

Transcription is computer generated and not reviewed for accuracy

Transcript

Speaker 1

Welcome to the bridge, the official podcast for the University of Maryland Baltimore School of Pharmacy Patients program. The patients program is the bridge between the community and the researchers. The patients program created this partnership to help researchers listen to the Community's voice in order to build a bridge to an effective learning healthcare community. Here's your host, Rodney Elliott.

Rodney Elliott

Hello everyone. Rodney Elliott, Community engagement specialist at the patients program here. Today on the bridge talking to two guests that have participated in projects. With the patients program, one in particular, the Patient Professor Academy and then another partner, friend, colleague. The patients program, who been with us before I even got here and kind of understand where the patient program started and love to hear her perspective on where the patient program is growing up to this point and also happen to see what she's got going on because she was very integral in helping me get. Acclimated to patients programs. So without further ado, you guys know me already? Rodney Elliott, I'm going to introduce Lisa Shill and Myeisha Thompson. The ladies, how are you guys doing?

Lisa Shill

Doing well.

Myeisha Thompson

I am doing well Rodney, thanks for having me on.

Rodney Elliott

Thank you guys for joining me. Really appreciate it. Lisa Shill, you mind giving us a quick intro to who you are and what you got going on.

Lisa Shill

Yes, thank you so much for asking Rodney. I would say I'm an A passionate patient advocate and engagement consultant working to improve patient outcomes through collaboration. So families can have more quality moments together.

Rodney Elliott

Thank you. I really appreciate that. And that your specialty is kind of what the patient program is all about. One particular area, and I know you participated in the PPA last year, so as we're gearing up for year two of PA, I'd love to hear your insight on a couple things that happened last year. So we'll get to that. Myeisha Thompson. How are you? Would you mind sharing with our audience a little bit about

who you are, your early participation in the patients program and then what you got going on? Right now.

Myeisha Thompson

Well, I am marketing communication strategist and as you mentioned, I work with the patients program. I think for maybe three or four years part time as someone who helped out with the communications and in marketing. And I remember you know, helping to promote the 1st. Couple of patients, patients, days and things like that. So really been around the the program for a while and just always love the the work that you guys do there and and I'm just happy to see all. These new new initiatives and new things, particularly the patients, Professor Academy, which I remember when you know Doctor Mullens first had the inkling of it. So I was super excited to see it come to fruition and to anticipate in it.

Rodney Elliott

Lisa, you participate in the PBA. Can you share with our audience your experience with the patients, Professors, Academy and if there was anything in particular during your time with the Patient press Academy that? Stuck out to you.

Lisa Shill

Sure. I think you know healthcare needs to speak to people's culture. You can't fill another person's cup until you already know what's in it. And I think that the patients professor program it, it helps you to continuously learn. You know, advocacy isn't something that you can just do in a day. And I love the patients professors program because not only do you. Learn about the tense. Ten step framework. You also learn about you know how to plan, research how to do the research and how to deliver solutions. And also you know, all my classmates we have stayed in touch, we share, you know, with through newsletters and sharing information and to bring class other classes that we find. And it really has helped me stay engaged because I think as an advocacy consultant, you see a lot of times that people make assumptions. Time's always making assumptions and it's easy to fall back into assumptions about patients and their families. So it's always important to remind yourself, you know, you need to constantly think outside of the box about other people who you're not including and and make sure that patients are included every step of the way. So I was really impressed with the patients, professors. Academy for helping make sure that I'm engaging patients continuously as partners. If the engagement learning, if the engagement is meaningful, you know, are the right patients engaged at the right time.

Rodney Elliott

I love it. I'm writing it down. You can't fill the cup until you know what's in it. Personally, I'm always the guy. That's kind of glass half full. So I'm gonna add that to my repertoire when I say, you know what? You can't fill a cup until you know what's in it, because somebody could be drinking. Water and you pour some Gatorade in it. And it just don't. It just don't fit. It's not gonna. It's not gonna make sense. I love that and that speaks to how. Patients Professor Academy made everyone who attended, no matter. If you work. In patient advocacy, no matter if you were contracted with the university or the researcher, that you have to understand what's in. A person's cup. Before you try to fill it. I love it. Love it.

