

**Jason Jepson:** when you think about your advocacy, how do you recognize success?

Not by a paycheck, not living in a mansion, but the amount of comments I get from, uh, people who have my diagnosis that, thank you so much. I, I feel less alone. Or caregivers, that now I understand what my loved ones is going through.

Mm-hmm. , they have schizophrenia and it's powerful. That's the best. , I would rather have that than the money. Mm-hmm. , you know, it makes, it's just, it inspires me to keep going. Mm-hmm. , I'm doing what I should be doing. Mm-hmm.

**Estella Mata:** Yeah. Okay. Um, in your advocacy, how do you recognize success? Wow. I'll tell you one of, in my advocacy, I recognize success if I'm able to help one person. Okay. Wow.

**Sharnae Smith:** So in your advocacy work Yeah. How do you recognize success? Oh my gosh. Um, this is gonna be the craziest thing when someone comes up to me and they're like, Because of you, I'm gonna keep going Uhhuh. That's, that's what I measure as success. You know, all the accolades and stuff, you know, all the public, you know, accolades that you can get and stuff that doesn't compare to one person coming up to you being like, you know, because of your story, my life changed. And so, you know, that's why I got into advocacy work because when I first got diagnosed, people didn't know what lupus was and I didn't have anybody to turn to, you know? So I felt like, okay, I don't want anybody else to experience what I've experienced when they get diagnosed. Us. And so the success of someone saying, you know, I wanna keep going, I wanna keep pushing on, I wanna, you know, bring awareness too. That was make me be like, Oh, okay, yes, I'm, I'm being successful in this thing.

**Jim Snedden:** I actually have a story to go with that. Please. I was in the doctor's office and I said, Come on, come on. I need my medicine. Give it to me now. And he laughed. Uh, it's biologic. He says, I wish everyone was as willing to to use medication as you are, and I said, If you have somebody that you know needs it, please give my business card. And I hated him a stack of business cards. About six months later, I got a phone call and I talked to the guy and we bounced back and forth for about almost an hour. He called me back two months later. He says, Jim, he says, My life has changed thanks to thanks to this medication. Thank you so much. He says, I went from 90% covered in psoriasis to now I'm down to about only 5%. I'm on the beach. I haven't been here in years. Thank you so much. That is success.

**Christine Von Raesfeld:** How do I recognize that's a hard one, right? Because I think, I think a lot of us in a, in advocacy, we put a lot of work in and we don't see those immediate results. Um, I think what gives me a measure is really just talking to other people, meeting people who have that same vision, and sharing my thoughts and getting people to think a little bit differently, you know? Yeah. And I think that's just a measure of my success is to get someone to think outside of their box and to consider something else. I think if I can do that, there's a shot.

**Hetlena Johnson:** Success? Um, in my advocacy work, I think success is just being able to tell your story. Okay. Success is being able to share with someone who's going through the same thing that you're going through. That was a successful moment. Whether you're stepping out in the hallway or right in a hospital room or in the hospital, in a doctor's office, and all of a sudden you're speaking with someone who's not feeling well and they just want it to be heard. Whether it's the same thing that's going on with you or not, that's success.

**Jason Crum:** I recognize success by people adhering to what I'm teaching you. Uhhuh, you know, if I see the people. They tell me they got tested and their test is just negative. You know, that doesn't make, that doesn't make me successful. Doesn't make my advocacy advocacy successful because they got test. What makes it successful is that they're spreading what I've taught them to other people.

**Brooke Abbott:** I don't know. Oh, I don't know if I would use success. just because I think that we measure success as big wins and, um, I think that, I know that I'm making an impact when I'm a, when I'm at least able to help one person. Because I know that that one person, uh, will pay it forward in some way. Um, and it doesn't come in the thank yous. It doesn't come in any of that. It comes from someone asking for something, and I have a way of either connecting them to someone else or providing a resource for them.

**Phyllisa DeRoze:** I recognize success by people telling me that something I've done has been meaningful to them. Because that's what drives me. Um, my story of getting diagnosis includes having two near death experiences back to back. So I spent a lot of time questioning like, why was I saved? Like Yeah, within 60 days of each other, like twice, right? What I have made meaning of that is, Reaching out to other people. So when someone says, Part of my advocacy has helped them, then that's successful, even if it's one person. For a while, only one person would read my blog post. Okay. So you're a blogger? Yes. I, I want, I started out as a blogger. I do more things now, but yeah, it was

a blog. Okay. And. . And what's the blog? Diagnosed, not defeated. Diagnosed, not defeated.

