The Brave Minds Project – Alyssa Carfi

Alyssa Carfi founded the Brave Minds Project after a bleed in her brain at age 15 and then brain surgery to remove the cavernoma at age 18

Instagram: Alyssa Carfi and Brave Minds Project
Facebook
Website

Transcript:

Highlights
3:30 Brain stem cavernoma
6:40 Ticking time bomb
24:11 Didn't let it run my life
30:01 Brave Minds Project
33:15 Your ears pop all the time, my ears up all the time
41:04 Favorite things

Alyssa Carfi 0:00
I was 27 when I met someone who had a brain stem cavernoma, and that was the first time I had ever met anyone who had what I had. Like, if I met someone years ago, we could easily text and be like, oh, oh my gosh, your ears pop all the time, my ears up all the time. And you know you don't feel so alone. So, if I could just help to create that with other people. That makes me happy.

Intro 0:32
This is Recovery After Stroke with Bill Gasiamis helping you go from where you are to where you'd rather be.

Bill 0:41
Bill Gasiamis here from recoveryafterstroke.com This is Episode 72 and my guest today is Alyssa Carfi. Alyssa is the founder of the Brave Minds Project which was brought to life 10 years after her brainstem surgery. She was just 15 years old when a bleed in her brain from a cavernoma caused her to be seriously unwell.

Bill 1:04
Alyssa was 18 when the cavernoma bled again causing even more damage, and Alyssa underwent brain surgery just a few days after her high school graduation. Now just before we get started with the interview, I wanted to let you know about a free webinar that is available for you to download. If you go to recoveryafterstroke.com/webinar, and click the Download Now button, I will send it to you directly in your inbox.

Bill 1:30
The webinar was created for people on the road to recovery after a stroke, and by watching it you will learn how to take action on your recovery now, how to build a vision for the future that will inspire you, and what to do when you are faced with hard decisions about your path forward. You will also learn the importance of creating a supportive team around you and what people that recovery journey should include.

Bill 1:55
As well as how recovery after stroke coaching can help speed up your healing. So don't just be a stroke survivor. download this free webinar at recoveryafterstroke.com/webinar and become a stroke thriver, Alyssa Coffee from the Brave Minds project. Welcome to the podcast.

Alyssa Carfi 2:15
Hi, thank you for having me.

Bill 2:17
Thank you for being here. It's really exciting to get another person onto the podcast and from an amazing recommendation from Kyle Mengelkamp, from Share Your Stroke of Genius whom I interviewed a couple of episodes ago. It's really good to connect with people who have made connections all over the world. I know you guys are in New York, is that right?

Alyssa Carfi 2:46
Yes, that's correct. We're in New York. And I know that you know, Mimi Hayes as well. So it's kind of interesting. We all connected through social media. And that's how we found each other. So It's great that we have this community.

Bill 3:02
Yeah, it is brilliant. Mimi Hayes is somebody who I also interviewed, she wrote

that quirky book. It's Okay. It's Just a Hole in My Head.

Alyssa Carfi 3:14
Yes, yes.

Bill 3:16
And I got excited when I met Kyle and interviewed Kyle. And he told me about the Brave Minds Project. And I thought that's something that we need to know about before we go into what The Brave Minds Project is. Can you tell me a little bit about what happened to you?

Brain stem cavernoma

Alyssa Carfi 3:30
Sure. So when I was 15, I was diagnosed with a brain stem cavernoma, which as many of your listeners probably or, many of them might know. But for those who don't, it's a group of blood vessels that kind of look like grapes. And for me, this was lodged in my brainstem.

Alyssa Carfi 3:51
Anytime it would bleed, it would affect my sixth and seventh nerves, which are my eye and my smile before that, I was 12 when I had my first episode, and I went to brush my teeth one night, and I noticed that I couldn't smile. And I immediately ran out and told my parents, and they were like, you know, you're tired, just go to sleep, it'll all be fine.

Alyssa Carfi 4:18
And then they came up probably like 20 minutes later and brought me to the emergency room where we had a bunch of tests done. They tested for Lyme disease, took some other vials of blood, and did some other tests. However, they did not do a CAT scan or an MRI. At the time again, I was 12. They said, Okay, you know what, it's probably Bell's palsy.

