

# EMP

EUROPEAN  
MYELOMA  
PLATFORM

patients for patients



*Umbrella organisation of European Myeloma  
Patient groups and MM patients*

## *Annual report*

*Jahresbericht  
Rapport annuel  
Relatório Anual  
Årsrapport  
Jaarverslag*

# 2009

[www.emp-myeloma.eu](http://www.emp-myeloma.eu)

## EMP

Member Countries

Austria  
Belgium  
Denmark  
France  
Germany  
Portugal  
The Netherlands  
Switzerland

# EMP

EUROPEAN  
MYELOMA  
PLATFORM

patients for patients



## Annual Report of the European Myeloma Platform 2009.

*Report of the EMP Board of Directors in behalf of the  
Annual General Meeting,  
to be held on May 21 and 22, 2010 in Brussels, Belgium.*

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## PATIENTS FOR PATIENTS

The European Myeloma Platform (EMP) was launched on **February 25 2006** during the First European Multiple Myeloma Educational Programme in Vienna.

The initiative of founding EMP was taken by MM patient representatives from 6 different countries: Austria, Belgium, Denmark, France, the Netherlands and Switzerland. EMP is an independent all-patient Myeloma network to bring their common interests to the attention of European policy makers and public. EMP was officially registered under Belgian law as a non-profit international organisation on June 9, 2006. Company nr: 883 004 262.

EMP's secretariat is located in Brussels, Belgium.

EMP's aims:

- Ensure equal access to medication and treatments for all people;
- Ensure access to information for patients on new and current trials;
- To foster and promote the research of new treatment methods and medications;
- Exchange information between Myeloma patient organizations

In order to be able to reach these aims, EMP focuses on the following activities;

- Collaboration with relevant European and International organizations;
- Representation at relevant European Health authorities;

- Organization of Symposia, workshops etc.
- Provision of information via EMPs' web-site

The membership of EMP is growing. Currently EMP has 14 members from 8 different countries. The EMP constitution states that at least 50% of the board members need to be MM patients in order to ensure that the voice of European MM patients is best represented.

During the year 2009 EMP has worked out the results of the Symposium: 'No Policy without Patients', organized by EMP and CKP in October 2008, Maastricht. A final report was published and distributed among all interested parties. As a result a strategy plan has been developed.

Focus in the year 2009 has been on co-operation with health professionals particularly in the field of research and availability of new medications.

For future strategy see chapter I.C.

On behalf of the Board of Directors, EMP likes to thank its members and partners for their commitment and support.



Joao Salazar  
Chair EMP

## I REPORT OF THE SECRETARY

### I.A ABOUT EMP

#### I.A.1 EMP Members

January 1, 2009:

- MMSÖ: Multiples Myelom Selbsthilfe Österreich, Austria, represented by Ilse Hein
- CMP: Contactgroep Myeloom patiënten Vlaanderen vzw, Flandres- Belgium, represented by Johan Creemers
- MYMU: Myelome Multiple, Wallonie-Bruxelles asbl: Belgium, represented by Marc Leuridan
- Wildgroei-vzw, Belgium, represented by Luigi Chirillo
- DMF: Dansk Myelomatose Forenings, Denmark, represented by Peter Randlov
- Morgane Yvon, France, individual member
- PMM NRW: Plasmoytom Multiples Myelom Selbsthilfe Gruppe, Nordrhein-Westfalen , Germany, represented by Rolf Pelzing
- MHT: Myelom-Hilfe Thüringen gemeinn. V., Germany, represented by Reinhardt Waitschies

- CKP: Contactgroep Kahler en Waldenstrom Patiënten, Netherlands, (MM&WM Patient Association, the Netherlands), represented by Lia van Ginneken
- APLL: Portugal, associate member, represented by Guilhermina Barros Lima Pinheiro
- Joao Salazar, Portugal, individual member
- MKgS: Myelom Kontaktgruppe Schweiz, Switzerland, represented by Ruth Bähler

December 31, 2009:

