



EWMnetwork

European  
WALDENSTRÖM'S  
MACROGLOBULINEMIA  
network

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## ANNUAL REPORT 2011

### European Waldenström Macroglobulinemia network in brief

The Foundation “ Stichting EWMnetwork” ([www.ewmnetwork.eu](http://www.ewmnetwork.eu)) has been active since 2009.

EWMnetwork is an umbrella organization for national and regional WM patient support groups. The mission is to enable patients with Waldenström's Macroglobulinemia (WM) to represent their interests at a European level. EWMnetwork gives WM patients a voice within relevant European political and healthcare organizations.

In 2011 EWMnetwork counts eight affiliates representing a WM patient organization (in Belgium, Denmark, Finland, France, Greece, Ireland, The Netherlands, UK) and two individual affiliates (in Norway and Switzerland). There are contacts with Germany and Sweden. Some of the WM patient organizations are very well organized and active, some are just starting.

For health reasons **Joanna Van Reyn** had to give up her membership of the board of EWMnetwork in the course of 2011. We are very grateful to her for all the work she has done, for her enthusiasm and her perseverance. Fortunately she still continues her activities for the WM patients in Belgium and as one of the moderators of the on line WM community ( for French language).

**Board members in 2011:** Lia van Ginneken, chair a.i., The Netherlands; Marlies Oom, secretary/ treasurer, The Netherlands; Veikko Hoikkala, Finland and Roger Brown, UK.



f.l.t.r. Roger Brown, Lia van Ginneken, Marlies Oom, Veikko Hoikkala

## Highlights 2011

### Networking & Information:

#### Co-operation and partners:

- As a member of ECPC (European Cancer Patient Coalition, [www.ecpc-online.org](http://www.ecpc-online.org)) and EURORDIS (European Organization for Rare Diseases, [www.eurordis.org](http://www.eurordis.org)), board members of EWMnetwork attended the general meetings and workshops of these organizations, had regular contacts with them and gave feedback on relevant issues.
- Veikko Hoikkala had a meeting with the IWMF board about developing a closer partnership between EWMnetwork and IWMF and encouraging the development of more WM patient support groups in Europe. EWMnetwork and IWMF decided to sponsor jointly WMUK for organizing the 3<sup>rd</sup> European WM Forum, London, 11 March 2012 ([www.wmuk.org.uk](http://www.wmuk.org.uk)).
- A new project, which brings closer partnership between IWMF and EWMnetwork in practice, is the **WM online community**, part of the international "Rare Disease Communities project".  
Eurordis, the American NORD (National Organization for Rare Disorders) and international patient organizations collaborate to develop these rare disease communities. Thanks to much help from Eurordis and Nord the WM on line community was launched in October 2011, offering translation in 5 languages (Spanish, Italian, French, German, English) and thus enabling WM patients and their caregivers to share experiences and find more information. At the end of 2011 about 20 WM patients participate, including patients from Italy and Spain. Formerly there were no patient contacts with or between those countries. Many thanks deserve the moderators of the on line community Joanna Van Reyn and Phil Manning.  
<http://www.rarediseasecommunities.org/en/community/waldenstrm-macroglobulinemia>.
- Marlies Oom had a meeting with the Belgium WM patient support group, which was founded by former board member Joanna Van Reyn and is growing fast.
- In close co-operation with IWMF and EWMnetwork, Roger Brown took, on behalf of WMUK (contact point for WM patients in UK) the lead of the organization of the 3<sup>rd</sup> International Patient Forum on WM, to be held 11 March 2012 at the Royal Society of Medicine in London.
- In view of the high travelling and hotel expenses, EWMnetwork did not attend the General Meeting of Lymphoma Coalition in San Diego, US in December 2011.

#### Advocacy:

- The most effective way for EWMnetwork to influence EU health care policy issues related to WM proves to be, as in earlier years, through ECPC and EURODIS.
- EWMnetwork was involved in ECPC's advice concerning the new Reform of the European Clinical Trial Directive (which had become much too bureaucratic since the last Reform).
- EWMnetwork was (via ECPC's Rare Cancer Action Group) also involved in the preparation of a meeting with representatives of the European Commission. January 2011, ECPC met with Joanna Darmanin, Health Commissioner John Dalli's Head of Cabinet, and Paula Duarte Gaspar, responsible for public health and risk assessment, to consider issues affecting rare cancer patients. The meeting raised the importance of increasing research funding for rare cancers, encouraging the establishment of centers of excellence, reference networks, registries, and promoting a dialogue between researchers, pharmaceutical industries, Health Technology Assessments (HTA) and patient advocacy groups in rare cancer policy.
- Via Eurordis EWMnetwork was involved in a survey on off-label use of medicine.

#### Conferences, meetings attended:

- Marlies Oom attended 12 January 2011, a meeting in Brussels where Forum Against Cancer Europe (FACE) launched its 2011 programme with a workshop bringing together Members of

the European Parliament (MEPs), patient groups, and representatives from the pharmaceutical industry, the European Commission, researchers and the oncological community.

- Lia van Ginneken and Marlies Oom attended the Eurordis Membership meeting held in Amsterdam 13-14 May.
- Veikko Hoikkala attended the annual IWMF Ed Forum, this time held in Minneapolis 24-26 June.
- Marlies Oom attended a meeting organized by EHA (European Hematology Association) and ECPC with some MEP's and European patient organizations in the field of hematology, held in Brussels 30-31 August.

#### Newsletters:

- August 2011 a Newsletter was sent to the affiliates and contact persons of EWMnetwork.

#### Organization:

##### Board meetings:

- In 2011 two board meetings were held, one 23 March in The Hague and another 18 July in London.

##### Affiliates:

- In 2011 two new affiliates joined EWMnetwork, one representing a WM patient organization (Greece), the other as an individual affiliate (Norway), because there is no WM patient support group yet).

##### Medical Advisory Board (MAB):

- In 2011 there have been some informal contacts between individual board members and individual members of the MAB. Dr. Oivanen, Finland, left the MAB, because he has taken up an administrative appointment.

##### WM Patient Organizations in Europe:

- We have seen in 2011 a rise of membership in some WM patient organizations, like the one in Belgium. We hope that contacts with e.g. Spanish and Italian members at the WM online community will result in more WM patient organizations in these and other European countries. Finding volunteers to organize patient support groups however, remains a problem.

##### Finances and potential funding possibilities:

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

##### Website:

- In 2011 the interest in the website ([www.ewmnetwork.eu](http://www.ewmnetwork.eu) and [www.waldenstrom.eu](http://www.waldenstrom.eu)) went up again compared with 2010. There were 1888 "unique visitors" (2010: 1150); 2884 "visits" (2010: 1650) and 13.740 "hits" (2010: 10.323). The chapters "Useful addresses", "Treatment", "Board, affiliates", "News" and "Partners" were in this order the best visited parts. Visitors came, as far as traceable, (in order of frequency) from USA, The Netherlands, Germany, UK, France, Belgium, but also from USSR, China, India and South America.

Rosmalen, The Netherlands, 14 February 2012,  
Marlies Oom, secretary EWMnetwork