

Lauren Hixenbaugh (00:00):

Welcome to Living Beyond Cancer. I'm Lauren Hixenbaugh the manager for the West Virginia University Cancer Institute's mobile cancer screening program, and a member of the West Virginia Cancer Coalition Mountains of Hope. I'm excited to be your host for today's episode. For those who haven't joined us before, Living Beyond Cancer is a series of podcasts created for cancer patients, survivors, and their caregivers. This series is created at the WVU Cancer Institute in collaboration with Mountains of Hope, the State Cancer Coalition, cancer Prevention and Control. Today I have Sydney Kushner with me to discuss Connecting Champions Champion, a unique resource that connects children diagnosed with cancer, with a mentor who shares similar interests. I'm thrilled to have Sydney today with us and get to chatting about this awesome program. Sydney, could you just tell us a little bit about yourself and what Connecting Champions is?

Sidney Kushner (00:55):

I'm happy to. Thanks so much for having me. I've been really looking forward to it. As you mentioned, I'm Sydney Kushner and I'm the executive director and founder of Connecting Champions. We ask kids and young adults who have cancer or are in survivorship, what do you want to be when you grow up or what are you passionate about? And we find them a mentor in that field who can help them achieve a brighter future. That could be everything from exploring career paths to gaining specific skills and knowledge to simply having a friend during your cancer journey to help you pursue your passions.

Lauren Hixenbaugh (01:29):

Wonderful. It's such an awesome program, and I have to tell you that when I first heard you present on this program, I was so inspired and many of the people that I work with and myself included, we're driven by our passion for helping others and for West Virginia, and this program is just the epitome of that. So I am really excited to kind of talk about beyond the obvious reasons why this program is so amazing, but can you talk to listeners about why it's so vital to the community?

Sidney Kushner (02:02):

I started the organization when I was 19 years old in memory of my friend Lauren, and she was diagnosed when we were in high school, and she passed away during my freshman year of college. And I knew I wanted to do something more in her memory. And I started volunteering at the local children's hospital where I was in school in Rhode Island. And every time I would walk into the room, I would walk in with a smile and I would ask the kids or teens, what do you want to be when you grow up? And I was just amazed to see their eyes light up as they shared their vision for what life looked like beyond the disease. And it was such an incredible experience and I didn't realize it until later that I had been doing something that was unique and wasn't being done before, which is that I walked into the room and I didn't talk about cancer.

(02:58):

I ask about their cancer. I didn't tell them something about their cancer and I didn't inquire about their cancer. I walked in and I just asked them about the things that they love, the things that they envision. And in a world where when you're going through cancer treatment especially, or anytime you're in the hospital, everyone around you is trained in one single language and that is cancer, it's medicine, it's hospital, it's sickness. And I just by chance happened to be the one person that walked in the room and spoke their language, the language that really made them tick, that brought them joy. And I think that that's something that is so important in the communities that we're able to see someone not as a cancer

patient or a cancer survivor or a young adult with cancer, but seeing them as an individual, seeing them as a kid, seeing them as a teen, as a young adult, as an adult.

(04:10):

And starting at that point before we dive into cancer as a community saying, who are we? Who is our essence? How do I still be able to be independent and be me at a time when I'm not feeling my best and I'm losing so much and I'm so isolated? And so that really drove connecting champions in memory of my friend, but also as I learned from all these kids in teens, is that there is this opportunity to bring people into their lives who speak their language and by providing someone who is in their career path or shares their passion and creating these long-term mentorships, and our mentors and our participants are meeting on average for about a year on a weekly to monthly basis, it happens virtually. It happens in person, it happens during treatment, and it happens long after treatment. All of that has the common thread of saying, let, every time you're with us, you get to talk about the things that you love, and that's all we care about. That's the most important thing in the world.

Lauren Hixenbaugh (05:24):

I just love that. And you're absolutely right. There are so many of us, myself included, and we're very focused on survivorship or prevention, the whole cancer continuum, and that is our role. But you're right. I mean the power of being able to say, I brought joy to somebody that really is inspiring. And as you know, I've heard you talk before and so that's why you're here today and we can talk about how we can bring more joy to other people. And now a wider range of people, which I'm sure you'll talk about a little bit later. Can you tell us how you connected with Mountains of Hope?

