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Edition 9

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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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,

"Death ends a life, not a relationship" Robert Gale MD on the passing of Professor John Goldman in December 2013.

This is how we at the iCMLf view our time with John as our Chairman. The vision and leadership he had as one of the founding members of the iCMLf shaped the mission, aims and initial focus of the Foundation and we are what we are today because of him. In this Newsletter the first since John's death we take the opportunity to reflect a little on what the Foundation meant to John, what we have achieved so far for the CML community and how the iCMLf community remembers the man, clinician, scholar, scientist and friend that was and will always be remembered as John M Goldman MD.

"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"
Professor John Goldman, April 2010

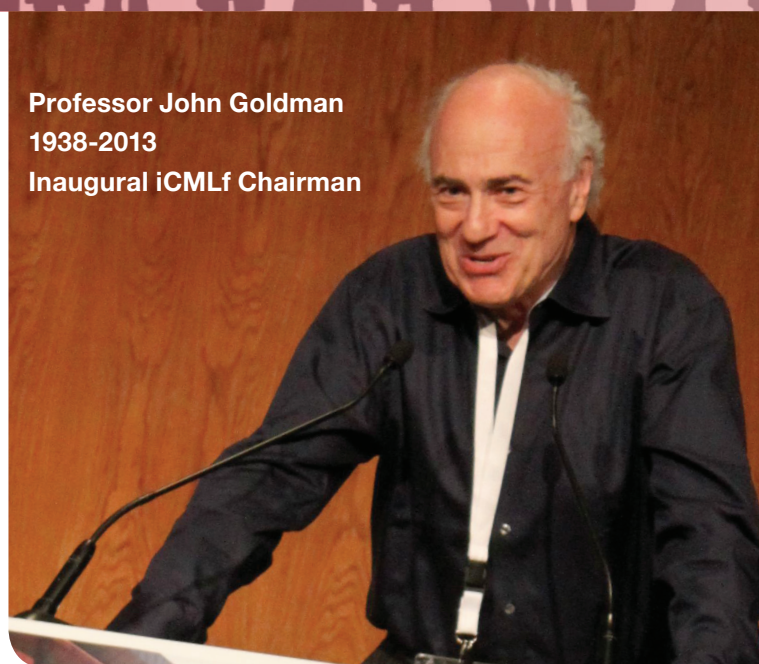
It is this that became the initial focus of the iCMLf and our programs and activities in the emerging economic regions (EER). Through these we work to 1) increase access to high quality CML education, 2) increase access to CML diagnostics and through this, 3) the best possible therapies for CML.

The inaugural program of the iCMLf, designed to increase access to CML expert teaching and experience for those who usually cannot access this, is our Clinical Preceptorship program. Now with over 90 attendees the program continues to go from strength to strength. In this newsletter you can read two comments from preceptors who took part as preceptors in 2013. It is pleasing to hear of the changes in clinical practice implemented as a direct result of this iCMLf program along with the long-term networks formed to enhance CML management.

Professor John Goldman

1938-2013

Inaugural iCMLf Chairman



The iCMLf Diagnosis and Testing Program has the specific aim of increasing access to CML diagnostics in the EER. In 2012/2013 2,000 tests were a direct result of iCMLf funding and countless others a result of the training offered and equipment purchased with iCMLf grants. The 2014 grant awards have just been announced and we share with you an overview of the projects and the expected outcomes to build local capacity for CML diagnostics.

Access to tyrosine kinase inhibitors remains one of the greatest challenges in emerging economic regions and without these, people with CML are resigned to the traditional forms of chemotherapy, interferon and most likely a shorter life. The Glivec International Patient Assistance Program (GIPAP) implemented by Novartis and run by The Max Foundation goes a long way to address this problem. The iCMLf National Representative from Moldova Dr V. Musteata has written of his experience setting up GIPAP at his centre, his analysis of the program over the first years and the challenges they still face accessing therapy for their patients.

So with this in mind, much done and much still to do, we continue in honour of John Goldman, never forgetting and always stronger for his wisdom.



Tim Hughes, Chairman



Nicola Evans, Chief Executive



Thank you - in the name of CML patients worldwide

“ The CML patients community has lost one of the heroes in CML history. John was one of the key pioneers that paved the way for a revolution in treating CML. Many of us owe their lives to the dedicated, courageous and engaged work of John in the last 15 years to turn CML from a deadly into a chronic disease. Without people like him, I wouldn't be here today, and the same applies for thousands of other CML patients across the globe.

He will not only be missed as a role model, a mentor, an advisor, a visionary, and a founder of so many activities. We will miss his smart mind, his wit, his great humour - in the iCMLf, at our global patient meetings of the CML Advocates Network, at the ESH, ASH and EHA conferences, I will never forget him. Patients and patient advocates across the globe will never forget him and will be grateful forever. Thank you, John. ” Jan Geissler CML Advocates Network

It is very difficult to express the loss of a person such as Professor John Goldman. What he meant to the CML community, clinicians, research, patients and patient advocates. He changed the course of CML in so many ways and continued to do so right up until his death on 24th December last year. John's vision and leadership as the inaugural chair of the iCMLf have shaped the successful early years of the Foundation and continue to inspire us to step up, make a difference and hopefully do this with the same dignity and humanity that he did.

