MIGRAINE WORLD SUMMIT

INTERVIEWS WITH WORLD-LEADING EXPERTS

TRANSCRIPT

BEST PRACTICES FOR TREATING CHILDREN WITH MIGRAINE

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Introduction (00:05): We want to make sure we have lots of water during the day and we stay hydrated. We want to make sure we don't skip meals and we try and eat a healthy diet. We want to make sure we sleep an adequate number of hours on a regular basis, which sometimes can be challenging when you're a young person. And we want to make sure that we exercise regularly, because the stronger our body is and the healthier we are, the better it is to cope with any illness. So, there's healthy habits. There's adherence to healthy habits, figuring out how you can fit those in your day; there's school notes that help you work with your school so you can get treatment right away and you don't run into roadblocks. If you think about it, a lot of that's about confidence and plans.

Wendy Bohmfalk (00:44): Nothing can make a parent feel more helpless than seeing their child in pain. Why is it so difficult to get the right diagnosis and treatment for our children with migraine? Migraine has been reported in kids as young as 18 months old. Half of those with migraine had their first attack before the age of 12. Childhood migraine can seriously affect the child's quality of life. What do parents absolutely need to know about the unique challenges of migraine in children and teens? Dr. Scott Powers is a pediatric psychologist and an expert on pediatric migraine. We're fortunate to have him here with us today to provide some answers and hope. Dr. Powers, welcome to the Migraine World Summit.

Dr. Powers (01:27): Thanks, Wendy. It's a pleasure to be here.

Wendy Bohmfalk (01:29): We're so glad to have you.

Dr. Powers (01:31): Thank you.

Wendy Bohmfalk (01:32): I'm going to start out with a question from our community. Gwen wrote in and said, "Both my mom and I developed migraine at around age 10, but had unexplained stomach problems prior to that, going on into our teens. Now I have a son of a similar age, and there are a few warning signs that he might develop migraine, too." So how does migraine present in children, and at what age does it start to be observed?

Dr. Powers (01:55): That's a great question. And it can start early in life for some children, particularly if many members of the family know they have migraine. That's, sort of, one of your first indicators to say, "Well, I'm seeing some symptoms in my young child that look like they could be migraine-like," like stomach problems or vertigo or dizziness when driving. And if you have a family history, that might be a good time to start talking to your pediatrician. A lot of times for children that we see in clinic, they started their headaches somewhere around eight or nine, but they may not even get to us until they're 11 or 12. So they've had headaches even during primary school before they hit the teenage years. But it can begin pretty much anytime during childhood.

Wendy Bohmfalk (02:39): OK. Well, good to know. And what are some of the additional signs and symptoms? You mentioned a couple of them.

Dr. Powers (02:44): There are other features to make a full diagnosis. But a throbbing, pounding pain that's pretty intense, at least for some of the headaches, and that limits [their] activity are some of the main things to look for as a parent. In addition, going into a dark room or staying away from noises — so some photophobia, some phonophobia. But for your children that are maybe in the primary school years, it might be more your observation as a parent of what you see them doing in response to their head pain. As we get into adolescence, it's a little bit more

likely to have a dialogue for them to explain what those symptoms feel like to them or what's limiting them.

Wendy Bohmfalk (03:20): How many children and adolescents are affected by migraine?

Dr. Powers (03:24): Migraine is one of the most common chronic illnesses of childhood and is often underrecognized and underappreciated. In young children, pre-puberty, it's about 10% of youth, somewhat equally divided between boys and girls. In the pubertal years into later adolescence, it tends to be more often in females than males. And by the time someone's in the age range where they could be going to college or they're right out of high school, a very good epidemiologic study in Poland showed that it may be one out of four young women have migraines in that age group.

Wendy Bohmfalk (03:58): Wow. Is it difficult to get a diagnosis? And if so, why is that?

Dr. Powers (04:03): It's getting better. I think because of educational efforts by a lot of organizations and grassroots and advocacy organizations, as well, like all the people listening today. Pediatricians are becoming a little bit more aware of migraine and asking more questions. But there still is a very few number of pediatric headache specialists, at least in the United States; and I think that's true around the world. And many neurologists, while they might be familiar with the concept of migraine, we might even have delayed diagnosis in that group. So, I think to make it better is just education of everyone, and having everyone that works in schools, teachers, pediatricians, as well as parents and families, be more aware of its prevalence — so that it's one of the first questions asked if someone who's young is complaining of head pain.

