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IN
VISIBLE
PROJECT

DISPARITIES

2ND EDITION



11

inspiring stories
from real people
facing health
disparities

PLUS

Inclusive medical
appointments for
trans & nonbinary
individuals

BIPOC, clinical trials,
& rebuilding trust

Mental health,
chronic pain,
& underserved
populations
and more!

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NOW IS THE TIME TO SHINE A LIGHT ON HEALTH CARE DISPARITIES

CHUCK VEGA, MD

I've noticed that people have a certain mannerism when they're about to say something racist, sexist, or xenophobic. They look around, they hunch their shoulders, they lean in—I see that body language, and I'm like, "Here it comes. It's going to be something awful." As a family medicine doctor primarily treating Latinx patients who live under the poverty level, I see the ways that discrimination and structural factors can be detrimental to the health of those facing disparities because of their race, ethnicity, gender, sexuality, socioeconomic status, or age.

It's really hard to thread the needle of creating better health outcomes and patient experiences for a lower cost. But the most basic way is to improve patient-centered care. Give those patients a better experience, and they will have better patient outcomes. In turn, that will reduce costs, because those patients will be living longer and living healthier.

No health issue has captured the public consciousness like COVID-19. In the same way that COVID disproportionately affects minorities, there's evidence of unequal treatment based on race and ethnicity across a broader array of different disease states. Now is the time to examine the spotlight that COVID has shined on unequal treatment so that we can extend solutions to all health care disparities, including pain management.

These disparities aren't all about diagnoses or treatment modalities. Insults and microaggressions add up and eventually can contribute to chronic illness, resulting in early mortality. Being kinder is something that everybody can do. I hope that a shift to a greater sense of humanism, and continued illumination of health care disparities and the reality of pain through initiatives such as this project, will play a role in eventually eliminating these disparities. •



ABOUT CHUCK VEGA, MD

Chuck Vega, MD, is a family medicine physician at University of California Irvine's Family Health Center in Santa Ana, California, the largest safety-net clinic in Orange County. He is a clinical professor of family medicine at University of California Irvine, Director of the UC Irvine Program in Medical Education for the Latino Community, and Assistant Dean for Culture and Community Education at UC Irvine's School of Medicine. He created HEAL-LC, a program providing new physicians with information about the language, cultural customs, and health beliefs of Latino patients. In 2021, he was named a top "Diversity Leader to Watch" by Modern Healthcare in its annual examination of diversity, equity, and inclusion efforts in the health care industry.

IN VISIBLE PROJECT

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The *Invisible Project* is a program of the U.S. Pain Foundation, a 501(c)(3) nonprofit. The mission of the U.S. Pain Foundation is to empower, educate, connect, and advocate for individuals living with chronic illnesses and serious injuries that cause pain, as well as their caregivers and clinicians. Through its multiple programs and services, the organization works to enhance the quality of life for people with pain, improve patient outcomes, address access and affordability issues, and increase public awareness and empathy for the issue of pain. Learn more at uspainfoundation.org.

MAKING THE INVISIBLE *VISIBLE*

The evolution of the *INvisible Project*.

In 2010, Nicole Hemmenway was relatively new to patient advocacy. She had just written a book describing her journey living with chronic pain and was searching for more ways to become involved with the pain community. Nicole felt certain others would benefit if they had an avenue to share their stories, too.

While attending a conference, Hemmenway connected with a small organization that would later evolve to become the U.S. Pain Foundation. Hemmenway decided to join forces with U.S. Pain to help amplify the voices and stories of people with pain. That first year, nine people were featured in a magazine-style publication, with profiles written by Hemmenway and photos taken on a day in the life of each person.

A decade later

Today, the *INvisible Project* has published a total of 21 issues (including this edition) and distributed more than 120,000 copies to patients, caregivers, and health care providers alike.

More than 200 patients and their loved ones have been featured over the years. In addition to individual stories, each issue includes roughly a dozen educational articles quoting experts on topics that matter most to patients with pain.

The *INvisible Project* recently brought on former journalist Rebecca McKinsey as its new director, with Hemmenway maintaining an active role in the magazine's creation.

"We continue to believe in the power of a printed publication, along with making our issues readily available online," says Hemmenway. "A magazine is an easy way to make sure people can

access the project, return to it frequently for information and inspiration, and share it with others."

INvisible Project on the road

Beyond print and online editions, the *INvisible Project* is also available as a traveling display. These photo displays, which show images and quotes from those affected by chronic pain, are lightweight and easy to set up. They have a huge impact at pain awareness events, disability expos, health fairs, medical conferences, and other public events.

U.S. Pain Foundation has even taken the displays to state legislatures, taking the opportunity to educate lawmakers as they consider legislation that affects the pain community.

Want to participate?

Do you want to share your story to educate and inspire others? To put a face on the invisible challenges you face as a chronic pain patient? We welcome your ideas, and we're looking for candidates to be featured in the upcoming editions of the *INvisible Project* magazine. •

➤ **Learn more and introduce yourself at invisibleproject.org.**



Above: Nicole Hemmenway, CEO of U.S. Pain Foundation and Co-Founder and former Director of the *INvisible Project*.



Above: Rebecca McKinsey, Director of the *INvisible Project*.



Want to read past editions? Visit invisibleproject.org to view PDFs of previous magazines or order copies.



U.S. PAIN FOUNDATION PROGRAMS

HERE ARE SOME OF THE PROGRAMS THE ORGANIZATION OFFERS.



AWARENESS & ADVOCACY PROGRAMS

Invisible Project - The *INvisible Project* is a print and online magazine that highlights the bravery and perseverance of pain warriors through stories and photos.

State and Federal Advocacy - Pain warriors deserve direct and affordable access to individualized, multidisciplinary care. We fight for change at the state and federal level on a range of priority issues related to pain care.

Pain Awareness Month - During Pain Awareness Month in September, U.S. Pain strives to increase awareness about pain through a number of activities, events, and initiatives.

Medical Cannabis - This program seeks to increase safe, fair access to medical cannabis for people with chronic pain. It also aims to provide education and resources on medical cannabis as a treatment option.

EDUCATIONAL PROGRAMS

About Pain - This dedicated section of the U.S. Pain website, along with a corresponding 16-page print booklet, provides detailed information about how to live day-to-day with chronic pain.

MyPainPlan.org - This interactive site allows individuals to explore 85+ types of treatment across seven categories of pain management. Users can then create a personalized list of treatments to discuss with their health care provider.

Webinars and Pain Education Portal - U.S. Pain offers hour-long educational webinars featuring renowned experts on topics ranging from meditation to clinical trials. These webinars are presented live and recorded so they can be watched at any time from the comfort of home.

Building Your Toolbox - This monthly educational series invites practitioners to teach individuals a pain management strategy or skill. Unlike traditional webinars, events are held in a meeting format so that participants can interact with the speaker directly.

KNOWvember - Each November, this educational campaign takes a closer look at a particular topic through events, informative materials, and social media content. Past topics include creativity through pain and neuromodulation.

Educational materials - People with pain face more challenges than ever before and need educational resources and tools for taking control of their health. U.S. Pain regularly creates informational handouts and worksheets, all of which are available free of charge.

SUPPORT & EMPOWERMENT PROGRAMS

Volunteer Network - This volunteer network raises awareness about chronic pain, educates those living with pain on available resources, and advocates for change at all levels of government.

Pain Connection - Our national network of support groups provides compassionate support and evidence-based education to help people with pain reclaim their quality of life. The support groups, which are offered nationally and by state, are led by individuals who receive comprehensive training from a licensed social worker. Pain Connection also offers special population groups for veterans, caregivers and care partners, LGBTQ+ individuals, BIPOC, teens, and Spanish-speaking families. In addition, there is a Functional Nutrition group as well as Reading Room and Writing Room groups.

Pediatric Pain Warrior Program - The Pediatric Pain Warrior Program assists children and their families in finding a network of support and resources. This program offers in-depth retreats and programming featuring expert speakers, workshops, and more.

Share Your Story Storybank - U.S. Pain invites people with pain to share their stories online. Each person who submits details about their pain journey receives a packet of information and resources, along with a pain warrior bracelet, in the mail.

CLINICIAN PROGRAMS

National Coalition of Chronic Pain Providers and Professionals -

This network of health providers, professionals, and organizations has come together in a coalition to more effectively serve the chronic pain community. It offers networking, education, and more.

THANK YOU

The U.S. Pain Foundation thanks Johnson & Johnson for its platinum sponsorship of this issue of the *INvisible Project*. Thank you for supporting this important initiative that addresses health care disparities while educating, empowering, and inspiring those living with pain.

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GLOSSARY

Following are definitions of some of the terms used throughout this issue.

BIPOC: Black, Indigenous, and people of color.

Gender/sex/gender

spectrum: Sex is assigned at birth based on physical characteristics, while gender describes how a person identifies. Gender spectrum describes the fluid nature of gender beyond the male/female binary.

LGBTQ+: Lesbian, gay, bisexual, transgender, and queer or questioning, with the plus sign representing all other gender identities and sexual orientations.

Transgender: Describes people whose gender identity is different from the sex they were thought to be, or “assigned,” at birth.

Nonbinary: Describes individuals who do not identify as male or female, or who fall elsewhere on the gender spectrum.

Health literacy: The capacity to obtain and understand health information and make health decisions. Low health literacy may be more common among older adults, minority populations, those who have low socioeconomic status, or medically underserved people.

WHERE DO WE GO FROM HERE?

The COVID-19 pandemic has shined a glaring light on health care disparities—roadblocks or unequal treatment faced by individuals because of race and ethnicity, gender, sexuality, socioeconomic status, lack of health literacy, age, rural residency, or other factors.

Some clinicians still believe certain minorities experience less pain. Women’s pain is understudied and disbelieved. Men hesitate to seek out treatment because of the stigma attached to their health issues. LGBTQ+ individuals are misgendered and stigmatized by medical professionals. Young children and older folks have their pain brushed aside. Individuals with low incomes are treated differently when they seek out care. Those living in rural areas face greater challenges when they need specialized treatment.

As you read this issue, you’ll meet people who are working to fix these problems. You’ll get to know 12 incredible people living with pain who have faced health care disparities. You will meet individuals using their scientific backgrounds to advocate for better health, and people who have turned their pain into a calling to improve health outcomes for all.

Health care disparities are in the spotlight, and now is the time to move past lip service. Please join us in not looking away, not letting this slide, and not forgetting about the long-rooted disparities that block so many people from accessing the health care and treatment they need and deserve. The U.S. Pain Foundation will continue to advocate for those who need it—and to support and stand with the individuals and organizations tirelessly laboring in so many ways to eliminate these disparities.

INFORM

REAL STORIES. REAL PEOPLE. REAL HOPE.



PHOTO BY CHRISTIN VEASLEY (PG 57)

➤ WHAT IS THE INVISIBLE PROJECT?

We strive to make visible the internal, often-hidden challenges faced by those with chronic pain. We want to show what it's like to live with daily health challenges—and to thrive in spite of them.

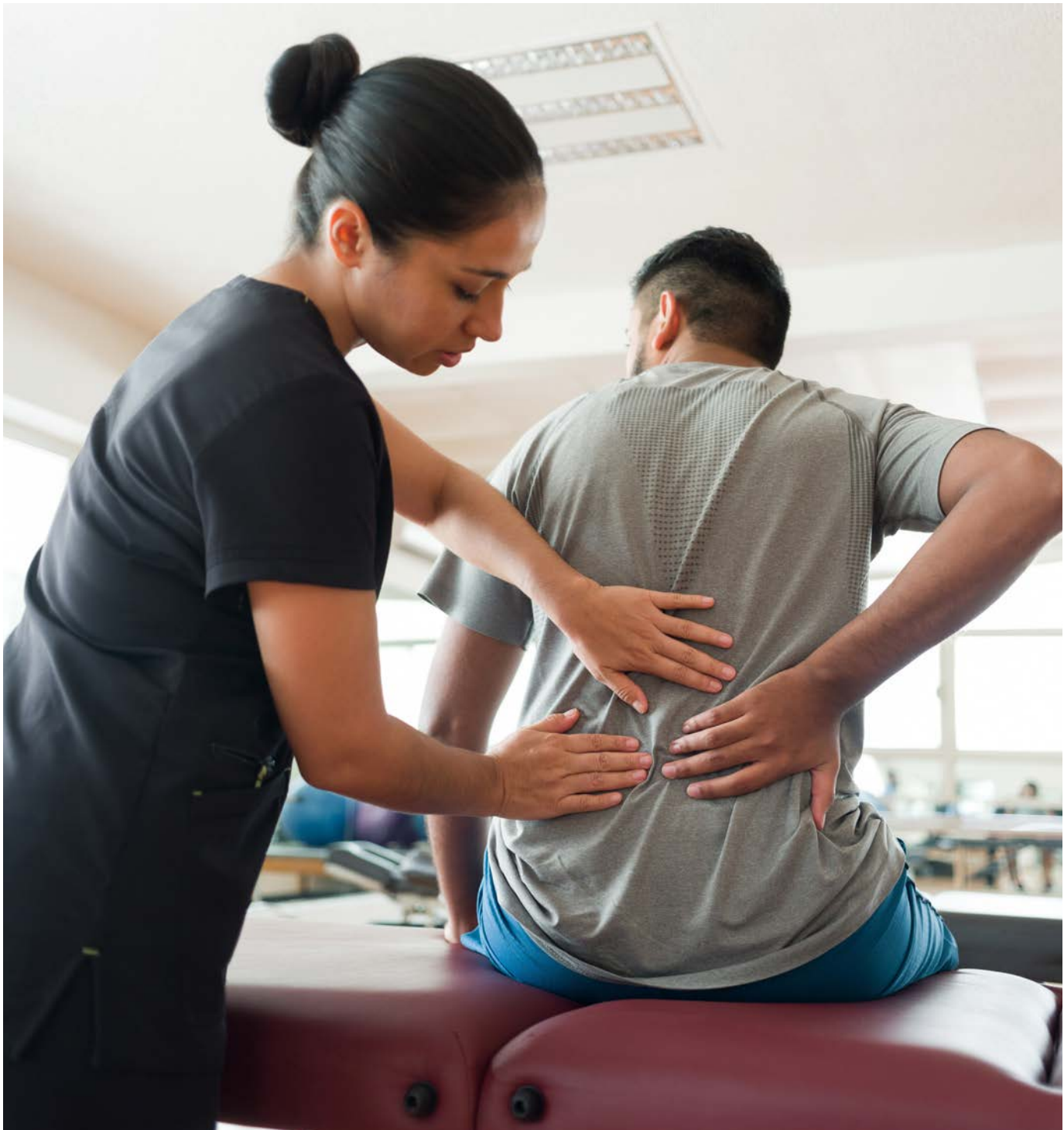
Our goal: To show the reality of life with pain, and why people living with it need and deserve more help, treatment options, and research, while offering hope and inspiration. >>>





INADEQUATE ASSESSMENT OF PAIN: *WHERE A 1-10 PAIN SCALE FALLS SHORT*

BY REBECCA MCKINSEY



When a 36-year-old Latino man walks into a clinician's office seeking help for pain, chances are good he will be asked about his pain level on a 1-10 scale.

Without digging any deeper, the clinician would never learn that this man has worked a construction job since he was 15, and doesn't have the option to take time off because he has to put food on the table for his family.

"These are important things to consider for marginalized populations: the day they take work off because they're in too much pain is the day they lose their job," says Chuck Vega, MD, a family medicine physician who sees primarily Latinx patients under the poverty line at the largest safety-net clinic in Orange County, California.

But those considerations never see the light of day when the conversation starts and stops at "How is your pain on a scale of 1 to 10?" Clinicians, pain specialists, and individuals living with pain are finding that effective pain treatment plans can't be achieved without exploring the circumstances surrounding the individual's pain. What valued activities can't they do anymore that often are even more meaningful than a numeric pain level?

And for Black, Indigenous, and people of color (BIPOC); LGBTQ+ individuals, including those who are transgender or nonbinary; and people who are low-income, have low health literacy, or are elderly or very young, how does the discrimination they experience affect their pain and the treatment they get for it?

Pain as a vital sign

Paul Arnstein, PhD, RN, FAAN, is a certified family nurse practitioner, clinical nurse specialist, and pain management nurse with Massachusetts General Hospital. He works to reduce fears and mistaken beliefs about pain—and to find more nuanced ways to assess and treat it.

Arnstein reflected on a decades-old study that examined children undergoing a painful bladder surgery—they were rarely given even acetaminophen, much less stronger pain relief. "It's been said that no child experienced pain before 1970, because there was no medical literature acknowledging that children have pain," he says.

One issue contributing to the lack of pain treatment for children at the time was a lack of concrete measures to assess their pain, Arnstein says. A child's fever, for instance, is easily quantifiable.

"Physicians seem to be responsive to numbers," Arnstein says. "We know if the treatment is working or not based on how these numbers change in response to therapies. But we need to have professionals stop ignoring pain and pay attention to it as they would if Johnny's fever was 105, his blood pressure was 200/100—something that gets our attention and says, 'Hey, you have to treat it.'"

But pain is subjective: Not only does a 10 on the pain scale mean something different to everyone, the actual definition of what each number "means" can vary depending on which pain scale is used. What patients consider a 1 can fluctuate, too—pain scales, when they're used correctly, should actually start at 0, Arnstein says.

Examining function as a better measure of pain

For best outcomes, clinicians need to move beyond a numeric scale or their own observations of an individual's demeanor—which can be misleading, if patients are trying to remain positive for the doctor or are brought up by their culture or community to act a certain way toward health care providers, Arnstein says.

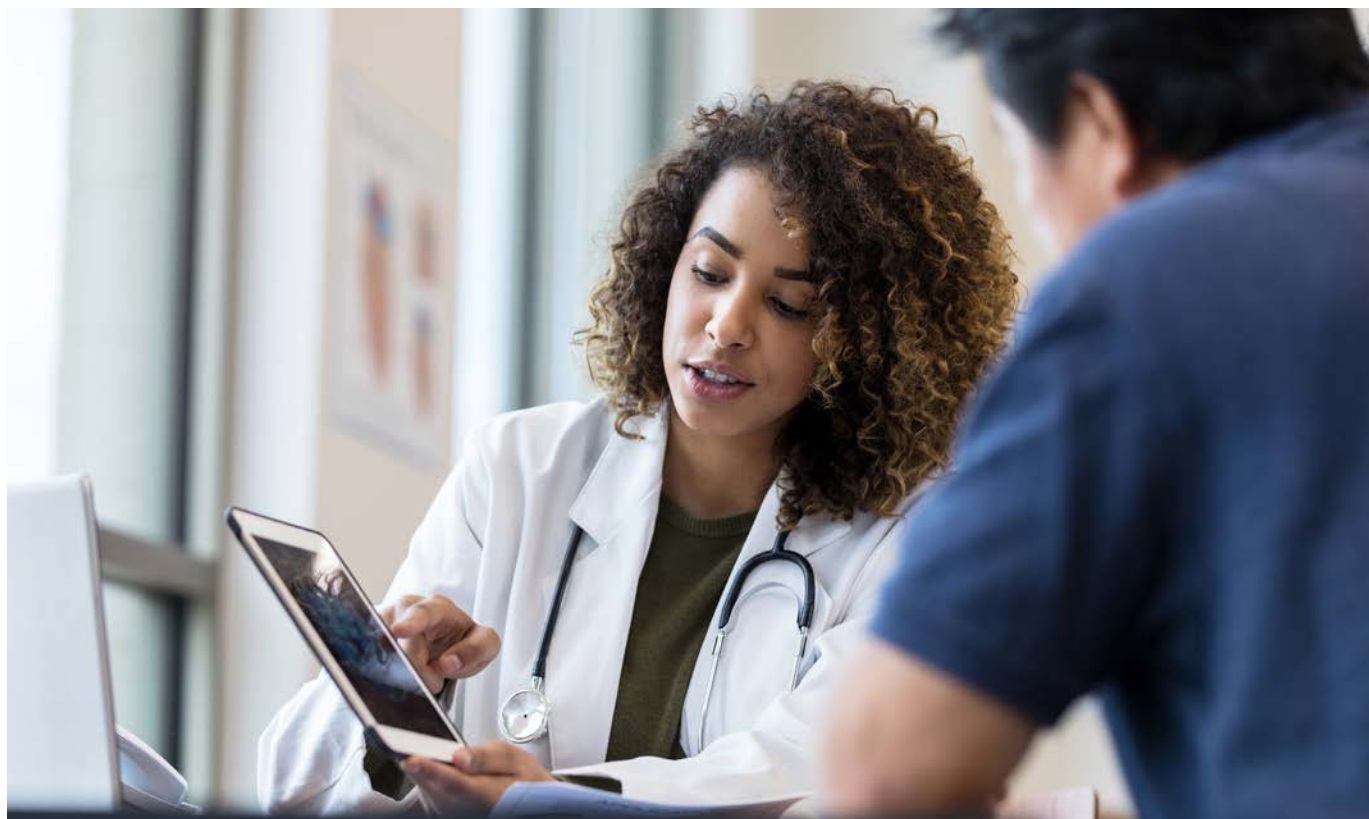
"To distill the whole experience of pain down to a single number and to determine who gets treated based on the number" leads to inadequate and inequitable treatment plans, Arnstein says.

A comprehensive assessment of pain should also include functional tests to see how the person is able to move, what they are able to do, and how their pain changes when they are completing certain activities. Beyond that, Arnstein says, he also asks patients how much pain interferes with their general activities, and how strongly pain prevents them from enjoying life.

Assessing function as a measure of pain is different for every individual. Some people can't get out of bed at all. If individuals like that can turn in bed, cough, and take a deep breath, "that's the level of functioning I want to see," Arnstein says. On the flip side, for someone who recently was running a marathon, the inability to run or complete a workout is an indication that pain is drastically affecting function.

From the very first visit, says Vega, it is important that clinicians look at the type of chronic pain and ask how it affects one's daily life. "How is pain holding you back? How can we get to that place to

"You have to understand the patient's symptoms and their goals of care in the context of their social life, their family life, their work life. And that's going to be different for folks from different walks of life. If they have a different cultural background than you, a different race, different experiences or goals, the key is to put your own agenda aside, listen to the patients, and try to work toward their goals. Don't impose your will on those important objectives."



reach your goals?” Vega says. “I need patients to partner with me in that—I can’t tell them what their goals are.”

