

## Join MYELOMA EURONET – “Join Me!”

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.



If you would like to join our network as an individual, associate, full or supporting member, or if you have a question or a comment, we would love to hear from you. Membership is free of charge and all members have the right to retire at any time from the association.

Information about membership in MYELOMA EURONET can be found on our multi-lingual Web site

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

### MYELOMA EURONET

is an international non-profit association (Association Internationale Sans But Lucratif, A.I.S.B.L.) registered in Belgium.

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## Full and Associate Members

**Austria:** Myelom & Lymphomhilfe Österreich\* • **Croatia:** Mijeloma CRO Društvo pacijenata mijelome i plazmacitome / UOLL- Leukaemie-& Lymphoma Patient Association • **Czech Republic:** Česká myelomová skupina, nadační fond; Mnohočetný Myelom Klub Pacientů • **Germany:** Deutsche Leukämie- & Lymphom-Hilfe e. V.\* / Arbeitsgemeinschaft Plasmozytom/Multiples Myelom (APMM) / BMS Bayerische Myelom-Selbsthilfe / Leukämiehilfe RHEIN-MAIN/ Leukämie-& Lymphom-Hilfe Metropolregion RHEIN-NECKAR / MHM Myelom/ Plasmozytom Hilfe München/ Myelom-Hilfe Nordbayern / Selbsthilfegruppe Plasmozytom/Multiples Myelom Berlin / Multiples Myelom SHG Kur- und Westpfalz / Myelom Selbsthilfegruppe Osnabrück • **Latvia:** Mielomas pacientu atbalsta biedrība, • **Lithuania:** OPA - Krautjas • **Portugal:** Associação Portuguesa de Leucemias e Linfomas, • **Romania:** Myeloma Euronet Romania / Spitalul Județean de Urgență Pitești-Argeș / Spitalul Universitar de Urgență București Clinica de Hematologie • **Russia:** St. Petersburg Pavlov State Medical University / Interregional social organization of patients with oncohematological diseases / Russian Research Institute of Hematology and Transfusiology • **Serbia:** Udruzenje obolelih od multiplog mijeloma, • **Slovakia:** Slovenská myelómová spoločnosť • **Slovenia:** Slovensko združenje bolnikov z limfomom in levkemijo, L&L, • **Spain:** AEAL, Asociación Española de Afectados por Linfomas, Mielomas y Leucemias / Mieloma.com • **Sweden:** Blodcancerförbundet\* • **Switzerland:** Stiftung zur Förderung der Knochenmarktransplantation\*, • **Turkey:** Ege Üniversitesi Hastanesi / KOKDER - Pioneering Association of Cancer and Stemcell transplantations • **Ukraine:** Hematology Department of SI "Institute of Blood Pathology and Transfusion Medicine, UAMS" • **United Kingdom:** Myeloma UK\* / Myeloma UK-Yorkshire Support Group / Myeloma People Network (Scotland)

(\* Founding Member; listing as of April 2011)

## Supporters

Ortho Biotech – A division of Janssen-Cilag (Founding Sponsor), AMGEN GmbH, CELGENE GmbH, CELGENE International Sàrl, Genzyme, JANSSEN CILAG EMEA, NOVARTIS PHARMA AG, ROCHE PHARMA and private donors as well as individuals supporting MYELOMA EURONET by providing in-kind services.

# Me

## MYELOMA EURONET

### European Network of Myeloma Patient Groups

**A European initiative dedicated  
to raising awareness of  
Multiple Myeloma,  
an increasingly common  
form of bone marrow cancer.**

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



**The voice of Myeloma patients in Europe**

## What Is MYELOMA EURONET?

A registered non-profit network organization of multiple Myeloma patient groups from throughout Europe, MYELOMA EURONET works to raise awareness of multiple Myeloma; to provide information on the diagnosis, treatment, and care of persons living with multiple Myeloma, and to offer support to multiple Myeloma patient families and loved ones.

### Our Aims

- ME>** Raise European awareness of multiple Myeloma amongst the public.
- ME>** Build partnerships among members of MYELOMA EURONET in order to share experience and expertise.
- ME>** Provide information on appropriate diagnosis, treatment, care, and support for Myeloma patients and their families.
- ME>** Encourage the growth of new multiple Myeloma patient groups throughout Europe, particularly in cities and countries where they do not currently exist.
- ME>** Advocate the cause of Myeloma among EU health care policy makers where appropriate, as an independent organization and as part of the European Cancer Patient Coalition (ECPC), the European Organization for Rare Diseases (EURORDIS) and the European CanCer Organisation (ECCO), and share best practice in shaping appropriate policies on the national level.

### Our Web site

Our content-rich, award-winning Web site is currently available in Arabic, Czech, English, French, German, Greek, Italian, Polish, Portuguese, Romanian, Russian, Spanish and Turkish. More languages will follow. Please visit [www.myeloma-euronet.org](http://www.myeloma-euronet.org).

## About Myeloma & Multiple Myeloma

Myeloma is a cancer that affects white blood cells known as plasma cells. Plasma cells produce antibodies that help the body rid itself of harmful substances. In Myeloma, the body produces unneeded plasma cells, known as Myeloma cells. Myeloma cells tend to collect in the bone marrow and in the hard, outer part of bones. Sometimes they collect in only one bone and form a single mass (tumour), but most often they collect in many bones, forming many tumours. When this happens, the cancer is known as multiple Myeloma.

If untreated, multiple Myeloma can compromise the immune system and lead to recurrent infection and damage to the bone, bone marrow, and other organs of the body.

### The Need for MYELOMA EURONET

- ME>** Recent statistics indicate an increasing incidence of multiple Myeloma and an earlier age of onset.
- ME>** The causes of multiple Myeloma are still unknown.
- ME>** Public awareness is low: most people with Myeloma and their family members have never heard of the disease at the time of diagnosis.
- ME>** While there is currently no cure, but - multiple Myeloma is treatable.
- ME>** Without prompt and active management of multiple Myeloma, bone destruction can become severe and lead to immobility.
- ME>** Patient-friendly information about Myeloma diagnosis, treatment, and care is not widely available.
- ME>** No patient living with a rare cancer like multiple Myeloma should be left behind in the race for cancer cures.

## MYELOMA EURONET Membership

MYELOMA EURONET membership is free of charge.

- ME> *Founding members*** are those groups that helped establish MYELOMA EURONET. They enjoy no special rights or privileges.
- ME> *Full members*** are patient-focused multiple Myeloma organizations.
- ME> *Associate members*** are organizations not exclusively focused on multiple Myeloma (e.g., cancer societies).
- ME> *Supporting members*** are non-voting sponsors who lend financial support. MYELOMA EURONET welcomes corporate grants and sponsorships to enable the Network to grow and develop.
- ME> *Individual members*** are patients, family members, and other men and women interested in the cause of multiple Myeloma.

## GOVERNANCE

### Board of Directors

The board consists of at least seven members who serve for terms of two years. No more than two member groups per country can serve on the board at any one time.

### Medical Advisory Board

Medical Advisory Board members review MYELOMA EURONET materials for accuracy prior to publication and dissemination and provide ad hoc counsel as needed and requested.

### Annual Meeting

The Annual General Meeting of members is usually held in May or June each year, sometimes in connection with the annual congress of the European Haematology Association (EHA).