

CLL SPOTLIGHT

 **The Leukemia & Lymphoma Society®**
Fighting Blood Cancers

News for People Living with Chronic Lymphocytic Leukemia

LEUKEMIA

LYMPHOMA

MYELOMA

Volume 1 • Issue 1 • 2008

CLL Expert Shares New Discoveries



The Leukemia & Lymphoma Society launched *CLL Spotlight*, a new education series for people living with chronic lymphocytic leukemia, on June 25, 2008, with a live telephone education program titled *CLL Therapy: An Update from the*

***American Society of Clinical Oncology*.** The program featured renowned CLL physician and researcher Dr. Thomas Kipps, who shared exciting news about advances in understanding and treating CLL.

“We have learned a lot in the last few decades about the biology and treatment of this disease, but our knowledge is not yet perfect,” Dr. Kipps explained. There is still much to be learned about CLL, and through research in the laboratory and patient participation in clinical trials, new discoveries are being made every day.

TREATING INDIVIDUALS

According to Dr. Kipps, physicians have learned that the course of CLL varies among patients. This means it is important to tailor the treatment approach for each individual. He described exciting advances that are emerging from research studies around the world. Researchers are studying the relationship between a patient's course of CLL and specific gene mutations, or changes to the proteins made by certain genes. This research may help physicians to identify a patient who would benefit from early CLL treatment (a patient with disease that is likely to progress quickly) and a patient who would be better served with a watch-and-wait approach (a patient with slow-growing CLL).

COMMUNICATION IS KEY

Dr. Kipps stressed how important it is for patients to have follow-up visits and good communication with their physicians. The factors that go into determining when a patient with CLL should begin treatment and what the treatment should be need to be discussed between a patient and his or her physician, he explained.

NEW OPTIONS ON THE HORIZON

There are several newer therapy options today for CLL patients who need treatment, compared to just a few years ago, and many more on the horizon. Dr. Kipps discussed several promising types of CLL drugs, including monoclonal antibodies, which work by attaching to cancer cells and triggering the body's immune system to destroy those cells. Alemtuzumab (Campath®) is a drug in this class that has been approved for the treatment of CLL. Another, rituximab (Rituxan®), approved for patients with non-Hodgkin lymphoma, has been shown in recent clinical trials to improve outcomes in patients with CLL when given in combination with other therapies. Bendamustine (Treanda®), a drug that works by damaging DNA in CLL cells, was just approved by the FDA this spring as a front-line therapy for CLL. In recent clinical trials it improved response rates and significantly increased progression-free survival in patients with CLL. Dr. Kipps described other innovative CLL studies, including the development of several vaccines designed to see if the body's natural immune responses can be enlisted to fight CLL cells. What is the goal of this research and Dr. Kipps' hope for the future? “To be able to give patients curative strategies at the time of diagnosis and not have to worry about waiting.” ●

Would you like to learn more about advances being made in understanding and treating CLL?

You can hear a replay of Dr. Kipps' entire program or download a written transcript of the program by visiting www.LLS.org/leukemiaeducation.

The LLS CLL Spotlight program includes:

CLL Spotlight News • *CLL Spotlight Telephone Education Series* • *Chronic Lymphocytic Leukemia Booklet** • *CLL: A Guide for Patients and Caregivers Easy-to-Read Booklet** • *First Connection* • *Co-Pay Assistance Program* *Available in English and Spanish

Spotlight on Survivorship



Mark Notestine has not slowed down since his retirement as an AT&T executive. He enjoys

spending time with his wife, four adult

children and three

grandchildren, and currently works with two of his sons in their real estate business. He says that his third “career” is keeping up with follow-up appointments and periodic treatment for chronic lymphocytic leukemia (CLL), which was diagnosed in March 1998 when he was 62 years old.

“Take your time, find out as much as you can, and don’t settle for anything other than the best possible treatment available.”

The first oncologist that he met gave him this advice: “You have the benefit of having time to understand this disease. I’m not going to do anything now, and I recommend that you go home and learn.” Some patients with CLL do not need treatment right away. In these situations, a physician may suggest a period of observation during which he or she will use periodic medical exams and lab tests to check the patient’s CLL status. This is an approach known as *watch and wait*. Mark says, “I spent the first few months after my diagnosis on an emotional ‘trip,’ wondering why this was happening to me. It took me some time to get my feet back under me. Then I set out to find out as much as I could about CLL and what my options were.” Many patients like Mark turn to The Leukemia & Lymphoma Society’s Information Resource Center (IRC) for help in understanding their

diagnosis and treatment options.

Information specialists in the IRC are master’s level oncology professionals who are specially trained to help patients and family members navigate diagnosis and treatment and connect them with valuable support services.

Mark did a lot of research in those first months after his diagnosis, visiting several cancer centers across the country. He decided to enter

a clinical trial under the care of Dr. Thomas Kipps at the University of California in San Diego. Since then, he has been involved in six CLL clinical trials. Most recently he participated in a study in which he received ISF35 (Immune Stimulatory Factor 35), a vaccine that was developed to stimulate the body’s natural immune system to fight CLL cells. Much of what is known about CLL therapy today is because of clinical trials: carefully monitored and controlled research studies conducted by doctors to improve treatment and quality of life for patients. Mark says, “Anyone who has been told that they have a disease for which there is no cure should consider a clinical trial, both for the opportunity to get treatment that is better than the standard and also to possibly help society as a whole.” He quickly clarifies, “It can be hard to get excited about the rest of the world when you’re concerned about your own survival, but my goal is to live to see all patients benefit from these advances.”

Ten years after his diagnosis, Mark says, “I’m 72 years old and happy to be so. I’m feeling good and I’m very grateful for that.” His advice to other patients? “Take your time, find out as much as you can, and don’t settle for anything other than the best possible treatment available.” ●

Information specialists in the IRC are available to answer your questions about CLL, CLL therapy, clinical trials and resources available for support. They can also conduct a clinical trials search to help you find a trial that might be right for you.

You can reach an IRC information specialist Monday through Friday 9 AM to 6 PM ET by calling (800) 955-4572, or visit www.LLS.org and click on “Live Help.”

Join Us... for our next CLL telephone education program

CLL: Update from the American Society of Hematology (ASH) Annual Meeting

**Tuesday, December 16, 2008
12 PM - 1 PM ET.**

Speaker: Michael J. Keating, MD from MD Anderson Cancer Center in Houston, TX

Watch for an invitation in the mail or visit www.LLS.org/leukemiaeducation.

Want to receive *paperless* e-mail invitations to our free telephone education programs? Go to: www.LLS.org/email

LLS Co-Pay Assistance Program is Available for Patients with CLL!

LLS offers a Co-Pay Assistance Program to help patients pay for public or private health insurance premiums and co-pay obligations. Assistance of up to \$5000 is available for eligible patients whose household income is at or within 500 percent above the U.S. Federal Poverty guidelines.



For more information, please call (877) LLS-COPAY or (877) 557-2672 or visit www.LLS.org/copay.

