

Hypertrophic Cardiomyopathy HCM with Bethany and Hannah Keime

Speaker Key:

VO Voiceover

CB Chantal Boyle

LS Lynn Smith

BK Bethany Keime

HK Hannah Keime

00:00:00

VO

Welcome to the Sunflower Conversations, where we explore the Hidden Disabilities Sunflower and its role in supporting people with hidden disabilities.

CB

Hi. I'm Chantal, and I am very excited because today I'm being joined by my colleague in the US, and that is Lynn. Lynn is the regional sales director. Hi, Lynn. How are you doing?

LS

Good. Very happy to be here, Chantal.

CB

And joining us today are sisters Bethany and Hannah Keime. They have a condition called hypertrophic cardiomyopathy, abbreviated to HCM, which is a disease of the heart muscle where the muscle wall of the heart becomes thickened. So, we are going to find out all about this heart condition today in our conversation, and I'm really looking forward to discovering more about it.

00:01:13

But first of all, before we dive into that, Lynn, I want to know how is everything going in the US? How is the sunflower? How is it rolling out? What highlights have you got for me?

LS

Well, the sunflower is doing great in the US. We're really picking up some speed. This month we're having Atlanta Airport join us, and Atlanta Airport is one of the busiest airports in the US, I think maybe even the world.

CB

Is that Atlanta?

LS

Atlanta, yes.

CB

Atlanta. That's huge.

LS

That is huge, and it's going to give us a lot of visibility and a lot of people will see the sunflower, which will be fantastic.

CB

Do you know roughly how many airports we are currently [overtalking]?

LS

Yes, just about 80. A little over 80 now.

00:02:07

We go from small regional airports now all the way to Atlanta. So I'm hoping that with Atlanta coming on board, we'll get some of the other larger airports like LAX. So, a little shoutout to them if they're listening, they should be next.

CB

We're coming for you, LAX.

LS

We are.

CB

The thing is, with the country being so vast, many people take domestic flights, don't they, in the US? So, being supported within your country is going to be of huge benefit to so many people with invisible disabilities. So it's really exciting how the momentum has been growing.

LS

Yes, it is. It's very exciting. I'm looking forward to more and more people joining and for it to be more recognised because it can only help people like these guys today.

CB

Yes. So, welcome to Bethany and Hannah. I think you discovered us via Instagram. The power of social media connecting people is brilliant. I want to thank you for taking the time out of your jobs and your charity, HeartCharged, to educate us on your heart condition, which I mentioned already is called hypertrophic cardiomyopathy. And you will tell me if I have pronounced that incorrectly please.

00:03:29

And I believe that the statistics around that are that it currently affects one in 500 people, and it is one of the most common heart diseases. Is that right? They're nodding, just for the purposes of the podcast audio format. We're getting some nods.

Okay. So, either one of you, can you please explain what hypertrophic cardiomyopathy is and how it affects you both?

HK

Yes. So, hypertrophic cardiomyopathy, the two biggest words we have in our vocabulary, or HCM, as you were saying, it deals with the thickness. So, the left ventricle is overgrown, hypertrophied or thick, and that affects the blood flow, so the blood flow going in and the blood flow going out, because there's not much room to have blood in that chamber because of the growth. So it leaves not much room.

So we definitely have to keep hydrated to help the pumping of our blood better, but that's also just a general note for anybody to just drink plenty of water. It actually helps you keep hydrated, but also, with HCM the left ventricle can stiffen as well. So it never really relaxes, which is another issue, again, having pumping problems with your heart. And then you also have fibre disarray, which you have an abnormal arrangement of your fibres of your heart cells, and that can lead to irregular heartbeats or arrhythmias, which can be deadly.

And in the general population it affects about one in 500, but in India it's one in 50. So it very much is very common. And it's classified as asymptomatic, yet there are symptoms, but a lot of the times people get diagnosed with it after they have died, because it is the number one heart condition leading to sudden cardiac arrest or sudden cardiac death, because sudden cardiac arrest, that already is 10%.

00:05:34

So not everyone is lucky if intervention, having an AED or CPR, so they can end up dying. So, when we found out we were diagnosed with a deadly heart condition, we didn't take that very lightly. But it's definitely affected our everyday life.

CB

Yes. Bethany, do you want to expand a little bit more on how the impacts have been for you and obviously for your sister?

BK

Yes. So, definitely in fact affected me, especially Hannah and I both, is that we were both physically active, and we were both dancers. Hannah was a dancer, played basketball. I was in a pre-professional ballet programme. I was home schooled. That was my goal, that was my trajectory that I was on. And unfortunately, with hypertrophic cardiomyopathy, because of that thickness of the wall, and it can get worse, Hannah and I both had to stop physical activity to a certain point.

So, that's the biggest thing I think we've had to deal with in that aspect. And then the other thing daily is the fatigue. And definitely with the condition you feel tired, just normally more tired than others, even though you're not doing anything and you're getting normal sleep. It's just that your heart is constantly overworking. So the fact that it's constantly overworking, now you're constantly more tired.

And then other things that we deal with daily is of course abnormal heartbeats or rapid heart rate. And then other things I would say is sometimes we have light-headedness or dizziness.

00:07:10

CB

So, what was it then? What was the moment? As you mentioned, Hannah, people unfortunately don't find out until it's too late often. What were both of your telltale moments?

