

# ANNUAL REPORT 2006 - 2007

Me

MYELOMA  
EURONET

**Evropský hlas pacientů s mnohočetným myelomem**  
**Die Stimme der Myelom-Patienten in Europa**  
**The voice of myeloma patients in Europe**  
**La voz de los pacientes con mieloma en Europa**  
**La voix des patients atteints du myélome en Europe**  
**La voce dei pazienti affetti da mieloma in Europa**  
**Europejski głos chorych na szpiczaka mnogiego**  
**A voz dos doentes com mieloma na Europa**  
**Vocea pacientilor cu mielom din Europa**  
**Avrupa'daki miyelom hastalarının sesi**  
صوت مرضى المايلوما في اوروبا



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## Myeloma Euronet

Myeloma Euronet, a non-profit network organisation of multiple myeloma patient groups, is a European initiative dedicated to raising the awareness of multiple myeloma, an increasingly common form of bone marrow cancer. Myeloma Euronet also seeks to provide information on the diagnosis, treatment and care of persons living with multiple myeloma as well as support for their families and loved ones.

Launched at the 10th Congress of the European Hematology Association (EHA) in Stockholm on 3 June 2005, Myeloma Euronet's constitution was adopted at the network's first Annual General Meeting on 18 June 2006 in Amsterdam, The Netherlands (during the 11th EHA Congress). The organisation's founding members are:

- Myelom Kontakt Österreich, Austria
- Deutsche Leukämie- und Lymphom-Hilfe e. V., Germany
- Blodcancerförbundet, Sweden
- Stiftung zur Förderung der Knochenmarktransplantation, Switzerland
- Myeloma UK (then International Myeloma Foundation (UK)), United Kingdom

The image shows a document titled 'Copie à publier aux annexes du Moniteur belge après dépôt de l'acte'. It features a 'Vol 61 B' stamp and a 'Réser au Moniteur belge' stamp with a barcode and the number \*06151625\*. A date stamp from the 'TRIBUNAL COMMERCE CHARLEROI - ENTRE LE' reads '25. 09. 2006' and 'Greffé'. The document lists the following details:

- N° d'entreprise: 883.729.287
- Dénomination (en entier): MYELOMA EURONET
- Forme juridique: Association internationale sans but lucratif
- Siège: 6000-Charleroi (Belgique), rue de Dampremy, 67/32
- Objet de l'acte: CONSTITUTION
- L'AN DEUX MILLE SIX
- Le dix-neuf septembre.
- Devant Hubert MICHEL, Notaire à Charleroi
- Compareissent :

First section of the official registration document, published in the "Moniteur Belge"

Myeloma Euronet was officially registered as an international non-profit association (Association Internationale sans but lucratif, AISBL) under Belgian law on 25 September 2006. The headquarters is located at rue de Dampremy, 67/32, B-6000 Charleroi, Belgium, and the registration number is 883.729.287. Myeloma Euronet's Secretariat is located in Berlin, Germany.

## Board of Directors

Myeloma Euronet's Board of Directors was elected at the first Annual General Meeting on 18 June 2006 and is made up of seven individuals:

### President

Anita Waldmann, President of the Deutsche Leukämie- und Lymphom-Hilfe e. V. (German leukaemia and lymphoma support association of self-help organisations for the support of adults with leukaemia and lymphoma), Germany



### Vice President

Roman Sadžuga, President of the Polskie Stowarzyszenie Pomocy Chorym na Szpiczaka (Polish Myeloma Patient Help Association), Poland



### Treasurer

Begoña Barragán García, President of the Asociación Española de Afectados por Linfomas (Spanish association of people affected by lymphomas), Spain



### Secretary

Robert Schäfer, President of Robert Schäfer – International Communications, Germany



### Observer

Viorica Cursaru, President of Myeloma Euronet Romania, Romania



### Observer

Candy Heberlein, President of the Stiftung zur Förderung der Knochenmarktransplantation (Foundation for the Promotion of Bone Marrow Transplantation), Switzerland



### Observer

Assoc. Prof. Miroslav Hrianka, PhD, Representative of the Klub pacientov of the Slovenská myelómová spoločnosť (Patients' Club of the Slovak Myeloma Society), Slovakia



## Medical Advisory Board

Myeloma Euronet Medical Advisory Board members review information materials for accuracy prior to publication and dissemination and provide their counsel when requested. Medical Advisory Board members include:



Prim. Univ. Prof. Dr. Heinz Ludwig  
Wilhelminenspital, Vienna,  
Austria



Prof. Dr. Roman Hajek  
University Hospital Brno,  
Czech Republic



Prof. Dr. Hermann Einsele  
Universität Würzburg, Germany



Prof. Dr. Hartmut Goldschmidt  
Universität Heidelberg, Germany



Priv.-Doz. Dr. med. Christian Straka  
Interne Klinik Dr. Argirov, Berg,  
Germany



Prof. dr hab. Anna Dmoszyńska  
Katedra i Klinika Hematoonkologii i  
Transplantacji Szpiku. Lublin, Poland



Prof. dr hab. Wiesław Jędrzejczak  
Klinika Hematologii, Onkologii i Chorób  
Wewnętrznych, Warszawa, Poland



Dr n. med. Artur Juczyszyn  
Katedra i Klinika Hematologii  
Collegium Medium UJ, Kraków, Poland



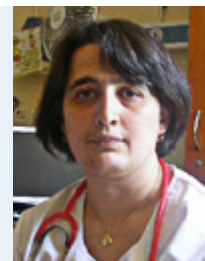
Prof. dr hab. n. med. Aleksander Skotnicki  
Katedra i Klinika Hematologii Collegium  
Medium UJ, Kraków, Poland



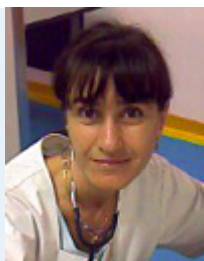
Prof. Krzysztof Warzocha  
Instytut Hematologii i  
Transfuzjologii, Warszawa, Poland



Horia Bumbea MD, Assistant Professor  
Spitalul Universitar de Urgenta Bucuresti,  
Bucharest, Romania



