



MELISSA ALSINA, MD



KATHY DAILY, RN, OCN

Improving Treatment and Quality of Life: Experts Share Exciting Progress in Myeloma

“The first thing I tell my patients is ‘You are going to get better.’ I can say that with confidence because I know that one of the many treatment options we have today will produce a remission in the vast majority of patients,” explains Dr. Melissa Alsina of the H. Lee Moffitt Cancer Center in Tampa, Florida. Dr. Alsina and Transplant Nurse Coordinator Kathy Daily, RN, OCN, will discuss progress in myeloma treatment and side effect management during The Leukemia & Lymphoma Society’s upcoming live telephone/webcast education program.

Combining treatments, improving outcomes

Dr. Alsina recently presented at the American Society of Hematology’s (ASH) Annual Meeting, which brings together the world’s experts on leukemia, lymphoma, myeloma and other blood diseases to share their research. “Some of the most exciting presentations at ASH focused on combining treatments previously known to be active against myeloma. These combinations are proving to be extremely effective, particularly in newly diagnosed patients. Several of the studies showed response rates of 90 percent, which was unheard of a few years ago,” says Dr. Alsina. Researchers are continuing to study whether adding stem cell transplantation to combination therapies can lead to even longer

remissions. “Knowing we can achieve this level of response tells me we are closer to finding a cure for myeloma. Equally exciting were studies of novel therapies, including pomalidomide and carfilzomib, which are showing promising results in patients with relapsed myeloma.”

Working together to manage side effects Dr. Alsina stresses that effective treatment need not come with increased side effects.

She and Ms. Daily work together to ensure patients know what to expect from treatment and how they can manage side effects. Ms. Daily explains that simple lifestyle changes can help maximize quality of life. She teaches her patients, for example, to pace themselves to combat fatigue, a common side effect of myeloma. “People live their lives in the mode of ‘I want to do everything now,’ but by learning to balance periods of rest and activity, patients can really improve their long-term stamina.”

Managing treatment-related side effects is an important focus of myeloma research. Neuropathy, a common side effect of treatment, was the topic of several presentations at this year’s ASH meeting. Dr. Alsina explains, “One important study confirmed that by simply changing the dosing of bortezomib (Velcade®), a drug very active in myeloma, we can dramatically reduce the incidence of neuropathy while still maintaining the

treatment’s effectiveness.” Dr. Alsina and Ms. Daily urge their patients to inform them immediately of any new symptoms. “The sooner we know what’s going on, the sooner we can do something about it. Some side effects, like neuropathy, can often be completely reversible. The important message is that you don’t have to feel sick and tired when you’re receiving treatment,” explains Ms. Daily.

Improving quality of life

“These advances would not be possible without the participation of patients in clinical trials. We are now able, in most cases, to take someone who is very sick, treat them with a combination of therapies, and get them back to a place where they can resume most of their normal activities,” says Dr. Alsina. “Patients are living longer and feeling better, and this is not just something we read about in journals or hear about at international meetings. We see it every day with our patients.” To learn more from Dr. Alsina and Ms. Daily, listen live on Tuesday, March 23, 2010.

FREE UPCOMING TELEPHONE/
WEBCAST EDUCATION PROGRAM



Myeloma: Progress in Treatment and Side Effect Management

TUESDAY, MARCH 23, 2010
1:00 PM – 2:30 PM ET

Speakers: Melissa Alsina, MD
Kathy Daily, RN, OCN

OUTLOOK on MYELOMA

Want to receive paperless e-mail invitations to our free programs?
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Two easy ways to register:

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



Living with Hope

As a retired medical technologist, Kathy Rieck knew more about myeloma than the average person when she was diagnosed in October 2004. That knowledge, however, did not initially make the diagnosis easier to accept. She says, "At first I was overwhelmed. No one wants to hear that they have something for which there is no cure. But I'm the type of person who will cry, and then take a deep breath and do what needs to be done." She was told that the myeloma she had was an aggressive type, and Kathy has been equally aggressive in seeking out all possible treatment options. Since 2004, she has had two stem cell transplants, participated in a clinical trial and received several novel drugs for myeloma. Timing, she says, is everything, explaining, "If I had to get this diagnosis, I'm glad it came at a time when so many new discoveries are being made."

The nurse on Kathy's treatment team told her about the resources available through The Leukemia & Lymphoma Society (LLS) and encouraged her to call. She contacted her local LLS chapter in Wisconsin and found out about a monthly myeloma support group they offered. In spite of some initial reluctance, she says, "I went to the group and there I found people who were compassionate and caring and who knew what I was going through. They have been a tremendous source of support for me. My husband and my daughter have also been wonderful, but they are experiencing this from a different place. The people in my group know what I am feeling, sometimes without my even having to say a word."

In addition to support, the other group members and her chapter's Patient Services Manager have been an ongoing

source of information for Kathy, about treatments, side effect management and available resources like the LLS Co-Pay Assistance Program. She explains, "Information gets shared in the group that I just wouldn't normally come across."

The group has also helped to fuel her positive attitude. "I've met people in my support group who have been living with myeloma for over 10 years, and that gives me hope. I'm grateful for the five years I've had so far, but I want more. I'm always looking for the next new promising treatment that is coming." For the past two years, Kathy has been on the planning committee for a myeloma conference sponsored by her local LLS chapter, helping to make sure other patients in her area have access to the latest information about myeloma. She is also a volunteer for the LLS *First Connection* program, and speaks one-on-one with others diagnosed with myeloma. "There are things that I'm not able to do since my diagnosis, but volunteering is something I can do. It helps me to take my mind off of myself and it's a good feeling knowing that I can give hope to someone else just by being there."

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Her advice to other patients? "Reach out—to other people living with myeloma and to your family and friends. Be open and let people know what's going on and how you're feeling." Most importantly she says, "Every day, enjoy your family and your life, and know that there are always new things coming along."

Exciting News from the LLS Co-Pay Assistance Program!

Eligible myeloma patients can now receive up to \$10,000 in support to offset costs of prescription drug co-pays and other insurance-related expenses. This increase is retroactive for expenses incurred from July 1, 2009 through June 30, 2010, and is available to new and currently approved patients. Applications may be submitted online at www.LLS.org/copay or by calling (877) 557-2672.



Light The Night®—Raising Funds, Touching Lives



Each year, Light The Night Walks raise funds for lifesaving research and patient services. Neil Diamond, myeloma survivor and Light the Night volunteer who has raised over \$40,000 for LLS through this event, explains, "Light The Night has been my platform to give back. I would not be here today without these fundraising efforts." To learn how you can participate, visit www.lightthenight.org or call (877) LTN-WALK.



NEIL DIAMOND

The LLS Outlook on Myeloma program includes:

- Myeloma News* • Outlook on Myeloma Telephone/Webcast Education Series
- Living with Myeloma Chapter Education Program • First Connection • Myeloma Booklet**
- The Myeloma Guide: Information for Patients and Caregivers Easy-to-Read Booklet**
- Co-Pay Assistance Program**

*Three Spanish issues available. **Available in English and Spanish.

Find Support Near You

The Leukemia & Lymphoma Society's (LLS) chapters across the U.S. and Canada offer in-person Family Support Groups for people living with myeloma and for anyone affected by blood cancer, as well as several weekly online support groups. LLS support groups are facilitated by trained health professionals and are a place where information and support is shared in a comfortable and caring environment. **To learn more, contact the LLS Information Resource Center (IRC) at (800) 955-4572. For information about online support, please visit www.LLS.org/onlineSupport.**

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