



The Think Inclusive Podcast

Season X, Episode X

Zachary Fenell | The Cerebral Palsy Vigilante

Audio Transcript

Zachary Fenell:

Hi, I'm Zach and you are listening to the Think Inclusive Podcast.

Tim Villegas:

Recording from my office in beautiful Marietta, Georgia, you are listening to the Think Inclusive Podcast, episode 17.

Tim Villegas:

Today we have speaker, marathoner, and author of two books, Zachary Fenell. The first, *Off Balanced*, is a memoir about what it was like growing up and living with cerebral palsy. As well as *Rock Realities*, a compilation of 13 interviews he did with Indie and Alternative Rock musicians.

Tim Villegas:

We discuss his most recent endeavor, completing a marathon and all of the challenges that came up for him, being a person with cerebral palsy. After the podcast, please visit patrion.com/thinkinclusivepodcast where you can support our goal to bring you in depth interviews with inclusive education and community advocacy thought leaders.

Tim Villegas:

Also, you can help other people find us by giving us a five star review on Apple Podcast, or wherever you listen to the Think Inclusive Podcast. So without further ado, here is the interview.

Tim Villegas:

Alright, I'd like to welcome Zachary Fenell to the Think Inclusive Podcast. He is also known as the cerebral palsy vigilante. He is a disability advocate who uses multiple platforms to send messages to dispelling misconceptions and encourages everyone to examine the possible.

Tim Villegas:

He recently completed a marathon. That is why I wanted to have Zach on to talk about his experience, his training and I guess how that informs what we know about disability, or disability rights. So thanks for being on the podcast Zach.

Zachary Fenell:

My pleasure. I'm excited to be here.

Tim Villegas:

Now, if you've been either a long-time reader, or a long-time listener, to Think Inclusive, you know that Zachary has been a contributor for since practically the beginning of Think Inclusive. So Zach and I go way back.

Tim Villegas:

But this is the first time we've actually had a chance to record an interview. So I'm really excited about this. We actually haven't caught up in a while, so why don't I ask you, Zach, so what have you been up to for the last six months to a year?

Zachary Fenell:

Six months to a year, let's see. Where to start. I basically, since the summer, you mentioned the marathon. Since the early summer I've been training heavily for that. Back in, what was it? May I started working part time at the Beachwood Public, at our local library as a page. So I've been do that part time and then keeping my purpose with, I have my own blog in addition to contributing to Think Inclusive's website.

Zachary Fenell:

I have my own blog at zacharyfenell.com and as actually it's been recent, a couple of recent honors. One was I was named among 100 of the ... I'm trying to remember the exact title. Is it like 100 best disability blogs by Stairlifts UK. And then recently also HealthUnlocked, I was short-listed out of the 100 of blogs nominated, I was one of 30 short-listed in the running for one of their health blogger awards.

Zachary Fenell:

What is really neat about that was that it wasn't just cerebral palsy, which is the disability I focus on a lot. Or just any disability. It was a health blogger thing, and not just blogging or disability blog. So the two fields are very have a lot of commonality, but at the same time there is a lot of that ... It's you know when you open it up from disability to health blogger, you are opening it up to a larger field and to be even short-listed among the blogs considered was an honor.

Tim Villegas:

Wow, that's amazing. Congratulations on that.

Zachary Fenell:

Thank you.

Tim Villegas:

So it sounds like you've been pretty busy.

Zachary Fenell:

Yeah.

Tim Villegas:

Let's talk about, let's talk specifically about the marathon. 'Cause I know that that is something that you just finished. That was last week, correct?

Zachary Fenell:

Yeah.

Tim Villegas:
Go ahead, go ahead.

Zachary Fenell:
I was just going to, actually at the time of us recording this podcast, I would have been in the final two and a half miles on the way to the finish line. So the timing of it, there's parallel timing there.

Tim Villegas:
Yeah, so you'd be in the home stretch.

Zachary Fenell:
Yes.

Tim Villegas:
So let's talk a little bit about how you trained. And then after that, maybe just the experience of running the marathon. Because this isn't actually your first marathon. You did a half marathon previously. Is that correct?

