LEUKEMIA & LYMPHOMA SOCIETY® is now

Blood Cancer United

The Bloodline with Blood Cancer United Podcast

A podcast for patients and caregivers

Episode: 'Making Your Voice Count: The Power of Patient Advocacy'

Description:

Behind every policy is a patient, caregiver, or family whose story helped make change possible.

In this episode, we speak with Andrea Sanchez and Becki Chandler, volunteer advocates with Blood Cancer United, about the power of patient voices in shaping public policy. Drawing from their own family experiences with blood cancer, they discuss issues ranging from medical debt and insurance coverage to clinical trial access and research funding and explain how patients and caregivers can make their voices heard.

Learn why sharing your story matters and how personal experiences help lawmakers see that patients are more than numbers on a page. Behind every statistic is a real person, a unique story, and a family impacted by blood cancer.

Transcript:

Elissa: Welcome to *The Bloodline* with Blood Cancer United. I'm Elissa. Thank you so much for joining us on this episode. Today, we are speaking to Andrea Sanchez and Becki Chandler, two volunteer advocates with Blood Cancer United. Andrea is an incoming Master of Social Work student at Portland State University and serves as Oregon's first grassroots advocacy leader for Blood Cancer United.

Becki is the Blood Cancer United advocacy leader and patient and community outreach liaison for Washington State. In addition to volunteer work with Blood Cancer United, she also is involved in committee work with Fred Hutch Cancer Center's Office of Community Outreach and Engagement, the Cancer Action Coalition, and the Cancer Control Plan of Washington State. In their volunteer advocacy work, Andrea and Becki work with patients, caregivers, healthcare providers, and elected officials to improve access to care and reduce barriers faced by individuals living with blood cancer. Welcome, Andrea and Becki.

Andrea Sanchez: Thank you so much for having us.

Becki Chandler: Thank you. It's great to be here.

Elissa: Well, thank you for being here with us today. So, our episode is on volunteer advocacy and how public policy affects blood cancer patients and their families. To start us off, both of you have personal connections to blood cancer. Would you share those and also share why you decided to volunteer with Blood Cancer United?

Andrea: So, my mom was diagnosed with multiple myeloma in 2014, and she was a registered nurse, and her whole ethos with how she went about everything was to help other people. Even when she was sick and diagnosed, she was like, "Okay. I'm gonna take notes, and I'm gonna see how I can help someone else who's gonna come up behind me."

And she started to mobilize for an autologous stem cell transplant, which at the time was the standard of care for first line for her type of myeloma. She was going through the process, and her transplant was originally pre-approved. And then right when they were coming down to the final details and she was getting ready to be admitted to the hospital, her insurance company kicked it back and said, "It's not medically necessary."

Elissa: Oh, no.

Andrea: Which is infuriating. Like, what do you mean it's not medically necessary? This is the treatment my doctor has said is the best shot for me, and she'd had a second opinion at a doctor in New York who agreed and said, "This is what you need to do." And so, my mom being a nurse, she kinda knew where to flex and press and try to move forward, and so she just said, "No it's just the beginning conversation, and it's gonna happen. So sorry, here's what we're gonna do."

So, watching her go through this, I remember talking to a friend whose dad was involved in his state's government and said, "You know, you can always reach out to your elected official if you can't get anywhere with your insurance company." I thought, "Oh, I didn't know that was a thing, but thanks." Luckily, my mom was able to get the approval. She had her transplant, and I didn't think much, again, about talking to an elected official about needing to get an insurance approval.

And then, when she was going through maintenance chemo and things after her transplant, I became familiar with how communal the whole chemo and cancer lab experience really is, and getting to know people and hearing their stories and talking to them and understanding that no two people are diagnosed with the same cancer have the same experience. And it was just maddening.

My mom's "no" answer to her treatment wasn't uncommon, and I became familiar with Office of Public Policy with Blood Cancer United, who was The Leukemia & Lymphoma Society at the time, and I started being a digital advocate. It sort of grew from there and bloomed into what it is now.

Elissa: Becki, what about you?

Becki: So, my mom was diagnosed with Waldenstrom's macroglobulinemia in 1989. At that time, you know, it's still hard to talk about cancer, but it was something that wasn't talked about. She didn't wanna share it with people, so it was really difficult. It was a challenge. And my mom was also an RN, so she wanted to take care of other people and didn't want the focus to be on herself.

She was fortunate. She had a chronic illness that was dealt with fairly conservatively. She was on oral chemo for 10 years and then went on Rituxan®, which The Leukemia & Lymphoma Society, now Blood Cancer United, was instrumental on helping get to patients. And her journey was up and down. I could see things that were going on with

her and with other people when I'd go to her appointments with her, and it was challenging.

Medications were hard. There were times where there were things that may not have been available to her or to other patients, and doctors were having to make decisions on whether or not she was gonna get it or another patient was gonna get it. She was on IVIG for 30 years every month, and it was what was helping keep her alive in addition to the other medications that she had been on.

