

**National Bone Marrow Transplant Link**  
**How to Take Ownership of Your Survival Plan, Post Allogeneic Transplant**  
**October 9, 2024**

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**Presenters**

**Jennifer Gillette, LMSW, nbmtLINK**

**Dr. Minoo Battiwalla**

**Meagan Jourdan-Brown**

**Beth Ades**

**Operator**

Hello and welcome to today's nbmtLINK webcast, "How to Take Ownership of Your Survival Plan, Post Allogeneic Transplant."

At this time, all participants are in a listen only mode. If anyone should are operator assistance, please press "\*", "0". There will be a question and answer session, following the formal presentation. You may ask a question at any time by typing it into the "Ask-a-Question" feature on your screen.

As a reminder, this conference is being recorded.

It's now my pleasure to turn the call over to Jennifer, Gillette nbmtLINK Staff Social Worker. Please go ahead, Jennifer.

**Jennifer Gillette**

Thank you, Kevin, and thank you always for helping us with these webinars. Welcome, everyone. So glad you could attend today. We have a wonderful lineup of presenters here, today, to help you, as you are owning your survivorship plan, post allogeneic transplant.

Just a brief little outline and an introduction to us at the LINK, before we get started. First of all, today, we will hear from Dr. Minoo Battiwalla. He is the Director of Outcomes Research at Sarah Cannon Transplant and Cell Therapy Network And then, you will hear from Beth Ades, an MDF survivor, a wife, a mom and more. And then, we will have our question and answer period.

As you might note on your screen, there is an area to ask questions, and we will be answering those, once the presentation part is complete today or at least he will answer as many as we can, depending on how many there are.

For anyone who is new to nbmtLINK, the National Bone Marrow Transplant LINK is dedicated to helping individuals and their families from diagnosis through survivorship. We work with hospitals, cancer centers and other organizations to reinforce and complement medical care by providing resources, support and education.

We link you to experts across the country in all topics related to transplants and to others who have made it through the journey before you. To get in touch with us, there is our phone number and some emails you can reach out to us, as well.

Some of those resources we have are our Lunch & Learn Programs, monthly. We have 15 seasons of podcasts with over 30,000 downloads. We do multiple webinars, one which you are on here today on survivorship. We do a GVHD, or Graft-Versus-Host Disease webinar. Our next one will be in December.

And we have blogs for those who have been through a transplant process and really just all things related to transplants, including disease specific information, survivorship issues, coping and symptom management.

We have our Survivors Thrive Book Club and other programs to connect to community and fellow members. Peers Support Mentor Program is for both patients and caregivers, looking to talk to someone who's been through the experience and is doing well.

We have our Second Birthdays Recognition Program, as well as award winning books and materials, emotional support and a licensed social worker for referrals and resources.

A special thanks to our webinar events sponsors, the Leukemia and Lymphoma Society, Johnson and Johnson and our esteemed LINK partners for their continued support for all we do.

Just as a reminder, today's presentation is meant to inform and support. It is not intended to replace your individualized medical advice.

Now, introduction to our wonderful speakers here, today. Again, Dr. Mino Battiwalla, he joined Sarah Cannon in 2018 as the Director of Outcomes Research. In his role, he designs and leads retrospective outcomes research across the Sarah Cannon Transplant and Cellular Therapy Network with a special emphasis on blood and marrow stem cell transplantation and cellular therapy.

Dr. Battiwalla received his medical degree from the Medical College in Calcutta, India, in 1994. After completing an internal medicine residency at Stony Brook University Hospital in New York, he finished a fellowship in hematology/oncology/BMT at The National Institute of Health in Bethesda, Maryland. He also earned a Master of Health Science degree in clinical research in 2003 from Duke University School of Medicine.

Prior to joining Sarah Cannon, Dr. Battiwalla served as the medical director of the blood and marrow stem cell transplant program at the National Heart, Lung and Blood Institute in Bethesda, Maryland, from 2010-2018, and he chaired the NIH BMT Consortium. Previous to

this, he was an assistant professor and associate scientific director at Roswell Park Cancer Institute in Buffalo, N.Y. from 2003-2009.

Dr. Battiwalla has spearheaded efforts in the field of stem cell transplant survivorship and has co-chaired the NIH Late Effects after BMT consensus initiative, as well as the Center for International Blood and Marrow Transplantation Late Effects Working Committee.

