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# **NEWSLETTER**

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# **Support Group Meeting Highlights**



#### Patna - Music Workshop

The Support Group meeting organized at AIIMS in Patna featured a Music Workshop, which turned out to be a complete hit amongst the audience. The group was divided into four teams and a power-point presentation was shared highlighting information about the origins of music, sounds of nature, the seven musical notes and different melodies and harmonies from all genres of music (Sargam and Ragas of Indian Classical Music was added by

Amma in her presentation for the regional flavour). In addition to this, we had a musician playing the saxophone in one meeting and a school band in the other, who replicated the sounds and notes for a better understanding, which made the workshop more interesting. Each team was asked to prepare a song from the following genres: prayer songs, film songs, and a song based on a Classical Raga Ghazal (An Arabic word, it is a short poem

consisting of rhyming couplets put to music).

The energy inside the auditorium was contagious, competition was at its peak and each team was seen rehearsing songs they had selected. Their performances were an absolute delight to witness and left us stunned in our seats!

- Anshika Tandon (Max Team)



25TH NOV 2018

## Aurangabad - Art Workshop

An extremely fascinating session awaited us at this meeting - 'The Art Therapy Workshop' conducted by our very own Amma. This session was the pinnacle of our meeting and a greatly successful one at that. Everyone from Dr. Indurkar and his family to the patients and their caregivers participated wholeheartedly in this

workshop. The audience was divided into 4 groups and each group identified an emotion that matched the colour of their name cards viz. Hope, Love, Courage and Peace, which resulted in a fabulous artwork collection. Following this, every group came forward and shared their picture with the rest of us while explaining the colour

they picked and highlighted its association with their chosen theme. For over two hours, the auditorium was a riot of colours, leaving everyone engrossed during this therapy.

- Seema Goud (FOM Volunteer)



## Amma Speaks

Friends of Max is the largest Support Group of its kind in the world and our Patient Support Group Meetings are a means of building community resources and providing patients and caregivers with treatment-related information and emotional support. Such meetings are an important part of Friends of Max's intervention in the CML and GIST community in providing advocacy & support. These gatherings held in different cities and towns all over India, bring patients together and

empower them by the sharing of and learning from each other's experiences. This is a unique platform for physicians, patients and caregivers to come together so that patients can freely discuss their apprehensions, concerns and queries about their medical condition and managing their lives while on medication.

As both CML and GIST are life-long conditions which have to be managed with lifelong therapy, patients are advised to strictly adhere to daily treatment protocol recommended by physicians. For well over a decade and

a half, Friends of Max has made many positive interventions which have been acknowledged by the eminent physicians on our panel. Finally, these meetings are nothing short of a celebration - of life and the love that has created lifelong bonds amongst one another. Of course these meetings will never be possible without the great efforts put in so lovingly and diligently by the Max Foundation team in India. Featured in this issue of our Newsletter are excerpts from reports on eight of such meetings by FOM patient advocates and Max Team members.

- Viji Venkatesh



#### Kanpur - Compliance Workshop

Not being such a big group - we were about 70 odd people; there was an intimate feel to the day and before I could say "Workshop" all my doubts about the participation levels were dispelled. The participants happily divided themselves into their colour coded groups but not before some fun definitions of the word, "Workshop" was elicited from them and reasons for the coloured badges proffered too. I am amazed again and again at how happy these meetings make everyone feel and how within a couple of hours into the day we are all like one big family. There's bantering and back slapping and selfies

and life stories exchanged and the kind of bonding one may see at family weddings or school reunions. If I were not standing at the head table and in full view of everyone, I would have burst into tears...my heart was bursting anyway.

- Viji Venkatesh

A compliance workshop was conducted to ensure that the patients take their medicine regularly and with the appropriate dosage as well as to monitor their health conditions. Patients were divided into four groups represented by different colours and were asked to choose a group leader. All the groups were then guided to note-down reasons

for questions asked, for example, "Why do I take medicine regularly?" The group leaders would then note-down the reasons after an in-group discussion and one member of each team would share their responses with the rest of the audience. The next exercise was for groups to respond to the question "Why don't I take my medicine regularly?" There were some interesting responses to this. A lot of patients said that they do not take medicine while fasting and had their reservations. All the groups handled this question well and interacted beautifully in this session.

- Manav Bhargava (FOM Volunteer)





## Jaipur - Drama Workshop

At the Jaipur meet, Amma presented an interactive Drama Workshop that we conduct at our Patient Support Group meets. She decided to spring a surprise on the audience and threw a little challenge at them which, she says, they picked up with great élan. Here is the scenario she gave them: A cast of characters and 5 minutes to script out an 8 minute skit. So, much to his mother's consternation, a young school boy comes home with a packet of Gutka in his mouth which he bought from a tobacco vendor's store, right next to his school. The parents

take this up with the school principal involving a municipal official and a media person in the fracas. Dr. Purvish M Parikh, Ritu Biyani, Dr. Prakash Chitalkar, Jyoti Joshi rocked this showcase with their performance and creativity.

- Anshika Tandon (Max Team)





## Chandigarh - 22/9 World CML Day

The Max Foundation and Friends of Max in association with the Postgraduate Institute of Medical Education and Research (PGIMER) organised the World CML Day Meeting in Chandigarh. This was the eighth World CML Day Meeting here and has been tradition now that we conduct the meeting every alternate year. There were 794 patients and caregivers who participated in the meeting. Viji

(Amma) presented a Music Workshop which had a great impact on our patients. In addition to this, Eddy, the musician playing his guitar was the icing on the cake. The Auditorium was full of energy as the participants geared up for the medical session. Dr Pankaj Malhotra and his team covered all the aspects of treatment during a Question & Answer session. On the occasion of World CML

Day, the FOM City Chapter leaders gave a special treat to their physicians. A clock (with the World CML Day logo) - a symbol of Time was presented to all the physicians. This was a way acknowledge the precious time physicians give to all the patients.

