

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Timothy's Turning Point'

Description:

Listen in as Alicia and Lizette from The Leukemia & Lymphoma Society (LLS) speak with Timothy, an ALL young adult survivor, who shares how his culture, attitude and relationship with his healthcare team during treatment steered him towards a profession he would have never envisioned for himself.

Transcript:

Alicia: Welcome to *The Bloodline* with LLS. I am Alicia.

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

Alicia: Today, we have Timothy, a young adult, acute lymphoblastic leukemia survivor, also known as ALL, who will be sharing with us a little about his story and how his diagnosis shaped his life. LLS's introduction to Timothy is an interesting one. Lizette, how did you meet Timothy?

Lizette: I was actually down in Phoenix in July; yes, it was hot, and I was partaking in the NAHN conference; that is the National Association of Hispanic Nurses. I actually met one of your friends, Timothy.

Timothy: Angel, right?

Lizette: Yes. He actually came up to our table because the Leukemia and Lymphoma Society had a table and said, "you know, one of my colleagues in school has leukemia and he is studying to be a nurse just like me." I said, oh that is really interesting". He told me that you would probably love to partake in our activities since you had leukemia. I asked him, of course, what kind of leukemia, but he did not know. He texted you and, thank you, for texting back so quickly.

Timothy: Anything for my buddy, Angel.

Lizette: Then you said you had ALL. I thought that was very interesting. I am so happy that we were able to connect in that way and that you are so happy to really join us and really partake in telling your story and partake in sharing your cancer journey with us. I know, today, you actually met with your local chapter.

Timothy: Yes; in New York City, with Gungeon.

Lizette: That's great. I know you will probably do some activities there.

Timothy: Yeah. I am looking forward to working with her. She told me about the opportunities that I can be a part of. One of them was that I could call and talk with other patients affected with cancer throughout the whole country and to share my story with them, and just hear them out, and be a support person to them. I am looking forward to that.

Lizette: That's great. That is our peer-to-peer program. It is really important because a lot of people are diagnosed, and they feel alone; they feel like I know nobody else with leukemia. What should I do? What should I ask? They feel like they have no one to talk to. This peer-to-peer program really allows you to really talk to somebody that is newly diagnosed and let them know what you went through and give them tips—tips that they would not have if they didn't talk to somebody else who actually went through it.

Alicia: Exactly

Timothy: Yeah, I completely agree.

Alicia: Timothy, about your diagnosis, can you share what was going on at that time and thoughts prior to diagnosis and after being diagnosed with ALL?

Timothy: Ok, so this was back in 2012. I was a sophomore in high school, just 15-years-old. I was just a hooligan in high school. I didn't study that hard. I didn't take school that seriously and, all of a sudden, I started to feel differently. I felt very tired all the time. My lower back and my legs were in pain constantly and I was just short of breath whenever I did just a little bit of exercise. That is when I went to the doctors. That is when I went to a blood cancer clinic in Manhattan called Hassenfeld Clinic. I went with my parents and they told us that day what I was diagnosed with, which was acute lymphoblastic (I can't say it) ALL, anyways.

Alicia: It's a mouthful!

Timothy: My parents were notified first by the doctors and then they brought me in to tell me. When I went into the room, I saw my parents crying. I knew right away that it was bad news. Once the doctors told me that I had ALL, I honestly didn't even feel scared or sad because I did not know what leukemia was at that age. That was the first-time hearing about it. They gave me a brief summary of what it was and, once I heard cancer, that was when I actually got scared and realized that I might die from this. He told me that there was an 80% survival rate for ALL, which is pretty high, but all that was going on in my mind was the 20%--the 20% that you couldn't survive. We went straight to the hospital from there and started the treatment.

Alicia: In regards to getting a second opinion, was that something that your family had discussed with the doctor or maybe among yourselves after doing research or were you comfortable and confident in the decision of your doctor to move forward with treatment?

Timothy: We were all very confident in our doctor's decisions because we aren't that knowledgeable about the scientific world and the healthcare field. We just did whatever the doctors recommended and hoped that they were making the right decisions for us.

Lizette: What did your parents tell you about how they were feeling, or did they tell you how they were feeling?

Timothy: My parents are from Korea and they are immigrants. Growing up in Korea, they have a different culture there. I feel that parents don't really share their weaknesses and their emotions with their children. My parents did not tell me how they felt. They kind of held everything inside. I could just tell by their expressions and their facial expressions, that is what I used to tell how they felt—not from their own voices and their mouths.

Lizette: Did you share with them how you felt or how you were feeling?

Timothy: No; I also did not share how I felt. It is not that we don't like to, it is that we are just not comfortable doing it. We would like to, but we are just not used to it.

