



Ways to Reduce the Financial Burden of Cancer

### Ms. Alicia Patten

Greetings and welcome to our program, "Ways to Reduce the Financial Burden of Cancer." Upon completing the program, you will be able to submit a question to our speaker. Directions for how to do so will be given at the end of this program.

The Leukemia & Lymphoma Society exists to find cures and ensure access to treatment for blood cancer patients. Our vision is a world without blood cancer. For more than 60 years, LLS has helped pioneer innovation, such as targeted therapies and immunotherapies that have improved survival rates and quality of life for many blood cancer patients. We advocate for patients, survivors, and their families, helping them [to] navigate their cancer treatments and ensuring that they have access to quality, affordable, and coordinated care.

We're fortunate to have as our presenter Monica Fawzy Bryant, Esquire. Monica is a cancer rights attorney, speaker, and author, dedicated to improving access to and availability of quality information on cancer survivorship issues.

Monica is the cofounder and chief operating officer for Triage Cancer, a national nonprofit organization that provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers through events, materials, and resources.

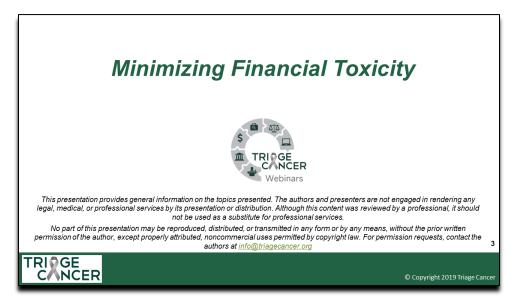
Throughout her career, Monica has provided hundreds of educational seminars, written articles, blogs, and coauthored a book published by the American Bar Association called *Cancer Rights Law: An Interdisciplinary Approach*.

Thank you, Monica, for volunteering your time and sharing your knowledge with us. I am pleased to turn the program over to you.





### **Disclosure Slide**



### **Minimizing Financial Toxicity**

### Ms. Monica Fawzy Bryant

Thank you so much. I'm absolutely delighted to be here to talk about this incredibly important and complicated topic of financial toxicity.

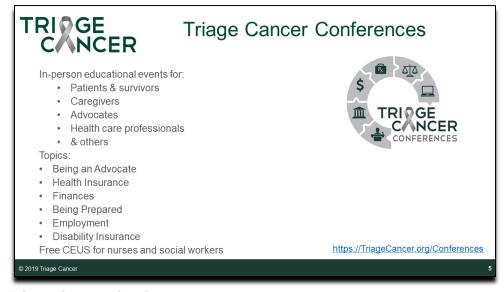




### **About Triage Cancer**

Now, since we only have an hour today, we're going to sort of be talking at a pretty high level about these different issues, so I want to just spend a couple of minutes telling you all about Triage Cancer and the resources that we provide. So that if, after you listen to this program, you still have questions, you certainly can go to LLS and check out all of their fantastic resources, but also know that you have Triage Cancer to go to as well.

So, as was mentioned, Triage Cancer is a national nonprofit that provides education on the legal and practical issues that can impact individuals who are diagnosed with cancer and their caregivers, and we provide this education in a couple of different ways.

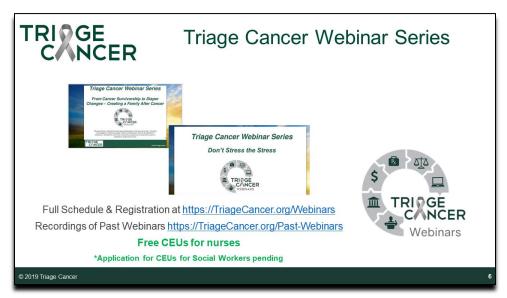


### **Triage Cancer Conferences**

Every year we host Triage Cancer conferences at various locations around the country, and we're delighted to have LLS as one of our sponsors.



This daylong event covers a variety of topics that impact individuals beyond diagnosis, and it's open to patients, survivors, caregivers, healthcare professionals, advocates— anyone who's interested in learning more about these issues.



### **Triage Cancer Webinar Series**

We also have a monthly webinar series, and if you are unable to join us for the live events, note that we record every single one of our webinars and they can be accessed at a later date.



### Triage Cancer & Cancer and Careers: Navigating Cancer: Work and Insurance

We host two trainings specifically for healthcare providers, because we know healthcare providers are on the front lines. The first is navigating work and insurance, and we spend the whole day doing a deep dive into employment issues.

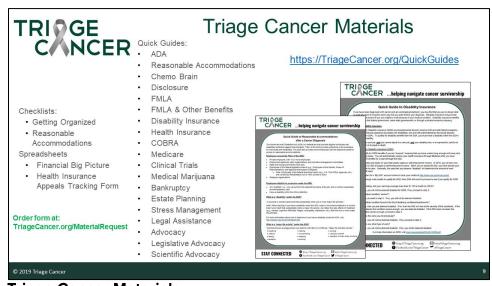




### **Triage Cancer Insurance and Finance Intensive**

And the second is all about health insurance, disability insurance, and finances, in our insurance- and finance-intensive.

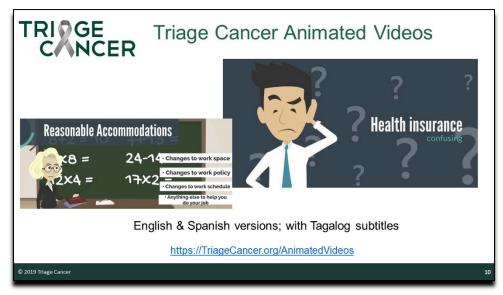
You can check out where we're going to be coming soon on our website at triagecancer.org, and registration and attendance to these events is all free.



Triage Cancer Materials

We also have a number of educational materials on our website, and throughout today's presentation you're going to actually see I've included the links to our quick guides and checklists that are relevant to the topic that I'm speaking about. These can all be downloaded for free on our website, or you can order them in bulk on our website as well.





### **Triage Cancer Animated Videos**

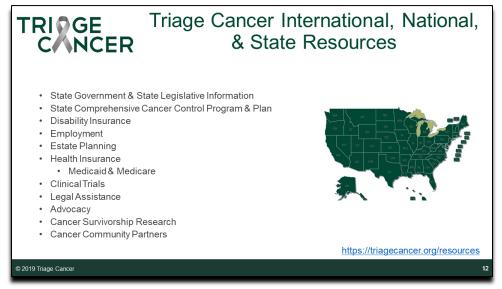
And we know that people learn in different ways, and these are complex topics that I'm going to be talking about. And so, we created some short animated videos that try to explain these topics. So, after today if you think to yourself, "Wow, I really wish I could hear that one more time," certainly you can watch this again or you can go watch some of our animated videos.



