# Paul Turner

You can watch the video of this podcast at: youtu.be/vj2NFuDwo-Q

[00:00:01] **Dr. GG deFiebre:** Hello and welcome to the SRNA “Ask the Expert” podcast series. This podcast is a “Community Spotlight” episode featuring SRNA community member, Paul Turner. My name is GG deFiebre and I moderated this podcast. SRNA is a non-profit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org. Our 2023 “Ask the Expert” podcast series is sponsored in part by Horizon Therapeutics, Alexion, AstraZeneca Rare Disease, and Genentech.

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[00:01:36] Again, for today's podcast. I was joined by Paul Turner. Paul is the youngest of five kids and grew up in South Florida until he was 19 years old when he moved to Southern California and lived there for another 35 years. He has been married to his wife for 33 years. They raised their son and daughter in Ventura County, California. He worked in IT at the entertainment studios in Southern California. Paul and his wife recently moved back to Florida a few years after the onset of his transverse myelitis in 2017 at age 55. You can read more about Paul on our website.

[00:02:11] Thank you so much for joining me today. Do you mind just briefly introducing yourself?

[00:02:15] **Paul Turner:** I'm Paul Turner, 59. I'm married for 35 years or 36 years with a couple of grown kids. Got TM five years ago. My anniversary was about a week ago. So, yay for Paul. And I live in Florida. I was in California for the last 35 years, grew up in South Florida, then moved back here. A bunch of family is here. I went on disability. Just more affordable here than California in a big way. So, that's who I am.

[00:02:56] This happened to me and it's the next chapter in my life. So, it happened at 54 and then I was in California for a couple of years. And then we were going to move anyway but we just pushed that quicker. So, that's a quick background of who I am. I worked in IT for the studios in LA for 24 years and I was on-site at Warner and Paramount, and I was outsourced. So, I had the IT staff for most of the studios for desktop support, help desk, some networking, but a couple 100, 300 people, maybe, whatever. So, I grew up in that. So, that's who I am.

[00:03:52] **Dr. GG deFiebre:** So, when did you start experiencing symptoms of transverse myelitis, and what were these initial symptoms?

[00:03:57] **Paul Turner:** I don't know that I had a lot of symptoms early. I had some urinary incontinence showing up, but I thought it was prostate stuff, being 55. I see the doctor to see if I can get on Flomax or whatever. The last couple of weeks before, kind of worse. And then I went to the doctors. I had Kaiser at the time, out in LA and really good doctors. And with them, you got to have to push your way through to find one and I was there for 23 years. So, I'm like, “I’m not feeling great.” She goes, “Okay. Well, you don't have a fever.” And so, anyway, it went away. I was good to go. So, I didn't have a lot of symptoms. I just woke up one morning at 4:27. I felt like someone put a girdle on my butt and my legs. I went to go to the bathroom and my wife had to come get me and try to get me back and we'll get into that later. Not a lot of symptoms. So, it was pretty quick, like 90 seconds to two minutes. I went from old Paul to next chapter Paul.

[00:05:04] **Dr. GG deFiebre:** And so, when this happened, did you go to the emergency room?

[00:05:09] **Paul Turner:** Yeah.

[00:05:09] **Dr. GG deFiebre:** You went to the emergency room there?

[00:05:12] **Paul Turner:** Yeah. We called the paramedics after 10 minutes. I'm like, “Okay, I can't breathe really well.” My wife's like, “Okay, we're calling them.” So, these paramedics show up and they're all good-looking guys. It’s just what happens with firemen. After 20 minutes they took me and took me to Los Robles in Thousand Oaks. My wife was with me, and my son happened to be staying over that night. And I walked into the ER, and they had called in because I think that’s what the paramedics do. I think they tried to eliminate what you don’t have rather than trying to figure out what you have, if you're not having a stroke, not having a heart attack.

[00:05:50] So, I went in there and I was nervous. And so, we went in there and they knew I was coming. It's a smaller hospital. I went in there and the nurse says, “Okay. We're going to put you in here.” And the doctor met me two minutes after I walked in there and he didn't look really confident, and I wasn't really pleased with that. I said to him, “Look, I just urinated and can’t move my legs, and I need you to look more confident right now for me and my wife.” “Okay.”

