Faces of TBI Podcast Interview October 22, 2017

Introduction [Les Schwab Tires commercial]

ANNOUNCER: BlogTalkRadio.

AMY ZELLMER: Good morning, everyone. Welcome to the <u>Faces of TBI podcast series</u>. Today, I will be chatting with filmmaker Cheryl Green about her newest documentary.

This episode is brought to you by Minnesota Functional Neurology, a Minneapolis-based clinic staffed by a caring and progressive team of Functional Neurologists who are experienced in treating post-concussion rehabilitation, chronic pain, dizziness, whiplash, and migraines. They are the concussion doctors you can trust for comprehensive brain health in the Minnesota area. They've greatly helped me and many others in the Twin Cities. Find them online at <u>MNFunctionalNeurology.com</u>.

Hello, everyone. I'm Amy Zellmer, and you are listening to Faces of TBI, a podcast series for survivors, by survivors, raising awareness about traumatic brain injury one podcast at a time.

Those of you who might not know who I am, I'm a TBI survivor from a fall on the ice in February of 2014. I'm a frequent contributor to the Huffington Post and volunteer on the Brain Injury Association of America's Advisory Council and recently released my first book, Life with a Traumatic Brain Injury: Finding the Road Back to Normal. You can learn more about me and the podcast at FacesofTBI.com. You can also follow me on Twitter and Instagram @AmyZellmer.

Today's guest is Cheryl Green. Cheryl integrates her training in Performance as Public Practice and Speech-Language Pathology to explore how story can be used to break down stigma and barriers. After decades of sustaining mild TBIs, in 2011 she began making films that combine personal narrative and activism to create dynamic, artistic tools to challenges misconceptions and stereotypes of disability while celebrating pride in disability experiences. A filmmaker, podcaster, blogger, and public speaker, Cheryl also provides Closed Caption and Audio Description services to make media more accessible and to encourage a disability aesthetic.

She recently released a feature-length documentary, "<u>Who Am I to Stop It</u>," which focuses on isolation, art, and transformation after brain injury. Instead of injury or medical details, it focuses on the [psychosocial] consequences of brain injury. The film shows how peers with TBI use the arts to navigate an inaccessible world and to reconnect to a sense of self-pride and contribution to society.

Welcome to the podcast, Cheryl. I'm so happy to have you here.

CHERYL GREEN: Thank you, Amy. I'm really happy to be here, really honored to be on your show. Thanks for having me.

Sharing your TBI story

AMY: Yeah, and thank you for being here to share your story today. I'm very excited to kind of jump into this and get to know you a little more. I think I would love to have you start by sharing with our listeners your TBI story.

CHERYL: Cool. Sure. So, [clears throat], oh, I should've cleared my throat before we started. Excuse me. Sometimes I like to start my TBI story by saying that my story is about dropping out of rehab because I didn't like it, and I didn't like what we focused on or how people talked to me or how they treated me. So, sometimes the most important part of my story is that I'm a rehab dropout, and that's what led me to go to the arts and collect personal narratives and try to focus on the parts of life after TBI that are everything but rehab. So, that's one part that I often end up telling when people ask what happened. Well, I dropped outta rehab. That's what happened.

But in terms of how I got to be in this community, I'd say it's about at least 25 years of sports concussions, one assault, and these things--as you know really well, Amy, and probably most, if not all of your listeners--that they just add up. You recover, and you get another one. You recover mostly. And then it got to the point where I had these three about seven years ago, one of which was a big one. I just never fully recovered from that. I'm doing great. I'm doing much better. I notice improvement every year, but I did not...I'm not, I'm not who I was before. So, that's how I got into the community. I think it started when I was maybe 8 or 10, and now I'm here.

AMY: Yeah. So, like you said, you're not who you used to be. I think that's the underlying story with so many people listening. I think it's challenging for people to really-- I explain it as it's even more complicated because we can remember very clearly who we used to be.

CHERYL: Yeah.

AMY: It's not like we've forgotten that!

BOTH: [laugh]

AMY: And so, it makes it even more challenging because we can't do the things we used to do. I think the fact that we can remember who we were is really challenging at times to move forward. You have to learn how to live in the present, not the past.

CHERYL: Yeah!

