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The UMB Pulse Podcast

PATIENTS Program Connects Community to Research

April 01, 2022 University of Maryland, Baltimore Season 2 Episode 3



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Apr 01, 2022 Season 2 Episode 3

University of Maryland, Baltimore

Bridging research to the community, [The PATIENTS Program](#) at the University of Maryland School of Pharmacy excels at giving communities ownership in visiting medical research through patient-centered outcomes. Executive Director and School of Pharmacy Professor **C. Daniel Mullins, PhD**, and Engagement Specialist **Rodney Elliott** are our guests.

They discuss an exciting partnership between PATIENTS, Mount Lebanon Baptist Church and CVS Health in Baltimore (7:21), another [project with the Southwest Partnership](#) that gives the community stake in research (20:23), and more. They also tease the return of [PATIENTS Day](#) in August at the UMB Community Engagement Center (36:50), plus a new program called the [PATIENTS Professors Academy](#), (23:17) which is [accepting donations](#) to fund future cohorts.

You can also learn more about what PATIENTS does by listening to their [Facebook LIVE programs](#), "Real Talk with Rodney" and "BJ's Corner" every other Thursday (28:37).

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Bridging research to the community, [The PATIENTS Program](#) at the University of Maryland School of Pharmacy excels at giving communities ownership in visiting medical research through patient-centered outcomes. Executive Director and School of Pharmacy Professor **C. Daniel Mullins, PhD**, and Engagement Specialist **Rodney Elliott** are our guests.

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Jena Frick: 0:04

You're listening to the heartbeat of the University of Maryland, Baltimore, the UMB Pulse.

Charles Schelle: 0:17

Welcome to our April 2022 episode of The UMB pulse. I'm Charles Schelle.

Dana Rampolla: 0:22

I'm Dana Rampolla.

Jena Frick: 0:23

And I'm Jenna Frick. On this episode, you're going to learn how one University of Maryland School of Pharmacy program is being a change maker both in West Baltimore and nationally through advancing health equity in communities.

Charles Schelle: 0:35

Yes, the PATIENTS program works with care providers, and of course, patients on the best treatment options to improve their health and quality of life. They do this through a combination of listening to patients about the care they're receiving, and bridging what's happening in the research laboratories to disseminate to community members. This program was launched in 2013, with a five-year \$5 million infrastructure building grant from the Agency for Healthcare Research and Quality, which is part of the US Department of Health and Human Services.

Dana Rampolla: 1:03

Yes, and not only are they going to senior centers and congregations to talk with West Baltimore residents, but they're also leaders in their field, speaking in front of the Food and Drug Administration Centers for Medicare and Medicaid Services, the National Academy of Medicine and numerous universities and patient advocacy organizations.

Jena Frick: 1:20

And so joining us here on the Pulse are School of Pharmacy professor and PATIENTS executive director Daniel Mullins and engagement specialist Rodney Elliott. So thank you both for coming on the Pulse today.

Daniel Mullins: 1:30

Thank you for having us.

Rodney Elliott: 1:31

Thank you for having us. Glad to be here.

Jena Frick: 1:33

Yeah. So I guess the the old adage is kind of that people say Oh, my doctor doesn't really listen to me, my pharmacist doesn't understand what I'm trying to say, or I don't know what's happening to my information, once I give it and the PATIENTS program is challenging that notion. Can you kind of give us a snapshot of what the PATIENTS program does to help both patients and researchers?

Rodney Elliott: 1:55

Yeah, that's a good way to put it. I mean, basically, we're the bridge with a bridge between the community members and the researchers and we try to give the community members that information that they need to be confident when they're in those doctors meetings, or when they're talking to their pharmacists. And, you know, when researchers come to us, we want to them to make sure that when they do decide to partner with us, that it's not like a one stop shop, you know, you got to come in, let us know what you want to do, what your plans are, and how we can help you from beginning to end. So that's kind of a nutshell of what some of the PATIENTS program does.

Jena Frick: 2:27

Got it. That's, that sounds really important opening up that line of dialogue and communication. So why is the PATIENTS program important to both of you personally?

Rodney Elliott: 2:38

Well, to me, I mean, I'm, I have a background, I'm born and raised in Baltimore, a background is in sports. But I've been in the PATIENTS program for about three and a half, four years now. And I've always had a passion for helping helping people helping the community, Dr. Mullins and I met through a friend of a friend, and heard a little bit about the project, PATIENTS program. And then more and more I learned about it, I knew there's a good opportunity for me to, again, extend that, you know, post my basketball career was to have an opportunity to stay connected to the community in a real genuine way. And for years I've been here, we've been able to do that.

