



ANNUAL REPORT

2016-17

IMPROVE EDUCATION • INCREASE DIAGNOSTICS • ENHANCE SURVIVAL

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“*My clinical judgement has been better helped by the preceptorship. What to do and when has been of help in better care of our patients. Also having access to the CML international community, regular updates on practice is helping in doing what is best for the patients.***”**

Dr Durogbola, Nigeria (Glasgow)

Welcome from the Chairman

How do we make a difference? As a not for profit, with a large international mandate, but a small budget how do you select the right areas to focus on to make a significant impact to the lives of people with CML around the world? Especially when the challenges vary from no access to therapy, to limited resources and therapies, through to all potential resources being available.

The fundamental way to make difference is to increase access to life saving therapies. We know that we do this through increasing access to CML diagnosis and monitoring through the iCMLf diagnosis and testing projects. Time after time physicians report on how many of their patients were able to be tested, receive therapy, or switch therapy because of the iCMLf funding.

For those that have access to therapy, we know we make a difference by supporting access to the best possible clinical practice. Our clinical preceptorship program and iCMLf Forum do this directly, discussing the specific challenges and situations for low and middle-income countries. This overlaid with our extensive and expanding online content means that the CML expert presentations and opinions are more accessible to more people than ever before.

And what if you have access to all the therapies and the best possible clinical care? We make a difference by continuing the research, continuing the science, searching for a cure. That is where the John Goldman meeting comes in, bringing the best minds in CML together, striving to make a difference.

I am confident to say that the iCMLf does make a difference, and thank you as our members, supporters, partners and community for helping us.



TIM HUGHES
iCMLf Chair

Chief Executive's Overview

In 2015 we titled our annual report - Connecting our global community – and we did, but wow has it grown now! From 13,000 visits to the website per month, to 27,000 per month. From 7,000 views of the expert CML presentations, to 63,000 per year. These increases and the individual feedback we receive from all over the world, illustrate how valuable our global network of clinicians and scientists find our online content. I am immensely proud of the high quality, continuously expanding, information and educational resource we have and the work of the operational team that makes this happen.

Having this online network provides additional support to the physicians involved in the on site iCMLf Programs. This year this includes the 21 clinical preceptors and the 18 centres progressing with iCMLf grants increasing local capacity for CML diagnostics. As one of our preceptors said “I feel like a CML expert is just a click away”.

So this is our goal for next year, continue to expand, continue to improve. Make sure our programs reach the people that need them most and make sure that all people treating CML can feel like a CML expert is just a click away.

A stretch? Maybe, but something to aim for.



Nicola Evans
iCMLf Chief Executive

Governance of the iCMLf

BOARD OF DIRECTORS



TIM HUGHES
Chair
*Royal Adelaide
Hospital, Australia*



JANE APPERLEY
*Imperial College
London, UK*



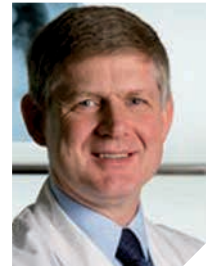
**MICHELE
BACCARANI**
*S. Orsola University
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Italy*



JORGE CORTES
*University of Texas
MD Anderson Cancer
Center, USA*



BRIAN DRUKER
*Knight Cancer
Institute, Oregon
Health and Science
University, USA*



**ANDREAS
HOCHHAUS**
*University Medical
Center, Jena,
Germany*

SCIENTIFIC ADVISORY COMMITTEE

There are 12 members of the iCMLf Scientific Advisory Committee. Members are respected hematologists, scientists and patient advocates who provide advice and support for the activities of the Foundation.

BOARD OF NATIONAL REPRESENTATIVES

The 35 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 needs specific understanding and programs to address local situations.

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
- 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

iCMLf AIMS AND PRIORITIES

Registered as a charitable foundation in England and Wales, the iCMLf has a global charter. Formed by a leading group of hematologists, the aims of the iCMLf are to foster and coordinate global clinical and research collaborations and to improve clinical practice and disease monitoring in CML. There are numerous activities that could come within this broad charter but the initial focus is to meet the needs in CML that are not already being met by other groups, particularly those needs that are best met by a global organisation.