**Bethany Yeiser:** Success to me is when I talk with the caregiver and they tell me, or, or even a patient, and they tell me, because of your videos and because of our conversations and because of the information you provided, you know, my life has changed. I have a better understanding of what people with schizophrenia are thinking. More information to take with me to my doctor because of you. Something has changed in a positive sense and that's very rewarding. Yeah, do so what's your, um, what's your channel? You know, your either, you said you do videos, so that, is that on YouTube? Yes. So I am president and co-founder of a foundation called CURESZ. CURESZ stands for comprehensive Understanding via Research and Education in schizophrenia. Okay. So my main advocacy is on that CURESZ website. Yeah. And we have a CURESZ YouTube channel. I also have a personal website, which is bethanyeer.com. And I primarily use the website to sell my, my memoir, which is called Mind Estranged.

**Ken Taylor:** We're Ken and Barbie. There's many ways actually, but I, I look at it as did we affect or help anyone? If it's just one person, it's a success. I used to think, well, you've gotta have a room full to change the minds of, and all this, it's, it's really not that at all. Um, cuz everybody has a story to tell. And if you can affect and change one person's life, isn't it worth it?. Okay, so I, you know, I've, I've changed my mind over the years on what advocacy actually is, does and means, you know, to each person. obviously the obvious as far as medical attention you know, Did you get the, your right treatment? How do you find the right treatment? What are you diagnosed with? Do you got an expert? Do you, um, have any, anything like that? Helping somebody find, even find the, the right diagnosis. Yeah. Because there's a lot of misdiagnosis out there and there's a lot of, uh, there's a lot of, uh, overlapping symptoms among conditions. Yes. So it's, it is not, you know, easy sometimes to diagnose. Yeah. Um, so that's a, you know, a success. Treatment options are a, a huge success if you can find somebody, you know, get somebody going down the right path. Um, and then, you know, the whole mental aspect of it, um, there's, there's not any, nobody's gonna, uh, have a diagnosis, a catastrophic event, and not be affected mentally. Right. It's just the way it is. Yeah. Um, and we've, we've talked about that quite a bit this weekend, haven't we? Yeah. But, um, so there's a lot of different ways I, I look at a lot of different successes in, in how somebody is helped or treated.

**Cindy Chmielewski:** That's hard. You know, like what makes something successful? I guess for me, what I'm doing in advocacy is more patient education. Okay. Because I'm a retired teacher, and education. Learning about

my cancer and learning the treatment options and learning who were the doctors I should be seeing and just learning about things was what made me finally be able to start living with my cancer. Prior to that, I kept on second guessing, Am I doing what I'm supposed to be doing? Does my doctor know what's going on? Am I getting the best treatment? So I just kept on being worried because it took a while for me to be initially diagnosed. I was misdiagnosed in the beginning, so that fear was there. But once I learned about what should be going. It became, it became more peaceful with myself. And able to live my life. And I think, so I went into the area of patient education cuz I'm, no, there's others like me there, there are others that really don't care there. Everything's in the doctor's hands, but there are others like me. So I, I think being able to talk to someone one on one. Educate them, have them make a connection with a specialist and start receiving treatment and then having that person come back and say, Oh, I'm so, I'm doing well. Or, Thank you for sharing this resource. Like so I just, just, I think I'm successful when I'm able to reach a patient, share a resource and that resource meant something to them.

**Jesus Guillen:** For me, if, if every day at least one person, I can make them smile or I give them some information on somebody, just say, Thank you. You know, because I was able to see this information or felt better in this way. Just with one person like that, I'm incredibly happy. I even sometimes I ask myself, how did we do it? Because now I have people help me, we stop about three suicides, one of them in England, and I'm still amazed of how, even through social media or things like that, we can do that, you know, we can help people. Yeah. So for me, success is. First I'm feeling good about what I'm doing. But second, if one person, just one person, I, I, I don't need more than that, you know?

**Christopher Quimbar:** I think when you, uh, believe in something so passionately and something that affects everybody, everybody across the world, something as your health. Success is really reaching as many people as you can and understanding that you're affecting their lives as much as, as health has affected your life. So when you reach out to people and that ripple affects really start to come back and, um, you know, you, you see the difference it's making in people. That's, that's when you realize you're doing something right.

