



MIGRAINE WORLD SUMMIT

TRANSCRIPT

INTERVIEWS WITH WORLD-LEADING EXPERTS

MIGRAINE FOMO: ARE YOU MISSING OUT?

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Introduction (00:05): You never know what people are dealing with kind of behind the curtain. We all have our external face and life that we present but everyone is dealing with different challenges. And comparing yourself to somebody who looks like they've got it all together — and then that they're making it all happen — isn't probably a good idea, because you don't know. They're probably dealing with some struggles, too, and maybe you just aren't aware of them. So try not to compare yourself to how successful or how active somebody else that you're observing is, and just try to do the best that you can for you.

Paula K. Dumas (00:50): Have you missed out on many of life's special moments due to migraine? We feel you. FOMO, or fear of missing out, is widespread in our community because of the challenges many of us face making plans that migraine often interrupts. Until we all have reliably effective acute treatments, or a cure, we must learn to navigate those family commitments, social outings, and work engagements that we desperately want to attend. In this interview, we'll talk to a leading migraine and headache patient advocate, Katie MacDonald. Katie has held leadership roles in two different migraine nonprofit organizations, Miles for Migraine and Alliance for Headache Disorders Advocacy. She works on advocacy, raising funds for migraine research, and reducing the stigma associated with migraine and headache disorders. Katie MacDonald, welcome to the Migraine World Summit.

Katie MacDonald (01:44): Thank you so much, Paula. I'm excited to be here.

Paula K. Dumas (01:47): Well, we have a lot to talk about. Now, you're in the event business. So, what do you tell those people with migraine who are worried about canceling?

Katie MacDonald (01:56): I think one of the biggest things is, you have to try to show up. So, don't hesitate to sign up for an event out of fear that you might have to cancel. I think it's better, and I would encourage you to put yourself out there and sign up for an event. And maybe let the person know, depending on the type of event. Are we talking about a walk/run event? Are we talking about a family gathering, talking about a social event? Just give people a heads up ahead of time, and let them know that you live with migraine or headache disease, and that there's a chance you may need to cancel, but you really want to be there. And I think if you set yourself up and believe that you can do it, hopefully you'll be able to make it happen.

Paula K. Dumas (02:43): Well, you're right. And I think you also point out something that is tough for many of us, which is, we start to not commit to things because we feel badly that we might let people down. So we just avoid committing, and that starts a cycle of isolation and withdrawal that is not healthy.

Katie MacDonald (03:01): Exactly. I'm guilty of that myself. I think sometimes I say it's easier to not make the plans than to make the plans and have to cancel. But I think it's a good challenge for myself to try to accept when there are invitations to attend events or gatherings with people, and give that heads up that your plans may need to change, but that your intent is to be there because that social interaction is so important to our overall well-being.

Paula K. Dumas (03:33): Have you personally experienced this, where you've had some major event or something big that you really, really wanted to be at, and migraine interrupted those plans? And if you did, how did you handle it?

Katie MacDonald (03:47): Yeah, I have, and it's come in all different varieties. One of my most recent situations, which wasn't a last-minute cancellation, but I have a group of friends and we



like to travel together, and this year's trip was going to be a longer trip. They're going to Italy and they're going to be hiking in the Dolomites, and sadly, I had to say no. And that's been — it was a really hard decision for me. I hate to think that I'm missing out on something, but I also needed to be realistic about what my body could handle. This was a trip where we're going to have to be changing locations every day on the hike. I can't not feel well and stay in bed for the day. So I realized it wasn't going to be the right fit for me. And that's really hard.

Paula K. Dumas (04:37): It is really hard, but I love how you phrased it: It's not the right fit for me. Those friends probably respect you for making a tough choice.

Katie MacDonald (04:47): Yeah, I think one of the hardest parts is feeling like — not only the disappointment for yourself — but feeling like you're letting other people down. But I think ... When you communicate well and you try to communicate in advance about your situation — and this could even be with an employer, it doesn't have to be somebody that you're really good friends with — but if you help people understand prior to the situation where you need to cancel or say no, I think they're going to be perhaps more receptive because this isn't a shocking news to them. You've given them a heads up already.

