



## New Treatments Bring Hope to Myeloma Patients

**DR. SEEMA SINGHAL: MYELOMA EXPERT**

A dose of optimism is standard treatment for the myeloma patients of Dr. Seema Singhal. With recent advances in myeloma, she has good reason to "prescribe" optimism.

"In the last 6 to 7 years, there has been a revolution in the treatment of myeloma, with the introduction of new, highly effective drugs. These advances are encouraging. We've been able to dramatically prolong the lives of patients," said Dr. Singhal, Professor of Medicine and Director of the Multiple Myeloma Program at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University in Chicago.

“There has been a revolution in the treatment of patients with myeloma. We’ve been able to dramatically prolong the lives of these patients.”

Dr. Singhal helped to bring two of these drugs—Velcade® (bortezomib) and Thalomid® (thalidomide)—to market for treatment of myeloma. Northwestern University's myeloma program, one of the largest in the country, was part of the clinical trials that led to Food and Drug

Administration approval of Velcade and Thalomid for myeloma. Participation in clinical trials is often part of the long-term treatment strategy Dr. Singhal develops with each of her patients. She and her partner, Jayesh Mehta, MD, care for about 1,000 patients each year, including some who come from hundreds of miles away. "I try to make my patients understand there is a life beyond myeloma," said Dr. Singhal. "I don't want them to let their disease creep into every part of their lives. I encourage them to think positively and live as normally as possible."

Dr. Singhal provides cutting-edge treatment through clinical trials and by keeping updated on advances in myeloma treatment by participating in professional organizations like the American Society of Hematology (ASH). In December, nearly 20,000 hematologists from around the world, many of whom specialize in myeloma treatment and research, attended the ASH 2006 Annual Meeting, held in Orlando, Florida. At the meeting, Dr. Singhal presented some of the clinical trials she is conducting. One of these clinical trials looks at the combination of Velcade and PXD101, a new molecule that can change the way genes are expressed within a cell.

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**FREE TELEPHONE  
EDUCATION PROGRAMS  
UPDATE YOU ON MYELOMA**

**OUTLOOK<sup>on</sup> MYELOMA**



Learn about the latest updates on myeloma through the *Outlook on Myeloma* teleconference series. Each program features a leading myeloma expert, who presents cutting-edge information and answers participants' questions during the hour-long question-and-answer session.

Patients, caregivers and healthcare professionals can call in from any phone. Before the teleconference, The Leukemia & Lymphoma Society will provide you with the toll-free phone number and a packet of information about myeloma, the featured speaker, and the Society's services.

**Two easy ways to register:**  
Call our toll-free number  
(866) 992-9950 (x302) or visit  
[www.LLS.org/myelomaeducation](http://www.LLS.org/myelomaeducation).

### UPCOMING PROGRAMS

**JANUARY 24, 2007**  
**1:00 – 2:30 PM ET**

"Latest Advances in Myeloma Therapies:  
Update from the American Society of  
Hematology (ASH) Annual Meeting"  
*Seema Singhal, MD*

**APRIL 4, 2007**  
**1:00 – 2:30 PM ET**

"Myeloma Treatment:  
Exploring Your Options"  
*Asher A. Chanan-Khan, MD*

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

### PAST PROGRAMS YOU CAN ACCESS

Read, listen to, or view past programs at [www.LLS.org/myelomaeducation](http://www.LLS.org/myelomaeducation), including:

- "Understanding Myeloma: Current Issues and a Look Ahead," with Robert Z. Orlowski, MD, PhD (October 25, 2006)
- "Exploring Myeloma: An Update on Emerging Therapies," with Asher A. Chanan-Khan, MD (October 26, 2005)



## Taking Control and Sustaining Hope

**GALE SMITH: SOCIAL WORKER, SUPPORT GROUP LEADER AND MYELOMA SURVIVOR**

Gale Smith has been living with myeloma personally for 3 years and professionally for 16 years. A licensed clinical social worker for the Bone Marrow Transplant Unit at the University of Florida Shands Cancer Center in Gainesville, Gale was diagnosed with myeloma in 2003 at the age of 46. She had a stem cell transplant and chemotherapy, and has been in remission since fall 2005. As a social worker, Gale evaluates patients with myeloma and other blood cancers before their stem cell transplants, and supports patients and their family members through counseling and leading a local *Family Support Group* of The Leukemia & Lymphoma Society.