Sidney Kushner (06:07):

Yeah, mountains of Hope is incredible and has become honestly a real centerpiece to a lot of my life and a lot of our work. We started the organization in Pittsburgh, which is my hometown, and we did our work here. I still live here. We did our work here for about eight years, and we reached a point where we said, we're ready to expand. There are more people in our region who could benefit from this, and we want to be there for them. We want to make sure everyone who needs this can have this no matter where they are in their cancer journey. And we were trying to decide where we wanted to go next. And we thought about Michigan and we thought about Chicago and we thought about Cleveland, we thought about Buffalo and Rochester. And I kept having this sort of thought in my mind, which is I thought about my grandparents and my grandparents lived on Cheat Lake, and I always say, my sister and I, we grew up every summer on Cheat Lake on the boat, and being able to just have that incredible joy.

(07:21):

And I just kept thinking, what if we expanded there? What if we expanded to West Virginia? I know it's smaller, I know that there are fewer hospitals, but the opportunity is so valuable. I mean, there are people that come from across the state to WVU Medicine or whatever hospital they're going to, and there's so much opportunity to be able to create that connectivity. And so I met with Dr. Tomba, who is the chief pediatric oncologist, still is at WVU Medicine Children's Hospital. And as soon as I met him, I shared my story like I'm sharing today, and he said, okay, what is it take? We want to get you here. And he was so excited. And within a matter of a few months, we were in West Virginia, we expanded to our second location there and things kept growing and growing and growing. Mountains of Hope reached out to us and said, the work that you're doing in Morgantown is amazing, but how can we help expand this across the state? Because everyone, this could be for everyone. And over the last year, plus that's

been our relationship is we've been able to be a part of thinking through how can we not just focus on expanding connecting champions throughout the state, but how can we focus on expanding our services to older participants, to those in survivorship to anyone who needs us wherever they may be.

Lauren Hixenbaugh ([08:57](#)):

We're so glad, obviously, that you came and joined Mountains of Hope and especially expanded to West Virginia. There are often a lot of services that we don't have here, as you know. So having this is really a true delight for us. And as soon as I heard the presentation, I have several friends that work in pediatrics and I couldn't get to the phone fast enough to text them and email them and say, check out. I don't know if you've already connected with this, but you need to right away, you need to be connecting with your kids. And I have a very good friend that is a childhood cancer survivor, which you and I have talked a little bit about. And so I was really excited to talk with him about this program. And he just talked about how for him, this would've been so changing at that age. So personally I have a connection as well. So if folks wanted to get involved with the program, is that something that they can help with?

Sidney Kushner ([10:04](#)):

Absolutely, yeah. There are multiple ways that people can get involved. And the most obvious one, and the one that is so central to our work is we're always looking for more mentors. And it doesn't matter if you think you have the coolest job in the world or the not coolest job in the world. Whatever you do, there is someone young who wants to be like you when they grow up. And that's something that is so exciting for me to be able to watch young people share their vision. We've paired our participants in their childhood teens, twenties and thirties. We've paired them just in the last two and a half years with over 200 different professions.

([10:56](#)):

I can't even name 200 professions. I don't think. It's everything from the people at NASA who run the Mars Rover to veterinarians to constitutional lawyers and traveling barbers. If you can imagine, there is everything in there. And that's the most important way is without our mentors, we wouldn't be able to do the work that we do. So if anyone is interested in volunteering or if you know anyone who's interested in volunteering, please reach out to us through our website@connectingchampions.org. Another way is if you know anyone who may benefit from our program, please let them know that we exist. Like I said, we are there for people in their childhood, teens, twenties, and thirties. Obviously it looks very different for a young kid than it does for someone in their thirties. For the young kids, it's very much more based on maybe projects and activities and friendship.

