



ANNUAL REPORT

**2017  
2018**

IMPROVE EDUCATION  
INCREASE DIAGNOSTICS  
ENHANCE SURVIVAL

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*I am so much thankful to you for all the things you have done and your foundation is doing to provide an opportunity for the people of the third world country to learn.*

Dr Nath, India



*The improved survival in CML... is so dramatic that these new agents must be made available... as rapidly as possible throughout the whole world.*

Professor John Goldman, inaugural Chairman of the iCMLf (August 2009)



**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.

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



*CML is predicted to become the most prevalent leukaemia by 2040 when there are projected to be over 3 million patients worldwide. A concerted global effort working towards a cure is imperative. The iCMLf is uniquely positioned to drive this effort.*

Professor Tim Hughes  
iCMLf Chairman (2018)



## Welcome from the Chairman

As we wrap up our first 10 years and look towards the next 10, I feel that this year is a bridge between two parts of the iCMLf's mission. In this annual report we connect these parts, highlighting both what we have achieved and providing you with an overview of our vision for the years to come.

On one side is the fact that effective therapies are available for CML and it is our imperative to work to get these to everyone who needs them, wherever they are in the world. For the last 10 years this has been the primary focus for the iCMLf. We have worked hand in hand with our partners and supporters to improve the access to therapies in low and middle-income countries by increasing the availability of high quality regular testing for CML. We support this increased access to the drugs by improving the ability of physicians in these regions to manage CML more effectively through education opportunities both in person and online. We will maintain our programs in these areas.

However we also need to recognise that despite the excellent progress we have made in managing patients with CML, major global challenges remain. Even with our current choice of 5 tyrosine kinase inhibitors (TKIs), 15-20% respond poorly to TKI therapy and half of these patients will die from CML-related causes. Among those who respond well, less than 25% are able to stop therapy and remain in remission with current approaches. To optimise outcomes for CML patients we need to bring CML management into the precision medicine era. As a global organisation, the iCMLf is uniquely positioned to drive this effort. Planning for this has begun.

In 2018 the Foundation formed the iCMLf CURE Consortium designed to bring clinicians and scientists together to work on specific projects under the banner of cure. The first of these projects is the Genomic Alliance looking at developing a risk calculator for CML. The second will be a multicentre project developing biomarkers to optimise treatment free remission attempts.

Of course, this new program needs funding and we don't want to shift funds away from our successful projects supporting the expansion of TKI use and access to diagnostics. Therefore in 2019 we embark on a fundraising venture 'Climb for a Cure: Mount Kilimanjaro'. I will be climbing along with Jorge Cortes, Nicola and we hope many of our Directors and Advisors and other supporters of the iCMLf. We look forward to sharing our adventures along the way and how the funds we raise will help us work towards a cure for CML.

Thank you for joining us on the journey so far. Will you also join us on Kilimanjaro to Climb for a Cure?

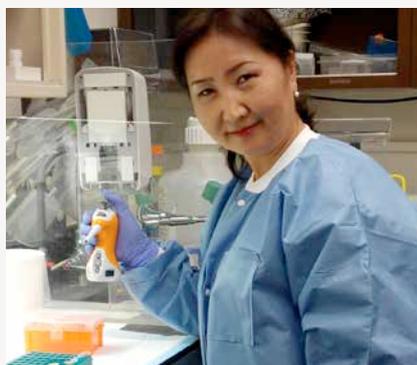


**Tim Hughes**  
iCMLf Chair

## iCMLf Guiding Principles



+ A focus on chronic myeloid leukemia and related disorders



+ A truly independent not-for-profit foundation



+ A global foundation with broad representation from all geographic regions

## Chief Executive's Overview - Your mastery is your purpose.

Earlier this year I heard a phrase that really resonated for me on how the iCMLf is so successful. Your mastery is your purpose. Physicians founded the iCMLf and it is their continued support and dedication that leads to what the Foundation achieves. Every program of the iCMLf relies on the expertise and time of each of the clinicians and scientists involved, yet they do it willingly to help others. This single minded determination is the foundation of our success.

