Corey Andrew Powell ([00:02](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Hello everyone. I am Corey Andrew Powell. And in today's episode of Motivational Mondays, we are thrilled to introduce a remarkable individual whose dedication to improving the lives of patients and caregivers is truly inspiring. So, joining us today is Pam Cusick, a seasoned research professional with over 30 years of experience in study design, implementation, and analysis. Now, Pam's journey is deeply rooted in her background of public health, communications and research where her passion for patient advocacy shines through in all that she does. So, Pam, welcome to Motivation on Mondays.

Pam Cusick ([00:35](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Thank you so much for having me. I'm excited to be here.

Corey Andrew Powell ([00:37](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Thank you. Thank you. We're happy you're here. And, um, as I mentioned to you a little, uh, before we started recording here, that, um, the caregiver thing for me is I think something that a lot of people may go through as they watch their parents get older, and even like a double dynamic of watching if your parent is a caregiver. So you're watching your parent get older while they're taking care of a parent, getting older, who are your grandparents. I mean, it's really pervasive in our society. So what I wanna just first tell you is that I love that you're giving the caregivers a voice because I really feel, and correct me if I'm wrong, I feel like that segment of healthcare is not necessarily at the forefront very often to hear from those who are in those positions. Expand on that. What do you think?

Pam Cusick ([01:23](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Sure. So I think sometimes, um, the caregiver knows more than the patient does. You know, they, they are dealing with, you know, ordering medications, setting up appointments, dealing with the day to day if the patient can't really manage things on their own. So it becomes, um, they're the surrogate for the patient. So getting their input into research, into the design of products and services is really essential because they have that information that the patient often doesn't maybe even see or know that part of it.

Corey Andrew Powell ([01:56](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Yeah, yeah. And very often too, um, it's, it's interesting around when I watched my mother, for example, be a caregiver for two people at once, um, and she did it like around the clock. And I would say, mom, you know, like even like a professional caregiver gets like a weekend <laugh>, like they like the day the day ends at the after eight hour shift. Right. They get to go home.

Pam Cusick ([02:18](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Right.

Corey Andrew Powell ([02:18](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

But, you know, for family who's caregiving up, I think people don't also realize that, you know, in many cases it is just literally a, a round, uh, the clock thing. So I just love that you're, you know, given a voice to that. Um, yeah, it's,

Pam Cusick ([02:31](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

It's exhausting. It's exhausting. It's, um, it is round the clock. And I think that's the thing that, you know, when you're paying for a caregiving service, they come in at a certain time and they leave and with, you know, a parent, like my dad was the caregiver for my mom, and it was 10 or more years of around the clock kind of planning what, you know, and he loved my mom and wanted to take care of her. But it's a lot on a person. And I think when you're in it, you don't always see the toll it's taking on you and the exhaustion and just the mental difficulty of, of seeing your loved one in a situation like that.

Corey Andrew Powell ([03:10](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm. <affirmative>.

Pam Cusick ([03:10](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

And trying to care for them while still doing whatever else you're doing around your home. It's a lot. And I don't think that people see that and, and or get the support for it that they really need.

Corey Andrew Powell ([03:22](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Yeah. I many don't know where to even go. I mean, I, I looked at a lot of, uh, online information. It's very confusing. Uh, you don't know where to turn. Um, I got lucky where there was a, a lovely woman who began to follow the podcast and she reached out to me on LinkedIn. My name is Dr. Hickman, and she had written a book about her own experience as a caregiver.

Pam Cusick ([03:40](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Wow.

Corey Andrew Powell ([03:41](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

And it was interesting because, you know, there are these things that we don't think about with, you know, uh, when it comes to, um, a health proxy or, you know, just all these things that, you know, as an aging society that we have to Definitely, I encourage everyone, and even if you think you're too young to know these things, just realize we're all gonna get older eventually <laugh>. So the earlier you put those ducks in a row, the better off.

Pam Cusick ([04:03](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Right.

