Transcript Details
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Effective Treatment Discussions in PI: Expert Clinician and Patient Insights

ReachMD Announcer:
Welcome to *Clinician's Roundtable* on ReachMD. This medical industry feature, titled "Effective Treatment Discussions in PI: Expert Clinician and Patient Insights," is sponsored by CSL Behring. Here's your host, Dr. Matt Birnholz.

Dr. Birnholz:
This is the Clinician's Roundtable on ReachMD, and I'm Dr. Matt Birnholz. Today, we'll be talking about primary immunodeficiency, or PI, and the role of shared decision-making in choosing the right treatment.

Joining me in this discussion are Dr. Beth Younger and Janet R.Dr. Younger is an Assistant Professor in Pediatrics at Johns Hopkins School of Medicine.

Dr. Younger, welcome to the program.

Dr. Younger:
Thank you so much for having me, I'm looking forward to it.

Dr. Birnholz:
Great to have you with us. Also with us is Janet R, a patient advocate who not only has PI, but also cares for her son Jacob, who shares the same condition.

Janet, thank you for joining us.

Janet:
I appreciate the opportunity to be here today.

ReachMD Announcer:
Discussing PI Diagnosis and Initial Treatment Decisions

Dr. Birnholz:
So, Dr. Younger, why don't we begin with you? For many patients, the path to getting diagnosed with primary immunodeficiency can be a long and challenging journey. Can you just walk us through how you approach delivering this news to your patients and their families?

Dr. Younger:
So, it's true, getting a diagnosis of a primary immunodeficiency can be a long journey. For the patient, it can feel incredibly long. On top of having a poor quality of life and recurrent infections, patients often feel unseen and misunderstood by healthcare providers.[1] Many times their chief complaint is, "I'm sick and tired of being sick and tired" and their question is "*why* am I sick and tired?"

But once we make a diagnosis, that's when the real journey begins. That's where the provider plays a crucial role in how the patient will perceive their disease, because it's usually a mix of emotions – oftentimes both relief and anxiety.

So, I always start with the absolute basics: what is the primary immunodeficiency, what part of the immune system is affected, how it's affected, and what it is we can do. This conversation can vary in length depending on the patient, but it's important that providers don't put a timer on it, because it's absolutely not a one-size-fits-all kind of discussion.

Dr. Birnholz:

Thank you, Dr. Younger, those were great insights. Now, Janet, let me turn to you now. You've been through this journey not just once, but twice—first with your son Jacob, and then with your own diagnosis. How did your family handle the uncertainty before Jacob's diagnosis, and how did you feel when you finally had answers?

Janet:
It was hard for everyone, but particularly my son. He was extremely sick, and for five years, nobody could tell us what was going on. There was a lot of uncertainty, and as a parent, not knowing what his life would look like was a heavy burden. So, when we finally got his diagnosis, we were relieved—overjoyed actually—because we finally had an answer. And we knew what it was, and it had a treatment.

Dr. Birnholz:
Thank you, Janet, for relaying that experience. I want to talk more about treatment options for patients with certain types of PI's, specifically Hizentra®. But before we do, let's just take a minute to review some Important Safety Information on Hizentra.

ReachMD Announcer:
IMPORTANT SAFETY INFORMATION
Indications and Usage
Hizentra®, Immune Globulin Subcutaneous (Human), 20% Liquid, is indicated for:

- Treatment of primary immunodeficiency (PI) in adults and pediatric patients 2 years and older.
- Maintenance therapy in adults with chronic inflammatory demyelinating polyneuropathy (CIDP) to prevent relapse of neuromuscular disability and impairment.
    - Limitation of Use: Maintenance therapy in CIDP has been systematically studied for 6 months and for a further 12 months in a follow-up study. Continued maintenance beyond these periods should be individualized based on patient response and need for continued therapy.

For subcutaneous infusion only.

WARNING: Thrombosis may occur with immune globulin products, including Hizentra. Risk factors may include: advanced age, prolonged immobilization, hypercoagulable conditions, history of venous or arterial thrombosis, use of estrogens, indwelling vascular catheters, hyperviscosity, and cardiovascular risk factors.

