



MIGRAINE WORLD SUMMIT

# TRANSCRIPT

INTERVIEWS WITH WORLD-LEADING EXPERTS

PROTECTING OUR KIDS: NAVIGATING MIGRAINE AT SCHOOL

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**Introduction (00:05):** The school system is starting to understand and be educated on what migraine is, that it is complex, and that even if a child isn't experiencing an attack, it doesn't mean they don't have migraine. We know you have migraine; you just have migraine. It doesn't go away. It is something we live with on a daily basis, and the better understanding that we can get in a school system, inevitably, the better support we can get.

**Lisa Horwitz (00:36):** Headache is one of the top reasons a child visits the ER, second only to stomachache. Did you know that stomachache is also a known symptom of migraine in children? Chronic headache is thought to be present in around 4% of children. It can significantly affect school attendance, — impacting social skills, academic performance, mental health, and overall well-being. Understanding and managing migraine is incredibly important for children. Small changes today could save them years of suffering later in life. That's why today we welcome in our expert, Amy Graham, the executive director of Migraine at School. Amy, welcome to the Migraine World Summit.

**Amy Graham (01:22):** Hello, I am so honored to be on the agenda this year, so really happy to be here and have this conversation.

**Lisa Horwitz (01:31):** So, this is the first time you've joined us at the Migraine World Summit. Please tell us a little bit about yourself, what you do, and how you've come to be involved in migraine advocacy.

**Amy Graham (01:44):** Sure. So currently, I am serving as the executive director of Migraine at School. Before I took on this position, I was the director of advocacy and the creative director for CHAMP [Coalition for Headache and Migraine Patients]. So, I found my way to CHAMP after I had experienced several years of chronic migraine and sort of opened my eyes to what migraine was, how it was very different than obviously what people think, and sort of switched gears in terms of where I wanted to focus my life in terms of my advocacy work.

**Lisa Horwitz (02:23):** So, tell us more specifically about the program, Migraine at School.

**Amy Graham (02:27):** The Migraine at School initiative originally started out as a way to create materials. There was a stigma committee that was a part of CHAMP and very quickly grew into something bigger. So, what we see ourselves as is a one-stop shop, a place where parents, families, students, educators — they can come and they can get the information or the resources that they need regardless of where they are on their migraine journey.

**Lisa Horwitz (03:00):** So, you say you're a one-stop shop. Does this mean there's a website people can go to learn about this information?

**Amy Graham (03:07):** Yep. Pretty simple, [migraineatschool.org](http://migraineatschool.org).

**Lisa Horwitz (03:10):** So, we know that you have migraine. Do you have any children, and if you do, do they also experience migraine?

**Amy Graham (03:17):** The answer is yes. Yes, and yes. I now realize, now that I know so much more about migraine disease, I can now see all the different ways that migraine showed up for me in my childhood. For my own children, it showed up a little bit stronger and a little bit more obviously as they were kids. My youngest was diagnosed with abdominal migraine when they



were about three, and my oldest started really getting symptoms around that puberty age, and now I would say is high-frequency episodic.

**Lisa Horwitz (04:00):** Is that what pushed you towards more advocacy in schools?

**Amy Graham (04:06):** Of course — my own relationship with my children and wanting to do what I could for them. That being said, working in whatever sort of nonprofit arena I have worked in, I've always really geared my efforts towards children. So, when I worked in hunger relief, I found myself creating programs that would benefit children. So it felt like a no-brainer to me. If we can change the conversation about migraine and what migraine is in a younger generation, we can completely change that conversation in 20 to 30 years. The added benefit is that we are helping children understand the disease earlier, hopefully get diagnosed earlier, treat earlier, which could make a huge difference in that chronification of the disease.

**Lisa Horwitz (05:11):** Yeah. You say that when you were first figuring out your own migraine, that you looked back and realized your childhood — the things that were actually migraine at the time. And I've had that experience, and so many other people I've talked to also, so that's why I'm so excited that you're here to help us figure this out.

**Amy Graham (05:32):** No, I mean, that's exactly right. If we can change how the child living with migraine is more willing to speak up and more willing to be honest and advocate for themselves, we change how they can internalize the disease. And at the same time, we are impacting the other kids around them, where they start to see this as something that is spoken about. It's something that then is more common, or, I should say, is as common as it is already. We know that migraine is an incredibly common disease. We just don't talk about it at the same level as we talk about other ailments.

