



MIGRAINE WORLD SUMMIT

INTERVIEWS WITH WORLD-LEADING EXPERTS

# TRANSCRIPT



**HOW TO AVOID OR PREPARE FOR THE ER**

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**Introduction (00:05):** And I think having that protocol written up really kind of helps direct that medical professional that you're seeing in a direction that you need the care to go into. Sometimes they need a helping hand. And so, it helps that physician in that moment with you, and hopefully educates them at the same time and realizes well, there needs to be more options given to patients that come in with migraine, especially if they have a long history with it. And they obviously have a slew of medications at home to treat the different stages of their attack, and when that fails, they need something like this.

**Elizabeth DeStefano (00:47):** Jaime Sanders epitomizes the term migraine warrior. She's lived with migraine since childhood and manages multiple additional chronic conditions. She's channeled her pain and experiences into powerful advocacy, such that countless others have been able to feel seen, heard, and inspired by her. Jaime's here today to speak with us about how to avoid or best prepare for the emergency room for migraine treatment. Jaime, welcome back to the Migraine World Summit.

**Jaime Sanders (01:20):** Thank you so much. It's a pleasure to be here.

**Elizabeth DeStefano (01:25):** So, there are several different things to cover here. What necessitates ER care for migraine, what that is like, and then how to avoid or limit the need for it? So let's start with when to go. Years ago when discussing this very thing on the Migraine World Summit, Dr. Richard Lipton mentioned the "first or worst" syndrome as one of the reasons someone may go to the ER, referring to the very first instance of a headache or an excruciating level of pain. How have you determined when to seek emergent medical attention for migraine care?

**Jaime Sanders (02:00):** Now, what it is for me, it is a part of my toolkit. When my first-, second-, or third-line treatments fail, that's when I know I need to approach trying to abort that migraine with more intense treatment. And that's when I seek acute care in the ER.

**Elizabeth DeStefano (02:21):** We also hear a lot of people living with migraine talk about what Dr. Lipton has also referred to as the "last-straw" syndrome — you know, when pain, it just is ongoing and unremitting over a long period of time. And even if it may not be the top level of pain, it's just something that can't be broken over a period of time.

**Jaime Sanders (02:43):** Exactly. And as someone that lives with daily migraine, sometimes it's hard to tell when is the right time to go to the ER. But again, I have to look at the history of my migraine, how it shows up for me, and what my body is trying to tell me. And going to the ER is not an easy decision to make because it's not the most conducive space for people with migraine. But again, when my resources at home fail to abort my migraine, or decrease my symptoms, or I'm not able to stay comfortable, then I know I do have to take that step.

**Elizabeth DeStefano (03:22):** Can you elaborate a little bit on exactly why it is that the ER setting is not exactly where you'd like to be in the midst of a migraine attack?

**Jaime Sanders (03:31):** Sure. So, the ER is a very loud and bright place, and it is not where you want to be, especially if you have to wait for several hours before being seen. There are so many triggers happening at one time. The seating is not comfortable. The lighting is extremely bright, and also there just isn't a need for expediency when you check in with migraine at the emergency room. You're not seen as a priority. And having to ask for things to help you get through the time it takes to be seen — asking for ice packs, or asking to be placed somewhere



where the room can be darkened — sometimes that's not met with a lot of compassion and empathy. So, it's not only the environmental setting, but the lack of empathy and consideration for people coming in with migraine attacks.

**Elizabeth DeStefano (04:32):** That's interesting because even in a neurology office, I think sometimes about people who are coming in with other conditions, and it's very easy to see how, myself as a migraine patient, can be deprioritized. And how I may even do that in looking around and thinking how serious other conditions are. But to see that that applies, too, in the emergency setting, I guess, should be no surprise.

**Jaime Sanders (04:57):** Yes, exactly. I mean, unfortunately, we deal with a lot of gaslighting about the severity and intensity of migraine disease. And oftentimes we kind of gaslight ourselves about it not being as bad because that's the experience that, you know, we receive, that we go through seeing how other people acknowledge or invalidate our experience. And so it makes it difficult to want to go up and ask for the things that you need. It is just as serious, and we need to be able to receive that same level of validation that other people that turn up into the ER do.

