

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'The Bloodline Live: Emphasizing the Patient Voice in Young Adult Cancer Care'***

#### **Description:**

When adolescents and young adults (AYA) are diagnosed with cancer, they face unique challenges that aren't seen as frequently in other age groups. Healthcare and nonprofit professionals around the world are listening to patients and researching these issues to improve quality of life during and after treatment.

In this episode, we are taking you onsite to the 5<sup>th</sup> Annual Global Adolescent and Young Adult Cancer Congress in Long Beach, CA. Elissa met with experts who discussed mental health, the resiliency of AYA patients when facing uncertainty, healthcare transitions and disparities, and how patients can advocate for their care.

#### **Transcript:**

**Elissa:** Welcome to the *Bloodline with LLS*. My name is Elissa, and today we are podcasting live from the Global Adolescent and Young Adult Cancer Congress, a cancer conference for healthcare and nonprofit professionals in Long Beach, California.

LLS is a proud sponsor of this event, which is attended by professionals around the world to present on the most pressing issues facing adolescents and young adults with cancer.

You may hear the acronym, AYA, throughout this episode. This stands for Adolescent and Young Adult and generally covers patients who are diagnosed between the ages of 15 and 39, as well as pediatric patients who may have late-term and long-term side effects.



In this episode, we will be speaking to some of the presenters at this conference and will be covering young adult healthcare disparities, mental health, and the uncertainties that young adults face after a cancer diagnosis.

For our young adults as well as other patients and caregivers listening to this episode, we hope that the information presented will empower you to speak to your treatment team and advocate for the best care for you. So, let's get started.

**Abby Rosenberg, MD, MS, MA:** My name is Abby Rosenberg. I am currently the Chief of Pediatric Palliative Care at the Dana-Farber Cancer Institute and Boston Children's, and I've been there for a few months. Previous to that, I was at Seattle Children's Hospital and the University of Washington, where I was the Director of Pediatrics for the Cambia Palliative Care Center of Excellence and the Director of the Palliative Care and Resilience Research Lab.

**Elissa:** What was the name of your session, and why is this subject important for the care of AYA's with cancer?

**Dr. Rosenberg:** My session name is entitled "Transitions and Resiliency." And what I'm going to talk about is evolving uncertainty and how resilience can help us in times of change.

We talk about transition all the time in adolescent and to young adult oncology. There are half a dozen transitions that we toss around almost to normalize them. So, the transition from being a well person to a person with cancer. The transition from being somebody who is receiving cancer-directed therapy to somebody who is no longer receiving therapy and is labeled as a survivor. We talk about transition from curative to end-of-life care. We talk about transitions from pediatric to adult medical settings. And every single one of those comes with a ton of uncertainty and a ton of stress, and all of those are in the midst of the transitions that are adolescents and young adulthood, the growing up and the transition of becoming your own person.

I think, we who live in this AYA oncology space really understand that this is hard, on top of hard, on top of hard, for many of the folks that we work with and care for. And so, I'm really excited that we're going to be talking about this explicitly.

**Elissa:** Yes, definitely. So, can you tell us some of the highlights of your presentation?

**Dr. Rosenberg:** Yeah. It's funny because the presentation has been in transition, too, a little bit.

**Elissa:** Yes.

**Dr. Rosenberg:** And when we first decided to have me talk, we were going to spend most of the time talking about my own research in resilience and specifically how developing resilience resources can buffer some of the stressors of change and transition.

**Elissa:** Right.

**Dr. Rosenberg:** And, honestly, I am making a little bit of a last-minute pivot because what I really want to talk to folks about is some ideas that I'm playing with about how there's a lot of examples of transition within AYA oncology, and the world has gone through a lot of transition in the past few years.

**Elissa:** Yes.

**Dr. Rosenberg:** And I think that there are things that we can learn from the AYA oncology space and applying it to all of the transitions that global societies are going through. And I think that we have actually learned some stuff in the last years from watching global society transition that we can translate back to adolescents and young adults with cancer.

And so, I'm doing something that I rarely do in a talk, which is not a lot of actual research and a lot more of my ideas and opinions and sort of -

**Elissa:** Okay.

**Dr. Rosenberg:** - tossing them out and saying, “What do you’ll think about this because here’s the stuff that’s been on my mind as we navigate our own transition as a society.

**Elissa:** Yeah. There’s definitely been a lot of change for the cancer community in general, but certainly young adults with COVID.

I myself, while I’m interviewing you, I’m in a mask as a leukemia survivor, and we’re still trying to navigate this whole new world where it’s not just cancer.

**Dr. Rosenberg:** Right, right.

**Elissa:** And there’s this other thing that a lot of us now are higher risk and dealing with that level of uncertainty as well.

