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Edition 15

About the iCMLf

The International CML Foundation (iCMLf) is a Foundation established by a group of leading hematologists with a strong interest in CML. The mission of the iCMLf is to improve the outcomes for patients with CML globally. The Foundation is registered as a charitable organisation in England and Wales but its charter is global. Its aims are to foster and coordinate global clinical and research collaborations and to improve clinical practice and disease monitoring in CML, especially in emerging economic regions. Scientific advisors and national representatives spanning over 30 countries provide guidance and advice to further the aims of the iCMLf.

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T Hughes (Chair), J Apperley,
M Baccarani, J Cortes,
B Druker, A Hochhaus,
J Radich, C Schiffer

Please support the iCMLf!

Your donations and unrestricted grants enable us to support the opportunity for all CML patients to have the best possible outcome no matter where they live.

Dear Colleagues,

Just as we were completing this edition of the iCMLf Newsletter we learnt of the death of Professor Jean Khoury from Winship Cancer Institute at Emory University in Atlanta, USA. Dr Khoury was known as a compassionate, pioneering physician and he will be sadly missed by his patients and colleagues. In 2015 Dr Khoury approached the iCMLf to become a host for the clinical preceptorships and although this did not occur because of his illness it is indicative of his desire to the CML community. His enthusiasm and camaraderie will also be missed at the annual Goldman fun run.

When a friend and colleague passes, it reminds us to take stock. Therefore, we wanted to take this opportunity to once again thank all those who contribute to the work of the iCMLf; our hosts and mentors of all the physicians and scientists from the emerging regions, our advisors and partners that support our programs through their knowledge and donation of services and the people and companies that financially support the work of the Foundation. Increasing access to quality diagnostics and CML management enables more people to access the therapies they need to manage their CML. Thanks to everyone who helps us, the iCMLf can transform the lives of those we reach.

Speaking of transformation...

We are honoured to award the iCMLf Prizes this year to three leaders in the field of CML. Their work has transformed the way CML is understood and managed and it is our pleasure to recognise Professor Tessa Holyoake, Professor Tim Hughes and Professor Jerry Radich with the Rowley, Goldman and iCMLf medals in 2017.

Work in the emerging economic regions

Dr Radich is awarded the iCMLf Prize in 2017 in recognition of his constant drive to improve the access to diagnosis and monitoring CML in low and middle-income countries. You can read about his latest innovation to develop low cost shipment of blood samples on page 5. This is one of the projects supported by the iCMLf diagnosis and testing program, another is the iCMLf grants to increase access to CML diagnostics. So far 42 grants have been put towards improving access to testing for CML, directly affecting the access to medications and high quality care. The 2017 Grant Program is now open for applications. Once again 10 grants of up to \$10,000 are available to support local CML diagnosis and monitoring. Increasing access to diagnostics always needs to be supported by clinical decision making and we are pleased to say that to support this, our Clinical Preceptorship Program continues to go from strength to strength. This year we had 67 applications for the program from 33 countries. This is the most applications ever received by the Foundation, demonstrating a continued interest and need for the program from those it benefits most.



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Online CML education

We continue to extend the online educational content we offer on the iCMLf website. We have new presentations on 'Modern Diagnostics', expert opinions from the key hematology meetings and each month Professor Tim Hughes shares his 'key CML publications of the month. We also highlight the CML sessions from each key hematology meeting so that you can plan your agenda. If you haven't already, come and have a look at www.cml-foundation.org.

We hope you enjoy this edition of the iCMLf newsletter and remember, become a member of the iCMLf, join our community and together we will continue to work towards improving outcomes for CML patients worldwide.

Your iCMLf team



iCMLf Prizes for outstanding contributions to CML management

The iCMLf is delighted to announce the recipients of the 2017 iCMLf prizes. The three winners are recognised for their outstanding achievements to better understand the biology of CML and to improve the management and care of CML patients around the world.