HB

Well, we finally got diagnosed, and I had actually had some fainting episodes, but actually our paediatrician dismissed us, which sadly 65% of the time paediatricians dismiss warning signs in kids that actually end up having heart conditions.

So I had had fainting episodes, but the only real reason we got checked is because of family history, which is also a big warning sign that, hey, this is a genetic heart condition. It's not necessarily always genetic. We know people who don't have other family members who have HCM, but it is very much common, something that is genetic.

So our aunt, our mom's sister, found out she had it, and that is the only reason we got checked. And because I had fainting episodes, that seemed... And also, my mom just had a feeling. There's nine of us kids. Out of everyone, a very strong feeling that I should go get checked first, and thank goodness, because I ended up finding that I had this condition, and I had it severely.

And my doctor, my cardiologist, was like, I'm surprised you haven't dropped dead with how active you were and how thick your heart was at this stage. So, very grateful to still be alive,

but yes, we would have kept on going if it wasn't some family history, because it's not always the case that...

00:08:49

Oh, and that's the thing. Because you're exercising, yes, I would have rapid heartbeats, but they say, oh, your heart rate increases, right, when you exercise. So I think you don't know what is too fast or what is too slow or what is irregular, especially since we've technically been living this our whole life. So it kind of gets hard when that has always been your normal to then know, wait, that isn't actually quite normal compared to an average person.

CB

I think that's the thing, isn't it? When you are born with something, it is your normal, so you wouldn't probably even think to say to your mate who you've just run a race with, how's your heartbeat racing, how do you feel? It doesn't really come up, does it?

BK

No. Even I have this story. Two years before I got diagnosed, I had been in physical education class and we were doing step aerobics, and at the end our PE teacher always made everybody call out their pulse, and so I would call out mine, I'm counting it or whatever, and I'd get a pulse of 214 beats per minute. And that's crazy. That is not normal. And then I'm like, I must have just counted wrong, because everybody else started yelling out, 90, 100, 95. So I just took one of those numbers and called it out. That was a huge red flag.

But then I just thought I either didn't know how to count my pulse or that might be normal, but that totally was not at all.

CB

That's a really sensible safety measure for your, what do you call it, physical ed teacher to do that, because when I was at school, I don't remember anybody ever asking. Mind you, I barely moved, to be honest. I was a bit lazy.

00:10:38

LS

We used to do that either. And now with the iPhones, they measure your heartbeat, right, or there's phones that do that for you.

CB

[Overtalking] watch.

LS

Yes, yes, and they catch some conditions.

CB

I actually had my first panic attack last week, and at the time I didn't know what the hell was happening. And my husband, he came home from work and he has an Apple Watch, so he put it on my wrist, and it was like, well, everything's fine. So it was quite good that he was able to assess that, because in that moment I thought I was going to die. But it was fine. It was a panic attack. Go on.

HK

Oh, sorry. I was going to say, but that's the helpful thing with having something, because not everybody, for instance, has a blood pressure cuff or stuff like that, where I'm going to show up at the pharmacy to go use a freeone when I'm literally having an attack.

I had a college good friend of mine who was like, hey, my heart's being very fast, and luckily he had an Apple Watch to really test it, because a blood pressure cuff is not something everybody has on your own, but it does help to actually really know and then tell your doctors, yes, my heart rate was reaching this much and I'm very concerned about it. So it is nice that that is getting into the daily use of people.

00:11:59

I will say, as heart patients we don't use it because I can already see my heart shaking out of my chest. I don't need to know the number, I'm good. [Overtalking].

CB

Yes, you're in tune with your body now.

HK

Yes. You're like, I don't want to see that number, I'm good. Or being like, oh, you're doing crazy exercises. I'm not, I'm just sitting. So let me not be reminded.

CB

Can I ask how that has affected you guys both mentally? I don't know how old you are, but to my eyes you look very young. So, having to alter your life and the things that you really enjoyed doing before, which were very physical, how have you both dealt with that?

HK

No, we appreciate you asking that because, surprisingly, people don't think that you suffer mentally. When your body's unwell or you have something wrong with one of your vital muscles or organs in your body, of course, it's going to play with you, play with your head. Definitely, we remember the date we were diagnosed. It's a thing that changed our lives forever, especially me, because I was told immediately I had to stop playing every sport I was doing. Literally, don't do anything that will get your heart rate accelerated. So it very much changed.

But now the lazy person in me is like, okay, good, I'm chilling here doing whatnot, but I also, when I was 17, so we're now in our mid-20s, we won't go into exactly the specifics, but actually when I was 17, I went into sudden cardiac arrest in my sleep.

00:13:38

So, also knowing the date and time I would have died if I wouldn't have gotten on heart screening, then would have gotten an implanted defibrillator that would have literally saved my life, I would have been dead because no one would have known, as I'm sleeping alone in my room.

So that definitely greatly impacted us. Personally, for me, that changed my whole outlook on life, like, oh, I would have been dead, what do I do with my life now? And that has always been our outlook on our diagnosis, that we want to be grateful and being seeing those kids of, oh, I would have been the headline of some kid dropped dead in their sleep, and knowing this is a preventable death. And I think that's what makes it so upsetting, is that there's things that we could have done to prevent it.

