CML HORIZONS 2017

CML AdvocatesNetwork

FRANKFURT
GERMANY
26-28 MAY 2017

CML AdvocatesNetwork

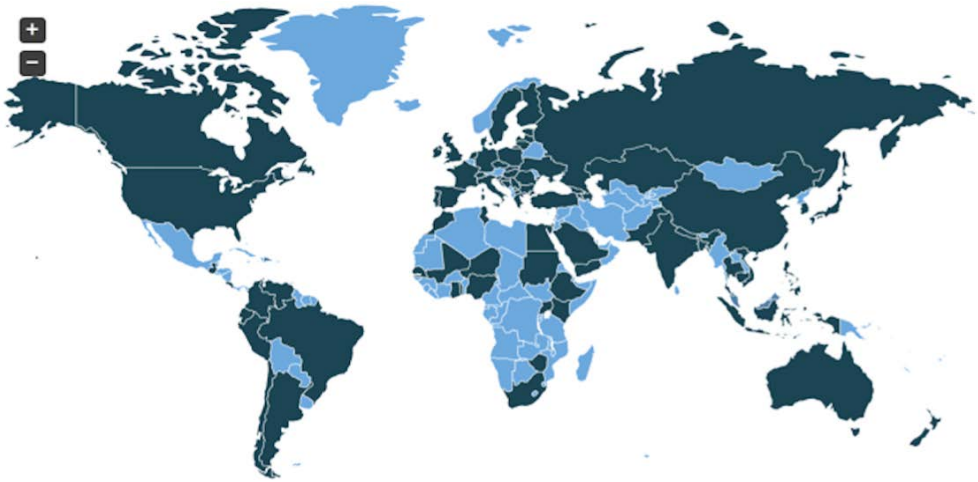
Update on the CML Advocates Network

The global network for CML patient advocacy

May 2017

LEUKEMIA PATIENT ADVOCATES FOUNDATION

CML Advocates Network: Connecting 114 leukemia patient organisations & 85 countries today



http://www.cmladvocates.net/members

About 1/3 of members represent different leukemias, not only CML

Western Europe

1 Denmark: LYLE, Association for lymphatic cancer and leukemia
2 Finland: The Finnish CML Patient Network
3 France: Leucemie espoir 06
4 France: LMC France
5 Germany: Elternverein für Kinder mit CML e.V.
6 Germany: German Leukemia and Lymhoma Aid (DLH, Deutsche Leukämie- und Lymphom-Hilfe e
7 Germany: Leukämie-Online / LeukaNET
8 Greece: "K.E.F.I. of Athens" Association of Cancer Patients of Athens
9 Ireland: CML Society
10 Italy: AIP - Italian Patients' Association of CML
11 Italy: Gruppo AIL Pazienti Leucemia Mieloide Cronica
12 Netherlands: Stichting Hematon
13 Portugal: Associação Portuguesa contra a Leucemia
14 Portugal: Portuguese Leukemia and Lymphoma Association
15 Spain: AEAL, Asociación Española de Afectados por Linfoma, Mieloma y Leucemia
16 Spain: AELEMIC, Asociación Española Enfermos Leucemia Mieloide Crónica
17 Spain: Pacientes LMC
18 Sweden: Blodcancerförbundet
19 Switzerland: Foundation for Advancement of Bone Marrow Transplantation
20 UK: CML UK - Facebook Group
21 UK: CMLSupport
22 UK: Leukaemia CARE

Asia and Pacific

1 Australia: Leukaemia Foundation
2 Bangladesh: Bangladesh CML Support Group (BCSG)
3 Cambodia: Max Miracle
4 China: New Sunshine Charity Foundation
5 China: Shanghai Roots & Shoots: CML Home of Hope

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Welcome our 8 new member CML organisations!

