



LEUKEMIA &  
LYMPHOMA  
SOCIETY®

**ADDRESSING THE  
FINANCIAL IMPACT  
OF CANCER**

**Joanna Fawzy Morales, Esq.**  
Chief Executive Officer  
Triage Cancer  
Chicago, IL

**Slide 1: ADDRESSING THE FINANCIAL IMPACT OF CANCER**

Welcome to Addressing the Financial Impact of Cancer patient education program.

## WELCOMING REMARKS

ADDRESSING THE FINANCIAL IMPACT OF CANCER



**Lizette Figueroa-Rivera, MA**  
Sr. Director, Education & Support  
The Leukemia & Lymphoma Society



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### Slide 2: WELCOMING REMARKS

#### Lizette Figueroa-Rivera:

Hello, everyone. On behalf of The Leukemia & Lymphoma Society I would like to welcome all of you. We have over 2,500 people participating from across the United States, as well as others participating from other countries including Argentina, Canada, Egypt, Georgia, Greece, India, Iraq, Kenya, Philippines, Sweden, United Kingdom, Uzbekistan, and the Vatican City. Thank you all for joining us.

Today Joanna Fawzy Morales, Esquire will discuss how cancer can impact your finances, health insurance coverage, and employment during and after cancer, as well as financial budgeting and resources.

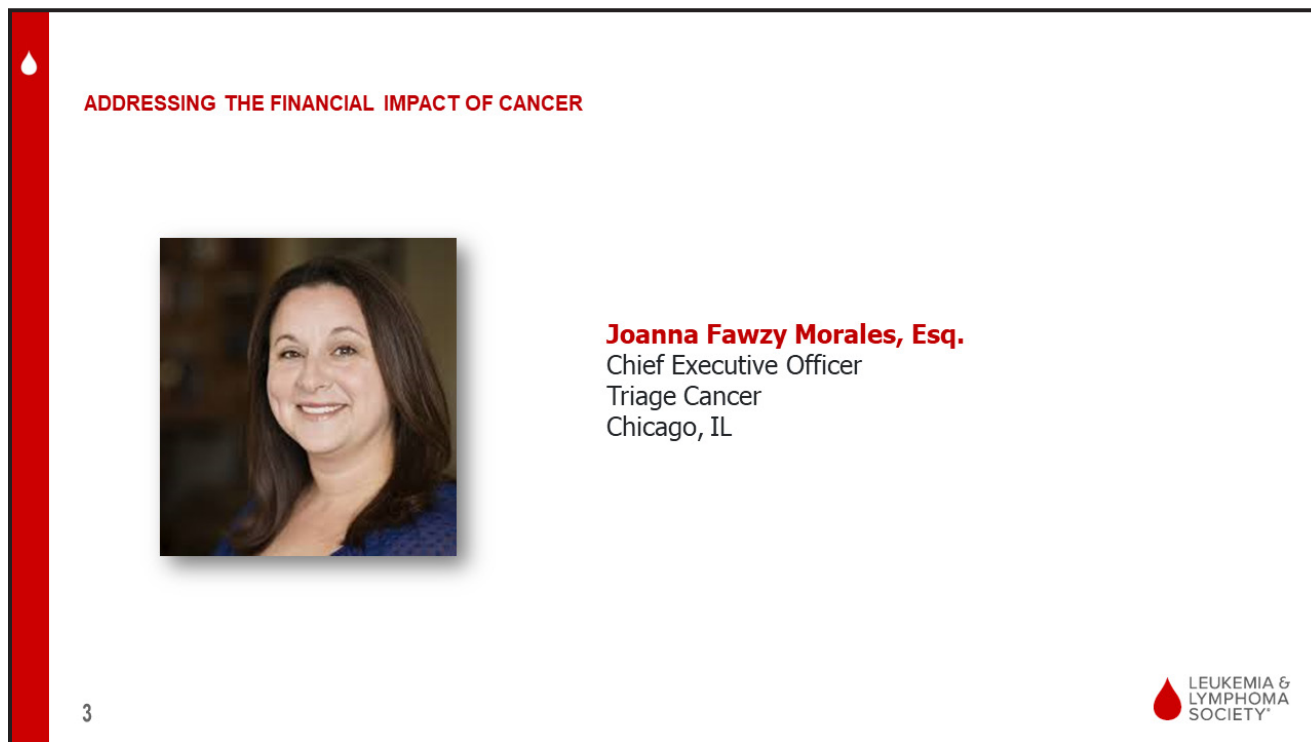
As a leading source of free blood cancer information, education, and support for patients, survivors, families, and healthcare professionals, LLS helps you navigate you or your loved one's cancer treatment and ensures you have access to quality, affordable, and coordinated care.

Research will help us achieve an end to cancer. In the meantime, patients and caregivers need help before, during, and after a cancer diagnosis and treatment. LLS is the leading nonprofit that does just that.


Please continue to inform us of what you need during this time and please continue to let us be here for you.

For this program, we would like to acknowledge and thank Bristol Myers Squibb; Genentech and Biogen; Pharmacyclics, an AbbVie Company, and Janssen Biotech; and Takeda Oncology for their support of this program.

Following the presentation, we will take questions from the audience. I am now pleased to introduce Joanna Fawzy Morales, Esquire, the Chief Executive Officer at the Triage Cancer, located in Chicago, Illinois. Joanna, I am privileged to turn the program over to you.




