



Can Do MS Podcast Transcript

CAN DO Month: Learning the Legacy of Jimmie Heuga with Blaze Heuga and Tyler Hamilton

Episode 86

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Mandy Rohrig: Hello and welcome to the Can Do MS podcast. My name is Mandy Rohrig, physical therapist, and senior programs consultant at Can Do MS. I'll be your host today for this special episode just for Can Do Month. Can Do Month is made possible thanks to the support of Sanofi Genzyme and other generous sponsors.

Throughout September, we celebrate Can Do Month in honor of our founder and Olympic ski medalist Jimmie Heuga. When Jimmie was diagnosed with MS, his doctors advised him to avoid physical activity because it was thought that exercise would exacerbate his symptoms. But as an high-caliber athlete, he rebelled against his prescribed sedentary lifestyle and Jimmie began developing his own program consisting of exercise, nutrition, and mental motivation. It improved his overall physical and emotional health as well as his outlook on his life with MS.

In 1984, he founded the Jimmie Heuga Center for Multiple Sclerosis, now known as Can Do MS. He spent years sharing and teaching the principles that transformed his own life from one of uncertainty to one of an active pursuit of personal health and well-being. Today, the whole person philosophy and approach that Jimmie pioneered in 1984 is acknowledged within the MS community as a standard of MS care.

I am honored to welcome 2 board members as our guests for today's episode. [(2:00)] A special welcome to Blaze Heuga and Tyler Hamilton. Thanks for joining us. Many of us knew Jimmie. I was personally fortunate to know him professionally, but you two certainly have unique perspectives. You knew Jimmie much differently, much more personally. Blaze as his son and Tyler as his dear friend and fellow professional athlete. We are pleased that both of you are here to help share Jimmie's story and help us celebrate Can Do Month. Welcome.

[background music]

Mandy: Blaze, I wanna start with you first. Um, just tell us a little bit about your dad. Tell us about, um, maybe one of your earliest memories that you had with him.

Blaze Heuga: When we were very young, I was probably about 4 or 5 and he was fairly disabled at the time, um, kind of going from a walker to a wheelchair, but he would still always drive us to school. And I just remember, you know, my mom would load us up into the back of, uh, his van at the time and then she would go and help lift him into the driver's seat. And I remember just kind of looking at my brothers, like, you know, he can't walk very well and he's about to drive us to school. And so he's the... Uh, I kind of giggle about that. That's always a memory that I like looking back home and we always enjoyed those car rides together at a very young age.

And then another memory, there is this bridge. It was underneath I-70 right by our house and our dad had a four-wheeler. And he would always, uh, tie some sleds to the back of the four-wheeler and kind of whip us around the neighborhood. Then we would go down to the bridge [(4:00)] and kind of scream underneath the bridge and we got a really good echo. And so those are kind of two of my earliest memories of my dad.

Mandy: Those are great memories. So-

Blaze: Mm-hmm.

Mandy. -so, Blaze, did-did you only know your father at when he had MS? Because he was diagnosed while before you were born, correct?

Blaze: Correct. Yeah, that's correct.

Mandy: I can imagine kids flying behind a four-wheeler. I bet that was pretty awesome when you were young.

Blaze: Yeah, we loved it. I think it kind of implemented our adrenaline addiction. Um...

Mandy: Yeah.

Blaze: ...you know, our-our dad had a lot of that, so, you know, certainly, apple didn't fall far from the tree.

Mandy: Yeah, yeah, definitely. So, tell us a little bit about how you did become aware that your dad had me... had MS? It sounds like it was part of your... of your day-to-day life when he...

Blaze: Mm-hmm.

Mandy: ...drove you to school in the mornings. You were aware that he had some challenges.