- MMSÖ: Multiples Myelom Selbsthilfe Österreich, Austria, represented by Doris Mayerböck
- CMP: Contactgroep Myeloom patiënten Vlaanderen vzw, Flandres- Belgium, represented by Johan Creemers
- MYMU: Myelome Multiple, Wallonie-Bruxelles asbl, Belgium, represented by Marc Leuridan
- Wildgroei-vzw, Belgium, represented by Luigi Chirillo
- DMF: Dansk Myelomatose Forenings, Denmark, represented by Kaare Kristensen
- Morgane Yvon, France, individual member
- APMM: Arbeitsgemeinschaft Plasmazytom/Multiples Myelom , German speaking organisations in Germany-

Austria- Switzerland-Belgium, represented by Rolf Pelzing

- PMM NRW: Plasmazytom Multiples Myelom Selbsthilfe Gruppe, Nordrhein-Westfalen, Germany, represented by Rolf Pelzing
- MHT: Myelom-Hilfe Thüringen gemeinn.V., Germany, represented by Reinhardt Waitschies
- CKP: Contactgroep Kahler en Waldenstrom Patiënten, Netherlands, (MM&WM Patient Association, the Netherlands), represented by Lia van Ginneken
- Joao Salazar, Portugal, individual member
- CHN: Centro de Histocompatibilidade do Norte, represented by Helena Alves
- APLL: Portugal, represented by Guilhermina Barros Lima Pinheiro
- MKgS: Myelom Kontaktgruppe Schweiz, Switzerland, represented by Ruth Bähler

## I.A.2 Governing Body of EMP.

### Board of Directors

Composition on Jan.1, 2009:

Ilse Hein, Austria  
Peter Randlov, Denmark  
Ruth Bähler, Switzerland  
Johan Creemers, Belgium  
Lia van Ginneken, the Netherlands  
Morgane Yvon, France

Composition on Dec. 31, 2009:

Doris Mayerböck, Austria  
Kaare Kristensen, Denmark  
Ruth Bähler, Switzerland  
Johan Creemers, Belgium  
Lia van Ginneken, the Netherlands  
Joao Salazar, Portugal  
Rolf Pelzing, Germany

### Management Team

Composition from Jan. 1, 2009 until Dec. 31 2009.

Chair-person: Joao Salazar, Portugal  
Treasurer: Johan Creemers, Belgium  
Secretary: Lia van Ginneken, the Netherlands  
Special task Counselor: Doris Mayerboeck, Austria  
Special permanent Counselor: Greetje Goossens,  
Belgium

### Meetings and Communication.

In the year 2009, the Management Team (MT) has met 4 times: February 15, Brussels; April 26 Brussels; July 16, Brussels; November 8, Porto, Portugal.

Next to the Board meeting at the AGM May 15, an extra Board meeting was organised during the EHA congress in Berlin, June 4.

Communication between members of the MT, the Board of Directors and general members was mainly via e-mail contact, by telephone and during international meetings where often several EMP members were present. Contact also sometimes took place via Skype/MSN/video connection.

For the time being all working communication is in English.

## I.A.3 Medical Advisory Board (MAB).

EMP medical advisory board members review EMP materials prior to publication or dissemination and provide counsel and support when asked for.

The board exists of 16 members of 8 different countries

Belgium:

**Prof. Dr. Ben van Camp** (Chair of Medical Advisory Board)  
Universitair Ziekenhuis Brussel

**Prof. Dr. Michel Delforge**

UZ Gasthuisberg, Louvain

**Prof. Dr. Chantal Doyen**

Cliniques Universitaires ULC de Mont-Godin

Austria:

**Prof. Dr. Heinz Ludwig**  
Wilhelminenspital, Wien  
**Prof. Dr. Johannes Drach**  
Medizinische Universität Wien

Denmark:

**Dr. Peter Gimsing, M.D.**  
Rigshospitalet, Copenhagen  
**Dr. Niels Abildgaard, M.D.**  
Odense University Hospital, Odense

France:

**Prof. Dr. Jean- Luc Harousseau**  
CHU Hôtel Dieu, Nantes

Germany:

**Prof. Dr. med. Hermann Einsele**  
Direktor der Medizinischen Klinik und Poliklinik II, Würzburg  
**PD Dr. med. Guido Kobbe**  
Oberarzt Ambulantes Therapiezentrum &  
Stammzelltransplantation  
Klinik für Hämatologie, Onkologie und Klinische Immunologie  
Düsseldorf

