

NBMT LINK
Let's Focus on Exercise and Its Importance
Regarding Chronic Graft-versus-Host Disease
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Presenters

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Operator

Greetings, and welcome to today's NBMT-LINK Webcast. At this time, it's my pleasure to turn the call over to Jennifer Gillette. Please go ahead.

Jennifer Gillette

Thank you so much, Kevin, and thank you everyone for joining us today. We are really excited to bring you our program today, which is Let's Focus on Exercise and Its Importance Regarding Chronic Graft-versus-Host Disease.

Before we move on, I want to give also a big thank you out to our sponsors today, Insight and Sanofi, as well as all of our LINK partners because we couldn't do all the great programs we do, without them.

Just so everyone knows the outline for today, we will first hear from Dr. Shernan Holtan. She will talk about the importance of exercise after transplant, but especially with GVHD. And then we will hear from Samantha Lebner, who will talk about the psychosocial and emotional needs of chronic graft-versus-host disease patients. And then we'll hear from Matt Willen, a CLL survivor. He's going to give a survivor perspective, especially in regard to exercise and living life to the fullest. And then after our speakers today, we will have a question-and-answer period.

Just a basic little introduction to us, in case you're not familiar. The National Bone Marrow Transplant Link is dedicated to helping individuals and their families, from diagnosis through survivorship. We work with hospitals, cancer centers and other organizations to reinforce and complement medical care by providing resources, support and education. We link you to experts across the country and all topics related to transplant. So, if there's any way you need help, any services we can provide, I've got our phone number on this slide, which you can print after today's program, as well as the emails for our Executive Director, Peggy Burkhard, and myself.

Now, some of those resources that you might want to reach out to us on. First of all, we have a great healing arts program. We have virtual watercolor, journaling workshops, and we have all kinds of creative programs that can help connect you with other people going through the journey, as well as unique ways to just help yourself emotionally cope with the many things you're going through. We have our Lunch and Learn programs. Those are virtual programs that talk on anything related post-transplant, even pre-transplant at times, and things of interest to survivors.

We have our Merrill Masters podcast program, which covers things like chronic GVHD, survivorship, new treatments. We've had over 45,000 downloads. So if you've not listened to that series, I encourage you to check it out where you download your podcasts.

We also have our annual webinar series like you're on today. And then we have our peer support program that connects patients, caregivers, and survivors with trained volunteers that have gone through the journey before you. We have our Celebrating Second Birthdays Program, which honors transplant anniversaries with a special card and acknowledgement. Our Survivors Thrive Book Club, as well as you can reach out for other resources or emotional support.

And here we have some of our books. You can check those out at nbmtlink.org. And we have them here, our finance guide, our survivorship guide, and resources in graft-versus-host disease. But we also have more for you to check out.

We also have a very active Facebook community. We try to provide daily inspiration, support, tips, and reminders of the great programs we have going on. And then, also, these are some of our sponsors. Again, we just, or I should say our partners, we just want to thank them for their continued support because they make these programs possible.

A quick little medical disclosure, everything we talk about here today is to stimulate conversation with your healthcare provider, but it is not meant to replace your individual medical plan, individualized medical plan.

So now to introduce our speakers. Today, we have Dr. Shernan Holtan. She joins us from Roswell Park and she is a transplant and cellular therapy physician scientist who focuses on toxicity reduction and care delivery redesign. She served as Chief of a TCT program at Roswell Park and achieving among the highest survival rates in the country, brings deep expertise in GVHD biology and transplant program operations.

We also have with us Samantha Ledner, who is a licensed clinical social worker at Dana-Farber. She earned her Master of Social Work from Montclair State University and has experience supporting patients and families in oncology care. She provides psychosocial support and helps people navigate cancer treatment, survivorship and the challenges of living with chronic illness.

And then Matt Willen, our survivor speaker today. He lives in northern Vermont where he works at Stone Mountain Resort in the base operations department. He is an avid skier, hiker, kayaker, and general outdoors kind of guy. But before moving to Vermont, Matt was an English professor for 16 years, specializing in writing and the literature of travel and exploration. Matt is currently recovering from a stem cell transplant he received as a treatment for diffuse large B-cell lymphoma. October 15th will be his one-year transplant birthday, a milestone that represents hope, resilience, and a return to the activities and adventures he loves. Happy pre-birthday to you, Matt. And now on to Dr. Shernan.

Shernan Holtan

Thank you so much and I'm so happy to be here. I appreciate this opportunity. We're going to do a little bit of a deep dive into the weeds on why exercise matters to those who have undergone stem cell transplant and those with graft-versus-host disease. What you see on this slide here is a QR code for my Instagram account. Please, if you do have Instagram, feel free to scan that code and join me on Instagram where my name is "blood cells and barbells."

So some of my qualifications, I am a physician and chief of blood marrow transplant, but I speak about exercise to a place of someone who really does love exercise. I briefly held a national record in the barbell back squat in 2019. Honestly, that's one of my proudest accomplishments, that was really fun to strive for. I held date records in the bench press and deadlift and then I've a marathon and a half marathon and I'm certainly not going to set any records in those types of races. So that's my exercise background and happy to take you through this journey now.

So what we'll cover includes why movement matters, what cancer treatment does to the body and the immune system and what research is showing on how to overcome or mitigate some of those effects. We'll talk about why it's hard, addressing some of the real barriers and try to identify some paths around those barriers. We'll also briefly talk about new medicines that are being developed. We recognize that, sometimes, it's not possible physically to exercise and might there be medications or support for those times when you're just physically not able to do it because of illness or hospitalization.

And then we'll talk about some practical tips of things that you can do now, even if you don't have experience with exercise and some take home points.

So let's dive in, "Why Movement Matters." So this is the big idea, and it's a pretty exciting thing that happened in the field of oncology, just very recently. For the first time, there's a large, randomized trial that showed that structured exercise after cancer treatment doesn't just make people feel better, it helps them live longer and be cancer free. Now, we could almost think of exercise as an anti-cancer drug. We now have that level of evidence.

And we know that the muscle is an organ. It sends signals that help control inflammation and support the immune system. And the dose of exercise that's necessary for these benefits is

something that can be just walking. It doesn't have to be anything too fancy that requires the gym. So we'll be going into some of these studies in detail.

Now why does this matter? I think all those listening are well aware that chemotherapy and radiation do take their toll on the body. There can be loss of muscle, lean mass. There can be fatigue, low energy reserves, meaning, activities that you once did are harder. That can be worsened by ongoing inflammation during graft-versus-host disease, so it can be really difficult to overcome. And then we also learned recently that cancer and its treatment can actually age the immune system, providing you with fewer fresh T cells to help respond to new threats. And all of this can be at least, in part, mitigated by exercise.

Now a point about frailty, you might be hearing about literature surrounding frailty and transplant and cancer therapy. This doesn't necessarily mean old age. The components that contribute to frailty include low energy or feeling worn out, unintentional weight loss, weakness, slow walking speed, low physical activity. And things that you once did are now harder to, and even those who are young can experience frailty.

And now, this is something that is so common, to be honest, we as doctors don't diagnose it enough. Even when we see all these signs and symptoms, we just say this is a normal part of cancer treatment. But if we actually recognize this syndrome, we diagnose it, then we can have ways to mitigate it.

We know that especially after a transplant, the difficulty tends to be earliest on in the first 100 days. Activity can be very challenging because we're recovering from intensive chemotherapy, radiation, and building a whole new immune system. This typically improves with time. So six months, people feel better. By 12 months, better still. But there can still be a lot to overcome to help people get back to their previous state of health, before a transplant.

