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### Introducing Teresa Wright-Johnson 00:51

Watching acrobats and cheerleaders create a pyramid thrilled me as a child. They look so calm, confident, and strong! I could never do that. Yesterday I was on a Zoom call with my podcasting fellows helping each other puzzle through technical, business, story arc, and life challenges. I left the call with the image of those acrobatic pyramids. We podcasters are standing on each other’s shoulders. I was part of that pyramid. Sixty-seven and disabled, I can do it! We are calm, confident, and strong together.

I’m pleased to introduce you to Teresa Wright-Johnson. Teresa is a Multiple Sclerosis Warrior and Congenital Heart Disease Survivor. A retired Parole Officer, Teresa uses her life experiences to inspire and inform others. When I met Teresa at the HealtheVoices Conference in May, I felt her appreciation of and contribution to the pyramid of health care advocacy. I heard her warm, confident, and compassionate voice. Teresa tells a great story. Let’s listen in.

**Health Hats:** I'm here with Teresa Wright Johnson. Teresa, how do you introduce yourself when you go to a social engagement?

**Teresa:** I say, Hi, I'm Teresa Wright Johnson. I am [A Heart That Matters](https://www.teresawrightjohnson.com/).

**Health Hats:** You're A Heart That Matters. I like that. There must be a story behind that.

**Teresa:** I was born with a congenital heart defect - an aortic valve defect. For my entire life, I've been fighting and thriving with heart disease. Years ago, my parents spoke into my life that I had a great big purpose. Growing up, you don't understand what that means. But as you reach many heights; as you go through the ups and downs of life; as you mature and become comfortable with who you are, that comes forward and expands. When I try to think of something that encompassed my personality and my journey, and my life work A Heart That Matters is what came up.

### First open-heart surgery at 13 03:50

**Health Hats:** Where were you when you first realized that health was fragile?

**Teresa:** That's a tough question. I'm going to tell you why. As a child growing up with a disease, you feel different. I remember my peers used to be able to participate in certain activities that I wasn't able to do. I think I've always felt different. But when did I recognize how important health was? When I had my first open-heart surgery.

**Health Hats:** How old were you?

**Teresa:** It was four months before my 13th birthday.

**Health Hats** Was that your first surgery or the first surgery that you remember?

**Teresa:** That was my first open-heart surgery. Because, remember heart disease and treatment didn't look like back then, what it looks like today. So, years ago - and I'm 47 years old - treatment was very passive. It was watch and wait. We know something is wrong. We don't quite know what we're going to do yet. So, we're just going to watch it. It's been so enlightening and transformational to see how science, research, and technology has changed and has impacted the quality of life for kids growing up with heart disease. It was then I realized, wow, I could lose my life. I recognized my mortality.

**Health Hats:** Wow, that's pretty sober at 13.

**Teresa:** It is sober at 13. But I have to talk about my faith and my family. I had a whole village surround me. I believed that I was going to make it through. My parents prayed for me and believed me through that. I had a church family. I had friends and siblings. I had a close-knit group that supported me through that. I also realized that's when the transition, where the internal transition, occurred because that's when I say, “oh my God, this could go either way.” My surgeon spoke that, too. This could go either way. I'll never forget those words.

**Health Hats:** So, you must either have had limited function and then it got worse. That's when it was okay; now you need surgery. Right?

**Teresa:** I remember that very day, year after year, of course, I would go for my yearly checkup with my cardiologist. And in this particular year, we went for my regular checkup. Right away, I knew something was wrong just from my doctor's face and his thorough examinations. I've learned to read faces. If you talk to other adults who had illnesses as children, they probably would say the same thing. You learn to read faces. I just knew something was wrong. It was at that visit that we were told we have a problem now. And this problem is too big for me. I'm gonna send her to this great esteemed hospital with these great doctors. That was when it changed. My heart health changed.

