

## Acromegaly with Martin Cornally

### Speaker Key:

Chantal Boyle – Host

Scott Casson-Rennie - Host

Martin Cornally - Guest

00:20

On The Sunflower Conversations today are me, Chantal, and I'm joined by my colleague Scott. Scott runs Hidden Disabilities Sunflower in Ireland. Hi, Scott, how are you?

Scott Casson-Rennie

00:31

I'm very good, very good. The sun is out Yay.

Martin Cornally

00:34

The sun is out.

Scott Casson-Rennie

00:35

I don't know if it's hot, but the sun is out.

Chantal Boyle

00:38

The sun is out and the dandelions are out as well apparently a really good thing. So we've just been discussing dandelions with our guest Martin Cornally. Today, we're going to be discussing rare diseases, focusing on the pituitary disease called acromegaly. Our guest is Martin Cornally, as I've already mentioned, who is joining us from Ireland. Martin was diagnosed with this in 2012. So thanks for joining us today, Martin, and I am fully aware that I'm not pronouncing it correctly, of which I do apologise.

Martin Cornally

01:11

You're fine did I have to be long?

**Chantal Boyle**

01:14

Thank you. So, Scott, you say that the sun is shining in Ireland which is a good thing.

**Martin Cornally**

01:20

It is, yeah, a wee bit yeah yeah yeah for the next couple of days,

**Chantal Boyle**

01:27

I mean, it all is going to be during the week, isn't it? And then when we're on holiday at the weekend that will be at the rain will rejoin us. So acromegaly is a rare condition caused by a pituitary tumour that signals the gland to produce too much growth hormone. So Martin's going to help explain to us what that is and how it affects the body. There's quite a lot in there I think that we need to have explained. So first of all, can you explain what is the pituitary gland and what role does it play in our body, please, Martin?

**Martin Cornally**

02:03

The pituitary gland and, as the medical profession call it, the master gland, because it's a small little gland based just at the base of your skull and it produces all the growth to keep your organs working normally your liver, your kidneys, your heart and your general well-being. So it secretes the growth on a daily basis and it knocks around all the organs and, as I say, it keeps everything ticking over nicely. And the problem becomes when it starts to secrete too much. And then organs, in my case, started to grow excessively, like kidney, heart, etc. They all continue to grow and obviously they're only supposed to grow to a certain state and then maintenance thereafter. So it does pose the kind of problems it posed. I suppose, if I can go back to the start of it, where the problem starts,

Chantal

Yes, please,

**Martin Cornally**

You don't just wake up today with acromegaly and go to your doctor, explain your symptoms, get a diagnose and then get a treatment plan. It took so I was diagnosed in July of 2012. And when they had taken so what they ask you to do is bring a sequence of photographs going back over the years and they can kind of pinpoint fairly accurately as to when it started. So my case diagnosed in 2012, and they reckoned it started in about 2005. And you'd wonder why it takes so long. Then you know why there wasn't a cop from 2005 to 2012.

03:53

But the changes, it's a sneaky little thing, they're small. It's not that you wake up with the huge hands that I have today or move from a size 11 shoe, as I did, to a size 14, or on my skull and my facial features change overnight. It's a very slow, ongoing process and along the way you know things are not right and you have various difficulties. But when you go to your general practitioner, it's not that they don't understand it, but most of them will tell you that they spend very little time in college or in training with it because it's a rare disease. So they focus more on the everyday diseases that you know cancers and so on and so forth, diabetes and etc. Etc.

04:42

So that is the period that I found the most troubling, because you, you know yourself that there are changes to your body and yet there's no explanation for it. And I was very fortunate that I was having a knee surgery and at the end of it and the surgeon came in and he says look, I don't want you to get upset with me, but I've never seen feet as big as that um and that that kind of triggered off. Then he wrote a letter and it started me on the journey of getting the diagnosis. But most people don't get their diagnosis for, you know, between six and eight years and in the meantime the damage is done like, I'm riddled in arthritis now because my skeleton is. It was the one thing it really done an awful lot of damage to. You know, as I said, my feet went from 11 to 14. Now that's a 40 odd years of age, not as a growing young fella.

