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**Executives:**

Jennifer Gillette - Staff Social Worker at National Bone Marrow Transplant LINK

Jeannie Wiarda- LMSW at Corewell Health BMT

Ellie Lenarduzzi- AML survivor

**Operator:**

Hello. Thank you for standing by. At this time, I would like to welcome you to the Regaining Yourself Post Bone Marrow/Stem Cell Transplant. All lines have been placed on mute to prevent any background noise. After the speaker remarks, there will be a question-and-answer session. If you would like to ask a question during this time, simply press star followed by the number one on your telephone keypad. If you would like to withdraw your question, press star one again.

I would now like to turn the conference over to Jennifer Gillette. Please go ahead.

**Jennifer Gillette:**

Thank you so much, Jericho, and thank you, everyone, for being here today. Yes, I'm Jennifer Gillette, and I am a Staff Social Worker at the National Bone Marrow Transplant LINK. I'd like to welcome you to this month's program, which is focusing on Regaining Yourself Post Bone Marrow/Stem Cell Transplant, with the focus on mental and physical health.

A special thanks to our generous sponsors, the Leukemia & Lymphoma Society, Incyte, and Johnson & Johnson. We also thank our esteemed LINK partners which we would not be able to do all the great programs we have without you.

Just so everyone is aware of our outline today, we're going to do just a brief introduction to the LINK before we start the program today. Just so anyone who might not be aware of the National Bone Marrow Transplant LINK is made aware of what we offer. And then, I will introduce our first speaker, which will be Jeannie Wiarda, who is an LMSW at Corewell Health ENT. And then, we also have with us a survivor, Ellie Lenarduzzi, she is an AML survivor. And then, we'll open up the floor for questions.

So, for those of you who are not familiar with the LINK, our mission is dedicated to helping individuals and their families from diagnosis through survivorship. We provide resources, support, and education. Some of the resources we provide to help families are our Lunch & Learn programs, which are monthly, and they're on a variety of topics.



They can be disease-specific, treatment-specific regarding GvHD, or any survivorship issues. And those are recorded and put on our website. So, that is a great resource if you go to nbmtlink.org. All of our programs have been recorded, and you can access them there. Today's program will also be one that you can check out in a couple of days on our website as well.

We also have our Marrow Masters Program. Currently, we have 16 seasons with over 36,000 downloads, and that too is on all things bone marrow transplant, GvHD, survivorship, treatments, and more. And those are with experts across the country. We also host our annual fall webinars. We have Coffee Klatch, which is basically like a Zoom support group. We have our peer support program. We have our Celebrating Second Birthdays program and our Survivors Thrive Book Club, as well as we have our healing art program. We have an art therapy program, a writer's workshop, and we also just have all kinds of programs all the time coming. So, check it out at the nbmtlink.org. We also have our Facebook page with daily inspiration and tips. We have some wonderful books, and we also assist with resources and referrals for people, so feel free to reach out if more support is needed.

Just before we begin today's program, we have to remind everyone be mindful and try to be concise with questions so that we may answer as many as possible. If you have more than one question, we ask that you get back in line to ask that just in case there are multiple questions, we want to try to help as many people as we can. We also want to let you know that anything set in today's program is not to be taken as medical advice for you. It is to serve conversations with your healthcare team.

Now, on to the educational part of our program. Jeannie Wiarda, like I said earlier, is a Medical Social Worker at the Adult Blood and Bone Marrow Transplant Center at Corewell Health in Grand Rapids, Michigan. She has been a Medical Social Worker at Corewell Health for 20 years, including 14 years in Hospice and Palliative Care Inpatient and time in the emergency room prior to that. She has currently spent three years in bone marrow transplant, and we are so thankful to have her here with us today. Thank you, Jeannie.

**Jeannie Wiarda:**

Thank you so much. Well, welcome, everyone. I'm really just feeling thankful that I get to come on here and be able to hear a little bit of Ellie's story and to hopefully provide some topics that will enlist some conversations and discussions, not only here. Hopefully, you can glean some things that will be helpful to you. But also, I want to recognize that we all have different journeys, and all of those that are on here that are survivors, you live in different areas of the world, some in rural areas, some in large cities, probably places in between. Our family systems and support are in different places are financial situations are different. There are so many elements to this that we take into account when we talk about survivorship and coping and with the focus today on living beyond the transplant and recovery, especially with mental health, and just tools with coping and focusing on our physical, emotional and health is so important, but it is impacted by all those things.



