Lizette Figueroa-Rivera:
Greetings and welcome to The Leukemia and Lymphoma Society’s Navigating the Financial Maze for Cancer Survivorship education program. On the behalf of The Leukemia and Lymphoma Society, I would like to welcome you. The Leukemia and 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 innovations, 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 navigate their cancer treatments and ensuring that they have access to quality, affordable, and coordinated care.

We are fortunate to have as our presenter, Ms. Joanna Morales, Esq., a cancer rights attorney, author, speaker, and CEO of Triage Cancer, a national non-profit organization connecting people to cancer survivorship information and resources through a national speaker’s bureau, educational events, and online tools. Ms. Morales has spent more than 23 years working on behalf of individuals with cancer and has presented hundreds of educational seminars on employment, insurance, healthcare, and advocacy issues throughout the country for patients, survivors, caregivers, healthcare professionals, advocates, lawyers, employers and the general public.
Slide 2 - Disclosures

We thank Ms. Morales for volunteering her time and sharing her knowledge with us. I am now privileged to turn the program over to you.

Slide 3 - Navigating the Financial Maze for Cancer Survivorship

Joanna Fawzy Morales:
Thank you so much, Lizette. Today, I am going to talk about some of the financial issues that can impact cancer survivorship and provide you with some tips to navigate those issues.
“Financial Toxicity:”
New Term, Old Problem

2013 - Researchers from Duke:

“Out-of-pocket expenses might have such an impact on the cancer experience as to warrant a new term: "financial toxicity." Out-of-pocket expenses related to treatment are akin to physical toxicity, in that costs can diminish quality of life.”

Financial toxicity is a term that was only coined in 2013 by some researchers from Duke, who focused on the facts that out-of-pocket expenses that come as a result of a cancer diagnosis create a financial burden for patients and, that financial burden, is very much like toxicity related to cancer treatment. Financial toxicity is a relatively new term, but it is actually a pretty old problem. I have been doing this work for the last few decades and, certainly, the financial expenses that patients incur going through treatment are not a new issue and, certainly, drugs have gotten more expensive, but this has been an ongoing problem.

Contributors to Financial Toxicity

- Health Insurance Status
  - Out-of-pocket Costs
  - Consumer Protections
  - Medical Bills

- Employment Changes
  - To work or not to work - accommodations
  - Disability Insurance

- Life Changes
  - Marriage/divorce, moving, graduating from school, etc.
And there are a lot of contributors to financial toxicity; primarily making sure that people have adequate health insurance coverage is one of the most significant contributors. And so, making sure people have health insurance, but also the right health insurance for them can minimize out-of-pocket costs. There are also consumer protections that have an impact on what people actually pay out-of-pocket for their care and, figuring out how to manage medical bills, can also be a way to minimize the financial burden of the cancer diagnosis. But there are other things that have an impact on a financial burden of cancer. Things like being able to work through treatment, or being able to take time off and being able to replace those wages while you are taking that time off, can have an impact; and then life changes, like getting married, or moving to another state, or graduating from school. These are all things that can have an impact on your finances and either create a challenge for you in managing the financial toxicity of the cancer diagnosis or help you.

**Slide 6 – Don’t Understand Health Insurance? You are not alone.**

But today, I want to talk a little bit about health insurance and also how to be able to pay for some of the expenses related to cancer care.

As I mentioned, I have been doing this for a long time and I would argue that there are very few people across the country that understand everything about our healthcare system because it is very complicated and it touches so many different industries and there are lots of different regulations. So inexorably, I would say that no one really has a grasp of every aspect of our healthcare system, but now it is not anecdotal experience, I also some research to back that up. So, in a survey of employees who get their healthcare insurance coverage through their employer, very few of them actually understand the health insurance coverage that they do have; things like not understanding their policy terms, or even knowing what they pay for their health insurance coverage. And when we don’t understand how our healthcare system works or how our insurance coverage works, we are ill-prepared to actually use our health insurance effectively. So, if you feel that you don’t understand your health insurance coverage, you are certainly not alone.
So, to start with, I want to talk a little bit about our healthcare system and some terms that are very important for you to know about your own health insurance coverage. There are actually 3 places where we get our health insurance coverage in the United States. We are either getting it through our employer as an employee benefit, or we are getting it directly from an insurance company, or we get through the government; and, by that, I mean we have Medicare, or Medicaid, or a military or veterans’ health plan, or even a state high risk pool, or some other type of local coverage.

**Health Insurance Terms**

**Cost to Have Health Insurance**
- Premium – each month

**Costs When You Use Your Health Insurance**
- Deductible – each year (fixed $ amount)
- Co-Payment – each time you get care (fixed $ amount)
- Co-Insurance or Cost-Share – each time you get care (%)
- Out-of-Pocket Maximum* =

  \[ \text{deductible} + \text{co-payments} + \text{co-insurance} \]