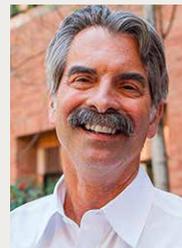
ROWLEY PRIZE
Recognising outstanding lifetime contributions to the understanding of the biology of CML

The 2017 Rowley Prize is awarded to **Professor Tessa Holyoake** in recognition of her groundbreaking work understanding and targeting CML stem cells. She has developed laboratory methods to purify the cells of interest from leukaemia patients and from normal donors, allowing side-by-side comparisons of leukemic versus normal stem cells.



GOLDMAN PRIZE
Recognising outstanding lifetime contributions to the management of patients with CML

The iCMLf has awarded the 2017 Goldman Prize to **Professor Tim Hughes** acknowledging his contribution as an internationally recognised expert in the biology and treatment of CML. Dr Hughes led the establishment of the molecular response criteria that are now used worldwide to measure response in CML. He has also been Principal Investigator and on the management committee for many of the key global CML trials using tyrosine kinase inhibitors.



iCMLf PRIZE
Recognising outstanding contributions to the improvement of CML treatment in the emerging economic regions

The 2017 iCMLf prize is awarded to **Professor Jerry Radich** in recognition of his dedication to overcome the challenges of access and expense of CML testing in the emerging regions. He has consistently worked to develop methods to make molecular monitoring less expensive to increase access to CML diagnosis and monitoring for so many patients.



Jean Khoury (1967-2017)

In memory of H. Jean Khoury (1967-2017)

We are saddened to hear about the recent death of Jean Khoury. Professor Khoury led the Division of Hematology of the Winship Cancer Institute at Emory University in Atlanta (USA). Known as a compassionate physician and clinical investigator, he received many awards and published more than 140 articles in peer-reviewed journals.

“Jean’s departure is untimely and a great loss to the CML community and the medical and scientific community at large. He was also a real gentleman that always saw good in all and everything that surrounded him. As a final gift, he left us with the charge to develop a CML consortium that he championed and very selflessly brought to fruition. He will be sorely missed, but his memory will stay with us forever.”

Professor Jorge Cortes



‘Managing the high risk CML patient’ with specific perspectives from India and Botswana

The iCMLf Forum for Physicians from Emerging Economic Regions has become a key event on the CML calendar. Once again in December physicians came from all over the world to discuss the specific challenges treating CML in low and middle-income countries. As always, presenters included both international CML experts and leaders of CML treatment from the emerging regions. All the presentations were followed by lively discussion with the audience.

The Forum is presented in partnership with The Max Foundation, and Pat Garcia-Gonzales, CEO of The Max Foundation always does an excellent job of soliciting questions from the audience and inspiring useful discussion. The meeting would also not be possible without the long-standing support from Novartis Oncology and we thank them for this continued support.

Professor Brian Druker, opened the meeting with a keynote presentation outlining his personal perspectives ‘Meeting the new challenges in CML therapy’. He started with the good news that, with access to new therapies over the last four decades, those newly diagnosed with CML can now pretty much expect a normal life span. Other topics and questions included; the current state of CML, challenges for patients on long-term therapy, how can we move from control to cure? Do we need to eradicate stem cells? Can the immune system control CML? Dr Druker also highlighted the challenges for future clinical trials.

“Benefits to patients of moving from control to cure are significant” Prof. Brian Druker

Frontline therapy challenges

Professor Tapan Saikia (India) and Professor Andreas Hochhaus (Germany) discussed high-risk CML cases and the current treatment for high-risk CML-CP. Additional therapies to avoid adverse events, prognostic scores, and unfavorable bone marrow data were covered. Specific Indian scenarios and the challenges locally in managing high-risk patients were also outlined.

