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Executives:

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Operator: Thank you for standing by. My name is Eric, and I will be your conference operator today. At this time, I would like to welcome everyone to the Rebuilding Strength and Stamina after a Bone Marrow Stem Cell Transplant.

All lines have been placed on mute to prevent any background noise. After the speaker's remarks, there will be a question-and-answer session. If you would like to ask a question during this time, simply press star followed by the number one on your telephone keypad. If you would like to withdraw your question, press star one again.

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

Jennifer Gillette: Thank you so much, Eric, and thank you, everyone, for being here today. Yes, I'm Jennifer Gillette, I'm the Staff Social Worker at the National Bone Marrow Transplant LINK. This month's program will focus on Rebuilding Strength and Stamina after a Bone Marrow Stem Cell Transplant.

A special thanks to our generous sponsors, Blood Cancer United, which, in case you haven't heard, is formerly the Leukemia and Lymphoma Society, Incyte, and Johnson & Johnson. We also thank our esteemed LINK partners because we could not do all these great programs without you.

Just so everyone knows, a great outline for today's program. One, I'm just going to take a couple of minutes to tell you about the National Bone Marrow Transplant LINK for anyone who might not be familiar with us. And then we'll hear from our first speaker, Courtney Bush, a physical therapist and certified lymphedema therapist at the Fred Hutchinson Cancer Center in Seattle, Washington. And then we have our survivor speaker, Laurie Perkins, a recent multiple myeloma survivor, who will share her story and how she implemented physical therapy before and after transplant, and how she is enjoying her life today with extensive travel, energy, and strength. And then we will open up the floor for questions and comments.



So, for those who might not be familiar with the National Bone Marrow Transplant LINK, our mission is dedicated to helping individuals and their families from diagnosis through survivorship. We provide resources, support, and education. Some of those programs are like this Lunch & Learn call you're on. Sometimes we talk about different diagnoses of cancer, sometimes different treatments, survivorship issues, psychological or social supports, and all kinds of things there. So monthly, we have that program. We also have our Marrow Masters podcast, which is almost at about 39,000 downloads. If you have not checked that out yet, I encourage you to go to where you listen to podcasts. As well as there, you can find them on YouTube and everything. And those are on all kinds of things like chronic graft-versus-host disease, survivorship, treatments, and more. We also host our annual fall webinars, which we have one coming up. Corey Cutler is going to be joining us, and we will be talking about GvHD. And I'll share more about that at the end. We have our Coffee Klatch program, which is basically like a support group. And we have one of those coming up in November as well. And we have our Peer Support program, where you can talk to other survivors who have gone through this and are doing well. We have our Celebrate Second Birthday's program, our Survivors Thrive Book Club, our Healing Arts program. We have an active Facebook with daily inspiration and relevant tips, we have books, referrals, and we provide emotional support. So if you're interested in any of these things, I'd like you to go to our website or give us a call. Our website is nbmtlink.org. Or like I said, you can give us a call, and we'd be happy to help you out.

Before we begin today's program, I'd like to review just a couple of housekeeping items. One, when it does come to the question-and-answer portion, we ask that you keep your questions as concise as possible so we can answer as many as we can. Also, please know that we will answer as many questions as we can today, but due to limited time, we might not be able to get to them all. Also, please note that the information provided in this program is meant to stimulate conversation with you and your own healthcare provider, and is not meant to replace your individualized medical plan.

So now onto the educational part of our program. Our first speaker, Courtney Bush, is a graduate of Regis University in Denver. She is a physical therapist and certified lymphedema therapist at Fred Hutchinson Cancer Center. She is a board-certified clinical specialist in oncologic physical therapy and currently serves on the Board of Directors for the American Physical Therapy Association's Academy of Oncology Physical Therapy. Courtney works with patients receiving stem cell and bone marrow transplants, both inpatient and outpatient. She sees patients both pre- and post-transplant, helping them optimize functional mobility, independence, and physical recovery. Courtney will focus on rebuilding and regaining stamina and physical challenges, such as fatigue, steroid myopathy, and chemotherapy-induced peripheral neuropathy. Thanks so much for being here with us, Courtney.

Courtney Bush:

Hi, Jennifer. Thank you so much for having me and that lovely introduction. I'm so excited to be here. This is a passion of mine. I've been working with patients receiving stem cell transplants for almost as long as I've been a physical therapist.



I've worked with these patients both in the hospital, if they have been admitted for a hospital stay during their transplant, or just incidentally found themselves in the hospital for something like a neutropenic fever, which can happen pretty frequently. And I spent about a year and a half in acute care in the hospital, where I started treating this population and just absolutely enjoyed the wins that we were able to have when patients learned more about what they could be doing to help keep their strength up and keep their body healthy through their transplant process. And I then transitioned over to here at Fred Hutchinson Cancer Center, which was Seattle Cancer Care Alliance at the time. We've had a little rebranding in the last couple of years. and began to get to work with these patients on a longer-term basis, and see what goes on in the later phases, and how that rebuilding process can look and what is useful and valuable as patients do start to get back to some of their more normal life and want to rebuild their strengths. So I thought what I would work on today is just sort of an overview. I imagine we have people tuning in who are on all sides of this possible journey. Maybe someone pre-transplant thinking about it, planning it. People possibly who've been through it already and looking for more tips where they're at, caregivers, providers, potentially. So I want to kind of speak to all angles. So I'll give a little bit of both sides of it. And I hope that it's helpful no matter where you find yourself today.