  *usually only for in-network services
Now, when we are talking about important terms to know, the first is your monthly premium and that is what you pay each month just to have your health insurance coverage. So, if you never went to the doctor during the year, you would still have to pay your monthly premium just to have the insurance coverage. But then there are costs that we pay out-of-pocket when we actually use our health insurance coverage and get medical care. And the first is our annual deductible. This is a fixed dollar amount that we pay each year, first before our health insurance coverage even kicks in. So, you can have a $500 deductible or you can have a $5000 deductible, depending on the type of coverage that you have. And then, there is something called a co-payment and this is something that you pay each time you get certain types of care and it is a fixed dollar amount for each type of care. So, you might have a $20 co-payment to visit your doctor's office, or you might have a $40 co-payment to see a specialist, or you might have a $150 co-payment if you are going to visit the emergency room; again, depending upon the type of coverage that you have. And then there is something called co-insurance or cost share and these are terms that are used the same way. And it is the difference between what the insurance company pays for your medical expenses and what you pay for your medical expenses. So, you might have an 80/20 cost share, where the insurance company pays 80% and you pay 20%; so, you are literally sharing the cost of your medical expenses with your insurance company. Medicare is an 80/20 plan for example. Now, the last term that you should know about your coverage is probably the most important and that is called your out-of-pocket maximum. And this is the most that you are going to pay out-of-pocket during the year for your medical expenses so they put a cap on how much you have to pay during the year and this is also a fixed dollar amount. So, you might have a $1,000 out-of-pocket maximum or you might have a $10,000 out-of-pocket maximum, depending upon the type of coverage that you have. And the way that you reach your out-of-pocket maximum is by adding up all the expenses that you pay out-of-pocket during the year; so first your deductible, then any co-payments that you made during the year, then any co-insurance amounts that you paid during the year. And when you reach your out-of-pocket maximum, then your insurance kicks in at 100% and you don’t pay for anything else out-of-pocket for the rest of the year; and then it starts over in your new plan year.

**Case Study: David**

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**  
   \[ \text{\$102,000 - \$2,000 = \$100,000 left} \]

2. **His co-insurance amount of 20%**  
   \[ 20\% \times \$100,000 = \$20,000 \]

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.

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So, to give you an example to how this actually works, I give you David. David has spent a week in the hospital and walked out of the hospital with a $102,000 hospital bill, but he has a plan that has a $2,000 deductible. He has an 80/20 co-insurance and his out-of-pocket maximum is $4,000. Now, assuming that he has had no other expenses during the year, how much does David actually have to pay of that $102,000 hospital bill? So first, he is going to pay his $2,000 deductible, and that leaves him with $100,000 of that bill. So, of the $100,000, the insurance company is going to pay 80% and he is responsible for his co-insurance of 20% and that leaves $20,000. So, out of that $20,000, how much does David actually have to pay? He only has to pay $2,000 and then, at that point, he will have spent $4,000 out-of-pocket and his insurance is going to pick up the rest. So, I have not suggesting that $4,000 isn’t a lot of money, but it is certainly better than the $102,000 that he started out with, or even the $20,000 that he would have been left with if he didn’t have an out-of-pocket maximum on his plan. So, this is how an out-of-pocket maximum works.

**Employer-Sponsored Health Insurance**

**COBRA**

- Employers with 20+ employees
- Cost up to 102% of applicable employee rate
  
  = Employer amount + Employee amount + 2% fee

<table>
<thead>
<tr>
<th>COBRA Qualifying Event</th>
<th>Max COBRA Coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment ends or hours reduced</td>
<td>18 months</td>
</tr>
<tr>
<td>Loss of dependent child status</td>
<td>36 months</td>
</tr>
<tr>
<td>Employee enrolls in Medicare</td>
<td>36 months</td>
</tr>
<tr>
<td>Divorce or legal separation from employee</td>
<td>36 months</td>
</tr>
<tr>
<td>Death of employee</td>
<td>36 months</td>
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Now, when we are talking about accessing health insurance options, there are still some laws that are very relevant like COBRA. And COBRA is the federal law that allows employees to keep the same health insurance coverage that they had when they were employed for an additional period of time. Now COBRA only applies to private employers with 20 or more employees, so if you work for a smaller employer, COBRA is not going to apply to you. If you have to leave your job or your hours are actually reduced, so if you maybe move from full-time to part-time, but your employer does not offer health insurance coverage to part-time employees, you can actually take COBRA for up to 18 months. If you are a young adult who is aging out of your parents’ health insurance plan, that’s also a qualifying event for COBRA, but you get to keep COBRA for 36 months. Now, the benefit of COBRA is that you get to keep the same health insurance coverage. The down side of COBRA is that you are now responsible for paying the full amount of that health insurance premium; and I often say that we don’t appreciate what our employers pay for our health insurance coverage until we have to pay it ourselves.
State COBRA Laws

States with state COBRA laws:
- AR, CA, CO, CT, FL, GA
- IL, IA, KS, KY, LA
- MA, ME, MD, MN, MS, MO
- NV, NH, NJ, NM, NC, ND
- OH, OK, OR, RI, SC, SD
- TN, TX, UT, VT, WV, WI, WY
- Details vary by state
- Most cover employees with 2-19 employees
- Coverage lasts between 3-36 months

If you do work for a smaller employer, most states have a state COBRA law which typically covers employers with 2 to 19 employees, but each state law is very different and that coverage can range from 3 months to 36 months so you need to look specifically at your state COBRA laws to see what is available to you.