Alyssa Carfi 4:43
911 had just happened here in America. They thought that I may be reading off of the stress of the adults around me. I just started a new school. So they said, All right, we're just going to give you a steroid and watch it and that was In September, and then by Halloween time, the end of October, I was back to normal, like nothing ever happened.

Alyssa Carfi 5:08
So went about my life then, as I mentioned, when I was 15, I had another episode and my parents saw that I just didn't look right. And that was what drove them to bring me to the emergency room. And then they again diagnosed me with what they thought would be Bell's palsy. And we left the emergency room. And by that time, there was probably like, two in the morning, and my pediatrician called our house and my daddy answered and our pediatrician said, Okay, can she follow a finger with her eyes?

Alyssa Carfi 5:46
Can she stand on one foot and ask these random questions my dad I think? He was like, I want to see you guys in my office tomorrow. So we went in and now this is the day After New Year's Day, so it was very much still in the high season of the holidays. And my pediatrician had all these books laid out on his desk. And he was like they misdiagnosed you.

Alyssa Carfi 6:15
It's your sixth and seventh nerve. We need to get you back into the hospital, you have to have an MRI. So we go back to the hospital, have an MRI, CAT scan, blood work the whole thing. angiogram, they did everything. And that was done when they found that it was a cavernoma. At that time. We weren't sure if it should be taken out, or it should be left alone.

Ticking time bomb



Alyssa Carfi 6:40

And ultimately, we just decided it was best to keep an eye on it. I went about my life. And I saw a bunch of different doctors and then by the time I was 18, it had bled again. And at that point, we realized that this was. It was time for it to come out essentially, One doctor said that I was like a ticking time bomb and it had to come out, it was going to cause even more damage than it already had.

Alyssa Carfi 7:12
And so I was able to go about my high school time and was able to graduate, go to prom, do everything. But then I had to have brain surgery, just three days after my high school graduation. Wow. Yes, so I had it removed. And then you know, through that it was quite the journey to get me to where I am today.

Bill 7:40
Yeah, I can imagine so how many years ago was the surgery now

Alyssa Carfi 7:44
10 years ago, so I just had my 10 years this past June. And I went skydiving and celebration of that. But so over the 10 years While you know I only had one brain surgery, which I'm very thankful for, I did have to have a lot of cosmetic surgery following that because as I mentioned, it affected, my eye and my smile.

Alyssa Carfi 8:14
So I've seen many different plastic surgeons and have had probably close to 11 different cosmetic surgeries. Some were done in New Jersey and New York City and others were done in Los Angeles. Yeah,

Bill 8:31
yeah. How was the skydiving

Alyssa Carfi 8:34
It was awesome. I highly recommend everyone try it. Um, it was on my bucket list and I thought what better time to do it than to celebrate my 10 years it is the most exhilarating thing I've ever done.

Bill 8:53
I take my hat off to you I'm a bit of a chicken when it comes to that type of fun on that type of excitement. And I figured that only people who have had a stroke would go skydiving. You can't have a proper brain and think about how I'm gonna jump out of a perfectly good airplane onto the ground when I could just sit there

and wait for it to land.

Alyssa Carfi 9:15
Exactly, no. It was a little odd. I mean, it's a little contradictory. I was celebrating life by jumping out of a perfectly good plane.

Alyssa Carfi 9:26
It's just the rush like.

Bill 9:29
Now, if you or someone you know, has experienced a stroke, and is in recovery, you'll know what a scary and confusing time it can be. You're likely to have a lot of questions going through your mind like how long will it take to recover? Will I recover? What things should I avoid in case I make matters worse?

Bill 9:50
Doctors will explain these things to you but obviously, because you've never had a stroke before you might not know what question to ask. If this is you, you may be missing out on doing the things that could help speed up your recovery, If you're finding yourself in that situation, stop worrying, and head to recoveryafterstroke.com where you can download a guide that will help you. It's called Seven Questions to Ask Your Doctor About Your Stroke.

