



International
Chronic Myeloid Leukemia
Foundation

**ANNUAL
REPORT
2013/2014**

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“He was one of the key pioneers that paved the way for a revolution in treating CML. Many of us owe our lives to the dedicated, courageous and engaged work of John Goldman in the last 15 years to turn CML from a deadly into a chronic disease.”

Jan Geissler CML Patient Advocates Network

Welcome from the Chairman



This year has been a time of reflection for the iCMLf in many ways. After the unexpected death of our Chairman, colleague and friend Professor John Goldman, we have all been forced to pause and take stock. As tributes flooded in we made plans to honour this great scientist and humanitarian and as this continued it became clearer what John would have wanted in this situation.

We set up the Foundation to be truly global in perspective. This means that we prioritise activities where a global approach is needed – facilitating standardisation of PCR testing globally, ensuring education programs are universally available through our e-education program and many others. From the start John Goldman, Jorge Cortes and I wanted to improve outcomes for CML patients in the emerging regions spreading the benefit of new knowledge, effective drugs and accurate monitoring beyond the developed world. This was our first and is still our highest priority.

As you will read in this annual report we continue to expand the reach and role of the iCMLf exactly as John envisaged. We will continue to honour his work and memory through the well established, but newly titled John Goldman International CML Conference. In addition to the Rowley Prize that we award annually for lifetime achievements in understanding CML biology, the iCMLf will now also recognise outstanding lifetime contributions in the management of CML with an annual 'Goldman Prize'. We have also

established a special 'Goldman Fund' for future projects inspired by John's past commitment. I would like to personally thank M.J. Smith, C. Schiffer, J. Mingo and K. Falconer for their generous donations to this fund. We welcome further donations and look forward to sharing more details of the funds use in the coming 12 months.

Now we have the challenge to continue to build our programs without the benefit of John's wisdom and extraordinary leadership. To achieve this we need to maintain the strong momentum that we have built up over the first five years. John, Jorge and I developed a strong consensus on where we need to go over the next decade. Fortunately I have the support of an excellent executive team lead by Nicola Evans as well as our dedicated Directors and Scientific Advisors.

In February we welcomed Professor Jane Apperley to the iCMLf Board of Directors and with myself as iCMLf Chair, we look forward to what is next for the Foundation, knowing that we can build on the work done so far under John's guidance, knowing we can do more to change the way CML is managed around the world, just as he would have wanted.



TIMOTHY HUGHES
iCMLf Chair

Chief Executive's Overview



The fundamental strength of the iCMLf is the people who are part of it. The iCMLf Directors, Advisors and National Representatives are all leaders in the field of CML. It is through the commitment of these people and their centres that we can provide the outstanding educational programs, discussion and guidance for CML

physicians globally. One of the key challenges of the iCMLf is to make sure this knowledge reaches all places in the world while still addressing the multiple differing situations in the places that need most assistance to improve CML treatment.

This year visitors to the iCMLf website came from 80% of all countries around the world. With 130,000 page impressions per month and over 24,000 visitors per month the iCMLf website goes a long way to achieve a global reach. In 2013/2014 we launched a new easy to navigate site, providing access to up to date CML publications, meeting content, expert opinions and CML presentations. Cases in the interactive online Clinical Case Discussion Forum have had over 16,000 views this year.

This global web platform is balanced by the specificity of the iCMLf's programs to improve management of patients in emerging economic regions.

More than 100 physicians attended the iCMLf Forum for physicians from Emerging Regions at the annual ASH meeting last year. This is a unique meeting for these physicians to share experiences and practical solutions at overcoming limited resources. With 22 personalised preceptorships at CML centres of excellence the iCMLf Clinical Preceptorship Program continues to have far reaching and long-term impact on the management of CML.

It is so pleasing to see that the iCMLf can make a huge difference to the treatment of CML. Centres that could previously only offer testing by sending blood to other countries at a cost of hundreds of dollars can now, confirm CML diagnosis locally and offer regular monitoring along with well rounded support and care for their patients. This is directly due to the education, partnerships and funding from the iCMLf. It is hard to overestimate what that can mean for those patients, their loved ones and the physicians who treat them. Thank you for making this possible, not only to our sponsors, supporters and partners, but also to the physicians we work with who inspire us to continue.