CML ARMENIA (Armenia)

MIELOPRO (Romani)

MOHA (Hungary)

CML Palestine (Palestine)

AELEMIC (Spain)

PACIENTES LMC (Spain)

CML Zimbabwe (Zimbabwe)

PHILADELPHIA LMC (Algeria)

CML Advocates Network management team, now with Celia and Lidija, supported by a great CML Steering Committee

Our current and ongoing projects

Web Platform

- CMLadvocates.net, Facebook, Twitter, YouTube

Conference

- CML Horizons 2017

Adherence

- Mobile Adherence App version 2
- Adherence study data

Advocacy, Policy and Collaboration

- CML-Community Advisory Board (CAB)
- EuroBloodNet European Reference Network
- Coordination EHA 2016/2017 Fellowships & Advocacy Track
- Rare Cancers Europe, ECCO, ESMO, EURORDIS, iCMLf, EU Commission

Our current and ongoing projects

Campaigning & Awareness

- World CML Day + Toolkit

Information resources

- CML trial registry
- Summary of ELN Recomm. in 22 languages
- Webinar “Generic TKIs in CML”
- Generics Knowledge Base
- ASH 2016 report
- Book “Faces of Courage & Hope”
- Book Videos

Research

- IMI2 “HARMONY”
- Advisory boards and investigator meetings

Publications in Journals

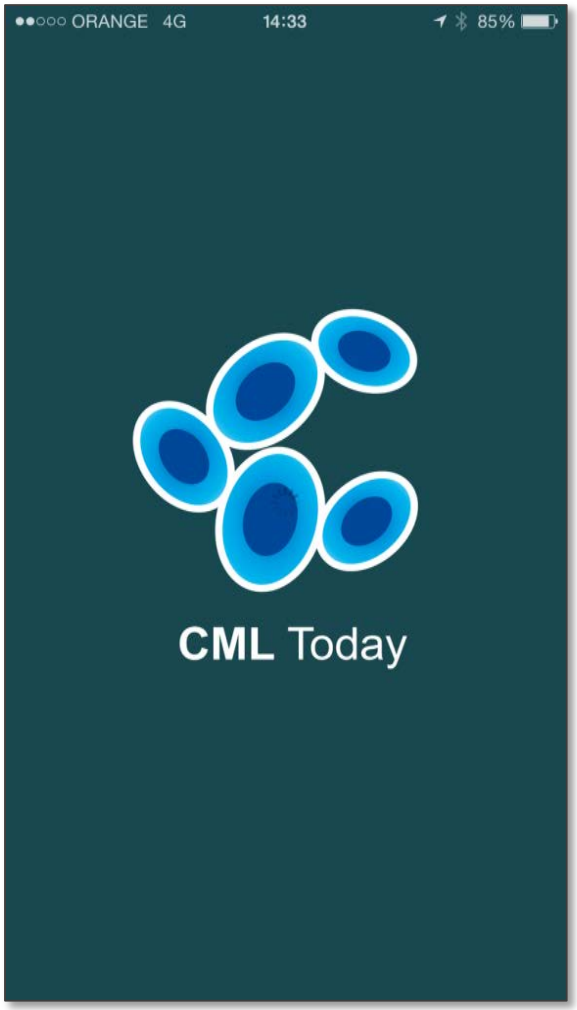
- Generics declaration in “LEUKEMIA”
- Adherence publication in “Cancer Research and Clinical Oncology”

Other indications @ LePAF

- MPN Advocates Network
- CLL Advocates Network
- 1st MPN/CLL Horizons 2016
- Launch of Acute Leukemias Advocates Network at EHA 2017

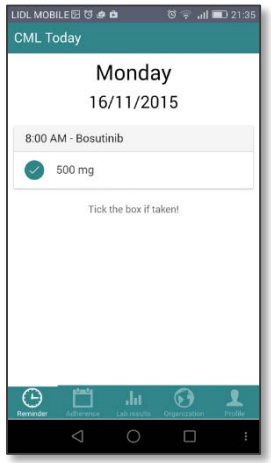
CML TODAY APP

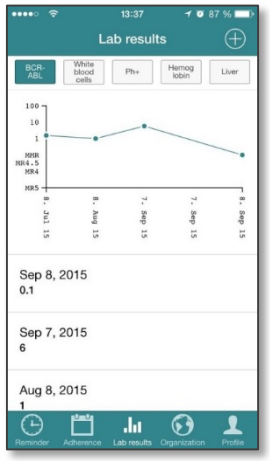
- Available for free in the iPhone App Store and Android Google Play.
- Available in 7 languages: English, German, French, Spanish, Portuguese, Hebrew, Arabic.
- Not limited to specific drug, brand or manufacturer.

