

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Anxiety and Hope: Living with Chronic Lymphocytic Leukemia (CLL)'

Description:

Join us as we speak to Donnie Hill, a patient living with chronic lymphocytic leukemia (CLL) and small cell lymphocytic lymphoma (SLL). In this episode, Donnie shares his experience and the stresses of living with a chronic disease like CLL/SLL, the various treatments he has had since he was diagnosed in 2008 and how he has worked with his doctor to determine the best treatment for him. Don't miss this engaging story of how, throughout his cancer journey, Donnie continues to celebrate life and hope with volunteering, advocacy and the love of his family.

Transcript:

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

Edith: I'm Edith.

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

Elissa: Today we will be speaking to Donnie Hill who was diagnosed with chronic lymphocytic leukemia, or CLL, and small lymphocytic lymphoma, or SLL, in 2008. Donnie has had multiple treatments throughout the years and remained cancer free from 2014 until 2021 when he recently relapsed. He is now considering his options for watch and wait or targeted treatments.

Throughout Donnie's cancer journey, he has joined the fight with LLS to promote patient care and the development of new treatments. He has been a leader in fundraising as well as active in-patient services and lobbying. Donnie states that LLS is the one agency fighting for all blood cancer patients so everyone of us has a fighting chance.

Even though he has faced multiple battles with CLL/SLL, he has been able to lead his electronic company as president and is proudly an active papa to his three granddaughters. He is a husband, father, and papa and refuses to allow cancer to take joy from his life. Welcome Donnie.

Donnie: Thank you. Thank you for that introduction.

Elissa: So, Donnie, let's start with your diagnosis of CLL/SLL. Those diagnoses are closely aligned. Could you tell us what CLL/SLL is?

Donnie: Sure. They're really the same disease or seen as the same disease. What differentiates the two is where the cancer cells are mostly expressing themselves. With SLL it's expressing itself out of the lymph node, and with CLL it's mostly expressing itself out of blood, so it's leukemia. But if you look at the cells under a microscope, they're exactly the same, treatments are the same; it's always referred to as the same disease.

Edith: So, Donnie, what were some signs and symptoms leading to your diagnosis?

Donnie: Well, like everyone, cancer was the furthest thing from my mind, and I had had the beginning of the year a little nodule at my hairline. I thought it was just a little infected cell from the hair or perhaps just a small lymph node from infection. I would get a swollen lymph node every now and then if I got an ear infection or whatever, so we didn't think much about it. But after time, couple months, it wasn't going away. And we were getting ready to go on a cruise, and I even joked, like, "Oh if this turns out bad and I don't make it to the cruise, you have to have an umbrella drink in my honor." And just kidding around, not thinking anything.

So, I come back from the cruise and within a couple months that one nodule now is two nodules on the back of my neck and I'm like, "Maybe this isn't good." So, I go to my general practitioner. He's not too concerned, but he's, like, "We're not going to fool around. We'll send you to a surgeon to make sure what this is." And literally the

surgeon walks in, feels my neck, and, of course, before that, I did what every good American does. I went to Google to figure out what I had. And I had a-

Elissa: Oh, that's dangerous.

Donnie: -long list of things I knew I had. Cancer was way down at the bottom. And, unfortunately, the surgeon pretty immediately rubbing them said, "It's some type of cancer, but we won't know till we get the CAT scan and a biopsy." So, we scheduled both and, as you can imagine, my legs are kind knocked out from under me and very scared and concerned, and you start thinking all these things about my family and wait a minute, how am I handle all these things?

And we got the CAT scan first. The biopsy was a couple weeks out, and I got a call on a Friday morning, it was pouring rain down, and the surgeon said, "We're not going to do the biopsy because it looks like you have tongue and throat cancer also, and from the CAT-"

Elissa: Oh my gosh!

Donnie: "-scan, we could see all these swollen nodules on your tongue and throat." So, it went from bad to worse if you would. You look up tongue and throat cancer and it's just horrible things. So, my wife and I today laugh and say, "We were probably the only people in the world who prayed for lymphoma."

So went through some tests. I did all kind of biopsies on my esophagus and my tongue. It turned out I do have a knotty esophagus but not cancerous and my tongue had a little piece of skin left there when I had my tonsils removed, and so we did the biopsy on the nodules in my neck, and it came back as CLL. And thus, my journey began.