NICOLA EVANS
iCMLf Chief Executive

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

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

Governance of the iCMLf

BOARD OF DIRECTORS



TIMOTHY 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

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

To ensure global influence and representation for the iCMLf, physicians from countries on all continents have agreed to become national representatives of the iCMLf.

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.



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, 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

Personalised, CML focused educational preceptorships



22 preceptors undertook the program at 11 CML Centres of Excellence.

The iCMLf Clinical Preceptorship Program provides the opportunity for physicians from emerging economic regions to undertake intensive education over 3-4 weeks at a global CML centre of excellence.

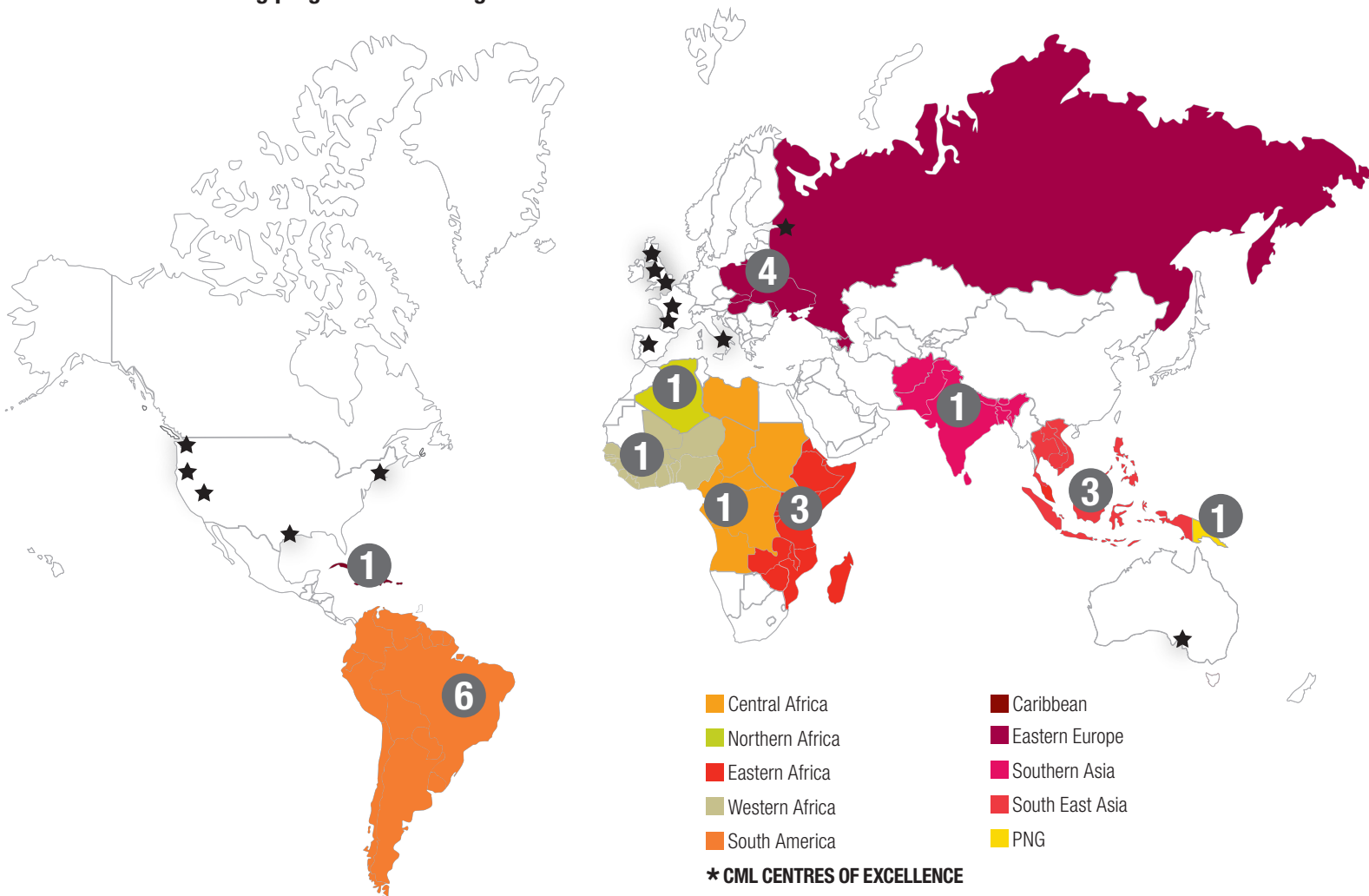
During this observational program preceptors participate in out-patient clinics, hematology ward rounds, seminars, discussion forums and laboratory work as appropriate. They leave with a solid understanding

of the most up-to-date protocols and guidelines to treat CML. The network of CML contacts is long lasting, further benefiting the participating site.

