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Jennifer Gillette- Licensed Staff Social Worker NBMT LINK
Laura Beilke- Staff Attorney for Triage Cancer
JR and Deb Brandt- Couple and Speakers from Bozeman, Montana

**Operator:** Ladies and gentlemen, thank you for standing by. My name is Desirae, and I will be your conference operator today. At this time, I would like to welcome everyone to Expert Tips on Navigating Finances and Insurance Before, During and 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 again, press the star one.

I would now like to turn the conference over to Jennifer Gillette. You may begin.

**Jennifer Gillette:** Thank you, Desirae. Thank you, everyone, for being here today. Yes, I'm Jennifer Gillette, the Staff Social Worker at the National Bone Marrow Transplant LINK. This month's program will focus on Expert Tips on Navigating Finances and Insurance Before, During and After a Bone Marrow/Stem Cell Transplant.

A special thanks to our generous sponsors, the Leukemia & Lymphoma Society, Incyte, and Johnson & Johnson. We also thank our esteemed LINK partners; we know we could not do all these great programs without you. So, thank you so much for being a part of our team.

Just a brief outline for our program today. I'm going to do a brief introduction about the National Bone Marrow Transplant LINK for those who may not be familiar with it, and then I'll introduce you to our professional speaker today, Laura Beilke, who is a Staff Attorney for Triage Cancer. And then, we'll hear from our survivor speaker JR and his wife, Deb, who we consider a secondary survivor because she was his caregiver, and they'll be joining us from Montana to share with us how they have navigated all these financial hurdles. And then, we will have questions for the remainder of the call.

So, for those who may not be familiar with the LINK, our mission is dedicated to helping individuals and their families from diagnosis through survivorship. We provide resources, support, and education. Some of those resources are our Lunch & Learn programs, like you're on today. They can be disease-specific, survivor issues, GvHD, or a variety of other coping types of topics.

We also have our Marrow Masters podcasts. We just released our 18th season today for young adults dealing with this journey, and so I highly encourage you to go check it out. It is a very popular program with over 36,000 downloads. We also have our webinars in the fall, our Coffee Klatch, which is basically a Zoom support group. We have our peer support program, our Celebrating Second Birthdays program, and our Survivors Thrive Book Club, as well as our Healing Arts program that has been a great coping tool for people going through this journey. We have a content-packed Facebook page with daily inspiration and relevant tips for survivors. We have a great book series on all things transplant, and we can assist you with referrals, so if you feel like you need some more support, please reach out to us. We are happy to help.

Before we begin today's program, I'd like to review just a couple of housekeeping items. One, we ask that you please try to keep your questions concise, as we want to answer as many as possible today. We know that there's a lot of questions on these subjects, but if you have more than one question, please ask one at a time and get back in line in the question queue. We also ask that you use this as a way to stimulate conversation with your providers or the people on your team. We cannot give actual individual advice today. Okay?

So, now on to the educational part of our program. We're going to begin with Laura Beilke, who is the Staff Attorney for Triage Cancer. Laura earned her Juris Doctor from Brooklyn Law School and her Bachelor of Arts in Neurobiology and Psychology from the University of Wisconsin, Madison. Laura is a member of the State Bar of Wisconsin, and she is driven by a desire to leverage her legal expertise and background to make a positive impact within the cancer community. Thanks so much for joining us, Laura.

**Laura Beilke:** Hi, thank you so much. Hi, everyone. I am very excited to be here today, and I want to first start out by saying thank you for having me. And before I dive into this topic, tips for navigating health insurance, I would just like to tell you a little bit more about Triage Cancer. We are a national non-profit organization that provides free education on the legal and practical issues that may impact individuals diagnosed with cancer and their caregivers. And we provide this free education in a variety of ways, whether it is through our educational events like our monthly webinar series and our Triage Cancer conference, through our written materials like our quick guides and checklists, that are fact sheets that provide information on some key topics within the cancer community. Or through our legal and financial navigation program, which is where we are able to provide one-on-one support to individuals. All of these free resources can be found on our website at triagecancer.org.

To process today's topic on health insurance, I first wanted to acknowledge that navigating health insurance can be very challenging. They do not make health insurance easy to understand, and a big part of that is the language that they use. It really can be like learning a whole new language. In fact, 96% of Americans cannot define the terms used in a health insurance policy. And because of this, it makes sense that we have a difficult time understanding how health insurance works, or even how to make choices between our options. And it really is important to understand all of your health insurance options. If you don't understand all of your options, it is difficult to pick the best plan for you. And what is best for you, and your care needs now, may change in the future. So, having all the information to make it much easier to make an educated decision, which could result in saving you money in the long run.