So that, I don't call it survivor's guilt, I like to call it survivor's gratitude that we really use in our charity, in our nonprofit, in our just outlook on life, is pushing for those kids who unfortunately passed away and holding them close to our heart to keep fighting, that we feel privileged to still be alive today, and we want to use something with that. We want to use that to keep going and to fight for them.

CB

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00:15:06

LS

So, are there other members of your family affected by this disease?

BK

So, as we mentioned, our aunt has hypertrophic cardiomyopathy, our mom's sister. Our mom as well also has hypertrophic cardiomyopathy, and then in the lineup of our nine siblings, it goes six boys, and then it's me, Hannah, and then a younger sister. So the brother number six, or the brother right before me, actually when all the family did genetic testing, found out that had the gene for it, and just recently he started expressing very minor symptoms. But he does not have hypertrophic cardiomyopathy in the extent that Hannah and I both have it.

CB

Nine siblings. Even trying to wrap my little brain around that is a bit mind blowing. My goodness. But out of the family, it's you two who have the most exacerbated symptoms

from it?

BK

Yes.

CB

How did you aunt find out that she had it?

HK

So, she's had a few other heart-related issues, like a valve replacement and such, and she was at just one of her normal cardiologist follow-up appointments, and she had said something regarding some type of symptoms, and they basically said, oh, well, that makes sense because of your condition, hypertrophic cardiomyopathy. And she was like, what?

00:16:30

And supposedly this condition was marked in her chart, but she had no idea she actually was living with it. And since she has no children of her own, she immediately calls my mom and goes, hey, I did some research, it's a genetic condition, you need to go get the kids tested.

CB

Thankfully.

HK

Yes.

CB

So, you mentioned about your implantable defibrillator, is that how you say it? Can you tell me about that, or tell us about that?

HK

Yes. So, a year after I got diagnosed, so we were talking about it's the thickness, so a normal thickness of a left ventricle is 11 millimetres. Mine was 22 when I got diagnosed. And then a year later, it was 28, 29. You have your EKGs where they get your heartbeat, and then you have your echocardiograms, your ultrasounds, that really can measure the thickness.

And then they were concerned with how thick it was that they were like, ooh, you qualify for an implanted defibrillator, but we're going to run an MRI to get more accurate measurements. And so, with that they were like, yes, your heart is substantially thick, you are having tachycardia, irregular heartbeats, so we're going to get you an implanted defibrillator with you.

And thank goodness I did, because then six months later I went into cardiac arrest in my

sleep. And even my doctor was like, thank God, we got it implanted just in time.

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And then, because I had an implanted defibrillator, and then Bethany about four years later was in college and then she was having syncope or fainting episodes out of nowhere, which is also alarming because that's not normal if you're fainting, it doesn't matter for what reason.

And because I had one in the family history, they were like, hey, we want to make sure that you are safe too. And she got her implanted defibrillator as well. That is because with HCM there is no cure. It's very much lifestyle changes. It's not the end all, be all, kind of cure thing, but that's one that they feel very safe because, again, of sudden cardiac arrest. It's an electrical problem of the heart, and really only the thing that's going to save you is a shock from a defibrillator to get your heart back to normal beating.

So that's the big thing that they want and they hope when they implant it, that it never shocks you. It's just as a safety measure. So you feel very safe, and we both felt very... I felt more assured, even before I went into cardiac arrest, because I knew if something were to happen, I didn't have to rely on other people, that I would be okay.

And Bethany felt the same, but definitely I think Bethany can talk to also just that whole aspect of having surgery, having scars, getting this big chunk of metal implanted in your body.

00:19:23

CB

Yes, I'm intrigued to know what that was like for both of you. But yes, if you can tell us, Bethany, that would be good.

BK

Yes. So, when Hannah got hers, I think they did a really good job of hiding her device. If you every go to our Instagram page @heartcharged, you'll see mine, and mine protrudes pretty big. And at the time, I was still dancing. I was in school for dancing. I had a full scholarship in college. So I was allowed to keep dancing to a certain extent.

And so, they wanted to put a device in me. So, defibrillators are a little bit different. Some of them have leads going into your heart, and some of them have the lead going around your heart. So they wanted to put one around my heart just because I was still physically active to a certain extent.

So, of course, they come to you and they say, hey, this is what the device looks like. Basically, mine was like a big brown chunk of metal, and I would say it looks like... Have you ever seen maybe a pretty big thick coaster, almost an inch and a half thick? And so, being a young girl, and I like to wear bathing suits and leotards, I'm looking at this and I'm like, um. And so then I asked somebody, hey, can you do what you did on my sister? They hid it

behind the breast. And the guy was looking at me like, I just don't think that's going to work. The device is really big.

So, of course, they say I need it. I get the phone call, you have surgery in a week and a half. And definitely your mind starts racing and you're like, what are people going to think of me? Am I going to be deformed? Is somebody going to see those scars, because I have one here and one in the centre of my chest. What are people going to think? How are they going to look at me?

00:21:06

And of course, it definitely took a mental toll, but I kept reminding myself, well, I know it saved Hannah's life, and I know it's so needed, because what if something happened to me? And it's better to be safe than sorry, and I shouldn't think what other people are going to think of me when I didn't choose this condition, but I want to try to live as long as I can. So, to keep working with that and stuff.

