

Community Roundtable

You can watch the video of this event at: youtu.be/n_E_L97ERDA

[00:00:00] **Skye Corken:** Good morning, everybody. Thank you so much for joining us today. My name is Skye Corken and I'm the Communication and Engagement Coordinator with SRNA. And today I've got three very special guests with me, Scott, Francis, and Andreas, who I will let introduce themselves in just a moment. But today we're going to be doing a Community Roundtable, which is really exciting. We first did one of these for Rare Disease Day in February and you guys loved it. So, we decided to bring it back for MOGAD Awareness Month.

[00:00:40] So just really quick if you have any questions or anything that you want to ask our three guests, that is great. We will have some time for some Q&A at the end, but we might weave in some questions as we go along. So, feel free to put those questions in the chat. There is a specific section for Q&A, and you can put that there as well. And we'll do our best to answer them as we go along. So, with that, I just want to get us rolling because I know we're on time today.

[00:01:30] So like I said, my name is Skye Corken. One of the first things I wanted to talk about first was just asking our three speakers, how has your life changed since your diagnosis? Have you found a new normal, and if so, how? This is a big conversation that comes up with our community members a lot. And it was a big thing that we talked about at our previous round table. So, I want to start there. So, Scott, Andreas, Francis, one of you can go first and introduce yourself and then get right into the question.

[00:01:55] **Scott Tarpey:** I don't mind starting. So, hello everyone.

[00:01:56] **Skye Corken:** Yes, go ahead, Scott.

[00:01:58] **Scott Tarpey:** My name's Scott Tarpey. I'm from the UK who live in the north of England. And my journey with MOG antibody disease started back in 2020 just before the pandemic started. So, in March 2020, I was studying for - I'm training to be a chartered accountant and I was down to my last four exams, and I'd taken the week off work to sit to exams. And I remember waking up on the Monday morning with a small bruise-like feeling on my lower back, felt like a bruise but without the pain, it's the best way I can describe it. And over the course of the next four days that spot spread all the way up my chest. And then eventually that led me to being admitted into hospital on end of day 4 with lack of sensation from the neck down and lack of strength from like the waist down.

[00:02:51] Thankfully, I made a really good recovery. I was treated at a really main teaching hospital that we have here in the UK and originally diagnosed with transverse myelitis, inflammation of the spinal cord. But my neurologist actually predicted it was MOG antibody disease before it was confirmed by a MOG antibody disease test. So that was pretty impressive. And so, I made a pretty good recovery overall, the treatment

was good. And I'm almost back to - I'd say normal, let's say it's 95% of the way there. I still have some issues mainly to do with bladder issues due to where the inflammation on the spinal cord occurred.

[00:03:33] So how has my life changed since the diagnosis? Walking back, now it's a bit weird. I keep referring to that attack as being the best and worst thing that's ever happened to me. So, the worst thing in terms of having to go through the recovery, being bedbound for a few days and then slowly working my way back up to walking and then running and then trying to get back to normal. And so, I've been through a lot in terms of that way, but I also look at it in terms of probably the best thing that's ever happened to me in terms of the connections that I've made. I think some of the involvements that I've had with the nonprofit organizations and advocating for MOG antibody disease, the people I've met has been absolutely phenomenal.

[00:04:20] And also my perspective of life before the condition in terms of now, I think I had a lot going on and I was doing well, but I was almost coasting in life and taking things easy. And ever since then I've taken to, you don't take every day for granted, we don't know what could happen in the future. So, it's definitely spurred me on to do bigger and better things and my mindset, my mentality on life has changed a lot. And I think overall it's a definitely a net positive. I feel much better with the person I am now than I was before being diagnosed with a condition and dealing with it.

[00:04:59] **Skye Corken:** That's really great. You mentioned that you have gotten into some advocacy work, and can you talk just a little bit about MyMyelitis and how that got started? And then we'll move to Andreas and Francis to answer that question.