Lizette: Wow, a lot of times people don't know that it's a lymphoma or a leukemia and other diagnoses start popping up here and there. It sometimes takes a long time

for a lot of our patients to get diagnosed with a blood cancer because it could be so many other things. How long did that process take you?

Donnie: The actual diagnosis was fairly fast after that little sequence I went through, and that sequence took probably a month to get through those other tests and things. But once the biopsy on my lymph node was done, I had a diagnosis back within a week, and I was referred to an oncologist. I was blessed that I was referred to a very good oncologist and he was an older man that was nearing retirement but very skilled, very knowledgeable. Lizette, I was thinking about you said as you're going through this early stage and getting these diagnoses. First of all, when you hear the word, "You have cancer," I don't care how tough or how prepared you are, it puts your head in a little bit of a spin. It's, it's only natural. And then all of a sudden you start hearing lots of terms that you've never heard before, medical terms and even when someone's trying to break it down for you.

So, one of the things I always tell people, "Make sure you have someone with you." It's just so important it's someone you can trust because you can't hear everything and neither can they, but together you'll pick up things. And don't be afraid to write things down and ask your doctor to repeat it and say the words again to you because you're going to want to do research like through The Leukemia & Lymphoma Society who can help you so much. It's over, too overwhelming early to be able to get all the information correctly. So, make sure you have someone who'll be with you.

Lizette: That's great advice.

Elissa: We actually hear that a lot. We've had a lot of people say, "Once you get told you have cancer, it's kind of like the Charlie Brown, like, wha wha wha."

Donnie: Yes.

Elissa: That's kind of all you hear. So, it's good to have-

Donnie: Right.

Elissa: -somebody with you to actually listen to what is being said and where we go from here.

Donnie: Right.

Lizette: Right. A lot of people say that, once they're hearing that wha wha wha, they talk so fast about trying to tell you what the cancer is, what the treatments are, and you're just not there yet.

Donnie: Right.

Lizette: You're just processing that you have cancer and sometimes there isn't that time.

Donnie: You're right and it's just not processing that you have the cancer, which is a huge thing to get hold to, but it's, "How does that fit into my life?" Your life will never be the same once you have that diagnosis. It is changed forever. And what does that mean now? I'm a father with cancer. I'm a husband with cancer. I'm an employee with cancer. It bleeds into all those areas and processing that and reorganizing your life is a challenge.

Lizette: Definitely.

Elissa: So, we mentioned in the introduction that you went through a variety of treatments. With CLL, sometimes the treatment starts with what's called watch and wait or active monitoring. Did you start with that or another treatment?

Donnie: Well, we discussed watch and wait. And of all your treatment options, sometimes wait and watch is the most difficult because I think we're all trained, if you have cancer, you got to immediately do something about it. Let's cut that thing-

Elissa: Right.

Donnie: -out and zap it with some kind of radiation and stab it and, you know.

Elissa: You're like, "What do you mean you're not doing anything right now?"

Donnie: Right. "What do you mean go home and we'll see you in three months? No, no, no. You're going to see me now and I want something done!" And we talked about that. In fact, as I said, my first physician was very wise. And he explained that he had had a CLL/SLL patient that never went through treatment. Now his tumors grew, and he was an old farm boy that didn't care, but he died of other causes many, many years later.

But for me at that time after some more tests and evaluation with my oncologist, we decided we probably needed to push it back. Back in 2008, things weren't quite as sophisticated with DNA testing, and we weren't quite there yet. We're starting to come around. All those things were starting to come around. We knew how to do some of them, but we didn't know what to do with the information. So, we did something called COP-R, which is old time chemo. It's very rough. The R is rituximab and rituximab is a monoclonal antibody that The Leukemia & Lymphoma Society helped bring to the forefront and has served just wonderfully now for well over a decade. And those monoclonal antibodies while they're not a great treatment by themselves, they help other drugs be way more effective. It kind of weakens the cancer cell and allows the other drugs to do their job.

