MYELOMANEWS

The Leukemia & Lymphoma Society *

Fighting Blood Cancers

THE LATEST NEWS ON TREATING AND LIVING WITH MYELOMA

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Pioneering Researcher Offers Hope Through New Discoveries

DR. SEEMA SINGHAL, MYELOMA EXPERT

"I am able to speak to my patients with a great deal of optimism," says Dr. Seema Singhal, of the Robert H. Lurie Comprehensive Cancer Center at Northwestern University in Chicago, Illinois. "Because of the growing depth of knowledge and the frenzy of research activity around myeloma, it is quite possible that patients diagnosed today may see a cure for myeloma during their course of treatment." Dr. Singhal will bring this sense of optimism when she presents for The Leukemia & Lymphoma Society's (LLS) upcoming live telephone

education program on May 14, 2009.

Changing the landscape of treatment

Dr. Singhal is a pioneering researcher in myeloma and was the first to observe that the drug thalidomide (Thalomid®) was effective in treating myeloma. "Thalidomide, and later bortezomib (Velcade®) and lenalidomide (Revlimid®), were all drugs that were new to oncology when they were approved for use in myeloma, all within the last 11 years." Dr. Singhal points out that these drugs are proving effective not only when used alone but also in combination with each other and with older chemotherapy drugs. "In one fell swoop, we had not only three new therapies, but therapy options in combinations that are almost too

innumerable to count. This has completely changed the landscape of myeloma treatment."

Building blocks for new discoveries Dr. Singhal explains that each new discovery becomes the building block for the next new discovery in myeloma. "Every time we find a new drug that works, we go back to the laboratory to understand how it works. Each successful discovery helps us to understand more about the pathways that are involved in the growth of the disease. This allows us to develop even more targeted therapies." Advances in stem cell transplantation coupled with these new drug discoveries are leading to longer remissions and improved quality of life for patients. "We are able to achieve longer remissions because these agents are generally well tolerated, and we are able to give them without interruption over a longer period of time. We are still searching for the treatment that has no side effects at all."

Providing hope through education Dr. Singhal stresses the importance of patients staying informed about all of their options, and she is a strong advocate of patient education. She says, "Thanks to LLS, many patients come to me already having an understanding of myeloma and knowledge about the importance of clinical trials. That allows me to take the conversation to the next level. explaining to my patients about their specific options for therapy."

"I want the patients who leave my office, as well as the patients who listen to this teleconference, to feel reassured and hopeful. Hope gives people the fuel they need to get through the initial adjustment to their diagnosis and treatment." Dr. Singhal will share more hopeful advances in stem cell transplantation and myeloma drug therapy during the LLS live telephone education program, Myeloma: Understanding Drug Therapy and Stem Cell Transplantation.

FREE UPCOMING TELEPHONE **EDUCATION PROGRAM**



Myeloma: Understanding Drug Therapy and Stem Cell Transplantation

THURSDAY, MAY 14, 2009 12:00 PM - 1:30 PM ET

Speaker: Seema Singhal, MD

Extended Time for Questions and Answers

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.



First Connection Volunteer Shares Her Experience and Insight

Staying connected, to other people and to good information, is important to **Deborah Rutledge.** When she was

diagnosed with myeloma in February of 1997, she was 47 years old, working full-time, and a busy wife and mother of two school-aged sons. At that time, she was not aware of the resources for support and information that she now knows are available. Through a friend, Deborah was connected to someone who had myeloma. That connection was so valuable to her, she wants to ensure that no one diagnosed with myeloma has to walk this road alone. As a volunteer for The Leukemia & Lymphoma Society's (LLS) First Connection program, she speaks one-on-one with other patients who are where she was 12 years ago. In her conversations, she often discusses how she has come to terms with her "new normal." She explains, "What I do today is different than what I was able to do pre-myeloma. I've had to shift my expectations of what I do and how I do it." Many of the people she speaks with are also struggling with questions of how and why they got this disease. She too had these questions, but says, "At some point early on I realized what mattered was I had myeloma and I had to move forward to determine my next steps."

Deborah's next steps involved finding a healthcare team experienced in treating myeloma. In September of 1997 she received a stem cell transplant and was in remission for 22 months. When the disease relapsed, one of the options offered to her was a clinical trial. She had several questions: Who would be providing her care? What follow-up would she receive? What would be the potential benefits and side effects? Many patients turn to the LLS Information Resource Center (IRC) and the LLS-supported TrialCheck® Web site (www.LLS.org/clinicaltrials) for information about how to find and participate in clinical trials. Deborah decided to participate in the

Phase 1 trial of an investigational drug, bryostatin-1. Phase 1 trials test a new treatment in a small group of patients to determine its safety, appropriate dose and how it should be given. Patients are watched closely for any possible side effects. Deborah says, "The results for me have been wonderful. I am doing well, I have received excellent care, and for 10 years I have been watched very closely by my medical team. I also know that my participation in this trial has the potential to help other people."

Deborah feels that it is important to stay informed about treatment advances in myeloma. For the past two years she has attended the *Milestones in Myeloma Therapy* program at her local LLS chapter in Northern Ohio. This education program, offered at chapters across the United States and Canada, is presented by a local myeloma expert and gives attendees the opportunity to ask questions. She says, "I am still learning more about

"It's important for me to have good solid information upon which I can advocate for myself, ask questions and make decisions."

this disease even after 12 years. I always want to know what my options are. It's important for me to have good solid information upon which I can advocate for myself, ask questions and make decisions."

Along the way, Deborah has learned a great deal about the importance of the support of her family and friends. "You have to figure out what it is you need and be able to ask for help. Too often, caregivers are going through their own sense of helplessness. When I was newly diagnosed, I spent a great deal of energy trying to protect my husband. When I started talking to him and sharing what I was feeling, it helped us. That continues to help us even today."

My Clinical Trials Journey

You are invited to participate in an interactive online video education program, *My Clinical Trials Journey*. Visit www.LLS.org/Journeys to follow the stories and experiences of three cancer survivors, including a myeloma survivor, who have participated in clinical trials. A healthcare professional provides expert insights about clinical trials along the way. As you participate in the journey, your session becomes an interactive experience that you can save and access at any time.

To learn more about clinical trials or resources, programs, and volunteer opportunities at your local LLS chapter, contact the LLS Information Resource Center (IRC) at (800) 955-4572 or visit www.LLS.org.

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.





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