Introduction and Donna Hartlenu2019s background

Again, I'm so glad you are here. As part of the MS and Neuroimmune Summit. We have a real treat here. this is Donna Hartlen. She is the executive director of GBS/CIDP And we'll explain what that is.

in a few minutes. the foundation of Canada. She was diagnosed with GBS, which is Guillain-Barre syndrome. In 2009. And then diagnosed with cidp. Chronic inflammatory demyelinating pioneer apathy.

Like a double whammy. in March of 2011, she became the executive director in the fall of 2013 with a personal mission to bring awareness across Canada of the rare inflammatory peripheral neuropathies, so that patients diagnosed, easily, and earlier and treated, more effectively for better patient outcomes.

You know, and I'll tell you, this really matters. also to me, my father had mono neuritis multiplex, and he had, you know, about 25 years of progressively, severe difficulties.

And we'll probably talk about, her experience and my father's experience, during our interview. Now, Donna's married to Wayne. she has two girls, age 18 to 16.

And prior to, her medical, adventures, she was an IT consultant for many years in telecommunications engineering. and she finds gardening very therapeutic.

That's a bond that we both share. we both love gardening. she, enjoys her bike and her treadmill. and there are constant personal challenges to stay fully engaged.

Donna, thank you for all the work that you do. And thank you for chatting with us today. Dr. Wahls, it's, it's a privilege for me to participate in the MS and Neuroimmune summit.

And, I'm hoping today, by bringing this awareness, to your participants, that maybe someone out there watching will have an moment and, maybe potentially get diagnosed on this rare condition journey that all of us tend to be on.

Yeah. You know, so my father had, you know, a a progressive pain in his legs, ultimately diagnosed as modern or itis multiplex. So it's an autoimmune disease.

Damages peripheral nerves. can you explain it since you have personal issues with two things GBS and Cidp. Do you want to explain what those are? how they're alike and how they're different?

They're very alike. the mechanism of the destruction of the nerves is very similar. So these are neuromuscular conditions. So they are neurological conditions.

They are inflammatory attack on the peripheral nerve coding myelin.

What GBS and CIDP are

so your MS, viewers will know that the whole myelin thing, the difference is the attack on the myelin is the nerve fibers that branch from the spinal cord to the peripheries.

So your arms, your legs, sometimes there's some autonomic damage that can happen in some individuals. so our, our actual immune attack has nothing to do with the brain or spinal cord.

And, it causes paralysis. It causes sensory problems. So it affects both the motor and the sensory nerves, which

leads to weakness of the limbs, and lack of feeling and numbness in your legs and your arms and other areas of your body.

And, you know, for people with, many, autoimmune conditions affecting the brain or the spinal cord, symptoms often are going on for years, occasionally a decade.

They see the, you know, personal physician do an exam campfire thing and just say, well, yeah, I don't know what to sort of watch and wait, is that, a common scenario for, those two conditions as well?

So for Guillain-Barré, it's a very acute presentation. So Guillain-Barre can happen within when it starts its onset, it can happen within hours. So you can feel the weakness and the progression.

It can be catastrophic. you can go from walking to fully, paralyzed in an ICU invented within 24 hours. For everyone listening that is been on a ventilator.

Having a machine help you breathe. So that's going to be terrifying. Terrifying. We call it locked in. So you're fully cognitive. You understand what's going around in your surroundings.

It's not like a stroke or you're in a coma. You're fully aware. It's terrifying. it leads to a lot of PTSD and a lot of, a lot of our patients. and then with chronic inflammatory demyelinating, it tends to be a more progressive condition.

Slowly progressive. And that's how it leads to this long rare disease journey. because we don't have enough knowledge in, you know, primary care, with your general practitioners what that condition looks like.

And, there are some acute patients in the space as well, but it's a smaller percentage form. And, that weakness, the rules around symptoms and cidp is that it's progressive eight weeks or longer.

