# INTERNATIONAL MYELOMA FOUNDATION





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

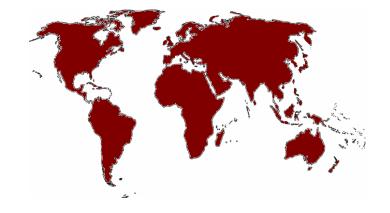
- Four areas of focus:
  - Education
  - Advocacy
  - Research
  - Support

"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





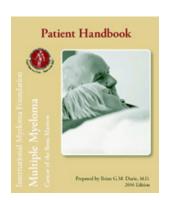
### IMF Education – Website

- 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.

Here is a Cure... There's

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

There is a Cure... There

### **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.





### **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

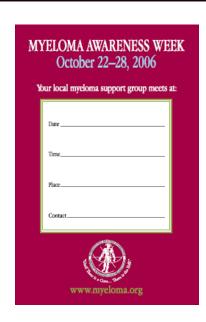
- The International Myeloma Working Group is comprised of more than 60 of the world's top myeloma researchers and clinicians. Their collaborative efforts have produced the following publications:
  - 2003 Myeloma Management Guidelines
  - 2004 Diagnostic Criteria for Myeloma
  - 2005 International Staging 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 *Mensajiero 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*



Der Myelom Merkur wird 9x ./Jahr veröffentlicht werden und ist kostenlos verfügbar durch ein Registrierung bei merkur@mveloma.org.

4. Ausgabe, November 2006

#### LANGSAM ABER SICHER

Ja, Ja. Ich weiß es dauert ein bisschen länger als wir dachten. Aber die nächste Ausgabe kommt ziemlich schnell. Sicher!

Am Wochenende wird Dr. Robert Kyle von der Mayo-Klinik – er ist auch Vorsitzender des Wissenschaftlichen Beirates der IMF – bei zwei Patientemeranstaltungen sprechen: Am 18. November in Nürmberg und am 20. November in Berin. Das ist ein Beitrag zu den Bemühungen der IMF, die Kommunikation innerhalb der Myelomgemeinschaft zu erweitern.

Am Samstag, dem 18. November, wird Dr. Kyle von 10:30-14:30 Uhr gemeinsam mit Dr. Wandt und Dr. Schäfer-Eckart im Hörsaal der Frauenklinik des Klinikums Nürnberg-Nord zugegen sein.

Am Montag, dem 20. November, werden Dr. Orhan Sezer und Dr. Kyle von 16:00-18:00 Uhr am Chantle Campus Mitte, Charitejolatz 1 (ehemals Schumannstr. 20) ein Patientenseminar leiten. Wenn Sie an der Klinik ankommen, gehen Sie bitte zum Neubau der Medizinischen Klinik (Sauerbruchweg 3), zum Hörsaal Ebene 3.

In dieser Ausgabe bringen wir einige ausgewählte Artikel aus der Sommer-2006-Ausgabe von Myelome Today.

#### ASCO BERICHT

von Lynne Lederman, PhD

#### Ermutigende Neuigkeiten

Das Treffen von der amerikanischen Gesellschaft für klinische Onkologie (ASCO) im Jahr 2006, das im 2. Juni das sechte Mal in Altants, Georgia stattland, lieferte ermüligende Nachrichten über die Verwendung neusräger Therapeutike für sowohl Einzel- als auch Kombinationstherapie für Patienten mit neu diagnostiziertem oder Myelomrezider. Außerdem gehen die Studien über den Nutzen von Therapeutika, die den Krochen betreffen, weiter.



### 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...