This year the iCMLf Forum for physicians from emerging regions added a new component. Round table discussions with 5 CML experts. Physicians from the emerging regions got the opportunity for small group discussions about specific patient challenges. The American Society of Hematology is always a busy time and nevertheless these experts take the time to support and help colleagues from around the world.

The Clinical preceptorship program is the founding program of the iCMLf. The clinical and laboratory teams at the host sites organise the educational program for each preceptor according to what they want to learn most. With 16 preceptors this year the program continues to have great impact.

*"I have no words to thank you for providing me with such a great opportunity to learn from one of the world class center run by a group of highly intellectual people and at the same time very helpful people."* said Dr Islam from Pakistan on his return.

The mastery of the people we work with in the diagnosis and testing program never fails to inspire me. The effort that so many clinicians in low and middle-income countries go to to improve the access to CML drugs for their patients is amazing to see.

We have 16 projects active as part of the program this year and once again how these enhance the capacity of centres to treat their patients and access the drugs that will save lives is incredible.

*"Now patients in Macedonia are monitored in standardize lab with valid Conversion factor. During this process our laboratory gain significant experience and improve the process of monitoring of imatinib treatment in Macedonia."* was the comment from Dr Pavkovic.

Physicians and scientists also support the online programs of the Foundation. We have 17 new presentations on the iCMLf website this year, all by CML experts sharing their experience and advice. The iCMLf Knowledge centre is a new formalised education program and again, it is the leaders in the field that made this possible.

We thank everyone involved in each and every one of our programs and appreciate that your mastery is your purpose for us.



**Nicola Evans**  
iCMLf Chief Executive



+ Priorities and policies determined by hematologists and scientists involved in CML research and patient care



+ Close consultation and cooperation with CML patient groups



+ Active collaborations with key national and regional leukemia groups

# Governance

## BOARD OF DIRECTORS



**TIM HUGHES**  
Chair

Royal Adelaide Hospital,  
Australia



**JANE APPERLEY**

Imperial College  
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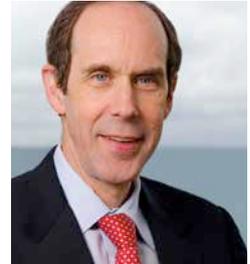
**MICHELE BACCARANI**

S. Orsola University  
Hospital, Bologna, Italy



**JORGE CORTES**

University of Texas MD  
Anderson Cancer Center,  
USA



**BRIAN DRUKER**

Knight Cancer Institute,  
Oregon Health and  
Science University, USA

## OPERATIONAL TEAM



**NICOLA EVANS**

Chief Executive



**JAN GEISSLER**

Communications  
Manager



**ARLENE HARRISS-  
BUCHAN**

Emerging Regions  
Support and Partnership  
Program Coordinator



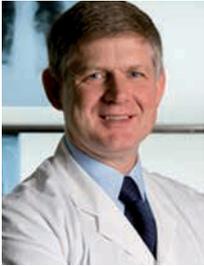
**STEFANIE  
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Director



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Seattle, USA



**GIUSEPPE SAGLIO**

University of Turin, Italy



**CHARLES SCHIFFER**

Karmanos Cancer  
Institute, Detroit, USA

## Scientific Advisory Committee

**13**

There are thirteen members of the iCMLf Scientific Advisory Committee. Members are respected hematologists, scientists and patient representatives who provide advice and support for the activities of the Foundation.

## Board of National Representatives

**36**

The 36 iCMLf National Representatives provide advice to the iCMLf Directors and assist implementation of initiatives at a local level. Through this global board we are able to offer specific understanding and programs to address local situations.