Arnstein urges patients to make lists and determine prior to a meeting what exactly they want out of it, whether that’s information, analysis, advice, understanding, or reassurance—then vocalize that.

Assessing pain when disparities exist

When looking at underserved populations, one barrier to successful pain assessment is the history of health care in America and the distrust toward medical providers it has led to among BIPOC, LGBTQ+ individuals, or people with low incomes or low health literacy. A key ingredient to successful assessment and management of pain is trusting the health care provider and not feeling judged, Arnstein says.

“There has been a lot of research regarding women, people who are very young or very old, people of diverse cultural or racial backgrounds,” Arnstein notes. “Especially when their backgrounds are different than the health care

provider who is providing care, they don’t get treated as quickly or as thoroughly in terms of follow-up as their counterparts who mirror the health care provider who’s evaluating and treating the pain.”

Vega urges health care providers to keep unconscious biases in mind.

“You have to understand the patient’s symptoms and their goals of care in the context of their social life, their family life, their work life,” Vega says. “And that’s going to be different for folks from different walks of life. If they have a different cultural background than you, a different race, different experiences or goals, the key is to put your own agenda aside, listen to the patients, and try to work toward their goals. Don’t impose your will on those important objectives.”

Does the individual want to be able to play with their grandkids, go to church on a regular basis, and comfortably make the walk from the parking lot to the building? Creating a patient-centered treatment plan can help reduce preconceived notions when a patient comes from a different background than a provider, Vega says.

For providers who may recognize that there is bias in their practice, take a step back and look at the standard guidelines for treating certain conditions, Vega says. If a provider is not treating a patient living with pain based on existing treatment guidelines, they should ask themselves, “Why aren’t I offering this treatment to this patient?”

“Think about it; be honest about why—is it because you think this person of color is going to be more likely to abuse the controlled substance you give them?” Vega says.

He adds, “We’re all guilty [of making snap judgments]. Be the best provider you can, work on it, work on your practice and policies. Take a hard look at that bias, so that you can see that pattern, hopefully before it manifests.”

Whether or not a medical provider shares their patient’s background, the best way to treat chronic pain begins by understanding how that pain is affecting the day-to-day life of a patient. The only way to effectively manage pain, especially for underserved populations, is to focus on the entirety of a person’s experience, not just a number on a pain scale. ●

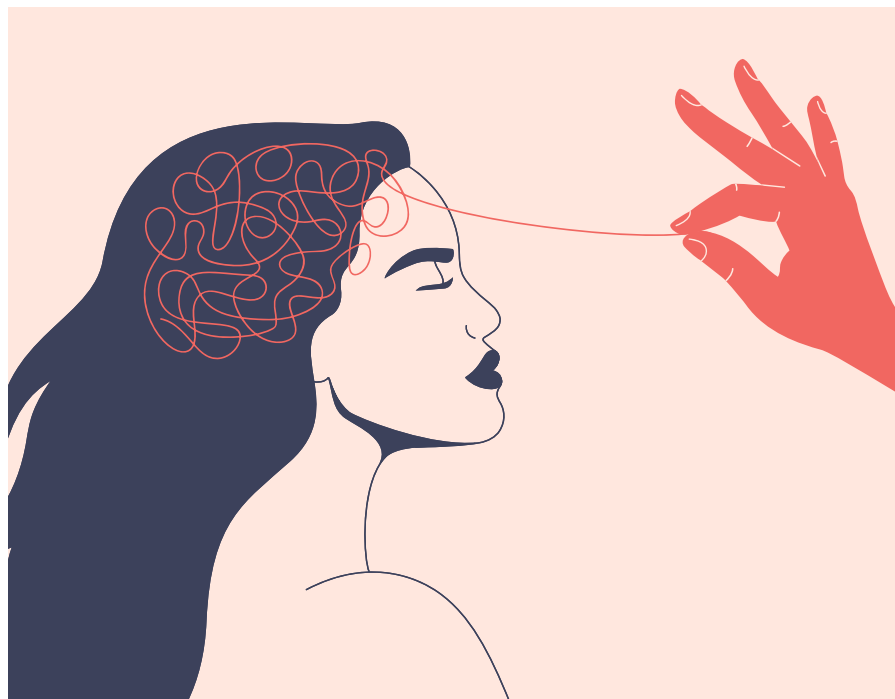


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INFORM

WHEN MENTAL HEALTH AND PHYSICAL PAIN COINCIDE, CERTAIN POPULATIONS ARE HIT HARDER

BY REBECCA MCKINSEY



The tie between physical pain and mental illness can feel like a never-ending and inseparable cycle, with pain causing or worsening mental health symptoms, and mental health issues provoking or exacerbating pain.

Unfortunately, some factors can make that cycle even worse, like being a person of color, qualifying as low-income, having low health literacy, or identifying as LGBTQ+, particularly those who are transgender or nonbinary.

Mental Health of America (MHA | mhanational.org), a nonprofit that promotes mental health and offers resources to those living with mental illness, recently explored this tie in

a report titled “Early, Equitable and Trauma Responsive Care for Chronic Pain and Mental Health.”

The report examines thousands of results from individuals who took one of 10 anonymous online screenings for mental health—including depression, bipolar disorder, anxiety, substance and alcohol abuse, psychosis, and post-traumatic stress disorder (PTSD)—and also reported experiencing chronic pain.

MHA found repeated evidence that the challenges inherent in the combination of mental and physical health issues were more stark for members of populations that traditionally have faced disparities, says Maddy Reinert, MHA’s senior director of population health.

“We see a lot of individuals with

mental health concerns, *and* chronic pain, *and* who are from some of these populations like BIPOC [Black, Indigenous, and people of color] communities, feel especially written off when they try to engage in care, or like they’re not believed because of how invisible both conditions are and how intertwined they are,” Reinert says.

Stark inequity in screening results

MHA’s screenings found that 31% of LGBTQ+ individuals taking a mental health screening reported chronic pain, while 57% of respondents reporting both mental health issues and chronic pain identified as low-income.

“For people who identify as LGBTQ+, for BIPOC individuals, with increasingly visible discrimination and violence and the trauma that carries—all of these experiences are really intertwined and are likely to exacerbate both pain and mental health,” Reinert says.

The MHA report notes that the majority of respondents with chronic pain were white, which reflects research that has found racial disparities in diagnosing chronic pain, particularly among Black individuals. “Other communities of color are even less likely to report experiencing chronic pain in screening, indicating a possible need for more research in the pain experience among diverse communities, to ensure equitable diagnosis and treatment,” the report states.

Of the BIPOC individuals who did fill out a screening, some said they were labeled as “pill shoppers” when



“For people who identify as LGBTQ+, for BIPOC individuals, with increasingly visible discrimination and violence and the trauma that carries—all of these experiences are really intertwined and are likely to exacerbate both pain and mental health.”

they tried to be honest with health care providers about their pain. Others said their experiences with health care providers were so negative that they’ll continue to live with pain and mental health challenges rather than seeking out help again.

Disparity-related trauma worsens health outcomes

Trauma plays a major role in both physical and mental health, notes the MHA report, including trauma that disproportionately affects vulnerable populations, such as the COVID-19 pandemic, police brutality, or racial violence.

“Intentional interpersonal trauma”—in which a perpetrator harms someone knowingly and on purpose—is even more related to pain than non-intentional trauma such as accidents or illness. According to the report, “Widespread exposure to intentional interpersonal trauma that Black, Indigenous, and people of color

(BIPOC) experience both in-person and through media may contribute to higher rates of chronic pain and mental health conditions, including PTSD.”

More than half of all adults with a mental illness in America don’t receive treatment, Reinert says. The percentage of Black individuals able to access mental health treatment is 15% lower than that of white patients, while statistics show that access by Asian American individuals with mental illness is 31% lower. Individuals of color are also less likely to have health insurance.

“Those percentages are wild,” Reinert says. “Those are very stark disparities in who’s able to access care.”

For underserved populations seeking mental health care, finding culturally appropriate care and representative providers is one more challenge to add to the list.

“A lot of people of color and people who identify as LGBTQ+ have had

negative or even actively traumatizing experiences when they’ve either had a mental health crisis or sought help for their mental health,” Reinert shares. “That creates another barrier to staying in care.”

Closing the gap

On a provider and policy level, there are steps that can be taken, the MHA report states.

Health care providers should proactively initiate conversations about mental health and chronic pain, and should include behavioral health as a central feature of care for chronic pain.

Medical school curriculum needs continual updating to address discrimination and bias—a National Academy of Sciences report found that about half of medical school students falsely believe there are biological differences in pain between Black and white patients, “which leads to racial bias in pain recognition and treatment,” the report states.

On a state and federal level, the MHA recommends that there be a greater investment in better treatments both for chronic pain and mental health conditions.

“This includes investing in better, more representative research to find treatments and develop better pain measurement tools that work for a diverse population,” the report states, “so BIPOC, LGBTQ+, gender diverse, and other communities traditionally underrepresented in this research can be identified, diagnosed, and treated more effectively and appropriately.” ●

MENTAL HEALTH, CHRONIC PAIN, AND DISPARITIES: WHERE TO FIND ANSWERS AND HELP

LGBTQ+ communities:

mhanational.org/issues/lgbtq-communities-and-mental-health

BIPOC communities: mhanational.org/bipoc-mental-health

Social determinants of health:

mhanational.org/social-determinants-health

Chronic pain and mental health:

mhanational.org/chronic-pain-and-mental-health

Specialized support groups from the U.S. Pain Foundation:

painconnection.org/support-groups/specialized-chronic-pain-support-groups

CONNECT WITH PEOPLE WHO UNDERSTAND.

Within the chronic pain community, **specific populations face unique challenges** as they navigate their or their loved ones' health conditions. Pain Connection, a program of the U.S. Pain Foundation, provides **monthly support group meetings**. Current groups include:

- Basic Training for Veterans with Pain
- LGBTQ+
- BIPOC
- Grupo de apoyo familiar de habla hispana para el dolor crónico
- Caregivers/care partners
- Teen Pain Warriors
- The Writing Room
- The Reading Room
- Functional Nutrition Group

Pain Connection support groups leaders go through comprehensive training **led by a licensed social worker**.

Groups focus on **support and connection**, but they also incorporate **evidence-based education**.

All discussions are strictly **confidential**.

Pain Connection also offers state and national support groups. For the most up-to-date schedule, visit **painconnection.org**.



CONNECT EFFECTIVELY WITH YOUR DOCTOR: *TIPS ON COMMUNICATING DIRECTLY, CONCISELY, AND PRODUCTIVELY*

BY SAMANTHA MELTON



To communicate effectively, Vega suggests:

- Make declarative statements: Tell your provider your functional goals and objectives, like seeing your grandkids get married or walking a 5K.
- Be honest: Tell your provider about barriers to your health. Ask why tests, procedures, or medications are needed. “It is the provider’s job to educate, inform, and work with you on solutions,” Vega says.
- If you are feeling unsatisfied, be frank: For example, if you have not heard back about lab results, Vega suggests directly asking your provider for an update. “Giving a negative grade online is not nearly as effective for change,” he explains.

Visiting the doctor—for the first time or for yet another follow-up—can be overwhelming.

Chuck Vega, MD, a family medicine physician in Santa Ana, California, offers these suggestions for preparing for an appointment:

- Pick the top three concerns you want to discuss: If you are seeing a clinician and have multiple issues to address, let them know before the appointment so they can make sure to schedule enough time for the visit.
- Bring a list of your current medications: This includes over-the-counter medications, supplements, and anything you are ingesting for your health.
- Set up early for telehealth appointments: Ensure you have a good Internet connection, and that your camera and microphone are working prior to your appointment.

Vega says it is important to understand a few key things:

- You and your doctor may have different priorities: Doctors want to keep their patients healthy. While a colon cancer screening may not be on your agenda, it may be for your doctor.
- There are few perfect solutions in medicine: Providers cannot solve every challenge, but they can try to work together with patients to create the best outcomes.
- Doctors are human too: Everyone has bad days, including your health care provider. However, they should always treat you with respect.

Vega, who frequently sees Latinx patients, notes that while no provider is completely free of bias, having a culturally responsive provider is important for individuals in underserved populations, who may have a fear of the health care system.

Effective patient-provider communication is important for improving health outcomes. Arriving at your appointment prepared, bringing someone with you if that is helpful, and being honest with your health care provider is the best way to ensure a successful visit.

“No patient-provider relationship is perfect, but the best alliances come from both parties working together,” says Vega. •

*“It is the provider’s
job to **educate,
inform, and work
with you on
solutions.**”*



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INFORM



MAKING OVER-THE-COUNTER MEDICATIONS *MORE ACCESSIBLE*

BY JILL WALDBIESER

For the more than 50 million Americans who live with chronic pain, over-the-counter (OTC) pain relievers may be right up there with “phone, wallet, keys” on the checklist of items to keep with them at all times.

Many people rely on these medications—almost a quarter of American adults use acetaminophen weekly, according to the Protecting Access to Pain Relief (PAPR) Coalition,

a multi-stakeholder advocacy coalition that receives part of its financial support from the pharmaceutical industry. Many OTC drugs are generally safe to use, some on an ongoing basis (although it is always important to consult a health care provider about each person’s specific circumstances and possible long-term effects). But it’s not always clear from the labels exactly how to use these medications properly.

Issues include a lack of detailed instructions, too-small fonts, a lack of dosing guidelines for children under the age of 2, little to no information in

any language other than English, and few or no visual instructions like diagrams or linked video for people who take in information better that way.

The U.S. Department of Agriculture (USDA) recently overhauled food nutrition labels in an effort to make them easier to understand is: There is talk of doing something similar for OTC medicines, says Ethan Jorgensen-Earp, policy advisor for the PAPR Coalition. “Labeling and the information on it is certainly an access issue” when it comes to safe and effective OTC pain relief, he says.



*The NIH notes that an analysis of 40 OTC products' label language found the grade level and ease of reading were **beyond the average consumer's capabilities.***

The lack of uniform labeling standards on these products leaves a lot of room for error when it comes their use, including:

Legibility and clearness of directions

Most dosing instructions appear in tiny, difficult-to-read print. Food and Drug Administration (FDA) guidelines specify the use of 6-point font on labels, which can be too small for some visually impaired or older individuals to read, according to an analysis by the National Institutes of Health (NIH).

The NIH notes that an analysis of 40 OTC products' label language found the grade level and ease of reading were beyond the average consumer's capabilities. Beyond that, "none of the products I know of have instructions in other languages," says pharmacist Jeff Fudin, PharmD, FCCP, FASHP, FFSMB, adjunct associate professor of pharmacy practice and pain management at Albany College of Pharmacy & Health Sciences. Instructions with larger fonts, pictures, videos, or a QR code you can scan with your phone to access instructions in other formats or languages would help.

Measurements and dosages that make sense

Since many Americans don't use the metric system, "people don't know that 5 milligrams is equal to one teaspoon," Fudin says. Some medications come with a dosing cup, but that's easy to misplace, and consumers are left trying to do conversions to figure out dosage.

Additionally, adult dosages calculated based on a "standard" body

weight may not always be accurate. For some medications, the optimal dose won't be the same for someone who weighs 120 pounds and someone who weighs 240 pounds, says Fudin.

Clear instructions for kids—and dosing guidelines for children under 2

Weight-based dosing for children isn't always listed on labels. Even when it is, it can be fraught with complications, especially when recommended dosages are given in terms of both age and weight. Which instructions should be followed, for instance, when a seven-month-old baby weighs more than the weight range for that age listed on the dosage chart?

Additionally, some products that are formulated specifically for children may be concentrated to make administering the medicine easier (because there's less to swallow), but that can also cause confusion.

Drug interactions and safety

OTC pain relievers fall into one of two major categories: acetaminophen (Tylenol), and non-steroidal anti-inflammatory drugs, or NSAIDs, such as ibuprofen (Advil or Motrin) and aspirin. But products that contain both also exist. Certain populations, such as organ transplant recipients, shouldn't take acetaminophen, and these combination products can be tricky for people who just grab a familiar brand name off the shelf without scanning the ingredients.

OTC medications can interact negatively with prescription drugs, alcohol, or certain foods. They can

also have long-term effects, especially among people with pre-existing conditions. "It's okay to use NSAIDs chronically if recommended by your doctor," says Fudin. "The issue is if you have a patient who has a high risk for, say, heart problems or kidney dysfunction, and they take NSAIDs beyond their recommended time. Their safety profile isn't going to be the same as someone without those conditions."

OTC drug labels also sometimes lack detailed instructions about proper storage. Extreme temperatures or excessive humidity can affect their viability.

Where to go from here

Historically, label modification has been difficult because of the complex regulatory environment for these products, says Jorgensen-Earp. He hopes to see relevant agencies, including the FDA, make this process easier over the next few years. The best way forward is education. "Making people, such as members of Congress, aware of issues that affect you with regard to safe and effective OTC use is helpful," he says. Advocacy groups like the PAPR Coalition and others can sometimes help amplify specific concerns, too.

In the meantime, someone using an OTC medication for pain relief should always read the instructions thoroughly and investigate potential interactions. Until the labels for OTC pain relievers improve, there is one resource available to alleviate any doubt or confusion about how to take them, and it doesn't cost a dime or require an appointment, says Fudin: "Ask a pharmacist." ●



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BIPOC AND CLINICAL TRIALS: *REBUILDING TRUST AFTER GENERATIONS OF ABUSE*

BY KIRSTEN BALLARD



In 1932, the U.S. Public Health Service began a study on syphilis involving 600 Black men. Despite being promised medical care, these patients were kept in the dark about their disease while doctors studied its progression. In 1943, when penicillin started being used to treat syphilis, the men in the study did not receive it.

In 1951, while seeking treatment for cervical cancer, Henrietta Lacks, a young Black mother of five, had extra tissue removed for research. These cells were the first human cell line able to reproduce indefinitely and have been behind many subsequent medical advancements. She did not consent to having her tissue removed and cells used, and never received compensation.

In 1993, the National Institutes of Health (NIH) Revitalization Act required that research studies include women and people of color. It also set guidelines for their participation, requiring researchers to analyze if the factors being studied affect women and people of color disproportionately.

In 2012, research showed that 80% of clinical trials globally experienced setbacks because of challenges recruiting and retaining participants, delaying the approval of potentially life-saving drugs.

Abuses of power throughout the history of clinical trials with BIPOC (Black, Indigenous, and people of color) have led to mistrust and hesitancy—and building trust going forward is a slow but vital process.



Encouraging other BIPOC to join after positive experience

Dawn Edwards serves on the NIH HEAL Community Partner Committee, consisting of members living with painful conditions or opioid use disorder who offer insight on issues facing them to bolster research. As a Black woman, she understands why BIPOC hesitate to participate in trials.

“Most of what I hear is eugenics, the Tuskegee [syphilis] experiment, ‘they’re just doing tests on us,’ ‘we’re guinea pigs,’ ‘nobody is really trying to help us,’” Edwards says.

Edwards was diagnosed with kidney disease at 23 and, through her advocacy work to support others living with the same disease, was connected with a pain study. “I had no idea what I was doing, I just did it because a physician colleague suggested it, and I trusted him,” she remembers. “And, oh my goodness, everybody was so nice, and they took their time to explain things to me.”

Now, Edwards advocates for other people of color to get involved. “We’re really doing ourselves a disservice as a people by not getting involved in the study process,” she says.

Rebuilding trust: Not just checking off a box

Community outreach is an important factor in rebuilding trust between the medical research field and communities of color.

Working toward this goal is Richard Towne, a Senior Clinical Informatics Manager at Antidote (antidote.me), a clinical trial patient recruitment and patient engagement company working to bridge the gap between new treatments and the individuals who need them. Antidote breaks down the medical jargon and obstacles that make clinical studies difficult to engage with.

Towne stresses accessibility when engaging with communities of color—taking into account the location of the testing site, providing a travel stipend, and laying out the study in digestible terms.

“A lot of the criteria in clinicaltrials.gov

“This has been such a trying, trying illness, and I don’t want anyone else to go through this. I was so young when I was diagnosed, and once I got out of the space of feeling low about it, I just thought, ‘What can I do to support it?’ And clinical trials were one way.”

are written for the medical staff to screen patients,” Towne says. “So when a patient reads it, they say, ‘I don’t know whether or not I meet these criteria,’ and it can be very overwhelming.”

Edwards urges those conducting community outreach to treat each person as an individual. “Please don’t talk down to us,” she says. “Include us in the conversation so we can understand. Don’t just have us there as a box that you check to say, ‘Yes, I included the community.’”

Towne notes that clinical trials can be a useful tool for patients.

“Especially for pain patients, the treatment options are limited, but there are quite a few trials looking at pain medications,” he says. “And outside the benefit of getting treatment is the thought that as a patient, you can help drive medical research forward.”

Helping others tomorrow by participating in studies today

Stacey Kennedy-Conner got involved with clinical trials at the age of 18, three years after she was diagnosed with lupus.

“I read up on [clinical trials], I asked

questions, so I wasn’t really hesitant,” Kennedy-Conner says. “Being a woman of color, African-American, a lot of my family, especially from the South, said, ‘You don’t wanna be a guinea pig.’ So I had that component in the back of my head, but I felt confident.”

Kennedy-Conner, now 35, has taken part in five trials. “This has been such a trying, trying illness, and I don’t want anyone else to go through this,” she says. “I was so young when I was diagnosed, and once I got out of the space of feeling low about it, I just thought, ‘What can I do to support it?’ And clinical trials were one way.”

Now, she meets with other individuals of color who have fears or hesitancy about getting involved in trials.

