

January - March 2024 NEWSLETTER

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MESSAGE FROM THE TRUSTEES

For Friends of Max, the year 2023 has been a year of transformation. FOM accelerated itself further towards reaching out to more patients and hospital networks providing support in various forms. Through several



Nagendran Nagarajan Trustee, FOM

channels, our fund-raising activities reached every corner of the country. With the support of The Max Foundation we conducted 16 patient support group meetings and met over 1885 patients, caregivers and physicians during the course of the whole year.

FOM partnered with the prestigious Adyar Cancer Institute (WIA), Chennai to support BCR-ABL tests for hundreds of economically weaker patients to ensure compliance adherence.

As FOM marks its 22nd year of inception in 2024, we have plans to upscale our initiatives and, campaigns. We continuously strive to better our efforts in realizing the dream of 'Together we Share and Learn' in making a positive and warm impact to every family of survivors and create a circle of vibrance and joy. Let's join hands and pledge our commitment onwards!



Top 10 First-Time Achievements of the Year

Welcome to this special edition of our Newsletter celebrating the Top Ten first-time achievements of the year gone by. As we bid farewell to the year 2023, we take a moment to acknowledge and document these special milestones. We are confident that these will inspire us to do better and bigger year after year.

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Friends of Max makes a mark on the international platform

Amplifying the voices of thousands of patients (and their families) living with CML and GIST from India

Through the dedicated advocacy of our Trustees and City Chapter Leaders, FOM continues to elevate the voices of thousands of patients and families living with CML and GIST in India on the global stage.

STOP PRESS!

Viji Venkatesh, Managing Trustee, wins the prestigious 2024 iCMLf Prize for her outstanding contributions to improving the care of people with CML in resource constrained regions around the world.

FOM's Project providing Diagnostic Testing at no cost to CML patients, receives 7000 euros from CML Advocates Network's Fundraising Campaign conducted over the CML Horizon conference held in Berlin, Germany

Project Shiksha, (supporting schooling for pediatric patients) wins the Runner Up Prize at the CML Horizons conference in Berlin.

If anyone had told me that 20 odd years after setting up a Support Group for CML and GIST patients I would be writing a little note on the ten new projects that the group now in its 21st year, has developed and put on track successfully, I would have not believed it.

But that is what Friends of Max is all about and these achievements mean a lot more than just what they look like on the surface.

Relentless in the pursuit of their mission, the Trustees do not hesitate to explore any opportunities that will bring them closer to their goal of impactful patient care. For patients on life long treatment for their chronic leukaemia and the even rarer GIST, compliance is of utmost importance. What they need most is awareness and practical assistance to ensure good adherence behaviours. All our support programs focus on this one aspect. Over the decades, our Trustees and City Chapter Leaders, and patients themselves, busy with their

day jobs and family responsibilities have demonstrated their dedication towards this cause and worked towards bringing others into the fold so that they can all benefit from shared knowledge. What has been equally or perhaps more challenging is reaching out to and building relationships with partners who believe in our work and are happy to support us; partners, donors, volunteers, advisors and community leaders. When I look at each of these achievements of the past year , I realise these have been possible only because of the coming together of like-minded people who recognize the need of the hour. Funding is what every group needs to implement and sustain any support programme. And finding funds is the most challenging aspect of patient centric care.

As we enter our third decade of existence, this last past year's achievements fill us with hope and good cheer. We continue relentlessly.

01



To celebrate World CML Day 22/9, FOM included two new tests to its package of tests provided to CML patients. FOM's Project providing Monitoring Tests at No Cost to CML Patients provides relief to patients by under writing the cost of these tests so that they may undergo their treatment and tests as per their physicians' advice and lead a healthy and close-to-normal life. We are happy to report that along with the BCR ABL and CBC tests, Liver Function Test and Kidney Function Test have also been included.

Breakthrough initiative starting September 2023: Addition of Liver & Kidney Function Tests to our Diagnostics Project

Providing Monitoring Tests at No Cost to CML patients

The project launched in June 2021 has now picked up a momentum of its own. Thousands of patients are using FOM's home sample collection service to get themselves tested. Since we extended this service to our patient meetings, nearly a year ago, we have crossed the 100 patients per month number.

All this has been possible due to the untiring support from and the teamwork between The Max Foundation, our City Chapter Leaders, our Trustees and our generous donors.