Now muscle is so important to the body. It does more than just moves you. It also sends signals or chemical messengers throughout the body that help to resolve inflammation and improve your immune function. And in future slides, we'll be going through some of that data. So again, muscle is not just aesthetic. It doesn't just look nice. It doesn't just move you. It's actually a very important organ that contributes all of these signals that help maintain your health, so it's really important to try to enhance their activity, whenever you can.

So now let's go into some studies, some things that we have learned in the past few years about how exercise can help mitigate effects of cancer and its treatment. So go through five studies.

And before I dive in, I just want to give a quick overview of medical evidence. There are different levels of evidence that we refer to in the clinical trial community. The highest level of evidence is a randomized trial where people are assigned, by chance, to one approach or the other. This is, we think, the strongest kind of evidence has the least likelihood of bias.

Then we have smaller studies such as pilot studies. Pilot studies can be the first to test whether something is safe, doable. It's very promising but doesn't give the same level of evidence because you're not comparing it against something else.

And then there are laboratory studies where we're testing ideas in a dish or in animals. And so this can help us understand mechanisms, but it doesn't prove that the study will work in humans. And so, I'll be going through different types or different levels of evidence in these future slides, and I want you to keep these levels of evidence in mind, as we go through them.

So, one major trial that really shook the oncology community was the challenge trial. This was a randomized study. This was 889 adults who had finished chemotherapy for high-risk stage two to three colon cancer after surgery and chemotherapy. So I know it's not transplant but, nonetheless, I think the lessons may apply.

These patients were not very active at the start of therapy. And so, what they did in the study, it was a three-year walking-based program with coaching about 45 to 60 minutes of risk walking three to four times a week, compared with just providing written health and nutrition information, plus the usual checkup. And these patients were followed for eight years, on average. It's a huge study across 55 medical centers.

And this is what it meant. So let's take a look at this graph here. These dots represent 100 people. And let's say that these were 100 representative people on the study. At the end of the study, 74 of these patients out of 100 were cancer-free with just the information alone, so just the usual medical care. That's what we see in the teal dots. But in the bronze dots, six more patients were cancer free, just because of the exercise program. So using a randomized approach, we could actually determine that six in 100 patients were cancer free because of the intervention.

And honestly, if we saw that kind of result in oncology, we might actually approve that as an anti-cancer drug. More patients were alive and cancer free because of the exercise program.

So here we see in the bar graphs with the exercise program in the dark teal, those were cancer free versus the usual care. And more patients were alive at eight years, as well. This corresponded to a 28% lower risk of cancer returning. So I think this is incredibly important data. It is not in the transplant space, but this really gives us the highest level of evidence in cancer that an exercise program actually has substantial benefits.

So, this was the missing proof, we didn't have such a large, randomized study before. The equipment was simple, just a pair of shoes, just walking shoes. And so, this is very translatable to the real world. The benefit is substantial; I think it's very meaningful and comparable to some drugs. If this were a pill, it might be FDA approved to treat cancer.

And this was reasonably safe, yes, there could be some muscle and joint pain, it was more common in the exercise group, but that was manageable. And so, I think this is really exciting evidence for us and we should take this information and, quote, unquote, “run with it.”

Now, let's talk about another study. This is a preferable effect. Can exercise help people living with cancer that has spread? So in the previous study, those were patients who are undergoing curative intent colon cancer therapy. What if we're in a situation where the cancer is spread and the goal is no longer cured? Can exercise help people live better and longer?

This is a large study, 357 adults with metastatic breast cancer. This is a nine-month supervised program that combines strength training, aerobic training and balance training, two one-hour sessions per week, across six countries. And this showed that with exercise, multiple parameters improved, including physical fatigue, quality of life, fitness and physical function, everyday activities, social life, pain, and shortness of breath. And these improvements lasted at nine months, which would be the end of the supervised program.

But is it safe? And this was obviously a significant worry because in a number of these patients, the cancer had spread to bones. There were two serious exercise-related events, so a wrist fracture and a stress fracture in the pelvis. But none of the fractures occurred at a cancer site, and these patients were able to keep going, despite this. And so, importantly, this shows you that we are able to adjust exercise based on a person's unique cancer situation. It was the tailoring that made it safe, and the benefits were clear.

Now what about exercise in the transplant setting? We have a nice study here that was showing that exercise based on a video call can be feasible and helpful, after a transplant. This is 139 adults who are more than six months after a stem cell transplant. Both types are a donor transplant or an allogeneic transplant or an autologous transplant. This is six weeks of personalized exercise plus stress management delivered entirely online.

You can see here that, at the end of this intervention, patients were able to walk further when they were measured at a certain time scale than before the intervention. So these gains were substantial and just delivered by video, only. So this made the intervention very feasible, no travel, no gym, no infection risk from a crowded space, which is really important to those who are undergoing a stem cell transplant.

So really nice evidence in the transplant population here that exercise can help improve physical function.

Now, this is a study here, strength training with a care partner. This is a study that I actually co-led with my own personal trainer. We decided to apply for a grant and study the effects of his strength programming on long-term survivors of transplants and their caregivers.

So here we had transplant recipients, but also whoever they designated their caregiver was their partner in strength training, but also the control subject. So most of the time, this is a spouse, but it may have been a friend or another family member. This is a pilot study. This is just eight survivors and eight care partners. So it's a pilot study, but what we did was extremely detailed physiologic and immunologic testing, which I'll go into in a moment.

So we had patients and their caregivers do strength training in a community gym. This was a 10-week personalized strength training program with my own trainer. So of course, there's my bias, I think he's great. Indeed he is. And what we measured before and after the 10-week strength training intervention, we measured strength, body composition, so how much lean mass, how much fat mass do we have.

We also looked at measures of your immune system being active in the blood with very specialized testing. And we also looked in the stool to compare gut bacterial abundances or the microbiome and what exercise might do for the microbiome. So yeah, it was just eight patients, but we did a lot of work to understand what exercise was doing under the hood.

So we found, not surprisingly, that after 10 weeks, people got stronger. On average, after 10 weeks, strength actually doubled. That's amazing. So strength was able to double in 10 weeks. On average, patients had about 25 sessions, so about two and a half exercise sessions per week over 10 weeks. So it's not like they were in the gym every day, two to three times per week.

We had no serious problems, during the course of this study. And one thing that this study puts to rest is the idea that a transplant makes it impossible to build strength. And in fact, patients who had undergone transplant were able to build just as much strength as the caregiver. So it should put to rest that concern that I'm just too weak, I just can't build muscle again, you can't.

So what we found on the inside before training, patients and a lot of these folks did have chronic graft-versus-host disease. They had higher inflammatory signaling than their partners. They had fewer signs of naive immune cells that are important for shaping immune responses and there were substantial differences in gut bacteria. But after 10 weeks, we could no longer tell the difference between a patient or a healthy control based upon their immune activity, with the immune gene signature being identical, and I could no longer detect any differences in the stool microbiome, either.

So all of these changes that we saw benefited the patients. I didn't see any change in the healthy partners. So maybe 10 weeks isn't enough to see a signal in those who are already healthy. But in those who had gone through a transplant, we saw all these parameters basically make them look like a normal person on the inside, after 10 weeks. So, exercise is potentially an intervention that can help cancer therapy and the immune system to work better.

Why might this work? So this is a laboratory study that has identified that exercise can change your gut bacteria, as we saw in our study. But in this laboratory study, it was identified that a

compound called formate comes from gut bacteria, and that formate strengthens immune cells, especially those that help to fight cancer, and those who had this gut producing formate had a better response after immunotherapy in laboratory models.

