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Mendya Griffith - A survivor of AML

**Operator:** Thank you for standing by. My name is Carly, and I will be your conference operator today. At this time, I welcome everyone to the Last Results Post Bone Marrow/Stem Cell Transplant: What to Expect and What You Need to Know Conference Call.

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. If you would like to ask a question during this time, simply press star followed by the number one on your telephone keypad. If would like to withdraw your question, press star one again. Thank you.

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

**Jennifer Gillette:** Thank you so much, Carly. Yes, I'm Jennifer Gillette, the Staff Social Worker at the National Bone Marrow Transplant LINK, and I'd like to welcome everyone on this call today. Our program will focus on Lab Results Post Bone Marrow/Stem Cell Transplant, what to expect and why these lab results are important.

A special thanks to our generous sponsors: Blood Cancer United, Incyte, and Sanofi, as well as our esteemed LINK partners.

Just a brief outline of what our program will look like today. Our first speaker will be Phyllis McKiernan. She is an advanced practice nurse in the Blood and Marrow Stem Cell Division at John Theurer Cancer Center. And then we will hear from Mendya Griffith, a survivor of AML from Augusta, Georgia. She was diagnosed in 2022 and had a transplant in 2023.

For those who may not be 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 navigate their transplant journey are our Marrow Masters podcast, which right now we have over 40,000 downloads, and you can listen to those wherever you download podcasts, such as Simplecast or on Apple, and we have webinars a couple of times a year. We have other Lunch & Learn programs monthly, like the one you're on today, and they're on a variety of topics, sometimes disease-specific, sometimes survivorship-specific, and sometimes treatment-specific. All of those programs are recorded on our website, so you can also go there and do a search for topics that interest you at nbmtlink.org. We have our peer support program, where you can talk to other people that are thriving after a transplant. We have our Celebrate Second Birthdays program, our Survivors Thrive Book Club, and our Healing Arts Program, which has been very popular. We also have a content Facebook page, our content-packed Facebook page with daily inspiration and relevant tips for survivorship. We have books and we offer referrals and emotional support. So if you need some extra support, please feel free to reach out to us.

Before we begin today's program, just a couple housekeeping items. One, when it comes to our question-and-answer period, we will be answering one question at a time, and then you'll get back in line in the queue, because we want to give everyone a fair chance with their questions. We also ask that you try to be as concise as possible, just so we can get to as many questions answered today as possible. We also might not be able to get to them all, but we will do our best to answer as many as we can. Please also know the information in this program is meant to stimulate conversation with your healthcare team and is not meant to replace your individualized medical plan.

So now, on to the educational part of our program. Phyllis McKiernan is currently the Manager of Advanced Practice Nurses and Oncology Nurse Navigators in the Liquid Tumor Divisions at John Theurer Cancer Center, Hackensack Meridian Health. She works as an advanced practice nurse in the stem cell transplantation cellular therapy program and formerly worked as the inpatient advanced practice nurse for the leukemia division. Ms. McKiernan has over 40 years of experience in oncology, bone marrow transplantation, in both the acute and ambulatory settings, as well as in home care. She has given numerous presentations and has published articles in journals such as the Clinical Journal of Oncology Nursing and the Journal of Advanced Practitioner in Oncology. She's also served as an adjunct faculty at Seton Hall University and Felician University. Thank you so much for being here, Phyllis.

**Phyllis McKiernan:** Oh, thank you very much. I am very excited to be here, to have to speak to all of you this afternoon and thank you for that very kind introduction.

So my goal today is to give you all a better understanding of what to expect after transplant, related to the testing and monitoring you're going to need as part of your recovery. And let me start by reminding you that each transplant center will have specific timelines as to the testing you'll need. It depends on the type of transplant you had, including the type of chemotherapy or radiation, the underlying illness, any prior treatments or infections you may have experienced. All of these will determine what type of testing you can expect after your transplant.

So I'm going to in general terms based on my experience, but as Jen mentioned, your transplant team will be able to give you more information and details regarding the specific testing you are going to need and over what timeframe.

Now, the first few weeks after transplant and discharge from the hospital, you can expect to be seen often at your transplant center. And this frequency will depend on what treatments, if any, you need, how you're feeling in general. Fatigue is to be expected, and your appetite may not be great, so you may need to have IV fluids or even blood transfusions until your blood counts are fully recovered. So the blood tests that you're to expect would be complete blood counts, your CBC, and blood chemistries. And I'm sure many of you are familiar with them, so forgive me if this is repetitive, but I just want to make sure that everybody has a good understanding. You know, CBCs will measure your white blood cell count, your hemoglobin, which is your red blood cell count, and your platelet count.