Dr. Battiwalla is actively certified by the American Board of Internal Medicine with further certification in hematology.

And then we have the lovely Beth Ades. She is a survivor. She is from rural Iowa, married with one daughter, and is also a cat mom. She was diagnosed with MDS in 2021 and received her stem cell transplant in 2022 at Mayo Clinic in Minnesota.

Beth is passionate about giving back, helping/educating donors and their families and shares an infectious joy for life. She currently sits on our Board at nbmtLINK and helps us make our organization the best it can be.

And without further ado, I would like to welcome Dr. Battiwalla. Thank you for being with us, today.

### **Dr. Minoo Battiwalla**

Good morning, everyone. I would like to appreciate the opportunity to speak to all of you and this kind invitation from our sponsors at nbmtLINK.

My name is Minoo Battiwalla, and I'll be talking to you about how you can actually take control and own your survivorship, after ongoing allogeneic transplant.

As you have heard, I have been performing stem cell transplantation for more than 25 years and I consider that survivors are very special in the battle against the sort of diseases that many of you have faced. I want to acknowledge your journey through this very extreme treatment.

So, increasing success in the field of allogeneic stem cell transplant has led to an ever-growing increase in the numbers of transplanted survivors. And this such success comes a focus on long-term survivor health.

We believe that, by the year 2030, we'll have at least one half million transplant survivors in the United States with about 40% having undergone an allogeneic stem cell transplant and 60% being adults in the age group 18 to 59.

And as you can see in the graphic on the right, the growth is expected to be exponential. But it's important to understand that as time goes out after transplant, in about typically, if you have

had a transplant for acute leukemia, your risk of relapse diminishes to almost nothing if you haven't relapsed, by three years.

However, beyond that time, survivorship is assured from the standpoint of the malignancy but there could be growing health problems.

Also, I want you to realize that given the huge numbers of survivors, there's a risk that survivors can simply overrun the resources transplant centers have to care for them, which is why I would like to bring up this concept about taking ownership of your own survivorship care.

And we can only wish that all our transplant survivors look as healthy, fit and trim as the participants on a television show. But as you know, the reality is somewhat different. You could survive the transplant but there is often a cost. I like to use the term battle-scarred. Here are some statistics. Forty percent of childhood cancer survivors will have severe illnesses or die from such illnesses.

After a transplant, even if you recover from the treatments, there could be later effects and there's a psychological burden, the so-called Sword of Damocles, looming over one's head constantly remind us of additional problems yet to come.

Now for an allogeneic transplant survivor, more than 80% will have at least one late effect at five years, post transplant. And the sad reality is that it's not just quality of life issues; five-year life expectancy for a transplant survivor is actually lower than that of the general population.

So, this is a serious issue, and we need to tackle it with a lot of foresight. Alexander Solzhenitsyn is quoted as having said that "It's not the sea that drowns you, it is the puddle." In other words, you don't want to succumb to correctable minor issues that are created in the wake of the transplant.

So, congratulations, you are a survivor. Now, what should you expect? The message for today is it's important to take ownership over your health. Why? The benefit is that you avoid drowning in a puddle. In other words, avoid possibly reversible issues. And the big benefit is you can also greatly improve your quality of life.

So, what do you need to do? You need to stay alert for long-term or late effects. These are health problems which can occur later and or stay for a long time, after transplant.

When to expect these complications? The time frames for each complication are actually very different. And this is why we talk about transplants, and we use time frames, and we discuss time after a transplant because complications have their time frames. And if you enter a certain time, frame, it's very unlikely that you are liable to have complications, which could have occurred a long time ago.

So, how do you manage this? You do this by taking control over complex multidisciplinary care delivery.

Next slide. So, these sort of survivorship issues can affect all domains of health, not just the physical. It is important to recognize that there could be sexual side effects, emotional side effects, psycho-social issues and almost universally financial issues.

And many stem cell conditions can actually be ascribed to the transplant process, itself. So, if you are undergoing something strange, one of the questions you must always ask your physician, your care provider is, could this be related to my transplant, itself? And if so, does it have some sort of different treatment?

When we consider the causes of these long-term and late effects, they fall into several overlapping groups. The first obvious reason is there could be complications of an underlying disease. But the conditioning chemotherapy and the cumulative chemotherapy that patients undergo, has a major role. There could be underlying genetic preconditions or pre-transplant comorbidities.