Dr. Viola Popov  
Spitalul Judetean Arges,  
Pitesti jud Arges, Romania



Ana Maria Vladareanu, MD, PhD  
University Hospital, Bucharest,  
Romania



Professor Dr. Darinka Boskovic, PhD  
Clinical Center of Serbia,  
Belgrade, Serbia



Ass. Prof. Dr. Jelena Bila  
Clinical Centre Serbia, Belgrade, Serbia



Veronika Ballova, MD  
National Cancer Institute,  
Bratislava, Slovakia



Prof. MUDr. Elena Tothova , PhD  
University of UPJŠ and Faculty Hospital  
of L. Pasteur, Košice, Slovakia



Dr. Christian Taverna  
Kantonsspital Münsterlingen,  
Switzerland



Professor J.A. Child  
University of Leeds, United Kingdom

## Members

Membership has been continuously growing since the network's founding in June 2005. There are four different types of members: full members, associate members, individual members, and supporting members. Only full members have voting rights at Annual General Meetings. On 31st December 2007, Myeloma Euronet had 38 members from 17 European countries:

### Full members

1. Myelom Kontakt Österreich, Austria (since 3 June 2005)
2. Mnohočetný Myelom Klub Pacientů, Czech Republic (17 August 2007)
3. Deutsche Leukämie- & Lymphom-Hilfe e. V., Germany (3 June 2005)
4. Arbeitsgemeinschaft Plasmozytom/Multiples Myelom, Germany (2 November 2006)
5. Plasmozytom/Multiples Myelom Selbsthilfegruppe in der Pfalz, Germany (22 May 2006)
6. Plasmozytom/Multiples Myelom Selbsthilfegruppe Berlin-Brandenburg, Germany (11 September 2006)
7. Myelom Hilfe München, Germany (1 December 2006)
8. Bayerische Myelom-Selbsthilfe e.V., Germany (20 November 2007)

9. Myelom-Hilfe Nordbayern e.V., Germany (20 November 2007)
10. Mielomas pacientu atbalsta biedrība, Latvia (21 September 2006)
11. Polskie Stowarzyszenie Pomocy Chorym na Szpiczaka, Poland (5 November 2005)
12. Myeloma Euronet Romania, Romania (12 October 2006)
13. Udruženje obolelih od multiplog mijeloma, Serbia (10 September 2006)
14. Slovenská myelómová spoločnosť, Slovakia (31 January 2007)
15. Asociación Española de Afectados por Linfomas, Spain (14 October 2005)
16. Blodcancerförbundet, Sweden (3 June 2005)
17. Stiftung zur Förderung der Knochenmarktransplantation, Switzerland (3 June 2005)
18. Myeloma UK, United Kingdom (3 June 2005)
19. Myeloma People Network (Scotland), United Kingdom (1 June 2006)

#### **Associate members**

1. Croatian Myeloma and Plasmacytoma Network, Croatia (since 18 July 2006)
2. Česká myelomová skupina, nadační fond, Czech Republic (14 October 2005)
3. Associação Portuguesa de Leucemias e Linfomas, Portugal (28 November 2007)
4. Spitalul Judetean Arges, Romania (14 October 2005)
5. Spitalul Universitar de Urgenta Bucuresti Clinica de Hematologie, Romania (5 November 2005)
6. Mieloma.com (online community), Spain (23 January 2007)
7. Ege University Hospital, Turkey (1 July 2007)
8. Myeloma UK – Yorkshire Support Group, United Kingdom (5 November 2005)

#### **Individual members**

1. Guy Fontaine, France (since 31 January 2007)
2. Sergio Heras Aranda, Spain (22 January 2007)
3. Cigir Karakilavuz, Turkey (15 October 2007)

#### **Supporting members**

1. Ortho Biotech – A Division of Janssen-Cilag, Austria/United Kingdom (Founding sponsor)
2. Amgen Inc., Switzerland/Germany (since November 2006/April 2007)

3. Celgene GmbH, Germany (July 2007)
4. Celgene International Sàrl, Switzerland (March 2007)
5. Novartis Pharma AG, Switzerland (June 2005)
6. Pharmion Ltd., United Kingdom (February 2006)
7. Roche, Switzerland (November 2006)
8. The Steel Charitable Trust, United Kingdom (June 2007)

Myeloma Euronet has issued a comprehensive policy on commercial funding which is based on the European Cancer Patient Coalition's Paper on Funding Arrangements with Commercial/Corporate Organisations, EURORDIS's policy on corporate sponsorship and the recommendations of the UK's Long Term Medical Conditions Alliance. This policy can be viewed on the Myeloma Euronet Web site at <http://www.myeloma-euronet.org/en/myeloma-euronet/fundingpolicy.php>.

### Geographical overview



## Annual General Meetings / Board Meetings

On 17th June 2006, the day before the first Annual General Meeting (AGM) which was held in Amsterdam, The Netherlands, Myeloma Euronet hosted an international myeloma treatment update, featuring presentations from some of the leading myeloma experts in Europe:

- Prof. Pieter Sonneveld, The Netherlands: New developments in standard therapy
- Prof. Hermann Einsele, Germany: New developments in transplantation
- Prof. Roman Hajek, Czech Republic: Benefit of autologous transplantation and new therapeutic options in the real life – Can a patient organisation help?
- Dr. Mauricette Michallet, France: New developments in combination therapy – combinations with Bortezomib
- Dr. Javier de la Rubia, Spain: New developments in combination therapy – combinations with Thalidomide and IMiDs – and future outlook
- Prof. Heinz Ludwig, Austria: New developments in supportive care

The treatment update was followed by an international panel discussion on “Access to Care for Myeloma Patients in Europe”, involving the following experts:

- Dr. Nils Wilking, co-author of the study “A pan-European comparison regarding patient access to cancer drugs”
- Mr. Roman Sadzuga, President of the Polish Myeloma Patient Help Association
- Prof. Dr. Heinz Ludwig, past President of the European Society for Medical Oncology (ESMO)

At the AGM on 18th June 2006, Myeloma Euronet’s constitution was adopted and signed by the Founding members, and the Board of Directors was elected. The 2006/2007 plan of action and budget were approved and the members also adopted an internal mentor programme where experienced members share best practices with new members.