Now, we don't expect [indiscernible] when you're first discharged. And you may notice that many of the values on your CBC, when you're looking at the report, may be labeled as abnormal. And that's because as your bone marrow recovers, your red cells may be different sizes, your white blood cell count may fluctuate, and your platelet count may rise slowly. This is all expected, and your transplant team is going to look at those values, and that will help them determine how well your bone marrow is functioning. But a slight drop in one of your blood count may occur, especially platelets, they tend to go up and down. And it can happen for many different reasons, and it doesn't mean that the transplant is not working. The changes can indicate the normal recovery process, but it could also be early signs of infection or maybe other complications. So this is why your team's going to monitor your blood counts often to look for trends. We look for trends up or trends down.

Patients have asked me what their blood count levels need to be that would allow them to go out safely in public or see more family and friends. So, you know, even though your blood counts are “normal”, there are other factors that go into that decision. So, whether the patient is on immunosuppression or has graft-versus-host disease, what previous infections do they have? Can those infections be reactivated? Do they have lung disease? Do they have frequent respiratory infections? What infections are common where you live, and what season is it? Is it flu season or RSV season? So, all of these decisions and discussions have to be made with your transplant team. So, while your blood counts play a part in that decision, there are other things that go into that.

So, in addition to a CBC, you're going to have blood chemistries done, which will measure your kidney and liver functions, as well as your electrolytes and minerals, such as sodium, potassium, magnesium. If you're taking a medication to prevent graft-versus-host disease, which is called tacrolimus or prograf is the other name, your magnesium levels may be low, and then this can lead to muscle cramping or abnormal heartbeats, arrhythmias. If you're not eating normally, your sodium and potassium may be low, which can also lead to arrhythmias or make you feel sluggish.

If you're not drinking enough fluid, your kidney numbers, your B1 and creatine may be elevated. So based on your chemistry, you may need to take supplements for potassium and magnesium, or need IV fluids, and your team will make adjustments in doses and frequency of those supplements based on your levels. Your liver numbers, we look at what's called your transaminases, and that would be AST and ALT. We look at your alkaline phosphatase, your bilirubin. These may be elevated as well and can happen for a number of reasons or complications, including infection or graft-versus-host disease. So if your liver function tests are elevated, your team may want to do additional blood tests. Sometimes you even need an ultrasound to look more closely at your liver. That's very common. So certain values in a CBC or a chemistry can also indicate early relapse or inflammation. So that's why close monitoring after the transplant is crucial. And remember that while the numbers are important and they give us really good information, we just don't treat the numbers. We need to look at you as a whole. We need to examine you, listen to you, see how you're feeling, what other clinical things are happening. All of these things together will help your team determine the best plan of care. So it's not just the number. While the numbers give us clues, we have to do more digging.

So moving on, other blood tests common after the transplant are used to identify the potential for what's called viral reactivation. All through our lives, we're exposed to different viruses, and the most common ones are CMV (Cytomegalovirus), HSV, which is Herpes Simplex Virus, EBV which is Epstein-Barr virus, there's also adenovirus. And when we have a healthy immune system, these exposures that we have over our life may lead to minor illnesses that are usually easily managed and resolved quickly, such as a respiratory illness, like a mild cold. Other exposures you may not even know about, as you don't even become ill. And when you recover from these exposures, the virus, though, does not leave your body, and it's held in check by your immune cells. And after a transplant, when your immune system is not fully recovered, the viruses can now reactivate and potentially cause illness. So before your transplant, your team may have tested your blood to determine previous exposures to some of these viruses, as there are medications that can prevent reactivation, such as we have one to prevent CMV reactivation. So your transplant team will let you know that. And after your transplant, your blood's going to be monitored for these viruses, and if the levels hit a certain amount, that would indicate that there's treatment that is necessary. The tests are done frequently in the first three months and may continue longer if you're being treated for graft-versus-host disease, as that graft-versus-host disease in and of itself and the treatments for it can further suppress your immune system and continue that risk for viral reactivation.

Measuring medication levels are also done in a blood test. The medications you take after transplant to prevent graft-versus-host disease need to be within a certain therapeutic range to be effective. You don't want it too low, because that can increase your risk for graft-versus-host disease, and if the level's too high, that can increase your risk for toxicities. So the most common medications we measure for in terms of the therapeutic level are cyclosporin or tacrolimus; those are the most common ones that we use to prevent graft-versus-host disease. And there may be other medications that will check levels on certain antibiotics and things like that.

So your team will let you know and let you know, for example, with tacrolimus and cyclosporin, you don't take your morning dose of the medication, so we can get a low level. And that's what we're looking for. But you'll have instructions about that. In terms of the range that they're looking for, it really depends on your transplant, how aggressively they want to prevent graft-versus-host disease, whether you have an infection, and whether your other organ function is, so your team will be able to let you know what the range is.

