



Transcript of our program that can also be used as a closed captioning tool while listening to our program.

**Executives:**

Peggy Burkhard- Executive Director of the National Bone Marrow Transplant

Kathryn M. Smolinski- MSW, JD Director, Legal Advocacy for People with Cancer Clinic, Associate Clinical Professor, Wayne State University Law School

Jennifer Leal- Board Certified Patient Advocate, AML/Stem Cell Transplant Survivor, and Clinical Data Scientist

This is a transcript of our program. At times, with transcripts, there could be errors, so we recommend using this tool in a conversation with your provider and not as medical advice.

**Operator:** Hello and welcome to the **Advocating for Your Care, Rights & Accommodation as a Bone Marrow/Stem Cell Transplant Patient Call.**

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

**Peggy Burkhard:** Thank you, JL. Welcome, everyone. My name is Peggy Burkhard, and I'm the Executive Director of the National Bone Marrow Transplant LINK, and I'd like to welcome you to our Lunch & Learn program today. So, I'm filling in for Jen today. So, I hope everyone will be patient with me. She had a family emergency and I'm ready to go with my wonderful speakers, but I'm not Jen. So I just wanted to make sure everybody knew that. So, as JL mentioned, we're going to be talking today about Advocating for Your Care, Rights & Accommodation as a Bone Marrow/Stem Cell Transplant Patient. Special thanks to our generous sponsors, the Leukemia & Lymphoma Society, Incyte, and Johnson & Johnson, I don't know where we would be without these sponsors. They are so generous and kind to us and we appreciate them. We also thank our esteemed LINK partners.

So, just so everyone is aware of our program today, we're going to start with a brief introduction by me. It will tell you a little bit more about the LINK, and then I'm going to introduce Kathy Smolinski, an Associate Clinical Professor at Wayne State Law in Detroit. Then I'm going to introduce Jennifer Leal, who is a Board Certified Patient Advocate. She's also an AML survivor from a stem cell transplant and a Clinical Data Scientist. You are going to love these speakers. We are so lucky to have them today and this is going to be a great program. We will then open the floor for pre-submitted questions, comments, and live questions, and then when we wrap things up at the end with a few minutes just going over some resources.



So, those of you that are not familiar with the LINK, our mission is dedicated to helping individuals and their families from diagnosis through survivorship. Some of the resources that we provide, including this Lunch & Learn today are webinars, our Marrow Masters podcast, which we're in on season 14, we're recording right now. We have 14 seasons that are available on our website to check them out or whatever way you'd like to get to our podcast, and that's Marrow Masters. I wanted to fill you in a little bit on if you're new on some of the Lunch & Learn subjects that we cover. We covered Chronic Graft Versus Host Disease, disease, specific information, caregiving, coping, treatment options, and survivorship after a transplant. And you can check those out at nbmtlink.org. We have all the recordings there.

Thanks to our Jen Gillette. We have a robust Facebook page with daily inspiration and relevant tips for survivorship. We have a pure mentor support program. We have a book club. We have a coffee clutch. We have a new healing arts program. We have a second birthday program, and of course our books which we work very hard to keep updated on our website. You can see all of our listing of all of our books, some are now downloadable. And we just finished up the finance guide in January, a brand new book, the first of its kind that covers the specific needs of our financial needs of bone marrow stem cell transplant. Please reach out to us if you need us. Jen Gillette is an incredible licensed staff social worker. We can do individual calls. She's always available. Not the day you need her, but she's available within weeks' time. She works very part-time for us.

So, before we begin today, I want to review a few housekeeping items. To maximize the experience for everyone on the call today. So, please be mindful and being concise with your questions so that we can answer as many as possible today. After your first question, you will be muted. You can then go back to the queue, and you can hit star one, and you can ask a second question. Please note that the information provided in this program is meant to stimulate conversation with your own healthcare provider and is not meant to replace your individualized medical care.

So, now on to the educational part of our program. We are so thankful to have our speakers with us and I will start by introducing Ms. Kathy Smolinski, who is an Associate Clinical Professor at Wayne State Law School in Detroit, where she directs the legal advocacy for people with cancer clinic. Wow! A medical legal partnership designed to provide free legal services, free to eligible patients at Karmanos Cancer Center as a part of the law school's curriculum. She has a long career in Oncology Social Work in cancer rights, attorney, and has published articles, books, chapters, and lectured nationally on legal and psychosocial issues in Cancer Center. She was honored, this is pretty neat, the 2023 Wayne State University President's Award for Excellence in teaching. Wow! Kathy, congratulations on that. Thank you so much for being with us today, Kathy.

**Kathryn Smolinski:** Thank you, Peggy. Thank you so much. Yes, I've done a lot. It's because I'm a little bit older. And so, as we go through life, if we have the privilege and ability to get an education, which I took advantage of and got my MSW, and then my JD. And I've worked exclusively in Oncology ever since I graduated some 30-some years ago. So, I'm delighted to be here to share what I know and hopefully, it will be helpful to all of



you out there listening. And it's... I'll be giving an overview of a lot of things and my hope is that it will stimulate enough for you to look up more things and maybe reach back to Peggy and Jennifer if you have more questions. There's a lot when it comes to the kinds of rights and benefits in laws that can touch an individual who's going through any kind of treatment with cancer, and especially with a BMT. So, I was asked to talk for about 20 minutes, which knowing that I'm a social worker and a lawyer, that's a lot to ask me to only talk for 20 minutes, but I totally appreciate that I'm having the opportunity to cover as much as I can in that time.

