

Lauren Hixenbaugh (00:00):

Welcome to Living Beyond Cancer. I'm Lauren Hixenbaugh, the Manager for the West Virginia University Cancer Institute's Mobile Cancer screening program. And I'm your host for today's episode. For those who haven't joined us before, Living Beyond Cancer is a series of podcasts created for cancer patients, survivors, and their caregivers today to discuss triage cancer, an extensive free resource for individuals diagnosed with cancer caregivers, healthcare professionals on the legal and practical issues that may arise after a diagnosis. We are so pleased to have Joanna with us today. Could you tell us a little bit about yourself and what triage cancer is?

Joanna Doran (00:43):

Well, I am happy to be here with you. So I am actually a cancer rights attorney by training, and usually when I tell people that I get kind of a funny look and people inevitably ask me, well, what's legal about cancer? And my answer is almost everything, because whether or not the Food and Drug Administration approves a particular treatment is a legal issue, whether or not health insurance actually covers that treatment is a legal issue. Whether or not you get to take time off work to get access to that treatment is a legal issue. We just don't think of those things as legal issues. So our goal at Triage Cancer is to provide education on those legal issues and the practical things that come along with those legal issues so that people can get access to the care that they need and manage the financial costs that comes along with a cancer diagnosis.

(01:42):

And we co-founded triage cancer about 12 and a half years ago after working in the cancer community for many years. And really what drove us to do that is because we saw a pretty big gap in the cancer community around education and access to information around these legal issues. And we thought that we were going to spend our time focusing on underserved communities to provide education there. And what we really realized is that everybody is underserved when it comes to this information and that a lot of it is just things we should have been taught in high school, but no one ever taught us. And so while we certainly focus on the cancer community, a lot of what we're sharing is practical information for everybody.

Lauren Hixenbaugh (02:32):

I really like how you explained the external pieces that we might not think of traditionally. So is this resource just available to folks in West Virginia?

Joanna Doran (02:44):

We are a national organization, so we provide information across the country and we are providing resources and materials and educational events for patients and caregivers. And then we're also doing that for healthcare teams and advocates so that they are better at navigating patients and caregivers to the information and resources that they need. And so we are tracking what's happening at the state and federal level all across the country because there are constantly changes in the law. If there is one thing that is constant, it's change when we talk about the law. So there are always things happening that are improving people's ability to get access to care or potentially threatening it, and we're paying attention to what those things are and then turning around and translating that information for the cancer community so people understand what's happening and how it impacts their daily lives.

Lauren Hixenbaugh (03:42):

So is this a brick and mortar that people are coming to?

Joanna Doran ([03:46](#)):

No. So we are actually a nonprofit corporation based in California, but our staff are all over the country and we are all remote. So everything that we provide is actually in communities where we're hosting in-person events in communities, or it's available online.

Lauren Hixenbaugh ([04:08](#)):

Great. Okay. And one of the things I thought was amazing about this resource, I was just shocked to see how many places you cover and how many languages were listed on the website. Like I said, I was just absolutely amazed. So what if listeners have additional questions about resources?

Joanna Doran ([04:31](#)):

So our goal is to provide education in a way that people understand, and so everybody learns it a different way. So we try to provide that education in lots of different formats. So we have those educational events that people can participate online or in person in a community. We also have those materials and resources and lots of different formats. So everything from a five minute animated video because we know no one really likes to actually learn about health insurance coverage. So we try to make it at least a little bit entertaining. And then we have our podcast, we have print materials that people can download or order copies of. We have recorded webinars, so we try to make it available in lots of different ways and in different languages. But then we know that that isn't going to answer everybody's questions. So we know that people might still have questions after they attend an event or listen to a podcast episode.

([05:32](#)):

And so we have a legal and financial navigation program that is free and available to anyone to contact us with their questions about their individual situation. So people can go to our website@triagecancer.org slash get help and fill out a form about what issues or questions they might have. And then it sends them an automatic email to pick a calendar appointment to be able to set up time to talk with our staff so that way we avoid some of that phone tag, so to speak, and let people actually find the time that works for them to have that appointment.

Lauren Hixenbaugh ([06:11](#)):

If folks have questions, they get, they can talk with a live person.

Joanna Doran ([06:15](#)):

Yes, they can sign up for a time to meet with our staff so that they can get answers to their questions.

