

Cushing's Syndrome with Gretchen Jordan

Speaker Key:

CB	Chantal Boyle
LS	Lynn Smith
GJ	Gretchen Jordan
UF	Unidentified Female

00:00:00

UF

Welcome to the Sunflower Conversations, where we explore the Hidden Disabilities Sunflower and its role in supporting people with hidden disabilities.

CB

Your hosts today on the Sunflower Conversations are me, I'm Chantal, and I am joined by my colleague, Lynn, who manages the Hidden Disabilities Sunflower in the US. Hi, Lynn, how are you?

LS

Hi there. I'm very good, thanks, Chantal.

00:00:33

CB

It's lovely to see you. And to hear you. It's really nice. I really enjoy doing a bit of co-hosting. It's a great opportunity to catch up with you and other colleagues, and it adds a nice dimension to these conversations that we have with our lovely guests.

LS

Yes, well, I'm really excited to do this today, and I'm especially interested in today's guest, to hear about everything she's gone through.

CB

Okay, let's find out what are we going to be discussing. So we're going to be discussing rare diseases, focusing on the pituitary disease called Cushing's. Our guest is Gretchen Jordan, and she's joining us from Minneapolis. Gretchen was diagnosed with Cushing's in 2020. Now, Gretchen is a very busy lady. She's a patient advocate for pituitary health and the associate director of Cushing's Support and Research Foundation.

That's quite a lot of words, I feel like I've just said. And so, first of all, welcome, Gretchen. Welcome to the Sunflower Conversations.

GJ

Thank you. Thanks so much for having me. And it is a privilege to be sharing my story for Sunflower and appreciate that opportunity. Yes, thank you for having me.

CB

I think, I guess, the key thing that I've said in the introduction is that it's a rare disease, and that's why it's so important for us to be able to have a space to talk about rare diseases, and help raise awareness and cognisance of what they are and how they impact people. First of all, can you explain what the pituitary gland is and what role it plays in our body?

00:02:18

GJ

Sure. Yes, the pituitary gland is a small, pea-sized gland that's positioned at the base of your brain. It sits in a little chamber behind your eyes. And it's considered the master gland of your body's endocrine system. It makes hormones and also tells other endocrine glands to release other hormones. Hormones can carry messages throughout the body, through blood, to our organs and skin, muscles, things like that. A bunch of other tissues. These messages tell your body what to do and when to do it.

You might ask, well, what's the endocrine system? It's a large thing, right? Without getting into too much biology, the endocrine system, as a whole, is made up of these organs, glands, and tissues that are in charge of creating the hormones and maintain countless body functions, as well as continuously monitoring those functions.

You can have more than 50 different hormones that impact nearly every aspect of our health. Some examples, okay, be ready for this. Metabolism growth, balance of your blood sugar and blood pressure, fluids and electrolytes, body temperature.

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It impacts your digestive system, your nervous system, immune system, cardiovascular system and heart, respiratory system, the reproductive system.

Even the placenta, when the woman is pregnant. It impacts your mood, your circadian rhythm, which is your sleep-wake cycle, your liver and pancreas, your cognitive development and memory formation, your bone and muscle health, your skin, hair, nails, your response to stress and adrenaline, and suppressing inflammation.

So, the endocrine system is pretty vital to our existence, and certainly impacts that master gland, or pituitary, and impacts to that can be life threatening. But some people's condition require the removal of the pituitary gland, which, you can live without it, but you must then take medication to replace the pituitary hormones that you're missing, that maintain all those functions.

CB

So, basically, that's everything?

GJ

Yes, pretty much.

CB

Because when I think about hormones, I think testosterone, oestrogen, progesterone, and I don't really think of too much more. Now, I do want to ask you something about cortisol. Is cortisol a hormone?

GJ

It is. Yes.

CB

What does it do?

00:05:02

GJ

Cortisol is commonly known as the fight or flight hormone. You might have heard that in the past. It is a steroid type of a hormone, but it does much more than just regulate stress. The pituitary gland would send a message to your adrenal glands, and the adrenal glands are the little lobes that sit on top of your kidneys. The adrenals then produce the cortisol.

