



MIGRAINE WORLD SUMMIT

INTERVIEWS WITH WORLD LEADING EXPERTS



TRANSCRIPT

COVID IN THE REAL WORLD

LINDSAY VIDENIEKS, J.D.



Introduction (00:05): Persons living with migraine disease have been early adopters of telehealth. But our survey found that 22% had used it before the pandemic; that skyrocketed to 78% who were using it during the pandemic. This is a technology, or a way of treatment, that folks felt somewhat comfortable in using. And so, the survey showed that 83% reported that they'd like for that to continue to be available. And hopefully, through reform legislation and other workaround measures, that can continue to be the case.

Paula K. Dumas (00:47): The scream heard 'round the world has a familiar sound: COVID is throwing everyone off balance this year — *way* off balance. The once-employed are now scanning the "help wanted" ads. Former commuters are crammed into a corner of the bedroom to get work done, while kids are underfoot, trying to learn. And, you know, it's enough to turn the once-composed into a state of unrelenting stress or depression. And for people with migraine, COVID's impact is real — both positive and negative. If you think you're the only one struggling with the massive change that this virus brought, our next guest is here to remind you: You are not alone and help is on the way. Lindsay Videnieks brings decades of legislative campaign experience to her role as the executive director of the Headache and Migraine Policy Forum (HMPF), an organization that works to help identify and resolve public policy issues that constrain us from getting the care, or legislative protection, that we need. Lindsay, welcome to the Migraine World Summit.

Lindsay Videnieks (01:50): Paula, thank you so much for having me today. I am one of those moms making it through the pandemic. I have three little kids, two are homeschooling; if you hear a kindergartener with "Mary Had a Little Lamb" in the background, that might happen. But I also realize I'm one of the lucky ones, right? So we now, as you mentioned, we're kind of living through a "she-cession" right now, too, which is, you know, for those women who haven't left the workforce, we know 11 million women have lost their jobs and two-and-a-half million have decided to leave because they have to take on extra work right now. So, what a time that we're in. I'm really interested in exploring some of the issues that folks are dealing with during COVID, and their health. But all of us are just trying to get through this moment right now.

Paula K. Dumas (02:52): Survival is key! And it's a really tough time; there's no doubt about that. What we're going to talk about today is the real-world impact of COVID on people with migraine, and in particular, a study that you and I had the opportunity to work on through HMPF and MigraineAgain.com, and just help people understand what is actually going on. I appreciate you sharing what you're dealing with at home, and I'm sure that many people can relate to that. So, HMPF and MigraineAgain conducted a survey in October of 2020 of over 1,000 people with migraine. Tell us, what was the health impact? What impact is the pandemic having on the frequency of people's attacks?

Lindsay Videnieks (03:36): Yeah. You know, we thought it was important to undertake a study at that moment in time, which was: Enough time had passed to be able to collect real data, but at the same time, people were still very much right in the thick of it. So, I guess I'm not surprised to report that, according to our survey, 69% reported an increase in migraine attacks. And so, there are a lot of reasons for that, but that was the stark number that came right out.



Paula K. Dumas (04:08): Sixty-nine percent is the vast majority. I'm impressed by the 30% who are not affected. Tell us why you think those attacks are on the rise.

Lindsay Videnieks (04:18): Yeah. You know, for migraine patients, any morning waking up brings uncertainty. And so, what does that mean when you add a layer of anxiety of, "I might lose my job," or, "I don't know if my kids are going to be able to homeschool," or, "Can I even leave my house?" So those are all triggers and have caused instability for persons living with migraine disease. So we're not surprised by that.

Paula K. Dumas (04:51): No. It's not surprising. Many of the experts we talked to, talk about the neurology of migraine brain, saying they really just don't like change and don't respond well to massive changes in the weather or massive changes in society. So that could easily explain it. What effect is this having on our stress levels?

Lindsay Videnieks (05:11): Oh, they've just gone through the roof. I think everyone watching can feel that. Eighty-four percent of our survey respondents said that their stress levels have increased. And that's for everything that we've just talked about. It's also because we're spending more time — if we're lucky to be — on a computer. And if you have photosensitivity issues, that's a new trigger. People are being asked to do the same amount of work. I don't know *anybody* who has taken their foot off the gas right now. It is, sort of, packing more into an environment that's even more unstable than before.