Zachary Fenell:
Correct. In 2016, the Towpath Marathon is the name of the event. 2016, they have a 10k, a half marathon and marathon in October. I did the half marathon last year, 13.1 miles. And then after I completed that, my friend who did the marathon with me this year, challenged me. "What are you going to do now?" I was just kind of like, "Well my goal was to do half." So I didn't really have an answer. And he kept pushing me to do the marathon, encouraging me to do the marathon.

Zachary Fenell:
I finally said, "I'll do the marathon if you do it with me." And he's like, "Okay." So one day I got a text from him in the morning, early morning, showing me that he had registered for the Towpath full marathon and I was like, "Okay, this is real now." I got with my training and started with my training in moving forward with that.

Tim Villegas:
That's so awesome. So in case you don't know how hard it is to prepare for something like that, just for your body to be used to be in motion for that long. I had the privilege of running a half marathon in 2015, and trained, I mean I trained.

Zachary Fenell:
Yep.

Tim Villegas:
But it was definitely time consuming. It took a lot of wear and tear on your body. But it was a great experience. So I want to hear from you, what and I guess what inspired you, or what prompted you to even go down the road of doing these marathons, from the half marathon to the full marathon?

Zachary Fenell:
So it really all starts back in the spring of 2011. I was hanging out with a couple of friends weekly, and they were training for a triathlon. At the same time I was reading a book, Unlikely Story of Challenge and Triumph Over Cerebral Palsy. Someone like me, by John W. Quinn. John has cerebral palsy like me. He

spent 20 years, he had to hide his cp from the Navy, but he spent 20 years in the Navy, reaching the second highest rank.

Zachary Fenell:

Reading his story really made me feel like, "Wow, I want to do something physically challenging." Just reading what John had wrote. How much of a physical challenge what he went through was. It motivated me to want to go to do something physically challenging.

Zachary Fenell:

The friends I was hanging out with at the time were doing triathlon. Don't ride a bike. So my thought was, "Well I'll do a marathon." And I asked, "Well how long's a marathon?" They're like, "26.2 miles." So I'm like, "Well I'll do a half a marathon." Because in my mind it was unreasonable like, "Oh that's a lot. I can't do a marathon." So I was just like, "I'll do a half marathon."

Zachary Fenell:

Fast forward a couple years and I really wasn't making too much progress on the goal. It was something I kept saying I was going to do, but didn't do. And then I did a one mile. Tim knows, and those of you who know me, know I'm a huge Cleveland Indians fan. They had an event at their Progressive Field, their home field where the last mile was going through ... It was a 5k and then a one mile fun walk. You end up on the field. During the one mile fun walk that year, this was 2014. That gave me that taste of what I needed to motivate myself to get serious about doing, about going after a half marathon.

Zachary Fenell:

I started training. It took me two years to get to the point where I can do the half marathon. 'Cause when I first started training, the most I could do was 4 1/3 miles, and then was just completely wiped out. Completely exhausted. When I ... Like I said, towards the end of that goal, a month before that half marathon, my friend James, who I did the marathon with had me come in to speak to ... He coaches cross country at a local high school. He had me come in to speak to them, give a quick five minute pep talk.

Zachary Fenell:

Afterwards, him and his other coaches were asking me what's next, and hinted like, "What's next?" And I'm like, "The goal is the half." It was still in my mind I considered unreasonable to do a marathon. In my head I was telling myself, "It's unreasonable to do a marathon. I have cp." I exert extra energy just with each step than usual. So I'm just going to get exhausted faster. I want to be able to do a marathon, but like I said, James kept persisting, and finally I said, "I'll do it if you do it."

Zachary Fenell:

That led us to June this year, 2017. James had said, "I did this." And I'm like, "Okay." He registers and I'm like, "Okay. No excuses. I told him if he did it I would do it." So I started training in the ... First thing I did in training was I just started getting out regularly where three times a week I would be going out and walking about six miles. Just to get out, do the six.

Zachary Fenell:

After the half marathon, I actually, admittedly, I fell off my training, and I fell out of half marathon shape. So I had to really re pick back up. So I would do a six mile walk three times a week, just to get my body used to, I guess being tired. So that by the time I would do the actual full marathon, and I'd get

tired instead of letting myself shut down, I'd be like, "Okay, I'm used to this. I can persevere through any fatigue I'm feeling."