With multiple options for health insurance, whether it's multiple marketplace plans or COBRA versus a marketplace plan, or choosing between Medicare plan options. There are a few factors to consider when trying to pick a health insurance plan with the lowest cost. While it may be tempting to pick the plan with the lowest monthly premium, your monthly premium only accounts for one expense related to a health insurance plan. You will also want to look at the deductible, the out-of-pocket maximum, the cost share or co-insurance, and co-payment. Your monthly premium lets you know the bare minimum of what you will pay for health insurance in the year if you don't actually receive any healthcare. So, you are going to pay this monthly premium whether or not you go and receive medical care for the rest of the year. Your deductible will determine what amount you must pay before your insurance even kicks in. Once you've met your deductible, the insurance company will start contributing to your healthcare expenses in the amount provided in the cost share. This means that if you have a cost share of 80/20, once you have met your deductible, the insurance company will cover 80% of the cost, and you will be responsible for the other 20%. The out-of-pocket maximum tells you the amount of money that you have to pay out of pocket before your insurance covers 100% of your care.

There are other things that you need to be paying attention to when comparing health insurance plans. The two main things I would recommend looking at when picking a health insurance plan are the planned networks and the planned formularies. A planned network determines which providers the insurance plan will cover. So, an in-network provider is going to be covered by your insurance and will factor into all of the financial considerations that we just talked about. An out-of-network provider is likely not going to be covered by your insurance plan, and you will likely have to pay for that care entirely out of pocket, and that amount will not go toward your out-of-pocket maximum. So, when taking a health insurance plan, you want to look into whether your current providers are considered in-network for that plan. Now, a formulary is a list of prescription drugs that are covered by your health insurance plan. If there is a prescription drug that you take that is not included in your plan’s formulary, you may have to pay for it entirely out of pocket. So, you do want to take into consideration whether any medications that you take are included in a planned formulary before selecting that plan.

On our website triagecancer.org, we do have some resources to help you with comparing plan options, including an animated video and a health insurance comparison worksheet that can help you compare the costs of different health insurance plan options. Now, once you have the right health insurance, you want to make sure you use it in the most effective way. You should try to use in-network providers and pharmacies to help keep the cost of care down. You can also request pre-authorization before you receive certain care in some circumstances, and the insurance company may require you to get your care approved before you receive it. And you can do this by asking your insurance company whether a pre-authorization is needed and how to get one. You can also ask your healthcare team whether they will get the pre-authorization for you or if you need to do it yourself. You will also need to complete and submit the necessary forms on time to get the pre-authorization.

Now, when it comes to prescriptions, remember, your insurance company has a formulary, and that is the list of drugs covered by your insurance plan. Formularies break drugs up into different levels, and usually, the higher you go on the level, the more expensive that drug is going to be. If there is a prescription drug that you need that is not included in the formulary or is on a higher level, you can request an exception. In the request, you will likely have to explain why you need the exception. This could be because you're allergic to another drug, or maybe you tried the drug recommended in the formulary and it didn't work. If the drug you need is not in the formulary, an exception request can help you access that drug without having to pay for it entirely out of pocket.

One of the things that we think is incredibly beneficial for people to understand with health insurance is that they don't necessarily have to take no for an answer if they are denied coverage for their care by their insurance companies. When that happens, as consumers, we generally have two rights or two opportunities to appeal that decision. The first step after an insurance company denies coverage for your care would be to submit an internal appeal. An internal appeal is going to be an appeal directly with your insurance company, and you are going to follow your insurance company's appeal procedure. There is usually a time limit on filing the appeal, so make sure you submit your internal appeal within 180 days of receiving the denial. If the insurance company denies their internal appeal, you can request an external appeal. And an external appeal is going to be a process through your state or through the Federal Department of Health and Human Services. It is sometimes called an external medical review or independent medical review. And you must submit your external appeal within four months of receiving the denial of the internal appeal. If there is an urgency to the appeal, you can submit an internal appeal and an external appeal at the same time for what is called an expedited review. Expedited reviews are decided within 72 hours of receipt. These appeals are reserved for instances where a delay in treatment would seriously jeopardize someone's life or health. Triage Cancer does have a variety of resources on health insurance appeals, including quick guides and an animated video, and an appeal tracking form to help you with this process. And again, all of these resources can be found on our website, triagecancer.org.

