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Goals of Treatment for Primary Biliary Cholangitis: A Balancing Act

Announcer:
Welcome to CME on ReachMD. This episode is part of our MinuteCE curriculum.

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Dr. Kowdley:
This is CME on ReachMD. I'm Dr. Kris Kowdley, and here with me today is patient Sabrina, who is going to talk about primary biliary cholangitis and her symptoms of pruritus related to having PBC.

PBC may not result in symptoms for many patients, but a substantial proportion of our patients, up to half of the patients who have PBC, may be affected by a range of different symptoms, the most troubling of which frequently is pruritus or itching and which may be accompanied by fatigue.

So, Sabrina, can you tell us a little bit about your symptom journey with PBC and how it's been affecting your life and how it was diagnosed.

Sabrina:
So when I first found out I had liver disease, it was about 7 years ago when we discovered it when my gallbladder was taken out. And it took about a year and a half until I was diagnosed with PBC. And then, I'd say, about 2 years in is when I started getting some itching. It wasn't significant at first but then it really had increased. They had tried a few different medications to see if it would help; it really didn't. I ended up on a clinical trial, which has made a huge difference for the most part. The last week and a half the itching has been pretty severe, and it's all day long, all night long. It interrupts my sleep, prevents me from falling asleep. When I'm out in the public, I'm very self-conscious, I worry about what people think, and it tends to make me not want to go places just because of the stigma that's attached with itching.

Dr. Kowdley:
Do you feel like when you were first diagnosed and had talked about the itching, do you feel like it was something that providers were open to hearing more about? Did they proactively ask you about your symptoms, or do you feel like it was something that you had to voice to be taken seriously about?

Sabrina:
When I was first diagnosed, my providers were not proactive. They weren't asking me about my symptoms. When I would mention them, they would just kind of go, oh, that's – there's nothing we can do. You just gotta deal with it. It was really shoved off to the back burner and disregarded, and it took me, kind of, becoming a lot more proactive and looking for a provider that would listen to me, that listened to what I said, and heard.

Dr. Kowdley:
Yeah, no, I think those are really important points and a couple of things I want to provide some color and commentary on, which is that

your symptoms are not atypical, and first and foremost, it’s not in your head. You’re not imagining it, it’s not a dermatologic problem. And I think that, you know, for a lot of physicians it is very difficult to really get an understanding of the degree to which pruritus can affect quality of life and patients’ symptom burden.

It's also important to recognize that the worsening and improving of the itch does not necessarily mean that your liver disease is getting worse or better. It’s simply a symptom complex that is affected by a variety of different conditions that is related to the liver disease.

So the key takeaways here would be patients should not hesitate to bring up their symptoms of itching. I think we need to be not only cognizant about pruritus as an important symptom burden for patients with PBC, but also learn to quantify it. And it’s very important to identify those patients who have moderate to severe pruritus from those who have mild or intermittent pruritus and really find those patients who are appropriate for clinical trials to consider clinical trials. And also to manage the pruritus using our currently available therapies for which a number of treatments are available and should be implemented in clinical care.

So that’s my key takeaway, and this has been an excellent case review. Thanks for listening.

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