

# Kim Harrison

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[00:00:02] **Lydia Dubose:** Hello and welcome to the SRNA "Ask the Expert" podcast series, "Community Spotlight Edition." My name is Lydia Dubose, and I moderated this episode. SRNA is a nonprofit focused on support, education, and research of rare neuro immune disorders. You can learn more about us on our website at [wearesrna.org](https://wearesrna.org). "Ask the Expert" is sponsored in part by Amgen; Alexion, AstraZeneca Rare Disease; and UCB.

[00:00:33] And for this episode, we are pleased to be joined by Kim Harrison. Kim used to live in Atlanta and was a co-leader for the Georgia support group there, and she currently lives in St. Augustine, Florida with her husband of 38 years, Brian. Kim contracted transverse myelitis in 2004 while on a business trip in Dallas, Texas and is the adaptive athlete that rolled the 500-mile Camino in Spain with her adaptive wheelchair. You can view her full bio in the podcast description. So welcome, Kim. Thank you so much for taking the time.

[00:01:10] **Kim Harrison:** Thanks for having me, Lydia. I appreciate it.

[00:01:13] **Lydia Dubose:** Would you mind just briefly introducing yourself—who you are, where you are, and then we'll get into a little bit more about your experience with rare immune disorders?

[00:01:25] **Kim Harrison:** I moved from Atlanta down here to St. Augustine now going on right at three years. I guess, because the adaptive sports are a lot bigger down here. And I still like to do tennis and hand cycling. When I was in Atlanta, Shepherd Center put on a lot of adaptive sports events. And so, there's a rehab hospital around here called Brooks, in Jacksonville. That does the same thing. So, I'm able still to golf and use my hand cycle on a lot of the riding trails and stuff like that.

[00:01:54] And having transverse myelitis and leaving your comfort zone was very hard for me. One of the hardest things leaving was my TM family in Atlanta. We met once a month for support group meetings in person. When COVID came around, they continued to do meetings but with Zoom. Now they still have the meetings monthly in person, except for the summer when they take off, they still have them in person, but they also offer online. So, if you can't make it down to Shepherd Center in downtown Atlanta, you can still participate in the meetings, which is really nice. I mean, there were times when the meetings were so big that we'd have to add chairs and go find chairs on the floor to add on. I think twice a year, we would do meetings where the patient would stay in the room and then the family and caregivers would go to another room.

[00:02:41] The one thing Jody and I really stress is it's not just us that TM affects, it's also friends, family, anybody in your life. And sometimes it's like you're not comfortable talking about things when the person you want to talk about is sitting there. So, they would have us—we would separate it—and even the family and friends would say, "It meant a lot to us that we could openly talk about how it's affecting us without trying to hurt the person with TM's feelings," because it is sometimes not a burden, but it can be stressful for family members. One does just see what we go through daily and know they can't help or there's nothing they can

do for us other than empathize with what we're going through. So, I think it was a very good idea that we did something like that twice a year where other people could just vent without worrying it.

[00:03:28] Because the same thing, maybe if I want to vent about—I wouldn't—but let's say my husband's doing something and you don't feel comfortable bringing up. They're sitting there, but we could all talk amongst ourselves. The ones with TM could vent about what's going on without either hurting their feelings or worrying them. Sometimes something's going on that we don't want to worry them, but we could openly talk amongst ourselves. And then, like I said, the other months when we would meet together, it'd be everybody in the same room. Lot of times we'd have guest speakers come in sometimes from different medical vendors, anything that was going on in the community. Jodi was so well versed on NMO, and I would come in with what was going on with TM. So, we coexisted so well with the group, it wasn't like us or them—you have this, we were all together like a family and we all understood what each were going through.

[00:04:17] Any new treatments, trials, anything going on, we try to keep the group apprised of it and then we start our own Facebook group or if anything was coming up in between, we could post what was going on, or let's say there was an adaptive golf event, there was two people with NMO and someone TM and then myself, a TM, that would go to events this. So, anything that was going on in the area, we would apprise the other members of what's going on locally.

[00:04:42] **Lydia Dubose:** Yeah, I love that. And that fits so well with our mission of being stronger together, you might have one thing, and that Jody might have another thing.

[00:04:52] **Kim Harrison:** But we all got it, regardless of if it's what kind of pain or fatigue or whatever. We all still understood. You get someone who broke a leg, and they'll come up to you and go, "Well, I was in a wheelchair for two weeks after I broke my leg." And you're looking at him, "Glad that worked out for you." But we all, when we would talk about aches or pains or fatigue or just the mental part of dealing with it, we all just got it. We understood.

[00:05:19] **Lydia Dubose:** Absolutely. Well, going a little bit further back in time, can you share a little bit about what the onset of TM was like for you? When did you start experiencing your symptoms? And what did that look like? Did you seek medical care right away? And what were those initial days looking like for you and your experience?

[00:05:40] **Kim Harrison:** Well, being on a business trip, I was actually had been out in Dallas for four weeks, and I was two days shy of coming home. When I got up, my foot was asleep. It was tingly, and I kept tapping it on the floor thinking it would wake up. Well, the day before I had been on a forklift, training other people how to load trucks and how to pick up boxes and do stuff. So, I really thought I had just pinched a nerve or pulled a muscle in my back, and it would start feeling better because I had a backache too. And so, it was my right foot that was tingly.

[00:06:08] So I drove on in about two miles to the warehouse and as the morning started progressing, the tingling and the numbness started creeping up my leg real slow, it's like you could feel it moving. And by 9:00, every time I stood up to walk, I kept falling on my face. Literally, I stood up and when I put my right foot down, I fell. And I remember I was stumbling down the hallway, I was holding onto the walls, and I remember this girl walked by me and she goes, "Is that girl drunk?" I'm like, "It's 9:00 in the morning. At least I wait till noon." And so, there was a conference call we had, but I had to make my conference call, and when I stood up, I kept falling.

[00:06:43] So the people in the office there put me in a little office chair and spun me around and got me out into a car and took me to an urgent care. And the doctor didn't want to say anything out loud. But I guess the way the paralysis was on my right side, he thought I was having a stroke. So, he in turn, had me go straight to the ER. Now I make jokes about a lot of stuff. So, by now the tingling is up to about my knee. And so, when we pulled in, they literally were waiting outside for me. And so, I'm cracking jokes like, "Tell mom, I got clean underwear," and just making light of it.

[00:07:16] I remember they took me in the back, and I had just a barrage of doctors running in and checking stuff. Of course, I'm making light of it thinking, just give me a pill or a shot and send me home. It's no big deal. About by noon, by noon is when I couldn't walk anymore. I remember about 11:30 or so, I stumbled to the bathroom and came back and that was the last time I walked without any assisted aid. So, they did an MRI and then they called my husband in Atlanta and now he's back here panicking because he doesn't know what's going on, and I'm making light of it, and the nurse says, "Oh, we're going to admit her, and she'll probably come home tomorrow." And I'm like, "For my foot being asleep, you're going to admit me?" That's what I said.

[00:07:56] Now they're doing an MRI and of course I'm thinking, "Okay, now you just want money out of me." I don't know, I wasn't comprehending, it was really serious. I was making real light of it. So, this was on a Wednesday—they admitted me Wednesday afternoon, my husband flew out on Thursday because it wasn't getting better. But by the time 5:00 rolled around, the paralysis was up in my rib cage, and I could not move my leg at all. Even with the high dose steroids, they started giving me, they suspected they weren't sure what I had. So, they started giving me high doses of IV steroids. So, Thursday morning, the left foot started doing it. So, they upped my steroids again. It took him until Sunday to diagnose me. And we still kid around about this.

