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Founder Feature - Transcript

[Speaker 1]

Welcome to Charity Therapy, a podcast from Birken Law about building better nonprofits. I'm your host, Jess Birken. You know, it's easy to talk about all the ways a new nonprofit founder can go wrong, and I do that on a regular basis.

But today's guest, Heidi, is a shining example of a new nonprofit built right. Her story is so inspiring, and she had some really great advice for folks just starting out. Stay tuned.

[Speaker 2]

Hi, my name is Heidi Seaman, and I am the executive director of Parotid Patient Project.

[Speaker 1]

Hey, Heidi, thanks for being here today. I'm so excited for you to join me and full disclosure to everyone listening that Heidi and I work together. So this is a group that I'm very well acquainted with their founder journey, and I am so excited to have you here today.

Thanks for being here.

[Speaker 2]

Thanks for having me, Jess. I'm really excited to be here as well and appreciate the opportunity to talk a little bit about the Parotid Patient Project.

[Speaker 1]

Yeah, right on. So we've been working together for a little while, and sometimes it's hard for me to remember all the way back to the beginning. So it would be cool if you could share with us, like, you know, why, how did you get here?

Like, why did you decide to start a nonprofit of all the things that you could be doing with your free time? Why this?

[Speaker 2]

Well, I, I was diagnosed with a rare salivary gland tumor is called a parotid tumor for people that don't know what that is. And I know I certainly did not know what it was until when I was first diagnosed. And at that time, I started to do some research to try to figure out what this, you know, diagnosis meant and the treatment that I was going to have to undergo.

And I just found that there was not a lot of information available. And the information that was available was outdated. It was focused on all the negative things that could potentially happen when you have treatment, which most of the time is surgery.

And this is a very delicate operation. And it's a very emotional journey because, you know, for people that are not aware, the facial nerve runs through the parotid gland. And so if anything should happen to damage that nerve during surgery, your face could potentially be paralyzed.

And so there was a lot of things that I wanted to make sure that I got this right. And so as I'm going through this process, I just didn't find the right amount of information. And I joined a support group of people who also had this condition.

And I saw this common theme in these conversations with other patients that we all just felt like there's not enough information out there for us to be able to make informed medical decisions. And everybody was terrified to go through this process because of all of these uncertainties and the fear of the unknown. And I just after I went through this process and had a successful surgery at the Mayo Clinic in Minnesota, I just really felt like I wanted to change that environment.

And I didn't want other patients to feel like they didn't have information or they couldn't make informed decisions or to be so terrified that they put off treatment of this parotid tumor. And so I started off my journey really by volunteering my time at the Mayo Clinic with my surgeon. And we produced a series of informational videos to try to provide people with information about all aspects of this journey.

During that process, at one point, my surgeon made a comment to me that, you know, you really should consider some at some point starting a nonprofit organization like you have the organizational skills and you have the energy and the desire to make things better in this area. And maybe that's something that you should consider. Quite frankly, I thought that he was crazy in the beginning because this is not something that I knew a lot about.

And this was when I was diagnosed, I certainly did not see myself ending up running a nonprofit organization. But as time went on, I just really felt like he was right. This was an area that was lacking.

We needed to get more information out there that was current and trusted information to help other patients through this process. And, you know, it was at that point that when I was doing research on how I could potentially accomplish this, that what really pushed me from an idea

into action was there was a young baby that was diagnosed with a very aggressive form of this, you know, and rare form of this type of tumor. And just seeing the parents of this baby in there and seeing all the things that this baby had to go through that nobody should have to go through at any age.

But this young baby having to go through all these treatments just to try to survive, I just really felt like, you know what, if I'm in a position to do something to help, you know, this baby and help things get better for other patients, I'm going to do it. So it was at that point that I then decided I'm going to move forward and create this nonprofit organization.

[Speaker 1]

That's awesome. I think, you know, it's one of those things that it's so rare you don't hear about it a lot. And having your face be potentially permanently impacted by it makes it it's not just like, oh, yeah, I had a little cyst and I got it removed.

It's like you're literally choosing, do I allow this cancer to be here or do I risk having my face be paralyzed? Which that I can't even fathom, right?

[Speaker 2]

Yeah, it's definitely not an easy process to get through, and it's really difficult to explain to other people who haven't been through it how it truly feels to be in that position. And then on top of that, to feel like you don't have enough information and you're not exactly sure what you're supposed to do and there just aren't resources out there. And I just really feel like, you know, there are certain things that happen to you in life that push you to where you're supposed to go next.