### **Chantal Boyle**

05:48

That's right. Yeah, you stop growing in your sort of early 20s.? I think men generally, men generally stop growing in their early 20s growing at 21, 22, yeah, so to say.

### **Martin Cornally**

05:56

But so that's that's. That's the big issue with it. It's trying to get an earlier diagnosis, trying to get more awareness among the medical professionals. And you know as well, when people come in with you know I had a trait of different symptoms, like I put on six stone without changing my diet and or my exercise. I

used to have to wear, bring a spare shirt to work with me because I started sweating like it was crazy, and severe headaches. There's so many little signs all the way along, but they don't make sense to anyone until you get a diagnosis. And unfortunately, even though it's brilliant, you get your diagnosis.

06:59

And I had an operation in 2012 to remove the tumour, which was successful for a period of time, but it came back again, and I had a second surgery in 2019. And now my endocrinologist is telling me that my acromegaly is back again. There is no third operation at the pituitary, so they're trying to devise. I have two professors now, I'm under two professors now and they're trying to devise a medical plan that will slow it down or contain it. So yeah, it's a tough, any disease is a tough one to be with. But that six years of unknown, knowing that something's wrong with you and it can't be explained. It's hard to take, not just physically but mentally as well, because then there's so little known about and people ask you what's wrong with you. And you're trying to explain that kind of look and go Jesus, you know, because then there's so little known about them, people ask you, well, what's wrong with you? You're trying to explain to them. They're kind of looking and going, Jesus you know what's that?

**Chantal Boyle**

07:49

Do you know what the statistics are?

**Martin Cornally**

07:52

Yeah, well, the latest stats I was just looking at them last night in Ireland anyway is between one and three people per 100,000 people.

**Chantal Boyle**

08:01

Right.

**Martin Cornally**

08:03

Yeah, so you have a better chance of winning the lotto.

**Chantal Boyle**

08:06

Yeah.

**Scott Casson-Rennie**

08:08

I'm sure you prefer to win the lotto as well. I wouldn't mind at this stage.

**Martin Cornally**

08:13

But you know so, once you get then into the system, as they say, you know the system in Ireland is quite good once you get into it and they get very helpful and they put you through all the treatments and test that they can. They try and make the best out of a bad lot, if you know what I mean. But, as I say, the period of when you have it and you have the, there's other stuff that goes with it as well, sleep apnoea, and I'm sure you're well, well you've heard of it.

**Chantal Boyle**

Do you want to explain sleep apnoea for people that haven't?

08:53

**Martin Cornally**

Sleep apnoea is where there's a narrowing in your airway so as you're sleeping at night you can't draw breath and you snore like a bear. But a couple of times I remember waking up Jesus, thinking you know, something was going on there, and my wife would explain that she would have to wake me because you kind of stop reading properly because, of the narrowing of the airway, and then you can get this machine.

09:22

it's a mask that you have to wear every night. Thankfully I'm not that at the minute, but that was hard. It's a very invasive kind of a thing.

**Chantal Boyle**

09:34

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**Martin Cornally**

09:43

GH1. That's it, it, it growth hormone.

09:50

they medically just call it gh1.

**Chantal Boyle**

And is it different to, because there is something called gigantism. Is that the same or is that something different?

**Martin Cornally**

09:59

Same, and just the thing with acromion is, as I said to you, diagnosis, pardon me, is early 40s right gigantism. Gigantism is in younger people. It can be in 18, 19 year olds, who continue to grow as well, but it starts in their teens, where gigantism is well into. We call it middle age.

**Chantal Boyle**

10:26

Okay.

**Martin Cornally**

Yeah, but the symptoms are very similar.

**Chantal Boyle**

Yeah, so the gigantism would be for the teens.

**Martin Cornally**

10:37

Yeah. Yeah, for younger people, yeah, and then in your 40s for acromegaly.

**Chantal Boyle**

10:42

And that's linked again to the pituitary gland, the master.

**Martin Cornally**

10:47

Yeah the master gland. The smallest gland, but it's the master gland.

**Chantal Boyle**

10:52

And you said it's a pituitary, pituitary sorry tumour. Does that mean that you have the risk of it being cancerous?

