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THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'LIVE! At CancerCon: Navigating Young Adult Cancer'

Description:

Please join us for our second live episode from CancerCon®, a young adult cancer conference presented by Stupid Cancer®. In this episode, we'll be speaking with experts who discussed survivorship planning, imposter syndrome, and developing a growth mindset.

Cancer patients and survivors of all ages, whether newly diagnosed, in treatment or post-treatment, can benefit from hearing from these experts.

Be sure to tune into the previous episode from CancerCon, where we hear from young adult cancer patients and survivors on what the word, *"survivorship"* means to them and how that meaning may have changed throughout their cancer experience.

Transcript:

Elissa: Welcome to *The Bloodline* with LLS. My name is Elissa, and today we are podcasting live from CancerCon®, a young adult cancer conference put on by Stupid Cancer®. This year the conference is taking place in Minneapolis, Minnesota, and is attended by around 200 young adult cancer patients, survivors, caregivers, and healthcare professionals.

LLS is a proud sponsor of this annual event, which is attended by people affected by all cancers. However, blood cancer patients and survivors often represent around 40% of the total attendees each year. The LLS theme at this year's conference is survivorship. The term survivorship is defined by the National Cancer Institute (NCI) as the health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond.

In the last episode, we interviewed blood cancer patients and survivors on what the term survivorship means to them. Today, we want to hear from the presenters at CancerCon about the highlights of their presentations on the unique issues that affect young adults with cancer. So, let's get started.

Crystal Reinhart, PhD: I'm Crystal Reinhart. I'm a research scientist at the University of Illinois, and my connection to blood cancer is that I'm a 12-year AML survivor.

Amelia Baffa, MSN, APRN, PMHNP-BC: Hi, my name's Amelia Baffa. I'm a psychiatric mental health nurse practitioner, and my connection to blood cancer is I'm the psychiatric provider for hematology and oncology division at Rainbow Babies and Children's.

Elissa: What was the name of your session, and why was it important for each of you to present on this subject?

Crystal: Our session was called "*From Day One: Planning Your Survivorship Care*," and this is really important for survivors like myself to keep track of the care that they're getting during their treatment but also during follow-up, any long-term side effects that they might experience, what kind of screenings and testings they should get. Beyond just the medical treatments, any mental health needs, addressing those financial needs and a lot of things like that. So really important, I think, to be able to plan for that and know kind of what the guidelines are for someone your age and someone with your diagnosis. So very important.

Elissa: And why was it important for you, Amelia?

Amelia: Well, I agree with Crystal. I think just even to get a feel for the young adults in the room and appreciate that really the survivorship care plan is an investment in their health long term. They need to know their cumulative doses; they need to know what they need to be surveilled for and watched for in the future and what they need to monitor for health reasons. So having that discussion live with them was wonderful and seeing a show of hands of how many had them and how many did not was very insightful. So, encouraging them to talk with their primary care providers or their oncologist or their nurse practitioner to begin to work on that survivorship care plan, so that they can stay healthy and have good outcomes.

Elissa: Yes. And I was struck by that as well. I'm also an AML survivor and I didn't know what a survivorship care plan was until I started at LLS. It is so important for you to share that information with all the attendees here.

Now can each of you tell us some of the highlights of your presentation.

Crystal: Sure. I actually conducted a study about survivorship at National Cancer Institute designated cancer centers around the United States. We surveyed about 70% of them, and we asked them what services they provide, who they provide services for, how many people they give survivorship care plans to, and, also, what they felt were some of the gaps and barriers. And they all kind of fell into the same categories that we need longer-term follow-up care, that we need to be addressing mental health needs and financial needs, as well as healthy behaviors, maintaining your health across your lifespan.

Amelia: I guess from my perspective, which is mental health, addressing that. One of the things that came out of the discussion with us today is, "When I'm done with my therapy," some of them said, "I just felt lost. I felt like what do I do next? This routine, this team that I had, where are they?" So, paying attention to that and understanding that it's a process. It's really a recovery process after you're done with treatment. Paying attention to your mental health needs and getting help and support that you need.

And sometimes, unfortunately, you just have to ask for it. If they can't see that you're struggling, make sure you let folks know.

Elissa: Yeah, definitely.

Crystal: I would also say it's important to me to reassure survivors that there is a resource out there for any need that you have, and you just have to be able to seek it out and find it. I think one of the hardest things is connecting patients to resources, and I think that's one of the great things about LLS is that they do that no matter where you are. So that's really important for people to know too because they were asking today in our session, "Hey, do you have resources for caregivers or friends in addition to survivors?" So that's important.

