



**Vision**

- To ensure that every childhood cancer survivor finds his/ her way to celebrate life after winning their battle with cancer.
- To facilitate their life's journey on the correct path & in the right direction.

**Mission**

- Empowerment of young survivors
- Helping children with cancer undergoing treatment
- Social awareness and re-bonding with society

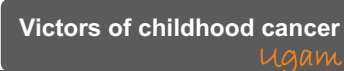
Donations are exempted from Income Tax under section 80 (G) of the Income Tax Act Cheques / DD should be drawn in favour of Indian Cancer Society, payable at Mumbai, with a covering letter stating that the donation is for UGAM.

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**Indian Cancer Society**

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DESIGNED BY: **DISPLAY HOUSE**  
EXHIBITIONS | EVENTS | RETAIL

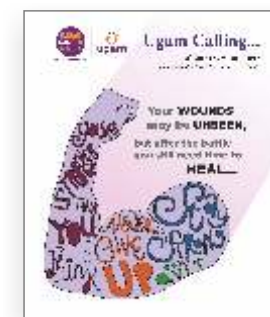
BACK



# Ugam Calling...

10<sup>th</sup> Anniversary Issue - 2019

*Together we can create miracles*



8<sup>th</sup> Anniversary



9<sup>th</sup> Anniversary



1<sup>st</sup> Anniversary



7<sup>th</sup> Anniversary



2<sup>nd</sup> Anniversary



6<sup>th</sup> Anniversary



3<sup>rd</sup> Anniversary



5<sup>th</sup> Anniversary



4<sup>th</sup> Anniversary

# Celebrating 10 years of Togetherness!

**Indian Cancer Society**

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Edited by: Dr. Purna Kurkure / Arun Kumar Nadar  
Illustration by: Shweta Chawre



