



CONNECTING. OUR GLOBAL COMMUNITY

ANNUAL REPORT 2014/2015

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“...This is one of the best program of clinical learning on international platform...more candidates will participate and more it increases the views and advances the health care system in treating the Leukemia patients.”

iCMLf preceptor 2015

Welcome from the Chairman



As a physician treating CML I have shared the CML treatment journey with many CML patients. I have seen them through the difficult time after they have been diagnosed with a life-threatening cancer, we form treatment plans, work together on therapy and celebrate the highs and lows of a challenging journey. A journey, which for many, in these days of effective treatment, results in long-term control of their CML, in some cases no longer needing drug therapy. I am privileged to get to know families over the years, see them grow and change; children, grandchildren, the 'normality' of life. It's one of the great pleasures of this job to see the impact made by my work and that of my team.

I'm also privileged to travel often, to speak and lecture round the world and it's through this global community that I see the potential for the work and the benefits of the iCMLf. The idea of equitable worldwide CML management has always been the guiding principle of the Foundation, the desire that

the journey for all patients with CML has the best possible ending, that lack of resource or access to treatment no longer hinders the opportunity for long-term control of CML.

It is so pleasing to see the impact of our extended reach through the iCMLf programs this year. We have more clinical preceptors, further increased access to CML diagnostics and now over 13,000 people accessing information on the iCMLf website per month. Together with our members and partners we are increasing the potential for more people to access the most effective treatment possible. As this happens centres evolve, access to therapy increases and lives and communities are changed for the better.

It is now an integral part of my life that the iCMLf helps improve the CML journey for people globally so that 'normality' is a possibility more often.



TIM HUGHES
iCMLf Chair

Chief Executive's Overview



Increased access to best practice education + increased access to diagnostics = greater access to treatment. Greater access to treatment leads to a better quality of life for more people with CML.

It's a simple equation, perhaps too simple in reality, but at its heart, true, and this fundamental statement is at the core of all the iCMLf activities over the year.

When we consider that more than 13,000 people visit the iCMLf website per month looking for information and we have more than 500,000 page impressions, we know there's a real need for CML education. Our online programs aim to address this and with 7,000 views of the clinical case discussions and over 13,000 views of the lectures in the virtual education program we are reaching 73% of the globe. With 62% of our visitors coming from the emerging economic regions we know we offer key information to those who

most need it. The reach of the iCMLf preceptorship program and diagnosis and testing programs has also increased this year. Today more physicians have access to unique tailored education and more patients have access to CML diagnosis and monitoring tests because of these programs. This directly relates to greater access to effective CML therapy.

The challenges are great, the distances are large, but together we make a difference. Each centre of excellence training preceptors, each iCMLf grant supporting local PCR, the reach of our online education supporting physicians in Africa, Asia, China, Latin America, all of these have an impact and are changing lives.



Nicola Evans
iCMLf Chief Executive

Governance of the iCMLf

BOARD OF DIRECTORS



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Australia*



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*University of Texas MD
Anderson Cancer Center,
USA*

Scientific Advisory Committee

12

There are twelve members of the iCMLf Scientific Advisory Committee. Members are respected hematologists, scientists and patient representatives who provide advice and support for the activities of the Foundation.

Board of National Representatives

36

The 36 iCMLf National Representatives provide advice to the iCMLf Directors and assist implementation of initiatives at a local level. Through this global board we are able to offer needs specific understanding and programs to address local situations.

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



BRIAN DRUKER
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*Communications
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MELISSA DAVIS-BISHOP
*Emerging Regions Support
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 Coordinator*



STEFANIE BOCKWINKLE
Editor

iCMLf AIMS AND PRIORITIES

Registered as a charitable foundation in England and Wales, the iCMLf has a global charter. Formed by a leading group of hematologists, the aims of the iCMLf are to foster and coordinate global clinical and research collaborations and to improve clinical practice and disease monitoring in CML.