And finally, there could be immune dysregulation. Immune dysregulation refers to the paradoxical setting where you have both hyper inflammation with chronic graft-versus-host disease and at the same time, you have weakness of the immune system which gives rise to infection.

So, one way to consider these risks and individualize address is to ask your doctor the question, did you receive radiation? You have chronic GVHD, how bad is it? What organs are affected? And are you male or female because survivorship health is influenced by all these factors.

Now, we talked about the timeframe of complications. And in this graphic, it shows the timeframe in years after a transplant. Understand that transplant side effects can happen many, many years, even decades after the transplant. There is an initial first year we worry about, and actually in the first 100 days, we worry about acute forms of graft-versus-host disease. But they are 100 days, typically, and up to two, three, four years after transplant, chronic graft-versus-host disease can clearly be a problem.

Infection can be a problem. Typically, very early but also later. And then the risk of relapse from underlying malignancies is usually over, by three to five years. However, this is just the beginning of several other transplants.

For example, late cardiovascular issues and late new malignancies can happen and can actually be prevented. So, maybe we'll talk about some of this, but I just want the message to go out that events can occur many years, even decades after the initial transplant.

So, when we think of key late effects, I like to divide them into two groups. First is those on the left which actually influence your survival and the second group on the right which influence your quality of life. And these inflections, second cancers, heart issues and lung issues can greatly impact your very survival. So, it's very important to be on top of them and it's actually fairly easy to address them, if you catch them early.

Chronic graft-versus-host disease, which is the inflammatory storm induced by bone or immune system attacking innocent body cells, is a driver for all these late effects. And quality-of-life issues basically can affect almost any organ system and include endocrine problems, bone problems, sexual and fertility problems, iron overload issues, general health, including fatigue, cramps, sleep, chemobrain, as well as mental and emotional problems. These are distressingly common in all our transplant survivors.

Thankfully, they are not necessarily fatal.

So, let's move on to the immune system. As I pointed out earlier, immune dysregulation is very common, after transplant. And the graphic on the left demonstrates that even years after an allogeneic transplant, really up to 12 years, we can demonstrate that late infections occur and are fatal, potentially fatal.

So, the vast majority of these infections are bacterial infections. And you can also have fungal, viral and multiple infections at the same time.

So, how do you manage this? Thankfully, most infections can either be prevented or treated. And many of you are already on treatment like antifungal, antiviral, anti PCP drugs and occasionally, antibacterial drugs, particularly if you have significant chronic graft-versus-host disease then a prevent prophylaxis is generally recommended.

Now, vaccinations. Vaccinations after transplant represent the biggest bang for your buck. And when should you start? I recommend starting at three months after the transplant with COVID and influenza vaccines because these are critical disorders and even partial immunity that you can get by immunizing at three months can be a big deal.

However, the routine re-vaccinations against all your baby illnesses should generally be deferred for at least six months after allogeneic transplant. And I generally insist that they are off all systemic immunosuppression. So, this might mean that it might be two, three, four, five years after transplant before you actually start getting the rest of your baby shots.

Do not be in a hurry to get them because if you are in active immunosuppression, the vaccines don't work.

Now, second cancers are actually quite a challenge in patients who have received a prior allogeneic transplant. The new terminology in the field labels them as subsequent neoplasms.

And there's a threefold higher risk. And this is an entirely different cancer from the original disease for which you might have been transplanted.

And it is linked to the cumulative doses of chemotherapy and radiation. The more treatments you have received to control your original malignancy, the more likely you are to have subsequent neoplasms.

Thankfully, this will happen gradually but if you see the graphic on the left and you look at the incidence curve for the expected rate of cancers versus the incidence curve for what is seen in transplant survivors, it is quite staggering.

So, how do we manage this? Well, it's really dependent upon having a very comprehensive approach to your cancer screening. The skin is one of the prominent types of cancer. And I will give you an example. I had a patient who used to expose himself routinely to the sun when he would drive his truck with one arm outside the cab and the other arm inside.

And this was while the patient was living in Buffalo, a place which is really not noted for its strong sun. Five, six years after the transplant, I had to remove about 15 skin lesions, many of them cancers, from the arm which was left outside the and none on the arm, which was left inside the cab, suggesting a huge influence of sun exposure.

