



VOICES OF VALUE: THE UNMET MEDICAL NEEDS OF MIGRAINE PATIENTS

Event Transcript

Terry Wilcox: Since 1999. Prior to the business journal, she was an editor for independent newspapers at Common, a community newspapers chain based in Scottsdale. Before moving to the valley in 1989, Elaine served as a reporter and editor for Pulitzer Prize newspapers in Chicago. She also worked as a script writer and associate producer for the NBC TV affiliate in Chicago.

She serves as an Associate Professor at the Arizona State University's Walter Cronkite School of Journalism and Mass Communication, and she is also on the executive board of Gabriel's Angels. Elena also as a member of the prestigious women's professional association, Central Phoenix Women and Charter 100. Elena joins us not just as an esteemed journalist, but as a migraine patient herself.

She herself suffers from migraines and will add her personal insight tonight as our moderator, please welcome Elaine Laurie.

Elaine Laurie: Thank you. Good evening everybody. Thank you for being here. I can't see any of you. Hopefully you can hear me. The first thing that I want to explain to everybody is our format. The way Terry described it to me, was it was going to be very talk-show like, very Oprah like. I'll just tell you right now, there will be no cars given away at the end of this. Although, I don't know, Terry, you might have something else planned for these folks. I'm not sure.

Terry Wilcox: Dessert and coffee.

Elaine Laurie: Dessert and coffee, that's darn close. First, what we're going to do, we talked ... Terry mentioned that we were going to talk to a patient, an advocate, and then my very first guest, I guess if this is talk show like, Mary, I guess you're my very first guest. Mary Franklin is the executive director of the National Headache Foundation. Mary was named the Executive Director in June of 2016, so a new post.

She joined the National Headache Foundation staff in September, 2011 as Director of Operations. She previously held several positions at the Diamond Headache Clinic in Chicago, in the nursing and the administrative departments. She retired from the clinic as Vice President of Publishing and Administration in September 2011.

She is currently Managing Editor of the magazine HeadWise. Previously, she served as Managing Editor of the professional journals Headache Quarterly and Headache and Pain Current Treatment and Research. She has authored several articles on headache, and with the Dr. Seymour Diamond as the co-author of Conquering Your Migraine and Headache through the Ages. Mary? Thank you for being here.

Mary Franklin: I'm glad it's not Dr. Phil.

Elaine Laurie: Oh we're going to have fun with this analogy, aren't we?

Mary Franklin: Okay.

Elaine Laurie: Okay. I have a ton of questions because, as it was mentioned, as I suffer from migraines as well, but we want to make sure that we're touching on what every here wants to hear about. We'll also ... I didn't mentioned, but we'll have a little Q&A afterwards with everybody, so that you'll be able to get all of your questions answered.

The first thing I want to find out from you Mary. We talked a little bit before we started. You mentioned a pilot program where you were going to be working with companies. Both insurance companies and HR departments at larger companies. Can you talk a little bit about that pilot program and how it could impact employees?

Mary Franklin: What we want to do is reach out to corporations, particularly to number one, help them realize the amount of revenue and productivity they are experiencing because of their employees with migraine. We also want to do health wellness programs, educating both the employees and their supervisors about headache. We also want to educate whoever in the HR department or the insurance departments about how to talk to the insurance companies to plan.

It is a travesty that headache patients are not feeling appropriate care. If you have migraine and I bet, if you don't have migraines, somebody you love has

migraines, it's why you're here. If a patient get eight headaches a months and your insurance company only gives them four of their acute medications, like a trip then per month what do you? Which ones do you treat?

This is what we need to change, and we need to have patients so it would be their employees advocating for themselves. Saying, "Look, I can't come to work because I can't take anything that's going to help me to get to work. If I do get to work, I'm not at my full productivity level." That is the pilot program that we want to start and see if we can really accomplish changing the demeanor of the insurance companies in the corporations.

Elaine Laurie: Changing the demeanor of insurance companies?

Mary Franklin: Right. Good luck, uh?

Elaine Laurie: Yeah. Let's talk about that for a minute. That sounds like quiet an uphill battle.

Mary Franklin: Yeah.

Elaine Laurie: I mean tell us ... Do you really feel like they might listen? Do you feel like, and I don't want to talk about politics. I really don't want to talk about politics, but the political climate is different. Obamacare may have a completely different look to it, feel to it in a year. How is that going to play into what you're trying to do?

Mary Franklin: I don't know. I don't know how the changes in the insurance. I do know in my past life as a clinical manager, we fought insurance companies so the patients could be admitted for their migraines. We had a hard time doing that. We had to go in and educate them and tell them, we're going to save you money because those patients aren't going to have to have repeat ER visits, urgent care visits, and taking medications that aren't really ... their just focus are shadowing the headache. They're not really getting to the core of them.

We think for past experience it can be done, but we have to do a grassroots so to say, and get the employees, get the patients themselves as self-advocates.

Elaine Laurie: Migraines are the sixth most disabling diagnosis, right?

Terry Wilcox: Yeah. It's true.

Elaine Laurie: Okay. Why is it then that patient access to quality care for something that is the sixth most diagnosed disability ...

Mary Franklin: Disability.

Elaine Laurie: Yeah. Can you talk about the resources? Can you talk about what is it that is hindering that? I know it's a huge subject, I mean it's like this big and I ...

Mary Franklin: Yeah, I think the questions that Terry presented “Oh, it’s just a headache and it’s not life threatening.” In some cases it is because people are so depressed that they take their life. That to me is life threatening, but it’s disturbing seeing myself on the screen. Let me turn here. I wonder if Oprah has that problem. Anyway, I think it’s perception on the patient’s part. They’re afraid of being stigmatized because they have headache. They are just not vocal.

I was in a discussing today with the President, National Headache Foundation Dr. Vincent Martin and he said, “Think about the swell of support and action that the folks with HIV had in the 1980s. Because of their work, their advocacy for themselves, there are drugs out there now, and people live with HIV, but it was because they brought it to ... attention to the public. They got the government’s attention, and they got the pharmaceutical companies attentions, and we have to do that with migraine.”

We have to have a ground swell. We have to let people know that this is a disability condition. 37 million Americans have migraines. I don’t know how many of them, I don’t know the statistics don’t know they have margarine. Or if they do have migraine, they’re not getting treated appropriately. Another concern for us is the access to care. If you live in a city ... if you live in Scottsdale, you’ve got access to headache clinics. If you live in Bedingfield, Arkansas, lots of luck. If you live somewhere in Alabama, lots of luck.

There are probationers there that we have to recognize. We try to do that on our National Headache Foundation website. We have a credentialing program, which we just started about three years ago. What we did differently than some of the bit professions organizations, we opened it up to non-physicians, so nurse practitioners like Heather McCrory, physician assistants, clinical psychologist and dentist can get the certification, and gives them recognition that they have experience in head. They have at least three years of experience.

