

Dedicated to Nikhil Guhagharkar who passed away on 26th June, 2020

Along with The Max Foundation team in India Nikhil worked hard to bring our GISTers and their caregivers together and find a platform to share and learn from each other. Nikhil was the voice of our GIST community taking our work across borders and collaborating with groups such as Sarcoma Patients EuroNet (SPAEN) and The Life Raft Group. Nikhil served twice on the Board of SPAEN bringing to the International Community his vast experience and sensitive knowledge of coping with GIST in this part of the world. He made us so proud!!! Nikhil was also awarded the special Victor Award by The V Care Foundation on their 25th Anniversary in recognition of his exemplary services as a patient advocate par excellence ...

Says Viji Venkatesh who mentored him in his exceptional journey as an advocate and patient leader, "We are heartbroken and devastated by Nikhil's untimely death. But we also know he would want us to take this blow on the chin and continue to take his work for GIST Awareness to greater heights. We cannot let his hard work be in vain."

Dear SPAEN members and friends!



July is Sarcoma Awareness Month in the USA and other countries. But for patients, every month is Sarcoma Awareness Month! We lost our dedicated board member Dr. Nikhil Guhagharkar to GIST in late May. Nikhil was a role model in advocacy and a shining example of what we can achieve through patient advocacy.

We at SPAEN will continue to work for a better situation for sarcoma GIST, bone cancer and desmold patients in memory of Nikhil and all those who have lost their lives to these diseases. Together with our member groups, patients and advocates, experts and healthcare professionals - during Sarcoma Awareness Month and every other month! Please stay active for all patients around the globe!

The SPAEN Board of Directors & Team



Amma Speaks

Patient Support Group Meetings play a very important role in creating awareness, promoting compliance and good adherence behaviours as well as promote feelings of wellbeing and a sense of belonging in our patients who are on lifelong therapy for a potentially fatal treatment. These meetings bring together hundreds of patients from different parts of India and the sub-continent on one common platform. For over 18 years The Max Foundation team in India has organized such meetings in different cities on a regular basis. After we formed our Patient Support Group Arm in India Friends of Max in 2003, we have groomed and trained many City Chapter

Leaders who now are our active partners in making these meetings a success. These meetings have also been replicated in other countries in the region. Over the last few months, the COVID- 19 pandemic has made it impossible for us to conduct these meetings as they were done all these years and it has been of great concern to us that we may not be able to use this effective tool in patient engagement during these times.

It goes without saying that during these hard times it is even more important for us to continue these interactions to ensure that our patients are compliant and aware of the precautions needed to be taken by them. It also at the same time

our responsibility to keep them connected with their physicians through this platform and keep them in the know of the new procedures around visiting the hospitals for consultation and supply collection.

With this in mind, we planned very early during the lockdown period to organize virtual meetings for different FOM City Chapters and our patients in other countries in the region. We have been successful in holding such virtual meetings once a month as usual and reached out already to almost 1500 patients from over seven states.

- Viji Venkatesh

GIST Awareness Day HOPE 2020 Virtual Meeting



Our first Virtual Support Group Meeting was held on Sunday, July 12th, 2020 to observe GIST Awareness Day and to honour the memory of our beloved patient leader & GIST advocate Nikhil Guhagarkar.

GIST Awareness Day is observed on July 13th every year. Ever since it was set up by The Life Raft Group in 2014, we have joined them in making it a day devoted to the cause of GIST awareness.

"The ultimate goal of GIST Awareness Day is to bring so much attention to GIST that knowing what it is will no longer be so "rare". GIST Awareness Day serves as the yearly pinnacle of our education, awareness and advocacy efforts and provides those outside the GIST

community a chance to learn about and lend their support to this important cause." - *The Life Raft Group*

GIST Awareness Day (GAD) Events are held across the world every year and this year, **The Max Foundation team in India and Friends of Max hosted a Virtual GIST Awareness Meeting via Zoom on July 12th, 2020.**



THE FACE OF HOPE

Remembering Nikhil Guhagarkar
*Friends of Max Patient Leader and
passionate GIST Advocate*

"We had patients, caregivers, physicians & advocates waiting to join the Zoom call and every single one on the call

stayed on till the very end. Every single patient we invited attended the meeting. Those who had never attended a Zoom Call before were sent tutorials on how to do so and everyone's excitement and eagerness was palpable! Both, the physicians and Nikhil's friends and peers found themselves sharing their memories of their loved friend and some of our GIST stalwarts shared their stories of HOPE!" says Viji Venkatesh, Region Head at The Max Foundation & Friends of Max Managing Trustee.