And we can see patients in the city speak cidp space that take years to be diagnosed. And you mentioned in some of the other, like MS You know, we hear those comparisons when we're in a hospital.

when I was diagnosed with 2009, they said this is either Guillain-Barre syndrome or aggressive. MS And I was 39 at the time, female. so you can understand, you know, why there was some comparisons being tossed around?

the good thing about our condition, it is a neuromuscular condition that is treatable and a lot of neuro muscular conditions are not treatable. so there is a positive there.

So if we get diagnosed early, get on treatment early, we can stop a lot of that, nerve damage and, have a hopeful outlook. If we are sent home multiple times from emergency rooms with gamma ray that can lead, that can lead the journey to ICU because they're not recognizing the condition.

And with CIDP we don't know if we're going to get back what we lose, after damage. So for either of these conditions, you know that, say, this is probably true for any, disturbance that you can perceive of the motor nerves are not working quite right.

Your, less coordinated, weaker. There's, changes in sensation. But go see our primary care to. Well, what do we do? What what what would you be advising the listeners to do?

Because in reality, you have this all all this funny neurologic stuff going on. Is it peripheral nerve, is it spinal cord, is it brain? You know, we can't tell as patients and often the primary care person, they don't have enough neurology knowledge to be able to sort that out either.

So what kind of guidance do you are you giving to your tribe. So the key clinical features in our conditions is that the major ity of our patients, when there is weakness on one side, it will be on both sides.

So there's some clinical features that are, you know, can be obvious to where, diagnosing our conditions. It's when

it, when you have sensory issues or weakness, it should it typically runs on both sides of the body.

So it's. It's symmetric. It's symmetric. It tends to be symmetric. We do have some variance within our umbrella city variance. that may not be. But the majority of cases it tends to be symmetrical.

So if you start to lose, abilities on one side feeling you get weak on one side, usually the other side is going to catch up. the other thing is the one of the key features that we speak to at medical conferences when we're trying to gain awareness in the medical community is that often we have a reduction or absence of reflexes, and that's an easy test.

so why don't you explain reflexes to our audience? Because they may not know quite what a reflex is. So, do you know why don't you go for it first, and then I'll add the medical jargon?

so when you go into your doctor, they will tech check deep tendon reflexes for us. There's different conditions. They'll be, hyper reflexes. Ours are reduced.

So when they, you know, look for your reflexes in your ankles, your knees, your wrists. A lot of people just think of reflexes in the knees, but you actually have them in wrists and elbows, knees, ankles.

they will either be reduced or in the case when they clinically looked for that feature for me, they were completely absent. in children that can be a bit confusing.

So what we've been told by our medical advisory board is sometimes reflexes may be absent in children and our condition is, not prejudice to sex, age, race.

so in kids, it can be a little more difficult on the reflex. So when your, physician takes a little rubber hammer.

Symptoms, reflexes, and when to seek help

Yeah. Taps your knee, taps your ankle. it should have a little bit of a jerk. Like that, right? With EMS, it's a big jerk. can any upper motor neuron problem.

So a stroke or injury of the spinal cord when the peripheral nerve is attacked? that there's not a hyper reflex, and then it becomes smaller and smaller and finally, absent when they're tapping and we have a bunch of different tricks that we do to try and get the reflex when we can't get it.

but it always starts out with a hammer, to the knee and a hammer to the ankle. Rubber hammer. Rubber hammer. Well, could you tell us about your personal journey?

when you first began to have symptoms, and then you got to a diagnosis. So it goes back to 2009. I was actually traveling to see my parents in Halifax, Nova Scotia.

my kids were born to and we had Christmas dinner, and it was a Boxing Day party at my sister's house. And, that night I was in seventh year. I had severe back pain.

And that's also another symptom of gamma ray is severe back pain and sometimes headache. And I couldn't get it to go away. I was in and out of a bathtub for hours at a time, trying to get rid of this back pain, and the next morning I knelt down to change my two year old's, you know, pull up.

And I couldn't get off the ground. And, it was just that weakness that that whole cycle was really fast and aggressive, and you don't know what's happening to you.

So, you know, like you say, you don't know to check for feeling in your feet or feeling in your back or feeling in your hands. You're not doing that type of thing.

