Lupus with Paul Howard, Lupus UK and Rachel Hall

Speaker 1:

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

Chantal Boyle:

I'm Chantal. Thank you for joining me on the Sunflower Conversations. Today we are going to be talking about the autoimmune disease lupus. And to do that, I am joined by Paul Howard, the CEO of Lupus UK and Rachel Hall who has lived experience of lupus. So welcome to you both. Hope you're both-

Paul Howard:

Hi Chantal.

Chantal Boyle:

... okay, and ready for-

Rachel Hall:

Hi.

Chantal Boyle:

... our chat today. So Paul, can we start off, what is lupus?

Paul Howard:

Absolutely. So lupus is an autoimmune disease, which means that basically your body's immune system is dysfunctional and rather than just protecting you against foreign invaders like viruses and bacteria, it's also attacking your body's own cells. So this creates the circulation of antibodies throughout the bloodstream, which causes inflammation in various tissues in the body. So that inflammation then presents in a range of different symptoms including pain, but it can also affect lots of different parts of the body. So common symptoms include extreme fatigue, and joint pains, but then it can also affect any of the organs such as the kidneys, the lung, the heart, the brain, and present with a range of other things such as skin involvement like rashes, hair loss, and it can often cause an overlap with other autoimmune diseases as well.

Chantal Boyle:

That sounds like it has wide arranging array of symptoms on the body. Do you have any statistics around the condition? For example, does it affect more men than women? I-

Paul Howard:

It's a disease that predominantly affects women. So 9 out of 10 cases are diagnosed in women and it's much more prevalent within certain ethnic groups as well. So people from Black, African, Caribbean and Asian ancestries are around three to four times more likely to develop lupus than white Caucasians and they're also more likely to have severe disease. So kidney involvement is much more common within those groups. Lupus can affect anyone, so whilst it's less common in men, it can affect men and it's most commonly diagnosed during the child bearing years. So between the ages of around 15 and 45-50, but around 20% of cases are diagnosed during childhood, so that's called juvenile onset lupus. And again, that can be more severe than adult onset lupus with a higher incidence of kidney involvement.

Chantal Boyle:

So it's hormone related?

Paul Howard:

There's definitely a hormonal link. So we know that from the development of the disease where there seems to be either a genetic or a hormonal factor there, hormonal changes seem to be an important trigger for the development of the disease because we see women are much more likely to develop the disease during puberty, pregnancy and menopause. We also see a lot of cases where women's disease activity is linked to their menstrual cycle. So in addition to having their period, their lupus symptoms can also be more severe around that time as well.

Chantal Boyle:

Is there any research into why it would be people from black, ethnic, minority groups, why this would affect more?

Paul Howard:

There is some research, so it does seem to be a genetic factor, but ultimately it's not really understood sufficiently at this time. So there's certainly more research that needs to be done to really understand why beyond those environmental factors someone might be more likely to develop lupus and why it might be more severe as well. We know that lupus develops as a combination of having a genetic predisposition and environmental triggers. So it may be a combination of those or certain genetic factors within particular ethnic groups. But hopefully given more time, research will get some of those answers for us.

Chantal Boyle:

Finally, I just wanted to ask you as well, do you know how many people in the UK have lupus?

Paul Howard:

There was a study done in 2012 which estimated that there was around one in a thousand people in the UK who have lupus, which would mean somewhere between 60 and 70,000 people in the UK. But one of the things with lupus is that it's very difficult to diagnose. It takes an average of about six and a half years from the onset of symptoms for someone to get a diagnosis and that means that there's probably a significant proportion of people who don't have a diagnosis of lupus and might just be living with the symptoms, perhaps managing it themselves and untreated. So it's really important to raise awareness about the disease. So if someone is struggling with symptoms, they can hopefully get it investigated by their doctor and perhaps get a diagnosis.

Chantal Boyle:

So Rachel, how did you seek to get the diagnosis yourself? How did your symptoms first present themselves and how old were you?

Rachel Hall:

I started having symptoms about 19 years old. So in the beginning it was mainly joint pain. It just seemed to get worse over about a year. And then I started getting a lot of infections. So I was getting everything from urine infections, I was getting abscesses underneath my arms. It is just anything and I just used to catch it straight away. I was just always unwell. I also had unexplained weight loss. I just suddenly started losing weight. I had no appetite, no energy. I was extremely fatigued. So I used to sleep on average, I would say about 18 hours a day and-

Chantal Boyle:

[crosstalk 00:06:33] that is a lot.

