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THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Siblings, Stem Cells, and Second Chances'

Description:

What happens when a sibling match becomes the key to survival?

In this heartfelt episode, we speak with Peter and Susan Feinberg, a brother-sister duo connected by both family and a lifesaving stem cell transplant. Peter, an acute lymphoblastic leukemia (ALL) survivor, shares his experience from diagnosis to remission, while Susan offers a rare and intimate view into what it means to be a stem cell donor. Together, they reflect on the emotional and logistical challenges of transplant, the determination to succeed when miles apart, and the hope it represents. Their story sheds light on the real impact of donation—and why joining the registry can mean everything to someone waiting.

Transcript:

Elissa: Welcome to *The Bloodline with LLS*. I'm Elissa. Thank you so much for joining us on this episode. Today, we will be speaking to Peter and Susan Feinberg about Peter's stem cell transplant. Susan is Peter's sister and was his stem cell donor. We will be hearing about both of their perspectives as they navigated through transplant.

Peter is an acute lymphoblastic leukemia, or ALL, survivor and a corporate and commercial attorney. He was diagnosed in December of 2020, nearly two years from his first abnormal blood test and seven months after symptoms started. After chemotherapy and a stem cell transplant in April of 2021, he reached remission. Peter shared his story in the September 2023 episode, "Patient-Doctor Perspectives: Adult Acute Lymphoblastic Leukemia (ALL)." Susan was a professor at Temple University in Philadelphia, Pennsylvania, when she heard about her brother's diagnosis. After testing, she was found to be a ten-point match and became his stem cell donor at 55 years old. While the COVID pandemic complicated the transfer of stem cells, she was able to have a successful collection and transfer to Peter, leading to his eventual remission. Welcome, Peter and Susan.

Susan Feinberg: Hi.

Peter Feinberg: Thanks, Elissa.

Elissa: Thank you so much for being here with us. So, Peter, let's start with your diagnosis of acute lymphoblastic leukemia or ALL. What signs and symptoms did you have that led you to the doctor?

Peter: Well, I, initially had a series of bad blood tests after an unrelated orthopedic accident in May of 2019. And my doctor just kept doing the same blood tests, and it got a little bit better, but they were still out of whack. But I felt well, and it was her belief that my blood work was out of whack because of the accident. So, fast forward about nine months later; and I've been a fairly avid athlete throughout my life and, in particular, a runner. I started noticing that my running times were dropping off dramatically and that I was feeling much more breathless at the end of my runs.

In addition to that, I was finding that at the end of my days, I just had a degree of exhaustion that I had never really experienced before. And this happened pretty much all of a sudden. And in most other regards, I felt absolutely fine; so I was kind of inclined to attribute this, perhaps, to the pandemic or to other different things going on. And my sister has always been very encouraging of me getting follow-up medical care; and when I talked to her about the drop-off in my running times – I had said something along the lines of "Getting old sure stinks. I just can't run the way I used to. And it's just fallen off dramatically." And she said, "You're right that getting old does stink, but it shouldn't have dropped off as much as it did. You really need to follow up on that."

And it was a very busy work year for me, so it took a while for me to get in. And when I finally got in, my blood work was even worse than it had been about 15 months earlier. And I was kind of going on the theory at that point that I probably had some sort of a low-to-medium grade anemia; and they were going to tell me to go into the doctor every three months or so and get a shot of B12 and just kind of keep at it. But the first thing my doctor did was give me an endoscopy and a colonoscopy, and when I asked why, she rattled off a litany of different kinds of cancers in the stomach.

All of those turned out to be negative, and then she did a lot of heart work, and that was negative. I thought maybe I had had some kind of long-tail COVID, that I had had COVID and it had been very mild, but the symptoms were hanging around because these things seemed very similar; and that was in the news. And I did not have antibodies, so that was not an issue.

And finally, after all of this, they did a test called cytogenesis, and the cytogenesis showed that I had a 90% likelihood of either leukemia or lymphoma, with a 10% likelihood of a different, but equally insidious blood disease.

So, the next step was getting what's known as a bone marrow biopsy; and about a week after the bone marrow biopsy, my phone started blowing up one morning when I was out with a friend. And it was an oncologist who I had never met telling me I had ALL, and I needed to report to the hospital within 36 hours to begin CVAD (cyclophosphamide, vincristine, doxorubicin, and dexamethasone), which is the primary chemotherapy given to ALL patients.

Elissa: Wow, that is shocking. So, what was the reaction of your family after your diagnosis of cancer when really you were thinking all these other different things?

Peter: Yeah, well it was an interesting time in a bunch of different regards, first of all, because of the pandemic. My sister's on the East Coast, and I'm out here in San Francisco, so we weren't seeing each other. As I was going through the testing, I was keeping my sister apprised of what was going on; and I think she was concerned that they started out testing for cancers.