And although when I was diagnosed, I never thought for one moment that this is where I would end up. I have no doubt now that this is what I was destined to do. Right on.

[Speaker 1]

So you you decide, OK, this I'm a doer and I am doing and this would be better if it were a nonprofit. How did you kind of go about getting started? Like, what was your process?

[Speaker 2]

Well, this should come as no surprise. Sorry, Jess, this should come as no surprise to you. Since you know me and anybody who knows me well, I started to do research once again and started reading a lot of things about how you would go about starting a nonprofit, what is required, the proper steps that you need to take and in what order.

I consulted with experts in different areas to try to get feedback of things that I needed to consider. I'm fortunate enough that I know some people who are in the nonprofit industry. So I reached out to those people to talk to them about lessons learned.

What are some pitfalls? What are some things that I need to do, things that I need to avoid? And, you know, I just asked a lot of questions to try to figure out what I needed to do next.

And then I just really had to keep focusing on what is most needed in this area and what do we need to need to do to accomplish that? And to me, the most important things were education, creating awareness about this and creating a mechanism in which we could raise funds for much needed research. And so I just and that then became this is our mission statement and this is what we're going to do.

[Speaker 1]

I love it. I wish more people that thought I should start a nonprofit did as much research as you do, although I will say you are a rare beast because you definitely do have the organizational

skills and you have a great background for everything. And just being you, you're a lawyer by training, right?

That's correct. Yeah. So like you totally could have just gone out and like tried to do it yourself.

And one of the other things I love about you is that you're like, let me talk to other people in the nonprofit sector. Let me get professionals to help, which just always sets people up to start out so strong. So what, given that you are this like powerhouse, badass woman, pardon my French, so given that you are this like badass, you know, capable woman, what has been the most challenging part of getting it off the ground?

[Speaker 2]

I think it's just primarily not having any sort of background in this. So you're starting from ground zero and having to learn so much about every single thing that you have to do. And so there was a lot of research that needed to be done and a lot of time that was spent trying to get this organization set up in the right way.

And, you know, that and also making sure that you are in compliance with all the state laws and federal laws. And there's just so many things in the nonprofit industry that you have to think about that maybe you don't have to think about in other industries. And so not having any sort of background in this, I think that was challenging, but clearly it can be done.

And many, many people do it. And, you know, I think the second thing for me is that, you know, the education piece of this is a huge piece of what we do. And I had to create a website and you create that from scratch to try to provide the information that I felt like I wished was out there when I first was diagnosed to try to create that space for other people.

It was challenging in the sense that, you know, my husband and I always joke around about the fact that I barely know how to use phone apps, which is true. But yet here I am having to write an entire website from scratch. And it's just not something that I ever thought that I could do or would do.

But, you know, it turns out that I can. And, you know, it was a little bit challenging and time consuming because I'm writing a lot about medical information. I'm clearly not a doctor.

I was not, you know, the greatest kid in math and science. So this is really outside of my wheelhouse. So I had to do a lot of reading of medicals information, try to understand it myself and then turn around and write it in a way that I felt other people could understand it.

And, you know, at the end of the day, it worked out great. But that was really a challenging part of this. But, you know, the entire time that I was going through the process, I just every second that I spent was worth it if we even just helped one person.

[Speaker 1]

Yeah, that's awesome. And I love that, you know, that that's what you need to do, because you are, at the end of the day, a human being who has gone through this yourself and you know that you're looking for like clear information. And it's so easy to take a bunch of like medical studies or a bunch of doctor speak or like in my industry, you know, lawyers, right.

They do this all the time. They have like blogs about DUIs or something. And it's all about the science behind the mechanisms and the intoxicizer that you breathe in.

It's like nobody cares, right? Yeah, that's not the information the person really needs to feel like they're being educated. And so I love that, you know, you've got doctors that you're working with.

You're making everything, you know, eighth grade English so people can understand it. And you built that incredible online space for your community where people can connect and support each other, which is like so, so cool. So where are you at today?

Like what's, you know, 2021 plans? What are you, where are you at right now?

[Speaker 2]

So the website is, you know, fully set up and operational. And that went online, you know, back in April. And we really, it was important for me at that point to really push to get that website out there because we're in the middle of a pandemic.

People can't see their physicians. They're, you know, scared because they don't have information. And at least this gave them a resource that they could utilize to help get them through that period of time when they could actually go and see a physician in person to try to get a proper diagnosis and treatment.

