

**2022  
2023**  
ANNUAL REPORT



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**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.

## Reflections after 10 years as Chairman



ERSAP 2015

When John Goldman, Jorge Cortes and I met in Athens in 2007 we agreed that the time was right to set up a Foundation to foster research and education related to CML on a global scale. Our mission would be to improve outcomes for CML patients globally using our expertise as clinicians. We worked closely with other global foundations with complementary expertise including the MAX Foundation and the CML Advocates Network to work out how we could make the biggest contribution. John was eventually persuaded to lead this new Foundation and put all of his vision and energy into the Foundation until his untimely death in 2013. I took on the role of Chair and have continued in that role for the past 10 years. As I step down as Chair, I reflect on the key challenges facing us:

### 1. Ongoing poor access to drugs and tests.

We continue to work with the MAX Foundation to get TKI therapy and PCR testing into low/middle income countries. The role that iCMLf can play here is to educate and train local clinicians and laboratory scientists about the critical step of diagnostic testing to enable patients presenting with CML to qualify for TKI therapy through the MAX Foundations Global Drugs Access Program. The iCMLf has supported the paper-based blood extraction process developed by Jerry Radich and multiple shipments from the Philippines for testing in Adelaide. We also recently helped clinicians in New Guinea and Swaziland gain access to diagnostic testing for this purpose. One accredited PCR test opens a pathway to lifelong drug supply for these patients – an incredible return on investment. A lot has been achieved here but the challenges are no less daunting.



Climbing Killi

### 2. Ensuring that advancing knowledge in CML is widely disseminated.

Engaging the regional CML leaders in low and middle-income countries in educational sessions targeted to their needs to ensure that advancing knowledge about monitoring and therapy for CML is reaching as many clinicians in these regions as possible. Selection of optimal frontline therapy, management of pregnancy, approach to resistant disease, and practical approach to treatment-free remission are some of the areas we cover. For over a decade we ran our preceptorship program to enable clinicians from these regions to receive on-site training at expert centres overseas. Over 200 preceptors gained first-hand experience in this way. COVID put a stop to the Preceptorship Program, but it remains an aspiration of the Foundation to restart if we can gain sufficient funding from our donors. In the meantime, we continue to engage virtually in regional education and discussion sessions.



The operational team

### 3. Maximising the research impact of the Foundation.

Perhaps our greatest challenge is the steady rise in the number of CML patients needing life-long therapy and molecular monitoring - most living in low-income countries. Only by making treatment-free remission an achievable outcome for most CML patients can we hope to address this global challenge. The iCMLf CURE Consortium aims to bring the leading researchers together globally to work on projects to improve treatment pathways and personalised therapy options with the eventual goal of cure. Our 'TFR Alliance', looking at biomarkers to predict treatment-free remission will be a critical program over the next few years. We are making steady progress with the iCMLf Genomics Alliance looking at clonal hierarchy in CML

– see update in this report.



Sharing knowledge



The great strength of the iCMLf is that almost every researcher with a strong focus on CML is an active member of the Foundation. We have seen that CML global collaborations have great effect, from the development of the TKIs, the introduction of standardised monitoring and the work of the iCMLf improving outcomes for patients in the developing world. I am looking forward to the next decade of collaboration where we work towards cure for our CML patients.

One of the privileges of leading the iCMLf over the past decade has been working with a remarkable executive team led by our Chief Executive Nicola Evans. A clear demonstration of the dedication of the team is their willingness to join the Climb for a Cure and actively fundraise at considerable personal sacrifice and cost. Stefanie Bockwinkel our Communications Officer joined us on the Mt Kilimanjaro climb, Arlene Harriss-Buchan our Program Manager is joining us for the Annapurna Climb, and Nicola has signed up for both climbs. We are also very well served by a Board of CML experts and our Scientific Advisory Committee who continue to provide (free) expert advice and assistance to the executive team.

It is now time for the Foundation to move on with another leader and the iCMLf Board unanimously voted for Jorge Cortes to take on that role. I am extremely confident that Jorge will take the Foundation to new levels of impact during his term as Chair. He is an extraordinary clinician, researcher, and person. Jorge and I will be climbing together in a few weeks on the Annapurna Track for the Foundation's second Climb for a Cure, in a group of 25 dedicated scientists, clinicians, patients and family members, which will be a nice chance to symbolically hand over the gavel.

