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Edition 11

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.

Registered Address:

International CML Foundation
20 Eversley Road
Bexhill-on-Sea, East Sussex,
TN40 1HE - UK

info@cml-foundation.org
www.cml-foundation.org

Board of Directors:

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

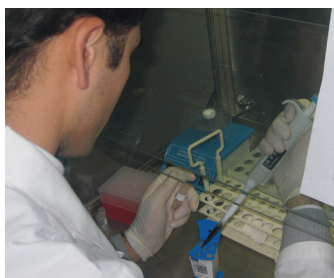
Please support the iCMLf!
Your donations and
unrestricted grants enable
us to support the opportunity
for all CML patients to have
the best possible outcome
no matter where they live.

Dear Colleagues,

The most heartening part about working in the world of CML is that there's effective treatment available, and it's the goal of the iCMLf to expand access to everyone who needs it!

Increasing access to CML diagnostics

One of the most challenging aspects of managing CML in low resource areas, is even where there is CML therapy available through



CML testing made possible with iCMLf grants.

access, or co-payment programs, accessing these is still difficult due to the lack of available tools to diagnose and effectively monitor CML. The iCMLf Diagnosis and Testing grants program aims to address this by providing small seeding grants to increase local access to CML diagnostics, this could be through provision of equipment, consumables, training and sample shipments. Our programs in 2012, 2013 and 2014 have helped 22 centres and 1,000's of patients access reliable CML tests. The program for 2015 is currently open for proposals for grants (see page 8 for more information). Over the last couple of months we have been delighted to see another diagnostic shipment from the Philippines to Australia. 30, predominantly treatment resistant, CML patients were able to access mutation analysis to help determine the appropriate next step for their treatment. The article on page 3 provides more insight to what is involved for these shipments.

New iCMLf Prize to recognise contributions in the emerging regions

The iCMLf has established an annual prize to recognise work that is being done to overcome the challenges of treating CML with inadequate, or no resources. After receiving nominations from throughout the CML community the iCMLf Directors and Scientific Advisors have awarded the inaugural iCMLf ERSAP Prize to Pat Garcia-Gonzalez, CEO and co-founder of the Max foundation. Pat

was widely recognised for her personal motivation and dedication towards the work of The Max Foundation and by extension those living with CML. Read more about this and the other iCMLf Prizes awarded in 2015 on pages 6 and 7.

Up to date CML education for all



Speakers at the 2014 iCMLf Forum.

Information about CML is continually evolving. New data, guidelines, scientific publications and expert opinions are constantly available. Sharing this up to date knowledge within the international CML community is key to translating it into clinical best practice in all parts of the world. The annual iCMLf Forum for Physicians from Emerging Regions is a unique opportunity for clinicians to meet with CML experts from the iCMLf and discuss the specific challenges faced treating CML in these regions. Page 2 outlines the discussion topics at the iCMLf Forum in December 2014. The iCMLf website, www.cml-foundation.org is also a good knowledge source for up to date expert opinions and presentations through the virtual education platform. The latest topics include 'When front line TKI therapy fails' and 'Mechanisms of resistance to TKI therapy'.

The iCMLf has joined the world of social media!



You can now keep in touch with the latest CML news, events and iCMLf programs through Facebook and LinkedIn. 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

"We may not be there yet, but we are closer than we were yesterday!" Author unknown

Exploring perspectives treating CML from around the world

More chairs were required and then it was standing room only at the iCMLf Forum for Physicians from Emerging Economic Regions held during ASH in San Francisco last December. This reflects the importance and uniqueness of this annual meeting bringing together international CML experts with physicians who treat CML in countries where resources are often limited.

The annual iCMLf Forum is a partnership project between the iCMLf and The Max Foundation. The aim of the meeting is to focus on the challenges faced by physicians in emerging economic regions. The iCMLf Forum showcases specific topics relevant to these regions, highlighting local projects that enhance CML patient management.

In 2014 the Forum promoted discussion on key topics of CML management between those working in the emerging regions and the iCMLf experts. The aim was to outline and share understanding of challenges faced and to promote discussion and ideas to overcome these. For example: What is the difference diagnosing and monitoring CML in Italy and Ethiopia? Can you compare stopping CML therapy in India and Germany? Are there different cultural concerns when managing pregnancy in the UK and Brazil? These were just some of the questions addressed at the most recent iCMLf Forum.

Over 115 physicians from 26 countries attended. With 100% of survey responders stating the meeting was of value to them and 100% relevant to their work.



Nicola Evans, the iCMLf
Chief Executive,
opening the 2014 Forum.

General comments on the meeting:

"An opportunity to meet the experts and clarify some basic bedside doubts."

