



THE INTERNATIONAL  
CML FOUNDATION  
**ANNUAL REPORT**  
**2015-2016**



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“The 14 patients diagnosed within the project year represents an improvement in CML diagnosis (compared to 5 patients in 5 years) at our centre. We lost 2 of the 14 patients diagnosed (we think owing to delays in diagnosis) but still although the numbers diagnosed under the project are small, the 12 surviving CML patients would not have survived without timely diagnosis that was made possible by this grant.”

Dr Molombe, Malawi  
(iCMLf grant recipient)

## Chairman's Reflection

### Every now and then you meet a person that has a profound impact on you for one reason or another.

We would like to take the opportunity to share the story of a CML patient advocate from Niger, who did just that for the iCMLf this year. Boukary Abdoul Nasser contacted the iCMLf for one of our Diagnosis and Testing grants in July 2015. His motivation was clear as he outlined the need for PCR in a country that had no access to this for CML patients. He saw the grant as a way to purchase a GeneXpert machine and bring PCR testing to Niger and more specifically the CML patients in the advocacy group he formed.

On learning that a clinical lead was also required for the grant to move forward, Boukary engaged his physician, Dr Andia. The proposal was promptly written, reviewed and granted. Even with the preferential price agreement through The Max Foundation, the iCMLf grant of \$10,000 is not enough for a GeneXpert machine and the cartridges required to begin testing. Of course, shortly thereafter, we received word that the additional funds had been raised and they were ready to receive the equipment in Niger. In addition, we were also able to secure Dr Andia place on the iCMLf clinical preceptorship program with Professor Nicolini in Lyon. The preceptorship will enable Dr Andia to complete his training on the GeneXpert machine and up date his CML knowledge.

This is a perfect example of how the network of the iCMLf programs link together to support access to therapies through diagnostics and education.

In January the iCMLf called for nominations for the 2016 iCMLf prize. This annual prize recognises outstanding contributions to improving the management of CML in the emerging economic regions. Friends and colleagues both local and international nominated Boukary Abdoul Nasser. It quickly became apparent the admiration and respect his work had generated amongst his community and this soon spread to the iCMLf Directors and Advisors learning of his work.

As we came to write the overview of the year for the iCMLf we learnt of the death of Boukary Abdoul Nasser in July. We extend our sympathy to his family and the CML advocates who knew and loved him. His dedication, passion and ability to motivate others will be missed. However his memory will surely live on through the lives he has saved by bringing PCR to Niger.

For us, although we did not know him personally, Boukary Abdoul Nasser is a reminder of why the iCMLf exists, why we do what we do and why we need your support to do it.

Vale Boukary Abdoul Nasser and thank you.



**“ NIGER is a country who knows the great difficulties in the management of patients with chronic myeloid leukemia. In fact these patients were left to themselves without any care, without medicine and medical examinations of patient monitoring. And the number of patients continues to increase. However, since August 2011, a person took in hand the problems of CML patient in the poorest countries.**

**This is Mr. ABDOUL NASSER BOUKARY, personality full of talent and imagination. He first undertook sensitization campaigns on CML. Indeed it is the first person in this country to come out in the media to raise awareness about CML. ”**

*(One of the many iCMLf prize nominations for Boukary Abdoul Nasser)*

Tim Hughes  
iCMLf Chairman

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  
Hospital, Bologna, Italy*



**JORGE CORTES**

*University of Texas MD  
Anderson Cancer Center,  
USA*

## Scientific Advisory Committee

# 12

There are twelve 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 needs specific understanding and programs to address local situations.

The mission of the iCMLf is to improve the outcomes for patients with CML globally



**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*

## OPERATIONAL TEAM



**NICOLA EVANS**  
*Chief Executive*



**JAN GEISSLER**  
*Communications  
 Manager*



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



**STEFANIE BOCKWINKLE**  
*Editor*

## 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.

## 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



# Practicalities Managing CML – perspectives from around the world



The 2015 iCMLf Forum for Physicians from Emerging Regions was opened by Professor Tim Hughes and moderated by Pat Garcia-Gonzalez (CEO of The Max Foundation).