And when I told my sister about the cytogenesis, I think it really didn't so much move the needle with her, not that she was unconcerned about me, but it's just sort of, well, you're feeling well. They've been testing you for these things. We'll see what happens when it comes back.

And then I found out that it was the acute leukemia, and the acute leukemia was a particularly hard one to convey to her because, as you may remember from the last podcast we did together, our mom and our mom's mom both died of leukemia. So, leukemia is a word in our family that probably is about one step closer to the lowest level of hell than bubonic plague.

Elissa: Yeah.

Peter: So, when I said that to her, obviously, it had a real effect; and it was very hard to say that to her. We had always thought, for no particularly rational reason, that it seemed like a matrilineal thing in our family that, if anything, she was going to be more at risk for it than I was. So, it was fairly shocking. It was very, very hard to talk to her about that. It was as hard as getting the diagnosis.

Elissa: So, could you tell us a little bit about the treatments that you had prior to stem cell transplant?

Peter: Yeah. So, I was mentioning a moment ago that the initial treatment is a chemotherapy treatment called CVAD, which is multiple different chemos given in two tranches. And the first tranche typically can last about a month, but I got through it so well in terms of minimal side effects that I was out of the hospital in three weeks. And I had been going through this whole process, I think, frankly, with a sense of kind of arrogance and denial that this wasn't really happening to me; and I was going to beat this for sure. And when I was discharged from the hospital and I put on my little puffer jacket and I had my wheelie bag and one of my nurses said to me, "You look more like an arriving patient at San Francisco Airport than you do like somebody leaving the Oncology ward," it only added to that.

The second part of CVAD was much, much harder. In particular, there was a combination of two chemos, cytarabine and methotrexate, which absolutely floored me with fevers and mucositis, and nausea, and rashes from top to bottom on my body. That was very, very hard. And, the way that this is typically set up is that after you go through that two-part CVAD, they then do another bone marrow biopsy to see what extent the chemo has been working.

And my doctors were very optimistic. Sort of shockingly so, considering the mortality rate from this disease that the CVAD was going to if not get the leukemia out of my body, then at least significantly diminish it. And I had gone into this with 15% cancer spikes. After the two rounds of CVAD, my cancer spikes actually increased from 15% to 50%. It was what they called severely refractory; and that was sort of like the bell going off that this thing might actually really kill me at this point. So, that was very, very unnerving.

Even though I had had this bad result, I went over to Stanford for a day of tests and appointments; and Stanford continued to be very optimistic that we could get to a point where I would be a candidate for transplant. The alternative would have been if the initial chemo had worked, I might have been eligible for maintenance therapy, but

Stanford deemed my leukemia at that point to be sufficiently serious that I was going to need a transplant to get a lasting remission.

So, a fairly recently approved monoclonal antibody by the name of Blincyto® was administered to me in a one-month dosage. The first 11 days were in the hospital so they could make sure that my body was not adversely reacting. And when I did well with that, they sent me home with a little cartridge that looked like, you're too young to remember this, Elissa, an old Walkman and-

Elissa: Ha! I'm not that young. I do remember Walkmans.

Peter: Okay, okay, okay, yeah. Your parents, your grandparents told you about them. So, I carried that around everywhere; and I really felt great. And then the thought had been this was sort of the reverse of the CVAD. The thought was, well, the Blincyto probably won't cure you in one shot; but, we're looking for some improvement for you to get down from the 50%. And I remember after getting that second bone marrow biopsy or third bone marrow biopsy, actually, talking to my oncologist to express what I can only describe as shock that in one round of Blincyto, there was no measurable cancer in my body at that point.

So, then the question became what are we going to do with this? And, the consensus seemed to be, again, that the only way to deal with it was going to be a stem cell transplant.

Elissa: So, what was that conversation like when you were talking about transplant? Did you feel like there were any other options or was that like, "Hey, this is really going to be the best thing," and you just talked that through? What was the conversation like with your doctor?

Peter: Well, again, I had this feeling of adrenaline at this point; and I knew a number of people in the community from the prior few months who had gotten into remission on their initial treatments and either had been going through maintenance or were on watch and wait or something else and the cancer came back. And they were struggling to get back into remission again. I was really freaked out that I was going to lose remission. So, I clearly needed to do something; and as I said, maintenance, going back on, you see that had not worked. So, the idea of doing that again or doing some other kind of chemo wasn't going to work.

No one really threw out the idea at that point among my doctors about the idea of a longer-term dosing regimen with Blincyto. I don't want to get too far off point, but as I mentioned, we have this fairly unusual circumstance in that this is not viewed as a genetic disease; and yet we have two direct lineal relatives who died from it.