Elissa: Yeah. We handed out the Young Adult Survivorship Workbook, which you went over as well, and the resources available, so people can actually keep track of their treatments. And for those that didn't have MyChart®, like Crystal, that you were before MyChart time and being able to have those resources all in one place, all your treatments, all your diagnostic tests, everything like that is really important.

I loved seeing what this dream is of what a great survivorship care team would look like. Can you tell us a little bit about that?

Amelia: Well, it should be comprehensive ideally, including multiple specialties. So, when an individual's coming in for a survivorship visit, they can get all of the surveillance and monitoring they need at that visit.

For some folks, it's talking maybe to a reproduction specialist, an endocrinologist, a neurologist, a nutritionist, someone from psych, as well as their survivorship physician. So, making sure that it's as comprehensive as it can be to embody all the needs that that individual has, ideally. So, when they go home, they're ready and set for the next six months, year, and they know what they need to do to stay healthy.

Crystal: Yeah. And one other thing that I would mention too is that young adults are a special population. They're often in transition. They're going from pediatric patients to adult patients, as Amelia mentioned in her presentation. But like for myself, I had just gotten out of college and just moved to a new place where I didn't really know anybody. So, I think there's often like special considerations for young adults, especially if they get treated in one place and move to another place. So having that information in a portable format is really key.

Elissa: Yes, definitely. So, to finish this off, on our patient podcast homepage, we have a quote that says, "After diagnosis comes hope." Based on your professional experience, what would each of you say to current patients and those who have completed treatment to give them hope after a diagnosis of cancer?

Crystal: I think one of the most important things that I've learned is that my voice has power, so if you need help, you really just have to ask for it. There's help out there for anything that you might need help with. And there's people just like you. For the longest time, I was searching for another young adult who'd been diagnosed with AML and now I'm talking to one.

Elissa: Yes.

Crystal: So, it's amazing the resources out there. There's people just like you, there's support out there for you, and you really just have to ask.

Elissa: Yes.

Amelia: Although everyone's journey is unique to themself, like you said, you're not alone, so we're there to travel with you. Sometimes as healthcare providers, we get busy, we get distracted. Please remind us that we work for you.

Crystal: Right.

Elissa: That's good advice.

Amelia: I mean truly, and we appreciate that too. So just to your point there, Crystal, if there's something that you need help with, remind us that you need help with it, when do you need that help by, and stay on us because, ultimately, we want the best outcomes for everybody. Get your team together, make sure we're doing our job for you.

Elissa: And that all comes back to advocating for your own care.

Crystal: Yes.

Amelia: Absolutely, you got it.

Elissa: Thank you so much, Crystal and Amelia, for speaking with us today and, of course, being amazing presenters for our LLS-sponsored session all about survivorship. We really appreciate you talking to us.

Crystal: Thank you.

Amelia: Thank you for having us.

Susan Moser: Susan Moser, I am an attorney, Vice President of mergers and acquisitions. I also run a company called *Grow Into Greatness,* which is a platform for motivational speaking and mindset mentorship, and I am a lifetime cancer survivor having been born with cancer in 1985.

Elissa: Now you actually did two things. You were a keynote speaker for our opening session, and then you also have a session this weekend. So, could you tell us about the name of your session coming up and then also a little bit about the keynote?

Susan: Sure. So, the session which is coming up on the last day of the conference is called "Mindset of Survivorship: Authentically Owning an Empowered Survivor Experience." And it's tied to what I spoke about during the keynote. The keynote was really about my story and how I, really over the last ten-ish years, have transformed my relationship with my cancer status. I didn't really talk about it or acknowledge much of its impact in my life for almost 30 years. And through sort of the power of mindset and a lot of what work I've done over the last decade; I have been able to really own survivorship as an empowering character trait.

During the breakout session, what I am really excited to bring to the table and to the attendees here, it's really all about how can you define how you want to feel about your survivorship as opposed to just reacting to it. And how do you set yourself up really every day and throughout your life to feel empowered by your cancer experience as opposed to debilitated by it.

Elissa: Yeah. One thing that really struck me that you said in the keynote speech was that cancer doesn't define you, but it does shape you though, and it has shaped your life. What would you say more about that?

Susan: Yeah. As somebody who doesn't have a before and after to her cancer experience, it's hard to separate sometimes your diagnosis and your everyday experiences with your health realities that result from treatment separate from who you are. And I know a lot of our AYA community they struggle to sort of,what's the before and after, right? How do I define who I am? And we can often get stuck in this perspective that our cancer survivorship really is such a big part of us that it's all of us and every part of our lives because we might get consumed by a lot of the anxiety or the fears that comes with being a survivor, it takes over our lives in a way that can feel like it defines you. You don't want to share at work or share with your friends or you're afraid of relapse or any number of things that could creep in and it becomes all-consuming.