Presentations focused on three topics highly relevant for regions with limited resources. Following each presentation a member of the iCMLf scientific advisory board provided their personal and global perspective on the topic.

### 1. Managing children with CML

Dr Deepak Bansal, India,  
Dr Meinolf Suttrop, Germany

### 2. Practicalities treating CML with generic therapies

Dra Carolina Pavlovsky, Argentina,  
Dr Jeff Lipton, Canada

### 3. Challenges continuing long term CML therapy

Dr Qian Jiang, China,  
Dr Michael Mauro, USA

After each presentation there were intensive discussions with the panel of experts and the audience and many questions raised about the considerable challenges of treating CML in countries with low resources.



More than **80** physicians from 28 countries attended

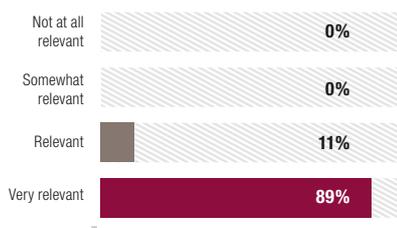
*‘The iCMLf Forum is always a great opportunity to network. While meeting at the Forum the idea was born to run a clinical trial together with one of the iCMLf scientific advisors.’*

*“Liked the sincerity of the people who have everything, yet ready to come to this meeting, pre- ASH”*

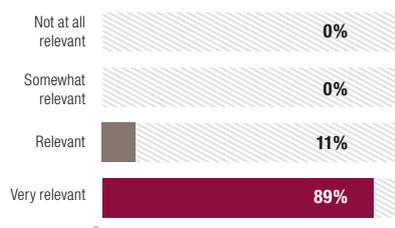
## RELEVANT AND PRACTICAL PRESENTATIONS:

Participants were surveyed as to the relevance and value of the presentations.

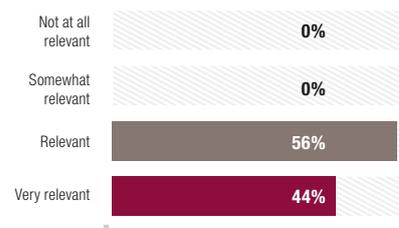
### How relevant were the following topics to your practice?



Challenges with long term CML therapy



Practicalities treating CML with generic therapies



Managing children with CML

The iCMLf Forum for Physicians from Emerging regions is a partnership project with The Max Foundation

# iCMLf Prizes

## RECOGNISING EXCELLENCE IN CML BIOLOGY AND MANAGEMENT

During the annual John Goldman Conference the iCMLf was very pleased to award the 2015 iCMLf prizes including the inaugural ERSAP prize.



### 2015 ROWLEY PRIZE

The iCMLf Rowley Prize is designed to honour persons who have made major contributions to the understanding of the biology of CML.

#### **Richard A. Van Etten**

Professor of Medicine and Director,  
Chao Family Comprehensive Cancer Center  
University of California, Irvine

Recognising his ground breaking research focusing on the development of new therapeutic strategies such as the tyrosine kinase inhibitors.

*"Richard Van Etten is one of the pioneers of murine models in CML"*

Dr Steffen Koschmieder presenting the Rowley Prize to Richard Van Etten



### 2015 GOLDMAN PRIZE

The annual Goldman Prize awarded recognises outstanding lifetime contributions to the management of patients with CML.

#### **Michele Baccarani**

Professor of Hematology at the Universities  
of Trieste, Udine, and Bologna

In acknowledgment of his over forty years of dedication to clinical excellence in the management of CML.

*"This decision was made due to his contributions to clinical practice in CML by developing internationally recognised guidelines and recommendations".*

Tim Hughes, iCMLf Chairman



### 2015 iCMLf EMERGING REGIONS SUPPORT AND PARTNERSHIP PRIZE

The Emerging Regions Support and Partnership Prize will be awarded each year to an individual, or organisation that has made outstanding contributions to the treatment of CML in the emerging economic regions.