So again, this is a lab study. We don't know if this works in patients yet, but this study might show us how exercise fights cancer. Otherwise, it wasn't quite clear what the mechanism was. This might be just one of many mechanisms, but we're starting to kind of disentangle just how exercise might work.

So this is a summary of the studies that I just went through at a glance. We have the challenge and preferable effect studies that were both randomized. Telehealth after transplant was a randomized study, so very high levels of evidence that simple exercise interventions can significantly help. And then we had our pilot study that showed that the immune parameters and the gut microbiome changed significantly after 10 weeks of strength training and some laboratory evidence that suggests how, specifically, exercise might make cancer therapy better.

So now let's pivot and talk about why this is actually pretty hard to implement. How active are people, actually? Not just those who haven't undergone chemotherapy or radiation or stem cell transplants, but a lot of people are not adherent to the guidelines for activities. Life is busy, there's a lot to do. We can be overwhelmed by all of the tasks of just daily living.

Because of this overwhelming need to do other very highly important things in our day, 83% of patients didn't meet guidelines for exercise, a year out from transplant. I don't think that's a huge surprise. Just survival is a lot of work. So we have to build it in and make it easier for people.

Patients after a transplant at day 100 are measuring about 3,700 steps per day. If you're tracking that, that's below the recommended levels for activity, 16 minutes of active time, daily. This is, again, below what is recommended. And this point is not to shame anyone. This is to say, you know what, most of us are not where we need to be and we need to actively think how can we incorporate exercise in our lives in a way that is not so burdensome in a way that's actually doable.

There are many barriers. Timing can be difficult because of all of the other appointments and everything that has to be done for caring for your body, after a transplant. There can be complications such as graft-versus-host disease that affects the body, tightens the skin, tightens the joints, makes it difficult. Those who have had to go on steroids note that they don't actually build you up, they actually cause muscle weakness, and that can be prohibitive towards exercise.

There's an infection risk, and so, certainly there's a perception that going into a crowded gym is not what you want to do, especially during respiratory virus season. So how do I access equipment in a way that doesn't predispose me to infection? Blood counts may be low, and

that can be a challenge, especially if platelets are low, we risk bleeding with some types of exercise, so this is a concern. And then there can be effects on nerves and the heart after chemotherapy and radiation that can make this a challenge, as well.

So these barriers are real, but there are reasons to modify the plan, not reasons to do nothing. So there are ways to overcome some of these barriers. A number of barriers are built right into the healthcare system. There's an estimated only 15% of patients were even referred to an exercise program, 24% of community cancer practices offer exercise or rehab services.

So basically, three quarters of those don't even have these services that we're talking about. Only 2% of hospitalized transplant patients were referred to physical therapy afterwards. And then unfortunately, exercise is rarely covered by insurance, so referral to an exercise professional, such as a personal trainer, is an out-of-pocket cost. That could be quite a barrier.

So what are the other physical barriers? In a survey of 420 patients, about a quarter of patients felt too weak or too tired, and there was no program available in about a third. So there is interest, but there is substantial weakness, fatigue, and just concern of not knowing where to look or how to get started. So this is where we come in and we need to help people access exercise, better.

So what if we can't exercise? Sometimes, because of complications leading to hospitalization or other factors, it is not possible to exercise. Can we use medications as a bridge for those who can't exercise? So there's nothing that really exists, yet. What I'll be talking about are bridging agents that are theoretical. They're in the laboratory only, but perhaps in the future, patients who are going through transplants or other major medical procedures might be able to receive a medication that helps protect their muscle, preserve their ability to respond, and maybe even have some of the immune benefits of muscle stimulation.

So, these agents or methods I'll be talking about now are not available yet, but I do think that the field is actively looking for some alternatives.

One type of approach is blocking a hormone called GDF15. GDF15 is a protein that can be produced in the body in response to cancer, and it actually blunts the appetite and activity. So it's known that high levels of GDF15 contribute to a syndrome that we call cachexia. That is where there's very low appetite, very low food intake, rapid muscle loss, very low energy expenditure.

And so, there's been a Phase 2 study that was a randomized study completed, looking at using this blocker of GDF15. And in this randomized study, blocking GDF15 improved appetite, muscle mass, and daily activity. There are larger studies that are ongoing, and I have to give the caveat that most of this testing has currently been done in those with solid tumors, not in transplant. But we have some early signals that this may be a beneficial approach to help preserve the muscle mass.

What about blocking the brakes on muscle growth? There are these proteins that the body can make that actually blunt muscle growth. These proteins are called myostatins and blocking them or blocking their receptors might help preserve muscle mass.

There is currently a randomized Phase 2 study of such agents in obesity, but not yet tested specifically in cancer, nor after a transplant. But it was found that blocking some of these inhibitory hormones in patients who are receiving a GLP-1 receptor agonist that's often now prescribed for diabetes or obesity can help protect muscle mass. And so, those who receive this muscle agent actually gained lean mass, instead of losing muscle mass on the GLP-1.

And so, this is potentially a promising area to look at. One caveat here is that bigger muscles don't necessarily mean that you have the same metabolic or immunologic benefits that exercise might produce. Nonetheless, this is interesting and something to watch.

Now there's a concept called senescence, cellular senescence. This is a phenomenon where cells become zombies in the body. I'll describe that a little bit more. Senescent cells are kind of the cells in the body that have shut down. They no longer are functioning the way they're supposed to. And typically, the body gets rid of these senescent cells with a regular turnover.

And so, our body is always producing these, but we're supposed to be able to clear them out. When there's a buildup of these senescent or zombie cells, these cells can make a lot of pro-inflammatory molecules that can reduce your ability to build muscle.

And so right now, there are some trials that are looking at drugs that can help clear out these zombie cells, and we will see if this is one of these potentially feasible methods in the future. There's a trial in adult survivors of childhood cancer that is currently testing these drugs, so we do have some data that will be coming soon in the cancer space, but nothing specific for transplant, yet, so, this is a very exciting area. I look forward to seeing this.

The way this type of therapy would work is it would be given as brief pulses, basically medications to help clear out these zombie cells in just two to three days, not something that people would have to take forever and ever, long term, so this could be very interesting in the future.

There's also the concept of using external stimulation to the muscles, using a gentle electrical current to help keep the muscles intact. This is currently undergoing testing on autologous transplant and so this is interesting. If we are not able to exercise and we don't yet have an available drug, can we actually just give the muscle some gentle electrical stimulation and preserve their activity? So we look forward to what this trial might show. We'll see if this can help preserve mass in those undergoing transplants.

And then what about some of those gut-derived molecules I was mentioning, earlier? What about formate or other molecules such as urolithin A? So, the gut microbiome is known to

produce molecules that could, in theory, help preserve muscle mass. We do not yet have randomized trials on cancer patients, although there are tests that are currently being conducted in healthy adults. So this is a concept that I think is also very interesting, hopefully safe, but we don't have evidence yet that this will help after a transplant. So this is not me advising you to take these, but just know that research is ongoing and this could, potentially, be interesting in the future.

So the bottom line on medications, we have real reasons for optimism. Multiple approaches are being tested now, but I would certainly exercise some caution. Although some of these agents might be available with supplements right now, we don't have safety data in humans. We don't have safety data in those who have undergone a transplant or graft-versus-host disease. So, I think it's too soon to reach for any of these supplements just yet, but just know that I do think that more promise is coming in this space.

So what can we do now if we don't have a gym, we don't have a trainer, we don't have equipment? Is there something that we could do today? So yes, obviously, we want to start where we are. One place to start, if feasible, is walking. If walking isn't feasible, then just contracting the leg muscles, doing sit to stand, basically doing what you can now, measure it and try to increase that slowly, over time.

