LEUKEMIA & LYMPHOMA SOCIETY® is now

Blood Cancer United

The Bloodline with Blood Cancer United Podcast

A podcast for patients and caregivers

Episode: 'A Parent's Guide to Childhood Cancer: Support, Advocacy, and Hope'

Description:

When a child is diagnosed with cancer, parents are suddenly expected to manage medications, appointments, treatment decisions, family life, and overwhelming emotions, often all at once.

In this episode, we speak with Laura DeKraker Lang-Ree, pediatric cancer parent, advocate, and author of *The Cancer Parent's Handbook*, about the practical guidance she wishes every family received from day one. Laura shares powerful insights from her family's journey after her three-year-old daughter was diagnosed with acute lymphoblastic leukemia (ALL). She offers actionable guidance on child advocacy, trusting parental instincts, engaging siblings, and maintaining normalcy during treatment. Additionally, Laura explores strategies for helping children thrive post-treatment, providing crucial hope and support for families facing some of their hardest days.

Transcript:

Elissa: Welcome to *The Bloodline* with Blood Cancer United. I'm Elissa. Thank you so much for joining us on this episode.

We are launching this episode in September; and in honor of Childhood Cancer Awareness Month, we are speaking to Laura DeKraker Lang-Ree, a parent advocate,

lecturer, and author of *The Cancer Parent's Handbook: What Your Oncologist Doesn't Have Time to Tell You* - a practical guide for families navigating childhood cancer.

After her daughter's diagnosis with acute lymphoblastic leukemia, or ALL, Laura became a leading voice for family-centered care and caregiver advocacy. She volunteers with Blood Cancer United as a Dare to Dream Ambassador and a recent Visionaries of the Year candidate. Recently, Laura also lectured Stanford University's third-year medical students on fostering collaboration and advocacy in the doctor-patient relationship. Her work focuses on bridging communication between medical teams and families to improve both outcomes and emotional resilience. Welcome, Laura.

Laura DeKraker Lang-Ree: Thank you for having me.

Elissa: Well, thank you so much for being here with us today. So, let's start with your daughter's diagnosis of acute lymphoblastic leukemia, or ALL. When was her diagnosis, and how old was she at the time?

Laura: She was about 3-1/2 years old and really nothing remarkable. She seemed to have a cold that would never go away. And mom instincts kicked in. Took her to the doctor once. They said, "She's just got a cold." And then I watched her deteriorate in terms of her lethargy and her skin color, and I knew something wasn't right. So, we

insisted, my husband and I, on a blood draw that that afternoon confirmed she did indeed have childhood leukemia.

Elissa: Wow, that must be so hard having, probably, what was a normal 3-year-old all of a sudden had these issues and then end up having leukemia.

Laura: Yeah.

Elissa: What was that emotional impact for you and your family after she was diagnosed?

Laura: It's the words you never expect to hear that your kid has cancer. And we knew something was wrong, and the night, she knew something was wrong the night before the blood draw that we insisted on. I asked her where she hurt, and she went over her whole body with her hand and said, "Everywhere, Momma."

So, it shook all of us so much. I think, initially, she was relieved to know that she was going to be getting help.

And from the second you're diagnosed, you're thrown into a world that is so overwhelming, regardless of whether, you're someone who can handle a lot or not. You're really frozen in your tracks. And we were.

Elissa: Yeah. Now, I know your daughter, I believe is now out of treatment. How old is she now?

Laura: Ha, she's 30, so yes. She's well out of treatment.

Elissa: Oh, good, good, good, good. Hopefully doing very well now.

Laura: She's doing great. And a lot of the things that we learned along the way, in addition to the incredible medical care that she got, helped her become a survivor and not just survive, but really truly thrive. And she's a part of an aftercare clinic now that just checks on her annually and checks boxes, and that's very reassuring for her, as well.

Elissa: Wonderful, and we'll get into a little bit later how you can, first, advocate for your child, but then also how you can help your child thrive after cancer, after treatment and how parents can thrive after all of this.

So, what immediate challenges did you find yourself facing as you started navigating pediatric cancer?