Corey Andrew Powell ([04:04](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

You're gonna be for sure. Yeah. Well, let me ask you, uh, so that's one aspect of course, of, of the work you do. But I am curious to know, just in general, because y your work is as a patient advocate and, um, I guess more of an in the, in, in, in the rare disease area. So I'm just curious for you personally, uh, with that as a, as a current career, uh, what was a pivotal moment for you that led you to this path?

Pam Cusick ([04:31](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

So, um, in our, our advocacy is really around helping patients share their voices. So through research, um, so my, my path is really as a public health researcher and, and then I got into pharmaceutical research around patients and getting information to them that was, um, in, in a format they understood and something that spoke to them, and something that helped them to make decisions. And that led me to, you know, down the line to this, um, this organization where really what we are as a matchmaker. So we go to events, we'll go to the National Hemophilia Foundation Conference or National Sickle Cell Conference, meet patients, meet their caregivers, explain what type of research they could be involved in. And that's everything from surveys and focus groups and interviews all the way through clinical research. And they join our community. They never have to participate in anything.

Pam Cusick ([05:31](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

They just, if they join, um, we'll invite them to participate in studies, but, um, if they do, they earn $120 an hour except for clinical research where you're not paid for your time. But mm-Hmm. <affirmative>, it's really a, um, a wonderful way for them to share their, their journey and their experience with a, a seasoned researcher who understands their disease, understands what they're going through, and then can share that with companies developing products and services. So our, our advocacy, if you know, in that using that term, is really kind of making sure that we find all those opportunities for patients to, and caregivers to share their experience and to share what they have learned, um, through their diagnosis or through being a caregiver to help, uh, to help companies to develop those products and services to make life a little better for them.

Corey Andrew Powell ([06:24](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Hmm. That's wonderful. And I, of course, you have your graphic there behind you, uh, on the screen, but we should, I should note that the company is called Rare Patient Voice again. And that is the, the organization that does this, right? That you're, that, that you, you are the founder of the organization and

Pam Cusick ([06:42](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

No, no, my colleague, um, Wes Michael founded the company in 2013.

Corey Andrew Powell ([06:47](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Okay.

Pam Cusick ([06:47](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

And I came on board a little more than seven years ago. So he and I had worked in a, an organization 25 or so years ago that was a pharmaceutical market research company, and we worked in the patient, kind of consumer area where Yeah. Um, there was kind of a growth in that industry and, and hearing the patient's voice and, and that patient centricity, um, was needed. And so we worked together there. And during that time, kind of, he came up with the idea that, you know, there was really no organization that was specifically recruiting patients for research, and we would have, you know, very complicated, you know, patient recruiting, uh, or projects that we were working on. And it was hard to find the patient. So eventually it became the right time, and he started the organization and I said, Hey, let me know when you need somebody. And so he eventually did, and now we're back working together.

Corey Andrew Powell ([07:41](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Yeah. That's super. And I love from the leadership standpoint, one, one of the things that we always talk about here at the NSLS to young college students, or even non-traditional students or, or professionals out in the working world, is that very often the greatest opportunities are where you find there is an opportunity, right? There's something that's not being serviced, or there's some area or a demographic that's not pro provided with, um, a need. And so I know there's a, a part of your work also deals with, uh, underrepresented communities. So I am wondering, like, do you find that in that particular segment of the business, there's even, uh, less or fewer opportunities for people in underrepresented communities to be heard? So there's like a disparity, or is it equal that no one's listening to anybody <laugh>, and so you had to kind of help <laugh> help help everybody across the board? Or is it a little bit of both? I don't know, <laugh>,

Pam Cusick ([08:34](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Uh, well, it, it, it kind of depends. So yeah, we need to help everybody be able to share their voice and be heard. Um, and more and more organizations are, are looking to do that. So that's a positive. In terms of, you know, underrepresented communities, there are certainly, um, you know, different feelings about research in, in specific communities. There's a bit of distrust among, you know, some, some groups that interesting thing. We have the, we have a lot of women who are great at responding. Men are not as great at responding to, uh, research requests. I don't know if they, they sign up, but they're not as excited to participate or don't really want to, you know, get to the touchy feely of their why and all that other stuff. I don't know <laugh>, but, um, I don't really have an answer for that. But they're not as, as, as, um, the response rate among men is not as, as great as it is among women, you know, for research.