That was the key feature for me at that time was the fact that my legs were becoming so weak. so what we did is we put me in a car and took me to emerge.

And at that time, it was a swine flu pandemic, not Covid. But at the time it was a same and pandemic. And they put me in, flu isolation and, thought I had the flu based on how I was saying, you know, body ache, you know, headache, weakness.

They thought I had the flu. I sat in emerge for ten hours. things seemed to be getting worse. And my husband got a have started to advocate for me and get vocal that she needs to be seen and I was told later by the neurologist that was called in overnight that I was very lucky that an emergency physician recognized that it was neurological.

She did a clinical exam for me and picked up on some of the neurological, tests. And that's when she said, I think this is either aggressive Ms.. Or this could be Guillain-Barré syndrome.

They called in the overnight neurologist. He came in and he started to poke my body with a pin. And it wasn't until that point when he was running a pin up my body, that I could feel nothing, that I knew I was in serious trouble.

at that point, he wasn't telling me that. He was thinking it was Guillain-Barre. lucky for me, there was an on call. Neurologists, you know, some of our smaller local hospitals don't have that.

That. Yeah. So I was lucky I was on I saw the neurologists at 12:00 at night and I was on treatment. I was on immune, high dose of immunoglobulin, which is a plasma derived product for our conditions.

by 4 a.m.. And, I was lucky it literally slowed, if not stopped a lot of the progression. But my weakness, the progression did continue with it. I lost the use of my legs.

I lost the use of my arms. I had severe pain. I had no feeling and hands and feet. And eventually, two days later, I had slowed it, but didn't stop it completely.

I lost my ability to swallow. I lost my ability to move my face. I couldn't blink my eyes. Oh my God, that's terrifying. It is terrifying. And I spent, three months, overall in hospital, another three months in rehabilitation.

But as I said, the good news for our Guillain-Barre patients or Cidp patients is that treatment can get us out the other side of that darkness. Yeah. because I had a lot of facial like, because it was so aggressive head to toe.

The neurologist came back in and told me a couple of days later that I was lucky the ear doctor recognized it because I was on a tour directory for ICU because of the facial paralysis.

My lungs. the reason why we end up on life support is because the diaphragm is a muscle, is a muscle. So we lose the ability to breathe not because the lungs don't function, but the diaphragm, the ribcage.

In order to exhale, bring. The air in. You know, that stops. So that's why the lungs. I think we have to give people hope here. Like so this was catastrophic.

It was terrifying. Yes. You got diagnosed, you got treated. And it looks like your face is working pretty well right now. I have some residuals. what happened with my face is the right side is slightly still paralyzed.

If I get some photos taken, it's better to on this side, because maybe it looks like I had a little bit of Botox on the side. It's funny. but I can do some tricks, with.

But no, I mean, if I didn't tell someone my history, they would not know. Today. And, you know, that's why it's so important for us to get awareness out there.

Because in some hospitals, they think that when we're in ICU, this is as good as it's going to get.

Donnau2019s GBS diagnosis and recovery

And some of our families are told that. And, that's scary. And we try to. I think, a key message here is we could have a rapidly accelerating neurologic disease.

We want to be sure that you get a neurologist, involve appropriate treatment because we can stop the damage, and have remarkable recovery. so I'm thinking your arms are working.

Your legs are working. You're okay. Your face is working pretty well. You got, a wonderful laugh and a great sense of humor. so that's the the young beret, story.

Yeah. And then the IDP story. Why don't you tell us about one? So, well, physicians like to say fully recovered as patients. We don't like to say fully recovered, because when you've had Guillain-Barré or even Cidp and you may go into remiss of states, you still have residual damage.

But from a medical perspective, they considered me fully recovered. Months have gone by. It's a year later, passed a year later. my daughter ended up getting a flu.

she was in kindergarten. You know, kids are like, they just bring home a lot of stuff. And I ended up getting the flu. I had a fever for five days, and then all of a sudden, I started to feel that decline.

I started to feel that same feeling from 2009, in 2011, where that weakness, that onset of weakness was starting and I panicked, got a hold of the neurologist and, sat across from her and she did the clinical exams and all that good stuff.