Wendy Bohmfalk (04:51): Well, one thing that makes me think of, too, is a lot of young people present with abdominal problems as well, right? Or stomach problems. I think we're going to get into that during the course of the interview, but that might be something else parents could look for; is that right?

Dr. Powers (05:02): Certainly. And sometimes the abdominal problems can precede episodes later where there's pain involved, as well. So certainly, talking to your pediatrician or family practice doctor; it may be a combination of seeing a gastroenterologist and a neurologist, as well as a headache team over time to really tease out what is happening. And I would go back to, if there's someone else in your family who has migraines — which is probably about 80% to 85% of the time true for young people — that's where you might say, "Well, it could be something that's genetic, runs in our family. Let's go check that out, as well." And you might even do that before you pursue more invasive procedures in the GI world, where they might be doing scopes and other kinds of things to look at abdominal types of problems. You might say, "Well, let's see the neurologist first and see what they say before we go through a bunch of testing that might not be as pleasant for the young person." I would recommend that for sure.

Wendy Bohmfalk (05:57): That's a great suggestion. And why is it so important to get a diagnosis?

Dr. Powers (06:02): Couple of things. If you're a person who's having pain, understanding what that pain is caused by is certainly a relief. So, if you get nervous about something, or you feel like maybe someone didn't believe you or think something was serious, it can kind of weigh on your mind and affect you as a young person. So having someone really listen to you, really have an interview with you as the person whose head is hurting, and then give you information about

how common this problem is, how we can get it better if we work together in smart ways, can be so reassuring for a young person. And it gives them a name: "Oh, I have migraine." So you can really think about what the difference is in terms of understanding your pain condition and getting a plan to get better, versus being in the unknown.

Wendy Bohmfalk (06:49): Parents have told us that their child's migraine disease worsened after a concussion or a traumatic brain injury. Can you talk about that as a risk factor, as well?

Dr. Powers (06:58): Sure. And you can certainly understand the reason for that, right? Even some really serious viral illnesses of someone who's predisposed to have migraine might be something that gets the body reacting genetically and genomically to show those risk factors in their genetics. So even a really serious illness that gets you down and has bad headaches might be a precursor to your migraines starting. But concussions in particular will cause some headache themselves. And usually, young people recover from that within a few weeks, but sometimes it lingers. Many times, if you've had migraines before, concussions can be a little bit more likely to have post-concussive headaches that linger long term. But in some ways, it's probably the migraine phenomenon just continuing to happen, but your body had an insult that might have perturbed the way the brain is processing information for a while.

Wendy Bohmfalk (07:50): And when, in the more severe cases — regardless of the start of it, I guess — when should you consider an ER visit or push for an MRI?

Dr. Powers (07:58): Those are great questions. I think it's really important. And one of the real values in our health care system, even though it has a lot of things that need to be better, is the relationship the family has with their primary care doctor. So really relying on talking to your pediatrician or family doctor about: These are the symptoms we're seeing, what's our game plan? How would you go about treating someone who's 14 with a migraine that hasn't gone away for a day? That's really tried some over-the-counter medicines, maybe some prescription acute medicines. So going to the ER with a plan with your pediatrician, I think is the best way to think about that.

Dr. Powers (08:34): Imaging's an interesting issue in migraine because there's, sort of, two ways to think about that. The doctor might do a full neurological exam and really do a careful history. And generally speaking, most of the times with migraine, that's going to satisfy them that there's not a major concern structurally that they're looking for. So we do not do an awful lot of imaging in our headache center because I think we do such thorough investigation. And we do so much of this. However, under the age of 6 or 7, where maybe the history from the young person isn't quite as clear because you're just younger and it's hard to describe your feelings, we will oftentimes think about an MRI then. We'll also think about it if there's no family history. Because if 85% is family history and it's not, are you looking for other potential concerns? The second part, though, is more about reassurance and what do we need to know as a patient and a family to not worry about things that might be scary to us. So, we don't necessarily do imaging just for that reason, but it is a conversation to have with your provider.