[00:06:29] They called someone in to do an MRI and they did that around 5:00, and then I was put in ICU. And so, I went in there. They didn't know just like everybody else, TM, they don't know. That's the other thing, Guillain-Barré. Everybody thinks that. So, I was in there for a couple of days, like a day and a half to two days. That wasn't Kaiser, that was a local. And then had this really uncomfortable doctor in ICU, the guy was just brutal.

[00:07:06] So, Kaiser found out quickly, so they had me transferred within a day and a half to the-- it's just under ICU, I forget what they call it. And at sunset, Kaiser, which is one of the bigger hospitals where I was put under Dr. Langer from Stanford for a bunch of years. So, that's what happened. I went in and they got me out of there as soon as they could, because they didn't know. And time’s of the essence, I think they knew that they put me on steroids right away. So, that was good looking back. And they were trying to figure out what's going on. But they were lost, but that's, how it is. They don't know.

[00:07:51] **Dr. GG deFiebre:** So, did they do an MRI or lumbar puncture, what testing did they do?

[00:07:58] **Paul Turner:** When I got to Kaiser, they did everything. I think I had three MRIs, one with contrast, had a CAT scan early on, because that's what they can schedule for. And then I was up and down the whole time just to get back into the lab and I got to know these guys pretty well. And actually, the one I first went in was about three-and-a-half hours, it was a long one. They put me out for that. Anyway, so I had all these, and they did the puncture and they sent that out, I think to Mayo, and I heard there's one in Arizona, they sent that out. I think Kaiser does that. And so, we're waiting on that. Meanwhile, they're trying to figure it out, trying to eliminate. Is it Guillain-Barré? Is it MS? And they are looking for lesions in my brain because they saw the lesions on my spine in two spots. I have it in two spots. I don't know exactly where. I should probably know that. It's high and it's low.

[00:08:50] I have it in four spots. Both sides. So, I was in there for three weeks and then they were just, "Okay, that's what you have." I guess they were trying to figure out whether I had NMO. That was a push. And so, they're in every day, I didn't see my doctor until the end, but she had her people in there every day. They were figuring it out. They were working hard at it. People give Kaiser a lot of grief because it's a big, huge HMO. But if you're part of the sheep, you're part of the herd. That's what's going to happen. But I was really happy with what they did and how they did it as quickly as they did it, because I don't know. But I can't walk, I can't go to bathroom, whatever. Looking back, I think they did a majority of stuff timely. That's what we're looking for there.

[00:09:43] Then I had plasmapheresis four nights in a row. I had people come in, all my buddies came in, people hang out for four-and-a-half, five hours. Anyway, did that, and then once they figured out, not going to happen, they're not going to figure it out. So, it's going to be inclusive, it's autoimmune. They don't know any of them. They don't know the cause, only how to treat them. So, then they say, "Okay, we're going to discharge you to a spinal cord rehab in Northridge." Northridge Hospital was good.

[00:10:23] So, there's a lot more to it. Obviously, we've all gone through that. But I had great nurses, which is something we need to talk about. I think the front-line people, not so much the doctors. The doctors, they're taught what to look for. And same with the nurses. But the nurses and your CNAs are the front-line people with you every day. They need to be aware of what this is, and it's not their fault they don't. It's just they don't see it. Everybody, "It's Guillain-Barré." I don't want to hear that word again. There's two words. Because I don't.

[00:11:02] So, I just think there needs to be awareness on that and that's something down the line. We'll talk about it. I think that's something I can help with. Because you're with them every day. And I was in this back corner room at Kaiser, and I was under observation, they didn't know. Just under ICU a lot of heart patients in that wing. And so, I was there and everyone come in and eat their lunch with me at 3:00 in the morning or 2:00 in the morning, you talk about stuff. They're interesting people, nurses and some are traveling and people just trying to -- And so, it's just interesting listening to the younger people and older people, what they're doing with their lives. It was good for me mentally and that's a whole another thing. So, that happened and then I went to rehab.

[00:11:50] **Dr. GG deFiebre:** And so, you said you had IV steroids and also plasma exchange, or PLEX?

[00:11:56] **Paul Turner:** I had it over four nights. They did that.

[00:12:01] **Dr. GG deFiebre:** Got it. And so, you said you went to rehab hospital? What did you do there? And what was that experience like?