**When Gale was diagnosed with myeloma, she didn't let the disease run her life.** Instead, she drew on past life challenges, and the way she conquered them, to take control. This is something she says everyone can do. "People don't realize that they have the inner strength to get through having myeloma. Everyone can find some challenge they've overcome, and use the inner strength that pulled them out of it, to get through this," said Gale, who calls herself a "myeloma survivor."

**From age 4 to 12, Gale had a kidney disease that put her in the hospital for a month or two at a time.** The hospital was 50 miles from her home, where her parents were caring for 10 other children. Gale filled her time by teaching herself about the medicines the

doctors prescribed. That prepared her to deal with myeloma. "The minute I was diagnosed, I went online. I went to The Leukemia & Lymphoma Society and other myeloma resources, getting as much information as I could on myeloma and its treatment."

**Gale also drew strength and comfort from her faith.** "My parents taught all of us to pray every day and to be grateful for whatever God has blessed us with. I am a strong believer in prayer."

**While Gale had some unusual challenges to deal with, other past challenges**—such as children leaving home or losing a loved one—can help you cope with myeloma. "We have to adapt to changes," she said. "We grieve, but we still have hope."

### ASK FOR HELP

**Taking control also means asking for help—from family, friends and other people living with myeloma.** When Gale was going through her stem cell transplant and chemotherapy, she relied on people in her life. The experience made her realize just how important it is to have support. "People need to know they are not the only ones going through this," said Gale. "Someone else who is going through this understands them and can offer words of encouragement or comfort."

### GET SUPPORT

**Local family support groups are a great way to get support and meet**

**other patients and their families.**

Gale's local *Family Support Group* is one of 230 available nationwide through The Leukemia & Lymphoma Society.

**The support group includes people who are living with myeloma, as well as family and other caregivers.** As the facilitator, Gale encourages people to attend the support group, selects topics to stimulate discussion and gently persuades attendees to share. "We're giving people a means of expression. We are here to support each other." Gale added that many of her support group members have to travel long distances for their treatment. "The support group can help patients and their families cope with the stress of being away from home for treatment as well as the treatment itself."

### BE HOPEFUL

**With the many research advances and new medications to treat myeloma, Gale is optimistic about the future.** "People are living longer. Myeloma is being treated more like a chronic illness. I'm hopeful that one day there will be a cure."

**Gale encourages other people with myeloma to be positive.** "In a lot of ways, helping patients is not a job for me anymore; it's a ministry. I want to be here to touch as many lives as I can, and to say to people that there is life after a diagnosis of myeloma." ■



## New Treatments Bring Hope to Myeloma Patients (Continued from page 1)

Dr. Singhal attended several sessions reporting on clinical trial results of other myeloma specialists from around the world. These presentations introduce emerging therapies such as a molecule that suppresses a protein, which confers a growth and survival advantage to malignant plasma cells. As a clinician and a researcher, the information that Dr. Singhal learned could lead to better ways of diagnosing and treating myeloma, and of measuring response to myeloma treatment. Treatment options in myeloma are evolving rapidly, and patients have more choices than ever.

Dr. Singhal will share some of these meeting highlights on January 24, 2007, during The Leukemia & Lymphoma Society's free telephone education program, "Latest Advances in Myeloma Therapies: Update from the American Society of Hematology (ASH) Annual Meeting." This program will feature an hour-long question-and-answer session with Dr. Singhal, and is for patients, caregivers and healthcare professionals. ■

**To register for this program, call toll-free (866) 992-9950 (x302) or visit [www.LLS.org/myelomaeducation](http://www.LLS.org/myelomaeducation).**



## The Society's Resources Help You Take Control

The Leukemia & Lymphoma Society has many free programs and services to help you find support and stay informed about myeloma.

### Stay Informed: Live Help

- **Information Resource Center (IRC):** Get accurate, current, disease-related information and support and guidance from a myeloma expert. Information specialists (social workers, nurses and health educators) are available Monday through Friday, 9 AM to 6 PM ET and can also help you:
  - Understand how myeloma is diagnosed, treated and monitored
  - Find information on clinical trials
  - Order free educational materials about myeloma
  - Find your local chapter
  - Get information about the Society and its programs
- **LIVE Help: Answer Chat:** Talk to an information specialist online Monday through Friday, 10 AM to 5 PM ET.