ADDRESSING THE FINANCIAL IMPACT OF CANCER



**Joanna Fawzy Morales, Esq.**  
Chief Executive Officer  
Triage Cancer  
Chicago, IL

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## Slide 3: ADDRESSING THE FINANCIAL IMPACT OF CANCER

### Joanna Fawzy Morales:

Thank you, Lizette.

I want to start by talking about some of the things that Triage Cancer has to offer to help people address the financial impact of cancer, so that as I go throughout the presentation today then you will know where to go for more information.

## Slide 4: About Triage Cancer

Triage Cancer is a national, nonprofit organization that provides free education on all of the legal and practical issues that come up after a cancer diagnosis.

## Slide 5: Triage Cancer Webinar Series

We do that through the hosting of free educational events and those include our webinar series, where we provide monthly webinars on a variety of topics.

## Slide 6: Triage Cancer Conferences

We also offer our Triage Cancer Conference Series, which provides information on some of the topics that we think come up most often for people diagnosed with cancer and their caregivers, and that includes things like insurance and finances and employment issues. Our next conference is coming up on October 1st in Chicago and it is free to everybody.

## Slide 7: Triage Cancer Materials

In addition to our educational events, we also offer educational materials and resources and those materials take some different formats, so we have our quick guides and checklists, which provide a quick overview on a topic, and then we also have some worksheets and spreadsheets to help you actually navigate some of these issues and I will explain some examples of those.

All of our materials you can find on our website at [TriageCancer.org](https://www.TriageCancer.org), and for healthcare professionals we also ship them copies for free to share with their patients.

## Slide 8: Practical Guides to Cancer Rights

We also have a new series of educational guides called our Practical Guides to Cancer Rights, which cover again some of the topics we think are most important for people to understand, and we have our general guides, but we also have some options for young adults and seniors and caregivers as well.

## Slide 9: Triage Cancer Animated Videos

We know that learning about insurance and some of these other topics is not really exciting to learn about and that everybody learns in different ways, so we have a series of animated videos. These cover key things in 5 minutes or less, like how to pick a health insurance plan or how to manage side effects at work, or practical things to think about when estate planning.

## Slide 10: Triage Cancer Resources By Topic

We also, on our website, sort our information in 2 ways. We have resources by topic, where you can pick a topic and then find all of the resources that we have available on that topic.

## Slide 11: Triage Cancer International, National, & State Resources

We also sort information by location. We have state-specific resources and information based on where you live.

### Slide 12: Triage Cancer Chart of State Laws

Because where you live matters in terms of what you have access to, we also have a chart of state laws on our website that cover topics related to insurance and finances and employment issues and estate planning and a whole host of other topics that we want people to understand what is available to them based on where they live.

### Slide 13: CancerFinances.org

We also offer a resource called Cancer Finances and this is a tool where you can go onto the tool and pick a topic that can impact your financial situation, and then start to answer questions based on your situation or what you are looking for, and it will tailor the information based on how you have answered those questions. You are getting directed to the information that is most relevant to you. We are constantly adding new resources on all of these topics.

### Slide 14: Contributors to Financial Toxicity

When we are talking about addressing the financial impact of a cancer diagnosis, there is a term that is often used, the issue of financial toxicity. And even though this is a relatively new term, it is really an old problem where a serious medical condition can cause a financial impact. At Triage Cancer there is one way to try to lessen that financial impact by having adequate health insurance coverage. And I am going to share with you some key tips on how to actually do that.

But it also can be changes in your employment situation, where if you need to take time off work, how are you replacing those lost wages. That can also have an obvious impact on your financial situation.

The problem with financial toxicity is that there is not one solution, there are a lot of contributors to financial toxicity, so we have to address each one of those to try to prevent that financial burden.

### Slide 15: Don't Understand Health Insurance? You Are Not Alone.

Turning to health insurance. The biggest challenge is that most people don't know how to navigate our health insurance coverage in the United States. Only 4% of Americans could actually define the key 4 terms that are used in health insurance coverage, and only about maybe 40% of people in the United States can actually pick a health insurance plan that's appropriate for them.

If no one understands the terms that are used in health insurance or how to pick a health insurance plan that works for them, it makes sense that it is difficult to avoid that financial burden. If you feel like you don't understand your health insurance coverage, you are absolutely not alone.

### Slide 16: Where We Get Health Insurance

In the United States there are only 3 places where we get our health insurance coverage. We are either getting it directly from an insurance company or getting it through the government, and by that I mean Medicare or Medicaid or military and veterans' plans, or even state or local programs, but still about 50% of people in the United States get their health insurance coverage through their employer. Even if you get your health insurance through your employer, we think that it is incredibly important for everybody to understand all of their health insurance options, so that you can actually make sure that you are comparing the options that you have and picking the plan that is best for you, as opposed to maybe the plan that is easiest to figure out, like the employer's just providing you with the information, but you actually might have access to less expensive or better insurance from other sources. And so, at Triage Cancer we have a lot of information to help you understand all of your health insurance options on our health insurance topics page.

### Slide 17: Health Insurance Terms

When we are talking about the terms that are important for people to understand, there are terms that relate to the cost for having health insurance and that is what we call our premium. It is what we pay just to have health insurance coverage. And most of us pay a monthly premium, where we pay that fixed dollar amount each month just to have insurance. Even if we got no medical care during the year, we would still have to pay our monthly premium.

