

Embracing our old world, but with lessons learnt

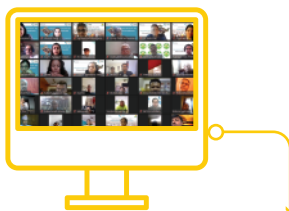
"It's been three years since we have had a patient meeting at this hospital. And how nice it is that the first meeting after all this time is for Friends of Max".

- Dr Shripad Banavali
(Prof. & Head, Dept. of Medical & Pediatric Oncology,
Tata Memorial Hospital)

on 5th June 2022 at the Patient Support Group Meeting organized by The Max Foundation and Friends of Max at the Tata Memorial Hospital.

The challenges posed upon the CML & GIST community in India by the raging virus and the consequent lockdown restrictions during the three years of the COVID-19 pandemic have taught us some valuable lessons. In the previous editions of the FOM Newsletter, we have covered in detail how the pandemic had affected FOM's patient interventions and how we adapted to "the new normal".

As we step into our old world, it is important that we remember the lessons learnt during this time -



1. The FOM Community is a group of remarkable patient leaders who will always find ways to help their fellow members.

2. The healthcare personnel in India go beyond their call of duty to ensure that the patients receive the treatment they deserve.

3. The Max Foundation team in India will always ensure that the patients and their families receive all the support that they can get.

- Aashray Paul,
Admin & Communications Manager,
Friends of Max.

Impact Story

Years ago, when Rambabu Mahto was diagnosed with Chronic Myeloid Leukemia (CML), he was very non-compliant - skipping his medicines and being irregular with his follow-up. Once, he was visiting The Max Foundation's South Asia office in Mumbai when Viji Venkatesh probed him to find out the reason behind his non-compliance.

Viji found out that Rambabu had lost his job as a truck driver because of his cancer. He had no money to travel from his village in Bihar to the Tata Memorial Hospital, Mumbai where he was being treated. Further, Rambabu informed her, he was unable to swallow the capsule as it made him nauseous.

Says Viji, "I asked him if he had shared this with his doctor. Yes, he had and Doctor Sa'ab had advised him to have it with a glass of milk. So why don't you do that, I asked him never realising how very thoughtless that question was. And



insensitive. Ammaji, he told me looking away, if I had money to buy milk, I'd give it to my little baby. I couldn't drink it".

That was the moment of reckoning for Viji and FOM, when it was decided that there had to be a way to support patients like Rambabu who did not have money to even collect the medicines that were given to them at no cost. And thus, Chai for Cancer was born with the twin objectives of creating awareness about the needs of and raising funds for patients

from weaker socio-economic backgrounds.

Started in 2014, Viji's brainchild - Chai for Cancer - has raised ₹ 2.75 crores in funds for supporting the unmet needs of several other patients like Rambabu Mahto. Here he is today, doing as well as he can. His little baby is all grown up now. Rambabu visits his treating physician regularly because he knows he will receive all the support he needs for lodging and travel.

Amma Speaks

For two years and more, all we could speak about was the pandemic, with a plethora of new words and phrases in our vocabulary we'd never used before - COVID-19, lockdown, social distancing, physical distancing, mask up, virtual meetings, online consultation, hand sanitizers, vaccination certificates, booster doses, RT PCR testing. The tragedy of the pandemic induced deaths and loss of livelihoods was something which every family, world over had to experience first-hand. Every generation, every segment of society was impacted. For those with already existing co morbidities, the stress was compounded. Planning and completing follow up visits to treating physicians was a nightmare - ensuring supply collection and compliance an equally a daunting task. The feeling of isolation intensified; fear of the unknown froze sensibilities.

Somehow, we seem to have come through this nightmare and now fervently hoping it is behind us. We are in 'Back to Normal' mode now - well, almost and perhaps for some of us, a 'New Normal'.

Personally, I am not a fan of the New Normal bit. I am in 'I Want My Old Normal Back' mode. But I also know for that I have to be very mindful of lessons learnt during these last months and continue to exercise extreme caution.

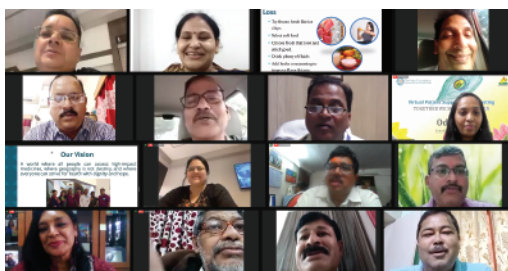
So let us do this together - like T. S. Eliot said, "Every moment is a fresh beginning".

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



144 Total
Participants

Odisha Virtual Meet



This was the first Support Group Meeting organized for patients in Odisha since 2019. It was attended virtually by more than 140 patients, caregivers, physicians and volunteers. Another 100 people joined the livestream on Facebook.