We take this opportunity to share with you some of the tributes written on the iCMLf website.

You can view these and more at www.cml-foundation.org/remembering-john-goldman.



John with Michael Mauro at a CML patient meeting in India

“ I will always treasure your memory and all the wonderful care and support you gave me when I was your patient first in Hammersmith, London and later at NIH, in Bethesda, MD. I will miss your great sense of humour and your jokes that little wry smile, the eyeglasses on the forehead... I will miss the best doctor I have ever had, the one I owe to the fact that I am still alive today. You were great and unique and I will never forget you. Sleep in peace.”



John Awarding the inaugural iCMLf Rowley Prize to Brian Druker in 2009.

“ We lose a great scientist and science loses much elegance in hematology.”

“ For me John was the most important mentor and teacher of haematology.”

“ A gentle soft spoken teacher with an incisive mind, who brought home to us the myriad complexities of CML.”

“ My CML patients and myself are the main beneficiaries from his lifetime advances that he has accomplished. From the establishment of organisations like iCMLf thousands are benefitting even at this very moment as well as for a long time to come. He accomplished much more than his share and more than anyone.”

A tribute to John Goldman (1938-2013) - Ray Lowenthal Menzies Research Institute, University of Tasmania

When I had the good fortune to join John Goldman and his team at the newly formed Leukaemia Unit at the Royal Postgraduate Medical School in London's Hammersmith Hospital from 1972 to 1975, the general view was that leukaemia was incurable, and most medical practitioners at the time (and indeed the general public) would have considered any attempt to change this situation as 'pie in the sky'. However the view in the Leukaemia Unit itself was different. The air of cautious optimism that prevailed was due to the remarkable group of scientific visionaries that were gathered under the overall direction of the late Professors John Dacie and David Galton, one of the key proponents being John Goldman. John found a niche for himself in the study of chronic myeloid leukaemia (CML) and brought into clinical practice a number of ideas which have since totally transformed the management of the disease. Where once the average survival was 3-4 years, now with modern treatment, much of it pioneered by Goldman, most patients live normal lives for many years or decades and indeed many may well be cured.

His early ideas, tested at the time I was working under his direction, included the collection (leucapheresis) and cold storage (cryopreservation) of circulating leukaemia cells, based on the then novel concept that one might be able to prolong patients' lives by administering intensive chemotherapy at the time of leukaemia progression, while the previously collected leukaemia cells were in cold storage (ex vivo) and then re-infusing the unaffected cells to return the patient to an earlier stage of their disease. Although in its pure form this concept has not survived, such thinking led directly to the development of bone marrow transplantation which John pioneered in the 1980s and 1990s as the first curative treatment for CML. Many CML patients are alive today, 20 or 30 years later, thanks to this work in London.

In parallel with such clinical developments John maintained a keen interest in the burgeoning laboratory understanding of the molecular basis of CML. Thus he was in on the ground floor of the introduction of imatinib, a remarkable targeted pharmaceutical agent logically developed as a specific antagonist to the abnormal protein (bcr/abl) that was responsible for the uncontrolled growth of the CML cells. Imatinib and its progeny have led to a second revolution in CML treatment; in retrospect one can see bone marrow transplantation as 'intermediate

technology'. Today a newly diagnosed CML patient can have his or her disease quickly and easily brought under control, and quite possibly cured, by taking a tablet a day, with in most cases minimal side effects. John can also be credited with having played a significant role in persuading the pharmaceutical company Novartis to bring imatinib to market, rather than discarding it as unlikely to help the company's bottom line.

John was not only an outstanding clinician and scientist, he was one of the rare people who was able to stand back and take a broad view of his work, and see where it fitted in with the work of others and where collaboration would advance the cause. Thus he reached out to those working on CML all around the world, acting as mentor to many, and developed international alliances that in many ways were as important in enabling the new treatments to be brought to patients everywhere, as were the scientific developments themselves. In this vein, his work as founding editor of the journal *Bone Marrow Transplantation* and his chairmanship of the International CML Foundation, amongst many other important global roles, were as significant as his research.

As a person he was always polite and quietly spoken, the epitome of an English gentleman, always respectful of other opinions. Two years ago he did me the enormous honour of taking time out of a rushed antipodean trip to attend and speak at my own *Festschrift* in Hobart, Tasmania. I am most grateful that good fortune and timing enabled me to work with him during those crucial early years.

The world has lost an important player in the quest for a cure for all forms of leukaemia. Fortunately his legacy lives on, in the form of the many thousands of CML patients who are alive today thanks to John Goldman's dedication and his vision.



In memory of John Goldman

The "Goldman Prize"

To honour John's commitment to clinical excellence treating CML the iCMLf will award an annual Goldman Prize in his memory.

The iCMLf Goldman Prize will be awarded to an individual who has made a major lifetime contribution to the management of patients with CML.

The "Goldman Meeting"

From 2014 the international CML meeting is renamed the John Goldman Conference on CML: Biology and Therapy.

