S3 E12 Innovation in Five: Empower Yourself to Live an Active and Engaged Life

**Molly Lazarus** 00:01

Welcome to Changing What's Possible: The Disability Innovation Podcast brought to you by Cerebral Palsy Alliance Research Foundation. My name is Molly Lazarus. Today on Innovation in Five we're going to discuss how Kelly Brush and their Active Project are helping folks with disabilities, and more specifically spinal cord injury, to get more active in their community.

**Edie Perkins** 00:24

Hi, I'm Edie Perkins, and I'm the Executive Director at the Kelly Brush Foundation. The Kelly Brush Foundation is an organization with a mission to inspire and empower people with spinal cord injuries to lead active and engaged lives. So we use sports and recreation as a catalyst to get people there.

**Molly Lazarus** 00:44

I love it. Edie, we are so excited to have you join us today, and this felt particularly timely because the Paralympics are going on and we're all feeling super motivated, and the Cerebral Palsy Alliance Research Foundation, we have our big STEPtember campaign, and it just felt like the right time to talk about what it means to be active in all the ways that are good for your body. I know you all are working on a lot of different projects around helping people find and figure out how to participate in sports. Could you share a little bit more about that work?

**Edie Perkins** 01:20

Sure, yeah. One of our newest programs is called The Active Project, and it's an online platform that connects people to places to get active. There are hundreds of adaptive sports programs across the country, and oftentimes people don't know about them, so it's a way to log on, explore adaptive sports. We have a whole hub and resource section that introduces people to what sports there are and what they look like and what you need to know to get started. And then once you're interested, you can look for a place to try them. And on top of that, there's a way to set up a profile so you can introduce yourself to the disabled community and to other people who want to support the community and find others who are interested in the same sports, or maybe have more experience and can be a mentor or help answer questions about sports you're interested in, or concerns you have about getting started.

**Molly Lazarus** 02:25

Amazing. And let's zero in on adaptive sports a little bit more, because I imagine there's a whole host of technology and modifications and things that folks are doing to be able to participate. What are some of the adaptive technologies that you're seeing, or the ways that people are getting involved in using adaptive technology to do that?

**Edie Perkins** 02:48

So, yeah, there are a lot of great technologies for helping people get active. I mean, there's all sorts of adaptive sports equipment. One of the most popular things right now is adaptive mountain biking, and this has become really popular because of the innovations in E-assist. So now bikes come with an E-assist that when you pedal, it boosts your power in response to how hard you're pedaling. There's also a throttle. So if you need to, like, really gas it to get over a steep space, there's that assistance as well. So because of that, getting into the woods and exploring and using these mountain bikes has become much more popular. So that's one trend we've really seen take off. There are other things, like power chair soccer, which is a really cool way to get high-level injuries and people who are severely paralyzed, into team sports. Another new technology is this, using sip and puff to control skis. So now somebody who's paralyzed from the neck down can use sip and puff technology to turn, to stop and to ski independently, which is really amazing.

**Molly Lazarus** 04:15

Wow, that's incredible. And I assume it's safe.

**Edie Perkins** 04:20

Yeah, it's safe. You know, it begins with a lot of support from instructors and people who are skiing with you. If you were to do this, you would get started with somebody who's holding on to you with tethers and once comfortable, slowly moving to independence.

**Molly Lazarus** 04:40

Amazing. And I know the Kelly Brush Foundation started with a focus on spinal cord but a lot of our listeners have a variety of different disabilities. So would these sports leagues and adaptations — would they apply beyond spinal cord injury?

**Edie Perkins** 04:55

Definitely. You know, these technologies work for anybody with limited mobility, and the adaptive sports programs that we're connecting people to — spinal cord injury is probably a small percentage of their populations that they serve. So.

**Molly Lazarus** 05:09

Amazing. I know Kelly Brush in Vermont, but are these leagues across the country, and how do people get involved in them?

**Edie Perkins** 05:16

Yes, definitely across the country. You're right. We are mostly focused on spinal cord injuries. But as we launch The Active Project, our digital platform that's for anybody and connects people to leagues and teams and programs that people can go to to get started in sports, and those are everywhere.

**Molly Lazarus** 05:38

And I'm curious about your experience. Have you participated in these sports through Kelly Brush? Do you have a favorite?

**Edie Perkins** 05:44

My favorite is hand cycling. I'm a bit of a cardio junkie. Before my injury, seven years ago, I was a competitive runner and cyclist, so when I got injured, I quickly got into hand cycling and fell in love with it. But I love to try new sports. I've tried the mountain biking and really, really love that I can just get into the woods again. It's amazing. It was probably five years before I got into the woods after my injury and before my injury, I loved nothing more than getting out into the woods and exploring. So I love that. I've tried skiing. Skiing is hard. Mono skiing is what I've been trying to learn. And I think I'm just about there, but it's not easy. I also like cross country skiing and swimming, and I'm dying to learn tennis.

**Molly Lazarus** 06:40

Fun! So if you are, you know, watching the Olympics, wanting to get involved in STEPtember, and you're not super active, you want to be but joining a league feels like a big jump. Do you have any recommendations for folks who are kind of dipping their toe in the water?

**Edie Perkins** 07:00

Yeah, definitely. I think going and watching is a great way talking to people who have participated. And that's where something like The Active Project comes in, because you can find somebody who does a sport with a similar disability and just shoot them a note and be like, "Hey, how did you get started?" And oftentimes they'll find that most people are tentative at first and feel like maybe quad rugby is out of the range of something that you'd want to do. But then you find out that other people, just like you got started, and then love it. There's also other things, going for walks and getting out in nature, doing things like bird watching or going for a roll in a beautiful area is a great way to just enjoy nature and get your heart rate up a little bit. So there's something for everyone, really. There's other sports too, like bocce is really popular, and just doing things like that that connect you with the community and give you a chance to find something that's fun.

**Molly Lazarus** 08:08

Totally. And we know that activity is not necessarily the goal, but community is really the power that kind of underlies it, and so I love that you all are bringing a community aspect into this.

**Edie Perkins** 08:19

There's nothing more powerful than connecting with your peers. There's so much that people learn from one another, and seeing your peers do things that you didn't think you could do is probably the most motivating thing, because you see, oh my gosh, that's possible, or you learn all the tips and tricks that otherwise you'd have to sort of reinvent the wheel and figure out on your own, and the camaraderie and sharing all the battle stories and tips and tricks and hacks and all of that is a great way to get more independent and challenge yourself.

**Molly Lazarus** 09:01

Amazing. Well, we are so grateful for The Active Project and the work that you're doing. Is there a website or somewhere that folks could go find you?

**Edie Perkins** 09:11

Yeah. So the active project is AP, dot KBF, short for KellyBrushFoundation.org, and you can always visit us at kbf.org

**Molly Lazarus** 09:22

Amazing. Edie, thank you for being here.

**Edie Perkins** 09:25

Oh, thanks for having me. It's great talking.

**Molly Lazarus** 09:28

Feel free to jump in, visit the website, and if you want to start a challenge of your own for STEPtember, you can always come and visit us, and we'd be happy to support you in doing whatever fitness challenge that is exciting for you, join 1000s of people across the country to raise funds for life changing cerebral palsy research and assistive technology that will positively reshape what it's like to live with a disability. And if you want to pair any physical activities with your fundraising, you can challenge yourself to get moving all. All September long. Make a team of up to four people and get your friends and family in on the fun. Sign up for free today at www.steptember.us that's S, T, E, P, T, E M, B, E R, dot, U, S. Once again, I'm Molly Lazarus, and thank you for joining us for Innovation in Five.