**Lisa Horwitz (06:20):** So, looking towards the classroom specifically and the school environment, what are some of the largest difficulties children with migraine experience at school?

**Amy Graham (06:32):** One, I think that the environment in general — if you think about a classroom, it's noisy, it's bright. You are sort of told that you need to sit in one spot for a certain amount of time, so lack of access maybe to drink. These are not really conducive situations to treating our migraine properly. I personally — I mean, it would probably throw me in an attack on a daily basis if my structure was set up like that every day. So, as we look at how our school system is set up and then we look at our students that maybe are a little bit more chronic or their triggers stack a little bit more easily, what can we do to accommodate those students so that they're not having as many attacks?

**Lisa Horwitz (07:30):** Are there any specific issues that you've heard from your community that you've built at Migraine at School?

**Amy Graham (07:37):** The school system is starting to understand and be educated on what migraine is, that it is complex, and that even if a child isn't experiencing an attack, it doesn't mean they don't have migraine. We know you have migraine; you just have migraine. It doesn't go away. It is something we live with on a daily basis, and the better understanding that we can get in a school system, inevitably, the better support we can get.

**Lisa Horwitz (08:08):** I love that because I think so many people, even today, who have migraine attacks still don't identify themselves as "a person with migraine." This thing that is there all the



time, whether you are currently experiencing an attack or not. What are the most common symptoms of migraine in children?

**Amy Graham (08:29):** So obviously, you're going to see a lot of the same symptoms that we see in adults. We have that sort of nausea; we have the possible visual auras that we can get — brain fog, anxiety. Then, as we look at sort of our younger generation, we really have to be mindful that head pain doesn't always come with migraine. That migraine can often look like reoccurring stomachaches, reoccurring vomiting, and nausea. When I think of my youngest, they really — it was just the cyclical vomiting, and it didn't make sense to me. It was like it looked like the stomach flu, but then, unlike the stomach flu, within an hour they were fine. So what was that? That doesn't make sense. And you realize, no, that, that's migraine. So if you have a child that is experiencing regular stomachaches or vomiting that doesn't seem connected to anything and is maybe going away a little bit quicker than say, again, your typical stomach bug, they may have migraine.

**Lisa Horwitz (09:37):** Yeah, I know that recently they did release — and I say they, I should probably look up my facts — but I learned it on the Migraine World Summit — that colic can be a symptom of migraine in babies.

**Amy Graham (09:52):** My oldest, [at] 3 months, it was full colic. And now when I saw that study came out I recognized, "Oh, well, that makes sense. That checks out. Of course." Again, I have migraine; their father has migraine, so it was pretty inevitable that both of our kids were going to have migraine.

**Lisa Horwitz (10:14):** What tips can you give to parents who discover that their children have migraine?

**Amy Graham (10:21):** So, one, I would always tell parents, "You need to take this seriously. Learn as much as you can about migraine." If you're already at that place where you really do understand the disease, then it's sort of looking in your life. And to all parents: "What can you do on a daily basis to make a difference in terms of how the migraine journey is going to be traveled?" Migraine is best when it has a routine: going to bed at the same time every night; making sure that you get regular exercise, or just regular movement; make sure that you're hydrated every day; make sure that you're eating enough every day; make sure that you are not spending too much time on a screen. And I know that that is so hard for all of us now. Our lives center around screens, but sometimes our migraine needs a break. I would also say as a family: Looking at what you can do for overall wellness, what are you doing for your mental health? How are you approaching anxiety? Meditating as a family, maybe doing some yoga as a family. These are things that have been proven to make a real difference in terms of our migraine.

**Lisa Horwitz (11:51):** I like the idea that you want to include the entire family, because then it doesn't single out any children who have this. Because maybe only two out of four kids in your family have migraine. But making this something that everyone takes part of as opposed to, "You're different; you're the one who needs something extra," and just make it a part of everyday life for everyone.

**Amy Graham (12:16):** Yes! Yes, I mean, we don't want to add to the stigma that already exists with this disease. So if we can involve the family as a whole in sort of shifting our lifestyle, that will be best for our migraine, it's also best for the child and their mental health. And you may have other kids that maybe it looks like they don't have migraine, but the catch is they may still



have it, so you're not doing anything wrong by having them do things that are also healthy for them.

