

SPEAKER: Once a diagnosis of Fabry disease has been confirmed, then one of the questions is, well, how do we go about plugging in the patients for treatment? And what are all of the aspects of care? So the initial presentation can be to a cardiologist, a nephrologist, a neurologist with stroke or pain, or frequently will also be a geneticist. And each of those specialties, quite frankly, should be involved in the care of most patients.

So I like to use a multidisciplinary approach. I am a clinical geneticist, and I take care of a number of patients with federal disease. But I do not know the intimate details of the cardiology at a level where I will always know what is the state-of-the-art management from a heart standpoint. So I need to have input from the cardiologist on those patients.

Similarly, if I have a patient who has some evidence of kidney disease, I can't do dialysis. I am not the person who knows when dialysis should be considered, or when a kidney transplant might need to be considered, or what the best preventative kidney interventions are. So I need the nephrologist.

On the other hand, if a nephrologist is the person who's recognized the condition, they may be very much capable of managing the kidney disease that led to the diagnosis, but they may not be as comfortable with, for example, tracking down the other family members who are at risk and talking to them about Fabry disease or with what medications to use to manage the Fabry pain. And so we need the input of-- it needs to be a multidisciplinary approach with kidney problems being monitored by nephrology, cardiac complications being monitored by the cardiologist, and some of the non-specific aspects of fibrinolysis disease being managed by a geneticist and/or neurologist.

And finally, there is also a role for specialty centers in Fabry disease because, just to be blunt about it, you get good at what you do. And so if new questions are coming up or if there are questions as far as are we optimizing the therapy completely, somebody who has seen dozens of patients with Fabry disease is more likely to be really sensitive to those issues than somebody who only has one or two.

On the other hand, we need the local providers who only have one or two patients to be involved because I can't see patients every two weeks if they're five hours from my office. So there is a collaborative model that we need to put together for multidisciplinary care that addresses needs based on the location that the patient lives, as well as each of the systems that's involved with Fabry disease.