[00:08:38] The neurologist comes in with a little clipboard and sits down. He goes, "Doesn't look up, doesn't make eye contact." He goes, "Well, the good news is you don't have MS." He says, "The bad news you have transverse myelitis." And he got up and walked out. I said I know what cooties are. You could have told me I had something I understood. I mean, I literally just was staring like, "What is that?" And unfortunately, what he did is he had the nurses station print what transverse myelitis is off a WebMD and hand it to me. And I guess being a support group leader, that's the one thing I tell people is one, stay off of WebMD, it's the same information from 2004 when I got transverse myelitis as it is now, nothing has changed.

[00:09:18] Reading it off the Internet was, to me, devastating. It made it sound like I'm never going to pee by myself or poop or I'll be dependent on people. If I felt like it was very depressing and upsetting to read something like that off of WebMD. So, what they did was—that was Sunday, they diagnosed me—and then when they realized it wasn't what they call life threatening they moved me from ICU to a regular room. I was in a regular room for four days and then I was supposed to fly back to Atlanta for physical therapy because I could stand on my left foot, but it was numb. I couldn't feel it, but I could still stand on it. And I guess someone dropped the ball, and we're not sure who, and I end up having to stay out there. Well, they put me in assisted living, a 12 bed facility. It was mostly knee and hip replacement people that were in there.

[00:10:08] No kidding. And I still, to this day when they were admitting me, I was on the stretcher, and I remember sitting at the nurse's station and I could hear the two therapists there Googling transverse myelitis. They had heard of it. They had never treated anyone with it. So, they admitted me in my room and the next day, we started therapy, which was maybe an hour, 45 minutes in the morning and then in the afternoon, maybe an hour. So, they were sitting here with pieces of paper like this. Reading what I've got, trying to figure out how to give me therapy. A lot of the therapy they were giving me was more like I said, knee replacement climbing up stairs and trying to get the knee strength. Well, that's not what I had.

[00:10:46] I was admitted there Friday. They don't do therapy Saturday and Sunday. So, I had therapy Monday, and then Thursday they decided I could go home. I had no life skills. I couldn't manage outside the room. So, when I left, I learned how to use curb cut outs with the wheelchair leaving, I learned how to get in a car without a transfer board, going to the airport. I learned how to use public restrooms at the airport. I mean, I was literally given a walker and a wheelchair and just sent home after four days of basically what they call "therapy." Got back home, found a neurologist here, didn't care for him. When I was asking all these questions that I of course, made a mistake of looking off the WebMD, and he goes, "Well, what do you expect me to do?" "Well, I don't know, tell me what I've got." I just still didn't understand what I had and how I even got it. They still couldn't tell me how it happened.

[00:11:38] And so I started going to a neurologist down at Shepherd's Center, which is a larger rehab facility that understood transverse myelitis, Guillain-Barre, things like that, that most facilities don't. And it was almost like when I rolled in there, I felt like I was at home, it felt welcoming. When I talked to the neurologist, he was completely versed on what transverse myelitis is. They've got a pretty good MS clinic down there that understands TM and NMO and other things like that. So, I started going down there to the neurologist and then I started joining some of the adaptive sports events because I could see them on the flyers. One of them is called ASW Adventure Skills Workshop, where we had jet ski, water ski, zip-lining, rockwall climbing—just events all weekend geared for the person with a spinal cord injury.

[00:12:38] I know I've read up a lot, and transverse myelitis is actually classified as a spinal cord injury, but it is under the heading of nontraumatic because we weren't in accident, something didn't break, it's a nontraumatic spinal cord injury. So, we're still classified as a spinal cord injury. A lot of times it's hard to explain to people that I wasn't in an accident. I wasn't doing anything adventurous. I literally woke up, my foot was asleep, and then I was basically paralyzed my waist down. In the house, I can use a walker. My right leg—I can't pick it up. I can't put pressure on it. It just basically drags. Once I leave the house, I use a wheelchair. I can't wear shoes because of the neuropathy pain. I'm always barefoot.

[00:13:08] Everyone's always laughing that—I did do something a while back and I had shoes on, and people are like, "Oh, I jumped out an airplane. I did skydiving." And no one sees me skydiving. All I heard is, "You've got shoes on. I've never seen you with shoes." That is what you took away from this, is that I'm wearing shoes? So, the big joke is that I'm always barefoot. I don't like anything touching my feet. I sleep with my feet outside the bed. I don't even want the sheets touching them. They're that sensitive.

[00:13:35] So as I was coming back home and going to the new what they call normal, I had to self-teach myself a lot when I got home. I'm also a support group leader or an admin on three of the TM pages. And so, a lot of times for its open group, transverse myelitis is open. Anyone can get on the page. Laura, which is amazing. She runs transverse myelitis coalition, it's open, but she definitely stresses medical professionals. Anyone can join and see about transverse myelitis. The one thing is being an open group, it helps family, friends, or anyone even looking about transverse myelitis can find the information. Then there's people living with transverse myelitis. Now, it's only for people with TM and it's closed.

[00:14:22] Because we need areas sometimes - again, like we were talking about the separate support group. A lot of times there's things we want to talk about. We found on some of the open pages, we were talking about our back stinging or something going on, and someone that didn't have transverse myelitis would say, "Well, I understand I pulled my back out last week." You can't compare the two. So, they did make a Facebook page for only people with TM, but it's closed. So, we can still discuss what we're going through without having someone who doesn't understand piping in, that started to get to be an issue.

[00:14:57] I said transverse myelitis page was started by Andrea Denzel back in '09 or so. It's one of the first Facebook pages for transverse myelitis. She's now a registered RN, and she has transverse myelitis. And by her starting that, it opened up so many more doors for other people that they could openly talk about what's going on. And so, if they don't want people seeing what they—they can go to one of the private groups or one of the closed groups, I think one good thing about the open groups is like I said, it lets medical professionals scroll through there and see sometimes firsthand what we're saying. A lot of times doctor's appointments, they get you 10, 15 minutes at the most. Even my primary physician will get on some of the pages and scroll through.

[00:15:43] When I moved down here, I had to find a new primary, which my—the one in Atlanta was awesome. She understood about TM, and this one here, before I went to see her, did a lot of research. So, when I came in, she understood how to treat the whole body with transverse myelitis. I pretty much quit going to a neurologist about five years ago. I did go to one down here when I moved just so I'd have one on file in case something ever happens. Just for me, personally, nothing is going to change. I take the time, I drive up there, you spend \$50 and literally one visit was, "How's the poop and pee?" That's exactly how the visit went.

[00:16:23] So for me, personally, I quit going only because I didn't see the purpose in it. Others that have acute, they have reoccurring—they need to stay on top of it. I don't like taking away from appointment for someone who may need to see a neurologist when nothing's going to change when I leave out the door. My big brother actually has progressive MS. So, I look at someone who needs an appointment to get in there and see the neurologist, versus he's just going to look at me and go, "Well, nothing changed and there's no cure. So, see you in six months." And actually, here's what's interesting. My little brother had Guillain-Barre. So, you have Guillain-Barre, transverse myelitis, all three of us. And originally, they thought my little brother had transverse myelitis, and they changed it to Guillain-Barre because he ended up getting better. So, I mean, the odds of having three family members, all the neurological disorders.

[00:17:19] **Lydia Dubose:** That's really interesting. And you spoke to this a little bit about this, but what does your day look like with TM? And you spoke a little bit about not wearing shoes, but how else does TM impact your day-to-day experience as you're going around life? What does that look like?

[00:17:39] **Kim Harrison:** I think fatigue is the hardest thing to deal with and especially as I've gotten older, October would be 20 years. I was 45 when I got TM, and I'm going on 65. A lot of times I have to look at—let's say we're going to do something at 4:00 in the afternoon depending how physically exhausting it is. A lot of times I have taken a nap before we go to some event, or I won't make it. I have cognitive issues. When I start getting tired, I can't put words into order. I can hear it in my head saying, "The book is red," but what comes out is "red the book," and the words are jumbled, but that's not how I hear them coming out.

