

ANNUAL REPORT

2021
2022

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Financials

Thank you





THE MISSION of the iCMLf is to improve the outcomes for patients with CML globally.

THE AIM of the iCMLf is to foster and coordinate global clinical and research collaborations and to improve clinical practice and disease monitoring in CML.

Leadership

BOARD OF DIRECTORS



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Chair

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S. Orsola University Hospital, Bologna, Italy

**Retired December 2021*



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GIUSEPPE SAGLIO

University of Turin, Italy

Scientific Advisory Committee

14

members makeup the iCMLf Scientific Advisory Committee. Respected hematologists, scientists and patient representatives provide advice and support for the activities of the Foundation.

National Representatives

36

national representatives provide advice to the iCMLf executive and assist implementation of initiatives at a local level.

OPERATIONAL TEAM



NICOLA EVANS

Chief Executive



**ARLENE HARRISS-
BUCHAN**

Program Manager



**STEFANIE
BOCKWINKEL**

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Director



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Digital Media
Officer



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Communications
Manager

From the Chairman and Chief Executive

Dear Friends and Colleagues,

This year as we slowly work our way into a new normal after the peak of the pandemic, our efforts have solidified into two key areas:

- 1) Harnessing our power through global research
- 2) Raising the bar for CML best practice around the world

As we began our financial year in September 2021 the Omicron variant of SARS-CoV-2 had yet to arrive and we were still collecting cases for the iCMLf COVID-19 registry. Two hundred physicians from 58 countries submitted a total of 1,050 cases giving a truly global perspective of the impact of COVID-19 on people with CML. The four publications from this registry data have all shown that people with well-controlled CML have the same risk profile as that of the general population for outcomes of COVID-19. We are incredibly proud of the work and global collaboration that resulted from this registry in spite of the devastation that made it necessary.

We further expanded our international collaborations with two research projects under the iCMLf CURE Consortium. The Genomic Alliance is investigating the genomic impact on CML and the Treatment Free Remission (TFR) Alliance is using 'big data' to identify optimal treatment pathways to successful TFR. Both projects are well underway and we are excited to see the first analysis next year. Our sincere hope is that through these and future studies we will move to a cure for all people with CML wherever they are in the world.

As we work towards a cure, we recognise that for many people with CML optimal treatment is still the immediate goal. As such, this remains a key objective for the work of the Foundation through our many and varied education programs. A highlight this year was on World CML Day 09/22 when we launched a new iCMLf Knowledge Centre. Designed specifically for physicians and scientists in non-academic centres and particularly those facing resource challenges, in the words of its Chairman, Professor Beppe Saglio,

"...this Knowledge Centre is a perpetual congress for the CML community. . . a forum for sharing cutting edge, best practice CML management."

With 33 presentations from 16 countries we aim to address the challenges of CML management around the world. With over 4,000 views already, we are on the way to achieving this.

So what next? When we climbed Kilimanjaro in 2019, we likened it to the challenge of developing a cure for CML. Really, tough, but with preparation and a great team, not impossible. We came down Kilimanjaro and into a pandemic. This year has shown we are refocused and ready to continue the climb.

Thank you to all who support us on the journey.



Tim Hughes
iCMLf Chair



Nicola Evans
Chief Executive

Maximising Treatment Free Remission (TFR)

The iCMLf TFR Alliance aims to maximise achievement of TFR while minimising failed TFR attempts and other negative outcomes. In partnership with HARMONY PLUS and utilising 'Big Data' we will be able to effectively evaluate multiple factors that likely predict and influence successful tyrosine kinase inhibitor discontinuation for patients with CML.

The iCMLf Global TFR Registry is Underway

- > November 2021 – needs analysis and expressions of interest for the global TFR registry survey undertaken
- > February 2022 - The research proposal 'Use of big data to identify optimal treatment pathways leading to successful treatment-free remission in CML' officially been accepted by HARMONY PLUS.
- > Ongoing - Site selection for the study

Next Steps

- Sites continue to be onboarded next year
- Data analysis in 2023
- Investigate further big data projects and prospective studies



"By harnessing the power of pooled patient-level data we hope to identify the optimal treatment pathway leading to an increased likelihood of a successful, prolonged TFR. This would allow for a better guided clinical care, possibly even cure, as well as a more precise construction of future clinical trials"

Dr. Torsten Dahlén,
Leader of the iCMLf TFR Registry



Current Global TFR Registry Sites



24 sites



From
16 countries

2,900 potential
patient data-sets

The iCMLf is proud to partner with HARMONY PLUS to use Big Data to improve treatment opportunities for people with CML.



