



CLL SOCIETY

Webinar Transcript

Treatment for CLL: When is the Right Time to Start?

June 3, 2024

In science and medicine, information is constantly changing and may become out-of-date as new data emerge. All articles and interviews are informational only, should never be considered medical advice, and should never be acted on without review with your health care team.

This text is based off a computer-generated transcript and has been compiled and edited. However, it will not accurately capture everything that was said on the webinar. The complete recording of this webinar is available on-demand.

00:09:58.000 --> 00:10:08.000

Hello and welcome to today's webinar. I am Robyn Brumble, a registered nurse and CLL Society's Director of Scientific Affairs and Research.

00:10:08.000 --> 00:10:19.000

At CLL Society, we are dedicated to bringing incredible and up-to-date information to the CLL and SLL community because we believe smart patients get smart care.

00:10:19.000 --> 00:10:28.000

As a reminder, you can rewatch all of our educational programs by going to the section of our website called Education on Demand.

00:10:28.000 --> 00:10:39.000

Prior to beginning, we would like to mention a few pre-event items. All attendees in this webinar are muted and the only people on camera are speakers.

00:10:39.000 --> 00:10:46.000

We ask you to please direct all questions to the Q&A section displayed at the bottom of the screen.

00:10:46.000 --> 00:10:55.000

Questions will be sent directly to our moderator, speakers, and CLL Society staff. And are not visible to the audience.

00:10:55.000 --> 00:11:03.000

After today's event, you will receive a very brief survey that will help us plan for future events.

00:11:03.000 --> 00:11:21.000

We greatly appreciate your feedback. This session will be recorded and made available to everyone on our website. Close captions are available if you want to turn them on or off go to the captions and select show captions or hide captions.

00:11:28.000 --> 00:11:39.000

This program was made possible through support from both our donors and our industry partners. At this time, I would like to introduce our moderator.

00:11:39.000 --> 00:11:45.000



CLL SOCIETY

Thank you. Thank you, Robyn. I would like to welcome our audience to today's event.

00:11:45.000 --> 00:11:57.000

I am CLL patient advocate Stephen Feldman, member of CLL Society's Patient Advisory Board, a senior support group advisor, and co-facilitator of the City of Hope Support Group.

00:11:57.000 --> 00:12:08.000

We are joined today by Laura Zitella, nurse practitioner with the hematology, blood and marrow transplant and cellular therapies programs at UCSF,...

00:12:08.000 --> 00:12:16.000

Helen Diller Family Comprehensive Cancer Center. She is also a clinical assistant professor in the Department of Physiological Nursing...

00:12:16.000 --> 00:12:29.000

at the University of California, San Francisco. We will be answering audience questions at the end of this event, so please take advantage of this opportunity and ask your questions in the Q&A box.

00:12:29.000 --> 00:12:37.000

I'd now like to welcome Laura Zitella.

00:12:37.000 --> 00:12:55.000

Welcome to the CLL Society webinar "Treatment for CLL: when is the right time to start?" My name is Laura Zitella and I'm a nurse practitioner in hematology at the University of California at San Francisco and I'm delighted to join you today.

00:12:55.000 --> 00:13:12.000

So let's start by talking about what is CLL and SLL. This is actually the most common adult leukemia and it's a cancer of B lymphocytes which results in ongoing growth and accumulation of the normal B lymphocytes.

00:13:12.000 --> 00:13:20.000

So what are B lymphocytes? B lymphocytes are a special type of white blood cell that help protect you from infection.

00:13:20.000 --> 00:13:30.000

And under normal circumstances, you have trillions of different types of B lymphocytes because each one can fight one type of infection.

00:13:30.000 --> 00:13:40.000

So, you need to have trillions of unique and different B cells to protect you from any infection that you might encounter.

00:13:40.000 --> 00:14:00.000

And what happens under normal conditions, is when an infection or germ enters your body, those B lymphocytes, the one B lymphocyte that matches that infection, will copy itself and make an entire army of itself to help treat that infection.

00:14:00.000 --> 00:14:14.000



CLL SOCIETY

And once the infection is treated, then those B cells die off and they suffer with just a couple that remain as memory cells.

00:14:14.000 --> 00:14:26.000

So, what happens with CLL and SLL is that something goes wrong inside the cell and it starts making copies of itself when it doesn't need to...

00:14:26.000 --> 00:14:34.000

so there's an abnormal growth and these cells also live longer than they should and so it accumulates.

00:14:34.000 --> 00:14:40.000

And the area where these cells accumulate is in the peripheral blood, so in your blood,...

00:14:40.000 --> 00:14:51.000

the spleen which is an organ right under your left rib cage, the lymph nodes and in the bone marrow.

00:14:51.000 --> 00:15:07.000

So, CLL and SLL are the same type of cancer, but we call it CLL when most of the cancer cells are found in the blood in the bone marrow, and we call it SLL when the cancer cells are mainly in the lymph nodes and spleen.

00:15:07.000 --> 00:15:21.000

Now that being said, people who have CLL can also have large lymph nodes. So that's one of the things that we look out for and I wanted to show you where lymph nodes are located in the body.

00:15:21.000 --> 00:15:29.000

Lymph nodes are in almost all areas of your body, the ones you can feel the best are here in your neck...

00:15:29.000 --> 00:15:36.000

but you have lymph nodes that are in the chest, lymph nodes in the abdomen, lymph nodes in the arms and in the legs.

00:15:36.000 --> 00:15:46.000

And these lymph nodes are all connected by lymph vessels and lymph vessels are sort of like veins and arteries but they carry fluid...

00:15:46.000 --> 00:15:55.000

and I like to think of it as the lymph nodes are filtering station.

00:15:55.000 --> 00:16:03.000

So as fluid travels throughout your body, if there are any microbes or any germs,...

00:16:03.000 --> 00:16:22.000

because you've acquired an infection, those lymph nodes sort of dot the lymphatic vessels and act as filtering stations so that the B lymphocytes can respond and make an army of itself to fight an infection.



CLL SOCIETY

00:16:22.000 --> 00:16:33.000

So, I wanted to show you where lymph nodes are located. Because one of the things that you look for when you have CLL or SLL is if you're developing swollen lymph nodes.

00:16:33.000 --> 00:16:41.000

And these pictures here show some of the places in the neck and under the chin where you can get swollen lymph nodes.

00:16:41.000 --> 00:16:42.000

And the picture here, shows a man who has a swollen lymph node that's actually not very large.

00:16:42.000 --> 00:16:55.000

It's noticeable but that size of lymph node would not necessarily need to be treated.

00:16:55.000 --> 00:17:04.000

So how do we diagnose CLL or SLL? Well, most of you watching this probably already have the diagnosis...

00:17:04.000 --> 00:17:10.000

and so you might know that most people don't have any symptoms at all when they're first diagnosed.

00:17:10.000 --> 00:17:21.000

Usually what happens is you go and you see your health care provider and they draw a sample of blood and they notice that the white blood cell count is elevated...

00:17:21.000 --> 00:17:30.000

and then there's another, there's a total white blood cell count in the CBC and then there's also...

00:17:30.000 --> 00:17:46.000

a breakdown of neutrophils and lymphocytes and CLL SLL is a cancer of the lymphocytes and so you'll see the total white blood cell count the elevated as well as the absolute lymphocyte count.

00:17:46.000 --> 00:17:59.000

So, the diagnosis is usually by peripheral blood. This is the most common. And when your healthcare provider notices that you have an elevated white blood cell count, they'll send another special blood test...

00:17:59.000 --> 00:18:21.000

called flow cytometry. And flow cytometry can look for certain proteins on the cell surface and can identify a group of cells that all look alike and have the same combination of proteins on the outside of the cell and that identifies it as CLL.

00:18:21.000 --> 00:18:35.000

Now in other cases, other biopsies may be done; for example, if there is a swollen lymph node, to make a diagnosis of SLL.

00:18:35.000 --> 00:18:47.000

There's also a test called a bone marrow biopsy where we look in the bone marrow and take a sample of the bone marrow to look for CLL or SLL.



00:18:47.000 --> 00:18:57.000

But a bone marrow biopsy is not needed to make the diagnosis so this is not done for every patient.

00:18:57.000 --> 00:19:12.000

So, CLL does not need to be treated right away. In fact, CLL is unlike many other cancers because it grows very slowly and some people might never need any treatment at all.

00:19:12.000 --> 00:19:26.000

And most people won't need any treatment for months to years after they're diagnosed. A lot of studies have been done trying to understand CLL, trying to figure out the best treatment and one of the multiple studies done have been looking at what happens if you start treatment early.

00:19:26.000 --> 00:19:39.000

You start treatment right when someone is diagnosed. And what we've learned is that it does not.

00:19:39.000 --> 00:19:50.000

It does not lengthen the amount of time that you live with CLL. So starting treatment early does not prolong life.

00:19:50.000 --> 00:20:03.000

And in fact, depending on the treatment, if you start treatment, you can have some unwanted side effects related to the treatment for the CLL.