**Martin Cornally**

1:00

There are. In my case not, and in most not. But as one surgeon said to me one time, it might be easier outcome if it was cancerous, because it would be easier to diagnose and because there has been so much, unfortunately, cancer. There are so many great treatments for cancers now. You know if they're like everything caught early, but acromegaly is known as the sneaky disease. You know if they're like everything caught early, but, um, acromegaly is known as the sneaky disease. You know, because it just moves quietly and slowly along and causing the problems that it does for people medically, physically and mentally I would say aswell.

**Scott Casson-Rennie**

11:47

I would say as well so you mentioned that you had an operation and the surgeon kind of said he hadn't seen such big feet before.

I mean, not something you would want to really wake up to after an operation, I'm sure, but did you have any symptoms looking back?

**Martin Cornally**

11:53

Oh yeah, like as I say, you see, you know headaches, so severe headaches. Well, if you went to your GP and said I had a severe headache, you'd probably have to go home and take some paracetamol, whatever putting on weight, they'd put it down to you're drinking too many pints or your diet or whatever. But I was in my younger days very weekend hurling and all that, but it kept us in fairly decent order and even when I finished I still kept active.

12:27

But I couldn't understand this weight gain, you know, and, as I say, I hadn't changed my diet, drank a few pints, but not an excessive, you know, wasn't doing anything that should cause six stone change in a couple of years. You know, and

yeah, the hands, the growth of the hands. Some of my friends call me Shovels, you know my nickname. But you learn to laugh at all that stuff too, because if you don't you'll be crying on your own. But mean well it's just a bit of a laugh amongst ourselves.

**Scott Casson-Rennie**

13:03

I mean a six stone. That must have been quite worrying. I mean a six stone that's you know, that must have been quite worrying. I mean, I know it wasn't overnight like you say, but you know, even then, six stone that's yeah.

**Martin Cornally**

13:12

I weighed in one time I can remember to the gentleman 21 stone 10.

**Chantal Boyle**

13:20

How tall are you? If you don't mind me asking.

**Martin Cornally**

13:23

I'm shrunk a little. I'm 6'2 now. I was 6'5. But I'm back down to 15 stone.

**Chantal Boyle**

13:32

Right wow. So is that difficult then for you to manage that? I mean, if it's something that's just happening and you've got no control over it?

**Martin Cornally**

13:41

Yeah, well, I mean, it's like playing cards with the devil. You know You're not going to win. Yeah, the frustration part of it all is the unknown why, why, why? And you know the journey is not an easy one. It's a very expensive journey, may I say too, because I funded mine privately. Now I have private health care, so that paid for my surgeries and they're they're very expensive. But, like you go to see a consultant, now it's 250 euros, you know, for consultation and at one time I was going to see five different guys up and down to Dublin every other day there for



a period of time, you know, and that's just what I had to do, but it's very expensive.

### **Scott Casson-Rennie**

14:30

Yeah, and you said that one in three sorry, one to three out of 100,000 people may have it. So how difficult is it to diagnose then, if only that number of people have it? I mean, is that globally or just Ireland? I think you said it was just Ireland.

### **Martin Cornally**

14:46

That the latest in Ireland, and America, I think, is pretty similar. Now I stand corrected. It is a very low rate. You ask a good question how is it so difficult to diagnose it? And a few GPs that I've spoken to would say look, rare diseases. When we go to train to be whatever the physician and then specialize in an X, y or Z, they don't take much heed of it, they kind of flip through it because it's something that they're not going to spend a lot of time dealing with as a physician or a consultant with as a physician or a consultant, even the endocrinologist who would specialise in endocrinology.

15:32

So in terms of diabetes, thyroid, that's where acromegaly falls under, or problems with maturity, what I've seen went to see two different endocrinologists and one that went to see and said well, I don't really specialise in that, so you know there will be a lot of people with diabetes. There will be a considerable number of people who would have thyroid under or over. So it's because of the numbers being small and in a rare disease that I can understand there isn't the focus on it. You know there is more now than there was when I first engaged with it, definitely more awareness, but still not what it needs to be, the more we can do to just have people, even not being afraid to go in and say, look, x, y and Z is wrong with me now and it wasn't before, or my hands have grown or whatever. You know the key, the key things that changes that you'll see will be growth, certainly in your bones, your hands, your feet, and you'll see changes to your face. But because they're gradual, it's you know, it doesn't happen in a week, a month even. It goes on over years and you'd love to see it because the earlier it's caught, the better chances of the problems that will be there thereafter and mightn't be gone, but they might be minimized in some way.