So, even if you have done your best by taking the best health insurance plan for you and utilizing that appeal system, you're still going to have to deal with medical bills, and I would like to now focus on some key practical strategies to help manage the medical bills. So, once you receive care, you're likely going to get a ton of correspondence. Just from your insurance company, you could get three different pieces of mail: one saying that they have received the claim, one saying that they're processing your claim, and one called an Explanation of Benefits or an EOB. This EOB will give you an idea of how much you are going to have to pay out-of-pocket for a specific claim. Plus, it will give you information on how much you've already paid toward your deductible and your out-of-pocket maximum. Now, you will also get a bill directly from your provider, and this could be the hospital where you've got care, from your doctor's office, or from a lab company. The challenge is that all of these pieces of communication from the insurance company and the provider may be sent in different manners, like physically in the mail, sometimes it's e-mail, sometimes you get access to it through a patient portal. And they don't always come in the order that we've been talking about them in. Many providers are, in fact, faster than the insurance company at signing the bill than the insurance company is at processing the claim. So, it is important to keep track of these pieces of communication and make sure you are comparing the EOB before paying any medical bills. There is a chance that your medical bill will be for an amount that is much larger than you actually owe, because the insurance company hasn't even processed your claim yet. If you are waiting for the EOB before you pay a medical bill, it can be helpful to communicate this with your provider, so don't just think you aren't planning on paying. This could also be a great time to ask any questions you might have about your bill, like why am I being charged for this particular service, to appeal any denials that you might have received. This can also be a time to see if you qualify for what is called Hospital Charity Care. So, non-profit hospitals are required to offer free or discounted health care to patients with certain incomes. This is called charity care, but it could also be called patient financial assistance or ability to pay programs. Charity care can include inpatient and emergency room services. Non-profit hospitals are required to post their financial assistance policy online and in the hospital, but there is this amazing non-profit organization called Dollar For, and they can check to see if you're eligible for charity care at your hospital, send you tips on applying, or even submit an application to the hospital on your behalf. Again, that non-profit name is Dollar For.

Now, if you are in a situation where you owe healthcare providers, try talking with them. We do suggest doing this before the due date of the medical bill, and especially before they turn any… or turn over your unpaid bills to collection agencies. If you cannot make a payment, you could always ask for more time or to see if they'd be willing to negotiate a payment plan or accept a lower lump sum payment, or to see if they have any financial assistance programs at the place of where you received care, or if they may know of any. The motto we like to remember here is that it can't hurt to try. So, with all these correspondences, it may be difficult to keep track of everything, and at Triage Cancer, we do have a medical bill tracker worksheet to help with this. It is an Excel document that you can download, and as you start to receive medical bills and EOBs, you can put in information about the specific bill, and it can help track how much you have left to meet your deductible, and to meet your out-of-pocket maximum.

One of the reasons why we think it is beneficial to keep track of all of this is because you do not want to pay more upfront than you have to, especially in a scenario when you have already met your out-of-pocket maximum. While your insurance company usually keeps track of what you have to pay for medical care out-of-pocket, your healthcare provider most likely will not know. And when you visit a provider, you may be asked to pay a co-payment when you check in. If you have an insurance plan that includes your co-payments in your out-of-pocket maximum, you may be asked to make that co-payment unnecessarily. Your provider may not know that you've already reached your out-of-pocket maximum and therefore aren't responsible for paying any more co-payments for the rest of your plan term. It is better to know that before you make the payment, rather than trying to get paid back from your provider.

Lastly, it is good practice to keep records of medical bills, payments, EOBs, and any pre-authorizations. Plus, any expenses you paid related to your medical care, like meals, travel costs, and lodging, you'll need to keep them if you're submitting bills to health savings accounts or flexible spending accounts. But even if you aren't, some of these expenses that are paid towards healthcare can, in fact, be tax-deductible. But you do have to keep records of that.

Lastly, I would like to talk about Medicare and some recent changes to Medicare. So, Medicare is a government health insurance available to those who are 65 and older or who have been receiving Social Security Disability Insurance payments for two years, or who have end-stage renal disease or ALS. There have been some major changes to Medicare in 2025 to help with out-of-pocket costs, specifically with Part D prescription drug coverage. Now, these changes have been somewhat convoluted with the implementation of the changes, but it did get a little bit simpler in 2025.

So, in 2025, because of the Inflation Reduction Act, there is now a $2,000 out-of-pocket maximum for Part D drug costs. This $2,000 out-of-pocket maximum applies to Part D Plans and Medicare Advantage plans with drug coverage. It does not apply to drugs covered by Part D. So again, the out-of-pocket maximum for Part D drugs in 2025 is $2,000. For next year in 2026, we know that this number is going to increase, and it will be a $2,100 out-of-pocket maximum for Part D drug costs.

Another major change that came from the Inflation Reduction Act was a new program called the Medicare Prescription Payment Plan. This plan allows you to spread the cost of your prescription drugs over the calendar year rather than having to pay a large amount of money all at once. Keep in mind, though, this is about spreading out the cost. It's not about saving money. You will be paying the same total amount for the year regardless of whether you enroll in the program or not. The Medicare prescription payment plan is a voluntary program that you can electively choose to enroll in, whether you have a Part D prescription drug plan or have a Medicare Advantage plan that has drug coverage. The program is administered by the drug plan, so if you want to and will in this plan, you will need to contact that drug plan to let them know that you want to enroll. Just like it's voluntary to enroll, you can choose to unenroll in it at any time. But if you do choose to unenroll, you have to pay the balance that you owe.

If you do choose to enroll in the Medicare prescription payment plan, you won't pay the pharmacy when you pick up the prescription drugs. Instead, your plan will send a monthly bill for what you owe. So, you will end up receiving two separate bills from the drug plan each month. So, one for the monthly bill from the payment plan and one for your monthly premium.