<https://friendsofmax.info/odisha2022/>



144 Total
Participants

Maharashtra Virtual Meet



115 people from across Maharashtra joined this meeting virtually, while another 136 joined the livestream on Facebook. This was the first FOM virtual meeting with a dedicated segment on "Impact of Cancer on Mental Health". It also included impressive presentations on "Importance of Adherence" and "Reasons for Non-Compliance" by FOM City Chapter Leaders.

<https://friendsofmax.info/maharashtra2022/>



138 Total
Participants

Venue: Tata Memorial Hospital,
Mumbai

Mumbai Meet



Organized at the Tata Memorial Hospital, Mumbai, this was the first in-person patient support group meeting organized by The Max Foundation and Friends of Max since 2020. Patients and caregivers – new and old – were happy to reconnect with the FOM family. It also featured a Chai for Cancer Adda and a "De-Stress with Drama" workshop by The Create Foundation.

<https://friendsofmax.info/mumbai2022/>

Know the Max Team



Meet Beena Narayanan who works out of her Home Office in Kochi, Kerala and is a Program Officer with The Max Foundation's South Asia unit. Beena looks after the patients in the Max Access Solutions Program both in India and Sri Lanka.

It was when Beena was volunteering with renowned oncologist Dr V P Gangadharan (who is now on FOM's Medical Advisory Board as well) that Viji Venkatesh (Region Head for Max in South Asia) met her and decided to ask her to come on board.

In Beena's own words "Little did I know that I was going in for a major change in my life when I received a call from Viji in 2004. From then on, I have been with The Max Foundation and what drives me the most is the opportunity to provide support and care to the patients we serve. The love and gratitude received from the Friends of Max community has been enriching to say the least". FOM thanks Beena Chechi, as she is lovingly called, for her sincere and tireless service to the cause.

From the Physician's Desk

Imagine if the drug Glivec was not there...?

Imagine if the drug Glivec was not available in India...?

How would have been the world of CML or GIST patients without Glivec?

What if Friends of Max did not exist?

We never want to think about these hypothetical scenarios even in our dreams. We know now the impact and difference Glivec has made in the lives of CML and GIST patients. We also know



how Friends of Max with its various activities for more than a decade now has brought thousands of these patients together and kept them bonded like a family.

Friends of Max is in its teens, full of energy and enthusiasm. It gets its power from the patient leaders, the CML and GIST community, physicians, and The Max Foundation staff, who are doing so much more work than expected of them. I feel privileged and lucky to be associated as a member of this great organisation. I can only thank and appreciate Friends of Max for their outstanding work for CML and GIST community.

- Dr Pankaj Malhotra, Professor & Head,
Dept. of Clinical Hematology & Medical
Oncology, PGIMER

CHAI FOR CANCER SEASON 9



Season 9 of Chai for Cancer was launched virtually this year.

Armed with our new mascot, the Super-hero Kulhad – designed by Susruta & Saswata Mukherjee, better known as “Bob & Bobby”, we set ourselves a new target – to raise ₹75 Lakhs to support the unmet needs of cancer patients from weaker socio-economic backgrounds.

We are proud to inform that in just six weeks since the launch of this season, Chai for Cancer has already raised ₹ 4.2 Lakhs in funds!

MAY 16 VENUE : Taj Mahal Tea House, Mumbai
HOST : Viji Venkatesh

As is tradition, the inaugural Adda of Season 9 was hosted by Viji Venkatesh, this time at the Taj Mahal Tea House in Bandra. It was attended by old and new supporters of Chai for Cancer and some well-known social media personalities.



MAY 22 VENUE : Lodhi Gardens, Delhi
HOSTS : FOM Delhi City Chapter Leaders

Hosted by the enthusiastic FOM Delhi Volunteers on a summer morning at the Lodhi Gardens. Morning walkers, youngsters and CFC patrons joined the Adda and generously raised their cups to our cause.



MAY 23 VENUE : Delhi
HOST : Sindhushree Khullar

A spontaneous Adda organized by long-time supporter of CFC, Sindhushree Khullar in her driveway. It saw members of her household sharing stories and exchanging experiences.



MAY 25 VENUE : The Max Foundation Office, Mumbai

The fishermen of Worli joined The Max Foundation team for chai and snacks at the latter's South Asia office in Mumbai. The Max team informed them about their work with cancer patients and educated them about the ill-effect of tobacco consumption.



MAY 16 VENUE : Red FM Studio, Mumbai
HOST : Red FM

Our Radio Partners Red FM hosted their annual CFC Adda at their studios. It was attended by their complete team and staff. Also in attendance were their RJs JMan, Yamini and Akriti as well as the radio station's fans invited by Red FM to the Adda.



MAY 16 VENUE : Pune
HOST : Sujata & Satish Mane

Long time supporters of Chai for Cancer, Sujata and Satish Mane hosted their second Adda at their home in Pune. It was attended by friends, family, colleagues and neighbours of the Manes. Also joining were FOM Pune City Chapter Leaders.



About our Collaborators

Meet Alexander Nadar, a senior graphic designer who has been associated with Friends of Max for the last 12 years. He is thankful to FOM Trustee Sujeesh Pottekkat, who introduced him to the organization.