[00:18:19] I've learned to deal with the neuropathy pain without taking the medicines. I was on Lyrica and Gabapentin and all the medicines you take for transverse myelitis; it made the cognitive issues even worse. And I'm retired now, but at the time I was working, and I said, "I can't take something that's going to make me..." I felt like I was underwater, and I could hear people talking, but I couldn't engage. And so, I just slowly weaned myself off at all the different medications that they put me on. And again, that's what works for me. That doesn't work for everybody, but it's what worked best for me. I just couldn't function feeling like I was in a fog. I was afraid to drive because of the cognitive issues.

[00:19:01] Like I said, my feet feel like they're on fire and someone's putting them out with an ice pick. That's about the only way I can explain it. If I'm sitting there in a pair of shorts and someone brushes something

up against my leg, it just feels like a porcupine just stung me. I still had the banding pain on my waist. It's on my right side from my belly button all the way back to my back, all my pants come up way up over my waist, even the underwear, everything has to come way up over where the banding pain is. Or it digs into it. I guess, doing the Camino—and there's a surf event coming up here in two weeks and it's at one in the afternoon. Then I know I need to get to bed early the night before and try to sleep in a little bit before we go, or I'll be too tired to do it.

[00:19:51] So I think fatigue is the biggest issue for me having transverse myelitis because a lot of times it does affect things I'm doing because I'll—let's party at the clubhouse. It's going on 7:00, 8:00, and I'm already starting to get tired because I didn't sleep. I didn't take a nap earlier. Then I have to excuse myself or leave. Because once I get fatigue like that, again, the cognitive issues kick in. I'll start slurring my words or I can't put things in place or in order. Again, nobody can ever explain why that happens—the fatigue for no reason. Some days I don't even go anywhere or do anything. I'm just tired and I don't feel like going out or engaging with other people. I'm just tired. I try not to let it affect my social life and that's why I have to look at, like, we have a big paper calendar in the kitchen, and I have to look at what's going on that day. So, I know how to plan if I need to take a nap or am I okay? Sometimes I have to choose two events, which one's going to be the least exhausting for me.

[00:20:57] **Lydia Dubose:** So, there's lots of ways that impacts?

[00:20:58] **Kim Harrison:** Yeah.

[00:20:59] **Lydia Dubose:** And you've been doing a lot to raise awareness for TM over the years. I know with the Georgia group, there are some awareness events that you participated in, and you're telling me you've been carrying this blue sign with you. Can you tell us a little bit about that?

[00:21:17] **Kim Harrison:** It says TM will not win. I don't know if you guys can see that. I've been carrying something like that for about 10, 12 years. What I want people to know is it's not saying a death sentence, but it's going to change our lives, but we can't let it. We've got to try to keep what we say is "our new normal." What can we do to show this it's not going to beat us? We have to keep fighting every day. I have a little retractable sign, I'll carry too, but a lot of times I'm doing something where it's windy and the sign will curl up or it'll bend. So, I try to keep the one that's laminated with me. I've been skydiving and holding that sign out so people can see there still is life after transverse myelitis—the problem is we just have to learn how to deal with how our life changed, both us and the people in our family and friends because it affects them, too.

[00:22:22] As I said, a lot of times, close friends of mine totally understand what I'm going through. But if someone new I've met, it's hard to explain to them, "Yes, I just woke up. No, I didn't do—" People don't understand, and it's hard to explain how I got TM. I don't know. It's still labeled idiopathic. They don't know. I had an upper respiratory infection. And the one thing the neurologist says, he says, "We think what happened was with the upper respiratory infection, your immune system was trying to fight it, it went haywire and attacked your spinal cord," is basically how the layman's terms it was explained to me. So, I go in with a cough and come out in a wheelchair, really?

[00:22:59] So I like carrying my sign around and people see the sign, they see the wording on it, and they ask questions, and it also brings up a conversation about transverse myelitis. As when people ask when I'm in public, I don't care if it's strange or not. I don't have a problem talking about it. When I was doing the Camino, every person I ran into was asking about the chair or why we were there. I'd tell them about transverse myelitis, and I have these little business cards I carry, and it has SNRAs website and their information on it

and I would hand those out so people could go to SRNA and get the information, valid information they're looking for. Certified information and not something off of Google.

[00:23:41] **Lydia Dubose:** And tell us a little bit about why you decided to do the Camino de Santiago. What started that adventure for you?

[00:23:49] **Kim Harrison:** Well, in 2019, a group called I'll Push You did their inaugural Camino de Santiago. They did the French way from Syria. It was 100 kilometers basically right at 60 miles, and it was a six-day event, and I applied for 2020, and with COVID, it was canceled. Then '21, they thought they were going to go, but still COVID was an issue, especially international. So, we had to cancel again. So, I went in 2022 with them. I went with a dear friend. She was a rec therapist from Shepherd Center, Abby Greer. She ended up being my roommate. So, it was six wheelchair users and about 50 plus walkers that were there to help us if we needed it.

[00:24:30] And so it was a lot of people helping push and pull the whole way, and I just felt so empowered, and I found out there's a 500 mile, I thought what we were doing was the Camino. And I started reading up more about it, and there was a 500-mile Camino. And I'm like, "Well, I'd like to do that." And of course, people are like, "You can't do 500 miles in a wheelchair." "What did you just say?" And that's what started it. I had two people say, "You can't do that in a wheelchair." So, someone I met in the 500-mile push, we started talking about doing the five or the, I'll Push You. So, I took up talking about doing the 500 miles and end up being myself as the only wheelchair user having transverse myelitis and then five people help push, pull, or get me unstuck, basically.

[00:25:18] I think I did it more, one, when people said you couldn't do it that a wheelchair won't be able to do the 500 miles, and two, to prove people with TM, still have a life to live. I think that was the biggest thing. I've made so many friends with transverse myelitis. I mean, it sucks having TM. But I'm so blessed with the people I've been able to either meet via social media or in person.

[00:25:47] Real quick, I was in Vegas one time. There's a friend that has—Mary has TM. And she picked us up at the airport and took us to the hotel and I was able to meet with her. So, it's anywhere you travel, you always, "Look, does anyone have TM in this area?" And try to meet up with them while you're there. But they have so many—a lot of people are very negative about me trying to go. They kept saying, "Oh, you're not going to be able to do it?" or "What do you do if you get tired?" And honestly, that's one of the things I worried about was the fatigue. But it's almost like when you're there and you're doing it, your adrenaline's going, and there's so much going on. You don't have time to really think about it until you were done.

[00:26:22] Now, I won't lie, when we were done that night, shower and eat and straight to bed. A lot of the group will go out bar hopping at night. I'm good. I'm going to bed because I knew I needed to get some sleep to be able to conquer the next day. Few days, the fatigue started getting to me and I struggled. I couldn't drink coffee, I started getting tired because then I'd have to go to the bathroom in the middle of nowhere. Literally, it was a field. Not even trees. So, I started carrying caffeine gum. So, if I started feeling fatigued, I could throw a piece of caffeine gum and energize myself. Because I don't have to use a catheter, I'm not for a TM team, I'm surprised. And so many people have told me that, I'm not on a bowel or bladder program. If I feel I need to go, I just go.

[00:27:13] But I did try to limit how much I drank during the day because, I said, sometimes it wouldn't even be a tree. If we could find somewhere to go, then two of the girls would hold a blanket up and I had a thing called a she-wee, and you just go in this cup, and it funnels out like a man's... and I would just have to go in

the middle of nowhere. I used this little folding stool that I used as a shower bench or a walker if I needed. One room we stayed in—our room was on the fifth floor. It was 53 steps just to get to the room. So, I had to sit on my butt and bump.

