

Ben Harris

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[00:00:00] **Intro:** Hello and welcome to the SRNA "Ask the Expert" podcast series, Community Spotlight edition. 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 2022 "Ask the Expert" Podcast series is sponsored in part by Horizon Therapeutics, Alexion, AstraZeneca Rare Disease, and Genentech.

[00:00:33] Horizon is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare autoimmune and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Horizon believes science and compassion must work together to transform lives.

[00:00:57] Alexion AstraZeneca Rare Disease is a global biopharmaceutical company focused on serving patients with severe and rare disorders through the innovation, development, and commercialization of life-transforming therapeutic products. Their goal is to deliver medical breakthroughs where none currently exist, and they are committed to ensuring that patient perspective and community engagement are always at the forefront of their work.

[00:01:24] Founded more than 40 years ago, Genentech is a leading biotechnology company that discovers, develops, manufactures, and commercializes medicines to treat patients with serious and life-threatening medical conditions. The company, a member of the Roche group, has headquarters in South San Francisco, California. For additional information about the company, please visit gene.com.

[00:01:49] For today's podcast, Dr. GG deFiebre was joined by Ben Harris, the Chief Executive Officer of HCA Florida Woodmont Hospital in Tamarac, Florida. He has worked in healthcare for 11 years and the pharmaceutical industry for 10 years. In 2017, Ben was diagnosed with transverse myelitis as a result of neuroinvasive West Nile virus. His experience as a hospital patient for more than six months provides him with a unique understanding of the patient perspective. He and his wife, Abby, live in Parkland with their two children.

[00:02:24] **Dr. GG deFiebre:** Thank you for chatting with me today about your experience with your diagnosis with transverse myelitis. To start, do you mind just briefly introducing yourself?

[00:02:35] **Ben Harris:** Thank you, GG. My name is Ben Harris. I live currently in Parkland, Florida. I'm originally from Texas, which is where--when I was diagnosed and experienced transverse myelitis, it is when I was living in the state of Texas. I've got a wife, two beautiful kids, live here in Florida. The rest of my family is still in Texas. And I'm blessed to be in a spot where, having the life experience of having lived through transverse myelitis, to be in a situation where I am now as the CEO of a hospital where we get to care even for some folks that are dealing with it. And so that's a little bit about who I am. I've been in the healthcare industry for

20 years. I've been with my company for 10 years. And certainly, family and work, and faith are a big part of me. And we used the transverse myelitis experience as something that doesn't define me or doesn't define us as a family, but it's certainly something that happened, and we like the opportunity to share the story that happened and as it happened to me.

[00:03:38] **Dr. GG deFiebre:** Great, thank you and thanks again for being willing to share your story and experiences. So, when did you start experiencing symptoms of transverse myelitis? And what were these initial symptoms?

[00:03:52] **Ben Harris:** So, in 2017, in mid-August, I started feeling a little off. I started feeling a little bit ill. It lingered for a couple of weeks, but it wasn't so challenging that I didn't go to work. I kept going to work, I kept doing things and I actually left town to go out to rural West Texas on a hunting trip and still felt crummy but fought through it. I had even gone to the doctor, and he appropriately said, I think you have something viral. And he ultimately was proven right. But I fought through, I went out on this trip to West Texas, but once I got there, I just felt extremely poor, but just more like a traditional thing. You could have said I had the flu, or I had strap or anything like that and I would have believed you, but I just said, I'm going to stay in bed. So, I stayed in bed for essentially about a day and a half and early morning on September 2nd of 2017, I got out of bed to get something to drink, and I fell out of bed, and I couldn't move. And so, I was at that point essentially paralyzed, didn't really know what it was at the time because prior to that day in 2017, I had been active. I ran regularly to stay fit, I coached my son's baseball team, so I was outside all the time.