Alicia: Now, was it an issue of sharing it with their son or just sharing it period; or did they seek support services outside or, across the board, sharing their emotions is difficult?

Timothy: It was difficult, in general, just to anybody. They didn't even look for any support groups or anybody to speak with about their situation. They just kept everything to themselves, which is pretty hard, in my opinion. I don't think that is the right decision to make. You should reach out for support, in my opinion.

Lizette: Who did you share with then?

Timothy: I had a girlfriend at that time. She is the only one I shared it with from school. I didn't share it with any of my friends, even though they asked me where I went because I went missing for about a year. I got home-schooled. All my friends asked me where I was, but I just told them, "I'm home; don't worry about it." I just kind of brushed it off. I only told my girlfriend and she is the only one who knew about it besides my family. That is the one person from school that I kept in touch with throughout that year, throughout the treatment.

Alicia: Do you think culture does have a huge impact on someone's diagnosis and the way they handle their treatment and their diagnosis?

Timothy: Culture, in my opinion, definitely affects how the parents feel about the diagnosis; how severe it is because my parents, in Korea, did not have the technology we have in America. Once my parents hear about leukemia, they automatically think that there is no cure for that. You will die in a matter of time, like in a year or so. It's hopelessness. They feel hopelessness once they hear leukemia, but that is because they grew up in Korea and everyone, they heard of getting leukemia in Korea, died, because they didn't have the treatment they have in America. That is what I think about culture having an effect.

Alicia: You mentioned going missing. When you were away and you withdrew and you were being home-schooled, how did you balance or how did you try to balance your new normal having been diagnosed?

Timothy: I made new friends. My new friends were my caretakers in the hospitals and my clinic. I saw my nurses and my doctors as friends because they were the ones I spoke to and had conversations with daily. We just had laughs and shared our

stories and all that. They were my new friends. Home-schooling was actually pretty nice. You get to stay home. The teachers come to your house and they are very lenient with you because they know what you have. If you miss a homework, they just let it go. I kind of missed a lot of homework; not purposefully. I actually was not feeling well enough to do them, but it was pretty nice—to be honest.

Lizette: Obviously, you did well because, right now, aren't you in nursing school?

Timothy: Yeah; I am at NYU for nursing and loving it right now.

Alicia: From hooligan to nursing—look at that!

Timothy: Yeah; a hooligan from high school with a 70 average. Don't tell anybody—oh wait!

Lizette: You just did.

Timothy: Now, everybody knows. The whole world knows except for my parents. They won't find this, hopefully.

Alicia: Earlier, you were saying that your parents didn't know where to go, your family didn't know where to go, and Lizette mentioned the peer-to-peer, did you think about connecting with others who may have been in a similar situation or did you really feel as if there were no support resources available.

Timothy: I never actually thought about reaching out for a support group. I would say that I am kind of an introverted person. I don't really like to go out and meet new people unless somebody comes to me first. Unfortunately, I didn't get to meet any support groups.

Lizette: What makes it different now that you are looking to be a part of the Leukemia & Lymphoma Society's offerings.

Timothy: My eyes have been opened to all the resources that are available for these patients. They can find somebody in their similar situations, like someone around their age with the same disease. I feel if you can speak with somebody going through the same thing you are, that would definitely help you and make you feel better. Also, resources that can educate you more about your disease because, like I said, I was

just 15 and I didn't know anything about leukemia. I just did whatever the doctors told me to, but I feel I would like to have a say in my treatment if I knew more about my disease. If patients get educated on their diseases, then they will be able to look for other treatments; maybe like new clinical trials and look for the best treatment; not just following what their doctors tell them what to do. I think if you know about LLS, that is a very good plus or a good bonus.

Lizette: Yes; we are definitely trying to reach people close to when they do get diagnosed so we can be there for people throughout their whole cancer journey.

Timothy: That would be great.

Alicia: I think, like you said, both Lizette and yourself, finding other people who are in similar situations is such a plus. Have you ever heard of the organization called Stupid Cancer?

Timothy: Stupid Cancer?

Alicia: Yeah!

Timothy: No; I never heard of that.

Alicia: Well, the founder, Matthew Zachary, he is a national advocate for adolescent and young adults, also known as AYA, cancer patients. He said that he went 7 years without knowing anyone or having a peer that he could relate to. His answer to this lack of support was to start an online community called, Stupid Cancer, and it is geared towards young adults, as well. I think it is so important to find the places and the resources that you can tap into because being diagnosed is not an easy thing. That is why with LLS, it is always top of mind to make sure that we are providing what we can to patients and caregivers so they don't have to go through this alone, especially initially when the shock is there.

Timothy: Yeah; for me it was 5 years without having any support groups, so I am sort of in a similar situation as him.

Lizette: We have also spoken with another young adult that was diagnosed early with lymphoma and she said that she felt like she put her life on pause because she had all these plans and then, all of a sudden, she was diagnosed and she needed

treatment. She couldn't go along with those plans just at that time. Did you feel that way, too?

Timothy: For me; it wasn't really a pause in life. It was a turning point. It was a complete turning point for me because it made me realize and learn a lot about how valuable each day is in life. I was wasting my life away in high school, my first year or two—year and one-half. Because of this event, I tried harder in school and I actually had a goal in life. I just wanted to do better in life and have an impact. For me, it wasn't a pause, it was a learning point, a turning point, and that is why I am nursing school because I want to help others in the future.

Lizette: And is that what really made you want to go to nursing school?

Timothy: Definitely. Yeah, in high school, I had no idea what I wanted to be in the future. Maybe a cop, a police officer, but I am not fit for that; physically, I am not fit for that. I met a few nurses during my treatment who were very memorable. One of them; her name was Broca; she was my nurse at NYU Langone. I was in the hospital for about 2 weeks straight and was never able to go out. The only thing in my mind was to take a breath of fresh air. That was my dream. I really wanted that. That was the only craving I had—just to go outside and breathe the air, not the hospital air conditioning. You get tired of that. I requested that to my nurse, Broca, and she asked the doctors and everybody if they could do anything for me to go outside. They were actually able to allow her to take me downstairs to the garden area at NYU Langone and we walked around for about 15-20 minutes just talking about whatever, through a garden with grass and trees and flowers. I was so touched. I have been touched by many nurses like her. That is also why I also wanted to be a nurse to be there for the patients, side-by-side, and make their dreams come true at their hardest times and be there for them.

Alicia: That is inspiring. Being in nursing school and having experienced what you experienced, do you think it has made nursing school easier, being able to relate to a lot of the terms?

Timothy: Yeah; I feel that going through nursing school with this diagnosis definitely pushes me harder and harder to get through school and all those exams and reach my goal because, at the end, I just want to help other patients with the same disease that I had, or similar diseases. My diagnosis definitely had an effect, yeah!

Timothy: In nursing school, they stress a lot about patient relationships and communicating with patients and patient-focused care. I was better able to relate with patient-focused care because, as a patient myself, I really enjoyed being the center of attention by all the nurses. It felt that I was getting the attention, the care I needed during the hardships. I feel that I am better able to relate to the patients and to show compassion for them because I was once in their shoes.

Lizette: Yes; usually you hear about nurses and taking blood or doing something else that is physical, but a lot of nurses at the conference that I went to, it was really highlighted that it is the support that you are giving the patient, as well as all of the other medical things that you have to do, but really, that support makes nurses so special.

Timothy: Yeah, I agree. It is not just the drugs they inject you with and the pills they make you swallow, but the emotional support they give you by just talking to you, stopping by to see if you are okay and showing that they actually care. I think that helps a lot.

Lizette: And we know that you'll have a light to night team this year; probably, right? With all of your colleagues there at nursing school.

Timothy: I will invite my whole cord. I will try to get all 300 of them out to the nightlight ball.

Lizette: That is great.

Alicia: That would be amazing.

Lizette: Team Tim. I know that you were diagnosed early, at 15, 5 years ago. You did say it changed your life. What was the biggest thing that you learned and what would you tell others that were just diagnosed?

Timothy: The biggest thing I learned, through my treatment and my experience, is that just medicine and drugs, science can't be the only cure. That cannot be the only cure to your sickness or your disease, you have to have emotional support; you have to have happiness and positivity to help you get through everything and to help you towards the path of getting cured and 100% well-being. I felt that being positive throughout the 3 years of treatment, I was able to distract myself from what I was

going through—all that treatment, chemotherapy, that made me feel disgusting. I just tried to stay happy and think about the positive stuff in life like having family. I was thankful for every little thing in life.

Lizette: So, you would let the kids know that there is happiness in the world even though they are going through such a tough time.

Timothy: Definitely. Every day that you are able to wake up and see your family and see yourself in the mirror and know that you are alive still, means that there is hope that you can get cured and live a normal life right after that and pursue your dreams and live even bigger. That is what I think.

Lizette: And that is what you are doing.

Timothy: I am trying to.

Alicia: You are making your mark. Did your doctor talk to you at all, not only about fertility, but at all about planning for the future being diagnosed so young?

Timothy: They told me to never smoke and live a healthy life just like any ordinary person—just exercise, don't smoke, eat healthy, but nothing specifically unique. They treat me as a normal person now.

Lizette: Did they tell you about possible long-term and late effects that they would have to monitor you for more carefully--something that might come about 5, 10, 15 years after treatment?

Timothy: I heard from the beginning that once you are cured for about 5 years, once you are in remission for about 5 years, you don't have to worry about relapse or anything like that. I haven't hit my 5-year mark yet. I have been normal for 2 years. I still have a long way to go, but they always tell me to not worry about it. The chances are very low and, yeah, they just tell me not to worry about anything.

Lizette: Do you worry about anything?

Timothy: No. I am just praying that it will never happen again. I am just really hopeful.

Lizette: You have a great positive attitude, which is great. I think it really does help during treatment to have a positive attitude.

Timothy: Just speaking for the chemotherapy drugs that are going inside your body, even though it is really making you feel like poop, just be thankful for every little thing. Be thankful for the needle that is going inside your body, even though it hurts, because it is helping. If you saw me in the past while I was getting treated, I would look the same as I look right now. I am just always like this. I don't really show sadness. I cried once.

Lizette: You cried once in your life?

Timothy: No; once during treatment.

Lizette: Was that from pain, physical pain?

Alicia: Just thinking about everything?

Timothy: No; I actually got appendicitis during treatment, too. During that day, my Mom was crying so much because I had cancer and appendicitis at the same time and that is when I cried. I was just, "Ahh, goodness, this is my life".

Alicia: When you are that young, you don't know what it means.

Timothy: I didn't know anything. I didn't know what appendicitis was or leukemia.

Alicia: You have a very interesting spin on it. Like you said, I think that is very, very important because once you hear cancer, again, there is that shock. Once you go over treatment with your doctor and your healthcare team, you are automatically thinking, "Oh my gosh, how am I going to feel? How is this going to affect my life? What do I have to stop?" You automatically think that way. I think that you have done a really great job encouraging not only yourself, but I'm sure your family, your parents saw that you were very positive and saw that you were hopeful. That changed, not only you, but your environment.

Timothy: I never really complained about anything. I feel that if you are going through this hardship right now, what is the whole point of being more negative and making it even harder for yourself and for the people around you. You are going

through a hard thing right now. Everybody knows that you are so just try to stay positive and make the best of it as you can and hope that you will get through it.

Lizette: You returned to high school so did you ever tell your high school friends what had happened during that year?

Timothy: During treatment, I had a lot of steroids, prednisone for my treatment, and that boosted up my appetite and I gained about 20-30 pounds. I don't know, I just got really fat. When I came back to high school, everybody was surprised about how much weight I gained. I didn't really tell them that I had cancer, but I just told some of my closest friends and maybe they told other people, but sooner or later, they stopped bugging me about my weight and how I looked. I wasn't really bullied-bullied—they were just joking around that I gained a lot of weight. It was kind of embarrassing for me to go back to school looking how I looked before at the time.

Lizette: Then, after you stopped the steroid?

Timothy: I lost the weight instantly—very fast.

Lizette: It's one of the more common side effects of the steroid.

Alicia: Having now, like you said you are 2 years out, having experienced what you experienced, it being a scary time for you and your family, but also a hopeful time, has this changed them in any way, having gone through what you guys have gone through?

Timothy: They have definitely gotten closer to me. They are warmer with me and we have a stronger relationship because of what we went through together. We are definitely a lot closer. We share what we do every day together with each other. We are like friends now. We can never forget what we went through.

Alicia: Seeing that you did not have the support at the time of diagnosis, what more do you think organizations can do to help young adults when they are diagnosed?

Timothy: I think that organizations reach out mostly to big hospitals such NYU Langone, Mt. Sinai (the main hospitals), but they don't really reach out to the small clinics, the outpatient clinics. That is why I feel I was never reached out.



Lizette: Thank you, Tim, for sharing your story with us and for letting people know that you can make it through and you can really excel going from a high school student that didn't know what he wanted to be to going through treatment and really valuing what your treatment team did for you. Then, actually getting into the nursing school of where you were actually treated. That is excellent.

Timothy: NYU is deep within my heart.

Lizette: I am sure you are a part of NYU now.

Alicia: And we are so happy to hear that you connected with our local chapter during your journey. We encourage you to stay connected so that they can help you and be a point of reference for any questions that you have or any resources that you are looking for. We wish you the best in life and we hope to hear amazing things about what you're doing about school, but everything that goes on so thank you for your time and that you for sharing your story with us today.

Timothy: Thank you so much. You're welcome, it's my pleasure.