**HTH2021.03.30\_Elisa**

**Jule:** Hi, I'm Jule, and this is *Hard Times & Hope,* a place for real conversations with regular people about a real hard time. We talk about what it was, how they got through it, and something good that came from it.

My guest today is Elisa Graf. Elisa and I met in the Akimbo podcast workshop, where she was a student and I was back as an all-star, essentially, a peer coach. Elisa is the host of *Mystic Takeaway,* a podcast where her guests share extraordinary, real life stories to nourish the soul. She is also a freelance writer and editor. A native Californian, Elisa moved 10 years ago to Steinberg, a small village in Northern Germany.

Elisa and I connected and because we have similar interests, she offered to be a guest. And I was delighted. Elisa’s going to talk about when her son became ill, what was that like?

Let's find out.

**Elisa:** I could start this conversation by talking about when my son was only four, and I had this very powerful intuition that he was going to have a blood disorder. He was going to have leukemia. And I don't even know what started this in my mind. He was a totally healthy child, like completely top of the charts. And so there was no reason for me to have any suspicions or concerns about this, and I didn't know what to do about that at all.

I mean, you know, it just felt like this reality to me, even though I couldn't explain it. And then my daughter was only a baby at the time. So anyway, you just think, well, all I can do is look at him now and he's totally fine. So there's nothing to worry about, but I was still harboring this fear in my mind.

**Jule:** How did that fear show up? Like how did the intuition appear …

**Elisa:** It’s hard to say actually, it's so long ago now, like 25 years ago, but it was just like one day I had this… it was like a realization. My child is going to have a blood disorder. He's going to have leukemia and all the fear about the potential loss was very real to me.

And I couldn't tell you why it was just like, uh, something hit me. And, um, I don't know why. Anyway, what happened though, was the fear was strong enough in me that I ended up having a very powerful dream. And I don't know where it came from really, but I feel like it was a blessing. It was given to me. So I had a dream in which I was looking for my son age four, maybe he was a little older.

Might've been five. I was looking for him at this park and the park was very weird because it was really only made up of empty swimming pools. So I was walking between these empty swimming pools and there were people milling around. Like there was some kind of an event taking place and I didn't know anybody.

And I was carrying my baby daughter looking for my son, like where did he go? Where is he? And I finally found him, and it was really very interesting cause there was like literally only maybe three feet or a meter, or four feet between these empty swimming pools. And they were all over the place. And I found my son sitting at a table with people I didn't know. And he turned around and greeted me and said, “Hey mom, here I am.” And there was a woman standing across the table. And she looked at me, she really stood out to me. She was standing, and she was standing across the patio table and she had green eyes and red hair and she was wearing a green dress.

And she said to me, very powerfully, “You don't need to worry about him. He's going to be okay.” And then in my mind I said to her, are you a nurse? And then I thought to myself in the dream, literally, Oh my God. That's so un-PC just because she's a woman. I asked her if she's a nurse, that's ridiculous.

And so I said, no, I mean, are you a doctor? And she said, “Yes, I'm a doctor.” And I felt super compelled to go and touch her hand. I felt like I was super drawn to this person. There was something very magnetic about her and I wanted to touch her, and I reached my hand across the table and then the whole scene disappeared.

And I got this amazing blessing. This just raining down of blessing of energy that woke me up. It was in the morning and I woke out of the dream and I just kept saying, thank you. Thank you. Thank you. So that was the end of the dream. So then fast forward and life goes on and my son is now 11 years old.

And everything is fine. He's super healthy. Just like always, we were actually, we were waiting for a home to be built for us in a co-housing community that we had helped to develop with 29 other families, 30 families together.

**Jule:**  Wow.

**Elisa:** It was an amazing, amazing place. It's like it takes a village to raise a child and that was the village and we decided we would spend the summer living on a friend's property in California and just wait until our house was done because they had a big, beautiful property. And we thought this is perfect. Let's just do this. We'll save all this money on rent, which was extreme in California. So we, um, we were living in our camping trailer and my daughter was starting up second grade.

It was the fall of 2003. But just before my daughter started school, we were going out to get some clothes for her and my son or I got a virus. I picked up a little bug and I was sick for a few days over the weekend. And then my son picked it up. And after day three, he still wasn't getting over it. And he couldn't really stand without feeling dizzy.

