

Vita: Anita Waldmann, \*1946,



- 1991 - Co-Founder and Chairwoman of Leukaemihilfe RHEIN-MAIN e.V. (LHRM)
- 1994 - Co-Founder and Honorary Chairwoman of the German Leukaemia & Lymphoma Patient's Association e.V. (DLH)
- 1997 - Co-Founder and spokesperson of patient support coalition in Ruesselsheim (SHG-AG)
- 2002 - Co-founder and former steering committee member of the international Lymphoma Coalition (ILC)
- 2005 - Co-Founder and President of the Myeloma Euronet (ME)
- Merging 2012 to Myeloma Patients Europe (merging)
- 2010 - Co-Founder and steering committee member of MDS-Alliance (former Life beyond Limits 2010)
- 2011 - Co-Founder and Board member of MDS-NET Germany (Myelodysplastic Syndrom)
- 2012 - Co-Founder of MDS-Patienten Interessen Gemeinschaft (MDS-Pat-ig)
- 2012 - Co-Founder of H.O.P.E. (Hematologic Organisation of Patients in Europe)
- 2015 - Co-Founder of WBMT-Patient Advocacy (World Bone-marrow Transplant)

Anita Waldmann was confronted with the term leukaemia for the first time in 1990. She lost her son, age 27, 1992 after two years suffering with acute lymphocytic leukaemia.

Since then she dedicated her life to care & advocate for patients with blood & lymphatic diseases and their relatives.

In **1991** Anita Waldmann founded the local Leukaemia Patient-Support Group RHEIN-MAIN (LHRM) which has been enlarged to a network of 5 self support groups (with more than 1.200 contacts) in the area over the years. She is the leader from the beginning and since 1994 chairwoman.

After having composed educative material in 'easy to understand language' for patients and families, she started an active search for suitable bone marrow donors in 1991.

Since then, more than 40 campaigns with about 60.000 potential donors have been supported and organized in cooperation with the *German Bone Marrow Donor Registry* - "DKMS".

When the regional organisation LHRM was registered as a non-profit-organisation in **1994**, she abandoned her professional life in order to spend her time since on 100 % honorary work for the Deutsche Leukaemie- & Lymphom-Hilfe (DLH) and LHRM. She was founding member of the DLH in 1995 and from the early beginning she became an active DLH-board member (responsible for: advocacy, public relations, organization, finances, and human resource management, educating DLH-group leaders, awareness & information days and congresses) and chair till 2008.

Many contacts to other self support groups throughout Germany and Europe have been established by her as well as to other patients' associations.

In **1997** she encouraged Myeloma patients to build up patients support groups in their own hometowns, also in that year she founded the coalition of 33 self-support-groups (with all kinds of diseases) in her hometown (SHG-AG Ruesselsheim) to give handicapped people a voice. This coalition is grown to more than 40 and offers each year a patient-health-day with several workshops. [www.LHRM.de](http://www.LHRM.de), [www.shg-ag.de](http://www.shg-ag.de)

From 2001 to April 2008 she was chairwoman of the DLH and also member of the patients' advisory board of the Deutsche Krebshilfe (German Cancer Aid) and at the cancer plan steering committee of Deutsche Krebsgesellschaft (German Cancer Association).

In **2001** she became the first winner of the "Mechthild-Harf-Award" of the DKMS.

Under her leadership, the DLH became 2001/2002 a founding member of the *Lymphoma Coalition* (LC) [www.lymphomacoalition.org](http://www.lymphomacoalition.org) and 2005 of the *Myeloma Euronet* (ME) [www.myeloma-euronet.org](http://www.myeloma-euronet.org), 2006 she became the president of ME, she was also a supporting member of ELN (European Leukemia Net), ECPC (European Cancer Patient Coalition) and DPWV (Paritaetischer Wohlfahrstverband, NGO) [www.paritaet.org](http://www.paritaet.org)

October **2006** she received the "Federal Cross of Merit" (*The Order of Merit of the Federal Republic of Germany* = Bundesverdienstkreuz).