The Question Hour with the physicians was the height of the session with questions flowing fast and free and the physicians fielding them with care, compassion and gentle humour. COVID-19 and related precautionary measures were discussed along with many issues related to the treatment and management of GIST, during these times. We are thankful to our physicians Dr. Jagannath, Dr. Shrikhande, Dr. Sirohi, Vandana Gupta of V Care Foundation, Rashi Kapoor and all the Friends of Max for joining us and for making this session what it was!



Virtual CML & GIST Patient Support Group Meeting - Kolkata:



Friends of Max and The Max Foundation hosted their first virtual CML & GIST Patient Support Group Meeting, on July 26, 2020, specially designed for Friends of Max in and around Kolkata. Within the first five minutes of the meeting, the participant count on Zoom shot up to 100, with more requests coming to join the meeting. Dr Jeevan Kumar from Tata Medical Centre was the moderator of the meeting. After a warm welcome by Dr Reena Nair, Senior Consultant, Department of Clinical Hematology, Tata Medical Centre, a Q & A session was

conducted with Dr Jeevan Kumar taking patient queries that were addressed by the panel of Medical Experts including Dr. Reena Nair, Dr. Mohandas, Dr. Saurabh Bhawe, Dr. Mayur Parihar, Dr. Soumya Bhattacharya and Dr. Vivek Radhakrishnan. Their responses were extremely impactful and a great resource for our patients. Priyanka Kandalgaonkar of the Max Foundation India team gave a short presentation regarding program guidelines during the pandemic after which our City Chapter leaders shared their feedback. All the

attendees raised their cups to Chai for Cancer and were extremely positive about how useful they found the virtual meet despite the challenges we've faced over the last few months. We are so grateful for the support we have received from our physicians and patients! We also want to thank the Tata Medical Center, The Max Foundation India team and our Friends of Max City Chapter leaders for their efforts in making this meeting a success.

Virtual CML & GIST Patient Support Group Meeting - Bengaluru:



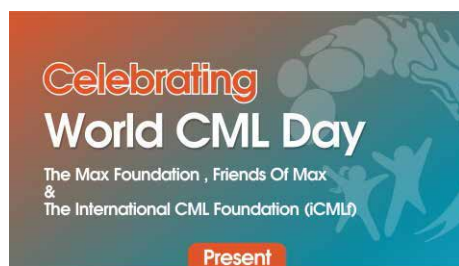
Friends of Max and The Max Foundation hosted their second virtual CML & GIST Patient Support Group Meeting on August 29, 2020 specially designed for Friends of Max in and around Bengaluru. Once again, we had more than 100 participants present at this virtual meeting. Viji Venkatesh was the moderator of this session. After a warm welcome by Beena Narayanan of The

Max Foundation India team, Ashika Naik of the Max team gave a short presentation regarding program guidelines during the pandemic after which a Q&A session was conducted with a panel of medical experts including Dr. Hari Menon, Dr. Shekhar Patil, Dr. Krishna Prasad, Dr. Sachin Jadhav and Dr. Avinash C.B. Their responses were extremely impactful and a great resource

for our patients. After the Q&A session, our City Chapter leaders shared their feedback with everyone. We are so grateful for the support we have received from our physicians and patients! We also want to thank the Max India Team and our FOM City Chapter leaders for their efforts in making this meeting a success.

World CML Day 2020:

Today Together, More Than Ever - For A Life Without CML



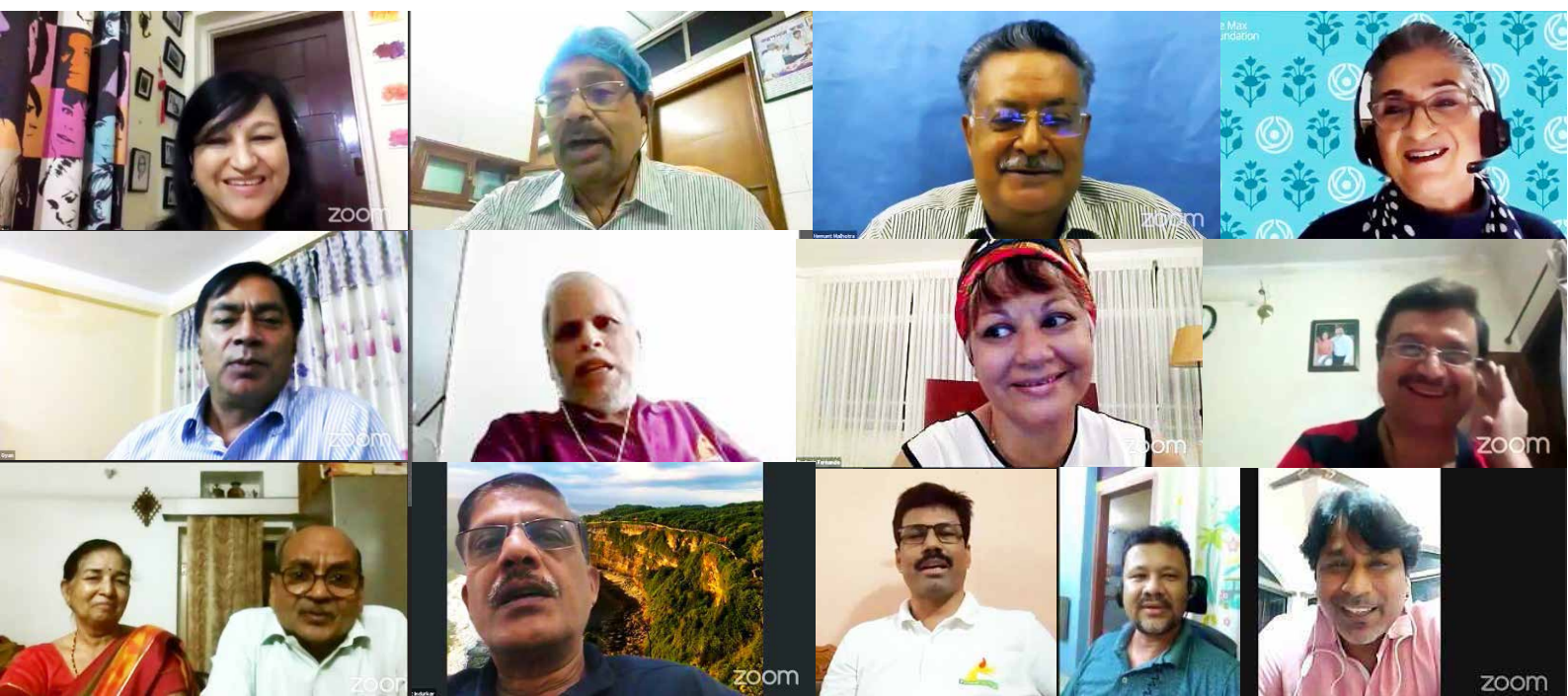
Every 22nd September, the CML Advocates Network leads the World CML Day global awareness campaign. On this day, chronic myeloid leukemia (CML) patients across the globe come together to raise awareness about our needs to the general public, policymakers, and medical professionals across the world. Today, together, more than ever due to the COVID-19 pandemic, the CML patient advocates need to connect as a worldwide community through digital tools by developing online activities.

The Max Foundation and Friends of Max are committed to observing World CML Day and are proud to be the voice of thousands of CML patients from the Indian Subcontinent. This World CML Day, we stood united with CML Advocates and all the other patient organizations, healthcare providers and our CML friends across the world as we join the global movement under a powerful motto, "Today together more than ever. For a life

without CML."

This year, we conducted a simple activity asking our patients to send us their message on World CML Day along with an image or video, which we framed and shared on our social media platforms.

Our virtual meeting saw close to 300 CML patients come together on a virtual platform and went on for over three hours. A big shout out of thanks and appreciation to Viji Venkatesh and The Max Foundation team in the region as well as the wonderful doctors - Dr. Hemant Malhotra, Dr. Pankaj Malhotra, Dr. Gyan Kayastha, Dr. Md Yunus, Dr. Jayant Indurkar, Dr. Jina Bhattacharya who stayed with us sharing their expertise and comforting patients and their families. We are also grateful for our patient leaders not just from India but Nepal, Sri Lanka & Bangladesh who inspired everyone with their stories of courage and hope.