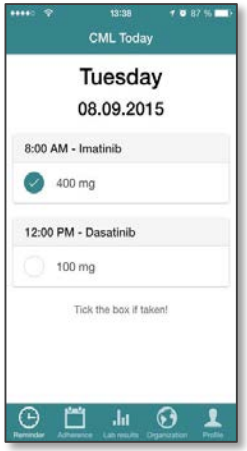


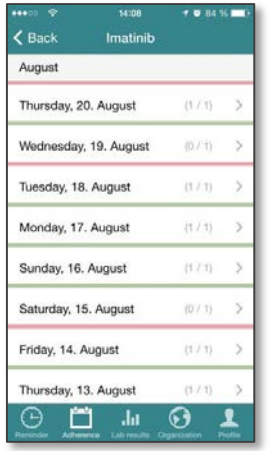
Features

- Tracks the regular intake of CML medicines (incl IFN)
- Reminds to take prescribed medication
- Tracks PCR results and other laboratory parameters
- Helps connect with local support groups in your country
- Shows worldwide CML Patient Organizations´ profiles containing useful information in the respective local language









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Our publication in LEUKEMIA, 2016: Patients' declaration on the use of generics in CML treatment

Recommendations by the patient community may support experts' discussion on CML management with TKI generics.

Our paper were published in the journal LEUKEMIA (August, 2016)

Adherence data published in the Journal of Cancer Research and Clinical Oncology

>2000 downloads

2 citations in other journal articles

Very important findings on the motivations and risk factors of patients on intentional and non-intentional non-adherence: potential tools to drive adherence.

Evidence-based patient advocacy

Springer Link

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Journal of Cancer Research and Clinical Oncology
pp 1–10

Factors influencing adherence in CML and ways to improvement: Results of a patient-driven survey of 2546 patients in 63 countries

Authors · Authors and affiliations

Jan Geissler, Giora Sharf, Felice Bombaci, Mina Daban, Jan De Jong, Tony Gavin, Jana Pelouchova, Euzebiusz Dziwinski, Joerg Hasford, Verena Sophia Hoffmann

Original Article – Cancer Research

First Online: 13 March 2017

DOI: 10.1007/s00432-017-2372-z

Cite this article as: Geissler, J., Sharf, G., Bombaci, F. et al. J Cancer Res Clin Oncol (2017). doi:10.1007/s00432-017-2372-z

2 Citations · 43 Shares · 2k Downloads

Abstract

Optimal adherence to CML therapy is of key importance to maximize treatment effectiveness. Two clinical studies (ADAGIO and Hammersmith) have proven a clear correlation between adherence and achieving optimal treatment response and have revealed that non-adherence is common in CML patients (Marin et al. in J Clin Oncol 28(24):2381–2388, 2010, Noens et al. in Haematologica 99(33):437–447, 2014). The aim of this study is to assess the extent of