AMY: And maybe that's what you kind of came to terms with in rehab [laughs].

CHERYL: You know, it's so interesting that you say that 'cause I don't think that I came to terms with that in rehab. Part of that is because I dropped out. I just really hated all of it except for my counseling and my vision therapy. I loved that. Interestingly, my vision therapist and my counselor both survived severe TBI. While that doesn't automatically make them great clinicians, they were so much more understanding, I thought, than a lot of other people.

AMY: Mmhmm. Yeah.

CHERYL: And I just liked the therapy that we did better in those two areas than in the other areas. But I think that coming to terms and learning to be in the present really came from being in the disability arts community, which is cross-disability. It could be anybody with any kind of disability. And getting involved with them, and it's a lot of people who were born with their disabilities or acquired them a much-longer time ago than I did, that's where I got to come to terms and to be in the present. It's where I started making films about brain injury. It started with a couple of short comedies about executive dysfunction.

AMY: [laughs]

CHERYL: Yes, I mean, right. You have to laugh. At this point, you have to laugh about executive dysfunction. But they're really, that's really where I got into the present and spent less time remembering what it was like before. I could just be there in the moment, like, OK, now we're here. We're creating art. We're doing personal storytelling. What part of this do I wanna keep? What do I wanna discard? What do I wanna share with the public? So, sorry, rehab people! No offense [laughs]. But it was the arts, really, where that happened for me.

AMY: I mean, I really do feel that brain injury and concussion, they're so misunderstood. I mean, I went through doctor after doctor after doctor. I actually didn't even get sent to any rehab. So, that was frustrating to me 'cause I felt that I needed it. But then, when I finally did find my doctor, and he totally understood it, and we did the right rehab, you know, it had a profound effect on me. So, I think that's a great lesson for everyone listening, is if your rehab isn't doing it for you-I noticed vast improvement just in two weeks, but I was also 2 1/2 years out. So, I might've been at a point where my body was ready to heal more quickly.

CHERYL: Mmhmm.

AMY: But if you're not seeing any results, and if you're not feeling like you're being treated properly in your rehab environment, you have the right to move on and do something else. I like to drive that home. You dropped out of rehab. I'm not saying you have to drop out of rehab!

CHERYL: [laughs]

AMY: I'm just saying you can find someone else who might have a better understanding.

Having rehab clinicians who had TBI

AMY: Ironically too, my doctor also has had two concussions from skiing. So, I think he gets it better than a lot of doctors as well. You know, they have that compassion side.

CHERYL: They do. There's compassion. I mean, anybody could have compassion, but there is this weird thing where you do something just off-the-wall or ridiculous or something that makes no sense, and you just so no judgment come across their face.

AMY: Right.

CHERYL: 'Cause they're like, "I've done that before. I've seen that." And they just-- For me, it was such a different vibe. In terms of my vision therapist, I had no idea she had a TBI. I kept telling her all the time, "I don't know what it is about you, but you just get me. You know how to, when I'm struggling with something, you just immediately change it. You never judge me. You don't tease me. Why are you so nice? Why do you get this so well?"

AMY: [laughs]

CHERYL: And I kept, like week after week, I kept telling her, "Oh my god, you get me. You get me!" And finally. You know, it's not like your clinicians should open up and spill their guts and tell you their personal information. But after months of this, she finally said, "You know, Cheryl, I wanna share something with you that I don't usually tell people, but you keep asking. And here's why I get it." So, it's not like I walked into it like, oh, you're automatically gonna get it 'cause you've been there, because I didn't know that she had. And it really, it was an amazing experience to have her open up like that. I think I cried for the whole rest of the session, and we didn't do anything.

AMY: [chuckles]

CHERYL: But then when I graduated out of vision therapy, I cast her in one of my short films, one of my brain injury short films. We had a really nice relationship, and there was really some neat bonding that happened in understanding more about her story.

Becoming a filmmaker, exploring arts after TBI

AMY: So, Cheryl, were you a filmmaker before your brain injury, or is that something that came afterwards?