Laura: I can remember it from the beginning, and I distinctly remember when they decided that she was okay enough to get discharged, and this was after an initial diagnosis and spinal taps and all the things that we parents and the children go through. I distinctly remember this lovely nurse coming up to us, Arne, my husband, was with Cecilia, with a bag of chemo and some instruction orders; and I just started balling. And she's like, "No, no, no. It's okay. You got it." And then she had to go. She

had to go see the next patient because they're overwhelmed too. That's kind of the point.

And so, you're left thinking I am not qualified to handle this. We decided really early on, because we had other children at home, that that first month is always very tricky. Today, it's very tricky too for cancer patients and their caregivers. And we had children at home, so we decided to do this together; and one of us would stay home with our toddler and get a little bit of her magic, and the other one would be at the hospital so that no one person was responsible for all of that information and data, which is really hard to keep track of and very scary.

And a pivotal moment for me was, I was with Cecilia. I remember this woman with a baby in her front pack and a kid Cecilia's age in a stroller marching up to me and saying, "You look like you need help." And I was like, "Yes, I do." And she introduced herself as Irene; and her child was the same diagnosis, same cancer, and had been in treatment for probably six months to a year longer than I. And she said, "Let me help you." We exchanged information, and suddenly I was part of a parent network that is so necessary for all of us parents to handle the day to day. Our doctors and nurses and our medical teams are amazing, and they're responsible for curing your kid with medicine. And the rest of it is really up to us. And that's not shared widely. That's something that I was speaking to the Stanford Med School students about. It's not something that's shared, and it's not something where there's a guidebook for it.

So, I took all of Irene's information, added more, joined a parent's group online, and started to do the same thing for other people that I would meet because there's so much that we can do and can be of help with at home and that makes a difference to our child's life and treatment and the rest of our family's life. And I would regularly declare, "Well, I have a book in me. I'm so annoyed by this. Where is this information that should be handed to me on diagnosis?" I needed a lot of time and space, obviously, she's 30. And COVID was the perfect time to circle back and make it happen.

Elissa: Wonderful. So, we're going to get into practical tips for parents in just a moment. But is there any advice that you wish someone would have told you when you first started this process of navigating cancer? I know you connected with somebody. Is there something that was missed? Is there something that you can look back now and say, "I wish somebody would have told me that?"

Laura: Well, not to be coy, but that's really what the book is about because it's an entire book of all the things that are not shared because people are doing their jobs and they're busy and it is up to us. And so, it's kind of like folklore. We're passing it down parent to parent. And I aim to make it simple so that anyone, from whatever circumstance they're from, can have the same roadmap, like *What to Expect When You're Expecting*, but for pediatric cancer.

Elissa: Yes.

Laura: But I think the main thing that was overwhelming to me and so important is to know that no one knows your kid better than you. So, the doctors and nurses are experts in their medical care; and you are the expert in your child. So, even if you're not born a little bit of a leader, maybe somebody who enjoys that kind of advocacy or pushing what your needs might be or for your kid, it is a situation where you have to learn how.

Elissa: Yeah. I'm curious. When you and your husband had decided for one person to stay with your toddler and one person to stay with your daughter who was in the hospital, did that come from advice from parents; or did that come from somewhere else, just talking about how this would work best for your family? I'm sure a lot of parents listening have siblings at home, and they want to know how to navigate that part of it.

Laura: It's true, and they have siblings at home. First of all, I'm coming from a conversation about being in a partnership. So, there's that. There's ways of doing this if you're not in a relationship or a partnership or a marriage too.

We learned pretty much off the bat. We were desperate for information; so, I remember that first night we bought 200 books online on anything remotely having to do with cancer or pediatrics. There really wasn't anything and just sort of, we're cultivating our space. And we were told early on that it's devastating for couples. And we knew we didn't want to end up being a statistic; and we both were working, but I

really advise parents, it doesn't matter if one of you is employed and one of you is not. You're still both working, either in the home or outside of the home.