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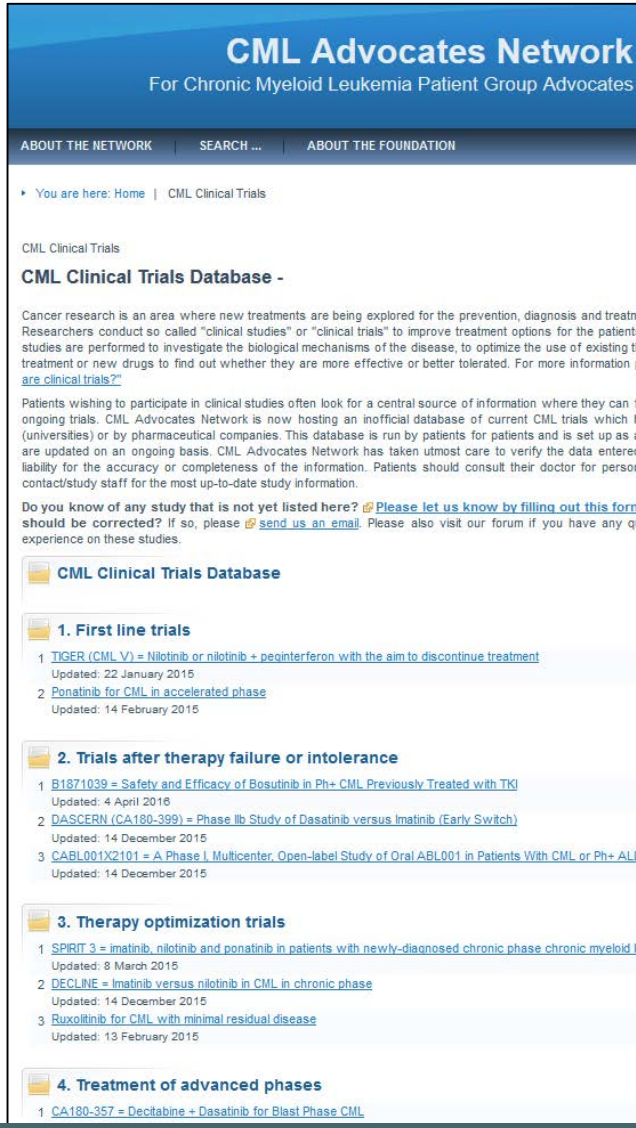
Article · Abstract · Introduction · Methods · Results · Discussion · Author contribution · Compliance with ethical... · Supplementary material · References · Copyright information · About this article

CML trial registry
@ cmladvocates.net/cmltrials

- Currently 29 CML trials listed
  - 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”



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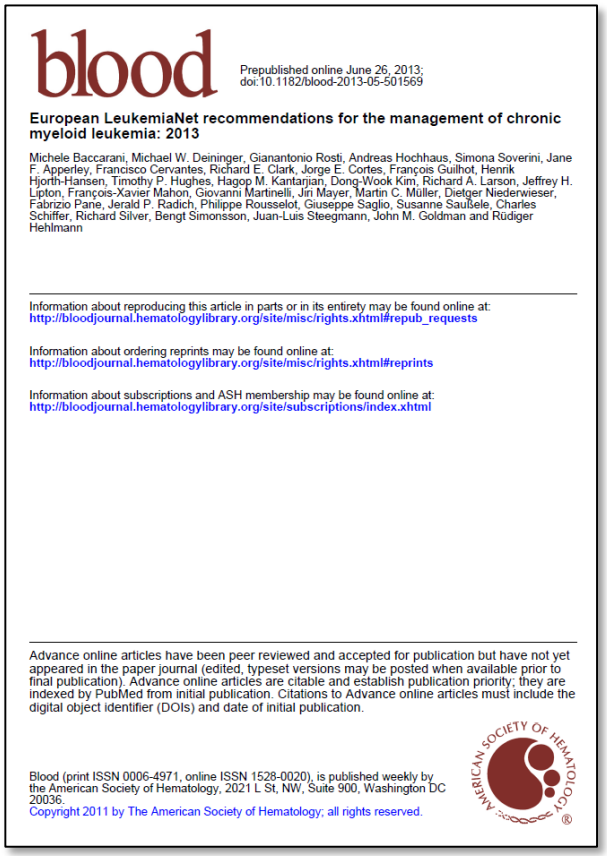
Patient-friendly summary of ELN CML recommendations in 22 languages @ cmladvocates.net/cmlsummary



blood

Prepublished online June 26, 2013;
doi:10.1182/blood-2013-05-501569

European LeukemiaNet recommendations for the management of chronic myeloid leukemia: 2013