'So of course, I get the device implanted and my surgeon first tells me, we didn't realise how tiny you were, so we had to flip it around to make it fit. I'm like, wow, that's so great, exactly what I want to hear right now. But finally, after the surgery, which is an overnight surgery, basically what they do is they go in there and they take your skin and your muscle long, they pull it apart to create a pocket for the device to sit in, and then they basically move the wire either to go up and around your heart or, like for Hannah's, inside your heart.

And then the bandages finally fall off and I was faced with my reality. And I just smiled so big. I love my bionic bulge, I call it sometimes, or my jolt, I call it. But very grateful for my device. And even though it's pretty big sometimes, and you can see it, you can't miss it, but I love it. I'm very grateful for it.

CB

So, why were you not given the same one as Hannah?

00:22:27

BK

Because of the lead. Hannah's lead went in her heart, and since I was still physically active at the time, they were scared that in dancing, since I'm really petite, I did a lot of lifts and stuff, and they were scared that if I did the wrong move or something, that that wire could be pulled out of my heart and puncture it. So that was the biggest concern.

So, recently a few, well, not a few, but there was that soccer player, Christian Eriksen, and he went into sudden cardiac arrest. So, usually they put the device that I have in more active people that are allowed to stay active for a little bit longer.

CB

Yes. So, would you mind describing whereabouts on your body it protrudes from, and what

would I see if I was in the room, or if I was on the beach with you, what would I see?

HK

Just flash them right now.

BK

I can show you.

CB

Oh, okay. Yes.

BK

So, basically, for anybody that can't see, basically it's right below my armpit, I would say, right sitting on top of my ribcage. And sticks out about an inch and a half, and you would probably just see this big box coming out of me, and I've definitely had people look at it strangely or them finally have the courage to ask, what's going on there? What's wrong with you?

But it sticks out. It's looks, I would say, like maybe I'm hiding a little box of chocolates under my skin.

00:24:05

CB

And does it hurt when you lie? Are there certain ways that you can't be?

BK

Yes. Definitely sleeping has been the hardest thing for me because if I roll over to that side, it almost feels like all my weight is just sitting on that device. So definitely sleeping is a hard thing, so I try to sleep on the other side or on my back now more.

And then I would say the other big thing with women and this device is bras. We're told that we cannot wear any wired bra, so of course, being a young lady, I'm being told that after they put the device in you. Wait, what? So definitely certain bras or wired bras hit at a certain point that are just uncomfortable and it almost feels like it's pulling, which is not the best. So, certain things like that definitely have changed for me.

CB

Yes. Although you used the expression of survivor's gratitude, which is a brilliant way to reframe that, I love it, which is why I got a little bit choked up, it is difficult still, isn't it? Your body has changed. And we are very visual in the Western world. Society, we look at each other's bodies and the type of clothing that we choose to wear, what have you. So, I can imagine that the journey of acceptance must have been a bit difficult. But as you say, it

means that you are safeguarding your life, your precious heart.

BK

Exactly.

LS

After the implant of the device, how long could you dance for? Can you still dance today?
Can you still be active?

00:26:03

BK

Yes. I got the device in 2018, and then I graduated school 2020, so about three years ago. So I got to keep dancing, but unfortunately though we went to a cardiologist appointment and they did a few tests, and there I was told I was going to need a heart transplant in my future and that I needed to stop any type of really adrenaline-based activities.

And unfortunately, I could see it in myself that I couldn't keep up like I used to, going from dancing eight hours plus a day and feeling like I was on top of the world and then suddenly you feel like you can't even catch a breath. And so, I started noticing that myself, but I kind of didn't want to believe that, you know what I mean, until at that doctor's appointment.

Thank goodness Hannah and I both have heard the word heart transplant in our future, but right now we're stable and they're just going to keep us with the defibrillators. But I no longer dance anymore.

CB

And that's what lies ahead for both of you. Eventually you both will need to have a heart transplant.

HK

Yes, because if you think about it, at our young age, we both were diagnosed in high school. Our hearts were already crap, so it's not going to get any better. It's not like it's going to magically... But with anybody's health journey, sometimes you have a good year where you're like, wow, I'm not having to up my medication or I don't need to do further testing, and then you have where it's bad.

00:27:42

So of course, it's eventually, but right now with the care that we're being seen under, they want that as a last resort, that there's a lot much more. But it's been almost a decade this September that we've been diagnosed, and just seeing all the new things that have happened in science, what new studies that they have come out with and the new things they're doing, that now I'm being encouraged to actually exercise more and do things and get my heart pumping, when I was literally told to stop everything.

So there is hope and there's a future to have, maybe a more, air quotes, normal life or better active life. But it's just also, no offence, as a patient it is a bit of a rollercoaster because you're like, I've gotten so used, I've become accustomed now, and now I have to change that again. But welcome to living with a chronic illness where you never know what's going to happen, right?

But that's the beautiful thing about our patient-to-patient community, is that we have people who've gone through heart transplants. So when we are worried or question that, we have people that we can reach out to and talk about it, because we felt blessed to have each other to talk about symptoms or, oh my gosh, do you get a thing where you start seeing black lines in your eyes and your heart's beating really fast? Okay, same.

