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**Executives:**

Jennifer Gillette - Staff Social Worker NBMTL

Teresa Steele - High-risk MDS patient

Bruce Steele - Teresa's husband and caregiver

**Operator:**

Thank you for standing by. My name is Tina, and I will be your conference operator today. At this time, I would like to welcome everyone to the National Bone Marrow Transplant LINK. Extraordinary Resilience and Grace: Meet Teresa and Bruce Steele: This couple is determined to live their best life post-transplant.

All lines have been placed on mute to prevent any background noise. After the speaker's remarks, there will be a question-and-answer session. To ask a question, simply press star one on your telephone keypad. To withdraw your question, press star one again.

It is now my pleasure to turn today's call over to Jennifer Gillette. You may now begin.

**Jennifer Gillette:**

Thank you so much, Tina, and thank you, everyone, for being here today. Yes, I'm Jennifer Gillette, I'm the Staff Social Worker at the National Bone Marrow Transplant LINK, and we are so excited to have Teresa and Bruce with us today. We thank them for their time, and I think we're all going to be enriched by hearing their story today.

I also want to have a special thanks sent out to our generous sponsors, which are Blood United and Incyte, and of course, our esteemed LINK partners. We could not do all the great programs we have without you.

So today, just real briefly, I'm just going to do a quick introduction to the LINK for those who aren't familiar, and then we'll hear from Teresa and Bruce Steele about their story and overcoming and living their best life post-transplant. I myself will do a small talk as well, sharing some of the information from other survivors on how they coped and thrived after transplant, and then we'll open up the floor for questions.

So, for those of you who are not familiar with the LINK, 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 navigate this journey are the Lunch & Learn programs. Like you're on today, which can be disease-specific, treatment-specific, survivorship issues, caregiving, a variety of programs, and those are recorded and put on our website. For those of you who want to re-listen or share this with anyone today, usually we have it on our website within two days of the program. So you're welcome to go to [nbmtlink.org](http://nbmtlink.org), and you can pull up all of our previously recorded programs. We also have our Marrow Masters series with right now we have over 40,000 downloads. It's a very popular program, and it's all things bone marrow transplants. We offer a couple of webinars a year. We have our peer support program, where you can be matched to talk to someone who has a similar journey with yours and is doing well. We have our Celebrating Second Birthdays, which acknowledges the fact that you have a second birthday after a transplant, and because you get two birthdays a year after a transplant. And then our Survivors Thrive Book Club, and we have the Healing Arts programs. And we also have our content-packed Facebook page with daily inspiration and relevant tips. We have books, you can receive emotional support and also referrals. So if you need any extra help, please reach out.

Before we begin today's program, just a couple of things. Please, when it comes to our questions section, please try to be concise so we can get to as many as we can today. And also know that the information in this program is never meant to replace your individualized medical plan. It is meant to stimulate conversation with your healthcare team.

So now on to the educational part of our program. We are here with the Steeles. Teresa was diagnosed with high-risk MDS and had a lifesaving stem cell transplant almost three years ago. Prepare to be inspired by this couple. I know they have inspired me and Peggy.

And without further ado, I'll hand it over to you, Teresa.

**Teresa Steele:** You know what, I'm going to let... thank you very much. First of all, let me just say, I appreciate everything that you all are doing for people that have to suffer with GvHD. And I'm amazed at how much you actually do and what you share. But Bruce wants to start first to introduce who we are and how he has had to suffer with me for all these 40 years.

**Bruce Steele:** So I would like to thank my wife, Teresa, which is probably the first time she's ever let me talk before her.

**Teresa Steele:** I know.

**Bruce Steele:** Okay. You know, for us, as we all know, there's quite a bit of challenges in transplant and certainly, survivorship, and with GvHD. And so one of the things that we've tried



to do is to have a lot of laughter in our lives, because we [indiscernible] that laughter is the best medicine. So hopefully we'll be able to do a little bit of that here as we talk.

So I'm going to run through a little bit of history here. We've been together, you know, and doing things together for 40 years, our 38th wedding anniversary coming up in May.

**Teresa Steele:**

The 28th.

**Bruce Steele:**

Yes, she's not afraid to interrupt you either. And that will be after her third anniversary of transplant. So May is a good month. And, you know, I've always known that Teresa is a very determined and independent person. And one example that stands out for me, and if you'd like to hear more about it, maybe you can do a Q&A. So when she told me about her two encounters with Ted Bundy, as a student at the University of Washington, I didn't doubt that she would never go with him on his rowboat. She blew him off both times. So I think that's a significant glimpse into the kind of person she is and how it's really helped her through many of life's challenges, including stem cell transplant and GvHD.

