

International CML Foundation Annual Report

1st September 2010 to 31st August 2011



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Welcome to the inaugural annual report of the International CML Foundation (iCMLf)



John Goldman

The iCMLf was formed in 2009 by leading hematologists specialising in CML with the goal to improve outcomes for people with CML globally. I feel that the Foundation has made great progress over its first two years launching 3 major projects in developing countries and opening communication and education mediums throughout the CML community. We aim to give

you a sense of these achievements in this document, focusing most specifically on the period September 2010 to August 2011.

We set up the iCMLf recognising that while there has been tremendous progress in the understanding and the management of CML in wealthier countries, we need to improve the outcomes for people diagnosed with CML in many other parts of the world. In 2010/2011 the Emerging Regions Support And Partnership (ERSAP) Program remains the cornerstone of the iCMLf's current activities. Very effective treatment for CML has been available since 1998 and it has transformed the management and outcomes for patients in the western world, but many patients in developing countries are still unable to access treatment due to cost, or lack of facilities. Clinicians from developing countries may face challenges accessing up-to-date knowledge and skills regarding best practice for the treatment and management of their CML patients. The ERSAP projects directly address these issues and are specifically designed to support, educate and share best practice treatment.

20 clinicians from all continents took part in the 2010/2011 ERSAP Preceptorship Program, benefiting greatly from 3-4 week educational preceptorships at CML centres of excellence — for many of them a once in a lifetime opportunity. The ERSAP Diagnosis and Testing Program is probably the most critical project of the Foundation at this time. Increasing the capability of centres to confirm the diagnosis locally and then to monitor CML patients is vital to their overall care. In

2011 we were able to take a small step to achieve this, awarding 9 grants to centres in emerging regions. While this project focuses on increasing capacity to manage CML these projects have the potential to enhance the capability of these centres to diagnose and manage, positively impacting the treatment of many thousands of patients with cancer.

The need and thus the implementation of the ERSAP Diagnosis and Testing grants was a major administrative load, yet we sincerely hope to be able to increase the number of grants we can award for next year. There is enormous potential to have a positive impact in this area and with sufficient funding and the right partners the iCMLf will be able to make a significant difference.

The iCMLf has formed strong partnerships with people and organisations that have goals similar to those of the Foundation. We work closely with the team at The Max Foundation on many projects and thank them for their ideas, passion and commitment. The iCMLf Directors also thank our Premium and Major funding supporters, namely Novartis oncology, Bristol-Myers Squibb, Ariad and Pfizer along with all the other Friends of the Foundation who donate time and money. Without your support the activities of the iCMLf would not be possible.

Looking forward we might be discouraged by the fact even in a disease area with such effective treatment, so much still needs to be tackled to make sure that all patients around the world receive the best possible therapy and care. Quite the contrary - we believe we are pioneering a global formula that will eventually come to apply to many other treatable diseases. We continually hear from people who benefit from the iCMLf's activities, both physicians and patients, and our individual projects extend worldwide. The iCMLf will continue to take small steps and try new initiatives, knowing that each of these individual successes means so much to the people we can help.

We look forward to sharing our successes and lessons learned over the next year.

John M Goldman
Chairman of the Board

Mission, aims and objectives

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

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 organization.



iCMLf advisers hard at work during the first iCMLf advisory committee meeting in September 2010.

Guiding principles

- A focus on chronic myeloid leukemia and related disorders
- A truly independent not-for-profit foundation
- Collaboration with, but independence from, the pharmaceutical industry
- 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

"CML is not a common disease, but it's an important disease. It's deadly, but now a days it can be managed very well and nobody should die of CML and that's our goal in our professional lifetime and for this foundation that nobody should die of this disease."

Jorge Cortes, Houston, USA

"Our particular strength is our expertise in CML and our global focus"

Tim Hughes, Adelaide, Australia

"The improved survival in CML directly attributable to the use of tyrosine kinase inhibitors is so dramatic that these new agents must be made available to the greatest possible number of eligible patients as rapidly as possible throughout the whole world"

John Goldman, London, UK

"The reason I was one of the cofounders of the iCMLf, is that since 45 years I have been involved in research and treatment of CML. When I began CML was a fatal disease. All the patients with CML died in a few years of the disease as they were treated with conventional chemotherapy. After this there was a progress due to Interferon, due to stem cell transplantation and now we are in what I would say the happy era of TKIs and I am proud and I am happy to be here to report on the progress which has been made over so many years in the treatment of CML, particularly with the so called TKIs"

Michele Baccarani, Bologna, Italy

"I think the iCMLf is very important for China. We hope we can focus on the training and education of the physicians in how to use the therapeutic strategies and how to improve the outcome of the Chinese patients, also how we can improve the quality of the tests for minimal residual disease, of CML. So I hope we can have close collaboration with the iCMLf. I very much appreciate the iCMLf's help to improve the outcomes of the Chinese patient's treatment."

