

20 Years of CML

2022 is a special year for the CML community in South Asia as it marks twenty years since The Max Foundation, in partnership with Novartis, brought access to lifesaving drugs through its patient assistance programme in the region. As the world's largest support group for CML patients, FOM, with the help of The Max Foundation team has started conducting surveys to gain insights on the needs and challenges faced by the CML community. This year's survey aimed at gauging the "Impact of COVID-19 on the CML Community in South Asia".

Key features -

1. Holistic survey focusing on the impact of the pandemic on treatment, monitoring, nutrition, economic and psychosocial aspects.
2. Constructed on a popular online platform and circulated over Instant Messaging Service, Email and Social Media.
3. 1039 responses collected between 1st August and 4th September.
4. Translated into Hindi, Kannada and Tamil

Lessons learnt -

- The concept of a survey and willingness to participate in an exercise like this is still an unfamiliar concept to patients in the region.
- There is a need to impart training to patients and caregivers on how to answer surveys and participate in online activities.
- Patient leaders and members of the community need to be encouraged to actively participate in FOM events.

Some insights -

23% of respondents had tested positive for COVID-19	57% experienced a wage loss during the pandemic
94% have been vaccinated against COVID-19	37% experienced bouts of anxiety or depression
55% faced at least some kind of disruption in their treatment	35% experienced a decline in their nutritional intake.
25.5% of respondents in need approached the Max team for support in collection of medicine supply, while another 16% approached FOM City Chapter Leaders	33% were unable to attend any online support group meetings by FOM and Max due to one of several challenges.

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Amma Speaks

This year marks the 20th anniversary of the patient assistance programme that gave thousands of patients the Gift of Life; the advent of what came to be called The Magic Bullet which burst upon the firmament of CML therapy like the brightest star ever.

This year also marks the coming together of partners from the world of pharma, non-profits and medicine in a project without any kind of precedence.

But most of all this year marks that Dawn of Hope which brightened the lives of so many families in an unimaginable fashion.

These are men and women, little boys and girls who were told they had cancer and had to live with lifelong therapy. An accident of life that brought together hundreds, nay thousands, from all walks of life who then found strength and solace in each other - a safe platform upon which to share and learn with and from each other. They called themselves the Friends of Max. Together they found a new normal for themselves and forged a parallel path ahead.

Twenty years is a long time to have traversed together upon a path of self-discovery and learning and deserves celebration.

22/9 is World CML Day and what better way to celebrate this day than by dedicating to it, this special anniversary. This then is just that - a celebration of two decades of perseverance and courage. I speak for Friends of Max and The Max Foundation

Personally, for me it has been two decades of discovering every day the power of unconditional love and acceptance.

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

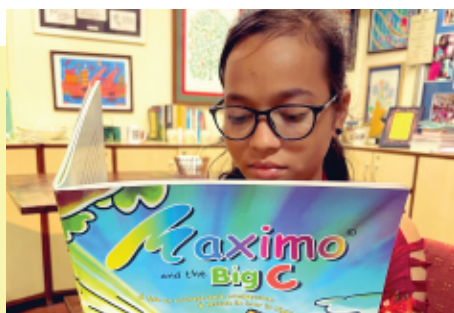
A part of the funds raised through Chai for Cancer go toward supporting Yamuna's education. By contributing to our cause, you help make many a father's dreams come true - like Yamuna's father's dream.

Impact Story

"Papa aapko kabhi mujhpar gussa nahi aaya ke aisa baar baar mujhe Bombay leke aana padta hai?"

Yamuna was four years old when she was diagnosed with Chronic Myeloid Leukemia (CML). Today, she is a ninth grader and an avid reader. She carries her sparkling energy with her every time she visits The Max Foundation's Mumbai office after following up with her treating physician at Tata Memorial Hospital.