Investigating the Impact of Genomic Variation in CML

The iCMLf Genomics Alliance has had a successful year and is making progress, through the use of global data, to better understand the impact of genomic variation on treatment response for patients with CML. In June 2022 we officially partnered with HARMONY PLUS to establish a CML database to upload and analyse multicentre genomic data..



"A goal of the iCMLf Genomics Alliance is to pool mutational data through a shared database. This will enhance statistical power in order to understand the impact of genomic variation on treatment response for patients with CML".

Sue Branford
Chair of the iCMLf Genomics Alliance

Investigating Clonal Hierarchy in CML

- > 12 sites from 10 countries are submitting data for the project
- > 3 sites from the Genomics Alliance have completed their data upload, and data is now being harmonized and mapped.
- > 2 statisticians have been engaged for data analysis

Next Steps

- Remaining sites to complete data upload by October 2023
- Preliminary analysis of the first data December 2022

iCMLf GENOMICS ALLIANCE	Local Ethics/ IRB Complete	Data Sharing Agreement Signed	Data Entered into the Data Preparation file	Data Transferred	Data Harmonised
Sue Branford Australia	✓	✓	✓	✓	✓
Dennis Kim Canada	✓	✱			
Katerina Machova Polakova Czech Republic	✓	✓	✓	✓	✱
Andreas Hochhaus & Thomas Ernst Germany	✓	✓	✱		
Federica Poggi Italy	✱	✱	✓	✱	
Tiong Ong & Charles Chuah Singapore	✱				
Rolando Vallansot, Catalonia, Spain	✱				
Ruth Stuckey & Maite Gómez Casares Gran Canaria, Spain	✓	✓	✓	✓	✓
Lee-Yung Shih Taiwan	✓	✓	✓	✓	✱
Jane Apperley UK	✱	✱			
Chris Eide USA	✱				

The Impact of COVID-19 for Patients with CML



“All analysis completed so far shows that people with well controlled CML have the same risk factors for COVID-19 as the general population. The iCMLf CANDID study gave confidence for physicians worldwide that their patients with well controlled CML were not at greater risk from COVID-19 than the general population and no changes to CML therapy specifically due to SARS-CoV-2 infection were required.”

Professor Jorge Cortes

THE iCMLf CANDID (Cml AND covid) STUDY

The impact of COVID-19 for people with CML remained a key focus for the iCMLf this year.

The iCMLf CANDID study represents the largest global cohort study to date characterizing COVID-19 in CML.

This real world data collection is essential to differentiate the impact of patient, disease, and therapy specific factors on risk and outcomes, as the pandemic continues.

Case collection began in March 2020 and finished in November 2021.



1,050 cases



200 physicians



58 countries



Poor outcomes for patients with comorbidities, older age, advanced phase disease, and those from low income countries: an update of the CANDID Study.

Katia Pagnano | Brazil
Oral presentation at the American Society of Hematology meeting 2021.

Conclusion

We confirmed a higher mortality for CML pts with COVID-19 in older pts (>75y), pts with cardiovascular or pulmonary comorbidities and from low and low-middle income countries, the latter probably related to limitations in supportive care. Additionally, more deaths occurred in pts in advanced phases and in pts not in MMR.

FOLLOWING INITIAL ANALYSIS THE iCMLf UNDERTOOK 4 SUBANALYSIS OF THE DATA.



1) COVID-19 In Patients With Chronic Myeloid Leukemia In Treatment-Free Remission: Disease Severity And Impact On TFR Status

Susanne Saußele | Germany
Lead author. Poster presentation at the European Hematology Association Congress 2022.

Conclusion

In this sub-analysis of the CANDID study, CML patients in TFR had similar severity and survival to CML patients who were on TKI therapy and there was no evidence of an increased risk of TFR loss after SARS-CoV-2 infection.



2) Sub-Analysis of Patients with COVID-19 in Chronic Myeloid Leukemia on TKI Treatment: Update from the International CML Foundation (iCMLf) CML and COVID-19 (CANDID) Study.

Ana-Ines Prado | Uruguay
Author. Poster presentation at the John Goldman meeting on CML: Biology and Therapy 2022.

