



NEWSLETTER

Friends of Max

(January - March 2017)



AMMA SPEAKS

Looking back at the last 12 months makes me realise how we have coped and grown in spite of setbacks - the foremost being the ruling that Glivec will no longer be granted Customs Duty waiver - and the considerable time invested in meeting various Govt officials to convince them to change their minds. We continue to hunt for ways to extend our reach by supporting the extremely poor who require BCR-ABL tests (a monitoring test) and stress the importance of compliance, monitoring and sharing information. In this issue we also feature FOM Volunteers who have done us proud as advocates and role models. On the Chai for Cancer fundraiser front its amazing how new well-wishers and supporters have emerged through the power of word-of-mouth. Strangers turn into life-long friends and well-wishers in a matter of hours. It is testimony to the fact that what we are doing is right. It is what keeps us going against the odds.

- Viji Venkatesh

FEATURE STORY: KARAN VYAS



Nerves of Steel

His youth belies nerves of steel and a heart of gold. Fourteen years ago, in 2003, at the age of nine, he was told he had CML. Fresh-faced Karan Vyas has not only been living with CML for over a decade but has graduated as a Mechanical Engineer from Sigma Institute of Technology Vadodara in 2016 and made incredible strides in the sport of rifle shooting - 50 Metres and 10 Metres ("I was myself surprised by my hidden talent", he says). His skills have taken him from district level competitions to the dizzy rank of 54 in the latest All-India National Shooting Championships.



This year he has qualified for the India Shooting Team trials where a Top-8 ranking will pitchfork the modest youngster from Vadodara into the India team for future World Cups. He sets his sights high: his goal is to make India proud and win a gold medal in the 2020 Tokyo Olympics.

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Throughout his journey, he says with disarming candour, "I never remembered that I have blood cancer, i.e. CML. Thank you to the Max Foundation and the Friends of Max family who are connected directly and indirectly to my life".

Death Be Not Proud



The young man who battled CML with dignity. Whose message resonates till today :
Maximiliano (Max) M. Rivarola
 19 Oct 1973 - 9 March 1991

V Care Victor Award

Our very own **Suresh Pawar**, a stellar long-term FOM Volunteer, received the prestigious **V Care Victor Award** from **Dr Anil D'Cruz**, Director **Tata Memorial Hospital** at their *23rd Cancer Survivor's Day ...A man who always does us proud.*



Dr B C Roy Award



FOM's Medical Advisory Board member **Dr Raghunandharao Digumarti** has done us proud by being awarded the **Dr B C Roy National Award 2016**.

True Exemplars

Every month we choose a Volunteer from the Friends of Max fold; people who have selflessly devoted their time to others while coping with adversity in their own lives. They are people whose lives are an example for others to draw inspiration from: **Shajahan Naduvattam** (January), **J P Tiwari** (February) and **Vikramaditya Agrawal** (March)

JANUARY: Shajahan Naduvattam

Shajahan Naduvattam is not only a key member of Friends of Max Calicut (Kerala Chapter) but also a senior member of Pratheeksha, a patient support organization for cancer patients which he joined as a volunteer 12 years ago. His deep sense of involvement in social causes began as a youngster.



Shajahan and his wife Mumthaz

FEBRUARY: J P Tiwari

J P Tiwari is a person capable of spontaneous acts of charity, exemplified by the all-round support he mounted for a 30-year old stranger stricken by cancer: Sushma Singh, whose husband, a daily wage earner, was unable to fund her treatment. He is the founder of an NGO in Bhopal - Jijivisha ("Will to Live") counselling all cancer patients and is also a regular host of our fundraiser "Chai for Cancer Addas"



J P Tiwari (left)

MARCH: Vikramaditya Agrawal

Vikramaditya Agrawal decided to forgo a career as a Chartered Accountant when he was told that he had CML. Instead he decided to dedicate his energies to health and fitness and stress the importance of nutrition in life. He is associated with Herbalife Nutrition as a Wellness Coach. In Nov 2016 he was felicitated with the Nargis Dutt Award at the Annual Awards ceremony of "Helping Hand 4 Cancer Care" Foundation.