FRONT





**Organizing Committee, UGAM Anniversary 2019**

**Organizing Chairperson**

Dr. Purna Kurkure

**Organizing Secretary**

Dr. Vandana Dhamankar , Col. Abdul Khader

**Joint Secretary**

Jaitri Mandal, Krishna Pandey

**Cultural Committee**

Mrs. Savita Goswami, Aishwarya,  
Sushant Bane, Subham, Preeti Phad

**Newsletter Committee**

Arun Kumar Nadar,  
Ekta Rawat

**Hospitality & Registration**

Bindu Dighe, Shekhar Jha,  
Sampada Sakre, Anita Gupta

**Fund Raising Committee**

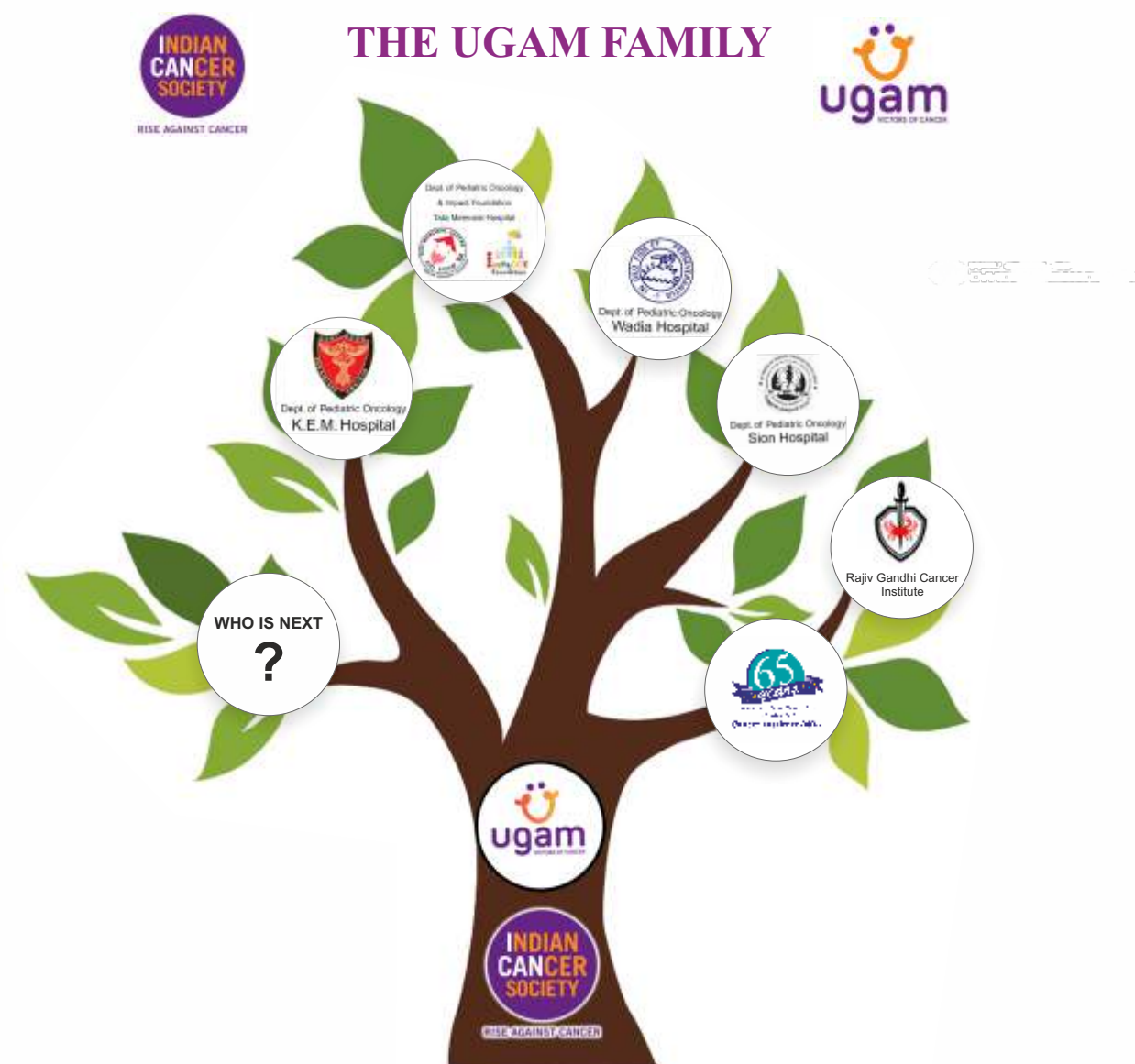
Narendra Shetty, Vanchinathan,  
Shahbaz

- We are grateful to board of trustees and the national managing committee of ICS for their unconditional love and support.
- We are grateful to all UGAM friends, donors and volunteers for their generous support and Display House for technical support.

Victors of childhood cancer  
ugam

**UGAM PROFILE**

Indian Cancer Society (ICS) was established in 1951 by Dr. D. J. Jussawalla and Mr. Naval Tata as India's first voluntary, non-profit, National Organization for Awareness, Detection, Cure and Survivorship of those affected with this disease. UGAM, Emotional support group of childhood cancer survivors, is the youngest unit of ICS under its survivorship program. UGAM means "To Rise", underscoring the determination of childhood cancer survivors, to rise above all obstacles in life & be VICTORS. UGAM was launched in 2009 on the first Sunday of June celebrated as Cancer Survivors Day across the world as a mark of celebration of life.



**WHAT WE DO?**

- Create awareness about curability of childhood cancers.
- Help childhood cancer survivors to begin new life after cancer and make them aware that there can be and there is "normal life" after winning the battle with cancer.
- Promote the importance of monitoring the late effects of cancer therapies.
- Advocate against discrimination in society to cancer survivors.
- Highlight the need of public support for the cause of Childhood cancer survivors.
- Monthly UGAM Meeting last Sunday of every month at ICS.