### **Triage Cancer Spanish Resources**

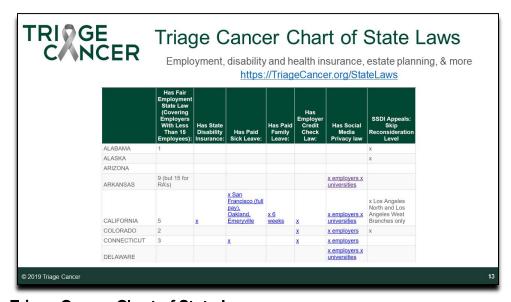
We're delighted that we have many of our resources in Spanish as well.





### Triage Cancer International, National, and State Resources

And then, we have compiled the contact information for some of the most frequently used statespecific agencies and resources, because we know that while the Internet provides so many opportunities for us to access information quickly, it can also be daunting and hard to find the information that you're looking for. And so, we've tried to make that a little bit easier.



### **Triage Cancer Chart of State Laws**

And, as we'll talk about today, because where you live can impact what protections you have access to, we have charts of state laws on employment, disability, health insurance, and other cancer-related issues. So, you can see what the laws are in your states.



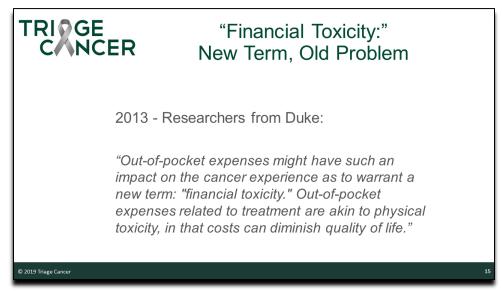


### CancerFinances.org

Now, over the years, we would hear the comment that people wished they could—you know, put us in their pocket and be able to ask the questions over and over again. And so, we created a website called cancerfinances.org in partnership with The Samfund, and this website provides practical information on topics that can impact your finances. So, it's designed to guide users to the information that's most relevant to their situation.

We currently have modules on health insurance, disability insurance, financial assistance resources, estate planning, and we're adding topics frequently.

So again, I just wanted to spend the first couple of minutes telling you about the resources that we provide so that if you have additional questions, or you need additional guidance, you know where you can find some more information, in addition to LLS.



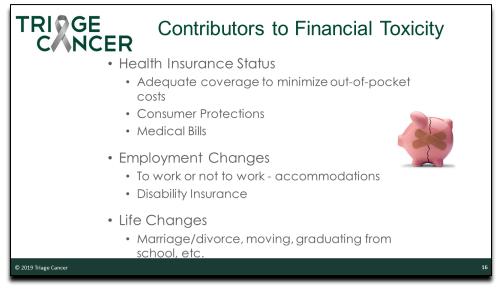
<sup>&</sup>quot;Financial Toxicity": New Term, Old Problem

### Ways to Reduce the Financial Burden of Cancer Speaker: Monica Fawzy Bryant, Esquire



So, to the heart of the topic today. In 2013, researchers from Duke coined the term "financial toxicity." And in their research, they focused on the financial burden of a cancer diagnosis and how significant that burden can be—not just in an acute way, when somebody's in the midst of active treatment—but also that long-term financial burden and the impact that that has on somebody.

And what was particularly interesting about this research is that they didn't just focus on the dollars and cents. They really looked at how the financial burden causes stress, depression, anxiety, and it diminishes overall quality of life. So, while this is a new term, it's certainly not a new problem.



### **Contributors to Financial Toxicity**

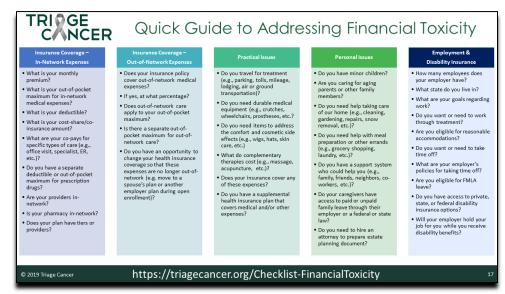
But there are multiple components or factors of financial toxicity, and that's why there's no easy solution. All or most of these factors must be addressed in order to effectively mitigate the financial toxicity of a cancer diagnosis.

Now, one of the primary culprits of financial toxicity is having inadequate health insurance. So, we're going to talk about how somebody can make choices to ensure that they have adequate coverage that meets their needs and most effectively minimizes out-of-pocket costs.

And then, certainly, there are employment changes that may occur as a result of a cancer diagnosis. Someone may have to stop working altogether or take an extended period of time off, and how does that affect somebody's financial health?

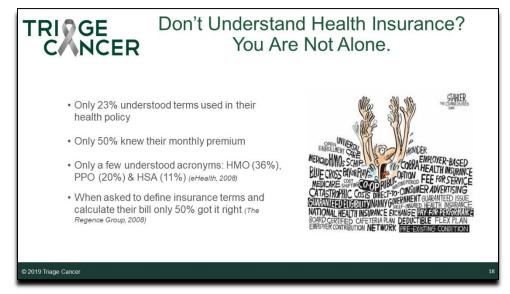
And then, we don't get a pause button with a cancer diagnosis. Life continues to move on, and all of these life changes that would have a financial impact on somebody regardless of cancer can also impact post-diagnosis. So, relationship changes, moving, graduating from school, and student loans—how do all of these life factors impact financial toxicity?





### **Quick Guide to Addressing Financial Toxicity**

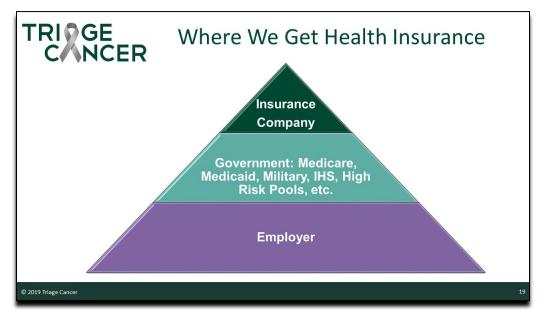
Now, we have created this checklist to addressing financial toxicity, and I realize it's quite challenging to read in this tiny print, but you can print out a full-page version on our website. But this is really a visualization of all the questions that could be asked of an individual who's been diagnosed to help address financial toxicity. And, as you can see, it touches several aspects of somebody's life: from insurance to work, practical issues, to what their life looks like. Again, you can download this for free on our website.



### Don't Understand Health Insurance? You Are Not Alone

Now, there is a general lack of understanding around health insurance in this country. It is complicated. It is like learning a new language. We have all these statistics about regardless of where somebody gets their health insurance, through an employer or purchasing it themselves, they just don't necessarily understand what they're purchasing or how it is used.





### Where We Get Health Insurance

Now in the United States, there are three main places Americans get their health insurance coverage. The largest number of Americans get their insurance through an employer. The next largest group of individuals get their insurance through the government, through programs like Medicare, Medicaid, a military program, or a high-risk pool. And the fewest number of Americans get their insurance directly from a health insurance company.