Pam Cusick ([09:28](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Um, but, you know, we do endeavor to find people who are in underrepresented communities, and that's becoming a bigger ask. Um, when clients come to us, they will be looking for, you know, specific, um, subgroups of people within, you know, whatever the disease area is, pick one, you know, hemophilia, and they want to, you know, they wanna make sure that there are different, different genders represented, different ethnicities represented. And so we make, you know, an effort to identify those people who are already in our community. We have a hundred, I don't think I said this, 145,000 patients and caregivers who've signed up with us across 1500 conditions. So we do have, um, you know, a fairly good diversity. One of the areas that, um, that is not as well represented in research is the disability community. So, you know, ensuring that you include people with mobility issues, hearing loss, vision loss, chronic pain, all of these things, depending on the product or service you're creating impact people in a different way. And so getting the, the voice of those, um, different groups is also important. So there, there are a lot of different ways to kind of, I guess, parse the, the information and who you're trying to bring in.

Corey Andrew Powell ([10:53](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Yeah.

Pam Cusick ([10:54](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

But you have to be very intentional about it because if you just sort of throw out an invitation, um, you know, you'll get the people who respond most. So, you know, some women and, and <laugh>, you know, this is our experience. Right?

Corey Andrew Powell ([11:07](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Right.

Pam Cusick ([11:07](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

You know, but you might not find, um, you know, an older population or a younger pop, you know what I mean? It depends what you're looking for. Right. So you have to make the effort to, um, look for those, those patients and intentionally invite them in.

Corey Andrew Powell ([11:22](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm. <affirmative>.

Pam Cusick ([11:22](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

To be part of the research. And I think that's, um, becoming more of a, a, something that we are asked for more often now. Um, because there is a, a a, a light being shown on DEI and making sure that, you know, we are, you know, when we present research results or our clients do that, it has included different groups and different points of view.

Corey Andrew Powell ([11:47](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

You know, I'm really happy you brought up the DEI conversation, because obviously right now that's a really political, that's a big political hot point. And I mean, like within the last 24 to 48 hours, you know, there's been headlines about DE and I initiatives being completely dismantled across various organizations or universities. And I'm glad you brought up DE and I in your line of work because people are often forgetting that we're not talking about just race and ethnicity.

Pam Cusick ([12:14](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm. <affirmative>.

Corey Andrew Powell ([12:15](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

DEI is inclusivity of people with disabilities, you know, physical challenges and body limitations. And so to just broadly get rid of DEI is com, I said, I'm not gonna get political. But, uh, <laugh>, it's completely negligent though. It really is to, you know, because it, it's, it's not a broad stroke, it's a lot of things under that umbrella. So that was a little bit of a disconcerting thing to see that, you know, with the stroke of a pen, just no more de and I, I'm like, well, wait, there's a whole lot of stuff under that umbrella.

Pam Cusick ([12:47](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

It's interesting because while that is happening in some sectors, we are seeing an increase in the interest. And I just had two calls today, um, prior to our call, that we're focused on making sure that there is more inclusivity in clinical trials.

Corey Andrew Powell ([13:03](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm.

Pam Cusick ([13:04](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Okay. So, you know, there, you know, there are, there are efforts underway where they may be ending in some areas. It's really becoming a bigger, um, a bigger concern where we see our clients making an effort to identify and invite patients who are from different races, different, um, you know, socioeconomic groups, um, disability groups, making sure that those voices are included. Because, you know, when you look at a, a product that you're trying to bring to market, it's not just one subgroup that's gonna purchase it.

Corey Andrew Powell ([13:38](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm. <affirmative>.

Pam Cusick ([13:38](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

You wanna, you know, you wanna make sure your messaging appeals to people across a variety of groups, whether that be ethnicities, whether it be a disability, you know, every people have a different way of interpreting things. And you wanna make sure you're addressing that in a way that you're going to reach the broadest number of people. You're going to communicate effectively with them and invite them to use your product, test your product, buy your product, whatever it is.