But the reality is there are some really great character traits that exist as a result of having gone through something like this. There's, obviously, a resiliency. There's, obviously, a strength. There's, obviously, for most I think, a sense of an ability for compassion and for understanding and connecting with others. All of those are incredible human being character traits that you may have actually learned and honed because of your health realities. And so instead of just saying, "I am a survivor," and not having meat on the bones to that statement and letting whatever your mind thinks of that label consume, it's about, "Here's what my experience has given me, here's what I choose to take from it, and here's how I can use it to feel empowered in my own life and bring empowerment to other people."

Elissa: I love that. Now you have been involved with CancerCon and its predecessor, OMG, for quite a long time. Why did you feel like this topic was important for you to talk about this year?

Susan: So, as you mentioned, I was involved with Stupid Cancer way back in 2010, '11, '12 for several years. I had actually really just started my own journey back then, and within the last couple of years have started to use my journey, what I've developed out of my journey and it's mindset for everything, not just mindset of survivorship but including mindset of survivorship, and it's now that I feel two things. One, that I'm in the position to be able to share in a way that's helpful to other people. As opposed to not just my story, it's, "Here's a framework you can use, and here are tools you can use, and here is how you can initiate this kind of an experience and a process for yourself." So, part of it is it's the right time because it's only now that I'm equipped to do that in a way that I felt would be the most powerful.

The other thing is I think the conversation around mental health and how your mental/emotional health is impacted by your experience it's, obviously, just become more and more prominent over time, and it's really at the forefront of things. And I want people to understand that there's a multitude of ways to do this.

Therapy for me was not the right path. It wasn't something that resonated with me. I wasn't in a place over many times of trying to utilize it to its fullest advantage in a way that I've seen it work so powerfully for other people, but learning about and developing this approach to mindset work and how to actually hone the power of our mind to work for us instead of put us down, that was the way that I was able to overcome a lot of that anxiety and negative self-talk and fear and we'll call it depression because I'm sure if I had been in therapy they would have diagnosed it as that and recognition of survivor's guilt and what that means. And I don't ever want people to feel like, because they might not be getting the breakthroughs in therapy or feel aligned with formal therapy that they're alone in that. There's nothing wrong with them.

Elissa: Right.

Susan: Right. It may not be that they're not trying. This is just another tool in the toolbox for people to be thinking about. And as a companion to everything else, all the other resources that they have this is just another resource under the umbrella of how might we be able to support people in their journey to managing the emotional and mental components of this.

Elissa: Yeah. That's a really good point that there are just so many tools that are available, whether it is support or therapy or things like this where people can come and meet other young adult cancer survivors, and so that's a great point.

Now regarding your breakout session coming up, could you tell us some of the highlights of that presentation?

Susan: Yes. Like I said, that's going to be a working session.

Elissa: Yeah.

Susan: We've got to workbook packet that I'm going to walk through with everybody, go through a bunch of exercises. And the goal is twofold. One is to help people start thinking about how do they want to feel about their survivorship. Instead of just this is how I feel as a reaction, it's really actually being proactive and thinking about how do you want to feel about your survivorship? What kinds of conversations would you like to be having?

The first big piece of this is going to be bit of self-reflection and really encouraging people to ask themselves the hard questions. The second part of it is going to be providing a framework for them to go out and actually create that reality for themselves. So, we'll work through some exercises that'll help them get from point A to point B and equip them moving forward with some really tactical things that they can do every single day to help solidify their desired relationship with their survivorship.

Elissa: That's great. Sometimes working through all together with those exercises can really be helpful as they move forward.

Susan: Yeah. At Grow Into Greatness, we sort of frame everything through the lens of our three simple tenets, which is prioritize, vocalize, and emphasize.

Elissa: Okay.

Susan: And it's the key framework for unlocking the power of your mind. So, prioritize is what allows you to set your intentions, and that breeds clarity. Your mind isn't trying to pick through a bunch of options, it's focused; and we all know when you focus on something, that's where the energy goes.

Elissa: Yes.

Susan: The second tenet is vocalizing. Vocalizing does two really, really important things to help you shift into an empowering mindset. The first is it breeds excitement. Think about when you have something to celebrate, you don't keep that in. You want to share it because you understand there's like an amplification of energy when you vocalize, and you share.