Blaze: Yeah, y-you know, I can't really remember any particular discussion. As I mentioned in the first story, I could tell that my dad was disabled from a very young age. So, I knew that he had MS. Um, and we discussed it a lot as a family, uh, but there really wasn't a particular discussion or age that I recall. It just kind of seemed something that-that we understood as a young age where it was gonna be there for the rest of his life. But he didn't really focus on the disease itself. He focused on, you know, what he could do, which is exactly what we're doing with this foundation. He never, you know, really felt bad for himself, or told the negative sides of-of what was going on with his disease. He really was very consistent with focusing on, you know, the-there's really nothing that-that he couldn't accomplish if he really set his mind to it.

Mandy: I love hearing that you were seeing and experiencing Jimmie's [(6:00)] can-do spirit from a young age. Thank you, Blaze, for sharing. Tyler, I want to pull you into the conversation. Thank you so much for being here.

Tyler Hamilton: Well, first, yeah... And it's really special to be, you know, on this podcast and talking about-about Jimmie. He was just an incredible individual. As you can see here, I've got goosebumps just talking about him.

Mandy: I agree. So you were close friends with Jimmie. Certainly, you didn't know Jimmie when he was first diagnosed, but you did become friends later on. Can you talk us through your earliest experiences with Jimmie and how you first met him?

Tyler: Yeah, I met him in the fall of 2004. I, uh... You know, I was a ski racer growing up. You know, I was born in 1971, so I... He and Billy Kidd were, uh, the first Americans to win alpine medals. But there was what... In Innsbruck in 1964, Billy Kidd won silver and Jimmie won bronze. I grew up in a skiing family, so I knew about Jimmie. Yeah. Well, before I ever met him, my dad was a huge fan of his. And, uh, yeah, I got to meet him in, um... [clicks tongue]

I-I guess to go back a little bit, I-I started working on the fight against MS in 1997, um, actually through cycling. And finally, our-our, uh, our paths crossed in the... in the fall of 2004. And I was going through a really hard time in my life when I met Jimmie, and man, you know, he had a lot to maybe complain about, but I didn't feel that one bit. He was very positive. He was just a[?] light up a room without even having to say anything. Very positive attitude and he was really in it, just exercise and activity, you know, even though he really couldn't use, you know, the bottom half of his body at the time.

And, uh, yeah, I take him out on bike rides. I remember one time, you know, he li... he lived [inaudible] in a full care facility just outside of Boulder, Boulder, Colorado where I was living. And I went-went there one time to help to go out and take him for a bike ride, [(8:00)] uh, a hand cycle, [clicks tongue] and he had already been out waterskiing that-that earlier, that

morning. And, you know, and that was the first thing I was doing all day and he was that[?]. out in Boulder Reservoir, um, on... [clicks tongue] on the kneeboard. And, uh, I said... I said, "Jimmie, you know, what happens when you fall?" And he-he would just tip over and be looking at the bottom of the Boulder Reservoir until the boat turned around and someone jumped out to flip them back over. Um, you know, yeah, he was an ad-adrenaline junkie right up to the end.

Mandy: Yeah.

Tyler: Right up...

Mandy: Yeah.

Tyler: ...to the end. Yeah.

Mandy: [laughs]

Tyler: Yeah. To see him, you know, going down a hill on his hand cycle with the wind blowing through his hair, with a big smile on his face, it was just... it was priceless, priceless, so... Yeah, I-I knew him last 6-7 years of his life and, yeah, super special times. I think about him all the time. You know, what would Jimmie do? I tell him[?], I ask myself a lot.

Mandy: What would Jimmie do? [crosstalk] So cycling brought you, brought you to MS, brought you to the community of multiple sclerosis as...

Tyler: Correct.

Mandy: ...just a fundraising effort, but Jimmie brought you, brought you into Can Do MS and to the mentality and the thinking around exercise, wellness, um, determination, above and beyond determination like none other. It sounds like, I like that. Um, Jimmie had already been waterskiing and he was just picking you up for a light cycling ride at the end of his... at the end of his workout, it's great. So, you touched a little bit about kind of what connected you and what drew you to Can Do MS. Clearly, it was Jimmie's, like, aura and the presence about him. But was there something about the organization and about how he led that and the leadership that Can Do MS has that really attracted you and really made you committed and dedicated as much as Jimmie was to Can Do?

