

MESSAGE FROM THE TRUSTEES

At Friends of Max (FOM), we believe that every patient deserves more than just treatment. What is required is a complete, holistic approach to healthcare that considers their unique needs, preferences, and offers dignity. We understand how challenging it can be to navigate illnesses, especially life threatening ones, which is why we strive to be a strong support system for both patients and their families.



*Amruta Patidar
Trustee, Friends of Max*

We are so thankful about the top ratings received from our community of patients, their families and caregivers. This recognition highlights our commitment to enhancing the value of patient advocacy and care worldwide.

At FOM, we focus on a few key areas that make a real difference:

Empowering Patients: We educate patients about their health and treatment options, helping them make informed decisions about their care. Our workshops and resources equip patients with the tools they need to advocate for themselves.

Working with Healthcare Providers: We build strong partnerships with healthcare professionals to improve communication between patients and their treating physicians. This collaboration fosters a more understanding and responsive healthcare system that values patient voices.

Research and Innovation: FOM stays updated on research that focuses on patient-centered care. By supporting studies that evaluate the effectiveness of patient advocacy, we contribute to interventions that disburse better healthcare practices.

Community Engagement: We actively engage with local communities to raise awareness about the needs of patients and families. By hosting awareness and support group events and providing resources, we aim to create a supportive network that encourages dialogue and understanding.

As trustees of FOM, we are fully committed to this mission. Together, we can set high standards for patient-centered care, creating a future where every patient feels valued, understood, and empowered.

Who are the Friends of Max you may ask. They are patients of all ages and gender and belonging to varied socio economic strata. They are those children we have seen grow up into young adults; they are the young adults who have grown into working men and women and householders. They are middle-aged couples growing older and becoming grandparents - all with one thing in common. They are all living with cancer diagnosed years ago and on life-long medication.

Here were people who suddenly found themselves abandoned by the roadside while others continued on the journey of life. They were left to find their own, now unknown, destinations, set apart from their peers, school mates, friends, colleagues - and even family members.

My mind goes back 23 years today, to the time when I brought a handful of people together to help them find their 'New Normal'

FOM Setting New Standards in Patient Advocacy...

as it receives top ratings on World CML Day, gaining global recognition for its programs and leaders. This edition recaps key report highlights and quarterly activities.

read more on Page 2



on a parallel track. The numbers swelled with more and more people joining the group. The story of FOM then is the story of how these individuals have charted and navigated their own journeys towards that once seemingly unobtainable future.

There are mothers worried about children as young as two and three years old. There are teenagers. There are worried husbands, there are families who are filled with dread when the sole bread winner is diagnosed. There are children whose parents or grandparents are diagnosed. This patient group was set up to provide a safe and secure platform for everyone to share, learn and cope.

They thronged the meetings organised in cities, towns, parks and beaches throughout the length and breadth of this vast country. Always "team players", they walked hand in hand and shoulder to shoulder with one another in community service. They began exchanging their stories in ways that motivated their peers. Their outpourings took the shape of artworks which became inspiring stories themselves .

The voice of a patient is the most powerful. It has become our responsibility to amplify it. It is only with empathy and understanding that we can identify the patients' needs and make effective those result oriented interventions.

Just as the patients have evolved and grown in the last so many years, so has Friends of Max. I feel like someone who is watching a child proudly take its first firm steps without any handholding, secure in the knowledge that guiding hands are always there when needed.

- Viji Venkatesh

Managing Trustee, Friends of Max and Region Head (India & South Asia), The Max Foundation

FOM Receives Top Ratings from CML Patients and Caregivers!

On September 22, 2024, we unveiled the findings of our **Impact Survey Report: Friends of Max & Its Activities**.

The report highlights FOM members evaluate its efforts, and more importantly, it gives us actionable insights to keep raising our standards and amplifying our voice on a global scale.

Highlights:

- 171 respondents, from a chosen cache of FOM members including patients, caregivers, City Chapter Leaders, and Trustees, participated in an in-house developed online survey.
- The feedback was overwhelmingly positive, reaffirming the effectiveness of our patient advocacy efforts.

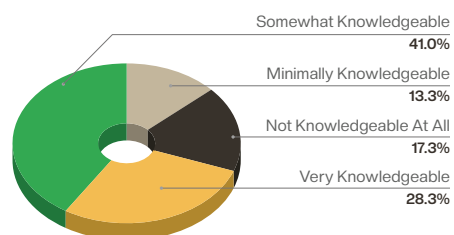


Key Findings

30.4% Knowledge Gaps at Diagnosis:

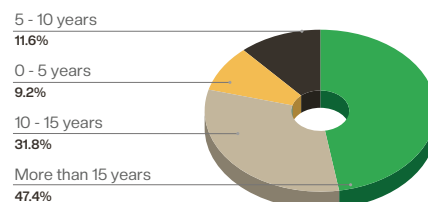
Over 30% of respondents indicated minimal or no knowledge about CML at the time of diagnosis. This highlights the critical role FOM plays in providing vital information and support from the start of the cancer journey.

** This is a surprising outcome; we feel there could have been a bigger percentage of respondents with minimal knowledge of CML at the time of their diagnosis. This we feel could be a result of having lived with CML for so many years and reflects their current knowledge of the condition.*



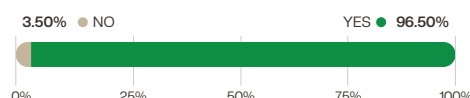
47.4% Long-Term Engagement:

47.4% of respondents have been connected with FOM for more than 15 years, showcasing FOM's long-standing commitment to its mission of ensuring no CML patient is left behind.