Thank you to all who support us on the journey.



Tim Hughes  
iCMLf Chair



## From the Chief Executive

The iCMLf's mission of improving outcomes for people with CML has firmly solidified into two key goals:

- 1) Share best practice CML education from global and regional CML experts so that CML patients get the best possible treatment with the resources available**  
*=> Optimal outcomes for CML patients*
- 2) Utilise the iCMLf's global network to shift the treatment paradigm => Cure**

The iCMLf efforts and expenditure directly address these goals 82% of the iCMLf program expenditure goes towards our efforts to share best practice capabilities to manage CML and 58% of this is directed to help those in low and middle-income countries, through the iCMLf Knowledge Centre, Regional Discussion Groups and Diagnostics activities. These are enhanced by the expert knowledge shared through the CML papers of the month, clinical case discussion forum and our live discussions in the Clinical Conversations - our highlights from ASH and EHA were particularly popular this year.

The impact of our education programs is immediate, people change therapies, side effects are managed, relapse is prevented. The impact of our research programs is slower to see, but we have made exciting progress with the two Big Data HARMONY-Plus partnership projects. The Genomics project now has 2/3 of the data ready for analysis and three of the 24 sites in Treatment Free Remission (TFR) project have now completed data upload. Next year we will see the first results of these projects giving us more understanding of the impact of genomic variability on CML outcomes along with pathways to maximise TFR.

As Professor Delphine Réa stated at the iCMLf Forum. "We have to go on working on all aspects of CML from transformation to the Cure" This Forum held during the annual American Society of Hematology was an excellent opportunity to discuss the 'Next Big Challenges in CML' and how we continue the conversation to move towards a cure. The conclusion from Associate Professor Ted Braun "My hypothesis would be that a focus on universal rapid leukemia depletion and early immune modification will move us closer to curing CML over the next decade."

It has been my absolute privilege to co-pilot the iCMLf with Professor Tim Hughes over the last 10 years. As Chairman his guidance, kindness and patience has unwavering and will be sorely missed.

As Professor Jorge Cortes becomes iCMLf Chairman in October 2023 we look forward to continuing this journey and thank all the CML experts who give their time to guide us, our partners, and supporters as we move forward together.



Nicola Evans  
Chief Executive



## iCMLf Global Research Network

Big Data projects look to optimise treatment pathways

### Investigating Clonal Hierarchy in CML

The iCMLf Genomics Alliance continues to partner with HARMONY – PLUS for the project to investigate the impact of genomic variation in CML. Data upload continues and the initial assessment of the multinational data has begun.



**12 sites**



From  
**12 countries**

**989** data-sets uploaded

**644** data-sets available for analysis

**~600** still to upload

## iCMLf GENOMICS ALLIANCE

### Site lead

### Country

Sue Branford	Australia
Dennis Kim	Canada
Katerina Machova Polakova	Czech Republic
Jiri Mayer	Czech Republic
Andreas Hochhaus, Thomas Ernst	Germany
Ruth Stuckey, Maite Gómez Casares	Gran Canaria, Spain
Federica Poggi, Carlo Gambercorti-Passerini	Italy
Ahmad Alhuraiji	Kuwait
Tomasz Stoklosa	Poland
Mohamed Yassin	Qatar
Tiong Ong, Charles Chuah	Singapore
Lee-Yung Shih	Taiwan



“The iCMLf is proud to be a partner with Harmony Plus to use BIG DATA to improve treatment opportunities for people with CML. The two iCMLf projects allow international sites to ‘pool’ data for enhanced statistical power to define best treatment pathways and patient outcomes.” **Nicola Evans, Chief Executive**

