

# INTERNATIONAL MYELOMA FOUNDATION



[www.myeloma.org](http://www.myeloma.org)

# International Myeloma Foundation

- Founded in 1990

- Mission:

*To improve the quality of life for myeloma patients while working toward prevention and a cure*

- Four areas of focus:

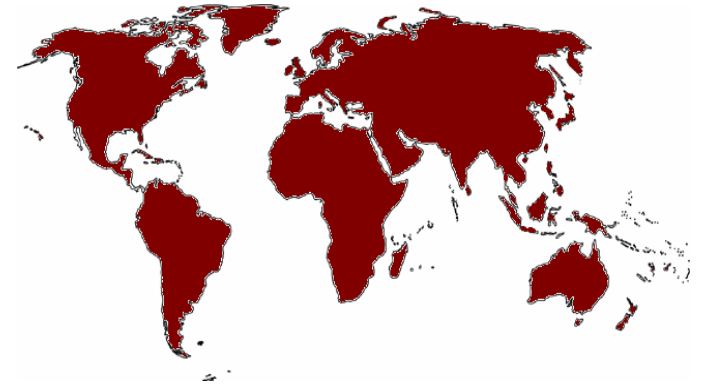
- Education
- Advocacy
- Research
- Support

*“Until there is a Cure...  
There is the IMF.”*



# International Myeloma Foundation

- Membership – more than 165,000
- Global reach - 113 countries
- Scientific Advisory Board
  - 71 world recognized experts
- Raised more than \$40 million dollars



# IMF Around the World

IMF Europe

IMF Japan

IMF Latin America

IMF Israel

## IMF Affiliates

Myeloma Canada

Myeloma Foundation of Australia

Česká Myelomová Skupina



# IMF = International

## Catalyst for Change

- ❑ Support group development and assistance
- ❑ Originated Patient & Family Seminar concept
- ❑ Patient Advocacy – Public Relations and Policy
- ❑ Caregivers, families and community oncologists are central to our mission

*Disease knows no political  
boundaries*



# IMF Patient Education

## IMF Patient & Family Seminars

- 1993 – 1<sup>st</sup> IMF Patient & Family Seminar
- 1995 – 1<sup>st</sup> European Patient & Family Seminar
- More than 170 have been held worldwide to date
- European seminars have been held in:
  - Austria
  - Czech Republic
  - France
  - Germany
  - Italy
  - Spain
  - Switzerland
  - Turkey



# IMF Education – Website

- **Multilingual Website - 40 Million “hits” per year**

- The IMF website provides viewers with continuous, timely information on a wide variety of topics:

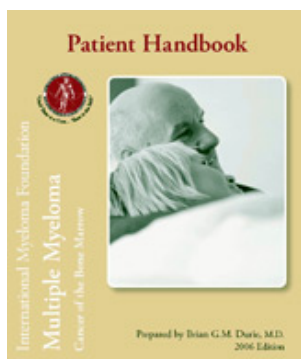
- IMF programs, resources, and services
- PDF's of all publications
- The IMF's extensive video library
- Exclusive web casts with leading myeloma experts taped live at major medical conferences.



- The IMF website is the #1 myeloma resource that appears on the search engines of Google, MSN, Yahoo and Ask.com.



# IMF Education – Materials



## ● 2006 Publications updates

- ❑ The IMF disseminates thousands of brochures every year to educate readers on myeloma and deliver the latest, cutting-edge research and information
- ❑ All brochures are updated post-ASH each year and are developed by a team of medical writers and reviewed by IMF Scientific Advisors.



## ● Info Packs

- ❑ The IMF distributes approximately 20,000 information packages (Info Packs) a year.
- ❑ These packages are sent to patients, caregivers, nurses, physicians, and facilities, and are also available upon request.
- ❑ Included are:
  - Key publications
  - Information about the foundation
  - Patient & Family Seminars
  - Upcoming events and clinical conferences





# IMF Education – Publications

## ● Myeloma Today

- ❏ The quarterly IMF newsletter is sent to more than 7,500 subscribers worldwide for free. *Note: Total readership is approximately 60,000 due to pass-along rate and web readers.*

## ● Myeloma Minute

- ❏ An e-newsletter with more than 13,000\* subscribers offering:

- The latest myeloma research news
- Links to key abstracts
- Clinical trial information
- Relevant current events for myeloma patients
- Other IMF news
- Links to relevant information, physician interviews from major medical meetings, and clinical trial information.