JERALD RADICH
*Fred Hutchinson
Cancer Research
Center, Seattle USA*



**CHARLES
SCHIFFER**
*Karmanos Cancer
Institute, Detroit, USA*

OPERATIONAL TEAM



NICOLA EVANS
Chief Executive



JAN GEISSLER
*Communications
Manager*



**MELISSA
DAVIS-BISHOP**
*Emerging Regions
Support and
Partnership Programs
Coordinator*



**STEFANIE
BOCKWINKLE**
Editor

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

The iCMLf Forum for Physicians from Emerging Regions

Once again during ASH, physicians came from all over the world to discuss specific challenges treating CML in low and middle-income countries.

A PARTNERSHIP PROGRAM WITH



Professor Brian Druker opened the Forum speaking about 'Meeting the new challenges in CML therapy'.

'MANAGING THE HIGH RISK CML PATIENT' WITH SPECIFIC PERSPECTIVES FROM INDIA AND BOTSWANA

TOPICS INCLUDED



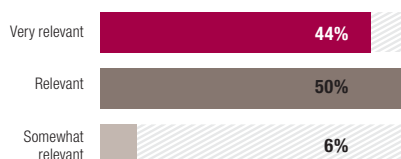
Frontline therapy challenges
Professor Tapan Saikia (India)
Professor Andreas Hochhaus (Germany)



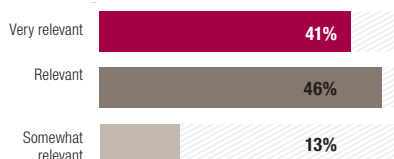
Comorbidities when managing CML
Dr Anthony Oyekunle (Botswana)
Dr Delphine Réa (France)

RELEVANT AND PRACTICAL PRESENTATIONS

How relevant were the following topics to your practice?



Comorbidities when managing CML



Frontline therapy challenges

More than
80 physicians attended
100% found the Forum valuable

All webcasts of presentations are available on the iCMLf website.

Physician education supported by the Goldman Fund

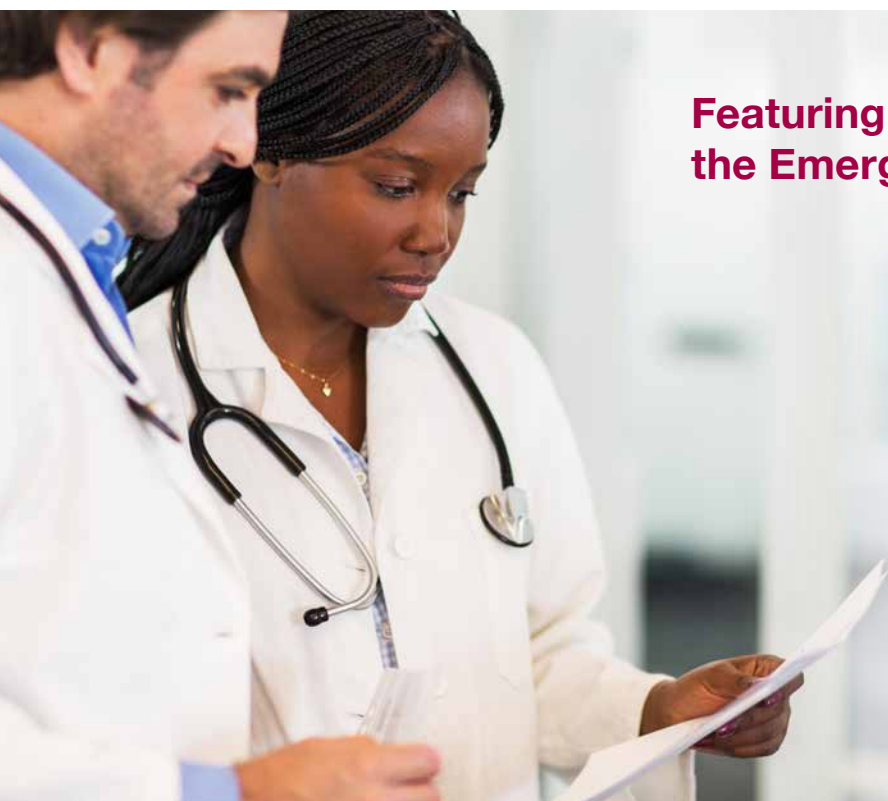
Since 2015 the fund has supported physicians from low and middle income countries to attend the John Goldman conference to present their work, have the opportunity to strengthen research networks and learning.



Dr Zaidi with Nicola Evans, Chief Executive of the iCMLf in Houston

“ I thank iCMLf for providing me the opportunity to participate in the 18th John Goldman Conference. I got a chance to listen to international experts, to see what approaches they are following and how they are managing their patients. This meeting has greatly enhanced my knowledge on CML and given me so many new ideas to better help my patients in home town, both from the diagnostic and the management point of view. **”**

Dr Uzma Zaidi, Karachi, Pakistan



Featuring key CML publications from the Emerging Economic Regions

As part of our commitment to support and promote clinicians and research in low and middle-income countries, the iCMLf launched a new section of the website that features key CML publications from these regions.

