April - June 2024 NEWSLETTER



MESSAGE FROM THE TRUSTEES

Our success as the largest patient support group in the world for CML and GIST patients has been a collective effort, and in this edition of the FOM newsletter, we celebrate the remarkable contributions of The Max Foundation and our dedicated treating physicians.

The landscape of patient care is ever-changing, presenting both exciting opportunities and significant challenges. As a community-based organization, we understand the importance of transparency and partnerships that share a common goal. Collaborations with trusted entities not only add value to our mission but also validate our efforts in the most meaningful way.

Friends of Max has been fortunate to have strong and enduring support from The Max Foundation. From the outset, their presence has been a cornerstone of our growth. The highly motivated and capable Max Foundation team has relentlessly assisted our City Chapter Leaders in their efforts to help community members, collaborated with our Trustees to implement care programs, and helped organize Patient Support Group Meetings every month in various parts of the country. Their passion and commitment go beyond their professional responsibilities, embodying a true spirit of service.

Equally critical is the unwavering support from the community of oncologists and treating physicians, without which the patient support meetings and other outreach efforts would have been impossible. Their combined expertise, compassion, and dedication to patient care have been instrumental in empowering Friends of Max to evolve from a small group into the largest global support network we are today. For these busy physicians to be associated with FOM for over 20 years speaks volumes about their commitment to collaboration.

Going forward, as we continue to expand and enhance our efforts, we are reminded of the invaluable role played by The Max Foundation team and our treating physicians. They are the bedrock of our network, ensuring that every CML and GIST patient in India has access to the warmth, guidance, and support of Friends of Max.

Together, we aspire to continue this journey, reaching out to more patients, offering hope, and building a community where no one faces their challenges alone.

With heartfelt gratitude.



The Power Of 3

Three is a magic number, and at Friends of Max, we harness the Power Of 3 to create meaningful change. By uniting the knowledge, medical expertise and operational skills of The Max Foundation, our Treating Physicians and the Friends of Max community, we extend our reach and amplify our impact.

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A Note From The Max Foundation

Friends of Max (FOM), the patient support group arm of The Max Foundation in India was established in 2003 with the motto "Together We Share and Learn". Since its inception, the dedicated team at The Max Foundation in India has significantly contributed to supporting FOM's objectives. We provide guidance and assistance in organizing Patient Support Group Meetings, raising cancer awareness and advocating for patient needs. Max and FOM have collaborated on numerous successful campaigns and activities in the South Asia region. Our work with FOM in patient intervention is a crucial responsibility within the realm of Social Determinants of Health (SDoH).



By working with FOM, we gain a deeper understanding of the challenges and needs that patients face every day. This collaboration allows us to amplify patients' voices and ensure their perspectives are heard. We also strive to provide all possible assistance to help them continue living with dignity and hope.



Sudha Samineni Program Officer, The Max Foundation

'It takes a village to raise a child' the old African proverb is an oft quoted saying and it resonates powerfully within the success of any community-based project. Be it a literacy programme, a screening project, a vaccination campaign or in our case the setting up of a patient support group, we live in equally exciting and challenging times where needs of those depending on us and the means to cater to them are both very volatile and constantly being questioned and evaluated.

Transparency is the need of the hour and partnerships that

respect a common goal. The primary need of any Not for Profit is the value that collaborations with trusted and respected entities can bring to them. This adds value to their mission and vision and serves as validation of the best kind. Friends of Max is lucky to have this kind of equation with The Max Foundation and the Oncology Community in India.

We remain so grateful to this blessing.

Celebrating Collaborations:

The Max Foundation Team and our Treating Physicians

From the very beginning, the collaboration between Friends of Max and The Max Foundation has been instrumental in shaping our mission and expanding our outreach. From supporting our City Chapter Leaders in their peer to peer to interventions; working with the Trustees and helping them implement our patient outreach programmes to organising with meticulous attention to the smallest details, monthly Patient Support Group Meetings in cities and towns all over the country the Max Team, performs all these duties and more with a passion and sense of commitment that goes beyond their role and responsibilities.

