Update on CML Advocates Network

ŠARŪNAS NARBUTAS
Chairman of CML Advocates Network
CML ADVOCATES NETWORK

12 Years / 122 Patient organisations / 92 Countries / 6 Continents
Highlights

From the medical sessions most understandable was medical session 3 “Side effect management”

From the patient advocacy sessions most helpful was patient advocacy session 3 “Stopping cml treatment”

The parallel regional networking session were considered as very helpful
Regional Networking Sessions done for the first time

- In your opinion what is the direction CML advocates should take in future regarding research?
  - Being from India a resource-poor country there are many research projects we want to undertake, but have limited resources and knowledge. It will be great if CML Advocates partners on one project to guide us through
  - CML Advocates should actively participate in all kind research related to CML and a communicative with all hematological Association in his country
  - Need funds raising to sponsor academic study to address issue not in the agenda of pharma
  - Assuming that many don’t have the opportunity to attend ASH, etc. it may be helpful to educate them on the top 3 news in CML, through research presentations
What you valued most?

- For most of the participants (22) the most valuable aspect of the conference was the opportunity for networking.
- Then, 8 people consider that the topics, content and presented information were most valuable, as was TFR.
- Other valuable aspects were: medical sessions, side effects, advocacy session, new drugs, etc.
CML Horizons 2019 (Lisbon)

119 / 62 / 22 / 21
Participants / Countries / First time participants / Speakers

CML Horizons 2018 (Warsaw)

117 / 61 / 41 / 18
Participants / Countries / First time participants / Speakers
18 CAB meetings in 3 years

- 7 meetings with Novartis (imatinib, nilotinib, asciminib)
- 1 meeting with BMS (dasatinib)
- 4 meetings with Pfizer (bosutinib)
- 4 meetings with Takeda / Ariad (ponatinib)
- 4 meetings with Incyte (ponatinib)
Considerations for Treatment-free Remission in Patients With Chronic Myeloid Leukemia: A Joint Patient—Physician Perspective

Giuseppe Saglio, Giora Sharf, Antonio Almeida, Andrija Bogdanovic, Felice Bombaci, Jelena Cugurovic, Nigel Deckes, Valentín García-Gutiérrez, Jan de Jong, Šarūnas Narbutas, Peter Westerweel, Daniela Zackova

Abstract

Treatment-free remission (TFR) after discontinuation of tyrosine kinase inhibitor therapy is now an emerging treatment goal for patients with chronic myeloid leukemia, who have achieved a deep and stable response to treatment. Although guidance is now available, patients’ questions regarding this progressive concept have yet to be addressed. The overall aim of this European Steering Group is a patient-centered approach that educates patients on their treatment options, including TFR, facilitates better patient—physician relationships, and meets patients’ emotional and psychological needs. The present report outlines 5 key topics on discontinuing tyrosine kinase therapy and the implications of TFR for patient—physician consideration: what TFR is; when TFR is appropriate; which patients might and might not be eligible for TFR; and patients’ considerations for discontinuing therapy, such as tyrosine kinase withdrawal syndrome, potential psychological implications, molecular recurrence, and repeat treatment. This Steering Group advocates that patients with chronic myeloid leukemia should have access to high-quality, frequent molecular monitoring and be treated in a specialist center with appropriate medical and psychological support. As patients concern with attempting TFR become forefront in patient—physician discussions, a greater number of eligible patients might be willing to discontinue therapy.

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Keywords: CML, CML advocates, TFR, TKIs (Tyrosine Kinase Inhibitors), Therapy discontinuation
TFR survey: response rates

Total of **1016** respondents

Covering **69** countries

Methodology:

- All online – Recruited by patient associations via online forums and other methods
- Available in eleven languages: Arabic, Danish, English, Finnish, French, German, Hebrew, Italian, Japanese, Russian and Spanish
- Fieldwork – 14th March 2018 – 1st August 2018
WE ARE HIRING!

APPLY FOR THE EXECUTIVE DIRECTOR POSITION

DEADLINE

15 JUNE 2019

recruitment@cmladvocates.net
QUESTIONS?
NEW GOVERNANCE MODEL
Top 4 areas where CML AN provides most value

**Global voice for CML patients**
- represent voice of CML patients
- support regional initiatives
- tailor activities to regions, address national/local needs

**Leader of cancer patient community**
- be a role model for other patient organizations
- be a role model for other disease areas
- realize synergies

**Create partnerships with other stakeholders**
- give other stakeholders a patient perspective
- conduct CML-CAB meetings

**Build members’ capacity / capability**
- share best practices
- learn from other organizations
- help members be more effective
- grow through CML Horizons
Strengthening regions

Regional project – can receive up to 40,000 USD
• A project qualifies as “regional” if >70% of CML AN member organisations from the region benefit from the activities

Local project – can receive up to 5,000 USD
• A project qualifies as “local” once it is organized and held at the country of one CML AN member organization in the region
Strategic priorities CML AN will focus on

- Continue CML Horizons
- Continue CML CAB - develop partnership with other stakeholders
- Continue World CML Day
- Tailor activities to regions / support regional activities
- Focus on priority needs in different regions
- Take leadership role in wider cancer patient community
- Be proactive in taking collective action
- Generate evidence
Evolved Steering Committee Competencies

Member-based network of CML organisations, represented by the SC
Takes full responsibility of CML Advocates Network & CML Horizons
Global projects decided by the whole SC
Regional projects decided by the regional SC representatives
All regional representatives elected by the member organisations only in their respective regions
Changes: Term – 3 years
2 SC members elected every year

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<tr>
<th>Region</th>
<th>Term</th>
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<tr>
<td>North America</td>
<td>(Term: May 2019 – May 2022)</td>
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<tr>
<td>Central and Eastern Europe &amp; West Asia</td>
<td>(Term: May 2019 – May 2022)</td>
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Responsibilities of CML AN Steering Committee members

- CML Horizons
- CML-CAB
- Regional activities
- Strategic direction of CML AN
QUESTIONS?