They have their licenses, and they take an exam that test their knowledge about headache, diagnosis, and treatment. That’s another potion, is that we have to get access to care for patients with migraine.

Elaine Laurie: You mentioned that this is not something where we woke up one day and suddenly we have migraines?

Mary Franklin: Yeah.

Elaine Laurie: This has been around forever.

Mary Franklin: Right.

Elaine Laurie: What is it about having a migraine, or what is it about going to your doctor and saying something is wrong? Why aren’t they seeing it?

Mary Franklin: Why aren't they picking it up?

Elaine Laurie: Yeah.

Mary Franklin: They don't listen. They don't listen to their patients.

Elaine Laurie: Talk about that.

Mary Franklin: As one of Terry's questions, all migraines you have to have an aura. You always have to be sick with your migraine, not necessarily. Medicine it's an art, it's really not a science. Everybody's an individual. My years of experience at the Diamond Head Clinic all the patients I saw, they all had a different story as an individual. Doctors ... and luckily this is growing. There's almost 800 people at the meeting at the Camelback this week.

People are aware of headache and it's a lot better than it was 20 years ago, 40 years ago, and ... but you just have to be a doctor who's interested and is willing to listen to their patient. I don't ... we just have to keep working in it.

Elaine Laurie: We have a smaller group here tonight, but I want to make sure that we're not passing over certain definitions, because I know myself sitting up here, some of these things I know, some of them I don't. I feel like I want to make sure that everybody understands what an aura is. Everybody understands some of those kind of I hate to call it jargon. In the newspaper business we call it jargon because lawyers can't use a sentence without jargon and things like that. Can you explain a little bit about that, about what ...?

Mary Franklin: Back in there I mean there's many types of migraine, but they would divide them into what we used to call classic migraine was when you would get symptoms 30 to 60 minutes prior to your acute attack in it. You might lose half of your vision. You might have blown vision. You might have flashing lights. You might have ... smell something different. You just knew that there was something going on, and then the headache would come on.

Not everybody that has migraine gets these warning symptoms, but that was the classical picture of migraine. The delusions or hallucinations that you see in Alice in Wonderland, they actually call it Alice in Wonderland syndrome. They believe Lewis Carroll had migraine and this was part of his aura, and then he depicted it in his books. Not everybody will get that warning about classical migraine. I could go on and on about the differences.

Then there's patients who may have hemiplegic migraine where they lose function in on one side of their body, or they may not be able to speak. There's all these different types of migraine with neurological complications.

Elaine Laurie: We know that the level of severity can sometimes have a scale.

Mary Franklin: Yeah.

Elaine Laurie: Say one to probably a hundred.

Mary Franklin: Yeah.

Elaine Laurie: Really.

Mary Franklin: Yeah.

Elaine Laurie: When you say that doctors don't listen, what are they looking for? What should they be hearing when you ... what are those key words. Not necessarily symptoms, but are there some key things that doctors should be looking for or hearing I should say, when you go in and you talk to them and you say, "This is what I'm experiencing."

Mary Franklin: I think knowing what the symptomology is, but also Dr. Diamond, Seymour Diamond who's 91, who's the Executive Chair of the National Headache Foundation he used to say to patient, "How long does it take you to finish a bottle of 100 Aspirin or Tylenol?" If you're getting rid of a bottle of 100 in less than a month, something's going on. What are you missing from your life because of these headaches? Are you missing a lot of school? Are you missing work? Have you had relationships impacted?

I think they have to understand that this isn't just, "I had a headache two weeks ago I took a couple of the aspirin," it's impacting my entire life.

Elaine Laurie: So more than spending 11 minutes?

Mary Franklin: Right, yeah. More than spending 11 minutes.

Elaine Laurie: Yeah.

Mary Franklin: There's tools. A patient can be sent into an office with a calendar. Guys, I know anybody that breaks his headache medicine uses this tools, that you follow each day in a month. Did you have a headache? If you had a headache, was there anything you could identify like perceptive headache? Were you having your period? Did you eat a cheese pizza? Did you drink a lot of coffee, or did you miss your coffee? Did you fast? Did you get enough sleep? These are tools that they can use. A primary care doctor can use it for his headache patients or her patients.

Elaine Laurie: Okay.

Mary Franklin: You can tell I'm old I still call physicians [inaudible 00:38:13].

Elaine Laurie: Can you talk a little bit about your foundation ...

Mary Franklin: Sure.

Elaine Laurie: ... and what we can expect if we go to your website, call up, who do we talk to?

Mary Franklin: Okay. You might talk to me, you might talk to Joel Kelso who's my colleague who's here. The National Headache Foundation was founded in 1970 kind of as a sister organization to the American Headache Society because they felt there was a need for a patient organization. Our mission is to cure headache and end its suffering. Our vision is a world without headache. We advocate for patients through forums like this.

With government we're going to participate and we have participated in a thing called Headache on the Hill, where groups of patients, physicians, advocates go to congress and try and speak to their representatives or senators or their staff about getting funds for headache, recognizing headache's impact on someone's life. We educate, we have brochures. We go out and present to different groups. We produce the magazines to raise awareness and to educate the public about headache.

We also support research. We will give grants to ... not for pharmaceutical research but for scientists who want to study different aspects of headache. We've had two research incentives or projects on hemiplegic migraine in the adolescents. Right now we have just done ... selected a study on cluster headache, which is different than migraine. It's the suicide headache. Again, I could go and on talking about cluster, but we had someone who was interested in supporting cluster studies, so we match the funds and we're going out and supporting the research.

Elaine Laurie: Wow.

Mary Franklin: We have a monthly electronic newsletter. We have our website. We have a Facebook page, Twitter so we're actively interacting with the patients all the time.

Elaine Laurie: I always like to ask people that I talk to tell me a story. Tell me a success story about someone that you've worked with, that the foundation has worked with where the result was exactly as it should have been or the result was what you had hoped.

Mary Franklin: My favorite story is a young lady who developed hemiplegic migraine at 12. She was sitting in her room with her sister, and he had to write a note to tell her sister I can't talk. This young lady lost two years of school. When she got better she finally found a doctor that could help her and she actually ... she still had the headaches. Her teachers and principals were educated about what to do when she did get a headache.

She was able to finish high school, but she wanted to help other kids and she established a fund, and this is part of the funds that helped us with the studies. She is in her third year at Columbia University now and she's actually doing a semester abroad. For her as a kid that couldn't even speak, that she had these weeks of bad headaches that she was paralyzed and couldn't do things, she's actually assumed a normal life. She still gets migraine, but they're not as bad.

Elaine Laurie: Wow, well Terry I can't see you. I don't know how long I have. I still can't see you, are you holding up fingers?

Terry: We're fine.