Equally vital to our success is the contribution to our cause by the treating physicians and the community of oncologists in the country; the best of them having signed up with us as Advisors to

our Medical Board. They work tirelessly alongside the Max team and our patient leaders to ensure a 100% support to our activities. Their combined resources, expertise, and guidance, along with their sense of compassion and commitment to patient care, have empowered Friends of Max to grow from a small informal focus group (in 2003) into the world's largest Patient Support Group to individuals living with CML and GIST, two types of rare cancers.

Year after year as we implement new projects and programs directed towards patient support, we remain grateful to The Max Foundation team and our treating physicians who remain the cornerstones of our network. Together, we aspire to ensure that every CML/GIST patient in India, has access to the warmth and support of Friends of Max.

Our Impact through the Eyes of our Treating Physicians

Dr. Hemant Malhotra

Director, Oncology Services, Sri Ram Cancer & Super-specialty Center & Professor & Head, Dept. of Medical Oncology, Mahatma Gandhi Medical College and Hospital, Jaipur



Despite progress in CML treatment, much remains to be done in our country. Only 7 out of 10 patients respond well to Imatinib. Support is needed for second generation drugs and BCR-ABL testing, which is costly for many. Financial aid for stem cell transplants is crucial for those who fail current treatments. We must ensure access to new advancement and third generation medicines, and prepare for 1.5 lakh new CML patients by 2023 with qualified physicians and resources.

Dr. Lalit Mohan Sharma

Assistant Professor and Senior Consultant, Dept. of Clinical Haematology, Mahatma Gandhi Medical College and Hospital, Jaipur



CML is the only disease in which with proper adherence to treatment the patient is able to lead a normal life. This is not so in any other critical disease. With wonderful oral drugs available hardly any patients need to undergo transplants. What makes a difference is also the extensive support that CML patients are getting from organisations like Friends of Max, The Max Foundation and Novartis, is unbeatable, there is no match for that. \ref{Max}

Dr Pritanjali Singh

Professor & Head, Dept. of Radiation Oncology All India Institute of Medical Sciences, Patna



CML Patient Support Group Meeting conducted by The Max Foundation and Friends of Max is a festival for patients of Bihar, who really look forward to the same every year. Learning, sharing and being together is the USP. As doctors we get time to connect to our patients and understand their point of view better. The communication skill workshop was exceptional, as with everyone doing their part and enjoying. 17

Dr Hari Menon

Professor and Head, Dept. of Haematology and Head Medical Oncology, St. Johns National Academy of Health Sciences, Bangalore



Thank you, The Max Foundation and Friends of Max, for organising a CML Patient Support Group Meeting at St John's during the Leukemia Awareness month of September. The support group always provides the platform and opportunity for people to share personal experiences and feelings, coping strategies and or firsthand information about their disease and how to live their life in almost a near normal way.

Dr Subhash Chander Varma

Director of Internal Medicine, Fortis, Mohali



Meetings like this give us an opportunity to encourage and motivate the CML patient community to remain treatment compliant, in spite of the side effects that some of them may face. It helps to provide the emotional support and camaraderie which possibly the physicians are unable to provide; to share and learn from each other's experiences, be happy and ultimately remain healthy.

Dr M.V.T. Krishna Mohan

Senior Consultant, Medical Oncology, Basavatarakam Indo-American Cancer Hospital, Hyderabad



These meetings give everyone who participate an escape from the fast-paced world we live in. It provides a safe space for all patients to assemble, think, and raise questions that may have previously gone unanswered. These sessions provide the patients with a sense of community, which boosts their spirits and confidence.

Dr Vikas Goyal

Sr Hemato Oncologist, Sanjeevani CBCC Cancer Hospital, Raipur



Congratulations to the whole team of The Max Foundation and Friends of Max for successfully organising the Patient Support Group Meet at Raipur. I found that the participants got actively involved, educated, inspired and had fun at the event. Looking forward to such events."

Dr Parathan Karunakaran

Associate Professor, Medical Oncology, Adyar Cancer Institute, Chennai



The Max Foundation and Friends of Max is like one seamless family with no hierarchy whatsoever. The whole team is dedicated and fully committed to the wellbeing of our patients. This is the true landmark of a partnership.