**Lisa Horwitz (12:57):** If I'm a parent and I know nothing about migraine and I just found out — I have a 10-year-old [and] they got diagnosed. What should I do from there?

**Amy Graham (13:09):** One of the things that we have on the website, and we've tried to make it as easy as we can for parents, is just a step-by-step. Step one: Do this. Step two: Do that. So once you've gotten that diagnosis, you really want to learn as much as you can about migraine. So really educating yourself: What is migraine, how does it show up, and what can I do on a day-to-day basis to help my kid?

**Lisa Horwitz (13:39):** Parents really have to take the lead in care because the nature is, children are children. They don't have the capacity to make decisions for big things like this yet. However, migraine is such a personal disease and so wildly varies between person to person, and lifestyle changes can make a huge difference. So how do you incorporate care management for students? What is appropriate for them to own in their own care journey?

**Amy Graham (14:18):** So, this is going to be age-dependent, obviously. If you have a 3-year-old, you're probably not going to sit them down and talk about what their migraine plan is going to be. But once they're old enough to really sit and have a conversation, and if the migraine is chronic enough that you really are coming up with a health plan, I would say this is something you sit down every year with your kid: "Let's talk about what we can do to help manage the migraine." And they need to be involved, and they need to have ownership in whatever this plan is, because if they're absolutely not going to give up their phone time, then putting it on the plan isn't going to work. "Well what can you do to maybe help? Can you put some sort of sticker that prevents the blue light, or can you get glasses?" You can't force your kid to buy into a plan that you come up with on your own. So it's really giving them the ownership of the treatment of their own disease. And the more ownership that they have, the more likely they are to buy into the changes that they need.

**Lisa Horwitz (15:28):** Looking at the schools, how can schools best handle migraine within their students?

**Amy Graham (15:35):** Yeah, No.1, I would say take it seriously. If you see a child that is coming in repeatedly and complaining about head pain or complaining about stomachaches, don't just assume they don't want to be in gym class. Don't just assume that they hate their math teacher. Look for those patterns and identify whether or not they may or may not have migraine. I would then say allowing those students to have the accommodations that they need so that the disease has less of an impact in their life. Letting them have water and to hydrate themselves, allowing them to maybe put glasses on in the classroom, or if they do sometimes need to just remove themselves and be in a darker space for a moment so that they can give their brain a rest, giving them that opportunity. And then there are bigger and bigger accommodations that you can add to that, that you can ask your school for, but then it's telling the schools: Take it seriously, honor it, and make it as easy as you can for these families to get the accommodations that they need.

**Lisa Horwitz (16:47):** Do you recommend parents contact teachers, or who should they contact in the school? Talk to the teacher, talk to the principal, the nurse ... What is the best route?



**Amy Graham (17:00):** Obviously, we know that migraine is sort of this spectrum and that, depending on where you are in the chronification of it, what you're asking for may look different. We do have a [saying], though: "You think you don't need a 504 plan until it's too late, and you needed a 504 plan." A 504 plan, at least in the United States, is specifically — you're getting official accommodations that your child then can use in the school system. And it is legally your right to ask for these: The school cannot tell you no; legally, you can get a 504 plan.

**Amy Graham (17:35):** But if you're looking for real accommodations, I would say you start with the person who is sort of in charge of those student resources in your school. And school to school, that's going to look different. Some schools have a nurse that's on staff the whole time. Some of the schools do not. Sometimes it's going to be the person who leads the counseling department who's going to be your go-to; that's going to be really your advocate in this journey. If you have a really good relationship with one of the principals, that's a great place to start, top down.

**Lisa Horwitz (18:06):** So that's something ideally that could be set up at the start of the school year or at the beginning of the school year so that the modifications your kid needs can be accomplished.

**Amy Graham (18:18):** Yeah. You'd want to definitely get that going before the school year started, and then I would say that you revisit your plan every year. Is it still working? Again, if you're involving your child in their own healthcare journey: "OK, well, what can we do or what do we need to do to shift our healthcare plan?" 504 plans actually do carry on to college, so it's really smart to get that officially going before you're out of high school. And I do know in Canada and the U.K., they have sort of similar systems. They're called something else, but you just need to have that conversation with the appropriate person at the school. Counselors are such an amazing place to start. They really understand the language and what this is.