The annual CML meetings Dr Goldman initiated are now in their 16th year and are organised jointly by the European School of Haematology and the iCMLf. Due to Dr Goldman's inspiring leadership, these meetings attract basic and clinical scientists with an active interest and a prominent role in CML science worldwide.

The "Goldman Fund"

The iCMLf has established a special fund for people wanting to donate to the iCMLf in memory of Professor Goldman.

The "Goldman Fund" will be used specifically to support the training of young CML clinicians and scientists. This was something that John was passionate about.

To donate to the iCMLf in John's memory go to www.cml-foundation.org/about-icmlf/support-us



Clinical Preceptorship Program provides long-term impact for emerging regions

The iCMLf Clinical Preceptorship Program is designed to offer individual preceptorships to clinicians from emerging economics regions hosted by some of the world's most experienced hematologists. This educational program combines practical experience, one-to-one tuition and seminars as appropriate. Since the implementation of the program in 2010 over 90 preceptors from 43 different countries have attended a 3-4 week program at one of the hosting CML centers of excellence.

During their preceptorships the participants are fully integrated into the host site's clinical team, participating in outpatient clinics, hematology ward rounds, seminars, discussion forums and laboratory work. This enables them to establish close contacts with renowned CML experts, to observe and learn the up-to-date protocols and guidelines to treat CML and to gain insights into state-of-the art laboratory facilities.

Clinicians participating in 2013 program share their experience

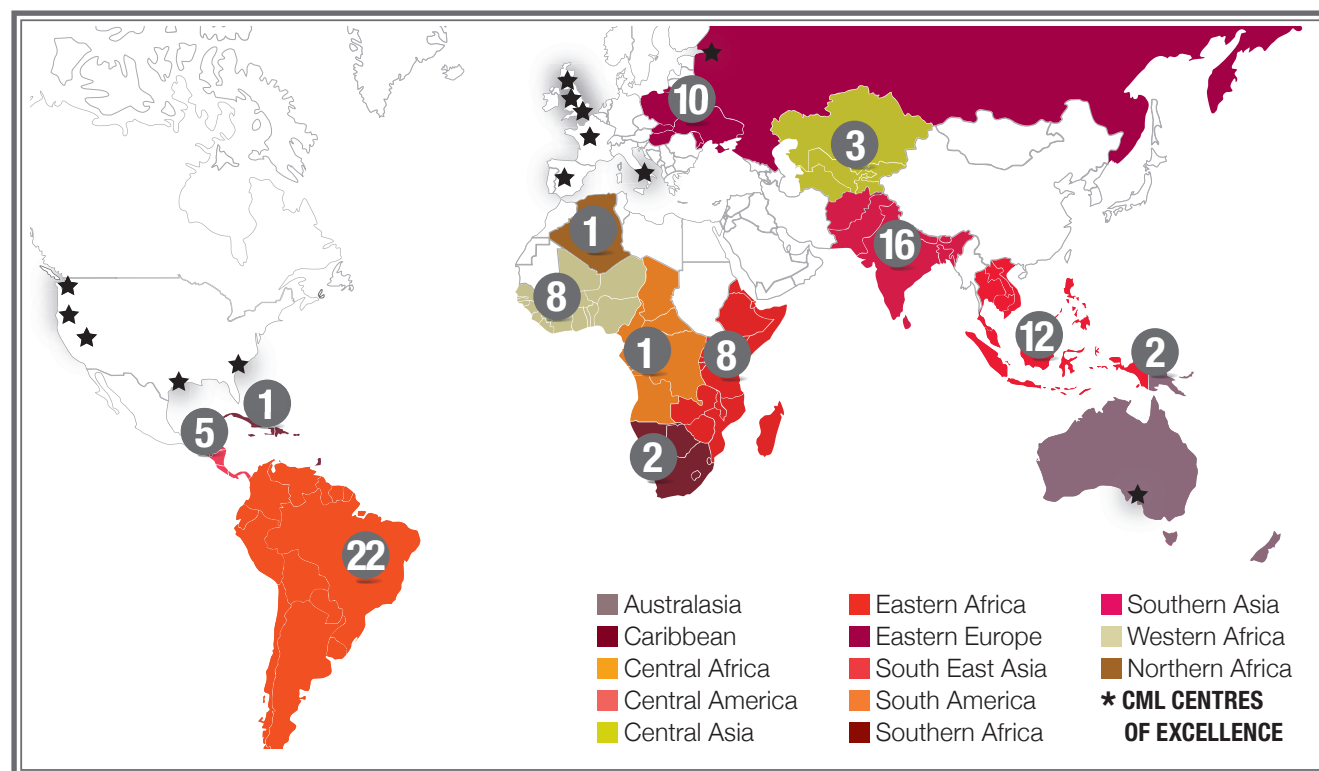
Evaluation of our programs is very important to the iCMLf as it enables us to adapt and meet the evolving needs of those we aim to help. There are two formal reviews of each preceptorship, one on completion and one after six months.

We survey the individuals about their key learnings, what specific changes to clinical practice are made due to the education received and any recommendations they have to improve the experience.

It is always very inspiring to hear how much the participants learn from their stay and how the gained knowledge is being shared with other clinicians. The feedback clearly demonstrates that the program provides a profound, long-term impact by improving the way CML patients are being monitored and treated. On the following pages we share with you the experiences of two preceptors from the preceptorship program in 2013.