Medicare

- Eligibility
  - 65+ years old
  - On SSDI 2+ years
  - ESRD or ALS
- Open Enrollment: 10/15 – 12/7

Medicare is one of the 2 federal health insurance programs that are available. And Medicare is only available to individuals who are 65-years or older and eligible for Social Security retirement benefits, or for individuals who have been receiving Social Security Disability insurance benefits for 2 years or longer.
Medicare is also available to anyone who has end stage renal disease or ALS. Now, Medicare.gov is actually a very useful resource for patients and anyone who is eligible for Medicare. You can find a great deal of information about the plans that are available to you based on where you live, the providers that you see, and the prescription drugs that you take. So, there are a number of tools on the website that can be very useful, but there is also a booklet called, “Medicare and You” and they update it every year. And, it really provides everything that you need to know about Medicare as a consumer. We included the link on the side, but you can certainly also “Google” Medicare and You and find the booklet on the home page of Medicare.gov.

There are actually 4 parts to Medicare coverage. The first part is called Part A and that really just covers hospitalization. For most people, Part A is actually free if you have paid into the system throughout your work history. Part B of Medicare is actually medical insurance. It really covers everything else except prescription drug coverage, which is covered under Part D of Medicare. Now, Medicare Part B has a premium attached to it. So, when people become eligible for Medicare, they are offered Part A and Part B together. When people see Part B with a premium associated with it and they say, “I don't need Part B, I'll just take Part A”, and then they go to the doctor and realize they actually needed Part B because that is what covers most things. So, if you decline Part B and you don't take it when you are first eligible for it, you actually pay a lifetime penalty for the months that you would have been eligible for Part B, but didn't take it. So, it is important to know that before you make those decisions. Part D also has a premium attached to it and, depending on the type of Part D plan you choose, it is going to determine how much you pay for it. But the way that a standard Part D plan works is that you have that $405 deductible for 2018 that you have to pay first for your prescription drugs before Part D actually kicks in. If you need help paying for your prescription drug coverage, there are actually financial assistance programs that you can actually apply for. Then, there is Medicare Part C, which is called Medicare Advantage plans and these plans are Medicare managed care, like HMO's and PPO's. And, you are getting the same coverage available under Part A, Part B and Part D, but you are getting them from a private health insurance company that is offering a Medicare Advantage plan. Some of the benefits of these plans is that they cover some additional things that Medicare doesn't cover and sometimes actually cost less. And, some
of the plans that are sold through Medicare Advantage have out-of-pocket maximums whereas original Medicare, which is what we refer to as Part A and Part B, Part B does not have that out-of-pocket maximum so you pay 20% of your expenses and there is no cap on that. So, there is some cost differences in original Medicare versus Medicare Part C that you might want to take into consideration—that when you go into a managed care plan, you are limiting some of your choice in terms of the providers that you see, so that is the trade-off. You have less choice, but it may be less expensive in a Part C plan.

If you have original Medicare and you have that 20% of out-of-pocket costs that don’t have a maximum on them, you might want to consider buying supplemental Medicare insurance coverage, which is referred to as Medigap. You can buy a Medigap plan that picks up some of those expenses including that 20% co-insurance amount.

Medigap Plans

- aka Supplemental plans
  - Helps cover some of your cost share
  - Plans A-N
  - Note: Plans F & C eliminated in 2020 (except for existing enrollees)

- Cost
  - Premium: Varies by plan
  - Deductible: Varies by plan
  *Only available if purchasing Original Medicare

[Link to Medicare.gov]

So, these Medigap plans are also lettered, which can sometimes be confusing. There are plans from A through N and, some of the plans that are most popular in the cancer community, are actually going to be eliminated in 2020 for new customers so if you already have a Part F or Part C plan, you can keep it, but new enrollees can’t enroll in F or C, starting in 2020. If you want information about Medigap plans, that is also something you can find on Medicare.gov.
So, when you become eligible for Medicare and, each year during the open enrollment period, you have a choice. You can go down the path on the left and pick Parts A and Part B and then pick a Part C plan and then decide if you want a Medigap plan; or you can go down the path on the right. You can pick a Part C plan and then, if your Part C plan doesn't happen to include Part D coverage, you can pick a Part D plan, but many Medicare Advantage plans actually include Part D coverage as well. So, those are the choices available under Medicare.

New Medicare Benefits

1. Free Wellness Visit
2. Free Preventative Care
3. Lowers the cost of prescription drugs

2017: Part D donut hole = $400; Donut hole between $3,700 and $7,425 (in total drug costs)


<table>
<thead>
<tr>
<th>Year</th>
<th>What you pay for brand name drugs in the coverage gap</th>
<th>What you pay for generic drugs in the coverage gap</th>
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<tbody>
<tr>
<td>2017</td>
<td>40%</td>
<td>51%</td>
</tr>
<tr>
<td>2018</td>
<td>35%</td>
<td>44%</td>
</tr>
<tr>
<td>2019</td>
<td>30%</td>
<td>37%</td>
</tr>
<tr>
<td>2020</td>
<td>25%</td>
<td>25%</td>
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</table>
Now, the Affordable Care Act actually created some new benefits to Medicare; the first being a free annual wellness visit. It also added some free preventive services with no out-of-pocket costs associated and it also lowered the cost of prescription drugs by closing the Medicare Part D donut hole. The donut hole is a term that we have given for a gap in coverage that was created when Part D was established about a decade ago. So, each year, what someone pays for their prescription drug costs, actually goes down a little bit and this chart shows you how it goes down for the next few years.