Lauren Hixenbaugh ([06:23](#)):

Great. Okay. I'm sure lots of people feel better when they're talking to a live person. I know sometimes when you're trying to find answers, you go on a wild goose chase, and so I'm sure that it's nice to hear a friendly voice. Absolutely. What about communities? If they have, I'm thinking maybe some of the senior centers that we work with might have some questions or might be wanting to give a presentation maybe to their patrons. Is that something that you guys would help

Joanna Doran ([06:54](#)):

With? We absolutely do. So we have the navigation program where anyone can contact us with their questions, and that might be a patient, it might be a caregiver, it might be someone who works at the senior center contacting us to get answers to a question. Triage cancer also provides educational seminars in communities. So we host about 30 of our own educational events a year, and that includes our conferences. We have a monthly webinar series, and then we do trainings for healthcare teams and advocates, but we participate in another 200 on average per year. So that includes communities like a senior center contacting us and asking us to provide a presentation on a particular topic like Medicare, for example. That definitely is a common request, especially around open enrollment and being able to make sure people have the information they need to make choices about how they get their Medicare coverage.

Lauren Hixenbaugh (07:54):

Okay, that's great. Could you walk us through where to start? If I were a survivor or caregiver, walk me through where I should go and look on the site. Where would the information most be helpful? What am I looking for? Just walk me through the process.

Joanna Doran (08:15):

It really depends on what types of questions people have when they come to the site. So sometimes people don't know what they don't know, and so they don't even know what questions to ask. And so I think it's helpful to start by looking at resources by topics page. So if you go to the site and you look at resources, you can find all the topics that we cover. And when you click on that topic, like health insurance for example, you can find all the resources that we have available about that topic. If you go to the employment page, for example, it's broken down by someone who's trying to learn more about staying work or someone who's going back to work or someone who needs to take time off work. So we try to sort the information based on someone's situation to help them find the resources that are going to be most applicable to

Lauren Hixenbaugh (09:08):

Sure. Others are curious as how you came to affiliate with the State Cancer Coalition?

Joanna Doran (09:18):

It's kind of a long story. Mostly. First, we really feel strongly about taking education into every community. So before covid, we delivered most of our programming in person and our annual conferences, we would host three times a year, and we would take them into communities. And we have actually hosted one of our annual conferences in Morgantown. And so we were connected with many of the healthcare professionals who are providing care in the area, and certainly had patients and caregivers attend as well. And so we were sort of locally connected, but I have personally also spent a lot of time in West Virginia and know that there's a lot of need for education as there is in many communities across the country. But I was also very involved with California's state cancer coalition, which is called oc, the California Dialogue on Cancer. And so that was my first experience in working with state coalitions. And as Triage was looking to be more connected in communities across the country and also understand the issues that communities are experiencing so that we could be responsive to those needs. We joined a number of coalitions across the country so that we could be better informed and be better connected to be able to provide those services. And so we currently participate in about 30 of the state's cancer coalitions, but West Virginia was definitely top of the list based on our previous work in the area.

Lauren Hixenbaugh ([11:02](#)):

Well, that is a lot of coalitions, so you're definitely getting the full spectrum of what people need, so that's good.

Joanna Doran ([11:09](#)):

Yes. It's actually kind of interesting too to get that perspective that many of the issues are actually not different, that even though communities are very different and diverse, that the needs of communities and the cancer community overall are really not that different.

Lauren Hixenbaugh ([11:27](#)):

You guys definitely cover the spectrum. I feel like when it comes to, like you said, being nationwide and covering multiple languages, covering multiple resources. I know one of the main questions we get a lot within, of course, my work with mobile cancer screening, but also just with a lot of patients in our cancer center as well as those in the coalition. And that is of course about managing finances and how that looks and how maybe people could utilize your resources to help manage those finances after a cancer diagnosis.

Joanna Doran ([12:05](#)):

I think there's a lot of focus in the cancer community around the potential financial hardship that a cancer diagnosis can bring. And there's a lot of focus on trying to help people manage the cost of care and get access to financial assistance. And that's incredibly important, and we certainly can help connect people to those resources, but we also want to try to address the underlying causes of why somebody needs financial assistance. So most of the time it's because someone has inadequate health insurance coverage or maybe not even have health insurance coverage that's causing part of the problem and why someone needs financial help. So triage cancer, we're really trying to help people address those underlying causes. And sometimes it might be about health insurance, sometimes it might be about employment. If somebody needs to take time off of work and deal with treatment or recovery or side effects, that's a loss of potential income.

([13:12](#)):

And so that's also creating a part of the problem if somebody has less income, that creates financial hardship as well. So we're trying to address some of those underlying causes where even if somebody has inadequate health insurance coverage today, how can we help them understand or make different choices moving forward so that they don't continue to experience that financial hardship? So if it means in open enrollment understanding how to make better choices moving forward based on their needs for coverage, that's our goal. So at Triage Cancer, we think the number one contributing factor to financial hardship is having inadequate health insurance. But even once you have the best health insurance policy for you, you still have to know how to use it. And unfortunately, our system is set up to make it really difficult for us to navigate. So we might be in a situation where we need a prior authorization from an insurance company before we actually get care, or they deny coverage for care, and we have to understand how to appeal those denials.