"When The Max Foundation decided to do its first Virtual Patients Support Group meeting with us, I had no doubt that it would be well received by the CML survivors, but that we would cross all limits of registrations even before the meeting started was not what I had anticipated.

It is the dedication of the organization in making and maintaining a personal connect with the CML community that is instrumental in the success that these meetings have received across the country.

I commend The Max Foundation in keeping the information channels open to the CML groups when all else in the country was under lockdown and wish them greater success in all their future endeavours."

- Dr Reena Nair

Senior Consultant, Department of Clinical Hematology at the Tata Medical Centre, Kolkata

Chai for Cancer Season 7

An Online Event (Rohini & Chirodeep)



Chai for Cancer hosts Rohini Bhowmick and Chirodeep Chaudhuri hosted an online Chai for Cancer campaign on Facebook for 10 days. They invited their family and friends to raise their cups and drink to the cause. Here's their message on their virtual campaign:

"Last year, Chirodeep and I, along with Spices and Friends hosted our first Chai for Cancer Adda at our home. This year, the global pandemic forced us to stay indoors and we were unable to host our Chai Adda at home, therefore decided to hold an online adda from 8th-18th May 2020.

The beauty of a Chai Adda really lies in its simplicity. Anyone, anywhere can host an adda session, be it in the comfort of your own home or an office space... more importantly at your own convenience. There are no limits except for the one you've set for yourself. Call as many as 5 or more friends over... and DRINK TO A CAUSE. The collection generated supports to raise funds for cancer patients living with CML and GIST and act as a patient support/advocacy group to create awareness and improve the quality of life of those living with these two cancers.

To know more:

<http://chaiforcancer.org/about-chai-for-cancer/>

Chirodeep and I, are most thankful to every one of you for your generosity and support through donations, for sharing the details within your circle of family and friends and for making Chai for Cancer Season 7 - An Online Event a success.

So, next year, would you like to host your own Chai Adda and raise a cup of chai? I know, we will."

- Rohini Bhowmick

04

daily dossier

When the chai adda moves online

Ever since writer Viji Venkatesh started the Chai for Cancer adda on the second Sunday of May seven years ago, the warm evenings have become a part of the city's social calendar. However, with the lockdown underway, it was not possible to host the gathering this time. And that is why the Thane-based Venkatesh and her friends have taken the fundraiser online with #Chailies, Zoom gatherings and a donation link. "Yesterday was the Chai for Cancer day. I started this to help people get comfortable with the topic of cancer over chai, because it's so relatable. At the same time, we were able to raise funds for

cancer patients. Since we couldn't gather physically, we decided to shift the adda online. My friend, Rohini Bhowmick who hosts some of the gatherings every year, created a Facebook event, with a link where people can donate. This time, the need for the funds is even more as we help patients with a rare type of leukaemia that requires long-term treatment," said Venkatesh. Bhowmick, meanwhile, added that she was initially apprehensive about setting up the Facebook event, but it has worked. "The aim was to raise awareness and funds for a cause that I know is actually helping people," she said.



Chai for Cancer 2020 Launch - Viji Venkatesh and RJ Rishi Kapoor

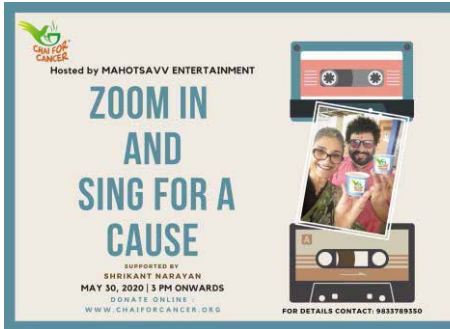
Our first Virtual Chai for Cancer Adda was hosted by Chai for Cancer Founder Viji Venkatesh and RJ Rishi Kapoor of Red FM India - our radio partners.

The Adda was hosted via Zoom on May 17th, 2020, which was a great start to the Chai for Cancer 2020 season. It was filled with laughter, conversations, sing-alongs, a few technical glitches and lots of love, cheer and hope.

