

LESSONS LEARNED IN TREATING PATIENTS WITH DYSAUTONOMIA

An Interview with Miguel Trevino, MD

By Kelly Freeman

Dr. Miguel Trevino started treating patients with dysautonomia in October 2011. He is in private practice specializing in internal medicine and medication research in Largo, Florida. Although he has no formal training in autonomic medicine, he regularly sees patients with POTS and other forms of dysautonomia. He is also a member of The Dysautonomia Project's Local Medical Advisory Board.

Describe your first patient with dysautonomia.

My first patient was you, Kelly. You came in and had 50 different symptoms, including headache, brain fog, fatigue, dizziness, intestinal issues, palpitations, and jitteriness. You had a ton of symptoms. We went through them all one by one. Your heart rate was going too fast for no reason, so I figured there was something wrong. We ordered a tilt table test, and that's how we got started.

How did you learn about POTS?

I read and learned about POTS on the Internet. As I recall, you directed me to some different websites.

Describe other dysautonomia patients you've recognized and treated.

I have everything from dysautonomia patients that are completely functional to dysautonomia patients that are not functioning at all in their daily lives. In most cases, with trying different treatments, and often a different combination of therapies, you can get them to a place where they are at least more functional than they were. So if their dysfunction was a 10 out of 10 and we can get them to a 4 out of 10, I consider that a great success. A lot of the non-functional patients don't do anything. They don't go out, don't go to the mall, and don't go shopping. Some lie in bed all day. But with a combination of therapies most patients do improve. In some of the really complex cases, I've seen patients that don't improve. Nothing I've tried so far works with them.

Besides POTS, what other forms of dysautonomia have you treated?

I'm not a dysautonomia specialist, so I see a lot of different types of patients on regular basis. For a lot of them who have diabetes, dysmotility problems, Parkinson's and other conditions, dysautonomia is also a part of their disease.

Do you think most physicians miss the connection that autonomic dysfunction exists in other conditions?

I think most physicians recognize dysautonomia in general but most don't recognize the variety and amount of symptoms that it can cause. So what I think happens is the patient comes in, has 50 complaints, and they only have 15 minutes to voice them. It's hard to connect that all the symptoms, all 50 of them, are because of dysautonomia. I don't think many physicians make that connection.

Were you familiar with dysautonomia before treating your first patient? I knew what dysautonomia was, but I didn't know the extent of dysautonomia that people with POTS have.

Do you think dysautonomia is more common than most physicians recognize?

Yes, I do. But I have no statistics on that.

What advice would you give to a physician dealing with a dysautonomia patient for the first time? When you have somebody with a ton of symptoms, you have to really try to figure out each one of them. And I think an important question is, "Does it get better when you lie down?" Sometimes the patient doesn't know. But if the symptom generally gets better when the patient lies down, it is probably dysautonomia. There are some symptoms that don't improve when you lie down. And there are a lot of residual effects of epinephrine and norepinephrine when a patient is upright. Once that cascade triggers and tachycardia occurs, the effects can last for days. So one of the most important questions is: "Does it go away when you lie down?"

I'd say in 60% of POTS patients, when you stand them upright, you can see their heart rate go from 80 to 120 in two minutes. So you don't even have to do a 10-minute standing test. As they are standing in front of you, they'll start having symptoms. And the symptoms will go away when you lay them back down. That is a simple thing a doctor could do on a day-to-day basis. This is especially important when you are faced with a patient with so many non-specific symptoms.

What treatment has been most effective in patients you've treated?

It takes three to four months to figure out what is going to work for most patients. It is usually a combination of things that they do along with medications. There is no single treatment that works in every patient. For example, I had a patient with POTS yesterday. The way I found out she had POTS is that she mentioned craving salt since she was a 13- year-old. She is now in her 20s. She gets very sick when she takes beta-blockers, although most patients can tolerate a little bit of beta-blockers. You may have to change treatment and try different ones. There is a great deal of trial and error involved. *Is there anything that is important for physicians and/or patients to know?*

The most important thing is to be patient. The biggest problem treating dysautonomia is, it takes time. And nobody has extra time. Time is our most precious commodity.

Miguel Esteban Trevino, MD, is Medical Director of Innovative Research of West Florida, Inc. and maintains a large private internal medicine practice in Clearwater, Florida. Dr. Trevino has been a Board Certified



Internal Medicine Practitioner since 1990. His hospital appointments include both community and private practice in Pinellas County. Innovative Research is at the forefront of Clinical Trial Research, and he has been in charge of over 250 important clinical trials bringing new drugs to market in the United States since 2002. Dr. Miguel Trevino is member of the Tampa Bay Local Medical Advisory Board for The Dysautonomia Project. He has no formal training in autonomic medicine, but has been treating patients with dysautonomia since 2011.