00:20:03.000 --> 00:20:20.000

So, the general approach to CLL is not to start treatment unless you have symptoms that are affecting your life or affecting any function of your organs like your bone marrow or your kidneys or your liver.

00:20:20.000 --> 00:20:21.000

So, if there are no symptoms and you feel well, it's really better to avoid taking a medication that might have side effects...

00:20:21.000 --> 00:20:34.000

or be costly or be inconvenient having to take pills every day or coming into the clinic.

00:20:34.000 --> 00:20:50.000

Another important factor is that there might be better treatments in the future. I have been working in hematology for 30 years and I've seen amazing advances in medicine and the treatments that we have for today.

00:20:50.000 --> 00:21:07.000

We didn't have those when I first started working with people who have CLL so I expect that we're going to continue to do research and there will be even better treatments in the future.

00:21:07.000 --> 00:21:12.000

So when you're first diagnosed, if you're not going to start treatment, then what do you do?

00:21:12.000 --> 00:21:25.000



CLL SOCIETY

We call it active surveillance. So, we're actively monitoring the disease. We're actively discussing your symptoms with you...

00:21:25.000 --> 00:21:34.000

and we're actively watching the labs. So active surveillance is the period of time after you're diagnosed but before any treatment is needed...

00:21:34.000 --> 00:21:43.000

or after you have a treatment, is the period of time after treatment, when you're not on any treatment at all and we're monitoring things.

00:21:43.000 --> 00:22:11.000

So, what this looks like is routine visits with your health care provider and depending on your situation, you and your healthcare provider will decide how often you need to have those visits; sometimes it's every month sometimes it's every three months. And what you do with these visits is your health care provider is going to do a physical exam, paying particular attention to the lymph nodes and to the spleen, because those are places that can...

00:22:11.000 --> 00:22:19.000

be involved with CLL, a review of symptoms, so how you're feeling, and looking at lab tests. You might be wondering, is there anything I can do during active surveillance?

00:22:19.000 --> 00:22:44.000

Well, there are a lot of things that you can do. One of the more important things is to stay up to date on your vaccinations and the reason that is important is because CLL causes your immune system to not function one hundred percent.

00:22:44.000 --> 00:22:45.000

So, there's some level of immunocompromise, meaning that you can get infections more easily.

00:22:45.000 --> 00:22:58.000

So, any vaccines that you're eligible for are good because they'll help prevent infection. Some other things you can do is make sure you're living a healthy lifestyle.

00:22:58.000 --> 00:23:11.000

Regular exercise is important. Getting at least 150 minutes of moderate exercise every week with some strength training.

00:23:11.000 --> 00:23:20.000

Eating a whole food diet, meaning eating foods that are natural and are real foods and minimizing processed foods.

00:23:22.000 --> 00:23:30.000

Maintaining your emotional health. This is very, very important. And we'll talk about some of the ways that you can do that.

00:23:30.000 --> 00:23:46.000

Avoid smoking. Another thing is checking vitamin D. There is some early research looking at the relationship between vitamin D and overall survival in CLL.



CLL SOCIETY

00:23:46.000 --> 00:24:00.000

And it looks like if your vitamin D level is low, you would benefit from taking a vitamin D supplement to replace that low vitamin D.

00:24:00.000 --> 00:24:04.000

And then you can also talk to your health care provider about clinical trials and see if there are any clinical trials that are available.

00:24:04.000 --> 00:24:17.000

There are some trials now looking at starting treatment for CLL earlier because the treatments that we have are more effective...

00:24:17.000 --> 00:24:28.000

than the chemotherapy that we used to use, CLL. So that might be something that you're interested in.

00:24:28.000 --> 00:24:49.000

How will my healthcare provider determine when it's time to start treatment? Well, this is a really big question and we start talking about the possible treatment options right at the beginning so that you have time to think about it, ask all of your questions, and when the time comes, you feel you're prepared.

00:24:49.000 --> 00:24:50.000

But we really don't have to start any treatment unless you have symptoms that interfere with your daily life.

00:24:50.000 --> 00:25:10.000

So, for example, if you have severe fatigue, not that, you know, you're tired a lot, but severe fatigue that disrupts your daily activities and makes it hard to do your daily activities.

00:25:10.000 --> 00:25:21.000

If there are drenching night sweats where you're waking up and the bedsheets and your bed clothes are soaked through and through and this happens every night for more than a month.

00:25:21.000 --> 00:25:28.000

If you start losing weight, even though you're not trying and you lose at least 10% of your body weight over six months.

00:25:28.000 --> 00:25:43.000

If you start having fevers and there is no infection. Some of those symptoms, these are constitutional symptoms, that are related to CLL and that warrant treatment.

00:25:43.000 --> 00:25:52.000

Other findings would be an enlarged liver, an enlarged spleen, or very enlarged lymph nodes.

00:25:52.000 --> 00:26:00.000

So not the size of the lymph nodes that I showed you in that picture earlier, but much larger than that.

00:26:00.000 --> 00:26:12.000



We also look at the laboratory tests if the absolute lymphocyte count is rising quickly, like for example, if it doubles over a period of six months...

00:26:12.000 --> 00:26:25.000

that might be the time to talk about starting treatment or if the CLL is causing you to become anemic and you have a low hemoglobin level or a low platelet level.

00:26:25.000 --> 00:26:35.000

Platelets are the cells that help your blood clot and so having a low platelet level puts you at a little bit higher risk of bleeding.

00:26:35.000 --> 00:26:42.000

So, when we see the platelet count drop, that is the time to start talking about treatment.

00:26:42.000 --> 00:26:59.000

If you start developing repeated or prolonged infections, that is a sign that the CLL is affecting your immune system's ability to protect you from infection and that can improve when you start treatment.

00:26:59.000 --> 00:27:18.000

And then lastly, you can get autoimmune cytopenia so what that means is that you have an antibody against your red blood cells or against your platelets and it's causing a low hemoglobin...

00:27:18.000 --> 00:27:32.000

or a low plate count. You don't necessarily have to start CLL treatment for that because we can treat that with steroids or a medication called rituximab...

00:27:32.000 --> 00:27:49.000

so if those treatments work for you, you don't need to necessarily treat the CLL but if they don't, then treating the CLL will help correct autoimmune low blood counts.

00:27:49.000 --> 00:28:04.000

But I really want to make the important point here that the relationship between you and your health care provider is really a partnership...

00:28:04.000 --> 00:28:22.000

and deciding when it's time to start treatment is going to happen in collaboration with you. So, shared decision-making is a partnership with your health care provider where we help you understand all of the available treatments...

00:28:22.000 --> 00:28:32.000

and we give you the benefit of our experience, we give you advice, we talk about the likely benefit and we talk about the potential side effects.

00:28:32.000 --> 00:28:42.000

But you help us understand what matters most to you. We want to know what your preferences are. We want to work with you to select the best course of action.

00:28:42.000 --> 00:28:57.000

So, it's always a discussion and it's always a partnership. So, for example, if you are feeling fatigue and you're talking about well, is it time to start therapy for CLL now because I'm feeling tired?



00:28:57.000 --> 00:29:13.000

It's hard to, fatigue is a very common thing to feel and there are a lot of reasons to feel fatigued like, for example, if you have a low thyroid level, that could be an explanation for it.

00:29:13.000 --> 00:29:22.000

So, your health care provider will run some tests and determine if the fatigue is due to some other corruptible condition or if it's due to the CLL...

00:29:22.000 --> 00:29:30.000

and then you can work together to decide if it's time to start treatment.

00:29:30.000 --> 00:29:39.000

I really like this graphic because the whole point of shared decision-making is combining perspectives,...

00:29:39.000 --> 00:29:42.000

so the health care providers perspective and your perspective. And we can help you by teaching you about the guidelines,...

00:29:42.000 --> 00:29:56.000

what treatments are recommended to start with, what treatments are recommended if the CLL has already been treated and now has recurred again.

00:29:56.000 --> 00:30:12.000

We can give you the benefit of our experience working with many people like you. We can talk about the clinical research and what the goal of therapy is.

00:30:12.000 --> 00:30:23.000

But we want to hear from you about your lifestyle, what treatment is going to fit in, how can you live as long as possible and as well as possible with CLL.

00:30:23.000 --> 00:30:34.000

We want to know about your values and your preferences and what resources you have. How able you are to come into the clinic frequently...

00:30:34.000 --> 00:30:40.000

and your personal goals for treatment.

00:30:40.000 --> 00:30:49.000

So, all of these play a very important role in determining which treatment to start with when you are ready to start treatment.

00:30:49.000 --> 00:30:55.000

There are the two most common treatments for first line therapy for CLL are BTK inhibitors, which are pills that are taken indefinitely,...

00:30:55.000 --> 00:31:16.000

so you take these pills every day and you continue until the pills don't work anymore and when people choose this option, it often works for many years, 7, 8, 9, 10 years.



00:31:16.000 --> 00:31:24.000

They're very, very effective medications, but it does mean taking pills for an extended period of time.

