Paul Garrett

You can watch the video of this podcast at: youtu.be/JPjZnJEzEFk

Intro: [00:00] Hello and welcome to the SRNA “Ask the Expert” podcast series, Community Spotlight edition. SRNA is a non-profit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org. Our 2022 Ask the Expert Podcast series is sponsored in part by Horizon Therapeutics, Alexion, AstraZeneca Rare Disease, and Genentech.

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

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

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

For today’s podcast Lydia Dubose of SRNA was joined by Paul Garrett. Paul has enjoyed a long and varied career as an entrepreneur and innovator, involved in warehousing, construction, and renovations.

A transverse myelitis diagnosis in 2019 put Paul’s world on hold. Recognizing he was no longer up to the task of managing the physical aspects of his previous world, he decided to put his years of construction and customer service experience to good use and became a Mortgage Advisor.

Paul’s awareness of the challenges faced by people living with a disability inspired him to become involved in several research projects at Lawson and Parkwood Institutes. He is a member of the St. Joseph’s Patient and Family Council, a Care Partner with the Care Partnership at Parkwood, a peer mentor for Spinal Cord Injury of Ontario and a member of their Southwestern Executive Council, and an international peer mentor with the Siegel Rare Neuroimmune Association. He has recently joined the Kiwanis Club of Forest City - London. An avid aviator, he enjoyed over 4,600 hours in the sky. Paul and his wife live in London, Ontario, Canada. He is the proud father of three children, and grandfather of nine.

Lydia Dubose: [03:08] We're joined today for this Community Spotlight edition of the "Ask the Expert" podcast by Paul Garrett. Paul is one of our community members and one of our volunteers as a part of the Peer Connect program. And I think we'll just jump right in and start getting to know his story a little bit more. So, Paul, welcome.

Paul Garrett: [03:35] Thanks, Lydia.

Lydia Dubose: [03:35] Thanks for joining us. And just to get started, can you share a little bit about your background, where you're from, and anything else just to introduce yourself?

Paul Garrett: [03:47] Sure. I'm Paul Garrett and where I'm from, well, a few places. I'm from London, Canada, Ontario, Canada, which is basically southwestern Ontario, which is a warmer climate of this country, because Lydia and I have that conversation. I was brought up in a place called Collinwood, which has got, we call the mountains, but they weren't that high. And I was educated there and then we moved back to Brampton, which is also in Ontario, to the south, towards Toronto. And became involved in electricity, electronics, and became an electrician with a company that did installations for many years, which I owned. And I did installations of kitchen appliances and lighting, and pretty much everything anybody did if I got move transfers. At one time, if people were transferred say from California to Toronto, they'd want everything the same as it was in their other home. So, my job was to make sure it was done like that. So, I did that for many years, and I had a warehouse operation, which I ran for about 15 years with a partner, and we sold that just before everything hit the warehousing market as it went to. And then I started just doing renovations and I had a crew of people that I worked with renovations, etcetera, and building, and house building.

And in the meantime, I was married, and I had three children who managed to grow up just fine despite me, and they're great kids and I was fortunate to have nine grandchildren and I have a wonderful wife. It's my second wife. My first, we ended up, they're fine, everybody's fine, but just part of life, we ended up in a divorce situation. And I've got Brenda, my wife, who has been part of this journey with me with transverse myelitis since it started. When it started, and it was a strange thing. I was in a contracting business and that's what I did for many years. I flew for many years. I've got 4,600 hours as a pilot, airborne singles, and twin-engine aircraft. I was pretty diverse. I'd do pretty much anything that I thought I might want to put my hand to and I enjoyed doing it. So, I have no regrets that far. So that's about me in a nutshell. And now, I'm a mortgage advisor because things have changed, and I started another business after my business stopped the day I got TM. So that's about who I am to this point.

Lydia Dubose: [06:28] Thank you, Paul. Just to start, do you want to share about when you first started experiencing symptoms and what were the symptoms and what was that like for you?