([14:20](#)):

So even once you have great insurance, you still have to know how to use it. And unfortunately, that's not something that they teach us in high school. So we have to figure it out. And usually we're trying to figure it out in a moment where we're sick and it's harder to actually deal with at that point. And then once you know how to use your insurance, that still doesn't eliminate those out-of-pocket costs. And so

understanding how to manage medical bills when you get those bills coming in, figuring out how do you compare them to the explanation of benefits from your insurance company, make sure they're right, negotiate with the provider a payment plan. So there's all these steps that someone could take through this process. And really our goal at triage is to provide the education about how you can navigate all of those steps effectively.

Lauren Hixenbaugh ([15:14](#)):

Joanna, you sound really passionate about this particular topic. I don't think I asked you earlier, but how did you end up working with triage cancer?

Joanna Doran ([15:26](#)):

So many, many, many years ago, I was working at a cancer center and I worked for the psychosocial care program in a cancer center. And one of my responsibilities was actually working in the Positive Appearance Center, which was the onsite boutique for the comfort and cosmetic side effects of cancer treatment. And one of the things that I did was fit patients for mastectomy, brass, and prostheses, and then I would have to bill insurance for those items. And all the time it would come back as denied. And then I would have to call up the insurance company and say, I don't understand why this was denied. This should be covered. It's a covered service. And they would say, no, it's not. And I would say, well, what about WRA with the Women's Health and Cancer Rights Act? And it turns out at the same time, I was also in law school while working at the cancer center.

([16:22](#)):

And so if I hadn't been in law school, I wouldn't have known about that particular law, which actually requires insurance companies to cover those items. And so once I said WRA to the person on the phone, they would say approved. And so I only had to demonstrate that I even knew the acronym of the law for it to change the outcome of the situation. I didn't even have to explain the full name of the law or what it did or why that was pertinent to the conversation, but just knowing that was enough to change the outcome. And I found that really infuriating actually, that the system is set up to make it impossible for us to navigate. And you shouldn't need a lawyer to be able to get access to the care that you need. And so ultimately, that was a really good example of why it's so important for people to understand their rights and frankly is what drove me into this work and why we founded Triage to be able to provide this education for people.

Lauren Hixenbaugh ([17:26](#)):

Not only that, but it's also the insurance coverage that people already pay for. So I think that makes it even more infuriating. You're spending your hard-earned dollars on something that's supposed to help you. And then like you said, you have to know things that you don't even know you need to know, and you're sick and your family's trying to figure out the best way to support you. And so they shouldn't have to be figuring that out either. A lot of times when I do these podcasts, and I've done several with patients, the number one thing that comes out is overwhelmed that every step of the way is overwhelming. It seems like loss of emotions ebb and flow, but that emotion just continues throughout the journey.

Joanna Doran ([18:17](#)):

And certainly insurance is just the icing on the cake in a really negative way in terms of how much more frustrating it can make an experience.

Lauren Hixenbaugh ([18:31](#)):

Absolutely. Well, I'm really glad that you're here with us today to shine some light on a really needed topic. I, again, know that people are very frustrated a lot of times when it comes to resources. There are a lot of them out there. So I think kind of honing in on what people need is what it seems like you all have done and tried to make it a pretty simple step for people. So as we begin to wrap up today, I just want to make sure that we revisit I key points. So if listeners were to remember one thing from today's podcast, what would you hope that it would be?

Joanna Doran ([19:11](#)):

I think if people have questions about those practical aspects of navigating healthcare, like dealing with insurance and work and finances, that they know that there's a resource. Even if they don't know exactly the questions to ask, there is a resource that can help them navigate that process and get them the answers that they need.

Lauren Hixenbaugh ([19:35](#)):

Great. And so I have, folks can visit your Facebook page at Triage Cancer.

Joanna Doran ([19:43](#)):

Yes.

Lauren Hixenbaugh ([19:44](#)):

And they can also, of course go to the website, which is [triage cancer.org](https://www.triagecancer.org).

Joanna Doran ([19:49](#)):

Yes, they can.

Lauren Hixenbaugh ([19:50](#)):

Okay. And then there'll also be a link on the Mountains of Hope website. The Mountains of Hope site is [West Virginia mountains of hope.org](https://www.mountainsofhope.org). And so of course, all of our podcasts are there, as well as other resources that are specific to West Virginia, and then links to some of our partners and their sites where triage cancer also resides. So Living Beyond Cancer would like to thank you for joining us, and especially thank Joanna for joining us as well from Triage cancer and speaking with us, telling us about this wonderful resource. We hope that you'll continue to join us.

Joanna Doran ([20:29](#)):

Thanks for having me.