"Back home I have tried to apply the standards of care I have seen at the Hammersmith Hospital. I am confident that this will make a big difference to the way we treat our patients here". Dr. Abdulaziz Sherif

Countries with attending iCMLf preceptors 2010-2014.



Immediate Results

Dr Abdulaziz Sherif from Addis Ababa, Ethiopia Preceptorship at the Hammersmith Hospital, London, UK

Dr Sherif is an internist and hematologist and serves as Assistant Professor of Internal Medicine at the Tikur Anbessa Specialized Teaching Hospital in Addis Ababa, Ethiopia. His hospital is the main referral center in the country and the only hospital in Ethiopia that offers treatment to patients with CML. Dr Sherif is one of only two hematologists in Ethiopia. He has been treating CML patients for six years and currently treats around 600 CML patients.

In September 2013 Dr Sherif undertook a 3-week clinical preceptorship at the Hammersmith Hospital under the leadership of Professor Jane Apperley.

Key practice changes after the program.

- I have tried to apply the standards of care I have seen at the Hammersmith Hospital to the patients at my hospital. I am confident that this will make a big difference to the way we treat our patients here.
- I have gained much experience with next generation TKIs and now feel more confident to advise and treat patients who have resistance to imatinib.
- We have recently launched a fellowship-training program in Hematology. This put me in an ideal position to transfer the experience gained from my preceptorship easily to all my colleagues and future physicians, internists and hematologists.

I can say that I have benefited to the maximum from the interaction with CML experts in London and it was great to be part of the clinical team at the Hammersmith Hospital. The patient exposure at follow up clinics was very practical and I gained a lot from the following interactive discussions with the consultants who were very cooperative. I also had the chance to attend the transplant ward and to experience inpatient exposure twice a week, which was very exciting to me. I also enjoyed very much the clinico-pathological sessions in which cases from other hospitals were discussed through teleconferences. The laboratory visits were also very interesting to me because I had the chance to see all the important tests for CML that were routinely done at the Hammersmith Hospital. Moreover I had the chance to gain very valuable experience with other advanced tests like flow cytometry, cytogenetic and other tests for a wide range of hematological diseases. I also had the chance to make personal links with the consultants at the Hammersmith hospital first of all with Professor Jane Apperley and the late Professor Goldman.



Dr Wattergama during his preceptorship at the City of Hope.

Long term the laboratory exposure I experienced will help me to advise on the establishment of improved laboratory facilities. The academic sessions have also sharpened my teaching capacity in transferring knowledge and skills to my medical students as well as hematology fellows who are being trained in our hospital and my relationships with the consultants at Hammersmith give me the opportunity to discuss and consult difficult to treat cases.

The preceptorship was one of my greatest experiences in hematology and I benefited a lot from all the activities. Thank you very much for giving me this great privilege to attend the preceptorship program that was conducted so smoothly. This is a program that should be continued and is worthwhile for physicians caring for patients with CML.

A six-month review

Dr Sarath Wattergama from Kandy, Sri Lanka Preceptorship at the City of Hope, California, USA

"I have advised all my colleagues in my team how to monitor the response to TKI treatment. We now use the terms CHR, CCyR and PCyR in our follow-up notes, which is a big change".

Dr Sarath Wattergama

Dr Wattergama is a clinical oncology consultant working at the Lakeside Adventist Hospital in Kandy, Sri Lanka. He has been treating patients with CML for over 30 years. Dr Wattergama undertook a 4-week clinical preceptorship at the City of Hope in California, under the leadership of Professor David Snyder in June 2013.



Key changes implemented after the program.

- I started dose escalation on some CML patients who were not showing a good hematological response
- I have been able to introduce nilotinib in one patient who did not achieve a cytogenetic response after 18 months of imatinib
- The preceptorship has had given me lot of confidence in managing the side effects of the TKIs

My 4-week preceptorship program at the City of Hope gave me a lot of confidence in managing my CML patients with imatinib and I now have the skill to target the anticipated outcome at appropriate time period. This knowledge was lacking in the past, and has helped me to consider second line drugs at the appropriate time, or to consider dose escalation earlier than in the past.

As a result of my time at City of Hope I have advised all my colleagues in my team how to monitor the response to TKI treatment. We now use the terms CHR, CCyR and PCyR in our follow-up notes, which is a big change in our system. All my colleagues have also realized the importance of continuation of TKI treatment even after CCyR. In the past there were concerns about a continuation of TKI treatment after a patient has reached CCyR. It is now clearly understood that even in the absence of Q-PCR test, the current management strategy of continuation of TKI is helpful to CML community.

Elsewhere in Sri Lanka there are facilities to use a q-PCR assay and I am now negotiating with my colleagues in Colombo to help us in using the GeneXpert System to



City of Hope, California. An independent cancer research center with one of the largest and most successful transplant programs in the USA.

measure BCR-ABL1 transcript levels. This will allow us to provide ongoing monitoring and reassurance for our long-term imatinib users.

My preceptorship was a well planned, knowledge based program that was executed extremely well. My sincere thanks go to all my friends at the iCMLf for the wonderful work you do.

