

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'I'm a Caregiver & Advocate: Kristin's Story'***

#### **Description:**

Join us as we speak to Kristin Fuhrmann-Simmons, a caregiver and an LLS volunteer. Kristin talks to us about caring for her father who is a CLL survivor, and how she decided to join LLS's advocacy efforts through our Office of Public Policy. For Kristin, it was a great way to connect with people in her community and share her family's story. And she knew that for her dad, being as sick as he was, it was helpful to have her as his voice to bring forward some of the issues that her family was facing as a result of his treatment. This episode highlights how advocates carry the ability to uphold a voice that may have been silenced by a diagnosis.

#### **Transcript:**

**Alicia:** Welcome to *The Bloodline with LLS*. I'm Alicia.

**Edith:** I'm Edith.

**Lizette:** And I'm Lizette. Thank you so much for joining us on this episode.

**Alicia:** Today we will be speaking with Kristin Fuhrmann-Simmons. Kristin is a caregiver who resides in Maine and is very involved with LLS's advocacy efforts, working on behalf of blood cancer patients and their families, sharing personal stories, and taking action on public policy issues that matter to blood cancer patients and survivors. Welcome, Kristin.

**Kristin Fuhrmann-Simmons:** Thank you so much. We're so happy to be here.

**Alicia:** Awesome, we're happy to have you on. Now earlier I just mentioned that you are a caregiver. Who is it that you're caregiving for, and what was their diagnosis?

**Kristin Fuhrmann-Simmons:** Certainly. So, I actually am a caregiver for my father, and he was diagnosed a little over ten years ago with CLL, so chronic lymphocytic

leukemia. And things didn't kick into action till about eight years ago when he was hospitalized with pneumonia, so that's when we really started moving out of that watchful waiting stage and into the active stage. And since that time, he's been through three different treatment cycles and really has been doing really well with his ongoing current treatment.

**Alicia:** That's good news. At the time had you ever heard of CLL or had your father heard of CLL or was this completely new for everyone?

**Kristin Fuhrmann-Simmons:** It was new for our family, but it was not new for both, well, I should say my family meaning my sister and I and my husband. Not new for my parents. My father is a physician. My mom's a nurse practitioner, and at the time, something like CLL, they knew about it. They knew that it was something to take very seriously. Treatment just ten years ago was very different than from what treatment is now.

So, we sort of, we had a very different attitude towards taking care of it then than what we do now. And it's really nice to be able to be part of the progression of how CLL is treated, where many, many patients who have it are now living very healthy, very full, very happy lives with it.

**Lizette:** Yes.

**Alicia:** Absolutely. And on today's episode, we're going to be talking about advocacy and the impact of advocacy and how people can actually get involved when it comes to advocating for our patients and survivors and caregivers as well.

Being an advocate, it means taking action; and that can look like many different things. How did you decide to get involved with advocacy?

**Kristin Fuhrmann-Simmons:** I love this question so much because being an advocate has been being the best part of being involved with The Leukemia & Lymphoma Society. When I first got involved with LLS, I was a Team in Training



runner. I had never trained for a running event in my life, and I ended up signing up for my very first half-marathon about eight years ago when my dad began treatment because I needed something to do to get my mind off of the stress of caregiving.

And I got involved with the incredible community LLS, and I got to see people from all different backgrounds, not only out on the racecourse, but people who were doing so many wonderful different things for LLS, not only in raising money for Team in Training, but I started to talk to people who were doing clinical advocacy.

And I'm a person, I teach at the University of Southern Maine. I love to be in front of a crowd of people, so that seed was planted in me eight years ago. And just over four years ago, I decided to take that step as really what felt like a natural progression from Team in Training and running and doing intensive fundraising, to taking that story to not only Capitol Hill but also to the State House here in Maine and working with local groups of people to raise awareness for what's going on for cancer patients.

So it was really a wonderful, natural outgrowth for me; and it was a great way to connect with people and tell the story of what was going on not only with my family but what it felt like to be part of the community. And I know that my dad, being as sick as he was, it was helpful to have me as his voice so that I could bring forward some of the issues that my family was facing as a result of his treatment.

**Alicia:** Absolutely, and that's so beautiful to hear. I remember reading an article that said, "Advocates are upholders. They're protectors, they're champions," a number of different adjectives that they also associate with that. I think they also said, "promoters and backers and proponents."

And like you said, when your dad was very sick, he found comfort in knowing that there was someone who he knew advocated on his behalf. And I think that's the beauty of advocacy is that you're able to uphold a change or uphold a voice that may have been silenced by a diagnosis and bring that to the forefront of people who may

not be that connected to the actual ground, you know, have their foot on the ground and seeing what's happening, in real time I guess you could say.