#### **Patricia Garcia-Gonzalez**

Chief Executive Officer of The Max Foundation

For her role leading The Max Foundation, and also to recognise the personal passion and motivation that she brings into her work aiming for dignity and hope for all in the face of cancer.

*"Pat well deserved this inaugural ERSAP prize for her tremendous work in granting access to diagnosis and treatment for so many people in the emerging regions"*

Professor Jorge Cortes

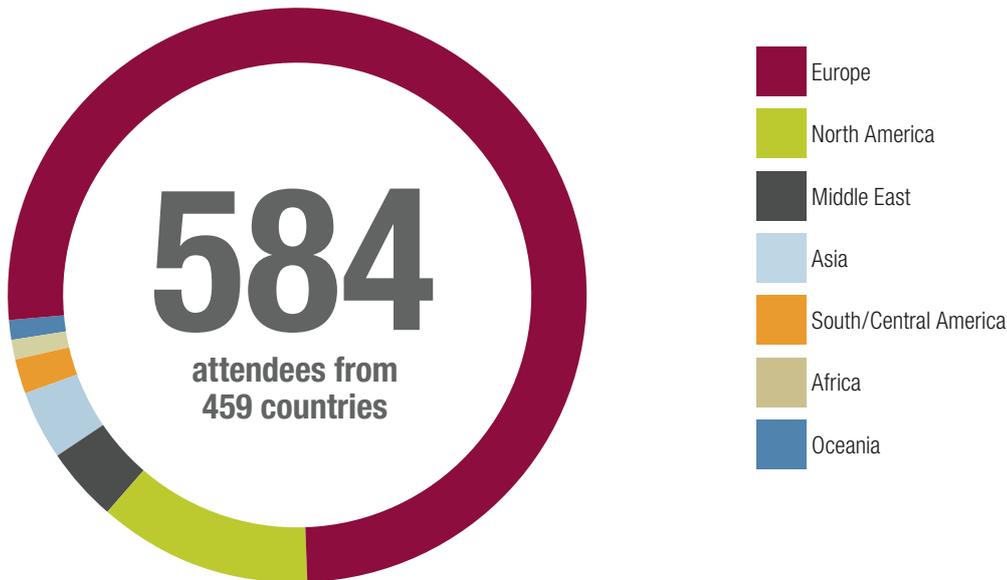


# John Goldman International CML Congress

## 17TH JOHN GOLDMAN CONFERENCE ON CML

From October 1-4, 2015 clinicians and researchers gathered for the 17th John Goldman Conference in Estoril to discuss latest findings in the biology and management of CML. This premier CML meeting is co-sponsored by the iCMLf and the European School of Hematology (ESH).

## PARTICIPANT GEOGRAPHIC COVERAGE



## MEETING HIGHLIGHTS

The top-class scientific program again gave a biological and a clinical perspective during various scientific sessions dedicated to CML only:

**9 SCIENTIFIC SESSIONS:** Topics included; top scoring abstracts 2015, stem cells, autophagy, apoptosis and epigenetics, the biology of blast phase CML, immunology of CML, mechanisms of resistance, new drugs and new targets, monitoring, evolving concepts in safety of TKI and clinical trials

### 2 WORKSHOPS FOR NON-CLINICAL SCIENTISTS:

Topics included: genomic editing and proteomics

### 2 BREAKFAST SATELLITE SYMPOSIA:

Topics included: improving perspectives for patients with CP-CML and value of real-world research advancing patient care and outcomes in CML

### 2 SATELLITE SYMPOSIA:

Topics included; beyond the guidelines: individualising therapy in CML and optimizing treatment of CML in the 21st century