And said, Donna, we're going to give you a get out of jail free pass on this one. We think that this is flu related. You had flu for five days. You've still got residuals.

You're still healing because we heal up to 2 to 3 years later after January. So, you know, maybe there was a lot of, you know, you're exhausted. So let's hope this is residual.

We'll move on then. What happened is in March of 2011, my daughter had a stomach flu. And, to the point where we had to take her to emerge and get nausea shots and stuff.

And we were leaving for Mexico two days later for a ten day holiday. Family wise. And I got to Mexico and I managed to pick up that stomach bug. And on the 10th day of our trip, I was trying the these two flights of stairs to get down to washrooms, you know, beside the pool.

And I was having trouble getting up the stairs. And I said, Wayne, we gotta get back to Canada now because this it's starting again and that onset and and you know, I'm not covered by treatment.

I'm not diagnosed by cidp at this point. So, you know, I don't have treatment in my system. This is a flare. I got home on a Wednesday, and by Friday I had no longer I, I had no use of my arms in my legs at that point.

And at that point, being seen in the hospital by my neurologist, I was diagnosed with cidp. Now, some folks get diagnosed eventually with cidp because the GBS may seem mild.

And then what happens is you have these relapsing remitting events and it could end up being cidp. my neurologists have said my between the cidp and GBS, they were separate events.

My GBS was GBS and I was lucky and managed to get cidp in 2011. And since I was diagnosed in 2011, I've had three major flares, all of which had, for a period of time, made me quadriplegic.

Well, and, and now I'm going to be curious. The treatment for cidp. Yep. is immunoglobulin. Yeah. Right. So for Cidp, there's the first line treatment we'll call it.

First line is immunoglobulin. It's a plasma derived product, that is created from plasma donation. and there's multiple products out there for it. And then the other the other treatments are plasma exchange.

So they take out, a plasma out of your body and then replace the volume. And that's to strip out all those bad antibodies that are out there, attacking.

And making their myelin. Attacking the myelin. And then. But plasma exchange is not easily accessible in Canada anyway. I'm not too sure about other countries, but here it's it's got a very busy schedule, so it's not easy to.

Get on it. It's hard to access. But yeah, hard to access. And then we've got that lovely third one, which is steroids. And we all know steroids after long term use the problem, you're gonna end up with other health problems.

Yeah. So now I'm going to ask you, you know, think about this from an integrative functional medicine perspective. has there been, any, work with the environmental factors that contribute, to either a better response to treatment?

are you aware of anything? And from a integrative functional medicine perspective for these conditions. I am not aware of anything. But, you know, you've got this narrative.

You you get patients together and you start to talk about, What we're doing. Well. What was the trigger? And that's the other thing for us. We don't have biomarkers, you know, although we we can talk about it later down the line.

But Guillain-Barré is a syndrome. Cidp is the same mechanism. So triggers or causes are suspected in our areas. And I agree, we need more research. This is you know, this is part of our motivation of getting awareness out there and, building out a research program and funding so that we as patients can drive the research that is important to us.

yeah. Right. And I think that's an important message is that although our neurologists and our health care teams obviously care very much for us, in the end we have to look after ourselves once we're diagnosed and have to care for ourselves daily.

You know, treatment is a very small aspect of how we manage our conditions. Yeah. so that's our goal. I want to put you on the spot in your, in your tribe.

is there any discussion about the role of, diet or supplements or any particular rehab toxin exposures? What? What's your tribe saying? So, doctor walls, you were, a guest on, one of our educational events a couple of years ago.

It's very much a topic, within our. We have support groups that run across the country. it's definitely a topic that we all care about. And we've actually geared a lot of our content in our educational events now to be about self-care and awareness in these in these areas, a lot of our patients want to know more about, anti-inflammatory diets.

They want to know more about, decreasing stress and what that means.

CIDP relapse and treatment options

you know, we're told decrease your stress, but we're not given the tools to decrease stress. So we're, you know, doing things like mindfulness and all these types of things.