Dr Huang, China

Governance of the iCMLf

Board of Directors:



*John Goldman
(Chair) Imperial
College London, UK*



*Jorge Cortes
University of Texas
MD Anderson
Cancer Center, USA*



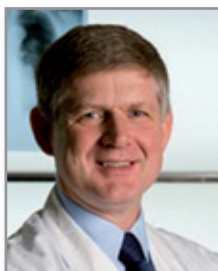
*Brian Druker
Knight Cancer
Institute, Oregon
Health & Science
University, USA*



*Michele Baccarani
S. Orsola University
Hospital, Bologna,
Italy*



*Timothy Hughes
Royal Adelaide
Hospital, Australia*



*Andreas Hochhaus
University Medical
Center, Jena,
Germany*



*Jerald Radich
Fred Hutchinson
Cancer Research
Center, USA*

Scientific Advisory Committee

The iCMLf Board of Directors invited respected haematologists, scientists, nurses and patient representatives to join the iCMLf Scientific Advisory Committee to provide feedback and support to the activities of the Foundation.

As of 1 October 2010, there are eleven members of the iCMLf Scientific Advisory Committee.

Board of National Representatives

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

Countries currently represented are:

Germany, Brazil, France, Italy, India, Korea, Spain, Ireland, Australia, New Zealand, South Africa, Austria, Czech Republic, Lithuania, Serbia, Israel, China, Hong Kong, United Kingdom, Argentina, Venezuela, Cuba, Malaysia, Moldova, Netherlands, Nigeria, Portugal, Canada, USA, Belgium, Sweden, Croatia, Finland, and Poland.

More countries will be added as the Foundation expands.

Operational Team

The iCMLf's work is supported by two officers:



*Nicola Evans
Emerging Regions
Support and
Partnership
Programs Director*



*Jan Geissler
Communications
Manager*

The Emerging Regions Support and Partnership Program – The priority projects of the iCMLf

As a foundation dedicated to CML, the aim of the iCMLf is to address the challenges faced by the international CML community, be they patients, carers, clinicians, nurses or scientists. This will be through specific programs, unrestricted grants, clinical trials, education and influence.

The first priority of the iCMLf is to establish a support program for clinicians working in the developing regions who may not have easy access to appropriate monitoring assays and who are likely to face difficulties in their efforts to update their knowledge and skills regarding best practice for CML patients.

The Emerging Regions Support and Partnership (ERSAP) program is designed to establish supportive one-to-one relationship between key centres of excellence and clinicians in developing regions who have a significant commitment to CML patients.



The Adelaide ERSAP Preceptorship attendees; Dr Lukavetsky (Ukraine), Dr Rajendranath (India), Dr Damodar (India) with Prof. Tim Hughes

"The iCMLf will become a very important organisation for the development of the treatment and research in CML and this extends to the developing countries because we need enough knowledge to follow our patients to treat them the best way. This requires very good training and I think the proposal of the iCMLf shows exactly what you need in several steps. I understand this will be a very important development in developing countries in treating CML. Support in having the help from the iCMLf in terms of training and collaboration."

Ricardo Pasquini, Brazil

"On behalf of myself, my institution, the Institute of Blood Pathology and Transfusion Medicine AMS of Ukraine, and on behalf of the whole hematology service of Ukraine I would like to thank very much once again the iCMLf, the Board of this foundation and its whole team for the possibility to attend this training and support during my participation in ERSAP project. I am sure that our joint work and efforts now and in future will improve significantly the level of CML management in my country."

Dr Lukavetsky Ukraine 2010

The ERSAP program is regarded as the highest priority and will remain the iCMLf's major focus of activity and fund raising over the first few years.

The first three ERSAP projects address enhancing clinician's knowledge, sharing best practice and improving the access to diagnosis and testing facilities.

- The Preceptorship Program - Initiated in December 2009, continued in 2010 and 2011
- The Virtual Education Program - Initiated in December 2010 continued in 2011
- The Diagnosis and Testing Program – Initiated in June 2011

"I was fortunate enough to meet four of the preceptors throughout the year and have been impressed by their enthusiasm to share the knowledge gained with colleagues. All of the preceptors have discussed plans for enhancing CML management when returning home, either through increasing diagnosis, improved monitoring, or with new therapeutic protocols. The networks formed with the host laboratory teams and clinical mentors are invaluable, clearly demonstrating the continued benefit and support offered through the preceptorships."

