

PRESS RELEASE

First Ever European Network of Myeloma Patient Groups Launched at the 10th Congress of the European Hematology Association (EHA) in Stockholm

The launch of the very first European network of myeloma patient Groups, the MYELOMA EURONET, took place at the 10th Congress of the European Hematology Association (EHA) in Stockholm on 3 June where they unveiled their new website, www.myeloma-euronet.org.

The organisation is an innovative alliance of myeloma patient groups in Europe who are working together on shared goals and objectives to bring benefit to patients and their families living with myeloma. Myeloma is an increasingly common cancer of the plasma cells that is incurable, but treatable, and affects over 31,000 people in Europe at any one time.¹

Anita Waldmann, president of Deutschen Leukämie- und Lymphom-Hilfe e.V. (DLH) (the German Leukemia and Lymphoma Aid Organization) and founding member of MYELOMA EURONET said, “This is a very important initiative for myeloma patient groups across Europe and we are proud that over a year’s hard work by seven key founding members has resulted in the launch of this innovative and vital network. Our hope is that the network will enable us to share experience and expertise between the groups and provide important access to information through our website to patients, families and the wider public, who want to learn and understand more about myeloma.

“Awareness of myeloma is worryingly low within Europe and yet it is one of the most rapidly increasing cancers in the Western World. MYELOMA EURONET members will work together to change this and raise awareness of the disease, as well as to advocate the cause of myeloma and seek to influence the European policy agenda”.

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¹ www.depdb.iarc.fr/globocan

At its launch event in Stockholm, MYELOMA EURONET announced its aims and objectives, which are:

- To raise public awareness of myeloma
- To provide information on the appropriate diagnosis, treatment, and care of people living with myeloma within Europe and support for myeloma patient families and loved ones
- To build partnerships among members of MYELOMA EURONET in order to share experience and expertise
- To encourage the growth of new myeloma patient groups throughout Europe, especially in cities and countries where they are not now found
- To advocate the cause of myeloma among EU health care policy makers where appropriate, as an independent organisation and as part of the European Cancer Patient Coalition, and share best practice in shaping appropriate policies on the national level.

Mr Roger Oscarsson from Sweden, a patient living with multiple myeloma, who attended the launch event added: "Myeloma is a complex and difficult disease to understand and the level of information and support available within different European countries varies greatly. I welcome the establishment of this network in providing an important source of information for patients and their friends and families, enabling groups to talk to each other and share expertise and encouraging the development of new support groups in countries where they currently do not exist."

MYELOMA EURONET already has seven founder members from six European countries (Austria, France, Germany, Sweden, Switzerland and the UK) and it is now inviting groups from all over the continent to join the network and contribute to its work.

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About Myeloma

Myeloma is a type of cancer that affects white blood cells known as plasma cells. Plasma cells are found in the bone marrow and are responsible for protecting the body against viruses and infections.

In myeloma, the body produces unneeded plasma cells and these multiply rapidly, disrupting the immune system and displacing healthy bone marrow.

The myeloma cells 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.

About MYELOMA EURONET

MYELOMA EURONET's founding sponsor is Ortho Biotech, the biopharmaceuticals division of Janssen-Cilag. Myeloma EURONET is also supported by an unrestricted grant from Novartis Pharma AG.

Further information

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