The uniqueness of this iCMLf program is not only that it is solely focused on CML, but also that each program is individually tailored to the needs, experience and resource of the visitor. This directly reflects and addresses the individual challenges faced.

FIGURE 1. NUMBER OF PRECEPTORS PER REGION IN 2013/14

A wide reaching program with lasting results

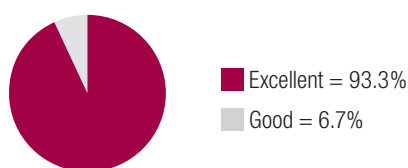


CONTINUING EVALUATION

Preceptors are surveyed on completion of the program and again after six months. These surveys demonstrate tangible results that are seen on a clinicians return home and have far reaching long term effect on clinical practice and patient care.

Immediate Impact

Overall rating of the program



Potential to improve clinical knowledge of the treatment of CML.



Long-term benefit

After six months do you still view your iCMLf Preceptorship as beneficial?

Participants answering yes

a) for you	100%
b) for your CML clinic	100%
c) for your colleagues	100%
d) for your CML patients	100%

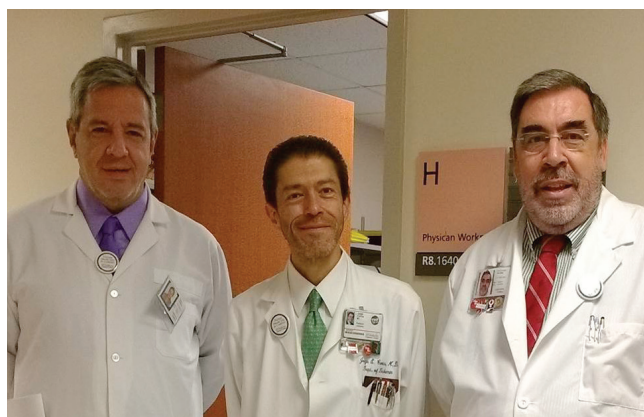
"I have been using BCR:ABL quantitative assay and cytogenetic study more frequently now to monitor CML treatment after the preceptorship. Due to this practice, I have been picking up suboptimal responses requiring mutation analysis and change in the treatment plan."
Dr Patel, India

Seeing the improvement of the management of CML through this valuable iCMLf educational program is immensely rewarding. We look forward to this continuing in 2015.

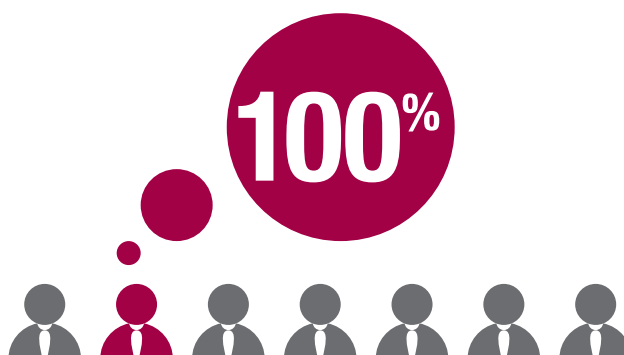
"Just in the week upon my return, I was able to see the difference this training was having in my daily medical activities and my colleagues that were aware of this new training started referring CML patients to my clinic for better management."

"My patients will benefit a lot from this program because, not only I know more about the disease but I am now connected with a few experts who are willing to advise me on patient management if needed."

"I am confident that this course will mark a turning point in my practice and I take this opportunity to thank the Foundation for allowing me to attend this program." Ruth Damuse, Haiti



Drs Novoa and Teixeira with Jorge Cortes during preceptorships at the MD Anderson.



100% of participants would recommend the iCMLf Clinical Preceptorship Program to their colleagues

The iCMLf Preceptorship Program is part sponsored by Pfizer.