Site lead	Country
Carolina Pvalovsky	Argentina
Naranie Shanmuganathan, Tim Hughes	Australia
Fernanda Seguro, Katia Pagnano	Brazil
Dennis Kim	Canada
Rolando Vallansot	Catalonia, Spain
Francois-Xavier, Fanny Robbesyn	France
Franck Nicolini	France
Philippe Rousselot	France
Delphine Rea	France
Susanne Saussele	Germany
Andreas Hochhaus	Germany
Hemant Malhotra	India
Carmen Fava, Silvia Marini	Italy
Carlo Gambacorti-Passerini, Giorgia Quitarrini	Italy
Gianantonio Rosti, Alessandro Lucchesi	Italy
Fausto Castagnetti, Miriam Iezza	Italy
Vasile Musteata	Moldova
Charles Chuah	Singapore
Dong-Wook Kim	South Korea
Ruth Stuckey	Spain
J Valentín García Gutiérrez	Spain
Torsten Dahlén	Sweden
Lee-Yung Shih	Taiwan
Jane Apperley	UK



### Maximising Treatment Free Remission

The research project 'Use of big data to identify optimal treatment pathways leading to successful treatment-free remission in CML' aims to effectively evaluate multiple factors that likely predict and influence successful tyrosine kinase inhibitor discontinuation for patients with CML.



**24 sites**



From  
**15 countries**  
are submitting data

**3** sites have transferred data  
**10** sites have transfer underway

Expecting more than  
**3,000** data-sets

## Projects that began in 2023

New opportunities to improve treatment outcomes

### Challenges in management of paediatric chronic myeloid leukemia in Low and Middle Income Countries: Insights from an International CML Foundation multi-national survey

Through the network of the iCMLf, Professor Nirmalya Roy Moulik from Tata Memorial Hospital, Mumbai, India conducted a survey on treatment of paediatric CML in low and middle-income countries. Little is known about treatment of this rare leukemia where resources are constrained.

This multinational survey provides valuable insights into the challenges faced in managing paediatric CML in low and middle-income countries and suggests priorities for improvement going forward.

Review publication is imminent



Professor Nirmalya Roy Moulik

#### PROJECT 1

Our thanks to: Diana Altuna (Argentina), Sabina Karim (Bangladesh), Israel Bendit (Brazil), Prof Qian Jiang (China), Isabel Cristina Sarmiento Urbina (Columbia), Abdulkadir Mohamed Said Gidey (Ethiopia), Miri Turkana (Fiji), Banbeng Adrianto (Indonesia), Nur Melani Sari (Indonesia), Irene Nzamu (Kenya), George Chagaluka (Malawi), Norma Lopez-Santiago (Santiago), Sucharita Tuladhar (Nepal), Gregory Harvet (New Caledonia), Prof Lateef Salawu (Nigeria), Adefehinti Olufemi (Nigeria), Salam Al-Kindi (Oman), Zeba Aziz (Pakistan), Gwenda Anga (Papua New Guinea), Mohamed Yassin (Qatar), Eli Mkwizu (Tanzania), Milenalay Santos (Timor L'Este) and George Aho (Tonga) for completing the survey.

### Hepatitis B Virus (HBV) prophylaxis on TKI therapy iCMLf survey of practice.

Most centres have very few CML patients who are Hepatitis B positive and on TKIs. Guidance from hepatologists that suggests patients should be on antivirals and that viral load should be monitored.

However there are currently, limited and mixed messages in the literature. In 2023 the iCMLf formed a working group to collect experience about reactivation, prophylaxis. A survey of practice will be distributed in Q4 2023.

Our aim is to collect global experiences treating people with CML who also have HBV, with the desired outcome to publish our findings and recommendations on monitoring and treatment for HBV.



Professor Dragana Milojkovic

#### PROJECT 2

HBV and CML – iCMLf working group:- Dragana Milojkovic, Lead (UK), Katia Pagnano (Brazil), Qian Jiang (China), Delphine Réa (France), Giuseppe Saglio (Italy), Fausto Castagnetti (Italy), Mohamed Yassin (Qatar), Jorge Cortes (USA)