Cortisol is an essential hormone that impacts many things. All those systems that I talked about, the organs and tissues. Your body continuously monitors the levels of cortisol. Having too much or too little can be a bad thing. When the body has too little cortisol, the pituitary then sends out that signal for the body to produce more. Or, produce less if there's an excess. But it is essential to life to have some cortisol.

CB

Yes. I just thought of another hormone, which is really terrible for me to have forgotten it, because it's something I have, which is underactive thyroid. So, thyroid is a hormone, isn't it?

GJ

The thyroid is a gland, but it does control a few hormones.

CB

Okay. Right. I don't even understand about my own workings of my own body. I mean, you sound so, so knowledgeable. Have you learned all of this since having a diagnosis yourself, or were you already quite scientifically minded?

00:06:30

GJ

I had never heard of Cushing's. I knew of the pituitary gland, just from high school biology class. But I had no idea what, really, truly, the body does and what it's made up of. So, even when I was diagnosed with Cushing's, I had such little time to process that. I was just taken into treatment pretty quickly.

It wasn't until, really, I started recovery and feeling better, that I had the energy to really dive in and learn more about it. That's when I just uncovered a myriad of things and challenges, and had a better expectation of what my life might be. And then, of course, joining the foundation and volunteering more, getting to talk to other patients and hearing what their stories are, really made a difference.

You hear the impact to every individual's life, that happens. They all have their unique story, even though there's maybe a common foundation. But everybody, really, has their own, their own path.

UF

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CB

So, you've got your diagnosis in 2020, I believe?

GJ

Yes.

CB

Yes, so that's not really that long ago. Let's find out what is Cushing's, for a start, and then what led you to get a diagnosis? What symptoms were you experiencing?

00:08:04

GJ

Yes. Cushing's syndrome is a disorder with both physical and mental changes that result when the body has too much cortisol for a long period of time. This can result from the body making too much cortisol, or from taking medicines called glucocorticoids, or steroids, which affect the body the same way as cortisol.

So, a person might get prescribed a steroid medication to treat things such as rashes or asthma, arthritis, inflammatory disease, allergies, and also used to prevent organ rejection in transplant recipients. The steroids really help ease inflammation.

But most of the time, if you're prescribed a steroid for allergies or a temporary rash, you don't take it for a long period of time, so it is a benefit. There are two types of Cushing's syndrome, and then there's also Cushing's disease. Cushing's syndrome can be exogenous, or caused by factors outside the body, like taking steroids for too long, and can be treated by the patient just stopping the steroid.

CB

Okay. What's this extra? What was that word? Extranogous?

GJ

Exogenous. Yes, it took me a while.

CB

What does that mean?

GJ

That means that an external source is causing a disease?

00:09:28

CB

I see, okay.

GJ

Yes, it's not your body doing something. Then the opposite then is, endogenous, which is caused by factors within the body, where the adrenals are releasing too much cortisol. It's usually a tumour that's taken over and directing that hormone.

Then there's Cushing's disease, which is a form of Cushing's syndrome, and a bit more rare. It's caused by a tumour on the pituitary gland, which then causes the gland to produce the hormone that's called ACTH. That hormone then signals the adrenal glands to release too much cortisol.

Cushing's disease only affects about 10 to 15 people, per million, every year. It is more common in women, and occurs most often between, or in people between the ages of 20 and 50.

I was diagnosed with it at 43. According to the Endocrine Society, I looked this up quick, a large study that was finished in 2021 found that patients with the disease had a threefold increase in death, mostly due to cardiovascular disease and infection. But death rates have fallen since 2000. But it's still unacceptable, right?

But life expectancy can improve if Cushing's is treated, and that the patient goes into remission. So, there is light at the end of the tunnel. But what we really need to work for is quicker diagnosis, so that the patient can get treated and help them.

CB

What symptoms were you experiencing, that led you to go to the doctors?

00:11:07

GJ

Similar to others that I've talked with. Because it's a rare disease, it's harder to diagnose. And, it's also harder than other rare diseases because it has non-specific symptoms.

So, even though there are many of them, the more common symptoms start with abdominal weight gain, despite weight loss and exercise efforts. You've got loss of concentration, a round red face, a fat hump on the back of your neck, high blood pressure and diabetes. But that describes most people, right?

CB

This is when you're getting to our midlife, where your body shape changes anyway, and other things are occurring in the body. And, that's not necessarily what you jump to. Oh, I might have Cushing's.