N. Evans ERSAP Program Director

It is through these programs and the future activities of the Foundation that people with CML and their supporting healthcare professionals get the knowledge, skills, therapies and equipment they need to achieve the best possible outcomes.



Dr Kazakbaeva (Uzbekistan) and the Hematology team in Bologna, Italy in March 2011.

The ERSAP Preceptorship Program - providing training, education and support for clinicians from emerging countries.



Dr Bedu-Addo (Ghana) with Professor Clark and his team at the Royal Liverpool Hospital in July 2011.

Launched in December 2009 the Emerging Regions Support and Partnership (ERSAP) Preceptorship Program is a unique opportunity for clinicians from developing countries who treat CML to undertake an intensive educational program to develop and expand their CML management skills.

Clinical data for CML is rapidly evolving, posing a challenge for clinicians in developing regions as to how to enhance their education and continue to provide optimal treatment and monitoring for their patients. The aim of the ERSAP Preceptorship Program is to facilitate the sharing of best practice treatment for patients with CML in the areas of the world where this is most needed.

Learning through practical experience and one to one tuition

The ERSAP Preceptorship Program enhances clinical knowledge and skills in the treatment of CML through preceptorships at internationally renowned CML centres. Participants are part of the clinical team at the host site for the duration of the preceptorship, undertaking seminars and laboratory work where appropriate.

Participants conclude the program with a practical understanding of the latest information influencing the care of patients with CML. This includes: therapies to treat CML; efficacy, toxicity and the management of side effects, monitoring guidelines, management of resistance, the role of allograft in CML and developments in novel therapies, vaccines and drug cessation. Where possible preceptorships are coordinated with existing CML and haematology training programs at the host centres. This further increases potential learning and interactions between local and visiting clinicians.

CML Centres of excellence

In 2010 five specialist CML centers acted as preceptorship hosts:

- **Hammersmith Hospital, UK** - Clinical lead, Professor Jane Apperley
- **MD Anderson Cancer Centre, USA** - Clinical lead, Professor Jorge Cortes
- **OHSU Knight Cancer Institute, USA** - Clinical leads, Professor Brian Druker and Associate Professor Michael Mauro
- **Royal Adelaide Hospital Australia** - Clinical lead, Professor Tim Hughes
- **S.Orsola-Malpighi University Hospital, Italy** - Clinical lead Professor Michele Baccarani

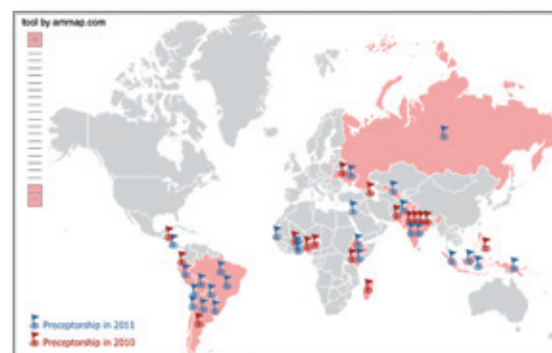
In 2011 centres in Bordeaux, Liverpool and Madrid were added to allow more diverse candidates to apply for the program.

- **Centre Hospitalier Universitaire (CHU) de Bordeaux, Bordeaux, France** - Clinical lead Professor Francois-Xavier Mahon
- **The Royal Liverpool University Hospital, Liverpool, UK** - Professor Richard Clark
- **Hospital Universitario de la Princesa, Madrid, Spain** - Professor Juan Luis Steegmann

Remarkable global response to the program

As the first project implemented by the iCMLf, it is very pleasing to see how well the ERSAP Preceptorship Program has been received. Double the number of applications for the program was received in 2011 and from a broader range of countries.

This map illustrates the originating countries of the preceptors in 2010 and 2011 demonstrating the wide reach of the program.



The Preceptorship Program has been a rewarding first project for the iCMLf to implement and we continue to learn how to meet the individual needs of hematologists as they travel from such diverse countries with varying facilities. Reports from the clinicians attending preceptorships have rated the program as exceptionally worthwhile and of great benefit to both the attendee and therefore, their patients.