Now, just to say our backgrounds, both of us have had jobs that required not only hard work, but discipline. So that helped us, and particularly helped us do what was important in our lives, which was to have fun. Our first date was the doubles tennis date. And she played well. And so I decided, well, you should keep playing. And we did. And when it looked like we were becoming serious, she did two important things. One, she bought me a nice bike bicycle and then she bought me a bike work stand, and she said, "If you're going to be with me, you've got to work on all my bikes." And so I have for 40 years. So in addition to having to work, we did a lot of sports. We did tennis, hiking, walking, mountain biking, road cycling, including [indiscernible] road cycling, racing, northern skating, and alpine skating. We have had a lot of fun in our lives. And it kept going until November 6<sup>th</sup> of 2016, which was a week before her 66<sup>th</sup> birthday. We went out for a training ride around 10:40 Sunday morning. And she, I, and a friend were up the road waiting for her when someone drove up and said, "Hey, there's been an incident involving a bicyclist and a car." And I said, "Oh my goodness, male or female?" And he said, "Female." So with my heart up in my throat, I rode down, and there was Teresa behind the car, lining the gutter. She had been put through his windshield and his roof, part of her helmet, always wearing a helmet if you cycle within his front seat. And she was unconscious. When the EMTs say they thought she was brain-dead. When she was presented at the ER, they only raised that a little bit. That hit, and it looked very much like when a deer hit your windshield. That caused her to have three traumatic brain injuries, all of her spinal processes broken, all of her ribs broken, and a non-displaced fibula. She was in a coma for three days in the high-level



ICU and paralyzed on her right side. While she was able, thank goodness, to come out of the coma, she still needed to spend two weeks at the ICU, and then moved to another hospital for two weeks in rehab. I was told by the neuro doctor at the ICU that with her injuries, she was among only about 5% of people who made it out a lot. Thank goodness I had my wife back to me. But the traumatic brain injuries caused her to have what was called torsional double vision. So she saw everything double.

So we spent all of 2017 trying to fix that double vision through therapy. And it just didn't work. During that time, to face her challenges, she had to walk on a balance beam that rocked, juggling beanbags while reading in an eye chart, and walk back and forth, and she could do it. So that was an early indicator of what she could do to face life-threatening challenges.

Fortunately, in 2018, we found a wonderful surgeon who fixed about 98% of her double vision. So this was a chance now for us to try to get back to the normalcy that we had before this horrific incident. Teresa wants to say something.

**Teresa Steele:** Well, I want to just add one thing, which he always says to everybody about my eye surgeon. That, no, he looked like Antonio Banderas, and he sounded like Antonio Banderas. And Bruce thinks that's so funny because when he removed some stitches out of my eyes the day after my surgery. The doctor said to me look into my eyes and Bruce says I said "Oh yes, doctor," and I didn't, but in any case, continue...

**Bruce Steele:** Teresa, I wasn't going to tell that story, but since you did...

**Teresa Steele:** It's a funny one.

**Bruce Steele:** Okay, so keep going with this history, from 2020 to 2021, COVID was raging. And so that's where it set us back a bit. And moving into 2022, when things looked a little bit better, Teresa, who had always been very athletic and in great shape, started having problems climbing our stairs at our house. She had to stop halfway up. So something was wrong. So, being that she takes matters in her own hands, she requested and received a blood draw. And our primary care physician called from church and said, "Get to the ER immediately, your hemoglobin is down to 4.2." So I'm sure a lot of you on the call know that that is dangerously, dangerously low. And then she received four bags of blood after that. So following that, she was then diagnosed with high-risk MDS. After looking around to see who might be able to effectively treat her, we decided to go to City of Hope. She'll talk a bit about what went on there, the process, the pre-transplant process during the hospital, and then some of the implications after.

But in 2025, following our finally coming home, we noticed that she was having some skin issues. And a few other things, she is now diagnosed with having chronic GvHD, okay, and at that point in time she was on around 12 medications to control that. Okay,



so to kind of finish up my long and old story, Teresa is going to now talk about it. And I'd like to say that although everyone brings to their transplant and GvHD journey, a personal history, I think Teresa's history of athleticism and determination is to be the best she can be, has given her an ability and motivation to meet the challenges presented by these complications. She challenges herself in many different ways to constantly try to get better. And the two of us continue to challenge ourselves and each other in several different ways to get back to normal and overcome GvHD.

And so with that, Teresa, go ahead and talk about your journey.

**Teresa Steele:**

Well, it looks like you've covered a lot of how I'm doing. But in the hospital, of course, I guess if people have had a skin cell transplant, they know that in the beginning, they put us or put me through a lot of different tests to be sure that I was in good enough shape to even withstand the stem cell transplant. And luckily, I was in really good shape at that point. And I passed all their exams perfectly well and then went into the hospital to have my stem cell transplant. And yes, it was not fun, but I will say that City of Hope doctors and the nurses were superior. And they really, really deserve my welcoming them to anyone's life because they were perfect.