### **Health Insurance Terms**

Now something as basic as having an understanding of the terms used in a health insurance policy can make a significant impact. So, before I get into the specifics of how you can choose the right plan, I just want to make sure that we're all on the same page with respect to some terminology. These are terms that are often used but frequently misunderstood.

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So, starting at the beginning, when we talk about a premium, we're talking about the amount that you're going to pay monthly just to have health insurance. And you're going to pay this whether or not you go to the doctor. It's very similar to the concept of having car insurance but never getting into an accident during the year.

Now, there are some additional costs that you're going to incur when you actually use your health insurance. So, the first is your deductible, and your deductible is a fixed-dollar amount. It's going to vary plan to plan. So, some plans have a zero-dollar deductible, some plans have a \$6,000 deductible, but it's always illustrated as a fixed dollar amount.

Now, the deductible is the amount that you have to pay out of pocket before your health insurance company starts to pick up their share of the costs of your medical care. Now, their share of the costs is referred to as coinsurance, otherwise known as cost share. Your portion of the cost share is the amount that you're responsible for paying after the insurance company pays their portion. And cost share is always illustrated as a percentage.

So, for example, if you have an 80/20 plan, that means that your health insurance company is going to pick up 80% of the costs of your care, and you will pay 20% of those costs once you've met your deductible.

Now, another payment that you might have to make is your copayment. And this is a payment, again, it's a fixed dollar amount, and you pay it each time you get care. So, for example, many policies have a \$25 copayment when you go into the doctor's office. And you pay that right then and there before they even let you in the door. Sometimes there's a \$10 copayment for your prescription drugs.

Now, one of the most useful things to understand about your health insurance policy is the out-of-pocket maximum. When we talk about the out-of-pocket maximum, generally speaking, we're talking about everything you've paid towards your deductible, everything you've paid towards copayments, and everything you've paid towards your coinsurance. So, it's going to be everything that you pay out of pocket except those monthly premiums.

Now, of course, like with everything else, the devil is in the details. So, typically, health insurance policies will only count payments made towards in-network services towards your out-of-pocket maximum.

Additionally, over the years, we've seen some plans start to carve out the deductible from your out-of-pocket maximum or carve out copayments, so it's critical to look at your specific policy. But again, generally speaking, understanding the out-of-pocket maximum is one of the most useful things you can know about your plan.



### David's Plan: Deductible = \$2,000 Co-insurance = 80/20 plan OOP Max = \$4,000 If David has a \$102,000 hospital bill, what does he pay? 1. His deductible of \$2,000 \$102,000-\$2,000 = \$100,000 left 2. His co-insurance amount of 20% 20% of \$100,000 = \$20,000 But OOP max is only \$4,000. So, he would only pay the \$2,000 deductible +

\$2,000 of the \$20,000 co-insurance amount, for a total of \$4,000.

Case Study: David

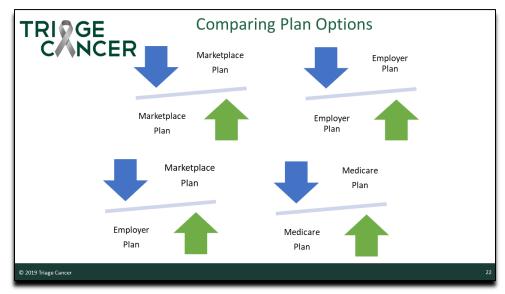
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So, I want you to meet David. David has a plan with a \$2,000 deductible, coinsurance amounts of 80/20, and his out-of-pocket maximum is \$4,000. He gets into an accident and he ends up with \$102,000 hospital bill. What does he actually have to pay? Well, the very first thing you always have to pay is your deductible, so he pays his \$2,000, which leaves \$100,000 left of his bill. He has that 20% coinsurance amount, which is equal to \$20,000, but does he actually have to pay another \$20,000? No, he doesn't, because he's already paid \$2,000 towards his deductible. So he's only responsible for another \$2,000 of that coinsurance amount, for a total of \$4,000.

Certainly, this is a simplistic example of how all of this could work. But what is so beneficial about understanding the out-of-pocket maximum is we can now start to make some decisions about what we're going to do for our healthcare for the rest of the year.

For example, if there's any other care that David might need, perhaps now is the time for him to get it because he's already met his out-of-pocket maximum for the year, as opposed to waiting until January when his plan year starts over. Now, I'm not advocating getting care that you don't need, but again, if you understand the system you can make some very educated decisions to your benefit.

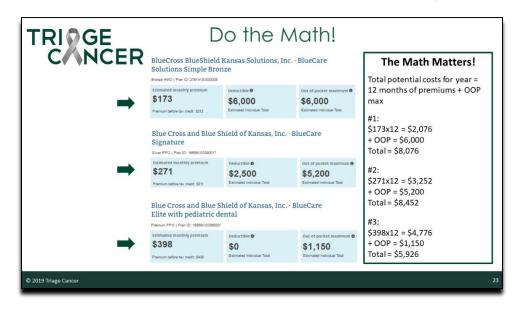




### **Comparing Plan Options**

Now, as I mentioned earlier, one of the most effective things that people can do to mitigate the financial toxicity of a cancer diagnosis is to have the right health insurance plan. But how do you go about picking a plan when you have more than one option to choose from? This is something that none of us are ever taught how to do, and yet, suddenly we become adults and we have to make these decisions and we don't always know how to do that.

So, I'm going to go through an example using the state health insurance marketplaces as an example. But know that the same analysis can be done, whether you're choosing between marketplace plans, whether you have more than one option offered by your employer plan, whether you're trying to decide if you should keep your employer plan, or if you should go buy a marketplace plan. There's a big misconception that if we get an employer plan we have to keep that plan. Or, if you're trying to decide between two or more Medicare plans, the same analysis can be used.



### Do the Math!



So here we have three different options available to this imaginary person in the Kansas state marketplace. The top one is an HMO Bronze plan where the monthly premium is \$173 with a \$6,000 deductible and a \$6,000 out-of-pocket maximum. The second option is a Silver PPO plan with a \$271 monthly premium, a \$2,500 deductible, and a \$5,200 out-of-pocket maximum. And then finally, the Platinum plan with almost a \$400 monthly premium, a \$0 deductible, and an \$1,150 out-of-pocket maximum.

So, assuming that we are talking to somebody who's had a cancer diagnosis and is likely going to meet their out-of-pocket maximum for the year—that is [a] pretty easy thing to do when you're going through cancer treatment. Which is going to be the plan that is the cheapest at the end of the year?

You actually cannot tell just by looking at these numbers. You have to do the math because what we tend to hear from people is, "I can't possibly afford \$400 a month for a monthly premium, so I'm going to pick the one that's only \$173 a month. That is what I can afford." But, if we do the math, we might be able to make some different decisions.