A big shoutout to our hosts Viji Venkatesh and RJ Rishi Kapoor for putting this together and for all you lovely folks who joined in to support our cause. It was indeed a bliss to be able to gather together virtually, raise our cups and drink to Chai for Cancer 2020! We also want to thank Red FM India our Radio Partners, for being the voice of Chai for Cancer and spreading awareness about our cause to thousands of listeners through their channel. We are so grateful for their dynamic team who raised their cups in support of our cause!



Zoom In and Sing for a Cause - Mahotsav Entertainment



Mahotsav Entertainment and Friends of Max go a long way back together. We have been a beneficiary of their generosity and it has always been an honour to have been recognized as worthy partners in the events organised by Hinal Jayawant under the aegis of this group.

Shrikant Narayan has sung for us first in 2005 and continues to raise his voice for us and our cause. Every year through Mahotsav, Hinal and Shrikant have hosted Chai for Cancer Addas bringing like-minded people together to support our cause. This year again they decided to continue with their plans without

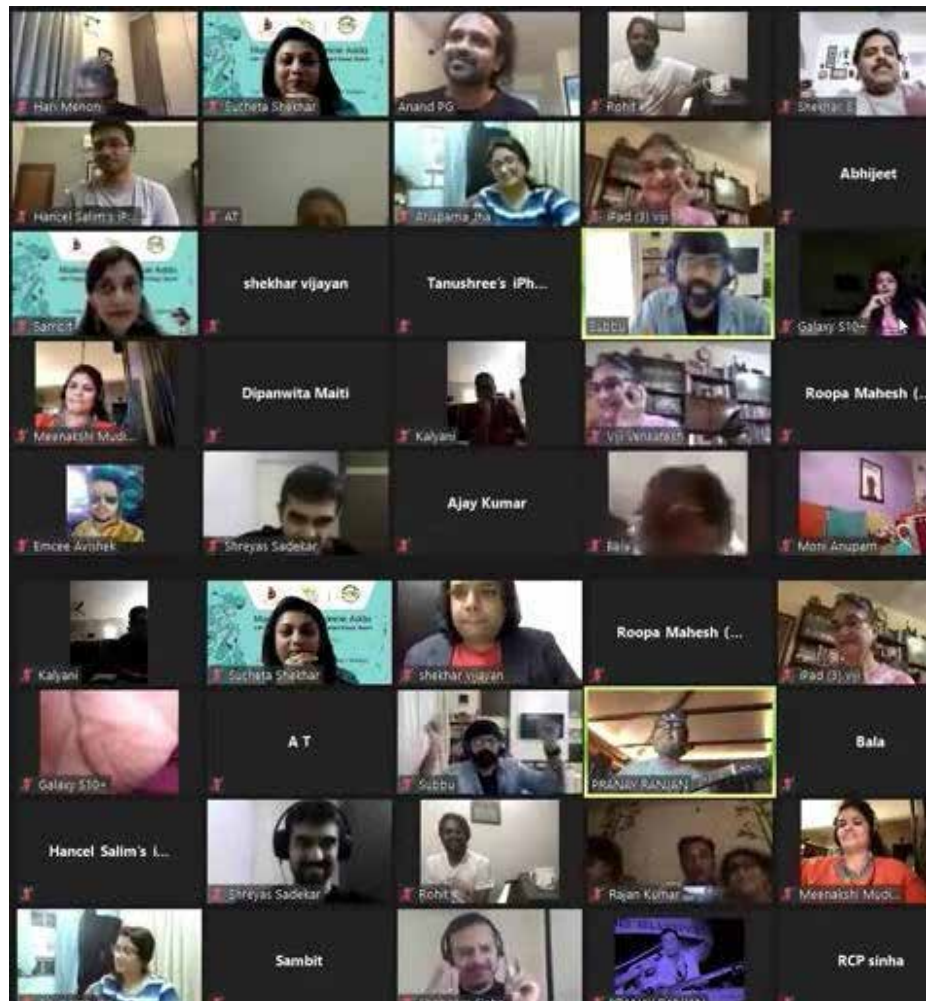
letting the pandemic and the lockdown come in the way of their determination to raise a cup - in song. They hosted their virtual Chai for Cancer Adda, inviting their friends to Zoom In and Sing for A Cause on May 30th, 2020.

