African patient advocacy and key African projects

Bahija Gouimi

Asian patient advocacy and key Asian projects

Rod Padua

CML HORIZONS 2017

CML AdvocatesNetwork

FRANKFURT
GERMANY
26-28 MAY 2017

European patient advocacy and key European projects

Jan Geissler

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

22 member orgs

Eastern EU
- Access to 2nd/3rd gen drugs
- Access to quality care
- TKI generics
- Low number of clinical trials

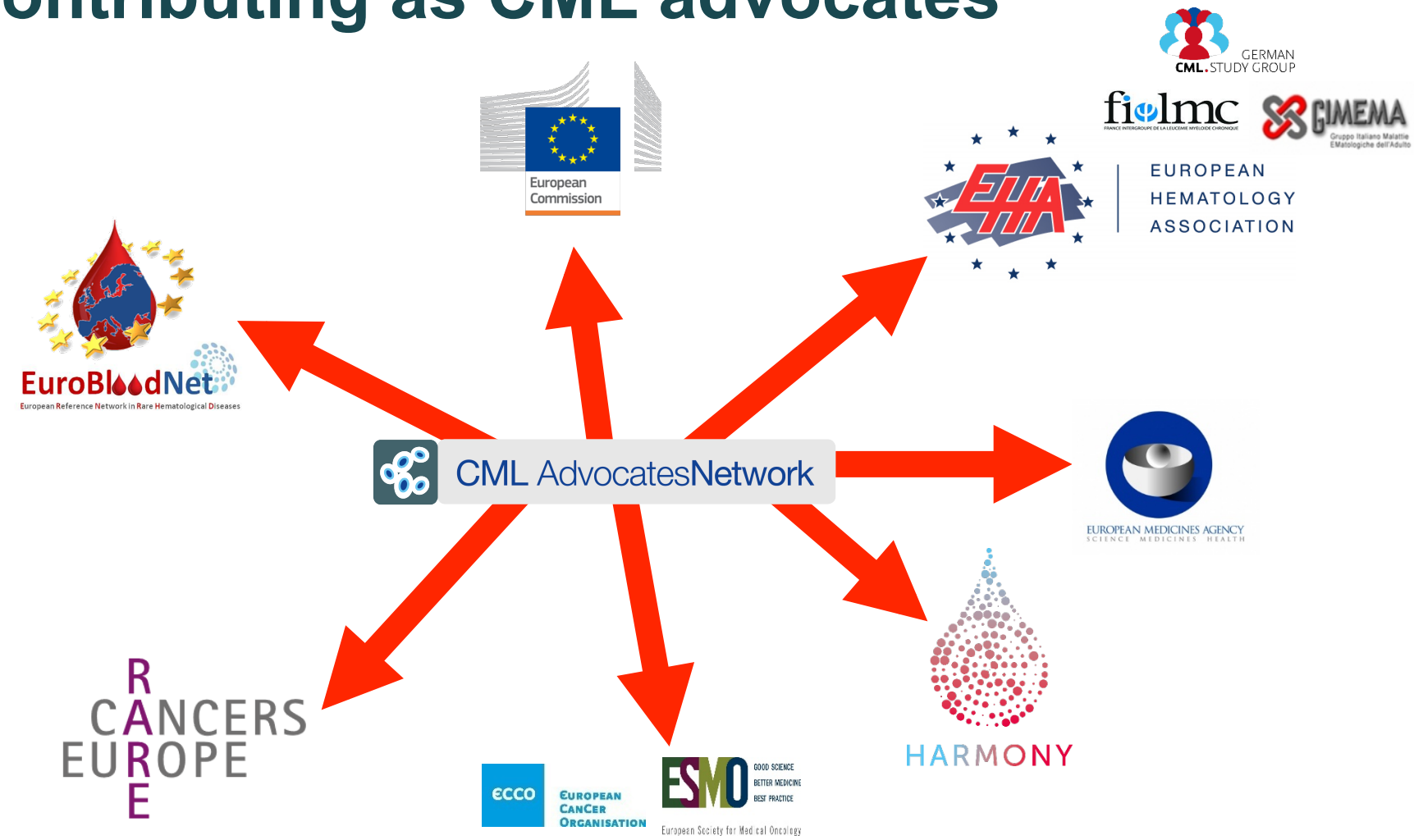
30 Member Orgs

Eastern Europe / West Asia
- Access to all drugs
- Access to quality PCR
- Drug quality of copy drugs
  2nd gen TKI rare
- Access to quality care

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

CML Advocates Network European Survey (April 2014)

European platforms to which we are contributing as CML advocates



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: Thalassaemia International Federation (TIF)	→ 120 members (18 Europe)
Waldenström's Macroglobulinemia: EWMnetwork	→ 14 members

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

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 Lymhoma 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