00:31:24.000 --> 00:31:31.000

Another option is venetoclax and obinutuzumab and venetoclax is a pill...

00:31:31.000 --> 00:31:43.000

and Obinutuzumab is an IV infusion. It's a monoclonal antibody that attaches to a protein on the CLL cell to destroy it.

00:31:43.000 --> 00:31:52.000

And this treatment requires many more visits to the clinic because you have to get the IV infusions.

00:31:52.000 --> 00:31:58.000

The obinutuzumab infusions are given,. initially they're given a little bit more often...

00:31:58.000 --> 00:32:08.000

during the first month, but after that, monthly for six months and the venetoclax....

00:32:08.000 --> 00:32:16.000

pills are given for a year. So, this is what we call a time defined therapy, where you're on...

00:32:16.000 --> 00:32:27.000

therapy for one year, but then you're off therapy for a period of time. And that period of time usually lasts for several years.

00:32:27.000 --> 00:32:43.000

So, when we talk about these treatment options, some of the things to think about when you put together your list of questions as you're getting ready for your appointment with your health care provider is what kind of response do you think I'm going to get from this treatment?

00:32:43.000 --> 00:32:53.000

What is the benefit? How long do you think the CLL will be in remission if I do option A or why do option B?

00:32:53.000 --> 00:33:00.000

And then what are the potential side effects? Like what are the things I might experience that I will have to manage?

00:33:00.000 --> 00:33:17.000

It could be something like a rash or diarrhea, headache and we have a lot of things that we can do to help manage side effects because the goal is for you to feel as well as possible while you're on this therapy and living well with CLL.

00:33:17.000 --> 00:33:25.000

And then the logistics, as I mentioned, the venetoclax and obinutuzumab means that you have to get some IV infusions.

00:33:25.000 --> 00:33:35.000



CLL SOCIETY

So do you live close to the infusion center or is it two or three hours away? And logistically, what is going to fit in your lifestyle?

00:33:35.000 --> 00:33:43.000

Convenience is an issue. Some people might find that it's more convenient to take pills to treat their CLL.

00:33:43.000 --> 00:34:00.000

And then cost, unfortunately, is something we always have to consider. There's not only the cost of the medication, but the cost of taking time off work, the cost of driving to the clinic, or maybe even having to stay in a hotel close to where the clinic is.

00:34:00.000 --> 00:34:08.000

So, there's a lot of considerations depending on your situation.

00:34:08.000 --> 00:34:19.000

Can anything be done to improve my symptoms? So, this is assuming that you're not on any therapy at all.

00:34:19.000 --> 00:34:31.000

And I think it's really important during the time of active surveillance that you consider keeping a symptom journal because that will help you recognize any patterns in how you're feeling.

00:34:31.000 --> 00:34:40.000

It's also really important that you let your healthcare provider know if your lymph nodes are suddenly getting bigger quicker.

00:34:40.000 --> 00:35:03.000

If you start having worsening fatigue that's disrupting your daily activity, if you're feeling short of breath, if you have a decreased appetite or when you eat, you feel like you get full really easily because sometimes that can be a sign that the spleen is getting enlarged because the spleen is under the left side of the rib cage and when it gets big it can kind of press...

00:35:03.000 --> 00:35:11.000

on the stomach and when you eat, that makes you feel full easily. If you have any new pain anywhere,...

00:35:11.000 --> 00:35:24.000

if you have persistent fevers, even though you don't have an infection, if you start getting frequent infections or if you've drenching night sweats.

00:35:24.000 --> 00:35:33.000

What is cancer related fatigue? It's the physical and emotional exhaustion that's related to CLL or its treatment.

00:35:33.000 --> 00:35:38.000

And this is not just being tired. It's not the type of tiredness that improves with rest or sleep.

00:35:38.000 --> 00:35:46.000

It's a lack of energy that doesn't improve with rest or sleep and it limits your usual activities.



CLL SOCIETY

00:35:46.000 --> 00:35:57.000

So what can you do? Well, you can exercise, you can be in nature, you should have a healthy balanced diet.

00:35:57.000 --> 00:36:14.000

You should conserve your energy by prioritizing what's important to you and making sure that you schedule those things during a time of the day where you have the most energy.

00:36:14.000 --> 00:36:19.000

Sleep hygiene is really important. We're going to talk about that on the next slide.

00:36:19.000 --> 00:36:33.000

I think it's also really important to learn to accept help so that you have the energy to do the things that you want to do, but you allow people to help you with things that they can take some of the burden off.

00:36:33.000 --> 00:36:42.000

And then lastly, relaxation techniques can be really helpful to manage cancer related fatigue.

00:36:42.000 --> 00:36:50.000

So, sleep hygiene, sleep hygiene is a very big issue. Many of us have sleeping difficulties.

00:36:50.000 --> 00:37:05.000

And so, some of the pro tips for helping improve your sleep quality is to try to go to bed and wake up at the same time every day, even on the weekends and holidays.

00:37:05.000 --> 00:37:20.000

Getting into a consistent pattern really helps. Also, avoid taking naps if you can. And if you do take a nap, it should be a short nap of 30 minutes or less and avoid taking naps after 3 pm...

00:37:20.000 --> 00:37:27.000

because you don't want to lose that drive to go to sleep when it's bedtime.

00:37:27.000 --> 00:37:36.000

Sometimes it helps if you take a warm shower or bath about an hour and a half before you go to bed, a hot bath will raise your body temperature...

00:37:36.000 --> 00:37:49.000

but then after you get out of the bath your body temperature will drop and that drop in body temperature can help signal that it's time to go to sleep.

00:37:49.000 --> 00:37:52.000

Keeping your bedroom cool, dark and gadget and TV free. You really shouldn't do anything in your bedroom except for sleep...

00:37:52.000 --> 00:38:11.000

and have sexual relations. So, we don't want people watching TV or playing with their phone because that really impairs the ability to fall asleep.



CLL SOCIETY

00:38:11.000 --> 00:38:27.000

Limiting caffeine after 12 pm can help. Avoiding exercise within 6 hours of bedtime and establishing a relaxation routine when it's time to go to sleep.

00:38:27.000 --> 00:38:33.000

So some of the relaxation techniques that might be helpful for you. But one of the best ones is...

00:38:33.000 --> 00:38:46.000

imply breathing. Breathing can really calm your nervous system and induce a state of relaxation and there's many, many types of breathing techniques.

00:38:46.000 --> 00:38:55.000

One of them is belly breathing, which is simple. You just take long, slow, deep breaths and your abdomen rises and falls while you're breathing.

00:38:55.000 --> 00:39:04.000

Another one is called 4-7-8 breathing where you inhale for 4 seconds, hold your breath for 7 seconds and exhale for 8 seconds.

00:39:04.000 --> 00:39:19.000

A body scan can be helpful and that is where you lay quietly and focus on one part of your body or group of muscles at a time and then mentally release any physical tension that you feel there.

00:39:19.000 --> 00:39:29.000

Guided imagery can be really helpful. This is where you think about soothing scenes, places, or experiences that help you relax and focus.

00:39:29.000 --> 00:39:43.000

Mindfulness meditation. This is a relaxation technique where you focus on what you're feeling in the moment and when your thoughts drift, you just keep bringing your thoughts back to focus on the present moment.

00:39:43.000 --> 00:40:00.000

Other things that can be helpful are yoga, tai chi, qigong, and you may have some other relaxation techniques that work well for you.

00:40:00.000 --> 00:40:13.000

Now typically, lymph nodes are not painful but if you do develop painful lymph nodes, you should let your healthcare provider know and sometimes using warm compresses or resting helps.

00:40:13.000 --> 00:40:24.000

Acetaminophen is also an option after you discuss with your health care provider to make sure that that's an appropriate medication for you.

00:40:24.000 --> 00:40:28.000

Weight loss related to lack of appetite. If you're struggling with a lack of appetite, it's really helpful to eat small frequent meals.

00:40:28.000 --> 00:40:41.000

It's hard to eat a lot of food in one sitting when you don't have an appetite.



00:40:41.000 --> 00:40:49.000

So, you can get in the calories that you need by eating small frequent meals, like every two to three hours.

00:40:49.000 --> 00:40:50.000

It also helps to eat food that's high in protein and healthy fats and so I've listed some ideas here.

00:40:50.000 --> 00:41:04.000

Nuts, seeds, trail mix, and nut butters are excellent sources of calories and protein and healthy fats.

00:41:04.000 --> 00:41:11.000

Full fat Greek yogurt or full fat cottage cheese. Beans, bean dips and hummus.

00:41:11.000 --> 00:41:19.000

Avocado or guacamole. Oats or granola, eggs and fatty fish.

00:41:19.000 --> 00:41:37.000

And these are just some suggestions. There's lots of other good ideas too. And if you are struggling, you could also ask for a referral to a dietician who could help with additional eating hints.

00:41:37.000 --> 00:42:07.000

Night sweats. If you're having night sweats, make sure...

