



International Myeloma Foundation

RESEARCH EDUCATION SUPPORT ADVOCACY

Serving the myeloma community for nearly 20 years!

SUSIE NOVIS

President and Co-founder

Susie Novis founded the International Myeloma Foundation (IMF) in 1990, along with her late husband Brian Novis, and hematologist Brian G.M. Durie, M.D., a multiple myeloma specialist who was then practicing in England. Susie brings to the IMF a background as a business executive along with her personal drive and commitment to myeloma patients based on her own experience:

Shortly after she and Brian Novis were engaged, he was diagnosed with the myeloma. Brian received his diagnosis over the phone. His doctor called him at work and said, "You have multiple myeloma." Brian said, "What's that?" The doctor replied "It's a cancer of the bone marrow, you have 3 to 5 years to live, stop by my office on your way home." He was just 33 years old.

Like everyone who hears the words multiple myeloma for the first time, they were in shock and, worst of all, they felt completely alone. At the time there was no place for myeloma patients and their families to turn to for help or support. Susie remembers that when she should have been picking out china and a wedding dress, she was searching for medical information for her fiancé.



"We wanted to help prevent future myeloma patients and their families from experiencing the same sense of isolation we had to struggle with." Susie Novis

Despite Brian's illness, he and Susie got married, and together with Dr. Durie they formed the International Myeloma Foundation to help other patients and their families. Just four short years after his diagnosis, Brian Novis succumbed to the disease; he was 37 years old. Susie was devastated, of course, but she and Dr. Durie agreed to continue the work of the Foundation, the work Brian Novis had begun.

185,000 members in 113 countries

In 1992 Susie was elected executive director of the IMF and became its first president, a title she still holds today. Under her direction the IMF has grown from three people to 185,000 members in 113 countries around the world. The IMF has raised over \$40 million, with more than 86% going directly to support IMF programs and myeloma research.



Susie started the IMF's flagship *Patient & Family Seminars* program in 1993 to bring experts and information directly to people affected by myeloma. To date, the IMF has held over 100 of these seminars in 13 countries around the world. Susie has also overseen the development of multi-lingual patient materials; the IMF distributes more than 25,000 information packets each year in more than 13 languages

To support research, in 2003 she conceived of Bank On A Cure®, the first-ever myeloma specific DNA data bank, and she developed the IMF Scientific Advisory Board Retreat to bring the world's myeloma experts together to engage in focused scientific discussions.

Susie has testified before Congress, urging greater resources for myeloma research, and each year she logs more than 100,000 miles to personally help bring information and inspiration to patients and families in need. Susie is the recipient of the Joseph Michaeli Award and the Baylor-Charles A. Sammons Cancer Center Award for her outstanding contributions to the understanding and treatment of myeloma.

Susie was born and raised in Connecticut, and currently resides in Los Angeles. Susie and Brian Durie found friendship, support and guidance working side-by-side, and in 1994 they were married.

The IMF can be reached at (800) 452-CURE www.myeloma.org.