**Elizabeth DeStefano (05:38):** That's an excellent reminder. Thank you. So, how do physical symptoms of migraine beyond the head pain itself play a role in migraine treatment and what can become the need for emergent medical aid? For instance, we know that nausea and vomiting can play a big role in attacks for many people with migraine, and certainly, that can have impacts on absorption of medications, not to mention dehydration.

**Jaime Sanders (06:07):** Yeah, so for me nausea is a big, big symptom and I deal with tremendous gastric distress. So, not just vomiting, but also diarrhea on top of that. And it's very dehydrating going through that, and not being able to keep anything down. So, having the right modality of treatment at home is so important. Having different varieties of maybe the same medication, if possible. Having an intranasal spray, or being able to have intramuscular injections that you could administer yourself at home, is really important because you need a fast delivery that can bypass the gut. Because it's just not going to get absorbed if you're constantly vomiting or you have diarrhea all day. It's just not going to have any positive effects in treating your pain or your symptoms.

**Jaime Sanders (07:04):** And I think sometimes that creates a barrier for some patients because you're not always able to access different types of ways to give yourself these acute medications. Having a variety of different modalities, including neuromodulation devices — if I could stack my treatments at home and attack my migraine attack in different ways, I find myself achieving a greater sense of relief and longer sustainable relief.

**Elizabeth DeStefano (07:37):** Well, this is such a great point, because you kind of bring us to the idea of what can we be doing at home to, number one, try to avoid the ER visit? But also, really as a result, have the best chance at effectively treating our migraine ourselves? And it sounds like you've brought up the fact that we need multiple lines of attack, you know, first-line, second-line options, at least.

**Jaime Sanders (08:04):** Just stacking those treatments that I normally would get in the emergency room. I can do that at home. And that helps also with me having to not put myself in a situation where I have to deal with the anxiety of being treated in the ER. And that is a big part I think, of why people avoid going to the ER when you have a severe migraine and you've had



prior bad experiences of being dismissed, invalidated, or being inadequately treated. And giving stuff that you can have given yourself at home. So, to avoid that PTSD and that anxiety, having the option of having those treatments readily available to me at home whenever I need it, is really, really great. And it also serves a dual purpose because when I travel, I have those options, also. So I don't have to go and seek out emergency care in a city that I'm not familiar with, in a hospital that I'm not familiar with. I can do those things comfortably in my hotel room.

**Elizabeth DeStefano (09:15):** Wonderful. And we're actually going to come back a little bit to this idea of preparation because what you've outlined here already shows that the more we can do when we're feeling a little bit better, to kind of come up with a plan of attack, it really can help in so many ways, clearly. And so speaking about, as you mentioned, the PTSD that you have experienced: A lot of people really kind of talk about the fact that there is such an emotional impact, of course, to migraine, period, and to seeking care in an emergency setting, and all of the circumstances that you have talked about. You have been very open about the impacts of migraine and other chronic conditions on mental health, including previously here on the Migraine World Summit. So, how do you see ER care for migraine intersecting with emotional impacts of migraine?

**Jaime Sanders (10:10):** Oh wow. That's a really great in-depth question. There are so many intersections when seeking emergency care for migraine. There's the intersection of gender. Many women's pain is just dismissed, and not treated the same as, say, a man coming in with the same symptoms. He might be offered a stronger medication where a woman might just be given something like an anti-inflammatory. There's the intersection of race also. As a Black woman, my pain is just completely ignored as if it doesn't exist at all. So, having that intersection of gender and race with a disease that is not seen as a disease, and that's [not] seen as something that is actually a whole-body disease [that] affects more than just my brain, is very frustrating. And then there's also the intersection of that patient-physician communication.