"My patients and colleagues will benefit from this preceptorship in several ways: in the areas of clinic organisation, the need for a national CML registry, my better understanding of the processes for MRD monitoring and the time to request for such, relative risk scoring at diagnosis by the attending physician (or at least the transmission of data required for the determination of the Sokal and Hasford risk profiles), and clinical and research collaboration between my clinic and my preceptorship hosts."

Dr Oyekunle, Nigeria, 2010

"It was an honor and a pleasure to have participated in this training, despite the vast difference between these institutions and hospitals in developing countries. It is certain that all is not feasible to us but we can certainly learn to improve our management."

Dr Harivony, Madagascar, 2010

The ERSAP Preceptorship Program is supported by unrestricted grants from Novartis Oncology and Pfizer

Given its continuing success, the iCMLf is pleased to announce that the ERSAP Preceptorship Program will continue in 2012.

iCMLf Virtual Education Program for physicians from emerging regions has been well received

In December 2010, the iCMLf, in partnership with The Max Foundation (TMF), launched the iCMLf Virtual Education Program for clinicians from emerging regions. In this innovative format, leading haematologists provide e-learning tutorials about best practices for the management of patients with CML, taking into consideration the specific challenges in these regions.

CML Treatment with imatinib



- Biology and mechanisms of CML
- Mechanism of action of imatinib
- Results of the IRIS study
- Adverse effects of imatinib
- Methods to detect residual disease
- Imatinib in children and in pregnancy

European LeukemiaNet (ELN) recommendations 2009



- Predicting response to imatinib
- Depth of response, does it matter?
- Primary and secondary failure to imatinib
- How to monitor response
- Treatment recommendations

Optimising Response and Managing Resistance to Treatment 2009



- Definition of optimal response to imatinib
- Suboptimal response
- Considerations for managing suboptimal response, case study
- Adherence and molecular response
- Role of mutations, criteria for mutation screening on first line therapy
- Dose related toxicities with TKI's; concomitant medications

Treatment of patients after first line therapy



- Survival post imatinib
- Treatment with second generation TKIs (2nd line and 1st line)
- Optimal time to switch therapy
- Strategies to prevent imatinib failure
- Role of interferon and transplantation
- Presentation of new agents under investigation

Practical recommendations for the management of CML patients: Interview with Prof. Timothy Hughes



conducted by Pat Garcia-Gonzalez, Executive Director of The Max Foundation

The iCMLf Virtual Education Program has been made widely available in two ways: via video streams on the iCMLf website, and on USB flash drives for offline viewing.

The online version of the Virtual Education Program is available on the iCMLf website. Each video has been viewed over 875 times and over 90% of viewers watch 95% of the content.

To help physicians overcome the barrier of limited online capacity, the VEP presentations have been distributed to 1,000 physicians in more than 50 countries on USB drives

The Virtual Education Program was launched and showcased during the American Society of Hematology (ASH) annual meeting. A networking meeting for physicians from emerging economic regions was held on the 4th December 2010. This iCMLf/TMF event had over 153 attendees including 120 physicians representing 26 emerging markets.

In 2011 the iCMLf will add to the program, incorporating presentations on the management of CML in Spanish (Jorge Cortes) and French (Francois Mahon). Dr Susan Branford will give an overview of CML mutations and the importance of monitoring CML and Dr Jerry Radich will speak about the role of Bone Marrow transplant in 2011. As with 2010 the VEP will be made available to low tech environments on USB drives.

The second networking meeting between CML key opinion leaders and physicians from the emerging regions is planned during ASH 2011.

In 2010 the iCMLf Virtual Education Program was supported by an unrestricted grant from TMF.

In 2011 the iCMLf Virtual Education Program will be made possible with an unrestricted grant from Novartis Oncology.

Presented by the International CML Foundation (iCMLf) in partnership with The Max Foundation

iCMLf Virtual Educational Program Launch
"CML Management in Emerging Regions"

A networking and small group discussion forum with the Directors of the iCMLf including Prof John Goldman and Prof Tim Hughes, on the challenges and solutions of treating CML in emerging regions.

Attendees will receive the iCMLf Virtual Education Program on a flash drive, a series of presentations on best practices in the management of CML.

For physicians treating CML in emerging regions
RSVP at info@thmaxfoundation.org
Light lunch will be served
Use ASH Shuttle from Convention Center

Saturday, December 4, 2010
11:00 a.m. to 12:30 p.m.
Rosen Shingle Creek Hotel
Sebastian Room
Orlando, Florida

The ERSAP Diagnosis and Testing Program – supporting increased diagnosis and monitoring of CML in emerging economic regions

The third iCMLf ERSAP project supports diagnostic testing and ultimately disease monitoring for CML patients in developing countries where it is not currently available.