Rachel Hall:

Yeah, I was in university at the time as well and it just got to the point where I stopped going. I was just so tired all the time. I just felt like I had no energy. My joints were always hurting. So I was going back and forth to the GP a lot. I had everything thrown at me from, I'm partying too hard, I need to change my diet. No one was really making the connections that the infections, the tiredness and also the fatigue was the same thing until I started getting the rashes. So out of the blue I started getting rashes all over my body. In mainly my arms and my legs. At first, they said it was eczema, but after a bit more investigation I was referred to a rheumatologist and I was finally diagnosed in 2010 when I was 21 years old. So it was about two years after my onset on of symptoms.

Chantal Boyle:

And that's quite a pivotal time. Did you move away from home to go to university or did you stay-

Rachel Hall:

No, no. Luckily my university was just in London and I was able to take a sabbatical as well. So actually when I did get better I was able to finish my degree, but at the beginning we kind of didn't know what was going on. I was mainly in bed most of the time before I was diagnosed. So as soon as I was diagnosed, I was admitted into hospital, but he actually had to go to a private hospital to get a diagnosis because when I was referred to a rheumatologist it was eight week wait. And at that point, I was just really unwell and so he was able, luckily for me, to get a private hospital appointment and that's when I was diagnosed in 45 minutes after my blood test.

Chantal Boyle:

That's interesting.

Rachel Hall:

[crosstalk 00:08:26] 45 minutes and said you've definitely got lupus, so we have to get you to hospital straight away.

Chantal Boyle:

Yeah, because Paul said the diagnosis is typically about six years.

Rachel Hall:

Yeah.

Chantal Boyle:

So it sounds like as though your life had basically come to a stop-

Rachel Hall:

Yes, I would say it definitely did.

Chantal Boyle:

... put on pause of all of those symptoms.

Rachel Hall:

Yeah.

Chantal Boyle:

After your diagnosis, you've obviously been on a health journey because you did complete your degree and you have a job at successful and very well known construction company, Mace. So your symptoms have improved over time since your diagnosis or can you tell us a bit more about that?

Rachel Hall:

Yeah, it's been a journey. So as I said, I was diagnosed in 2010, so a lot's changed since then. So in the beginning, my symptoms were very much joints, skin rashes and fatigue. Those were my main symptoms as well as being able to catch infections quite easily. But over the years, unfortunately I am one of those that it has affected my kidneys. So it wasn't until about, I want to say 2013, it started to present itself in my kidneys. So since then it's been much more of a battle to try and get my kidneys under control. So I have tried various medications, I've been on a trial as well and we have managed to sometimes get my kidney under control. So for example, I probably got to my best health-wise the end of 2019 after doing the beat trial, which was a mixture of a drug called rituximab and belimumab.

We was able to get my lupus under control and I was able to actually have a child and get pregnant. Something I wasn't sure I was able to ever do, but unfortunately since my pregnancy, since I've had my daughter, I have started to be unwell again. So it has presented itself in my kidneys again. So I'm back on rituximab just last week, actually. So I would say lupus is very much an up and down journey. It goes through something called flares. So sometimes you could feel well within yourself and your lupus might not be presenting itself and then you would have a flare up where your lupus is more active and it can affect different parts of your body, as Paul mentioned earlier.

Chantal Boyle:

Can I ask, it is obviously having a big effect on your kidneys. In practical terms, how does that affect you? What does it mean to you?

Rachel Hall:

So for me, it's mainly high blood pressure, how it presents itself. Retaining water is a big one as well. So actually the doctor said I've put on about 12 pounds in about six weeks, but he's like, that's water weight. It's very obvious. My ankles get very swollen, and my legs get very swollen, which actually can make it very difficult to even walk by the end of the day. It's usually just so big, so I can't even get my shoes on properly. So those are how it physically presents itself. But obviously again it makes you tired. I would say I'm constantly tired again. And then for me, it also starts presenting itself in my joints because my lupus is as active, so other parts of my body is going to be affected as well. So particularly over Christmas, my joints were bad, my kidneys were bad, so I just spent most of it in bed, unfortunately. But I would say that's the way it kind of presents itself for me.

Chantal Boyle:

And that must be very challenging with a little girl running around.

Rachel Hall:

It's very, she's just 16 months, and as you mentioned, I have a job. I don't mind saying that my job is very supportive. I do get to work from home quite a lot, which has really helped me. I would say without that, I'm not really sure whether even working would be a possibility at the moment.