**Dr. Rosenberg:** Right.

**Elissa:** What are some of your ideas? I’d love to hear.

**Dr. Rosenberg:** The first is that, for a long time, when we thought about resilience, we have thought about like a line. Maybe it’s a bumpy line or a pathway, but there was this sense that when we go through tough times in transition, we continue to move forward.

**Elissa:** Right.

**Dr. Rosenberg:** And I think the pandemic has taught us that that is not entirely true. That it’s more like a lot of loop-de-loops.

**Elissa:** Yes.

**Dr. Rosenberg:** And sometimes it’s backwards, sometimes it’s forward, sometimes it’s up, sometimes it’s sideways. And, really, how we need to think about resilience is

less that there is this always forward movement, and more that we can shift between different phases of resilience and all of those phases are valid. So sometimes, for example, there's a day where you just get out of bed and get through the day because that is the best you can do. And previously people would have said, "Well that's not resilient." And I think that that absolutely is resilient because that day is a day where getting out of bed was hard.

**Elissa:** Yeah.

**Dr. Rosenberg:** And then, there are other moments where we do move forward maybe by leaps, and so I want to call out how we need to think about and give credit where it's due.

And then a flip idea is almost the opposite, which is that we, during the pandemic, especially for marginalized communities, hear a lot about how we glorify resilience. We, who didn't go through the adversity look at those who did, and we say, "Wow, you are so incredible and amazing, and how can you do what you've done all this time?" And we hear from a lot of folks, they're like, "Just stop calling me resilient and fix the problem. I don't want to have to be resilient."

**Elissa:** Yes.

**Dr. Rosenberg:** And so, if one is about, how do you recognize getting through a day versus a leap forward day, the other big idea is how do we celebrate resilience without making it exceptional. We need to be able to recognize and support people who need resilience when they need it. And we need to be doing more to change the system so that they need it less.

**Elissa:** Yeah. I think it's definitely important for healthcare professionals, nonprofit professionals, to hear this and hear how they can interact with young adults with cancer in a better way.

**Dr. Rosenberg:** Yeah, yeah.

**Elissa:** And I think everybody with cancer listening right now will understand when you just said, it's almost too much credit sometimes for being brave.

**Dr. Rosenberg:** Yeah.

**Elissa:** Sometimes, I'm just getting through my day. That's all I'm doing. How can you say that I'm brave?

**Dr. Rosenberg:** Right.

**Elissa:** But at the same time, there are those small victories -

**Dr. Rosenberg:** That.

**Elissa:** - that somebody can do that feels so good to them in that moment, or that they're just completing their goal for that one day.

**Dr. Rosenberg:** Right. And you want to celebrate that. I think about this when I think about folks with cancer, like they'll say, "I could do nothing but be resilient." I had no choice -

**Elissa:** Yes.

**Dr. Rosenberg:** - but to get through this. That was the new reality that was in front of me. And those of us who are bearing witness look at it with such awe. And there's a little bit of a balance where it does deserve to be recognized, and you also have to recognize the person who did the work and the person that they were before, during, and after.

That I think is the thing where we're stuck. Resilience as a word has become taboo. We don't like talking about resilience anymore. People roll their eyes when you talk about resilience these days.

**Elissa:** Yes.

**Dr. Rosenberg:** That's a bummer for somebody who built their career studying resilience, but I think this is where we're at. This is why the field is transitioning. We have to think differently about how we measure and label and celebrate both everyday resilience and exceptional resilience.

**Elissa:** Yes. I'm wondering if there's something to be said from taking the cue from the patient as well.

**Dr. Rosenberg:** Yeah.

**Elissa:** If they are excited about something small that they did. It felt good to them, even though they may think it's small, to treat that as a victory.

**Dr. Rosenberg:** Exactly.

**Elissa:** But then, not go over above and beyond if they aren't leading that way.

**Dr. Rosenberg:** I think that that's exactly right. A lot of what we do at the bedside is ask people, not only like how are you doing this, what are the things that we should be celebrating with you? And giving the patient their own moment.

And I think the other thing is, to give them a moment to say I don't want to talk about this today.

**Elissa:** Yeah.

**Dr. Rosenberg:** Or today, I'm getting through the day because I'm angry, and that's okay. We can give them that space.

**Elissa:** Yes, absolutely. So where do we see this going? Are there going to be studies done on this, surveys, more connection with patients?

**Dr. Rosenberg:** The research that I will present is, we have a resilience intervention that we built in partnership with Adolescents and Young Adults with Cancer, and that

program is called "*Promoting Resilience in Stress Management*," or PRISM. We've done lots of research with PRISM, and it works. It improves quality of life, reduces depression, and alleviates psychological distress, and it improves hope amongst teenagers and young adults with cancer.