Also, train with a friend, a caregiver or another buddy. This can really help motivation and adds consistency that can help keep you going. As I mentioned, start where you are and measure it and try to add a little bit of intensity gradually, over time. This is a concept known as progressive overload. So slowly, you build capacity by adding additional reps, adding additional weight, adding the amount of time you exercise and over time, the body can adapt and build more muscle and make you stronger.

This is how I accidentally set a national record. I certainly didn't intend to when I started exercising at the gym. I just very slowly added weight to the bar and before I knew it, I accidentally got really strong. So be careful what you do here. You might end up holding a national record. Just be watchful that could happen.

And then, fuel your body. You need protein to help build muscles. You need sleep to repair. And so, make sure you're giving your body adequate fuel and adequate time to rest to build those muscles.

So walking with intent, brisk walking is great. Try to build time if you can, but even small amounts count. So if you can only do one minute, two minutes, five minutes, 10 minutes, that's okay. Whatever you can do, start there and build, over time. That is enough to significantly improve quality of life and very likely, your muscle mass and your immune function as well. So even something as simple as walking can be very beneficial.

Stand up from a chair and keep count. If you're able, sit to stands are a fantastic exercise for your lower body. And if you can build your quads, build your posterior chain, this is a huge benefit to you. You can do push-ups against the wall or against the counter. You can do step-ups against the stair. Be very careful, but this is all good. These bodyweight exercises are excellent. Hip hinges to work on your glutes.

This is all fantastic. You can work over 10 to 15 minutes, two to three times per week. Write down how many reps you did and add one to two reps per week or a set per month, something like that. Counting is really key and you're hearing me mention this multiple times because you start where you are and build over time, and that will make you stronger.

Train with a care partner, that helps keep motivation, that keeps accountability and it makes it more fun, too. And so, I'm blessed to have multiple exercise partners that help keep me motivated and show up and help me do things that I don't necessarily want to do any given day. So this element is really very useful.

And then measure something. Keep a notebook or something in your smartphone, whatever you do, keep track of what you're doing and add to it gradually, over time, and it will add to something really meaningful.

And then feed the work. Protein is very important. Identify protein sources that you like and try to have protein, if you can, at each meal. You don't have to eat crazy amounts of protein, even 20 to 30 grams at each meal would really substantially add up. And then make sure you're getting enough sleep, if you can. It's during sleep when you're doing all of that recovery and repair work, so this is really important.

So before you get started on an exercise program, it is a good idea to ask your healthcare team, are there any limits on my bones? If there's cancer in the bone or thinning bones or a previous injury, this might need to be taken into consideration. Ask, are my blood counts safe for exercise? If you have low platelets, you might want to be a little bit more cautious around strength training. Do I have any joint or skin restrictions? Graft versus host disease can certainly cause mobility issues and so ask which joints need particular care and how to exercise with them.

And obviously, if you feel worse, have chest pain, shortness of breath, dizziness, fall, anything concerning, stop and let your healthcare team know.

So, this is an example of what a week could look like for a structured exercise planning. This looks kind of boring, but to be honest, this is how I plan my week, as well. So decide what you're going to do each day and write it down. It'll make you more accountable. Let's say Monday could be walking 10 minutes. Tuesday could be chair sit to stands and pushups against the wall. Wednesday, walking 10 minutes, Thursday is resting or gentle stretching. Friday, chair sit the stands and step ups. Saturday, walking a little bit more with a partner and Sunday, rest. I

do this exact same thing every week. I write down what I'm doing on each day and I build in rest and go from there.

And then now some take home points. So four things to remember. Movement is treatment, not just self-care. This is really important. I may possibly reduce your risk of infections. It may possibly reduce the risk of cancer coming back. So this is more than just something that's nice to do, it really is important for your body. Your body can still respond. So even though you may have been through a lot, you still will be able to respond to exercise, positively.

So if you're feeling down or frustrated, just know it takes time. Start small and build from there. There are many barriers. We recognize them, and they're mostly not yours. There could be no referral, no program, no insurance coverage. Regardless, ask your team about what you can do. And again, start small. It does not have to be anything really crazy and in fact, it's not good to start off too big. Start small and build from there.

On these next two slides, I show my references. Again, this is a pleasure. Thank you so much for the opportunity to share these ideas. And I'll just leave you with the idea that two minutes of exercise is better than zero minutes. And we can continue the discussion a little bit later but now I look forward to hearing from the rest of the speakers. Thank you.

Jennifer Gillette

Thank you so much, Doctor. We appreciate such a great presentation. I definitely learned some new things today. I appreciate you. And now, we are on to Samantha Lebner, our social worker.

Samantha Lebner

All right. Hello, everyone. My name is Samantha Lebner. I'm one of the social workers at Dana-Farber, and I'm specifically in the hematology department, and I specialize in bone marrow transplant, leukemia, lymphoma, and all other cellular therapies.

Specifically, we're talking about moving within your limits and exercise safety limit setting within the social work lens. So I'm very excited to be here and talking to everybody.

So just to begin with, the main goal of this portion of the presentation is that I would like to center around autonomy and safety and movement being a tool for living well and not just a test of athletic performance. So I want to normalize that graft or supposed to these treatments affect things like fatigue, pain, finances, fear, even transportation and changing symptoms can really alter what is realistic on any given day.

So I want to introduce kind of the core message and my main goal is to kind of introduce that we're going to talk about knowing and understanding your limits and then getting creative, in spite of them, which is very exciting. And I want to let patients and caregivers here know that these examples are all educational. Their oncology transplant team should individualize activity

recommendations and that all of the examples that I use are from medical oncology specialists and providers in the field, as well as peer-reviewed meta-analyses.

And why movement still matters. So these domains act as a patient-centered method to reiterate that exercise is only part of the whole person's wellness model. And the why kind of reminds us that strength and function, energy fatigue, sleep and mood are all equal, not just the exercise. And Dana-Farber notes that the combination and prioritization of all of these key areas encourage stronger muscle, bone health, better sleep, maintaining a healthy weight, muscle mass, increasing energy, lowering fatigue, improving mood, managing anxiety, and its benefits to recurrence of risk infection.

So I want to emphasize that exercise is not an all-or-nothing prescription and that rest and recovery are also part of that plan, too. And then from the social work lens, goals may be functional, more like walking to a mailbox, returning to work, playing with kids, rather than numeric in terms of minutes, miles, pounds, things like that. So, these goals will help kind of set the frameworks that I discuss.

As we go on, and grasp versus host disease considerations and knowing your body. Graft-versus-host disease obviously affects people very differently. Symptoms may involve the skin, joints, muscles, mouth, lungs, GI symptoms, and overall energy levels. So, two people with graft-versus-host may have very different experiences with movements. And what's important with that in mind is paying attention to what the patient's body is telling them.

And for that person, it could look like noticing changes in fatigue, weakness, pain, stiffness, mobility, breathing, balance, or how you feel during and after activity. Listening to your body does not mean giving up, if it's telling you, you need to stop. It is an important part of the exercising safety model.

So this might take some time and in the beginning of a diagnosis for graft-versus-host, I often see people feeling scared and overwhelmed and we kind of helped bridge breathing into and learning about what your body's shifting patterns and limits are, rather than having a fear-based approach. So, learning your patterns, energy and symptoms can fluctuate throughout the day from one day to the next. So keeping track of symptoms and activity can help you and your care team recognize the patterns and make better informed adjustments.