Elissa: Right.

Peter: So, my sister, ever the academic and always interested in more information, rather than less, wanted to find out a little bit more about what there was out there on genetic stuff and found this professor and doctor at MD Anderson who was doing some interesting research. But it turned out when we talked to him, he wanted to talk less about that and more about the Blincyto, the antibody that had gotten the cancer out of my system and the fact that he was running a trial at that point which, while he had not published his results, were showing an almost identical survival rate after five years to stem cell transplant with far less toxicity.

I found this out two days before I was supposed to go into Stanford. This was during the middle of the pandemic. I would have needed to have moved to Houston for treatment, and I would have needed to have switched health insurance. The whole thing was sort of more than my brain could have even really contemplated-

Elissa: Yeah, that's a lot.

Peter: -at that point in time. And, Sue was lined up at that point as my donor. The course of least resistance was to go through transplant and certainly if I had known about some of the consequences that I had after transplant, it would have been something I think I would have thought longer and hard about but just did not seem viable to do anything other than transplant in the moment.

Elissa: Right. So, let's go backward a little bit. When you decided to do transplant, what then happened with the search for the donor? Were you looking at unrelated donors first-

Peter: Right.

Elissa: -or was it, hey, who in your family might be able to get tested for this?

Peter: Well, the whole thing was sort of surreal because when I began the process, Kaiser was just like, "Let's get the cancer out of your system; then we'll worry about what comes next."

Elissa: Yeah.

Peter: So, the first time there was really a serious conversation was when I went to Stanford, which was ironically when my leukemia was so severely refractory. And I was like, "Are you sure we're even going to get the cancer out of the system to get to that point?" They were very calm; and they said, "We think we will, but under any circumstances we feel like we need to plan." So, they said who were your family members? And I was, obviously, old enough at that point so even if I had living parents, and I did not, they would have been too old to have been donors.

Elissa: Right.

Peter: I don't have kids, and I have one sibling. So, no pressure, Sue, but it's you or it's nobody here. But this was more complicated than that because of the leukemia in the family. And while leukemia has not been as successfully studied as say breast cancer or prostate cancer where you have that very direct link with the BRCA gene, there are genetic markers that they look at.

So, the concern with Sue, before they even started looking at matching her, was, we don't want to get rid of your leukemia and give you Sue's leukemia. So, they did extensive genetic testing. And Sue was toward the older end of where they'd normally look at for donors; so, they said, "Let's get your sister tested, both in terms of proclivity for leukemia and as a match because, as you remember from your high school biology, there was a 25% likelihood only that she would be a match. But let's also look at the list." And it turns out as someone of Central and Eastern European background, my genetic matches are overrepresented on the list. And they immediately found four perfect matches.

But they said, the gold standard here is really a sibling match. They said it's a little bit too late for you to have an identical twin, but if your sister is a match, then, that would be where we would go, assuming that we don't find any markers for leukemia. And as it turned out, they did not find any markers for leukemia with her, but interestingly enough, they also did not find the genetic marker for leukemia in me. So, it's not a total get-out-of-jail-free card, but it's like to the best of our knowledge we believe that she is not going to get the disease herself; and she will be a good donor for you if that is something she is, in fact, willing to do. We had had a call at this point about it, and Sue said, "Anything I can do, of course, I will do for you," which was wonderful. So once we found out she was a match, I wasn't really expecting her to back out and she did not disappoint.

Elissa: Good. So, Susan, when you found out that Peter would need a donor for a stem cell transplant, what thoughts were going through your head?

Susan: Well, I'm going to back up just a little bit because as Peter said, this was a pretty long time into the process. So, he had the unsuccessful round of chemo first, and then he moved over to Stanford; and so, I was watching all this from a distance. And Peter and I are very close, so, it was really just agonizing to watch all this kind of unfold from a distance. And, for me, I always want to help.

So, it was very hard to both watch this and not be able to do anything, especially as he started getting sicker and sicker. I mean, there was never a question in my mind that if there was anything that I could do I was going to do it. There was never a question. And I didn't know at the time that it was going to be stem cells rather than bone marrow. I had no idea how the process was going to unfold until it started unfolding. But, just as far as whether or not I asked myself do I want to be Peter's donor, never.

Elissa: Okay. So, could you tell us a little bit about the process for those who don't know what that process is for just finding out if you're a match. So, what that testing is?

Susan: As Peter said, the whole thing was a little surreal, particularly because of COVID. So, I kept having to go into Georgetown University in [Washington,] D.C. where I live; and they would take blood and then overnight it by human courier to Stanford. So, I didn't know exactly what was going on. And as Peter said at one point, as well, I got a kit to do the genetic test to see if I had a proclivity for leukemia.