Tim Villegas:
Now-

Zachary Fenell:

And I started doing that and at the same time I started reaching out to anyone who had the marathon experience that I knew of, that I could get advice from them. John actually, John Quinn, the author of that book that I mentioned was somebody who had done a marathon, so I reached out to him. I have a friend, Michael Minozzi, who is, represented United States in race walking. So he has done a lot of long distances. So I asked him for advice.

Zachary Fenell:

James had a friend, Shawn who has done marathons and I asked them for advice about, "Okay, what do I need to do? What else do I need to do for training? What do I need to eat?" 'Cause that's one of the things to me that woke me up about training for a marathon. It isn't just putting on some miles and getting ready for building up your endurance. It really is a lifestyle change. You have to be eating more calories to be able to have the fuel in your body. You want to make sure that ... One of the pieces of advice they gave me was, "Train when you're going to do the race."

Zachary Fenell:

No, I actually started, the Towpath marathon, their course runs from, they have a walker and runners registration. I registered to walk it. I was the walkers can start at seven and then the course technically closes at two. That's when their permit goes to, and then the course opens back up to the public.

Zachary Fenell:

I had contacted Towpath saying that I thought it was going to take me longer than that. So if I could start at 5:30, if that would be possible. They worked with me to set that up. So I was training early morning to get out and putting on. I increased my miles from doing six to doing, basically doing a half marathon distance a couple times a week and just continuing with increasing miles and building up endurance and basically simulating what the environment was going to be.

Zachary Fenell:

Early on in my training, I used canes to complete the marathon. Early on in my training, I knew that, that might be an option, but I was going to train without it first, just to make sure. Just to see if I could do it. In my mind I worried that if I use my cane, that I'd be cheating myself out of some of the workout. And it just came and I had to realize that when you choose to do a marathon, you're not cheating yourself out of anything. My legs are still getting the workout. The cane is just there to help me with my balance.

Tim Villegas:
Right.

Zachary Fenell:

So John was the one who told me, he's like, "Train in what you're going to wear. Train with what equipment you're going to use." So I started using the cane after a couple months. Eventually I had ... I had a couple of falls as I was training. I just decided that I noticed that they were coming, the falls were coming when I was hitting the 9, 10 mile mark.

Zachary Fenell:

So I realized that it was just this level of exhaustion that I should really, I should take my cane and start training with my cane. That's what I did and just gradually increased the miles I was doing a number of times a week. Is there anymore specifics about my training regimen that you would like me to go into?

Tim Villegas:

Yeah. Well you kind of answered a few of the questions I had, like how many times a week did you train? I think that was three times per week.

Zachary Fenell:

Yep.

Tim Villegas:

And then typically I guess here's my question is, because of the cp, was there anything that you did that was different or unique than any other, I guess how any other person would train? Like if you reached out to certain people and they said, "Well you should do this specifically because you have cp." Or was there nothing like that?

Zachary Fenell:

There was a couple things. One of the biggest obstacles you mentioned this when you were talking about training for the half marathon is it is really time consuming. When I do ... I basically was expecting to do three miles each hour as my pace. So to find the time to continuing to increase the training, it was difficult to find the time. I talked about how I increased, I started with doing six miles three times a week and then I increased it to where was doing a half marathon twice a week and going from there.

Zachary Fenell:

The last month of training, especially the latter two weeks, I was told that, John was actually the one who told me and my friend Mike, who Team USA race walker, agreed with him that you should be shooting to be able to do 20 miles before you do the marathon. Because if you can do 20, you can do 26.2. I started ... I never actually got to that 20 because of finding the time to do it. I ended up eventually going back to doing 9, 10 miles three times a week and again, it was just a lot of it just do to finding that much time to train with, or to have to train.

Tim Villegas:

Right.

Zachary Fenell:

So I knew, I felt going in, I felt like my legs were strong enough. If I'm doing this consistently, week after week, my legs feel strong. I felt strong that I was going to be able to do the marathon. Part of me, there was a little doubt because I've never actually done a marathon.

Zachary Fenell:

It's hard to know 100% for sure whether or not I'm ready. But I felt ready and I was like ... So that was one aspect of the training where I didn't get exactly to where I was told to get. A lot of the reason just dealt with finding the time and the fact that it ... To train to that level, I would have had ... To train to that milestone of 20 miles, I would have had to find seven hours worth of time to train and around seven hours of time to train.

