

Rick Telander

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[00:00:02] **Dr. GG deFiebre:** Hello and welcome to the SRNA "Ask the Expert" podcast series. This podcast is titled, "Community Spotlight, Rick Telander." My name is GG deFiebre and I moderated this podcast. SRNA is a non-profit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org. Our "Ask The Expert" podcast series is sponsored in part by Amgen, Alexion, AstraZeneca Rare Disease, and UCB.

[00:00:33] For this podcast I was joined by Rick Telander. Rick Telander is the Senior Sports Columnist for the Chicago Sun-Times. He is the author of 10 books and was previously a senior writer for Sports Illustrated and ESPN, the Magazine. You can view his full bio in the podcast description. So, thank you so much for chatting with me today about your story and your experience with transverse myelitis. To start, do you mind just introducing yourself?

[00:01:02] **Rick Telander:** Yes, I have no problem doing that. I'm Rick Telander. I am the Senior Sports Columnist for the Chicago Sun-Times, a long-time sports writer. Yeah, and I got TM, not that I remember but it was exactly on October 24th, 2009.

[00:01:19] **Dr. GG deFiebre:** And so, when did you start experiencing symptoms of TM? I know you said that you were diagnosed in 2009 but when did you kind of start experiencing symptoms? And what were those initial symptoms?

[00:01:34] **Rick Telander:** Looking back on it I had felt like an odd heaviness and numbness in my arm one time and I had no idea what it was. This might have been a month before I actually felt this incredible pain building in my neck. C4, C5, C6 that area, the back of the neck. And I thought it was a neck issue. I just needed my neck cracked or I needed it adjusted. And I had just talked with a friend of mine who I played college football with. I played four years scholarship football and a buddy of mine who was a judge down in Arizona had been driving and all of a sudden, his neck hurt him so bad and one arm sort of like paralyzed.

[00:02:21] He laid down and pulled off the side of the road, laid down in his car, and called his doctor and the doctor said, don't move, I'm sure you have a herniated disc and he did and they fixed it, he had surgery and fixed it. I thought that's what I had. He was a line-backer. I remember him taking a lot of blows and thought it's an old football injury. It started to hurt really badly again in that area. And I felt this like tingling in both arms just a little bit.

[00:02:51] Of course, it was a Friday night. Nothing ever happens to me on a weekday 9:00 to 5:00 ever in my whole life. But I asked my daughter, my youngest daughter who was there. I said, "Would you just like try to massage my neck there?" And I was sitting on the floor in the living room and she came in and when she touched it, it hurt so much, I said, "No, don't do that." We called my doctor. I called him on my cell phone and

he listened to it and he said, "Maybe you should get a neck brace. Get one, you know, at Walgreens. Just zip it up. Have somebody go get it and let me know because I think I want to prescribe you some prednisone." And he wasn't sure right at that moment because I was still describing it.

[00:03:35] I called him back. The pain was getting worse. The neck brace didn't help at all. He prescribed prednisone. Got it real quickly at Walgreens. Not sure if I'd even taken one. And I was lying down on the floor on the carpeted floor and I could lift my arms up like I do a curl you know with weights, but I couldn't push them down and I was amused by this. I was like, what is going on? I had no strength in my triceps and it was almost like I said, it was so novel and weird. No pain in them. They didn't work. And I thought that's incredible.

[00:04:15] If I lay down, I couldn't push my arms forward. I could pull them back perfectly. I knew something was going on, but still I thought I need my neck adjusted, but it hurt so badly. What I was going to do being a Friday night, probably like eight o'clock at night. I thought, "Well, I'll just take some Ambien." I had some Ambien sleeping thing. I'll take some of that and see how it is tomorrow morning. As I lay there, I butt-called my doctor again on his personal phone. Thank God. And he called me back. He said, did you call? I said, no, don't recall doing it, but it really hurts. It's really bad. I can't move my arms. He said, get to the emergency room immediately.

[00:05:04] So, my wife drove me there and to tell this story, she let me off right at the emergency room exit, which is pretty close. She had to park the car, there's no place to park because ambulances are coming. And I saw this woman, she was staggering towards the emergency room and this is the summer when or not the summer, the year it was late fall or fall that swine flu was going around. And I figured this woman has swine flu. I don't even know at this point if my mind was working right.