**Kristin Fuhrmann-Simmons:** It's, really interesting you bring that up. I think that for me, becoming an advocate changed the way that I think about politics. It made me really understand that my voice mattered and that the people who were enacting legislation were people that I could have a face-to-face conversation with. They weren't people who were just out there or people who were on TV. That it really mattered what I had to say and that what I had to say was backed up by the research and support and statistics and all of the wonderful work that LLS does. And I really was able to be the one that brought a lot of that to life, and it made me feel so much better about being active politically as really feeling like we had the ability to effect change. So, it was powerful really all around.

**Alicia:** Absolutely. And what sort of training did you receive from LLS?

**Kristin Fuhrmann-Simmons:** Well, yeah, it's something that I had a tremendous amount of enthusiasm, which was wonderful.

**Lizette:** We can tell that, right?

**Kristin Fuhrmann-Simmons:** Yes, it's a great start. But they ended up connecting with a wonderful woman named Jen McGarry here in the Northeast of the United States. And Jen worked with another individual named Steve Butterfield here, and the two of them together really helped me understand policy issues.

I was terrified that somehow, you know, I knew that I was outgoing and that I could tell my parents' story and tell the story of what had happened to our family. But I was worried that I wouldn't be able to substantiate what I was saying with that research and the facts and all of those things. And I was like, "I have to memorize all this stuff." They said, "No, you don't." That's, and that's where the training at LLS came in. They said, "We are there to support you. We are going to walk in there with you.

We have a long-term relationship with many of these legislators. You are there really to tell your story.”

And that was the baseline that they helped set for me, and everything else from there was just really learning about how to grow the relationship and really relying on LLS’s expertise in the protocol, meaning how do we schedule those meetings, what do we say when we get into those meetings? How do we follow up so that that story continues to make an impact? And that was something that they really walked me through.

And, again, meeting them halfway already with that passion and interest, all of that other support that they offered me, it just felt easy; and it was, they were so incredibly supportive and enthusiastic about having me there that it really became a wonderful relationship and something that continues to grow.

**Alicia:** Absolutely, and I think you highlight a great point, those who might be interested in advocacy might think to themselves, “Okay, well before I do this, I have to know facts and figures, I have to memorize charts and graphs and really have everything scheduled before I begin this journey.” And I think you make a good point that they will be, they will be helped throughout this process; and it begins with, one, enthusiasm, which you mentioned, which is great. And also, your story, your personal story. I mean that’s what it boils down to; and that’s what the motivation is. You shed light on a great fact that you don’t have to have everything in place and memorized and informed about all sorts of, you know, diagnoses and treatments but really just come in with your story and allowing LLS to help, get that journey going and being that resource for you.

**Kristin Fuhrmann-Simmons:** Absolutely, and that’s where the greater team at the policy office really helps to support you. I mean they had everything, not only from the protocol of what it’s like to go in the office, but they had a team helping us with how to post on social media, how to talk about and directly make contact with your

Senators and your House of Representatives through things like Twitter and through things like Facebook.

So they really provided a very, it was like an open door; and it was a wonderful thing that as long as you wanted to walk through it and realize that, again, coming back to that idea that our story as caregivers, as patients, as survivors, that's the thing that brings all of that research to life. That's the thing that matters most because that story that gets into the mind of that staff, of that Senator, of that person, and then they can take that story and see how that legislation really affect real people in their districts.

So, again, it, was really that emphasis on teamwork and that they were there to support me; and I just really appreciated that from day one.

**Alicia:** And what was your family's reaction when they found out that you were going to speak with the lawmakers about some of the issues that they've struggled with?

**Kristin Fuhrmann-Simmons:** Oh, I love that you asked that because, my dad and I have a wonderful, we have an academic relationship, we have an intellectual relationship, and it's something my dad has spent a lot of time writing to his Senators over his entire lifespan. And when I first told my dad that I was going to be spending a day on the Hill, he cried. And my dad is a very emotional person and he was so happy that I can take his story to Capitol Hill; and, of course, he gave me a bunch of letters that he wanted me to share directly with our legislators here in Maine.

It was just such a special moment; and my mom, too, was very proud because it's one of those things, again, where it is so important to feel like you feel heard. It's so important to feel like the things that stress you are really understood at the national level. And my parents really were having a very difficult time financially and paying for my dad's lifesaving new cutting-edge treatment. And at the time that I decided to go into advocacy, it was very important; my dad is on Medicare, that our legislators

understood that these lifesaving treatments are available, but yet they were not affordable.

**Alicia:** Yeah.

**Kristin Fuhrmann-Simmons:** And so, getting that message out, I became an extension of that reality for my family; and they were really proud.

**Alicia:** Yeah. I was reading this article about someone who had a similar reaction in that she was an advocate for her mother in this case. And, she has the diagnosis, and she was doing fairly well; but she was on a lifesaving drug as well in which she knew that this could be it. This could be the drug that saved her mother's life and actually improve her quality of life dramatically.