Elaine Laurie: We're fine.

Mary Franklin: Okay.

Elaine Laurie: Okay, good.

Mary Franklin: Anything else?

Elaine Laurie: Anything else I just want to make sure we have time for ...

Mary Franklin: What can we do for you today? That's our motto at the clinic.

Elaine Laurie: That's good. Talk a little bit about ... one of the things that is the theme tonight is access. In a number of different ways, access to medication, funding, there's ... so talk a little bit about the foundation and what role you play in terms of helping with just that piece of the puzzle I guess would be the way.

Mary Franklin: Right. If anybody's looking for a headache care practitioner, we do have a headache care practitioner finder on our website, but there's a lot of folks that don't have sadly email access or internet access, they can phone us. We go through ... we find out their geographical area and see if there's anyone who is working with headache. If it's not on our list and you happen to get me, I will go through the American Headache Society too to see if I can find.

The major metropolitan centers, I think there's a headache clinic ... There's at least three or four in Chicago. There's a couple here in Scottsdale. Like I said the people out in the rural areas don't have the access.

Elaine Laurie: Which reminded me of another question and that was telemedicine, which I think we started to talk about, and then we got off track when we were over there, but I would imagine that could help those rural areas the people in ...

Mary Franklin: Oh absolutely.

Elaine Laurie: What's out there for them in terms of telemedicine? I know it's hard because if you don't have internet access and you're out in the middle of nowhere ...

Mary Franklin: Right. Sometimes they have satellite clinics. I know the story about Mercy Research in St. Louis. They established telemedicine and I think they had satellite offices and the patients could go in. They did headache. They did hypertension. They did diabetes because these patients couldn't get into St. Louis. It's a huge system and access to any type of care was limited, so that was a very successful project. We actually the National Headache Foundation funded the headache portion of it.

Elaine Laurie: One last question. You mentioned grassroots, and you mentioned being able to start from the bottom and just you know. What can people do to push that, to promote that, to get on that grassroots train I guess and have a voice?

Mary Franklin: I think there's bloggers out there. I think we're trying to open it up so that people can come to us. We would like to identify patients that are willing to be advocates, and help them maybe go to Headache on the Hill. Maybe do it at the state level by the department of insurance in your state, anything. We want to be a resource for anyone who wants to go out and advocate for themselves, and the easiest thing is to call us 1-800 ... wait, 1-88 ...

Terry Wilcox: 1-88. It's in our [inaudible 00:45:20]. Can you see here?

Mary Franklin: Yeah.

Elaine Laurie: Look at the materials on your tables.

Mary Franklin: It's National Headache Foundation. Go on our website. We publish reader's questions in our newsletter and we also have them in the magazine, so if someone ... I had somebody sent us a long letter the day. This lady has had terrible headaches since her cataract surgery, so I'm trying to find ... the neurologist didn't want to touch her, so I'm trying to find someone in neuro ophthalmology that will respond to this question, but we try and do things like that.

They can write to us, call us, and we'll try and get them connected with who could be doing some work we assume. There's Miles for Migraine. It's a race that they're doing. They're going to do one here in Phoenix. It's a great way. If you don't want to race, at least volunteer and go out. Their hope is that the media will see a lot of people there and recognize the need for more advocacy.

Elaine Laurie: Your organization is a wonderful resource.

Mary Franklin: Thank you.

Elaine Laurie: Anybody who hasn't been to the website or who hasn't ...

Mary Franklin: Thank you.

Elaine Laurie: ... who hasn't seen that then they really, really should.

Mary Franklin: Right.

Elaine Laurie: Thank you very much.

Mary Franklin: Thank you.

Elaine Laurie: We're going to move on to our next ...

Mary Franklin: Okay.

Elaine Laurie: ... after the video. We're going to see a video then we're going to bring up our next guest.

Video: My husband said, "You know you should write a blog." "No, I'm not interested in a blog." About a year and a half later I said, "You know, I think I should start a blog." I started the blog for myself, and I very quickly discovered that it was an incredible way to connect with other people. For migraine you had to fight so many battles. I would write a lot about sort of the emotional experience.

I laid myself pretty bare, and so I get a lot of deep emotional responses and so I feel like I am really helping. People don't believe us, and it's really hard to be so sick and feel like you have no social support. It's not just an excuse to get out of work, and it's not just your run of the mill headache. There were many years where I didn't think I would ever feel as good as I have felt in these last few months.

It took me a lot of work to get here, and it was ... it's been almost 15 years since I was diagnosed. It's been a difficult road, and the reward of finally finding something that's helping it's unbelievable. It's really amazing.

Elaine Laurie: Kerrie I don't see you, but we're ... Oh okay, so our next guest is Kerrie Smyres and I don't think I'm not saying that right.

Terry Wilcox: Smyres.

Elaine Laurie: Smyres, okay, well come on up Kerrie and I will tell everybody about you. Migrane.com and The Daily Headache are two of the websites that you write for, correct? You're also obviously a patient advocate, but let's talk a little bit about you. Kerrie has had chronic migraines since you were 11, but you've always loved writing and you needed a creative outlet, something we have in common.

When you became too sick to work, she started The Daily Headache in 2005 and joined migrane.com in 2011. What began as a way to share her experience quickly became the best job she's ever had. Not only does her work teach about migraines, headache disorders, and chronic illness she also has met incredible people who are working hard to live the best lives they can despite chronic illness.

Her passion is to write about the emotional experience of chronic illness. Thank you so much for joining us today Kerrie.

Kerrie Smyres: Thank you for having me.

Elaine Laurie: And obviously for sharing some of your story on that video. We will talk about your story. One of the first things that I did want to ask you when we were over there talking and I didn't get a chance to is explain the glasses, because that is probably the first question everybody asked you anyway, so why should I be different?

Kerrie Smyres: Okay. It feels like free advertising which I'm not trying to do, I just have to wear them. They're for photo phobia. The tint has been shown in research to be effective for people with migraine, to both reduce photophobia and manage light triggers, but my husband and I have a company that sells the glasses. He's actually started it to help me, and then we ... the company came out of that, so that's what they're for.

Elaine Laurie: Okay but something very good came out of something very bad, so I think that's wonderful, and entrepreneurial. Very entrepreneurial, so I love that. You also in the video talked about emotional symptoms, which I think we both just had one. Let's talk a little bit more about emotional symptoms, because that's what you write about. You write about the emotional side of what you're suffering from. Talk about how you've been impacted and how you've been able to navigate through a lot of that.

Kerrie Smyres: I always say that there are two sides to migraine. There are the physical symptoms which doctors treat, and then there are the emotional symptoms. The grief, I'd say almost everything comes down to grief. Grief over not being able to go to your kids soccer games or going to family dinners. Just so much you miss on, and so much of life with migraine. I like to work through like ... I'm working what I'm feeling when I write about it, but I also try to connect it to other people and sort of find the universal experience.