[00:05:38] That's the other thing about TM. And I had to lie down on a bench because I couldn't walk any farther. About 50 ft from the door, the emergency room door and she is staggering towards it. And I had this in my mind, I have to beat her there and I couldn't, and she staggered into the place. I finally got there to the emergency room. And at that point, they put me in a room, and all of a sudden, I couldn't move my legs at all. And the pain was incredible in my neck.

[00:06:08] So, now my triceps don't work. I had this deep burning through much of my body and I can't walk. And so, things get a little blurry at that point, but they hooked me up to IVs. I was at a hospital near where I live. They put me in an ambulance. I went to Evanston Hospital, Evanston Illinois Hospital, which is a bigger hospital and I was in intensive care for four days and that's how it all began.

[00:06:42] **Dr. GG deFiebre:** Well, there's a lot of similarities in your story to my story as well with really, really intense neck pain. It was kind of like radiating down my arms. And I did the same thing where I said I was with my grandmother. I said my neck is hurting can you please give me a neck massage? Like I must have just pulled something, you know? And so, it's always interesting hearing the similarities there in that experience, but it was a pain.

[00:07:09] **Rick Telander:** It's wonderful just to hear anybody who's been through this because it's anywhere from one to maybe eight in a million people and in any given year it might be one in a million in the United States. So, we have nobody to compare anything with. And thank God, I don't know how your original doctor was or how it progressed for you, GG. But for me, my doctor, Doctor Todd Neuberger, he was a great doctor. He's since retired.

[00:07:39] He's younger than me but he retired and he was a very serious guy and he somehow in his mind thought after he thought, not Guillain-Barre, this sounds like transverse myelitis. How he knew that I don't

know. I don't know if he'd ever had another patient with it, but time is of the essence and if you don't get it diagnosed, you're screwed.

[00:08:05] **Dr. GG deFiebre:** Yeah, for sure. So, what was done to actually determine the diagnosis that you had transverse myelitis?

[00:01:02] **Rick Telander:** Well, first of all, they went on the symptoms, the lack of mobility, the paralysis. And then one of the things I had to do right away at Evanston Hospital was do an incredible amount of CAT scans on my head and I was freaking out. I hated it. I mean, I think I was in there for hours literally. And finally, they just sedated me. So, that was one thing to see what was going on. See if there's lesions and things like that. The other thing was I had to do a spinal tap and I had to get on a bed or a metal thing and it slowly raised up until it was vertical almost.

[00:08:55] And I had a needle in my spine. And I'm telling the guy as it gets farther up, I said, the reason I'm in here is I can't stand. So, I was literally hanging on to the top of that. I could still grip things I couldn't stand while they're doing the spinal tap. Which hurt but it was one of the worst experiences ever because I was so sick. I didn't know they were going to tilt me up because I guess he had to. And I felt sorry for the guy who did it because I was yelling at him and all.

[00:09:25] So, they're testing that for every bacteria and virus they could, whether it's West Nile, whether it's Lyme disease, whether it's HIV, whether it's anything that could be, a bacterium or a virus. And short of finding that which they never found for me. And I guess that's the case. I don't know if it was the case for you and a lot of other people. It's just, "Hey, you got TM and we don't know why." So, there in the intensive care I was hooked up to a lot of prednisone, that kind of steroidal thing, to calm things down which it's a nasty drug.

[00:10:13] I mean, it messes you up, it makes you crazy. It's like a stimulant. It makes your mind race. It does all kinds of things, but that was to stop the inflammation. The best way I can say, the best way I think I've had it explained is it's like an electrical fire. It's like only the wires are burning and the sheathing around the wires in your house is burning and then the two wires will crisscross and you'll get a short circuit and it's kind of like that.

[00:10:42] So, I was hooked up to that and a painkiller and in certain ways, I was kind of almost like in and out of delirium because it's kind of messed up in my mind what happened how long I slept, when I didn't sleep. It's a very traumatic thing at first. And it's wonderful not for anybody to go through it, but just to know somebody else has. My hands didn't work. To this day I have big pits in my hand where those muscles, whoever thinks about the muscle in the middle of their hand, it never came back. My thumb muscles are atrophied.