So, I want to start by really just giving a brief review of the difference between stress and trauma. I really do focus a lot on this, especially when we're moving into just people wrapping their minds around this transplant thing, right? And I'm sure that you can go back to that time when you were sitting in front of your care team and they're explaining everything you never wanted to know about what this may be. And so now, some of you may be on the other side of this, and you were working on your survivorship, or you're in the middle of this ongoing recovery, this marathon of a recovery that sometimes can be 10 steps forward and two steps back. Sometimes we can celebrate the victories, and sometimes I think it's easy to struggle in the trenches of the symptoms or the hospitalization, or just the normal life things that are happening. Cars break down, and roofs leak, and we experience loss, whether it be jobs or relationships or all of those things. It's all encompassing because life still happens at the same time.

So, we all know that stress happens in life. And so, when stress happens, our brain is really good at reacting to that and sending those signals to our nervous system that put us in a kind of that fight-or-flight mode. But when we go through something like a diagnosis of cancer and that prolonged treatment that moves into a stem cell transplant, and then that slow recovery, that can be years for individuals, that prolonged experience, that chronic experience of stress, really turns into what would be defined as a trauma. And so, what we see when we have that prolonged stress is that our bodies or our brains' ability to come down out of that fight-or-flight doesn't happen the way it does when we have stress and then a break in between that stress, if that makes sense. And so, it can really disrupt the synapses that regulate our social ability, our ways of being able to sleep well, how we connect with or respond to or take in information and be able to retain those things. There's so many things that are directly affected by prolonged trauma without that time for our brains to kind of come down and be restored to more of that stasis mode.

And so, with all of that, we come out on the other side of transplant, and people ask, how do I get back to things that help me feel safe again? How do I physically feel stronger again? How do I reevaluate and maybe redefine relationships with people that could be a romantic relationship, that could be a parent-child relationship, that could be friends and family? I find patients will come to me and say, "A lot of people think I had my transplant, and I'm I should just be normal again. I should just be fine." They think about it more like, it could be a transplant or a heart transplant to where their idea of that is which I'm guessing is probably not necessarily accurate, is that once you have that done that you're back to normal and we all know that this is a slow climb in our recovery and our survivorship. So, what I encourage patients to really do is I first want to say there is hope. There is hope that as you're moving through this recovery that you can regain a sense of stasis and safety, and in that, start to develop new coping strategies, new and better ways to physically grow stronger, new and more helpful ways to reconnect with yourself as well as with people that you care about. There's this word that you hear, I think in the medical or maybe the scientific community, called neuroplasticity, and it really what it says is that our brains can heal our brains can recovery.



There are a few specific things that really make that happen, and I think a lot of that is related to finding, even if it's just one thing, if we're going to keep it very simple, that we believe would be helpful, and repeating that thing. So, repetition is very important. The second thing is that it's very specific, though our brains say, okay, if I notice that every time I am going to my doctor's appointments, my follow up care appointments. I feel really anxious and almost to the point where maybe I am nauseous, or maybe I do throw up. I'm noticing that I've just become very anxious, what is going on if it's not a specific medical thing related to my treatment or medications that I'm giving. So, that's the specific thing would be, okay, maybe this is anxiety because of what I've gone through. So, there's something that is identified that's specific, and that's an example. Maybe it's that I'm so exhausted, I used to be able to walk two miles, and now I struggle to even get to the mailbox and back. It could be that people continue to reach out to you, and you would love to pick up the phone and dial it and call them. But mentally, emotionally, it feels just very difficult to reconnect with people. And so when you can identify something in your life that specifically you want to improve or that you feel will really help you and your recovery and then, when you find that thing you've identified it, it's specific to you, then you're able to do an intervention or find an activity or commit to something that you can do. And then when we repeat that thing over and over again, what we find is that neuroplasticity happens where we do start to feel improvement in that area.

So, what could that look like? And I try to bring up a lot of those examples because I want you to think about for yourself what that might be, because I think for each of us, it's probably different because we're in different places in our lives.

I would really divide this into three categories:

- The first would be practicing relaxation, or sometimes people will say also mindfulness.
- The second would be physical activity
- And the third would be social support or connection.

So, I know these are very broad topics, but let's kind of bring it even more detailed.