Working towards equal access to CML diagnostics around the world

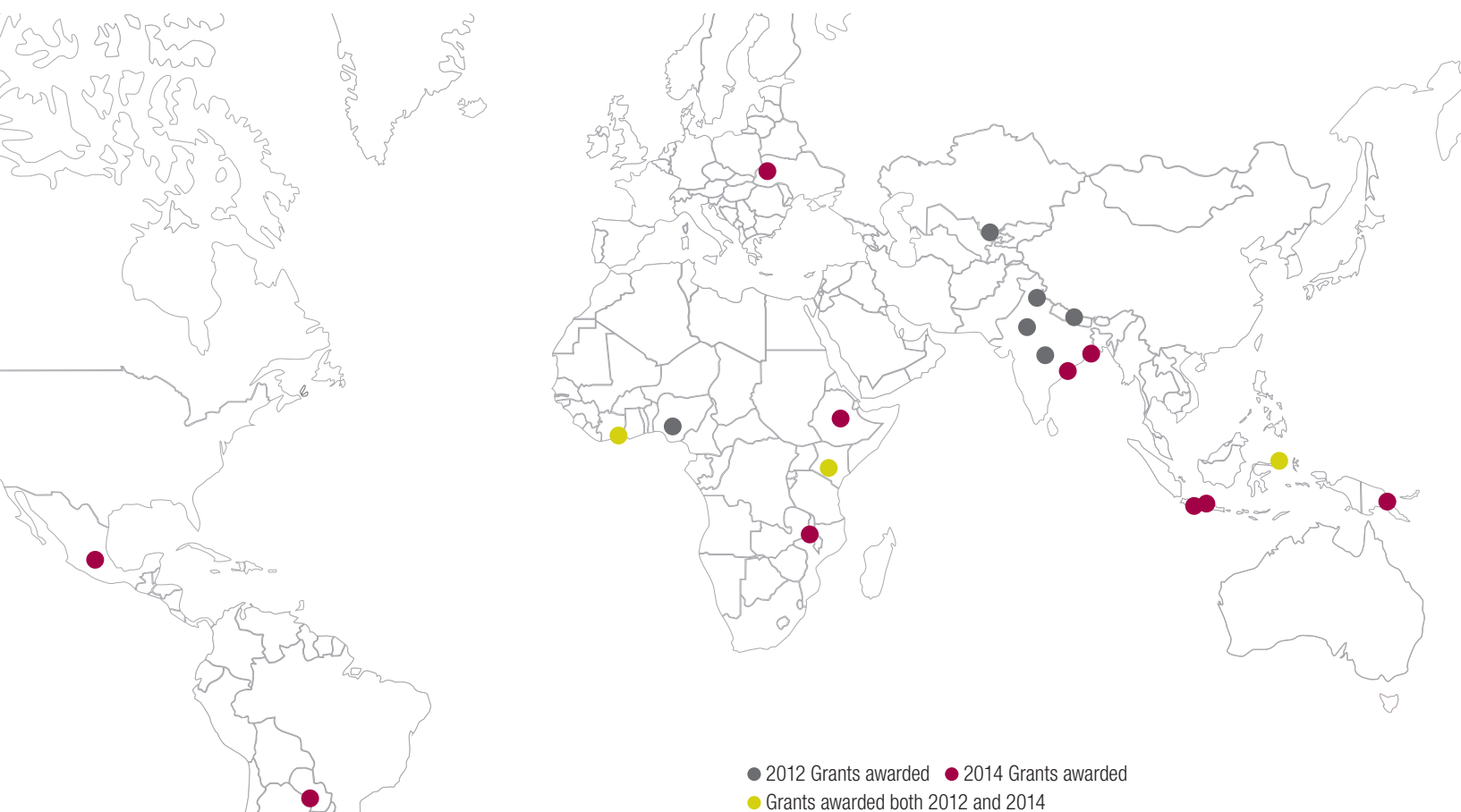
The iCMLf Diagnosis and Testing Program provides a multifaceted approach to build sustainable local capacity for CML diagnosis and testing while ensuring on-going support from clinical and laboratory mentors.