[00:27:45] And to practice for it, I went to the Lighthouse here in St. Augustine. It's 219 steps, 150 feet up. So, I practiced there a few times—what's the safest way, without me falling, especially if I'm fatigued? Because I start—same thing. My mind doesn't catch up with your body. And so, I just found sitting on my butt and just bumping up and down. We said in the 12th century monastery and it was 30 steps to the room. Then we got up there and it was only two-inch mat on the ground. There was 60 people on these mats with two showers for everybody.

[00:28:19] The Camino was definitely not accessible. Going over there makes you appreciate the ADA to start with quite a few of the curb cut outs. I know they tried but I couldn't help but laugh at them. It's just like this. One place actually advertised, they were wheelchair accessible, and we got there, and they aren't until you get past the first eight steps, and then it was accessible. So again, it's not accessible by any means. And I think one of the things we were trying to show is that if anyone with a disability wants to try it, you need to see the real way we're doing this. With I'll Push You, when we finished at the end of the day, a bus picked us up and took us back to the hotel. Then we had one roommate, you got a comfy little shower. You got meals at the hotel, then meals in the morning, the bus picked us back up and took us where we left off.

[00:29:09] Well, every day we were in a different place. We stayed in hostels the whole way. They call them Mt. Burgess over there. But we stayed in a different place every night. Only two nights in the Camino do we have a rest day where we stayed in the same place twice. So, we left May 8th, started walking in Saint John, France and finished in Santiago, June 11th. So that whole time we only had two rest days. Every day we were up 15-20 miles a day.

[00:29:35] **Lydia Dubose:** Oh, my goodness. Wow.

[00:29:36] **Kim Harrison:** When we went through abandoned—we took the Saint James route, which is the route they took Saint James to his final resting place, and it's called a pilgrim's route. One time, the police were actually sitting in the roadway and told us it was too dangerous to go that route, and they needed us to go around, and we just were around the place and just kept going. There was one time I had to get out of the chair, the chair was too wide for the path, and it was a 30 feet drop off. So, I had to sit and sketch on my butt and then they were trying to bring the chair behind me. And they lost their footing, and the chair just slid 30 feet to the bottom.

[00:30:07] Old abandoned riverbeds, which had rocks like this in it that we had to try to get over. And that's where they had straps in the front that could help pull me or help me get through areas like that. I end up falling seven different times. You can't see it now. But my arms got all these scars on them where I hit a roof, and the chair just flipped, and I put my arm out and the arm took the brunt of it. Quite a few days if we were going off a lot—well, most of this was off-road. It was gravel, dirt, climbing up mountains that weren't paved.

[00:30:42] And I ended up falling seven different times. One of the ones, it was muddy, and the front wheel dug into the mud. And when it did, I went flying headfirst out and then after they got the wheelchair out of the mud, it was so much mud on the wheel, it wouldn't even turn. So, we're trying to get a stick and dig the mud off of it. And then once we got into a bigger village area, we'd have to ask for a garden hose to try to wash. The mud was in the chain, I couldn't even get the chair to go. It's a grit freedom chair, which has two handles that you pump like this, and it had one wheel in front and then your two on the side. What I did with



the side wheels is where the tube is, then I put a Kevlar liner in, then we had the wheel put on. So, the Kevlar liner was between the tube and the tire, which would help prevent any punctures.

[00:31:31] I end up taking three extra tubes with me and then a set of tires that I zip tied underneath the chair because that's an odd size tire. And if something happened to the tire or along the way, there's nowhere you can go get it fixed at. I didn't have my manual chair, so I had to use the grid chair everywhere I went, which could be a little frustrating because that front wheel sticks out about three foot. So, to try to turn or do anything in public, it was very difficult to maneuver in it. I think that was probably the most frustrating thing I had the whole time was just trying to maneuver with that chair out in public. Once I got home, my husband met me at the airport. He had my manual chair, and I got in it. I thought I was like a princess rolling around because it was so—the grid chair weighs 45, 50 pounds. So, it's a heavy steel chair to start with. And it's not comfortable at all. It's just a hard steel chair and...

[00:32:22] **Lydia Dubose:** It's for offroading but not for being in town or getting around other places?

[00:32:26] **Kim Harrison:** No. And not for everyday use. It's just very uncomfortable. So, luckily, I had a good Roho cushion, and I checked the pressure on it every day, made sure it was set just right because I can't get up on that left leg. The big joke was when we would rest, the people who are walking would sit down and rest and take their shoes off and then I'm sitting there standing so I don't get pressure sores. So, we've actually had a cute little video where Andrew's like, "Well, what's wrong with this picture? The people walking or sitting and then the one in the wheelchair is over here standing," which is still funny because people—it freaks them out when they see me stand up, get in a wheelchair and they'll see me stand up and they all just look like that.

[00:33:07] And sometimes people give me that funny look and I'll look, "It's a miracle," because you don't know. They look at you like, "Why is she standing up if she's in a chair?" And I think I like to educate people about what being an incomplete paraplegic is. Incomplete means we do still have some movement, but I can't walk unassisted, but I could stand on my left leg, and I can pivot with it. But that's about as far as I can go without any assisted device. Being over in Spain, the people there were so gracious. It was actually funny. A few of the places, when they saw the wheelchair, were trying to make it accessible, but they were making it worse. It's like they were trying.

[00:33:52] One of the hostels we stayed in, the lady was so sweet. It was level, but the rooms were again, four flights up. So, what she did, she had them bring a bed down and put it in the dining room for me. So, we were laughing at breakfast that I got breakfast in bed because my bed was there, and the dining room table is there. But I look at it as, that was so nice of her to do that. So, I didn't have to climb up the stairs. I've talked to quite a few friends that really want to go do that. And I said, "You really got to look at the terrain and look at places we had to stay."

[00:34:23] We made reservations for all the hostels before we went over. And quite a few wouldn't even let us book the room because of the wheelchair. They were afraid for safety reasons that they wouldn't even let us book it. So that's some of the issues we ran across. Like I said, bathrooms are inaccessible. A lot of the terrain was. I mean, I'm not kidding, if there wasn't boulders like this, we were going over. You definitely have to have the right off-road chair to do that. You can't take a manual chair over or anything like that. It would definitely break it.

[00:34:57] My famous thing, too, is I love to go downhill and put my arms up and go, "Wee!" So, they're always laughing at—it's a thing I do all the time. They said, "Some of these hills and stuff, you're not going to be able to go 'wee.'" And one of the ones was a 3,300 feet mountain we went up; it was a 12% grade getting up.

So, it took all five of us about an hour and something to get up it, and we got our pictures and stuff, and we started to go down and I'm even looking down, it's 18% grade going down. And they said anything over 14 is considered dangerous. And I'm literally looking straight down going, "Wow." So, to pull back on the brakes instead of pulling like this, I grabbed my arms because I could get a better grip this way. I was completely bruised on my arms here by the time we were done, and I burned a hole in the brakes. Because when you brake it, you pull back. There's a bar on both sides of the handlebars. And when you pull back, that's your brake. I was pulling so hard; it burned a hole.

[0:35:52] We thought that was going to happen. So, my husband made me two stainless steel sleeves to put over it. So, once I burned a hole in the brake, we slid the sleeve over and put a pin in it. And I'd say about three weeks later, we started burning a hole in it. And so, I had to turn it. So that's how much I was using the brakes. There were quite a few times that even going down some of the streets, I was passing cars. One of the hills we went down, I passed a car in the wheelchair. That's wild.

