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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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Board of Directors:

T Hughes (Chair), J Apperley,
M Baccarani, J Cortes,
B Druker, A Hochhaus,
M Mauro, J Radich, G Saglio,
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,

This year the iCMLf turns 10! It is both an opportunity to reflect on what we have achieved in our first 10 years, as well as a time to build on the foundation we have firmly established to start new endeavours.

With now over 180 participants the iCMLf Clinical Preceptorship Program, this remains the flagship program for the Foundation. Participants continue to report benefits of their visit over the long term, changing clinical practice, improving clinic facilities and meeting mentors for life. All, as a direct result of their preceptorships.

“I have established a one-year program which includes strategies to improve access to medicines, establish practice guides and develop workshops or educational events on leukemia. All this to involve residents and fellows in the management of CML.”

Dr Enriquez, Peru

The preceptorship program, along with the iCMLf Diagnosis and Testing Program and our online education platform has cemented the iCMLf at the forefront of global CML education and best practice management.

However, it has become increasingly obvious that providing quality access to diagnostics and through this, access to the best possible drugs for every person with CML is nigh on an impossible task with the ever-increasing prevalence of the disease. Global collaborations led to the early leaps in fighting CML and global collaborations will get us to the next step. From the beginning a fundamental aim of the iCMLf was to foster and coordinate global clinical and research collaborations, to improve clinical practice and disease monitoring in CML. The iCMLf Cure Consortium has now been formed with this in mind to take us to the logical next step, a cure for CML. You can read more about this vision and our first step on page 2.

Of course to get to a cure we need major funding! To start us on the way, create awareness of our goal and also show the commitment of the members of the iCMLf to this goal, 26 people are climbing Mount Kilimanjaro on the iCMLf

Climb for a Cure 2019.



Tim and Nicola preparing for their climb

Three people with CML are making this climb, traveling from Australia, Germany and Nigeria. They will be joined by three of the iCMLf directors; Tim Hughes, Jorge Cortes and Michael Mauro, along with Nicola Evans the iCMLf Chief Executive. Our other climbers are CML patient advocates, researchers, scientists and iCMLf supporters, all with a vested interest in seeing a cure for CML. We truly are a global group with climbers from every continent. To see more of the people climbing and read of their reasons to make the effort, visit us at <https://icmlf-kilimanjaro2019.raisely.com>.

“We want to get every patient with CML into a long-term remission that doesn't require ongoing therapy.”

Tim Hughes, Chairman of the iCMLf

Please support us and inspire us up the Mountain with your donations. At the time of writing we have almost raised \$50,000, which is an amazing start, but our goal is \$200,000. With your help we can get there!

For more information on how you can help the Foundation, or how we can work together, please email us at info@cml-foundation.org.

Your iCMLf Team

Working towards a cure for CML

In 2019 the iCMLf is actively seeking funds to move towards a cure for CML. A cure for CML may mean different things to different people, but in essence we want to get every patient with CML into a long-term remission that doesn't require ongoing therapy.

We recognise that this will not be achievable in 100% of patients, but we aim to get as close as possible over the next decade. To achieve this we need the CML research community to work together effectively. We also need to be innovative and ambitious to make this a reality. The iCMLf has formed a CURE CONSORTIUM to focus our efforts. Specifically, we plan to build multicentre global research collaborations to accelerate the development of more effective and safer treatment strategies with the view that these will lead to a cure.

The potential impact of this program is substantial. There are currently estimated to be over 800,000 CML patients globally. CML is predicted to become the most prevalent leukaemia by 2040 when there are projected to be over 3 million patients worldwide.



The potential impact of this program is substantial.

STAGE 1

The iCMLf Global Genomic Alliance

Despite the excellent progress we have made in managing patients with CML, major challenges remain. Even with our current choice of drugs, 15-20% respond poorly to all therapies and half of these patients will die from CML-related causes. Among those who respond well, less than 25% are able to stop therapy and remain in remission with current approaches. To optimise outcomes for CML patients we need to bring CML management into the precision medicine era. This requires detailed assessment of a patient's individual risk profile so that a risk-adapted approach to therapy can be applied. However, there is currently no accurate and reliable way to determine patient risk. Furthermore, for a small minority of very high-risk patients, all current drugs are ineffective and new approaches are needed – preferably at diagnosis, rather than after resistance or progression has developed.