And so we spent about 90 days total at City of Hope. And then when we got home, I remember driving up the street thinking, "Oh my God, I forgot we have a view of Catalina from our front yard." I mean, that's how much I just forgot about our life here. So it was good to get home. And dealing with this, you know, the GvHD, it was a real shock. I remember the first time I thought that my arms were sore because I carried in heavy grocery bags all the time. But then I noticed that my legs were getting that way, everything. So my ankles, you name it. I was very stiff, and I found out I had GvHD. So like Bruce said, I was on about 12 drugs to begin with. Now the doctor has me weaned down since I'll be May 9<sup>th</sup>, I'll be three years. He has me weaned down to three pills. And once I have my pulmonary function test in May, hopefully he'll wean me down to even, you know, getting off of more of them. But the thing is, I was always intrigued with the body and the muscles. Because even when I was like eight or 10 years old, I remember when I would go for walks and have my hands in the back of my pockets. I was mesmerized by the movement of muscles. They were... it just amazed me what muscles would do. So, being an active kid, I continued to be active. And then when I decided to go to UW, I majored in Psych Ed and Kinesiology, and that's what my degree is in. Although I never worked in that field, I feel like I've lived my life through sports and activities. Bruce and I raced bicycles. So we, like he said, we in order to see, we pretty much did everything.

**Bruce Steele:**

So we were forced to be disciplined.

**Teresa Steele:** Well, exactly. We were forced to be disciplined. And I think that's what's helped me with what I'm going through now, is I was used to always training for all my events. And so today, I make it a point every day to, first of all, stretch before I get out of bed. I went to a physical therapy person that lives, that is down the street from us, and she gave me some exercises to do that are pretty much like a person who has fibromyalgia. I guess the symptoms are quite the same. And so I do those stretches every morning. It sounds weird, but every time I get up, I stretch my calf muscles, which helps to stretch out my tight ankles. And I do that many times throughout the day. Because I was athletic, I went back to the gym. I go to the gym to do weights for an hour on Monday and Thursday. And my opinion is that it really helps with stretching all the muscles and using my muscles.

I know that the donor cells, obviously, he was a 24-year-old male, and apparently, he thought my body was foreign because maybe I'm female. And I've decided to tell my donor cells that I'm in charge and I'm going to work my muscles. Whether it ever goes away, I don't know, but I'm going to do the best I can. I love doing weightlifting. I had a personal trainer when I was 59, and I figured, well, I'm going to continue to do it on my own. And you're going to say something, Bruce?

**Bruce Steele:** Well, I know. What about your eyes and your mouth?

**Teresa Steele:** Well, in fact, in one of my eyes, my mouth is constantly dry. And I have to take water right now. My skin is very sensitive on the shins of my legs. Fortunately, it isn't sensitive anywhere else. But in any case, I was trying to think of something. And you know, I go walking. And like I said to Tina, yesterday, like a fool, when it was 87 degrees, I decided to go for a walk at a park we have here locally that has one area that's shaded. Well, it was so hot that even in the shade, I had to stop and take a break.

**Bruce Steele:** And what did I say to you? "I told you so."

**Teresa Steele:** Yes, you told me so. But anyway, so I know there's days you just have to take a break. But I am the type I am... well, when I got hit by the car, the attorney that we used said to me I was a very determined person, and I guess I am. I didn't realize I was, but I'll do everything I can to use my body. I cook as much as I can, and I have to lift my arms up in the air to pull oil out of the cupboards up top. I don't ask for help. Bruce wants to help me I don't want him to. I get those bottles of oil out for myself. It may be a little bit sore, but I'm stretching those arms. Likewise, when I put on socks, I have to do it a special way. I sit on the stairs like a second run down, and I put those socks on, my baby toes are curved down, they will not curve up. So I have to struggle to get those socks on, and I refuse to let Bruce do it. I'm going to do it, and I finally succeed.

**Bruce Steele:** I guess I will jump in and say here as a caregiver, you know, I want to help too. And certainly, it was very challenging when she was in the hospital since we had to move



in and out of the hospital to somewhere else. I had to also, but now that we're home and she is very determined to get back to as much normalcy as possible, I feel like I need to do more as a caregiver. And so because we've always been competitive, we sometimes... we challenge each other if we have to do a wash, for example. When I hear that the wash is through, I went in there surreptitiously and fold the clothes before she gets to do that. Same thing with the dishes and the dishwasher. So we have these little games we play, and we laugh at each other, but at the same time, we're competitive, and it helps to give us a sense of normalcy. The one thing that I cannot do is to cook food. Teresa was a very good cook even before all this happened. And this is another way that she is returning back to normalcy.