Paula K. Dumas (05:25): Is there any role that guilt and FOMO play in your life with migraine?

Katie MacDonald (05:30): Absolutely. I think maybe different than what a lot of people think, but guilt and FOMO are actually a motivator for me. I think FOMO has helped me in dealing with migraine in that there are so many things I don't want to miss out on. I'm fortunate to have a really fun group of friends who are often doing great things. And as much as I know the limitations of migraine, I will do everything I can to try to be a part of something. Because I think I've never regretted saying yes or showing up no matter how awful I've felt, but I've had that awful feeling of *not* having participated and wondering what would've been if I had been there.

Katie MacDonald (06:31): I think one of the ways that I manage living with migraine is — because I have attacks every day — I feel like I know I'm going to end up not feeling well at some point during the day. I'm probably going to end up spending a little time in bed or time on the couch. And if I have the opportunity to get out there and do something and be surrounded by other people, a new environment, and doing something fun, I feel like there's a good chance that the energy that I get from that is going to be more beneficial to me than — even if I still get that attack, and maybe it's going to be worse than it would be if I didn't go do something — at least I've been able to have that experience. So I almost say it's a price I'm willing to pay to put myself out there and use that FOMO as a little bit of a motivator, and then deal with the consequences on the backend.

Paula K. Dumas (07:35): I want to go back for just a minute and learn more about your migraine journey. When were you first diagnosed?

Katie MacDonald (07:41): I was diagnosed when I was in high school, so that was about 35 years ago.

Paula K. Dumas (07:48): OK, and were you episodic for a while and then turned chronic? Was there some event that happened in your life that changed the way migraine presented itself?

Katie MacDonald (07:59): I don't have a specific event. I did start out episodic. I started out maybe getting a couple of attacks a month and, unfortunately for me, it has just slowly



progressed over time. I think it was after college that they started becoming more frequent. And when I got into the workforce, I started having daily attacks, and it's now been quite a few years that that has been my norm. I've continued to try lots of different treatments and lifestyle modifications, and ultimately it led to my career change. I had to leave my corporate job because of migraine. And it wasn't working for me to get up and go to work every day and come home and go to bed immediately. And so, I left the workforce for a while and I actually had visions that maybe not working would get rid of that stress, that could be just the exacerbating factor that was tipping me over the edge. But I think one of the biggest lessons I've had is that I realized when I was not working and I was still dealing with daily attacks, that this really is a disease. It's not my work. It's not one stress. We talk about the layering of things that can contribute to the way your attacks act. But that helped me realize that that's not what's causing my migraine. And from there, I ended up getting involved in migraine advocacy and basically starting a new career, which has been amazing.

Paula K. Dumas (09:46): Well, we are so grateful for the work that you've done. For those who aren't familiar with the Alliance for Headache Disorders Advocacy, it's the largest [migraine] policy organization in the United States, which tends to create a model that other countries often follow. And you organize a big event, or had organized a big event, called Headache on the Hill each year, which I've had the opportunity to be a part of, where we get people from as many states as possible — but the majority of the 50 states — there to meet with congressional leaders. So, I want to know, and other people who are listening are probably wanting to know: How in the world do you function with chronic migraine and a really important advocacy leadership role?

Katie MacDonald (10:34): I don't know exactly what the magic answer is. I think, for me, organization is really important — trying to stay organized, kind of knowing that at any time, I could have a bad attack and I don't know how long it's going to take me offline for. So I try to stay as on top of my game as I can while I'm feeling as well as I can. The fact that I'm working in a community that is very understanding — I'm working on migraine advocacy, so the people that I surround myself with are understanding and are willing to help out in the times when I'm not as sharp or as productive as I'd like to be. And in turn, I do the same for other people. But I also think it's really important to put ourselves out there and have these challenges for ourselves. To help — it just helps me feel more productive and feel like I'm doing something good with this disease.

Paula K. Dumas (11:39): You do do a lot of good, and we're grateful for that. So how did you get involved in migraine advocacy?