02

Cancer Patients' artwork unveiled in a unique fundraising exhibition held in Mumbai

Colors of Hope

Friends of Max in collaboration with Nine Fish Art Gallery, Mumbai organised Colors of Hope, a unique fundraising exhibition of artworks created by cancer patients. The collection featured the creativity and the talent of cancer patients while providing them with a platform to express themselves and find solace in art during their challenging journey. The artwork created by patients from all walks of life over the last 20 years, represented different stages of their cancer journey. Each piece told a unique story, capturing the emotions, challenges and triumphs experienced by them. The



exhibition attracted a diverse group of art enthusiasts, cancer survivors, caregivers and individuals passionate about supporting the cause. Over 30 pieces of artwork were sold, with all proceeds going towards supporting the patient centric activities of Friends of Max.

03

Taking the fundraising and awareness campaign on the road for the first time

Launch of Chai for Cancer Road Show October 2023

To celebrate the legacy of Max in whose name The Max Foundation is set up and who inspires and motivates Friends of Max every day, a special Chai for Cancer Roadshow was flagged off from Udumalaipettai in Tamil Nadu, on 19th October 2023, Max's birthday.

Taking the awareness and fundraising campaign on the road for the first time were Karthikeyan, City Chapter Leader from Tamil Nadu and ace motorist, and Managing Trustee Viji Venkatesh, supported by the active, enthusiastic and dependable City Chapter Leaders from South India led by Nagendran and Sajeevan, who with their proactive thinking, tremendous creativity and zest for teamwork, elevated FOM operations to an all new level of efficiency.

The Roadshow traversed a distance of 1500kms in nine days,



across eight cities (Udumalaipettai, Kochi, Calicut, Gudalur, Mysore, Bangalore, Pondicherry and Chennai) with a Chai for Cancer Adda hosted at every pit stop. Beginning from Karthikeyan's home town Udumalaipettai in Tamil Nadu, the duo drove through Kerala and Karnataka before concluding the Road Show in Chennai on October 26 at the iconic Adyar Cancer Institute. All along raising awareness for patients living with CML and GIST and raising a total donation of Rupees Ten Lakhs generously contributed by well-wishers towards their many unmet needs.

04

FOM makes its debut at the Tata Mumbai Marathon 2024

We Ran, We Conquered, and We Made a Difference!

For the very first time Friends of Max ran the Dream Run at the Tata Mumbai Marathon 2024 on 21 January 2024 in support of its Project Shiksha. Representing Friends of Max was Viji Venkatesh, accompanied by Anusha Singh both Lady Shri Ram College for Women, New Delhi alumni. It was an exhilarating experience watching them put the Friends of Max footprint out there at the

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Tata Mumbai Marathon, participating amidst thousands of like-minded individuals, each with their own unique reason for participating but bound with the overall intention of doing social good.

The Tata Mumbai Marathon proved to be an excellent platform to raise awareness and funds for Project Shiksha, an initiative to provide financial aid to cover the education costs of paediatric patients and children of patients who are on lifelong medication; an initiative with a dual objective- to ensure that they are able to continue education while remaining compliant to their cancer treatment therapy. Through the support of well-wishers, FOM City Chapter Leaders and Trustees we raised over Rupees three lakhs!

Our participation in the Tata Mumbai Marathon is just another glimpse of how collective action helps FOM bring dignity and hope to the lives of thousands of patients who are coping with two rare cancers, CML and GIST. A special thanks to United Way Mumbai, Red FM, Mumbai team of The Max Foundation, contributors, friends and all our well-wishers out there who were there to cheer on Viji and Anusha representing Friends of Max in our first ever Marathon attempt!

Chai for Cancer Campaign earns top mention at the APPIS Summit 2023

Cited as one of the Best Examples of Digital Fundraising and Awareness Campaigns

Chai for Cancer and Viji Venkatesh, Managing Trustee Friends of Max and the brainchild behind the campaign showcased at the prestigious APPIS Summit 2023 to speak about Chai for Cancer and how the campaign combines technology with in-person interaction to successfully raise awareness and funds for the many patient centric activities carried on by Friends of Max.

APPIS Summit 2023 took place on 20-21 March 2023 in Manila and

Alliance & Partnerships for Patient Innovation & Solutions

APPIS SUMMIT

Chai for Cancer

Chai for Cancer

was attended by over 1,400 participants across the healthcare ecosystem from over 60 countries. They came together with the common goal of accelerating access for patients and prioritizing action towards better health outcomes in Asia Pacific, Middle East, and Africa.

FOM's Membership Project Breaking Records

Welcomes Over 80 New Members Monthly!



Keeping in mind that the growth of the organization is related to the number of active members in its fold, the Managing Committee had taken up the task of increasing its membership in the last financial year (FY 2022-23). The benefits of the efforts made then have been reflecting in this financial year with a noticeable increase in the number of annual memberships.

