

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'Perspectives on Quality of Life: Chronic Myeloid Leukemia (CML)***

#### **Description:**

Join us as we hear two different perspectives from people living with chronic myeloid leukemia (CML); Tim Sohn, a 16-year survivor and Becky Dame, a 32-year survivor. In this episode, we hear how CML treatment has changed since 1991, when Becky was diagnosed. Becky had a difficult journey through cycles of relapse, transplant, and remission, while Tim shares his experience using newer therapies. Both share their stories and how CML has impacted their lives.

Both Tim and Becky have worked to build and maintain a good quality of life and have used their experiences to help others in the cancer community and find connection.

#### **Transcript:**

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

**Jesse:** I'm Jesse.

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

**Elissa:** Today, we will be speaking to Tim Sohn, a 16-year survivor of chronic myeloid leukemia, or CML, and Becky Dame, an Information Specialist with The Leukemia & Lymphoma Society and a 32-year survivor of CML. After years of treatment, Tim was found to have no evidence of disease in 2021. He has been involved with LLS and won the mission award last year for a 24-hour livestream fundraiser he and his team put together for his Man and Women of the Year campaign.

In his spare time, he hosts a weekly livestream show called *Showing Up: Perspectives on Cancer*, a safe space where cancer patients, survivors, and supporters come to



share stories and connect as well as find resources that provide healing, hope, and resilience. It is Tim's purpose to let other cancer patients, survivors, and supporters know that they are not alone and to encourage them to share their stories.

Becky is a registered nurse who joined LLS as an Information Specialist in 2017. She was diagnosed with CML at 18 years old and has had multiple bone marrow transplants, which at the time were the only curative options. Thankfully, after a new donor, the last transplant was successful and has kept her in remission for over 11 years. She has used her cancer experience to help patients and caregivers navigate a blood cancer diagnosis with support, resources, and education.

Welcome Tim and Becky.

**Tim Sohn:** Thank you so much for having me, Elissa.

**Elissa:** So, Tim let's start with your diagnosis of chronic myeloid leukemia or CML. What were your signs and symptoms leading up to diagnosis, and how did you end up getting diagnosed?

**Tim:** So, 16 years ago I had some purple bruises on one of my legs. I never had anything like that before. I went to my primary care physician, he took some bloodwork, and he called me up, and said, "You need to go to the hospital right away." I went to Westchester Medical Center, and I was there for 4 days. And in that time period, they diagnosed me with chronic myeloid leukemia. I had 400,000 white blood cells in my body.

**Elissa:** Wow.

**Tim:** Yeah. It pretty much came out of nowhere and they did a process called leukapheresis on me, which basically means they filter out white blood cells in your body because I had too many. And that was the start of my journey. In terms of my treatment, I took oral medication called Gleevec® to start. That changed over time, but that's the start of my journey.

**Lizette:** Sure. And did they put you on Gleevec right away when you were in the hospital those four days?

**Tim:** They did, yeah.

**Lizette:** Did they explain to you that CML has a different type of treatment. So, Gleevec, which is imatinib, is a type of tyrosine kinase inhibitor (TKI) which, like you said, is an oral form of medication. Were you surprised that you were just told you had leukemia, and then you were put on an oral medication?

**Tim:** I really did not know much about leukemia at all, so I wasn't really familiar with treatment options. I do remember that they had discussed a clinical trial option, but they had never tried it on anybody else before, so we decided not to go that route.

**Lizette:** You said that as you've been treated, that the treatment has changed over these past 16 years?

**Tim:** Yes. I started out with Gleevec, and then after so many years, the number of leukemia cells in my body started going up. My oncologist suggested that I switch to a different oral chemotherapy medication. We tried Bosulif®. That one didn't like my body at all, and luckily over time, the number of options have changed; so now I take one called Sprycel®, and that one has worked great. And both with Gleevec and Sprycel, I haven't had any side effects; so, I've been very blessed in that way.

**Elissa:** That's good. What does that mean when it didn't like your body? Did you have a lot of bad side effects?

**Tim:** I just had a lot of vomiting.

**Elissa:** Oh.

**Tim:** Yeah.

**Elissa:** So, Becky, you have been through quite the journey with multiple relapses and transplants. The landscape of CML treatment has really changed since your diagnosis and with the introduction of tyrosine kinase inhibitors, or TKIs. Could you tell us about your treatments?

**Becky Dame RN, BMT-CN:** Absolutely, my diagnosis did come many years before TKIs were even on the market. Before TKIs, the only curative effect was a bone marrow transplant and that was back into the '90s. I had my very first bone marrow transplant back in 1992.