**1 CLINICAL SYMPOSIUM** on modern diagnostics

**1 DEBATE** on discontinuation of therapy

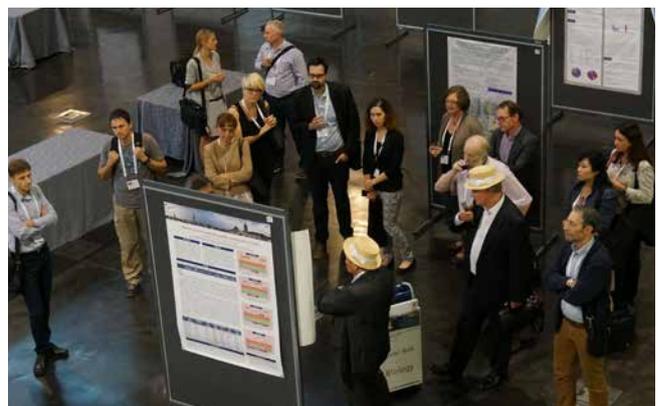
### 5 SPECIAL LECTURES

**3 iCMLf PRIZE** presentations

**181 ABSTRACTS** from 66 scientists

**23 BIOLOGY POSTERS**

**37 CLINICAL POSTERS**



## Clinical Preceptorships



### 23 PRECEPTORS

The iCMLf Clinical Preceptorship Program continues to improve the knowledge and skills of physicians treating CML in emerging economic regions through individually tailored observerships.

During their 3-4 week intensive program, participants are involved in outpatient clinics, hematology ward rounds, seminars, discussion forums and laboratory work to arm them with a practical understanding of the most up-to-date protocols and guidelines to treat CML.

One of the most valued benefits continues to be the close contacts and networks established during their time at the centre which continue to support their needs even after they have returned home.

### PROGRAM OUTCOMES Immediate Benefit



90%

believed that the quality of their preceptorship to improve their clinical knowledge of the treatment of CML was excellent whilst the remainder believed the quality was of good standard.

100%

of participants would recommend the program to their colleagues



76%



rated the overall program excellent; 24% rated it good

### Continuing Progress

#### Six months reported value:



clinic (100%)



colleagues (95%)



patients (100%)



4/5 have maintained contact with their host site and benefited from:

- + sample analysis
- + teaching materials
- + ongoing case discussions

Significant changes include;

- + improved and more regular monitoring
- + earlier intervention for non response or intolerance
- + initiating referral centres
- + information for GPs



## Increasing Access to Education and



*Without the support of iCMLf, I would have never been able to visit a Hospital like Hammersmith.*

*Within three weeks I learnt more hematology than in my three years of residency. Thanks iCMLf for providing me such a wonderful opportunity.*

*Dr Sajid, Pakistan*

*An Xpert BCR-ABL testing system has been set up in Malawi through this project that would not have been possible without this grant. There is room to sustain the availability of this facility to cover every suspected CML patient in Malawi.*

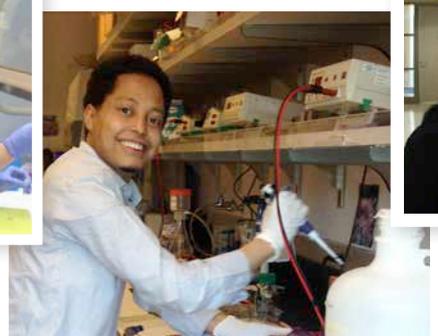
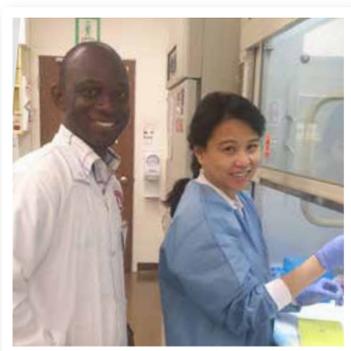
*In all, every part of the program was unique and rewarding. I am now confident and equipped with more vivid knowledge in CML management.*  
*Dr Ezire, Nigeria*

*Increase domestic testing capacity in range and volume by upgrading laboratory equipment; Support laboratory workforce development by training laboratory technicians; Establish a protocol for good quality sample transportation from the referral public hospitals to the laboratory.*