So, when we encounter life-threatening situations and surges of stress and hormones like even just going through a doctor's appointment, right? Or waiting for that test result or just the time in between and trying to think through, okay, well, what did we just go through over this last year or two years. Our bodies, our muscles tense, right? Our heart could be pounding. That sudden feeling of being really on high alert happens. So, if we're paying attention to our body's response to what's coming at us right the situation, the thing that's happening, then we can look at what can I do right now in this moment to bring myself back down to stasis? Not everybody is for all of these things, but some of the things that I would recommend are practicing a tension relaxation exercise can be very helpful. What I mean by that is very simply, you could... while you're lying down, just paying attention to your breathing. Starting at your feet and tightening up those muscles in our feet, counting to five, and releasing.

And then, going to your calves, tightening those calves, counting to five, and then releasing, and kind of do those things in each muscle group as you go up. To try to have an increased awareness, but also to slow down that stress response in order to be able to feel a sense of relaxation or a sense of safety, that can be one very helpful, simple thing that you can do. Some people even practice that to get to sleep. If your mind is racing and you're just really unable to settle in. For some people, if you are a spiritual person, prayer or meditation can be very helpful. So, if you're feeling really out of your body, especially depending on what you're doing in your treatment journey and your recovery, sometimes just focusing on a phrase or a word. Sometimes it's called "mantra meditation". And just repeating that thing over and over again, very slowly, eyes closed, paying attention to your breathing. "I'm safe". "I'm safe". Or you can choose there probably many other words or things that you can use as your calming repetitive phrase, or word would be just the name. Sometimes people use guided meditation and, like I said, prayer.

Also, we're not all very introspective people, so I also look at things like writing, not all of us are eloquent journalists or poets, right? But I think we surprise ourselves when we just take a pen and put it to paper and just start writing. And I think what some people experience is when I just start writing, my thoughts pour out, and the importance of that is that we're not just stuck in our heads or in our bodies that we're getting those worries, those concerns, those thoughts, those feelings out of our bodies and onto paper. And it really isn't for anyone else; it really is for you so that you can process that. And some people do find it helpful to revisit what they wrote. And sometimes you just shut it, and you move on with the rest of your day. But writing can also be very specific way that you can focus on a kind of tension-reducing or relaxation activity or a focusing exercise to really put you back to a mode where you feel safe or you feel focused, or you feel connected to yourself.

Sometimes people feel very connected to nature, right? So I feel like there are times where you can look back, if you love being outdoors, that just taking a walk in the woods, hearing maybe birds or smelling the air in an evergreen forest for instance, or just having your feet on the dirt ground or in the grass. For you it is very grounding, and what I mean by grounding is that you feel like yourself inside of your body. And so those things can be very helpful for people to move into healing, into developing neuroplasticity, into a reminder. Okay, yes, there are things that have changed who I am because I went through and am going through a very difficult thing, a superhuman thing to go through this transplant. And now, you are focusing on your survival. And so, what does that mean? What parts of myself do I need a reminder of who I am and what things can I take from what I've been through, and continue to move forward and be the amazing person that I am? How can I rebuild those connections and things, and some of that starts with calming our nervous system down, connecting with our bodies, and our minds.

Physical activity, like I said is one really important thing. I think I've heard in other podcasts, and I think this was even mentioned here, that people do practice things like Tai chi and yoga or walking or even running.



I've even heard people say, "I used to be an avid biker, and I just know my energy level. If I bike so far, I have a hard time knowing that I'm going to be able to turn around and come back." But biking for that person is life-giving, it was part of how they cope with stress, it was part of who they were as a person. And so, it's very important to them.

So, how do you do that? So, it just makes me think of a patient that I had recently, and he's in his first year of post-transplant recovery and just very in tune with and very involved with nature, even his job. I think he had multiple jobs, was in outdoor things, right, outdoor sports, outdoor leisure activities, all of that. And he had a friend reconnect with him that he hadn't seen in a long time, and they decided to go on a hike, and they just talked and talked for so long because they're both going through some things and just reconnected. And he said, "Jeannie, I just can't believe that we walked for a while" And then we got back, and he said, "Dude, do you know that we just walk like three miles?" And he said, "But boy, did I pay for it the next day." So, you don't know your limitations in those moments, but it was such a good thing for him in some ways. And yes, he had to take like a six-hour nap afterwards. But then, what he did, he didn't say, "Well, I can't do that." What he said was we set a timer, and we decided we're going to go a half a mile, and because we don't want to get lost in our thoughts, we're going to turn around and come back. And that worked for him for a while. And then after about a month, they decided to set his timer for a mile and then turn around and come back. And so, sometimes taking those chances to do the things that we love, even if it feels like man, that maybe was more than what I could handle, we can adjust our expectations of where our bodies are at and still hold on to those things that are life-giving for us. And so, that is an example of a physical activity that I know for this person has since been really healing and helpful in their journey and survivorship, and recovery.