I think for me, the genetic testing was the toughest part, particularly because, when you're the sibling, even when you're the donor, your needs are not out there. And so, no one had really talked to me about, what would I find if I got the results of a genetic test. And as the process dragged on, as the first kit was lost and then they had to do it again, I started to really think about that. What am I going to find out? Am I going to find out the equivalent of the BRCA gene or what exactly am I going to learn? And I think, at that point, really started bugging Peter's doctor at Stanford and the various nurses to explain to me what I was going to hear back as far as the results went. So, I think that genetic testing was the trickiest part.

Elissa: Yeah, that sounds kind of nerve-wracking with the history of your family.

Susan: It was very nerve-wracking. And as Peter said, when the two of us grew up, I think because the leukemia in our family has been among women that I always thought that it was going to be me. So, I grew up thinking it was going to be me; and so the testing had that other special kind of thing. "Oh, I'm going to learn now that it's going to be me as well, and this will also mean that I can't be my brother's donor."

Peter: Yeah, I think for me that the horror of Sue finding out that she had a proclivity for this above and beyond any proclivity we'd expect just from mother and grandmother having had this and me having had this really added an element of poignancy to this because I felt that even though if she had this marker, it was far from 100% certainty that she'd get leukemia that it was going to be an incredibly intense thing to find out at a moment that she was super vulnerable and that, I was going to need to be very consoling to her because she was putting herself out there for me at a moment that I really didn't have a lot to give to anybody else.

Susan: And I really felt as though I tried to talk to my friends here about it rather than you.

Peter: Oh.

Susan: And, so one of the things you learned to do as a professor is you write your "Dear Professor Letter". So, I was combing through all the academic literature and writing to other professors to ask them stuff. And I was able to track down the email with the academic email address of Peter's doctor and wrote her the Dear Professor Letter. But it was a little bit scolding because I said, "You know, no one thought of me in this process, and I don't mean to be saying, 'Oh, what I'm going through is the equivalent of having leukemia, but it's something.'" And I just wanted someone to tell me what was going on and give me a sense of what I could learn from the test.

Elissa: Well, I'm so glad that it turned out the way that it did; and you didn't have any genetic markers that would, put you at higher risk of getting this. And so Susan, after you were found to be a match, could you tell us a little bit more about the process from that point? So, was there any particular preparation or more testing needed prior to the actual collection of cells?

Susan: There was certainly preparation, so for about a week before the donation, I was doing daily shots of Neupogen®; and for some reason, I had a very strong reaction to it. I'm told that this rarely happens, and I'll sort of tell you how that went going forward. And the main thing is that I was just getting brain fog, and it started to accumulate as the week went on. And we were joking, my husband and I, that, I had trouble following the plot of an episode of *Law & Order*. I was so out of it. It was one of the first times I've ever taken any time off. I took one week off of teaching. I couldn't have done it, I don't think, because I was quite foggy.

So, there was really very little to do other than, I may have gone in for one round of additional blood testing at Georgetown, but to wait until the moment when Peter needed his transplant, go back a week in time, and then start taking the shots of Neupogen.

Elissa: Yeah. So, I mentioned in the introduction that COVID complicated things a little bit; and you had to donate from your local hospital and then have the cells transferred. Could you tell us what donation day was like for you and then what the process was to get the stem cells over to Peter on the opposite coast?

Susan: Absolutely. So, on donation day, you go in quite early in the morning. And they don't know how long it will take to give the donation; and I think this is part of the reaction to the Neupogen. But you go in and they run another series of blood work before you do the donation; and they give you one final shot of Neupogen. So, that day effectively you're getting two shots. And you go up to a donation room, and essentially there are just a lot of beds. And there's a centrifuge next to the bed, and basically what they do is they hook you up to two sets of intravenous inputs. For me, it was one on each arm. And your blood gets taken out of one arm and spun through the centrifuge. And the centrifuge removes the stem cells from the blood, and into the other arm they put the blood back into you.

Elissa: Oh.

Susan: Yeah, it's kind of crazy. So essentially, you're just hooked up on the two sides. The thing is working behind you and spinning it back to you. And normally that process takes anywhere from, I would say, 3 hours, 5 hours. Some people have even longer, which is why you get there so early in the day to start the process.

But I think because the Neupogen worked so well, they called the perfusion, and told the nurse that my collection was off the charts and that it was going to take no more than an hour for me to do the donation because they were collecting such a high volume-

Elissa: Wow.

Susan: -of stem cells with the donation. And so, it ended very quickly, even though I brought, reading material for a whole day. And then when it ends, they just essentially unhook you-

Elissa: And that's it?