GJ

No, you just think, well, this is what over 40 is like. We're women, and we go through all these changes. So, yes, my path to diagnosis started in about 2015 or

16. It's, when I think back to when some of those noticeable symptoms started to become apparent.

My husband and I began a plant-based diet, at home, around then, and he was feeling great, but I didn't feel much of a change. But I kept up with it, knowing I as eating healthier, and I was, somewhere, I was getting a benefit out of it, even if I didn't really feel different.

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I've always been kind of up and down on my weight, so gaining weight wasn't too alarming to me. I had a lot of pain in my knee and leg, and joint pain can be part of this. But turns out I had hip dysplasia and had a full hip replacement in 2017. That's how I spent my 40th birthday. But that aside, that alleviated a lot of that pain and I felt much better, in general, after that healed.

Then, a couple of years later, in 2018 and 2019, the other symptoms started becoming more noticeable. Like, my hair was thinning, and I was growing facial hair. Again, as a woman over 40, I just figured that's part of life. I gained more weight, and my job responsibilities changed in a way that I couldn't really keep up, which wasn't my character. It was an odd feeling for me.

I just felt different, and I couldn't remember new information. I couldn't remember my clients' contract details. I couldn't even focus enough during the day to accomplish the tasks that I wanted to. Almost eight hours would go by, and I was like, what did I do today? I just felt so scattered. It felt like I was spinning wheels, and I was easily agitated and my thoughts were all over the place.

And I began not really able to sleep at night. At first, I thought, this is great. I can stream TV until 5 AM, and start work at eight and get through the day. But a couple of days in a row like that, then I would sleep pretty well, just for being exhausted. And then the cycle would start over again. I would also sweat through my clothes at night, when I could sleep. So, a lot of changes that happened.

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I also, another point of this was, I worked from home and my husband did too, at the time. Especially during COVID. During the day, he would come into my office and he would comment on how, just angry and red in the face I looked all the time. I didn't necessarily feel angry.

We had been fostering senior age dogs. Of course, that means they typically have ailments like seizures or bladder issues, and things like that, which took extra time and care on my part. I noticed I was becoming ultra-focused on them, and just overly concerned. I was feeling everything to the extremes, emotionally. It was just exhausting, and just wasn't feeling like... More nonchalant, I guess.

Then these feelings just continue to get more excessive. I thought it was my job and it was getting too stressful. And I travelled a lot. And I talked to my husband

about it, and we agreed that the best thing for me would be to quit my job. That my health and happiness was more important than a paycheque.

So, I quit my career in 2020, June. I felt lucky to have that opportunity to do so. Make that decision. I focussed my energy on two rental properties and houses that we have, and I spent time fixing up one of them during that summer. Like, renovating the kitchen and new floor, cabinets and trim and painting and patching drywall and such. But, with the exception of having a friend help me a few times, I did everything myself, because it's COVID, and so, not a lot of people were around.

00:16:01

But then, during that time, I noticed even more symptoms started popping up. More on that physical side. Where, I had extreme weakness after doing work, only for a short time, and I'd have to take a lot of breaks. It was like I would feel light-headed and have to sit down a lot. And then I would do some work and my hands would start shaking.

The thing that sticks out the most was, I needed to measure something, like maybe put up curtains or whatnot. I would read the tape measure, and then turn around to write it down, and the numbers just vanished from my mind. That type of thing, so easy, just happened over and over. It was so frustrating.

CB

Yes, your functioning memory was just completely obliterated. I'm thinking, in the wild, animals get a boost of cortisol when they're either being attacked, or about to attack. I guess that's... I'm just looking for an analogy here. They are like, they're in wild mode, aren't they? It's like there's no relaxation there. It's, everything is pricked up. Every tingling sensation, they're on high alert for, because it's a life or death situation, potentially. And that's what you are experiencing every day.

GJ

Yes, yes, all the time. Every day. And that's a helpful thing when it's correct in your body. You know, it's not the right dose, right? We need that to help us through those situations. Or that story of the baby getting trapped under the car and the mom lifts the car up. That extreme rush of adrenaline and that power that you have, but just for a short time. There's other systems in your body that actually shut down so that it can compensate and give you the boost in those other areas.