The lack of diagnostic capabilities for CML is a major barrier to optimising clinical outcomes in many low and middle income countries. In the inaugural iCMLf Diagnosis and Testing Program over 2,000 direct tests were made possible by the iCMLf grants. It is impossible to quantify the tests made possible through the purchase of equipment and consumables, along with the training and mentoring that were also facilitated by the program. However it is quite clear that tens of thousands of CML patients will be impacted by the improvements made.

Awarded Grants

From the 23 applications this year the iCMLf Directors selected **9 Phase I projects** and **4 Phase II projects** to be funded. The phase I seeding grants comprise funding of up to \$10,000. Phase II funding is for previous awardees that have achieved outstanding results with initial funds and can be up to \$20,000.

FIGURE 2 iCMLf FUNDING AT CENTRES TO INCREASE LOCAL CML DIAGNOSTICS



Expected Outcomes

The reach and impact of this iCMLf program has been widely extended this year. The results of these iCMLf funded projects to build local, sustainable capacity for CML diagnostics will be seen in 2014/2015 and beyond. Patients and their physicians will have better knowledge about their CML facilitating access to treatments and allowing clinically meaningful treatment decisions. This can change lives and benefit whole communities.

The iCMLf Forum for Physicians from Emerging Regions

It is always inspiring to hear how the work of a team can positively influence patient management and outcomes in spite of limited access to resources, therapies and diagnostics. Presented in partnership with MAX the iCMLf Forum is a unique opportunity for physicians from emerging regions to meet face to face to discuss the challenges and solutions for treating CML with limited resources.

In 2013:

- Over 100 attendees at the iCMLf Forum. >80% were physicians
- 21 countries were represented
- $\frac{2}{3}$ attendees had attended previous Forums, demonstrating continued perceived value
- 100% of survey respondents rated the Forum as 'valuable' with 33% rating 'very valuable'
- 100% of survey respondents rated the presented case studies as relevant to their practice with 27% 'very relevant'
- The format and timing of the meeting was also positively reviewed

The aim of the iCMLf Forum is to recognise and to share the work and initiatives of physicians in emerging economic regions. For this reason the meeting showcases solution focused presentations from iCMLf award-winning physicians and also features practical advice, discussions and networking with iCMLf Directors.

The three presentations in 2013 were:

1. Implementation of molecular monitoring of p210 BCR-ABL fusion transcript for CML patients – Dr Lilian Pilleux, Valdivia Hospital Universidad Austral de Chile Valdivia, Chile
2. An efficient way for multi-centers to simultaneously derive and validate conversion factors for the conversion of BCR-ABLIS in CML – Dr Ya-Zhen Qin, Peking University People's Hospital, Peking University Institute of Hematology, Beijing, China (presented by Professor Xiao-Jun Huang)
3. Overcoming challenges treating CML – The Ghana experience Dr Benneh, Department of Haematology, Korle-Bu Teaching Hospital, Accra, Ghana



Speakers at the iCMLf Forum in 2013

While all three of the presentations were unique, each demonstrated that the implementation of molecular monitoring in emerging regions, however this is achieved, has true, tangible benefit for patients.

Held during ASH each year, the iCMLf Forum for Physicians from Emerging Regions has become a fixture on the CML calendar for emerging regions clinicians attending ASH. We look forward to seeing you in San Francisco in 2014.

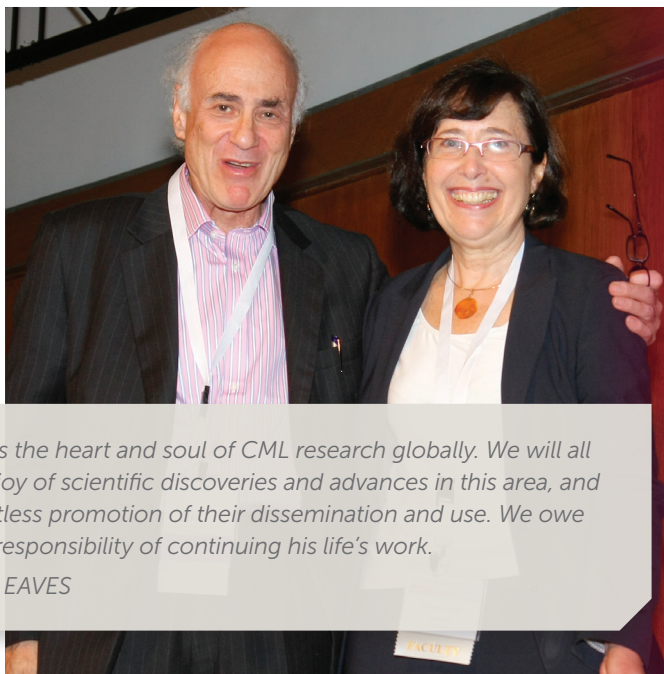


The iCMLf Forum is supported by an unrestricted grant from Novartis Pharmaceuticals.