[00:05:20] **Scott Tarpey:** Yes. So MyMyelitis, it was originally started as a website as basically an accountability blog to hold me accountable. Also looking back through the attack and it oh, could I have gone to the hospital a bit sooner? Could I have sought help a bit earlier? What could I have done a bit better? And in the end, I was like, this is a rare condition. Not many people know about it. My main doctor didn't know about it. And even after it happened, he was reviewing my notes and said he'd never heard of it, so I can forgive myself for that part. But going forwards now that I know that I'm diagnosed with this condition, if that was to happen again, that's much more on me. So, I use the website as an accountability blog to say this is where I am. This is what I've been diagnosed with, and this is what I need to do to keep my life on track.

[00:06:05] But then as time has gone on, it turned into more of an advocacy platform with creating blog posts and videos on YouTube to basically talk about MOG antibody disease because outside of a few nonprofit organizations, there wasn't much information out there. And basically, when I was recovering, I had to read through all the research papers, which is an absolutely horrible experience having to Google every other word, especially if you don't come from medical background like me. So, I just wanted to take that information, distill it, and bring it down to a level where people could understand. And then I'd be doing that for my own benefit. But if I can then take that information and spread it to more people, then that's great as well. So that's where it's turned out to today.

[00:06:55] **Skye Corken:** That's great. That's really wonderful work. Thank you so much for sharing. Andreas or Francis, do either one of you want to hop in and address that question and introduce yourselves?

[00:07:12] **Andreas Melitsanopoulos:** Yeah, I'll go. My name's Andreas Melitsanopoulos and I was diagnosed with MOG as well as CIDP last February 2022. Then a similar story to Scott, a month or two prior, I was just working from home looking at the screens and I noticed that, the vision in my right eye was a little blurry and gradually my feet started to feel it's really cold and numb and, a week or two prior to that, I had gone for a few miles run. I was feeling really good. I played division one soccer and in my undergrad. So, I always tried to take care of myself.

[00:07:58] And my body was just changing slowly, and I went to my local ER, did a couple different tests but they ultimately pegged it to stress and anxiety, which at the time I was working incredibly long hours and I was probably working too much. But over time as I saw ophthalmology, neurologists, we found optic neuritis in my right eye and then a number of lesions down my spine. So, the first I guess thought or well diagnosis was multiple sclerosis. And at that point, I was just happy to have an answer so I could try to tackle something. I think the unknown of it is probably one of the more scarier things. So, I wasn't really perturbed by that, but like any life changing diagnosis, you should always seek other opinions. And I thankfully was able to get admitted to see some MS specialists in New York who again typically wouldn't look at these super rare diseases, but they were able to look at my MRIs and deduce that it was pretty atypical for MS.

[00:09:12] So, I mean, in about a month's time I went from - I could say, going for a run to using a walker. I lost about 40 pounds, and I was there for two weeks. I got treated with Solu-Medrol and IVIG and I was able to stand up after and walk on my own. Over time through more spinal taps and more tests, we ultimately found MOG, which again, it was just a big relief just to have the answer. And I think the first thing I said was it's just a really rare thing, but ultimately just happy to know. And I left the hospital walking, but about a few weeks later I was back on my walker. I guess I just relapsed from there, lost strength sensation in my legs. And I was like, okay back to the drawing board. What do I need to do from here? And it was just a lot of physical therapy, occupational therapy. I lost all sensation and use of my right hand. So, I was there for five days a week. I was able to take a few months off from work.

[00:10:24] And I think ultimately, when I look at where I am now, basically a year later, I still have some sensory issues, numbness in my feet and like that tightness and spasticity. But I've since stopped going to OT, I've got cleared from that and back to playing sports again, which is a bit of a new normal because maybe I'm like the surface of things with these types of invisible diseases people wouldn't know that I can't really feel my feet when I'm doing things. But ultimately, I guess part of finding that new normal is just knowing that you still can. There were a couple of different goals that I'd always had, like going to grad school, which I'm doing currently. And part of that was just accepting that I needed my time to rebuild and focus on myself and really just focus on what's important, which would be my health where I was probably way too bogged down or focused on my work.

[00:11:31] It definitely gave me a newfound perspective on what's more important in life, like the family and friends who supported me and helped carry me up the stairs when I couldn't do it myself, being more involved in my communities and everything like that. So definitely finding that new normal is important. But I think it's also important to say that doing it on your own time and finding what's best for you is important. I wasn't going to live my life by anybody else's accord or put my focus into things that weren't benefiting me. So, it definitely put things into a much more broader perspective than probably how I was living my life previously.