And she advocated for those who aren't able to afford this type of lifesaving drug because not everybody can. That's the reality of it, and that's many stories of patients in that something is available and it's a horrible thought to think that if something is available that can save lives, you also may not be able to actually attain that said drug because of cost. So, it's interesting that you bring that up because it's a similar story to so many people in so many families.

**Kristin Fuhrmann-Simmons:** Absolutely. One of the first times I was in a room with fellow advocates down in DC, we had patients, survivors, caregivers from all over the country, I told this story of how, when my dad again, we talked a little bit earlier about treatments for CLL when he first started. It was an IV therapy, and it was, it's something that, while it saved his life, it was something that necessitated him retiring from his practice. He's a long-time family physician and internist, and his life is seeing his patients and being able to treat people in a critical setting. This is a big part of his identity.

So, giving that up and taking this kind of treatment, it was a very difficult tradeoff for my father. He did very well on it, but, of course, for two years he was not able to

work. Things settled down, but then his leukemia came back; and the option was either this one IV therapy or oral chemo. And we knew that with the oral chemotherapy, he would be able to go back to work, he'd be able to live the life he wanted for quality of life, right? this is the story we hear all the time.

**Alicia:** Right.

**Kristin Fuhrmann-Simmons:** He could go back and be in that setting and feel fruitful and feel like he is using his intellect and his skillset, or he could go back on this IV therapy because it was something that was completely covered. And we knew we had to do everything we could because he was in such an emotional state. We knew we had to do everything we could to help get him that medication.

And I mentioned something to this group of people. I said, "Has anybody here looked around their house and thought about things they could sell in order to get the medication?" And the amount of hands that went up in that room were too many hands. Right? Too many people raised their hands at that moment, and I realized how impactful that story was. And it wasn't just, us, that had to deal with that. It was a majority of people in that room who had to look around and say, "How can we access this care?" And I knew, okay, if it's more than just our family, if it's everybody in this room, then our legislators need to hear this. They need to understand that we need to make sure we have things like oral parity, which we now do, which is very, very exciting.

So, again, coming back to that idea where, this issue is one thing. When you're home alone and when you're, and you're saying you think that you're by yourself and you're absolutely not, and it's really powerful to get into that group of people and to get with other advocates and people who have experienced the same thing that you have and you realize that, "Okay, here's an issue we need to talk about it. We need to raise awareness, and we need to make change."

**Alicia:** Right



**Lizette:** I think your stories make it real, for people, including legislators. I think that people can read about it, people can hear somebody talk about it. But when you make it feel real to someone, I think that's when the real change comes.

**Kristin Fuhrmann-Simmons:** Absolutely. It's interesting that you mention that, and I'll tell a funny side story. So, after my first year of becoming an advocate of LLS, my dad and I were invited to a local meeting here in the State of Maine with our independent Senator, Angus King. And my dad decided to bring one month's supply of medication with him to show Angus King and to really make a quite visceral point about what \$12,000 in this particular medication looks like. And it's very small.

And Angus King stopped where my dad shook this medication. He's like, "I wanted to just show you what \$12,000 looks like." Angus King stopped and talked to my dad for almost five minutes, which for a Senator is a big deal; this is a room filled with people. And we heard that story echoed back to us, that since I've gone back to Angus King's staff every subsequent visit, he's like, "Oh, you're Dad's the guy with the medication in the room, right," because it made-

**Lizette:** Wow!

**Kristin Fuhrmann-Simmons:** -a big impact on him to say, "Here is what \$12,000 looks like." And, again, you know, that just reiterating that point is that really bringing it to life, showing people that, you know, my dad, my parents, both of them, they're in the healthcare field, they did well in their lives; but nobody can afford \$12,000 a month in medication. And he really, he made quite a visual impact as well as an emotional impact by just showing that.

So, again, really, the power of story, the power of realness and that connection coming back to how key it is for patients and caregivers and survivors to really share that because that's what really drives it home.

**Lizette:** Yeah, definitely.

**Alicia:** Yeah, every time I think about advocacy, the, the phrase that always comes into my head is “from paper to people. It’s weird because it pops into my head and I’m thinking because it’s one thing to, read the budget and, look at numbers regarding how much a drug will cost and read the context about why it costs that much. And in theory, okay, you understand that.

But then, when you actually hear the story, when you shake that medication bottle, that’s when you take all of those words and you say, “What are we going to really pay? What are you going to follow? Who are we going to help?” You know what I mean, that I think it’s so important for people to understand that it’s the people part of it that makes voices heard and action be taken and really change to be made for those who need it the most.