So the transplant journey from a rehab perspective, kind of, I think of it like if you've ever had like or heard of a friend having a total knee replacement or a joint replacement surgery and they might be offered prehab or have to go take a class ahead of time to learn about what they'll need to be doing when they're having their rehab and how they prepare themselves for it first. We try to do that with stem cell transplants here, both in our inpatient practice and here in the outpatient clinic, where in a perfect world, we would see every stem cell transplant candidate prior to their transplant and be able to do a physical assessment beforehand to see what their own personal functional baseline kind of looks like. And we don't get to do that with everyone, but it's our goal. It's our dream, if only we could. But we do get to see many patients before they even have a transplant. And so if you find yourself on that side of it, or you are tuning in on behalf of someone who is preparing for a stem cell transplant, it's helpful to know ahead of time what to expect and to start thinking about the value of a consistent program before you find yourself in the throes of the side effects of the stem cell transplant. Because it's a lot harder to hear that information when you're in the worst moments of it and start an exercise program that day is a tough challenge. And I've been there with a lot of patients where I'm trying to be that motivation to say, I know it's hard, but we can do a little bit. And what I find is patients who receive education and learn this ahead of time really have a lot more sense of self efficacy to say, I know this, and I know how important it is and I've already started. So it makes it, I think, a little easier through the process to keep an exercise habit going, which is one of my greatest tips for anyone in the stem cell transplant process is to start early and be kind with yourself. It doesn't have to look like a lot. One of our favorite phrases we throw around a lot is something called exercise snacks. So using any moment in the day, even a few minutes at a time, to be able to just do a little bit of something. And I'll give some examples of some of my favorite somethings as we move a little along here. But it can be a little bit at a time, bite size exercise moments throughout the day until you build that stamina.



And then over time, those exercise snacks start looking like whole meals and you start exercising more like you used to exercise in the sense of going for a longer walk or maybe doing a little strength training exercise at home or at the gym or with a friend or a family member to really feel those muscles starting to engage.

So as the transplant picture overall, starting early and getting a sense of what is important and what is a meaningful strength. And some of those tests I do are things like being able to stand up out of a chair without using your hands is a real strong indicator of a person's balance as well as their strengths. And that sometimes is a test that people can't achieve at a certain stage, and some things that contribute to that, a big factor is something Jennifer did mention, is steroid myopathy. And one of the treatments for the side effects of the transplant process. So not everybody will have this, but many patients do, is a treatment of high-dose corticosteroids to treat inflammation, basically, to bring down some of those urgent, acute side effects of transplants that tend to come along with the graft-versus-host disease. And that steroid treatment can actually add to weaker muscles. It can take away some of that muscle strength in a more rapid fashion than it typically would be happening. And it's mostly in your proximal muscles. So that means muscles really close to the body at the top of the legs and at the top of the shoulders, those hip and glute muscles, as well as shoulder muscles, can become weaker. So some of the tests you can think about for yourself, if you are thinking about this in your own self or for a family member, is how they get up out of the chair? How well can you get up out of bed? Are you feeling weak when you're trying to move your body weight up or down? And then to strengthen that, starting small. Using small things is really the critical component because cancer-related or chemo-related fatigue, you'll hear it both ways, is another major factor in the stem cell transplant process. I've seen numbers in the research anywhere from 75 to 99% of patients undergoing any kind of cancer treatment or even just a diagnosis report that fatigue is a major factor in how they go about their day, in their limitations, and how they're able to address things they need to do. And I think that kind of goes even stronger in the stem cell plant process. It is a primary driver for patients to face deconditioning that there's just a profound fatigue. The body gets put through a lot, and it is a really, really intense recovery. It's a lot on the body, and then it's a slow process, and it can be frustrating. So thinking again about that exercise snack, I like to help my patients think about what is a high value exercise. If I'm going to spend two, three minutes at a time on something, what's going to be really meaningful to me and how am I going to use that to my best advantage to maintain my energy and get something really valuable out of the time I'm spending every time I decide I can spend a few minutes on doing some exercise for my body.

So, thinking about the exercise snacks, thinking about weakened muscles, there's also an element of safety. And I want to give just a couple of examples. These examples, when I give examples for exercises specifically, blanket examples that are safe for most people, but I would encourage everyone who may be in this position, if you aren't already seeing a physical therapist, to find out if you can, if there's anyone in your community who can help you with personalized education.



There are some things we think about to keep our patients safe when we talk about exercise, and that requires a personal look, because I don't...I can't see what everybody's blood values and bones look like today on the call.

So couple things for safety. If you're thinking of starting exercise and you haven't seen a physical therapist yet, look into with your oncologist whether you can ask them about your blood values. And these are probably numbers you know really well. If you're in this process, you've learned this stuff, but your platelet counts and your red blood cell counts have critical values that we take into account every time we see a patient, and we take our teach our patients how to look at these numbers themselves. If things are so low that it's not safe to exercise. Those are limits that people need to be aware of when they're starting a program, especially if it's something new you're starting. So looking for those blood value numbers, they exist in your institution. You can look at what your doctors use and ask about what are my blood value limits for exercise. And that's an important thing to get a handle on before you start any program. A quick, easy reference is if you're low enough to need a transfusion, don't exercise until you've received your transfusion. And if you tend to run low and require a lot of red blood cells or platelets, please, please touch base with a physical therapist before you start a program so they can make sure you're guided safely.