And he was pretty tired, and this was really strange. And there was something deep inside me that felt like there's something wrong. This isn't, this isn't normal. And just a few weeks before he had actually been at the playground and he'd been hit in the arm by a tire swing and it had left a mark, like a tire mark on his arm in blood blisters.

Oh, and of course I should have said to myself that is not normal. I've never seen that before, I thought what is wrong? But my son was super healthy and it was like, I just said, I'm not going to worry about it. It's probably fine. And it went away. So, you know, I thought, okay, everything's fine.

So when he started to feel like he really was having trouble, he had low grade fever for three days, wasn't getting over it. And I thought there's something wrong. So the friends whose property we were living on, the wife was a doctor. And so after work, I went and talked to her and she said, sounds like he needs to have blood work done.

So my husband and my son went to have the blood work done and the next morning at six in the morning, when we were still asleep in our camping trailer, we had a knock at the door and our friend was standing there and she said, I just got an emergency fax and you need to go rouse your son because I'm concerned about him.

He doesn't have any platelets left and we need to make sure he's okay. Cause if he'd had a bleed in the night, he would have died. Oh, it was so intense. It was like it's… I still get goosebumps when I think about that day. That was so… We just got ourselves ready. And we were like, okay, well, we'll just go to the emergency room in Santa Rosa.

So we went, we got to the hospital. And the way that it works is that when you look at platelets in a healthy person, the baseline, the normal baseline for a healthy person is a hundred and fifty count. It actually translates into 150,000 platelets per cubic milliliter of blood. And our son had 10 instead of 150, he had 10, so you know, less than 10,000.

So by the time he got to the hospital and they checked it again, it was eight.

**Jule:**  Oh gosh.

**Elisa:** We were like, okay. And my husband was talking to the doctor who was saying, well, we're on the phone with a hematologist at Oakland children's hospital. And they're suggesting it might be acute leukemia. And my husband almost passed out.

He's six foot nine. He almost passed out in the, in the hallway. And, um, we were just in this little emergency side room with our kids. My daughter was there too. She was only about seven. She'd almost turned eight. So they said, well, listen, we need to send him to children's hospital Oakland, which was an hour away.We have to send a by ICU ambulance.

I hadn't really spent much time in hospitals and to go to a place like children's hospital, which is an incredible operation. They just are right on it. As soon as you get in there, doing all the things that need to be done to test, and then they want to figure out where this person is going to go, which part of the hospital, which department did they need to be in?

So they put him in the immunosuppressed word on the fifth floor. And they said, well, there are only two options. He either has acute leukemia or he has a plastic anemia and we will do a biopsy tomorrow morning of his bone marrow. And they told us at two o'clock in the afternoon, the next day that he had aplastic anemia, which is a really rare condition.

Only one to two people out of a million will get it in a year in the United States. There were three options for us for treatment. And the first one was a bone marrow transplant. Aplastic anemia is bone marrow failure. And so you're not producing blood cells. So you don't have an immune system.

Essentially, they tested us all to see if we were a match because the first option is a related-donor match and it's only 25% of siblings and 2% of parents who are a match. In the end, none of us were a match. And so the next option was to go to immunosuppressive drug therapy. That's only been around not very long, actually. They had only discovered it like 15 years before. And they use a drug called cyclosporin, which is used for donor transplants. So they don't reject because it, it shuts off the T-cell function. And so they were preparing for treatment. He had to have a PICC line put in or a,

**Jule:** I don't know what a PICC line is.

**Elisa:** a PICC line is like they put in a little tube into the bloodstream and there's a little port at the end of it. So it made transfusions easier. So, yeah.

**Jule:** So it's putting, it's putting the platelets he doesn't have into his bloodstream, right?

**Elisa:** Exactly. He needed a hemoglobin, too. And actually he had to have blood transfusions every week. So he, we went as outpatients down to children's hospital once a week for a whole day and they would run a bunch of tests and whatever. And he would have lunch there and play video games. Cause he didn't get to do that at home. And they would give him a transfusion of hemoglobin and platelets and they had to be irradiated. Whoa, because he didn't have any immune system.