So that is fully set up. There are many patients that have visited the website already. I've, you know, received feedback from many of those people that it helped them make decisions for their medical care, which is awesome.

You know, and so we are continuing on with our mission of educating and helping and supporting patients through this process. And so at this point, you know, our moving forward, we are continuing on with our education piece. So we are going to be starting a podcast shortly

here as well to help educate patients kind of along the same lines that we did with these informational videos.

And I'm very fortunate to, you know, have these doctors that are willing to work with us and help educate patients. And so we're really excited about getting that up and running. And, you know, then just moving forward, trying to maximize your social media strategy so that you can do some online fundraising because the reality is, is that due to the pandemic, it's very uncertain right now.

And, you know, you can't really hold fundraisers in person like you might otherwise do. And so we're going to have to kind of pivot and adjust it just like any other nonprofit would have to do, and quite frankly, any business in these times, and just do something different to try to accomplish your mission. So that's, in essence, what our plan is moving forward.

But, you know, primarily just continuing on and focusing on this mission of educating patients, supporting them, and getting them the information that they need in a different variety of ways, because some people don't like videos, or if they're sitting in their car for long periods of time, it's, you know, easier for them to listen to a podcast or if they're working out or taking a walk or whatever it is. So we just want to be able to have a wide variety of ways that people can learn about this condition so that they can make informed decisions for themselves.

[Speaker 1]

Yeah, that's so smart. It's really tempting to kind of like communicate about our mission in the ways that we like to be communicated with. But I love that you're, you know, kind of pushing that out to say, okay, where are people at?

Let's go meet people where they are. Let's adapt to the current situation because you're right. Like, I know almost nobody that's doing in-person fundraisers right now.

It's just really hard. And, you know, living in the Midwest where, you know, I'm in Minnesota, you're in Illinois, it's like we're about to go into winter. It's not like you're going to have a big gathering anytime soon as we're all going to be under six feet of snow here for the foreseeable months to come, right?

So when you think about, you know, the next three years, five years, what are you thinking as sort of the visionary founder of this whole thing? Like, where do you see this going?

[Speaker 2]

I really see this going in the direction of us being able to raise enough funds where we can fund research projects in this area because it is so important to patients and it's so critical to this entire process because, you know, for so long, parotid patients haven't had answers. They don't even know what causes these tumors. And so you're kind of in this like strange limbo where you're like, I'm not really sure what causes this.

And am I doing something? Am I eating something, drinking something, doing something in my environment that's going to cause this to come back? And not having those answers is very unsettling for people and it can make it difficult for them to move forward.

But at the same time, you know, when you have a rare condition, it's difficult to get funding from some of the resources that might be out there because you're competing against all these other disease groups that affect greater numbers of people. And so, you know, sometimes it's easier for them to get funding and rightfully so because it does affect a lot of other people. But, you know, then those of us who have rare conditions are kind of left to the side or left to our own devices.

And so where I really see this going forward is that, you know, we will hopefully be able to fund enough projects that we will be able to find these critical answers that patients need and deserve.

[Speaker 1]

Yeah, so true. And that's where I think some of these niche causes can be so powerful because, yeah, there might not be, statistically speaking, lots of people that deal with this, but you do have, there's strength in numbers, right? And all of us is greater than any one of us.

So I love that you're bringing everybody together under that mission. It's really awesome.

[Speaker 2]

And there still are a lot of people affected by it. So, you know, again, but it certainly is not the numbers of lung cancer or breast cancer or things like that. But, you know, on average, 20,000 people a year in the United States are diagnosed with this.

So you do have that number of people per year that are affected by this as well. So, you know.

[Speaker 1]

And including little kids and who doesn't want to help little kids, you know.

[Speaker 2]

And that's one thing about this. It affects all age groups. It affects, you know, all ages, all races, you know.

And so it's just, you know, trying to find answers for people. It's not like it's just, you know, a distinct group of people that are getting these types of tumors. It's, you know, a wide variety.

And so we need to try to find some way to pinpoint what we all have in common that blessed us enough to have this tumor. So. Right on.

[Speaker 1]

What advice would you give to other folks who are thinking about starting a non-profit?

[Speaker 2]

I think, number one, you truly need to be passionate about whatever cause it is that you are representing. Because that passion is what is going to help power you through the day. It's going to help motivate you when, you know, times are tough.

To, you know, keep doing all the hard work that you're going to have to do, setting up and running an organization like this. You know, I think that. Do you think it's not just easy street?