So, I did six rounds of what's called COP-R, and it pushed the chemo back. I was cancer free, but my oncologist, explained to me it was not gone, that at some point it would come back. And it stayed back for several years. You go for whatever your doctor sets up in three-month, six-month checkups. Those checkups are another kind of difficult thing. You kind of leave the doctor's office and he tells you you're cancer free but when you all of a sudden look at your calendar, it's like, oh yeah, Friday I've got to go to the doctor and find out is the monster back attacking. It slaps you in the face. And, even to this day, when I realize the date's coming up, it's just a kind of a harsh reminder that, hey, I do have cancer.

And the battle with CLL and SLL, as well as many of the indolent lymphomas is that you do wait and watch, or you have these long periods. Part of that struggle is I always feel like it's like being in a room with a bear or a lion, this monster. And most of the time it's in one corner and I'm in the other and everything moves along fine, but you're always aware it's going to wake up at some point and you're going to have to deal with it. And so, there's a stress level that's underlying, it's very subtle, but it's always there.

Elissa: Yeah. A lot of cancer patients, once they finish treatment, it's kind of that worrying about relapse, worrying about a secondary cancer, worrying about it coming back, but it's very different with a chronic cancer like CLL/SLL where you know it's coming back.

Donnie: Right.

Elissa: And it's just always there in the background. I mean that sounds like it would **be just incredibly stressful to just have that little piece there all the time.**

Donnie: In addition, you have all the other worries you just mentioned. This treatment, this COP-R, I know it damaged some of my DNA and my chances for other cancers go way up and so, you have those concerns. So, every time you get a funny looking thing on your hand, you think, oh my gosh, you have skin cancer or, oh, my big toe is hurting, I must have toe cancer. It raises that level a little bit. But the big one is just what you say, knowing that you'll never be free of the cancer is a challenge unto itself.

Elissa: Right.

Donnie: And you haven't asked this, but I'm a First Connection volunteer.

Elissa: Oh good!

Donnie: Yeah, and that's really been good. First Connection is an opportunity for newly diagnosed patients to be hooked up with by phone someone that is usually five years out with the disease that you have, like CLL/SLL, and they try to put someone similar to you in a sense of age or proximity, those kinds of things. And I remember one call I got from a lady who was recently diagnosed with SLL/CLL, and she was about my age; I'm 63. This was probably ten years ago I was in my mid-50s, and she started the conversation. Probably for 20 minutes, I just listened. And the whole part of her conversation was how to plan for her death.

I finally broke in and said, "You're not dying. You're not going to die tomorrow. You got to plan for living." One of the mistakes you can make is assuming you're not going to be alive. You spend all your money, or you sell your house or whatever.

Elissa: Right. That's not good!

Donnie: People do that sometimes. And ten years later you're still here and you're going to be here. It's an indolent cancer, it's not eating away at you, and so think about how you're going to live with this and plan your treatments out and make sure you have a good doctor that you can trust, and you have confidence in.

And about four months later, I was at a conference speaking, and I came down off the stage and she come running and hugged me around the neck. And it was her.

Elissa: Aw!

Donnie: She's like, "Thank you so much." She said, "I'm living now, and you got me turned in the right direction." And that was so moving, but that's the focus we have to make sure we have with CLL/SLL is that we're focused on living, not dying.

Elissa: I love that. That is such the benefit of something like First Connection when you can talk to somebody who's been living it for years and be talked off that death track that-

Donnie: Right.

Elissa: -you can live with this, you can survive this, it's going to be okay.

Lizette: Yeah. I think it's great that you were able to speak with her. I echo Elissa, our First Connection program is great because people who are newly diagnosed really want to talk to somebody else that has gone through it, has been in their shoes, not so much other people who are just kind of giving you advice but have not walked in those shoes. They don't really know how you're feeling, what you're going through, especially, like Elissa said, CLL where you know it's going to come back. You're in watch and wait or you're in a remission after taking medication and you know it's going to come back and that is really difficult for a lot of folks.

I remember being in the Information Resource Center as an Information Specialist and talking to patients. And it was really tough having that conversation of, you're diagnosed with CLL/SLL and now you're on watch and wait. And it's counterintuitive. You know, "I have cancer and I don't feel like I'm doing anything about it." And then that conversation of "I'm in remission, but how do I live my life without thinking every day that it's going to come back?"