"Easy way of understanding all the information"

Webcasts of the presentations and discussion at the meeting are now available on the iCMLf website.

www.cml-foundation.org/emerging-regions/icmlf-forum

Topics

1. How I diagnose and monitor CML patients.
The past, present and future.



Dr Amha Gebremedhin, Ethiopia

My approach to diagnosing and monitoring CML – blood counts, bone marrow, PCR, FISH. Assessing SOKAL risk. Considerations given to co-morbidities when starting therapy. How patient resources impact treatment.



Professor Michele Baccarani, Italy

A brief perspective on the optimal tests at diagnosis and for long term monitoring and how these would be prioritised if resources were very limited.

2. The Management of Pregnancy in CML



Dr Carla Boquimpani, Brazil

My approach to managing pregnancy in CML patients and those who are considering becoming pregnant. How the patient's resources impact the management of pregnancy. Cultural aspects to consider.



Professor Jane Apperley, UK

A perspective on the considerations for treating CML patients who are pregnant or are considering pregnancy and how this approach might be adapted in a more resource limited environment.

3. Treatment free remission: opportunities and dangers



Professor Alok Srivastava, India

The local situation regarding stopping therapy, my perspective and that of my patients. Positive and negative considerations when stopping therapy. How my perspective on stopping therapy is impacted by the resources of my patients.



Professor Andreas Hochhaus, Germany

A perspective on stopping therapy – when, why and how as well questions from patients.

We are now planning for the iCMLf Forum in Orlando, December 2015 and welcome your comments. If you have topics you would like to see discussed please email us at info@cml-foundation.org

Partnering to bring access to PCR and mutation testing to the Philippines

Molecular monitoring of CML patients is vitally important for optimal outcomes. Unfortunately, in many parts of the world, diagnosis and monitoring of CML patients is limited by the availability and cost of molecular testing. In countries, or centres without molecular diagnostic capabilities, blood samples can be shipped to central laboratories, but this is both hampered by sample degradation, and the high costs of shipping. In country shipping costing up to \$500 and international shipping \$1,500, or more. In the following article we share the report from The Max Foundation in the Philippines on the recent partnership that enabled 30 patients to access PCR and mutation analysis through an international sample shipment.



The 30 patients who received tests at the Philippine General Hospital.

A few months ago, The Max Foundation received a request from the Philippine General Hospital (PGH) for mutation analysis of some of their patients who have failed to reach the therapeutic milestones with their current treatment. PGH is a government hospital that serves more than 350 people living with CML in the Philippines.

The Max Foundation, in partnership with the local patient group Touched by Max (TBM), the International Chronic Myeloid Leukemia Foundation (iCMLf), SA Pathology and the University of Adelaide, and Fred Hutchinson Research Center, were able to arrange for 30 CML patients who were not responding to their current therapy to receive both PCR and mutation testing. The Max Foundation, TBM, and the iCMLf worked to coordinate the shipping of necessary testing materials to PGH for the mutation tests, and on March 24th, the PGH medical team assisted in taking the blood samples of the 30 individuals, the majority of whom had shown a lack of response to their first and second treatment options. Simultaneously, PCR tests were also collected for the same individuals thanks to the donation of easy to use paper diagnostic cards donated by Dr. Jerry Radich of the Fred Hutchinson Cancer Research Center. The cards were sent back to the Fred Hutchinson Cancer Research Center for analysis, while the mutation tests were sent to the University of Adelaide, Australia for mutation analysis.

The 30 people who were selected to receive the tests were extremely appreciative of being chosen as recipients of this project. Florenda, 44 years old who has live with CML for almost 15 years, said that even if the result are not good, it means a lot to her that her blood will be analyzed. Likewise, another CML survivor named Oscar said, that he is lucky to be selected to help his physician choose the right treatment protocol. It strengthens his hope to fight his disease. On the other hand, Mary Joy immediately sent a thank you message. She mentioned that it was her first time to have PCR and mutation test since she was diagnosed five years ago.

Dr. Rico Paolo Gomez Tee, the Chief Fellow in the Section of Hematology also said *"We are now at an age where we have to do more for our patients. We have discovered more about the biology of the disease, and we have seen its behavior when things go awry. Thus the importance of molecular monitoring and mutation testing. Molecular monitoring makes us more confident in assuring that the leukemia is "asleep". Eventually, as future researches come, we look forward to achieving a total cure where patients would stop taking drugs and be worry-free that their CML would not come back. There are times when even with excellent care, our patients do not seem to respond to treatment. And thus the further need for mutation testing. Such an examination would allow the physician to tailor treatment strategies for the patient. All of these strategies translate to excellent patient care, where thankfully the iCMLf and The Max Foundation have been very supportive especially to less fortunate countries. Efforts such as molecular monitoring and mutation testing have changed the therapeutic landscape of CML in the Philippines. Hopefully, the Philippines receives continuous support for our patients."*

Written by Nelia Medina, The Max Foundation, Philippines

The iCMLf online – sharing the latest CML information

The world of CML is ever evolving. New data, guidelines, scientific publications and expert opinions are constantly available. Sharing this up to date information within the international CML community is key to help translating this knowledge into clinical best practice in all parts of the world.