Michele Baccarani, Michael W. Deininger, Gianantonio Rosti, Andreas Hochhaus, Simona Soverini, Jane F. Apperley, Francisco Cervantes, Richard E. Clark, Jorge E. Cortes, François Guilhot, Henrik Hjorth-Hansen, Timothy P. Hughes, Hagop M. Kantarjian, Dong-Wook Kim, Richard A. Larson, Jeffrey H. Lipton, François-Xavier Mahon, Giovanni Martinelli, Jiri Mayer, Martin C. Müller, Dietger Niederwieser, Fabrizio Pane, Jerald P. Radich, Philippe Rousselot, Giuseppe Saglio, Susanne Saußele, Charles Schiffer, Richard Silver, Bengt Simonsson, Juan-Luis Steegmann, John M. Goldman and Rüdiger Hehlmann

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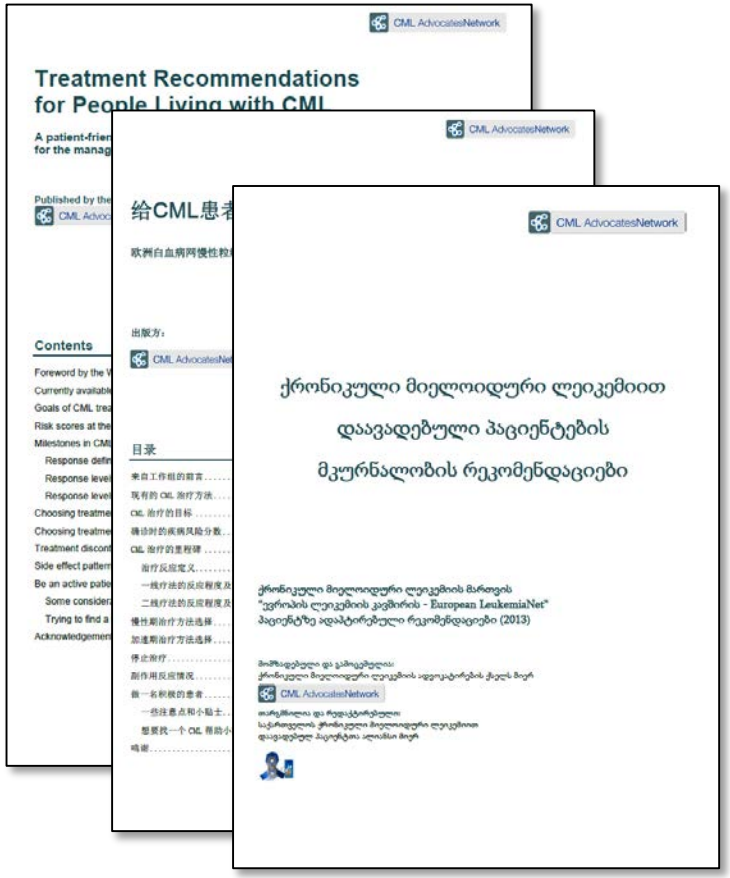

CML AdvocatesNetwork

Treatment Recommendations for People Living with CML

Contents

给CML患者

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ქრონიკული მიელოიდური ლეიკემიის მართვის "ევროპის ლეიკემიის კავშირის - European LeukemiaNet" პაციენტზე ადაპტირებული რეკომენდაციები (2013)

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Language
English
Albanian
Arabic
Azerbaijani
Bulgarian
Chinese (Simplified)
Chinese (Traditional)
Croatian
Danish
Dutch
French
Georgian
German
Hebrew
Italian
Polish
Portuguese
Russian
Serbian
Spanish
Turkish