You will find interesting articles on CML that have been published in peer-reviewed journals in;

- Middle East,
- Africa,
- Asia and
- Latin America.

Access the new ERSAP Publications at
www.cml-foundation.org

Personalised, CML focused, educational preceptorships

The long-standing iCMLf Clinical Preceptorship Program provides the opportunity for physicians from emerging economic regions to undertake intensive, personalised, education at a global CML centre of excellence.

21
Preceptorships
2016/2017



67
Applications in 2017



“ *It's a once in a life time opportunity to experience hematologic/HCT center in developed country. It will help physician from developing country to understand international guidelines, and the current ideal way to manage patients.* **”**

Dr Amrita – Indonesia (City of Hope)

DATA FROM POST-PRECEPTORSHIP SURVEY

Quality of preceptorship to improve clinical knowledge of treatment of CML

92.3%

Overall preceptorship experience

84.6%

Recommend to colleagues

100%



Prof. Hughes with Dr Gundeti during an Adelaide preceptorship

“ *I have learnt new treatment strategies for CML patients and we can implement this in our clinic.* **”**

Dr Hakobyan, Armenia (St Petersburg)

6 MONTH REPORT DATA

- **100%** agreed that their preceptorship was still beneficial.
- **100%** were able to share the knowledge they had gained from their preceptorship with their colleagues.
- **63%** maintained contact with their host site.

Access to therapy through testing

30 patients from PGH had blood samples shipped to Australia for PCR and mutation analysis

8/12

patients with mutations have been able to access second and third line new TKIs

2

patients with high BCR-ABL quantitative values also accessed next line TKIs

Sadly, 2 patients passed away before accessing new therapy.



A partnership project between Touched by Max in the Philippines, the Philippine General Hospital (PGH) and the iCMLf.

GRANTS TO BUILD LOCAL CAPACITY FOR CML DIAGNOSTICS

2015 – 9 centres now completed 12 months

Grants cover:

- 4x GeneXpert machines
- 2x Supplying GeneXpert kits
- 1x Laboratory standardisation
- 2x Sample shipping
- 1x Laboratory staff training
- 1x Supporting physician education
- 1x Patient education sessions

“The GeneXpert PCR machine has been installed and we are now able to test, diagnose and monitor our CML patients in the hospital at a much reduced cost and less stressful to the patients.”

Dr Ukoma, Nigeria

2016 – 9 centres progressing

Grants cover:

- 1x GeneXpert machine
- 5x Supplying GeneXpert kits
- 3x Consumables for PCR
- 2x Laboratory staff training
- 2x Supporting physician education
- 1x Patient education sessions

Number of patients able to access CML testing due to the iCMLf funding*

	Site 1	Site 2	Site 3	Site 4
In the last 6 months	50	140	8	42
In the next 6 months	100	140	50	106

*4 centres have completed 6 months

“The major goals for the first phase which included development of a registration software, establishment of CML patients database and establishment of diagnostic services for CML patients have all been achieved in time.”

Dr Taj, Pakistan

Global programs impact CML education

“ I have applied MD Anderson's guidelines on our patients in Vietnam to help them more aware of the disease and compliance with treatment. **”**

Dr Dung, Vietnam (MD Anderson)



“ We started offering the Bcr-Abl testing at the new subsidised rates early this year and we have seen a fourfold increase in the number of patients tested, in fact we have even surpassed the number of patients we tested last year. **”**

Dr Githaiga, Kenya

12 CML CENTRES OF EXCELLENCE

- Australia** + The Centre for Cancer Biology and Royal Adelaide Hospital, Adelaide
- England** + Hammersmith Hospital, London
 - + Paul O'Gorman Leukaemia Research Centre, Glasgow
- France** + Centre Hospitalier Universitaire (CHU) de Bordeaux, Bordeaux
 - + Centre Hospitalier Universitaire des Hospices Civils de Lyon, Lyon
- Italy** + S.Orsola-Malpighi University Hospital, Bologna
- Russia** + Almazov Federal Centre of Heart, Blood and Endocrinology, St Petersburg
- Spain** + Hospital Universitario de la Princesa, Madrid
- USA** + The University of Texas MD Anderson, Cancer Center, Houston
 - + Memorial Sloan-Kettering Cancer Center, New York
 - + Fred Hutchinson Cancer Research Center, Seattle
 - + City of Hope, California

on, access to diagnostics and therapy

“ The grant has been of great help to our patients, thanks to it in some cases it has been possible to determine the need of dose change and in other cases therapy change, which directly influences in the prognosis of patients. **”**