Donnie: The one important thing, I think, with understanding wait and watch that's been helpful to me is, unfortunately, with many cancers, you get one shot with the treatment. Once you use it, you don't get to use it again. The cancer is real smart, unfortunately, and usually a second time around doesn't work. So, wait and watch went from being kind of my enemy to my friend in my thought process of, okay, if I use whatever treatment I'm going to use today, is there something else out there that when this stops working or when my cancer comes back and takes me out of remission, will I have another option?

I've always been fortunate that while I did a treatment, there was always something else out there and something else on the horizon. And those things on the horizon is part of what LLS is about because they spend the bulk of their money on research for

treatments. And ibrutinib, which is one of the drugs that I'll be considering, was primarily found at The James Center in Columbus, Ohio, and LLS was a leading contributor to helping bring that to the forefront. So, the wait and watch the longer you can wait, and it's been proven that there is no advantage to treating early. The longer you can wait, the more years you're gaining both in life – you've lived that before you have to do another treatment – and two, it's giving research time to be bringing these new treatments and new alternatives. So, wait and watch can be a very powerful tool in helping you have a very long life with CLL.

Lizette: Yeah. And also, you have life without side effects at that point because there may be some side effects from the treatment that you're eventually going to have that I guess you don't have to worry about just then.

Donnie: And it's like my doctor says, "Every treatment I give you, every pill I give you has a little bit of poison in it." And I mean there's no perfect pill, there's no perfect like your body is. And you watch the commercials on TV about all these different drugs now and they all have beautiful music playing, there's flowers out, and it's like, "Wow, I don't have that disease, but I think I want to take that drug so-

Elissa: Right.

Donnie: "-I could have my life," you know.

Elissa: And then side effects.

Donnie: But I realize the difference between how difficult a treatment is and its being not too bad that what determines that is who's giving it and who's getting it. The person that gives it, it's just like advice. Everybody has advice, but until your name is called and put under the cancer diagnosis, you don't know how you're going to react and you don't know what you're going to feel inside. And same way with these treatments. There is no easy treatment. I just don't believe that.

Now people handle them bravely and they do great things, but there's challenges. And when you look and you're seeing these things being put in your body and you're wondering about it, what effects and you don't feel good and all the hundreds of possibilities from diarrhea to nausea and to many, many more, it's difficult. So, as you said, Lizette, the longer you can be in wait and watch, the longer you have without having any side effects of these treatments.

Elissa: Yeah. That's a tough thing. We actually discussed it in a recent podcast about how the cancer medications need to be strong enough to kill the cancer but not kill the host. It's such a fine line in there, that it has to be strong. It has to go and kill that cancer, so you are probably going to get side effects from it, but it is going to affect people differently.

And there's something to be said also which you said earlier is that, just kind of staying alive in the watch and wait and more treatments coming out and more options coming out. And I think that's a great thing to be able to have hope that new treatments are coming out all the time. And especially now in the cancer world, new targeted treatments are coming out all the time. So, it's just kind of staying alive and you don't really know what's around the corner that could be that great treatment for you.

Donnie: When I was first diagnosed in 2008, I remember getting a pamphlet from one of the National Cancer Institute facilities, and the doctors being interviewed made this statement and it really stuck in my head, "There will come a time when we'll look back and say we were barbaric in treating with chemo." And we're pretty much getting there now. Almost all the drugs are being developed as targeted drugs. It goes in and repairs some protein or the cell. It's all DNA driven and it's truly after that cancer cell and not hurting the rest of your body. It's a huge difference and it's changed the whole landscape for patients and how we deal with cancer.

Elissa: Yeah, definitely. So, speaking of chemo, you had said that that was one of your first treatments and then you were in remission for years. I do have a question,

maybe for listeners who might not know how the treatments for CLL work or newly diagnosed. Is it essentially a watch and wait then? So, after you go into remission and you're doing well and you're just kind of do the watch and wait until the cancer comes back?