**Jule:** So they're giving him clean platelets and hemoglobin because he doesn't have them.

**Elisa:** That's right.

**Jule:** It's sort of like filling his gas tank with exactly the blood components he doesn't have.

**Elisa:** That's right. You know, it's, it's kind of amazing. When I think about it, he never really looked sick. He never really felt sick or acted sick. I mean, the drugs were the hardest part. They put him on prednisone in the beginning.

They have a whole suite of drugs they use. And my son, I don't even know if he'd ever had antibiotics because I was super careful and my kids were raised on organic food and breastfed, and I was super careful about everything. So I didn't do antibiotics. I took care of them with holistic medicine and whatever.

So this was also a big shock, and it was really hard for me to let go of not being able to do anything. I really, my hands were completely tied. I couldn't even bring him yogurt.

**Jule:** I was wondering about that because, okay. You're feeding him organic food. I don't think that's what he's getting in the hospital.

**Elisa:** No, he loved being in the hospital because somebody came around every morning and said, “What would you like to eat today?” And there was a menu, and it was all kid food. Like chicken nuggets and pizza. And you know, he just, he ate all this junky stuff, but he loved it. Somebody came around and asked him what he wanted to eat.

And then he got to order his dream food every day.

So he had a lot of fun in the hospital, actually. He loved it there because it was in the immunosuppressed ward. And that's where all the celebrities come through to see all the kids who are really, really sick. And there was a great kid's room, and he could play with all these video games he never got to do at home.

We were really strict about that. We didn't have a TV. I mean, we were super crunchy compared to the mainstream. So he thought it was a ball.

**Jule:** Yeah. The hospital was a bit of a playground for him.

**Elisa:** It was, he had a great time. So they start you off with this cocktail and intravenous solution of a chemotherapeutic agent that's called ATG, antithymocyte globulin. It's made from horse’s serum and it's the main chemotherapeutic agent that will suppress the T-cells, which required him to spend four or five days in the hospital again. And then you start using this drug called cyclosporin.

**Jule:** I used to work in a transplant clinic.

**Elisa:** So you know about cyclosporin?

**Jule:** Yeah.

**Elisa:** Well, he had a thousand milligrams a day of cyclosporin, but there were other drugs that caused him lots of problems. Like prednisone made him panic. So he had panic attacks.

**Jule:** Wow.

**Elisa:** My husband had to take him one night to the hospital in the middle of the night, because he was sure that he needed to start treatment right away, even though they weren't ready for him. And then they sent him back and said, don't worry, it's going to be fine. They took him off the prednisone.

**Jule:** But he needs the prednisone, but it's a tough decision. It's tough.

**Elisa:** All these little things were tough. So he wasn't yet on the agents yet. So they hadn’t started him yet, but then we went in, literally on Halloween for his treatment to start. And it was really fun because they had a big Halloween party and bingo party. And my son actually really was anxious about what he was going to dress up for. He was mostly concerned with that than anything else. And he, um, he decided because he was really into wearing suits at that time.

You know, he was 11 years old, and my mother used to buy him suits at the Goodwill and he decided he wanted to be the dead Bill Gates. And my mother had sent him some makeup to make his face all white. So he basically made himself look like a dead businessman or something.

**Jule:** Wow.

**Elisa:** And the doctor was so funny. She said when she saw him in the hallway, she forgot completely it was Halloween. And she said he looked so pale that she thought, ‘Oh my God, I got to do his blood numbers again.’

**Jule:** That's funny.

**Elisa:** It's really funny. But so they had a bingo game and he just had a ball that was four days, four days in the hospital for the ATG.

And the nurses would come in wearing like hazmat suits and like putting this thing, hanging it up and then delicately putting it into his port in his arm. And I'm thinking, ‘Oh my God, I can't believe this is happening.’ They would say, “We're really sorry. We hate to have to do this, but it could make a sterile.”

**Jule:** And they're putting it into your son,

**Elisa:** Straight into his bloodstream. Anyway, I have to say, honestly, the doctors and nurses at that hospital were amazing. I was blown away. I just get goosebumps when I think about how they just were so dedicated and there were 12 pediatric hematologists on staff and I could call at any time, day or night, 24 hours a day, and talk to a pediatric hematologist about my son's situation.