I think the next step is, how do you bridge some of the systems' challenges that we're starting to see with individual patient level programs like PRISM. So, when I hear, for example, from a marginalized community that they don't want to talk about resilience anymore, they want us to fix the system, I, as somebody who understands resilience, also understand that I can do something for that person who is living with that adversity. What we need to do now as a research community is also think about how do we take away some of the constant stress from the system to make it a little bit easier for people who are already dealing with so much.

And so that research is entirely different. It's systems level, policy level stuff.

**Elissa:** Yes.

**Dr. Rosenberg:** And I think we need to think as a community about what that might look like.

**Elissa:** Well, that is exciting to see where this could potentially go to help patients. Our final question today, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." So, based on your professional experience and research, what advice would you give to patients and caregivers to give them hope after a diagnosis, and help them to navigate the uncertainties that come throughout treatment and survivorship?

**Dr. Rosenberg:** Well, I think hope is one of the most important resilience resources there is.

**Elissa:** Yes.



**Dr. Rosenberg:** And I think we, in general, need to really be talking with patients and families about their hopes, helping them to support and diversify those hopes. We often talk about hope and what else you're hoping for, so that we can really enable folks to see something that they would like to move forward towards.

I think though for resilience, it's not actually that complicated it turns out. The ways that I do this as a clinician is I ask people about their resources and their strengths and their struggles. What have you done in the past when times are hard? That helps me understand in a snapshot what their resilience resources are. Who helps you? I can really quickly get a sense of how to champion some of those things that they will need. And then I normalize and validate their struggles.

On their hard day, if you're having a bad time, if all you can do is get out of bed today, you're normal.

**Elissa:** Yeah.

**Dr. Rosenberg:** And you're pretty damn resilient. And that's okay, and we're going to talk about that too.

**Elissa:** Oh, that's wonderful. That's great advice. And I know we're getting to you before your session, so I'm so excited to listen to it. And thank you so much for speaking with us today.

**Dr. Rosenberg:** Yeah, thanks for having me. I appreciate it.

**Christabel Cheung, PhD, MSW:** My name's Dr. Christabel Cheung and I'm an Assistant Professor at the University of Maryland School of Social Work, and I'm a member of the Greenbaum Comprehensive Cancer Center.

**Mike Roth, MD:** My name is Mike Roth, I am a pediatric oncologist at MD Anderson Cancer Center where I co-lead the Adolescent Young Adult program, and I also chair the AYA Committee within the Children's Oncology Group.

**Nelson Parelta:** Hi, my name is Nelson Parelta, he/him/his. I'm 28-years old, I am a survivor of acute lymphoblastic leukemia (ALL). I've relapsed twice, and currently about to hit a two-year mark of my bone marrow transplant in August, so I'm really looking forward to that.

**Elissa:** So what was the name of your session, and why is this subject important for the care of AYA's with cancer?

**Dr. Cheung:** So, the title of our session was "Marginalized and Minoritized: Disparities and Unequal Treatment in AYA Oncology."

It's an important topic because the experiences of inequities that we see in the general population, they just continue in the AYA space just because it's an extension of the larger medical community. So, it's to be expected.

**Dr. Roth:** We see disparities across the board in cancer care for patients from underserved populations. And, unfortunately, like Dr. Cheung said, these disparities persist and we're not moving the needle. So, it's really essential that we come together and identify real world ways to actually make improvements.

**Elissa:** So can you tell me some of the highlights of your presentation today?

**Dr. Cheung:** Yeah. I think the biggest highlights were our patient advocates. The point of our session was to partner patient advocates with researchers and clinicians in the field doing the work. And what we showed is that we used their embodied knowledge and used an embodied research technique that I've been developing to then make demands of researchers, and clinicians, and ask real questions that were derived from their personal lived cancer experiences.

And so, we had three partnerships that we demonstrated.

And then the researchers, and clinicians like Dr. Roth, each responded in their own style. So, we saw how Dr. Roth turned his into a conversation and a dialogue.

**Nelson:** I was part of a panel in which I shared my experience being a queer person of color, specifically indigenous, and talked about what it felt like to be diagnosed, and then having relapses, how that's affected both my personal, professional academic life. And one of the things that I wanted to ask Dr. Mike Roth, was if there was a protocol in terms of sexual orientation or sexual practices, activities, as it relates to gay men who are either AYA or survivors. And I was just very interested to know about that.

**Dr. Roth:** Yeah. Coming from the provider side, where we really struggle to meet the needs of our AYA's from underserved communities, it was a learning experience for me personally, and for many in the audience. And the most impactful part of the session was just to hear the patient experience and what our AYA's go through that, as a provider, we don't think about. I think all of us have a lot of learning to do and a lot of processing to do. What we really need to do most is partner with our patients and partner with our advocates to implement change, and change that makes a difference.

**Elissa:** Yes. I think that's what I've seen as a theme of the conference as a whole, is that we really need to listen to the patient voice, right?