Dr Duarte, (Honduras)



“ We will be able to improve the treatment monitoring, which will help us greatly improve the life quality of patients. Attending this training is a step forward to introducing qRT-PCR for detecting BCR ABL gene method in Mongolia. **”**

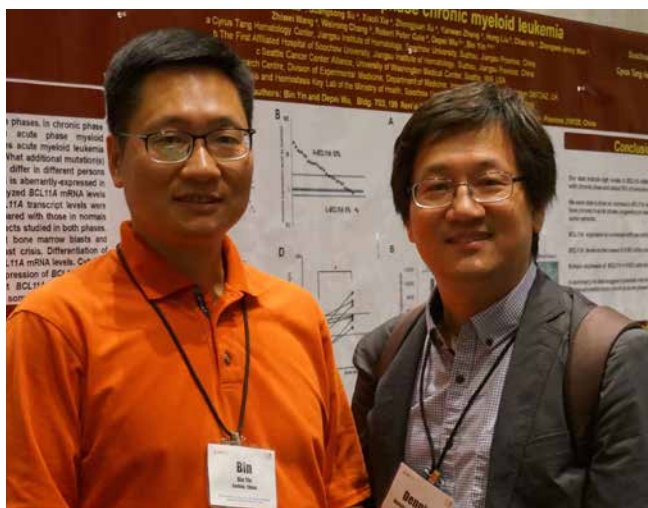
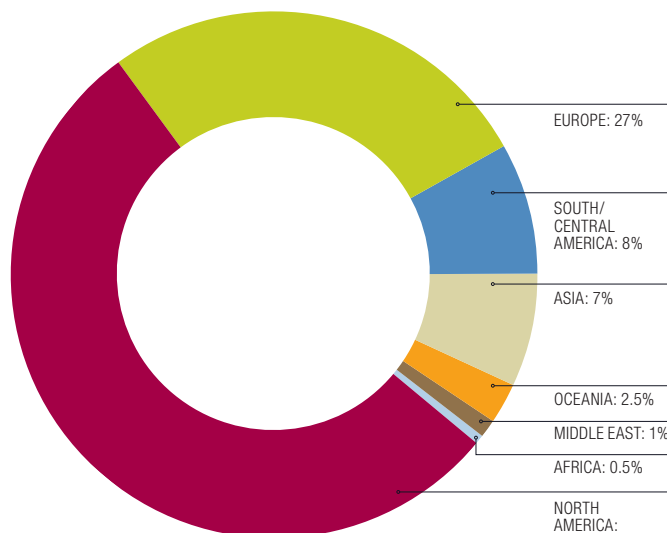
Dr Otgonbat (City of Hope)

- Diagnosis and Testing Grant recipient
- Preceptorship Program participant

18th John Goldman Conference on CML



380 clinicians and scientists from 33 different countries



Comprehensive CML focused program:

The various scientific sessions covered a broad range of topics from both the clinical and the biological perspective on CML.

“ A packed agenda with a good mix of science and clinical sessions. **”**



“ Lots of experts and all the CML thought leaders are around here – a great opportunity to catch up. **”**



Recognising excellence in CML biology and management

During the annual John Goldman Conference the iCMLf was very pleased to award the 2016 iCMLf prizes.



ROWLEY PRIZE

**Professor John Groffen and
Professor Nora Heisterkamp**

"The iCMLf Rowley Prize is designed to celebrate persons who made outstanding contributions to the understanding of the biology of CML." "Both scientists are recognized for their roles as co-discoverers of the genes that are directly involved in the 9:22 Philadelphia translocation found in CML."

"The discovery of these genes is a historical milestone in CML research"

Professor Ravi Bhatia awarding the Rowley Prize to John Groffen and Nora Heisterkamp



GOLDMAN PRIZE

Professor Hagop Kantarjian

"This second iCMLf prize is for people who have done an outstanding job in the clinical research for CML." "This year we had several nominations for this award but the selection was easy because Professor Kantarjian has helped so many patients with CML and other leukemias through his research and through all the thoughtful discussions that make us think into different directions."

