



NEWSLETTER

Friends of Max

(July - September 2017)



FEATURE STORY: PRABHUDAYAL

Living with CML - A tribute to our patients on World CML Day by Viji Venkatesh

Children grow up to become young adults, young adults become responsible citizens holding down good jobs, finding partners and start families and these adults then move on in life to see their children in turn grow up and cross many milestones – they become grandparents, celebrate anniversaries, contribute to their community in many ways while living the life to the full.

Normal and routine occurrences in the journey of our lives... but when this life is touched by cancer each seemingly routine milestone becomes a very special achievement.

As we observe World CML Day this year, with patients, caregivers, volunteers, advocates and other partners in our interventions with thousands of patients diagnosed with this rare form of leukaemia, my thoughts go to some of the families I know who have been living with CML in their midst for over a decade and a half – and I cannot stop marvelling at how they have done so. A rare cancer, one that had no curative treatment and a life expectation of just a handful of years is now a condition that can be factored into the lives of those diagnosed with CML and



their families.

Making this possible are a number of unlikely partners who joined in the journey at various stages, became co-travellers, each bringing with them their own unique contribution to the CML Marathon of Hope and Dignity.

Novartis and the Magic Bullet, Glivec and their incredibly generous assistance programme GIPAP that gave thousands and thousands of patients the Gift of Life, the treating physicians who learnt how to

Continued on Page 2

AMMA SPEAKS

Worldwide, the 22nd of Sept is observed as CML Day.

In India, I have seen thousands of patients and caregivers under the Friends of Max fold travel from far-flung villages, towns and cities come to meet us and their physicians on that day. In a sense it's such a paradox. Such people undertake a momentous yet largely private "journey" in the shadow of social stigma and fear. No medals and adulation. Just raw, quiet, courage.

Watching them congregate on CML Day is testimony to their continuing bravery that lasts a lifetime. For me, being a part of their lives, playing a role, however small . . . has been deeply gratifying.

Working with patients and caregivers, helping them to cope and overcome day-to-day challenges that only they can fully understand. To be part of their lives, watching them grow and make a place for themselves, to carve out a niche for themselves in a competitive and often uncaring world.

Above all - giving them the chance to live with dignity and hope. These are our "rewards". And for that chance, one feels truly blessed.

- Viji Venkatesh

IN THIS ISSUE

- 01 Feature Story Prabhudayal
- 01 Volunteer of the Month
- 02 CML Day Events in India
- 03 CFC Adda hosts
- 04 Medical Page FAQs (What is My PCR)
- 04 Patient Group Meetings

True Exemplars

Every month we choose a Volunteer from the Friends of Max fold: people whose courage in the face of adversity is exemplary.

JULY:



Nikhil Guhagarkar

from Mumbai: suave and sophisticated, a dentist by profession and much-respected volunteer

AUGUST:



Pramod John George

from Mumbai, works with a national daily, networks with all, a passionate advocate and thorough professional

SEPTEMBER:



Pramod Agarwal

a successful Hyderabad-based businessman, available 24 x 7, a man who gets things done

Living with CML... - Continued from Page 1

look after hundreds of patients each, guiding them through a never-before-treaded-path of living with cancer, families and caregivers who gave the love and support required in the changing environment and all of us at The Max Foundation as administrators of the program who found ourselves occupying such a very special place in these blessed lives.

Soon our interventions went over and above that of just programme administrators – we became a parallel family, helping these patients find a new normal and a parallel track too so that they may continue with their journey uninterrupted. Support Groups came into being, new and long lasting relationships were formed and a sense of deep responsibility towards one another, unquestioning and unconditional.

So it is not just Today Together as the CML Day tagline calls out. It is Together

Forever. Some bonds defy definitions.

Let me share a story of an amazing person who has made living with a life altering condition like CML seem like a cake walk.

Prabhudayal whose eyes still haven't lost that naughty gleam that lit up his 14-year old face when he first walked into the Max office with his hospital file more than 15 years ago ...