And quite frankly, in our space as well. And, and we can talk about this down the line as well. But exercise is huge. you know, we are given in hospital for Guillain-Barre patients.

For some reason. The medical care team always give out referrals for things like physiotherapy, occupational therapy. These types of therapies. But our cidp patients are left behind.

and that's, that's. They need they should be getting the same stuff, you know. The they should be getting the.

Same stuff that we have. and you know, my, my thoughts and, certainly I admit I'm not a neurologist.

but I try to help the cells as well as we can. So we gotta be sure that your people have great nutrition. We want to be sure that your people are sleeping.

Well, and, get guidance and support on how to begin exercising safely. That's right. So this fall, we have, we have an educational event coming out, and it's heavily weighted on self-care.

because once again, we need the tools to manage our conditions once we leave our doctor's office, you know, our day to day. that is so, so important. So let's talk a little bit about your organization, the kinds of events that you do, and who all they would be good for.

So we we are a not for profit organization, that supports families and patients. So not just patients families as well. Oh, yes. The name of your organization first.

All right. So we're the Cidp Foundation of Canada. one more time. Slowly. Oh, sorry. We are the GBS Cidp Foundation of Canada. Okay, we will continue.

We have four pillars that, we base all of our initiatives on, and that is support, education, research and advocacy. And the support piece is is hugely important.

you know, we need our patients not to feel alone. This is these are rare conditions. They need to know that they have a community and a community that they can turn to.

So we run, peer to peer support group meetings across the country. We run them virtually like online. We also do them in person. Well, we had shut down a lot of the in-person stuff during the Covid pandemic, but we're taking steps to, bring in-person meetings, to our cities and our communities.

more so now. And on the educational piece, we run national conferences every two years. Those. Okay, I'm going to interrupt for a moment. So can only Canadians come to your virtual meetings, or could I come as a Yankee?

So, for instance, so we do have sister organizations, that, represent patients with GBS and Cidp. the one out of the US runs out of Narberth, Pennsylvania, and, they're the GBS Cidp Foundation International.

So they do runs support some some support efforts there. But to answer your question, yes, we do have, people from outside the country that connect with us that say we don't have access.

Can we jump on some of these meetings and, they do. So I think the message I want everyone here is, this is a really great organization. I have done, work with them, I love them, I love their mission.

So if you have a peripheral nerve problem, be sure to sign up. Be sure to check check them out. Even if you're not a Canadian, they'll still let you come, be part of their, zoom meetings.

and I suppose if you fly into Canada for the in-person, that would be fun to, know what? What is the, long term prognosis for somebody who has either GBS or C?

cidp. So a progressive, you know, relentless decline or can I, can you look forward to, you know, a rich and full life? So, as you know, some people may or may not realize autoimmune can be very individual.

So it's hard to put a blanket statement on it. It really depends on that person's immune system and what it decides to do. But in general, Guillain-Barré syndrome has a morbidity rate of around 5%.

And that really comes down to our severe patients and the inability to breathe. but also the autonomic involvement in some of those severe patients. So we have people that crash, like, have heart attacks during, you know, the onset of Guillain-Barre.

and and to be very clear, I should mention this. The you reach your worst within about 4 to 6 weeks with Guillain-Barre. so it does its thing for 4 to 6 weeks, and then it stops.

Then it's up to your body to recover that damage. but yeah. So there is a morbidity rate, for GBS and for Cidp. They do not actually connect, morbidity with Cidp.

so typically it's other health conditions that you will pass away with. You can live decades with cidp. We cannot guarantee what, how that life is going to look.

we have individuals like me that I have been very lucky that treatment works for me very well. But we do have patients that treatment is not working well for.

And there is a decline, a consistent decline where they go from walking that a gradual weakness to being in a wheelchair, and just losing their mobility overall.

So it's very critical. And, and again, to the listeners, I will tell you, I've taken care of people with Cidp.

Self-care, rehab, and integrative support

I've not had any GBS. and my approach has been keep working with your neurologist, and let them give the here in the US FDA approved treatments and my role is assessing nutrition what nutrient deficiencies they have.

