# MYELOMANEWS

The Leukemia & Lymphoma Society \*

Fighting Blood Cancers

THE LATEST NEWS ON TREATING AND LIVING WITH MYELOMA

Volume 2 ■ Issue I ■ 2007



## **Expert Insight: Teaming Up to Tackle Side Effects**

DR. MELISSA ALSINA, MYELOMA EXPERT

"Patients with myeloma can achieve the goal of improved quality of life by balancing control of the disease itself and its side effects," says Dr. Melissa Alsina, Associate Professor of Medicine and Head of the Myeloma Program at the H. Lee Moffitt Cancer Center and Research Institute in Tampa, Florida. Dr. Alsina is the featured speaker of a free telephone education program offered by The Leukemia & Lymphoma Society (LLS) on managing myeloma side effects, to take place on Wednesday, October 10, 2007.

"Managing side effects takes a collaborative effort between patients, family members, and the healthcare team." Two simple but essential steps can be very effective. First, patients should ask the healthcare team about what to expect from myeloma and its treatment. Second, patients should communicate promptly with their healthcare team if they experience any new symptoms or changes in how they feel. Healthcare providers can offer essential information to help patients maintain a healthy lifestyle and reduce side effects. However, patients are the ultimate experts on how they feel. Dr. Alsina suggests that "patients pay attention to how they feel early on, and then promptly communicate any symptoms to their doctor." Keeping a diary is an effective strategy to track symptoms, document

treatment changes, and list questions for future doctor visits. Family members can help patients tackle these tasks, and others.

"Managing side effects takes a collaborative effort between patients, family members, and the healthcare team."

Patients need to be candid with their doctors and report all side effects, even those that may seem minor compared with other problems they may have. For example, fatigue is a common myeloma side effect and patients may believe it is not important. When left untreated, however, fatigue can profoundly affect a person's quality of life by limiting participation in enjoyable activities. Kathy A. Daily, RN, Transplant Nurse Specialist at the H. Lee Moffitt Cancer Center and Research Institute, has this advice: "Discuss all side effects with your healthcare team, and remember that anything that negatively affects your lifestyle is important. To fight fatigue, patients should stay active within their own abilities, for example, by walking or swimming. They should eat a healthy balanced diet, drink lots of water, and take a multi-vitamin daily." Patients should always check with their doctor first before taking any nutritional supplements or starting an exercise program.

Sometimes solutions to side effect control can be as straightforward as adjusting the dose of medication.

Dr. Alsina says, "Patients who respond to treatment can often continue to do well with lower doses of most myeloma medications, which can allow for better side effect management in the long run." Patients can also tap the experts on their treatment team to reap the benefits of the progress being made in new medications to

(Continued on page 2)

#### FREE TELEPHONE **EDUCATION SERIES TO** UPDATE YOU ON MYELOMA

## OUTLOOK on • • • MYELOMA



Each program features a leading myeloma expert, who presents the most recent information and answers your questions.

Patients, caregivers and healthcare professionals can call in from any phone. Before the teleconference, an information packet about the program, the featured speaker, and Society services will be provided.

#### **UPCOMING PROGRAM**

OCTOBER 10, 2007 12:00 PM - 1:30 PM ET

Managing Myeloma Side Effects: What You Need to Know

Q&A: Over one hour dedicated to answering your questions

Speakers: Melissa Alsina, MD

Kathy Daily, RN

Two easy ways to register: Call our toll-free number (866) 992-9950 (x304) or visit www.LLS.org/myelomaeducation.

#### **ACCESS PAST PROGRAMS**

Read, listen to, or view past programs at www.LLS.org/myelomaeducation.

## The Society's *Outlook on Myeloma* program includes:

\* Myeloma News \* Outlook on Myeloma Telephone Education Series \* New Directions in Myeloma Therapy Education Program ★ First Connection ★ Myeloma Booklet\* ★ Facts About Myeloma Easy-to-Read Booklet \* Myeloma: A Guide for Patients and Caregivers Easy-to-Read Booklet\* \*Available in English and Spanish.

## Partnering to Manage Side Effects: A Survivor's Inspiration & Advice

JOHN GALLAWAY: PAST CO-CHAIR, PATIENT AND FAMILY ADVISORY COUNCIL,
H. LEE MOFFITT CANCER CENTER AND RESEARCH INSTITUTE, AND MYELOMA SURVIVOR

Sixty-three-year-old John Gallaway had frequent back pain. In 2004 the pain became so intense that he was hospitalized. To his shock, he was diagnosed with myeloma. John's journey over the last 3 years has not been an easy one, but partnering with his healthcare team has allowed him to maintain a good quality of life. John's positive outlook is inspirational, and he has excellent advice for other patients.