I mean when someone is diagnosed, the last thing they should have to think about is advocating for why they need something to stay alive, right? So, I think it’s such great work that advocates do; and I think that once people realize that it’s digestible, it’s not this huge, it’s not a huge mountain. It can be something that people come on board with, and there’s power in numbers. And so, it’s a beautiful thing to even hear your story and know there’s so many people like you stepping up and doing the work.

**Kristin Fuhrmann-Simmons:** Yeah. And the fun part about being an advocate, too, is that when you walk into these offices, you’re with people from your state. You’re with your LLS team. You’re not alone, and once you get over that hump of the first visit, right, you, you’re nervous, you’re like, “It’s your very first day.” You have to go through security at the Hart Senate Building, and it’s big and it’s white marble; and there’s a giant Calder black mountain statue in the middle of it. I mean it’s very impressive and slightly intimidating, and you realize that you walk into these offices and you see all of these wonderful memorabilia from your state. You see other people from different organizations in there. It’s a very proactive and congenial environment.

Many times, I've gone in, for example, back to Angus King. He has this blueberry bread teatime with his constituents. I didn't know that this happens, but I happened to walk in on one when I first went into the advocacy office. And, of course, I got dry mouth; and I'm not a person that I speak a lot for a living. I got dry mouth. I started to cry immediately. I was worried that I was a, just a mess when I got into the office.

And my LLS team was around me. They're like, "No, that was perfect. That was perfect." Because, again, it brought it all to life. And once you get over the hump of that first visit and then you see other LLS advocates wearing their red, wearing their blood drop pins on their lapels and you see them in the hallways of the Senate building, and you high-five when you're on the way through, it feels so powerful, and it's awesome.

And then when the day is done, of course, you're exhausted, but you have a great dinner and you just really enjoy your time; and you realize that what you have done, you showed up. You showed up for people that can't physically show up. You showed up for people who may otherwise be afraid. But you're there, and you're making it happen. And it's such an important part of really bringing the mission of LLS to life.

**Alicia:** Absolutely.

**Lizette:** So, you're really working as a team then?

**Kristin Fuhrmann-Simmons:** Oh, absolutely. Absolutely. Whenever there's an advocate Day on the Hill or even when someone does advocacy at a state level, you work with the LLS team as part of your district. Those leaders who are, who are part of your region show up and go with you to the State House.

Now, there are some advocates who are seasoned vets who coordinate with their LLS team and say, "I'm going to go out and have a meeting." But that's further down the road for a lot of advocates. The majority of the time when you go to the Hill, you are absolutely with a full team; and you have a chance to meet with the entire country's

team first and practice your talks, practice the way that you're going to tell your story. You have a chance to hear other people's reflections, so, again, you're never alone.

And we all, I should say we suit up. Everybody wears red in some form, right? We take great pictures, and we make sure that we have a chance to connect with each other throughout that Advocacy Day so that we share the energy, share the story, and really lift one another up.

**Lizette:** So we know you're comfortable speaking in front of an audience, but what would you say to someone who's interested in becoming an advocate that feels a little bit more intimidated by the idea of speaking with a politician?

**Kristin Fuhrmann-Simmons:** Yeah, oh, the terror is real; and even for someone like me. What I noticed, and, and I'll give an example. I had an opportunity last year to go out with a woman who was, it was her very first time on the Hill; and she was extremely nervous. And I just turned to her and I said, "Michelle, I will be there with you every step of the way. And if you forget what to say, we had practiced enough together beforehand," which is part of the whole program when you become an advocate that I knew her story, that I could ask questions of her if she forgot.

For example, I would say, "Michelle, can you tell a little bit more to Senator So and So about when you first got diagnosed?" so that I was her wing man so to speak. And that put her at ease so that I was someone who could be her partner. And, again, you have that kind of partnership when you go and work with the advocacy team so that you're really ping-ponging questions off of one another. Most every single time I've gone into a legislator's office it has been one where it is conversational.

And I try to stress that with everybody. The staff members that you're meeting with are there to really listen to you, and they care, for the major- the majority of the time. So the nice part is that if you forget something, you can say, "Oh, I forgot something" or "Oh, I'm sorry I'm turning into a blubbery mess and crying all over your office" or "This is really important to me, and I'm sorry I have dry mouth. Do you have a glass

of water?” And every single time you’ve been treated with respect. So, again you’re not alone; and it’s okay to be in there and, be real and be yourself.

The ending part of every single session when you go in, your LLS team is there with a packet of information; and they always direct that legislator or that legislative team member to that packet that contains everything in regards to the bills that we’re looking to support so that they have all that information in hand and that our job as volunteer advocates is to get that card, right that follow-up letter, and to leave with a smile and a sense of gratitude to have that time.

**Lizette:** That’s great. So like Alicia said, you don’t have to feel that you have to memorize all of these things about, which legislation you’re talking about or anything like that.