So, I've kind of picked five areas that I'm going to quickly go over, and they are, just so you know:

- What types of income replacement benefits that you might want to apply for when you are unable to work while going through your BMT or treatment?
- Two, what are your rights to take a leave from work and still have your job upon your return?
- Three, what are your rights when it comes to accommodation at work?
- Four, what legal documents could be helpful to prepare at this time?
- And then five, what rights do you have with your health insurance providers?

So, I'm going to just review those areas and give you some information and then, hopefully, it will stimulate some questions through the Q&A part.

So, the first thing I really want to talk about is what we call a lot is like disability-related cash benefits because most individuals when they're going through treatment, many times need to replace the cash or the income they would typically get from their job or from their employer because they can no longer work. So, through your employer, depending on your employer, a lot of people have access to like sick days or vacation, short-term disability or long-term disability. Okay, so those are some through the employer, and talk a little bit about those. And then through the government, there's through in Michigan through the Michigan Department of Health & Human Services, there's some cash assistance programs. And then through the federal government, there's the Social Security Benefit. So, I'm going to talk a little bit about those.

So, when it comes to short-term and long-term disability benefits, usually they pay out anywhere between 60 to 80% of your routine pay. But they're very policy-specific. So, when I talk to individuals about short-term and long-term disability through their employer, the first thing you have to realize is do I even have these benefits? And so, a lot of times a quick way to look is just to check one of your pay stubs because when you look at a pay stub, it usually will tell you and record everything that you've paid into, like your health insurance that you've paid into. Maybe a short-term disability, a long-term disability, a catastrophic illness plan. Usually, there's a premium involved and that is taken out of your paycheck, so that's a good first place to start. It's just to look at your pay stub to see, "Hey, look, it looks like every month or every two weeks this gets taken out. It says long-term disability, I must be in the program." So, that's just a quick way to start. Obviously, you can ask your supervisor or your human relations staff to see what you're eligible for. A lot of times people have been at work,



it so long they've lost their sort of employee benefits, like information so they don't know. But a lot of employers now have a portal online, so you can go online, and see what your benefits are. But again, you can always ask your human resource department.

So, with short-term and long-term disability, it's always policy specific. What does that mean? There's a policy. There's a written policy. So, like, how you make a claim, how much you're going to get replaced in your income, how long that particular short-term disability lasts? How long the long-term disability lasts, etc. How it's defined, so what actually defines a disability? All of that is in the policy. Okay. So, it's just important to know, to ask, to look at your policy. And a lot of times they'll send you what they call like a summary disposition of your policy. It's like a...or summary plan. Usually like about a few pages long, but it's usually enough to be able to kind of understand and then usually there's instructions in there how to make a claim. But short-term usually pays for about three to six months, sometimes up to a year. And long -term usually pays for about two years, but sometimes it can pay as long as five to 10 years. Sometimes they can pay all the way up until the age of 65, depending on what's going on. Okay, so that's just something to think about through your employer. Again, not all employers offer it. And even if they offer it, not everybody pays to be in it. So, you just need to check and make sure. But that's one way to get income while you are out receiving treatment, if you can't, I'll work at your job like you typically would.

In Michigan, the Department of Health & Human Services has a couple of benefit programs, State Disability Assistance, or SDA and (FIP) Family Independence Program. And both of these will allow for some income, SDA or State Disability Assistance is for individuals who have a low income and low asset or resources. They can apply and get about \$200 a month. It's not a whole lot, but that's for usually individuals without children. An individual with a child can apply for FIP, which is the Family Independence Program. Again, it's income-based, and resource-tested. But if you qualify you can get some income replacement for you and your children. Again, it's usually not a whole lot of money, but it is some cash assistance. And then, you can also apply for food assistance through the state, which again is an income and resource base.

Now, what typically a lot of people will apply for is disability through Social Security. So, there's really two programs that Social Security runs. It's the Social Security Disability Insurance and Supplemental Security Income, or SSI. And basically, both of those have their own...both those have the same definition of what it means to be disabled. And for individuals who are receiving a bone marrow transplant from the time you actually get the transplant itself, so the day you get the transplant, you are considered disabled through Social Security, and you're actually considered disabled up to a year. So, sometimes Social Security can find that you actually became disabled before the bone marrow transplant based on the symptoms you were having. But with Social Security, if you've paid into the system, meaning if you've had Social Security taxes taken out over your lifetime of work, and you qualify because you have to have paid into the system long enough and recent enough, then you can get a benefit there and that that will occur until they determine that you're no longer disabled. And usually after about a year or two, they'll do what's called a continuing disability review and determine whether or not you're still disabled, and they'll ask for more medical



information, etc. What's important about Social Security is, even if you're younger and only have worked a few years, you can still qualify. Obviously, the longer you have worked and the more you've paid into the system, the higher your benefit will be. The benefit under Social Security Disability Insurance is based on your income amount and how much you've paid into the system. Okay.