00:42:11.000 --> 00:42:18.000

that you're bedding is lightweight. It can help to have fans or a cool, well-ventilated room.

00:42:18.000 --> 00:42:33.000

You can consider taking a shower before bed because, the same as we mentioned earlier, a shower will initially increase your body temperature but when you get out of the shower there will be a drop in your body temperature and that can help.

00:42:33.000 --> 00:42:56.000

Consider a cool gel pillow. Practice relaxation techniques to promote calmness and reduce stress, avoid stimulating activities or screen time close to bedtime and try to stay really well-hydrated throughout the day and maintain a healthy weight.

00:42:56.000 --> 00:43:09.000

So, in summary, CLL is not like many other cancers because it grows very slowly. And some people may never need treatment and most people will not need treatment for months to years.

00:43:09.000 --> 00:43:19.000

Your health care provider is a partner in your care and together you will decide when to start treatment and which treatment is best for you.

00:43:19.000 --> 00:43:31.000

People with CLL have increased risk of infection and it's important to protect yourself by staying up-to-date on immunizations.

00:43:31.000 --> 00:43:43.000



CLL SOCIETY

The CLL Society has a lot of really helpful information and these are some links to some of the content that we talked about today.

00:43:43.000 --> 00:43:44.000

Thank you.

00:43:44.000 --> 00:43:45.000

That was an excellent patient friendly presentation on this important and often confusing topic so thank you very much, Laura.

00:43:45.000 --> 00:43:47.000

Okay, we're going to begin answering audience questions and try to get to as many as possible. Unfortunately, due to the time constraint, we're not likely...

00:43:47.000 --> 00:43:59.000

to be able to get to every question. So please, email our ask the expert at the email address after this event and we will share that email address on our closing slide.

00:43:59.000 --> 00:44:06.000

Here we go with question number one. When is the right time to begin treatment when on watch and wait?

00:44:06.000 --> 00:44:14.000

And just a reminder to our audience that watch and wait is synonymous with active surveillance.

00:44:14.000 --> 00:44:32.000

Hi Stephen, it's so nice to be here this morning with everyone. So as we talked about in the presentation, there are some guidelines that have been put together on when is the best time to start treatment but those guidelines vary a little bit and we really take into account...

00:44:32.000 --> 00:44:49.000

the individual person. So, I saw in some of the chats of people asking about like a certain white blood cell count.

00:44:49.000 --> 00:45:05.000

For example, a certain white blood cell count does not indicate that you need to start treatment. You can have a white blood cell count of 60,000 or 100,000 or 150,000 and you might not need to start treatment, just based on the white blood cell count, if you don't have any other symptoms.

00:45:05.000 --> 00:45:06.000

So really what would be an indication to start treatment is if the CLL is making you feel bad...

00:45:06.000 --> 00:45:16.000

in some way, if it is determined that it's the CLL is making you feel bad in some way,...

00:45:16.000 --> 00:45:18.000

if it is determined that it's the CLL that's responsible for really severe fatigue or drenching night sweats where you wake up every single night...

00:45:18.000 --> 00:45:35.000



CLL SOCIETY

and you have to change your bed clothes, your sheets, persistent fevers, if the CLL is causing anemia or a low platelet count...

00:45:35.000 --> 00:45:44.000

if you have a really large spleen that maybe it is pressing on your stomach, making you feel full easily, or really large lymph nodes.

00:45:44.000 --> 00:45:58.000

And the guidelines, like for example, say that, you know, your lymph node should be at least 10 centimeters if you have enlarged lymph nodes.

00:45:58.000 --> 00:46:09.000

that's really big, that's like the size of a grapefruit. So, mildly enlarged lymph nodes aren't necessarily an indication to start treatment either.

00:46:09.000 --> 00:46:22.000

So really, I think what's important is that you feel comfortable with your health care team and you're able to have these discussions with them and talk about what is best for you.

00:46:22.000 --> 00:46:28.000

Great, thank you. I'm going to try and combine the next three questions because they're kind of similar.

00:46:28.000 --> 00:46:35.000

So, if you can discuss again the pros and cons of starting treatment early when you're on active surveillance.

00:46:35.000 --> 00:46:46.000

And might high risk CLL patients benefit by starting treatment early? And then lastly, is there a criteria for determining a tipping point...

00:46:46.000 --> 00:46:52.000

in symptoms when they've arrived that would signal time to start treatment?

00:46:52.000 --> 00:47:04.000

Well, it's important to keep in mind that CLL behaves differently in different people and most of the time CLL is very slow growing.

00:47:04.000 --> 00:47:18.000

And so, it's something that you can live with and if it's not causing you any symptoms, it doesn't make sense to start treatment because the treatments can potentially have side effects that we've talked about.

00:47:18.000 --> 00:47:31.000

And it's sort of, like if it isn't broke, you know, why fix it type of thing where if you're not having symptoms why treat something that's not causing you any problems.

00:47:31.000 --> 00:47:45.000

Now, in other situations, the CLL is a little bit more aggressive and so it is causing symptoms or it's growing more rapidly.



00:47:45.000 --> 00:47:58.000

And in those situations, it would be good to start treatment. Because if the CLL is making you feel bad, then the treatment should make you feel better by treating the CLL.

00:47:58.000 --> 00:48:05.000

Great. You know, we often hear that CLL and SLL are the same disease, essentially.

00:48:05.000 --> 00:48:06.000

Yeah.

00:48:06.000 --> 00:48:16.000

One person writes in asking, are the treatment recommendations, are they the same or different regardless of whether you have CLL or SLL?

00:48:16.000 --> 00:48:29.000

Yes, they are the same treatment recommendations with one exception. Some people have CLL that is only involving one lymph node area.

00:48:29.000 --> 00:48:36.000

And if that is the only spot, like the only lymph nodes that are involved, is just this one place,...

00:48:36.000 --> 00:48:48.000

you could potentially, receive radiation therapy. And, but that's only used if the CLL is limited to one lymph node area... *[note: this point was corrected to be related to SLL, not CLL at time stamp: 1:14:21.000]*

00:48:48.000 --> 00:48:51.000

otherwise, the treatment recommendations are the same.

00:48:51.000 --> 00:49:00.000

Thank you. Many if not all CLL'ers experience enlarged lymph nodes as a feature of the disease.

00:49:00.000 --> 00:49:07.000

The degree of enlargement varies and not all enlarged lymph nodes are conspicuous from the outside, like the picture you showed.

00:49:07.000 --> 00:49:17.000

At what point do new and or enlarged lymph nodes suggest that it's time to begin treatment?

00:49:17.000 --> 00:49:30.000

So as I just mentioned, the guidelines say that lymph nodes, treatment of lymph nodes that are more than 10 centimeters, which is about the size of a grapefruit.

00:49:30.000 --> 00:49:38.000

So, that's pretty big and if your lymph nodes are getting that big in your neck, it's probably becoming uncomfortable.

00:49:38.000 --> 00:49:45.000



CLL SOCIETY

And so, you might even, you and your health care provider might even decide that you need treatment sooner than that.

00:49:45.000 --> 00:49:51.000

In..

00:49:51.000 --> 00:50:01.000

some lymph nodes are conspicuous and some are not and if there is any concern that you might have enlarged lymph nodes that you can't see...

00:50:01.000 --> 00:50:11.000

sometimes we will order a CT scan so that we can see if there's any enlarged lymph nodes in other parts of the body.

00:50:11.000 --> 00:50:22.000

I probably would not do that unless there were symptoms, like there was pain somewhere or there was an abnormal laboratory test like for example if the creatinine or kidney function was abnormal.

00:50:22.000 --> 00:50:32.000

I would, I might, want to get a CT scan to check and make sure there weren't any lymph nodes in the abdomen that were affecting the kidney function.

00:50:32.000 --> 00:50:41.000

So, I would probably only order imaging if there are symptoms.

00:50:41.000 --> 00:50:48.000

Can patients request getting an MRI instead of a CT scan?

00:50:48.000 --> 00:51:07.000

They could. I'm not sure why. Sometimes we would do an MRI if someone had kidney problems and the CT scan had contrast in it.

00:51:07.000 --> 00:51:22.000

We would want to avoid that. But I would probably order a PET scan if there were kidney problems instead of a CT scan.

00:51:22.000 --> 00:51:36.000

MRI, we may order if we were concerned about like central nervous system involvement or if there's another specific reason, but generally the best imaging is a CT scan or PET scan.

00:51:36.000 --> 00:51:40.000

Great, thank you. Alright, I'm going to try and combine a bunch of questions in this next...

00:51:40.000 --> 00:51:51.000

round. Many patients are understandably apprehensive about starting or remaining on treatment for extended periods over concerns of the potential side effects.

00:51:51.000 --> 00:52:00.000

Side effects are also referred to as adverse events caused by the medications. How have the side effect profiles of the targeted treatments...



00:52:00.000 --> 00:52:14.000

improved over time? And one person, this is more specific, one person wrote in that they've experienced a full body rash and was wondering whether it might be caused from taking Calquence, which is also called acalabrutinib,...