“Right now, clinical trials feel very distant from the patient,” Kennedy-Conner says. “Be very transparent—it may not help [the patient participating in the trial], but maybe it will help the next person dealing with the disease along the way. I feel like that would make a major difference, especially for communities of color.” ●

LEARN MORE ABOUT CLINICAL TRIALS

antidote.me
clinicaltrials.gov
uspainfoundation.org/pain/research

LEARN MORE ABOUT NEW MEDICATIONS

The FDA releases information about new drugs, who participated in clinical trials, and side effects. Learn more here: accessdata.fda.gov/scripts/cder/daf



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OPIOID RESTRICTIONS LEAVE BIPOC BEHIND: *A LOOK AT THE 2016 CLINICAL PRACTICE GUIDELINE FOR PRESCRIBING OPIOIDS, THE RECENT DRAFT UPDATE, AND THE DISPARITIES THAT REMAIN*

BY KIRSTEN BALLARD



Ethleen Peacock was born in Sierra Leone, a country in West Africa, with sickle cell disease—a disorder in which red blood cells are misshapen and have difficulty moving through the body, causing intense pain episodes called “crises.”

“[My family] said I was always crying,” Peacock says. “In my country, we do not have [adequate pain medication], so for 25 years, I lived in serious pain.”

Today, Peacock is a digital media specialist and women’s advocate,

often working with the organization Sick Cells to elevate those living with sickle cell. When she first moved to the United States, she encountered increased health care access—but it came with problems: “Sometimes, you need certain amounts of a pain medication, and they do not want to give it to you, because they feel you are an addict or you are just pretending to have pain.”

Sickle cell can cause severe pain and requires medical treatment. But when Peacock has gone to the emergency room in crisis, she has frequently encountered medical staff who don’t believe her, and has been made to “stretch” her

medication, lengthening the period of time between doses. However, she gets better responses when her white boyfriend asks on her behalf. “They don’t listen to me,” Peacock says. “They don’t really care. They just don’t believe and respect the request of a Black person.”

Opiate access for BIPOC: The numbers don’t lie

Kate Nicholson, executive director and founder of the National Pain Advocacy Center, underscores how common it is for BIPOC (Black, Indigenous, and people of color) and low-income individuals to not be prescribed opioids.



"Carmen Green [MD, an expert in pain management and health disparities] did early research about pharmacies not even stocking pain medication in Black neighborhoods," Nicholson says. "Research shows some medical providers actually rate the pain of Black and Indigenous people as being less severe than their white counterparts. There are also lots of studies showing that [members of these populations] do not receive equal analgesia even after surgery."

National restrictions on opioid prescriptions: 'Increased pain and suffering'

In 2016, the Centers for Disease Control and Prevention (CDC) released the Clinical Practice Guideline for Prescribing Opioids. Its dosage limits caused great harm to the pain community, says Cindy Steinberg, national director of policy and advocacy for the U.S. Pain Foundation.

"There's a big difference between what you would prescribe to an 80-year-old that's 70 pounds or a middle-aged guy that's 300 pounds, or a patient with an advanced disease as opposed to one in the early stages of a disease," Steinberg says.

Doctors and prescribers began reducing or cutting off individuals' dosages.

"They did that in an unsafe way. In a lot of cases, people were just immediately taken off opioids and they went into withdrawal," Steinberg says. In 2019, the FDA issued a warning against rapidly tapering patients off of opioids, or abruptly halting their use.

"It's caused people to go into depression or anxiety, and people had enormous amounts of pain," Steinberg says. "Some people died by suicide." The U.S. National

Academy of Sciences reports rising mortality for adults in the United States, largely attributable to "deaths of despair" like these.

"The issue we have seen with policy regarding opioid prescribing is that we are only measuring success in terms of gross drops in opioid prescribing and not looking at patient outcomes," Nicholson says. "The outcomes we have seen are increased pain and suffering, patients being dropped in care, and rising overdose deaths."

Updated Guideline draft: Some problems solved, but more exist

This year, the CDC issued a draft revision of the Guideline, which included the removal of specific dosage limits and durations of opioid therapy for acute pain.

The original Guideline excluded cancer treatments, palliative care, and end-of-life care—meaning the entire Guideline is not meant to apply to the treatment of these conditions. In 2019, the CDC noted that opioid therapy beyond the scope of the Guideline could sometimes be used in the case of sickle cell. The new draft officially added sickle cell to the excluded condition list.

However, providers became apprehensive following the original Guideline's release and discontinued filling opioid prescriptions even for individuals with cancer and end-of-life care.

"History has shown that these exclusions will not likely protect the patients the CDC is seeking to exclude," Nicholson says.

Beyond that, dictating that only some conditions merit opioid treatment is wrong, advocates say.

"Most people in pain management believe pain is pain, and there's not really a difference," says Steinberg. "Pain is fundamentally a disease of the nervous system and brain, so excluding certain conditions is a false choice. Are these pain conditions more worthy of pain control than other conditions?"

Acknowledging disparities for BIPOC is a start, but further work remains

Unfortunately, BIPOC individuals often have to navigate racial bias on top of the already-existing stigma surrounding opioid use. The new Guideline draft notes "specific, long-standing disparities in the treatment of pain."

"There is evidence that application of safeguards in opioid prescribing are disproportionately applied to Black patients," the Guideline draft states. "Pain being differentially untreated or undertreated as a result of clinician biases persists and demands immediate and sustained attention and action."

This acknowledgment is just a start, Nicholson says: "The opioid aspect [of disparities] is just the tip of a very deep iceberg." •

"Pain is fundamentally a disease of the nervous system and brain, so excluding certain conditions is a false choice. Are these pain conditions more worthy of pain control than other conditions?"



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SSDI EASES FINANCIAL BURDENS WHEN YOU CAN'T WORK —HERE'S HOW TO NAVIGATE IT

BY CALLI BARKER SCHMIDT



One of the most significant stressors experienced by those living with debilitating chronic pain is how to pay for the treatment and health care they need—and those concerns are multiplied for individuals unable to work any longer because of their pain.

Social Security Disability Insurance (SSDI) may alleviate some of that burden.

If you have worked at least five of the last 10 years in a job in which you and your employer paid Federal Insurance Contributions Act (FICA) taxes, you may qualify to receive SSDI benefits if you are unable to work for at least 12 months.

Here's how to apply

Qualifying for SSDI requires providing documentation surrounding work history

and medical records, including specific forms such as an Activities of Daily Living questionnaire.

"People often make mistakes in this part of the process, perhaps because they're not specific enough in their answers or they don't want to admit their struggles," says T. J. Geist, a principal advocate with Allsup, a company that helps its clients through the SSDI approval process.

There are several levels of appeals after an initial rejection. An appeal must be submitted within 60 days of receiving a denial letter. Reconsideration appeal forms include Form SSA-561 and a Reconsideration Disability Report, Geist says. Forms and additional information are available at ssa.gov/benefits/disability/appeal.html.

Throughout the sometimes years-long process of applying and appealing, an average of only one-third of applicants eventually are approved for SSDI benefits.

"People often make mistakes in this part of the process, perhaps because they're not specific enough in their answers or they don't want to admit their struggles."

How SSDI helps

Qualified recipients receive a monthly income based on how much they paid into the system through their Social Security taxes when they were working. Those approved for SSDI can also receive benefits for dependents under the age of 18.

SSDI offers return-to-work incentives for those whose health improves (learn more at choosework.ssa.gov/about/work-incentives). The program also offers Medicare benefits 24 months after the date when Social Security has determined you were eligible for SSDI.

Effective communication with your health care providers is key to getting SSDI benefits as quickly as possible, Geist says.

"It's a medical records-based program, so you need to make sure that you are seeking treatment and getting it documented," he says. "If your doctor feels like you can't work, you should apply [for SSDI] sooner rather than later, because it can take an extremely long time to process."

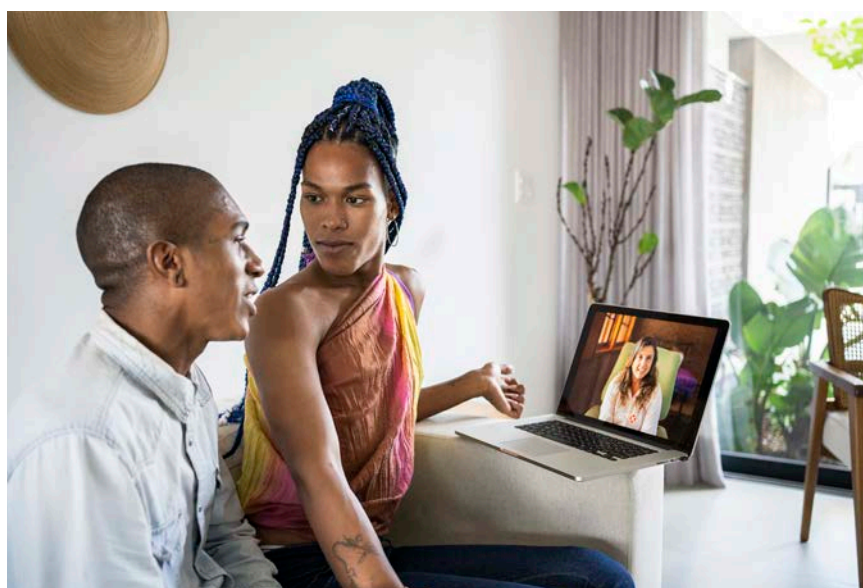
To learn more about SSDI, visit ssa.gov/applyfordisability. •





MAKING MEDICAL FORMS AND DOCTOR VISITS MORE INCLUSIVE: *CREATING SAFE APPOINTMENTS FOR TRANSGENDER, NONBINARY, AND GENDER DIVERSE INDIVIDUALS*

BY GRAYSON SCHULTZ



*“Getting misgendered by health care providers affects my ability to communicate my needs and trust the providers. **If they don’t honor my gender, do they honor my need for safe and effective treatment and care?**”*

Medical appointments that are not affirming of patients’ gender, name, and pronouns can be traumatic for individuals who are transgender, nonbinary, and gender diverse.

Similarly, medical forms that are appropriate for cisgender and heterosexual people often aren’t a good fit for individuals in the LGBTQ+ community.

Here are some ways to fix that.

Gender assigned at birth or sex

The gender we were assigned at birth is often assumed to be what our gender continues to be as we age. For transgender, intersex,

or nonbinary people, that isn’t necessarily the case.

If a provider or clinic needs sex and gender information from their patients, the best option is to ask for gender assigned at birth and current gender identity, with blank spaces for folks to self-identify.

Pronouns and chosen name aren’t ‘preferred’

Some paperwork asks for both an individual’s legal or birth name and a name they might otherwise go by. However, they often request a “preferred” name or pronouns, insinuating that it’s optional to use this name. It isn’t. Being deadnamed (called by the name they no longer use) can have a

significant psychological effect on these individuals and is something providers should avoid.

Relationship status

Many people never get married. Asking for their “relationship status” instead of “marital status” allows folks to share more: Do they date multiple people? Are they asexual or aromantic? Do they live with a partner? This opens the door to talk about important issues that could have bearing on the individual’s health.

Are there specific words you’d like to use for certain parts of your body?

For some transgender folks, using terms like breasts or penis can cause gender dysphoria. Hearing that when

you might already be activated by, say, having a pap smear as a trans man can be really difficult. Genitals may be a preferred term, or chestfeeding rather than breastfeeding. Asking about the correct terms helps providers demonstrate they are safe and trustworthy.

Gender-neutral language

There are great examples of gender-neutral language, from the standard Southern “y’all” to “theydies and gentlethems” and beyond. Forms don’t need to use stand-ins for people’s names, like s/he, which fails to describe everyone.

From Shakespeare and Chaucer to the current dictionary definition, the use of “they” to describe an individual is correct and grammatical English: health care spaces should

use the term, too. In addition, use other neutral terms, such as: birthing parent rather than mother, pregnant person rather than woman, child instead of daughter/son, and partner/spouse rather than husband/wife.

Gender-affirming care is vital for improved health outcomes

It’s OK to correct providers who use the wrong name or pronoun for you—or to bring someone with you to appointments who can take on that task. Stephanie Budge, PhD, a gender-affirming psychologist and part of the Trans CARE Collaborative, also suggests planning a pleasurable activity for right after what may be an upsetting appointment.

Being misgendered during health care appointments, or receiving care that is not gender-affirming, can be

traumatizing and can contribute to anxiety and depression, Budge says.

“Folks tend to avoid going to their medical provider or seeking therapy because they are worried about how they are going to be treated, which only exacerbates these negative effects,” she says. •

For great ways to make clinic forms and spaces more inclusive, check out:

- **A Clinician’s Guide to Gender-Affirming Care** by Chang, Singh, and dickey
- **Gender Spectrum:** genderspectrum.org
- **PFLAG:** pflag.org
- **The National LGBTQIA+ Health Education Center from The Fenway Institute:** lgbtqihealtheducation.org
- **The Human Rights Campaign:** hrc.org
- **Think Again Training & Consulting:** thinkagaintraining.com

To find health care providers who are LGBTQ+-friendly, see if your benefits include care coordination services such as Included Health. If not, check out:

- **GLMA:** glma.org
- **OutCare Health:** outcarehealth.org
- **Trans Care Site:** transcaresite.org
- **Trans in the South:** bit.ly/transinsouth
- **Your local PFLAG chapter or LGBTQ+ center**
- **Your local Planned Parenthood**
- **Supportive online communities**
- **Clinics that have done the work to be LGBTQ+ friendly and display “safe space” stickers**

GENDER-DIVERSE INDIVIDUALS SPEAK OUT

Long after legally changing their name, Quinn—who has fibromyalgia and is seeking affirming specialists to further explore test results that suggest an autoimmune condition—continues to get called their deadname by health care providers. This puts the burden on Quinn to correct them. “I want providers to know that they have to do their homework,” they share.

When providers haven’t, it shows. Charis, who lives with axial spondyloarthritis, “almost always get[s] misgendered” in medical notes. “Getting misgendered by health care providers affects my ability to communicate my needs and trust the providers,” they share. “If they don’t honor my gender, do they honor my need for safe and effective treatment and care?”

Sloane—who lives with cerebral palsy and regularly experiences

painful spasms due to muscles that are overly toned to support misaligned joints and bones—was misgendered after a provider inputted their pronouns into an electronic health system without their consent or knowledge. The fact that Sloane, living in a heavily transphobic area, could not see that their pronouns were listed in the system came up in abrupt and distressing ways—such as when they were about to have top surgery, a procedure to remove chest tissue that can help make the outside match the inside for transgender, nonbinary, or gender-diverse individuals.

“While I was getting wheeled into the OR, the person said something like, ‘Don’t be upset if I call you the wrong thing! I’m always calling my kids the wrong pronouns, too! He, she, it, who can remember anymore!’” Sloane recalls.





WOMEN'S PAIN IS WIDESPREAD, *BUT RESEARCH LAGS AND DISBELIEF ABOUNDS*

BY KIRSTEN BALLARD



For as long as she can remember, Claudia King has experienced pain with urination as well as pain during and after sex. She thought it was normal. She was diagnosed with severe endometriosis at 17, but later, when a urinary tract infection wouldn't clear up, a doctor wrote her off as having a sexually transmitted disease.

"There were no other questions, no attempt to discuss symptoms and figure it out. I just 'must' have an STD," she shares. "This was humiliating. It was just over a month from my wedding, and this doctor (in my mind) is calling me a slut." After a barrage of embarrassing and invasive tests revealed she did not have an STD, King was sent to her gynecologist for further testing.

Her gynecologist correctly diagnosed King with interstitial cystitis (IC), a painful bladder disorder. But since her gynecologist didn't feel familiar enough with IC, he offered her only a few days' worth of pain medicine and said he was not comfortable prescribing more.

Like many individuals living with

Women disproportionately experience chronic pain—but remain underrepresented in research

Monica Mallampalli, PhD, MSc, is an expert in women's health and the senior scientific advisor for HealthyWomen (healthywomen.org), an organization that provides health-related resources and programming to women so that they can make informed decisions for themselves.

Studies have found that 70% of people living with chronic pain are women. Yet 80% of pain studies are conducted on men or male mice, according to a report from Harvard Health Publishing. In fact, until 30 years ago, it was not common to include women in clinical studies at all.

"We don't know how a certain medication will work for women," Mallampalli says. "We don't even know the extent of the biological mechanisms that are different between men and women; they still need to be researched."

Mallampalli notes that women need equity in pain research and treatment. "If you don't have equity, you will never have equality, because if your health is bad and you are not getting the treatment you need, you will never achieve true equality," she says.

"Migraine is such a great example,"

"There is no benefit to being a martyr: If you have to get a man to advocate for you because that's what you need, then do that. Ignoring disparities doesn't make them go away."

chronic pain, King has been labeled a drug seeker or denied medication strong enough to treat her pain. Nurses have made comments or challenged her to ask for morphine only if "really needed." King brings her husband with her to appointments as an advocate and to provide additional support. "Of course, as I say this, I realize that this was actually getting a man to advocate for me because I felt like my own word wasn't good enough," she says.

she adds. Women are twice as likely as men to have migraine. "These women are debilitated to the point they can't even work, and most of the treatments out there don't work well for migraine patients, particularly women."

There is a lack of scientific information surrounding migraine and many women's health conditions, including endometriosis, polycystic ovary syndrome, and uterine fibroids, because "certain conditions were not funded," explains Mallampalli.

"Policy change takes time," she says. "That's why self-advocacy is so important. If you're diagnosed with something, it is important to inform and educate yourself on your condition. Ask your clinician if the treatments are available, if they would work for you. The FDA has made some information available now about whether a drug is being approved or has just been approved. You can go find who was in that trial—were there more men than women? Were there any side effects that they found?"

She also acknowledges the importance of traditional advocacy. "Research funding happens because of advocacy. It is so key for people to speak up," she says. "How do they get funding dollars? Because advocates are so passionate, they go to Capitol Hill, they bring attention to an issue, get Congress to hear them. And then, Congress can require the federal agencies to respond."

For women who don't feel heard

Mallampalli notes that the reality for many women is not being listened to or believed, even when they're knowledgeable about their condition or pain.

"What I have heard mostly [from women] is not being heard, not being believed, being told it's all in your head," Mallampalli says. The women she speaks with "feel very frustrated. [They] like to explain and communicate what they're feeling. Clinical visits are very short. The clinicians do not have time to listen, but I think communication with physicians is crucial. Communication is so important to get a full picture."

King advises women to bring a list of questions to appointments so they can make sure their concerns are addressed. "Have your list ahead of time, and don't feel bad about asking legitimate questions about treatment, symptoms, medication," she shares. "And, like me, if your advocate is a man, that's OK. There is no benefit to being a martyr: If you have to get a man to advocate for you because that's what you need, then do that. Ignoring disparities doesn't make them go away." ●



GENDER-BASED HEALTH STIGMAS CAN EXACT EVEN HIGHER TOLL ON BIPOC MEN

BY EMIL DEANDREIS



There are many reasons that men may avoid going to the doctor. Whether it's pride or machismo, finances, culture, or just wanting to avoid hearing "turn your head and cough," men often put off these exams for too long.

"[Many] men reach a certain age and say, 'I ain't never going to the

doctor,'" says New Orleans-based Eric Griggs, MD, a community medicine and wellness doctor and the health and wellness chair for 100 Black Men of America (100blackmen.org), an organization that provides mentoring and development opportunities to African Americans. "But the 30s kick in, testosterone drops, genetics kick in, prehypertension, pre-diabetic, BMI is up," so doctor visits become more necessary. But men still hesitate to go.

One of the goals of 100 Black Men is to chisel away the stigma around men's health. Men are less likely than women to seek treatment for, or even mention, mental or physical health issues.

"It's a machismo thing," Griggs says. "The harder we work, the more valuable we see ourselves. It's no surprise women live an average of seven years longer than men. When I give these talks to men, I start out

with, 'Have you started to pick out your wife's next husband?'"

Vulnerability is vital

Griggs uses humor, connection, and trust to have these important conversations with men.

During a recent presentation to a group of men, Griggs asked, "Has anyone ever had their soldier just fall down in the middle of the fight?"—before pausing to let the audience process the erectile dysfunction analogy.

Only a few men responded, until Griggs put his own hand in the air, and then, "every hand in the room went up," he shares.

Griggs places great emphasis on the power of men being vulnerable, which is why his example resonated with his audience: he allowed himself to be one of them.

"There's a distrust of doctors for Black people that goes back centuries, and then you don't see any [doctors] who look like you, or who can understand your experience," he shares. "If you're talking about your health, where you could die, it's really scary walking down that path following a stranger."

Even when BIPOC men do push through the stigma and lack of providers who share their experiences, they often face further barriers.

One man's story

Isiah Lineberry grew up with what he described as an athlete's mindset: to "suck it up" when you got hurt. "I learned to persevere through pain," he shares.

But when back pain first sent him to the emergency room in 2012, his subsequent experiences with physicians have left him suspicious and hurt.

He recalls, "The exam took place and the physician went behind the curtains and said to the nurse, 'I don't believe this guy at all. I'm going to change the diagnosis and

indicate I don't believe he has an injury.'" Lineberry filed a formal complaint, but nothing changed.

In 2015, Lineberry had a heart stent procedure and was treated with statins (drugs that reduce fats or triglycerides in the blood) without permission or consultation with his family. This triggered gout, causing pain that worsened over the years.

When Lineberry lost use of his hands, he received one cortisone shot and then was denied further pain medication without explanation other than "there's nothing more we can do." Left to self-medicate, his overreliance on over-the-counter painkillers contributed to severe kidney damage.

By 2021, after years of pain, Lineberry was again diagnosed with gout, with the addition of Sjogren's syndrome and inflammatory arthritis, without a definitive diagnosis for his chronic stiffness and pain. However, in March 2022, a patient-centered physician, surprised by the lack of concern shown by other physicians for Lineberry's pain, prescribed long-term medication that has almost entirely eliminated his pain and stiffness from suspected lupus. The physician was a person of color.

There's no question, Lineberry says, that his pain was minimized. After learning more about historical patterns of bias and unequal medical treatment, and realizing that all of his negative experiences were with white physicians, Lineberry believes that as an African American man, his race was a major reason why.

"I'm always cautious, because I can never tell how a physician will respond," Lineberry says. "There's an undercurrent of, 'I hope that the doc isn't dismissive or trying to belittle me.' Every new clinician visit, that's always in the back of my mind. It's real."