Chantal Boyle:

And has your daughter, have they tested her for lupus or is she too young?

Rachel Hall:

Ooh, no, they've not tested her for lupus. When I was pregnant, I think they monitor you a lot more. So when you are pregnant and you have lupus, I was under St. Thomas's hospital and I think I saw three different doctors that were looking after various bits and the kidneys. As well as, my overall lupus in general. As well as, your normal doctor that you see when you're pregnant. His name, it's just completely gone out of my head. But no, I think they just said that they were looking out for certain signs. So I think it could be any heart deficiency. They would be looking at the heart during pregnancy and also I think that some babies can be born with a rash. So it's like a lupus rash and they were looking out for that as well, but she didn't seem to have any of those complications. So it's fine.

Chantal Boyle:

As far as you're aware, you haven't got this from a family member, partly like your immediate family, none of them have lupus, do they?

Rachel Hall:

No, no. It's not something that runs in my family or any type of autoimmune. Doesn't seem to run in my family.

Chantal Boyle:

Have you heard that of that before Paul?

Paul Howard:

So lupus isn't classed as a hereditary disease. Unlike some other conditions where there's a very strong genetic connection, perhaps a single gene, which might decide whether you develop the disease or not. So because there's such a large number of genes involved in lupus and the requirement for an environmental trigger, it's uncommon for someone with lupus to have close relatives who also have lupus. I think it's around 1 in 20 from one study that I've seen. We do know some families where lupus or other autoimmune diseases seem to be very rife and everyone in the family had some kind of autoimmune disease and then there's other families like Rachel's; where there doesn't seem to be any familial connection.

So it's a tricky one. There's no real way to guess whether someone might have lupus or develop lupus. It's not something that is screened for at the moment. There have been a number of research projects looking at whether we'll be able to predict who might lupus in the future and perhaps even prevent it in some way by giving them some form of treatment before they develop the disease. But that's still quite a way off. And so we don't routinely screen, but obviously if someone were to develop symptoms of lupus and they had someone else in their family who had the disease, then it might be worth mentioning to your doctor that you've got a family history of it because then they'll make sure that they include that in their tests that they're doing.

Chantal Boyle:

Are Rachel's symptoms typical of what somebody might be experiencing?

Paul Howard:

Yeah, I think what Rachel's described is really something that I've heard a lot from other people with lupus. So extreme fatigue, a tiredness that doesn't go away no matter how much you rest, that is one of the most commonly reported symptoms of lupus and it's really hard to attribute that to anything because especially if you develop at a time when you are a teenager, then most GPs will just say, well, you're a teenager, go to bed on time. Or they might say you're stressed and therefore you need to sleep more or attribute it to depression or anxiety. There's a lot of things that can cause fatigue and a lot of the times in lupus it might be more than one factor affecting it, but that can be a telltale symptom.

I think having it in combination with joint pains, especially if you've got the pains in more than one joint. So if you've got one knee that's playing up, then maybe that's not likely to be lupus. But if you've got pains in your knees, and you also get them in your shoulders or your hands, having them in more than one place, that is more indicative of having lupus. And then usually we'd see some other clear signs. So you have some form of anemia, that could be a sign of having lupus. So if you've not got enough oxygen circulating around your body. It could be rashes, like Rachel had. A lot of the time in lupus, they're sun sensitive. So if you tend to come out in a rash after being out in the sun, then that could be a sign that you've got lupus. And a lot of people with lupus also have hair loss, so it can present in a couple of different ways. Sometimes you might have a patch of hair that comes out, but it might be more common that you've got thinning hair. So when you shower, you see an abundance of hair coming out when you're brushing your hair. More than you would normally expect, and that as well could be a sign.

Chantal Boyle:

Thank you. You are listening to the Sunflower conversations with Chantal. To share your story and find out more information, details are in the show notes. Rachel, you touched on work how your work is very supportive of you, which enabled you to remain in employment.

Rachel Hall:

Just recently I did a talk at work and one of the questions that came up was just how to approach an employer at interview or when do you basically say to your employer, "Hey, I have lupus", just to let them know. So I just wanted to just give my own story a little bit about how I have always approached it when it comes to work. Worked for a few employers, but with my previous employers before the employer I'm with now, I didn't mention it at interview, but I mentioned it on my first day of work. So my first day of work with my line manager when we were introduced, one of the things I always did was like bring in some information, actually pretty certain I got some of that information from Lupus UK and I would basically present that to them and just go over my condition with them and let them know how it could affect me and so we could know some of the things that they can put in place if they needed to.

