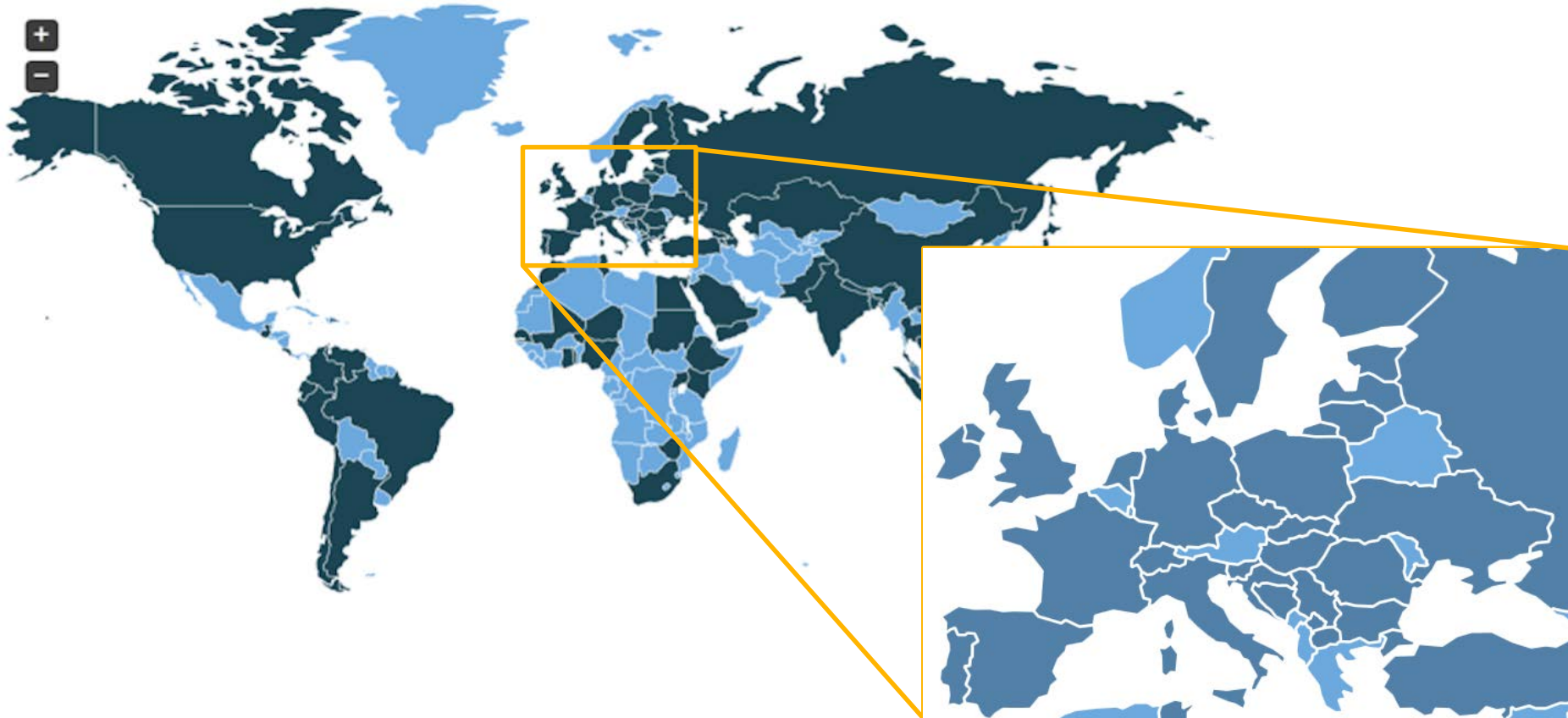


# European patient advocacy and key European projects

Jan Geissler

# CML Advocates Network: 115 CML organisations, 85 countries:

of those: 22 organisations from Western Europe,  
30 from Central and Eastern Europe & West Asia



# Challenges and priorities: Strong diversity in Europe

## European Union



- 27/28 Member States
- 24 official languages
- 28 different health systems
- Centralized **medicines approval** (EMA)
- **Member States take Reimbursement decisions**
- Strict EU legislation e.g. on clinical trials, drug safety
- New EU policy for cross-border health services
- Multi-billion programmes on health research
- EU coordination on rare disease and cancer policy
- Strong patient voice in Brussels

