NHF InSights™
Fighting to Feel Better

Katy Oakley:
Welcome to NHF InSights, the National Headache Foundation's podcast where we host fireside chats developed with support of our industry partners. This is where we talk about what's new in the headache and migraine care space, from the latest studies and research to real world experiences and treatments. I'm your host, Katy Oakley, the CEO and executive director for the National Headache Foundation.

If you live with a headache disorder or migraine, you know how hard it can be. Attacks can be incredibly debilitating, painful, and exhausting, but there's also a logistics and an emotional draining aspect of it. There's just a lot of challenges that people experience. They could be trying multiple medications to see what's working for them. They could be experiencing insurance hurdles and denials, and it can be a lot, even between attacks. And that's exactly what we're here to talk about today. This conversation is an access focused conversation. We're going to dig into real world barriers patients face when they are trying to get help and find a treatment option that works best for them and what it can look like to keep moving forward.

I am so excited for our panel of speakers today. We have three incredibly passionate and educated people that we're going to talk to, and they're going to help us to look at this from quite literally all perspectives. The first, we have Michelle Mayer. Michelle lives with migraine and has spent years navigating treatments, insurance barriers, and she is a pro at advocating for herself. Michelle, welcome.

Michelle Mayer:
Thank you.

Katy Oakley:
We also have Dr. Wade Cooper who is a headache specialist, and he is actually Michelle's headache specialist. He's going to help to share what the process looks like from the provider side, and why delays and denials can really matter. Welcome, Dr. Cooper.

Wade Cooper, MD:
Hi, Katy. Thanks for having me.

Katy Oakley:
Thanks for being here. And last but absolutely not least, we have Julienne Verdi, who, if you know her, she is an advocacy expert. She's going to help us to zoom out and to understand why these barriers exist and what patients can do to take action. Hi, Julienne, thanks for being here.

Julienne Verdi:
Thanks for having me.

Katy Oakley:
Thank you all. This episode is created with support of Lundbeck, and I am excited to get started. So, Michelle, let's start with you from the patient side. When people often hear migraine, they think about the attack itself, but they don't realize that there's a very full reality that's happening between attacks and a battle that a lot of patients are facing in getting care. Can you talk a little bit about your experience and what that's been like?

Michelle Mayer:
It's been difficult. I've had migraine for probably since I was 15 or 16. Somehow during all this, I still managed to graduate high school, grad school, still working, been at my agency for 25 years. And in the last probably five, six years constantly fighting my insurance for medications that Dr. Cooper has felt that I needed. And I've tried medications that didn't work. Went back, they kept saying that I needed to try this, this, and this. And it was difficult, frustrating, very hard. We tried everything under the sun, nothing works. We find something that somewhat helps, and then it gets denied, or my insurance goes and changes the formulary. So, I was on an injection and said I had to try a different injection all of a sudden. They just keep denying.

Katy Oakley:
That's so incredibly frustrating. Dr. Cooper, can you talk about on your side, what's happening on the provider side when a patient is experiencing something like this?

Wade Cooper, MD:
Yeah, absolutely Katy. And for those who don't know, Michelle, I've known Michelle for quite a long time, and she's a warrior. A lot of us providers see our patients as kind of warriors because as many people know, if you have chronic migraine, you may have a lot of symptoms day to day in addition to the severe spikes of headache which makes it hard for people to follow through with requests from their insurance, or following up on details that are requested to bring in.

And from a provider's perspective, if we have a tool or a treatment option that we think is going to be very effective, we really want our patients to get started on that. We want them to get started on it now, not with a delay, not with the frustration of going back and forth with phone calls or portal messages or whatever else. And internally on our side of the equation, when we request a treatment, there's a whole process that happens behind the scenes for trying to get a third-party payer to agree and to fund that treatment option that we're looking for.

I'm happy to share with you some of the details of that when we get to it. But indeed, the mission that us headache specialists have is how do we get the best tools into the hands of our patients so that they can be most effectively treated. And that's something that we tend to battle with on a regular basis.

Katy Oakley:
One of the things that you and I spoke about before was about the delay in treatment that often happens because of this. Can you speak to that and why it's so important from the patient and the provider perspective?

Wade Cooper, MD:
Yeah. So this is the thing. Michelle and I will have a very productive conversation from my perspective at least about what we're trying to accomplish. And if we're talking about a new treatment option,

what we expect it to do. We'll talk about mechanism, how it might be really effective for either Michelle or whatever patient we're speaking with directly. And then we get kind of all excited about it. I get excited about it. Our patients get excited about it. We want to try this. We want to see forward power and forward progress. And our patients will go to the pharmacy or go to wherever they need to get their treatment and then be told, oh, I'm sorry, we don't have that quite yet, come back. So, there's the first frustration experience. And who wants to wait in line at a pharmacy for an hour to be told, I'm sorry we can't help you today.