Another key piece is bone health. There are certain cancers that end up in the stem cell transplant population, like multiple myeloma, which can tend to metastasize into the bones more frequently. And when we have those types of outcomes, we look really carefully at our patients' imaging and their status, and we often teach them certain modifications, especially if there's anything happening in their spine. If there's anything like that going on, you might have heard the phrase no BLTs, no bending, lifting, twisting. That's a pretty generalized spinal precaution that we can start with for most patients and build upon from there.

So just some safety information, because I want everyone on the call to start a safe and healthy program if that's what you're looking to do. If you have complications like this, and this sounds familiar to you, I would absolutely encourage you to look into your community for a physical therapist who can help you on the journey. Some ideas that I do like for exercise that are generally pretty safe for most folks is a real simple one. It's the test I mentioned. Trying to stand up out of a chair. If you have a hard time with that, I have patients sit on the edge of their bed, which tends to sit a little taller and easier to get up and down from, just that seated edge of bed with your feet planted normally, maybe something in front of you or a family member nearby to make sure you're safe and stable, not dizzy or lightheaded. And try sitting and standing five times and not using your hands or putting them very lightly down, but letting your legs do the work. That sit-to-stand exercise helps us train our balance and our strengths. And it's one of our go-tos for most patients. And it's very functional because it is the actual thing we're trying to test and make stronger and more independent. So we love a fit-to-stand exercise. Almost everybody gets it at some point in that journey, and it's truly a really, really functional, valuable thing to spend time on. Walking. Walking is wonderful exercise. It helps build your stamina. It does help build endurance. One of



the high reported things I hear from patients is I'm too tired to walk. I can't go far enough. And so when those things are being reported, I encourage people if they're safe to walk, they're, you know, not falling or having other side effects, but walking is a safe thing to do. It's just very tiring.

To start small, start in the house. You can start walking laps around your kitchen island for, you know, one minute, two minutes, even that short distance makes a big impact. impact if you start to add it up throughout the day. And that's a thing that I teach patients is exercise is additive. You can do two minutes in the morning and two minutes before lunch and two minutes before dinner, maybe another two minutes before bed. And you've added that all together. And that counts in small chunks like that. And I think that sometimes surprises people because we get a picture in our head of exercise of I have to go to the gym and I have to sweat and breathe heavy and otherwise, why was it, how was it worth it? But truly, any intentional movement of the body for the purpose of exercise is exercise, whatever it is. So walking even in short bouts. Utilizing whatever assistive devices have been recommended to you. A walker sometimes gets brought up with a hospital stay. Patients have a harder time with their balance or their blood pressures, and a physical therapist might come along and order you a rollator, a front wheel walker, the one with the seat and the brakes. Those are one of my favorite tools, actually, because that gives you access. If a person has a hard time walking far enough to go into the community, community and somebody puts a walker under their hands, they now have access to the community that they didn't have access to before. And I always read reiterate to patients that I don't often give a walker that I anticipate someone to have to use forever. It's a bridge. And so if you've been encouraged to use help assistive devices or ask for more help, the bridge there is what's important. That's the thing that's going to liberate you towards more activity so that you're able to do more and over time walk further distances before needing to sit on that seat and rest. And then every time you add that training round of walking that five minutes to walking that six minutes to walking, that seven minutes. You're building your endurance just like a marathon runner, learning how to run five minutes, you know, five miles to seven miles to nine miles. You're training for your own personal marathon, even with a walker, even with a cane, even with really short bouts and long rest breaks. It's all worth it. And I think that's the biggest message I always try to help patients really believe and feel is those little steps are so valuable, and I think sometimes that can be the hardest place to start is in the small moments and the little things. But those are the stepping stones to those bigger goals and to those larger walking, taking a walk at the park with your children or grandchildren and getting back to those group activities you enjoy. That's really it, is we start small, and we stay consistent. And so consistency with day-to-day exercise in those small bouts, the way that that adds up is truly phenomenal. And it just takes that hard part, that beginning to get through that and get to that place. But I see value in it every day. I see patients going through this process daily, truly, and whatever step we're at in the process, when can get on this path and stay consistent and do small things and do them consistently, that's where we start to break through and push over those plateaus. So I think that's my largest picture.

I did also neuropathy was on the on the handout. So I'll speak a little bit to the chemotherapy induced peripheral neuropathy. It's a mouthful. And it doesn't happen to everybody. But I in some cases are more likely than others. And it can be anything