So how do we do the math to find out what's going to be the most affordable plan for the year? We take those monthly premiums and we multiply it by 12 because that's what we're going to pay in premiums for the year. And then, you add the out-of-pocket maximum, because that is the most that you're going to pay for the year assuming that you see in-network providers.

When we do the math, we see that, actually, that quote/unquote "expensive Platinum plan" ends up being the cheapest at the end of the year by almost \$2,000.

So, we do this all over the country. We pull the numbers from various states and locations, and it always comes out a little bit differently. But the point here is you cannot just look at that monthly premium and make an accurate assessment as to how much the plan is going to cost you for the end of the year.

# TRIFGE What are the differences between plans? Cost Premium, Out of Pocket, Co-Pay, Deductibles, Cost-Share Networks of doctors and hospitals Check to make sure your doctors are covered by the plan you choose Prescription drug coverage Which drugs are covered? Is there a separate drug deductible?

### What Are the Differences Between Plans?

But, looking at that total annual cost is actually only the first step. Some plans might have a really high deductible, which means that you have to pay a lot of money up front out of pocket before your plan starts to pick up their share of the costs. So, if you think about that Bronze plan that I showed you earlier, that had a \$6,000 deductible. So, you have to write a \$6,000 check before the insurance company starts picking up their share of the costs.



So, other plans might have a more expensive monthly premium but a really low deductible and a lower out-of-pocket maximum, which essentially ends up spreading out the amount that you have to pay out of pocket throughout the year.

Now, after you've looked at the cost of the plan, you also need to make sure that your doctors and healthcare providers are in the plan's network. Plans that, even if they provide coverage to out-of-network providers, it's never going to be at as high of a rate. So, it's always in your best interest to pick a plan that has the majority of your doctors and hospitals and specialists in-network.

And finally, you want to look at your prescription drug coverage and what rates the drugs that you're taking are covered at. So again, I fully recognize that this is complicated, and so I just want to remind you that we have an animated video on how to pick a plan that goes over everything that I just talked about, if you'd like to see it again.



### Checking Providers, Facilities, and Drugs

Now, I mentioned that it's useful to make sure that your providers and facilities and drugs are all innetwork. That can be easier said than done, so certainly you can go to your providers and ask if they take a particular plan. But what we generally recommend in those cases is that you're very specific about the plan name when you ask your providers. For example, we have heard stories of people who have gone to their state health insurance marketplaces, purchased a plan from Blue Cross/Blue Shield, called their providers and said, "Do you take marketplace plans?" And those providers say, "No, we don't take marketplace plans." And then they say, "Oh, well do you take Blue Cross/Blue Shield of North Dakota, Blue Direct 80 Silver?" "Oh, yes, we take that plan." So, we hear things like that happening all the time, and so we want people to be very specific about what they are asking their providers so that they can get correct answers.

The other thing that the marketplace provides, and some Medicare plans provide is online. Once you find the plan that you're interested in, if you see on the right-hand corner you can actually see a list of doctors, facilities, and drugs covered. This makes it a little bit easier to get the information, but [it is] always useful to check with the providers and the plan to make sure that that information is still accurate.





### **Triage Cancer Resources on Health Insurance**

So, there's so much more that I could spend talking to you about health insurance, but given today's time constraints I just want to point you to resources on health insurance, and that we have a plethora of guick guides and videos and webinars for more information.



### **Employment Rights**

Now the second largest contributor to financial toxicity after a cancer diagnosis are employment changes. And we often hear stories of healthcare providers telling patients, "You have to stop working through treatment. You should just take time for yourself." Or, individuals who have been diagnosed just assuming that they can no longer work. And that might be the reality for somebody, but it might not be. And, in fact, there are several laws and benefits that may provide protections to individuals in the work arena if somebody wants to continue working or needs to take time off.

And there are a number of places to go to find this information about your employment rights. There are federal fair employment laws and state fair employment laws. There are both federal and state lead



laws. And then, if you're an employee working under a contract, then you may have additional rights or options. For example, if you're a member of a union, you should be sure to be looking at your union contract for any additional benefits that that contract may provide.

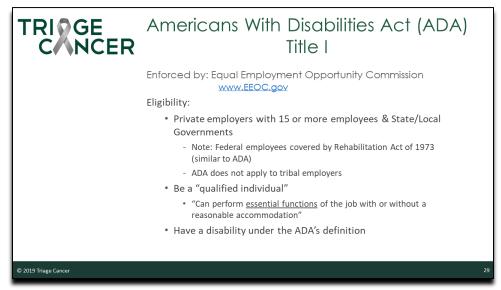


### **Employer Policies**

But, as I talk about rights and benefits, it's really useful to remember that the state and federal laws are only the bare minimum of what employers have to provide their employees. There are tons of employers that provide benefits that are much better than those bare minimums. So, it's a really good idea to look at your employer's specific policies to figure out what your employer offers you. You know, typically, you can find these policies in some sort of employee manual or policy and procedures document. Every employer is different in how they do this. Not everyone has a formalized handbook or procedures manual. But, if you don't have access to a manual or policy and procedures document, perhaps asking a coworker, a human resources representative, or whomever in the company deals with things like pensions and health insurance.

And some of the things that might be helpful to look for in these manuals are your insurance options. Does your employer offer health insurance? Disability insurance? Is there a policy already in place that allows for telecommuting or some sort of flex time? Does your employer allow other employees to donate their paid time off to a pool that you can draw from? Because if you can access these benefits, it makes the entire process a little less arduous. And, typically, a good employee manual will also lay out a process for how to ask for medical leave or a reasonable accommodation, which we'll get into in just a few minutes.





### Americans With Disabilities Act (ADA) Title I

Now, many people who are diagnosed with cancer don't consider themselves to have a disability. And therefore, they don't always assume or understand that they're protected under the federal law called the Americans With Disabilities Act, otherwise known as the ADA. But this is one of those situations where I really urge people not to get caught up in the label because you may end up missing out on protections if you do.

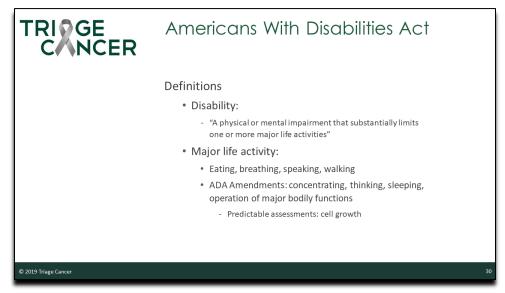
So, as I mentioned, the ADA is a federal law that prohibits discrimination against people with disabilities in several contexts, including in the workplace. But not everybody is going to be eligible for protection under the ADA. There are a few hurdles that you have to jump. So first, you have to work for a private employer with 15 or more employees or for a state or local government.