For patients at risk of thrombosis, administer Hizentra at the minimum dose and infusion rate practicable. Ensure adequate hydration in patients before administration. Monitor for signs and symptoms of thrombosis and assess blood viscosity in patients at risk for hyperviscosity.

Please stay tuned to hear more Important Safety Information in this program.

Please see full prescribing information for Hizentra including boxed warning at Hizentra.com/HCP.

ReachMD Announcer:
Switching to Hizentra and Addressing Common Patient Concerns

Dr. Birnholz:
So now that we've heard the important safety information, let's pick up where we left off. And, Janet, as I understand it, once Jacob was diagnosed, he started intravenous immunoglobulin, or IVIg, but eventually switched to Hizentra, which is a subcutaneous immunoglobulin, or SCIg. Now, what were some of the challenges you faced during that transition, and what concerns did you have as a caregiver?

Janet:
IVIg wasn't a great experience for Jacob as a patient or for me as a caregiver, and we knew immediately that we didn't want to do that forever. It consisted of very long days, with a lot of tears and struggles just to get the IV placed.And the highs and lows associated with IVIg made school really difficult for him. He would fall asleep at his desk or have to miss days because of the side effects.So, when they gave us the option to infuse at home using SCIg, with the ability to offer steady-state Ig levels, it felt too good to be true.[2]

At first, being the sole person responsible for his treatment felt overwhelming. But after practicing and gaining confidence with the infusions, I saw that starting my son on SCIg was a life-changing decision. He felt like himself again.

Also, we really liked doing the therapy in the comfort of our own home with the convenience of working with his healthcare provider to modify and adapt the therapy to our life, instead of the other way around.

Dr. Birnholz:
That's a remarkable story, Janet. And Dr. Younger, coming back to you, many patients and families like Janet and Jacob have concerns when starting Hizentra. What are some of the most common things they're worried about, and how do you proactively address those concerns?

Dr. Younger:
As you can imagine, there are some patients who don't think they'll be able to do their own infusions and stick themselves, but when I show them that we're talking about a needle much smaller than what's used for IVIg, it makes many patients feel better.

Sometimes patients who have been on IVIg, especially those who have been doing it for a long time, ask, "Why make any changes if IVIg is working for me?"This is a completely valid question, and it's important for providers to go through therapy options and talk about the differences between IVIg and SCIg objectively. I do emphasize that Hizentra provides consistent Ig levels with low infection rates.[2]

I also discuss the flexibility and control that patients can have with Hizentra because of the ability to self-administer, especially with prefilled syringes.Then, when we teach patients about self-infusing, we keep it simple and straightforward.Above all, though, I think offering support and guidance is the most important when starting a new therapy with patients.

I know that's been my experience, but I'd be interested in what you think, Janet. What expectations do you have for clinicians to help navigate the transition to Hizentra?

Janet:
Well, finding a provider capable of three essential qualities—education, empathy, and emotional support—is critical. Being able to do our therapy at home is a huge advantage, but it's also a huge life change.

And so I encourage providers to share training and support resources with patients. For example, Hizentra Connect can help them find training and answer questions about their therapy. They also have people like me in their corner advocating for them through their journey.

Dr. Birnholz:
For those just tuning in, you're listening to *Clinician's Roundtable* on ReachMD. I'm Dr. Matt Birnholz, and today, Dr. Beth Younger and patient advocate Janet are sharing best practices for using Hizentra for PI based on their real-world experience.

ReachMD Announcer:
Best Practices: Eliciting Information and Adjusting Therapy

Dr. Birnholz:
So, Dr. Younger, when you're checking in with your patients to see how they're doing on therapy, what questions do you ask to make sure the treatment is working for them?

Dr. Younger:
Well, if patients say they're not feeling good about how their therapy is going, it's really good to ask specific questions, because sometimes the issue is nothing that you'd expect.

And if it comes down to patients having an issue with the infusion process itself, I kind of point out the variables that we can tweak or change to make Hizentra fit into their lives better.

Providers can sometimes overlook the emotional and lifestyle impacts of the therapy. So, having patients talk about what they can do and what they can't do, and *what* they want to do most importantly, is really important information for providers to consider.

