

**In this episode of the podcast, we are joined by Trish Sail. Trish Sail is the Community Connections Co-ordinator for the Royal National Institute for the Blind in the South West of England. Trish joins the podcast to talk about her own experience of living with sight loss as she has an eye condition called uveitis which affects the inside of the eye originating in a part of the eye, call the uvea. Trish is no stranger to adventures and with her best friend, Cathie Rowe entered the Race Across the World screened by the BBC in Spring of 2023.**

Be uplifted, be inspired. This is Step Forward and Volunteer.

Welcome to the latest episode of the popular Step Forward and Volunteer podcast brought to you by Lions Clubs British Isles.

My name is Samantha Boffin and I'd like to thank you for tuning in.

If you haven't listened before, our aim is simple. We want to celebrate the positive difference volunteering makes to communities across the British Isles and beyond. To do that, we'll be speaking to those who give up their time to help others, inspiring more people to step forward and volunteer.

In this episode of the podcast, we are joined by Trish Sail. Trish Sail is the Community Connections Co-ordinator for the Royal National Institute for the Blind in the South West of England. Trish joins the podcast to talk about her own experience of living with sight loss as she has an eye condition called uveitis which affects the inside of the eye originating in a

part of the eye, call the uvea. Trish is no stranger to adventures and with her best friend, Cathie Rowe entered the Race Across the World screened by the BBC in Spring of 2023.

But first, I have a favour to ask. We'd like your help in getting the word out about Step Forward and Volunteer. Tell your family, tell your friends - and if you're a Lions member, why not let other members of your club know about the podcast - and how easy it is to listen. All you need to do is either go on the website [www.lionsclubs.co](http://www.lionsclubs.co) where you will see a link to the podcast, or you can search for Step Forward and Volunteer on apps like Spotify, Podbean, Apple podcasts and Google podcasts.

You can listen on-demand or subscribe so that you never miss an episode. We publish a new programme each month, and we're really keen to spread the positivity and get as many people listening as we can.

Hello, and today we are talking to Trish Sail from the RNIB, the Royal National Institute for the Blind, who earlier this year shared her inspiring personal story with Crediton and District Lions.

Hello Trish Hi Sam. How are you?

Fine, so lovely to meet you.

I wonder if you could tell the podcast listeners a little bit about yourself.

Hi, yeah, so my name is Trish. I work for the Royal National Institute for the Blind as you said. I am severely sight impaired and have been since 2011. I am 25 years old times two. So just a little bit over 40 line, originally from Wales, but now I live in Devon. I've lived in Devon since 1999. I married my husband and now living in Exeter and absolutely love it.

Oh wow. So Trish, would you mind telling us how you began to lose your eyesight and what that meant to you?

Yeah, so prior to 2011, I had full eyesight so I 20/20 vision, never had to wear glasses. Never had a problem, got my sight tested regularly.

And I was like walking with Cathie. Just walking along the beach front. And my right eye popped. But it didn't feel like a pain. It just sounded like an internal pop, was really quite weird.

And all of my sight went completely out of my right eye. So believe me I literally buried my head in the sand. Went back to her, her house. Her husband is a pharmacist and says yeah, I think you need to get to the optician. But it could be that you've just got sand in your eye or something like that. So it was a weekend, it was a bank holiday weekend. So I waited till I got back to Exeter and then carried on working for a week thinking oh, it's fine. My sight will come back. Umm went to the optician who sucked air and kind of did the oh, I'm not sure about this. You need to go up to the hospital. So off I went up to Exeter hospital two days later because he did say it was an emergency - so I left it two days! Went up there did they did the same and they went oh it can't be what we think it is.

So we need to send you to Moorfields. I did the oh am I like dying here, cause they kind of didn't tell me anything.