## Wider European region

- Additional western countries (e.g. Switzerland, Norway)
- Additional Eastern European / West-Asian countries
- Balkan countries
- More languages, healthcare systems, authorities

# Challenges and priorities in CML: Strong diversity in Europe

## Western EU

- Variations in quality of care
- Managing quality of life
- Adherence
- Stopping treatment
- TKI generics

## Eastern EU

- Access to 2<sup>nd</sup>/3<sup>rd</sup> gen drugs
- Access to quality care
- TKI generics
- Low number of clinical trials

## Eastern Europe /West Asia

- Access to all drugs
- Access to quality PCR
- Drug quality of copy drugs
- 2<sup>nd</sup> gen TKI rare
- Access to quality care

## Southeast Europe

- + Parallel export/drug shortages
- + TKI generics
- + Access to quality PCR

# **We've got enough to do in CML. Why bother about EU policy, research projects, networks?**

- There is no specific CML policy.  
There is health policy, or maybe cancer policy instead.
- To improve the system for CML patients, we need to work in alliances and networks to change the overall rules and to influence research.
- Over years, the CML Advocates Network has become one of the most influential cancer patient network in the European community.

**EU level**

# National vs. European level: Barking up the right tree!



- Health policy is subject to EU Member States, but many things are decided on EU level:
  - Medicines authorization (EMA)
  - Clinical trials regulation, data protection, drug information
  - Networks for excellence in clinical excellence and cross-border healthcare (European Reference Network EuroBloodNet)
  
- Most CML research is pan-European, if not global
  - Industry-sponsored trials
  - Medical societies (ESMO, EHA, ECCO) → Guidelines
  - Academic research networks (e.g. European LeukemiaNET)
  - EU research programmes (e.g. IMI Harmony)

