



NEWSLETTER

Friends of Max

(April - June 2017)



AMMA SPEAKS

The March of Unsung Heroes

We've completed one year of this newsletter (since April 2016). Sharing stories and information has been absorbing and gratifying. At another level however, this newsletter has been a vehicle to pay tribute to those coping with change and making the best of the situation they find themselves in.

Patients are unsung heroes whose lives are paradoxically made doubly heroic by adverse circumstances. The sudden and recent passing of FOM Hira Goma drew to a close a life lived by a simple mortal who stayed strong till the end. In a sense, we are all survivors in a sea of change. Which way the winds of chance blow dictate the course we must take - as long as we are prepared to take on new challenges, nothing else matters.

Many years ago, the idea of "Chai for Cancer" sprang from the urge to 'create' something 'normal' in the midst of the chaos that I saw in the minds and hearts of those whose lives were cruelly disrupted by the disease. We are now well into our fourth fundraising season. I marvel at new supporters and well-wishers emerging from all corners of the country.

Chai for Cancer's simplicity ensures its longevity and acceptance among a growing community of CFC hosts.

- Viji Venkatesh

CML HORIZONS 2017

Trustee Pramod John George represented Friends of Max at the advocacy & medical sessions at CML Horizons in Frankfurt (Germany) 26-28 May 2017.

The CML Advocates Network is an active network specifically for leaders of **Chronic Myeloid Leukemia (CML)** patient groups, connecting **114 patient organisations in 85 countries** on all continents. Its aim is to facilitate and support best practice sharing among patient advocates across the world.

Sudha Samineni Programme Officer The Max Foundation South India (seated second from right, foreground in photo below) represented The Max Foundation (South Asia) at the Meet.



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True Exemplars

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

APRIL:



Karan Vyas
from Ahmedabad,
Gujarat: charismatic,
steely-nerved and a
highly-skilled shooter

MAY:



Sanjeev Jha
from Bokaro,
Jharkhand: hard-
working, persuasive
and a staunch
advocate

JUNE:



Sangeetha Param
from Bangalore,
Karnataka: assured
young professional,
author and an active
volunteer and caregiver

Our Chai for Cancer journey since 2014 in pictures

Chai for Cancer is now the bedrock of our fundraiser and advocacy efforts, sustaining our efforts to meet and provide emotional and practical support to as many CML & GIST patients as possible all over India. A look at our journey since 2014 - in photos.



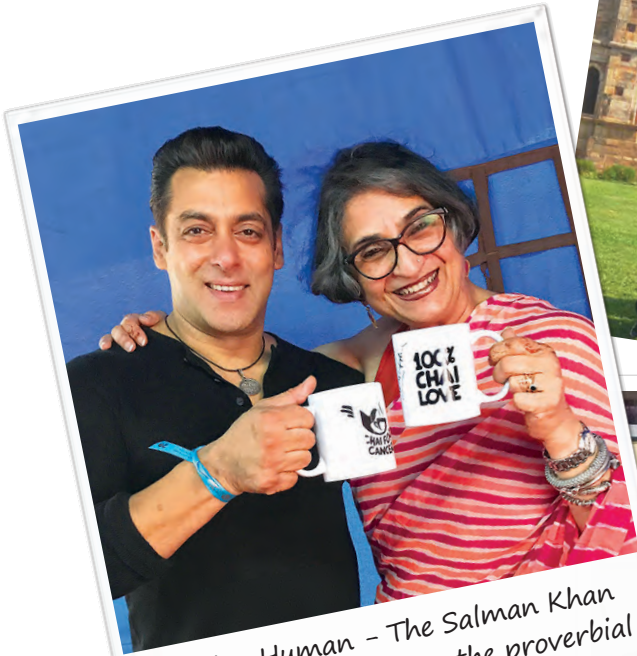
Raise that Cup - Drink to a Cause



Lodhi Gardens: An iconic venue is fast-becoming a favourite Adda venue



First Among Equals: We owe a huge Thank You to all our supporters like '100 Saree Pact' founder Anju Kadam



Being Human - The Salman Khan Foundation has been the proverbial Rock of Gibraltar for our cause