So off I go to Moorfields, and they did a load tests, they did blood tests, poked and prodded me as you know, they all do. And they came back with a diagnosis of White Dot Syndrome or Birdshot. But they said don't look it up because it will frighten you. But until we get everything back, we can't guarantee what it is. So in the meantime, I was just kind of on steroids and other immunosuppressants. And they got back to me about a month later to say we've just had some of the bloods back from a place in America, because we weren't 100% sure. And it's this thing called Chorioretinopathy Uveitis right? Yeah, yeah, exactly. There's one in 750,000 people ever get it? And it's basically my immune system attacking my eyes saying they don't belong to me anymore. The rarity of it is because there's a lot of uveitis but it's because it's this Chromeo bit and what they said is that they've never seen anybody with it under the age of 70. And I was 40 at the time. And it never affects both sides. So one anomaly because I was under the age of 70. But they said, Don't worry, we'll get some of your sight back. You know, you'll be able to drive, you'll be able to do everything it's absolutely fine. Don't worry about it. So uh I carried on. Exactly six months later, I had exactly the same happened in my left eye. Yeah. And unfortunately, at that point, I was actually driving a car right at that second. Trish. Yeah. So my sister who was in the car with me, I slammed on the brakes. she took over driving, and we went straight up to Bristol Eye Hospital, because by then they'd said I needed to go to Bristol rather than London because it was easier for me. They put me on a load of antibiotics and IV steroids and this, that and the other. And they got some of my sight back in both eyes. But they said this is very, very rare to see it in both eyes. And they don't really know still to this day, why it's in both eyes? And

they don't know what happens to it because it's so rare and is normally over the age of 70.

People normally get cataracts or they get macular degeneration. And unfortunately, because of the age category, people tend to die with it. And so they don't really know what happens to it. So yeah, that's kind of what happened.

That is an incredible story. I mean, and come completely out of the blue. I mean, no warning at all.

No, they said that I was born with this disease but it had never presented itself. And they couldn't tell that I had it through any eye tests or anything. Because it is my immune system just all of a sudden decided, ah, we'll attack her eyes.

It's not something that would have ever shown up anyway, it's not something anybody ever looks for in a test.

No, unfortunately not, and back when I was having my eye tests, they weren't doing things like eye pressures and things like that. I mean now it's come a long, long way. So you know, they are doing eye pressure, and they are doing peripheral visions. And they do so much more now when you go to the optician. So they can pick up on things. Because they were saying that, if I'd had a scan done at the back of my eyes, which they never used to do, they might have picked it up at that point. But they now do it as a given, it's one that they do. So I think now science has come a long way, and has helped out a huge amount.

Yes, we're a similar age, and I've been short sighted all my life. And you're right, the eye tests that I have now are vastly different from the ones that I had when I was younger when I was a teenager into my 20s and my 30s.

Absolutely you used to read off the screen and then see if you could see a balloon in the background. That's what it used to be, and now it's so much more.

So am I right Trish, the Royal National Institute for the Blind, they helped you enormously they gave you your life back.

They absolutely did. So when I started losing my sight, I became very introvert, I wouldn't go out of the house. I became really anxious, depression set in. And yeah, I became very isolated. I isolated myself to the extent that I wouldn't even go down to the shop, because I was so scared that something was going to happen to me. And at this point, I still had about 70% left of my eyesight. So I still had quite a bit left. But I was the only person in the world that had sight loss as far as I was concerned, because I didn't know anybody with sight loss because it was something that I never came across. So I don't know how to this day it happened. But I got a knock on my door. And this lady Dawn says hi, I'm from the RNIB. I've come to speak to you and I went, okay. So she sat in my front room. She told me all about her life that she was a full time mum. She married, somebody with sight loss. She's got three very small children or did have at the time. And she worked full time. And I thought this woman is super woman, you know? How does she deal with that? I don't know. Anyway, we sat for about an hour or something like that. And she said, can you show me where the shops are? I was like, oh, it's down the road and take a right to it. I get lost in everything.