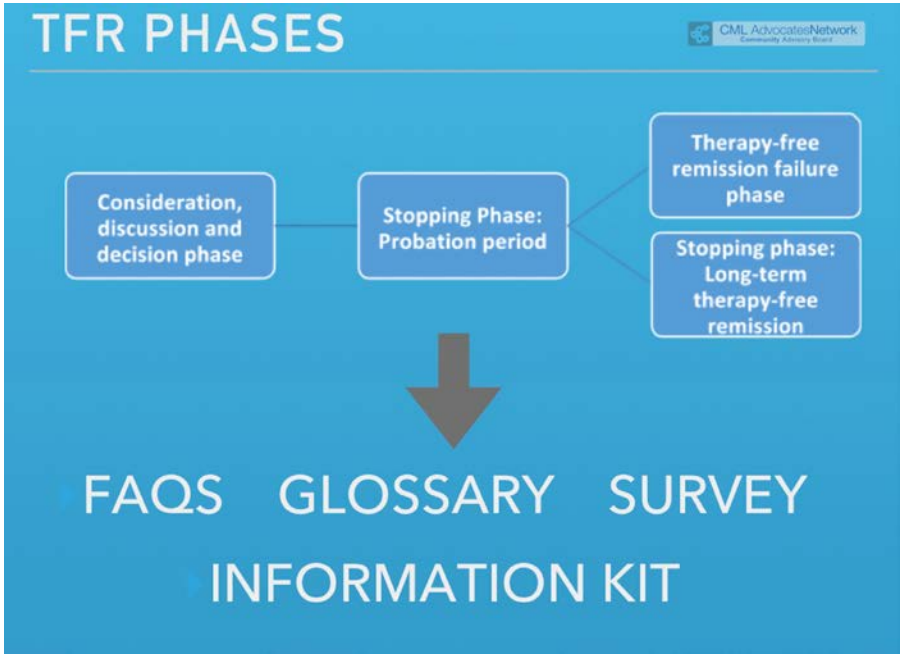
Faces of Courage and Hope

cmladvocates.net/book

- Published in 2015, shipped to 52 countries
- Stories illustrating the life of 16 CML patients from 15 countries.
- Available for 20 EUR on Amazon, worldwide shipping
- We still have significant stock of books, please promote / use them!
- #CMLHZ17 #CourageHope participate!

TFR Information Kit

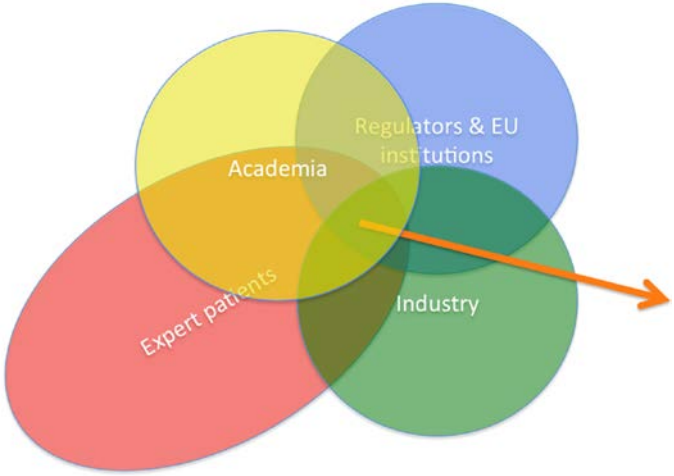
- TFR advocates group
- TFR survey: Collaboration of CML Advocates Network members
- Analysis and publication
- Information kit on TFR for patients & doctors



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, 2nd and 3rd CML-CAB held in 2017
- Presented on Sunday this week!



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 2016, Feb 2017 (+ May 2017)

- 8 patient advocates of the CML Steering Committee and 6 expert patients from different world regions.
- Training with Tamas Bereczky *(European AIDS Treatment Group, EATG)*
- CML-CAB meetings with Novartis, Pfizer, Takeda/Incyte/Ariad

CML-CAB Members

9 CML Horizons Steering Committee 2015-2016 members,
+9 additional members suggested by the 6 world regions

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

What's next?

- Enforce and strengthen the CML Community Advisory Board
- Generics quality test
- Continue with CML Trial Registry, Website, EHA Fellowship Programme, CML Horizons (2018), CML-CAB 2017, Harmony, EuroBloodNet
- Potential projects: TFR, pregnancy registry,

Thank you to everyone who has contributed to all the activities!

Please engage with the Network!