As he sits at my table today, he reminisces about the time of his diagnosis and says laughingly, neither then nor now, Amma ji, does this Cancer thing frighten me. Yes, my father was very upset. I could feel his sorrow and fear but I was too busy having a good time. I was careless in the beginning and I know I caused him a lot of grief but today I am proud to say I have made him proud of me. I still live life without a care in the world but I have made a life for myself.

I love my job and I am so thankful to my family for encouraging me. I have a complete musical group / ensemble and we play at all religious functions and community events. I feel a very powerful energy within me when I play the Dholak and see the happiness with which people dance to the beat and rhythm I create.

I have never let anything in life get me down. With or without cancer I would have been this way. But as I grew older, I realised how much my father was doing for me. I became serious. I understood where my medication was coming from and how important it was for me to be regular. Being a 15-year old and a 30-year old are two different things.

Today I know I have given my father great joy by giving him grandchildren. Yes, I got married because my family wanted me to settle down. Now as a husband and father, all the more reason I have to look after myself na?

#WCMLDay17 #TodayTogether

Today, together we are treated, Tomorrow we need cure!

WORLD CML DAY 9/22

Today, Together

BECAUSE OF YOUR CARE, CHRONIC MYELOID LEUKEMIA IS NOT A DEATH SENTENCE BUT A CHALLENGE THAT WE CAN OVERCOME TOGETHER.

KEEP SHARING YOUR KNOWLEDGE, KEEP LISTENING, KEEP HELPING.

The Max Foundation
www.themaxfoundation.org

TEL: 91 (22) 6889 3320/31
FAX: 91 (22) 6889 3327 / 3328/29
WEB: www.themaxfoundation.org
E-MAIL: maxindia@themaxfoundation.org

To mark **World CML Day 2017**, The Max Foundation team in India and South Asia along with the Patient Support Groups in the region: **Friends of Max (India)**, **Blood Cancer Society Nepal**, **Children Cancer Foundation (Nepal)**, **Kiran (Pakistan)**, **CML Collectives (Sri Lanka)** and **Bangladesh CML Supporting Group**, rolled out events in various cities.

This year's motto was *"Today, together we are treated, Tomorrow we need cure"*. The campaign focused on being together and

Today, together we are treated, Tomorrow we need cure!

WORLD CML DAY 9/22

Today, Together

BECAUSE OF YOUR CARE, CHRONIC MYELOID LEUKEMIA IS NOT A DEATH SENTENCE BUT A CHALLENGE THAT WE CAN OVERCOME TOGETHER.

KEEP SHARING YOUR KNOWLEDGE, KEEP LISTENING, KEEP HELPING.

The Max Foundation
www.themaxfoundation.org

TEL: 91 (22) 6889 3320/31
FAX: 91 (22) 6889 3327 / 3328/29
WEB: www.themaxfoundation.org
E-MAIL: maxindia@themaxfoundation.org

united in this journey. The Max Foundation team along with Friends of Max in India conducted meetings in various parts of the country on 22nd Sept 2017. Specially created and individualized CML Day Today Together posters were presented to physicians acknowledging their support. The events also featured cakes with CML Day and PCR themes. This year being the 20th Anniversary of Max - the team tied special Max blue ribbons as a symbol of celebrating life.

Today, together we are treated, Tomorrow we need cure!

WORLD CML DAY 9/22

Today, Together

BECAUSE OF YOUR CARE, CHRONIC MYELOID LEUKEMIA IS NOT A DEATH SENTENCE BUT A CHALLENGE THAT WE CAN OVERCOME TOGETHER.

KEEP SHARING YOUR KNOWLEDGE, KEEP LISTENING, KEEP HELPING.