Says Viji Venkatesh, "Her father has been so diligent, never missing an appointment no matter what it took - leave of absence from his job included. After all these years, he says

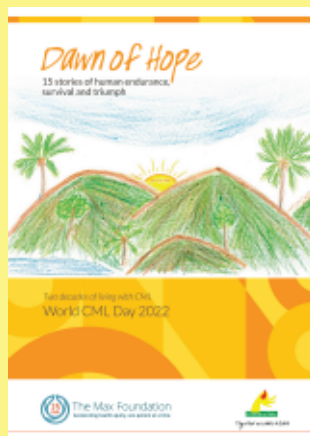


she posed this question to him - perhaps understanding only now completely what it means to manage her treatment & keep her healthy. Papa, don't you ever get upset because you have to bring me to Bombay again and again like this? Never ever have I been angry or upset with her and I never will be. I will do everything to make sure she studies hard and makes a life for herself."

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The Max Foundation and Friends of Max are also proud to announce the book release of "Dawn of Hope – 15 stories of human endurance, survival and triumph". Written and edited by Viji Venkatesh, and with a warm and heartfelt foreword by Pat Garcia-Gonzalez, the book celebrates the lives of CML patients in South Asia who are on lifelong treatment and serve as a beacon of hope for the entire community.

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



Know the Max Team



Meet Santosh Kadam who has been an indispensable part of The Max Foundation and Friends of Max for over 18 years.

Superman Santosh wears two capes – he is the Accounts, Office and HR Manager for The Max Foundation; he also provides his services as Consultant – Accounts and Audit for Friends of Max. He works out of the Max South Asia office in Mumbai and looks after accounts, filing statutory returns, government compliance and takes care of all banking and audit preparations amongst other things.

Santosh has been an inspiration for everyone at the office because of his incredible work ethics. He is always available for any issues that may arise and he makes it a point to resolve these matters keeping the organization and the team's best interests in mind. He takes pride in the work he does.

Santosh has been instrumental in the unparalleled 18 years' journey of Friends of Max. We thank him for his dedication towards the organization and his unwavering support and positive attitude. When asked recently by a team member at Max's South Asia Rising Conference about the challenges in his work, he said, "This is something that I have chosen. How can I have any challenge?"



34 Total
Participants

GIST Awareness Day



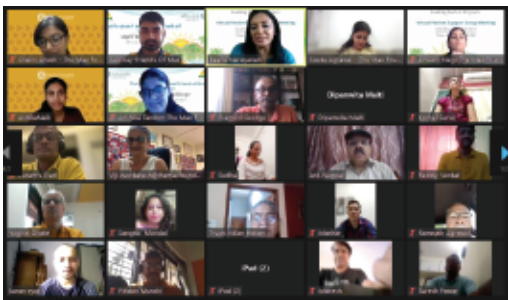
As part of our GIST Awareness Day Celebrations, a hybrid support group meeting was organized with patient leaders in Mumbai attending at the Max office and others joining us virtually from the rest of the country and Nepal. A unique feature of this meeting was a "quilt-making" workshop organized by Tapan Mittal Deshpande of Thotpot.

<https://friendsofmax.info/gist-awareness-day-2022/>



75 Total
Participants

Dawn of Hope



The Max Foundation and Friends of Max hosted a Virtual Support Group Meeting to commemorate 20 years of the launch of Max's Access Program in South Asia. Patient leaders from all over the subcontinent joined us at this celebration where they shared their journey of living with CML.

<https://friendsofmax.info/dawn-of-hope-meeting-report/>

From the Physician's Desk

We have come a long way with the help of The Max Foundation and Friends of Max over the past two decades.

We have learnt to reconcile the side effects of treatment, get over them and regain confidence to lead normal lives.

Most importantly perhaps, with love, affection and gentle goading from our dearest Amma and her compassionate elves, we have learnt to bond together



and manage every aspect of the impact of CML on our lives.

Let us pledge to continue to be torch bearers and beacons of hope, extending succour to the needy and helping each other.