**Stephanie Chiang:** It's a great question I find that success number one goal for me is when I get comments from our audience and the people who are watching and reading us that the content that we're putting out has been so impactful. What's your, what's your content? Yeah. Um, because my background storyteller love talking to people just like you. And so created a platform called the patients story. The patients story. The patients story. It is right now focused

on cancer because I wanna do one area really well. And as you know, cancer is made up of so many situations, um, and experiences. But what I can say, regardless of whether it's cancer or something else, in. health. We have a lot of shared emotions and experiences and our stories are not the same as has been talked about a lot, but being able to put the stories out there for people to understand, I am seen, I am heard, I'm connected, I am not alone. Is so important. The patient story, the patient story.com. Okay.

**Michele Nadeem-Baker:** I'm always my own worst critic, but the first time I felt success was the first time someone wrote to me and told me how much. Oh what I'm doing, My advocacy helped them in their life with clo and that that was such a warm feeling that that just made my day, not only my day, but what I had been doing.

And I was like, this is exactly, I'm in the right place at the right time. And all roads have led me here. Whether I knew it or not, that that was just, it was meant to be, cuz. My background is in broadcast journalism. Okay. And in communications. And here I was communicating, um, as a journalist, I'll be it online, uh, to help other people and by having something to help communicate to them. Cause there was hardly a thing at the time when I started doing this. The intranet wasn't what it is today in, in 2022, and my doctor had no information to give to me the day I was diagnosed, and it drove me insane. I was like, This is got to change. Someday when I'm ready, I'll change this.

**Jenna Green:** Well, that's an excellent question. Okay. For me, I think success absolutely a combination of the very small things, including feeling comfortable to be vulnerable with you on this interview, or be silly on an Instagram video and the larger things such as testifying on legislative bills that will help the greater community. And putting out content that helps people to be their own best healthcare advocates, and hearing from people in the community how that helps them. Um, for me, that's huge. I don't care if a lot of people like it or follow me or although that's all. I, I do marketing for a living, so I do enjoy the statistics behind it, I don't find success in that. I find success in helping someone live their best life, whatever that means to them. What are your platforms? You said put stuff. Oh, here. I primarily use Instagram. Okay. Um, I am finishing a YouTube video series, which I got the Health Voices 2022 Impact Fund Grant Award it'll be on YouTube for public speaking, for patient advocacy work, um, which is something I'm passionate about, and I've developed a lot of skills on over the years and now had to pivot with having some chronic pain, chronic fatigue, brain fog and things, but still wanting to use my story and my voice to help make a positive impact in change. And when I hear most from people is that they want to get started in that type of public policy, advocacy, volunteer



work, but they're not comfortable speaking publicly. Like people would rather swim with sharks than public speak. For me, it's a pleasure. So I am, um, very much looking forward to publishing that. So, um, what's your Instagram handle? Oh, at the, like, t g Jenna Green. J e n n a g r e n. Like the. Um, because Jenna Green is my name, and that was taken when I first started on Instagram. And so now it's just a running joke with my friends and your, um, YouTube channel. Um, that one doesn't have a specific, um, URL yet because I haven't um, gone to that point.

But if you go to the jenn green.com, it directs you to subscribe to. My Yes. Okay. Yes. Or my Instagram bio also directs you to subscribe to the YouTube channel, which will be coming soon.

**Kara Beck:** Honestly, when I have someone reach out to. Whether they are saying you have inspired me, or if they're just asking me for advice, because I feel like that's when the people who need to hear what I'm saying have found it. Because then I'm interacting with these people and I'm able to at least give some sort of advice, even if it's not end up, you know what they end up doing. But I feel like as long as I can connect with people, I feel like that is success to. . And where do you connect with people? I'm on Instagram. You're on Instagram? Yeah. And at, what's your Instagram? I'm at Cara underscore r y and that's r y for ruin y for the gastric bypass. Okay. Um, and Bear is just Kara Bear, like Cara, cuz I'm Oh, okay. Not Big Tara is my first name. E a r?

**Jasmin Pierre:** Wow, that's another good question. honestly, being here right now and just being amongst all of the other advocates because, you know, everybody is not invited to this conference. And just being able to be surrounded around so many good people and have important conversations. And, you know, Jansen does a pretty big pharmaceutical company, so it's like just being able to be here and, well, I still do other things with them as well. Like, it just makes me feel like I belong here.

**Sue Rericha:** When some I, when someone says thank you, when they say that my story touched them, my story helped them to not feel so alone. I think that's the biggest success.