Katie MacDonald (11:45): I think back, I first got involved in migraine advocacy when I was being treated, seeing a headache specialist and not feeling like I was getting the response that I needed. I wasn't getting the information I needed. And it started back probably in college or right after college when my mom would say to me, "It's not OK that you're not getting those answers. It's not OK that someone's not getting back to you. You need to speak up and you need to help them understand why, and maybe you should reach out to the patient advocacy office at the local hospital and see if they can help." And that was kind of a new concept to me. But that's when I started to learn that having my own voice and standing up for myself and what I was dealing with was really important. And as time evolved, I think I started to get to know my headache specialist a lot more, and at one point, he encouraged me to get involved in Headache on the Hill actually. He invited me to attend that event, and that was one of the most life-changing things that's happened to me just even beyond the migraine world. Just having that



experience of going to [Washington], D.C., and being a partner with other people who live with this disease. I think that was the first time I was in a group of people with migraine.

Paula K. Dumas (13:22): It's very empowering, isn't it?

Katie MacDonald (13:24): It is, and it was just a very eye-opening experience. After the first presentation —[to] hear people talking about needing to take a medication to stop their attack — I'm like, people are talking about this out loud. Nobody's whispering. That's just nothing I'd been around before, and knowing that we were going to speak to members of Congress, which sounds really scary. These are just regular people, but as a combined force with many of us making the same ask, we were really making a difference. And these people seemed really interested in not just the ask we were presenting, but about my personal journey. They wanted to understand what migraine looks like and how it's impacted me. And then it continued to grow from there. I got involved in organizing the Headache on the Hill event and as I said, I left my career and I started working in the field of migraine advocacy.

Paula K. Dumas (14:32): Excellent. So, you and your husband lead a very active outdoorsy life in the beautiful state of Vermont. How do you handle the FOMO when a migraine attack interrupts the plans that the two of you have made?

Katie MacDonald (14:45): I am very fortunate to have a very understanding and supportive husband. I think we've been through a lot of different iterations of trying to figure out how this works. We've had the earlier years in our relationship — it would get to the point where there were too many things I felt like that I couldn't do, and he would want to stay home with me so that I didn't feel, you know ... if we were canceling plans with friends, for example, he'd be like, "I'll stay home too." But there got to be a point where I said, "You've got to live your life. You can't stay back with me every time I have an attack. As much as I appreciate that support, I want you to still get out there and do the things that make you happy." And I think over time we've figured out a good balance where there are times when I'm not feeling well that he will also cancel and stay home with me. He has become very used to the fact that plans are fluid.

Paula K. Dumas (15:51): Well, I know you know you're fortunate to have an understanding partner. Not everybody has that, unfortunately. But we can only hope and work on those relationships to try not to live with the guilt that sometimes comes from letting someone else down. But I want to understand what you might've learned from behavioral therapists that would be useful to someone with migraine who's just listening to this and is really frustrated by living life on the sidelines.

Katie MacDonald (16:23): One of the most important things I've learned is, if something is worrying you or stressing you — especially about making plans or thinking about being a part of something — I think it's important to talk about it. Migraine is not a mental health disorder — I think there are some people that still think it is — but there is a lot of connection. A lot of people with migraine live with depression and anxiety, and vice versa. And so I think taking care of and paying attention to your mental health and well-being is a really important aspect of living with migraine. And so, like I said, one of the lessons I learned was try to get stuff off your chest versus keeping it in your head where you're just going to start ruminating and catastrophizing and making up stories for yourself. If you could just say to a trusted friend, co-worker, partner: "I'm really worried about saying yes to this," or just, "I'm worried about this in general." Sometimes, just when you say it out loud, it kind of helps you problem-solve yourself and release that extra tension that you might be causing for yourself.



Paula K. Dumas (17:53): That's good advice: Get it out of your head and off your chest in order to process it.