Please, can you just show me and I was like, oh, I don't want to go. Anyway, I did, I hung on to her leg, like a little child hanging onto their mum's leg, no don't go to the shop alone. I'll never forget it, I need some tomato ketch-up and something else, never fails. We picked up the tomato ketch-up and went and paid for it. And on the way back up the road. I said to her, how are you getting home. She said, oh, I've got a driver. I said oh that's posh. Do you get a driver, she said, I've got no sight whatsoever. She said I'm completely blind. And I thought, wow, this really is the blind leading the blind, but also how on earth she can do that, full time job. And look after three very small children and a husband that's severely sight impaired. And what I love is she could do that with no sight whatsoever. I've got 70% what am I thinking about. I then got invited to a living well with sight loss course or it was called living with sight loss course then. And went onto this, it was a day each week for four weeks. And I went in and I spent the whole day crying. And I was bawling my eyes out. And the guy who was running it came up to me afterwards and said, I'm so sorry, we set you off, no you haven't, I'm not alone anymore. And it was just the relief and the knowing that there's help out there. And that, you know, I wasn't alone in this. And people understood it, it was like the world had just been lifted off my shoulder. And I was crying because I was just so happy not to be alone. I mean without RNIB? I would not be here today.

Wow. I mean they just do incredible work. Can we turn now to this big adventure that you've just experienced with your best friend Cathie. So you entered for the BBC's Race Across the World. What made you do that?

Um, the honest answer is I don't really know. I must have had one of those moments that wow, this is gonna be a good idea. Let's do it. But what it was like, I've watched series one

and series two and I absolutely loved it. At the end of series two is if you're interested, please apply? Yes. I thought, yeah, let's give it a go. I don't think for one second, like I said a menopause or middle aged woman that lives in Devon would ever, ever get on a programme like that. Anyway, I applied. We did a one minute video, which is the first part of the application. I think I put, I think I'd actually said I'm crazy, I love travelling and I'm going blind, I really said that.

There's a winner there. Wow. That's incredible. So, you got through all of the various stages, because there's a lot of hoops to jump through. Isn't there when you're getting on a programme like that, you have to go for a lot of interviews and things.

Yeah, yeah, cause they need to make sure one, that they've got the right person but two, that you're not criminally insane.

So what was the adventure like? So this was traveling from the west coast of Canada to the east. I think for those listeners that haven't, haven't tuned in to the third series yet. So what was it like? What did it entail? What did you do?

So we were given the same amount of money that it would cost for a one way ticket from the east to the west, for a flight, okay, which worked out to be about 2000? Well, it's \$4,000, which seems a huge amount of money. But actually, when you break it down, it worked out, because it's over eight weeks, it worked out to be \$1,000 a week. But, you've got to pay for your food, your accommodation, and your travel in that. You cannot fly. So everything has to be done via foot, car, train, bus or ferry, basically. So, when we worked out that one bus



ticket, that was four hours was gonna cost us \$250 each. It was a little bit on the tight side. So during the west to the east, we had different checkpoints that we had to get to. You didn't have to get there first. But if you got there first, you then left first, which meant you had a bit of a lead on the other teams when it came to that. And so we started doing some jobs in amongst kind of our weeks out on the race, to supplement the travel. But also, you know, we did jobs that we ended up spending the night at theirs and have a bed and board, which meant that it didn't cost us anything to sleep at night and for food, or we would get travel or whatever. So that's kind of the crux of the race itself. They're were four other teams, and we basically had to beat them to the end.

And we're all the teams double as it were, it was, two people per team. Yes.

So we had a husband and wife Zainib and Mobeen. We had two brothers, Mark and Michael. And then we had two lots of father and daughters. So we had Ladi and Monique. And then we had Kevin and Claudia. And then you had best mates myself and Cathie.

Did you meet them all at the beginning, so did everybody kind of, was there a meeting point? And then you all went your separate ways as it were?

Yeah, so we all met at the start line. We were all then given an envelope saying, You're having your phone taken away from you. Any GPS taken away from you, or any access to internet at all taken away. Here's your money. Oh, by the way, this is bear spray just in case you encounter some bears. And then they gave you an envelope saying you're going from Vancouver to St. John's in Newfoundland. Your first check point is Tllaal. Oh, and they gave

us a map of Canada. The map of Canada, when you stood it up was the same height as Cathie. So to find a tiny little town called Tllaal on this huge map was like trying to find the needle in a haystack. It took us forever to find it, and then we went to the start line, and we met our competitors. So that's the first time we met each other. And it was like do you know where Tllaal is, umm might do, might not, might do, not giving anything away. Myself and Cathie were the eldest of the group because the two father daughters, the fathers were the same age as themselves the daughters were 25 and 27, the brothers were 28 and 29. And Zainib and Mobeen who are married and in their mid-late 30's.

