



# NEWSLETTER

## Friends of Max

(April - June 2016)



### AMMA SPEAKS

Here is the first Friends of Max newsletter.

While communication in the modern world through social media is instant and gratifying (I am in equal measure a devoted fan of and hopelessly addicted to this wonder-cum-malady) there is something to be said for an old-fashioned newsletter to reflect upon the recent past and ponder over the future. It is essentially our latest channel of communication to engage with a close-knit community of well-wishers and friends.

I believe in keeping in touch, being positive - and sharing news and information.

- Viji Venkatesh

### FEATURE STORY

## Advocacy: a voice for the voiceless

They say adversity brings out the best in us. Never has this been more evident than in our struggles since February 2016 when the Government of India announced its decision to withdraw exemption of customs duty on Imatinib Mesylate Glivec – the Magic Bullet that has served thousands of patients in the Friends of Max fold for over a decade – throwing the Novartis-supported free donation programme (GIPAP – Glivec International Patient Assistance Programme) into disarray and possibly a premature end.

But we have fought like cornered tigers for the thousands of poor patients that we have shepherded for so many years. An online petition on **change.org** not only drew nearly 2000 signatures from India but significantly from other countries as well. We garnered the wholehearted support not only from our Friends of Max Medical Advisory but from

other prominent oncologists too. Others who joined in the fray and lent us valuable support have been the **CML Advocates, The Life Raft Group and The ICML Foundation**. Persistence led us to a meeting with the officials in the Ministry of Health and Family Welfare where we pointed out the impact on patients who would be denied access to life-sustaining medication. We are grateful to the Health Ministry for supporting our cause and recommending the immediate restoration of exemption status on the imported drug; however the Revenue Department has yet to implement this recommendation. In fact, along with Novartis we have jointly taken up the matter with the Finance Minister and the Revenue Dept. who have given us their attention. We await their decision and are hopeful of a positive outcome while examining other routes to help thousands of financially-challenged patients all over India.

### IN THIS ISSUE

- 01 Advocacy
- 02 The People Behind FOM
- 02 Global Award Of Excellence
- 02 FOM International Forum
- 03 Chai For Cancer
- 03 Region Stories
- 04 Medical Page

### Friends of Max

Friends of Max ([www.friendsofmax.info](http://www.friendsofmax.info)) is the Support Group arm of The Max Foundation in India and is registered as a Public Charitable Trust with the Charities Commissioner's Office in Mumbai. Its objective is to increase awareness and act as a patient support / advocacy group for underserved chronic myeloid leukaemia (CML) and gastrointestinal stromal tumour (GIST) cancer patients. FOM has developed a network of City Chapter Leaders, trained over 260 volunteers and held over 150 meetings in cities all over India. Its Medical Board Advisory includes the finest oncologists in the country.

### The Max Foundation

The Max Foundation ([www.themaxfoundation.org](http://www.themaxfoundation.org)) offers people around the world the opportunity to face cancer with dignity and hope. Through access to treatment, support and education, and their global advocacy network, Max aims to give all people living with cancer, access to the best treatment and support. Max's Vision is a world where all people facing cancer live with dignity and hope. Max's Mission is to increase global access to treatment, care and support for people living with cancer.

### The FOM logo

A drop of blood to represent the CML and GIST disorder encapsulated by a helping hand that will reach out in support no matter where you are. However paradoxical it may sound, we are an exclusive family that will include anyone with CML or GIST.

### Early beginnings



Year 2008: "Chulo Aasman" our clarion call to overcome adversity

## The people behind FOM

### FOM Medical Advisory Board

**Dr Advani, Suresh**

*Jaslok Hospital & Research Center, Mumbai*

**Dr Agarwal, Mohan B**

*Bombay Hospital, Mumbai*

**Dr Aggarwal, Shyam**

*Sir Gangaram Hospital, Delhi*

**Dr Chandy, Mammen**

*Tata Medical Center, Kolkata*

**Dr Digumarti, Raghunadharao**

*Homi Bhabha Cancer Hospital & Research Center, Visakhapatnam*

**Dr Malhotra, Pankaj**

*Post Graduate Institute of Medical Education & Research, Chandigarh*

**Dr Menon, Hari**

*Tata Memorial Hospital, Mumbai*

**Dr Rajappa, Senthil J**

*Indo-American Cancer Institute & Research Centre, Hyderabad*

**Dr Rajendranath, Rejiv**

*Apollo Speciality Hospitals, Chennai*

**Dr Ramanan, Ganapathy**

*Kumaran Hospital Pvt Ltd, Chennai*

**Dr Saikia, Tapan**

*Prince Aly Khan Hospital, Mumbai*

### FOM Board of Trustees

**Venkatesh, Vijayalakshmi**

*Chairperson & Managing Trustee*

**Prakash, Nirmesh**

*Secretary*

**George, Pramod John**

*Joint Secretary*

**Krishnan, Sunder**

*Treasurer*

**Shah, Ushakant**

**Parmeswaran P S**

**Ranganathan, Sriram**

**Nagpal, Anil**

**Kankani, Shyam**

**Agarwal, Pramod**

**Koner, Subrata Nath**

**Sukumaran, Sujeesh**

Friends of Max gratefully acknowledges the contributions of several people who have made significant contributions to our growth.