There are numerous activities that could come within this broad charter but the initial focus is to meet the needs in CML that are not already being met by other groups, particularly those needs that are best met by a global organisation.

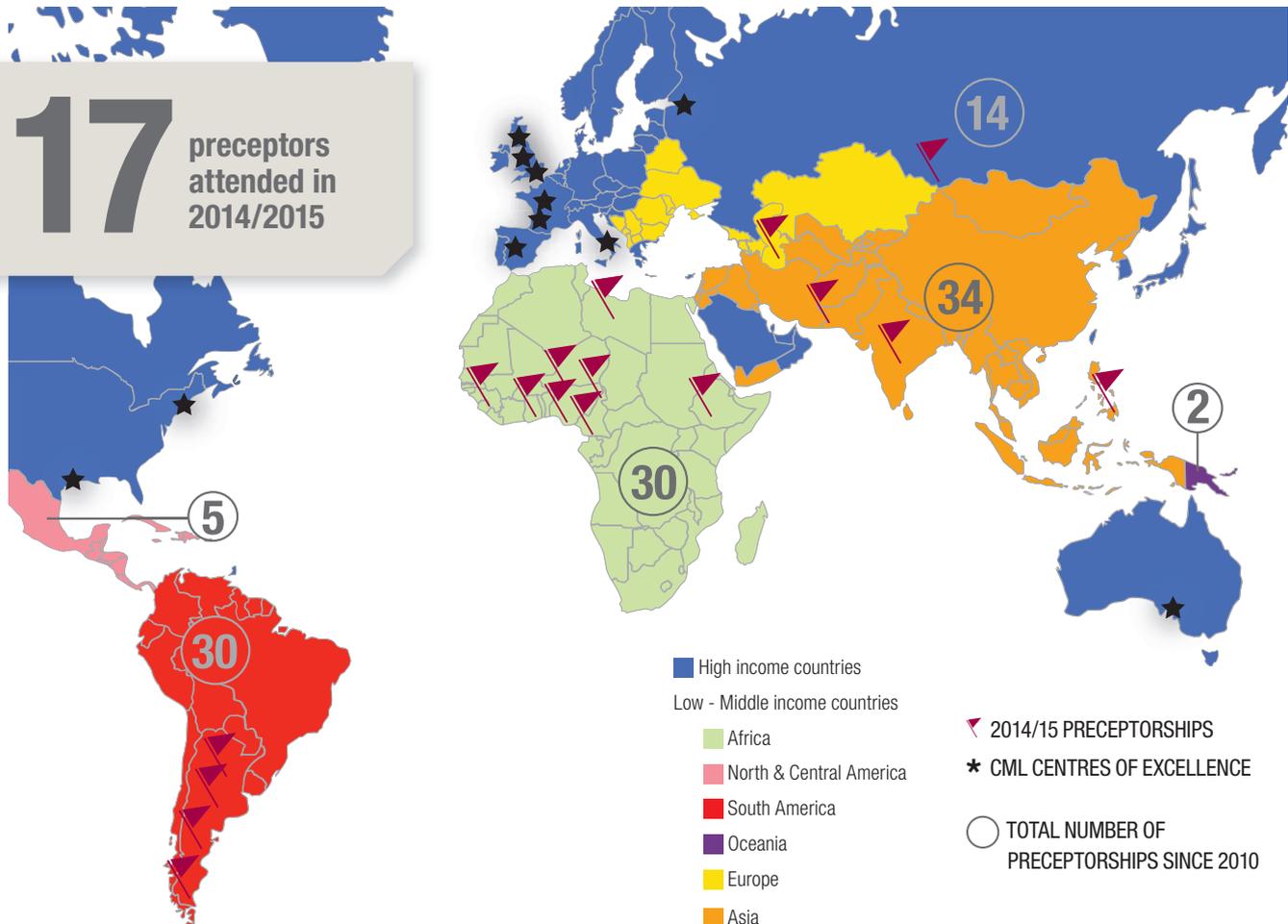
iCMLf GUIDING PRINCIPLES

- A focus on chronic myeloid leukemia and related disorders
- A truly independent not-for-profit foundation
- A global foundation with broad representation from all geographic regions
- Priorities and policies determined by hematologists and scientists involved in CML research and patient care
- Close consultation and cooperation with CML patient groups
- Active collaborations with key national and regional leukemia groups



Personalised, CML focused educational preceptorships

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.