from a nummy, tingly sensation in hands and feet is usually how it starts, to feeling like your socks are balled up in your shoes, not really painful or, or anything like that, but just what is this weird sensation I can't get rid of. And what it really does is it impacts balance. And I mentioned falls earlier, balance and falls is a major part of what we're doing. And that's the walker situation and learn, you know, asking for help sometimes and you know, the hard parts. Neuropathy is another level of that where if we don't feel our hands or our feet specifically, if we don't feel our feet well. If our feet feel weird to us, if we can't tell where they are in space, we have a hard time to balance, right? And it's not a hard stop that, well, that's happened, and you'll never be able to balance again at all. But we need to start to train it. And when I have patients with neuropathy, there can be some things done at the neuropathy site to say, what if we do some light massage to help calm down the nerves or retrain the nerves to feel normal sensations. Sometimes that helps a lot, and patients can do their own self-massage or have a caregiver massage their feet gently just for a couple of minutes on each foot to bring some circulation and blood flow it helps, and it's been shown to help. And then I help patients train their balance. And this is a thing that is really valuable to have someone with, like a physical therapist, help you with because it can be a lot of different elements of balance are involved and it can be hard to know where to start and how to do it safely. So one of the things I test with people is can you stand with your feet totally together and not holding on to any surfaces? Can you start to stagger your feet just a little bit, one a little bit ahead, one a little bit behind? These are tests that are truly safest and best done with a professional watching and helping you and giving you guidance and feedback. And then learning how to train your balance can be really valuable as well. Walking trains your balance. If you're out on a walk and you're looking ahead and using tall posture and breathing deep breaths, you are helping yourself balance. You're helping yourself build that balance and awareness in your postural chain. And I would recommend if you're having neuropathy and you're like, "Wow, that sounds like my feet," check in again, see if there's a PT in your community and your network who can help you test your balance and see if that's actually impacting things. Because I think sometimes we don't put the two together that having those weird sensations in your feet might actually be part of that difficulty of getting out of a chair and feeling your balance as you shift your weight around. And there's ways we can improve that. We can start to use better balance sensations from our knees and our hips and our spine, we can build that strength and balance up the body to help compensate for the feet. And exercise truly helps improve neuropathy. If we're moving more and getting better blood flow and getting more circulation, our neuropathy tends to improve over time as well. So there's a lot of layers. It's such a big topic, and I could talk about it all day. But I think I've hit most of my highlights. So I want to I want to recede the floor. I want to give the floor to Lori, so she can share a little more.

So Jennifer, I think for now, I'll pause and let us hear from Lori.

Jennifer Gillette:

Thank you so much. We really appreciate you, Courtney. A lot of great information. And yes, we're going to move on to Laurie. Laurie Perkins spent 40 years in Alaska and now lives in Edmonds, Washington. She's a former auditor for the governor's office in Alaska and was a division director in the State of Alaska's Department of Revenue for many years. She moved to Washington State to be near her grown grandchildren or her grown children and perfect grandchildren after losing her husband in 2019. Laurie was diagnosed in late 2023 and had a bone marrow transplant in June 2024. She's



currently in remission, and this summer she is one year post-transplant. She sailed the coast of Croatia, hiked the Irish coast, and will sail the British Virgin Islands in January 2026. So she is full of energy and life, and I can't wait to hear what she has to say. Thanks for joining us, Laurie.

Laurie Perkins:

Oh, thanks, Jennifer. Yes, and thanks for giving me this opportunity to speak today. Peggy asked me to speak about the strategies I used to rebuild strength and stamina before and after my stem cell transplant, and that's generally what my talk is centered on.

I thought I'd start today with a little bit of my medical background. In 2019, as Jennifer said, I was diagnosed actually with MGUS, which is a medical condition that is sometimes a precursor to multiple myeloma. Four years later, in 2023, that progressed to multiple myeloma. And last summer, in 2024, at age 69, I had a stem cell transplant. When I was diagnosed with MGUS in 2019, I knew that I might eventually develop multiple myeloma and need a transplant. My awareness of my physical condition was heightened, and I knew I had to be and stay as healthy as possible so that if I did develop multiple myeloma, I could fight it as effectively as possible. At that time, I had a nagging back problem. I had had it for years, spinal stenosis, which was not related to multiple myeloma. I periodically went to physical therapy as the pain would come and go. I always had good results with my physical therapy. I apologize today. I'm having seasonal allergies here and my throat and voice sound a little bit scratchy. But anyway, when my condition graduated from MGUS to multiple myeloma, I immediately switched my physical therapy provider from a local practice to the gynecologic physical therapy department at Fred Hutchinson Cancer Center, where I had just been diagnosed with multiple myeloma. I think that was the single most important decision I made that affected regaining my stamina after the transplant. During the six months between diagnosis and stem cell transplant, I really focused on getting as strong as I could. I knew I would be very weak after the transplant and that my recovery would be quicker and easier if I was as strong as possible going into it. So during that six months, the great physical therapists at Fred Hutch not only addressed my chronic back pain and age-related arthritis, they also started strength training and exercises that would build core strengths and leg strengths. Courtney just discussed a few of those exercises. I really believe that helped me bounce back much quicker after the transplant. The physical therapists at Fred Hutch were familiar with conditioning medications I was receiving prior to the transplant, so they also addressed side effects to those drugs with physical therapy. For instance, the Revlimid I was taking caused my neuropathy to get worse. It was very helpful to have physical therapists who were familiar with the drug and its side effects. As Courtney stated earlier, balance and neuropathy are real issues with both Revlimid and a stem cell transplant. The physical therapist at Fred Hutch helped me with both of those issues.

So, I had a transplant in June of 2024, and I won't lie to you, I had a rough time. I was in the hospital for 16 days and contracted an infection that left me weaker than I should have been, but I know it would have been much worse if I had not had had the physical therapy leading up to the transplant. While in the hospital, my son made me get up and walk several times every day. Those walks helped me to regain my strength. Eating was also difficult. Everything tasted terrible. I lost 25 pounds. I had to force myself to eat and drink because I knew I would get stronger, faster, if I did.



Prior to the transplant, my oncologist and physical therapist had emphasized how important it would be to move as much as possible once I got home. My physical therapist recommended I get an inexpensive seated pedal exerciser to use during my first days and weeks at home. This was an excellent recommendation. I ordered one before the transplant and had it ready to use when I got home. I would sit and pedal while reading or watching TV those first few days at home. It was really beneficial to have this portable piece of equipment those first weeks when the weather was bad or I just didn't feel like getting out. It was a good way to get the blood moving even when I had no energy.