Victors of childhood cancer  
ugam





**Dr. Purna Kurkure**  
 Convener, Ugam  
 Trustee In charge,  
 Cancer Survivorship &  
 Rehabilitation Vertical  
 Indian Cancer Society.  
 Chairman, Clinical  
 Collegium Oncology  
 Services  
 Narayana Health  
 Group

Head, Division of Pediatric Oncology & BMT  
 SRCC Children's Hospital, Mumbai

**Welcome again to Grand venue, The Royal Opera House, courtesy, The Royal Family of Gondal & Management, for celebration of 10th Anniversary of Ugam !**

**I congratulate Ugam on completing 10 years of a successful & productive existence!**

It all started on 7th June 2009, first Sunday of June celebrated as Cancer Survivors Day across the world, when a small group of committed childhood cancer survivors came together with a focused vision of self-empowerment. Ugam was then born & formally launched under the survivorship banner of Indian Cancer Society (ICS). Coming together was just a beginning. However, staying & working together over a decade has led to many achievements such as participation in International Relay For Life, a franchised cancer awareness event of American Cancer Society, Mumbai Marathon, Awareness activities, sharing stories and giving hope to the children with cancer who are undergoing treatment. Ugam is getting opportunity to get engaged & work from a wider platform of Childhood Cancer International (CCI) as active member of the Asian network of survivors. Ugam members have been regularly awarded fellowships since 2013 to participate in Annual conference of CCI alongside the Annual conference of International Society of Pediatric Oncology (SIOP)

A decade has passed, & this is an opportune time to learn from yesterday, work for today & hope for tomorrow. Ugam needs to do introspection and scale up its activities in a more organized manner which will touch many more lives & improve the quality of life of survivors. A Childhood Cancer survivor is considered to be potentially cured 5 years from diagnosis. However, there is no one

better than you—the survivors to realize that follow up does not & should not end at 5yrs but continued for life long as per the medical requirement in ACT clinic for surveillance of late effects. The childhood cancer survivor can be considered as ideal candidate for availing health coverage which is currently denied by many insurance companies for the false fear of higher risk involved considering the past history of cancer. Survivors have their whole life ahead of them in which they may face non cancer related issues ( eg. Malaria, Dengue, Accidental injuries) like any individual in society for which they should get coverage to live a fearless & productive life. Advocacy by Ugam members & awareness about this issue will help survivors to get the insurance cover rightfully! Another area of concern is matrimonial prospects for survivors who are now adults & willing to settle down in family life but face societal resistance. Ugam has to be torch bearer & advocate for these burning issues at societal, non-governmental & governmental level.

Theme for this year's anniversary celebration is partnership. ICS has partnered with pediatric cancer units of hospitals in Mumbai, Delhi & Chennai to get organized towards a goal of standardizing survivorship care. We have realized that alone we can do so little but together we can go far & do so much more. It will take us time to bring likeminded people together but we are confident & determined to take this movement forward to include many more partners at pan India level.

On this day, thousands gather across the globe to honor cancer survivors and show the world that life after a cancer diagnosis can be fruitful, rewarding, and even inspiring. CELEBRATION for those who have survived, an INSPIRATION for those recently diagnosed, a gathering of SUPPORT for families, and an OUTREACH to the community.

I want to wish each and every member of Ugam the very best in life and may success always be with them. Celebrate what you have accomplished, but raise the bar a little higher each time you succeed.

Perfection may not be attainable but if we chase perfection, we can catch excellence!

Vince Lombardi.

## Surviving Childhood Cancer: What Next?

Advances in the treatment of childhood cancers have dramatically increased survival rates. But the treatments that help these children survive their cancer can also cause health problems later on.

It is often difficult for the cancer patients and his/ her family to make the transition from active patient to survivorship. The fear of relapse being always intense despite counseling. It is safe to say that most childhood cancer survivors can be considered potentially cured 5 years from the diagnosis.