When it came to the workplace I'm with now, I was very upfront actually at interview and it was the first time I mentioned it at interview, simply because I was asking for a different work pattern. So I already knew that I wanted to make sure that I was working from home some days and that was included. So I told them upfront, I said, I have a health condition and I have learnt to manage it, I've had it for over 10 years, but I know that it would help me out if some days I could work from home. And that's actually all I said.

They put it in my contract, once they offered me the job, they put it in my contract that I'm able to work from home. I didn't know Covid was going to happen and everyone's going to be working from home anyway. But the fact is, covid or not, that was already put in place. That was already there and I was just upfront. And I've always said to people, I think no matter how worried you are, it can only benefit you to be upfront and tell them from the beginning. And I would say it can go one or two ways. They'll either supportive or they're not. And if they're not supportive, then you know you need to leave because it's just going to make your life awful.

Chantal Boyle:

That's right, if they're not going to be supportive. You don't tell them now, they're not going to be supportive in a month's time, so.

Rachel Hall:

Exactly. So if you tell them upfront and they are supportive, then it can only work out for you in the end because they've known from the beginning, they can put things in place and they're happy to as well.

Chantal Boyle:

In what other ways, since being 19 and your flare up that you had over Christmas, would you say it's impacted you your life?

Rachel Hall:

Just with this flare or in general?

Chantal Boyle:

In general.

Rachel Hall:

In general with lupus, so many things. So Paul just mentioned about being sensitive to going out in the sun. So in the beginning we wasn't quite sure what was triggering off the rash. So for a good two years I was trying to avoid the sun, always an umbrella up, always wearing a hat, always covered up. And the highest factor sunscreen just in case that was one of my triggers. It turned out it wasn't, but just the fact that, for a good period of time, I was basically scared of the sun, which that should be really worrying. I'm-

Chantal Boyle:

Anxiety inducing.

Rachel Hall:

Yeah, I've noticed a lot for myself, various things can bring on a flare, but especially stress and stress presents itself in different ways. But it also means anytime when I feel like I could be getting slightly overwhelmed, I'm constantly having to take a step back. And that affects you, I think, when that comes to work because even though I've been lucky enough to be in work, I know probably I will never be that go-getter at the top of the chain in the workplace simply because I would never want to put myself in a position where I'm too stressed or too overwhelmed because I don't know how that could present itself or how my body could react.

Obviously now I have a child, but I've been married for 10 years, this year. And for a long time we just assumed that, that was something we was never going to be able to do. And I know for a lot of people that is something that might be out of their reach with lupus. It can cause, should I say, you have more of a chance of having a miscarriage or a high percentage chance of having a miscarriage if you have lupus. So I know there's some people that they may have got pregnant but unfortunately they've lost their children time and time again and they don't want to try again or they don't know how their body will react.

So lupus affects your day-to-day, you really have to make choices of what you are going to do, especially during a flare. I've missed people's birthdays, I've missed family functions, friends functions, school, work, sorry, events just because I don't want to overdo it or I think, "You know what, I've already agreed to do something else in the week and doing two days of going out could be a bit too much for me." So it just even affects the day-to-day planning of even trying to be a bit spontaneous just because you've got to think, "Is that going to push me over to the edge of it?"

Chantal Boyle:

Yeah, and so high up there is the stress level as well, isn't it?

Rachel Hall:

Yeah.

Chantal Boyle:

So everything you've got to do is has to be so carefully considered and planned. So Lupus UK was founded by Cheryl Marcus.

Paul Howard:

That's right.

Chantal Boyle:

So can you tell us a little bit about Cheryl Marcus, did she have lupus? How does she come to create such a fantastic charity?

Paul Howard:

Yeah, I'd be delighted to tell you. So Cheryl is a fantastic and really inspiring lady. I just spoke to her the other day, she's still in touch regularly. So she started, what became Lupus UK, back in the late seventies. She has lupus and she was very unwell. She was hospitalized at the time and didn't know anybody else who was affected by lupus. So she did a radio broadcast calling out for other people affected by Lupus to get in touch with her so that she could build a connection with other people. And she got an influx of letters from people all across the UK who had heard the radio broadcast. And from that she then started a newsletter.