Daniel Mullins: 3:16

As a researcher, you're always aware of the fact that there are real people behind the data points. But the first part of my academic career, you know, I really sat behind a computer and I analyzed data. And there was a lot of interesting information that came out of that. But what I realized is that we were then trying to see how that could influence patients. And I began to realize that instead of analyzing data and then presenting what we found, we really should be talking to patients upfront and having them help us think through how do we really ask important questions, and and then yes, it's important to collect data and analyze data. But if we're not asking the right questions, then the results of analysis really aren't going to have the impact that they could.

Charles Schelle: 3:56

Can you give us like an example of like how that works?

Daniel Mullins: 3:58

A lot of researchers will come to us and they'll say, we're having trouble getting people to come into our study, and can you help us find patients for this study? What we try to get them to realize is, what you should have done is you should have come to us two years ago when you were designing your study, because you're asking us to try to get people to participate in something that's not important to them. If we had changed your research so that it was meaningful to patients, you wouldn't be in the situation today. So how we're trying to change this is getting researchers to talk to us early bring patients in, not just as participants in a study, but really as co-designers framing the question so that it's important in the minds of patients, and then designing the study so that it's convenient for a patient to participate so that they understand what the research question is and what the research is going to answer. And that way we think that people will participate. They'll also be able to understand what we're learning because the question makes sense to them. So a solution that can help them to improve their health, their diabetes, their HIV, their cancer diagnosis, and survivorship journey. they'll be able to really understand how to take what we're learning and incorporate that into their lives, if they're part of designing research,

Dana Rampolla: 5:07

Getting their buy in early, because they'll feel like they have an ownership in the outcome

Daniel Mullins: 5:12

And not just buy in. But But what you need to understand about what this research is doing so that they see the importance of it first, because that's when the buy in happens. Exactly.

Dana Rampolla: 5:22

Gotcha, gotcha. Well, let's shift gears a little bit, how did the pandemic become a disrupter to the PATIENTS program? And how did you pivot?

Rodney Elliott: 5:30

Oh, man, multiple ways. You know, one of my roles as the engagement specialist is to literally engage go out into the community so that when the pandemic hit in March 2020, we first got word we were literally get ready to participate in a community event, BMore Healthy Expo, but we got the word that you know, something's not right, we need to fall back off that event. So post March 20, I couldn't be out in the community, our team couldn't be out at health fairs engaged in the community. That was challenging. But, you know, as far as projects are concerned, we do a lot of focus groups, things of that nature. And we do those in the community. We do those in the basements of churches, we do those in senior citizen, buildings, things of that nature. But we couldn't do that anymore. But we found a way to pivot, and we were able to be somewhat successful with focus groups, virtually, though, that was something that was very helpful as well. So you know, we still found a way to stay connected. took us a while to get there. But, um, it's something that we're doing now. And, excuse me, even post pandemic, I'm pretty sure we'll probably so consider that.

Dana Rampolla: 6:37

You know, that's good.

Daniel Mullins: 6:39

The early days of the pandemic, the challenge that we're facing is we knew that we needed to stay in touch with the community. When when research started opening up again, we knew that we wanted to continue to do research or doing focus groups using things like a zoom platform. But the community of West Baltimore had pockets where people, one might not have access to the internet. But even if they did, they weren't using Zoom. So how did you get on to, you know, Facebook or a phone and teach people how to use another platform, because, remember, in the early days, a lot of the platforms weren't HIPAA compliant. So we couldn't do research using some of the platforms. And we needed to be very aware to not just connect with the community, but to do it in a way that was following policies and regulations.

Dana Rampolla: 7:21

So now your community based work in partnership is building to something much bigger. Tell us about the new initiative between patient Mount Lebanon Church and CVS Health.

Daniel Mullins: 7:30

This is incredibly exciting. You, you can imagine, as a researcher that we think we have all these important questions, but a lot of our questions in the PATIENTS program actually come from our community partners, and in particular, the leaders whom we work with the senior pastor of Mount Lebanon Baptist Church, Pastor Frank Lance. He's been wanting to expand their community outreach. He's been working with CVS Health, as the School of Pharmacy has been working with CVS Health, they convince CVS Health to use CVS dollars, to refurbish a significant portion of the basement of their church to be a job training program for pharmacy technicians that's very much aligned with the School of Pharmacy, right. And so what we thought was that this is a great opportunity to bring together what the community says they want, which is jobs training, with an opportunity to talk about health and health related research. The initiative that we're doing is looking at how if this partnership of CVS Health in the basement of Mount Lebanon Baptist Church working with the PATIENTS program at University of Maryland, Baltimore, if that partnership had been in place, when the COVID-19 pandemic started, we would have been prepared to work with the community at the beginning of the pandemic. And so our current initiative funded by the National Institute of Minority Health and Health Disparities at the NIH is looking at how do you develop that kind of authentic community academic partnership, so that the next time a pandemic hits we'll be prepared to deal with it in an even better way? Wow.