### 13 CML CENTRES OF EXCELLENCE

- America** + 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
- Australia** + The Centre for Cancer Biology and Royal Adelaide Hospital, Adelaide
- England** + Hammersmith Hospital, London
- 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
- Scotland** + Paul O'Gorman Leukaemia Research Centre, Glasgow
- Spain** + Hospital Universitario de la Princesa, Madrid

# CML Diagnosis and Testing Globally



- Diagnosis and Testing Grant recipient
- Preceptorship Program participant



## Increasing global capacity for CML Diagnostics

The iCMLf Diagnosis and Testing Program provides a multifaceted approach to build sustainable local capacity for CML diagnosis and testing in the emerging regions. Ongoing clinical and laboratory mentors ensure the successful outcomes of the projects.

### Projects under this program result in access to therapies through initial CML diagnosis

Grants – seed funding of \$10,000 to build a centres diagnostic capacity through equipment/ consumables, staff training



**8**  
2014 grants closing  
1009 direct tests



**9**  
2015 grants underway  
5 x access to  
GeneXpert machines  
3x initiation of local  
PCR capacity  
5x enhancing current  
monitoring facilities  
1x sample shipments  
for monitoring

**10** 2016 grants to  
be announced in  
September 2016



**28**  
applications from 21 countries.  
13 countries were unique  
applications for funding

### Projects under this program lead to life saving treatment decisions

#### Sample shipments

In 2015 30 blood samples were shipped from the Philippines to Adelaide for mutation analysis. Samples were from patients with established imatinib resistance. Of the 30, 9 were identified with BCR-ABL mutations.

PB Mutation Analysis			Known sensitivity of mutations to kinase inhibitors	Outcome
Nucleotide Substitution	Mutation	% mutated clone		
757T>C	Y253H	95%	sensitive to dasatinib	Recently approved for free access to Dasatinib
1075T>G	F359V	100%	sensitive to dasatinib	Recently approved for free access to Dasatinib
757T>C	Y253H	100%	sensitive to dasatinib	Recently approved for free access to Dasatinib
944C>T	T315I	95%	sensitive to ponatinib	Awaiting drug access approval
757T>C	Y253H	85%	sensitive to dasatinib	Recently approved for free access to Dasatinib
1064A>G	E355G	90%	sensitive to inhibitors except imatinib	
764A>T	E255V	80%	sensitive to dasatinib	Patient passed away
944C>T	T315I	100%	sensitive to ponatinib	Recently approved for free access to Ponatinib
763G>A	E255K	100%	sensitive to dasatinib	Recently approved for free access to Dasatinib

# Online Education Services

**WWW.CML-FOUNDATION.ORG**

The iCMLf website is one of the key worldwide educational online resources for CML.

In 2015/16:



More than  
**19,800**  
visitors per month\*



More than  
**564,700**  
page impressions per month\*



Most frequently visited pages – Top 5 pages

- + Case Discussion Forum
- + Scientific news CML
- + Virtual Education Program
- + Meetings
- + Clinical Preceptorships

## TOP 10 COUNTRIES

- + USA 
- + UK 
- + Germany 
- + France 
- + Spain 
- + Italy 
- + Australia 
- + Brazil 
- + Russian Federation 
- + China 



Visitors from  
**93**  
countries

Visitors from  
**41%**  
Emerging Regions



\*(source: webanalyzer Jan 2016 – July 2016)



# Online Education Services

## VIRTUAL EDUCATION PROGRAM Additional modules in 2015/16



Stopping TKI therapy in chronic myeloid leukemia  
Prof. Francois-Xavier Mahon



Treating pediatric chronic myeloid leukemia – an update  
Prof. Meinolf Suttorp



Perspectives on CML in the emerging regions  
Pat Garcia-Gonzalez

More than  
**160,000**  
web streams viewed  
in English

More than  
**40,600**  
web streams viewed  
in French

More than  
**29,200**  
web streams viewed  
in Spanish

More than  
**200,000**  
web streams viewed  
to date

(sources: pages hits)