Held on 19th May 2007 in Warsaw, Poland, Myeloma Euronet’s second AGM was preceded by two internal training sessions on setting up and running a successful myeloma patient support group/organisation and on fundraising. A set of internal rules of order and the action plan and budget for the years 2007/2008 were adopted.

Between June 2006 and December 2007, the Myeloma Euronet Board of Directors had four meetings, in Frankfurt and Düsseldorf, Germany, in Warsaw, Poland, and in Barcelona, Spain.

## Membership / Collaboration

Myeloma Euronet has become a member of the European Cancer Patient Coalition (ECPC) and the European Organisation for Rare Diseases (Eurordis). Representatives of Myeloma Euronet have actively participated in meetings hosted by these organisations respectively.

Over the past two years, Myeloma Euronet has also collaborated with the following organisations, notably around the development and promotion of the Multiple Myeloma Manifesto (see below for further information):

- European Group for Blood and Marrow Transplantation (EBMT)
- European Myeloma Network (EMN)
- Lymphoma Coalition

Myeloma Euronet has also been granted free or low-cost exhibition space at congresses hosted by national and international organisations and societies, including among others the European Group for Blood and Marrow Transplantation (EBMT), the European Hematology Association (EHA), the European Society for Medical Oncology (ESMO), the European CanCer Organisation (ECCO), the Austrian, German and Swiss Societies for Haematology and Oncology, the Turkish Society of Hematology, and the Greek Myeloma Study Group.

Even though Myeloma Euronet has made several attempts, it has so far been impossible to establish collaborations with other pan-European myeloma initiatives, which have constituted themselves after the founding of Myeloma Euronet, such as the International Myeloma Foundation (IMF) Europe and the European Myeloma Platform, a myeloma patient initiative which, according to the EMP, was founded in 2006 with "a substantial financial grant" from the IMF.

As Myeloma Euronet has stated repeatedly at various occasions as well as in a widely-distributed position statement on European myeloma patient group cooperation, Myeloma Euronet "is committed to the idea that partnership best advocates the cause of myeloma patients. It believes that competition and duplication of effort amongst myeloma patient groups work to the detriment of myeloma patients everywhere. To that end, the network actively encourages European patient groups to work together in partnership, rather than working against each other and thus damaging the credibility of the European myeloma patient community."

## Summary of Activities 2006 / 2007

Following is a brief overview of Myeloma Euronet's activities carried out during years 2006 and 2007. Some of these activities are explained in more detail further below.

- Developed and approved organisational structure, constitution, and internal rules of procedure
- Developed and approved Myeloma Euronet's tag line: *The voice of myeloma patients in Europe* and core graphic design
- Filed and completed registration as an international non-profit association (Association Internationale sans but lucratif, A.I.S.B.L.) registered in Belgium, registration number: 883.729.287
- Developed and approved Myeloma Euronet position statements on European Patient Group Cooperation and on Access to Thalidomide and Lenalidomide
- Conducted an international treatment update session and a panel discussion with leading myeloma experts from six European countries (June 2006, Amsterdam, The Netherlands)
- Developed and implemented an internal mentor programme (experienced members share best practices with new members)
- Conducted internal trainings for member groups on management and fundraising
- Expanded membership base from six to more than 30 members from 17 European countries
- Expanded the Medical Advisory Board from five to 19 members from nine European countries
- Expanded the network's multi-lingual, content-rich Web site, [www.myeloma-euronet.org](http://www.myeloma-euronet.org), from five to eleven languages and added new content and features
- Developed, conducted and evaluated an international survey on barriers to myeloma diagnosis, treatment, and care
- Produced Myeloma Euronet flyers, posters, banners, and give away pens to encourage survey participation and increase visibility during international congresses and at other occasions
- Developed and launched the pan-European Multiple Myeloma Manifesto campaign
- Established and enhanced working relationship with different Units of the European Medicines Agency (EMA)
- Developed, produced and distributed a German-language patient information brochure on Lenalidomide for use in Austria, Germany and Switzerland

- Started a multi-lingual multiple myeloma publication series (ongoing)
- Assisted member organisations in Poland and the UK in fighting for access to Bortezomib (Velcade)
- Myeloma Euronet's President served as a member of the ESMO Cancer Patient Working Group and the EBMT Patient & Family Day Organising Committee
- Contributed articles and presentations to patient organisation publications and various national and international meetings
- Updated members regularly on new developments in the field of multiple myeloma (medicine, politics, etc.) and on Myeloma Euronet's progress
- Represented Myeloma Euronet at national and international meetings, including, among others:
  - 2006, March: Polish member AGM, Warsaw, Poland
  - 2006, June: 11th EHA congress, Amsterdam, The Netherlands
  - 2006, Sept.: Myeloma Patient Day, Podebrady, Czech Republic
  - 2006, Sept.: Launch of Polish Myeloma Infodays, Poznan, Poland
  - 2006, Sept.: Myeloma Patient Information Day, Heidelberg, Germany
  - 2006, Sept./ Oct.: 31st ESMO Congress and 5th ESMO Patient Seminar, Istanbul, Turkey
  - 2006, Nov.: Joint Annual Meeting of the Austrian, German and Swiss Societies for Haematology and Oncology, and Patient Information Day, Leipzig, Germany
  - 2006, Dec.: 48th Annual Meeting of The American Society of Hematology (ASH), Orlando, FL, USA,
  - 2007, March: Polish member AGM, Warsaw, Poland
  - 2007, March: 1st EBMT Patient and Family Day during 33rd EBMT Congress, Lyon, France
  - 2007, May: 1st International Lymphoma-Leukemia-Myeloma Congress, Fethiye, Turkey
  - 2007, June: 12th EHA congress, Vienna, Austria
  - 2007, June: 10th DLH Patient and Family Congress, Heidelberg, Germany
  - 2007, June: 11th Int. Myeloma Workshop, Kos Island, Greece
  - 2007, July: 6th ESMO Patient Seminar, Lugano, Switzerland,
  - 2007, Sept.: Myeloma Patient Day, Lednice, Czech Republic
  - 2007, Sept.: 14th ECCO Congress, Barcelona, Spain
  - 2007, Sept.: DLH Patient and Family Seminar, Freiburg, Germany
  - 2007, Oct.: Joint Annual Meeting of the Austrian, German and Swiss Societies for Haematology and Oncology, and Patient Information Day, Basel, Switzerland

