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.

CONTACT
• Dr Purna Kurkure – Convener, UGAM
  E-mail: purna.kurkure@gmail.com
• Dr Vandana Dhamankar
  - Trustee In Charge, Cancer Survivorship
  E-mail: vandana@indiancancersociety.org
• Ms Jaitri Mandal - Psycho Oncologist
  E-mail: jaitri@indiancancersociety.org
• Mr Krishna Pandey– UGAM Officer
  Ph no : +91 7007066236
  E-mail: krishna@indiancancersociety.org
• Ms Savita Goswami - Mentor
  E-mail: savittata@yahoo.co.in
• Ms Ekta Rawat – Co-ordinator Ugam
  Ph no : 08805267800
  E-mail: ugam.mumbai@gmail.com
• Ms Preeti Phad - Member
  Ph no : 9702488007
  E-mail: preetiphad@yahoo.com
• Ms Shekhar Jha - Member
  Ph no : +91 9699975276
  E-mail: jhashekhar56@gmail.com

Indian Cancer Society
74,Jerbai Wadia Road, Parel, Mumbai,400 012. Tel. No: 022-24161875/24139445/51
ugam.mumbai@gmail.com / info@indiancancersociety.org
www.indiancancersociety.org

Victors of childhood cancer
ugam

10th Anniversary Issue - 2019
Together we can create miracles
Celebrating 10 years of Togetherness!

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Edited by: Dr. Purna Kurkure / Arun Kumar Nadar
Illustration by: Shweta Chawre
Victors of childhood cancer

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

It all started on 7th June 2009, first Sunday of June celebrated as Cancer Survivors Day across the globe. 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 visionary leadership of Dr. Purna Kurkure.

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!

Dr. Purna Kurkure
Convener, Ugam
Trustee in charge, Cancer Survivorship & Rehabilitation Vertical
Indian Cancer Society
Chairman, Clinical Collegeum Oncology Services
Narayana Health Group
Head, Division of Pediatric Oncology & BMT
SRCC Children's Hospital, Mumbai

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.

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.

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.

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.

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

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.

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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.

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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

Financing is no longer a challenge. It is now possible to raise funds for multiple purposes related to the cause of childhood cancer.

Victors of childhood cancer
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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.

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

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.

Participation at ICS events

Participation in Conferences by UGAM members
Victors of childhood 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. D.J. Jussawalla 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 IIInd 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 support.

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.
I was diagnosed with Acute Myeloid Leukemia (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 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 full-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 I 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 have to keep moving forward.” (Martin Luther King Jr).

Vivek pandey 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.

Parents Story

Vijay Joshi Father of Veedesh Joshi

His story ended just 13 years ago, but she left behind a legacy of love, strength and determination.

Vijay Joshi was a dedicated father who never gave up hope for his daughter. Despite the challenges and obstacles she faced, he remained a constant source of support and encouragement. His unwavering belief in her potential inspired him to fight for her and to ensure that she received the best possible care.

Vijay's journey with his daughter was not an easy one. He was deeply impacted by the fight she went through and the toll it took on both of them. However, through it all, he remained strong and resilient, always putting his daughter's needs and well-being first.

Vijay's story is one of love, resilience, and the power of hope. It's a reminder that even in the darkest of times, there is always a glimmer of light that can guide us forward. He will always be remembered as a loving father who never gave up on his daughter and fought tirelessly to help her overcome her struggles.

Victors of childhood cancer

Ummul are proud to be one of the founder members of Ugam and blessed to be a part of it.

With a heart full of affection, I want to express my gratitude for all of you. It's been a pleasure working with you and serving the children who need our support the most. I am deeply touched by the love and dedication that each and every one of you brings to this cause.

I want to especially thank all of the staff at the hospital, the doctors, and the nurses who work tirelessly to care for our children. Their unwavering commitment to the well-being of the children is truly inspiring.

Finally, I want to thank all of the families who have shared their stories with us. Your courage and resilience are a source of great inspiration for all of us.

Thank you for being part of this incredible journey. Together, we have made a difference in the lives of so many children. Let's continue to make a difference in the years to come.

Viacors of childhood cancer
We are proud of you

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

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

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

Shalaka Mane
Successfully completing ‘KEVAT’ Post Graduation Diploma

Sachin Chandorkar
His sculpture was selected at All India Art
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Shruti Nirmal Mhatre
Best Student Nurse Award by Nurses Welfare Association, Nair Hospital.

Sanjeev Kumar
His painting was selected at National All India Art
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Sampada Sakre
Awarded by western Railway for exceptional service-All India level.

Song Written by: Shashank Johri & Composed by: Immanuel

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

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