Then there are costs that we pay when we use our health insurance and get medical care. The first is our annual deductible. It is what we pay first before our health insurance even kicks in. It is a fixed dollar amount, so you might have a \$500 deductible or you could have a \$7000 deductible, or maybe even a zero dollar deductible, depending on the plan that you have.

Then there is something called a copayment and that is also a fixed dollar amount that you pay when you get certain types of care. You might have a \$20 copayment to see your primary care physician, or you might have a \$50 copayment to see a specialist, or a \$500 copayment if you go into the emergency room. Again, the amounts are going to be dependent on the plan that you have.

And that is different from co-insurance or cost-share. Those are 2 terms that are used the same way. It is a percentage. It is the difference between what insurance companies pay for our medical expenses and what we pay for our medical expenses. If you have an 80/20 cost-share, the insurance company is going to pay 80% and you are responsible for 20% of your medical expenses.

Probably the most important thing for people to understand about their health insurance coverage is their out-of-pocket maximum. This is a fixed dollar amount that when you reach that fixed dollar amount in out-of-pocket expenses, your insurance will kick in at 100% for the rest of the year. You can plan around a worst case scenario of the most that you are going to pay out-of-pocket for your medical expenses each year. And how you get to that number is actually a math problem. So, you get to add up what you pay for your deductible, plus any copayments that you make, plus any co-insurance amounts that you pay, get you to reach your out-of-pocket maximum. And again, when you do, then your insurance will kick in at 100% for the rest of the year.

### Slide 18: Case Study: Dan

To give you an example of how this actually works, Dan has a plan that has a \$2000 deductible, it is an 80/20 plan, and he has an \$8000 out-of-pocket maximum. Now he spends a week in the hospital and he walks out of the hospital with a \$102,000 hospital bill. And assuming he has had no other medical expenses during the year, how much does Dan actually have to pay of that \$102,000 hospital bill? So first he is going to pay his \$2000 deductible, which leaves \$100,000 left of that bill. And then, his insurance is going to pick up the co-insurance amount, so they will pay 80% and he is responsible for 20%. Of that 20%, that leaves him with a \$20,000 bill. But, how much does he actually have to pay of that \$20,000 bill?

Well, he has already paid his \$2000 deductible and he has an \$8000 out-of-pocket maximum, so he only needs to spend another \$6000 of that \$20,000 bill and then he will reach his \$8000 out-of-pocket maximum.

I am definitely not suggesting that \$8000 is not a lot of money, but it is better than the \$20,000 bill that he would have been left with if he didn't have an out-of-pocket maximum.

So, everything that we just described on the last 2 slides is actually in one of our animated videos. If you want to see that again or share it with somebody else, you can share that animated video.

## Slide 19: Out-of-Pocket Maximums

But here is some nuance to this. You might have a plan that has an individual out-of-pocket maximum, but if you have family members on your plan you might face a family out-of-pocket maximum as well.

It is important to know that if we are talking about marketplace plans, that plan is required to include everything in that one out-of-pocket maximum, which means that it includes your deductible, plus any copayment, plus any co-insurance amounts, both for your medical care and your prescription drugs.

But when we are talking about employer plans, they can make exceptions. Some employer plans don't include the deductibles and the out-of-pocket maximums, where it is just going to include your copayments and your co-insurance. And then some employer plans don't include deductibles or copayments, so the out-of-pocket maximum is just including the co-insurance amount, and then some employer plans might have a separate out-of-pocket maximum for prescription drugs, where it is going to include the copayments and co-insurance amounts that you pay for your prescription drugs.

As with most things, the devil is in the details, and so it is important for you to understand how your plan works, so that you can figure out the true costs to your health insurance coverage.

## Slide 20: Comparing Plan Options

I mentioned that picking a health insurance plan and having adequate health insurance coverage is the number one way to avoid financial toxicity and I want to walk you through an exercise that can help you figure out how much a plan will actually cost you. This exercise is useful if you are comparing different marketplace plans. It is useful if you are going to compare different options that your employer offers you, you can compare what is in the marketplace to an employer plan and you can compare Medicare Advantage plans using the same exercise.

## Slide 21: Total Annual Cost

Here we have 3 plans. There is a bronze level plan at \$200 a month with an \$8000 out-of-pocket maximum. There is a silver level plan at \$275 a month with a \$6000 out-of-pocket maximum. And there is a platinum level plan at \$400 a month with a \$2000 out-of-pocket maximum. The question is, can you tell, just by looking at these plans, which is actually going to cost you the least by the end of the year, assuming that you are going to hit your out-of-pocket maximum? Because, when we are talking about the cost of cancer care or really any serious medical condition, the likelihood of you hitting your out-of-pocket maximum is much higher.

## Slide 22: Do the Math!

The short answer is no, you can't tell just by looking at them, you actually have to do the math. And the way that you do the math is that you take the monthly premium and you multiply it by 12 because that is how much it is going to cost you to have the plan for the year, and then you add the out-of-pocket maximum because that is the most that you are going to spend on your medical expenses out-of-pocket for the year.

So, looking at these 3 options, you actually have some differences between the plans, in fact the platinum plan can save you a couple thousand dollars by the end of the year.