00:52:14.000 --> 00:52:18.000

a type of BTKi, Bruton's tyrosine kinase inhibitor.

00:52:18.000 --> 00:52:25.000

I know that's a mouthful. The questioner notes a fear of going back on Calquence owing to possible side effects.

00:52:25.000 --> 00:52:31.000

Would you suggest they discuss with their doctors switching to a different BTKi?

00:52:31.000 --> 00:52:40.000

Oh, these are great questions. The So I'll look at the BTK inhibitors.

00:52:40.000 --> 00:53:00.000

The first one that was approved is ibrutinib, and now we have acalabrutinib and we have zanubrutinib and we have pirtobrutinib and with every generation of BTK inhibitors, we're seeing fewer and fewer side effects because they're more and more targeted for CLL.

00:53:00.000 --> 00:53:08.000

So in general, there are fewer side effects with acalabrutinib and zanubrutinib than there are with ibrutinib so that's one part of the answer.

00:53:08.000 --> 00:53:20.000

The other part of the answer is that we also have now a lot of experience in managing the side effects.

00:53:20.000 --> 00:53:30.000

And what we've learned is that dose reductions or holding the medication for a week or two to let the symptoms...

00:53:30.000 --> 00:53:37.000

resolve is very, very effective. And most of the time, that side effect will go away.

00:53:37.000 --> 00:53:46.000

And then we can restart the medication either at the same dose or at a reduced dose and most of the time that side effect does not come back.

00:53:46.000 --> 00:53:54.000

So, we've looked at how people do taking the BTK inhibitors over a long period of time.

00:53:54.000 --> 00:54:13.000

And what we've seen is that people who have dose reductions because of side effects or have to hold the dose for a little bit because of side effects are generally able to restart it without having recurrence of those side effects...



00:54:13.000 --> 00:54:21.000

and they have similar overall survival. So they live as long as people who don't require dose reduction.

00:54:21.000 --> 00:54:28.000

But, they live much longer than people who have to stop the BTK inhibitors completely.

00:54:28.000 --> 00:54:43.000

So for someone who has a really bad side effect like this full body rash, I mean without knowing how bad it was or seeing it, I can certainly understand being fearful of restarting it.

00:54:43.000 --> 00:54:54.000

But it, depending on the situation, it may be worth starting it again and seeing if it happens again.

00:54:54.000 --> 00:55:05.000

And if it happens again, then stop or consider changing to zanubrutinib and either option is reasonable to discuss with your health care provider.

00:55:05.000 --> 00:55:13.000

Great, thank you. Here's a question that comes up pretty frequently. Under what circumstances should someone seek out a second opinion?

00:55:13.000 --> 00:55:19.000

And what's the best way of going about that?

00:55:19.000 --> 00:55:32.000

I think that, so the initial treatment of, there are a couple of reasons, a couple of reasons you might want to seek a second opinion.

00:55:32.000 --> 00:55:41.000

You may just want a second opinion because you want the reassurance that you've explored every option...

00:55:41.000 --> 00:55:50.000

so that would be one thing. Another reason to get a second opinion is if the CLL doesn't respond as you would expect to the initial therapy.

00:55:50.000 --> 00:56:00.000

So usually with these initial therapies we see the CLL in remission for 6, 7, 8 years.

00:56:00.000 --> 00:56:12.000

If your CLL, if you have already been treated and your CLL comes back in a short period of time, that might indicate that it's just a little bit more aggressive and you might want a second opinion for that.

00:56:12.000 --> 00:56:27.000

If you've had all of the standard therapies and you're interested in exploring clinical trials or if you need a specialized therapy like CAR-T therapy at a specialized center, those are other reasons to get a second opinion.



CLL SOCIETY

00:56:27.000 --> 00:56:53.000

So to get a second opinion, you could go to an academic medical center where you see a hematologist that specializes specifically in CLL rather than a general cancer doctor or you can go to the CLL Society where they offer a second opinion with a CLL expert that works with the CLL Society.

00:56:53.000 --> 00:57:20.000

And on the website, well, we'll put the link in there for the website but that is an option that the CLL Society offers that's a free review of your medical records and a video meeting for 30 min with a CLL expert to discuss your case.

00:57:20.000 --> 00:57:29.000

Right. You know, one of the things that's confounding for patients sometimes is if they get different opinions from two different oncologists.

00:57:29.000 --> 00:57:34.000

I don't know if we can address that a little bit, but that can be a source of confusion.

00:57:34.000 --> 00:57:47.000

I mean, maybe you can expand a little bit more about the distinction between a CLL expert, you know, versus the local community oncologist or hematologist.

00:57:47.000 --> 00:57:51.000

What makes a CLL expert an expert?

00:57:51.000 --> 00:57:55.000

That's a great question. So, a community oncologist treats all different types of cancers,,,

00:57:55.000 --> 00:58:15.000

so knows a lot about a lot of different cancers, but a CLL expert specializes in CLL so that means instead of seeing maybe you know, 5 or 10 people who have CLL per year...

00:58:15.000 --> 00:58:22.000

we're seeing, you know, 5 or 10 a week, people who have CLL.

00:58:22.000 --> 00:58:37.000

And the CLL expert really, usually also does research and so is involved with some of the clinical trials and has experience with new and upcoming medications.

00:58:37.000 --> 00:58:45.000

And I'll add that many CLL patients have both a local hematologist and a CLL expert on their team...

00:58:45.000 --> 00:58:51.000

so you don't necessarily have to rule out one or the other, having both is ideal.

00:58:51.000 --> 00:59:18.000

I think that's a really good point. I mean, I work at an academic medical center and I work very closely with a lot of physicians and other health care providers in the community and I would personally, I would want my health care provider to feel comfortable and collegial with other health care providers.



00:59:18.000 --> 00:59:27.000

And so I hope that you don't feel like, you know, we would be offended if you wanted to get a second opinion or...

00:59:27.000 --> 00:59:36.000

that we wouldn't be willing to work with somebody. Because most of us...

00:59:36.000 --> 00:59:47.000

do and should, like I'm in constant contact with other health care providers who, you know, we share the care...

00:59:47.000 --> 00:59:49.000

with.

00:59:49.000 --> 00:59:57.000

Thank you. We have a question regarding testing. What are the routine blood tests that patients should receive?

00:59:57.000 --> 01:00:08.000

What is the role of flow cytometry, which you discussed? And when should patients receive this and what is the importance of testing before treating?

01:00:08.000 --> 01:00:14.000

Okay, there's a lot to unpack there. Now, first of all, flow cytometry is the first test that you do when you see an elevated...

01:00:14.000 --> 01:00:27.000

absolute lymphocyte count. So I mentioned that in, in a complete blood count, you'll get a total white blood cell count...

01:00:27.000 --> 01:00:35.000

and then that total white blood cell count is broken down into neutrophils and lymphocytes and basophils and eosinophils...

01:00:35.000 --> 01:00:42.000

so all the different types of different white blood cells. And you want to look specifically at the absolute lymphocyte count...

01:00:42.000 --> 01:00:53.000

and if the absolute lymphocyte count is elevated, you want to know if that is because you have an infection or if it is...

01:00:53.000 --> 01:01:13.000

a malignancy like CLL. So the flow cytometry is done on the peripheral blood and it can identify whether or not there's a population of cells that have specific markers on it that indicate that you have CLL, so that's done at diagnosis.

01:01:13.000 --> 01:01:21.000

And then if you're on active surveillance, some of the blood tests...



01:01:21.000 --> 01:01:26.000

that should be done is a complete blood cell count so that's monitoring the lymphocyte level.

01:01:26.000 --> 01:01:33.000

It's also monitoring the hemoglobin to see if you're developing anemia, it's looking at platelet count and platelets are the cells that help your blood clot...

01:01:33.000 --> 01:01:42.000

so we want to make sure that that is at a normal level and that's not dropping low.

01:01:42.000 --> 01:01:55.000

We would also look at any function, liver function and LDH. And LDH is an enzyme that's found in every single cell in your body...

01:01:55.000 --> 01:02:00.000

and it's a very non-specific test. It can be elevated for a lot of different reasons.

01:02:00.000 --> 01:02:09.000

It can be elevated even with strenuous exercise, any sort of tissue damage, breakdown of cells.

01:02:09.000 --> 01:02:16.000

But in lymphoma, it can be elevated when there's a lot of lymphoma activity...

01:02:16.000 --> 01:02:25.000

so we look at LDH because it's typically normal in most people who have CLL.

01:02:25.000 --> 01:02:33.000

If it was elevated that would give us a clue that maybe the CLL is becoming much more active...

01:02:33.000 --> 01:02:49.000

or in very rare cases, CLL can transform from a low grade lymphoma slash leukemia into a higher grade aggressive lymphoma which would need to be treated differently.

01:02:49.000 --> 01:03:02.000

A related question. What information does a bone marrow biopsy provide to the treating physician that they wouldn't necessarily glean from...