In many blood cancers drug selection is now based on a patient's genomic profile at diagnosis. Specific gene mutations can be targeted by a specific therapy. Furthermore, the genomic profile can categorise patients into risk groups, which aids the assignment of treatment strategies for best outcomes. In contrast, CML has been considered a genetically uniform disease because all patients have the same initiating genetic mutation, which is targeted by the same drug therapy and most patients respond well. However, recent studies of CML patients from a number of research groups suggest that some already have other genomic mutations at diagnosis and these may be responsible for poor response to standard therapy. Importantly, some of these additional mutations may be targeted by drugs that are already in use for other diseases.

The iCMLf Genomic Alliance will harness the wealth of genomic information that is generated in local CML research projects by building a platform to facilitate data assimilation, sample exchange, cross-validation and ultimately, validation of a genomically-based predictor in prospective clinical trials. Combining many data sets and facilitating global collaborative studies will enable us to develop a baseline predictor of adverse outcomes. No single assay currently available has high enough sensitivity and specificity to allow us to identify high-risk patients with sufficient confidence to be clinically actionable. This genomically-based predictor will then be validated prospectively, subject to adequate funding being secured. Following that, we will test whether a composite approach combining the validated genomic risk score with a clinically based risk score will allow us to more reliably identify these high-risk patient categories.

With the increasing prevalence of CML a concerted global effort working towards a cure is imperative. As a global organisation led by clinicians and researchers at the forefront of this disease, the iCMLf is uniquely positioned to do this. However, we need funding to begin our global collaborations.

STAGE 2

Climb for a Cure 2019: Mount Kilimanjaro

In 2019 the Foundation is breaking new ground with a fundraising adventure. From 26 October to 3 November 2019 a strong team of 26 clinicians, researchers, advocates, CML patients and supporters of the iCMLf are climbing the highest freestanding mountain in the world, Mount Kilimanjaro.

Participants are from all five continents and everyone has a common goal: to reach the top of Mount Kilimanjaro and to raise urgently needed funds for the iCMLf CURE Program.

For many of us climbing, this is completely outside our comfort zone, but we know that curing CML is a huge endeavour and so we want to undertake a big challenge to raise funds and awareness of our work. CML can be cured, Mount Kilimanjaro can be climbed!

All of the money raised on this challenging adventure will help the iCMLf get closer to a cure. The big unknown is how much money, how much time and how much inspiration it will take to get to a cure.

Our aim is to raise \$200,000 – but there are no limits!

You can help us to achieve our fundraising goals and beyond.

Donate at <https://icmlf-kilimanjaro2019.raisely.com/>

The CURE CML Climb

MOUNT KILIMANJARO 2019

Examples of what the funds will go towards:

- **\$20,000 will provide a PCR machine for CML diagnosis and monitoring to expand the number of patients who can receive best-available therapy**
- **\$100,000 will support a mutation screening project to further our understanding of drug resistance**
- **\$400,000 will support a project to optimise our approach to treatment free remission**
- **\$1,000,000 will fund a multi-centre genomic alliance to accelerate the development of more effective and safer treatment strategy**



Mount Kilimanjaro can be climbed. CML can be cured.

Our Climb for a Cure team of 26 is working hard and with a lot of passion to climb the Mountain and exceed their fundraising goals to cure CML. Meet four of our climbers here.



TIMOTHY HUGHES

Australia

“Without effort and commitment, you don’t achieve your goals.”

“For the last 3 decades I’ve been treating people with CML and researching better ways to treat them. In the 1990s nearly all my patients died. They would be doing OK on treatment for four or five years, and then lose response and lose their battle.

That really motivates you.

Dying of CML is now uncommon, although most patients remain dependent on therapy for the rest of their life to stay well. We now need to take the next step.

The iCMLf, which I Chair, is now forming a global alliance of CML researchers in a push to cure CML. We think this is the best way to make a big impact at this stage, but we will need substantial funds to do this.

Climbing Mount Kilimanjaro is way outside my comfort zone, but that’s OK. Without effort and commitment, you don’t achieve your goals.”

(Timothy Hughes)



YUNUS, AYLA AND CONNY BOROWCZAK,

Germany

“We are committed to raising money because without money there will be no research and no cure.”

“Since the first day my son was diagnosed with CML we firmly believe that he will recover. Our family supports organisations and projects that are committed to making CML curable. Therefore we became part of “Climb for a Cure 2019”. We are committed to raising money because without money there will be no research and no cure.

Thanks to effective medication, CML has changed from a fatal to a chronic disease. This is a great achievement and gives CML patients hope. But this is not enough – more can be done!