So, a dermatologist skin exam, annually, is recommended for most patients, particularly if you have had significant sun exposure. Sunscreen is important. Avoid peak sun, sunglasses, hats and use sun protective clothing.

This is a such a simple thing to do but you really have to avoid the sun. I encourage my patients to think of themselves as vampires, the sun will kill you.

Thyroid problems, first of all, you need an annual physical examination. Oropharyngeal cancers, mandated dental examination every six months to a year, stop all tobacco and alcohol, including oral tobacco. Human papillomavirus vaccination is really important in stopping a large number of human papillomavirus-based cancers because HPV led malignancy is seen in maybe 5% of the general population but can influence 25% of the cancers seen, after transplant.

So, the lungs, if you were ever a smoker or a vaper, that has to stop and select patients may be eligible for low dose cat scan screening, particularly, if you have been a smoker.

Breast cancer guidelines exist. And women who have, particularly those who have had radiation, will require breast examination and screening, even earlier than the general population.

Cervical cancer, the gynecologic cancer, a very high risk of cervical dysplasia and precancerous issues, typically, by reactivation of the human papillomavirus, although may need regular

gynecologic testing, including HPV testing, such as by a Pap smear or an HPV DNA test and HPV vaccination.

Esophageal issues are possible. Colorectal cancers are possible and those follow guidelines for the general population.

What can you do about heart problems? So, what are the issues here? Transplant survivors are at a higher risk of cardiac events. So, there's actually all the underlying problems that give rise to coronary arterial disease and heart disease are actually accelerated in transplant survivors.

And by risk factors, I mean risk factors such as hypertension, diabetes, cholesterol issues, obesity. All of these are all represented in transplant survivors.

When you have all these risk factors acting in tandem, you can have a risk of premature events. On average, the first heart attack occurs 14 years earlier in transplant survivors. This risk is permanent and increases with time, after transplant.

Thankfully, all these risk factors are correctable. So, once the dust settles after a transplant, I recommend starting screenings in the first year, making sure you correct the correctables, factors such as cholesterol and blood pressure. And then, in select patients, you can do additional testing, such as echocardiogram, and cardiac CT scans.

The lungs are the last major vulnerable organ. Nobody should be smoking or vaping, after your transplants. Infections are common and it's important, therefore, to get vaccinated and seek medical attention, early.

Also, lung inflammation both presents with what we call infiltrates that are shadows on x-rays or scans. And not all of them are infectious. Very often, they are inflammatory. And this is where you really need to call your transplant center the moment you have any problems with your lungs because it might not be a simple pneumonia. Even though it's labeled as a pneumonia, it could be an inflammatory non-infectious complication.

These can occur early post transplant or late post transplant, and this is a very distressing issue and if you ever have any problems with your lungs, please do contact your transplant center.

There are two forms of graft-versus-host disease of the lungs. One is called cryptogenic organizing pneumonia, and the other one is called bronchiolitis obliterans. Recognizing and distinguishing them is very critical and this is why lung function tests are very important to pick up early traces of lung graft-versus-host disease, and we recommend that you get lung function testing regularly, at least every three months if you have chronic graft-versus-host disease in any other organs, or six to 12 months, otherwise.



And usually, this frequency can start up to three to five years but in those three to five years, detecting lung inflammation early is very critical.

Now we come to the more common and more frequent issues but less life-threatening. About a quarter of patients will have low thyroid levels and that can be easily supplemented. Higher risk of diabetes and dyslipidemias can be corrected.

Sex hormones are universally reduced because of ovarian and testicular failure. So, this can result in causing low sex drive which may not matter to some individuals, but more importantly, can you fatigue, gradual changes and pain, erectile dysfunction is common and infertility for the vast majority of transplant patients, particularly, those who have received more intense chemotherapy or radiation in their conditioning.

So ovarian failure, I strongly recommend hormone replacement therapy, up to the natural age of menopause, which is early 50s. For patients with documented low testosterone, that has to be documented on the basis of a free testosterone level and not a total testosterone level. In my personal experience, all men who had this condition tried testosterone supplementation and it just does not seem to make any difference to the quality of life.

Bone health is important. Again, there are two patterns. The first is osteoporosis or osteopenia, shown on the left, and the other pattern is avascular necrosis.

Osteoporosis affects all the bones and results in weakness and the bones becoming progressively more spongy and loss of the tissue which holds up the bone. And eventually, this can crumble and cause painful compression fractures.