[00:12:18] **Skye Corken:** That's huge. Thank you for sharing. And I'm glad you brought up friends and family and stuff because we'll be getting to that in a little bit because I do have a question about support. But thank you so much for sharing. Francis, did you want to hop in and answer that question for yourself and say hi?

[00:12:39] **Francis Fullon:** Yeah. Hi, guys. My name is Francis. I'm a Filipino. I'm a nurse here in Germany and I was diagnosed with MOG last 2019. And it really changed my life and I completely agree what Scott and Andreas shared and really, it's a new normal even right now. It happened last time during that time, first headache and then eye pain and I thought it was just migraine. So, I was just sent to check for my eyes to check if I need glasses. But they told me it's not. So, my mom told me you need to go to the hospital. And then I was sent there and then they made a lot of blood works and then lumbar puncture. And first they suspected if it is multiple - if it is viral or bacterial meningitis. So, they started antibiotics. And then after one week, it got a little bit better, but it started with my right eye that I can't -- that it's starting to see blurriness.

[00:13:49] But the worst thing is first, I was false diagnosed first because I was sent to the rehab for further check. And then during that rehab, within that one week, I tend to get worse. I tend to walk to the left and my coordination and balance was really, really not good. And I completely understand some of the patients even helped me by walking there with the Nordic walking and stuff. And then I was sent back to the hospital, and they started prednisone for five days. They suspected first if it is multiple sclerosis. And then after five doses of prednisone, they started to think if I will continue, or I will get plasmapheresis. So, they suspect that if it is ADEM or NMO. So, they started me with plasmapheresis [IJ] for five days. But during the third day, I got worse because I tend to like stroke, I have left sided weakness. I can't walk, I can't eat alone.

[00:15:03] And then I'm really thankful also for my friends who helped me. And then I tend to have double vision during that time. And then I tend to see darkness and a lot of [blurriness]. So, they made again a lot of blood works. And then I was sent to another hospital to check if it is multiple sclerosis or not. So, they made brain biopsy for me. And after two weeks, I was sent back again to a hospital and then waited for the result. And then they told it is only vasculitis. So, the question is, what is my diagnosis? So, they made again blood works and lumbar puncture. And then finally, they were able to check from the other hospital that it says that I have a high level of MOG. So, the question is, how are they going to handle me? So, they asked again for a second opinion and then they started me for rituximab and then after two weeks again rituximab and then they planned after six months and then every eight months and once a year.

[00:16:13] The worst thing is for this rituximab because it really helped, it killed these autoimmune antibodies, but it made me immunocompromise. So, I got herpes zoster and then it started with my left face until now I still have left facial paralysis a bit. But still, I can move. But during that time, I really could not. And then they tapered this prednisone from IV for seven months. And then the worst thing of this MOG is I got hiccups for a whole day. Like it closed my larynx that I can't breathe, and I was sent to the stroke last time just to monitor me. And then, honestly, this rituximab it helped. First, it started every six months, then every eight months and then during the Corona situation, they started to lengthen it and my last therapy was 2021 March. So now it's already two years. So far, no relapse. And I understand that it's a new normal. I really believe what you are all experiencing also.

[00:17:47] It's like I changed my diet. I tend to eat these anti-inflammatory foods, like taking smoothie or this spinach and also turmeric tea, and I'm doing workouts in my home and then I'm really glad that I'm here in Germany because they really made a lot of research with this. So right now, I've transferred to Hamburg because they are now doing research also with this MOG, they told me that is really rare. So, we are doing a lot of research. So, for now it's already three results, blood result of my MOG titer that I'm negative. And then so far last November, I got again, MRI and they told me that there's no lesions anymore, but until now they told me we need to still control you. So, every year until last month I got another appointment there and we talk and then they still told me that we need to control you because this MOG is really rare. And I...

[00:19:16] **Skye Corken:** So, it looks like Francis froze but that's okay. Hopefully he can rejoin us in just a moment. Can you hear us, okay?

[00:19:28] **Francis Fullon:** Yes.

[00:19:29] **Skye Corken:** Sorry. Go ahead.

