

A RENEWED PURPOSE:

Addressing the Evolving Needs of Our Patients

As we move forward into a new year, we are reminded of the journey we have shared with patients over the past two decades. From the revolutionary advancements in treatment to the growing strength of our global community, each milestone has been a testament to the resilience, courage, and hope of the patients we serve.

Yet, this journey is far from over. The needs of our patients continue to evolve, and so must our efforts to support them. Whether it is advocating for better access to life-saving treatments, addressing the long-term physical and emotional impacts of chronic conditions, or empowering patients and caregivers to find their voices, our purpose remains steadfast.

This year, we embrace a renewed sense of urgency to meet these challenges head-on. We are committed to strengthening our programs, deepening our connections, and ensuring that no patient feels left behind. Together with our partners, caregivers, and physician community, we will work tirelessly to bring hope, knowledge, and support to those who need it most.

As we embark on this next chapter, let us remain united in our shared mission to create a brighter, healthier future for all. Let's rise together to make 2025 a year of impactful change.

Beena Narayan who is based in Kochi is the new Country Head (India) at The Max Foundation. She is committed to continue driving its mission forward. We wish her great success and look forward to benefiting from her vision and leadership!



Beena Narayanan
Country Head (India),
The Max Foundation

As we ring in 2025 we can very rightly say that this may well be the watershed year for the CML Community. After a quarter of a century of being on treatment, patients are asking for their voice to be heard as they seek answers for a plethora of questions.

The foremost in their minds are:

- How much longer do we have to be on treatment?
- What long term side effects should we be wary of?
- Do we have a cure for CML?
- Is TFR the closest to cure?
- Have we not proved ourselves worthy of easy access to 3rd and 4th Gen TKIs?
- How can we advocate for ourselves and those dependant on us?

It was in 2001 that the U.S. Food and Drug Administration (FDA) approved Gleevec (Imatinib Mesylate) for the treatment of Chronic Myeloid Leukemia (CML). In 2002 Novartis and The Max Foundation put in place an access program which was the first (and till now the only) of its kind, bringing the Gift of Life to thousands of patients.

I have in these many years personally seen patients go from one stage of their lives into another carrying the undeniable burden of living with a life limiting and life threatening condition. Add to that being on life long treatment and not knowing what all this is really doing to them. Physically, emotionally and otherwise...

Friends of Max has for 23 years offered a safe platform for patients to express themselves and seeking answers for all these questions and more. We recognize the hunger for

Re connecting with our CML

Kickstarting 2025 with renewed energy, this edition is an ode to new learning! Empowering patients, caregivers and advocates with CML breakthroughs, advocacy updates, and inspiring stories!

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Highlights from Patient Support Group Meetings and Chai for Cancer Addas



read more on Pages 3 & 4

knowledge here, the hope for the future as well as the fear of the unknown in our patients and their families. We try and bring as much accurate and pertinent information to them as possible and continue to identify and groom volunteers and patient leaders who can represent them in the world out there.

Throughout these years we're so grateful to our physician community who have always been by our side and been our sounding board with invaluable advice and guidance.

So 2025 is the year of Resurgence which will see us strengthen our bonds, re charge and re connect as we come up again determined to weather the next quarter of a century?

Wish us luck.

- Viji Venkatesh

Managing Trustee, Friends of Max, Member, Board of Directors, The Max Foundation and Trustee, Being Human Salman Khan Foundation

Congratulations to Viji Venkatesh on her well-deserved appointment as Member of the Board of Directors at The Max Foundation!

Her remarkable 23-year journey as Region Head for India and South Asia has left an inspiring legacy. We wish her the very best for her continued success in this new role as she continues to spearhead Friends of Max!