So, I got involved with the organization. Originally, I was helping out with events and fundraising, and I just really wanted to do more. My mom was out there advocating for people in our community and talking with government officials about different things, and it was kind of a learned experience for me. And so, it was something that I knew that change needed to happen, and this was one of the ways to do it.

Elissa: Yeah, I can see with both of you just having those caregiver roles has given you that inside look at what happens with blood cancer patients and dealing with insurance and dealing with all of those things that come with navigating a diagnosis, and I can see how that drew you to advocacy work.

Andrea: Well, it sounds cliché to say, but it's so incredibly spot on that when somebody in your family is diagnosed with cancer, everybody's receiving that same diagnosis. And, obviously, you may not be the one that's physically going through the

treatment or the care, but it affects every part of your life. And I can honestly say that it changed the trajectory of my life in many different ways.

I mean, ultimately, my mom passed away in 2017, and it made me rethink how I want to live my life in service to others and also in her memory because I know that, if things had gone differently, she would've been doing this. I mean, this would've been her sitting next to me doing these things, and we would've gone together to do this. And she can't, so I will, and that's kind of how it's transformed the way I look at things. And Becki, I'm sure you've had a similar brush with that too.

Becki: Yeah. My mom passed away two years ago in 2024. She was actually diagnosed with a second cancer, with pancreatic cancer, and it was hard to have a second diagnosis. It was a whole different type of cancer. We dealt with different things but, you know, you go on this journey for 35 years of living with a chronic illness and, we owe it to her doctors and the people out there who are doing research and making all these things happen for these patients.

And it's just a huge blow. And it's so hard to watch someone go through all of this. And it was a year that she was diagnosed and then passed away.

Elissa: Yeah. Now, both of you are the advocacy leaders for your respective states. And then Becki, you also volunteer as a community outreach liaison for Washington State. Could you tell us what those roles entail?

Becki: So, as much as I can be, I am out in the community patient-facing, so I will try and get to events and programs that other organizations are hosting and have conversations with patients about what they're going through, how they need support, how I can get them resources through Blood Cancer United.

And a lot of times, we'll talk about really personal things. They'll talk about not knowing how to talk to their doctors, what questions they can ask. I love doing it. I love being part of this because I feel like I'm able to give back. I learn something from them. They learn something from me, and I'm so invested in the work that this organization is doing.

I think it's just absolutely amazing how far they've come with supporting research, supporting patients one on one, helping them through financial issues. I mean, it's making a really huge impact, and I just want everyone to know about it.

Andrea: So similar to Becki, in the state of Oregon, I try to be out in the community to do liaison work as well with outreach. You can't advocate on behalf of patients and families if you don't really know what's going on in your community, and so I think it's vital to get out there and to talk to people. And I love talking to people anyways. I think that's just a real joy of this volunteering effort is to get to know all these different folks that I otherwise most likely wouldn't have crossed paths with.

I think it's a horrible group to be a part of in the sense that nobody wants to be touched by blood cancer, but it's a blessing to get to know and an honor to walk this road with so many of these amazing people. And I feel like, it sounds weird to say, but it's maybe the one good thing that came out of my mom's cancer diagnosis is that we met these amazing people, and we still have connections with these amazing people. And the work that we've done since then has been really transformative and vital.

But like what Becki was saying, you go out into the community. You meet people, and then you introduce to them the different ways they can get involved. And some folks want to take part in the different tabling events through community outreach, but some folks also are angry at the way that they've been a victim of the system, and they don't want that anymore, and they don't want that for someone else.

And so, I always like to share with folks that, if you wanna get involved in advocacy, there's a lid for every pot, and you can get involved in different ways. If you don't have a ton of time. You can be a digital advocate. If you have a little bit more time to give, you can leverage that. If you have a skill that you're not using right now, like say you love to write, you can write op-eds or letters to the editor based on different issues.

And if you're like me and you have no problem just sitting in a room and talking to people, then hey, come with me to a legislative meeting, and we'll chat it up and we'll give some context and color to the issues that are going on so that you're not just a statistic. You're a person, and you can be represented appropriately.

Becki: I think it's so important too that we give people an opportunity to have a voice because having cancer can be such a lonely thing. And it's something that you have no control over. You know, you go to the doctor, and you're relying on medical professionals to do things to you. It's really hard for people to have to make split decisions on their healthcare, on what needs to be done to them.

And they just have to go with what someone's telling them. So it gives people an opportunity to use their voice and to express what they're going through and feel that they're advocating for themselves and others through the journey.

Andrea: It kinda gives the power back, right?

Becki: Yeah.

Andrea: Because so much of your cancer journey, you're at the will of somebody else and somebody else's plan for you. And even sometimes when you're a patient at larger academic institutions, you're literally a statistic and a number. And sometimes the doctors that are on the academic side of things tend to forget that there's a human component to that.

And I remember that was something that my mom had mentioned, like, "Hey, I'm in the healthcare profession, I know what's going on. I have a better understanding than your average patient, and you can talk to me like a person. You don't have to speak to me

like I am case number X, Y, Z." A lot of that gets stripped away from you when you're going through treatment.