17:05

I mean my skeleton. Now I'm on a drug for pain and I hate taking about half time. It's called Etoricoxib. It's got an opium product in it and I can take one every three days. But without it, without it, my quality of lifestyle would be brutal. Where it's okay at the moment.

**Chantal Boyle**

17:30

Okay and is there like a concoction of other things that you've had to take, so you've had, you've had two surgeries, did you say?

**Martin Cornally**

17:35

I had two surgeries, yeah, and the first one was a disaster because I had to bleed on the table. Well, that was a horrible experience. I spent 13 hours in theatre on the first one in 2012, and a week in ICU, and then in the second one was an absolute pleasure. I was in and out of theatre in three hours and I was at home drinking coffee two days later. But for the second one, I spent four months preparing myself for it because I knew it was coming, obviously, and I went into a very strict regime of in the gym making sure I had no extra weight, and the healthier you are going in for these operations, the better outcomes you have. So I prepared very well for that one and it worked well for that one.

**Chantal Boyle**

18:30

So, they're basically going into your skull?

**Martin Cornally**

18:30

What they do now is don't crack your skull anymore. They come up to your nose and they drill a hole just at the base here, and then they work their way through.

**Chantal Boyle**

Just to explain Martin's pointing to the bridge of his nose in between his eyebrows.

**Martin Cornally**

And they just take out a piece of the bone there and then they go in and they remove the piece of tumour that's causing the problem and then they repair that.

18:57

And yeah, there's been great advances in the technologies of these things, from being very invasive to now being acceptable, if you know what I mean. No one wants to be having surgery, but if you can get out home after a few days.

**Chantal Boyle**

19:15

It's nice, yeah, sipping tea after three hours, yeah yeah, sounds quite incredible. So, like can you give us a little bit more insight into what impact the treatments had on your symptoms? So if you're taking this really heavy duty painkiller, presumably there are certain things you have to avoid. Uh, drinking alcohol, presumably?

**Martin Cornally**

19:39

Absolutely. Yeah, well, it's not good to take powerful medication with alcohol. I wouldn't suggest or recommend that to anyone. Um, yeah, it's really. You know, I would have been good with my diet, but now, like I wouldn't touch chocolate, any of that kind of stuff, anything that's will put excessive weight on you. Just minding the alcohol level that you drink. Kind of gone off red meat and pork because of the amount of antibiotics that goes into it, that kind of stuff. But now I still have a steak every once a week.

20:17

I don't live like a nun, as they say, but I just try and eat fruit and just try and do the right things. I like to exercise, but that's dependent on the body. The body tells me what I can do and I listen to it. Now, where before I wouldn't, I may have went against it. That's not the right thing to do. But if I am in a lot of pain now I don't do a 10k walk and I have two golden retrievers that need walking but you know, you just have to listen to your body and it's telling you. If it's in a lot of pain, that means something is wrong.

**Chantal Boyle**

20:54

That's a warning.

**Martin Cornally**

20:57

Yeah. So sometimes I'd have to rest for a few days and then get back up and go again.

**Chantal Boyle**

21:06

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So, with these physical symptoms, you've got. You've got pain because you're, you've got arthritis, which presumably affects every part of your body.

**Martin Cornally**

21:21

I've been treated for eight years with rheumatoid arthritis and two months ago I was told that diagnosis is incorrect. It's osteoarthritis, so the medication had to change completely, and it's brittle bone syndrome.

21:38

So to be very careful and not to be breaking bones to handy or falling.

**Chantal Boyle**

Are you still getting the headaches?

**Martin Cornally**

Not as bad, thankfully uh, I don't miss them, not as bad, but I do from time to time get uh about and again it's just about closing the blinds. Get yourself into a dark room doesn't get rid of it, but it abates it a bit, you know, to just manage it. It's all about managing. You're not going to beat your problems, but what you can do is, I feel, is you can try and best manage them to have the minimum impact on them.