- 2007, Oct.: UK Magic for Nurses Education Day and Myeloma Infoday, London, UK
- 2007, Oct.: DLH Patient Information Day, Marburg
- 2007, Oct.: Myeloma Patient Day, Heidelberg, Germany
- 2007, Oct.: Myeloma Patient Day (as part of German Cancer Patient Congress), Würzburg, Germany
- 2007, Nov.: II Congreso AEAL para pacientes con linfomas y mielomas, Madrid, Spain
- 2007, Nov.: Myeloma Patient Day (as part of German Cancer Patient Congress), Leipzig, Germany
- 2007, Nov.: ESMO Patient Advocacy Forum, Brussels, Belgium
- 2007, Dec.: 49th Annual Meeting of The American Society of Hematology (ASH), Atlanta, GA, USA

## Public Information and Education

### Brochure

A six-page English-language information brochure informing readers about myeloma as well as Myeloma Euronet was developed for distribution at international congresses and events. The brochure also contains a reply coupon for readers interested in joining the organisation.



**Information Request Form**  
Please send me more information about membership in MYELOMA EURONET.

Name \_\_\_\_\_

Organization Name \_\_\_\_\_

Mailing Address \_\_\_\_\_

Telephone \_\_\_\_\_

Fax \_\_\_\_\_

Email \_\_\_\_\_

Please mail or fax this request form to:  
**MYELOMA EURONET Secretariat**  
c/o Robert Schaefer  
Brunnenstrasse 178/179  
D-10119 Berlin  
Germany  
Fax: +49 (0)30 28 87 97 66  
[info@myeloma-euronet.org](mailto:info@myeloma-euronet.org)  
[www.myeloma-euronet.org](http://www.myeloma-euronet.org)

**Join Us**  
Partnership and cooperation amongst patient groups and across national boundaries is critical to promoting greater awareness of myeloma and working toward a cure. Ours is an unbiased, European non-profit organization. We encourage you to join us in our efforts.

**Full and Associate Members**  
Myelom Kontakt Österreich, Austria (Founding Member) • Croatian Myeloma and Plasma Cell Network, Croatia • Česká myelomová skupina, radnický fond; Mnohočetný Myelom Klub Pacientů, Czech Republic • Deutsche Leukämie und Lymphom-Hilfe e.V., Germany (Founding Member) • Arbeitsgemeinschaft Plasmazytom/Multiples Myelom (APMM), EMS Bayrische Myelom-Selbsthilfe, M-H Myelom / Plasmazytom Hilfe München, Myelom Hilfe Nordbayern, Selbsthilfegruppe Plasmazytom / Multiples Myelom, Berlin, Multiples Myelom Plasmazytom Selbsthilfegruppe Rhein / Pfalz, Germany • Mielom as pacienti abalada biedriba, Latvia • Polska Stowarzyszenie Pomocy Chorym na Szpiczaka, Poland • Associação Portuguesa de Leucemias e Linfomas, Portugal • Myeloma Euronet Romania; Spitalul Judeean de Urgenta Bucuresti Clinica de Hematologie, Romania • Udruzenje obolalih od multiplog mijeloma, Serbia • Slovenská myelomová spoločnosť, Slovakia • Asociación Española de Afecidos por Linfomas, Mieloma.com, Spain • Blodbanor-förbundet, Sweden (Founding Member) • Stiftung zur Förderung der Knochenmarkstransplantation, Switzerland (Founding Member) • Ege Üniversitesi hastanesi, Turkey • Myeloma UK, United Kingdom (Founding Member) • Myeloma UK - Yorkshire Support Group; Myeloma People Network (Scotland), United Kingdom

**Supporting Members**  
Ortho Biotech - A division of Janssen-Cilag (Founding Sponsor) • Amgen Inc. • Celgene International Sàrl • Novartis Pharma AG • Pharmion Ltd. • Roche • The Steel Charitable Trust

**Me MYELOMA EURONET**  
November 2007

**European Network of Myeloma Patient Groups**  
A European initiative dedicated to raising awareness of multiple myeloma, an increasingly common form of bone marrow cancer.

MYELOMA EURONET is an international non-profit association (Association Internationale Sans But Lucratif, A.I.S.B.L.) registered in Belgium.  
Headquarters: rue de Dampremy, 67/32  
B-6000 Charleroi/Belem  
Registration number: 883.729.287  
[www.myeloma-euronet.org](http://www.myeloma-euronet.org)

**The voice of myeloma patients in Europe**

## Poster

An English-language poster is intended to inform the public about the four main areas of activity of Myeloma Euronet. The blank space on the right-hand side gives local groups or organisations the opportunity to announce public events or provide their contact information.