And I think probably a lot of people on the phone can relate to that. And for me, because our diet is the same, I am the beneficiary of her determination here. So I applaud her. Go ahead, Teresa.

**Teresa Steele:** Well, thank you. I forgot what I was going to say now.

**Bruce Steele:** Sorry.

**Teresa Steele:** No, one thing I will say is, yes, I feel like I don't need a caregiver anymore. Bruce is more than a caregiver to me now. He's my husband, but like he says, we are, we do compete. It's become a joke with us. He'll walk in there and see that I've already folded the laundry, or I've already put the dishes away. And it's just kind of become a joke with us. But the other thing is, backing off to when I first noticed my GvHD, my ankles were so stiff, it was so hard to really walk. But Bruce made it a point to take me out every day to walk at a neighborhood park. We have a different one than I mentioned yesterday. And we would start walking, and I walked peg-legged. And maybe we could get in a mile if I was lucky. But each day he did that for me. And I finally got up to the point where I was walking on my own and doing four miles. And I remember calling him and saying, I did four. He couldn't believe I did that. Then I got all the way up to five miles a day. And I will say that Bruce also did the same thing for me when we were in the hospital in the hotel village. He was making, after taking down 20 dumb drugs, he would say, " Okay, we're going to go walk in the halls." And as much as I didn't want to, he made me walk in the halls. And we got to the point, well, finally we went outside and actually did a mile. So I will say that Bruce has been absolutely wonderful.

**Bruce Steele:** Thank you. Thank you. I've paid for that comment. Let me say one other thing, too, about caregiving and what we're doing to protect ourselves. Because Teresa is still on immunosuppressants, but our GvHD doctor is tapering them. I'm very conservative. And so we have been pretty much isolating to a large degree that we'll go out and eat dinner outside. So I'm really reluctant to eat too much, but that's only because we're



conservative, and I'm sure other people have different approaches to that. We certainly always wear masks when we grocery shop and when we go to the various doctors' appointments. But we are going to more and more, I think, as she tapers, we're going to be able to start doing more from a social standpoint to get out and be part of the life we had before all this started. Sorry, I just wanted to jump in the back.

**Teresa Steele:**

No, but mentioning the fact about wearing a mask, I go to the gym. And I go to the gym that's just up down the street from me, where my physical therapy is, and I go at noon because it's lunchtime, I figured nobody will be there. The last four times I've gone, I have been the only person in the gym, and it's like I own the place to myself. It's wonderful. So the thing I would say is even if you're not athletic, maybe you're an artist, or maybe you love to sew, it doesn't matter.

What matters is that you do that again. If it means you have to do it differently, then you do it differently. I mean, when I try to dress and undress, it's a new experience. I have to do things differently than I did before. I have to maybe put my legs, my foot goes through one hole of the pants, but I have to drop the pants to the ground to get to slip the foot through the other hole. So you learn to get dressed and undressed differently than you did before. I mean, things are just different because you have to accept it, and that's pretty much what I've done at this point.

**Bruce Steele:**

When one friend of ours whose wife had another very dangerous challenge, what he describes his wife as a kangaroo. Now that sounds funny, but what he said was a kangaroo never moves back. Kangaroos always go forward. And so I think Teresa doesn't look like a kangaroo, but she's definitely moving forward all the time. You know, we're coming up to 26-27 minutes.

**Teresa Steele:**

I don't know. I think that I pretty much... I guess I'm lucky we have stairs in our house because that means I've got to go up and down the stairs. And I remember the first time trying to go down the stairs. I couldn't go down the stairs, forward, because of my tight ankles, but I kept working at it until finally I remember telling my friends, "I went down the stairs the normal way." So it's little things like that. That little tiny accomplishments mean a whole heck of a lot.

So in summary, I feel like I've got a great life. Sure, I missed what I did before when we were younger, but then we were younger, so I want to live a heck of a lot longer than 75 years. I plan on living to be 100. Moving forward, my only prayer is I don't ask if this ever goes away because I doubt it would. I just don't want it to get worse. That's all. I feel I'm very fortunate with what I've got and where I'm going at this point.

**Bruce Steele:**

I think that's... I think we're through with our talk.



**Jennifer Gillette:**

Okay. Well, Bruce and Teresa, I thank you so much for all these wonderful pearls of wisdom that you're sharing today. And I want to share some more from other survivors as well. You know, over the years, we have been just so blessed to be able to hear all the great tips from people. And I tried to put some of them together for you today because I know for someone listening, I know myself listening to Bruce and Teresa, I feel like, Oh my goodness, I could take on a mountain with the things that they say today. But for those of you that are really struggling and maybe feeling like my journey looks different than that and are maybe discouraged, I want to just really feed you some of the other pearls of wisdom. And so, lessons from transplant survivors, living well after transplant. Those undergoing a stem cell transplant join a very small community, and this journey can be unpredictable, and recovery rarely follows the path we imagined.

