

Kleinhans Final

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00:00 Allison Yacht: Hello to our podcast listeners. Thank you so much for joining our second episode of the More Than 4 Cast. On this podcast, we share stories of pediatric cancer. We know that cancer stinks, and it's hard to talk to other people about it, even if they're going through a similar experience. I'm Allison Yacht, and I started this podcast because my daughter Mary is a cancer survivor. Thankfully, she finished treatment in 2012, but in March of this year, she was in the hospital for two weeks fighting pneumonia. As much as I tried not to let cancer affect us, it brought us right back to our experience. I realized one thing that I needed when we were in the hospital was stories. I needed to hear stories of other kids and how they handled their experiences. I needed to hear stories of other moms and how they handled their experiences, but unfortunately, it's very difficult to talk to others who are going through it.

00:50 AY: You don't wanna burden them with your story, and they don't wanna make your journey any harder. So I thought a podcast might be a good way to tell stories and to hear stories, without having to ask. Before I tell you about our next guest, I have to do a plug for our organization called BraveHoods. My daughter was diagnosed with rhabdomyosarcoma when she was almost five-years-old. She had an aggressive cancer and was on treatment for a year, and therefore she was bald for a year. This was very hard for her, and we couldn't get her anywhere but the house and the hospital. This was a hard adjustment, because we were an active family before this.

01:23 AY: Finally, we found a light-weight hoodie worked perfectly. She could put the hood up when she was feeling self-conscious, and she could put it down when she was comfortable among her friends. Once she was finished with treatment and started recovery, we started to think of ways that we could give back to the incredible community we now found ourselves in. BraveHoods was born in 2013. We are a nonprofit and we give soft, inspirational, cool hoodies to kids with cancer and their siblings. BraveHoods helps to make kids feel better and more comfortable, but they also help to make families feel like a team. And everything is better when you have a team behind you. We also sell our cool inspirational hoodies, and for each one sold, one is donated. To date, we have donated over 4,000 hoodies to kids all over the country.

02:06 AY: Please visit BraveHoods.org to see what we have. Now, I'd like to introduce you to our next guest, Sarah Kleinhans. I met Sarah at a Wapiyapi Family Camp while Mary was still in treatment. Before her son was diagnosed with cancer, she and her kids were, and they still are, professional actors and models. I hope you enjoy our conversation. As you will see, Sarah is a very funny lady and has an amazing outlook on her experience. Thanks for listening.

02:31 AY: Well, first I wanna thank you very much for being our second guest on our More Than 4 Cast. It's a podcast about pediatric cancer and experiences with it. So thank you so much for being here, I really appreciate it.

02:44 Sarah Kleinhans: I am excited.

02:46 AY: Well, perfect. Well, I wanna start with the beginning. Tell us your story about Addison's

cancer, and how you found it out, and I'll ask you some questions along the way, but tell us the story.

03:02 SK: Absolutely. It's interesting, because now that I'm an experienced pediatric cancer mom, when I look back at it, there were so many red flags coming into it. But being a, I don't wanna say typical mom, but being a typical mom who had no experience with cancer or anything like that, I thought Addison had an ear infection, because he had a fever the night before, not anything crazy, like 102. And he woke up pointing at his jaw and his ear area saying it really hurt there, and it was really painful to touch. And he was in a production that week, we're professional actors. And so he had a show, and so this sometimes happens that he'd get a fever or overtired during dress rehearsal week. So I called the pediatrician and I said, "Oh, it's dress rehearsal week, I think he's overtired. Can I just bring him in and make sure? I think he's got an ear infection."

04:00 SK: "Sure, bring him on." And I said, "We got a show this weekend." And I thought that they might just give him Amoxicillin and on we would go. And when I brought him in, she said, "He's really pale, I'm just gonna do a blood test." And I thought, "Oh, you know, well, maybe he's anemic and he needs more Flintstones vitamins," 'cause that's what we think as parents. And a couple hours later, she gave me a call, and I was just really waiting for a normal answer. And she said, "I hate to tell you this over the phone," she said, "but it's not good news." And at that point, you have that out-of-body experience, where you detach. And I sort of braced myself, but I still wasn't ready for what she said. And she said, "He has leukemia," and she said, "I don't like to do this over the phone, but he has so much. You've gotta go now. Children's Hospital is waiting for you."

04:55 SK: And I didn't know what leukemia was. I didn't realize it was cancer. I knew it was a terrible illness, but I thought it was its own entity, like lupus, or Crohn's, or just something like that. I didn't realize it was in that cancer category. And so, you go into automatic pilot mode. And I somehow booked a ticket for my mom to come out. And I called the director of the show and I said, "My daughter is gonna be there tonight for the rehearsals and still pick up Addison's role and his lines." And you just go into automatic pilot. And I don't remember much from there, and I just... The one thing I remember is we get to Children's, and they're waiting for him at the door, and I was like, "What the... Why are they waiting for him at the door?" That was the first sign that something was big and bad.