Most treatment related side effects appear during or just after treatment and subside soon. But some problems may not go away or may show up months or years after treatment. These problems are called late effects. Because more children with cancer now survive into adulthood, their long-term health and these late effects have become a focus of care and research.

Every child who is treated for cancer does not develop late effects—the risk depends on the type of cancer the child had, the treatments used and other factors such as age, intensity of chemotherapy radiation given, and time since treatment was completed.

The problems seen in the survivors fall into two broad categories: medical and psychosocial. Medical Late effects can involve more than one part of the body (or more than one organ system) and can range from mild to severe. Effects on brain ( Learning/cognitive issues) , eyes/ears, Hormonal problems, Growth & sexual development, fertility ,Issues with heart ,second cancers are some of the possible medical late effects of cancer. Continued surveillance of childhood cancer survivors is a good medicine. The frequency of follow up is individualized according to problems anticipated by doctor based on treatment and disease history. Early diagnosis of late effect can lead to effective treatment. Hence it is very important to follow up after completion of treatment. Psychosocial problems are more diverse and include issues of school performance, vocational training, employment opportunities, marriage, reproduction and intra-family interaction.

Cancer survivors will be increasing in number as the time passes. In spite of their overall wellness, they are at risk of complications and need a close supervision. It is the responsibility of survivors to come for regular follow up, of health professionals to be vigilant & care for these long term issues and of members of civil society to aid these survivors in realizing their optimum potential.

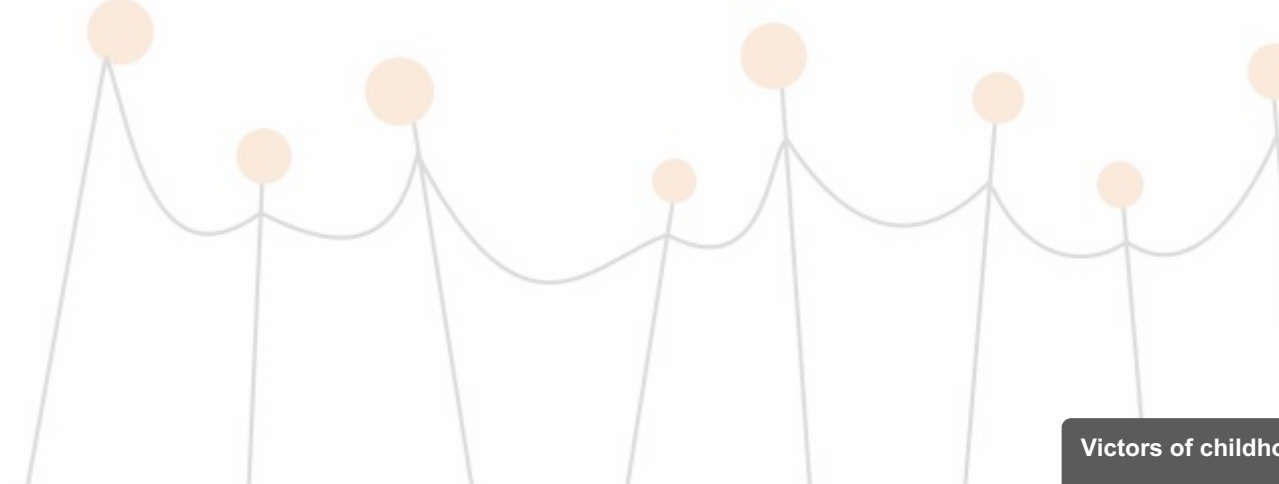
### HOW CAN YOU CONTRIBUTE

Volunteer- Help in capacity building. Help find jobs for cancer survivors

Advocacy- help in promoting the issues faced like denial of Insurance, refusal of jobs

Financial assistance for educational program for survivors

Financial assistance for the late effects of treatment









**Events organized by UGAM**  
UGAM's 9th Anniversary Celebrations



UGAM celebrated its 9th Anniversary on 3rd June 2018 at Royal Opera House. The theme was culture of north eastern India. It was a grand celebration on the achievements and growth of Ugam.