Katie MacDonald (17:59): Yeah. I think another important thing that I've struggled with is, don't get into the game of comparing yourself. I'd be like, "Why can't I be a part of committing to doing this volunteer activity once a week? So-and-so's doing it, and she's got two kids and works full time and has a 45-minute commute each day." You never know what people are dealing with kind of behind the curtain. We all have our external face and life that we present but everyone is dealing with different challenges. And comparing yourself to somebody who looks like they've got it all together — and then that they're making it all happen — isn't probably a good idea. Because you don't know — they're probably dealing with some struggles, too, and maybe you just aren't aware of them. So try not to compare yourself to how successful or how active somebody else that you're observing is, and just try to do the best that you can for you.

Paula K. Dumas (19:12): Yeah, getting out of the comparison trap is also some very healthy advice.

Katie MacDonald (19:17): Absolutely. And there's so much to the treatment plan. I think when people say how your treatment plan is working, a lot of people immediately think, "Well, what medication are you on?" But I think those of us who have been dealing with migraine for a very long time have come to learn that there's so many aspects to the treatment plan — which includes your mental health, behavioral health, lifestyle modifications, the way you interact with and get support from your community, so to speak.

Paula K. Dumas (19:56): Yeah, it's multidimensional for sure, and not just up to one medication. And what you're here doing with us today around education, we also believe is a really important part of the treatment plan.

Katie MacDonald (20:10): Exactly.

Paula K. Dumas (20:11): Is your advice any different when somebody misses a work function versus a personal function?

Katie MacDonald (20:16): In both cases, I think one thing that's really important when you're going to miss an event, or you have to cancel an event, is to communicate that. Just not showing up, I don't recommend that because that kind of leads to the stigma that we're already fighting around people with migraine. I think that's also — it's an advocacy opportunity because it's a chance for you to say, "This is what I'm dealing with right now. I'm vomiting or my vision's really blurry right now, or I just feel like I can't concentrate, and it's not going to be beneficial for me to be at this event. And I regret to say that I can't be there."

Paula K. Dumas (20:57): You just made a really important point I want to underscore: You told them what your symptoms were. So, people oftentimes don't want to say, "I have a migraine," because that person on the other end is going to hear it and think, "Well, my wife had a migraine and she just took a couple Advil and it went away." But when you say, "I'm vomiting, and my vision is compromised, and it's not safe for me to drive." That's a whole different conversation. And you're educating the person on the other end.

Katie MacDonald (21:32): Yeah, I think that's the advocacy piece, and I think it makes such a big difference. I think it can be harder to do that when it comes to a workplace event versus a



personal event. When it's a personal commitment, we're usually talking about friends and family, who — hopefully someone in that mix is supportive of you. But you can't be sure at work that you have a community of people there that understand. I've certainly had those situations at work where I've tried to say, "I can't do this right now. I've got a bad migraine. Could we reschedule?" And the answer is: "No, we can't reschedule. So either you come or you don't come, but we're going to move forward." And those can be really, really frustrating. And I think the only way we start to break that down is through education. And maybe you can't be there and maybe there's repercussions but try to still use it as an opportunity to educate that person about what it means to you.

Paula K. Dumas (22:47): So, in your work with Miles for Migraine, you've met many people with migraine who have stories of missing out on life. What do you think is the link between missing out on life and seeking out a new doctor or treatment plan?

Katie MacDonald (23:02): I think we all have kind of our baseline where we know where we're at — we know what a normal week looks like for us in terms of the number of attacks and the severity. And the longer you live with it, you kind of come to better understand, through — like interviews at the Migraine World Summit. You just come to better understand the disease. And I think for myself, every once in a while, I just get to this point where I'm like, "I know there's no quick answer to this, but things ... I'm canceling more often, I'm spending more time in bed than I'm used to. I think that now it's time to reach out to my headache specialist and just check in." Communication can be challenging depending on who your headache specialist is and what their availability is. When it comes to thinking about, "Do I need to have a different provider than I'm working with?" I would say if you don't feel like you're being heard or if your calls — requests for communication — are not being met to a level that you feel is acceptable, then it might be worth checking with another provider.