Our children need a healing therapy! This is our highest priority as a family and we want to reach the top and achieve a cure for CML.”

(Cornelia Borowczak)

WILL YOU SUPPORT OUR CLIMB FOR A CURE 2019: MOUNT KILIMANJARO TEAM?

Every climber is covering their own climb costs. ALL the money you donate goes directly to the iCMLf to support the iCMLf CURE Program.

Donate here to support the Climb for a cure team:
<https://icmlf-kilimanjaro2019.raisely.com>



OJELABI AYODELE,

Nigeria

“Your donation will go a long way to help me and other patients to live a normal life.”

“May thirteenth, 2015 – I will not forget this date until a cure for CML is in sight. This was the day I got my diagnosis. That day, everything stopped.

In Nigeria with such diagnosis, you are on your own.

But thanks to Novartis and The Max Foundation I am still breathing and so are a 1,000 plus Nigerian patients, too.

Yes, a thousand plus.

So few, because Nigeria is an emerging economy and many patients still die from CML for lack of proper diagnosis.

Your donation will go a long way to help me and other patients to live a normal life.”



RIHAB NASR

Lebanon

“I am looking forward to fulfilling my passion for community engagement and participating in creating tangible improvements in CML. . .”

“I am a cancer researcher and my research focuses on the development of targeted therapies for leukemias. I am also a cancer prevention advocate, and I believe that more efforts should be invested in cancer education, prevention and research.

I believe scientific research does not happen in a vacuum. Scientists belong to a community that extends beyond geographic borders where they share the unique goal of spreading knowledge and finding solutions to major societal and health issues such as cancer. For this goal is a must to achieve, I chose to participate in this campaign to support CML research at the international level. Being part of a group of leading scientists, oncologists, advocates and CML patients in this adventure will hopefully give me the chance to be exposed to differing perspectives, looking forward to fulfilling my passion for community engagement and participating in creating tangible improvements in the CML realm.”

Recognising inspirational efforts in CML

The first iCMLf Prize, the Rowley prize, was awarded to Professor Brian Druker at the CML meeting in Bordeaux in 2009. Over the last 10 years the Foundation has continued to honor those who make significant contributions to our understanding of CML and its management. It is through the work of these people and their teams that there has been such considerable progress in the treatment of CML.

In 2019 we meet again in Bordeaux to present the 2019 iCMLf prize medals at the annual John Goldman Conference on CML.

Rowley Prize

Professor Michael W. Deininger
(USA)



The 2019 Rowley Prize is awarded to **Michael Deininger** in recognition of his achievements in researching the biology of CML for over 20 years now. As a clinician-scientist with a translational research focus, he has constantly strived to develop more effective therapies and strategies to prevent drug resistance. This has contributed to the establishment of TKI therapies in CML and significantly transformed the way CML is being treated today.

Goldman Prize

Professor François-Xavier Mahon
(France)



The iCMLf has awarded the 2019 Goldman Prize to **François-Xavier Mahon** recognising his breakthrough achievements in the clinical development of CML therapies and his pioneering research on treatment discontinuation in CML. He was amongst the first to explore the concept of treatment-free-remission (TFR) and is internationally recognised for initiating and leading treatment discontinuation studies in CML.

iCMLf Prize

Dr Carolina Pavlovsky
(Argentina)

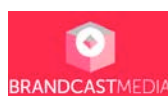


The 2019 iCMLf prize has been awarded to **Carolina Pavlovsky** for her efforts to continually bring the 'real-world' perspectives of the emerging economic regions into the discussion of CML management. She has always been committed to finding workable solutions for areas with limited resources and to providing practical advice and guidance for management of CML to non-academic centres.

Recognising 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.



iCMLf Forum 2018

Perspectives on treating CML from Ghana and Thailand



Prof. Hughes opening the 2018 iCMLf Forum

Now in its ninth year the annual iCMLf Forum for Physicians from Emerging Economic Regions is a successful meeting that continuously evolves in structure and content to meet the needs of the audience. The Forum is a partnership project between the iCMLf and The Max Foundation which, held during ASH each year, has the specific aim of providing a discussion-based forum to recognise and address the challenges faced by physicians in the emerging regions. It is the only event where physicians from all over the world come to address specific needs treating CML in a resource limited setting.