Now, if you're a federal employee, you're likely covered under the Rehabilitation Act of 1973. It is very similar to the ADA in its employment protections.

In addition to working for a large enough employer you have to be a qualified individual. Legally, that means that you can perform the essential functions of the job with or without a reasonable accommodation. Practically, what that's trying to say is that you're qualified for the job in question and you can perform the essential job responsibilities, but you can get help to do that through an accommodation, which we'll come back to in just a minute.

And the last hurdle is that you have to have a disability within the ADA's definition of disability. Now, I probably use the word *disability* a hundred times in a day when I am talking to people, but it's important to remember that every time we use it and every law that we talk about has a different definition of disability.





### Americans With Disabilities Act

So, under the ADA a disability is a physical or mental impairment that substantially limits a major life activity. It's a mouthful, so let's break it down because there's a couple parts to that.

The first is that you have a physical or mental condition that limits a major life activity, and that limitation is substantial.

So, what's a major life activity? It's going to be anything that the average person in the general population can perform with little or no difficulty. So, we're talking about things like sleeping, walking, breathing, eating, communicating, concentrating, operation of major bodily functions. These are all considered major life activities. Now, when we talk about cancer, oftentimes it is not the cancer diagnosis itself that creates the disability, but rather, it's the side effects from treatment that somebody's experiencing. The nausea, the chemo brain, the fatigue, the anxiety. And it could be that one of those side effects is substantial by itself, or it could be that it's a combination of those things that create the presence of a disability under the ADA.



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### **Americans With Disabilities Act**

So, once we have determined that an individual has cleared the hurdles and is therefore protected under the ADA, there are four ways to actually use the ADA's protections. First, you currently have that physical or mental impairment that's substantially limiting a major life activity. So, maybe you're going through treatment and suffering from extreme fatigue, and it makes getting through the workday impossible.

The second is that you have a history of having that impairment. So maybe you're, 10 years out of active treatment with no current symptoms but your employer is treating you differently because they know of your cancer diagnosis.

The third way is being regarded as having a disability. And that really isn't about your experience or capacity at all, but rather, it's about the employer's perception of you. And the employer is perceiving you to have a disability even though you may not be substantially limited in any way.

So, for example, maybe you've lost all your hair, but other than that you can go to work and do your job and, you know, there's no problems. But because of that bald head your employer's treating you differently.

And then the fourth way that you can be protected is based on an association with a person with a disability. And this is where caregivers may be able to be protected from discrimination under the ADA.

So, what does the ADA actually give somebody? Well, in all of these circumstances—so, they currently have a disability, history, regarded, based on an association. The ADA protects against discrimination in the workplace, so being treated differently because of your medical condition.

Now, if someone currently has the disability or has a history of having a disability, in addition to being protected from discrimination they're also entitled to something called a "reasonable accommodation."

Now, the ADA applies to all phases of the employment process. So, that means that even before somebody has the job, in the job search and application phase of employment they are protected against discrimination. And that goes all the way through from hiring's to promotions to benefits to demotions to firing—the ADA applies.





### Reasonable Accommodations

So, I mentioned that someone who currently has a disability or has a history of having a disability is entitled to a reasonable accommodation. What is that? The legal definition is, "Any change in the work environment or in the way that things are customarily done that enables an individual with a disability to enjoy equal employment opportunities." It is a mouthful, I recognize.

The easiest way to talk about reasonable accommodations is through some examples. And accommodations can be put in three major categories. So, the first category is about physical workspace. So, maybe it's about somebody who needs a closer parking spot to the office building so that they don't have to walk a mile and a half to get to their office. Or, maybe it's about special work equipment or a special chair that they might need. It could be about moving offices so that you're closer to the elevator or further away from the smelly cafeteria. So, the first bucket's really about space.

The second is about schedule. So, we live in a time where not many jobs are a traditional 9 to 5 anymore, but some are. But with accommodations there are many ways to adjust a schedule to make it easier for an individual to be the productive, stellar employee that they might want to be. So, it could be about working part time. It could be about taking additional breaks or changing the breaks. So, if you have a job where you get, you know, two 15-minute breaks and a 30-minute lunch, but for you, maybe getting four 15-minute breaks for through the day would be better. That would be a reasonable accommodation.

It could be about telecommuting. Now, telecommuting can mean different things to different jobs. So, it could be about just working at a different location that's maybe closer to home so you don't have to deal with, you know, an hour on the train. Or, it could be working from home. Or, it could be a combination of "I work from home some days" and "I go into the office other days." A reasonable accommodation may also be about extended leave, which we'll get back to.

And then, finally, the last category is sort of everything else. Maybe it's about technology, so using speak/type software if someone's suffering from neuropathy in their hands or if they're coping with cognitive challenges due to treatment. Maybe it's about using tape recorders in meetings. It could be about a change in policy. So, we had a gentleman once who worked somewhere where there was a policy that you couldn't wear hats or head coverings. And, in his words he had this open wound on his

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forehead that made everybody very uncomfortable. So, he was able to get a change in the policy and he was allowed to wear a hat. So, very simple change but made a big impact.

It could be about shifting responsibilities. So, for a schoolteacher who was asked not just to teach his classes but also to do AM and PM bus-line drop-off and recess duty, and all of those things together are just too much for the day, maybe we can shift bus duty and recess duty to somebody else. And then finally, it could be about changing jobs entirely. Now, this is only possible if there is a vacant position. Employers are not required to create a new job as a reasonable accommodation.



### Reasonable Accommodation Tips

But when considering reasonable accommodations, some people can feel like they're asking for a favor of their employer and it makes them really uncomfortable. So, I like to remind people that this is a right under the law for eligible employees. And that employers who fall under the ADA are required to provide you with a reasonable accommodation unless they can show that it's an undue hardship or a direct threat, which is a very high bar for them to clear.

Reasonable accommodations are really going to depend on your individual condition and your job responsibilities. Accommodations have to still be reasonable. So, if you are a school bus driver, telecommuting probably isn't going to be considered reasonable. But it is common that we hear people assume that there are no reasonable accommodations that would be useful. And then after we do some talking and a deep dive, we can come up with at least one that might be helpful.

Now, the Job Accommodation Network is an entity of the US Department of Labor, and their sole purpose is to help employers and employees come up with reasonable accommodations. And their website is askjan.org, I also have provided the links to our quick guide on reasonable accommodations and our checklist on reasonable accommodations. We have a ton of resources on this, because it is one of the most useful things for individuals who are trying to either work through treatment or who are trying to return to work after treatment and are still experiencing late or long-term side effects.

Reasonable accommodations are very flexible in that it is not a one-and-done situation. You can get more than one if you need more than one to deal with what you are coping with. It could also be that your needs change over time, and a reasonable accommodation can change with it.