### Listen to my body. Honor it. 07:45

**Health Hats:** You're a person who has taken charge of your health care. You're 47 years old, and you're clearly in charge of your health. But I think that was a transformational process. And when you were 13 part of this family and church community, I would imagine that you were not as much in charge as you are now?

**Teresa:** Of course.

**Health Hats:** Can you tell me a little bit about that evolution that you made to take charge of yourself?

**Teresa:** Like you said, at 13, I did not have the maturity or the knowledge to take charge. I was still a minor. But the one thing I know that this journey has taught me and that my parents laid the foundation for was that I know my body. Listen to my body. Honor it. And the words you just used were the same words they used. To take charge of my health. That grew into who I am today. Let me explain this. With my limited activity and being 13 years old and going through adolescence, even through those processes, I knew that my body needed extra special attention. I accepted that. But I have to say I did not really take charge or become so strong in advocacy probably until about six years ago. I've always been an advocate. I've always shared my story. When I realized that my story could affect change on the greatest scale, that's when everything in my world transitioned.

**Health Hats:** Okay. So, say more.

**Teresa:** Going through this process, I would talk to other children. I would talk to other parents. It was personal, and it was one on one.

**Health Hats:** Saying, “I had this experience?”

**Teresa:** Right. If friends and family knew someone that was going through something, they would direct them to me to talk. But a very pivotal moment for me was when I recognized the power of my voice. I had begun volunteering with my local AHA (American Heart Association) chapter. And from my volunteer work, I was appointed to a committee, Go Red Committee. And then I was asked to speak at a Go Red for Women luncheon and share my story. That was one of the most pivotal aha moments that occurred in my life for this reason: Speaking my truth and then watching everyone in the audience and connecting, a real spiritual connection with the people who were there. It led me to know that this is the work I've been set aside to do. After that was over, I had so many people come up to me. It was then that I realized that I say this is not only my story, but this is the story of me.

**Health Hats:** Let's go back to 13. If we think about what it means to take control of your health. What comes to mind for me are nuts and bolts - managing your medications, your appointments, eventually, your insurance, your life habits, these are all pieces. There must have been an evolution of those things from where your parents and your community were guiding you?

**Teresa:** Oh, absolutely.

**Health Hats:** But then you started either seeing it differently than they did or thinking, “this is mine to deal with.” How did that evolve?

**Teresa:** Thank you, Danny. Going through my adolescent and teen years, I had a very open relationship with my parents. We always talked about my condition. Health insurance was always important because of my condition. Not only my parents, my doctor, my childhood cardiologist also spoke about these things to me. I believe that I matured a lot faster than some of my peers because the things I had to think about they didn't. Even about careers - I had to think about a career where I would have good medical insurance that would mirror what I wanted to do with my life. I come from a family of public safety, government workers, and elected officials. We are service workers. Service has always been a big deal in my family. Growing up, my parents were humanitarians. I was taught to give back. So as I'm transitioning through these years, I'm thinking about what my life is going to be. What the choices that I make now and how they can impact my life? I had to watch my diet. I had to watch my lifestyle, my patterns.

**Health Hats:** You couldn’t go out and get drunk with everybody when they were all drinking, right?

### Careful, conscious, and confident 13:57

**Teresa:** I had a little bit of fun, but not that much. You always had to have that in mind. To this day, I tend to think more critically about everything that involves me. Cuz growing up I always had to come from that perspective. That, okay, Teresa, you have this, and you have this, and you have this. So, it makes you much more careful. But it makes you careful, but conscious, and confident.

**Health Hats:** Confident. So that's interesting. Confident, meaning that you could see that you decided to have a little bit of fun instead of a lot of fun. Then you could see, this is all I can handle in terms of quote-unquote fun? Then, okay, I made the right decision, which gave you confidence?

