

NEWSLETTER

Friends of Max

(October - December 2016)



AMMA SPEAKS

A Leadership Summit brings together committed city chapter leaders from all over the country and is an overnight residential workshop. It sets the tone till the next Summit. We get the opportunity to forge plans and deploy resources and make certain that each Summit will be even better than the previous one in terms of comprehensive support group activities. Forging this path with the use of technology and adding the crucial human touch is what Friends of Max is all about. I am devoting the Oct-Dec 2016 newsletter to the 3rd Leadership Summit recently held in Kochi as a salute to all those physicians, FOM delegates and well-wishers who made it a success and to give a sense of the occasion to those who could not join us there.

- Viji Venkatesh

LEADERSHIP SUMMIT 2016 SPECIAL



A Leadership Summit that caters to the growing needs of 18000 patients, a programme that faces fresh challenges after more than a decade. The message was 'Full Steam Ahead' despite the crisis



**Address by Pat Garcia-Gonzalez,
CEO - The Max Foundation**

"This year more than ever I wanted to be present with you, to tell you that I am with you always and have been with you all along. The only constant in life is change... the catalyst of the change, the thing that popped the magic bubble was the levy that was imposed on Glivec imports, which completely disrupted an otherwise perfect program. So today we are where we are, like it or not; no new patients have come into GIPAP for 10 months and I have to be honest with you, I don't expect the program to open again to new patients. But here come the opportunities and responsibilities for all of us. The next few

weeks, months and years will define who and what we are; what we do, what resources we are able to create; who can we influence and who can we help, how many people can we help... all this is now up to us; you and me, all of us here."

(for the full text pl visit www.friendsofmax.info)

**Vice-Chairman & MD Novartis
India Ranjit Shahani's message**



"I marvel at how much a part of the Novartis and Max Foundation family you have come to be. This year Glivec received the prestigious 2016 Prix Galien Foundation

"Discovery of the Decade" Award for Best Pharmaceutical Product. The Prix Galien Award is considered to be the pharmaceutical industry's Nobel Prize (and) is a special recognition for distinguished industry achievement in medical innovation. As a healthcare leader we believe that it is our responsibility to help improve access to medicines."

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**Excerpt from Keynote Address by
Amit Vaidya**

"No doctor, caregiver, family member, friend, organization, spiritual leader can do the job we have to do ourselves. And because that commitment has to come from within, it is our job as advocates to ensure that every patient not only understands this but also has the resources and tools necessary to be the driver of their own medical lives."



Medical Sessions & Panel Discussions

The galaxy of leading oncologists present at The Leadership Summit 2016 meant several key issues were showcased and discussed by the panel of physicians and delegates



Dr. Tapan Saikia spearheaded discussions on identifying and managing side effects on long term survivors 15 years and more on TKIs – *Identifying and Managing Side Effects on Long Term Survivors*.



Dr Hari Menon led discussions on *Are we ready for STOP trials in India*, the concept of treatment-free remission and whether the data available was mature enough to embrace this concept.



Dr. Pankaj Malhotra spoke about *Asian Treatment recommendations* for treatment and management of CML / GIST and its feasibility vis-à-vis western guidelines / affordable society / insured society; in addition he explored

related challenges faced by patients and physicians in developing countries.

Panel Members

- Dr Advani, Suresh
Jaslok Hospital, Mumbai
- Dr Gangadharan, V P
Lakeshore Hospital, Cochin
- Dr Malhotra, Pankaj
PGI, Chandigarh
- Dr Menon, Hari
Cytecare Hospital, Bangalore
- Dr Rajendranath, Rejiv
Apollo Hospital, Chennai
- Dr Ramanan, Ganapathy
Kumaran Hospitals, Chennai
- Dr Pavithran, K
Cochin
- Dr Saikia, Tapan
Prince Aly Khan Hospital, Mumbai
- Dr Warriar, Narayanankutty
Calicut Medical College, Calicut

Dr B C Roy Award



Dr Mammen Chandy, Director of Tata Medical Center Kolkata and Member of Friends of Max Medical Advisory Board, was recently conferred with the prestigious **Dr B C Roy Award** in the field of Eminent Medical Person by the Medical Council of India (MCI). We are proud, honoured and humbled to have Dr Chandy as our mentor.



FOM Speak

FOM Panel Discussions included a broad range of topics and initiatives: Harnessing Technology; Online Surveys - an effective tool to monitor and analyze data/feedback; CML App- for Disease Monitoring and Management to help patients log daily experiences and collect data; SMS / Text Messages-based Alert Project to improve compliance among patients. There were also discussions on the way forward and challenges for FOM in the year ahead.