IMPACT

Both the short and long term benefits to preceptors are profound and clearly demonstrated.

"... I saw the usefulness of applying the risk scoring systems to patient prognosis and care and I have resolved to score our new CML patients. I was privileged to learn about the various researches ongoing in the CML world in terms of targeting of CML stem cells and possibility of stoppage of TKIs after prolonged periods of molecular remission. Armed with this knowledge, I will be able to better counsel patients as regards their diagnosis and effect on their lives."

Dr Ibe, Nigeria (Glasgow site 2015)



Dr Duru with Professor Snyder at the City of Hope.

"An important change I implemented in the clinic is the adjustment of doses of dasatinib, for example, lowering it because of adverse events as long as the patient maintains the cytogenetic and molecular remission. This was something I was reluctant to do in the past."

Dr Ventriglia, Argentina (MD Anderson site 2014)

Since May 2010



115

Clinicians from 49 countries have participated in the program.

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.



60%

of participants have kept in touch with their host site since their preceptorship, continuing the information sharing process beyond the few weeks of the program.

The uniqueness of the 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.



100%

of participants believe that program has given them excellent potential to improve their clinical knowledge of the treatment of CML.

THANK YOU TO OUR HOST CENTRES WHO DONATE THEIR TIME AND RESOURCES FOR THIS PROGRAM

CML Centre of Excellence	Program Leader	No. of clinical preceptorships undertaken to date
 The Centre for Cancer Biology and Royal Adelaide Hospital, Adelaide, Australia	Tim Hughes	19
 S.Orsola-Malpighi University Hospital, Bologna, Italy	Michele Bacarani and Gianantonio Rosti	10
 Centre Hospitalier Universitaire (CHU) de Bordeaux, Bordeaux, France	François-Xavier Mahon	7
 City of Hope, California, USA	David Snyder	7
 Paul O'Gorman Leukaemia Research Centre, Glasgow, Scotland	Tessa Holyoake	4
 The University of Texas MD Anderson Cancer Center, Houston, USA	Jorge Cortes	22
 Royal Liverpool University Hospital, Liverpool, England	Richard Clark	5
 Hammersmith Hospital, London, England	Jane Apperley	17
 Hospital Universitario de la Princesa, Madrid, Spain	Juan Luis Steegmann	5
 OHSU Knight Cancer Institute, Portland, USA	Michael Mauro	7
 Fred Hutchinson Cancer Research Center, Seattle, USA	Jerry Radich	9
 Almazov Federal Centre of Heart, Blood and Endocrinology, St Petersburg, Russia	Andrey Zaritskey	2



iCMLf Diagnosis and Testing Program – Building Global Diagnostic Capabilities

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.

iCMLf GRANTS

12 new grants
in 2015

13 continuing
from 2014



	Initial Patient Impact	PCR Tests	Molecular Monitoring	Mutation Analysis	Enhanced Laboratory Capacity	Establish local PCR	Established as a Referral Centre
2015 new grants	4059	605	9	-	8	3	3
2014 continuing grants	1831	787	10	3	8	3	2

*“A year later **31** new eligible patients have received treatment after on-site PCR analysis. Previously an average of **8** eligible patients who were able to afford PCR analysis were able to receive treatment annually.”*

Dr Benneh, Ghana (iCMLf grant recipient in 2014)

SAMPLE SHIPMENTS

In some instances shipment of blood samples to a referral centre for testing is the only feasible way to get reliable results. The iCMLf has had a long standing partnership with the Max Foundation in the Philippines to help patients access PCR, many for the first time.