Lisa Shill

Thank you. And I can't take credit for that. It was actually a tribal leader who came up with that. But I thought it was so insightful that I remembered it too, and wrote it down and I tried to say it to myself every day because I think we're so eager to share things. But we have to step back first and, you know, kind of get a lay of what what people already know and. How they want to learn?

Rodney Elliott

Putting that in to me, that tribal person, he whoever made that up, that makes all the sense in the world because you put in the language that everyone understands, that researchers understand that community members can understand that, you know, people in the Community can understand that. So it's not hard to to to decipher that and you know and and when you dealing with research, you got to find a way. To make people understand it. In the way that they receive it in a way they can. Standard, so that's great Maisha. Can you talk to us a little? Bit about your time. Before the patients program in that marketing space because you know if you are in marketing, you kind of have to be a part of these meetings. You have to be a part of these sessions to kind of understand what you're presenting from the patients program to the community. And what stood out to you as far as the PA is concern.

Myeisha Thompson

Well, what I what? Stood out to me. Well, I'll talk a little. Bit first like you asked. About my time with the patients program in the communications role. And like you said, I really did have to kind of understand what the program was about in order to make sure that I was able to speak to it to all of those different stakeholders. So everybody from you know, possible. Sponsors and writing grants helping the rate grants and pull together things for that to promoting events and getting the newsletter out. All of those things and really understanding what's important to all of the stakeholders. So I do know that that was always a focus, making sure that we speak to everybody in their language in a way they can understand. So what's important to our community Members, what's important to the organizations we partner with, all of those things mattered and there was always just this this kind of. Underpinning that, we couldn't just say the same thing to everybody. There was always nuance in how we approached each of our stakeholders and really making sure that happened all the time. So I was always just very taken by that consistent underpinning and just core value of the organization. And I think that that really translated into what I love the most about the patients, Professor Academy. There was such. A broad range of participants and that was to me, was one of the best things about it. I already knew the ten step framework, but seeing how other people thought about it so you have someone like me who is, you know, both the patient and. You know, just a novice and wanting to advocate for people who can't advocate for themselves with chronic illness. So I'm just learning the space from that perspective and with the patients Professor Academy did for me was get all of these different perspectives from, you know, people who worked at government agencies from people who you know were, if not decision makers close to decision makers in some of the firm's pharmaceutical spaces. Even then, I've I was on a call. Uh, one of the teams with someone who was in the technology space. So you, you know, you get to see all of these different viewpoints of how. You know, getting research done and really making sure that we're focusing on the right things and keeping the patient at the core. But you know you have the patients in the middle, but you have so many different touch points that make, you know, make everything go. And it was. It was so well represented, and it wasn't an echo chamber, you know, so that was the other thing that I really enjoyed about it. You didn't have the same people agreeing and saying the same things and you know, I agree with you. You agree with me. It was really that diverse

perspective. And getting those viewpoint. With an open mind that I found just refreshing and if you were like me and you didn't know a whole lot about it, people leaned in to help explain things about, you know.

Speaker

Be it the.

Myeisha Thompson

You know the the process on the government side or how technology incorporates research with patients and things like that. So it was. That kind of diversity of. Of participants was probably the highlight for someone like me who's just really trying to understand on this side of the fence what participating and advocating and. Research could be.

Rodney Elliott

Even in the work that I do in engagement specialist when? I go out. Into the community. I can't just go out to these communities, just talk at the community, talk at the community. I don't have to come with a listening ear. Kind of kind of, you know, see what's in that cup before you try to fill it a little bit. So we took that approach as well and I understood that some of those break rooms, breakout sessions that we had where again you had a mixture of folks break up.

Myeisha Thompson

Oh yeah, they got heated. They were respectful, but they were they were heated, but they were heated because of the diversity and viewpoints. And again, everybody came with an open mind. So even when the conversations did get a little heated, you knew that it was respectful and it was. Really, bringing all of you always off the way with hearing something that you might not have, you know, considered which I think is the most valuable part of of the groups, is really just walking away with perspective.

Lisa Shill

I was just going to say, you know, I also think it's looking at the barriers right, because we have these idealistic views on what patient advocacy should be and. And we also have to look at the barriers that are in place and how we can overcome those barriers on both sides.