05:48 SK: And then they took us upstairs, and they wheeled him upstairs, and we went through onto the oncology floor. And I remember saying to them, the nurse actually stopped when I said, "Oh, is the leukemia floor or whatever floor he'd be on, is that full?" And she looked at me, and I was like, "Well, 'cause why are we on the oncology floor?" And it was this moment, the nurse turned to me, and she put her hands on me, and she's like, "'Cause he has cancer." And I remember going, "I'm sorry, what?" It was so absolutely shocking, because you're going, "Wait, wait, wait, wait. He has leukemia, he doesn't have cancer." And it's that moment that suddenly you become a normal mom, and you become a cancer mom, and there's no turning back. You're never gonna go back to the way it was.

06:35 AY: So true. So true.

06:37 SK: I mean, you'll never... There's nothing that you can do that's gonna change it. And it's not

gonna be all bad, but there's nothing that's gonna change that. And from that point on, I was a cancer mom. So... That's how it all started. But when you look back, 'cause I have friends who go, "Oh my goodness, my kid has bruises, Addison had bruises, my kid has a fever, does he have cancer?" I'm like no, no, no, there's so many... We look back over the month prior to, and Addison, we've been in Florida on vacation, and he had been learning how to ride a two wheeler 'cause he was almost six and he was riding on the beach. And you're so excited, like your kids riding bike on the beach, and he loved it.

07:15 SK: And then after about the third day, he was like, "My legs are tired." And I went, "Well, you've been riding, you've been riding your bike, that makes sense." But every day, he'd say, "I don't wanna ride. My legs are tired, my legs are tired." So that's kinda your back of your mind. You're like, that's unusual, but you Google it, and he's growing, it's growing pains. And then, I would wake him up in the morning, and he's, or in the middle of the night, and his pillow was soaking. When I say soaking, I mean, it was like I poured a cup of water on it. Soaking, soaking wet. And so that was the second sign, he had night sweats, and then he had bruises all over his legs. But the bruises were because I thought he was in his play, and he was falling backstage, and I looked at his sister legs, and she was just as bruised. So, everything separately was normal. I just didn't put everything together until he got sick.

08:12 AY: Right, and how could you? It's almost impossible.

08:14 SK: Yeah.

08:14 AY: Absolutely.

08:15 SK: And I mean don't Google, don't Google.

08:20 AY: Yeah.

08:21 SK: Never Google, that's all I'd say.

08:22 AY: I remember my doctor saying the same thing.

08:24 SK: Oh my goodness, yeah.

08:27 AY: Tell us about treatment. I know leukemia is a particularly long treatment. And for boys it's extra long, so tell us about that.

08:35 SK: Yes. So I remember, you know, there are these things that you remember from diagnosis. There's things that you completely don't remember, but then there the sound bites, if you will, that you remember. And I remember the doctor saying, "You can do this, but it's long." She said, "It is so long." And I was, "Oh, we can do this, we're gonna fight, yay." Whatever. And for boys it's 38 months of chemo every single day, and it is seems like it is 20 spinal taps, which is chemo into the spinal fluid. And it's to be exact, I have it here, he had chemo for 1,168 days.

09:21 AY: Wow.

09:21 SK: So, and it's every single day. And then three bone marrow aspirations and 20 spinal taps is his treatment. And boys are a year longer than girls, which is tricky, because then you have girlfriends or friend girls who were diagnosed the same time as him...

09:35 AY: Right.

09:36 SK: And they finished, and he kept going for another year, and he was just like ah, 'cause it gets in to the boy's testicles.

09:41 AY: Right.

09:42 SK: Or it can... And so boys have to go longer. But I related to, do you remember the breast cancer walks that were the three day walks?

09:51 AY: Mm-hmm.

09:52 SK: For breast cancer, and that first day I had friends who did it, and that first day they're like, "Yeah, you're so pumped, and you can just, I can do this, and you push through, and that's that first year." And you just get through it, and that third year you're like, "Alright, we're almost to the end. We can do this," it felt like the third day of the walk. "I can see the finish line." But that second year is horrid, because you're in the middle. You don't feel like there's an end in sight, you've got all of this behind you, you still got a ton in front of you, and everyone has, I won't say forgotten you, but it's not novelty anymore.

10:29 AY: Right, exactly.

10:29 SK: And so the meals have stopped and the calls have stopped, which is fine. People get back to their life, which they should.

10:37 AY: Right.

10:38 SK: But then you feel very isolated as a parent, because you're like, but I'm still here going through this living hell. And everyone's kind of faded back, as they should. I mean, they need to get on, and it's long, and you don't wanna wear your friends out by going "Oh, hi, we're still doing this and we're still complaining about it." So I think you tend to kinda shut in yourself a little bit that second year. And that's where you really have to fight to keep afloat, if you will.

11:08 AY: Right, right. Oh, boy. And when you say chemo every day, and what I've learned a day after day after day is that every cancer has its own recipe. And because Mary had a sarcoma, we did not have that same experience. So could you tell us, when you say chemo every day, I remember seeing Addison's poster at the end and...

