## Progress Made in Myeloma Research Through Multiple Efforts

More than 60,000 people in the United States are survivors of multiple myeloma (National Cancer Institute [NCI], 2011). According to the NCI (2011), multiple myeloma is highly treatable but rarely curable. However, we have made tremendous progress in the treatment and control of this disease. The median survival of someone with multiple myeloma was about seven months before chemotherapy, which stretched to 24-30 months with chemotherapy. The median survival now is 45-60 months with further improvements due to the addition of newer therapies such as bortezomib, thalidomide, and lenalidomide, as well as pulse

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corticosteroids and stem cell transplantation. Although no one wants their expected lifespan to be measured in months, the change from 7 to 60 months over the past 20 years is a significant improvement.

Part of that progress has been due to the work of a small group of people. Brian Novis had been diagnosed with multiple myeloma before he and Susie Novis married; she remembers that when she should have been picking out china and a wedding dress, she was instead searching for medical information for her fiancé. Along with her late husband Brian and a multiple myeloma specialist named Brian Durie, MD, Susie founded the International Myeloma Foundation (IMF) in 1990. The IMF has grown since then to become an organization that empowers patients through education, advances research to find a cure, and has become a role model for advocacy organizations. Today, IMF holds seminars in 15 countries, distributes more than 25,000 information packets each year in more than 13 languages, and has raised more than \$60 million to support programs and research about this disease. The IMF now has more than 195,000 members in 113 countries around the world.

One of the instrumental activities of the IMF, supported with donations from a variety of pharmaceutical companies, was

> the development of the Nurse Leadership Board (NLB), which is made up of expert oncology nurses from the leading cancer centers treating patients with myeloma in the United States. The mission of

the NLB is to develop broad recommendations for nursing care for patients with myeloma. The NLB has developed patient education sheets and nursing programs to advance the care of patients with myeloma. In June 2008, this group published their first supplement with the *Clinical Journal of Oncology Nursing*, which focused on managing side effects of the newer novel agents approved for use in

this population. This current supplement represents their latest efforts in addressing common problems that can affect the quality of life in myeloma survivors. It is based on both existing evidence and the expert opinion of the NLB.

Depending on the type of practice you are in, you may or may not have taken care of someone with multiple myeloma. Regardless, this supplement has something to offer you as it identifies common problems facing cancer survivors. Many patients with cancer develop bone metastases, experience sexual dysfunction, or need a plan focusing on health promotion. Your patients will benefit from the recommendations in this supplement.

As Margaret Mead said, "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has." The story of the IMF and the NLB is one of the impact of just such a group.

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## Reference

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