The last part of the physical, I think, would be connecting. Connecting to the physical, so I know I mentioned walking on a dirt path or in the grass. For some people, just being their foot in the sand. And I know things like we have to be careful, right? After that chemo, we're at higher risk for skin cancers. But if you're comfortable with you know, talking with your medical team about safe ways to be outdoors, where maybe the sun is, and it is not something that would risk your health, being able to take those shoes off and be in the sand can be really grounding. But I think even doing simple things like holding someone's hand, that you feel safe with that physical connection, I think we don't realize how powerful that can be. Now you know from being in the hospital for months or more than that months and months from being away from your family for months to who knows how long that, just having a hug or holding someone's hand, we don't realize how much we need that and how that kind of physical connection is still healing for us. We're built to be in relationship with others. Some organizations and transplant centers offer massage with oncology-trained massage therapists. For some people, that can be really helpful, but it can be even outside of that. Physical connection can be about practicing baking, kneading dough, or maybe it's dancing. And maybe you're not going to a physical studio to do those things but putting that music on in your home and just movement and feeling the vibrations of the music, or connecting with somebody else because you're having that dance party spontaneously.



Those things are so important. And then, I think creative expression artistically is another piece, whether that be through clay or sculpture or sketching or drawing. And that really encompasses more than just that physical, I think that's visual. I think it's emotional. There's a lot that I think can really help in that survivorship and recovery related to artistic expression. I think it really is even emotional, right? Because it helps us process. Grief and loss, it helps us express what we've gone through in a way that maybe it's wordless, and really it can connect us to other survivors as well in telling our story in a way that doesn't maybe have the pressure of telling our story right? If we're not verbal people.

So, for the last part of this, what I'd like to do is just give you guys an exercise that you can do. If you're open to it. And then we will move on to Ellie's story, I would guess, next. If you're willing, I would ask that if you're in a chair or a place where you feel comfortable and are able to sit, if you have to stand, that's fine too. But if you could find a spot where you could just sit, we're just comfortably stand, and I'm going to give you a second.

**Jennifer Gillette:** Could I maybe have you mute for just one moment? Go ahead.

**Jeannie Wiarda:** Okay. So, if you're all those who were participating here, if you're all willing to just pay attention now to your breathing, To think about your transplant journey so far, the day maybe you found out your diagnosis, the people you've met along the way, past experiences through your transplant journey. All these things are things that represent the past. And now, we're going to leave those things in the past just for this moment. And we're going to turn to base center again, turn your head to your center. Concentrating on our breathing through your nose, out through your mouth. And now, turn your head to the right. Eyes are still closed, concentrating on our breathing with our heads turned to the right, this represents the future. When we think about the future, we think about the future unknown that upcoming appointment we may have. Maybe a bill that's due or an important event that we are trying to get to, the hope of a vacation or a place that we've been dreaming of traveling that we're hoping our recovery will finally allow us to get to. Think about those future things. And now, we're going to shift our heads from the right back to center. Eyes just still closed and breathing. The center represents now. Sitting right where you are focusing on our breathing in and out. This moment, take a couple of moments there, and when you're ready, you can open your eyes.

And this is just a really simple thing that you can do on your own. And really, what it does is just tries to bring us to the present, helps us really kind of simplify and let go of some things that aren't important, but also things that maybe we can mentally and emotionally just refocus ourselves to this moment and be present in our bodies. Focus on what's happening right here and right now and bring our brains back to a safe space.

So, please take that and if it's helpful to you, use it. You can really do it anywhere. And again, I just can't say enough how, proud is the wrong word, but just how proud I am of every person that's here today.



You're reaching out to gain information and advocate for yourself. You're making sure that you're taking care of yourself or maybe your family members and trying to improve your life every day. You know people I heard someone say once I didn't go through all this not to live life, right? And so, that's really what this is about. How can I find ways to recover well, take care of myself, and improve physically, emotionally and mentally. So that I can thrive, so that I can continue to take steps toward a hopeful future. So, I wish that for all of you, and I appreciate you taking some time with me this afternoon.

