# MYELOMANEWS

The Leukemia & Lymphoma Society \*

Fighting Blood Cancers

THE LATEST NEWS ON TREATING AND LIVING WITH MYELOMA



# **Leading Expert Offers Unique** Volume 3 ■ Issue I ■ 2008 Insights on Myeloma Diagnosis and Treatment

DR. ASHER A. CHANAN-KHAN, MYELOMA EXPERT

"Myeloma therapy

has evolved significantly over the past five years," says Dr. Asher A. Chanan-Khan, Associate Professor of Oncology at the Roswell Park Cancer Institute in Buffalo, New York. Dr. Chanan-Khan will help patients understand a diagnosis of myeloma and the evolution in myeloma treatment during The Leukemia & Lymphoma Society's (LLS) upcoming free telephone education program.

#### Fueling the pace of new drug development

"This is one of the most encouraging times for myeloma patients. While we still have a lot to do, patients can be assured that we are moving in the right direction," says Dr. Chanan-Khan. He explains that much of the research over the past several years has been fueled by the need to develop more effective therapies for older patients and patients with relapsed disease. The result of these efforts? The consistent approval of new drugs to treat myeloma. Three of thesethalidomide (Thalomid®), lenalidomide (Revlimid®) and Doxorubicin HCl Liposome Injection (Doxil®) in combination with bortezomib (Velcade®)—have been approved in the last two years alone. "New therapies have revolutionized what we have to offer patients. Even in the short span of five years, we have started to see a positive impact on

patient survival," explains Dr. Chanan-Khan. "We are also fortunate that many of these new therapies are pills that patients can take at home with few side effects."

#### Making an impact physically and emotionally

Dr. Chanan-Khan sees the tremendous impact these advances have on his patients physically and emotionally. "Today we're able to offer patients not only more options, but also more hope." According to Dr. Chanan-Khan, until there is a cure for myeloma, a major goal of researchers is to make myeloma a chronic illness that can be controlled for many years with few symptoms. Several large myeloma clinical trials are looking at ways to achieve this goal, including optimizing the effectiveness of new drugs by giving them in combination or sequentially.

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## Sharing a unique perspective

Dr. Chanan-Khan has a very unique perspective. He is both a physician and a cancer survivor himself. He explains, "I know firsthand what it feels like to wait to see a doctor and worry about what he was going to say, to wonder who I should tell about my diagnosis or how I would be perceived, to worry

about who was going to care for my family, or how this would impact us financially." He stresses to his patients the importance of finding support not only medically, but also socially, emotionally and financially. He directs his patients to the local LLS chapter in western New York, one of 68 LLS chapters in the United States and Canada. "LLS has supported research grants, helped patients financially, and provided much-needed opportunities for patients and their families to learn and share." On Wednesday, October 15, you will have the opportunity to listen, learn and ask Dr. Chanan-Khan questions during a live LLS telephone education program, **Understanding Myeloma: From** 

FREE UPCOMING TELEPHONE **EDUCATION PROGRAM** 

Diagnosis Through Treatment.

WEDNESDAY, **OCTOBER 15, 2008** 12:00 PM - 1:30 PM ET

**Understanding Myeloma:** From Diagnosis Through Treatment

Time for Questions

and Answers

Speaker: Asher A. Chanan-Khan, MD

Two easy ways to register:

Call toll-free (866) 992-9950 (x304) or visit www.LLS.org/myelomaeducation

Want to receive paperless e-mail invitations to our free programs? Visit www.LLS.org/email



### The LLS Outlook on Myeloma program includes:

\* Myeloma News\* \* Outlook on Myeloma Telephone Education Series \* Milestones in Myeloma Therapy Education Program \* First Connection \* Myeloma Booklet\*\* \* Myeloma: A Guide for Patients and Caregivers Easy-to-Read Booklet\*\* \* Co-Pay Assistance Program \*Two Spanish issues available. \*\*Available in English and Spanish.

For more information, contact the LLS Information Resource Center at (800) 955-4572.



# Connecting, Sharing, Reassuring

Three years after her diagnosis with myeloma, Ann Craig, a writer living in Greenwich Village in New York City, wanted to pass along what she had

learned from her experience and help others who were just beginning their journey. She heard about The Leukemia & Lymphoma Society's (LLS) First Connection program from a fellow myeloma survivor and contacted LLS to find out more.

#### Support when and where you need it

Ann was trained as a First Connection volunteer in December of 2007, and since then she has spoken with 17 patients with myeloma and often their family members, too. Many of the people she speaks with live several hours from a major cancer center and do not have easy access to other support resources. Because First Connection is a one-on-one telephone support program, it is accessible for people who cannot attend a support group or who do not have other support resources available. Ann says, "First Connection provides people with the very essence of support: the ability to connect with someone who understands their experience."

#### Sharing with someone who knows

Ann feels that making these types of connections is particularly important for people living with myeloma. She explains, "If you tell a friend you have breast cancer, they know what it is, they're automatically in the loop. If you tell a friend that you have myeloma, they usually aren't familiar with it. You have to explain it, and even then, it's hard for other people to understand. Every part of this journey, from diagnosis through treatment, involves things that are not familiar to most people, and that can make someone feel very alone." First Connection provides a unique opportunity to make a connection with someone

who really can understand what you are going through, because they have been there. "I can just sense the relief people feel from talking to someone who is further along on the path," she explains.

#### Providing reassurance and practical advice

Ann's conversations often include intimate discussions about fears the individual is experiencing, questions about when they will start to feel better, ways to cope with side effects or talk with their medical team, as well as resources for information and support available through organizations like LLS. In addition to reassuring the people who she speaks with and validating their concerns, Ann also often provides concrete, practical advice. For example, she suggests that patients who are preparing for a stem cell transplant (which she herself received two years ago) prepare meals ahead of time and freeze them. "After a transplant, the last thing on your mind is cooking a meal, but heating something up is manageable. That's something your doctor won't tell you and you won't read in any literature."

#### "Every single conversation moves me in some way."

Ann credits Patient Services Manager Meg Harrison of the New York City LLS Chapter for making her volunteer experience even more enjoyable and meaningful. She says, "Meg is wonderful in every way—warm, caring, and enthusiastic. She's great to work for and with!" For patients who are considering contacting LLS to speak with a First Connection volunteer, or who want to volunteer themselves, Ann says, "Absolutely, do it! I started doing this because I wanted to make a difference in someone else's life. Now it helps me to help someone else. Every single conversation moves me in some way."

#### Would you like to speak with a First Connection volunteer or become a volunteer yourself?

To learn more, contact the LLS Information Resource Center at (800) 955-4572 to be connected with your local LLS chapter or log on to our Web site at www.LLS.org.

#### **Make a Local Connection!**

Your local LLS chapter can also connect you with:

- Support from a patient services manager
- Patient financial aid
- Chapter education programs, including Milestones in Myeloma Therapy
- Support groups for patients and family members
- Fund-raising programs and special events
- Volunteer opportunities

#### The Leukemia & Lymphoma Society's **Co-Pay Assistance Program**

is available to help eligible patients pay for health insurance premiums and meet co-pay obligations.

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