Clinical preceptorships continue in 2014

Twenty-two hematologists for emerging economic regions will attend preceptorships in 2014. Their educational experience is expected to provide great benefit for the CML community in their home countries. Selected preceptors for 2014 come from 17 different countries including: Africa, South America, Central America, South East Asia and Eastern Europe including Argentina, Armenia, Azerbaijan, Brazil, Chile, Egypt, Guinea, Indonesia, Kenya, Malawi, Malaysia, Mexico, Nigeria, Philippines, Russia and Uganda.

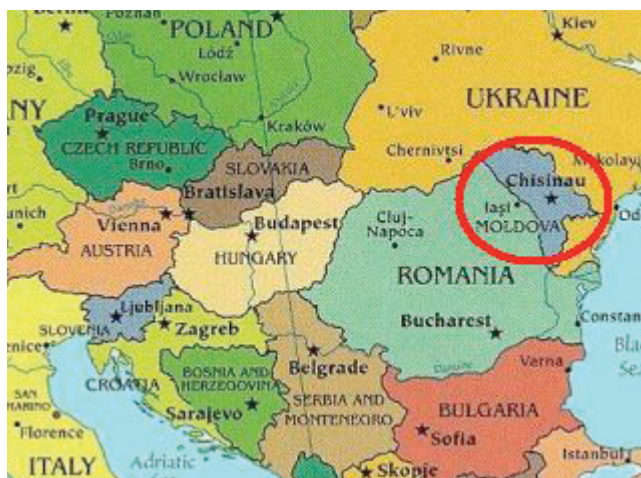
We look forward to hearing about and sharing their experiences with you.

Access to CML medications in the emerging economic regions

Access to CML therapies is one of the greatest challenges for people with CML in the emerging regions. High cost of medication, lack of reimbursement and limited testing facilities are all barriers to the effective medications whose availability in the western world is often taken for granted.

For imatinib, Novartis designed the Glivec® International Access Program (GIPAP), one of the most comprehensive and far-reaching cancer access programs ever developed on a global scale. Run by The Max Foundation, the “direct-to-patient” model is designed to provide the drug directly to individual patients by their treating physicians. Since its implementation in 2002, GIPAP has provided imatinib to more than 19,000 patients in 80 developing countries who would otherwise had no access to the drug¹.

In the following article we highlight the work of one of the GIPAP centers and physicians. Their ensuing results and impact for their patients clearly demonstrate the importance of access to imatinib through this program.



The Republic of Moldova is a country in Eastern Europe located between Romania and Ukraine. Its capital city is Chisinau.

A report from Moldova - Dr Vasile Musteata, MD, PhD, MPH, Associate Professor of the Chair of Oncology, Hematology and Radiotherapy, State University of Medicine and Pharmacy "N. Testemitanu"

Background

Moldova declared itself an independent state within the boundaries of the former Moldavian Soviet Socialist Republic in 1991. Moldova remains one of the poorest countries in Europe in terms of official GDP per capita, which recently has been at \$3,368 (The World Bank Data, 2012).

The Institute of Oncology is a unique scientific and clinical medical institution in Moldova that offers specialised medical assistance in diagnosis, treatment and prophylaxis for cancer patients. Of more than 40,000 patients with neoplastic diseases registered in the Moldovan Cancer Registry, approximately 27,000 patients are being treated annually at the hospital. The annual incidence of CML ranges between 0.6–0.8 cases per 100,000 in Moldova. The disease accounts for approximately 15–20% of leukemia in adults.

The therapeutic landscape for patients with CML changed dramatically when imatinib, the first tyrosine kinase inhibitor (TKI) was launched. Unfortunately, at the start of the imatinib era, laboratory facilities were not available in Moldova to provide CML patients with PCR and cytogenetic test for Ph+ chromosome. CML patients had to undergo these tests in neighbouring countries in order to become eligible for treatment with imatinib.

Access to imatinib in Moldova

In 2006, with the aim of facilitating the donation of imatinib to patients eligible to the program, GIPAP was introduced in Moldova at the medical laboratories in Chisinau. Dr Vasile Musteata was selected as a manager and qualified physician for the program as one of the leading physicians in the treatment of CML in Moldova.

A GIPAP application form is completed and submitted to The MAX Foundation by a qualified physician on behalf of their CML patients. If patients meet the required criteria and the application is approved, a 90-day supply of imatinib is granted at no cost and provided to the Institute of Oncology. The GIPAP administration maintains a patient tracking system including an evaluation and approval process, patient re-evaluation, and patient treatment follow-up. The cytogenetic and molecular testing for CML patients is carried out at the medical laboratories in Chisinau, or at the cytogenetic and immunologic laboratories in neighbouring countries. Detailed records are kept including the number of GIPAP patients using imatinib, treatment schedules, patients names and GIPAP ID numbers, diagnostic test results confirming indication for imatinib and the signed patient consent forms.