**Chantal Boyle**

22:18

Your internal organs. Can you explain what's happening with them?

**Martin Cornally**

22:22

Okay, well, so my heart is enlarged, but thankfully this present time it's working, functioning okay. My left kidney is twice the size of my right one. Now it's coming under a wee bit of pressure and I'm being investigated at the moment for a little problem with my pancreas. But that's not to finish yet. I have to go in for another investigation the week after next. But the giant thing that kills me more than anything, because I was very active and loved it, because it's good for you, but I don't get to do anything like what I was able to do.

**Scott Casson-Rennie**

23:10

And I just want to go back to the headaches, if I can. Was the headaches because obviously now you've explained exactly where it is and all that sort of stuff. Is it because of the tumour?

**Martin Cornally**

23:27

Yeah, it is, it is, that's just one of the symptoms. You know the way you get an odd headache if you're in a stuffy room or something for an hour or two, this kind of a headache is like a drill in your head and it doesn't go away after 10 or 15 minutes.

**Scott Casson-Rennie**

23:41

I know what it can be like.

**Martin Cornally**

It can be prolonged for a day or and you're drained after it like you're literally just whipped, you know.

**Scott Casson-Rennie**

I know my headaches and I know how that one feels, I'm afraid yeah, it's not nice, but my, my medical complaints are irrelevant at this stage. So yeah, but that's really interesting because I just wondered with where you said they went through.

**Martin Cornally**

24:02

That must obviously have an impact on the rest of the kind of brain and head.

**Martin Cornally**

But to be fair, it's, it's when you think about it's probably better that they go in there and you know the old way environment was. You know, literally, literally take your skull open, yeah, where you know. Thankfully, as I say, things have moved on yeah.

**Scott Casson-Rennie**

Gratefully

**Chantal Boyle**

24:26

I think you don't mind me saying Scott, but Scott has um two brain aneurysms do they cause you to have headaches?

**Scott Casson-Rennie**

24:35

Yes, that's why I was asking the question.

**Martin Cornally**

Sorry about that boy.

**Scott Casson-Rennie**

24:53

Well, I've actually got four, two ruptured, two didn't. But yeah, so they kind of. As soon as you said you went through, sorry, the bridge of your nose I was like this is going into the brain, isn't it? So I just got you straight away and, yeah, headaches, especially after it all happened as well. I think I had headaches for about five months. The constant headache, just a constant headache. Nothing could shift it and I eventually managed to control it. And the headaches were caused because of, obviously, everything that went on in the brain, but they also were caused by the blood and everything that went on in the brain. But they also were caused by, um, the blood that was still gathered in kind of the bottom part of the brain that was trying to drain away. And they, you know, they say to you it will eventually drain away, but it took five months for that to happen and a lot of headaches yeah, and a lot of consumption of water as well.

25:43

That's, that's a massive thing for it. So yeah, they're not headaches are. You know, I can probably deal with a lot of things, but headaches are just.

25:53

They're quite debilitating actually.

**Martin Cornally**

25.56

Yeah the drain, you're the right the drain, yeah absolutely yeah.

**Chantal Boyle**

25:52

So with your physical health and then your mental health, what impact did that have on your life basically, you know your relationships?

**Martin Cornally**

25:59

Yeah, well, if you look at it, you know when you're sick or not well, so you're kind of not as inclined to be as active or as interacting with people. You know you might skip the party. You skip, you know all these social events and people go. What the feck is wrong with him? You know there's always something wrong with him. And again, you don't want to be telling everyone your life story, boring people like so I kind of used to say nothing and just kind of you know, but if I was well enough I'd go on, if I wasn't well enough I wouldn't go. But yeah, it does. It does you find yourself removing yourself socially a bit? Now, I never had a mental, what would we call, you know, crash. But yeah, there's a time you can say I have enough of this, you know, because it's not something that it's going to go away. To go away it's a lifetime condition and no one's going to come around and say you're now released from it. So I suppose then it's trying to teach yourself again, as I said, to live with things and to best manage them by how you interact during the day, your diet, your sleep, et cetera, et cetera.