Paying it forward

Recently, Lineberry came out of retirement, having formerly worked

"It's a machismo thing. The harder we work, the more valuable we see ourselves. It's no surprise women live an average of seven years longer than men. When I give these talks to men, I start out with, 'Have you started to pick out your wife's next husband?'"

in the areas of homelessness prevention, rural health, and more, to work as CEO of Harrisburg Family Health Care, a provider that sees uninsured and underinsured individuals without any cost to them. "We're providing care to people who otherwise wouldn't get it," Lineberry says. "It was my adverse experiences, in part, that led me here, where we treat patients with dignity and respect."

Griggs uses the acronym "MEHE" to represent 100 Black Men of America's core principles: Mentorship, Education, Health and Wellness, and Financial Empowerment. That acronym paints a picture of one man passing these virtues onto someone else, who in turn will do the same. Lineberry and Griggs are devoted to living out that standard.

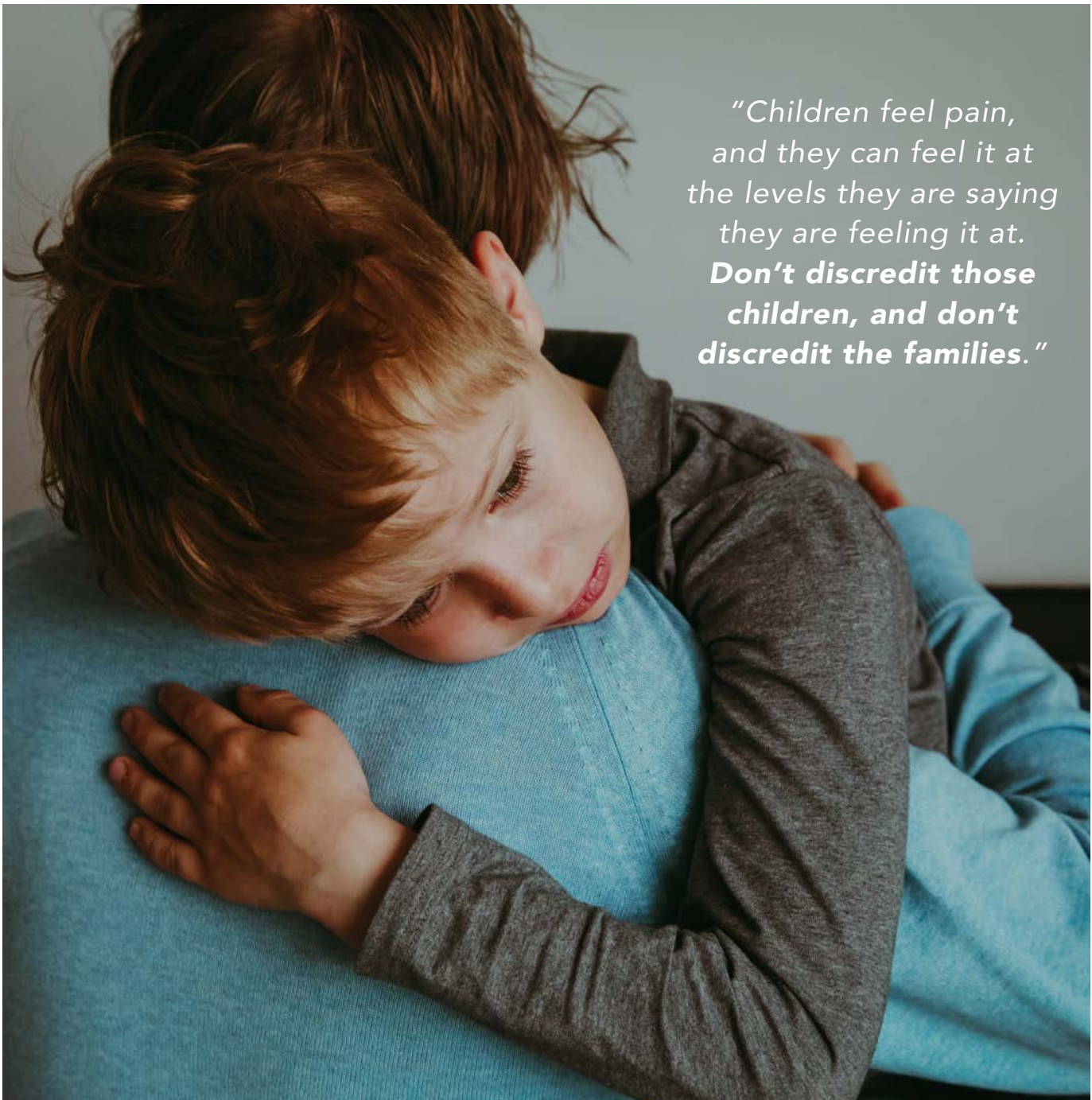
"I like to joke," Griggs says. "Men like to joke about their health. We can still have the jokes, but it's time to have them with the solutions." ●





DISBELIEF, SCHOOL CHALLENGES, AND COMPREHENSIVE CARE: *TACKLING BARRIERS FACING CHILDREN LIVING WITH PAIN*

BY EMIL DEANDREIS



*"Children feel pain,
and they can feel it at
the levels they are saying
they are feeling it at.
**Don't discredit those
children, and don't
discredit the families."***

In the United States, 50 million individuals live with chronic pain—about 1 in 6 people. This metric, while staggering enough, only includes adults.

To shed more light on pain experienced by children, the U.S. Pain Foundation conducted a survey in 2021 regarding pediatric pain and published a findings report. The responses of the 125 families participating in the survey painted a bleak picture of struggles across the entire spectrum of pediatric pain treatment.

For instance, 82% of parents indicated their child has had pain at least half of their lives. The emotional toll is clear, too: 84% have experienced anxiety, 79% have felt isolated, and 48% expressed guilt about being sick. Alarming, the survey found that more than one in five of their children had considered suicide, 16% had carried out self-harm, and 4% had attempted suicide.

Much remains ambiguous about youth pain—and there are many challenges that stand in the way of effective treatment for children.

Letting children speak up

Parents often play middleman, helping their children communicate with medical staff and process information about their condition.

“Many children look to their parents to do most of the talking during [appointments],” says Robert Wilder, MD, PhD, an anesthesiologist at Mayo Clinic who specializes in pain and works in pediatric and adolescent medicine. He also serves as president of the Society for Pediatric Pain Medicine (SPPM | pedspainmedicine.org). “Sometimes a parent will dominate the interview even when the child is willing and able to answer.”

Even if the motivations behind these actions are good, such patterns from parents can distort the treatment process for children. Allowing children to speak up about their pain and needs whenever possible is crucial to getting the best treatment possible.

Difficulties in school

Challenges at school are intertwined with children’s pain as well.

“Stress from school can trigger or amplify the pain experience,” shares Cristina Benki, PhD, a pain psychologist with the University of California San Francisco’s (UCSF) Benioff Children’s Hospitals who works with kids and teens living with chronic pain and illnesses. “They may have less motivation to go to school because they’re in pain.”

Unfortunately, many of the school environments Benki and Wilder have seen aren’t ideal for children living with pain or other health challenges.

“School districts vary widely in their willingness to support children with chronic pain,” Wilder shares. “Some are quite supportive in allowing accommodations to allow patients to stand up in class, have extra time in passing between classes, or have water bottles. Others do not allow any accommodations at all and prefer to simply send patients home.”

School closures during the COVID-19 pandemic highlighted how some students thrive while working at their own pace from home.

Wilder elaborated, “Recent evidence says that pediatric chronic pain actually decreased during the pandemic. This data suggests that school stress worsens chronic pain.”

Access to comprehensive care

Of families surveyed by U.S. Pain, 65% couldn’t find a provider who was knowledgeable about their child’s condition, and 38% said that their children would benefit from, but cannot access or afford, working with a pain management specialist. Many insurance companies will only cover a certain amount of physical therapy or occupational therapy a year, and children living with a chronic illness are apt to go through those appointments quickly.

A significant number of families expressed a desire to access restorative therapies. But unfortunately, more than 60% of survey respondents reported having to forego services and treatments due to the cost.

“People just say, ‘You should go try a massage,’ ‘Go try acupuncture,’ ‘Go try heat therapy,’ but those treatments all have a dollar sign associated with them,” says Casey Cashman, director of the U.S. Pain Foundation’s Pediatric Pain Warrior program.

Hope starts with believing kids about their pain

While the landscape of pediatric pain can seem grim, children with pain may actually have a greater chance of improvement than adults with similar issues: “With chronic pain in pediatrics, especially because children’s brains are more flexible and can adjust more easily than adult brains, we see a better prognosis for treatment of chronic pain with children than adults,” Benki says.

One important consideration is to recognize that children’s pain is real and examine its effect on the child’s life as a whole.

“If you look at the definition of pain put out by the International Association for the Study of Pain, pain is both an emotional and physical experience,” Benki says. “In terms of treating pain, you have to address both. If you’re not addressing pain through that lens, you’re not getting full treatment.”

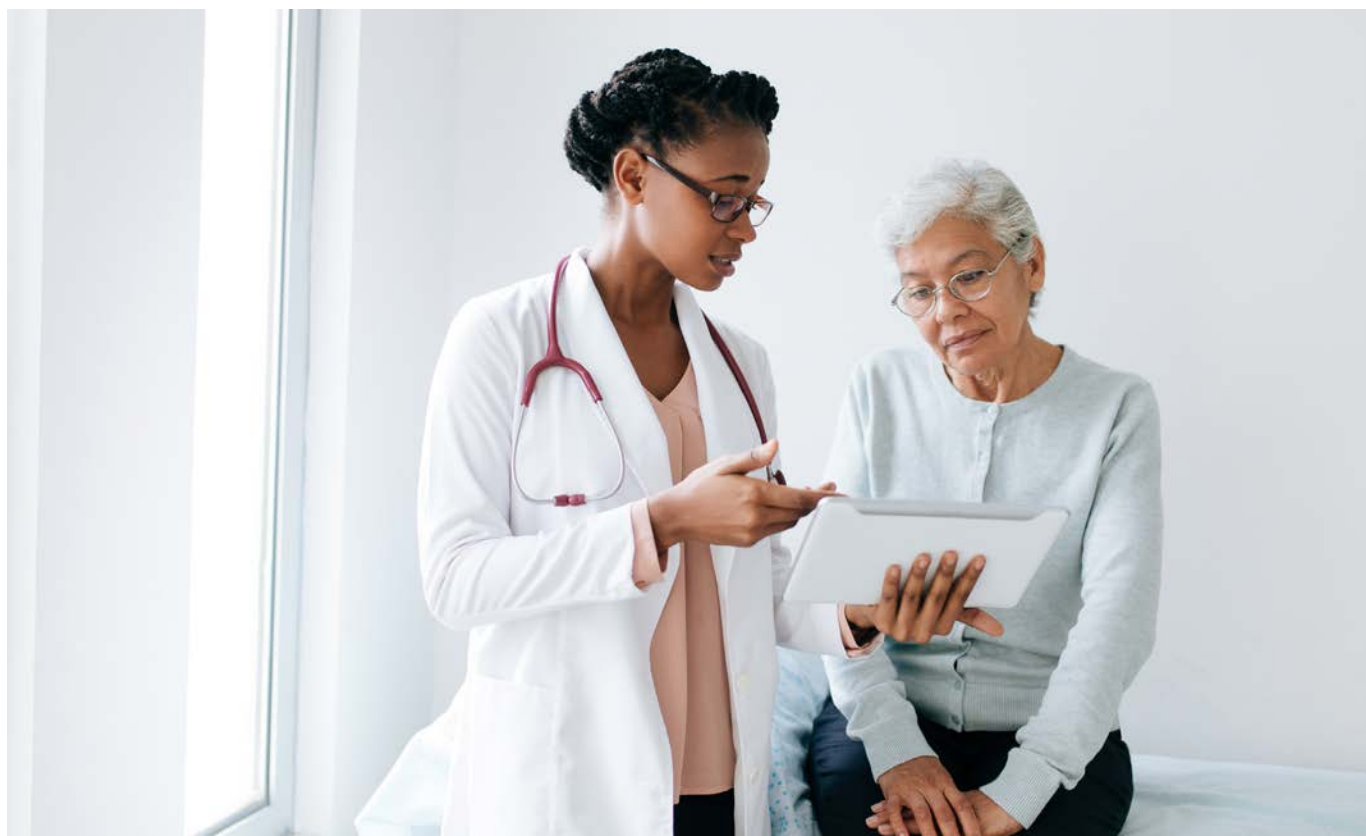
A successful path forward also starts with schools, society, and health care providers believing children about their pain. Of the families taking the survey, 58% felt their provider didn’t believe their child or take them seriously.

“Children feel pain, and they can feel it at the levels they are saying they are feeling it at,” Cashman says. “Don’t discredit those children, and don’t discredit the families. Hear them, listen to them, believe in them, because the minute you believe in them, that opens the doors for so much better communication. If a child and family feels that support, the chance of a greater outcome and having them reach their goals is going to be so much greater. If we all believe in them, then they can believe in themselves.” ●



AGING INDIVIDUALS' PAIN SHOULD NOT BE IGNORED: *COMMUNICATION AND ACCESS ARE VITAL*

BY KILEY REITANO



Many people living with chronic pain have at some point felt dismissed by medical professionals—and for older individuals experiencing pain, their age often becomes an additional barrier when they seek out medical help. When older patients' pain is overlooked because of their age, it can affect quality of life and even life expectancy.

Telehealth technology has been a positive change for many—but for some, it is not a workable solution, whether because of an unfamiliarity with the tools or the absence of a hands-on diagnostic approach. This may significantly impact individuals with limited mobility, hearing, or vision, also common as people age.

Lindsay Clarke, senior vice president of health education and advocacy at the Alliance for Aging Research (agingresearch.org), notes that telehealth can be particularly challenging for aging individuals.

"More than 60% of adults over the age of 65 are smartphone owners, and many are very adept at using them," Clarke says. "However, providers should consider font size, volume controls, ease of use, and other accessibility standards when designing and offering telehealth and other health care technologies."

Transportation can be a challenge as well. Not every person can drive or has a caregiver to bring them to appointments. The physical and financial cost of ride-sharing and public transportation limits some individuals'

options even further. Clarke suggests contacting the local Area Agency on Aging to ask about local organizations that can help with rides.

Ellen Lenox Smith and Stu Smith, co-directors of Medical Cannabis Advocacy for the U.S. Pain Foundation, offer insight from an advocacy standpoint. And with their own health issues—Ellen lives with Ehlers-Danlos syndrome and sarcoidosis, and Stu has Parkinson's disease—they have firsthand experience when it comes to health care disparities, including those related to age.

Ellen identifies another challenge for seniors: traveling longer distances to get to appointments. For individuals living with pain who can't find help from a nearby physician, options may be limited. Traveling to find second opinions or doctors specializing in certain conditions can cause a significant physical, mental, and financial burden.

"Traveling to the right medical specialist [that may be out of state] isn't always covered [by insurance]," Ellen shares—and many older individuals are not able to travel long distances to find the right specialist because their medical conditions or pain make the trek impossible. "Adding [medical] complications to aging becomes a real problem."

When pain is brushed aside

Some individuals living with pain are incorrectly told they are overreacting or that pain is a natural part of aging. For people with serious underlying conditions, hearing the words "you're fine; you're just getting older" from a physician can cause feelings of helplessness and belittlement.

"If you have any symptoms as you get older that are getting misinterpreted as being old and whiny, doctors won't search for a solution," Ellen says. "It's really hard to fight the battle, and if you don't

have the type of personality where you stand up for yourself, you get lost in the system."

For those who may struggle to even get to an appointment, having their pain be dismissed due to their age shows how badly the current health care landscape is failing aging people with pain.

"Older adults are less likely to report their pain because they may not want to be perceived as complaining, or they may believe that it's an unavoidable part of their disease or disease treatment, that there are no treatments for their pain, or that their pain is a part of aging that can't be changed and must instead be accepted," Clarke shares. "More training for clinicians on treating pain in older patients could help increase self-reporting and lead to more effective treatment plans."

Creating a clinical environment in which individuals feel comfortable speaking about their ailments and pain is vital, Ellen adds: "Many elderly people find it embarrassing to bring these issues up that probably should be spoken about."

Sometimes, this leads to incorrect diagnoses or incomplete treatment plans. Lack of communication can also cause serious issues with medication interactions.

"[Doctors] have an obligation to present the best plan for people," Stu says. "I'm not sure they do that with elderly people. ... When you have a special condition, it's very difficult to get the amount of time you need."

Advocating for equitable care

As a physical therapist assistant with 22 years of experience, 19 of those providing care to seniors, Teresa Gardner has seen firsthand the struggles and disparities many aging individuals face. Her place of employment offers assistance with telehealth and transportation. "If it were not for our employees helping,

many would not be able to be seen," she says.

Gardner encourages open communication between individuals and their health care providers as they work to find an effective treatment plan, using trial and error to find what helps with pain and what does not.

"Never stop being your own advocate," Gardner advises. "Push for the medications that help, push for the therapy to help with pain, learn alternative approaches to pain, practice self-care, learn your limits."

Urging health care professionals to treat aging people with respect and empathy, Ellen and Stu note that older patients are not looking for a cure-all, but rather belief, understanding, help, and direction: "Doctors need to remember that it is OK that you can't fix us." But aging patients with chronic conditions still deserve the best quality of life medicine can provide. •

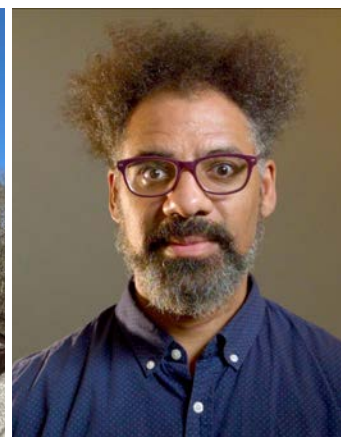
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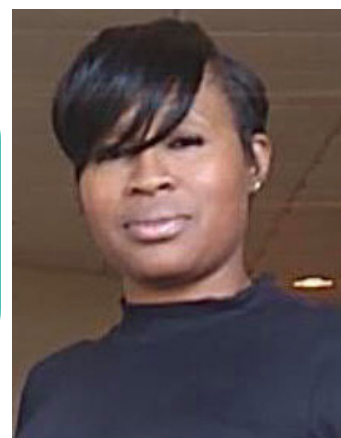
PROFILES

STORIES THAT SHOW THE REALITY OF PAIN, AND BRING INSPIRATION AND HOPE



ADVOCATING FOR BETTER CARE

As you read this magazine, you'll meet individuals facing health care disparities and learn about their experiences.



➤ EMPOWERMENT THROUGH STORIES

For 12 years, the *INvisible Project* has brought to light the often-hidden challenges faced by those living with chronic pain. Through raw and inspiring stories and personal photographs, the profiles of the following individuals and their support systems provide an intimate glimpse into what it's like to encounter disparities in health care—and to thrive in spite of it. >>>



SCAN THE QR CODE
for the digital article

Manisha Gupta, PhD

From Scientist to Patient: When Health Care Equity Becomes a Personal Struggle



Some of the hobbies Manisha has enjoyed in the past—cliff jumping, skydiving, helicopter flight lessons, white-water rafting, hiking, and trekking—have become more difficult or impossible to continue as her spine and musculoskeletal conditions have worsened. Making the switch to lower-impact activities such as walking and swimming has been a major mental and physical adjustment.

Manisha Gupta, 39, has battled a constellation of chronic pain symptoms for more than 15 years. And for just as long, she's fought a parallel battle: getting providers to believe that her pain is real.

Manisha was 23 and doing development work in India when severe bilateral sciatic pain abruptly announced itself in her life. She was rushed to the emergency room over concerns of exhibiting cauda equina syndrome, a rare but serious condition that can lead to permanent neurological impairment. Surgical intervention to decompress the spinal nerve roots is usually recommended in these cases, but because Manisha was young and alone in a different country, surgeons decided not to move forward. Since then, she has accumulated a number of additional injuries and diagnoses that have resulted in chronic migraine, neck, back, myofascial, and multi-joint pain. She also regularly experiences neuropathic pain throughout her entire body, including burning, electric shocks, and stabbing sensations.

After completing a PhD in social psychology, Manisha moved to Washington, D.C., in 2015, where she worked on science policy and advocacy with policymakers, researchers, and practitioners, trying to combat health disparities and the chronic pain

epidemic. Her chronic pain conditions have made it difficult for her to maintain steady employment since the COVID-19 pandemic began, but she has remained in Washington, D.C., because it is one of the only places in the country where she qualifies for the health care assistance necessary to manage her disabling conditions. Manisha has faced several obstacles in her pursuit of a comprehensive pain management treatment plan.

“As a woman of color who has had multiple invisible disabilities from a young age, it can be hard to find doctors who are willing to listen and take your symptoms seriously,” Manisha says. “Women and BIPOC are more likely to be targets of bias, stigma, and discrimination when seeking access to pain care—data shows we often face longer waits to be diagnosed and are treated less aggressively for our acute and chronic pain conditions, leading to poorer outcomes and higher rates of morbidity.”

EVEN WITH TOOLS IN PLACE, DISPARITIES ABOUND

With two doctors as parents, and professional experience collaborating with medical and legal professionals, Manisha plays a very active role in her health care. In her 15 years with chronic pain, she has solicited advice from family members and friends



“Trust in the validity of your experience. It’s OK to be ‘difficult’ and to speak up if your concerns aren’t being taken seriously.

Many women and BIPOC are starting to voice similar frustrations about their experiences—and these conversations are helping to push the envelope on addressing systemic bias and barriers in our health care system.”

who are medical professionals and has researched her symptoms, possible diagnoses, diagnostic tests, and treatment.

Despite that, she has repeatedly been given generic instructions such as to lose weight, exercise more, or use over-the-counter painkillers. For years, the only referrals she received for pain management were ones she researched and pushed for.

“Like many women and BIPOC, I kept getting referred to a psychiatrist when I asked for help managing my chronic pain conditions,” Manisha says. “We have to work that much harder to try to get providers to take our symptoms seriously, and offer us the same breadth of pain management treatment options as they would other patients walking into the room without questioning if their conditions are real, or if they can afford it, or if they deserve access to those services.”