So you and Cathie am I right that you actually won the race?

You are quite correct. Yes, we did. Spoiler alert. So yes, we we've done 16,000 kilometres. With, like I said, very little money. It worked out to be something like 50 pounds a day. We had. And yeah, we beat everybody to the finish line by two hours. Oh yeah.

How did that feel?

It was mad. It was absolutely crazy. I can't believe that we've done it even now. But it's also a little bit sad, because we'd had the most amazing adventure that's ever, ever happened and will ever happen to us. I think we made every single moment count. We loved every second of it. But we were racing to finish it. And it was like the end of it. So it's a little bit sad. But you know, winning money, you know, 10,000 pounds, each kind of made it a little bit better, you know, as it does.

Not bad at all. Wow. But but yes, you're right. It's almost like a bittersweet thing, isn't it? You're, on the one hand, you need to win, so you need to go quickly. But on the other hand, you want to spend that time really soaking up this, this incredible moment.

Absolutely, absolutely, I mean, they were I keep saying this, so many pinch me moments on the race. I mean, the highs were incredibly high. The lows were the worst thing that ever happened in the world to anybody. So things like dropping a banana on the floor. That was free, was the worst thing in the world. Oh no we've got food and just dropped it.

So are you planning any more adventures?

Yes myself and Cathie, Zainib and Mobeen, go to China, and we're doing a five day trek on the Great Wall of China in aid of RNIB.

So now you've got the bug now, basically,

Yes, most definitely. When we actually got back from Canada, myself, and Cathie decided that we'd walk up the Inca Trail, which was another five day track to go see Machu Picchu. So yeah. And I got up to the top, and I was looking down on Machu Picchu, and I phoned my old boss. Because I used to work for a bank. And I went, I quit. Umm I quit. Ah right. Okay, so yeah, I left because I just thought, you know, I want to do something different. So, after volunteering for RNIB for several years prior to it, I got hold of them. And I said have you got a job. They went we have actually, if you want to apply, there's a few. So I applied for a

Community Connections Coordinator and I got the job. So I actually now work for the Royal National Institute.

Wow, I mean, so, so not only did they support you and, and turn your life around when you needed them.

Absolutely

It's an incredible story. It's just wonderful, isn't it? So going back to what happened to you? What would you say to people that have experienced something similar, a personal point in their life where I don't know if something went terribly wrong, like it did for you? What would you say to those people?

I would say, bear with it, learn from it. But don't forget, it will get better. I don't feel if it's not getting better reach out for help. Because there's help out there. It doesn't matter whether it's a sight loss thing. There is help out there. But reach out for it and ask for it don't suffer alone because you're not you know, no matter how daft or how horrible you feel. There's somebody there that understands and sympathizes and empathizes, so reach out to it.

Amazing advice. Thank you. So Trish have you got anything else that you would like to share with our listeners?

Enjoy every day that you can you've got one life, like I said right at the beginning of this I kept myself in my house for six months. Now and although I don't regret doing it because I am where I am now. Don't let life pass you by just grab it by the horns and just go for it.

I've always said, I want to go into my grave, regretting something I've done, rather than regretting something I haven't done.

Well on that note, I think I'll leave it there. Trish, thank you so much for sharing. Well, not just your incredible story. But all the adventures that you've had, since then, and all your advice. That's so fantastic. Thank you. Thank you for coming on to the step forward and volunteer podcast.

Oh, thank you for having me, Sam. It's been an absolute pleasure.

It's time now for a short break, we'll be back after this ...

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Lions Clubs also act to prevent avoidable blindness through their healthy vision campaigns, sight restoration operations around the world and early detection eye screening programme.

Well, that is all we have time for on this month's podcast. Don't forget you can also listen to past editions of the Step Forward and Volunteer podcast any time via [www.lionsclubs.co](http://www.lionsclubs.co) or on Spotify, Podbean, Apple podcasts or Google podcasts.

Thanks once again to our special guest Trish Sail and a big thank you to our listeners as well.

Take care and goodbye.