([11:55](#)):

Whereas for our 30 somethings, it's about career transitions. Maybe they've been diagnosed and are looking to transition to a new job. Maybe it is that they're trying to, they miss this critical year and they're trying to gain specific skills and get back into the workforce, whatever it may be. So it looks very different. And then there's the in-between of course, too, with psychosocial support and post-secondary education trade schools. And if there's anyone, whether they've just been diagnosed, they're entering survivorship or they are long into survivorship, we serve participants from the day that they're diagnosed until 10 plus years into survivorship. So that's another way. And then of course, we're always looking for people who are interested in supporting our work financially too. And that goes without being said. And then we've got some fundraisers as well. We have a charity run walk that people can do from wherever they are in the world. We have people from all across the country who participate in

that. And then we have a charitable March Madness fundraiser too that people can recruit their friends, family or their offices to make their bracket pools charitable.

Lauren Hixenbaugh ([13:06](#)):

So I think at a very minimum, if you're listening to this and you can't do anything else that Sydney mentioned, at a very minimum, you can spread the word, right? You can share the posts, you can share the website and keep talking about this great organization. And so speaking of which, I don't think I asked this earlier. So we are glad that you're in West Virginia. Are you anywhere else? And if you're not, how can people look for similar programs?

Sidney Kushner ([13:39](#)):

That's a great question too, and I appreciate just going back to what you just said, I appreciate that you kind of zoomed out, you zoomed out wider about the conversation that we have. And I just wanted to build on that. I think even if it's not anything to do with connecting champions, something that I've learned is that there is an incredible power to, when you're talking with someone who's going through a diagnosis or a different part of their cancer journey, being able to talk about the future, being able to talk about life beyond the disease. And it doesn't matter how long future means because everyone has right now and tomorrow. And so I think our job as communities is to be able to be there for people, not just in a way that's constantly talking about how they're feeling or how can I help you with your treatment schedule or something like that, but is talking to them as them, if that makes sense.

([14:46](#)):

In terms of your second question, like I said, we expanded from Pittsburgh to West Virginia. We're still in both of those locations. But something really incredible happened in 2021 when we started telling our network about what we were doing in West Virginia and the ways that we were expanding. And other hospitals started reaching out to us and said, this is exactly what we need to, how can you help our patients? Or we had parents saying, how can you help my child? Or we had young adults saying, how can you help me from literally across the country? And we started expanding nationally. And we've since become a national organization. We actually have participants in 27 different states. We have partnerships with 30 hospital systems, but West Virginia is still one of our most major hubs. We have staff here, it's multiple staff in West Virginia. It is, like I said, really close to my heart for specific and general reasons and is something that I think in many ways has become a template around the country. And that's what you were getting at too, is I think that there's this ability that, well anyone qualifies for connecting champions no matter where they live.

([16:12](#)):

And I think also it speaks to the importance of us as a community being able to continue creating that connectivity. Because something I saw with my friend Lauren was when she was diagnosed that very day when she was 16, she was pulled from school, she was pulled from choir practice, and we didn't see her again for six months as she was going through treatment. And that isolation is something that we all of us need to be able to fill that gap as opposed to expecting the individual to ask for help, expecting the individual to bring up conversations just about life or just complain about things or just joke about things. It's our job to make sure that we create that space too.

Lauren Hixenbaugh ([16:56](#)):

That's great. And I think that's great advice. Yeah, definitely pulling it back, like you said, to more of a bird's eye view of it. So I think that's wonderful. So one of the other things that I think you and I really

talked about that it will be valuable for listeners is talking about more about the unmet needs and survivors.

Sidney Kushner ([17:21](#)):

That's something that we've, so one thing that's really important to us is we don't want to be an organization that just creates a series of feel good moments. I know the work that we do is really exciting and joyful, and you can see the smiles just by hearing the stories, but there's so much depth behind that as to why we do the work that we do and what gaps exist in this world. And specifically we know there's research that shows that 85% of young people are surviving the disease medically, but they're surviving with this wide array of challenges. Because when you finish treatment, you've just had this incredibly intense period in your life and you finished treatment, and now everyone says, okay, great. You're cancer free now go be normal again. And we know that it's not that simple. And so what we've seen, there's a wealth of research that shows that adolescents and young adults and children as well, that they're surviving with significantly higher rates of unemployment and depression and significantly lower rates of educational attainment and quality of life.