[00:36:19] **Lydia Dubose:** But it sounds like you were prepared, you brought those pieces and -

[00:36:26] **Kim Harrison:** Right. I think going with I'll Push You, which is an amazing organization, they opened so many doors and they let people experience the Camino. Even if you need assistance, there was three people on ours that had no use of their arms. And if you try to do what I did the 500 miles, there's no way they could do it. This is just not going to happen. But with I'll Push You, they made it accessible by staying in hotels, by picking the right route to go. I look at somebody, he had progressive MS, Michael, and there's no way he could have done a Camino without going with I'll Push You. Anyone who's looking forward or wants to try to do a Camino. I would strongly suggest looking at I'll Push You. They are already starting the registration for 2025.

[00:37:15] They go two routes. Now they go the French way and then they go the Portuguese way. And so, it's about 60 miles, about 10 miles a day, but it's also what you can do. So, like for me, there was days I was pumping and pushing, I get tired, there's someone there to help, push me. So, you don't feel like you have to do it all on your own the whole time. There's people there to help you the whole way. And a lot of people give up their time and effort, and they pay to go do the Camino to help push. The pushers get a lot out of it, too. Just watching the resilience of the people in the wheelchairs trying to do what they can. Like I said, after going with I'll Push You, I just got this fever, and I wanted to do the whole fight. So, I did. So, we left May 8th from Saint John, France, two days later we crossed into Spain, and we finished. We were supposed to finish June 12th, but we ended up coming in a day early, June 11th.

[00:38:07] **Lydia Dubose:** Did you know your team beforehand, or did you meet them on site and get to know them throughout the journey?

[00:38:13] **Kim Harrison:** I knew three of them from I'll Push You. They were on the I'll Push You group. And then the two ladies that were on the group, I met them when we got to Paris. We all flew into Paris, first met each other, toured for a day, and then took the bullet train down to Saint John. I guess I would suggest if anyone ever wants to do something like this, make sure you know the people well, before you do it. Sometimes we had some issues gelling because, like I said, some of the people, we didn't know each other. So, we were trying to get to know each other in a tough situation, trying to go up and down mountains and rocks and hills and mud and rain and everything else.

[00:38:50] John Martinez, which is from Texas, he was instrumental and getting me across that finish line. He stayed with me the whole way. He was very supportive. He found after about the seventh time I fell; it was because I was getting overconfident. And so, if I started to take off, he'd hold on to the chair and says, "Go

look at that again." I'll be honest, I got cocky a few times, "Oh, I got this." And we actually named this whole bloody thing I got here is, "I don't got this." We named it that.

[00:39:19] It's humbling to know people gave up their time in six weeks to come help me do this. Without the support of the team, I couldn't have done it. I mean, some of the hills were so steep. I was trying to push, and it was so steep. It was actually popping the front wheel up. It was that steep that I'm trying to push the chair, and it's wanting to flip the chair backwards. That's how steep the hill was. So, I would say anyone needs assistance doing that. If they don't, they're a lot younger than me. So, we'd get to laugh and say, "Grandma's got some guns," trying to push all those hills. It was very empowering. I think after the first couple of days when I started feeling, "Okay, you've got this, you can do this." I didn't say it became easier, but it was more of a mental challenge after that than it was physical to keep pushing, to keep doing it.

[00:40:14] And like I said, only having two rest days the whole time. Some mornings we were up at 4:00 in the morning with headlights on our head, and we had one in front of the chair just to see the path. It was so dark when we took off. One of them, we wanted to go to the top of this one mountain and see the sunrise over across, which, we had to get a head start before the sun. Luckily, we finished every day while the sun was still up. A lot of the hostels we stayed in had—they called Pilgrim Mills, where it's just a community meal inside a big dining room, which was a lot of fun. He had people from different countries. He had Google translate out. I met so many amazing people along the way. If we came across anyone that wanted to help push, we'd let him help, push my chair. If I wasn't comfortable, we had a safe word, I'd say, "Oh, look at the squirrels." And "squirrel" was the safe word, and they knew I wasn't comfortable if someone pushed my chair, then they knew not to let him have.

[00:41:04] One day this group, they've been drinking quite a bit, and they wanted to help push. Well, I wasn't comfortable. So, I said, "Oh, look at all the squirrels running around." Then the group knew, don't let them. Sometimes we walk with people, and they'd want to grab on, push for a while. And I think it also helped just complete strangers. I had a lot of people say, "I was getting tired, and I want to give up here. This wheelchair goes by me." They said, "I was wanting to quit and then I see you go buy in a big old pink wheelchair," because I took duct tape and blinged out the chair with pink duct tape. And then on the spokes, I put those plastic straws you put on a kid's bike and those were pink. It got to the point after about the second week where we come to a village and people come, "Oh, I heard about the chair. We heard about you guys along the way." They heard about the wheelchair on the trail. We started a Facebook page called 500 Mile Push, and there's a lot of videos and pictures on there of our ventures along the way, too.

[00:42:04] **Lydia Dubose:** And you spoke a little bit to what access was like and what you did to prepare. Are there any big highlights that stand out to you over the six weeks that you'd like to speak about?

[00:42:19] **Kim Harrison:** It's hard because so much of it was empowering, so much of it. I mean, I cried a lot, and I don't cry. I was just so overwhelmed sometimes by looking up with something, I just - I could finish something and then turn around and look at it and I get real emotional. I can't believe I just made it through that. There's one or two hills that I wanted to get to the top by myself and the group standing there, their hands up ready to help if I needed it. And I said the wheel is popping, I'm struggling, I'm almost in tears, but when I got done, it was... same thing. You just look back. I was crying because I was so emotional that I did it. Not that it was a sad moment.

[00:42:55] I guess finishing was—I said, "We're about two miles from the finish," and people wanted to get coffee, and I said, "No, I can see the cathedral right there, we're finishing." And, I mean, I start crying. When we pulled in, I couldn't stop crying. It took me six takes to even do a video that I had completed because I couldn't stop crying. I was so overwhelmed. I'm looking around... all these people that walked it kept saying,

"I can't believe I walked 500 miles," and they're looking at me going, "I can't believe you pushed 500 miles across." There's one or two times. I think one of them—the most emotional is—and I can't pronounce it. So, I don't want to butcher it.

[00:43:34] It's a cross, and it's the highest point of the Camino, and that's where you leave a memento or you leave something, you leave your sorrows and your worries behind, and you take joy away. Well, I couldn't get up to it. So, I had to crawl through rocks to get to it. And I left something for my sister who had passed and my in-laws. And then when you leave—it's closure, you leave a memento and then you leave away with happiness, you leave your sorrow behind, you leave happiness. Obviously, getting back down is always a lot easier because of gravity. But to get up to the top, I had to crawl on my hands and knees. So, I did get a little bloody doing that. But it's something everybody else was doing, it's something I wanted to do, too.

[00:44:12] Like I said, there's just so many moments that—it's hard to pinpoint one thing because there's so many days it said we'd get done. I'm just looking at the grit chair just going another day. But we got this many miles down. The halfway point was very emotional because it said 248 miles left or however many kilometers. And I'm looking at that going, "Wait a minute. We're already here four weeks, and we're going on 4.5 weeks, and we're only halfway. How are we going to finish in two more weeks?" But then the terrain changed. They sit in a Camino. It's three stages. The beginning, the Pyrenees, which is a lot of the mountains and very rough terrain. They said that's the physical.

[00:44:51] Then halfway at the halfway point, that's the emotional, it's called the Metes, which is the desert, which we think desert cactus and stuff like that. But what is more of just flat, dry, no trees, and not a lot of scenery. And they said that's the emotional part because it gives me a lot of time to think because it's just quiet, nothing to look at. And in the end of it, the last part for Syria on, they call that the spiritual, where you just start feeling it more in your heart than you do the physical part of it. So, there's three stages and actually looking back now, I could feel the difference in the stages as we went along.