**Kristin Fuhrmann-Simmons:** No, not at all. You want to be familiar with it, but again, part of the training before you get out onto the Hill is to understand what we refer to as the ask. Right, so that we understand that, for example, this year when we go up, we’re asking for a cap on out of pocket expenses for patients who are on Medicare, or we’re asking for an end to surprise billing. And your LLS team will let you know if your Senator or your congressperson is in support of it or who’s on the fence. Many times, issues with LLS, but not always, have bipartisan support which makes things really nice because we can all agree that people should get quality to good healthcare. I shouldn’t, it’s not true for everybody, but for the most part, we’ve seen a lot of positive support for what LLS is doing.

So, again, you’re not in there on your own; and you have a packet of information in front of you that’s spelled out so clearly. It’s basically like a cheat sheet that you can look at. It’s your Cliff Notes that you can say, “Aha. This is still, if you feel like you want to say that.” But you don’t have to.

And then there’s the synopsis that’s sitting right in front of you. So that if you completely blank out during a meeting, which may have happened to someone I know.

Maybe it was me; I'm just saying, you can refer back to that sheet of paper and come back to that. But, again, that's not going to make or break you. That doesn't take away from the impact if you forget because it's still all there for them at the end, and you have a chance to follow up.

**Edith:** Kristin, what was it like visiting Congress for the first time?

**Kristin Fuhrmann-Simmons:** Whoo, yeah, that's a great question. I will never forget my first time walking into meet with my State Senators. The first person that I met with again, I think that I had talked about the fact that I had walked right into their blueberry bread and tea conversation. And I sat down, and I felt like, "Wow, I'm here, I'm on, it's showtime," and immediately I started to cry. And I realized that, that crying, to me, was more of a signal of the passion and intensity that I had felt for six years of my dad being sick.

And I just asked for a box of Kleenex, and one of the legislative aides came over, gave me some Kleenex, and squeezed my hand. And then I knew right away that it was going to be all right and that I could keep going, and it was wonderfully supportive. The team member I had with me from LLS just smiled at me. She said, "You've got this." And that's just to give everybody who's listening an idea of just what a camaraderie is there and what a supportive environment is there, that's exactly what it was like.

So, once I got that initial flood out, I was fine; and I was lucky that it was with one of my senators, Senator King from the state, who was a congenial person.

My second visit was with the office of Susan Collins, much more formal. And it turned out that the young woman that I was speaking to happened to be the cousin of one of my Team in Training teammates.

**Alicia:** Oh, wow.

**Kristin Fuhrmann-Simmons:** It was fantastic because it was like throwing her a softball if one of them should miss, including your running team. Your running team does these crazy, multiday 5K, 10K half-day, half-marathon events. So it was almost like a divine intervention came into the middle of that meeting and said, “Oh, you have an easy opening with this woman because she had heard about our Team in Training running team.”

So that made that meeting; now that does not happen often. But, again, that was my very first visit with our senators here from Maine. And so, it made it a lot easier, and it made me realize how those staff members were meeting me as conversationalists, they want to know where you’re from. Understanding that your constituent is a big part of this, so really bringing to life where you live in the state and making chitchat about where you’re from goes a long way in really easing the tension around the state.

So, when I recommend to all advocates, when you get into those meetings that you can ask questions like where are you from in the state? Sometimes those staff members are not necessarily from the state, but you can let them know where you’re from and what’s going on. It really is a great way as an icebreaker because then you get down to the heart of the matter, and you get over that nervousness.

And then by the afternoon, when you have your afternoon meetings, and it depends on if you’re meeting with the Senate first or House of Representatives, it feels much easier. But, again, allowing yourself that grace and space to let yourself be emotionally expressive, potentially the first time, there are a lot of other people who’ve done that same exact thing that very first time that they’ve met with somebody. But then you move through it, and you realize that you have the power, and you have that chance to connect. And, you know, it was much less intimidating the second, third and then fourth time around.

So, but yeah, I turned on the waterworks the first time. I didn’t even realize, and, and it was funny because the woman that I was with, she’s like, “It ended up being

perfect. It was the perfect person to cry with because it's all, it's all okay. It was like perfect." "Great, great." Glad it worked out well.

**Alicia:** And I love that you talk about the personalities and environments of when you went because I think it's important to remind people that politicians are people too. And so, I mean instead of being intimidated and it's natural, of course, but I think this also reminds people that you're telling your story to another person who may or may not be able to relate. However, they're just a person. I think reminding yourself of that, helps to get through the process a little better or a little more at peace, than going in and being completely dismayed.