iCMLf-ESH International CML Meeting and iCMLf Rowley Prize 2013

RECOGNISING LIFE LONG ACHIEVEMENTS IN CML

Named in honour of Dr Janet Rowley the iCMLf Rowley Prize is an annual award recognising outstanding work in the field of CML. The 2013 Rowley Prize awardee is Professor Connie Eaves, a distinguished scientist at the Terry Fox Laboratories in Canada.



John was the heart and soul of CML research globally. We will all miss his joy of scientific discoveries and advances in this area, and his relentless promotion of their dissemination and use. We owe him the responsibility of continuing his life's work.

CONNIE EAVES

Connie is a most deserving winner of the 2013 Rowley prize. No single person has contributed more in recent decades to our understanding of the biology and kinetics of CML stem and progenitor cells.

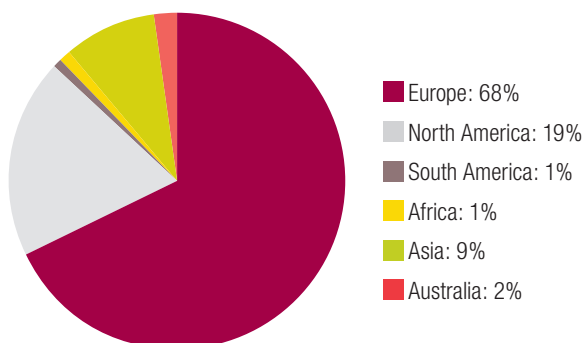
PROFESSOR JOHN GOLDMAN

545 PEOPLE ATTEND THE INTERNATIONAL CML CONGRESS

The 15th International Conference on CML: Biology and Therapy took place in Estoril, Portugal, from September 26-29, 2013. This leading international CML meeting was again co-sponsored by the iCMLf and the European School of Haematology (ESH).

Attendees from were 43 different countries. The group of participants represents the increasing global nature of the CML scientific community.

Participant geographic coverage



Meeting highlights

The latest updates in therapy and research in CML were reviewed from clinical and scientific perspectives:

- 1) Nine different scientific sessions highlighted the latest research findings in CML. Topics included; molecular genetics and leukemic stem cells, molecular biology, progression to blastic transformation, and predicting and monitoring response to CML. New clinical strategies in CML, novel therapeutic approaches and immunology and immunotherapy were also discussed.
- 2) The new session dedicated to CML in children was well received.
- 3) Poster presentations including a series of poster walks were a strong focus, covering over 100 abstracts of key scientific and clinical findings.



A GLOBAL INTERACTIVE EDUCATIONAL PLATFORM FOR CML

The iCMLf website (www.cml-foundation.org) is an established worldwide educational platform for healthcare professionals and scientists managing and researching CML.

People from 80% of countries around the world have viewed the iCMLf website in 2013/14



State-of-the art science and education

In 2014 the iCMLf relaunched the Foundation's website. This interactive platform now has a new clean structure to make its multi-layered content more accessible. The website consists of three major areas.

1 About the iCMLf

Information on the organisation, programs, publications and prizes of the Foundation.



2 Science and Education

- Get information on important scientific meetings
- Read latest publications on CML in peer-reviewed journals
- Find links to active clinical CML trials
- Submit interesting articles and publications
- Get expert advice on challenging CML cases

The Pediatric CML section provides a selection of articles and scientific publications relevant for physicians treating children and young adolescents with CML.

3 Emerging Regions

The "Emerging Regions" section is specifically customised to the needs of haematologists from emerging economic regions.

