Think global, act local: Results of Workshop on CML advocacy in Europe

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Goals of this session

- Understand **EU/European activities and forums** so where we’ve been active and influential

- **Brainstorm and work out with you**
  - What are the **main issues** for your CML patients in Europe
  - **Identify stakeholders** where we can work with to tackle these
  - Brainstorm about **potential actions and solutions** of CML Advocates Network and its members in Europe

- Leave with **priorities on tangible, achievable actions**, and people who are willing to work on them
CML Advocates Network:
118 CML organisations, 88 countries

22 organisations from Western Europe,
31 from Central and Eastern Europe & West Asia.

All EU countries except Belgium & Austria,
Wider Europe: all Countries except Norway, Cyprus, Iceland, Moldova, Monaco, Andorra, Albania, Montenegro, Belarus
Challenges and priorities in Europe
(51 of 118 member orgs in CML-AN are from wider 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 EU fora

**EU Affiliated Countries**
(Switzerland, Norway, Iceland)
- Most EU rules apply or are in sync
- Close collaboration of authorities, e.g. EMA

**EU Candidate Countries**
(Serbia, Macedonia, Montenegro) (Turkey)
- Increasing collaboration and intent to join EU rules/systems

**Third countries** (e.g. Russian federation, Ukraine, Israel, Azerbaijan, Armenia, ..)
- Bilateral agreements, e.g. prevention, infectious diseases, global health risks, research programmes
European platforms to which we are contributing as CML advocates

- Understand EU policy, bring in rare cancer perspective
- Bring relevant CML topics to EHA congress, build our capacity
- Provide CML patient perspective in medicine appraisals
- Understand big data, establish CML as a disease in the project
- Shape the EuroBloodNet ERN to focus on activities relevant to CML patients
- Bring relevant CML topics into rare cancer related activities and policies
- Bring relevant CML topics into med societies, collaborate with cancer patient groups
Clinical treatment and care

Collaboration with industry

Research & Science

Drug regulation and access

Education of pts & advocates

Step 1 – The issues you face

Step 2 – The actors we need to work with

Step 3 – Potential actions and solutions of CML Advocates Network and its members in Europe

Voting & Volunteering
Clinical treatment and care
- Push for CML agenda in EuroBloodNET
- Create (and use) reference centers

Collaboration with industry
- Continue CML-CABs with industry
- Convince pharma to communicate more and better with patients

Research & Science
- Run academic CAB with European CML experts
- Use app to collect experience from CML-AN European members
- Promote patient-friendly clinical trial reports (create patient focused abstracts)
- Prepare project proposal to ELN and academic entitites about pregnancy & CML

Drug regulation and access
- Build a CML-AN workgroup of patient experts on regulatory & HTA

Education of pts & advocates
- Run a training programme for European CML patient experts
- Access to reliable online CML information
- Cross-border collaboration of CML groups - translate info and support each other