Dana Rampolla: 8:54

That's incredible. That's incredible. Oh, my gosh.

Charles Schelle: 8:58

So how do you think then, I guess post pandemic this can be utilized?

Daniel Mullins: 9:03

Well, we were really excited. We believe that CVS is such a large company, that when we demonstrate because in my mind, there's no doubt we'll demonstrate the success of this model. You could scale that to every rural part of America, every other city in America. And there's a lot of community based pharmacies that could be partnering with lots of community institutions, not just churches, but other institutions. And we can bring the idea of health and what the community wants in West Baltimore, it's jobs and other communities, maybe something else, but bringing together what the community wants, and our ability to educate and provide health care in those communities together, so that the community sees us as a partner. Then when we're trying to do research to improve health, people are going to want to partner with us because they've seen us help their communities, right,

Dana Rampolla: 9:51

The relationships they're established, trusted. Exactly. And this speaks obviously to Dr. Jarrell's initiatives for the university his commitments to not just the city and the people just adjacent to the university, but Maryland as a whole. So really exciting, exciting stuff. What difference do you think patients is making in the communities with these programs like on a day to day tangible level?

Rodney Elliott: 10:15

Day to day tangible level, I think when I first started going out into the community, a couple of years ago, I would go out and, you know, have a button up shirt, and I got my jeans and slacks on and a clipboard in my hand. And you know, I would get a little bit of tension. But then, when I realized that, you know, I'm talking about a project or talking about the patient's program, and I mentioned the R word, which is research, I can immediately see people kind of, you know, tense up a little bit, you know, but when I started going out into the community, and meeting the community, where they are at a local health fair at a recreation center, where, for example, a senior senior home center where I did a project that was in between food giveaway, and in between bingo, the senior care coordinator said you need to come in here to shower but you better wrap up right before bingo, because the seniors don't play about that bingo. But it was because I came out there and have my shirt on. And I'm talking to them and ask them how they are the institution, the project and the program. And we don't force our information on anyone, but we just make it readily available. So just being being out there out in the community. You know, I'm one of three at the engagement team, four in the engagement team. And we find ourselves out in the community all the time. And we're excited about getting back out into the community, not only just for projects, but again, just for educating them on the importance of you know, having a seat at the table when it comes to research.

Jena Frick: 11:33

Right. One of the places that you do this community outreach is in barber shops, right? Yeah, yeah, I remember you all talking about that. It was oh my god years ago at like, some MPower event where you were presenting about, like your different research, and it was particularly the barber shop program. And I was like, wow, that's really cool. And what a great way to reach like a very specific demographic that maybe is not into research and and being a part of that. So that's really

Rodney Elliott: 11:57

It's just that literally going to the barbershop. I mean, when you go to the barber shop, that's where you talk about everything sports, you talk about what's going on, you know, current events, things in nature, so why not talk about health, you know, those topics do come up. And I forget where I was, after that project. In the barber shop, I was somewhere someone recognized me and they said, Hey, are you Rodney Elliott from the PATIENTS program? I said, Yes, I am. And he said, um, you know, because you stopped at the barber shop, I went home and I spoke to my husband, I told him to make sure he get a health checkup. And he wound up finding a small lump. It was rare because it was breast cancer, I think for for a male or something like that. And it was really profound, because she heard overheard the conversation in the barbershop and heard us talking about how important it is for men, African American men, particularly, to go get checked out. And, you know, things worked out for my situation, and his little tidbits like that, that kind of let me know that the work that we're doing, I'm doing out in the community impacts our community, you know, beyond the projects, just sometimes just something just as simple as just having a conversation that was all about having a conversation.