After the first couple of weeks, I would try to walk outside even if it was a very short walk. My son helped me. At first, we would walk just a few yards, but persistence paid off. After two and a half months, I was walking about a mile three times a week. It helped mentally to get outside too. At first, I needed support, but my strength rapidly came back with the walking.

Another thing that helped me to recover quickly was frequent visits to the oncologic physical therapist at Fred Hutch. They were familiar with the challenges that transplant patients face with weakness and drug side effects. They were instrumental in giving me effective exercises that aided in rebuilding muscle strength that I had lost in the hospital and first few weeks at home.

Nutrition also played a big role in recovering my strengths. I didn't feel like eating much. You discover after a transplant that your taste buds are out of whack. Even water tasted awful. What worked for me was weekly visits to the Fred Hutch nutritionist. She had great recommendations for food and drinks to try. Everyone is different, but the nutritionists have heard what works for patients more than anyone else, and they give great tips. I followed her recommendations and found what worked for me, ginger ale and strawberry lemonade, in the early days. Later, I drank flavored water, gallons of it. I was told to drink at least 80 ounces a day, and that was hard at first. But soon I found the more I drank, the better and stronger I felt. The nutritionist's advice worked hand-in-hand with the physical therapist. I think combining both of those visits really, really helped me. I also heeded the diet the nutritionist recommended. I ate no uncooked vegetables. I stuck to canned fruit for the first weeks when my immune system was rebuilding. No raw meats or no rare meats, no raw sprouts or raw oats. Fred Hutch prepared me well with a list of what I could and couldn't eat, instructions on how to keep the house as clean as possible, what cleaners to use, and what I could and couldn't do myself. For instance, I like to garden, but made arrangements for all my plants to be cared for after the transplant. I think following these strict guidelines helps me to avoid the common infections that negatively impact the recovery time of some transplant patients.



And I had great caregivers who attended the transplant caregiving classes. My caregivers, which in my case was my family, pushed me to move, eat right, and maintain good personal and environmental hygiene, all critical factors in the recovery process. They assured that my living conditions were clean and safe. So all of these factors contributed to regaining my strength as quickly as I did the transplant.

Six months after the transplant, tests revealed that I was in remission. A year after the transplant, as Jennifer mentioned, I sailed the Croatian coast with my brother and hiked for two weeks in Ireland with my sister. That was in June of this year. I spent six great weeks in Europe. In August of this summer in 2025, I took my two grandsons to Florida for our annual trip to the beach, and I just returned from two weeks in Portugal and Italy with my kids and grandkids. I am still on maintenance dosage of Revlimid, and I do have off days, but my strength and stamina is almost back to my pre-diagnosis days.

So just to summarize what I believe helped me regain my strength after the transplant. Before the transplant, I prepared for it by trying to fix my pre-existing ailments. I sought physical therapy and saw doctors to address problems with my back and shoulder and arthritis. I also worked with the oncologic physical therapist for several months before the transplant. This was the best thing I could have done. They got me ready for the transplant by increasing my strength in preparing me physically for the transplant. They recommended equipment for me to use right after the transplant, and I had that equipment at home when I arrived home from the hospital. My physical therapist understood the physical challenges I would face, and they helped me prepare mentally for them. After the transplant, I think I improved quickly because I pushed myself to move more and more each day. I walked in the hospital, I used the seated peddler when I first got home, and I walked outside soon after, increasing my endurance daily. I heeded the advice of Fred Hutch and kept my living environment very clean and sanitary, hiring cleaners for my house and people to take care of my plants. I followed the nutritionist's advice on what to eat and how much to drink. I continued PT after the transplant and am still in PT. This has perhaps been the most important aspect of regaining my stamina.

So that's basically what I had to say today. Thanks for allowing me to tell my story, and I hope it helps.

Jennifer Gillette: Thank you so much, Laurie. We really appreciate you being here and sharing all these things that were so helpful to you. And Eric, could you please let our listeners know how they can ask questions?

Operator: At this time, I would like to remind everyone, in order to ask a question, please press star, followed by the number one on your telephone keypad.

Your first question comes from the line of David. Please go ahead.

Dorothy: Hi, this is David's caregiver, Dorothy. I sort of inadvertently pushed us early on, but I want to thank both of the presenters very much.



We learned a lot today. David is here with me. He had a stem cell transplant in August of 2024, so the timing is kind of similar to what's going on with Laurie. And we're especially encouraged about the travel she described because David loves traveling, and we very much hope to be able to travel again like we did. We have been to Europe, and we'd love to return. So we, David has received physical therapy, but he worked with a local physical therapist, and I don't think there's an oncology physical therapist locally and it's really important us to use local providers because we're 200 miles from our transplant center. So yeah, that I understand what you're saying that that would be really, really good. The problem with the local physical therapist was that he just didn't seem to...I don't know. I don't think he had the special expertise that might have been more helpful. David, what did you think?

David: I agree.

Dorothy: Okay.