**Lisa Horwitz (19:09):** And having something official like a 504 is great because then if you do reach a grade level or have a teacher change and you meet with someone who has that stigma against people with migraine, then you have the protections in place and you're not at the mercy of an individual.

**Amy Graham (19:27):** That's exactly right.

**Lisa Horwitz (19:28):** What are the most common accommodations that you've seen made for children in school?

**Amy Graham (19:33):** That's a really — cause it's so, it's so individual. But what we have done is, again, on our website, we have a list of possible accommodations that we suggest to you.

**Lisa Horwitz (19:43):** I love that because I think parents ...

**Amy Graham (19:45):** It's overwhelming!

**Lisa Horwitz (19:46):** Students may not even realize what you can ask for. So, things like going to a darker space?

**Amy Graham (19:54):** Yes, having that opportunity to go into a room that may be a dark room. Usually it's like the counselor's office, the nurse's office. You may also have a late start time,



depending on what you need as a high school student. Having more time to take tests, maybe not taking Scantron tests: There are all sorts of things that you can ask for. 504 plans can be really big, and in fact they can be — I mean, the next step beyond a 504 plan is what is called an IEP, which is an Individualized Education Plan. That is [for] a much larger, much more severe sort of case of migraine. So, 504 should take you pretty far. And again, don't be shy to ask. And that is a conversation that you have as a family, and you have with your healthcare provider, and then you basically are going to the school to say, "This is what we need, and this is what needs to happen."

**Lisa Horwitz (20:55):** It also seems like having a plan in place would reduce the anxiety for the child: "Knowing that if this happens, I can do this." It takes us away from some of that uncertainty. And anxiety is often a trigger for an attack, so it's just good all around.

**Amy Graham (21:12):** Absolutely. Well, and they're comorbidities. You know, anxiety can lead to a migraine attack. Migraine attacks lead to more anxiety; they're very interwoven. Children who are living with more chronic cases of migraine do experience a much higher rate of depression and anxiety. So anything that we can do to sort of reduce that piece to the puzzle. I think we've nationally been having more conversations about mental health, and this will benefit that, as well. Again, having that freedom to do what you need to do for yourself and not being called out every time you need to excuse yourself to go to the restroom or you need to excuse yourself to go sit in a dark room, it makes your life a little bit easier. And gosh, I mean, especially middle school and high school, anything we can do for kids' lives to be a little bit easier, we need to do that.

**Lisa Horwitz (22:09):** What does an adequate health plan look like, from your doctor to your child? How do you know that you're getting adequate migraine care?

**Amy Graham (22:17):** Trying to navigate this with your pediatrician — there are resources that maybe you can point your pediatrician to that could help them understand migraine better. There is a portion of the CHAMP website called HeadEd, and what that does is basically list all the different ways that healthcare providers can get their CMEs, and it all is headache- and migraine-related. I know that the Association of Migraine Disorders has an amazing program, their Migraine Toolbox. So bring in resources to your healthcare professional because the more they know, the better they can treat your child. Then it's looking at, how is your child responding to the care that they're given? Is their migraine getting better? Is it getting worse? Is it staying the same? Sometimes, staying the same is a good thing. It doesn't necessarily mean that it's bad; it just means that it's not getting worse. Obviously, if you're extremely chronic, you want to see some reduction. We know — we know people in this community, that that's not always the journey. It doesn't always get better the way that we would want it to.

**Lisa Horwitz (23:32):** In [regards] to how a doctor can help the family get accommodations at school, do they often need to be involved directly to get things like a 504 or an IEP? Do you need a note from a doctor?

**Amy Graham (23:45):** We have made it as easy as we possibly can for the family. We have a sample doctor letter. Just print it out. Take it to the healthcare provider that your child sees. I mean, you can just easily sort of fill in [the] name, have them sign it, and now you have what you need to start the conversation at your school.





**Lisa Horwitz (24:09):** How has your work changed schools to make them a better place for students with migraine?

**Amy Graham (24:17):** What we're able to do is — and I think one of the biggest things we're able to do is educate the schools. Helping them understand what migraine is, what it looks like, and helping identify migraine. We've also partnered with the Children's Hospital in Cincinnati. They have a validated screening tool that we send to the school, so they're able to screen children if that's something that they're willing to do as a school. And then the materials that we have that can help educate our families and our students about what migraine is, what it looks like, the other symptoms.

