Episode 3: Introducing Epilepsy Waikato Charitable Trust.

Please note: This transcript has been lightly edited for clarity, flow, and readability.

Welcome to our podcast Epilepsy Uncovered where Kayla, Brooke and Bella, three occupational therapy students, bringing to you a special series focused on shining a light on epilepsy. In honour of being November, which is Epilepsy Awareness Month, join us as we explore four different topics over the next four weeks. Whether you're living with epilepsy, supporting someone you know, or simply just curious to learn more, this series is for you. So, sit back, relax and enjoy.

Welcome back to Epilepsy Uncovered. You are listening to episode number three. Today we are learning about the incredible mahi being done at Epilepsy Waikato Charitable Trust, including what they do, what support they provide and how our community can get involved. We are joined again today by Esther, who is the Epilepsy Advisor for Epilepsy Waikato Charitable Trust. Hello, Esther. Kia ora.

Well, I think to start us off, can you tell us a little bit of history about the trust?
Yeah, sure. So, the trust has been around for at least a decade. Although I meet people every day in my job and they say, we didn't know you existed but, we've been around for at least a decade. There's a little bit of history so, we started up when there was a gap that wasn't being serviced for people with epilepsy in the Waikato, there wasn't a support service for them. Previously in the past there was Epilepsy New Zealand. Now us and Epilepsy New Zealand actually do both function in the Waikato. So, people in the Waikato are really spoiled for choice. They can get help from either one of us or both of us. So, they have an educator in the Waikato, and my title is Epilepsy Advisor. Yeah, that's a little bit about the history. All right.
Thank you for sharing.

Can you kind of tell us a little bit about what EWCT is?
Yeah, EWCT is an NGO or non-government organisation. So, we don't get any government funding. We're funded by community grants and also by donations. Sometimes we get very kind donations from members of the community to help us to enable the work that we do so we operate in that NGO space. It also gives me a little more flexibility in terms of my role and how I'm able to help people out because we don't have that government funding over top that says, you can only help people with these sorts of things. So that does kind of help in that space.
Yeah, I think that's really cool. You can actually support a wide range of people and also working with people with epilepsy and otherwise just general seizures as well.
Yeah, that's something I hadn't quite mentioned. So, we do support people who have other types of seizures as well. So, people can have non-epileptic types of seizures, we support them and also, we do support people from outside the Waikato. We just can't travel there. So, Waikato DHB is our main area, but we have a broad range of clients on our database from outside the region and outside the country even.
Yeah definitely.

Can you tell us a little bit about your role at the Trust?
Yeah, so my role, epilepsy advisor, although actually when I interviewed for the role it was epilepsy advisor slash advocate, and then I think they it down to epilepsy advisor. Advocacy is still a part of my role, so I can certainly advise people around epilepsy, around supports, be kind of that middle person between the clinical setting and them. The advice that I give comes from a non-clinical background, It comes from the training that I received from the previous Epilepsy advisor. So, I come with what she's taught me. I don't come with any preconceptions around epilepsy or around their seizures, from not having that medical background. But I do have a personal connection to seizures my partner has had seizures in

the past. So that allows me to be empathetic with people that I see and my non-clinical background in anthropology allows me to see things holistically with the people I see and really take in all the different aspects of their life and see a little bit more than outside that clinical setting.
Definitely. Thank you for sharing that.

So, can you tell us a little bit more about what your day looks like day to day?
So, I guess in terms of what a day could look like for me, for example, I was out on a home visit this morning, so, it may be a couple of home visits in a day. It may be a talk on epilepsy to a community group and then it might be administration work in the office answering emails, answering calls that are coming through from people. Updating our website, updating our Facebook page, making sure that I'm up on kind of like the latest articles and information that people might want to know. It may be going with a client to a doctor's appointment or maybe to WINZ writing a letter of support for them so that they can get what they theoretically are entitled to. So, the main parts of my role, when I talk about my role to other groups, I say that their advice, advocacy and education.
For sure, it sounds like your day to day is so different all the time.

What drew you into this role working within the trust?
Yeah, a lot of different things. One I guess is my personal connection to seizures. Another part of it would be that I enjoy working with people and helping people. I've worked in a lot of roles in the past where I have been in that kind of community support, customer service, but this is not so much customer service, but I've been a part of unions when I was at uni, so that advocacy lens kind of comes from there, and I've been a tutor up at the University of Waikato, so I understand kind of that teaching side. I wanted to know a little more around the community and social space because that was something I hadn't really delved into before. And I love being able to see different parts of the Waikato and see what exists for people, where they are, really get a sense of the region as a whole.

So that leads into my next question. Within your role, how do you incorporate principles of Te Tiriti o Waitangi? And what can you kind of do with that within the community?
I think it's really important that we take into account Te Tiriti o Waitangi I think it's really important and the Treaty Principles Bill that was going around in Parliament earlier this year, personally when I heard about that coming about and was like, this is not right, I put in my own submission but us as a trust at Epilepsy Waikato Charitable Trust, we also put in a written submission against the Treaty Principles Bill because we didn't at all agree with what it was stating. We already know that those who are Māori and have epilepsy, it's harder for them to get diagnosed. They are seen later within hospital environments. And so, we really use that evidence to say, this is already the case. If this is put in place, it's going to make it worse It's a document that we're all to live by in New Zealand and it's got its place in our society.
Really shows your advocacy coming out right there.

