

Celebrating our Caregivers

A caregiver is a person who provides care for another person. Care giving comes without any expectations. However, one hopes that the concept of giving care will always remain. For instance, if A cares for B and provides care to B, B may provide the same care to C. C in turn would care for D. Thus, Friends of Max today has become an association of caregivers to others and one another. We pass on our experiences, knowledge and share our strength with each other.

Increasingly, experienced personnel attend our patients' meetings and share their wisdom, skills, and knowledge. Caregivers in the form of doctors, volunteers and patient advocates attending our Support Group meetings address the various challenges and problems faced by patients. Our patient leaders having been on treatment for long have realized that, post a period of 5 years of clinically acceptable BCR-ABL levels in their reports and subject to medical advice of the treating doctor, it is now possible to

live without any medicines.

We take pride in being able to assist and facilitate diagnostic testing of hundreds of patients, across India. Today, so many patients from weaker sections of the society are able to undergo their BCR-ABL and CBC tests thanks to FOM's home collection diagnostic support.

However, to scale up and achieve coverage of all the patients we need the support of CSR granting organisations to extend financial benefits to FOM. Hence, I appeal to all organisations to come forward and support FOM in its objective to increase awareness and support us in our varied patient centric activities for the underserved Chronic Myeloid Leukemia (CML) and Gastrointestinal Stromal Tumor (GIST) cancer patients.

S.V. Sunder Krishnan
Trustee and Treasurer,
Friends of Max



Amma Speaks

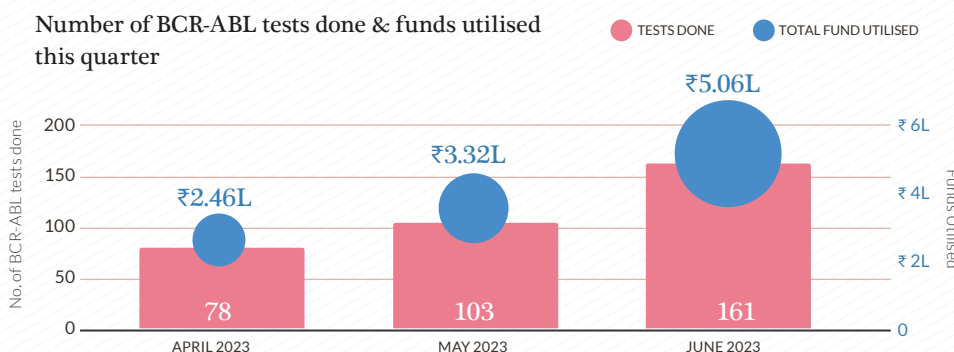
When I look at the Friends of Max family I am surrounded by many heroes. A hero, to borrow from the ancient Greek description of the word, is someone of great strength and capability who has gone beyond all parameters of human endurance and experience and emerged as a savior. I see men and women as well as young adults and children who could easily fit this description. They come across as people with a great sense of self-esteem, capable of compassion and courage; at the same time flexible, creative and blessed with a great sense of humor – always ready to take on challenges.

They rarely complain about some of those challenges they may face – burnout, exhaustion, disturbance in sleep patterns, self-doubt, anger, frustration and even depression. These amazing people are the fulcrum upon which their family revolves – a family facing the sudden diagnosis of cancer – they are the primary caregivers to the patient in the family. A grandfather, sometimes a granddaughter; a sibling or a parent, a favorite uncle or aunt or a close family friend. It is on the shoulders of this person that the whole responsibility of caring for the patients sits squarely and unrelentingly.

The 'caregiver' who does not know that he or she should be able to share responsibilities especially for making decisions; can seek rescue and support systems that would ease the burden as well as help set and achieve realistic goals.

How many of us realize that as caregivers we too need adequate rest and breaks, access to recreational or even spiritual outlets and accept the fact that we too need to follow very disciplined health routines? And that even the most devoted and caring of caregivers must accept there will be personal and professional limitations...