[00:12:08] **Paul Turner:** Well, I got the shower which was really cool. Finally got a shower. But at Kaiser, I had this guy that came in every week, didn't speak English, because I just came in every morning right after they took my blood. This lady was the greatest of taking blood. I hate needles. Right now, it's no problem. She just was fantastic. At 6:10 every morning she'd take my blood. But this guy would come in every morning and go, "Shower?" So, he'd give me this bath. It was just the greatest. And you start your day like that is good, because someone cares for you and this guy was respectful and you just knew it was important to me.

[00:12:42] And so, I got to take showers. First thing I got to rehab, which was like, all right. And then they put you on a schedule, and I can't remember the head of the-- who it was. But he was from, not City of Hope. He was there for about six months as doctors. He was great. He commended me to hang out and watch sports and whatever it was, and he was just very helpful and a little younger than me and which everybody is at this point, it's weird seeing everybody's younger that's taking care of you.

[00:13:16] So, they put me on a schedule, one of it was how to catheterize, and it's not something I was looking forward to or how to DigiStim. These are things I didn't want to do. So, after a week or two, that's all you're going to do this because you're going to leave and you have to do this. So, it was every day I did something, I did four or five different things, whether it was occupational, you had a transfer or working out and things like that.

[00:13:49] So, it was really cool. I had these two physical therapists. One was in her last year of college and I had one that had been a physical therapist for like 30 years. The combination of them was wild because young girls want to do all this crazy stuff. And I'm like, "Yeah, let's do it." Anyways, and then the other one was like, Yeah -- and she was very funny. We had a lot in common. So, I think I got a lot out of the physical therapy just because I had two ends of the spectrum and they were very helpful with that. So, it was great. And they said okay, you're going after two weeks and I had to really fight with the head of Kaiser. This doctor, she was adamant. I'm like, "No, I'm about to be able to walk in a walker and you're not sending me home." And she's like, "No, we're sending you home." And so, we got into a beef a couple of times and I went over her head and I didn't need that. So, she did. She kept me for another week and I was completely appreciative and I called her on that. But you have to fight for that. It's another week and I was close to be able to walk five feet with the walker, which I wasn't able to do, I wanted to get that. And they sent me home, and that was it. You're home and you get that big clunky drive wheelchair and you're on your own, go figure it out.

[00:15:18] **Dr. GG deFiebre:** That transition is always challenging. I think you have a system when you're in the hospital, you have people to help and then you get home, and it's exciting to be home because you're out of the hospital, no one wants to be in the hospital. But even though it's a good transition. It's still a lot of stuff you have to figure out and it's challenging.

[00:15:37] **Paul Turner:** I was to talk about this later. I think insurance or part of the process should be automatic, whether you want it or not, you should be assigned a psychiatrist. Not a therapist, a psychiatrist in case you need someone to talk to, or if you need meds, nobody wants to be on meds. This is a next chapter, life-changing thing where being on meds, maybe you want to do that. And I think that's not permanent if you don't want to be. And the whole mental health thing, I think it's overlooked or it's just a small percentage.

[00:16:18] I would go to these sessions thinking and most of the people never like gunshot wounds or car accidents stuff. No one had some autoimmune thing, I didn't fit in a lot of times. But I think that needs to be pushed in health care that when you get this, it's the next chapter of your life. And I keep saying that, but you can't walk, you can't go into the bathroom where you used to, things are different and you need help with that and it's not just talking about it. And if you choose to be on meds, that's fine. But you should have that option. Anyway, that's a whole different conversation we can have on that.

[00:16:53] **Dr. GG deFiebre:** It's a good point. I think it's very good at treating the physical aspect, but the mental aspect can be a challenge to get care and chat with someone and figure out how to manage that. So, that makes sense. This was several years ago, what symptoms do you currently experience? And how do you manage them?

[00:17:17] **Paul Turner:** I have neuropathy and everybody was pumping up on the gabapentin which just works, you have to watch that. I think it affects my cognitive and I'm working with my doctor on that on a couple other things, but nothing major. But my biggest problem is I have pain behind my knees, which shouldn't be able to feel anything, but I could feel there, and my hip, my right hip hurts. And I have fatigue. Fatigue is one of the worst things. And I heard this about what they say, fatigue isn't part of spinal cord. Someone explained it to me this one time. Look, it's like wireless, things always going out trying to connect with your head, trying to connect with your brain, and it's getting bounced back and bounced back and it's not going, and mentally get tired and it makes sense. And I do, I get tired and I was never that guy that got really tired all the time.