**Jennifer Gillette:**

Thank you so much, Jeannie. That was wonderful. That was a great exercise and some wonderful tips. We appreciate you being here. Thank you. And now I'm going to introduce Ellie by telling you part of her story and then she's going to chime in. And it's from her perspective.

At age 46 in late 2023, I started to get sick all the time with colds, sinus problems being tired, and bleeding gum. In December, I went to the hematologist after a bone marrow biopsy, and I was diagnosed with AML leukemia. On January 4, 2024, I got a call. "Come to the hospital right now if you want to live and pack your bags for one or two months." I immediately went into warrior mode with the help of my brother, who came over right after I called him and broke down on the phone. My husband and daughters were in Arizona for the Christmas break. I decided to stay behind because I was not feeling well and didn't want to ruin their vacation. I spent 35 days in the hospital for the first day. It wasn't easy, but I took the big bull by the horns. I had to. There was no other choice. It wasn't going to take me down, at least that easily. I hung under my face so tight I probably scared the angels. I used all my strength and faith to fight it and made my husband shave my head right away. And if I had face pain, I probably would have smeared it on my face. I have some Indian blood in me, so maybe that's where I get that. Despite my dangerous mutations, I was able to reach remission after my first treatment. Even though everyone kept saying there will be another month coming after this one, get ready, I kept a different mindset. Inside of me, "Not me, I'm going home and it's going to work." I somehow pulled it off. I visualized the chemo drugs going in and killing everything like little warriors in my blood, with machetes killing the cancer cells, all while happening to a rap beat in my head.

It makes me laugh now when I remember. I tried as much as I could to walk and keep moving, wearing my favorite Harley-Davidson hoodie. I used to ride my bike, sometimes under my leather vest, and after that I did maintenance chemo for a month and the following month in March I did my transplant. My brother was my donor, and he was a full match and saved my life. He also went on protective older brother mode like he did when we were kids. Even when he came to pick me up to take me to the hospital, he had this "we will beat this together, sis" vibe.

My poor husband was in shock along with my daughters. I only allowed them on Sundays for an hour or so to see me. The rest I was alone. I didn't want anyone around to ruin their lives since this was already ruining mine and I didn't want a pity party either.



I only had a few visitors, people that were strong and gave me strength, and made sure I ate as much as I could and sought to the cafeteria menu as an inpatient since the inpatient hospital food was like eating cardboard and I couldn't get takeout delivered due to my low blood counts. I took my motorcycle boots with me for my transplant and more than down to get radiation, and I kept them when I could see them for motivation. I also promised myself that I would not use a wheelchair or a bedpan, or commode, or diapers, and I was able to do it even if I could barely do it.

After my transplant, I was sent home for a month later to recover, and when I got home I realized how much not only physically, but mentally I needed to heal. I got started on looking for support groups and found many and I have been doing them all for the past year. They helped me tremendously because although I was strong to fly it all alone in the hospital, the minute the flight was over, I didn't know how to even start to pick up the pieces and put things back together in my new normal life. My new life.

Well stated, Ellie. Thank you so much for being here and I can't wait to hear from you.

**Ellie Lenarduzzi:**

Well, thank you. Thank you so much for having me and giving me the opportunity to be here to share my story and the things that I've been through. And I'm sure a lot of the people on this call have been through themselves. I can say that it's not easy, but you have to. I was thinking this morning about speaking and I think what helped me move forward to where...after the transplant, how to begin to put it all back together was to really grieve my old life. I think that I kind of did that in the hospital. While I was doing the treatment I was grieving and doing the treatment at the same time because I was really angry about what had happened to me. And I think after being able to grieve it is what helped me kind of move on to the next chapter, which was the transplant and then the healing. And when I got home from the transplant, it was like, okay, the fight is over. Now it's all about the healing and the recovery. And I was like, okay, I know my body is okay, but my mind is not okay. I was very traumatized because everything happened so fast.