Musical Chai for Cancer Adda with Pranay Ranjan and B Reloaded Music Band



Pranay Ranjan, FOM City Chapter Leader from Bangalore/Hyderabad has been a great Chai for Cancer supporter over the years and has hosted multiple Addas which included wonderful performances by B Reloaded Music Band. He has hosted a Chai for Cancer Adda year after year since its inception - if it is July you know it is time.

This year was no different yet different. Together with his partners in crime B Reloaded Music Band and Banana Boat Entertainment Network India, Pranay hosted a virtual Musical Chai for Cancer Adda on July 18, 2020, that brought together 70 fans and friends on a virtual platform. What ensued was a musical bonanza as cups of chai and sweet voices were raised for the cause!



Chai for Cancer Virtual Adda hosted by the Patnaiks and the Tawares



"Last time when Nihar Pattanaik and I had hosted "Chai for Cancer" - it was for Neena Taware, a breast cancer survivor.

This time Neena Taware is hosting it. Isn't that so inspirational?

Last time someone who needed that small support of everyone saying - "Yes, it's difficult but this too will pass" is this time going to say that to so many others!!

A Virtual Chai Adda on 25th of July, 5:00 pm onwards on our Zoom platform. We love Chai, we love stories, we love Music and we have survived the Big C! What

better Adda than a Chai Adda to sit, listen and share some inspirational stories and also some fun stories about our memory with our cup of Chai. All of us can share our memory with our cup of chai. A story from our memories with our cup of chai along with some songs!!

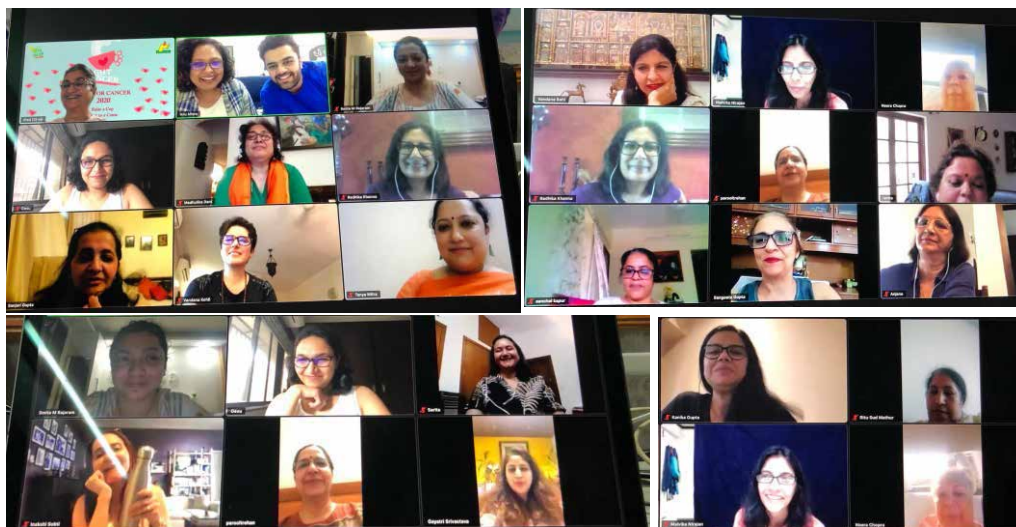
Dr. Sewanti Limaye who has been a huge support system for Neena will be sharing some very valuable information about Cancer. Neena Taware and Anjana Adappa will be sharing their story with the Big C. Viji Venkatesh of course will charm us as usual with her inspirational stories from real-life situations.

Let's just all come together, connect through STORIES, MUSIC and CHAI like last time and support the cause," was the message shared by Chai for Cancer host Lopamudra Mohanty inviting people to be a part of the campaign.

Over 60 friends joined the Virtual Chai for Cancer Adda and some of the power women who shared their cancer experiences were patients, physicians, volunteers and advocates - raising their voices for a cause!

Chai for Cancer Adda hosted by ELSA Alumni

Viji Venkatesh along with the ELSA Alumni Mumbai group hosted a Virtual Chai for Cancer Adda on August 15, 2020. "What a delightful Chai for Cancer Adda my wonderful ELSA Alumina hosted with me - A unique Antakshari Adda with a 100/- or more per song sung and oh boy we raised our voices and our cups and gave with our hearts to the cause. A surprise guest joined in making it even more special! Manish Paul joined in, sang and contributed too," she said.



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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