Everyone's journey looks different. If your bone marrow transplant journey looks like or doesn't look like anyone else's, that's okay. It doesn't mean you're failing. It's a reflection of how uniquely your body, your immune system, and your story are written. Outcomes of transplants vary widely based on diagnosis, donor match, conditioning, regimen, age, and things like Teresa said with the GvHD. Yet research consistently shows that healing is not linear and hope remains medically justified, progress can be uneven, and it's important that you hold on to a perspective that just because it's different doesn't mean you're doomed. Lower does not mean impossible, and today's setback does not predict tomorrow's outcome. Some people seem to thrive from the start, and others have constant setbacks, and many have a mix between the two.

So, continuing to live meaningful lives, here are some of the nuggets.

First of all, number one, redefining normal. Many survivors begin transplant believing the goal is to return to life exactly as it was before illness. Over time, many discover that healing means creating a new version of ordinary instead of trying to make everything it once was. Instead of waiting to become who you were before transplants, many survivors have told us that often peace is found by asking what is meaningful today? What can I still enjoy, even if it looks different? You know, there was one gentleman who shared a story with us about how he used to love to bake pies when he was dealing with stress, and that was so relaxing to him. But he found after transplant, standing for a long time in the kitchen was hard. And so it became an activity that him and his wife did together. And he would sit at the table, and his wife would help bring some things, but he still was able to make those pies. So just like Teresa said, being able to have some of the parts, living fully now, even with limitations, can bring joy.

And then number two, grief what was lost. Transplant can bring physical changes, disability, fatigue, chronic GvHD. Allow yourself space to grieve. It's not a weakness, it's part of healing. Survivors describe themselves, giving themselves permission, I



should say, to acknowledge the loss, allow yourself to feel the anger or sadness, and allow it to slowly rebuild. But also remember, grief and gratitude can live simultaneously. You can still grieve the body that's maybe not doing what you want it to do, while still being thankful for the body that got you through.

And number three, advocating for yourself. One of the most common things we hear from survivors is the importance of self-advocacy. Patients sometimes must push for testing when symptoms feel dismissed. Or specialist care. One of the things I'll send out in my notes from today, there's a great site on BMT InfoNet regarding trying to find specialists, especially with GvHD, if you're having a hard time getting those symptoms managed. Or there's also things like on the NMDP site, and again, this will be on my notes that I send out, where it's a post-transplant guide, explaining to you the things to look out for. And we also need to advocate for ourselves for treatment options and symptom management.

For example, if you're dealing with fatigue, sexuality issues, educating yourself on sites like nbmtlink.org or the gvhdalliance.org to find things that you can discuss with your doctor if you feel like you're not being heard or you're not getting management. You know, for example, with fatigue. Fatigue can be a result of deconditioning. It can be anemia, inflammation, steroid myopathy, sleep disturbance, needing to build yourself back up with energy, nutrition, hydration. There's so many things that could be discussed with your team. And so looking into those things and advocating for yourself are important. Your voice matters, and you know your body better than anyone else. So you have a very important part on the team.

Number four is build your village. Transplant recovery is rarely something a person can navigate alone. Support may come from family, caregivers, survivor support groups, like we had one survivor that attended many of our groups, and she said she was in about six. She had a writing group. She had a support group where they talked about the feelings. She had a healing arts group. And some great places to turn to if you want support groups are the Blood Cancer United support groups, the BMT InfoNet support groups, or checking with your healthcare center and seeing what they have. There's also online communities, such as the Cancer Buddy app. You can download it on your phone, and you can connect with other survivors. Also, having people on your team from spiritual or mindful practices, or churches, synagogues, or any of those types of communities. Survivors often say connecting with others who understand the transplant experience can be life-changing.

Number five is to find meaning in small moments. Many survivors describe becoming more aware of everyday joys. That sunlight hitting you just right through the window, music, conversations, meals with loved ones, time outdoors. Meaning doesn't always come from big accomplishments; sometimes it comes from just simply being present.



Another nugget of wisdom is protecting your energy. Living with chronic illness often means managing limited energy. Many survivors have told us to use the concept of spoon theory, thinking of energy as a limited number of spoons each day. This can mean pacing your activities or communicating boundaries to those close to you. If you have, let's say, 20 spoons of energy in your tank, and taking a shower took two of them, or getting out of bed or preparing food, any of those things. If you look at it, there's a certain amount of energy spoons you have, and you have to be very mindful of how you choose to use those, especially in the earlier days. Resting before exhaustion. I remember many times hearing from survivors that you have to figure out where that spot is that you can push yourself without making it worse for yourself. Some people say like, "Oh, if I go too hard this day, it might knock me out for three days. And so I've learned that this is what I can handle today, and I still have some fuel in my tank for the next day." So learning where that line is for yourself, using adaptive tools as necessary, and then choosing what matters most, prioritizing for your day, and scheduling times that you're more likely to be successful.