Donnie: Yeah. Once you go through whatever treatment you decide, and each of the treatments are different. I've done chemo twice. It was a set amount of treatments. I did six of each of them and then you're in remission. And you would go back and visit your oncologist at whatever timeframe, somewhere between three and six months, every three to six months. And, of course, he'll do a complete blood study and you get to know your body pretty well, you know. And so you're constantly checking feeling nodules under your arm, the back of your neck in the areas you know they could come. And you wait. And you watch your blood counts and until the day, it seems like they might be coming back. Hopefully, it's a long one, long wait.

Elissa: Hopefully, it's a long one. Yeah. It seems like several years for you. So then what happened next? 2014 is when you had relapsed and started treatment again?

Donnie: Yeah. It's just it wasn't coming back real strong, but I had a good reaction with rituximab with the chemo, so my oncologist, again, suggested, "Why don't we just do four rounds of rituximab? It's targeted, it's not harsh. You're just showing a little bit, and this probably will push it away." And it did. It was IV treatment, four rounds of it, and it pushed it away for a few more years. And, again, always looking at, okay, the more time I get the more chances there'll be other treatments laying out in front of me.

Edith: Donnie, we mentioned in the introduction that you relapsed again recently and now we have some new treatment options available. Could you talk about those?

Donnie: Sure. Well, if you go back, I had another treatment in 2014, and at that time, I took what was considered the gold standard for CLL/SLL, at least by MD Anderson in Houston, which is one of the premier cancer institutes. It's called FCR,

and it's two chemos and rituximab again. But making that decision to take that is a good example of having a good relationship with your oncologist. When my oncologist and I first started talking about it was time to do treatment, he was suggesting that maybe we do a different chemo called bendamustine, which is a chemo that was developed in Eastern Europe, during the Cold War. It's effective, not as long term, but it's not as harsh either to your body. And he was thinking maybe we would do that.

And I had been doing a lot of research and was reading a lot of papers from MD Anderson and it talked about this FCR. And by the end of the conversation, he's like, "You know, you're in your mid-50s. Probably the next the time you're ready to do this again you might not be able to handle FCR. It's pretty tough." He's like, "I admit you're right. This might be your best option."

So, it was a conversation I had with my doctor, but if I didn't have the educational tools from LLS and the knowledge of going to some of these conferences and the experience of having a really good doctor that wanted to hear how I went through it or what my thought process was, I would've gone with a different treatment. Maybe it would have been just as good effect, maybe not, but it's real important don't feel like your doctor will get mad if you ask questions. And I was constantly pulling out the study from [former] Yugoslavia and some doctor, some silly things, "Have you read this one?" And he's like, "Yes, I know that one." And but he quickly found out that I was a knowledgeable patient and he appreciated that.

And it's real important that you're your best advocate, and it's been proven that people who are informed have a better outcome than people who just go in and say, "Whatever you think." There's no blue book that the doctor goes to and says, "Well at this age with CLL at this level, this is the treatment." There's always alternatives and options and only you can make the best choice for you because it's your life and it's your life experience that's going to be affected.

So, I did FCR. And the end of last year, I had had a CAT scan. Actually, it was for something else. I keep having this little nodule show up in my lung and they keep assuring me it's nothing, but we got a CAT scan with it, and that nodule was gone but I had a nodule under my left arm. It was very small, but the radiologist noticed it. So, we knew that's the CLL starting to come back. Now you never know will it take a long time or come back fast. Over this year, it's kind of growing exponentially. The nodule now where you couldn't see it is pretty big under my arm about like fist size, and I think they're growing under my other arm. I'm going to have a CAT scan next week, and we'll see if it's on both sides of my body which is one of the determinations if it's just sitting on one side or has it gotten on both sides of your lymphatic system.

And so, I've had a conversation with my doctor. There's two drugs. The first one is ibrutinib, which was really coming out when I decided to do FCR. I was in the middle of FCR when it was being opened up to all CLL patients and it's proven to be very effective. But a couple years ago another drug called venetoclax has come out. Both of them are targeted therapies. The venetoclax, if I'm remembering correctly, actually goes to the protein. There's one protein on a cell that is the protein that tells it when to die. And when you have CLL or a cancer cell, that protein shuts down. So venetoclax goes in and tells it, "Hey, wake up! You got to start working again." And it works so well, like ibrutinib, that you have to be real careful because it'll kill so many cancer cells you can get what's called tumor lysis. It can overrun your kidneys and your liver it's trying to process so many bad cells. All these drugs they don't kill the cancer. It tells the cancer cell to get out there and do what you're supposed to and let the body kill it. And that's kind of a cool thing. So, your body starts killing all these cancer cells like it's supposed to.