Tyler: Yeah. I mean, I would say it was, you know, it was his-his [(10:00)] can-do spirit that eventually kind of filtered down through the whole organization, you know, which there... which is there today. It's like, you know, you do what you can do. And, you know, you keep a positive attitude, you know, you pick yourself up, you dust yourself off every day, you-you do what you can do. You-you go through... you work hard, you know, you stay active, you

exercise, you take good care of your body. You know, you live a-a happy and healthy life. Um, you know, that-that just has, you know, taken over the whole organization. It-it's awesome. It's awesome to be around the group of people working there. They breathe Jimmie. They breathe Jimmie. That's, uh... it's awesome. I feel... I feel lucky to be involved in... lucky to have known them. Yeah, lucky for a lot of things.

Mandy: You mentioned, Tyler, that there are times when you think what would Jimmie do? There are circumstances when maybe things are challenging for you personally or professionally or whatever it might be. Can you... would you mind sharing an example of a time when you said to yourself what would Jimmie do? When you really channeled his energy and his inspiration to-to make a decision, to make a choice. And I'll give you a moment to think about that.

Tyler: Yeah. I mean, sometimes it's just about, you know, responding in a, you know, i-in a difficult situation, maybe take a nap, extra 5 or 10 seconds, take a few deep breaths and-and respond the way Jimmie might respond, you know. He... I never saw him lo-lose his cool. Like he was always very positive. He... Sometimes he would sit there and think for a-a few moments before he would, uh, you know, talk to you, or respond to you. And, um, yeah, I try to do that. I'm not as, um, you know... I'm still learning but, you know, Jimmie was really good at that and...

Mandy: Blaze, what about you? I mean, many of us have things that, um, that our parents have told us over the years that resonate, that will carry us through in difficult times. Are there any moments where you hear your dad's voice, it helps to guide you to make a decision or [(12:00)] to think differently or live differently?

Blaze: Yeah, absolutely. I mean, I think the greatest part of my dad's legacy is that he was given a diagnosis that he needed to pretty much stay dormant and give up all the passions in his life. And the best thing he ever did in his life is ask why and question experts, which isn't always the right thing to do, but sometimes is. And he challenges the norms of our society and allows us to think in a different way and act in a different way and create a-a better world. And so whenever I'm faced with adversity or, you know, kind of question the-the culture of the norms that-that we've all been raised with, um, I do think about how he would... he would think through that situation and see if there's a-a different way to look, um, you know, what[?]-... you know, sit... life in general, um, situation specifically whatever it may be. And, uh, I-I-I think that [clicks tongue] has brought a lot of enlightenment to my life, um, and inspiration to keep an open mind. So, I'm-I'm very grateful for those lessons that he provided to us.

Mandy: An open mind, endless determination, those are certainly life skills that can be valuable regardless of career path, regardless of life path. But [crosstalk] it was also...

Tyler: Uh, [inaudible] Jimmie wasn't just an incredible leader. I wish that, you know, I wish everybody could have met him, you know, incredible leader but didn't always have to do it w-with his voice. You know, a lot of times he was... It is the presence about him that was just-just incredible.

Mandy: I can imagine, Tyler, for you especially like the opportunity to meet your idol. I-is that okay? Is that okay [crosstalk] to describe it like [inaudible]?

Tyler: Yeah, and my dad's as well. My dad got to meet him. The f... the first time I met Jimmie, my dad met [(14:00)] him as well and so... He was over the moon.

Mandy: Blaze, how does that make you feel when you hear about how your dad has touched Tyler's life, but also the lives of many other people?