Challenges of managing HR CML: in emerging countries (perhaps for all CML cases)

- Full work up:
 - Availability of facilities and inclination of physicians
 - Need more concerted efforts
- Cost of medicines from the perspective of country's per capita income
- Frequent molecular testing costs
 - Unlike one day's cost of gloves in Europe
 - It could be month's or fortnightly income
 - Access to accredited laboratories for IS BCR-ABL level
 - There is access, but not in every nook and cranny
 - Lack of clinical trials: Newer drugs needed for this group
 - Allogeneic SCT: widely available, but ...

“Water, water, water everywhere, not a drop to drink”

iCMLf Forum 2017 slide presented by Prof. Saikia

Comorbidities when managing CML

Dr Anthony Oyekunle (Botswana) (left) and Dr Delphine Réa (France) outlined the prevalence of comorbidities among CML patients, along with the impact of comorbidities on therapy choice and overall survival.



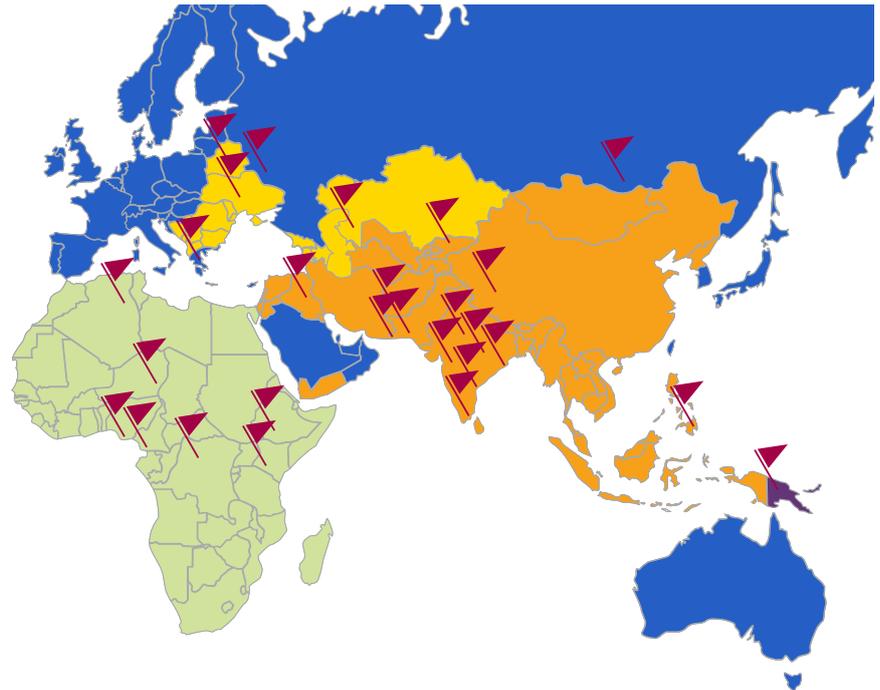
You can view all the presentations and following discussion including monitoring and stopping therapy, on the iCMLf website at www.cml-foundation.org/index.php/emerging-regions/icmlf-forum/826-ersap-icmlf-forum-2016-streams

We are now planning for the Forum in Atlanta on the 8th December 2017 and welcome your comments. If you have topics you would like to see discussed please email us at info@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. 2017 saw 67 applications for the program. This is the most of any year so far, showing continued interest in and need for, the program.

30 preceptors accepted from 21 countries.



2017 PRECEPTORSHIPS

"I gained knowledge in the standard management of CML at various stages and how to monitor the disease. I also observed that treatment is individualized. I also have knowledge of how to do cytogenetic analysis on CML blood samples. The program has strengthened my ability to manage CML cases and other Hematological conditions. I can comfortably interpret BCR-ABL results. I acquired laboratory skills in samples processing and storage. I thank professor Jane Apperley and authorities of Hammersmith Hospital for the opportunity to observe and learn. Back here in Nigeria, in my centre UNTH our CML patients are already benefiting from the skills and knowledge." Dr Agu (Hammersmith March 2017)



Professor Apperley with Dr Agu during his preceptorship

Building diagnostic capabilities in the emerging economic regions

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

Sample shipments

On January 31st another 30 CML patients from the Philippines had blood shipped to Australia for free PCR and mutation testing. These patients have been showing signs of resistance to treatment but are unable to raise the funds for the necessary monitoring tests.