**Dr. Cheung:** Right, but then, also, not just listen and then feel bad about it, or listen and feel good about what you're doing. It's really to listen and then learn something and take that and respond to it. And so, we showcased that in our session in the sense that we listened to the patient stories, they had questions from us. We learned from what their stories told us. And then, we each responded in our own way, and sometimes the response is "I'm sorry, I don't have the answer yet."

**Elissa:** Yes.

**Dr. Cheung:** But other times it's, "Hey, we have a framework for systems change and here it is, here you go." And so, if you want to do something, let's advocate for this at your institutions.

Or even at the individual professional level, this is what you can do to be more of a reflexive professional. So, I think we offered different types of solutions, and we were real to what answers we have and what answers we don't have.

**Elissa:** Yeah. What I really liked was when you put up on the board all the different types of experience or types of physicians and providers that a patient might experience. So one who's very inclusive, one who maybe is egalitarian, middle of the road, doesn't really know what to do, doesn't bother them, and then anti-inclusive. Could you go over that and what that's about?

**Dr. Cheung:** Yeah. I never want to get in the business of labeling people.

**Elissa:** Right.

**Dr. Cheung:** It's kind of like in my anti-racist work, I always say, when you label something anti-racist, it means you will stop the conversation about that thing oftentimes, right?

**Elissa:** Yes.

**Dr. Cheung:** And so, you're really saying that there's no hope for whatever that thing is and that we should completely replace it, right. So, to say that someone is anti-inclusive, no person is anti-inclusive.

**Elissa:** Right.

**Dr. Cheung:** It's the behavior or the action of the things.

We've all done all of those things of being egalitarian, reflexive or anti-inclusive at various moments in time. But it's pointing out the moments that maybe, by rushing past asking pronoun preferences, that's anti-inclusive for some patients. Getting that feedback to the clinician is important then so that they don't accidentally do that to someone. It doesn't mean that they're an anti-inclusive clinician all of the time.

**Elissa:** Right.

**Dr. Cheung:** It's just that they need that little bit of feedback, and they can continue to work on it. We're all learning and we assume that we're all in this because we really care and we're all well-meaning, but let's make sure that we're well doing now as well.

**Elissa:** Yes. And that's what I really like about this conference as well is that you are educating healthcare professionals to do better for their patients, to listen to their patients, to ask those questions, to help the patient advocate for themselves, right?

**Dr. Roth:** Yeah. The partnership between the patient advocates, the providers, and the researchers, and having everyone in the same space is just really powerful, and it's not something that typically exists to this extent with this many people who are so passionate about improving outcomes for all people.

**Elissa:** Yes.

**Dr. Roth:** And I think traditionally, we've been proud of the progress we've made for many AYA's, but now we really have to make sure that we're making progress for all and meeting our patients where they are and where they want to be met.

**Elissa:** Yeah. And there's so many disparities within the young adult community, and then we're, of course, looking at LGBTQIA+ disparities and racial health disparities as well. And so, I think it's really important what you all talked about today and, again, really educating the healthcare providers to make it better for the patients at the end of the day.

**Dr. Cheung:** Right.

**Dr. Roth:** Yeah. I mean, we just appreciate the forum and the opportunity to connect and share and, personally, I appreciate the opportunity to learn from my colleague, Dr. Cheung and others. These are learning opportunities and we need more of them. And one of the challenges is the communication or lack of communication

and being in the same space at the same time and having the opportunity to hear directly from our patients. We need more of that and that needs to be the standard as opposed to the exception.

**Dr. Cheung:** Yeah. And I do have to say that, hopefully, folks saw that we modeled a little bit of a mini revolution on that stage. And it takes people with sort of a revolutionary mindset because we're not trained. It's not everyone's fault, we're not trained, and our systems are not designed for us to be inclusive. And so, I think like everyone does their little part and just pushes it a little bit further.

**Elissa:** Yes.

**Dr. Cheung:** And then we create this amazing impact.

**Elissa:** And I think it was great what you both did, bringing in that patient voice. I loved how they were there sharing their stories, and, Christabel, you, too, sharing your story and being able to ask that question and partner with the doctor. That was wonderful.

So. Final question today. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." One aspect of hope is empowerment to advocate for care as we know AYA patients can face unequal care and disparities before and after a cancer diagnosis. Based on your experience and research, what advice would you give to patients and caregivers to advocate for their own care?

**Dr. Cheung:** It's interesting. I think that we all do such a good job of telling other people what they should do, but then, when you think about like in your own life, when have you advocated for your own care? And when I think about even like for myself in survivorship, my own managing cardiotoxicity, recently, my cardiologist retweeted one of my tweets on Twitter, and then we had a little exchange. And he was just kind of like, so where are you on your follow-up, when was your last echo (EKG)?