Zachary Fenell:

It was very ... Having a part time ... Talking about earlier, what I've been doing the previous six months and how busy I am. It was hard to find. It's hard to find that time.

Tim Villegas:

Right. So how long did it take you to finish the marathon on Sunday?

Zachary Fenell:

It took me 11 hours 40 minutes and 31 seconds. I went in there with the expectance of finishing in eight and a half hours. Obviously that was blown out of proportion. I basically was walking for nearly half a day, almost half a day to complete it.

Tim Villegas:

Right.

Zachary Fenell:

But I think a lot of that, I think the three hour difference from what I expected and what I achieved it in, a lot of it dealt with listening to my body. It was around the 10 mile mark, my right ankle started bothering me a little bit and I stopped for a minute, cleared out. I had some debris get in my shoe, so I cleared out my shoe and then I worked my ankle a little bit with my hand and then continued on.

Zachary Fenell:

But I didn't try to overdo it. I respected what my body was telling me. I think that's where the difference in time, what I expected and what I did it in was. But at the same time, there were, we were seeing other people being carted off the course who were unable to finish because of injuries. So it's one of the things you have to do, respect what your body was telling you.

Tim Villegas:

Yeah.

Zachary Fenell:

I did end up finishing.

Tim Villegas:

Now did you have any ... You talked about your cane. But is there anything in particular, any other unique gear that you had? I saw some of the Facebook videos that you posted, or that the Facebook lives where ... So I saw some of the stuff that you were wearing but was there anything unique about what you used?

Zachary Fenell:

One of the things that wouldn't be obvious from the Facebook live videos, this is just for my regular, day-to-day walking too. I have a half-inch leg discrepancy between my left leg is a half inch longer than my right. So I have foot orthotics in my right shoe. It has a lift to compensate for that.

Zachary Fenell:

That's something I use on a daily basis, just walking. That was something that was ... That I was using to help relieve the height discrepancy. But outside of that, I can't really think of anything that I used special that would have been, that you would have been able to see in the video.

Tim Villegas:

Yeah. I also saw people cheering you on and calling you an inspiration, just overall sense ... Were there people that knew that you were doing this, and were there for you to specifically cheer you on? Or was it just people who saw you while you were in the race?

Zachary Fenell:

It's a combination. There was a combination. Actually that day, our area paper, The Plain Dealer, they had the metro columnist did a story on me, about my training for the marathon. That ran the day of the paper. So we had some passersby who were like, "I saw you in the paper this morning." And knew about it, knew about me from that.

Zachary Fenell:

Then there were friends I invited out to basically cheer me to the finish, 'cause that was one of my things, 'cause mentally was, if I have people at the finish line waiting for me, it's going to be that extra motivation to get to the finish line, instead of giving into whatever physical pain I might be feeling.

Zachary Fenell:

Two of my friends who I had told family and friends to show up between 1:30 and 2, as I expected to finish around 2. But once a couple of friends of mine, once they got word that I was a lot farther behind than I had expected, they had actually, the permit, I mentioned earlier, the permit the Towpath people had ended at 2 o'clock so the Cuyahoga Valley National Park opened back up to the public.

Zachary Fenell:

A couple of friends I had, they decided, you know what, let's go find him. They knew I was around the 19. I think they started walking towards our way. I was on the 19th or 20th mile. So they had walked out with about four miles left, they had caught up with us and they walked with James and I, the final four miles. Those are two of the individuals seen in the Facebook live video of my finish.

Zachary Fenell:

So they had actually, so they had showed up for me and they made that decision, "You know what. We're going to walk out. We're going to find Zach and we're going to go the rest of the way with him." At that point, I knew four miles left, I was getting it done. But it made the last four miles a lot funner than they would have been otherwise.

Tim Villegas:

Yeah, I bet. I wanted to ask you too, with people calling you an inspiration. Certain disability advocates and disability rights advocates are not comfortable with what they've done or their life being an inspiration. But I wanted to get your take on that, as far as how you feel about being called that.

Zachary Fenell:

I used to have that mindset where it was just like, "Why am I ... It's that attitude of, I set a goal and I wanted to complete my goal. Just because I have a disability doesn't make me an inspiration. I understand that mindset. But what really took me back was it going back three years, I have an aunt who lives out in Tucson, Arizona. Or had an aunt who lived out in Tucson, Arizona. She had been

diagnosed with leukemia and given two months to live. She had always been one of my biggest supporters.