Conclusion

Survival from SARS-CoV-2 infection for CML patients on TKI is remarkably high and there is no difference in survival considering the type of TKI used. This supports that is safe to maintain all TKI treatments during SARS-CoV-2 infection.

3) The impact of major molecular response status on people with CML infected with SARS-CoV-2 – Abstract submitted to the American Society of Hematology meeting in December 2022.

4) The impact of country income on people with CML infected with SARS-CoV-2 – Lead Author, Hemant Malhotra, India – Publication in progress.

ACKNOWLEDGMENT

The iCMLf sincerely thank all physicians contributing data, the patients willing to help and our partners, The Max Foundation and the CML Advocate Network.

Sincere thanks to Novartis Oncology and Pfizer for study funding.



Raising the Bar for CML Practice Around the World

Launched on World CML Day 2021, the Knowledge Centre is an interactive, online resource providing educational content on CML patient management, options for molecular monitoring and practical considerations of BCR-ABL1 testing.



“A perpetual congress for the CML community of physicians and scientists, a forum for sharing cutting edge, best practice, CML management.”

Professor Giuseppe Saglio (Italy) Chairman of the iCMLf Knowledge Centre

iCMLf Knowledge Centre



33 individual presentations from **16** countries
shown on the map



“I speak about laboratory testing in a resource constrained environment – in the real world – what is happening now.”

Dr Neelam Varma (India)



Professor Qian Jiang
(China)



Dr Rafael Hurtado
(Mexico)