So, there are some potential programs to access help paying for Medicare if you are trying to deal with the out-of-pocket cost for Part A and Part B. Collectively, these programs are called Medicare Savings Programs, and there's actually four different programs with different requirements based on your income level. And each program has different benefits. If you'd like more information about these programs, we do have an entire quick guide on Medicare Savings Programs that provides information about the eligibility requirements and the benefits for each program.

Now, if someone is struggling with a pocket cost under Part D prescription drug coverage, there is a program called the low-income subsidy, also sometimes called LIS or extra help, and this program can help pay the premiums, for deductibles, and the co-payments for prescription drugs. Then, at the state level, some states have state pharmaceutical assistance programs to help with these costs. These state pharmaceutical assistance programs are not available in every state, but you can find information on the Medicare website.

So, these is some of our tips to navigating health insurance, and I do just want to quickly remind everyone that all of the information I went over, and even more information, can be found on our website, triagecancer.org. Thank you, everyone.

**Jennifer Gillette:** Thank you so much. That was so informative. We really appreciate you being here today, Laura.

And now, we're going to move on to our dynamic duo, Deb and JR Brandt. Deb is the wife of JR and caregiver throughout his transplant journey. She was instrumental in directing family finances during that difficult time. She is currently employed by the State of Montana of Vocational Rehabilitation Department, and Deb works with people who have disabilities to help them reimagine their work goals. As far as JR, he's the husband of Deb, and he has leukemia and is a stem cell transplant survivor. In 2016, he had chemotherapy at Kaiser Hospital in Roseville, California, and underwent his transplant in 2017 at Stanford University Hospital. JR is currently retired and receiving Social Security Disability due to a common transplant side effect known as chronic graft-versus-host disease. He was formerly a practitioner in the orthotic and prosthetic profession, where he served in many capacities.

Thank you so much to the both of you for being here today.

**JR Brandt:** Thank you, Jen. I'd first like to start off, I guess saying thank you, Laura. Some of the things that you had talked about earlier, and we'll probably touch on a little bit, because we've actually, you know, experienced some of those things.

I guess first and foremost in our journey was after my diagnosis, and I actually went into the hospital through the ER, and I didn't get out for a month. The first thing I think that we did within the first few days after the debt was settled was to connect with the Social Services Department super early. I know that Deb kind of was in on that for the most part, kind of tied into that.

**Deb Brandt:** Yes. Hello. This is Deb, wife of JR. Our social worker was essentially our angel and was trying to connect us with community resources as well as in-hospital resources. Financially, the hospital itself jumped right in for what they could help us with. As far as what our financial plan looked like through them, that was very, very, very helpful. This social worker also aligned us with JR's particular cancer diagnosis organization. And for us, that was the Leukemia and Lymphoma Foundation; this particular organization allowed JR, diagnosed with that particular cancer, to apply for some of their grants and funding to be put towards his care. And that was very instrumental in assisting us financially. JR?

**JR Brandt:** Yeah, I think the other thing that was key for us is to apply for Social Security very early because they have what's called a "Blue Book", quote unquote, list of diagnoses. And I think most blood cancer, mine at ALL, was certainly included in that. And then they turned on the Social Security Disability payments for me right away. And I think, later, Medicare initiated with that diagnosis and Social Security, although I believe right it took like 10 months or so before I finally was on the Medicare rolls for that. I know that by doing that early, it takes some of the pressure off because, one day I was working full time, everything is going great. That's working full-time. Next day, I'm in the hospital, and you're you feel like you're done. You know, the income is cut off. You've got payments to make to Medicare, you've got the rent, mortgage, etc. So, that's an important part you want to speak about the GoFundMe a little bit.

**Deb Brandt:** Oh yes, I come from a very large family, and one of my siblings decided that this was the perfect opportunity to start a GoFundMe, and essentially, my brother just wrote our story out. He's my baby brother. He can never remember a time without JR in our lives. Quite a few years separate us. And so, he started GoFundMe, shared that with friends, family, close community members, and those funds really assisted us as we progressed to the transplant stage of JR's diagnosis. We moved several 100 miles away from our home and had to look for temporary housing in the Bay Area around the Palo Alto area in Stanford. That was a very, very daunting proposition, extremely expensive. There wasn't housing on campus while JR was hospitalized for the better part of two months. We leaned into relatives, local churches, local cancer support centers are a wealth of support and information. We had an offer by a religious organization and aligned ourselves with a friend of a friend while he was at Stanford in the hospital, whose just doors were opening up more than we could have ever imagined. By just going through each day, expressing the need that we needed help, making it well known, and really leaned into our medical providers and social workers.