If you notice that, like at lunchtime, you seem to have the most energy or you're most clear in thought, typically around that time, schedule the most important activities around that time. And then protecting energy helps survivors continue doing the things they love.

And keep hope for the future. Even while adjusting to limitations, many survivors continue to make travel plans, set personal goals, pursue hobbies, and help other patients. Hope doesn't mean ignoring reality. It means believing life can still hold purpose and meaning. However, I also say here, give yourself grace to pivot if you need to without shame. You know, keep making the plans, but also if something goes wrong, if you're not feeling well, enough one day. Rather than shaming yourself or doing all that negative self-talk, allow yourself to hear what your body is saying. And if you learn to grow with that neuroplasticity, that flexible thinking, that I'm always going to do my best, but I give myself permission to need to pivot if I need to. A lot of survivors have told us that it's helpful. So survivorship is not about returning to who you were. It's about graciously growing in acceptance, nurturing yourself as you heal, and discovering who you are now.

And on that note, Tina, if you could please tell our callers how they could ask some questions if they would like to.

**Operator:**

Absolutely. To ask a question, simply press star one on your telephone keypad. Again, that is star one to ask a question. And we'll pause for just a moment to compile the Q&A roster.



**Jennifer Gillette:** While we are waiting for them, I ask both of you, but I'll start with you, Teresa. When you first had your transplant, I know you gave us some stories of how things had to gradually improve. For the person who might be earlier in their transplant, who is really just struggling to walk at the hospital and things like that, is there anything that you can share that was helpful to you?

**Teresa Steele:** Well, I mean, obviously Bruce was. But I think part of it was my own spirit that I was so used to being strong and being active, and all of a sudden, I wasn't. And so just the people and the nurses and the aides and everyone were wonderful, and they were supportive. They would get me up with a walker if I needed to, and to walk the hall. If only I could do it once, I did it once. And then I must say I was lucky that Bruce was there every single day, and he would walk with me. And I think I even walked a few times by myself, but no, it was difficult. There were times where you wouldn't even want to get up and take a shower, and I couldn't even get up to brush my teeth. And I consider myself a strong person, but that gives you a new perspective on who you are and what you're able to handle.

**Bruce Steele:** And I'll jump in from the caregiver standpoint. I would say, and like you had said in your very good points, you don't have to try to push it. Do what you can do. There was a physical therapy person in the hospital, and then afterwards, that was helping Teresa. And yes, we would want to get her, you know, moving, but we wouldn't overdo it.

We would do a couple of laps, maybe around the hospital bed, and then afterwards, we were at the City of Hope, has a hotel there that you can stay with your caregiver. We would take maybe one round and then come back and sit down. So the point is, don't push it, do what you can do. And don't feel frustrated if you need to replenish your batteries.

**Teresa Steele:** Well, you know, I remember that it was really fun just to be able to get out of bed and sit at that chair that they had, or where I would eat my food, versus eating in the bed. So it was just little by little. I mean, the people there were so helpful and so caring that they made it all much better than it could have been. I feel as though I was treated so... I was respected so much for who I was. And I remember one girl, she called me beautiful every single day. And I'm thinking, boy, but they were just so wonderful, they made me feel happy. And I remember, I do remember after I had my stem cell transplant that day, and then the girls all put on clothes, hats, and balloons, and opened the door and sang happy birthday to me. So there are good memories, I mean, very good memories, as much as it was a shock in the first place.

**Jennifer Gillette:** Good insight, thank you. Tina, is there anyone in the queue?

**Operator:** We have no questions at this time.



**Jennifer Gillette:** Okay. You know, we'll give them just a couple more minutes. If anyone has anything they want to ask, they are welcome to get in that queue. And Tina, can you remind them how they do that?

**Operator:** Yes. To ask a question, simply press star one on your telephone keypad.

**Jennifer Gillette:** Okay, and I'll ask you another question. Go ahead, Tina.

**Operator:** We do have a question from Forrest Buskirk. Please go ahead.

**Forrest:** Hi.

**Jennifer Gillette:** Hello, welcome.

**Forrest:** This is Forrest Buskirk. Can you hear me?

**Jennifer Gillette:** We sure can.

**Forrest:** Hello? All right, so I have... My birthday, my second birthday, is October 29<sup>th</sup>, 2025. And I've just gotten home after two weeks, really gotten home to be able to start doing normal, quote unquote, "normal life". My question is associated with your GvHD, because I also have GvHD, mine is skin-related so far. But the question I have is, did they find that the issue you have with your muscles and your ankles, and then everything else, was that tied to nerve damage because of all the chemo and everything you had to go through?

