

“We are the World”

We have often come across phrases like “The world is one”, or “Every drop fills the ocean”. It is true what they say – there is power in Unity. Every time mankind has faced an unfathomable challenge, it has been our ability to come together as one formidable force that enabled us to overcome it. Because, in the end, we cannot be human alone.

We wish to serve our CML and GIST brethren in the same spirit that the great poet Rabindranath Tagore envisioned our country – “Where the world has not been broken into fragments by narrow domestic walls”. It is ironic that in a time where globalisation, the internet, advances in

travel have made the world a smaller place, Tagore's utopian vision remains just that – a utopia. We as a being are still divided, whether by borders, race, religion, or otherwise.

But if there ever was a cause noble enough to overcome these challenges, it is to save and serve humanity. And if there ever was a right time, it is right now. At Friends of Max, we seek to break these narrow domestic walls and reach out to the most prominent physicians and advocates – across this country, and the world, so that we may empower ourselves and our City Chapter Leaders to implement the best practices for

the benefit of our patients, our community and humanity.

After all, We are the World.

The 5th FOM Leadership Summit 2021 is a testimony to our efforts. In a time where it is no longer safe to shake hands, we brought together 13 of the top physicians in the country and 5 of the most prominent cancer advocates worldwide on one glorious platform for a weekend of sharing and learning together and empower our City Chapter Leaders to serve our patients to their best potential.

- Aashray Paul,
Communications Manager, Friends of Max

5th FOM Leadership Summit 2021



Amma Speaks

Today we have in Friends of Max, CMLers and GISTers who have been on medication for close to from anywhere between 10 to 15 to 20 years. In this incredible journey of theirs with cancer by their side, they have found amidst themselves great strength to keep moving ahead.

Technology and Social Media have enabled them to be in touch with their peers across the world. Many are a part of several email/Facebook groups and of course our own groups. Our patient support group meetings held periodically in many cities and towns brought everyone together in what can almost be described as celebrations of life, not to mention our Leadership Summits. The energies and positive vibes these gatherings produced can be likened to those at one of our Great Indian Weddings.

Now, I have for ever wanted to have some of our champions in the international arena of

CML & GIST to be part of our meetings. During meetings like CML Horizons and Rising Sun when a few of us have met with them I have so fiercely wanted only one thing. To bring them to India so all of my dear FOM City Chapter Leaders can meet them, listen to them and talk to them.

But somehow many things came in the way of that dream coming true. Then the Pandemic happened.

I quote below what I read in The Economist recently: “*The pandemic has been an exercise in subtraction. There are the voids left by loved ones who have succumbed to COVID-19, the gaps where jobs and school used to be, and the absence of friends and family. And then there are the smaller things that are missing. To stop the spread of COVID-19, people have forsaken the handshakes, pats, squeezes, hugs and strokes that warm daily interactions.*”

And we know how much we have missed seeing each other, hugging each other and

breaking bread together!

But then it is an ill wind that blows no good as they say, and the pandemic too taught us a few things. The most important being how to harness technology and continue to be in touch even when we were locked in.

We continued with our patient meetings, our physicians worked with us online and made sure no patient went without a prescription or their meds and yes, this last Leadership Summit just concluded made my dream come true.

Though we could not shake them by the hand and hug them close, we could see our international brethren and listen to them. And what an amazing experience it was to listen to Giora, Jan, Sohag, Rod and Razzak – each a champion bringing to us their experiences from all corners of the world.

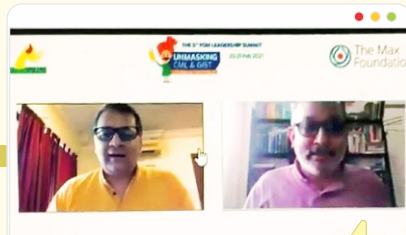
Indeed, We are the World. ”

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

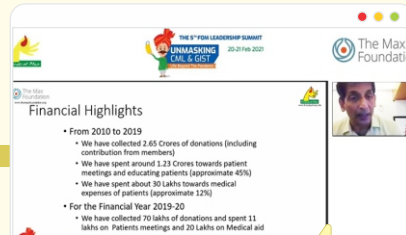
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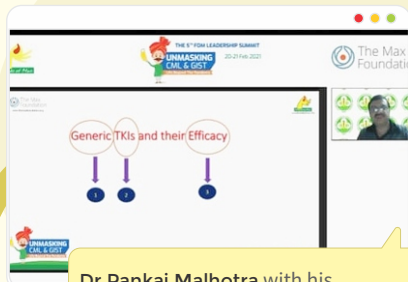
No FOM event is complete without The Bhai & Bhidu Show. In their inimitable style **Trustees Pramod and Nirmesh** kicked off the FOM Leadership Summit explaining the purpose behind it and the need to follow protocol to stay safe from COVID-19.



