LEUKEMIA & LYMPHOMA SOCIETY® is now

Blood Cancer United

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'We are Blood Cancer United: a new name, an unstoppable community'

Description:

In this special episode of *The Bloodline,* we introduce our new name and what it means for blood cancer patients, caregivers, and the wider community. Joining us from Blood Cancer United are Dr. Andy Kolb, President & CEO; Dr. Eric Cooks, Senior Director of the Equity & Access Research Program; and Bryon Daily, myeloma survivor and Senior Manager of National Community Outreach. Together, they share why inclusivity and unity are at the heart of Blood Cancer United and how this evolution strengthens our mission to support every person 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.

Now, you may have noticed that this podcast has a new name and that is because The Leukemia & Lymphoma Society is now Blood Cancer United. We have a very special episode today to help us introduce our new name and what that means for blood cancer patients and their loved ones.

Joining us today are Blood Cancer United staff members, President and CEO, Dr. Andy Kolb; Senior Director of the Equity & Access Research Program, Dr. Eric Cooks; and National Community Outreach Manager for Myeloma Link, and a myeloma survivor, Bryon Daily. Dr. Kolb is a world-renowned pediatric hematologist-oncologist and researcher who devoted his life's work to caring for children with pediatric blood cancer and advancing research to accelerate treatment and cures for all blood cancer patients. He joined LLS, now Blood Cancer United, as President & CEO in 2023.

Dr. Cooks is a trained health communication scientist who has devoted his career to advancing solutions that reduce health disparities and improve care for patients and families across a wide range of communities. He joined Blood Cancer United as the Senior Program Director of the Equity & Access Research Program in 2023.

Bryon is a multiple myeloma survivor who has turned his passion for advocacy into a life mission and is a staunch supporter of blood cancer patients and their families. After a successful bone marrow transplant, he joined Blood Cancer United first as a volunteer and in 2021 as a Community Outreach Manager. You might remember Bryon from when he shared his story on our November 2021 episode, "Patient-Doctor Perspectives: Hope for Myeloma Patients" or in September 2022 when he took our listeners onsite at a Myeloma Link event in the episode: "Community Outreach in the Field: Blood and Chess Atlanta." Welcome, Dr. Kolb, Dr. Cooks, and Bryon.

Andy Kolb, MD: Great, thank you, Elissa. It's really an honor to be with you today.

Eric Cooks, PhD: Thank you for having me. Happy to be here.

Bryon Daily: Thank you, Elissa.

Elissa: Thank you for being here.

So, Dr. Kolb, we'll start with you. Could you tell our listeners about our new name and why The Leukemia & Lymphoma Society is now becoming Blood Cancer United?

Dr. Kolb: Yeah, thank you, Elissa. This is such an exciting time for our organization. And as you said, The Leukemia & Lymphoma Society is now Blood Cancer United. So, why did we change our name? We are doing this because we want to make sure that everyone with blood cancer, not just those with leukemia and lymphoma, but everyone knows that we are here for them. There are more than 100 different types of blood cancers, like myeloma, myelodysplastic syndromes (MDS), myeloproliferative diseases (MPN), and there are even diseases under an umbrella like lymphoma with different names like Waldenström's macroglobulinemia. We recognize that it's time to change our name so that it better reflected that we are here for all blood cancer patients and that they are at the center of our mission.

So, we went out and we got feedback from the cancer community, we got feedback from all of our stakeholders, and they agreed that we should revisit our name, revisit how we show up for the communities that we serve and the patients that we serve.

So, now with the name Blood Cancer United, our organization is going to be able to reach more people faster so that they can benefit from our programs and our services. We'll be able to reach more patients and families who right now may not know about all the support that we can offer them.

And Blood Cancer United says who we serve; and it says how we serve them. We serve blood cancer patients, and the word "united" is inviting and inclusive; and it conveys a sense of community and a sense of collaboration. It's this kind of community and collaboration that we want to be able to share with all our patients.

As an organization, we believe in the power of bringing together patients and families, scientists, volunteers, donors, business leaders, and health systems under a shared purpose and in service of blood cancer patients.

Blood Cancer United is a complete sentence. It reflects who we are today and who we aspire to be. We want to be a unifying force advancing progress and providing support for every patient impacted with blood cancer.

But we have to remember that while we're changing our name, our mission is the same. Blood Cancer United is here to cure blood cancer and improve the quality of life for all patients and their families. This is what we've done for the past 75 years; this is what we will continue to do. We will continue doing the important work that matters to all of you. That means funding research, advocating for improved healthcare policies, and providing programs and services to support patients throughout their diagnosis and treatment.

