



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

We appeal to your organization/trust for financial aid. Please consider donating generously towards the care & rehabilitation of cancer survivors. Donations are exempted from Income Tax under Section 80 (G) of the Income Tax Act, 1961.

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

74, Jerbai Wadia Road, Parel, Mumbai, 400 012. Tel. No: 022-24161875/ 24139445/51.

Please visit our Website: <http://www.ugamcalling.org>, **Email id:** info@ugamcalling.org

You can also visit : (<http://www.indiancancersociety.org>)



Ugam Calling...

6th Anniversary Issue



Indian Cancer Society

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The UGAM FAMILY

Dr. Purna Kurkure
Convener
Shekhar Jha
Executive Administrator
Savita Goswami, Dr. Maya Prasad
Mentor

TMH
Dept of Pediatric Oncology
Dept of Medical Social Worker
Dept of Psycho Oncology

ICS
National Managing Committee Members
Shankar Bose (COO, ICS)
Lalitha Nair (Deputy Director ICS)

Volunteers

TMH
Niranjan Parikh
Shalini Jatia
Sanjeev Sharma
Ameeta Bhatia

ICS
Lolita Saletore
Urmila Jain
Sophie Ahmed

Working Groups

Patient support group
Shekhar Jha / Smruti Ambre / Shifa Sheikh
Prashant Sooryavanshi / Nilesh Dokhe

Survivor support group
Shekhar Jha / Preeti Phad/ Bhaskar Pandey

Creative group
Sushant Bane / Sachin Chandorkar /
Shweta Chawre /Emmanuel

Educational & Vocational support group
Shalaka Mane / Vishal Tamhankar/
Priyanka Jadhav

Marriage counselling group
Mrs. Sampada Sakre / Anita Gupta /
Vanchinathan

Public Relations
Ekta Rawat Pawar/ Narendra Shetty

Web Masters
Arun Nadar /Ajay Pawar

Fund-raising group
Pranav Mukhi / Aishwarya Nikale

We are grateful to management of Tata Memorial Hospital & Indian Cancer Society for their unconditional love & support.

We are grateful to all Ugam friends & donors for their generous support.

We are grateful to Display House for technical support.



Dr. Purna Kurkure
Convener, Ugam
Indian Cancer Society
Incharge, ACT Clinic
Tata Memorial Hospital

Greetings from Ugam on its 6th Anniversary Celebrations!

The journey of Ugam and the impact it has created on many lives speaks volumes & emphasizes that Childhood Cancer Survivors need a lot of continued support and care. They need to be well informed and well prepared to navigate the next part of their journey - the new normal life beyond childhood cancer.

Ugam was launched in 2009 on the first Sunday of June which is celebrated as Cancer Survivors Day across the world as a mark of celebration of life. It will be a watershed in the history of Ugam that this concept has been recognized this year by Childhood Cancer International (formerly known as the The International Confederation of Childhood Cancer Parent Organisations- (ICCCPO) in partnership with the CCI Survivors Network, International Society of Pediatric Oncology (SIOP) and the Union for International Cancer Control (UICC) . CCI has declared June as childhood cancer survivor month during which **International Childhood Cancer Survivors Week (ICCSW)** can be celebrated. It is a time for **retracing the childhood cancer journey and understanding the issues and challenges that unfold during survivorship.** ICCSW is also an opportunity to **create awareness** among the general public of the realities of childhood cancer, but more than that, it is a **shout out** to showcase that **childhood cancer is indeed curable.** ICCSW is a declaration that this devastating disease can be overcome with early diagnosis, timely and appropriate treatment, increased availability and better access to affordable essential medicines, adequate quality care and sufficient support for the child/adolescent with cancer and their families. It is time for everyone to appreciate that the **C-word is no longer a death sentence.**

The C word has been reconfigured. There is a new C-word: Celebration of Life, Continuation of Life - Beyond Childhood Cancer.

Ugam is an active member of CCI & is very happy to join hands with CCI for celebration of ICCSW from this year starting with the Ugam anniversary. ICCSW celebrations will continue in the following week with a workshop on **Educational & Vocational** counseling for adolescents & young adult survivors of childhood cancers to facilitate their careers on the right path. There will be a workshop on **communication skills** to train survivors for counseling which will enable them to play as role models for active childhood cancer patients and their parents.