SYMPTOMS DISMISSED, SUGGESTIONS IGNORED: ‘YOU’RE TOO YOUNG’

In several cases, citing Manisha’s young age, providers have told her they can’t justify referrals, additional testing, or treatments, stating that they’ve “done everything they can.”

She recalls, “Every time I would go to the doctor’s office, I would ask them, ‘Is it possible I have chronic nerve damage? Is it possible I have XYZ?’ and I was told, ‘That’d be highly unusual; you need to calm down; you’re too young.’”

She’s been told many times that her pain is in her head, that her symptoms are predominantly psychosomatic, a result of anxiety or stress. Manisha was dealing with chronic pain from her neurological and musculoskeletal conditions for more than 10 years before she was able to get a referral to pain management—and only under the label of fibromyalgia. In her experience, she says, women are frequently diagnosed with fibromyalgia when they have complex pain conditions. She has found that the diagnosis can carry heavy stigma and bias, and often halts further investigation into a patient’s other symptoms. These delays can cause those conditions to worsen and pain to become more intractable to treatment.

Manisha has also dealt with a difficult cycle for years in which she can’t get the accommodations she needs at work and her work conditions have exacerbated her pain, causing other



Above: Manisha graduates with a PhD in psychology, incorporating social, cognitive, and neuroscience training.

Below: Manisha credits her neurorehabilitation team, consisting of physical, occupational, and speech therapists, and physical medicine and rehabilitation physicians, as playing a vital role in her diagnostic journey and recovery.





Above: Manisha is pictured with U.S. Sen. Mazie K. Hirono, the first Asian American woman to be elected to the Senate. As a science and technology policy fellow, Manisha helped the senator advance issues of diversity, equity, and inclusion in STEM, education, health, immigration, and criminal justice reform.

Below: Manisha goes white-water rafting in India.



instances of feeling under the microscope in the doctor's office.

"I've had it insinuated that I'm malingering, or trying to use providers to get access to unemployment or disability benefits by asking them for help securing accommodations that could enable me to return to full-time work," Manisha shares.

Ironically, Manisha has found that her Medicaid coverage has provided her with increased access to a range of conservative,

interventional, and alternative pain management treatment options that she has routinely struggled to get covered by top-tier commercial plans in the past. While being dependent on Medicaid comes with its own challenges, for now Manisha is grateful that it provides her access to leading research hospitals and treatment programs. The coverage allows her to seek out routine care to help manage her chronic conditions, decreasing the chances that they will become permanently disabling.

Manisha has even had providers joke, after seeing her extensive medical record, that she must love going to see the doctor. "I've been labeled a hypochondriac, a doctor shopper, a 'frequent flyer,' a drug seeker. Why would anyone want to do this?" Manisha wonders. "I don't understand why they'd think a person would enjoy going over and over to the doctor, begging for help."

THE CONSEQUENCES OF DISBELIEF

Not being believed affects how Manisha sees herself and her pain.

"Once providers gaslight you into believing that there's no physiological explanation for your pain, or your pain is all in your head, then you start to believe that as well," Manisha says. "I started to question my own judgment and ignore potentially dangerous symptoms because I was convinced they weren't real."

When women and BIPOC aren't believed about their pain and aren't offered help, it's easy to become desperate—and that can be dangerous, Manisha says: "The more we feel stigmatized, scrutinized, and invalidated about our painful conditions, the less we will be motivated to seek help from our providers, and the more we are at risk for resorting to unsafe and harmful methods for managing our pain."

Recent tests, which Manisha has had to push for, have suggested an autoimmune cause of her painful small-fiber neuropathy. She doesn't have all the answers yet, but she's found hope in the potential of new therapies, as well as in providers who trust her judgment and are willing to help her find ways to improve her day-to-day function while they continue to search for a comprehensive diagnosis and treatment plan.

Manisha has also found the validation, motivation, and courage to continue with her pursuits by hearing the stories of other young women and BIPOC chronic pain patients who are facing similar challenges. She says it can be particularly difficult for women of color to learn how to advocate for themselves.

"We tend to blame ourselves for our struggles, and don't believe that we deserve access to better treatment," she says.

To other women of color, she shares, "You're not alone. You're not the problem, or the one who is broken—it's the system. Trust in the validity of your experience. It's OK to be 'difficult' and to speak up if your concerns aren't being taken seriously. Many women and BIPOC are starting to voice similar frustrations about their experiences—and these conversations are helping to push the envelope on addressing systemic bias and barriers in our health care system."

—Emil DeAndreis





William Hatchett

Fighting for Access to Treatment for Dual Diagnoses

William meditating and doing yoga on a birthday hike with his son.

William Hatchett II knows that money can't buy happiness.

But he has learned that it can buy access: to better medications, better therapies, and doctors willing to treat his multiple conditions. William fights that disparity in care every day in his own life and through his volunteer work.

William, 45, was born and raised in Detroit, but reconnected with his family's Arkansas roots when he started college at the University of Arkansas at Pine Bluff. An athlete in high school, William began experiencing back pain when he was 15 that intensified as he got older.

He married, started a family—his daughter Alynn is now 22, son William III is 15—and began a career in the transportation industry. But his back pain worsened, and William was fired after 15 years because he could no longer work a regular schedule.

Without health insurance, William depended on free clinics for treatment of his chronic pain. At 30, he had been diagnosed with Crohn's disease, and then with rheumatoid arthritis and ulcerative colitis. Crohn's disease and ulcerative colitis are inflammatory bowel diseases that affect the digestive system,

causing pain and a variety of other symptoms; in rheumatoid arthritis, the immune system attacks the tissue and joints, causing inflammation and pain throughout the body. William's treatments were a patchwork of steroids and other low-cost options.

A ROLLER COASTER OF TREATMENTS AND INSURANCE HURDLES

When Congress passed the Affordable Care Act, William's situation improved drastically. With his new health insurance, he could now begin receiving infusions of a biologic drug that could more effectively treat his diseases.

William spent four years getting monthly infusions, and was distraught when he showed up for treatment one day only to find that his insurance no longer approved the infusions.

His health took a nosedive, and William relapsed.

The Crohn's sent him to the bathroom "30 to 40 times a day." He shares, "I was probably 110 pounds, and I am 6 feet tall. My son would help me get to the bathroom and back to bed, and that would be the extent of my day."

Eventually, he learned there had been a clerical error and he

qualified for the infusions after all. But after eight months off, he couldn't restart on his prior biologic protocol. "You have to be on [the biologic] for life, so it was no longer effective," he explains.

His provider suggested a treatment that would require William to give himself daily injections, but he refused: "There was no way I was going to be stabbing myself in the legs every day. I told them never mind, I was just going to figure it out."

William's decision alarmed his team of medical providers—the gastroenterologists, nutritionists, therapists, neurologists, and other professionals William finally had access to once he had insurance. Somehow, they managed to get him qualified for a different biologic infusion treatment, which William said is the gold standard for his conditions.

"It's access. It's all about access," William says. "When I went for my first infusion, I was next to an older white guy who was also getting [the new biologic]. I asked him when he was diagnosed with Crohn's and he said, 'Last month.' Meanwhile, I had been waiting four years."

PHYSICAL ACTIVITY PROVIDES NEW MOTIVATION

William was finally getting the treatment he needed, but he needed to do more. As a former athlete, he knew that if he could get to a proper weight and improve his muscle tone, he would feel better. "The stronger my midsection is, the less pain I feel from my Crohn's disease," he says. "Exercise also gave me an appetite, so I no longer had to force myself to eat." With help from his nutritionist, William's weight increased from 110 pounds to 145.

After getting the OK from his medical team, William went from physical therapy and water aerobics to walking and strength training at a local gym—then fitness competitions. "I wanted my son to see me go from being in bed all day to competing with people who don't have any disabilities," William recalls. "He knows what I went through."

FINDING—AND OFFERING—VITAL SUPPORT

William's declining health left its mark on the rest of his family. He and his wife divorced after his Crohn's diagnosis, and relationships with extended family members were strained. "I didn't have a whole lot of support in the beginning," he says. "When you can't work and you have a family, you are going to need money, and they may turn away. You can't linger on that. You have to move on and still love these people, but your main support doesn't come from them. They may not understand your disease. I mean, when you are 110 pounds and on a cane, you can tell that they are scared."

William turned to support groups to meet others living with Crohn's and other diseases. He reached out to the Crohn's & Colitis Foundation. "I was able to talk to people who are dually diagnosed about their treatment," he says. "That was the first support group I found, and they were really vital in steering me in the right direction."

He joined the men's group at his church and got involved with Color of Crohn's & Chronic Illness (COCCI), whose mission is to advocate for and support Black, Indigenous, and people of color who live with digestive diseases and associated chronic illnesses.



William and his son, William III, attend a Crohn's & Colitis Foundation event in 2019.



William with his daughter Alynna.



William's mother and William's son.



Left to right: William with his cousin, who is currently battling cancer; William's son with William's father (left) and uncle. William lost his uncle to prostate cancer; William waiting for a biologic infusion.

"It's access. It's all about access. When I went for my first infusion, I was next to an older white guy who was also getting [the new biologic]. I asked him when he was diagnosed with Crohn's and he said, 'Last month.' Meanwhile, I had been waiting four years."

He also found a therapist. "[Crohn's] messes with you mentally and emotionally," William shares. "You may not know how to deal with this, and therapy helps you get on track."

William compares notes with group members who are on the same medication, or have issues with their health insurance. He helps assuage the fear of those who are newly diagnosed. He cheers on their successes as they cheer on his own.

In March 2022, preparing for the Little Rock Shamrock Shuffle 5K race, William knew he might need to walk some of it, "but I will try to run at least half," he promised himself. He ended up finishing first in his age group. Warmer weather means short hikes with his son and taking out his kayak again. "It's challenging, but I love it," he says. "It keeps you mentally strong, because you need to stay focused to stay stable."

He and his son like to tinker with his old BMW and play with his dogs, and most recently, William became a proud grandfather when his daughter had a baby.

"Just because you have an illness, the world does not stop," William says. "It just gets tougher, but you have to learn how to navigate it. My biggest fear concerning my health is being denied infusion or coverage, because it happened before to me. That's another reason I feel I need to be in shape: to deal with the pain easier when it comes."

—Calli Barker Schmidt

This is a portion of a poem William wrote while experiencing a relapse in 2019.

No pain no gain, isn't that what they say,
If they only knew how pain changes lives, it might
have been phrased a different way.
Pain is subjective, but I'll share with you my foray.
What's your pain level today, they always say,
As I arrive for another, scheduled doctor
appointment today.
I respond, I'm ok
Cause no 1-10 can measure the pain I endure
today, or any day.

...
10 years of pain, 10 years of strain
On everything, because that's what it touches,
Pain is like a parasite, when you're in its clutches,
It takes energy, drive and determination from its
host,
But the mind is what's affected most.
...
Pain is with me, and here to stay,
So if you ask me how I feel, I'll say ok and smile,
But actually, I been in pain for a while.



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Charis Hill

Photo by Glenn Jones/Ikona Photography.

Pain Paves an Unlikely Path to Becoming Whole

Charis Hill, 35, delights in wordplay. As a person who identifies as nonbinary and uses they/them pronouns, Charis playfully refers to themselves as a “king *and* queen” of puns. And when the elegant tail of their cat, Juno, flicks in front of Charis’s face, they wryly smile and offer another quip: “I call myself the cat *they*dy.” Four cats currently share their home, including two former ferals taken in during the COVID-19 pandemic.

The furry housemates are nurturing companions to Charis, who navigates the chronic pain of axial

spondyloarthritis (axSpA), a multisystemic inflammatory rheumatic disease primarily affecting the spine and other large joints, and sometimes the body’s organs. In addition to severe joint pain, symptoms include fatigue and limited mobility.

In their blog, BeingCharis (beingcharis.com), they use metaphors to describe the disease’s bodily sensations, ranging from “a pocket of lava explodes in my joints” to “zapped by a live wire.” Charis adds, “There are times that it’s like being stabbed in a joint with a barbed poker.”





Charis visits the California State Fair with Sofia Webster. The two were featured in the film *"Becoming Incurable,"* which spotlighted chronic illness.

FINDING AN ANSWER IN GENES

Psychological pain and invalidation flanked Charis' decades-long quest for an official axSpA diagnosis. Charis first sought treatment for debilitating lower back pain, a common symptom of axSpA, during their years as a collegiate soccer player. Prior to playing in college, as a person assigned female at birth, they played as the only girl on the high school boys team. However, even after an MRI showed that Charis' lower vertebrae were starting to fuse, doctors routinely told them that the pain was simply a result of being an athlete. Furthermore, health care providers were particularly dubious on account of their gender. A 2014 study reported that all general practitioners who were interviewed believed axSpA was almost exclusively diagnosed in men.

Charis reflects, "I was socialized as a girl, and was told axSpA was a man's disease." At one point as a young professional, Charis struggled to breathe, which they now realize is a response to ribcage inflammation, and was told it was "all in their head." The doctor prescribed depression and anxiety medicine for panic attacks.

Determined to find an answer for what they knew to be primarily physical pain, Charis heeded intuition's call and emailed their estranged father to glean more understanding of possible genetic factors, and maybe even uncover an answer. According to a 2020 study, the disease is indeed highly

heritable. Their father explained his own symptoms of axSpA, which immediately opened a long-bolted door of understanding for Charis: "I realized that all these separate symptoms I'd had over the years were the same disease."

FROM ATHLETE TO ADVOCATE

Recognizing the genetic component of their health issues emboldened Charis to press even harder for a diagnosis, a quest that finally gave a name to the source of the pain and knitted together the strands of symptoms. However, to accomplish this feat, Charis needed to draw on their grit as an athlete: "I had to go down the road of convincing doctors that's what I had with minimal income, very bad insurance, and with the fewest tests possible," they note. "From the very start, I was advocating for myself."

In 2013, after a rheumatologist officially diagnosed Charis with axSpA, they felt grateful but "gutted." Within two years, on account of increasing symptoms, Charis sought and was eventually granted disability benefits. In spite of experiencing pain since youth, they had always identified as an athlete, which helped them cope after the diagnosis. While initially shaken by this new aspect of their identity, Charis soon experienced a metamorphosis, a strengthening, of voice and purpose, and even an epiphany—they had been unknowingly preparing for this ever-arduous trek their entire life.

While Charis recognizes that pain paved their path, they are now in an unexpected role: fierce advocate for disabled people. As a writer, speaker, and activist, Charis fights to dismantle the current ableist paradigm. Speaking softly but with a firmness that reveals steely focus, they say, “The disability process is dehumanizing, forcing you to define yourself by everything that you cannot do.” Part of Charis’ mission in becoming anti-ableist is to embrace a proud disabled identity. “So many disabled people will not reach that first level of Maslow’s hierarchy of needs [physiological; the most basic needs a person can have]. To consider the hypervigilance, the fight or flight, that’s been forced on us by negligence of government policies is infuriating.”

ILLUMINATING VULNERABILITIES TO INCREASE POWER OF AWARENESS

Charis continues to act to use their power to spearhead awareness and change. In their work, Charis refers to the social model of disability and pinpoints how society creates obstacles for equitable movement through the world. Charis believes, for example, the current medical model works in a way that blames the individual for not being able to climb the metaphorical stairs in front of them.

Today, Charis serves on several nonprofit committees, including CreakyJoints, part of the Global Healthy Living Foundation; Spondylitis Association of America; and the National Pain Advocacy Center. In addition to striving to expand awareness of axSpA and improve disparities in health care, Charis is an advocate for the nonbinary and transgender community. Since coming out as nonbinary in 2019, they have personally experienced ignorance and carelessness from medical professionals in recognizing their identity. They share, “My clinical notes are a mixture of misgendering and appropriate gendering, which feels awful.” Charis also references the mental fatigue of deciding when to correct health care providers in an already vulnerable space.

CHALLENGING DISABILITY MODELS

Charis continues the search for well-being and dignity for themselves and others, redirecting the societally accepted and flawed framework of disability by channeling focus on a person’s capabilities rather than limitations. Charis’ own life is a testament of approaching their disability on their own terms. They share that not only do they use braces, a coccyx cushion, cane, rollator, or wheelchair when needed, but also that they *proudly* use these resources.

Prior to the pandemic, Charis lived an adventurous life. They modeled for three years for Tumbler & Topsy in New York City and for Fuschia Couture in Los Angeles Fashion Week; attended Burning Man—where, at times, friends pushed them in a wheelchair through the fine dust of the desert; and even interviewed Dan Reynolds—the lead singer of Imagine Dragons, who also lives with axSpA—for their

“The disability process is dehumanizing, forcing you to define yourself by everything that you cannot do.”

blog. Now, sheltering in place since February 2020, Charis funnels their creativity into their home and nearby community in Sacramento, California. They have become an urban homesteader, aiming to grow or create, rather than purchase, all that they consume.

A brown-bag chandelier of sorts hangs in Charis’ home, each parcel containing dried herbs ranging from citronella to sage. Their newest project is growing alfalfa to provide hay for the neighbors’ chickens. Charis refers to gardening as their form of meditation and estimates they’ve put in 10 or 11 miniature fruit trees, including peach, lemon, plum, and cherry. Their yard is an example of regenerative landscaping, an intentional type of cultivation with an objective to restore nutrients in the ground, provide shade or food, and attract pollinators.

As Charis considers the garden, they smile: “It all serves a purpose.” Fitting words for how Charis shows up each day—broken, whole, and proudly disabled.

—Sara Walsh





Tiffany speaking at a protest in Webster, New York.

Tiffany Porter

Disabled, Black, Female, and Queer: The View from 'the Bottom of the Barrel'

People still ask Tiffany Porter when she is going to finish college. She stopped attending 10 years ago, three courses shy of earning a degree in social work, because she was in too much physical pain to continue. While Tiffany, who lives in Fairport, New York, may look fine most of the time, simple everyday tasks can be excruciating and exhausting. These days, she would like people to be more sensitive and stop asking her to do things she is unable to do.

"Enough is enough," she says. "I'm not going to feel bad for being disabled."

Owning her disabilities was a 13-year journey. The 39-year-old mom lives with fibromyalgia, arthritis, tendonitis, polycystic

ovary syndrome, and Type 2 diabetes. Over the years, she's tried various medications, diet changes, trigger point injections, and even morphine—but they didn't help. She even underwent two unnecessary surgeries—one for weight loss and another for her knee—when doctors wrongly attributed her symptoms to those conditions. She was finally diagnosed with fibromyalgia, a condition that causes pain throughout the body, in 2014, after years of constant pain.

"My diagnosis should not have took that long. Black women are constantly dismissed by medical professions," she says. "My fibromyalgia wasn't diagnosed for nine years. My best friend, who is white, got diagnosed in high school."

That wasn't the only time Tiffany's doctors didn't take her seriously. In 2015, after six months of fatigue, she insisted that her doctor run a full blood panel. "I saw many physicians and told them about my extreme fatigue, and everyone just brushed



Above: Tiffany has three sons: Randall, 16, Tayvon, 15, and Jayden, 9.
Below: Tiffany sprained her wrist and her tendinitis flared up after she held a megaphone at an event.



it off and attributed it to my fibromyalgia,” she says. When the test results came back, she was rushed to the hospital to treat an abnormal blood count due to the heavy menstrual periods caused by her polycystic ovary syndrome. She received three blood transfusions at the hospital, she says, followed by regular iron infusions for a year and a half.

“If I didn’t go in there and say, ‘I need you to do this panel,’ I would’ve been dead,” she says. “That’s the story of my life. Being Black and female, I don’t get listened to.”

As a single, Black woman supporting her family on disability benefits, Tiffany has experienced a range of disparities—from her pain not being taken seriously by doctors, to not being able to afford healthy food, to not having access to necessary spaces like bathrooms.

“When you’re disabled, you already are at a lower level,” she says. “When you add race to it, you’re at the bottom of the barrel.”

LIVING WITH DAILY PAIN

Tiffany is in constant pain. She can’t walk long distances, everyday tasks deplete her energy, and simple household chores are enough to cause debilitating flare-ups.

As the arthritis in her knees and tendonitis in her hands worsen, the fibromyalgia brings on whole-body pain and exhaustion that can last for days, weeks, or months.

“Trying to cook a meal every day, I can’t do it,” she says. Pots and pans are too heavy, she can’t open jars, cooking is fatiguing, and loading the dishwasher wears her out. Her sons—ages 9, 15, and 16—help, but the frustration with her own limitations is evident in her voice.

“I get very emotional about it,” she says. “I’ll think, ‘I got this,’ and I’ll be in the middle of shopping and then I flare and I have to sit down.”

Tiffany uses canes and braces, and an electric wheelchair when she goes grocery shopping. She intentionally shops later in the day, when she’s less likely to have neighbors ask about the wheelchair or strangers stare at her.

The emotional toll has also shown up in other areas of her life. It’s depressing for her not to work a full-time job, and dating has been difficult and lonely.

“Dating with a disability is hell,” she says. “Disclosing that I am disabled to potential partners was difficult.” Last year, Tiffany came out as queer, and since that time, she has been upfront about her sexuality and her disabilities.

“I’m not hiding that anymore,” she says. “I just feel more comfortable with who I am now and what I’m looking for.”

ADVOCATING FOR SOCIAL JUSTICE

Tiffany has been teaching friends and family how to advocate for themselves in the medical system, because receiving good health care can be a matter of life and death.

She notes the necessity of mandated anti-racism training as part of the medical school curriculum, as well as education for current medical professionals. “We have medical books that still say things like ‘Black people have higher pain tolerance,’” she says.

And a delayed diagnosis and lack of proper care can significantly impact a person’s life economically. Tiffany didn’t qualify for disability benefits until she was diagnosed with fibromyalgia, and even with this support, she can’t afford medically necessary glucose-free foods for her diabetes, or fresh vegetables for her family.

She says the idea that the poor can eat healthy is a myth: “You really can’t budget your way out of poverty. You can do





Left: Tiffany was awarded the Anna Murray Douglass Award from 21st Century Arts in New York for her activism work. Above: Those involved with Tiffany's organization, Being Black in the Burbs, put on a cookout, giving away food and masks.