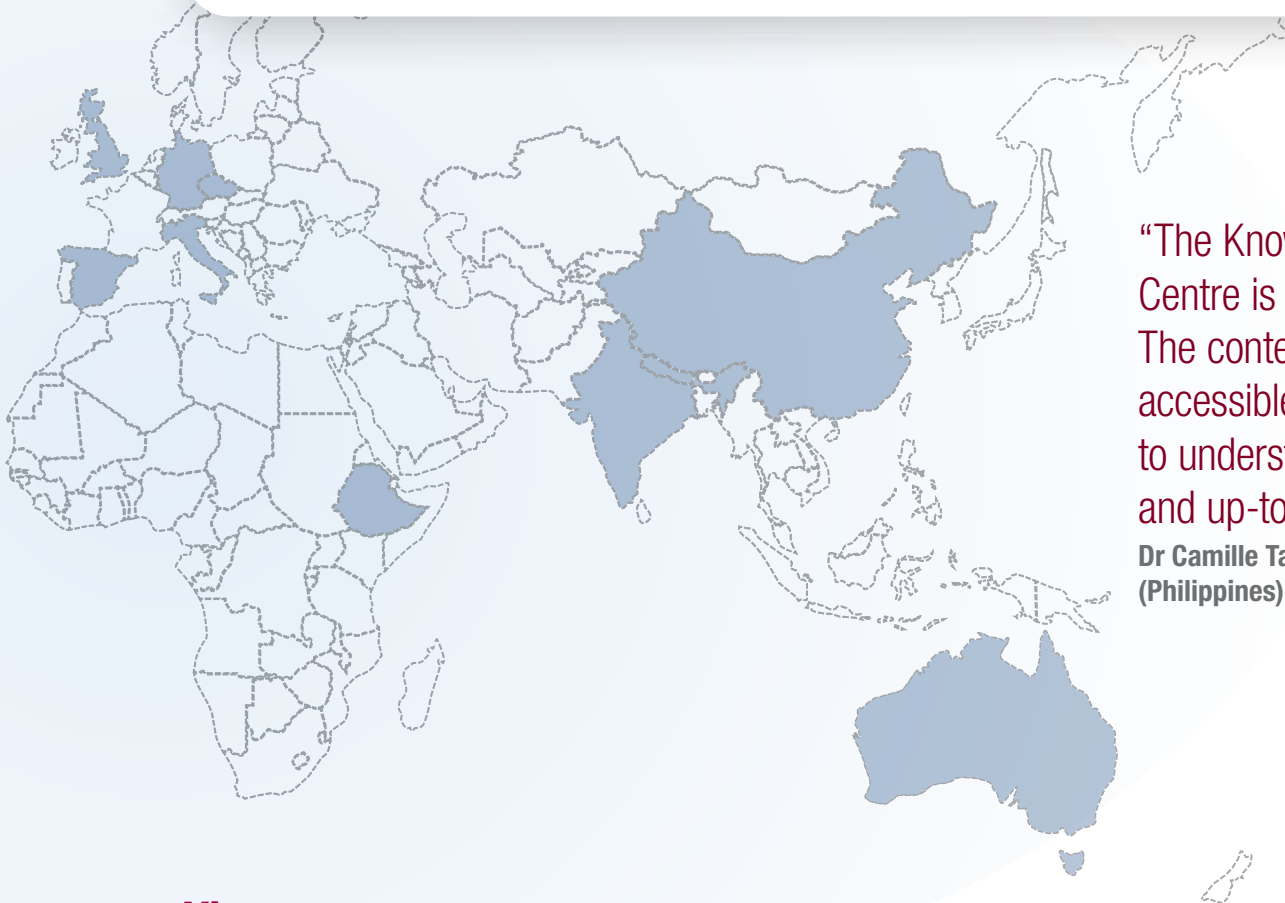


Dr Mipsang Lama
(Nepal)



Associate Professor Amha
Gebremedhin (Ethiopia)

Perspectives: leading haematologists from China, Ethiopia, Mexico and Nepal talk about how the ELN recommendations are adapted in their countries to reflect local needs.



“The Knowledge Centre is very helpful. The contents are accessible, easy to understand and up-to-date.”

Dr Camille Tanchanco
(Philippines)

Views



1,900 users



4,100 page views

Top viewed modules:

- 1 Module 1: CML therapy
- 2 Module 5: Management practicalities
- 3 Module 3: Treatment-free remission

Advancing CML Expertise Globally



9 conversations

iCMLf **CONVERSATIONS** ON CHRONIC MYELOID LEUKEMIA

Attendees from Mozambique to Milwaukee attend this informative, comprehensive, CML educational program. During these regular live online webinars, international CML experts cover a broad range of topics around CML management, the biology of CML and highlights from major scientific meetings.



With
16 experts



"First of all, I would like to congratulate you for the cycle of conversations, which has been excellent, and encourage you to resume it in the future."

Dr Ana-Ines Prado, Uruguay



From
10 countries








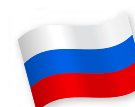


More than
300 live participants

Topics

- Biology of CML related to TFR
- Clinical and biology highlights of the John Goldman Conference on CML 2021
- CML highlights of ASH 2021
- 4 updates on COVID-19 management and CML (French, Portuguese, Russian and Spanish)
- CML highlights of the Congress of EHA 2022
- Treatment of CML patients after failure of 2 TKIs

Our audience is truly global with scientists, clinicians treating CML and patient advocates from around the world.

We thank all presenters for sharing their expertise and commitment:

	ARGENTINA	Dr Beatriz Moiraghi Dr Carolina Pavlovsky
	AUSTRALIA	Professor Susan Branford Professor Timothy Hughes
	AUSTRIA	Professor Dominik Wolf
	BRAZIL	Dr Carla Boquimpani Dr Katia Pagnano Dr Ana Toreli
	FINLAND	Professor Satu Mustjoki
	FRANCE	Dr Delphine Réa
	GERMANY	Professor Andreas Hochhaus Professor Daniela Krause
	RUSSIA	Dr Elza Lomaia
	SINGAPORE	Professor Charles Chuah
	USA	Professor Ravi Bhatia Professor Jorge Cortes

All expert discussions are available to view on-demand on the iCMLf website.

Top-3 viewed webinars in 2021/22

- 1 Highlights of the John Goldman Conference on CML 2021**
> 680 views
- 2 Highlights of ASH 2021**
>580 views
- 3 Update on COVID-19 management and CML**
>470 views

more than
 **3,000**
views



“My favourite (non educational) part of the webinar was seeing physicians from Ukraine and Russia 'sitting' side by side in the gallery. A reminder that no matter what is happening in the world we have the ability to bring people with a common goal together.”

Nicola Evans – iCMLf Chief Executive

Recognising Excellence in CML

We are delighted to present the 2022 iCMLf prize winners, who were chosen from many nominations from the CML community, by a panel of past prize winners, iCMLf Directors and Advisors.

The 2022 medals will be awarded at the annual John Goldman Conference on CML.



ROWLEY PRIZE

Professor Oliver Hantschel | Germany

Director of the Institute for Physiological Chemistry, Chair of Biochemistry, Faculty of Medicine, Philipps University of Marburg.