Netherlands:

**Dr. P. Wijermans**  
HAGA ziekenhuis, den Haag  
**Prof. Dr. P. Sonneveld**  
Erasmus MC, Rotterdam

Portugal:

**Dra. Adriana Teixeira**  
Hospitais da Universidade de Coimbra  
**Dr. Herlander Marques**  
Hospital de S. Marcos, Braga

Switzerland:

**Dr. med. Christian Taverna**  
Kantonspital, Münsterlingen  
**Prof. Dr. med. Ch. Driessen**  
Kantonspital, St. Gallen

#### **I.A.4 EMP Office**

During the year 2009, the University Hospital (UZ) Brussels (Prof. van Camp and Prof. Schots, Dept. of Hematology) has continued its support for the EMP office. Mrs. Sonia Goossens is the contact person for EMP.

EMP office

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B-1090 Brussels

Tel: ++ 32 (2) 476 31 06

Mobile: ++ 32 495 617 846

[EMP-office@uzbrussels.be](mailto:EMP-office@uzbrussels.be)

### I.A.5 AGM 2009 and annual EMP Workshop

On May 15 EMP's third **Annual General Meeting** took place in Brussels, sponsored by UZ Brussel.

The secretarial and financial reports of the organisation were approved.

Introduction of two new members took place (MYMU and MHT) and applications of membership of two more members were approved (APMM and CHN).

EMP does currently have 14 members of which 10 full members, and 4 associated members.

Because of the approved membership of APMM it was felt that Germany should be represented in the board as well. Election procedures were followed and the composition of the board changed accordingly. See also under I.A.2.

The day following the AGM, May 16, the annual EMP **Workshop** was organised.

Subject: The development of the EMP strategy plan on the basis of the results of the Symposium: 'No Policy without Patients' organised by EMP and CKP in October 2008 in Maastricht.

Francois Houyez, health policy officer Eurordis, chaired the workshop, Prof. van Camp, UZ Brussels and Peter Gielen, Univ. Leuven, participated as advisers.

Starting point were the conclusions of the Symposium in Maastricht in which the following areas were discussed: Drug development, Regulatory Process & Policy, Access and availability of Drugs and Standards of care. The priorities forthcoming from these discussions served as the backbone for recommended actions for EMP and its member organisations in the future. In Maastricht, a start was made for the development of 3 action plans:

1. Participation in clinical trials;

2. Dialogue with regulatory bodies;

3. Tackling inequality in Europe.

In view of the issues that needed to be resolved before making decisions on action plans, and in view of the available time, it was decided to work on action plan 1 (clinical trials) only.

A strategy plan has been worked out during the year and was approved by the Board of Directors in December.



Participant to the EMP workshop on May 16, 2009

From left to right:

Front: Johan Creemers, Ruth Bähler, Kaare Kristensen

Back: Doris Mayerböck, Rolf Pelzing, Greetje Goossens, Francois Houyez (Eurordis), Lia van Ginneken, Joao Salazar.

### I.A.6 Membership

EMP is a full member of the following organisations:

European Cancer Patient Coalition (ECPC).

EURORDIS, the European Organisation for Rare diseases.

## **I.B ACTIVITIES**

### **I.B.1 Co-operation with Partners on a European level.**

During the year 2009 our focus was to intensify our co-operation with all our partners, particularly with health professionals in the field of research and access to innovative medicines.

Short descriptions in alphabetical order:

#### **European Cancer League (ECL)**

An article about EMP was published in their newsletter, based on an interview with Lia van Ginneken.

#### **European Cancer Patient Coalition (ECPC).**

As member of the ECPC, EMP has been closely following their activities on a European level taking an active part whenever possible.

EMP's feed-back was asked and given about the European Clinical Trials Directives in view of an evaluation of these directives by the European Commission.

Two EMP members attended their master class: 'Members in action' in October.

Lia van Ginneken gave a presentation.

EMP is one of the participants in the Action Group for rare cancers of the ECPC.

#### **European Haematology Association (EHA).**

EMP was represented with a stand at their annual meeting in Berlin (June 4-7) by 5 members.

Contacts were intensified with EMN, University Brussels, Me, IMF, Myeloma UK, MDS, Novartis and several other pharmaceutical companies.