Bill 10:17
These are the seven questions that I wish I had asked when I was recovering from my stroke. They'll not only help you better understand your condition, they'll help you take a more active role in your recovery. head to the website now Recovery after Stroke.com and download the guide It's free

Alyssa Carfi 10:35
You feel you have to try it.

Bill 10:36
Yeah, I do believe you every person that I know that's been telling me the same thing. So who knows, maybe one day I'll get the courage to go there. So cavernous angioedema is a very common thing that happens to several people who have experienced a stroke. I've interviewed a few people, I'm pretty certain that there a been at least three or four people that I've interviewed who have had cavernous angioedema.

Bill 11:03
And one of those was my friend, Antonio Iannella, and I interviewed him for Episode 29. But he had it appears that he had no symptoms leading up to his big episode until he was overseas on a family holiday in Vietnam. And he had a massive bleed there. So then it's affected his smile and his eyes well, and he's had a massive journey to get back to some kind of a full version of full health, which he is a very healthy man.

Bill 11:39
And he does have deficits. And it impacted his ability to play guitar because he was a guitarist. And it's from being able to hold his guitar and play the notes. So, he continued in his field of music by becoming a music producer and by now playing the piano. Because you can play with one hand on the keyboard, you can play that with one hand.

Bill 12:04
So he's found a way to adapt his skills, you know, into a passion that he has. Has it impacted some of the things that you did as a child as a teenager, that you had to relearn how to do or rediscover in another way?

Alyssa Carfi 12:22
Um, so definitely right after surgery, I would say that I had a lot of probably the same setbacks that most people with brain surgery experience I had difficulty walking and had to relearn how to walk, I guess I was very, very tired. I slept all the time, which is very normal. But then something that I thought I would get back just like I got my walking back. I thought that this would come easily, would be my smile and then my eye movement.

Alyssa Carfi 12:59
So as I've mentioned you know I had all of these reconstructive surgeries and it's now much better than what it was. But in my right eye, I wear what's called a pros device. And because my eye doesn't fully close on its own, I it is an issue because I could get dry eye and it could be very serious and hurt my cornea.

Alyssa Carfi 13:23
So we saw a ton of doctors and they all suggested different things between Botox and my eye and taping my eye shut and then we found these doctors in New York at while for now who work with the Boston site crew and they told us about the

pros device which is a fitted contact lens and I had to go once a week for six months to get it perfectly fitted or my eye and were regular contacts are Kinda like a little slimy and foldable.

Alyssa Carfi 14:03
This is plastic and hard plastic and pops it in my eye and it keeps my cornea safe. Um, how it affects me is that I can't wear a lot of makeup like I used to which as a girl is kind of a big deal. But I'm, , I'm very very lucky if that's the biggest problem that I have fine, I can't balance like I used to so riding a bike I can't do that.

Alyssa Carfi 14:31
Driving is okay. But riding a bike I cannot do even if I'm walking down the street and if I'm walking next to you, I'll start to kind of push you and you'll veer over. So you know, those are things that I don't think I will ever regain. But, um, I make the most of it.

Bill 14:53
That's weird with the walking thing because I thought that was only me if I try and walk down the street next to my wife she always says, Can you please walk on your side? Get out of my way. Why are you there? how did that happen?

Alyssa Carfi 15:07
Well, my equilibrium is completely off I'll even notice it in like yoga or things like that. And, you know, at first, everyone was like, you know, paying attention to what you're doing. And then they started to realize that okay, this is from the brain surgery, and it just has not recovered in 10 years. So I don't think it will.

Bill 15:27
Yeah, well it might, you never know. But I know what you're saying. I have the same issue. My left side is a bit numb. And as a result, my balance is affected, especially when I'm tired. And I find I really can't walk next to people there really is a problem. I didn't realize that it was only me. I don't veer to the left. Until I'm walking next to somebody which is bizarre up until then, I'm fine. I'm doing fine.

Alyssa Carfi 15:53
Wow. Yeah. You know, it's weird sometimes I do think that that makes sense when you're tired because I do notice When I'm tired, I noticed my eyes will kind of go in and out and more so than before the surgery. So it affects me in a bunch

of different ways. But before my surgery, we didn't know how I was going to come out.