Susan: -and you walk out. And so they put your blood into an IV-type bag. And they put it into a cooler. And LLS and also NMDP, formerly Be The Match, who did all the work getting me ready for the donations, they do need an extensive medical history, and you do get a full medical checkup early on. And they have volunteers at Be The Match, and one of the things that those volunteers do is they courier anything, whether it's blood work or, in this case, stem cells or bone marrow cells. They put it in a cooler. They go to the nearest airport. They get the first flight, so that Peter had my stem cells the next day at Stanford; and those were transfused into him.

Elissa: Well, it sounds like it was a pretty easy procedure for you.

Susan: It was very easy. That evening, I came home relatively early in the day. And again, I was sort of confused. Our joke was that I couldn't watch a Yankee game and figure out what was going on at that point. But, I remember walking out of Georgetown and feeling elated. All those months had gone by, and it was this feeling. It was the first actual thing that I felt like I could do. I felt hopeful, really, and obviously by that time I knew that Peter had tested negative for any discernable cancer cells. And so, I remember really just for the first time in many, many, many months getting out of that hospital and just sort of going, "Yay. I felt like we were really moving towards something different."

Elissa: Yeah, it seems like a lot of times that caregivers can feel very helpless, especially if they live farther away. I imagine that that was such a good feeling to feel like that you actually were able to physically do something to help Peter, even though he lived so very far away from you.

Susan: Exactly. That's exactly right. You know, the Dear Professor Letters, they were helpful. And can I give a shoutout to a doctor who was very helpful?

Elissa: Please do.

Susan: It's Eli (Elias) Jabbour is the doctor at MD Anderson who was extraordinarily generous with his time. And, in fact, after Peter had the dose of Blincyto, we had talked to Eli, and I think at that point your transplant was supposed to be like two weeks away or something like that.

Peter: Not even. I think the transplant was like nine days away. But I think I went into Stanford 48 hours after we talked to him."

Susan: But he basically said, "I would not let my patients go that long without"

Peter: Oh, yeah. We talked to him twice, yeah, that first time.

Susan: Right, and he said, "I would continue the Blincyto essentially right up to the date that or maybe 24 hours before Peter was supposed to get the transplant". He said, "I worry that the remission might not hold; and just out of an abundance of precaution, that's what I would do if he were my patient." And we actually did do that. And initially, I did contact him because I had access to PubMed (National Institutes of Health scientific publications), so it was easy for me to look and say, "If you're looking at X or Y kind of research, who's the person whose name keeps coming on peer-reviewed journals?" I was also, at the time, looking at the genetics of leukemia; and I know Dr. Jabbour's also involved with that. And that was the context initially that I contacted him. But I think we had at least two Zoom® calls with him.

Peter: We did.

Susan: And I think that was the point where he started talking about the Blincyto. One of the things that he does with some of his patients is that instead of getting a transplant, he puts them on sort of a longish term maintenance regime with the Blincyto.

Peter's doctor judged him not necessarily to be a great candidate for that, but he was just wonderful. And again, it was just a Dear Professor Letter, but he was willing to give us all that attention.

Peter: Yeah, I think that there's been a shift in the last four years or so from thinking about not only Blincyto, but there's a second monoclonal antibody and CAR T as being conduits to get to a stem cell transplant to, in fact, being alternatives to a stem cell transplant because, as I said, they seem to be showing, I mean it's still early in the game on this, similar levels of survivability with far less toxicity. I know a number of people in my support group have been on longer-term Blincyto regimens and have been doing quite well with it.

Elissa: That's good. Yes, sometimes it just takes a little bit of time to see how effective it really is at keeping somebody relapse-free. What you've talked about, Susan, is really what we try to do on the patient education side of LLS is educating patients and caregivers about their disease enough so that they have this information at hand and they can ask doctors about it. They can go back to their doctor and say, "Hey, I just wanted to check in about this. Is this a good option for me? What about this?"

And then also, the value of second opinions is so wonderful; and doctors have different opinions about things; and, it's great to be able to see what other opinions are out there so that, again, you can be very educated about your disease and make sure that you are participating in the treatment process and the decision-making process. And so, I love what you did with connecting Peter and yourself to make sure that you had all the information available to you and could make the best decision for yourself.

Susan: And I think it kept me sane as well during the process, reading all those academic articles.

Peter: I think you're so right. As a patient, feeling like you don't have agency is, I think, one of the hardest aspects in all of this. I mean, being in a hospital for weeks at a time, in some cases months at a time, and you feel like you have no control over what's going on in your life. I do a program through LLS called [Patti Robinson Kauffman First Connection Program®], where they put a graduated, if you will, or recovered blood cancer patient in with a newly diagnosed person. And that's one of the things I stress to people as much as possible because, I think doctors will default into making decisions for you. And, obviously, they know the medicine a whole lot better than any of us do;

but they don't necessarily know us as well as we know ourselves. So, I think that the combination of those two things together is really so important for patients in keeping themselves psychologically strong as they go through what is, for anybody, an incredibly trying process.