I was a healthy 46-year-old, and I have never had anything, no diagnosis of anything. My whole life, I had only been in the hospital twice and that was to have my daughters. And so, when I got home, it was kind of hard to wrap my mind around. How am I going to get back to what I used to be? Well, let me figure it out what do I want to do. I need to stay busy. Okay. I can't do much activity but let me see what I can do. I can try to do some crafts. Let me see, okay, I like to sew. My girls are in Girl Scouts, and I love to sew all their patches. I've been sewing patches for the last 10 years almost. So, I'm like, okay, what about needlework? So, I ordered. I was so weak, I couldn't even drive to go shop around. So, good old Amazon, I was like, okay this is the cheap little kit for needlework. Let me start with that. So, I did that, and I loved it, and it turned out really nice. I got a frame for it, and I was like, okay, what else do I want to do? I like scents. The scents they help ground me. And so, I was like, okay, what can I do with scents? I would like to try making soap, so I looked it up on YouTube. How hard is it to make soap? I looked at a video, I'm like, I can do that. So then again, I bought a little soap kit, and I started making soaps, and kept some for me. I gave some



to my family and friends and a way of saying I love you, thank you, and this is from me to you. And then I also made candles. I was like, okay, I really love the fragrance of the home. What else can I do? I made candles. And then I kind of got into little like flower arrangements because I still can't really be around dirt because of the soil and the bacteria or real flowers. But I started making cute little like fake flower arrangements. And then I started to kind of declutter the house a little bit. And that made me feel great. Just doing little things that I could do that made me happy and made me feel useful in a way and kind of back into my old self. And before I knew it, I could drive again, and I could clean, and I could start doing things on my own.

And little by little, one huge thing that helped me tremendously was doing the support groups. I think I'm into like six different support groups. They're all different groups. Some are writing groups, some are specific blood cancer groups, some are just general, all kinds of cancer groups. And some are like post-recovery, posts where you're not in active treatment anymore, so it's like a post-cancer recovery group. And they have helped me tremendously to heal my mind. And because I felt like I needed to connect my body with my mind. When I came out of transplant out, I'm like, my body's healed, but I want to heal the whole body. Head to toe, not just the body, and feel traumatized after everything.

I'm on my third journal. I've been journaling like you wouldn't believe, and it just feels great to be able to get all my feelings out in these journals. And at one point I thought, well, it's good to get all the feelings out. But in a way, it's like it's my own private personal journey, and we never know what our destinies are like. We never know if we're here tomorrow. I'm just grateful to be here today. So, if one day tomorrow I'm not here, at least my daughters will have all these journals and read through all of it, and kind of know more about their mom's cancer journey and get to know me a little bit more.

I lost my dad to brain cancer when I was in my 20s and it would have been nice to read something about my dad like what he was thinking or going through, while his treatment. In a way, I'm like, well, I can leave that for them too. But just little by little the little things that you can do to help yourself, I think with time and healing, it's huge. It's huge to get back to what you used to be or where you used to be or where you would like to be because of course it's a new normal. It's like our lives get shattered by it and then we just have to kind of figure out where to go from that. Always forward, always pushing, but also trying to figure it out as we go who we are.

That's my story. Sorry if I rambled on. I don't know about that. I lost track of time.

**Jennifer Gillette:**

You did not ramble on. You are an inspiration, and we appreciate you so much being here. And we have just really adored you and your authenticity. Peggy and I are glad that you are here. But at this time, of course, thank you to our speakers, we want to hear from any of you that might have any questions or comments for these wise ladies today.



And so, Jericho, could you please let everyone know how to ask a question or to speak?

**Operator:** Yes. We will now begin the question-and-answer session. If you have dialed in and would like to ask a question, please press star one on your telephone keypad to raise your hand and join the queue. If you would like to withdraw your question, simply press star one again.

Your first question comes from Agnes. Please go ahead.

**Agnes:** Hi everyone and everybody that has been in the presentation, the social worker, the patient, I'm very appreciative of your contribution. I'm a post-transplant patient, two years post-transplant with a cutaneous T-cell lymphoma. And I would like to join a support group as well in Facebook. But could you just tell me how to join some support groups in a place right now where I'm having a lot of mental trauma because as of two weeks ago, the doctors told me that my cancer may have been recurring. And I am emotionally exhausted from them, from it all, the treatment. I was in remission one year ago, but now the doctors think that it may have recurred. So, I'm having a lot of emotional trauma. I'd like to join some support groups, maybe some people who have been to the same journey. Maybe they can give me advice on how to deal with their cancer, some treatment options maybe. So, I just want to know how I can get some support groups? Since I need to join Facebook, how to get your support groups on Facebook or any other options? Thank you.