So, we'll see what my CAT scan says, and, again, it'll be a conversation I'll have with my physician do I do ibrutinib, do I do venetoclax? They are advantages. The ibrutinib you take until it stops working. It could be years and years and years. The venetoclax is more of a two-year regimen you take and then you're done. There's

even talk now and some research that you take them together. I probably won't do that primarily with the thought, okay, if I take one now and I get remission five years, seven years, whatever it may be, I still have one drug that I haven't used that I could use down the road. And there's new research coming out with even newer ones, so I've always got that thought process of keeping an extra bullet in my pocket.

Elissa: Yeah. And you said a couple things that I think are really important. One is to make sure you have a good specialist who knows your type of cancer and all the different kinds of treatments and can really talk to you about that. But one thing that we focus a lot about at LLS is shared decision-making. So, working with your doctor to advocate for yourself and understand your treatment and make decisions together so you have that important part of your treatment and those decisions to make as well.

Donnie: And I would say not all physicians are created equally.

Elissa: Yes.

Donnie: And you hit it, Elissa, make sure your physician is very experienced in the disease you have. That's very important. They can be a general hematologist/oncologist and maybe not have a ton of experience with CLL and when they start talking things like, "Well this is just a very generic cancer; it's no big deal," maybe it's time to go get a second opinion.

Elissa: Yeah.

Donnie: And the second thing I would say, and I have found this, the better the doctor, the more confident he or she is, the more willing they'll talk to you and want you to be involved. It's the doctor who gets insulted when you ask questions or have concerns that's one that's not real confident. So, make sure you have someone that will be your partner and have that exact conversation. I've had two doctors now. My first one retired and I went to my new one who's amazing, amazing doctor. But right off the bat, I explained, you know, "I want your expertise. I'm coming to you because

you're the expert, but it's my life and I'm going to be doing the research. And I've got to have a partner, and if that bothers you, then I'm going to be a terrible patient and I should go somewhere else."

And I remember the oncologist I have right now who is truly an expert in the field and he looked at me and he said just what I said. He said, "I would expect no less. You're fighting for your life, and I would expect you to want to be involved and make sure where we're going."

Elissa: Absolutely. And it is just so important. And we actually have a new resource on shared decision-making for chronic leukemias. So, we're hoping that other people can understand the experience that you've had with talking to your doctor and being part of your own treatment and being able to make those educated decisions with your doctor. So that's great.

Now moving on to your life with cancer, in addition to sharing your story on this podcast, you have gotten involved in other ways with LLS, one of which was First Connection. How did you get started with being involved with LLS and what other things are you doing?

Donnie: Well after I was diagnosed, a couple things happened. One, we were talking about getting that early diagnosis and how did it affect you. I remember coming home from the hospital after one of the first diagnosis and I literally had three messages on my phone from facilities wanting to know about payment options and-

Elissa: Like, give me a second.

Donnie: -I just wanted to throw the phone through the wall. I mean it's like, I wanted to scream, "Do you understand I'm fighting for my life? I might be dead. I don't care how you're going to pay for this,". But it hit me, I've been very blessed. I have a family that supports me. I have a work that supports me. I have good



insurance. I got involved early with LLS. I have all the tools necessary to do the very best in my battle.

But not everybody does. Cancer doesn't discriminate and it picks the single mom who's barely making it already and, boom, she's got cancer, or maybe the individual who has no family support system at all, or the hourly worker who can't afford to be off. And it really struck home to me that this isn't fair. I mean it's not right that I can fight the same fight, maybe have a better chance than others.

So that drove me to call The Leukemia & Lymphoma Society and, I talked to Tom, who was a regional director, I remember telling him, "I don't know what you need, I don't know what all the organization does, but surely you need someone to stuff envelopes or load trucks or something.

Elissa: That's great.

Donnie: I just want to do something to help." And so, we met, and we decided I would run for Man of the Year, which is one of our big fundraisers in the spring. We have Man and Woman of the Year competing. Usually, ten or so individuals competing to raise as much money as they can in a ten-week period. And so, I ran it pretty successful. I didn't win, but I raised, I don't know, \$58,000, I think.