- Dr D. Raghunadharao
Professor of Medical Oncology,
GSL Medical College, Rajahmundry

CHAI FOR CANCER SEASON 9 continues...

With the lockdown restrictions now completely lifted, CFC is marking its presence in cities across India.



The awareness-cum-fundraising tool of Friends of Max has so far raised ₹14 Lakhs to support the unmet needs of cancer patients on life-long treatment.

JUL 13 VENUE : The Eryr Café, Indore
HOST : Manoj Dhanotiya

Hosted by the magnanimous FOM Indore City Chapter Leader Manoj Dhanotiya and IMRT297, this Adda was organized at The Eryr Café in Indore. It was a gathering of likeminded people and supporters of our cause. Also present were FOM CCLs from Indore and Bhopal as well as The Max Foundation's Viji Venkatesh and Anshika Tandon, along with Red FM's RJ Tathagat.



JUL 15 VENUE : Tata Medical Centre, Kolkata
HOST : Dr Reena Nair

JUL 16 VENUE : Victoria Memorial Gardens, Kolkata
HOST : FOM Kolkata City Chapter Leaders

As is tradition for CFC, Kolkata saw two Addas happening in July – the first hosted by Dr Reena Nair and team at Tata Medical Centre, the second by FOM Kolkata City Chapter Leaders at the Victoria Memorial Gardens. Red FM Kolkata's RJs Nilam, Praveen and Neil lent their full support covering the Addas on ground and making sure the voices of our supporters were amplified throughout the city.



About our Collaborators

Meet Deepa Vishwanathan, a creative consultant who has been associated with Friends of Max for over 18 years.

In her own words-

"I was brought into the fold by Amma (Viji Venkatesh) in the initial days to create the first Friends of Max website. My time with FOM has proven to be an enriching and learning experience every year."



I have met and been inspired by all the patients and volunteers at many events - from the First All India Annual Meet in Mumbai to the support group meetings at Bengaluru and Kolkata."

Deepa's work can be seen on the FOM website, newsletters, reports, information booklets and other FOM publications. She says, "I try to bring across the warmth and joy that I feel for every person's story in all the communications I design for FOM."

How well do you know your GIST?

Here are some Frequently Asked Questions by GIST patients.

These FAQ are a part of FOM's disease awareness booklet specially put together for our GIST patients and first published in 2013.

Q. 1 What is Gastrointestinal Stromal Tumor (GIST)?

A gastrointestinal stromal tumor (GIST) is a rare type of cancer that grows in the supporting (connective) tissue between muscle layers in the digestive (gastrointestinal or GI) tract or close to it. It belongs to the general class of cancers called sarcomas. Most GISTs occur in people over the age of 50. GIST in children and young adults is quite rare.

Q 2. What is sarcoma?

The name comes from the Greek word "sarkoma" (fleshy growth). These cancers develop from connective tissues that act as supportive frameworks for the organs and structures of the body, such as muscles, tendons, cartilage, fibrous tissue, fat, blood

vessels, nerves, and others.

The vast majority of cancers are not sarcomas but carcinomas, which develop from skin-like tissues called epithelial tissues. This includes not only the skin covering the outside of our bodies, but also the skin-like linings of our body cavities and our digestive tracts. Ordinary "stomach cancer" and "colorectal cancer" are carcinomas.

Gastrointestinal stromal tumors (GISTs) should not be confused with these common cancers of the GI tract. Both may occur in the same parts of the body. Distinguishing GISTs from these diseases is important because GISTs behave differently and require particular drugs for treatment.

Q 3. Why have I developed GIST?

There are no known environmental, behavioural or lifestyle risk factors that are known to cause GIST and hence there are no preventive strategies. The only exception is for GIST that runs in families (familial GIST), but this is extremely rare, with only about a dozen families reported in the medical literature.