We address those. We assess hormone balance. usually the adrenal, pituitary axis is not working so well. So we have to address that. There may be some other hormones that are a little off that need to be tweaked.

and then, we work on sleep, to try and improve sleep. and then I typically send people to physical therapy, sometimes occupational therapy, to get a safe exercise program going.

And, you know, what has been super interesting is, nutrient problems, are certainly often uncovered, in the people that I've seen. And as I address the nutrient insufficiencies with, you know, targeted supplements function improves.

Now, the person has not come back to being the athlete that they once normally had been previously. But, you know, they are remarkably improved. So, to the listeners, I want you to realize if you have funny neurologic symptoms in your primary care, doesn't know what to do, advocate for yourself to get a neurologist so you can get a proper diagnosis, and then you may well benefit from, you know, the conventional treatments, which can be really very impactful for stopping the damage.

And then an integrative functional medicine approach, which your neurologist probably doesn't know anything about. So now you're gonna have to try and find someone, with sort of the expert point of view that I have that we have to assess your nutrition, your hormones and all those environmental factors to fix them as well as we can.

So yourselves have the best chance to fix you up. and, it certainly sounds like, your organization is helping people think about that self-care part of making your cellular environment work better so they can do your cells, can do a better job of the repair.

So I have to tell you so I, you know, I, we try to express to our patients why looking after yourself and all these aspects of managing stress, managing your diet.

you know, it's very well known that sugars and starches are inflammatory things to ingest and these types of things. And then we had you want a couple of years ago, which was just phenomenal and was very well received.

And I myself, you know, this is 14 years after Guillain-Barré. I used to run. And I said last year to Kim, Kim was with you online. I said, that's it, I'm done.

I can start looking after myself so we can look after everyone we we care about. That's a member nation. And I'm not doing that. You know, I'm stressed, you know, all over the place.

So last December, I took it upon myself to really dive in to looking after myself. And I changed my eating habits. And I can tell you, I immediately started to feel better.

You know, I didn't have the body bloating and I didn't have the drag and my energy levels were better. And then I said, that's it. I had this treadmill in the basement that was broken forever.

And, I said, that's it, Wayne. No one buy me Christmas presents. That's my husband. No one buy me Christmas presents. I'm buying my own Christmas present.

This year. And I bought a really good treadmill. And I can tell you now that the treadmill, although it's helped my mobility, it has helped my pain levels dramatically.

I am not waking up anymore like I get up in the morning. I have a really good walk. Or, I'll get to the good news and I get that exercise in. It gets those endorphins going, and I don't have pain during the day anymore.

And I used to severely with pain. I don't have pain anymore. And that in itself is a stress relief. I mean, pain causes stress. but I lost the. And I don't know, I'm not a doctor, so, one of the muscle in my buttocks was severely damaged during GBS.

That it's my balancing muscles. I don't know if it's a strap that goes around. And I used to run prior to GBS. And, you know, every time I go to my neurologists, they do surveys about, you know, your abilities.

And one of them was, can you run? And, you know, for 14 years, I said, no, I wouldn't even look at it. I started walking on that treadmill and getting more aggressive and and increasing my speeds.

And finally I took a leap in early March and said, okay, this is probably not the safest thing. You know, you should probably have someone around you if you're going to try something crazy.

I said, that's it. I'm I feel really strong. I'm going to try. I start jogging, I'm jogging again. I mean, I'm jogging again. And and this is a message that needs to go out there is that there's hope.

There's a hope for improvement. We can't guarantee that improvement. But you're allowed to hope because it's been 14 years for me and I'm running again.

I love the story. you know, and I, similar to I, you know, terrible, terrible outcome. Couldn't set up. Could take just a couple steps with my two walking sticks.

Horrible trigeminal neuralgia pain. that was 2000, seven that my neighbor, 2024, don't have, pain, mentally clear writing books, doing research, writing grants.