SECTION 01

Latest Medical Advancements

Recent developments in Chronic Myeloid Leukemia (CML) research and treatment have shown promising advancements:

Asciminib: Approved by Drugs Controller General of India (DCGI) in late 2023, Asciminib (marketed as Scemblix and a novel STAMP inhibitor) is now being prescribed as a second-line treatment for CML patients who develop resistance or intolerance to first-line therapies. Known for its improved safety profile (fewer side-effects), it marks a significant step forward in targeted CML treatments. Other Tyrosine Kinase Inhibitors (TKIs) like Imatinib, Dasatinib, and Nilotinib remain widely available. Patients are advised to consult their oncologists for tailored treatment plans and information on accessibility.

During the trial, just 5% of Scemblix patients discontinued treatment due to adverse side effects, compared to a dropout rate of 10% of those being treated with any of the TKIs, which can cause fatigue, depression, disrupted sleep, diarrhea, and have other side effects.

Source: <https://www.reuters.com/business/healthcare-pharmaceuticals/novartis-leukemia-drug-more-effective-than-older-treatments-trial-2024-05-31/>

Expert Opinions

Treatment-Free Remission in Chronic Myeloid Leukemia: A Paradigm Shift in Management

Treatment-Free Remission (TFR) in Chronic Myeloid Leukemia (CML) represents a transformative goal in oncology, enabling selected patients to sustain molecular remission without continuous therapy. TFR alleviates the burden of lifelong Tyrosine Kinase Inhibitor (TKI) therapy and mitigates associated adverse effects, healthcare costs, and patient quality-of-life challenges.

The concept of TFR emerged following the advent of TKIs, particularly Imatinib, which revolutionized CML treatment by enabling durable cytogenetic and molecular remissions. Second and third-generation TKIs, including Dasatinib and Nilotinib, further refined outcomes, with deeper molecular responses achieved more rapidly. Achieving a sustained Deep Molecular Response (DMR), defined as at least MR⁴ (BCR::ABL1 transcript levels \leq 0.01%), for a minimum of two years is a critical precondition for TFR eligibility.

Clinical trials, including the landmark STIM (Stop Imatinib) and ENESTfreedom studies, underscore the feasibility of TFR in select patients.

These studies reveal that approximately 40-60% of patients maintain TFR at three years, contingent on rigorous monitoring via quantitative Polymerase Chain Reaction (qPCR). Relapses typically occur within the first six months and are swiftly responsive to TKI reinitiation, underscoring the safety of TFR attempts.

Key challenges in achieving TFR include identifying biomarkers predictive of sustained remission and addressing individual variability in immune surveillance mechanisms. Research suggests that Natural Killer (NK) cell activity and cytokine profiles may influence relapse risk, highlighting the potential role of

immunological factors in disease control.

For the patients of CML in Low—and Middle-Income Countries (LMIC) like India, who are younger by at least one decade, TFR remains an even more attractive goal. Emerging evidence from several studies from India and other LMICs proves that TFR is eminently possible and doable. Several problems, however, remain, particularly the cost of frequent molecular testing, laboratory quality control, and issues related to regular follow-up.

The pursuit of TFR signifies a shift from indefinite treatment paradigms to a precision medicine approach, aligning therapy with biological response dynamics. With ongoing advancements, TFR in CML exemplifies a patient-centered model, combining molecular insights and therapeutic innovation to enhance long-term survivorship.

*By Dr Hemant Malhotra,
Director, Oncology Services, Sri Ram Cancer &
Super-Specialty Center & Professor & Head,
Dept. of Medical Oncology, Mahatma Gandhi
Medical College Hospital, Jaipur*



Pregnancy and CML

Chronic Myeloid Leukemia (CML), once a dreaded cancer, is now considered potentially curable with regular medication and follow-up. Parenthood, once a distant dream for CML patients, is now achievable, but it demands shared responsibility between physicians and patients. Male CML patients on Tyrosine Kinase Inhibitors (TKIs) can father children with the approval of their treating physician, while female patients can conceive and bear children under close medical supervision.

Management of pregnancy in CML patients involves tailored approaches for different scenarios to ensure the safety of both the mother and the child. Ideally, female patients planning pregnancy should achieve a deep molecular response or attempt Treatment-Free Remission (TFR). However, in India, sociocultural pressures and limited awareness often lead patients to pursue pregnancy under less-than-ideal circumstances.