If you're a female, if you're older, if you have been exposed to a lot of steroids or you're vitamin deficiency or GVHD, you're more likely to get this. And this is totally preventable with calcium vitamin D supplementation, exercise. There are medications which can be used to treat this and for women, preventive hormone replacement therapy, if you are eligible.

In avascular necrosis, as the graphic on the right shows, is a complete destruction of the joints, sort of tiny micro fractures in the cortex of underlying the joint's cartilage. And this can cause severe pain. And this is related to steroids and radiation and usually will not show up on simple x-rays and requires an MRI.

There are a number of specialist orthopedic interventions which need to be done but often culminating in joint replacements.

Other general health issues which you should recognize, which are related to the transplant, fatigue is very common. It's important to treat underlying medical causes, consider reducing the workload, as well as exercising and taking strategic naps.

Sleep disturbances are common. Again, sleep hygiene is something everybody should try. Emotional changes will require a mental health counselor. Muscle cramping is also very common in the first few years. I recommend tonic water. This generally tends to improve, over time.

Brain fog, also called chemobrain, improves one to five years after transplant but there are certain therapeutic approaches, including cognitive rehabilitation therapies, as well as medications, which can be used.

For the eyes, there is a high risk of premature cataracts, as well as dry eye syndrome. Having an ophthalmologist on speed dial is a very, very important consideration.

Mouth, dry mouth, cavities and the risk of oral malignancy require regular dental exams. Kidney, liver, issues can happen.

Iron overload for certain patients, particularly men, will require bloodletting to remove the excess iron. Initially, you don't do this for the first couple of years.

Neuropathy is not so common and requires a foot exam, as well as medications for pain and discomfort.

So, as you take control of your transplant, what are some of the questions you can ask your transplant team? One question is ask about your underlying disease. When will you be deemed cured of your malignancy? Usually, if you have an acute leukemia and you haven't had an occurrence, I tell my patients that they can break open the champagne at three years after the transplant.

Ask about graft-versus-host disease, particularly chronic graft-versus-host disease. Which organs are affected, and which organs are not affected? How long will you need to be on immunosuppression therapy? What changes are permanent and what is expected to resolve?

There are other non-GVHD complications. How are you affected? What complications are you likely to get in the future, given the nature of your individual condition? Which potential complications are life-threatening? How long will you be at risk? How serious are these potential complications? There's a lot going on. How do you prioritize addressing all these health issues?

Also, in terms of reclaiming your life, how long will you be disabled? When can you plan to return to work or school?

And then I think the biggest challenge many patients face is how to manage their care because this is multiple disciplinary and often, patients are now remote from their transplant centers

and who is going to be responsible for your care? Who takes care of which components? Exactly when do you call the transplant team or when do you go to your local doctor?

When should you visit the emergency room? How quick should your reflexes be in back care because you are much more vulnerable than a normal individual. And when do you call your primary care physician?

So, some of the things that you can focus on are it's important to commit to survivorship. You can not go through this process thinking, well, I'm feeling well, therefore, nothing is wrong with me. No, because that's when problems happen.

You need to learn about your risks, learn about potential complications and their time frames and, aggressively, seek to correct them. Not everybody will have access to a survivorship clinic. And this is a big gap in our field.

You should generate very good habits such as sun avoidance, stopping all addictions, including smoking, making sure you regularly get cancer screening and having a good healthy diet. Activity is very important. I recommend weight-based training, particularly for women because that really helps with your bone strength.

You will have to develop a panel of consultants for your eyes, gynecology, skin and dental. This is routine for everyone.

I also recommend that you generate, you take responsibility for your medical information because you need them to be with specialists and your medical records don't automatically transfer and nobody has the time to go through hundreds of pages of medical history.

You could short-change yourself, so it's important to carry a binder with the essence of your medical history, a survivorship care plan and your most updated current medical lists, medication lists.

So, at Sarah Cannon we have a matchbook of transplant centers. We have developed the concept of a dedicated survivorship clinic. Then beneath that, simple screening and preventative measures can greatly improve health.

So, we are patient centric. The patient is at the center of everything we do and, of course, there's a physician, there's also a nurse practitioner, nowadays called an Advance Practice Professional. So, it's going to be nurse practitioner or a physician assistant. We have coordinators who are trained nurses. First, there's a an acute allo coordinator who coordinates the patient in the first three to six months and then hands off the coordination of the patients to a long-term follow-up coordinator.