In the meantime, you just did some maintenance therapy just to keep bloodwork control, but none of it was curative. It was really just to keep blood counts from being sky high.

**Elissa:** Was that chemotherapy for the maintenance?

**Becky:** So, they don't call it chemotherapy. The patients would understand it as more of a Hydrea® or things like interferon. Neither one of them are considered chemotherapy. They're really just a suppressive agent to suppress the bone marrow, so it's just not overproducing, but it's not quote/unquote "chemotherapy."

For the first decade from '92, really to 2001, transplant was the only true treatment for CML patients. So, I had my first transplant but would end up relapsing even after that. At three years, after the first transplant, still no TKIs on the market, just transplant, which if you've done one, then you're like, "Okay, there's nothing else, what do you do next?" And so, then they do this experimental thing of taking T cells from the donor and giving them back to you and creating something called graft-versus-leukemia, which absolutely worked, but it also gives you graft-versus-host disease (GVHD). So, it's like this double-edged sword.

**Elissa:** Yeah.

**Becky:** But it absolutely worked for me as a CML patient and put me back into remission.

But then as time progressed, that would be somewhat a good therapy for me, except that I relapsed every two and a half years.

**Elissa:** Oh gosh!

**Becky:** And so, we would continue to do this type of therapy, this donor lymphocyte infusion, DLI, and it would give me graft-versus-host disease and graft-versus-leukemia and put me back into remission. And we would do that all the way up until 2001. And then 2001 is when the first TKI was FDA approved and that was Gleevec.

**Elissa:** Yes.

**Becky:** So, during that relapsed period of time, when that one came, we would try Gleevec. And, unfortunately, for me, Gleevec just had too high side effects for me.

Cardiac wise I had a resting heart rate of 140, so really it was just totally physically limiting me, and I was unable to work or even go get the mail out of the mailbox because my heart rate was just so profound. And so, we would go back to my old standby and do more of these DLI treatments and that would put me back into remission.

I would do several more relapses, and then we would get to the second generation of TKIs, and I would go on Sprycel when it was finally FDA approved. So went on Sprycel, and I would quickly go into having both pericardial effusions and pleural effusions. So, that means fluid around my heart, fluid around my lungs, all these wonderful side effects.

**Elissa:** That's tough.

**Becky:** Again, physical symptoms limiting for me to stay on that and have a functioning livelihood. So, we would go back to another DLI treatment then the graft-versus-leukemia, graft-versus-host.

The next go around would be my sixth relapse in 2010. At that point, we made the decision to try a different donor and have a repeated bone marrow transplant.

**Elissa:** Okay.

**Becky:** So that would be done in September of 2010. And it absolutely worked as far as finally keeping my CML controlled. Even to the point I did not need any TKIs as a filler after the transplant. It was profound enough that I did not need any additional TKIs to stay in remission, and I've now been in remission from the last transplant. September will be 12 years.

**Elissa:** That's so amazing. I'm so glad that that worked for you. That is a lot of side effects with all of those various treatments and the transplants and the GVHD.

**Becky:** So, there are a lot of side effects involved both from the TKIs that I had but I also, the graft-versus-host disease, the side effects list can be very long and it include anything from creating hair loss to muscle stiffening to GI tract, liver, lung involvement. You just name it and those can be side effects from graft-versus-host disease. So, it is a lot to go through, but I can't say that I regret any steps of that process.

**Elissa:** Our podcast today is focusing on quality of life during CML treatment. Tim, what have you done to maintain a good quality of life throughout these past 16 years?

**Tim:** I try to eat healthy. I have had periods that I do well with that and periods that I don't do so well with it. But I try to.

One thing that I consistently do is walk. I love to be out in nature. I live in Pennsylvania near the Delaware River, so I love to take walks.

A challenge that I've had besides cancer is chronic migraines. So, fresh air is something that has helped.

**Jesse:** That's good.

**Elissa:** I think it's really good for cancer patients to be able to get outside and get moving. Movement, in particular, is always very good. And if you can find something that you like, like walking along the river, that just sounds lovely right now.

**Tim:** Yeah, something else that I really love to do is take photos while I'm out in nature and videos as well.

**Elissa:** Oh.

**Tim:** So, that's just become something that I do; and I post them on social media. That's a passion that I've developed as well along the way.

**Jesse:** That's great.

**Elissa:** Very nice.

**Lizette:** And you were able to work with your physician when you were on one of these medications that you said you were having side effects, vomiting. It's really important for patients to really have that open communication with doctors to let your doctor know if you're not feeling well. I'm sure that during that time your quality of life was affected. Was it easy for you to communicate that with your doctor? To say, this is going on and it's really affecting me?