Supplemental Security Income is different. Supplemental Security Income is again needs-based. It's for individuals who are disabled, maybe who don't have as much of a work history, haven't worked recently, but have little or no income and little or no resources. For a single person, you can't have resources or assets over \$2,000, and for a married couple, you can't have assets or resources over \$3,000. That's a standard benefit for an individual, it's no more than I think about \$973 a month, whereas the Social Security Disability Insurance Benefit can vary based on what you've paid into. So, those are both programs you apply through the Social Security Administration, and you can do that online or in-person. They can even do telephone interviews for something like that. Sometimes, it doesn't happen very often, but sometimes people will have a catastrophic illness policy, they may have purchased that through work or through a private insurance provider, which means it's a one-time payout. So, we had an individual who thought she had paid into short-term disabilities. She had not. But she did pay into her catastrophic illness benefit, and she got a one-time payout of like I think it was about \$5,000. She had to make a claim, she had to fill out the paperwork, but she qualified and then she got a one-time cash amount of \$5,000 to just help with her living expenses.

So, the next thing is what are your rights to take a leave from work and then be able to still have your job? The biggest thing there is the Family and Medical Leave Act or FMLA. It's a federal act and it comes for people who have protections based on their employer and meaning that not every employer has to provide it but most employers were because it has to be an employer who employs at least 50 or more employees within 75 miles. So, if you work at a bank that only has five employees but within the 75-mile radius that bank employs at least 50 or more people then it qualifies. So, most employers qualify except for very, very small employers. So, if you have worked for that employer for at least 12 months and at least 1,250 hours over those last 12 months, then you qualify. You're an eligible individual. Okay. And so, if you qualify and then you want to take leave under FMLA, you make a claim, and it protects your job if you're found eligible. It will protect your job for 12 weeks. Now, it's unpaid. It just means that you can take off as much as 12 weeks, come back, and still have your job, or at least an equivalent job. Okay.

Now, people will say, well, do I have to take my vacation and my sick time simultaneously, and the answer is most likely. Employers have a right to say while you're off on FMLA, we expect you to also use your sick time and your vacation time. Why? Because they don't want people backing up vacation to sick to FMLA, and then be gone for like a year and a half. Okay? So, the way it works is based on the FMLA policy in your particular company, most will require that you take sick and/or vacation time simultaneously with FMLA. FMLA doesn't pay you, all it does is protect your job. So, taking the sick leave or the vacation is where you're going to get the income.



The other thing you want to remember is by still getting paid through your sick time and your vacation time, you're also getting your premiums taken out for your health insurance and other benefits that you have through work. So, you always want to remember that if you're no longer getting paid through work, but, for example, you're on unpaid medical leave. Let's say you want to just be sure to make sure you have some plan in place on how you're going to still pay your healthcare premiums because if you're no longer getting a paycheck, they're not automatically being deducted from there. And then, that just leads us to sick leave and illness and PTO. Every employer, an employee has a different amount of sick time and paid vacation time, or paid time off PTO based on how long they've worked, etc. So, you just want to know, you want to know for yourself, Michigan about five years ago passed a Paid Medical Leave Act, which means that pretty much most employers have to allow for at least one week of paid leave, no more than that, but at least one week based on people who are eligible. And you can't lose your job and you get at least one week of paid leave. That's just something that is also can be used simultaneously with the FMLA. Some employers will allow people to donate their sick days or their vacation days to your bank. So, let's say you're running low on sick days. Sometimes an employer might say, "Hey! Your fellow co-workers can donate them." So, that's just something that you'd want to talk to HR to see if that's an opportunity for you. So, then when some people will say to me, well, what are my accommodations if I want to stay at work or come back after my cancer treatment or during my cancer treatment, can I be accommodated? And the answer is you may be able to through the Americans with Disability Act. One thing people will say is, do I have to tell my employer I have cancer and the answer is no, you absolutely do not need to tell your employer you have cancer. However, if you're going to ask for an accommodation, you're going to need to fill out paperwork that says why you need the accommodation. It doesn't... you don't have to say you have cancer; you can just say "I have a medical condition that requires me to take frequent bathroom breaks." For example, something like that. And then, a doctor has to certify that. So one of your physicians will have to certify that. If you don't want your employer to know that you have cancer, it would be helpful to have your family physician fill out the paperwork because the minute the employer sees that it's coming from an oncologist, they're going to make the assumption that you have cancer, and if that's something you want them to know, then I would suggest that it might be helpful to have a primary care physician complete that paper works.