96.5% Community Support:

96.5% of respondents reported a deep sense of community and belonging due to FOM's activities, which helps in fostering emotional resilience.



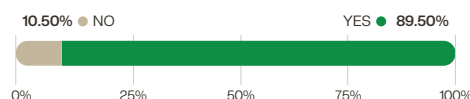
87.7% Effective Interventions:

Respondents highly rated FOM's initiatives such as Financial Support, Support Group Meetings, Project Shiksha, and Guidance from Volunteers, with 87.7% finding Patient Support Group Meetings particularly valuable and 71.9% highlighted the importance of access to BCR-ABL testing.



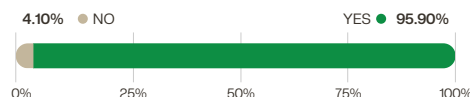
89.5% Improved Doctor-Patient Communication:

89.5% of respondents felt FOM empowered them to engage in more informed discussions with their doctors, improving understanding of treatment options.



95.9% Caregiver Support:

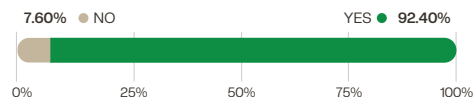
95.9% of respondents highlighted that FOM's emphasis on emotional support significantly reduced caregiver stress.



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92.4% Accessibility:

92.4% agreed that FOM's activities were accessible to everyone, regardless of location or financial barriers.



Helping Patients Tackle Key Challenges:

When asked about FOM's effectiveness in helping patients manage critical challenges—such as Understanding CML, Maintaining Treatment Compliance, and Coping with Side effects—respondents overwhelmingly gave FOM the highest rating.

FOM's comprehensive approach equips patients to navigate their treatment with better understanding and confidence.

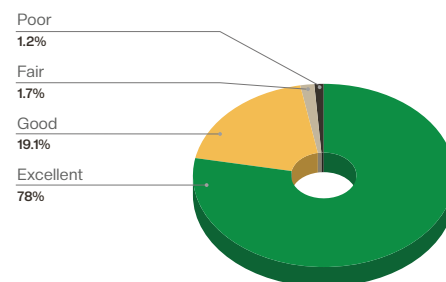
PERCENTAGE OF RESPONDENTS WHO GAVE THE HIGHEST RATING

Understanding CML	80.70%	😊
Compliance	65.50%	😊
Managing side-effects	64.91%	😊

78.4% A Resounding Endorsement of FOM's Impact:

With 78.4% of respondents rating their overall experience with FOM as excellent, the organization's impact is undeniable.

This exceptional rating underscores FOM's effectiveness in creating a robust support system for CML patients and caregivers, meeting—and exceeding—their needs with compassion and dedication.



Winning Global Recognition

FOM's advocacy knows no boundaries! We're pleased to share that at the 9th Annual MPN Horizons event in Warsaw, Poland (September 6th - 8th, 2024), FOM participated in critical discussions around the latest MPN treatment modalities, emerging therapies, and new technologies. Representing FOM were Viji Venkatesh, Region Head (India & South Asia), and Trustee Nagendran Nagarajan.

Adding to our success, FOM secured 2nd Prize in the prestigious Poster Competition that showcased a selection of Best Practices worldwide. FOM's poster "Collaborating for Impact", showcased our work in the field of MPN patient care and management. This recognition highlights the incredible joint efforts of Tata Memorial Hospital, The Max Foundation and Friends of Max in supporting CML and MPN patients through Weekly Clinics and disbursement of disease information.



A Big Win for Our Leader!

We are beyond proud to announce that Viji Venkatesh, FOM Managing Trustee, was honoured with the 2024 International Chronic Myeloid Leukemia (iCMLf) Prize in Prague on September 29th, 2024. This prestigious award recognizes her exceptional contributions to advancing cancer care and patient support, particularly in low-resource countries. Under her leadership at The Max Foundation and Friends of Max, pioneering initiatives have transformed the lives of countless cancer patients in South Asia and beyond.

22nd September

World CML Day 2024 Recap



Patient Support Group Meeting at NIMS, Hyderabad

Leading doctors and resident physicians shared insights on treatment adherence and regular testing, while patient testimonials added a personal touch.



Patient Support Group Meeting at HCG Cancer Center, Jaipur

Nearly 145 attendees, including renowned physicians, gathered to discuss CML treatment, FOM support, and the importance of treatment compliance.



Chai for Cancer Adda at KBR Park, Hyderabad

Hosted by Telangana City Chapter Leaders, over 1,500 cups of chai were raised in support of cancer patients. Special thanks to Café Niloufer and Red FM Telugu for their generous contributions and to Pramod Agarwal, Trustee FOM, for making the Adda a grand success!



Launch of The Max Foundation's Day-by-Day Program, Kozhikode

This initiative was launched on a pilot scale in collaboration with Dr. Hemant Malhotra from Mahatma Gandhi Medical College & Hospital and Dr. Narayanan Kutty Warriar from MVR Cancer Centre & Research Institute. The program aims to improve and sustain patient adherence to treatment, ensure access to essential monitoring tests, provide comprehensive disease information, and offer wraparound support to patients.

Engaging Activities across India:



JUL
13

A GIST Patient Focus Group Meeting was held in Mumbai to mark GIST Awareness Day. Patients shared personal stories, celebrating resilience and raising awareness.



JUL
27

A Patient Support Meeting in Faridabad, held in collaboration with Sarvodaya Healthcare, provided crucial support to patients and families.



AUG
25

A gathering in Coimbatore brought together patients, caregivers, and physicians to strengthen community ties and share knowledge.

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Twitter : @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