And if you are blessed to not have to handle this on your own, you must tag team this experience because the data and the information that you get at the hospital is overwhelming; and you need to be able to be in communication with it. It's a surefire way for someone to collapse from exhaustion if they're the only person handling it in a marriage or a partnership. And if you are not married, you've got extended family, you've got extended community/family. Perhaps, your extended church family that you take someone with you, and somebody else can stay home with the other kids so that they can still go to soccer practice and live their lives and feel somewhat normal.

And I think that was our main objective was, we knew it could destroy a marriage. We had a toddler who needed us, and that's the reason we wanted to do it. We had also very early on established how we wanted to enroll in a wonderful cancer camp that we went to when she was stable. And the parents got to go to a therapy session which was so amazing.

And we were very new to it, so we really didn't feel like we had much agency to say anything because we were learning. But we had parents in there. They were all survivors. Their kids were in treatment - a year out, ten years out. And for whatever reason, the mix in the room happened to be one of despair and lots and lots of tears of ruined lives and conversations and reports of how it destroyed everything. And we left

mortified and horrified and committed that no matter what, we didn't want to end up a statistic and how were we going to do that? And we just figured it out, bit by bit, from the help of a lot of wise people around us.

Elissa: That's great. I'm glad that you had so much support surrounding you and that you were able to get advice from other people. So, how did the siblings do together? I know the younger one was just a toddler, but-

Laura: Yeah.

Elissa: - ALL treatment is quite long. It's several years, and so how did they do together, since they were kind of separated, at least a bit, in those early times?

Laura: We decided early on, and I have a lot of conversations with parents who are trying to protect their other children from the big, scary stuff. And my advice would be, your young ones can handle more than you think. And doing it in a way that is age appropriate and most certainly having your tears and despair, but privately is the way to go.

So, for Ceil and Maddy, we let Madeline be part of the process. So I think maybe the first week or two, we were just leaving her with grandparents; and we were fortunate enough to have them nearby. And you could see this toddler crumbling and dissolving because where is her sister? Where are her mom and dad?

Elissa: Yeah.

Laura: And so, we changed the game; and in the early days when we were inpatient all the time, she would come every day. Someone would bring her. She'd crawl into bed with her sister, worry about the IV pole, and they'd watch *Teletubbies*. As we got a little bit safer, this is a little bit of an advocacy story too, the nurses asked Cecilia if she wanted to come in for her weekly methotrexate shot, which is really nasty. They plunge it into their thigh. And her labs or do it at home. And she's 3, and she's like, "Oh, at home." And at first, I thought that was the most devastating thing ever, but it turned out to be such wisdom from our nurse. And so, we included Maddy.

We would take the little bike trailer with their books and snacks; and we'd bike to the local phlebotomist, who got to know Cecilia. And we had a drill. Madeline knew she had to hold the left hand. Cecilia was on my lap. The phlebotomist counted to three, Maddy would squeeze the hand. She had a job. And so, for Madeline, she knew her sister was in treatment for something. She was not referred to as "sick" but rather she's getting help for a bug that she had.

And that really made a big difference. So, Maddy was all game to help. And then once a week when we had methotrexate night, same drill. Maddy would spray the cold spray. Somebody was holding a hand. Somebody was sitting on a lap. Someone would impale the needle; and then everybody handed out popsicles. So, everyone had a job; and when that happened, it was normalized-

Elissa: Yeah.

Laura: -so that no one was crying all the time because, let me tell you, I've met families who are struggling for three years with that; and it's just toxic. So, the more you can involve your kids and in some way normalize it, we as the adults in the room know that this is deadly and could take our children. But if we can manage through, hopefully, some mental health help to have places to have that outlet as adults and try to keep our family light, it really lightens all the moods and having a job is key.

Elissa: Yeah. And I'd love to hear how you recognized that things were not going well and you were able to adapt for your family, and just make things better for everybody involved, including Madeline. So that was, wonderful.

I'd now like to cover some of the major themes in your book and to discuss those challenges that families may face and practical advice to get through them. To start, we may have families listening at all points of their cancer experience, including newly diagnosed. So, let's start at the beginning. One of the first things you mentioned is getting your stuff together. What are some of those challenges in those early times after diagnosis, and what are your recommendations for parents or legal guardians?