## Slide 23: What are the differences between plans?

Most of the time when we are talking about purchasing something, we usually just look at those upfront costs. And so, a lot of people when choosing a health insurance plan, they're just looking at that monthly premium as the cost to have the plan, but even though we might get sticker-shock when we see that \$400 a month for the platinum level plan, because most people do not understand how out-of-pocket maximums work, you might miss out on an opportunity to save a whole lot of money, and in this case it is about \$3000 that you are saving over the course of the year. And, that's why when we are talking about mitigating financial toxicity, this is the number one way that you can do that. And really the bottom line is, whichever plans you might be looking at, you have to do the math to see what it is actually going to cost you by the end of the year.

## Slide 24: Checking Providers, Facilities, & Drugs

There are other things that you need to be looking at besides the cost. You need to be making sure that your plan is going to cover your providers, any facilities that you are going to, like a hospital, and does it cover your prescription drugs, because if you pick a plan that doesn't cover those things, it is going to be pretty useless to you and then you are going to have to pay more out-of-pocket to see those out-of-network providers and to get access to drugs that aren't included in your plan. So, there are other things besides cost that you need to be paying attention to.

## Slide 25: Picking a Health Insurance Plan

If you are shopping on the marketplace, it actually gives you some tools to be able to figure out if your plan covers the providers and the facilities and the prescription drugs that you take. You can actually narrow down your plan choices and then once you click on a plan you can look up the list of drugs covered and whether or not the doctors and facilities that you go to are included in that plan. But I always recommend that you double-check with your providers because you want to make sure that you are actually getting access to a plan that is going to cover their providers.

We feel so strongly about this at Triage Cancer that we have a lot of tools to help people pick a health insurance plan. We have an animated video on picking a health insurance plan. We actually also have one specific to Medicare to help you pick a Medicare plan. And then we have worksheets to help you do the math. We have one for marketplace and employer plans, and then we also have a worksheet if you have Medicare, so that you can compare the various plan options under Medicare to figure out which is the best plan for you and will have the lowest out-of-pocket cost. Those are all available on our website at [TriageCancer.org](https://www.triagecancer.org).

## Slide 26: Managing Medical Bills

Turning to the issue of managing medical bills, we get a lot of communications in the context of managing medical bills that may be piling up or even notifications in your e-mail that new things have been added to your online portal for your insurance company or your providers.

The types of communications you typically get from your insurance company is that we've received a claim and you do not have to do anything, they are just letting you know they have received a claim from your provider. Then they might send you another notification that they are actually working on processing that claim, and again you don't have to do anything, they are just letting you know. And then, you might receive what is called an Explanation of Benefits or an EOB. This is usually evidenced by the fact that somewhere on the page it says "this is not a bill". It is just an explanation of what the insurance company received as a claim from your provider and how they handled that claim. How much they are going to pay for that claim, if anything gets applied to your deductible, and ultimately how much you are responsible for that particular claim.



## Slide 27: Managing Medical Bills

Then from the provider you are going to get a bill. The problem with this process is all of that mail, your communications, don't necessarily happen in a logical order. You might get a bill from your provider before you receive the Explanation of Benefits. Or they might even send you the bill before they have gotten information from your insurance company. Sometimes they might bill you the whole amount of the service because they have yet to get the details from your insurance company about how much the insurance company is going to pay for that claim. It is very important that as you get all these communications, you wait to pay the bill until you have received the Explanation of Benefits from your insurance company and you match those 2 documents up and make sure that they do match and that they are accurate, because it is always worth double-checking to see if there are any errors.

Billing is a human process and so someone has to type information into the computer and typos are possible, so it is very important that you check for mistakes. If you have any questions, to talk to your provider or your insurance company about those discrepancies.

Then if your insurance company comes back and says we're not covering that care, we deny coverage for that care, it is very important that you appeal any denials of coverage.

## Slide 28: Consumer Protections: Appeals

When we are talking about all types of insurance, you have the right to appeal those denials of coverage. When we're talking about private insurance, whether it be through an employer or an individual plan, you have the right to appeal inside the insurance company, which we call an internal appeal, but you also have the right to go outside the insurance company, to an external appeal, if the insurance company is still saying no. These external appeals are required under the Affordable Care Act and every State's process is a little bit different, but the State Health Insurance Agency is the agency that is going to oversee the process or it is the U.S. Department of Health and Human Services.

The value of going outside the insurance company to an independent entity is that they are going to decide whether or not the care that your healthcare team has prescribed is medically necessary, and if they decide that it is medically necessary, that decision is binding on the insurance company and they have to provide coverage.

I often talk about the external appeals process is the best kept secret of our healthcare system and it really is. Unfortunately, there is data that shows most people don't appeal and, for example, in 2019 there were 40 million claims denied through marketplace plans that year, but only 0.2% of those denials were appealed and not even to the external appeals process, just to the internal appeals process.

What is important to keep in mind is that about 50% of the time once a claim goes to external appeal, the patient is winning and the insurance company is being required to cover their care. When you think about on average 50% of the time insurance companies are getting it wrong, when you think about 40 million claims being denied, half of those claims are people that either didn't get access to the care that they were prescribed because their insurance company said no, or they paid for that care out-of-pocket when their insurance company should have covered it. And so, when we are talking about how do we minimize the financial impact of a cancer diagnosis, this is one more huge step that patients can take to protect themselves. Unfortunately, it is hugely under-utilized.