And then if there's a delay, if there's a week or two of a delay before there's an answer, all of the things that we spoke about, all of the energy and positivity that we have built towards that treatment option kind of melts away. And even if the patient finally gets access to that treatment, let's say it's 2 or 3 weeks or 4 weeks later sometimes, they finally get their hands on it, it's like, well, what is this supposed to do again? How do I use this again? And you have to kind of reconvene and have that conversation all over. And it's not just the frustration of the 4 week delay or however long it's going to get that solution in front of our patients, but it's 4 weeks of lack of treatment, 4 weeks of further persistent migraine symptoms that perhaps could have been addressed, treated, prevented, improved if that appropriate therapy was in their hands. I mean, multiple layers of a challenge. And we'll get to it, but there are some strategies on how to improve this too.

Michelle Mayer:
We recently had, I think from my appointment in October, I had come in and my appointment was on a Monday. And we found out that the medication that I'd been trying to get for a year had been authorized, and it expired the day before. And none of us knew it, and I could have had my medication that we've been trying to get. So, then we had to start the whole authorization process over again, and it got denied again.

Wade Cooper, MD:
And that's the thing, Michelle, you're so patient with this. And it was frustrating to both of us because we'd requested this a long, long time ago. It got stuck in the shuffle. It got argued back and forth like a tug of war match. We finally got an approval. None of us knew about it. And then lo and behold it was available, not activated, and then now start back at zero again. So gut punch city, right?

Michelle Mayer:
Yeah. So, it was really frustrating because it's the one med that we kind of found that will help me. It'll take me from like a 9 or 10 down to my normal 7, which is really sad. I want to get back to a 7, but it will get me back down to my normal within 30 minutes.

Wade Cooper, MD:
Right. And also, Michelle, as you and I know, some treatments are just so unique. The one that you and I are talking about is a very specific way of helping that our other medicines just don't focus on. And to find a path that was helpful. And if I remember correctly, Michelle, I think you had samples of that a long time ago. We felt like it worked, and now we're trying to arm wrestle through this insurance process and then we know it works. So, this is the tease, we knew that you had a positive response. And Michelle, we will do anything to help you feel better and to know that there is a tool out there. But it was just ridiculously expensive without insurance coverage. With insurance coverage, it's minimal cost to you. We just had to have that partnership with your third-party payer, and it was the frustration there.

Michelle Mayer:
Yeah. And then we had the issue with because I was trying samples, that didn't count towards whether it was going to be effective. Insurance wouldn't pay for it.

Wade Cooper, MD:
I can't wait to get to this part, Katy. There's this whole experience with the tried and failed list. And sometimes even if someone's tried a medicine before, but it was given as a physician sample, or if it was given, someone purchased something outside of their insurance plan, sometimes it's not counted. There's some strategies around that too, I think, that we can figure out. But there's that piece to it also.

Katy Oakley:
I agree, I'm really excited to get to that. And I'm just loving this perspective here of having a patient and their provider on the call. I think that that's really unique. And so I'm really grateful that both of you are willing to do this.

Dr. Cooper, you were talking about I mean, that situation is unique, but unfortunately common for migraine and headache patients. When you're experiencing delays that long, what the cadence? What's the process that you should be following up with your insurance company? How does that work? Do you recommend the patient does that? Is the provider's office also doing that?

Wade Cooper, MD:
There's a whole process to this. So, for those who aren't aware, if you're a physician or your provider makes a request for a medicine that requires an authorization, there's like different pieces to this. Let me just explore that so people have this built out and they know what happens perhaps behind the scenes. So, your provider makes a prescription, it gets sent to the pharmacy. The pharmacy then tries to process it. If it's a medicine that needs special authorization, meaning your insurance company thinks that it might be a good medicine, but they want to make sure that you've tried other things first that may be cost savings before you try one that's a bit more expensive for them, they'll request the physician's office to show what's been done before. Sometimes that requires a description of how many days of migraine someone's had, or how long someone's had migraine, or how many symptoms someone's had along with that. Do they have light and sound sensitivity or nausea or whatever else. Sometimes it's a requirement to show what's been tried before. And you may be familiar if you're listening to this podcast about this concept of a step edit, which is has someone tried two triptans before they can get to a specific class of medicine for rescue?

Or have they tried two tablet prevention medicines before they can move to a newer class of medicine that prevents therapy. And the onus is on the physician group, your provider, whoever's prescribed that medicine, to kind of show that that path has been taken. But here's the hook. Sometimes patients are new to our practice, and they will tell us, oh, yeah, I've tried this before, but I don't know what they've tried. I can't prove that. Or sometimes someone switched pharmacies and we don't have pharmacy records. Or sometimes there's a statement of it needs to be used for three months. Can you prove that it's been used for three months and not just one month if it's a prevention therapy.

