



**WARSAW
POLAND
4-6 MAY 2018**



CML Advocates Network

Update on the CML Advocates Network

The global network for CML patient advocacy

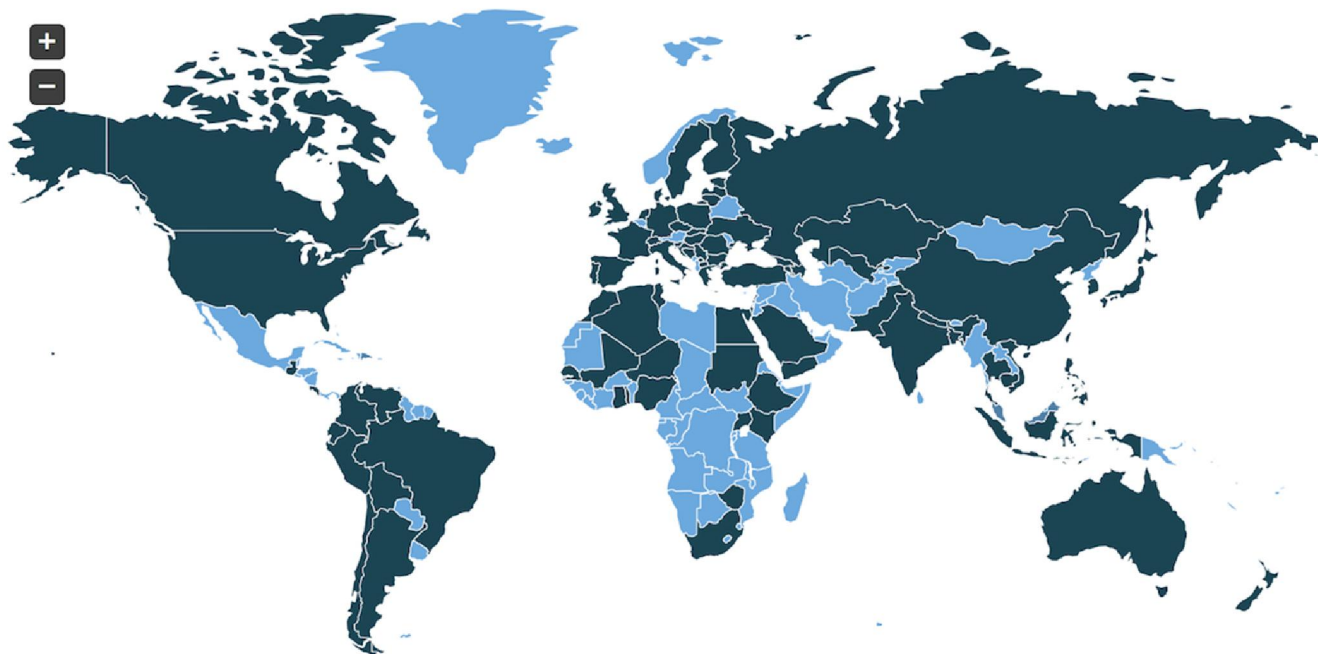
Jana Pelouchová, May 2018





**WARSAW
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CML Advocates Network connecting 118 leukemia patient organisations in 88 countries today



**+3 organisations
+2 countries
in the past year**



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POLAND
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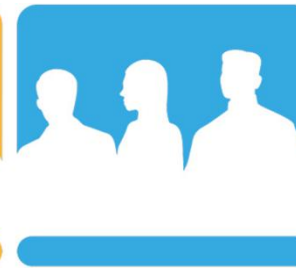
Welcome our 3 new member CML organisations!