# European platforms to which we are contributing as CML advocates



European Expert Groups  
on Rare Diseases and Cancer Control



EUROPEAN  
HEMATOLOGY  
ASSOCIATION

Patient Advocacy Track and  
Capacity Building at the EHA  
congress



Pan-European Reference Network  
in hematology



CML AdvocatesNetwork



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH  
Scientific Advice

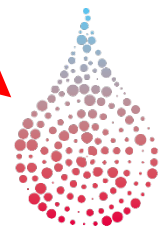


EUROPEAN  
CANCER  
ORGANISATION



European Society for Medical Oncology

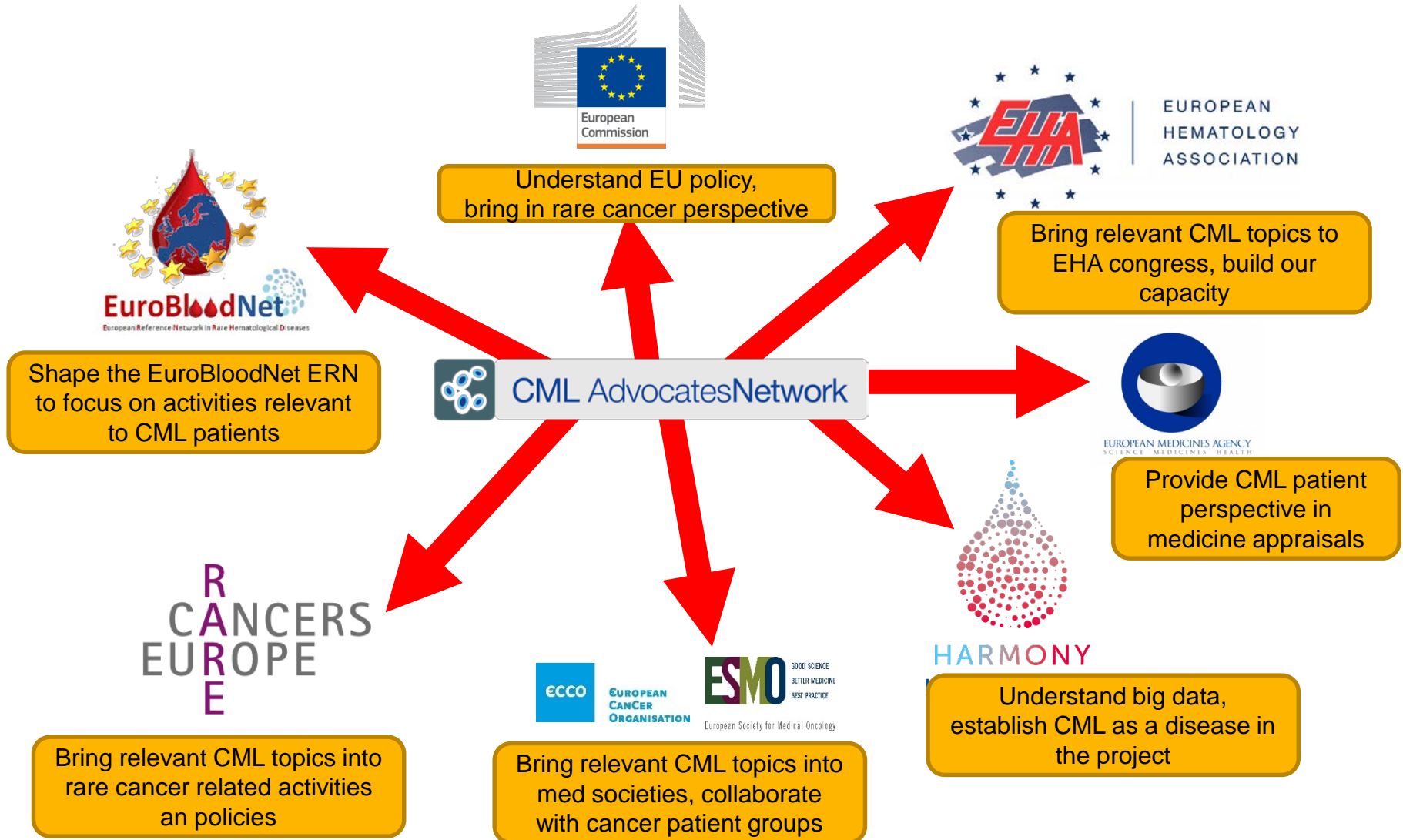
Medical societies



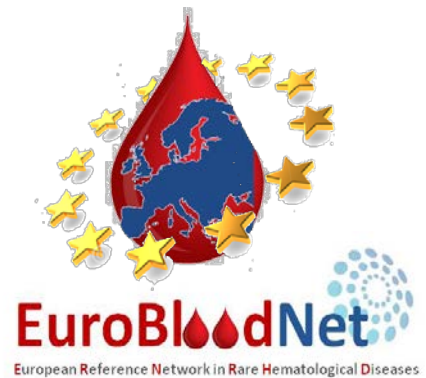
HARMONY  
IMI2 Research Project  
on „Big Data“



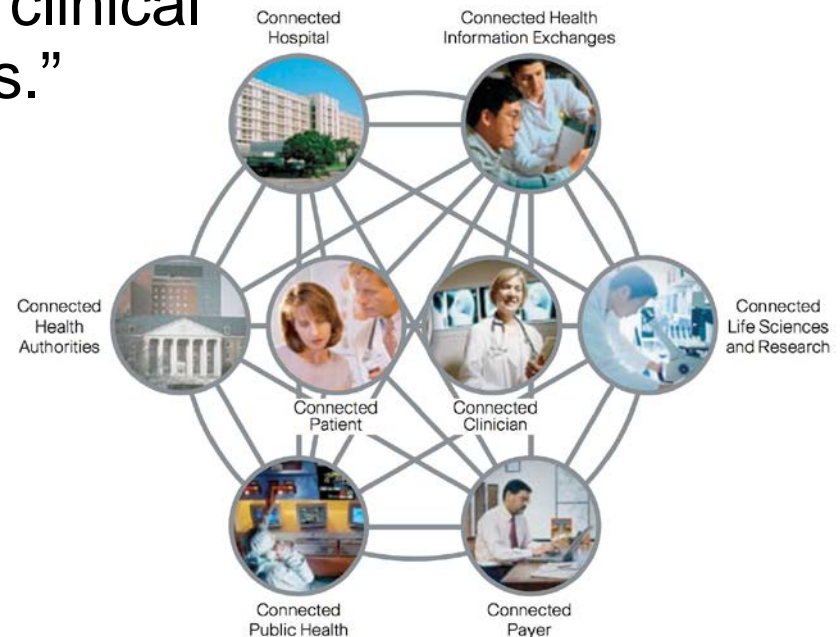
# European platforms to which we are contributing as CML advocates