If someone wanted to reach out and get support or education, how do they approach this?
Yeah, we can take referrals. from anywhere. Self-referrals can come through. We get referrals from family members. We get referrals from different community groups through, sometimes through neurologists and paediatricians, through schools, workplaces. Whoever is connected to the person or is the person themselves and feels like they could do with that extra bit of support, We take referrals from anywhere and we also don't require a diagnosis of epilepsy for someone to be referred to us and part of that is around diagnosis for epilepsy being really hard. Another part of it is around misdiagnosis being quite a common thing for epilepsy. And the other is around making sure people who are having seizures have that

support because even if they don't, necessarily have epilepsy, they may struggle with some of the same sorts of challenges as a person with epilepsy.
For sure, and I think that's really great how you can take these referrals, especially from the non-clinical backgrounds, so you're making your support really accessible.
Yeah, there's always something that we can do for someone, even if it's just a listening ear, they feel like they're actually being heard. But even quite often, I meet with new clients and I'm talking to them about different types of seizures or they're telling me about something they experience, and I say, well, that could be a symptom of this type of seizure. Oh, I didn't know about that so, yeah, I think a part of it comes from our health system being so stretched and doctors not necessarily having a lot of time that they are able to give the patient. So yeah, we try and answer those questions or give them that information that they perhaps haven't had access to in the past, just so they are more aware.

In terms of those self-referrals, what does that actually look like? Do they pick up the phone? Do they send you an email?
Just to make it really clear for the listeners. Yeah, totally. So currently at the time of recording this podcast, people can text me or text David our numbers are on the website, or they were at the time of this recording.
And I've course you can also email so thanks for clarifying that Esther, and listeners if you'd like to know more then you head over to the EWCT website for lots of other useful information.

So, we've kind of discussed what your role is working with individuals with epilepsy and their whānau. I was wondering how does the Trust work with like schools or workplaces or other health professions?
We work with them a lot. So, in terms of those parts of my role that I mentioned before, the education side of it is quite broad. Anybody who says, you know, it'd be really helpful to have a talk on epilepsy, we're quite happy to go into their space and provide them with some education around epilepsy. Some groups have regular talks from us, places like Aspire Community Support, Te Kōhau Health, they have pretty regular talks from me. And then we'll get organisations that'll come to us and say, hey, can we have a one-off talks we've given talks to all sorts of community organisations out there. Sometimes schools say, can we have a general talk on epilepsy? They might have several students who have epilepsy at their school and want to know a little bit more generally about it. But mostly for schools, it'll be education around a specific person's action plan that I create It's a very individualised action plan around the person's seizures, triggers, emergency management kind of thing. In terms of other organisations that we connect with, the person that we're supporting needs advocacy in their workspace or with their finances or with housing, then hopping in and sometimes going into those appointments or writing something like a letter of support to go alongside their action plan can be helpful in those instances and figuring out is there something specific for that particular client, are they of a particular age group where there's certain sorts of organisations out there to kind of provide that advocacy or support just, getting a really good grasp on what's going on.
You sound like one busy lady.

So, what's an area that everyday people in the community might not realise that EWCT does or can provide?
Hmm, good question. Yeah, I think probably the advocacy side of things would fit that question but there is that side to advocacy where you want the person to be empowered and advocate for themself where they can. But if they need that extra support that we can kind of jump in there. So, I think that side of things is an area where it really does show how many different areas of life could be impacted by someone having epilepsy and shows the need to have that side of our service.

Yeah that's definitely some great services and really cool that you can provide that.
Yea for sure, and sometimes it's even just being an extra person at a meeting or on the other end of the phone. The amount of times a client has had a phone call from MSD or WINZ and this is no hate to anyone who works at MSD or WINZ. But there are several uh examples that I can give where I introduce myself say, I'm the epilepsy advisor and there's a whole lot of things I talked about while that phone call's happening. The phone call ends and the client say, they never told me about this. Why are they so much nicer when you're on the phone? So I think sometimes it's even just the name of our organisation, my title being chucked out that people are like, oh, OK, I've got to take this seriously.
Yeah. And I can imagine that those processes are really hard to navigate for individuals. So great that you guys are there for that.

So how can the community get involved in giving back and supporting EWCT?
There's a bunch of different ways that the community could get involved in giving back. For example, listening to this podcast, educating yourself around epilepsy with the right information. If you have someone in your family or you know someone who has epilepsy and you're not sure if they are being supported by someone like ourselves or Epilepsy New Zealand. Then giving them details and kind of giving them a few ideas of where they could get support from us. Even if it's just a few things that they haven't heard about before and we're making them aware of that. I guess the big one would be ah any kind of donation. Yeah, I mean, money's a hard side of things it's something that community organisations like ours do struggle with. You know we want to be able to do the work that we're currently doing or do the work that we're doing now better to better support people but it obviously does rely on our funds and what we are able to resource. There's a reason why I'm the only epilepsy advisor for the trust and David's the administrator. We don't have the funds to have more staff. So I think even though it's a really hard one to talk about, if anybody, even if it's a couple of dollars, we've had families of children who have epilepsy who have been doing some sort of donation as part of like a school activity and they said, we've raised this money, we want to give it to the trust. So yeah, really simple things. I think even, you know, wearing purple during Epilepsy Awareness Month or on Purple Day earlier next year, wearing a purple ribbon, there's small little things that we can do. Coming up to us at expos or if we're out in the community and asking a few questions. Yeah, there's a lot of simple ways.
And I'd also like to say, despite these limitations, I think you're doing an amazing job and also spending the time to come and record these podcasts with us out of your busy day. Thank you so much.

A big thank you for joining us, Esther. Ngā mihi nui. We really appreciate you taking your time to share your knowledge and insights with us. *Ngā mihi.*

And that's a wrap on episode three of Epilepsy Uncovered. Join us next time as we hear from someone with lived experience of epilepsy, sharing their personal story and strategies for everyday life.

Be sure to tune in for the rest of our Epilepsy Awareness Month series and help us spread the word by sharing this episode with your whanau and friends. Ka kite anō!