11:31 SK: Yeah.

11:33 AY: All the things that he had done. So what does chemo every day look like? Is that a pill, is that an injection? How does that work?

11:41 SK: Sure, so the thing was hard with all of the cancers have their difficult things through them. The thing that I found the hardest with leukemia is he has pills every day, that are chemo pills. And you have to wear gloves and a mask.

11:57 AY: Right.

11:57 SK: To deal with them and work with them, which but then you're putting them in your child's body, which is unbelievable. And the hardest thing for Addison is he had this one that's called Mercaptopurine, and he had to have it two hours after his last meal, which meant he was also on steroids, which made him hungry all the time. And so there is no meal when you have a little kid who's hungry all the time. So, I found that the only time that worked for him and every family is different, was 11:30 at night, because he would always get up for a snack at like 9:00, 9:30. So 11:30 at night every night I had to give him chemo, but he was asleep, and it was a pill, so I would have to walk him to the bathroom in his sleep, and he'd go to the bathroom, and I put all these pills in his mouth. But then the problem was, he would tuck them into his cheek, and they would burn holes in his cheek, because it's chemo.

12:49 AY: Right.

12:50 SK: So or he'd chew them, and I was freaking out cause he's chewing chemo. It was just, there's no way to get them into them. It's so hard. And some days, there were like seven chemo pills at a time and as he got bigger, he's very small, and so he didn't have as many pills as some of the other leukemia kids who have to take handfuls of pills. But it's so many pills, and then he had chemo in his ports. At least once a month and sometimes... The first year, it's totally different, they get just a ton more chemo. But the second and third year, he'd get chemo in his [13:27] and then he'd get chemo in his spinal tap as well. And it was... It's just, when you have to put on a mask to give your child something, there's something really, really wrong about that, and...

13:38 AY: I completely agree.

13:40 SK: Absolutely brutal. But the hardest thing with the meds, though, wasn't the chemo, it was the steroids. So he had to have steroids for seven days a month, starting on the days of his spinal tap, seven days a month. And by that third day, he would go into depression and be tired and just not even be himself.

14:00 AY: Oh, gosh.

14:00 SK: And then, as soon as he came off those seven days of steroids, he would start throwing up. So then he'd throw up for four days straight. So two months out of... Two weeks out of every month were gone. They were just destroyed. For three years. So, two good weeks a month. And then, after, his immune system still hasn't really recovered to a normal level. It stayed so low that it

was much, much lower than a child who should be on chemo, and so, we had to really take so many extra precautions with him because it was so... It was like that of someone who was almost in that very beginning of treatment. For all three years. And even now, his immune system now is the same as a kid on chemo.

14:48 AY: Oh, wow. Oh, wow.

14:49 SK: So, yeah.

14:50 AY: That must be continually challenging.

14:54 SK: It is "wash your hands world". [laughter]

14:57 AY: Right, right, exactly. Oh my gosh.

15:00 SK: I would [15:00] [redacted] if I could.

[laughter]

15:02 AY: Tell us about how before... Tell us about your family. How things were going before, how treatment affected your family, and you have an older daughter, and all that stuff. Tell us what happened related to cancer, but not so much with Addison.

15:24 SK: Right, so before we were never a normal family, because I'm an actor and a model, and Addison was an actor and a model, and he did like call it a Shakespeare Festival, and then he was modelling a lot. And it was interesting, because his last shoot that he did... And I would never have a kid who is a model unless... He was grandfathered in because of my career, but otherwise... That's a whole another opera. But anyway, his last job that he shot before he got cancer was for [15:58] [redacted], which was really... For blood donation, and so, the poster went up, and so it was really, really interesting, 'cause the poster went up on the walls of [16:09] [redacted], so people were donating blood for him in his honor, and he got cancer. And they're like, "Oh, we saw the poster. Is that a picture of him that they made because of his cancer?" And I said, "No. Ironically, that was his last shoot."

16:22 AY: Oh, wow.

16:23 SK: Which is kind of creepy and interesting. So we traveled a lot, because we don't have any family here, which is very difficult when you have a child with cancer. My husband's family's in Michigan and mine's on the East Coast, and so, we're very far from any family. I have amazing friends, though, I was in the organization Up With People for many years, and so, I have a huge, huge network of friends here, which was my saving grace. There's no way I could have done this without them. But no family. And we traveled, we traveled two months out of the year, I did, with the kids. Traveled two months out of the year, 'cause my mom was down the coast, and so, I online schooled them, and we would go to the coast when the rates were cheap to fly. And we would just be on the beach, and that's how we would school online, and it was wonderful, it was easy.

17:19 SK: Well, it wasn't easy, but it was a normal life, and I liked it. And we did the normal, "Oh, you're going to baseball, you're going to gymnastics, you're going to dance." You did the typical parent thing of this generation, where you overbook your kids. And it was really busy, but it was very normal. And then, as soon as he got sick, obviously, your normal's gone. And since then, we've never gone back to normal. And I've asked Addison before, I've said, "What do you think of... Would you change anything?" And he says, "No. I'd never go back and not have cancer."