00:28:56

It's nice to have somebody to talk to because your doctor can't answer all those questions. Even with having a defibrillator, there are certain questions your doctor can't answer, like how will you look in a bikini. They don't really know that answer.

CB

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We talk to many people with many different disabilities, health conditions, and one of the things that seems to be the common theme is to find people who are having the same lived experience as you are, because nobody else can really fully put themselves in your shoes. So, I'm assuming that's why you started your charity HeartCharged?

HK

Yes.

CB

Right. Hit us with it. Come on, tell us. What are you doing?

HK

What are we not doing, that's the main question.

BK

So, do you want to go, or me?

HK

No, you go.

BK

So, I definitely think it's like our work mirrors our journey. So, since we both feel like we

escaped death, but that we also have each other to go through this journey with, we realised, what can we do? So we had this idea, and I told Hannah and I was like, there's got to be others like us out there. There's got to be others like us going through this. We could be there for them.

So we began HeartCharged, and it almost started as just basically using the power of social media to bring other people like us together, and then it turned into now a full nonprofit.

00:30:33

But through our work, we not only do patient-to-patient support where we meet other people just like us. And I kid you not, we stay up texting some of these people till three a.m. because you just don't want to feel alone. We just had somebody last week send a picture of their scar because they'd just got a defibrillator. Doesn't it look great? And we were like, yes, we love it.

And we'll send care packages to newly diagnosed heart patients and also people going through their defibrillator journey. And then also through the work that we do is we talk a lot about either pre-preventable or post-preventable. So, either you get that EKG. So we just got passed in Miami-Dade County schools, free heart screenings for all students.

So, just starting last October, 8,000 students have already been screened. And out of that, a good chunk of them have already gone to see a specialist and get further treatment. And then we also talk about the post-preventable, which is making sure people know that they can grab an AED and use it and that they can start CPR.

So we hosted in just the last two weeks three free CPR and AED classes to teach more people. But I think our biggest thing is that we use our Instagram to really show off just the awareness advocacy, but in a way that's very light-hearted and fun, very us, very bubbly, just to make people start talking about it, realising what's going on, realising how many people are actually affected by heart conditions.

00:32:08

CB

That's a great legacy, by the way, and you're in your mid-20s. So, what are you including in the care packages? That's question one. And question two, it's now just literally floated out of my mind. Oh, yes. It's about the campaign for the defibrillators. Now you've done something about Flash the Boobs? So, tell us more about that.

HK

So, to answer your first question about the care packages, that was something that we always wanted to do, is to go to the hospitals and see the kids who had just gotten their implanted defibrillators, and knowing what that was like for us and having somebody.

So we graciously, through a grant that we applied for, a small grant, we were able to... With HeartCharged we make it like a symbol, like a community. So we have a little tote bag. We

have water bottles that we got graciously donated to us. We use the water bottles since the biggest thing is stay hydrated. We have cute little heart pill containers. We have hats, we have stickers, little fun stuff.

And then in every one, which I enjoy doing, is writing a personal note to them, to every person that we go to, just to remind them. Sorry, I'm getting choked up. It's just to remind them, and that's the whole point of having even the cute little stickers that they can proudly put on their water bottle and stuff, is that they're part of a community because when you're going around, you may not... At high school, I was really the only one, even though I had my sister. We didn't go to the same high school.

00:33:41

So sometimes you know that there's a community out there, but not necessarily right there in your community is there someone there to remind you. So it was just these little physical reminders that they were part of something bigger.

And also, if somebody had a question like, oh, what's that sticker, that it was a conversation starter, that they could talk about it and be proud, because that was also a reminder to them that they weren't alone, that there were more people out there who had their back and who weren't a freak or, oh my gosh, what is this? There's other people going through their struggle.

So it's very big for us to make them feel like they're part of a community, and we love it when people post of them wearing our hat or little things like that, because it's just a warm reminder. And we give it to anybody, not even just implanted, any heart surgery, because we found, oh my gosh, this person's been diagnosed for 15 years but they're going in for another open-heart surgery stuff, so a reminder. So anybody new that comes and tells us that we think, oh my gosh, you should get a reminder that you're part of this community.

And we'll ship it internationally. We have a lot of great friends in the UK. One day hopefully we'll go over there and visit that person. But yes, it's kind of a physical reminder, even though we're not physically there with them.

00:34:58

CB

That's really thoughtful. It's so thoughtful to reflect back on a time that was very difficult for you, in school. Many people might want to block that out and not revisit that. Gracious is a word that you've used a couple of times, and I think that that's really gracious of you both to have to sit with those feelings again of how you felt, but in order to support other young people.

And your followers, would you say that they're quite young, the people who are following you, who you interact with, or is it difficult to tell the age range?

BK

It's a good amount. Of course, we were very much geared early on to young people, and then we actually found out middle-aged people were like, we resonate with you because, no offence, there's Facebook groups with a lot of older... It is [unclear], like I have defibrillator. Oh, my grandpa has one too. And you're like, yes, it's probably the only thing I can relate to is your grandpa.

So even the middle-aged people, we've found a lot of them coming like, hey, we just like you guys' energy and spirit and welcoming community, and it's too old for us over there.

