



# NEWSLETTER

## Friends of Max

(January - March 2018)



IN THIS ISSUE: The Cancer Narrative

- 01 Embracing Our Mortality
- 02 On Coping With The Camel In The Living Room
- 03 CML - A Boon In Disguise
- 04 Chai for Cancer is in its 5th year
- 04 Amma Speaks

### TEDx Bangalore



#### A Dialogue on Embracing our Mortality - Viji Venkatesh in conversation with Kerul Patel (FOM Volunteer) at TEDx Bangalore on 25 Feb 2018

**Viji V** : Kerul walked in to my office the day he was diagnosed with leukaemia. He was 32... I'm going to put some tough questions to you. Five stages of grief you have to go through: Denial, Anger, Bargaining, Depression, Acceptance. How did the journey happen for you?

**Kerul P** : I was diagnosed in Sept 2003. Months prior to that I led a normal life, was well settled in business ... local gym to keep fit. Then (came) dengue virus... notorious in Mumbai... doctors asked for a blood test. While at Bhatia Hospital ICU the news broke that I had leukaemia. Not until I went back home that the news knocked the daylight out of me. I was in depression, I started bargaining... Anger stayed with me a very long time

**Viji V** : Your life has been punctuated by periodic episodes of hospitalisation... invasive intervention... life was turned on its head, what kept you going? Your values, goals - You must have had to make a lot of changes

**Kerul P** : As soon as I was diagnosed my first priority was to survive. Doctors informed me that if you're fit you'll be able to fight leukaemia better, probably live longer. I took that literally. Gymming, spending time with family and friends, business came third.

**Viji V** : (It's) a crusade, not fight or wage war, a long-term commitment to restoring the loss of (a) previous life. What was the turning point - when you turned to karate and used that as a big resource in your campaign?

**Kerul P** : The turning point ironically was in 2008, five years after I was diagnosed. I was at my lowest after a string of infections, in and out of hospital. My mind was at a certain place, my body was lagging behind; it was a very confusing time. I bargained with myself. If I bridge this gap, I'd start feeling better. I started training in karate. I went through the cycle of improvement, my mental strength improved, I started sleeping better.

For every cancer patient, (a certain) toxicity builds up in his head... when I trained my mind was absolutely clear. In 2010 - I cleared my black belt, in 2012 I went on to clear my 2nd degree (my dream in college), in 2015 I got my third degree. Basically I just felt good.

**Viji V** : Your karate and your karate group. Each cancer patient

struggles to find his own support system / relationships, to come to terms. Your son was part of your support system

**Kerul P** : I had a very strong support system: family, parents, wife, brothers, friends laugh riot - laughter is the best medicine. My son was 18 months when I was diagnosed. In the first few years he was too young, so my wife and I spoke freely about cancer. As he got older we knew it was having an effect on him. Once he drew a picture of me in a hospital; when his teacher asked him what papa does - he said "nothing, he's at home, chilling".

I asked him do you know what cancer is? He nodded in a way that he knew what it was all about - he's an avid cricketer himself. "Yuvraj Singh has cancer, he plays cricket. You have cancer and train karate".

**Viji V** : Your family... all have been a support to you

**Kerul P** : Viji, you've been an important part of my life, a sounding board, you had a good effect on me, gave me the strength of character to go on

**Viji V** : Your burden of cancer... the finality, the mortality, but familiarity makes a difference

**Kerul P** : I'm not dying of cancer, I'm living with it. The probability of dying of cancer is high - that's the burden I carry. I live each day... I try to maximise...

**Viji V** : Do you have time to make a bucket list?

**Kerul P** : Watch my son blow out 21 candles, wife likes to travel, I'd like to visit as many countries... visit my alma mater in the US. At 46, I have a sense of giving back and would like to train kids at karate and make a champion of one kid.

**Viji V** : How would you like to be remembered?

**Kerul P** : As a crazy guy who took up karate after cancer and went all the way. Who kept things simple in life and put a smile on people's faces

**Viji V** : I'd like to dedicate this verse by Jalluddin

Maulana Rumi to Kerul : *"This place is a dream | Only a sleeper considers it real | And then death | Death comes like dawn | And you wake up laughing at what you thought was your grief"*

Listen to the full conversation:

<https://www.youtube.com/watch?v=VJw5H4wNpzw>

## On Coping With The Camel In The Living Room

by Dr Jude W Vaz



**There seemed something cruel about the abruptness of it all...**

After having spent a lovely vacation in Lucknow with the family, we took a long train journey back to Mumbai. I had contracted a rather nasty respiratory infection which was exacerbated by the prevailing cold weather in the north. I hadn't gone even after two courses of rather potent antibiotics and I was still troubled by a hacking cough some weeks later. Finally I decided to have a routine check-up and ran some blood tests.