Obafemi Awolowo University Teaching Hospitals, Ile-Ife, Nigeria - one of the ERSAP Diagnosis and Testing grant recipients.

The mission of the iCMLf is to improve outcomes of CML patients globally. However, many hospitals in developing countries do not have the capability to confirm the diagnosis of CML either by cytogenetics or by molecular tests, which results in patients not being able to access

the medication available to enhance and extend their quality of life. Moreover continued monitoring is essential to detect early evidence of drug resistance, or disease progression, that in many cases could be better managed with a change in therapy.

Through the ERSAP Diagnosis and Testing Program the iCMLf will enhance facilities at a local level to either bring high quality testing to the patient, or to develop a low cost strategy for sending patient samples to a central reference laboratory for testing.

ERSAP Diagnosis and Testing Grants

In 2011, during phase one of this program, the iCMLf will offer grants to hematology institutions in emerging economic regions to facilitate the diagnosis of CML along with long term monitoring of CML patient samples. Institutions awarded these grants will partner with a CML centre of excellence to ensure the successful implementation of the proposal and ongoing mentoring and support at a clinical and laboratory level.

The grants will provide funding of up to a maximum of US \$10,000 per grant along with additional support from a partnering CML centre of excellence.

On behalf of director of Hematology Institute, I would like to thank you for your support. This news is very exciting for us and a success in the support and treatment of patients with oncohematological diseases. Also, this award demonstrates the power and effective stated mission of the iCMLf.

Dr. Kazakbaeva, Uzbekistan

Application evaluation procedure

In June 2011 the iCMLf called for applications for the ERSAP Diagnosis and Testing Grants. Grant applicants were reviewed by the iCMLf Directors and evaluated based on the following criteria:

- The primary focus for the iCMLf grant will improve or introduce facilities for CML diagnosis and monitoring
- The project will impact an existing area of need
- An indication that the iCMLf funding could underpin the development of on site facilities
- The project utilises both the partnership with the CML centre of excellence, and the iCMLf funding
- Clear plan of action with reporting of measurable outcomes
- Clear budget outline
- Applicant's CV/biosketch

Awarded Grants

9 grants have been awarded in 2011.

- Obafemi Awolowo University Teaching Hospitals complex Ile-Ife, Osun State, Nigeria
- Birla Cancer Center, SMS Medical College Hospital, Jaipur, India.
- Nizam's Institute of Medical Sciences, Panjagutta, Hyderabad India
- Korle –Bu Teaching Hospital, Korle-bu, Accra, Ghana
- Patan Hospital, Patan Academy of Health Sciences Katmandu Nepal
- Institute of Hematology and Blood Transfusion, Health Ministry of Uzbekistan Tashkent, Uzbekistan
- Post-graduate Institute of Medical Education & Research (PGIMER), Chandigarh, India.
- Kenyatta National Hospital/University of Nairobi, Nairobi, Kenya
- Sam Ratulangi Medical Faculty / Prof.Dr.RD. Kandou Hospital, Manado, North Sulawesi, Indonesia.

The progress of the awarded grants will be followed, evaluated and reported at 6 and 12 months.

The response to this program has been overwhelming and the iCMLf hopes to extend this program and the grants available in 2012.

"I am really happy that iCMLf has come up with an innovative program and I am very confident that this will help save a lot of lives around the whole world."

Dr Kayastha, Kathmandu, Nepal



Extending communication through the global CML community

"How did we ever do this before we had the Internet?" springs to mind when looking at international networks like the iCMLf, the European Leukemia Net or the CML Advocates Network. The Internet has become indispensable to share knowledge, collaborate and communicate globally. Despite CML being a rare disease, experts on all continents collaborate very closely to improve CML treatment. This worldwide community of hematologists is a perfect example for the Internet era. The iCMLf website aims to strengthen that community collaboration further.

Jan Geissler, iCMLf Communications Manager

iCMLf Online Discussion Forum features lively conversations about challenging CML cases

To share and enhance best practice management of CML, the iCMLf opened an online Discussion Forum, for clinicians to discuss difficult or interesting CML patient cases.