[00:05:09] And so, at about 2:30 in the morning when I woke up and couldn't move, fell out of bed, I had people nearby that would have been able to help me, but it didn't really make sense to me. So, I was trying to process like, what's going on, why can't I move? Is it something associated with the illness? So, I laid there for three hours. I could have called out at any time and probably awaken somebody, but laid there for about three hours, processing what was happening. When the other folks that were staying with me woke up, they quickly saw that something was wrong with me. So, they assisted me getting into the back seat of a pickup truck, drove me to a Critical Access Hospital out there in West Texas that started us on a medical journey that we had never expected. So, to walk through that next step of the process, GG, so once I got to the ER there, the additional diagnosis was that I was dehydrated and that the ER physician was going to hang a bag of fluid and then once I got hydrated, I was going to be able to move again.

[00:06:04] So I remember laying there in that ER and watching that bag of fluid go down thinking, all right, things are going to get better, but not improving. And they hung a second bag of fluid at that point. I still wasn't getting any better. And so, they went through a couple other hypotheses and tested things out and they made the decision of, well, we'll go ahead and do a spinal tap on you. But working for a hospital system and working in the healthcare industry, I knew at that point it was probably inappropriate. This wasn't a spot that I wanted to be to seek that kind of care. So, they were able to arrange medical transport via helicopter for me back from rural West Texas to the Dallas metroplex. And I certainly remember that day getting to the ER, certainly knowing some of the folks that I had previously worked with at that hospital were the ones taking care of me as well. And so, I kind of have memory up until they admitted me to the neuro-ICU there on September 2nd, 2017.

[00:07:04] From there, it was within a couple of days I was placed on a ventilator. So, I think the diagnosis of transverse myelitis came pretty quickly in the stay, upon imaging. They knew that that was something what was going on with me. It wasn't until about five days later that they determined that the cause for me was West Nile virus. So, I contracted West Nile virus from a mosquito and to this day, people say, "Do you remember the mosquito bite? Do you remember the mosquito that got you?" But as I said, I was active, I

was outside all the time. And so, it doesn't really stand out to me as that, but that particular mosquito was one that happened to be carrying West Nile virus and infected me.

[00:07:44] And so from a West Nile virus perspective, generally what the research and data would say is that 80% of people with West Nile virus are completely asymptomatic. They get it and they never know it. It's no big deal. Most of the rest of those folks get some level of symptoms of fatigue, but it's transient and temporary and they go back to normal. And then a small percentage of the West Nile virus is classified as neuroinvasive West Nile. Most of that ends up with encephalitis and various things that are on the brain side. But for me, it stayed in my spine.

[00:08:22] And so it manifested itself as transverse myelitis and as one of the doctors later described to me, I had the worst case of demyelination that he had ever seen. So, in my case, certainly for me, I wouldn't have known what transverse myelitis was at the time or what myelin did or the importance of it for the entire nervous system. But for me, it went from the top of my spine to the bottom of my spine. So, any signals that my brain was doing, telling me to move or to breathe or do any of the basic functions of life weren't getting to their destination. Again, so upon imaging, I think is when they determined that it was transverse myelitis, but kind of a unique factor for me is that the trigger forward or the cause they were able to identify was West Nile virus.

[00:09:08] **Dr. GG deFiebre:** Yeah. And so, you mentioned that they did an MRI and found inflammation in your spine. Do you know what other testing they did to determine your diagnosis or even how one gets tested for West Nile or how they came to that diagnosis?

[00:09:27] **Ben Harris:** So certainly again, the transverse myelitis was quick, they were able to see on imaging but beyond that, there still is not to this day a rapid test around West Nile virus. So typically, the lag time is always five days. Even to now it's my understanding that it's a five-day window. But at that point it becomes they're treating symptoms, being the symptoms of transverse myelitis from having to do steroids and plasmapheresis and all the different things that happened to me. I'm not familiar with everything that happened to me because I kind of have a gap in my recollection of it. But I think I have a novel of papers; it comprises all the things that they did for me. But I think because West Nile was a media catcher a period of years ago. It was something that people talked about. But then as other viruses have come and it was Zika and then certainly what we've all been dealing with the past couple of years, I think kind of the bandwidth for research and resource allocation around West Nile virus hasn't been where it once was. And so that's why I don't think the needle's really moved as far as diagnosis and ability to have rapid intervention.