So, a lot of times your provider might even ask you, what have you tried before? How long were you on this medicine? What happened? Were there side effects? Because all of that information is essentially logged into the approval system from the provider's side, so that when you request a medicine, your insurance carrier knows what you've tried before, and then they can determine have you tried other things to prove you're a good candidate to respond to those newer therapies out there? So that should happen on the provider side.

Now here's what can be helpful from a patient's perspective. If you can, even if you bring like a list of what you've tried before, if it's possible to include the dates of that, that's helpful to your provider. Or if you don't know what that is, sometimes we've asked our patients to go back to a pharmacy they've used before and just print out your previous medicines for the last five years or whatever it is. Bring that to your provider, because I can sift through that in maybe about 90 seconds and extract what's important for me to put in my office note so that then it's factual and everyone's on the same page. And it doesn't put as much memory power into someone like Michelle. Michelle, you've been through this. How do you feel about this experience?

Michelle Mayer:
For me, it was easy because I have a three-ring binder that I will take to my appointments with Dr. Cooper that lists all of the medications I'm either currently on or I have tried. And I think I have like three pages of medications that have been tried over the years. So, we can easily go back through and say, yes, she's tried this or she's tried this. This has been a long time. Let's go and try it one more time. But yeah, I bring a three-ring binder with all my medications that I am continuously updating.

Wade Cooper, MD:
Michelle, not everyone has your skill set of organization and determination. I mean, for those who don't know, Michelle and I have known Michelle for a while. There's lots of amazing things about Michelle, but one of the things is that she comes supremely prepared, which is super helpful from my perspective. But here's the unfair part of this. A lot of our patients, they're beaten down by migraine. They may not know what they tried before.

It's kind of unfair to ask our patients to speak in the clinician's mindset of what's been used and what the name was, and for how long. They just might say no. I took a tablet didn't work. It gave me side effects, and that's a challenge. So, it is super helpful, as Michelle's implied. If you have even just a very basic list of what you've tried for prevention therapy, if that's what you're focusing on, what the names were, if you can remember them, how long you're on them for and why it was stopped, didn't work, had side effects, didn't like the color of the packaging, whatever it was.

And then the acute therapy side of it, if you try acute therapies, did you have side effects? What was tried? What was the outcome? And if it's a very basic, simplified list that you can share with your provider at your first visit or at your follow up visits, man is that super helpful from our perspective.

Michelle Mayer:
I can't do numbers for rating my migraines. It's too hard for me, so I do the green, yellow, red. I bring my calendar into Dr. Cooper every appointment, and he says how many green and if I have any green, which is a few occasionally, but it's more yellow and red. But that helps us too.

Wade Cooper, MD:
Yeah, we pray for green.

Katy Oakley:
I love seeing how much you've documented and how prepared you are, but also, Dr Cooper, such great tips. Thanks for sharing that and how patients can help their provider. I think that that's really important.

I really want to zoom out for a second. You spoke about step therapy, and we have the step therapy expert on this call. Julienne, can you speak to these issues on a larger scale? What's happening nationally speaking, where there's barriers that are structurally in place and how this can be so hard to access treatment options?

Julienne Verdi:
When people hear terms like step therapy or insurance denials, it can sound really abstract. But for people living with migraine, we know that this is incredibly personal. At its most basic level, step therapy means an insurance company is requiring someone to try and fail one or more treatment options before they'll approve the treatment their clinician actually prescribed.

You'll often hear this called something like failed first policies. And for migraine patients, that can mean months or even years of cycling through treatments that may not work or may cause serious side effects. And what's important to understand is that this decision isn't being made by your clinician. It's not being made by the patient. It's being dictated by an insurance policy that applies the same rules to everyone, even though migraine is a highly individual disease. And part of the problem we see, and something we're actively working on at the Alliance for Headache Disorders Advocacy, is that not all insurers have updated their formularies to align with current clinical guidelines from leading medical societies, like the American Headache Society. In many cases, insurers are still prioritizing older, cheaper treatment options, even when there are newer evidence-based options available that may be more appropriate for a particular patient due to side effects or contraindications. And this is often happening. The insurance companies doing this for a reason. They're framing this as a cost saving measure, but it doesn't account for the full picture here. It doesn't account for side effects that force people to stop working, or the progression of disease when migraine becomes more frequent or chronic. It doesn't account for emergency room visits, urgent care visits, hospitalizations when someone gets stuck in an intractable migraine.

And it certainly doesn't account for the emotional toll of living in constant pain, uncertainty and frustration. In real life, this can mean lost jobs, strained relationships, worsening health, and eventually people just giving up because the system wears them down. And again, it can cause overall higher medical costs from a systems level as well, because, Dr. Cooper could probably talk to this a bit, but it takes a lot of work behind the scenes to try to push back against some of these step therapy requirements. And even just the prior authorization to begin with, there's usually in larger hospital systems, whole departments, someone's complete job is to deal with these prior authorization requests and then the step therapy issues along with it. And so, you have the higher costs in the medical system. And then on the insurance side, there's someone on the other side whose job it is to process all of this.

So, all of these things together, it's a systems level issue that that's why this is happening. It's because the law allows it to currently in many plans. There are some laws in some states, but we don't have a federal level law right now that applies to all plans. And so that's why this is happening behind the scenes. This is happening because we are allowing it to happen. The law is allowing it to happen. And insurance companies know that they can get away with this, unfortunately.

Wade Cooper, MD:
Jillienne, can you comment a bit to what it means to patients when something's, quote, on formulary or off formulary, or what's a preferred medicine versus a non-preferred medicine? That comes up a lot in my clinic, and I feel like it might be worthwhile to define what that is.

Julienne Verdi:
Yeah, I think that's really important. Basically, insurers have in the individual plan, they will have a formulary that basically says what medications that they consider appropriate for a specific condition. And so, they will only cover drugs that are on formulary for that patient. So, if you're trying to get something covered that is not on formulary, you're going to hit a lot of barriers and often it's just not going to be covered. You're going to have to go through all of the steps, all of the things to try to get something covered.

But even something on formulary, again, it's going to dictate what those steps are before you can get to X treatment option. And the issue is that not all insurance companies have the exact same formularies. And so, people change jobs in this country all the time. You move different insurance companies. And so, what could have been on formulary, a medication that you were on, your stable on, when you were on one insurance plan, you then switch insurance plans and all of a sudden that medication is now not on formulary. And so now you have lost access to that medication even though you have been stable on it.

So, there are some commitments out there. So AHIP, [formerly] America’s Health Insurance Plans, basically the trade associations for the insurance industry, has come out and said basically they had this six-point pledge of different reforms that they’re going to do around prior authorization. One thing in there is this idea of continuity of care. And so coming hopefully in the next year or so, I think by 2028, there's some things that are going to be phased in. But the American health insurance plans that signed on to this pledge have said, we're going to do a 90-day continuity of care. So, if you are stable on a medication, you switch insurance providers, you switch jobs, etc., that you would have 90 days to stay on that medication. So, your coverage will transfer over for 90 days, so to maintain access to a medication that you might be stable on. That's really promising, and we think that that's going to be really helpful for folks. But we know there's still a heck of a lot of work that needs to be done, and more reform needed to make sure that migraine patients do not need to be jumping through these hoops and getting sicker.

As a migraine patient myself, I know how tough it can be to get on the phone and deal with this, especially when you don't know how well you're going to feel in any given day. You might be in the cave of migraine with a blanket over your head, and now you're having to sit on a call for hours, getting hung up on and calling back, transferred a million times, just trying to access the care that you need to live your life to your fullest potential.

Wade Cooper, MD:
And Jillienne, I do want to point out, it's kind of cool, some of what you've shared there really relates to what we see in clinic. I just had this conversation with the patient, not Michelle, but one of our other patients who's done really, really well with the treatment. And she's been on this preventive treatment for two years now. We know it works really well for her. And she's switching jobs just like you identified. And so, when her job switch occurs and her insurance changes, for her it's coming up in about two and a half weeks, she was terrified that she would have to come off of this treatment. And you can imagine

spending all this time finally finding an effective therapy. She's doing really, really well. None of us want to make a switch at all. Thank goodness her insurance has followed the same exact advice that you've described, which even though the medicine that she's currently on is not on formulary and not a covered medicine, they've agreed to cover it if you were previously on that, even though the insurance was switching over in her situation. So, I don't know what magic you've been able to do Jillienne on your end in advocacy for people like you, but we're seeing it translate in some situations in the clinic already.

Julienne Verdi:
That's great to hear. And one other piece I'll say is, unfortunately, insurance plans do change their formularies year to year. So sometimes there are changes. So even if you're not changing plans, the formulary could change in the next year or even in the middle of the year. So those are also things that patients experience as well. I'm glad to hear that you had a patient where there was this continuity of care piece that's incredibly important. And again, we're hoping that we see this more across the board in the coming months and years ahead.

Wade Cooper, MD:
And one last thing I do want to add and sorry to keep on just butting in here, but the thing is, from my perspective, the insurance companies aren't evil or nefarious. The way I look at this, they have a bucket of money. They have to cover things like migraine and a bucket of money to cover other health issues they're responsible for. So, they're trying to be judicious with the expense. If someone can do really, really well with a simple once a day tablet that's not very expensive to the insurance plan, that's more money available to treat more refractory, harder to treat patients. So, I don't feel like they're trying to, like, stand in the way of therapy. They're just trying to make sure that people who need expensive therapies get it. The problem is it feels frustrating from the patient's perspective about having access to care that might be helpful.

And then one last thing, Michelle, you've probably seen this too, but sometimes a medicine is really hard to get three years ago. And then if it's been around for three years and it's proven to be effective and helpful in our patients, proven that our patients want it, proven that providers want to prescribe it, it tends to become more and more accessible on insurance plans. Have you seen that before either of you two guys?

Julienne Verdi:
Absolutely. And one thing that you said that kind of brought something else up for me, I think understanding why insurers do this in the first place. I think you're absolutely right. Some patients will do well on those less expensive medications, older medications. And that's great and that keeps our overall healthcare costs down. I think one of the issues though is often insurers, there's kind of two lines when they're looking at budgets. They're looking at the pharmacy line and then the medical lines separate. And so often what happens with migraine patients is the pharmacy line, again those newer class medications, are going to be more expensive on the pharmacy line.

But if we can get access to them, it may reduce costs on the medical side. That's where we're talking about the E.R. visits, the urgent care visits, just having repeat visits with specialists because they need to keep coming because they're not stable on a medication. All of those things are tracked in a very different way. And so often the insurers are not looking at the holistic cost of a patient from both the pharmacy and the medical side. So that's one of the things that we're trying to really talk about when we're talking about reform and saying, hey, you can't just look at this one line. Because if you just look at this one line, yes, all the time, you're just going to notice that the older class drugs cost less, and so there's a cost saving if you only allow access to those and make it harder to access the newer medications and therapies. However, if you take into account that medical side, that's where you're going to, we believe, see the savings. And so that's where conversations are being had with insurers trying to help them understand the longer-term costs of what it means for a patient when they're not getting timely access to the care that they need.

Wade Cooper, MD:
Jillienne, and just to kind of throw numbers at that one, one year visit for a migraine patient can cost 5 to $7000 when you take into account all of the expenses to it. And that could fund some of these more specific migraine therapies for someone for an entire year. And I think that's what you're kind of referring to. Michelle, I know you had something to say and I just rudely interrupted. I'm good at that.

Michelle Mayer:
Oh, no. You're fine. I was just going to say that that was recently what happened with the medicine that we've been trying to get for a year that got approved and then expired. My employer went back because we're self-insured. My employer went back and pulled all my medical records, and somehow they said I was in the E.R. and it was $52,000. I don't remember this E.R. visit. I remember going to the E.R. for being sick over the summer a year ago. So, they called the insurance company up and said, approved this medication for her. So, I ended up getting the medication, but only because my agency, decided it was more cost effective for them to pay for the medication than for me to keep going to the E.R.. So that's how I finally got this medication this last time.

Katy Oakley:
Michelle, can you speak on the patient side of how things like this impact your life personally?

Michelle Mayer:
You're already in a lot of pain. It's already hard to do things. I have no idea how I maintain working 40 hours a week. I'm not one to take time off when I have a really bad migraine. I have gotten better over the years. I have signs all over my office, is it time to take your meds? Is it time to take a break? Is it time to leave work?

Granted, I do work from home, so I have more control over things now. The lighting, the noise. I can stop and take breaks when I want to, but it's really hard. It's hard to focus. It's hard. I can read the same thing. I've done this job for over 16 years in my current position. I can read the same thing over and over again five times. And if I get to the fifth time and I'm still not understanding because it's just not making sense to me, I know it's time for me to take a break because it should not take me five times to understand what I'm reading when I see this every day. It's hard for me to do, like, stuff around my house. I may go down to my family's house, my parents house to visit, but I don't do much. I just relax and rest. And I don't go to a lot of family functions when I have a really bad migraine, or I have a plan on what I'm going to do if it's really bad when I'm around all of my family. Even if that is, I go up to my car in the freezing cold if it's in the winter just so I can get a break and try to get the pain to go down.

Katy Oakley:
I'm curious. As a patient, what role have you taken to help yourself and your provider in all of this to help give folks some tips that are also in your shoes right now as to how they can better advocate for themselves?

Michelle Mayer:
I've been involved with the Alliance for Headaches Disorder Advocacy for, I believe, three years now. After I attended my first Headache on the Hill is when I started having like really had bad problems trying to get my medications, and I used the skills that I had learned from Julienne and the AHDA and decided I'd had enough of this. So I went right to our governor, and she forwarded my email to her on to the state Department of Insurance and Financial Services, who contacted me, who asked for more information, and I provided it to them. And they got in contact with my insurance company and filed a complaint. And I ended up getting my medication that we had wanted.

The second time, I believe after my first in-person Headache on the Hill, I again had problem getting another medication that we were trying. And I went right to my federal representative's office after hearing that they had case managers that help with this stuff. And they asked for more information, provided it to them, and they filed an appeal with my insurance. I ended up getting the medication. And I was getting ready to do this a third time when my employer decided to pay for the medication. So, I used all the skills that I learned from AHDA to go to all my governor, my reps. And I recently went through the process and became a board-certified patient advocate, so I can help other people do this and know that they're not alone and there are people to help them.

