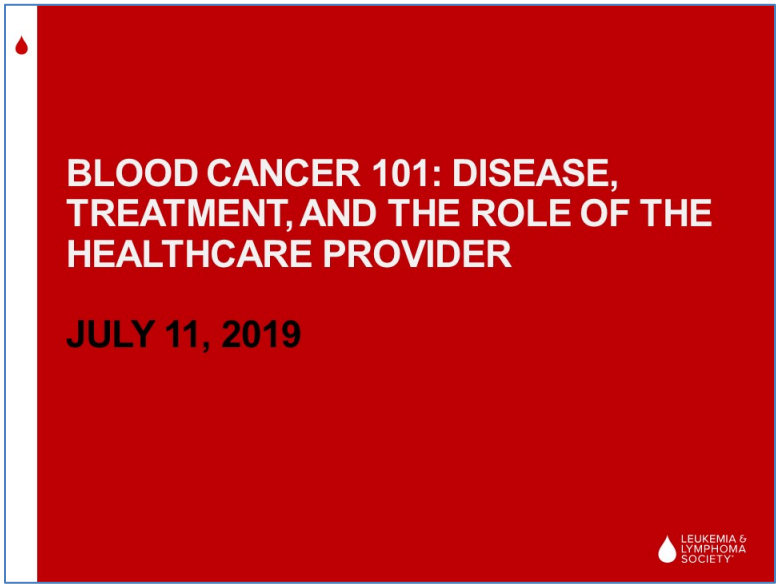
# BLOOD CANCER 101: DISEASE, TREATMENT AND THE ROLE OF THE HEALTHCARE PROVIDER

LEUKEMIA & LYMPHOMA SOCIETY®

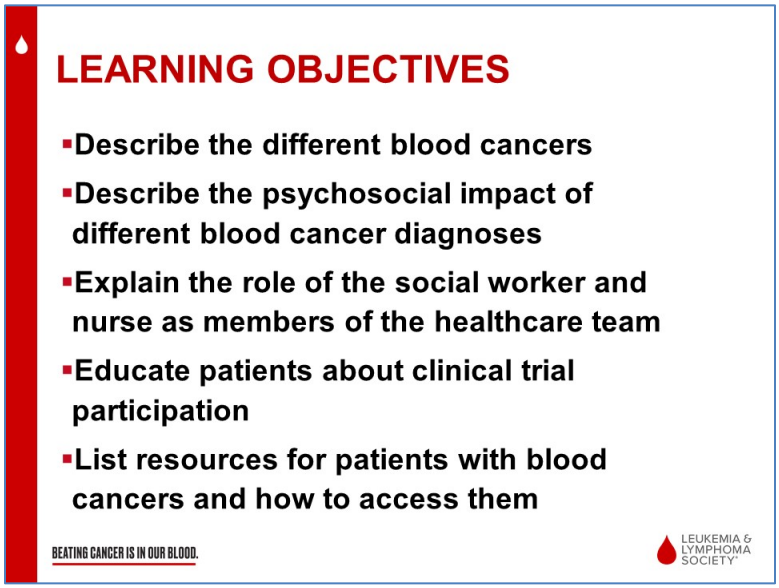
**TRANSCRIPT**

## WELCOME AND INTRODUCTION

**Caroline Kornhauser, MSW**




Good afternoon. On behalf of the Leukemia & Lymphoma Society (LLS), thank you for joining us today. LLS is committed to improving patient's quality of life through programs such as this one and other professional and support education programs. We offer live and archived patient and professional programs for which you can earn CME, nursing and social work credit. LLS advocates for funding to accelerate the discovery and development of blood cancer therapies. To date, LLS has invested more than $1.3 billion in research to advance therapies and save lives.




Today our presenters will describe the different blood cancers, describe the psychosocial impact of different blood cancer diagnoses, explain the role of the social worker and nurse as members of the

healthcare team, educate patients about clinical trial participation and list resources for patients with blood cancers and how to access them.


I am now honored to introduce our speakers for today. Laura Romundstad is a Clinical Trial Nurse Navigator in the LLS Clinical Trial Support Center, and Kristin Scheeler is an Information Specialist in the LLS Information Resource Center. Thank you both for sharing your time and expertise with us today. It is now my pleasure to turn this program over to you.

## PRESENTATION

**Laura Romundstad, CRNP, MSN, RN**

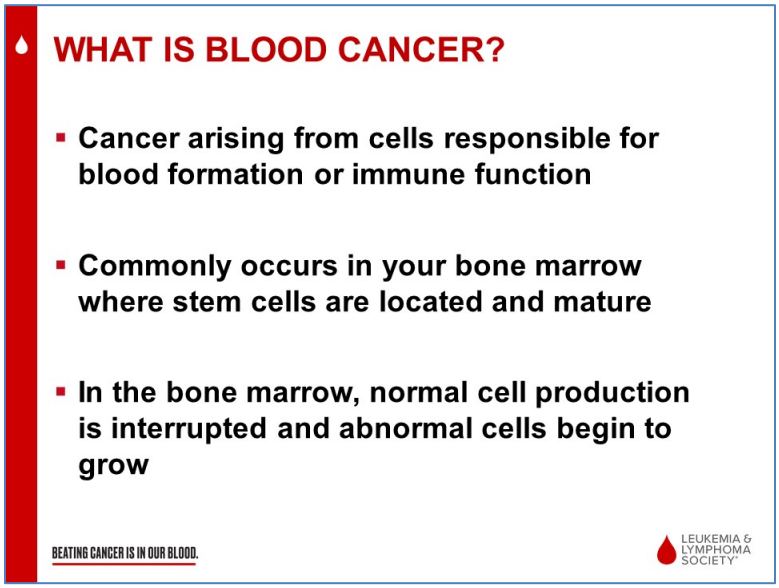
Thank you, Caroline. As you mentioned, my name is Laura Romundstad. I am a nurse practitioner by training and recently joined LLS as a Clinical Trial Nurse Navigator. My experience lies in bone marrow transplant, malignant hematology and radiation oncology. I feel so fortunate to be able to join you all today and greatly appreciate you taking the time out of your busy schedules to learn more about blood cancer. I'm hoping that after today you take away a piece of useful information that you're able to implement into your own practice.

We're going to be covering the basics of blood cancer, which I feel are so important to understand, because you all are the frontlines of patient care. As we continue to improve the outcomes for people diagnosed with blood cancers, patients are living longer; and it is our role to help them in this process. Over to you, Kristin.

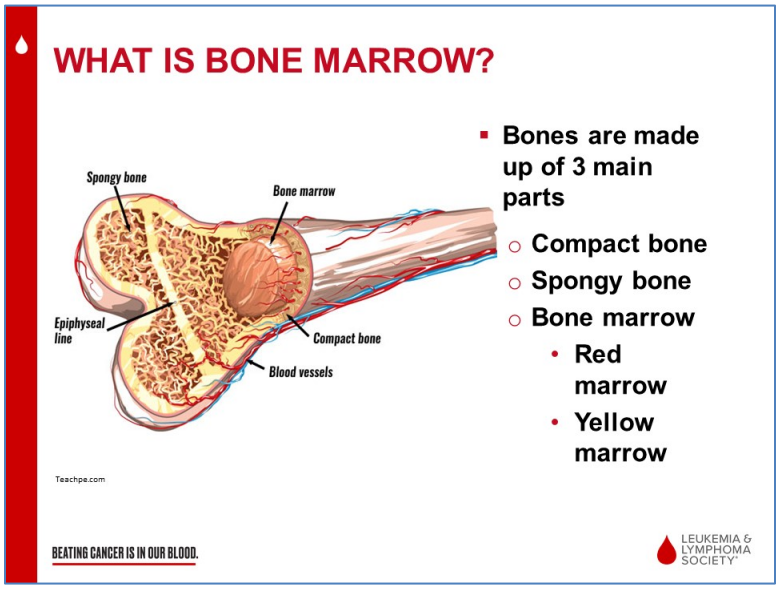
**Kristin Scheeler, MSW**

My name is Kristin Scheeler. I am an oncology social worker and certified in oncology social work. And my background is working in hematology, oncology and bone marrow transplant. And I wanted to convey this information today because it's the sort of information that I wish I had known when I was working with patients in the clinic and in the hospital because it would have helped tremendously to help those who live long term with either acute or chronic blood cancers because understanding the general prognosis and treatment effects of each would have helped me tailor my support in social work intervention better. So, I'm hoping we can give you some of that. This is just a very basic overview, and if you want more information, we certainly have more on our website at LLS.org and in our educational materials.

**Laura Romundstad, CRNP, MSN, RN**




So, moving ahead, the first topic we're going to speak about is getting to the basics of blood cancer. What is a blood cancer? It's a cancer that arises from the cells which are responsible for your blood formation and immune function. All of these blood cancers originate from your hematopoietic stem cells of some varying degree. This frequently occurs in the house where these stem cells are made, which is your bone marrow. The stem cells there grow and mature into their final product. And then it's in this bone marrow that at some point normal cell production is altered, and the normal cells become abnormal, leading to a cancerous state.

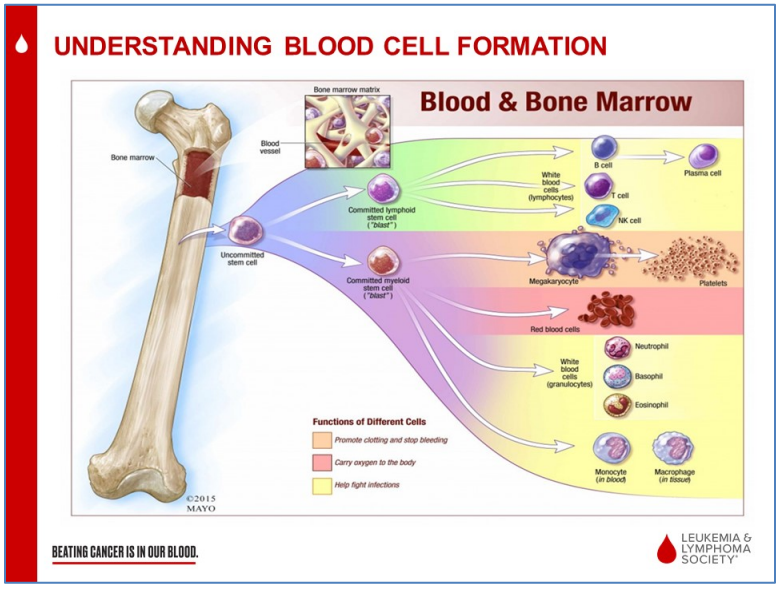



So, what is bone marrow? Where does it occur? Here you see a picture of the bone. Obviously, we all know and recognize the outer layer of compact bone, which is the hard portion. But I think oftentimes we forget about the spongy part of that bone. Inside we have the tissues which allow for some

cushion, and then further we have the bone marrow, which is made up of both red marrow and yellow marrow. It is highly vascular, meaning it has a very rich blood supply, as, obviously, this is where the blood components are made and how they're transported into the body. Red marrow is the piece that makes up red blood cells, white blood cells and platelets. And then the yellow marrow is actually mostly contained of fat and fat stores. And as we age, we lose a portion of this red marrow, and ultimately, it's composed mostly of yellow marrow.

So where is bone marrow? You find the bone marrow typically in your long bones and your flat bones. For example, your skull, vertebrae, sternum, pelvis and then the long bones of your femur, humerus and tibia.

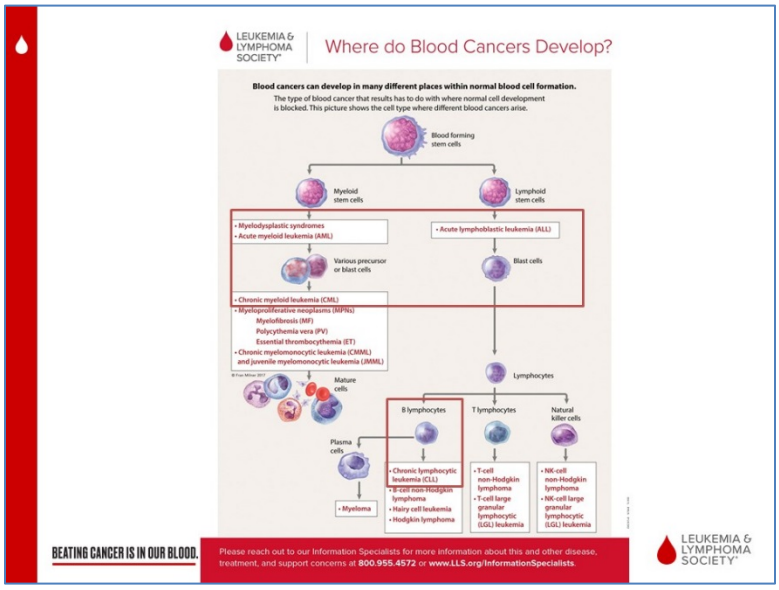
**Kristin Scheeler, MSW**



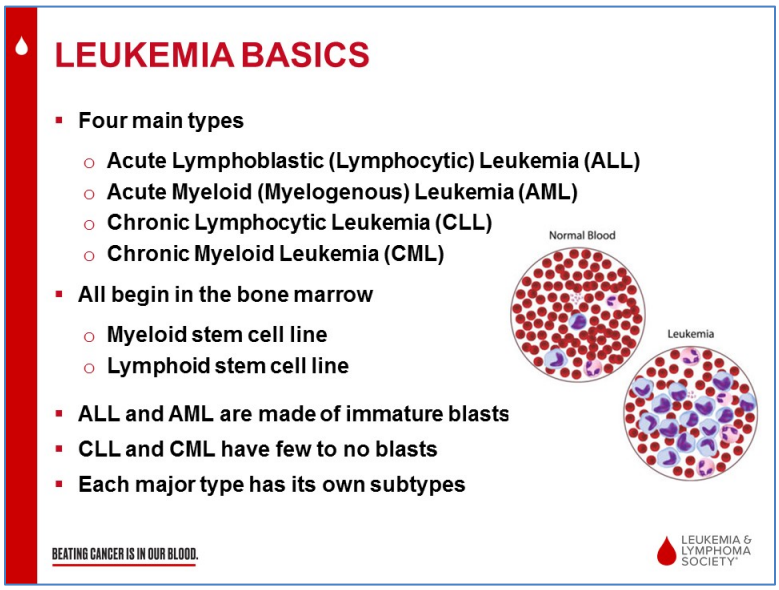

And this pictograph talks a little bit about understanding the blood cell formation. So that bone marrow that Laura just talked about is inside of our bone and is the factory of all the blood cells that will make up our immune system. Or at least it will be the factory of the precursors of those cells.

The first cell that you can see there, and it's a little blurry, so I apologize for the quality of this drawing, but it says "uncommitted stem cell"; and those are also known as pluripotent hematopoietic stem cells. And that just means that they have the potential to become any type of blood cell.

Then they mature into either lymphoid or myeloid stem cells, and you can see that division there or sometimes called lymphoblasts or myeloblasts. And then the lymphoid stem cells go on to become B lymphocytes which also produce plasma cells, T lymphocytes, or NK cells or natural killer cells. And the myeloid stem cells go on to become platelets, red blood cells and several of our white blood cells. Most of the lymphoid stem cells go onto complete their maturing in the lymph nodes, rather than in the bone marrow.