In 2015, 30 patients with imatinib resistant CML had blood taken and shipped to Australia for mutation testing. These tests allow meaningful treatment decisions to be made.



Staff and patients at PGH involved in the CML sample shipment

“Efforts such as molecular monitoring and mutation testing have changed the therapeutic landscape of CML in the Philippines.”

Dr. Rico Paolo Gomez Tee, the Chief Fellow, Hematology, Philippine General Hospital (PGH)

2014 iCMLf Awards



JANET ROWLEY PRIZE TO RECOGNISE SCIENTIFIC ACHIEVEMENTS IN CML

Professor Owen Witte
(Los Angeles, USA)

Rationale: recognising Dr Witte's outstanding contributions in fundamental CML research such as the discovery of tyrosine kinase activity for the ABL gene and the demonstration of the BCR-ABL oncoproteins in leukemia.



INAUGURAL JOHN GOLDMAN PRIZE TO RECOGNISE CLINICAL ACHIEVEMENTS IN CML

Professor Rüdiger Hehlmann
(Heidelberg, Germany)

Rationale: the important contributions to clinical management of CML that have improved the outcomes for CML patients globally. Professor Hehlmann also created international CML study groups and networks to foster international research cooperation.



iCMLf Forum for Physicians from Emerging Economic Regions



The aim of the annual iCMLf Forum is to focus on the challenges faced by physicians in emerging economic regions. The meeting showcases specific topics relevant to these regions, promoting discussion CML management between the developed and developing centres.

Presenters from Ethiopia, Brazil and India discussed monitoring, pregnancy and stopping CML therapy with the iCMLf experts and audience.

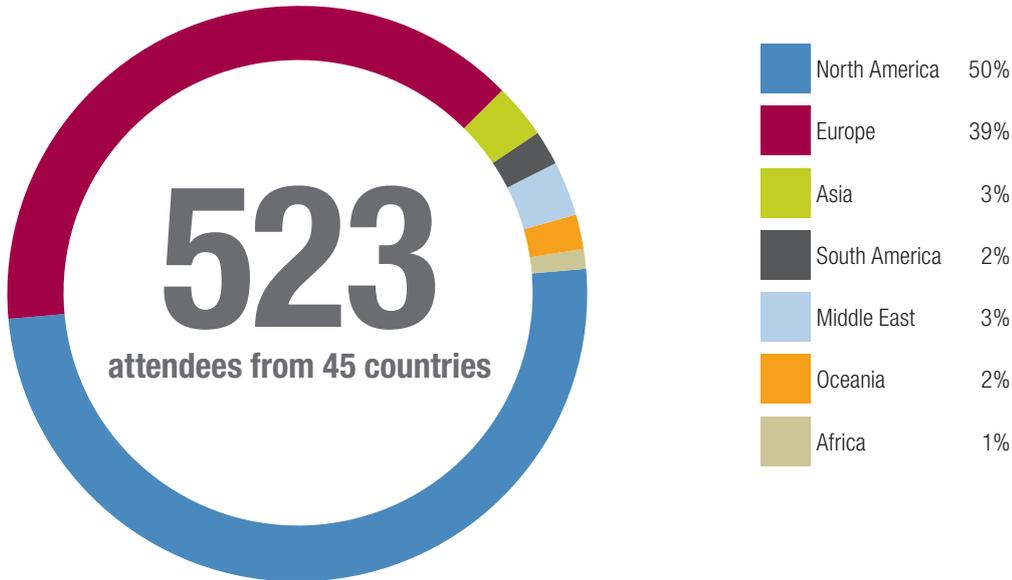
The annual iCMLf Forum is a partnership project between the iCMLf and The Max Foundation.

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

16th John Goldman Conference on CML

The annual international CML Conference co-sponsored by the iCMLf and the European School of Hematology is well established as the premier CML meeting. In 2014 it was renamed the 'John Goldman International CML Conference: Biology and Therapy' to honour the late Professor John Goldman.