The resultant CBC report was the stuff of which shock and awe is made of: my white cell count had crossed 130,000 per micro litre. Moreover, the blood test was suggestive of chronic myeloid leukaemia. I was admitted to hospital and a bone marrow aspiration confirmed the dreaded diagnosis of Chronic Myelogenous Leukaemia (CML). I guess I was overwhelmed but not shaken by the gravity of this personal catastrophe. Faced with a diagnosis of a deadly form of blood cancer I figured that I had only a few months to live and I had visions of being violently ill.

A dear friend and fellow pathologist steered me in the direction of a physician, a medical oncologist who was well-versed in the treatment of leukaemia. He was a genial man with a kindly smile and a charming Assamese accent who offered

advice and support for dealing with the condition. He seemed quite sanguine in his approach and when I asked him about the prognosis with a tentative query, "How long do I have to live?" he answered, with a twinkle in his eye, "Wait and see. This is a disorder which continues to offer hope and pose challenges. If the cytogenetic analysis shows that you are Philadelphia positive, I have something up my sleeve!" He assumed that being a pathologist I was cognizant of the Philadelphia chromosome, which of course I was. That evening I retreated to a nearby seaside promenade to be alone, to absorb the enormity of the diagnosis, and to watch the sunset. It was spectacular - clouds of salmon pink and ecclesiastical purple with myriad shades of interspersed crimson made the sky appear like a surrealist canvas as the golden orb descended towards the waiting horizon. It felt great to be alive and experience the salt spray of the sea breeze in my face.

Strangely in the face of this monstrous calamity that had struck me like a bolt from the blue I realized that I had come to personify Albert Camus' quote: "In the depths of winter I finally learned there was in me an invincible summer." So much to do, so little done! Strange thoughts raced through the troubled recesses of my mind. Being the same age as Tony Blair, Orhan Pamuk, Vladimir Putin and Mel Gibson (give or take a few

weeks) places unwarranted demands on one's ordinary existence. Churned by my recent indisposition the ghosts had returned to haunt me. Why had I not achieved any significant accolade yet? I always believed that somehow or other I would be famous, and now, with the finality of a sledgehammer's stroke I realized that well... this was it: the last act of a mundane life and then it was curtains for me. I would not be achieving any special honour after all. Like that memorable line from an old John Lennon song "Life is what happens to you while you're busy making other plans". It dawned on me then that most people die with much of their music still trapped inside them.

I thought about all the places I wished to travel to but would never visit: the commanding Andean heights of Machu Picchu in distant Peru, the unblemished Wordsworthian countryside of England's Lake District, Sikkim, that Shangri-La in the eastern Himalayas, and Egypt, once more the eternal encore. I thought of the books I always intended to read but hadn't yet: *The Catcher in the Rye*, *To Kill a Mockingbird*, Emily Bronte's *Wuthering Heights*, Amitav Ghosh's *The Calcutta Chromosome*, Somerset Maugham's *Of Human Bondage*, Thomas Hardy, Oscar Wilde, Katherine Mansfield .... The unread list went on and on.

**If God puts you to it, He sees you through it.**

The Camel ("CML") had strode into my well-ordered life and I had resolved to do battle with "the slings and arrows of outrageous fortune". If CML needed a sobriquet what could be more appropriate than the Camel?! This great, prodigious unwieldy beast had cantered into the living room of my existence, uninvited, like a biblical mirage portending rough sailing ahead. The challenge lay in the fact that I had to rise above it, which I did, notwithstanding the fact that the camel is a tall animal!

The signs of chronic myeloid leukaemia are sometimes discovered unintentionally during a blood test for some unrelated condition.

*Continue reading at:*

<http://friendsofmax.info/home/on-coping-with-the-camel-in-the-living-room/>

## CML - A Boon In Disguise

by Pramod George

Dengue fever (caused by infected mosquitoes) was knocking at various doors in and around town. There was a suspected case in my building too. It was a Thursday and my daughter who was 4 and a half at that time was at home due to a school holiday. She called to tell me that a doctor had come to our house to check if anybody had fever. I worked in the marketing department of Indian Express Newspapers (Mumbai) Ltd at the time. The doctor's visit prompted me to visit our own doctor, a close family friend. He advised me to do blood and urine tests.

