



NEWSLETTER

Friends of Max

(July - September 2016)



FEATURE STORY



9/22 World CML Day

Dr Pankaj Malhotra of PGI, Chandigarh and a member of the Medical Advisory Board of Friends of Max, hosts a World CML Day meeting.

9/22 Celebrating a sacrosanct day across India saw The Max Foundation and Friends of Max associate with various hospitals and doctors in Mumbai, Kolkata, Guwahati, Hyderabad and Delhi.

In Mumbai the guest list included the ever-supportive Ranjit Shahani (Vice Chairman & Managing Director Novartis India) and stellar FOM volunteer Suresh Pawar; in Kolkata the enthusiastic FOM team hosted the meeting in association with Tata Medical Center; Guwahati's first-ever meeting saw 71 patients and caregivers turn up to share their stories. The team concluded this year's World CML Day with a meeting in Delhi which emphasized the needs of patients on 2nd Gen TKIs.



9/22 World CML Day at The Max Foundation office in Mumbai - Sudipa Das, a 13-year old CML patient from Bengal, spoke simply and eloquently - with the gracious Ranjit Shahani (Vice-Chairman & Managing Director, Novartis India) among the listeners.



Play You Tube video - What CML Day Means To Me

"... You became the password of my life"

I first met him at our school re-union in 2011 and became friends on Facebook! One day, he requested me to meet personally. Confused and anxious, I started questioning myself - "What happened!" "What should I do?" Finally, I decided to meet him!



At the cinema hall (INOX) where we decided to meet, I found the tall, fair and handsome guy standing with a glowing smile on his face. I smiled back. I asked him "please what happened?" He said, "I called you for

two reasons. Firstly, since we chat day and night, I am getting a hangover, I can't work! Yes! I have fallen for you and can't be at peace without you! And finally, I need to share something really important about my life! I am a CML patient. I was detected with CML in 2004."

Tears rolled down my cheeks. I asked him "You don't seem to be sick! You're joking, right?"

He looked confidently into my eyes and said "Yes! I said leukemia". He clarified further. "It's actually a chronic type of leukemia, where white blood cells are

AMMA SPEAKS

Observing 9/22 as World CML Day takes on a very important hue especially at this crucial juncture. Thousands of people are living with cancer factoring it into their lives and forging ahead on a parallel path embracing a new normal. Their needs go beyond just access to medication. Non-compliance, drug fatigue, personality changes are added to other life-altering changes. These are enhanced in our patients' cases because of the burden of the disease. They continue to live with stigma and discrimination at various levels. Disease progression, resistance, having to transition to 2nd and even 3rd Gen TKIs and its financial implications, keeps the fear of the ever present Damocles' sword hanging over their heads. - *Viji Venkatesh*

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9/22 FOM Delhi team at Sir Ganga Ram Hospital



9/22 World CML Day at Kolkata

present in excess. It's a chronic disease like diabetes or blood pressure! It is neither genetic nor contagious and I am perfectly fine!"

Right at that moment my heart made the decision: "This is the guy!" I remember the only sentence I asked him was "When are we getting married?"

My man... my best friend Arindam Das, the guy with a golden heart! We've been married for four years and he makes me feel like I am his lucky-charm.

One statement sums up our story, as Arindam puts it: "It started with a friend request and then you became the password of my life!"

- *Satadipa from Kolkata*

The Max Foundation Team in India



Ameya



Ankita

The exuberance of youth wedded to the solemnity of experience.

A blend of newcomers and old hands. A small team that has evolved from catering to the needs of 1000 patients a decade ago to the largest of its kind in The Max Foundation fold caring for over 18000 patients today in the South Asia region.



Anshika



Ashika



Azim



Beena



Jyoti



Komal



Philip



Prasad



Priyanka



Santosh



Shalini



Sudha



Vidya



Vijaya



Viji

The Global Award of Excellence



Viji Venkatesh receiving the Life Fest 2016 Global Awards of Excellence on behalf of Friends of Max from Rodrigo Salas at Redondo Beach CA

Friends of Max at international forums



Dr Nikhil Guhagarkar was the Friends of Max representative at the 7th Sarcoma Patients EuroNet (SPAEN) Annual Conference for Sarcoma Patients in Warsaw (Poland). An active advocate for GIST, he chaired a Best Practice session and was elected Board Member of SPAEN.