**Awareness  
Information  
Support  
Advocacy**

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

Me  
MYELOMA  
EURONET

Evropská síť organizací sdružujících pacienty s mnohočetným myelomem  
Europäisches Netzwerk von Myelom-Patientengruppen  
European Network of Myeloma Patient Groups  
Red Europea de Grupos de Ayuda para Pacientes con Mieloma  
Réseau européen de groupes de patients atteints du myélome multiple  
La rete europea di gruppi di assistenza per pazienti affetti da mieloma multiplo  
Sieć Europejska grup wsparcia chorym na szpiczaka mnogiego  
A rede europeia dos grupos de doentes afectados do mieloma múltiplo  
Miyelom Hastaları Grubu Avrupa Ağı  
الشبكة الأوروبية لمجموعة مرضى المايلوما

MYELOMA EURONET The voice of myeloma patients in Europe

## Press releases / Announcements / Position Statements

A fact sheet on multiple myeloma and the following press releases/announcements/statements were issued by Myeloma Euronet in the years 2006/2007 and can be downloaded from the newsroom section of the organisation's Web site at [www.myeloma-euronet.org](http://www.myeloma-euronet.org):

- Myeloma Euronet Treatment Update and International Panel Discussion on Access to Treatment and Care for Myeloma Patients in Europe (March 2006)
- Myeloma Euronet launches international survey on barriers to myeloma diagnosis, treatment, and care (May 2006)
- Myeloma Euronet empowers patients and highlights inequalities in access to treatment and care for myeloma patients in Europe (June 2006)
- Myeloma Euronet Web site [www.myeloma-euronet.org](http://www.myeloma-euronet.org) now available in Turkish language (September 2006)
- Multiple Myeloma Manifesto (September 2006)

- Myeloma Euronet Position Statement: Access to Thalidomide and Lenalidomide (January 2007)
- Late diagnosis and slow drug approval are the greatest barriers to multiple myeloma treatment and care (February 2007)
- Myeloma Euronet Position Statement: European Myeloma Patient Group Cooperation (October 2007)

## Banners

Different banners on Myeloma Euronet and the Multiple Myeloma Manifesto (see below for more information) were developed for display at congresses and meetings. The banners are easy to transport and help to make information stands both visually attractive and informative.



The image shows four banners arranged in a row. From left to right:

- Banner 1 (English):** Features the 'Me MYELOMA EURONET' logo. Text includes: 'Europäisches Netzwerk von Myelom-Patientengruppen', 'European Network of Myeloma Patient Groups', 'Red Europea de Grupos de Ayuda para Pacientes con Mieloma', 'Réseau européen de groupes de patients atteints du myélome multiple', 'Rete europea di gruppi di assistenza per pazienti affetti da mieloma multiplo', 'www.myeloma-euronet.org', 'Myeloma Euronet - Die Stimme der Myelom-Patienten in Europa', 'Myeloma Euronet - The voice of myeloma patients in Europe', 'Myeloma Euronet - La voz de los pacientes con mieloma en Europa', 'Myeloma Euronet - La voix des patients atteints du myélome en Europe', 'Myeloma Euronet - La voce dei pazienti affetti da mieloma in Europa'.
- Banner 2 (English):** Titled 'Multiple Myeloma Manifesto'. Text includes: 'Multiple Myeloma... is a cancer of the bone marrow... is currently incurable but treatable... affects more than 77,000 people in Europe at any one time... is one of the fastest growing cancers in the western world'. It lists requirements for care: 'Equity in biomedical and clinical research', 'Multidisciplinary care from trained professionals', 'Increased information and support services', 'Access to optimal treatment', 'Policies that put patients and their needs at the centre of treatment and care', 'Reduction in the isolation that characterises the lives of people living with myeloma and other rare cancers'. It concludes: 'No myeloma patient should be left behind in the race for cancer cures. Show your support and sign the Multiple Myeloma Manifesto at [www.myeloma-euronet.org](http://www.myeloma-euronet.org)'. Logos for Me, EMN, and EFG are at the bottom.
- Banner 3 (German):** Titled 'Manifest zum Multiplen Myelom'. Text includes: 'Das Multiple Myelom (Plasmozytom)... ist ein Knochenmarkkrebs... ist noch nicht heil- aber behandelbar... betrifft mehr als 77.000 Menschen in Europa... ist eine der sich am schnellsten ausbreitenden Krebsformen in der westlichen Welt'. It lists demands: 'Gerechtigkeit bei biomedizinischer und klinischer Forschung', 'Fachübergreifende Versorgung durch ausgebildete Fachkräfte', 'Verbesserte Informations- und Unterstützungsangebote', 'Zugang zu bestmöglicher Behandlung', 'Politische Verfahrensweisen, die Patienten und ihre Bedürfnisse in den Mittelpunkt von Behandlung und Versorgung rücken', 'Minderung der Isolation, die für Menschen, die mit Myelom und anderen seltenen Krebsformen leben, charakteristisch ist', 'Kein Myelompatient sollte beim Wettlauf um Krebsheilmittel zurückbleiben'. It concludes: 'Zeigen Sie Ihre Unterstützung und unterzeichnen Sie das Manifest zum Multiplen Myelom! [www.myeloma-euronet.org](http://www.myeloma-euronet.org)'. Logos for Me, EMN, and EFG are at the bottom.
- Banner 4 (English):** Features the 'Me MYELOMA EURONET' logo. Text includes: 'European Network of Myeloma Patient Groups'. The aims are listed: 'Raise European awareness of multiple myeloma amongst the public', 'Build partnerships among members of Myeloma Euronet in order to share experience and expertise', 'Provide information on appropriate diagnosis, treatment, care and support for myeloma patients and their families', 'Encourage the growth of new multiple myeloma patient groups throughout Europe, especially in cities and countries where they are not now found', 'Advocate the cause of myeloma among EU health care policy makers where appropriate, as an independent organization and as a part of the European Cancer Patient Coalition as well as to share best practice in shaping appropriate policies on the national level'. 'www.myeloma-euronet.org' is at the bottom.

## Myeloma Euronet Pen

A cost-effective and handy Myeloma Euronet pen was produced and has been used as a give away at international meetings and events. The transparent pen has helped to encourage participation at the international survey on barriers to myeloma diagnosis, treatment and care carried out in 2006 (see below for further details). The pen features the logo, Web site address and the tagline of Myeloma Euronet.



## Information Materials

Thanks to an unrestricted grant from Celgene GmbH, Germany, a comprehensive German-language patient information brochure on Lenalidomide (Revlimid) was developed, produced and distributed for use in Austria, Germany and Switzerland.