So, understanding that, we can sort of look at where do blood cancers develop in those lines of maturation. So first we're going to look at leukemias, which are outlined in these red boxes. There's one sort of up higher on the chart and one area kind of down a little bit lower on the chart that we're going to talk about.




So, in general, there are four major types of leukemias, and leukemias can sort of be conceptualized as acute or chronic and all beginning in the bone marrow, either of the myeloid stem cell line or the lymphoid stem cell line. Acute leukemias tend to be aggressive and need timely treatment, and they're made up of blast cells. So, the very first cells after the uncommitted stem cells, so either lymphoid or myeloid blast cells, can become cancerous in acute leukemias. Acute lymphoblastic leukemia (ALL) is typically, it's actually the most commonly diagnosed cancer in children and is also more often seen in adults over the age of 60. So, you can see acute lymphoblastic leukemia diagnosed at any age.

In children, it's over 90% curable; and it's less curable in adults. You may have heard of a very recent and innovative therapy called CAR T-cell therapy or chimeric antigen receptor T-cell therapy, and that's approved by the FDA for those who are under the age of 25 whose acute lymphoblastic leukemia persists despite two or more previous treatments or after a bone marrow transplant.

Acute myeloid leukemia (AML) is typically difficult to treat and cure, especially if it has what we call high-risk cytogenetics, meaning the DNA of the actual cancer suggests that it's likely to recur or be difficult to treat if it has high-risk cytogenetics. So, for people who are able to tolerate it and have intermediate or high-risk cytogenetics, they usually receive a bone marrow transplant. AML is seen less often in children, but some children do get it; and it's difficult to treat in children just as it is in adults.

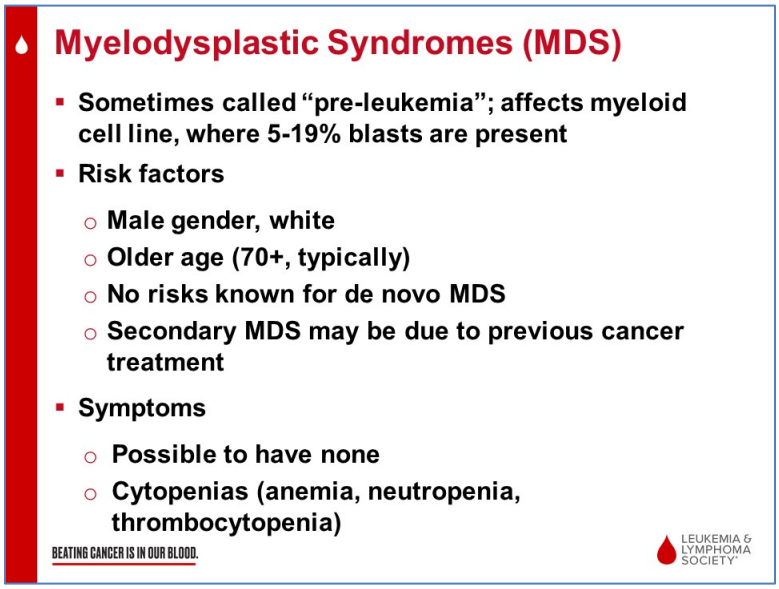
Chronic leukemias, on the other hand, may persist for years or may be present for years before causing a patient problems; and sometimes patients don't even know they have them, and they're incidentally found during workups for an orthopedic surgery or just at their annual physical. And they do not usually present with many, if any, blast cells.

Chronic lymphocytic leukemia (CLL), in some people, is a long-term chronic illness that never needs treatment and is something that they will die with rather than from. But most people do eventually need treatment with chronic lymphocytic leukemia. Many don't need it at diagnosis though, so they are monitored under what doctors call a "watch and wait" or some people characterize it as a "watch-and-worry" protocol because it's hard to know that you have a cancer diagnosis but not do something to treat it. Doctors don't always treat it right away because their toxicities and risks of the treatment outweigh the risks of the damage that the leukemia is doing to the patients when it is first diagnosed, if the doctor wants the person on the watch-and-wait protocol.

And the average age of a CLL diagnosis is about age 70. There are many different subtypes that can be determined by that cytogenetic testing or molecular profiling that would suggest whether and how quickly treatment might be needed for chronic lymphocytic leukemia.

Chronic myeloid leukemia (CML) requires treatment upon diagnosis to prevent it from becoming aggressive. But people who are taking the drugs that have been FDA approved over the last 20 years or so, the tyrosine kinase inhibitors, can usually live a normal lifespan if they take their medications as prescribed. Some patients are even able to stop those medications after several years with undetectable cancers, but, of course, patients should never stop medications without the support of their doctor who will monitor them more closely while they attempt that trial of not taking medications.

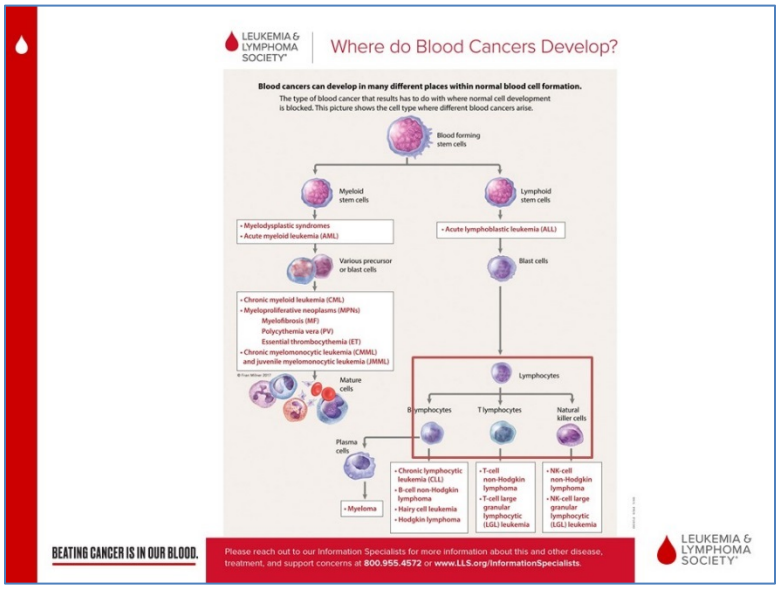
Leukemias should receive cytogenetic analysis so that research into what the DNA of the leukemia is telling the doctor to determine the potential behavior, whether it's aggressive or slow growing, and whether it's likely to recur or not and to help the doctor decide which treatments are likely to be effective to treat each type of leukemia.



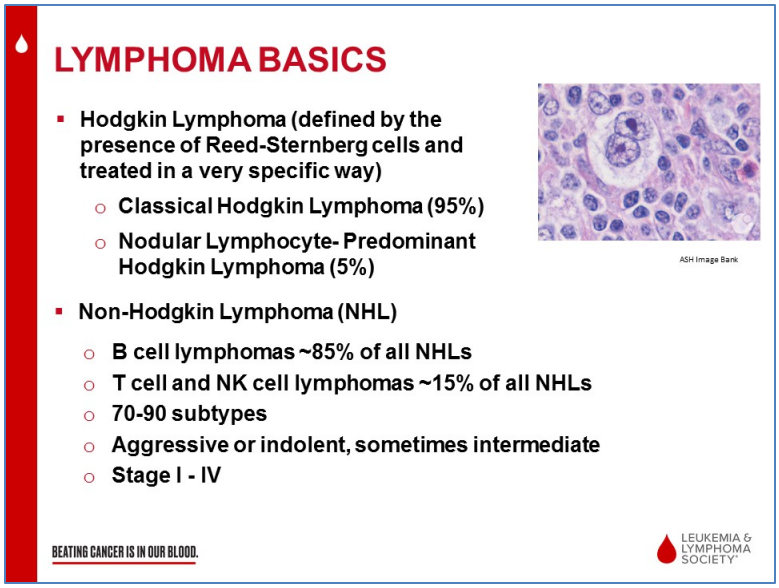

Moving onto myelodysplastic syndromes, these are sometimes called preleukemia by doctors, so if you have a patient who comes to you saying that their doctor told them they have preleukemia, it could be that they're talking about a myelodysplastic syndrome. In general, these are diagnosed when there's 5% to 19% blasts found in the bone marrow; and then AML or acute myeloid leukemia is diagnosed when there's 20 or more percent blasts in the bone marrow. Healthy people can have 0% to 4% blasts in their bone marrow, so it's possible to be completely healthy and still have a few blasts that may appear leukemic, but they're actually not. You're a healthy person, but you can have some blasts.

The risk factors for myelodysplastic syndrome tend to be that the person is older, usually over age 70, white and male. And we don't really know what the risks are for someone who gets MDS as just a diagnosis. However, some people can develop myelodysplastic syndromes after they've had treatments for breast cancer, other solid organ tumors like lung cancer or liver cancer. And those treatments can make people at risk for developing what they call secondary MDS due to the treatment, and that can sometimes also progress and transform into acute myeloid leukemia. So, it can be really important to pay attention to and treat MDS especially that is resulting from previous cancer treatment.

There are several subtypes of MDS. Some are more slow growing or indolent in nature and are managed by blood transfusions and careful monitoring, and others require immediate chemotherapy or even bone marrow transplant to manage or cure. It's possible to have no symptoms and have MDS. Some people just have low blood counts.




So, in this next section here, we're going to look at the lymphocytes, and so those are outlined in red here.




And we're going to talk about lymphomas, which are blood cancers, usually characterized as one of two different types, either Hodgkin lymphoma or non-Hodgkin lymphoma. The Hodgkin lymphomas are among the most common cancers to be diagnosed in young adults and are highly curable in that age range, in young adults. Of course, you can be diagnosed with Hodgkin lymphoma at just about any age. Most Hodgkin lymphoma diagnoses are of the classical type, and they present with these Reed-Sternberg cells, which you can see on the slide here. And a few are diagnosed as nodular lymphocyte predominant type, which can be trickier to treat and cure.

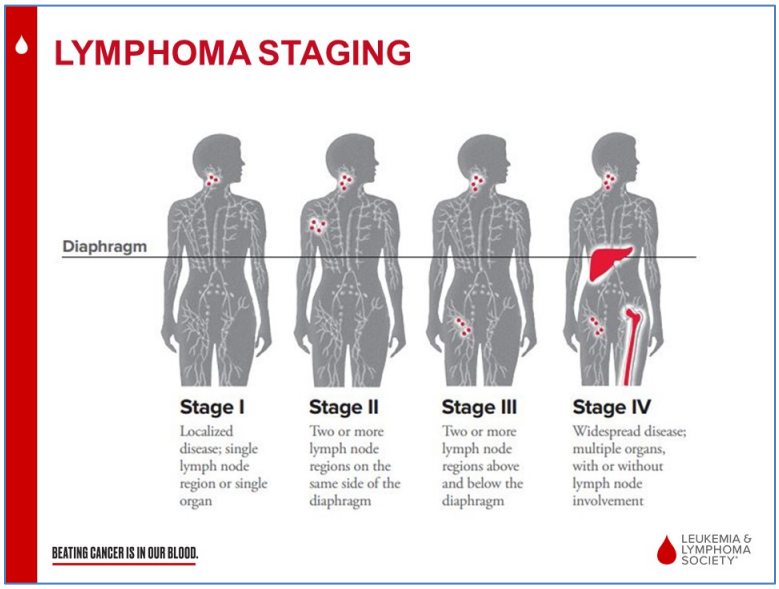
## TRANSCRIPT

Non-Hodgkin lymphomas are a very wide range of blood cancers that affect the B lymphocytes, T lymphocytes, or natural killer cells. The Hodgkin lymphomas affect the B lymphocytes. Non-Hodgkin lymphoma are usually characterized by their cell type and then their aggressiveness, whether they are aggressive or indolent, which means slow growing. Eighty-five percent of all non-Hodgkin lymphomas are B-cell lymphomas, and the other 15% are T-cell and NK-cell lymphomas.

The most common aggressive non-Hodgkin lymphoma is diffuse large B-cell lymphoma (DLBCL), so you might hear that quite often with your patients. And the most common indolent non-Hodgkin lymphoma is follicular lymphoma (FL). Those two B-cell lymphomas represent about 65% to 70% of all non-Hodgkin lymphomas; and the other 70+ subtypes represent the other 30% to 35% of lymphomas.

The treatments really vary widely, depending on the subtype of non-Hodgkin lymphoma, so it's really important that patients are educated about their non-Hodgkin lymphoma subtype, so it's not enough for someone just to know they have non-Hodgkin lymphoma. They need to know if they have follicular lymphoma or diffuse large B-cell lymphoma with the particular subtype of diffuse large B-cell lymphoma so that they can educate themselves about their disease and so that they can continue to ask their doctors intelligent questions and get the information that they really need to understand their disease.

Some subtypes of non-Hodgkin lymphoma are monitored closely by doctors under a watch-and-wait protocol and are not treated until the benefits of treatment outweigh the risks of the toxicity of the treatment to the patient. And this might be a little counterintuitive in some ways, but aggressive lymphomas tend to be more curable. There's a hope for cure with aggressive lymphoma versus the indolent lymphomas which are considered incurable at this time; and a lot of that has to do with how the chemotherapy is able to target fast-growing, aggressive lymphomas versus the slow-growing lymphomas.




The staging we'll talk about on this next slide. I like this picture because sometimes patients will come to you, telling you the stage of lymphoma, and if you don't know what that really means, it just doesn't mean much to you. So, I really love this pictograph depicting the different stages of lymphoma.

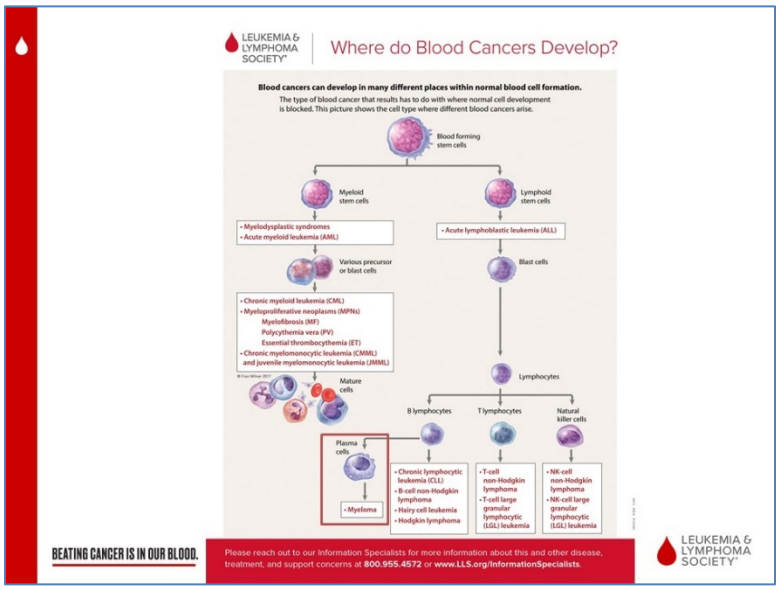
So, as you can see, Stage I means that somebody has just one small area of enlarged lymph nodes in one part of their body, above or below the diaphragm. In Stage II, they may have two different areas of enlarged lymph nodes, but both on the same side of the diaphragm, so either above or below. Stage III is diagnosed when there are enlarged lymph nodes, both above and below the diaphragm, and Stage IV means that there's widespread disease. You can find the lymphoma in the bone marrow. You may find it in organs outside of lymph nodes as well.