This June, let us urge cancer centers, governments, civil society organizations and resource institutions to **DO MORE** for childhood cancer survivors and their families by implementing the following Action Plan.

Optimal information and education campaigns to

- Increase awareness of late effects and their implications for long-term health and well being of childhood cancer survivors.
- Address stigma and discrimination against childhood cancer survivors.
- Reinforce and strengthen public programs, services and health insurance coverage for childhood cancer survivors.
- Enhance training on survivor needs, late effects and their management for both specialty care professionals and primary care medical practitioners.
- Ensure national cancer control plans have a component on childhood cancer survivors.
- Expand and scale up researches on the nature, extent, implications and interventions to avoid or minimize impact of emerging challenges of late effects on the survivors health and overall well-being.

Let us all continue to **STAND UP, SPEAK OUT** and be **PARTNERS** with the childhood cancer survivors and their families.

Let us be **CHAMPIONS** for Childhood Cancer Survivors and their families.

We Stand Stronger, Together.

MYTHS AND MISCONCEPTIONS ABOUT CHILDHOOD CANCER SURVIVORS

By:



Adopted by:



1) MYTH: Children with cancer and childhood cancer survivors pose a health risk to other children/adolescents. They are disease carriers.

FACT : Childhood cancer is not contagious. It is not an infectious disease. Neither is it a virus that can be transmitted or transferred by interaction. Thus, it is safe for other children and teens to play, socialize, interact with kids with cancer and childhood cancer survivors.

The reality is that children/adolescents with cancer who are immuno-compromised (i.e. have a weakened immune system during treatment), are at risk for catching the colds, measles, mumps, chicken pox, other common childhood illnesses from other kids.

This is why you see some of them wearing masks-to protect themselves. This is also why parents or carers oftentimes isolate their kids from large groups or public gatherings, when they know their kids are vulnerable.

2) MYTH: Childhood cancer survivors are “genetically inferior” and are unable to have children.

FACT: While some childhood cancer survivors may face fertility and reproductive health challenges, this is not the case (is not true) for the majority of childhood cancer survivors. The type of childhood cancer that they were treated for and the treatment protocols that were followed will influence the impact of childhood cancer on the survivors' fertility and reproductive health.

3) MYTH: Childhood cancer survivors have a short life.

FACT: Studies have shown that childhood cancer survivors are at increased risk for late effects and secondary cancers; however, reductions in life expectancy depend on: a) how timely the cancer diagnosis was; b) what the initial treatment was; and c) the appropriateness of the treatment received. The nature and severity of the subsequent late effects will also influence life expectancy.

4) MYTH: Childhood cancer survivors generally do poorly in school and during employment.

FACT: While research has revealed that 2 out of 3 childhood cancer survivors suffer from “late effects,” these late effects do not necessarily affect cognitive and learning capacities.

Anecdotal reports indicate that childhood cancer survivors are determined and motivated to do well. There are many inspiring stories around the world of childhood cancer survivors who are successful, high performing achievers and/or make noteworthy contributions to their communities, despite life-threatening or life-limiting conditions.

5 MYTH : Childhood cancer survivors are socially challenged and generally have poor interpersonal and relational skills.

FACT: In most countries, during treatment, children/adolescents with cancer are separated from their peers and unable to engage in regular schooling and other activities. However, numerous studies have shown that as a

consequence of the challenges they faced and their experiences, survivors tend to have better coping and increased resiliency. This is most true in countries where there are psychosocial support programs for children with cancer and childhood cancer survivors and/or where there are programs and services that help create a supportive and nurturing environment for children undergoing treatment for cancer.

It should be noted however that there have been emerging exploratory studies indicating that some childhood cancer survivors exhibit behaviour associated with PTSD (post traumatic stress disorder). This further emphasizes the need for robust follow up care, safe spaces (e.g. places where the kids can “hang out“ and be with peers who accept and understand them etc.) and strong circles of support for kids with cancer and childhood cancer survivors. This is why a number of childhood cancer foundations and patient support organizations provide alternative education facilities, in hospital or in their offices.

