairs, and I even had a few falls. As things progressed, daily activities got harder. I eventually had to stop working and driving, and simple things became more difficult. What made it especially hard was not knowing what was happening. I knew something was wrong, but there was a lot of uncertainty and I was frustrated. I went to see my primary care doctor, and they referred me to physical therapy. But by the day of my appointment, I couldn't even stand.

I ended up spending weeks in the hospital and then in rehab, trying to figure out what was causing my symptoms and learning how to use a wheelchair. At the hospital, they ran a lot of tests looking for the cause. They thought it might be diabetes, but my symptoms didn't really fit. They also considered other conditions, like Guillain-Barré syndrome.

I know not everyone goes through this, but in my case, I developed a deep vein thrombosis while I was in the hospital receiving IVIG. When that happened, my doctor decided to stop the IVIG and start me on a blood thinner. In the end, I was sent home without any answers and without a diagnosis. That was really hard for me because it left me feeling unsure of what to expect. I was worried about what my future might look like

Dr. Bhadola:

What David just told us is something many patients with CIDP go through not infrequently. Before they have answers, they often deal with uncertainty and a loss of function. They experience frustration of not knowing what's happening. Many of my patients with CIDP describe the time before diagnosis as one of the most difficult and uncertain parts of their journey. And it's exactly here where we can do the most for our patients.

CIDP is a rare disease that lacks a known biomarker, and diagnosis is complicated by multiple different sets of diagnostic criteria. It is also quite heterogeneous in its expression – there are many variants, and some patients do not show typical symptoms. When a patient presents with a length-dependent neuropathy with progressive symptoms and an unknown etiology, it's important to refer them as early as possible for electromyography, or EMG, and nerve conduction studies to detect underlying nerve damage. Doing this will help to support a timely and accurate diagnosis of CIDP.

Now, the symptoms David was experiencing – loss of balance, distal weakness, numbness in his legs, and having trouble with stairs – alongside a comprehensive approach helped establish differential diagnoses. Nerve conduction and EMG studies were key in David's case to confirm his diagnosis of CIDP. Ultimately, when patients see confidence in the diagnostic process, it can go a long way. In David's case, while he and his care team were not able to have immediate answers regarding his condition, his doctors worked carefully to understand his medical history and establish a clear path that eventually led towards an accurate diagnosis of CIDP.

Patient VO:

Getting to a diagnosis was hard. I saw so many doctors. In November 2024, I went to Dr. Bhadola's practice, and after reviewing my tests, my treatment team felt confident I had CIDP. Shortly after that, diagnosis was confirmed.

After so much uncertainty, hearing that brought me a real sense of relief because by this point, I was no longer able to walk on my own. Finally having a diagnosis meant so much to me and gave me hope that there might be a treatment right for me.

Dr. Bhadola:

Once we reached a clear diagnosis, we were able to turn our attention to treatment and finding an approach that was right for David. As we considered the options, we talked openly about his goals, his concerns, and his questions, so we could make decisions together and move forward with a plan tailored to his needs. Typically, when I am considering treatment options for patients with CIDP, I would look at the severity of symptoms, functional status, and diagnostic findings, and consider treatments in the context of my patient's overall health status and treatment goals.

I manage CIDP with treatments like VYVGART Hytrulo, IVIG, corticosteroids, or plasma exchange, but it's important to weigh efficacy, safety, and patientspecific factors before deciding. I take time to review the treatment options with my patients, answer their questions, and make sure we're making decisions together based on my clinical insights and what matters most to them.

Given David's medical history, we had to consider the benefits and risks of treatment carefully. Plasma exchange and steroids, while appropriate for some patients, were not suitable options due to his comorbidities. And continued IVIG could not be considered, given his history of thrombotic events. We also focused on achieving David's personal goals for treatment, particularly preserving his arm and leg function.

With those considerations in mind, we began to consider how VYVGART Hytrulo might offer a different path forward. VYVGART Hytrulo is a once-weekly subcutaneous injection, or self-injection, that has been evaluated in clinical trials and offers an established efficacy and safety profile. When we started discussing VYVGART Hytrulo as a possible treatment option, it was important to have an open conversation with David about his initial impressions and to make sure he felt comfortable raising any questions or concerns he had about the treatment.

Patient VO:

When I first learned about VYVGART Hytrulo from my doctors, they explained that it might be a good treatment option for me. I remember feeling hopeful, but I also had a lot of questions. I wanted to understand how VYVGART Hytrulo works. I also had concerns about possible risks because of my other health issues.