**Elissa:** Uh oh.

**Dr. Cheung:** And I was like, uh oh! And then he very quickly made that appointment for me, and so why does it take that to do our own stuff? You know the answer, Dr. Roth.

**Dr. Roth:** I think it's partly on the providers to empower the patients to really make them know that we need them to advocate for themselves because in the current world that we live in, if they don't advocate for themselves, many fall through the cracks. And it's something we need to address, and it's something that we need to deal with together. But advocating for ourselves is hard at every level.

**Elissa:** It is.

**Dr. Roth:** But we need to change how we do things, so patients do feel empowered, and they feel like that is the norm as opposed to the exception as well. It's just so hard when many of us are a little bit hypocritical in our own personal lives.

**Nelson:** Yeah. I think specifically, I can speak about being Latino and, at least for me it's been, I should always be grateful about the fact that I got care. So to even ask for anything extra because it seems extra is to almost be ungrateful. And one of the things is if you feel pain, ask for pain medication. If it's greater pain, don't be afraid to ask for greater pain medication because a lot of the times, we think we have to just sit by and let it happen. And that also has to do with mental health. If you're not feeling okay, ask to be seen by a mental health specialist, and know that you know more about your body than anybody else can know, and allow yourself to be honest when you don't feel okay is very, very crucial because, ultimately, it's going to help for you to get access to the help right away. And it also lets your doctors and the people that are your support system to get to know just how you might react.

So, not being afraid of asking for more because we didn't choose to have cancer and we didn't choose to have to get care, so allowing yourself to ask I think is very important.

**Elissa:** And I think that it all goes back to a little bit of the theme of what you all were talking about today, was really just making the patient feel safe, right? Feel safe with the doctor. I think that really helps with self-advocacy as well to be able to share what's going on and continue to improve the care, improve their relationship with their doctor and treatment team.

**Dr. Roth:** Trust is important in every aspect. I mean, patients are coming to us and giving us the privilege of sort of entrusting us with their lives, and we need to respond in a way that allows them to trust us and partner with us to better their health, better their happiness. It's hard to come in, meet a stranger who you need their help and expect that right away you're going to bond and everything they say is going to be the right information, which is not always the case. But we've got to get better at partnering, at communicating, at really just being on the same team.

**Elissa:** Absolutely! Well, thank you all so much for joining us today. We really appreciate you, and I hope the rest of the conference goes well for you.

**Dr. Roth:** Thank you so much.

**Christabel:** Thank you, Elissa.

**Nelson:** Thank you.

**Brad Zebrack, PhD, MSW, MPH:** I'm Brad Zebrack. I'm a Professor of Social Work at the University of Michigan. I'm also a 35-plus-year survivor of Hodgkin's Lymphoma. I was diagnosed at the age of 25 years old.

**Elissa:** That is wonderful, such a long time to be surviving and thriving.

**Dr. Zebrack:** Oh, yeah, for sure.



**Elissa:** That's great. So what was the name of your session, and why is this subject important for the care of AYA's with cancer?

**Dr. Zebrack:** So, the session was called "Mental Health and AYA's: Cancer's Impact on Life and Life's Impact on Cancer." And what we were really trying to say in our session was that it's not only important for clinicians and care providers to take into account how young people are being affected by cancer and the treatment and how it's impacting on their life, but to also consider that young people have had a life before they were diagnosed with cancer. And for all the good or the challenging things that might have been happening in their lives before their diagnosis, those things are relevant, those things are significant, and are going to carry over into the cancer experience and their ability to cope and deal with those challenges. And I would hope that our healthcare providers, and our researchers, and our cancer center programs really take that into account.

**Elissa:** Yeah, yeah. Any other highlights of your presentation that you'd like to share with our patients and caregivers?

**Dr. Zebrack:** Sure. What I was really trying to emphasize in that presentation is that the world is a very different place today than it was 10 years ago, 20 years ago, you know, even 30 years ago for some of the older folks, who have been in medicine and have been working in healthcare for a really long time. And we have to remember that young people today are living in kind of a rather unstable world.

**Elissa:** Yes.

**Dr. Zebrack:** And that expectations for the young people are different. In my early years, my goal was, I wanted to be this career or that career, and the expectation was I could get in a job and that's the one you want to carry through, hopefully for the rest of your life.

**Elissa:** You're in there forever.



**Dr. Zebrack:** Until you retire, right? But, today, we know that young people on average are going to have five different jobs in their lifetime as an adult.

**Elissa:** Yeah. And that almost sounds low.

**Dr. Zebrack:** That's the average.

**Elissa:** Yeah.

**Dr. Zebrack:** So you know that some of them are carrying two or three jobs at the same time.

**Elissa:** Yes.

**Dr. Zebrack:** Cost of living is expensive, living in these cities with high rents or the ability to buy a house. Again, back in the 1950s, 60s, buying a house was the American dream. And now, I think a lot of young people just don't see that as a real possibility in their life. And that could be contributing to mental health challenges.