PARTICIPANT GEOGRAPHIC COVERAGE:



MEETING HIGHLIGHTS



9 scientific sessions



2 workshops for non-clinical scientists



2 Satellite symposia



4 Mentored and biology poster walks

More than
520

people attended the CML meeting in Philadelphia.



iCMLf Website and Social Media

A RELIABLE INTERACTIVE EDUCATIONAL PLATFORM FOR CML

The iCMLf website (www.cml-foundation.org) is an established worldwide educational platform for CML. It provides up to date information on CML through web lectures, an online discussion forum on challenging and interesting CML cases and scientific information on CML to an international community of healthcare professionals and scientists managing and researching CML.

In 2014/15:



More than
13,000
visitors per month



More than
511,000
page impressions per month



Most frequently visited pages are:

- Case Discussion Forum
- Scientific news CML
- Virtual Education Program

TRULY INTERNATIONAL AUDIENCE WITH STRONG FOCUS ON THE EMERGING REGIONS



People from
73%
countries around
the world



Visitors from
141
countries



62%
of visitors are from
Emerging Regions

Top 3 non-English language countries



China



India



Germany

CML SCIENCE & EDUCATION – UP TO DATE SCIENTIFIC INFORMATION ON CML

Important scientific meetings, relevant scientific publications on CML, links to active clinical trials and expert opinions.



SOCIAL MEDIA

In 2014/15 the iCMLf has joined the world of social media to further strengthen networking and collaboration within the international CML community.

iCMLf on Facebook (established in March 2015)

- 90 followers
- 17 iCMLf posts

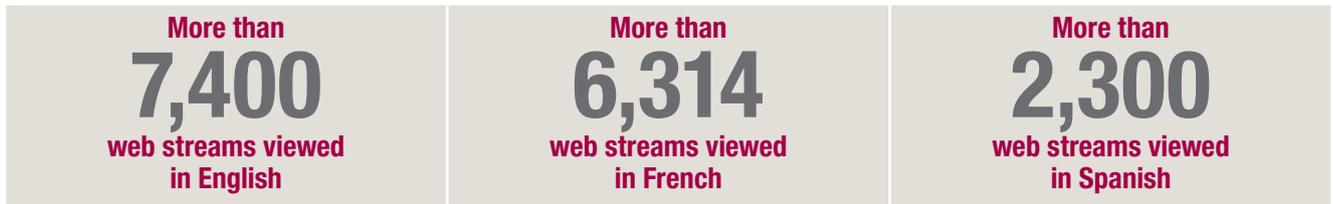


Virtual Education Program

The iCMLf Virtual Education Program is another valuable educational tool providing webcast presentations from leading haematologists.

Presentations in 2014/2015:

Front line therapy of CML-CP, Optimizing Therapy, High Risk CML and New developments in CML



Prof Junia Melo



A/Prof. Susan Branford



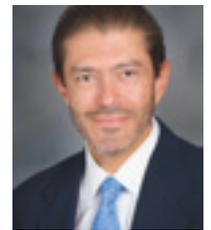
Prof. Tim Hughes



Dr Agnes Yong



Dr David Ross



Prof. Jorge Cortes

Online Expert Discussions on CML cases

The Clinical Case Discussion Forum is the most popular section accessed on the iCMLf website. To share and enhance best practice management of CML, experts and interested clinicians can discuss difficult or interesting CML patient cases. Each clinical case gets a brief independent response from the iCMLf expert clinical panel and is open to discussion with other experts around the world.