Dr. Bhadola:

I find it's important to talk through the safety profile of any CIDP treatment with my patients early on. These conversations help educate patients about the potential benefits and risks of treatment, while also creating an opportunity to set expectations for what treatment may look like and the outcomes we hope to achieve together. I tell my patients that VYVGART Hytrulo may increase the risk of infection and can cause serious allergic, infusion-, or injection-related reactions, and that the most common side effects include respiratory and urinary tract infections, headache, and injection site reactions. I ask my patients to let me know if their neurological symptoms get worse,

because that may be a sign the treatment is not working. I also let them know that there have been reports of worsening signs and symptoms of CIDP when transitioning from intravenous immunoglobulin treatment to VYVGART Hytrulo.

Once a patient and I have decided to start treatment with VYVGART Hytrulo, I typically set expectations around maintaining arm and leg function, and emphasize the importance of well-rounded care, including physical therapy, occupational therapy, and home exercises. I like to share how other patients have responded based on my clinical experience. Some maintain arm and leg function, while others go from relying on a wheelchair to using an assistive device such as a cane or walker.

With that said, patients can respond differently, so I encourage my patients to be patient and check in with me regularly as they start treatment. Some patients may notice changes sooner, while for others, it may take longer. It's important to set expectations based on each patient's individual situation and how each patient can reach their goals.

In David's case, we discussed that his aspirational goals were to improve mobility, resume daily activities, and gain feeling and movement in his extremities, so he could work towards being able to drive. He also wanted to go back to flying drones. Setting expectations is an important part of the shared decision-making process. For David, those conversations helped him feel informed, heard, and part of the treatment team as important treatment decisions were being made.

Patient VO:

I learned a lot during those early conversations, but most importantly, I felt like my doctor really listened to my concerns and goals and took them seriously. It truly felt like we were working as a team. Those conversations were important because they helped me understand what to expect, and that helped make me feel more confident moving forward and more in control of my care.

Dr. Bhadola:

At the end of the day, my main goal for these conversations is to help my patients feel supported as they adjust to daily life with a new treatment. I do this through monitoring their symptoms and progress. When I start a patient on a therapy that is new to them, I follow up after a few weeks, and I always tell them to reach out to me or the nursing staff to discuss any changes in symptoms or side effects.

I closely document motor function through objective exams during clinic visits and track any specific changes in certain muscle groups, particularly those important in daily activities such as using the hands, getting up from a chair. This helps me assess progress over time, especially since I have found that motor improvements often correlate with improved daily functioning.

Since not all patients respond to therapy the same way, ongoing monitoring is always important. Maintaining an open dialogue with patients about any symptoms or side effects is also important. As David continued on treatment, his care team kept a close eye on his progress and had ongoing conversations about his treatment status.

Patient VO:

Through my conversations with my doctors, I understood that progress with VYVGART Hytrulo might be gradual, so in those first few months, I really focused on the small wins and the steps I could take toward my goals. I started physical therapy shortly after beginning treatment. At first, I couldn't even stand, so I started with seated exercises and built up from there, little by little. Over time, I began making progress.

First of all, I don't rely solely on my wheelchair now. I've also maintained my arm and leg function, and I'm hopeful I can keep moving closer to my goals, like walking up stairs more easily and maybe even get my driver's license back. I'm excited to keep making progress.

Dr. Bhadola:

As David continued treatment, he maintained function, with injection site pain that occurred with initial treatments and subsided with continued treatments. His progress is certainly inspiring and an example to remember as we treat patients with CIDP.

One of the most valuable lessons David highlighted for me is that it is so important to find the treatment that's right for your patient, based on individual factors and treatment goals. VYVGART Hytrulo has shown effectiveness in adult patients, including those who are newly diagnosed or have never had treatment for CIDP. Additionally, I was able to rely on David's multidisciplinary care team to help ensure that we continue to address all aspects of his condition, from neurology to physical therapy to emotional support. This collaborative approach helped us align his treatment with his broader goals. Looking back, David's progress was not only clinically meaningful, but also personally meaningful to him.

Patient VO:

It was a long road, but I'm so glad I kept trying. My treatment helped me maintain the function I had worked hard to preserve.

Now, I'm focused on staying active.

Dr. Bhadola:

Thank you, David, for sharing that perspective. That's helpful for me to know what's important to you. Ultimately, David's story reminds us of the importance of closely listening to our patients, so we can better understand their needs. Shared decision-making isn't just a clinical approach; it's a way to build trust, align on goals, and deliver care that genuinely reflects what matters most to each patient.

Ensuring that treatment decisions are made jointly between clinicians and patients is key. That shared approach gives patients the best chance for success with any therapy, as we've seen with David and VYVGART Hytrulo. I think it's important that we consider VYVGART Hytrulo as a treatment option for adult patients living with CIDP. In my clinical experience, I now consider this as one of my first-line options, based on the outcomes I have seen in my clinical practice.

Announcer:

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