Our efforts continue and we hope to spread our outreach PAN India. Membership benefits were also re validated this year. A new brochure highlighting the benefits of an FOM membership was also created to better communicate its value to patients.

The Programme offers Annual and Life Memberships, with equal benefits for both categories.

7 Toys Bank & Project Shiksha Toy Joy!

Project Shiksha is an ambitious initiative by Friends of Max which aims to provide financial aid to cover the education costs of paediatric cancer patients who are on lifelong medication.

It was launched in October 2022 with the overall objective to ensure that the disease does not come in the way of their accessing educational opportunities enabling them to remain compliant to their treatment protocols. Under this project, support is provided to cover travel costs for their periodical follow up visits with physicians. In this manner both the financial burden and



psychological stress on the families is reduced. These are cancer patients from weaker socio-economic backgrounds.

Today over 43 children ranging from Class 1 to 12 have been able to continue their education with the support thus provided.

Another new initiative in 2023, called "The Toys Bank", an extension of Project Shiksha, further helps to provide creative and educational toys to children during their visit to The Max Foundation office in Mumbai.

FOM Develops New Disease Information Material

Empowering patients to make informed decisions

Supported by FOM's Board of Medical Advisors and The Max Foundation, FOM successfully publishes updated and state-of-the-art disease information booklets to help patients keep up to date with all recent developments from the world of CML and GIST. This in turn helps them to make informed decisions. Some of the new booklets published include:

Continuing with the FOM's series on MPNs (Myeloproliferative neoplasms) FAQs, which addresses common questions, a second and third booklet published on disorders termed "Essential Thrombocytosis" and "Myelofibrosis". The booklets have been put together for FOM by Dr. Sumeet P. Mirgh Associate Professor, Adult Haematolymphoid & BMT, Tata Memorial Centre, ACTREC Mumbai and Dr. Lingaraj Nayak, Assistant Professor Department of Medical Oncology Tata Memorial Hospital, Mumbai respectively.

On World CML Day 2023, FOM released CML FAQ 2.0 version, which has been diligently prepared by Dr Pankaj Malhotra, Professor and Head of Department of Clinical



In a strategic move to enhance the role and scope of the FOM Leadership Team, the Trust has welcomed three new Trustees to its board. They are Nagendran Nagarajan, Amruta Patidar and Neel Kankani who will bring with them new skill sets and expertise.

Their long tenure and rich experience as exemplary Patient Advocates and City Chapter Leaders from diverse regions, will help enhance our patient-centered program development with new perspectives, better empathy and more understanding. We are also looking at improved stakeholder engagement as FOM

Lights, Camera, Action!
Viji Venkatesh dons the cap of a cine actor

Managing Trustee Viji made her debut as an actor in the successful Malayalam film Pachuvum Athbutha Vilakkum (Pachu and the Magic Lamp), which was released in 2023 both in theaters and on OTT platforms. The film is written, directed and edited by Akhil Sathyan, son of veteran filmmaker Sathyan Anthikad, stars Fahadh Faasil in the titular role of Pachu and Venkatesh as the wise and feisty Laila called Ummachi (mother) by everyone. The film has been a super success and her performance has won many hearts-both of the Malayalam film audience and elsewhere. Viji says she accepted the role because she identified with the message it carried on the importance of girl child education, a cause dear to her own heart and the passionate enthusiasm shown by Director Akhil.



Hematology and Medical Oncology at PGIMER, Chandigarh. The booklet originally published in English is now translated into seven regional languages.

On International Women's Day an e-copy of Breast Cancer FAQs was launched. FOM remains committed to support the cancer community and in this endeavour we were supported by The Max Foundation team as well as, Dr Bhawna Sirohi, Medical Director, BALCO Medical Centre, Raipur.

We hope the material will provide patients and their families with a better understanding of the disease, its management and the available treatment options.



strives to scale up and achieve higher levels of excellence in providing support to patients living with CML and GIST.

Our outgoing Trustees, Ushakant Shah, Professor Koner and Sriram Ranganathan will assume advisory status to the Board of Trustees.







The tremendous success of the film has significantly raised awareness of the role of Friends of Max and The Max Foundation in supporting CML and GIST patients. Our work has gained visibility, and Chai for Cancer continues to receive unwavering support from the entire team of Pachuvum Athbutha Vilakkum. A special shout out to the Director and his team and Viji's co-stars Vineeth Radhakrishnan, Veena Nair and Piyush Kumar to whom we are deeply grateful for their ongoing support.

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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