And then there's also some letters that can go behind these different stages. If it's a Stage IA, that means that there were no lymphoma symptoms present, and lymphoma was only found in one area or a couple of lymph nodes close together in one area on one side of the diaphragm. If someone has a Stage IB, however, that means they had some lymphoma symptoms, primarily unexplained fevers, drenching night sweats, an unexplained weight loss of 10% or more in the last six months. So, when doctors talk about B symptoms, that's what they're talking about is those unexplained fevers, drenching night sweats and unexplained weight loss of 10% or more in the last six months. And then sometimes you will see a letter E, which means that there is an involvement of organs or tissues that were outside of the actual lymph nodes.

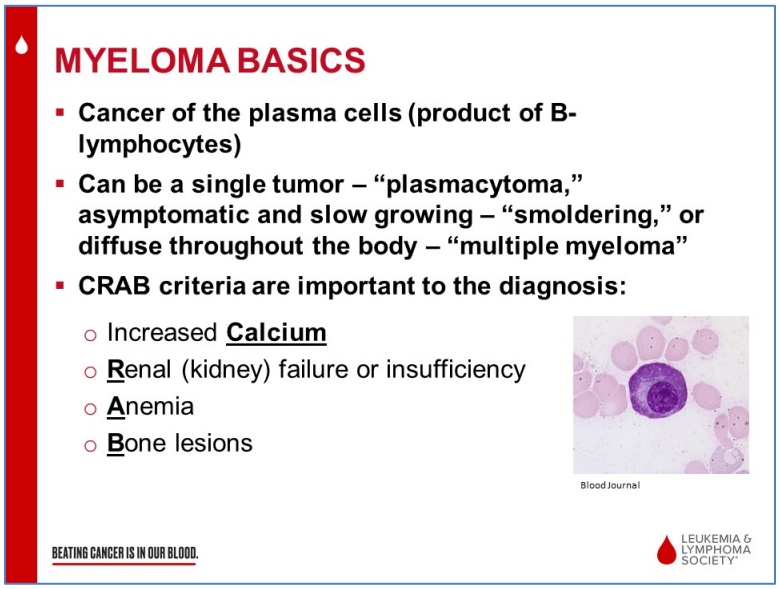
But even if someone's diagnosed with a Stage IV lymphoma, that does not mean that the cancer is not potentially curable or highly manageable for a long period of time. Unlike with solid organ tumors, Stage IV lymphomas can be cured. With solid organ tumors at Stage IV, I know, can mean a much more dire diagnosis sometimes. And Stage IV lymphomas can sometimes be cured within six months or so if they are aggressive. The more aggressive lymphomas tend to become Stage IV more quickly but also more likely to be curable. So, somebody with a Stage IV lymphoma shouldn't immediately think death sentence unless they're otherwise very ill with other comorbidities, very frail, or unable or unwilling to receive intensive chemotherapy to treat or cure the disease.

## TRANSCRIPT

Just a little note about staging people with leukemia, sometimes ask what their stage was; and leukemias are not staged because they already are in the bone marrow, and by their nature, because they're in the blood, they're already diffuse and widespread throughout the body, so we don't stage leukemias, which can be difficult and upsetting to patients. But I think it's important for you to know that's why you don't see a stage with a leukemia. They're just not staged.




Now we're going to talk about myeloma, which is a cancer of the plasma cell, which is a product of the B lymphocyte, and that's outlined in red in kind of the lower left here.




And, of course, with all of these diagnoses, I'm giving you just a very, very basic 30,000-foot description. There's a lot to learn about each one.

## TRANSCRIPT

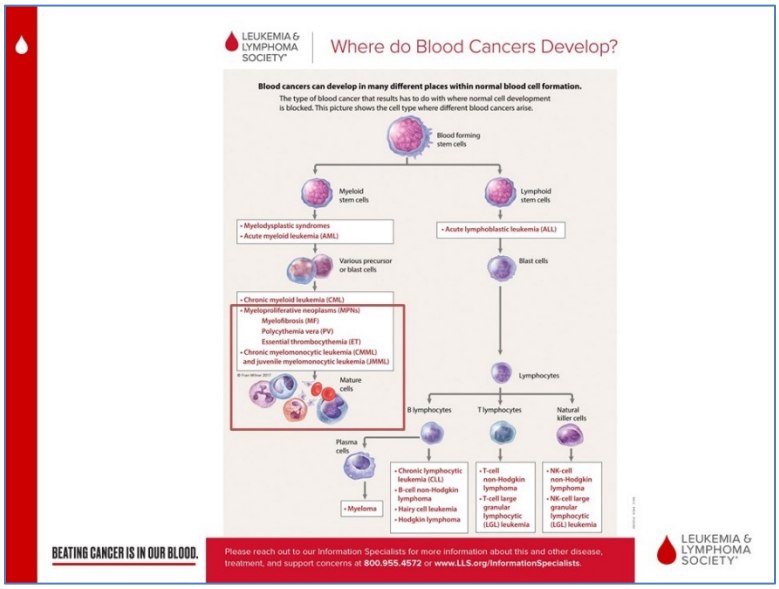
So, myeloma is a cancer of the plasma cells, like I just said. It can be a single tumor, which is called a plasmacytoma. It can be asymptomatic or slow growing, so some doctors call that smoldering myeloma, or it can be diffuse throughout the body, and doctors call that multiple myeloma.

Sometimes people will come to you having had a precursor condition to myeloma called MGUS or monoclonal gammopathy of undetermined significance. Not everybody with MGUS will see their condition transform into myeloma, but some people will. So, if you hear M-G-U-S, those letters associated with myeloma, it's just that somebody's MGUS transformed into myeloma.

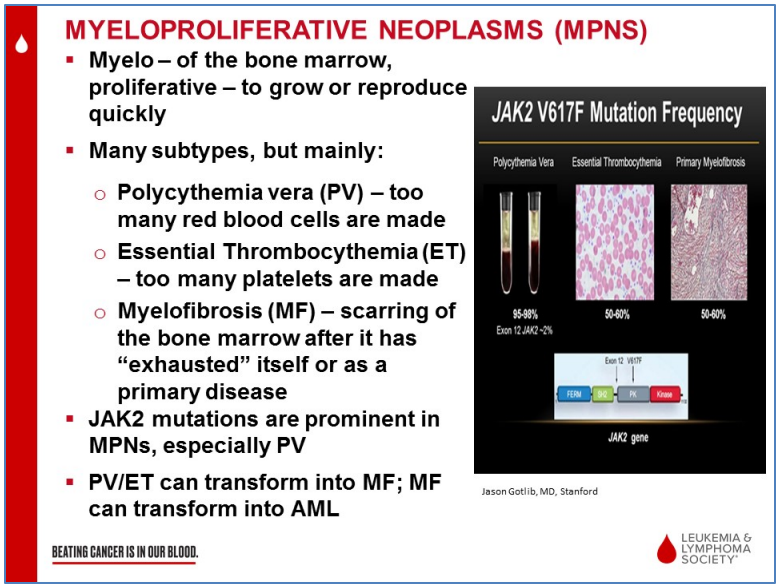
People often complain about hip pain, back pain, or ribs unexpectedly cracking from a hard cough or a sneeze when they've not yet quite been diagnosed with myeloma. Maybe they've gone to physical therapy with no helpful results, and then finally the doctor finds something wrong with their blood count or their kidney or calcium labs and then sends them to a hematologist/oncologist who will proceed with bone scans, bone marrow biopsy and possibly a 24-hour urine collection to look for protein in the urine. And, also, they may offer additional lab testing to determine whether the person has myeloma.

Routine treatments for myeloma are generally well tolerated, even by older adults, and this is typically a diagnosis of older adults, people over the age of 60. People can have just that single tumor made of myeloma cells. If they have the smoldering myeloma, they may not be treated right away and be monitored under a watch-and-wait protocol. And if they have multiple myeloma, they likely will receive treatment right away.

Doctors look at these CRAB criteria to help them with the diagnosis, so it's a nice, easy way to sort of remember that they are looking for increased calcium, kidney failure, or insufficiency, or renal failure, anemia and bone lesions. So that's why they always want to look at the bone. Sometimes doctors will describe bones as looking like they're quote/unquote "Swiss cheese" if myeloma has really infiltrated a bone.




And then, finally, we're going to look at this group of diagnoses called the myeloproliferative neoplasms which are outlined in the red box on this slide.




So myelo is of the bone marrow; proliferative is to grow or reproduce quickly.

So, people often get referred to a hematologist/oncologist when they have an abnormally high red blood cell count or abnormally high platelet count for an extended period of time. Our blood counts fluctuate daily, and it's normal for sometimes things to be a little bit higher than normal and a little bit lower than normal. But if it's consistently high or much higher than the normal range, doctors start to wonder if they should refer to a hematologist/oncologist.

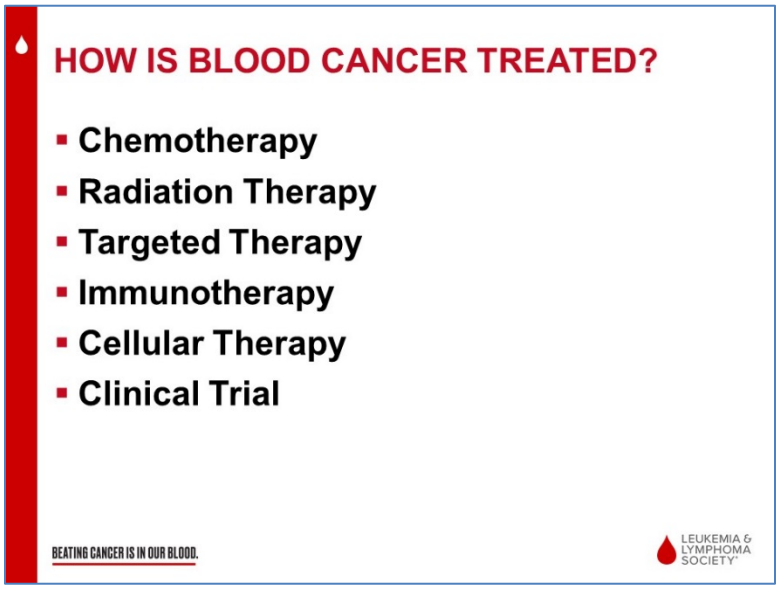
If someone is diagnosed with polycythemia vera or PV, they are making too many red blood cells. Their bone marrow is making too many. If they're diagnosed with essential thrombocythemia (ET),

their bone marrow is making too many platelets. And if they're diagnosed with myelofibrosis, they're experiencing a scarring of the bone marrow, either as a primary disease or after it has exhausted itself so to speak from making too many red blood cells or too many white blood cells in PV or ET. These three subtypes of myeloproliferative neoplasms are three of many MPN subtypes, but they are probably the most common myeloproliferative neoplasms that you'll hear about.

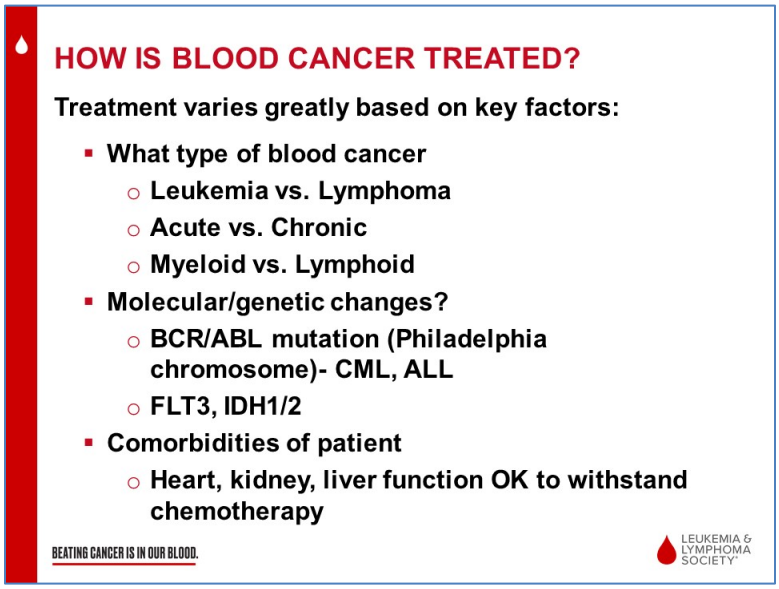
So, the doctor will check for JAK2 (Janus kinase), CALR (calreticulin) and other mutations; and they may do a bone marrow biopsy to make a diagnosis. And as you can see in the picture here, most people with polycythemia vera will have a JAK2 mutation. About 95% to 98% of people do, so you can be pretty sure that's a myeloproliferative neoplasm if they meet all the other criteria and have that JAK2 mutation.

And then many people with essential thrombocythemia and myelofibrosis do have that as well. There are many troubling symptoms of myeloproliferative neoplasms; but they can often be managed with relatively inexpensive and easy-to-take treatments like low-dose aspirin, phlebotomy, or mild chemotherapy treatment. When somebody's myeloproliferative neoplasm is myelofibrosis, often there does come a time when the hematologist/oncologist will recommend a bone marrow transplant or a hematopoietic stem cell transplant to hopefully cure the patient of their disease because there is some concern that myelofibrosis can transform into acute myeloid leukemia.
Now I'll hand it over to Laura.

**Laura Romundstad, CRNP, MSN, RN**



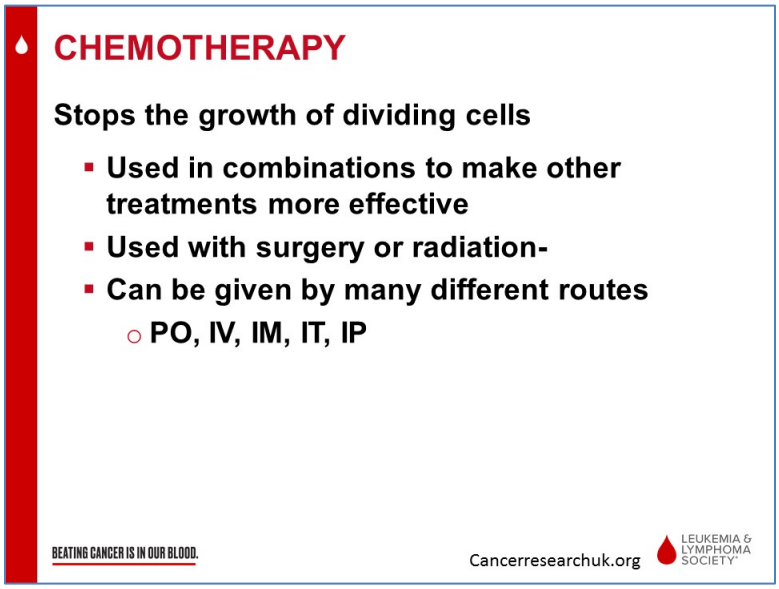

All right, thank you, Kristin. So now we're going to move into the next realm of after diagnosis, what do we do? How do we treat these blood cancers? So, there's many different mechanisms and ways to go about treating it. You've all heard of things such as chemotherapy and radiation. In this new age, we're moving more toward targeted therapies, immunotherapies and then branching off into our cellular therapies and clinical trials.