27:18

I've stopped working because I physically wasn't able to do. I was a retail manager for 25 years but it was hands-on and that's the way I loved it. But the body didn't love it anymore. Me standing for eight or ten hours clocking up 30,000 steps a day in a 10,000 square foot shop. And now I loved it and I missed, missed it terribly. But physically wasn't able to do it and was advised that was the proper thing to do so. But, um, and that was a huge transition because you're gone from being busy, busy, busy, busy to not being busy and that's a bloody huge cliff to fall off. You know, but I've managed to keep myself as busy as I need to just be at the minute. But full-time work is finished.

**Chantal Boyle**

28:23

So you've got your other pursuits to give you a purpose and keep you ticking over.

**Martin Cornally**

28:29

Yeah, I interact in the community there and I'm involved in a massive community creche where I look after the finances for them free, you know, so that kind of stuff, and I have the birds, two dogs and yeah, look, I have a son and a daughter

as well. But yeah, I would prefer to still be working in some shape or vibe but that was just ruled out.

**Chantal Boyle**

28:55

As well as coping with the physicality of what you've got, the mental side of it, of actually having this acceptance that it's. It's not going away, like said, it's a lifelong and that you have to adjust your life to fit in with it.

**Martin Cornally**

29:11

Well, you can be stubborn, you know, and I would have been a bit stubborn and I'd been honest enough to admit it a bit, as they say in Ireland you would have been a bit of a thick, yeah, and that doesn't work in your favour because you're only frustrating yourself more. That's what you're doing. So I've done that for a while and realised it was getting me nowhere fast. And then we tried plan B, and plan B was to acknowledge what you have and deal with it the best you could.

**Chantal Boyle**

29:47

Have you met many people through, like, I know that the statistics are really, really low, but have you been able to connect with anybody else?

**Martin Cornally**

29:57

Oh, yeah, yeah. Yeah, certainly, through the Pituitary Foundation in Ireland. It's a fabulous organisation and there's plenty of new people who get their diagnosis. They come on to seek a bit of advice about consultants and you know it's a group there and there's a bit of chat going on. I won't say I diagnosed two people, but I direct people on my way and I'm looking at them and I'm saying you have acromegaly, the features are just there. And one was a young fella, 26 years of age, a young guard, and uh, he contacted me after saying yeah, you were spot on at the time he was laughing at me, yeah, and, and another lady in a coffee shop. She was 43 years of age.

**Chantal Boyle**

30:46

That's what I meant to ask you, um is it a bias to one gender or the other, or not?

**Martin Cornally**



30:53

Yeah, it's more biased to causing harding for males. It's not as hard on females.

**Chantal Boyle**

That's interesting. Yeah it doesn't cause their organs to grow at the same rate?

**Martin Cornally**

Of course, it depends on the level of secretion as well that each individual gets, because everyone might just have a slightly different level of what's being secreted, you know.

**Chantal Boyle**

31:19

What do you think about the Hidden Disabilities Sunflower Martin?

**Martin Cornally**

31:24

Well, I'm going to be very honest. I don't, won't say I know everything about it. But my understanding and I'm sure you'll correct me is that again, you're trying to create awareness of people in this case, I think, with a disability and to trying to make life a little easier from where it's possible, and I think it was, one of the ideas was that the lanyard going to the airports and the transport and things like that, that they could be prioritised. I think that's wonderful and I think that should be brought across with all people, with all disabilities, because people think, unless you're in a wheelchair, you don't have a disability. Do you know what I mean? There are people who have mental illnesses, and that's a disability, right? There's physical disability, so it comes in various forms. In my view.

**Scott Casson-Rennie**

32:14

But I mean, it is relatively new to Ireland. But I think that our kind of campaign style is probably trying to recruit organisations. So you're right, airports are a massive thing, obviously, and airlines, because you know people travel, they may need extra time or support or just you know, just some understanding. And I think that you know we've got quite a few larger kind of organisations joined up recently. So you know, as we kind of grow and develop, I think you know you'll probably see it a little bit more than you may have done in the past.