Dr. Rajiv Ranjan Prasad

Director, Radiation Oncology, Medanta, Patna



The Max Foundation program was started in 2002, which provided benefit to many CML & GIST patients. It attracted patients not only from the state of Bihar but also from adjoining states where such programs were not available

back then. It gave relief to patients, especially pregnant women. Thanks to the program and its timely treatment, the same women today are leading healthy lives with their children all grown up."

Dr Pankaj Malhotra

Professor and Head, Dept. of Clinical Haematology and Medical Oncology, PGIMER, Chandigarh



Meetings like this help to increase awareness among the growing CML patient community. Just by taking a daily tablet, doing periodical tests and follow up visits with the physicians, patients can today lead a near normal life. "

Dr Shruti Toshniwal Mantri

Consultant hemato-oncologist and BMT physician, CARE CIIGMA hospital, Aurangabad



There are no words to explain the work you all are doing. It is really a boon for society. The family I experienced was so warm and welcoming that I felt like I've known you all for a very long time. Meetings like these have a positive impact on patients & their minds, no doubt.

Dr. Arijit Nag

Consultant, Clinical Hematology and Cellular Therapy, TATA Medical Center, Kolkata



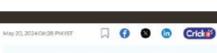
As a cancer physician, it is humbling to meet CML survivors specially looking at how much they value their lives and their gratitude at getting a second go at life. It has been an honour hosting the Patient Support Group Meeting this year. Meeting Viji Ma'am and the entire team is always a bonus. "

Dr Venkatraman Radhakrishnan

Professor and Head of Department, Medical Oncology, Adyar Cancer Institute, Chennai



As more young patients are diagnosed with CML and effectively treated with Imatinib, their condition becomes manageable. However, they face challenges like behavioural changes, mood swings and treatment non-compliance as they enter adolescence. I urge The Max Foundation and Friends of Max to publish a book similar to Maximo & Big C, tailored for older children, addressing these issues and promoting treatment adherence.

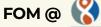


Viii Venkatesh hosts Chai for Cancer adda at her home to raise funds for underprivileged cancer patients. 125 people donated ₹4 lakh.



'Chai, cancer and unbounded love: How a Thane woman is raising funds for cancer patients'

Written by Aditi Shah-Bhimjyani, the article showcases how Viji Venkatesh's passion is helping to raise funds to provide basic necessities for underprivileged cancer patients.







CML Horizons - the world's No.1 CML conference with 75+ countries participating was held in Vilnius, Lithuania, in May'24.

The key topics of discussion were:

TFR*: Increasingly, doctors & patients are opting for TFR across the world.

Communication: Patient communities are growing on digital media.

LMIC** Countries: Challenges faced by LMICs include availability of medication, diagnostic labs & adhering to compliance.

FOM was well-represented & won the 2nd prize in the prestigious poster campaign. We will go for Gold next year!

*TFR: Treatment-Free Remission. We invite you to consult your doctor about TFR.

**LMIC: Low-Middle Income Countries

Concluding Chai for Cancer Season 10 and Launching Season 11

We are thrilled to announce that Chai for Cancer Season 10 has been an extraordinary success, surpassing all expectations. This season has set a new benchmark, making it our most successful till date. Thanks to the unwavering support and generosity of our hosts, we've achieved remarkable milestones:

- Total Addas: 39
- Total cups of chai raised: 100,000+
- No of cities covered: 25
- Overseas: New York & Seattle in USA
- No of people: 2000+

Our Super 11 exceptional hosts are individuals who have truly embraced our cause and been instrumental in making the campaign a huge success.





Year after year, they have welcomed their friends, family, children's friends, neighbours and colleagues into their homes to Raise a Cup and support Chai for Cancer!

Join us as we celebrate these remarkable people, institutions and collaborators whose collective contribution has helped us reach more and more patients who are in need of our support and guidance.



Building on the incredible momentum of Season 10, we've set ourselves an ambitious target of Rs. 1.5 crores for Season 11.

Launched on 12th May 2024 the season is off to a fast-paced start setting some amazing milestones of its own!

- No of Addas: 3
- Cities covered: Thane, Mumbai and Delhi
- Over 4000 cups of chai raised so far and continuing

For private circulation only

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Website: www.friendsofmax.info Website: www.chaiforcancer.org : friendsofmax@gmail.com

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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

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