Paula K. Dumas (24:22): Sometimes it's a different provider and sometimes it's a different plan. So many people watch the Migraine World Summit and learn about new therapies, new approaches that they haven't tried before. So, being able to share those with your HCP, whoever they may be. It could be a nurse practitioner, it could be a GP, could be a neurologist, an OB-GYN, and saying, "Hey, I learned about this here, and I'd really like to try this." But when you miss out on too much of life, that's oftentimes the impetus or the tipping point for people saying, "I'm not going to miss another 'X.' I'm going to go do something different." So, in the people that I've met, it can be a strong motivator for seeking out a new doctor or treatment plan.

Katie MacDonald (25:10): I was just talking with a woman recently who is not being cared for, for migraine specifically. It's clear she has it, but she's not going to a doctor for it. And she had a list of reasons why. And we talked for a while, and I explained that one of the reasons you might want to see a headache specialist, specifically, is migraine can become more chronic over time: If you don't treat it, it can get worse. And she was like, "Oh, I was kind of hoping it was just going to go away." And don't we all just hope — just wish it would go away. But sometimes we do need that expertise of whether it's your primary care provider that you start with or you end up with a headache specialist to talk to about a treatment plan. And a treatment plan doesn't mean that you have to take pharmaceuticals. It can mean lots of different things.

Paula K. Dumas (26:14): And just the difference you made in that one person's life can be an amazingly rewarding part of this work as patient advocacy, in patient advocacy.



Katie MacDonald (26:25): Absolutely. There are so many different ways that patient advocacy gives back to me. I think it's helpful for me in my journey with migraine to be advocating and feel like I'm making a difference, and I'm trying — I'm not just sitting back and being angry about it, but I'm going to put my energy into trying to help other people. And when I have those conversations with somebody one-on-one, somebody that's struggling, that a friend's sister's, husband's daughter reaches out because they just need someone to talk to. That can feel really rewarding. But there's also — there's that type of advocacy where you're standing up for yourself and representing your own needs. That's really rewarding. And then there's the federal policy advocacy where you're driving change that's impacting millions of people at a time through legislative or policy changes, and that is really rewarding. So I don't see any downsides to getting involved in advocacy, really.

Paula K. Dumas (27:33): Yep. It's just about time and how we invest the 24 hours we get each day. Can you envision a day, Katie, when FOMO is going to be a thing of the past?

Katie MacDonald (27:44): I can. I don't know if it'll be in my lifetime, but the past couple of years we've seen so much advancement in migraine in the world of preventive treatments, in the abortive treatments. Unfortunately, I haven't found the thing that has stopped the attacks from me yet, but I'm still holding out hope. And I think we will get to a place where this disease is well researched, understood, and treatments that work for all people will be available.

Paula K. Dumas (28:24): Thanks, in part, to the incredible work that you're doing. So, what final thoughts would you like to leave with the audience?

Katie MacDonald (28:31): I think getting involved in patient advocacy — I just mentioned this, but I think it's really worthwhile. We do only have so many spoons and so many hours in the day, but learning how to tell your own story about what you're living with, and how you're experiencing it — your elevator speech, so to speak — could be a great first step. Advocacy can be sharing information on social media. It could be passing along an article that you've read, or it can run all the way up to something like attending an advocacy event like Headache on the Hill or going to a walk/run event. There are so many ways to do it, and I think similar to what people say about volunteering, that when you help others, it can really help yourself and it can really influence your own sense of worth and happiness to be advocating and helping yourself and helping others.

Paula K. Dumas (29:37): Well, I'm inspired. So, thank you so much for that encouragement, and I know many other people will be as well. What's the best way to connect with you or follow your work?

Katie MacDonald (29:47): You can find me at Miles for Migraine. You can email me. I'm Katie — K-A-T-I-E — katie@milesformigraine.org, and that's probably the best place to see what I'm up to and follow me.

Paula K. Dumas (30:03): Terrific. Well, we are so grateful for your time here today and your work in the migraine community to help people with all kinds of headache and migraine-related disorders, and we look forward to hearing more. Thank you, Katie, for being with us.

Katie MacDonald (30:20): Thank you for having me.