

Addressing stigma through advocacy: working to change the face and language of migraine



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We sat down with Sarah Reneé Shaw to talk about perceptions and stigma related to migraine and chronic pain.

We learn about her experience living with migraine and how this inspired her to become a patient advocate. She shares her thoughts on the significant issues facing the community, the lack of diverse representativeness of migraine sufferers and her first-hand experience with the stigma facing the community.

Special accommodations
Debilitating Women
Scared
Middle age problem
Fear
Invisible
Complain
Misrepresentation
Just a headache
Stereotypes
Attention seeker
Weak
Underrepresented
Stigma
Overwhelmed
Dismissed
Discrimination
Marginalized
Over-exaggerating
Disability
Stressed
Paranoid
Ignored

Q&A



➔ Please introduce yourself and give us a brief history of your involvement with patient advocacy?

My name is Sarah Reneé Shaw, and I am the BIPOC (Black, Indigenous and People of Color) Patient Advocate at the Global Healthy Living Foundation (GHLF), a non-profit organization dedicated to improving the lives of people living with chronic illnesses through advocacy, education, and patient-centered research.

I didn't wake up one morning and think, "I want to be a patient advocate". It was something that happened to me, and what I think happens to a lot of people who are called patient advocates.

When I received a migraine diagnosis, I felt very alone, confused, and lost. I wasn't getting the right answers from doctors, and I wasn't finding a lot of resources online. So, I looked to different social media avenues. I took to Reddit. I took to Twitter, and I found a community of people like me. A lot of them were older, and a lot of them were white, but I was at least able to find resources and information that explains "this is what you do" or "this is how you find a better headache specialist". I would tweet about my experience of living with migraine and endometriosis, which is an interesting combination. I talked openly about my experiences online, not really expecting people to say anything back, but over the years it turned into this great community of people.

It's amazing to be in a community where you never have to explain why you wear sunglasses. There is an unspoken level of understanding compared to my experience at previous workplaces; I would get weird looks. I faced an attitude of, "It's a migraine, just take some ibuprofen". That's not what you do for a migraine attack. So, I kept doing what I was doing, talking into the void, but the void spoke back. And it directed me to a lot of really interesting opportunities that led to the work that I'm doing now at GHLF. I can't see myself doing anything else.

➔ Why is your advocacy in this area particularly important to you?

I think that as a culture, we do not speak enough about pain. Black women don't speak about pain. There is added stigma on Black women to be perfect, to not be too loud, and to always carry on. I think the pressure from society to be perfect definitely played into my not wanting to rock the boat by saying something as simple as, "I have a migraine attack, and I need to go home" or "I have a migraine attack, and I need access to care" or "I have a migraine attack, and I cannot do this right now".

This fear led to me changing my name online. I've used Reneé on Twitter because I was so scared that my employer was going to find me talking about my experiences living with migraine. And when I was job searching, I was so paranoid that it was going to be used against me, because that does happen.

I have observed that when somebody sees or perceives you have a disability, they expect you may be asking for special accommodations. There is a level of discrimination that takes place with respect to chronic pain. This is really important to us as an advocacy group and there is a lot we have to work on together as a society to help break these stigmas.

➔ What are the biggest challenges facing you and other migraine patients?

Not a lot of people understand the challenges of living with migraine. It is a neurological condition which can cause multiple symptoms, and is not 'just a headache'. It is automatically defined by head pain, but people need to hear more about the debilitation it causes from nausea, light and sound sensitivity, speech disturbance, brain fog and fatigue. It's not something that people caused or did wrong. And everybody's migraine is different as there are so many different types of migraine. There's vestibular migraine, hemiplegia, menstrual migraine, just to name a few.

When people think of migraine, when they try to visualize it, they have an image of a middle-aged white woman furrowing her brows or maybe sitting in the dark on a bed. She has a cloth over her face. And sometimes that is what I look like, but there are so many other different things that happen and go into migraine, and so many other types of migraine sufferers. But this is how it is widely portrayed. You rarely see images of children with migraine. You hardly ever see Black men with migraine. You never see queer people with migraine. It's always just been this one image that has permeated through media, and I think it's because it was easy to say, "Oh, let's put this on women".

I changed my name online. I was so scared that my (now ex) employer was going to find me talking about my experience living with migraine. And when I was job searching, I was paranoid that it was going to be used against me. There is a level of discrimination that can take place with respect to chronic pain and working.

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When I was going through the diagnosis process, I was sent for several scans and my doctor declared, "good news, it's not a tumour, you're fine", but I was still experiencing upsetting and weird symptoms. Perhaps because the media was portraying migraine as a middle-aged white woman's disease and I was young, doctors felt, "Well, you're young, you're healthy, you're just stressed, you're just overwhelmed, you're just adjusting to working full-time". I like to imagine how their response would be different if there were more clinical studies that included younger people, and more Black, BIPOC and LGBTQIA+ people. This is the first year that I am seeing a Black doctor for migraine – and I've been living with migraine for nine years now – and that, for me, means everything.