Hopefully, you're all not watching a lot of news on TV because watching the news on TV can be really distressing. We know that constant exposure to social media is not good for our mental health. Obviously, there's the FOMO (Fear Of Missing Out) that young people experience.

**Elissa:** Yes!

**Dr. Zebrack:** That's kind of normal. But then I think it's gone beyond that.

**Elissa:** Yeah. And then when you're going through cancer, you're also seeing everybody else around you just go on with their lives. They get married, have children, go on vacations, when you are stuck.

**Dr. Zebrack:** Exactly. And I think that can be really disappointing and frustrating, saddening, depressing for young people. And what I would just say is that, as challenging as that is, it's normal. I want to affirm for young people that cancer sucks.

**Elissa:** Yes.

**Dr. Zebrack:** I will always remember when I was going through my therapy and talking with my girlfriend at the time, who's now my wife of 30-plus years. We would often talk about positive attitude.

**Elissa:** Yes.

**Dr. Zebrack:** And it's like, yeah, I want to have a positive attitude, but for a while I felt there was this unfair expectation that, oh, I have to always remain positive. And there were some days that just really suck, you know?

**Elissa:** Yes.

**Dr. Zebrack:** Emotionally or physically. And I remember my wife saying to me, you know what, positive attitude doesn't mean being happy all the time. Positive attitude means just being okay with where you are on any given day.

**Elissa:** Yes.

**Dr. Zebrack:** And just getting to a point of being okay with whatever I'm able to do in that day. And that was really helpful, especially in those days when I would come back from my chemotherapy. And I remember, I would just want to crawl into bed and pull the covers over my head, and not want to do anything, I'd feel sick for a day or two.

**Elissa:** Yeah.

**Dr. Zebrack:** And then I would start, in my head spinning about, "I can't do any of the things I used to do". I loved to go hiking and bicycling, I was a big outdoors

person; still am. I had to kind of do this reframe in my head around, "Well what can I do today? And I remember, usually, it was the day after chemotherapy, all I could really do is reach out from my bed and turn on the radio and just shift the radio dial back and forth and back and forth during the day.

**Elissa:** Yeah.

**Dr. Zebrack:** And maybe, by the second day I'd feel a little bit better, and I would get out of bed, and I'd walk down to the refrigerator, and I'd get something to eat. And rather than see those things as like, "Oh, I can't be out there running three miles and being fit.

**Elissa:** Right.

**Dr. Zebrack:** But I can walk down to the refrigerator today, and that's my success for today."

**Elissa:** Yes.

**Dr. Zebrack:** And maybe tomorrow...

**Elissa:** A small victory.

**Dr. Zebrack:** Exactly. And, it's really important to not discredit those things.

**Elissa:** Yeah.

**Dr. Zebrack:** And really take them into account and see them as little victories that can eventually add up over time.

**Elissa:** Yeah. And even just those small goals for the day. I remember when I was going through my leukemia treatment, my only goals were to walk downstairs and cook for myself. That is all that I wanted to do.

**Dr. Zebrack:** Yeah, uh huh.

**Elissa:** And, and if I was successful at just doing that, I felt good, and it was a small victory.

**Dr. Zebrack:** Yeah, it's really, it's really important, yeah.

**Elissa:** Yeah. What other issues are affecting young adults today that could affect their mental health while they're going through cancer?

**Dr. Zebrack:** I think one of the big challenges that young people have today, whether they have cancer or not, is the disconnection and social isolation that so many of them are describing.

**Elissa:** Yes.

**Dr. Zebrack:** There was a report that came out just a couple of weeks ago from the Surgeon General of the United States who said that the biggest threat to the mental health of our country, not just young people but all people, is social isolation.

**Elissa:** Yes, especially after Covid.

**Dr. Zebrack:** It's Covid and it's also actually related to social media. It's that we've disconnected ourselves from one another, and we actually bear that disconnection within our bodies, it accumulates. And what I really appreciate about the Surgeon General was that he also came up with a remedy, and he said the remedy is connection.

**Elissa:** Yes.

**Dr. Zebrack:** We need to make efforts to build connection, real physical connections to the extent possible, in our families, in our communities, and in our society. A lot has been taken away from communities.

**Elissa:** Yes.

**Dr. Zebrack:** When I was growing up, I'd come home from school, go to the public parks. The parks had after school programs from sports to writing, to dance, all sorts of things for kids to do. Those things don't exist anymore.

**Elissa:** Yeah.

**Dr. Zebrack:** City budgets have been cut. There's talk about how the wealth in this country has been concentrated amongst a very small proportion of people.