## Slide 29: Employment Rights

Turning to employment rights, there are actually a lot of places where we can go for information about our employment rights. There are laws that we refer to as Fair Employment Laws, like the Americans with Disabilities Act, which protect people against discrimination in the workplace based on their medical condition and give them access to reasonable accommodations. Those exist both at the federal level, but they also exist at the state level as well, and sometimes state laws are better than federal laws. It is important to know both.

There are also laws that we refer to as Leave Laws and these are laws that allow us to take time off of work and sometimes provide job protection when we are doing that, as well as health insurance protection. And again, those exist at the federal level, like the Family and Medical Leave Act or FMLA, but they also exist at the state level and sometimes even the county and city level.

Then if we are working under an employment contract or we are a member of a union, that union bargaining agreement can also provide additional information about employment protections that we have access to and other benefits in the workplace.

## Slide 30: Employer Policies

We forget that the law just provides the bare minimum of what employers have to do. There are so many employers that go way above and beyond what the law actually requires them to do, so do they give you access to employee benefits like health insurance or vision or dental, maybe they offer you a life insurance policy or disability insurance. Most employers have additional information about how you can actually take time off of work. In most states, counties and cities across the country, if you have ever taken a sick day, it is not because the law requires it, it is because your employer has offered that as a benefit. And so, sick time and vacation time, can coworkers donate their hours to you, all of those things are going to be specific to your employer and that information is usually contained in some version of an employee handbook or manual. If you work for a smaller employer, they might not have all those policies written down, but they do have that, and so it is important to talk to whoever at your place of employment is making those decisions or has the details. Maybe it is the person you turn your timesheet in to or maybe it is the person that health insurance is taken care of by. You can ask questions of those individuals about any details specific to your place of employment.

## Slide 31: Americans With Disabilities Act (ADA) Title I

The Americans with Disabilities Act or the ADA is a federal law that most people are familiar with only in the context of the fact that there are accessible parking spots or ramps into buildings for individuals who use wheelchairs or accessible bathrooms. But there is an entire section of the ADA that we call Title I, which focuses on the employment of people with disabilities. The ADA is enforced by the Equal Employment Opportunity Commission and only applies – I should say Title I only applies – to private employers with 15 or more employees, or to anyone who works for a state or local government.

Federal employees actually aren't protected under the ADA's Title I, but they do have access to similar protections, it is just coming from the Rehabilitation Act of 1973. The same protections, it is just technically available under a different law.

In order to use the ADA's protections, you have to be qualified, meaning that you can perform the essential functions of the job with or without a reasonable accommodation, and that you have a disability under the ADA's definition of disability.

### Slide 32: Americans With Disabilities Act

Once you show that you are allowed to use the ADA for protection, there are 4 ways you can actually do that. The first is that you currently have a physical or mental impairment that substantially limits a major life activity, which is the definition of disability under the ADA.

It also applies to individuals who have a history of having a serious medical condition that qualifies for protection under the ADA and that could be very useful for someone who is going back into the workplace and is looking for protection and from being treated differently because of their medical condition.

The third way really is not about you at all, it is about your employer's perception of you, where your employer is regarding you as having a disability and not able to do your job in the same way and treats you differently because of your medical condition. That is enough for another protection under the ADA.

The fourth way is actually for caregivers. Caregivers, because they associate with a person with a disability, are protected against discrimination at work. Because of their caregiving status, they can't be treated differently because they are associating with a person with a disability.

The ADA actually applies to all phases of the employment process, which means that job applicants are protected, and employees are protected as well. And really, the bottom line of the ADA is that employers can't take into consideration your medical condition when making employment decisions. Employment decisions are things like hiring and firing and benefits and promotions and bonuses and assignments. All of those things shouldn't be taking into consideration your medical condition when they're making those decisions.

### Slide 33: Reasonable Accommodations

The ADA provides protection against discrimination at work, but it also provides access to reasonable accommodations. Reasonable accommodations are defined in the law as: "Any change in the work environment or in the way things are customarily done that enable an individual with a disability to enjoy equal employment opportunities". That is the legal definition of a reasonable accommodation. There are lots of practical examples, especially ones that come up in the context of a cancer diagnosis and treatment. But I want to highlight for a second that it says "any change". Any change at work could be a reasonable accommodation to help people stay at work, to help people return to work, or potentially to take time off as a reasonable accommodation. I highlight this because really it means everything is on the table as a possible reasonable accommodation. And so, we want people to think as creatively as possible about what might solve the challenges that they are experiencing at work because of their medical condition.

## Slide 34: Reasonable Accommodation Tips

Employers have to accommodate you if you are eligible for protection under the ADA, unless it is going to impose an undue hardship, which is a very high financial standard for an employer to meet, or it is going to cause a direct threat either to you or to someone else. Those are 2 pretty small exceptions to the requirement that employers have to provide you with an accommodation.

They have to provide you with an effective accommodation. Something that actually is going to be effective for you to help address the challenges that you are having at work. But it does have to be reasonable based on your job responsibilities. If you are an airline pilot asking to telecommute as a reasonable accommodation, it is probably not going to be reasonable, at least not yet. You do still have to have it tie back to your job responsibilities and be reasonable based on those job responsibilities.