Knowing when to pause and check in. If symptoms are new or worsening or significantly interfering with your usual activities, it's very important to communicate with your medical team, rather than assuming that you can push through them, and your care team will advise for you.

So your provider, your physical therapist or other members of your care team can help determine appropriate types and levels of activity based on your symptoms, treatment, current function and individual goals. So the goal is not to ignore limitations, it's to work with your

team and the people around you to work around them. And sometimes, the best choice might be changing the intensity, duration, type of movement, timing, or amount of support, rather than stopping the movement, altogether.

And of course, where and how to start. So providers, this means meeting the patient where they are. And for the patient, this means listening to your body's limits. Patients with graft-versus-host have such a diverse level of fitness, strength, stamina and prior experience with their physical activity, of course. So graft-versus-host disease and its treatment can also create barriers such as fatigue, pain, stiffness, weakness, and changes in your physical functioning.

So the goal is not a one-size-fits-all exercise plan. It is to identify what is realistic and meaningful for the individual and then to adapt with creativity, different intensities, different durations, or support in ways to make the movement more possible and safe.

So I'm going to say this pretty much, throughout the entire presentation on my end, is to always check with your medical team and your medical provider. They really help determine what level of activity are appropriate based on your current symptoms, treatment, functional status and any limitations or precautions that you need to be taking. So as symptoms and treatment changes need, adjustments, your exercise plan will also change with that, as well.

And this is our kind of safety first, kind of getting to know your own zone. So if we break down, after we start getting motivated and what it means to start wanting to work out more, especially during graft-versus-host disease, I've created this kind of system, green, yellow, red, to kind of identify where you are on any given day and what you can actually accomplish, so you can be checking in with yourself.

So this is supposed to be a framework, the green, yellow, red zones. They're more of a self-management tool, I would say, that you can create with your medical team. And it's definitely not a diagnostic tool. So it's important to know from your medical team what your limitations specifically are. And you can use those considerations in creating your own specialized green, yellow, red plan.

Green obviously means to proceed with the planned activity if you're feeling well and your usual symptoms are well controlled. Yellow means maybe we need to modify the plan. That could mean shorter durations, lower intensities, gentler modalities, more breaks, or completely different activities. Red means absolutely to stop. So new or worsening symptoms including fever, infection, concerns that you would otherwise be contacting your clinical team for means it's a good time to stop working out and take that day off.

An important nuance with all of these different ideas is that specific restrictions may be individualized based on your count, your bone health, cardiopulmonary status, medications, and activity of graft-versus-host disease. So again, discuss all of these things with your medical teams that you are proceeding with movements according to your medical recommendations.

So now that we know when to stop and ask a doctor, when to continue the workout, a lot of people ask what kinds of exercises you can do. Here is a little movement menu that I've created, and it's definitely meant to be used as a menu and not as much as a checklist.

So a patient doesn't need to do every single activity on this category list, but Dana-Farber's Zakim Center does offer pretty much all of these options in either virtual classes or virtual courses that you can go through on your own time, and it's completely free for everybody.

These exercises include things like strength training, low impact aerobic exercises, yoga, Yogilates, Tai Chi, Qigong, core training, stretching mobility. And those are all things that you can look into and kind of build your own movement menu around what kind of activities you would like to do.

So some examples of adaptations to include are things like seated yoga, which is also something that you can find online. It's at the Zakim Center for virtual. So those are all sort of different areas you can look to, to find what might work best. You can also adapt things like wall pushups instead of regular pushups, shorter walks, using resistance bands, chair supported balance or workouts and gentle range of motion.

So, you can really match the choice of the goal and aim for strength over function. So low impact cardio for stamina, mobility for stiffness and mind-body movement for balance and stress.

And another important framework is limit setting. This is a central social work-based theme, and it starts with kind of naming your limitation and connecting it to more of a meaningful goal, adapting that method and then redefining what success means.

So an example of this kind of looks like a limitation of I cannot walk for 30 minutes. You can redirect this thought into making a more attainable goal and connecting it to a meaningful activity. So I want to walk with my partner becomes the new adaptation to your barrier. And then it can become, well, I can exercise for 10 minutes, do a chair break, and then do an indoor route walking with my partner.

This approach is meant to protect dignity and autonomy because the patient remains the decision maker. So the team can help design these safe boundaries, and then the patient really has the ability to input what their values are and set more meaningful goals, rather than numerical goals. So this also encourages patients to track what works for them, rather than focusing on what they cannot do.

It's important to remember that with movement, everything and anything counts. So when you're moving your body, even in small doses, that is always an accomplishment.

My next slide is about my new favorite term, which is exercise snacks. And I want to introduce it as a way to challenge that idea of all or nothing thinking when it comes to exercising. And the way that that is modeled is, sometimes, people believe that exercise only counts if it happens in a formal 30-to-60-minute workout. So an exercise snack is actually a brief bout of movement, often just a few minutes, around two to 10 minutes per snack even.

That can be repeated throughout the day. The importance is not a specific prescription; it's flexibility during your day. And I can give an example of that, being some people pick to do two-minute workouts of gentle mobility after waking up, one before they brush their teeth and one after they brush their teeth. Or maybe someone else will pick a few sit to stands from a sturdy chair, if medically appropriate, of course. Walking down the hallway for several minutes, stretching during a television commercial, or a brief breathing and movement sequence. Or sometimes, people will pick a short walk, after lunch.

For someone having a low energy day, one small movement opportunity like that may be the entire plan. And on a better day, you can combine or add some of these snacks all up. So if you do something during the morning, something during the afternoon, 10-minute differentials between both of these things, you can add them up to actually create that 30-minute exercise, but just breaking it up throughout the day. And this is directly connected to our social work lens of exercise snacks can address common and very real-world barriers.

Fatigue, limited time, transportation, limited access to equipment, anxiety about performing a full workout, caregiver responsibilities and unpredictable symptoms all play a role in being the barriers. So instead of asking, how do we get this person to exercise for 30 minutes, we can ask what are natural openings for movement in this person's actual day-to-day? And this framework also supports the patient's autonomy.

So a patient can build a personal movement menu. If I'm having a good day, I can do this. If I'm having a moderate day, I can do this. If I have a difficult day, my minimum version of movement today is this. That fits into the green, yellow, red framework, as well, and it reinforces that modifying your plan is not quitting.

So exercise does not have to be a hard five-to-10-minute bout of exercise, or even be two to three times a day, if that's possible. So people with cancer-related fatigue, graft-versus-host, it also recommends realistic expectations. So planning activities around higher energy periods of the day and discussing an individualized plan with your healthcare team.

And overall, movement does not have to take over your entire day to be a part of your day. So it's important to remind patients with graft-versus-host that the type, intensity, duration, and safety of activity should be completely individualized with their treatment team and be based on your symptoms, each day.

And now, of course, getting into motivation because that is often the hardest place to start. A very common experience that I think many patients with chronic graft-versus-host disease experience is knowing that movement is helpful, exercising is helpful, but that doesn't automatically create motivation. So during treatment and recovery, especially when energy symptoms fluctuate so much, a goal that feels too large can actually create an immediate sense of failure, before even beginning.

So the social work lens is trying to make this goal small enough to start, instead of making a goal that feels too big to even begin. So instead of asking, how do I make myself exercise more, you can reframe that to ask, what is small enough that I can actually accomplish today? This shifts the conversation from willpower to problem solving.

So we can go through an example of that together, too. So this four-step method is kind of how we'll do that. And the first is connect your barrier to a why and also mention that your goal should be directly addressing that barrier. So, the goal can connect to something meaningful to the patient. Maybe movement isn't really about exercise, maybe it's about being able to walk with your partner, play with the grandchild, get back to gardening, maintain independence, or feel more confident in your body after a transplant. So connecting movement to value can make that goal feel more relevant.