**Childhood Cancer Awareness Month**



September being the Childhood cancer awareness month, drawing competition was organized for the children at ICS. Childhood cancer survivors along with UGAM members illustrated their thoughts through painting.

**International Childhood Cancer Day (ICCD)**

**One Year Completion of ACT Clinic at SION Hospital, Mumbai**



ICS through Project PICASSO (partnership in survivorship optimization) is partnering with various hospitals to facilitate ACT clinics for organizing survivorship care. One year celebration of ACT clinic & ICCD took place on 15th February 2019 at SION hospital.

**Celebration of ICCD at SRCC Children's Hospital, Mumbai:**



ICCD was celebrated at SRCC children's hospital, managed by Narayana Health on 16th February 2019 with the childhood cancer survivors and their caregivers. The objective was to rejoice with them and celebrate their courage and determination.

**Friendly cricket match**



ICS /UGAM participated in a friendly T20 cricket match with employees of Tata Trusts at Shivaji Park, Mumbai, on 23<sup>rd</sup> February 2019.

**Participation at ICS events**

**Relay For Life**



**CANCER DOESN'T SLEEP. SO FOR ONE NIGHT NEITHER WILL WE'**

Indian Cancer Society has been licensed as nodal agency for RFL in India from 2014. This year Dhirubhai Ambani International School & RBK international school had organised RFL on 19th Jan & 8th February, 2019. UGAM members won the cricket match against the In house students of RBK international school.

**Tata Mumbai Marathon, 2019**



UGAM took part in the Mumbai Marathon organized by Tata Consultancy Services (TCS), on 21st January, 2019, for enhancing awareness and for raising fund for cancer treatment

**ZEE TV, Sa Re Ga Ma Pa L'il Champs**



On 21st April, 2019, childhood cancer survivors, caregivers along with ICS support team got an opportunity to participate in Zee TV programme Sa re ga ma pa, Little Champ which had a million views

**Participation in Conferences by UGAM members**

**SIOP/CCI Japan**



Aisharya Nikale represented UGAM at SIOP international conference at Japan on 15th November. She presented a paper at CCI conference on "Personality development through cultural activities of Ugam- a childhood cancer survivor group".

**TYACON 2018**



UGAM members participated in Teenage and Young Adult Cancer Conference (TYACON) held at Cancer Institute, Adyar from August 31<sup>st</sup> to September 2<sup>nd</sup> 2018

**CCI ASIA 2019**



Dr. Vandana & Narendra Shetty represented UGAM at CCI ASIA conference at Abu Dhabi on 5th April, 2019. They presented scientific papers which were well received. Ugam will be part of local organising committee for CCI Asia meeting at SIOP Asia 2020 in Mumbai.



### Can Rehab, 2019



The childhood cancer survivors from D J Fund and a few participants from UGAM participated & presented the indigenous folk dance from the Indian state of Assam during CanRehab 2019 conference. The performance proved their emotional and cognitive maturation to the fullest extent

### HOPE



Ugam members participated in Hope which is an annual event organised by Pediatric oncology department of Tata Memorial Hospital on 23<sup>rd</sup> December 2018.

### Counselling sessions with parents:



UGAM members, regularly attend the parent support group meetings held at partner hospitals and also at St. Jude's India Childcare Center, for parents' counselling

## Awareness activities and spreading hope about curability of childhood cancer

### Gokulashtami / Dahi Handi Event



Ugam members celebrated Dahi Handi at Talav Pali Thane on 2nd September, 2018. The objective was to spread awareness about how smoking leads to cancer.