And this last, six months, I've started jogging again, slowly, slowly, you know, and, I was jogging. I love jogging outside than two miles. and, I stumbled like shit.

so then I realized, okay, as much as I love rain outside, I should jog on my treadmill. Yes. And that, So that that's what I'm doing, like, okay, I'll do tiny little jogs, around my yard, like, okay, if I stumble there, I'm so on the ground, it's not a big deal.

I don't want to be stumbling on the road or on the sidewalk. So I'll, I'll I'll walk. I'll do Nordic, Nordic poles walking. I'll do hiking and but I'll do my jogging on my treadmill.

I also find for me the treadmill, because you've got that shock absorbing of the treadmill.

GBS/CIDP Foundation of Canada and community resources

It's, it's easier on on my muscles, because, you know, we get atrophy, you know, I, I can I can induce pain by what I'm doing. Yeah. Whereas, you know, a concrete road, tends to gear up some pain that I wouldn't typically have.

But we have walking rules that we do across the country nationwide, and it's to build awareness in our communities. And we have one coming up in Toronto on May 4th.

And I decided this year I'm going to jog for others. it has a wonderful way. I figure. I've got lots of friends and community members that can help me if something happens.

I'm not going to do it every day. But, we need to let people we need to give hope. We got to, you know. And, with the honestly tell a story that this doesn't come easily, you know, it's a lot of work.

it's certainly a lot of work. but to everyone who's listening, think about the most satisfying hero's journey movie hero's journey book that you ever read or experience.

The hero is facing a very difficult challenge. Success is not guaranteed. That's the key part is success is not guaranteed. The person may fail, but they try anyway.

You have a wonderful hero's journey my friend that you're you are on and you are inspiring so many people there in Canada and around the world that yep, life is difficult.

You decided I'm gonna work at it anyway and you keep setting yourself up with the next goal. The next goal, the next goal. I am so, so proud of you. and, proud to be, I sometimes partner in getting to do, programs with you because you are, such a wonderful person and such a wonderful, hero, to look up to.

So thank you. Thank you for all that you do. Thank you. Dr. Wahls like you, we have to decide to invest in ourselves. We have one life and we have to decide, you know, how we're going to live it and to fight for it. And, I can't guarantee that the next day I won't have another flare.

In fact, it's not a matter of if it's one. And I want to go into that strong so I can come out the other side strong the best possible way. Yeah. The other wonderful thing that you have, and I have us children who are watching my choices, I guess it's like, okay, they can see me give up or they can see me like, okay, I gotta keep working at it.

I'm going to keep working at it. I'm not going to complain. I'm going to keep working at it. I'm going to keep working at it. And now that my kids are adults, it's super interesting to hear them talk about, having watched me, you know, do my little workouts every day, and that I kept at it.

And then I started recovering, really working out there like, oh my God, my, my daughter, was doing comic books that she made herself. And so she made a little comic book about, you know, the electro woman, and that, that was me.

So super fun. Your kids are watching. They're going to be inspired to everyone who's listening, I invite you to reimagine your life that you are on a hero's journey.

Yes. Success is not guaranteed, but if you come at it every day, you'll be inspiring the young people around you and the adults around you to be more fully engaged in their lives.

Okay, so what is the one thing you want people to take from our conversation today? Donna What I would like people to take away is the fact that, even if you're diagnosed with one of these rare conditions, and GBS and CIDP, there is hope, there is treatment, there is hope, and there is a community out there that holds our arms open, welcomes you, and will help you along the way.

Every step of that journey. And, how do they find your organization? so if you easiest way nowadays is through, a

website. So, if you look up www.gbscidp.ca you'll find our website and a lot of tools and information to help you.

We have a lot of video, patient journeys out there. Like I said, they're very individualized. You will probably find your own story reflected in someone else's and help you not feel so alone.

And, you can register with us there so that you can stay connected and, take part in community events, whether they're education, support or awareness.

this is wonderful. I so, so enjoyed our conversation, and I look forward to, being hopefully featured in another program with you guys, sometime soon.

It's fantastic. Dr. Wahls I truly appreciate the privilege to be here, with your tribe. And, all the best with the rest of the MS and neuroimmune summit. Thank you so much.