Courtney Bush: This is Courtney. I would chime in here. Just as an alternative, something to think about. If you can't find an oncology specialist or there's no oncology PT near you, another alternative is to look for a clinic that has geriatric specialists. There tends to be a little more crossover with oncology because we often see oncology in older populations, and there's a lot of crossover in how we treat and study our populations. And it might be...they might have just a little more insight or sort of this specialized training in terms of pacing and what they're looking at in terms of function and balance. Sometimes the local orthopedic PTs are used to seeing more sports and ortho, and I might be projecting, I don't know what your guys' experience was, but I do find that sometimes seeing a geriatric clinic or a person who's studied or works with our geriatric populations can be just a little more in the same sort of vein as what an oncology PT is looking at. So that may be something to look at. I know it's really hard in rural communities. You may also ask if there is someone in your oncology office that is far away right now. We can't do telemedicine, but we are anticipating telemedicine to come back for physical therapy. And that may be an option in the future as things kind of settle down with getting us our telemedicine back with Medicare rules right now to maybe see if you could do a virtual visit just for education and some personalized education and training. But I do recognize that, and I'm sorry to hear that you don't have someone close to you. That is a limitation we recognize as a specialty, and we are trying hard to start to bridge the gap with more training out to rural communities.

Dorothy: Great. Thank you very much.

Jennifer Gillette: Thank you. Do we have another caller?

Operator: Your next question comes from the line of Steve. Please go ahead.

Steve: Thank you. I so appreciate both presentations, Laurie, my equivalent to your son is my wife, who's a certified trainer and unrelenting about staying fit. So my question is for your advice, Courtney.



So two and three quarters years ago, I had a transplant for adverse mutation AML. And now they tell me among the 10% who live this long, so I'm blessed. I have ongoing GvHD. I've had a few hospitalizations related to gut GvHD. But recently, I was hospitalized, surprisingly, last Sunday. In the middle of the night, my wife insisted that I go to the hospital by ambulance because I spiked a big fever. It turned out I had sepsis. But I was treated in time. Another two or three hours, they tell me, I would not have been in time. So I have ongoing steroids on board, including some for adrenal insufficiency, and then lots in the past. I have end-stage spine, no discs, but I'm mobile. And I have a PICC line currently. I can't lift anything over seven pounds. So now I lost my ability to walk briefly during this last episode. And I'm going to take your advice and get a rollator. But what advice do you have for me, Courtney, in rebounding? I've rebounded several times. I'm still, I can pass your tests, and I can walk 25 or 30 minutes now, but I've got a long distance to go. What's your advice on what I should do?

Courtney Bush: Oh my, what a story. I'm so happy to hear of your long recovery from your transplant and what a...I can't imagine that scary event of sepsis in the middle of the night. And I'm so happy you're doing okay and back on a space of how do I get strong again? You said something about your spine, and I missed what you said. What is happening in your spine?

Steve: I can't remember the long-term for it. End stage. I have no discs left.

Courtney Bush: Oh, okay. Like disc degeneration, but it isn't cancer. Okay.

Steve: No, I struck a little struck a little five inches, which is amazing. Still upright.

Courtney Bush: Shrinking humans. Yes, it happens for sure. You know, I think it's hard to give a real like specific answer for advice, but my general advice is I like the sound of a rollator. If you're getting your walking back on track, that will help you be confident and able to walk maybe further distances with a safety element to sit and take a break as needed. Thinking about the long-term steroids that you're on, especially with adrenal insufficiency, you kind of have to keep treating that. Thinking about the strength of your glutes and your legs, and your core. So the things like sit-to-stand exercises from a high enough surface that is A, not painful. Sometimes, with back issues, that deep sit-to-stand is strenuous and can feel painful. So sitting up on the edge of a bed or something that's a little taller. One way you can make your sit-to-stand even more strength-based is to stand up at a normal speed and then try to sit down as slow as possible. So sitting three times as slowly as it took you to stand up. And this helps us train our muscles in a fashion called eccentric training, where we're building the strength of the muscle as we lengthen the muscle. And it shows incredible improvements in strength over time in a faster fashion than it does if you just do a billion sit-to-stands really fast. If you do a lot smaller number with more attention to how slowly you control your seat, the descent back down, you're building more muscle a little more quickly and a little more functionally. It also helps you train your balance and making sure that you are in control of that descent, right?



When we watch people kind of drop down into chairs, we want to train that sitting balance so that even someday you could lower yourself down until you just touch and stand right back up again, turning it more into a squat. So there's some progressions we get into starting from that simple sit to stand. Then can we slow down the sitting phase, so you sit very, very softly. And then can you make that sit phase almost, almost there, and then stand back up. So if there was a whoopee cushion under your backside, it wouldn't make any noise. At the bottom, right? And those little progressions can be really helpful to build your strength of your legs and your glutes, as well as your core and your balance, which one of the big things with steroid myopathy that I'm looking at is how strong are my people's legs and backsides, because that's what's really taking the hit, possibly from those steroids. So that would be one. I think that's a place you could start if you're comfortable doing that, you don't have back pain when you do it, and you can find a seat that's high enough to give you that practice, that would be a little progression, maybe you'll take on and see how that goes.

Steve: Outstanding. Thank you so very much.

Courtney Bush: You're so welcome.

Jennifer Gillette: Glad your wife made you go in, Steve. You know we're a fan. Glad you're doing better.

Steve: She saved my life. Yeah, she saved my life. And thanks to God, I'm here.

Jennifer Gillette: Absolutely. Well, we're glad you're here today, and I'm glad Courtney could give you some tips, but hi to you and your wife. But Eric, do we have any more callers today?

Operator: Your next question comes from the line of Cathy. Please go ahead.