Within the first four months, lively discussions started, featuring 42 contributions and more than 3,200 views. Current cases include:

- Paediatric CML cases; feeding and nutrition in young children with CML
- Menorrhagia complicating Tyrosine Kinase Inhibitor therapy
- Marrow aplasia during CML treatment
- CML and pregnancy
- A multi-resistant, difficult-to-treat CML patient
- TKI therapy and cardiomyopathy
- Chronic phase CML with granulocytic sarcoma

Clinicians submit a brief history of the patient and the case for discussion to the iCMLf web-site coordinator. Each clinical case accepted for the forum will initially be sent to the iCMLf expert clinical panel for a brief independent response. The clinical case and the expert opinions will then be posted on the iCMLf forum and comments, questions and discussion invited. The iCMLf expert panel is comprised of leading hematologists in the field of CML from the iCMLf board of directors and scientific advisory committee.

The iCMLf will only accept cases where the patient and their clinician give permission for the case to be published on the iCMLf web-site. Details that are not critical to the case can be changed to preserve anonymity.

The suggested audience for this forum is clinicians treating CML. Other interested individuals can view and make comments on the forum as long as their qualifications are included with any comment.

More information: <http://www.cml-foundation.org/forum>



International partnerships, sharing experience and knowledge, are critical to the success of the iCMLf

Sub Saharan Africa Coalition– the iCMLf joined forces with other expert partners to improve CML outcomes in Sub Saharan Africa

For the past 10 years there has been unprecedented access to Glivec treatment for CML in many countries in Sub-Saharan Africa as well as in other low-to-middle-income countries. However, socio-economic barriers and lack of infrastructure have prevented the achievement of optimal clinical outcomes for patients diagnosed with CML in the region.

The Max Foundation has formed a coalition of expert partners to work towards rectifying this situation. Along with the iCMLf; FIND Diagnostics, the International Network of Cancer Treatment and Research (INCTR), Axios International and the CML Advocates Network are all participants.



Tim Hughes, Nicola Evans, Dr Amha (Ethiopia), David Yeung, and Devendra Hiwase celebrating the completion of Dr Amha's Preceptorship in Adelaide.

As organisations with overlapping interests in the area of cancer control in Sub-Saharan Africa, our activities directly or indirectly benefit CML patients. Learning about each other's projects will help the coalition leverage our collective efforts for the benefit of patients. Further more, working in coordination will enable more efficient use of resources and tracking of results.

"As we launch into 2011 we feel there is great momentum to put all these organizations together and generate a joint project. Our goal is to form and launch a coalition to improve CML outcomes in Sub-Saharan Africa. We hope to start with a pilot project in Black Lion Hospital (Tikur Anbessa) in Ethiopia,"

said Pat Garcia-Gonzalez, Executive Director of The Max Foundation.

This coalition compliments the work of the iCMLf through the Emerging Regions Support and Partnership Projects. The iCMLf will play a key role in providing training and support to physicians. In July Dr Amha Gebremedhin took part in the ERSAP Preceptorship Program supported by the iCMLf and will continue to partner with The Royal Adelaide Hospital through the ERSAP Diagnosis and Testing Program. Professor Tim Hughes and his team will provide mentoring and guidance as CML diagnostics become available at the Black Lion Hospital.

The iCMLf supports the call for an International CML Awareness Day



The CML Advocates Network, a worldwide network of CML patient associations, is calling for the proclamation of 22 September (9/22) as International CML Awareness Day.

The date 9/22 represents the genetic change of Chromosomes 9 and 22 that causes CML. The iCMLf welcomes the initiative, and calls on all physicians worldwide to actively support it.

Recognising an annual International CML Awareness Day aims to encourage patients, caregivers, healthcare professionals, government and industry, as well as the wider community, to work together to improve diagnosis, treatment and care of CML patients.

While many organisations have recognised 22 Sep as CML Awareness Day with success in years gone by, September the 22nd 2011 will represent the first International recognition of the date.

Proclaiming September 22nd as the annual International CML Awareness Day allows the global CML community to collectively celebrate the achievements within the treatment of CML, recognise what still needs to be done while acknowledging the bravery of the people impacted by the disease and the commitment of those who treat and care for them.



Faces of CML





Enhancing CML management and therapies through international scientific meetings



The iCMLf is proud to contribute to education in the field of CML in association with the European School of Hematology. The 12th iCMLf-ESH international conference, CML: Biological Basis of therapy, took place in Washington DC on September the 24th-26th 2010.

These annual CML meetings have become the most important international scientific event in the field and 450-500 scientists and clinicians attend the meeting each year. Despite the impressive clinical results of tyrosine kinase inhibitors in the management of patients with CML, many unresolved questions remain. The International CML meeting brings together scientists with new data on the cellular, molecular and immune biology of CML. Some of which may eventually translate into new therapeutic approaches that would en-

able the clinician to discontinue therapy with the expectation that the leukemia would not recur.

