



International Myeloma Foundation

Marking the 20th Anniversary of Serving the Myeloma Community

Research - Education - Support - Advocacy

OVERVIEW

The International Myeloma Foundation (IMF) is the oldest and largest myeloma organization, reaching more than 195,000 members in 113 countries worldwide.

The IMF is a 501 (c) 3 non-profit organization dedicated to improving the quality of life of myeloma patients and their families.

The IMF has global headquarters in North Hollywood, CA, USA; with European headquarters in Brussels, Belgium, Latin American headquarters in Brazil, and affiliated support groups available worldwide.

“KNOWLEDGE IS POWER”

Multiple myeloma is a cancer with an unusual and often unfamiliar name, leaving newly diagnosed patients and their families feeling alone and confused. But there are encouraging developments about managing the disease with more effective and less invasive treatments.

The IMF is dedicated to delivering comprehensive information to patients about these developments and to supporting and promoting research to continue this encouraging trend.

PROGRAM HIGHLIGHTS

- **PATIENT & FAMILY SEMINARS:** The IMF is the first organization to provide ongoing educational seminars. To date, the IMF has conducted more than 200 educational seminars worldwide. The IMF also serves patients and families with a **Hotline, Multi-Lingual Website, Educational Materials, and Global Support Groups.**
- **BANK ON A CURE®:** The IMF operates a unique global gene bank to advance myeloma research.
- **ADVOCACY:** The IMF represents its patients in meetings with government representatives, private insurers and pharmaceutical developers.

Until there is a Cure... There is the IMF

The Story of the IMF

In 1990, Brian Novis, a 33-year-old myeloma patient, started the International Myeloma Foundation in the basement of his Los Angeles home with his wife Susie and his doctor Brian G.M. Durie. It was a long way from where Brian Novis had been just two years earlier. In 1988 he was working as an executive headhunter and about to be married, when a routine insurance physical delivered the news that would change his life.

At age 33, Brian Novis was diagnosed with multiple myeloma and told he had just three to five years to live.

Susie Novis, then his bride-to-be, remembers she should have been picking out china and a wedding dress; instead they were searching for information about a disease they'd never heard of before.

‘We felt as if we were sailing down a river alone...’ Susie Novis

Brian and Susie got married, but their lives focused on the struggle to find information and support. Determined not to let anyone else with the disease feel so isolated and alone, Brian borrowed a typewriter to start the IMF in a tiny home office. As his condition worsened, Brian ran the Foundation from his bed. In July 1992, Brian passed away.

“One person can make a difference, two can make a miracle.” Brian Novis

“Brian gave his life for the foundation,” says Susie Novis. And so she, along with Brian’s doctor, myeloma specialist Brian G. M. Durie continued the work with Susie as president and Dr. Durie as chairman.

Today the IMF has global reach with 196,000 members in 113 countries worldwide.

And, oh yes... Susie and Brian Durie found friendship, support and guidance working side-by-side with each other. And in 1994 they were married.

Myeloma is a cancer of the bone marrow affecting production of red cells, white cells and stem cells, and it can damage bone.

It is also called “multiple myeloma,” because multiple areas of bone marrow may be involved. Myeloma is the second most common blood cancer after lymphomas, affecting an estimated 750,000 people worldwide and its prevalence is increasing.

Myeloma is an important focal point for advanced cancer research.

Today there are more than 100 drugs in clinical trials for multiple myeloma in the United States alone. There are also multiple drug regimens that can be used in combination and in sequence to help some patients maintain their daily routines for years and even decades.



International Myeloma Foundation

“Since starting the International Myeloma Foundation 20 years ago, we are proud to have raised over fifty million dollars for research and patient education.”

Susie Novis
Co-founder & President

IMF LEADERSHIP



Susie Novis
Co-founder & President



Brian G.M. Durie, M.D.
Co-founder & Chairman

David Girard
Executive Director

Thomas Reiser
Director Europe

Dan Navid
Sr. Global Analyst

Diane Moran
Sr. VP Strategic Planning

Lisa Paik
VP Clinical Education & Research Initiatives

PATIENT & FAMILY SEMINARS

A cornerstone of the IMF educational outreach programs, Patient & Family Interactive Seminars bring experts to communities around the United States and literally around the world to provide patients and their family members the opportunity to get the latest information - first-hand - about current therapies, research advances and emerging treatment options. These seminars help patients fully understand their options and make informed choices about treatments.



PATIENT & FAMILY SUPPORT GROUPS

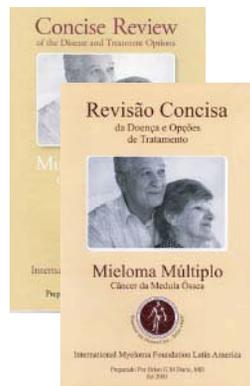
The IMF has helped establish and maintain a comprehensive network of support groups around the world to assist patients and their families. The support groups serve as a clearinghouse for information and an opportunity for patients and families to meet with each other and share their experiences. The IMF leadership regularly travels around the world to meet with support groups to discuss new developments in myeloma treatment and management.

THE IMF HOTLINE

This is an information service staffed by a knowledgeable team at IMF global headquarters to answer questions from patients and family members and to provide information about medical services, pharmaceutical access, and patient support groups. The service is especially important to newly diagnosed patients. The service handles more than 400 calls per month. In the United States and Canada it is accessible toll-free at 800 452-CURE (2873), Monday through Friday, 9am to 4pm PST, or by e-mail: TheIMF@myeloma.org.

MULTI-LINGUAL MATERIALS

The IMF maintains a website with up-to-date details about drug treatments, medical care, conventions and seminars, including webcasts and video interviews with research physicians from major medical meetings. The global website can be accessed at www.myeloma.org, with companion websites in Spanish: www.mielomala.org, and Portuguese: www.myeloma.org.br. The IMF also distributes more than 25,000 information packets per year providing details about myeloma and disease management in more than 13 languages including Chinese, French, German, Hebrew, Italian, Japanese, Korean, Polish, Russian and Turkish. Publications include the *IMF Patient Handbook*, *Multiple Myeloma: A Concise Review of the Disease and Treatment Options*, *Myeloma Today* - the IMF quarterly newsletter, and the *Understanding Series* - treatment-specific brochures on new therapies and clinical trials.



BANK ON A CURE®

The world's first repository of myeloma-patient DNA collected globally through large clinical trial groups, clinical centers, hospitals, and individual patients. More than 3,000 DNA samples along with custom gene chip analyzers and other high-tech equipment are housed at the University of Minnesota and at the Institute of Cancer Research in the U.K. Published research from BOAC is showing a possible link between myeloma and environmental toxins.

RESEARCH

In 1994, the IMF established the **BRIAN D. NOVIS RESEARCH GRANTS** program to support both junior and senior investigators. The IMF also sponsors the **International Myeloma Working Group**, maintains global expertise through the prestigious members of its **Scientific Advisory Board** and sponsors the biennial **INTERNATIONAL MYELOMA WORKSHOP**, focusing on advances in myeloma diagnosis and treatment.

ANNUAL EVENTS

Robert A. Kyle Lifetime Achievement Awards and the Comedy Celebration benefiting the Peter Boyle Memorial fund.