## iCMLf ON SOCIAL MEDIA



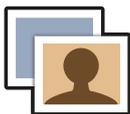
**200**  
followers



**32**  
iCMLf posts



**119**  
likes for  
iCMLf posts



**30**  
shared articles



Social Media (sources: Facebook)

## CLINICAL CASE DISCUSSION FORUM



**11** cases



MORE THAN

**8,000**  
case views



**882**  
average views per case



**27**  
physicians contributed  
cases and replies

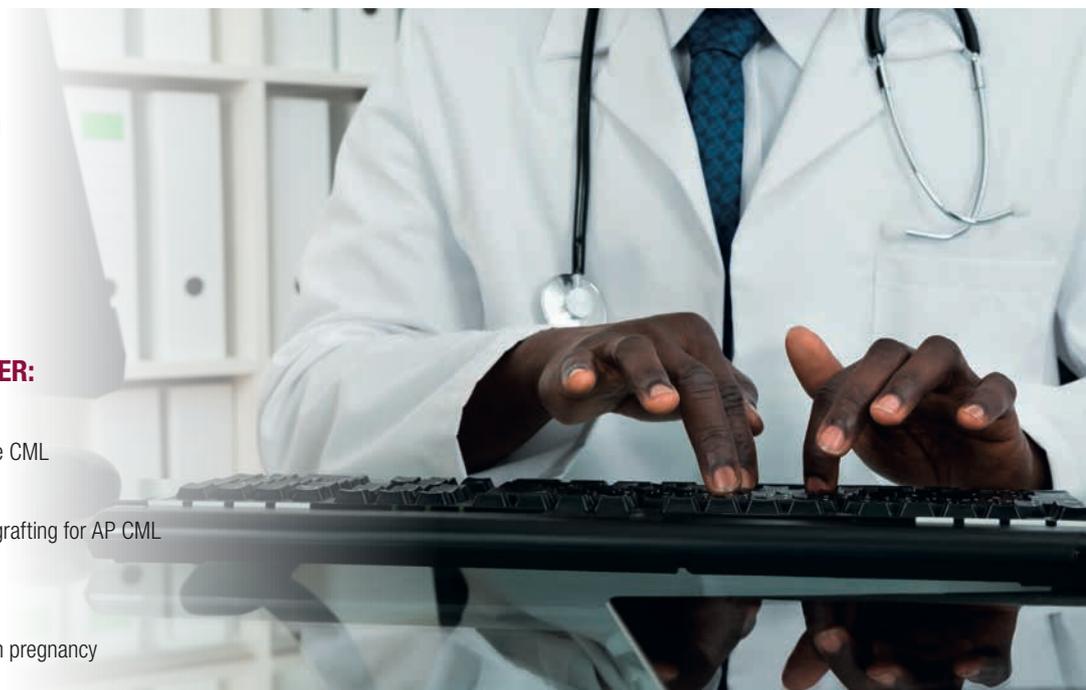
Average number of responses per case 4, with highest number of 11 responses for the case CML and pregnancy

### MOST FREQUENTLY VIEWED TOP 3 TOPICS:

- 1 Pregnancy on 2nd generation TKI
- 2 CML and pregnancy
- 3 CML and MDS 7q-

### OTHER CASES DISCUSSED COVER:

- + Side effect of nilotinib?
- + Pregnancy and accelerated phase CML
- + Adolescent CML case
- + Myeloid sarcoma after stem cell grafting for AP CML
- + Any TKI and breast feeding
- + Isolated CSF blast crisis
- + Comfort level with pulse hydreia in pregnancy



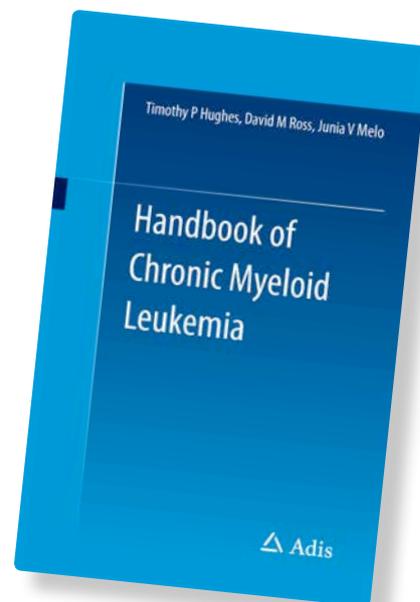
## New iCMLf Educational News Services

In cooperation with Springer Healthcare, the iCMLf launched three new educational services covering the latest clinical and scientific advances in CML.