Katy Oakley:
Yeah. It's a lot of persistence. You spoke to a few really amazing things that, Julienne, I would love to have the listeners understand more about. So National Headache Foundation is a member of AHDA and the work there. Can you talk about what you're doing on a systematic level, Headache on the Hill, how people can get involved?

Julienne Verdi:
Absolutely. So patients and clinicians alike can take action not just for their individual situation, but also in ways that can actually help change the system that is creating these barriers to care in the first place. So, one of the most important policy efforts right now is a federal bill called the Safe Step Act. This is a bipartisan piece of legislation introduced in both chambers of Congress.[1] And the goal of this bill is not to completely get rid of step therapy entirely, but it's to put important guardrails around step therapy in employer sponsored health plans. And it would create clear exceptions so patients and clinicians can bypass step therapy protocols that are ineffective, inappropriate or potentially harmful. So it lays out like five different reasons on why you'd be able to bypass those step therapies.

And what's significant is that this bill already has broad bipartisan support. That tells us this is not a partisan issue. There's agreement across the aisle that the system as it currently exists is not working for patients. But even bipartisan bills don't move forward on their own. They move forward when lawmakers hear from the people that they represent. And that's where a constituent matters. A constituent is simply someone who lives in a lawmaker's district or state, and every person listening right now is a constituent, if you live in the United States, of three members of Congress: one representative in the House, and two senators. And those lawmakers are accountable to their constituents, and they really do pay attention when they hear directly from them as you heard kind of what Michelle is talking about.

And so, I think it's really important to say this clearly that both patients and clinicians should be having these conversations. Patient stories bring that human impact to life. And clinician voices help bring the medical credibility and real-world insight into how these policies affect care. So, when these voices come together, they are especially powerful. And that's what we try to do with our program called Headache on the Hill.

Headache on the Hill is a patient and clinician advocacy event that happens twice a year by the Alliance for Headache Disorders Advocacy and the Headache Alliance. We host it in person in the spring, where advocates travel to Washington, D.C. to meet directly with members of Congress and their staff. And then we have a virtual program in the fall which allows people to participate from anywhere in the country, from the comfort of their home.

During Headache on the Hill participants receive training and support. Again, they meet with their elected officials. They share their personal experiences with migraine and headache disorders, including barriers like step therapy, and ask their representatives to support legislation like the Safe Step Act that would make life better for people living with migraine and headache disorders. And these meetings matter because hearing directly from constituents puts a human face on policy and helps lawmakers understand why reforms like the Safe Step Act are so important.

And one of the ways that we can bring attention to these issues is even also doing things like what Michelle has done. And when she has actually put in those complaints with her federal representatives and state representatives, yes she's taking action on a personal level for her personal circumstance, but it's also bringing attention, yet again, to those lawmakers that the reason they're getting this call from their constituents and the reason why they're going to have to do some work behind the scenes helping Michelle is because of the step therapy policies that allow this system to kind of perpetuate.

And so that process alone is a form of advocacy. And so, I literally had tears in my eyes listening to Michelle's story. And I've heard it before, but it still gets me every time. Patients shouldn't have to go through this, right? They shouldn't have to call their lawmaker just to get access to a medication that their doctor prescribed to them. But while we still have these processes in place, it's a really powerful tool that we have.

And there's also a few other tools I can mention. Besides being involved with Headache on the Hill, which I hope listeners will join, the next Headache on the Hill application period will open in June, another thing that you can do in the meantime is just to visit our website allianceforheadacheadvocacy.org, and find our Take Action section, and you'll find opportunities to be able to send a message to your elected officials in support of the Safe Step Act and other legislative issues that impact migraine and headache patients. Those messages do get counted and tracked, and you will often receive a response from the office.

You can also pick up the phone and call your member of Congress or senator's offices directly. And that feels really intimidating. I'm a millennial. I don't like picking up the phone, but it's really simple. All you need to do is look up a phone number, tell the staffer who answers that you're a constituent. You can say that you're calling to ask them to support the Safe Step Act. You can mention the bill number if you like. You don't have to have it. If they ask you, it's okay. They'll know where the Safe Step Act is. And briefly share why this issue matters to you personally. You do not need to be a policy expert to make your voice heard. You just need to be honest and share that personal story.

And then one other thing I just want to mention, another powerful option is to write a letter to the editor to your local newspaper. Letters to the editor are just short pieces written by community members in response to current issues, and they are actually widely read by policymakers and their staff, especially when they come from local constituents. So, a letter can simply explain how migraine and insurance barriers are impacting your life or your patient’s lives and why reform like the Safe Step Act matters to you and your community. These letters help us to raise awareness, reduce stigma, and build public momentum for change.

