

July 2015

Living With Myeloma Managing Side Effects and Quality of Life

Meet our guest speaker **Sagar Lonial, MD, FACP**

Patients with multiple myeloma experience side effects from both the disease and its treatment. In a myeloma program sponsored by The Leukemia & Lymphoma Society (LLS), Dr. Sagar Lonial, Executive Vice Chair for the Department of Hematology/ Medical Oncology and Chief Medical Officer of Winship Cancer Institute at Emory University School of Medicine, discussed treatment options, disease and treatment-related side effects and how patients with myeloma can care for themselves.

“Since 2000, we have begun to have pretty significant improvements in overall survival,” Dr. Lonial stated. “From 2005 to 2010, we’ve seen some of the best growth in survival rates.” Treatment of multiple myeloma has advanced tremendously during that time. Dr. Lonial discussed some important goals of therapy when treating multiple myeloma patients, such as achieving a maximum response to treatment as quickly as possible. “The goal is to pick a [treatment] regimen that will give you the best chance of achieving a major response.” What is the advantage of that? Dr. Lonial commented, “Patients who achieve major responses—complete response (CR), very good partial response (VGPR), stringent complete response (sCR)—stay in remission longer and live longer.”

So, how are doctors improving patient outcomes? Better induction regimens, longer duration of treatment, the inclusion of maintenance therapy and more patients with access to stem cell transplants have all contributed to better outcomes. Patients with myeloma are living longer, which means that side-effect management and quality of life are more important than ever before. “You want to achieve a maximal response. You want it to occur quickly. You want this to occur in a way that actually improves how functional the patient can be, and you want it to have minimal effects on quality of life,” emphasized Dr. Lonial.

Treatment Side Effects

The healthcare team should be well-versed in helping patients navigate their way through side effects and treatments. This allows patients to be better informed and take part in their own care.

The immunomodulatory drugs (IMiDs) lenalidomide (Revlimid®) and pomalidomide (Pomalyst®) are important building blocks in the treatment of myeloma.

These therapies can cause some side effects that need to be monitored, such as myelosuppression (a decrease in the formation of white blood cells and platelets in the bone marrow). Because of this, there may be times when treatment is interrupted or the dose is reduced, or when a drug such as filgrastim (Neupogen®) is given to try and increase a patient’s white blood cell count.

Deep vein thrombosis or pulmonary embolism is also a concern. For patients with only one risk factor for these conditions, which would include about 75–80% of patients with multiple myeloma, aspirin can be used as a preventative measure. However, patients with two or more risk factors may need more than aspirin.

Bone protective therapy with bisphosphonates is recommended for almost all patients with myeloma, regardless of whether or not they have bone lesions visible on X-rays, although the duration and frequency of this treatment is still up for debate among myeloma doctors.

How Patients Can Care for Themselves

In order to help maintain good gastrointestinal health and nutrition, Dr. Lonial recommends that patients drink at least 2–3 liters of fluids per day, or more if they are doing strenuous work outside or it is the middle of summer. Additionally, Dr. Lonial suggests that “a well-balanced diet is probably sufficient... you want to just make sure that you have a diet that includes all of the major food groups and, again, lets you have a good quality of life over time.”

Dr. Lonial encourages patients to discuss any issue with their healthcare team, especially side-effect management. The goal is to move myeloma away from being an incurable disease. The quality of life for patients living with myeloma is very important.



UPCOMING AND PAST PROGRAMS

Multiple Myeloma and the Immune System

Coming in October 2015

For more information, please visit www.LLS.org/programs.

To view our new myeloma video, as well as other education videos, visit www.LLS.org/educationvideos.

To access virtual lectures, transcripts, program slides and audio replays from past programs, visit www.LLS.org/programs.

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are available to talk with you Monday through Friday between 9 AM and 9 PM ET, by calling (800) 955-4572 or emailing infocenter@LLS.org.

Myeloma Blog is a platform to discuss key issues for myeloma survivors. Read and comment by visiting www.LLS.org/myelomablog.