*"When you're disabled, you already are at a lower level.
When you add race to it, you're at the bottom of the barrel."*

all the budgeting you want, but it is not going to equate to you eating healthy."

Tiffany started an online Facebook group in 2020 called Being Black in the Burbs. The group shares tenant resources, provides community stands with toiletries and food for low-income neighbors, and advocates for state and nationwide efforts to stop racism, such as protesting police brutality.

The experience of Black people is "out of sight, out of mind," Tiffany says, and anti-racism education is needed in all school subjects, in all grades. She is also advocating for curriculum changes that teach children about disabilities and chronic illnesses.

But her advocacy on these social justice issues has not been well received in her suburban neighborhood. She says that there are Facebook pages that criticize her, she's been shamed for her disabilities, she's been verbally attacked at school meetings, and she's been doxxed, with the names of her kids and their address published online—all in an effort to intimidate her from speaking out against racism.

Her focus is to draw attention to issues so there can be change. "We can say something is wrong with someone or the community and give them a chance to rectify it," she says. "It doesn't mean we throw the whole person or whole community away."

ADVISING OTHER PEOPLE WITH DISABILITIES

Tiffany urges others living with disabilities and disorders to remember that the society and bureaucracy they're struggling

with were not created to benefit people with disabilities.

"You're working with systems that are just not built to make your life any easier," she says.

She encourages joining support groups, finding ways to reduce stress, and showing up to doctor appointments prepared with questions. Talking with others can be a great resource for advice on meal plans, exercises, specialists, assistive devices, and medications. After years of experience, she has found chiropractor visits, massage therapy, yoga, and ketorolac injections are helpful for her.

Tiffany leans on her family for support and acknowledges that it took a village to raise her three sons. But for people to truly be supported, there needs to be more understanding in society at large.

"Even though I don't need assistive devices all the time, I need the accessibility 100% of the time," she says. "When you make stuff accessible for one demographic of people, it's really making it accessible to all people."

People with disabilities need accessibility in all spaces—bigger bathrooms, wider walkways, and more—which she says would help everyone, especially as people age. And yet, our society doesn't make this a priority.

"This country couldn't care less about the disabled people in it. Imagine being disabled and Black," she says. "We need our children to understand what disabilities are and break down the many stereotypes and stigmas attached to them."

—Tara Bracco



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Jacob & John Smith

Young Twins Navigating Pain Together

The idea of having a child who lives with chronic pain is unbearable to a parent. Mary Smith, 36, has two.

Her identical twin sons, Jacob and John Smith, have endured a lot in their 11 years. As a nurse with one child already, Mary anticipated that twins would mean a little extra time in doctors' offices and twice the maternal worry. But she never anticipated that their lives would be plagued by one medical crisis after another, or how much time and energy she would have to devote to chasing down a diagnosis, let alone treatment, for both of them.

"Sometimes I feel like this is normal," she says. "Because they needed an advocate and a case manager. But sometimes I miss just being able to be their mom."

NOT OUT OF THE WOODS YET

Mary went into labor at 31 weeks; doctors struggled for three weeks to postpone delivery to give the babies a fighting chance. They spent three more weeks in the NICU. Mary and her older

son James, then 4, were familiar faces to the staff there.

A few weeks after the twins were discharged, Mary made the difficult decision to pack up her kids and move from Washington state to Ohio to be closer to her family.

A week after the move, John got sick.

"My belongings were still in a truck somewhere in the Midwest, I was living in my mom's living room, basically homeless, and now someone is telling me my baby has meningitis," Mary recalls. "There were some pretty dark days in that ICU."

Baby John spent a month in the hospital. The inflammation in his brain went away, but imaging scans indicated permanent brain damage. Fortunately, as John grew over the years, he never exhibited any issues more severe than a slight hand tremor. "His neurologist would say that, judging from the scans, this kid should be having trouble walking and talking and maybe having seizures," Mary says. But from the way John acted, skipping into the office and telling the staff he loved them, it was as





Left: Jacob and John in the hospital at about 10 weeks old in 2011, with older brother James, then 4. John was admitted for meningitis, then Jacob was admitted as well after he choked and turned blue and doctors were concerned he had meningitis as well. A diagnostic spinal tap caused a hematoma, and Jacob stayed in the hospital for several days. Right: Jacob in the hospital for an endoscopy and colonoscopy.

though the scans didn't belong to him.

MYSTERIOUS SYMPTOMS

Both boys presented with strange symptoms over the years. Jacob's difficulty swallowing and eating was dismissed by doctors as typical infant reflux. Both boys complained of leg pain and fatigue as toddlers, and by the time they were 4, John was having migraine attacks and Jacob was experiencing chest pain.

"It's scary when a little kid tells you their chest hurts," Mary says. But any time she brought the symptoms up to a doctor, her concerns were brushed away and the problems chalked up to the twins having been born prematurely. "I knew it wasn't in my head, but all these tests came back negative," she recalls. "I started to doubt myself. It made me feel crazy."

It wasn't until Mary had to carry 6-year-old John into an appointment that his doctor finally began to suspect something more was going on. Both twins were eventually diagnosed with a rare genetic condition called hypermobile Ehlers-Danlos syndrome (hEDS), which affects connective tissue.

The relief of a diagnosis was only momentary, because both boys continued to have other unresolved health problems.

DIAGNOSIS PART II

Jacob's eating issues affected his growth so much that by third grade, people didn't recognize him and his brother as identical twins because of the dramatic difference in their heights and weights.

Mary took him to specialist after specialist, but, she says, "it got to the point where he would just cry when he got to the

doctor's office because he didn't want to go through any more tests." Just as they had been with hEDS, his symptoms were dismissed, this time as anxiety, before he was finally diagnosed with gastrointestinal issues that included ineffective esophageal motility and gastroparesis. In effect, Jacob's esophagus wasn't squeezing food down his throat correctly, and his stomach wasn't emptying in the proper fashion.

"He was sent for anxiety counseling before he ever received those two diagnoses," Mary says. "When you're dealing with chronic issues, anxiety tends to come into it, but his anxiety was from not knowing when his next pain flare would be and not knowing what was causing it or how to manage it."

The constant doctor visits continued to be hard on Jacob. "I like my doctors now, but sometimes I'm scared I'll have to have another test or procedure, and I hate enemas or any tests that involve something like that," he says.

John, meanwhile, was having chronic migraine attacks, complete with nausea, light sensitivity, fatigue, and brain fog. "Once," Mary recalls, "he forgot the word 'beef' when he was trying to order a taco." The longest he's ever gone without an attack is two weeks.

Mary recalls, "When he was in second grade, he said that if this was how his life would be, he would rather not live it."

It's hard to imagine a mother hearing more heartbreaking words from her child than that. "I felt helpless because I couldn't take it away from him," Mary recalls. It was John's neurologist who ultimately gave him hope when she explained that boys sometimes outgrow migraine. "After that," Mary says, "even on his bad days it never got that bad again."



Left: Jacob, John, and Mary Smith at U.S. Pain Foundation's Pediatric Pain Warrior retreat at Disney World in 2018.
Right: John and Jacob at a Cub Scouts Pinewood Derby.



*"I want to be able to play with my twin, and if I'm not well and he is, that makes it more difficult. In some ways it is also easier, though, because **I always have someone that understands me, my twin.**"*

HOPE TIMES TWO

A recent procedure seemed to help initially and allowed Jacob to have one of the first pain-free meals of his life. Unfortunately, the effects didn't last long before the pain crept back, so they are still searching for solutions.

Every time they tackle one health issue, another seems to crop up, like an endless hydra. But Mary never gives up on the herculean task of advocating for her sons and their health.

Like their mom, the boys have risen to the challenge, taking an active role in their treatment.

"Sometimes I get tired of having to talk to different doctors, but I also like that they now include me and give me a choice with my medications," John says.

The now fifth-graders are Cub Scouts and play on their school's basketball team. They enjoyed the U.S. Pain Foundation's Pediatric Pain Warrior retreat in 2018 and the virtual retreat in December 2021. There, they learned for the first time that they weren't alone or the only kids who had to deal with the conditions they had.

On tough days, it helps to have a twin who understands. "I want to be able to play with my twin, and if I'm not well and he is, that makes it more difficult," John says. "In some ways

it is also easier, though, because I always have someone that understands me, my twin."

They've also learned to advocate for themselves, to teachers or other kids at school who don't understand their largely invisible disabilities, or to physicians who dismiss symptoms. Jacob says he would like more people to know that, "I don't fake it to get out of schoolwork. I do the best I can, but I hurt every day." And John adds, "I have chronic illnesses. This isn't just a cold that will be gone in a few days. I've been dealing with this for years."

Their mom continues to chase down specialists, drive to appointments, and figure out copays, but, Mary says, "It doesn't do any good to wish that life was different, because these are things you can't change. I could focus on the fact that they are in pain pretty much every day, or that these are chronic conditions there are no cure for. But I focus on the positives."

To Mary, her family is the biggest positive of all. "My sons have very big hearts and are very caring," she says. "I can't imagine a world without them in it."

—Jill Waldbieser





Lorrie with her first service dog when she was in grad school.

Lorrie Starr, PhD

Through Pain, a Profusion of Hard-Earned Lessons

If Lorrie Starr were to write a book about her life, she'd call it "Life with a Circus Dog."

Lorrie, 67, began using a service dog decades ago and has a memoir's worth of lessons and experience—including a humorous encounter where a woman misheard the word "service dog" as "circus dog" and loudly shared her mistake with a packed restaurant.

Lorrie recounts the story with a laugh and a joke about getting back to Barnum & Bailey. She manages to see the bright side of a dark journey fraught with pain, tragedy, and loss.

RELIEF OF SERVICE DOG TEMPERED BY OTHERS' LACK OF UNDERSTANDING

Lorrie was diagnosed with undifferentiated connective tissue

disease in her 20s, a disorder that affects the tissue supporting the organs and parts of the body. Lorrie's condition resembles Raynaud's disease; hot and cold temperatures cause discomfort in her extremities and joint pain. She also began experiencing vertigo and the sensation of the room spinning.

While juggling medications, dietary restrictions, and treatments, Lorrie began a dual PhD program in counseling and school psychology. Her vertigo continued, and she began to experience falls. Her doctor advised her to use a service dog instead of a cane.

"I was kind of mortified to be using a service dog," she says. "It was really an uphill battle a lot of the time. People are better educated now, but [back then], they wouldn't want to let you in a restaurant or a movie theater or whatever."

"The ambulance driver said, 'What hospital do you want to go to?' And I said Phoenix Indian Medical Center, because I knew everybody there. They laughed and said, 'Oh, you don't want to go there.' You know, it was that kind of prejudice."

Lorrie's hypothetical memoir would include stories about being accused of not having a disability when using accessible parking spots. About people running up to pet her dog while the animal was working, increasing her risk of falls. About being denied entry or service.

For her psychology residency, Lorrie matched at a well-known and reputable medical institution. "It did not even cross my mind that I needed to talk about my service dog. It's perfectly within the law," she says. "When I showed up with a service dog, you would have thought that I brought a giraffe and an elephant. It was absolutely abhorrent what happened."

Lorrie was told she could not use her service dog, named Roughette in honor of a favorite horse, and had to leave him in the intern office. Every morning when she arrived, an administrator would wait for her at the end of the hall and repeatedly harass Lorrie by calling her dog, trying to break his concentration.

"My dog got to where he was just shaking when we would be going into the building, because he knew he was supposed to be doing his job with me," she says. "That was very traumatic."

An administrator suggested Lorrie could "grab onto" someone if she was having balance issues. "I'm sure this did not endear me

to [the administrator] any further, but I took her glasses and said, 'Just ask someone if you need to read; it's the same thing.'"

Lorrie filed an Americans with Disabilities Act complaint. The next year, she transferred her residency to the Phoenix Indian Medical Center, whose mission she said was close to her heart. "It was a great fit, and everybody loved my dog," she says. Lorrie uses a Bouvier des Flandres as her service dog because of the breed's height and ability to brace—her new coworkers in Phoenix compared her dog to a buffalo, which Lorrie says is the greatest compliment she could receive.

Lorrie is a tribal member of the Western Cherokee Nation. She was born to the Long Hair Clan. She credits her tribe's spiritual beliefs and customs for centering her and keeping her balanced.

"I can only do what I can do in my corner of the world," she says. "I can join with others in praying and sending loving kindness and energy to the people who need it, that are in really tough situations. My situation may seem tough at times, but you look around and there's always someone whose situation is harder."

A VIOLENT SETBACK

As her residency continued, Lorrie began having double vision. At the end of a weeklong conference, her dog was exhausted, and Lorrie decided to leave him home to rest and go to dinner alone at the end of the week. "My animal needed to be thought of too," she says.

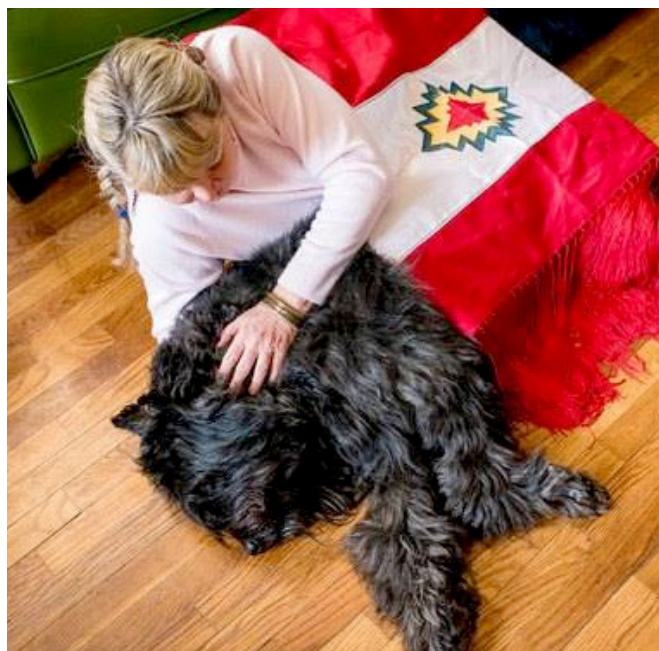
She was assaulted in the parking lot that night.

"A man grabbed my ankle from between cars. I didn't even have time to put my hands up. My face hit the concrete. I was unconscious fast and just left for dead."



Left: Lorrie participating in a neuropsychology research project at Grand Cayman Island that studied the healing effects of dolphins' echolocation on those with brain injuries.

Right: With a shawl that her tribe uses to send someone on their journey after death, Lorrie says goodbye to one of her earlier service dogs, Tessa, who died from cancer at the age of 4.





This African grey parrot, Veda, provides comfort to Lorrie.

Lorrie had a traumatic brain injury.

"I'll never forget seeing the face of the woman who saw me and the kind of car she was driving," she says. "I was in shock, just shaking all over. The ambulance driver said, 'What hospital do you want to go to?' And I said Phoenix Indian Medical Center, because I knew everybody there. They laughed and said, 'Oh, you don't want to go there.' You know, it was that kind of prejudice."

Shortly after her TBI, Lorrie began experiencing uncontrollable crying and was diagnosed with pseudobulbar affect. The injury also caused headaches and balance issues.

"That combined with the connective tissue stuff, and my neurologist said, 'You can't work anymore,'" she remembers.

Even now, she gets teary recounting it. "My dissertation chair said, 'You might as well admit you aren't going to finish this.' I was just so determined, because that is what my dream was. I knew what I wanted to do."

It took her six years—and a new adviser—but Lorrie graduated with a dual PhD.

CALLING FOUND IN SERVICE—THEN ANOTHER BLOW

Lorrie has always felt called to service. She started a child life program at the University of Missouri Hospital. "I saw a young mother who was a single parent, whose young child was sick and eventually died. This woman was out of pocket over \$30,000. She was a secretary. And I thought, there is no way she doesn't need the support of having the option to go to therapy without a copay or having to pay for it."

Lorrie's dream was to start a nonprofit and offer pro-bono therapy services for children and families in similarly tough

spots. She did that through the founding of "A Little Kinder" in Phoenix, working primarily with seriously ill children and their families. After almost a decade, the land she used was sold, and she was not able to renew her lease. Her nonprofit was shuttered, and that chapter of her life was over.

A friend who lived in Columbia, Missouri, reached out and offered Lorrie a place to stay. Lorrie packed up and moved. Her friend passed away shortly after.

"I moved here just spontaneously. Part of the problem with my brain injury is that it affects executive functioning," she says. "It was an impulsive decision."

Continuing her spell of bad luck, Lorrie's service dog also passed away, another was stolen by a trainer, and then the pandemic struck. She worries her current dog, again named Roughette, hasn't gotten enough exposure and training in the "real world."

PUSHING FORWARD

Despite living with pain from her brain injury, as well as arthritis, fibromyalgia, and irritable bowel syndrome, Lorrie wants to get back to work—but with her head injury, she is worried she won't be able to study and pass Missouri's counseling credentialing exam.

Even after doctors said not to work as her double vision worsens, Lorrie can't see a world where she doesn't help others. She has obtained a variety of certifications in energy medicine techniques and is developing a toolkit to virtually help people build coping strategies. As the world becomes more overwhelming, she wants to empower people to tune into their emotions and find peace.

"I miss terribly being of service," she says.

—Kirsten Ballard



Lorrie at a concert with musician Ben Taylor, the son of James Taylor and Carly Simon. Lorrie had a service dog and wore an eye patch to help with her balance issues and double vision. Ben Taylor donated to Lorrie's pro-bono therapy nonprofit.



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As a video producer and hobby photographer, David often experiments with photos of himself to become more familiar with design software, theory, and techniques.

David Simpson

Staying Upright—And Helping Others Stand, Too

In 2008, David Simpson was at a capoeira class. This Brazilian martial art is intensely acrobatic, incorporating musical accompaniment and choreography. With its cartwheels and flips, it almost looks like ancient breakdancing. When two people spar, the symmetry is as obvious as the danger inherent should the synchronization fail. In capoeira lurks the possibility of pain.

David was seasoned in a variety of martial arts. He'd sparred countless times. But a single kick, at the age of 28, changed everything.

"It didn't land," he recalls. "It was a kind of spasm. I was on the ground in pain for 15 minutes. But I walked out of there."

Although the acute spasm wore off, he felt as if something insidious was now in his back. More than a decade later, David still thinks about that kick.

AN ACTIVE LIFE STYMIED BY PAIN

David, now 42, grew up in Paterson, New Jersey. After college, he took a job as a production assistant for various companies in New York City, helping manage motion graphics projects for TV shows and music videos. To pass the time, David rollerbladed around

NYC and practiced capoeira. After a few years, he moved to Los Angeles to continue his career and continue training.

After the kick that changed everything, David attempted other forms of exercise—yoga and jogging, particularly. The pain in his back persisted and spread upward into his neck. MRIs yielded a diagnosis of spinal stenosis, in which the vertebrae gradually narrow, causing pain by putting pressure on the spinal cord and spinal nerve roots. David's pain remained manageable, in part thanks to the top-tier health care he had at the time, which covered acupuncture and massage therapy.

But after years in LA, the demands of his work—the deadlines and long hours—became overwhelming and physically draining. David took some time off to backpack through Panama, Nicaragua, and Costa Rica, where he enjoyed the culture and change of pace, but dealt with compounding pain.

"Bus rides were really brutal," he says. "I was walking around with a heavy backpack. After a few months of it, I couldn't take it anymore, and I came back."

After flying to a bachelor party ski trip, David found himself lying on the floor of his room, in complete agony.



“My whole upper back was spasming. I basically couldn’t move,” he recalls.

After realizing that his back pain was exacerbated by the long hours he spent hunched over his computer working, David moved back to New York to do freelance work. He searched for affordable out-of-pocket treatment options, but the pain continued to worsen.

TREATMENT VARIES FROM NEIGHBORHOOD TO NEIGHBORHOOD

“I was getting really worried,” David recalls. “I would wake up unable to move my arms. I decided in 2016, after consulting multiple doctors and getting X-rays and MRIs, that I had to have surgery.”

As a freelancer, David was without health insurance because private insurance was too costly.

“I got on Medicare to be able to afford [surgery], and began the process of finding surgeons that would take my insurance,” David shares.

The further David traveled on his road to relief, the more layers of unequal treatment he uncovered. Few hospitals took his insurance, and those that did prioritized people with other insurances. The system in place to provide for folks in his situation was broken, and nothing was being done to fix it.

“I’d go on a hospital’s website to see if they took my insurance, and learn that they were only allowed to take a certain amount of patients with my insurance, or they’re involved in clinics where doctors work shifts to provide for people with Medicare or similar insurances,” he recalls. “So I had to track down doctors who worked in these clinics. No matter what time I was scheduled, I always had a two-to-three-hour wait. Sometimes while waiting I’d have my appointment canceled. So many times, my referrals to spine specialists were lost.”

David also came to learn that the location of the clinic determined the quality of the care, and how seriously patients were taken.

“I was putting so much effort into the research and finding appointments, and getting sent away, and being spoken to rudely and impatiently by staff and also doctors,” he says, explaining how he learned the outsized effect that economic class can have on treatment quality. “A number of times, when I asked a question to a doctor, I was dismissed and asked why I wanted to know certain things. After a lot of failures, I realized that it was a geographic issue, and I needed to go where rich people go. I learned that I needed to go to midtown, to downtown Manhattan, and find the doctors that took my insurance *there*.”