18:00 AY: Wow.

18:01 SK: Which is alarming to people, especially my husband. He's like, "Are you... Really? This was hell for us." And I think for men and women it's very different, because women communicate with their friends, and they listen to this podcast.

[chuckle]

18:18 SK: If you out there listening, are probably women. Not as many of the husbands are listening to it, because this is what women do, and this is how... This is our therapy. And men internalize it. So he internalized it, and I didn't. I went out there and I became public, and I used my modelling career and my acting career to make it a public story and to help others. And I've always asked Addison's permission, "Do you want to do this?" And he said, "Yeah. I'll make it public." And so, we've made it very public and we public-speak and we travel around speaking about it to help others. And not just to cancer people. He speaks in high schools, all sorts of... He'll speak to doctors, he'll speak at fundraisers, telling people how to not take life for granted and how to take really hard situations and make them a little bit more positive. And so, that's what he's done with it.

19:16 SK: And my daughter... It's very hard, she was two years older than him, so she was just about eight years old when he was diagnosed. And so, think about 8, 9, 10, almost 11 eleven years old, you can't have anyone in the house who's sick, which means nobody can come in, 'cause everyone's always sick. So no one can come in, you can't even go to playdates, your mom's always at the hospital, your dad's at work, and you're very neglected for three plus years, and that takes its toll. So when Madeline was 12, she said, "Mom, everybody always says how's your brother, and he gets to open the toy box at the hospital," and she said, "I never do, I never did all that," and she wasn't being selfish, she was being real, very, very real. And we tried to remember her. But it's hard, you're worried about your kid, and she would come up to me and say, "Mom, Addison's really, really hot."

20:15 SK: And I would freak out, and I'd snap at her, maybe, she said, "He's really, really hot," and I would say, "Stop, go get his stuff. We have to go to the hospital," and she'll try and help, and I'd snap 'cause I was terrified. And I didn't mean to, but suddenly she's on the back burner, and she's like, "What did I do wrong?" And that's a really hard position to be in, for a long, long time. And so we talked about it, and I said, "Why don't you do something about those feelings? 'Cause you can either complain about it, or you can do something." So she tried to collect toys and make a toy box for the siblings.

20:53 SK: And it was hard to bring... Which is a great idea, because people would donate stuff to

us. And she's like, "Addison doesn't need another stuffed animal." And new cancer families know out there. I mean bless them all, but you don't need another stuffed animal 'cause that's your go to thing. And your kid wants it, and they love the stuffed animals, but there's no room in the bed anymore. And anyways, she collected all these toys and things like that, and she would go to little groups at the hospital and hand out the toys.

21:21 SK: But it's hard, 'cause there's red tape, and there's safety issues and everything like that. And so, she came up with this plan to have fun days for just the brothers and sisters, and this is great. We'll go to like the pumpkin patch. So we sort of put it out there for the other cancer moms. And we had two kids come the first day, and I just handed them each a bottle of water, and I was like, "Here's a little ticket, go get a pumpkin. And this is your special day." And that's all I did.

21:48 SK: But we just wanted the kids to realize that this is just for them. Well, then the next time, there were like 10 kids and then 20 kids and then it became a non-profit. She partnered with another organization There With Care in Boulder, and she now has a non-profit for siblings of brothers and sisters. And every two months she does these events, and they're like 100 participants per event, and it's become this huge non-profit because the siblings are so forgotten.

22:19 AY: Oh, that's so good.

22:19 SK: And I know we can talk about that later, but that's what she did. What's that?

22:23 AY: Tell us more about that, so for local Colorado people, that they have other kids, how can they get involved with the agency?

22:32 SK: Oh yes, and you know, it's not the hospital's job to partner the families with all these wonderful camps and resources out there, but it's the other parents. It's word of mouth and things like that. And you have to let everyone know because there's all these wonderful resources out there that as a parent, you don't know about, and you find out later, and you're like, "Oh, I sure wish I had had that." So we try and spread the word about this. And it's called Heartfelt Hugs, and you can just Google Heartfelt Hugs, but it's Heartfelt Hugs2015.weebly.com. And it tells about it and everything sort of in the Broomfield Park north metro area, and it is things like we rent out in the summer, we rent out a huge park, and we rent out paddle boats and toggle boards. And there's a zoologist who comes with these crazy snakes and tortoise, so it's like all ages come, and we get food sponsors, and we play volleyball, and a lot of the counselors from the cancer camps come down and they volunteer.

23:39 AY: Oh, neat.

23:40 SK: It's a joyous time. And the parents... The first meeting that we had, I asked the parents, I said, "Well, the kids are doing ice-breakers, so everyone tell us who your kid is here and maybe who your sick child is." Well, everyone started crying. It was a terrible idea. I was like "Okay, honestly forget it. This is not what I wanted."