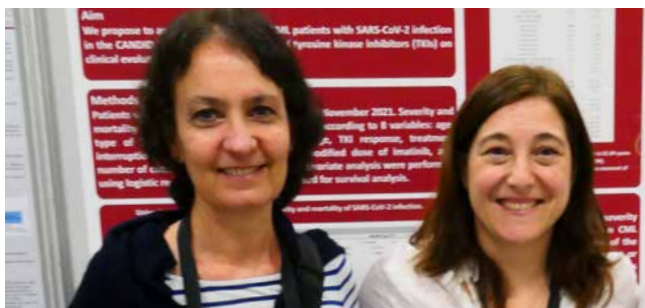


## Projects that closed in 2023

The iCMLf COVID-19 and CML study provided data driven guidance

### The iCMLf CML AND COVID 19 (CANDID) Study

This year saw the closing of the iCMLf CANDID Study and the final two presentations from the data.



**Mariana Lorenzo and Ana Inés Prado** | Uruguay

Poster presentation at the John Goldman meeting 2022.  
A subanalysis of patients with CML and COVID-19 on TKI treatment.

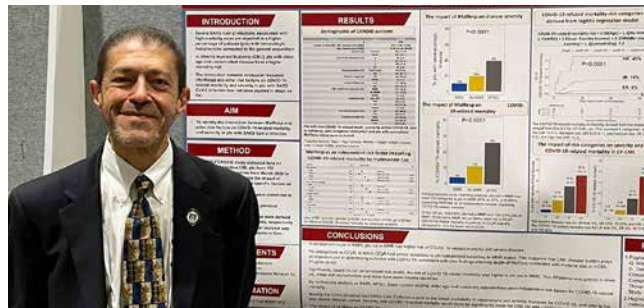
The data supports that it is safe to maintain all TKI treatment during SARS-CoV-2 infection.

#### THANK YOU

To all physicians contributing data, the patients willing to help and our partners,

The Max Foundation and the CML Advocate Network.

For the funding towards the study from Novartis Oncology and Pfizer.



**Professor Jorge Cortes** | USA

Poster presentation at the American Society of Hematology 2022 - A risk model for CML patients with COVID-19: importance of molecular response in the context of age, comorbidities and country income.

Based the personalised risk model, risk of COVID-19-related mortality was higher in points not in MMR. This difference was greater in older points, those with comorbidities and from lower income countries.

## Recognising excellence in CML

Congratulations to the 2023 iCMLf prize recipients

### Rowley Prize Professor Jerry Radich (USA).



The iCMLf Rowley Prize recognises outstanding contributions to the understanding of the biology of CML and is awarded to Jerry Radich in recognition of his visionary work in investigating the molecular basis of therapy response, resistance and relapse in CML as well as the development of modern molecular biology techniques towards the early detection of leukemia.

### Goldman Prize Professor François Guilhot (France).



The iCMLf Goldman Prize recognises outstanding contributions to the clinical management of CML. François Guilhot receives the Goldman Prize to award his pioneering achievements in important clinical trials in CML and his long-standing leadership in the management of CML.

### iCMLf Prize Irina Dyagil and Kostyantyn Kotlyarchuk (Ukraine).



The iCMLf Prize acknowledges outstanding contributions to improving the treatment of CML in low and middle-income countries. In 2023 the Prize recognises the work of Ukrainian hematologists in this time of war and disruption. The iCMLf Directors and Advisors have chosen the two nominated Ukrainian haematologists, Professor Dyagil and Dr Kotlyarchuk to jointly accept the iCMLf prize.

We thank all the prize recipients for their tireless work, their inspiration to others and their consistent dedication to patients with CML.

## Sharing best practice CML education from CML experts

Addressing regional challenges to improve treatment outcomes

### iCMLf Knowledge Centre

A global education hub focussing on CML management for non-academic centres. Presentations provide valuable, up-to-date content, developed by key CML leaders with the support and input from a physician working with CML patients in a low or middle-income country as co chair of each subject.

#### Newmodules this year:

##### Management of Pediatric CML

Chaired by Professor Meinolf Suttorp (Germany) and Professor Nirmalya Roy Moulik (India), this module outlines a comprehensive review of the treatment of paediatric CML.

##### Management of Advanced Phase CML

Chaired by Professor Mhairi Copland (UK) and Dr Virginia Abello Polo (Colombia) this module will feature topics on the practical management of advanced phase CML.