But you have to make a request that you would like an accommodation. It does not have to be in writing, but I strongly suggest it. And basically, you just need to tell them you don't have to come up with the accommodation. You just have to tell them what you're having difficulty being able to do, like "I need to use the bathroom frequently." And then, an employer can come up with the accommodation and it has to be reasonable. What does that mean that it has to be reasonable? It just has to mean that it doesn't cost the employer and inordinate amount of money to make that accommodation, and that can be debatable. But like having to shift around the entire way that the operation or the way the workplace operates wouldn't be reasonable. But for example, moving your desk closer to the bathroom could be considered reasonable depending on what's going on. Allowing you to work remotely could be reasonable, depending on the employers. Some employers based on their security systems and their computer systems working remotely isn't reasonable based on the security breaches and risk. But it's always helpful to make the request in writing. You can make it to your



direct supervisor, you can make it to HR, but you want to make it as soon as you think that you need it, and then they will work with you or have to work with you to at least tell you whether or not they can make the accommodation. And again, it's amazing how individuals, employers, can come up with really unique ways to accommodate individuals. An individual who worked at one of the major grocery store chains and worked in one department and that department was just too demanding for her energy level and the employer worked with her to consider maybe just moving her to a different department for a period of time.

The other thing I wanted to go back and talk about FMLA really quickly about is you don't have to take it all at one time. So, if individuals say, "Do I have to take 12 weeks all at one time?" No, you can take two days off every week for several weeks until it adds up to the equivalent of what would be 12 weeks of your employee. So, if you're normally an employee five days a week, 12x5 is 60. So, you can take up to 60 days in a year. So, sometimes people take FMLA intermittently, they'll take two days off this month, two days off next month, etc. So, that's something else to think about.

I was asked to talk about what legal documents could be helpful to prepare at this time. I think it's always helpful to have powers of attorney in place. Financial power of attorney, meaning that you nominate somebody, or you appoint somebody to be able to help with your financial affairs in the event that you become too tired or unable to do so. They can step in and advocate on your behalf with the different entities, your insurance company, the federal government, the state government, depending on what's going on, maybe health to prepare your taxes if you're too tired, etc. So, it's called a financial power of attorney. It's really helpful to have an attorney draft it because there are certain parameters in which to make it a legal document. A medical power attorney, or in the State of Michigan it's called a patient advocate designation, it's always really helpful to have. I recommend it for every one of my clients and it's just nominating somebody who can speak on your behalf and voice a decision, a medical decision, or preference that you would have in the event that you can. And sometimes we get loopy from a medication interaction, and we can't voice what we need to and then this person would step in and say, "I know this is what Kathy would want, yes, proceed with that or no, don't proceed with that." If people have young children, I say it's always helpful. In Michigan, we have something called the Delegation of Parental Powers. It's a way to do for six months at a time, allow to share your parental powers with another adult who can then take your children to school, take them to the Doctor's office, etc. So, it's limited to six months, but then you can draft a new one for another six months, but it can really help, especially when you're going through a tough part of treatment.

And then finally, people said, "What rights do I have with my health insurance provider?" Well, you have a right to ask a lot of questions. That's what I always tell people. Challenge any kind of cost you see on your bill, any kind of charge, if something's denied, you can always appeal it. There's always an internal appeal process. You should do that first, especially with private insurances like Blue Cross Blue Shield half, etc. But if you go through the internal process and still it's denied, in the State of Michigan, there's something called DIFS, the Department of Insurance and Financial Services. You can find it on the michigan.gov website, DIFS (Department of Insurance and Financial Services), they have an external appeals process and they will



help you. You can go online and do it in paper form or online and they will go ahead and conduct an external review for free to challenge the denial of your claim.

So, I think for right now, I'm going to stop and hand it back over to Peggy.

**Peggy Burkhard:**

Wow! Thank you so much, Kathy, I was taking notes as fast as I could. There was just so much great information there, and we really appreciate your expertise in all that you shared, and of course, if anybody has any questions after the program, they could always e-mail the LINK as well.

So, on to our next speaker. I'm going to introduce now Jennifer Leal, who knew at a young age that she wanted to work in the clinical research field focusing on Oncology. However, she didn't know what would lie ahead. Her cousin passing from CML, her sister from Ewing Sarcoma, and her mother becoming brain damaged, blind, and unconscious following surgery and her own health life-threatening issues with cancer. Experiences led her to use her voice in the health care space, not only in interactions with medical teams but also in speaking engagements. Jennifer is also passionate about patient advocacy as a two-time leukemia survivor and stem cell transplant recipient herself. She has used this experience and turned it into her mission to raise awareness, increase the number of donors, and reduce healthcare disparities in the stem cell registry. Oh! Wow! Jennifer is an advocacy ambassador with the National Marrow Donor Program. In addition to that, speaking to handle speaking engagements, she meets with legislators to secure continued funding for the C.W. Bill Transplantation program, she meets with legislators in Washington, D.C, and in the state of Rhode Island to garner support for the Lifesaving Leave Act. Jennifer is currently lives in Westerly with her husband, Dom, and her son Ben, while her daughter Isabel is away at college.

Well, Jennifer, thank you so much for being with us today and we cannot wait to hear from you as well.

**Jennifer Leal:**

Thank you so much, Peggy. And wow! Second wow! Through everything that Kathy shared, that is a lot of really valuable information. So, thank you for that great introduction and I'm really going to try to cover two different areas. Really what you touched upon with my experiences and how I advocate for the registry. And also, really how what I call I've used my voice through since I was young. But really in my own health care journey. You know how I've used my voice to advocate.