Medicaid is the other federal health insurance program. And, prior to Jan. 1, 2014, Medicaid was only available to individuals who had a low-income level, a low asset level, in terms of the resources that they had, and had to meet some other category of eligibility. So, those categories were like doors into the Medicaid program and these are what the doors look like. And, most of the time, someone in the cancer community was accessing the Medicaid program through that door on the left, through the program called the “Aged, Blind and Disabled Program”. And so, the only way to get access to that program was by showing that you had a disability under Social Security’s definition of disability, which is a very high standard to meet, and then once you can qualify for Social Security Disability benefits, if your income was low enough and your assets were low enough, then you could get into the Medicaid program. So, there were lots of barriers for individuals with cancer to get access to Medicaid through these options.
After Jan. 1, 2014, the Affordable Care Act made it mandatory for every state to expand access to its Medicaid program and this created a new door into the Medicaid program for any individuals who has a household income under 138% of the federal poverty level. So, for individuals this year, you would have to make under $16,642 in order to be able to qualify for Medicaid. Now, the benefit to this new door is that it didn’t have that asset or resource test, it only focused on income so you didn’t also have to show that you had a disability either. So, it really expanded access for many in the cancer community to be able to get health insurance coverage through the Medicaid program. However, despite the fact that the ACA made this mandatory for every state to expand access, the Supreme Court ruled that it had to be voluntary for states to participate.
So, as of this moment, this is what it looks like. The states on the left have chosen to expand access to their Medicaid program, where the states on the right have chosen not to. Those 19 states represent between 3 and 5 million people who would have gotten access to Medicaid, but haven’t because their states chose not to expand coverage. Now, just a few weeks ago, Maine passed a voter proposition to expand access to their program, after their governor vetoed the state legislature’s decision to expand access to the program 5 times. And, since then, the governor has said that he is going to choose not to implement so that is why Maine is in red because, technically, they have expanded, but not actually.
In addition to expanding access to Medicaid, the ACA also created a new way to access private health insurance coverage by creating state health insurance marketplaces. These marketplaces were originally called “exchanges in the law”, but the Department of Health and Human Services thought that no one would know what an exchange is so they decided to call them marketplaces. So, we have 2 terms for the same thing and it is actually just created some confusion. And, there are some states that run their own marketplace and have created names for those marketplaces. If you hear your state’s marketplaces name or the work “marketplace” or the work “exchange”, it actually all means the same thing. And, the best way to describe these marketplaces are like insurance shopping malls. It is one place that you go to find all of your private health insurance options available based on where you live. But there are some benefits to actually buying health insurance coverage through the marketplaces; the first being that all the plans sold through the marketplace have a cap on how high their out-of-pocket maximum can be. For 2018, there can’t be a plan sold in the marketplace with an out-of-pocket maximum higher than $7,350 for an individual plan. So, that is pretty high, and it doesn’t mean all the plans sold will have that out-of-pocket maximum, it just can’t be higher than that. And, we often see in other areas of health insurance where there aren’t these caps on how high the out-of-pocket maximum can be so that is actually a benefit for consumers. The other benefit is that you might be able to qualify for financial assistance to buy your health insurance coverage through the marketplace based on your income level. There are actually 2 different types of health insurance coverage (financial assistance); the first is called a premium tax credit. The premium tax credits actually lower your monthly payment for whichever plan you choose based on your income level. So, you might qualify for a $50 a month premium tax credit, and you pick a plan that is $300 a month, and you subtract the $50 a month premium tax credit so you only actually pay every month $250 for that plan. That is different from the cost sharing subsidies, which are also referred to as cost sharing reductions. These actually lower what you pay for your co-payments, your deductibles and your co-insurance amounts depending on your income level and the plans that you choose. Now, when we think about the marketplaces, it does create a lot of confusion. Some people think that they are buying health insurance through the government, so that bottom level of the triangle, but that is actually not the case. You are buying health insurance coverage from a private insurance company, you are just doing that at the marketplace that was created by the government. So, you are not actually buying government health insurance coverage from the marketplace.
One other benefit of buying a plan through the marketplace is that all the plans that are sold are standardized and the benefit to that is that, as consumers, we can actually compare apples to apples and oranges to oranges. And, we haven’t always been able to do that when buying health insurance. So that the way that the plans are standardized are through their cost share or co-insurance. There are 5 levels of plans that are available. The lowest level of coverage is the bronze plan and the bronze plan has a 60/40 cost share so the insurance company pays 60% and you are responsible for 40% of your medical expenses out-of-pocket. A silver plan is a 70/30; a gold plan is 80/20; and platinum plan is 90/10. That 5th level of coverage is called “the catastrophic” plan and these catastrophic plans are only available to individuals under the age of 30 or for anyone who qualifies for the financial hardship exception to having to purchase health insurance coverage. One of the recent changes to the laws around health care was that, for the silver level, insurance companies are now allowed to drop that coverage down to 66%. So, at the silver, instead of it being 70/30, it is allowed to be 66/34 coverage so in case you happen to see that as you are shopping around, that is why.
I mentioned that having adequate health insurance coverage and the right type of coverage for you is one of the most important ways to keep your out-of-pocket costs low. So, one of the ways to avoid higher medical bills is to make sure you are shopping around and really comparing the options that you have available to you. And one of the ways to do that is to see what is available in the marketplace. Now, this is the homepage of what healthcare.gov looks like and you can start at the homepage, but if you want to go directly to the page to see your options, you can go to healthcare.gov/see-plans and, when you go to that page, you don’t have to create an account or put in your name, you only have to enter in your zip code, your age, your household income, and the number of people in your household and it will show you all the plans that are being sold in your zip code and how much those plans would actually cost you, specifically, based on your income level and tell you how much financial assistance you actually qualify for to buy those plans. So, once you have actually put that information in.
It looks something like this. So, it allows you to see things and compare things the way that you can do when you are doing other types of shopping online, if that is something that you have done before. So, I have put in an imaginary individual in Phoenix for this example and this person has 69 different plans available to them. And you can sort the plans by premiums or by deductible or you can choose to only see plans that are less than $300 a month, or choose to only look at silver level plans, or choose to only look at PPO plans, or even pick the insurance company’s plans that you want to look at. So, it gives us some flexibility as consumers to be able to shop for coverage. But then, once you have narrowed down your plan choices, there is one more step that you have to take. You have to do the math.
When you are comparing plan choices, this exercise of doing the math is actually applicable if you are comparing different types of market plan choices, when you are comparing different employer plan choices, so if your employer offers you more than one choice—when you are comparing what your employer offers to what is available in the marketplace and when you are comparing your Medicare plan choices. So, this exercise that I am about to go through applies in all of these circumstances.