Zachary Fenell:

I went out there with my uncle, her brother, to visit her and just be there to be a support for her. One night, me and her, we were having a conversation, and she called me ... And I mentioned that, she basically called me an inspiration, and I called her an inspiration. I called her an inspiration because she wasn't letting ... Despite the bad hand that she was dealt with her leukemia, she didn't let that change who she was, and she kept fighting. To me, that was inspiring.

Zachary Fenell:

She called me an inspiration. It was just in ... The dialog, it was just like, "Well I don't consider myself an inspiration." She didn't consider herself an inspiration. But so when ... That's where I realized, that is in the idea. Being inspiration really it's the eye of the beholder, if you're inspirational.

Zachary Fenell:

My whole thing with I would ask is, if someone says you're an inspiration, is it just blind compliment because you have a disability? Or my question always is, "What makes me an inspiration to you?" So that's like, I'm okay with being called an inspiration for especially for doing the marathon if ...

Zachary Fenell:

There was a, I had one biker who passed us after the course opened back up to the public. She wrote me later on. She got my name off the results page and found my website and she wrote me later on to tell me that she at first thought I was an injured runner. Then where she was at the point where the finish line was and she ended up talking with my mother, who both my parents were there to also support me.

Zachary Fenell:

In talking to my mother she found out I had cerebral palsy, I was doing the marathon. She had done four marathons herself before. She said, "As a perfectly able-bodied person, I know how difficult it is to do a marathon." So she found me inspirational for the reason of even trying to attempt what I even once consider unreasonable for myself. I'm okay with that. I think that's great.

Zachary Fenell:

So I think really my opinion on the inspirational comment really weighs in is asking, "Well why do you say that? Are you ... I think sometimes people mistake, certain situations people might mistake inspirational for in awe. I don't know if this works in all disability situations, but I know it relates to the marathon situation, because I know I had a couple of individuals where I work make mention to me this past week that, "I could have never done that. You inspire me. I could have never done that. I would be done after two miles, or three miles."

Zachary Fenell:

In my mind, that's not really inspiring you then. That puts you in awe of what I've done, but you're not inspired to go out and do something. You're not necessarily going out there to improve yourself, which I think is a part of what inspirational is, is being that motivation to go tackle something yourself.

Tim Villegas:

Yeah, I like that perspective. Not being content with just being called an inspiration, but really digging in and finding out what that means to that person. And also, the idea that something that you have done

can spur on action for another person. I look at your life and that makes me want to do something, and causes me to do something. So yeah, I like that perspective.

Tim Villegas:

I have a couple more questions, when you were running, when you were in the race, the marathon, did you feel like the, I guess the marathon was accessible to you as in ... You said that you had contacted them beforehand saying, "Hey, I'd really like to ... It's going to take me a long time to finish. Can I have an earlier start time?" Did you feel like they were accommodating? And was there anything else about the race that you felt like they made an accommodation for you for?

Zachary Fenell:

The Towpath race itself, the course is pretty flat, which is really nice and a big reason why when James was like, "What marathon are we going to do?" I said, "The Towpath." Because I knew it was pretty flat and it would be accessible.

Zachary Fenell:

They were very accommodating. The person who responded to my initial email, she actually had, I came from talking with her and arranging everything, I came to know that she had a nephew who passed away, who had cerebral palsy. So I don't know if that helped at all, to make her more understanding of what I was going through. Or more understanding of my situation.

Zachary Fenell:

But they were very accommodating. I know that's not always the case when someone asks for accommodations. That's one of the fears you have sometimes, you trick yourself into thinking, "Well I don't want to be in the way." And it's just ... It's all about inclusion, John Quinn, going back to him for a second, he has a great definition for inclusion, that is having opportunity to complete something. So it's like, give me the same opportunity to do it. For me it was just time.

Zachary Fenell:

They were very accommodating with their attitudes and in general, I have found that I kept a group of people who were working the marathon three hours past what they normally would have been there for 'cause they were waiting for me to finish and see this thing through.