## Forum for Physicians from Emerging Regions



The iCMLf Forum for Physicians from Emerging Regions is one of the key events on the iCMLf calendar. Specifically for physicians from low and middle-income countries, the meeting features important CML topics from both a global perspective and the perspective of physicians managing CML with only limited resources for diagnosis, treatment and monitoring.



### Topics:

#### Perspectives on Molecular Monitoring for CML

Associate Professor Susan Branford (Australia)  
Dr Elza Lomaia (Russia)

#### Perspectives on Treatment Free Remission

Professor Susanne Saußebe (Germany)  
Dr Katia Pagnano (Brazil)

### A VALUABLE AND RELEVANT MEETING

#### How valuable did you find the meeting?



#### How relevant were the topics to your practice?

##### Molecular Monitoring



##### Treatment Free Remission



(\*10% did not answer)



### Meet the Experts:

Thanks to our partners, The Max Foundation, a new highlight of the Forum was a 'Meet the Expert' round table discussion specifically for physicians from the emerging regions. This was a unique opportunity for these physicians from Honduras, Argentina, Brazil, Venezuela, Ghana, Ethiopia, Russia and China to have in depth conversations with key leaders in CML.

/// excellent meeting with this new small experts discussion. ///

## Building capacity for CML diagnostics leads to greater access to therapy

The iCMLf Diagnosis and Testing Program is instrumental in changing the way CML is managed in low and middle-income countries. Increasing access to diagnosis and testing increases not only initial access to therapy, but knowledge on the course of a persons disease and therapy modification. The iCMLf works across emerging economic regions to increase access to equipment, laboratory training and education to ensure that more people get the therapies they need.

# 16

active diagnosis and testing projects in 2017/2018.

On average each site tests

# 124

new patients in the first 12 months.



Dr Duru with Dr Snyder at City of Hope

### Using the PCR-GeneXpert Ultra in emerging economic regions.

#### Dr. Augustine N. Duru

University of Nigeria Teaching Hospital Ituku-Ozalla  
Nigeria

*The impact of the grant on my CML patients have been great and impressive. The era of diagnosis based on total white cell count, morphology and clinical presentation is over. The speed at which results are generated and turn around time has been wonderful. My CML patients now go to Obafemi Awolowo University Teaching Hospital Ile-Ife for enrolment into the GIPAP free access to Glivec program. A remarkable change in my clinical practice noted since the arrival of the GeneXpert is drastic reduction in the prescription of Hydroxyurea. Above all, our CML patients now heave a big sigh of relief with the easy access of UNTH Enugu to the three geo-political regions in the Southern part of Nigeria. All these are courtesy of the iCMLf fund.*



Robert Hood. Fred Hutch News Service

### SPOT on CML

#### Professor Jerry Radich

Fred Hutch Cancer Research Center, USA

*One of the major barriers of PCR testing for centres that have no local resource for this is the extremely high cost of shipment of samples. One sample can often cost up to \$500 to get tested. The Radich lab has devised a method to assay blood spotted on filter paper for the BCR-ABL genetic marker of CML. This method to spot blood on specimen-grade paper, and perform the diagnostic testing accurately even after weeks of transit greatly decreases shipping costs, and greatly increases the number of samples that can be shipped together for testing. SPOT ON CML ensures accurate diagnosis, and ultimately therapy for patients that previously had no means of getting the test. The aim of this project is saving the life of one CML patient per day to reach 365 people over the course of a year. Working with the Fred Hutch, The Max Foundation and Cepheid, the iCMLf was pleased to support this project with an iCMLf grant in 2017.*

## Changing the perspective of managing cancer in the emerging economic regions

The iCMLf Clinical Preceptorship Program continues to enhance the knowledge of physicians treating patients with CML in emerging regions. The 3-4 week program takes place at a global CML centre of excellence under the leadership of some of the world's most experienced hematologists.