Number of BCR-ABL tests done & funds utilised this quarter



SOME TIPS

Care for the Caregiver

1. Admit to yourself that caregiving is difficult
2. Take your Me Time
3. Center yourself
4. Reach out for help
5. Eat well

This issue of our newsletter is dedicated to and celebrates these wonderful human beings who put before them their loved one and stay in the background, always giving of themselves.

FOM is committed to offering all and any practical and emotional support they may need and provide them a platform where they can share personal concerns, seek training for development of self-awareness skills and receive the care and guidance a caregiver may need.

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



An Ode to our Caregivers

We bring to you in this newsletter a few voices from the FOM family of caregivers who have volunteered to share with us their thoughts and insights on what it means to be that pillar of strength and support to a loved one. A treating physician or a member of the Max team who walks that extra mile; a brother, wife, and husband - in their own words. On behalf of FOM we salute all our caregivers - this feature is an ode to each one of you who provide the daily care for your loved ones in their cancer journey.

Regardless of age or stage, it is but natural for a newly diagnosed patient to feel distressed and anxious. Patients, newly diagnosed or otherwise go through a wide range of emotions ranging from complete denial to fear, anger, sorrow, helplessness and depression. Their main challenge is maintaining their physical and emotional wellbeing. The cancer diagnosis turns their whole life upside down. While treating physicians and their own extended social community may help them to connect with people in a similar situation, how do they cope on a daily basis? Whose counsel do they rely on? It is to the primary caregiver in their family or immediate circle they turn to for seeking the support they need.



Dr Manju Sengar

PHYSICIAN

It has been a pleasure to work with "Friends of Max" who are an incredible source of support for patients with CML and GIST. They not only make lives easier through Access Programs but go beyond that to ensure dignity, and emotional support at every step in the journey of patients and their caregivers. Their work during COVID-19

ensured that all patients could get their drugs without interruption which is a major factor in ensuring treatment success.

Personally, I have learnt a lot from their entire team. Their empathy, understanding, and efforts to empower patients are unmatched. I look forward to the continued association with them.



Dr Niranjini

SPOUSE

The toughest days were when my husband had excruciating pain while on interferon injections. My two boys were in their middle school and I had to shield them from his temper caused by the pain in both legs...he used to say "Somebody should cut my legs!"

Creating a sense of normal even with him was very difficult (for all our sakes I wanted everything to feel normal) and those days truly stand out as the toughest.

Imatinib was like manna from heaven....in so many ways!!!



Navin Agarwal

SPOUSE

It's been 16 years and I have never seen Anshu struggle with managing CML ever. She has taken everything very bravely and is a real warrior. Never has she asked me for any help or favour or shown any signs of weakness.

Life has been really smooth for me as a Caregiver. All thanks to Anshu!



Dipanwita Maiti

MAX

I joined The Max Foundation in November 2019 as the Program Head of South Asia Region. Over the last three and a half years, I have become a part of the Max family with loads of love, respect and warmth from the team members.

My role is to handle the Program in South Asia and some important responsibilities include managing drug access to patients through the MAS program, trouble shoot any supply related issues

at the dispensing outlets and coordinate with the headquarters.

What I like the best about my job? I am fortunate to be a part of the Max Family, getting to know and connecting with our patients, listening to their needs, whether they are emotional, psychological, medical-related or for any other aid with their general comfort and wellbeing.



Shyam Kankani

SIBLING

Being a caregiver to my brother, I always had to maintain a strong image. No matter what the situation was, I could never get carried away by my emotions. I remember there were times when medical reports came and they weren't really what we expected, those were some difficult times as I had to maintain my calm and make everyone believe that we will be able to overcome this situation no matter what.

In the starting days, everyone used to be very tense, although I did not express it. To me, being a caregiver means being available always, being

someone to whom you can come for support and hope at any point in time.

Our whole family works as a unit. My wife takes care of all the household needs while also looking after my brother. It is a huge support for me in many ways. The financial burden was something that made us all question if we could ever keep this going but I took it as a challenge and rose up to the task. As time went by, I started getting adapted to this role of mine and developed a strong faith that no matter what we will win this together.



Vijayalakshmi

SPOUSE

As a caregiver, I would like to divide my story into three main parts- diagnosis, chemo & post chemo.