We can also measure immune function after the transplant. We look at things called immunoglobulins. Immunoglobulins are antibodies or proteins produced by some of the white blood cells, and they're involved in the body's defense against bacteria or viral infections. So when your immunoglobulins are low, you may be more susceptible to those types of infections. So if you're developing frequent viral infections like respiratory illnesses and your immunoglobulins are low, your team can give you Intravenous Immunoglobulin, known as IVIG, and some of you may have already had that. We can also check your lymphocyte counts, and we can measure your T-cells and your B-cells. T-cells are those white cells that actively fight infections and recognize cells versus non-cells, while B-cells can fight infections, but they're also memory cells. So, by measuring your T-cell and your B-cell count recovery, your team can determine what type of prophylaxis you need to prevent infections and when is the optimal time to administer vaccines, because vaccines need those memory cells so that you can have a memory of being vaccinated and have the protection against those diseases.

There are other tests that are done at different intervals after the transplant. One is a pulmonary function test, which you probably have before your transplant, where you breathe in and out through tubes, measuring your lung function and volume. And after the transplant, the PST volumes will then be compared to your pre-transplant volumes. And if it's changed, then the team can intervene to improve lung function. Bone density is a low-radiation X-ray of your lower spine, the upper part of the femur or thigh bone, and the forearm. So, a transplant can lead to early menopause in women, and medications such as steroids can lead to bone loss over time, putting people at risk for fracture. So the bone density test can help determine your risk for fracture and diagnose potential osteopenia or osteoporosis where you have mild bone loss or even severe bone loss. And, of course, there are treatments and exercises we can do to increase that bone density and decrease the risk of fracture. Many centers do thyroid testing, testing of lipids and cholesterol, to identify hypothyroidism and hyperlipidemia, which can develop due to the conditioning regimens and other medications we use after transplant, and the idea here is that early detection leads to early intervention.

Now, the most stressful test that we have after transplant determines the success of the transplant, I put success in quotes. “Success can be defined in many different ways, but the basic goals of a stem cell bone marrow transplant is to have the donor cells take over the bone marrow and to have the underlying disease eliminated and not come back.” All right, so how do we determine that? Chimerism studies determine the percentage of donor cells in your blood or bone marrow.

They measure the percentage of donor T-cells, or CD3, you might see that on your report, or the percentage of myeloid cells, which is CD15. Ultimately, the goal is to have 100% donor cells and 0% recipient cells, and depending the type of transplant, the conditioning regimen, it may take longer for your donor chimerism to increase, but we're definitely looking for a trend up. And if the trend is going down and not up, then the team will be able to intervene and do some things to help move that towards 100%. And the frequency of chimerism testing depends on your center. At my center, we test the blood chimerisms every month for the first three months, and if they're 100%, then we'll test every three months for the first two years. If we see the chimerism drop, then we may increase the frequency. And that can happen even if your chimerism reaches 100%. Doesn't mean that there's a relapse, but again, we're looking for trends over time. And we also, when we're looking for a chimerism, we're not just looking at that, but we may do additional testing. We have to look at all of your blood work, your chimerism, your CBC, your chemistry. They all add a piece to the puzzle, and that's how we will look at it as a whole together. Now, sometimes patients never have 100% chimerism, and that's okay too, depending on the type of transplant you have. As I said, there are many things that we have to look at, so please discuss with your transplant center when you get your results and what it is that they're going to be looking for.

Now, if you have a blood cancer, more than likely you're going to need at least one bone marrow biopsy after your transplant. Some centers require more at various intervals, and if you're on a clinical trial, that may require more as well. The bone marrow biopsy gives us a wealth of information regarding your disease and the status of your bone marrow after transplant. We collect two samples: the aspirate, or fluid from the center of the bone, and a small core of the bone taken from the back of the top of the pelvis. The aspirate is sent for there are many different tests. One is the flow cytometry that looks at the physical and chemical characteristics of all these different cells and to determine the amount and intensity of those cells, and then can recognize if cancer cells are there versus normal cells. Cytogenetics and karyotype look at the structure and number of a person's chromosomes. In some diseases, the chromosomes can be missing, broken, or have an extra copy. It's important to remember that abnormal chromosomes from your disease are typically not the disease passed down to your children, so that's always a concern if they have abnormal chromosomes. These are not passed down. These are just something happened that broke down these chromosomes, and that's why you develop these diseases. So based on the previous cytogenetic testing on your marrow, after the transplant, we're looking for those chromosomes to now be normal chromosomes from your donor. In fact, if you're a female with a male donor, you will now have a male chromosome in your blood. But don't worry, you're not going to develop male body characteristics. It's just your blood that has the male chromosomes, not your tissue type. In fact, I always tell a story here, since your tissue type doesn't change; if you want to commit a crime, then you can bleed at the crime site, because that's your donor. But it don't fit at the crime site, because that will be your DNA. So you don't change, it's just your blood.

FISH testing, or Fluorescence in situ hybridization, much easier to say FISH, is another technique that allows us to look for abnormalities in the chromosomes.