So, a little background about really my story is, you know, you touched upon my sister and when she was young and I think that's where I really first started to advocate without knowing I was advocating, I was pretty young. But while she was ill and in ICU, I would often stay at the hospital with her and would be a part of the conversations with the nurses and her medical team. And really, I didn't realize that was really setting me up for what was to come in my other challenges in my family, in my health.

So again, to my story, specifically that ties into probably many on this call is back in 2017, I was diagnosed with acute myeloid leukemia and went through the standard of care, you know a number of rounds of chemo. I did return to work after being on



disability and shortly after returning to work relapsed. And it was at that point where I was told, really my chance to survive would be through a stem cell transplant. Not knowing too much about the registries, I didn't realize really how limited it was for many of us. And so, when I was told I was quote unquote "lucky", which was a shocking thing to hear out of my medical team, you know, my lead oncologist now, I was told I was three matches. I was shocked and devastated, number three. Because I thought, of course, there'd be hundreds, but then I quickly learned, I asked to understand more how am I lucky? It doesn't sound lucky to me. And he had said, "Well, look at this spreadsheet because on this spreadsheet, and of course I didn't see any names, on this spreadsheet you see zeros on most of it and some ones, so you have yours three." And so I asked him, "Well, why do I have three and all these other people have zero or one?" And his reply was two reasons. One, your ethnicity and your race. I'm white and my background is strongly European. And so I realized, okay, what I need to do during this time is I want to raise awareness of these registries and I want to try to equalize this...there's so many things, disparities, but where's one where I can try to make a difference and give chances to others.

And so I started on social media with Facebook Live. I'd already been doing that sharing with my friends and family what I was going through. And so I started using it about the registry and then Twitter and all of that. And during that time, I caught the attention, formally Be the Match, now the National Marrow Donor Program, and they asked me to become an advocate ambassador with them. And through that, I've had a lot of great opportunities to speak often at colleges and events like that. And to also go as you had referenced; I went to May last year to meet with congressional representatives, and I continue to do the work here in Rhode Island. And a lot of that is what that's referring to with the Life Saving Leave Act, as Peggy already touched upon FMLA, for all of you who don't know that FMLA does cover solid organ donors. Does not cover what you would think of as liquid donors.

So one, the number one reasons people decline to donate are because they are afraid they will lose their job. When you're a donor, your time is spread out about 40 hours over a number of weeks, right? You're having tests, you're getting injections of Neupogen, and then you give your donation and recovery. So just a little bit about that, that's really a lot of what my work is on, my volunteers and my advocacy. So I wanted to share that part. And I do, I continue to speak anytime I can about these registries and trying to use my voice in that way to give others the chance that I've had to have this transplant and be here today.

The other area I want to touch upon that I think, I'm guessing a lot of people out in the audience are patients just like I was at one time. And so I want to share with you some of the ways I advocate for myself. So one of the mindsets I have and back when my sister was ill, I also had a number of autoimmune diseases before I was sick with leukemia and I spent a number of years really working hard on finding a doctor or doctors that are detectives. That are really detectives try and help me figure out what going on. I also...my mindset is I treat my health and my health care like it's my job, and that I'm the leader. And my medical team is my team. So I always think of myself again as kind of, I'm the leader, I'm in charge. And I think that's one mindset or behavioral aspect I have that I've just always had. One thing I did too is like with any relationship, I want to establish a really great relationship with my medical team and



that's anywhere from the folks at the desk when you walk in, to the schedulers, to the doctor, the PA, etcetera. And I want to establish a good relationship with them, and part of that relationship is me being a proactive participant and tell...you know, listening to what they're guiding me on, but also sharing with them what my thing was. So what's really important to me is establishing a relationship and being an active participant in it.

Another thing I do, and even when I was sitting in the hospital for weeks at a time and I was at a teaching hospital in New Haven, Connecticut, and I had a notebook, and every day I would look at my blood work, and I would write down how I'm feeling and what are my questions. Because as many of us know, and it's been referenced, sometimes you just don't feel well, you're weak, or you're tired or you're nauseous, whatever it may be. And so I try to write down whenever I think about it. And when I'm...I do a few things. One thing I've done is, a lot of times, especially if you have an outpatient visit, you have very limited time with your medical physician or the team. And so I will sometimes provide questions and topics I want to talk about. Before the appointment, I will ask, "I would like to discuss these results, or have we considered this, could we cover this topic?" I have some thoughts on this. So one thing I try to do is maximize my time, but I also want...It's also my way of having them focus on me and what my situation is. And I do that too sometimes with follow up. I'll take notes during an appointment or when they're visiting my hospital room. And I would take notes and I follow up, I write things maybe I think of questions after or we've agreed to discuss something. And so I keep notes of that to follow up.

Another thing that was helpful, I referenced sometimes you don't feel well or you're weak or maybe some of us just don't feel comfortable. Maybe sometimes being as vocal. And one thing that could help that you could consider is having a family or a friend with you that can help relay what your concerns are or your questions. You could also possibly, depending on where you're being treated, inpatient, outpatient, your facilities, you may have social workers available that can help have your concerns addressed.