Advocacy does not have to be an all or nothing thing. You've heard about a couple of ways that you can do this here with Michelle talked about and what I've talked about, but you can start small. It can be one call, one letter, one meeting and one story shared. But when enough of us take those steps, it can really create pressure. And pressure is what leads to change. Migraine is hard enough. Again, you shouldn't have to fight your insurance company just to access care on top of already fighting this disease. But the Safe Step Act, Headache on the Hill, and these civic tools that we talked about are ways that patients and clinicians can work together to push back and say that timely, evidence-based care matters. And again, it will reduce overall healthcare costs for the system as a whole.

Wade Cooper, MD:
Hey Julienne, I'm hoping we can put the link to that in the chat. And then also, can you just remind folks if they're going to send a letter to their elected official, it doesn't have to be super complex. Just explain briefly what goes into that. It can be 1 or 2 lines of reference. They're really counting the number of lines and not so much seven pages. So, some of our patients feel it's arduous, hard to do, to put their whole story into a thing and send it away. It really just has to be I need migraine care. I want these medicines available. I can't get them. Please look at this bill or this act or whatever else. Is that your perspective on this, Julienne?

Julienne Verdi:
Absolutely. And what I always say to you Headache on the Hill advocates, is that you don't need to come to this with a bunch of statistics and know all of the facts about the bill and things like that. Because if statistics alone were enough to change hearts and minds, we wouldn't exist. We wouldn't need to do what we're doing because we know we have that on our side already. It's really those personal stories and just the action of taking the time to contact an elected official.

I've worked in government. I will tell you, it's actually surprising how few people take advantage of this opportunity to contact an elected official’s office. So, when you are one of the people who do that, it gets noticed. And again, it doesn't need to be long. The phone call can be 30 seconds, but it's going to be tallied, and your name is going to be written down. And that's really meaningful because at the end of the day, elected officials care about being reelected, right? And they hopefully care about representing their constituents. And so that's what this is all about. When you are telling your story and you're asking for something as a constituent, your members of Congress are supposed to be representing you. And so they listen and hopefully they take action.

Katy Oakley:
Thank you so much for sharing that. I think it's really important. There's definitely community that's so involved, but there's so many who don't understand all the different ways that they can be advocating for themselves and others who are just like them. I'd like to zoom back in on that patient who's sitting in their clinician's office. Dr. Cooper, can you talk about what advice you would give for patients who feel stuck or discouraged with the process, what you see from your perspective before we close out?

Wade Cooper, MD:
Oh, sure. I was thinking about this too. You don't have to be Michelle to be infinitely impactful in helping your case move forward. I mean, Michelle may be a bit intimidating because she's awesome, a lot of what she does. But here's the thing, if you're trying to get access to care and you feel as though you want access to a medicine and there's been a hiccup, or there's been a pause or there's been a delay in getting an answer, respectful but relatively frequent nudging of your healthcare provider is welcomed. To put numbers to it, maybe if you haven't heard back in five, seven business days a polite, respectful. hey, I'm just curious, what's the what's the outcome of this? Because as you're probably well aware, provider's offices are really busy. And know you're not bothering them in a respectful way if it's a reasonable chunk of time in between. Sometimes a nudge is kind of important.

The other thing, please come prepared as best as you can. What have you tried before? What worked, what didn't work? What was the reason why it didn't work? I would never be offended by this, and I'd actually prefer it if our patients came up with here's what I've done before. Here's what the outcome is. One piece of paper or one very brief portal message about what's been done before, what the outcome was, that will really expedite this review approval process from this.

And the other part about this is, I promise you it may not feel like this all the time, but your providers are really trying to help. And they may be just as kind of frustrated by a delay or frustrated by lack of access to care as you're feeling too. We all want the same thing from this, and it's sometimes a frustrating process to go through. Michelle, I know you felt that before. Michelle is intimately professional on how she interacts with folks. But man, talk about getting crap accomplished, Michelle's like an ace at this stuff. And it's so hard to ask our patients to kind of muscle through that when they're not feeling well. It is okay to have someone advocate for you. If you have a loved one family member, a significant other, as long as they have signed consent to be advocating on your behalf, they can call or they can advocate too if need be. Even sending a letter to your elected official, that can be done by a caregiver, not just the patient themselves.

Julienne Verdi:
And Dr. Cooper, I think one of the other things that I've heard from my providers in these situations is sometimes they don't get the same letter, or it gets kind of lost in the system and they don't know that a medication has been denied. So, I wonder if you could talk a little bit about that and just making sure that you are telling your provider that you've received this denial letter and asking about those next steps, I think is important. And then, we didn't touch on it, but I think that the peer-to-peer process, I don't think a lot of patients kind of understand what that's all about.

Wade Cooper, MD:
So, first of all, Michelle and I both would have loved to know about that approval like six months ago. That would have been kind of cool. And that got kind of lost. An approval comes through, but it may sit in the chart unacted on, which is really frustrating. Going back to that kind of nudging aspect, do you feel like a ball has been dropped. Give people a reasonable amount of time, be respectful, polite about it, but it's okay to nudge.