Daniel Mullins: 13:10

I also think, too, that, you know, we talk a lot about bringing the voices of patients into a university setting or into our research. And for a lot of people, they might have been asked questions in the context of research before, but there wasn't a sense that their opinion really mattered. I think the difference between kind of a traditional research program and ours is that we have some patients who are actually advisors or co-developers of the research, and those individuals are really helping us to think through how to phrase things, how to implement our research, our recent project on COVID-19, with the FDA was helping them to understand how they could enhance their communications early on during the pandemic, when it was about testing. Remember, back when you couldn't find testing? Nothing was available at that point? And then how do we talk about testing, as testing comes out for people to understand that what they were saying could help a federal agency to enhance their communication so that people would have better information and be able to understand that's a really empowering experience for an individual to think that their voice can have that kind of an impact. And as we were completing that project, we saw a new form of testing come out. So you see what we learned in those early focus groups that we did with community members comes up again, because now we're going to be in a similar situation, right? What is the difference between a home test and a test that I get at, for instance, a clinic and how do I know which test to believe if two different tests say the opposite one says I'm negative one, since I'm positive? How

do we how do we make sure that agencies like the Food and Drug Administration have what they need so that they can communicate with the general public in a way that helps people to make really informed decisions? And that's what, that's what healthcare research should be about. Right? Right.

Charles Schelle: 14:47

It's just kind of amazing, like all the stuff that we've been working on to kind of communicate with the campus population with some of this and it's like, oh, we're actually doing that here on the front lines with PATIENTS programs of telling people this is what you need to tell people to understand the differences between these tests.

Daniel Mullins: 15:05

But I think one of the things, Dejuan Patterson is one of the community partners who's an advisor on that project. And he talks a lot about that he was willing to help us do this project, and that the point of that project was supposed to be to make sure that when we phrased our questions, that the committee would understand that, that there was nothing racially insensitive that that, that people would feel comfortable sharing their views. But you know, then you go home at night, and you talk with your family. And he talks about how his grandmother, who was very hesitant about, you know, a lot of things related to COVID, eventually became almost an advocate for getting people into testing for getting people into treatment, if they get a diagnosis. And that had, you know, nothing per se to do with our study. But but when you're involved in a study, and you have conversations, suddenly you go home, and what you're doing impacts what your family thinking about, right. And so when you're trying to change people's perceptions about research and, and health related decision making, sometimes it's just that it's that because of an experience in a research study, people are thinking more about how to be healthy and how to make healthy choices.

Rodney Elliott: 16:09

Right? Yeah, that that that popped up. Another project I worked on, was in a focus group where we had to first time virtual focus group seniors at a senior home here in West Baltimore. And prior to the focus group, I talked to them over the phone and help them navigate how to get on Zoom, which was a challenge to get it. And then they found out they literally lived in the same building, they didn't know that, originally, it's funny to add to the focus group a call back just for another opportunity. And they mentioned that they started actual, during the pandemic, they started a virtual kind of just talk session on social media, on Zoom with other residents in the building. Because back then, you know, we were told to stay home and isolate a lot of things people don't realize, like when you isolate that also go to social isolation. And a lot of the older adults seeing just kind of dealt with that and not being able to go out for their normal walk, they weren't inviting their family members up things in nature. So that helped him out a lot to still be able to communicate with each other in the same building, virtually in a safe space.

Charles Schelle: 17:12

Shifting gears now to to national level, you do a lot of work to build health equity, in all sorts of spaces. So what's the dynamic then of doing this on a national level, and building trust in pockets of like rural America?

Daniel Mullins: 17:27

The interesting thing is when you talk to groups that typically don't participate in research. It's all about trust, right? And so that populations may may be different, kind of the specific issue may be different. But eventually you're going to get to the word trust. And and what we believe is that we're learning how you can build trust. But that that means being very respectful as you enter a community to make sure that the community leaders know that you're entering their their community, right, I think it's a mistake that researchers make, sometimes they just literally walk into community thinking that that community is going to want to participate. They don't keep people informed. And so we don't have good relationships sometimes then with the community leaders, because those are the people that get asked questions, right? We know this from health care. If you go into a community clinic, and you have a physician refer one of their patients into a study, and that physician doesn't know what the study is about. When the patient goes back to their primary care provider, the primary care provider is not going to be excited about recommending a patient to research in the future. If we don't keep that community provider informed. Well, the same thing is true with the pastor of the church, or any other community leader, if they don't know what we're doing, they're going to get questions that they can't answer. And they're going to be less likely to refer people into a study at University, Maryland, Baltimore, right? In contrast, if they do know what we're doing, and they see how it could make their community healthier, then they're going to help us to convince people that you might want to talk with this group, because they're doing something that maybe won't have a direct benefit to today, but can help our community to be healthier in

Charles Schelle: 19:01

And it goes back to that concept that you the future. described on your website of you don't want to continue that helicopter experience, right? Of researchers coming in and, and work communications folks, we hear a lot about national media, doing the same thing with national news stories of they helicopter in, get the story and come out. And so it was interesting to learn how research for time being was being done the same way, and

Daniel Mullins: 19:29

It still is in a lot of places.