[00:11:21] So, what I first found out early on was that different parts of my body were affected, including a wide band all the way around my middle was numb. You worry about bladder bowel control all these things that I knew nothing about. I'm still thinking, I'm not sure about the first person who had transverse myelitis. I'm still thinking, hey, man, this all will come back. I'll pop out of here. No problem. Four days later, I did go out and I had a cane, and I kind of stumbled, and I was on loads of prednisone to take, and then lots of sleeping pills because my brain, it would chatter like almost like I'd seen electrical graft going through.

[00:12:10] It was awful trying to sleep. I had to dope myself to sleep. And then I had this prednisone was working on me, but it appeared that the fire had at least been put out in my spine, that it only appeared that way. That's the second part of this. It hadn't been completely. So, after I got released and I immediately went to rehab and I had to put blocks in this thing and stuff like that and take visual tests. I knew what was wrong with me. I could tell my triceps don't work.

[00:12:43] It's amazing how quickly a muscle atrophies. I mean, I could do a lot of push ups before I couldn't even begin to do one. My triceps muscles were like in the course of five, six days like flabby almost non-existent. Weird, very weird. The nerves are so critical. So, then I thought it was better and I had to go to a dear friend's funeral. Something entirely different up in Minnesota in Minneapolis. And we had at that point, this is a month later, cut my prednisone down to almost nothing. You know, 5 mg here and 10 or whatever, how it was going.

[00:13:26] And on the plane I started to have incredible fire in my chest all the way across from one shoulder to the other in my pectoral muscles mostly. And the pain was incredible. And I also found that I was sweating when I wasn't hot and I was cold when I wasn't cold. My entire sense of heat and sensitivity in my hands or my skin to heat and cold was gone. My thermostat was off. I could just start my brows start sweating. I was like, what? I would have incredible spasms in my legs.

[00:14:08] My quadriceps had just about vanished and my calf muscles all the way down to my feet. And what we found out when I had that pain in my chest, I needed to get back on this stuff. Heavy. This is probably a month or so after maybe six weeks after the onset. It wasn't done with me. The doctor didn't know that. We had a neurologist involved. He thought it was, "you're lucky." Not lucky but things are going to get better. They didn't get better. And during that fire in my chest, I lost things that never came back.

[00:14:47] So, if that had been treated immediately or hadn't gone off prednisone maybe it wouldn't have happened, but it did. And I was a quarterback in high school and I can barely throw a ball. I don't have whatever muscles are needed to do that. And as time went on, I started to realize what I had and what I didn't have. And at that point then I'm wondering what's permanent.

[00:15:21] **Dr. GG deFiebre:** So, you mentioned that you did IV steroids and then you took steroids as pills, right? So, for this kind of when you started having the symptoms again or worsening of symptoms that didn't really get better. Did you take additional steroids or did they admit you to the hospital again or kind of what happened at that point?

[00:15:42] **Rick Telander:** Well, I started going to, I went to another neurologist. Everybody says get second, third opinions. They immediately up my steroid dose, the prednisone dose up to like 80 mg a day or 80, 100 mg a day, which is quite a bit. If you get a little bug bite you might get 5 mg, you taper it and all that. 80 to 100 is quite a bit. And it has side effects. I remember I was growing these bumps on my face. I don't know what it all affected. They would test me for diabetes, all of a sudden start really testing my sugar levels.

[00:16:23] I guess that's all a function of that hormonal element. And then I went to Mayo Clinic to get that third opinion. And when I went up there, I went with my daughter, she went with me, my wife had stayed home to take care of the other kids who are older but my daughter went, met one of her friends up there. This is in Rochester, Minnesota. And it was funny, I went in for a diagnosis to see a couple of people very thorough and they told me, they were trying to rule out multiple sclerosis, trying to find out if this was a one off, one time or this is going to be continual possible flare ups.