**17** speakers from  
**11** countries



**2,431** users



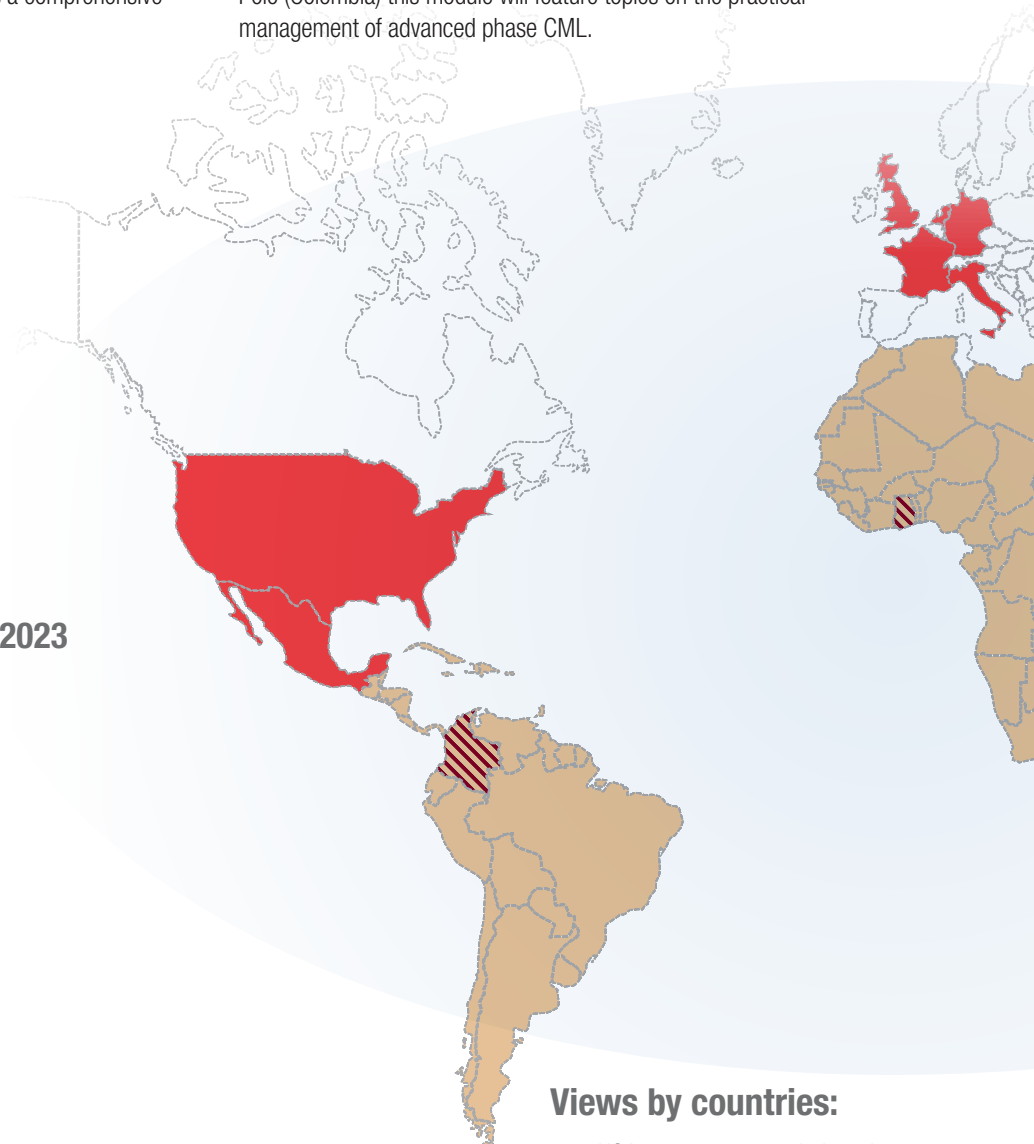
**800** new users 2023



Total  
**7,700**  
page engagements



Visitors from  
**96** countries



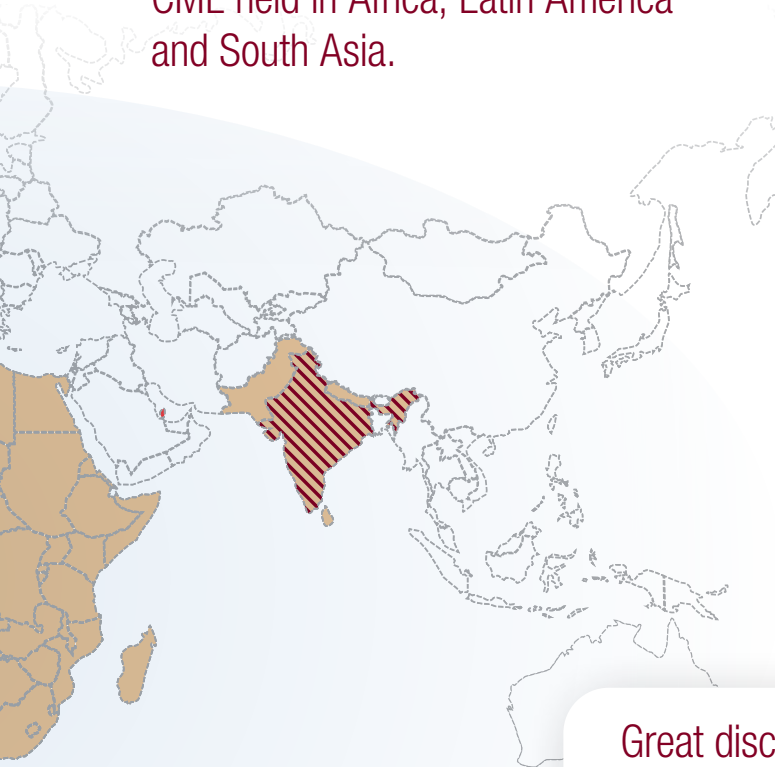
#### Views by countries:

- |              |                |
|--------------|----------------|
| 1. USA       | 6. Indonesia   |
| 2. India     | 7. Argentina   |
| 3. Australia | 8. Netherlands |
| 4. Germany   | 9. China       |
| 5. UK        | 10. Cyprus     |

The iCMLf Knowledge centre is critical in empowering and educating physicians and scientists with current information and for best practice and CML management.

Since 2010 our programs throughout low- and middle-income countries have expanded access to CML education, networks, and discussions - all of which have improved the way CML is managed. In 2023 we introduced a new program – iCMLF Regional Discussions on CML.

## Regional Discussion Groups on CML held in Africa, Latin America and South Asia.



### All three steering committees selected the same topics for discussion:

- Paediatric CML: Key issues in treating children and young people with CML
- The Impact of CML on fertility and pregnancy
- The realities of Treatment Free Remission in low and middle income countries
- CML From the Laboratory Challenging case and how to address them
- Challenging scenarios in CML

Great discussions, and people really interested in this topics. I think this meetings are very useful , and much time for discussion has a plus!" **Dr. Carolina Pavlovsky, Argentina**

- Speakers for Knowledge Centre
- Regional Discussion Group attendees
- ▨ Both

Over **150** physicians attended from **26** countries

"Thank you for the very informative webinar. The discussions were very practical. I realise that we have almost forgotten cytogenetics in present day management of CML. And, a lot of emphasis in compliance..." **Professor Raghunadharao Digumarti, India**

## Clinical Conversations on CML

Live discussions with CML experts to update knowledge and best practice



**7** conversations  
with  
**200** participants



### Top-viewed:

- Management of advanced phases of CML
- Clinical highlights of ASH 2022
- Meet-the-expert Q&A Session 2022

More than

**3,150**  
new topic views

More than

**18,400**  
full program views

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





## 24th John Goldman Conference on CML

Bringing together research and clinical practice



After two years of meeting virtually this John Goldman Conference on CML: Biology and Therapy felt very special in many ways: The opportunity to meet colleagues in person again, with plenty of time for interaction and collaboration between presenters and participants.

“So great to see colleagues from around the world again. It makes it so much easier to connect and to work on new collaborations together.”