Rodney Elliott: 19:30

It still is. And that was the concept I mentioned to you earlier about me, you know, lab coat, clipboard going into the communities, you know, saying oh word yet that is not, that's not you know, the community that we serve. That's a faster way to get a rejection, more than even not even rejection, which is obviously a closed ear and a closed heart. You know, when you find a way to get into these communities, and my biggest thing is I just want to, you know, present them with opportunities and give them information so they can make an educated decision in their choice. Right. So that's the major thing so when we see helicopters here in Baltimore fly around and downtown area, we kind of know what's going on they surveying and seeing what's going on seeing where they can get in research, that doesn't work, you can't swoop in and get what you need and get back out of that. That's what I was talking about. Program started come to us in the beginning, so we can help form it, we can help shape it, you know, and that goes, again, from beginning all the way to the end.

Charles Schelle: 20:23

So back here at home, you have a new \$250,000 award from the Patient Centered Outcomes Research Institute to work with the Southwest Partnership. What does that grant work involve?

Daniel Mullins: 20:34

This is a, a contract with the Patient Centered Outcomes Research Institute, to build the capacity to do research in the future. So it's not a research study in itself. It's called an engagement award. And the idea is for the University of Maryland, Baltimore's PATIENTS programs staff to work with the Southwest Partnership, and over a two year period to figure out how could these two groups work together on future research. I give a lot of credit to PCORI, for giving this type of funding to really build an infrastructure to do research in the future. And I think that's why we've been successful. We don't start by knocking on someone's doors and asking them to start today, on a research study, we go we knock on the door to say, in the future, we're going to want to work on a research project with you. Let's talk about what would you be interested in working with us on? How do you want us to approach you? And then how do you want us to approach the community that you represent? Right? It's building those relationships and, and this new award is called Co-Driven. It's because the future agenda will be co-driven by the Southwest Partnership, and the University of Maryland, Baltimore.

Charles Schelle: 21:43

Hhmm. Wise. So I was reading up on it on your website. And it mentions there's going to be a stakeholder advisory board. Is that right? And that there are flashcards involved. So tell me about that this flashcard method.

Daniel Mullins: 21:59

Right. So first, yes, there's an advisory board and the advisory board members are chosen by the Southwest Partnership. That's another thing that we do as we ask our community partners to decide who do you think we should be inviting to our sessions? The flashcards come from a prior PCORI award that that developed this idea of when you ask people, How do you think we should engage your community? They may not understand the question. And so we've come up with flashcards, and they have different ways of engaging people. We all know that we get surveys, right? So you know whether to ask people to fill out a survey, that's one way that you can engage people. Another is to hold a town hall meeting. Another is to actually do an individual interview or a focus group. And there are a bunch of these different methods. Another is social media, right. And so the idea is giving them flashcards so that even people with low literacy levels can look at the picture, know what this is, and then say pick up the flashcard that for this study, you think is the best way to engage patients and tell us why. So we're having them, not just tell us how to do research, but how to engage people who are going to then be involved in the research. And we think that type of interactive play with our community partners will make it more enjoyable for them to help us design our research studies together.

Charles Schelle: 23:13

Yeah, that's very inventive. And I can't wait to see how that shakes out here. You know, all this is about building trust. As you mentioned, that's, that's the common theme here. And you really want a two-way street of communicating. But you also need advocates. So you have this PATIENTS Professors Academy being developed for both patients and researchers. Tell us a little bit about that.

Daniel Mullins: 23:32

The PATIENTS Professors Academy really is in response to the fact that we have so many government agencies, so many universities, so many other groups asking us to come and share how we're doing what we're doing. And it got to the point where we couldn't keep up with those requests. So we thought instead of are flying around the country, doing individual training