Laura: For sure. I think it's come a long way. It depends on your hospital and your situation, but having some way to track the medication and the side effects is very key. So, whatever your comfort level may be, that could be writing it down. I recommend

you always take a device where you can record the conversation you're having with the doctor or the nurse about the treatment so that you know what's coming next because you're going to need to be able to advocate for your child if a particular drug is sending them to the ground and they can't move.

And learning that you are the one that needs to advocate for them, so be it advocating having local labs, advocating that they shouldn't be nauseous and vomiting all the time. "My kid doesn't respond to it this way. We need some anti-nausea medication."

Also, connecting with other parents online is both extremely helpful and really hard. So, the extremely helpful part is you can post, "Hey, my kid's taking this drug. What are the reactions? What can I do to help?" and get an amazing amount of responses that are very helpful. The con to that is you see a lot of devastating stories. So, I recommend doing that in very small doses, especially in the beginning because, really, the truth is all we're imagining is our child's funeral. That's just a fact.

So, get your information, but get it in small doses. I am hoping that *The Cancer Parent's Handbook* is a place you can go that's not emotional, so you can just read facts and go, "Oh, okay. I know what I can do now." So, be it *The Cancer Parent's Handbook* or on your own, figuring out where can I do something that's going to make this better.

A huge key is getting support. So, in the beginning, even if you're a super, but capable person or somebody who really struggles, we all struggle asking for help when we're diagnosed. It's just a weird thing. And people are weird still about the word cancer, especially when it comes to kids. It's like, a dark cloud. But you'll figure out fast who your real friends are and who's really not helpful. And it will surprise you, sometimes, and that's okay. But I highly recommend early on, immediately – it can be overwhelming if you do have a lot of people asking you what you need. Tell one person what you need and let that one person disseminates the information to your friends.

So, it might be a half-hour, 40 minutes of your work to give this person names, emails, and for you to really have a list of what's important to you. Do you need a kid-driven every Thursday somewhere? Are you just not being able to stock the house with groceries right now? There are people out there who want to help you with errands and with helping your other kids. Maybe a group that you belong to can organize and maybe you love doing something special for you, like a massage. But make this wish list, give it to what I call your point person, and let them run with it.

This person might not be your best friend. Sometimes, they're not as helpful as you'd want them to be. It might not be your family because they're in crisis too. It might be this cool person in your neighborhood or work or your church life that is really good with a spreadsheet and just gets stuff done. Let them help you. It's too much for most of us to tell all of our friend networks and then keep up with all the emails and all of the

advice. There are some great and some up and coming new websites like CaringBridge®, where you can get some help that way too. But having a person that you trust who connects with you once a week and says, "Tell me what you need. I'll get it done."

Elissa: Yeah. I absolutely love that idea of having that point person because it is hard to ask for help, especially when you're having to ask for multiple things. Ask for a ride somewhere, ask for meals, ask for this, ask for that. All these different ways that you could be helped and make this experience easier for you, for your family, and it's really hard. And so, finding that person who has no problem asking others-

Laura: Exactly.

Elissa: -is a great, great idea.

Laura: Take yourself out of it. It's awesome.

Elissa: Yeah, absolutely love that.

So, before we go to the next topic, I do want to acknowledge for a quick moment that we know as we discuss this advice for parents, we understand that it's not only the biological parents navigating this, but also legal guardians, grandparents, siblings, foster and adoptive parents, and more. And so, we want you to know that this episode is for each and every one of you, and we thank you for being here with us.

Laura: Absolutely.

Elissa: So, next, I'd like to discuss establishing a new normal. In the cancer sense, we often talk about a new normal being after cancer. But as many pediatric patients have years ahead of them for treatment, it seems like the new normal is starting very quickly. What advice would you give on establishing that new normal?

Laura: I may have given a little bit of that away with the story about Maddy and Cecilia and doing local labs and stuff. But it's taking the stuff that you can make mundane and make it mundane.

Elissa: Yeah.

Laura: So, we started off by every shot, every spinal tap, every everything, Cecilia got a prize. And believe me, there is so much power in the well-placed bribe. However, it's three years long.