CHERYL: It came afterwards, and it was totally an accident. It was never something I planned for. Even when I started, I didn't think I was going to keep going. I never thought I would make a feature-length film. No, I did acting and dance and weird performance art stuff. Not super weird. Not the really weird stuff you see. But yeah, it was all live performance that I did. And I was invited into this storytelling project for Deaf and disabled people, and I didn't think that I could attend the live performance at the time because I was so tired all the time.

AMY: Mmhmm.

CHERYL: I just couldn't handle the stimulation of-- Oh, right. You get it [laughs]. I couldn't handle crowds. I couldn't handle the sound of clapping. I just thought I was gonna be a total failure at live performance. So, I thought, oh, I'll just make a little movie. Like that's all it takes: Oh, I'll just make a movie!

AMY: [laughs]

CHERYL: I learned pretty quickly that it's not just that easy. But I made a 10-minute comedy about how I lost the ability to cook. Which I got it back. I mean, my food's not good, but I can cook now. But I made this short film, and a filmmaker friend of mine actually filmed and edited it. That was it. It just kind of on a whim, I said, oh, well, I'll make a film. And then it just--what's the word--it just...exploded? I don't know if that's the word, but it just kept going from there. It kept building.

AMY: Mmhmm. So, I had been a photographer for 20 years. I had my own studio. When I had my injury, I completely lost my instinctual ability of how to use my camera.

CHERYL: Oh!

AMY: I knew something wasn't right, like I'm over-exposing my image. OK. I'd have to go through it all. I'd be like, OK, my f-stop, my aperture, my ISO. Why is this happening, you know? Where before, it was just instinctual. I knew what needed to change. I didn't even have to really think about it. And this was like, I had to sit and think about it, and it was so frustrating. And that's slowly come back, but it was really frightening when you don't know how to do something that was so instinctual before.

So, that's when I kind of moved to writing. I'd always been a writer but not to the extent that I do now. I have found that, <u>through my writing and sharing my story</u>, I'm able to touch so many more people. And I feel like that's sort of what you're doing through your filmmaking as well, just reaching and raising awareness and helping others. So, it's quite a process, isn't it, how we get to where we are sometimes [chuckles]?

CHERYL: It is. It is. And I mean, I totally relate to what you're saying about wait, this was second nature. I knew how to fix the exposure without thinking. Yeah, I can totally relate to that! And it is scary because it's almost like the things you can't do show up one at a time. You think, OK, I've got this down. And you try something slightly different, and all the sudden, you get confused again, or you can't figure out what exactly is the thing that's wrong or that's hard. And boy, it just is really a process to uncover those things. And then at the same time, like with your writing, you discover oh, wait a minute! Here's something I really can do. This is really cool, and I can do it well. I think it's kind of a never-ending process, actually.

AMY: Mmhmm. Yeah. The self-discovery that we continue along the journey.

CHERYL: Yeah.

Who Am I To Stop It

AMY: So, tell us a little bit about your current documentary that you released, the Who Am I To Stop It. Tell us a little bit about how this came to be.

CHERYL: Yeah. Again, an accident [laughs]. I never meant to do it! I had gotten a grant from a local arts council to make my second short film, the comedy about brain injury. And getting that grant, I don't know, through some partnership, it qualified me to do this online fundraising thing that comes with a mentor, and it's only for artists. So, it's like some elite Kickstarter that usually you have to apply to get onto this platform, but they automatically let me in because of this local grant that I had recently gotten. And because I was just so spacey all the time, I went online and opened up my profile and got started. And they called me! I was totally surprised that these fundraisers called me.

And they said, "Oh, we see you've started your profile. What's your project that you wanna raise money for?"

And I'm thinking to myself, I don't have a project!

AMY: [laughs]

CHERYL: Like, who goes on a fundraising platform to raise money with no idea of what you wanna raise money for? I mean, I didn't even see what was wrong with it at the time. So, I'm on the phone with this person, and I'm like, "Well, I'm going to interview artists with traumatic brain injury" [laughs]. And I just went on and wove this whole story.

And she's like, "Great. OK. Get started on your platform."

And so, I called that filmmaker friend who had made my first two comedies. And I was like, "Oh, Cynthia. I'm fundraising for a documentary. Will you make it?" [laughs] Oh my god.

She was like, "Um, sort of, but we need to actually come up with a real plan."