The second is to choose the minimum, identify the smallest version that still counts. That might be a five-minute walk, a one lap, three stretches, dancing along to one song, or any other medically appropriate amount of movement. CSCO's exercise guidance specifically describes starting with a small, easily attainable goal, even a two-to-five-minute walk and building from there.

So the point is to create an achievable first step, habits over time. So the third is to make it easy to start. You can look at the environment and reduce the number of steps between intention and action. So if we attach a movement to something that is already happening, put the needed equipment somewhere visible, like your shoes right under the staircase, or choosing a convenient location so that you can maybe involve your support person if you want to.

If fatigue isn't better at a certain time of the day, you can use that as information, too. So most providers will recommend planning activities around times when energy is better and prioritizing what matters most. So you can pick between if after breakfast you have a bout of energy and the exercise bands and your sneakers are right by the door as you're throwing out your K-cup for the morning, that is a really good way to create a habit of maybe I can walk outside for a little bit and if I can't walk outside for a little bit, what if I can use my exercise bands and do some stretching?

And the fourth item is to count the win. Success is not only created in increased distances, duration, or intensity of workouts. You can ask what you've learned. Did you discover that mornings work better? Are five minutes more manageable? Does movement improve

confidence or your mood? Did you recognize that you needed a rest day? So self-monitoring can help patients see progress and adjust their plan, as well.

And to give an example, I recently had a patient who said, I want to walk 30 minutes a day, every single day, but I keep failing. And I used to be able to do it, but I feel like I can't anymore. And rather than me reinforcing that 30-minute target, I asked, what would actually make starting easier for you? So we decided to shift the conversation into creating a new goal, which was just to do a five-minute walk, three times a week. And if that becomes more sustainable, then that patient could decide whether to build more from there. If symptoms change, then the plan changes too.

And that's purely anecdotal. It'll be different for all patients, but this just happened this week, too.

And I want to emphasize that making the goal smaller or breaking it down is not giving up. It is a strategy for creating meaningful while the first step becomes more manageable. This patient beginning to do five-minute walks, hopefully, as time goes on, maybe in the next week it can turn into seven minutes. And then after seven minutes, feeling more confident in going to 10 minutes and building from there.

So, making that goal small enough that you can start, meaningful enough that you care, and flexible enough so that you can change with it. And for patients with graft-versus-host and any other complex medical needs, the type, intensity, duration and safety of movement should again, always be individualized and considered with the treating team or physical therapist.

Getting a little bit more into small enough to start and meaningful enough to matter. So there is a huge distinction between a big goal and a starting goal. So during treatment or recovery, patients may compare themselves to where they used to be and what they used to be able to do. That comparison can make movement feel impossible, even before it starts. So creating small attainable goals creates a different entry point, something specific enough to do, small enough to succeed at and meaningful enough to care about.

So I'm going to introduce this four-part framework, the why, minimum, plan and track. So first is the why. Connecting a movement to something personally meaningful, like I want more stamina is useful, but I want enough energy to have the stamina to walk around the neighborhood with my partner can be much more motivating because it connects to a value.

And the second is the minimum. So identifying the smallest version that still counts. That could be five minutes, one lap around the block, one stretch routine or one set of repetition of an exercise-based training. And that's all depending on the person's medical guidance from their provider.

The third is plan. Decide where, when, and what makes behavior easier for you. The fourth is to track, which is recording completion and how the body responded, not just your performance and if you're able to complete the full task that you are intending to do.

I do want to stress that the purpose of tracking is not enough. A patient might discover that mornings are better than the afternoons. So, if that's the case, your activity is going to look different in the mornings as opposed to trying to build something in the afternoon into your routine. And appointments happen, scheduling conflicts happen, so you really need when you have the free time.

Some people who do flow yoga will have a chair next to them, mostly because it makes them feel safe, but also if they need to, they can take a seat. or that short walks will improve move without causing major energy crashes can be used throughout the day, as well. So that information can help the patient and care team adjust the plan as needed.

And motivation is easier to sustain when success is visible. So encouraging patients to celebrate consistency, flexibility, and listening to their body is not just a tool used to increase distance, time, or intensity. So it's especially important to encourage realistic goals, tracking activity and side effects, setting goals and supporting from exercise partners and the care team.

So say a patient misses several days of exercise, avoiding this framework of I fell off the wagon and asking what got in the way. This kind of reframe allows you to reboot the plan and maybe shift the goal because the goal is not perfect adherence here. The goal is creating a plan that can survive real life.

So again, main goal of this, part of the presentation is to highlight that making a small enough goal that you can start, make it meaningful enough that you care and flexible enough that it can change with you.

And in true form, I want to have a little bit of a break in between getting motivation and mindfulness into this mix, because mindfulness is really something that helps to reframe the entire activity of movement, along with having good days and bad days.

So I wanted to start by just saying that mindfulness can be thought of as something that patients can do while moving, rather than just another task that they have to add on to their day. So with GVHD, the body can feel incredibly unpredictable from the day-to-day. So the goal with this your symptoms or push through discomfort, it is to become more curious about what your body is communicating and use that information to make a safer choice.

I want to also introduce this aspect of body scanning as a way of using mindfulness. So while you are working out, and I recommend starting with a low intensity workout when utilizing mindfulness for the first time, this framework to keep this in mind is first notice, then adjust, and then continue. So before your next movement in any given activity, notice your energy,

notice your breathing, notice your tension, the pain, your mood, and any symptoms that might be affecting your plan.

During movement, you can periodically check in with, what am I noticing right now? Am I holding my breath? Is my effort feeling appropriate? An example of this is, say you are in the middle of a virtual yoga flow class of Dana-Farber Zakim Center, you can check in with your body during any of these movements that you do in the flow, and you can ask yourself if you are feeling lightheaded when you stand up. Do I need to slow down or take a break?

If the answer feels like yes, then you can either stop your movement or adjust your movement to a lower intensity. You don't necessarily have to keep pushing through your movement to say that you completed your workout. You can sit down or lay back into child's pose and practice some mindful meditation and just thinking about doing a body scan.

And that counts as a movement when you think about all of the things you're doing, going into a small child's pose or laying down on your mat with your palms up. You could even switch to grabbing a chair and be present with mindfulness in that way. And then afterwards, notice how your body feels and if it was helpful before going back to your next movement.

Thank you so much for providing us with the social work lens Samantha. We appreciate all the great tips you gave.

And now we would like to hear from Matt Willen, our survivor speaker. Matt, are you with us?

Matt Willen

I was on mute. Thank you, Jennifer and Peggy and the other speakers. Thank you for having me here. I'm honored to be here to tell my story and I'll just start off a little bit about who I am.

I live up in northern Vermont in a little town called Jeffersonville. If there are any skiers out there, you may be familiar with the Smugglers Notch ski area that's right here in town. And I'm 67 years old and I have two sons. And that's very important to me and that's been very important to me and my journey through this transplant process that I've had. And I work at Stone Mountain Resort and base operations. I've been there for about 10 years.

Before coming up here to Vermont, I was a college professor and my specialization was in writing and the literature of travel and exploration. And before that, I lived out in the Southwest where I worked in outdoor programs for some private schools and for the Colorado Outward Bound School, which some people may have heard of.