Within the past six months the iCMLf website has been accessed by people dedicated to CML from 132 different countries. A clear focus is from visitors from the emerging economic regions where access to information and resources are most limited.

Our recent survey on what our members want to hear from the iCMLf showed:

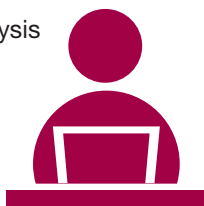
	% OF TOTAL RESPONDENTS
Expert opinions	100
CML reviews from scientific meetings	95
CML publications - clinical	91
iCMLf online education	86
CML publications - biology	67
iCMLf programs / grants	62
iCMLf meetings	52
Information / tools for patients	52
iCMLf prizes	29

We already have much of this on the iCMLf website which provides an interactive platform to keep up with scientific news on CML, discuss interesting CML cases, and listen to presentations from renowned CML experts.

1. Clinical case discussions

Have a look at recent CML cases discussed on the Clinical Case Discussion Forum. With an average number of 3.3 replies and more than 1,000 views, topics include:

- CML therapy for patients on dialysis
- Granulocytic sarcoma
- CML and dasatinib
- CML therapy in HIV patients
- Stopping therapy after 10 years
- Treatment resistant CML
- CML under 18 years
- Imatinib or nilotinib patients exposed to Ebola



2. Expert presentations

The iCMLf Virtual Education Program that has been accessed more than 14,250 times to date. New topics in 2015 include:

- High risk CML
- Optimizing therapy in CML
- Front line therapy of CML in chronic phase



Expert presenters in the 2015 Virtual Education Program

3. Latest peer reviewed publications

The CML Science News section is updated every month and you can view the latest CML abstracts and decide what to read further. So far this year we have:

- 21 new clinical papers on CML including: managing pregnancy in CML, discontinuation of TKI therapy in CML, up-date on emerging treatments in CML, the role of observational studies and a number of clinical studies with different compounds.
- 26 new scientific papers on CML including: response related predictors of survival in CML, emergence of BCR-ABL kinase domain mutations associated with newly diagnosed CML and laboratory recommendations for scoring deep molecular responses.

You can also; submit interesting papers to share with others, catch up with the iCMLf programs, check for important scientific meetings, nominate for the iCMLf prizes, subscribe to the iCMLf monthly email update and support our activities by donating to the Foundation.

We hope to see you here www.cml-foundation.org and watch out for new features later this year such as treatment guidelines, generic therapies and patient information.

iCMLf on Facebook and LinkedIn – join us and share what's new



Our communications survey also showed 58% of iCMLf members would like to see us on Facebook and 25% would like to see us on LinkedIn. So the iCMLf is joining the world of social media to further strengthen networking and collaboration within the international CML community.

Come and follow the iCMLf on Facebook and or LinkedIn to keep up to date with CML news from around the world, share what's new within the CML community, connect with other people dedicated to CML and receive regular updates on the Foundation's activities and publications.

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.

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Other Supporters



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

iCMLf Prizes recognise outstanding contributions to CML management

Each year the Foundation calls on the CML community to nominate people who have made an outstanding contribution to the understanding and management of CML. Following these nominations the iCMLf Rowley Prize and the iCMLf Goldman Prize are decided by a panel of past prize winners and the iCMLf Directors. Previous prize recipients include leading CML scientists and clinicians well-known for their achievements within the scientific community and beyond.

THE iCMLf ROWLEY PRIZE is designed to recognise persons who have made major contributions to the understanding of the biology of CML.

Previous winners are; Brian Druker (2009), Moshe Talpaz (2010), John Goldman (2011), George Daley (2012), Connie Eaves (2013) and Owen Witte (2014).

THE iCMLf GOLDMAN PRIZE is the clinical equivalent recognising outstanding lifetime contributions to the management of patients with CML. The inaugural Goldman Prize in 2014 was awarded to Rüdiger Hehlmann due to his important achievements in creating international CML study groups and networks to foster international research cooperation.

Rowley Prize 2015 Recipient: Professor Richard Van Etten

In 2015 the Rowley Prize is awarded to Professor Richard Van Etten, Director of the Chao Family Comprehensive Cancer Center of the University of California. The award recognises his ground-breaking research focusing on the development of new therapeutic strategies such as the tyrosine kinase inhibitors (TKIs).