[\(18:40\)](#):

And that's something that when we started doing our work, it was the basis of our work and we wanted to really pinpoint what is going on here? What are the specific needs of this population? And we adapted a scientifically validated scale developed out of Wake Forest University that measures a wide array of different needs that young people with cancer have. It's everything from cancer care to identity and psychosocial wellbeing to emotional wellbeing and work in education. We took the work in education section and we expanded it greatly to include very specific items such as, I need more help with networking or scholarships or understanding job options, stuff like that. And when we administered that scale to over a hundred different adolescents and young adults in our program, what we found is that the top seven most reported needs were all needs related to career and school. So more than two thirds of participants were saying that they need more help with internships, with understanding job options, with gaining career experience, with career planning, with scholarships, with networking, all of those.

[\(20:04\)](#):

And that was up to two to four times more frequently than items related to their emotional wellbeing, like anxiety or feelings of needing to be independent. And that was really striking to us because we knew that cancer care and emotional wellbeing were critical needs of this population. We had no idea that career in school was being reported so much more than those other needs. The last thing that we found is that those needs don't just exist while you're going through cancer treatment. When we compared our participants who are in treatment or recently completed treatment versus our participants who are five or more years into survivorship, we found that the top most reported needs were statistically insignificant in their differences. They were nearly identical. And that was shocking to me. We knew that the needs still persisted. We had no idea that they were going to be at the same levels.

Lauren Hixenbaugh ([21:05](#)):

Gosh, just meeting people where they're at, using that assessment to really just meet them where they are is such a valuable resource for all of us to have that are working in the cancer continuum working with survivors. And I hope that listeners here, as you're talking, the passion in your voice for the work that you're doing, because I think truly one of the best things that we really can do is spread the word about this great program, but truly, I hope people are listening and hearing the passion in your voice,

because sometimes I think we miss that and it's really important. So as we wrap up today, I want to revisit some key points. So if listeners were to remember one tip from today's podcast, what would you hope that it would be?

Sidney Kushner ([21:58](#)):

Oh man, I love this question. It's definitely really challenging. I think in terms of one tip, as I had shared before, I think it's being able to see someone for who they want to be versus who we think that they are. And that can be sort of, it's a weird way to say it, but I want to share just a quick example. When my friend Lauren was diagnosed, like I said, we didn't see her again for six months. And at that six month period, the first time we saw her, she surprised us by coming to a choir concert. And I remember she walked in the room and she totally turned my world upside down because she walked in and had the biggest smile on her face. And that's Lauren. She was always the president of the welcoming committee, the first person to say, hi, welcome with a big smile.

([23:01](#)):

I'm so glad you're here. And everything that I thought I knew about childhood and young adulthood, cancer was what I had seen on tv. You see, everyone is black and white, very, very solemn. And yet here, Lauren walked in with this bright smile, and with that smile was telling us, I want you to see me as who I am, not as who we expected that she would be. And if there's one tip to me, that's what it is, is letting people walk in with their smile and tell you who they want to be and how they want to be seen, as opposed to projecting how we think they are and who we think they are. And whether that's through a program like Connecting Champions, whether it's through somewhere in your community, a community center, or other organizations and people in the hospital, people out of the hospital. I think that can happen in all different corners of the world. And that's so special to me is that everyone, we are all in this. We are all in this together. And the passion that I feel is something that I have this passion because I've gotten to see so many of those people smile throughout this time in their life. And so we can all share this passion together.

Lauren Hixenbaugh ([24:28](#)):

Absolutely. Well, I just can't thank you enough for being here with us today, and I know we had a short time together, but I feel like when people listen to this, they will be as inspired as I was when I walked away from your presentation and want to do good in the world and bring that joy and passion that you have. If folks have questions or want to get involved, I will add the link into the blurb that goes along with your podcast that you're listening to, but also they can find a connection to connecting champions on the Mountains of Hope website. And they can find that at West Virginia mountains of hope.org. And thank you just so much for being here with us today. I know our Mountains of Hope membership would be really excited to hear this, and I hope that folks at home are excited to hear this as well, and that they'll continue to join us on Living Beyond Cancer.

Sidney Kushner ([25:33](#)):

Thanks. Thank you, Lauren. This was a real joy. I consider you all really dear friends.