So, to talk more in-depth, obviously, the treatment of these blood cancers is going to vary greatly. They're going to be based on several key factors such as what is the type of blood cancer? Is it a leukemia versus a lymphoma? Is it acute in nature or chronic? Are we looking at a myeloid line or a lymphoid line? Those are things that play in when the doctor's making the treatment decision. But ultimately, it's getting to the level where we're looking further than that. So, physicians are running very specified tests. You'll hear things called FISH, which is fluorescence in situ hybridization or PCR (polymerase chain reaction) to tell what mutations are present.

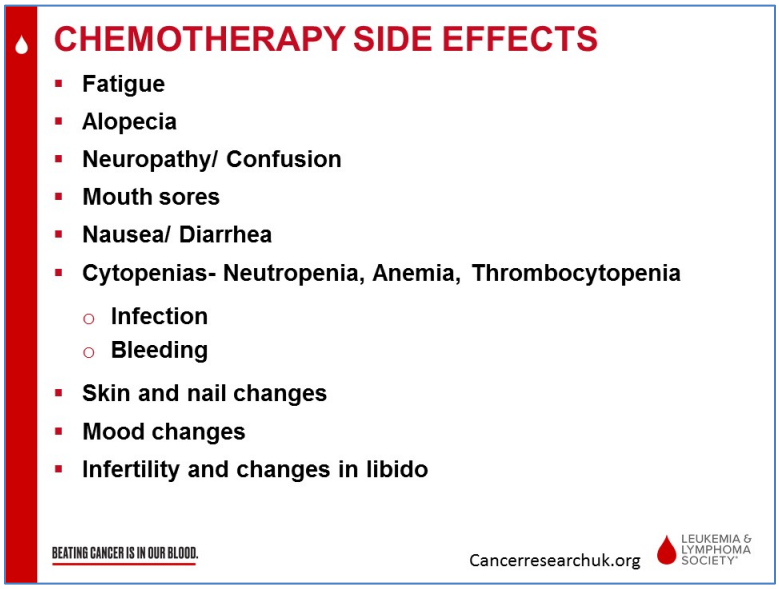
So, we're looking at the BCR-ABL mutation. That's called a Philadelphia chromosome. You see that frequently with CML or ALL. We also see a FLT3 mutation with AML and an IDH1. And there are treatments emerging for all of these and many, many more to be able to more accurately target these conditions.

The other thing, obviously, that physicians are going to take into account are the patient. How do they look? Do they have comorbidities? Do they have good heart function, kidney function and liver function to be able to stand a more intensive chemotherapy or are we looking towards something that's going to be less aggressive but also possibly just as effective?




So, branching into chemotherapy, in particular, chemotherapy has been around for many, many years. It was initially noted around World War II. As the military was discovering more effective agents for war, nitrogen mustard was discovered, that it could help cure some of these conditions. This actually became the basis for the alkylating agent that we use now.

So, what chemotherapy does overall as a broad term is it stops the growth of dividing cells. So, for chemo to work, cells have to be dividing. It doesn't just kill a cell as it is. Frequently, multiple different classes of chemotherapy are used in combination to make each other more effective or to target different mechanisms. Again, they're used in combination with other chemos but then also with surgery and/or radiation. And they have the advantage that they can be given in multiple different ways. You can take them as pills, they can be given through IVs, also intramuscular injection. Frequently, with a lot of our leukemia or lymphoma patients, you'll see them get it intrathecally, meaning it's injected into the fluid surrounding the spinal cord and the brain. And then there's also intraperitoneal installations as well that you see more common in abdominal diseases.




So, obviously, we know chemotherapy works; but many people are afraid of the toxic side effects of it. Because of the nature of how it works, we do see that it kills not only cancerous cells but also healthy dividing cells as well. And so, you're going to have reactions from that. So, patients complain of fatigue, also alopecia, meaning hair loss; and they may completely lose their hair, or they may just have hair thinning. Not all chemotherapy will make patients lose their hair, but that is typically their number one concern and, honestly, one of the first questions.

There are also some further neurologic deficits that can relate. We've all heard of chemo brain, just based on the nature of these cells being killed. Patients can have some confusion. They can also have neuropathy, which is nerve pain. And then it also hits strongly on the GI tract because those cells divide most quickly. You're going to see that manifest in many different ways, whether it be mouth sores or ulcers, nausea, vomiting and diarrhea. And now we've come a long way in managing those side effects. So, honestly, I tell my patients that's something that we can handle. We just have to kind of sort through it and get good medicine on board.

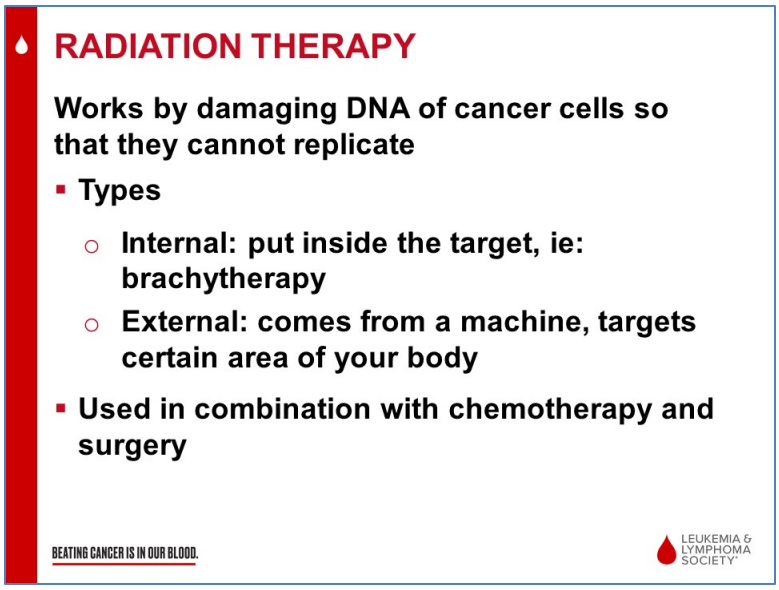
Obviously, the main thing that we want to see when we're treating blood cancer is, we want to induce what we call cytopenias. We want to kill the cancerous cells and, as a result, allow new cells to form. So, you're going to see things like neutropenia, meaning low white blood cell count; anemia, which is low red blood cell count; and thrombocytopenia, which is low platelet count. The results of this, obviously, we have low white blood cells which help your immune system. The patient is going to be at an increased risk of infection. Things that would not normally affect someone that's healthy can be very detrimental to patients and ultimately even lead to their death if you're not cautious.

Also, bleeding is something that we take great precautions against. We encourage them to be careful and, obviously, not shave with straight razors. But the other risks of bleeding intracranially or in places that we can't control as easily are also big risks.

And then there's other side effects which may not seem as big but can still affect the patient overall. So, changes in their nails and their skin, mood changes, whether it be from the chemotherapy and

just the stress their body's under, or the medications we have to give to support them like steroids and things like that.

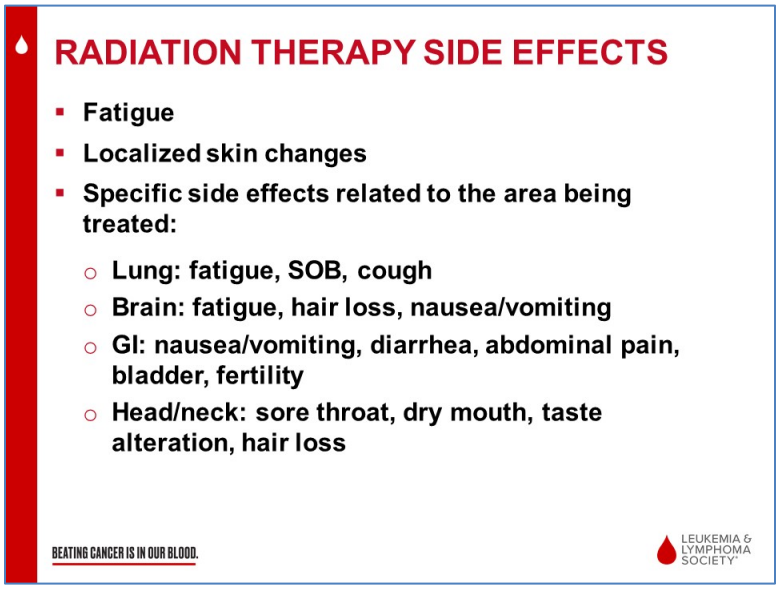
And then something that we have to really take into account, not even just for our young patients but patients of any age, is the possibility of infertility; and so, we want to educate them and also encourage consultations with reproductive endocrinology and fertility preservation to make sure that if they want to continue to have a family, they can do so.




So, moving onto radiation therapy, this has also been around for many, many years. X-rays were first described before the 1900s and ultimately gained use in and around the 19-teens, in 1915. And they have both good properties and bad, so we've all heard that radiation can ultimately cause cancer; and many patients have that concern. We don't want to be exposed to too much. We don't want to cause cancer. But we do know that it is very effective in curing as well, and so it's a matter of weighing the risks and the benefits; and ultimately the benefit is to treat their cancer at that time.

Interestingly, many radiologists tested doses on their own skin. Knowing the dose to give as a daily fraction is what it's called, which is just the daily treatment. They would test it on their skin to get this erythema dose; and as a result, many of them developed a leukemia because of that daily exposure.

Radiation has advanced very far past that, fortunately. There is amazing technology to allow us to precisely target areas that we want the radiation to be and stay out of other areas that we don't. It's highly conformal treatment. It can be given in multiple different ways, both internally when seeds or BBs or things like that are placed inside the target with brachytherapy. And then there's also external radiation that comes and is delivered through a machine and delivers many different types of energy – protons, there are even electron therapies – and these target certain areas of your body. It's frequently used in combination as well, either with surgery or chemotherapy or a radiosensitizer. Radiosensitizers are other agents that are known to make the cancer more sensitive to the radiation.




So, as I mentioned, radiation has side effects. We know that it can lead to other cancers, and so typically what you're going to educate your patients are of overall that long-term risk of exposure. But it's with higher, higher doses over lengthy periods of time. The main complaint of patients receiving radiation therapy is going to be fatigue. It works by damaging the DNA of the cancer cells, and so their body is working to repair itself, causing that fatigue.

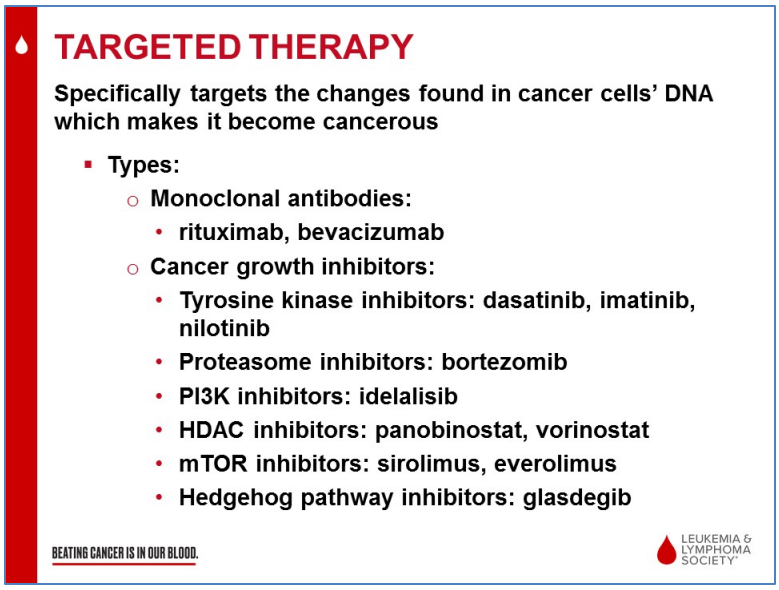
They also are going to complain of localized skin changes. Most patients will say they feel like they've been burned, and it's very important to educate your patients that that's not actually the mechanism. It can have a very, very negative connotation but is actually very, very useful. The skin changes occur only where the radiation is being delivered, and then the side effects that they experience up on top of that are going to be specific to that area as well.

So, for example, with lung cancers or lymph nodes up in the chest, patients are going to have shortness of breath and cough. If they're having treatment to the brain, they have overwhelming fatigue, even more so than normal, along with hair loss and the potential for nausea and vomiting due to the amount of increased swelling from inflammation in that area.

Also, if they have treatment in the GI region, patients can have an increased risk of nausea or vomiting again due to the inflammation along with abdominal pain. The other thing you have to think about are all the organs in that area. So, they may have some dysuria if the bladder is anywhere near the field. And then also fertility if the ovaries or uterus are there. We have to also protect against that.

And, lastly, head and neck. There's many lymph nodes that lie along the neck with the cervical chain. And so, you'll frequently see patients be treated in that area. It can be very, very difficult because there's a lot of critical structures very close in that region. So, you have your esophagus and your trachea, salivary glands. The patients will have a sore throat and dry mouth and, obviously, taste alteration, which then leads into another adverse effect of them not wanting to eat. And so, it's very important to make sure that we manage those as best we can. Ultimately, if they get a lot of treatment

in that region, they may need to talk about other ways to feed themselves, either through a G-tube or PEG (percutaneous endoscopic gastrostomy) or some way to get nutrition.




And as we have moved forward in our treatments, we are looking more towards targeted therapy. I'm sure you have all had patients mention that they want targeted therapy. They don't want chemotherapy because it can be so toxic. And so, in and around the 1980s and '90s, there's been more of a push and a growth in this arena. Targeted therapies is a very, very broad term. There're many different ways that we can use this and many different pathways that can be affected to cause changes in these cancer cells' DNA.

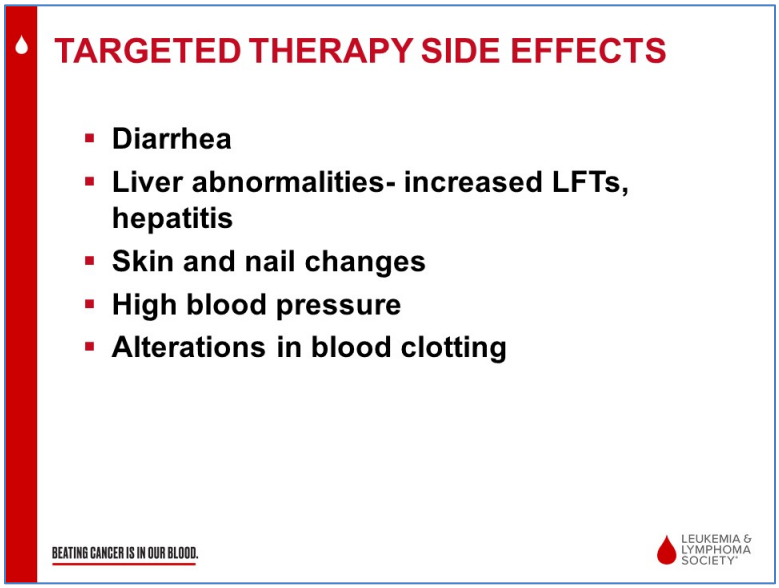
So, what this does is it, these different classes target that specific pathway. They work by stopping growth or division of the cancer cells. They can also find cancer cells and kill them. And another way is by stopping angiogenesis, which is the growth of blood vessels which feed the cancer. They work together with chemotherapy and are pretty highly effective.