And even though we've changed our name and we might bring a different look forward, we are still the same passionate community for patients, caregivers, and families envisioning a world without blood cancer.

As an organization, we have a bold goal that will enable patients with blood cancer to gain more than 1 million years of life by 2040 – that means more birthdays, more treasured moments with family and friends; and as Blood Cancer United, we are entering this bold new chapter that reflects both the urgency and the hope that we see across the blood cancer landscape. And united under a common cause, we're going to continue to be there for all patients and reach more patients and families who need us.

Elissa: Wow. Thank you for sharing all of that, Dr. Kolb. I love hearing about our bold goal and I know that it will mean so much to blood cancer patients and their families to be given the chance at more life to enjoy those moments that mean so much to all of us. So, Dr. Cooks, let's move onto you and your role here at Blood Cancer United. Could you tell us more about what the Equity & Access Research Program does?

Dr. Cooks: Absolutely, absolutely. So, the Equity & Access Research Program was created in 2021 in order to provide funding for health services research; and this is a specific type of research that looks at questions surrounding how people get healthcare, what are the costs of that care, how it's organized, and how it's delivered as well as how does it work.

So, we're funding this type of research with leading scholars from all across the country in order to generate high quality data that's going to help us to better understand the barriers that prevent many patients from getting the care that they need and deserve because we're on the verge of some really breakthrough treatments; and all patients, regardless of who they are, should be able to benefit from these advancements. And this innovation also means that patients are living longer as well, and we want them to live fulfilling lives.

Blood Cancer United is committed to ensuring that patients receive the care and support that they need; and through the Equity & Access Research Program, we're producing data that can inform our efficacy work for changes in healthcare policy as well as healthcare practice in order to create a more equitable healthcare system.

In terms of the work that we've supported to date, we focused in on two key areas. The first being exploring the role of health insurance in accessing care, as we know that having access to quality insurance coverage is linked to better health outcomes. But barriers do, unfortunately, exist for many patients to get coverage which ultimately impacts their ability to access timely and effective treatments.

And we've also been supporting work that's testing new ways to increase participation in clinical trials. As we know that clinical trials offer high quality cancer care and are critical to advancing treatment options, however, very few patients participate and even fewer patients from groups that have been historically underrepresented in trials. So, these are just two significant areas that we've been focusing on that hold great promise in moving the needle to get people the care that they need when they need it.

Elissa: Right, yeah, our organization, in general, really focuses on making sure patients can access those treatments because we're funding so many incredible lifesaving treatments. And what is the point if patients can't get them, whether it is financial reasons or, other barriers to care, they can't get to treatment for transportation or something; and so that is such important work that you're doing.

Now, what do you think will be the effect of becoming Blood Cancer United when it comes to patients and caregivers being able to find resources and increasing access to cancer care?

Dr. Cooks: Right, yes, so I think as, Dr. Kolb mentioned, evolving our brand to Blood Cancer United recognizes the inclusivity and a sense of community and collaboration that have really always been at the core of our mission. So, this is going to allow us to better serve patients and caregivers through the amazing suite of resources that we provide.

Blood Cancer United signals belonging, and it builds awareness amongst patients and caregivers, also offering clarity that these resources are here for them, regardless of their blood cancer type. So, our new well-defined brand is going to make it easier for patients and caregivers to understand what it is that we offer. And I think that it's also going to influence, ultimately, how information choices are being made, which can be a very daunting task for anyone in today's overly saturated media environment. And I would assume even more so for patients and caregivers that are already dealing with so much.

So, I think that reducing this uncertainty about who our resources are for and whether the information we offer is relevant to their needs is going to reinforce people's confidence and trust and is ultimately going to allow us to reach more people who can benefit from our programs and services.

And lastly, I'll just say there as, an organization, we are committed to improving patients lives through our holistic approach across research, patient support, as well as advocacy. And this brand evolution to Blood Cancer United is really a key piece in this work.

Elissa: That's great. Now, Bryon, you have one of the blood cancers that is not leukemia or lymphoma, yet is important and still very much included in our funded research and educational programming. I'd love to hear your personal thoughts of the new name, Blood Cancer United, as a myeloma survivor.

Bryon: Sure Elissa, absolutely. As a myeloma survivor, the brand name change represents a significant acknowledgement to the fact that myeloma, even though it's rare, it's a significant disease, specifically in the population of very vulnerable patients.

Blacks have been shown to be diagnosed at a 2:1 rate for this disease, which puts it in that category of having a malignancy that's got the disparity stigma attached to it. And there are various reasons. Most of it has been attributed to lack of access, late detection. A lot of social and other determinants of health are factors in the diagnosis.