programs for people, why don't we invite a large group of individuals to come to the University of Maryland, Baltimore, and participate in a session in which over a six week period, they will learn how to do something. Of course, we've now all learned how to do training using virtual platforms. So most of the six weeks people will be learning using platforms like Zoom. But the idea is to go through our 10 step framework for continuous patient and stakeholder engagement and really teach people things like how do you build that type of partnership that we have with Mount Lebanon, Baptist Church and CVS Health? How do you form an advisory board? Have community members and other stakeholders for a research project? How do you make sure that you're addressing health equity when you're designing your study, and then we teach them like how do you make sure that your recruitment is something that people will buy into right? And so we go through over the six weeks from health equity, the beginning as the target to then how do we make that happen in very pragmatic ways, then a lot of its interactive. The idea of the academy is that we have these amazing patients who have taught us so much about how to do research. And so those who have been on this journey with us for five or 10 years, we call them patients, professors, because they teach us how to do research with their communities. And so one of these patients, professors, and one of our researchers, will co present how we've been doing things, and then give about 175 people an opportunity to practice how they would do that when they go back home to whatever part of the country they live in.

Charles Schelle: 25:28

And this has some weight behind it, because you have Bayer AstraZeneca, Novartis and some private donations, how big is this? And when will it start?

Daniel Mullins: 25:37

It will start in July, we currently have seven major donors, our our target is a million dollars for this. And we are about three quarters of the way to our funding, we still have a couple others that have given us verbal commitments. So we're very confident that we'll have that. Yes, our sponsors include pharmaceutical companies like Novartis, Bayer, Lilly, JanssenJ&J Pharma, and but it also will include we believe other groups, like from the insurance industry, or from the banking industry. So any of the groups that understand about holistic health, and that's not just physical health and mental health, but spiritual health, working with the, with the religious groups that we work with. And then also financial health, because if people don't have the finances, to afford what they need to be healthy, they're not going to be healthy. And bringing all of those four pillars of health, physical health, financial health, spiritual health and mental health together in one in one training academy, and teaching people how to partner, we believe that that will then take what we're doing here in Baltimore, and allow it to spread across the nation.

Charles Schelle: 26:40

And how many students do you think you'll have in this first cohort?

Daniel Mullins: 26:45

We expect to have 150 to 175. We're reserving 50 for actual patients, or care providers, right. So perhaps the child or the spouse, of someone with a condition, and those will be from around the world. We also have people from the life sciences industry, so pharmaceutical companies, device companies, those who pay for care, so insurance companies, but also large corporations that self insure government agencies, and not just the federal agencies, like the Food and Drug Administration, or the National Institute of Health, but but local agencies, right. So thinking about local government agencies, not just here in Baltimore, but you know, in some rural areas of our country where they're setting policies that affect people's health, and then a variety of community health care providers, but also other community leaders who we know influence health. And what's really unique about the PATIENTS Professors Academy is that all of those types of quote, students will be learning together, right? So we're not going to have a breakout room for patients and a separate one for researchers or providers. Everybody comes together, because that's how we believe research should be done smart. Right.

Dana Rampolla: 27:53

And so is it completely underwritten, then by these different entities, so there's no fee for the participants?

Daniel Mullins: 28:00

At least in the inaugural year, there will be no cost for quote, tuition to come into the academy, it will be free for everybody. And fortunately, our funding for the first year includes travel stipends for anyone who needs it. So we earmark that not just for the 50 patients who will be coming. But there could be people from a local government agency that really just don't have a travel budget. We want those individuals to be able to come to Baltimore as well. Yeah.

Charles Schelle: 28:25

Well, we will make sure to post a donation link in our episode description.

Jena Frick: 28:31

Yeah, so this starts in July. Oh, wow. It's coming up very soon. That's really exciting. Obviously, you guys do a lot of work engaging all different types of people from all walks of life, all different backgrounds. And Rodney, you specifically, do some real talk on Facebook Live with your program, real talk? Can you tell us a little bit about that and the topics that you cover?

Rodney Elliott: 28:58

Oh, man, that was one of our pandemic pivots. You know, I see you guys here on your pandemic pivot. Lovely joining you guys. But right, you know, we couldn't go out in the community, I couldn't go out. So we found a way to still stay connected with our community, keep them updated on what the patient's program is doing, what our project was doing in the community members who was working with the project who's working on it. And it's also a way to stay engaged, live. So we have a couple bullet point questions we want to talk about during the conversation, but we also engage with the community members who watch us so our viewership actually grown since pandemic started. I think when we started a doubled so we started in March 20. And we had to 243 members on our social media platform. As of March 2, we got 431 Wow. So that was an opportunity for us to share the word share we'll be going on and also talk about the PATIENTS the (Patients Professors Academy) PPA, you know, talk about the CO-Driven projects, right and we've we've had everyone from Pastor Lance has been on our show before we've had the President Bruce Jarrell was on our show, as well. And you know, again, we've had community members who participate in some of our focus groups, right? Because we want to find a way to still stay connected with everyone. And social media is a platform that we're all using right now. It was new to the patience program, but it's been an awesome tool. Plus to spread the word.