*“ It changes the perspective of managing cancer. We can bring a lot of practice changing concepts from these centers to our country and improve the management of CML. ”*

### THE IMPACT OF THE PROGRAM IS ASSESSED ON COMPLETION

Please rate the quality of your preceptorship to improve your clinical knowledge of the treatment of CML:



Please rate your experience of the iCMLf Clinical Preceptorship Program overall:



Would you recommend the program to your colleagues?



Doctors Dima and Burnasheva with Professor Rosti in Bologna

## THE IMPACT OF THE PROGRAM IS ASSESSED SIX MONTHS AFTER COMPLETION

### 1 Do you still view your iCMLf Preceptorship as beneficial?

a. For you

b. For your CML clinic

c. For your colleagues

d. For your CML patients

Yes 100%

Yes 100%

Yes 100%

Yes 100%

### 2 What changes, if any, have you been able to apply or implement since you attended your iCMLf preceptorship?

*“ We started a dedicated specialized clinic for CML patients. It’s easier for the patients to come to the clinic. ”*

Dr Kayastha Nepal



### 3 How have the skills and knowledge you have learned benefited your CML patients?

*“ I think those who can be started on imatinib are more confidently being treated with imatinib. I am also able to explain well why a specific TKI is chosen. They also understand that although TFR is not yet a common practice in the Philippines, if they qualify, there is a possibility of stopping TKI. ”*

Dr Sapinoso, Philippines



### 4 Have you been able to share the knowledge and skills you have learned during your preceptorship to your colleagues and hospital team?

*“ I teach my fellow interns. I share with them everything I was taught in Bologna, I showed them my final report... I hope that I will help my colleagues be the best among their fellows... I hope to create a team of doctors focused on CML. ”*

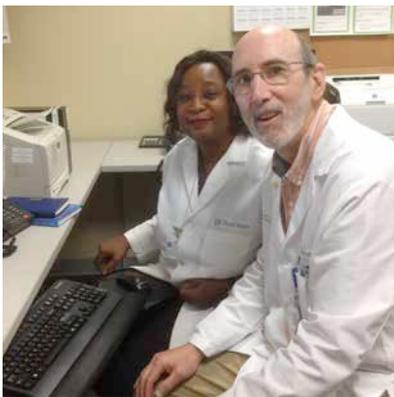
Dr Dima, Romania

*This is one of the best programs for Oncologists working in developing countries to get a bird-eye view of state-of-art oncology care at World's best Oncology centres.*

Dr. Batra, India

*This grant made a huge impact in the diagnosis and monitoring of the CML patients. Before this grant tests were charged around \$ 300 and it took a month to get the results. Now it takes no more than 2 days and it is for \$100.*

Prof Awa Toure, Senegal



*The number of death about CML are decreasing.*

Dr Andia, Niger



*Words can never explain what I have learnt from my experience and how it will help my patients in general and specifically cml patients. It is a wonderful experience and opportunity to gain from the developed world.*

Dr Hafeez, Pakistan



*I want to thank the iCMLf for help our patients of CML and for your improving the quality of survival.*