Corey Andrew Powell ([14:05](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm. <affirmative>.

Pam Cusick ([14:06](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Um, but not including those voices in the early development and in the marketing of those things, you lose a whole sector.

Corey Andrew Powell ([14:14](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm.

Pam Cusick ([14:15](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

With, um, disabilities, as an example, 25% of the world's population has some sort of a disability.

Corey Andrew Powell ([14:22](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Hmm.

Pam Cusick ([14:22](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

That's 25% of people who could, you know, use your pro, use your product, buy your product, talk to their doctor about your, their whatever it is.

Corey Andrew Powell ([14:32](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Right.

Pam Cusick ([14:32](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Um, you know, so that's just, it's a big, a big number. And so when we exclude those people from anything, whether it be education as you were, you know, you were mentioning, or, um, you know, research in a, in a broad sense, you know, you're losing that opportunity to communicate with a larger group.

Corey Andrew Powell ([14:50](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm. Yeah. Um, and it would be like really anti-business if you were trying to sell something. I mean, it doesn't even make sense. It's like, I know we'll create this great product and only allow like 10% of the population to even use it.

Pam Cusick ([15:02](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Percent the people wants to buy it. Right.

Corey Andrew Powell ([15:03](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Right. That would make sense. Yeah, exactly. So also with that point being made too, one of the things that I became conscious of, um, maybe the second year I was doing the show, and I guess I'm going on like maybe my, maybe three years now of doing the show, but it became more important for me as well to bring voices on. We have people who had physical challenges or disabilities, and, um, so one of my favorite guests, a woman named, a young woman named Chelsea Bear, and Chelsea has, um, she was born with cerebral palsy, and she created this whole platform on Instagram, sort of inadvertent, like accidentally just kind of showing her day to day, uh you know, I go get Starbucks, like you, it may look a little different, I run, but it may look a little different. And if your kid, if you're Yeah, she tries to normalize what, you know, life is for her.

Corey Andrew Powell ([15:51](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

She's like, if your child looks at me and says, mommy, she walks funny, don't pull your kid away like, I'm a disease, just explain, you know, talk to me. And, um, so her numbers rose, I like astronomically on Instagram. So she's just really great advocate for just allowing people to, um, understand that we all have these different possibilities. But I, I brought her up to say, you mentioned that 25% of the population, she said something so profound I didn't really think of. She goes, Corey, I want you to also know that whether it be sickness or some other sort of maybe God forbidden accident or just natural aging, like at some point nearly everybody on the planet <laugh> at some point in their lives will be quote unquote disabled through some situation. So I think in sort of normalizing the fact that this is a, a, a typical possible body condition for humanity, it de it sort of, uh, demystifies, it makes it not so scary. And, uh, those efforts are so, so important. So I, I definitely commend you on that, and I'm glad you're saying that in that sector of the business, there's still a need and a request for it.

Pam Cusick ([17:01](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Right.

Corey Andrew Powell ([17:02](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Yeah. That's, that's really super. So let me ask you as well, when it comes to the sense of community, uh, or, or I guess if there's a correlation between, uh, community and a, a connection between like empowering patients to share their own experiences for the sake of doing it, not just to have buried bearing their grievance, but is it empowering to say to them, listen, you know, you're being a part of a bigger thing that is going to help people. Is that sort of what is a bigger driver and people wanting to share? You think?

Pam Cusick ([17:33](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

It's really very cool. So, um, I think I mentioned that we go out to events, we'll go to the, these different conferences where we meet patients and caregivers. We set up our booth and, and people come up and say, oh, what do you do? And we'll explain. And a lot of times people will say like, well, why would anyone wanna hear from me about my disease?

Corey Andrew Powell ([17:51](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Hmm.

Pam Cusick ([17:52](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

And then I'll say, well, you're the expert. You live with this every day. You know, more than in some cases your doctor might know. You know, you're 24 7 with this condition, and they get a little crap. And, you know, they're like, oh yeah, I am the expert. And, you know, then when they go and they talk to a, a moderator, someone who's doing an interview, a focus group, and that person is, you know, kind of asking them about, you know, details about their journey and what they experience every day, it's very like, therapeutic and motivating.