## Victors' Stories

### Ritesh Kumar

I was diagnosed with osteosarcoma of left tibia at 10 years of age. After 1 year of treatment at Tata Memorial Hospital I was fully cured. Although my cancer



treatment was very painful, I never lost my hope, because I knew I will definitely win over cancer, and hence I decided to become a doctor, so that I can serve other cancer patients. In 2015 I cleared the AIPMT exam and currently I am 21 years old and pursuing Final year MBBS at Seth GS Medical College, Mumbai. I am thankful to Indian Cancer Society (ICS), Mumbai for providing me holistic care which includes financial and emotional support in education and other aspects of life.

### Kamlesh S Gupta

I am Kamlesh S. Gupta, a Cancer survivor, UGAM member and Dr. DJJussawalla Education & Vocational Skills Fund beneficiary. I was diagnosed with PNET



at 11 years of age and completed my treatment from Tata Memorial Hospital, Mumbai in 2012. Currently I am a BE student of Information Technology II<sup>nd</sup> year and I have a dream to be a Software Engineer. I am thankful to the Indian Cancer Society for helping me and other cancer survivors for their Financial and psychological

### HARSH BAXI, "Enjoying a new Life"

- a Cancer Survivor. Working with UGAM has been an amazing experience as every time I get to learn new things and explore various skills. Yes, I am more confident now.



In October 2007, during my S.S.C. Prelim exams, I had a sudden pain in my backbone. This pain went on for a month and it just wouldn't stop. After having MRI & Biopsy done, it turned out that I had PNET dorsal spine. The only thing I knew about Cancer at that time was that, it kills. When I found out that I was diagnosed with Cancer, I was terrified. But my parents and doctors gave me the motivation to fight against Cancer. I endured 17 cycles of Chemotherapy and 31 sessions of Radiation. My treatment lasted for one year. I started studying once again after a year. I can proudly say that I passed my S.S.C. & H.S.C. exams with First Class. Thereafter, I took my admission in Engineering college. I got placed at Infosys and currently am working as Senior Systems Engineer at Infosys. I would like to thank the entire Ugam group who supported me and helped me gain a lot of experience and for encouraging and supporting me in every way. Once again, I extend my heartiest thanks and appreciation to Ugam family and doctors. 'Be Brave and Never Give Up' as cancer is curable and there is Life beyond Cancer.

### Mrs. Indumati Dineshkumar Yadav

I was diagnosed with Wilms tumour at 5 years of age. I completed my MSc. chemistry in 2014. I got 21 months industrial experience (research and development) and one year teaching experience as a chemistry lecturer. I got married on 4th Dec, 2017. I cleared ICT PET exam and Mumbai University PET exam in October 2017 and January 2019 respectively. Currently I am pursuing Ph.D. from Mumbai University. My dream is to become an R&D scientist officer. I am thankful to Indian Cancer Society, UGAM, friends and my family who supported, motivated to achieve my dreams.





**Ummull** am proud to be one of the founder members of Ugam and blessed to be a part of it. At the tender age of six when I was at school, the bench hurt my left knee which gave rise to an unbearable knee pain along with an extreme fever. I was



examined at J. J Hospital and was advised to go to Tata Memorial Hospital. Here, the doctors informed that I am suffering from Cancer which was at the last stage. My parents were shattered and heartbroken, but they stood by me very bravely. They taught me to have faith and encouraged me to fight this battle and defeat cancer forever. In a year my journey with cancer ended successfully forever. Thereafter, I just followed my regular follow up with ACT clinic till date. Throughout this journey, I bonded well with all my family members, doctors, teachers, friends who always supported me and accepted me the way I am and I thank everyone for making me a successful, well settled human being. I own my business into the Events and Advertising agency named as "S Seven". I would love to add one phrase "my parents not only gave me birth but my mom & dad even gifted me a life with all the happiness.

**Dhiren Kiri** I was diagnosed with Hodgkin's Lymphoma, stage III at 17 years of age, in the year 2008. I could never imagine that I will be starting my life again. I endured six cycles of chemotherapy and fourteen radiations.