Blaze: I mean, i-it's the same way that I feel about him. I have so much admiration for how he conducted himself, um, when he could have been, you know, a total sob story. And, um, you know, what he does for other people, he-he did for us as well, um, as did my mom. And so, I... you know, I feel very blessed to be their son and, um, I just have so much respect for-for what he's done, um, for himself, for the foundation, and for other people. It's, uh... I never get sick of hearing it. So, it's-it's a great feeling. Uh, Tyler, I was wondering if you recall the first time hearing about my dad, um, and or what triggered you to reach out, connect, um, and, get involved.

Tyler: Yeah. I re... Uh, you know, I grew up a ski racer, uh, back in the East Coast. I grew up in Marblehead, Massachusetts. And, uh, we were... we were weekend warriors from driving[?] the car up to New Hampshire every Friday night and ski on the weekends. I became a ski racer young, following-following my brother's footsteps. And yeah, at a young age I heard about Jimmie Heuga and-and Billy Kidd, you know. They were the first Americans to-to win alpine medals, first athletes[?]. Yeah. And, um, so yeah, I knew about, I knew about him probably since I was about[?] 8 or 9 years old. Uh, ski racing was my, you know, true love.

Um, and yeah, I-I followed all-all-all-all the... all the big ski racers who... from the past, in the present, and-and, uh, h-he certainly was one of them. And then that in... But, you know, I knew he-he suffered with MS, but [(16:00)] I didn't really know anything about the disease. And then in 1997, I was a professional cyclist at this point, uh, my agent, his mother-in-law, was diagnosed with MS. He-he asked me to go do a ride south of Austin, you know, to-to get back to the cup, the fight for MS.

And the rest is history. That-that day, you know, I-I met people with MS. It was husband or wife had MS, it was co-worker had MS, it was brother or sister had MS. And-and, you know, everyone was in a different battle. And from that point on, I was like I need to give, you

know, for as long as I live, I need to give back to this, uh, to-to the fight against MS. And, uh, and then, uh, I started my own foundation. I think it was[?] around the year 2000. And then... and then, uh, the executive director of the foundation was one of the, uh, linking members to link us together. They're in, uh... There were Jimmie.

It was also that with the help of Richard Rokos, the CU ski team head coach. Uh, Richard was a huge fan. Richard did so much, so much for Jimmie. He loved Jimmie dearly. Um, I remember, uh, Richard set... he helped set up, uh, Jimmie's van that he had there outside of Boulder with a low like crane, so it can help lift him in and lift his, uh, hand cycle into the back of a, uh, the minivan.

Blaze: Mm-hmm.

Tyler: [inaudible] and a lot easier then[?]. Yeah, that was all thanks to Richard Rokos, so...

Blaze: Yeah.

Tyler: But yeah, I, yeah, I've known him for a l... I-I knew about him for a long time and then I finally got to meet him. And, you know, I was... I felt very lucky.

Blaze: Awesome. I don't think I ever heard that story.

Tyler: Yeah. Uh, what was he like as a skier, Blaze, from his ski room? I heard he's pretty fearless.

Blaze: Yeah, I mean, um, he was mostly in a sit-ski when I saw him ski but I-I do remember this one time, he had a guy that was bothering him and my brothers and I would kind of, you know, [(18:00)] shelter around him so that other skiers wouldn't run into him. But one time a skier did cut him off and, um, he tipped over a road[?] pretty good. And, you know, my brothers and I, we were furious. And, uh, you know, I think a couple of us went and chased after the guy, um, screaming at him. And then we kind of hiked back up to my dad and he's just laughing. And, uh, we-we were so confused. And he pretty much just said there's no better day than a-a day on the snow. So, um, he loved it. It was, uh, everything he wanted to do. And even late in life, he still had that passion, which is great. So, he was a crazy person. He loved falling. He loved, um, going fast, it didn't matter. He loved it all.