It is not. I was hoping it was going to be, but that is not the case. But it's, you know, it's just, I think it's just really taking one step at a time.

Because if you look at everything that has to be done and you have all these thoughts, like, I need to do this and this and this and this, it can become overwhelming. So you're really taking one step at a time so that you don't feel overwhelmed. And I mean, and I know this is going to shock you again, Jess, but I'm a big organization checklist person.

So I like to make, you know, lists and things like that about what I need to do and then check those things off one at one by one so that you can see that you're making progress, but you don't have to accomplish every single thing in one day. And so, you know, again, just taking that one step at a time. And you'll be amazed when you look back months later or years later, like how far you've come and how much you've been able to accomplish.

And I also just think having some sort of written list just keeps you focused on what you need to do. I would, again, spend the time and effort doing some research upfront to ensure that you're doing things correctly and that you're getting the organization set up in the right way so that you are setting it up for success. And then it's also going to just make it easier down the road to make sure that your financial reporting is accurate.

And, you know, if you ever get questions by the IRS, you can easily turn around and say, well, here's all the answers. And here's everything that we've done because you have everything organized and ready to go. And it just makes it so much easier if you do that work upfront.

Again, ask questions, lean on people with expertise. That's what I do. I'm not afraid to admit that I don't know how to do certain things.

And I'm like, I'm not tech savvy. And I've relied on all numbers of people, including you, Jess, because not only are you providing me legal advice and things that I need to know and look out for in the nonprofit world, but you also are very good and tech savvy. And you have a lot of resources and things that you know.

And you've given me suggestions for try this software, this has worked well, or be careful of this and be careful of that. And that is extremely helpful. And it also saves time so that I can just focus my research efforts on the things that are going to, in the end, be the best and most efficient for the organization.

I think that I would also spend some time surrounding yourself with a good board of directors. I am extremely blessed that Jess can corroborate this and I have an amazing board of directors that surrounds me, all of whom are extremely passionate about this cause as well. So it's not like it's just like, oh, man, I gotta this is just like something I'm trying to put on my resume, and I need to go to this board meeting.

Like, everybody is super excited to be involved in this process and in this project and what we're going to do moving forward. And they've been extremely supportive and provide good guidance. And I made sure that I selected people from a wide variety of areas, people that have social media experience, people who have medical experience, who work in this field and know so much about parotid tumors.

And I have people from the business side and people who have experience with the legal side, people who have experience with budgets and how to manage grants and things like that. So it's really critical that you surround yourself with such a good and diverse group of people so that you guys can kind of cover together as a group, all the bases that need to be covered for the nonprofit to be successful. And I think my final piece of advice and overall would just be, you can do this.

There's going to be days where you're like, my gosh, I don't know why what I'm thinking. I don't know how to accomplish my next task. And I think when you have those moments, like I mentioned earlier, you really just need to focus back on the mission, focus back on the reasons why you got involved with this in the first place and focus on all the people that are going to be helped by your work.

And that's going to, again, carry you through those times that can be tough.

[Speaker 1]

Yeah, I love all of that advice. That is solid, solid advice. And you do have an incredible board, which is I really think you're dead on that.

That is the key. That is the key. Heidi, thank you so much for joining me today.

It was fabulous to have you here. I'm so grateful to have you in my world as my client. And I think you're amazing.

And thank you for sharing your story.

[Speaker 2]

Yeah, Jess, thank you so much for having me. It was my pleasure to be here. And, you know, I thank you, too, for all the work and the guidance that you've provided and look forward to working with you more in the future.

You're too kind.

[Speaker 1]

All right, folks, that's our show. Be sure to follow me on Instagram or Twitter at Jess Birken. We want to hear from you.

Send us a message at our website, charitytherapy.show. And don't forget to subscribe to our newsletter at birkenlaw.com/signup. Charity Therapy is a production of Birken Law Office PLLC. Our theme song is by Whalehawk, and remember, folks, this podcast is produced for your entertainment and is not a substitute for actual legal advice.

About the Author



Hi, I'm Jess Birken.

I'm the owner of Birken Law Office, I help nonprofits solve problems so they can quit worrying and get back to what matters most – The Mission. I'm not like most attorneys, I actually have an outgoing personality, and – like you – I like to think outside the box. Most of my clients are passionate and have an entrepreneurial spirit. I'm like that too. My goal is to help you crush it. Getting bogged down in the minutia sucks the joy out of the important stuff. My clients want to do the work – not the paperwork.

Let's connect!

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