And I think too, the thing with sudden cardiac arrest and these undiagnosed heart conditions is you can go into sudden cardiac arrest, and it happens to anyone, any time, any age, anywhere. And it's just a huge reminder because people look at us like, you're young, you can't have heart disease, you can't have a heart condition. And it's just pushing anybody can have a heart condition from the little five-year-old that we meet to the 55-year-olds.

00:36:41

CB

Yes. And what was my second question? I've forgotten it now.

BK

Flash the Boobs.

CB

Oh, yes, that's it.

BK

Well, I just wanted to touch really quick. Actually, recently too we had donated a couple of AEDs to City here in Miami, and one of them that we donated was just used to save somebody's life. So, really cool.

CB

Applause for that. An AED is abbreviation for something something defibrillator, presumably?

BK

Automated external defibrillator. So the Flash the Boobs campaign came along because, unfortunately, women are less likely to receive by standard intervention with either CPR or AED because of their breast. And we as women, we're like, no way, we're not standing for this, this is not okay.

And so they recently did studies, and it ranges from 27 to 35% women are less likely to receive help. And it shouldn't be because they have breasts. The person has gone unconscious. That's their life that you're holding and that you could help save them.

00:37:50

So we took to Instagram to bring our Flash the Boobs campaign to life, and Hannah is a film major, and so she's amazing at bringing our story ideas to life through the camera and editing. So we did a few different campaigns. One of them is, if you know Dr Seuss, Green Eggs and Ham, we did a spin on it which is basically all about flashing your boobs and the different places that I might have to flash them to save your life.

So we talk about how sudden cardiac arrest is the number one killer on school campuses, so you might have to flash them there, you might have to flash them at a park. You never know.

And then another campaign we did which was really fun through the Flash the Boobs was the Little Mermaid Kiss the Girl song, but instead, it was Flash the Boobs. And it's really fun, and it got a lot of traction and people just absolutely loved it.

And then another one that didn't go over so well... No, it went over well, but I would say some men did not like it or whatever because I stand there and I'm wearing a blazer and I go, I'm Bethany Keime, and it's flashing news, and I open my blazer. But of course, there's a bar covering me. You can't see anything. But it was just to get people to think. And of course, people were thinking they loved it, but then unfortunately, some people were like, oh my gosh, that is too much.

CB

It's not though. That's the whole point. This is the whole point.

BK

That is the whole point. Yes, exactly.

CB

Oh, gosh. Was it mainly men that were complaining?

00:39:28

BK

Basically, yes. They were like, you need to take that down. We were like, no, no way.

CB

Don't look at it if you don't like it.

HK

Yes. It's probably one of our most viewed ones too because it's also shorter. She's a reporter for flashing news. So, heck, no, not taking it down, it's got the most views. I don't care what you say.

BK

But it went to go and show why we have to keep talking about it, because even now, I'm a CPR instructor, so when I go and do those classes, we're used to your white male mannequin. And that was what we grew up on. And now it's amazing to see that all these CPR mannequin companies now have the ones with boobs on them, they come in different colours, skin tones, which is awesome. And so we tell everybody, if you're not willing to flash the boobs, you need to leave the class.

But it's just an important thing to remember. And so, when you hear that feedback, that people are still thinking twice about it, that's somebody's life right there, regardless. Why does it even matter? And especially now in fashion, I was sent a video yesterday and the girl was wearing a pretty sheer dress, and you could see. And I was like, yes, go you, because everybody seems to have a pair, is what we like to say.

CB

Yes. It's one of the things that definitely in the UK and I'm guessing in America that we are so prudish about our bodies and accepting of our bodies.

00:41:02

That's why a lot of health conditions, say, I don't know, breast cancer, bowel cancer, things like that where you're talking about your bodily functions, if it's related to intimate areas of our bodies, then we are embarrassed to even share something that might be of a concern, that actually if you spoke to your friend or your neighbour or whoever, that might give you the indication of actually, yes, let me go to the doctor and check this out. So, yes, we've got boobs. News flash. It's fine.

LS

Yes, and we would like them exposed if it saves our lives.

HK

Exactly.

BK

Exactly. We went to DC a couple of weeks ago and we had this huge banner and we were on Capitol Hill, and it said Flash the Boobs really big, and we had these tops that were the colour of our skin, and then they had the outline of boobs. And everybody was stopping, taking photos, like we love it, we love it. But do you know why you need to? And they understood it, and it was just really cool to see that switch in people, like why would I even hesitate? Why would I even think twice? It's true, it's just a pair of boobs, and it's a life that I could save.

CB

Yes. Do you sell those tee-shirts?

HK

We should. We have not started, but that's actually something we've been thinking about starting to do.

00:42:31

CB

It'd be a really nice social campaign, wouldn't it, if you could get people to wear them, take a picture and say why it's important or something like that, and create a nice montage. I'd be happy to put one on.

BK

Yes, because we were doing it. We had signs that we had that you could print out or use as digital things that we had to hold it right over the outline of your boobs, so it looked like topless, even if you weren't, to take the picture and say [unclear] we've got a good amount of people and women who are like, no, I stand with it, and to get the conversation going.

With any campaign, which we've been trying to... Getting a celebrity, you know what I mean, because the minute a celebrity... Which is kind of upsetting where it's like either I have to become a celebrity or get one to really get it going, doing it.