Paul Garrett: [06:37] It's a good question, Lydia. I didn't realize I was having symptoms before the event. There was a time where I was 59, 60, but I was still very fit. I went to the gym four times a week. My job, although I was a supervisor, I still did a lot of lifting. I did a lot of building because I liked doing that, but I found in the last six or eight months before this happened in 2019, that my legs seemed weaker. I used to be able to run two stairs at a time, no problem at all. No, I put it off going, "Garrett, you're just getting older." And then, at nighttime, I'd go home, and I'd relax. I got sharp pains going through my leg down to my side of my leg to my thigh down to my ankle. And I had twitches and it was like restless foot, restless foot syndrome where you can't get them to settle down. And I didn't think anything of it. And I asked my doctor, and this is nobody's error because he would not know you were looking for this. And we were thinking it was an iron deficiency or a vitamin B12, maybe a change up because of my age and needing to do supplement differently.

So, I was holding on that because I was in some vitamins and things because it was pretty fit, ate well, tried not to overindulge in whatever. And then on May 25th, 2019, at 8:30 in the morning, I was getting ready to go on and look at a couple of jobs. I always make coffee for my wife and myself, take it up for her before I left, having time with each other. And I was down making the coffee and my gosh I got a real tingling in my right foot and like pins and needles. It was going like I couldn't feel it. So, I thought, that's weird. So, I started banging my foot and shaking, "Oh this is crazy!" And it gradually started working its way up my leg and my legs started getting weaker. And it went to my rear end, my glutes, and then across and gradually made itself down the right leg. I made it back upstairs and as I went upstairs, my legs were clomping up the stairs, laboring, laboring. And I remember thinking as I was doing that, "Boy, this could be the last time I'll ever climb the stairs." It was going through my mind, something bad was happening. And I laid down on the bed and I thought, "Well, I'll still keep the job because if I rest for a half an hour, I'd be good to go again." Well, I went to get up in a half an hour and I fell on the floor. I was paralyzed from the waist down and I had no idea.

The hospital attendants came, my wife called the ambulance only after duress because I was going, "This will recover." And she's going, "No, no, we have to get in there." And I have wonderful, you know how the attendants are so wonderful and they try to figure out what you need when you're in there. We're lucky here in London because it's like Texas. The medical people here are really resolute in finding solutions to problems. We have the MS division here, we have heart people, we have everything you could imagine. So, I was fortunate to be in the city, is what I was saying. So, he was trying to determine what the problem is, to determine which hospital I should go that specialized in certain, and so he said, "Well, I'm going to put you in as a stroke," because they couldn't figure out what the problem was. And he said, I don't think you have a stroke because I was talking properly.

And he took me to London University Hospital, which specializes in brain traumas and things of that nature. And they got me in there and they got me into a stroke sequence first off. So as soon as I got there, he was so smart, the technician, because there was like eight people waiting to rip off my clothes and start testing me and saying, how many fingers in here and what's going there and probing here. And they had me down for scans before you knew what was happening, MRIs, and it was just everything was so quick and I was hooked up to every imaginable device, with wires coming out of places I don't even want to talk about. And they couldn't determine at that point what the problem was. So, they determined it wasn't a stroke and it was nothing to do with my, which I was quite relieved about. And then, after that was done, the neurology team came in and that was after I'd been there for about eight or nine hours.

And we've got a lovely, Dr. Casserly is her name, and she came in and she looks down, she goes, "What do we have here then?" As I'm lying on this gurney, legs not working and just having to have a catheter. So, I'm trying to come to terms with all these things. My wife is trying to come to terms, all these things that are happening, and at the time she says, "Well, we have to get you up to the observation and we'll get you down for an MRI and we'll try to determine what this is." And they didn't at that point, but that's how my first day was. So that's how I got there.

Lydia Dubose: [11:35] What a jarring experience. Yeah. Can you share a little bit more about what was done to determine your diagnosis and then what kind of treatments you initially received?

Paul Garrett: [11:49] Sure. Well, originally, when they got me up into observation and observation in these places is like intensive care but not as intense, it sounds like. But I of course had intravenous going in and things of that nature, and they were testing. They sent me down for an MRI and nothing showed up. But that's not unusual in the early stages. Originally, they were looking if there was something they could surgically do and the surgeon couldn't do anything, there was nothing to do. And they thought it might be, I think, GBH, I can't remember what GBH stands for at the moment but it's a syndrome that can give the same, I should look that up.