During that difficult phase my parents lost many things which I can't even explain. Professionally now I'm a CrossFit level 1 trainer and working with CrossFit Shakti (Vashi). I am completely adhering to the medical and psycho-social follow up at both TMH and Indian Cancer Society (ICS). I would like to convey, "If you can't fly then run, if you can't run then walk, if you can't walk then crawl, but whatever you do you have to keep moving forward." (Martin Luther King Jr).

**Vansh Gupta** I was diagnosed with Osteosarcoma at the age of 6 in the year 2011. I finished my treatment in the month of December, 2011. Currently I am in 9th standard and 14 years old. I enjoy playing football and in 2017 I



was awarded for winning the football match. I received Spirit award by Make a wish Foundation for winning the dance competition in 2018. I was awarded by TMH for performing a dance during Hope, 2018.

**Shahbaz.** I am a childhood cancer survivor and Ugam member since 5 years. When I was in 10th Std when I was diagnosed with Acute Lymphoblastic Leukemia (Type of blood cancer). It was very difficult for me and my family also to cope up with this news. I completed my SSC, HSC, and B.Com. when I was undergoing treatment. I would like to thank my family, friends and my doctor for their support in my cancer journey. After completion of the treatment I did MBA in Finance with the financial support of ICS. Now I'm completely cured, healthy and currently working with Tata Trusts as a MIS Coordinator Accounts. I am also a part of cricket and football team at TATA trusts and I recently played and won the Inter Tata company football tournament 2019 and was a runner up for Tata executive cricket tournament 2019. I also participated in the Mumbai Marathon 2019 in the 10km category and finished successfully. In this journey I have learned 'everything is possible, if you are ready to deal with it'. I am thankful to ICS and Ugam for all the support provided.



**Priti Nag** I was diagnosed with Acute Myeloid Leukaemia (AML M2), in the year 2016. I am from Kolkata, but during my treatment I shifted to Mumbai, Badlapur. I am grateful to Indian Cancer Society (ICS)



for helping me financially for my studies. Currently, I am studying in 9th standard and enjoying my life. I love swimming, painting. I secured 14th state rank in Indian talent G.K and also received an excellence award for the same. I really want to thank my parents, all my doctors, nurses ICS and UGAM for constantly supporting me throughout my cancer journey..

**Vivek pandey** I was diagnosed with cancer at the age of 4. Irrespective of all financial hazards my parents initiated my cancer treatment and they never lost hope. Finally, I completed



my treatment successfully from TMH in the year 2000. I never stopped my education during my treatment and currently I'm working as an UGAM officer at Indian Cancer Society. I would like to thank my mother for always being with me, from the initiation to completion of my treatment. Remember: If we have to defeat the enemy, named cancer, proper medication, treatment, regular medical and psycho social follow up and healthy lifestyle is necessary.

I am really happy to share my achievements with my UGAM Family and would like to Congratulate all of you for successfully completing 10 years and many many more such years. So lets come together and make it a Grand Celebration

**संजीव कुमार** मे संजीव कुमार, एक कंटेम्पररी आर्टिस्ट हूँ. तीन साल के उम्र में, मुझे कैंसर हुआ था. उसी समय, मे चुपचाप बैठा रहता था और सिर्फ कार्टून का ड्राइंग बनाता था. मैने अपनी प्रॉब्लम को अपनी



ताकत बनाया. भगवान, उगम, डॉक्टर, सोशल वर्कर और परिवार वालों के प्यार का ताकत के वजहसे २०१९ में नेशनल आर्ट गैलरी मेरा पेंटिंग चुना गया है. इससे मेरी मेहनत को एक नयी मौकाम मिला है. लाइफ में कोई भी प्रॉब्लम हो, अपने उद्देश्य को कमजोर मत होने दो, सफलता जरूर आएगा.