In 2018 the topics discussed were:

- **Perspectives on treating CML in pregnant patients** Professor Dragana Milojkovic (UK) and Dr Amma Benneh-Akwasi Kuma (Ghana)
- **Perspectives on treating CML in pediatric patients** Professor Meinolf Suttrop (Germany)
- **Perspectives on adherence during TKI therapy** Professor Saengsuee Jottar (Thailand)



Dr. Benneh discussing CML treatment for pregnant patients in Ghana

The 'Meet the Expert' round table discussions, specifically for physicians from the emerging regions, were an addition to the Forum in 2017 and continued in 2018. These discussions are a unique opportunity for physicians from low and middle-income countries to have in depth conversations with CML experts. These more specific, personalised, discussions are especially useful as the availability of TKIs has expanded in the emerging regions through the Max Access Solutions program. Physicians with limited exposure to these drugs are able to address specific clinical issues in this setting. This year physicians from Paraguay, India, Mexico, Chile, Bolivia, Argentina, Uruguay and Honduras were able to participate in this part of the program.

“Excellent meeting with excellent discussion,”

The longevity of the content is another important aspect of the Forum. People throughout the CML community can view the presentations online at <https://www.cml-foundation.org/emerging-regions/icmlf-forum/1280-ersap-icmlf-forum-2018-streams-2>.

The iCMLf Forum is now the most frequently viewed content on the iCMLf website clearly demonstrating the interest in the discussion topics for the wider community. The 2019 iCMLf Forum is planned for 12-3pm on the 6th of December in Orlando, during ASH. We hope to see you there!

We hope to see you at the following meetings



SAVE THE DATE



iCMLf Forum for Physicians from Emerging Economic Regions

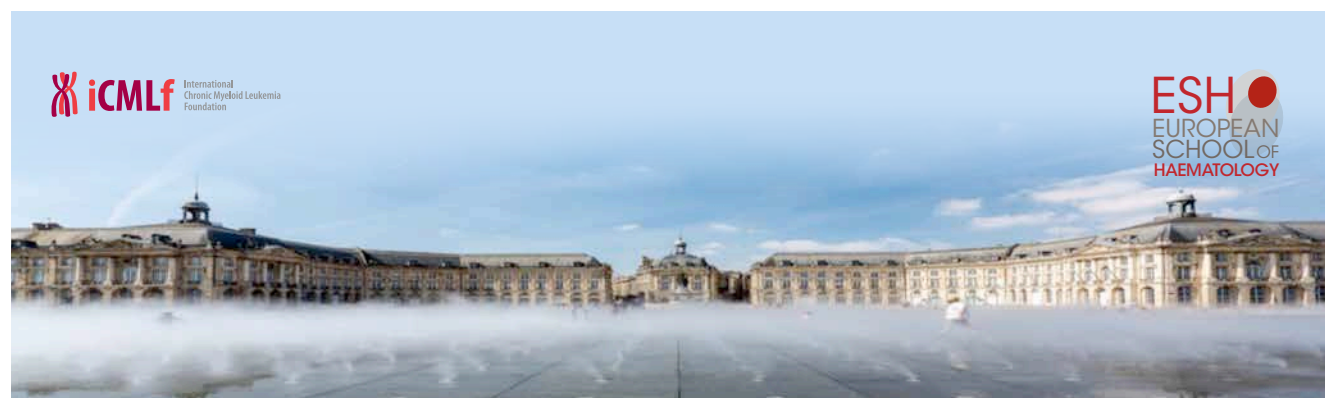
'Overcoming challenges treating CML'

Featuring practical innovations sharing experiences and discussion with CML experts.

Held during the annual American Society of Hematology meeting.

**Orlando, Florida
Friday 6 December 2019**

To register your interest and reserve your place, please email arlene@cml-foundation.org



21th Annual John Goldman Conference on **CHRONIC MYELOID LEUKEMIA: BIOLOGY AND THERAPY**

Chairs: J. Cortes, T. P. Hughes, D. S. Krause
Organizers: R. Bhatia, M. Copland, M. Deininger, P. Hari,
D. Perrotti, J. Radich, D. Réa

BORDEAUX, FRANCE | SEPTEMBER 12-15, 2019

Program will include:

- John Goldman Prize
- Janet Rowley Prize
- iCMLf Prize
- Keynote lectures
- Special lectures and oral presentations selected from submitted abstracts
- Workshops for non-clinical scientists
- Clinical and biology manned poster walks
- 2019 Symposium on Ph+/PH- like ALL
- Concurrent 'Meet the Expert' sessions