Elissa: Yes.

Laura: So, Arne and I realized, okay, this is not sustainable. And also, kids are smart. I happen to teach high school, so I know kids. They're smart. If they realize, oh, if I have a little bit of a fit here, I'm going to get something I want. That's what they're supposed to do.

So, by normalizing it, you take that away. So, there should be an expectation of, so, for example, after the Beanie Baby plethora party, we would tell her, now, of course, this is pending no emergencies, just the regular appointments, regular shots, regular bone marrow aspirates, "Look, this is what's happening today." Always share what's happening. Be very honest. You don't need to be graphic but give them the lay of the land.

Elissa: Yeah.

Laura: Say what you expect. For Cecilia, it was, "We expect you to be sweet and kind and say hello to your doctors and nurses. And then afterwards, if all goes well, you're going to get a popsicle, and we'll go to the park. What do you think?" And we remember the first time that we did that with Cecilia, and we were nervous, of course, and were repeating it over and over again, trying to hype ourselves up more than her.

Elissa: Yeah.

Laura: And she stops for a second. She goes, "Wait a minute. You mean you want me to have a *positude*?" And that little word, *positude*, obviously, positive attitude is how she took it-

Elissa: I love that.

Laura: -changed everything for our little family because we're like, "Yeah, you're right." And, of course, I am not speaking to the circumstance where it's an emergency situation or suddenly you have chicken pox, which we did. You know, but the stuff that is normal, the more you can make it boring and mundane so that each little shot, each little, I know it's so little for our kids, right, would send another child into hysteria. But each blood draw, each poke isn't met with a fight and met with tantrum and met with refusal because you do need your kids to do it.

So, figure out a way to give them agency and make it boring. Do you want it in your left hand, or do you want it in your right hand? Do you want to get some sparkling fizzy water today or do you want to get that popsicle? Would you like to roller skate or go to the park? So, that also normalizes it. That normalizes it and gives them advocacy that like, "Oh, I'm in power to make my own choices. I get it. I have to still do this thing, but it's going to be okay." And that makes the extraordinary thing all of you parents are doing more mundane and normal. And once the house has calmed down and there isn't hysteria over every food choice and every poke and all the rest, it feels a lot better because it's less heightened. That's a new normal.

Elissa: Yeah. Did you find as you went on that that normal had to change, had to be adapted as you moved forward?

Laura: Yes, because the point of school comes into play. It's like, "Do I sent my kid to school? Do I not?" And I know that's a very personal choice.

Elissa: Yeah.

Laura: And the truth is, you don't know if something's going to happen to your child. So, for us, in a strange way, it went in the reverse. We had six buddies, including us, ahead of us in treatment. And three of them relapsed, repeated treatment, and ended up with successful bone marrow transplants. But that is a horrific journey. You just sort of say that causally, but that is massive. And the other two passed away.

So, for us, in our little community, we didn't, as much as I wanted to look at the end as the hooray, it's we're getting better. We can loosen the leash. You can't really loosen the leash. The trick is, how do you do that for your kid if they're doing well, in this later phases of treatment and not freak them out for the rest of their life?

Elissa: Yeah.

Laura: So, we opened the leash for Cecilia because, really, our friends' relapsing bone marrow transplants and passing away was our cross to bear, not hers. So, how could we handle that but yet allow her to go see friends when she was healthy? That's one of the early things you can do is to let your community know about this and what can't happen when you're together.

And so, our friends knew. If we've got the sniffles, no big deal. We will change the game. We always came to whatever party, whatever school event, both pockets full of Purell® and Ceil knew if we just whistled or whatever, she'd put her hand out, we'd

squirt her. We would never say to her, "You have to do this. You're sick." That's a surefire way to not turn this into a new normal, but to constantly remind your child that something's wrong with them. As opposed to, "You have child leukemia that's now in remission. You're just getting treatment, so it stays away forever." The words are very distinct, so I think that is really key as you go along; and that you want to empower them to be strong, and strong to, go out and love life, have a good time.

It is statistically true that joy in our lives and lightness really does boost our body, or some say our immune system. And if we can do that for our child and get them outside and get them in the sun, even if you can't be around other kids, the farther you get along in treatment, the better.