Wendy Bohmfalk (09:38): Great. That makes sense. And back to the ER visit, or potential ER visit: I think that advice makes sense for adults, as well — you know, you should have a plan. Think ahead. If you get to such a point of severity, what you're going to do, have talked about it with your neurologist in advance. So, I think that's great advice for all of us actually, and also ...

Dr. Powers (09:55): And you might even have a plan that you and your neurologist developed. So, you take a paper in that the doctor signed that says: This is generally what we've tried before we came; this is what we'd recommend when we get there. Because certainly the use of powerful pain medications like opioids is not necessarily the evidence-based treatment if you go into an ED to get treated, particularly in young people. But I think that's also true of the literature that's evolving in adulthood.

Wendy Bohmfalk (10:19): Well, I think, too — just as a parent myself of two children who've exhibited migraine — that gives me a lot of comfort to know that I could have a plan if we got to that point where things were so scary you need to go to the ER, that you do have that plan. I think that would give you some control over the situation.

Dr. Powers (10:34): And that's another example of where we need to do more research. I don't know that we really have the best evidence of exactly what you do if your migraine didn't respond to your over-the-counter and your other prescription medicine. So, there is some evolving literature that's showing some agents that can be done through IVs are effective. And I think we just need to continue to learn more as we do that.

Wendy Bohmfalk (10:56): Well, let's kind of talk a little bit about the most common types of migraine in children. And certainly, we've touched on this, but if you could just walk us through the most common types that you see.

Dr. Powers (11:07): Sure. It kind of goes back to that diagnostic question. If you look at the epidemiologic studies that have been done, human beings, by the time they're 15 or 16, probably eight out of 10 have had a headache. That's also a reason why there might be some stigma and people don't believe you as quickly. Because if everyone's experienced something and you say you're having a headache, they might say, "Well, it's just a headache. I've had that." And that's not what a migraine is. And it's not what some of the other headache disorders are. They're quite painful. Migraine is the most common headache disorder in young people, but there are also other rarer primary headache disorders that neurologists and headache specialists can better understand and explain to you. But generally speaking, if it's throbbing, pounding, hurts pretty good, keeps you from activities — there's a really good chance that the diagnosis is going to be migraine.

Dr. Powers (11:56): You can also have auras: Visual auras are relatively common in young people. They can happen before they had pain or coincident with it. And it may not happen for every headache.

Dr. Powers (12:06): And then based on frequency of headache, the doctor might refer to you as having more episodic headache versus chronic headache. Those are probably more useful to the way physicians think about diagnosing than they are to you as a person. If you're having headaches, if they're interrupting your life, they're too frequent. But it is true that you can start out with maybe a headache a week and they're migraine-like; and over time, without good treatment, you might get to the point where they transform into more frequent — even up to more than 15 days per month, which is just a miserable experience for anyone, but one we can get better. So even if it's high frequency, don't feel like, as a family or as a young person, that we can't help you get better. We've done studies that show we get a lot of kids better — the preponderance of kids, upwards of 90%, [get] better with chronic migraine, with combined medication and behavioral treatment.

Wendy Bohmfalk (13:00): And how common is depression and anxiety in children and adolescents with migraine?

Dr. Powers (13:04): There's no one who has pain that recurs, that's unpredictable, who's going to be in a great mood about it. But the way I think about it is, all young people with migraine need a coping skills toolkit. And if we start early and give you the coping skills and we have success, we're probably going to be less likely to have those other things develop related to your pain disorder. Doesn't mean you might not have depression later in life if you have a family history or if you have life events, but at least the pain disorder that gets under control, that you understand, cannot be something that's a risk factor for that.

Wendy Bohmfalk (13:40): Speaking of coping and having coping strategies, one of our community members wrote in and asked: "How can parents help children cope with feelings of loss and isolation — loss of friends, loss of activities and events — when they're dealing with migraine disease?

Dr. Powers (13:54): We do play a role as a coach in a young person's life, so: thinking of ways to keep them active; be involved in things; seeking out those good professionals who can give you a clear diagnosis, a clear treatment plan, so you can start to get better. And then as you get better, really reinforcing the efforts by the young person to go try things. Because if you have intermittent pain, even if you're starting to get better, you might be worried about the football game Friday night. And just sympathy alone and empathy isn't going to necessarily help if I'm Dad talking to you on a Wednesday, knowing that you're worried about getting a headache on Friday.