And again, this is going to be compared to any previous abnormalities you may have had prior to your transplant. PCR testing, or polymerase chain reaction, looks for specific biomarkers in the blood or bone marrow, and this test is done only if you have certain diseases that have those bone marrows, those biomarkers, most commonly Chronic Myelogenous Leukemia (CML) or Acute Promyelocytic Leukemia (APL). These are very sensitive tests that can find these traces.

NGS or Next-Generation Sequencing, this is kind of the newest test we have in our arsenal here. This test is done on blood or bone marrow and allows for sequencing DNA and RNA to look at all different genes, all at one time, instead of one gene at a time. And it can identify mutations that you may have had that were present before your transplant and were associated with your disease. The idea of looking at all these tests in the [indiscernible] is to look for something called Minimal residual disease (MRD), all right? We're looking to make sure that your disease is completely gone, and if any of these tests show anything that show a little bit, a minimal residual disease, then we can do things and we can manipulate your immune suppression, we can do other things to perhaps put you on a particular therapy that targets one of those mutations, those things we can do to help get you in remission, keep you in remission, and get a complete, stringent remission.

Now, the core biopsy of the bone is sent for what's called morphologic analysis by a pathologist. They look under the microscope at how the cells look, if they're properly formed, if they're mature, how numerous they are, and again, the pathologist can distinguish between normal and abnormal cells. They look at the amount of iron in your bone marrow, whether there's scarring or fibrosis, and which can interfere with the development of blood cells from the marrow. So these are all the things that we can from a bone marrow biopsy. And also, we can also get chimerism from a bone marrow biopsy, too. So you'll get a chimerism in your blood, and you can get chimerism in your bone marrow.

So again, when your bone marrow tests reveal any abnormalities, your team can do a number of things. There are therapies that target some of the abnormalities. You may need additional treatment. Some people need more cells from their donor, not another transplant, but maybe a little bit of donor lymphocytes. So there's a lot of different things that can be done. So the idea behind doing these tests after the transplant are to capture these abnormalities early and intervene early to get the best possible outcome, which is a stringent remission. And the risk of relapse, which is what we all fear after a transplant, is the highest early on. So once a year goes by and there's no relapse, then we can kind breathe a little bit of a sigh of relief because the risk of relapse goes down significantly with each passing year. So that's why a lot of these tests are done frequently in the first year.

Other tests that measure your disease and how well you're responding to the transplant can be done depending on the underlying disease. PET scans, CAT scans, MRIs, they're done for lymphomas or other cancers that develop tumors. PET scans and CAT scans look at larger areas and MRIs look at specific areas.

And again, these tests are compared to previous scans you may have had prior to your transplant, so it's important that your transplant center has those films to compare, or you're going to get your testing done at the same place that you had it before.

Other testing can be done depending on your underlying disease or transplant. So, for example, myeloma. Myeloma testing can be done in the blood or the bone marrow. Again, the results are compared to your original disease. Sometimes, PET scans can be done for myeloma patients, but not all will need PET scans, especially if the disease can be measured in the blood or bone marrow. I had some questions, some pre-questions regarding kappa and lambda measurements, so I'm just going to touch on that for a second. In myeloma, the bone marrow produces abnormal proteins, some are heavy chain proteins, such as immunoglobulins (IgG, IgA, IgM), and some are light chain, which is kappa or lambda. And your disease is going to be characterized on the presence of those abnormal proteins. So, for example, an IgG kappa myeloma has abnormal IgG and kappa. Some myelomas just have light chain disease, such as free kappa or free lambda. So these levels will be measured after your transplant and compared to the levels you had when you were first diagnosed. If you have kappa light chain disease and your kappa rises, but your lambda stays low, your kappa-lambda ratio will be off. And this could be indicative that the disease may be progressing, so we have to do additional testing. However, if your kappa and lambda are both elevated and the ratio is normal, this is just part of the normal recovery process and will just be monitored. So myeloma is tricky as there are many variations, so please discuss your specific disease and how it will be monitored after your transplant for recurrence or complete remission.

In general, to summarize, your transplant center will be able to tell you the testing you'll need, how frequently, when you need the testing, and the frequency can change at any time depending on the results or what's happening clinically with you. Most transplant centers will do the most frequent testing in the first year after transplant, as I mentioned before. And then, five years after transplant, for example, at our center, we only see the patients once a year if they're doing well. And then they can see their primary oncologist or PCP for blood work or exams as well. And sometimes that produces anxiety. You're coming in so often to us and seeing… we're getting all these blood tests all the time, getting your bone marrows, getting your markers sent. So when we decrease the frequency, it produces anxiety, but we will… As we said, based on your transplant and what you need, we'll do the frequency as often as you need to give you the best medical outcome. So it's normal to have anxiety about these tests. Don't be afraid to ask your team why the testing's being done and what to expect, because your transplant team is there to help you understand your testing to relieve that anxiety.

So I hope that was helpful. I know I went quickly and I said quite a bit, but I'm going to turn it over to Jen now, and we can continue the program.