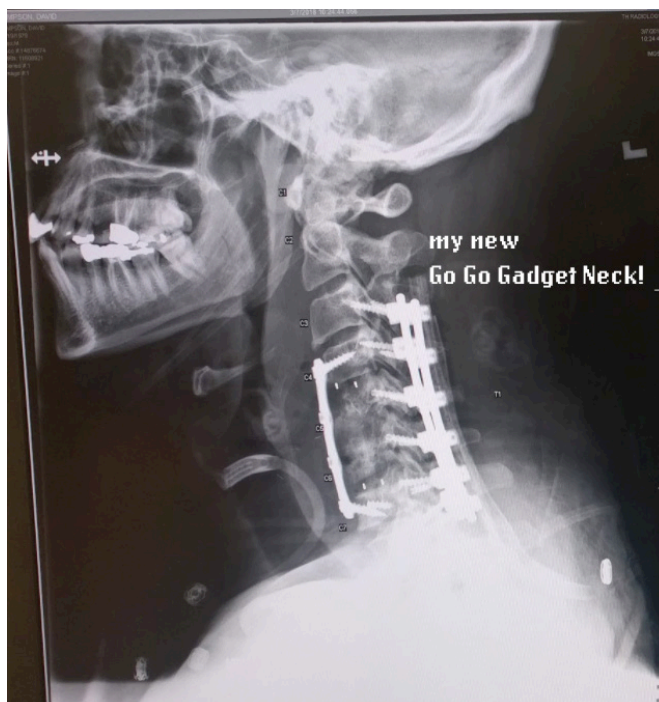
POST-SURGERY, A NEW NORMAL—AND A NEW MISSION

After working through the roadblocks of insurance, geographics, and demographics, David finally had spinal fusion surgery. This transformed several vertebrae into one long piece of “bone.” The procedure can cause a loss of mobility,

“A number of times, when I asked a question to a doctor, I was dismissed and asked why I wanted to know certain things. After a lot of failures, I realized that it was a geographic issue, and I needed to go where rich people go.”



Below: An X-ray of David’s neck following his spinal fusion surgery.



and one of the results is increased stress on the adjoining vertebrae as they take on the motion that would otherwise be handled by the fused vertebrae. He ended up needing a second surgery after a screw broke—and finding that out was a battle, too, with one pain management specialist suggesting David see a psychiatrist instead of trying to diagnose his continued pain.

After several years of therapy and rehab to recover from the surgeries, David now works from home to accommodate the need for frequent rest breaks. He has limited range of motion in his neck and a weakened right arm from long thoracic palsy that developed after one of his surgeries.

With his chronic pain and inconsistent quality of health care, David maintains a healthy mental homeostasis. He does tai chi to engage his mind and build his upper body.

He still rollerblades, a movement that keeps him upright, literally and figuratively. And his work has shifted, too.

“I always really felt like I was working so hard, with the express intent of making someone else super rich,” David says. “I myself was making good money, and it afforded me a life I thought I wanted. But one of the reasons I left advertising was because the stress and responsibility was exacerbating my pain. And I never felt like it was a natural fit for me.”

David now takes his creativity, his self-described kaleidoscopic personality, and pours it into nonprofit work. Specifically: video mitigation. He helps produce mini-documentaries, which are used as pre-sentencing evidence in criminal cases.

“In essence, we humanize the person to illuminate what would otherwise just be a crime or indictment number on a rap sheet,” David explains. “If someone is convicted of a crime and is pleading guilty, we create these videos to show to the DAs and the judges with the hopes of establishing the circumstances surrounding the arrest that are significant to why they ended up where they are. For instance, I worked on an immigration case where someone got arrested at 19 for weed possession, and he’s been struggling for years to get residency, and we created a video for him that was successful—they threw out the case, he got married, and is now eligible for citizenship.”

Mitigation videos are not uncommon in the private sector for people with means, but this organization is the first of its kind in New York in the public defender space. Through his experience with chronic pain, David knows this is a world that unevenly spreads its resources: “If you live in the wrong neighborhood, you’re f***ed.”

David continues facing these cold truths, but is working to level the playing field and help others stand up for what they deserve. In the meantime, you can find him rollerblading, staying upright.

—Emil DeAndreis



Above: David when he was 5 or 6 years old. Below: David enjoys photography and likes to focus on bright colors and small details.





Mia Robinson

Turning Pain and Tragedy into Advocacy

For Mia Robinson, every day is planned around chronic pain. “How I move in life is dictated by my chronic illness,” she shares. But she has turned the challenge of pain into a positive: “I use it as fuel when I’m advocating.”

Mia, 38, is a Black woman born and raised in Atlanta, Georgia. She has a form of sickle cell disease called sickle cell hemoglobin C disease (also called hemoglobin SC disease or HbSC). According to institutions involved with learning about this disease, HbSC is a milder form of sickle cell disease. But according to Mia, “I think it’s just more silent.”

In the average body, a protein called hemoglobin helps transport oxygen to various places in the body and returns with carbon dioxide. Picture an old-fashioned milkman using red blood cells as their truck, traveling through the bloodstream. Those red blood cells are usually shaped like discs, making it easier for them to travel through the body. For people with sickle cell disease like Mia, a mutation causes their red blood cells to be shaped more like crescents. Because of their shape, these cells can bunch up in the bloodstream, limiting blood flow. On top of that, they aren’t able to carry enough oxygen where it needs to go.

All of this can cause incredible pain attacks, often called crises, that can require trips to the hospital or emergency room.

Mia counts herself lucky. “I would have hospital admissions every several years, unlike my peers with sickle cell—they may have to go every several months.” As she grew older, though, that changed.



TRAGEDY EXACERBATES HEALTH PROBLEMS

Shortly after turning 16, Mia was diagnosed with avascular necrosis (AVN) in her hips. AVN occurs when the blood supply to the bone is cut off; it is fairly common for those with sickle cell disease. Mia's left hip deteriorated more quickly after she broke her right leg. Still, it wasn't until a little over a decade later that Mia got her hips replaced.

When Mia was 20, her sister, Toya, died an hour after giving birth. Mia suddenly found herself helping her own mother raise her niece Devyn. Mia believes some of her sister's symptoms, including darker and swollen legs, were ignored. Toya had preeclampsia, toxemia, and gestational diabetes, and staff members realized too late they had not given Toya a medication to avoid complications from preeclampsia. "When they noticed this, they immediately administered the meds. However, I believe this made things worse," Mia says. "My sister had a seizure right after asking to hold her baby girl. They told her to wait, but she went into cardiac arrest and passed away. She never got to see her baby girl or even hold her."

According to a 2021 study funded by the National Institutes of Health, Black mothers and birthing parents are nearly four times more likely to die during pregnancy or shortly thereafter than their white counterparts. "It should not matter what one looks like," Mia says. "We are all human—no matter the race, gender, religion, sexual orientation, or socioeconomic status. We all deserve fair treatment."

Facing so much grief on top of physical pain, Mia turned to emotional eating to cope. "I was against therapy at the time," she says. "I didn't really wanna talk about my dead sister the whole time."

She wondered: "Why did God take the healthy one and leave the sickly one here?" The additional weight she put on during this difficult period worsened the deterioration in her hips. She had to have both hips replaced at the age of 27.

Mia also developed a neurological disorder, idiopathic intracranial hypertension. Pressure had built up in her brain due to swelling around her optic nerve, causing increased pain and bulging eyes. She underwent regular spinal taps to relieve the pressure before having surgery on her optic nerve.

A NEW CALLING

Mia co-founded the nonprofit Sickle Cell Awareness 365 or SCA 365 in 2014 with Jennifer Callwood. Best friends for many years, they had even been featured in a piece about Camp New Hope, a camp for children with sickle cell, in *The Atlanta Constitution* back in 1993.

Years before founding the nonprofit, given the economic factors she was facing, Mia had to leave college to work a government job. But she felt like she was missing her calling. In 2016, she was able to leave her job to put her health first. After spending time resting and tending to her family's needs, she focused her energy on anything and everything related to sickle cell. "It's really God's reason for giving me sickle cell. I have to make sickle cell pay rent," Mia shares, laughing. Sickle cell isn't the ideal roommate, but making it contribute to the household



Above: Mia and her friend and nonprofit partner Jennifer Callwood at an advocacy day at the Georgia state capitol.
Below: Mia as a child with her older sister, Toya. Toya later died while having her daughter, and Mia and her mother ended up raising Mia's niece, Devyn.



income by turning activism into a job is a great move for Mia. "I get to do what I love and make my health the first priority."

Through her work with SCA 365, Mia works on fundraising, events, and supporting other sickle cell warriors in the Atlanta area, often partnering with other local organizations. Mia now serves as the creative arts instructor for Camp New Hope, and also is an ambassador for Sick Cells, an organization that gives a voice to those living with sickle cell.

GRIEVING, LEARNING, AND MOVING FORWARD WITH NEW PURPOSE

Eliminating the stress from her prior job has paid off. As Mia





After Mia turned to emotional eating to cope after her sister's death, her weight gain caused additional difficulties with her health. She has since lost 70 pounds, which has helped ease the pain of some of her medical conditions.

lost weight, her neurological condition improved. She lost and has kept off about 70 pounds since then, making peace with her history of emotional eating. “The physical transformation was a lot quicker than the mental one,” Mia says.

In the past, Mia has been accused of seeking pain medication for fun or to “feel the high.” Because she doesn’t look sick, people call into question how ill she actually is. As with many people with invisible illnesses, she still struggles to find providers and hospitals that she can trust. Mia’s pain levels vary throughout the day, ranging from manageable to extreme pain that sends her to the hospital.

Mia also returned to school, finishing her bachelor’s degree of sociology in December 2021. Unfortunately, her graduation experience was bittersweet: Jennifer passed away the next day. “She tried to prepare me for that,” Mia says. “As morbid as it is, we would joke about [death].” Mia once told Jennifer to give her a day or so to adjust before popping in to haunt her. “She didn’t do that!” Mia says, laughing again.

“Her spirit was heavy with me that day [that she passed], and I needed it,” Mia recalls. “It keeps me going, knowing that she’s there.”

Mia isn’t a stranger to loss. She says, “I’ve lost so many more

“It should not matter what one looks like. We are all human—no matter the race, gender, religion, sexual orientation, or socioeconomic status. We all deserve fair treatment.”



Mia with her mother and niece at a Sickle Cell Awareness 365 event.

people because I’m in the advocacy realm. Anytime someone transitions [to death], I draw on their spirit to keep me going.”

True to honoring those who are gone, Mia points out connections between losses in the sickle cell community and losses on a larger scale. “I see a lot of positives happening right now with COVID-19 because we’re talking about health disparities now,” she says. There are also more options for virtual connections and care.

Mia advises advocates and potential volunteers to “try different communities and see which ones they’d work well with.”

She’s also quick to point out that the connections each person makes in their community are vital and how important it is to develop friendships with people who understand. From persevering through her health problems, to graduating college, to eventually founding a nonprofit that helps people all over the country, Mia has used her passion and skills to uplift both the sickle cell community and herself. As her friend Phillip Okwo says, “It takes a village to raise a child. And it takes a tribe to sustain a warrior.”

—Grayson Schultz



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Christin Veasley

Fighting for Women in Pain

Christin Veasley knows what it feels like to wonder whether there's a point in getting out of bed.

For more than three decades, she's dealt with multiple chronic pain conditions brought on by a severe car crash. She knows what it's like to get a diagnosis only confirming that she has chronic pain, rather than telling her how to treat it. And she knows what it's like to be misdiagnosed and stigmatized because of her pain.

But she also knows that finding her purpose and learning how to live with her pain has changed her whole life.

"For anyone who has a chronic illness, it can become your entire world," she says. "You need your own thing that gives you some sense of joy and some sense of purpose."

Christin, 46, who lives in southeast Rhode Island, finds that purpose through spending time in nature, practicing her photography—and dedicating her career to advocating for women like her who live with multiple chronic pain conditions every day.

A DEVASTATING INTRODUCTION TO PAIN

Christin's chronic pain story starts when she was just 15 years old, when she was hit by a car on the right side of her body while she was biking. In 1991, the imaging available could only tell her doctors so much. But, as best they could tell, she experienced a traumatic brain injury on her right side.

"This was a massive accident where I was not supposed to survive the first 24 hours, much less ever," she says.

She's gotten "dozens of different diagnoses" over the years. Her pain is mainly in her neck, shoulder, and the middle of her back—the result of breaking all of her ribs. She also





Above: Christin and her husband Melvin have two daughters, Grace and Faith.

Below: Photography is an important hobby to Christin, and she particularly enjoys taking photos that represent resilience and perseverance.



has pelvic pain from a condition called vulvodynia. Although Christin sustained pelvic damage from the crash, doctors aren't certain if that led to the development of vulvodynia three years later—or if, as research is showing about people with multiple pain conditions, the crash triggered changes to Christin's central nervous system, making her more vulnerable to developing pain conditions in other areas of her body.

Christin still regularly experiences what she describes as “moderate, sometimes severe” pain. But, through various pharmacologic and nonpharmacologic treatments, she's found a way to manage it and is now “able to be functional enough to work, to fulfill my responsibilities as a wife and a mom, and be physically active,” she says.

But she knows that's not the case for everyone—because for many people, especially women and minorities, it's a battle to even get a doctor to believe that they are actually experiencing physical pain.

'A WHOLE OTHER BALL OF WAX'

Because of her accident, Christin wanted to go into the medical field. She worked as a research assistant in neuroscience at the Johns Hopkins School of Medicine in her 20s. With the confidence of youth, she was convinced she'd find a cure for the pain that plagued her and others. But she quickly learned that science—often out of necessity—moves slowly, and that there was a great need for people like her on the advocacy side, who understood and worked in medicine and science, but also had lived experience with chronic pain. Her own experiences, and those others shared with her, swayed her toward activism.

When she would go to the doctor with a new ailment, almost every single health care provider pointed to a potential cause in her medical history: her car crash.

“There's something for them to look back at in my record and say, ‘Oh, this makes sense that you would have that massive pain,’” she says. “It's different from other people, when [doctors] look at their history and there's no reason why they should have pain.”

One instance in which Christin experienced bias and disbelief from the medical community was in her diagnosis for vulvodynia, a chronic pain in the opening of the vagina or other areas of the vulva. This condition causes intense pain with any kind of vaginal penetration or insertion, be it sex or a transvaginal ultrasound.

"For anyone who has a chronic illness, it can become your entire world. You need your own thing that gives you some sense of joy and some sense of purpose."

It's often misdiagnosed as a yeast or bacterial infection, which is what happened to Christin. She first began experiencing the pain when she was 18 and was misdiagnosed for six months before finally finding a doctor who knew what vulvodynia was.

Many women have told Christin that their doctors wrote off the pain completely.

"I've heard from other women that doctors have said to them, 'Just go home and have a glass of wine the next time before you try to have sex,'" she says.

People experiencing any type of chronic pain have to fight through "tremendous stigma and disbelief due to all of the biases and misconceptions that still surround chronic pain," Christin shares. But chronic genital pain? "That's a whole other ball of wax," as Christin puts it.

"Many people today feel comfortable enough to say, 'I've got a killer headache, or back pain.' It's something that people can relate to, even if they've only had it transiently," she says. "But you can't be like, 'Oh, yeah, I'm burning down there.'"

BROADENING THE SCOPE

Christin's personal experience with vulvodynia led her to work for the National Vulvodynia Association for more than a decade, eventually as its executive director. She's worked extensively with organizations studying pain disorders across the country, including the U.S. Food and Drug Administration (FDA), National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), and multiple universities.

Through that work, she's seen just how difficult it can be to get funding to research any chronic pain condition—let alone one with stigma attached.

"Health disorders that are deadly or transmittable tend to be prioritized to receive more research funding than 'benign' conditions like chronic pain that do not kill you and that you cannot transmit to another person," Christin says. "The problem, however, is that America has now become a nation of chronic illness—more than 40% of Americans have at least one chronic illness, including chronic pain."

She adds, "Lawmakers and federal health and research agency administrators have a difficult job in figuring out how much money should be spent on hundreds of equally horrific medical conditions."

In the late aughts, the National Institutes of Health released results from two long-term research studies on people with multiple chronic pain conditions. These studies showed



Above: Christin speaks on a panel for The Hill discussing the opioid epidemic. Below: Christin testifies during a U.S. Senate hearing.



that 75 to 80% of women who have one pain condition actually have multiple pain conditions. No one knew this before these studies because, as Christin puts it, "The guy who's treating your jaw pain is not asking about your pelvic pain."

Christin decided to do something about it. She began meeting with leaders of other organizations that represented individual chronic pain conditions, and they founded the Chronic Pain Research Alliance in 2009.

The Alliance advocates for women who live with several of 10 different chronic pain disorders—a condition called chronic overlapping pain conditions, or COPCs. These include urogynecological conditions like vulvodynia, endometriosis, and interstitial cystitis/painful bladder syndrome, as well as irritable bowel syndrome, fibromyalgia, and chronic migraine, among others.

"We felt it was really important to have an advocacy initiative focusing on advancing science for this group of people" who experience multiple chronic pain conditions, Christin shares.

For her, this multi-pronged approach is a calling.

"If you're advocating for science and you're working within agencies like the NIH, you need people who understand science, but you also need people who understand the patient experience," she says.

—Pressley Frevort


Dina on a trip
to Morocco.

Dina Thachet

Formerly Hesitant to Question Doctors, She Now Speaks Up for Others

Until she was 19, Dina Thachet was “100% healthy,” hardly ever going to the doctor.

In February of 1992, she began experiencing pain in her fingers. Doctors continually asked her if her fingers were turning blue or white—but as an Indian woman, Dina never experienced changes in color to her darker skin.

“I was getting a lot of ‘Well, it’s February in Chicago, so just wear an extra pair of gloves,’” she says.

The doctors missed the diagnosis of Raynaud’s disease, a condition that limits blood flow to certain areas of the body and often causes numbness or cold, just as they would continue to miss other signs and symptoms as Dina’s health began to spiral. Anemia and lower back pain were brushed off as indicators of an active college life, with campus providers suggesting Dina was trying to get out of class. She withdrew from college, re-enrolled, and withdrew again as her symptoms worsened.

Her parents believed her, but providers did not, with some recommending her for a psych consult. “I did certainly, at some points, start to believe, ‘Maybe I am making things up, or what if I am crazy?’” Dina recalls. “I had a very warped sense of what normal felt like, because I had been living with pain for so long.”

WITH EACH DIAGNOSIS, MORE QUESTIONS

Dina eventually received a diagnosis of endometriosis, had emergency surgery, and was given a birth control pill to help regulate her menstrual cycle. The day she took her first pill, she landed in the emergency room with meningitis and an E. coli intestinal infection—a succession of events that baffled doctors at first.

“The pain of meningitis is like nothing I could ever describe,” she says. “I felt like my head was about to explode, like the pain was because my brain was pushing against my skull. But the doctors didn’t believe me.”

She was told to stop hyperventilating, to stop looking for attention.

It was a nurse who identified the meningitis. “She had to

step in and interrupt, and the doctor was one of *those* guys, so he gave her an earful,” Dina recalls. Once the nurse had the doctor’s attention, Dina was rushed into a treatment room for a spinal tap as the doctor swore, the situation’s urgency now clear.

“I was not one to question doctors,” she says. “My family also [wasn’t]. Culturally, as Asians, we are just kind of like, ‘Okay, that’s what the doctor said!’”

She doubted her own intuition: “They’re telling me that the labs aren’t showing anything, and they’re the experts. They’re telling me I should feel better, then I just have to believe them. It is very isolating.”

She began inpatient treatment for the meningitis and *E. coli* and was discharged after 12 days. Within a half hour, she was back at the hospital, her pain “excruciating.”

AN ANSWER, THEN CHAOS

Finally, she saw a rheumatologist.

“This rheumatologist sat with us for about two, two-and-a-half hours and said, ‘Tell me everything—even if you had a hangnail, I don’t care,’” Dina recalls.

As Dina and her mother walked through her medical history, the doctor seemed puzzled until they mentioned her starting birth control.

“He almost fell out of his chair,” she says. “He’s like, ‘You have something called lupus.’” The shift in hormones had triggered a lupus flare, inhibiting her immune system and leading to the meningitis and *E. coli* infections.

“It was absolutely a relief to know I’m not crazy, I didn’t make any of this up,” Dina says. “But I was also equally terrified, because my best friend had [lupus] and I knew what she had been through and experienced.”

Lupus causes the immune system to attack the body’s tissues and organs. Dina was amidst a bad flare that landed her in the ICU.

“I was in pain from head to toe,” she shares. “I had rashes all over my body. I couldn’t breathe. I was pronounced dead three different times over the course of the five weeks I was in the hospital.”

A “megadose” of steroids reduced inflammation everywhere but her kidneys, and a biopsy found her kidney function had dropped below 10%. Her kidney biopsy caused a blood clot. “It was a very chaotic and awful five weeks,” she explains. “My parents have never fully recovered from the PTSD of it.”

She ended up on chemotherapy to help her kidneys.

“Just like steroids and all the drugs that we’re on—especially the ones not FDA-approved for lupus—they’re double-edged swords,” she shares. “They’re life-saving; they are life-giving. We are glad that we have those options. But on the flip side, we have a lot of side effects as a result of those treatments. But at the time, that is what saved my kidneys. It is what saved my life.”

But the chemotherapy also caused fertility challenges, and Dina and her husband, Nittin, tried for 13 years to get pregnant. Initially, Dina’s doctor wouldn’t discuss it, asking her why she wanted to throw out her hard-won health for a risky pregnancy.

Dina fired him. “I said, ‘Thank you, but you’re not looking at me as a young woman. You’re only looking at me as a lupus



Above: Dina and her husband, Nittin.

Below: Dina and fellow Lupus Research Alliance advocate Margaret visiting the U.S. Capitol to advocate for people living with lupus.



"This is where I can make a difference, not just for myself, but for other people along the entire spectrum of lupus, autoimmune disease, pain issues. We deserve to have a voice. We deserve to share our perspective and our desires and needs with the people that get to make the decisions about what funding there is, where it goes, how it's spent."



Left: Dina and her cousins on a trip to England. Right: Dina and her husband with her parents.

patient, and I'm a million other things besides that."

She found a supportive rheumatologist who offered a nuanced discussion about the risks and options.

Dina and her husband now have a 3-year-old daughter who loves to dance and play.

A VOICE FOR HERSELF—AND OTHERS

Following her diagnosis, Dina struggled: "Why me, and what did I do to deserve this?" And then it was like, pardon my French, but F this. There's a life out there for me, and I need to get back to it."

While undergoing chemo, Dina re-enrolled in school closer to home and went on to finish her degree. She trained to facilitate a support group, applied for lupus research studies (always denied when she mentioned her ethnicity), and got involved with advocacy through what is now the Lupus Research Alliance (LRA).