When I was diagnosed back in 2018, I was very fortunate. I had great insurance. I had great family and friends around me. I was very conscious of my own health and also was financially prepared for the diagnosis. Although we had no history of cancer in my family, my wife and I purchased a supplemental policy covering cancer years before. So, those things really assisted in helping me to recover and maintain stability in my health, even with that disparity stigma attached to the disease.

Now, just a little bit more about what this means to me. I was so impressed with Blood Cancer United, then The Leukemia & Lymphoma Society, that I decided to volunteer once I got well enough. And saw the commitment and the dedication of the staff, how they performed and, just in comparison to some of the other nonprofits out there. We were doing a lot of things that were helping patients and families to cope with this malignancy.

And so after a few months, I joined the organization as a staff member. I learned more about the disease in a very short period of time. It was eye-opening just to see how it devastates families in many ways – financially, emotionally, and also the fact that once I was out in the community, that I discovered that many people didn't know anything about myeloma who were not impacted. Like myself. Never heard of myeloma. Thought it was melanoma, and I very easily confused. And not really sure why that is, but melanoma is a little bit more recognizable; and as a result of that, people have come to me who had myeloma or knew someone who had myeloma. They'll ask me questions about, something that's related more to diabetes or sickle cell because they just did not know that myeloma was a blood cancer. They knew it had something to do with blood but wasn't sure what.

What Blood Cancer United means to me is just a full embrace of all cancers, regardless of, the type, whether it's a cell-related or plasma-related issue. It impacts many people, and it's typically a devasting disease to deal with. So, I'm proud to continue the fight; and I'm also proud of the people I work with and their dedication as well.

Elissa: So, you mentioned bringing awareness of myeloma and other blood cancers to the community. So, let's talk a little bit more about your role at Blood Cancer United. What is the Myeloma Link program, and how does it bring awareness of blood cancer resources?

Bryon: So, Myeloma Link was the brainchild of one of our Senior Vice Presidents back in 2017 in recognition of that disparity that exists in the Black community. We were uniquely qualified to address that, and we had the resources to make a difference.

So, we launched in two cities. One was Atlanta. The other one was D.C. And we specifically designed education and put material together that members of the community could digest. We had a specific intent to go in and meet the community where they are. So, we partnered with churches, we participated in health fairs. We also partnered with members of the community who influenced health in those communities, and slowly it became recognizable. In fact, I've been told that many people weren't aware that Myeloma Link and the former The Leukemia & Lymphoma Society was the same entity. So, I guess that's a stamp of approval that we did something good and we did it right.

Right now, we're partnering with national organizations who have a local presence in communities. Many of these are fraternities and sororities with alumni chapters whose members are still active, and they do a lot of community work. These organizations are key to establishing relationships because they bring a reputation of work in the communities where they're well known.

In the past we didn't have much of an opportunity to really build awareness and show people who we were. But that's changing, and large organizations are embracing our message; and we're doing great work by drilling down to the local chapter level of these organizations and partnering with them and actually showing up in the community.

Elissa: That is wonderful. No sense in reinventing the wheel when you have groups that are already so connected with their own communities.

So, how do you see Blood Cancer United helping to bring more awareness and resources to patients and caregivers through our new name?

Bryon: Well, as I mentioned, the one thing that kind of struck me when I joined the organization is myeloma wasn't mentioned in name. It kind of limits what we do when you only have two particular types of blood cancers that are out in front. And now that we are Blood Cancer United, we've got the opportunity to really educate people on all hundred plus different types of blood cancers out there.

And that, I think, will elevate us. We're already a worldwide recognizable nonprofit; but I think it's going to help people who don't really see us as often. It'll be clearer who we are.

Elissa: Yes, I'm very, very hopeful with the new name that it will bring more resources and access to care to patients and caregivers with all different kinds of blood cancers. And so thank you so very much Dr. Kolb, Dr. Cooks, and Bryon for coming on here and sharing all about our new name and what we are continuing to be able to do for patients and how we're going to continue to increase that access to care and make sure that all patients can have access to these incredible lifesaving treatments that are coming out all the time.

And so, again, thank you all so much for joining us today. We really appreciate you.

Bryon: Thank you, Elissa.

Andy: Thank you.

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.

Did you know that you can get more involved with *The Bloodline* podcast? Be sure to check out Subscriber Lounge where you can gain access to exclusive content, discuss episodes with other listeners, make suggestions for future topics, or share your story to potentially be featured as a future guest. You will also receive an email notification for each new episode. Join for free today at TheBloodline.org/SubscriberLounge.

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 a 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. This link and more will be found in the show notes or at TheBloodline.org.

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