**Tim:** Yeah, absolutely. I just called up his office and told him, and we made another appointment, and he just explored other options. Thankfully, there are other options for CML.

**Lizette:** Exactly.

**Tim:** I remember early on in my journey when I started taking Gleevec, I remember there weren't as many options as there are now. So, we're really lucky now to have more options.

**Elissa:** It is amazing how things have changed on the CML front in 16 years.

**Tim:** For sure.

**Jesse:** Yes, vast improvements.

**Elissa:** So, what about you, Becky, with your side effects and your cycles between remission, relapse, transplants, how did you maintain a good quality of life?

**Becky:** I will say it was difficult, especially with as many relapses as I had. I felt like I would have a year and a half of good health and good quality of life, be able to return back to normal functioning per se, and then a year and a half of treatment again.

And so, of course, during that time, obviously, not doing as much as I had wanted to. Sometimes it would limit my working conditions. I did have to go on medical leave several different occasions with those treatments and different things that were needed. I knew that I had a year and a half good, a year and a half would be involved with just treating my disease and trying to get past it to get back to that year and a half of good quality of life.

**Elissa:** Yeah. That's good.

**Lizette:** Yeah. Now Tim, we know that cancer can come with a lot of emotional effects, right, particularly with a chronic cancer. How have you dealt with the emotional effects of cancer since your diagnosis?

**Tim:** That's a really interesting question because from my journey, for the most part physically I felt fine because I have taken oral chemo medication that has worked really well. It's been kind of surreal to doing a cancer journey where my physical



aspect is fine. But then the mental part has been more of a struggle for me when I became a cancer survivor, depending on how you define survivor.

When I went no evidence of disease is really where the mental part became more of a struggle for me and, also when I started the show. When I started having more conversations with other patients and survivors and supporters, people who were struggling more than I was and who had family members who had passed and struggled more than I was, that survivor's guilt aspect, that really came into play for me.

**Elissa:** So was it the survivor's guilt in particular once you were found to have no evidence of disease that really affected you?

**Tim:** Definitely. A close family member had just passed like two weekends ago, and it was the first time that a close family member had passed since I went "no evidence of disease" and since I started the show. And that just brought a whole new perspective for me just recently.

**Elissa:** Gosh, I'm so very sorry to hear about the loss of your family member, Tim. It can be so hard to see others with the same disease pass away when we are doing well.

Now, Becky, you've had a much different experience than Tim, particularly in the first 20 years after your diagnosis. What were the emotional effects of cancer for you and how did you cope with those?

**Becky:** I will say it is a rollercoaster of emotions. I mean, especially for me, the whole timing of multiple relapses and, that whole one and a half years of good, one and a half years of bad; you're constantly on this rollercoaster. I do have faith on my side. I'm very much a believer and really clung to my faith and my prayer teams and those people who supported me well. It was emotional.



I was married for most of all of those 20 years that we had mentioned, and my husband was just a champion as far as a caregiver for me. But it does create difficulties. I mean just daily living difficulties. But we managed through those together and with our faith and those supporting us.

But I will say that actually my husband, my caregiver, he has probably PTSD from this experience because if you put yourself in the opposite side of the patient, they're looking back feeling helpless on how they can change the situation for better. I will say I believe the positive on some of this for me would be that my husband and I have a unique marriage that we've never had the opportunity to take each other for granted. So that, to some degree, is a blessing in itself and has made us have a very strong marriage.

**Jesse:** Tim, one thing that can prove quality of life for some patients is helping others. We mentioned in the introduction that you participated in the Man and Woman of the Year campaign, now known as Visionaries of the Year. You won the Mission Award in the campaign for doing a 24-hour event. Congratulations! Can you please tell us about your overall experience and more about your personal fundraising campaign?

**Tim:** Yes, thank you for asking. It was such an amazing experience. So, I was planning on being a candidate for Man and Woman of the Year for two or three years. But then I got chronic migraines and some other things, so it just didn't work out. And then the pandemic happened, and I ended up creating a course on how to create livestream shows; and all these people from around the world came into my course that I created.

And so in 2022, being a candidate for Man and Woman of the Year, the main way that we raised money for the Man and Woman of the Year was we held a 24-hour livestream fundraiser.

**Jesse:** Oh.



**Tim:** And we brought on cancer survivors, cancer supporters, cancer patients to share their stories over the 24 hours.