"Oliver devoted his entire scientific career to structural biochemistry of tyrosine kinase inhibitors, in particular ABL1 and first described the option to target the allosteric binding site of BCR::ABL1. He started this research as a PhD student and has collaborated with many laboratories worldwide."

Professor Andreas Hochhaus, Jena University Hospital



GOLDMAN PRIZE

Professor Andreas Hochhaus | Germany

Head of the Department of Hematology and Medical Oncology at Jena University Hospital



"Andreas Hochhaus is an international leader in the clinical management of CML and has been involved in the management of randomised trials by the German CML Study Group for more than 30 years. Professor Hochhaus's notable contributions include development and application of molecular monitoring for optimisation of treatment, understanding mechanisms of resistance and promoting access to clinical trials for all patients."

Professor Nick Cross, University of Southampton



iCMLf PRIZE

Giora Sharf | Israel
Co-founder of the CML Advocates Network.



iCMLf PRIZE

Jan Geissler | Germany
Co-founder of the CML Advocates Network.



"The iCMLf Prize for Giora Sharf and Jan Geissler is a natural and almost due recognition of their passionate work establishing a bridge between the worldwide community of CML patients and their doctors. They have built an open forum for the voice of patients expressing their needs, their aspirations and also their fears are clearly heard and understood by the treating clinicians. In this way, Giora and Jan have been able to transfer a more serene vision on their status to many CML patients and have also directly contributed to the great success achieved in CML therapy."

Professor Giuseppe Saglio, University of Turin

23rd Annual John Goldman E-Conference on Chronic Myeloid Leukemia: Biology and Therapy

A Virtual Success



1178
Participants



98
Countries

Breakdown of Participants by Country



e-Conference Live Broadcast Views

5,153

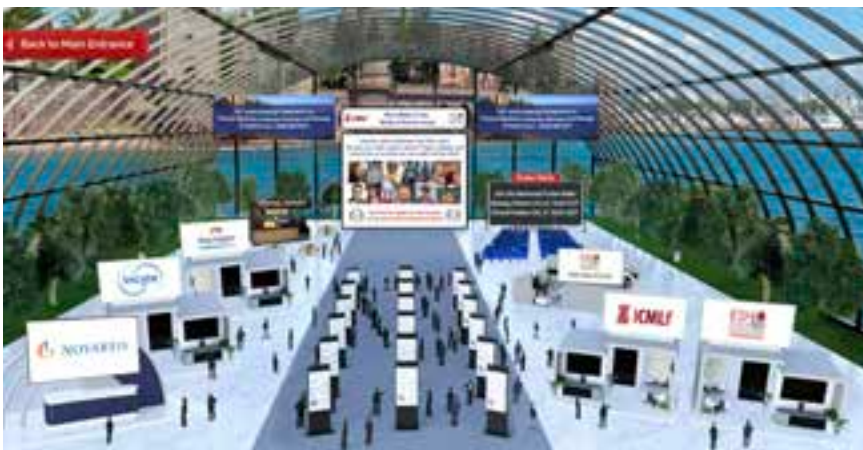
Total views over 4 days

5,668

Visitors

13,031

Sessions



ESH
EUROPEAN
SCHOOL OF
HAEMATOLOGY

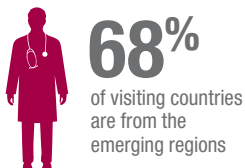
Global Reach with our Online Platforms

Website



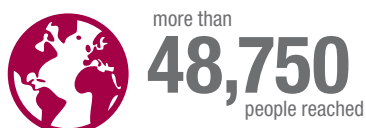
MOST VISITED PAGES

- ★ Case Discussion Forum
- ★ iCMLf Conversations
- ★ COVID-19 Hub
- ★ Scientific News CML
- ★ CML Publications



As a foundation with a mission to improve outcomes for people with CML globally our online platforms are a key part of our activities to reach this goal.

Social Media





Tim Hughes' Monthly Publication Notice

Monthly emailed news service with key scientific and clinical papers selected by Professor Tim Hughes.



more than
321
new publications
featured on the ICMLf
website.

140 Clinical papers

108 Scientific papers

17 Papers from low and
middle-income countries

20 Pediatric papers

36 COVID-19 papers



Professor Jerry Radich was kind enough to step in twice as moderator.