The second piece of vocalizing is the accountability because we can rationalize for ourselves internally till the cows come home, but when you put it out in the world in whatever way, you hold yourself accountable and you can create a dynamic for your community to hold you accountable.

The third is emphasize. Emphasize is just about making it an everyday habit. So, if you're deciding something about your survivorship status that you want to celebrate, so like for me, being able to celebrate my intensity was huge. So, every day I used a hashtag "Celebrate Intensity" on social media, and I would say it to myself. Some people use I am affirmation. Some people journal. Pick something that you can do, emphasize every single day that supports what you declared was your priority for your relationship and what you're bringing excitement and accountability to by putting it out there.

And emphasize habit formation, as we all know, is the key to making something automatic. So, if you're setting up a habit of thinking in a certain way and speaking in a certain way, in the moment where you might be inclined to think otherwise, your mind is going to remember that you prioritized this other way of thinking about it.

Elissa: Yes.

Susan: That's the framework that we'll walk through, and we'll help apply that to survivorship.

Elissa: Wow! That's really neat. When you were talking about vocalizing, it made me think of your keynote speech, when you talked about saying that you're survivor out loud for the first time when you were at First Descents®. And it was really neat because I think a lot of us have our own experiences with when we're comfortable with telling people that. And so it's good to just put it out there and put it out there whether you can be proud of it or not, and I think that's really excellent advice.

Susan: Thank you. Yeah, that moment is really a line of demarcation for sure, and it's just one of those things in what I hope people walked away for the keynote with was just about a sense of feeling empowered to decide for yourself and also a sense of responsibility to say, "Hey, this is happening to me, but I also get to decide how I experience it and how I live through it and live beyond it."

Elissa: Yeah. Our last question today. On our patient podcast homepage, we have a quote that says, "After diagnosis comes hope." Based on your professional and, of course, personal experience, what would you say to current patients and then those who have completed treatment to give them hope after a diagnosis of cancer?

<u>Susan</u>: I said this in the keynote, and I'll reiterate it here because there is so much that cancer has the capacity to take from us. We all know that, that's the reality. But the beauty is that it can give us so much if we look for it and if we choose to acknowledge it. And as a now multidecade survivor, all I can say is that being open about my survivorship has done nothing but enhance my life. There is actually not a single moment since I have started to be vocal about it that sharing it has resulted in something negative. Whether that's in my personal life or my professional life.

I just want encourage people who are either going through treatment or survivors to understand that sharing about it, connecting with others about it, even if they've never experienced cancer for themselves, will enhance your life in ways you can't even possibly imagine right now.

<u>Elissa</u>: That's wonderful. It's just such amazing advice. Thank you so much, Sue, for taking the time to talk to me. I'm so excited to see your breakout session later on this weekend, and your keynote speech was just incredible. I know a lot of people will take a lot of stuff away from that, and I hope that our listeners will also get some really good advice for today. So, thank you so much.

<u>Susan</u>: Thank you so much for having me.

<u>Robert Bennett, PhD, CPNP-AC, PPCNP-BC</u>: My name is Robert Bennett. I'm a Postdoctoral Fellow in Palliative Care and Aging research at the University of Colorado, and I'm also a pediatric nurse practitioner. My connection to blood cancer is my mom is a lymphoma survivor, and the population I serve clinically has that as a diagnosis.

<u>Peter Drams, RN, BSN</u>: My name is Peter Drahms. I'm a registered nurse from Savannah, New York. I've been an RN since 2005, and I have ten years of hematology/oncology experience. I currently work as an ICU travel nurse. My connection to cancer is professionally at University of Rochester, Strong Memorial Hospital through the Wilmot Cancer Center and then also personally through my parents. My father is currently undergoing treatment for multiple myeloma.

Elissa: Now what was the name of your session, and why was it important for each of you to present on this subject?

Robert: The name of our session was "*Imposter Syndrome During AYA Cancer Survivorship*." So, imposter syndrome is the inability to recognize your own strengths and efforts that you've put forth in your treatment phase and daily lives during cancer survivorship. This is something that a vast majority of the population deals with in daily life.

We'd thought it'd be interesting to get to discuss it as it pertains to the population of cancer survivors that would be present here. So, we thought it'd be interesting to discuss imposter syndrome as it pertains to the population of AYA cancer survivors. We've heard many stories about people who don't feel like they're worthy of the survivor label or that their course of treatment wasn't as difficult as someone else's. Unfortunately, people discredit themselves when they have feelings of imposterhood.

We wanted to bring awareness to this phenomenon because experiencing imposter syndrome can be extremely isolating. We want cancer survivors to know that we see them and that we stand with them.