Vikramaditya Agrawal (right)

Another Chai for Cancer season beckons

In the months leading up to the new Chai for Cancer season (Sunday 14 May is the launch date for the 4th fundraiser season) donors have come forward from unexpected quarters: School Of Hospitality & Tourism Studies- D Y Patil University Navi Mumbai, IDEAL (Institute of Design Expression Art & Learning) in Ahmedabad, Mahotsav Entertainment in Mumbai, Silver Talkies & Red Fork in Bangalore, Mahotsav Entertainment & Mettler-Toledo in Mumbai

Donate today's Chai for a Cause

14th May 2017
Chai for Cancer
www.chaiforcancer.org

Save the date

14th May 2017
 Chai for Cancer
 Now in its 4th year
www.chaiforcancer.org

Drink to a Cause
Chai for Cancer
Donate online instantly
 Visit
www.chaiforcancer.org

Chai for Cancer
Raise your Cup & Drink to a Cause
www.chaiforcancer.org

4th
 Now in its fourth year
Chai for Cancer 2017
 Come raise your cup
 Drink to a Cause
www.chaiforcancer.org

World Cancer Day 4 Feb We Can, I Can



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)

What are symptoms of CML?

CML does not have any symptoms as it develops slowly. Tiredness, weight loss, excessive sweating, fullness in the left part of the stomach, discomfort or lump in the same region and feverish feeling may occur. These symptoms are very common while CML is rare. Once the disease is advanced (e.g. after a few years into blastic phase) there can be anemia (lack of blood) leading to pale appearance, bruises on the surface of the skin due to bleeding, infection leading to fever and development of glands in the neck or at other areas (lymphadenopathy)

Does CML have stages?

CML has phases i.e. chronic phase, accelerated phase and blast phase. These phases may loosely be called stage I, II and III or early, intermediate and late. The disease remains stable for years during which there are not many complaints and one can work normally. It is during this phase that the treatment is started usually in the form of oral pills (Glivec-Imatinib) taken daily. No one requires hospitalization in the Chronic Phase. During this phase there are very few or no blast cells in the blood or marrow. The next phase is the Accelerated phase which can sometimes develop very rapidly. In this phase there are more blasts in the blood or marrow. The patient may also develop fever (infection) or bleeding. Spleen becomes larger and may stop responding to treatment. Subsequently the Blast Phase develops. This is like acute

leukemia. Here the number of blasts in the blood or marrow is maximum. Patient becomes very weak and often requires blood transfusion and even hospitalization.

Are there any serious side-effects of Glivec?

Although rare, the occasional patient can get a serious side-effect of Glivec. In the first few months some patients have significant drops in their blood cell counts i.e. white cells, platelets and haemoglobin (Hb). To detect this early, the physician usually orders blood counts frequently in a patient who has been newly put on Glivec therapy. This is important and must not be avoided.

If the white cell counts are very low the Glivec dose is reduced to 300 mg/day. There is an injection called G-CSF (Granulocyte-colony stimulating factor) which can be taken under the skin to stimulate white cell production. Similarly if Hb counts drop to a very low level, i.e. below 7 g/dl and the patient is feeling weak, he can be given another injection called Erythropoietin or EPO, once again, under the skin. Lastly if the platelets drop to a serious level (below 50,000/cmm) one often stops Glivec as there is no drug to push the platelet (count) up. Platelet transfusion is another way to handle this situation.

Does Glivec affect vital organs e.g. liver?

Yes. Occasionally patients have developed jaundice secondary to Glivec-induced damage to the liver. This is rare. Sometimes it has happened if patient takes paracetamol (crocin, metacin) to control fever as Glivec and paracetamol interact. Majority of such patients are taken off Glivec for a short period and the treatment can be reintroduced after a few

weeks. Some patients need a small dose of steroids to take care of this side-effect.

Patient Support Group Meetings Jan-Mar 2017

City	Date
Silchar	28 Jan
<i>Volunteer Training Workshops</i>	
Silchar	29 Jan
<i>Volunteer Training Workshops</i>	
Silchar	30 Jan
<i>Volunteer Training Workshops</i>	
Mumbai	18 Feb
<i>GIST Patient Support Group Meeting</i>	
Bangalore	25 Feb
<i>Bangalore Patient Support Group Meeting</i>	

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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