\*Total readership is approximately 60,000 due to pass-along rate.

# IMF Research

## ● Bank On A Cure®

- ❖ Bank On A Cure is the first global, myeloma-specific DNA bank and was launched in 2003.
- ❖ Involves the majority of major myeloma centers worldwide, plus the thousands of myeloma patients who participate in trials through these centers.
- ❖ Results will enable better treatment decisions for patients and will hopefully lead to a myeloma cure.



## ● Brian D. Novis Research Grants

- ❖ The late Brian D. Novis was the co-founder of the International Myeloma Foundation (IMF). In his memory, the IMF has established annual grants to promote research into better treatments, management, prevention, and a cure.
- ❖ Made possible through donations from private individuals and awarded during the ASH conference to doctors and researchers doing work in the field of myeloma.



# IMF Research

## ● International Myeloma Working Group

■ The International Myeloma Working Group is comprised of more than 60 of the world's top myeloma researchers and clinicians. Their collaborative efforts have produced the following publications:

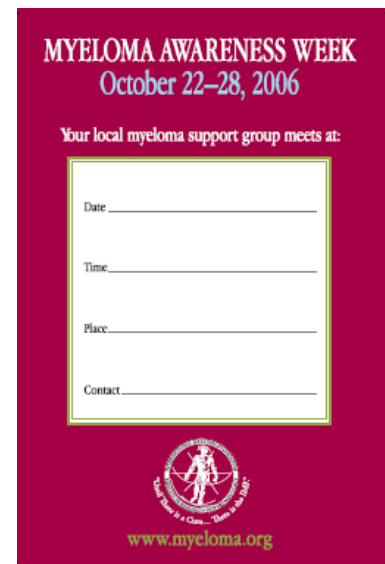
- *2003 Myeloma Management Guidelines*
- *2004 Diagnostic Criteria for Myeloma*
- *2005 International Staging System*
- *2006 International Uniform Response Criteria*
- *2006 Better Outcome in Young Patients with Myeloma*
- *2006 DVT Guidelines - ASH 2006 & manuscript*
- *2006 Overall Management Guidelines for Myeloma (update)*



# IMF Support - Creating Connections

## ● Myeloma Awareness Week

- This annual grassroots effort enlists the help of support group members across the US and Canada to promote awareness about myeloma; the local support group and the purposes it serves; and the IMF's many programs and services that benefit those affected by myeloma.
- Past campaigns have been designed to:
  - Increase support group attendance
  - Promote awareness amongst the groups at highest risk for myeloma;
  - Drive advocacy at the local, state, and federal levels;
  - Foster the establishment of new support groups in underserved areas; and
  - Ensure that the local oncologist's office is aware that a local support group is available to their patients.



# IMF for Caregivers and Families

- Caregivers have always had an integral role in IMF programs and projects.
- “Caregivers Need Care Too” sessions at IMF Patient & Family Seminars.
- Articles in all publications and website address specific challenges caregivers face.
- Caregivers key to completing circle of quality patient treatment and support.



# IMF and the Community Doctor

- Patient education information also key resource for community oncologists.
- Special Publications: *Citings*, Major Professional Meeting Updates, webcasts, press releases.
- Local doctors' meetings combined with Patient and Family Seminars.
- Inclusion of local doctors at IMF events



# IMF Europe: Email Newsletters

- Translation of *Myeloma Today* articles of interest to European Myeloma community
- German *Myelom Merkur* launched in Spring 2006
- Spanish *Mensajero de Mieloma* produced in 2006, to be relaunched Summer 2007
- French edition to be launched in Summer 2007
- Italian edition to be launched in Winter 2008
- Minimum of 5 issues per year
  - ❑ Recruit team of translators (hem/oncs)
  - ❑ ASH Special Edition w/ video interviews
  - ❑ German demand has led to 9 issues to include selections from the *Myeloma Minute*



# IMF Europe: Building Collaboration

- Develop and help maintain new Support Groups and Patient Leaders.
- Working with existing groups/structures.
- Collaborate with Scientific Advisors to meet patient needs.
- Meeting with doctors and patients throughout Europe on continuous basis to identify opportunities.
- Refine and expand services, publications, and events.





# The IMF: Setting the Standard

- For Patient Care, Patient Advocacy, and Science and Research
- We have a proven record, but we cannot do it without your help.
- Help us set the standards for Myeloma patient support in the Czech Republic and throughout Europe.



Until there is a cure...