So, an example are monoclonal antibodies. I'm sure we've all heard of this. They have grown in popularity and have very high effective rates. And so Rituxan® is one of the first ones that has come out and used for many, many years. So, it targets one of the cell proteins called TD-20, and what it does is it helps them recognize this protein on the cell surface and kill the cancer cell, stop it from growing. It also has the ability to deliver a toxin to the cancer cell so that it dies ultimately.

There's also, they use cancer growth inhibitors. We've mentioned kind of briefly these tyrosine kinase inhibitors and that they work to target the BCR-ABL mutation. You see these used in CML and acute lymphoblastic leukemia that are pH-positive or Philadelphia chromosome-positive, meaning they have that mutation. They have to have that or else it doesn't work because that is the pathway that is targeted specifically.

Proteasome inhibitors, there's one called bortezomib which is frequently used in combination for multiple myeloma. These proteasomes break down proteins, and so these drugs stop that and allow the cancer cells to die.

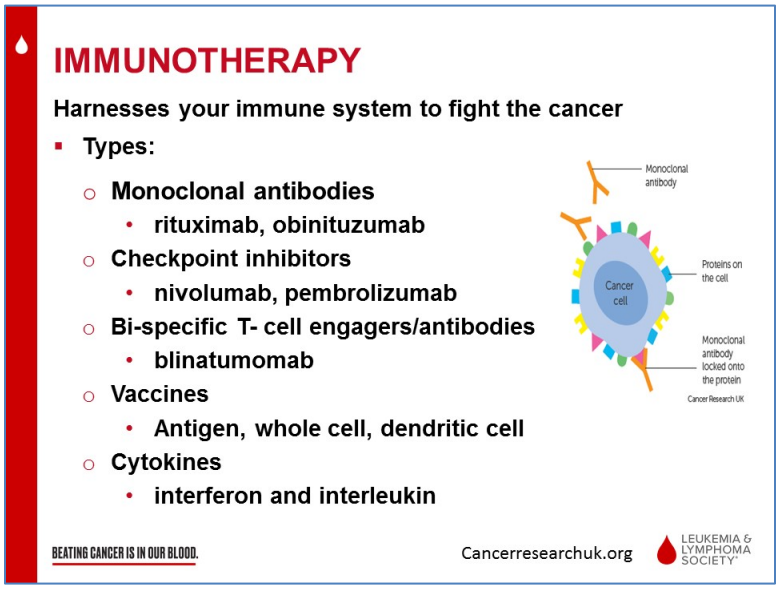
There's also PI3 kinase inhibitors. There's multiple, but idelalisib is one of them. There's also copanlisib and duvelisib. They're typically seen with the lymphomas, follicular lymphoma, CLL and SLL (small lymphocytic lymphoma). But the way they work is they inhibit enzymes in this pathway which are responsible for cell growth and survival; and so, by inhibiting those, they cause cell death. There are also HDAC (histone deacetylase) inhibitors, which long story short, cause cell death or apoptosis by preventing a process called deacetylation. There's panobinostat which is used in combination with multiple myeloma and then vorinostat as well. Most of these are not frontline therapies, just want to put that out there, mTOR pathway, also are similar to PI3 kinase inhibitors in that they regulate the growth factor pathway. And then the last are Hedgehog pathway. There's one approved currently which is used in AML in older patients in combination with another form of chemotherapy.




So, that brings us to dose side effects. You know, ultimately people thought that receiving targeted therapies were going to be less toxic than some of the chemotherapies which have this connotation of killing all the cells. And while, yes, they do have kind of less side effects of the profile, sometimes the side effects can be more intense and more life-threatening than the effects of chemotherapy, but not always.

But what they cause are more of inflammatory type reactions, so diarrhea, liver abnormalities, increased liver function tests and hepatitis. Not the viral type hepatitis but inflammation caused by the killing of these cells and the liver having to process all that out. They also have skin and nail changes. High blood pressure can also be an issue which, if not managed, can lead to ultimately other complications.

And then it also has the ability to cause alterations in your blood clotting because we are affecting pathways in their blood cell formation. There's always a cascade effect, and so it's important that we make sure to monitor all the systems and make sure that patients have the ability to form clots as necessary.




Moving into the other realm of immunotherapy, which can also be looked at as a form of targeted therapy, but what it does is it harnesses your immune system to fight the cancer. So, introducing things that your body has innately in them and either altering it or enhancing it in some way to make your immune system more effective at killing this disease.

So, I mentioned in the last slide, in targeted therapy, monoclonal antibodies. Well they're also a form of immunotherapy. So monoclonal antibodies have the ability to not only bind to the protein and ultimately stop cell growth, they also have the ability to bind to these proteins and put up a flag, in a sense, so that your immune system can recognize those cancer cells as foreign because ultimately that's the crux of the issue here is that cancer cells are your own cells. They've just mutated, and so that's why our immune system is not readily able to see them as different and kill them and get rid of them; and so that's a way that these monoclonal antibodies can do so.

There are several, but as I mentioned, rituximab and obinutuzumab target a cluster of cells called CD20. There's another one that's used in Hodgkin lymphoma called brentuximab that targets CD30.

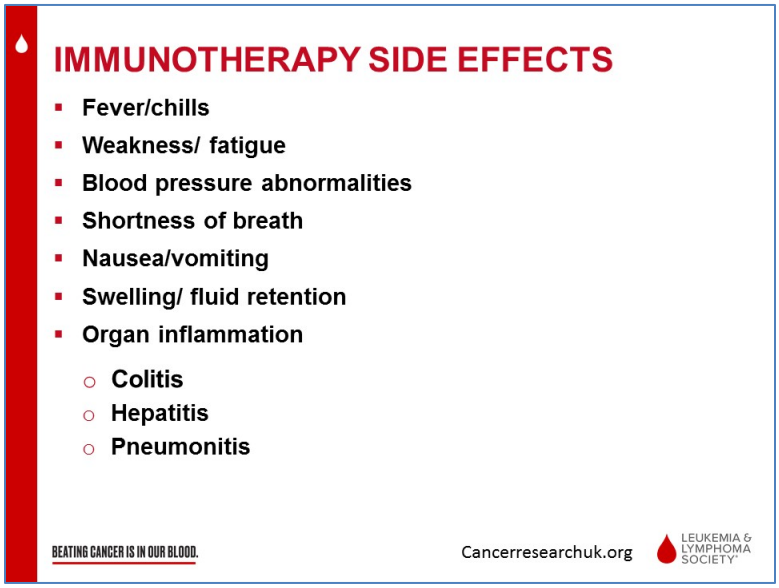
Checkpoint inhibitors have come a long way. What they do is they essentially open the flood gates and release T cells to fight your cancer. So, our body has T cells as a part of our immune system, and they are killer cells, and they recognize different pathogens. And so, these inhibitors allow them to be utilized to their full capacity.

Examples, I'm sure we've all heard of nivolumab and pembrolizumab. They have many approvals in solid tumors, and so what we're working towards is using them in clinical trials to find kind of a niche that they can be used in other cancers. They both target PD-1, which are found on T cells.

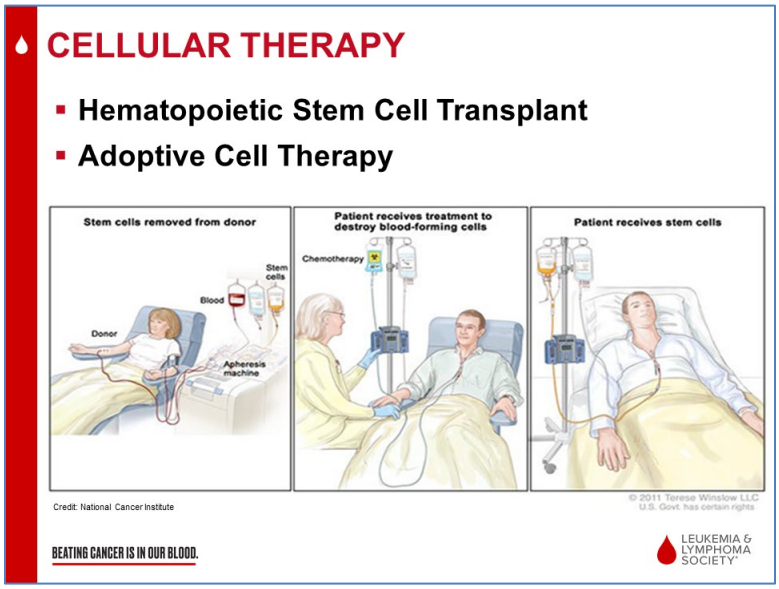
## TRANSCRIPT

There's also vaccines. And while no vaccines have yet been approved in hematologic malignancies, they are showing good promise in other diseases. What they do is, there's different kinds, but with antigen vaccine, they're made from special proteins in the cancer cells; and they stimulate your immune system to ramp up and, again, recognize the cancer. There's whole cell vaccines, meaning they take the whole cancer cell and make it into a vaccine, again, so that your immune system can recognize that as foreign. And then dendritic cells are another part of your immune system. But what the dendritic vaccine does is it helps the immune system recognize and attack that cancer.

And lastly, we have cytokine therapy. These have been around for a little while longer, interferon and interleukin. And what they do, our body has cytokines naturally. They're proteins that we make in normal responses to inflammation or injury or cancer. And so, what we do with that is we introduce these cytokines to further promote a response from your immune system.




Obviously, these again are going to have side effects. Immunotherapy side effects, again, tend to be more like an immune response. Many patients will say, "It feels like I have the flu." You're just overcome with fever, chills, weakness, malaise. You can also have blood pressure abnormalities, both high blood pressure and low blood pressure, shortness of breath related to the inflammation in the lungs. It can be called pneumonitis. We also have the inflammation with hepatitis and colitis, which, again, are inflammation of the liver and the colon. And that leads to nausea, vomiting, diarrhea. You also have the risk of swelling and fluid retention, so you're going to be monitoring your patient closely for both of those. There are times when they progress far enough that you have to stop the patient on that therapy and try another pathway. So, while we have definitely made good strides, we know that there are some toxic effects to these based on ramping your immune system up.

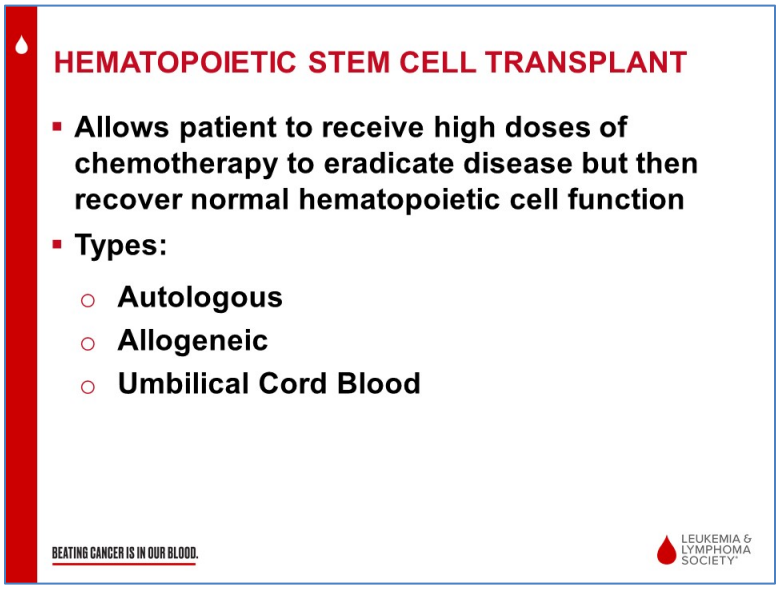



And so, another mechanism that we have kind of grown to embrace over the past few decades are cellular therapy, and this is a growing category. We know about hematopoietic stem cell transplant. There's multiple different forms that we'll get into. But a newer emerging type is called adoptive cell therapy or CAR T cells is probably the one everyone is the most familiar with. That can kind of be lumped into the cellular therapy category or also immunotherapy, and I'll explain why in just a little bit.

I like this picture because it shows kind of the process for how we collect stem cells. A patient is hooked up to what we call an apheresis machine. And now this is described for a transplant, but it's similar for adoptive cell therapy as well.

The patient's in the chair. You have IV access. The blood is removed from the patient. It's inserted through the apheresis machine and then returned. You're able to remove whichever part you're targeting. So, for a stem cell transplant, you're pulling out those pluripotent hematopoietic stem cells. For CAR T or some of the other therapies, you're pulling out T cells.

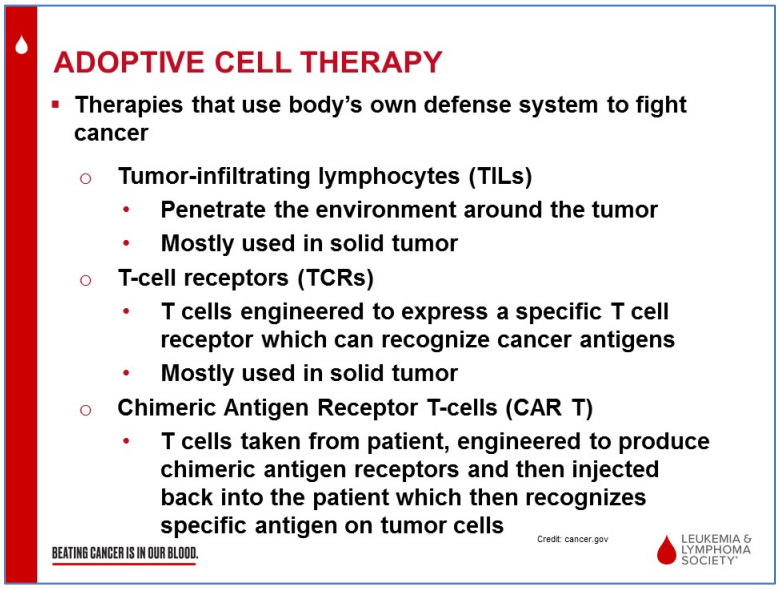
And then what you do is ultimately the patient, however you prepare that product, that product is ready. The patient is going to be prepared typically with chemotherapy to deplete their lymphocytes, which are what ultimately attack and cause that to not work. And then, at a certain point, they receive whatever cell back it is to be given.




So, as I mentioned with the hematopoietic stem cell, there's different types. There's autologous when a patient receives their own stem cells back, so they would be the one hooked up to the apheresis machine and their cells would be collected. There's allogeneic stem cells as well where patients receive stem cells from someone else. It can be someone that they are related to, someone that they are unrelated to, and there's different variations of how they go about matching that. It's based on a tissue typing and not a blood type. And so, what they're looking at is either matching completely or sometimes they'll use a mismatch or even a half-match. And then there's also umbilical cord blood transplant as well, which that, as we know, umbilical cord blood is high in hematopoietic stem cells of the most pure form because they haven't been exposed to the environment. And so, they are able to give that back as well.

The purpose of a hematopoietic stem cell is to allow patients to receive these very high doses of chemotherapy that we call myeloablative, which will hopefully eradicate that disease, cause death of all of those cells, but then allow patients to recover normal hematopoiesis or normal blood cell function, red blood cell, white cell and platelet.