Elissa: Yeah.

So, the next theme I'd like to talk about that you brought up a little bit earlier is advocating for your child. We talk a lot on this podcast about shared decision-making. So, working with your doctor to discuss options and be part of your own care. But it's obviously different with a child who can't really advocate for themselves and need a parent to step up. So, how can parents or legal guardians make sure they are part of that decision-making and advocating for the best care of their child?

Laura: You know, it's an ongoing issue; and I know for a fact, because that's why Stanford asked me to speak with them. It's a systemic issue in hospitals that this is the

kind of stuff that's not taught. And so, in writing, even though my book title sounds a little saucy, "What Your Oncologist Doesn't Have Time to Tell You," I didn't mean it that way. I mean it literally.

Our doctors and nurses contributed to the book and felt exactly the same way. So did the Stanford med students I talked to. There's nobody teaching them the art of how do you get in a relationship with your families? Because the more you have that relationship and they learn how to advocate and speak up for themselves, the better that they're going to be more compliant to what you're asking them to do, which could lead to a better outcome because they're taking their meds on time. They're doing what you've asked them to do.

I think it's really at this point still, from what I've understood and this is globally too, it is the luck of the draw if you have a medical team that's engaged with you and wants to hear your opinion and asks for what do you think. Often, it's the nurse practitioner who might be more of that person, which is fantastic. But it is, from what I am still being told and the people that I've been working with for the last five years, it's pretty uncommon.

So, that leaves us, the parents and the caregivers and the grandparents and everyone to be the one to have to be a little bit, I hate to say the word "bossy" because it's not. You're just advocating for your kid. You need to know more information. And if you don't understand something, you must speak up and ask. If you're curious about an

alternative, do some reading and ask. It is not a horrible thing to do research in whatever format you want and bring that to your doctor, even send it to your doctor ahead of time and say, "I've been doing some reading. Can you explain this to me differently? I want to make sure this is the right thing for my kid." It's not only the right thing to do, it's our job as parents. And it's a job that none of us signed up for. So, it's pretty daunting.

Elissa: Yeah.

Laura: My first advocacy moment for me came when our regular doctor insisted she was fine, and we had to insist on the blood draw. You must trust your gut. No one knows your child like you.

The second came when our oncologist on day two very casually said, we've spoken about this when he wrote the forward for the book, and he apologized profusely. But at the time, he said very casually her statistics for survival and said, "But she's never going to do math or science, so, you're just going to have to get over that."

Your face is, is saying all. And I understand. There's a half of me is like, "I get it. I just need my kid to survive." And then the other half of me was like, "You are kidding me. She's a little science kid. She's outside with her bugs and snakes all day long. You're telling me that cancer may take her life, and now you're telling me that she may never do math or science."

So, this really angered me. This was really the catalyst for me in my advocacy journey. And I'm also a teacher, so I think that may be part of it. So, I ended up researching who was the head of her protocol, and I called him. And after he got over the shock of some random mom calling him to ask about these drugs and is this true, he said, "Well, it's kind of true, but she's young. You can rework their brain. Young brains can be rewired."

He gave me 10 to 15 tricks. We did all of them very quietly. Like we never sat her down and said, "You're fixing your brain now-

Elissa: Yeah.

Laura: -or this is because you have cancer." She thought it was fun. She'd get a certain computer game on Sundays; and we made it into, again, a well-placed bribe. She had no idea. Fast-forward, she ended up graduating from Stanford with a Masters and an undergrad in Math and Science. So-

Elissa: Amazing.

Laura: I hate pulling out college names, but I just say that to tell parents you can make a difference in how their brains are metabolizing these drugs because one of the amazing things that Blood Cancer United is trying to do is to get better drugs so that these severe side effects, which have been around for so long, that really do change

how a child can think and work and move in the world, that that doesn't happen to them. That's the amazing work that Blood Cancer United does.

And in the meantime, we as parents need to know, "Ooh, I can do something at home to make sure that my child isn't stuck reading at a fifth-grade level or can't do math or science or won't become who they're supposed to be or even better because of their cancer experience." That's a major piece of advocacy that you have now.