During the first trimester, all TKIs, should be avoided due to their potential teratogenic effects. From the second trimester onward, imatinib and nilotinib can be cautiously reintroduced with close monitoring. However, pregnant women on these medications may face a higher risk of delivery complications. Interferon is the only medication deemed safe for use throughout pregnancy.

It is imperative for CML patients of reproductive age to consult their physician before planning a pregnancy. Current insights into managing pregnancy in CML largely stem from patient-reported outcomes, highlighting the importance of open communication with healthcare providers. Reporting pregnancies to CML physicians not only ensures optimal care but also contributes valuable data to improve future management strategies.

*Dr Pankaj Malhotra
Prof HOD of Clinical Haematology and Medical
Oncology, Postgraduate Institute of Medical
Education and Research, Chandigarh*



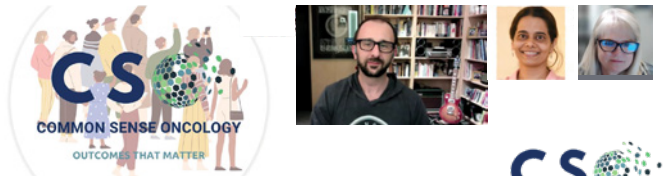
For the full report click on the link:
<https://acrobat.adobe.com/id/urn:aaid:sc:AP:e6bc7482-a923-4e82-99e3-426a2e80ffa4>

SECTION 02

Patient Advocacy and Support

Global Patient Advocacy Groups have been showing a keen interest in collaborating with Friends of Max. Together we are playing a pivotal role in amplifying patient voices, promoting healthcare policies that prioritize patient needs, facilitate access to treatment and patient centered clinical trials, thereby creating a healthcare system that is realistic for patients and healthcare providers.

FOM collaborating with Global Advocacy Groups for Patient Rights and Enhancing Healthcare Access:



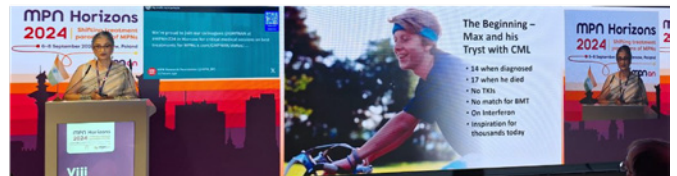
Common Sense Oncology (CSO):

In April 2024, FOM City Chapter Leaders and Patient Advocates participated in a virtual focus group session on a Patient Charter for 'Patient Centered Clinical Trials in Oncology' spearheaded by CSO followed by a zoom meeting session with the CSO Organising Committee, where a team of leading haematologists and medical oncologists including (Manju Sengar, Tata Memorial Centre, Mumbai, India), further listened from the participating FOM representatives their views on how the charter could be made more useful to cater to the needs of patients from this part of the world.

Today where cancer care needs to focus more on patients, ensuring treatments improve both life quality and survival, our interventions help organisations like CSO to hear first-hand from patient leaders and advocates on patient needs and helps them to draft the charter with clear communication and plan better to make cancer trials and treatment fair, affordable, and effective; an approach that prioritises:

- patients' needs with treatments that improve survival and quality-of-life
- patient informed decision making
- making treatments accessible to all patients

Our Managing Trustee Viji Venkatesh is one of the Steering Committee Members of CSO.



MPN Advocates Network: Understanding the New Complexity of MPNs 2024

At the MPN Horizons 2024 Viji Venkatesh in her talk, 'Opportunities and Realities in Access – The Elephant in the Room', shed light on the crucial issues surrounding access to treatment with an urgent appeal to the present global pharma industry and regulatory bodies for more compassionate programs like GIPAP (The Glivec International Patient Assistance Program) which can help to bridge the gap and ensure life-saving treatments are within reach for all.