Almost very frequently people tell me it's like reading their own thoughts because it's really hard to live with the physical symptoms of migraine especially because so few people believe that it is as disabling as it can be. I'd say my most effective tool it's been evolving but I use mindfulness because that's the best word these days. I would say I get a lot of push back on this, but accepting that I have chronic migraine and that it's a part of my life has been really helpful.

That's not saying ... that's not giving up, it's not resignation. It's that this is something in my life that I'm going to have to deal with, and I can't just put my life on hold while I'm waiting to get better, so I've been trying to live my life as well as I can. In that time I spent years lying on my couch, but with mindfulness and some techniques that I've used, and honestly therapy.

Therapy has been amazing; finding a therapist that I click with. I feel like we do brief work every other week, because it's so ... if something comes up, there's grief over a treatment not working and things that you miss. Even though I've lived it for so long, it still surprises me how emotionally painful it can be.

Elaine Laurie: Can you talk a little bit about that journey? When we were talking offline, we know that you at 11, at age 11 you knew you were having migraine.

Kerrie Smyres: I didn't actually know.

Elaine Laurie: You didn't know what it was but something was not right.

Kerrie Smyres: Right.

Elaine Laurie: Did you have a family member? How did the journey start? I know you said that it was a very long time before you were diagnosed and really able to start working on the issues.

Kerrie Smyres: Yeah. I put it together retrospectively with the help of a doctor that it's when I was 11 when they started. They were basically headaches for a long time. That was well ... at least that was the primary symptom that I noticed. I took a lot of Advil. My parents took me to doctors and I didn't ... I don't have an aura, the pain is on both sides of my head. I don't vomit. I get nausea, but I don't vomit.

This was the 90s ... 80s, and doctors were looking for what Mary was talking about, what used to be called classic migraine. They were looking for an aura, one sided pain and so I wasn't diagnosed. I was actually diagnosed when I was 25. My husband has migraine and he fits them all, so he was actually diagnosed when he was young, and it was episodic. That taught me that having a headache all the time is not normal, and it's astonishing to think that that's what I used to believe. It just seemed like that's how you live.

With his help I was able to push and I finally had a doctor say, "I know you're not feeling well and I don't know what's going on so maybe you should see a specialist." That was a primary care physician.

Elaine Laurie: Then you did that?

Kerrie Smyres: Mm-hmm (affirmative).

Elaine Laurie: Okay, so what was ...?

Kerrie Smyres: Then long journey, many specialists since I moved around the country, but yeah I was diagnosed. I learned one of the statements I respect the most is, "I'm not sure what needs to be done but somebody else can help you." When a doctor reaches their limit and can say, "I'm out of ideas but that doesn't mean there's nothing that can treat you." I've had that happen along the line and the first specialist I saw said that to me and I just appreciated it so much.

Elaine Laurie: We also talked a little bit about ... you have traveled around, you've been in Phoenix and then you were in Seattle and then back to Phoenix, talk a little bit about why you came back from Seattle.

Kerrie Smyres: Boston was in there too.

Elaine Laurie: Oh Boston was in there. Oh it was Boston that was the reason?

Kerrie Smyres: Right.

Elaine Laurie: Yeah, so you came back from Boston?

Kerrie Smyres: Right. For I don't know the first 30 years ... No, I can't give you a number, but for much of the time with migraine I just ... my symptoms got worse and worse and worse starting when I was 11. They've only started getting better in the last few years. We were in Seattle ... I'm from here. My husband and I moved to Seattle for his job. I loved Seattle. It was my favorite place.

We were there for six years and in that time my migraines were getting worse. We moved to Boston and my migraines got even worse. I call it the worst year of my life. It was awful. We discovered, because in phoenix we've got pretty stable weather, at Seattle it's cloudy, but it's cloudy all the time so it's stable. In Boston the weather changes very frequently and with those weather changes I was able to see that weather is actually a big migraine trigger for me.

Since my husband and I are from Phoenix, we came back here. He gave up his favorite job ever, but we came back here for my health.

Elaine Laurie: Something else about suffering from migraine, your entire life has been turned upside down more than once.

Kerrie Smyres: Oh yeah. All the time, and not just mine my husband's. Yeah, we talk about having a third person in our marriage, this unwelcomed roommate, because migraine just affects everything.

Elaine Laurie: Right. Talk about those. Talk about the treatments. Let's talk a little bit about during that journey what kind of treatments you had, what maybe worked, what didn't work. What we're looking at now in terms of maybe some alternative treatments, some things that you've found because you're probably one of the most knowledgeable people there are even out there, because

you've probably tried so hard to find your own answers and to research and everything. What have you found and what kind of alternative therapies have you looked at?

Kerrie Smyres: So many. Starting with my diagnosis at 25 and then until I was about 35 I tried many different medications. It's over four dozen now and nothing helped, and I tried all sorts of things. I was in Seattle so acupuncture, massage. I did energy healing. I drank scorpion tea, which was disgusting. Anything I could try, I tried and my motto is that if I don't think it's going to hurt me, I'll try it. There are times when I don't know if it's going to hurt me and I try it anyway, because that's what desperation can do.

Then after we moved here, that was ... we moved back it was like just getting a hand hold. That helped enough that I was no longer so sick that I couldn't even fight for myself. I couldn't even research. Magnesium helped and it was just one little thing after another that started adding up, but it was finding that first thing that I needed to do. Of course there were lifestyle changes, but sometimes like I get a migraine anytime I eat anything, and so there are only so many lifestyle changes you can do.

It's been a lot of tracking and just trying to keep myself on a good schedule and consistent and doing everything that they tell you to do. I reached at a point where I felt like I've done everything they've told me to do and it's not helping, and then eventually it helped. All that energy I put into it has led to like I said on the video me feeling the best that I've felt in a really long time.

Elaine Laurie: Was the yoga part of that? Plus when we saw you doing yoga.

Kerrie Smyres: It's actually ... no.

Elaine Laurie: You just like yoga?

Kerrie Smyres: I love yoga and it helps with the mindfulness part. I highly recommend it. It does give physical relief to some people, just not me. Not for me.

Elaine Laurie: If anybody has not seen Kerrie's blog, you need to go look at it, and you need to read it because it's really good. I had not been aware of it until I was doing my own research for this and you're funny and you're serious all at the same time and it's really, really good.

Kerrie Smyres: Thank you.

Elaine Laurie: Please make sure to see that. The question that I asked Mary I want to ask you too because as a blogger you get a lot of feedback, you get people writing you letters like you said experiencing the same things and wanting answers and all that, do you have a success story? Is there somebody that you've been

corresponding with or somebody that you felt like you've really helped that you can share?