Cathy: Hi there. I've got two quick questions. One is for Laurie, just for clarification. For your treatment of the multiple myeloma, did you have an autologous transplant?

Laurie Perkins: I did.

Cathy: You did. Okay. So I guess one thing to clarify with folks that hope you didn't have any graft-versus-host disease because you had your own stem cells.

Laurie Perkins: That's correct.

Cathy: Because I got to say, I am so happy for you that you got better so well and so quickly, and we're able to do all those fantastic things. But I want to make sure that those of us who've had an allogeneic stem cell transplant recognize that maybe our progress might not be as quick because of the GvHD and the associated problems it presents to us.

Laurie Perkins: Absolutely. You're absolutely right. There are far fewer problems with the transplant that I had. Yes.

Cathy:

Yeah, I'm 10 years out from allogeneic and all your adventures are the things I want to do so badly, and I just haven't been able to with GvHD basically head to toe. So it's like, you know...but it seems to look forward to, but I didn't want to make folks who have had the allogeneic stem cell say, "Oh my gosh, why am I not sailing in Kuwait"? But I'm just so happy for you and how you've bounced back so well and thrilled that you're doing so great.

And just another quick question for Courtney is, with regards to steroid myopathy, Does it ever really all go away? I've been on two bouts of high-dose steroids tapering down from like 70 to nothing, and then six months later went back on 80 and then tapered down over about seven years, I think where I'm finally at six milligrams, but my muscles are still, you know...I try as best as I can, but I got to admit that I get disheartened from time to time. And the fatigue associated, I didn't get fatigue until about four years ago. I was younger, I was running for six years, but last four years have been pretty bad. But does the steroid myopathy itself ever go away? I mean, once you've had it, are you at risk of having it forever? And now, so like for someone like me and for many others, when you taper down and you do get the adrenal insufficiency, you do have to stay on prednisone or whichever type of steroid you're going to be on for life because you don't have properly working adrenals anymore. But that's a physiological dose usually, so I wouldn't think that that would necessarily affect your muscles. But once you have the steroid myopathy, is it supposed to dissipate as you go lower on your steroid dose?

Courtney Bush:

That's a really great question. It is harder when you have repeated high-dose steroids. Just the nature of it from my understanding, and the way we tend to think about it is. It is an acute event, and it is a short-term side effect in theory, but that really depends on your overall bigger picture and how well you're able to rehab your muscles after that event. And so I think it's different for everyone, I would say physiologically. We wouldn't expect it to be a, oops, you've had this happen, and you'll never have your muscles the same way again. I don't think I would think about it quite like that. But I would say it makes it way harder to bring your muscles back up once they've had that event. They've had a higher...had a more rapid weakening event. And there can be something that happens where fat infiltrates the muscle. And when you have a fatty infiltration of the muscle, which is common with sudden, rapid deconditioning, that makes it harder for the muscle fibers themselves to engage. Those little balls of fat that get down in there mean the muscle fibers are being stretched at the tiniest level. The little tiny fibers are already on stretch, and they don't fire as well as they could. So I think it gives you a...it can give a little bit of an uphill battle to say, we've had this steroid myopathy, which weakened our muscles and may have left some fatty infiltrates in the muscle itself. Now we have a muscle that doesn't fire as well as it could, and it's going to be harder to initiate it and harder to make it stronger, but it isn't impossible. I think it's still something that could be...could certainly be in rehab with help. You probably need somebody to help you do that, a physical therapist or a really good exercise trainer who's cancer aware would be helpful to be able to really look individually at little muscle groups. When I have patients with, I think about this with people who've had real specific muscle loss, and like certain muscles aren't firing, but others are working fine.

This is a common little pitfall we can drop into, where our muscles that do work okay start taking over. And we have our brains, and our body is so intelligent that it will work around just about anything. Have you ever known anyone who walked around on a stress fracture for like six months because they refused to get an X-ray and then went, oh my gosh, I've had a fracture this whole time? Their body figured out how to offload that just enough to get around anyway, right? And when we have a sudden weakness in a certain muscle group, like a big picture, a big part of our steroid myopathy is our proximal gluteal muscles. Our glute med and our glute minimus in particular are little guys, but they're heavy hitters and they do a lot to stabilize our pelvis. So if you try to stand on one foot, your glute med is basically holding you up in place. It's one tiny, strong muscle, and it's one of the ones that can be affected by a steroid myopathy, but it's a really important functional muscle. And when we lose some strength there, we have a whole bunch of other muscles that can jump in and say, I got this, don't worry, take a break. And then that glute need doesn't have to rebound, and it doesn't have to get stronger. But if we find someone who can help test the specific muscle groups, and then teach you funky little exercises that just target that one muscle, we start to bring it back to life. So I don't know what your rehab journey has looked like, my friend, and I'm just speaking in blanket terms. So I apologize if you've like...

I've done it all. I've tried it. It's not working. But sometimes, it's finding that right person who really gets it and who like gets really excited about the challenge of it and says, I'm going to find which muscles aren't working and we're going to make them work again. And those little small interventions sometimes just kind of spark life back in a muscle that's kind of gone dormant because we have other muscles, and our body is built on redundancies. And if this stops working, that one's going to take over, and we'll build a lot of compensations. We use our knees more. We use our arms. We do things to help get the functional task achieved, even if the pieces that should do it are kind of losing their strength. But I wouldn't say that...I definitely wouldn't say, "Oh, it's over." You still have to take steroids. You'll never get your muscles back. Not even a little bit, especially like you said, I think your intuition on the physiologic dose is exactly where I would go, that it's really the high dose steroids we look at, which for most people, a baseline for that depends on your body mass. But we're looking at doses 40 milligrams a day and up. Like that's what a high-dose steroid usually looks like for most people. So when you're down in that smaller dose, we don't really expect myopathy. It's not generally doing that. But I think repeated steroids, and depending on your graft-versus-host disease, if it involves your skin and you're tight, that can make it really hard to stretch and strengthen your muscles. And so sometimes the skin graft-versus-host can be a factor if that's something you deal with as well.