Pam Cusick ([18:26](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

And I, I, there was one woman who, um, we worked with for some time, and, and she was a, she had participated in a number of different studies, but when she, and I didn't realize this, it, she was interviewed a, a publication that, um, we work with called Rare Revolution Magazine. And they did an interview with me, and then they wanted to talk to a patient who had participated. So they did an interview separately with her. I didn't know what she was gonna say. And what she said was that before she started doing research, she really didn't like, I guess, feel like she was an expert in, in, I guess in her disease. And, and she, by doing this and sharing her story and being part of the research community, she like found her voice and that then she, you know, started working in advocacy and some other things.

Pam Cusick ([19:17](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

And it was, it was really gratifying to hear that, you know, doing this one thing we're, we're a matchmaker. Right. We connect patients with these opportunities. I'm not doing the research myself, but by being part of our community, it helped her to find her voice in a place, which I thought was very cool. Yeah. And I think that story is probably a lot more common because when you have a medical condition that you're living with, you might not wanna talk about it all the time with your family.

Corey Andrew Powell ([19:48](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm. <affirmative>.

Pam Cusick ([19:48](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Like, they already heard your story, they know it. You don't wanna burden them in some cases or worry them. But then you get to talk to this moderator or researcher who is asking all these questions, and it's like a waterfall.

Corey Andrew Powell ([20:02](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm.

Pam Cusick ([20:02](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Of information comes out.

Corey Andrew Powell ([20:04](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Yeah.

Pam Cusick ([20:05](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

That you've been holding inside 'cause you don't wanna freak people out.

Corey Andrew Powell ([20:08](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Right.

Pam Cusick ([20:08](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

You don't wanna upset them or, you know, and, and so it is, I think it is, um, self-affirming and therapeutic and, and motivating for people to be able to share their story and know that their story can make things better for other people.

Corey Andrew Powell ([20:24](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Hmm.

Pam Cusick ([20:24](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Maybe, you know, other people coming after them, um, if it's a product, you know, that they're, that someone is developing. Like we have a, one of our colleagues who he said he, he was doing usability work with a, a cane, and he said he's absolutely sure that his input helped them to add this other foot to the cane and make it much better.

Corey Andrew Powell ([20:43](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Yeah. Yeah.

Pam Cusick ([20:44](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

I'm sure that's true.

Corey Andrew Powell ([20:45](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm. <affirmative>.

Pam Cusick ([20:45](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

You know, and that's, that's a really empowering moment to know that you made a difference seeing an ad on TV that you might have worked on the, you know, kind of on the formative information. You're like, wait, I was, I, I know that I've seen that before I was in that study.

Corey Andrew Powell ([21:00](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Yeah.

Pam Cusick ([21:01](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

It's pretty cool.

Corey Andrew Powell ([21:01](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Yeah, no, that is wonderful. And I love that. It also, another thing we talk about just in a leadership conversation is this idea of things that are in life. Well, I, I can't take this, uh, quote, but I interviewed a, an amazing woman named Jennifer Kaufman, who was one of the, the marathon runners in the Boston bombing years ago. And she has this remarkable story about how it transformed her and how it became a positive that that changed the trajectory of her life in a very positive way. Where she's a, an award-winning filmmaker today, which was not even her, her career beforehand.

Pam Cusick ([21:35](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

It wasn't her thing.

Corey Andrew Powell ([21:35](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

<laugh>. Yeah. It wasn't her thing. She was like in finance, but, you know, a documentary about her experience led to awards and Oscar nomination. It was just interesting. So she recalibrate and rethought her sentiments about the experience, and her, her comment was, in life things that you think are happening, uh, to you are sometimes happening for you. And just as you were sharing that, it made me think about how a person with disabilities who have, like you said, they're longing to sort of share the experience, they're now empowered to kind of own it, lean into it, and it's a superpower now that only a few people can probably talk about. Right,

Pam Cusick ([22:10](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Right. Yeah. Absolutely.