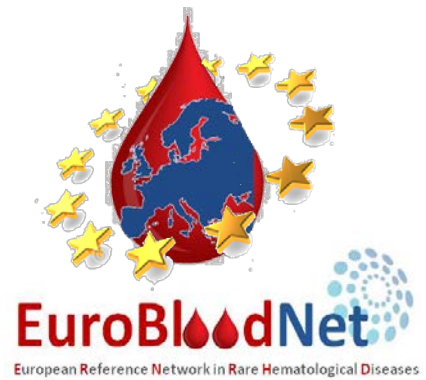
# EuroBloodNet European Reference Network



“EuroBloodNet’s main goal is to improve the healthcare and overall quality of life of patients with a rare hematological diseases by facilitating best practice sharing for safe and high-quality cross-border healthcare and developing more evidence-based clinical tools and cost-effective treatments.”



# Patients' hopes and dreams in EuroBloodNet



Improve the life of hematology patients through...

- National healthcare pathways for all rare diseases and across all EU countries
- Access to knowledge and expert advice for timely, accurate diagnosis, treatment
- Optimal use of existing knowledge, production and adherence to clinical guidelines
- access locally to clinical excellence through best knowledge and leading expertise
- accelerated production of new knowledge and pace of research, integration of healthcare and research infrastructures

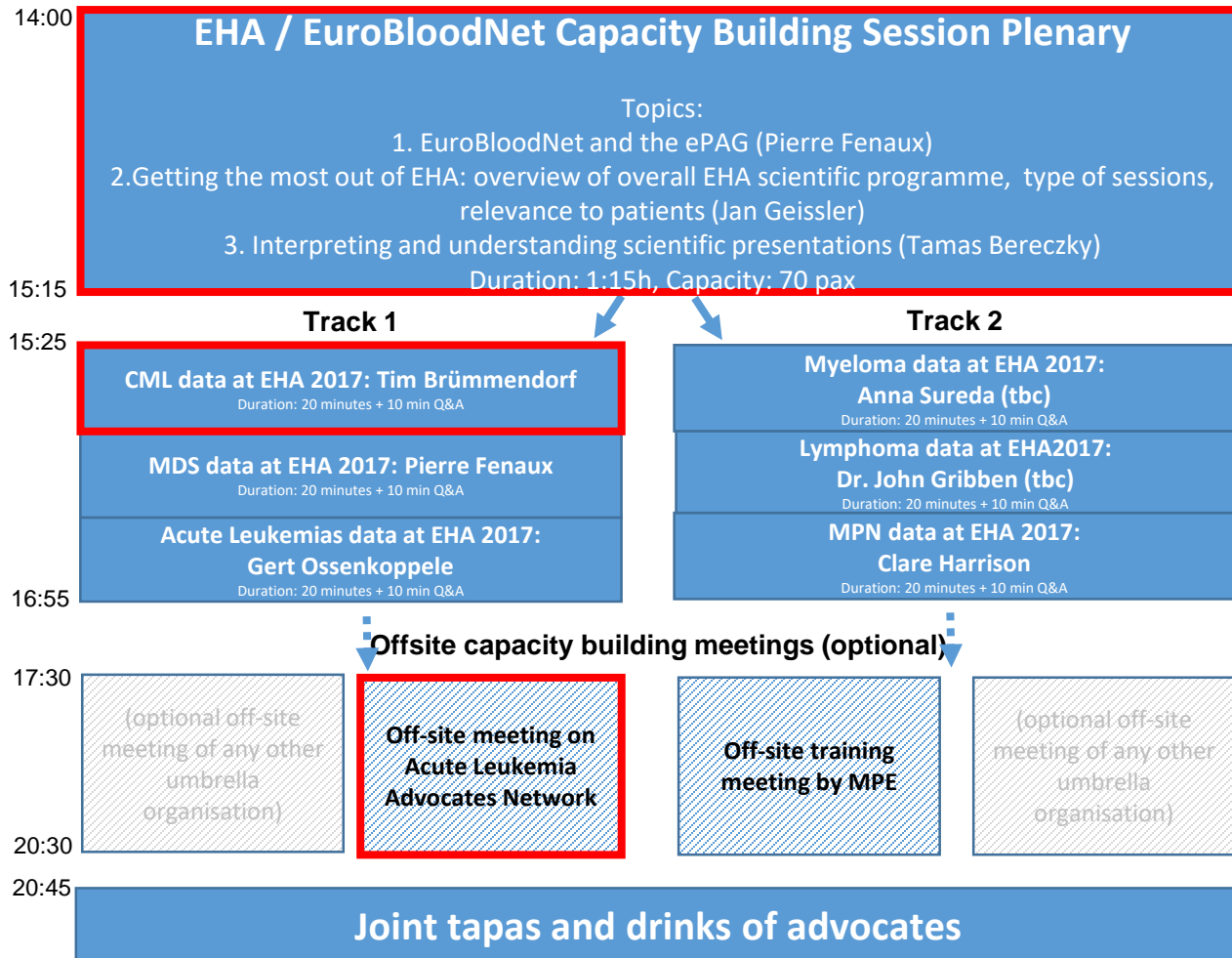
# **Collaboration with Hematologists and EHA**