**Lizette:** Right, yeah.

**Kristin Fuhrmann-Simmons:** Or starstruck when you just don't even know what to say. I think you-

**Alicia:** Right.

**Kristin Fuhrmann-Simmons:** -bring up a really great point is that every single staff member or even senator or congress person I talk to, they're happy to chitchat. Now, granted, you don't want to take up your entire time with chitchat, but like it really helps you to understand the humanity of who they are. Many of these offices are filled with great things that you can look at and be like, "Oh, I've been there, or I've eaten that food, or I've, you know, tried this thing." So, it's, a great way of, to look around and say, "This is, this is the person from my home state. They want to connect with me." And, again, as you mentioned, they're humans too. They want to hear from you, they want to connect with those stories.

And, unfortunately, we are in a situation where blood cancer is so incredibly prevalent that once we start telling the story of what happens is that many of our politicians can connect with it quickly and easily because they know somebody who's been affected



by a blood cancer and they understand that impact, and they're hearing from patients all the time.

One of the things that our team of Jen and Steven would really emphasize, and I know this happens with teams all across the country with LLS, every time we leave those offices, we really make a point to say to that staff member, to that senator, to the congress person, "You are going to have constituents that have blood cancer who need resources. If anything, else happens today and we open up the door for you and your constituents to have support, please reach out to us because we are here too. It's a two-way street."

So, of course, we're there to do the ask in terms of legislation, but we're also there so we're to say, "You and your constituents need to know that LLS is there for you. We have so many programs that support caregivers. We have so many programs that can support patients who are in need with understanding the pathway to care. We have programs for patients who can't afford their medication. We want to get the word out."

And that's been a really interesting part of advocacy as well is that I've had staff members reach out to me and say, "You know what, I've had some people call about this. Who do we call at LLS to make that connection for this group of townspeople or this town nurse, or this particular leader?" And that's a wonderful relationship that has started as a result of, of the advocacy program. So that's somewhat secondary, but it happens, and we really make a point to say, "You know, we have something to offer as well. We are here to support your community." And we really make a point of really uplifting all of the different programs that LLS has to offer so that people become more aware of the access they have to care.

**Lizette:** They're actually helping their constituents by getting them to us for support and assistance. So, that's really important.

**Kristin Fuhrmann-Simmons:** Yeah, it was how I first heard of LLS was a flyer that was sitting in the Emergency Department of Maine Medical Center. And someone had left it there, and it was “Do you want to run a race?” It was a TNT purple flyer. And I picked it up and this two hours after my dad was admitted to the Emergency Department, I was signed up for my first half marathon.

**Alicia:** Wow!

**Kristin Fuhrmann-Simmons:** It’s one of the things you’re like, you’re in this moment of family crisis, would you want to sign up for a half marathon? Well, it was at Disney World. It seems like a lot of fun. It gave me a great connection. And I think what has happened as a result of being part of LLS is being able to spread the word to other people that, especially in the caregiver role, what has been so important to me is to connect with other people that understand not just the stress but the real desire that we have to improve people’s lives. That I’m so interested in, of course, helping my dad and help helping him feel better and helping him get everything from his groceries to get back to his quality of life and gardening and seeing his own patients, but also so that when people are in that moment of fear, of crisis where everything feels like it’s shutting down around them, that they feel like they have someone they can talk to.

And it happened for me and so I want other people to feel like it can be a reality for them too. And it’s so nice to be able to get involved at any point where you don’t necessarily have to go run a half marathon, but you can. It’s amazing. And you, can come and be an advocate if you want to be as well. You don’t have to be comfortable in front of a crowd. You can be comfortable just sitting one on one with somebody because you’ll have that same kind of support from LLS no matter if you’re gregarious or if you’re a wallflower. You can have both. So that’s nice.

**Alicia:** I love that.

**Lizette:** Yeah. And, and one thing you're saying, and one thing that I think is really important is that you're a caregiver and we do have our caregiver community. And it's really important for our caregivers to know that, yes, you can be an advocate. It's not just patients telling their own stories. You're also part of that story, so it's very important just to know that patients as well as caregivers are invited to be part of our advocacy team.

**Kristin Fuhrmann-Simmons:** Absolutely. I would love to see caregivers come forward and be able to share what has happened for them, what they have seen because we have really dealt with so much in terms of helping to navigate, navigate cancer care, you know, as a whole. We understand and see the stress in a very different way than our loved ones see it, and it's really important that our legislators understand the holistic impact of what cancer does to a family, to a community, to well-being overall. And I think meeting together with other people who've been in the same situation like me and my own family, I know that that's a story that needs to be heard because there's so many different things that people have had to deal with. And really, we want those nuances; we want those details. We want the things that maybe we're not seeing already. Maybe we need to become aware of other facets of cancer care that aren't yet coming to life to really round out how we can become better advocates for the cancer community as a whole. So, I would, I firmly feel like calling all caregivers out there right now who want to become advocates. I'd love to have you with us. I'd love to have you be part of this.