24:01 SK: So now we have our ice-breakers, my daughter is like, "Oh my gosh, mom, you guys are

so loud and annoying." Because we're laughing so hard, because I have things like what was the most scandalous thing that you've done that you can't believe you haven't gotten in trouble for? Or like it's stories like that parents like we laugh so hard, and that's what this is about, it's about laughter because there are enough tears, so we need some laughter. And children who, siblings who've lost their siblings, are very welcome at this group. Which is nice because the parents come to us and say, "We don't wanna go to a bereavement group."

24:36 AY: Right.

24:36 SK: "We don't wanna sit around and be sad." And so here... And no one has to talk about it, nobody has to say, the kids don't say, "I lost my sibling, or my siblings in treatment," unless they want to. But they don't have to, and they just know that everyone around them gets this story. Absolutely understands it. And a lot of times the parents who need to find someone else, they'll talk to someone, and if they need to, they do, and it's great. And the summer one, Madeline calls it the birthday party, because she said it represents all the birthdays that the siblings have lost, because of parents are at the hospital with the other sibling.

25:08 AY: Right, what a unique experience.

25:10 SK: And everyone gets issued a present, so much fun. Yeah, and she's really trying to get the teenagers to come, because it's hard... Especially teenage boys, they're too cool, and they... Well you have a teenage boy, you know.

25:23 AY: Yes, I know exactly.

25:25 SK: They internalize it, and they're, "Oh, I'm not gonna go. That's stupid that's for little kids." And so she just did a fundraiser, and she made enough she's buying a soccer team of these big inflatable balls that the kids get into, and they're like, stick out. And they like run and bounce off each other so like all the teams can do this. And I said, "Great I'm gonna have girl's night with..." [laughter] I'll do my own fundraiser with them, woohoo, we cancer moms need our own night, geez.

25:53 AY: That is so true. Oh, that is beautiful. I love what she's doing.

25:58 SK: Yeah.

25:58 AY: That is phenomenal.

26:00 SK: Yeah.

26:00 AY: Awesome.

26:00 SK: It's so, my boss is 16 years old, which is not a great thing. It's really not a great thing. Let me tell you, we've all quit at one point from her non-profit. Like everyone in the family at one point, like you look at the pictures, and we're like, "Why weren't you in that... Oh, yeah 'cause you quit that day, 'cause your sister was so annoying."

26:20 AY: What a great experience. Oh, wonderful, I love it. I love, that is just so beautiful. Good. Okay, and tell us how is Addison doing now? Tell us a little bit about what's going on... Tell us how long he's been done with treatment and all that good stuff.

26:37 SK: Yes, so yesterday was a huge day for us. So, when we first went into the hospital, and I remember saying to the doctor, "How long is long?" And it's neat that the oncologist understands that you're brain dead. And she wrote everything on a paper towel. It was really funny, and I remember going... She drew everything like I was a first grader, which was perfect 'cause you have like a first grade mind at that point, and no disrespect to first graders, but you have no brain cell going on at that time. And I still have these paper towels with these drawings that she did for me, and I remember going, "Oh my goodness, she has to do this every time someone's diagnosed."

27:16 SK: She breaks it down. She must be the most patient person in the world, but she said to me, "It is a three-year treatment, and then he will be considered "cured", whatever that means, five years from his last day of chemo." And that was the hardest thing for me. I was like, "Oh, I thought it was five years from today. The diagnosis date." She said, "Nope. Not with leukemia." She said, "It's five years." So she said, "Technically, it's gonna be eight years." And I was like, "Oh my gosh! Oh! He's just five years old."

27:50 AY: Right. And was five years from last treatment yesterday? Is that what yesterday was?

27:57 SK: Five years from last treatment was yesterday. So, yeah, and it's so surreal to me, I'm like, "What?" And so I've been kind of... My friends who know me know I'm stoic. They have not seen me cry, they're always... They just know, and you have to build a wall 'cause otherwise you're gonna cry all the time. And especially because Addison and I now are public speakers, and we travel around, and this is what we do, we go around and we speak about remaining positive, and we do things like this. And if every time I gave a speech I cried, forget it, I'd be a mess, and so I just had to build a wall, and so, everyone's like, "How are you feeling about this? So here it is." And I was like, "I don't know," like I haven't let my guard down, to feel it.

28:42 AY: Yeah. That makes perfect sense.

28:44 SK: Yes. And so, yeah, that wall is still up, and it's gonna be up for a while. And I think this is a hard thing, and the newly diagnosis is a really hard thing, and I'm sure you can relate to this. You hear all these good stories and you go, "Oh, this is good," and people will tell you all these wonderful stories when you're newly diagnosed. "My friend's daughter did it da-da-da," then you hear one bad story of someone who lost the battle, and that's all you hear, you forget all the good things, and all you do is focus on that one story and you're like, "Why did they tell me that? I didn't wanna hear that."