Lydia Dubose: [12:28] Guillain-Barre, I don't know if, yes.

Paul Garrett: [12:31] Yes, syndrome, Guillain-Barre syndrome. Thank you. Well, I didn't have it, so I didn't have to remember that. But that's what they thought it might be. And so, they gave me IGIV, five doses of it, which is $40,000 worth of stuff. I'm just saying what they spent to try and find. And she was miraculous because she was there with me that night and she had an attendee with her and they did a lumbar puncture. You're just having all these things done and the best thing to do is to give into it. They know what they're doing, advocate for yourself, ask questions but let them do it. It has to be done. So, they did this, the lumbar puncture and when that was done, my neurologist took it herself to the lab across town so she could get the results in her hands immediately so she could see what the results was. And that came back fairly clear, so we went back down.

And then it was about two days I was in there and there was still no determination, it wasn't working, the IGIV, I wasn't moving still. But I remember saying to my wife, it was day one in there and I was feeling very unwell, and they've taken about 32 things of blood out of me overnight and the phlebotomist says, “If I have to do one more, I'm just going to refuse.” I said, “Well, somebody else will just do it.” And they still hadn't figured, they asked me everything, as to what might have caused this reaction. So, Dr. Casserly got on to everyone, from the Mayo across to England to everywhere they had specialization in this kind of a spinal cord injury. She is primarily an MS specialist. And what I have, transverse myelitis, is a cousin and most of our issues in our spine are cousins of MS. So finally, and I will try to cut this short. It was not a short story really but let me try to bring it down.

They still didn't determine. And finally, I had an IV with the dye in it so they went in and it was two hours long. And I was in pain and my legs were jumping, and they wouldn't stop jumping. But she said, “I need this. You've got to stay still. I really need this picture.” You have a squeeze thing in your hand if you get panicky. I don't get panicky but after two hours of this thing going [mimics sound of an MRI]. Am I right? Oh.

Lydia Dubose: [15:03] Yes.

Paul Garrett: [15:03] No, but it goes, yes. And so, she saw it, by God, that's where she saw the lesion. And that night, there was a group of neurologists gathering here in London for a convention that they had together that, coincidence? I don't know. And she said, “Can I take your results to this tonight and use you as my discussion?” And I went, “Yeah.” And it was amazing, it was amazing. And so, she went down, and they said that it might have been a spinal stroke and she didn't agree. And her mentor said it could be a spinal stroke and she says it's not because if it was, he wouldn't walk, period. It would be gone. There'd be no movement, period. Not walking. No movement. I couldn’t walk. And she came back, and she started treating me for transverse myelitis.

Lydia Dubose: [15:55] So then after that point, did you receive rehabilitation? What other kinds of treatments did you have to address it at that point?

Paul Garrett: [16:06] The treatments, when she determined it was transverse myelitis, she put me on steroid injections, high volume steroids, which got movement back in my legs. And I'll finish up with the hospital journey. And I was there for about three weeks, and they're not really built for this kind of thing. But they put me right on to physio right away, occupational therapy. They wanted to make sure I could shave and all that and of course, I was doing that from day one. I shaved at that time. I decided to go rough. But every morning I said to my wife, water, shave, get your day started, doesn't matter because I knew what wasn't working, but I had to find out what was working. So that was my top end, and I knew the bottom end we can work on that but that's not an issue right now. They're dealing with that. Now I have to try and get myself together.

So, I learned very quickly to transfer. I learned very quickly to shave and get dressed with my legs popping and jumping. I didn't even know where they were spatial, in space. They had me doing stretches, my legs were moving like this. I called one Bing, because Bing didn't move much because he's more of a singer. And the other one was Fred, like Fred Astaire, because it moved everywhere. And they got to know my legs as Bing and Fred in the hospital because you got to have fun or you're not going to survive. And so, after I was there for a week, I was in a, as soon as they got me in a wheelchair, I was flying all over the hospital and getting to know everybody. You can't stay still. I had problems with my legs, but I wasn't sick, I was just.