**Jule:** Wow.

**Elisa:** So we just felt totally blessed. As I said, my son was just a trooper through all of it. I mean, he did get sick. The ATG, made him feel really, really awful. That was hard. And the last day he was there and my husband and I were switching off. I had to leave and go. I was going to go to San Francisco to stay with my sister who had just had a baby, but I stayed too long.

It was like 10 o'clock at night. And the nurses said, one of you has to go. And my son was saying, “Mom, I don't want you to leave. I don't want you to leave.” And it was the hardest thing for me to leave him, even though his dad was there. It was just like, I felt that was my breaking point actually, because I had been keeping it all together.

It had already been almost, I don't know, three weeks or something since it had all started. And, um, I got into my car and I started driving because it was late and I was, I didn't even know where I was going to go because I knew my sister was already asleep and I felt bad about disturbing her. So I just fell apart in the car, driving across the Bay bridge to San Francisco.

I didn't know where I was going. I didn't know where I was going to stay. And I just started sobbing about my son and feeling like he's too young to have to deal with this facing all this. You know, it's really tough to watch your kid go through this stuff and not know what's going to happen on the other end of it.

You don't know you have no. And that's, I think what the beauty is in this situation is you just don't have any control and you'd have to let go. It's about surrender and that's all you can do.

**Jule:** Yeah. Yeah. And you can't let go when you're in front of your son. So yeah, you know, it all kind of builds up until there you are by yourself, in the car, on the Bay bridge and it all comes out.

**Elisa:** Yeah. And, um, I didn't know what I was going to do. I just was, I couldn't stop crying. I was, I was hitting my steering wheel. I was just hitting it over and over again, like furious that my son had had to go through so many things already in his life. And it just felt so unfair. So just coming back to me, it's so strong. It’s so long ago, you know, but*…*

**Jule:** It doesn't matter how long ago it was when we go back there mentally, and we tell somebody our story and they hear us. We're back there and we feel these things again.

**Elisa:** It's amazing. Stored in there. Yeah. Well, the good news was at that time, I didn't know what I was going to do.

And I'm like, even on the Bay bridge, you can't stop the car. There's no place to go. But then the phone rang, and it was two of my closest friends in San Francisco and I was shocked they were calling me this late. Because they never did that. So somehow, I felt like they got this little message. “We've got to call Lisa” and they guided me on the phone to their house.

And I was, I was rescued.

**Jule:** And you had been driving, not knowing where you were, it was too late to call your sister.

**Elisa:** Exactly. And I just was like, so I got to their house and I spent another hour or two crying and talking about the whole situation in their living room. And then they put me to bed and it was so sweet.

It was like, I was so rescued. Um, at that moment I was very grateful.

**Jule:** Yeah. And you'd let yourself be rescued.

**Elisa:** Yeah, that's right. So there were a lot of those kinds of moments in this whole time. It was nine months. We moved into a community. The community was amazing. They were all so supportive. Everybody wanted to do something for us.

And the hospital was amazing. My daughter's school, her whole class really, they sent us all this food they had purchased from a company that was actually making meals for people. They purchased like a whole cooler and would send us a week's worth of food. So amazing. They were just, people were just so kind and so supportive.

So kind of life went into a normal phase because he was on these drugs and he kind of had a fairly normal existence at home. And then we'd go down once a week for transfusions. And then a month went by and we were doing stat labs every week to find out what was happening with his blood, if anything was changing.

And they told us that you'll start to see when the STEM cells are regrowing because that's, what's been destroyed. The T-cells have destroyed the STEM cells and your own body has kind of, for whatever reason, they assume a virus has gotten into your bone marrow cells. And so you see them regrowing with these things called reticulocytes, which are the very earliest stage of blood cells.

So they said, when we see these, we'll be sure that things are working. So we kind of just try to sit still and be patient. And they said it might take some real time. And then around Christmas time, we called up to get the details on his labs and they said, well, we have good news for you. It's working. We can see, we're starting to see. It was like a Christmas blessing. So yeah, that was a huge relief. And literally from that point on, he didn't have to go down anymore for blood transfusions. So that was huge.