The manuscript was developed jointly with the Deutsche Leukämie- & Lymphom-Hilfe e.V., Germany and involved myeloma patients and patient representatives in Austria, Germany and Switzerland (DGKS Elke Weichenberger and Elfi Jirsa, Myelom Kontakt Österreich, Brigitte Reimann, Multiples Myelom/Plasmozytom Selbsthilfegruppe Rhein/Pfalz-Kreis, Candy Heberlein, Stiftung zur Förderung der Knochenmarktransplantation) as well as members of the Myeloma Euronet Medical Advisory Board (Prof. Heinz Ludwig, Prof. Hartmut Goldschmidt, and Dr. Christian Taverna) in all three countries.

Myeloma Euronet has also started developing a multi-lingual publication series including general information on multiple myeloma diagnosis, treatment and care for patients and their loved ones. The project is to be realised in collaboration with myeloma patients and patient representatives as well as medical experts in the respective countries (France, Italy, and Poland) and will be continued in 2008.

## International survey 2006

From June through October 2006, Myeloma Euronet conducted an international survey on existing barriers to myeloma diagnosis, treatment, and care. The survey revealed that advanced disease stage due to late diagnosis and the slow drug approval process constitute the two greatest barriers to myeloma treatment and care in Europe.


Even though the majority of survey participants rated the overall standards of myeloma diagnosis, treatment and care in their countries very high or above average, patients and patient relatives claimed that better education and information of healthcare professionals, including General Practitioners, is the most important step to be taken to overcome existing barriers to myeloma diagnosis, treatment and care.

Physicians shared this opinion only as it relates to myeloma diagnosis and considered tackling cost or reimbursement issues the most important step to overcome barriers to myeloma treatment and care in their countries, followed by faster drug approval and the availability of, and access to, treatment options.

Survey results were distributed through a press release distributed in 19 languages to media outlets in 36 European countries, and a full report is available for download on the Myeloma Euronet Web site.

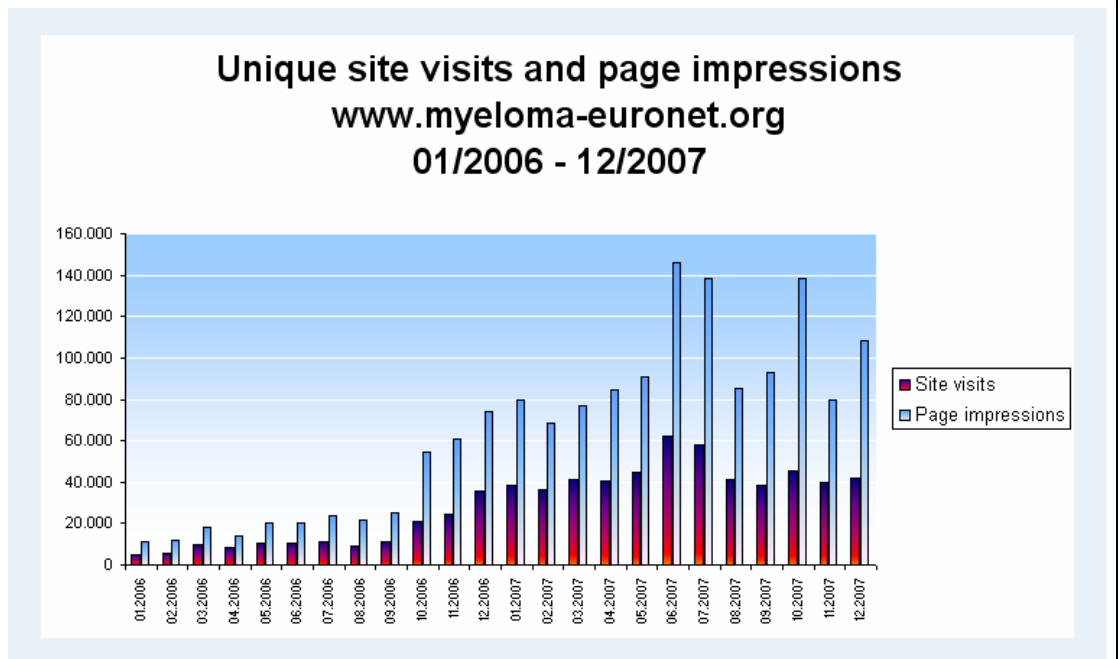
## Multi-lingual Web site

During the years 2006 and 2007, Myeloma Euronet has expanded its content-rich and HONcode-accredited Web site, [www.myeloma-euronet.org](http://www.myeloma-euronet.org), from five to eleven languages and has added a lot of new content and features, e.g., discussion forums, an online subscription form, Multiple Myeloma Manifesto signature and event calendar update opportunities, the aforementioned international survey results, press releases, medical information, and Latest News, Multiple Myeloma Manifesto, Support us, Survey, and Multiple Myeloma Art sections, etc.