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So, yes, it's interesting to feel that all the time. I would get profuse sweating in the easiest of situations. That was embarrassing. The whole situation was just frustrating. And I was kind of worried because I didn't know what was happening to me. I thought, this just can't be about getting older. This is ridiculous.

CB

Got to be something more. Did you think the hip was also linked to it, or was that something different?

GJ

I originally thought it could have been, but because it was hip dysplasia, that was something that I was born with. It just happened to come up at the same time, where the bone joint started rubbing together and causing the pain, so that was inevitable.

But there are people that do get bone and joint pain, the osteoporosis and that inflammation, and things like that. There is a lot of that that does happen. But then, eventually, after all this, I had my wellness check in July of 2020. I prepared for that appointment by just writing down all of the symptoms and issues that I had, regardless of how small.

I think that's really important for people to really own their own health in that way. You get to an appointment and you tend to forget things that you wanted to talk about. So, I thought that was helpful for me to do. I would try to remember when each symptom started, or it got worse. That, I wasn't so good with.

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But I told my general practitioner about the hair loss and my growing chin hair and the insomnia, and feeling stressed all the time. Didn't really know how to put it into words, but I had known about cortisol from having thyroid issues in the past. And so, I told her I wanted to check that, along with vitamin D and some other general blood work.

But she diagnosed me on the spot with hirsutism, which is the male hair-growth pattern in women. So, the losing of the head hair, the growing of the chin hair and chest hair. Which, I learned later, was a symptom of Cushing's. And then the cortisol results were extremely high, and so she wanted me to go see an endocrinologist. From there, I started getting more labs done and talking about any symptom that I had.

Again, I didn't know it at the time, but I also had that buffalo hump, that they call it, or that fat bulge at the back of my neck. And purple striae, which are marks on your stomach, or stretch marks. [Inaudible] pressure, which I'd had for years, but I didn't correlate really anything. He asked if I was diabetic, which I wasn't. But many Cushing's patients are. It's hard to control diabetes when you have Cushing's.

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That's another red flag that that endocrinologist should watch out for when they have diabetic patients. To see, is it hard to control? Just test that cortisol. He asked if I had menstrual issues or PCOS, that polycystic ovarian syndrome, which

is common among women. Which I didn't, but those are other common symptoms in female patients.

Gynaecologists should be aware that, if they have patients with PCOS, that's, again, hard to control, they just might have cortisol issues, or Cushing's, themselves.

There's that, a lot of people could be on alert or more aware of this disease, and try to catch it. I was lucky with the multiple testing that I had done. It came back with clear results. The next step was to order an MRI of my brain because of the Cushing's disease suspicion. This had all happened within a span of about three to four weeks.

And, when I started reading about Cushing's for the first time, I started getting concerned. But when the MRI came back and showed an eight millimetre tumour on my brain, I literally did a fist pump. I was so happy that I had this diagnosis.

CB

Right. It's an explanation.

00:21:47

GJ

Yes, I could explain how awful I was feeling. I think many people who have rare disease, or any complicated disease, feels that way a little bit. Because you have that path forward. That uncertainty just can drive me nuts. But I say I was lucky for many reasons, and I understood my body and tracked these changes over time, and I was able to talk to my doctor about how I was feeling.

Many times, especially women, will make up excuses for why they don't feel well, and ignore it, or push through. They tend to take care of others before themselves. Also, I had been with my doctor for almost 20 years, and she knew me. She was listening to me. I know a lot of people that struggle with that.

But then, when seeing the endocrinologist, he was aware of Cushing's. He knew what it was. I wasn't gaslighted with the talk of, well, just eat better and exercise more, and come back in six months. Which is the path of many patients.

Or, the ridiculous things I've heard patients go through, such as, well, you're black. Black people don't get Cushing's. Or, you don't look like the typical Cushing's patient, so it can't be Cushing's.

They're referring to the physical symptoms, which almost 30% of Cushing's patients don't even get that typical look, and that extreme weight gain. Then that further delays the diagnosis. That's why the average time to diagnosis is five to seven years.

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It wasn't until after the diagnosis, and understanding of the disease, that I could look back over the years and better understand why I visited an arthritis specialist, some mental health therapists, saw a chiropractor consistently.