[00:19:32] **Francis Fullon:** And sometimes I'm scared about relapse and stuff. But just going to be - it really changed our life of this disease. There is positive and negative, and the really good thing is what we're going to share also with the family because during of my disease, my mother came here for me for six months. She stayed with me and to help me because she was really, really worried during that time.

[00:20:07] **Skye Corken:** Yeah, I bet. Thank you so much for sharing, Francis. So, all three of you have been on quite the journey, especially getting diagnosed, and it took a lot to get to where you are right now. And I think it's great that all three of you have just a different perspective on what that new normal means and the changes that have occurred in your own lives. But let's jump ahead just a little bit. Let's talk about that support network. What does that currently look like for you three right now? And are there improvements that you're wanting to still make in that area? Is it something that you feel really confident in that you have a great support network? And maybe if you want to just throw in any advice, I know Andreas and Francis, you are both very newly diagnosed. So, if there are audience members who are newly diagnosed on today, what you would tell that person in terms of support network and finding support. So, whoever wants to start first with that one.

[00:21:27] **Scott Tarpey:** I don't mind going first answering this.

[00:21:29] **Skye Corken:** Go ahead.

[00:21:30] **Scott Tarpey:** So current support network, I'd say I too have got my personal or - I don't know how you describe it not rare disease directly associated. So, I count that as friends, family and then so like mentors in personal lives and both in my work life and some of the coaches I've had when setting up MyMyelitis and then I've also got the rare disease side. So that turns under the support groups links to nonprofit organizations such as like the SRNA, Sumaira Foundation, the MOG Project. All those have been absolutely brilliant. I'd say that the biggest one for me would be the support groups because I think when you get diagnosed with a condition like this, they are really rare. The odds of you knowing someone like in your normal life that either - I'd even say that even aware of this condition is a big bonus, let alone someone else who's been diagnosed with it. So, the user support groups to just get in contact with people who understand what you're going through.

[00:22:42] It might not be the exact same case to yours because I don't think I've ever heard of two exact cases which are exactly the same, but there's at least be similarities and even just that little bit of similarity. After first being diagnosed, it helps so much just to know that you're not the only person in that position. So, support groups and especially just listening to other people's stories, I think you learn so much more when you get taught or told someone else's story because you find your own little ways of relating to it or you might not have the exact problem that they have, but you might think, oh, I can have that same problem. But with this area, it definitely helps you to explore some potential solutions or ways that you can improve, that might not be obvious or might not get told to you through the health care system. Any improvements? I don't think I really have too many improvements per se. I think there's a lot of the support networks offered by like the SRNA, the MOG projects are absolutely great and definitely get involved with them if you can.

[00:24:05] **Andreas Melitsanopoulos:** I'll pick up from there. I think the one thing that I learned really from the beginning of my journey is that it takes a village similar to Francis, I mean, I was with my mother for about 6, 7 months who was helping take care of me. But there is something about, I guess that sense of isolation and going through something that no one else around you is. And I think like you can find a lot of solace and the types of support groups that Scott mentioned and the various events that are held. Like I recall going to like a young adults meeting through SRNA a few months back and just sharing our stories, I was able to connect with some of the attendees and talk about our treatment plans, what physical therapy has been like. Because even when you go to physical therapy or even your doctor's office, there's just a level of ambiguity with these types of diseases, not just for MOG all the other diseases that SRNA supports.

[00:25:12] So just being able to talk to people going through or who have been through similar instances, helps with that, feeling of isolation in that sense. Of course, having physical support is important as well, varying on level of disability, but it takes a village I would say in the physical sense, as well as in the emotional sense, just

being able to talk to people. And being able to branch out of that shell can be very difficult when it comes to these types of diseases. I guess for me, I don't know if I could say any improvements, I'm incredibly grateful for the support that I received from family friends, but even more so from groups like this and charities like this where you at least have an outlet to not even that you need to say anything but just to learn that you're not alone in it, I think there's a lot of power in that.

[00:26:16] **Skye Corken:** That's great. Thank you for sharing. Francis, do you want to go ahead?