**JR Brandt:** Yeah. And I think going back to what Laura had talked about, as far as medical bills, as they start to rack up, for us, we were very, very fortunate because Kaiser is kind of an HMO organization. And they gave us the financial aid, or we qualified for it right away, and it wiped out all of our remaining out-of-pocket max deductible, etc. So, we had no bills. They actually paid for our on-campus housing over at Stanford, so they were able to pay for that. And then when I was at Stanford, they had a financial aid department, of course. And we were able to get in there and qualify on that because once my income dropped, it kind of freed us up as far as being able to qualify in those types of situations. I had a situation prior to cancer that was in…and we were uninsured for a brief period of time, and I had a kidney stone. And just for an example, I had to go to the local hospital there, it wasn't Kaiser at that point. It was another non-profit hospital. And so, I went as a kidney stone taken care of, and I got my bill for $10,000 and then another $2,000 bill from the doctor that was on call. And I was then able to get in line with that charitable foundation portion of that hospital, write a letter to them, they approved my request, they dropped the bill down to like two grand. And then I negotiated with the office staff at the Physician's office, down to $400. And I finally went back and forth, and they're like, what can you afford? I'm like, I can afford $400.00, I'll pay you right now. And they're like, alright, give me the credit card, and so that was done and out of the way. So, kind of you just kind of got to sneak into that. I think another important thing is to always investigate your pharmaceutical companies; they have patient support plans as well as clinical trials that you can get involved in. And also communicate with your insurance company, identify your coverages and financial assistance that they may have available, and then you can kind of go from there and hopefully get some assistance that way.

I think that's about it. Unless we can take questions, of course, at the end, but I think we're good.

**Deb Brandt:** Thank you so much.

**Jennifer Gillette:** Thank you both. We really appreciate you sharing all the creative ways that you have figured out how to navigate these financial hurdles, and we really appreciate you being here. I am going to hand it over to Desiree and let you tell our callers how they can line up for questions in our queue.

**Operator:** Jennifer, we will now begin the question-and-answer session. If you have dialed in and would like to ask a question, please press star one on your telephone keypad to raise your hand and join the queue. If you would like to withdraw your question, simply press star one again. If you are called upon to ask your question and are listening via speakerphone on your device, please pick up your handset to ensure that your phone is not on mute when asking your question. We do request that today's session to please limit to one question and review for any additional questions. Again, press star one to join the queue.

**Jennifer Gillette:** Okay. As we start having people line up for questions, I'm also just going to throw out a couple of other resources. One, I want to let everyone on this call today know that we have a free download book, our financial resource guide. If you go to our website again, you can download it for free. It has several financial organizations that are helpful. It also has information on how other people have navigated through this journey, so it's a guide that I highly recommend for anyone dealing with the financial aspect.

I also wanted to make you aware, just as JR and Deb we're talking about, a lot of drug companies have financial assistance programs, and it's not always just for people that are truly destitute; the middle class is often included in these types of programs. There is a great website called needymeds.org (N-E-E-D-Y-M-E-D-S.org), and you can type in the name of your medication, and it tells you what programs are available to help with that. I also want to let everyone know that we have been working with an organization, the Bone Marrow Foundation, they have the Cancer Buddy app. And they also have something for people that are looking to do some fundraising. Not only is there the GoFundMe, but they have one that is on their website that helps you organize those types of fundraisers. And when you receive the funds, it's not taxed; that's considered a gift. So, that is something…it's called Carelines, and that's through the Bone Marrow Foundation.

And just one word on applying for Social Security Disability, over the 25-plus years that I've been working in this field, I've seen several people apply for disability and get denied the first time. With Social Security Disability, if you truly are dealing with something that's going to be keeping you out of work for a year or more, or like JR said on that Blue Book list of diagnoses, if you get denied, I encourage you not to give up. You can even seek out an attorney to help you if assistance is needed there. But that is an important part of the many pieces of a puzzle to help you through.

But on that note, I'll stop for now because I could keep talking. But let's get to our first caller and hear the question for today.

**Operator:** And we do have a question comes from the line of Aurora. Your line is open.

**Aurora:** Hello. I want to know how JR and his wife were able to find the housing at Stanford.

**JR Brandt:** Okay. I mean, I can jump for that one. It actually is my father-in-law (Deb's dad) reached out to their church back in New York, which was a Quaker church where they were at and put the message out to their congregation if they knew of anybody in that area of California that might have a bedroom to allow someone to stay in for a little while. And it only took…what was it? It was only a couple of days, I think, and we received a call from a wonderful lady that had an extra room in her house that was right up the road, just off campus. And Deb was able to stay there for the whole time while I was an inpatient. And then when I was an outpatient, Kaiser put us in.

They have a…Stanford has some apartments right across from the hospital that they put a lot of their transplant patients in that need longer term follow up and Kaiser was able to pay for that for us. So, hopefully that answered that.

**Aurora:** Okay. Thank you.

**Jennifer Gillette:** Thank you. Can we have our next caller, please?

**Operator:** And again, if you would like to ask a question, please press star one on your telephone keypad.

**Jennifer Gillette:** As we're waiting for more questions, I have one question that I saw that was submitted a couple of times previously on our site. People asking for an advocate, Laura, are you aware of…I know JR and Deb, we're talking about like having a great social worker helping them out. But if someone doesn't have someone that's helping them as much as Deb and JR had, are you aware of organizations or anyone that helps someone find an advocate to help them with these kinds of things?