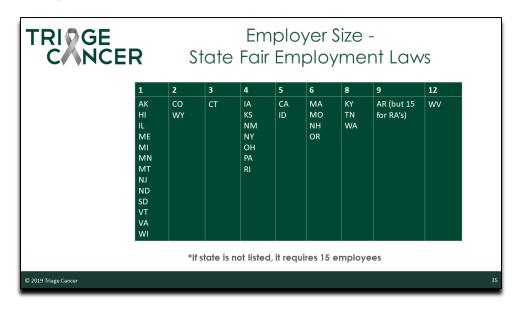
Now, caregivers are not legally entitled to reasonable accommodations under the ADA, but it doesn't hurt to ask. Many employers, as I mentioned, are much more generous than what that bare minimum required or what that law requires. So, if you think back to the idea of, "Why would somebody want to provide a reasonable accommodation?" Well, it's beneficial for the employer and the employee. Employers get to keep a valued employee and their work production goes up. They don't have to try to hire and retrain a new employee.

So, when I say don't think of reasonable accommodations as asking for a favor. It's not just because you are entitled to it under the law—it's because it really is mutually beneficial for both you as the employee and your employer.



### **State Fair Employment Laws**

Now, there are state laws that are very similar to the ADA, but some state laws can actually be more protective. And one of the ways that the state laws can be more protective is by covering smaller employers.





### **Employer Size – State Fair Employment Laws**

So, this chart shows the number of employees that each state requires an employer to have to be covered under the state fair employment law. So, for example, if you live in Illinois with me, then your employer only needs to have one employee for you to be protected. Now, if you don't see your state listed here, then it means your state law is the same as the federal law, so it only covers employers with 15 or more employees. And, if you are interested in more specifics about your state law you can check out that chart of state laws on triagecancer.org.



### Family and Medical Leave Act (FMLA)

Now, whether the employee is the one who's been diagnosed with cancer or the employee is caring for a loved one, that employee may need to take some time off for treatment and recovery. And that's where the Family and Medical Leave [Act], or FMLA, comes into play. The FMLA allows eligible employees to take time off to deal with either their own serious medical condition or to take care of a seriously ill child, parent, or spouse.

Now, that's a pretty narrow definition of family, so under this law you're not entitled to take time off to care for a grandparent or a sibling or an aunt. I like to point that out because there's a lot of misconceptions about this: what/whom people can care for under the FMLA. But I will also say that some states are expanding this definition and it [is] certainly an advocacy opportunity.



## Employer: private employers with 50+ employees and all government employers (federal, state, local) • 75 mile radius • "As the car drives, not as the crow flies" Employee: 1,250 hours, 12 months • 12 months = total of 12 months in 7 years • Pald vacation or sick leave counts • 1,250 hours = 24 hours each of the 52 weeks/year • Only count hours physically worked, not breaks, vacation, travel time

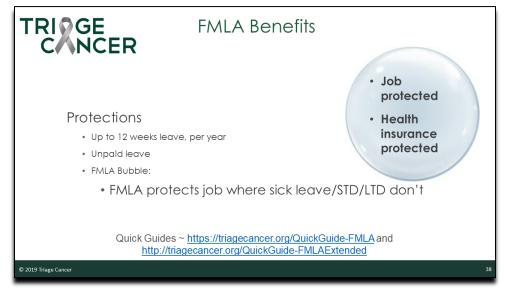
### **FMLA** Eligibility

Now, just like all the laws that we talk about, there are requirements that you must meet in order to be eligible to use the law. So, under the FMLA, the employee must work for a public employer of any size or a private employer with 50 or more employees who work within a 75-mile radius of your work site.

This means that if an employee works for an employer with multiple offices and all those offices are within 75 miles, you can actually add up all the employees at each office to get to that 50-employee mark. So, that can be really useful for some people who their specific office might be small but the employer is large. In addition to working for a large enough employer, the employee has to have worked for that employer long enough. The FMLA requires that employees work for their employer for at least 12 months and in the last 12 months worked at least 1,250 hours. So, that comes out to be a little bit more than 24 hours a week if you work all 52 weeks out of the year.

The 12-month requirement doesn't need to be consecutive, only cumulative. So, you can actually look back over the last 7 years and add up all the time you've worked for that employer to get to your 12-month mark.





### **FMLA Benefits**

So, what does the FMLA actually do for you? The FMLA entitles an eligible employee to up to 12 weeks of unpaid leave per year—again, to deal with their own serious medical condition or to act as a caregiver. Certainly, the downside of this is that it is unpaid leave and many people cannot afford to go 12 weeks without income, and that's where disability insurance comes in, which we'll talk about in just a minute.

The benefit of FMLA is that the leave is job-protected, which means that an employee cannot be let go or demoted for taking leave. There are also return-to-work rights, meaning that when an employee returns from leave, they generally have to be reinstated to the same or an equivalent position that they had.

Job protection under the FMLA is so important, because generally when you're taking time off using sick time or vacation time or even using disability insurance benefits, your job is not protected in the same way that it is under the FMLA. If you live in what's called an "at-will" state, an employer can let you go for any nondiscriminatory reason. So, if you're taking leave as vacation or sick time, your employer can let you go.

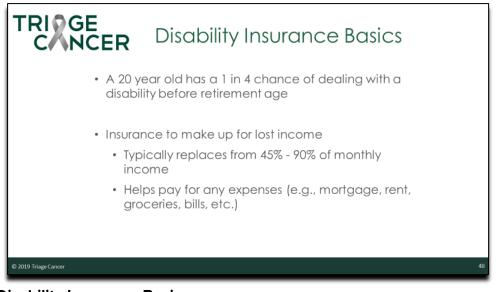
FMLA leave is also health insurance—protected. So, if your employer pays for a portion or all of your health insurance coverage, they have to continue to do that while you're out on leave. So, in other words, they can't force you to elect COBRA or buy another insurance plan while you're out on leave. So, we call this the FMLA Protected Bubble. So, it's not just about being able to take the time off—it's about being able to take the time off while being in this protective bubble of your job being protected and your health insurance being protected.



## \*\*State Leave Laws\*\* \*\*FMLA type leave for smaller employers: \*\*DC (20), ME (15 pvt, 25 public), MD (15), MN (21), OR (25), RI (30 public), VT (15) \*\*Expanded definition of family: \*\*CT, DC, HI, MD, NJ, OR, RI, VT, WI \*\*Expanded use of FMLA leave: \*\*CT, ME, MD, OR \*\*Paid sick leave: \*\*DC, CT, CA, MA, OR + Cities – see chart \*\*Federal Contractors - EO \*\*Unpaid leave to take family members to routine medical visits: MA, VT

### **State Leave Laws**

And while the FMLA provides critical protection to so many Americans, you should also look at your state law. Many states have passed laws that are different or more protective than the federal law, so some cover smaller employers. As I've mentioned, some have expanded definitions of family—some even have paid sick leave. So, again, if you're interested in what's going on in your state around leave laws, check out the chart of state laws.



