

CML Advocates Network
Community Advisory Board

CML Community Advisory Board: Status Quo, Learnings and Next Steps

Jan Geissler



Why CML Community Advisory Boards?

- **Research** is key towards better outcomes and CML cure, but often the trials are made without patient input.
- **Care** (incl monitoring) are often not reflecting true patients needs'
- **Access** to treatment and monitoring is often suboptimal.
- **Patient information** doesn't do what it should do.

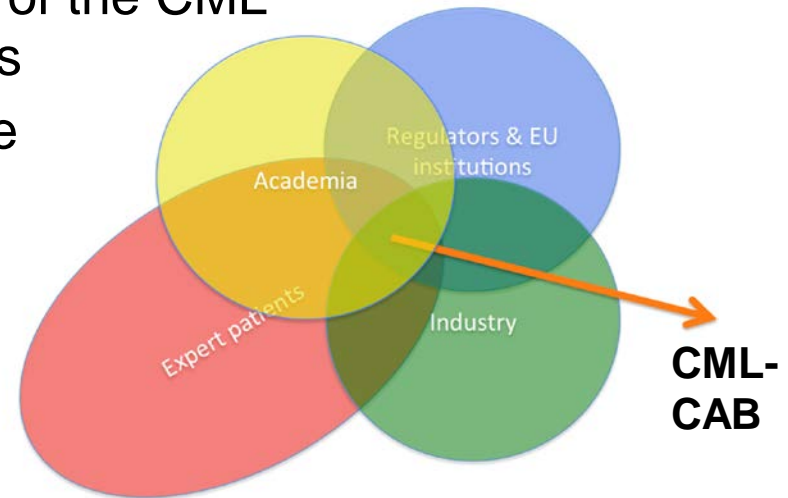
- **We patients have a key role to play** in CML patients' access to optimal support, treatment and care.
- **Patient centricity** is often just a glossy mission statement, a marketing tool, a lip service.
- **We are increasingly invited**, but our opinion rarely has impact on direction.

What are the CML-CABs?

In 2016, we established a CML Community Advisory Board (CML-CAB) as a working group of CML Advocates.

Objective:

- **Two-way dialogue** with researchers, academics, authorities and pharmaceutical industry, to improve patients' well-being and outcomes
- **Global platform** with needs & views of the CML patient community of all world regions
- Address challenges that patients face in **accessing optimal diagnosis, monitoring, treatment and care**
- Improve quality of **patient information** and education
- Develop **patient-focused trials**
- **Build capacity** and knowledge in our community



How do CML-CABs work?

- **We invite** participants from clinical development, medical affairs, market access, patient relations – not marketing
- **We set the agenda and pick the topics** which are „hottest“ for the community. We chair the meetings
- **We discuss in confidentiality** to access key information e.g. in research and on access
- **We provide public minutes** and confidential minutes to inform the community about outcomes and to follow-up
- **We provide training** to CML-CAB members

Day 1
14-18h
Training

Day 2
8-12h
Company 1

Day 2
14-18h
Company 2

Day 3
8-12h
Company 3

Day 3
13-17h
Company 4

Why confidentiality?

- We want to discuss **issues of highest relevance to both the patient community as well as the company**, which should lead to impact and action on both sides.
- Without confidentiality agreements, pharma would not provide **confidential information that is commercially sensitive and unpublished** – and must be “firewalled”

Confidential	Non-confidential / public
<ul style="list-style-type: none"> • Corporate strategies • Development pipelines • Unpublished data • Commercially sensitive information • Discussions at the CML-CAB 	<ul style="list-style-type: none"> • Concepts of treatment and care • Advocacy strategies • Patient information • Positions and decisions taken by CML-CAB

Who is currently a CML-CAB member?