**Teresa:** Right. That's the big issue that I'm going to talk about. I don't know who's going to listen to this and how old they are or what they're going through. When you grow up with illness, self-confidence is something that diminishes, or it can diminish while you're going through those adolescent years. Because, again, you feel different. I think our society needs to focus more on embracing differences. Where I came from, I had this foundation telling me I'm different. That's the one purpose. Some people don't understand what difference mean. Sometimes people can say, different, and you feel defective.

**Health Hats:** Yes. That's huge.

**Teresa:** That's huge. I noticed that as I grew into my adult years, I did struggle with confidence and self-esteem issues. It wasn't related to who I thought I was inside. It was related to what society told me I was supposed to be and how I was supposed to look. It was totally illness-induced.

And now a quick break to hear about our sponsor, Abridge. I see many clinicians on a regular basis, way too many. I'm appalled at how little I can remember when I get home. My wife asks, What did she say? What about this medication or that test? I'm happy to remember half of it. To help me remember everything, I downloaded a new smartphone app called Abridge.

Now, when I go to the doctor, I ask if it's okay to record our conversation. Nobody has said no yet. I push a big pink button to record, and after I’m done, the transcript from our audio appears -- not the whole thing that's too much, but sections around medical keywords like fatigue, pain, tests, exercise meds. Now when I’m done, I can share my visit with my wife, and she can listen to exactly what the doctor said. Abridge was created by patients doctors and caregivers. Check out the app at abridge.com -- a b r i d g e .com, or download it on the Apple App Store or Google Play Store. Record your health care conversations. Let me know how it went!

### You matter 18:14

**Health Hats:** Let me take this in a slightly different direction. One of the things that I think you're talking about is how people learn to be in charge of their health. You learned it because your family and your community gave you a foundation of it and you sort of had to. Because if you didn't, it would be the end of things. There's only so stupid you can be. I don't mean stupid. You're talking about that there's this quality of self-confidence. That it's a lot harder to take charge or to learn about taking charge If you don't have, or you feel like you're down instead of up.

**Teresa:** That's an interesting comparison. But that's not my story. That's not what I'm trying to say. Let me explain about taking charge, taking charge at 13, making conscious decisions. If I were a 13 or 14-year-old or 16-year old who did not have heart disease, maybe a lot of choices I made would have been different. But when you talk about self-confidence, I'm just talking about the internal transition that goes on as you age and you come to, not only realize, but accept your illness. That's the major point. So, whenever I talk about self-confidence, I’m also talking about acceptance.

**Health Hats:** But I'm sure when you're working with other people, whether they're young people or adults, you can see here's a person that is coming from a place of self-confidence. Or maybe they're not. So, your approach to coaching them or the stories you tell may be different because they're starting from a different place. How do you calibrate yourself when you see this person in front of you? Whether they have a serious chronic illness or not, they have no confidence in themselves. It's a different advocacy and coaching problem if they do or they don't?

**Teresa:** It's a different coaching problem, but it is all under the same umbrella. If it's a child I am speaking to - and I have done some activities where I had shared my story with adolescents and children - my first point of reference is always that you matter. **You matter**. You're here for a purpose. Life is going to throw some things at you. It may not be an illness. It may be some other form of adversity. But guess what? You are strong enough to make it through. And you will make it through because you matter. So, I start from the point of reference where I'm empowering.

My first point of reference is to empower, to let them know that they're here for a reason. And that's the same thing with adults. When I meet someone with chronic illness, when we talk about our illnesses, I say, this is really hard. It's really difficult. But guess what? We're getting through this. We don't know how. Some days are easier than others, but we're doing it. The reason why we're doing it is that we don't have any other choice. We're fighters. We're thrivers. We're survivors. Whenever I speak, I come from a place of empowerment. Because to me, that is important. If you can empower someone, if you can show them how much power they have, they automatically will feel that. They will take that. They will show up in the world that way. They are the vision for the minute. They were created to show up and share.

### Set an example. Plant a seed. 22:44

**Health Hats:** So, in a way, you're laying a foundation as an example.

**Teresa:** Absolutely.

**Health Hats:** That's interesting. You're modeling it for them. So, your words will have some impact, and your modeling will have some impact, as well.