But we're trying our best to just get the message out there because the more people know, and with us, knowledge is power, and that's why we do CPR and AED classes for free when we should be making money from that. But that shouldn't be the thing of, oh, that's going to cost money, I don't know if I... Do I really need to know that? But just getting that information out there so people are aware and know what to do.

And that's why we post a lot of videos, is, okay, I can learn. We have a whole music video about how to use an AED and we teach and show it to little kids, and they could tell you all of the steps of what to do just by watching that video. That's why we feel impactful, being able to share that with people, and knowing exactly what to do. And the price isn't a matter of knowing that knowledge or not.

00:44:04

CB

Yes. And what's the most common question that is presented to you by your community? What's the thing that people are most worried about or intrigued by or basically searching for an answer to? And what's your answer?

HK

We would say it's kind of hard to find one, but we find the general question is what does my life look like with this diagnosis? When new people are getting diagnosed, I think it's everyone's question. Who's out there, and what does life look like for them?

And we get a lot of questions asked about implanted defibrillators, and for me as a proud sister, it's just been beautiful to see how so many young women have decided to get an implanted defibrillator because they saw Bethany's pictures and her embracing it and flaunting it and showing you can still be beautiful with it.

To be able to see that, that's been something quite beautiful, to know that, hey, yes, those are questions the doctors can't answer, like how is my life going to look like? And I think that's why we're very big on getting that patient-to-patient support and working with doctors to be like, hey, we can answer questions that you can't answer. Hey, this medication is bad to take, hey, do you have any tips or tricks of taking it better or whatnot, or things like that.

00:45:34

But it's really more like what does your life look like. And something very big that we wanted to do that I always was like, I don't want our page just to be about, oh, smiles and gratitude, but we do show the reality of it, that we do show, oh, here I'm crying myself to sleep tonight, it wasn't a great day, or hey, I just found out this news, or here's an immense allergic reaction to an iron infusion, showing all of the bits in between of living with this, not giving people false hope, but we want to give them that actual reality of, hey, it's not going to be easy, but at least you'll have support.

And that's really what the HeartCharged community is. It's that support, but showing, here's everything that could happen, and also even connecting people, because not everyone has HCM that's in our community. There's a lot of other heart things that we don't know about. So that's the beautiful thing of when someone reaches out to us and asks, hey, do you know somebody with this certain condition? And then we post it on the Story.

And one time we got 60 responses. And look at that, 60 people that that person could reach out to and get a different bunch of answers and perspectives on. So we even find that beauty of just connecting other people with each other and seeing friendships blossom in our community, because they might be better at answering that question because we haven't experienced everything heart-related.

00:46:52

CB

I think that that is a very sensible move, to put the good, the bad and the ugly. Otherwise, somebody won't be able to relate to your page and think that they've got it a lot worse. What's wrong with me, because they're really happy all the time. And I don't feel like that all the time.

So, some of the side-effects there that you mentioned about an iron infusion and things like that, is that something that you both have to have?

BK

I just became really anaemic. That does happen to people in the thing. I wouldn't say it's a

huge common thing, but I've been fatigued. I was noticing myself lower on energy than I had ever been. There's fatigue, and then I was like, wait, I'm feeling I have no energy at all. And then through tests I found out I was anaemic. And then I was like, yay, I'm getting iron infusions, I'm going to have energy again. And then I broke out into hives and all that stuff.

And then thank goodness [unclear] because was I was lowkey being gaslit by the infusion centre. They were like, no don't your feet always look like that? I'm like, no, they're not usually purple and swollen. I think I'm having a reaction to this. But because I went to HeartCharged and I was like, guys, I don't know what happened, what's going on, and they were like, no, take Benadryl, no, it's not because this. And they were giving me so much helpful tips.

So it's a blessing for us to have because we're not the ones really gearing the conversation. It's sometimes people giving us tips. So that was helpful, to think I wasn't going crazy, because I felt like in that little world, I was.

00:48:30

CB

So, you will presumably have to have this treatment again at some point because it doesn't last. The iron must deplete.

BK

Right now, it's good. Right now, it's good. So let's just hope it stays good right now. But now I'm better prepared for next time, to be like, I should get the Benadryl right away, let's go and do it. So now I'm better prepared, and that's the thing with people who have a disability or a chronic illness, is you learn all this stuff that want to pass along to other people. And I think that's why people are craving that connection with other patients of, hey, I don't want anyone to have to suffer this, let me tell you what I learned.

Or all these years of living with this diagnosis, let me give that off to someone. And I think that's the greatest thing you can give as a patient, is that advice that you have learned and helped and feel like, oh, it is helping other people.

LS

I'm sure the support group is fantastic for the families as well, because especially when you have kids that are diagnosed and you're reliant on doctors that give you medical terminology or the medial outlook, and you never get the real story. So I'm sure that having you guys around and even coming in and giving your little support gift, that probably makes the families feel so much better and that they have somewhere they can go as well.

00:49:50

BK

Oh, definitely. Definitely, parents thank us for showing, as Hannah was saying, all those

different parts of our life, just so that they know that their kids will end up probably having the most normal life, and of course, they know there's going to be the ups and downs, but look at what my kid could become, look, they could still be happy and learn how to live with this condition. So I think it's a beautiful thing.