And we have a model for standardized processing and staffing and training and resources, which is spread across all our centers.

So, at the heart of this approach, is the coordinator. And interfaces with the transplant doctor, the referring to oncologist, as well as the primary care doctors. Finally, on the right, we have all the other consultants, be it a pharmacist, social work, as well as individual medical specialties.

The transplant doctor, I feel, is the least important in promoting long-term survivorship health because the transplant doctor will have very limited time and will have to focus on just the most important issues, such as malignancy restaging, active graft-versus-host disease and infection. And a lot can slip through the cracks, if you don't have everything else addressed.

The way we do it is that patients have regular visits, as shown on the bottom. This is the planning sequences with the medical team, be it the transplant physician or the nurse practitioner or physician assistant.

Interspersed with these regular visits, we have dedicated landmark or survivorship visits. At our center, we do our intake, the first survivorship visit is at day 100 to establish a baseline and then we have another at six months and then annually for the first three years and then a declining frequency.

At these survivorship visits these are very long visits with a lot of time and follow a very exhaustive multidisciplinary evaluation, multiple tests done, which are all summarized at that visit.

That visit is actually conducted by the nurse practitioners who then spare an hour for each patient at each landmark. And the focus is on all the other issues. putting aside the graft-versus-host disease, putting aside the active treatment and the malignancy, etc., but focusing on general health issues.

This is how we have managed to try to look in terms of managing survivorship help. But we understand that such intense focus on survivorship is generally not available to most patients who've undergone a transplant. This is why when patients, for example, need our center, we generate a survivorship care plan which highlights some of the transplant conditioning, whether they had GVHD, what the risks are, what the recommendations are, and it's like a passport that the survivor carries with them to take them through life, especially as they move away from our center and they go home.

In addition to the nbmtLINK, there's also resources available for survivorship, so the National Marrow Donor Program. I encourage you to take a look at that, as well.

We've also some direct resources, not just information which can help if you're enrolled there.

So, let's summarize. It's important for survivors to take charge. You have to commit to lifelong follow-up, understand that being asymptomatic does not mean you are without health risks. Understand that you will require complex, multidisciplinary care to promote your health. Survivorship clinics, if possible, are fantastic but not everybody has access to that. Individual survivorship--individualized survivorship care plans are very helpful.

And you should ask questions and seek help.

It's important to own your health, to start with general awareness, asking questions, staying organized in terms of keeping records, prioritizing problems because you can't address everything at the same time, and generally committing to a healthy lifestyle.

And finally, the reason why we do all this is so that you protect your health, and you enjoy your success.

Thank you very much.

**Jennifer Gillette**

Thank you so much, Dr. Battiwalla. So much great information on there and so thorough. We appreciate you being here with us, today.

And now, we will have Beth joining us.

**Beth Ades**

Hi, thank you. First of all, I just want to thank Dr. Battiwalla. I could have listened to him, all day. That information was fantastic to give us all hope for a long and healthy life. So, I'll just jump right in.

Hi, I'm Beth Ades. I'm so happy to be here with all of you and getting to share my story. I am a small-town Iowa girl, married to my awesome husband, Justin, and we have one daughter, Haley, who is 15. I work full-time and I'm a cat mom.

My diagnosis of MDS came in 2021, but getting to that point took about seven months. I first went to my local doctor in May of 2021 with bruising on my legs. But other than that, I felt pretty good. She ran bloodwork that showed critically low platelets and then sent me to a larger hospital that was in Ames, Iowa, for further testing.

And my doctors there ran a bunch of tests, but we just weren't getting any answers. So then they referred me to Mayo Clinic in Rochester, Minnesota. And that was a couple different departments and teams before getting diagnosed with myelodysplastic syndrome, or MDS, and the only chance of survival was an allogeneic stem cell transplant.

Both of my sisters were tested; neither was a match. And then they located my donor. She was a 19-year-old from Germany, and she was a perfect 10 out of a 10 match. So, I moved from Iowa to Minnesota for my transplant, then lived in Minnesota for 100 days, post transplant. And that was February 17 of 2022. Got to tell you, moving to Minnesota in the winter was not my best planning.