Paula K. Dumas (05:48): You know, you raised a really good point about the light sensitivity of staring at a screen for too long. And I'll just take this as a moment to remind everybody that you can listen to these interviews, and you can also get the transcripts, so that the light sensitivity is not compounding anything.

Paula K. Dumas (06:04): We compared some of this data from the HMPF MigraineAgain study to the Migraine Buddy data, which is really people self-reporting what's occurring on an ongoing basis. And because they track 24/7/365, they were able to see this significant spike of about 30% to 45%, depending upon the country, of people reporting stress as a migraine trigger in mid-March when the news came out of the announcement of the pandemic. And that, kind of, is an indicator that news consumption is a factor that we should all be considering.

Lindsay Videnieks (06:42): Yeah. Paula, I would also add on to that, too: We are still hearing from patients and providers that, in many cases, access to treatment is still a problem. So, you would think that, while some — we'll talk about telehealth a little later — we know that insurers are still denying claims for certain therapies. And if you add that stress, coupled with perhaps a financial stress — has your spouse lost their job? Have you lost your job? — that's a whole other layer of a burden to have to undergo right now.

Paula K. Dumas (07:18): Yeah. It absolutely is. How about our overall health? What did the data say about the impact of COVID on our overall health?

Lindsay Videnieks (07:27): Yeah. About 57% of respondents said that their overall health had declined. And so, that's significant, and again, not surprising. I think this entire survey reinforced what we're all experiencing. But yes, 57% felt that it declined.



Paula K. Dumas (07:45): I'm going to ask you why you think that is, aside from the glaringly obvious?

Lindsay Videnieks (07:51): Yeah. It's the being off balance. Do you ... can you keep your appointment? Does that mean that you have further attacks because perhaps your migraine days have increased? And so, those types of obstacles in a path to treatment, in a journey to treatment, have only increased.

Paula K. Dumas (08:15): You know, I also wonder about isolation. Personally, I have felt — I say this is "survival of the introverts," because as an extrovert, I feel so isolated. I miss my people so much that I find myself on edge and a little blue many days.

Lindsay Videnieks (08:36): Yeah. I think that's right. And there've been many studies — HMPF has one on our website — about the comorbidities associated with this disease. And so, we know anxiety and depression, and all of those things relating to isolation, play a big part in whether folks can manage effectively their disease and also can just function day-to-day. So, that's absolutely true.

Paula K. Dumas (09:03): Yeah. Now you mentioned access issues, and in the study you explored the challenges that people are facing with access to migraine care, especially procedures. How many people reported some level of fear about getting care?

Lindsay Videnieks (09:19): Yeah. So again, this survey came out at a time when there was a *lot* of uncertainty, but I think it's probably still true. We found that 61% of respondents were afraid to seek care or treatment from their provider or the ER. And so, they obviously had some hesitancy about going out in the world to effectively manage their disease.

Paula K. Dumas (09:47): Yeah. And fear levels are something that are going to fluctuate over time, I think. As more people get vaccinated, there may be a sense of less fear. As states or countries may, you know, deregulate or revise their risk levels, that's going to change over time. So, I don't want everyone thinking that that is a static number. Do you think that fear of getting care means that *no one* is going, or are they just feeling anxious about it?

Lindsay Videnieks (10:19): I have to say, I think it's probably a little bit of both. At one point — and we've talked about this — but one of the nation's largest headache centers was itself repurposed entirely for COVID patients. So, certainly at that time, you're not going to be able to see your provider in person. But I also think that that number we talked about — that 52%, I think it was — that number is just still too high. And so, there has to be some personal anxiety associated with that. And so ... hopefully that changes and I think as the vaccine is rolled out, I hope that people feel more comfortable. But again, we know what happens to migraine patients when they're not able to effectively control their disease. And so, that's sort of a disaster waiting to happen, if they can't get care.

Paula K. Dumas (11:15): Well, you lead me to my next point, which is migraine emergencies. You know, many of us have had a round-trip ticket to the emergency room. Are people getting care for migraine emergencies?