So to your point, Becki, it's giving that power back and giving you an opportunity to speak for yourself and for other people and to have some control over a control-less environment.

Becki: And also, on the flip side of that I finally got to the point where, you start realizing the people who are in front of you are people too, and they have their own personal experiences even though they're a doctor. And towards the end with my mom's second diagnosis, she was in the hospital a lot and hospitalists were rotating in and out very frequently. And, if you're in the hospital for five weeks, you're having to retell the story. You're having to advocate for the things that you've already advocated for.

But, I've had to put in my mind that we're all here to work together as a team to try and get through all of these hard times. And if you think about it in a different way, not that they're to tell you what to do, but you are there to work with them and provide them information, hopefully that, the advocacy part of it will come naturally at some point to help you get through it.

Elissa: Yeah. And I love what both of you have said, that you're really wanting to get into the community and listen to other people's experiences. Because, while you've

seen your mothers go through their own experiences, there's a whole wide range that patients can end up going through, and their families can end up going through. And it's great to hear those experiences, so you know what you're going to fight for, right? You know that you're going to the legislators, and this is what I need to fight for. This is what is important to all of these patients. And there's also power in numbers, as well, so that you aren't just that number on a spreadsheet. You aren't a case number. You're a person with a story and a unique story. Even though a lot of ours kind of match up a little bit, it is still a unique story to you. And it's great to be able to listen and to also get that out. Now, could you tell us how advocacy works on a state and federal level, and what you're doing in that role?

Andrea: Yeah. Beck. So, essentially, we work with staff partners at Blood Cancer United, and we have a dedicated regional staff team at the state and federal level. And they direct us on what our legislative priorities for our region, for our state, and federally. And we are then charged with the opportunity to provide patient stories and to provide support to help move the legislation along.

So, staff are doing the lobbying work and the legislative work behind the scenes, and then we come in with the grassroots piece from the community with patient stories and testimonials. And we provide a voice to give color to why this particular piece of legislation is important and why it needs to be in front of our legislators and why they should care.

And that can look like different things. It can look like legislative meetings. It can look like participating in town hall events. It's also getting involved with local media or even federal media as needed, for press conferences, letters to the editor, interviews, things like that. It's testifying in front of the state legislature if there's a particular piece of state legislation that we're in support of, and then also having legislative meetings on the state level.

So it looks different for different pieces of legislation, but the core is the same, where we come together with our repository of stories. We provide patients with opportunities to tell their story and to talk if it resonates with a particular priority.

Becki: And each state is different. So for instance, maybe, throughout the organization, we're talking about medical debt, and that's a huge issue with patients. But particularly in Washington State this past year, we worked on a bill that would reduce the interest on a patient's medical bills, because currently, right now, Washington State is at 9% of interest on medical bills.

And so, it's not fair to a cancer patient or any patient who didn't ask to get cancer, and they have no control over it. They have to stop working, and they're going to the doctor. And they have all these medical bills, and they can't pay for them upfront. We sometimes will save for a vacation or a new car, but whoever thinks about saving for cancer? So it's different in each state, but Washington State this past year, that's what we were working on.

Andrea: Yeah. And then last year in Oregon, similar to that, because medical debt, like you said, has been a priority, we worked on protecting patients from predatory medical debt collection. So basically, the legislation that we worked on made it so that medical debt wouldn't appear on credit reporting, and it could not be a reason why you'd be denied a loan for a car or for housing, things like that.

I mean, you still have to pay your medical debt back. It didn't erase it, but it made it so that it can't preclude you from living your life and having opportunity. Because if you are a cancer patient or having a chronic illness, you need a car. You need transportation. You need housing, and the last thing you should be worried about is, like, "Okay, well, I have this huge hospital bill that I haven't paid, and now it's gonna keep me from having a roof over my head." Like, no. So, that was one way that we worked at the state level last year.

Elissa: And for our patients listening about medical debt, we do have a medical debt case management program. We are going to share a little bit more about that right now, and we'll be right back.

So, one of the things I want to point out was how you mentioned testifying in front of our legislators. And one of the things that actually came out of Oregon that then transferred to other states and nationwide was oral parity laws. And that came from the development of Gleevec® for chronic myeloid leukemia, where you had an oral pill

to take rather than a chemo infusion. And that was huge to be able to get insurance companies to pay for that.

And that was first approved in Oregon, the oral parity laws, and then it just moved on to other states. And so, that was just a huge part of advocacy and public policy that we really got involved in, and that worked and then passed on. So, I did want to point that out. So, I'm sure some listeners today are wondering, how does this affect me? Why is public policy important for blood cancer patients and their loved ones?

Andrea: Ooh, I don't know if we just have enough time for all of that. Public policy is vital for anybody that's ever had to leverage any sort of government agency from insurance onward. But it affects everything from the development of the drugs that you use to how you can pay for your drugs and how you can access them. You know, it's interesting to me how the system truly works. And without having the policy backbone for the research, you don't get the drugs.