- Catch up on current iCMLf programs and download application forms
- View e-lectures from CML experts in English, French and Spanish
- Access a network of international contacts, including leading hematologists and scientists, with a common interest in CML


Clinical Case Discussion Forum

ONLINE EXPERT DISCUSSIONS ON CHALLENGING CML CASES


This key program of the Foundation aims to share and enhance best practice management of CML and to facilitate a dialogue amongst physicians through an open discussion on their cases.


IN 2013/14

MORE THAN
 **16,000**
case views

 **790**
average views per case

 **21** cases were posted
on the Case
Discussion Forum
in 2013/2014

 **17**
physicians
contributed cases

 The average number of
responses per case was 3.8
with the highest number of
8 responses for the case
“CML patient with HIV+ status”

Most frequently viewed, the top 3 topics are:



1 CML during pregnancy
- **8134 views**



2 Persistent/relapsing localisation
of CML in brain - **1095 views**



3 Second malignancy in a case
of CML - **868 views**

Other cases discussed cover:

- Side effects of second line therapy
- Mutations and CML resistance
- Response to therapy
- Blast crisis CML
- Concordant conditions with CML
- Treatment of Paediatric CML
- Questions regarding Ponatinib and arterial events

The Case Discussion Forum is for registered iCMLf members only. As a full clinical history is necessary for accurate comment, cases and comments on the Forum are only accepted from clinicians. We thank all our members for their support and contributions.

VIRTUAL EDUCATION PROGRAM – MORE THAN 100,000 E-LECTURES PROVIDED



Best practice in CML management is constantly changing and continuous education is key. On the iCMLf website CML practitioners can access up-to-date education in multiple languages online where ever they reside and at any time.

In 2014 an additional module on non-adherence of CML patients has been added to this educational series. Giora Sharf from the CML Advocates Network presents data from the global adherence survey of the CML Advocates Network.

In 2013/2014:

- > 100,000 webstreams of modules
- > 80,000 webstreams viewed in English
- > 12,000 webstreams viewed in French
- > 7,000 webstreams viewed in Spanish

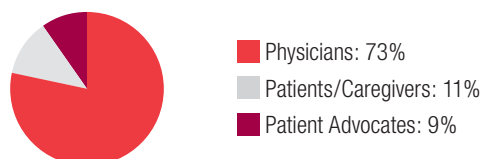
The iCMLf Virtual Education Program is supported by an unrestricted educational grant from Novartis Oncology and was developed in partnership with The Max Foundation.

iCMLf Membership

INCREASING THE INTERNATIONAL NETWORK OF PHYSICIANS AND SCIENTISTS DEDICATED TO CML

Members of the iCMLf become part of an international network of physicians managing CML and researchers dedicated to CML.

Support from > 510 members from 91 countries worldwide

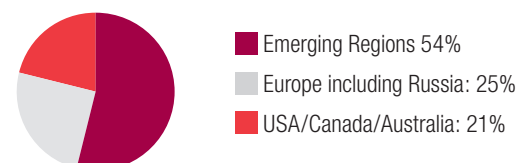


It is only through the contribution collaboration and commitment of the CML community that the iCMLf can achieve its goals. Currently 511 members have access to this network of international contacts, including leading hematologists and scientists. There is currently no cost associated with the iCMLf membership.

Majority of members are from emerging economic regions

This reflects the initial focus of the Foundation to improve access to education, diagnostics and treatment where resources are most limited.

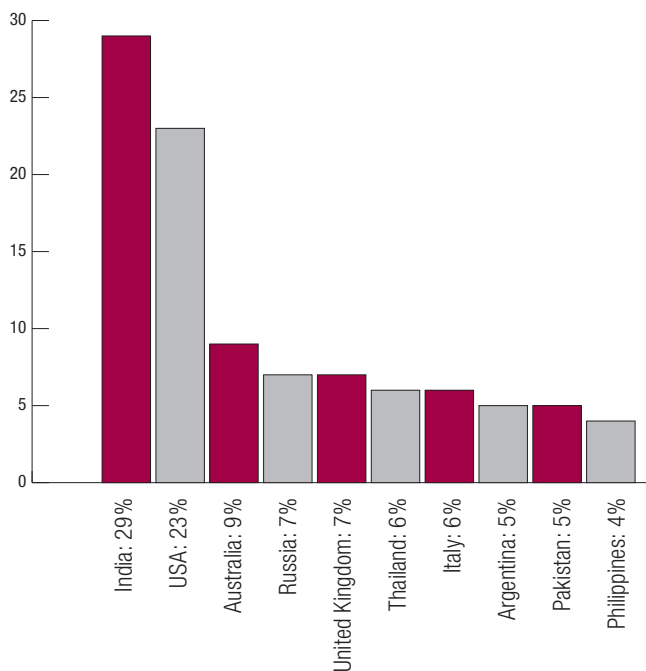
Members of the iCMLf community per region of origin



29% of iCMLf members India is the most frequent country, followed by the United States and Australia.