So, at any rate, after about a week, they had a discussion and my doctor, Dr. Casserly, had come off my case because it was a training hospital and then somebody else comes on and trains others. And he came in for a week and he didn't think I had any chance at all. He figured that the steroids were placebo and I'd never walk again. Now, he didn't tell me that. What had happened was I had come in from outside and I was just sitting in the area where they were discussing patients around the nurses' station and they happened to be talking about me and my nurse practitioner who was in my corner saying, Paul, it's always team Paul, let's go, let's get moving, "He has a great, great chance of doing this." They wanted to get me in rehabilitation. And I said, "Thank you, Pat." And she said, "He's right behind us."

Lydia Dubose: [18:29] All right.

Paul Garrett: [18:30] And I quickly said to that doctor, I said, "You have not seen anything yet, you have no idea whether I can walk or not and you shouldn't make comments like that, but I appreciate you didn't think I was there." But he was sort of saying it was a placebo and it was never going to work. But I did know after that that it was up to me. There wasn't going to be a magic injection. There wasn't a pill they finally say, Eureka, take this, Paul, you'll be fine by Tuesday. I realized that it was going to last a bit longer. So that's when they transferred me. I was very fortunate. I was a good candidate for it because there's only a few-- like 15 beds available from an area, a lot bigger area so you knew you have to fit all the criteria. And that's a whole different issue but you got to-- and I fit the criteria and they had me transferred to Parkwood and that's where my new life began. Parkwood Institute is a rehabilitation center. They do it for mental illness. They do it for stroke patients, for spinal cord injury patients and that's what they specialize in is getting you back.

And the first day I got there, I was not a pleased puppy at first because suddenly, all your control is gone. People tell you do it this way and do it that way. But back on the first day and I remember sleeping. I was quite upset. I remember I was in bed. My wife was there, I said, you know something - I got to let go to this. These people know what they're doing. I have to learn from them. And that changed my whole life towards it. I realized that I was there and fortunate enough to be in a place to get help. So, they started the very first day, they got me set up and they got me to the occupational therapy and physiotherapy. And they were doing things in physiotherapy, and I was on this machine where I thought I had to walk really fast, and my legs were flying all over. He says, you're not in a race. He's trying to get me to do it correctly. And he says, "You know how do you really get well quickly?" I said, "Well, what's that?" He says, "To do everything slowly." Okay.

So, he finished with me, and we've been through all this. And he says to me, "Well, what do you want to do?" I said, "I want to walk the you know what out of here." He says, "Okay, we can do that, but you can never say can't." I went, "Well, that's not in my dictionary, so you and I are good." And that was what started and every day, every day, three hours a day, occupational therapy, time, and physio. Never like three hours each because that would be far too much. But in occupational, they taught you how to build blocks on a table. They taught you how to stand. I had two wonderful people holding me up so I could stand, and I hadn't stood up in about a month and I forgot I was six feet tall. Because you're looking up from a wheelchair. It's a whole different revelation. And they stood me up and it was a gradual, gradual movement from there.

Lydia Dubose: [21:42] And then, from there, what was it like transitioning back to home? What was that like?

Paul Garrett: [21:52] Well, I tried, closed in the hospital. My wife is very good. She set the place up with pictures of my kids and grandkids, and she'd make it homey. Not that it's your home but it makes it very, very nice. It calms you and helps you with your recovery. And then suddenly, you have all this going on. And I tried to do everything myself the best I could, but I was still in a wheelchair at times. But you've got nurses at your disposal. You have PSWs. You've got all these hardworking people, doctors, you name it. Somebody, morning, seven o'clock in the morning puts a fresh cup of water on your table. All your breakfast is there, your lunch is there. Don't miss that. Here's your pills. Oh, you've got a little problem, push that button. I will come and fix it up for you, and then you go home and it's silence. None of that's around. You come off the stage. It’s silent. And now you're looking in the surroundings, you're sitting in surroundings that are very familiar and in other ways not familiar at all because you can't run upstairs. You can't just go into the washroom, you can't go into the kitchen, which I started learning quickly how to do. And I should have also mentioned that the occupational therapy people came to our home to make sure I had the railings and said we were lucky the home was pretty nicely set up, washrooms on every floor and that kind of thing.