AMY: [laughs]

CHERYL: So, she and I got it together, got it all started with me, with raising initial money. She really helped me shape it. Her name's Cynthia Lopez. She helped me shape it into a reasonable idea. Interviewing five people's a bit much. She really mentored me through the process of starting this film. She got a new job while we were filming, and so, she sort of backed off the

project a little bit. And then I took some filmmaking classes at a film center here in Portland and just go more and more into it.

But when I think back, I don't remember what I told the fundraiser person on the phone. I don't remember what I literally said, but I know that what interested me was I lost almost all my friends. Because I...I was somewhat impaired for a while. I was not a real good communicator. I lost a lot of people, and I had to resign from my job. Those things were really hard for me, and getting involved in the disability arts community here in Portland and meeting a whole bunch of friends, it gave me a sense of purpose, it was super fun. The process of learning how to make a film and write and rehearse is a form of rehab, in fact. It was very helpful for me in addition to being fun. And [laughing] I lost my train of thought! Oh my god!

Yes, OK. So, I got friends. I got purpose. I got fun activities to do. I got to be creative. And I just felt good about life even though life felt very hard still at the time because so many things were a struggle. And I wanted to know, first of all, do other people feel isolated after TBI. Which, I mean, I knew the answer to that. But the other one was, do other people feel like art saved their life, gave them a way to create a life that they wanted to live. And so, that was what was behind interviewing people.

It ended up being three. All of them are isolated in different ways from society. And all three of them really, they just find so much positivity in creating art. They are proud of themselves in a way they were before the injury. They're proud of their artwork. People love their art and want more of it. There's so much connection back to the community and back to the self that I found in creating art.

And since I've been screening it, I'm hearing the same story from people in the audiences. I'm hearing stories about art literally saving someone's life: A Veteran with TBI and PTSD who was suicidal, and he got into it was either art or art therapy. And it just really grounded him and gave him something to do and something to live for and a way to--like you were talking about--get his story out and be heard and be respected. So, it's been fabulous to hear how many people are like, "Yep. Me too, me too, me too."

Helping the community through sharing stories

AMY: You know, when you do something like what you just did--you've got your documentary; I have my writing. I have my podcast series--but then when you hear from other people about how much that it's helped them and like, "Me too. I feel that way too, and I can so relate to what this is talking about," don't you find that that's part of your own healing process too, to know that you're helping other people through your work?

CHERYL: I...I mean, healing doesn't even begin to capture it. I don't even know if there's a word to describe the feeling of it. It's very emotionally healing.

AMY: Yeah.

CHERYL: It is...I came up with another word, and I already forgot it.

AMY: [laughs]

CHERYL: It is so humbling. Right [laughs] Oh my god! Talking! Talking live! Live radio! It's very humbling too, like wait. Really? I made this thing, and it speaks to you? Oh, my goodness. I'm so grateful because that's what I want. But then sometimes it's hard to believe that it's happening.

I mean, I've had people-- At one of the screenings, somebody came up to me in the middle of the screening and started talking to me. I'm like, "Wait. We have to leave the room because the movie's playing!"

AMY: [laughs]

CHERYL: "There's 50 people in here. Let's go!" So, we go outside. This person had been taking notes through the documentary and needed to leave the screening and talk to me and share his notes and ask me a bunch of questions and tell me what was on his mind. There were parts of the movie that were really, he really hated, and he wanted to tell me what those were and get that off his chest. And there were parts that he really loved. He had a bunch of questions. He's not a TBI survivor, but his mother is. And he was watching this, and he's seeing his mom onscreen. He was so overcome with thoughts and emotions and things he needed to process. And it was an honor beyond honors to stand out in the hallway with him and talk through his notes and the issues that were coming up for him. I mean, you just feel so privileged and honored when somebody wants to share their thoughts with you and get support from you. It's very cool!

AMY: It is. It's very cool. And you know that the work you're doing is really, truly affecting others and helping them and helping their friends and family as well in some instances. And like you said, you go through this huge isolation because people just don't get it. So, to have this vehicle to help them get it a little bit, it's really profound and powerful.

CHERYL: Yeah. It's neat [laughs]. I have a really neat life, I think.

Other arts projects and marketing Who Am I To Stop It

AMY: [chuckles] So, do you have any other projects in the works, or are you taking a break right now 'cause you just released this one? What's your art schedule look like?