And also, another tip I would have is you can, there are...Peggy referenced, me being a patient, a certified patient advocate, I have done the testing. I do have the certification. I don't professionally practice that way currently, but you can find a patient advocate that you can work with that can also represent you and help you navigate your medical journey here.

And a few others I want to share with you is setting boundaries where possible, and for some of you already may be past the initial point of your diagnosis, and you're well into treatment now your transplant recovery. To me, it was important to always set boundaries, so when some of you may have experienced this when I was first diagnosed, my life changed very rapidly. I went from working at home and having my two young children and my husband here at home is suddenly being one day in a hospital for six weeks. And so I need, I set boundaries right away for what was important. I was alone and in this hospital alone. And so it was important, I set kind of ground rules, if you with my team, including when we're going to meet or when you do your rounds, I need my husband on the phone. I want him to hear everything and



be involved in it because he's a part of this decision-making with me. And sometimes another thing I referenced, I was at a teaching hospital and one experience I had is often the Physician would come in with the residents and a whole slew of people. And so I said, I would like someone to come in and ask me first if I feel up to having these conversations with everyone in my room or if I just want to see you.

So all of these tips I'm giving you is again all wrapped into the fact that I want you all to feel empowered, that this is your health care and you really have that whole team, your medical team to support you through this process. I'm sure, Peggy, we're just...if I know, we probably have questions in the queue. If this is a good time for that. I thought of one other thing that...Oh, sure. I thought of one thing that I'd like to share is, Kathy had referenced to resources and I think that's often on people's minds whether it's financial or support for whomever is a caregiver to me. I do want to point out for those who will one, probably your medical facilities. They often again have social workers or someone that can help you find those resources for yourself or your caretaker or your family, but also the registry. So again, my donor came through. Be the Match, they have a lot more services than of course the super important finding you a donor, but they have foundations that can help financially, a lot of other resources. So if people aren't aware of that, I would reach out if you've had a transplant or to your medical facility and ask them what of our services they have. Sometimes it's even self-care. When I was in the hospital, I found someone that could come offer me Reiki in massage and that just really helped me emotionally. I just wanted to include that as well. So thank you, Peggy.

**Peggy Burkhard:** Oh, wow! Thank you, Jennifer. You know, when you were talking, I was taking some notes and I put the word empowering with an exclamation point. And I love that you said it as well. So much great advice here, and from a personal place as well for this professional. And thank you for sharing all of that. So let's just jump right in with questions.

So JL, I'm going to just remind people that please address yourself when asking the question in the way that you want to protect your identity as an individual. And I know that JL will probably say this, but again, star one on your phone. So I'm going to hand it over. JL, do you have anything to add to that before we get started with your questions from the queue?

**Operator:** No, thank you. If you have a question, please press star one on your telephone keypad. If you wish to remove yourself from the queue, simply press star one again. And at this time, there are no questions.

**Peggy Burkhard:** Okay. Well, that's okay because we are ready with some questions. I am going to throw this one out to Kathy. This is interesting. How long can I use the side effects of cancer such as foggy brain and trouble concentrating as an excuse to my employer?

**Kathryn Smolinski:** Thank you, Peggy, and thank you so much, Jennifer. So fabulous information. It's interesting because I don't know what excuse means, right? So I think if you're talking about how long can I have an accommodation? I think the answer would be as long as you need one. And it's not an undue hardship to your employer. So don't think of it as



an excuse, think of it as I'm able to do my job, but I can only do it if I have this accommodation. And your employer, if they're one of the qualified employers, should be able to accommodate you. So I don't want you to worry about "Oh my goodness, my employer is going to say this is going on too long." I think what's really important is to just be honest with your employer about what type of accommodation you need or what you're struggling with, and they should be able to keep on employing you and accommodating you. Now is that to say that employers never discriminate? Of course not. Employers discriminate, unfortunately, and sometimes people end up losing their jobs, and it may be due to the fact that you have cancer, etcetera. If that's the case, if you really feel like you've been discriminated against and you really want that job back and you want to pursue that, then that's something that you would want to take up with an attorney and the EEOC Employment Opportunity office just to file something there. But I think as far as being able to continue to be accommodated, that shouldn't be a problem as long as you're still able to perform your job with that accommodation.

**Peggy Burkhard:** Well, thank you for that. Let's move on to Jennifer. So Jennifer, someone asked about different funds to help while in recovery. This is just a great question. Would you be able to tackle that?

**Jennifer Leal:** Well, yeah, thank you so much, Peggy. I did reference earlier that I'm not sure I know there's a number of stem cell registries. Again, I worked with Be the Match, which is the National Marrow Donor Program, and they do have a foundation. They do a lot of fundraising through this to help families, and to help the patients and their families in these situations. So I know theirs are available. And also, I have a friend unfortunately recently that was diagnosed with stage 4 colon cancer. And I called the American Cancer Society, and they gave a lot of really valuable information that I provided to her family, and they've been able to get funds for her with different grants and programs. She, of course, there's always, you know, some people do GoFundMe, which is very helpful to many people. And also, let me just look here. I wrote some...even leukemia, so many of us who are on the call may have had a blood cancer. If it's a form of leukemia the Leukemia Lymphoma Society again, they also have a foundation where they help people financially. And I would again reach out to these social workers, or they might be called patient advocates at your medical facility to find out what resources might be available.