- 9 CML Horizons Steering Committee 2015-2016 members
- 9 additional CML-CAB members, suggested by the 6 world region representatives
 - Jan Geissler, Germany (co-chair)
 - Giora Sharf, Israel (co-chair)
 - Bahija Gouimi, Morocco
 - Cornelia Borowczak, Germany
 - Felice Bombaci, Italy
 - Ferdinand Micho, Kenya
 - Gail Sperling, USA
 - Jelena Cugurovic, Serbia
 - Jana Pelouchova, Czech Republic
 - Lisa Machado, Canada
 - Mercedes Arteaga, Argentina
 - Puthen Parameswaran, India
 - Rita Christensen, Denmark
 - Rod Padua, Philippines
 - Pat Garcia-Gonzalez, USA
 - Sarunas Narbutas, Lithuania
 - Silvia Castillo De Armas, Guatemala
 - Yair Bar David, Israel
- A mechanism to add additional knowledgeable advocates to the CML-CAB will be discussed

What has the CML-CAB done so far?

- We held 2 CML-CABs:
 - **May 2016** with Novartis and Pfizer, and training on the drug development process and CML research
 - **February 2017** with Novartis and Takeda/Ariad/Incyte, + training on partnerships and CABs to achieve change
- 3rd CAB on 29-30 May 2017



What was the outcome of the CML-CAB?

- Understanding the **drug development pipeline** of the companies who are engaged in CML
 - Invitations to investigator meetings, impact on future trials
 - Input into our CML trial database
 - Background knowledge e.g. for regulatory discussions
- Dialogue about **improving access to drugs**
 - Companies often not aware about inequalities and real-world access issues outside of their „big markets“
 - Advocates learned about corporate access programs, good to know when individual patients need help
- **Discussed improving collaboration** of companies with CML community
- Influenced **patient information** developed by companies
- **Built capacity with training** of CML-CAB members
 - Increased the number of advocates with technical knowledge about CML trials, interpreting science, access barriers, working with pharma

What did we discuss with Novartis? (non-confidential)

May 2016:

- Clinical development pipeline
- Novartis TFR trial programme
- Access to Novartis treatments in 3 types of markets
- Collaborative models

Feb 2017:

- TFR: Data and community questions on TFR trials
- Development plans for ABL001 and treatment scenarios
- Patient-reported outcomes tools
- Online survey on doctor's perception in CML management

What did we discuss with Pfizer? (non-confidential)

May 2016:

- Clinical Development Road Map in CML, future trials with Bosutinib, Real-world data trials, additional investigative therapies
- Access challenges and access programme to Bosutinib in 3 types of markets
- Collaborative models

What did we discuss with Takeda/Incyte/Ariad? (non-confidential)

February 2017:

- Clinical Development Road Map in CML (PACE, OPTIC, OPTIC 2L, OMNI registry)
- Label and approval status of Ponatinib
- Access challenges to Ponatinib via alliance partners and compassionate use programme
- Collaborative model (with the 2-3 companies)

Where can I find the results?

→ www.cmladvocates.net/cml-cab
(minutes only available after log-in
for CML Advocates Members)

The screenshot shows the website www.cmladvocates.net/cml-cab. The page has a blue header with the CML logo and the text "For Chronic Myeloid Leukemia". Below the header is a navigation bar with links for "THE CML ADVOCATES NETWORK", "ABOUT THE NETWORK", and "SEARCH ...". The main content area is divided into two columns. The left column has a "THE NETWORK" section with links for "CML Patient Organisations", "Partners", "Web Links", "Frequent Questions/FAQ", "Newsletter", "About the Network", and "Contact Us". Below this is an "ADVOCACY & KNOWLEDGE" section with links for "News from the Network", "Book Faces of Courage&Hope", "CML Horizons Conference", "World CML Day 9/22", "CML Generics", "CML Education & Science", "CML Clinical Trials", "Junior CML Advocates", "Faces of CML", "Community Advisory Board", "CML-CAB 2017", and "CML-CAB 2016". A red arrow points to the "CML-CAB 2017" link. The right column has a "Community Advisory Board" section with a sub-section "What is the CML Community Advisory Board" and "Objectives".

What's next?

- 3rd CML-CAB on 29-30 May 2017 with 4 companies
- 4th CML-CAB in autumn 2017
- Follow-up on activities discussed in the CML-CABs – with the companies, in the community, with clinicians
- Training for CML-CAB members