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Interdisciplinary Cross Talk—Putting It All Together (Part 1)

Announcer:
Welcome to CME on ReachMD. This episode is part of our MinuteCME curriculum.
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Dr. Patel:
Hi, I'm Dr. Bhumika Patel. I'm from Prisma Health University of South Carolina-Greenville. And here with me is Dr. Ilene Weitz.

Dr. Weitz:
Hi, I'm Dr. Ilene Weitz. I'm from the Keck School of Medicine-USC in Southern California.

Dr. Patel:
Today, we're going to have an exciting discussion about talking about PNH and Dr. Weitz and I will, you know, tell you about our experience with PNH from diagnosis and the current therapies available. So Dr. Weitz, we know that PNH is a rare disease. What are some of the things, what are the some of the challenges have you faced with diagno- disease awareness and diagnosis of this disease in your practice?

Dr. Weitz:
Well, because it's such a rare disease very few people think about it. And in order to diagnose it, you need to think about it. Most of the time, the patients will have seen at least four doctors before they get to me or get to you. And the biggest challenge is recognizing that the patient has unexplained hemolysis and that's probably the hardest thing for people to diagnose.

Dr. Patel:
Have there been any circumstances, I know personally I've come across it, where misdiagnosis have happened, right? Where there's delay to diagnosis to PNH and misdiagnosis of PNH. Have you had any circumstances where you've come across complex cases where, you know a T- like I've had TIAs that have come across and it was a misdiagnosis. Like they just said it was iron deficiency, a TIA, but it was actually PNH. Have you had any of those types of cases and scenarios?

Dr. Weitz:
Well, I think most people think of PNH as only a hemolytic disease, but in fact it's a highly pro-thrombotic disease. So if you have patients who are, who are diagnosed with unusual, especially unusual thrombotic events you should think of PNH in that setting. Especially if they have evidence of hemolysis.

Dr. Patel:
Totally agree. And where do you think primary- do you- I know that community doctors are really involved in in helping us evaluate these patients. You know, what do you think is the role of primary care doctors besides recognition of hemolysis? I think there's a delay to referral to hematologists. What are some of the things that do you think we should recommend to community doctors and sending them to us, so that way we can accurately diagnose them and getting them on treatment promptly?

Dr. Weitz:
Well, I think if the patient has evidence of hemolysis and they have evidence of unusual thrombosis or their pancytopenic, I think it's pretty clear that that patient needs to go to a specialist. So, it's not a fault if to not manage that patient yourself. The problem is that it's PNH is such a complex disease and the treatments are complex. So, it's much better to refer that patient to a center of excellence with somebody who had experience taking care of that patient

Dr. Patel:
Agree. And so in, you know, with diagnosis of PNH some of the PNH complications can be overlooked, you know like such as, you know, thrombosis, right. We know there's atypical sides but, some patients show with typical sides that we commonly see. What are some of the recommendations could you give to community doctors or the community that if they do see a clot, would you screen everybody with a unprovoked clot for PNH?

Dr. Weitz:
No. I think we probably would not screen every unprovoked thrombosis, but I think patients who present with a Budd-Chiari syndrome, patients who present with cavernous sinus thrombosis. Those kinds of patients there are specific things associated with those disorders but PNH is one of them. So you might think about it in that setting.

Dr. Patel:
Right. And in this setting, you know, like, so with diagnosis from diagnosis, from, you know, diagnosis to now when they get to their primary hematologist what are some of the key points should patients be aware of when they're diagnosed with PNH? What should they be aware of in your opinion?

Dr. Weitz:
Well, they need to receive some education on the disease and what it means to them. And since there are now several approved treatments with more coming down the line I think it's really important for them to understand why it's important for them to get treated, when they should get treated, and the fact that once they start treatment, all of the treatments will need to be continued for a lifetime.

Dr. Patel:
Right. And I think patients, you know that's the first question at least I got was am I gonna have to take is this a treatment for six months to 12 months? I'm like, this is lifelong treatment. And, you know, and I think a lot of there's a lot of anxiety also for patients once they're diagnosed, right? There was a delay to diagnosis for most patients because they've gone through several doctors as you mentioned, but I guess lifelong treatment is one of the concerns I always see, like, you know they're like, you know, can I afford it? Affordability because of insurance, you know, can I, does it, you know have complications with other medications? So, you know, once patients are diagnosed you know, there is, as you mentioned there's several therapeutic options available. How do you decide on what initial therapy do you start them on? Because now we have we have C5 inhibitors that are FDA approved and we have C3 inhibitors that's FDA approved. How do you decide on the sequential, you know, treatment of these patients now?

Dr. Weitz:
Mm, well, I think we're all working through this. There's no question that we have multiple years of efficacy of a C5 inhibitor. So, and we don't would not necessarily need to start a patient on eculizumab unless they were in the hospital with complications. And in that setting, we would only be able to use eculizumab because of pharmacy restrictions. But, we would probably start someone on a C five inhibitor. That would be the initial treatment but we have recently started someone just on a C3 inhibitor.

On pegcetacoplan so, and there is an insurance very large insurance company in the in Southern California that has made that their mandate that you have to start a C3 inhibitor first even though, the published literature is not there. But in spite of that, so you may be able to start on a C3 inhibitor without even doing a C5 inhibitor. So I think that the waters are a little murky right now because we just don't have the body of experience yet.

Dr. Patel:
Thank you for participating in this podcast putting it all together. We hope you enjoyed the dynamic conversation with Dr. Weitz.

Announcer:
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