It definitely comes with risks, and so that's something that patients absolutely have to talk to with their doctors and determine are they eligible or not. Is it in their best interest? And that also is based off of more of the genetic mutations present in their leukemia as well when they make that decision.

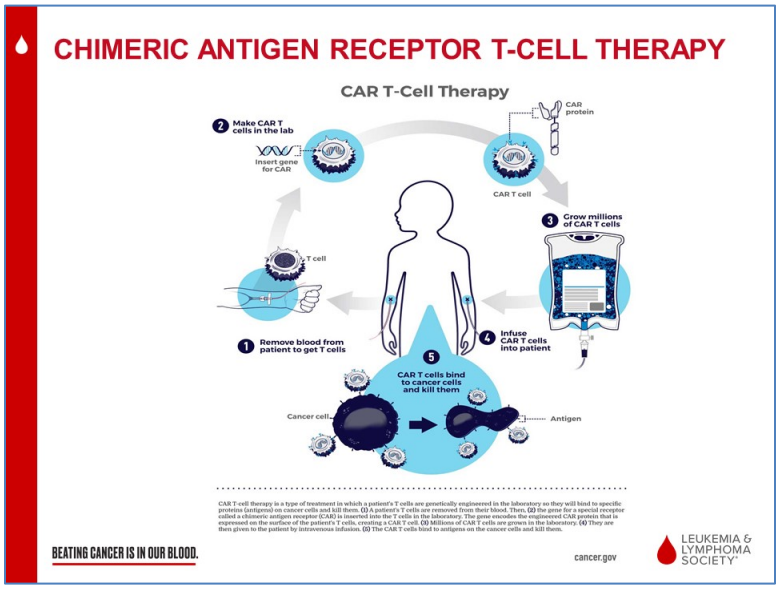



Moving onto adoptive cell therapy. These are therapies that use your body's own defense system to fight this cancer. I'll hit on the less common ones that we've probably not all heard of briefly. Tumor infiltrating lymphocyte, these lymphocytes penetrate the environment around the tumor. We see this most often with other solid tumors, but they are also effective.

T-cell receptors is kind of a broad term, but what they do is they take out these T cells. They're engineered to express this certain receptor which can recognize the cancer antigens; and, again, it's most commonly used in solid tumor, but things are crossing over into the hematology realm as well.

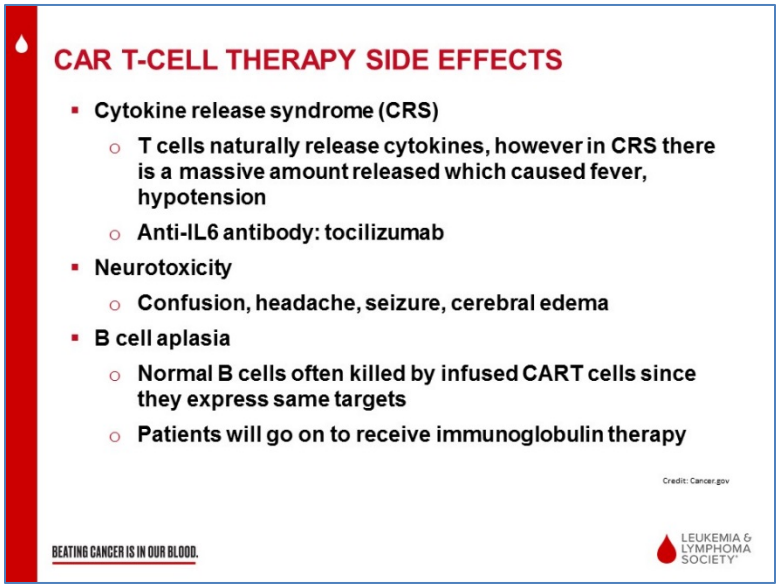
And then the most common one that we've all heard, and I'm sure you have patients ask you about, are CAR T cells or chimeric antigen receptor T cells. The patient goes through the same process as far as apheresis. They have the T cells taken out. They're engineered to produce this chimeric antigen receptor and then are given back to the patient.

There are many different products, and many are under clinical investigation on trials to see exactly which pathways and which cell markers are the best ones to provide longevity of these CAR T cells to provide the longest killing time. And so, I think we still have a ways to go, but we do have two approved therapies, which I'll talk about in just a minute.




This next slide shows kind of the process of CAR T-cell therapy. It mentioned, again, removing the blood from the patient to get their T cells. You take the T cells into the lab. You insert this gene for the chimeric antigen receptor, and that allows it to express that protein; and then you want to expand that. You want to grow these by the millions so that you have the longest killing time as well.

The patient then at that point would undergo the chemotherapy, the lympho-depleting chemotherapy, and then be infused with CAR T cells. They then bind to the cancer cells and kill them.



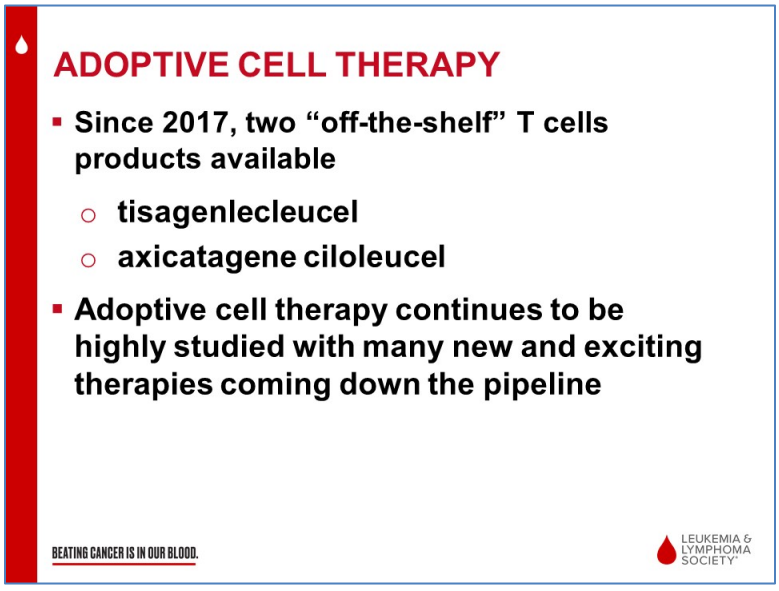

So, I'm not sure if you all have heard about the side effects that go along with CAR T-cell therapy. As I mentioned, cytokines are something that our body produces in inflammation and when under stress. And so, anytime you're introducing this foreign thing, our T cells are naturally going to release that, which is fine until we influx large, massive amounts of these cells. So, in cytokine release syndrome, there's this massive amount of cytokines released which cause fever and inflammation and

hypotension. You can have other side effects as well, and it can almost look like sepsis type if you will, so you have capillary leak and swelling and things like that. And so, it is managed and graded based on different scales that are out and published, and there is an antibody called tocilizumab which can be given to prevent this cytokine release syndrome. But that's one of the main things that's still being monitored.

There is a risk for neurotoxicity, and ultimately this was initially thought to be related to the cytokine release; but I believe, from what I understand, physicians are kind of lumping this as its own separate entity. It has varying degrees and can be as mild as just some confusion which resolves but ultimately has the risk of higher issues like cerebral edema leading to seizure and ultimately has to be managed in the ICU (intensive care unit), etc. They're still kind of understanding the mechanism of how this works.

And one kind of byproduct side effect which doesn't really affect this therapy per se or whether a patient would go on, but it's called B-cell aplasia. And so, because we give these CAR T cells to kill the cancerous B cells, the normal B cells also express a lot of these same markers. And so, they can be killed by these CAR T cells which are infused.

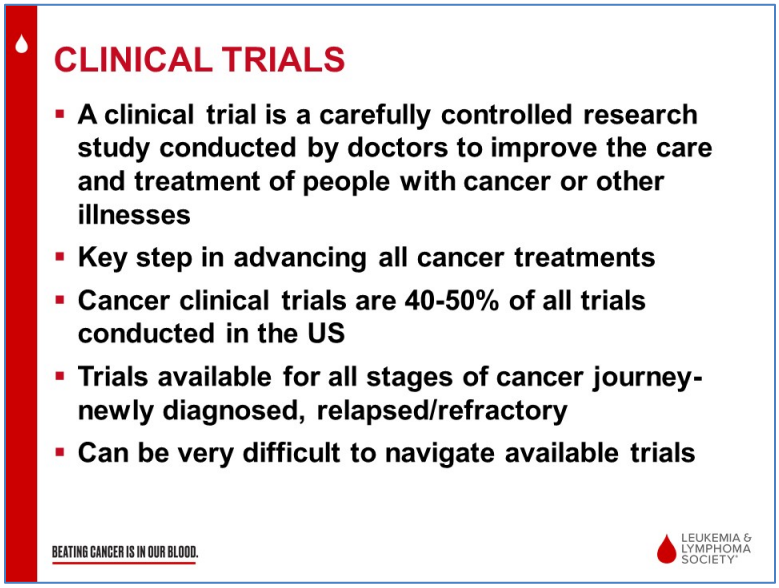
Ultimately, patients may need to go onto receive IVIg or (intravenous) immunoglobulin and can be an ongoing process. And so, it's something that you want to mention to your patient, educate them that just because you get a CAR T-cell therapy doesn't mean that you're cured, and you don't have any follow-up or anything else to do. There can be long-lasting effects that you have to manage because B cells play into your immune function, and we want to make sure that you are as healthy as possible moving forward.




And so, as I mentioned, there are two "off-the-shelf" products. The short-term way to say these are tisa cell (tisagenlecleucel) and axi cell (axicatagene ciloleucel). They have been approved for ALL and diffuse large B cell, respectively. And, obviously, they continue to be highly studied, adoptive cell

therapy does. And there are many, many new therapies that are in different stages of development and hopefully coming down the pipeline.

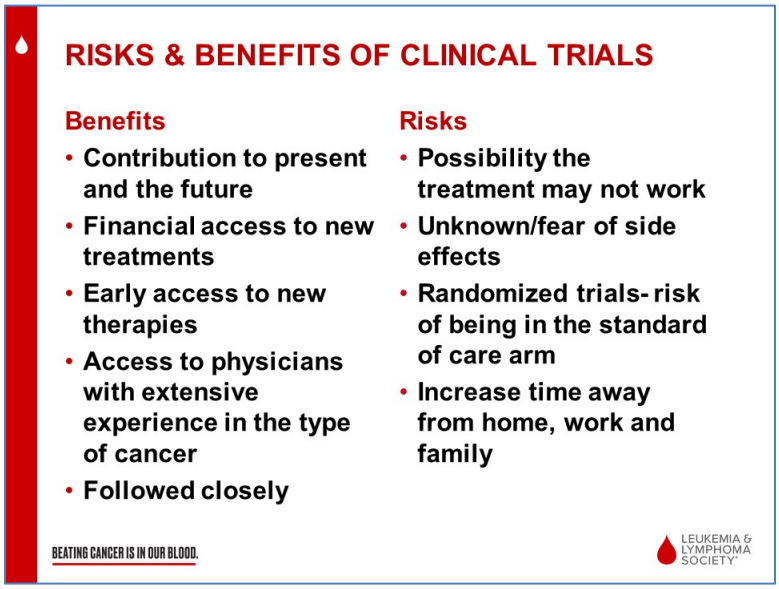
As you have noticed, both of those are only approved in the B-cell lineage, and so in talking to other researchers, we have some ways to go in this myeloid lineage because of the nature of how those cells are. And if you kill off those cells, if you think about the pictures that we saw earlier, you're going to be killing off the blood cells that are responsible for your red blood cells, your white blood cells and your platelets.




So, talking about research and kind of the ways that we're moving, we have many patients come to us at different stages of their disease interested in clinical trials, whether it be newly diagnosed. We frequently see patients in the CLL watch-and-wait who don't want to just wait. They want to do something, and so we need to move forward with advancing science at varying stages, whether it be newly diagnosed or relapsed or refractory or at the end of their rope with no approved therapies.

And so clinical trials definitely have a place in cancer treatment. Clinical trials are carefully, very controlled, very scrutinized studies that are conducted by specific institutions and physicians to overall improve not only the quality of care that we're providing and the treatment options that are available but also to promote quality of life; and there are trials for survivorship and even after. And so, there's many different options available.

Cancer trials make up approximately 40% to 50% of trials which are conducted in the US. And, unfortunately, it can be a very arduous process for patients and caregivers to navigate on their own. They're hard to break into. It's hard to get in based on spots that are available and very strict inclusion and exclusion criteria.




There are definitely some risks and benefits associated with clinical trials. Obviously, a benefit is the ability to contribute to future science but also to their own health as well. They have the ability to gain access to treatments that would otherwise financially be unaffordable. We know that the cost of medication can be exorbitant, and so that gives them access to that. Also, therapies that are not yet approved but are showing good promise, patients have access to that.

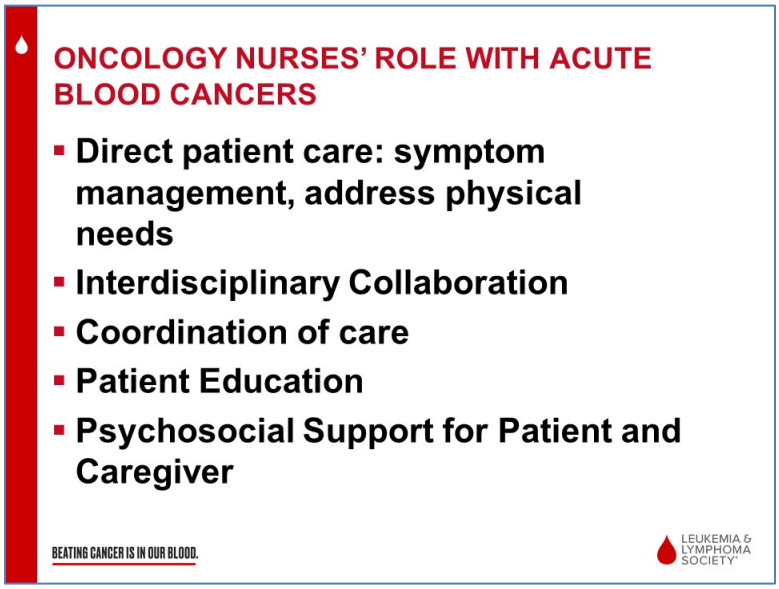
And then it's typically physicians that have expertise in these fields that are studying new novel approaches, and so they gain access to physicians who have high levels of knowledge in certain specialties and certain diseases in particular. And so, they get the ability to be followed closely with an expert in their field.

There are definitely risks. There's always the possibility that that treatment may not work. It's being studied. It's not known how it will do. There are side effects that we don't know, and it can be very mild, or it can be a higher risk side effect.

And then there's always the concern and possibility of being in a randomized trial that you're not going to get the new novel therapy or the study medication, and so that causes some fear in patients, along with just having to be away from home, work and family with frequent doctors' appointments; and frequently these clinical trials may not be close to where patients live. And so, it takes more time away from where they are.


So, all that being said, with clinical trials being very difficult to navigate, how is LLS moving this forward in helping patients and supporting not only patients and caregivers but also healthcare providers who have a patient that's in need of a clinical trial but have no way of knowing what's available?