**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

Campaigns

- World CML Day

Conferences

- CML Horizons 2018
- ASH Reports
- EHA European Affairs Committee, Fellowships booth

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)

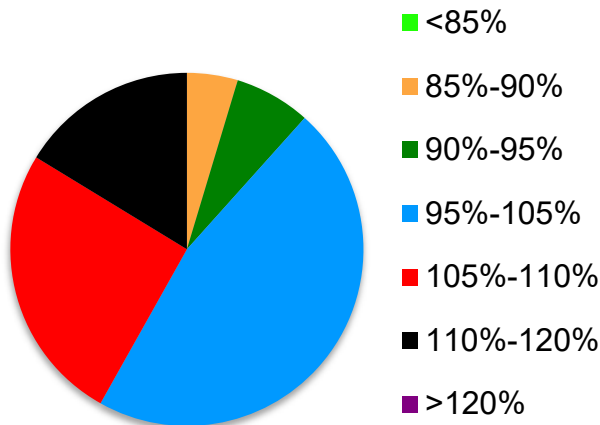
World CML Day 2017: Today, Together

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

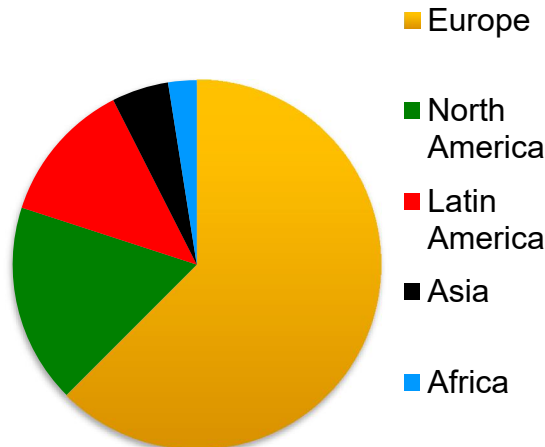


Determination of Imatinib active ingredient in generic drugs in 43 different Imatinib products from 22 countries

Active ingredient (% of 400mg)



Countries of sale of samples



Determination of Imatinib Mesylate active pharmaceutical ingredient in generic drugs

	NAME	COUNTRY OF SALE	ACTIVE INGREDIENT EXPECTED (mg)	ACTIVE INGREDIENT FOUND 1 PILL (mg)	PERCENTAGE
1	Mesilato de Imatinib	Brazil	400	432	108
2	Matinac	Colombia	100	89	89
3	Meaxin	Slovenia	400	400	100
4	Siotinib	Ecuador	400	432	108
5	Sandoz	Finland	100	104	104
6	Accord	Finland	100	104	104
7	Imatinib Ratiopharm	Finland	100	99	99
8	Imatinib Heumann	Germany	400	418	104
9	Imatinib VMG	Guatemala	400	429	107
10	Nibix	Hungary	400	442	111
11	Imakebin	Luxemburgo	400	409	102
12	Accord	Malta	400	415	104
13	Imatinib Accord	Malta	400	446	111
14	Imatinib Cooper	Morocco	100	116	116
15	Sandoz	Netherlands	400	372	93
16	Sandoz	Netherlands	100	98	98
17	Teva	Netherlands	100	104	104
18	Imatinib Accord	Palestine	400	440	110
19	Timab	Peru	400	417	104
20	Nibix	Poland	400	434	108
21	Imatinib Accord	Poland	100	112	112
22	Telux	Poland	400	408	102
23	Imatinib	Russia	400	383	96
24	Alvotinib	Serbia	100	119	119
25	Imatinib PharmaSwiss	Serbia	100	95	95
26	Meaxin	Serbia	100	108	108
27	Imatinib Teva	Spain	400	399	100
28	Imatinib Kern Pharma	Spain	400	387	97
29	Alvotinib	Thailand	400	407	102
30	Teva	UK	400	429	107
31	Intrapharm	UK	400	431	108
32	Imatinib Teva	Ukraine	400	399	100
33	Imatinib Grindex	Ukraine	100	106	106
34	Gleevec	USA	100	106	106
35	Gleevec Novartis	USA	100	98	98
36	Gleevec Novartis	USA	400	436	109
37	Imatinib Mesylate	USA	400	443	111
38	Imatinib Mesylate	USA	400	375	94
39	Gleevec (Flat Pack)	USA	400	360	90
40	Gleevec	USA	400	397	99
41	Teva		100	104	104
42	Novartis		400	446	111
43	Novartis		100	109	109

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 centre's, informed consent
- Basics: “What are clinical trials”