**Laura Beilke:** I do always think asking your provider or wherever you are receiving care if they have any sort of social worker, a patient advocate, maybe a financial navigator, they usually will have resources or someone to hopefully point you to. There are other nonprofit organizations, like Cancer Care. Their hotline is all staffed by social workers, I believe, and they may be able to help anyone that has questions on their helpline or may be able to know where to refer you to next to help you.

**Jennifer Gillette:** Great. Thank you. Desiree, do we have any other questions yet?

**Operator:** I'm seeing no further questions at this time.

**Jennifer Gillette:** Okay. Well, I am going to put a few more things out there and ask some more questions that were pre-submitted. I just want to piggyback on what Laura had said as far as organizations that are very helpful. I agree. I have worked many times over the years with Cancer Care. They are an amazing organization, as well as the Leukemia & Lymphoma Society. They have wonderful people on the other line, and NMDP and the Patient Advocate Foundation, all great organizations if you are looking for someone to help.

And so now to some of our pre-submitted questions, as far as here…one moment here, I am getting my place back here on the questions at hand. But one person wrote, I've been off having treatment for eight years now, and so many problems with the clinic, hospital, or insurance filing things incorrectly. Is there anyone who can help when things or what is a good process when it has been filed incorrectly? And Laura, maybe we'll start with you.

**Laura Beilke:** Well, if something is filed incorrectly with the insurance company, like there is some sort of administrative error from the hospital, the insurance company will most likely come back with a denial to provide coverage for that service. If that is denied, that's usually a quick appeal or even asking your healthcare provider to resubmit the claim. Some resources that can be helpful are like those financial navigators; usually big cancer centers or facilities will have financial navigators that can specifically help with communications with the insurance companies. Or you can always ask the insurance company if they would be willing to assign you a case manager and they can be the ones who are your direct contact with any type of insurance claims. It is important to remember though, that case managers do work for the insurance companies, so the insurance company is probably going to be their number one goal, but they are someone that can be helpful for you though in the long run and it's really helpful to have one person that you're contacting when you were calling your insurance company. So, a lot of the times when we call the insurance companies, we are getting multiple different people on the line, and it can be hard to keep track of who we're talking to plus, they can give us different information depending on who we are talking to. So, having one point of contact with that insurance company can be really helpful. Also, keeping this track of all of the medical bills and services that you are receiving, like that medical bill tracker form I was talking about. That can be really helpful in keeping everything organized and making sure that things are getting submitted and that you are receiving information back from the insurance company like that EOB.

**Jennifer Gillette:** Thank you. I see another one here. Oh, yeah, go for it, JR.

**JR Brandt:** I was just going to piggyback onto that because I don't want our listeners to feel like they're alone because I'm fortunate, because Deb has health insurance through her employer. So, I'm in a situation where it's Blue Cross Blue Shield as a primary, but then I have Medicare as a secondary. And for whatever reason, the care providers can never get that straight. So, they're always billing Medicare first, and then Medicare denies them. So, this thing goes on and on. And so, it's probably I'm still got bills that are out there from last year, sometimes that they're still trying to get paid for because they didn't process it correctly. And well, every time I check in, hey Medicare secondary, but it's just one of those things. You beat your head up against the wall, and it's like they're not listening. I'm not sure how that works, but they want to get paid. I'm like, look, I want you guys to get paid, but you've got to do it the right way.

**Jennifer Gillette:** Isn't that true? That was a very good thing to add JR. I know they are not alone; that's for sure. And thank you for adding that. Lots of phone calls dealing with all these financial issues on a cancer journey. It's like having a full-time job and it can be very frustrating, but yes, people are not alone.

I have another question here, and I'll start with Laura, but of course, JR and Deb, if you have anything to add, feel free to jump in. One person is saying they're at the point where they're probably going to need to apply for Medicaid, but they're also scared. Is there anything they need to do to protect like their home? They were talking about do they need to have their home put in a trust or something like that.

Laura, do you have any guidance on how to help them feel a little more secure with the steps they're taking?

**Laura Beilke:** So, Medicaid is federal government health insurance. However, each state has the flexibility to run their own Medicaid program. So, Medicaid does act differently depending on the state that you are in. And one thing that can differ with Medicaid across states is if they have what is called a estate recovery, and that is the process where if someone is on Medicaid and then ends up passing away, the state does have a right to recover any money that they paid for medical care through Medicaid and try and recover from that person's estate, and sometimes that does include a person's home. Again, the rules very much do differ across states on this estate recovery. There are some exceptions to this estate recovery. One thing, though that people could think about if their state does have a state recovery is to do what it called a Medicaid Asset Protection Trust. It's a very specific type of trust that protects someone's assets if they were to use Medicaid, and their state has an out-of-estate recovery. It is very specific in how it needs to be set up, and also, there are very specific rules around it. If someone is considering doing a Medicaid asset protection trust, it would be highly recommended to contact an attorney who either does estate planning or specifically does Medicaid planning. If anyone ever has questions about their specific state rules around it or how to get in contact with an attorney, they can always reach out to us and we'd be happy to speak to them through our legal and financial navigation program because again, it is very state specific both on the Medicaid side and also the estate planning side.