# Good collaboration with EHA has expanded over years



- Patient Advocacy Track 2010-2017
  - This year:
    - Cancer and fertility
    - Innovative clinical trial designs and regulatory pathways
- 55 free registrations
- Free exhibition booth for CML, CLL, MPN
- Capacity building meeting (with CML, CLL, MPN session)
- EHA European Affairs Committee membership

# EHA Capacity Building Meeting, 22 June



CML advocates at EHA this year:

- Ibolya Kéri, HU
- Lars Raae, DK
- Rita O. Christensen, DK
- Natacha Bolanos, ES
- Jesus Martin Murga, ES
- Stanislav P. Kulikov, RU
- Pru Etcheverry, NZ
- Tone Hansen, NO
- Elen Petrosyan, Armenia
- Riikka-Leena Manninen, FI
- Marja Tamminen, FI
- Lara Kuerzer, FI
- Pepo Levi, MA
- Lidija Pecova, MA
- Celia Marín, ES
- Teresa Terren, ES
- Felice Bombaci, IT
- Cornelia Borowczak, DE
- Diego Villalon, ES
- Karen Meliksetyan, Aermenia
- Zack Pemberton-Whiteley, UK

# Collaboration of CML patient groups with CML research groups

- Presentations at investigator meetings
- Contribution to research, e.g. workgroups and studies
- Adherence survey - paper copies

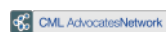


# **Collaboration with the patient community (outside of CML)**





# Pan-European patient networks, comprising of 257 hematology patient organisations



**Chronic Myeloid Leukemia:** CML Advocates Network

→ 115 members (52 Europe)



**Chronic Lymphocytic Leukemia:** CLL Advocates Network

→ 8 members (6 Europe)



**Hemochromatosis:** European Federation of Associations of Patients with Haemochromatosis (EFAPH)

→ 21 members



**Hemophilia:** European Hemophilia Consortium (EHC)

→ 45 members



**Immune Thrombocytopenia:** ITP Support Association

→ 1 member



**Lymphoma:** Lymphoma Coalition (LC)

→ 66 members (34 Europe)



**Myelodysplastic Syndromes:** International MDS Alliance

→ 22 members (15 Europe)

**Myeloma:** Myeloma Patients Europe (MPE)

→ 40 members



**Myeloproliferative Neoplasms:** MPN Advocates Network

→ 12 members

**Thalassemia:** Thalassemia International Federation (TIF)

→ 120 members (18 Europe)



**Waldenström's Macroglobulinemia:** EWMnetwork

→ 14 members



**= 260 European haem. patient organisations (161+99)**



# Pan-European Networks of hematology patient organisations and the hematology ePAG



**Chronic Myeloid Leukemia:** CML Advocates Network



**Chronic Lymphocytic Leukemia:** CLL Advocates Network



**Hemochromatosis:** European Federation of Associations of Patients with Haemochromatosis (EFAPH)



**Hemophilia:** European Hemophilia Consortium (EHC)



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**Myelodysplastic Syndromes:** International MDS Alliance

**Myeloma:** Myeloma Patients Europe (MPE)



**Myeloproliferative Neoplasms:** MPN Advocates Network

**Thalassemia:** Thalassemia International Federation (TIF)



**Waldenström's Macroglobulinemia:** EWMnetwork



**ePAG**

- **Amanda Bok** (EHC)
- **Ananda Plate** (MPE)
- **Angelo Loris Brunetta** (TIF)
- **Jan Geissler** (LePAF)
- **Pierre Aumont** (EWMNetwork)
- **Sophie Wintrich** (MDS Alliance)