Rodney Elliott

What have you learned during the PPA or or her during the PPA that can help you address some of those barriers in your patient advocacy work?

Lisa Shill

That's a really tough question. I think one thing that we really need to work on is changing public policy. So everyone can have a seat. At the table. So that's gonna that's going to take a while, but I love how the patients Professors Academy has created working groups to work on some of these barriers. Also understanding the government regulations on how patients and industry. You know, pharmaceutical companies can interact with one another. You know, there are rules and we need to make sure everyone understands what those rules are. So lines aren't being crossed.

Rodney Elliott

Change of policy definitely could be a long term approach and you know I'm the patients program is all for that like we're here for the long the long haul you got some stuff going on over there in Arizona where you're helping folks manage anxiety, depression and and chronic pain. So can you share a little bit about you know what you've learned? Which you discovered during your time with the PPA or just for the patient program in general and how that? Has helped you navigate to that next phase where again, you're helping those folks manage that anxiety and depression and chronic pain.

Myeisha Thompson

Well, one of the things that you know, I always loved particularly about the 10 step framework is everybody says, you know, you have to have a conversation. You have to have. How you know? Like, where do you? Start with this. You know, so I think having a framework as a you know. And it's a framework, but it's flexible within it, right? So that's the other thing, but. I think just having the how. To have these conversations, how do you work with various stakeholders? It's so important and I think that's what you know for me. That's what you know. Really kind of digging into it and where it came from and integrating the personal stories. Into teaching this the the framework was integral because it was like, OK, this is the. Step but then. Here's a story about how this works in someone's life, right? So it was really that kind of balance of yes, this is a, you know, kind of clinical framework, but they put real lives next to it. And I think that. That was just an amazing approach in teaching it and the patients. Professor Academy is kind of marrying. Those two things up. So it's like, OK, yeah, we're in this world of research, but we know that this touches real lives and we need everyone to understand that. And I thought that that was just. Just amazing. And as far as the work that I'm doing here now, I mean just. Kind of following, you know, my heart with something that I struggled with for most of my adult life. And then, you know, as far as anxiety and depression and really, you know, having to take myself for a process of marrying, you know, pharmaceutical intervention with all of the lifestyle changes and all of the other things that I needed to do just from a. You know health standpoint without pharmaceuticals, right? So really trying to figure out what that balance is between, you know, lifestyle holistic health and you know, other interventions was, you know, it was a long term prospect for me and it was a lot of trial and error and it can be frustrating. And this is from someone who understands health insurance. This is from someone who understands, you know, I understood it and it was still. Goal very. Frustrating and depleting for many years trying to get, you know, just kind of get through and maneuver. And I know a lot of people who don't even understand that and don't have the agency to, you know, even just call someone to go to appointments with you because you're in pain. You know, just all of the little things and a lot of steps that I, you know. I have to kind of figure out myself. I want to be able to help other people kind of understand what. That looks like. And right now it's funny because I I started down that path and ended up in massage therapy and meditation. So I'm I'm now a licensed massage therapist here in, in, in Arizona and I'm opening my own this. But what I did with that as well is got a meditation. Certification so that I can teach that along with. So really trying to figure out how to marry those things together and help people to understand how it all works together. Yes, you're on your medications, but you have to do your other things too, to kind of, you know, manage what. You know, chronic after a while. So those are things that I'm passionate about that I'm working towards right now and you know, set up a foundation alongside the for profit business. So that I can do the work with people who can't afford it. So, you know, those are things that I'm working on right now, but really just understanding that in our communities. People need to understand that there is not this, you know, 11 approach this

one way to to managing needs. You have to take a, you know a 360 view. But and it it can be hard for people who don't understand it. So that's kind of the work I'm doing right now along with my marketing stuff, so. It's it's a lot, but you know it's it's a it's a heart. It's a heart thing for me because I've been there. Like I said for many, many years and getting to the other side. Of it, you just. You know, you feel compelled to to reach back in and share and understanding that, you know the research aspect of it is important. You have to lend your voice. Nothing gets better until we're able to, you know, safely and and feel confident that you know we can do this without being taken advantage of. Being inappropriate like this in in the patient Professor Academy and just the patients program in general, you know it says. OK, yeah, this isn't the research of the of the past. This isn't what you have in your mind. So really trying to change the narrative around that as well. I'm I think it's super important and that's something that I'm interest. Then, because we all make mistakes and institutions included. But when you have a program like this that's working to kind of, you know, move past those mistakes and really engender that trust, I think it allows people to to, to better understand it and be more willing to participate in. And and getting those interventions and treatments that we all.