**Jesse:** Oh, that's awesome.

**Elissa:** Was it kind of like one of those old telethons?

**Tim:** Yeah, except kind of in a new way, right, in a modern way. And we brought on the boy and girl that were featured by LLS and the parents and had conversations with them as part of the event. It was called "Open Your Hearts and Wallets."

**Jesse:** Oh, I like it.

**Tim:** Also, 24 livestream hosts volunteered from Alaska to the United Kingdom and across the United States; and they all volunteered their time to put this together. And we ended up raising \$6,000. We had 24 hours of awareness and conversations with people and all this content, which was just amazing. I just have chills talking about it. I can't even explain what the experience was, just like such a beautiful 24 hours of support for LLS and the cancer community.

**Elissa:** Can you explain what the Man and Woman of the Year campaign is?

**Tim:** Yeah, absolutely. So, the Man and Woman of the Year campaign is a philanthropic competition by the Leukemia & Lymphoma Society. It's a 10-week campaign to raise money to go towards research and so many other things that LLS does to support cancer patients and their families and others.

**Jesse:** And how much did you end up raising overall for that campaign?

**Tim:** We ended up raising about \$15,000; and then we also ended up doing a second livestream fundraiser that was 12 hours long as well - I think two months later.

**Jesse:** That's great. Well thank you so much for your support for LLS's mission.



**Tim:** Well, thank you. LLS has been so important in my cancer journey as well, through your family support groups. My mom still goes to them.

**Jesse:** Oh.

**Elissa:** That's good. Yes, it is important to share that we do have support for caregivers as well; and so that's wonderful.

Now in addition to fundraising for LLS, you have a livestreamed show called, "Showing Up: Perspectives of Cancer." Why did you start that, and why is it important for you to share cancer stories?

**Tim:** I started the show in 2021. I started sharing my cancer journey in June of 2021, kind of unexpectedly after I was inspired by the hashtag movement called #radiatingreel, which encouraged you to share more personal aspects of your lives on social media.

And there's someone named Steve Sullivan who is an acute leukemia survivor; and he created a video on National Cancer Survivors Day, and so that inspired me. And then somebody else also invited me on her show. Her name's Jenny Gold, and she has a show called *Podcast-Not-Podcast*.

And so, she invited me on her show to share my cancer story for the first time. That kind of is how this all started. I never planned on sharing my cancer story publicly ever, because of that survivor's guilt, because I've felt physically fine for my cancer journey for the most part.

I kept sharing my cancer story on other shows and virtual events. This was all during the pandemic. Then I ended up creating this show with someone named Kara Oelker. Her perspective on cancer was her mom had passed of cancer, and so we co-created the show; and this show is really a space for cancer patients, survivors, and supporters to show up and share their stories. It's a livestream show. We stream it on Facebook, LinkedIn, Twitter, and YouTube; and it's a weekly show. People show up in the



comments to support each other, share their perspectives in the comments, and it's just a very beautiful community of people that show up to share their stories and connect and support.

**Jesse:** Happy to hear that you found this community. I think it's great.

**Tim:** Thank you, Jesse. I appreciate that.

**Elissa:** So, when you're talking about Perspectives of Cancer then, you're coming from a survivor perspective and a caregiver, family member perspective as well. That's really interesting.

**Tim:** Yeah, true.

**Elissa:** Now this also turned into a book for you. Would you like to tell us a little bit about that?

**Tim:** Sure. The book is called *Perspectives on Cancer*. Cancer patients, survivors, and supporters share their stories. And the book really has two purposes, one to let others in the cancer community know that they're not alone and to encourage them to share their stories, if and when they're ready. It has my cancer story, and then it also has the stories of ten other people who have been on *Showing up: Perspectives on Cancer*.

The guests have taken the time to write their stories. It's not just transcribed from the show. The thing that's really cool about the book is that there are perspectives and connections to cancer that I did not even know that our guests had. It's a really touching, heart-felt book. If you need some healing, hope, or resilience, definitely check out the book for sure.

**Elissa:** That's really neat. There is something cathartic, I think, about sharing your cancer story, whether you are a patient, survivor, a supporter of some kind, family member, caregiver. If you are comfortable with sharing, it can feel really good to get

your story out there and have other people connect with it. They may have a similar story. I'm sure CML patients listening might be connecting with your story right now, they may have had similar experiences with that medication or with the survivor's guilt aspect.

**Tim:** Yeah, I just had a conversation with somebody the other day that really resonated with the survivor's guilt aspect, which I really haven't had many conversations with people about survivor's guilt. And I was like, "Ah, you got me. This is great."