As usual this meeting received excellent reviews from attendees on the quality of data and presentations from CML specialists.

The 13th iCMLf –ESH meeting will be held in Estoril, Portugal on the 22-25 September 2011.



Dr Talpaz accepts the Rowley Prize at the 12th iCMLf/ESH International CML Meeting

Recognising lifetime achievements in improving outcomes for CML patients

The iCMLf awards an annual Rowley Prize

The iCMLf Rowley Prize is awarded each year to an individual who has made an outstanding lifetime contribution to our understanding of the biology and/or to progress in treating CML. Dr Janet Rowley has kindly given the iCMLf permission to name this award in her honour.



Dr Janet Rowley

Dr Rowley MD is the Blum-Riese Distinguished Service Professor of Medicine, Molecular Genetics and Cell Biology and Human Genetics at the University of Chicago. In 1973 she made a seminal discovery in CML when she used newly developed chromosome banding techniques to show that the Philadelphia chromosome is formed by a translocation between chromosomes 9 and 22. This discovery led to the eventual identification of the fusion gene BCR-ABL and ultimately to the development of targeted inhibitors of this leukemia-specific oncoprotein.

This is one of many major contributions made by Dr Rowley and her team to our understanding of the molecular biology of leukemia and other cancers. She was recently awarded the Presidential Medal of Freedom, the highest civilian honour awarded in the USA.

The award is presented annually at the International CML Meeting: CML – Biology and Therapy. The inaugural winner of the Rowley Prize in 2009 was Dr Brian Druker.

The recipient of the Rowley prize in 2010 was Dr Moshe Talpaz. Dr Talpaz is Associate Chief of the Division of Hematology/Oncology at the University of Michigan Comprehensive Cancer Center, Ann Arbor, Michigan, USA. He is one of the leading clinical investigators in hematologic malignancies worldwide. Dr Talpaz' focus is on the treatment of CML and brings special expertise in immunotherapy, cytokines and biologic response modifiers. Internationally known for his role in the development of targeted cancer therapeutics, Dr Talpaz pioneered the study of interferon in CML. As a pivotal member of the team that developed imatinib (Gleevec), Dr Talpaz was instrumental in bringing this new CML treatment to the market. As a leader in the development of novel therapeutics, Dr Talpaz has unique experience in the building of early Phase clinical trial programs.



CML in young patients: iCMLf and CML Advocates Network join forces



Prof Meinolf Suttrop

The iCMLf and the CML Advocates Network, the international platform of patient groups supporting patients and relatives suffering from CML, have joined forces to support physicians treating young patients affected by CML. As CML in children is very rare, collaborating across national borders is all the more important. The project was launched on International Childhood Cancer Day on 15 February 2011.

The newly launched web resource on paediatric CML is available on the iCMLf website and provides:

- a description of paediatric CML,
- a comprehensive overview of scientific publications and ongoing trials in paediatric CML,
- links to patient organisations supporting young CML patients.
- the iCMLf Discussion Forum features a number of discussions on young CML cases
- in the future, regular teleconferences will give paediatricians additional opportunities to share data and experiences.

Various persons with a special interest in paediatric CML give their views:

"As the coordinator of a number of clinical trials in paediatric CML, I know well how important it is to share best practice between those that treat young patients with CML. I am very supportive of this initiative and wish both organisations great success", says Prof. Meinolf Suttrop, Division of Paediatric Haematology and Oncology, Department of Paediatrics, University Hospital Carl Gustav Carus, Dresden, Germany.

"We perceive a need for communications between paediatricians treating children and adolescents with CML. At the same time, parents feel uncertainty how young CML patients can be managed in the best way. Joining forces between the iCMLf, connecting physicians, and the CML Advocates Network, connecting patient advocates, is a perfect match", says Jan Geissler who is both a CML patient, a co-founder of the CML Advocates Network and the manager of the paediatric project at the iCMLf.

"Five years ago, my youngest son just turned 9 years old when he was diagnosed with CML", says Rod Padua, president of the patient organisation 'Touched By Max Philippines'. "We are grateful that the international community is now collaborating to improve care of this very rare childhood leukaemia", he adds.