### Parents Story

**Vijay Joshi Father of Veedesh Joshi**

हमारा बेटा जब १३ साल का था तो उसे अचानक बुखार आना शुरू हो गया. दो महीने की कल अवधि उससे चार से पांच बार बुखार आया तो हमने उसे अस्पताल में एडमिट करवाया. सीबीसी रिपोर्ट देखने के बाद डॉक्टर



बोले की अब बॉन मेरो करवायो. हमारे लिए सब नया था. लेकिन बोन मेरो करवाने के लिए उन्होंने जिन अस्पतालों का नाम लिया उनका नाम सुनते ही हमारे पैरों की निचे की जमीन खीसक गई. उन जगहों की खर्चा उठाने में हम सक्षम नहीं थे, फिर भी हमने बिना समय वर्थ किये मुंबई जाने का फैसला किया. मुंबई हमारे लिए एकदम नयी जगह थी. वडिआ हॉस्पिटल में हमारे बेटे को फिर से कुछ जांच करने के बाद उन्होंने एडमिट करवा लिया और हमें इलाज कैसे होगा, कितने दिन चलेगा, इसकी पूरी जानकारी दी. अब हमें पता चल चुका था की हमें अपने परिवार के साथ मुंबई शिफ्ट होना है. ये हमारे लिए बहुत बरी बात थी कियुकी कियुकी हमारे पास ऐसी कोई व्यवस्था नहीं थी. हमने जैसे जैसे महालक्ष्मी मंदिर के पास रहने की व्यवस्था कर ली. बेटे का इलाज पूरा होने के २ साल बाद में नागपुर वापस आया. जिन को ये पता था की मेरे बेटे का इलाज मुंबई में करवाया. यो लोग अगर किसीको कैंसर चिकित्सा करवाने के लिए जानकारी का जरूरत होता तो हमारे पास वेज देते. आवश्यक अनुसार हम उनको सब जानकारी देते और अस्पताल जाके मदद करते. जिन मरीजों का अस्पताल या उनके घर में उपचार सम्भव नहीं है उनके लिए कुछ करने का प्लान कर रहे है. इन सारे कामों में मेरे पत्नी का मुझे पूर्ण सहयोग है.



❖ We are proud of you ❖



**Dr. Shripad Banavali**  
Was awarded Lokmat  
Maharashtrian of the year-  
Medical field



**Oindrila Banerjee**  
Painting selected for Art  
exhibition at ICCR,  
Nandalal Bose Gallery.



**Sanjeev Kumar**  
His painting was selected at  
National All India Art  
Exhibition-2019



**Shruti Nirmal Mhatre**  
Best Student Nurse Award  
by Nurses Welfare  
Association, Nair Hospital.



**Shalaka Mane**  
Successfully completing  
'KEVAT' Post Graduation  
Diploma



**Sampada Sakre**  
Awarded by western  
Railway for exceptional  
service- All India level.



**Sachin Chandorkar**  
His sculpture was selected  
at All India Art  
Competition and  
Exhibition 2019-2<sup>nd</sup> edition,  
by State Gallery of Arts,  
Hyderabad

**Ugam theme song... launched on 3rd June, 2012**

चल दिए हम लेकर अपना कारवाँ  
लिखेंगे खुशियों से भरी एक दास्ताँ  
राहों के टेढ़े मेढ़े जो मोड़ हो  
टूटे ना इन हाथों के जो जोड़ हो  
जीवन की धुप में हम पले हैं  
काँटों के रास्तों पर चले हैं  
महकाए फूलों से ये चमन  
देखा जो दर्द को हम मिटा दें  
एक लौ से ये जहाँ जगमगा दें  
भरदे उमंगों से ये गगन  
हम हैं उगम हम उगम

जीवन की आशा को  
प्यार की भाषा से  
अब तो महकाना है  
खुशियों को लाना है  
बढ़ते ही जाना है.... उगम  
बिखरे उन सपनों को  
फिरसे उठाना है  
बढ़ते ही जाना है.... उगम

चल दिए हम लेकर अपना कारवाँ ....

Song Written by: Shashank Johri & Composed by: Immanuel