[00:17:10] And also there was a thought that it might be a type of, I think it was some kind of neoplastic spinal cancer which that's not good. And the doctor said we'll find out we'll know by tomorrow. So, I had that night it's like, well, okay, I don't know what that is. It's actually, that doesn't sound good and it sounds like maybe I could be dead in a couple of months or I could have transverse myelitis and I'll live with this. Whatever, I'm going to live with, I'm going to fight it or I'll do what can be done. We went to see a movie. I remember my daughter was like 19 and her friend she knew and it was called Dear John, not that I remember, starring Channing Tatum as a lifeguard. I thought it was a great movie. He became my man crush, Channing Tatum. I

said this dude he's knocking guys out and stuff, but he's always got his shirt off and everything, and I thought it was a pretty good movie, you know? And we get out of it and these girls, you know, it's a movie made for teenage girls, basically. And they said, that was terrible.

[00:18:18] My brain is so fried I thought it was one of the best movies I've ever seen. So, that night I had to, in a way come to grips with dying. I thought, well, that's it. I'm 59 whatever, 60 years old at that, I've had a decent life. I've had a great life and maybe this is it. And I'll find out tomorrow morning. And oddly I slept pretty well. And when we went in there, they said no, it looks like you have transverse myelitis. It appears that it's a one off. It's just one time. You should not have additional flare ups. We don't believe that.

[00:18:54] So, now you just need to get on with therapy. And at that point we also think about the plasmapheresis and the immunoglobulin IV treatment, which I then did. Went back to Chicago, went back to Evanston Hospital and would go in there. I can't remember how often. I'd sit for three, three and a half hours, eat graham crackers, drink apple juice, shoot the breeze, watch TV, whatever, and have a big drip bag going of immunoglobulin and that seemed to help too.

[00:19:29] **Dr. GG deFiebre:** And so, in addition to the kind of acute treatments you had steroids and then the IVIG, did you do any rehabilitation? And if so, what was that experience like?

[00:19:41] **Rick Telander:** Yeah, I started doing rehabilitation right away. The first one was an intensive one just to find out if I needed crutches. Did I need a wheelchair? Could I feed myself? Could I dress and all that? I play guitar and I couldn't even begin to hold the strings down or do anything like that. And that made me very sad to think of losing that mobility but things slowly started to come back. I was lucky in that regard. I don't know that anybody is lucky who gets this but you know what I mean.

[00:20:14] And the rehab I did was I went to one of the Athletics, I believe it was. I worked with balls with strengthening things with getting things active. I improved. I stayed on prednisone high dosage of prednisone for a whole year. Almost a whole year. Really messed me up psychologically. I mean, my anger was way up. I had to take an antidepressant because of it was making me not depressed but the chattering in my brain it was almost like somebody was typing the screenplay when I try to sleep. Very strange what was happening.

[00:20:59] And I also craved sunlight. I found this odd craving I needed to be in the sun. I was exhausted all the time. I was fatigued in this way that I didn't even know how to describe it. I might not be sleepy but I was fatigued. I just like I just can't move. I'm just lazy. All that's working is my brain in this awful way. I remember getting up in the morning and then just lying on the floor, getting out of bed, I'm getting dressed, lying on the floor in a little since it's winter time a little pool of sunlight coming through our second floor bedroom window just to feel the sunlight.

[00:21:37] I wanted to sell our house and move to someplace sunny. There's nothing wrong with our house. We have four kids. A couple of them were off to college but still this was bizarre things going on in my head. I was not completely rational, I think. I recommend nobody making big decisions when they're on serious prednisone. So, that was about a year. But then the rehab I actually improved I have to say for two full years. I felt I noticed improvements and the other problems I had big ones were with my feet, particularly my right leg was affected more than my left.

[00:22:21] My right quadricep it was horrible. I'd have spasms where my knee would come up and I hit my chest while lying in bed and nobody thinks about the muscles in their feet. You know, we have muscles in our feet. I never thought about it but mine were fried. My feet immediately became flat as boards and I had drop foot. I still have it. They gave me this thing called foot up which I could use and I'm thinking about

doing it. But as I walked, I had a noticeable limp, that foot drags if I'm not incredibly careful trip and fall very dangerous, but I could walk.

[00:23:03] So, I was happy about that. I couldn't run. And the other things that I still am noticing that have affected me that I think anybody that has, this probably will be figuring out things for years. It's just such a strange attack on your body. We know what a broken arm is, you know? And having played sports my whole life I know what a bad knee is or a broken finger or a broken foot, ankle all that stuff. That's one spot.