Elissa: Yeah. And I want to point out what you mentioned with these trials. It is called the PedAL trial, and so it's Pediatric Acute Leukemia; and it is currently looking at relapsed and refractory acute leukemias like AML, ALL, acute myeloid leukemia, and acute lymphoblastic leukemia and looking for those targeted treatments, seeing how their gene mutations may differ, and how we can target those specific gene mutations and get the right dosages for the kids to hopefully make the treatments less toxic, like you said, and then also reduce those late- and long-term effects for children which we're still learning about as we move forward. And so, we want to reduce those effects for children, and it's a great trial. We'll have links in the show notes for that. And also, what you talked about was making sure that you're educated. We also have tons of information and good accurate information about pediatric cancers. And so, we'll have links for that.

That's why we do this podcast. That's why we do educational resources so that patients and caregivers can see this information and bring it back to their doctor and

say, "Hey, what about this? Is this a good thing for me? Is this a good treatment for me? I saw this side effect that I hadn't thought about before. I actually have this side effect. How can we manage it?" Things like that, and then they are fully advocating for themselves and participating in that process with their doctor.

Laura: Yes. And it's incredible. It's incredible what is happening. And remember parents that right now, most of the drugs that are given to our kids for these diseases are adult dosages. And that's what Blood Cancer United is working so hard to rectify.

And in the meantime, you have to start to think of yourself as a survivor before you're a survivor rather than waiting until the end to say, "Okay, now what can I do to eliminate some of this toxicity? What can I do to help this process?" But even as scary as it is to think of yourself as a survivor early on, it's really important and to connect with those organizations that do aftercare, which is something that your kids need forever.

And we do not have yet a systemwide database that updates us, parents and then as our children age, updates them as the adult as to side effects that come up. We were on a protocol that was a, I can't remember the right language; but it's a trial, if you will. And it didn't show up that it caused fertility issues until decades later. And no one's going to call you for that yet. I'm hopeful that happens someday. You really have to stay on top of it and encourage your child as they go into adulthood to stay on top of

that with an aftercare clinic, even remotely, so that they know if they need to harvest their eggs, or they know whatever they need to know.

Elissa: Yeah, yeah. Survivorship clinics are wonderful. It seems like a lot of pediatric hospitals are now having survivorship clinics. And to be able to, again, keep up with the patients as they get older and make sure they're getting checked, getting the care that they need.

So, that moves me onto the last part I'd like to talk about is survivorship. So, we know that cancer treatment is just so difficult for the entire family and especially your emotional well-being. What advice do you have to help patients and their children both thrive and then turn that page to the next chapter?

Laura: Yeah, I think earlier is better. I was on a podcast, *The Deep C,* out of Canada, which is wonderful. And one of her big mantras is that you can't really come out of this unscathed. It's going to hit you; some form of PTSD (Post-traumatic stress disorder) is going to happen at some point. And being aware of that early is super important.

And the sooner that you can know that you can't do this alone and that you're going to need times to breathe, the better. So, that point person during treatment, giving you an afternoon off every week to do whatever you want to do. You might want to go, you know, your favorite coffee shop and hide in the corner and cry. Or maybe that's when you know you're going to get your workout in. Or you can go have a massage if

you're able to or something for yourself because this takes its toll. There's no way of escaping that.

And so, the earlier that you can have self-recovery practices in place for your family it depends on the ages, of course. But we had small ones at the time, and a baby came shortly thereafter. And the more that you can find joy with each other in ways that, I think we spent a lot of time in Tahoe, where we could be not around people but could be fun at the lake; and they didn't know the difference.

Elissa: Yeah.

Laura: But finding those joys. And for you as adults, if you're lucky enough to be in a partnership, and if you're not, get help from your friends and family, to tag team when you get a work or a walkout in, to tag team when you get your breath. Because afterwards hits pretty hard. You're so psyched, and all you can think about is the end. And I've yet to meet a parent that didn't get to the end and go, "No, one told me about this." It's scary because all of the lifelines go away. And you're so excited, and you're so grateful; and there's no getting around how beautiful it is to finish. And it is scary, and it will take time to feel normal again. And that is normal.