CML Clinical Trials Database

1. First line trials

- 1 [KISS = Kinase Inhibition With Sprycel Start up \[New Zealand\]](#)
Updated: 23 April 2018
- 2 [SUSTRENIM = Sustained Treatment-free Remission in Chronic Myeloid Leukemia \[Belgium, Italy, Netherlands\]](#)
Updated: 1 December 2017
- 3 [DasaHIT = Dasatinib Holiday for Improved Tolerability \[Germany\]](#)
Updated: 30 August 2017

2. Trials after therapy failure or intolerance

- 1 [BOSTRO = CML Treated With Bosutinib After Relapse \[Spain\]](#)
Updated: 13 February 2018
- 2 [OPUS = Optimizing Ponatinib Use \[Italy\]](#)
Updated: 18 December 2017
- 3 [PF-114 Dose-finding Study in Ph+ CML Patients Resistant to 2nd Generation TKI or Presenting T3151 Mutation \[Russia\]](#)
Updated: 7 February 2018
- 4 [CABL001X2101 = A Phase I, Multicenter, Open-label Study of Oral ABL001 in Patients With CML or Ph+ ALL \[Asia, Australia, Europe\]](#)
Updated: 29 March 2018
- 5 [CABL001A2301 = ABL001 versus bosutinib in CML-CP patients pretreated with ≥2 TKI \[Asia, Australia, Europe, North America, South America\]](#)
Updated: 28 March 2018
- 6 [BEST - Bosutinib in Elderly Chronic Myeloid Leukemia \[Italy\]](#)
Updated: 18 December 2017

3. Therapy optimization trials

- 1 [ACTIW = Therapies in Combination or Sequentially with TKIs in CML-CP Patients in Complete Cytogenetic Remission \[France\]](#)
Updated: 29 March 2018
- 2 [OPTIC = Ponatinib in resistant chronic phase CML \[Africa, Asia, Australia, Europe, North- and South America\]](#)
Updated: 25 July 2017
- 3 [Pioglitazone and TKI \[USA\]](#)
Updated: 16 August 2017
- 4 [DECLINE \(CAMN107ADE18T\) = Imatinib versus nilotinib in CML in chronic phase \[Germany\]](#)
Updated: 7 February 2018
- 5 [Ruxolitinib for CML with minimal residual disease \[USA\]](#)
Updated: 29 March 2018

4. Treatment of advanced phases

- 1 [Matchpoint - Ponatinib and Intensive Chemotherapy \[UK\]](#)
Updated: 1 February 2018

5. Treatment discontinuation trials

- 1 [QMH-CML-001 = Cessation of TKI in CML \[Hong Kong\]](#)
Updated: 27 April 2018
- 2 [TRAD = Treatment-free Remission Accomplished With Dasatinib in Patients With CML \[Canada\]](#)
Updated: 1 November 2017
- 3 [NAUT \(CAMN107ADE22T\) = Efficacy of nilotinib in inducing persistence of molecular remission after second TKI stop \[Europe\]](#)
Updated: 29 March 2018
- 4 [MSIT = Malaysia Stop Tyrosine Kinase Inhibitor Trial \[Malaysia\]](#)
Updated: 29 March 2018
- 5 [ENESTPath Patient's Voice Italian Substudy \[Italy\]](#)
Updated: 15 February 2016
- 6 [PIO2STOP = Second STOP After Pioglitazone Priming in CML Patients \[France\]](#)
Updated: 28 March 2018

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



#TFR4CML

Please click here to complete the questionnaire in English

Bitte klicken Sie hier, um den Fragebogen auf Deutsch auszufüllen

Haga clic aquí para completar el cuestionario en español

Veuillez cliquer ici pour remplir le questionnaire en français

Clicca qui per completare il questionario in italiano

Täytä kyselylomake suomeksi

אנא לחצו כאן להשלמת השאלון בעברית

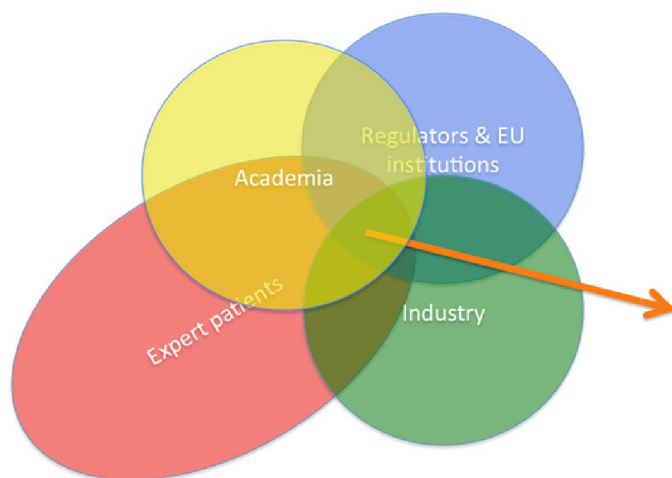
Klik her for at udfylde spørgeskemaet på dansk