16 cases were posted
on the Case
Discussion Forum
in 2014/2015



MORE THAN
7,000
case views



490
average views per case

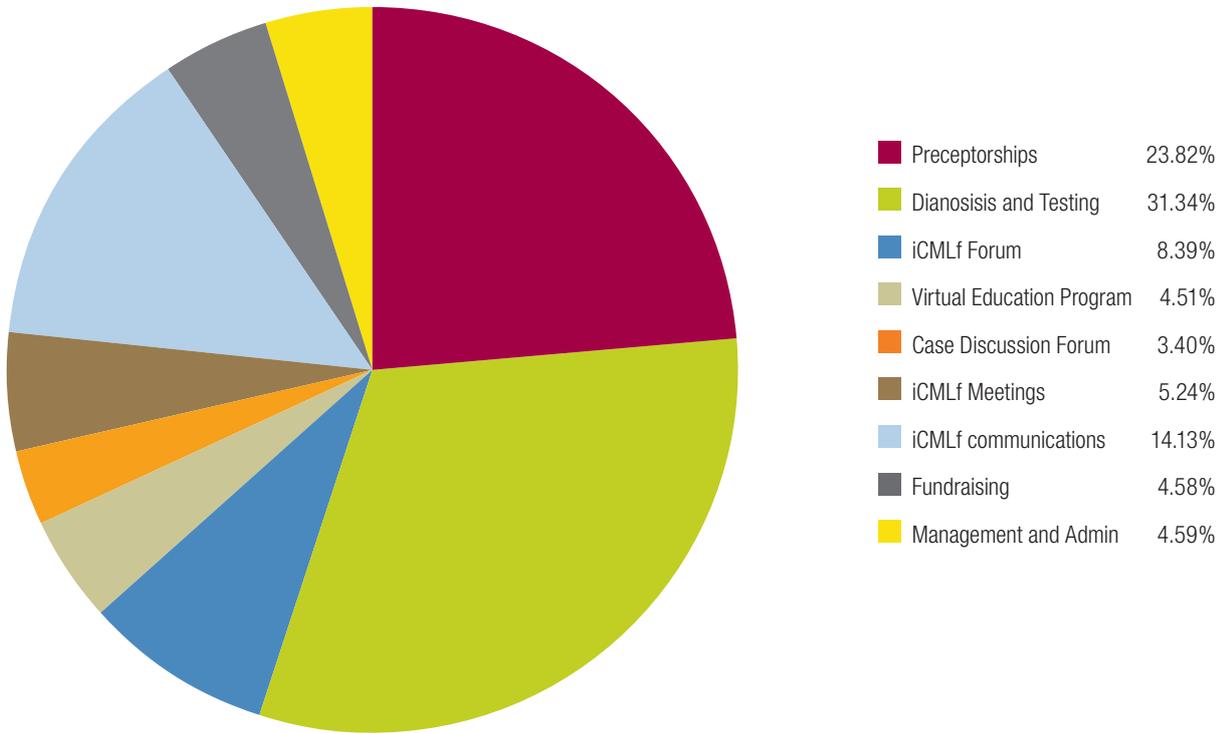


30
physicians contributed
cases and replies

We thank all our members for their support and contributions.



Expenditure



71%

on specific iCMLf programs increasing education and access to diagnostics.



63%

directly to programs in the emerging economic regions.



14%

sharing CML information and education with the CML community.

Thank you!

GRANTS AND DONATIONS

As a charitable Foundation the iCMLf relies on grants and donations to continue the programs and activities that positively influence the lives of patients with CML. The mission of the iCMLf is to improve the outcomes for patients with CML globally. We thank our corporate partners for their generous contributions that help us achieve this.