Because I have severe neuropathy in my feet and hands, and I definitely see or see that affecting a lot of things that I do.

**Jennifer Gillette:** Theresa, any thoughts?

**Teresa Steele:** No one's ever said why that I got GvHD, whether it was from the chemo. I mean, literally, I was just told that it was the graft, the donor cells thinking my body was foreign, and it attacked it. So I've never been told anything else about why I got it. I mean, the skin.

**Bruce Steele:** Or what symptoms.

**Teresa Steele:** I have scleroderma, I guess it's called, where it's kind of thick on one side, but then I can pinch my skin in other places. So no, really, Bruce, has anyone... we were never told, I don't know that my communication with the doctor that I had was that great about my GvHD. In fact, they wanted me to immediately go to a GvHD doctor. The first one, I didn't like at all. I thought he was self-serving and said things that weren't true. So then the one I deal with now every two months with my blood draws, he's



good, but no one's really said anything about why. No, I just figured it was because the donor cells think I'm foreign.

**Forrest:** Okay. Thank you very much. It just gives me food for talk.

**Jennifer Gillette:** And that's really hard. Sometimes there's the different parts, because you're right, the GvHD part is the immune system, whereas the neuropathy is, like you were saying, it can be from the damage from the chemo and things. But if ever you're struggling with having symptom management, there certainly are second opinions. And as well as perhaps if you want, you can also reach out. I'd be happy to look into some resources for you to see if there's any sites we could connect you with that might give you some additional ideas.

**Teresa Steele:** I will say one thing, though. Going back to when I was still in the Villas Hotel and they started me on a new chemo, the second night, luckily, I wore my Apple Watch when I went to sleep, it alerted me that I had AFib. Now that was from the chemo, and the doctor had told me it can mess with your heart. And so they put me on medicine for it, metoprolol, and I was on it for about four months, and it finally went away. It was typically... I mean, it was caused by the chemo, and I've been fine ever since. In fact, I just saw my cardiologist that I've always had here, and I was totally fine

**Bruce Steele:** Just to jump in real fast. Okay. For Teresa, she had a 100% HLA match. Okay. And which was great. It was allogenic. So it was an unrelated donor. And then it was the male. So we have read that anytime there's a different gender, that could be a potential risk issue for GvHD. That's just out of, you know, the Internet, so I don't know if that's true.

**Teresa Steele:** No, I don't know either.

**Bruce Steele:** Those are the only variables we know right now, that 100% HLA match, okay. Male donor, female host. And you know, otherwise Teresa was in really good shape beforehand. She passed all the tests. But why did it happen?

**Teresa Steele:** No, I guess not genetic, apparently.

**Bruce Steele:** Yes.

**Operator:** And your next question comes from the line of Eva.

**Eva:** Hi, my name is Eva. Can you guys hear me?

**Jennifer Gillette:** Yes, we sure can. Welcome.

**Eva:** Hi. Well, I do have GvHD in my eyes, my vagina, my mouth, and I have it on my skin. I'm not sure if anybody else here has seen any improvement in their symptoms after a

few years. I got my stem cell transplant on June 13, 2023. And quickly thereafter, I did get graft versus host. That was something that we had spoken about before the transplant. And unfortunately, I did end up getting it. So I did take some steroids, and I ended up with AVN, and there's no cure for that. So I just received AVN avascular necrosis. I got it because I took up prednisone, the steroids, to cure the graft-versus-host. That did make my symptoms a lot better. They have been a lot better than they were when I first got everything. It was really hard to eat. I had sores in my mouth, my lips. But now here we are, almost three years later, and I have to use daily things to get some relief. My eyes are really gritty all the time. I still have strawberry skin. I still can't smell or taste that well. I do have some smell and taste back, but it's not completely back. I guess I could say I can't complain from how far I've come, but I did. I'm recovering from my second hip replacement right now. I had my first hip replaced in October due to the AVN, and that was because of the graft versus host. And now I'm recovering from my left hip. I'm five weeks post-op this Wednesday. But I was just curious to see if there was anybody on the call that has maybe have had all their GvHD issues resolved or... I'm just...

**Teresa Steele:** No, I have... my left eye, it might be getting better, but it feels gritty. And I have been using... the doctor wanted me to take Restiva, I think it is. So I'm taking cyclosporine.

**Eva:** I take the same thing. Yes.

**Teresa Steele:** Yes, it's called cyclosporine, what I get from the... And I put, I was doing two drops. I mean, I was using the vial in both eyes. And I just asked my doctor this last couple of weeks ago if I... because it dries my... It's hard to read after I've used it. It burns like ever. And he finally said, well, how often do you have to use your regular refresh drops? And I said, probably only once a day. And I said, but I feel like, why am I putting it in the eye that isn't bothered? And he said, I didn't have to anymore. And he said, just to try doing it once a day instead of twice, which is what I'm doing so far.