The Math Matters!

Total potential costs for year = 12 months of premiums + OOP max

#1:
$173 \times 12 = \$2,076 
+ OOP = \$6,000 
Total = \$8,076

#2:
$271 \times 12 = \$3,252 
+ OOP = \$5,200 
Total = \$8,452

#3:
$398 \times 12 = \$4,776 
+ OOP = \$1,150 
Total = \$5,926

This is another example where I have put in an imaginary individual in Kansas and have picked the cheapest bronze plan available to this person. I have picked a silver plan in the middle and the most
expensive platinum level plan. And you can see for the bronze level plan that it is $173 a month after the premium tax credit of $213, based on the income level of this person, and it has a $6,000 deductible and a $6,000 out-of-pocket maximum, which is pretty high. It is almost at the highest it can be. Now, the silver level plan is another $100 a month, but has a $2,500 deductible and $5,200 out-of-pocket maximum, which is also still pretty high. The platinum level plan is another $120 a month more than the silver plan, but has a $0 deductible and an $1,150 out-of-pocket maximum. Just by looking at these options, it is difficult to tell how much it is actually going to cost you without actually doing the math. So, the way that you do the math is that you take your 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 that to the out-of-pocket maximum, because that is the most you are going to pay out-of-pocket for your medical expenses during the year. Now when we are talking about cancer care, almost everyone is going to hit their out-of-pocket maximum, which is why you factor in the total cost of your out-of-pocket maximum. For someone who doesn’t actually have many medical expenses, this might be less important, but assuming you are going to hit your out-of-pocket maximum during the year, this is what it looks like. So, which plan actually ends up being less expensive by the end of the year, assuming you are going to use your whole out-of-pocket maximum; and it turns out that it is the platinum level plan by almost more than $2,000. So, we often get sticker shock when we look at just at the monthly premium and we don’t pay attention to that out-of-pocket maximum and that is really where the highest out-of-pocket expenses tend to come from. So, you might spread out the cost of your medical care over the year by paying it through your monthly premium and not be stuck with a huge bill at the end of the year. This is a way to actually factor in some of those costs that you might not be anticipating when you are looking for new health insurance coverage or comparing the options that you have available.

What are the differences between plans?

• Cost
  – Premium, Out of Pocket, Co-Pay, 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?

Slide 26 – What are the differences between plans?

But it is not just cost. So, you want to make sure that it financially works out the best for you, but you also have to make sure that the plan actually covers your providers because, if it doesn’t cover your providers and you have to pay out-of-pocket to see your providers, then the coverage doesn’t really work for you. There is no point in having that plan. You also want to make sure that it covers your prescription drugs because, again, if it doesn’t cover your drugs and you have to pay out-of-pocket for those, then the plan is pretty useless to you.
Checking Providers, Facilities, & Drugs

Enter your doctors, medical facilities & prescription drugs to see if they're covered by each plan

The marketplace actually gives us a tool to be able to see whether or not a particular plan covers our providers and drugs. So, you can either do that at the beginning of the process, before it shows your plan options, by entering in your providers and the drugs that you take or you can do that once you have seen your plan options. And, where that green arrow is pointing to is the link to show you the drugs, and facilities, and doctors who are actually covered by that particular plan. So, again, it gives us some tools, as consumers, that we didn’t actually have before.

When to Enroll?

- Medicaid applications accepted year round
- 2017 Open Enrollment Period: closed

- 2018 Open Enrollment Period: new!
  November 1, 2017 to December 15, 2017
  - California, D.C., Massachusetts, New York, Rhode Island – November 1 to January 31
  - Colorado – November 1 to January 12
  - Connecticut - November 1 to December 22
  - Minnesota – November 1 to January 14
  - Washington – November 1 to January 1
When you go to enroll in a marketplace plan, you can only do that during certain times of the year that are called “open enrollment periods”. Medicaid applications are actually accepted year-round, but if you are looking for 2018 coverage from a private health insurance company, open enrollment is actually from November 1, 2017 to December 15, 2017; and this is new. However, some states have chosen to keep their open enrollment periods open longer and these are just a few examples of those states. So, you should check to make sure that you are in a state that doesn’t have a longer open enrollment period if you are still looking for coverage for 2018.