Premium Supporters



Major Supporters



Other Supporters



FRIENDS OF THE FOUNDATION

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

'JOHN GOLDMAN 5K FUN RUN FOR A GOOD CAUSE'

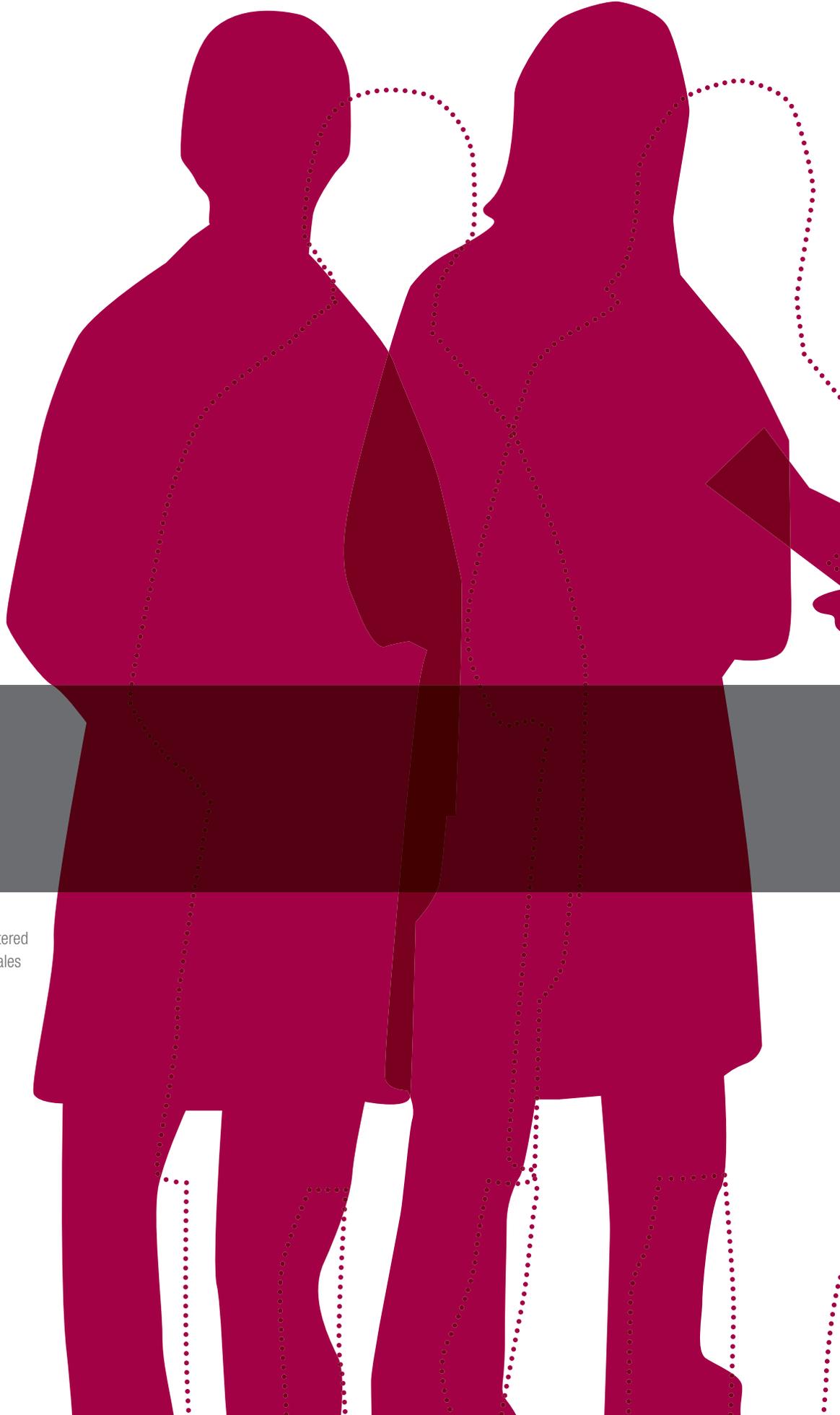


During the 16th John Goldman Conference on CML the iCMLf and the ESH invited meeting attendees to the first 'John Goldman Fun Run'. Over \$1,500 was raised for the iCMLf Goldman fund.

Thank you to all participants we look forward to seeing you in Estoril in 2015!

Donate to the Goldman fund on the iCMLf website www.cml-foundation.org. Funds go specifically to support the training of young CML clinicians and scientists.





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

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