These initiatives, supported by an educational grant from Novartis Oncology aim to keep the global CML community up-to-date in the fast moving world of CML research and clinical practice.



IME



### HANDBOOK OF CHRONIC MYELOID LEUKEMIA

# 3000

 free PDF eBooks

We thank the authors who donated their writing fees and royalties to support the work of the iCMLf through the 'John Goldman Fund' (see page 17)

### MONTHLY iCMLf NEWS SERVICES

Since April 2016 the iCMLf offers a monthly overview of key CML publications written by medwireNews, Springer Healthcare's independent news bureau.

Top 3 stories from April – August 2016:

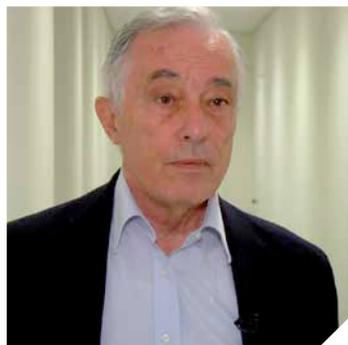
1. CML treatment-free remission criteria outlined: 387 views
2. EPIC results shed light on first-line ponatinib risk-benefit profile: 277 views
3. Additional chromosomal abnormalities prognostic for CML: 261 views

**Total summary views to date: 2,911**

medwireNews

### EXPERT INTERVIEWS AT EHA: PERSONAL PERSPECTIVES ON CML

Three CML experts provide their personal perspectives on latest scientific findings and highlights from EHA.



Professor Michele Bacarani.



Professor François-Xavier Mahon.



Professor Susanne Saußele.

We thank the presenters who donated their honoraria to the John Goldman fund.

# iCMLf Goldman Fund – Supporting young physicians from the emerging regions

The iCMLf has established a special fund in memory of Professor John Goldman for people wanting to give a donation to the foundation in his memory.

**MORE THAN**  
 **50**  
**DONATIONS**

 **2**  
**scientists funded**

 **\$1200**  
**from the Fun Run**

## Aim of the Fund

Training of young CML clinicians and scientists from the emerging regions:

- 1 Attend the annual John Goldman Conference on CML
- 2 Present their scientific work to the CML community
- 3 Provide access to the latest scientific and clinical advances in CML
- 4 Build lasting networks with colleagues from around the world

## YOUNG SCIENTISTS SUPPORTED BY THE FUND IN 2015/16

### Dr Adeagbo Babatunde (PhD)

Country: Nigeria

Position: lecturer at the Faculty of Pharmacy at the Obafemi Awolowo University (OAU) in Ile-Ife (Nigeria)

Poster: 'Pharmacokinetics on imatinib in Nigerians'

*'It was an honour for me to present my data at this well-known conference on CML following in the footsteps of so many renowned scientists and 'big names' such as Professor John Goldman' (Dr Babatunde)*

### Dr Kostyantyn Kotlyarchuk (MD)

Country: Ukraine (Lviv)

Position: Research Associate at the Department of Hematology at the Institute of Blood Pathology and Transfusion Medicine (NAMS) in Lviv (Ukraine)

Poster: 'Pregnancy on chronic myeloid leukaemia – an analysis of 19 cases'