**Lizette:** Definitely.

**Edith:** Kristin, how has your day job in marketing helped you be a more effective advocate?

**Kristin Fuhrmann-Simmons:** Oh, that's such a great question! One of the things I realize is so important is the use of whatever tools we have in our toolbox. I do a lot of marketing through digital media, so social media, blogging is a big part of what I

help my clients with. So, I really understood the impact of those platforms and how they're a wonderful way to share the story of what's going on in cancer care. And they have an immediate feedback so that people can see what we're doing on a day-to-day basis. Every time I've gone out and done any work with advocacy, I always make sure that I'm posting about it and doing videos about it.

And I also understand that it's a way that we can immediately get in touch with our legislators where in the past we had good old-fashioned letter writing, which I still absolutely advocate for, or we had op-eds and editorials in newspapers. But I think coming from a background in digital marketing, I understood that there was an immediate return with being able to reach out on social media with the real responses happening a lot more quickly as a result of reaching out on platforms like Twitter or even Facebook. And, also, coming from the marketing world, I understood how to craft that message. Video is huge, and the more that we as advocates and LLS, as a whole, are sharing through video and even photos, the more we're giving a visual to that story, the better the algorithm. And I, coming from the digital marketing world, I understand the algorithm and how important it is to get top of mind in the mind of the public. So, really, I've brought those skills to bear in how I advocate for cancer care.

**Edith:** Kristin, can you tell us a little bit more about your meetings with lawmakers in May?

**Kristin Fuhrmann-Simmons:** Certainly. So, this year it was a little bit different because we didn't go to the Hill per se and we just had telephone calls with our legislators. And it was a little bit different because we packed everything into one day where, in the past, we typically have a three-day event where we'll arrive, then we have our Day on the Hill, and then we have a follow-up meeting. But this year we packed everything into one day, and we had not only our training from the policy office but best practices training where we were able to pull in advocates from, who had had experience being on the Hill before to share with the new advocates in our group. And then we broke out and we talked to our legislators over the phone.



The same thing that had happened in previous years where we got on these calls as a team. And we practiced beforehand with who was going to go first, who would make the introductions. So that the storytelling and the flow of that conversation would go easily. And every single person, every single legislator or staff member showed up on time to those meetings. We made plans for follow-up. So, it was a little bit different because we didn't get that face-to-face time. The calls were much shorter than our face-to-face meetings typically are in person, but this year was a little bit different as well in that we were really looking for, to support issues that are affecting people in the healthcare community as a whole.

So in the past we were asking for legislation around supporting things like, as I mentioned, oral parity for new chemotherapy drugs that were coming out and making sure that those were covered under a prescription benefit versus a hospital benefit.

This year we were advocating for a cap of out, out-of-pocket costs for Medicare Part D, and also asking for an end to surprise billing. Surprise billing has been an issue that has affected people across the board in the healthcare setting where they're getting an egregious surprise bill where all of a sudden something will pop up for a treatment that they were not made aware of and then they end up with this monstrous bill that they cannot cover. And luckily we're in a position where, many of the folks, at least that I met with on the Day on the Hill, were in support of making sure that we put an end to surprise billing, that patients would not be held responsible for those surprise and egregious bills out of pocket.

So, again, it was a little bit different, but we kept that same plan of action where we really work together as a team and we practice as a team. We'll use the tools of technology available to us like our online webinar breakout rooms. We were able to meet face to face with some of the other folks who were in our districts, and, of course, then in our state, and we practiced with the people that we were going to be making those phone calls with so that we kept alive that energy and camaraderie and,

of course, that training that's so important to help everybody who's a volunteer advocate feel that level of support.

**Alicia:** Kristin, you mentioned how advocacy looked a bit different this year due to the current Covid-19 pandemic. For those who may be interested in advocacy but unsure of what that looks like now, what has the experience been like for you? Is it mostly phone calls and online meetings?

**Kristin Fuhrmann-Simmons:** So that's one part of it for sure. And I think for the time being, I think that that's where it will live. I think in many ways we're looking to exercise our advocacies in that digital space, and we really talked heavily about coming back to some of our outlets that we had not exercised before. So, this year, for example, we talked heavily about things like editorials and op-eds and soliciting that kind of coverage for the issues that we are hoping to talk to our communities about.

In the past several years, we've relied more on face-to-face appointments or social media, but we really took some time this year to really put forward the fact that some of these older forms of media are still incredibly powerful. And because we have to make this shift where we're not able to meet in real life, to take the time to put together that op-ed for your newspaper or your letter to the editor, and what that looks like. We had wonderful training this year from a team that really helped us to construct step by step what that is. So it was really nice to be able to feel empowered to do so because many of us have not done that level of writing in the past, so that was nice to come to that because we aren't, unfortunately, we're not going to have that chance to do face to face for this time being. And until we come back to that, we need to really exercise, really use all the tools in our toolkit.