Alyssa Carfi 16:17
A few doctors had told us, you know, you may come out and you may not be able to breathe or speak or have a feeding tube, your arm might not work. So to just be able to come out and have these cosmetic issues. I can live with that.

Bill 16:33
That was sending a dramatic wasn't it at the beginning? How do you reconcile that? How does a kid about to go into school final exams or the last part of school and then the next couple days be faced with that? How do you reconcile it? What were you going through?

Alyssa Carfi 16:56
I mean, well, I was 18 at the time, so looking back I definitely put on, you know, a brave face and just like faced it and did what I had to do to get through it. My family and friends were extremely supportive as were my doctors, my doctors did not sugarcoat anything. They sat down at my bedside and told me and everything that I needed to know answered all of my questions, and I'm very grateful for that.

Alyssa Carfi 17:26
But at the same time, looking back, I realized that I went through the motions and didn't process everything that was happening. And that's mainly just because I was going about it the only way that I knew how to and the only way that I thought I needed to because if I was okay, my family and my friends were okay. And I was acting as I thought they would want me to be acting.

Alyssa Carfi 17:56
Right, I was putting on a happy face so that they saw that I was okay. But, um, my mind wasn't fully developed, so I wasn't able to even process what was happening. But now, that's kind of why I started Brave Minds Project, you know, there's a lot of resources that are available with, you know, doctors they're fantastic and they can help you along the way.

Alyssa Carfi 18:24
But what do you do in between the point of hearing the news that you have to have surgery, and then scheduling your surgery? You know, your mind is running

100 miles a minute trying to figure out how you're getting your life in order, and aren't able to have anyone to lean on who has gone through what you're about to endure.

Bill 18:49
When you were 18 you were obviously, you would have been a typical teenager looks would have been important. You woke up from surgery, with some very different, very different As compared to how you went into surgery. How did you navigate that? What? What did you feel and what kind of emotional trauma did you have to overcome?

Alyssa Carfi 19:14
Yeah, so before the surgery exactly like you said, I was completely fine. I was very lucky. Leading up to that I was very nervous because I had my prom and I had my graduation and as an 18-year-old, especially as an 18-year-old woman, my looks were you know, something that was very important to me. So I was very lucky in that regard.

Alyssa Carfi 19:38
But waking up from surgery, and realizing that my eye was very dry and my smile wasn't what it should be. And my eye was turned in my right eye turned in towards my nose, right after surgery, and so it was about a year before I could have strabismus surgery to fix that. But, um, I, it was a it was hard. I mean, it was hard.

Alyssa Carfi 20:07
But there was so much else going on that I couldn't focus on that I knew that I had to heal. And I knew that that would take time. And so, in those months after surgery where I was healing, I assumed that my smile would come back and that my eye would be straightened down and fixed. And that wasn't the case.

Alyssa Carfi 20:29
But in my mind, and even in my family's mind, it was like, okay, you know, we're going to do this one thing, we're going to fix it and then like, we focus on the next hurdle. I had to defer college for a semester because I was not physically able to go to college after surgery. I got very sick after surgery and lost a lot of weight.

Alyssa Carfi 20:54
We don't know if that was from the medication, or if that was just from the

location that they were in. In the brain, um, but yeah, I mean, I took a semester off. And then I started college in February. And by the time I started college, the back of my hair had grown back. So I was very happy about that. That was probably the one thing that I was nervous about.

Alyssa Carfi 21:19
And I hear that a lot that, a lot of patients are always like, as long as I still have my hair I'm okay, and I think it, it serves as some kind of a security blanket. And that's exactly what my hair was. And now I'm like, yeah, you want to cut it, do whatever you want. But at that time, that was all I had to hold on to. It was like my identity.

Bill 21:41
It's tough for women. I know women do say that. Men just shave their heads and then they get on with it and it's all good. And it's not a problem. And we also like to wear our scars. You know, make it visible, make sure that people can see it so they can tell us about it and we can make up a story that happened in a gunfight or something.

Alyssa Carfi 22:02
Right right. I always say because now I have scars all over from them taking different tendons and muscles I'm putting it in my face and I'm always like well just another battle wound like it's you know it's all over my body I can make up all these I got bitten by a shark and all these crazy stories that are not true.

