

News for People Living with Chronic Lymphocytic Leukemia

Volume 2 • Issue 1 • Fall 2009

Expert Will Share the Latest Developments in Treating CLL



Each year Dr. Susan O'Brien, an internationally recognized chronic lymphocytic leukemia (CLL) expert, attends the American Society of Hematology's (ASH) Annual Meeting. This early December meeting brings together more than 20,000 clinicians and researchers who

specialize in the treatment of leukemia, lymphoma, myeloma and other blood diseases to share their research. Dr. O'Brien explains, "Because of the large international presence at ASH, we're able to find out what is up and coming from all over the world. We really get to hear hot off the press what is new and important." Dr. O'Brien will share the news from this year's ASH meeting during a live telephone/webcast education program presented by The Leukemia & Lymphoma Society (LLS) on Thursday, December 10, 2009.

UNDERSTANDING WHEN TO WATCH AND WHEN TO TREAT Dr. O'Brien points out that some people who have CLL can be managed with observation only for years before the disease progresses. This is often called a "watch and wait" approach and consists of medical examinations and periodic testing to determine whether the disease is stable or progressing. When, or if, the disease begins to progress, active treatment is started. Dr. O'Brien explains that one of the challenges for researchers is to determine which patients are at high risk for rapidly-progressing disease, and whether treating those patients early would be beneficial. Currently, two large clinical trials are underway to look for these answers.

"It's always good to get a second opinion from a physician who specializes in treating CLL to make sure the recommended treatment is the cutting-edge best approach. It's also important to see what clinical trials are available," says Dr. O'Brien. Currently there are some 400 clinical trials worldwide to learn about new treatments and new combinations of treatments for CLL. "Clinical trials give patients access to promising drugs that aren't yet available outside of clinical trials. This is how we make progress in CLL. Almost everything we do is based on information we learned from clinical trials."

SHARING RESEARCH AND KNOWLEDGE

There is not yet a cure for CLL, and this fact makes the clinical trials that will be presented at the ASH meeting this year so important. One key study Dr. O'Brien expects will be discussed is a follow-up to a trial presented at last year's ASH meeting that showed that adding rituximab (Rituxan®) to the standard combination of fludarabine (Fludara®) and cyclophosphamide (Cytoxan®) significantly improves response rates in patients without adding major side effects. "Everyone is looking forward to hearing about further results of this study. including whether there is any effect of this combination on overall survival." Dr. O'Brien also expects to hear results of studies for ofatumumab, a promising new monoclonal antibody that targets CLL cells. Other presentations at the ASH meeting will include studies of other novel CLL drugs and studies of new combinations using approved CLL treatments, such as bendamustine (Treanda®) and alemtuzumab (Campath®). You can hear more about these developments and other important information about CLL during Dr. O'Brien's upcoming live telephone/webcast program. •

FREE UPCOMING TELEPHONE/ **WEBCAST EDUCATION PROGRAM**





New Developments in CLL from the American Society of Hematology (ASH) Annual Meeting

Date: Thursday, December 10, 2009

1:00 PM - 2:00 PM ET

Speaker: Susan O'Brien, MD **The University of Texas**

M.D. Anderson Cancer Center

NEW OPTION:

Listen to the Program From Your Computer or Telephone

Two easy ways to register: Call toll-free (866) 992-9950 (x315) or visit www.LLS.org/leukemiaeducation

Help us save mailing costs and paper. Sign up for e-mail invitations to our educational programs at www.LLS.org/email.