[00:26:21] **Francis Fullon:** Yeah, I agree with what you guys shared. And with the support group, I'm really thankful that I - first, I'm really thankful that I met Julia in MOG Project and then we shared, and she connected with me and then also in SRNA, one of the support members also here in Europe, we really met here. She came here in Hamburg just for us to meet and then share with each other and also with Sumaira Foundation. And this support group I'm going to say is - I know people will just say, oh, he's normal, she's normal. You don't know inside because physically we are okay, but inside it's not like that. And this support group is a feeling that is empathizing and then saying that you are not alone sharing how you feel and how you are experiencing because some people can't understand how we are dealing with it. They just say, oh, he's okay like that. She or he looks fine like that. But you don't know because we still have a lot of weird stuff in our body that we can't even explain also.

[00:27:47] With the bladder problems also. And also, sometimes when we are stressed - I'm going to say sometimes when I'm stressed, I'm still seeing a little bit of [blurredness] a bit. And then with this support group, I'm going to say it really helped me also to share that, that I'm not alone. And also, for the people to listen to what they are saying or I'm experiencing because placing yourself in their shoes because you experience that also and at least they will be able to lift them up and say that you're not alone. So, whatever you are, I'm experiencing guys, this support group, they really help at least. And also, your family, I understand I've met also that his or her family can't understand how he or she is feeling, but at least the support group is one of the people who can understand you and then what you are experiencing, this stuff.

[00:29:02] **Skye Corken:** Thank you. Andreas, if you don't mind, I want to go back to something that you had said at the very beginning. And this was actually brought up by Julie from the MOG Project yesterday in her conversation. It took her a long time to get diagnosed and even prior they even at one point referred her to a psychiatrist. And you had said when you were first trying to figure this out, they had just told you it was anxiety. So, there was the sense I'm assuming of it's in your head or it's just not what it is. And unfortunately, I do think this is something that is pretty common amongst our community members. So how did you, I guess deal with that is my question? And if there was anything that you can tell somebody who might be experiencing that now from doctors, what would you share with them? Do you have any advice to navigate that?

[00:30:06] **Andreas Melitsanopoulos:** Yeah. That's definitely one of the harder parts I think, or was one of the harder parts of the whole process I think just being honest, like honesty is the best policy. I found that in my diagnosis journey that I was trying to adhere to or tried to make my family less worrisome through the process. My mother was with me in the ER, when they said it was stress and anxiety and she was relieved, but I knew deep down that something was inherently wrong. So, I think the main word is advocacy. If you can sit there and advocate for yourself, like, I left the hospital that day knowing that something was really wrong, and it unfortunately took my disability to progress as fast as it did in that month's time to really get the red alert going in it.

[00:31:01] But even in the next steps, when I got my first spinal tap, I remember asking the doctors that were doing it, are we testing for anything else? I had Lyme disease a few years back. Are we testing for that, and

then MOG? And they just said, oh no, we're going to confirm it's MS. We believe it's MS, which is like, it's not daunting to hear because they're saying it's MS but just that lack of exploration and it's meant to be a diagnosis where you try to cross everything off of the list. So even then when - it's tough because you don't even know that the questions to ask to really figure it out. I'm not a neurologist but if your gut is telling you one thing, I would say to trust it and then you just keep trying to get the answers.

[00:31:51] Even again, when I went to the next hospital going through the same processes, there's always going to be a lot of doubt for medical professionals. I was on the Neurology and Stroke floor and one of the nurses that I had in the first few days, they really hammered home, how important it was for me to just advocate for myself. There's a lot of people on that floor that couldn't. So, dealing with, I guess the doubt of doctors or managing through that is just you need to have that voice for yourself because no one's going to speak for you. And I thankfully had family around me as well to help verify that, but there's a distinct difference between stress and anxiety and then the physical things that I was going through.

[00:32:42] So being completely honest with what you're feeling, not leaving anything out, feeling that it would be embarrassing or anything because you only get this one life and the more you try to search for those answers, at least you're giving yourself a chance that the doctors advised to me that if I had stuck with the MS diagnosis and got treated, I would have ended up in a wheelchair. So that really hammered home the fact that if we didn't seek further opinions or, if I just went against my gut feeling that something was wrong and we didn't try to go through every avenue that we could, then my life would be very different now.

[00:33:30] **Skye Corken:** Thank you for expanding on that. Like I said, I think unfortunately, that's something that a lot of our community members face. So, I appreciate you sharing more. I do want to open up the floor to the audience who's watching. If you have any questions now, let's go ahead and ask, I do have one more question that I want to ask the group. But if you have questions, please put them in the chat and in the Q&A and we'll pull from there, so don't be shy. But I did want to ask a question related to identity. This is something that has come up a lot within our support groups over the last few months. I guess I want to know how do you view your diagnosis in terms of your - and how it fits with your personal identity? Is it a big part of it? Is it a small part? And Scott, I'd actually love to start with you if that's okay. But do you want to expand on, I guess how you view your own personal identity with this if you're comfortable sharing?

[00:34:40] **Scott Tarpey:** Yeah. So, it's funny this came up in my workplace not too long ago. So, I work for the NHS in the UK as an accountant. And we're currently going through in my part of the organization, a big restructure. And one of the questions which got posted on one of the big announcements or webcasts that they did was how is this restructure where they're planning on reducing the head count of the organization from 30-40% down? How is this going to impact on people who have disabilities, all different ethnic backgrounds and all that? And it got me thinking that it's, well, where does my position fit into this? Because here in the UK, we have the law, which is the Equality Act 2006, I believe has a list of protected characteristics and one of those is disability.

[00:35:36] Now, for the legal case of being disabled in the UK there is a very fixed definition of what you have to meet in order to be classed as disabled. And I was looking at this criteria and I was like, I don't think I quite meet this criteria, but just because I'm not disabled by that amount, it's what actually am I? Because I know I'm not 100% healthy or what I was before this happened. So, it's a bit of a confusing one. I don't really like the word disabled anyway. And the other one is differently able, which I think I just like even less what does differently abled mean? I'm an accountant. I can do accounts, but you can't, does that mean we're different? So, I'm not. I don't think I'm a big fan of much of the language in terms of it, but ultimately on social media it's how people choose to present themselves with those sorts of things.

[00:34:46] So for me personally, it's been difficult because I'm not too sure where I quite fall. I just know that I'm a person who has this condition and that's how I relate my identity around and then all the other things on top of it with my job, my interests and that also involved in that. But I haven't quite found one word where I fall wonder in terms of what describes me from the identity. I guess advocate is probably like the best way because I'm not just a patient, ultimately, I want to both help myself and help other people and collaborate with other people in this space so that we can have better effects for more people and more positives. So, I guess advocate is probably the best way. I'm not too sure about anything else. It's definitely a tricky one as to where people think they fall on that.

[00:37:30] **Skye Corken:** I appreciate it. And I appreciate you just saying that you're still trying to figure it out because I do think it is something that a lot of people feel that they're also still trying to figure it out. So, I do appreciate you saying that. Andreas or Francis, do you want to answer that? And then I did see we had a question coming in from the audience as well. So, go ahead.

[00:37:56] **Francis Fullon:** Actually, I experienced also what Scott told with this handicap or with his disability. I tried also to apply in 2019 here in Germany, but I was denied because still after I got sick - I got sick for more than seven months during this month. And then I came back, I was working before in intensive as intensive nurse here in Germany. And then I was transferred to endoscopy because the company doctor told me it's really stressful for you and you are taking this rituximab and you are really exposure for infections like that, but I was denied disability. And the really funny thing is I transferred here in Hamburg and now I am working as optha nurse here. And it's really funny because it's just saying I got optical neuritis and then I'm here in optha ward also.

[00:39:09] And then I asked also some of the doctors here with this optical neuritis. And they told me most that it's one of the symptoms of MS and then for me - identity for me even though I would say positive - even though I am positive from MOG, but I'm still being positive of what happened to me right now. I'm a bit sometimes scared of this relapse. But I can say there's no - until now they can say if you are monophasic or multiphasic this MOG. But I'm just going to say being positive and just keep going. I know it's really hard. It's easy to say this but just keep going because I know it's still understudied, this MOG. But just continue and don't give up.

[00:40:15] **Skye Corken:** Thank you. Andreas, are you comfortable sharing?