The Max Foundation
www.themaxfoundation.org

TEL: 91 (22) 6889 3320/31
FAX: 91 (22) 6889 3327 / 3328/29
WEB: www.themaxfoundation.org
E-MAIL: maxindia@themaxfoundation.org

In Mumbai, Hyderabad, Chandigarh, Coimbatore and Bhopal teams hosted full-day events. In Chandigarh a special Know Your CML interactive Quiz was conducted for participants. A session on "Movement Therapy" which focused on supporting intellectual and emotional functions of the person, was also held. Elsewhere too, in Nepal, Sri Lanka and Pakistan World CML Day was observed with physician partners and patients in attendance.

ROLL OF HONOUR : CFC Adda hosts in 2017

Friends, well-wishers, volunteers, strangers and corporates have been willing Chai for Cancer Adda hosts, again, this year. A mention of this year's hosts (so far) reads like a Roll of Honour but cannot capture the myriad of emotions and the sense of satisfaction we feel when Adda succeeds Adda.

Every voice of support reinforces our commitment to the cause. Every rupee donated helps a patient on his brave, yet arduous journey.

- Mahotsav Entertainment, Mumbai
- D Y Patil University, Navi Mumbai
- IDEAL, Ahmedabad
- Nidhi Chawla Silver Talkies, Bangalore
- Mettler-Toledo India Pvt Ltd, Mumbai
- Manish Mandhana Retail Ventures Ltd, Mumbai
- Tata Memorial Hospital, Mumbai
- Red FM, Mumbai
- Tata Medical Center, Kolkata
- Victoria Gardens, Kolkata
- Alakta Kar, Thane
- Rajiv Gandhi Cancer Institute & Research Centre, Delhi
- Lodhi Gardens, Delhi
- Niraj Soneji High On Tea, Mumbai
- Shalini H Pillay, Chennai
- Meghnaa Dixith, Mumbai
- Bobbie Vijayakkar, Thane
- Jayanth Jayaprakash India To Excellence 2020
- Dilip Tikle at Ganesh Utsav, Pune
- Advanced Technologies, Thane
- Thirupati and Kothai, Coimbatore
- Reshma Krishnamurthy, Bangalore
- Viji Venkatesh, Thane
- FOM Pranay Ranjan, Bangalore
- FOM, Pune
- FOM Karthikeyan, Coimbatore
- FOM & Sanjeev Jha Bokaro, Muzzafarpur
- FOM Pramod John George, Kalyan
- FOM Rishi Ranchi, Jharkhand
- FOM at Indo American Hospital & KBR Park & Aparna Sarovar Hsg Society, Hyderabad
- FOM Manoj Dhanotia, Indore
- FOM & Sahayta Renu Saigal, Chandigarh





Patient Support Group Meetings Jul - Sept 2017



City	Date
Mumbai	8 July
GIST Awareness Day Meeting	
Hyderabad	22 July
GIST Meet	
Indore	27 Aug
CML & GIST Patient Support Group Meet	
Coimbatore	22 Sept
CML Day Meet	
Chandigarh	22 Sept
CML Day Meet	
Hyderabad	22 Sept
CML Day Meet	
Mumbai	22 Sept
CML Day Meet	
Bhopal	22 Sept
CML Day Meet	

Medical Page

Excerpts from **What is My PCR ?** FAQs written by Michael J Mauro, MD, Leader Myeloproliferative Disorders Program Memorial Sloan Kettering Cancer Center. Content compiled by The Max Foundation

What is PCR?

PCR stands for 'polymerase chain reaction'. It is a diagnostic and monitoring tool used in CML to measure the response to treatment. It is not only used in CML; PCR is also used in other conditions and is generally one of the most sensitive ways to 'detect' something; for example BCR-ABL can be detected in a person with CML, anthrax on a mailed letter, or evidence of a specific virus in a person after bone marrow transplant.

Why should I know my PCR level?

Every time the PCR is run the value is important and conveniently can be compared to prior values. 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. PCR is often said to measure the residual (remaining) disease as it can detect very small levels of BCR-ABL 'blueprints'.

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 (and a lot easier to get)!

Why is PCR important in the management of CML treatment?

PCR is a crucial tool in CML for a number of reasons. 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.

For private circulation only

Acknowledgements: Cover painting Sanjay Kapoor

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

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