Kerrie Smyres: I wrote an article for migrane.com about guilt and how guilty I felt for letting people down. My husband, friends, family, just the list goes on and on. I even felt guilty for letting down my local farmer, because even when I managed to make it to the farmers market I'd throw the produce out and I felt like I was somehow I don't know wronging him. I realized I felt that deeply because I was ashamed. I was ashamed for being sick.

I felt like I was failing by not being able to get better using all the things I was told to do. I wrote about this sense of shame and I had a couple of people say that they were going to talk to their therapist about it which was a huge compliment.

Elaine Laurie: Absolutely.

Kerrie Smyres: I get that kind of thing. Like I said in the video, I lay myself pretty bare and I talk about the really horrible grief filled moments and I hear a lot about people just the validation of knowing that that's normal is pretty amazing.

Elaine Laurie: That's great. Again timing? We're okay? A couple of more questions. Okay. Some of what we've been talking about is access, and the availability of certain medications and things like that, what have you found in your journey in terms of access either being able to try and have different medications available to you or what have you researched or what have you found that might seem interesting to you as maybe a treatment or a therapy.

Kerrie Smyres: I would say the treatment I'm most interested in right now is the umbrella is neuromodulation. There are nerve stimulators, Cefaly the migraine head band people call it has been in the news for the last couple of years. Then there's also Spring TMS, so different types of electrical medicine, that they're not medications. They're devices that somehow stimulate a nerve or change something in the brain.

I'm actually hearing Spring TMS has been available for a couple of years, and I'm hearing a great success from a lot of people that use it as an acute medication when they have a migraine and then are finding the more they use it, it becomes preventive. My doctor told me about the Spring TMS years ago and suggested I go to Europe for it.

Elaine Laurie: Just a quick jaunt over there to [crosstalk 01:03:19].

Kerrie Smyres: Right exactly. Even if my husband had the frequent flyer miles and he could take time off work and all of that, I was too sick to travel and really going to Europe for a treatment. He's told me about patients who go to Canada for treatments. That's a little boring and feasible since I have friends in Seattle, but I think that

neuromodulation is a really exciting possibility because people with frequent migraine are told, "Treat all your migraines," and then they're told "but don't take medications more than 10 days a month because then you'll get medication overuse headache." What we're seeing with neuromodulation is that it can be used acutely and then in time it can also be a preventive.

Elaine Laurie: I'm not a medical person. Is that at all like the ... I should be asking you this I bet. The brain stem, like if you have Parkinson's, they have experimented with the neuro stimulation of the brain stem. Is it like that?

Kerrie Smyres: It's not in the same area but yes. Nerve stimulators, that's probably the type of neuromodulation that people know about the most.

Elaine Laurie: Okay. If there's one thing that you wanted the audience to know about anything. About your journey, about where you hope to see, access treatment, whatever. If there is one thing that you wanted to say, what would that be?

Kerrie Smyres: Always keep trying. Unfortunately I can't really talk about the treatment that I'm using right now but I'm getting a lot of benefit from it and all that research that felt wasted, like figuring out my [inaudible 01:04:57] and stuff, that's all coming into play. It's been really hard work and I've certainly taken treatment breaks. There have been times that I'm just too sick to research and do all the work necessary, but I have kept trying and it's actually making a difference and even though for 15 years I thought that it wasn't.

Elaine Laurie: Thank you so much for sharing your story.

Kerrie Smyres: Thanks for having me.

Elaine Laurie: Just the honesty and the candor is really refreshing so we all thank you very much for joining us today.

Kerrie Smyres: Thanks for having me.

Elaine Laurie: I believe we have another video that we're going to see.

Video: Any time that you tell somebody that you get migraine, "Oh yeah, I had one of those ones and it was terrible and I took some Advil and it went away so maybe you should try that." The reaction is sort of, "It's just a headache." You can say all you want about how intense it is they may be thinking about it's just like the last bad headache they had. As a kid, I just stopped telling people that I wasn't feeling well because nobody believed me. Everybody thought I just wanted to get out of school

It's definitely a conversation that needs to change. It's the more who do understand it are going to express support for it even if it's not something that affects them or somebody they know really well. In that sense, that would be a

good thing too. It is getting more attention. I'm really excited for the attention that it's getting. Like we have a new class of drugs coming out in the next couple of years that looks great.

More and more people express interest in headache medicine. A lot of general neurologists are getting into it for the first time and I feel like we have so many advocates on our side and don't even know it. There's organizations like Patients Rising who are giving us a voice as well, which is super exciting.

There are a lot of treatments on the horizon. The drugs that work on CGRP they're getting all the attention by going to conferences there's a lot of talk about what's called Neuromodulation, which is various kinds of nerve stimulation. I want people to know that it's not just a headache, it's a disease.

Elaine Laurie: Our next guest is Heather McCoy. Heather is an adult nurse practitioner here in Scottsdale with Integrative Headache Care. She has more than 15 years of experience as an advanced practice clinician in neuroscience. Dr. McCoy is one of only three nurse practitioners in the United States to hold board certification in headache medicine by the National Headache Foundation and focuses her expertise on the complex needs of adults and adolescents who suffer with various headache disorders. Heather if you can join me up here, that would be great.

Heather McCoy: Before we get started I want to say two things, one about each speaker if I could.

Elaine Laurie: Absolutely.

Heather McCoy: The National Headache Foundation Mary, you did not mention that there are webinars that patients can tune into and get free lectures from headache specialists all over the country including the ability to ask questions at the end. With Kerrie, if you could look that badass in those glasses, who would not want those glasses.

Elaine Laurie: They are total aviator. I know. I love it.

Heather McCoy: You're so cool.

Elaine Laurie: I love it. Thank you for being with us.

Heather McCoy: I'm happy to be here.

Elaine Laurie: This part of the discussion I think maybe will get a little clinical. I don't know.

Heather McCoy: Make it as clinical as you want.

Elaine Laurie: Because I have a lot of questions still. I didn't get to any of these. Okay. Let's first talk ... Let's look at prescription assistance programs because we talked about that and I found that to be really interesting so we're just going to start right there.

Heather McCoy: Sure.

Elaine Laurie: Most people don't know they exist. Lots of doctors don't want to go through the hustle I guess, you want to call it, of working with a patient and you are over there telling me all kinds of great information about what's available.

Heather McCoy: It's true. With migraine, the medicines are notoriously expensive as any of you who are migraine sufferers know. They're cost prohibitive and not only are they limited in quantity, which may or may not be a good thing. I want to know if you're having more than nine attacks per month, that's one way of tracking it but there's always a way to get your medicine. Even when it's expensive, there's always ways that we as clinicians can find out how to get your medicine.

Unfortunately the prescribers aren't always able to ... either they don't have the time that it takes because it does involve extra work from the prescriber or they don't have the resources to support that, it's a very busy clinic. They just don't have the time. A lot of physician practices have policies in place that don't allow drug companies to come and market to them so they don't know about these programs.