### **Disability Insurance Basics**

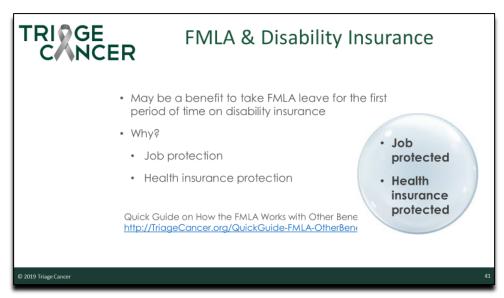
Now, when I mention that the FMLA is unpaid leave, I also said that that's where disability insurance comes into play. Most people need to find a way to make up for the fact that they aren't bringing home a paycheck, especially when we're considering cancer treatment and the medical bills.

So, disability insurance can be very useful because it replaces income that you lose because you're not working due to your medical condition. Insurance policies will only typically pay a portion of what



you normally get paid, but the policies range widely. So, there's policies that pay 45%. There's some that might even pay 90%. It's really going to depend on the policy itself.

And what's different about disability insurance compared with health insurance is that the money can really be used for any expenses. So, it helps pay your bills, groceries, rent—it's not just about medical care.



### FMLA and Disability Insurance

Now, when we start to tie all of this together, it's important to understand how the FMLA can work with other benefits. Many people need to take more than that 12 weeks off from work and then they usually just don't think about FMLA. They go straight to disability leave. But there may still be a benefit for taking the first three months off work under the FMLA, because remember: Not only does it provide that job protection, it also provides the health insurance protection. So, if your employer pays 100% of your health insurance then they have to continue to do that for the period that you're on FMLA leave, which could save you 3 months of paying for your health insurance.

So, we have a quick guide on how all of these things work together, if you are interested.





### More on FMLA and Disability Insurance

And we also have a webinar specifically on FMLA and disability insurance, so you can understand how those things work together as well.



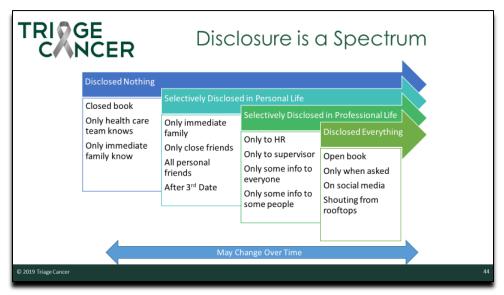
### **Disclosure Rights**

Now, the last thing that I want to talk about is disclosure. Disclosure and privacy is a topic that we spend a lot of time talking about generally, because we find that people often don't realize that they have choices related to disclosure decisions, especially at work. And I hear on a daily basis from people who regret the decisions that they made because they didn't think through some of the ramifications of disclosure.

Generally, you are not required to share any information about your medical condition with an employer. But, if you want to use the ADA's discrimination protections or access reasonable accommodations or medical leave you may need to disclose some information about your medical condition. But that doesn't necessarily mean that you have to disclose your specific diagnosis, because



usually your need for leave or an accommodation is due to the side effects, which are medical conditions all on their own.



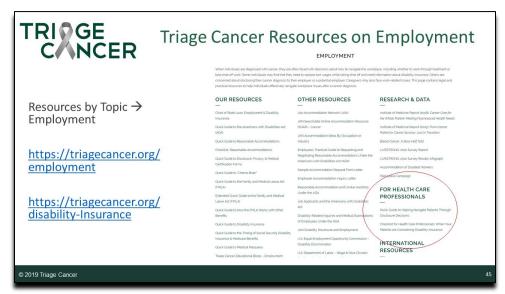
### Disclosure Is a Spectrum

And you can talk about those side effects without tying them back to an original cancer diagnosis if you are concerned about disclosing a cancer diagnosis at work. And we generally like to talk about the fact that disclosure is a spectrum. So, there are people that are all the way here on the left where they are a closed book: Only certain people know—we're not talking about it. To somewhere in the middle, where they've selectively disclosed in their personal life, immediate family only, close friends—maybe after they've gone on a few dates with someone they'll talk about it. Then you have some people who have selectively disclosed in their professional life—so only to a supervisor or HR because they need to access these benefits.

And then you have on the right, which is I'm an open book: I'll shout it from the rooftops! I'm all over social media!

And all of these places along the spectrum are absolutely fine and a totally personal decision. But what we want to empower people with is that they have some decisions and some choices around disclosure, and how they feel about disclosure may change over time.





### **Triage Cancer Resources on Employment**

So, with that, I'll just leave you to remind you that we have some additional resources on employment that do a little bit of a deeper dive into some of the topics that I've talked about today.



### CancerFinances.org

And then also, to remind you about CancerFinances, which has some financial assistance resources if you're having trouble paying for some of those costs, and it includes a lot of LLS resources, certainly. But we talk about financial resources at the very end of this presentation because we think that if people have accurate, actionable information about health insurance and employment rights, their need for the direct financial assistance may decrease.





### **Continued Relationship with Triage Cancer**

So, I certainly hope that you have a continued relationship with Triage Cancer and that you found this helpful, and I'm happy to turn it back over for questions.

### Ms. Alicia Patten

Thank you so much, Monica, for providing us with this very important information. We are truly grateful for partnering organizations, such as Triage Cancer, that help patients and caregivers answer such difficult questions.



### **LLS Education & Support Resources**

It is now time for the question-and-answer portion of our program. We have received some presubmitted questions from patients and caregivers alike that have contacted LLS through our online LLS community or have spoken to our information specialists.

### Ways to Reduce the Financial Burden of Cancer Speaker: Monica Fawzy Bryant, Esquire



Our first question is: "On Triage Cancer there's an article that reads that only 16% of workers in the US receive paid family leave through their employment. Is there more attention being paid to paid family leave on a state and federal level?"

### Ms. Monica Fawzy Bryant

I think that there is a lot of attention being paid. There are bills pending in the state and federal level. It's, you know, one of those things where this is an advocacy opportunity. And for people who think that paid family leave is important, in my opinion, I think they need to be talking with their elected officials about why. What is the real-world impact to actual human beings of offering or not offering paid family leave? And I think that that's the only way that we've seen change happen in the past and it's certainly the way that we're going to see movement on paid family leave at a federal and state level.

### Ms. Alicia Patten

Our next question is, I have Medicare and I'm having trouble understanding the cost of care. I'm concerned that I or my doctor may make a treatment decision based on cost and not efficacy. How do I get the financial information about the cost before I make a treatment decision?