"It really gives me great pleasure to award the iCMLf Goldman Prize to my friend and my mentor who supported me in my career and so many others through his outstanding leadership."

Professor Jorge Cortes awarding the Goldman Prize to Hagop Kantarjian



iCMLf PRIZE

Associate Professor Susan Branford

"This third prize reflects the true goals of the iCMLf to achieve better outcomes for patients worldwide." "Sue Branford has done an amazing work in getting PCR technologies up and working to all parts of the world. She has also taken over the task to provide standardization services to many centres in the world with huge dedication."

"Sue is an incredibly worthy winner of the iCMLf prize because she performs beautiful science, she is masterly in her communication skills and she showed sincere humanity and generosity."

Professor Tim Hughes awarding the iCMLf Prize to Sue Branford



Website – Fact and Figures

www.cml-foundation.org

 MORE THAN
27,000
Visitors per month¹

 MORE THAN
519,000
page impressions
per month¹

TOP 5 MOST VISITED PAGES:

- 1 Clinical Case Discussion Forum
- 2 iCMLf Forum for Physicians from Emerging Regions
- 3 Scientific news CML
- 4 Clinical Preceptorship Program
- 5 Virtual Education Program

 **52%**
of visiting countries are
from the Emerging Regions²

 **81**
Visitors from
various Countries²

“ Thank you a lot for these regular
announcements they help to follow
the CML news. **”**

EC, Russia

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

Monthly iCMLf News Services

medwireNews

From April 2016 – April 2017 the iCMLf offered a monthly news service covering latest advances from key CML publications written by medwireNews, Springer health's independent news bureau. We thank Novartis Oncology for supporting this initiative with an educational grant.

Top 3 stories:

- STIM1 findings confirm safety of controlled imatinib discontinuation
- EURO-SKI confirms TKI discontinuation 'feasible' for selected CML patients
- 'Promising' CML phase I results for ABL001 BCR-ABL inhibitor

 **14,704**
Total summary views

Clinical Case Discussion Forum



14 cases posted



26 physicians contributed cases and replies



647 average views per case



MORE THAN

9,000 case views

MOST FREQUENTLY VIEWED TOP 3 TOPICS:

- 1 Is this CML or PH⁺ AML?
- 2 Ponatinib dose for pediatric patients
- 3 Triple mutation in ABL1 kinase domain –RX?



Virtual Education Program

ADDITIONAL MODULES IN 2016/17



**Mutation screening:
What is standard
of care today and
the role of new
modalities**

Dr Simona Soverini



**Molecular monitoring
in CML – getting to
a safe place**

Dr Martin Müller



**Biomarkers and
response monitoring
beyond PCR?**

Dr Deborah White



**The role of
cytogenetic
monitoring in CML
management**

Prof. Jorge Cortes



**Treatment outcomes
on Bosutinib: Data
from the real world**

Prof. Jane Apperley



**Factors affecting
clinical decision
making in refractory
and relapsed
CP-CML patients**

Dr Delphine Rea



**How to treat
CML in 2017?**

Prof. Andreas Hochhaus



More than

63,000

web streams viewed
(sources: pages hits)

Expert interviews: Personal perspective on CML

ASH 2016 perspectives from:



Dr Fabio Efficace
(472 views)



Prof. Jorge Cortes
(371 views)



Associate Prof.
Susan Branford
(242 views)

EHA 2017 perspectives from:



Prof. Jerald Radich
(113 views)



Prof. Tim Hughes
(177 views)

Time Poor?



Every month iCMLf Chairman, Professor Tim Hughes, selects key, newly published scientific and clinical papers to help the iCMLf community keep up to date with the latest ideas and data.

E14a2 BCR-ABL1 transcript is associated with a higher rate of treatment-free remission in persons with chronic myeloid leukemia after stopping tyrosine kinase inhibitor therapy.

Claudiani S. et al. Haematologica, May 2017



Assessment of imatinib as first-line treatment of chronic myeloid leukemia: 10-year survival results of the randomized CML Study IV and impact of non-CML determinants.