Over the years, Alex has become our go-to person for all design related tasks. He has used his designing skills and finesse to create aesthetically pleasing



Here's Alex in a frame he designed for the Chai for Cancer Season 9 campaign

graphics - posters, invites, Chaifie frames and educational material for FOM and CFC which attract attention and engages minds.

In his own words, "It is a great pleasure to be a part of Friends of Max. I am very thankful to Amma, Sudha and the team for giving me such an opportunity".

Alex is an indispensable part of the FOM family and we look forward to showcasing his creative talents in the years to come.

How well do you know your CML?

How well do you know your CML? Here are five Frequently Asked Questions by CML patients.

These FAQ are a part of FOM's disease awareness booklet specially put together by Dr MB Agarwal, (MD, Dept of Haematology, Bombay Hospital) and first published in 2007.

Q. 1 What is Leukaemia?

Leukaemia is blood cancer. Our bone marrow produces blood and blood cancer begins from the bone marrow. There are three types of blood cells and Leukaemia is cancer of the white blood cells.

Q. 2 What is Chronic Myeloid

Leukaemia and how common is it ?

There are four main types of leukaemia. Two of them are acute and two are chronic. The Acute Leukaemias are Acute Myeloblastic Leukaemia (AML) and Acute Lymphoblastic Leukaemia (ALL) while the Chronic Leukaemias are Chronic Myeloid Leukaemia (CML) and Chronic Lymphocytic Leukaemia (CLL). Acute leukaemia develops quickly while Chronic Leukaemia develops slowly. In CML, white cells are present in excess. Their production goes out of control. These cells fill the bone marrow and also come out in the blood.

CML is the commonest blood cancer in India and other Eastern countries. CLL is the commonest blood cancer in Western countries.

Q. 3 What is the age at which CML occurs?

In India, most commonly, CML affects the age group between 30-60 years. In the Western world, it affects the age group between 50-70 years. Rarely, it can occur in children and very old persons as well. It affects both males and females.

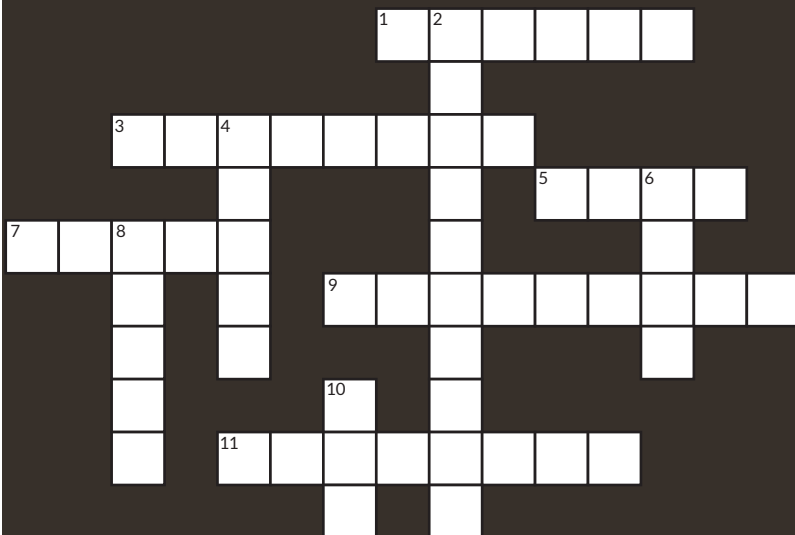
Q. 4 Is CML a genetic disease? If I have it, will my children have higher chance of getting it?

No. CML is not a genetic disease. Children or any other member of the household has no higher chance of getting it. CML is not inherited.

Q. 5 Is CML a contagious disease? Can it spread to my spouse, parents or children?

No. CML is not an infection and hence it is not a contagious disease. It cannot spread to other members in the house.

Test Your Knowledge



ACROSS

- 1 When your WBC is between 4,500 to 11,000 per microliter, it is considered _____ (6 letters)
- 3 The strategic process of influencing governments and policy makers to drive change. (8 letters)
- 5 The act of looking after and providing for the needs of a patient. (4 letters)
- 7 _____ crisis is the third and last stage of CML. (5 letters)
- 9 A prediction of the outcome of a disease. (9 letters)
- 11 An essential amino acid needed for the production of several important brain chemicals. Comes from the Greek word for 'cheese'. (9 letters)

DOWN

- 2 A medical practitioner qualified to diagnose and treat tumours. (10 letters)
- 4 Necessary to maintain life. Breathing is a _____ function. (5 letters)
- 6 Factors that increase a person's chances of developing disease. (4 letters)
- 8 _____ conditions in Leukaemia are severe and sudden in onset. (5 letters)
- 10 A medical imaging technique used in radiology to form pictures of the anatomy and the physiological processes of the body. (3 letters)

ANSWERS: 1. Normal 2. Oncologist 3. Advocacy 4. Vital 5. Care 6. Risk 7. Blast 8. Acute 9. Prognosis 10. MRI 11. Tyrosine

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Facebook :

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

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

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