Since that year she was involved in EMA (Unit for the Pre-Authorisation Evaluation of Medicines for Human Use Post-Authorisation Unit) to give Myeloma patients a voice.

Since **2006** she was responsible member of the organizing committee for the EBMT Patient- & Family Day's (2006 the 1<sup>st</sup> in Lyon/France, 2008 the 2<sup>nd</sup> in Florence/Italy, 2009 the 3<sup>rd</sup> in Gothenburg/ Sweden, 2010 the 4<sup>th</sup> in Vienna/Austria, 2011 the 5<sup>th</sup> in Paris/France). Since then it became a traditional part at the EBMT-Congresses.

She is member of the ESMO & ECCO Patient-Advisory Committee since 2005. 2008 Myeloma Euronet became member of the ECCO (membership changed 2012 to MPE).

**2009 to 2011** she was appointed by communal government to be an official spokesperson for all handicapped people in the administrative district.

Since **2009** she is member of the EHA scientific working group "Quality of Life & Symptoms", working to influence the guidelines (Patient Reported Outcomes).  
Currently she is member of the EHA Patient Advocacy Committee.

With her local organisation she is organizing together with clinics, many patient-seminars during the year all over Germany (also special seminars for Mantlecell-Lymphomas, Waldenstroems/Immunozytoma, MDS e.g.)  
Since 2009 her organisation was providing a virtually patient support group for 'Long Term Survivors' after haematological diseases [www.leukaemie-phoenix.de](http://www.leukaemie-phoenix.de) it moved 2014 under the umbrella of DLH.

Since **2010** she was part of the "merging-team" (Myeloma Euronet & European Myeloma Platform) to become one strong European organisation: Myeloma Patients Europe (MPE) in **2012**.  
[www.myelomapatientseurope.org](http://www.myelomapatientseurope.org)

In December **2012** Myeloma Euronet was dissolved and continues now as Myelom Gruppe LHRM (Germany).  
[www.myelom.net](http://www.myelom.net) (myelom-gruppe.LHRM.de)

At ASH **2012** she was co-organiser to start H.O.P.E. = **H**aematology **O**rganisation of **P**atients in **E**urope.  
[www.hope-eu.org](http://www.hope-eu.org) this organisation had to stop their activities in early 2014 because of human resources.

Since 2009 she also tries to build up better understanding and awareness for MDS (Myelodysplastic Syndrome) and was part of the steering committee "MDS-Life beyond Limits" and co-founder and board member of MDS-NET Germany in **2012**.

Because the needs of MDS patients have not been recognized in the way it was wanted by the patients, 4 former board members of MDS-NET Germany and her separated to found **2013** the **MDS-Patient Interest Coalition** [www.mds-patienten-ig.org](http://www.mds-patienten-ig.org)

Also in that year the **MDS ALLIANCE** started with her as a steering committee member of the worldwide alliance of patient support and advocacy organizations. [www.mds-alliance.org](http://www.mds-alliance.org), since **June 2015** she is chair of the group.

In **2014** LHRM started [www.blog4blood.de](http://www.blog4blood.de): providing experiences, information and guidance for patients with hematologic diseases and their relatives.

December **2015** she was awarded by Lymphoma Coalition ([www.lymphacoalition.org](http://www.lymphacoalition.org)) as "Mama Lymphoma".

Since that year she is also co-founder and member of WBMT-Patient Advocacy group.

She was attending several congresses and is invited to speak and encourage people to start with "advocacy" in several countries. <http://myeloma-euronet.lhrm.de/en/resources/presentations.php>  
also did many presentations in many meetings and conferences.

**The German Journal of Oncology Pharmacy published 5 page article about "Early detecting MM"**  
<http://myeloma-euronet.lhrm.de/en/survey/index.php>

The European Journal of Oncology Pharmacy • Volume 5 • 2011 • Issues 3-4 published a two page article about **"The role of a pharmacist according to patients"** [EJOP 2011-E3-E4 p10-11 CoverStory Waldmann](http://www.ejop.org/2011-E3-E4-p10-11-CoverStory-Waldmann)