[00:10:36] **Dr. GG deFiebre:** Right. And so, in terms of treatments, I know you said you don't remember much about that time, do you remember do you treat West Nile with antivirals or how does that work? Or is it, as you said, everything just kind of symptom management related to the transverse myelitis piece?

[00:10:56] **Ben Harris:** Yeah, so I think that is when it went from the West Nile being the trigger for it, but really it was how do we keep him alive? And so, there were crucial conversations that were held with my family and my wife. They had had the conversation that he might not make it out of here. As I mentioned, I was on a ventilator within a couple of days. What ended up happening is I was on a ventilator for almost four months. I was on a ventilator from the beginning of September until essentially Christmas Day of 2017. And these days, I really remember and internalize because they're impactful, and I tell folks when they come to work at my hospital, when I talk to patients that most people that do what I do for a living like to wear a tie, but I like to not wear a tie. I like to be able to show off my scars as kind of a badge of honor that that was where my breathing happened. That was life-sustaining technology was keeping me alive for those four months

when I was unable to even breathe on my own. And so, to kind of walk through the rest of the story is really so I spent six weeks in that neuro-ICU where they were really at that point trying to prevent death, trying to keep me alive, whatever it took to keep me alive.

[00:12:04] And so after a period of about six weeks, I think the consensus was I had stabilized enough. So, it moved from the life sustainment phase to the, let's talk about recovery. So, the first step for me after the neuro-ICU at that facility in Plano, Texas that I went to a long-term acute care facility where I tried to get weaned from the ventilator. It's an excruciatingly difficult process that took longer than anybody wanted. But as I said, it was ultimately successful. The last day I was on the ventilator was Christmas Day 2017. And so then about a week after that I was able to transfer to an inpatient rehab facility to begin the process of the next phase, like what's life going to look like when I get out of the hospital? What's life going to look like? What is the upside from a physical standpoint? Can you learn how to walk and talk and eat? And all those things and really work on that in a comprehensive inpatient rehabilitation setting where I was for about March of that year.

[00:13:02] So between neuro-ICU and the LTAC and inpatient rehab, I was in a hospital for over six months, away from my wife and my kids who were, at the time, they were nine and seven years old. So, it was tough on the family as well. My wife was a preschool teacher at our church, and she had to forgo that to really focus in on taking care of the kids. So, it was certainly a season of tribulation and disruption in our lives, but certainly grateful for the medical expertise that allowed me to make it through and to be at a spot where I am today.

[00:13:41] **Dr. GG deFiebre:** Yes, certainly. And so, you mentioned that you did rehabilitation. Was that kind of relearning just how to use your muscles again or relearning how to do activities of daily living and that sort of thing? And what was that experience like having to do all that?

[00:14:00] **Ben Harris:** Yeah, all of the above. So, when I got to the inpatient rehab facility, the first week of January of 2018, I really had not been out of a bed in four months. They had started some kind of bed based physical therapy at the long-term acute care facility where I had been trying to get me up on the walking bars. But essentially, I had no physical capability. I remember laying there, I'd always request my nurses come in at three in the morning just to kind of rearrange my legs because my legs would get uncomfortable. And I didn't have the ability to bend my legs or that kind of thing. And so, you just remember those significant experiences or any significant experiences that are impactful and meaningful in your life in context of what happened. And so, I had to learn how to walk and do everything.

[00:14:46] So it was a starting point. But even when I got out of inpatient rehab after a little over two months, I was still in a wheelchair. So, the recovery, and I think we'll have a chance to talk about this in a few minutes, but the recovery is something that doesn't stop when you get out of inpatient rehab. I made huge progress. To qualify as a patient for inpatient rehab, you have to be able to tolerate three hours of therapy a day and that could be a combination of speech therapy, occupational therapy, physical therapy, but you have to be able to tolerate three hours. So that was a period of the recovery and a period of this episode in our lives, in my life, that really was around how do we maximize outcome and quality of life on the back end of this? But even when I got out of that facility, I was still in a wheelchair and still had to do pretty substantial accommodations around the house and start a program of intensive outpatient rehab once I was discharged from the facility.

[00:15:40] **Dr. GG deFiebre:** Got it. And then, how are you doing now? What symptoms do you currently experience? And how do you manage them now? How many years? Four years out or so from your diagnosis?