**Jennifer Gillette:** Thank you so much for that. Desiree, is there anyone waiting in the queue with the question yet?

**Operator:** There are still no questions at this time.

**Jennifer Gillette:** Okay. Well, I'll keep going with our pre-submitted then. Another caller asks, I've heard that Social Security Disability will not approve anyone who is still working. However, if I quit my job, I'll be unable to pay my bills and will lose health insurance. I've been honest on my Social Security application that I'm hanging on by a thread at work. Suggestions on how to navigate this and how long it typically takes to get a response from Social Security for an AML case? I am able to take a four-week paid leave of absence and another four-week unpaid leave to retain my health insurance. I'm ready to do that now but recently applied for Social Security. Any thoughts? That's complicated, Laura.

**Laura Beilke:** It is complicated because there is multiple parts of this. So, when someone or we get that question a lot. Can I work and apply for Social Security Disability Insurance? And our answer is it kind of depends. So, when someone submits a Social Security Disability application, the Social Security Administration is going to go through a five-step disability determination process. And the first question they're going to ask is, are you working and earning what is called substantial gainful activity? And substantial gainful activity is a monetary number that the Social Security Administration puts out that determines whether or not someone is working. In 2025, that number is $1620.00.

So, if someone is working and earning that much money or more, they are going to say you are working and they're going to deny your application right away. If you are working and earning less than that, they are going to continue the disability determination process. However, I believe it's the fourth question they asked: Can you do your current job? And if you are currently working, even if it is part time or substantially less than you were working prior, they still might have a hard time understanding how you can say you cannot do your current job or it might be hard for you to explain why you can't do your current job even if you are working substantially less than you were before. So, it can be really difficult to get an application approved for Social Security Disability Insurance while working.

With the other part of the question, I believe they said the diagnosis of AML. There is what it's called the compassionate allowance list, which I think JR mentioned and used the word like Blue Book and it kind of is like that. So, the Compassionate Allowance list is a list of medical conditions that presumptively meets the Social Security Administration standard of disabilities. While having a medical condition on that list does not mean you're going to be automatically awarded benefits, it does mean that it's going to speed up the application process much quicker than if you didn't have a diagnosis on that list. I think the average wait time to hear back on an SSDI application is over 200 days. But I have seen where someone has a diagnosis on that Compassionate Allowance list, they could do back within like one to two months. However, even though that application does get spent up really fast, there is what is called that five-month waiting period with SSDI benefits, and there is no way to get around that five-month waiting period. And that five-month waiting period is going to start on what they give you as your disability onset date, and that usually falls around the last day that you are able to work. And from that date and five months on, you are not going to be paid any type of benefit. And then after that month, then you'll start receiving benefit payments each month. So, it is kind of a confusing and multiple part thought process with all of this. Again, if someone has any types of questions about the application, process, timeline, considerations about how to handle this with work, what about health insurance? Again, I'm happy to speak with them through our legal and financial navigation program because there are a lot of different moving parts to consider with this.

**Jennifer Gillette:** We appreciate you so much, and we refer to you all the time. Oh, I'm sorry. Did we have a question or Deb, are you giving feedback?

**Deb Brandt:** This is Deb. I wanted to just jump in with an idea about navigating how much you can earn on Social Security, and it still works. So, as the introduction stated, I am employed by the state of Montana. Voc Rehab or Vocational Rehabilitation is a department within DPHHS, and it has a state program in each state. It allows anyone with a mental or physical disability to apply for work services. And anyone with a cancer diagnosis is eligible for these services. And a very quick point to that is if you are no longer able to do the job that you were doing before diagnosis, the state has federal and state funds to provide you assistance with job searching, something that you can do. In typically, this does not look like a full-time position.

There's training available, whatever that might look like, vocational training or school training to try to figure out what you can do with your new abilities. That may look very different than they did prior to your cancer diagnosis. Within our services, each state will typically have a benefits counselor that can meet with you and look at your individual income and assets, and let you know exactly how much you can work and still continue to receive your Social Security benefits. That is very relevant for most of the clients that work with our program. And again, Vocational Rehabilitation is a department that should be available in each state. So, that's what I wanted to add, an incredible resource for anybody who's willing to apply and become involved with that.

**Jennifer Gillette:** Thank you so much for that. I really appreciate you adding that. That's a very important piece. As well as I want to point out, they show just like JR had spoke about, people dealing with chronic graft-versus-host disease, about 2/3 of people will have some form of disability if they are dealing with chronic graft-versus-host disease, and that depends on the severity of it. Some people might have milder versions. Some people might have much more severe experiences with it, but as people are dealing with that, sometimes things can change. And so, I know that when someone gets Social Security Disability, they also have an opportunity to do a trial work period.