- Priyanka Kandalgaokar (Max Team)





## Mumbai - celebrating our GISTers

With the Advent season upon us, we couldn't miss enjoying some delicious Christmas cake. By cutting the cake, we set on roll our last Chai for Cancer (CFC) Adda for the calendar year 2019. People contributed towards the cause. Carols were sung followed by a time of singing and dancing to the melodious rendering by our friends at the gathering. We then proceeded to have some wonderful food. Finally, we dispersed after greeting each other and promising to meet at the earliest - for more Sharing and Learning...Words cannot express our gratitude towards the entire Max

Foundation team, led by Amma, and for the hospitality and support we have received from them.

- Pramod George (FOM Volunteer)

The main objective of this meeting was to explain how CML and GIST being such different types of cancer are still connected via the same platform of FOM and the 'magic bullet- GLIVEC'. In this meeting, our very famous *Bhai and Bhidu* show was renamed as *Bhai and Amma* show starring Amma, Pramodji - our FOM Trustee and Sureshji - our FOM volunteer. Through this small but effective skit everyone present got comfortable and

shared their experiences. The patients talked about their diagnosis and the side effects they faced, without any hesitation. The patients with either CML or GIST could all connect on a common ground which was so wonderful to see. We had also invited one of our Help cases - who being as young as 18 years of age, shared her story, which was so powerful that it left us all in awe of her. She, in turn, felt extremely overwhelmed and positive after meeting everyone and listening to the stories shared.

- Komal Surve (Max Team)





#### Calicut - CML & GIST Quiz

The afternoon's interactive workshop at the Calicut Meet was by now very popular Quiz Session, which was a refresher course on both CML & GIST as well as the Access Programme, Max and FOM. All patients and caregivers actively got involved in this activity. We formed teams and each team had representatives who answered questions. The Quiz master was our own Viji (Amma) and the scorer was Beena. I took up the role of translating the questions into the regional

language- Malayalam. Question after question, the session became increasingly fun and interesting.

- Shalini Subramanian (Max Team)





#### Chennai - Tell Your Story

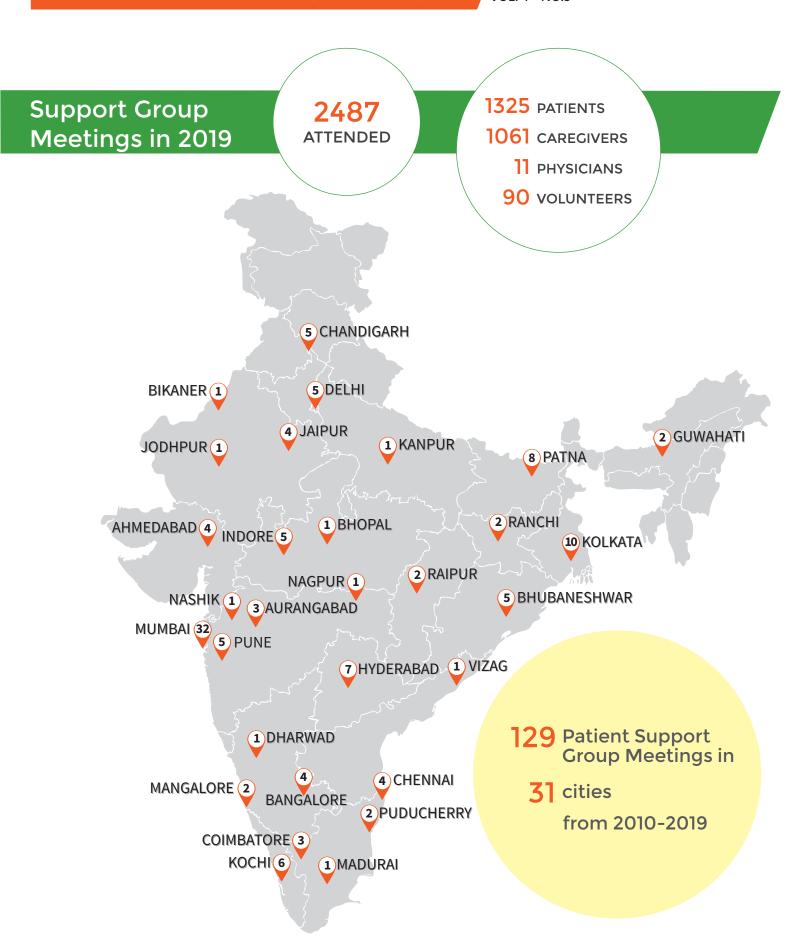
Keeping in mind the theme of the Maximize Life campaign this year, "Tell your Story: its Therapeutic Value", the afternoon session was devoted to Testimonial Sharing. From a young teenager who was diagnosed when he was only eight years old - the same number of years ago, to a young adult

who since his diagnosis in his early 20s, had married and fathered a child, to a young mother who discovered her independence and new talents and meaning to her life post her diagnosis, to the devoted wife of an elderly gentleman whose children found out how "bold" and "brave" their mother was only after their

father's cancer made an appearance... Listening to these stories and seeing how their tellers had maximized their lives, newly diagnosed patients and those who had held back all these years stood up to share their stories. It was truly what **Maximizing Life** was all about.

- Viji Venkatesh





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