



EWMnetwork

European
Waldenström's
Macroglobulinemia
network

European Waldenström's Macroglobulinemia network Annual Report 2013

1. Introduction

During 2013 most of EWMn's efforts were put into patient-oriented web-based activities and online contacts, partnerships and collaborations. A short report follows.

2. Patient-oriented web-based activities and online contacts

- **Webpage for each European country** www.waldenstrom.info

To promote contact and interaction between WM patients and/or caregivers within their respective countries, in October 2013 EWMn launched web pages for 32 European countries in their own language at www.waldenstrom.info.

These 32 "country pages" can also be reached via the (renewed) www.ewmnetwork.eu site.

Information of relevance to a particular country can be posted on its page.

In the case of a country where there is currently no patient support organisation, it is possible for an individual to be named as the volunteer contact point for the exchange of information, with the intention that this will eventually lead to the creation of a network of support within a country and the ultimate formation of an active patient support organisation. Contact

webmaster@waldenstrom.info

The 32 web pages on www.waldenstrom.info are also a useful supplement to the possibilities for online contact between patients via the online WM community at RareConnect.

- **RareConnect** www.rareconnect.org

Thanks to the monitor of this group, Phil Manning, a growing number of WM patients have found information and made contact (with translation on request into one of five languages). Since the RareConnect community was set up in 2011 about 100 patients have participated in it. Thanks are due also to the initiators of this project (EURORDIS – European Organization for Rare Diseases – and NORD – North American Organization of Rare Disorders) for their help.

3. Partnerships and collaborations

- **Advocacy**

EWMnetwork follows the development of new medicines for WM (notably Ibrutinib in 2013) from the patient's perspective with a view to securing fast access to new medicines and information about clinical trials. EWMnetwork also gives attention to subjects that are of importance for other rare diseases (RDs) besides WM and that need support in a European context, such as: registration of RDs and their patients, early diagnosis and palliative care, national plans for RDs translated into legislation on the European level, regulation of access to orphan drugs and clinical trials.

- **International WM Patient Forum, 17 March 2013, London**

More than 150 people attended this Forum, very well organized by WMUK (the UK contact point for WM patients and doctors) and sponsored by IWWMF and EWMnetwork. In addition to Dr Robert Kyle (USA), several European WM specialists gave interesting and informative presentations. An impression of this Forum can be found at www.ewmnetwork.eu/news-events/newsletters (see Newsletter May 2013).

- **IWWMF**

On its website and in its flyers and other publicity EWMnetwork gives much attention to information from the International WM Foundation (IWWMF). During the year we exchanged ideas and news with IWWMF, acknowledging that our activities are complementary. IWWMF offers worldwide information

and support to *individual WM patients* and awards substantially to research, while EWMnetwork, as an umbrella organisation, aims to represent *WM patient groups* on the European level.

- **Networking**

In furtherance of networking and advocacy EWMnetwork was represented at the following meetings:

- Eurordis (Eur. Org. for RDs) membership meeting/workshops, Dubrovnik, 30 May-1 June
- ECPC (Eur. Cancer Patients Coalition) membership meeting/master class, Brussels, 8-9 June
- ECCO (Eur. CanCer Org.) conference in Amsterdam, 28-29 September
- Eurordis-CEF (=Council of Eur. Federations for RDs), Paris, 29-30 October



Fitr: Phil Manning, Veikko Hoikkala, Marlies Oom, Lia van Ginneken, Roger Brown

4. Organisation

- **Affiliates**

At 8, the number of affiliates stayed the same as in 2012 and an affiliates' meeting took place on March 16 in London. In total 18 persons attended this meeting (affiliates from 8 European countries and their partners, together with Dr Robert Kyle, who is a trustee of the IWMF). Priorities, such as patient-oriented web-based activities and the promotion of online contacts, were discussed and a call for new active affiliates was made. An impression of the meeting can be found at www.ewmnetwork.eu/news-events/newsletters (see Newsletter May 2013).

- **Board**

One board meeting was held on August 21/22 in The Hague, Netherlands, and on that date Phil Manning joined the board as a new member. There were no other changes in the composition of the board during the year. The composition of the medical Advisory Board (MAB) remained the same.

- **Website and Newsletters**

The number of visitors to the websites www.ewmnetwork.eu and www.waldenstrom.eu is still growing. In 2013 there were 3557 "unique visitors" (2012: 3200) and 6356 "visits" (2012: 4927). Two newsletters were issued and posted on the website (in May and in November).

- **Finances**

Since 2009, CMWP, the Dutch WM & MM patient organisation, has been an affiliate member and has had a significant share in the responsibility for EWMnetwork, financially as well as by way of manpower. The board is actively looking for external support on both issues.

Eurordis contributed financially to the International Patient Forum in March and to travel/hotel costs for their membership meeting in Dubrovnik.

The board thanks both organisations for their generous support.

Marlies Oom, February 2014