I was told to have a sleep study. I tried naturopath doctors. I just couldn't figure out what was going on and why I felt that way. And, so many patients see so many specialists on their path and just don't get that diagnosis that they need, and all that time and money that's spent.

But other common symptoms that people have are diabetes and brittle bones. In fact, one person I talked to cracked her collarbone while washing her hair in the shower. It's just, that's extreme. Or the weight gain that gets excused as you're not trying hard enough. Another person ended up getting bariatric surgery, or a stomach band decided to lose the weight. Only to find out that, when the weight didn't come off, the surgeon suspected Cushing's. So, talk about your misdiagnosis.

CB

Oh no. Lynn, what do you think about that? That's an extremely roundabout way of doing treatment, isn't it?

LS

Yes. It's terrible. I had a question for you. Does it always show up in the blood, in the high cortisol? Is that a main indicator? Or, does everyone have a tumour on their pituitary gland? Because how are these things missed? And why would they not check that before they went for a stomach surgery or something?

00:24:44

GJ

I think you have the golden question that we ask to our doctors, so many times. There are actually people that have a pituitary tumour, but it's non-functioning. So, it doesn't actually produce hormones, and it's just fine. You can leave it as it is, unless it starts impacting your vision or something.

But cortisol can be tested, first, through the blood. A simple blood test that's done at 8 AM, because that's when your cortisol is peaking for the day. That's when you're trying to wake up, typically. But it's not really considered the gold standard. That can be an indicator, and lucky, I guess, for me, it was.

But some people that when you've got that insomnia and your sleep cycle is messed up, you might not hit your high at that time of day. Or, you might have cyclical Cushing's, which is the same thing, but it actually comes and goes. And so, you might not hit that lab result at the right time. Maybe you get it every couple of weeks, or that type of thing.

But there is a series of tests, still pretty darn simple to correlate with the blood draw, and that's taking urine tests, or late night salivary testing through your saliva. So it's really not invasive. It's just more the awareness. And, trying to start with, this person is just not getting better, with what you're trying to do. Testing cortisol, I think, it's going to become a lot more common. Or, at least, people are going to be more aware of that, because it can cause, or be the cause of so many issues for people.

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We're hoping to spread the word to get that, just more of a common... Just like your cholesterol, just like your blood pressure. Test your cortisol if you're just not feeling it.

CB

Yes, that's a good take-away.

LS

Yes, that is great, because I think we're all going to be asking that now. I know I will. It's just one thing that, and I get how you could totally just think it's getting older. And go through that struggle where you're misdiagnosed and people gaslight you a little bit, or you do it to yourself, sometimes. So, what treatment did you receive? And then, how did that affect your symptoms?

GJ

Yes. Two weeks after being diagnosed, my treatment was to have surgery to remove the tumour on the pituitary, at the base of my brain. Other treatments can be radiation if the tumour's very small, and the patient can afford a slower treatment. Because that takes a lot longer. Or, if the first surgery wasn't successful, they might have radiation. Also, if the patient doesn't want to have surgery, or the tumour is in the place that it can't be removed for... Because it's right next to your optic nerve and your carotid artery. So, it's [overtalking].

00:27:39

CB

It sounds like a very precarious position. Very, very dangerous.

GJ

There are also medications that can, either block cortisol receptors in your body, or lessen the amount of cortisol production, which is really helpful. Those medications aren't 100% effective, and they do come with side effects. So, surgery is the primary treatment option, when people can do that. Again, for me, luckily, the tumour wasn't impacting my vision. And since it is right by the optic nerve, as well as the carotid artery. I'll describe a little bit how it's done, but turn your volume down if you don't want to hear.

CB

Okay, a real content warning, everyone.

GJ

Yes. But just, the type of surgery performed is called a transsphenoidal procedure. They go up, actually, through your nose and then drill a little bone to get back to that cavity where the pituitary is. And then they remove the tumour, and then they can patch up that hole with a synthetic material so there's no visible scar.

Then, typically, after a successful surgery of removing the tumour, your cortisol actually drops almost instantly to nothing. So, you have to be monitored very carefully because, remember, your body needs some cortisol to live. But that tumour had taken over the cortisol production in my body, and so my pituitary then needs to wake up and learn again how to properly function. That can take months.

A doctor would do another brain MRI and check the cortisol blood level to ensure that everything is as low as it should be, and there's no visible tumour left.