Then lots of times the patient doesn't know about the program. They don't know that they can go to the drugs website and download a savings card that saves them hundreds or if not thousands of dollars on their medicine. I always tell patients there's always a way I can get you your medicine.

Elaine Laurie: I order mine 90 days at a time.

Heather McCoy: Some insurance plans let you do that, some don't. It's having my own clinic allows me to do these things that I think are important. I don't see patients on Mondays, I'm in the office all day in Monday just doing those things. I fill out prior authorization forms, I go through this prescription process with specialty pharmacies so patients can get the medicines. Sometimes I worry that patients think that I'm getting some kind of special thing if I order it this way but it's not.

I order through specialty pharmacies for patients so they can get a medicine that normally costs \$750 a month for \$20. The best medicine in the world won't work if my patient can't get it.

Elaine Laurie: Right. Absolutely. Talk a little bit about why so many patients and they probably come to you feeling dismissed. Feeling like ... I don't understand why. They're seeking treatment and there's nobody who wants to listen?

Heather McCoy: It takes time to listen. It takes time to listen. They feel dismissed because frankly in many cases they are dismissed. If you are a clinician who is used to seeing a patient every 10 or 11 minutes, how much can you tell your doctor in 10 minutes? How much can you tell them? They feel dismissed because they are dismissed. Headache medicine is a very time consuming specialty.

In fact the American Academy in Neurology is working on alternative ways of being reimbursed for headache patients because of the recognition that we know we can't cram in good care in an 11 minute office visit. They're working with insurance companies and government agencies to find alternate ways of providing the care that's required.

Elaine Laurie: Are there symptoms of migraine that people might be surprised about that you have seen?

Heather McCoy: Oh, very much. Very much.

Elaine Laurie: We've heard a lot of what's some of the normal, that's a relative term but ...

Heather McCoy: Most people who don't suffer from migraine aren't aware of the cognitive effects of migraine kind of a fog or an inability to perform at your highest functioning level. Patients have trouble processing information during a migraine attack, making sense of things. There's all kinds of neurology impairments that can occur with ... I have a patient who before the migraine headache starts, she has difficulty speaking.

She gets very frustrated because she can't articulate her thoughts and people try and press her for answers and yet this process is beginning. She knows a headache is going to follow and she is very frustrated, very scared, really all kinds of any type of neurologic impairment. Weakness, numbness, tingling, nausea, vomiting, dizziness, difficulty processing information, difficulty seeing. Sometimes smelling something, hearing something, feeling, yawning, tired, so many different things.

Elaine Laurie: I've always wondered this and I'll just use this as our session. Just send me a bill, I guess. My sisters ... I have two sisters. My sisters and I, all three of us get migraines at varying degrees. My older sister gets the worst. My middle sister she can deal with it and everything and then mine are less frequent than either the two of them.

My brother never had a migraine and never understood why his sisters always complained about having headaches. He always felt it was to get out of doing the dishes and all that kind of stuff. Is it hereditary? You also mentioned some of those other symptoms. My brother also had a stroke at 53.

Heather McCoy: How interesting.

Elaine Laurie: Is it hereditary is my first question. My second question, is there any correlation between migraine and stroke?

Heather McCoy: First question, there is a familial component to migraine? Absolutely. Absolutely, Migraine affects women three times more than men so it's no surprise that he's spared from that genetic blessing. Second question, stroke and migraine there is a two-fold increase of stroke among patients with migraine with aura. Regular migraine, there has not been a clear established connection between stroke and migraine among people without other stroke risk factors. I hope that answers the question in somewhat.

Elaine Laurie: Yeah. I was more curious.

Heather McCoy: Yeah. There's definitely a familial component. A good headache history should ask about parents, siblings and offspring to identify that.

Elaine Laurie: We all think my mom suffered from it but it was so long ago that nobody was talking about it. There were no doctors. There were no people like you.

Heather McCoy: No. Our moms were told to ... I've had patients tell me that their doctors said housewives get migraines.

Elaine Laurie: Oh. Oh good.

Heather McCoy: Yeah. Housewives get migraines. Go to bed.

Elaine Laurie: Yeah. Take two aspirins. Where do you think take two aspirins and call me in the morning came from?

Heather McCoy: Basically.

Elaine Laurie: It's probably that. So many migraine medication cause side effects. The nausea, vomiting, the dizziness. Let's talk a minute about Botox. It can be successful in treating migraines. I don't even know if you do it or don't do it.

Heather McCoy: I do, do it.

Elaine Laurie: Okay. Talk a little bit about how Botox injections work to alleviate or eliminate migraine.

Heather McCoy: Botox is the only FDA approved treatment to prevent chronic migraine among patients who have chronic migraine. Among patients who have ... who don't meet the diagnostic criteria of chronic migraine, in other words they're suffering maybe one or two attacks a month, there is pretty strict criteria for meeting the diagnosis of chronic migraine. More than 15 headache days a month. Headaches last longer than four hours. Other criteria that you have to meet.

Among those patients, the protocol for Botox injections for migraine is 31 injections in the head and neck. Most of them under the hairline. It uses a cosmetic needle it's not painful. It's not. Not when I do it. It's done every 12 weeks. It's not considered a treatment failure until after the second set. It does not preclude any other treatment that you're getting. The medication does not travel through the system, it stays localized in the muscles of the head and neck.

It works by ... it stops the cascade of neurologic events that occurs when a migraine happens. It's not simply a muscle relaxing type of thing. It's a very complicated neuro-modulating treatment but it's very effective. Statistically, it reduces a chronic migraines headaches. If you're meeting the diagnostic criteria of chronic migraine, you're having more than 15 headache days a month, we found that in randomized clinical trial, that's reduced by half.

You're still having some migraine. You may need other medication at the same time but when you're talking about that many migraine attacks or migraine days a month cut in half, it's pretty nice.

Elaine Laurie: Migraine, tension headaches, cluster headaches we can talk about the differences but how do you know you're getting the right diagnosis?

Heather McCoy: I guess you would know you're getting the right diagnosis if the treatment that was prescribed alleviates your symptoms. I suppose that would be one way of looking at it.

Elaine Laurie: It seems like a lot of trial and error.

Heather McCoy: A lot of trial and error unless hopefully you're seeing somebody with confidence in their diagnostic skill for those types of things.

Elaine Laurie: Which is another question because there's not a whole ton of you around.

Heather McCoy: That's true. That's true.

Elaine Laurie: The specialization and I know because I've looked but the specialization and I think Mary was the one that mentioned through living in a rural community somewhere, you're definitely not going to get the proper diagnosis.