And frankly, it's better than it was when I was doing it twice a day. So you basically have to ask your doctor and tell them what's going on so that maybe they can change things.

Now, I still have very bad dry mouth, and I have to take Biotene. I carry a spray bottle in my purse of it. I also couldn't taste anything in the very beginning days, and I did take prednisone. I don't know if it did anything for me, but once I quit a couple of the drugs he had me on, my taste came back, thank goodness. The only thing which is so weird that I could taste when I couldn't taste anything was chocolate. And I've never been a chocolate lover in my life. But I started loving chocolate because it was the only thing I could taste.

**Eva:** Same here.

**Teresa Steele:** But that finally went away. And then the mouth sores went away, probably by now a year ago. So those are gone. They weren't like horrifying, but they're gone, and I'm happy about that. I just wish I could get rid of the dry mouth. In fact, my doctor just said to me, when you see your dentist, ask him about a drug, if you know of a drug that would make the saliva glands work again. And quite frankly, I'm surprised that the GvHD doctors don't have an answer for that.

**Bruce Steele:** Would the cavities result in chemo?

**Teresa Steele:** Well, and see, I've been having... I've had two crowns recently, and I have to have another one on my teeth. Because when I was in the hospital, I understand apparently you couldn't brush your teeth a lot because you might bleed because you didn't have high platelets. But I've had more cavities and more of an issue between my teeth, where they're not really close together like they used to be. And that I think was just simply from when being in the hospital. I very seldom ever felt the energy to go brush my teeth, but they never came to bed and asked me if I... they would give you a bath in the bed, but they wouldn't, they never asked me to brush my teeth, which I found very strange. I mean, I'm dealing with my teeth right now. But they're fine.

**Bruce Steele:** Is chemotherapy the cause of?

**Teresa Steele:** Well, the chemotherapy may have caused some of it, but I also think some of it was just that of all the things they did for me, I never was asked ever about brushing my teeth. Would that sound weird?

**Eva:** Yes, I remember they did that to me as well. And it does have to do with your gums. I know you'll bleed more, but I'm sorry to go back on the GvHD for your eyes. Did you say that was cyclosporine?

**Teresa Steele:** Cyclosporine apparently must be a generic for the Restasis. My ophthalmologist gave me that. I will tell you what worked really the best, but you can't use it all the time. My ophthalmologist would give me prednisolone eye drops. Man, it works perfect.

If only you could use it all the time. But apparently, it's not something you can... the steroids, you can't use it in your eye very much. But I think that one drop, one vial at night when I go to bed, is all I'm doing now. I've been doing that now for like... of the cyclosporine or the eye drops. I do have refresh drops that I use if I need to, but what I'm finding is that we need to bring me back to only one vial at night seems to be working, and my eyes seem to be better.

**Eva:** Well, thank you so much for your answer and your time, and I'm so sorry that we have all had to go through this.



**Teresa Steele:** Yes, me too, but I agree with what she... No, I was just going to say Tina was so right when she mentioned that you accept who you are and you go forward with that versus trying to be somebody that you're not anymore, and I really think that's important to know that I still like who I am and I'm happy that I'm here.

**Jennifer Gillette:** That is a wonderful statement, and I really appreciate your question there, Eva. And a couple of things I just want to add here. One, we had a program about eye GvHD a couple of months back, and that is recorded on our website, and it was done by Dr. Jain from Chicago, J-A-I-N, and he had a lot of great tips about eye GvHD. As well as all of you suffering with GvHD, I want to remind you about the GVHD Alliance, which you can look at information at [gvhdalliance.org](http://gvhdalliance.org), and there are all kinds of great downloads and things to help you. As well as there's also something called the NCCN guidelines that talks about how the different types of GvHD are treated and the standards of care in this country for that.

Another thing I just want to add to your question there, Eva, too, is many people do experience that after about five years, with GvHD, that it starts to many. I'm not saying all, and statistically, many people, I should say probably about half, find that it becomes much more manageable or that they get significant relief. But there are also those people that continue to struggle in a difficult way. And so it's really important having providers that really hear you and getting the chance to try different treatments and people that really specialize in getting the care you need.

But on that note, we are at the top of the hour, and I again just want to thank Teresa and Bruce for inspiring us all today. You've been through so much, and we appreciate you sharing how you've continued to overcome. I thank all of you on the call. If ever you need more support, please feel free to reach out to us. Again, this recording will be on the site within a couple of days, and we hope it was helpful to you. Thank you for all being here.

**Teresa Steele:** Thank you very much.

**Bruce Steele:** Thank you.

**Operator:** Thank you again for joining us today. This does conclude today's conference call. You may now disconnect.