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**Special Enrollment Period**

When you have a life-changing event . . .

- Loss of minimum essential coverage, for example:
  - Change in full-time employment status
  - Loss of employer-sponsored insurance
  - Change in dependent status as a result of turning 26
  - COBRA ending

- Birth or adoption of a child
- Marriage, domestic partnership, divorce, legal separation
- Moving regions or states
- Gain eligible immigration status
- Release from incarceration
- Military returning from active duty

. . . you have 60 days to enroll in Marketplace plan

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But we know that life just doesn’t always happen during open enrollment periods so if you lose your health insurance coverage during the year, you might actually qualify for a special enrollment period and, at that point, you would have 60 days from when you lose your coverage to buy a new plan in the marketplace.
One of the other areas that we see a financial impact for patients in the area of health insurance is when a health insurance actually denies coverage for a particular service or procedure, or surgery, or a prescription drug, or some other type of treatment. When an insurance company denies coverage for that care, you don’t actually have to take no for an answer. You can appeal that decision and there are 2 different types of appeals. You can appeal inside the insurance company, which is referred to as an internal appeal. You can also appeal externally. When an insurance company says, no, they typically provide some paperwork and explain how to appeal internally. If an insurance company still says no, at that point, you can go outside the insurance company to an independent or external medical review board who is going to review your medical records and determine whether or not it is medically necessary for you to receive that care. And once that review board has made a decision, that decision is actually binding on the insurance company and, if they have determined that the insurance company needs to pay for your care, then the insurance company needs to do that. So, every state has an agency. It is typically the Department of Insurance, or whichever agency in your state that actually oversees insurance companies, that manages this external review process. Now, some states already have this as state law, but the ACA required every state to create this process. People think it is not worth going to the appeals process, but between about 40 and 60% of the time, appeals are actually won and people get the care that they need and their insurance company has to pay for it. So, it is actually worth going through the appeals process if you feel like your insurance company is denying you coverage for care that you need.
Once you get medical bills, it is important that you actually review those medical bills to make sure that they are correct. And, once you have done that and found that you do actually owe what it says what you are supposed to owe for that medical bill, you can still negotiate those bills. You can actually contact your healthcare providers like your hospital, or your doctor’s office, or a lab and ask them to set up a payment plan, or ask for more time to pay, or sometimes they will even accept a lower lump sum payment. So, maybe if you owe $1,000 on a medical bill, if you are only able to pay $500, you can offer to pay the $500 to the provider in exchange for writing off the rest of the bill. And, some providers actually prefer that than setting up a payment plan, but it doesn’t hurt to ask. So, it is always a good idea to talk to your providers and explain if you are having trouble paying those bills before those bills get sent to a collection agency.
Once you have made sure your bills are correct and negotiated down any bills, if you need financial assistance or help paying for those bills, there are different types of financial resources that are available.

So, I mentioned that sometimes having to take time off work and replacing lost wages can be a challenge and impact the financial burden of the cancer diagnosis. And, disability insurance allows you to replace those wages that you are losing because you have to take time off work because of a medical condition. And, there are lots of different types of disability insurance. You could have a private plan that you bought yourself or that you get through your employer. Some states have state disability insurance options and then there are also 2 federal long-term disability options so that might be a way to reduce the financial impact of the cancer diagnosis. For caregivers who are taking time off work, some states actually provide paid family leave so that caregivers can replace lost wages. And, some employers actually provide this as an employee benefit as well.

Then, there are lots of different types of financial assistance resources. So, when you are accessing health insurance coverage, I explained the options that are available in the marketplace, there are also financial assistance programs available through Medicare and Medicaid based on your income level. Hospitals, and cancer centers, and other types of providers often provide financial assistance to lower the cost of care. They are often referred to as “ability to pay” programs. So, you should ask your healthcare team if that is something that is available to you.

Then, there are programs that provide financial assistance for the cost of your prescription drugs. For example, a pharmaceutical company might actually have a discount program for their drug or can help offset the cost of the co-payments that you are responsible for. There are also cancer organizations, and healthcare foundations, and many other types of financial assistance resources that are available to someone who is going through a serious medical condition like cancer.
So, for information about those options, you can find all of those resources at cancerfinances.org. This is a website where you can not only find financial assistance resources, but you can also find valuable information about topics that have an impact on your finances, like health insurance, and understanding what your health insurance options are and how to navigate your insurance. There is also a module on disability insurance and there will soon be modules up on managing medical bills, employment and education for young adults who are still in school and managing those expenses.
This also is not the only place to find information on this topic. This has been an introduction to many of these issues and on the Triage Cancer website, there are quick guides and other educational materials and resources on some of these topics that have a significant impact on finances. So, we wanted to point you to some additional resources, including The Leukemia and Lymphoma Society’s “Cancer and Finances” booklet, which you find on our website as well.

Slide 35 – Triage Cancer Educational Events

We also have educational events on many of these topics in the community so you can visit our website to find out events that are going on near you or our webinar series that goes into a deeper dive into many of these topics.