"I was not happy with the fact I was on these treatments that were not FDA-approved for lupus," she says. "Lupus has been around for such a long time, and they still don't have treatments that are just for us."

Then Dina, who lives in Bolingbrook, Illinois, was invited to advocate on Capitol Hill. "I was hooked. This is where I'm supposed to use my voice," she shares. "This is where I can make a difference, not just for myself, but for other people along the

entire spectrum of lupus, autoimmune disease, pain issues. We deserve to have a voice. We deserve to share our perspective and our desires and needs with the people that get to make the decisions about what funding there is, where it goes, how it's spent."

Through her work with the LRA, she met Kathleen Arntsen, president and CEO of the Lupus and Allied Diseases Association (LADA). Dina became a patient advocate for LADA. Her testimony was included in an Institute for Clinical and Economic Review (ICER) report for two new lupus medications. ICER is a nonprofit organization that analyzes the cost-effectiveness of treatments and can influence what treatments and medications insurance companies choose to cover.

Now 48, Dina has lived with lupus for 28 years. The road has been bumpy—for instance, she recalls one doctor who said "you people" in reference to Indian women. But she continues to advocate for herself and others.

"[Advocacy] really kind of fell in my lap to some degree, but became the driving force," she says. "I can represent others who don't have a voice or aren't able to get out of bed or work. ... My experience and my survival is not in vain, because I survived all of this for a reason. That is so much bigger than I am."

—Kirsten Ballard



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Grace with her husband, seven kids, and two grandkids during an anniversary photo shoot.

Grace Chappell

Combating the Stereotype of the
'Angry Black Woman'

One day in 2021, without warning, Grace Chappell couldn't speak. Though her mind was racing, the 40-year-old mom of seven couldn't force a single word out of her lips.

There had been 13 years of frequent agonizing headaches, with a diagnosis of chronic migraine after seven years, but Grace had never been through anything like this before. Three months earlier, though, she had experienced a similarly terrifying event when one side of her face suddenly began drooping. While this is typically a clear indicator of a stroke, that wasn't the case for Grace.

A neurologist diagnosed Grace with hemiplegic migraine, a rare type of migraine accompanied by loss of feeling in one side of the body, mimicking a stroke. She also developed idiopathic intracranial hypertension, or pseudotumor cerebri. The condition causes increased pressure inside the skull, and Grace says it affects the right side of her body. "It mimics a brain tumor,"



she shares. “It’s a lot of pain, and it makes me sound as if I’m hyperventilating or humming.”

During the frequent attacks Grace experiences, which can last for up to seven hours, she is trapped in her body, still able to think but unable to communicate.

“That’s when I cry,” she says. “I get emotional. This is so brand new to me. I don’t want to accept it.”

DISBELIEVED, BELITTLED, CALLED ‘STUPID’ AND ‘BELLIGERENT’

Getting treated for her pain has been a long and difficult road. At first, she was the one who dismissed her migraine episodes: “It was just a bunch of pressure. I started feeling dizzy and nauseous. But I assumed that it was just a headache,” she says.

But soon it was doctors who were minimizing her pain, suggesting she lose weight or change her diet. “Did you ask me what I’m eating? No,” she recounts. “They keep pushing diabetes or high blood pressure on Black people, saying, ‘Watch what you eat, eat healthy, eat this...’ Every African American doesn’t have diabetes.”

When she goes to the emergency room during an attack, she often sees unfamiliar providers and is unable to communicate with them because of her speech loss. In the ER, it can be difficult to get anyone to take the time to read her charts.

“They’re assuming it’s a stroke, and I understand they’ve got to, but I’m trying to tell them I know it’s not,” Grace shares.

After too many experiences like this, Grace, who lives in Philadelphia, and her husband have developed a Charades-like way of communicating that allows her husband to act as interpreter when she can’t verbalize her thoughts for herself.

“I talk a lot now, because I know what it feels like not to be able to talk,” Grace shares. “I’m being more aware of all the things in life that I unconsciously may have taken for granted, big or small, because in the blink of an eye, it can all be taken away from you.”

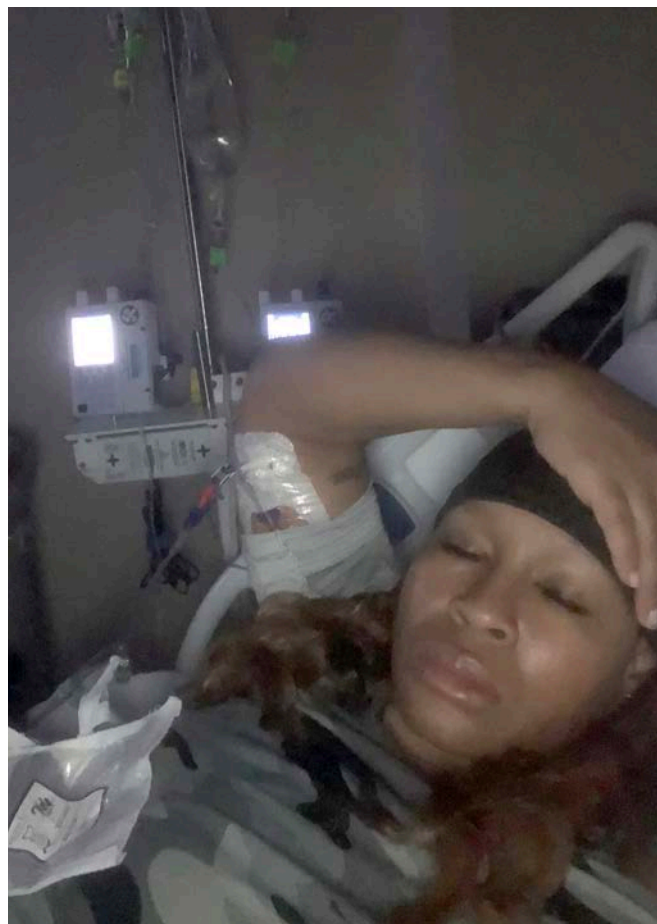
Grace is concerned about being seen as an “angry Black woman” when she seeks medical care. She sees very few Black faces around her at the hospital, “and if they are there, they aren’t doctors or nurses,” she says.

The lack of medical personnel who share her cultural background has further-reaching effects than just the ability to chit-chat during an appointment. A National Institutes of Health report notes that cultural differences between providers and patients increase the likelihood of “diagnostic errors, missed opportunities for screening, failure to take into account differing responses to medication,” and more.

Grace says she has felt disbelieved and minimized by health care professionals multiple times, including an instance when she went to the emergency room during a pressure headache caused by her idiopathic intracranial hypertension and was placed in a frightening tent-like room.

“It was so uncomfortable,” she shares. “It wasn’t safe at all; I didn’t feel safe.”

She called her husband to come pick her up and says a nurse called her “stupid” and “dumb” for leaving, and documented that Grace had refused care.



Grace receives a migraine infusion treatment during an in-hospital stay.





“That made me look like I didn’t want the treatment that I was fighting so hard to receive, but they didn’t understand; I wasn’t safe,” Grace says.

Another time, she had a bad reaction to a medication and was described as “belligerent” in her file.

The need to push past harmful stereotypes about patients of color takes a toll: “It gets a little frustrating, because [they think I look fine], but I’m not. I’m in pain. I might not cry all the time, because unfortunately, I have to deal with it. So I have to come in and be the ‘strong Black woman’ that people associate us with. But we’re in pain too!”

OPENING UP, FINDING SUPPORT, AND REMEMBERING TO LAUGH

For a while, the mother of seven and grandmother of two tried to hide her pain, wanting to appear strong. “There was a point in my life that I could not be active,” she says. “I was always in pain. I was really sensitive at times with the kids, with the noise, with the TV, and I didn’t want to project, so I would come to my room. I would always be silent.”

She finally sat everyone down and explained what was going on.

“I said, ‘Hey, this is what I deal with. I’ll try to be available as much as I can at the moment. But during times that I can’t, it’s not that I don’t care or I don’t love you guys. It’s just that I have to get myself together,’” she says.

She’s learned some tricks along the way, citing blackout curtains and sunglasses as especially helpful with her photophobia, or discomfort with bright light.

*“I talk a lot now, because I know what it feels like not to be able to talk. I’m being more aware of all the things in life that I unconsciously may have taken for granted, big or small, because **in the blink of an eye, it can all be taken away from you.**”*

She hosts movie parties for her kids, in part so she can keep the lights dark. She attends events, even if she has to leave early.

“I try to show up now,” she says. “I used to hide it from family members and friends because I didn’t want to accept it. I didn’t know if people would understand. But now with the hemiplegic migraine and then the pressure migraine, I think that kind of got everyone’s attention, especially for those who have witnessed my attacks or even heard how severe they are. [Before], I think a lot of people thought, ‘Oh, she’s got a headache. It’s nothing. We all have headaches.’” She adds that there has been an outpouring of love and support from family and friends.

She’s had to make adjustments in her daily life, such as how she styles her hair. The braids she used to love tugged on her head and caused pain, and she can’t handle wearing headbands or scarves around her head.

Grace is especially sensitive to light, smells, and sound. Her youngest son once compared her to a dog. “He said, ‘Mom, I think you have ears like a dog.’ I said, ‘Why?’ He said, ‘Because the TV volume is on five, but you still hear it in your room.’”

She laughs recounting the story.

“I know it’s a serious issue. But I always try to put a smile on my face,” she says. “My family, they feel so uncomfortable at times because I was crying so much. I just try to ease their mind because they’re afraid. Even though I’m scared, I try to make the best out of it.”

Grace found that connecting with others going through the same thing was a game-changer when she joined a support group that had a Black woman as one of its leaders.

“I said, ‘Wow, someone looks like me that’s going through this.’ She understands the whole thing we go through about being an ‘angry Black woman.’ The treatment that we get. People think that when we go to the doctor, all we want is medication. No, I just want help.”

—Kirsten Ballard

RESOURCES

BIPOC

Asian & Pacific Islander American Health Forum: apiahf.org
Association of Asian Pacific Community Health Organizations: aapcho.org
Chinese American Medical Society: camsociety.org
Color of Crohn's & Chronic Illness: cocci.org
Indian Health Services: ihs.gov
Latino Diabetes Association: lda.org
Looms for Lupus: looms4lupus.org
National Alliance for Hispanic Health: healthyamericas.org
National Indian Health Board: nihb.org
Papa Ola Lokahi: papaolalokahi.org
South Asian Public Health Association: joinsapha.org

LGBTQ+

Center for Black Equity: centerforblackequity.org
The Fenway Institute: fenwayhealth.org/the-fenway-institute
GLMA: glma.org
National Coalition for LGBTQ Health: healthlgbt.org
OutCare: outcarehealth.org
Planned Parenthood LGBTQ+ Resources: bit.ly/plannedparenthoodlgbtq
Trans in the South: bit.ly/transinsouth
Transgender Care Listings: transcaresite.org
World Professional Association for Transgender Health: wpath.org

EQUITY AND ACCESS

Agency for Healthcare Research and Quality: ahrq.gov
CareMessage: caremessage.org
CDC Office of Minority Health and Health Equity: cdc.gov/healthequity
Center for Medicare Advocacy: medicareadvocacy.org
Children's Health Insurance Program: bit.ly/childhealthinsuranceprogram
Diverse Health Hub: diversehealthhub.org
Extra Help (Medicare extension): bit.ly/x-trahelp
Findhelp: findhelp.org
HealthWell Foundation: healthwellfoundation.org
HHS Office of Minority Health: minorityhealth.hhs.gov
National Association of Free & Charitable Clinics: nafcclinics.org
National Health IT Collaborative for the Underserved: nhit.org
National Institute on Minority Health and Health Disparities: nimhd.nih.gov
National Minority Quality Forum: nmqf.org

(EQUITY AND ACCESS CONT'D)

National Patient Advocate Foundation: npaf.org
National Reach Coalition: reachcoalition.org
NeedyMeds: needymeds.org
Patient Access Network (PAN) Foundation: panfoundation.org
Patient Advocate Foundation: patientadvocate.org
Rx Assist: rxassist.org
Rx Hope: rxhope.com

SUICIDE HOTLINES, HELP & RESOURCES

Crisis Text Line: crisistextline.org
or text "HOME" to 741741
National Organization for People of Color Against Suicide: nopcas.org
National Suicide Prevention Lifeline: suicidepreventionlifeline.org to chat,
or call 800-273-TALK(8255) or 988
SAGE Advocacy & Services for LGBTQ+ Elders: sageusa.org
or 877-360-LGBT(5428)
Suicide Hotlines: suicide.org/suicide-hotlines.html
To Write Love On Her Arms: twloha.com
or text "TWLOHA" to 741741
Trans Lifeline: translifeline.org
or 877-565-8860
Trevor Project: thetrevorproject.org
to chat, call 866-488-7386, or text "START"
to 678678

U.S. PAIN OFFERS MANY DIFFERENT SUPPORT GROUPS TO SUPPORT UNDERSERVED POPULATIONS.

BIPOC: bit.ly/pcbipocsupport
LGBTQ+: bit.ly/pclgbtqsupport
Teen Pain Warriors: bit.ly/teenpainsupport
Spanish-speaking families: bit.ly/pcspanishsupport



WOMEN

Asian Women for Health: asianwomenforhealth.org
Black Mamas Matter Alliance: blackmamasmatter.org
Black Women's Health Imperative: bwhi.org
Center for Young Women's Health: youngwomenshealth.org
DiabetesSisters: diabetessisters.org
ENDO Black: endoblack.org
Endometriosis Association: endometriosisassn.org
For Grace: forgrace.org
Gaston and Porter Health Improvement Center: gastonandporter.org
HealthyWomen: healthywomen.org
National Vulvodynia Association: nva.org
National Women's Health Network: nwhn.org
Society for Women's Health Research: swhr.org
We Are ILL: weareillmatic.com

MEN

100 Black Men of America: 100blackmen.org
American Society for Men's Health: asmhnet.org
American Society of Andrology: andrologysociety.org
Black Barbershop Health Outreach Program: blackbarbershop.org
Black Men's Health Project: blackmenshealthproject.org
Let Me Run: letmerun.org
Men's Health Network: menshealthnetwork.org
Partnership for Male Youth: partnershipformaleyouth.org
Young Men's Health: youngmenshealthsite.org

RURAL

National Association of Rural Health Clinics: narhc.org
National Organization of State Offices of Rural Health: nosorh.org
National Rural Health Association: ruralhealth.us
Rural Center for AIDS/STD Prevention: rcap.indiana.edu
Rural Health Information Hub: ruralhealthinfo.org

YOUTH

The Jed Foundation: jedfoundation.org
Juvenile Diabetes Research Foundation: jdrf.org
KidsHealth/TeensHealth: kidshealth.org
The National Alliance To Advance Adolescent Health: thenationalalliance.org
National Black Child Development Institute: nbcdi.org
Pediatric Pain Warriors: pediatricpainwarrior.org
Rare Kids Network: rarekidsnetwork.org
Society for Adolescent Health and Medicine: adolescenthealth.org
Society for Pediatric Pain Medicine: pedspainmedicine.org
We R Native: wernative.org

SENIORS

Alliance for Aging Research: agingresearch.org
Alzheimer's Association: alz.org
Diverse Elders Coalition: diverseelders.org
International Association for Indigenous Aging: iasquared.org
Justice in Aging: justiceinaging.org
National Asian Pacific Center on Aging: napca.org
National Caucus and Center on Black Aging: ncba-aging.org
The National Consumer Voice for Quality Long-Term Care: theconsumervoice.org
National Council on Aging: ncoa.org
National Hispanic Council on Aging: nhcoa.org
National Indian Council on Aging: nicoa.org
National Resource Center on Native American Aging: nrcnaa.org



RESOURCES FOR HEALTH CARE PROFESSIONALS

American Society on Aging: asaging.org

EthnoMed: ethnomed.org

Gender Spectrum: genderspectrum.org

Mental Health Technology Transfer Center Network: mhttcnetwork.org

Migrant Clinicians Network: migrantclinician.org

National LGBTQIA+ Health Education Center: lgbtqihealtheducation.org

Safety Net Center: safetynetcenter.org

DIVERSE MEDICAL ASSOCIATIONS & ORGANIZATIONS

American Medical Student Association's Gender & Sexuality Action Committee:
amsa.org/action-committee/gender-and-sexuality

Asian Pacific American Medical Student Association: apamsa.org

Association of American Indian Physicians: aaip.org

Association of Black Women Physicians: blackwomenphysicians.org

Association of Clinicians for the Underserved: clinicians.org

Association of Minority Health Professions Schools: amhps.org

Association of Native American Medical Students: anamstudents.org

National Coalition of Ethnic Minority Nurse Associations: ncemna.org

National Council of Asian Pacific Islander Physicians: ncapip.org

National Medical Association: nmanet.org

Society for Advancement of Chicanos/Hispanics and Native Americans in Science:
sacnas.org

Society of Black Academic Surgeons: sbas.net

DISABILITY RIGHTS GROUPS

ADA National Group: adata.org

American Association of People with Disabilities: aapd.com

American Civil Liberties Union:
aclu.org

National Disability Rights Network:
ndrn.org

National Organization on Disability:
nod.org

CLINICAL TRIALS

Antidote: antidote.me

ClinicalTrials.gov: clinicaltrials.gov

MENTAL HEALTH RESOURCES AND HOTLINES

The Asian Mental Health Project:
asianmentalhealthproject.com

BlackLine: callblackline.com
or 800-604-5841

Inclusive Therapists:
inclusivetherapists.com

LGBT National Help Center:
glbthotline.org to chat,
or call 888-843-4564

LGBT National Senior Talkline:
888-234-7243

LGBT National Youth Talkline:
800-246-7743

The Loveland Foundation:
thelovelandfoundation.org

Mental Health of America:
mhanational.org

National Alliance on Mental Illness:
nami.org

National Queer & Trans Therapists of Color Network: nqttcn.com

South Asian Mental Health Initiative & Network: samhin.org

Therapy for Black Men:
therapyforblackmen.org

Therapy for Latinx:
therapyforlatinx.com



INDUSTRY-SPONSORED PATIENT-FACING SITES

Acadia: acadia.com/pipeline

Amgen: amgen.com/products

Axogen: rethink-pain.com

Boston Scientific: pain.com

Collegium: collegiumpharma.com/about/company-overview

Johnson & Johnson: getreliefresponsibly.com

Lundbeck: lundbeck.com/global/patients

Primus Pharmaceuticals: primusrx.com/diseases.html

Salix: understandingoic.com

Vertex: vrtx.com/research-development/pipeline/pain

OTHER PAIN ORGANIZATIONS

Alliance for Balanced Pain

Management: alliancebpm.org

Alliance for Gout Awareness:

goutalliance.org

American Chronic Pain Association:

theacpa.org

American Diabetes Association:

diabetes.org

American Migraine Foundation:

americanmigrainefoundation.org

American Porphyria Foundation:

porphyriafoundation.org

American Sickle Cell Anemia

Association: ascaa.org

American Thyroid Association:

thyroid.org

Americans for Safe Access:

safeaccessnow.org

Arthritis Foundation:

arthritis.org

Arthritis National Research Foundation:

curearthritis.org

Association of Migraine Disorders:

migrainedisorders.org

Autoimmune Association:

autoimmune.org

Beyond Celiac:

beyondceliac.org

Celiac Disease Foundation:

celiac.org

CHAMP (Coalition for Headache and

Migraine Patients):

headachemigraine.org

Chronic Migraine Awareness, Inc.:

cmaware.org

Chronic Pain Research Alliance:

chronicpainresearch.org

Clusterbusters:

clusterbusters.org

Crohn's & Colitis Foundation:

crohnscolitisfoundation.org

Danielle Byron Henry Migraine

Foundation: daniellefoundation.org

Dysautonomia International:

dysautonomiainternational.org

The Ehlers-Danlos Society:

ehlers-danlos.com

Foundation for Sarcoidosis Research:

stopsarcoidosis.org

Global Healthy Living Foundation:

ghlf.org

Gout Education Society:

gouteducation.org

Graves' Disease & Thyroid Foundation:

gdatf.org

Headache & Migraine Policy Forum:

headachemigraineforum.org

Infusion Access Foundation:

patientaccess.org

International Foundation for Autoimmune & Autoinflammatory Arthritis: aiarthritis.org

International Pain Foundation:

internationalpain.org

Interstitial Cystitis Association:

ichelp.org

Lupus and Allied Diseases Association:

ladainc.org

Lupus Foundation of America:

lupus.org

Lyme Disease Foundation:

lyme.org

Marfan Foundation:

marfan.org

Miles for Migraine:

milesformigraine.org

Multiple Sclerosis Foundation:

msfocus.org

National Headache Foundation:

headaches.org

National Kidney Foundation:

kidney.org

National Multiple Sclerosis Society:

nationalmssociety.org

National Organization for Rare

Disorders: rarediseases.org

National Pain Advocacy Center:

nationalpain.org

National Psoriasis Foundation:

psoriasis.org

National Vulvodynia Association:

nva.org

Reflex Sympathetic Dystrophy

Syndrome Association: rsds.org

Sick Cells:

sickcells.org

Sickle Cell Disease Association of

America: sicklecelldisease.org

Solve ME/CFS Initiative (Solve M.E.):

solvecfs.org

Spondylitis Association of America:

spondylitis.org

Vasculitis Foundation:

vasculitisfoundation.org

U.S. Pain Foundation:

uspainfoundation.org



**PROVIDING HOPE, RESOURCES, AND
SUPPORT FOR THE 50 MILLION AMERICANS
WHO LIVE WITH CHRONIC PAIN**



**U.S. PAIN
FOUNDATION**

WHO WE ARE

A 501(c)(3) nonprofit, the U.S. Pain Foundation is the leading patient organization for people with pain. Our mission: to empower, educate, connect, and advocate for individuals living with chronic illnesses or serious injuries that cause pain, as well as their caregivers and clinicians.

WHAT WE DO

Through our multiple programs and services, we work to enhance quality of life for people with pain, improve patient outcomes, address access and affordability issues, and increase public awareness and empathy for the issue of pain.

USPAINFOUNDATION.ORG