Bill 22:24
I love it. So one sec. Siri decided to talk to me just now.

Alyssa Carfi 22:33
She's joining in

Bill 22:34
Yeah, I'm not sure why that's okay, I'll put her to sleep. So you then you've gone through you've completed college Did you see through that part of your life as well and overcome the challenges to learning and the way the the tiredness and all that what was it like to go through college experiencing the recovery phase from brain surgery?

Alyssa Carfi 23:00

So you have to remember it right I'm 18 and had to defer a semester and I'm going to fashion school so I went to the Fashion Institute of Technology and so like many fashion schools it's it was a lot to go there and conditions that I was in no one was ever mean to me or anything like that. It was just um it's very different you know you're in New York and you want to be this you know, girl who's going to fashion school and that was not my case.

Alyssa Carfi 23:35
I was very much still recovering my balance was good but much better than when I got out of surgery. But by no means was I you know, I've been running. My eye was still turned in. My hair was still growing back but it was it was okay in the back. And I could not smile so every time there was a break within the semester, whether it was you know, the Christmas break or any holiday break, I was then having surgery.

Alyssa Carfi 24:11
And I was yeah, so while doing that I was still able to finish school on time. So I deferred a semester but I finished off four years on time and I was able to study abroad twice, I was able to go to Shanghai and London. So I didn't let it run my life. And my parents were very adamant about that as well. They were like, you know, you need a tutor and will hire a tutor, whatever the case may be.

Alyssa Carfi 24:42
It was very difficult taking notes like looking down and then looking up at the board, I would get nauseous. Someone asked me a little while ago if I still have that, and I honestly think that I just became immune to it because at work now, I type on a computer and I'll look up and down and it doesn't affect me but um, I also had to figure out where I would sit in the classroom because this I my right I was turned in I had to sit on the I guess on the far right side so that I could see the board a little bit better.

Alyssa Carfi 25:19
So it took a lot of navigating on my part. But you know, like with everything else, it is what you make of it and I had a choice of sitting home in my room and crying about it all day or going out and living my life and I chose to get up and go live my life.

Bill 25:38

Mindset is a huge part of stroke recovery and I know that people do tough They came from different backgrounds than all of us and they had less support than I get. But if I could encourage people to do a couple of things, you know, to help them heal after stroke. It's got plenty of sleep well and work on having a positive mindset and positive mindset.

Bill 26:00
That doesn't mean that you don't have bad days, you don't get cranky and you don't get tired and you don't fail at things, it means that overall, what you're doing is focusing on what's good about this or what I can do to influence this positively. So it sounds like you just had a really good positive mindset. And it's something that supported you through the whole process of being diagnosed, having to have surgery just after you finished school at 18.

Bill 26:26
And then having to deal with multiple surgeries during your college years, while at the same time studying to become qualified in your field. How do you have such a positive mindset? How did you get to that point where you were like that?

Alyssa Carfi 26:43
So again, I think it comes down to just seeing that if my family was okay, and if I made it that I'm okay then they're okay. And it wasn't like I was, you know, not telling them what I was feeling. I want I mean, even coming out of surgery, I mentioned that I lost a lot of weight. And that was because I was constantly throwing up, I wasn't able to keep my food down and for whatever reason, and then one day, my dad came into my room because I was lying down. After all, that's what you do after brain surgery.

Alyssa Carfi 27:20
And, and he was like, all right, get up, we're going out for dinner. And it was like 2 pm. And I was like, absolutely not going on in public like this. I can't even keep food down. And he was like, nope, we're all going I called the restaurant that it was going and I was like, fine, I hope I get sick and I grow up all over you. And that day, it stopped. Did not throw up at all.

Alyssa Carfi 27:43
And so now we always joke about that. And I think that yes, mindset is everything but you do need people to push you. And that's exactly what my parents and, you

know, they knew, okay, I can't walk from point A to point B by myself, they had to hold me. But at the same time, while they were a crutch for me, they made sure that I was able to live my life.

Alyssa Carfi 28:10
And that's something that I think all parents, whether they have a child with a disability or not, need to make sure that they do let their child live their life. And then mindset is very huge that plays into everything that we do. With Brave Minds Project, was another reason why I wanted to start it again, just because I saw that I had a support system.