That evening when I took the reports to the doctor, he was confused, as I did not have any symptoms for the diagnosis, which the reports showed. The WBC was showing 26100 and there were some more ups and downs in the report. He advised some medicines and told me to take a blood test after two days from a different clinic as he suspected that this report was faulty. The following report showed WBC at 29900. He recommended some medicines for a week and told me that we would have to do further studies if the WBC count did not come down. After a week, the WBC counts were showing 28300 and he told me to go for further information to Dr M B Aggarwal. I asked him what was in his mind. Something in him prompted him to tell me that he suspected that it was a blood disorder and looked like leukemia. (Later he got scolded by his wife for discussing it with me without confirmation). I did not discuss it with anyone then. My son had just been born on August 1 so we were all very excited and my tests took a backseat. Then my wife suggested that I should go for a second opinion and she fixed an appointment with a doctor in her hospital where she worked as a nurse. After a thorough examination, that doctor too felt confused as there were no symptoms that supported the reports. Call it a coincidence or destiny, but he also recommended Dr M B Aggarwal. I fixed an appointment and met Dr. Aggarwal on August 8. After looking at the case, he asked me if I was prepared for



more tests. A bone marrow biopsy was conducted. When I collected the reports and took them to Dr Aggarwal he congratulated me on having a good type of cancer. By that he meant a cancer for which medicine was available. I was diagnosed with CML. He recommended VEENAT. His reports were very systematic with a list of suppliers that would help me get the medicine at a reduced price. I asked him if there was any alternative medicine. He gave me a book which explained all technical terms related to CML like PH chromosome ... He said this book was from Novartis who were the original manufacturers and told me the mind-boggling price of the same. I liked what was written on the second last page of the book. It said "Laughter is the Best Medicine" and I practice that whenever possible, I broke the news at home that night. They were all set to cry. I told them

that I had overcome the bad part of the news the moment the doctor had congratulated me. I asked them to be strong for me so that I would cope. And since then they haven't cried about it in front of me although they did shed many a tear behind my back. I shared the news with my seniors and my team members in office who were also very shocked. The only reason I shared it with them was because I did not want anyone to hear it from outside and gossip behind me or pity me. Whatever illness I had was a gift given by God to me, similar to my life. I did not come into this world by choice so I would not leave this world by choice either. Like every hair on my head is numbered in His book, so is my every day. I took VEENAT for around six months. I had a lot of side effects - the worst were the severe cramps that I used to get especially in the middle of the night. It was so bad that I used to yell. I felt like someone was slicing off my calf muscles. Once, while discussing some financial issues with Dr Aggarwal, he asked me if I was getting any support for my medicines from my place of work.

When I said no, he asked me to get my salary certificate with a letter from my company, that they weren't supporting me. He said with these two letters, along with my photograph and a few other papers, I would be able to get the original medicine, GLIVEC, free from Novartis through The Max Foundation. I reconfirmed this with him a couple of times before getting the papers ready. I had to go to Max Foundation only once. I met Ayesha on my visit there and soon an e-mail came as a blessing, stating their approval. If getting diagnosed for CML was God's first gift, this was the second gift.



Continue reading at:

<http://friendsofmax.info/home/c-m-l-comes-calling/>

## Chai For Cancer - 2018

### Compassion. Support. Hope.

Weaving a network that CML and GIST patients and caregivers can rely upon while facing and managing a life-long condition.

In this the 5th year of Chai For Cancer - our advocacy and fund-raiser platform that attracts new well-wishers and donors each year - our designs give shape to our thoughts for those who have the right to live in dignity and hope.





2014-2018  
A Unique Campaign

---

FOUR YEARS.  
**150 ADDAS**  
**66 CITIES**  
**72000 CUPS**  
OF CHAI RAISED FOR A CAUSE.



## AMMA SPEAKS

*Of Tales Waiting To Be Told*

Two decades is a long time. I have been as close as possible to CML & GIST survivors for almost twenty years. Nearly 20000 of them are in India alone.

Their first response to the dreaded news is invariably traumatic. But shock, disbelief and fear is slowly replaced by adaptability and acceptance that is a salute to the human spirit. These people have to live their entire lives in the shadow of rare cancers. They lead two lives - one in public and often faceless; the other in private and invariably brave.

It is their private tales that need to be told because they are an inspiration to others. There is no limelight, no applause. On the contrary - they are often shunned by the ignorant. This makes it even more important to give them a platform to be heard. And if I can have succeeded in doing so as "an enabler" then it will be extremely satisfying.

This issue of Friends of Max Newsletter is dedicated to the stories that some of our patients have shared - of living with cancer.

- Viji Venkatesh



*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](mailto:friendsofmax@gmail.com)

**Website :** [www.friendsofmax.info](http://www.friendsofmax.info)

**Website :** [www.chaiforcancer.org](http://www.chaiforcancer.org)

**Facebook:**

[www.facebook.com/CMLGISTsupportgroup/](http://www.facebook.com/CMLGISTsupportgroup/)

[www.facebook.com/Chai-for-Cancer](http://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](http://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