**Jennifer Gillette:** We are so sorry about your recurrence, Agnes, but I'm going to let both Jeannie and Ellie respond to that because I bet they'll both have some great ideas for you. Jeannie, do you want to go first?

**Jeannie Wiarda:** Sure, that's fine. Agnes, is that right? So, I guess I think she made...

**Agnes:** Go ahead.

**Jeannie Wiarda:** Okay, thank you for your question. I mean, I just want to say first how brave it is that you're understanding and noticing like that you have a need, which is huge. And I don't know what area of the country you're in and that's fine. But if you're looking for online, I would say, you can be connected to online support groups or peer-to-peer support, which would be like someone maybe that you could connect with that has a similar diagnosis, who's gone through possibly a transplant through the National Bone Marrow Transplant LINK. You can look on the Leukemia Lymphoma Society or lls.org website, those are two good ones that both have not only links to online support groups that are run by these organizations who do a really good job of running support groups but also have peer-to-peer groups where you can go on via phone and they can connect you with someone who maybe has gone through some similar things for additional support.



**Agnes:** Okay. Just to let you know, I'm in Atlanta, Georgia, and I am with the LLS organization, but I don't think I've seen anything on their website where they do have peer-to-peer groups.

**Jeannie Wiarda:** So, Ellie will go ahead. And I want to look this up, hold on.

**Ellie Lenarduzzi:** Yeah, actually, I'm on the LLS, Leukemia & Lymphoma Society. And I have seen out-of-state support groups also because I just kind of, the way I started was, I just went on Google and I just put Zoom cancer support groups near me or something like that. And I do remember going on their website and they're all over the United States. But if you go on their website, you need to look at the support group or group like on their search, and it'll pop up for you where they are. And you just kind of, you just go in, you sign up.

**Agnes:** Okay, so I did go to Zoom cancer support groups, and I see some stuff come up over here [inaudible].

**Ellie Lenarduzzi:** If you Google, I've been able to find some in California out of Los Angeles here, there's a...it's called CSLA, which is a cancer center which is completely free, and they have that here in California. But I'm sure if you Google it should come up for like your state what is available resources for you.

**Agnes:** Okay, I'll do some more research and see if there's any in Atlanta.

**Ellie Lenarduzzi:** Yeah.

**Jennifer Gillette:** Also, if you have a paper and pen, I have an 800 number for the Leukemia & Lymphoma Society.

**Agnes:** Sure.

**Jennifer Gillette:** You could probably call them if the website's not making it easier for you to find. Their number is 800-955-4572.

**Agnes:** It's 800-955-4572.

**Jennifer Gillette:** Yes, ma'am.

**Agnes:** Okay. I appreciate that. Thank you so much.

**Jennifer Gillette:** Absolutely. Jericho, do we have any other questions?

**Operator:** Yes. Our next question comes from David.



**Dorothy:** Hi, I'm Dorothy, and I'm here with David. He's my husband. I'm his caregiver. I wanted to thank Jeannie and Ellie very much for this very wonderful sharing. It has been helpful to us both. And I thank my husband for participating in this. The first time that he's been wanting to be part of a support effort. David had high-risk MDS, and he was diagnosed in November of 2023.

He got an allogeneic unrelated stem cell transplant in August of last year, so he's coming up on his year anniversary. We were dealing with mixed chimerism for months and he had to have a DLI, an additional batch of donor cells. And now for the last six weeks, we've been dealing with GvHD. I really appreciate the chance to see the National Bone Marrow Transplant LINK. I wasn't aware of your organization. We've worked a lot with the National Marrow Donor program, but I think that you folks will maybe be able to provide us with some more information about survivorship with this now-added aspect of GvHD, which has made it's probably been some of the most difficult times that we've been through. Ellie, have you had any experience with GvHD? Or Jeannie, how do you counsel folks that are dealing with that?

**Ellie Lenarduzzi:** Yeah, I mean, so when you said mixed chimerism different blood types on the donors?

**Dorothy:** More than that, it was...she did have a different blood type. And David's blood type has changed, but the T-cells in the bone marrow biopsies were...and the peripheral blood is T-cells were not donor cells for a long time. The last test he had there finally, 100% donor, and that's good news. But now we have the GvHD.