**Teresa:** That's my hope - to educate and inspire. I'm not a medical professional, but I am an advocate. I have lived the life I talk about. I live with disease, and experiences that textbooks can’t teach – lived experience. And when you live something, your story is different. The way you show up is different. Your impact is different. So right now, what's important for me and what I want to leave in the world is my legacy. The legacy that when I met Theresa, when I saw Theresa, I felt good about myself. I felt that I'm here for a reason. She reminded me that I was here for a reason.

**Health Hats:** You're planting a seed, and that seed might not sprout the minute you have an interaction. But they may go another week or another hour or another year and all of a sudden - bang - a sprout and “oh, I remember talking to Teresa.”

**Teresa:** That is so correct. That has been a point of reference in my professional life that has been unveiled in my personal life. Danny, we never know the way a person impacts us. You never know when the words you speak may manifest in someone's life.

**Health Hats:** That's so interesting. When in my career, I've been a boss. Often staff has said, “but I said that like three weeks ago or I've been saying that for a year.” I say to them, well, congratulations. It has finally sprouted. Just because you had a good idea doesn't mean the ground was fertile yet. So, let's celebrate that it's sprouted now.

**Teresa:** Absolutely!

### Judgment has no home here 25:34

**Health Hats:** It's a patience thing - having a longer look. I'm big on how people learn to take charge of their health. Be the CEO of their health. There are people like you and me that it's all we know. We're wired this way, and we've refined it. But we started with a good base. There's the other extreme. Some people say, ”Just give me a pill.” They don't know that it's possible or would be beneficial to them. So if you come across that end of the extreme, are you thinking about planting a seed or what's going through your mind when you see, “oh my goodness, this person is nowhere on this spectrum”?

**Teresa:** What goes through my mind is: What can I say? What can I leave this person with? The one position that I won't operate from is a place of judgment. So that has occurred in my advocacy. I am with people who shared certain stories with me. They had a difficult time making lifestyle changes. I had a few tell me they just didn't want to. But what did I do? You know I had information there. I told them a little bit about my story. I told them, “change is hard. It's hard for everyone. Sometimes small steps are what lead to pivotal moments.” And I tell them - and I say this because this has been true in my life – “I didn't get where I am all of a sudden. I'm here because of all the small steps that were taken before this moment right now.” A person may not be as confident in their journey, or their advocacy as we are. It may look to us like they don't care about themselves. That's a hard call to make because I don't know where people are in their lives. Some people have to figure out how to pay their bills. You have to figure out families. There are always circumstances that may make someone react differently in a situation. That's it’s important for me to remove judgment. Or to remove my thought of how I think someone should react because that's not my place to do. I'm just the messenger. I'm just the vessel. The only things that I'm armed with are information and my life living with disease. Like you said at some point, that may come back or when something happens in their life. Something changes the trajectory of how their life was going. They may come back. You never know when someone is going to come back to you and look or listen or reach out.

**Health Hats:** You're charismatic and well-spoken. Some people who don't have our self-confidence. They feel or are oppressed. Or they're not accustomed to communicating in the scary world of healthcare. It can be tremendously intimidating, even when you are charismatic and well-spoken. It's still intimidating. You're saying that there are so many different circumstances and you're not judging. I think not judging is important. I think it quite hard. I can't help it, but sometimes I feel like my prejudices are when I judge. It's not about race. It's not about sexual orientation. It's why don't they speak up? I think that's not easy.

## Speak for the unspoken 30:01

**Teresa:** Right. And to your point, everyone Is not comfortable speaking up. That's why we are super important in this journey. We speak for the unspoken.