Dr. Powers (14:28): But if we had a discussion about: "What are we going to do? What's our game plan tonight, tomorrow night, and ready for this weekend? Because we're going to have a great weekend. We're going to get enough sleep. We're going hydrate. We're going do some of our exercise. We're going to get a good, healthy habit when it comes to eating regularly. We're going to do all the things the doctors have told us that we can be in charge of to be better."

Dr. Powers (14:49): And then on top of that, I would likely have taught that young person some relaxation skills as part of their biobehavioral skills. And we'd say, "We're going to really use those these next three days" so that we're going into Friday with a real healthy set of circumstances and maybe prevent that migraine from happening. It's not a 100% guarantee, but it's a much more proactive: Attack it, go after it, want to get better with confidence; than it is: Worry, wait, and see. And really, coping's a lot about what can you be in charge of that you can do actively? And if we've done it well, more often than not, it pays off and you get a good outcome. So then you're like, "That was a smart idea. It worked."

Wendy Bohmfalk (15:30): And then it reinforces that behavior. I love that. Again, I think it's strategies that are helpful for adults as well, to kind of like pre-plan, how you're going to stay as healthy as possible to get you to that event. And having some strategies of — and actually we're going kind of move to that next, in fact. I won't steal your thunder. And let's talk about treatment ...

Dr. Powers (15:46): Let me just say one thing about that, too.

Wendy Bohmfalk (15:48): Yeah, of course.

Dr. Powers (15:48): That question was very important. Let's say you do all that and it still didn't work. So how do you react to that? Certainly, you have to ... appreciate: Yeah, that's a loss. That was a bummer. It wasn't fair. And it's OK to have that time to say, "That wasn't fair. That just really was a bummer. All right, let's take a deep breath. Let's do something fun together. Let's do something we enjoy that might be quiet and calming versus active." But something together to keep that relationship going. Even if it's for the moment in a not-very-fun set of emotions. And then when you wake up the next day, you go, "OK, new day." Model that behavior: "New day, new opportunity. It's still Saturday, still the weekend. What would you like to do today?" So, I think you have to realize that there's ... the empathy part's important, too. But the coaching part really becomes the thing that you have to sometimes work on if you're the caregiver, because you've got to summon your energy to do that when you're watching and feeling negative, too. But sometimes you're the lead to get that rolling, to motivate that in young people.

Wendy Bohmfalk (16:56): Right. Just seems that that will build resilience in your child over time, too. So, it's not a total loss, as you said. Well, let's kind of segue into treatments. And how do children and adolescents get better? You've conducted, as we mentioned, extensive research into cognitive behavioral therapy [CBT] for pain reduction. Please tell us about it. What are the high-level findings, and why is it so important?

Dr. Powers (17:19): When you think about coping with a painful condition like migraine, almost everything has a behavior attached to it. So, before I get to cognitive behavioral therapy, let's talk about how we think about biobehavioral conceptualizations of treatment. So, if it's acute treatment — let's say it's ibuprofen — you still have to take it. You have to recognize your head aches, you have to get it right away. So, we do a lot of working with kids about different situations they're in to have a game plan of like: "When I'm at school, what do I do? How do I prepare if I go to a friend's house? What if I'm at Dad's house?" What is the plan to catch that pain early, do something about it, and see if you get better? So, while there is a medicine that might be the agent that relieves the pain, the behaviors and the confidence in your behaviors and the ability to do them in different situations, are all things we problem-solve around. The healthy habits we talked about: Might not be able to do 'em all perfect at the same time, but we want to make sure we have lots of water during the day and we stay hydrated. We want to make sure we don't skip meals and we try and eat a healthy diet. We want to make sure we sleep an adequate number of hours on a regular basis, which sometimes can be challenging when you're a young person. And we want to make sure that we exercise regularly, because the stronger our body is and the healthier we are, the better it is to cope with any illness. So, there's healthy habits. There's adherence to healthy habits, figuring out how you can fit those in your day; there's school notes that help you work with your school so you can get treatment right away and you don't run into roadblocks. If you think about it, a lot of that's about confidence and plans: "I've got something I can do and I'm confident I can do it."

