

## A tribute to the FOM Patient Advocates



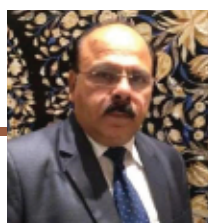
**Advocacy is an important tool that enables society to provide the practical support required to overcome issues related to health care and other socially relevant issues. Continuous and sustained efforts in this area result in a positive impact on the community as a whole. For us, in Friends of Max, timely and patient specific advocacy is directly responsible for the betterment and well-being of our cancer community.**

Our Advocate of the Month series features one member of Friends of Max every month. This is someone who is consistently working towards understanding the issues and concerns of the people in the group or in the cancer community at large and ensures support is provided to those who need it.

It is important to recognise such advocates and their efforts as it helps to boost the morale of fellow members and readers in general and inspires and encourages others to work with zeal and enthusiasm.

**FOM started this series of recognition in the year 2016 and till now more than 73 advocates have been recognised and their work appreciated and acknowledged.** This activity has helped to nurture the concept of advocacy in many more volunteers in different cities. It has also helped in changing the behaviour and attitude of people towards certain aspects of the management of the disease which are important and need to be discussed widely and openly within the community.

- Anil Nagpal,  
Trustee, Friends of Max.



## Amma Speaks

20 years and more of living with a life threatening and life limiting disease is no mean feat. Add to that being on lifelong treatment for that disease. In my two decades of working with The Max Foundation and the Novartis PAP for CML & GST I have been privy to the incredible manner in which some of the most extraordinary people have been doing exactly just that – living with cancer and on lifelong treatment; an endless journey. A journey that began in May 2002, for some of them even earlier – but for me with a handful of patients who were enrolled into the program at that time and before you knew it the count was in hundreds and then thousands. The Friends of Max then was the support group that was put together for all these patients and their families so that there could be a safe platform for them to share and learn from together. The most important lesson was how to navigate this unique path they were on.

Today we are the largest group of this kind with city chapters all over the country led by the most inspiring patient advocates and volunteers.

This newsletter is then dedicated to a few of these leaders (and let me assure you there are many more) who have turned their lives around after their diagnosis and living such exemplary lives one can only marvel at their strength and tenacity. They have not allowed their diagnosis to come in the way of their ambitions or life goals but rather they've let it fuel their aspirations while some have simply changed their goal posts and forged ahead. As one voice they have said their cancer has turned their life around and how!

As we come to the end of this year, I hope their stories can fuel our entry into the new year.

- Viji Venkatesh,  
Managing Trustee, Friends of Max and Region Head  
(India & South Asia), The Max Foundation

Sajeevan Parambath - **CALICUT**

Sandhya Godey - **HYDERABAD**

Sandeep Mahil - **CHANDIGARH**

Dishant Bhatt & Karan Vyas - **AHMEDABAD**  
(left to right)

Nitesh Verma - **PATNA**

Garima Jain - **MADHYA PRADESH**

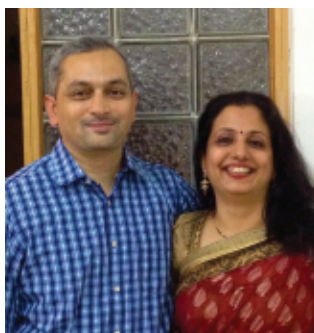
Pranay Ranjan - **BENGALURU**

Vinay Shukla - **MUMBAI**

Dhrubajyoti Kalita - **ASSAM**

Parmeswaran PS - **BENGALURU**

## In the Spotlight



### Rahul and Supriya Shinde

Rahul and Supriya Shinde are FOM City Chapter Leaders from Pune. They are regulars at the support group meetings not only in the city but our Mumbai meetings as well.

In 2022, they decided to start Atman Matrimonial to help cancer survivors find suitable life partners. *"We are seeking registrations from survivors who have fought their toughest battle and emerged successfully. We wish to be part of their personal journey of meeting and settling with a partner of their choice."* We cannot think of a better couple suited to lead this sensitive project.

Both Rahul and Supriya are excellent communicators and they project such positive and inclusive energies. FOM wishes them great success. This is the first support group of its kind where having and overcoming a medical condition sets the stage for a happy future.