[00:15:56] **Ben Harris:** So certainly, there is some level of nerve dysfunction or nerves that don't function like they're supposed to. Again, it becomes a question of what can you do versus what can't you do? So, what

can't I do? Some of the physical things that I did prior to West Nile virus and transverse myelitis include running and being able to move quickly. And so, where I have the nerve challenges is through my trunk. And so, for example, I'm okay distally, like my fingers are okay and I've got one arm that raises up, but this arm over here doesn't work because this shoulder never was able to regenerate those nerves and that's okay. So, I kind of have general trunk weakness, it affects when I cough and I sneeze, and some other things like that. But it's all things that I can deal with. So, there are physical limitations. There are things that I can't do. But there's so much that I can do.

[00:16:47] And so that was when I certainly engaged with SRNA as well to say, "Hey, how do I tell the story? How do I communicate what happened?" It's one of, there is a post-transverse myelitis world. The upside is unlimited. And I think it's also unique to be at a point where I not only work, I was able to continue to work. I was able to do well at work and do well enough to move roles and change roles and now be CEO of a hospital to where it's one that the focus is on what I can do versus what I can't. I remember not too long after I got out of the hospital, after I was out of the wheelchair, but not too long after I got out of the hospital, my son was out in the back of our house shooting baskets. And he said to me, he said, I wish you could still play basketball with me like you used to. And I told him at the time, and I've told people this story that, "Hey, man, it's about focusing on what I can do versus what I can't. And I'm here hanging out with you in the driveway. I'm here with you." And that's the part where that is the big life-changing perspective and that's the focus to where there certainly are things that I can't do. There are things that I certainly wish I could do, but I don't go there. I don't let myself go there because it's not constructive. I worry about what I can do and I'm able to love my family. I love what I can do, love my job, I love what I-- and so it just becomes one of taking that experience and making it a life lesson and a learning experience to really focus on the positive and the importance of a positive attitude. And certainly, it's something that I've seen correlate with my recovery as well.

[00:18:18] **Dr. GG deFiebre:** Right. For sure. Yeah. And I feel like, as people who have potentially lost function in certain areas, and then, like, for me, for example, even though I didn't really recover as much as I thought or had hoped at the time, I'm so grateful for the things I'm able to do, even if it looks different than maybe what I expected my life to look like. So that resonated with me as well, thinking about what I can do and focusing on that as well. So, do you mind just talking a little bit about what the most difficult part of living with TM is and if you have any fears or worries related to your diagnosis? And then we'll talk about what you're hopeful for as someone living with TM.

[00:19:03] **Ben Harris:** That's a good question, GG. And I think for me it's, I'm very fortunate that it's not necessarily the first thing you notice about me, that I have physical challenges or physical deficiencies. And so, people don't know. And so, it's kind of like, I don't feel like I want to tell everybody about it or I'm happy to share. I'm an open book. But like I said earlier, it doesn't define who I am. It's something that happened. But people will assume you can do this, or they'll say, "Hey, do this," and I have to be like, "I can't." They look at me like, oh, why can't you? Another example that makes us laugh is we live down here in Florida. So, we're all near the beach. So, when we go to the beach, and we take the kids and we've got the wagons going through the sand. I'm not much help doing that. And so, my wife, she's a saint, she's doing it and we joke that, you're my pack mule. And I always think like how people are looking at her and like, God, that guy, why is he-- what a jerk. He's making his wife carry all that stuff. And so those are things that are just almost trivial in the grand scheme. It's the things that we can deal with, but people don't realize some of the things that are going on.

[00:20:08] **Dr. GG deFiebre:** Definitely. And so, are there anything-- that you're hopeful for in terms of the future or as someone living with TM or obviously dealing with the aftereffects of West Nile virus as well?