Dr Batigul, Russia

**12 CML CENTRES OF EXCELLENCE**

- Diagnosis and Testing Grant recipient
- Preceptorship Program participant

## 19th John Goldman Conference on CML: Biology and Therapy



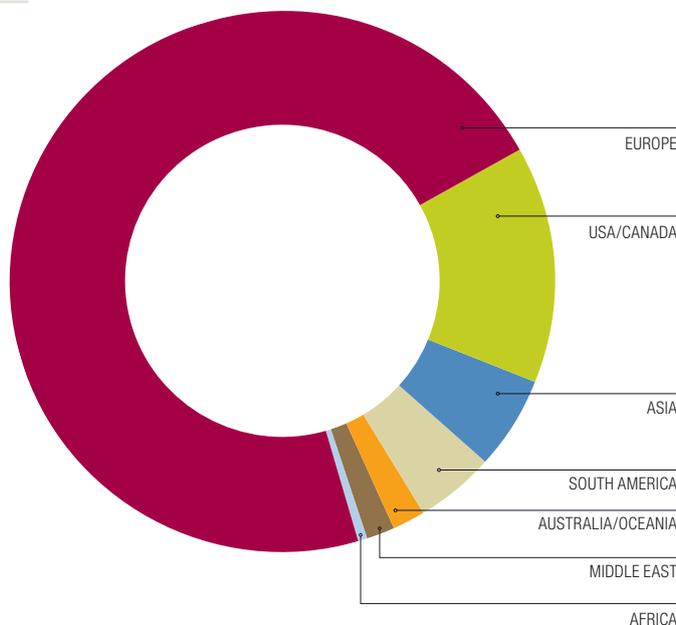
**“** The fact that this meeting takes place for the 19th time this year tells a lot about the passion of the CML scientific community to constantly improve the management of patients with CML and to better understanding the biology of CML. **”** said Jorge Cortes, chairman of the meeting, during the opening ceremony.

### Global scope of the conference – excellent opportunity to network

**439**  
clinicians and scientists

**43**  
from different countries

**“** This meetings always brings the perspectives from Europe, the US and other parts of the world together in one conference. **”**



### Comprehensive scientific program with interactive poster walks

**9**  
scientific sessions

**3**  
workshops for non-clinical scientists

**5**  
satellite symposia

**89**  
posters presented

**“** We had an excellent meeting. We came up with a lot of new questions and discussed how we can address these questions and how we can collaborate to further work on these questions. We now take all this with us home to further improve the care of our CML patients **”** said Jorge Cortes, chairman of the meeting, during the closing ceremony.

## Recognising excellence in CML biology and management

During the annual John Goldman Conference the iCMLf was very pleased to award the 2017 iCMLf prizes.



Connie Eaves presenting the Rowley Prize



### ROWLEY PRIZE Professor Tessa Holyoake



*At her request, Professor Holyoake's iCMLf medal was accepted by Professor Tim Brümmendorf, from the Universitätsklinikum Aachen, Germany and her keynote on 'CML stem cells: from discovering to targeting' was presented by Mhairi Copland, Professor of Translational Haematology at the Paul O'Gorman Leukemia Research Center at the University of Glasgow.*



Jorge Cortes awarding the Goldman Prize to Professor Hughes

### GOLDMAN PRIZE Professor Tim Hughes



*"There is no one who deserves this prize in honour of John Goldman more than Tim Hughes. He has contributed significantly to clinical research in CML and helped us to understand how to better manage our CML patients. He is also a great teacher always keen to share his knowledge."*

Professor Jorge Cortes



Pat Garcia-Gonzalez presenting the iCMLf Prize to Professor Radich

### iCMLf PRIZE Professor Jerry Radich

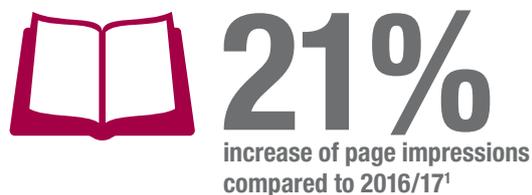


*"Jerry is a worthy winner of this award because his work makes a real impact on the life of CML patients in less developed countries by improving access to diagnostics. He is a true friend and important advisor to me and a real champion to CML patients around the world."*

Pat Garcia-Gonzalez, CEO of The Max Foundation

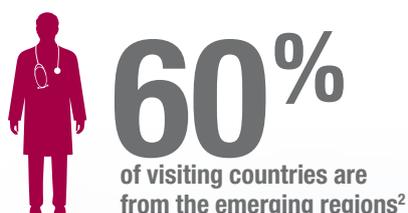
## iCMLf Online

www.cml-foundation.org



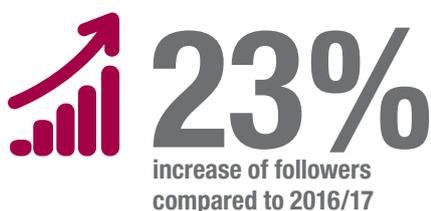
### TOP 5 MOST VISITED PAGES:

- 1 iCMLf Forum for Physicians from Emerging Regions
- 2 Science and Education
- 3 Virtual Education Program
- 4 Case Discussion Forum
- 5 Preceptorship Program



1. Source: webanalyzer Sept 2016 – Aug 17  
2. Source: Joomla Realtime Analytics

 [facebook.com/icmlf](https://facebook.com/icmlf)



# Clinical Case Discussion Forum

MORE THAN  
**9,200**  
case views

**611**  
average views per case

**25**  
physicians contributed  
cases and replies

**16** cases  
posted

## MOST FREQUENTLY VIEWED TOP 3 TOPICS:

- 1 Atypical CML? (1,515 views)
- 2 Pregnancy and hydroxyurea (1,413 views)
- 3 Unusual symptoms (1,049 views)



## Virtual Education Program

 **17** new modules added in 2017/18

Almost **14,000** web streams viewed (sources: pages hits)

 **96** web streams viewed in Russian in 1 month

2 presentations in Russian



3 presentations adapted from those given at EHA 2018



3 presentations adapted from those given at the John Goldman meeting in 2017



9 Presentations from a CML opinion leader meeting



## Personal perspectives on CML

### Expert interviews from the John Goldman Conference on CML



Prof. Jorge Cortes  
(599 views)



Dr Carolina Pavlovsky  
– in Spanish  
(412 views)

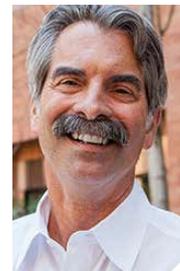
### Keynote presentations 2017 iCMLf prize recipients: (311 views)



Prof. Mhairi Copland:  
CML stem cells: from  
discovery to targeting



Prof. Tim Hughes:  
From safe haven  
to functional cure



Prof. Jerald Radich:  
WEIRD solutions to  
real world problems



## Tim Hughes' monthly publication notice

Professor Tim Hughes\* selects key scientific and clinical papers important to the CML community.

### 193 new publications featured on the iCMLf website:

- 73 Clinical papers
- 78 Scientific papers
- 35 Papers from low and middle-income countries
- 7 Pediatric papers



\*Thank you to Jerry Radich who stepped in for 2 months.

## The iCMLf Knowledge Centre

The iCMLf is pleased to offer a unique training tool to the CML community. The iCMLf Knowledge Centre is an online program providing educational content on CML for different user groups.

### Key features:

- Interactive eLearning tool
- Two distinct learning paths for clinicians and molecular biologists/pathologists
- Four learning modules with educational content on CML
- Relevant topics on CML patient management and monitoring



## COLLABORATION WITH INTERNATIONAL CML EXPERTS



Clinical Path:  
Professor Giuseppe Saglio, Italy (Chair)



Professor Tim Hughes, Australia



Professor Jerald Radich, USA



Laboratory Path:  
Associate Professor Susan Branford, Australia (Chair)



Professor Nick Cross, UK



Professor Martin Müller, Germany

## USE SINCE JUNE 2018

MODULE	Clinical Stream	Laboratory Stream
CML Treatment Goals	66	40
Monitoring in CML	43	47
Practical Considerations of Testing	17	29
Patient Case Studies	4	4
<b>TOTAL</b>	<b>130</b>	<b>120</b>

## THANK YOU

We are especially grateful to Novartis Oncology for their support of this program.



## Fundraising for a purpose

### The iCMLf Goldman Fund supports the training of young physicians from the emerging regions

The iCMLf has established the Goldman fund in honour of Professor John Goldman. The 'Goldman Fund' will be used specifically for the training of young CML clinicians and scientists from the emerging regions.

### Physicians from Macedonia and Pakistan supported by the iCMLf Goldman Fund

Dr Marica Pavkovic (Macedonia) and Dr Syed Owais Ali (Pakistan) were awarded grants to attend the 2017 John Goldman CML meeting.