**Peggy Burkhard:** Absolutely. LLS is known for that. We sometimes included in our newsletter to different opportunities. JL, is there anything in the queue at this time?

**Operator:** Not at this time.

**Peggy Burkhard:** Okay. Well, we'll move on with some of our pre-submitted questions. Kathy, how about this one for you? I'm having some trouble with attention to the details. I was reprimanded once before the cancer diagnosis, and it was forgiven. I was then rehired after termination due to my cancer. I'm afraid I'm still having symptoms like I used to.

**Kathryn Smolinski:** So that's...yeah...so a couple of things. So trying to follow the story there, it sounds like maybe somebody wasn't able to keep up with their task, didn't necessarily ask for an accommodation, right? So if you're not doing your job right, so employers have a



right to hold you to be able to do your job and if you weren't able to do your job. I'm sorry to hear that you were terminated, but you were rehired, right? So now you're hired and now you need an accommodation. You're having difficulty with some being able to concentrate. So the question is, is based on what type of work you do, if there is an accommodation, could that help you? For example, maybe you are more alert at different times of the day. Do you work at a place where they could maybe shift your hours? Is it that you need more breaks and that helps clear up your fogginess? So the thing is that by requesting an accommodation you want to think about first of all, if I had an accommodation, could I still complete the job the way I need to? Because you don't have to come up with the accommodation that's what the employer needs to do. But you want to think about whether or not you could still complete your job with some type of accommodation. And many times, you can based on, especially with fogginess like sometimes, like I said, you can be more clear during the earlier part of the day, etc. Maybe if you work from home, etcetera. So I think that instead of trying to focus on being nervous, think about if you went to your employer and said I need an accommodation, what might happen as far as what they could possibly accommodate based on the type of work you do? And that's what's really important because there are some types of jobs just based on your symptoms and what you do that maybe there isn't a reasonable accommodation. But a lot of times employers can be pretty creative and usually can find something.

**Peggy Burkhard:** Thank you, Kathy. That's great advice. JL, anything on your end?

**Operator:** Yes, I have a question from the line of Jim. Your line is open.

**Jim:** Yes, thank you very much. I was just curious on the statement that she had made earlier about the services that are available from...and in fact someone came in and gave them a message and just how does that work? Because aren't you limited on visitation and especially touching and things like that?

**Jennifer Leal:** Hey, Jim. This is Jennifer. I believe you're directing that to me. So I'm trying to think of the time, this was before I had the transplant. This is during regular chemotherapy. I was not limited at that time. It was through the hospital, so I didn't have to pay. They came and the social worker let me know they had some...they offered great tea and massage. So I took advantage of that. It wasn't as frequent as I'd like, but you know, like don't have a lot of people for the number of patients that's at the hospital at the time. So I didn't have any limitations. However, once I had the transplant, you are correct, there is a period of time when you're very isolated in a room and people are in full coverage from head to toe. So that's much more limited.

**Peggy Burkhard:** Thank you. Thank you, Jennifer. JL, is there any other questions?

**Operator:** No new questions at this time. I do have a follow-up question from the line of Jim.

**Peggy Burkhard:** Okay.

**Operator:** Jim, your line is open.



**Jim:** I'm sorry. I meant to hit to close that out and I thought I was supposed to get it all one again.

**Peggy Burkhard:** That's okay, Jim. We're just happy to have you and happy to have your question. So thank you. I have a question for Kathy. Someone asked, how long can I take time off with no pay from work due to side effects from treatments?

**Kathryn Smolinski:** So again, it really depends on your employer. It depends on...so again, under FMLA, you're definitely protected if you qualify, and your employer is one that has to allow for FMLA. You should be protected for 12 weeks out of a year. And what's really...I want to be a little bit careful here because a lot of times, what people don't realize is that a year can be measured by how the employer measures it. What do I mean by that? So a year could be measured from the time you first take time off of work. So for example, if it's a rolling 12 months, let's say I can't...I need to take some time off of under FMLA this June. So that's when my year begins, meaning I have the 12 weeks from this June up until the end of next May to have those 12 weeks covered.

Some employers they measure the year in an annual January through February. So what does that mean? That means that FMLA gets kind of replaced, if you will, January 1st. So sometimes you can have the ability to have your job protected for your FMLA. Let's say it's later in the year up until 12 weeks, and then when January 1st comes, it refills, and you can get an additional 12 weeks. It really depends on the employer and how they measure that. You really have to check with your human resource department. But for the most part, without losing your job, FMLA protects it. Now some employers may have their own internal policies, and depending on how long you've worked, how well you know your employer. I mean, there's a lot of smaller employers that we've worked with here in Michigan who have been phenomenal, who have said to employees, "Take as long as you want your jobs going to be here when you return, and it was." But a lot of that requires trust and etcetera and from a legal standpoint, FMLA is going to be your best protection, and that's 12 weeks or the equivalent of 12 weeks in a 12 month period.