**Alexis Newman:** Success for me is when I am able to educate or put my information out and I get word back that whatever I said helped somebody else either change their diagnosis or get the help they needed. Um, that has happened actually recently. Um, I met an individual who was originally diagnosed with type two diabetes and I'm like, Something doesn't seem right here. You should ask your doctor for these tests. And then months and months and months later,

she came back to me and was like, You're right. Like I am type one. I'm not actually type two. She's been diagnosed probably for almost 10 or 15 years as a type two,

**Ryan Williams:** To me, success is when I'm able to make a difference in just one person. Um, for instance, the children's book I came out with that explains Alzheimer's disease. It doesn't need to be a best seller. It doesn't need to make me a million dollars. As long as it helps at least one person explain what Alzheimer's disease is to their child, you know, what their grandmother could be going through. That's success in my book. So that, that's what I measure success on. Just making a difference in, you know, tens of people, not millions of people.

**Sam Seavey:** It's gotta be all the emails, all the, I'm, I'm on social media, so I get a lot of comments from people in the community letting me know how much my videos have helped them. Uh, I, I advocate for the blind and visually impaired. And when someone loses their sight, especially later in life, it's, it's terrifying. Uh, sight loss is the second largest fear, biggest fear that people have. And so they can watch some of my videos and realize that it's not the end of the world you can thrive with sight loss. Uh, it's just a matter of learning how to Yeah. And so when I get those emails of, how thankful they are that they found my videos and, and I was able to help them through that time. , that's truly how I measure the success of my advocacy. Where can they find your videos? I am mainly on YouTube. Uh, I have YouTube channel called The Blind Life. The Blind Life. The Blind Life. I have over 700 videos all about losing vision, how to cope with it, and assistive te.

**Andrew Schorr:** Well, one way of course is are you reaching a lot of people just numerically, But I don't think that's the answer. Success is when you hear from someone where they tell you you've made maybe a life changing difference for them. I work in the cancer field, so when people tell me because of you, I connected with a knowledgeable doctor in a more appropriate treatment, that made a difference for me and I've had some people say it saved my life. That's one way. The other way is really cool is cuz I work on the internet is there have been a couple of. When people have recognized me, cuz I do videos. Okay. And then that's like, whoa, I'm a celebrity, but that's not why I do it. Yeah. It's just, you know, you've touched someone. Yeah. So what's your platform that has been patient power.info. Patient power.info. Right. If you look it up, just patient Power Uhhuh and it primarily reaches about 200,000 people affected by cancer. A month on a website, but I do a lot of postings in Facebook and Instagram and Okay. Reach wider people there too.

**Howard Chang:** So, my advocacy started with a blog. I started writing like 15 years ago, and I, And what's that blog? It's called The Itch to Beat Psoriasis. It's on, Say it again? The Itch to Beat Psoriasis. Yeah, it's hosted by Everyday Health. Okay. Um, back then it was called Health Talk. Yes. Yeah. I don't know if you remember Health Talk. Yeah, I do. So I was on there, I was one of like three psoriasis bloggers. One of the, like in the beginning uhhuh, and it went through Revolution Health and then became Everyday Health and they kept, I think two or three of us bloggers had been kept on from those days all the way. Yeah. So I just stayed on with them, but my whole goal and they, they asked me to pitch. Like, like they were inviting authors, writers, and so I'd never really written about psoriasis too much, but I wanted to start doing that Uhhuh. So, um, success to me was helping one person feel that they're not alone. Yeah. And that was something, especially early days of, of health blogging it 15 years ago, there weren't too many of us out there. Um, that was the main comment I got. Yeah. Thanks for writing. Now I, you know, you're the first person I've known with psoriasis. Oh. That kind of thing. Cause it's something that people keep hitting and, you know, we didn't have like a lot of community groups or things that even if we did, most people don't go to those things. Yeah. So that was, that was my kind of measure of success. If one person could feel less alone or not alone with a disease that tends to be stigmatized and hidden. Yeah. That. And then as it grew, um, I needed to keep that to ground me because sometimes you get like lots of views, lots of comment, and you start thinking, Wow, you're like, your head gets so tone up sometimes.

**Rachel Star Withers:** I don't really see it as like a, um, success or not because for me it's just talking about what I'm going through. And I just kind of, that's just part of everything that I do, and if people respond to it, that's great. If they don't, that's fine. Also, it's not, you know, it's not meant for everybody, Not everyone you know is dealing with a mental disorder. However, I will say nowadays so much of the world is open. I think a lot more people are exposed to serious mental illnesses than they were in the past where it was, you know, kept quiet. It's more likely now that you're gonna hear someone, it says, Oh yeah, actually I have a family member who's dealing with that. Oh, one of my friends turns out this. Or just see it more on TV with like drug ads and things. You're like, Oh wow. I used to never hear about tardive dyskinesia, and now there's actual drug ads on tv.