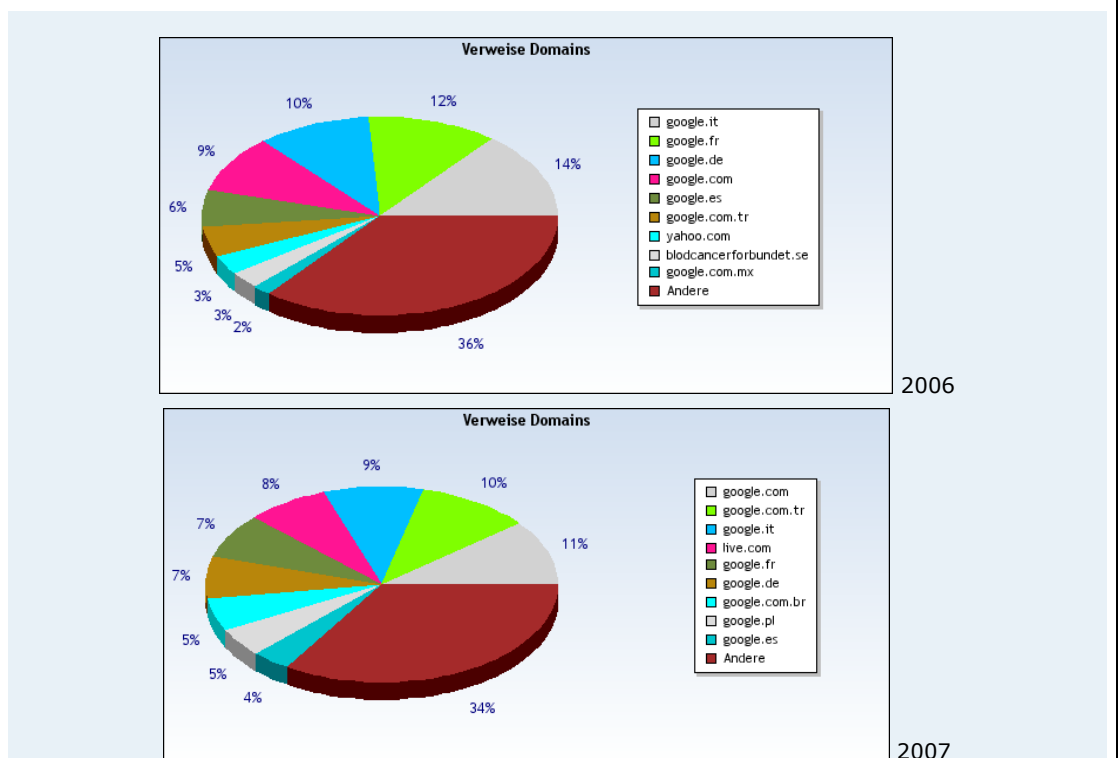


The screenshot shows the Myeloma Euronet website interface. At the top left is the 'Me MYELOMA EURONET' logo. To the right, it says 'European Network of Myeloma Patient Groups'. Below the logo are accessibility icons (A, A, A) and a list of languages: Český, Deutsch, English, Español, Français, Italiano, Polski, Português, Română, Türkçe, and عربي. A red banner below the languages reads 'MYELOMA EURONET The voice of myeloma patients in Europe'. The main content area is titled 'Latest News' and features three articles: 'International survey results available now!', 'Multiple Myeloma Manifesto' (signed by over 2000 people and 39 organizations), and 'Support us!' (requesting donations and fundraising). A sidebar on the left contains navigation links: Latest News, Myeloma Euronet, Members, Multiple Myeloma, MM Manifesto, Survey, Resources, News Room, Events, Links, Ask the expert, Discussion forum, Quiz, and Contact. At the bottom left of the sidebar is a HONcode logo with the text 'We subscribe to the HONcode principles.' and 'HONcode 07/2007'.

The development of the numbers of Web site users (unique site visits only, recurring visits not counted) and of successful page impressions (unsuccessful or interrupted page impressions not counted) is illustrated in the following graph.



The top-level domains ("referrer domains") from where users were referred to the Myeloma Euronet Web site (including bookmarks) over the last two years are shown in the following two graphs.



The majority of users access the Myeloma Euronet Web site via search engines, i.e. the Web site perfectly serves its purpose as a gateway or reference point for Web users. The graphs also illustrate the distribution of user language groups. As an example, it is interesting to note that the Turkish version of the Web site was launched at the end of September 2006. The rising proportion of Turkish-language users clearly shows that users from formerly under-served language groups appreciate the Web site's availability in additional languages.

The most frequently-accessed pages include the Latest News section as well as the sections on the Multiple Myeloma Manifesto (see below), Treatment, and Send this page to a friend.

### Web award

In September 2007, Myeloma Euronet received the Web Marketing Association's Web Award for outstanding achievement in Web site development for its Web site [www.myeloma-euronet.org](http://www.myeloma-euronet.org) in the following two categories:

- Health Care Standard of Excellence
- Non-Profit Standard of Excellence

Web designer: Andrea Rosenbaum, Germany

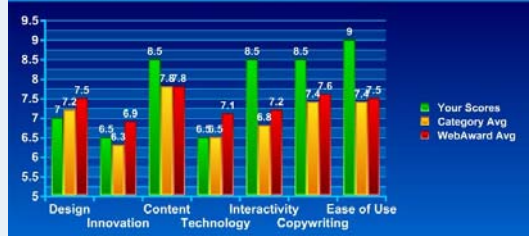
Programmer: Penny Kulow, Germany

Contributors: All members of Myeloma Euronet

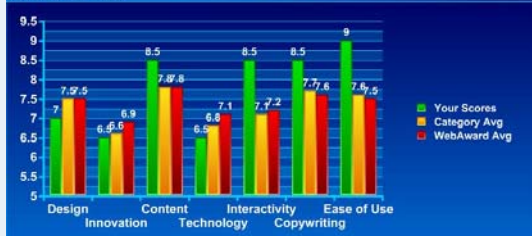


During this competition, more than 2,400 sites from 40 countries were adjudicated in 96 industry categories. Entries were judged on design, copy writing, innovation, content, interactivity, navigation, and use of technology. Each site was judged on each of the seven criteria, earning a score between 0 and 70 points. The highest score in a given category won Best Web site of that industry. If the remaining entries received a score of 60 or greater, they received the Outstanding Web site Web Award. Entries received the Standard of Excellence Web Award when their score was above the average of their industry, but below 60 points.

WebAward 2007: Health Care Category  
(Score Comparisons)



WebAward 2007: Non-Profit Category  
(Score Comparisons)



## Political Activities

### Silent no more – The Multiple Myeloma Manifesto

At the occasion of the 31st ESMO Congress and the 5th ESMO Patient Seminar held in September/October 2006 in Istanbul, Turkey, Myeloma Euronet kicked off its pan-European Multiple Myeloma Manifesto campaign. The Multiple Myeloma Manifesto (MMM) is a joint declaration of myeloma patients, physicians and researchers which is endorsed by the European Group for Blood and Marrow Transplantation (EBMT), the European Myeloma Network (EMN), the world-wide Lymphoma Coalition, and more than 30 other organisations in Europe and beyond.

The MMM outlines the six key needs of people living with multiple myeloma and calls on the European Commission, national governments, medical societies, patient groups, the media, and the pharmaceutical and biotechnology industries to take action to address those needs:

- Equity in biomedical and clinical research.
- Multidisciplinary care from trained professionals.
- Increased information and support services.
- Access to optimal treatment.
- Policies that put patients and their needs at the centre of treatment and care.
- Reduction in the isolation that characterises the lives of people living with myeloma and other rare cancers.