We did emphasize this year, a more robust social media and trying to teach people more about using video, which is exciting for me because I love seeing people tell their story online.

**Alicia:** Awesome.

**Edith:** Thank you. What do you hope to achieve this year in terms of policy reform?

**Kristin Fuhrmann-Simmons:** Oh, so many things! Policy is always on my mind. I'm really interested in seeing the continuation of that cap on out-of-pocket cost for Medicare Part D and cap on out-of-pocket costs across the board for patients. Many of our life-saving treatments that we have helped to support the development of at LLS need to be affordable for the people that need to have them. And I want to make sure that patients have access to them in ways that won't cause them undue stress. And, unfortunately, we have a situation where we have so many of our patients who are not filling their prescriptions because they can't afford them, and I'd like to see that end.

So, again, moving towards that cap on out of out-of-pocket costs especially in a way like Medicare Part D, is something that I will continue to be pushing towards because, again, we talked a little bit earlier about the fact that we have access right now to medications that have completely changed the quality of life for cancer patients; conditions that have turned once fatal things into chronic conditions. And I don't want to say that across the board because I know everybody is different, but we now have the opportunity to extend time, right? That's the thing. That's the most important thing is giving us time.

And the use of those medications are what give us that precious time to be together. And I think that each of us is focused heavily right now on the quality of our lives and how important that is, and affordability is key now more than ever because many of us are shifting in what our healthcare coverage is. We have a lot of people in a very flux state of what's happening with their own work. So, again, these kinds of things, making sure that our patients have access to those lifesaving treatments in affordable ways is huge for me in terms of what I can and will continue to advocate for.

**Alicia:** Awesome! Kristin, on our website, we have a slogan that says, or a motto that says, "After diagnosis comes hope." If you were to finish that sentence, what

would you say? Just based off of your experience with advocacy or just, you know, your family experience, how would you finish that sentence, "After diagnosis comes?"

**Kristin Fuhrmann-Simmons:** After diagnosis comes opportunity. And I don't know if you can hear the waterworks starting for me because I am filled up when I say that because we had the opportunity to examine how we were as a family, what we were focusing on, what really mattered to us. And as difficult as cancer can be, it's also filled with the opportunity to really come back to love, and to connection, and to understanding that the things that matter are being together and having time together. And so that's an incredibly powerful thing. And when you focus on that, that can drive you through anything, so fund raising, advocacy, caregiving, all the things that happen as part of the cancer diagnosis. So, I feel very strongly that after the diagnosis of CLL came real opportunity for my family, and I'm incredibly grateful for it.

**Alicia:** That's so beautiful. Kristin, thank you for everything that you're doing and those that you've inspired to become an advocate, everything that you've done with and for LLS and for telling the story of not only you but of your family. And we're so happy to hear it, to hear how well your father is doing.

**Kristin Fuhrmann-Simmons:** Thank you so much. It's such an honor, and I feel so grateful to be able to continue to tell the story and to hopefully inspire other caregivers that are out there to get involved with advocacy. It's a ton of fun, and it's really empowering.

**Alicia:** You inspired me. So, Kristin, for those listening who are very interested in becoming an advocate, how can they do that? What's the process?

**Kristin Fuhrmann-Simmons:** There are two ways they can become an advocate, and it's very easy. Toe in shallow end of the pool, which is a great way to go, is to become part of the Mobile Action Network where you can go online to the LLS advocacy site which is [LLS.org/Advocacy](https://lls.org/Advocacy) or email [advocacy@lls.org](mailto:advocacy@lls.org), and you can sign





up to get mobile alerts for what's happening right in your state and you can become an advocate directly from your phone, once you're prompted, you can send messages to your senators or your congress people right there from your phone and let them know how important these issues are to you.

If you want to take it a step further, you can sign up directly on the site, too, and one of the LLS advocacy team members will reach out to you, talk to you about your story, and see how you want to get involved either as a face-to-face advocate, once we open back up to face-to-face meetings, but also just share your story online. So, there are two great ways to get started.

If you're gung-ho and you really want to go all in, I highly recommend going to the website. Everything is there. It's spelled out for you. And if you just want to start with the Mobile Action Network, that is a great way to go because that makes a huge impact too.

**Alicia:** Awesome, yes. Thank you, Kristin. And for those, again, who would like to become an advocate or would like to read more about advocacy overall, you can visit [www.LLS.org/Advocacy](http://www.LLS.org/Advocacy).

Thank you so much for joining us, Kristin.

**Kristin Fuhrmann-Simmons:** Thank you all so much. I really appreciate it.