Mandy: Tyler, I have another question for you if you're willing to speak to this. I know you faced a lot of challenges when it came to your cycling career. I am curious how Jimmie might have influenced you during that time.

Tyler: Oh, yeah. I mean, yeah. I mean, I went through a lot in my cycling career. Yeah, my life, you know, went from winning a gold medal to whatever a month later, you know, finding

out I had a positive doping test. M-my life kind of falling out right from underneath me like straight down. And, like, luckily, uh, uh, maybe a month later, I m-meet Jimmie. You know, I mean, so maybe, you know, maybe it was meant to be but he really helped me get through some hard, hard times for sure. And I kind of... me after meeting him forced me to kind of take a few steps back and like look at the big picture and like really be-be thankful for... There's so... there was a lot to be thankful for, for sure, for sure.

And I knew if I just, um, kept chugging along, like things would improve, you know, if Jimmie can do it, I can do it, right? So-so yeah, it was great. I felt very lucky, very lucky and I met him at the, like, perfect time in my life. So, you know, it sounds a little bit selfish but... And then we just s-slowly became friends, and it was just, it was great. It was great. We had a lot of fun together. We laughed a lot [(20:00)] together. Yeah, he was crazy, like he bombed down these descents. And s-sometimes I think, oh, he's going to flip over on this turn. Sometimes I feel like he was on, just on one wheel.

Blaze: In a bigger way[?].

Tyler: Whether he wiped out or not, he-he always had a big smile on his face. So...

Mandy: Yeah, that's what I remember about him too, was his smile. If Jimmie were here now, and you've expressed a couple of different times during our conversation that you wish Jimmie were here, that you wish that Jimmie, uh... you could still talk to him. Can you just share, if he were here now, in this conversation with us today, what would you like to tell him? What would you...

Tyler: Oh, man. I mean, if I... I'll tell him I love him and that I miss him for sure. That's to start. And just, you know, thanks for all the inspiration. Thanks... I'm so grateful to have known him and taken all these lessons from him. But I cannot get my big hug.

Mandy: Blaze, what about you? If you, um... I'm sure you talk to your father in your mind all of the time and you hear his voice guiding you many times throughout your day. What, um, what would you like to share with him if he were able to join us today?

Blaze: Yeah, I mean, one of the last things that, uh, he ever asked of me is that that I stay involved with the foundation here. And so I-I suppose if I got to see him again, I would, you know, thank him for the-the inspiration and the courage and the opportunity to, uh, to do something bigger than myself.

Mandy: And Can Do MS has certainly evolved into that. What do you think, uh, Jimmie would think of Can Do MS and how it has evolved today? All of these years later and all of these lives that the organization has impacted, what will he say to that?

Blaze: Well, I-I think he would be pretty happy. I think there-there's a large part of the organization he wouldn't recognize, and I say that in a positive way. Um, [(22:00)] the direction that we as a board and as, you know, the-the employees have decided on is incredible. It is much more expansive than what I believe it used to be. And, uh, I-I believe it does a-a great job of focusing on, uh, long-term connection to people and families that-that are dealing with MS. Um, a more holistic approach is always something that he would have wanted. And I think he would be pretty surprised, um, specifically with the technology that is-is going on-on, um, all over the world specifically with Can Do. I think he would be pretty surprised and, uh, delighted with the progress that-that we've made.

Tyler: Yeah, I've had... The word that comes to my-my mind is I think he'd be proud of you. He'd be proud.

Mandy: I think Jimmie would be incredibly proud of both of you and how you have helped lead Can Do MS to become what it is today. Thank you again so much for joining us and for helping to continue his legacy.

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And thank you to our listeners for tuning in to another episode of the Can Do MS podcast. I'm your host, Mandy Rohrig. Thank you for joining us. I'd also like to give a special thanks to our sponsors for making this podcast possible. Special thanks to EMD Serono, Novartis Pharmaceuticals, Sanofi Genzyme, and Genentech.

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