Evaluation of the program in Moldova

In order to evaluate GIPAP in Moldova from 2006 to 2011, 125 patients with CML were enrolled in a study at the Institute of Oncology. Of these patients 113 (90.4%) were in chronic phase and 12 (9.6%) in accelerated and acute phase. 74 patients (59.2%) were eligible and approved for GIPAP. Patients enrolled in the program were 19 – 81 years old. The median age was 46.1 years. This indicates that the disease predominantly affects the working population. Imatinib was given as a first-line therapy to 11 patients (14.9%), and 63 patients (86.1%) had previously received treatment with conventional chemotherapy. Cytogenetic analysis and real-time quantitative PCR of the bone marrow cells revealed Ph+ chromosome and BCR-ABL p210 oncogene in all GIPAP patients. A rate of more than 75% of Ph+ cells was seen in 72.7% of patients.



Dr Vasile Musteata

Results

- A complete hematologic remission was achieved in 63 (85.1%) patients within one or two months of treatment with imatinib. This was superior to the results obtained with chemotherapy and interferon-in 14 (27.5%) patients ($p < 0.05$).
- The follow-up cytogenetic analysis of the bone marrow performed within 6 to 8 months after the start of imatinib demonstrated a decrease of Ph+ cells of 5–35% in patients with a complete hematologic remission.
- A complete cytogenetic remission was registered in 9 (14.3%) of patients within 12–18 months of imatinib treatment.
- The relapse-free survival rate at 18 months proved to be higher ($p < 0.05$) in patients treated with imatinib (82%), than in patients treated with conventional chemotherapy (20.5%).

The data demonstrated that the enrolment of CML patients in GIPAP with resulting imatinib therapy significantly improved ($p < 0.01$) performance status in 90.5% (ECOG-WHO score range 0–1, $P \pm ES\% = 0.25 \pm 0.06$), as compared to conventional chemotherapy. The results also showed an increase of longevity in those CML patients with a considerable improvement of the performance status (ECOG-WHO score 1: $P \pm ES\% = 46.2 \pm 8.92$ months) and complete physical rehabilitation (ECOG-WHO score 0: $P \pm ES\% = 51.6 \pm 4.63$ months) while treated with imatinib. Due to the physical rehabilitation and the improvement of quality of life, the working GIPAP patients were able to continue their professional activities.



Institute of Oncology Chisinau, Republic of Moldova.

The overall 3-year survival rate in the imatinib treated patients was 66.0% and superior ($p < 0.05$) to that achieved after conventional chemotherapy (44.5%). The median survival was superior ($p < 0.05$) in the age group of 40–49 years (61.65 ± 4.81 months) as compared with the age groups of 20–29 years (43.13 ± 2.80 months) and over 70 years (43.14 ± 3.92 months). The overall 3-year survival proved to be higher ($p < 0.05$) in females (66%) than in males (51%).

Discussion

The majority of CML patients treated with imatinib did not progress to accelerated, or acute phases and experienced much better short and long-term response rates, as compared to the treatment with interferon- α and conventional chemotherapy. The results also demonstrate an improvement in the quality of life and in the overall and relapse-free survival in CML patients. The evaluation underlines the importance of imatinib treatment to achieve recovery and restoration of the ability to work, as well as for social reintegration.

GIPAP aims to provide state of the art management technologies and treatment to those patients who have limited access to medical resources. Expanding the availability of novel anticancer agents such as imatinib has the potential to fundamentally improve the outcomes for cancer patients in Moldova.

A Physicians perspective

Why is GIPAP so important to patients in Moldova?

The implementation of the GIPAP Program supports continuous improvement in diagnosis and treatment of patients with CML in Moldova contributing to their recovery, restoration of their ability to work and social reintegration.

What are your key learnings from the program?

1. Significant progress in the management of CML patients can be achieved by setting up cooperation with international non-profit anti-cancer organizations and comprehensive cancer and hematology centers.
2. The centralized, cooperative, efficient and transparent management determined the success of GIPAP implementation and functioning in Republic of Moldova.
3. Improvement and diversification of laboratory facilities result in extended testing of CML patients.

What are your plans for the future?

We are aiming for a diversification of laboratory facilities at the Institute of Oncology in order to provide PCR test and cytogenetic test for Ph+ CML.

Implementation of a Novartis Oncology Access Tasigna® Program. In Moldova full donation is the only appropriate path to access nilotinib. The supply of nilotinib may be available to CML patients who have relapsed under the treatment with imatinib and meet certain clinical and economic criteria.

We also plan to participate in international clinical trials with the latest TKIs and other antineoplastic agents in order to ensure access to high-quality health care for patients with relapsed or refractory CML.

For more information on the GIPAP Program see 1): www.themaxfoundation.org/GIPAP

Improving global access to CML diagnostics

Getting the best possible CML therapy to more people is one of the key outcomes that the iCMLf works towards. One major way to make sure this occurs is to improve access to the testing facilities to diagnose and monitor CML. Early diagnosis results in more people accessing CML therapies earlier and potentially meeting important milestones. Long term monitoring keeps physicians and their patients informed of the course of the disease allowing therapy adjustments as appropriate. In the emerging economic regions access to diagnostics can be limited, or even non-existent. Some centres have no access and must ship samples to reference centres at a cost of hundreds of dollars. Many centres have potential access to equipment, but lack the knowledge to set up and manage a CML laboratory, others have PCR testing, but without standardisation have less confidence in the results provided.