So she worked with Professor Graham Hughes, who is a renowned authority in lupus and was the leading professor at the time. And he helped provide articles about the disease so that patients could learn more about it. People with lupus would send in letters and share their stories and experiences. And this newsletter would start going out quite regularly. And then a group formed called the British SLE Aid Group. So SLE is Systemic Lupus Erythematosus, which is the full name for lupus. It's not very catchy. So lupus-

Chantal Boyle:

Bit of a tongue twister.

Paul Howard:

Yeah, lupus is what we tend to call the disease, but at the time, that's what they were called. And then in the early nineties, that was when Lupus UK was officially formed, registered as a charity and began raising funds to provide information for people and to contribute towards research. And since then, over 10 million pounds has been contributed to lupus research and specialist lupus nurses.

Chantal Boyle:

Oh, that's amazing. Wow. Well done Cheryl. My gosh.

Paul Howard:

Yeah.

Chantal Boyle:

You have a similar story to that, Rachel, didn't you? When you first were diagnosed and you were reaching out to people via social media just trying to create a network?

Rachel Hall:

Yeah, no, definitely. Can I just say though, when I was diagnosed, Lupus UK was the first organisation we contacted. My dad actually called them because we literally knew nothing about lupus. So just typing it in and seeing there was a charity and someone to speak to was just so helpful. And just them putting a bit of our mind at ease and letting us know what to expect and so forth. It was just really helpful in the beginning. I just wanted to say that, but literally the same. So I felt like I knew nothing about Lupus and I didn't know anyone who knew about it or had it. So I literally started reaching out to people on Twitter. I used to just write and just put a hashtag lupus, "Anyone out there?" I've got about 4,000 followers on my Twitter now, but I was just able to really find other people that have lupus and connect with them.

And also on Instagram, I've got people that I've gone out to lunch with that I've met up with, that I've spoken to even just on the phone. It's gone beyond social media now. So yeah, I think finding other people with the same condition with you is priceless, especially with something like lupus and you feel like not a lot of people might understand. Just someone else who gets it like, "Oh my gosh, this person actually knows what I'm talking about" or understands when I talk about a certain pain or understands when I say, "I'm just tired." Just them saying, "I get it, same thing happens to me." That's just what's amazing.

Chantal Boyle:

It's really important isn't it, to feel validated and understood. So it is interesting how in the seventies this was started with a radio broadcast and penning letters to Cheryl. Fast forward to broadcast was on Twitter and Instagram. So we'll include your social media handles and obviously links to Lupus UK in the show notes. Paul, can you just tell us what kind of services you're offering at Lupus UK if anybody wants to get in touch?

Paul Howard:

Yeah, absolutely. So one of the most important things we've done since the very beginning is bringing people affected by lupus together for peer support. So if you want to talk to other people who are affected by lupus, as Rachel says, being able to speak to someone who understands and really knows your type of experience, then please feel free to get in touch with us. And we've got groups that meet all around the country. Some of them are face-to-face, some are virtual. We've got telephone volunteers you can chat with and online forums that you can get involved with as well.

The other things that we do is we provide a lot of information about the disease. So we've got a range of leaflets and booklets about the various things related to the disease, whether it's about treatments, certain symptoms, diet, all of these things that might have a role in the management of your disease. We also have a welfare fund, so we help support people affected by lupus who are experiencing hardship and need additional support. So at the moment we do have a cost of living fund. So we're able to help people who are struggling with their heating bills, treatment related expenses and things like that. And we contribute a lot of funding towards research and we fund specialist lupus nurses in NHS hospitals throughout the UK.

Chantal Boyle:

Quite a lot then.

Paul Howard:

Keeps us busy.

Chantal Boyle:

I think that's really nice though that you're able to support people with a grant or who are struggling financially. Rachel's already alluded how it can impact the ability to maintain employment and when you are worried about your health and you are also worried about paying your bills, that's not going to help your stress levels is it?

Paul Howard:

Exactly. I think that stress is a really unwelcome trigger for lupus disease activity and if it's an organization we can do anything to help alleviate some of that peak stress over this winter, then we'll do what we can.

Chantal Boyle:

And Rachel, we touched upon it earlier on that you work for Mace, and Rachel, that your employer is members of the Hidden Disability Sunflower. What do you think of the Sunflower firstly, and how does your employer support you?