**Elissa:** Yes.

**Dr. Zebrack:** And what's significant about that is that there's so much money concentrated amongst a few number of people, that means less money for everybody else.

**Elissa:** Yeah.

**Dr. Zebrack:** Less money for programs, less money for services. So what are young people to do when they come home from school and there's nothing happening in their community? They're thinking, "Well, I'll just connect with my friend, or I'll do my homework, or..." And they don't actually realize what they're missing or what they could have.

And I think this is where we all need to advocate for changes in our communities to say, "Hey, we have the right and we deserve opportunities in our community that allow us to connect with one another."

And I hope that our leaders and our policymakers can move to that place of starting to redistribute resources so that all people can benefit. And young people benefiting, young people with cancer will benefit because it will get us to that point of having more connection.

**Elissa:** Yes. And I think we see that a lot in the AYA community. There is such a need for connection. We have a lot of nonprofits stepping up and survivorship



programs at hospitals, and really providing those opportunities for connecting with other cancer patients.

**Dr. Zebrack:** Sure, yeah.

**Elissa:** There is such a need to get people together and to find other people who understand what they're going through.

**Dr. Zebrack:** Exactly. Those types of programs are so important. Two of the programs I really appreciate are First Descents and True North Treks, that take young cancer survivors out on river kayaking trips, white water rafting trips, surfing trips, rock climbing trips.

**Elissa:** Yes.

**Dr. Zebrack:** That challenge young people to get back into their bodies again. And when young people participate in those programs, afterwards what they say is, "I never even imagined how impactful this program can be. I never realized how important it could be to me to connect with other young survivors.

**Elissa:** Yes.

**Dr. Zebrack:** Who are going through the same things that I've been going through. And I know it takes a risk, it takes a lot of courage.

**Elissa:** Yes, put yourself out there.

**Dr. Zebrack:** To put yourself out there.

**Elissa:** Yeah.

**Dr. Zebrack:** I would just encourage young survivors to just take that step, say yes. Say yes to the world.

**Elissa:** Yeah.

**Dr. Zebrack:** Because when you do that, the benefits are just really tremendous.

**Elissa:** Yes. I always tell people that the research and my treatment team, of course, saved my life, but connecting with the young adult community saved my soul.

**Dr. Zebrack:** Oh, that's beautiful.

**Elissa:** Went to Cancer-Con and met so many young adult survivors, met so many blood cancer survivors.

**Dr. Zebrack:** Yes.

**Elissa:** And it was just incredible. It felt like they could understand me with very few words. And that is what I needed at that time in my life and now, still, seven years out where I need to have people that understand, and that helps me with my mental health as well.

**Dr. Zebrack:** Yeah.

**Elissa:** That I have people to reach out to when things are not going well.

**Dr. Zebrack:** Exactly. Yeah. What I really appreciate about a lot of these programs that are for adolescents and young adults with cancer is that they've been developed by AYA survivors themselves.

**Elissa:** Yes.

**Dr. Zebrack:** So they get it.

**Elissa:** Yeah.

**Dr. Zebrack:** And they develop programs. What I loved about Stupid Cancer ever since it's initiation was they got it. This idea of social meetups. It's like young people don't really want to go to a cancer support group.



**Elissa:** Yes.

**Dr. Zebrack:** Oftentimes, the last thing they want to do is to do more of something that has to do with cancer. And while these programs, like Stupid Cancer, have the word “cancer” in them, what they’re really about is just connection.

**Elissa:** Yes, just connection, yes.

**Dr. Zebrack:** Yeah.

**Elissa:** And for our listeners, we will have links for all of these different programs in the show notes for you to take a look and find that connection.

So, our final question for you today, on our patient podcast home page we have a quote that says, “After diagnosis comes hope.” One aspect of hope is empowerment to advocate for care. So, based on your professional experience and research, what advice would you give to patients and caregivers to advocate for their mental health care?

**Dr. Zebrack:** I would first want them to affirm for themselves that how I’m feeling today is valid. And, if they’re struggling with feelings of sadness, depression or anxiety, to mention it to their doctor. Sometimes the doctors ask, sometimes they don’t.

**Elissa:** Yes.

**Dr. Zebrack:** But what you’re feeling is important, and to bring it up with the doctor. If you don’t get an adequate response from the doctor, ask the doctor to refer you to a mental health provider. And be persistent.

**Elissa:** And this can be any time after diagnosis, right?

**Dr. Zebrack:** It certainly could be. Other issues too. Whatever you’re wondering about, sex for example, sex is often on the minds of young people.