Cathy: Right. And could also with a graft-versus-host, I mean, if you have graft-versus-host disease in your muscles, could you not get also the sclerosis fibrosis in your muscle fiber as well? That would impede...

Courtney Bush: Usually it's just this...it's generally just the skin. It's generally skin and non-contractile tissues that get that fibrosis and the sclerosis. But if your non-contractile tissues are really tight, one of the ways our muscles work is by stretching the muscle first.

So when we want to jump, think about what you do before a jump, you bend down and fire off. That is a pre-stretch of the muscle that preloads the tension so you can jump. And if you're too tight to load and stretch your muscles because your joints won't bend enough, we're going to have a hard time firing that muscle correctly. So there's a lot of layers, there's a lot of elements. And that's where, you know...I know not everyone has access to a cancer-trained physical therapist or specialist, but looking for the community and seeing, is there someone else who's maybe really into muscle disorders or neurologic disorders? There's other specialties who...especially if you're far out from your actual transplant and it's no longer like the blood values and the immediate transplant side effects, but it's a broader picture, you may find a neurologic clinical specialist or someone who focuses on other things who could try to help get into some of that detail. So the broader community still can come in to help.

Cathy: You know, the sad thing too, with physiotherapy is that so often it's not covered by insurance. And what I found, I've run out, I would love to see a physiotherapist, but I just can't afford it.

Courtney Bush: And yeah, that can be a barrier.

Cathy: And do you ever find people have barriers where they live, you know, I've had this for so long, 10 years, and some people have had it longer and shorter, but that sometimes you want your home to be a sanctuary where you don't want to think about cancer or that you don't have cancer. Like, you know, sometimes you can just touch my toes or my puffers or this or that. It's like, no, I don't want to do it because I want to pretend that I'm healthy. And so even doing exercises at home feels like I'm going back into that cancer world, whereas I would so much rather go out and do it like any, have you ever heard of that, or is it am I just strange?

Courtney Bush: I don't think you're strange. I think it's, you know, the psychology of chronic illness is its own entire conversation. And I have patients who have similar feelings where they've just had a surgery and their body looks different, and they tell me I don't look in the mirror because I just can't. I don't want to see it. And I think that's kind of similar, and everybody is different, and coming to terms with things in our bodies is its own journey, and I think sometimes reframing how we think about activities in terms of is this bringing up bad feelings or can I shift my perspective around? This is me taking some amount of control of my well-being, and I'm doing this because I'm caring for myself in my sanctuary versus the other side of the coin of the, why am I having to do this kind of feeling? And that's a bigger conversation to maybe undertake with someone who has skilled training in those things. But you're not alone in that. I know I have a lot of patients who have a similar kind of, how do I face this all day, every day? I need a break, right? And I think there's some work there too, where you can learn how to reframe your thought process around some of these things. They definitely don't think you're just strange. I think you have a similar, I think a lot of people have had that experience in some way or another through cancer and chronic illness. When things are out of your control, it can be incredibly difficult to figure out how to navigate the things you should do for yourself for wellness.



Cathy: I understand. Well, thank you very much. And Jennifer, maybe that would be another Lunch & Learn.

Jennifer Gillette: You know what? I'm taking notes, Cathy, don't you know, which hello to you too. Reframing is a great idea for a Lunch & Learn. And thank you for your thoughtful questions. And I also just want to kind of piggyback on what you said, too. For anyone who's listening today, not only is there a difference between an auto or an allo transplant, excuse me, also just everybody is individuals. You know, no matter what kind of transplant you get, everybody is different and everyone's going to respond differently. And so I think the key here is knowing what's available to try to help you heal and to manage the symptoms as best as possible. Because also, like Cathy said too, graft-versus-host disease, that's a whole other different aspect that can affect how you're healing after transplant. So we want to make sure you get the support you need. And also, just like Cathy said, as far as suggestions for next time, if anyone ever, I'm going to be sending out a survey today after this program. If anyone wants to give us feedback on any additional programming you would like to see, we're going to be sitting down soon and really looking at our program starting the new year, or as well as things that we submit and put out on our Facebook or our newsletters. So let us know what you want to hear more about, and we're here to help. If you need more support on your journey, please go to our website, please e-mail us, call us. We want to be here to help you. And our website is nbmtlink.org.

But I just want to thank our speakers. What an amazing program today. Thank you, Courtney. Thank you, Laurie. So many great tips given, and we thank you all for being here today, and we just wish you well on your journey. And also, a quick little plug too, in a couple of weeks, we are going to have our first webinar with Corey Cutler and some other speakers with GvHD. So I hope you can make that, and go to our website, make sure you get signed up for these great programs, and we will hopefully be in your presence again. soon. Everyone have a great day.

Courtney Bush: Thank you. Thank you so much. Bye.

Operator: Ladies and gentlemen, this concludes today's call. Thank you all for joining, and you may now disconnect.