**Elissa:** Yes. That's why I love going to cancer conferences because I feel like you can connect with other cancer survivors, and they understand you with very few words. You can just say something about, your hospital stay or a side effect or something like that; and they will just understand. They'll just get it.

**Tim:** Yeah.

**Elissa:** That's just so great that you are really encouraging people to share stories. Do you feel like that has really helped you with your survivor's guilt and just through your cancer experiences in general in sharing your story?

**Tim:** Yes and no. Depending on the experience, it has helped sometimes and has had the opposite effect.

**Elissa:** Yeah. Sometimes it's hard. I think it would be hard to listen to some cancer stories that haven't gone quite as well or hearing stories from caregivers who lost somebody. It does make that survivor's guilt a little bit harder to get through.

**Tim:** It definitely does, but it helps on the show to have such a supportive community who shows up. That's really what makes it and makes us want to continue to show up every week.

**Elissa:** Absolutely. And that's a good title for your show, *Showing Up*. I like it.



Now, Becky, you have also used your cancer experience to help others with your role as an Information Specialist and your willingness to be so open with your story. What has it meant to you to help patients and caregivers who have come after you?

**Becky:** It's really why I continue daily. I remember the evening that I got my diagnosis and I said, "Lord, if you'll just help me, and if this changes one person's life, then it'll all be worth it." And I had no idea how long I would have to be able to help and fulfill that, but I've been given these opportunities and I just couldn't imagine not taking them and to help that person who was in my shoes. And if I give them a glimmer of hope, then it's all worth it. It's just amazing that I can still speak about it and encourage patients and their caregivers and just give them maybe just that beacon of hope that they need. And like if you saw my picture, you would say, "Oh she looks totally normal."

**Elissa:** Yeah.

**Becky:** You can go through a lot of things and come on the other side and still be able to function, maybe not as normal, but still. Everybody's different what they feel is good and bad, but, for me, I'm happy with my quality of life that I have now and couldn't imagine it differently.

**Elissa:** It's just amazing how you've been able to utilize that experience. We can see between you and Tim that you both had very different experiences with CML and so it's good that you can see a different side and provide a different experience when you're talking to patients and caregivers so that, they can get that help if they aren't doing well and are able to have hope to do well. I mean, when you're looking at almost 32 years of survivorship, that's just incredible.

**Becky:** I think it's incredible as well. Being that I'm both on the patient side and the healthcare provider side of things, I know what it could be and so that gives me blessing. And I know how to relate on both sides, both the medical aspects that they're seeing but also in that personal aspect as well.

**Elissa:** So, our final question today. On our patient podcast Home Page, we have a quote that says, "After diagnosis comes hope." What advice do each of you have for patients and their families to give them hope of a good quality of life after a diagnosis of CML?

**Tim:** Figure out what it is that keeps you going. For me, what keeps me going is my wife and my kids, my family, right? What is it that motivates you to keep you going? Figure that out. I think that's my suggestion.

**Elissa:** That's lovely.

**Becky:** This sounds like a setup, but my life motto word is hope-

**Elissa:** Oh.

**Becky:** -and I have it plastered all over my house. I can't take full credit for this. It actually came from one of my pastors, but HOPE standing for having only positive expectations. And so that doesn't mean that everything's going to go exactly how we want it to go, but if we at least go into it having only positive expectations, then that gives you a leg up.

**Elissa:** That's wonderful. I love it.

Well, thank you so much to each of you, Tim and Becky for sharing your stories. You had quite the different stories and experiences with CML, so I am glad that both of you were able to come on here and share with our patients and caregivers the different perspectives of a CML diagnosis. And we're so happy to hear that both of you are in remission and doing so well and thank you for sharing your experiences on how to maintain a good quality of life. We hope that this will really help other CML patients and their families that are listening today. So, thank you both again so much for being here with us.





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.

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In addition to the lounge, we could use your feedback to help us continue to provide engaging content for all people affected by cancer. We would like to ask you to complete a brief survey that can be found in the show notes or at [TheBloodline.org](https://TheBloodline.org). This is your opportunity to provide feedback and suggested topics that will help so many people.

We would also like to know about you and how we can serve you better. The survey is completely anonymous, and no identifying information will be taken. However, if you would like to contact LLS staff, please email [TheBloodline@LLS.org](mailto:TheBloodline@LLS.org).

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.

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://LLS.org/PatientSupport). You can find information about chronic myeloid leukemia at [LLS.org/Leukemia](https://LLS.org/Leukemia). All of these links will be found in the show notes or at [TheBloodline.org](https://TheBloodline.org).



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