CML is very rare in children and young adults, accounting for less than 3% of all childhood leukemias and less than 10% of all CML cases. Incidence increases with age, being exceptionally rare in infancy, rising to 0.7/million/year at ages 1 to 14 years and to 1.2/million/year in adolescents. As a consequence, most CML data are derived from adult studies. Specific issues in children and adolescents with CML include the uncertainty about long-term effects of TKI therapy, challenges of adherence to therapy, fertility and family planning issues as well as psycho-oncology.



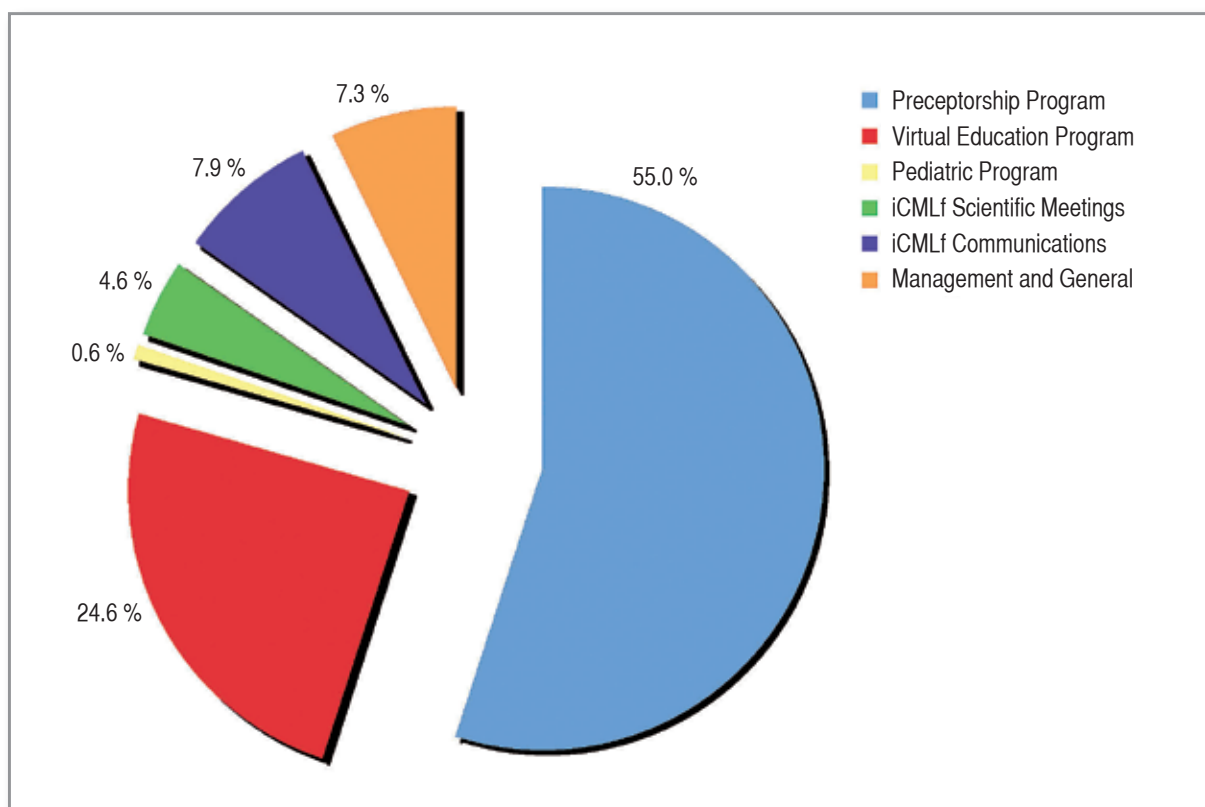
"The CML Advocates Network is a network of 60 patient groups across 49 countries today and we very much welcome the strong cooperation with the iCMLf. We think their work is extremely important for us as patients. To spread best practice and knowledge all across the globe and make sure patients are treated in the best way. So we really appreciate their work and we wish the iCMLf all of the luck to proceed and to grow and help patients in all of the different countries."

Jan Geissler, Germany



iCMLf Expenditure

iCMLf Expenditure on Activities

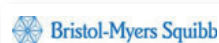


- Key iCMLf expenditure is towards projects with the greatest potential return
- 80% of iCMLf expenditure directed to assist CML management in emerging economic regions
- Administration costs well below 10% of generated income

Acknowledgement of support and donations

As a charitable Foundation it is only through grants and donations that the iCMLf can positively influence the lives of patients with CML in regions where this assistance is most needed. The mission of the iCMLf is to improve the outcomes for patients with CML globally. The programs and activities implemented to achieve this would not be possible without the generous contributions from our corporate partners.

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