**Health Hats:** Say more about that.

**Teresa:** We speak for the unspoken. I know people right now who are struggling with certain issues and certain illnesses and life. They need resources. They need to be connected to services. Sometimes they're sick. When you're sick, it’s hard to reach out as an advocate. We are empowered to stand in the gap. So, what I do is I try to connect whoever I can to whatever resources they may need. I try to empower. But I mean, here's the bottom line: You can give someone the tools. It's not a guarantee.

**Health Hats:** Right, they still gotta do it.

**Teresa:** They have to do it. But when it comes to speaking up or speaking out, what's more important to me? Even if you are not ready to speak up, that you're spoken for. That you're not ready to take on this task. You can't speak up right now. Guess what; these services are available because somebody has come and has done that. Those are the things that are important. I've met people on every end of the spectrum: just starting in their advocacy, just finding their voice. Here's where the transition comes. If you have not yet found the power of your voice and if you haven't really found the point of your existence or that moment that changes your life. It's going to be hard to step out and speak up,

**Health Hats:** Especially if you feel like crap.

**Teresa:** Feel like crap or unsure. Some of us are just unsure. Some of us are unsure of where we are at this point. Some of us are trying to survive illness. We're trying to get through the days.

See the show notes or my website [www.health-hats.com](http://www.health-hats.com) and click on blog/podcast for more information, to subscribe or contribute. If you like it, share it. Thanks.

### Diversity and inclusion – the ripple effect 32:59

**Health Hats:** I'm aware that I'm an old white man of privilege, and I'm Health Hats - a clinician, a caregiver, a patient, an informaticist. I wear all these different hats. So I either get invited to, or I invite myself to sit at a lot of tables. Part of my practice, my ministry, whatever you want to call it, is to open seats for people who have less of a voice than I do. I'm a smart guy, and I'm charismatic, and I know a lot. But I have this one experience. I don't speak for everyone. I speak for myself. I try to be aware of other voices. But, I can only do so much, because those experiences aren't my life. My job being a person of privilege is to open doors and seats and whatever for other people. To expand the voices that are out there and the experiences. How do you bring in other voices in your work?

**Teresa:** Number one, let me put it out there first and foremost. I am a big advocate of diversity and inclusion. So, when you talk about a seat at the table, yes, I'm always fighting for, and I'm always pushing for a seat at the table, and there are some tables that I sit at that weren’t easy to get there. I'm a fighter. Now that I'm here, I understand. I am charged with being that voice, with inviting people to take this message to whoever needs to hear it. My community is my race, my gender, my illness. These are my communities. So, when you have a seat at the table, the conversation changes. A person or an organization or company cannot say they support diversity and inclusion if there's no one there with a seat at the table that's impacting the change. Healthcare is not only pertinent, but it is also a necessity. Having people’s differences respected, their illnesses addressed, and their voices heard - those are pertinent. If I as an advocate can't go out and stand up for myself and who I am and all that I represent, then I'm doing a big disservice to myself. Let me explain this. We're not superheroes. We're not. We're people living with illnesses trying to effect change one step, one day, one life, one word at a time.

**Health Hats:** Oh, I like that.

**Teresa:** That's the meat and potatoes of it. We're not superheroes. We don't wear capes. We may not save the world. But what I learned throughout my career and my life is if you can reach one then you've done your just do. You never know who that one is going to reach and who that one that they reached. You never know where the impact is going to stop.

**Health Hats:** The ripple of it.

**Teresa:** Yes, the ripple effect. To summarize your point, yes, diversity and inclusion matter. As a woman, as an African American woman, there are times that I've been shut out of the conversation. There are times that I've been excluded. But guess what? I still come back knocking. I'm gonna come back knocking. I'm gonna come back talking until you listen to what I have to say. None of us got here on our own. We all stand on the shoulders of someone else. When I recognize that; when I recognize that my life is not by accident; when I recognize that I lost siblings when I was the only child born with an illness; when I recognize that and put that into perspective. I realize that nothing in my life happened by accident. That is all intentional. While I'm here, I'm going to live the most intentional, best life that I can. As my childhood cardiologist said, who's no longer here, he's no longer with me. But I remember as a little girl; he said to me, “Leave your mark in the world. kiddo.” Those things stick with me. Leave your mark in the world, kiddo. My mom, “you were different. I knew you were different. My baby was different and that you are a Survivor.” So, when you see my passion, and when you see my spiritualness, these things have transformed my life. We didn't talk about this, but I have multiple sclerosis, too. Now I'm dealing with two chronic illness. It gets difficult. But then I go back, and I remember just as you and I just spoke about, I remember those words. Those were the seeds planted in me.