Elissa: That's amazing!

Donnie: Yeah. I was excited. I got a grant named after me having raised 50,000. That got me involved. And then I got on the Patient Service Committee in our chapter, and we were doing things like, we had a conference every year for patients with doctors talking about diseases (LLS Blood Cancer Conferences). And that kind of spring me over to Light The Night, and I got involved in Light The Night, which is our fall fundraising event. And if you ever get the chance, even if you don't want to participate in actively raising money, you should attend a Light The Night event



because there's nothing more moving when all the lanterns are lit and you see all the patients there. You have people who you're supporting you had one color.

Donnie: And you have another color for people who have the disease and, unfortunately, have another color for patients who have lost the battle and have passed. And just thinking about it just really emotionally moves me I can't explain. At the evening, as you're kicking off, you go for this walk, and you look and see hundreds and thousands of lanterns, and you see people doing their best. You see children who lost their hair. I mean it's just a wide range of people there, parents and loved ones who've lost someone and are still fighting the fight. You want to be there. So, I got involved with Light The Night. I've been the corporate chair and I've had quite a bit of success in raising a lot of money. I know it's well over \$500,000 at this point.

Elissa: Wow!

Donnie: And I got the Chairman's Award a couple years ago at Light The Night and that was very moving.

Elissa: That's wonderful. Yeah, you mentioned Light The Night. I hope all the patients listening go to this because there is something so special about the survivor circle where you're holding that white lantern surrounded by other patients and survivors. And then you look around you and you're completely surrounded by this sea of red and gold lanterns, all of your supporters, all of those who are fighting for an end of blood cancer. And I just get chills even just talking about it now even though I've participated for years and I was a Light The Night campaign manager but it's just such an incredible event. And I'm so glad that you've been able to participate and that's wonderful.

Donnie: Yeah, it's really moving.

Lizette: Wow, I want to echo what everybody's saying. It's so great. I know that I was moved to tears with my first Light The Night also. So, it is a great event. And

thank you so much for really participating in so many types of events and support services at LLS. I think just hearing your story, just you empowering people to know that, you are the expert of your own body. And I just really need to thank you, again, before we start talking a little bit about your family.

I know that you're a grandfather. Three girls, huh?

Donnie: Three girls. You know-

Lizette: Wow! It's wonderful.

Donnie: -I always dreamed of having a grandson, but I'll tell you I wouldn't trade these three granddaughters for any son, even my son. They have taken their place. I just love having little girls run around. My wife captured a photo. I had my one granddaughter, Ava, and we were at the beach and there's a photo of the sun setting in front of us and have her feet in the water and it's a photo from behind. She's just holding my hand and we're both looking down. And it, honestly, has changed my life perspective. I mean I think about the blessings that I didn't even know were coming when we had these granddaughters, but it heightened my desire to fight and to win this battle because I want to see them grow up. It's real important.

Lizette: Your grandchildren are young. Do they know that you have cancer? How has it been with your family? Some folks don't even tell their families.

Donnie: My wife yells at me all the time, well for lots of reasons, but one of the reasons she yells at me is she's like, "No one knows how hard it is because you always act like it's just a piece of cake." That's sort of my nature of just, I put my big boy pants on, I go to work every day.

My family knows I have cancer. I've always been real open about, I have this disease. My friends knew. I didn't try to hide it. But I don't go on about how tough it is, how bad I feel, how this I feel. So, my grandchildren, they know papa has to go to the doctor. They don't understand what cancer is. And at four, five, and six, I don't want

them to fully understand it yet. It's a little too early. So, they know I'm being treated and I'm taking care of business, but they don't have to worry about it.

Elissa: That's very good.

Donnie: One thing I would say, and we haven't mentioned it, but it's real important for us; I have a feeling a lot of new patients may listen. And that is, call the 800 number at LLS. And like we said, everybody's on a different journey, in a different position financially, but you will talk to someone who's a trained social worker or trained nurse who knows everything that's available to you at the time. And that includes grants or co-funding for treatments. They can guide you to getting information on best treatments available. Just any question you may have.