**Jaime Sanders (11:26):** And that's lacking because you're seeing someone that you're new to, they're new to you. And if you come in educated about your disease, or you come in prepared, it's not always well-received, at least in my experience. So, because I know that these things exist, these intersections exist, I try to come prepared with a protocol from my physician that gives a brief synopsis of my history with migraine: treatments that I have tried and which have failed me in the past, what my current treatment protocol is, and what I do at home when I have a migraine attack. And when those lines of treatment fail, I have to come in and receive certain treatment to break my cycle. And sometimes that list of medications is intimidating and overwhelming for some physicians, and so they'll cherry-pick what they want to give me. And so I'll receive inadequate treatment because they're not comfortable with it. But essentially, it's a written prescription from my headache specialist saying, "These are the things that my patient needs in this time of need, in her treatment for her attacks." There are so many levels, and I think that's why so many people avoid putting themselves in a position to be subjected to being made to feel less than or have to prove their pain, in order to receive a treatment that may not be sufficient in the end.

**Elizabeth DeStefano (12:58):** I'm sure it's very validating for a lot of people to hear you really lay out just how complex this is when we're talking about even just the emotional impacts outside of what might be the driver to seek emergent care in the first place — the physical. So, thank you for encapsulating what could be a very in-depth talk all of its own about some of those impacts. So, you talked about these different intersections and the perceptions implied in them on the part of the medical provider, potentially. One thing that we hear about, unfortunately



not uncommonly, is for those with migraine to be treated as drug-seeking in the ER. You wrote about the impacts of that in an article for Migraine Again. What can you share about insights specifically into that particular issue?

**Jaime Sanders (13:55):** Absolutely. Unfortunately, there has been a history of people that would come into the ER claiming they have migraine who were seeking drugs. So that, I think, on top of this ingrained stigma that is behind migraine — about it not being a very serious illness, and that it is a women's issue, and that it really doesn't take much to treat, I think plays a part in why when someone shows up in the ER for care, and an anti-inflammatory or a triptan might not be what they need at that point. And might need something a little bit more strong, or might need a combination of several medications to help stop that attack.

**Elizabeth DeStefano (14:52):** So for instance, someone who may need stronger medications, or perhaps even the combination that you mentioned that we often hear referred to as “the migraine cocktail”?

**Jaime Sanders (15:03):** Exactly, it's going to take more than one line of treatment when someone receives care in the emergency room. It's going to take several different things to help combat that attack. Because at that point there are so many things going on in the body. You have to address the nausea, you have to address the inflammation, you have to address the head pain, you may need to address vertigo. And if somebody's coming in and, say, their blood pressure is really high, or they're having really bad anxiety. There really needs to be a full intake of that person, their history, and what they're experiencing. And then a really good treatment plan should then be prescribed instead of, “Well, let's just attack the head pain.” That's not the only issue. And I think having that protocol written up really kind of helps direct that medical professional that you're seeing in a direction that you need the care to go into.

**Jaime Sanders (16:10):** Sometimes they need a helping hand. And so it helps that physician, in that moment with you, and hopefully educates them at the same time. And realizes, well, there need to be more options given to patients that come in with migraines, especially if they have a long history with it. And they obviously have a slew of medications at home to treat the different stages of their attack, and when that fails, they need something like this. And, unfortunately, I think it has, you know, been put on the patient to provide that education in those moments. But I'm always hopeful that when I do come in with that protocol, and I'm allowed to talk about my advocacy — and what we're doing in this space without being shut down, and actually being actively listened to — that the next person that comes in gets a different level of compassionate and empathic care.

**Elizabeth DeStefano (17:09):** And what an incredible thing as those of us who live with migraine know, to be in the midst of an attack, an attack so severe that you're driven to the ER, that you're also functioning as an advocate for other people. So on behalf of all of us, I'd like to thank you for even wearing that hat at that time, which is a pretty tall order. Do you get this sense that the risks of drug-seeking treatment, for instance, have improved, worsened, or stayed the same in recent years?

**Jaime Sanders (17:41):** I can only speak to my own experience, and I haven't really been treated so much as a drug seeker since having the protocol. But I think the way I'm received is different now. It's not necessarily entirely positive, but I think sometimes it's not that well-received, as someone that's very educated about my disease. And I get pain-shamed a lot, because when they see my history, and I'm still dealing with the same issues, then it opens the door up to be



questioned about whether I'm doing enough to not be in pain. Which — I think I would prefer being treated as a drug seeker — than as someone who is willingly living in disabling pain without doing whatever it takes to not be in this level of disability. And I think that makes me feel disrespected, and invalidated, and not seen as a human being going through something.