Lindsay Videnieks (11:26): We know that our survey indicated that 74% of respondents said they were hesitant to go the ER. And you think about that: Migraine patients are the fourth-highest users of the ER because, when there's an attack, that may be the only recourse in



many cases. And so, if you have a patient population that is *that* nervous about going to the ER, it's not that the attacks aren't happening — we know that — it's just that they're not getting, perhaps, optimal care and treatment.

Paula K. Dumas (12:05): Right. Right. So in the case of an emergency, where else do you think people are going?

Lindsay Videnieks (12:09): Right. Yeah. I mean, I think that people are self-administering acute treatments, they are going to urgent care centers, they are trying triptan shots or DHE. And so, there are other options that folks are availing themselves.

Paula K. Dumas (12:30): Right. Or maybe just taking the time that they couldn't take pre-pandemic, because they're at home, to recover, to fully recover, and kind of let their brain reset. Maybe they're in the kind of job where people wouldn't notice that they were out for eight hours ...

Lindsay Videnieks (12:46): Very good point.

Paula K. Dumas (12:47): Yeah. So, telehealth has risen during this period. It's going up around the world. How is it being received by people with migraine?

Lindsay Videnieks (12:58): Persons living with migraine disease have been early adopters of telehealth. But our survey found that 22% had used it before the pandemic; that skyrocketed to 78% who were using it during the pandemic. This is a technology, or a way of treatment, that folks felt somewhat comfortable in using. And so, the survey showed that 83% reported that they'd like for that to continue to be available. And hopefully, through reform legislation and other workaround measures, that can continue to be the case.

Paula K. Dumas (13:42): I can think of several reasons why telemedicine is a really attractive option for people with migraine. What do you think? What makes it great?

Lindsay Videnieks (13:49): Yeah. You know, like we talked about earlier, if you wake up in the morning, you don't know if you can even get behind the wheel of a car or can you make it all the way downtown; or, you know, you don't have to go through traffic, sit in a doctor's office where there's these blinking fluorescent lights. There are all of these environmental triggers that are more within the control of the patient in a telemedicine environment. So I think that's very attractive to folks who are ultimately more likely to perhaps keep an appointment, if they can be there in their home.

Paula K. Dumas (14:27): Yeah. And for those who are seeing a specialist, you also have the option of seeing your specialist. I know one thing that kept me from using telehealth prior to that, was that my doctors were not using it. Now *all* of my doctors are using it. So, I get to see the same doctor. And in some cases, like my specialist, is over an hour away. That's a huge advantage for me to be able to — instead of taking an entire day to go up and see him — now I can see him on telehealth, and it's been incredible in that regard. Now, for the 20% to 25% who aren't using telemedicine, why do you think that is?

Lindsay Videnieks (15:05): I think that in terms of accessibility, some folks are never going to be completely comfortable with the technology, but also, you know, this is a patient population that relies on, in many ways, a clinician-patient relationship. And so, some folks



might just be more comfortable talking about their disease and their symptoms face-to-face with their provider. And that's OK. Telemedicine is not a panacea; it's not a one-size-fits-all — just like migraine patients are diverse, their treatment options and modes of treatment should be, too. And so, we think it's probably encouraging that the survey showed a high willingness to use it, but also, obviously, doesn't ever completely replace your clinician in-person.

Paula K. Dumas (16:00): No, it doesn't. And many of the, as you said, procedures cannot be done over telehealth. And some doctors I've spoken with have said they don't want to do telehealth and have it completely replace things, because they like the opportunity to do a neurological exam: to look somebody right in the eye, and check their balance, and some of the things that might give them clues about what's really going on with that person. So, I think that there's always going to be a place for that face-to-face visit, as well.

Lindsay Videnieks (16:35): Yeah. And that's exactly what the survey showed too, which is: 75% of folks said that even if they did do a telemedicine appointment, they wanted to do an in-person visit afterward. So, that makes absolute sense.

Paula K. Dumas (16:49): Yeah. And we should point out that a couple of services have risen up during this time, too, that are migraine specific, where people have been trained in migraine. And that's unusual, and a great new option for people to consider, if they can't get in to see a specialist or someone who has a good understanding of the disease.