**Elissa:** Yeah,

**Dr. Zebrack:** Can I, do it? If I have sex with my partner, are they gonna get hurt, am I somehow in danger?

**Elissa:** Am I contagious?

**Dr. Zebrack:** Yeah. Or I'm not feeling it and I'm worried about that. That's a valid concern.

**Elissa:** Yes.

**Dr. Zebrack:** And to bring it up with the doctors. Knowing, and I'm sure you'll be aware, doctors are going to kind of feel uncomfortable about it, so oftentimes they don't ask about it.

But what we're trying to coach doctors to do now is to be prepared for the patients who bring it up. And if it's something that they're not comfortable with, again, refer them to a specialist in their area. Challenges in work, mention it. Cognition, unclear thinking. There's no reason why a cancer patient or a cancer survivor should sit back and suffer. Mention it to the healthcare provider and be persistent.

**Elissa:** Yeah

**Dr. Zebrack:** Say I need help with this, I need help with this.

**Elissa:** Absolutely! That is wonderful advice. Well thank you so much, Dr. Zebrack, for joining us today. We really appreciate you. I know that you are huge in the AYA field.

**Dr. Zebrack:** Ah, it's a pleasure.

**Elissa:** So, yes, we so appreciate you joining us today and sharing all about mental health in cancer care.

**Dr. Zebrack:** You're welcome.

**Elissa:** We are in our very last day of this incredible conference. I did notice while I was here that there are several young adult patients and survivors that have attended. So, we wanted to know what they have learned from the conference. What are they taking away from a survivorship perspective?

So, let's go chat with a few.

**Alfonso:** My name is Alfonso, and I am an acute lymphoblastic leukemia (ALL) T cell survivor. Being here and see people from truly all over the world, from India to New Zealand, to here in the States, has been really astonishing and sincere to be able to share all this information. All these studies that are going on in AYA care from as early as diagnosis to after treatment, after care, years beyond treatment, has been really nice to see that more people care about this kind of work.

Just the amount of dedication that people have put their time and money in and investing in AYA care because, like everyone has been saying, it's not something that is really paid attention to. It's mostly pediatrics and geriatric care with cancer. But AYA's exist and there's a growing number of survivors and advocates that are here at this conference and all over the world that want to help and collaborate with providers, hospitals, institutions, organizations and nonprofits to spread awareness and actually build a space for us to be cared for properly.

**Tanya:** So, I'm Tanya, I'm from London, with Teenage Cancer Trust. I was diagnosed with Hodgkin Lymphoma when I was 20. I'm 24 now. Two years into remission. And, yeah, this Global Congress has been really incredible. I feel like cancer can be quite a dehumanizing experience sometimes. You sometimes feel like you're a bit of a statistic. And so, it's been really encouraging and nice to see young people and their experiences, myself included, at the front and center, and actually being able to feed into best practices on a global scale. I've really enjoyed it.



**Nancy:** Hi, my name is Nancy, and I'm a breast cancer AYA survivor. During this conference what I've learned is the community of AYA is so close together in reaching the same goals. And it's beautiful to see everyone coming together.

As a survivor coming into this conference, I wished I knew all the references and outreach programs that are there for AYA's. What I'm taking away from this conference is all the resources that are out there for this particular population. I am going to be taking all these pamphlets for work to share it with our AYAs.

**Mallory:** My name's Mallory. I'm a two-time Hodgkin Lymphoma survivor diagnosed in 2011 and then again in 2021.

Some of the takeaways that I've come out with are that patient voice is so important and it is so required in research, not only from the data side of things and the learnings that happen when we do research studies where we elevate a patient voice, but also from the very get go when we think about the way that we're designing research studies, the way that we're designing hospital and clinical programs in a survivorship clinic or on an infusion floor, and sort of everything in between.

And so, I think moving forward, hearing more from patients, elevating patient voices is just such an important thing. And patients should be loud and proud with their perspective and their voice because it's absolutely crucial.

**Elissa:** Wow, what an incredible conference. It seems the biggest takeaway from patients and survivors who attended the Global AYA Cancer Congress was that they appreciated the patient voice was being heard by healthcare providers. I hope that all patients, survivors, and caregivers listening today will feel empowered to advocate for your or loved one's care and open that communication with your healthcare team regarding all aspects of cancer from resilience and healthcare disparities to mental health. Always remember that you are your own best advocate and LLS is here to help. Thank you to everyone for joining us at the Fifth Annual Global Adolescent and



Young Adult Cancer Congress. Stay tuned for more resources that LLS has for you or your loved ones who have been affected by cancer.

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.

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In addition to the lounge, we could use your feedback 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](http://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. However, if you would like to contact LLS staff, please email [TheBloodline@LLS.org](mailto:TheBloodline@LLS.org).

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](http://LLS.org/PatientSupport).

You can find more information on programs for young adults at [LLS.org/YoungAdults](http://LLS.org/YoungAdults). All of these links will be found in the Show Notes or at [TheBloodline.org](http://TheBloodline.org).



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