Rodney Elliott

Here at the patients program, when we hear someone share something that's exciting or share something that's about awesome, we snap fingers. I'm snapping my fingers for you. My issue for.

Speaker

Oh good.

Rodney Elliott

That with us. Congratulations and best of luck with that. Over there in.

Speaker

Thank you.

Rodney Elliott

And thank you for sharing your lived experience because. With your living. You're able to go out there and again have an understanding for both sides. You sit right in the middle as a patient. Someone will have the experience with it and also understanding the importance of being a vessel or or. Or being a speaker somewhat for folks who don't. And I love that.

Speaker

Right.

Rodney Elliott

And you weren't able to. You're able to kind of step out on faith and and and bet on yourself. And that's something I know we shared a little bit about during the time when. We were here. The patients program, so I'm definitely totally proud of you for taking that, taking that on for sure, Lisa.

Myeisha Thompson

Thank you so much. I'm excited.

Rodney Elliott

You sat and listened to Masha talk about her story, about, you know. Her being that vessel and sharing her live experiences, what are you doing now? And has the patients, professors Academy, being a part of that helped shaped your approach? Shape your conversation, shape how you engage with patients, whether they're on the. Community side or in your research part has a being a part of the PPA helps shape your approach to some of those things.

Lisa Shill

Yes, definitely. You know, like I had said before, sometimes we come with. Assumptions and even when we try not to have assumptions when you work in patient advocacy for a long time, you know sometimes you fall back on some of those assumptions too. Right now I, you know I have. I have different clients, but one of the clients I'm working with is working on finding new uses for existing drugs that have been FDA approved. You know, collecting real world data from not only just healthcare providers, but patients, which is really exciting to learn the perceived benefits and risks of using these medications off label. So for example, if you took COVID, you know everyone sort of now knows what COVID is, and you don't have a treatment. Out there and I work in mostly rare diseases where, you know, over 90% don't have treatments. So and it takes so long and billions of dollars to create a new treatment, a new new type of. Location that it kind of makes sense to fall on what's on the shelf already, right? That might be approved for a different disease, but it might be able to. Help us. So we're kind of looking at that and trying to collect real world data in real time. So if I'm a patient and I take something, you know, my doctor has prescribed it off label. That hasn't been approved by the Food and Drug Administration that if I take that medication, the clinicians or and healthcare providers can fill out a form to say, OK, these are the perceived risks and benefits of taking it off label. And I as a patient, which is really exciting. I'm going to be able to say these. This is what I think is working and this is. What I think you know is not working with this medication and putting it on an app to then have anyone be able to look at the app. And see. What patients and clinicians have thought about these medications used off label and see, you know, is there a benefit to any of these? And if so, should we look at, you know, creating a clinical trial for? Another indication for that medication.

Rodney Elliott

Is that something that was? Created or established during the breakout or you know when when things were kind of new to everyone?

Lisa Shill

I mean this so this app does is collecting data on long COVID and it started in infectious diseases you know.

Rodney Elliott

OK. OK. OK.

Lisa Shill

So we could see, you know, cause there's a challenge when you have diseases that are new, but then there's also challenges to diseases that are small. You know it's not. For a company, it's not sort of always in their best interest to work in diseases that are small and diseases that are new. You know, it can just take a. Really, really long time. So you know this project is sort of trying to help help move the needle forward to find other treatments. And what? But what I love about it is because you're using real world data and information that's. Interesting to patients, it's asking the patients what they want to hear, right? The clinicians form is, you know clinicians are probably going to be more interested in you know quote comorbidities like what is eventually going. To kill you. Or you know what they specialize in, right? If they're a cardiologist or if they're a dermatologist, they're going to be focused on this one. Thing, but for a patient, they're focused holistically and they want to know, you know. How this medication is going to improve their lives or how it's going to hurt them in every system of the body, not just one place. So you know, it shows the importance of of the patient voice and you know I I think I use a lot of the. Lessons in our meetings when we're bringing all the stakeholders together that I learned from the patients, Professors, Academy.