Elissa: Yeah, yeah, absolutely. So, let's go back a little bit; and, Peter, let's talk about transplant day for you. What was that day like for you once the stem cells arrived? Were you already at the hospital ready to go?

Peter: I was. So, I think the typical transplant protocol is you getting to the hospital and they kind of give you a day to breathe. And then they give you six days of intense chemotherapy.

Elissa: Okay.

Peter: And it was two different chemos, one of which, Cytoxan®, is one of the components of CVAD. And I said to them, Cytoxan, no problem. I breezed through that and CVAD, and they said, "Yes, but this dose will be six times larger."

Elissa: Oooh!

Peter: Yeah. And then the second one is something called busulfan, and in the moment when I was getting these, a lot of people really don't react well because the doses are so intense. I really had very little reaction; and my doctors at all points were sort of telling me, "You're just going to feel so awful from all of this." And I felt like I just sailed through this to the point where I really almost wondered if they were playing a prank on me.

After the last of the six days of chemo, they give you a day off, and then it's transplant time. And I had had a totally mistaken notion of what a stem cell transplant was. I was thinking it was like a solid organ transplant, and I was thinking that the transplant itself was a dangerous procedure. The transplant is essentially like a transfusion. And while people can have bad reactions to it, there was a resident in the room while it was going on.

Really, the issue that comes up mostly is that chemo, because it is so intense, which in my case started kicking in about four days afterwards. But to go back to your initial question, I recall that the stem cells got in sort of early to mid-morning; and they had had my transplant scheduled to be about 11:00. And one of the things that's nerve-wracking for a Type A person like me, and I think will drive my sister at least equally up a wall, is that nothing happens in a hospital on the time that they tell you when to expect it.

So, I had told all of these people in my life I'd be getting transplanted around lunchtime, and not only did it not happen at lunchtime, but they said another hour, another hour, another hour. It was close to dinner time by the time it finally happened. And Sue's recollection of her donation was very similar to what Stanford said that, this is really a good large donation; and we think we'll have no problems with it. And the whole process went very, very smoothly. It feels literally like getting a shot in the arm. I mean, I felt sort of energized actually after getting it. Far from feeling bad, I felt good. And I mean maybe it was just a psychological-

Susan: That was my awesome stem cells.

Peter: Yeah, yeah, maybe. But, I really felt good when they were going in.

Elissa: Yeah.

Peter: It was no issue. One of the things I remember from that day is that there's supposedly a ceremony after you get your stem cells when you get a little birthday cake and other stuff goes on. And I kept bugging them about the cake, and I got a sort of very desultory Happy Birthday that came along with that because, I mean at that point in time, it almost seemed like an anticlimax because it had just gone on so long. But the mechanics of the transplant were very, very easy. Very easy.

Elissa: Yeah. But that is your rebirthday. So, you need cake, and you need to celebrate.

Peter: I think so, yeah. Well, I would soon lose my appetite, so it was good that I ate while I could.

Elissa: Yes, yes, definitely. I'm glad that that procedure seemed very easy as well. And so, just for listeners who don't know, you mentioned the very high-dosed chemotherapy coming into the transplant. Now that is to clear the bone marrow completely, right, so that the new stem cells can come right in.

Peter: That's exactly right. So, I had mentioned that I had this bone marrow biopsy that showed no cancer in my body. But, it doesn't really get down to the cellular level.

There is this concern that there may be some lingering cells. So, they basically zap your body with this crazy intense dose of chemotherapy just in case any cell might have some idea that it could hide behind something and live on afterwards.

Elissa: So, Susan, let's go back to you. What were the next hundred days like for you while you waited to see the results of the transplantation since 100 days is that magic number?

Susan: Stressful, I would say. But one thing that was really great for me was that after Peter got out of the hospital, what, about four weeks or something after the transplant?

Peter: Yeah, it was just about a month. Yup.

Susan: And you know that happened to coincide with the end of my semester, and I was able to go out finally to San Francisco to be with Peter for about a month and that made a huge difference.

And I think there was a lot of stress, obviously, in waiting to find out whether my stem cells were going to be engrafted. But, by the time I got out to San Francisco, Peter was feeling great. And I don't know how much this was because of the large doses of steroids that he was on, but he was full of energy; I think enough so that I could really put myself in denial to some degree because we were still, of course, waiting to find out whether my stem cells would be engrafted. But I just felt very optimistic at that point that things were going to work out.

Elissa: Oh, that's so good. Now, Peter, how has your life been since transplant? You're just over four years out, right?

Peter: I am.

Susan: Yeah.