[00:20:21] **Ben Harris:** Yeah. And so, I think there is legitimate-- it's something that doesn't certainly occupy my brain, but it is like, what does it look long-term? Because for me, while I'm blessed and fortunate to have had

the amount of physical recovery that I've had, I also think ahead to the future to where, when I hit retirement age or when I hit 70 or 80 years old because I'm here versus most people being here that when you have the physical-- when you reach the point in life where there is a physical decline, what does that look like for somebody starting at a lower baseline than me? West Nile virus, there is not a whole lot of good long-term research on the long-term outcomes, but the little bit they do have does indicate that there is a decrease in life expectancy. So that's there. But again, it becomes what do we focus on? So, it's about maximizing today and maximizing--and not worrying about what we can't control. Who knows what the world will be like in 30, 40 years? I don't really worry about that. It's something that's on the radar, but those are legitimate concerns and issues that I think people that have encountered West Nile have or have dealt with transverse myelitis as well is because the effect on the--what does the long term look like?

[00:21:28] And so I mentioned that the-- and then certainly my kids that are now-- my daughter is about to turn 14 and my son's 12. And so, it's important to me to always continue to push myself. So, I say that because when I was in inpatient rehab, I saw people that didn't push themselves and I saw that correlate with recovery to where kind of a family mantra that we live by now is about if you're not on the edge of your comfort zone, you're not getting better. And so that's what kind of led us to Florida. We're lifelong Texans and so when the opportunity to come to Florida came up, when my wife and I were discussing it, we said, "Well, it's really outside of our comfort zone, but based on what we've learned, maybe we give it a try." And it's been a huge blessing to me and my family. And so, as it exists today, that's kind of our governing ethos. We do it. If we're not at the edge of our comfort zone, we're not getting better and our strive is to get better each and every day.

[00:22:26] **Dr. GG deFiebre:** So, the next question is, if there's anything you wish medical professionals knew about treating someone with TM. And I think you obviously have a unique perspective as someone who has been through the-- as a patient, right? We all our patients, I guess, throughout our lives at various points, but you've dealt with this from the patient side but also obviously had the experience on the medical side as well. So, what is it that you wish medical professionals knew about treating those with TM?

[00:22:52] **Ben Harris:** So, there's a lot. Certainly, just the resources available. The fact that there is an organization like SRNA that specializes in these rare neuroimmune issues including transverse myelitis. Something else from a medical professional is kind of a consequence of words. And so, I still to this day, I work with a lot of doctors and as we reflect back and reflect back on what happened to me in my time at the various medical facilities, there was variation in demeanor by physicians. And so being a doctor is a tough job, but we remember the ones that were more negative or had a more negative outlook and to where again, we approached it with the top side here is unlimited.

[00:23:30] Not only will we recover, we're going to get back after-- we're going to get back at back after life. We're going to get back after life. And there were some doctors that said, "Oh, he's not going to be able to walk again," or "He might not get out of here," and that kind of thing. And the impact that language from medical professionals has on a family-- now, certainly, you have to calibrate that with reality because there certainly are times when the reality are those things. But as I think back, it still sticks out in our minds those doctors that we worked with that were either trying to calibrate expectations or were setting the bar too low when what I felt like we could achieve or what I could achieve was well beyond that. So that's from a doctor perspective. And then I'll also, GG, answer from a healthcare professional standpoint. And so, this is something I share with folks here at my hospital as well, is that patients can have 99 wonderful experiences with us, with each of us. But if they have a negative interaction with somebody that works at a hospital, that's the one they're going to remember.

[00:24:31] And so I think back to when I was at the long-term acute care facility, there was a provider there that made me feel unsafe, that made me feel insecure. And some of the other people with that hospital, my memory of them is kind of gone. I don't remember all the names, I don't remember-- but I remember that one person. And so, it's important that we as healthcare professionals, as we deliver care to the patients in our hospitals, and what I do on a day-to-day basis, is that we understand that the vulnerabilities and the fear and the insecurity associated with being a patient. And then we have to do our absolute best when we're interacting with patients to make sure that they know that there's nobody more important in our world than them. And that we're going to take care of them and we're going to make sure that each and every interaction we have with them is favorable.

[00:25:21] **Dr. GG deFiebre:** Got it. And then is there anything you wish your friends and family knew about TM?