Laura, could you tell our callers a little bit more about that three-year program after someone gets on disabilities that they can kind of dip their toes, if you will? Trying to see if they can get back into working.

**Laura Beilke:** Yes. So, there is what is called the trial return to work period, and that is a program that the Social Security Administration has set up so people can see if they are able to go back to work without losing their Social Security Disability benefits right away. Now, it is somewhat of a complicated program to fully understand, but it allows you to try and return to work and earn as much money as possible for nine months while still receiving benefits. Now these nine months are not consecutive nine months. Those nine months are determined whether or not if you earn over a certain income threshold. I don’t want to quote on this number, but I believe it's $1160 in 2025. But if you earn $1160 or more for one month, that is going to be considered a trial return to work period month. And once you earn…and once you've accumulated nine months of those trial return-to work months, the Social Security Administration is going to do a review over those nine months and see if you were consistently earning over that substantial gainful activity that I was talking about or the $1620 a month. If you averaged over that substantial gainful activity, your benefits are going to end; if you did not earn over that substantial gainful activity, your benefits are going to continue, and you can still receive benefits for any month that you did not earn over substantial gainful activity. Once those three years of that extended period of eligibility is over, your benefits may continue, they may end, but depending on whether or not your benefits ended after those nine months or after that extended period of eligibility.

You have access to what's called expedited reinstatement, and if for some reason after your benefits that ended you go back to work, and then now your medical condition has become severe enough where you're no longer able to work again, you can call the Social Security Administration and ask to apply for expedited reinstatement. And during that time, you will start being paid Social Security Disability benefits again, while they're are reviewing your application. And then, depending if they are awarded, the benefits or not, your benefits might continue on.

What is great about the expedited reinstatement is the fact that you don't have to go through that whole initial application again. plus you wouldn't have to go through that five-month waiting period again, it's basically your benefits being reinstated instead of having to start all over again.

We do have a quick guide on transitioning off of SSDI and SSI that does go over that trial return to work period, plus all of the other programs that the Social Security Administration has to help individuals trial and return to work, including that Vocational Rehabilitation that Deb was talking about.

**Jennifer Gillette:** Thank you so much.

**JR Brandt:** I have one quick thing to add to that, Laura. I know we're getting close to our end of our time. I was on that; I think they also called it the Ticket to Work program. And when we relocated to Montana from California, I went back part-time in my profession, just to see if I could still do anything. And I was able to work for about two months, and then COVID hit, and so with a compromised immune system and my chronic graft-versus-host getting worse and creating problems with my hands, I decided I couldn't do it anymore. So, I notified Social Security, and just the thing you need to be waiting for at that point is a medical review because they quick sent out medical review information to me, and it's a little arduous, and you have to really work through it. And they want documentation back in two weeks and then you hear nothing but crickets for three months, and then they'll ask you for another one that they went back in two weeks, same kind of thing. So, it does take time. You just got to maintain your sense of humor through the process.

**Jennifer Gillette:** And actually, JR that is exactly perfect I was going to say on this call. First of all, I just want to thank everyone for being here. This has been such great information, but I am sure people are listening. There's so many great resources, but it makes your head spin hearing all this too. What has helped you and Deb cope with this very involved, complicated journey? What has gotten you through to or two of you through this I should say?

**JR Brandt:** Well, I think from my perspective, and Deb will chime in a second, I always try. And I'm an optimist, and my glass is half full all the time. Trying, like I said, keep a sense of humor, but the other thing is I'm grateful to be here. Okay. So, it's better than the alternative, which I was very close to that alternative and so I feel very fortunate.

And so, I look at these things as being really small potatoes. It's not going to make or break my life, and I guess the ultimate thing is if you had to claim bankruptcy to get rid of some of the financial aspects of it, you perhaps could do something like that. But I'm a believer that you can really negotiate through a lot of these things, if you can just maintain a good attitude about it. And then, I don't know, Deb, do you have anything to add to that?

**Deb Brandt:** Well, and with a spider of a husband like that, all I needed to do was just lean into him, and it just seemed easy. I'm fortunate that I had a humongous community of family and friends around me. I did feel okay about being vulnerable. I cried a lot. I took a lot of walks. I talked about it. I acknowledged how hard it was, how excited we were to be together. The next day, it's just one hour of each day at a time. Cry when you need to, rejoice when you can. It is an incredibly, very, very tough journey, and you can acknowledge it for exactly that.

**Jennifer Gillette:** I think that is a perfect way to end this call today at one step at a time. And Laura, I want to thank you too so much with everyone on this call. Thank you for being here. We are going to be sending a survey out. You can give us some feedback about the call today, as well as future programming. And if you need any extra support, please reach out to us. But again, on behalf of our sponsors, our partners, and us at the NBMT LINK, we just hope everyone has a good day and that you found this program helpful. Thank you.

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