Dr. Powers (18:53): And if you have those two things going for you, in all likelihood, your headaches are going to get better across a number of different treatments we provide. And you have to be seeing people that truly care and believe you. Cognitive behavioral therapy is really like working with a coach. So, it may not seem like, especially to you adults, like, "Oh, that's not therapy." No, it's not a bunch of talk therapy and what you see on TV. It's coaching. So, we come in and we talk about how pain works in the body and how our brain relates to our nerves, and that you actually have some control over pain. So, your brain actually has the ability to turn on and turn off pain signals to some level. And if you start to think that you have some control over

how your body responds, then you can learn some relaxation skills that help your body calm down in your nervous system.

Dr. Powers (19:41): You can use biofeedback, which is a computer that kind of shows you ... we take the temperature of your finger with this little piece of tape around your finger. When your body's really relaxed, the blood flow through your fingers goes up and your peripheral temperature goes up. When your body's relaxed, the muscles on your forehead relax. If you learn relaxation as a young person, you can start to see that relaxation response on the computer. And you're dealing with a pain disorder that maybe you don't feel like you have much say over, because it's gotten pretty bad, and it hurts a lot. All of a sudden, you're working with me and I'm like: "We got this. We're going to control our body. You're getting really good at that." And the relaxation response is counteracting to the pain response.

Dr. Powers (20:22): In addition to that, we talk a little bit about activity pacing, especially in adolescence. You have a really good day, so maybe you do overdo it and maybe you don't do all your healthy habits. You stayed up too late and the next day or the day after you're like: "Oh, I shouldn't have done that." Doesn't mean I don't want you to have fun, but I want you to know your body well enough so that you can titrate that. And then as we get you better and better, your stamina goes up and you don't have to be thoughtful about activity pacing as much. And then there's a cognitive component to cognitive behavioral therapy. And that's the fact that our thoughts and our feelings are related. It is probably the most evidence-based treatment for migraine right now in young people;it's a combination of a pill therapy and cognitive behavioral therapy.

Wendy Bohmfalk (21:04): Nicole specifically wants to know how we can get kids to accept their condition and really tune in to early warning signs so they can treat effectively. And I think this might be particularly the case with teens who want to just rush fast.

Dr. Powers (21:16): So, we oftentimes sit down and have more of a discussion about: Where's your life at? What are you doing? What could you fit in? What can you not fit in? Homework's taking all hours of the night; might be hard to get those 10 hours of sleep. OK, can we hydrate while you're doing homework? So, it really is a collaborative discussion with the young person about their life and what they can fit in versus a perfection approach. And then some prioritization. So, the question that was asked about catching your pain early — I really do talk to young people in adolescence about: Why is it so vitally important, as soon as your headache starts, to do something? We talk about how pain can get revved up in the body. We talk about their own life experience. And I'll sit there and say, "So can you tell me about when you've waited? How does that go?"

Dr. Powers (22:01): But as opposed to being frustrated as a caregiver, I think the key is to say, "We're learning." They're learning skills you want with them to adapt later. You want them to feel confident in the ones they use. So, if all we do is dwell on the ones they're not doing versus the ones they are doing, then that doesn't make for a great interaction either. So, praise the things that are going well, congratulate them on trying versus being perfect. And keep it up. You can keep it up without being totally naggy, but adolescents are kind of used to us adults being a little naggy. And if we weren't, they'd go, "What's wrong with you, Mom? Don't you care about me anymore?"

Wendy Bohmfalk (22:40): What are other treatment options that parents do have for their kids? And how are they different from adults?

Dr. Powers (22:46): So, the good news is we're getting more and more knowledge about young people and what treatments can be effective. Still not enough. And it is very much true that responding to different treatments in young people is not the same as adults. So, we did a study of the two most commonly used prevention medicines in pediatrics by headache specialists: One's called amitriptyline, the other's called topiramate. We did this across the entire United States with 35 centers. It was a major study. We stopped that study early because neither medicine worked better than the placebo pill. But about six to seven out of 10 kids got better. So, it wasn't like, "Oh, nothing works." It's like, "No, kids get better." We don't know why exactly. So, if you're a physician today — if you go see a headache specialist, they may be very well likely to still give you a pill-based prevention medicine. But they'll do it in a lower dose and they'll monitor side effects to make sure it's nothing negative happening.