Zachary Fenell:

During the middle of the race, there might have been some who were waiting for me to drop out. 'Cause I remember around the 16 mile mark there is an aid station, Gatorade, water. When whoever was working that station, after I had drank some water and Gatorade I was like, "Keep going this way." And pointed to the direction, he goes, he was just surprised. He's like, "You're continuing on?" I'm like, "Yeah." And he's like, "Yeah, go that way."

Zachary Fenell:

So I think there was some surprised individuals that I think they were waiting for that point where I would drop out. But no, it was never ... I might have been oblivious to it, but I never felt like that was pushed on me like, "Really? You're continuing on?" I never was pushed on me. They gave me that opportunity to finish.

Zachary Fenell:

They were accommodating, I think some of it might have gone to the contact I had was Kathy, and I think some of it went to her own history with cerebral palsy, having a nephew who had had cerebral palsy.

Zachary Fenell:

So the course is accessible. It's a great course in that fashion. It's in a park, so there are some issues. I did fall twice in mile three and mile 16. In mile three I had tripped over a monkey ball that had fallen from a tree, that I stepped on it, I flipped and went down to my knees. But that's something I could have ... I think it would be impossible to expect them to clear all the debris from the course. I felt like they were reasonably accommodating. They were very accommodating in both the actual course and then their attitudes toward me.

Tim Villegas:

That's great. That's really good. So I'm going to ask you probably what a lot of people have asked you. So you've run your marathon, so what is next in for Zachary Fenell?

Zachary Fenell:

There is a lot next. There's a lot to do. I know with the marathon itself, I honestly would like to get the marathon, my finish time under 10 hours. So I'm going to ... James and I are already talking about going back and doing the Towpath again next year. I would like to as far as races go and that aspect, I would like to get my marathon down under 10 hours. So working on increasing my pace and continuing training to do that. That's definitely in the, that's something I plan to do.

Zachary Fenell:

I think from the response I have received all week from the marathon, I'm also thinking about putting together ... I'm actually in the works of ... No release date yet, but I would like to put together a memoir, my second memoir that details that marathon journey for me. I share my story with the hopes of, I don't share to brag. I share in hopes of exactly what I talked about as far as inspiring and helping, hopefully helping others see what they might at once considered unreasonable, attack it and go to work at it and then achieve what they once maybe thought was impossible for them.

Tim Villegas:

That's fantastic. Good luck with the other memoir.

Zachary Fenell:

We'll also be contributing to Think Inclusive in the future as well. My training took me away there for a second for some. But yeah, you can definitely expect to see my contributions to Think Inclusive in the future as well.

Tim Villegas:

Yeah, that's good news for us. I also want to mention to everyone that's listening that Zachary has his first memoir, Off Balanced, and you can find that on, I know you can find it on Amazon, can they find it on your website too?

Zachary Fenell:

Yeah, I have all the information on my website. So they can get all the details of where they can find it on my website.

Tim Villegas:

Okay, did you want to plug anything else? Do you have a Facebook page and Twitter?

Zachary Fenell:

Yeah, basically if you want to get in touch with me you can do so on Twitter @zacharyfenell it's Fenell, my last name F-E-N-E-L-L and then Zachary, Z-A-C-H-A-R-Y, so Z-A-C-H-A-R-Y-F-E-N-E-L-L. And then my Facebook page is Facebook.com/authorzacharyfenell, so A-U-T-H-O-R, then my name. You'll find me there. Yeah, I'm always ... One of the most rewarding things is getting feedback from individuals.

Zachary Fenell:

I also have a YouTube channel. That is youtube.com/zacharyfenell that would be ... I put together a YouTube video every week. That would be something else to check out of mine. But like I said, I always enjoy getting feedback from viewers, readers, whatever descriptor you fit in. So just having a conversation. Feel free to reach out to me on Facebook, Twitter, check out my YouTube channel.

Tim Villegas:

Alright, Zachary Fenell, thank you for being on the Think Inclusive Podcast.

Zachary Fenell:

It's my pleasure. Thank you for having me.

Tim Villegas:

That is our show. We would like to thank speaker and author, Zachary Fenell. Make sure you check out his website, zacharyfenell.com and you can find him on Facebook and Twitter. Follow Think Inclusive on the web at thinkinclusive.us as well as Twitter, Facebook, GooglePlus and Instagram.

Tim Villegas:

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