### The 2017 'John Goldman Fun Run' was a great success



**“** It's so much fun running together with colleagues and friends and at the same time a good opportunity to support the work of the Foundation. **”**

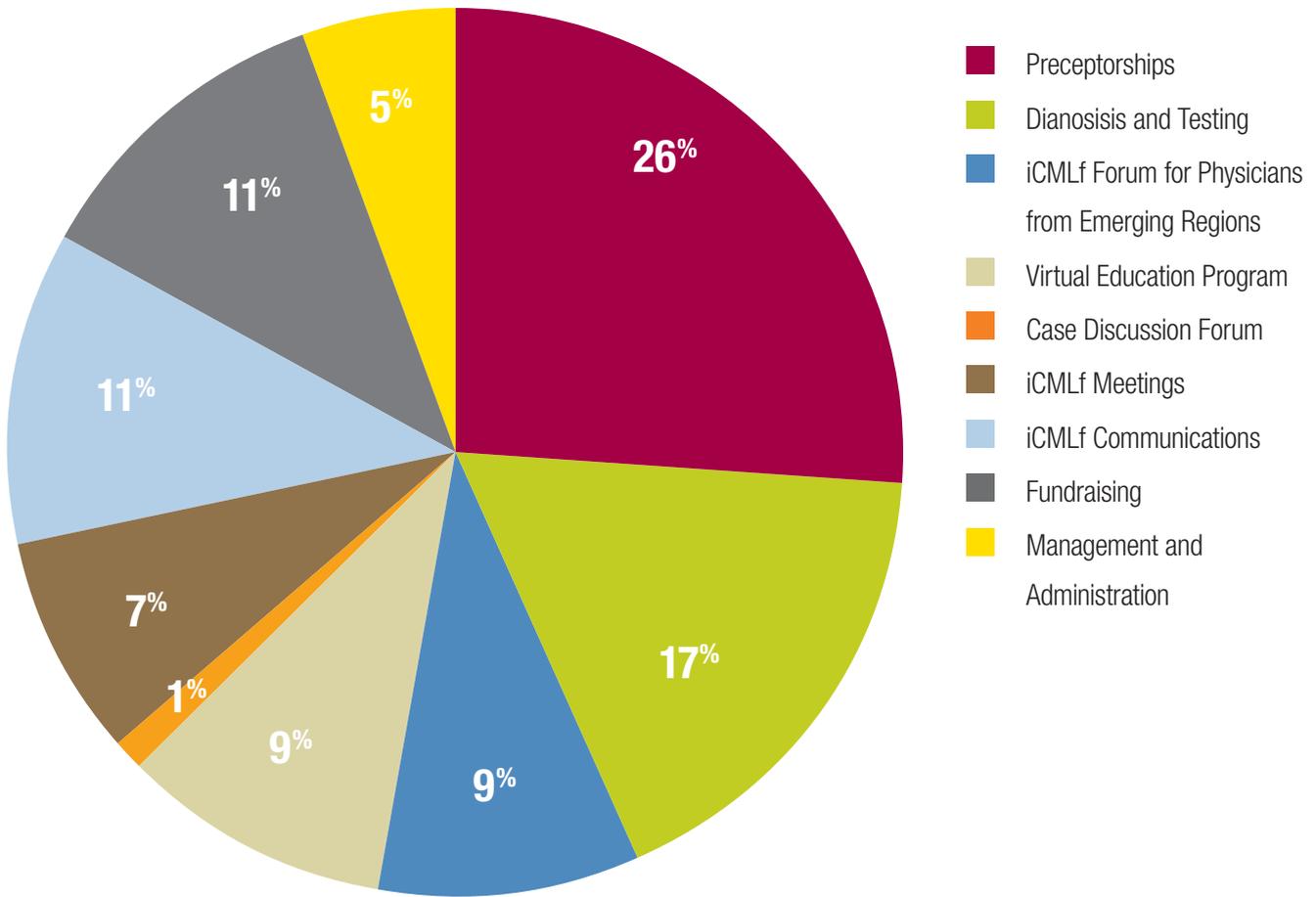
RAISING MORE THAN

**\$3,400**

We thank everyone for your generous contributions to support the work of the iCMLf in this way.