Patti Robinson Kaufmann First Connection Program links newly diagnosed patients and their families with trained volunteers who have been affected by a blood cancer and shared similar experiences. Visit www.LLS.org/firstconnection.

Myeloma Chat provides a live, online forum to discuss the stresses and triumphs shared by others living with myeloma from the comfort of your home. The chat is held every Tuesday evening from 8:00 PM to 10:00 PM ET and is moderated by an oncology social worker. Visit www.LLS.org/chat.

Blood Cancer Discussion Boards are where patients can post information about their diagnosis or communicate with others who may have a similar illness. Visit www.LLS.org/discussionboards.



The survival rate for myeloma more than tripled since the 1960s.

CO-PAY ASSISTANCE

The LLS **Co-Pay Assistance Program** helps you pay your insurance premiums and meet co-pay obligations. For more information visit www.LLS.org/copay or call (877) 557-2672.



Survival story: Scott

Taking Ownership: Living With Multiple Myeloma

Scott worked as a salesman, which required a lot of traveling throughout North America and overseas. During a business trip to Mexico in April 2010, Scott received a call from his doctor with some discouraging news.

The doctor told Scott he had cancer. “It’s called multiple myeloma.” When Scott asked if it was a death sentence, the doctor said, “No, but it is serious.” Scott’s head was spinning at that point. “Everything was numb...all I could do was think about my family.”

Scott immediately called his wife, Diane, to tell her the news. Diane researched all she could about multiple myeloma. By the time Scott returned home the next day, she had already set up an appointment with a myeloma specialist. “She’s the reason I’m as healthy as I am. I have a great team: my wife, my doctor, and myself,” Scott emphasized.

Scott’s doctor went over several different treatment options. Scott decided he was ready to start treatment as soon as possible. Later that day, Scott received the first of his twice-weekly infusions.

“It’s your life, and it all depends upon you.”

Scott asked his oldest daughter, Jenny, to come home from college so he could tell her in person. When she arrived, he sat her down in the kitchen and immediately said, “I have something to tell you. Everything is going to be fine, but I have a cancer called multiple myeloma.” Jenny was upset at first but felt better when she realized that her parents remained calm and had a plan in place.

Scott’s nine-year-old daughter, Hannah, was a little scared at first. But she was able to go along with him for his infusions and was present when Scott had a stem cell transplant in October 2010. Scott had good communication with Hannah, which helped make his experience less scary for her. She even nicknamed the machine that was giving Scott his medications “Charlie.”

Since his diagnosis, Scott has been on the same treatment regimen: lenalidomide (Revlimid®), bortezomib (Velcade®), and prednisone. He also receives bisphosphonates to help protect his bones.

Scott has experienced several side effects including diarrhea, constipation, fatigue, and neuropathy from both the myeloma and the treatment. Still, he continues to have a positive attitude. When walking became painful for his feet, he bought new sneakers, which made all the difference. After Scott started to develop neuropathy in his hands, he bought an electric screwdriver so he could continue to do work around the house. Scott has experienced some cognitive effects from the chemotherapy. He thinks that his “chemo brain” is improving, but his wife jokingly reminds him otherwise. Scott is able to enjoy spending more time with his family now that he is retired.

Scott and Diane are involved with a few blood cancer organizations, including The Leukemia & Lymphoma Society (LLS), which has a local multiple myeloma support group. Scott volunteers for LLS’ *Patti Robinson Kaufmann First Connection Program* and is a team captain for the Light The Night® Walk. Talking with other multiple myeloma, leukemia, and lymphoma patients and caregivers has been helpful. “Listening to their stories really helped me out emotionally.”

Scott recommends that patients see a multiple myeloma specialist and advises them to take ownership of their disease. “There is no cure for myeloma right now. It’s your life, and it all depends upon you. Not your doctor, not anybody else. Once you accept that, then you’ll start making the right decisions for you.”

Today, Scott is in complete remission. He believes that multiple myeloma has changed his attitude about life—little things don’t seem to matter much anymore. “My wife says our marriage is even better because I’m much calmer now.”