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FSGS: When Solutions Fall Short

Announcer:
Welcome to CE on ReachMD. This activity is provided by Medtelligence. This episode is part of our MinuteCE curriculum.

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Dr. Sise:
This is CE on ReachMD and I'm Dr. Meghan Sise. Focal segmental glomerulosclerosis, or FSGS, can be an extremely stressful diagnosis for a patient to receive. FSGS has a really variable prognosis, which can range from mild proteinuria to rapidly progressive kidney failure, and that uncertainty can be extremely challenging for patients. Treatment is complex. Patients may have side effects from the disease and the treatments they receive for the disease, and even if they achieve a remission with current therapies, there's always a chance of relapse.

Patients worry about the financial impact of treatment and disease. They're frustrated about the unclear cause of why they got this kidney disease. Having to manage dietary restrictions, losing time at work, adjusting to the social and emotional impact of a serious illness, and this may also impact their family planning, as well.

FSGS has important impact on quality of life beyond the financial impact and emotional impact. There is also day-to-day symptoms that patients experience. They can have persistent edema, gain weight; they may struggle with fatigue that interferes with their ability to be as physically active as they may want to be or to work. FSGS may affect their sleep, may, as kidney diseases advance, lead to loss of appetite, and many patients experience foamy urine.

So, next, let's hear from a patient with FSGS about their personal journey with this disease.

Matt:
I was first diagnosed with FSGS in 2020. I noticed a lot of leg swelling but also began to feel a little sluggish, and that was going on for a few months before I saw my primary care physician for a physical.

Before I left the office, my primary pulled me back in and said the initial tests they run, bloodwork and urine work, showed a lot of different things that were unexpected.

It took about 3 or 4 months of seeing different specialists, including a urologist, an endocrinologist, and there wasn't a clear diagnosis about what was going on. But my symptoms worsened, and that prompted my wife to make me go to a walk-in clinic.

The physician at the walk-in clinic sent me to the local ER, and he told me that it was clear I had something wrong with my kidneys and I should see a nephrologist as soon as possible. And at the time, I didn't know what a nephrologist was.

He explained to me what the different types of FSGS were. So that was quite a relief, just to know what was causing all the other symptoms. However, at the same time, it was a lot of anxiety around it. So being diagnosed with a disease which is degenerative in nature, for which there's no cure, and oftentimes can lead to kidney failure or the need for dialysis. So not knowing where I stood and when should I expect those things to happen?

At the time, I just started a new job. I was supposed to be traveling a lot, so being able to absorb that and then to explain it to my family was a pretty anxious moment as well. I didn't want to underplay it, but I didn't want to create unnecessary concern at the same time. But when you tell someone you have a disease, it's hard to minimize the impact.

But the more time I spent with my nephrologist and mapped out a standard course of treatment, it was less anxiety.

About 6 months ago I was officially in remission. But remission is a scary word even though it's a positive one, because it means the disease has stopped progressing. And the discussions I've had with my nephrologist is, how long does remission last? And it changes. Some people could be a couple years. Some people could be 10 years. You go out of remission, go back on treatment.

In my case, fortunately, FSGS, there's a lot of research going into it. There's multiple drugs going through various stages of clinical trials, so even if I were to come out of remission in a few years, optimistically, there'll be new forms of treatment which I could take advantage of.

Dr. Sise:
It's important to look beyond the blood and urine test results to determine how FSGS is affecting someone's life. This involves having enough time to have open conversations with patients and using patient-reported outcome tools to assess how their quality of life is. It's recommended that we ask open-ended questions, like: What is the hardest part of living with FSGS? What activities have you had to cut back on because of your disease? And what's changed since our last visit?

But there are also tools that can standardize this, and patient-reported outcomes allow the patient to report their symptoms without a clinician's interpretation. It's important going forward that clinical trials use patient-reported outcomes, both kidney disease-focused and general health status-focused patient-reported outcomes that cover domains like fatigue and edema so that we can really understand how the treatments that are coming down the line will affect patients’ quality of life.

Our time’s up, but I hope you found this information helpful and hearing about our patient’s journey enlightening. Thank you for joining me today

Announcer:
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