### Stay Informed: Free Programs and Materials

- **Exploring Myeloma:** Local Society chapters offer this free education program for patients, caregivers and healthcare professionals periodically throughout the year. A local myeloma expert will present the program, which covers:
  - Overview of myeloma
  - Review of current and emerging drug therapies
  - Management of disease and treatment-related side effects
  - Emotional aspects and support
  - Question-and-answer session
- **Myeloma booklet:** A free booklet for patients and their families that provides an overview of myeloma, including the different types, treatment options, and social and emotional aspects of living with the disease.
- **Myeloma: A Guide for Patients and their Families:** This free, easy-to-read booklet provides answers to questions about what myeloma is, how it is diagnosed and treated, and where to find more information.

For information on any of these programs and services, call (800) 955-4572 or visit [www.LLS.org](http://www.LLS.org).



## Frequently Asked Questions About Myeloma

### How can I get the most current treatment information?

New and better treatments for myeloma are becoming available regularly. Researchers are also studying many potential treatments in clinical trials. Ask your hematologist/oncologist about new treatments and clinical trials that may be right for you. You can also ask other members of your healthcare team, such as nurses and social workers, and the Society's Information Resource Center (IRC) about treatment options.

### Are there any new treatments for relapsed myeloma?

If your myeloma has returned after it had been in remission, there are some promising new treatment options. Among these are Revlimid® (lenalidomide) in combination with dexamethasone and a single agent, Velcade® (bortezomib), which have recently been approved by the Food and Drug Administration for patients who have had at least one prior treatment. Each of these medications continues to be studied in clinical trials in combination with other drugs. You can read or hear about current standard therapies and emerging therapies under study in the presentation by Dr. Robert Z. Orlowski, "Understanding Myeloma: Current Issues and a Look Ahead," the first in this three-part telephone education series, at [www.LLS.org/myelomaeducation](http://www.LLS.org/myelomaeducation).

### How can I find information on the latest research for treatment of myeloma?

Periodically ask members of your healthcare team or contact the

Society's IRC for research updates on myeloma and how they might or might not currently apply to the management of your disease. Myeloma specialists report on results of ongoing clinical trials at professional meetings and in medical journals. The Society offers information updates for the public through our teleconference series (register by calling (866) 992-9950 (x302) or visiting [www.LLS.org/myelomaeducation](http://www.LLS.org/myelomaeducation)) and on our Web site ([www.LLS.org](http://www.LLS.org)).

### What are clinical trials, and how can I learn more about them?

A clinical trial, sometimes called a research study, is a study conducted by medical scientists to improve the care and treatment of patients. For example, there are clinical trials that test and develop new and improved ways to diagnose and treat myeloma in people, prevent or ease treatment side effects, help prevent a recurrence of myeloma, or improve comfort and quality of life. Clinical trials are important for patients with myeloma because they provide promising new treatment options and offer the hope of increased survival, improved quality of life, or both. A treatment that is proven safe and effective in a clinical trial will often be approved by the Food and Drug Administration and become a standard treatment for future patients with myeloma. ■

*For more information on any of these topics, call the Society's IRC at (800) 955-4572 or visit [www.LLS.org](http://www.LLS.org).*



## Getting the Support You Need

As a caregiver for someone with myeloma, you are a vital part of the healthcare team. Because much of the treatment for myeloma now takes place on an outpatient basis, you may be responsible for managing many of the details of your loved one's treatment. This can seem overwhelming. It is important to take time for your own needs. By getting the help and support you need to take care of yourself, you'll be a better caregiver. Remember that many types of support are available through The Leukemia & Lymphoma Society.



**A Toolkit for Older Adults with Cancer and their Caregivers:** This Toolkit contains a *Take Action Plan* resource folder plus 4 pamphlets, each of which addresses a different aspect of supporting the person living with myeloma: *Caregiver's Guide*, *Choosing Your Healthcare Team*, *Money Matters* and *Understanding Treatment Options and Clinical Trials*. Order your copy through the Society's IRC.