Peter: Well, I wish I could give you an A+ answer, but the answer is it's been more like a sawtooth pattern.

Elissa: Okay.

Peter: I just flew through the first year. I had a couple of problems which were pretty transitory, and one of the aspects of going through allogeneic transplant is that you lose your childhood immunizations and vaccinations.

Elissa: Yes.

Peter: And after praising Sue's stem cells, we now have to talk about the fact that perhaps they were a little bit cantankerous. Somehow or another, some kind of a vulnerability opened up in my immune system. I don't know if it opened up at transplant or if it opened up as part of the revaccination process. But when I got to the one-year point, it was time to get revaccinated. And the way that Kaiser had did it was that over the course of four weeks, you would get two or three vaccinations at a time, half-doses and then a month later go back and get the remaining part of that.

Well, on the first round of half-doses, I got shots for shingles and pneumonia, and my body immediately reacted. I mean I just felt like I had been hit over the head with a baseball bat. And it's funny. When you get out of the hospital after transplant, Stanford gives you a book. It's about 110 pages long about things that you can't do or the circumstances under which you can do them or things that you have to do, and things you need to be cautious about; and there's no mention of vaccinations. And I don't want any misconstruction that I'm anything other than a pro-vaccination person generally, but these two first vaccinations really had an effect on me, even as my body improved somewhat after those first few days.

It didn't get back to normal, and I just had turned 60, and, as I said, I'd hit the one-year mark. So, my wife and I decided that we were going to celebrate by taking a month in Europe. And nobody was telling us that that was a bad idea or anything. But I just felt my body was a little bit off; and I had been feeling so well. I had not seen an oncologist in person for almost nine months at that point.

Now, I had another video appointment with my oncologist before I left, and I said, "Could I possibly come in, and you could put a stethoscope on me and look at me and tell me if you think I'm doing something crazy here or if you think something's wrong." So, I had a round of blood work done, and the blood work was great. And she put a stethoscope on me, and she said, "You look great, you sound great, your energy is great. Go and have a really good time, but when you come back, we'll send you to the pulmonary function lab and just make sure everything is good."

And I went on that trip, and I traveled as I think I said on the last podcast, more like someone your age than my own. I mean just going, going, going and hiking and eating and drinking and everything else. And I was just feeling worse and worse as time went on. And I barely managed to get myself on a plane back to the US; and I, fortunately, had an appointment with my oncologist a few days after we came back, so I did some blood work and my reds [blood cells] and my platelets had totally collapsed. And I went in for a virus scan, and it turned out I had both rhinovirus and RSV; and then I went in for a lung x-ray and MRI, and it turned out I had serious double-barrel pneumonia.

Elissa: Oh, no.

Peter: Well, the pneumonia was so bad, I quite literally could not ascend a staircase in my house. I'm a very fit person; so that was absolutely insane. It felt like I was being strangled, and probably of all of the different things, both the leukemia and the treatment, and this came the closest to killing me. I mean it really was absolutely unnerving; and it took my pulmonary function results a year to get back to where they had been beforehand.

And after a year, it was out of my system, and I was feeling better; and again, being a pro-vaccination person, having doctors who were people of science who were pro-vaccination people, they said, "This was a freak occurrence."

Elissa: Yeah.

Peter: "Let's try it again, but this time we're going to try it much more cautiously. We'll do it one shot at a time. We'll space them a month apart."

So, the first shot that I was signed up for was the third shot in the COVID sequence for immunocompromised patients, and I immediately got pneumonia again. And the second pneumonia wasn't quite as bad as the first. It only took eight months rather than a year to clear my system. But again, it was heavy doses of steroids. It was all sorts of other different kinds of things, and that finally got out of my system

And while I was going through that, I got a flu shot, which led to problems in my mouth and problems in my eyes. And then finally after I got over the second pneumonia, they said, "Look, let's take a break on the vaccinations." So, I can't blame vaccinations, but what I did was I picked up a number of relatively small viruses that were detected through virus swabs, rhinovirus again. I just had one called parainfluenza, and these are things that for a healthy person should be clearable within I would say five to ten days.

Elissa: Yeah.

Peter: It took me two to three months to get out of my system. And not only did they set off sort of more typical pulmonary functions, but they set off all kinds of neurological problems like intense headaches, brain fog, dizziness. It set off the mouth problems and the eye problems again. And a terrible shortness of breath, incredible fatigue, and I've had three or four instances of this. So, over the course of the 15 or 18 months since the last pneumonia, I've really been sick almost as much as I've been well. And as we're speaking today, I feel great.

Elissa: Good.