Given the range of emotions, it was difficult to realise as a carer to put the patient's needs first. I was able to deal with my emotions better since my husband has a strong will. It was nerve-racking to understand the diagnosis in the beginning and to wait for the confirmation & reconfirmation from the second opinions. Even for someone with a medical background, it can be challenging to understand the medical terminology and hospital environments, but with time, it becomes easier.

During chemotherapy it is important to have faith in the doctor. We had to go through multiple chemotherapy sessions, all extremely distinct from one another. But as we progressed, I learned

which symptoms were more typical for that specific regimen and knew what to watch for in my spouse. The emotional toll that the chemotherapy difficulties can have on a patient is important, as there have been occasions when I worried about my husband's prognosis. Thus occasionally, even noticing little side effects in him caused me to overthink.

Completing chemotherapy was not the end of sleepless nights. There are still side effects from medications that my husband experience even after many months of end of chemotherapy. I hope to resume a normal lifestyle again but we have the understand that the person both physically and emotionally has gone through a lot. So, it is better to build a healthy lifestyle and new activities to make it through this.

Patient Support Meetings

Mumbai



JUN 03 VENUE :
Tata Memorial Hospital, Mumbai

The meeting began with a networking Breakfast Session, a safe and secure platform for the patients and caregivers to meet and interact with their treating physicians.

FOM Trustees Nirmesh & Pramod brought moments of cheer and laughter with their popular Bhai & Bhidu show, recalling the hesitant beginnings of FOM - its 1st meeting in Horniman Circle with 22 patients.

Sessions with the doctors covered topics ranging from "Growing old with Cancer" to "Treatment Free Remission". Grateful to Dr Prem Naganathan and Dr Anupa Pillai, Dr Manju Sengar and Dr Sachin Punatar for insightful sessions.

Post Lunch workshop on 'Know Your CML' App conducted. CML Advocates Network has brought out the App in Hindi with the help of FOM patient leader J P Tiwari.

Delhi



JUN 24 VENUE :
Rajiv Gandhi Cancer Institute & Research Center, Delhi

Annual Trustees' Meeting



JUN 10 ... **JUN 11** VENUE :
Panvel

The Friends of Max Trustees Annual meet was held on 10-11 June 2023 at Panvel. Key insights and action plans emerged to create a roadmap towards greater impact of two decades of service to the CML & GIST community. A big Thank You to all our Trustees for providing their valuable time and strategic direction.

SEASON 10

Chai for Cancer

We will always remain grateful to and appreciative of all our hosts; their friends and family and all our supporters who remain steadfast in their belief in Chai for Cancer.

Our target for 2023-24, is a very ambitious Rs 1 Crore. This amount will be completely devoted to helping us support the diagnostic, travel & lodging, education and many other seemingly small yet unmet needs of our patients.



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

7000+ Cups of Chai raised

11

Addas held

1000+

Guests

Cities:

- Mumbai
- Bengaluru
- Ahmedabad
- Thane
- Delhi
- Chennai
- Vashi- Navi Mumbai

APR
02

VENUE : Thane
HOSTS : Rohini & Chirodeep

MAY
04

VENUE : Mumbai
HOST : Red FM Mumbai Studios

MAY
14

VENUE : Thane
HOSTS : Viji & Venky

MAY
20

VENUE : Ahmedabad
HOSTS : Karunakare Foundation & Pacific Group of Companies

MAY
28

VENUE : Bengaluru
HOSTS : Monikanika Guha & Arjun

JUN
03

VENUE : Mumbai
HOST : Tata Memorial Hospital

JUN
04

VENUE : Thane
HOSTS : Alakta, Salim, Aabir & Aashya

JUN
17

VENUE : Vashi, Navi Mumbai
HOST : Bharati Golatkar

JUN
24

VENUE : Chennai
HOSTS : Ambika & Sekar

JUN
25

VENUE : Lodhi Garden, Delhi
HOST : FOM Delhi Chapter

JUN
30

VENUE : Mumbai
HOST : Nine Fish Art Gallery



For private circulation only

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>

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