And so, a little bit about exercising me. And I'll start by saying is that I'm not a person who exercises. And I'll qualify that just a little bit because I have been spending much time in the last couple of months in the gym lifting weights because I lost quite a bit of muscle mass

when I went through my transplant, last year, and I realized that I was not going to get it back without doing some specific weight training but

But when I say that I'm not a person who exercises, I say that because much of my life is exercise driven. I spend much of my life outdoors and doing things, outdoors. So what are those things? Well, I work at a ski resort, so I'm a skier. And this is really important to me because it provides me not only enjoyment outdoors where I love to be but also provides me with the social life and family life, too.

My boys are both avid skiers and we get out and do and go skiing together quite often. I'm also a sea kayaker and I get out on the lakes around here in the summertime, quite often. I try and do two or three extended trips, every year. And in addition to that, I've spent a lot of time in the mountains and rock climbing and mountaineering and I do that. These photographs are of my son and he's become quite a partner for me in recent years.

And I think just generally, too, I'm an adventure traveler. And maybe I'll be going to the slot canyons of Utah or exploring the coastline of Newfoundland or the fjords of northern Iceland or even just getting out for a couple of days with one of my sons doing some snowshoeing through the woods in northern Vermont. The point is, my life takes place outdoors, largely, and I get my exercise through doing that.

For me, regarding the transplant process, it's a really big thing because anybody who's been through a transplant knows that retaining that sense of who you are can be really, really difficult. All of a sudden, your life is kind of taken away from you. So for me, a big part of the recovery process has been reclaiming my life back out in the outdoors.

So before I go on to how I did that, I'll tell a little bit about my clinical story. My first experiences with blood cancer date back, almost 25 years ago. I was diagnosed with hairy cell leukemia and treated twice for that and had very long remissions. And then in 2021, I was diagnosed with chronic lymphocytic leukemia with a couple of mutations, and the mutations are never a good thing when it comes to leukemia.

And I needed treatment pretty quickly after I was diagnosed, just a couple of months. And I was treated for a year with Venetoclax, a standard treatment. And It's a year-long program and I made it to 11 months before we needed to switch programs. And then I went on something called Caloquence, a BTK inhibitor. And I was on that for nearly two years, and it was remarkable.

I was going traveling out west, climbing mountains with my son, going to climbing areas, doing kayaking trips and it was great. It was a great period of life. And then last year in May, I had what's called a Richter's transformation, where my leukemia transformed into a form of aggressive lymphoma. And so, I spent last summer, the summer of 2025, doing chemotherapy,

R-CHOP chemotherapy and Venetoclax, which I did for four months. And then last year in October, I had a stem cell transplant.

And when I had that stem cell transplant, I had some minor graft-versus-host disease, some rash on the skin, some digestive issues, but nothing unmanageable. And the strange thing is that I had a relapse in January of this year and the doctors stopped all the immunosuppressants I was on. And as soon as we stopped those I had nearly an immediate remission. It was literally in a couple of weeks, my lymph nodes had been swelling up and they just went down, and I have been doing great since then.

One of the things about stopping all those immunosuppressants, particularly really quickly, is that it left me with some chronic graft-versus-host disease. And I've got three primary issues with that. One is dryness of the mouth, and that creates problems with some mouth sores and dental issues and stuff. And so, I'm being treated with medication to help enhance saliva production.

I also have dryness of the eyes, which is really a tough one because it's very, very uncomfortable. And I've actually met several other people who have had to deal with this. And we all talk about the wake up in the middle of the night with gritty eyes feeling. And so, I see an ophthalmologist about that and I have punctal plugs in my tear ducts and steroidal eye drops. I use those, regular eye drops.

And then the other thing that I've really been experiencing is this overall photosensitivity. And this is more than just the standard you have the threat of the secondary cancer, skin cancer that you need to wear long sleeves and sunblock for. It's like my internal thermostat has gone out of whack. And so, I have a hard time being out in the sun these days, and particularly when it gets warm out. So, oops, wrong way.

So in terms of exercise and my whole stem cell transplant experience is that, even before I had the transplant when I was going through the chemotherapy last summer, I tried to build exercise into my routine. I just, for me, it's a matter of retaining a sense of myself and wanting to be outdoors.

So where I live, I'm surrounded by about 10 miles of hiking trails. And so, I made a point of, even while doing the chemotherapy, of getting out every day and doing what I could do. And some days, I could walk for three miles and some days, it was a half a mile. And that would take me like 45 minutes, but that was all right. It just gave me a sense of something that I could do, while things were being done to me.

And being an outdoors type of person who does a lot of trips, planning and adapting is my mantra. You plan for trips and then you adapt when you're out on them. And I've been using that same sort of mantra with dealing with the graft-versus-host and the stem cell transplant.

And so, even before I had the transplant, I knew I would have to be down in Boston for 100 days, after the transplant. And so, when I was thinking about that, I asked myself, how can I spend time outdoors? How can I get out and walk? And what I did was I secured myself a place that was right on a greenway that goes through Boston and right across the street from a lake. And I would be out there walking around the lake, every day after I got off of the transplant. And some days, I could go all the way around and some days, I could only go part way around.

But I've also applied the planning and adapting mantra to my graft-versus-host. And so, for things like dealing with the dryness of the mouth, I always bring gum with me. I always pack a thermos of lemonade or tea so that I can drink and keep my saliva going, whenever I'm out in the field. And in terms of adapting, I just I chew gum a lot, which is kind of funny because I always thought chewing gum was kind of a bad habit, beforehand. But I've learned to adapt to doing that.

I stop for drinks a lot and I don't let myself get all dried out. And in the wintertime, as this photograph shows, I wear a face mask and it just helps to keep me from drying out a lot. And then with the eyes, dealing with my eyes, my planning is I've created an eye kit that I carry with me when I go out. And that consists of preservative free eye drops. I have wraparound sunglasses that I use, anything to keep my eyes from getting dry. I bring preservative free eyelid wipes and glasses cleaner.

And then and then I adapt my routine. I stop a lot to take care of my eyes before I need to. I don't rub them. I wear close fitting eyewear just to keep the wind out of my eyes. And I'm really cautious about going out in the wind actually, because that can really dry things out and make things uncomfortable.

And also, part of my planning and adapting is I don't drive after dark any longer, so I have to plan out my activities so I can be back in the car and on my way home before it gets dark because my vision gets blurry very, very easily from the things going on in my eyes.

And then in terms of the photosensitivity that I've been talking about, this has been really challenging for me. And in the summer, I had a really hard time getting out. And even on a day like today where there's not a cloud in the sky and it's about 60 degrees outside, the sun is still really hard for me to tolerate. And so, what have I done? I've learned to live like a bat. And it's funny because my doctor even said that, he said, you need to be a vampire. And so, I go out in the morning and the evening at, dawn and dusk. And during the day, I stay in the cool of my house and I eat insects, doing what bats do. And I take a lot of frequent breaks, pray for clouds, which we get a lot of up here in Vermont.

And I realized that there are things that I just can't do. I just cannot go out when it's really hot and when it's really sunny out. So under planning, I ask the question, when will I go out, and revolve my trips around that. How will I shape a trip? You know, when I go out hiking on the trails around here, some of them go through fields and are out in the bright sun and some of

them are through the woods. And if it's a sunny day, I go into the woods. And if it's a cloudy day, then I'll feel okay with going out into the fields and getting some of the views that I get around here.

And then so finally, just I'll summarize this, that planning and adapting has become my mantra for dealing with both life post-transplant and chronic graft-versus-host disease. And this is the last slide, and I put this picture here on this last slide kind of in the last minute. It's of a fjord up in Quebec. And I'm heading there this weekend and my friend and I are going to spend five days on the border paddling through the fjord. And I think about planning ahead for this kind of trip, the first big trip I've done since my transplant.