Slide 36 – Contact Information

Contact Information

Email
info@TriageCancer.org

Website
http://TriageCancer.org

Twitter
@TriageCancer

Facebook
www.Facebook.com/TriageCancer

Blog
http://TriageCancer.org/blog
And, this is our contact information in case you have some additional questions beyond today’s webinar. So, this concludes my presentation.

Lizette Figueroa-Rivera:
Thank you, Ms. Morales, for your very clear and informative presentation. It is now time for our question and answer portion of our program. The first question comes from Nancy. Nancy asks, “Do most insurances now cover chemo pills taken at home by a patient or just medications administered at a lab?”

Joanna Fawzy Morales:
That is a very good question. So, Chemo pills that are typically taken at home are referred to as oral chemotherapy, as opposed to IV chemotherapy, which typically has to be administered at a doctor’s office or some type of health care facility. And so, most health insurance plans actually do cover oral chemotherapy, but how they cover oral chemotherapy depends on the type of plan and it also depends on the state that you live in. And so, there are many state laws now that the cancer community has advocated for to make sure that the out-of-pocket costs associated with oral chemotherapy are similar to the out-of-pocket costs, not more than the out-of-pocket costs that are associated with IV chemotherapy. And we refer to that as oral chemo parity laws so that oral chemo is treated the same way as IV chemo.

Lizette Figueroa-Rivera:
Thank you; and we will take the next question from Robert. Robert asks, “How can I manage the treatment costs for labs or an MRI when I don’t know what the hospital will charge me or how my insurance payer will cover it?”

Joanna Fawzy Morales:
Anytime you are getting care like a lab test or some type of imaging scan, for example, you can actually shop around for those expenses. You can also talk to your healthcare team. So, if you need some blood work, you can talk to your healthcare providers and ask them things like, “how much am I going to have to pay out-of-pocket for this care? Does my insurance actually cover it and at what rate?” Sometimes, the provider will actually send blood work to a list of labs that they have and, sometimes, those labs are not in your network of providers. So, you want to make sure that if they are sending out your blood work or you
are visiting an imaging center, that those labs or centers are actually included in your plan so it lowers what you actually pay out-of-pocket if you are going to those centers or your blood is being sent there. You can actually manage some of this upfront. It is a little bit more work, but you can greatly reduce your costs on the back end if you can make sure that your providers are actually in your network. And you can also find out exactly what you would have to pay out-of-pocket. And don’t be afraid to ask. It is a completely legitimate question and they should be able to answer it for you. You can also go to your insurance company and ask them what your out-of-pocket costs would be for any types of care. And then, you don’t always have to go to the lab or the imaging center that you are being referred to. You can actually look around in your community and, if there is more than one place you can go to, you can actually compare prices. Again, it creates a little bit more work on the front end, but you can greatly reduce your expenses on the back end.

Lizette Figueroa-Rivera:
Thank you; and the next question comes from Theresa. Theresa asks, “Is there any agency that can help a cancer patient determine if they are eligible to apply for disability under Social Security?”

Joanna Fawzy Morales:
The easiest way to determine whether or not you are eligible to apply for Social Security Disability benefits is actually to start with Social Security. So, you can go into an office or you could go online to SSA.gov and there is actually a tool to help you figure out which types of disability you might qualify for. I would also suggest that you take a look at cancerfinances.org on the disability insurance module, which provides some information about the different types of options that are available, some tips for applying, and for appealing any denials of applications because, oftentimes, when you apply for disability benefits, you are denied. About two-thirds of the people who apply get denied, but that doesn’t necessarily mean that you don’t qualify. You should go through the appeals process to make sure you get access to benefits that you need and that you qualify for.

Lizette Figueroa-Rivera:
Thank you; and the next question comes from Jennifer. Jennifer is asking, “What impact will childhood cancer have on the ability of the patient when they are an adult, to find affordable insurance?”

Ms. Morales: Having a history of a cancer diagnosis as a pre-existing condition, at this point, isn’t a factor in being able to access health insurance coverage because of the protections available in the Affordable Care Act. Moving forward, as we see changes to our healthcare system, I think there could be the potential to go back to a time period where, if you have a pre-existing condition like a cancer diagnosis, you could be denied health insurance coverage and I think that is why it is so important that cancer organizations are advocating on behalf of their constituents to make sure that they continue to get access to those types of protections; and make sure that they are able to access health insurance and quality care.

Lizette Figueroa-Rivera:
Definitely; and here at LLS, we are advocating for our patients to make sure that every patient is eligible for care. Our next question comes from Maxine and Maxine asks, “How can I get help with drug costs for very costly drugs that are taken for an indeterminate amount of time?”

Joanna Fawzy Morales:
The first place that any should start with accessing financial assistance for treatment or prescription drug costs should really be their healthcare team. Talking with your providers about the costs of your medications is very important because they might have resources to help you offset those costs. They can point you towards pharmaceutical assistance programs, or local programs, or even hospital-specific programs that can reduce the costs of prescription drugs. Going to organizations in the cancer community like The Leukemia and Lymphoma Society can help you also access resources for financial
assistance to offset the cost of your prescription drugs or other medications that you might be taking. So, looking at the resources around you and talking with your healthcare team are good first steps. You can also look online—cancerfinances.org—compile some of the pharmaceutical assistance programs that are available. So, you can certainly start there as well.