The Leukemia & Lymphoma Society's (LLS) *CLL Spotlight* program includes:

CLL Spotlight News* · CLL Spotlight Telephone/Webcast Education Series · First Connection · Chronic Lymphocytic Leukemia Booklet** The CLL Guide: Information for Patients and Caregivers Easy-to-Read Booklet** • Co-Pay Assistance Program**

Spotlight on Survivorship

CLL SURVIVOR FIGHTS WITH WISDOM AND WIT



Harold Goodman
has many tools that
he uses to cope
with CLL: his
humor, a positive
attitude and fighting
spirit, and the support

of his wife and best friend,

Harriette. In 1994, Harold developed a cold while on vacation in Florida with his wife and granddaughters. A month later, after a course of antibiotics, he still wasn't feeling quite right. His internist did blood work that showed his white blood cell counts were high. After further testing, Harold received the diagnosis of CLL. Only 60 years old at the time, Harold remembers, "I was shocked. I normally don't let things bother me. But the first thing I thought was, 'how is my wife going to handle this?'"

66 My attitude is, I have things to do, and I'm going to be around to do them.⁹⁹

Together, Harold and Harriette have "handled" CLL as well as other challenges. He says that his wife has been his biggest supporter, and they "left no stone unturned" as they searched for information about CLL and looked for an expert to lead his care. On his first visit to Memorial Sloan-Kettering Cancer Center in New York, Harold said to his oncologist, "Let's not fool around here. How long can I expect to live with this?" The answer was something that he has held on to throughout the years. His doctor told him, "I can give you an average, but this is not about averages, it's about you. Everyone is different, and how you do depends on your specific disease and your body." Harold says, "Now it's been almost 16 years, and I couldn't ask for anything better."

Leukemia & Lymphoma Society's (LLS) First Connection program for many years, speaking one-on-one with others who are diagnosed with CLL. His lively spirit shines through as he explains, "First and foremost I tell people that this is not a death sentence. I want people to look at me, 16 years after my diagnosis, and say, 'he's not only handsome, he's healthy and strong.'" Harold encourages others to seek a second opinion, and feels it's particularly

important to speak with a physician who

is an expert in CLL. "There are excellent

cancer centers all over the country. Any

doctor who says a second opinion isn't

necessary is not someone you should be

dealing with. I learned that myself a long

Harold has been a volunteer for The

Harold's attitude has carried him through treatments for CLL and surgery for lung cancer last year.

time ago."

When he was first diagnosed with CLL, Harold, who is a retired salesman, was still working and spent most of his days traveling throughout Long Island to visit customers. He recalls, "I would go to the hospital in the morning and get 'gassed up' with my chemotherapy, and then spend the rest of the day working. I never really slowed down. Does the CLL bother me today? No. Does it hurt? No. Have I had any ill effects from it? A couple of times, but mainly because I tried to push myself too much." Someone recently told Harold that they thought that he was in denial. He was quick to correct them, saying, "I'm aware of what the consequences may be, but I've never been one to lie down and give up. My attitude is, I have things to do, and I'm going to be around to do them. Down the road, that may not be the case, but today it is and that is how I live my life." •

For more information about CLL and resources available for support, including First Connection, call The Leukemia & Lymphoma Society's (LLS) Information Resource Center (IRC) Monday through Friday 9 AM to 6 PM ET at (800) 955-4572 or visit www.LLS.org.

Do you have questions about the financial impact of CLL and resources available to help?

You are invited to view Financial Health Matters, the new LLS Internet webcast focusing on the financial impact of cancer on patients and their family members. In the program, experts discuss insurance programs and other resources available for information and support.

To view this webcast or to print/read the program transcript and slides, please visit www.LLS.org/survivorship.

TrialCheck® A Clinical Trial Search Service

LLS has partnered with the Coalition of Cancer Cooperative Groups to offer TrialCheck, a clinical trial search tool. Visit www.LLS.org/clinicaltrials and follow the link to TrialCheck. After answering a few simple questions, you will receive a list of available CLL clinical trials targeted to your disease type and stage and your ZIP code preference. For more information about clinical

For more information about clinical trials, call the LLS Information Resource Center (IRC) at (800) 955-4572.



The Leukemia & Lymphoma Society provides the most accurate and current information about CLL. www.LLS.org

Supported by a grant from:

