Leading Expert Will Provide Update on MDS Diagnosis and Treatment

“Myelodysplastic syndromes (MDS) are a very diverse group of diseases, and the diagnosis can be confusing for patients,” says Dr. Stephen D. Nimer from Memorial Sloan-Kettering Cancer Center in New York. Dr. Nimer will help patients understand the most current information about MDS diagnosis and treatment during the Leukemia & Lymphoma Society’s upcoming live telephone/webcast education program.

“Much of the terminology for the different subtypes of MDS can be difficult to pronounce and to understand. For example, refractory anemia with ringed sideroblasts—that’s a handful to say, let alone comprehend,” explains Dr. Nimer. To help make sense of the diagnosis, it’s important for patients to see a doctor who is experienced in treating MDS. “By seeing a doctor who specializes in hematologic cancers or, more specifically, a specialist in MDS, you will have the benefit of someone who has seen and treated the whole diversity of the disease and understands—and can help you understand—its natural course.”

**UNDERSTANDING DIAGNOSIS AND TREATMENT**

Dr. Nimer explains there are several questions that patients should ask their physician at the time of diagnosis, including, “Has an expert reviewed my pathology report, and have cytogenetics been done? Do I need treatment right away? What are my treatment options? Am I a candidate for stem cell transplantation? What clinical trials are available?”

“Bone marrow testing is necessary in order to make a diagnosis of MDS, and a chromosome evaluation, also known as cytogenetics, should always be part of the diagnostic work-up,” explains Dr. Nimer. The subtype of MDS as well as the presence and severity of chromosome changes in the cells of the bone marrow help determine whether MDS is categorized as high-risk or low-risk and what therapy options are appropriate. Some patients with MDS do not need treatment right away. They are followed closely by their physician with regular check-ups and blood tests, an approach known as “watch and wait.” Others may require periodic red blood cell or platelet transfusions, drug therapy, chemotherapy and/or stem cell transplantation. “There are some therapies that work specifically in patients with a certain type of chromosome abnormality. For example, lenalidomide (Revlimid®) is a drug that is particularly useful for patients with MDS who have a deletion in chromosome 5q, therefore it becomes essential to know if a patient has this specific chromosome abnormality.”

“The only way we can continue to find new therapies and make progress in MDS is through clinical trials.”

**MAKING PROGRESS IN MDS**

In addition to lenalidomide, two other drugs, 5-azacitidine (Vidaza®) and decitabine (Dacogen®), have been FDA-approved for MDS within the last six years. “The only way we can continue to find new therapies and make progress in MDS is through clinical trials,” explains Dr. Nimer. “Currently, stem cell transplantation is the only cure for MDS, but unfortunately it is only an option for a minority of patients. Therefore, there is a tremendous need for testing new treatments at all stages and for all subtypes of MDS. Researchers are also investigating new ways of using existing treatments and combining existing treatments with novel drugs to improve patient outcomes.” Dr. Nimer will discuss much more about MDS diagnosis and current and emerging therapies during his live telephone/webcast education program on Tuesday, May 18, 2010.
Finding Meaning and Joy in Service to Others

When Susan Adkison was pregnant with her daughter, a routine test showed her blood cell counts were low. She explains, “My daughter was born in July, and in October, when my counts were still low, we began to realize this was something serious.” Soon after, she was diagnosed with MDS and recalls, “I was devastated. At the time, there wasn’t a lot of information about MDS. I thought my little baby would never get the chance to know me.” Susan began writing Letters to Katy, a journal she filled with thoughts about her infant daughter. She remembers thinking, “She may not know me, but at least she’ll know how I felt.” Katy is now a college student, and Susan still occasionally writes in the journal that she began 18 years ago. “It’s still my book that I keep for her, and the story is not yet finished.”

While Susan has faced physical challenges as result of MDS (the most difficult being extreme fatigue), she says these challenges have helped to focus her priorities on what is most important—loving and encouraging the people around her. “Sometimes you might feel so bad that it’s hard to think of anything else. I’m able to get my mind off myself by focusing on helping others. I know there’s a purpose in why I’m here, and I believe it’s because I can make a difference in someone’s life.”

Susan volunteers for The Leukemia & Lymphoma Society’s (LLS) First Connection program and participates in her local LLS Light The Night® fundraising Walk.

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“If you’re at home by yourself, trying to figure this out, it can make you feel very alone. When I call people through First Connection, I tell them, ‘our situations might not be exactly the same, but we’re all in a similar place and I can understand how you’re feeling.’” Her participation in Light The Night further reinforces her connection to others facing blood cancers. “It’s amazing to look out and see thousands of red balloons interspersed with white balloons and know that everyone is there for the same reason.”

Susan has a type of MDS that has not required treatment, but she is monitored closely by her doctors for any change in her blood counts. She firmly believes in the importance of staying educated about MDS, and participates in LLS Telephone/Webcast Education Programs to do so. “You go to your doctor and hear these terms that are not your normal language, and it can be hard to process. It’s very helpful to be able to sit quietly in your home and hear one of the experts in the country clearly explain the latest information. It also gives me a sense of community to know there are so many other people listening as well.”

Susan credits her faith for helping to make sense of this experience. “I believe that I have been given so much, and I want to pass the blessing forward.” She encourages others to reach out to the people around them and to the resources for support and information available through LLS. “Even in the midst of challenges, you can experience joy. Be open to the possibilities and opportunities to help others that this experience brings.”

Like Susan, You Can Make a Difference in the Lives of Others Facing MDS

Volunteers play an essential role in LLS programs and services. Sue Sumpter, RN, MS, Patient Services Manager for Susan’s LLS chapter in Portland, Oregon, explains, “Patients newly diagnosed with MDS are facing a vast unknown. We can give them hope by connecting them with a First Connection volunteer like Susan Adkison. You cannot help but be uplifted after speaking with her. Like many of our volunteers, she has been living with this for many years, and it hasn’t stopped her from leading a full, happy life.”

To speak with a First Connection volunteer, or to learn about volunteer opportunities at your local chapter, please contact the LLS Information Resource Center (IRC) at (800) 955-4572.

My Personal MDS Journey

You are invited to participate in My Personal MDS Journey, an interactive online program following the story and experience of Charles, an MDS survivor, and Dorothy, his wife. Stephen D. Nimer, MD, of Memorial Sloan-Kettering Cancer Center provides expert insights along the way. Please visit www.LLS.org/Journeys.

LLS Co-Pay Assistance Program Available for Patients with MDS!

Eligible MDS patients can receive up to $5,000 in support to help offset costs of prescription drug co-pays and other insurance-related expenses. For more information or to submit an application, visit www.LLS.org/copay or call (877) 557-2672.

To order this Myelodysplastic Syndromes booklet or other free materials, please call the LLS Information Resource Center (IRC) at (800) 955-4572 or visit www.LLS.org/freematerials.