Government-Sponsored Programs in India:



Did you know that some state governments in India now include targeted therapies for CML in health insurance schemes? Initiatives like Ayushman Bharat offer health insurance coverage and primary healthcare services to economically vulnerable populations, while the Free Drugs Service Initiative (FDSI) provides essential medications at public healthcare facilities, reducing out-of-pocket costs for patients.

<https://ijmio.com/the-cost-effectiveness-of-chronic-myeloid-leukemia-treatment-strategies-in-the-indian-healthcare-context/>

Patient Support Group Meetings

FOM's Patient Support Group Meetings continue to uplift the CML and GIST patients and caregivers' community, providing care, guidance and connections to ease their journey. Here are glimpses from our impactful meetings held between October and December 2024.



OCT 14 Pat Garcia-Gonzalez, CEO Max Foundation, & global team with Project Shiksha beneficiaries at Mumbai office



OCT 26 Organised in association with JIPMER Hospital, in Puducherry



NOV 30 Christian Medical College & Hospital, Ludhiana



DEC 07 Mangalore Institute of Oncology, Mangalore

Chai for Cancer Addas

The Chai for Cancer campaign brewed heartfelt connections as both new and old hosts joined our movement with unwavering trust and support. Let's raise our cups in gratitude to these generous hosts, their friends, families, and well-wishers for spreading hope and dignity to patients living with CML and GIST.

OCT - DEC 2024

10
Addas held

800+
Guests

6000+
Cups of Chai raised

CITIES:

- Mumbai
- Indore
- Kolkata



To host an Adda please send an email to: chaiforcancer@gmail.com



OCT 02 VENUE : Rotary Club Ghatkopar West, Mumbai
HOST : Latha & Sunder Krishnan

Heartfelt Gratitude for a Special Chai for Cancer Adda in honor of our beloved Volunteer #1, Appa. Hosted by Latha, Sunder Krishnan (Friends of Max Treasurer & Trustee) supported by Rotary Club Ghatkopar West, Mumbai



OCT 02 — **OCT 04** **Rallying for CML Awareness!**

In an inspiring journey, Darayus and his friends embarked on a bike rally from Mumbai to Mahabaleshwar via Ganpatipule, covering a distance of 977 kms spreading awareness.

OCT 14 VENUE : Colaba Arts & Art for Humanity, Mumbai
HOST : Pallavi Sabnis

OCT 25 VENUE : Mulund, Mumbai
HOST : Pooja Patil & Viraj Soni



OCT 27 VENUE : Indore
HOST : Manoj Dhanotiya & MicroMitti

NOV 7&8 VENUE : Tata Memorial Hospital, Mumbai
HOST : National Cancer Grid Meeting

NOV 24 VENUE : Mumbai
HOST : Radhika Radia



DEC 12 VENUE : Tata Medical Center, Kolkata
HOST : Tata Medical Center

DEC 13 VENUE : Rabindra Sarobar Lake, Kolkata
HOST : FOM City Chapter Leaders

DEC 29 VENUE : Tamboo, Mumbai
HOST : Anu Singh Choudhary



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Address : Friends of Max, Secom Business Centre, A Block Basement, Shiv Sagar Estate, Dr A B Road, Worli, Mumbai 400018

Website : www.friendsofmax.info

Website : www.chaiforcancer.org

Email : friendsofmax@gmail.com

Facebook :

www.facebook.com/CMLGISTsupportgroup/
www.facebook.com/Chai-for-Cancer

LinkedIn : <https://in.linkedin.com/in/chai-for-cancer-702630117>

X : @Friends_Of_Max
@chaiforcancer

To Donate:

Cheques should be drawn in favour of Friends of Max and couriered to our office in Worli (Mumbai) To donate online visit www.friendsofmax.info Receipts u/s 80 G of Income Tax Act, 1961 will be issued.

Friends of Max is registered as a Public Charitable Trust: Regn No E-24284(B) Mumbai, dated 4-7-2007