Corey Andrew Powell ([22:13](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Yeah, absolutely. Like recalibrating your thinking. It's really, it's really a powerful thing. And so I guess when you talk about that, you're kind of, you're in that point, you're, you're utilizing, I guess, patient input as well, like market research. And I think that's essential for, for companies as well. So do you, when you work, I mean, do you work with companies specifically that say to you that we are trying to, um, initiate DI uh, programs and so, you know, they want bring people in as employees or speakers, or to what level does that work in your business?

Pam Cusick ([22:43](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

So in couple different ways. So, um, the, the majority of the people who come to us looking for, um, that kind of work are coming for research purposes. So they wanna make sure that there's diversity in their research.

Corey Andrew Powell ([22:57](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm. <affirmative>.

Pam Cusick ([22:57](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

But we do also have, um, companies, again, someone that I spoke with today who wants to create a kind of a, um, what would you call it, uh, expert panel.

Corey Andrew Powell ([23:08](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm.

Pam Cusick ([23:09](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Who can talk about inclusivity in, um, in, uh, clinical trials and you know, what their experiences have been. So there are, um, different groups who want to talk to people either, you know, as speakers in some cases. Um, sometimes we'll have, you know, we'll have clients who want to have someone come talk to their business so that they, you know, they can hear from a real patient. Um, but most of the requests that we get are to include diverse people in general in, um, in research opportunities.

Corey Andrew Powell ([23:42](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm.F<affirmative>, you know, going back a little bit to what you said, we were speaking about how certain demographics of the population may not be so open to having discussions about things. And, you know, men specifically, which is not shocking, that men would be more guarded. Um, I had a, a young black doctor on a woman, she's this fabulous young woman who has this whole platform called, uh, Faces of Medicine, where she talks to other black female doctors and a across the country and, and they share their experiences. And one of the things we talked about was how a lot of marginalized groups, ethnic groups in particular, are less likely to talk about their problems, especially if there's, uh, mental wellness. That's just, you know, traditionally black folks don't talk about that. That's kind of like what, you know, <laugh>, as you said, we don't talk about it.

Corey Andrew Powell ([24:28](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

And, um, but when they see other people that look like them in the profession, um, black doctors then going to the black community and saying, babysit down what's going on and talk to me, it's different. It potentially can yield results. So do you find that maybe in your line of work too, have you seen where there might be more of a likelihood, or, or maybe the reason why you might not get some of those, some of that participation is because maybe those groups are not seeing themselves represented and maybe the people who are trying to recruit them, or, I mean, I'm just asking like in general, if you think that might be something that could improve upon your work.

Pam Cusick ([25:03](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

That that could, that could be the case. I know in, you know, in some of the, you know, I'm speaking more to the qualitative research. So when you're doing face-to-face, connecting with someone, I think people, you know, companies try to make an effort to, um, you know, match with, you know, the, you know, women talking to women or men talking to men or, or, you know, African American moderator talking to, I don't think that that doesn't always happen, but I think, you know, that the level of awareness and cultural sensitivity is there in the qualitative space. You know, trying to make sure that it is, you know, things are culturally appropriate and you're talking to people, you know, in a, a, a space that they feel comfortable in a, you know, and, and talking to them about things that, you know, making them feel comfortable, so they'll wanna share with you.

Corey Andrew Powell ([25:53](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm. <affirmative>.

Pam Cusick ([25:54](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

And I think that's part of the, you know, the, the qualitative researchers, um, community, you know, trying to make sure that, you know, you have, you are welcoming to a, a larger population so that you are not, you don't want to exclude anybody. And I, I think that probably, you know, some of the things, you know, where you are, you're mentioning like mental health and, you know, that is probably a, an area that's harder to recruit in some ways.

Corey Andrew Powell ([26:25](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Yeah.

Pam Cusick ([26:25](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Because, you know, you, people don't wanna admit they have a problem or they're anxious or depressed or have bipolar disorder or what have you.

Corey Andrew Powell ([26:32](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm. <affirmative>.