EMP was represented during a press conference organised by Celgene.

A special EMP board meeting was organised. Topics discussed: strategy plan, co-operation with EMN in clinical trials, fund raising.



EHA Berlin June 2009

In July further contacts were made with EHA to investigate further co-operative activities.

See also under point I.B.4.

#### **European Medicines Agency (EMA).**

Greetje Goossens and Rolf Pelzing have been representing EMP. Other EMP members are supporting on ad hoc basis. EMP fulfils the "Criteria of Patients' and Consumers'

Organizations for involvement in EMA Activities. Our co-operation with EMA is one of our most important activities.

- In 2009 Greetje Goossens and Rolf Pelzing continued to work as *EMA-experts* for the review of documents (mostly Package Leaflets and EPAR-summaries) addressed to patients. The therapeutic area in which they did the review was in the first place blood cancers, but they also did some reviews in other areas (general oncology). These review activities take place on a continuous base. On an Ad-hoc basis, EMP gave advice on and did review of several other EMA-documents.
- Bendamustine: In the last trimester of 2009 EMP took action towards EMA and its CHMP in connection with the evaluation procedure for Bendamustine for European registration, and herewith advocating for better access to the medicine for MM-patients.
- Several EMA meetings and workshops were attended by EMP representatives during the year.
- Participation in the development and review of the ‘Code of Practice between Patient Organisations and the Healthcare Industry’
- EMP is involved in the development of the new EMA website on Clinical Trials (EudraCT) by reviewing the pilot website and user test the EudraCT public interface.
- EMA has asked the EMP representatives for further involvement in their activities in collaboration with

several of the EMA - Working Parties, which was agreed upon.

### **European Myeloma Network (EMN).**

In July 2009 EMP representatives met with Prof. Sonneveld, Prof. van Camp and Prof. Huijgens to discuss co-operation between EMN and EU MM patient organisations. It was decided to join forces with Myeloma Euronet (ME) in this project and a Letter of Intent, between EMN, ME and EMP was signed. The agreement stated that from 2009, all patient information of clinical trials, initiated by the EMN, will be screened by EU patients before being implemented. The first two trials will be ‘The Intergroup Trial’ and the ‘Allogeneic Transplantation Protocol’. Greetje Goossens represents EMP as the project leader, Eric Low represents ME in this project.

EMN has offered financial support for EMP. Steps were taken to accomplish this.

### **European Organisation for Rare Diseases (EURORDIS).**

Co-operation with EURORDIS has been intensive over the year.

Eurordis’ Health Policy Officer, Francois Houyez, has facilitated the annual EMP workshop in which the basis of an EMP strategy plan was worked out.

Greetje Goossens is a member of the EURORDIS Drug Information, Transparency & Access (DITA) Task Force. EMP is involved in several projects of the DITA task force and close collaboration is maintained by monthly conference calls and face-to-face meetings.

EMP volunteered to contribute to the Eurordis’ Polka Play Decide project.

The chairman of EMP, Joao Salazar, attended the Annual General Meeting of EURORDIS in Athens (May) and the

summer school on 'Patient participation in research' organised yearly by EURORDIS (June) in Barcelona.

EMP has joined a network for European Rare Disease Federations (CEF) which was initiated by Eurordis. Joao Salazar attend their meeting in May in Athens, Lia van Ginneken attended the second meeting in Brussels (Dec.). On request of Eurordis, Greetje Goossens presented the "Eurordis Charter on Clinical Trials" at the Patient Partner Workshop in London.

Lia van Ginneken has been involved in the organisation of their next European Rare Disease Conference (ERCD) in Krakow, 2010, as a member of the programme committee.

#### **International Myeloma Foundation (IMF)**

At the AGM it was decided to co-operate with IMF wherever applicable. Communication with IMF on specific topics took place at several occasions.

#### **Myeloma Euronet (Me).**

Joao Salazar and Lia van Ginneken attended a Congress organised by their Polish member association (PMPAH, February) and both gave a short presentation.

Johan Creemers and Rainer Waitschies attended a Myeloma Euronet meeting in Vienna.

Co-operation has intensified through the EMN project (see above under EMN).