CHERYL: Oh, my goodness, my schedule is...out of control. First of all, to answer one of your questions, no, there is no break. Because I am part of a film distribution cooperative that is self-distribution. So, we're a company; it's called <u>New Day Films</u>, and it's been around since 1971. We sell on the educational market: Universities, hospitals, non-profits, and that kind of thing. But because it's self-distribution, there's nobody out there selling my film for me. I have to do it myself.

AMY: Right. Mmhmm.

CHERYL: And we do share resources and share ideas and help each other a lot, but it's not paid work because it's not like I work at a distribution company. So, if I want to earn any money on this movie, it's about me getting out there and making contacts and selling the film. So, and then because it's a coop, we also do volunteer hours back into the coop to support it. So, there's no break there.

I actually just went to three conferences in three different cities in two weeks. I presented part of my film and did a presentation in Honolulu at the Pacific Rim International Conference on Disability and Diversity. The day after I came home, I went to Salem, Oregon to screen the whole film at the annual state speech therapy and audiology conference. Last weekend, I sat at a table at the NW Narrative Medicine conference with postcards and DVDs, telling people about the New Day titles related to disability. So, [laughs] there's no break!

But in terms of art, what I'm doing now is actually-- Well, I made a short documentary about why we really should not institutionalize people with disabilities. I mean, to me, it's a given. But in our culture, it seems to still be the default. So, I made a film for the <u>Center for Disability Rights New</u> <u>York State</u> and won first prize in their festival. I rarely get actual film ideas. So, it was exciting to have an idea for that one!

But I'm really moving a lot more into audio: Audio storytelling, audio documentary. I've had an interview-based podcast similar to yours for about five years, and I'm now moving into storytelling and sound design and music and that kind of stuff. I've been producing episodes for another podcast called the <u>Disability Visibility Podcast</u> by Alice Wong out of San Francisco. It's a really cool podcast. I'm one of three editors and producers on that. And I'm just super excited about growing my audio skills.

I really want to do storytelling and audio documentary with certain groups of the TBI community. I'm really interested in working with young people. I'm really interested in working with people who maybe are in, or have been in, a domestic violence shelter. I'm really interested in interviewing people who are, or have been, incarcerated who have a history of TBI that may play into some of how they ended up there. And yeah. I don't have a specific plan for actually doing those things, but those are the things that are on my mind right now [chuckles].

AMY: Well, that's awesome! And congratulations on your first place award. That's amazing.

CHERYL: Thank you.

Wrap-up

AMY: So, we are almost out of time. We have just a minute left.

CHERYL: Oh!

AMY: I just want to thank you so much for being here. This has been great. I think what you're doing with your documentary is just awesome, and I wish you so much luck with all that you are doing! You're a busy woman.

CHERYL: Thank you. Thank you, Amy. And thank you for having me on. I love your Faces of TBI project and reading what you're up to on your blog. I wanna thank you for your work and being out there so much, so, yeah.

AMY: Thank you.

CHERYL: Absolutely.

AMY: Thank you so much. Well, thank you. And so, if people want to find you, how can they find you online?

CHERYL: <u>WhoAmIToStopIt.com</u> is the website and blog. Facebook and Twitter are both <u>@WhoAmIToStopIt</u>. Although, I don't understand social media. So, I don't post very much, but I'm on there.

AMY: [laughs]

CHERYL: But WhoAmIToStopIt.com is the home base for everything.

AMY: All right. Who Am I To Stop It. Thank you so much, Cheryl. Have a wonderful day.

CHERYL: Thank you, Amy.

AMY: Thank you so much for being here today.

CHERYL: You too. Thank you.

AMY: And thank you, everyone, for listening. I hope that you enjoyed today's show. Again, you can visit <u>FacesofTBI.com</u> to listen to previous podcasts and see any upcoming topics we might have listed.

Another thank you to our sponsor, Minnesota Functional Neurology, the concussion doctors you can trust for comprehensive brain health in the Minnesota area. Find them online at <u>MNFunctionalNeurology.com</u>.

And thank you all for listening. Thank you for being a part of my journey. I will see you all again next time. Have a great day, everyone.

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