And one of the things when I came out of the hospital, I made sure of is one thing I need to do is learn how to walk upstairs. So, I progressed enough, it's very difficult, but I could walk up the stairs to the second story, which meant I could walk up the stairs again. I still can't walk up well, but you know--So I was wrong about that, yes, I could walk upstairs. But it was lonely. And then I--so what do you do? Now you have to try to find people that can assist you. You have to try and find drugs that may be available on programs. You have to try and find the therapists that may be--some that may be available on programs. Equipment, we're going to need equipment. There might be some grants that are available for people to buy wheelchairs and walkers and luckily, I didn't need it. But beds, hospital beds and things. There's so much to think about that. Then you have to talk to the government about your disability programs. Got this long list and coming out of the hospital, they've given you some idea, but you realize, now you have to get your life going in here. And my wife had a full-time job and I have to work on these things.

So, I gradually figured out my new life basically, how I looked after me and so, I could start--we had a galley kitchen, so I just started working in the kitchen so I can cook, which is scary but still I did this. I dropped a few eggs, and I didn't pick them up because I couldn't get down. And so, we did all of that and I learned how to be me again. And since then, we've moved into an apartment because it's easier and so on. Yeah, other than that, it's still difficult. But what I did do there is I came back, and I didn't have a business going so I started a mortgage advisory business, so I'm an agent and I've got a whole new career happening and some lovely people I deal with and it's just basically an offshoot of what I always did. I'm just doing the financing for them rather than the construction.

Lydia Dubose: [25:30] Wonderful. What symptoms today--or no, how many years out are you now?

Paul Garrett: [25:36] I'm almost exactly three years.

Lydia Dubose: [25:39] Okay.

Paul Garrett: [25:40] Some people call me baby still when I talk to them. I've met some folks that are 34 years with the spinal cord and so on. But anyway, three years.

Lydia Dubose: [25:50] Three years out. So, three years out, where are you now as far as what symptoms you currently experience and how do you manage your experience with TM?

Paul Garrett: [26:02] Yeah. Well, now, TM is one of those diseases that can go on three levels and the bottom level is you never walk again, your legs never move again. And that's there. The secondary level is you get 50-60% of your movement back. And the third level is, if you're lucky enough, everything pretty much comes back. Well, I ended up going to the second level. That could have been about my age too because younger people come through this, because their cells are regenerating and mine are degenerating. Anyway, so I got to about that middle level. So, the pain is still horrific, which we manage. I still have no ability to go to washroom without a catheter. Bowel movements are very, very hard but we manage it. You have a routine that you manage. We manage the pain medications, et cetera. I do a lot of stretching exercises. You've got to keep moving. Otherwise, the atrophy can set in. You have to move the same as you did any other way and I'm fortunate enough that I can. I can move. So, I do squats, best I can. I go to gym. I don’t work up a huge sweat but I'm working on it. Well, without your legs, it's hard to get the cardio going. So, I've been finding other methods. So yeah, that's what I've been doing since then and how we've been coping.

And then we have pain doctors and things. The worst thing for me right now is still managing the pain because right now I'm talking to you and it's about a five out of 10 and that's constant. It's like your bones are pushing through your skin. It's nerves trying to fire, right? And they just don't know what to do. They're going, “Do I do this?” And you go, “No, don't do that.” But the good news is I'm getting some feeling back even though being in pain. When I tap my foot, I know it's there, which I didn't. So that's the pain management. At nighttime it could go way off the scale. So anyway, just work with it, but stay moving, never stop.

Lydia Dubose: [28:14] And then do you mind talking a little bit about, and this may be some of what you just said, but do you mind talking a little bit about some of the most difficult parts of living with TM and if you have any kind of fears or worries related to your diagnosis?