Paula K. Dumas (17:08): Let's talk a little bit more about the workplace and how COVID has impacted the way that we're working. It has for me; it has for you. And we both worked together on the steering committee of Migraine At Work, which is a coalition of nonprofits creating healthier, more productive workplaces. How is COVID affecting people with migraine, at work?

Lindsay Videnieks (17:34): You know, it's this theme of accommodation, accommodation, accommodation. So, me sitting here, I have a platform to raise my laptop, I've got a special light, I have a lock on my door so my kids don't barge in. There are ways during the pandemic where your office or your work has intruded, but become, sort of, inside your home. And so, there's that need to accommodate that environment that existed before the pandemic, but certainly right now, where employers have to realize that this is an environment that if you want to retain employees, and you want to develop good employees, you need to be flexible, and accommodating, and provide maybe migraine-management program education in your job — to help make sure that the "she-cession" that we talked about earlier isn't permanent, and that we can make sure that there isn't a talent drain. And so, I think the Migraine At Work program is working hard to identify for employers the ways that that can happen.

Paula K. Dumas (18:47): Yeah. And we know that people who are listening to this have all different kinds of jobs: Some might work in health care that requires face-to-face engagement, some might work in frontline jobs that also require them to be out. So when we talk about how COVID affects people with migraine at work, you know, it's a different reality for those of us who have more desk-type jobs than it is for people who work on their feet and out on location. So, I think this is going to continue to evolve, but you raised some great points about the opportunity for employers to make some pretty simple and inexpensive accommodations to retain their best employees.



Lindsay Videnieks (19:31): I was going to say, it is absolutely not just office-based jobs. Like you said, there are such simple things that employers can do, and the Migraine At Work project is really designed to help them identify what those are, and tailor it for whatever size organization it might be.

Paula K. Dumas (19:49): Yeah. Yeah. Teachers are another huge segment of people with migraine. We know that that is quite prevalent — and vets — there's a lot of prevalence in those segments, and many of those people might be listening right now. So, if somebody is currently employed and struggling to hold down a job because of migraine, what resources can they get to better manage their disease at work?

Lindsay Videnieks (20:13): Sure. So, first I would send you to the website: migraineatwork.org. There are wonderful resources there — infographics, conversation starters. Part of this is reducing stigma with your colleagues and your bosses if you feel a comfort level that you can have that discussion. But it's also, thinking about, "OK, what are the ways that maybe I can help identify and bring the solutions?" I think most everyone is interested in solutions-based things to talk about. So, the website does a good job, I think, of identifying some of those ways.

Paula K. Dumas (20:48): Right. It does. There's a number of incredible resources there, from several different nonprofit organizations, that are all collaborating in this space. It's really, really important. And it's one of the biggest pain points — certainly one for me, it was a huge pain point — in trying to manage migraine. So, I want to talk a little bit more about HMPF and the policy work that you're doing right now. I know that you work in the United States and collaborate with people in other parts of the world. Tell us a little bit more about what HMPF does and how it's benefiting people with migraine.

Lindsay Videnieks (21:25): Thank you. Yes. So the Headache and Migraine Policy Forum — I hope folks can stop over at our website, as well, which is: headachemigraineforum.org. We're also on Twitter, if you're on Twitter: [@headachepolicy](https://twitter.com/headachepolicy). We're also on Facebook. We view ourselves as the identifiers of where there are these barriers to patient access, and finding ways to bring advocates — whether they're patients, or providers, or caregivers — together to effect change. And so, we use a campaign-style approach that is hyper-local. That means we might be asking folks to, say, write a letter, or an op-ed, or talk to their legislator, for example. One of the things that we do [is] include Capitol Hill policy forums and other large-scale events, where we try to educate policymakers about access issues with regard to migraine disease. And so, some of you out there might be participating in those in *your* country. We also provide educational materials to help some of these issues become more easily digestible for policymakers to understand — which is an important part of, "Are you remembering who your audience is?" But we work in partnership with our nearly two dozen coalition members to do those things.