[00:23:36] This is kind of like all over you. It's your whole body and it's like there was nothing I could, I didn't have any sense of, I didn't feel grounded in the world that everybody else was in. And I thought, okay, do I move on to the handicapped world? Is that it or am I in between or whatever? And one thing I did that was really beneficial, I'd say this is like two years after it, I went to Texas Southwestern, University of Texas Southwestern and Dr. Ben Greenberg was there and I remember him being just such a wonderful guy and having a chance to talk to him one on one was fabulous.

[00:24:24] And seeing these little kids I'm thinking you always feel sorry for yourself until you see somebody worse. And I see little kids, they had their wheelchairs all decorated and stuff and they're bopping around but they're about 8, 9, 10 years old and there could be people younger than that. They are people of all ages. It's like this group, this convocation of people. They're like, what do we have in common? Nothing except we all have TM. It was wild and of course, huge shout out the person that really helped me keep my sanity and my whole family was Sandy Siegel.

[00:25:02] The only guy that I knew that could even talk to and he talked to my wife Judy for a long time just explaining. Yeah, hey, there are others. This is what it is. There was nowhere else to go. Transverse myelitis good luck. I mean, what are we going to do? We're not going to have a big association since one in a million people have it. His wife, Pauline, she was just a wonderful, beautiful person and I met her there and I mean, Sandy, they should have a statue of him somewhere. He helped a lot of people. Man, did he help me.

[00:25:43] **Dr. GG deFiebre:** Yeah, Sandy is amazing and Pauline was as well. And that's part of why the association is named after them. So, in their honor and, yeah, they've helped a lot of people in the course of the past 30 years now at this point since Pauline was diagnosed in 1994. So, and you've mentioned that you have foot drop. Do you have any other symptoms currently? And how do you manage them?

[00:26:11] **Rick Telander:** I have lots of things if I stop to think about it. My feet burn constantly. I'm still taking quite a bit of gabapentin, been taking that ever since. I don't know what that's doing to me otherwise. If I ever cut back on it or I thought it's not doing much and I cut back, and all of a sudden I feel electric and I feel it's like I'm plugged into an electrical outlet and getting shocked. And it's a terrible feeling.

[00:26:43] I feel like constantly my legs tingle, much of my body tingles, especially from, I don't know, my quads on down. I still don't have a real good sense of hot and cold. At the beginning when I would take a shower, I had to find some part of my body to put in there that knew whether was hot or it was cold. I couldn't tell the difference. Ice water felt the same as boiling water. That's still with me. My thermostat is still a little off.

[00:27:15] I have general burning kind of around my whole midsection. My hand strength is gone. My triceps, my pectoral muscles are just basically not there. Whatever in here across from the deltoids, this thing whatever these are here they just got fried and they got burned up in that thing. The secondary one, I sometimes get this fatigue that I can't explain. I'll tell you my sleep pattern has never come back to normal. I sometimes find myself awake at four or five in the morning. I'm not tired and then I'll go to sleep for nine, 10, 11 hours.

[00:28:05] A lot of things are just a little haywire. The leg issues are probably the biggest one. I worry my right leg is not getting better and I do all kinds of weight training and stuff like that and it's getting worse. So, I don't know where that's going to lead. My limp anybody would notice it that if they're nice they say you got a bad hip or a bad knee, but I've had both my knees replaced. They're fine. They don't bother me at all. Not at all.

[00:28:39] I mean, they're great except for setting up metal detectors at airports, but the residual effect of just feeling not right and feeling that electric buzz throughout so much of my body, which I've never felt before I don't know what to compare it to. I don't know what else it's like. That's the residual stuff.

[00:29:03] **Dr. GG deFiebre:** And do you mind talking about what the most difficult part of living with TM is? And if you have any kind of fears or worries related to your diagnosis.

[00:29:16] **Rick Telander:** The biggest part probably is unless you're a little kid who gets it, which is just tragic. You remember what you were like. And it's like, why aren't I like that now? So, there's that before and after, and that moment that demarcation, that neck pain changed your whole life so that you have to remember I can't do that. Or I'd like to do what I used to do I can't do that anymore. And as I get older, a problem for me is, I don't know what is natural aging and what is the effect of transverse myelitis and the possibility that the one enhances the other is always there.

[00:29:59] So, I worry about the day when it's suddenly, I don't think it will kick in again. It's been long enough but the residual effect becomes exacerbated for whatever reason. Just that it's been there so long. Maybe the nerves, you know, I went to my 50th high school reunion and there was a guy there, he was a state swim champion 500 yards, 500 metres or whatever tall guy about 6'3" he's in a wheelchair. I said, man, what's up?

[00:30:27] And he said, well, I had polio as a kid and then he started swimming, his rehabilitation became very good and I remembered him in high school and I never know that there's anything wrong. Well, the nerves apparently in polio, myelitis, transverse myelitis get worn out compensating. At least that's a theory and it can come back later and that's what happened to him. So, he was 69 years old or whatever and he's in a wheelchair and so I guess I wonder about that. I worry about that. There's so few of us that you can't get that huge body of research. It's easy when you're dealing with COVID you got the whole world to use as your Petri dish not with us.

[00:31:14] **Dr. GG deFiebre:** Yeah, for sure. And you're not the only one who's brought up aging and how it's kind of hard to tell what's aging, your body changes, things are different, what's TM versus aging? It's definitely a complicated area that I don't think we have a lot of great answers for at this point, unfortunately. But what are you hopeful for as someone living with TM?

[00:31:29] **Rick Telander:** I'm hopeful for I think all the things that would be natural. First off to have a quick diagnosis and also an understanding of why it occurs and to head it off before it hits. If there were ever a vaccine that would be the gold standard. In fact, it's interesting the only thing anybody could point to and it probably is irrelevant. The only thing that had happened was I had gotten a flu vaccine two weeks before I got TM. Have no idea if that's connected, near proximity is not cause and effect.

[00:32:17] But anyway, I'm not fearful of any vaccines. But my doctor told me to wait, I mean, I waited like I don't know about five years after my TM before I did this. And I know Dr. Greenberg gave all of us the green light to get our COVID shots. I was worried about that. I don't want to set it off again. So, a vaccine or preventative something rather but after that, some way to instantly diagnose it and have emergency room treatment everywhere just like they do for strokes now. They're getting better and better.

[00:32:48] You get to the hospital within two hours of having a stroke, they can always reverse it. That's key. And then of course, figuring out ways to repair the myelin, which would be the most wonderful thing for anybody who's been in a spinal cord injury, broken neck, in a car accident, diving accident, anything, whatever, motorcycle crash, anything that might happen to help people who have spinal cord issues because we're all kind of little branches on that same tree.

[00:33:21] **Dr. GG deFiebre:** Definitely. And then is there anything that you wish medical professionals knew about treating someone with TM?

[00:33:32] **Rick Telander:** Well, I guess I just wish they were familiar with it and maybe it was part of basic training. But you think of all the other things, it's a tough one because it's so rare. Selfishly I'd like everybody to have that as right at the top of their mind when anything happens. I think that what's happening now, one reason I'm happy to publicize this, maybe somebody will see this. Maybe some doctor, maybe some nurse, maybe some training center, maybe Dr. Greenberg or you can, so the SRNA can spread it around and maybe it helps having a guy who is a sports writer man.

[00:34:14] He was a jock. He wasn't a little kid, he wasn't somebody from another country. He wasn't this, that, or the other. Maybe it'll help a little to make it more understandable, more common and I'm not embarrassed at all. I mean, to me it's nothing, you know, sh-- happens in life. Sorry but it does and this happened to me and it happened to others and there's ways that if we talk about it and get it out there it can help everybody.

[00:34:44] And above all, I would love to see it figured out quickly in little kids. I see this, is it flaccid myelitis or something like that. These sudden things that maybe can occur. I always want kids to be cured faster than adults.

[00:35:03] **Dr. GG deFiebre:** Yes, got it. Is there anything you wish your friends and family knew about TM?

[00:35:12] **Rick Telander:** I wish they could be more forgiving of me when I'm a jerk sometimes and let it go so they can say, "Yeah, that's just his TM talking." Because there is a mental thing that it does to you and I can't really put my finger on it. But I know, for instance, I've taken all this gabapentin it's got to do something. What it does I don't know. But also just to know that sometimes I get frustrated and I'm just mad, you know, try to accept everything but you'd never fully accept that bad things that happened to you.