And then I think your question is about the peer-to peer-process. What that really means and I'll be brief about this. But if your insurance denies something, but they say this can be appealed, an appeal usually means it needs a peer-to-peer to converse about this and see what that means. Every insurance plan out there has a medical director office, where it's staffed by clinicians who have some medical experience when there's a unique situation that comes up that perhaps there's a reason why a medicine should be covered, even if it's been denied by your insurance. Now, the challenge is that usually requires either a written statement which hardly ever works, or an actual discussion, phone discussion, between your medical provider and their insurance medical reviewer.

Now we tend to win those when we finally get to have those done, but it's really where a chance where your provider can advocate why you want to use a certain therapy and why, even if it's been denied, why it really should be available for you. And we usually point out the same types of things Michelle mentioned. This person has tried other things before. It hasn't worked. We have a strong suspicion it's going to be effective. And there's tricks to this to get this to go through. Sometimes we ask for a six-month approval, so give us six months to prove it's going to work. If it doesn't work, we're going to stop it anyways, as well as a justification why it needs to be done. But that's what happens when a peer-to-peer occurs. It actually falls on your provider's office to then initiate a phone call review with one of their medical providers to come to an agreement. It doesn't always turn out in your provider's favor, in our patient’s favor, but many times it does. And we really encourage people to be aware that that can be done if you strongly feel like a therapy should be available and it's been declined by your insurance.

Michelle Mayer:
Now, some of the frustrating part too is I don't even get information from my insurance on if something's approved or denied. And that's part of why I'm waiting and we don't know, because my insurance hasn't sent me anything.

Wade Cooper, MD:
That can be variable what you hear. And sometimes we get different information than our patient gets. A patient might hear, oh, it's declined and we get this step edit, no they have to be in these five different things. Sometimes your provider might call you and say, hey, in order to get the therapy you guys talked about two weeks ago, we have to have you try something else first. And that's frustrating for everybody. But many times, your provider feels good about the other treatment and it may be very similar to what they had requested, just a different one in the same class of medicines.

Oh, and by the way, if you're asked to try something and you have a side effect or you try something and it has a negative response for you, sometimes that counts as a trial, even if you didn't get a good response from it. And we advocate our patients to report that back to your provider as soon as you have that side effect or negative experience so you can explain why you're no longer on what was requested before they can get to a therapy you may want to have.

Katy Oakley:
That's such a good point. There are so many frustrations. This is not an easy process. Michelle, you do such an amazing job of staying positive and persistent and resilient in moving forward to live more fully. We all just want to feel better and live our lives. I'm wondering if you can share a little bit more about how you do that and end us on a really positive note for people who are in these shoes. They've got so many great tips and things they can do now. But it's also that mentality and that mindset that comes with it. Can you share anything there?

Michelle Mayer:
I have great family support. My parents are always there, willing to listen, help however they can. I treat myself to massages, which helps with all the muscle tension that I have. I just try to keep busy. I play with my dog. I just continue to learn. Try to help other people. That's part of my job anyway, is in what I do. I refuse to give up and refuse to let the insurance providers and other people win. So, I'm

going to do what I have to do, not only for me but for others, because I want to feel better. Will I? I hope to. But if not, I still have something that somewhat helps me and I can still function.

Katy Oakley:
Yeah. It's about celebrating those small wins and focusing on what you can control in those connections. The support system, it makes such a big difference. Well, this has been such an important and meaningful conversation. I can't thank all of you enough. Michelle, Dr. Cooper, Julienne, thank you for sharing your perspectives and your expertise and your honesty and for being with us today.

Conversations like this really remind us that access to care, it's not just a policy issue, it's personal. It affects people's day to day lives. And if there's one takeaway that we hope everyone here goes away with is you're not alone. You may have received a no, but maybe it's not a no. It's not necessarily the end of this treatment path. You can figure out something that works best for you. And progress is that partnership that happens between patients, providers, advocates. We can't do it alone.

If you are listening and you're navigating step therapy or denials or you're just feeling stuck, we encourage you to explore our resources on our website headaches.org. If you click the access tab, you can learn more about many of the things that we discussed here and how to break down some of those barriers. You can also hear from real patients. We have a lot of patient stories on our website. You can learn about headache types or even accommodations in school and in the workplace. And we're so grateful for everyone listening here today. And thank you. And until next time, take care.

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Resources:

Alliance for Headache Advocacy https://allianceforheadacheadvocacy.org
Headache on the Hill https://allianceforheadacheadvocacy.org/headache-on-the-hill
National Headache Foundation https://headaches.org

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[1] Safe Step Act - H.R.5509 https://www.congress.gov/bill/119th-congress/house-bill/5509/text
S.652 https://www.congress.gov/bill/118th-congress/senate-bill/652