6 MYTH: Childhood cancer survivors are cured and no longer need continuing, follow up care.

FACT: Continuing follow up care is very important for childhood cancer survivors. Studies have revealed that childhood cancer survivors are at higher risk for a secondary cancer, or a debilitating health condition related to their initial cancer treatment. Therefore, vigilance and regular monitoring are critical for early identification and treatment of any health challenge or impairment.

Childhood cancer survivors and their families should be informed about the facts and details of their cancer, the expected health and lifestyle consequences of their treatment and the required monitoring/regular follow up. Childhood cancer survivors should be provided

with age appropriate information and enabled to understand their conditions. Teens and young adults need to feel empowered and able to take charge of their own health.

7 MYTH: Childhood cancer survivors will have a miserable, sad and dismal future. They can never have a normal life.

FACT: Most childhood cancer survivors return to normal school life and activities after treatment. They effectively reintegrate with their family, friends and communities. In other cases, the survivor and their families adapt and modify their lifestyle to achieve the “new normal.”

Adjustment to the “new normal” - life after cancer, becomes much easier more fulfilling and happier, with a circle of care provided by an understanding and supportive network of family members, teachers, carers, community of peers and friends.

8 MYTH: Childhood Cancer Survivors will always carry the stigma of cancer in their adult life. They will always be discriminated against and looked down on for marriage, employment and in social circles.

FACT: In most countries, childhood cancer survivors are looked up to and viewed as heroes and warriors who courageously overcame cancer. Childhood Cancer survivors are living proof and testimony that childhood cancer is curable. They are the best ambassadors to bring hope, motivate and inspire other survivors, new patients and their families.

In countries where discrimination and stigma still exist, survivors and their supporters need to stand up and speak out. They need to challenge the stigma, share their stories and show the reality of their new lives.

Studies have shown that education, information and real life stories are powerful tools to break stigma and eliminate discrimination.



Dr. Maya Prasad

Mentor, Ugam
Asst. Professor
Pediatric Oncology
Tata Memorial Hospital

Congratulations to Ugam on the 6th Anniversary. It is extremely heartening to see Ugam grow stronger and more active as time passes.

The diagnosis and treatment of childhood cancer tends to be a traumatic and difficult time for the child and family. Often, there are health concerns, emotional challenges and social issues which persist in the long term. A support group such as Ugam addresses the unique needs of parents, the family and survivors, and acts as a forum to share ideas, information and support.

Although my association with Ugam has not been very long, it has been an enriching experience. Life had dealt a cruel blow to these young victors, but they have overcome setbacks and risen to come out as stronger people. The maturity, enthusiasm and confidence of the young cancer victors acts as a beacon of hope to all of us, and an inspiration for young patients and families currently undergoing treatment. The past year has seen Ugam members actively participate in activities ranging widely from Cancer Awareness sessions and Scientific conferences to wonderfully planned cultural events and fundraisers. Ugam has also been encouraging similar support groups in other parts of the country.

This cohesive and close knit group promotes not just team spirit, but also greatly encourages the growth of individual members. The workshops organized as part of this year's celebrations will also go a long way towards this.

Wishing the Ugam family all the best for a wonderful future.



Savita Goswami

Mentor, Ugam
Clinical Psychologist
Tata Memorial Hospital

My heartiest congratulations to all Ugam members, friends and supporters. We have come a long way and completed 6 years of our journey. In the year June 2014 – May 2015, Ugam has constantly been active in various activities like patient and survivors support, social awareness about cancer, networking with other organizations, participating in national and international conferences and educational programs, and in media programs for survivors' issues and cancer (talk shows, interview, debates). Self-empowerment of each Ugam member is the main agenda for all Ugam activities. There is a need for appropriate educational and vocational guidance for young childhood cancer survivors whose education is hampered due to illness, treatment, financial constraints or lack of educational facility. Ugam is addressing these issues of education and employment of young survivors & networking with various enterprising & enthusiastic individuals and organizations. This year we are conducting "Vocational guidance and counseling workshop" for young survivors so that they benefit by getting more relevant information, practical options & suggestions in education, training and career planning. We have organized "Communication skills training workshop" to empower Ugam members in communication, decision-making and problem solving.

As a mentor I am proud to say that there is a significant transformation in motivation, role-execution and self-worth of Ugam as a group. It has had a positive impact not only on group bonding but also individual performance in their respective lives. Ugam will continue in its set path of capacity building to rejuvenate and rise high from the ashes of adversity like a phoenix.