Clinical Case Discussion Forum



more than
3,700
case views



16 physicians contributed
cases and replies

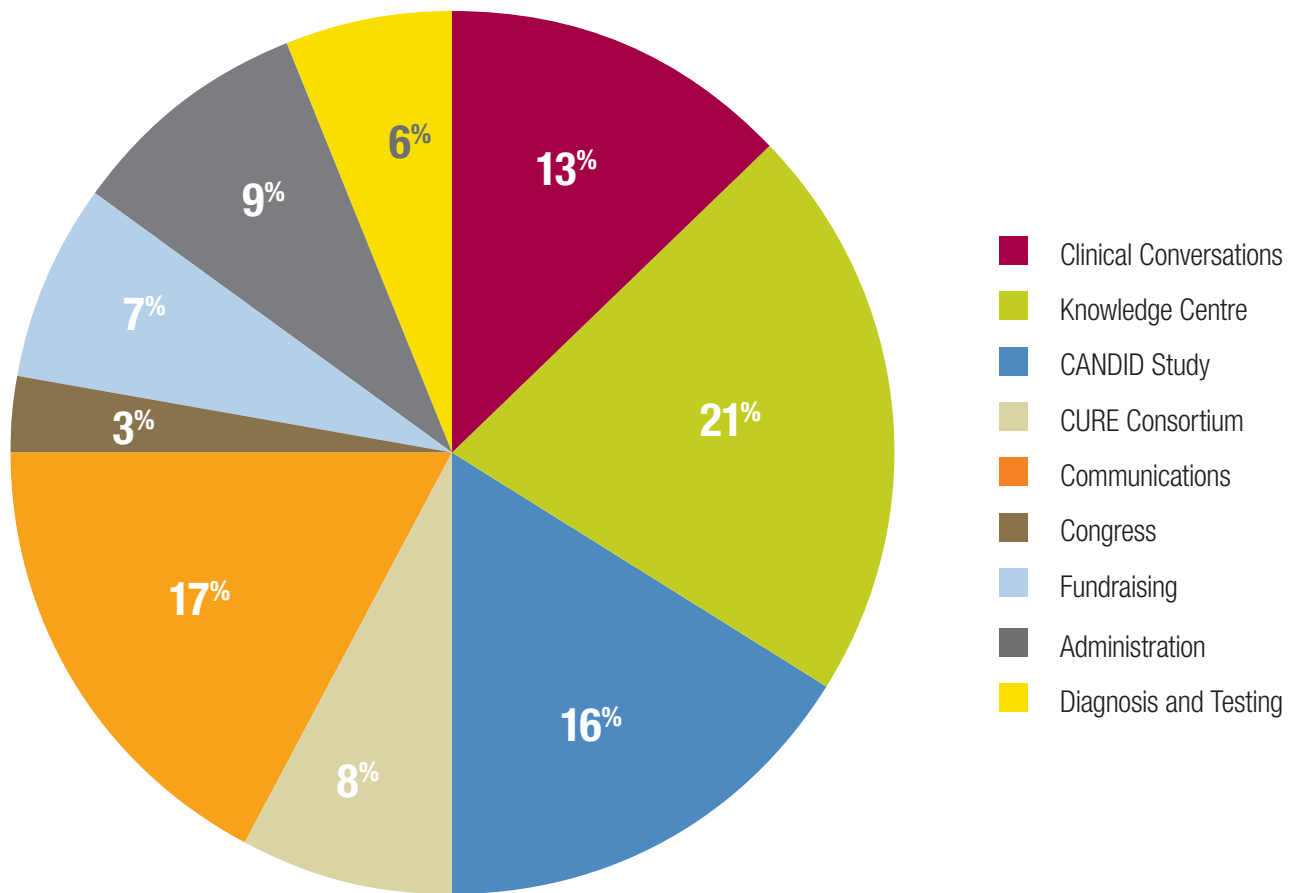


529
average views per case

MOST FREQUENTLY VIEWED TOPICS

- 1** Low BCR-ABL high WBC at diagnosis (1,043 views)
- 2** Dasatinib, L'asparaginase and pancreatitis (1,000 views)
- 3** CML-AP 11yr/3 TKI+ (T315I mut.) treatment after ponatinib (829 views)

Expenditure Allocation



64%

Program spend



34%

Raising the bar through CML education



24%

Global research projects

Thank you to our Supporters

CORPORATE SUPPORT

As a charitable Foundation the iCMLf relies on grants and donations to continue the programs and activities that positively influence the lives of patients with CML. We thank our corporate partners for their generous contributions that help us achieve this.



