



EWMnetwork

European
WALDENSTRÖM'S
MACROGLOBULINEMIA
network

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European Waldenström Macroglobulinemia network in Brief

The Foundation “ Stichting EWMnetwork” (www.ewmnetwork.eu) has been active since 2009.

The mission is to enable WM (Waldenström Macroglobulinemia) patients to represent their interests at a European level. This way WM patients are given a voice in policy and political issues of the European health care system.

EWMnetwork has contacts with WM patient organizations in Belgium, Denmark, Finland, France, Germany, Greece, Ireland, The Netherlands, Sweden, Switzerland and UK. Some of these organizations are very well organized and active, some are just starting.

Board members in 2010: Lia van Ginneken, chair a.i.,The Netherlands; Marlies Oom, secretary/ treasurer, The Netherlands; Joanna Van Reyn, Belgium; Veikko Hoikkala, Finland and Roger Brown, UK (since October).

Highlights 2010

Networking & Information:

Co-operation and partners:

- As a member of ECPC (European Cancer Patient Coalition) and EURORDIS (European Organization for Rare Diseases), EWMnetwork visited the general meetings of these organizations, had regular contacts and gave feed back on relevant issues.
- In 2010 EWMnetwork became a member of the Lymphoma Coalition, a global network of worldwide not for profit lymphoma patient organizations. In view of the high costs of the journey, EWMnetwork did not attend the General Meeting of this organization in Orlando, Florida in December 2010.
- In the margin of the 2nd European WM Forum, EWMnetwork tried to work out with IWWMF (International Waldenstrom Macroglobulinemia Foundation) how to enlarge the number of WM patient support groups in Europe.

Advocacy:

- EWMnetwork supported, as participant of the “Rare Cancers Action Group” (initiated in 2010 by ECPC) the special attention that rare cancers need in Europe, in co-operation with the patient organization for rare diseases EURORDIS and ESMO/EAARC (European Society for Medical Oncology/ European Action Against Rare Cancer, www.rarecancers.eu).
- The most effective way for EWMnetwork to influence EU health care policy issues related to WM, was, also in 2010, through ECPC and EURODIS.

Special mention here deserves FACE (Forum Against Cancer in Europe, www.forumagainstcancer.eu), launched by ECPC in 2010. Already 81 MEP's (Members of European Parliament) are committed to follow one or more issues for the term of their legislature, for example on cancer research, cross-border healthcare, rare cancers, clinical trials, palliative care, young people and cancer, etc. Several informative workshops have been held with speakers of the Commission, the European Parliament, Research Organizations and patients.

Focus was on: inequality in the EU with respect to available medication and treatment, support for more (rare) cancer research, development of national (rare) cancer plans.

Conferences, meetings attended:

- May, Krakau (Poland): 5th European Conference on Rare Diseases, organized by EURORDIS (European Organization for Rare Diseases). Important issues regarding rare diseases/ rare cancers were discussed such as: co-operation within and between countries, the forming of centers of expertise and European reference networks; the preparation of national plans for rare diseases within the European community due from 2012; the off label use of medicines for rare diseases and the problems that consequently arise with reimbursement.
- October, Brussels, debate in the European Parliament on: “ Orphan Drugs for Rare Cancers, Proposals for Action at the European level” This event was organized by the Association of European Cancer Leagues (ECL), the Flemish League against Cancer (VLK) and the Foundation against Cancer, in collaboration with the European Society for Medical Oncology (ESMO).
- October, Venice (Italy):
 - o Board and affiliates of EWMnetwork were kindly invited by the organizers (BING Center for WM, Dana Farber Cancer Institute Boston, USA) to attend the last day of the 6th International Workshop on WM for European Physicians, preceding the 2nd European WM Forum (www.wmworkshop.org)
 - o 2nd European WM Forum, organized by IWMF (www.IWMF.com) . The Forum was an interesting opportunity for European patients with Waldenström’s Macroglobulinemia (WM) and their partners to meet both WM medical specialists from Europe and USA as well as fellow patients.
- October, Brussels: ECPC Cancer Summit entitled “ Making the Cancer Partnership work”. This ECPC Summit brought together doctors, researchers, parliamentarians, patients’ organizations, EU Member States’ representatives and Commissioners.