This is shipment number 5 of a long-standing collaboration between the iCMLf and Touched by MAX of the Philippines and the Philippine General Hospital, to help their patients. This year, for the second time, mutation analysis was offered. From the 2015 shipment 8 of the 9 patients with identified mutations were able to transfer to an appropriate TKI. We hope the results of 2017 will be similarly successful.



Diagnosis and testing grants

The iCMLf Diagnosis and Testing Program offers seeding grants to hematology institutions in emerging economic regions. The program is to facilitate diagnosis, testing and long-term disease monitoring of CML patients where it is limited, or not currently available.

Building on the success of the previous forty-two projects awarded iCMLf grants, the Foundation will offer further funding in 2017 for ten new proposals with funding of up to \$10,000.

Expressions of interest are welcome to melissa@cml-foundation.org.

Applications close on the 30th June 2017.

Read more www.cml-foundation.org/index.php/emerging-regions/diagnostics-program

Apply Now!

SPOT on CML

Overcoming the barrier of diagnosis in low and middle income countries, one patient each day.

Powered by a unique partnership that brings together The Max Foundation, Fred Hutch, the International CML Foundation, and Cepheid, Fred Hutch investigator Dr Jerry Radich and his team are working to improve CML diagnostics — and lower their cost — in low- and middle-income countries. Using pilot funding, the Radich lab has devised a method to assay blood spotted on filter paper, sent from patients overseas via conventional mail, for the BCR-ABL genetic marker of CML.

In the past, diagnostic testing for CML had to be performed on fresh blood, requiring expensive overnight shipping from overseas to a diagnostics or research laboratory.

WHAT IS SPOT ON CML?

The Radich lab method, to spot blood on specimen-grade paper, and perform the diagnostic testing accurately even after weeks of transit will greatly decrease shipping costs, and greatly increase the number of samples that can be shipped together for testing. SPOT ON CML ensures accurate diagnosis, and ultimately through the access programs of The Max Foundation, a connection to lifesaving treatment for patients who previously had no other options.

The SPOT ON CML team is now scaling up this project, with the goal of diagnosing — and saving the life of one CML patient per day to reach 365 people over the course of a year.

Providing up-to-date online CML information

One of the key objectives of the Foundation is to disseminate the latest CML scientific news throughout the international CML community. In this way we work towards all physicians treating patients with CML having access to up to date CML data, information and practical advice. To achieve this goal the iCMLf has been providing online educational services, such as the Virtual Education Program and the Case Discussion Forum for several years now. In late 2016 we asked our members what information the iCMLf should provide to best meet the needs of our international audience.

The top four requested topics, with over 80% of total respondents, were; expert opinions, CML reviews from scientific meetings, clinical publications on CML and online education. During the past year the iCMLf launched three new initiatives that cover exactly these topics.

Come visit us at www.cml-foundation.org to access the iCMLf online services.



Virtual Education for CML

With more than **17,622** views to date the online presentations on the Virtual Education Program are among the most viewed sections of the iCMLf website.

New 2016/17 presentations cover topics on modern CML diagnostics;

- Mutation Screening (Simona Soverini)
- Molecular Monitoring in CML (Martin Müller)
- Biomarkers and response monitoring beyond PCR (Deborah White)
- The role of cytogenetic monitoring in CML (Jorge Cortes)

Featuring key CML publications from the Emerging Economic Regions

In order to better recognise the scientific achievements in the emerging economic countries the iCMLf has recently launched a new section of the website that features key CML publications from these regions. You will find interesting peer reviewed, published papers on CML from the Middle East, Africa, Asia and Latin America.

The page will be updated regularly with new publications from the emerging economic regions. We also rely on your help. If you have an interesting CML paper or article from your country to share, please email to info@cml-foundation.org and provide us with the details. We will be happy to review your suggestion.