### Listen to your body 39:30

**Health Hats:** Teresa, is there something that I should be asking you that I'm not?

**Teresa:** No. I'm following your lead. This is a great conversation. If I can put this into the atmosphere for whoever listens, I want them to know: You matter — your voice matters. You're intentionally taking up space. That's not by accident. There's no harm in asking for help if you need it. There's no harm in reaching out. With chronic illness, it takes a village. Only you can advocate best for yourself. You know your body. You know what you need and your circumstances. I think that's the most important point I can make is that you matter, and you know best your body. When your body tells you something, then listen to it.

### Inclusion in research 40:48

**Health Hats:** Is there anything you'd like to ask me?

**Teresa:** What has been your greatest - I hate to use the word accomplishment, but for the lack of another word - an accomplishment in your years of advocacy or what are you most proud of?

**Health Hats:** That's a big question. So, I'll say what is on top of my mind this minute. You know I've been doing merit reviews for PCORI (the Patient-Centered Outcomes Research Institute) for a lot of years - since 2013. When I first started doing that, the proposals would have $25 gift cards for patient stakeholders, which is to me was an insult. And a couple of years ago a proposal came that I reviewed where they budgeted for respite care so people who were caregivers could participate in the research. And I thought okay, ‘now this is putting your money where your mouth is.’ Thinking about what it takes for people with diverse experiences and viewpoints. What does it take for them to sit at the table? Well, if they have responsibilities. Those responsibilities are taken care of for a half a day or a couple of hours or a full day. I don't know whether the proposal got funded or not, but I thought, ‘okay, we've come somewhere.

**Teresa:** That's great. I also want to say this. As you know, I'm involved in a lot of organizations and a lot of advocacy platforms. But when you say research, automatically I think of iConquer MS (Research for Multiple Sclerosis). This goes for both heart disease and multiple sclerosis. Diversity and inclusion in research are a must. That's number one. Number two. How do you get it done? Just as you said, sometimes you have to meet people where they are. If you are telling me that I matter, but you don’t include me in your research, then how can you say that you’re diverse and inclusive? If you are looking to invite me into the research, is it something that I'm going to connect with? Are there images that I can connect with? Do I see someone like myself sitting at the table? Because the bottom line is this: the basis of our humanity begins with connection. We are designed to connect. Without connection, without being able to speak to someone, to meet them where they are, what change are you affecting? Heart disease is the number one killer of women. Minority women are more disproportionately affected. If every time I look on my television, I see someone other than myself. Why should I believe you? How am I going to believe you? When we talk about research and diversity and inclusion, we're still chipping away at this. I do know myself, and I know some other great advocates who are chopping away and eating away at this platform. Until we all are included and recognized, we're missing the work was supposed to do. This is my personal opinion.

**Health Hats:** Teresa, thank you. This has been a hoot and a half. Thank you so much.

**Teresa:** Thank you. I enjoyed it myself. I appreciate it.

**Health Hats:** I'm glad we met.

**Teresa:** I am too when I look forward to seeing you and talking with you again.

### Reflections 46:22

Isaac Newton stood on the shoulders of the giants, Copernicus, Kepler, and Galileo Galilei. Teresa Wright-Johnson is a giant of advocacy. We stand on her shoulders; she stands on ours. “You matter” coming from Teresa is powerful and uplifting, even to me, a person of privilege, already full of myself. Thank you, Teresa, for all you do.