Elissa: Can you tell us some of the highlights of your presentation?

Peter: Some of the highlights of our presentation include that imposter syndrome is something that is highly prevalent and equally unrecognized by the people who have it. Up to 70% or more of the population suffers from imposter syndrome. We also found that people with imposter syndrome largely suffer in silence and are afraid to talk about it or don't recognize it for what it is. So, a failure to control imposter syndrome can lead to clinical levels of depression or anxiety or it can exacerbate them if previously existing. And then, also, there are ways to manage imposter syndrome and change your relationship to challenges when they occur as well as to recognize and apply your own internal strengths.

Elissa: What I really loved about your presentation was going through all the different types of the imposter syndrome with everybody and having people in the group try to recognize how they felt like they were an imposter and how they related to the different types. It really got a lot of discussion going with finding connection there.

Robert: Yeah, I agree. I was really pleased that everyone was able to finally speak out and say, "I can relate to that because I feel like an imposter a lot and now, I can actually name what I was feeling and have the courage to speak out and help others speak out as well so they're not feeling alone anymore."

Elissa: Right. And it was really good at the end when you talked about what advice you give and how could we get rid of feeling like an imposter. What would you say about things that people were saying with that?

Peter: I think it was really important there at the end with our discussion that the audience took the lead with that because if anyone can be credible it's the people who are survivors, who are veterans of cancer treatment. So, I thought that some of the tips that they had in talking through their own experiences and acknowledging some of the successes that they've had and just realizing that, yes, we've all had our own journeys, but it doesn't mean we have to compare whose was harder or whose was easier; we can each appreciate each other and what we've been through individually.

Elissa: Right, absolutely. You actually brought up a really good point about what people refer to themselves as. You talked about survivors, talked about veterans, some still want to be called patients if they're in an active treatment. What was that discussion like?

Robert: It was really informative because for us it speaks to that formation of your own narrative moving forward, how do you define yourself as opposed to how does the community at large, whether that be medical providers or other people, define you. So that's your chance to say, "This is who I am. Not who other people tell me to be."

Elissa: Now on our patient podcast homepage, we have a quote that says, "After diagnosis comes hope." So based on your professional experience, what would each of you say to current patients and those who have completed treatment to give them hope after a diagnosis of cancer?

Robert: To that point, I would say that despite how alone you may feel, there are people to support you. Hope starts with feeling like you've been seen and heard. No matter the diagnosis, no matter how dire or severe, there is always something to hope for. By seeing and hearing you, we can support you on your journey with cancer.

Peter: I would echo the comments that Robert had. I just feel like hope is, in the end, one of the most important things to have. We can never lose hope even faced with some of the most difficult situations because when you don't have hope, you're not really left with much. It's always important, as people have said here, to see a light at the end of the tunnel. Always be looking forward and set goals for yourself because in the end, oftentimes, the goals we achieve are the ones that we think of consciously or subconsciously. So, maintain that forward-thinking process. Always think that the best is yet to come and, hopefully, it will.

Elissa: Absolutely. Well thank you so much for speaking with me today and telling us all about your session. I hope that our listeners will learn something from what you shared today, and we really appreciate you being here at CancerCon and sharing all your knowledge and really helping patients, survivors, work through this imposter syndrome and working through survivorship and growing in survivorship. So, thank you both, again, so very much.

Robert: Thank you, Elissa. This has been a fantastic opportunity, and we really appreciate you spending time with us.

Peter: Thank you, Elissa.

Elissa: This concludes our second episode podcasting live from CancerCon. Be sure to tune in to the prior episode where we interviewed young adult patients and survivors at CancerCon to hear their thoughts on survivorship.

Thank you, again, to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families. To help us continue to provide the engaging content for all people affected by cancer, we would like to ask you to complete a brief survey that can be found in the Show Notes or at TheBloodline.org. This is your opportunity to provide feedback and suggested topics that will help so many people. We would also like to know about you and how we can serve you better. The survey is completely anonymous and no identifying information will be taken. We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

Have you or a loved one been affected by a blood cancer? LLS has many resources available to you, financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to LLS.org/PatientSupport. Young adults who are aged 15 to 39 are encouraged to visit LLS.org/YoungAdults for all the resources that LLS has to address your unique needs.

For more information on CancerCon and Stupid Cancer, go to stupidcancer.org. All of these links will be in the Show Notes or at TheBloodline.org.

Thank you, again, for listening. Be sure to subscribe to *The Bloodline* so you don't miss an episode. We look forward to having you join us next time.