During 2009 discussions between the two organisations intensified to investigate possibilities for structural co-operation.

#### **Patient Partner Project.**

Greetje Goossens has taken an active part in the Patient Partner Project, a 3-year EU FP7 project, investigating, enforcing and advising on the role of patient organizations in clinical trials.

#### **Patient View**

EMP was listed in Patient View's European Patient Group Directory 2009.

#### **Pharmaceutical Industry.**

##### **Celgene.**

- Joao Salazar and Lia van Ginneken participated in a training workshop organised by Celgene in November (Windsor). Lia van Ginneken gave a presentation.
- Greetje Goossens gave a presentation to Celgene employees at several internal Celgene workshops.

##### **Novartis.**

- Greetje Goossens became member of the Advisory Board of Novartis Oncology Region Europe.
- Greetje Goossens and Lia van Ginneken have been asked by Novartis to participate in their research advisory committee related to Novartis MM-Clinical Trials.

##### **Amgen.**

- Skeletal Care Academy (SCA). Lia van Ginneken has a consultancy role as member of the Patient Advocacy Steering Committee of this project. Their training programme took place on March 12 and 13, 2010.

#### **University Hospital (Universiteits Ziekenhuis: UZ) Brussels**

UZ Brussels has been very supportive in all our activities. During 2009 they financed our Annual general Meeting.

They facilitate the EMP office and Sonia Goossens, the contact person for EMP, is one of their staff members.

Advise and support was regularly obtained from Prof. B. van Camp and Prof. R. Schots.

## **I.B.2 Co-operation with National Competent Authorities and other national activities.**

### **I.B.3**

Because implementation of European health policies depends mainly on actions taken by National Competent Authorities, EMP members have an important role to play on a national level as well.

For that reason, in addition to co-operation on a European level, each EMP member has established contacts with relevant health authorities in their own countries.

Main actions taken, represented in alphabetical order:

In **Belgium** our member organisations CMP and MyMu undertook joint advocacy actions to request a review of the very stringent re-imburement criteria of Lenalidomide. Due to these very strict criteria Belgian MM-patients had very limited access to this medicine.

In this advocacy activity, both Belgian patient organisations joined forces with the doctors of the MMSG, the MM working group of the Belgian Haematological Society. Collaboration with the pharmaceutical company Celgene took place in a transparent context. The action was very successful and the new re-imburement criteria, in line with the European Registration of the medicine, were approved. This is a big step forward that allows Belgian MM patients the same access to the medicine as in many other European countries.

### **Netherlands:**

- The process of implementation of local prepared Thalidomide through the National Pharmaceutical Board (KNMP) has been completed. Thanks to the help of the Stichting Eerlijke Geneesmiddelen Voorziening (Equal Access to Medication), re-imburement problems will be solved.
- Initiatives to fight Doctors' Delay with respect to the diagnosis MM and WM have been taken. With permission of Myeloma UK, their 'Diagnosis Pathway' has been distributed among Dutch patients and family doctors.

### **In Portugal:**

- The book on "Bone Marrow: Factory of Life" has been very successful in advertising the importance of the registration of bone marrow donors.
- Members of APLL visited Portuguese Parliamentary persons and discussed 3 issues: the creation of a public cord blood bank, the average 1.5 year gap between the EMEA medicines approval and INFARMED (Portuguese medicine agency), and the third issue was the rights of oncological patients regarding clinical trials and cord blood banks.
- The cycling against lymphoma was realized for the 5th year and there were over 1.500 cyclists (the secretary of health was present, some members of parliament, hospital directors, etc).

### **Germany.**

Rolf Pelzing and Johan Creemers have been elected to the Management Team ('Sprechenteam') of the Arbeitsgemeinschaft Plasmozytom/Multiples Myelom (APMM).

#### **I.B.4 PR and Web-site.**

- The outcome of the Symposium in Maastricht was published in an official report in April 2009. This report was sent to all our interested parties. (see web-site; [www.emp-myeloma.eu](http://www.emp-myeloma.eu))
- The Portuguese APLL contributed to the publication of a book: 'Bone Marrow, factory of Life'. This book was sent to all interested parties and posted on the web-site. See also under I.B.2
- New roll-up poster was developed.