### Ms. Monica Fawzy Bryant

So, Medicare is incredibly complicated and the answers to what something is going to cost you is going to depend on what type of Medicare you have. So, do you have original Medicare, do you have a Medicare Advantage plan, do you have a supplemental plan? So, what I would say is the first step is to make sure that you understand what you personally have and how your plan works. And one resource for you to take a look at is the Understanding the Medicare Maze webinar that is archived on the Triage Center website. We spend a whole hour getting into the Medicare options and what they cover. But then I would also urge you to be empowered to have a conversation with your healthcare team about the costs of care.

Often we, as consumers of healthcare, don't think that our healthcare team would have the answers or are the appropriate people to talk with money about. But certainly, they should have those answers for you or be willing to find them for you. And I would also say that there may actually be less expensive, equally effective treatments. But if financial concerns are never brought up, then your healthcare team is just going to make a decision based on what they think might be best.

So again, the bottom line is sort of understand your Medicare and what you personally have and if it's the right option for you. And then also, be empowered to have the conversation with your healthcare team.

### Ms. Alicia Patten

Our next question is, if my caregiver has difficulties at his or her job because of my cancer, who can help us understand our legal rights?

### Ms. Monica Fawzy Bryant

So, I would again say check out the quick guides on the Triage Cancer website. It's really going to be about understanding the ADA and the FMLA and your state's fair employment laws. Once you have an understanding of those laws and those rights, to have conversations with the employer. But I would also say feel free to, you know, reach out and we could give you more specific guidance based on your specific situation.





### **LLS Education & Support Resources**

### Ms. Alicia Patten

Our next question is, one of the costs associated with health insurance is, copay. This question is, if I have multiple visits to a doctor's office, do you know of any policy where I can pay copay once or not at all without the use, necessarily, of a third-party organization?

### Ms. Monica Fawzy Bryant

So that's an interesting question. I don't know of a specific policy, but one of the ways that we talk about reducing costs is having a conversation with your healthcare team about your concerns and seeing if appointments can in fact be grouped together, because then you're only paying the copay once. So, it may be that, you know, you need bloodwork on this day and you need an MRI on this day and an office visit on this day—and they were scheduled on three different days because those were the next available openings.

But if you have a conversation with your healthcare team about your concerns and say, "Can we actually do this all on one day?" It may be possible and that may be an ongoing way to reduce the copayments.

Also, keep in mind that it's useful to keep track of what you have paid towards your deductible, towards your copayments, and towards your coinsurance. Because if you have met your out-of-pocket maximum and you're seeing an in-network provider, potentially you're not going to be responsible for those copays. But the doctor's office doesn't necessarily know that—that's on you to understand that.

### Ms. Alicia Patten

Our next question is, where can I go for answers about how to apply for government programs?

### **Ms.Monica Fawzy Bryant**

It's going to depend on the government program as to where I would send you. I would also say you can take a look at the state resources page on the Triage Cancer website for the contact information. Different programs have different assistance programs, so for example, every state has a state health insurance—it's called the SHIP program—and it's to help individuals apply for Medicare. The health insurance marketplaces have in-person assisters in some states, so there's no one-stop shop. But certainly, depending on the type of program that you need assistance for, there is often help.

### Ways to Reduce the Financial Burden of Cancer Speaker: Monica Fawzy Bryant, Esquire



### Ms. Alicia Patten

Our next question is, how can life insurance help with my expenses?

### Ms. Monica Fawzy Bryant

That's a very interesting question. So, life insurance policies can certainly help with expenses after you've passed away if your beneficiary wants to use the money for those expenses. But also, there are some companies that will allow you to use your life insurance policy as collateral for a loan. So, you basically use that as your collateral and then you get cash immediately, which can help in the short term if you need cash on hand. There are also some companies where you can actually sell the value—it's called a viatical settlement—where you sell the value of your life insurance for cash on hand now.

The downside to that is that if you have a beneficiary that you'd like to take care of upon your death, that is no longer an option. But for some people they may have purchased the plan when they had minor children and they don't have minor children anymore. So, having cash on hand now can actually be more useful for them.

### Ms. Alicia Patten

And our last question is, with the advancement of cancer treatment, the conversation of clinical trials is one that we're having a lot here at LLS. How do the costs of a clinical trial compare with the costs of the standard treatment? And does one cost more than another?

### Ms. Monica Fawzy Bryant

It's a fantastic question and I'm delighted more people are talking about clinical trials. They're, you know, the only way that we get advancements in cancer care and they are unfortunately underutilized in a lot of areas. One of the reasons that they have been underutilized in the past is that insurance companies would say to somebody, effectively, "Oh, you're in a clinical trial. We're not responsible for covering any of the costs of your treatment."

Now some states stepped in and passed laws that said, "No, that's not the case." And then with the Affordable Care Act, otherwise known as ObamaCare, it made it federal law that said that health insurance companies are still responsible for covering the routine costs of care, even if somebody's in a clinical trial. So, the routine costs of care are going to be anything that's standard treatment.

So, for example, let's say that your cancer treatment requires that your routine care would be that you would get four blood draws a year. The clinical trial wants you to now get a blood draw every single month. The insurance company is still responsible for paying for the four they would have paid were you not in the clinical trial. And then, typically, the clinical trial will pick up the additional costs of the additional testing.

So, it has reduced or eliminated one of the barriers to participation in clinical trials, and that the insurance company is still responsible for what they would have been responsible for had the person not been participating. And if anyone has questions about this piece of clinical trials, we actually have an animated video that we just released recently in English and Spanish that talks a little bit more about it.





Thank You

### Ms. Alicia Patten

That concludes the question-and-answer portion of our program.

If you have a question that you would like to ask Monica you may do so by selecting the 'Submit a question' button located below the presentation window or the link located at the upper right corner on the platform. - Please check there to see if your question has already been answered. If you do not see your question listed, please complete the 'Submit a question' form and your question will be forwarded to Monica. You can expect to receive an answer via email within 2-3 business days. There is also an option to have an Information Specialist reach out to you.

Please complete the evaluation to help us improve future activities. We will also be reaching out to you in about 3 months asking you how this program has helped you and what continuing needs you may have, at that time, related to this topic.

If you have any additional questions, please call an LLS Information Specialist at 1-800-955-4572. Information Specialists are available to speak with you Monday through Friday from 9 AM to 9 PM Eastern time, or you can reach us by email at <a href="infocenter@lls.org">infocenter@lls.org</a>.

We can provide information about personalized clinical trial assistance and nutrition consultations, and answer other questions you may have about diagnosis, treatment, and support. LLS also offers financial assistance programs to help individuals with blood cancer. For more information about our financial support, please visit <a href="https://www.lls.org/finances">wwww.lls.org/finances</a>.

Thanks again, Monica, for sharing your time and knowledge with us. We appreciate your dedication and commitment to improving access to and availability of quality financial information for patients and caregivers throughout their cancer journey.

On behalf of The Leukemia & Lymphoma Society, thank you for listening and we wish you well.