Peter: I hope that that will continue; but I'm only about six weeks past the last of the effects of this parainfluenza. The parainfluenza was particularly poignant again because, as you know, my sister just got married. And one of the reasons we go through things like stem cell transplants is so that we can share these wonderful events with the people who mean the most to us in our lives. I was really worried I wasn't going to be able to make it out, and it finally receded enough so that it felt like it was a safe thing for me to do, and I did it.

But it was on my mind, and I mean it continues to be on my mind; and I continue to hope that my doctors are going to be able to find something which, both can minimize the effects of these things but also strengthen my immune system so that, not only will I be less inclined to be constantly picking up these viruses, but ideally, even at some point that I may be able to get vaccinations again.

Elissa: Good.

Susan: And this is something that, of course, I worry about a lot for my brother too because there are a lot of viruses out there. Unfortunately, he's gotten many of them. And I know what kind of life he wants to live as far as having more adventures and traveling and doing other things like that, and that makes things difficult.

Peter: There is a lot of anxiety on my part about, you know, can I be strong enough so I can go away for three or four weeks in the developed world and feel like I may not need to come back horizontally and medevac'd from my trip.

Elissa: Yeah, yeah. I think that can be so hard for blood cancer survivors is that a lot of us do remain immunocompromised to some degree. And even though a healthy immune system might get through something in a few days, it can be weeks or months for somebody who is immunocompromised to be able to get over something. And nobody wants to be sick all the time with anything. I don't want a cold for months. That's not a lot of fun.

So, I do hope that that gets better, and you stay healthy for a long while. But our final question for each of you today. Peter, I'm going to start with you. And you've heard this question before. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." What would you say to blood cancer patients and their families to give them hope if they are facing a stem cell transplant?

Peter: I would say that the medicine for blood cancer patients is improving all the time. When I talk to people, the last thing I want to say, and I'm sure you remember this when you were going through it was, "Everything's going to be okay." I mean, there are still a lot of people dying from this, even with all of the advances that have been made, and every case is really different. You want people to have a good medical team, particularly if they're looking at something like transplant. I hate to sound like a credentialist, but I mean I think it's really important to go to a major hospital that is doing these things all the time.

As we were talking about earlier, get yourself as well-versed as you can be on both the disease and the treatments, and you can ask your doctors good questions and find out what your options are. Rally your network of friends and family so that you can have support. Get looped in as quickly as possible to the different blood cancer groups like LLS, NMDP, and BMTinfonet.org. Both the sources of information on the one hand but also because LLS, in particular, has an incredibly strong support network of patients and former patients who really know everything you're going through. And as wonderful as your friends and family medical team are, they don't have the disease, and they don't really understand exactly what it feels like. So, these are all people who either have gone through it or are going through it and will be there for you.

So, I think that those are the things that will give you your best chance. Listen to your doctors, but not blindly. Ask them questions and be an active patient and hang in there. It's going to be an up and down process; and there are going to be good days and bad days. You don't want to get totally overconfident on the good days; and you don't want to become despondent on the bad days because there's going to be a lot of both and hopefully it nets out in the right direction, you get through it in the end.

Elissa: Yeah, that is very good advice. Now, Susan, after your experience as a stem cell donor who saved your brother's life, what would you say to potential donors or those considering signing up for a registry?

Susan: I think the main thing is how ridiculously easy it is and that, you know, you can go about your life, and you can do your thing. As far as my own reaction to Neupogen, I think that that was off the charts. So, I think most people really are very tolerant. And you know what, even if you have that reaction, you miss a day or so of work at the most, and that how incredibly important it is for people to become donors.

And I want to give a shoutout again to Be The Match (NMDP) because on the donor side, they walk you through absolutely everything. They make it totally easy for you. They're calling you. They're reaching out to you, leaving you messages, asking if you have any questions. I joke that I felt like I was going to have separation anxiety after giving the donation; and I missed my team at Be The Match, but what a great resource that is. And that for anybody thinking of becoming a donor, that's probably the first place that I would look. They have a great website and lots of information about donations and it was one of the best things I've done in my life.

Elissa: Wonderful. Well, we will make sure to have all of those links for those organizations that you mentioned, that Peter mentioned in the show notes. So, listeners, be sure to take a look at the show notes and check that out. And, I'd encourage you if you are healthy and between 18 and 40 years old, please consider signing up-

Susan: Absolutely.

Elissa: -and maybe saving someone's life someday.

Well, thank you so much, Peter and Susan, for joining us today and telling us all about these different perspectives of what transplant looks like and how it all happens. And so, for those that are considering, I hope that this gives them a little bit of peace and hope and seeing that it's a fairly easy process to go through it as a donor. And as the patient you work through those 100 days, and then you keep moving forward. And so, again, thank you both so very much for joining us today.

Susan: Thank you so much, Elissa. This was a real pleasure.

Peter: Thank you so much for giving us a forum to talk about these.

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.

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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. 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.

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.

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