Heather McCoy: You might not be. Rural clinicians really try and step up their game because they have to manage everything. I've actually found that rural clinicians can be some of the most astute, because they have to be. These are often the clinicians that are paying attentions to meetings like the American Headache Society and the recommendations of those communities and stuff because they know that that's it for patients.

When prescribed therapy doesn't help, when symptoms seem to be getting worse or there is some sort of atypical presentation, definitely time to seek out somebody with ... I would recommend a specific headache medicine training.

Elaine Laurie: Why did you get into this line of work?

Heather McCoy: I got into headache medicine the back way. I started with very high acuity in neuroscience working in neurosurgery and neuro trauma with some very high level neurosurgeons for 15 years, so I've seen everything. Literally everything. I've seen everything you can imagine could happen to the human brain under any ... I have seen. After I did neurosurgery, I did stroke and general neurology for five years, so I'm very comfortable with the brain. Very comfortable.

I'm very comfortable with headache. All of those patients have headache. All of them so I'm very, very comfortable knowing what something is not and have a ... that's really given me a confidence that's helped me in this specialty but I've also seen throughout the years how neglected that community is. It's very difficult to cure a headache and so it's a frustrating thing for a lot of clinicians because they can't make the patient better. It takes a special clinician I think to treat those patients.

Elaine Laurie: Well and a very patient. Patience is everything.

Heather McCoy: Yeah it is.

Elaine Laurie: In both sides really.

Heather McCoy: Yeah. It's nice to have that confidence of I've already seen the really super scary stuff.

Elaine Laurie: Yeah. Let's talk a little bit about treatments and some medications. Obviously you probably do research every second you're free. What have you seen in terms of what might be out there or what you're looking at as the next thing?

Heather McCoy: Kerrie started to talk about neuro modulating devices. Those are very exciting because the risk benefit ratio is very favorable for patients. These are devices that the worst case scenario is they don't work for you. The down side is they can be expensive, which seems to be the strong hold that people have over diseases where we're really seeking cures for, seeking treatment for. You get ahold of something that works and boy, it's expensive. The neuromodulation device is I think are very encouraging. I'm hoping they get to the point where they're accessible.

Elaine Laurie: I was just going to say, if you have to go to Canada or Europe, it doesn't ...

Heather McCoy: No, they're available here now. We have two FDA approved devices. The Spring TMS from eNeura is FDA approved and so is the Cefaly. They're ...

Elaine Laurie: Have you used those with your patients?

Heather McCoy: The Spring TMS is fairly new. You have to be trained on it. I do have that in my clinic, but when I say new I mean I just got in July, so it's very new and I've ...

Elaine Laurie: You're hopeful.

Heather McCoy: I'm hopeful. They're expensive, that's the problem. It's how you tell somebody, "Hey, this might work for you, but I know you can't afford it?" That's really difficult.

Elaine Laurie: Right. Tell me a story about somebody that you've treated, or somebody that you are treating, your success story. You probably have hundreds of them.

Heather McCoy: Oh boy.

Elaine Laurie: What's your favorite? What's the one that really touches you?

Heather McCoy: I can't nail it down to one, but something that I do know, and I'm lucky enough this last summer, I have a 19 year old and a 22 year old and I both suck them into working in my clinic sometimes answering my phones. They see their mom getting hugs from people every day. I'm telling you, I get more hugs than any neurologist I've ever met, and that feels great. That feels great.

I hear things like, "I'm so glad to find someone who doesn't think I'm crazy." Or, "Nobody ever told me that was because of my migraines. Things like, there's neurological phenomenon where you get really sensitive. Your scalp gets really sensitive, so things like washing your hair hurt, or putting your back to the head rest of the car hurts." That's an actual neurologic thing from being constantly bombarded by migraine. There's a name it's called Allodynia. There's a name for it.

Patients don't ... it's like, "Nobody ever told me that was because of my migraine." I just, "I don't know. I don't know why they didn't tell you that, it's not a secret." Just being able to validate the patient's anxiety, provoking symptoms that are often dismissed, that feels really good. It feels really good, and that happens to me every day.

Elaine Laurie: That's great. I don't know. Are you over there wrapping me up? Yeah. Okay. She's in the corner, I can't ... I can barely see it

Heather McCoy: I can't see anything.

Terry Wilcox: I will stay on the light.

Elaine Laurie: Okay.

Heather McCoy: Okay.

Elaine Laurie: Thank you ...

Heather McCoy: You're welcomed.

Elaine Laurie: ... so much, but I think you're going to stay up here? No, you're not going to stay up here? Okay, bye, bye.

Heather McCoy: I'll shrink away.

Elaine Laurie: Thank you very much. That's right. You don't get to stay up here because Terry is coming back up here. We're seeing a video first? Okay.

Video: My daughter was one, I was just sitting, looking at her thinking, "Wow, I have migraines and I'm still taking care of this beautiful baby." I was sitting there looking at her and I was like, "Jeez, I wonder what else I can do?" When it suddenly offered to me that I could changes names and that was powerful and capable. I set out to find people that I could work with, to change things, and that's what lead me to the organizations that I work with.

My daughter is really a good kid in that, she understands, and I wish she didn't understand, but she does understand. Unfortunately, my daughter will do things like bring me an ice pack because she knows when things are bad. She'll be like, "What else can I get you?" My son, because he's so young still, he's just one, sometimes will just snuggle up with me and fall asleep and it's just great, no matter who you are.

I want to be able to take my kids to the park, and three days a week I can't do it. 36 years of going through treatments and not finding one that works means that I have to try new things. The most important thing for migraine patients is developing new treatment. There's new medications coming out, and I'm almost positive that they're not going to be covered because they're going to be expensive. They're going to be new, and the insurance company is going to say, "We already have treatments," and without a strong patient organization the insurance companies are going to continue to just say, "We don't care. It doesn't matter. We're not covering that."

Elaine Laurie: That actually bring us to some of the questions that I have for Terry, and that is, access to mediation and access to treatment, especially the new ones.

Terry Wilcox: That's one of the major things that we do as an organization. In Patients Rising, we don't just focus on migraines, we focus on anything. We've spent a lot of the past year of our existence basically taking a look at what are called value frameworks and how insurances companies are creating these formulas or formularies to deny or include new medications.

I'm going to talk a little bit about, because we sort of focused on it. If you read anything about Patients Rising, you can go to our website. We have been following a group around and but they're many and this is what I'm going to speak to a little bit about value frameworks, but there's one particular institution out there called ICER which is the Institute for Clinical and Economic View. This is my third on of these this week, which is really a great milestone for us as an organization. I did cardio on Sunday and Psoriasis last night and now we're here for migraines.

One of the things that and this is what Eileen spoke to, and unfortunately Eileen could not be here tonight, she's in Maryland, but she is one some of these new medications, because they are ... they haven't been approved yet, but there're clinical trials and the things is ongoing and they're working for. There's a fear of sort of ... a fear of, "What's going to happen? What's going to happen when they are approved? What's going to happen? Are they going to be covered?" Because there's always this sort of waiting period.