The Web-site is serviced free of charge by a Portuguese web-company (Dom Digital).

Translation of the site into German is in progress. Links to our members, partner organisations and other relevant organisations have been established.

A Web-forum will be developed soon. EMP has a Facebook entry (EMP Myeloma)

Relevant press releases have been posted on the site.

However, much work still needs to be done. The web-site will be under constant development and improvement under the supervision Joao Salazar.

#### **I.B.5 Participation at Conferences, Seminars, Workshops, Master classes etc.**

In chronological order:

- Patient Association Poland PMPAH, Annual Congress, Febr. 20-22, Poland. Joao Salazar and Lia van Ginneken attended and both gave short presentations.
- International Myeloma Workshop (IMW), Febr. 26-March 1, Washington. Greetje Goossens and Ilse Hein attended.
- EBMT (European Bone Marrow Transplantation) Patient and Family Day; March 28, Göttenborg. Johan Creemers represented EMP.
- APMM meeting, March, Königswinter, Doris Mayerböck, Dina Schneidhofer, Rolf Pelzing, Johan Creemers.
- CMP (Contactgroep Myeloom Patienten), Symposium: April 25<sup>th</sup>, Kortrijk.
- CKP (MM&WM Patient Association, the Netherlands), Annual Symposium, April 25, Maarssen, the Netherlands. Lia van Ginneken co-organised, Johan Creemers attended.
- EURORDIS (European Organisation for Rare Diseases) Annual General Meeting and European Rare Disease

- Federation (CEF), May 8-9, Athens. Joao Salazar attended.
- Eurordis Summer school, June 14-18, Barcelona, Spain. Joao Salazar attended.
  - EHA (European Haematology Association); June 2007, Berlin, Germany (booth) Rolf Pelzing, Johan Creemers, Ilse Hein, Doris Mayerböck and Lia van Ginneken attended.
  - DGHO June 5, Berlin Interview - Celgene (Ilse Hein and others).
  - Advisory Board of Novartis Oncology Region Europe, September 3rd, Milan, Greetje Goossens attended.
  - Myeloma Hilfe Munich (MHM). Johan attended symposium.
  - Patient Partner workshop, June 11<sup>th</sup>, Brussels. Greetje Goossens attended.
  - DLH (Deutsche Leukämie-und Lymphom Hilfe), June 20-21, Berlin, Germany. Johan Creemers and Rainer Waitschies attended.
  - European Conference for Rare Diseases (ECRD) programme committee meetings, May and September, Paris. Lia van Ginneken.
  - MKgS, symposium in honour of the 10<sup>th</sup> anniversary of the Swiss patient organisation, Sept. 25, Basel.

- Organised by Ruth Bähler and her staff. Johan Creemers attended.
- DOSGHO (German, Austrian and Swiss Societies for Haematology and Oncology), Annual Congress, October 2-6, Mannheim, Germany, (booth). Johan Creemers, Rolf Pelzing were present.
  - Patient Partner workshop, October 12, 13<sup>th</sup> London. Greetje Goossens attended.
  - Myelom Tagen Heidelberg 23-25 October, Germany. Reinhard Starzonek, Johan Creemers
  - ECPC Master Class: Members in Action, October 24 and 25, Munich. Greetje Goossens and Lia van Ginneken attended. Presentation and Poster session.
  - Portuguese Haematological congress, October 29, 30, 31, Portugal. Joao Salazar attended.
  - Symposium CMP, November 14, Antwerp, Belgium. Greetje Goossens and Johan Creemers organised.
  - Workshop Celgene, November 18-19, Windsor England. Joao Salazar and Lia van Ginneken attended. Presentation given.
  - Novartis Advisory Committee on clinical trials, November 24, Milan. Greetje Goossens and Lia van Ginneken attended.