Rachel Hall:

Yeah, I think for me in the beginning with the Sunflower, I think, I won't pretend I was very nervous about wearing it. I felt like maybe it would draw too much attention. Suddenly people that maybe didn't know before would just be like, "Oh, Rachel's wearing that. Was there something wrong with her? She be off, maybe not." I didn't want it to be awkward for people that didn't know already about my condition, 'cause I am quite open, to be fair. But one day I was having quite a lot of joint pain. I needed to go into work and I decided to wear it, 'cause I needed to get public transport. I just needed to go in for one meeting.

So it's like I'm just going to go and then come back and as soon as I got on the train, the guy just looked up at me and was like, "Oh, do you want my seat?" And I was like, "Oh, thanks." And I was like, "Oh okay, this is a good thing then." So now I'm like, "Yeah, I'm going to wear this all the time", because clearly, I was having a rubbish day and people unfortunately might look at me and not really realize I'm not having a good day. Just being able to sit down with that little 20-minute journey would really help me out.

And for someone to recognise that, not have to ask questions, just like, "Here's my seat, sit down." I think that's amazing. So wearing it as well around work, I think it just makes people aware, if I am limping a little bit or if I seem a bit sluggish or whatever. I think people are just a bit more aware, "Oh, do you know what? Don't know what's going on with her, but there is something there. So just going to take it a bit easier or just understand." I feel a bit more free just to say, "I'm not really having a good day today." And people don't have to ask too much questions, so just like, "Okay, that's fine." So yeah, I think that's how it supports me anyway.

Chantal Boyle:

Yeah, that's wonderful to hear how it's supporting you in that way and just that little emblem-

Rachel Hall:

Yeah.

Chantal Boyle:

... lets everyone know there's a reason. What advice do you have for someone who feels alone or isn't sure where to go for support? We've touched upon Instagram and Twitter, but how you and your father phoned Lupus UK. What advice have you got for somebody who's just like, "I just don't know where to turn."

Rachel Hall:

I think for me, I would say, like you said, social media is such a big thing now. I do wonder how this might have gone if it wasn't for social media. I just met so much people that I'm just able to talk to. Like I said, there's people if I wanted to call, I could call. If I wanted to meet up, if I can meet up with them. So I would say don't be afraid to look around. My handle literally has lupus in it, but if you just type it in, even Instagram, you will find so much people that you can speak to and organisations as well. There are groups that you can meet up with as well.

But also blogs. So I used to read some blogs and then I even started my own blog. Just even just reading someone's story or just reading updates, I found really helpful as well. That's how I would sometimes hear about different medications and I thought, "Okay, I'll mention that to my doctor the next time I see them." Or you would hear about someone's diet, for example, or certain triggers that they found in certain foods and you think, "Okay, maybe I can research it a bit more and see if it will help me not to eat that food, et cetera." So yeah, just even looking at blogs, they do still exist and finding some that you might be able to learn from as well. That can be really supportive.

Speaker 5:

If you are interested in any of the advice discussed in this podcast, please follow up with your GP or healthcare practitioner.

Chantal Boyle:

How can people connect with you?

Rachel Hall:

So my Instagram and my Twitter is the same. So it's @lupus_gurl, that's G-U-R-L, and then my blog is lupusgurl.wordpress.com.

Chantal Boyle:

Thank you.

Rachel Hall:

Thank you.

Chantal Boyle:

And Paul, do you have any more information about these groups that actually meet up?

Paul Howard:

Yeah, so during the pandemic, a lot of our groups obviously stopped meeting 'cause they had to. And some of them haven't yet emerged from hibernation because a lot of people with lupus are on immune suppressant medications and at an increased risk for Covid. So a lot of them are slowly emerging and restarting groups. But we should have a lot of groups doing meetings moving into the spring and some of this year, if you want to find out more about them, have a look on our social media pages or on our website or on all of the social media sites. Just Lupus UK, you'll be able to find us and keep an eye out for any events going on in your area.

Rachel Hall:

I'm always happy to talk to people about finding work or going into work with lupus.

Chantal Boyle:

Thank you both. It's been a fantastic chat and I'm looking forward to sharing this podcast with everyone.

Rachel Hall:

Yeah.

Chantal Boyle:

Help raise awareness, and from the point of view of checking through symptoms, to being confident within your place of work as well.

Paul Howard:

I think there was a wonderful discussion and really lovely to hear about Rachel's experiences. I'm really pleased that she's got such a fantastic employer supporting her. So thank you for inviting me to join the conversation.

Speaker 1:

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 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.