**Jule:** And your Christmas present was reticulocytes.

**Elisa:** Yeah, exactly. Yeah. In July of 2004, he turned 12 and we had a huge, a hundred- person surprise party in our common house in our community.

**Jule:** Oh wow. A hundred people.

**Elisa:** A hundred people.

**Jule:** Was he surprised?

**Elisa:** Totally surprised. He almost didn't want to go. He actually, we had sent him off with our friends, our neighbors in the community to play Frisbee golf so we could set everything up and then everybody arrived and it's kind of hard to hide.The common house has all these windows and you can't really hide a hundred people and everybody was in there waiting and he, he saw it through the windows and he started walking away.

**Jule:** That’s funny.

**Elisa:** Oh, but it was really fun, just a fabulous party. So that was really our way to celebrate the whole thing.

And basically, he got to go off his drugs in August and his doctors still needed to keep an eye on him for a while, because there are things that can develop after, but he got through it all. So that was an incredible episode in our lives.

You know, it took me a few years to go back, but I realized. That the dream was about that. I went back in time to the dream that I'd had.

**Jule:** How was the dream about that?

**Elisa:** Well, it took me a while to really decipher it all, but it came up one day and I realized, okay, when we arrived at children's hospital in the emergency room, whoever is on duty in the ward that your child is assigned becomes your primary care doctor in the hospital.

We were in the immunosuppressed ward where everybody's hematologists. And there was a woman who became our doctor. Her name was Dr. T.T. Singer and she had red hair and green eyes.

**Jule:** Oh, wow.

**Elisa:** So she was the doctor in the dream that I didn't know yet, who I didn't recognize. And she told me that everything was going to be okay, that he's going to recover. And the dream when he was like four or five years old.

**Jule:** I have chills all over me now.

**Elisa:** It was amazing. I took me years to get to the point where I thought about it enough to realize that that was what the dream had been about. And the empty swimming pools were his bone marrow.

**Jule:** Ah! I was going to ask you what you thought those swimming pools might be about. They were his bone marrow and the pools should be full, but they're empty.

**Elisa:** Yeah.

**Jule:** Oh, and the concrete of the pool is so much like bone.

**Elisa:** Isn't that amazing? Like, how does that work? I don't know how this all works, but I couldn’t have known that, but it was a gift. It was a gift. I felt like it was a blessing given to me, you know?

**Jule:** Yeah, yeah. It was a gift. What helped you get through that time? Was it knowing that he was going to be okay or what, what got you through the year plus?

**Elisa:** You know, it was such a lesson for me because I'm somebody who wanted to control everything all the time. You know, I was very, very, as I said, I raised my kids super healthy, you know, I was really careful about everything and, um, I had to let go of a lot of things.

I, I remember I wanted to treat him homeopathically and of course, you know, that can only help so far. It can be an augment thing, but you really have no option other than to go for the extreme medicine, because that's all there is. That's the only option you have at that time. He was, he was really close.

They called it very severe aplastic anemia. There's aplastic anemia. And then there's very severe aplastic anemia, which is like, dire. There was really no time to waste. And, and I had to let go of a lot of things. My friends were very helpful. They were super intuitive. Once my, my friend said to me, you need to ask your soul for a dream to tell you what's going to happen. You know, you need to ask your soul to give you a dream.

And I said, I'm too stressed out. I can't remember my dreams. I'm just too stressed out. She ended up having a dream and she saw him as a teenager.

**Jule:** Oh wow.

**Elisa:** He had long hair and he had this, this kerchief, he were over his head, which. Like nobody in his age would ever, where she saw that in his dream.

And she told me about the dream. She said, “I think he's going to be okay.” She saw him as a 15-year-old. There were a lot of things, like friends that gave me lots of support and having some normalcy. Leaving the hospital, going home, having normal everyday life was really, really helpful. All of it was very humbling.

Having all this support, all these friends, all these people offering you things. It was… you kind of settle into, well, I'm just dealing with this, but I have to have faith and trust and that's the whole process. It's the development, right? So I can't say I was always feeling good, but you know, it helped that he had such a good attitude.