Chronic pain and migraine sufferers can often be afraid to talk about pain because pain makes us look weak, and because pain and migraine are often invisible. For instance, if I were to go into an emergency room with my hand cut off, I would immediately be rushed in, but you can't see a migraine attack. People can't see what level of pain you're in. Because it's an invisible illness, a lot of people just suffer in silence. I think now we're finally starting to see some change where more people are speaking up about migraine.

More needs to be done to ensure migraine and chronic pain sufferers have better access to better medications, and they are not just offered the cheapest option. Health insurance in the U.S. is one big cluster of annoyance. It shouldn't take hours upon hours upon hours on the phone dealing with your health insurance, justifying for the 50th time why you need the specific medication prescribed to you by a specialist.

Migraine patients don't have the time. If we're having a migraine attack, how can we even help fight these issues if we can't afford our medications? Because we're debating between, "Okay, do I pay for my groceries this month, or do I pay for my migraine treatment?" We need to see all forms of access be represented.

➔ How are companies and other patient advocacy organizations addressing your challenges?

Working at GHLF, I've seen a lot of evidence of support for BIPOC initiatives and organizations, proving they're embracing diversity. It's been amazing to see the amount of energy surrounding issues such as diversity, equity, and inclusion, because that's something that we've been seeking for years. We want to see ourselves represented.

Migraine patients want to be involved; we want to be engaged in medicine development and our care from start to finish. We want to help coordinate and give feedback on our treatment. What is going to be our plan if we can't afford medications? We need to be able to have support programs in place, and we need help to address those issues. We want the patient advocacy organizations that support us to look like us, value our time, and embrace our energy.

Tap into the community and listen to their needs. Let them shape clinical trials and marketing, and give back to non-profit organizations because that's where migraine patients are congregating. We are eager and want to be involved.

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➔ Are companies helping you address your challenges?

It's all about representation and in this respect I feel like they're doing a pretty good job. Recently in the US, migraine advertisements featuring Serena Williams and Whoopi Goldberg aired. Many people were questioning why these celebrities were getting involved in migraine, but this in itself gets people talking about it. For me, it was a critical moment to see two Black women talking openly about migraine.

I was so excited to visit a website and see they offered a 'dark mode' option to address the challenge of light sensitivity. I know this idea must have come from them speaking directly to patients living with migraine. I've recently been working on a podcast called "Talking Head Pain". The objective is to help confront stereotypes and stigmas surrounding migraine by featuring a diverse group of people living with migraine.

At GHLF, we love to 'pass the mic' to representatives from groups of people that typically get overlooked, not only in the migraine world, but in other forms of chronic illnesses too. We need to help get their stories told. Ultimately, by telling these stories we can help the pharmaceutical industry to better identify, understand and develop solutions for people who are not regularly recognized, represented or reached.

➔ What more could be done for patients in your view?

We need more instances of people breaking stigmas. Stigma has had a direct impact on my life. At a previous workplace, I was scared to admit that I experienced migraine attacks because I feared the judgement. Because I was young – I had just graduated from college – I felt like I shouldn't be stopped by migraine, but I was often stopped by my migraine attacks. I couldn't go out with my friends. I couldn't do the things that I normally used to do. Sometimes I couldn't drive places, and I was so afraid to talk to people about it because of this encompassing stigma and misunderstanding that surrounds you.

We need to consider the language barriers associated with diagnosing and treating chronic disease and migraine. My diagnosis was delayed because I didn't have the right word for 'nausea'. I kept saying 'my stomach hurts' and this led to investigations for gastrointestinal issues, and the entire neurological process was overlooked. Visuals, accessible language and a better understanding of the cluster of symptoms will help people (and healthcare professionals) describe and identify migraine.

There needs to be more clinical trial options. I searched for hours looking for clinical trials and they all seemed to be in New York City and in the middle of the day. We need to bring the trials to the communities and be prepared to support them, particularly for less represented groups.

➔ If you could change one thing to benefit your communities and reflect their needs, what would it be?

I think patients just really want to be involved. Meeting patients where they are is also super important. A lot of times organizations label people as "hard to reach communities". No, we're not hard to reach and we're not hard to find. We need to reframe when people say "hard to reach" because the communities are there, the patients are there, the migraines are there, but the marginalized and underrepresented communities are not always going to have access to the same resources that everybody else does. There are a group of advocates out there that are literally waiting to be involved. Tap into the community and listen to their needs. Let them shape clinical trials and marketing and give back to non-profit organizations, because that's where migraine patients are congregating. We are eager and want to be involved. And the bottom line is, you can't do something for a patient without a patient.

Sarah Reneé is the Senior Manager of BIPOC Community Outreach covering the chronic disease community, including neurology, autoimmune conditions, and oncology at the Global Healthy Living Foundation (GHLF). As a migraine patient, she also implements migraine patient activities as well as manages GHLF/CreakyJoints patient councils. She holds a B.A. in Journalism and Media and a minor in Labor Studies with a concentration on Diversity in the Workplace from Rutgers University. She is very involved in patient advocacy events and has been featured in various advocacy campaigns.