Dr. Powers (23:44): We just published a three-year follow-up to that study. And no matter what you took — the two drugs or the placebo — three years later, the people that got better in six months were still doing better. So, the great news is, once you get better, I think we can keep you better. And we know that pill-based therapy — even nutraceuticals, like riboflavin, have been shown in some studies that aren't tightly controlled scientifically, but reasonable studies — have low side effects and can have some benefit. But if you take the evidence today, I would certainly make sure you get a good diagnosis. You get a good acute treatment plan, because there's pretty good evidence for over-the-counter pain relievers, and medicines that are in a class called triptans. Some of them are approved in young people and have been shown to be effective.

Dr. Powers (24:28): Healthy habits. I would certainly learn some cognitive behavioral therapy skills — even if you don't go see the coach, I would build those coping skills into your plan. And then I'd work with your provider who can write prescriptions about what would be a pill-based therapy that would be reasonable to try, and over what time. Some of the newer therapies that are more injectables and molecular-based, like antibody therapy, are being tested now in studies with young people. So, we should, within the next three or four years, have some answers to if they're better than a placebo injection, because many of them are injectables. We'll have to see. And that's why we do research — to constantly learn what is better and what works.

Wendy Bohmfalk (25:08): What advice do you have for parents who encounter resistance at school that could come from administration or teachers or maybe other kids? How does stigma come into play, and how can parents really advocate for their child?

Dr. Powers (25:21): Couple things that we do in our headache center: First time we meet you and your family, we make sure there's a school note that we give you that we've signed. And there's not a young person that's ever left clinic that I haven't said to them directly, "Sarah, tell me about your teachers. Tell me what you're worried about, about school." So first off, we put it right on the line and we talk about it candidly. The other thing I tell them is, "If you and Mom and Dad, or your family talk to the people at school, you take the letter. And I want you to be present." So, I tell every parent, "I want the young person present when you talk to the vice principal. Because it's their head." And that vice principal needs to see Sarah in front of them saying, "She's telling me she needs help." But we have to have the young person with us working on them so that they feel enabled, and they feel confident. And they feel like they can have an appropriate coping skill for that. So, we do very much actively encourage young people to get to school because that's their job. But have a plan to get treatment when they're there;

have a plan if they can't make it, and work with their families. So, it kind of goes back to that active coping mentality, while still believing that, "Yeah, this is hard."

Wendy Bohmfalk (26:31): I know I have a great resource, too, called Migraine at School. For those that are watching, you may want to check that out. It's a great program and there's a website. So that's a resource to offer. What message do you have for parents of children with migraine, and maybe for those who felt like that they've tried everything? What message do you have for them today?

Dr. Powers (26:48): I think my main message is you always have to have hope, because there are people out there that can help. And the earlier we start and the more education we have ... So, if migraine runs in your family, you get to the doctor earlier. You get that young person in with the people that know the literature and know the research and do the best care they can. The really good news is, our evidence base, as it's evolving says: Once we get you better and you're younger, you have a high probability of staying better. So, if we all row in the right direction and we do it together, then my main message is there's a tremendous amount of hope for young people. We know how to help you get better. Once you get better, you stay better. And your adult life with migraine, I believe, is going to be very different than if you didn't get those excellent treatments when you're younger.

Wendy Bohmfalk (27:37): That's a great message of hope and a great way to end this conversation. I have a feeling a lot of people that are listening to us today are going to want to learn more about you and follow your work. And where can they do that?

Dr. Powers (27:48): They can go to Cincinnati Children's Hospital's website and just put in my name, Scott Powers, and it'll come right up on our webpage. To learn more about me, we also have a headache center webpage at cincinnatichildrens.org website, and they'll actually see some resources there, and even some of the things we've developed through research.

Wendy Bohmfalk (28:07): Well, thank you so much. I believe that you have given parents just so much great information and actually things that they can do right away, strategies to employ. So, thank you. It's been super helpful and thank you so much for joining us today with the Migraine World Summit.

Dr. Powers (28:21): Been my pleasure. Thank you very much and best of luck to everyone out there on everyone feeling better.

Wendy Bohmfalk (28:26): Thank you. Appreciate that.