ReachMD Announcer:
Real-World Experiences with Hizentra: Innovation and Long-Term Success

Dr. Birnholz:
So, Dr. Younger, let me stay with you for a minute because you've been prescribing Hizentra for years. Can you just share why you believe it has become a trusted treatment for patients with certain types of PI?

Dr. Younger:
Hizentra is the most prescribed Ig in the U.S. and it has a long record of proven safety and efficacy among other SCIg products.[3-5] It's been a tried-and-true option for managing certain types of primary immunodeficiencies since 2010.[5]

Aside from that, I like the prefilled syringes and how they've enhanced patients' lives. When these were first introduced, they really

changed things by eliminating vial draw and cutting back on the administration preparation time.

Finally, steady-state Ig level are a real advantage for my patients, since they offer a more consistent experience with fewer ups and downs between infusions. And Hizentra maintains those steady Ig levels regardless of dosing frequency, which is really important when you have patients who often switch up their dosing schedule.[2]

Those are my thoughts as a provider, but Janet, as a patient and caregiver who uses Hizentra, what are your thoughts?

Janet:
We started Hizentra back when vials were the only option, and my son, who was six to seven years old at the time, was doing his own infusions after I would measure up the dose. But if we'd had the pre-filled syringes back then, he may have become independent with his infusions even sooner.

As for me, I know I'll be able to continue doing this therapy as I get older because it's so user-friendly. I've met with a lot of people who have found that the prefilled syringes have made at-home treatment more accessible to them.

Dr. Birnholz:
Absolutely and great insights from the two of you. With that, I very much want to thank Dr. Beth Younger and Janet R for sharing their valuable experiences and insights on best practices for using Hizentra.

Dr. Younger, Janet, it was wonderful to have both of you on the program today. Thanks so much.

Dr. Younger:
Thank you very much.

Janet:
Thank you for having me.

Dr. Birnholz:
For ReachMD, I'm Dr. Matt Birnholz.

Please stay tuned to hear some Important Safety Information for Immune Globulin Subcutaneous (Human), 20% Liquid, or Hizentra®.

ReachMD Announcer:
Hizentra is contraindicated in patients with a history of anaphylactic or severe systemic reaction to human immune globulin (Ig) or components of Hizentra (e.g., polysorbate 80), as well as in patients with immunoglobulin A deficiency with antibodies against IgA and a history of hypersensitivity. Because Hizentra contains L-proline as stabilizer, use in patients with hyperprolinemia is contraindicated.

IgA-deficient patients with anti-IgA antibodies are at greater risk of severe hypersensitivity and anaphylactic reactions. Thrombosis may occur following treatment with Ig products, including Hizentra.

Monitor patients for aseptic meningitis syndrome (AMS), which may occur following treatment with Ig products, including Hizentra. In patients at risk of acute renal failure, monitor renal function, including blood urea nitrogen, serum creatinine and urine output. In addition, monitor patients for clinical signs of hemolysis or pulmonary adverse reactions (eg, transfusion-related acute lung injury [TRALI]).

Hizentra is derived from human blood. The risk of transmission of infectious agents, including viruses and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent and its variant (vCJD), cannot be completely eliminated.

The most common adverse reactions (observed in ≥5% of study subjects) were local infusion-site reactions, as well as headache, diarrhea, fatigue, back pain, nausea, extremity pain, cough, upper respiratory tract infection, rash, pruritus, vomiting, upper abdominal pain, migraine, arthralgia, pain, fall, and nasopharyngitis.

The passive transfer of antibodies can interfere with response to live virus vaccines and lead to misinterpretation of serologic test results.

Please see accompanying full prescribing information for Hizentra, including boxed warning.

To report SUSPECTED ADVERSE REACTIONS, contact the CSL Behring Pharmacovigilance Department at 1-866-915-6958 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

ReachMD Announcer:
This medical industry feature was sponsored by CSL Behring. If you missed any part of this discussion or to find others in this series, visit *Clinician's Roundtable* on ReachMD.com, where you can Be Part of the Knowledge.

References:

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5. Data on File. Available from CSL Behring as DOF HIZ-005. 2024.