Small towns with large hearts: Ranchi recently hosted yet another Adda



Unstinting support of physicians like Dr Reena Nair of TMC Kolkata



Drawing youngsters into the crusade: first donor at Lodhi Gardens



Society Tea our gracious partners for every season



FOM Trustee Param at an Adda during CML Horizons in Slovenia



Volunteers at an Adda at Tata Medical Center Kolkata



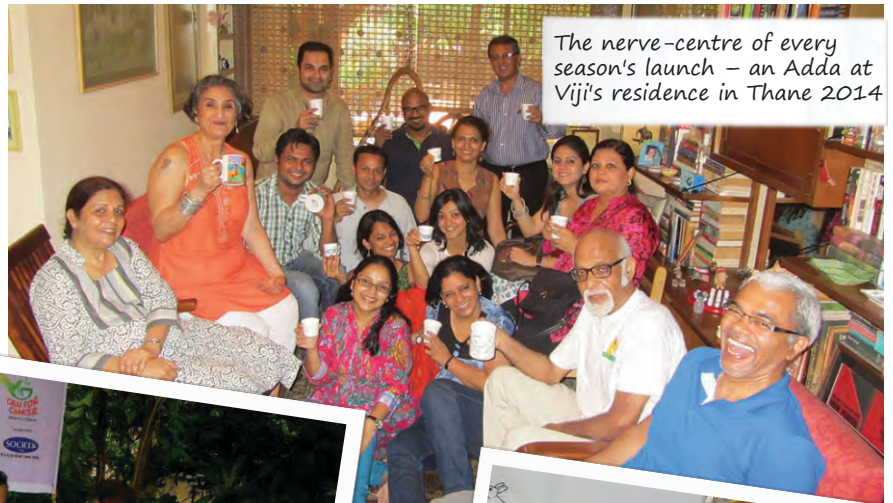
Premier hospitals, like Rajiv Gandhi Cancer Institute & Research Centre in Delhi, have consistently supported us



Vizag 2014 at Sandhya Godey's - an Adda is measurable by its heart



Carl Gawli's bikers group plays its part every season



The nerve-centre of every season's launch - an Adda at Viji's residence in Thane 2014



The 100 Saree Pacters' support is an enduring feature



FOM volunteers are key to sustaining the cause



The Mandhana Retail Ventures team have been extremely supportive



Catch Them Young: Getting the message across early at Alaknanda Society Nerul during a recent Adda



D Y Patil University School Of Hospitality & Tourism Studies hosted its first ever Chai Adda on its Navi Mumbai campus



The Vijayakars of Thane were at their creative best during an Adda



Family and friends form the kernel of the Adda season: advocacy



93.5 Red FM, our Radio Partners, are active and wholehearted supporters eg. at Victoria Memorial Gardens, Kolkata



Patient Support Group Meetings Apr-Jun 2017



City	Date
Patna	2 April
<i>Bihar Regional Meet</i>	
Pune	9 April
<i>Pune Patient Support Group Meet</i>	
Coimbatore	21 April
<i>Coimbatore Meet</i>	
Dhaka	29 April
<i>Volunteer Training Workshop</i>	
Mumbai	7 May
<i>Mumbai Patient Support Group Meet</i>	

Medical Page

Excerpts from **50 FAQ: Frequently Asked Questions on CML** (compiled for Friends of Max by Prof M B Agarwal, MD, Dept of Haematology, Bombay Hospital, Mumbai)

Can I be cured of CML by drug therapy?

Usually Glivec therapy does not cure CML. Most of the patients do very well but have to take Glivec daily probably lifelong. As of today it is difficult to visualize that someone can be cured of CML by drug therapy.

If not drug therapy can I be cured by any other technique?

Yes. One such modality of treatment which can cure a patient of CML is bone marrow transplantation (BMT)

What is bone marrow transplantation?

BMT is a procedure of replacing the abnormal stem cells of the cancer stem cells in the bone marrow with healthy stem cells. This was a popular and curative treatment for CML prior to availability of Glivec. In BMT healthy stem cells are obtained from a donor and infused in the patient's body. Before this is done the patient's own diseased, abnormal and cancerous stem cells have to be destroyed by chemotherapy and/or radiotherapy.

Can anyone donate a marrow for me?

No. Marrow has to be obtained from a donor whose immune system is similar to that of the patient. Medically it is called HLA (Human Leukocyte Antigen) typing. This is a special test very different from the blood group. Both patient's blood sample and the donor blood sample are tested by a technique called "tissue typing". This is also a PCR based test. Chance of getting a matched donor is highest from your siblings ie your own brothers and sisters. In some families if there is consanguinity (ie when parents are related to each other or belong to the same family), even other members may get matched. In the Western world there is bone marrow registry. Millions of people are tissue typed and their data is stored in the registry. This allows you to pick up a donor who matches with you although he is not related to you. It is difficult and expensive to maintain such a registry and hence in India the registries are few and contain data from limited number of donors. Hence to get an unrelated donor matched with you is a rarity.

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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