Alyssa Carfi 28:38
And I saw that I was very lucky and I was just able to just roll with the punches. But I know that that's not the case for everyone else. And I think back and I think about how if I did need a network of people who had gone through what I went through, it wasn't there. And so I hope that I can create that for people who are in this situation.

Bill 29:08
Sounds like Dad was a bit of a tough love coach. And we need that a lot though. We need that a lot sometimes. Sometimes we don't need it but it sounds like you picked the right time The right day, and the right everything and you decided to fall in line as well and stop throwing up at the side and start eating normally.

Alyssa Carfi 29:32
It just happened and now we all like to laugh about it. But, I mean, that was a coincidence. We won't give him that much credit.

Bill 29:41
As a dad as a dad, I'm gonna give him all the credit because that's what dads do. They take the credit where they feel credit is due. So that's what I'm gonna do. I'm gonna support him on that one. Now, let's dive into the Brave Minds Project. Tell me what is it about and, give me a bit of an idea of what it's designed to do

Alyssa Carfi of the Brave Minds Project



Alyssa Carfi 30:01
Sure so Brave Minds Project focuses on patients between the ages of 10 and 29, who have brain and brainstem conditions. So that's not to say that if someone came to us and they were in their 40s, or they were five years old, we would not help them. That's not to say that at all, but for ages 10 through 29, I view that as the Forgotten demographic, right?

Alyssa Carfi 30:28
There is a lot out there for patients who are under the age of 10. And, you know, you have your parents and your guardians when you're around those ages. But when you're 10, you're starting to change and you're starting to get into your pre-teenage years. And then when you are 29. Where, you know, trying to figure out your career and maybe you're starting a family and so I wanted to pinpoint those ages and the ages between that because that is the Forgotten demographic.

Alyssa Carfi 31:06
And so if I can build something that will help patients between those ages navigate their life a little bit easier. And then that, to me is a success. And so what we're looking to do is to help them with mentorship programs. So if someone wants to be a teacher or a doctor or a musician, whatever the case may be, and they are either recovering from brain surgery or they just found out that they have something with their brain.

Alyssa Carfi 31:39
We can pair them up with a proper coach to help them along the way. And then also creating a community as I mentioned, whether that's meetup groups at different hospitals and bars and what have you, and then also, just as we grow, I

hope to then raise enough money where we can help to offset some of the financial costs are also working on some research that's going to be coming out, which I can't speak too much to. But we're getting our ducks in a row to have that proprietary research and data launch, hopefully, in the spring of 2020.

Bill 32:27
Excellent. It sounds like a fascinating project and a great thing to be working on. What's bizarre about stroke and something that I never had experienced before, didn't understand. It's not only stroke, it's other people who are facing another life-changing sort of health challenge so many people have a stroke and then decide they're going to do something to help other people who have had a stroke.

Bill 32:52
It is just the most amazing thing about this adversity. You become somebody who needs to find a way to support other people who have gone through what you have through, It seems to help me when I do the podcast, and share stories, it seems to help me. What do you get out of it now? I know that it's about other people, but it must do something for you as well.

Your ears pop all the time, my ears are up all the time



Alyssa Carfi 33:15
Absolutely. Yeah. 100% I mean, just to see people come together, I was 27 when I met someone who had a brain stem cavernoma, and that was the first time I had ever met anyone who had what I had. And I just like, if I met someone years ago, we could easily text and be like, oh, oh my gosh, your ears pop all the time, my ears up all the time. And you know, you don't feel so alone. So if I could just help to create that with other people. That makes me happy.

Bill 33:52
Yeah, that's exactly what the feedback that I get is that I hear from people, and one of the ladies I interviewed A little while ago can't remember what name, what episode number it said that I was the first person she had ever shared her story to. And she had experienced a stroke decades before. And it was the strangest thing. And it seemed to have been a liberating thing for her to be able to do that.

Bill 34:20
But it was so strange that I was the first person that she had ever met who had a stroke and that they were having a conversation about it. So it is interesting when now we have the technology and the skills to be and the ability to do that. We can do that from anywhere in the world. And it does make a huge difference to know that for example, with the balance thing that I learned from you you seem to move into the other person's path. I thought I was the only one doing that and not that I want other people to be going through what I'm going through, but I'm kind of glad they are.