During treatment and then after treatment, we happened to have a local place called Jacob's Heart™ where we would go once a week as a family; and the kids had art therapy with volunteers they didn't have a clue it was cancer related. And the parents,

at the same time, could go have individual therapy. That was free. I can't recommend that enough.

Elissa: Wonderful, wonderful.

Laura: Mental health is hugely impacted during this; and there are ways to do that with your insurance. There are ways that cost money. There are ways that are free. So, really getting mental healthcare early through survivorship, a good year, is key.

Elissa: Yeah, yeah. And then what about children thriving? How can parents help their children thrive through all of this and then after treatment is finished?

Laura: Yeah, I think all of this goes back to the stories I told about making it mundane, making it feel ordinary. If you're fortunate enough that you really can let them engage with a few safe friends that you trust, if you even get a little farther and maybe even go back to school, even if it's a couple days a week, that's where they're going to thrive is when they're not thinking, "I'm at home and I'm different, and I can't be with my friends." And that gets worse the older they get because they're aware that something's wrong. So, the more that you can make them feel normal and have fun and never, ever refer to them as sick, so that you're lifting them up and empowering them to just be spunky little kids, regardless of if they have a bald head or not. But just to run around and be wild in a safe way, depending on what your counts are, that's really important.

So, I think for me, I think survivorship is letting them go and releasing them to just be free and have fun. Those worries for us as parents, they don't go away real fast. It does pass, and again, therapy makes a huge difference. Selfcare makes a huge difference.

For kids, I think, depending on their age, let them go be free. Your worries and concerns will not go away. You don't have to share them with your kid. Share them with the bestie, share them with your spouse, share them with your partner. Let them be free and have the best time.

Elissa: That is absolutely wonderful advice. So, our final question today, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." What would you say to families to give them hope after a cancer diagnosis?

Laura: Wow, there's so many things that could give you hope. You have an incredible medical team that is standing there right beside you who want nothing more than to see your child head to the finish line. There is so much hope there. You're surrounded by so many kids who are survivors and who've been through this. Some of their journeys have been really hard, and they've still made it through. And some have been more straightforward. Look to those people ahead of you for hope. I always found stories of people who were on the other side so inspirational, and they are everywhere. Let them be your hope, and let them empower you to go, "I can do this."

Elissa: Well, I mean, we can look at your daughter right now who's 30 and has a degree from Stanford in mathematics, and that is just so incredible how she has thrived and moved forward and done so well. I am so very happy to hear that.

Laura: Thank you. I thought of one other thing we did. It is a tricky one, because you don't know if you have the privilege of feeling hope when you're in this helpless state. And I remember, we happen to be Methodist, and it was really far into treatment; and, I think, it was probably when some of our friends had relapsed or passed away, and that's pretty hard to handle for everyone.

And we went to a pastor and we, you know, I probably cried a lot and blubbered and just felt like there was this constant angry thing on my shoulder, looking constantly over my shoulder. What's going to be us next? What's next? What's next? And just blabbed our whole story, and she paused for a minute; and then she said, "Have you ever considered that she's the hope? Maybe she's the hope." And that can be your kid too. You can consider all of the dark horrible things, because that's really easy for us cancer parents to do. But you can also consider that maybe your kid's the hope.

Elissa: Oh, I love that so much. That is such a beautiful way to think and still be realistic about-

Laura: Yeah.

Elissa: -what is happening in your world, what is happening with your child. And so, that's great.

Well, thank you so much, Laura, for joining us today-

Laura: Yeah, thank you.

Elissa: -and sharing all this amazing advice for pediatric parents and their kids. I hope that they will be able to take this advice and eventually thrive and make it through really difficult challenges that are ahead or that they're currently dealing with right now. And so, again, thank you so very, very much for joining us today.

Laura: You're so welcome, and parents and caregivers, you can do this. You can do this.

Elissa: And thank you to everyone listening today. *The Bloodline with Blood Cancer United* is one part of our mission to improve the quality of lives of patients and their families.

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