Even though caregivers are protected against discrimination under the ADA, they are not entitled to reasonable accommodations, even though you can think of lots of practical examples of how an accommodation could be useful to a caregiver, but it is not required under the law. That doesn't necessarily mean that a caregiver couldn't ask for an accommodation, because really employers want to keep good employees, and so if you can think through what might be challenging for you at work as a caregiver and propose some solutions, like an adjusted schedule or maybe there is a day that you telecommute while you are also dealing with caregiving responsibilities, it doesn't necessarily hurt to ask the employer, if you are being proactive in proposing potential solutions.

I think that reasonable accommodations are the most under-utilized tool that the law provides to help someone stay at work, return to work, or take time off. And so, we have a lot of information about accommodations and how you can practically use them.

## Slide 35: State Fair Employment Laws

I mentioned that the ADA only applies to private employers with 15 or more employees. There are also State Fair Employment Laws that track with the ADA and provide similar protections, but sometimes those state laws are actually more protective, and one of the ways that they are more protective is that they cover smaller employers.

## Slide 36: Employer Size - State Fair Employment Laws

These are all the states that have State Fair Employment Laws with smaller employers. For example, if you are in Idaho, the State Fair Employment Law in Idaho only requires the employer have 5 or more employees. If you happen to work for an employer with 5 to 15 employees, you are actually not looking at the ADA for protection, you are looking at the State Fair Employment Law for protection. Again, it is important not just to know what is available at the federal level, but also at the state level, because sometimes it is only what is existing at the state level that is going to be helpful to you.

## Slide 37: Family & Medical Leave Act (FMLA)

The Family and Medical Leave Act or the FMLA is a federal law that allows employees to take time off for their own serious medical condition or as a caregiver of a spouse, a parent, or a child. That is a pretty limited definition of family and there are some challenges with that on a practical level. It doesn't include parents-in-law or grandparents or siblings or aunts or uncles, so it is important to understand where the FMLA is limited.

## Slide 38: FMLA Eligibility

You also have to work for a large enough employer, a private employer with 50 or more employees or for a government. You also have to work there at least 12 months and you have to work there at least 1250 hours in the last 12 months that you worked for the employer. And so, there are some hoops to jump through to get access to the FMLA's protections.

## Slide 39: FMLA Benefits

But the FMLA provides employees with up to 12 weeks of leave per year. So, every 12 months you get access to 12 weeks of leave, that is job-protected leave, and health insurance-protected leave, if you get your health insurance through an employer. That can be a financial benefit because if your employer pays 100% of your health insurance premium, that has to continue for the period of time you are on FMLA leave.

The downside to FMLA leave is that it is unpaid and so that can pose a barrier because most people cannot afford to be off work for 12 weeks and not have any income coming in. That is where disability insurance comes into play and we will talk about that in just a second.

## Slide 40: State/County/City Leave Laws

FMLA is a federal law, but there are also some states that have state FMLA laws that actually cover smaller employers and have a broader definition of who can be a family member, who you can care for under that law. There are also state, county, and city laws around paid sick leave and unpaid leave if you are going to take family members to medical visits. All of that information is contained on our chart of state laws, so you can find out what is available to you based on where you live.

## Slide 41: Triage Cancer Resources on Employment

We also have all of our employment-related resources on our employment topics page as well.

## Slide 42: Disability Insurance Basics

Turning to disability insurance, disability insurance is the type of insurance that replaces your lost wages if you have to take time off work due to a medical condition. The challenge with disability insurance is, rarely is it going to pay 100% of what you were making when you were working. Disability insurance policies can range from 45% of your salary to 90% of your salary. Only once have I ever seen a policy that paid out at 100%.

But the problem is most people do not proactively go and purchase disability insurance the way we think about health insurance or car insurance. A 20-year-old has a 1 in 4 chance of dealing with a disability before retirement age, so the question becomes how do you get access to disability insurance benefits? And there are different types.

## Slide 43: Disability Insurance Options: Private

There are private disability insurance options that you can buy directly from an insurance company, which I already said most people don't do. Most people get access to private disability insurance through an employer, where the employer is offering employee benefits. Those policies can be short-term for medical conditions that last 6 months to a year or they can be long-term, which is typically for medical conditions that last at least a year or longer.

## Slide 44: Disability Insurance Options: State

There are a handful of states, and by handful I just mean 5 and Puerto Rico, that offer State Disability Insurance, where employees pay into the system through their payroll taxes to get access to these short-term disability benefits. We do have a quick guide to State Disability Insurance, which explains the programs in each of these states, as well as the contact information for how to apply on our state resources page.

## Slide 45: Disability Insurance Options: Federal

That brings us to the 2 federal long-term disability programs that are run by the Social Security Administration. There is Social Security Disability Insurance, which is SSDI, and there's Supplemental Security Income, which is SSI.

## Slide 46: Disability Insurance Resources

We also have a lot of resources to help you understand your various disability insurance options and then practically speaking, how do you actually apply for benefits, and if you get denied how do you get through the appeals process, as well as when do you actually get access to cash benefits and any health insurance coverage that is tied to those benefits. We have resources to help you navigate this process.

## Slide 47: Legal & Financial Navigation Program

But, if you are feeling a little overwhelmed by all of this information and you have personal questions about your situation, you can absolutely contact our Legal and Financial Navigation Program, where we will provide one-on-one help to help you understand health insurance, employment, disability insurance, finances, estate planning, and any of the other legal issues that come up as a result of the cancer diagnosis. If you go to our website and fill out the form, you will get the opportunity to schedule a calendar appointment with a member of our team to talk through your personal issues, so I wanted to make sure that you are aware that this individual help is out there.