Jena Frick: 30:23

Yeah. So it's called Real talk. You do it on Facebook Live? When does it air? When can people tune in?

Rodney Elliott: 30:28

Well, it's actually Real Talk with Rodney and we also have BJs Corner. BJ Shaneman is working with the PATIENTS programs, she is another engagement specialist. She has over 40 plus years of experience. So it's every other Thursday at 12, o'clock, noon, right on our Facebook Live page.

Jena Frick: 30:43

Awesome. And do you have a little tease of anything you have lined up coming up in the spring that people can look forward to on that?

Rodney Elliott: 30:48

Yes, we'll have a bunch of topics about the projects we're working on, we're also going to be talking about the PATIENTS Professors Academy. So we'll have some of our guests on there talking about their participation, but also some of the actual patient professors that we have currently, with the PATIENTS program. So it's exciting platform for us, I'm always excited about the engagement, because you just never know what you're going to get from some of that some of the questions that we have. But again, it's a way to stay connected in a safe way as well, because you know, as things are starting to open up and getting back to what the new norm is, folks still like to still stay safe in their home or safe in their devices. So stay connected to the community, during our Facebook Live session with Real talk with Rodney and BJs Corner is something that patients program is proud of.

Jena Frick: 31:33

Awesome. So everyone definitely tune in, as we said every other Thursday to

Rodney Elliott: 31:37

Thursday at 12 o'clock.

Jena Frick: 31:39

Great. Two years ago, you all had your first Community Research Jam, can you tell us a little bit about what that is. And if you're maybe planning another one in the future?

Daniel Mullins: 31:49

The PATIENTS program is quite involved in Institute for Clinical and Translational Research. In particular, in the Community Collaboration Core. That's the core that supports community engaged research. Two years ago, we held a session in which we thought about doing something like a dolphin tank of of having a session where researchers could somewhat present to community members and get some feedback, where the prize would be improved research as opposed to you know, some of the shows that do this where there's a financial prize. We thought more and more about that. And we brought our community leaders back and ask them how to do this differently. They came up with the revised version of it, which is a Community Think Tank on research, a community think tank on research. The idea here is that they -- the community leaders -- are the think tank members. They're the ones that really understand how you could do research in their communities. And so you as a researcher can apply for a spot to come in to present to the community think tank on the research that you're doing. And in the first six months of this, which is under an NHLBI award that's between five universities. So Johns Hopkins is the lead. Morgan State here in Baltimore, along with University of Maryland, Baltimore, and then down in DC, we've got Howard University and George Washington University are part of this is introducing the community think tank on research, in which the members of the think tank came up with what they call the rules of engagement. If as a researcher, you want to come and meet with us, here's how you will have to come into our think tank. The next thing they did is they came up with this slide set template. And they tell you, you can only present these six slides, you fill in the slides. But we don't want 25 or 30 slides the way he researchers normally come and talk with us. These six slides give us everything that we know so that we could give you advice. And then when it's over, the researcher doesn't get to ask the community members questions. The think tank asks the researchers questions so that then they can give you advice on how to change your research to make it more patient centered and community centered. I think it's a really cool concept. Yeah,

Charles Schelle: 33:57

Cecause you hear so many times of communities especially more so with like businesses like I wish they would ask permission to come into the community and everything. And so you hear the same with research. So now they have a bit of ownership and control over it. So when when is this starting or how far along is this?

Daniel Mullins: 34:14

We we are finishing our first year and we're keeping our fingers crossed, we expect that NHLBI will fund us for a second year. Again, our contribution is the community think tank on research. There's a lot of other programs. So Morgan is doing an ambassador training program for community ambassadors and the other three universities are doing other things. We fully expect that this will continue and the exciting thing about the committee Think Tank and research is in the second year. We're going to be using our funding to open it up so that researchers from Morgan or Johns Hopkins or George Washington or Howard can come into the University of Maryland Baltimore's community think tank so that those researchers can benefit from the structure that our community leaders have developed.

Charles Schelle: 34:55

Great to hear. We talk so much about COVID research, but you do a lot of other things too. Can you give us a little bit of a tease about some other areas of research that that you're helping with that's not COVID?