32:47

But certainly, no, I'm aware of myself. So I wear it because of my brain injury really. So if I'm in a place where I might feel a bit anxious or might feel a little bit

out of my depth, or you know, I've noticed, certainly with my condition, that you know, things I used to be able to do all the time I kind of now get a bit anxious about. So you know, know, traveling would be one of them. We live in quite, on quite a small island and sometimes I have to go to another country to visit family and friends and all that sort of stuff. So you know, airport travel is quite important to us when we live in such a small kind of country. Yeah, um, so it's, it's, you know it's really. It is garnering a lot of attention now, so hopefully, you know, you'll see a bit more. And of course you know, now that you're aware of it, we can perhaps keep in touch and talk about the Sunflower a little bit more so yeah, that's great.

### **Chantal Boyle**

You can help us spread the word Martin.

33:44

N problem.

### **Scott Casson-Rennie**

So, and then it's great to have an Irish voice on the podcast as well, which is great. We're, all you know, I'm always very conscious of you know people who can relate to other people, not necessarily just with one specific condition, but with a hidden disability, like yourself, and sometimes when you hear it in your own accent, you're like, oh okay, that kind of puts people in a bit more. So, given that you've got all this experience and all this kind of personal experience and lived experience, what would your advice be for anyone who has the condition? If you notice, I didn't say the word because I would never have been able to say it.

### **Martin Cornally**

34:23

That's fine. I suppose you know the few times I have spoken about and just going back to my own experience and I was often asking myself why didn't I go? And I would say to anyone if you have any doubt, go. The worst thing can be told is which is a great thing, you don't have it. But if you have any concerns, always go and seek the best advice. Try and make sure that you do a small bit of research, because you need an endocrinologist and a neurosurgeon for your journey and make sure you get the best that's available there are some really, really good ones out there thankfully now in Ireland, albeit, they're mostly in the private field.

### **Scott Casson-Rennie**

35:12

That's what I was just going to ask you, because obviously we have a different kind of health system to the UK in Ireland. If, for an example, someone was

unable to afford it or they were on the medical card would they still have access to good treatment?

**Martin Cornally**

35:30

Yeah, no, in fairness, to Beaumont Hospital, they have probably one of the leading research professors there who has changed things in Beaumont and there are far more people getting it done on the public in Beaumont now than there were in the past. I believe it's likewise in University Hospital in Cork. Again, there's been good effort, you see, in the past to raise the awareness, so I think that might have helped. There's been a lot of lobbying of the medical profession to raise awareness. Yeah, yeah, and there's been a lot of lobbying of the medical profession to raise awareness and hope, you know, so that if somebody comes in that they at least have a chat with them about it. You know, I mean, as my GP said, you know, when I told him that my shoe size had gone from 11 to 14, why they didn't train in it, he should have clocked that himself. He said that there was something not right.

**Chantal Boyle**

36:25

Like a central resource. Is it the Pituitary Foundation, did you say? Because we can put that in the show notes so that people can have a look.

**Martin Cornally**

36:42

There's the Irish Pituitary Foundation group and the foundation. They're all on all the social media sites there. They're quite good, In fairness. There's somebody who's maybe after getting the diagnosis or someone who's you know their life is upside down. They're fantastic. There's a guy there by the name of Bob Brady. He does unbelievable voluntary work. I don't know how he manages it, but he's a super boy. He does unbelievable voluntary work. I don't know how he manages it, but he's a super boy.

**Chantal Boyle**

37:13

Yeah, I must say thank you to Bob for putting us in touch with you.

**Martin Cornally**

37:15

Yeah, no, he's a really genuine, one of the best I've met.

He's so enthusiastic about it and about, you know, making it better for people. I think, in fairness, he deserves great credit.

**Chantal Boyle**

37:28

Well, thank you to you, Martin, as well.

**Martin Cornally**

37:34

No problem. Thanks very much for having me, and I wish you the very best.

**Chantal Boyle**

37:36

If you are interested in any of the advice discussed in this podcast, please follow up with your GP or healthcare practitioner. If you enjoyed this podcast, please share it, leave a rating and review to help raise awareness of non-visible disabilities and the Hidden Disabilities Sunflower. You can also follow and subscribe to The Sunflower Conversations podcast - [The Sunflower Conversations podcast](#).

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