With that, I am going to turn it back over to Lizette.

### Lizette Figueroa-Rivera:

Thank you so much Joanna for this presentation. Your explanations and examples are really very helpful for us as we navigate our finances.

It is now time for our question-and-answer portion of our program.

### Slide 48: Ask a question

#### Lizette Figueroa-Rivera:

Our first question today Joanna comes from Michael. Michael asks, what does one do when denied Social Security Disability? Would I need to get an attorney?

#### Joanna Fawzy Morales:

You don't necessarily need an attorney to file an appeal for Social Security Disability Insurance, but it is incredibly important that you actually appeal because about 65% of applications are denied the first time around, so if you take the next step in the process, which is called a Request for Reconsideration, you are basically just asking them to reconsider. If you are still denied, then you go to an Administrative Law Judge hearing or an ALJ, and this is really unlike anything you have seen on a television courtroom drama. It is just the judge and you and a vocational expert and if you brought someone to represent you. And it is the judge that asks the questions and is really going to delve into how your medical condition impacts your ability to work.

And so, at each stage of the appeals process you are much more likely to actually get access to the benefits that you are entitled to, so it is very much worth going through the appeals process, even though it is extra steps for you.

#### Lizette Figueroa-Rivera:

We will take the next question from our telephone audience, please.

#### Operator:

Kathy in North Carolina, please go ahead.

#### Kathy:

Hi, I'm wondering on the SSI, if you already are receiving your Social Security benefits and you have been unemployed, can you get Medicaid through your state to help instead of having to pay for the extra supplemental insurance that you would when you retire?

#### Joanna Fawzy Morales:

It sounds like there are a couple of parts to your question. I think what you are getting at is, if you are already receiving Social Security Retirement Benefits, where you are over the age of 65 and getting those benefits, then can you get access to Medicare, which is the health insurance coverage that is for individuals who are over the age of 65 and eligible for Social Security Retirement Benefits, can you also get access to Medicaid, which acts as a supplement, rather than having to buy a Medigap supplemental plan on top of your Medicare coverage. And the answer is yes, you can get access to Medicaid if you qualify for it. Do you have a low-income level and a low resource level in those states that would qualify you for Medicaid? If you do then that is actually very comprehensive health insurance coverage because there are things that Medicaid covers that Medicare does not, like dental care, for example, in some states. You can get both. If your income level is too high for Medicaid, there are also some Medicare savings programs that you might qualify for to pick up some of the out-of-pocket costs associated with Medicare.

At [TriageCancer.org](https://www.triagecancer.org) we have a quick guide to those savings programs, but if you want help understanding your Medicare options you can absolutely contact our Navigation Program, you can also contact SHIP, which is the Senior Health Insurance Assistance Program, and you can find the program in your state on our state resources page and they will help you navigate the application for Medicaid as well as to find out if you are eligible for those savings programs.

**Lizette Figueroa-Rivera:**

Thank you so much. Our next question comes from Zeke. Zeke is asking... what happens when you pay a bill before insurance pays and the doctor refuses to refund you?

**Joanna Fawzy Morales:**

That is a great question and that is actually why we recommend that you don't pay the bill until you get the Explanation of Benefits because having to track down the money is a whole lot harder of a process. If it is true that you don't owe any of that money back to the provider, your provider does have to refund you, and if you find yourself in a situation where your provider is not providing a refund, I would suggest that you contact your insurance company, that you contact the State Health Insurance Agency, and maybe even the Medical Bureau for that particular state to file a complaint against the provider. But I really think it is about communication and trying to explain to the provider why they owe that money back to you and to potentially speak to someone other than the provider, like someone in the billing department, who might provide more clear information.

**Lizette Figueroa-Rivera:**

Thank you. We will take the next question from our phone audience, please.

**Operator:**

We will go to Glenn in California.

**Glenn:**

Please explain the Medicare Part D doughnut hole and expected out-of-pocket cost for a very expensive anti-cancer drug called Revlimid® (lenalidomide).

**Joanna Fawzy Morales:**

I can't speak to specific drugs like Revlimid, but the doughnut hole is the standard way a Part D plan works. As of 2020, the doughnut hole has actually been closed. The way that a Part D Medicare prescription drug plan works is that first you pay a deductible and this year that is about \$480 out-of-pocket first for your prescription drugs, and then for any costs moving forward Medicare is going to pay 75% and you are responsible for 25% of your drug costs, until you reach catastrophic coverage, where Medicare pays 95% and you pay 5%. When you have a very expensive prescription drug, you can actually hit that catastrophic phase pretty quickly and you still don't have an out-of-pocket maximum, so there is not a cap on what you pay during the year, but you have to pay 5% of that cost for the rest of the year, which can seriously add up very quickly to thousands of dollars if you have a Medicare Part D plan and a very expensive prescription drug.

But I will say, this is actually an advocacy opportunity, something that LLS has been working hard on, and there is a bill pending in Congress right now, it was in the President's Build Back Better plan, that didn't make it for a vote in the Senate, but members of Congress are actually proposing other bills to cap the out-of-pocket cost for someone on Medicare at \$2000 a year, which would be absolutely game-changing for anyone on Medicare and who takes prescription drugs. I would encourage you to get involved in LLS's advocacy efforts and communicate with your elected officials about how it is actually impacting you.