[00:45:27] I think one day they did have to put me in a cab for six miles, an accessible taxi. The trail was actually closed, you couldn't go, and people were walking. Well, the problem was we were on a two-lane highway, and you had the cars here, three inches is the white line and then the guard rail, there was nowhere for the chair, and they were sending people ahead and on winding road, they're trying to slow them down. So, we found a cut out and I said—even the team all agreed. So, this is just too dangerous. We can jump out of the way, you can't. So, for six miles, they did put me in a cab and then I met them at the end.

[00:45:59] I got lucky I didn't get sick. I took a lot of Airborne. I honestly try not to be around a lot of people just because of the autoimmune part of it. If I saw anyone with a cold, "Sorry, you're over there." I didn't want to take any chances along the way. I made sure I took multivitamins while I was there and extra iron and things like that to try to help out. But it's hard to explain just one moment other than pulling in and finishing and looking because there's a picture at the very beginning. It's shells and arrows of what you followed on the trail. So, you could come in the trail, and you have to look for a yellow arrow and that's the way you turn. And there's a shell in the beginning that's brass, and you get your picture taken with your foot on it.

[00:46:39] And at the end, there's a shell right in the middle of the Santiago Cathedral, the pavilion there that you put your foot out and get a picture. So, I've got a picture of the start and finish. And I think my second favorite picture is—my front of the wheel was in Spain and the back wheel was in France. I was literally straddling two countries. I thought that was fascinating that the front wheels in Spain and the back wheel is over in France. But like I said, along the way, I did try to educate people. It's hard sometimes when you're passing, and you don't have a lot of time to talk about transverse myelitis because you just can't condense it.

[00:47:16] So I had to learn to give a reader's digest version of the younger people don't know a very short version of what transverse is. And then there's times when we knew we had plenty of time to talk at dinner, then I would go more in depth, but I tried to pass out as many cards as I could so people could look up and get valid information what transverse myelitis is. Like I said, being a support group leader and an admin on some of the pages, that's the first thing we tell people is, "Stay off of WebMD." And even right now someone posted it today, they were looking for a support group somewhere, [www.wearesrna.org](http://www.wearesrna.org), and I always tell people, "What you're needing is going to be on here, whether it be a virtual support group, in person."

[00:48:01] Sometimes someone just to talk to. A lot of times you need a support group leader or someone just to talk to. And those of us have transverse myelitis for quite a while, it's hard to explain. Some days I wake up and it doesn't seem like it happened. And then some days I wake up, "Well, the legs are heavy, they sting. You need to get out of bed and get going." Up until I went back to work, which is interesting because they said it'd be six months to a year before I went back to work. And I went back to work two weeks after getting out of the hospital.

[00:48:31] So I was in the hospital, I contracted transverse myelitis October 6th, 2004, and I went back to work right after Halloween. I got my first disability check and realized, "I need to go back to work," and work was really awesome, too. They had me come down with my chair before I came back to work and check to make sure everything was accessible, what I was going to need when I came back. Looking for new jobs in a wheelchair is very challenging because employers aren't going to say, "We're not going to hire you because of the chair." First thing they see is the chair. So, I always warned them before I was coming for an interview, "I'm in a wheelchair." So, you always get that surprised look.

[00:49:09] Honestly, when I left my last job, I had the best attendance of anyone there. It's interesting. You try to explain to employers that people with disabilities almost work harder to prove we can do a job versus someone without a disability. It's like we're always having to prove something. A lot of times we do stuff, and it's like we're overachievers because we're trying to keep proving to people, we can do what other people can do.

[00:49:33] **Lydia Dubose:** Well, that's amazing. And it's amazing that you completed this big trek, the big push of the Camino and showed that people say you can't, but you say you can and with the team, it was possible. So that's amazing.

[00:49:48] **Kim Harrison:** With the team and a lot of planning and like I said, I went in my eyes wide open, that is not accessible. It is not accessible by any means. But like I said, if you're looking for an accessible Camino, definitely look up, I'll Push You because they make it accessible. And they actually took someone this year with visual impairment. Besides the six wheelchair users, they took some visually impaired and walked with them with their visual aid and explained to him what the Camino was like, walking with it and explaining the trees and the flowers and stuff like that. So, it's not just people with physical impairment, they took someone visually impaired this year, which was new to them.

[00:50:26] So they're very open and very receptive to taking—there was someone that walked last year that walked with a walker the whole way. Like I said, you've trained for it. Now, training in Florida for hills didn't happen because it's flat here. So, I was swimming three days a week with these web gloves that give you more resistance and then a swim mask that has a snorkel here. So, I didn't have to turn and lift my head and turn back and forth, and I'd swim pretty close to a mile each time, three days a week. And in the days I didn't swim, I would go to the weight room down here and just work on upper body strength. It was more my shoulders than my arms because the chair, you push it like this. It was more of my shoulders that were doing the work. So, I did a lot of upper arm weights in the weight room.

[00:51:19] **Lydia Dubose:** Well, lots of preparation and -

[00:51:23] **Kim Harrison:** It took a year.

[00:51:24] **Lydia Dubose:** - everything and it's always a successful trip. So, congratulations on a successful trip.

[00:51:30] **Kim Harrison:** Thank you.

[00:51:31] **Lydia Dubose:** And it's just awesome to hear about the different ways that people can do things living with neuroimmune disorder.

[00:51:40] **Kim Harrison:** And it was also interesting, a lot of my friends with transverse myelitis were taking a lot of the videos and pictures and sharing them, "This is my TM sister and look what she's doing," and some of the other admins on some of the other pages were sharing it. Not to boast or brag or anything like that, I think it's more to show again with a lot of work, it can be done. And again, it depends on everyone's mobility and their physical issues. And if you can't do the 500 like we did, look up an organization that does plan and has it organized with hotels and stuff that has areas that are more accessible.

[00:52:21] But I can say what I did was not accessible at all. I think a few places that I stayed in that I would consider accessible. I did videos every night on the hostels we were staying in, and people were just laughing. One of them, it was flat when you came in, but it was nine stairs to get down to the bathroom. So, I'd have to—remember at night—and remember I stayed in a different place every night. So, I'd have to make sure when I got up, let's say to go to the bathroom, I didn't stumble downstairs. So, I'd have to sit and bump my butt down, go to the bathroom, bump back up again and get back in bed. I was lucky. I got the bottom bunk every time. I called bottom bunk every time, and I got it. But they said we're sharing—when you're sharing two showers with 60 other people. And I know I'm going to take a little longer.

[00:53:05] So, in our group was six total, I'd tell them when we get there. You guys get your shower because it's going to take me just a little longer to get there. And the little stool I carried; I would fold it out. I can use it somewhat as a walker and then I'd fold it out and had a little seat in it. And I could use that as a shower bench and then use it to go back and sit with. But I said, "There's so much about it that was just not accessible at all." Even though someone walking in our group fell and hit her head and got a pretty good egg up here and a big scrape on it. So, I fell out of the chair, but even people who walk fall and trip and get hurt. So, it wasn't just me falling. Laura fell and got a pretty good nod on her head, just slipped on a rock and fell. So, when I fell, it was a lot of it my fault. I was being cocky. I was getting overconfident and going too fast and wasn't paying attention.

[00:54:00] Like I said, I just hit a tree root, and it flipped. I could hit a rock, and it would flip. So, John definitely made sure when I was starting to get overconfident or cocky, he could see it, and he'd hold on to the chair and says, "No, you don't have this." And as we got down to bomb hill, "Oh, yeah, you're right. I couldn't have done that." But he was the voice of reason. So, he made sure I got in safely. A lot of times the other group, the people in the group would let go of the chair, and he grab back onto it and go quit, "Tell her she's okay. She's not going to make it to the bottom without falling." And like I said we got to the bottom; he was right there. A lot of times, I don't listen to the voice of reason because I want to go have fun and see if I can do it.