What will happen is you're in the system, so as you go through your journey, and understand this is going to be a long journey, they're there. And so, when you call back later, they have all your records, and they'll know and they'll be able to talk to you and guide you. That 800 number can help you in so many ways. As I said, they could help you find some money, maybe just enough to buy groceries or buy your copay. And they'll put you in touch with people.

What usually will happen is after you make the call, after a short period, maybe a month or so, you'll get a follow-up call make sure the information you needed was presented to you and given. Do you have any other questions? And after that it's up to you. And some people want a First Connection, some people don't and that's okay if you don't. Some people have a need to talk, some people don't want to talk. But everybody needs information. Information is power and LLS will provide you with the most accurate and true information and not Google information.

One thing I learned in Googling and all the websites where people are talking; people that get to those spaces, unfortunately, a lot of them aren't doing well and they're kind of a little bit in panic mode. And you get to those sites, you think, oh my gosh everybody's dying. I'm gone, it's over. And that could be self-defeating where the

information you'll get from LLS will be solid, scientific information that can be given to you in a way you could understand and can help you go talk with your doctor in a more intelligent way also.

Lizette: Yeah. We definitely want to be there for you. We definitely want to provide that information, like you're saying. We want to provide that support. Anything that you really need, we will try to find for you because after you get a diagnosis, there's so much. Like you said, it's lifechanging. So, we're definitely here for you. Let us be here for you. I'm thankful that you brought that up. And it's really an important and one of the best offerings that we have here at The Leukemia & Lymphoma Society.

Edith: Now, Donnie, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." Based on your cancer experience, what word would you choose to complete that sentence, "After a diagnosis comes?"

Donnie: A journey. And it's a journey that you don't have to let cancer dictate all the rules and paths. You can have control. And one of the things that I think is challenging about when you're diagnosed is you feel like you lose control. You're going to all these experts and they're doing all these things and telling you, "Go here, do this, be there." And pretty soon you feel out of control. So, for me after being diagnosed, I was put on a new journey.

Now I was fortunate, as I said, I had a great support system, and I had a very strong faith system. We haven't talked about that, but having a strong faith system, whatever that means for you, can really make a difference. I remember someone asked me, "Did it strengthen your faith? Did it change it?" And I was so happy to be able to say, "No. I'm thankful it was there before and it's here now, and it's as strong before as it is now."

And so, the journey cancer will put you on a different path, but it doesn't dictate your life. And you can do great things. Without having cancer, I wouldn't have met all the friends I've made in The Leukemia & Lymphoma Society, had opportunities like this to



speak. I tell people when we're talking about fundraising, "I'm no one special." I mean I've raised hundreds of thousands of dollars, but if you'd asked me ten years before I had cancer would I be able to do that, I would've laughed. But it put me on this journey. And you just have to get up and walk your race and don't compare yourself to anyone else. Some people can be doing better at times, some people be doing worse. You just do the best you can with what life has given you.

Elissa: I love that. Well, thank you so much, Donnie. Your positive outlook throughout all of these highs and lows of living with CLL is just amazing. And I hope that all of the CLL/SLL patients listening today will find so much hope in everything that you have said. So, thank you so very much for being here. We're happy that you're doing well and hope this next round of targeted treatments goes very well for you. And thank you for all that you've done for LLS. I can't tell you how much we appreciate that and appreciate you.

Donnie: Thank you. I appreciate the opportunity to talk to everyone. I hope I've maybe given something that can help everyone, but, you know, you can win at this battle. So that's maybe the best thing we can leave it at.

Elissa: And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families.

To help us continue to provide the engaging content for all people affected by cancer, we would like to ask you to complete a brief survey that can be found in the Show Notes or at TheBloodline.org. 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.

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

BEATING CANCER IS IN OUR BLOOD.



Have you or a loved one been affected by a blood cancer? LLS has many resources available to you – financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to [LLS.org/PatientSupport](https://www.lls.org/PatientSupport). You can also find more information on CLL at [LLS.org/Leukemia](https://www.lls.org/Leukemia). The shared decision-making program discussed can be found at [LLS.org/Programs](https://www.lls.org/Programs). All of these links will be found in the Show Notes or at [TheBloodline.org](https://www.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.