But after transplant, I suffered from acute graft-versus-host disease in my liver and on my skin. And now, I suffer from chronic GVHD in my eyes. Because of my GVHD, I needed to stay on my anti-rejection medicines for longer, so that delayed my vaccines. I only got them finished up, pretty recently.

So, the time before transplant when I was sick, staying from home until the time I was fully vaccinated, I was in isolation for three years.

All right, Deadpool says it best; the worst part about cancer isn't what it does to you but what it does to the people you love. And he also taught me how to say cancer in Spanish; it's el cancer.

I don't know if you're familiar with Deadpool, but it is played by Ryan Reynolds. His character is Wade Wilson, just an ordinary guy who has cancer. And then he goes through kind of a sketchy procedure that give him superpowers. I'll just go ahead and say, make that jump, maybe all of us have superpowers, maybe we're superheroes now, too.

But what Deathpool is talking about is the guilt that surrounds us when we get sick. And I struggled hard with guilt, and I still do. I felt so much guilt for what I had put others through. Like my husband who had to basically do everything. He was my caretaker, my driver, housework. For my daughter, who had to watch her mom go through something that was really, really scary.

And for all the worry that I caused my loved ones. I mean, I knew I needed the help, but I had a hard time accepting it.

So, after day 100, when I returned home back to Iowa, I became almost obsessed with how to pay people back. I could not shake the feeling of guilt, and it was a really, really hard place for me. It was the passion and the drive was coming from the right spot, but I eventually learned how to pivot that guilty feeling of paying everyone back into paying it forward.

So, with that, I'm having lots of fun and I'm getting creative. And so far, I've hosted two blood drives and a bone marrow registry event on my first and second re-birthdays. So, it was awesome seeing people fill up those time slots and come in and donate blood and just how many people got on the registry.

I've written a couple of blogs and recorded a podcast. I'm an ambassador for LifeServe. They're the blood donation centers in Iowa.

Justin, Haley and I did a virtual stand up to cancer 5K, together. You can see right there, Haley, she's out there for Ernest and Paley Herman. So, that was a lot of fun for us to do together. And you can also see in the slide, my husband's race car.

So, as a hobby, my husband drives race cars and one of our cars, this year, we had wrapped as a tribute car for the NMBP and LifeServe. So besides racing the car, we put it in parades and just other events. And it's been so fun because little kids, big kids, everybody loves race cars. And they start asking lots of questions, and it's been a great icebreaker for me to start talking to people about maybe getting on the registry or donating blood.

Some of the things that I've learned. I've learned the hard way that I need to be my biggest advocate, my own biggest advocate. So, some of the things like mental health, my sleep, my sexual health, got to tell you, with my mom in the doctor's office room with me, that is not a comfortable thing to talk to my doctor about, but I did learn how to speak up.

One thing that pops in my brain is about six months after transplant, I noticed this warm bump on my leg and I started feeling kind of cruddy, too. So, I met with my transplant team but, unfortunately, that day, I had a fill-in doctor and he just kind of kept brushing it aside. And I finally ended up saying something like, you know, I'm not going to head back to Iowa, until I can get this checked out, today. And he ordered the test and, sure enough, it turned out to be a blood clot.

Also recently, at my latest appointment, my incredible doctor put my next appointment at six months, which was awesome news. And we celebrated, it was great. But then I told him that it made me really nervous to go a full six months, without having my blood drawn.

So, we talked about it, and we decided that, every two months, I'm going to have my blood drawn. He was happy and I was happy, and we were both comfortable.

So, even though I have crazy respect for hematologists and oncologists, they're some of the smartest doctors out there, I know I'm the expert on my own body. So, I encourage you to keep talking with your team about the tough stuff. If possible, if you have portal access like an app, something like that, take advantage of it. Send those pictures, send those questions to your team.

I also learned about the National Bone Marrow Transplants LINK and their partners. My only regret is that I wish I could have learned about them, sooner. There's a peer connect program, and I talked with two different long-term survivors through that program. And the first question that I asked both of them was, how long was it before you could just put transplant behind you and get back to your real life? And they both answered, you never really put it behind you.

I was so hopeful that I could think of a transplant as a dark cloud on my timeline, something that I went through but got back to real life. But I'm so glad that's not true. For a while, transplant defined me and now, I've allowed it to change me and be a part of my everyday world.

I've learned so much. I've met some of the coolest people I've ever known. I live my life in the present and I don't take things for granted. We've survived something most people have never heard of, and we've lived to tell about it.