[00:54:37] But they definitely let me challenge myself a lot. There was a lot of things that - we said when I got to the top of the bottom of the hill or over rocks and stuff, I would just look back going, "I can't believe I did it." One of the mountains—we were actually, when the sun came up the next day we were above the clouds. That's how high up we were. And going down the trails, there was actually the white and red poles that they

put in the roads to gauge snow. That's how high up we had climbed. So, you're going by people walking, and they're looking at the chair like, "I can't believe you just came up that hill. We're huffing and puffing, trying to walk up and you guys just got a wheelchair up it?" And I went, "Yeah, we did. Go ahead and tell me we can't do it." But this is why—not going to win.

[00:55:22] TM is not going to get the better of us. We have got to stay positive, and we've got to push ourselves. Like I said, I didn't think I could do it. I'm older than a lot of people walking the trail, and I was able to finish it. But now I said, once you get started, there's no way you're backing out now, you're there, you're committed, you're going to finish it. But I'd really appreciate a lot of my transverse myelitis friends sharing and commenting on the videos because it helped me. It helped me a lot because I knew they were supporting me the whole way.

[00:55:51] **Lydia Dubose:** Encouragement.

[00:55:54] **Kim Harrison:** It really was. And I said we like to refer to each other like TM brother, TM sister, hey sis, hey bro, because this is how we just—because we're like family without being blood related. And so many of them are sharing a lot of the videos and just giving me encouragement. If I look at the thread, most of them are people with transverse myelitis that were posting the encouraging words to keep going. So that helped a lot. That really did. It's like my TM family really kept me going, and I think it's because of them I finished. It's like I had something to prove to myself, but I also wanted to prove to the transverse myelitis—even then, let's just say SNRA—community because there's other disorders that are not just transverse myelitis. I want to show to the community that it can be done with a lot of work and a lot of planning.

[00:56:47] **Lydia Dubose:** Well, thank you for sharing about it with us and thank you for sharing it all along the way and make sure to include some links to your Facebook page. So, if folks want to look back on those videos, they can check them out. Here before we finish wrapping up, I just wanted to ask, what is something that you wish more people would know or understand about living with transverse myelitis, as you have a lot of conversations with people?

[00:57:14] **Kim Harrison:** I guess a lot of it is you have the people that walk, that have TM, that you can't see. I'll mention Jenna real quick. She's in Georgia. She could walk in the room right now and you don't know if she has transverse myelitis, but she also suffers from a lot of what we do. You just don't see the wheelchair. When we did the Transverse Myelitis Awareness Day in 2013 or '12, when we petitioned the state of Georgia, which is not a proclamation, a lot of the states have a proclamation. It's a generic form you fill out, you send to the governor, he signs it. We actually got a house resolution which is basically law.

[00:57:50] We did it in February. A lot of the states did it in June, I understand that, but we did it in February because it coincides with Rare Disease Month and Rare Disease Day that we do at the State Capitol. We did it in February to coincide with Rare Disease Month. We had to go to the offices on one side, then back to the Capitol and then cross the street, the office. We had to cross back and forth about four times. Poor Jenna was just exhausted when we were done. I'm rolling back and forth in the chair. We're doing the press conference, and people kept asking me questions. They weren't asking Jenna because they saw her walking around.

[00:58:25] And I wish people would understand that. Just because someone walks, they don't see what they're going through, the numbness, the pain, the stinging, the fatigue. She said she had to take two days off of work after that. She was so tired from walking back and forth. But people don't understand that. Also, that... it's still hard to explain to people. We don't know how we get it. There's no explanation. How can you have a cold, and you leave in a wheelchair? It's hard to explain to people that and sometimes, like I said, you don't have a lot to find to discuss it.

[00:59:06] I think SNRA has saved the lives of a lot of people because it gives good information to start with. It's research. Unfortunately, when flu shots come around, we start getting the pros and the cons, and people get into politics. They get into fights whether to get them or not. The podcast put on by SNRA is what I always post on those threads. There are the five podcasts on getting a flu shot and getting COVID shots. And that's the first thing. Around cold flu season, I started posting that as a header so people can start seeing that ahead of time. And when people start getting heated in discussions whether or not to get the shots, that's what I post is the podcast by certified doctors that know about transverse myelitis and NMO and the other disorders.

[00:59:53] So that's usually one of the first things I post. I said first, I put, "Get with your physician. Information off of Facebook and other people's opinions is not medical advice." And then I give them, I said, then I also post the podcast, and I said, "Take a look at these, watch them, and then make an informed decision, but still talk to your doctor." Unfortunately, people still go on Facebook to get medical advice, just like opinions, and everyone has an opinion. But unfortunately, something like that gets very heated, it can get very ugly, and people can start name calling with the pros and cons on vaccines.

[01:00:31] Again, it's a personal decision between the person and their doctor, and really it doesn't belong on Facebook. But again, that's where people go now for advice. I wish it was just an easier way to explain it, but there isn't. Like I said, SNRA, I give that information out to so many people because like I said today, someone looked for support here. That's where you can find one. They ask about certain medications—go here and look at it. Stay off of Google. I tell people: "Don't go to Google. That's the worst information you're going to get." A lot of times people can find out information on transverse myelitis talking to other people at TM.

[01:01:14] I think that's the one good thing about the support groups because, let's say if I can't wear shoes and someone else says, "I can. Well, how do you get through winter?" Up in Atlanta did have some cold winters. I just learned to deal with the cold. Some people learn what to put over their feet or what they can do. And I think reaching out to others with it is probably the most helpful thing. When I got TM, there was no Facebook or Internet. There was a group we had like an email group. It was TMIC and Jim Lewin started it Transverse Myelitis Internet Club or something, and we would get on—it was a thread that we could write things, but it was huge. It was long, it was like an email and it just never—or the subject didn't change or anything like that.

[01:01:56] Then when Facebook came out, it opened the opportunities for others because prior to that, there was no way to meet up with someone with transverse myelitis. You didn't know who was out there because you didn't have social media like you do now, the extra positive is the podcast. All the information that SNRA puts out. If you don't have transverse myelitis in your family member, you can go look at the information that's there, too. Like my husband, he's very supportive. I mean, I wouldn't be where I am without him. He makes sure I have a hand cycle. If I want to go to a race, he makes sure it's loaded. I've got my food; I've got everything I need.

[01:02:32] It's also helpful for family members to go on there and look what other people are going through, especially like I said, a lot of it's invisible. I said, "You can have people clear from ventilators to walkers." Everybody's different. There's no "one size fits all" when it comes to our disorder. I can't even feel my feet, but I can stand on it. It makes no sense, and it probably never will. And it's hard to explain to someone who's not in our community, what you're going through. But I think fatigue is the hardest thing to explain to someone because like I said, I can be fine—I can have a day and didn't do anything, I still feel fatigued.

[01:03:10] There's no rhyme or reason to it. So, I wish there was an easier way to explain it, but there's not, you just have to pick and choose how long the conversation is to how do you explain having transverse myelitis. But I said it's not going to win.



[01:03:26] **Lydia Dubose:** It's not going to win.

[01:03:29] **Kim Harrison:** That's what we did. The TM Walk in in 2013, it was around a third of an acre pond and I got my walker, and it took me an hour and a half, but I would walk, and the wheelchair was behind me and I had to sit and rest, and we made the whole third of a mile around this pond when we did the TM walk. And now doing the 500 miles, and I'm looking at that walk and I'm like, "Wow, I didn't think I could use a walker and go that far around the pond." And now I'm doing 500 miles in an off-road wheelchair.

[01:03:58] Like I said, the communities coming together, is amazing. I wish more people would step up and become support leaders, group leaders. And I wish there was more in person meetings, but again, you can't because Florida is huge, it's hard to do something like that when you could be hours away from somebody. A line is a little smaller so a lot of people can make it in. But I really think the online support group meetings help a lot because it helps people look at others that—I mean, the first time I met someone with transverse myelitis, I just lit up, and now it's I've met so many people with it. I was like, "You got TM too? We just move on."