### Dr Aditya Dhanawat

From a very young age, Aditya would accompany his father, Om- prakash Agarwal to FOM's support group meetings in Bhubaneswar. He would participate in workshops, write meet-

ing reports, and interact with patients on a personal level.

After completing his schooling, he decided to make a career in medicine and subsequently completed his MBBS from SCB Medical College, Cuttack and MD from Kalinga Institute of Medical Sciences, Bhubaneswar. Today, "Doctor" Aditya Dhanawat is pursuing a DM in Medical Oncology at Tata Memorial Centre, Mumbai.

He believes in the 3 As of healthcare – Availability, Accessibility and Affordability – and is committed to building a healthier society with the help of technology.



### Omprakash Agarwal

OP as he is known by all in FOM is our tireless advocate and patient leader from Odisha.

In his own words, he tells us how his CML changed him: *"I was diagnosed with*

*CML in July 2008. My life has been transformed by this event and the venturesome and dynamic Friends of Max who are determined to succeed against CML. Earlier, I used to take life easy and relax, not taking it seriously.*

*But after CML, it made me serious. Every morning is a new morning gifted by "GOD ALMIGHTY"*

*I finish all my work on the same day, and there is no pending work for the next day, because we might not see a new morning. But with meticulous planning for the next morning and the future I became ready for whatever flat ahead.*

*My doctor M.B. Agarwal, taught me one more thing: do not complain about your health. Instead, try to cope with any medical situation, be mentally strong, and take Glivec without fail. 100% compliance for 14 years.*

*In the past few years, my business has grown many fold: from a small trading unit in chemicals to real estate, and stock market trading.*

*I have become a physically fit and active person. I go hiking, play games and look forward to planning family vacations.*

*Difficult roads often lead to beautiful destinations. Don't let cancer define you, let it refine you."*



### Monika Ahuja

Monika Ahuja is one of FOM's vibrant City Chapter Leaders in Delhi.

She actively participates in the support group meetings and Chai for Cancer events organized in the city. An AML survivor herself, she has been

a part of every FOM event in the city since 2004 and has also hosted a Chai for Cancer Adda at her home in 2016. Earlier this year, she was crowned the "First Runner-Up" and "Ms. Personality" at the Miss India Cancer Warrior Pageant 2022.

Monika says, *"Winning the pageant has empowered me to win the hearts of the masses. Now when I talk to them, they really understand the challenges in the lives of a cancer patient. I want cancer patients to see the bright side of life and I want the masses to empathise with our needs."*



## In the Spotlight



### Vir Krishan Bhat

Vir Krishan Bhat, City Chapter Leader from Jammu and Kashmir was once an ordinary young man going about his simple life in idyllic Srinagar.

Then, in 1990, the hills became angry and unfortunate circumstances took the 25-year-old and his young family hundreds of miles away from home to Jammu. There, his restless impatience drove him to assist in the rehabilitation of other refugees, mainly school children.

In 2002 he was diagnosed with Chronic Myeloid Leukemia. Married and with an infant son, 37-year-old Vir Krishan Bhat's world had collapsed. He sold all his belongings but it was not enough. After two years he was hapless and helpless. Then, quite suddenly, his fortunes changed. In 2004, on the advice of Dr Suresh Advani, the eminent oncologist, he approached the Max Foundation, and he started taking Glivec through the access programme. Now he is an enthusiastic and active Friends of Max volunteer and plays a vital role as an advocate at every Max Foundation & Friends of Max event for patients and caregivers.

A family man to the core, he and his wife are proud that their son is now a young man on the threshold of a fine career in the navy having completed his studies at the Indian Naval Academy.



### Kartik Selvam

Kartik Selvam from Tirupur, Tamil Nadu is one of the youngest CML patients associated with FOM. Diagnosed in 2008 at just nine years of age,

Kartik found great adversaries lying in the path of his education. With

support for treatment from The Max Foundation, Kartik's mother worked hard to see him through high school and Kartik himself made great efforts to study well and gain admission to college for further studies. Kartik worked alongside his mother at a garment making factory and when during the pandemic, they both lost their jobs, he single-handedly supported the family by taking up all kinds of odd jobs.