In 2013/14 we welcomed 162 new iCMLf members.

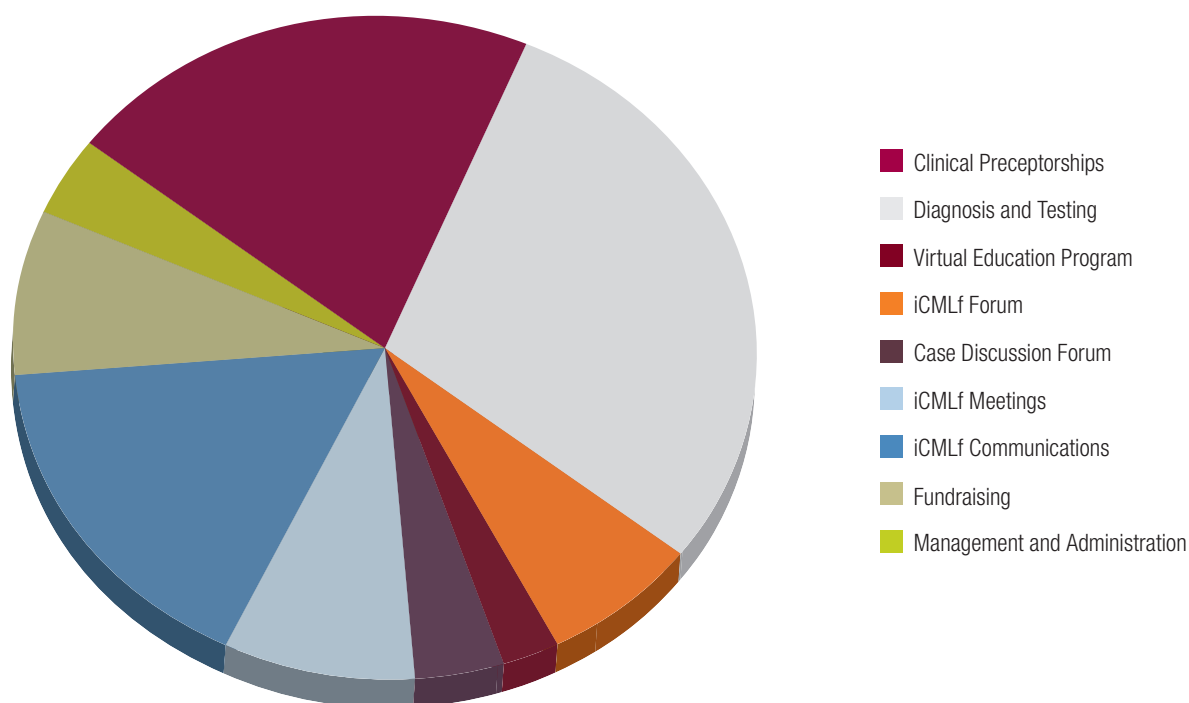
FIGURE 3. TOP COUNTRIES WITH iCMLf MEMBERS



New countries with iCMLf members include:



iCMLf Expenditure



- Over 85% of funds spent directly addressing education and access to diagnostics.
- Over 60% of funds spent enhancing treatment in emerging regions.

Working towards equal access to CML education, diagnostics and therapies around the world.

Acknowledgement of support

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



The ERSAP Diagnosis and Testing Program



General support for the iCMLf

Major Supporters



The ERSAP Preceptorship Program

Other Supporters



Publication of the
iCMLf Newsletters
and Annual Report



iCMLf Virtual Education
Program and iCMLf Forum



Support and use of
the GeneXpert System
and Xpert BCR-ABL
cartridges

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.



The International CML Foundation is registered
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