29:22 SK: And I think even to this day, I'm sorry to say it, but even to this day, I still... There's so many good stories, and I focus on the... Like I hear the bad ones, and they just resonate. And my, three of Addison's, three other people from Addison's cancer camp, they're 10 years out from treatment. They were 10 years, 12 years out from treatment from leukemia, and when I met them,

they were all fine, everyone was doing fine and they have since... And remember, everyone's journey is different, and they had treatment a long time ago. So we can't put ourselves in this same category, but they have since in college, all lost their journeys.

30:02 AY: Oh god!

30:03 SK: And their battles and that is, I don't listen to the thousands who survived, I go, "Oh my goodness! What's gonna happen 10 years down the road?" But you can't do that, it's easier said than done.

30:17 AY: Right.

30:19 SK: But I think all of us do that. You go... It's the same way if someone... You know Allison, if someone goes, "Oh, you look beautiful," and 25 people say you look beautiful and one person goes, "Oh, I love that blue dress on you better, but that's pretty." And you go, "Oh my gosh, I look terrible in this dress." Even though everyone else said, "You look great." All you hear is that one negative comment, and that's just human nature. I mean, that's sociology major and that is really more... We've done this since the dawn of time, and you focus on the bad instead of listening to all the good. And you have to be careful with that, because there'll be a lot of bad out there, and you're gonna hear a lot of bad stories, and I think we have to build a little bit of a wall, and you have to cut yourself off. I cut myself off from all these support groups for a while because there were so many kids having a really hard time and I went, "I can't do this 'cause I'm internalizing every one of them," so it's okay to go, "I gotta pull away for a little bit." That's fine.

31:19 AY: Absolutely. I totally agree with you.

31:22 SK: I mean, don't you find that?

31:23 AY: Oh, 100% that you... It's hard to put yourself first in that situation, but in order to keep everything moving in the right direction, you absolutely have to, and it's a very hard thing to do, but you do. You do.

31:37 SK: Right, and you can go back later and revisit it, but when you're in the throws of it, really, I dropped out of all these support groups because I could not handle another... Someone else's loss, I couldn't do it. And that is absolutely okay. In that time, when you're taking care of your child, the big thing I say is when you're flying, what do they tell you? Put the oxygen on yourself first, and then your child, and if you don't take care of yourself and protect yourself and you go into this tailspin, you're not gonna be any good for your kid, and your kid needs you at that time, which is a lot of pressure on a parent. Holy cow!

32:23 AY: Right. Exactly.

32:24 SK: [32:24] I'm responsible for my child's chemo at home. I could mess this... I could freak through, I could mess us this up completely. I could do this wrong, I can measure wrong. You cannot be hard on yourself, and it is okay to step back, and it's also okay to ask for help.

32:46 AY: Absolutely. I remember one time they... A couple of times they sent Mary home attached to an IV bag through her pores. I remember thinking to myself, "Are you kidding? Like I have to be responsible for this? I don't know what the hell that I'm doing."

33:01 SK: I know.

33:01 AY: But you do it. You do it. You find a way to do it.

33:05 SK: Yeah.

33:06 AY: Oh, gosh. Well, that leads me to our next part which is tips and tricks. Like what do you... I feel like we're already there, but I wanna make it formal. What are some things that you would say to either the newly diagnosed or in the middle the thick of it. Some tips about staying in the hospital, or I don't know, anything that you found that was helpful. You know, share it.

33:28 SK: Yes. I think the biggest thing we know and all of you, if I said raise your hand out, there you would all have your hands up. It is so hard to ask for help. We hate to ask for help. But you have to ask for help. So I had a situation. I'm not a... I'm a pretty in con... I like to think I'm an in control person. I've never... I don't have panic, or I don't have anxiety, I mean, aside from the normal I have a kid with cancer in my day, but I just have not had those issues, and I had a situation where I have an allergy where I can't breathe.

34:10 SK: And I had it when I was driving on the highway. And I grew up driving in Boston, so I could drive everywhere and I... I could drive anywhere. And I had that situation when I was driving, and so now I have PTSD from it, and I can't get on a highway that has like barricades around me. And so that's how you get to the hospital. So this has been quite the challenge for me, 'cause I like to be in control, and I don't like anything to slow me down or stop me, and you know, I don't wanna depend on anyone. Suddenly, I have to take my kid four times a week to the hospital, and I'm going, "Well, I can go on the toll road, but it's like \$20 a time."

34:49 SK: 'Cause I could drive on the highway on the toll roads 'cause it's big open roads. But in the city I can't do it, 'cause it brings me right back. So I was like, "What the heck am I gonna do? I gotta get my kid to chemo." So because Addison has a very public Facebook page and because I was a model, and I had a Facebook page that was very public, I put myself out there. And I... 'Cause all these people going, "What can we do to help?" And all these strangers, and I said, "Well, does anyone wanna drive with me?" And believe it or not, I got three years worth of drivers, people to go with me every single time.