You can access the new ERSAP Publications page

www.cml-foundation.org/index.php/emerging-regions/ersap-publications



Latest information from scientific publications

As a special monthly news service, the iCMLf in partnership with Springer Healthcare IME has provided 45 summaries of key clinical CML publications. Thirteen monthly email updates featured key CML stories of the month. The service was well received with over **11,350** views.

Top-5 most read CML-stories:

- | | |
|--|--|
| <ol style="list-style-type: none"> ❶ STIM1 findings confirm safety of controlled imatinib discontinuation ❷ CML treatment-free remission criteria outlined ❸ EURO-Ski confirms TKI discontinuation feasible for selected CML patients | <ol style="list-style-type: none"> ❹ Additional chromosomal abnormalities prognostic for CML ❺ Promising CML phase I results from ABL001 BCR-ABL inhibitor |
|--|--|

You can access the CML stories www.cml-foundation.org/index.php/summaries-of-key-cml-publications



CML expert opinions on scientific meetings

New on the iCMLf website is a section that provides you with a selection of expert opinions from leaders in the field. The topics featured cover a broad range of issues from CML science to clinical practice. You will find interviews with CML experts on meeting highlights, keynote presentations from iCMLf prize winners and additional expert opinions on various CML related topics. New expert opinions include personal perspectives on key 2016 meetings.

Highlights from EHA 2016:

- Michele Baccarani
- Francois-Xavier Mahon
- Susanne Sauße

Highlights from ASH 2016:

- Fabio Efficace
- Jorge Cortes
- Susan Branford

The CML news service and expert interviews were produced by Medwire News a division of Springer Healthcare IME and supported by a grant from Novartis Oncology.

Clinical cases for interest and advice

On the iCMLf Case Discussion Forum physicians can share their interesting CML cases to seek expert opinions and facilitate a discussion among the CML community. Cases are reviewed by a moderating physician and then posted to the forum with the first response for further discussion.

The Top-5 most viewed CML cases;

- ❶ Pregnancy and accelerated phase CML
- ❷ Side effects of nilotinib
- ❸ Is this CML or Ph+ AML?
- ❹ Triple mutation in ABL1 kinase domain – Rx?
- ❺ Y253H mutation and dasatinib intolerant

Social media

The iCMLf Facebook account has become a lively news stream that is well received by the CML community. If you have not joined the iCMLf on *Facebook* yet, go to [facebook.com/icmlf](https://www.facebook.com/icmlf) and like our page for your instant access CML news!



Register now

19th Annual John Goldman Conference on
CHRONIC MYELOID LEUKAEMIA: BIOLOGY AND THERAPY
ESTORIL, PORTUGAL OCTOBER 12-15, 2017



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Topics:

- Stem cells and the microenvironment
- Molecular biology and new targets
- Mechanisms of resistance
- Therapeutic interventions
- Safety and patient reported outcomes
- Symposium on MPNs
- Workshop for Non-Clinical Scientists on Metabolomics
- Workshop for Non-Clinical Scientists on Cell Fate Tracking
- Clinical and biology manned poster walks

Chairs: J. Cortes, T. Holyoake, T. P. Hughes

To register and for further information: www.esh.org or contact: pauline.jaillard@univ-paris-diderot.fr

SAVE THE DATE



**iCMLf Forum for Physicians from
Emerging Economic Regions**

'Overcoming challenges treating CML'

Featuring practical innovations sharing experiences and discussion with CML experts.
Held during the annual American Society of Hematology meeting.

Atlanta, Georgia Friday 8 December 2017

To register your interest and reserve your place, please email melissa@cml-foundaton.org

Thank you to all our supporters!

We appreciate and thank all the 'Friends of the Foundation' who give both of their time, and financially to further the aims of the iCMLf.

We thank our corporate partners for their generous contributions that help us to improve the outcomes for patients with CML globally.



To donate to the work of the iCMLf go to www.cml-foundation.org