My faith has deepened. God had transplant in His plan for me. I know that, now. I have suffered, well, so that I could live through this season and help others.

All right, fun, right, humor. Hair, let's talk about it. We're going to lose it, right. We all know we're going to lose our hair, so let's have as much fun as we can with it. So, in the one picture, you can see Haley. I donated my hair, before I moved to Minnesota so here, she's cutting off all my little pigtails.

The next picture is my one and only wig that my coworkers sent to me. But the joke was on them because I wore it during an entire Zoom meeting. And then, my dad and I having similar hair lines.

I thought I got ahead of my slides. Here is me. My favorite Halloween costume ever, El from Stranger Things. My mom in the waiting room. Haven't we all wanted to do that? How many hours of our life have we spent in waiting rooms. And there's Haley pretending to be run over by the race car. So, just a little bit more fun things that we try to do.

I owe it to myself to keep up with new information about transplant. So, every month, I've made a promise to myself, and I've held on to this, I attend at least one class. I want to learn. I read articles. I listen to podcasts. Some days, even just listening to others talk helps me feel connected.

Turn some days into today. When I finally got the green light to be out in public again, I started taking full advantage of it. I took my first vacation for many, many years, this year. I attended a concert. I went on a hot air balloon ride. My first ever girls' trip. And I recently attended the NMBP Gala. I try hard not to take one day for granted.

Taking care of myself is actually easier said than done. My recipe for self-care is rest, therapy, nutrition and movement, in that order. I didn't want to admit that trauma had taken its toll on me. I just had gone through something so incredible and difficult, but I felt like admitting that to myself that I needed therapy and that I was letting myself down and really, everyone who was rallying behind me, I felt like I was letting them down.



And I don't, at least at this current point, I don't want to imagine my life, without therapy. I think therapy is for everyone, as long as you're going to put the effort in for it.

Embrace your pace. Don't compare your journey to anyone else's; it's your journey. I was able to start running again, which is great, not as fast or as far, but I'm doing it.

One other thing that I want to talk about, I check in with myself first before going for a run. If my body is saying, no way, I know how important movement is but listening to my body is more important. And so, rest days are necessary.

Some of the things that I've done recently. I grieved for my old transplant life. I really long for those things that I could no longer do. But now I'm focusing on the things that I can do. So, I dove right back into hobbies like baking and crafting. And I've really enjoyed getting native, making things with my hands.

I also joined a creative writing class, earlier this year, through one of the LINK partners, where I've learned how to express myself. And I would encourage everyone to start writing and journaling. It's really one of the best things that I've done for myself.

I have to go ahead and talk about my donor, quick. I learned her identity, earlier this year, and she's incredible. She's at medical school. We email often and we share photos and some day, we hope to meet.

And where I am, today. I've returned to the job that I adore, and I am genuine and real in every relationship. And I say what's in my heart and tell people, as often as possible, how much I appreciate them. I finally feel like I'm right where I'm supposed to be. I choose joy, every day, and I've allowed transplant to change me for the better.

I'm so grateful that I got to hang out with all of you today and a huge thank you to the National Bone Marrow Transplants LINK.

### **Jennifer Gillette**

Thank you, so much, Beth. I really appreciate your wonderful presentation. And I'm so some of the things you have shared are things that ring true with others.

I want to thank everyone that came here, today. First and foremost, I want to thank our sponsors, the Leukemia and Lymphoma Society and Johnson and Johnson. I also want to thank our speakers. I know Dr. Battiwalla was answering questions, during some of the presentation.

And if anyone has additional questions, you can certainly reach out to us and we'll do the best we can to help. But if not, I also encourage you to take some of the questions that you might have gotten here today to your own provider.

As well as I just want to thank Beth and again, Dr. Battiwalla and our sponsors. And I want to make sure everyone is aware that we will be having our GVHD webinar coming up. So, keep an eye out for that. You will see on our website, as well as you will be seeing it in our newsletter. Or you can go to our website, directly, and we'll be happy to assist you in getting registered.

But anyway, you also will be getting a survey for today. This helps us with future programming. And so, we will be sending that out and we just hope everyone has a wonderful day. Thank you for joining us and we wish you much health in your survivorship.

**Operator**

Thank you. That does conclude today's webcast. You may disconnect your life at this time and have a wonderful day. We thank you for your participation today.