Today Kartik has completed his bachelor's degree in Visual Communications and aspires to be a cinematographer.



### Ushakant Shah

Ushakant Bhai, as he is fondly called, hails from Gujarat.

As a Trustee of Friends of Max, he has brought his wide experience to bear on the Trust's multi-faceted advocacy and fundraiser activities all

over India. He also devotes considerable time to his own NGO in Ahmedabad - Karunakare - chiefly aimed at supporting poor cancer patients socially, emotionally, and financially.

The equations of his life changed after he saw less fortunate people than him suffering from cancer and the urge to do something for them laid the cornerstone for his Karunakare Foundation. His personal health has seen various ups and downs, but he continues to serve cancer patients with the same zeal. He is a survivor and an advocate and his guiding principle in life is to keep serving those diagnosed with Cancer in every facet of their life.



### Ashok Cashyap

Ashok Cashyap is our City Chapter Leader from Bengaluru. An acclaimed cinematographer by profession, he has made an indelible name for himself in the Kannada film industry since 1999,

when his movie "Upendra" launched him to fame.

In November 2022, Ashok was appointed "Chairman of Karnataka Film Academy" by the State Government. He will hold the post for a minimum of three years. Ashok's next big dream is to produce and direct a movie centred around the subject of cancer and contribute the entire profits to Friends of Max for the betterment of his fellow patients.

*"As a filmmaker, I feel this is the best way I can show my gratitude", he says.*

## Season 9 - Chai for Cancer



## Know the Max Team

Meet Urvashi Negi who is a Program Coordinator at The Max Foundation and works from the Max South Asia Office in Mumbai. She looks after patients in the Max Access Solutions Program in India from the state of Gujarat & Mumbai city.

Urvashi started her journey with the organization as a volunteer in 2018 and within months because of her diligent work and commitment was onboarded as Program Coordinator. In 2023, she will celebrate her milestone anniversary of five years.

In her own words, 'I have grown professionally and personally through all these years at The Max Foundation and thoroughly enjoy the time I spend with patients. I consider myself fortunate that I was given this opportunity and be a part of something so important and meaningful. The support FOM provides to its community is truly remarkable, to say the least. The warmth and apprecia-



**Urvashi Negi**

Program Coordinator, The Max Foundation

tion received from everyone in this inspirational group is what keeps me devoted and motivated'.

Urvashi is a go-getter and is always ready for new challenges. She has grown into an exemplary member of the team within a few years and we would like to thank her for her support and dedication.

## From the Physician's Desk

I have been associated with The Max Foundation since the inception of GIPAP (Glivec Patient Assistance Program) in India. The CEO of Max, Pat Garcia-Gonzalez, and the region head of South Asia, Viji Venkatesh are incredibly committed ladies and wonderful human beings and are really making a difference in the lives of these patients. I have no hesitation in putting on record that, as far as I am aware, this is the largest and most well-organized support program being conducted in India. And in addition to India, they work in many low-income countries also.

Friends of Max, the support group arm of The Max Foundation is the largest of its kind. The wonderful volunteers at FOM India are not only super competent workers and organizers but are great friends with the patient. They know



almost every patient by name, no mean feat, considering there are still more than 15,000 patients just in India!! And

now with the science and the concept of treatment free remission (TFR) gaining worldwide, the importance of personal interactions with every single patient becomes even more important. And that is where the volunteers of FOM come in.

There is still a long way to go because we can confidently claim that every patient of newly diagnosed CML will receive the standard of care treatment and we will continue to need the support and services of committed NGOs like the Friends of Max and The Max Foundation.

My best wishes to them, and I pray to God to give them strength to carry on with their mission!

- Dr. Hemant Malhotra  
Professor & Head, Department of Medical Oncology, Sriram Cancer Center, Mahatma Gandhi Medical College Hospital, Jaipur

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**Address :** Friends of Max, Secom Business Centre, A Block Basement, Shiv Sagar Estate, Dr A B Road, Worli, Mumbai 400018

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

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

**Email :** [friendsofmax@gmail.com](mailto:friendsofmax@gmail.com)

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**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