Update on the CML Advocates Network

The global network for CML patient advocacy

Jana Pelouchová, May 2018
CML Advocates Network connecting 118 leukemia patient organisations in 88 countries today

+3 organisations
+2 countries
in the past year
Welcome our 3 new member CML organisations!

POWER OF CML
(Egypt)

CELEBRANDO LA VIDA
(Bolivia)

UZBEKISTAN CML PATIENTS LEAGUE
(Uzbekistan)
CML Advocates Network management team, CML Steering Committee and CML Community Advisory Board
Our current and ongoing projects

Website
- CMLadvocates.net, Facebook, Twitter, Instagram, YouTube
- CML trial database

Projects
- TFR Survey
- Generics Testing

Research
- Contribution to CML investigator meetings
- Speakers at research conferences

Advocacy and Collaboration
- CML Community Advisory Board (CAB)
- Contribution to European committees (EuroBloodNet, EHA, ECCO, ESMO)

Campaigns
- World CML Day

Conferences
- CML Horizons 2018
- ASH Reports
- EHA European Affairs Committee, Fellowships booth
World CML Day 2017: Today, Together

- 61 CML Advocates Network members
- 51 countries
- 6 world regions
- OTHER PARTICIPANTS: pharma companies, physicians, medical centers, patients, media, collaborators

Full report at: www.cmladvocates.net/world-cml-day-9-22/worldcmldayactivities-2017
Determination of Imatinib active ingredient in generic drugs in 43 different Imatinib products from 22 countries

Active ingredient (% of 400mg)
- <85%
- 85%-90%
- 90%-95%
- 95%-105%
- 105%-110%
- 110%-120%
- >120%

Countries of sale of samples
- Europe
- North America
- Latin America
- Asia
- Africa

CML Advocates Network (2018, unpublished)
CML trial registry
@cmladvocates.net/cmltrials

- 49 CML trials listed in 4 continents:
  - First line trials
  - After therapy failure or intolerance
  - Therapy optimization
  - Treatment of advanced phases
  - Treatment discontinuation
  - Paediatric
  - Other trials (e.g. registries, combination, QoL)

- Title, intervention, type, recruitment status, list of trial centres, informed consent

- Basics: “What are clinical trials”
TFR for CML Patients: global patients’ survey

- Launched in 14th March, 2018. Open until July, 2018
- Collecting & analyzing the viewpoint of CML patients considering stopping or have already started Treatment-Free Remission
- To support evidence-based patient's advocacy in TFR
- 7 languages + 5 more coming
- +550 responses & 55 countries participating
- CML-TFR website section on cmladvocates
CML Community Advisory Board (CAB)
http://www.cmladvocates.net/cml-community-advisory-board

- Model: European AIDS Treatment Group’s ECABs (1997)
- Working group of the CML Advocates Network with expert patient advocates from all world regions.
- Established in May 2016, 5 CML-CABs held so far

CML-CAB Goals:
- Ensure CML patient needs are reflected in research priorities and clinical trials;
- Address trial access issues;
- Address problems CML patients face in accessing optimal diagnosis, monitoring, treatment and care;
- Improve quality of patient information;
- Provide insight into the CML patient journey
CML-CAB in May+Nov 2016, Feb+May+Nov 2017, and 7-8 May 2018

- 9 CML Horizons Steering Committee 2015-2016 members, +9 additional members suggested by the 6 world regions
- CML-CAB meetings with Novartis, Pfizer, Takeda/Icyte/Ariad
- Minutes for CML Advocates Members of cmladvocates.net
What’s next?

- TFR FOR CML PATIENTS: Survey live until July 2018.
  - GENERICS TEST FULL REPORT.
  - WORLD CML DAY 2018: Today, Together…
  - PREGNANCY: Working on it…
  - BOOK FACES OF COURAGE AND HOPE: Still available for members.
- …

Thank you to everyone who has contributed to all the activities!
Please engage with the Network!
## Regional networks: Parallel sessions rooms

<table>
<thead>
<tr>
<th>Region</th>
<th>Location and Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Europe Region</td>
<td>Light room - Floor M2</td>
</tr>
<tr>
<td>North America Region</td>
<td>North America 4 + 1 SC = Lobby Lounge</td>
</tr>
<tr>
<td>East Asia / Pacific Region</td>
<td>East Asia / Pacific Region meeting 4,6,8 M2 floor</td>
</tr>
<tr>
<td>Africa and Middle East Region</td>
<td>Africa and Middle East Region Plenary room. Level WH</td>
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<tr>
<td>Latin America Region</td>
<td>Latin America Region Meeting room 1 (CML Office) Level M1</td>
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