**Lizette Figueroa-Rivera:**

Definitely. And that goes along with our next question because Lawrence was asking... with so many lobbyists in Washington employed by pharmaceutical industry and others, what can we do as patients to help advocate for lower medication prices?

**Joanna Fawzy Morales:**

It is very important to use your voice, even if it sounds obvious and that your elected officials should already know, it is important that they hear from you. This applies to everyone across the country, whether or not you think that your elected officials will be receptive to the information or not, it is very important that you use your voice on how these types of proposals have a very real-world impact.

**Lizette Figueroa-Rivera:**

Yes, thank you. Our next question comes from Deborah. Deborah's asking... I often receive mailings to purchase additional health insurance that covers cancer diagnosis only. Are these policies worth the price, are they legitimate?

**Joanna Fawzy Morales:**

I would say be very careful of any solicitation by phone or in the mail or over e-mail that is offering you additional health insurance coverage. If you have certain types of coverage, you are actually ineligible for those types of plans, so it is important to understand if what is being offered to you is legitimate or not and that is something you can absolutely contact us about in our Navigation Program or you can contact the State Health Insurance Agency to find out if what is being offered to you is legitimate.

That said, there are definitely supplemental policies that offer things like cancer coverage or accident coverage, or serious illness coverage and those policies can be incredibly useful because they add on top of health insurance and they pay for things that health insurance doesn't. If you get diagnosed with cancer, they might write you a \$10,000 check, or if you need to travel to treatment, they will cover the hotel and airline. So those policies can be very useful. The challenge is that they do include preexisting condition exclusions, so if you have already been diagnosed with cancer, it is very difficult to actually go and purchase one of those policies, it is something that you have ahead of time.

**Lizette Figueroa-Rivera:**

Thank you. Our next question comes from the telephone audience, please.

**Operator:**

We will hear from Betty in Pennsylvania, please go ahead.

**Betty:**

Hi. My question is... if there is any possible way that my daughter could become a caregiver without me involving my property?

**Joanna Fawzy Morales:**

There are ways where family members can get paid as caregivers if you qualify for Medicaid in your state and you are eligible for in-home support services, which is an optional benefit. Not every Medicaid program has this, but some of

those state programs actually allow family members to get paid as the caregiver and often for things that you would have done anyway as a caregiver, but it helps replace some of those lost wages. Betty, I am not sure if that is the program you are referring to, but if you are looking for more information on that, we do have that on our chart of state laws, which tells you which states actually offer that family caregiver benefit.

**Lizette Figueroa-Rivera:**

Thank you. Our last question today. Anita is asking... can you appeal an amount the insurance company will pay? For example, the drug costs \$4000 per month, but the insurance will only pay \$1000 per month.

**Joanna Fawzy Morales:**

Generally speaking, when insurance companies contract with a pharmacy, for example, to reimburse a certain amount for a drug, that isn't something that you can appeal. Sometimes you can appeal what tier that drug is being listed as. The formulary is the list of drugs covered by a particular plan and the formulary is broken down into these different payment tiers, where at tier one, for like a generic antibiotic, you might only pay a \$10 copayment. But if it is a more expensive, preferred brand name drug, you might have a higher copayment. So sometimes you can appeal where the drug is falling on the tiers, so that your out-of-pocket cost is less. But I always feel like with appeals it never hurts to try.

**Lizette Figueroa-Rivera:**

Thank you so much and thank you, Anita, for your question, which was our last question today.

And special thanks to Joanna for volunteering your time and your expertise with us today, especially during these busy times.

**Slide 49: LLS EDUCATION & SUPPORT RESOURCES**

If we weren't able to get to your question today or you want more information, you may speak to an LLS Information Specialist at 1-800-955-4572 from 9 AM to 9 PM Eastern Time or you can reach us by e-mail at [LLS.org/ContactUs](mailto:LLS.org/ContactUs). Information Specialists are available to answer your questions about treatment, including clinical trials, and answer other questions you may have about support, including financial assistance for treatment.

**Slide 50: LLS EDUCATION & SUPPORT RESOURCES**

For more information on finances and financial assistance, including copay programs, please visit us at [LLS.org/Finances](http://LLS.org/Finances). We do have many financial assistance programs, like I said, including copay assistance programs. And also, please go to [www.TriageCancer.org](http://www.TriageCancer.org), as Joanna mentioned, for more detailed information about practical and legal issues that arise after a cancer diagnosis.

Also, our advocacy team would like to hear from you about how cancer has impacted your finances, as we continue to work to ensure that laws are in place to protect cancer patients. Please share your story with us at [LLS.org/Advocacy](http://LLS.org/Advocacy) or [BIT.ly/sharemystory](http://BIT.ly/sharemystory) with LLS.

**Slide 51: LLS EDUCATION & SUPPORT RESOURCES**

As a reminder, you can download and print a resource document for this program, as well as view today's program on our website [LLS.org/Programs](http://LLS.org/Programs).

Again, we would like to acknowledge and thank Bristol Myers Squibb; Genentech and Biogen; Pharmacyclics, an AbbVie Company, and Janssen Biotech; and Takeda Oncology for their support of this program.

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### Slide 52: THANK YOU

Joanna, thank you again for volunteering your time with us today. And on behalf of The Leukemia & Lymphoma Society, thank you all for joining us. Goodbye and we wish you well.