What happens is, insurance, I always say an insurance companies job is deny treatments. That's sort of their model. Not necessary ... I don't want to say that there's people who sit in a room and they're like, "We're not going to pay for treatments," but when new treatments come out, there's a lot, "Whoa, whoa. How many of you are there and are we going to do this or?" Making these determination right out of the gates, and this happens with a lot of new medications.

I can speak to this because I've seen it this year. We just did an event for liver drug in July. This drug had been in clinical trial and been developed for 14 years and it was the only drug that his small company had. What they immediately did wad this ... This institution creating value frameworks which called ICER, had this might meeting and they were just beating up on this drug that it had just been approved a month earlier. Right out the gate, this is the only drug this company has. It's not even a big pharma company. It's a little bitty company for all.

Their job was to sort of rain in, who was going to be covered, who was not going to be covered. Now the reason we look at migraine patients now is they haven't had a new drug in 25 years. They haven't had any new treatments. It's important that we keep going. We understand as an organization that, yeah, price is always going to be ... we were talking about device price, medication price, but that you always think about treating the patient first. We have to figure that out first.

We were talking about Psoriasis last night. Psoriasis, people used to have to spend 17 days in a hospital for some treatment. I used that analogy because I'm like, "What if you still had to do that? What would that cost? What would 17 days in a hospital cost?" You don't have to do that now. There's amazing medications for that, and for everything. That's why innovation is so important and we have to as a society, and as medical institutions, and as payers and

providers, and manufacturers, we have to figure out how to get this to the patent, because if we're not going that, then what are doing?

If we're not making sure that the patients are able to raise the bar of how they live their life, there's work hours. There's ...

Elaine Laurie: Of course.

Terry Wilcox: There's so many ... quality of life. Eileen is a young mother. She's got two beautiful children.

Elaine Laurie: It's like giving her a gift and then literally taking it away.

Terry Wilcox: Right, so you have to take the whole picture into the thing. The reason I brought up these value frameworks because a lot of time they want to take it and they just too hyper focus on cost first. Like I said, I'm not saying that's important, but you have to focusing the patient first, and then we have to figure out.

Elaine Laurie: I think that's the medical industry in general.

Terry Wilcox: Yeah.

Elaine Laurie: If you think about it, it is backwards. Not everybody, some people put the patients first, but it's almost a mind set in the medical community, that this is just how it is. How do you change that Mary? What do you ... You're the National Foundation, so I figured we start with you, big. We go big.

Mary Franklin: Okay. I'm thinking there's [Inaudible 01:33:10] people attending this meeting [Inaudible 01:33:16]150, 200 years ago is I'm hopeful that they recognize the importance of medical treatment and they're willing to leave their practices, leave their homes and come and learn and that's, I'm hopeful.

Terry Wilcox: I think also just the innovation we're seeing in this space too, I can imagine that it is exiting. I always find and I've been doing patient advocacy for about 10 years now in all ... mostly in cancer to start, but any time there was a hyper focus and new innovation in a space, the excitement and the energy and the ... you could always tell if I went to disease specific cancer conference and nothing really new had happened that year in the space. It was just a different energy. It was sort of like, "Yeah, I don't know nothing's happening."

Elaine Laurie: Same old, same old.

Terry Wilcox: Same old, same old. We've still got this and this and this, but there's a lot of excitement in this space, and you know who's most excited? The patients.

Elaine Laurie: Of course.

Terry Wilcox: Right, I mean hands down. That's why we're here, and that's why Patients Rising exist. What I want to say, as we close up tonight it's been ...

Elaine Laurie: Let me ask you one more question.

Terry Wilcox: Oh you want to, I'm sorry.

Elaine Laurie: Because I think you can help with this.

Terry Wilcox: I'm doing her job.

Elaine Laurie: Yeah. Where can your organization, your advocacy organization come into play if a patient is denied treatment?

Terry Wilcox: A patient. One of the great things about it, is I have a little cluster of, and not to use the term ... I have a group of people that we work with, and actually it's an interesting thing you say that. One of the groups that we do a lot of work with, she often speaks at our events. She's not here tonight. Her name is Stacey Worthy, but she is the executive director of the Aimed Alliance, which is the alliance for the adoption of innovations and medicine.

She provided this wonderful pamphlet, which we will have in a PDF form on our website as well as hers and anybody else who wants it on their website, because it's real not a preparatory piece of information as much as it is a helpful bit of information to patients. One of the major things that we find is patients ... we are reaching a time, especially as invasion keeps going like this, and insurance companies keep going, "Wow" or whatever, the patients really need to learn to advocate.

We work with the Aimed Alliance quite a bit. They put together this lovely document that talks about step therapy and non-medical switching and prior authorizations, and all the things that can get in the way of patients getting the treatment they need and the personalized care that they need when they need it.

As far as what we do, we have two parts to our organization. We have our Patients Raising site, which is an education site. One of the things that ... the most gratifying thing to me, as we do these is to have patients come up. We did an event like this earlier this year, and we were talking about a lot of these things; value frameworks, and step therapy, and all this stuff. One of the things that a patient came up to me at the end and said this like, "I've never had any of these terms."

That just shows that there's this sort of that ... That's why insurance companies can get away with denying 50% of ... and patients just sit there and say, "Oh, I guess that's what it is," unless they have a doctor, or a nurse practitioner like you Dr. McCoy who will help them get through. There's a ... I can speak to the

community oncology space more than any because I know the most doctors in that space.

A lot of times these guys are ... I know a guy who flew from one side of Montana to the other. I mean he only has so much time. He was one of two oncology in Montana or something at the time when I interviewed him. It was crazy. They're busy. A lot of time patients and caregivers and their family, this is just a time when you deserve this. You're paying your premiums. You're doing this stuff, and you need to go out and get it.

That's why organization like the Aimed Alliance and the disease specific organizations, they know more than anything about this specific needs of a patient. That's why they are our favorite people to work with when we do events like this, because obviously migraines aren't our specialty. There are our specialty tonight with great people who have that. Please, take this home for those of you who are here.

We also have an article coming out in Women Magazine. It will be in the spring issue. There will be a whole migraine section as well, and that is, the insert for that is also on your table. We wanted to make sure you guys knew that. We have all of our guests here. I want to thank everybody here who came tonight. We have our ... all of our speakers are here.

We have dessert and coffee out in the foyer. We just want you guys to feel free to come up and ask them any questions you may have and feel free to come up and ask me any questions. I want to thank Elaine Laurie tonight. She did an excellent job in moderating our little Oprah evening on migraines. Thank you very much.

Elaine Laurie: Thank you.

How did we do?



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