Dr Van Etten was a medical resident when researchers first identified the genetic abnormality in the Philadelphia chromosome and the discovery of the leukemia specific oncoprotein BCR-ABL. This discovery led Van Etten to specialise in hematology in the lab of Nobel laureate Dr David Baltimore at Massachusetts Institute of Technology: *"This was very exciting to me because I was convinced that this protein might be the direct cause of leukemia"*, he said. His research on CML, including the development of the first animal model of the disease, later contributed to the development of molecularly targeted drug therapies such as imatinib that inhibits the abnormal protein.



Goldman Prize 2015 Recipient: Professor Michele Baccarani

The iCMLf awarded the 2015 Goldman Prize to Professor Michele Baccarani, Professor of Haematology at the University of Bologna, in recognition of his over forty years of dedication to clinical excellence in the management of CML.



Professor Baccarani has conducted many Phase I, II and III studies to evaluate the efficacy and safety of tyrosine kinase inhibitors and furthered the understanding of their proper use in clinical practice by developing internationally recognised guidelines and recommendations. *"I did not give any personal contribution to the development of tyrosine kinase inhibitors, but contributed to the best of my abilities to the introduction and clinical application of TKI's"*, Prof. Baccarani said. Professor Baccarani was Head of the Department of Haematology and Oncology at the University of Bologna until November 2012. Since 1989, he has served as the Chairman of the GIMEMA CML Working Party. He is Past-President of both the Italian Society of Haematology and the Italian Society of Experimental Haematology.





New iCMLf Prize to recognise contributions in the emerging regions

The iCMLf has established another annual prize to recognise work that is being made to overcome the challenges of treating CML with limited resources. Named after the iCMLf's primary program, the Emerging Regions Support and Partnership (ERSAP) Prize will be awarded each year to an individual, or organisation that has made outstanding contributions to enhancing CML treatment in the emerging economic regions.

Inaugural ERSAP Prize 2015

Recipient: Patricia Garcia-Gonzalez, CEO and co-founder of The Max Foundation

The iCMLf Directors and Scientific Advisors have awarded the inaugural ERSAP prize to Pat Garcia-Gonzalez not only for her role in leading The Max Foundation, but 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.



In 1997 Pat Garcia-Gonzalez co-founded The Max Foundation (Max) as a health non-profit organisation dedicated to increasing global access to treatment, care and support for people living with cancer.

Under her direction, Max has played an active role in a public-private-partnership that has enabled unprecedented access to imatinib treatment for over 60,000 people in low-and-middle-income countries, most of them diagnosed with CML. The organisation also works with other stakeholders making available a channel for access to diagnostics as well as to other TKIs. The Max Foundation works with hematologists in more than 80 countries and is highly committed to improving the lives of people diagnosed with CML in emerging countries.

"Pat strongly believes that people living with CML have the right to access the best possible treatment and support, wherever they live. This is why she has been so determined to make new drugs for CML fully available to patients in emerging economic regions through access programs, education and global advocacy efforts" Tim Hughes iCMLf Chair.

For the past 10 years the organisation has partnered with patients in emerging countries helping to develop CML patient associations in targeted communities. Today, their Max Global Network is comprised of 68 organisations in 58 countries.

Disease education is another key initiative of Max, in addition to their workshop series for patients, Max organises regional conferences for CML patient leaders. They also facilitate physician training through meetings in Africa, and by supporting the creation of the Virtual Education Program in partnership with the iCMLf.

Pat has a Masters degree from the University of Washington and a technical degree in nursing. She is a member of the Board of the Partnership for Quality Medical Donations (PQMD) and of the CML Advocates Network and has recently been awarded the Global Cancer Humanitarian Award by the National Cancer Institute's Center for Global Health

"I am grateful to the iCMLf for this recognition, which I accept on behalf of The Max Foundation, our dedicated team, our partners and collaborators, and the patients we serve. The iCMLf's programs and focus on emerging countries are a great contribution to improving the lives of people living with CML in these regions. I look forward to our continued collaboration." Pat Garcia- Gonzalez hearing of the iCMLf Prize.

Upcoming iCMLf activities

iCMLf Diagnosis and Testing Program: Apply now for 2015 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 twenty-two projects awarded iCMLf grants, the Foundation will offer further funding in 2015 for up to ten new proposals with a funding of \$10,000.

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

Applications close on the 19th June 2015.

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

17th Annual John Goldman Conference on **CHRONIC MYELOID LEUKAEMIA: BIOLOGY AND THERAPY** Estoril, Portugal October 1–4, 2015



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

Organisers: M. Copland, M. Deininger, F.X. Mahon, D. Perrotti, J. Radich, R. Van Etten

To register and for further information: www.esh.org

Email: pauline.jaillard@univ-paris-diderot.fr

SAVE THE DATE



Presented by the International CML Foundation and in partnership with The Max Foundation

iCMLf Forum for Physicians from Emerging Economic Regions

'Overcoming challenges treating CML'

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

Orlando, Florida Friday 4 December 2015

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