The MMM was translated into 16 languages and distributed along with a multi-lingual press release to media outlets in 36 European countries. Myeloma Euronet has also established a dedicated Web site section at [www.myeloma-euronet.org](http://www.myeloma-euronet.org) where people who want to show their support for this call to action can sign the MMM online.

Between the end of September 2006 and December 2007, 1,998 signatures from 80 countries were collected. Almost 90% of the signatures (1,793 signatures) came from 41 European countries. The following ten countries make up for almost three-quarters (73%) of the signatures collected:

1. France (249 signatures, 12%)
2. Germany (248 signatures, 12%)
3. Austria (224 signatures, 11%)
4. Poland (170 signatures, 9%)
5. Spain (161 signatures, 8%)
6. Turkey (100 signatures, 5%)
7. Czech Republic (97 signatures, 5%)
8. Romania (89 signatures, 4%)
9. Italy (71 signatures, 4%)
10. Greece (54 signatures, 3%)

The signature collection campaign will be continued throughout the year 2008.

### **Collaboration with the European Medicines Agency (EMA)**

Since the first half of 2006, Myeloma Euronet has been actively involved with the EMA's Unit for the Pre-Authorisation Evaluation of Medicines for Human Use. Myeloma Euronet participated in several consultations of myeloma patients and Thalidomide victims regarding the European marketing authorisation applications for Lenalidomide (Celgene Europe) and Thalidomide (Pharmion).

Myeloma Euronet's position with regard to the fact that disabilities caused by thalidomide have brought a lot of suffering for many people is summarised in the aforementioned position statement on access to Thalidomide and Lenalidomide: "No patient suffering from multiple myeloma must be denied the fastest-possible access to new treatment options."

In November 2007, Myeloma Euronet was also invited by EMA's Post-Authorisation Unit to provide assistance in reviewing a series of EMA documents addressed to patients and consumers.

## Assistance to national advocacy activities

Myeloma Euronet has actively assisted the Polish member organisation in fighting for access to Bortezomib (Velcade) in Poland, notably by attending meetings with the Minister of Health and representatives of the National Health Fund in March 2006. As far as access to Bortezomib is concerned, the situation in Poland has slightly improved in the meantime.

Myeloma Euronet has also worked together with Myeloma UK to protest against the October 2006 ruling of the National Institute for Clinical Excellence (NICE) regarding access to Velcade in England and Wales. The network has reached out to UK Members of the European Parliament who are members of the MAC (MEPs Against Cancer) EU Parliament all-party group. As a result of the joint efforts at national and European levels, a revised NICE ruling became legal in October 2007, i.e. the NHS (National Health Service) in England and Wales will now be obliged to fund Velcade for myeloma patients who relapse for the first time.

## Finances

### Revenue and Expenses Years 2006/2007

Revenue 2006		Expenses 2006		
Add carry from 2005	0.00 €	Administration (secretary, office, etc.)	44,177.15 €	35%
Restricted and unrestricted grants from supporting members; donations	133,596.79 €	Information/Education/Promotion (Web site maintenance/expansion, media relations, congress participation, international survey, brochures, banners, pens, etc.)	51,043.50 €	40%
Other	1,387.69 €	Member Activities (AGM, Board meetings, etc.)	32,380.08 €	25%
<b>Total Revenue</b>	<b>134,984.48 €</b>	<b>Total Expenses</b>	<b>127,600.73 €</b>	<b>100%</b>

**Balance 31 December 2006: 7,383.75 €**

Revenue 2007		Expenses 2007		
Add carry from 2006	7,383.75 €	Administration (secretary, office, etc.)	43,028.69 €	27%
Restricted and unrestricted grants from supporting members; donations	190,937.82 €	Information/Education/Promotion (Web site maintenance/expansion, media relations, congress participation, international survey, brochures, banners, pens, etc.)	95,025.86 €	59%
Other	4,387.30 €	Member Activities (AGM, Board meetings, etc.)	23,224.13 €	14%
<b>Total Revenue</b>	<b>202,708.87 €</b>	<b>Total Expenses</b>	<b>161,278.68 €</b>	<b>100%</b>

**Balance 31 December 2007: 41,430.19 €**

## Statement of Net Assets as per 31 December 2007

Assets		Liabilities	
<b>Cash as-sets/bank deposits:</b>		<b>Own funds</b>	
Sparkasse		Status as per 1/1/2007	7,383.75 €
KoelnBonn	41,430.19 €	Receipts	195,325.12 €
<b>Other assets</b>	0.00 €	Expenses	-161,278.68 €
<b>Total</b>	<b>41,430.19 €</b>	Status as per 31/12/2007	41,430.19 €
		<b>Liabilities</b>	0.00 €
		<b>Total</b>	<b>41,430.19 €</b>

## Summary and Thank You

Since its inception in June 2005, Myeloma Euronet has more than quadrupled its membership base, expanded its content-rich Web site, broadened its funding base, provided public educational meetings, conducted an international survey, launched its ongoing pan-European Multiple Myeloma Manifesto campaign, started a multi-lingual publication programme, established partnerships and collaborations with other organisations, advocated the cause of myeloma amongst health care policy makers at various levels, and helped to raise public awareness of multiple myeloma across Europe.

Myeloma Euronet members actively share best practices, establish new programmes, and encourage the development of new myeloma patient organisations in countries and regions in Europe where they do not currently exist. Thanks to the commitment of its members and supporters, Myeloma Euronet has already established itself as a credible, proactive and reliable European patient support and advocacy organisation.

An inclusive and unbiased international non-profit organisation, Myeloma Euronet strongly believes that partnership and cooperation amongst patient groups and across national boundaries is critical to promoting greater awareness of myeloma and working toward a cure. Myeloma Euronet will continue to work to be the voice of myeloma patients in Europe and we encourage you to join us in our efforts.

On behalf of the Myeloma Euronet Board of Directors, we would like to thank all our members and friends for their continued support!



Anita Waldmann  
President



Robert Schäfer  
Secretary