**Jennifer Gillette:** Thank you so much, Phyllis. We appreciate you and sharing all of that information.

And now we are going to hear from Mendya. Mendya Griffith is an AML survivor. She's from Georgia. She is an author. She has a book out called This Blood: My Story and Conversations with Cancer, Acute Myeloid Leukemia, and it's the second edition. She's also a singer-songwriter. with a gifted musical gift. You'll have to check her out on Spotify with her song Overcome. She's a blood cancer advocate and a firm believer of living life with intention and purpose. And we're so thankful that you're here today, Mendya.

**Mendya Griffith:** Thank you all very much for having me. I appreciate it. And Phyllis, you provided a wealth of knowledge. You just brought back so many memories of my diagnosis, you know, the importance of lab results. How I first came to know or understand about acute myeloid leukemia was when I was given the results of my CBC and all of my lab results. One morning, when I went to the emergency room, I heard the term blast cells. After they had done blood work, my tests revealed that I had a high number of blast cells, which, if you all don't know, those are immature white blood cells that crowd out your immune system. And so they were kind of like taking over. And I was immediately rushed over to a cancer center where I began… well, we started off with a bone marrow biopsy, which Phyllis touched on, which confirmed that I, in fact, had acute myeloid leukemia. And so following that, we proceeded with the 7+3 treatment, which honestly just tore me apart but it's such a brief time period. My world was rocked by like lab results of like a bone marrow biopsy and blood work and I mean there were all these terms that I wasn't exactly familiar with and really had never understood the importance of blood work and what they could possibly reveal. So I learned a lot upon my initial diagnosis. But my experience with having so much blood work, after 7+3, being at my oncologist's office three times a week, was like the norm to check my stats to see where I was in terms of how the chemo was doing, checking. I remember my potassium levels were always low, and magnesium. I mean, it was like an ongoing thing with having so much infusions because of what was being depleted from me with all of the treatment. So there were so many different laboratory tests, like all the time. And then following 7+3, there were consolidation treatments, which, you know, more and more blood work, and then ultimately blood work revealed that the AML, in fact, was creeping back in, and that's when we decided to go the transplant route.

From there, there were even more tests, more bone marrow biopsies, and once we went through with transplant, it's like I was getting blood work. Oh gosh! Like, sometimes four times per week. It was a lot. You know, as Phyllis talked about checking chimerism, I mean, I was eager to know after transplant, like, has the donor taken over me? Because in my mind, I really didn't want my own blood anymore. I wanted the donor's blood to… or stem cells to really take over because I understood that that would mean that I had achieved complete remission permanently, and the leukemia was wiped out of my blood. So I found myself monitoring my blood work, my lab results all the time on my chart, to see exactly what was going on.

I found myself researching everything, all of the blood work, all the terms, and things like that. So I kind of became a pro about lab results and blood work and things like that.

**Jennifer Gillette:** Are you still there, Mendya?

**Mendya Griffith:** Yes, I'm still here.

**Jennifer Gillette:** Oh, I'm sorry. You might have cut out a little bit. I apologize.

**Mendya Griffith:** Okay, I'm sorry about that. So now that I am about three, not quite three years post-transplant, my frequency with lab work has decreased. I started out like maybe after the first year, I was going every maybe three months, and now I'm down to maybe like every six months. Ironically enough, I actually have an appointment today at 3:40 to see my oncologist, hematologist to discuss some lab work.

**Jennifer Gillette:** Mendya?

**Mendya Griffith:** Yes, hello.

**Jennifer Gillette:** Oh, I'm sorry. It broke out again. I apologize.

**Mendya Griffith:** I know it's breaking up a little bit. I heard that in the beginning of the call. But yes, does anyone have any questions for me about my experience with understanding lab results?

**Jennifer Gillette:** Well, that would probably be a good time for Carly to tell our callers if they have any questions at this time that they can reach out. Can you tell them how to do that, Carly?

**Operator:** Certainly. At this time, if you would like to ask a question, press star followed by the number one on your telephone keypad. Again, that's star followed by the number one.

Your first question is from Keith.

**Keith:** Can you hear me?

**Jennifer Gillette:** We sure can. Welcome, Keith. Go ahead with your question.

**Keith:** Thank you. I'm two years post-transplant, and my provider has not done any chimerism study on me. Is this common or rare?

**Phyllis McKiernan:** Well, hi, Keith. This is Phyllis. You had a transplant from a donor?

**Keith:** Yes.

**Phyllis McKiernan:** Typically, chimerism studies are done. Perhaps they were being done, and you weren't aware. I'm not sure. But I would certainly ask your provider about your chimerism studies, for sure.

**Keith:** Thank you.

**Mendya Griffith:** Yes, and Keith, if I may add, because I am a survivor myself. I honestly inquired before my provider had the opportunity to educate me. I had already done research and found out the importance of chimerism tests. So I'm sure they were already being done, but I would recommend also that you ask, like if you inquire, so that you could be pointed in the right direction.