**Jaime Sanders (18:57):** And I think that's been the hardest part for me, is having to constantly explain why I'm at that point. And forced to list everything that I've done over the years. And what I can't do due to things like insurance barriers or the inability to access certain things because they're in different locations. And that we do have a limited amount of options to treat our disease. It's only within the last couple of years where we have migraine-targeted medications. So, being forced to go down a laundry list of things I've done, and validate my own experience in order to receive care, is exhausting. It's mentally abusive, in my opinion, and causes a lot of medical PTSD.

**Jaime Sanders (19:51):** So, I don't think there really has been a middle ground for me as of yet. There have been maybe three or four times where I've gone to receive emergency acute care where I didn't have to go through that. But it is far less than the amount of times I was forced to explain why I'm there and literally been asked, "Well, what are you doing? Are you doing enough?" And asking very, very insensitive questions. And I don't set myself up for that. And I think there needs to be better bedside manners when it comes to certain medical professionals. And I think the fact that it's migraine that I'm coming in with creates this implicit bias alone based on the condition of how they're going to respond to me before even speaking to me.

**Elizabeth DeStefano (20:51):** That's hard to hear, that this is something that it has to be yet another aspect of living with something that we don't have all the answers to yet. And as Dr. Dawn Buse — really, sort of famously, in our community — introduced the idea that we do not fail medications — medications fail us. Well, so too, we can't be at a point of successfully getting past a condition like migraine until our research and science helps get us to that point. Right? But to be facing all of that in an ER setting, wrapped up in seeking help and treatment, is too much.

**Jaime Sanders (21:28):** Definitely.

**Elizabeth DeStefano (21:30):** You've mentioned the protocol that you talk about bringing to really help try to guide your treatment and to get around the fact, I'm sure, or address the fact that a lot of the providers you may be meeting with have had very little education in migraine medicine, headache medicine. And may have a little familiarity with effectively treating and what current options exist beyond opioids, or certainly in addition to. And also the fact that you're dealing with providers who don't know you and what has or has not worked for you in the past. So, intrigued by this protocol that you also discussed online in a [migraineagain.com](https://migraineagain.com) article. If you could elaborate on that, please, for our viewers. How do we develop such a thing, and what do you do with it once you have it? How do you use that in an ER setting?

**Jaime Sanders (22:32):** I have to first acknowledge a very close friend of mine who had one done for herself with her headache specialist and mentioned it to me and I was like, "That is a great idea." And so I brought that to — at the time I was seeing a neurologist, and I brought that to him during one of my — I think I actually emailed him about it and said this will be so great for me whenever I have to go to the urgent care or to the emergency room. If it could just state my history with the disease, and what my current treatments are, and what has failed me in the



past. And what are the things that I need and their doses when I go into these settings for care? And have it printed on letterhead and signed by my physician.

**Jaime Sanders (23:23):** So it is an official document. And I keep that in what I call my "migraine binder." So, my binder contains a list of all of my prescriptions, all of my allergies, my past appointments, my upcoming appointments, any surgeries that I've had, and that is my suit of armor. It is a way that validates my disease without me having to say anything. Everything is there, my history is there, and if you have any questions, it's right there in my binder. Is it always well received? No, but it's something I have to carry with me in order to streamline the process of getting my treatment started. We just need to make sure that we get that same level of care with everyone that we interact with in those moments.

**Jaime Sanders (24:16):** But the protocol really does help streamline getting those orders in quicker. Especially after waiting for a long time. You want to get that treatment as fast as you can and that just makes it a lot quicker. I'm like, "Hey, this is what I need to get when I come into the emergency room. This is something my headache specialist and I have talked about and agreed works best for me." And they look at it. Sometimes they question the amount of medications, but I say, "This is necessary; otherwise, I'll be back tomorrow. So, let's just get this done today and get it done right."

**Elizabeth DeStefano (24:50):** So, this is really important. So, it sounds like there's a really great opportunity for us to partner with our provider, our neurologist, headache specialist, or whomever is caring for us outside of emergent care. To really outline, on letterhead, what may be or has proven to be, the best approach when all of your first-, second-, and so on, of line approaches at home don't work, have failed you, and it is time to go to the emergency department. So Jaime, would you be comfortable sharing with us what is in your migraine protocol for ER visits?