### Pro bono contributions

First among equals are **Bindu Sukumaran and Sujeesh Sukumaran** (also a Trustee) professionals in the field of advertising, specifically the health & wellness segment, whose advice and guidance and willing access to their Agency's resources has been invaluable.

No less so has been the professionalism and guidance of **Shyam Padia** our consultant in all matters of finance and accounting.

**Being Human – The Salman Khan Foundation** has been the proverbial Rock of Gibraltar in promoting and supporting our cause at all times.

## Friends of Max at international forums



### CML Horizons in Slovenia, 6-8 May 2016

Friends of Max Trustee Parmeswaran P S was at the CML Horizons Conference held in Slovenia, hosted by the Leukemia Patient Advocates Foundation. Delegates discussed different aspects of disease management, helped participants develop skills to grow as advocates, reviewed successful strategies for advocates to address common issues, build patient group capacity and provide a forum for networking and exchanging ideas on best practices.



### GIST MEETING in Sitges, 18-21 May 2016

Viji Venkatesh and Dr Nikhil Guhagarkar were present at the New Horizons GIST Meet in Sitges, Barcelona (Spain).

Viji Venkatesh spoke on 'The Indian Experience in GIST Management'. She dwelt on the challenges faced like low economics, illiteracy, lack of



knowledge, difficulty in access to GIST specialists in rural areas and how The Max Foundation through its access programs and educational meetings are connecting with the people of India.



Dr Nikhil Guhagarkar spoke at the Best Practices session on "FOM and GIST awareness activity in India". Its highlights were : the need for regular meets, printing GIST education material including a booklet on 'Nutrition and Holistic Way for Living with GIST', challenges faced including access to correct information, GIST specialist

doctors, compliance issues, myths and stigma.

## The Global Award of Excellence



**The Global Award of Excellence** for Friends of Max has been very gratifying and a fitting recognition for the hard work put in by us. In

truth however, accolades of any kind are just a spur for renewed effort.

## Chai for Cancer

Chai for Cancer is an awareness and fund-raising campaign directed at supporting cancer patients who are coping with CML and GIST. It's the brain-child of Viji Venkatesh who says: "it's a simple association between cancer and a cup of chai which is everyman's drink - it has recall value as well as brings a sense of comfort and normalcy to the feared condition".

Chai for Cancer, now in its third year, is an effort to give Friends of Max (the Support Group arm of The Max Foundation in India) a tool to raise funds to support its



"A Selfie with your morning cup of Chai please," was the call from Viji on Chai for Cancer Day 8 May 2016. And #chaifies was born.

wide range of patient-focused activities. It deploys informal hangouts or 'Addas' complete with a cup of chai and conversation that will bring together like-minded donors and supporters of the cause.

## From the heart

So far in 2016 we have hosted more than 30 Addas in cities like Hyderabad, Bilaspur, Pune, Mumbai, Kolkata, Delhi, Bhopal, Ahmedabad and Bangalore.

These Addas are an endorsement of our philosophy that if we create awareness and find avenues to raise funds, large-hearted people will respond to the needs of the less fortunate.

## Region stories

*Excerpts from a Report by a FOM Volunteer on the first Patient Support Group meeting for CML & GIST patients at Nashik 20 April 2016*

The venue Vishakha Hall was in the heart of the city and was quite a cool and pleasant place. It was a perfect place for a full day meeting in the summer. This was the first Patient Support Group meeting in Nashik city and hence we were expecting huge numbers. Amma, Ameya and Sharon from The Max Foundation reached the city a day prior to the meeting in order to make sure that

everything was in place. The Pune Gang including Amruta, Abhishek, Shashikant, Milan, Trupti and Ravi also reached a day prior to extend support to the Max team.

At the registration counter Amma along with Sharon and Ameya were all set to welcome our patients. Meeting patients at the registration counter is always a lovely sight. No matter how far they come from, they always carry a smile and meet each other like friends and family. After the registration patients along with their caregivers were served with breakfast.

The meeting started off with a presentation on The Max Foundation in

Marathi by Sharon. She managed to help us understand what The Max Foundation exactly is, what they do, who started it and so on. Amruta (Pune FOM volunteer) then explained what Friends of Max is, how it was formed, how one can become an FOM and why it is important to be a part of a support group like this one. This presentation was concluded by a simple story that was told by Amma in a very simple manner to make patients understand that Friends of Max is more like a common station in every patient's life where they will get to meet people of similar types.

## Unsung heroes

Many of our patients endure incredible hardships to come from villages to treatment centres to collect the free doses of medicine accessible to them under NOA-GIPAP. A couple of videos made in the Max Foundation office in Mumbai capture the mood of quiet resilience.

Milan and Abhishek were in office today and were sharing the challenges they faced coming all the way from the North and North East respectively by train to come periodically to see their oncologists. Having to take at least a week off from work ( sometimes going back to no work) and the struggle to get tickets in time and then the train being held up due to anything from nature's fury to the terrorist's bombs ...