01:03:02.000 --> 01:03:06.000

regular peripheral arm blood draws?

01:03:06.000 --> 01:03:16.000

Hmm, that's a good question. So if there is anemia or a low platelet count...

01:03:16.000 --> 01:03:25.000

and if there's a concern that that's not due to CLL, you could get a bone marrow biopsy because that could look for other bone marrow disorders.

01:03:25.000 --> 01:03:38.000



CLL SOCIETY

So for example, there are some bone marrow disorders called like myelodysplastic syndrome where, you are not making enough...

01:03:38.000 --> 01:03:50.000

red blood cells, you're not making enough platelets and that is a different type of...

01:03:50.000 --> 01:04:02.000

blood disorder and that is treated differently. So, a bone marrow biopsy is not generally done when there isn't any concern for other blood disorders.

01:04:02.000 --> 01:04:10.000

It's only done if there is a concern that there might be some other blood disorder.

01:04:10.000 --> 01:04:19.000

Thank you. When are drug holidays, that is temporarily stopping medication, appropriate for CLL patients?

01:04:19.000 --> 01:04:26.000

And what are the pros and cons from taking a break from CLL treatment?

01:04:26.000 --> 01:04:48.000

That is a more complicated question because it depends which treatment you're on. If you're on a BTK inhibitor, all of the research that we have done to date is that BTK inhibitors are much more effective if they're continued indefinitely.

01:04:48.000 --> 01:04:57.000

And if you stop the BTK inhibitor, that the outcomes are not as good.

01:04:57.000 --> 01:05:14.000

In contrast to that, if you're being treated with venetoclax and obinutuzumab, then you do get a treatment holiday because that is a treatment that is given for a period of one year.

01:05:14.000 --> 01:05:24.000

There are occasions though, sometimes when people have surgical procedures that might require going on a drug holiday for one of the CLL drugs.

01:05:24.000 --> 01:05:36.000

Yes, so with the BTK inhibitors, if you have any sort of procedure planned, you do need to stop the BTK inhibitor.

01:05:36.000 --> 01:05:44.000

And the reason is, it affects the way that your platelets clot, so the way your platelets clumped together.

01:05:44.000 --> 01:05:50.000

And so it increases the risk of bleeding if you stay on them when you're having a procedure.

01:05:50.000 --> 01:05:54.000

So, depending on if it's a minor procedure, ...



01:05:54.000 --> 01:05:59.000

or a major procedure. If it's minor, you hold it for three days before and after the procedure...

01:05:59.000 --> 01:06:06.000

and if it's a major surgery then you hold it for seven days before and after the procedure.

01:06:06.000 --> 01:06:18.000

Thank you. Tell us what Pemgarda is. Someone asks, do you recommend Pemgarda antibody infusion for CLL patients in watch and wait?

01:06:18.000 --> 01:06:40.000

That's a really good question. Pemgard is our antibodies against COVID and you may remember Evusheld which when COVID first, which is something that we used to have for an earlier variant of COVID...

01:06:40.000 --> 01:06:41.000

but the issue is that when you have CLL, sometimes you don't respond very well to vaccines.

01:06:41.000 --> 01:07:02.000

So the best thing to do to protect yourself against COVID is to get COVID vaccinated. But we would check antibodies and people with CLL after COVID vaccination and sometimes they didn't mount an immune response so they didn't have any antibodies even though they had the vaccine.

01:07:02.000 --> 01:07:16.000

So if the vaccine is always the most effective way to prevent COVID but if you don't develop any antibodies, then Evusheld was developed...

01:07:16.000 --> 01:07:22.000

to give you a passive way to give you antibodies to protect you against COVID.

01:07:22.000 --> 01:07:30.000

But then Evusheld went away, it was taken off the market because the COVID virus, mutated and it was no longer effective.

01:07:30.000 --> 01:07:41.000

So Evusheld is not used anymore. So Pemgarda just came out and it is thought to be effective against the current variance of COVID.

01:07:41.000 --> 01:07:49.000

And so it is recommended for people who don't have an immune response to the COVID vaccine.

01:07:49.000 --> 01:08:00.000

Although I have to say it's very hard to get. So, for example, we don't have it at UCSF right now...

01:08:00.000 --> 01:08:11.000

and one of my patients looked into it and he said the closest center he could find, from California, was in Denver, Colorado.

01:08:11.000 --> 01:08:18.000



CLL SOCIETY

So I'm not sure when we're going to get it and I don't know if anyone in the audience has any experience with it.

01:08:18.000 --> 01:08:23.000

But there have been issues in availability.

01:08:23.000 --> 01:08:31.000

Thank you. The next question, is again, about deciding when to start treatment, but it is also...

01:08:31.000 --> 01:08:49.000

inquiring about what your prognostics are, your cytogenetics. So the question is, how much weight is given when there are non-favorable markers, maybe like 17p deleted and the blood work or being unmutated for IgVH.

01:08:49.000 --> 01:09:19.000

Hmm. Those are really good questions. So first of all, before you start any treatment, it is really important to look for mutations in the immunoglobulin heavy chain and there can either be, we either classify it as unmutated or mutated and unmutated tends to have a less favorable prognosis, meaning that it's a little...

01:09:21.000 --> 01:09:31.000

bit more aggressive and it tends to recur quicker than mutated. So mutated is more favorable.

01:09:31.000 --> 01:09:37.000

And then it's also important to do FISH testing. So this is testing of the chromosomes.

01:09:37.000 --> 01:09:50.000

And there's a panel of different chromosomes that we look at that are associated with CLL and the least favorable is 17p.

01:09:50.000 --> 01:09:57.000

And then we also do. TP53 mutation testing.

01:09:57.000 --> 01:10:11.000

So these are all very important tests to have before you start any treatment. And the CLL Society has a test before you treat information page that we will make sure that you have the link too...

01:10:11.000 --> 01:10:22.000

and that has a lot of important information. So, how is that used? It's mostly used...

01:10:22.000 --> 01:10:29.000

to just get a sense of...

01:10:29.000 --> 01:10:46.000

how long the treatment is going to work for you. Because the available treatments that we have, work equally well.

01:10:46.000 --> 01:10:56.000

I guess what I'm trying to say is that we wouldn't necessarily recommend a BTK inhibitor versus venetoclax and obinutuzumab based on any of those...



01:10:56.000 --> 01:11:26.000

genetic features. Now that being said earlier you mentioned that when you talk to different experts, you get different opinions and that's true in all areas of medicine.

01:11:32.000 --> 01:11:40.000

Not a hard and fast rule and not all CLL experts feel that way.

01:11:40.000 --> 01:11:44.000

So there's an art to it, not just the science.

01:11:44.000 --> 01:11:46.000

Exactly.

01:11:46.000 --> 01:12:01.000

Here's an interesting question. Somebody wants to know how to distinguish between menopause symptoms and CLL symptoms, specifically hot flashes during the day and night sweats.

01:12:01.000 --> 01:12:10.000

Yeah, that can be really hard. So, with hot flashes, usually you have more...

01:12:10.000 --> 01:12:20.000

flushing and dizziness and it happens during the day...

01:12:20.000 --> 01:12:30.000

instead of just at night. So that can be, that can be challenging to to make the distinction.

01:12:30.000 --> 01:12:44.000

Someone writes, are there statistics on the recurrences of CLL if after treatment, and they mentioned chemo, if it's been declared in remission?

01:12:44.000 --> 01:12:55.000

Yes, there are statistics. I mean, generally with the BTK inhibitors or venetoclax and obinutuzumab....

01:12:55.000 --> 01:13:07.000

the average time, until the CLL recurs again is about 6 to 7 years.

01:13:07.000 --> 01:13:32.000

And I think I saw in some of the other questions, I had made a comment during my presentation that our goal is that people live as long as possible and as well as possible with CLL and someone was asking if that means that CLL is fatal or incurable.

01:13:32.000 --> 01:13:48.000

CLL is considered to be incurable with the very rare exceptions of doing an allogenic bone marrow transplant which is not typically necessary and not typically done in CLL.

01:13:48.000 --> 01:14:00.000

It is done in certain situations, but it's not usual.



CLL SOCIETY

01:14:00.000 --> 01:14:14.000

So, yes, it is incurable, but it's generally not fatal and most people will live with it without dying from CLL.

01:14:14.000 --> 01:14:21.000

That being said, unfortunately, sometimes it is fatal for some people, but most of the time it is not.

01:14:21.000 --> 01:14:35.000

And then one other correction Liza just brought my attention is I said that localized radiation could be used for lymph nodes for CLL, but I meant to say SLL.

01:14:35.000 --> 01:14:44.000

And that's true. I meant to say SLL. So, a localized lymph node if you have CLL is not treated with radiation.

01:14:44.000 --> 01:14:48.000

I meant to say SLL.

01:14:48.000 --> 01:14:58.000

Thank you for that. Somebody is asking something that's a little bit on the slightly nerdy side about, you know, the EVOLVE study.

