

## **Track 2: Treatment Options**

**Narrator:** Many people with cancer, including those with CLL, have found that taking part in education sessions and support groups are quite helpful.. Support and education groups take many forms: some are designed to meet the needs of people with all kinds of cancers; others focus on one type of cancer. Some groups aim to provide information while other groups offer emotional support to their members. Some groups are led by nurses or social workers, and others are led by peers – people just like you who have CLL. You are about to hear a discussion in a group that is very much like those that take place in cancer support and education groups throughout the country. This group includes people who are diagnosed with cancer, family members and other people in their lives. As you will hear, some of this group’s members have been living with CLL for quite a while, and there are some new members too – people who have only recently found out that they have cancer. Let’s listen to the group’s discussion during this meeting.

**Nancy (Social Worker):** Hello everyone. I am Nancy, and I’m an oncology social worker at the Cancer Center. I’ve been helping with this group for several years. It’s for people with questions and concerns around the illness known as cancer. Tonight, our focus is CLL, how the diagnosis is confirmed and how it is treated. Dr. Griffin, a hematologist/oncologist at our Cancer Center, is here to help us learn about this form of cancer.

**Dr. Griffin:** Diagnosing CLL is not always simple and straightforward, and many of the signs and symptoms are common to other illnesses. Also, they often develop slowly. Sometimes a person has no symptoms and the leukemia is discovered during a routine check-up. Other times, a person may have symptoms of CLL that include tiredness, weakness, weight loss, fever, recurring infections, night sweats, shortness of breath, an enlarged spleen, and swollen lymph nodes. How are we doing? Does anyone have questions at this point? You know, if you have a question, it’s likely that others have the same question. Feel free to ask anything...

**Charlie:** I've heard it's related to chromosomes. Can I pass it to my children?

**Dr. Griffin:** You are right that chromosomes are related to CLL. Even though chromosomes are altered, CLL it is not something you pass on to your children; in other words, CLL is not inherited. Some research does point to some genetic changes that are present among first-degree relatives -- that is, parents, brothers and sisters, and children -- of people with CLL, but whether this increases relatives' risks for developing CLL is not at all clear. What causes changes in chromosomes remains a mystery. Still, studying the genes that make up chromosomes - the so-called "genetic markers" of each person with CLL - helps to make the correct diagnosis and in deciding on the best and safest form of treatment for each individual patient.

**Renee:** Why does it take so long to find out if it's CLL? I had lots of blood tests done but, for the longest time, my doctor wasn't sure what was going on.

**Dr. Griffin:** Yes, I agree that it can take a long time to get to the diagnosis. As many of you have said, signs and symptoms can relate to many other conditions. There is a step-by-step process to making the correct diagnosis that mostly involves blood tests. After the doctor or nurse practitioner completes a really good history and physical, blood tests are needed. The first blood test that is done is most often a complete blood count – the "CBC". The CBC measures the numbers and types of red and white blood cells, and platelets. A person with CLL will have higher than normal numbers of lymphocytes or white blood cell count, and may also have low red cell and platelet counts. Other blood tests are used to determine the person's overall health status – especially to check the functions of the heart, liver, and kidneys. Women of child-bearing age for whom chemotherapy might be planned, will have pregnancy testing. When they are found, CLL cells are tested with an instrument called a "flow cytometer" to confirm the connection between the high white blood cell count and CLL. . Blood testing can be used to check levels of immunoglobulins – or "immunophenotyping – to check the levels of proteins that help fight infection, and to look for Beta 2-microglobulin, a protein that CLL cells produce. People

with CLL often have low levels of immunoglobulins, which contributes to the repeated infections that are common in people with CLL.

**Dr. Griffin:** Yes, I agree that it can take a long time to get to the diagnosis. As many of you have said, signs and symptoms can relate to many other conditions. There is a step-by-step process to making the correct diagnosis that mostly involves blood tests. After the doctor or nurse practitioner completes a really good history and physical, blood tests are needed. The first blood test that is done is most often a complete blood count – the “CBC”. The CBC measures the numbers and types of blood cells, including red and white blood cells, and platelets. A person with CLL will have higher than normal numbers of lymphocytes (one of the types of white blood cells) and/or total white blood cell count, and may also have low red cell and platelet counts. Other blood tests are used to determine the person’s overall health status – especially levels of function of the heart, liver, and kidneys. Women of child-bearing age for whom chemotherapy is planned, will have pregnancy testing. When they are found, abnormal white blood cells are confirmed to be CLL cells using antibody tests – a process called “immunophenotyping – and use an instrument called a “flow cytometer.” Blood testing can be used to check levels of immunoglobulins (antibodies) to check the levels of proteins that help fight infection, and to look for Beta 2-microglobulin, a protein that CLL cells produce. People with CLL often have low levels of immunoglobulins, a factor in repeated infections that are common to people with CLL.

**Renee**

If they had done a bone marrow test sooner, would all of the other tests I’ve had been needed? And, would I have gotten my diagnosis sooner?

**Dr. Griffin**

Bone marrow tests – bone marrow aspiration and bone marrow biopsy - are often not needed to confirm the CLL diagnosis. Even so, bone marrow tests are usually done before the start of treatment and help us to assess the effects of treatment.

**Charlie**

I am scheduled to have a bone marrow aspiration and biopsy next week, but I don't know how it's done. Will I need to go to the hospital?

**Dr. Griffin**

The bone marrow aspiration and biopsy can be done safely in your hematologist's office. They are most often done at the same time: fluid from the bone marrow is removed in the aspiration, and then a tiny core of marrow is removed in the biopsy. Usually, the aspiration and biopsy is taken from the hipbone. Usually, a local anesthetic is used to numb the area because the procedure can be uncomfortable or even painful. Sometimes, sedative medications are used to limit the degree of discomfort. The results of these tests are used to help determine the stage of CLL and to devise a treatment plan. These tests are usually repeated from time to time to assess and monitor the CLL and the effects of treatment. You can find more information about the stages of CLL at The Leukemia and Lymphoma Society website (<http://www.lls.org>), and by contacting The Leukemia and Lymphoma Society call center at (800) 955-4572.