Journey Of Ugam 2014-2015

No Tobacco day: 31st May 2014



Tobacco is one of the leading causes of cancer deaths in India. On the eve of World No Tobacco Day, Ugam members presented a street play in the Tata Memorial Hospital compound which was covered by IBN Lokmat & was televised on the news channel repeatedly on No Tobacco Day for public awareness. Clinical Psychologist Mrs. Savita Goswami who was interviewed by DNA news said, " We are doing this for people who don't have any idea about the kind of suffering cancer causes. We want to tell them to quit tobacco right now, otherwise life will be very difficult once they get affected with oral cancer."

Ugam 5th Anniversary Celebrations:

1st June, 2014

As we have been doing for the last 4 years, this year too we celebrated the Cancer Survivors day and 5th Anniversary of UGAM – the victors of childhood cancer on 1st June 2014.

Ugam, as we all know, is a voluntary support group of childhood cancer survivors, which was started on first Sunday of June 2009. The event was held at Tata Memorial Hospital to mark the 5th anniversary of Ugam. The response was very good this year. About 450 survivors, active patients with parents attended the program of which 160 were Ugam members.

The program started with a prayer by Ugam Members. Everyone in the auditorium observed silence remembering departed Ugam friend, Ms. Indrani Sen & Pediatric Oncologist Dr. Suresh Pai who took care of many patients who are now survivors & Ugam members.

West Bengal was the theme for this year's function. All Ugam members dressed in West Bengal style, Men wore kurta- pajama or dhoti & women wore sarees, some wearing typical Bengali sarees with traditional jewellery. Ugam members & friends under able guidance of Bengali Dance teacher Mrs Mahua Roy presented West Bengal dance performances with audio visual show explaining culture of West Bengal. Famous singer Abhijeet Ghoshal enthralled audience with Bengali songs.



Honourable guests, Actor Kunal Roy Kapoor & Director Amol Gupte famous for making child-centric films and four Child Artists who have acted in his film Hawa Hawaii, Mr Ranjan Kapur, Vice Chairman, Indian Cancer Society, Mr Shankar Bose, COO, Indian Cancer Society. Mr. A.N. Sathe, Sr Administrative officer, Tata Memorial Hospital along with Ugam Family members lighted the traditional inaugural lamp & released 5th Newsletter of Ugam. Adult survivors of childhood cancers who have married after revealing all facts about their past cancer experience were invited with their spouses & were felicitated by guests to

spread the message that **there is a life after cancer & cancer experience should not be considered a stigma in society.**

Mrs.Savita Goswami made a power point presentation summarizing various activities undertaken by Ugam during the year 31st May 2013 to 31st May 2014.

Ugam members and friends enacted a skit which highlighted vision & mission of Ugam.It was concluded by singing of Ugam's theme song composed & conducted by Emmanuel, one of the active Ugam members.

Nickelodeon, India's leading kids brand and a part of Viacom18 actively sponsored the event. They created an engagement activity around the theme Doraemon. Children posed with Doraemon for photograph. Photos were printed and given to all & young children were given gifts for the best pose with Doraemon

The morning programme ended with dancing with DJ & a vote of thanks. Highlight of this years programme was a special screening of Hawa Hawai movie by Mr. Amol Gupte in post lunch session.It was truly inspirational movie for our survivors that they should not be afraid to dream & nothing is impossible with determination & hard work. We are thankful to Mr. Amol Gupte for this kind gesture



Distribution of goodies to the participants was done at the end.

Ugam got a good media coverage this year also with its own efforts. Mid Day,DD Sahyadri,IBN Lokmat & Akashwani Mumbai covered the event & spread the message that childhood cancers are curable & there is life after cancer to celebrate. This has helped to raise societal awareness about childhood cancers & curability. Many survivors are joining Ugam & people from various fields are trying to help this vibrant group & give them opportunity to showcase their talents for overall development which will help them to get back to mainstream in society.