Our **Treasurer Sunder Krishnan** presented the Trustees' Address and made sure the FOM Annual Report was made available to all.



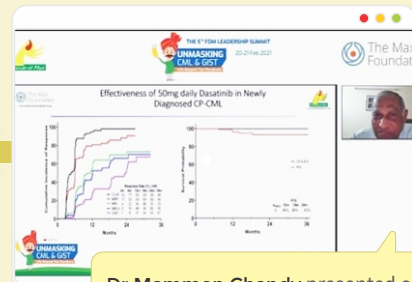
Dr Jude Vaz and Dr Raghu Krishnaswamy, our City Chapter Leaders from Mumbai and Hyderabad led the Medical Session moderating it with their customary ease and panache.



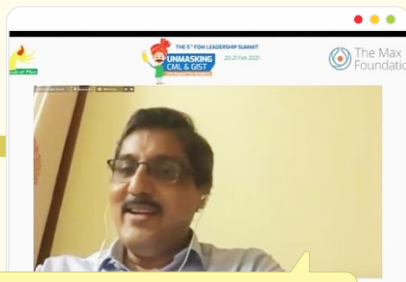
Dr Pankaj Malhotra with his presentation on "Generic TKIs and their efficacy" laid to rest many doubts in the minds of patients and caregivers alike.



Dr Hari Menon made his presentation on "Side-effects of 2nd Gen TKI" which at this point in the management of CML is vital knowledge.



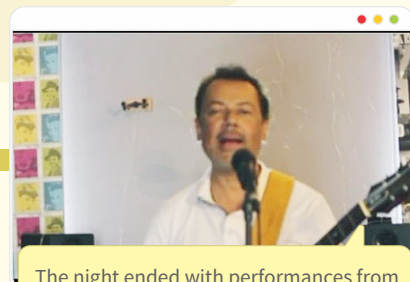
Dr Mammen Chandy presented on "2nd Gen TKI as First Line Therapy" bringing this all important milestone in CML therapy to us in his simple yet emphatic style.



Dr Ganapathy Ramanan's talk on "New Drugs on the Horizon for CML & GIST" filled our minds with so much optimism.



The Panel Discussion on "Living with CML /GIST during the times of COVID and after" was moderated by **Dr Shyam Aggarwal**, and the panel comprised of **Dr Hari Menon, Dr Hemant Malhotra, Dr Raghunadha Rao and Amma**.



The night ended with performances from our **Core Group Leader Pranay Ranjan**, **Trustee Sunder Krishnan**, patients & very talented artists like **Venky, Tanvi, Tusharkanti, Avinash** and of course our own **Amma** who all sang their hearts out.



From the Physician's Desk

It was a pleasure and privilege to moderate a session on the "Role of non-profits in managing patients with CML and GIST as seen by the treating physician".

My panelists were Dr. Bhawna Sirohi from Chennai, Dr. Pankaj Malhotra from Chandigarh and Dr. Dinesh Bhurani from Delhi. After an evening of science and evidence sharing it was time for a reality check on how FOM had made an impact on the lives of patients, care givers and physicians.

My first question was how life would have been without The Max Foundation and FOM – and pat came the reply – can't imagine a life without them. The panelists were unanimous in their opinion that FOM had added great value to the lives of patients, extending help at all levels – emotional, social, medical and so on.

FOM was able to address concerns about many issues which mattered in daily life which were of priority to patients but generally not addressed by physicians. Special mentions were made on the skits that were enacted in the FOM meetings emphasizing the importance of compliance and monitoring. We did spend some time discussing patient advocacy and how all

of us could make an impact.

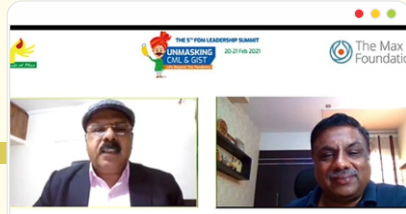
Patients and support groups can become more impactful when they become strong advocates for patients' rights. Physicians were ready to extend all support to make this a reality. The ultimate icing on the cake were remarks by Viji Amma and Pat on what they thought could be done to improve the lives of patients including problems that ail the system and how these can be surmounted with everyone's support, especially the physician's. The panel ended on a positive note with all stakeholders pledging to work together and help each other.