Hehlmann R et al. Leukemia, August 2017

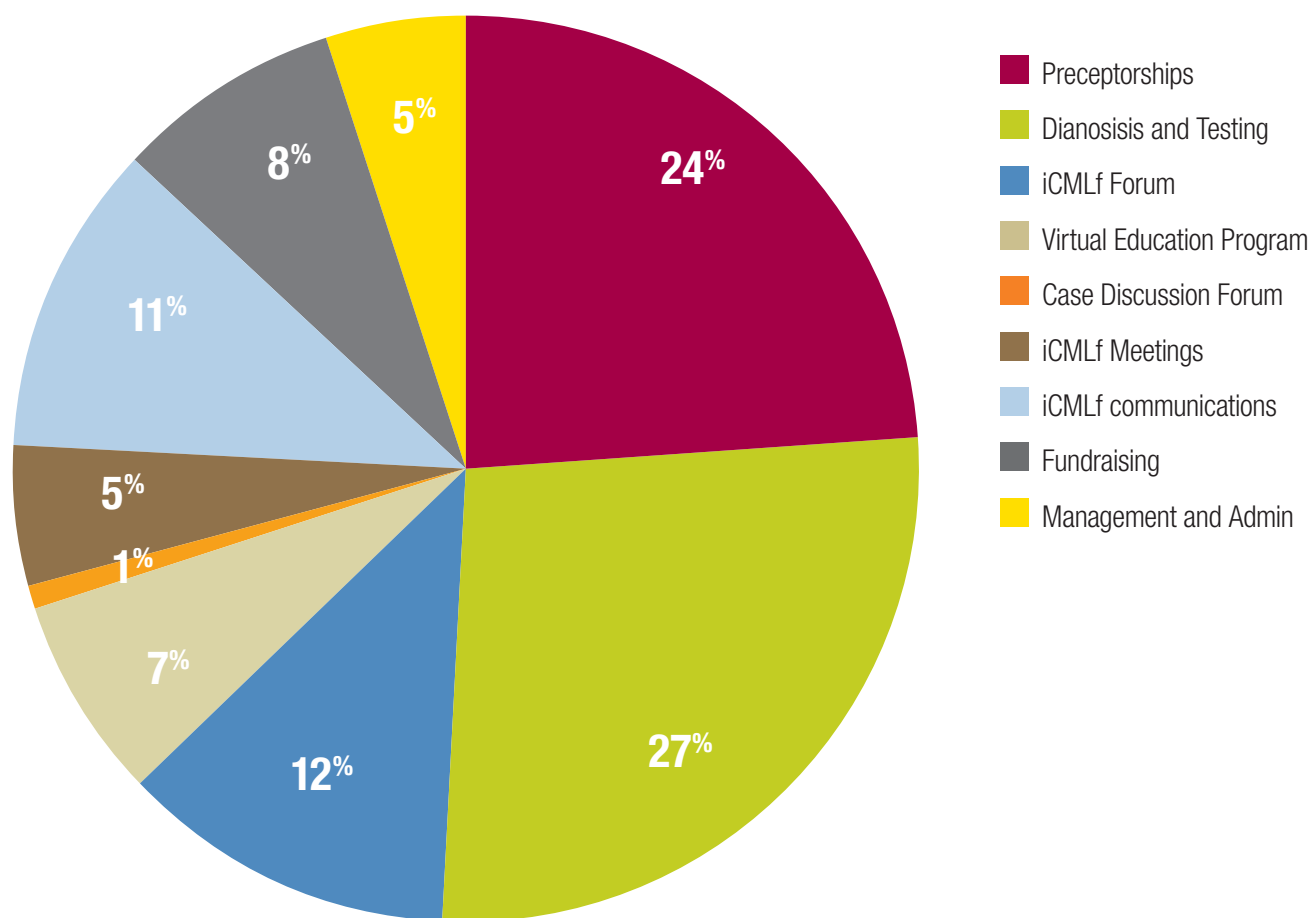
The complexity of growth failure in children receiving tyrosine kinase inhibitor therapy for chronic myelogenous leukemia.

Samis J et al. Pediatr Blood Cancer, July 2017

Overall survival with ponatinib versus allogeneic stem cell transplantation in Philadelphia chromosome-positive leukemias with the T315I mutation.

Nicolini FE et al. Cancer, April 2017





87%

goes towards enhancing CML education and access to diagnostics



63%

directly to support the management of CML in the emerging economic regions



25%

supports online CML education for our global community

Thank you!

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.



* Premium supporters



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.

JOHN GOLDMAN 5 K FUN RUN SUPPORTING THE JOHN GOLDMAN FUND



A special thank you to those who donated to the John Goldman fund for a run T-shirt.

RAISING MORE THAN

\$1,600

to support the training of physicians in the emerging regions.



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

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Bexhill On Sea
East Sussex TN40 1HE
info@cml-foundation.org
www.cml-foundation.org

 **iCMLf** International
Chronic Myeloid Leukemia
Foundation