SelfV Campaign for Cancer Survivors: 26th June,2014

HCG Cancer center started a SelfV campaign for cancer survivors wherein survivors all over India uploaded a 60 sec video recounting their battle against cancer. Cancer survivors were given an opportunity to come forward and share their experience in battling the disease and inspire others. Hundreds of survivors all over the country took the initiative and showed immense courage while narrating their endurance.

Ugam Members were also encouraged to take part in this wonderful proposal. 12 Ugam members uploaded their SelfV's on facebook on 26th June 2014 and they managed to rope in some excellent reviews . Audience in the social media were inspired and awestruck with the massive valor.

The SelfV campaign was not only a gigantic accomplishment to Ugam members but also cancer survivors all over the country. This surely must've inspired a lot of other survivors to come forward.

Educational Program at Taj Mahal Hotel : 6th July 2014



Like every year Taj Mahal Hotel cordially invited patients and survivors of Tata Memorial Hospital to attend an annual get together. This event is organized by the medical social workers department of the hospital. Some of the Ugam members also had the opportunity to attend the event. Magic show, dance performances were the entertainment for the day. Ugam members presented a Dance performance which was enjoyed by the children and also appreciated by the guests present. Ugam member, Shekhar Jha gave an inspirational speech about Ugam. Young survivors were also felicitated by the chief guests & were given need based scholarships based on their performance in exam. The event ended with Ugam's theme song.

Dahi handi Celebration: 17th August,2014



Ugam members were invited to Celebrate Dahi Handi on 17th Aug 2014 at Pali Talav, Thane, by Mr.Rajan Vichare, a Member of Parliament,Thane, Maharashtra. More then 20 Ugam Members participated in the event. Ugam members Priti and Priyanka , who had become "Govinda" on that day, broke the

Handi. They created awareness about cancer in this community event.

Participation in 46th congress of The International Society of Pediatric Oncology (SIOP),Toronto,Canada: 22nd-25th October 2014



This year too Ugam got an opportunity to participate in 46th congress of the International Society of Paediatric Oncology (SIOP) which was held from 22nd to 25th October 2014 in Toronto, Canada. Childhood Cancer Survivors, Parents, medical professionals, nurses, scientists, and researchers from all over the world came together with a purpose to find holistic approach for cure of Childhood Cancers. M/s. Shweta Chawre, Ugam member was awarded travel scholarship by ICCCPO (now known as CCI-Childhood Cancer International) which was further supplemented by grant from Indian Cancer Society to meet conference expenses. She presented her paper on educational barriers for Childhood Cancer Survivors in India and collaboration with universities that provide educational assistance to survivors. It was her maiden trip abroad & first oral presentation ever, but she presented it confidently. She presented it in ICCSN (International Childhood Cancer Survivor's Network) on 20th October as well as in SIOP on 22nd October. Many support groups and NGOs also presented in Pre-SIOP Workshops and ICCSN which gave her opportunity to interact with them & learn how the other support groups function, the creative workshops they conduct for children and their ways of spreading

awareness through social portals. Social Media is a powerful platform and they use it in a really good way to publish their updates/activities.

Race of Hope : 22nd November, 2014



Race of Hope is an Annual Fund Raising Event of the Indian Cancer Society which was supposed to be conducted at the Mahalaxmi Race Course on 18th Nov. 2014 but due to excessive rains was postponed to 22nd November. Despite the bad weather Ugam members managed to participate in the event. They distributed souvenirs to guests and helped in the fund raising activities. Ugam members also participated in a dance performance.



Participation in "Healthier India-BIG conversation on Cancer": 7th December, 2014.

GE in association with ET Now had organized an interactive session titled 'Healthier India - a BIG conversation on cancer' wherein they brought about India's leading healthcare experts, cancer survivors, researchers and industry leaders. Mr. Kewal Nohria, Chairman, represented the Indian Cancer Society along with Ugam members Shalaka and Narendra.

This session was attended by more than 100 people. Ugam members expressed their views regarding the issues faced by cancer survivors after completing treatment and the need for rehabilitation efforts. The participants at the session appreciated the matters raised by Ugam members.



21st Anniversary of Vasantha Memorial Trust : 7th December, 2014

On the occasion of completion of 21 years of yeomen services by Vasantha Memorial Trust, a cancer awareness session was arranged wherein doctors, patients and survivors were invited. Ugam members along with Dr. Purna Kurkure, who was the chief guest for the event. Experts from different hospitals gave presentations about cancer treatment and current research in dealing with the disease.