[00:18:12] So, you have to do that. And so, you have to manage that because it affects your mood, start getting cranky and moving around you. It's not fair to them. And then, just the physical things I'm in a wheelchair, and that really never bothered me. I just accepted that quickly, but my arms get tired. I'm really lucky I'm in a wheelchair. And I say that, because I'm viewed as disabled. Whereas people that have this, that aren't that have barbed wire wrap or have crazy pain, they're expected to live a regular life in life. And that's brutal.

[00:18:57] So, people view me and I'll go to the store and I lift my chair and have a van that someone gave me, my old business guys and I'll pull it into, it's a transit express. I have the sliding door on the driver's side and drive my hands and I'll pull it in. But every once in a while, and everyone wants to help. Every once in a while, you got to let them help, because helping is reciprocal. It helps them, it helps me. But it really helps the people helping you too, you got to give that. So, being in a wheelchair is tough, but it's not the worst part of my illness. It's something I can deal with and transfer. I can do all that. It's the fatigue and the mental aspect, I get depressed and affect that in a big way. But I've always had that now. It's exacerbated, but it's -- I'm 59, I'll be 60s soon. It's just part of what I said, the next chapter of going on, a lot of these things you have to deal with and you can avoid them or you can address them. The easiest thing is to avoid them. But is that the easiest, because it's just difficult to have taken that route. It's a lot of obstacles.

[00:20:09] So, fatigue and tingling in my feet. They get hot and I get restless leg, and my lower back hurts from being in the chair, and UTIs. I’m a guy. I have UTIs now because I can't take antibiotics all the time, because if I do go into the hospital and get some more, but they don't want to give it to you. They don’t want to have to put you on antibiotics because you're going to be resistant to it. So, stuff like that. But again, I have it better than most being in the chair and being a para. And I don't say that to make myself sound like, “Oh.” No, there are days I can't get out of bed, it's foetal. It's foetal position now. But I'm in a chair and I'm viewed as that. And with that, you get some breaks in life just from a perspective from other people. And I feel bad for people that have to work or have to live a regular life and they don't know what they're going through with TMs. TM is very painful and debilitating. I just feel bad for that for people like that. So, I feel bad for myself. But I hope that answers your question.

[00:21:29] **Dr. GG deFiebre:** Yeah. There's people who have invisible disabilities that society might not see them as disabled. So, then they have to operate in a world where they are disabled, but the world doesn't see them that way. And so, then labels them as lazy or not, that sort of thing. And then whereas for those of us who are in chairs, there's barriers there to society and things being inaccessible or assumptions that are made about us. But there's different challenges there. But when talking to people and I do this too, it's always interesting how people say, I'm grateful for this aspect of my experience, and that it's easier for me in this way than it is for other people. But I feel like everyone does that in there for their own circumstances though. It helps reframe and your perspective and helps you live your life with whatever kind of challenges the world throws at you. So, I definitely understand that. Do you have any kind of fears or worries related to your diagnosis?

[00:22:36] **Paul Turner:** I don't. COVID happened. Mine happened in late 2017. And so, I was living in California. We moved out here at my house that we have now, we're renting. My house has not been set up. But I was really concerned about the COVID thing. In Florida, not a big thing, not a big concern for that really. It's okay. It's all right. So, I just stayed in, that was good. I'm not a reclusive guy, I'm a guy that likes to go out and do things and see music or hear music. I want to do that and do things and I didn't. Just having the fear of not knowing what is required. If I got sick, would it really affect me whether it be some long-term stuff?