- Dr Senthil Rajappa

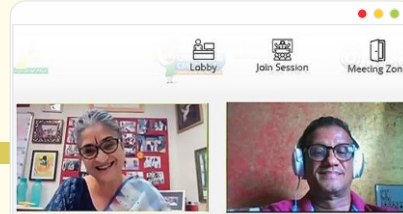
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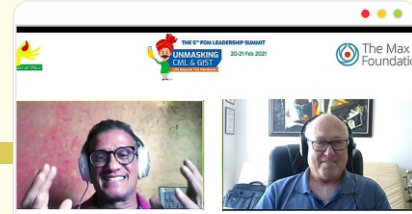
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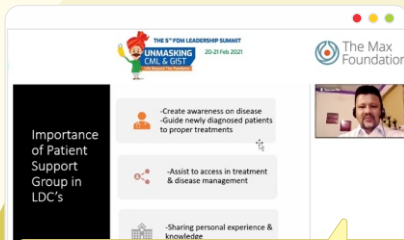
The FOM Trustee Duo from Delhi Shyam Kankani and Anil Nagpal took us through Day One's highlights and set the tone for Day Two.



FOM Trustees Viji Venkatesh and S. Parameswaran moderating our International Segment – “Beyond Borders: Sharing and Learning from our International Brethren”.



Delighted to have our dear friend from Israel Giora Sharf in conversation with Param on “Bringing MPN into the Fold”.



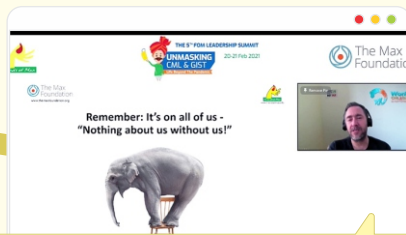
Shofiur Rahaman better known as Sohag inspired all with his courageous crusade in Bangladesh as she spoke on the challenges and Issues faced by fledgling support groups in the region.



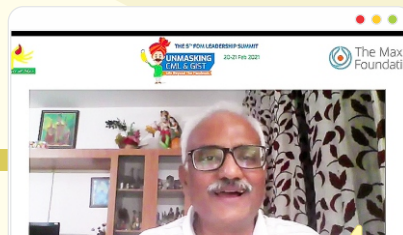
Everyone's favourite Dr Abd Razak shared the Max Family story from Malaysia and won our hearts all over again.



The world's best caregiver Rod Padua shared the best practices he and his friends in Touched by Max (Philippines) put to work in establishing and sustaining the success of their Patient Support Groups.



Jan Geissler literally brought everyone to their feet when he spoke of CML as the Tiger in the Cage. Presenting on “Latest updates in Disease Management from the Global CML Community”, his words resonated loud and clear with all of us.



Dr Digumarti Raghunadharao presented the all-important session on the other rare cancer in our midst - “Latest updates on Management of GIST”.



Dr Manju Sengar's clear and precise slides on “Monitoring Guidelines” to be adhered to brought into focus the importance of Compliance in our lives.



Beyond Borders

COVID-19 has had a serious effect on the CML community in Bangladesh. Due to travel restriction during March to July 2020, patients could not travel to visit their physicians or hospitals.

At the beginning of the pandemic, physicians and hospitals did not want to treat any patients due to the paranoia of COVID-19 spreading, and a lot of private hospitals stopped their services.

All the CML patients were disappointed by the health services. There is no right or wrong way to feel during that time.

Medicine supply was restricted; for those who were taking Indian TKI's, medicine supply was completely disrupted. Patients were overcome with anxiety.

I had conversations with some the CML patients, I suggested them to buy Bangladeshi TKI, rather than to stop taking medicines altogether, though the price of our local TKI's is double than Indian TKI's. They faced severe financial problems, their income went down, there was no scope to earn money, some of patients lost their jobs, medical cost increased, uncertainty of medicine supply impacted daily life of CML patients in Bangladesh.

Most of the CML patients lost sleep thinking of all the uncertainty in the

coming days. Patients could not visit their physicians or hospitals due to fare or travel restriction. Some of the patients could not even do a routine check-up.