FRIENDS OF THE FOUNDATION

The iCMLf also receive individual donations and donations of honoraria. We appreciate and thank all those who give both of their time, and financially to further the aims of the Foundation.



EXPERT COLLABORATORS

The work we do would not be possible without the support from the CML physicians, scientists and advocates in our network. Thank you for your time and expertise to help the CML community.



THANK YOU TO ALL THE PHYSICIANS PARTICIPATING IN THE iCMLf CANDID STUDY

Argentina

Beatriz Moiraghi
Carolina Pavlovsky
Eduardo Bullorsky
Luis Enzo Belligoy
Maria Elisa Riva
María Fernanda Tosin
Maria Josefina Freitas
Maria Veronic Ventriglia
Mariel Ana Perez
Maya Schweri

Armenia

Karen Meliksetyan

Azerbaijan

Kamila Pashayeva
Bangladesh
Hafizur Rahman
Mohammad Ali

Bolivia

Gloria Rodríguez Suárez
José Macías Abasto
Ricardo Villegas
Wendy Cabrera

Brazil

Acy Telles de Souza
Quixada
Ana Carolina Mourão Toreli
Andre Luis Gervatoski
Lourenco
Carla Boquimpani
Jacqueline Holanda
de Souza
Jaisson Bortolini
Jaqueline Sapelli
Katia Pagnano
Muriel Silva Moura
Natália Nunes Gonçalves
Vaneuza Araujo Moreira
Funke

Canada

Elena Liew
Isabelle Bence-Buckler
Jeff Lipton
Lambert Busque
Lynn Savoie
Pierre Laneuville

Chile

Alberto Rossle

China

Qian Jiang
Weiming Li
Xiaojuan Zhu

Czech Republic

Barbora Weinbergerova
Daniela Zachova
David Buffa
Edgar Faber
Ivana Skoumalova
Lukas Semerad

Lukas Stejskal
Michal Karas
Petra Belohlavkova

Ecuador

Juan Sghiria

Egypt

Mohamed Ahmed
Elbogdady

France

Delphine Rea
Franck Nicolini
Gabriel Etienne
Laurence Legros
M Gardembas
Maxence Bargoin
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Philippe Rousset

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Amma Benneh

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Honduras

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Nelli Saraí Padilla

Hungary

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T. Rajasekar
Tapan Saikia
Tulika Seth
Vibha Himanshu Naik
Vijay Ramanan
Vikram Mathews

Iraq

Alaa Fadhil Alwan

Israel

Ekaterina Wvitinov
Martin Ellis
Noam Benyamini
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Isabella Capodanno
Marco Cerrano and
Patrizia Pregno
Maria Cristina Miggiano
Mariella D'Adda
Massimiliano Bonifacio
Monia Lunghi
Patrizia Pregno

Japan

Naoto Takahashi

Kazakhstan

Vadim Kemaykin

Kenya

Gatua Mercy
Njoki Njiraini
Matilda Ongondi

Malaysia

Hon Siong Leng

Mali

Moussa Bathily

Mauritius

Vanisha chummun

Mexico

Elena Tuna
Gilberto Israel Barranco
Lampón
Rafael Hurtado

Moldova

Vasile Musteata

Mongolia

Ayurzana Nansalmaa

Nepal

Gyan Kayastha
Mipsang Lama

New Zealand

Peter Browett

Niger

Andia Abdoukader

Nigeria

Muheez Durosinmi
Temilola Owojuyigbe

Oman

Salam Alkindi

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Juanita Lu Lim
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Joana Desterro

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Marica Pavkovic

Russia

Anna Petrova
Darina Zammoeva
Ekaterina Borodina
Ekaterina Chelysheva
Elza Lomaia
Nadezhda Shnalieva
Eva Burnasheva
Evgeniya Sbityakova

Julia Vlasova
Margarita Gurianova
Nadiya Siordiya
Natalia Lazorko
Natalya Ilina
Natalya Lazorko
Oleg Shukhov
Tamara Chitanava
Tatyana Saburova
Yurii Dunaev

Senegal

Fatou Samba Ndiaye

Serbia

Andrija Bogdanovic

South Africa

Dr Littleton

South Korea

Dong-Wook Kim

Spain

Jean Luis Steegmman

Gran Canaria

María Teresa Gómez
Casares

Sudan

Mishkat Mukhtar Ali
Abdelhakim Gobara
Gaber

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 International
Chronic Myeloid Leukemia
Foundation