### CAREGIVER TIPS

#### Take time for your own needs:

- Eat a balanced diet
- Exercise to reduce stress
- Get a good night's sleep
- Ask for and accept help from others

The next time someone says, "If there's anything I can do, let me know," take them up on it. Delegating various responsibilities to others not only can give you a

break but can allow you to spend more time caring for your loved one.

#### Access support through the Society:

- *First Connection*: A free telephone support program that links you with a trained peer volunteer who has experienced a situation similar to yours
- *Discussion Board*: An online forum for sharing your thoughts and experiences with peers who have been touched by blood cancers

- *Family Support Group*: A local program open to patients, family members and caregivers and led by experienced volunteer nurses and social workers
- *The Society's Information Resource Center (IRC)*: Experts are available to answer your questions live by phone Monday through Friday, 9 AM to 6 PM ET

To access any of these services, call the Society's IRC toll-free at (800) 955-4572 or visit [www.LLS.org](http://www.LLS.org).

## Recursos Disponibles en Español

La Sociedad de Leucemia y Linfoma ofrece información y asistencia en español, incluyendo:

- Especialistas bilingües en información en nuestro Centro de Recursos Informativos (IRC): consigue información exacta, actual, enfermedad relacionada, da ayuda y apoyo
- Publicaciones, por ejemplo *Información sobre el mieloma*

Si usted siente que sería útil recibir este boletín de noticias en español, por favor llame el Centro de Recursos Informativos (IRC).

Para hablar con un especialista en información o para pedir publicaciones, llame a (800) 955-4572 o nuestro sitio Web de la Sociedad a [www.LLS.org](http://www.LLS.org).



**The Leukemia &  
Lymphoma Society®**

Fighting Blood Cancers

The Leukemia & Lymphoma Society's mission is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

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## MYELOMA TERMS YOU SHOULD KNOW

### QUESTIONS TO ASK YOUR HEALTHCARE TEAM

[Clip this portion and bring it to your next healthcare appointment.]

Asking good questions will help you get the most appropriate care. Here are some key questions. Be persistent until you fully understand the answers.

1. What is my planned first treatment? Will this jeopardize any subsequent treatments?  
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\_\_\_\_\_
2. Would I be eligible for a clinical trial? Which ones? Where do I learn about them?  
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3. How will I know if my treatment is working?  
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\_\_\_\_\_
4. If this treatment doesn't work, what other treatments are available?  
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5. What side effects can I expect from treatment? Are these short-term or long-term side effects, temporary or permanent?  
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6. How will my disease status be measured? Is there a number or rating I can track?  
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7. If I want to get a second opinion, how can I get a copy of my medical records?  
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8. Add other questions you may have prior to your healthcare appointment.  
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For additional questions to ask your healthcare team, call the Society's Information Resource Center at (800) 955-4572 or visit [www.LLS.org](http://www.LLS.org).



#### Autologous stem cell transplant

A procedure in which a patient's own stem cells from the bone marrow or peripheral blood are collected, stored and reinfused following high-dose chemotherapy and/or radiation therapy.

#### Allogeneic stem cell transplant

A procedure in which stem cells from another person's bone marrow or peripheral blood are collected, stored and infused into the patient following high-dose chemotherapy and/or radiation therapy. The donor is nearly always a match in tissue type to the recipient.

#### High-dose chemotherapy

Administration of higher, more effective doses of chemotherapy. Because high-dose chemotherapy destroys the bone marrow, a stem cell transplant is required to replenish blood-forming bone marrow cells.

#### Monoclonal (M) protein

Identical immunoglobulin protein produced by myeloma cells. M protein is found in the blood or urine and is used as a marker for the amount of myeloma disease present in the body.

#### Remission

A disappearance of evidence of disease, usually as a result of treatment. Complete remission means all evidence of disease is gone. Partial remission means the disease has been improved by treatment, but evidence of the disease lingers.

#### Responsive disease

Myeloma that is responding to therapy, with a decrease in M protein of at least 50 percent.

#### Stable disease

Myeloma that has not progressed or gotten worse.

#### Refractory disease

Disease that does not go into remission or improve substantially after initial treatment with standard therapy.

#### Relapse

A return of disease after it had been in remission following treatment.

#### Progressive disease

Active myeloma that is worsening, that is, increasing M protein and worsening organ or tissue impairment. Relapsed and/or refractory disease might be considered to be progressive disease.