Paul Garrett: [28:32] I did cover a little bit about that, but not--difficulties, as I said, is primarily the pain management and it is accessibility with being outside. I never would have thought--I went to drop off--I dropped off a gift to someone today. I'd done a trade show and they won the door prize. I gave them a nice prize. So, I dropped it off and there was two steps to go into the place and the door that I had to open, which had no power, but you struggle through it. And then they had stairs going down to where they were working. And I called them on the phone, I said, “Can you come up and meet me?” Because I looked at these stairs and I'm going, this isn't happening. So, you don't have the mobility and I have better mobility than some people do. I am blessed with that, don't get me wrong. I can stand, I can get around, I can move with my walker, I can use pulls. I get tired quickly, but I can use pulls. If I was in a wheelchair, forget that altogether because I couldn't have even got out there. So that kind of thing.

I guess the pain management, not being able to just pick up my grandbabies, little things like that. And I'm blessed because the Christmas before that, two of my granddaughters, I picked them both up in each arm. And it's the last time I did that and I'm so glad that it happened because I've got that memory, because that day for some reason I thought I'm just going to hold these two like this. So that and that's consequential and really the greater gift of it. That's what I've been doing to cope. If I got worries and fears, yes, absolutely. I don't fear falling. I don't fear falling because you just roll. But I'm still young enough not to bust every bone in my body when it happens. But speaking of the young and I'm not young, I'm getting older and this so that worries me is I've lost this mobility now. So that is something in my mind. I'm going, "What about when you get in your 70s and so on?" You could be very much confined to a wheelchair by that stage because I might not have the same strength. So, I can't worry about what the future holds. I have to get a grip of it, and I guess I'll just get there when it happens. But that is a concern of mine and it's not falling or injuring myself because I'll challenge that, just do what you need to do. But it is as time goes on and you don't want anybody to be responsible for you. And that's with time.

Lydia Dubose: [31:10] Yeah. And then on the flip side, what are you hopeful for regarding TM?

Paul Garrett: [31:18] Well, I take part of a lot of-- it's great journey because I do with a lot of the-- sorry, the institutes, I'm involved with a lot of programs. So, there's dietary programs, which I just finished the month, and they take your blood the first of it and then you go on this diet and it's hopefully for anti-inflammatories. So, they're trying to figure ways of decreasing the inflammation because that's a big part of what our problem is. So, I'm involved very much in anything to do with what might help in the future. So, I don't know if it will kick in for me. It might. They might come up with somebody who has stem cells going, I don't know much how that's going on. But there's some other very interesting things they're working on. I have some right here, right now that they gave me this morning, another program where they're trying to deal with how to directly affect the inflammation of the spinal cord injury directly. And it's all going to that program.

So, there's a lot of research being done. I've got part of that research. I'm very much connected with the Institute that I mentioned, Parkwood, and they have lots of-- which is a research--total research development. I'm in touch with the professors. I work on programs there. We're trying to do emotional well-being for people with this kind of situation. So, I want to be active from the inside so that if anything does come up, glory be, I'm here. Here. I've got something going on like that right now for my bladder and trying something that might help me be able to pee again. So yeah, that's what I do. I try to stay within it. You don't have to go crazy involved, like I did at first where I had to go, okay, I can't do as much now. But be involved. It really doesn't take you that much time. Even when you're involved with the SRNA, it's not a huge time consumption. It's just some time, you spend some time. So that's what I do for the TM. I try to stay involved with what's happening and what might happen in the future and maybe I will help someone later not have this issue.

Lydia Dubose: [33:34] Cool. Which is so important and thanks for being a part of it.

Paul Garrett: [33:37] Got to be there. That's right, yeah. It's not affecting me, it's okay. That's right.

Lydia Dubose: [33:45] Yeah. So can you tell us a little bit about how you're one of our Peer Connect volunteers, and we're grateful to have you volunteer your time. So can you tell us a little bit about how you got connected to SRNA in the first place and then after that, how you got involved volunteering?

Paul Garrett: [34:05] Well, I didn't get involved with the SRNA originally. Once I was in rehabilitation, my wife, Brenda, was studying everything that she could study about transverse myelitis to try and figure out what this--her husband who she hadn't figured that this would happen when we said, "I will." And suddenly it's upon us and she took to it. She took the bit and she's running with it ever since. So, she found you. She found the SRNA, and she said, "He'll like that." And she made me a member right away. The same as your group. She signed me up for that as well. And she said, "Go on this, look at this. They've got some great videos, some great things to listen to and some information you can watch, you can just watch it." Which I did. And I watched the doctor--sorry, Green--

Lydia Dubose: [34:55] Dr. Greenberg.