Pam Cusick ([26:33](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Um, but when they're invited in a specific way, so, you know, for example, when we, when we invite people to participate in research, it's very, um, we send them an email. It has just, you know, the information that they, you know, what kind of condition it is, how long the, the study experience is, what the compensation is, it allows them the time and space to sit back and make a decision about it themselves.

Pam Cusick ([27:02](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

They don't have to feel like someone's calling them on the phone. They have to do it on the spot and be, you know, worried and, and you know, oh no, I'm gonna, I'm gonna commit to something I don't wanna do. They can literally sit with it and think about it. They can, you know, do a little research. They can go to our website and, and kind of feel comfort in making a decision about whether they wanna be, you know, part of a study. And I think that that, that helps, at least, I think it helps for us because.

Corey Andrew Powell ([27:29](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Right.

Pam Cusick ([27:30](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

You know, we have become a trusted partner to our patients Mm-Hmm. So they, when they get an email from us and they see what the requirements are, they can then make a decision. And we don't hound them. If they don't participate, they don't participate.

Corey Andrew Powell ([27:45](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Right.

Pam Cusick ([27:45](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

That's completely up to them.

Corey Andrew Powell ([27:46](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Yeah.

Pam Cusick ([27:46](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

We want them to feel comfortable. So if it is something like a subject they're not comfortable talking about, they just move on to the, you know, their next email.

Corey Andrew Powell ([27:55](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm. <affirmative>.

Pam Cusick ([27:56](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

And so we're trying to make it a more open and accepting, um, experience. I think the one thing that I do know, or, you know, from being in research my whole career is not everyone understands what research is or how they could be involved. So, you know, that, but going back to what I said about, you know, people coming up to our booth and saying, well, why would anyone wanna hear from me?

Corey Andrew Powell ([28:21](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Right.

Pam Cusick ([28:21](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Not everyone knows.

Corey Andrew Powell ([28:23](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

They don't realize it.

Pam Cusick ([28:23](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

You know, they can Right. That, you know, they have a story to tell and that there are people who wanna hear it.

Corey Andrew Powell ([28:29](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Mm-Hmm. <affirmative>.

Pam Cusick ([28:29](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

And so being a part of, of a, you know, of a community where they could be, um, connected with research is really important. Because if they're not, if they don't share their voice, then that's a whole area, a whole group that's left out. Right. So it is a good, it is a good thing to do, to participate in research. And I mean, clinical research is a whole different thing. It's, it, there's a lot of, you know, inclusion and exclusion criteria and, and you know, whether, you know, you've, how long you've been diagnosed, there are all sorts of things depends on the, on the trial. But for, you know, a lot of market research studies, you're looking for someone who's been diagnosed with this condition for this long and tell me your story. And that's a, a pretty powerful thing. And by doing that, that show is, you know, giving the opportunity for people like you to be included in the design and development of something, which is good.

Corey Andrew Powell ([29:27](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

This has been one of my favorite conversations, I must say. I do a lot of these conversations, obviously. Uh, but uh, yeah, this has been great. And as I mentioned, I have a personal sort of connection as I'm at an age where I'm watching family, you know, sort of have to get through some health things. And so it's, it's fascinating and I'm very happy that you're doing the work you do. So thank you so much.

Pam Cusick ([29:47](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Thank you. Well, thank you so much for inviting me to be on and, um, I really enjoyed our conversation.

Corey Andrew Powell ([29:52](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

It's my pleasure, Pam Cusick, and we will give everyone the information to reach out to your organization. And, uh, thank you again for being here today on Motivational Mondays.

Pam Cusick ([30:01](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Thank you.

Corey Andrew Powell ([30:03](https://www.temi.com/editor/t/D0YHf4YzMhj1fXe6bd8-iQmKRalfnTJRHDgZ9rmZlVitOjLhLLKWJOZSkek8S5htNt3Abq7LhsdRx4iGJRwiIPehSrw?loadFrom=DocumentDeeplink)):

Thank you for listening to Motivational Mondays, presented by the National Society of Leadership and Success, and available wherever you listen to your favorite podcasts. I'm Corey Andrew Powell, and I'll see you again here next week.