برجاء النقر هنا لإكمال الاستبيان باللغة العربية

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

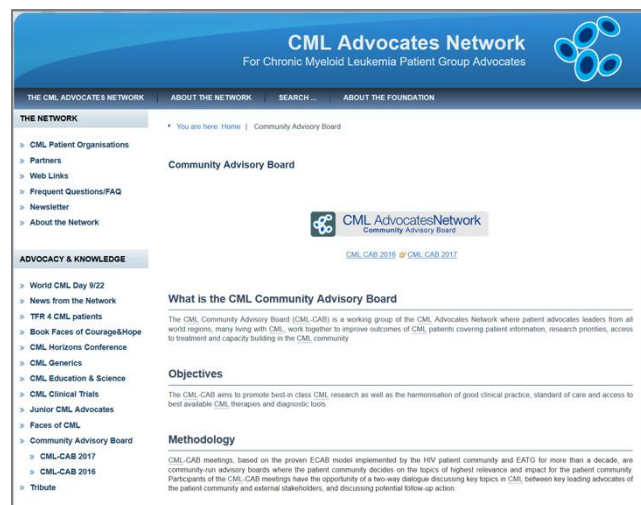


CML-CAB Goals:

- 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/Incyte/Ariad
- Minutes for CML Advocates Members of cmladvocates.net

CML Advocates Network
For Chronic Myeloid Leukemia Patient Group Advocates

THE CML ADVOCATES NETWORK ABOUT THE NETWORK SEARCH... ABOUT THE FOUNDATION

THE NETWORK

- ▶ CML Patient Organisations
- ▶ Partners
- ▶ Web Links
- ▶ Frequent Questions/FAQ
- ▶ Newsletter
- ▶ About the Network

ADVOCACY & KNOWLEDGE

- ▶ World CML Day 9/22
- ▶ News from the Network
- ▶ TPR 4 CML patients
- ▶ Book Faces of Courage&Hope
- ▶ CML Horizons Conference
- ▶ CML Generics
- ▶ CML Education & Science
- ▶ CML Clinical Trials
- ▶ Junior CML Advocates
- ▶ Faces of CML
- ▶ Community Advisory Board
- ▶ CML-CAB 2017
- ▶ CML-CAB 2016
- ▶ Tribute

Community Advisory Board

CML Advocates Network
Community Advisory Board

CML CAB 2018 CML CAB 2017

What is the CML Community Advisory Board

The CML Community Advisory Board (CML-CAB) is a working group of the CML Advocates Network where patient advocates leaders from all world regions, many living with CML, work together to improve outcomes of CML patients covering patient information, research priorities, access to treatment and capacity building in the CML community.

Objectives

The CML CAB aims to promote best-in class CML research as well as the harmonisation of good clinical practice, standard of care and access to best available CML therapies and diagnostic tools.

Methodology

CML-CAB meetings, based on the proven ECAB model implemented by the HIV patient community and EATG for more than a decade, are community-run advisory boards where the patient community decides on the topics of highest relevance and impact for the patient community. Participants of the CML-CAB meetings have the opportunity of a two-way dialogue discussing key topics in CML between key leading advocates of the patient community and external stakeholders, and discussing potential follow-up action.

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!

#CMLHZ18



Regional networks: Parallel sessions rooms

Europe Region
Light room - Floor M2

North America 4 + 1 SC =
Lobby Lounge

East Asia / Pacific Region
meeting 4,6,8 M2 floor

Africa and Middle East Region
Plenary room. Level WH

Latin America Region
Meeting room 1 (CML Office)
Level M1