“This meeting is the best opportunity to get a comprehensive overview of latest developments, clinical studies and new scientific approaches in CML.”



**287**  
attendees



from more than  
**30**  
Countries





## iCMLf Forum: The Next Next Big Challenges in CML?

Moving the conversation towards a cure for CML

### SPEAKERS

With a vision to explore what is needed to get significantly closer to a cure for CML in the next 5-10 years, the Forum set out to discuss the complexities of a CML Cure and how we can work towards this.



**Free Treatment or Treatment Free?**  
Where to invest limited resources in a highly manageable cancer.

**Professor Michael Deininger,**  
Medical College of Wisconsin,  
Milwaukee, USA



**Disease Persistence in CML:**  
Cell Intrinsic and Extrinsic Mechanisms

**Assistant Professor Ted Braun**  
Knight Cancer Institute, Oregon Health and  
Science University Portland, Oregon USA



**TKI Resistance:**  
More Than Just Abl Mutations

**Professor Jorge Cortes**  
Georgia Cancer Center, Augusta, USA

The iCMLf Forum, brought to the fore some of the many challenges we are facing in our journey to finding a CML cure and discussed the ways we can broaden our thinking on how best to overcome these.

### PANELISTS



**Professor Timothy Hughes,**  
Meeting Chair | South Australian Health  
and Medical Research Institute,  
Adelaide, Australia



**Lisa Machado**  
Canadian CML Network  
Executive Director,  
Canada



**Dr Delphine Réa**  
Hôpital Saint-Louis,  
Paris, France

“We have to go on working on all aspects of  
CML from transformation to the Cure”

**Delphine Réa**

# Global reach through our online platform

Extending CML knowledge and best practice

## Website

more than  
**6,000**  
visitors



more than  
**47,000**  
engagements



### MOST VISITED PAGES

1. Case Discussion Forum
2. iCMLf Conversations
3. Science and Education
4. Low and Middle-Income Countries
5. CML publications

**65%**  
of visitors are from  
Low and Middle  
Income countries



Visitors from  
**130**  
different countries



## Clinical Case Discussion Forum



more than  
**6,250**  
case views

## Expert Opinions

**12** new presentations  
with a total of  
**4,540**  
views



## Tim Hughes' Monthly Publication Notice

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



more than  
**292**  
new publications  
featured on the iCMLf  
website.

**133** Clinical papers  
**104** Scientific papers

**21** Papers from low and  
middle-income countries

**20** Pediatric papers

**14** COVID-19 papers

## Social Media



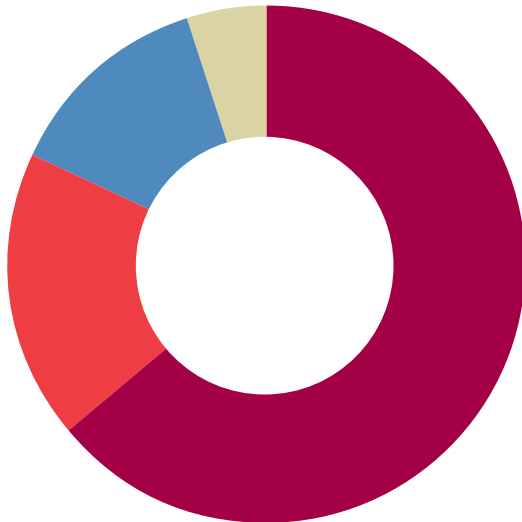
## Diversified expenditure in 2022/2023





Expenditure addresses the goals of the iCMLf

1) Share best practice CML Education so that CML patients get the best possible treatment

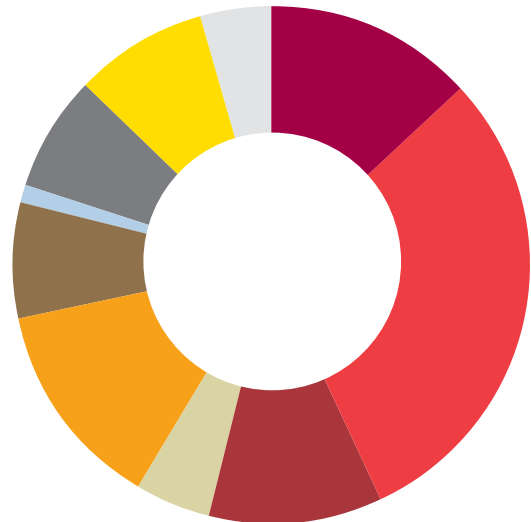
2) Utilise the iCMLf's global network to shift the treatment paradigm