Chai for Cancer USA and Canada (July-August 2016)

A Season in the Sun

The recent Chai for Cancer Addas in the US and Canada reinforced a belief that no matter which continent it is, “Giving” knows no limits. Fun, smiles, songs, networking, talking openly about cancer and fund-raising can go hand in hand.



Raising funds for Diagnostic Tests for patients in India saw a variety of hosts in

- Union City
- Phoenix
- St Louis
- Washington
- Raleigh
- Shoreline
- Bellevue
- New York
- Kendall Park
- Montreal
- Toronto
- Vancouver



We are grateful to all at The Max Foundation who ensured that the Addas were supported by their dear friends and family members.

Chai for Cancer USA called on New York to raise a cup for the cause on 26 August. At Memorial Sloan Kettering Cancer Center, the redoubtable Michael J Mauro, M. D., no less, nodded approval. (picture, right)



Medical Page

PCR



What is PCR? Why should I know my PCR Level?

PCR stands for 'polymerase chain reaction'. It is a diagnostic and monitoring tool used in CML to measure the response to treatment. It often is the only test which gives someone an idea about the depth and stability of their response to treatment.

What does PCR measure in CML?

CML occurs when a specific change happens between chromosomes 9 and 22; parts of them swap places, creating a protein called BCR-ABL (Philadelphia Chromosome). This BCR-ABL protein is what makes leukemia blood cells different and malignant. In CML, PCR measures the amount of genetic material (called RNA or DNA) or 'blueprints' for BCR-ABL present. PCR levels are thus linked to both the amount and activity of leukemia cells remaining in someone with CML.

Is PCR performed from peripheral blood or bone marrow?

PCR can be performed from either blood or bone marrow samples. Having enough material to test is important so peripheral blood is almost always preferred.

Why is PCR important in the management of CML treatment?

PCR is a crucial tool. First it is patient friendly, requiring a blood draw only. Second it is a broad-ranged test being able to measure untreated (high levels) of BCR-ABL all the way down to the lowest measurable levels.

What is the IS?

The IS stands for 'International Scale'. International Scale is a means for standardizing and validating a patient's PCR Test results. It refers to a reference range developed for reporting of quantitative PCR results for BCR-ABL for patients with Ph+ (BCR-ABL+) leukemias.

Why is it important to standardize PCR labs?

It is important to standardize PCR labs so that physicians in different medical centres or offices can all 'speak the same language' and 'use the same tool to measure'. Results can be compared between labs and centres and response milestones understood and confirmed. Without standardization of PCR for BCR-ABL it is hard to know how to interpret changes in BCR-ABL levels - for example does the change represent loss of a treatment milestone? Is the change the result of variations in the instrument used to run the PCR test? At the very least, in the absence of IS reporting, it is recommended that a patient's PCR is always done in the same lab to minimize variations and to improve the ability to interpret changes over time.

What should I ask of my doctor with regards to IS PCR?

Ask what your PCR results are on the IS Scale. If results are reported on the IS it is much easier to convey how someone is doing relative to well-established 'milestones' of

treatment response. Patients should ask their physicians if there is an IS standardized lab available to run their PCR and to use it preferentially and consistently.

Excerpts from My PCR Frequently Asked Questions (written by Dr Michael J Mauro, MD, Leader, Myeloproliferative Disorders Program, Memorial Sloan Kettering Cancer Center, Professor of Medicine, Weill Cornell Medical College)

World CML Day Events

City	Date
Mumbai	22nd September
Kolkata	22nd September
Guwahati	25th September
Delhi	2nd October



Leadership Summit 2016

Passing the baton

A key element in the growth of Friends of Max is creating a dynamic structure and environment in which volunteers can learn, assimilate learnings and grow as leaders. A sensitivity to others' needs, an eagerness to learn, to implement and practice and above all, to help. Every annual Leadership Summit grooms potential leaders to carry the torch.

This year's Leadership Summit will be held in Kochi on 17-18 December



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