A protein called "KIT", also called CD-117 is thought to be one of the major causes of GIST. Normal cells have a limited life span. The KIT protein is located on the surface of normal cells. It sends a signal inside the cells that tells them to grow only as needed. When KIT becomes abnormal, its signal stays on all the time, causing cells to multiply out of control forming a tumor. The longer the cancerous cells live, the more potential they have to become dangerous, and the more likely they are to spread to other parts of the body.

Q 4. What is KIT?

KIT is the name of both the gene on chromosome and the protein it produces that is thought to be a major cause of GIST.

Q 5. What are the symptoms of GIST?

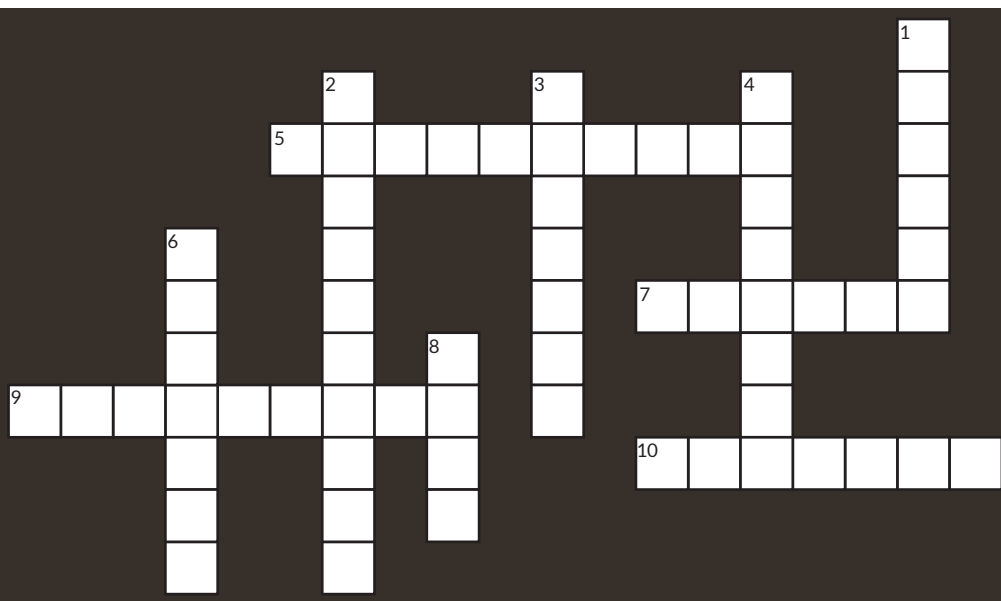
When GIST tumors are first discovered, the most common symptoms are:

- Vague abdominal discomfort or pain
- Presence of a palpable abdominal mass
- Feeling of abdominal fullness
- Secondary symptoms resulting from tumor bleeding and associated anemia

Test Your Knowledge

ACROSS

- 5 An approach in cancer care that improves the quality of life of patients faced with a life-threatening illness (10 letters)
- 7 A condition caused by less than normal RBC (6 letters)
- 9 Body structures that contain immune cells and help fight infection (5, 4 letters)
- 10 A process that makes pictures of areas inside the body using methods such as x-rays, ultrasound, and radio waves. (7 letters)



DOWN

- 1 A yellowish liquid that carries nutrients, hormones, and proteins throughout the body (6 letters)
- 2 Agents that can cause cancer are known as _____ (10 letters)
- 3 A type of cancer that forms in the bone and soft tissues (7 letters)
- 4 Cancer that occurs in the bone marrow and creates blood cells (8 letters)
- 6 Shortness of breath is medically known as _____ (7 letters)
- 8 The basic structural and functional unit of any living thing (4 letters)

ANSWERS : 1. Plasma 2. Carcinogen 3. Sarcoma 4. Leukemia 5. Palliative 6. Dyspnea 7. Anemia 8. Cell 9. Lymph Node 10. Imaging

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@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