And similar to what Becki was saying, Blood Cancer United was instrumental in some drugs for Becki's mom's case, same with my mom. You know, in myeloma, I think it was two or three drugs were released at the time when she was going through her refractory disease, and she was able to benefit from those. And they wouldn't have been possible without policy work to make the research happen.

And with that, we had a couple of extra good years with my mom where she was able to make memories, and we had good time because of it. On top of that, having access.

If you don't have access to the treatments that are available because of the research, then what good is the research? So, policy helps guide you in a direction to get the access to the drugs.

Unfortunately, our system is set up such that you need to have policy to be on board with your treatment plan as well as your oncology team.

Becki: I was gonna mention too that Washington State, speaking of access for instance, clinical trials, a big thing is, making sure that everyone has access, and that there's diversity in clinical trials. So, making sure that, everyone from every background has access to the clinical trials and that researchers are able to do the research that they need to do based on everyone, not just one population because, obviously, everyone's affected by cancer.

Elissa: And that has to do also with more rural populations. We want patients from all over the place to be able to have access to these clinical trials, right?

Becki: Yeah, that's another issue that we see too is, people need to travel from one place to another for specialty services. And so, we see it a lot here, for instance, in Washington State where, maybe there's a child that needs to get to Seattle Children's to have a clinical trial there or see a specialized physician, and they're traveling from another state.

And so, that means the family moves from maybe Hawaii and comes here, and they need housing, and they need all of the amenities that one would have back at home, but they're also still paying for all those things, you know, their rent or their mortgage back at home.

So, moving from state to state has been a challenging thing. Which, since I'm talking about pediatrics and state to state, we also worked on something for the past four or five years I think, the AKACA, a federal bill that we worked on, which is the Accelerating Kids' Access to Care Act passed this past year with flying colors and it allows a child who's on Medicaid to go from one state to another, and it reduces the red tape and the barriers that were there previously because Medicaid is run by each independent state. So, it's in the works. It's not fully in the works yet, but it's in the works. So,we'll be seeing children being able to get from one state to another for care to have immediate care and, not have to wait for a month, which there's no time to wait.

Andrea: You know, Elissa, I think you said something really important too that having rural populations. I mean, both Oregon and Washington have a considerable rural population. And I know Becki's probably the same in Washington. But in Oregon, if you have a complicated medical situation, be it cancer or something else, you need to get to Portland because OHSU is where they do a lot of the treatments and therapies and things.

Rural hospitals aren't supporting a lot of these treatments, and so that's not necessarily feasible or tenable for people to be able to take off work and drive a couple hours to get into the city for just a blood test or routine imaging if you're part of a clinical trial. And so, making these tests and treatments available as part of a satellite facility or a smaller community hospital if it's available, it makes it so that people can afford to be part of these clinical trials where the maintenance phase can happen at home.

And maybe they're just traveling for their infusions or different things, and it cuts down some of that burden because a lot of people don't even consider a clinical trial if they don't live near a center of excellence. And, again, what good is the treatment or the research if people can't benefit from it? And so, I think it's huge that that's something we've been able to work on and get exposure to. And then Washington passed it and that's amazing.

Elissa: Yes. And for rural communities I think some rural community oncology clinics are building up and we actually just interviewed one in Southeastern Washington because they're about a four-hour drive away from Seattle or Portland. And so, we wanted to hear how patients can do clinical trials there, and they can do the bulk of their treatment in the community setting back at home without having to travel.

It makes me think of a situation that happened when federal legislators were talking about telehealth and removing those telehealth benefits. And I remember hearing a

story of somebody in, I think, Eastern Oregon, and she said, listen, I live hours away from any doctor at all, and I have to actually drive and go and spend the night to be able to see a physician in person. There are no doctors who can see me anywhere close to my area.

And I remember our senator talking about that and bringing up that story, and he said, "Hey, here is an example right here of why we need telehealth, why patients need to be able to get some level of care through telemedicine."

Andrea: It's huge. I mean, it's a game changer. I know when my mom was going through treatment, obviously, it was before the pandemic and before telehealth was more of a commonly used availability. And there was a hospital in Seaside, Oregon that my mom's oncologist also was a treating physician at. He lives in Portland. For those who don't know, that's about an hour-and-a-half, two-hour drive from the Portland metro area.

So, what he would do is he had in-person clinic hours on Mondays or something, and then he would serve telehealth the rest of the week and see patients remotely that way. And I remember thinking, "Wow, that's a game changer for people," because you're able to access the care of a larger city hospital without having to leave your neighborhood.

And it's not always feasible for patients to be able to get you know, maybe your transportation isn't reliable or for lots of other reasons. Maybe your blood counts aren't supportive for you to be able to travel that far, you know? Maybe there's lots of reasons why you can't get there, so telehealth is just absolutely vital.

Elissa: Now, both of you have mentioned about sharing stories of patients. And you talked about potentially bringing them in and sharing their story with our legislators, either on the state or the federal level. What is the benefit of patients and their loved ones sharing those stories or writing letters or emails or texts? Does it really make any impact?