Paula K. Dumas (22:50): Yeah. And people are in other countries around the world and they want to know: How do I get involved in advocacy and in effecting policy? There are generally nonprofits for migraine or headache disorders in many of the countries we reach. Certainly, things like the Migraine Trust in the U.K., or Headache Australia in Australia, Migraine Canada in Canada. And we've met people from all over the world, right, at some of the conferences that are doing some incredible work in advocacy. So Lindsay, if somebody is listening to this for the first time and they thought, "I want to be part of this campaign. I want to do my part to really change the legislation, and get better protection for people



with migraine disease, or get better access to the treatments that I want for migraine disease," are there some simple ways ... that they can plug in to this whole movement?

Lindsay Videnieks (23:46): Yes, and thank you for asking. I think that the first step is to get in the mix which is: Follow us on social media. But feel free to send me a note through our contact form on the website, at headachemigraineforum.org. And, what we do, is try to matchmake opportunities. So, in the United States, for example, there might be an issue coming up in Pennsylvania or Texas, and that's where we would engage our advocates in those states on whatever the access challenge might be. So, the most important thing I would add is: There is a role for everyone to play. As Paula said, as an extrovert, or [as] an introvert, where you may not want to be the person who's testifying in front of a committee, but maybe you have time to write a letter. Advocacy is accessible at any interest level or bandwidth. And so, we work to matchmake those opportunities with folks at whatever level they're comfortable.

Paula K. Dumas (24:48): Yeah. And oftentimes, people who have a different expression of headache or something very rare — I've worked with people who have cluster disease, for example, and been on Capitol Hill with them in legislators offices — and they can have a really profound impact on their perception of this; same thing with hemiplegic migraine or vestibular migraine. As we raise awareness of some of these other subtypes of diseases that are *incredibly* disabling, that really goes a long way. I think stories really begin to move the minds of the people who are in these legislative roles, so that we can get the kind of protection that we need.

Lindsay Videnieks (25:29): You're exactly right. And we talked a lot today about data, which is so important. You have to really have both. So, if you have the information, like what we talked about, and then you have your personal patient story — those things, combined, make the most effective argument. And I think that they're both equally important.

Paula K. Dumas (25:48): So Lindsay, tell us about what has changed in the migraine community from an advocacy standpoint, that makes it a little bit easier for people with migraine to manage their disease today, and during this COVID period.

Lindsay Videnieks (26:02): Yeah. Thanks Paula. I think that if folks who have ever — here in the United States — have ever gotten an insurance-denial letter, or they have felt frustration in terms of how they've achieved access to maybe newer therapies, for example — we know a lot has come online since 2018. You should know that there is an army of advocates who have been engaging on these access challenges for a while, and winning a lot of fights. And so, a great example is: There is an entity that a lot of payers listen to, that had to decide whether or not newer therapies would be included in your formulary. And so, as a community, there was a record number of comments; people really joined together to provide patient-provider perspectives, and that moved the needle, and all of a sudden there's more access to some of these new medicines. And so, I think if folks are feeling like they are wondering if it's worth their time engaging: It *absolutely* is. Because this community is organized, it is mobilized, and we actually make some change.

Paula K. Dumas (27:14): Absolutely true. You know, just this morning, I got a letter from someone who had recently received the vaccine — the COVID vaccine — and was wondering if her case was anecdotal; that she had had a pretty strong reaction to the vaccine and wondered, "Is the COVID vaccine a migraine trigger or a headache trigger?" And I think that



our need for data is so great because we don't know if this is an anecdote, or if this is the beginning of a pattern. But another way I think people can participate in this movement, is every time a survey comes out, if you just take a couple of minutes and respond to that survey, that's the kind of data that we need to make a case, right?

Lindsay Videnieks (28:02): That's so true. And that data will get used with all sorts of different audiences; not just policymakers, but other sorts of decisionmakers: your health insurance commissioner, for example. They all need to have this very up-to-date information, or to make the best decisions to ensure that you get the care that you need. So just taking a few minutes to complete a survey, that information is really working on your behalf.

Paula K. Dumas (28:27): Fantastic. Well, Lindsay, it is always fascinating to talk with you and we so appreciate the work that you are doing to help lead this campaign movement for us and to get better protections for people with migraine. Thanks for joining us on the Migraine World Summit.

Lindsay Videnieks (28:43): Thank you so much, Paula. And to your team and everyone watching, we so appreciate being able to share this data and look forward to hearing from folks.