**Jule:** Yeah, it would.

**Elisa:** He wasn't scared. I never felt like he was worried that he was actually going to die. Maybe in the very beginning, the very beginning was such a shock for us all.

**Jule:** How did going through this experience change you?

**Elisa:** Well, I think just like everything else in life where you're faced with such a huge potential for loss, it's a process of really letting go and learning how to surrender.

I love that expression, ‘Let go and let God,’ because you really, you come to realize that there's no other option. It was a test.

I've had many tests in my life that have sort of asked me to develop in that way to really let go and realize that I'm not the one driving the boat. And I think that that was really the biggest lesson for me. And I think it has really shaped my adult life in a way that. It was very meaningful. Very powerful.

**Jule:** If you now could say something to you back then at the beginning, when you first learned that your son was sick, what would you say to yourself?

**Elisa:** Oh boy, that's a really hard one because you know, you're looking back in hindsight and I can almost barely remember what I felt like then, because so much has changed in 25 years or whatever it is it's been now.

I would really just have to say, you have to learn how to trust. And have faith in the process that everything's going to be okay, as I actually really believe now that nothing happens that's not meant to happen.

**Jule:** What is one of life's simple pleasures that you particularly appreciate?

**Elisa:** I love getting up in the morning and greeting my dog, who sleeps next to my bed.

And I love having a really nice cup of Darjeeling tea for breakfast, things like that. I really, there are lots of simple pleasures that I enjoy. So I don’t know if I could name one, but, but I think if I had to name one, it would just be, I just love being in communication with my family. That's to me the most important thing I need it, you know?

So I'm lucky that I have kids who are in touch with me a lot. They call me almost every day. My daughter's 25, my son is 28, and they're in touch with me all the time. We have a little family chat on WhatsApp and we're always texting each other back and forth the four of us, you know? So there's, that to me is like the greatest blessing to be in contact with my kids.

**Jule:** I realized I'm curious about something. He dressed up on Halloween as a dead Bill Gates, a dead businessman. What did he, what's he doing now?

**Elisa:** He's an entrepreneur, just like his dad. So he started his first business last year. It's called True Carbon. And it's about creating a market for trading certificates for soil that recaptures carbon through farming techniques. So it's a very cool thing. He's, he's definitely not wearing suits. He's he's, he's a kite surfer. He's like a serious surfer dude kind of kite surfer person. So he's definitely not wearing suits and he doesn't have to, thank goodness.

**Jule:** Did he ever have long hair and wear a bandana?

**Elisa:** Yes, he did! When he was, when he about 15 and he had this long sort of shoulder-length hair and, and we had, um, we lived in a community called Frog Song. The kids were froggies and somebody found this fabric with frogs on it, and they made head kerchiefs or neck kerchiefs and he used to wear it over his head like, like a bandana.

It was cute. It had little cartoon frogs on it. And I have pictures of him. I can send you one. It's incredible. And my friend saw him in her dream.

**Jule:** Yeah. Did she see the victorious?

**Elisa:** Oh yes. And it's not a surprise to either one of us. Cause we're both very intuitive. So we were like, okay, yeah, you saw it. Yeah. That's crazy. But so cool.

**Jule:** Very cool. Elisa, is there anything else you'd like to say about hard times or hope or anything?

**Elisa:** I just feel like what I think is really important that I share is that, you know, you never really know what's going to come down the pike in life. I never would have imagined, although I did say I had this intuition when he was a kid, which was also weird in its own way, but you're just never really sometimes prepared for things. I wasn't expecting at the age of 11, my son was going to have this terrible life-threatening situation. And, you know, at the end of it, you can always look back and say, okay, yeah, that was hard, but I'm much stronger than I was.

And I really learned a lot. And I think that through our own lives, whatever happens, we all have to remember that. We have to trust and have faith in God. So that's all I can say.

**Jule:** Thank you so much.

Thank you for listening. That was Elisa Graf. Alicia's podcast is Mystic Takeaway. You can find it wherever you get your podcasts, and you can learn more about Lisa at her website, elisagraph.com. To see photos of Elisa and her son, then and now, see the show notes.

I'm Jule Kucera host of *Hard Times & Hope.* If you think this episode would be helpful to someone, please share it. My website is julekucera.com.

Take care, take heart. See you next time. .