Becki: Absolutely. A lot of the times when we talk to legislators, they are unfamiliar with some of the things that we're telling them. I think that, oftentimes people just think that, oh, you go to the doctor. You have health insurance, things get paid for, and, these are the basic steps, and then that's what happens.

But there's so many loopholes that people are unaware of, and it is important for people to share with them what's actually happening to them because there's just no other way that they would know unless they've experienced it themselves. And we all experience cancer in different ways, and it's shocking just hearing other patients of things that they've been through that, would be different than maybe my experience, my mom's experience, Andrea's mom's experience.

It's a big puzzle. It's figuring out how to make these things work to benefit patients and caregivers. And, we're putting in the time and money for all of this support, and it should be working in a way to support communities and, people, and so there's just no other way of going about it.

Andrea: I had a staff person in a legislative office tell me one time early in my experience with advocacy, "I'm familiar with the legislation. I read these bills. I look at all of the things," she said, "but what makes it different is that, when somebody comes in here and tells me directly how it's affecting them and how it's gonna impact their livelihood and their families, it changes the text a little bit." It goes from just being this nebulous bill of ethereal things, like what could happen or what should happen or what will happen, to, hey, if I do this, this is how it's gonna impact, you know, Sally, who just told me her life story and how they've had to deplete their life savings in the first six months of their treatment. Or, they had to give up their work, and now they can't afford to pay for their mortgage or their food, or they can't help pay for their cost of childcare because, their treatment is so expensive.

That changes how you're gonna look at that legislation. It changes how you're going to interpret that data and take that back to their boss or their elected official. And they're gonna use that, and they're gonna remember that. And I've had meetings where a staff person or even the legislator has said, "This is really impactful, and I'm

really glad you shared this because it changed how I looked at the piece itself, the information." And that's why it's so important.

And I've had people ask me, "Well, I live in a state where my representatives are largely in support of everything that you're asking for. Like, why would I still write a letter? Why would I still call?" The truth is, is that it's still vital because the offices have to log every single person that calls them, that sends a piece of written mail, that sends an email, and they have to log why they contacted the office and what they are asking.

And if you can take that data and extrapolate, like, "Oh, X percent of my population of my state wants this," then it's important, and I need to make sure that it's a priority. And I'm gonna talk about it even though it should be a no-brainer that I'm supportive of it. And that's why it's important. So, it could be a really vital issue, and your elected official could already be in support of it.

But, if you don't take the extra step to provide that data piece for them, then it just becomes anecdotal. Then they're going back, and they're saying, "Well, I hear it from my constituents." Okay. How many people are telling you this? Who's saying it? What's the percent? And then they can come back and say, "I got 20% of my constituency that called in support of this thing. This is why it's important, and this is why we need to look at it." So it matters.

Becki: And it's also important to know that we're working with both sides of the aisle, too. No one is immune to cancer, and so it's important that we're getting this information to both sides. And we're all working together to fight for a cure or to get us to that next point.

Elissa: And I'd like to point out that, I've watched some congressional hearings on TV, and our legislators are using real-life examples of one of their constituents. Say, "Hey, I talked to Jan the other day, and this is what she has gone through," and they'll list out all the things and be testifying on behalf of that person that they spoke to, their constituent.

And so, it is important even if they agree with you already, they're being able to use that example in this particular hearing to showcase an example and, again, make it real life for people. This is something that's happening to this specific person. They're not alone in this, and we can do something to help it along.

So, you mentioned the pediatric bill that was recently passed, and you also mentioned, things going through with medical debt. What are some other recent issues that you have connected with legislators about, particularly on the federal level? So essentially, what are the top concerns right now?

Becki: Well, so Andrea and I were just in Washington, DC in May, and the two things that we talked about, one, was current funding through NIH (National Institutes of

Health) and how they're allocating those funds. So generally, what they do is they're allocating funds out to people who apply for grants.

And we wanna make sure that they're distributing money out to a lot of different people with a lot of different grants, so that it gives an opportunity for those grants to have a chance to make it through the whole process and to be successful. If they're giving money to just one or two grants, then, if one of them doesn't work out, then it really excludes all of the others, where they could be spreading the money around to help that research be successful.

Andrea: Well, it inhibits progress when you're only backing one or two candidates instead of having the opportunity to cover the field and back other opportunities that might prove just as valuable, if not more valuable. And, also one of the parts of that is international collaboration because, currently, the NIH they collaborate internationally with other, similar organizations.

A lot of blood cancers are considered rare diseases, and you don't necessarily have a sample size here in the United States that's gonna make the rest of the research move at the pace that's needed to escalate treatments. And so, by using international collaboration, you're able to data share and both gain from that experience.

And one of the issues that we were talking about in Washington DC this last May was that we wanna make sure that international collaboration is still available because,

there's this narrative about research dollars being spent here domestically and how our research needs to stay domestically.