If you would like to donate go to [www.cml-foundation.org](http://www.cml-foundation.org)

### Expenditure Allocation



**75%**

enhances CML education and access to diagnostics



**52%**

supports the management of CML in the emerging economic regions



First allocation for the Genomic Alliance meetings and related fundraising as we prepare 2019 activities of the iCMLf Cure Consortium

## 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.



### THANK YOU TO OUR HOST CENTRES WHO DONATE THEIR TIME AND RESOURCES FOR THE PRECEPTORSHIP PROGRAM

We are eternally grateful for the support that the host sites for the clinical preceptorship program dedicate to their visitors. The impact of the program is immense and would not be possible without the organisation and commitment from the following site leads along with their clinical, laboratory and logistic teams. Thank you for the work that you do.

Jane Apperley, Jorge Cortes, Mhairi Copland, Tim Hughes, François-Xavier Mahon, Michael Mauro, Franck Nicolini, Jerry Radich, Gianantonio Rosti, David Snyder, Juan Luis Steegmann, and Andrey Zaritskey with Elza Lomaia.

## 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.

## Future Planning

**///** *There are currently estimated to be over 800,000 CML patients globally. CML is predicted to become the most prevalent leukaemia by 2040 when there are projected to be over 3 million patients worldwide. A concerted global effort working towards a cure is imperative. The iCMLf is uniquely positioned to drive this effort.* **///** Tim Hughes iCMLf Chairman

### Minimal Residual Disease Consortium – iCMLf CURE Program

Despite the excellent progress we have made in managing patients with CML, major challenges remain. Even with our current choice of 5 tyrosine kinase inhibitors (TKIs), 15-20% respond poorly to TKI therapy and half of these patients will die from CML-related causes. Among those who respond well, less than 25% are able to stop therapy and remain in remission with current approaches. To optimise outcomes for CML patients we need to bring CML management into the precision medicine era.

Cure may mean different things to different people, but the aim of the consortium is to invite interested parties to work together on specific projects under the banner of 'cure'. This iCMLf program will be known as the "iCMLf Consortium Understanding Residual disEase (CURE) Program".

### Step 1. The Genomic Alliance

We aim to harness the wealth of genomic information that is generated in local CML research projects by building a platform to facilitate data assimilation and samples exchanges. Combining many data sets and facilitating global collaborative studies will enable us to develop a baseline predictor of adverse outcomes.

**PHASE I:** Global survey of current CML genomic studies and resources - Complete

**PHASE II:** Scope to be discussed at a workshop of genomic alliance members, during ASH 2018

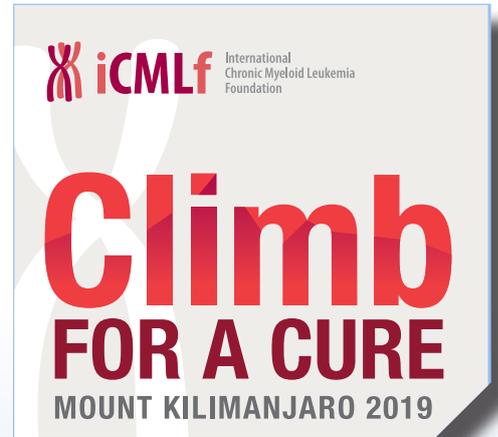


### Funding

To directly fundraise for the iCMLf CURE Program and mark the 10 year anniversary of the Foundation we are climbing Mt Kilimanjaro in 2019. Join us!

**Mount Kilimanjaro  
can be climbed.**

**CML can be cured.  
You can be part of it.**





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

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