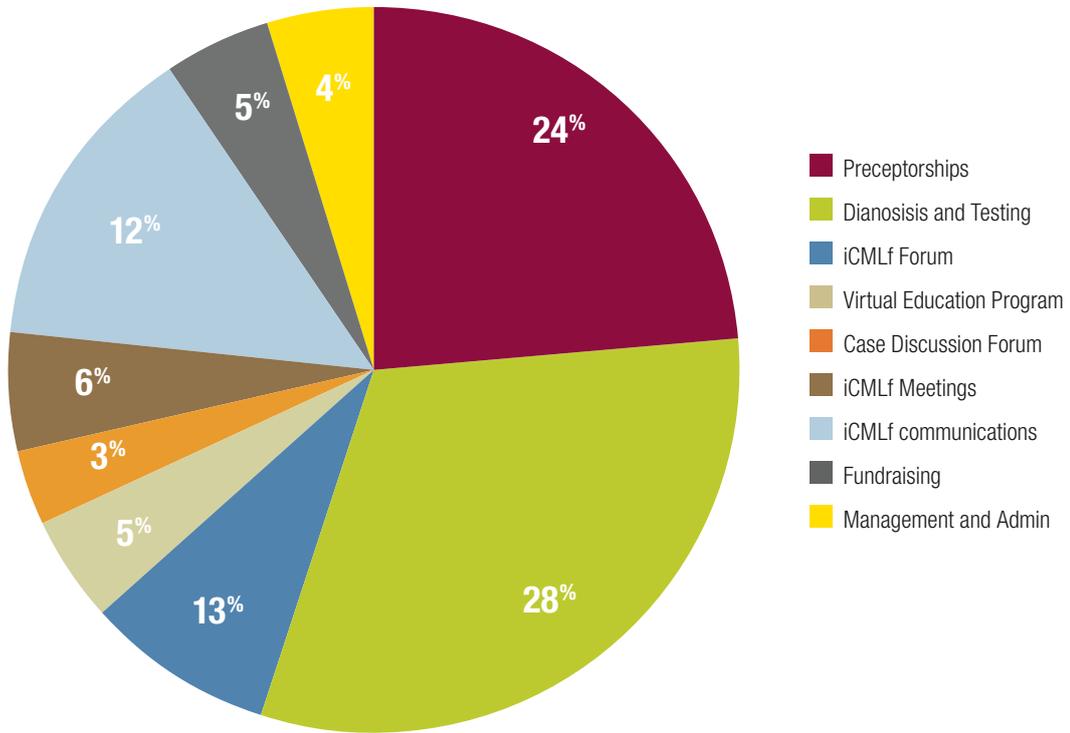
*'I have benefited greatly from the opportunity to spend four days of CML education from top lectures and have brought a lot of new ideas with me on how to further improve CML management at home'*



A special thank you to those who donated to the John Goldman fund. It's thanks to your contribution that the John Goldman Fund comes to life supporting young physicians from the emerging regions. We appreciate every donation that allows us to bring more young scientists to the John Goldman Conference on CML over the coming years.

To donate to the iCMLf John Goldman fund go to the 'John Goldman Fund' page on [www.cml-foundation.org](http://www.cml-foundation.org)

## Financials



**85%**

on programs to increase education and access to diagnostics



**65%**

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

**IMPROVE EDUCATION | INCREASE DIAGNOSTICS | ENHANCE SURVIVAL**

# Thank you!

## GRANTS AND DONATIONS

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. The mission of the iCMLf is to improve the outcomes for patients with CML globally. We thank our corporate partners for their generous contributions that help us achieve this.

### Premium Supporters

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### Major Supporters

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### Other Supporters

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## FRIENDS OF THE FOUNDATION

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

## 'JOHN GOLDMAN FUN RUN' – SUPPORTING TRAINING OF PHYSICIANS FROM THE EMERGING REGIONS



52 participants of the 17th John Goldman Meeting on CML had an early start to the day running with colleagues and friends at the 5 km 'John Goldman Fun Run' along the Estoril promenade. What a start to the day – and all for a good cause! **WE RAISED OVER \$1,200**

Donate to the Goldman fund on the iCMLf website [www.cml-foundation.org](http://www.cml-foundation.org)



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

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