**Peggy Burkhard:** Great. And I thought it was wonderful, Kathy, how you explained that it can be broken up. It doesn't have to be all at once. I think that was very helpful. So JL, anything else right now, or do you want me to just keep with the pre-submitted?

**Operator:** There are no further questions on the telephone lines at this time.

**Peggy Burkhard:** Okay. Jennifer, somebody asked about caregiver resources. Give me thoughts on sharing resources that can relieve their family members during the long recovery period.

**Jennifer Leal:** Okay. Thank you so much. You know again...yeah...so some ideas I can share. So my husband was my primary caregiver at that time and what really was most helpful to him was resources. Again, not only at the...well in two places. One, the social worker at the hospital was very, very helpful and would often guide him on some steps to take. Of course, the timing involved insurance and things along that line. But I think it is really helpful. Well, that's not the question, but it is really hard for caretakers. I know



it was really hard for him to focus on himself because he was focused on me and the children. So that was really, really hard. Of course, a lot with really friends and family helped us out tremendously. But also, again, through the stem cell registry, they also focus and offer services to support the caregivers. Now my husband didn't necessarily take them up on those, but they were available. So I do just want to really have people just reinforce that they work with their registry. And if that's not applicable for them, really work with the staff at their medical facility because in most cases, again depending where you're being treated, but at least when it comes to hospital, they usually have other patient resources. And I will say if you want to look into finding a patient advocate, an independent patient advocate, you can go to the PAC Board. So [pacboard.org](http://pacboard.org) and they could find someone in your area that again knows a lot more about your local community. Oh, and one other thing that popped in my mind is again, depending on what your ailment is, there's often, like we've talked about LLS, Leukemia Society right, or American Cancer Society. But there are...if you look online or again ask the social worker and advocate to help you find, there are a lot of community-based programs that are for patients and caregivers. So I would...you know, a lot of those, whether it's the bigger ones like LLS, they can help find smaller more community-based resources. So I would invest some time looking there.

**Peggy Burkhard:** That's great. That's so true. And on our website, we do have a whole resource section, and we recently updated our resource guide, which is available in a downloadable format or as a book. So if anyone is interested in that, please reach out. Well, I think we are... JL, were there any other questions in the queue before we wrap things up?

**Operator:** Yes, I have a question from the line of Cantelli. Your line is open.

**Cantelli:** Hi, can you hear me?

**Peggy Burkhard:** Yes.

**Cantelli:** So I'm a post-BMT patient, and my question is, and I apologize if this was kind of covered earlier and I just missed the specifics. But I'm wondering if you could speak to besides accommodations, what to consider when deciding when to potentially return to work if you've been on SSDI and long-term disability including like the financial aspects? They've had some people tell me that they thought that there was a certain time limit for those things if you had like a recurrence. Like, if I went back to work and then a few months later the answer showed up again, I wouldn't be able to get disability or leave with that sort of thing. So I was wondering if you could just speak to that well, whether that to be true or not?

**Kathryn Smolinski:** So this is Kathy. So I can speak long-term disability is a little tricky because it's based on the employer and the policy. But I'll talk a little bit about Social Security Disability Insurance. So Social Security Disability Insurance, there is...there's an incentive for people to return to work and it's called a trial work period. So what does that mean? If you've been on Social Security and you want to return to work, they allow you nine months of working and still getting your benefit. And those nine months, it depends on



how much you earn during that time for it to be counted as a trial work period month. So if you make a certain amount of money, then it's counted as a trial work period month and you get nine of those. And like, I think it's like a 36-month period. So the minute you've done that for and you keep your benefits, so you can make as much money you want as work and you still keep your benefits. But then once you're done with the trial work period, as soon as you make a certain amount of money, and it changes every year, then you're considered no longer disabled. They pay you your benefits for two more months, and then you go into what's called an expedited period of reinstatement, which means if you get a recurrence and the same reason you were disabled in the first part, then you submit documentation. And they can expedite much...expedite the...a good term for it can take as long as four months to reinstate your benefits. Now that's one way that you can get your benefits back.

Another thing is called a failed work attempt. And what it means is somebody tried to go back to work and was unable to base on their condition, and then the benefits can continue. So it really depends. It really depends on if you would like to go back to work. Again, Social Security wants people to try to go back to work and so that's why there's an incentive called the trial work period. And if you go to [ssa.gov](http://ssa.gov), type in trial

work period, they'll explain it. But it's really an incentive where it allows you to try to go back to work and still keep your benefits for a period of time.

**Peggy Burkhard:** Wow! I'm learning so much and I'm sure I speak for everyone on this call. Thank you so much both of you. This has been incredible. I think we're going to wrap things up. It's 1:00. Thank you, everyone, who was a participant. Please visit our website, or if you have any questions, you can reach out to me, 1800-LINK-BMT. And again, we have recorded programs to go check out if this is your first one to learn. We will have a survey that we will get out to you soon. And we thank you so much for your time today, especially our speakers. Thank you.

**Jennifer Leal:** Thank you.

**Kathryn Smolinski:** You're welcome.

**Peggy Burkhard:** Have a great day everyone.

**Operator:** This concludes today's meeting. You may now disconnect.