In most of the cases PCR test was stopped for over 5-6 months. As a patient advocate and survivor, I advised most of the CML patients during the pandemic situation, to try and focus on the three aspects of their health as suggested by Cancer Research UK-

- eat a balanced diet
- stay physically active
- look after your mental wellbeing

- EHM Shofiur Rahaman Sohag,
Bangladesh CML Support Group

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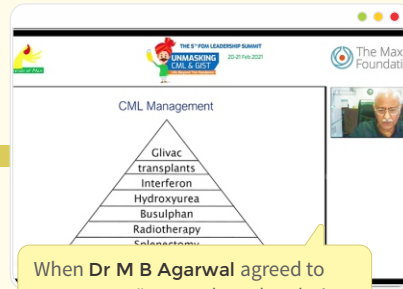
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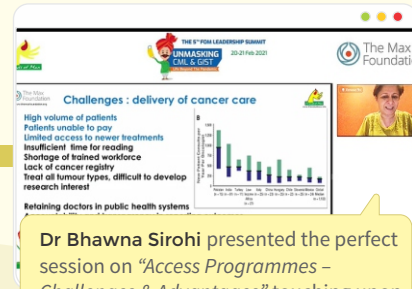
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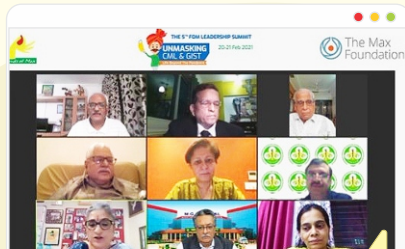
Dr Hemant Malhotra as always brought the house down with his emphatic presentation on one burning topic- "TFR and its feasibility in the region".



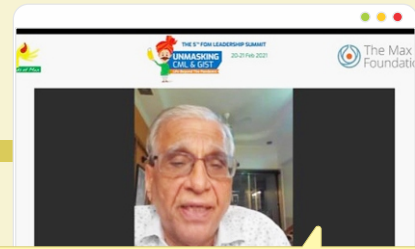
When Dr M B Agarwal agreed to present on "Is BMT the only solution when all else fails" we knew the audience would be spell bound.



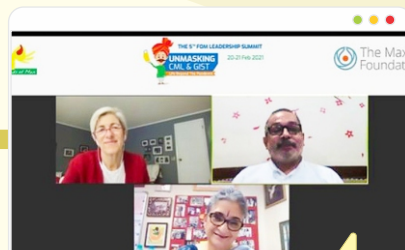
Dr Bhawna Sirohi presented the perfect session on "Access Programmes – Challenges & Advantages" touching upon every possible angle of what today is undeniably a right to all patients.



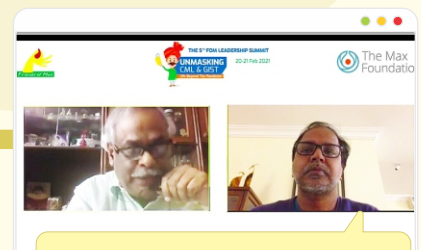
The Panel Discussion on "Role of Non-Profits & Support Groups in CML & GIST as seen by a treating physician" was moderated with so much love and admiration by Dr Senthil Rajappa, and the panel comprised of Dr Pankaj Malhotra, Dr Dinesh Bhurani and Dr Bhawna Sirohi.



Dr Suresh Advani joined us to make up for not being able to attend on Day One and as is his wont, infused so much confidence in so many of our long time CMLers with his crisp talk on "Management of long-term side-effects of Imatinib".



FOM Trustee Pramod George invited the CEO of The Max Foundation, Pat Garcia-Gonzalez, who gave us a detailed presentation on the functioning of The Max Foundation, its goals, challenges and plans to overcome them. As always, our dear friend Pat did not disappoint with her powerful talk.



The 5th Leadership Summit was brought to a close with dignified words of gratitude and appreciation from FOM Trustees Prof. Subratanath Koner and Sujeesh Sukumaran.



From our Trustees

2020 was the year of the pandemic which brought new norms of "SMS" - Social Distancing, Mask Adherence and Sanitization.

The Max Foundation team under the leadership of Amma, along with Friends of Max continued the SMS campaign to secure the distribution of medicines thereby ensuring all patients live with

Dignity and Hope.

During the year, Friends of Max in collaboration with City Chapter Leaders relentlessly worked engaging doctors, patients and caregivers through remote working and ensured that the patients were able to focus on adherence by taking medicines on time. A BIG THANK YOU

The year also saw online City Chapter Meetings held flawlessly with excellent participation from all, thereby the engagement experience of Sharing and

Learning was not deterred during the pandemic period.

It concluded with a very inspirational and motivating Leadership Summit of unmasking and opening up the boundaries with speakers from around the world allowing them to join in with our CML warriors and sharing the best practices and equipping them with the right tools to help serve our fellow CMLers to the best of their abilities.

- S. Parameswaran,
FOM Trustee

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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/
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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 issued.

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