[00:23:17] So, that was probably the worst thing. I don't have any huge fears. When I was in the hospital, I said, "Look, if someone put me on clinical trials for someone my age, I'm the guy." I'm older, there's probably a category for that. Probably not the highest category, because you want to get younger people in there. But it's not a lot of fear. I think it's about awareness, I would like to do or I think about a lot. But it's the mental aspect of the depression that makes me feel bad, but I'm aware of that. So, I work on it, but not a lot of fear of, "Okay, what's going to happen next?" I'm there, I'm in a wheelchair. I got to catheter. I had prostate cancer. So, I'm working on that, so I have other issues. But I'm better. So, not a lot of fear of what's going to happen. It's okay. Let's roll with it and see if you can get people to understand this. It's still new, five years in is new. But I'm older. If this happened when I was 20, holy smokes, I'd be when I was angry then anyway. I was a 20-year-old guy, not angry, but run it. Run it hard. So, I've been getting a little wiser, put some perspective on.

[00:24:42] **Dr. GG deFiebre:** So, what are you hopeful for as someone with TM?

[00:24:46] **Paul Turner:** I think helping people. Helping newly diagnosed people. For me, it's finding purpose because not having purpose, I'm working on that, it's a void. And so, working in the studio industry forever. It was a hustle. It’s personality, I had to put deals together, people working this down, people out sick, and I was running, and I love that. I was good at it. I aged out of that and was getting into supply chain management and this happened. So, this happened, I worked for another eight months. I realized I couldn't do it. Really gave it an effort. I went four days after coming to hospital, went to work and it was just, yeah, I did it and I had some deals I had to put together for this company that I had to just finish this project.

[00:25:43] I was just exhausted all the time and wearing whatever I wear for my incontinence. And I didn't give myself time to, I don’t know if it's grieve, that's not the deal. But deal with what it was aspect wise of physically as well as mentally what happened to me in two minutes. When I jumped back in, it's what I do. I don't think it was the smartest thing to do, because I didn't understand a lot of things. So, I'm really fortunate. My wife is a nurse and she works a lot of hours, and so I'm fortunate -- I spent a lot of time alone and when she's home, she's home for three or four days at a time because she works since 12 hours shifts. But my hope is that the next five years aren't as experimental. I kind of know what I'm doing. Just going to roll with it and start doing some more things.

[00:26:43] COVID is over. My thing was I would always go to music and the music and I did. I'm not doing that. And I think people that have this early, I'd like to maybe be part of a group that works with people that can have an opinion or voice. Maybe one on one, newly diagnosed spinal cord injury people just early on, because it's tough, man. It's tough if you don't have anybody to talk to, and if you don't know where to go and this is something that's not a lot of people know about it. It's like, oh, you have MS. No, I don't have MS kind of. But I just think there needs to be, maybe that's what I can do and then there's a couple of other things politically I'd like to see happen.

[00:27:39] I go get my driver's license here and I register my car in Florida. Well, they asked me right away, do you have modifications, you have disability? And, yeah. That's a fair question. And they put that on there, but they make you register to vote right then and there. Well, why can't you have that question there and people can check it or not if you don't want it? Maybe that's something I can go do. I'd just like to see a check box on your voters registration that, yeah, I'm disabled. No, some information on candidates that maybe you picked the five things from the ADA and say, okay, these are the five things they want to do. But I really like to see a check marker and it would be such a hard thing to do, but it's not impossible. Then you just scale it over on a national level, maybe Florida first, and just have a check mark and if it's on there, then these politicians can send you some information on what they're doing with the disability or for the handicap, whatever you want to call it, that population. But everybody should have a good wheelchair. You don't have a good wheelchair, you become sedentary. That's just reality. You get a big heavy wheelchair, you're not going anywhere, the older you get, the less you're going to be moving, it a problem. So, anyway, there's my long dissertation on that.

[00:28:52] **Dr. GG deFiebre:** Is there anything you wish medical professionals knew about treating someone with TM?

[00:28:57] **Paul Turner:** Yeah, we talked about before. I just wish that the front-line people were more aware of what this is. And the only way to do that is to get out there and talk to them, if someone comes in and out together, this is what they might have and they see you every day. And the other thing was the mental health part of it. I think that should be an automatic for people where they get assigned somebody. If you don't want to do it, don't do it. But to go see a therapist when it's not under insurance, it's cost-prohibitive a lot of times, and when you just went through a life-changing or you're on the doorstep of a life-changing event that happened, you need help and that's why this group is phenomenal. You can talk to people, you can get onto the top, you can see what the doctors are doing. You can get on these groups. I think that's important. It has to be much bigger. I need to be paid for a lot of the times through insurance or at least a year after whatever we decide to do.