The Leadership Summit 2016 afforded The Max Foundation's South Asia and Asia-Pacific teams a useful opportunity to share findings and ideas on the way forward.



Nirmesh Prakash, Secretary FOM reflects on a special occasion

“For those of us who have had the privilege of attending international patient support

group conferences such as CML Horizons (a global conference) and Rising Sun (focused on Asia Pacific), it's a matter of pride for us to showcase the work that FOM has done. Most participants are amazed by our scale and always wonder how we manage our patient meetings with over 200-300 people or how FOM has executed a simple idea like Chai-for-Cancer and made it our primary fund-raising tool! Similarly, when we hear about the great ideas other groups across the world have succeeded with, it's so inspiring. Another reason that FOM should participate in, especially Rising Sun, is that Rising Sun is managed by The Max Foundation - the reason for FOM's existence!”

Excellence in Patient Advocacy Award



The 'Excellence in Patient Advocacy Award' was awarded to Viji Venkatesh in recognition of her sustained year-long effort to convince relevant Ministries in the Govt of India to reverse its decision to impose customs duty on free Glivec distributed to all CML / GIST patients. She dedicated the Award to her team for their complete commitment to the patients and support throughout the year.

Help for BCR-ABL Diagnostic Patients



Pat Garcia-Gonzalez CEO - The Max Foundation presented a cheque for \$20,000 to the Trustees of FOM that was raised through Chai for Cancer USA 2016. This will be devoted to enabling deserving patients in India access BCR-ABL Diagnostic tests.



Together We Share And Learn

Friends of Max unveiled a short film capsuling their early beginnings and the quiet bravery of everyday heroes whose battle with cancer does not in any way prevent them from living normal, fulfilling and productive lives. A friend

of Max has a simple belief: openness and sharing personal experiences are powerful tools to fight fear and stigma associated with cancer. Together We Share and Learn. And Maximise our lives.



Yoga for Fitness at LS 2016: “most special”

Working as a yoga and holistic fitness coach for the last 15 years, I have had a chance to conduct sessions for many diverse groups - from Bollywood actors to Corporates to the Miss India Finalists, but the experience of conducting the session at FOM Leadership Summit in Kochi has been the most special.

I landed in Kochi on the evening of 17th December, without a concrete plan for the yoga session I had to conduct the next morning. I had to see the participants, the space and soak in the energy to devise the session accordingly. The beautiful terrace by the pool which was being used for the dance was to be the area where I had to conduct yoga in the morning. Vijaya, along with other volunteers helped me with my requirements for the mic, yoga mats etc. At the dinner, I also met my perfect yoga demonstrators for the session - the 11 year old, athletic Priyanka and veteran yoga practitioner, Sunder.



It was an exceptionally perfect morning and the weather was just right. At 6 am, the participants started pouring in wearing the new white FOM T-shirts. We tested the mics, decided the positions for the demonstrators at the elevated platform and adjusted the authentic local chatais from Kerala which were

to be used as yoga mats. By 6:30, about 100 participants had taken their positions facing the sunrise. Just as the sun began to rise, we started the session with a brief introduction by Viji.

I started the session with a short meditation, moving on to gentle stretches. There were people from all age groups and many had never done yoga before. We did a light cardio and few joint rotations to warm up the body before moving on to simple yet some of the most important yoga postures such as *bhujangasana*, *tadasana* and *shashankasana*. My intention was to give all participants an experience of yoga practice, energise them for the day as well as inspire them to include regular cardio, stretches and yoga practice for their overall holistic fitness in the New Year. After yoga poses, including many spinal stretches, towards the end of the session we did relaxing postures leading to *shavasana*. The session concluded with the chanting of *AUM* which created very powerful vibrations with so many people chanting it in sync. By the time we finished, the sun was up at just the right angle for a perfect group photograph to capture the glowing faces!

As I left for Mumbai later that day, I was full of positivity and really grateful for such a rich experience. While my attempt was to inspire the FOM members to include the physical aspect of yoga in their routine for their well-being, I found that they all were already living the higher philosophical aspect of yoga in truly living each moment to the max!

Abhishek Sharma



Mascot Kuttan adorned all LS material – name-tags, pens, carry-bags, folders

Patient Support Group Meetings in 2016

City	Date
Bhubaneswar	31 Jan
Hyderabad	27 Feb
Patna	28 Feb
Mumbai	5 Mar
Vizag	12 Mar
Bhopal	20 Mar
Nashik	3 Apr
Kolkata	23 Apr
Mumbai	22 May
Mumbai	9 July
Kolkata	22 Sept
Guwahati	25 Sept
Delhi	2 Oct
Bikaner	16 Oct
Chennai	22 Oct
Jaipur	13 Nov



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