Alyssa Carfi 34:55
Exactly no it's nice to feel like you're not the only one. Yeah. 100 Present. I agree with that, I hear that all the time. Like, I used the ear-popping example, I thought that I was the only one. And then a few people I've talked to they were like, yeah, my ears are always popping, and I noticed that it's after brain surgery, and I was like, oh, someone else. So, um, yeah, is it's not, that it's good to see that. But

Bill 35:24
Someone in your corner

Alyssa Carfi 35:25
Exactly

Bill 35:27
So how does the Brave Minds Project go about raising money? That's, I imagine that's a big task.

Alyssa Carfi 35:34
So, we've had a few fundraisers. And we just started in January. So we're very new. I'll preface it by saying that first but, we do have a fundraiser tomorrow here in New York City and we're going to be doing a Soul Cycle class and we called it Ride for Recovery. And my friend Bethany Holmes. She is celebrating her fourth

brain surgery anniversary.

Alyssa Carfi 36:03
And her story is very interesting. She left the corporate world after her brain surgery, and she became a certified health coach. And she's helping those who have brain conditions to kind of recover afterward. And so we're celebrating her tomorrow. So that will bring in money. And then with that money that we raise tomorrow, we're going to be giving it to a patient who's in recovery.

Bill 36:31
Wow. So the person who's in recovery right now is chosen that person?

Alyssa Carfi 36:35
Yes, we have.

Bill 36:37
Wow, how much do you have to raise?

Alyssa Carfi 36:42
You know, we are very small one day, I hope that I could answer that and be like, We hope to raise $50,000. But if I can just raise $1,000 or $2,000, I will be happy.

Bill 36:54
Yeah, that'll be fantastic. What are they experiencing at the moment with the person that you've chosen?

Alyssa Carfi 37:00
So we, I'm sorry, I misunderstood that question. We have not chosen the person we do have a few people in mind. But all of them are between the ages of 10 to 29. We are just waiting on some final details, but one of them had surgery a year ago and is still going through various therapies and things like that. And then another one had surgery maybe six months ago. So she's very much still in the thick of it.

Bill 37:33
I think that's a fantastic thing to be able to raise money to support people who are currently in hospital and just let them know that there are people already out there looking out for them. And, you know, looking to support you and to help you out it will be it will make it amazing and help navigate. It makes it a little easier to

help them navigate the recovery after their stroke, you know, in their surgery.

Alyssa Carfi 37:55
Absolutely. And something important. To me, and I know that it's important to you and all of your listeners. And I mean, now I think with technology, as you said, there's so much available that, you know, I didn't have 10 years ago.

So I'm hoping that that'll make the job that much easier. Especially, you know, I can't stress enough that this demographic is very important because it is the future.

Alyssa Carfi 38:26
And so if we can arm, every patient that comes out with a little bit of confidence, and almost like solidarity, and I think they'll be ready to take on the world.

Bill 38:40
Yeah, I've been looking at your website while we've been chatting, just to go through it and have a bit of an understanding of what it is. It's a great website, people that are listening can go to the brave minds project.org to have a look. Can they also donate via that website?

Alyssa Carfi 38:56
Yes. So if you go to the Donate tab, You can donate there and none of the proceeds go to myself or the others on the board who are helping out. So all of the money was directly to the nonprofit which was very important to me as well. Um, it's a lot of work, but I don't see a penny of it. I wanted to make sure that the money gets into the hands of those who are recovering.

Bill 39:32
Yeah, there wouldn't be anything better than to come out of surgery. Not that I needed that or expected it from anybody, but to come out of surgery with a spare thousand dollars that I didn't expect to have that I can just spend on myself for example, I know that it would have been great for some of the people that I've met to have had a piece of equipment purchased for them, especially people who ride bikes or wanted to get back on their bike.

Bill 40:00
You know, there's the Three Wheeler bikes that you can get where people can add a bike, an additional wheel to the back, or are these even new bikes where people

can sit down and almost be laying down in as they pedal? So that balance is not an issue.