Lakshmbai and her husband Reshmaji left their village in Parbani Distirct last night to take an overnight train to Bombay and made their way straight to Tata Memorial Hospital so that they would not be late for her appointment with her Medical Oncologist. They came to our office after the long OPD procedure at the hospital, tired, thirsty and hungry. It has been a tough few months for them back in the village where Reshmaji tills his small plot of land. The drought, mar... See more



## Medical page

### What is CML

By Prof Subrata Nath Koner

Chronic myeloid leukemia (CML) is a type of blood cancer that starts in certain blood cells of the bone marrow. Like all other cancers, in CML these cells grow out of control. A chromosomal interchange (between 9 and 22) takes place in embryonic stage of myeloid series of cells from which RBC, platelets and mostly WBC are generated. Because of chromosomal change an abnormal complex called BCR-ABL forms that transform the cell into CML cell. Once generated leukemia cells grow and divide, and ultimately spill over into peripheral blood. As a result, abnormally high count of WBC is observed in CML patients. Importantly these cells mostly remain immature and thus do not function normally.

*Excerpts from FAQ on CML (compiled for Friends of Max by Dr M B Agarwal, MD Dept of Haematology, Bombay Hospital, Mumbai)*

#### How is CML treated

Treatment of CML depends on its phase. We will first discuss the treatment of Chronic Phase. The standard of care is Glivec (Gleevec, Imatinib Mesylate), an oral pill. This is made by Novartis and has been made available for patient care for several years through their Glivec International Patient Assistance Programme (GIPAP). The usual dose is a single pill of 400 mg once a day. This has made almost all previous treatments as second-line therapy. Most patients respond to this treatment extremely well. They also tolerate it very well. Such patients should continue to take it for their whole life without interruptions. The dose should not be reduced without the treating physician's / specialist's advice and one should also not take it intermittently as both these reduce drug efficacy. Usually the pill is taken after 30-60 minutes of a major meal, often the night time meal – dinner. It should be taken with a glass of water. This minimizes stomach intolerance. However one can take it after lunch or even breakfast. The occasional patient may require a pill to prevent nausea. In this situation Tab Domstal is prescribed 30 minutes before Glivec.

#### How Glivec works

CML is associated with the occurrence of an abnormal chromosome – Philadelphia chromosome. This chromosome contains a faulty gene called bcr-abl. This gene produces an abnormal version of a protein, an enzyme called tyrosine kinase (TK). Under normal circumstances the TK protein helps in controlling cell growth and division. In CML, TK is defective it passes abnormal signals



Dr Suresh Advani (foreground, right) at a FOM Patient Group Meeting in Mumbai

resulting in continuous division of white cells. Glivec is a small molecule which works by targeting the faulty TK enzyme. It sticks to it and prevents it from stimulating the white cells to multiply. Therefore Glivec is called Tyrosine Kinase Inhibitor or TKI. As it targets the faulty TK it is also called targeted therapy. As it blocks the “grow” signal, it is also known as “signal transduction inhibitor”.

### What is GIST

By Dr Nikhil Guhagarkar

Gastrointestinal Stromal tumor (GIST) is a rare cancer affecting the digestive tract or nearby structures within the abdomen. GI stromal tumor, or GIST cancer, is a sarcoma. Common sites of occurrence are stomach and the small intestine. Common symptoms are weight loss, anaemia, bleeding and abdominal swelling. Diagnosis is done by CT scan, biopsy, CKIT testing and Mutational Analysis. Treatment consists of Imatinib (Glivec) as the main drug which helps in decreasing the size of the tumour, after which the tumour is surgically removed. After surgery Imatinib may still be continued for some patients.

*Excerpts from FAQ on GIST (compiled for Friends of Max by Dr Vikas Ostwal, Tata Memorial Hospital, Parel Mumbai)*

#### Why 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 medical literature. A protein called “KIT” also called CD-117 is thought to be one of the major causes of GIST. The KIT protein, located on the surface of normal cells, 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.

#### GIST symptoms

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.

## Patient group meetings (Jan - June 2016)

City	Date
Bhubaneswar	31 <sup>st</sup> Jan 2016
Hyderabad	27 <sup>th</sup> Feb 2016
Patna	28 <sup>th</sup> Feb 2016
Mumbai	5 <sup>th</sup> Mar 2016
Vizag	12 <sup>th</sup> Mar 2016
Bhopal	20 <sup>th</sup> Mar 2016
Nashik	3 <sup>th</sup> Apr 2016
Kolkata	23 <sup>rd</sup> Apr 2016
Mumbai	22 <sup>nd</sup> May 2016



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**Address:** Friends of Max, Secom Business Centre, A Block Basement, Shiv Sagar Estate, Dr A B Road, Worli, Mumbai 400018

**Email :** friendsofmax@gmail.com

**Website :** www.friendsofmax.info

**Website :** www.chaiforcancer.org

**Facebook:**

www.facebook.com/CMLGISTsupportgroup/

www.facebook.com/Chai-for-Cancer

**LinkedIn:** https://in.linkedin.com/in/chai-for-cancer-702630117

**Twitter :** @vijivenkatesh