And, okay, but you need to have the larger sample size, and you need to have collaboration in order to make these things happen. Otherwise, it's gonna take even more time, and you're gonna lose a lot more ground in terms of your research if you don't collaborate. And ultimately, at the end of the day, the whole world can benefit from this research. It's not just-

Elissa: Yeah.

Andrea: -one country, so why would we be, selective like that? We wanna make sure that we can open it up.

Elissa: Exactly. And we're benefiting from other countries' research-

Andrea: Yeah.

Elissa: -all the time. All the scientists are coming together for a general consensus. They're all coming together for conferences to share their research, and it is so very important. And I'd like to share an example of how important grant funding is to cancer research. If you look back in 2020 with the COVID vaccine, people were wondering a lot like, how did these trials go through so quickly, when we're looking at most vaccines are taking several years to get through, get approved?

And it was because there was so much money thrown at research all over the world that we were able to have all these different research programs going all at the same time and be able to recruit participants for these clinical trials, which also costs money. And so, they were able to get such a huge sample size for each different phase and move it through very quickly.

And so, it really goes to show, when a lot of money is put towards clinical research, you can get things done. And I think blood cancer patients and caregivers listening, they're seeing that they have hopefully, personally, benefited in some way from cancer research. All of their treatment, CAR T-cell therapy, stem cell transplant, all these amazing immunotherapies have all been a result of clinical research and funding grants.

And NIH funding is so very important. And like you said, international collaborations, there are some very, very rare diseases, and a lot of blood cancers are so rare. And especially if you're only looking at relapsed/refractory, that brings down the number even further. And it's such a small number, and we really need more sample size. We need more patients to participate, and there's only so many that could participate in US institutions versus having this worldwide collaboration for adults and pediatrics.

Andrea: Yeah. My mom had a couple of really fortunate experiences where she was able to garner a second and third opinion with some myeloma doctors on the East Coast that were top of the field at the time. And they all said that the goal with

myeloma is to put it into enough of a remission so that, when it relapses, because it will, you have the next great tool at your doorstep.

And that's not gonna happen if you don't have the research to back it up. That's not gonna be an option for you if we just keep things status quo If that happens, then these types of breakthroughs and therapies and treatments, they aren't gonna be available for the next time you relapse.

And, it shouldn't be the case. I mean, why? Why are we limiting people and limiting our opportunities like that? Nobody wants that, so let's fix it.

Becki: And there's been so much progress that's been made with clinical trials and partnerships throughout different communities. I mean we've put so much into the Dare to Dream program, and that's been really huge for pediatric cancer. It's moved the mark and, I'm proud to say that we have, someone here in Seattle at Seattle Children's who's working on that. So it's really exciting.

Elissa: And that is a worldwide master clinical trial as well.

Becki: Yes.

Elissa: Yeah. Because, obviously, when you're looking at pediatric leukemias, and we're looking at relapsed/refractory, again, there is only so many that we can look at, that we can research and get these participants into the studies. So, it was almost

crucial to have this worldwide collaboration with multiple different countries. And everybody is pulling from their own sample and getting all of these pediatric patients on board.

Becki: And, the reason is, of course, we have this drug that's been used for 40 years that is so harsh for children, and so these changes just really need to be made, and it's all these clinical trials they're working.

Elissa: So, one other issue that I wanted to bring up very briefly is the enhanced premium tax credits. Even though they expired at the end of last year, I feel like there's still a potential chance to get them back again by the end of this year by open enrollment. Could you share a little bit about what that issue is and what patients might be able to do now?

Andrea: That's a great question. So, the enhanced premium tax credits being the backend tax credit that was applied to the Affordable Care Act policies during the COVID era expired, and so premiums have now shot up, in some cases, astronomically. There are cases of families with a couple of children, like families of four, where their premiums ballooned to more than what their mortgage payment is monthly.

Becki: I think there's a lot of question around it, and I think that one way to look at it is, if you are working for someone who's providing you with health insurance or they're

paying for a percentage of your health insurance, your employer, I kinda see this as another, it's the same thing basically.

But if you're not employed, the enhanced credit is kinda the same thing as getting a credit from an employer. Some people can't work. I mean, you can't expect people who are sick to work. It's just not possible for a lot of people with cancer. And we're seeing that come down the pipeline too with Medicaid and people proving that they can't work, and doctors now needing to fill out additional paperwork aside from all the work that they're already doing.

So, I can't imagine my mom, she couldn't even get to the bathroom by herself, you know, if she had to go to work every day just to have coverage for her medical needs.

Andrea: There's a nurse navigator that I was working with here in the Portland metro area that was kind of helping me find patient testimonials and folks that were willing to share stories for a particular issue last year. And we were sort of touching on this, and he was saying that, after you have a transplant, be it autologous or allogeneic, you have that 100-day window post-transplant that you really need to be very careful with pathogens.

You can't afford to get sick. You can't afford to be under the weather because you don't have an immune system. And he had said that there were many people that needed to just go back to work prior to that 100-day period regardless, and they were

just needing to throw caution to the wind and say, "I can't afford not to, either to lose my insurance or to lose my paycheck," or whatever that may be.