Daniel Mullins: 35:06

One of the things that we heard really early on during the pandemic was that although COVID is a devastating condition, that the impact on health disparities is similar to in other diseases, and many of our community members said that devastating is this is that covenanting is not the only condition that is creating disparities in health status across America. Right. And so what we're learning with COVID-19 research, hopefully will not only help us to think about health equity for COVID. But how do we really advance health equity across the major killers because if COVID goes away, people are still going to be dying of heart disease, they're still going to be dying of cancer, right? They're still going to be dying of complications of diabetes. And we have such great disparities in those conditions, we need to really understand how to advance health equity, not to do it just disease by disease. But how do we advance the concept of using research to improve the health of the nation across all the different communities that are represented in America.

Rodney Elliott: 36:06

I mean, we are the projects working on with the National, the NIH National Institute of Aging, where we're looking at older adults who could be interested in participating in future research projects where we're signing them up into research registry. So other entities such as PATIENTS program can reach out to them other trusted entities can reach out to them and have them get an opportunity to participate, not the opportunity for older adults who may have some memory challenges, we have opportunities for them to come and share their experiences, our projects vary, but all of them still have the same concept. As far as meeting the community where they are, again, you know, we're doing a lot of some virtually right now, hopefully, I'll be excited to get back out into those communities, we can do it in person.

Jena Frick: 36:50

So you have a thing called Patients Day coming up, tell us what that's all about what it is?

Rodney Elliott: 36:54

Yes, August 16, right here at the Community Engagement Center, from 10 to 2, we're going to be a free event where we bring the community members and research community together a day where we talk about the projects that we have gone on, we also provide a health fair for the community members to have some tangible resources, and it's a free event is opportunity for the community members that talk to us have an opportunity to learn as much as possible as they want.

Jena Frick: 37:18

And that will be here in the UMB community engagement center. Yes, that will be here at 16 South Poppleton Street.

Dana Rampolla: 37:25

Well, before we let you go, we really should mention some congratulations to you guys for winning the Reverend Dr. Martin Luther King, Jr. Diversity Recognition Award this year here at UMB.

Rodney Elliott: 37:36

Yeah that was awesome. That was awesome recognition. I mean, the models kind of kept that on, he kept it on the low fours, it is quiet, we didn't know about it. But again, that just shows that our work out in the communities, you know, being represented by the community we serve, you know, we say that a lot about bridging the gap and the community we serve, but to be recognized, when war like that speaks a lot to the staff here at the PATIENTS program documents and all this effort from the very beginning. You know, he's been very, you know, engaged with the community. There's a lot of stories about not the most I heard before I got here about him literally being out in the community helping with the health fair. You know, you don't hear that a lot about when you have, you know, CEOs or folks who are, you know, leaders in their projects, but, you know, he's always been a hands on type person. And that's indicative of, of the PATIENTS program as a whole

Jena Frick: 38:29

That helps build trust, right, you want to put a face to to who's doing the work and who's organizing things

Rodney Elliott: 38:34

that was all about building trust, yeah,

Charles Schelle: 38:37

And really sustaining right and speaks to your overall mission of building health equity, which is fantastic. So So kudos, and congratulations again. And if you want to learn more about the PATIENTS program and listen to Real Talk with Rodney, or BJs Corner, visit [facebook.com/patients program](https://facebook.com/patients-program). For a link to the program website or to donate, visit our episode description or go to umaryland.edu/pulse. So thank you again to Daniel Mullins and Rodney Elliott, and good luck to you for the rest of the year.

Daniel Mullins: 39:10

Thanks very much.

Rodney Elliott: 39:11

Thank you for having us.

Charles Schelle: 39:13

Our next change maker on the Pulse will be School of Medicine Professor of Pediatrics, Dr. Karen Kotloff. We will talk about her research and all for upcoming projects that you may not know about including work with the Bill and Melinda Gates Foundation. It will drop on the first Friday of May May 6.

Jena Frick: 39:28

We really hope that you're enjoying the new season and format so far, so please subscribe to us on Apple podcasts or wherever you're listening. And if you have any questions for us or our guests next month, visit us at maryland.edu/pulse and drop us a line.

Dana Rampolla: 39:42

So thanks again to the patients program and thank you for listening to the UMB Pulse

Jena Frick: 39:52

The UMB Pulse with Charles Schelle, Dana Rampolla and Jena Frick is a UMB Office of Communications and Public Affairs production. Edited by Charles Schelle, sound engineering by Jena Frick, marketing by Dana Rampolla Music by No Vibe. Recorded in the University of Maryland Baltimore Community Engagement Center.

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