01:14:58.000 --> 01:15:05.000

So not everyone's going to know what that is. And the question is if early intervention is not usually warranted, why the EVOLVE study?

01:15:05.000 --> 01:15:13.000

So I guess you're going to have to start by telling us what the EVOLVE study is.

01:15:13.000 --> 01:15:17.000

Okay.

01:15:17.000 --> 01:15:25.000

I'm going to have to see what the EVOLVE study is. Oh, venetoclax and obinutuzumab.

01:15:25.000 --> 01:15:33.000

Okay. So, there are a couple of studies that are looking at...

01:15:33.000 --> 01:15:45.000

early intervention. So, I mentioned that at this point with all the research that we've done, there is no benefit to starting treatment early before you have symptoms.

01:15:45.000 --> 01:15:58.000

But all of the contemporary treatments, the BTK inhibitors, venetoclax and obinutuzumab, they have all been only approved in...

01:15:58.000 --> 01:16:23.000

the last five to 10 years. So, a lot of the information that we have about starting treatment comes from a time when we used chemotherapy like chlorambucil or other types of treatment and so there



CLL SOCIETY

are clinical trials looking at using this contemporary type of medications which are more effective to see if...

01:16:23.000 --> 01:16:28.000

if starting treatment early improves overall survival, so it improves how long you live or improves how long...

01:16:28.000 --> 01:16:41.000

the CLL is in remission. So we don't know the answer to that and that's why we're doing clinical trials...

01:16:41.000 --> 01:16:44.000

is to find out the answer. And so if that's something of interest to you, then I would highly encourage you to enroll in a clinical trial.

01:16:44.000 --> 01:17:07.000

And maybe we'll learn that starting treatment earlier is better, but maybe we'll learn that even with our new medications that work so well, starting treatment earlier, doesn't improve outcomes.

01:17:07.000 --> 01:17:14.000

Thank you. You mentioned in your presentation about vitamin D, the importance of vitamin D.

01:17:14.000 --> 01:17:27.000

Someone writes in, how much vitamin D is recommended for a 53 year old female? And I know that there's not a consensus on how much vitamin D...

01:17:27.000 --> 01:17:34.000

and even if it's efficacy, if you read the news, there's often some confusing information about that.

01:17:34.000 --> 01:17:38.000

So, take it away on vitamin D.

01:17:38.000 --> 01:17:54.000

Oh my gosh, that is a really hard question to answer so I can only offer my opinion. There is a lot of conflicting research on vitamin D and it's important to think about cause...

01:17:54.000 --> 01:18:01.000

versus correlation. So low vitamin D levels are associated with a lot of different...

01:18:01.000 --> 01:18:12.000

medical conditions. But we don't know for sure if correcting the low vitamin D...

01:18:12.000 --> 01:18:22.000

helps with those medical conditions or if it just happens to coexist with them. So, there is no...

01:18:22.000 --> 01:18:42.000

certain recommendation for how much vitamin D. a person should have. If a vitamin D level is checked and the vitamin D level is low, then it is reasonable and there's enough evidence that you should replace...



CLL SOCIETY

01:18:42.000 --> 01:18:49.000
that vitamin D with a vitamin D supplement.

01:18:49.000 --> 01:19:05.000
I think it's also important not to overcorrect vitamin D, like too little of something is not good, too much or something is not good and there's also considerations like there is in in the cardiac literature that...

01:19:05.000 --> 01:19:18.000
excess amounts of vitamin D may affect heart calcium levels which could be associated with more heart disease.

01:19:18.000 --> 01:19:32.000
So, I think it's important to not make a blanket recommendation about vitamin D, but to work with your health care provider who knows your medical history and can help you determine what's best for you.

01:19:32.000 --> 01:19:38.000
And I think that vitamin D supplementation should be based on vitamin D levels.

01:19:38.000 --> 01:19:47.000
Thank you. Okay, the next couple of questions may not be in your wheelhouse. But I think they are in everyone's mind.

01:19:47.000 --> 01:19:55.000
And the question is, are CLL treatment costs covered by insurance? And then someone mentions a little...

01:19:55.000 --> 01:20:02.000
something specific to them. Yeah, the cost is an issue. A year of treatment...

01:20:02.000 --> 01:20:14.000
protocol hospitals etc., not to mention venetoclax at \$14,000 plus a month. You know it was over half a million dollars in in one year of treatment so...

01:20:14.000 --> 01:20:21.000
costs financial toxicity. Is that something you can address?

01:20:21.000 --> 01:20:28.000
I wish I had the answer for it. It is real and it is a real issue. And it's with every single

01:20:28.000 --> 01:20:44.000
cancer medication that's approved. Yeah, it's a big issue. So, the costs are covered by insurance but there still may be co-pays.

01:20:44.000 --> 01:20:54.000
And certainly with Medicare Part D, there's the donut hole where there's the period of time where you will incur more costs...

01:20:54.000 --> 01:21:11.000



CLL SOCIETY

before there's better coverage so I think you know the CLL society has some resources. We often will work with the drug companies to help with patient assistance,...

01:21:11.000 --> 01:21:21.000

to help with some of the cost. And, yeah, I wish I had a better answer.

01:21:21.000 --> 01:21:46.000

I think cost is a very important concern. And there are some resources that we can help, but unfortunately we're not really addressing the root of the problem which is that the cost of medications in the United States is a lot.

01:21:46.000 --> 01:21:53.000

Here's something that's an easier question to answer. And it goes to blood counts.

01:21:53.000 --> 01:22:03.000

The person writes in, my white blood cell count is 40,000 plus and my ALC absolute lymphocytes are also high at 60,000 plus.

01:22:03.000 --> 01:22:11.000

Yet my oncologist still sticks to a watchful waiting period. Should I be concerned?

01:22:11.000 --> 01:22:23.000

If you don't have any other symptoms, I would not be concerned about that. I often, I have many, many...

01:22:23.000 --> 01:22:35.000

patients who have high white blood cell counts like 40,000, 60,000, 100,000 that don't require any treatment and have been stable...

01:22:35.000 --> 01:22:38.000

over many, many years.

01:22:38.000 --> 01:22:44.000

Yes, and in the CLL Society, we always say, we don't treat based on numbers...

01:22:44.000 --> 01:22:54.000

and to follow the trend. So if your trend is, you know, it's fairly steady and you have no symptoms, then it might not yet be time to start treatment.

01:22:54.000 --> 01:22:55.000

Okay, I'm going to read a couple of questions just cold. I haven't read them through.

01:22:55.000 --> 01:23:06.000

What do we risk by not ever treating CLL? How do we compare the risk to the risk of treatment?

01:23:06.000 --> 01:23:11.000

The risk of CLL versus the risk of treatment.

01:23:11.000 --> 01:23:24.000



So what do you risk by not treating the CLL.. If you're not having symptoms, then you don't risk anything by not treating CLL.

01:23:24.000 --> 01:23:33.000

If you're starting to have symptoms, then you know, you risk becoming, like it depends what the symptom is,...

01:23:33.000 --> 01:23:45.000

if you're anemic, you risk becoming more anemic or being short of breath. If your platelets are low, there's a risk of bleeding.

01:23:45.000 --> 01:23:59.000

So, if you don't treat the CLL because you don't need treatment, you're not having any symptoms, then there is no risk to you to not treat it.

01:23:59.000 --> 01:24:05.000

Yeah, I hear in that question, you know, the anxiety that many people have. I certainly had it.

01:24:05.000 --> 01:24:34.000

Prior to when I started treatment about how onerous the side effects of treatment might be. I've found in my experience and as in my role as a support group facilitator that most often people's adverse effects from the drugs are minimal and in my case I had ibrutinib and Gazyva seven years ago and I had virtually no side effects.

01:24:34.000 --> 01:24:48.000

I don't know if that's common. But I think people's anxiety about starting treatment, they may often hesitate to begin treatment because they think they're just going to be steamrolled by side effects.

01:24:48.000 --> 01:24:54.000

Yeah, I so...

01:24:54.000 --> 01:25:02.000

I think every step of the way there is a lot of anxiety. Like there's some anxiety associated with active surveillance and not doing any treatment.

01:25:02.000 --> 01:25:12.000

And then there's some anxiety associated with the idea of starting treatment and what to expect. In my experience,...

01:25:12.000 --> 01:25:19.000

most of the time side effects are very manageable. And there are many people like you,...

01:25:19.000 --> 01:25:30.000

Stephen who don't or who experience minimal side effects or no side effects when they're going through their treatment.

01:25:30.000 --> 01:25:44.000

There are other people that have some side effects, but they look back and they would do it all over again because either there were dose adjustments made or the side effects were temporary, they went away.



01:25:44.000 --> 01:25:51.000

So yes, I agree. I agree with your perspective.

01:25:51.000 --> 01:25:57.000

And a follow-up question from the, from the same, patient. Do night sweats come on suddenly and then happen every night or gradually on some nights getting more frequent?

01:25:57.000 --> 01:26:10.000

Can they happen before bed? Is there a fever associated with them?