**Ellie Lenarduzzi:** Yeah. So, I can tell you that my brother and I were different blood types. So, I went through that. It took me about five months to change to a positive now and I have been dealing with GvHD for the last nine months now, I believe. And you know it's not easy, but there are things that your doctor can give you and do to help you with it. Where does he have the GvHD?

**Dorothy:** It started with skin and that was pretty mild, but then his liver numbers were very, very concerning and we were actually hospitalized at Mayo Rochester for six days. Well, they started them on intense steroid Prednisone treatment. And so, I guess what we're kind of dealing with now is the taper to come off, the Prednisone. And it just, it feels like another, I don't know like another straw in the camel's back, I guess.

**Ellie Lenarduzzi:** Yeah. The way I look at it, I had to get on steroids for the skin too. And then I was only on them for a couple of months and tapered off of them. The way I look at it with GvHD is it's not easy but in a way, some of it is actually good, which means that the cells are attacking and they're doing what they're supposed to, and they're over attacking where they're attacking us. But the way I look at it is they say some of it is better than none when it comes down to the post-transplant. And it's...are you normal? I'm happy that with time, I would say, it's gotten a little easier. And they say within years it goes away. So, you just have to kind of hang tight and just get through it and listen to your doctors and do what they want you to do as far as staying away from the sun, things that can trigger it, and taking all the medicines. And just know that the cells



are just kind of attacking everything and I would rather deal with some of that than to have the leukemia come back by far and with time...

**Dorothy:** Thank you, Ellie.

**Ellie Lenarduzzi:** You know time. Yeah. With time it will go away and just hang in there and things will get better. This will also pass. This shall also pass.

**Dorothy:** Thank you. That's exactly what David says.

**Jeannie Wiarda:** And I love this funky "woohoo" that I heard from David in the background. So, you can tell you're a fighter, my friend, which is good.

So, there are definitely resources out there. I mean, I think Ellie said this earlier in her testimony when she talked about there was a point where I had to grieve, some of those, and I think, GvHD, there's grief along with that too. I mean it's pretty normal to be frustrated and angry. You what, you came this far, you did all these things, you went through so much only to have this new thing that...there's a lot of unknowns about how long it's going to be or how it's going to affect your life long-term or even day-to-day. And so, living with that can be really difficult.

I think there are definitely resources and you should definitely continue to connect yourself with GvHD resources. You can get them from the BMT Infonet website. There's also the GVHD alliance. I don't know if you guys have been on there. There's a lot of resources on there, specific to monitoring system symptoms and learning about upcoming treatments and making sure that you have information that you can take back to your doctor. But then also, that fine line of connecting still with people that care about you, so that you don't get lost in your own head. Because it's easy to get stuck because this is a prolonged thing where you're in and out of hospitals, and these doctor's appointments, the ways that you connect to each other but also not just for the patient, but for your wife. David, for your wife, make sure that she's taking care of herself so that she can take care of you. So, bringing in, even if it's one other person to allow for a break so that you guys can weather these storms together is really important. But I guess again, what I would say is educating yourself, continuing to ask your doctors questions and then connecting with outside resources and supports that you can find on some of these websites, as well as practicing some of this good self-care, whether it be connecting with people or a counselor or support groups. Or just doing things like if you're up for it, a walk or just those little things are not little, they're huge because they help us stay in the game because we're taking care of our minds and our bodies even through this.

**Dorothy:** Thank you, Jeannie. Thanks, Ellie.

**Ellie Lenarduzzi:** Thank you.

**Jennifer Gillette:** Can we have the next caller, please?



**Operator:** There are no further questions at this time. I'll turn the call back over to you.

**Jennifer Gillette:** Well, thank you so much. I really just feel like this was an amazing presentation today and I hope you all felt that to great tips from our speakers. And we are so thankful that you're here. We're thankful to our sponsors and our partners. And I really want to encourage anyone if you need more support, please reach out to us. We will be sending you a survey so you can even put in the survey if you want us to reach out to you. If you need anything. In regards to GvHD, if you go to our website @nbmtlink.org, we have so many materials on GvHD as well as, just like Jeannie said, the GVHD Alliance is actually a group of us that all pool our resources to. So, whether it be GVHD, or survivorship, there's so many resources that can be shared.

We know this journey is very difficult, but together we can get people more support and education and ways to cope. But thank you again to everyone for being here, and on behalf of NBMT LINK, I wish you all a great day.

**Operator:** This concludes the call. You may now disconnect.