One of the iCMLf projects to improve access to CML diagnostics is the iCMLf Diagnosis and Testing Grants Program. This has the specific mandate to build local capacity for CML testing in the emerging economic regions.

Supporting and mentoring specific local challenges with iCMLf grants has been very successful, demonstrating numerous improvements in CML management and clinical outcomes. In the inaugural annual program over 2,000 tests were directly funded by these grants and many more were made possible through the purchase of equipment and consumables, training and mentoring that were also facilitated by the program. It is quite clear that tens of thousands of CML patients will be impacted by the resulting improvements. These change lives and benefit whole communities.

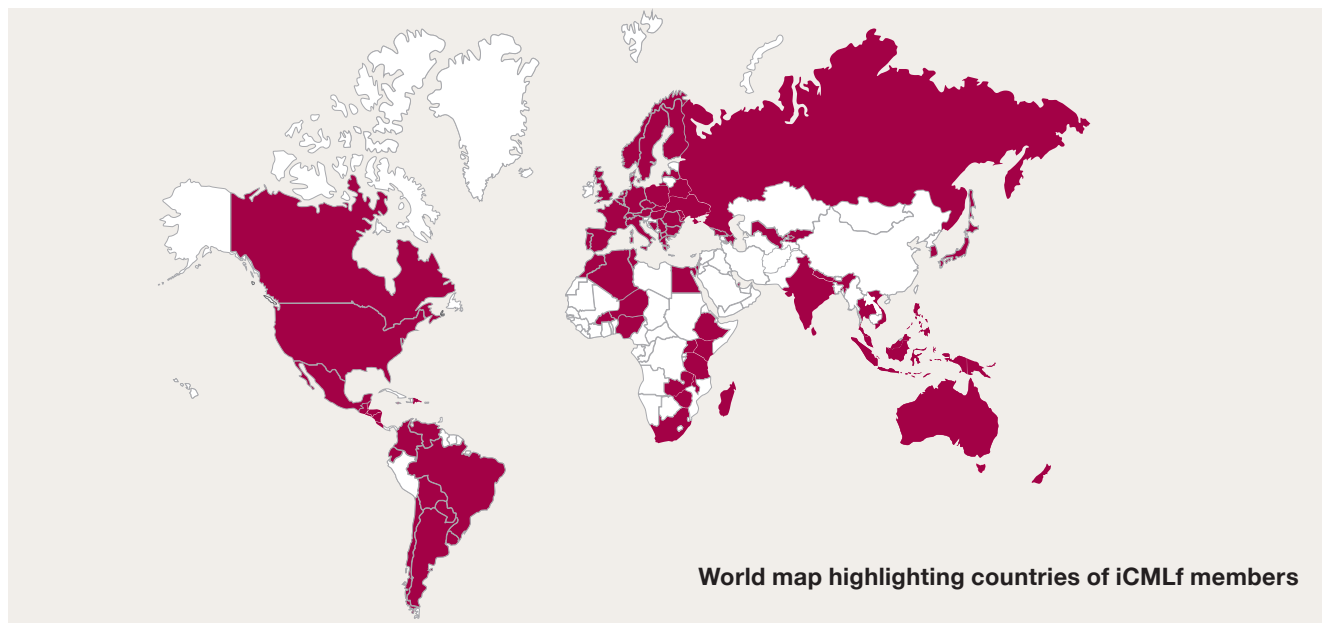
In 2014 we are delighted that the iCMLf grants program is continuing. From 23 expressions of interest the iCMLf Directors have selected 9 Phase I projects and 4 Phase II projects to be funded. We look forward to sharing the experiences and results for these centres over the next year, but to give a flavour of what each centre hopes to achieve with the grant we share the overview below.

Further information about this iCMLf program can be found at www.cml-foundation.org/ersap-dnt

2014 iCMLf Grants to increase access to CML diagnosis and monitoring

CENTRE	CITY	COUNTRY	SUMMARY OF EXPECTED OUTCOME
Black Lion Specialised Teaching Hospital	Addis Ababa	Ethiopia	Study on mutations in Ethiopia
Korle-Bu Teaching Hospital	Korle-Bu	Ghana	Establish onsite mutational analysis
Institute of Haematology and Transfusion Medicine, Medical College	Kolkata	India	Increase access to PCR and study transcript levels of 100 patients at 0,3,6, and 12 month time points.
Tata Cancer Hospital, Aganampudi	Visakhapatnam	India	Establish onsite mutational analysis
Prof. Dr. R.D. Kandou Manado General Hospital	Manado, North Sulawesi	Indonesia	Shipping of samples for PCR testing and training for local laboratory staff
Dr Kariadi Hospital	Semarang,	Indonesia	Establish local PCR testing
Universitas Gadjah Mada	Yogyakarta	Indonesia	Validation of local PCR and optimisation of quantitative analysis
University of Nairobi Kenyatta National Hospital	Nairobi	Kenya	Shipping of samples for PCR testing
University of Malawi College Of Medicine	Lilongwe	Malawi	Training and using a GeneXpert machine to start local testing
General Hospital of Mexico	Mexico City	Mexico	Diagnosis and monitoring of 40 patients
Health Research Institute of National University of Asunción	Asuncion	Paraguay	Enhancing CML Laboratory capacity with training and increasing test capacity
SI "Institute of Blood Pathology and Transfusion Medicine, NAMS of Ukraine"	Lviv	Ukraine	Training of 3 laboratory staff to set up a CML laboratory

The iCMLf community – truly international and collaborative



Experts all over the world collaborate very closely to improve diagnosis and management of CML. The iCMLf aims to strengthen this network further by facilitating communication and collaboration specific to CML. Physicians managing CML cases and researchers dedicated to CML are part of this growing community, working together to improve the outcomes for patients with CML worldwide.