We do have a Clinical Trial Support Center which I'm fortunate to be a part of. We are a group of highly trained nurses, nurse practitioners, and nurse educators. We all have varying degrees who are able to provide personalized, detailed, individualized searches for patients and caregivers based on their disease, their treatments that they've had, their location, their social contributions. But not only that, we provide follow-up for them. We walk this every step of the way with them, whether it's finding a clinical trial or breaking into the access or knowing about waiting lists. And we also are fortunate to be able to speak with the physicians on the frontlines and kind of really get a glimpse into how they think and how things are working and ultimately really develop a personal connection. We get to know our patients and caregivers and learn their stories so that we can guide them, whether they're newly diagnosed or relapsed or refractory or just scared and not knowing where to turn.



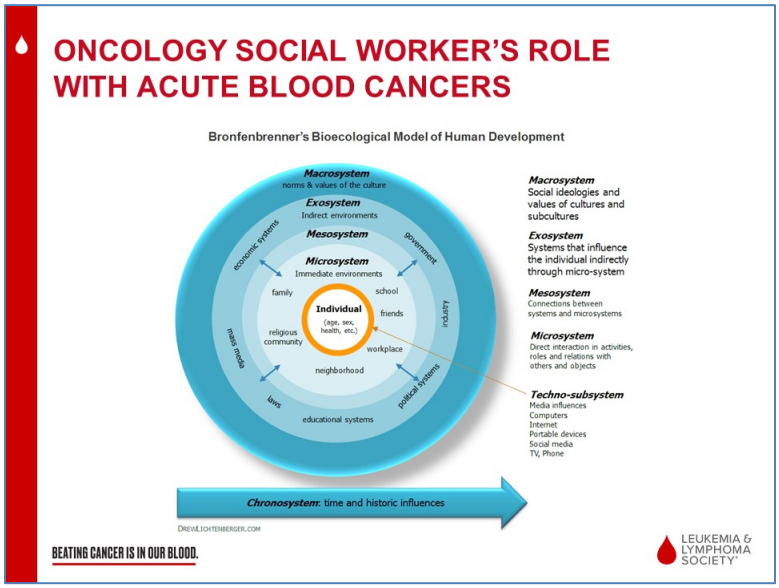

And so, that brings me into what is the oncology nurse's role? I know that several people listening are nurses, and so we know how to be a nurse as far as being at the bedside and performing assessments. But it's so much more than that; and, fortunately, the role of nursing is so vast in that we're able to really expand upon it and make our role what we can to best support patients and caregivers. Obviously, we're going to be here for direct patient care with symptom management and physical needs, whether it be nausea medication or anything like that. And then typically what we need to do is we need to collaborate with physicians. We need to work with our social workers and our support personnel to really address what the patient and caregivers' needs are and coordinate the care to make it as streamlined as possible.

I know many, many patients get very overwhelmed and need support through the whole process of why is this test taking so long, and how do I make this fit in? And that's where we can come in is just filling in the gaps and being there for them.

It's difficult to say that there is a big difference in acute blood cancer education and support versus chronic, but I will say the difference is typically with acute cancer, patients are thrust into this disease pretty quickly and then ultimately have to make a decision very quickly. And so, it's a high stress, high pressure environment for them. And so being there and being on your game and knowing the information that they're looking for and how to support them is going to be the best thing for them.

And just knowing that just because they have an acute cancer doesn't mean they're not going to live with this for a while. You know, we may be able to get them into remission and then, ultimately, they may have an issue and relapse; and so, we're going to have to build the relationship to continue long term. And also looking into what Kristin can do and how Kristin can move it forward as well.

**Kristin Scheeler, MSW**




Yes, so we social workers are typically taught to operate within a person and environment ecological model with practice, so I included Bronfenbrenner's bioecological model here for you to just look at as you think about how to assess and intervene with a person experiencing an acute blood cancer diagnosis. Like Laura said, it's an intense, stressful time for people. So, you'll do your assessment of each new patient's psychosocial situation, including distress screening as appropriate and as indicated by your institution.

You'll definitely want to provide information about applying for Social Security disability, especially for people who have a disease that's on the Compassionate Allowance list, so especially acute leukemia, for instance, or if the person will be undergoing hematopoietic stem cell transplantation. They should definitely be educated about applying for Social Security disability if they're eligible. You'll be providing some emotional support and brief counseling. I think it's important to understand the biology, treatments, adherence issues and side-effect management issues so that you can help the person prepare for the future in terms of healthy behaviors like taking medications on time and managing any important life activities that might be affected by having a serious illness.

You'll also want to try to understand how having this cancer diagnosis, this acute cancer diagnosis impacts somebody's work activities and childcare, volunteer activities, family activities that you can help them navigate those things if they need to make some plans. You may be providing fertility preservation information and education, and I try never to assume based on how old somebody looks or how many children it appears that they have that someone would not want that information. So, I always try to offer fertility preservation information or the opportunity to be educated that way if somebody wants it.

You also may need to educate about sexual health and make referrals to sexual health providers and therapists as needed. You'll facilitate family meetings as needed, assess advanced care planning needs and assist with creating advanced care plan documents if people need them and want them.

You'll provide support to a cancer caregiver. The cancer caregiver can often get overlooked but is often experiencing very high levels of distress and stress, sometimes even higher than the patient themselves because there's sometimes just so little that they can do to kind of control the situation and help the person that they love. And it's really hard to watch somebody that you love suffer, so the cancer caregiver cannot be overlooked in an acute blood cancer situation when a social worker is trying to help.

And you also will connect to spiritual guidance and then refer to resources like housing, transportation, insurance, billing, quality of life resources. And sometimes you won't have a lot of time to perform all of these activities, so you might need to work with the patient to prioritize your assistance to them, and you might not have a lot of time to help someone prepare for something like a bone marrow transplant or CAR T-cell therapy or for a long hospital stay, especially if that person is traveling from a long distance to you. So you might work over the phone or you might also just take time to prepare a routine assessment that you use with everybody that only takes maybe a half an hour or an hour to go through with every patient to help identify and prioritize needs quickly when you first meet them so that you can best help them in a short period of time if that's all that you have.

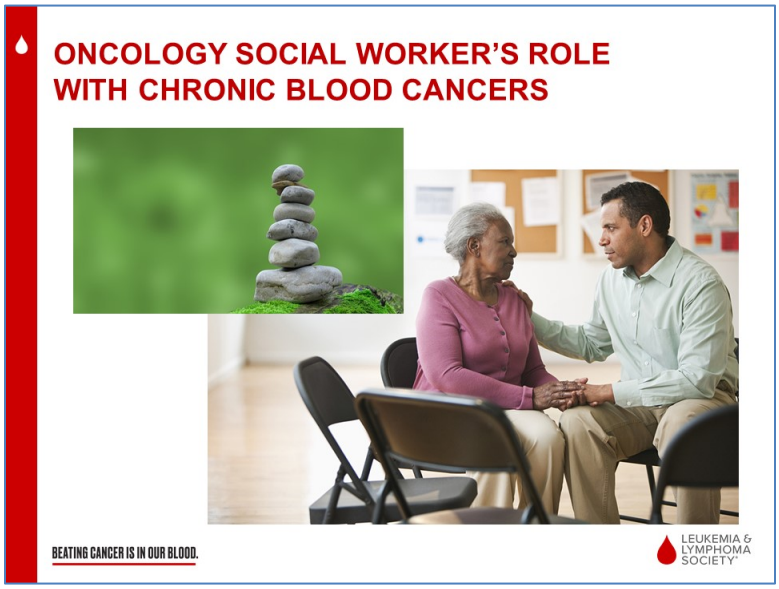
**Laura Romundstad, CRNP, MSN, RN**


And so as far as the oncology nurses' role and chronic blood cancers, as I mentioned, we are moving forward with our therapies, and patients are living longer and longer. I like to view some of these chronic cancers; and as Kristin said, it's not a disease that they will die of, but they will die with, just like with high blood pressure or diabetes. It's something that as long as they are managed appropriately with patient compliance and adherence, patients have the ability to live long, relatively normal lives with checking in with their physicians and being monitored.

And so, the support comes as far as giving them the knowledge to know that and the power to be an advocate for their health. I feel strongly that that is one of our nursing roles is to really encourage

them to be a proponent for their health and take their lives into their own hands because they're the main one responsible. Again, it comes down to assessing their support system and knowing who is in their corner and educating them as well; and, you know, the fear of the unknown is where a lot of these patients get hung up in not wanting to move forward or take care of themselves. And so, just educating them about what can they expect, what should they expect and kind of how the rest of their journey may look is very important.

**Kristin Scheeler, MSW**




So, then a social worker's role with people living with chronic blood cancers would incorporate all the things that we would do for somebody with acute blood cancers; but they might just look at little bit different in working with someone with a chronic blood cancer in that we might have some more time, in that one major thing that I come across in my work as an Information Specialist with people with chronic blood cancers is they can be feeling very anxious, partly because a lot of those patients are the ones who are on watch-and-wait protocol; and that's why sometimes it's kind of jokingly called watch and worry because you know you have cancer, but you're not getting to receive a treatment right now. That's very anxiety-producing, no matter who you are. So, you as a social worker maybe help identify tools for management of anxiety, meditation or relaxation resources, or referral to psychotherapy or counseling. Or you yourself may have the ability to do some counseling in your institution.

We also may do some education about behavioral strategies to manage symptoms or side effects like depression or fatigue or chemo brain or concentration issues, nausea, or pain. If you don't have the time to do that or the expertise to do that, a wonderful referral that you can make is to a health or a cancer psychologist. They have not only access to psychotherapy skills but to additional behavioral strategies for managing symptoms and side effects, and our psychologist partners are just wonderfully and uniquely trained to help people in that way.

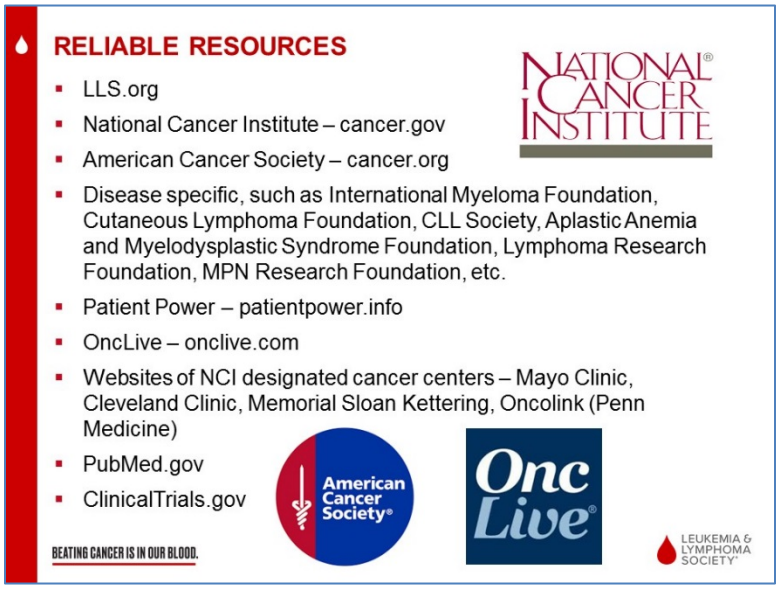
## TRANSCRIPT

You might help people adjust to disease as chronic and possibly incurable, so helping them to adjust to that. You may help people reframe their life goals as needed or appropriate. You may help assess work or childcare accommodation needs, so you might also incorporate referrals to Cancer and Careers, to the Job Accommodation Network, or to resources available at Triage Cancer to help people understand their rights and understand their needs in terms of their work or childcare. You may help people with family planning or sexuality discussions.

You will hopefully have ongoing advanced care planning discussions because advanced care planning is really meant to be done over a number of conversations over a longer period of time. As we age and grow and our understanding of our health changes, our wishes for our healthcare may change. So advanced care planning discussions ideally are not a one-time occurrence but are an ongoing discussion.

And then we'll refer people to resources as needed. There just might be more time to work with people, to identify long-term resources to help them cope. People might live for 10, 20 or more years after a chronic blood cancer diagnosis or really any blood cancer diagnosis potentially. But they might face some physical, emotional, or mental challenges that they did not face prior to their diagnosis that you can help them with.

You typically have time to revisit old discussions and check in with people as they adjust to their illness and their new needs given their diagnosis, so I would encourage social workers whenever possible to consider a longer-term relationship with those with chronic blood cancers or long-term survivors of blood cancers, especially if you're an outpatient social worker and you have the time and you can check in with people when they come in for their outpatient appointment.



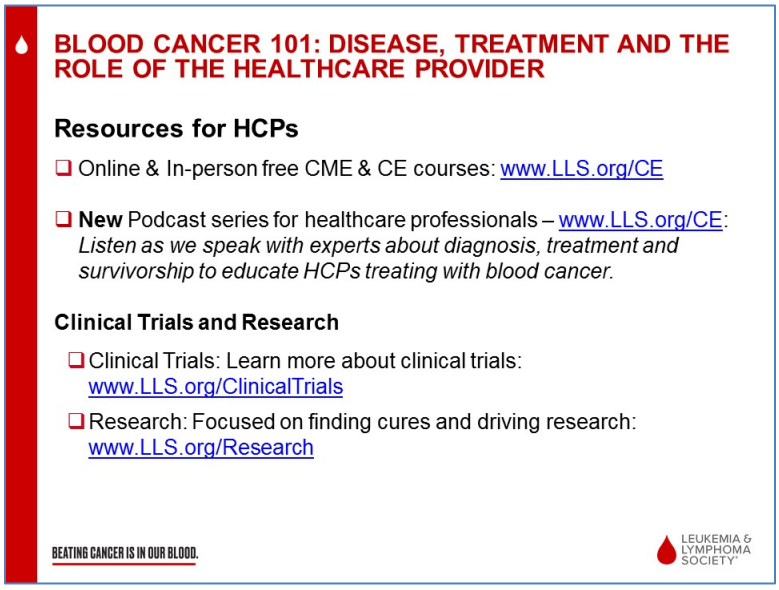

Just a little note about reliable resources. There's so much erroneous and sometimes damaging information on the Internet that we would encourage you to teach your patients and ensure that you yourself use reliable sources of information. So, using studies that you find at pubmed.gov or information from The Leukemia & Lymphoma Society, American Cancer Society, National Cancer

Institute, American Society of Hematology, reputable large academic medical centers, or the disease-specific foundations like the International Myeloma Foundation or the CLL Society or the MPN (myeloproliferative neoplasm) Research Foundation. We would suggest that you use those sorts of materials to help people get reliable and helpful information.