And there's the things that I mentioned about bringing an eye kit with me. I have gum in my life jacket. But also, we've been thinking, instead of going in a solo kayak, we'll be tandem kayaking. We'll have the two of us will be in a kayak, just in case something comes up with me, and we have escape routes planned out just in case something happens. And this is sort of the kind of the life I live. And so, I'm learning to get back into it and be Matt as best I can.

You know, as I think to future trips, I have to think well, what can I plan for and what can I adapt to and what can I do and what can I realistically not do? So, I hope there's enough time for questions. I'll just wrap it up with that. Thank you again for having me to talk and yeah, I will thank you again.

Jennifer Gillette

Thank you so much, Matt. I'm so glad you've been able to reclaim and adapt to some of those things that sound like are your passion in life. And I'm sure that's an inspiration to others on the call today. Kevin, can you remind everyone how they can ask questions and thank you so much.

Operator

Absolutely. Well, I'll be conducting a question-and-answer session. If you'd like to ask a question today, please type your question into the Ask a Question feature located on your screen. Once again, if you'd like to ask a question today, please type it into the Ask a Question feature located on your screen. One moment, please, while we pull for questions.

Jennifer Gillette

Thank you. I'm going to start directing some of these. Dr. Shernan, I wanted to point out one person had asked, what is the best way to outreach to someone to find a structured personalized exercise program? I had a BMT in 2012, but had to find my own program, and it took me over a year to connect with a trainer. Do you have any tips on that?

Shernan Holtan

Yes, I think that's a great question. And to be honest, the answer might be different for different people, based upon where they are. I think the first thing is to ask your health care team, physicians, APPs, nurse coordinators to see if there is a local program with your transplant center. Some places may have such a thing. If that is not the case, then perhaps even

look at the physical therapy department or even search the broader academic healthcare system where your transplant team might be based out of.

So, it's possible that there's something local, but there might not be. What I suggest then is actually go to clinicaltrials.gov and search for clinical trials. There might be a clinical trial of an exercise intervention in your area. The reason I recommend this is not only are we still trying to improve our science with this, but enrolling in a clinical trial might mean that you get some services for free because as I had mentioned, sometimes these services are very expensive.

For example, in our clinical trial, the participants received thousands of dollars worth of training equipment and other studies as a part of that program. And so, not that that's a long-term solution but in the short term, that might help get a foot in the door in a way to access programs.

And then the final method is just to do a local search for trainers. There can be databases locally and a number of personal trainers do have oncology certificates, on top of their standard personal training certificate. So, internet search in your area might yield something if that fails as well. Really, there can be some good online classes and all kinds of opportunities are available there.

It can take a bit of effort, though, I can appreciate. It is not always easy or straightforward. Certainly, I hope that we can do a better job of making more programs available to patients in the future.

Jennifer Gillette

Thank you so much. I also want to personally just add on to that question. One, Livestrong has a program with the YMCA that's a 12-week program to try to help cancer patients build strength, as well as I know we've done programs with Michael Kramer, who is a young cancer survivor that is a certified trainer, as well. So if anyone ever wants his information, feel free to reach out to us, as well.

But anyway, another question for you, Doctor. Will stretching help chronic GVHD?

Shernan Holtan

Another great question. The answer I would say here is, yes, but be careful. So I love the practice of yin yoga. If you haven't heard of that, it's the type of yoga that is typically done seated on the floor and gentle stretches are held for minutes at a time, three to five minutes or sometimes longer. Very gentle stretching, over time, can certainly improve mobility. So I do recommend it, however, I do caution folks to be careful not biting off more than they can chew at the start.

The theme that you're hearing from all of us, it's gradually building, right? We don't want to do too much, too soon. So gradually increasing your capacity, your work, but also gradually

increasing your stretching will help with mobility. We don't want anyone trying to do too much, too soon.

Jennifer Gillette

Thank you. And another one, lots of medical questions today. A healthcare provider asks, what about weightlifting during admission for transplant? Some patients ask for it. What intensity would be okay?

Shernan Holtan

Another excellent question. I will say that there is more than data in this space. The big limiter tends to be the platelet counts and our risk of bleeding with really heavy weights. And so, certainly, we don't want to increase that risk. So what is the safe and correct amount? I think it is unknown. But platelet counts notwithstanding, I think a really good way to get a good stimulus without a ton of weight are resistance bands.

So obviously, I'm used to barbell training. I like weights and that's great. But if I can't have access to heavy weights, I will take resistance bands on trips and I get a great stimulus with those. And so, I really encourage people to look at those types of options and learn different techniques of using resistance bands, you can get a great stimulus without lifting a heavy weight.

Jennifer Gillette

That's wonderful. Which of course with weightlifting can come that discomfort or muscle soreness. And we have another person here who asks, what are some things, other than supplements or pills, do you recommend for that discomfort that patients might feel that's just the normal exercise soreness?

Shernan Holtan

Yeah, I would say just know that it improves with time. So repeated exposures will increase your capacity. So when you first get started, you'll notice potentially more soreness because the stimulus is so novel. But over time, that won't happen as much. And in fact, you might feel your muscles, but they'll actually feel a little bit better and better.

So I would say, don't fear that pain. Maybe initially, there's going to be a little bit of stiffness, a little bit of soreness but over time, your body is resilient and it will adapt. And if you just gradually gently keep increasing the exposure over time, you're going to adapt in a way that doesn't leave you in chronic pain.

Jennifer Gillette

Thank you. And another one I see here is, how much calcium should we be taking for bone health after a bone marrow transplant?

Shernan Holtan

Great question. And that may vary for different individuals as well, so I'll actually defer that one to everyone's individual health care team.

Jennifer Gillette

OK. Thank you. And Samantha, if you are meeting with a patient and they're having a really rough day and just discouraged with where they're at physically, what is a tip that you would recommend to them just trying to cope with everything that they're going through on this journey?

Samantha Lebner

Yeah, so I am a big advocate in using CBT and kind of reframing some of the more challenging barriers that come with chronic graft-versus-host and its effect on your daily life. So a lot of what I talk to patients about is not necessarily just sitting with how difficult it is. That's definitely part of it and acknowledging the very real challenges it has, but it's also empowering people to reshape their narrative and learning about what the barriers are, getting creative around them and sort of creating a plan around that so it empowers them to think more creatively about these barriers.

Jennifer Gillette

I like what you're saying. That mixes well with Matt and how he adapts and plans but still finds a way to have his journey, which, Matt, for you as well. As you talk about what you've been doing to help yourself, to anyone that might just be discouraged today with some of those rough days, is there any last thoughts or messages or things you found helpful on the tough days to share?

Matt Willen

You know, I find the best thing to do is just to listen to my body and how it feels, every day. And I'm almost a year out. People still tell me that it's early in the recovery process and I have good days and I have bad days. And I just, I've learned to be okay with that. And there are some days when I go out and if I just don't like walking for three miles, I just feel like just getting out, getting some air, I'm okay with that. And I think there's no need to beat yourself up over this. It's okay to just listen to yourself and listen to your body and let it tell you what it needs.

Jennifer Gillette

I appreciate those words of wisdom. Small steps matter, for sure. And we might as well turn off the negative thoughts and the shame towards ourselves because we'll have good days and bad days.

But I just want to thank our three amazing speakers. There was so much great information shared here today. And we really hope that you found something in this program helpful for the goals you have as you are trying to heal from your transplant. And we also want to thank our sponsors, our partners, and Kevin, thank you for helping us again today. Great job, everyone. I hope you all have a great day. Thanks for joining us.

Operator

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