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But, at times, there can be an unsuccessful surgery, and that cortisol doesn't drop low enough, which means the whole tumour wasn't removed. And then there could be some tumour cells left behind, and still cause that elevated cortisol. Then the options then would be a second surgery, or radiation, or medication.

So, I needed to be careful for other signs of cranial fluid leaking out my nose, and, of course, any other signs of infection. But, as far as the change in the symptoms, it does take weeks for some symptoms to go away, but mostly months to even a couple of years, or more.

What's supposed to happen is, when you leave the hospital, you're given steroids for approximately six months. Could be longer. You might be thinking, well, wait, if having too much cortisol is the problem, then why are you given steroids in high doses?

But the body is used to being so jacked up on steroids for so long, and it's gotten used to that. And so, when you start with a higher than the normal level of steroids that your body needs, then you slowly taper down. Then, when it gets to the normal range, then your pituitary can wake up and start producing the hormones that it needs to, and tell the adrenal is the proper amounts of cortisol that your body needs.

But yes, by tapering down slowly, over time, it makes it easier to tolerate.

00:30:43

CB

Has your pituitary gland started producing the cortisol on its own?

GJ

It has, yes. I'm thankful that it started working again. Then, after three months, I started to be able to walk better, and felt a little bit more part of reality. I still couldn't walk up stairs without using a couple of hands on the railing to help pull me up. Usually, it took a couple of hands to lift a glass of water because I was so weak.

As far as my life goes, I guess what was strong to me is, with the foundation, we conducted a few quality of life surveys over the past five years or so, and the latest was done last fall. So, fall of 2023. And from Cushing's patients around the world, we learned that one in five serious relationships and marriages end because of Cushing's. The disease has a huge impact on people's lives.

But for me, personally, I feel lucky in that I had the most supportive husband throughout the entire journey. He had patience during the mood changes and the weight gain, and the stress before treatment. And again, so supportive during the months of that brutal recovery.

And since I was diagnosed and had surgery in 2020, my support network was pretty slim. People were in lockdown from the pandemic. But it was almost a blessing to have gone through the toughest parts during COVID lockdown, because I couldn't go out with my friends for months, even if I wanted to.

CB

Yes, you weren't missing out, as such.

00:32:14

GJ

Yes. And my husband is an introvert, so he was perfectly happy being at home. He did the best that he knew how, to take care of me, and with the limited knowledge that we had of this disease.

But I hear from most patients, including myself, it's hard for friends and family to understand what you're going through. My closest friends would stop by for short periods of time, when I could get out of the chair, or bed and we'd sit outside. I was grateful for the support that I had. I know many people don't.

But my relationship with my husband became closer, and my own perspective on life had changed. You find out what you really want to live for, whether it be a spouse, a child, or a friend who's watching over us. We have those people that take care of us when we're sick. And then when struggling with a long-term disease that changes you physically and mentally, it takes a toll on everyone around you. They need support too, to get through this.

So, I asked my husband if he would write down some thoughts about his experience and perspective through all of this. I just wanted to read you what he said [overtalking].

CB

Yes, please. Yes, we'd love to hear what he...

00:33:21

GJ

He said, it's hard to see her going through this, and knowing she's in agony and adjusting to a whole new way of life in terms of her abilities. All I can do is support as best as I can, but I can't make her pain go away. That was worse around the time of surgery, when her Cushing's was bad.

The recovery was also really hard, and dangerous, even. Personally, it is also hard adjusting to life where coping with this and seeking care is now a major part of everyday life. Replacing life as it was, when we were younger and healthier. So, not what you think you'll be facing at 40, but also knowing this is not temporary. It will be our normal life now. And as long as life goes on, in fact, it will probably never be better than it is right now.

So, wanting to try and get the most out of the time we have, but at the same time, having limited ability to do that. And thankfully, recurrence is unlikely. She is a superstar when it comes to managing her own care. Much better than I ever could. And all the help she has gotten, she's gotten first because of her own persistence and skills.

I'm afraid if she can't do it, will I be able to? For example, I couldn't do that and hold down a job. Grateful that we most likely have a good road ahead of us, but I don't think Cushing's is ever over. I'm also really proud of how she is using this experience to try and help others.

That was really nice to hear. Just, I couldn't ask for more, and I just wanted to give a shout out to the caregivers out there.