#### **FIND A MYELOMA SPECIALIST**

John was lucky to live near H. Lee Moffitt Cancer Center, which is a National Cancer Institute—Designated Cancer Center. As such, it offers cutting edge myeloma treatments, myeloma specialists, and high-quality care. There, John and his doctors had to decide his course of treatment. So far, John has had four different treatments and he is currently enrolled in a clinical trial. John says, "I'm an example of the many alternatives out there for patients with myeloma." Today all patients can have access to the most current myeloma treatments. Patients can have their local oncologist consult with a myeloma specialist at an NCI-Designated Cancer Center.

#### SHARE INFORMATION AND FOLLOW-UP ON FEEDBACK

Communicating about side effects with the healthcare team is an important part of treatment. John jokes that "Although I haven't had the opportunity to experience *all* of the potential side effects from my treatments, I have had my share." On a more serious note, John says, "I cope by sharing them with my healthcare team, finding out which are temporary, and learning how to control those that aren't." Taking action is a big part of side effect management.

One challenge of side effects is keeping track of them. John says, "Use a diary, and ask for help." John's wife, Grace, keeps a diary for him, recording treatments and how he feels day-to-day. They refer to it and then work together with John's oncologist to make connections between certain side effects and treatments. As a result, John's symptoms can often be controlled quickly and more easily. For example, John's gastrointestinal side effects from treatment are now being controlled with medications and some sleepless nights have been overcome by taking certain medications in the morning. These easy solutions were found because John and Grace carefully tracked John's side effects and then informed his doctor.

#### **FUNCTION AS A TEAM**

Recent advances are increasing myeloma treatment options and improving strategies for side effect management. Together, patients and doctors can make choices that make the most sense for individual patients. John relies on his healthcare team's experience to help him decide on his next step. He says, "I am lucky to be near Moffitt and to have Dr. Alsina taking care of me. Her expert guidance has provided me with great benefits."

#### STAY POSITIVE TO MAKE A DIFFERENCE

To help maintain a good quality of life, John does his best to take care of himself, eat healthy foods, keep active, and learn more about his disease. John has an upbeat outlook. "I feel lucky to be alive, and I am optimistic about the future of myeloma treatment."

## Teaming Up to Tackle Side Effects (Continued from page 1)

manage and often eliminate some myeloma side effects. Examples are treatments for bone loss, anemia, and infection. Bisphosphonates are available to control bone loss. Medications to stimulate red blood cell production are now routinely used to fight fatigue and chemotherapy induced anemia. Low white blood cell counts, which may lead to infection, can also be treated with medications that stimulate white blood cell production. Dr. Alsina says, "Patients should always tell their doctor immediately about any symptoms of infection [such as a cough or fever] so that treatment may begin promptly." Some myeloma side effects can be alleviated or stopped from becoming permanent when patients report them to their doctor quickly. One example is neuropathy, which causes a tingling or numbness in the hands or feet.

Dr. Alsina manages neuropathy aggressively and says, "When a patient experiences neuropathy I want to know right away so that I can lower the dose, or possibly change the medication. In that way, patients will be able to receive other myeloma treatments in the future."

### Information is power, and patients benefit from seeking out and taking advantage of myeloma resources.

The LLS is an excellent resource, with an experienced staff. Patients do not have to deal with myeloma side effects alone. Although side effects are part of life after a diagnosis of myeloma, they are manageable. With the help of family, friends, and the healthcare team, patients can maintain a good quality of life while benefiting from the advances in treatment that are dramatically prolonging lives.

#### Co-Pay Assistance Program

This new program helps patients meet their private prescription drug insurance or Medicare Part D premiums or co-payments. Household income must be at or within 500% **above** the US Federal Poverty guidelines. For more information, call (877) LLS-COPAY [(877) 557-2672] or visit <a href="https://www.LLS.org/copay">www.LLS.org/copay</a>.

You can listen to and ask questions of Dr. Alsina on Wednesday, October 10, 2007, from 12:00 PM to 1:30 PM ET during LLS's free telephone education program, Managing Myeloma Side Effects: What You Need to Know. Transplant Nurse Specialist Kathy Daily will also participate.

Newsletter series supported by



**MILLENNIUM**