Paul Garrett: [34:55] Greenberg, wonderful fellow and his panel discussions. So that's where it started. I started listening. Wow, this is everywhere. And I thought to myself, it's not just me, it's not just here. We are surrounded with people and we're spreading all over the place. So, I thought, well why don't we just all try to work together with this? So, I got more of this to do. And I remember what happened, whether I did--it said you could volunteer probably, and I just clicked, sure, let's check it out. And then I believe that's where I was introduced thankfully to you. And that's how that started when I became a volunteer. It was such an interest that it was--people were--and they'd never heard of what's going on down there. So, I'm introducing people with this now. They said there's people studying it all over. They're in the Hopkins, they're in Mayo, they're in Texas, they're in, I don't know, Paris. They are. They're in London. They're everywhere. So that's how I got involved. I was very excited.

Lydia Dubose: [35:57] As a volunteer for the program, can you describe to anybody listening what the Peer Connect program is and what your role is in it?

Paul Garrett: [36:06] Yeah. The Peer Connect, I find is a support organization basically. There's no pressure on anybody because God knows there's enough pressure on people who are suddenly dealing with this anyway. But it's finding a lagoon, a harbor, a safe port, if you will, because day to day people look at you and they don't understand that you're in violent pain. They don't understand that your spasms make you flail at nighttime. And it would embarrass you, it could embarrass you because you might have a bowel movement in public. Nobody would understand that because the world would just go, “Oh my God.”

But we understand it and it's not a problem. It's what we live with. And so, we have to find just daily small solutions. So, within our group and by being a Peer Connect, within our group, it is a safe haven, just to come and talk. Say what you want. I can go, “Wow, that's so similar to what I’ve suffered, not quite the same. Tell me a little more about that.” And they open up and people cry because they don't have anywhere to go. The people understand. So that's why and that's what I believe the Peer Connect program is. I believe it's a nice safe harbor for people to come and talk about things that are so important to them and what they're trying to cope with daily and it's not because they're weak. It's actually because they're strong. They just need--it's like, strong as one, stronger together, right?

Lydia Dubose: [37:42] So what has it been like, through the Peer Connect, being able to talk with others who have the same diagnosis as you or a different rare neuroimmune disorder?

Paul Garrett: [37:53] One thing is it made me learn a lot. You have a mild breakdown of all the different conditions, MOG, TM, and the list goes on. I'm not even going to try at the moment, but I have them in a binder. So, I have it all, I've said, I read, I haven't committed it to memory, but I have a fairly good idea of what each one is and when I find a peer, a person and I look up what they've got. So, I read because their symptoms are different to mine or whatever. It's just a matter of just, it's happening and then seeing where it does equate. So, it's made me learn a lot. It's made me learn about how people were going through a normal life and then at 8:30 in the morning, their life came to an end or people that it's happening to them over a period, which I really feel badly about. And I'm not there to teach anybody anything.

We're just there to listen and perhaps all of us can learn from it. I learned from these folks. And we both get some solace out of talking to each other. Yeah. So, I'm learning. I would have never--if this hadn't happened, I know that I'd never have been here obviously. I drove past that rehabilitation hospital, and I didn't even know what it was until I was in it, if you know what I'm saying. And we see people in wheelchairs, and we go, oh, that must be tough and then you keep walking. That's what I like about being part of the Peer Connect because you don't have to worry. You're with people that are going through things the same way. And let's just talk about it. It's communication.

Lydia Dubose: [39:38] So, with the Peer Connect program or just through meeting other people, I know you're involved in Facebook groups and different things too.

Paul Garrett: [39:48] Yeah.

Lydia Dubose: [39:48] What's some of the best advice you've been given or that you've received related to TM?

Paul Garrett: [40:00] Well, you just got to keep moving and I don't know what else to say except ever forward, due to the pilot thing. The reason I said what's working is because if you're in the cockpit and you have systems that fail, you can shut them down. You go, "Okay, I know they're not working. Now tell me what I've got working," because you want to land that aircraft. So, the whole time I saw the numbers on the runway in my eyes and I'm going, "Okay, we're going to make the numbers. We're going to land this plane." You've got passengers. You do care about the passengers, but you want to go home too. So, you land the airplane.

So, all I could say is, keep exercising. Try to be as positive as possible. Seek out others. Seek them out and even if you don't learn anything, at least you've got solace that there's other people there you can talk to. And don't get offended. It's a learning experience. Let your shackles go down. Let your ego go away. By God, by the time you've been through the whole hospital thing, you're really not concerned about anything of that nature. They're pretty much exposed. You can keep your mind open, and you never know what you might learn from them. So that's all I can say but that's what you have to do. Always, always work for yourself and keep moving forward.

Lydia Dubose: [41:22] And is there anything you wish medical professionals knew about treating somebody who has TM?

Paul Garrett: [41:29] Yeah, I wish they knew more. Working on it. This is working on it. You're doing it, yourself. The discovery is when you get more people to discover it. And that's what you're doing right now. Doctors are starting to come online. My neurologist is now tuning to you folks down there and she hadn't heard it before. And she's dealing with people all over the place. They called me the $3 million dollar kid because all the tests they did on me. We do have that medical thing up here. Once you're in the system, you pay for nothing. All that cost me was $45 for the part of the ambulance ride from my house to the hospital. Isn't that--Yeah, I know, and I can't say anything about that. But once you leave that hospital, you're on your own. Then you're totally alone. But when you're in, oh, it doesn't matter what you need. So, I was fortunate. I was fortunate who I was. So yes, I wish they knew more, and I think we're helping them learn more just by talking.

Lydia Dubose: [42:31] Absolutely. Anything that friends or family that you wish that they knew about TM?

Paul Garrett: [42:40] They know as much as they do. My grandbabies are fine because they just have fun pushing me around if I'm in the wheelchair, or on my walker, they like to sit in it and I push them. The family, they know everything. I don't take this lightly, but I also don't take it completely seriously. I make jokes about things. I can't explain it. Maybe I got a weird sense of humor. But ever since the start of this, I tried not to take it too seriously. So, it's never, oh, poor me. It's, this is the way it is. It's all under control as we have it to this point. All you need to know is I can't do certain things and if I come to your house, I need this. And nobody has a problem with that because it's like, "It's just Dad," or "Dad's coming in," or "Paul's coming in, so we just got to make sure."

I say, "I'll climb the stairs as long as you got a rail on one side, I'll just--coming down is easy." So, they know as much as they have to. And the groups that I'm involved in, I'm involved in quite a few business groups, and I clear the elephant in the room right away and I don't go into great detail about this, but I say, "This chariot is something I just have beside me,” and I explain to them slightly what happened. And I say, “That does not define who I am.” and we move on. So, I’m pretty strong about it.

Lydia Dubose: [44:08] We really appreciate you sharing your experience and also for being a part of the community, for contributing to the community as a volunteer, and for sharing your story. It's always meaningful to hear. Everybody has a different experience and it's wonderful to hear. Are there any--

Paul Garrett: [44:29] Sorry, go ahead.

Lydia Dubose: [44:29] I was just going to say, are there any last thoughts or anything else that you want to mention?

Paul Garrett: [44:33] Yeah, if you hear this or hear anybody talking through this, anybody that's--tell your friends, tell others that are involved or have it, that you've heard of somebody that might be having this kind of injury. Tell them, talk, communicate. The only way they're going to find something to help what this is and so many others to see this too is to communicate it. And stay strong, keep moving. Even if it hurts, it actually hurts better. I mean, it makes you better. That's about all my words of wisdom.

Lydia Dubose: [45:14] Well, thank you so much. Again, we really appreciate it. And we're so happy to have you as a part of community, like I already said.

Paul Garrett: [45:23] I'm really happy to be a part of this. And I believe it's an important thing and I think, again, I think we should be able to go forward with it and together we'll make it strong, we'll all be stronger. Absolutely.

Lydia Dubose: [45:37] Thank you so much.