**Jaime Sanders (25:26):** Absolutely. So, my protocol includes Toradol; Decadron (which is a steroid); Benadryl; an anti-nausea medication, usually it's Compazine or Phenergan; as well as magnesium and saline. And I start off with just one dose of Toradol. And usually, with the combination of all of those medications, including the magnesium — which is great for the tension and tightness in my head, neck, and shoulders — I am usually able to reach my baseline of two. But if not, then I'll add one more dose of Toradol, and I'm usually good to go after that.

**Elizabeth DeStefano (26:09):** You mentioned urgent care. So where, other than the emergency room itself, can someone potentially seek emergency help with migraine treatment?

**Jaime Sanders (26:21):** So, for years, with the insurance that I had, they have their own urgent care facilities, which operated like an emergency room. And so I prefer to go there instead. Because one, it's smaller, the wait times are less. You don't have to wait as long. You can actually make an appointment and go in, or you could just walk in, but making an appointment obviously is the smarter thing to do. And you're able to be put in a room where the lights can be dimmed. And that just worked much better for me. And the copay was \$30 cheaper than an ER copay visit. So, I utilize that a lot. Because I get intravenous medications, IV medications, it was important for me to have an urgent care with those capabilities. Not all urgent cares do that. You might just be able to get just intramuscular, or IM injections.

**Jaime Sanders (27:19):** But I get a bag of magnesium and I need that with my saline. And that's an important piece of my protocol during those visits to the urgent care, or to the emergency



department. So, if you're able to find an urgent care that has those same capabilities as a small ER. And you might be able to find that with some local hospitals. They may have their own urgent care centers separate from their emergency room, which operates just about the same. And the wait times might be a little less than having to go to the local emergency room where everybody's going. So looking, doing some research, and finding those areas might be helpful as well.

**Elizabeth DeStefano (28:05):** I've also heard of some people having access to maybe pain management clinics associated with their neurology offices, and hopefully that's an option for some of our viewers, as well. Jaime, what else would you like to share about what you have learned from your own experience with ER visits for migraine treatment?

**Jaime Sanders (28:27):** The biggest thing is making sure I prepare. I have a bag and make sure I have a really large water bottle that's refillable at a water fountain. Having small snacks to keep my blood sugar level. Having my ginger candy or my ginger chews for that nausea. Having my migraine glasses because it's so bright in those areas. I love to get these cool strips that go on your forehead, and you tend to find those more for kids for when they have fevers, but I love to throw that in my bag. And it stays cold for a couple hours so I can have like a really quick disposable ice cap for my forehead. Sometimes I even go in with one of my Headache Hats. And, you know, they serve a dual purpose. It shows how seriously in pain and disabled I am because I have all of these things I need to use. And it legitimizes migraine, and it also helps keep me comfortable in an otherwise uncomfortable situation.

**Elizabeth DeStefano (29:38):** That makes a lot of sense. So, yes, something else we can do really to try to take control on days we're better able to do so to prepare for those other days.

**Jaime Sanders (29:48):** Exactly. It's a way to make a very invisible disease visible to everybody else.

**Elizabeth DeStefano (29:54):** So Jaime, where can we learn more about you or follow you?

**Jaime Sanders (29:59):** You can follow my blog, The Migraine Diva at [themigrainediva.com](http://themigrainediva.com). I am also on Instagram and Twitter. My handle is @migrainediva and my blog also has a Facebook page, The Migraine Diva. And you can also find my work with CHAMP, the Coalition for Headache and Migraine Patients, at [headachemigraine.org](http://headachemigraine.org). And I'm just kind of everywhere, and again you can read my articles on [migraineagain.com](http://migraineagain.com).

**Elizabeth DeStefano (30:31):** Jaime, thank you so much for continuously offering so much empowerment, and inspiration, and practical advice that has come from your experience and insights to our community. Greatly appreciate you and thank you so much for joining us yet again on the Migraine World Summit.

**Jaime Sanders (30:52):** Thank you for having me.