And he said that's a tough position for patients to be in. I mean, you're fighting for your life. You just went through one of the most arduous treatments that you can possibly go through, and you're building your immune system back up from zero. And you have to think of work on top of it.

It's a terrifying place for somebody to be, and it's not uncommon. And so, removing the opportunity for people to have affordable care or having to prove that they need to work because of the Medicaid work requirements, it's potentially deadly.

Elissa: Yeah. And between Medicaid and then the premium increases, which are causing healthy people to drop off the rolls, that's going to affect everybody in the long run. Probably by next year, we'll all be affected by these changes with hospitals closing, with costs rising, and so this is such an important priority.

So, I encourage patients and caregivers to keep an eye on the public policy website, and also feel free to just share your story, share about premium increases, or if you've lost Medicaid or are in danger of it, to contact your legislators. We talked in the previous episode about what is potentially going to happen as these healthy people drop off the rolls, as Medicaid patients lose insurance, and what will happen to everybody. So definitely tune into that to hear a little bit more.

Becki: And another reason why it's important to become an advocate through this organization because there's staff there, federal and state, that are working on all these things. And there's just so many opportunities for your story to be heard. And so, it's top priority right now for us to be able to get these stories to staff and then staff to be able to get it to, our elected officials.

Elissa: Yeah. Now, besides the issues that we talked about, or I guess including them, what are some issues that each of you are personally passionate about?

Andrea: I was going back to what I said earlier about sitting in the communal infusion lab with my mom and hearing different stories from folks. It was really eye-opening to me that it has become sort of socially okay to just put yourself into obscene debt to just take care of yourself. And financial toxicity then became something I really wanted to get involved in because, that's not sustainable.

I mean, like Becki said, nobody budgets for cancer in their life. So why should that penalize you just because of your circumstances? I mean, that's not right. So, social determinants and why our cancer experiences are different really-- kind of opened my eyes too.

Two patients with the same disease should not be given different options based on their social determinants. It should be based on their disease process, and that's not

what's happening. And that is where the system lets people down. And I think that there's work that can be done.

And I'm not ever gonna be a clinician. I'm never gonna cure cancer, but if I can be part of the solution in a different way, that's what I wanna do. So, that's been kind of a passion point for me. We've met so many people through our journey through advocacy that have said similar stories of like, "This treatment is there, but I can't afford it," or, "This drug is there, but I can't pay for it every month," That doesn't sit well with me, and that shouldn't sit well with anyone.

It could be any one of us sitting in that chair and hearing that news and having to figure that out, and so we should lead with that in our lives that could be me one day, and I wanna have access to things. I want, my family to have access to things. I don't wanna be in a situation where you know there's a treatment available, and it's just out of reach for social reasons and not because it's not appropriate for your disease.

Elissa: Yeah.

Becki: That's a hard question to answer 'cause I just want to do everything. But I think that, when Andrea and I go on these trips to Washington, DC, and we meet people who are from all over the country and hear their stories, it's incredible the work that they're doing, the things that they've gone through, the change that has been made because of the work that they're doing.

I've had experiences too, aside from my mom, where I've been around other patients, and I've spent time at housing facilities for cancer patients. And I've, seen different circumstances with different people. One person I knew, she left her treatment, and she was living in her car after that. People can't afford to pay for a night in housing. They didn't realize that their insurance wasn't gonna pay for it.

So I see all these GoFundMe®'s that pop up on social media and, we should not be in survival mode and using GoFundMe to fund your care or your food or your gas money. So, we just need to get to a point where there's an understanding that people have cancer, and they're sick and they need support.

Andrea: Well, Becki and I were in a meeting. It was maybe a year or two ago, and one of the other advocates on the call had said that their hospital system had recommended that GoFundMe be part of their process. Like, "Okay. Well, we're gonna go and do a pre-approval with your insurance, but you should go ahead and start a GoFundMe." What? How is that the initial conversation that you're having with your team? How are we okay with this?

Elissa: Yeah. And I do wanna point out our very last podcast that we did just the prior to this one, we do have a finances podcast where we talk to Triage Cancer and hear all about how you can make sure you're getting the right insurance and hearing about those issues that are coming up for patients and how to navigate all of that.

So, I'd love to hear how do patients get involved in either advocacy like you are doing or even just writing letters or emails, et cetera, to share their story or share their stance on the issues with their state or federal senator or representative?

Becki: One of the ways is, if you go to the organization's website, there's a place where you can share your story. That's probably one of the top places that you can be heard or seen from, let's say, staff from different areas of the organization. If you're sharing your story, you're getting it out there, and they're able to, pinpoint kind of where they can support you.

Also, just being out in the community when we're out meeting people, having these conversations about different challenges that they're dealing with and introducing to them opportunities to lawmakers. And we do that through our grassroots staff and government affairs staff that we work with.