It's very low to the ground, but enables them to get around and enables them to exercise on the bike and enables them to do it out and about so to be able to have a spare $500 $200 $1,000 whatever you guys managed to raise, I imagine it would put a smile on the face of almost anyone who receives it.

Alyssa Carfi 40:37
One day I also want to help raise enough money for those who need seeing eye dogs because those are very expensive. And unfortunately, I've talked to a few patients with Chiari malformations and they are now legally blind and they are looking for different service dogs. And then we also put together care packages, which we call courage kits.

Favorite things



Alyssa Carfi 41:04
So anytime I have a patient in the hospital we'll fill it up with their favorite things, and I don't know, I can't speak to every hospital, but I know a few of my hospitals here in the States in the pediatric unit, which is a lot of times where patients are even if they are in their early 20s a clown will come by Santa Claus will come by, you know, different things to make the kids laugh. And while that's great when you're 18, it doesn't speak to you.

Alyssa Carfi 41:39
So what we're looking to do is to fill a box with you know, whether it's a face

mask for girls or nail polish or just things that will make them smile, but not so much things that are childish. So that's something that we've been able to do and it's really rewarding and exciting to see the look on.

Alyssa Carfi 41:58
The parents' faces that look on the patients' faces when we show up with these boxes, and they weren't even expecting anything. So anyone can donate as well to that cause. And if anyone is looking to donate items, we can also incorporate both into the Courage Kids as well.

Bill 42:21
That sounds like an amazing thing. Not only is going to be great for people to receive those things, but also to immediately have a community to immediately have people who understand them who know what they're going through, who can relate to them, and who can share stories with or they can share their, their emotional burden to a little bit you know, because we've been there 10 years ago, and we can look back and we can help mentor and guide that person along the path a little bit easier.

Bill 42:51
Then we did it. And that's like a really good thing that's even better than receiving some money or a care package, but how good is a care package for a girl I know a girl would love to receive I know girls would love to receive a care package. And I'm just thinking about if I was that age, what would I like to receive if I was a boy? What do boys get?

Alyssa Carfi 43:13
That's exactly what I was going to ask you. It's so hard to come up with different ideas for guys because even in video games if a child has epilepsy, we can't give them video games. So um, I do have a few different sports teams who were kind enough to sign a few memorabilia and put it into a box. So we had Kevin Weekes from the New York Rangers, a former New York Rangers player.

Alyssa Carfi 43:42
He signed a hat and a hockey puck and that went to a sibling, a patient whose sibling was having a hard time kind of adjusting to his new sister following her surgery. So we were able to give that to him and he was thrilled. And I have a younger brother who was just 12.

And then 15 when I had my surgery, he was 12 when I was diagnosed, and then 15, and he was being shuffled around from different family members while my parents were with me in the hospital, so anything that we could do to help siblings That's also really important to me too.

Bill 44:23
Yeah, I think anything sports-related would help some boys anything that's from just speaking about myself anything that's car-related, like an event that you could go and see that's car-related. Those types of things would have been something that would have interested me when I was younger, but my stroke happened when I was 37.

Bill 44:46
So you know, I was way beyond feeling the need to go and see sports events and car events and all that kind of thing. But I imagined those types of things. Well, it is a really important project. The Brave Minds project is really important. If somebody wants to get in touch with you, they can go to bravemindsproject.org. How else can they get in touch with you? Are you guys on Instagram or Facebook? Where would they find you?

Alyssa Carfi 45:12
Instagram and Facebook. It's just @bravemindsproject. And also my personal information is on the website as well. You can text call, email, whatever works. Um, you know, we are open to any ideas, suggestions, anything that the community needs to see and wants to see. I am willing to try and make that happen.

Bill 45:38
Brilliant. Alyssa Carfi. Thank you so much for being on the Recovery After Stroke podcast. I appreciate it. Congratulations on your recovery well done on setting up the Brave Minds Project and I am confident that it's going to be a very important part of the recovery journey for people all over the world but definitely in your hometown.

Alyssa Carfi 46:00
I hope so. Thank you so much. I appreciate the work that you're doing as well. So thank you

Intro 46:07

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