- EORTC symposium on Quality of Life in Cancer clinical trials, November 26, Brussels. Greetje Goossens attended.
- Symposium MYMU/IFM. November 28, Mons, Belgium. Greetje Goossens and Johan Creemers.
- AMGEN. Patient Advisory Committee, December 2, Brussels. Lia van Ginneken
- EURORDIS (European Organisation for Rare Diseases), Council meeting for European Rare Diseases Federations (CEF), December 3, Brussels. Lia van Ginneken.
- EMEA, Training with Patients' and Consumers' organisations, Dec. 7, London, Greetje Goossens.
- EMEA, Annual PCWP plenary meeting, Dec. 8, London. Greetje Goossens.
- EURORDIS, DITA Task Force meeting, December 9, London. Greetje Goossens

## ***I.C FOCUS POINTS FOR THE YEAR 2010***

EMP has had a busy year in which all active members have put a lot of energy into its activities in order to reach the aims of EMP. Their professional background and their experiences as MM patient offered a lot of potential. The result is that EMP is a partner in many MM related activities in Europe. However, in order to follow up and broaden these activities of EMP, it is clear that EMP needs a paid staff member. The Board of EMP has been taking steps during 2009 to obtain structural funding (next to the incidental funding obtained for projects, see under Financial Report) for this purpose. The first results were achieved in the beginning of 2010, but more work needs to be done in that respect.

Co-operation with all relevant stakeholders continues to be a focus point in 2010.

Particularly towards EU Health policymakers and regulatory agencies, joining forces is most effective to fight for the cause of MM patients in Europe.

During the year 2010 EMP will particularly investigate the possibility for stronger co-operation with Myeloma Euronet, the other umbrella MM patient organisation in Europe.

EMP will pursue its aims and will follow up the results of the Symposium 'No Policy without Patients' through:

- Continue and intensify working relations with health professionals, researches and clinical sponsors
- Continue and intensify dialogue with regulatory bodies
- Tackle inequality in access to treatment, discussing pricing and reimbursement

## II FINANCIAL REPORT OF THE TREASURER

### Introduction.

**Most of our expenditures in the year 2009 were directly financed by our partner organisations, EMP member organisations or by individual members.**

e.g.

- UZ Brussels financed:
  - EMP office running costs
  - EMP Annual General Meeting
  - Part of the MT meetings.
- Dom Digital financed:
  - EMP web-site
- European Hematology Association financed:
  - The stand at the EHA conference
- Most travel and hotel costs for conferences, workshops and symposia were directly granted by the promoting organisations.
- Other travel costs and some PR materials were directly paid by our member organisations and by individual members.

**EMP IS VERY GRATEFUL FOR THEIR CONTRIBUTIONS.**

See for an Overview of the finances on the next page (p. 30).

## Finances Revenue and Expenses Year 2009

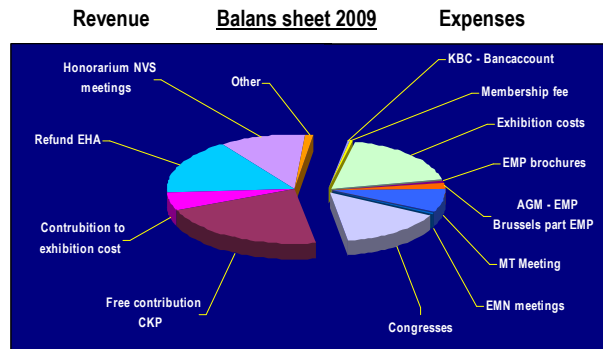
**STATUS AS PER 1/1/2009** **4.375,28 €**

REVENUE	<b>7.726,23 €</b>	
Free contribution CKP	3.000,00 €	38,83%
Contribution to exhibition cost	750,00 €	9,71%
Refund EHA	2.309,16 €	29,89%
Honorarium Novartis advisory meetings	1.500,00 €	19,41%
Interest KBC account	2,07 €	0,03%
Other	165,00 €	2,14%

EXPENSES	<b>6.228,58 €</b>	
KBC - Banc account	48,13 €	0,77%
Membership fee	20,00 €	0,32%
Exhibition costs	2.552,55 €	40,98%
EMP brochures	138,00 €	2,22%
AGM - EMP Brussels (part EMP)	250,50 €	4,02%
MT Meetings	1.084,23 €	17,41%
EMN meetings	58,30 €	0,94%
Congresses	2.076,87 €	33,34%

**STATUS AS PER 1/1/2010** **5872,93**

**MOVEMENTS 2009** **1497,65**



# EMP

## EUROPEAN MYELOMA PLATFORM

patients for patients



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