Andrea: You can also sign up to be an advocate on the Office of Public Policy's website. You can sign up to receive action alerts, and what an action alert is, is basically it's a text or an email that comes to you with a current legislative priority that they're trying to put in front of elected officials. And you basically plug in your information, like your name and your address, and then the system will generate for you a prefab letter that you're able to manipulate and add your own personal details to, and then it will automatically send it to your legislators.

So, they really take the grunt work out of getting involved if you wanna get involved, and you don't have a ton of time, that is a fantastic way to do it. There are also opportunities through action alerts where you can call your legislative officials, and what it'll do is it'll auto-dial the capital for you, so you don't have to try to look up-

Elissa: Oh.

Andrea: -your office's information. It'll come up with a script for you so that you can just read the prompts and then say your message. They really made it very, very easy to get involved. So, if you're looking to get involved and sharing your story in a different medium, that's one way you can do it, and it's a low lift in terms of time.

And also, sometimes we'll be out in the community at different events, and we'll meet patients and folks that have an amazing story of hope or an amazing story that ties to one of our legislative asks. And we'll ask them if they'd like to get involved and maybe write a letter. I actually have somebody that I just met the other day that I think would be amazing to write an op-ed piece, and so we're kind of working on that to try to see if they're able to share their story that way.

And I think, as grassroots leaders in our states, that's kind of our role is to be the conduit, right? We're not always gonna be the mouthpiece. We're the person that puts the people together. So, we're out in the community. We're meeting people. We're seeing things, and then we're taking that information and plugging them into the right

resources and making sure that our staff partners have the information they need so that they can tell a compelling story or work towards writing that piece of legislation that's gonna help everybody.

Elissa: Yeah. And I do wanna point out the action alerts are wonderful. Just as a leukemia survivor myself, I've done that, and it is about the easiest thing to do. I click on the link, and then I'll write, a couple sentences how my personal story relates to this, and then I click send.

And it goes off, and I get a response from all of my representatives saying, "Hey, we received your email,". But, I know that it's been received and logged and again, I got the opportunity to very briefly share my story and what this means to me. And so that is something that is just so, so easy.

But, we'll be sure to have links at the end of the episode and in the show notes on how to get involved and share your voice with Blood Cancer United Advocacy and Public Policy. So, our final question today, on our patient podcast homepage, we have a quote that says, "After diagnosis comes hope." With regard to all the things going on in the United States right now that have a direct or indirect effect on patients and their families, what would you say to give them hope as they navigate treatment and survivorship?

Andrea: I think there's a lot of hope to be had, even though things don't always feel that way. I think there's a lot of hope to be had in the community aspect. I know that

the resources that Blood Cancer United has are huge. A lot of them weren't available when my mom was going through treatment, and almost every single one of the more recent resources that have come out have all been things that we would've totally benefited from had they been available.

And I think, knowing that there's a community of people out there that are going through something similar, it means a lot because cancer's very isolating for the patient and the family. Like Becki said, you know, there's a privacy element that you sort of keep close to the vest, and you may not feel comfortable talking to people.

But if you've got this third-party organization that's willing to listen, that's amazing. You know, giving power to your story, taking some of that control back, it's huge. And I think if you're able to do that and you're able to leverage that community, it really does go the distance.

And doing this advocacy work now for as long as I've been doing it, I've connected with so many amazing people and they've become such a big part of my life, and I consider them friends. We talk all the time and these are people I would never have gotten an opportunity to know, and that's beautiful. I mean, that's the community aspect of it, and I'm forever inspired by the folks I meet.

I met Becki through this and, it's great. I just think the whole thing is wonderful, and I think there's a lot of hope to be had, that there's always something new coming down

the line, whether that's for your community, for your treatment. There's always something new. So have hope, hang tough,

Andrea: -and stick to that community.

Becki: I would not have been able to get through some of the things that I've gotten through when my mom was sick without this community. And people within it would remind me that I needed to take a break and it was okay to step away, but I didn't want to because, you need people around you that understand what you're going through.

And again, just hearing some of the stories of things that other people have gone through and the amazing things that have happened within advocacy, it makes me wanna be here and to do those things and to help make those things happen.

Elissa: Well, thank you both so very much for sharing your stories with us today and sharing about all these really important issues that affect blood cancer patients and their families.

Again, we will have links in the show notes on how to get involved, how to share your story, and make your voice heard, and really help not only yourself as a patient or caregiver, but other patients, as well. And we can all come together and really make a difference and have an impact on these issues affecting everybody. So again, we really, really appreciate both of you being here today.

Andrea: Thank you for having us, Elissa.

Becki: Thank you very much.

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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In addition to the Lounge, we could use your feedback to help us continue to provide 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. However, if you would like to contact Blood Cancer United staff, please email, TheBloodline@bloodcancerunited.org. We hope this podcast helped you today. Stay

tuned for more information on the resources that Blood Cancer United has for you or your loved ones who have been affected by cancer.

Have you or a loved one been affected by blood cancer? Blood Cancer United 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 BloodCancerUnited.org/PatientSupport.

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