[01:04:43] But I think having confidence—and for me having transverse myelitis, people always come up, "Oh, you're so open and you talk about it." And I said, "Well, to me, I have to because others need to know." And I said, "I'm a very open book when it comes to—like I said, I don't have the curb, I don't have a bowel program, and at T-ten, I don't know how I got lucky. But I just tell people this is something I've had to learn to deal with. It's like taking a kid somewhere. I have to go potty before we leave. And when we get there, I just got to stop and go potty because once I feel I have to go, it's almost too late.

[01:05:18] So we laughed at younger days because we didn't have kids at how long it took someone to get in a car with a kid. You got the car seat, and you got to put the stroller in the car and now we're looking, we come out, we got to put the walker in the car, we got the wheelchair in the car. And I'm like, "Okay, well, now I understand, I get the struggle." But I said, SNRA has been a lifesaver, and I said back when it was TMA, there's still so much information and I just look at how much the organization has changed and progressed in the 20 years that I've had transverse myelitis. There's so much more information out there, and they dispel so much false information.

[01:05:58] And that's what I like is that you can go and find—like I said, and I don't know, I've repeated it, but you've got medical professionals stating either medicines or therapy and things like that versus something that's 25 years old you get off of Google. If you go to WebMD, the same information is on there then when I got transverse myelitis in '04. One-third get better, one third are like me, walker wheelchair and then one-third are dependent on people or medical equipment. Nothing has changed.

[01:06:33] So to me going off of Google and WebMD, you're going off of old, outdated information. And to me, it's depressing, like it was for me when they gave me this and said, "This is what you've got." To me, it was depressing reading it because it just sounded not like a death sentence, but it just sounded terrible. Looking back now, it's not what I read off of WebMD. It's what you're going to make out of it. And it is hard—not everybody can deal with it the same way. And I'm hoping, seeing the positivity and seeing those of us that are trying or trying to improve or trying to break barriers that others can follow behind.

[01:07:15] Let's say they do a 5K somewhere. You can't do a 5K but walk from your car to where you're going or even roll that far, enter in your own wheelchair if you've got one, enter in a walker. A lot of 5Ks have kids' one mile run—little, short, little 50-yard run, try to enter that with whatever device you have, you don't have to be a kid. The important thing is to start and finish. Time doesn't matter, distance doesn't matter, start and finish. That's all that matters.

[01:07:44] Just like the Camino. I mean, if it took us another two months, we did, but I started and I finished. I think other people with all the neurological disorders don't look at miles, don't look at time, don't look at stuff like that. Try. Even if you sign up for one of the small little, like I said, a 5K that you see little kids running over there, go join them. You don't have to do the 5K, just go join in with however you can finish. If you can't, go support those that can. Cheer them on, even if you have fatigue or mobility issues. You're participating by supporting others—especially those with disabilities—to finish, being there as a supporter for others.

[01:08:25] But as I said, transverse myelitis—be part of the game, be part of the community, but don't let it get you down. I won't lie. I have bad days. I'm not cheerful and happy every day. There's days it does—it's a mental game, and it does get to me, but I try to get past them and move on. I don't let that bad day become bad days. It's the bad day. I have my pity parties occasionally, and I do the "Why me?" and "It's unfair," and get mad, but that's as long as it lasts. I mean, like I said, I wasn't doing anything. I didn't do anything wrong. Why did it happen? But I always look at it happened because maybe I was put—I was given TM to show others how to deal with it, how to survive it, how to live your best life, become a support group leader.

[01:09:18] I mean, you don't have to be this college educated, go through all this—I mean, for our training, we went through some online training courses and HIPAA and stuff like that, you can be a support group leader and not have to be in person. You can talk to someone on the phone and help them out. You don't have to be in person, and it's not a lot of work to become a support group leader to help others. If you have that confidence and you have that desire, I strongly suggest you get a hold of SNRA and become one.

[01:09:47] We didn't have a formal support group through any organization for quite a while until we found SRNA and then we went through you guys and had better training on what to do and how to handle certain situations because sometimes being a support group leader is more than what we are trained to help with. Sometimes it's a situation that—it's just over our head. You can give advice, but sometimes that advice is over what we can do. We also reach out to SNRA, "Here's someone we're talking to. Can you help us out? How do we answer this or can you give us information or ways to give them the support that they need?"

[01:10:24] So I like knowing there's still someone out there that, if someone comes to us and sometimes it's something we just don't know how to answer. We have the tools through SNRA to be able to help others, too. So again, I would strongly suggest if you be a support group leader, help others. You may not think you've got it in you, but a lot of people do, they just don't think they do. I never thought I'd go to Washington DC and advocate for wheelchair users and people with rare neurological disorders. I go once a year with United Spinal to roll on Capitol Hill.

[01:10:58] And again, we're talking about all, not just wheelchairs, just people with disabilities and what our needs are. And it gives me a chance to advocate for transverse myelitis, Rare Disease Day at the Capitol. All we did was call the Capitol, set up, got the day. Usually we did the 29th, but it was only every four years. So, we do around the 28th or around the TM Day, and we'd get other people with other rare disorders to NORD. And sometimes there'd be 10, 12 tables there at the State Capitol inside the Redondo. And we advocate for transverse myelitis, we put banners up, we had lots of flyers from SRNA. They were laughing.

[01:11:37] One year I emailed every single legislator in Georgia to attend. And when they were coming out of sessions, they come downstairs and then turn and go to the next session. So, they were actually laughing at me. I was at the bottom stairs making a figure 8, just rolling like that. And every time someone came downstairs, I handed him a brochure pointed where we were at and says, "I know you got the invite. If you want to come, go and look at what we're doing." And everybody was laughing, saying, "They're not getting by you." And I said, "No, they're not." I know they've got other things to do. But I invited every single legislator, somebody is going to show up.

[01:12:07] And we ended up having five that came and sat and listened to what our needs are, medicines and medical equipment and everything. So, it just takes that one. I said that Senator James took initiative when she read what I want to make the Transverse Myelitis Awareness Day. And she helped pass the house resolution bill, house resolution 809, and will always be in the books for that day. So, I said, a proclamation is easy. You can just, "What do you have? And the whereas, and the whatnot." Well, you just fill in the blanks, and they just send you a piece of paper, but we took the time to basically make a house resolution out of it.

[01:12:49] **Lydia Dubose:** Well, thank you for all that you've been doing to raise awareness for TM and for being a part of the community for the last 20 years and for being a part of SRNA for so long. You're not alone. Everybody else knows TM or other rare immune disorders is not alone. And like you said about your Camino big push, just encouraging one another is what it's all about. And so, thank you for being that.

[01:13:15] **Kim Harrison:** Thank you. Like I said, without you guys, I probably wouldn't be where I'm at. I can tell you that right now. Without the support from SRNA, I wouldn't be where I was at because I said, besides what they've helped me with, they've helped me help others. And that's what's important is to be able to reach out. You help one person, that person can help two or three others, they can help others. So, it starts to branch out. So, it's not just me, you guys have opened the door to help so many out there that, like I said, the first thing I tell people, "Welcome to the group. Here's SRNA." And I do. I said, "Welcome to the group if you haven't registered, [www.wearesrna.org](http://www.wearesrna.org)." And I just repeatedly put that on there so people can get the right information.

[01:13:58] **Lydia Dubose:** Well, thank you for doing that, and thank you for raising awareness and for sharing your story, and I can't wait to hear about your next adventure.

[01:14:12] **Announcer:** Thank you to our "Ask the Expert" sponsors, Amgen; Alexion, AstraZeneca Rare Disease; and UCB. Amgen 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. Amgen believes science and compassion must work together to transform lives.

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