35:26 SK: Some are strangers, and I know you guys are out there going, "You are crazy, girl." But I have made the most incredible friends, I opened eyes, people came with, and I mean, I didn't take complete strangers, like they had to know somebody who I knew. I mean, they weren't like, "Oh, I'm off the streets." They knew someone, or you know, they had an interest. And you know, I would check them out, it wasn't like completely random. But it was neat because for them they would always leave my house, drop us off in the afternoon and go, "This was such an eye opening

experience for us, and we're gonna go home and hug our child tighter. We're gonna argue less tonight. We're... "

36:08 SK: And it was really every single time someone new came with me, they said this, "Thank you for this experience." So I felt like hey, this kinda works out for both sides and then more people... And then so if people would go with me, they'd write on Facebook, "If no one's ever done this, you should try you should experience this one day to go with Sarah and see what this is like." So then I mean it was kinda funny, I always had people to go.

36:34 AY: That's awesome.

36:36 SK: So you have to ask for help. So I asked for help, and I received it. And the other thing is sometimes because Addison's immune system was so low, I needed something so simple as a gallon of milk, so I would put on Facebook, "I'm gonna leave money under my mat, can someone grab me a gallon of milk?" Well, suddenly I had like 10 gallons of milk 'cause everybody wants to help. But people wanna help, and it's so easy. I mean, think about how many times you go to the store. Would it be hard for you to pick up an extra gallon of milk and run it two streets over? No.

37:07 AY: Right.

37:07 SK: Do you feel good about helping someone? Yes. And so please ask for help. That's, it's... People wanna help, and if they can't, they're not going to. They really won't.

37:18 AY: That's exactly it. That's exactly it. And when you give them something specific, it's easier for everybody.

37:23 SK: Ahh, they need it.

37:23 AY: Yeah, absolutely. That's such a good point.

37:25 SK: That's a really good point. You have to give them something specific. You can't just say, well, you know, sure you know, do whatever." You can't do that, you have to say, could you bring, could someone bring a meal on Tuesday? I'm coming home from the hospital late that night. Could somebody pick up Madeline at school? And give them specific tasks, and they will help, and like I said, I stopped saying, "Oh my gosh are you sure?" Because people were like, "Sarah, I'm not gonna volunteer if I can't do it or I don't want to do it." And I had to realize that.

38:00 AY: Right. Right. Oh, it's so hard to ask for help, that's such an important thing.

38:05 SK: So hard.

38:06 AY: Oh, gosh.

38:06 SK: Yeah. It's so hard, and so that's my biggest thing, and the other thing is you can't, don't internalize it all. Talk to people, get out there, find other friends. And the other thing is I would beg

my friends for normal, and they're like, "You don't wanna hear my life. It's so boring compared to yours." I'm like, "No, no, no, no, I would love normal." That would be great, and I had this one woman, she stopped at my... She knocked on my door didn't know her, she knew she was like part of the mom's club or something, and I didn't know her.

38:41 SK: She knocked on the door and said, "Here's a pizza for your family. And if you can go out for half an hour, I'm going to take you out for a drink." And I was like, "What? What? I can't go, I can't go out." And then I was like, "Wait, why can't I go out for half an hour? I can go out." And I went out, and I didn't know this woman, but you know, we had mutual friends and everything, and it was the greatest half an hour 'cause I got to be like a human for half an hour. And so then she started coming back, like every month she came back, and now she's that person she's like, "Alright, let's go, it's time to go." And here we are eight years later, and she's one of my favorite people, because she still does, and she still goes, "My life is so boring, yours is so crazy." And she says so. And I was like, "Good, I like normal," and I went to...

39:27 SK: When Addison was... Early on, when he was sick, I went to her pool with her, and it was one of the first times he could swim. No, it must have been after treatment, 'cause he could swim. And so, he went in, and I remember sitting there with her, and I just started crying, because there he is, all by himself in the corner, and no one would play with him, 'cause he looked different. And he was shy and everything. And I saw all these moms... My friend had gone to the bathroom or something, and I saw these moms sitting in the corner chitty chatty, and I was like, "That used to be me. I took it for granted. And now, I am very isolated." Even though everyone tried to get me out and everything, I still felt like, "They're talking to me, but nobody gets it."

40:14 AY: Right, exactly. Even if you're amongst people, you're still alone.

40:20 SK: You're absolutely alone. And your head... People are talking about normal things and complaining about normal things, which is fine, I did that too before. And you're going, "Oh, if I..." Your mind never stops.

40:35 AY: Absolutely. You could be speaking my words.

[chuckle]

40:41 SK: Yeah, yeah. And it's not that you're doing... You're not doing a pity party, but people are going, "Oh, I couldn't take Susie to gymnastics because she had a stomach bug." Totally get it, I was there, I'm not knocking it at all. But in your mind, you're going, "I wish my kid had the stomach bug. I remember when my kid..." Suddenly you're going, "What the heck is going on with my head?"

41:03 AY: Yeah. Yes, and how lucky you are that your kid only has a stomach bug. [chuckle]

41:08 SK: Yes. And Addison's funny, 'cause his big thing that he would say is like, "You know what the good thing about having cancer is, mom?" I was like, "What?" He goes, "You stop worrying about having cancer." He goes, "So I'm gonna go eat all those hotdogs."