2022/2023 iCMLf EXPENDITURE



	Education	64%
	Research	18%
	Fundraising	13%
	Governance	5%

2022/2023 PROGRAM EXPENDITURE



	Clinical Conversations	11%
	Knowledge Centre	25%
	Regional Discussion Groups	9%
	Diagnosis and Testing	4%
	Education Meetings	11%
	Education Communication	6%
	CANDID	1%
	CURE	6%
	Research Meetings	7%
	Research Communication	3.5%



**82%**  
Program spend



**64%**  
Raising the bar through CML education



**37%**  
Specifically in low and middle-income countries

# Annapurna Base Camp can be Climbed. CML can be Cured

Together, we can reach new heights in the fight against CML!



**\$148,000**  
Amount raised to date

In November 2023, 25 scientists, doctors, CML patients and their supporters will climb for 7 days to Annapurna Base Camp in Nepal. Every climber has a minimum fundraising goal of \$3,000 and climbers cover their own costs. All the money raised goes directly to the iCMLf to support our work.

Every dollar raised brings us closer to vital breakthroughs in research, innovated treatments and ultimately, a cure for CML.



## MEET THE CLIMBERS:

Kendra Sweet	USA	Dianne Young	Switzerland	Jorge Cortes	USA	Yunus Borowczak	Germany
Ehab Atallah	USA	Ekaterine Asatiani	Switzerland	David Jones	Switzerland	Kimberli Johnston	USA
Judith Trotman	Australia	Katia Pagnano	Brazil	Jessica Guhl	USA	Andrew Ojelabi	Nigeria
Stephen Daley	Australia	Claudia Galoro	Brazil	Philippe Rousselot	France	Malgorzata Graczyk	France
Timothy Hughes	Australia	Vamsi Kota	USA	Michael Deininger	USA	Nicola Evans	Australia
Anne Corder	Switzerland	Beppe Saglio	Italy	Jutta Deninger	USA	Arlene Harriss-Buchan	Australia
				Cornelia Borowczak	Germany		

## We thank our corporate supporters of the climb:





## Our Supporters

Thank you to all who donate money, time and effort to support people with CML.

### 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.



### DID YOU KNOW?

Every presenter in the iCMLf Knowledge Centre donated their speaker fees to the work of the Foundation. "Thank you."

### 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.





## Leadership

World leaders in CML guide the foundation

### BOARD OF DIRECTORS



**TIMOTHY HUGHES**  
Chair

South Australian Health and Medical Research Institute, Adelaide, Australia



**JORGE CORTES**

Georgia Cancer Center, Augusta, USA



**BRIAN DRUKER**

Knight Cancer Institute, Oregon Health and Science University, USA



**ANDREAS HOCHHAUS**

University Medical Center, Jena, Germany



**JERALD RADICH**

Fred Hutchinson Cancer Research Center, Seattle, USA



**CHARLES SCHIFFER**

Karmanos Cancer Institute, Detroit, USA



**JANE APPERLEY**

Imperial College London, UK



**MICHAEL MAURO**

Memorial Sloan-Kettering Cancer Center, USA



**GIUSEPPE SAGLIO**

University of Turin, Italy

### Scientific Advisory Committee

16

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

NEW IN 2023



**Ehab Atallah**  
Wisconsin, USA



**Mohamed A Yassin**  
Doha, Qatar

### 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**

Communications  
Director



**TERRI HEATH**

Digital Media  
Officer



**CHLOE JACKSON**

Communications  
Manager



The International CML Foundation is registered as charity no. 1132984 in England and Wales.

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[www.cml-foundation.org](http://www.cml-foundation.org)

 **iCMLf** International Chronic Myeloid Leukemia Foundation