Attending these conferences/ meetings appeared to be very useful again for networking and information.



6th International workshop on WM, Venice 2010



2nd European WM Patient Forum, IWMF, Venice 2010

Newsletters:

- In January, July and October 2010 we sent information to the EWMnetwork affiliates and contact persons. From July this type of information was distributed under the name “Newsletter”. Newsletters will be sent on relevant intervals in the future.

Organization:

Affiliates:

- In 2010 three new affiliates joined EWMnetwork, either as an individual (Switzerland, because there is no WM patient support group yet) or representing a WM patient organization (Ireland, UK).

WM Patient Organizations in Europe:

- Good news is to be mentioned about the growth in 2010 of patient organizations in Belgium, Finland, France, Ireland, UK and Germany. May many more countries follow! Finding volunteers to organize patient support groups however, remains a problem.

Medical Advisory Board (MAB):

- In the first half of 2010 the following nine WM specialists from eight European countries joined EWMnetwork's MAB.
 - o Belgium, Dr. Jan Van Droogenbroeck, Haematological Center Hospital St. Jan, Brugge
 - o Denmark, Dr. Lars Munksgaard, Dept. of Haematology, Odense
 - o Finland, Dr. Petri Oivanen, formerly working for University of Tampere, now in medical industry
 - o France, Dr. Pierre Morel, Hematology, Centre Hospitalier Dr. Schaffner, Lens
 - o France, Dr. Veronique Leblond, Hematology, Hospital Pitié-Salpêtrière, Paris
 - o Germany, Prof. Dr. med. Christian Buske, Institute of Experimental Cancer Research University of Ulm
 - o Netherlands, Prof. Dr. Henk Lokhorst, Haemato-oncologist University Medical Center Utrecht
 - o Sweden, Ass. Prof. Dr. Eva Kimby, Karolinska University Hospital , Stockholm
 - o UK, Dr. Roger Owen, HMDS Laboratory, The Leeds Teaching Hospitals NHS Trust, Leeds

The board of EWMnetwork met with three members of the MAB, who participated actively in the 6th International Workshop on WM in Venice. Members of the MAB make WM patient organizations known to WM patients and other relevant stakeholders. In general the MAB provides counsel and support on relevant issues asked and unasked for. In 2010 there were no such issues.

Board meetings:

- In 2010 two board meetings were held, one in January in The Hague and another in October in Venice.

Meeting with EWMnetwork affiliates:

- A meeting with EWMnetwork affiliates was held in October in Venice, in the margin of the 2nd European WM Forum, organized by the IWMF. It was the first time that such a meeting was held and it was an inspiring experience. Representatives from eight European countries shared their information on how to organize WM patient support groups.



Meeting with EWMnetwork affiliates and partners, Venice 2010

Strategy plan:

- The board adopted a new Strategy plan in October 2010. The main priorities are:
 - o Recruiting additional board members and reallocate the tasks (autumn 2010)
 - o Working out with IWMF how to enlarge the number of WM patient support groups in Europe (autumn 2010/2011)
 - o Continuing and consolidating current networking and information activities (ongoing)
 - o Looking for funding possibilities

Finances and potential funding possibilities:

- For 2011 the Dutch organization for Multiple Myeloma and Waldenström (CMWP) will in principle support EWMnetwork financially again. For this the board of EWMnetwork is very grateful. How long CMWP will be able to support EWMnetwork is uncertain. So it is necessary to find funding (public or private sponsors).

Website:

- In 2010 the interest in the website (www.ewmnetwork.eu and (www.waldenstrom.eu) was twice as much as in 2009. There were 1150 “unique visitors” (2009: 539); 1650 “visits” (2009: 742) and 10.323 “ hits” (2009: 5400). The chapter “ Treatment” was the best visited part. Visitors came, as far as traceable, (in order of frequency) from The Netherlands, USA, UK, Germany, France, Belgium, Poland, Ireland.

Rosmalen, The Netherlands, January 17, 2011
Marlies Oom, secretary EWMnetwork