Lizette Figueroa-Rivera:
And Maxine; I will be giving you the number for our Information Specialists who can also assist in different financial assistance programs for you.

Lizette Figueroa-Rivera:
And our next question comes from John. He says that he has heard that if he is eligible for Medicare, even though he is on his wife’s insurance at this time, he should apply for Medicare because, if he doesn’t, it will be harder to get Medicare later if he chooses to have it. Is that true?

Joanna Fawzy Morales:
There are some potential penalties that someone might pay if they don’t accept Medicare when they are first eligible for it. The details of how your existing health insurance coverage would interact with Medicare are specific to the type of coverage that you currently have. And so, it is a good idea to contact Medicare to find out how they interact and to make sure that you avoid any potential penalties. There is also a resource in every state called the “state health insurance assistance program” or SHIP. If you go to Medicare.gov, on the Contact Us page, it has the information for the SHIP contact where you live. So, you can put in your zip code and it will provide you with the SHIP information. Those local individuals can actually help you with making choices about the Medicare coverage that is available to you so they can help you narrow down your plan options and make decisions in comparing Medicare coverage to what you have now and explaining how they interact. And they can also help if you have any challenges down the road. So, if Medicare denies coverage for something and you are going through the appeals process, SHIP can also be a resource for you as well.

Lizette Figueroa-Rivera:
That is really good to know because it is always helpful to have somebody assisting you navigate through this whole process.

Joanna Fawzy Morales:
They are a very great resource.

Lizette Figueroa-Rivera:
The next question comes from Eleanor. Eleanor asks, “Other than SSA and insurance, are there other programs to help mitigate the cost of ongoing follow-up care after treatment is completed or issues, like fertility, due to treatment? Also, are there programs to help with non-traditional aftercare, like acupuncture or dietary needs?”

Joanna Fawzy Morales:
There are actually a number of programs that are available and what you have access to might depend on the city that you live in, or the facility where you are getting care. So, some cities have organizations that provide some of those services entirely free of charge, or with very small payments to participate. So, you do have to do a little bit of research to find out what is near you in terms of financial assistance to offset the cost of care, even if it is ongoing follow-up care. Again, you want to continue to make sure you have the right type of health insurance coverage that is available to you and to also be looking at the financial assistance programs that are in the cancer community. There are programs that can help with fertility issues. Again, I would point you towards Cancer Finances and other organizations in the cancer community that can give you information on these financial assistance programs, as well I want you to stress talking to your healthcare team because they often know what is available to you locally.
Lizette Figueroa-Rivera: Thank you; and our next question comes from Anne. Anne asks, “what about orphan cancers that have one or no on-label treatments? How do patients navigate the maze of off-label treatments?”

Joanna Fawzy Morales: Any time you are receiving off-label care, it is important to work with your healthcare team to mitigate the costs associated with that care. They can be a great resource in working with your health insurance company to make sure the insurance company understands why it is medically necessary that you are getting that off-label care. And if an insurance company does deny that care because it is off-label, there is that appeals process that I spoke about to make sure that you can get access to that care. (And) Again, getting information from your healthcare team to demonstrate why it is medically necessary is part of that appeals process. Many states—those state agencies—actually act as advocates for consumers directly. So, there are resources to help you navigate that process with your insurance company and to make sure you get the care that you need.

Lizette Figueroa-Rivera: I am glad that you really brought up advocating for yourself and actually going through the appeals process because we have talked to a lot of patients that did not even know that there was an appeals process and I can tell you that most of the patients that we speak with that have gone through the process have been able to get their treatment through the appeals process. So, I am glad that you are highlighting that.

Joanna Fawzy Morales: Absolutely. It is an incredibly under-used process. Most people aren’t aware that it exists and if you—you know, just the data of an average of 50% of the time appeals are being overturned; that is 50% of the time people are actually getting the care that they needed and if you don’t go through the appeals process, then you are not going to get that care covered by your insurance plan.

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**The Leukemia & Lymphoma Society Offers:**

- **Information Resource Center:** Information Specialists, who are master’s level oncology professionals, are available to help cancer survivors navigate the best route from diagnosis through treatment, clinical trials and survivorship.
  - EMAIL: infocenter@lls.org
  - TOLL-FREE PHONE: 1-800-855-4872

- **Free Education Booklets:**
  - [www.lls.org/booklets](http://www.lls.org/booklets)

- **Free Telephone/Web Programs:**
  - [www.lls.org/programs](http://www.lls.org/programs)

- **Live, weekly Online Chats:**
  - [www.lls.org/chat](http://www.lls.org/chat)
That concludes the question and answer portion of our program. Thanks, again, to Ms. Morales for sharing her knowledge with us. I would encourage all of our listeners to visit your website www.triagecancer.org, as it provides a wealth of detailed information packaged in a way that is very helpful and understandable.

If you have additional questions, please call a Leukemia and Lymphoma Society Information Specialist at 1-800-955-4572. Information Specialists are available to speak with you from 9 a.m. to 9 p.m. ET or you can reach us by e-mail at infocenter@LLS.org.

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Slide 39 – The Leukemia & Lymphoma Society Offers

We can provide information or answer questions that you may have about support, including questions about financial assistance for treatment, or mail you one of our “Cancer and You Finances” booklets, which you can also download at www.LLS.org/booklets.
Slide 40 – Conclusion

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