**Operator:** Your next question is from Angela.

**Angela:** Hi. I was just wondering if it's being recorded or if there's materials that cover all of this?

**Jennifer Gillette:** Of course. And thank you for your question. Yes, this is going to be recorded and put on our website within a couple of days, as well as we put a transcript with it. And I know there was a lot of terms being shared today, and if you want to check that out when it's on our website at nbmtlink.org. Again, give it a couple of days, but we'll have it up there for you, okay? I also can send out a link to people when I send out the survey today. It won't be up yet, but I can let you know where to look for it on our site as well, if that's helpful.

**Operator:** Your next question comes from Pam.

**Pam:** Hello, this is Pam Mitchell. I'm in Chicago, Illinois. And unfortunately, my stem cell transplant actually failed, even though I'm on some kind of targeted drugs because I have two bad genes, and my leukemia cells are less than 1% from the bone marrow. Now, I was diagnosed with this thing called cachexia. I don't know how you pronounce it. And I wanted to know, Phyllis, if you've ever seen a patient who had it but was given another transplant? My stem cell doctor said… I just asked for a milestone, not to rush into it. He just said, "No, you can't have one. You wouldn't survive it."

**Phyllis McKiernan:** So I'm sorry, Pam, that you're going through that for sure. You say your diagnosis is called cachexia?

**Pam:** Yes.

**Phyllis McKiernan:** So cachexia is a syndrome where you have significant weight loss and muscle wasting. So, yes, there are situations where we can do a second transplant. It depends on a number of things. The length of time between the last transplant and when we would consider another one, the intensity of the chemotherapy and radiation that you received, the toxicity to your organs, and your clinical status now, your performance status.

But with cachexia, it's difficult because if you don't have the stamina and the reserve, then it may be difficult to survive a second transplant. So I would definitely be working with your oncologist, your nutritionist, to try and build up your reserve and then continue those conversations. If they can keep the disease at bay until you are more recovered and are feeling better, then it is a possibility. Sometimes we need to do that because if we want to delay the time between the first transplant and the second transplant, then we can use those medications to target the mutations and kind of keep them in check until we can get the patient ready and well enough for a second transplant.

**Operator:** Your next question is from the line of Stephanie.

**Stephanie:** Hello. Thank you so much for sharing your story. I'm about a little over two years post-transplant. And although it's not specifically about blood work question, I didn't know if you'd be able to answer how and if you got back to work afterwards, because I'm kind of in that process. Just didn't know if you had any tips, again, about rejoining the workforce after being out for a couple of years. Thank you.

**Mendya Griffith:** Yes, I can answer that. As a survivor myself, I started, and I actually work as a surgical technologist, so there are challenges with arthritis and things like that. You kind of have to listen to your own body and monitor your own symptoms along with your provider to see if you are well [indiscernible] or can tolerate like standing on your feet all the time, if you're dealing with any graft-versus-host disease. I know I had some of my digestive system. But I would definitely encourage being active and try going back to work, definitely. It may be easier if you had a position where you're sitting more frequently than standing. But yes, I went back to work within, let's see, two years. Two years of transplant.

**Operator:** Your next question is from the line of Steve.

**Steve:** Did she say Steve?

**Jennifer Gillette:** Yes, Sir. Hi, Steve.

**Steve:** Okay, I'm Steve. I'm out in Denver, and I am looking at a transplant in the next… how long it takes to find a match. So this is all kind of new to me. Going back to thinking what Mendya mentioned about her research, I was wondering if she has any suggestions from sources to do research on all this. You know, on all these tests and the things that you looked at.

**Mendya Griffith:** Yes. When I was preparing for transplant, I posed a question to my team about having an umbilical cord transplant. So I went over… I got a plethora of information from Blood Cancer United's website and also NMDP because it was challenging to find a match for myself, and I ended up having an umbilical cord transplant which was processed through this company, Gamida Cell.

So yes, I would definitely look on the NMDP website because they have a wealth of information about transplant and Blood Cancer United. And don't hesitate to, you know, have open, honest conversations with your transplant team to see what your options are.

**Operator:** Your next question is from Victoria.

**Victoria:** Hello.

**Jennifer Gillette:** Hi, Victoria. Welcome.

**Victoria:** Thank you very much. We are day 28-plus from my son's second stem cell transplant. And I think the question that I have is this. On flow cytometry, whether it's drawn peripherally or taken as a bone marrow biopsy. Would there be a difference? I had noticed that on some of his test results that the flow would show that there was no evidence of disease, yet when we went to the PET and stuff, there was evidence as far as tumors. How does that work?