[00:30:09] So, those two things, it's just awareness I guess, and give people a forum to go if they're scared. People are scared when this happens to them. I don't care if you're five years old or 54. They said you're not walking again in the next two years is what you have and then we'll go, I'm like, "Okay, I'm good with that." Let's see if we can come up with, I didn't walk, but I gained some other things stronger. And then I was fortunate, I pushed to have both a therapist and a psychiatrist, and the psychiatrist was great. She was tough, she was brutal on me. And I needed that because I was lethargic. I was angry about why me? So, that's things I'd like to see in the healthcare thing and then see if we can aim towards the government to help a little bit more, we can pay for everybody else's stuff. The funding for everything is tough and I get that, there's only a certain amount of money to go around. And I'm probably talking way out of line as people are fighting for this all day long, it just seems that's not to minimize what people are doing. But I just think it's important that we push these people to do what's important for us too, and we're a huge percentage of the population. We should have some say. There you go.

[00:31:31] **Dr. GG deFiebre:** And so, is there anything you wish your family or friends knew about TM?

[00:31:36] **Paul Turner:** Well, I think they know now. I think in the beginning, people are curious of what happens to you. I was in pretty big areas and did a bunch of things, and then, "Okay, Paul is in the hospital for seven weeks." My birthday was a couple months after, everybody showed up that birthday, we want to see what's going on with Paul. And I think, it's awareness and they understand now, they know and they're helpful and people want to help, get back to the healthcare. I think that's people are going to do and I think people are genuinely good and they do want to help. I just think that's an innate thing. I don't know exactly what I want them to do because there's going to be patient. It can be tough and I've seen it in my family, but you got to be patient with, like you said, the invisible stuff. People parking in the handicap, you don't know how to get out and walk away. You have no idea what that person is going through. I used to be that guy. You shouldn't park there. You're not handicapped. What do you have? You're almost running into the store? Well, we don't know, just a little more kindness, more patient, just in general, not just TM, but just disability in general. Just understanding. Everyone's a judge in life. I thank Simon Cowell for that. Just kidding.

[00:33:10] **Dr. GG deFiebre:** And then are there any last thoughts or anything else you want to mention that I didn't ask about regarding your experience of living with TM?

[00:33:22] **Paul Turner:** No, I think I hit them all. I just think it's something people don't know about, because it’s such a rare thing and we need to, you guys are doing it. If I can help, more than happy to do it, you got to push through funding. You got to push to get awareness. It's just I never thought I'd be in this position. I thought I'd retire and I'll be doing this and running around, and I'm still quite capable of doing a lot of that. But it was a roadblock thrown in front of me and I have to deal with it and like I said, sometimes it's the next chapter. It's not always easy to think that way. But you have to if you want to survive this thing, if you want to go on and have any quality of life and that's a quality of life is such a quoted thing. It's like you just have to be happy or be able to adjust. It's not easy. It's a tough situation and I just think you can make people feel included more. I think that would be step in the right direction. I think the world we live in right now is very polarized. I think it's very judgmental and we just don't know.

[00:34:38] So, let's just be nicer to people and it's tough sometimes I get it, but that's where we live. I think we need to take a step back and look at where we are, and this happened to me, and not happy about it. If you go to the bathroom and other things and not where I want to be. At least 60. I thought, 60, everything about retirement was forced into it. But living on disability is brutal. It’s not enough money. So, these are all my problems. These are not anybody else's problems, but they really are. So, forums like this make it incredibly valuable that they can voice opinions about this or just talk through something. Just have someone say, okay, I hear you. And that's the thing and I've watched you monitor a lot of these things and you do a good job at that. You get the answers and people talk and the doctors, people listen to them, because they're really trying to help them. They're up against the wall with a lack of funding and it's a small percentage of people that have this. So, it's not going to be hugely funded, but you can push for that. I don't know how to do that. I just need to go do it. And so, aiming at all. So, that's my thing. I'm not sure I answered that one.

[00:36:05] **Dr. GG deFiebre:** Well, thank you so much for sharing your story and your experiences. We really appreciate it. So, it's important to share.

[00:36:12] **Paul Turner:** Thanks for what you do. You good at what you do too. So, it's valuable.

[00:36:16] **Dr. GG deFiebre:** Thank you.