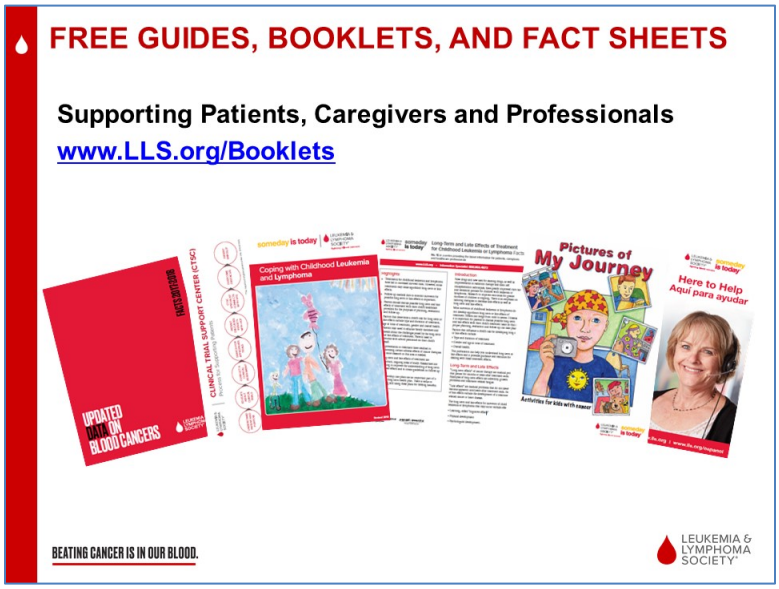
An example of how you can tell materials are reliable and helpful is sort of the process that we use at The Leukemia & Lymphoma Society. All of our educational materials are reviewed or written by a medical or professional content expert whose name, place of practice, and credentials are cited somewhere in every piece of our patient education. So, I would encourage you to look for that sort of information when you're trying to find reliable information.

And that concludes our portion of this presentation today. Thank you so much for listening.

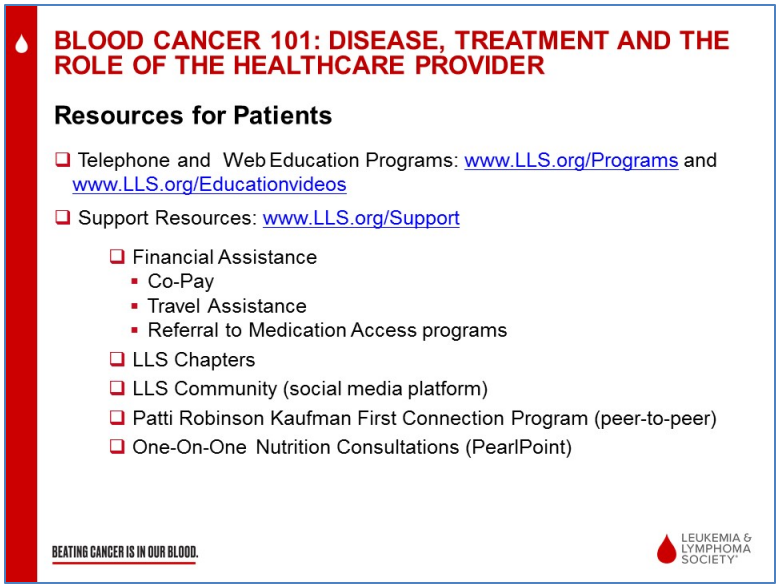
**Caroline Kornhauser, MSW**




Thank you very much, Laura and Kristin, for such a clear and informative presentation. I am now pleased to share free resources for you and your patients. Visit The Leukemia & Lymphoma Society website to access Web-based and in-person programs offering free CME and CE credit, our new podcast series for healthcare professionals with new topics added each month and information on research. Please visit www.LLS.org/CE for more information on CE programs.

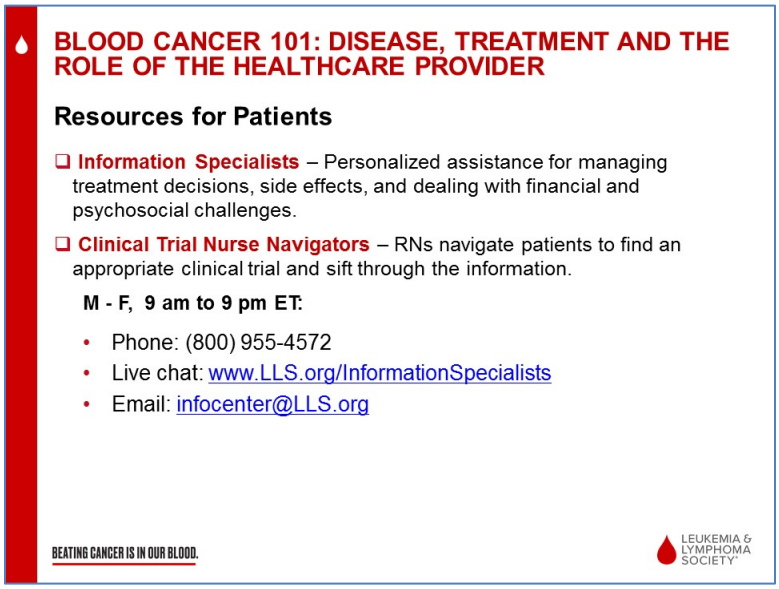



LLS offers blood cancer disease-specific information including booklets, telephone/Web education programs and videos and podcasts for patients and their caregivers.




LLS Information Specialists who are oncology social workers, nurses and health educators provide patients and their caregivers with personalized assistance for managing treatment decisions and side effects as well as dealing with financial and psychosocial challenges. Our registered nurses with expertise in blood cancers work one on one with patients via telephone to find appropriate clinical trials, assist through the clinical trial process, and help patients develop questions to ask their own healthcare team.

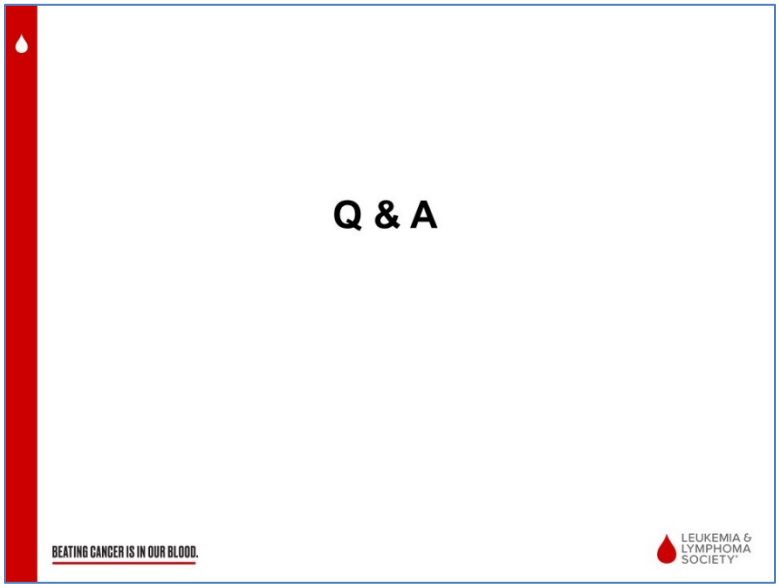
## TRANSCRIPT




All of these Specialists, as well as booklets and online programs for patients and healthcare professionals, can serve as additional resources to your healthcare team. To refer your patients, use the contact information provided on this slide. You can also order booklets from LLS at no charge to give to your patients, or they can access these resources directly from the LLS website.

## QUESTION-AND-ANSWER SESSION

**Caroline Kornhauser, MSW**




It is now time for the question-and-answer portion of our program. We will take the first question and Pamela asks, “Is targeted therapy not chemotherapy?” Laura, would you describe the difference between these two therapies.

**Laura Romundstad, CRNP, MSN, RN**

Yes, absolutely. So, you may often have a patient come to you and say they are receiving chemotherapy, and it may actually per se be a targeted therapy, and it’s not incorrect. Targeted therapy is just simply not a traditional form of chemotherapy in that the targeted therapy is not going to be killing healthy cells that are also dividing. What if the targeted therapy is more specific in that it’s only targeting those cancer cells that we want to through a certain pathway. So, it’s not wrong to say that it’s chemotherapy and I, typically when I’m talking to my patients, just talk to them about their chemo or their pills or whatever they’re taking. But overall there’s just a different mechanism.

**Caroline Kornhauser, MSW**

Great, thank you. Our next question is from Nina, and Nina asks, “Can diet help a patient going through treatment or in remission, and can you speak more about nutrition services LLS offers?”

**Laura Romundstad, CRNP, MSN, RN**

I will say that diet can absolutely help a patient going through this therapy. I think diet is something that can be very individualized, and so there's not necessarily one diet per se for every patient with ALL. I think there's many different things that go into that, but there are resources at LLS to discuss that. And we have nutrition consults, and I'll let Kristin speak to that further.

**Kristin Scheeler, MSW, APSW, OSW-C**

Yes, so if people want to call our Information Resource Center at 800-955-4572, we can connect them to a free consultation with a registered dietitian through our partners at PearlPoint. You can also find it on our website at LLS.org under our Nutrition Consultation area. But, yes, we have free consultations with a registered dietitian that people can use if they are unable to otherwise access a registered dietitian or want that opinion from somebody else.

**Caroline Kornhauser, MSW**

Thank you. And our next question is from Jill, and Jill asks, "Could you talk a little more about the different forms of stem cell transplant? What is the time course of that? For example, how long are people usually unable to work if they go through different kinds of BMTs (bone marrow transplants)? What level of caregiving support and in-home practical support needs to be available upon release from the hospital? And from a social worker's standpoint, what should we be most aware of during that time?"

**Laura Romundstad, CRNP, MSN, RN**

The different forms of stem cell transplant are an autologous stem cell transplant. It's used in certain diseases, and that would be determined by the physician. We most commonly see it with multiple myeloma. It's when a patient receives their own stem cells back. So, what you do is they receive a kind of preparative chemotherapy, they're hooked to the apheresis machine, the stem cells are filtered out and the rest of their blood is given back.

The timeframe of that varies, depending on multiple different things. Is their disease in remission? Do they have a good overall performance status and a lot of different things? Typically, it can take anywhere from just a handful of months. That one tends to be overall less time intensive, and the road to recovery is less. Now every case is different, so I say that with an asterisk because everybody responds differently.

There's also allogeneic or donor transplant, and cord blood transplant. They are a more lengthy process because, again, there's different variabilities that go in as far as where is their donor, how readily available are they in lining things up. The other thing you have to think about is time slots for these apheresis machines. I know a lot of institutions face issues with that.

The goal of doing this is, as of right now, still in first remission, there tends to be, you know, there's different data; and every patient decides differently. But you want to get to transplant more quickly if possible because the patient is going to be exposed to less chemotherapy, and their disease would typically be more refractory.

The length of time for that one, I believe the patients are still typically staying in the hospital around a month, give or take. And then depending on how far they live from the institution, they're being told that they have to be within a certain distance or at least 100 days or like right at three months. And the frequency of appointments after a stem cell transplant, it is very patient-specific, but it depends on how they're doing and how lab work is showing and multiple different things.

**Kristin Scheeler, MSW, APSW, OSW-C**
And I just want to say I generally always told people to expect at least around six months or so of recovery from an autologous transplant and around a year from an allogeneic transplant with, again, that asterisk of you may have complications and it may take longer or some people it takes less time. But those are really general timeframes.

The level of caregiving support and in-home practical support varies also. Most people come out of the hospital able to get themselves to the restroom and take their own shower and do their own self-care. So, it's not like you're doing a lot of personal hands-on care for people. But what you're doing, what a caregiver should expect to do is they're going to probably be doing all the home care, like cleaning the house and mowing the lawn and shoveling the driveway if you get snow and doing the grocery shopping and all of that kind of stuff. And making sure the patient gets enough water and, at least, gets their meals made for them and medication reminders. And then if there are children in the picture, the caregiver may end up doing a lot of the childcare too.

So, there's a lot for the caregiver to do, and they need to be there and available to take the patient to the clinic or hospital if they develop a complication that's important to be seen for at the hospital. Some people do need to kind of go to the hospital on sort of an emergency basis after they come home from a transplant, so that's why they want a caregiver to be available 24/7, at least at first. And that varies as to how long someone needs a 24/7 caregiver, so that's something people should discuss with the physician who's treating them.

But from a social work standpoint, those are the things I'd be aware of is the extra tasks that the caregiver's being asked to do and just kind of be looking at their whole, the person and environment, and what is everything that they're responsible for in their life that they will now be taking on in addition to what they already were doing in their life so that the caregiver gets the help that they need. The patient mostly will need encouragement and to follow up with their doctor as prescribed.

**Caroline Kornhauser, MSW**

Thank you. Our next question comes from Teresa, and she wants to know "if LLS offers the same type of support resources and distress screening and resources for MDS to preleukemia patients?"

**Kristin Scheeler, MSW, APSW, OSW-C**

So, yes, our services are absolutely available to MDS patients. They can use our educational materials as they wish. We have our Patti Robinson Kaufmann First Connection Program where they can talk to a peer support person. We have the Clinical Trials Support Center available to them, the free nutrition consultation, the podcasts, all the services absolutely are available to MDS patients.

**Caroline Kornhauser, MSW**

And as a follow-up to that, Kristin, you just mentioned the First Connection match program. Leslie asks, "I work with many non-native, English-speaking patients. Where can I find printed information about blood cancers in other languages, and can you find a First Connection to someone who speaks a different language?"

**Kristin Scheeler, MSW, APSW, OSW-C**

So, the answer to that is sometimes we can find somebody who speaks a different language for a First Connection match. Usually we can find somebody who speaks Spanish. Sometimes we can find somebody who speaks another language. We can look if you ask. Sometimes we don't have somebody, a volunteer in the First Connection Program who is able to speak the language that your patient speaks.

If you're looking for materials, printed materials with different languages, you can go to our website at LLS.org; and when you click on our Information Booklets page, you can actually filter by language; and we have several languages in that filter that you can choose from and you can see which materials are available for download or order in different languages.

**Caroline Kornhauser, MSW**

Thank you. Our next question is about clinical trials, and Dawn wants to know "if you can discuss more about blood cancer clinical trials and will the patient be getting a placebo if they go into a clinical trial?"

**Laura Romundstad, CRNP, MSN, RN**

So, yes, clinical trials in general, there are many out there for all of the blood cancers. Each trial is specific to the institution and the drugs that are being discovered. A lot of patients have that concern of will I be receiving a placebo; and while there are a few trials with placebo, it is very well known to the patient that they would have the option of receiving a placebo.

Typically, in trials with placebo, the patient is only going to receive a placebo pill if there is not an approved standard of care therapy which could be given in that case. And a patient is never going to receive less than what is known to be effective, and so I don't want patients to think that they're going to be told that they're getting treatment when they're really not because that's not the case. There are a few placebos that are used in combination with a therapy that's working. It's based on how the trial is built and designed but something that they would know up front.

**Caroline Kornhauser, MSW**

And our last question is from Jasmine, and she wants to know "if she can troubleshoot a situation with a blood cancer patient with an Information Specialist."

**Kristin Scheeler, MSW, APSW, OSW-C**

Yes, we're happy always to talk to healthcare providers about situations that they're encountering with their patients. We can do some research if we need to and get back to you, but we're happy to talk to you to troubleshoot your situation, yes.

**Caroline Kornhauser, MSW**

Well thank you very much, Jasmine, for that question; and thank you to the audience for all of your questions today. And, again, thank you to Laura and Kristin for your continued dedication to patients and fellow healthcare professionals.

## CLOSING REMARKS

**Caroline Kornhauser, MSW**


So, this concludes our program for today. I would like to thank you all for participating. We hope the information presented will be useful in your work with patients and families. Thank you.