Dr. Kurkure presented late effects of therapy on Childhood cancer survivors. Ugam members Shekhar, Shalaka and Narendra were invited to narrate their experiences in battling cancer and overcoming it. The event ended with an interesting Q & A session.

Mumbai Marathon :18th December, 2014

The Standard Chartered Mumbai Marathon is an annual international marathon held in Mumbai, on the third Sunday of January every year. It is the largest marathon in Asia as well as the largest mass participation sporting event on the continent. It is the richest race in India with a prize pool of USD \$350,000.



This Marathon is just not an event for world's leading athletes, it is an event where people from all walks of life participate including Bollywood celebrities, sports personalities, business tycoons and people in support of various charity organisations. Ugam got an opportunity to participate in this event as a unit of survivorship programme of Indian Cancer Society. Indian Cancer Society got space to put up a stage midway in the marathon route. Ugam members stood and chanted their theme song, displayed flag and banners which read messages of crusade against cancer. Many enthusiastic marathon runners on the way did take some time off to understand activities of Ugam & Indian Cancer Society.

HOPE : 18th December, 2014



HOPE is the biggest Annual Event at Tata Memorial Hospital organized by department of pediatric oncology. This year's theme was MUSIC. The event was attended by more than 300 cancer children and parents. Extraordinary performances by musicians and artists not only thrilled the kids but also entertained everyone present in the auditorium. Celebrities like actor

Emraan Hashmi, notable singer Shaan and the cast of Taarak Mehta T.V. serial were the chief guests for the event. They encouraged the kids and their parents to be strong and fight the disease with determination and also delighted everyone with their dance moves. Ugam members were involved in volunteering for the event. They were engaged in handling the crowd during the event and also after the event for distribution of gifts and food.

Late effects Symposium : 27th December, 2014



The 'First national Symposium on Late Effects of treatment in Survivors of Childhood Cancer' was organized by Tata Memorial Hospital on 27th December 2014 under the aegis of Pediatric Hematology-Oncology (PHO) chapter of IAP, ImPaCCT foundation and ICON. This symposium aimed to focus on common issues faced by childhood cancer survivors based on experiences from ACT clinic & Ugam. It also brought together all health care professionals involved in the care of these survivors on a common platform. Dr. Purna Kurkure shared the genesis of ACT clinic & Ugam & projected a roadmap for improved care of Childhood cancer survivors in India. Ugam members participated in the symposium to gain scientific knowledge about cancer survivorship which will help them in counseling other survivors. They were also involved in volunteering for this event.

**Relay for Life (RFL) : 24th Jan, 2015/
27th March, 2015**



Relay for life is a franchised fund raising event of American Cancer Society which is organized round the year in over 20 countries where more than 4 million people take part and raise funds and create awareness to save lives from cancer. Indian Cancer Society has been licensed as nodal agency for RFL in India from 2014. This year Oberoi International School and Ecole Mondiale World School had organized RFL on 24th Jan 2015 & 27th March 2015 respectively.

Ugam was invited to participate in the event. Relay for life is an overnight relay walkathon where groups take turns walking around the track till 8am the next day. 'CANCER DOESN'T SLEEP, SO FOR ONE NIGHT NEITHER WILL WE'. This was the attitude illustrated by each and every person present at the event. Relay for life is based on three principles : Celebrate, Remember and Fight Back. The event started with an introductory speech by the students which was followed by Ugam members sharing their cancer experiences.

The relay started with the survivors lap – an inspirational time when the survivors were invited to circle the track together and help everyone celebrate victories. Ugam members led the walk along with other survivors followed by teachers and students .

Cancer Awareness Rally – Deccan to F. C. College , Pune Participation by Ugam members Priti Phad, Ekta & Ajay Pawar: 2nd February, 2015

Mrs. Capt. Ritu Biyani, an army background woman is a Breast Cancer survivor and a founder of HighWay Infinite, NGO, based out of Pune. Through her NGO, she organizes cancer awareness sessions not only locally, in Maharashtra but across India. Her go getter attitude & undying efforts to spread cancer awareness attracts anyone to work with her including us at Ugam, partaking our common goal of spreading awareness about cancer.