# WECAN



- “Think tank” to develop ideas and actions on how to cross bridges between advocacy
- Share workload for meetings, but maybe send only 1-2, in close alignment, consultation and feedback structure with wider workgroup
- Coordinate and align our representation and community input in committees and expert groups
- Share resources on joint patient-driven evidence

# WECAN membership



1. Europa Donna
2. EuropaColon
3. EuropaUomo
4. European Men's Health Forum
5. European Network of Gynaecological Cancer Advocacy Groups
6. European Organisation for Rare Diseases
7. European Waldenström's Macroglobulinemia Network
8. International Brain Tumour Alliance
9. International Kidney Cancer Coalition
10. International Neuroendocrine Cancer Alliance
11. Leukemia Patient Advocates Foundation (CML, MPN, CLL)
12. Lung Cancer Europe
13. Lymphoma Coalition
14. MDS Alliance
15. Melanoma Patients Network Europe
16. Myeloma Patients Europe
17. Sarcoma Patients Euronet Association
18. Thyroid Cancer Alliance



**So how does this  
all help our CML  
patients?**

# Through our European projects, we influence policy and partnerships in the interest of CML patients

- **By collaborating with researchers, we make sure legislation on research meets our CML needs, e.g.** how clinical trials are regulated, and how „big data“ will turn out
- We shape **emerging clinical hematology networks** like EuroBloodNet to improve situation for CML patients through cross-border healthcare, education programmes, guideline development
- We raise the awareness of policy makers on **rare cancer policy**, as rare cancers like CML are often neglected when setting EU policy.
- Through EHA, we make sure CML advocates can attend the **EHA congress**, and CML-relevant topics are on the agenda

# Europe: United but unique!



**Azerbaijan:** 'Birlikde' Leukemia Patients Support Organisation \* Charter Of "Fighting Leukemia" Public Union \* **Bosnia and Herzegovina:** ZAGRLJAJ Association of leukemia and lymphoma patients "Embrace" \* **Bulgaria:** Association of People Suffering from CML \* Croatia: HULL Croatian Leukemia and Lymphoma Society \* **Czech Republic:** Diagnoza CML \* **Denmark:** LYLE \* **Estonia:** Estonian Leukaemia and Lymphoma Patients Society \* **Finland:** The Finnish CML Patient Network \* **France:** Leucemie espoir 06 \* LMC France \* Vivre avec la LMC \* **Georgia:** The Alliance of Chronic Myeloid Leukemia Patients of Georgia \* **Germany:** German Leukemia and Lymphoma Aid (DLH) \* Leukämie-Online / LeukaNET \* Parents' Organisation for Children with CML \* **Hungary:** CML & GIST Beteg Egyesület \* **Ireland:** CML Society \* **Italy:** AIP - Italian Patients' Association of CML \* Gruppo AIL Pazienti Leucemia Mieloide Cronica \* **Kosovo:** Association for Supporting Chronic Leukemia Patients \* **Latvia:** Association of Support for Leukemia Patients \* **Lithuania:** Community of Oncohematological Patients (COHP) KRAUJAS \* **Macedonia:** Association for help in treatment of patients with CML \* **Netherlands:** Stichting Hematon, Hematon Leukemie en MDS \* **Poland:** The Association for Blood Cancer Patients Aid \* **Poland:** The Nationwide Association for CML Patients Aid \* **Portugal:** Associação Portuguesa contra a Leucemia \* **Portugal:** Portuguese Leukemia and Lymphoma Association \* **Romania:** "Fighting and Preventing Lymphoma and Leukemia" Leukemia Association \* **Russia:** CML-Stop \* Sodeystvie \* **Serbia:** CML Association of Serbia \* Slovakia: CML Life \* Slovenian Lymphoma and Leukemia Patient Association, L&L \* **Spain:** AEAL \* **Sweden:** Blodcancerförbundet \* **Switzerland:** Foundation for Advancement of Bone Marrow Transplantation \* **Turkey:** The Leukemia, Lymphoma, Myeloma Patients Research and Education Society (LLMBIR) \* **UK:** Children with CML \* CML UK - Facebook Group \* CMLSupport \* Leukaemia CARE \* **Ukraine:** OSANNA