01:26:10.000 --> 01:26:13.000

Yeah, it can be variable so they can just start every once in a while and then increase in intensity.

01:26:13.000 --> 01:26:40.000

The technical definition of night sweats is every single night and drenching so not just a little bit sweaty for a month or more so if it's consistently happening every single night for a month that those are real night sweats.

01:26:40.000 --> 01:26:51.000

If it's happening every once in a while, that might not be something, an indication that you would want to treat that.

01:26:51.000 --> 01:27:03.000

Usually, it happens at night, not before you go to bed. Usually it's something that happens during the night and it can be associated with fevers.

01:27:03.000 --> 01:27:11.000

Although, you know, fevers and drenching night sweats can also be due to infection.

01:27:11.000 --> 01:27:23.000

So, if you were having fevers and drenching night sweats, I think the first thing to do would be to see your health care provider and, you know, rule out the possibility of infection.

01:27:23.000 --> 01:27:34.000

Thank you. Next question about immunizations. The member writes, I've heard other state that vaccinations don't work well with those with CLL.

01:27:34.000 --> 01:27:41.000

I always get them but wondering if there are considerations.

01:27:41.000 --> 01:27:52.000

Yeah, vaccines don't work as well for people who have CLL, however, they work for many people that have CLL.

01:27:52.000 --> 01:28:00.000

And even if they don't work as well, as in someone who doesn't have CLL, if you get some protection from it, it's worth it.

01:28:00.000 --> 01:28:05.000



So,...

01:28:05.000 --> 01:28:21.000

we recommend that everyone stay up-to-date on all the age appropriate vaccines. Like for example, anyone over the age of 50 should have shingles vaccine; if you're over the age of 60 there's an RSV vaccine now that protects against respiratory viruses.

01:28:21.000 --> 01:28:28.000

It's important to have the pneumonia vaccine, be up-to-date on the pneumonia vaccine and your tetanus vaccine.

01:28:28.000 --> 01:28:43.000

So it is a consideration but we still recommend all the same, age appropriate vaccines as we do for people who don't have CLL.

01:28:43.000 --> 01:28:49.000

And here's a related question. As a parent, there are some live vaccines given to children.

01:28:49.000 --> 01:28:57.000

What is the recommendation from staying away from live vaccines given to loved ones?

01:28:57.000 --> 01:29:11.000

Yeah, that's a good question. If you are not on active treatment, that is probably not too much of a concern, especially.

01:29:11.000 --> 01:29:22.000

You know, because your children do need to get those vaccines but I would talk to your health care provider about that.

01:29:22.000 --> 01:29:33.000

Okay. Someone asks, would lymph massages or bouncing on a rebounder be helpful?

01:29:33.000 --> 01:29:45.000

I wouldn't expect any manipulation of the lymph system to affect CLL.

01:29:45.000 --> 01:29:54.000

Another question. Have you come across anyone taking green tea extract for CLL? My 35 year old daughter has CLL since 2020.

01:29:54.000 --> 01:30:08.000

She was 32 at the time and she takes green tea extract. How many years that person has taken green tea extract, any side effects?

01:30:08.000 --> 01:30:31.000

There's some laboratory data that that has looked at green tea extract. But that is not currently one of the recommendations and I am not familiar enough with it to be able to comment on potential side effects.

01:30:31.000 --> 01:30:37.000

Here's an interesting question. Are CLL patients more likely to get other cancers?



CLL SOCIETY

01:30:37.000 --> 01:30:40.000
And any particular ones?

01:30:40.000 --> 01:30:47.000
Yes, that's a really good question. People who have CLL are at higher risk of getting skin cancers...

01:30:47.000 --> 01:30:56.000
and so we recommend that everybody have an annual skin check by a dermatologist.

01:30:56.000 --> 01:31:03.000
Thank you. Someone writes in, would you comment further about autoimmune hemolytic anemia?

01:31:03.000 --> 01:31:10.000
I've recently heard that this occurs in 10% of watch and wait patients. Outside of a blood test,...

01:31:10.000 --> 01:31:15.000
what do I watch for on AIHA?

01:31:15.000 --> 01:31:32.000
The main way to diagnose autoimmune hemolytic anemia is by blood test looking at the hemoglobin or hematocrit level so if you develop anemia,...

01:31:32.000 --> 01:31:39.000
your healthcare provider can do some other tests to determine whether it's anemia from the CLL or if it's autoimmune hemolytic anemia.

01:31:39.000 --> 01:31:51.000
And what the difference is, is in autoimmune hemolytic anemia you actually make an antibody that latches onto the red blood cell and then your body breaks down the red blood cell.

01:31:51.000 --> 01:32:09.000
So, you're basically have antibodies that are destroying your red blood cells. And that is treated with steroids or with rituximab.

01:32:09.000 --> 01:32:23.000
And that doesn't necessarily require treatment of CLL, but it is a, a known condition in people who have CLL.

01:32:23.000 --> 01:32:29.000
Bone density testing appropriate for CLL patients?

01:32:29.000 --> 01:32:38.000
Yes, depending on your age, you should have age appropriate bone density testing.

01:32:38.000 --> 01:32:47.000
And the next question, goes back to, test before treat. And the question is, do you treat CLL differently if you have a 17p deletion?

01:32:47.000 --> 01:32:56.000



Or I'll insert myself, what treatments should you not get if you have a 17p deletion?

01:32:56.000 --> 01:33:06.000

Well, if you have a 17p deletion, you either of the two initial...

01:33:06.000 --> 01:33:07.000

treatments for CLL would be appropriate, either a BTK inhibitor or venetoclax...

01:33:07.000 --> 01:33:21.000

and obinutuzumab. And as I mentioned earlier, some CLL experts would not...

01:33:21.000 --> 01:33:34.000

recommend one over the other if there is a 17p deletion, but there are other CLL experts that think if you have a 17p deletion that it's better to stay on some sort of continuous therapy.

01:33:34.000 --> 01:33:42.000

And this is, you know, this is opinion and not everyone has that opinion.

01:33:42.000 --> 01:33:47.000

Okay, this may or may not be our last question, but we're getting close to the end.

01:33:47.000 --> 01:33:56.000

Treatment of oral meds were discussed daily until they no longer work or IV and pills for one year.

01:33:56.000 --> 01:34:07.000

What is the opinion of treatment until measurable residual disease, MRD, or other fixed duration other than the one year regimen discussed?

01:34:07.000 --> 01:34:15.000

So, I guess the question is about MRD, how do you might use that to determine when to continue or discontinue treatment?

01:34:15.000 --> 01:34:25.000

At this time, MRD is not used to determine when to continue or discontinue treatment.

01:34:25.000 --> 01:34:34.000

So, MRD is measurable residual disease or minimal residual disease. And it is a,...

01:34:34.000 --> 01:34:50.000

there's a couple of ways to measure MRD but both of the ways that you measure it, you can detect like one in 100,000 or one in a million CLL cells.

01:34:50.000 --> 01:35:01.000

So that means that the treatment was so effective that when you look in the blood, you can't, you can't even find one CLL cell in 100,000 or in a million.

01:35:01.000 --> 01:35:04.000

And...

01:35:04.000 --> 01:35:15.000



CLL SOCIETY

we think that if we get such a good response to the treatment, then that translates into the CLL staying in remission for longer.

01:35:15.000 --> 01:35:30.000

So, this is still a question that is being looked at in clinical trials and at this time, MRD is not being used to determine the length of treatment.

01:35:30.000 --> 01:35:39.000

Right. That's going to end the Q&A part. So, Laura, do you have any final thoughts that you'd like to share with our audience today?

01:35:39.000 --> 01:36:09.000

I just want to echo what the CLL Society always says, which is that it's really important for you to educate yourself and learn as much as you possibly can about the CLL and use the resources that the CLL Society has available to you, to make sure that you are making the best decisions for yourself.

01:36:12.000 --> 01:36:21.000

Great, thank you. Okay. I think that's going to, once again, we'd like to thank our generous donors...

01:36:21.000 --> 01:36:28.000

and grant support from AstraZeneca for making this event possible. Thank you, AstraZeneca.

01:36:28.000 --> 01:36:37.000

Thanks to all of you for joining us today and a big thank you to Laura for her presentation and helpful responses to our questions.

01:36:37.000 --> 01:36:53.000

Please complete our event survey and provide your feedback to help us plan for future events. A reminder, this virtual event was recorded and will be available on our website along with the slide deck and a written transcript of the webinar.

01:36:53.000 --> 01:37:02.000

If your question was not answered and we had over a hundred of them, please send it to asktheexpert@cllsociety.org.

01:37:02.000 --> 01:37:10.000

Save the date for our next virtual event, Ask me Anything with Dr. Richard Furman on July 24th.

01:37:10.000 --> 01:37:18.000

Please remember the CLL Society is invested in your long life. And you can invest in the long life of CLL society by supporting our work.

01:37:18.000 --> 01:37:27.000

Be strong, we're all in this together. And thank you for joining today.