**Phyllis McKiernan:** Well, you know, it depends on how much of the tumor is secreting into the blood, and sometimes the flow cytometry can pick it up, and sometimes it can’t. It's not an ultra-sensitive test, the flow cytometry, but it can, you know, and it can vary from the bone marrow to the peripheral blood. It can look a little bit different. And yes, the flow cytometry can be negative. even though you may have tumors that are developing depending on the disease. So that's why you have to look at kind of everything, you know, and not just take one test.

**Victoria:** Right. Okay. Thank you.

**Phyllis McKiernan:** All right. Good luck to your son.

**Victoria:** Thank you. Thanks.

**Operator:** Your next question is from Angela.

**Angela:** Hi again. I just had a question about mental health resources. I know you offer peer support, but maybe I want to ask, sorry, Mendya, about how she handled it through her process.

**Mendya Griffith:** That's a good question because that's very important. So I know at my facility, and this should be the case with each facility, there was psych oncology, and she provided excellent service. For one, she helped me understand the disease more. You know, I was very comfortable talking to her about my mental health and my emotional well-being, and just being diagnosed all of a sudden with such an aggressive form of cancer. So she helped me to not only understand, but she was a source of comfort for me to talk about my day-to-day, just coping.

She helped me understand how to cope and basically to not have the fear-mongering over lab results, because we were getting so much blood work done so frequently, and there was like anxiety. So she helped me deal with the anxiety, stress, and sometimes depression. So I would definitely encourage each and every body that's going through any form of blood cancer to seek psych oncology at your nearest facility. And it is typically covered by insurance. I know mine was because it was a part of like post-transplant care. It's vital, you know, for someone to help you navigate just through the whole process and the mental toll that it takes. You can also help determine if you may need, you know, antidepressants or just things to help you get through the whole process.

**Angela:** Thank you, Mendya.

**Jennifer Gillette:** I'm sorry. I just wanted to add, too. Sometimes, at different centers, there might be different terms for that person, too. A lot of centers might have an oncology social worker, and they're trained as well. So, a psych-oncologist or social worker. Also, Blood Cancer United has support groups that I highly recommend, as well as BMT InfoNet, or like the programs that we have, too, where you can talk to other survivors. Even in our arts programs, talking to other people going through it can certainly help with the mental health aspect. Or Gilda's Club and the wellness community, they also have groups. BMT InfoNet also has a wonderful search tool on their site where you can look for providers that specialize. Because if you're looking for a counselor of any sort dealing with the cancer journey, it's good to have someone that has gone through this process and understands it. For example, just like with fatigue, if someone is going through fatigue and they go to a counselor that's not familiar with the cancer process, they might focus on things that are more like, "well, if you get enough rest." And we all know that in the cancer world, it's not always, you know, we certainly like to look and make sure that you're getting good quality rest, but fatigue with cancer treatment is a very common side effect that could be involving many other factors. So, if you go to BMT InfoNet, you can look at different providers that might specialize in your area and understand the process.

But Carly, are there other questions on the line?

**Operator:** Your next question is from Karen.

**Karen:** Good afternoon. Thank you for this marvelous information. I am 6-plus years post-bone marrow transplant and doing fantastic. One of the questions I had for Phyllis was I have MDS, and the lab that you're speaking about, am I correct in making an assumption that they would be… they're all similar with the AML and the MDS?

**Phyllis McKiernan:** Are you talking about in terms of bone marrow and complete blood counts, things like that?

**Karen:** Yes.

**Phyllis McKiernan:** No, we're looking for the same things with MDS. Making sure that the cells are looking good, that they're functioning appropriately. That there's not a decrease in one of your cell lines, either your platelets, your blood count, your white blood cell count, your red cell count, all those things. And also, in MDS, you can develop blast cells as well, as you may be aware of. But being six years out of transplant, that's wonderful. Congratulations.

**Mendya Griffith:** Yes, congratulations.

**Operator:** Your next question is from Greg.

**Greg:** My name is Greg. I have a little speech impediment from my stroke, so bear with me. But I'm pushing my fourth year in remission from multiple myeloma and a stem cell transplant. And I had to be re-vaccinated for all kinds of diseases. And the first time I found out the Hep A and B vaccination didn't convert, and my current care physician had a titer test done to see if it converted. And it did, but the test showed that I needed the pertussis vaccine and a measles vaccine. So, do you recommend at some point getting a titer test to make sure that the vaccinations converted? I also had a polio booster. And why do some diseases, the resistance or antibodies, stick with you like chickenpox and rubella, and some don't, like pertussis and measles?

**Phyllis McKiernan:** Well, yes, in terms of the question about titers, you can have titers drawn intermittently. You know, we don't typically do that here. We give the vaccination series recommended by the American Blood and Marrow Transplant Society, as well as the CDC. And they do recommend boosters of things, such as measles, as well as pertussis, pneumonia, things like that. So we will just go ahead and continue those vaccination series. We do measure titers and immunity to chickenpox because we can do that. And then there's different vaccines that you can give depending on what your immunity is. You know, why you develop immunity and antibodies to some diseases versus others, I think that's beyond my scope. I really couldn't answer that question. But knowing… but what we know is that you can develop antibodies, or you can develop immunity, and knowing what that is helps us to determine when is the best time to give you your vaccines and when you would need your specific boosters.