**Amy Graham (25:00):** But it's the better understanding that this is a complex neurological disorder. We say it over and over again in this community. It never fails that somebody says, "I had no idea that that was a symptom, or "I had no idea it was that serious." "I had no idea that many children ..." You know, 28% of our teens have migraine, and you sort of watch people's eyes open. So that's making a difference, too. We're educating not just the kids, but we're educating all of the adults in the school, as well.

**Lisa Horwitz (25:36):** So, what are some resources that you provide for schools?

**Amy Graham (25:40):** So, we have what we sort of call our basic resources. We even put them together as starter kits for schools. So, we don't want them to be confused as to what they should order and how many. We have infographics for our three main audiences: for our students, our parents, and our educators. And information in each of those is very specific to who it is that we're talking to. We have posters that are meant to hang up either in the front office, or the counselor's office, and the nurse's office — sort of your more common migraine symptoms that are not headaches. So maybe a kid or an adult can identify: "Hmm, maybe it isn't just a headache, maybe it's migraine."

**Amy Graham (26:21):** We also have screeners that the schools can use to identify kids who may possibly have migraine. We have a lesson plan that we worked with a team of educators to develop that should fulfill most of the requirements, that — all our kids in middle school and high school now have to take a health class. And that's what this lesson plan is for. It is a day-long lesson that they learn about migraine and headache, and educating the class as a whole as to how common this disease is.

**Amy Graham (27:01):** And we also have a really easy-to-use cheat sheet that would go home to families that kids screened "yes." It's sort of a way that they can more easily advocate for themselves when they go talk to their healthcare provider. So, we put all of that together in a kit, and we then mail it off to schools, and it's totally free of charge. You just have to ask for them, and we will happily send you what you need.

**Lisa Horwitz (27:28):** Wow. So if anyone is listening to this who is a teacher or a parent, they can go to your website and request this to be sent to their school?

**Amy Graham (27:35):** Absolutely. Just, yeah, just reach out. We have a contact form. We also have order forms on the website. If you want to directly communicate, a lot of schools will start with inviting us to present to — maybe at a staff meeting, [I'm] so happy to do that. Just shoot me an email, and I will happily set up a time where I can talk to you or your staff and do a little migraine education, and then talk a little bit about the kits and we can go from there.





**Lisa Horwitz (28:04):** What's next for Migraine at School?

**Amy Graham (28:06):** Oh, I mean, right now, I think it's like, how many more districts can we get into? Obviously, the more schools we have, then the bigger difference we are making. We're also making a real effort this year to grow our ambassador volunteer force. Those are our grassroots sort of organizers who do our training, learn how to be a Migraine at School ambassador, and then they're going into their own communities and advocating for this program. So making a real effort to increase that.

**Lisa Horwitz (28:42):** Amazing. You're doing amazing work. Are there any additional resources you would like to recommend for our audience?

**Amy Graham (28:50):** I would say that there are some amazing organizations out there. I'd like to note that the Migraine at School initiative is supported by the Danielle Byron Henry Migraine Foundation, and they really took this seriously at the very beginning and jumped on board and sort of put their forces behind this. They have a lot of other things on their own website, the [daniellefoundation.org](http://daniellefoundation.org) website. And then, if you were interested in learning about a lot of other organizations that may be out there, the CHAMP website has all these different organizations all over the country that are part of their coalition that you can learn more [about]: the Coalition for Headache and Migraine Patients.

**Lisa Horwitz (29:43):** Is there anything that you would like people to know that we have not already talked about today?

**Amy Graham (29:49):** You know, we talk about the stigma of migraine, and this is something that comes up, I'm sure, in a lot of the conversations during the Summit. If you know somebody who is living with this disease, you have to take them seriously. We have to take migraine seriously, and I'm not trying to get out of dinner when I cancel. I really want to be there, but sometimes I can't. I also know that I'm speaking to our audience here, so if you are living with migraine, just know that there are going to be people who aren't going to believe you. And that's OK because the people who really love you and are really, really there for you, they will.

**Lisa Horwitz (30:32):** Thank you so much for your time and for letting us know more about Migraine at School.

**Amy Graham (30:38):** Thank you so much. I really appreciate it.