LS

So, what do you think of the hidden disabilities sunflower, the concept?

BK

We love it. Sorry, I did not mean to cut you off.

LS

No, it's okay. I'm glad you love it. Are you guys still using it?

HK

No, yes. We love the whole concept of a conversation starter. As we said, we like posting... Us being a filmmaker, there's films that I make to start conversation. There's one that I just made about the struggles with friendships and having to talk, and when do you say you have a disability? And we even find struggle within our heart community of people claiming their disability because they don't want to seem what seems like less than, or oh, I'm weaker, whatnot.

But it's nice. We're hoping that... We like that it's going right. We're actually going to fly into the Atlanta airport here soon.

So, it's picking up so much speed and momentum because I feel like as a patient, you get so tired of rehashing your stuff and explaining to people and people, that it would be so nice to just wear a lanyard and you don't really have to fully explain yourself or keep telling your story, that people would know and see that symbol and know, oh my gosh, okay, so you have a hidden disability. Okay, I'm going to approach you maybe differently or a little bit better or more politely.

00:51:34

But I think the hardest thing with non-visible disabilities, and we were just having a conversation with two other women yesterday about it, is you feel like you're an imposter because people are like, well, you're walking fine, or you don't have those physical limitations. For instance, I cannot take stairs. I get light-headed, I get very out of breath, my heart rate increases. So I've had looks when I go to the elevator, or people are like, I'm taking the healthy option, I'm taking the stairs, and I'm like, well, that's not a healthy option for me.

So I think just having that sunflower is just so amazing. We're so excited to see it grow even bigger and bigger, that's it's going to help so much as a patient to just feel a little bit more at ease and a little bit less explaining and a little less looks. And that's exactly what we need in

this community.

CB

I think that everything that you've explained is definitely the purpose of what we intend for it. And you being end users, it's really great to hear such positive feedback about the sunflower. So, yes, look forward to seeing it on your socials.

HK

Oh, yes. Of course. And how many more we can help, yes.

CB

Yes. Spread the word.

HK

Yes. Well, we even posted on our story when we were travelling and we had a few amount of people like, what is this, oh my goodness.

BK

Like I want to get one, yes.

00:53:04

CB

Excellent, excellent. Well, I want to thank you both so much for your time, and it's been very interesting to learn more about HCM. As we said, there's one in 500 people. In India, just going back to that, is that something to do with the evolution of diet in India, why it's one in 50? Do you know what it relates back to?

HK

There's a lot of doctors from India that follow us, and they were the ones telling us and spreading it that there is a lot more. I don't know if it's...

BK

I don't know if it's diet-based because the biggest thing with our condition, it's never really changing the diet that much, except more water, but it comes because of a genetic mutation. So I don't know if it's maybe something in that. I wonder. Now we have to ask them and see.

CB

Yes. I had a conversation with somebody who's from south Asia, and she was saying that because of many years ago of invasion and the way that they were, I guess, what's the word, how they were not the masters of their own destiny, they were being ruled by

western people, the diet and the access to food, etc, altered. So there was an alteration in how they had survived up until then, which then caused some kind of genetic mutation in order to try and survive.

Now, this is not gospel, and I'm just trying to recall it from my memory banks, which is not brilliant, but I think there's obviously something in it, isn't there, somewhere along the line, how it is such a massively different stat for them compared to... I'm talking about the UK and the US, the one in 500.

00:55:23

HK

Definitely, yes. There has to be something like that. And definitely also the medical treatment too that they're able to receive as well. Oh, more people having it, it's being passed down more and whatnot. We were just told, which I hadn't heard before, but from an HCM specialist, oh, if you want to have kids, we can just choose your eggs that don't have the gene.

CB

Wow.

HK

Yes. That whole process of being able to play God and being like, oh, we won't have HCM, even though I don't regret my life having HCM, but that whole thing of, oh wow, here, maybe they don't have that in... You know what I mean?

CB

Yes. So this is a very personal question, and you can refuse to answer it. If you had the option, if you wanted to have children in the future, would you do that? Would you select?

BK

I don't know.

HK

I would not. I don't know actually. I don't want to put that condition on them, but having lived through it, I think it definitely shapes me into who I am, and the people that I've gotten to meet and help. And I think that was really cool. I don't know. I wouldn't want to take that away if that was their destiny and supposed to happen. But then it's hard, thinking [overtalking] by chance and then being like, oh, you could have had the chance to not have your child go through this and whatnot.

00:56:49

But it also gives me hope. Our mom wasn't diagnosed until we were, and she had nine

natural childbirths. Well, it was C-section, but had all these things and was able to do it because we can have kids, but yes, it's a hard question to [overtalking].

CB

It's a complex one, isn't it? Yes.

HK

Yes, very complex. Oh my gosh, do you, do you not? Yes.

CB

Yes. Right, I think that's a really good note to end on. So, thank you, Hannah. Thank you, Bethany.

HK

No, thank you.

BK

Thank you so much.

BK

Thank you for having us. We're super honoured and just love what you guys are doing. So happy to get to be a part of this journey with you guys.

LS

Thank you both. I appreciate it.

CB

If you have enjoyed this podcast, please subscribe, like and share to help raise awareness of non-visible disabilities and the hidden disability sunflower.

VO

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