[00:35:50] You know they did, you know you're not more special than anybody else but it's still, sometimes you just feel sorry for yourself. And maybe more compassion to how awful you feel especially during the onset. I don't know much about multiple sclerosis but seems to me that's almost like TM that happens over and over. And the optic one, I mean, each one is devastating in and of itself, even though they all have the same genesis and similarities there's still the, you know, once you get the physical, the medication, and the treatment down and figure that part out, boom right away. The next thing is to how to understand people psychologically who've gone through it.

[00:36:43] **Dr. GG deFiebre:** And then you recently published a book which is very exciting. Do you mind just telling us a little bit about the book?

[00:36:52] **Rick Telander:** All right, so here it is now. There's a slight glare. Can you see that?

[00:36:56] **Dr. GG deFiebre:** Yeah.

[00:36:59] **Rick Telander:** And here's the inside and a little kid can put his or her name right there, "This book belongs to." And each poem is illustrated. I wrote the poems. 42 poems. And each illustration is done by a different artist. 42 different artists. This is by Anita Coons from Canada. Four different countries represented. And it's all about going to sleep and trying to sleep, and trying to be comforted if you're sick.

[00:37:34] And my thought as I was doing it, here's a little boy. This one is called "Down in the valley." This little boy and if you look at this very closely, you can see he's talking about walking down the valley with his sister. I actually wrote this for my sister, Marcy. My older sister lives in Colorado. And if you look very closely you can see crutches in the foreground.

[00:37:57] **Dr. GG deFiebre:** Can you lift it up a little bit more because I can't really see the foreground there. Yeah, there's a little bit of a glare but I do see the crutches there. Yeah, that's good.

[00:38:09] **Rick Telander:** And then I have a couple about taking pills. I have a beautiful one right here of a sheep dog and a lost lamb. It was written with children in mind. 42 original rhyming poems. I studied poetry in college and throughout the years I've done some and it started when I was sick. Even before transverse myelitis, I had another stomach issue way back but then I really got into it when I had TM. And I was thinking about kids and so you can get it.

[00:38:49] It's on Amazon. It's called Sweet Dreams, Poems and Paintings for the Child Aged. And I did the cover. I'm proud of that cover. That's my luna moth. I made these little, you can't see them but the little icons in here. So, I think kids I know, they really enjoy it and it's good for parents to read the kids, or kids if they're old enough can read it themselves. So, there you go. Yes, it took me 30 years.

[00:39:17] **Dr. GG deFiebre:** Wow, that is impressive. And it is really a beautiful book. You were kind enough to send me a copy. And so, I haven't read through all the poems yet but the art is so unique as you said you use different artists for the illustrations and it just is a really beautiful book. So, we're excited to be able to also share it with people. And then if a kid has TM too it's pretty cool to be able to say the author of these poems was also diagnosed with TM.

[00:39:50] **Rick Telander:** I would love for people to think of that if they do have a child. Anybody who has TM, "This guy had it too. This guy knows and this is to soothe and comfort you."

[00:40:01] **Dr. GG deFiebre:** Yeah, it's awesome. And so, do you have any last thoughts or anything else that you want to mention that I didn't ask about regarding your experience living with TM?

[00:40:11] **Rick Telander:** No, it's just that again I want to thank Sandy. The SNRA has been this kind of lighthouse in the midst of this storm. And thank you GG for, they didn't have somebody like you doing this for years and I think it helps tremendously. And I would just say that with all the charities out there, I hope that people realize that every charity, every kind of thing like this works because of donations. I mean, that's it. You look for grants, you look for funds, you look for people who feel it's a worthwhile deal and I'm willing to do whatever I can.

[00:40:50] And that's one of the reasons I wanted to promote that book. I hope that it becomes kind of like a flagship where people talk about it. This started for kids and adults, and anybody who has transverse myelitis or a rare neurological disease. And it's the only one we know of that was done for that. And I hope that helps promote it. That's really my goal with all of this.

[00:41:17] **Dr. GG deFiebre:** Well, thank you so much for taking the time and sharing your story, and talking about your book. So, thank you.

[00:41:25] **Rick Telander:** Thank you GG. Best to all of you guys.

[00:41:32] **Outro:** Thank you to our "Ask the Expert" podcast 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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