**Operator:** Your next question is from Maura.

**Maura:** Yes, I am 14 years post-bone marrow transplant for MDS, a blood cancer. And I've done quite well, even though I have GvHD. And I knew that I would be at a higher risk for other cancers to develop because of the preparatory radiation and chemo. And even though that hasn't happened, something unexpected happened. And about a year ago, I was diagnosed with heart failure. And I'm thinking or going to ask, how standard is it? And maybe it should be standard for individuals like ourselves who are post-transplant to be monitored with cardiology or… see, I wasn't symptomatic. My symptoms for the heart failure were not significant. I never had an EKG or, you know, my oncologist, whom I saw regularly, and she had no reason to really be concerned until I had an EKG in my doctor's office.

And it showed, you know, some significant abnormalities and weakening of my heart. So now I'm being followed for the past year of my cardiology, and I would just like to advocate. I could be an advocate for this aspect of the cardiac effects of treatment for various types of cancer. Yes, any comments about your experience and whether that is, could that be more commonplace that it's recommended to have maybe an annual EKG?

**Phyllis McKiernan:** I mean, in certain cancers, it is recommended when you have certain types of chemotherapy that can potentially hurt the heart muscle, such as Adriamycin after a certain dose and things like that. So you would be getting frequent cardiac evaluation. In terms of secondary cancers, they're very… we see them, but they're not terribly common. I wouldn't call them common, but we do see them. The most common cancers that we see after transplant would be skin cancers. Skin cancers, and if you have a lot of GvHD in your mouth, potentially oral cancers. So that's where we recommend annual skin checks, and we recommend regular dental evaluations to look at them, to evaluate any lesions.

Getting back to the cardiac, I mean, I don't know what your other history was in terms of before the transplant, what treatments you had, what other medications that you had. I mean, certainly, people post-transplant are at risk for developing some of these issues, pulmonary issues, cardiac issues. So we do recommend an annual physical and examination by a primary care doctor, knowing that you had a transplant. Whether an EKG would pick these things up is hard to tell. So, I do appreciate that, you know, that's a concern for sure. But, you know, certainly keeping diligent with your primary care doctor and follow-up can be helpful.

**Operator:** At this time, there are no further questions. I'll now turn the call back over to Ms. Gillette for any closing remarks.

**Jennifer Gillette:** Well, I would just like to thank both of our speakers. We appreciate you so much for being here today and answering so many questions. I have one last question for Mendya. I know you touched on it with the mental health question. But you yourself, on those days where you were nervous about follow-up appointments or follow-up testing or just any of those things, what were some of the things that helped you those days the most that you feel just helped you cope with all the many testing and follow-ups that you needed?

**Mendya Griffith:** Sure. That's a great question. So, not to make light of the severity of AML, because there are some things that are out of our control, but the one thing that is in our control is mind over matter. To honestly expect the best outcome, to have positive thoughts, to speak words of affirmation. And I got to be honest, I'm faith-based, so a lot of prayer. Just maintaining a peaceful and I can't stress positivity enough. Like, don't go into your appointments for lab work and for, you know, meetings with your oncologist expecting the worst. You know, because we all know, like, stress and the inflammation, I mean, things just go haywire with stress. So, I would say just be positive, you know, that was the way I approached everything.

I tried to, I've read a lot of books. I, you know, I did a lot of talking to God. I talked to my therapist, we call her psych oncology, but you know, it could be social work. And I just expected the best outcome. I continued to work out because that helped mentally relieve a lot of stress. And I did things that allowed me to feel hopeful. So I never allowed myself to go down a dark path like, oh, you know, transplant wasn't going to work out. I just always expected life.

**Jennifer Gillette:** I really appreciate that, and I'm sure there's a lot of people listening closely on that. We recognize that it is very hard going through all these tests and follow-up, and we hope today that some of the things that were shared with you help make that journey a little easier for you. And I also want to remind people too that a bad test result does not mean a bad future. Just like Phyllis said earlier, they look for trends. Things can go up, things can go down, complications can happen, but it doesn't mean that determines your outcome.

But again, I want to thank both of our speakers for being here. I want to thank all of you for making the time for this call today. We will be sending a survey out if there's anything we can do as far as any future programming you want to hear about, or anything you can do to try to enhance your experience. We certainly pay attention to every thought that is shared with us. And if there's anything else we can do to help you on this journey, please feel free to reach out to us because that's what we're here for. We hope everyone has a good day.

**Mendya Griffith:** Thank you.

**Phyllis McKiernan:** Thank you.

**Operator:** This concludes today's conference call. Thank you for participating. You may now disconnect.