[00:25:24] **Ben Harris:** To me, I think it's just the awareness of it. Again, I think friends and family certainly know some of the limitations that exist for me, but there's different manifestations and I've gone-- my journey over the past few years, the number of people that say, "Oh my spouse had transverse myelitis," it is a little more proliferate than I would have realized at the time. However, there's just different manifestations. So, there's different long-term consequences. Different people have different levels of recovery. Some people have a much better recovery than I've had. And some people have not the amount of recovery that I have, and the variability associated with it. But for me, it's that there are, for instance, transverse myelitis Centers of Excellence. There are substantial resources. And I think that's one thing that SRNA does well is to be able to connect patients to those resources.

[00:26:16] **Dr. GG deFiebre:** Great. And then do you have any last thoughts or anything else you want to mention that I didn't ask about regarding your experience with this diagnosis?

[00:26:25] **Ben Harris:** So, I want to go back to a little bit of the attitude in life perspective. And so, as I mentioned, it's not life defining, but it's certainly something that happened. And sometimes I feel like it's even a bit cliché, some of the things that I have really internalized as a takeaway for me, but really the importance of a positive attitude. And what really, I saw certainly is when I was in the inpatient rehab facility, I was on the spine rehab floor. So, because what happened to me and because transverse myelitis, I was on the spine floor. Most of the other folks that were there with me in that unit were gunshot wounds or were car accidents. And I got to meet an amazing group of people, some people that I'm still connected with to this day. But what I saw as a patient was the importance of attitude and how it correlated with the recovery to where the folks that, perhaps rightfully so, but the folks that their leading emotion was anger or frustration, or disappointment that this bad thing that happened to them, I saw directly correlate with how much they recovered to where the folks that attacked-- that they got after it, said, hey, like I said earlier, kind of pushed the comfort level, maintain a positive attitude, their recovery was tied to that and having that positive attitude.

[00:27:45] I remember that there was a gentleman in the room across from me who had been in a car wreck. And even when I got there, I remember looking at him thinking, "Oh, that poor guy. That is a rough deal." As I stay connected with him today just on social media, he's running half marathons now and when I first saw him, he was in a halo and had had a traumatic spine injury. And so, I say that, and I watched his attitude for example, and how he had the family support, and he had a positive attitude to where now he's living his life and he's back on track. And so, I think it's one of-- transverse myelitis can be extremely disruptive, extremely awful, but there is hope. It can and does get better. And as long as you keep perspective on the gratitude for what we're able to do versus what we're not able to do, everything is good in the end. And so, it's all-- I certainly wish it hadn't happened, but even though it has happened, I'm so grateful each and every day to

be able to do what I do for a living, to be able to be around my family and have a network of friends who do what we're able to do, and I just feel that we're so blessed. And so, it doesn't have to be a life defining moment, nor does it have to be something that inhibits people from enjoying or experiencing life after they have lived through transverse myelitis.

[00:28:54] **Dr. GG deFiebre:** Definitely. Yeah. And when I speak to people who are newly diagnosed and they ask me for example, "How are you doing now or how are you doing currently?" And I have to say, "Well, I didn't really recover as well as I'd hoped, but you still find ways to adapt and figure out life." And it, again, maybe looks a little different than I expected, but there's ways that I, just again, I'm also so grateful for what I'm able to do and the things I have and all of that. So, I definitely appreciate your perspective and sharing your experience there. A lot of what you said has resonated with my experience too. So, I very much appreciate that.

[00:29:36] **Ben Harris:** Absolutely. I appreciate the opportunity to share my story. So, as I had reached out to SRNA, it was like, how do I share this story? Because I think it's one worth telling, it's a good story, it certainly has a happy ending. But what are some of the takeaways that I have? Because, as we talked about-- and I'm involved with groups around West Nile virus or transverse myelitis, a lot of times, the stories that rise to the top the most are the bad outcomes. And so, I think it's certainly important, I certainly feel a duty to make sure I share my story and say, "Hey, it's not all wonderful on the backside, but it can be." There's certainly challenges that we live with each and every day, but beyond that, life is good and there is plenty of room for hope and positivity and great things to happen after having a life setback, like getting to experience transverse myelitis.

[00:30:26] **Dr. GG deFiebre:** Sure, well, thank you. Thank you so much for sharing your story again.