[laughter]

41:20 AY: Oh, I love that.

41:22 SK: That's a good point. [laughter]

41:24 AY: That's so great.

41:26 SK: That was so... 'Cause I was like, "Don't eat all those hotdogs." And he goes... 'Cause I'm like, "They're so bad for you." And one day he's like, "Am I gonna get cancer? I already have it, mom." I was like, "Oh, eat those hotdogs, go for it, have a..." "

[laughter]

41:39 AY: That is too funny. [41:40] [redacted] just a little kid [41:42] [redacted] but it's the kids that [41:44] [redacted].

41:44 SK: Oh my gosh. So funny.

41:49 AY: God, excellent. Okay, let me see. This is perfect. Okay, so my last question is silver lining, but I feel like we talked about that with Heartfelt Hugs and other stuff and your public speaking, but are there other silver linings that you would take away from this?

42:08 SK: Absolutely, I think... So Addison speaks... And you might talk to him someday, so I don't wanna take all his talking points, but one of the things that he taught me, and he says this, is that someone is always having a worse day than you. And those words resonate now on those days where I go, "Oh my gosh, this is the worst." And then I stop and go, "Nope, it's not. I have my child here," which is also... There's a lot of guilt that a cancer parent feels when your friend's child does not survive. There is so much guilt, and it's awful, because you're going, "Why is my child surviving today?"

43:00 SK: And you have to drop that guilt, 'cause it's... You just do. It's what happens, it's life, and nobody is in control of it. And you just have to appreciate... So then, you take someone else's child's loss and you don't make it in vain. You go and enjoy that day. You shop and... And Addison and I were driving to his taekwondo class one day, and we're late, 'cause we're always late, and we're running late and he said, "Mom, stop." I was like, "What? What? What? What? What? Did you forget something?" He goes, "No, stop." I'm like, "Why?" He goes, "Look outside, look at the rainbow." And I was like, "Buddy, we're so late. No, we don't have time." And he's like, "Mom, please stop." And then I was like, "Wait, why am I rushing? Why am I rushing? Okay."

43:48 SK: Pulled over by the side of the road, we got out, and he just stood there, and there was this amazing rainbow. And here's the kid who loves taekwondo, why does he wanna be late? And he just stopped there, and I held his hand. He was old enough not to have me hold his hand. I don't know, he was 12 or whatever. But he let me hold his hand, and we stood there, and he goes, "Mom,

isn't that amazing?" And I was like, "Oh, dude, this is... Yes." And it grounded me. And now I have these moments, I call them Addison moments, where I stop. I'll be like, "Guys, come on. We gotta go, we gotta go. Let's go, let's go, let's go." And now I'm like, "Wait, if we're five minutes late, is the world gonna explode? Nope, it's not." We will stop, we will pull over, we will smell the flowers. I will put the phone down, I will play a game, I will... Not always, but...

[laughter]

44:38 SK: I will try to pause, and in that moment, I do this for the children who can't be here, and I do it for the moms who don't have their children. I take those moments as a tribute to them, and I stop and I breathe and I appreciate that moment.

45:00 AY: Absolutely. Oh, Sarah, that is so beautiful. I am... I'm choking up, that is so beautiful, thank you for sharing that. Absolutely. Oh, Sarah, thank you so much for sharing your story. I cannot tell you how much I appreciate it. I know that's gonna make a difference to the people who are listening and going through it right now. And thank you for everything, and we'll put something... I would love to put up the picture of Addison with his sign with all of the things he went through. So I'll get that from you. And thank you very much. I would love to have both your kids on also, so we'll have to schedule that when they get back from camp and all that good stuff.

45:43 SK: Absolutely, 'cause they have... It's different when you talk to the kids and their perspective. Even as parents or cancer parents, when we hear our kids' stories, both my kids have been interviewed by [45:56] [redacted] a year later, and I'm like, "Wow, I didn't know you felt that way," or, "I didn't know you thought that."

46:03 AY: Absolutely.

46:04 SK: 'Cause we don't interview our kids. In real life... I call it real life, 'cause we don't live... We are not in real life, you guys. All of us, this is not reality, so just know that, and there are no rules. The good thing about living this non-real-life, is there are no rules. So there are no rules to be broken, so we can do whatever we want to do. I give you guys that.

[laughter]

46:27 AY: I love it, I love it. Oh, that is perfect. Thank you so much.

46:33 SK: Oh, thank you.

46:35 AY: Oh, of course. I hope everybody goes out and likes Heartfelt Hugs, so they can see more about what they're doing and what they're needing and all that good stuff. And fantastic, thank you so much.

46:47 AY: Thank you so much to Sarah for sharing her story. I hope you enjoyed our conversation as much as I did. If you're local to Colorado, please visit the Facebook page for Heartfelt Hugs to see what Madeline and her family are up to. And if you have a story of pediatric cancer to share,

Kleinhans Final

please stop by our website at www.bravehoods.org to fill out a form. We would love to share your story. Thanks so much. Until next time.

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