[00:40:20] **Andreas Melitsanopoulos:** Yeah. I'll try to be quick cognizant of time. But I would say for your own personal identity, it's pretty difficult at the same time because it silos you or puts you into buckets, like when you're applying for jobs, disclosing if you have a disability or not, whether you feel like you need to say that for certain accommodations for things, it puts you in a difficult spot regardless of where you are physically. I agree with Scott in the sense that, emotionally just being an advocate and not letting the disease define you is ultimately what matters because you can still be yourself and you don't need to put yourself into a word, to be yourself a word like disabled or anything else. I think that's my main takeaway from that. I'm not necessarily letting the disease define me, but I am living my life trying to help as many people as I can with these types of diseases. And I think that's one way to find your own identity as opposed to just pigeonholing yourself into a bucket that you don't want to be in or that you don't feel like you need to be, you essentially make your own in a way.

[00:41:45] **Skye Corken:** I think that's really well said. Thank you. We did have - I know we're coming down just to the last few minutes, but we did have a question from an audience member, and I think Scott or Francis, if one of you are comfortable taking this one just because of what you mentioned. They said I've found it

difficult to travel or go out with friends and family with GI issues and cutting out inflammatory foods. How do I deal with that? Do either one of you want to take that one or at least talk about what you do?

[00:42:25] **Francis Fullon:** I'm going to say - with the bladder thing, I'm going to say, yeah, I'm still having trouble. Sometimes, even within an hour I tend to go to the bathroom two times or three times. It's really weird. And then I understand these anti-inflammatory foods because it's really - I'm not saying that I'm really religiously eating this stuff, but I'm eating every other day and stuff. With this GI, it will take time because I know even during that time, not only this bladder problem before I got also bowel movement problems and then it will take - I'm not going to say how many years or months, but I know it's really hard because for me, I struggled. That also is really not easy.

[00:43:25] And then some people were just going to question why are you going there like that, immediately like that? How can I say this? Try to just take step by step with this some - for example, for this anti-inflammatory, I'm taking turmeric tea every night and just to help me and also these probiotics like - also here in Germany they have this sauerkraut and also, I've learned also this Asian, this kimchi also anti-inflammatory stuff. And I'm taking also vitamins, not anymore just prednisone because it also has been 2019. Also taking this D3 and stuff and also Omega-3. And then I can't really say how to manage this GI stuff. But I know it will take time because it's not easy like that. Scott?

[00:44:45] **Scott Tarpey:** I can quickly jump in with this. So, in terms of like diet, when I was first recovering, I tried following the Wahls diet, that Dr. Terry Wahls created. That might possibly be the most difficult diet I think I've ever tried. And I admit I think it did make a difference in recovery, but I was definitely not perfect following it. And especially in terms of a diet, if you're trying go and eat out somewhere, the odds of you being able to find somewhere that will perfectly match that diet is highly unlikely. So again, just do as much as you can, you don't have to be 100%, a meal doesn't have to be 100% involved with that diet. So, it's just a matter of doing what you can with that because I don't think it'll ever be perfect.

[00:45:34] In terms of like managing bladder issues when out, the biggest change for me was self-catheterization. So, I still do it occasionally now, if I know I'm going to be out of the house for like a long time. It's definitely not the most pleasant thing, especially with doing it for the first time. But once you get used to it, you'll realize how quick and easy it is. And when you compare that to the amount of freedom it does give you, it's absolutely huge for me. And it's helped me both traveling in this country and then also when I've gone abroad on holiday or vacation, so I can highly recommend that.

[00:46:16] **Skye Corken:** Well, we are at the end of our Community Roundtable time. I just really wanted to say just a huge thank you to Scott, Francis, and Andreas for sharing their time and their stories with us today. As they all said, sharing it in this way is super impactful. It's incredibly important. So, I hope you as an audience really enjoyed the conversation today. I know I did. If you have any more questions, we actually are going to take a break. But then we will have our "Ask the Experts Live Q&A" session at one o'clock Eastern. So, if you do have questions really related and maybe more on the medical and scientific side, join in there and we'll try to get to as many as we can. But just thank you again, so much guys. We really appreciate it and I hope you enjoyed your conversation today together. Well, thank you everybody and we'll see you at the next session. Bye-bye.