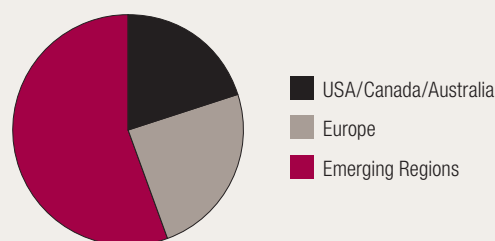
Members of the iCMLf become part of an international network and are welcome to contribute to the global research, education programs and other activities of the iCMLf. Currently around 430 members have access to a network of international contacts, including leading hematologists and scientists. Through the iCMLf network registered members can share ideas and experiences to learn from each other's expertise.

Where are we?

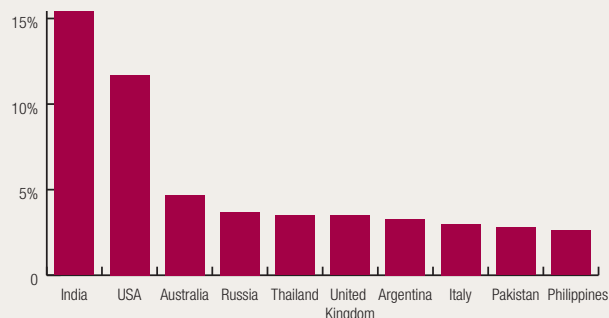
The iCMLf community comprises members from 91 different countries from all parts of the world. At 56%, the majority of members are from emerging economic regions in Africa, South America, Central America and Asia. This reflects the initial focus of the Foundation to improve access to education, diagnostics and through this appropriate therapy, in places where resources are most limited. We are delighted to have so many countries from emerging regions as part of the iCMLf network.

Another 24% of community members are from Europe including Russia and 20% are from the USA, Canada and Australia.

iCMLf members per region of origin



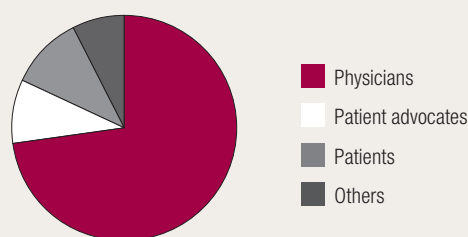
Top 10 countries with iCMLf members



Who are we?

73% of iCMLf members are physicians, nurses or scientists with a specific interest in CML. 11% are patients, or their caregivers and another 9% are from various patient advocacy organisations around the world. While the iCMLf activities are primarily directed to assist the clinical and research community it is vitally important to have patient advocates as part of the Foundations network. We value their input and hope to continue to work in close partnership with these organisations.

iCMLf members by role



Our online network

- The iCMLf website is designed as an interactive platform for this international CML community providing information and services. It features information about the iCMLf, the foundation's activities and educational programs including the Emerging Regions Support Program, important meetings and scientific CML news.
- The monthly online newsletter provides members with regular updates on iCMLf programs and activities. Important dates for meetings and program applications are also featured.
- The interactive Clinical Case Discussion forum provides the opportunity to share challenging and interesting CML cases with iCMLf experts and the CML community.

This is how the vision of a truly international and collaborative CML community comes to life.

Join us and make a difference!

It is only through the contribution and commitment of the CML community that the iCMLf can achieve its goals to improve outcomes for patients with CML globally.

Together we can all make a real difference. So we like to thank all our members for their continuous contribution to the foundation. If you are not already, you can become an iCMLf member at www.cml-foundation.org

The iCMLf website will soon be re-launched to make it easier to navigate and therefore more accessible to the iCMLf community.

So watch out for a refreshed www.cml-foundation.org coming soon...

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

***We look forward to seeing you at the following
CML meetings in the next 6 months!***

Janet Rowley and John Goldman Special CML Colloquium

**CLASSIC HALLMARKS AND OPTIMISING
CLINICAL MANAGEMENT**

MICO Milano Congressi, Viale Eginardo, Room Green 3
(North Wing, Level -1) Milan, Italy June 12, 2014

Speakers; Christine Chomienne, Tim Hughes, Tariq Mughal, Christine Harrison,
Michael Deininger, Jorge Cortes, Giuseppe Saglio, Jane Apperley and Jerald Radich.



16th Annual John Goldman Conference on
CHRONIC MYELOID LEUKAEMIA: BIOLOGY AND THERAPY
Philadelphia, USA September 4-7, 2014



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: nicolas.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.

San Francisco Friday 5 December 2014

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