00:34:50

CB

Hopefully, your husband enjoyed writing what he wrote, and having an opportunity to have his voice heard and celebrate you at the same time. It must be quite a nice thing for you to read there?

GJ

It is. It is. It's been. It's been lovely. We also haven't had the stress of children. You That's a whole other dynamic that people have. So, yes, as bad as it is, I'm grateful at the same time.

CB

Yes.

LS

I was just going to say, I'm just so impressed with all the advocacy groups you're doing, and all the help that you're giving to people like this. Because you're a big part of somebody's journey that's just starting this, or maybe doesn't know what this is. All the work you're doing is amazing. Even for caregivers, I'm sure, just knowing that what's going on in here and other people's story. The work you're doing is so helpful for others. So, I thank you. It's great.

GJ

Thanks.

CB

What work does the Pituitary Health and Cushing Support and Research Foundation do, and how can people reach out for support and information?

00:36:03

GJ

There are some decent pituitary health and Cushing's support resources around the world. There's the World Alliance of Pituitary Organisations, or WAPO. That's a global resource with member foundations in multiple countries. So, they can help guide patients with pituitary diseases, to support that they might find in their home country. Their website is www.wapo.org.

And then, the Cushing Support and Research Foundation, or CSRF, is the non-profit that I work for. We work to educate and support patients and caregivers, clinicians, and all the relevant stakeholders, through all aspects of the Cushing's syndrome and Cushing's disease journey. We aim to be that collective voice for change that we need to see. Because the average diagnosis time just remains too long, and treatment options are not easy or optimal.

The patients frequently suffer from the inadequate post-treatment care, and the mental health support. We can be found on social media, like Facebook or Instagram, YouTube, but it's easiest to find our website at www.csrf.net. Patients can email us at any time. We also host a global patient support Zoom call, for which you can sign up on the website as well.

And then, excitingly, next year, in 2025, we're planning to launch a Cushing's patient registry, which will be huge. It will gather the patient data, both clinically, and that quality of life that I talked about. Which then can be used for studies to improve that Cushing's patient time to diagnosis, and better understanding of what happens beyond, just, that disease itself, and the myriad of other things that get impacted.

So it'll first launch in the US, and then we plan to capture global patients as well.

00:37:58

CB

Oh, fantastic. Well, we will include those website addresses in the show notes so people can click on those if they weren't quick enough to write down the website addresses. That's really useful. Thank you.

LS

What do you think about the Hidden Disabilities Sunflower?

GJ

Oh, when I heard about the Sunflower from another patient support organisation in Ireland, I was so happy to see a resource out there for such a broad audience. A patient with a disability already has so much to bear and go through, and this is a simple way to get support when you're out and about and not have to explain what you're going through. It's such a relief when you have such a complicated story.

I saw the Sunflower at my hometown airport, customer service desk, and even a huge billboard outside the airport, here in Minneapolis. Now that I have a daily injection medication, I need to ensure I have proper disposal containers. The sharp containers. I need places to sit, or quiet room, just to remove all the stimulation from travelling.

Others that have adrenal insufficiency, they might need help with refrigerated medications, or more urgent needs that arise. But I know the recognition of Sunflower will spread, and I want to help others know that that problem program exists.

00:39:24

CB

I think that's the great thing about the Sunflower, because it is there for everybody. And so, if we can use the Sunflower to raise the profile of rare diseases such as Cushing's, then we are really delighted to be able to do that. Well, thank you very much for your time.

LS

I really enjoyed talking with you, Gretchen.

CB

If you're interested in any of the advice discussed in this podcast, please follow up with your GP or health care practitioner. If you enjoy this podcast, please share it. Leave a rating and review to help raise awareness of non-visible

disabilities and the hidden Disability sunflower. You can also follow and subscribe to the Sunflower Conversations Podcast.

UF

If you'd like to share your Sunflower story or conversation, please email conversations@hiddendisabilitiesstore.com. Find out more about us, or listen to this recording again by checking out our insights page at www.hiddendisabilitiesstore.com. You can also find us on Facebook, Instagram, Twitter, YouTube, and LinkedIn. Please help, have patience and show kindness to others, and join us again soon. Making the invisible visible with the Hidden Disabilities Sunflower.

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