Rodney Elliott

Yeah, I I can't. I heard the word live. I haven't heard the word. Lived experience. More ever since I've been here for the patients program and understand the importance of lived experiences, because when I'm out and about in the community or just talking in general, I understand that the doctors and researchers and professionals, they are quote UN quote experts in their field because they. Went to school when they studied they had. That's great. On top of that, I love how we make sure that the researchers doctors understand that the community members or the patients, so to speak, that we. Deal with our experts in their lived experiences as well. That information is just as important, if not more, when we're talking about coming together, collecting data coming together, having. A focus group. Collecting, collecting information that's pertinent in changing ideas, changing philosophies, and which you talked about earlier. When we first started is changing policies, so live experiences are awesome and fantastic and they help shape research going forward and I'm proud to be a part of that hand the patients program and excited for year 2 for PA. Which kind of leads me to my next question for both of you and if I would ask your question, Misha, what would you say to someone who is considering joining the next cohort of the patients, Professors Academy in 2023?

Myeisha Thompson

One of the things I would say is. Keep an open mind. I think that that's very important, particularly when we get into the the breakout groups and things like that, being able to listen critically. I think it's important also knowing that you can actually share, so sharing your lived experience in a in a safe space.

Speaker

Right.

Myeisha Thompson

Where it's valued and validated, I think I would encourage particularly patients in that regard, just knowing that your experiences are not taken for granted. I would also. Well, you know like to say that I'm not, you know, even though I've, you know, marketed and written about medical topics, scientific topics, all types of stuff across the, you know, medical and healthcare and insurance fields, you don't

have to be an expert in the science to gain something from this. So I really want to tell some of the. You know, people who may feel intimidated, they might be community members or community community advocates who haven't necessarily dug into the science of it. Be open and approach it with that. Mind that you don't have to be a scientist you don't have. To be a doctor or a researcher. To to add value to the to the program as well as to get value out of it. Because I found all of the material very approachable and and it was. You know, in a way that I think just across the board the curriculum was built in a way that everybody. I could understand it, so I I want to say that as well. So for people who were considering it, but they just, you know, might feel intimidated by it. Don't be because it's it's. It's approachable. And you will. You know gain value as well as heavier lived experiences as a non scientific or non medical. Professional it will be. It will be valued.

Rodney Elliott

Thank you, Aisha. Same question to you, Lisa was someone that's on the fence, you know about joining DPA? 2023 what would you say to them about joining the next cohort?

Lisa Shill

Yeah, I guess I agree with everything that Myesha said and especially having an open mind and you know to connect with others, you know. I had such a great time getting to know my classmates and still go back and and ask questions and also ask questions in in the seminars. There are no kind of stupid questions, right? We all come from different backgrounds and it's important that we all understand what's going on, I think. One of the greatest things about the patients professors program is the time that they take to. Define the terms right, because if I say what is advocacy to you, we we might all have different answers. So if we kind of discuss you. Know this is. Where we're starting from, this is how we're going to. Define it in this class. It's helpful. You know, for everyone. So we're sort of all starting on the. Same same ground. So there's no reason to be intimidated.

Rodney Elliott

Well, you heard it here guys. We have two outstanding graduates of PPA, 2022 both graduated, both took some of the information and knowledge. The stories from lived experience from our community members. The I would say intense breakout sessions and they've. Added that to the work that they do. They implemented it in their engagement. Opportunities with the community that they serve and their personal projects, but also professionals as well, and myesha and Lisa, I can't thank you enough for participating and joining us on the bridge. I truly, truly appreciate it, and we're going to get out of here. But again, I thank you for your time. Wish you luck. In both professional and your personal fields, and thank you again. For joining us, EPA was a success last year because of participants like you and it's going to be a success this year as. Well, you.

Myeisha Thompson

Thank you for having me on. I appreciate it.

Lisa Shill

Thank you so much for having me, Rodney. Really appreciate it. Thanks for all that you do for patience.

Speaker 1

Thank you for listening to the Bridge podcast. To learn more about the patients program, visit. Our website at. www.patients.umaryland.edu.