UGAM got invited for Cancer awareness rally in Pune on 2nd February 2015 at Shivajinagar. The rally got flagged off by one cute cancer survivor from Dinanath Mangeshkar Hospital in Pune, well known for delivering comprehensive Cancer treatment. We witnessed all age group categories of cancer patient, cancer survivors and family with friends taking part in this well organized rally. We were holding different placards/banners while walking on the roads to spread awareness. The onlookers & passerby's response was enthusiastic, added to it was a street act performed by school boys spreading the message of early detection & prompt & appropriate treatment & not to get panic but face it courageously.



At the end of the rally when other NGO's were talking about their work for cancer awareness, We highlighted UGAM activities in Mumbai. There is definite interest of starting such support group in Pune. We are grateful to Capt. Biyani for giving Ugam an opportunity to join hands with Highway Infinite in pursuing our common target of cancer awareness. As usual, we could not ignore one of the print media to take our interview, giving our satisfying impression about the rally.

NDTV Cancerthon- An Enthralling Experience for Cancer Survivor couple- Ekta & Ajay Pawar : 8th February, 2015



It was one fine evening when we received a call from New Delhi, enquiring about our availability for an awareness program, Cancerthon on N D TV. We accepted NDTV's invite to be a guest panel of a Cancer Awareness Live shoot program scheduled on 8th February 2015 at the very prestigious Yash Raj Studio in Mumbai. As we were never before been part of such live awareness program for any TV media, we both decided to divide our thought process to deliver on the stage. Ekta decided to talk about introducing UGAM & its activities, while I decided to focus on what are the current issues encountered by the Cancer Survivors.

While we were preparing this, as a part of audience of the same program (until our turn comes to be on the stage as a guest), we were closely observing what other prominent celebrities & guest of honor had their share to spread the awareness about Cancer. It didn't surprise us to see Bollywood superstar Salman Khan participating in show via video conference. It really touched everyone to see he entertaining one of his true cancer patient fan & been generous enough to give his autographed cap specially for the patient. We saw quite a few doctors coming on the stage, sharing invaluable Cancer detection symptoms, precautionary measures, how to proceed for treatment once cancer gets detected, how to keep faith in treatment & be patient with the chemotherapy. There were quite a few NGO's too present who shared their valuable support to help fighting cancer. When it was our turn to share our experience, the audience response was amazing knowing the fact that UGAM works for childhood cancer survivors in getting them back to mainstream to lead a normal productive life in society which does not have supportive approach to cancer survivors, be it in an education, job or marital life.

It was like icing on cake when Mohit Chauhan (famous playback singer) sung his own favorite tracks with his melodious voice live on the stage dedicating to cancer survivors. It was not less than an enthralling experience to be part of the show. Such program play pivotal role & an eye opener for the society to except the fact that Cancer can be cured if detected early & one can lead a successful life after getting cured from cancer like us. We genuinely expressed our gratitude to NDTV for organizing this show, before heading to catch the proud reaction from our parents for our work.

ICS founders day: 25th April, 2015



On 25th April 2015 we celebrated Indian Cancer Society's 64th Founder's day at Paladium Hotel Lower Parel. Ugam members were invited to be a part of this event. Chief guests for the day were State Education Minister Mr. Vinod Tavde & Bollywood star and ICS Ambassador Mr. Varun Dhawan. Ugam Members presented a Dance performance which was appreciated by all the guests present.

TYACON : 26TH-27TH July 2014 & 9th-10th May 2015 at Indore



TYACON is a Teen and Young adult conference (TYA) organized every year to discuss special issues faced by this vulnerable age group either as cancer patients or as survivors of childhood Cancers. 15 Ugam members participated in both these conferences. Dr. Purna Kurkure gave a presentation about ACT clinic and cancer survivorship scenario in India. Clinical Psychologist, Mrs. Savita Goswami presented on psychosocial issues of young adult survivors of childhood cancers. Ugam members presented a skit about the ill effects of Tobacco which was appreciated by everyone present.

Ugam Monthly Meetings & Birthday Celebrations:



Ugam members meet every month formally to discuss & plan the future activities. Birthdays of Ugam members and friends which fell during previous two months are celebrated during this meeting. These celebrations are sponsored by active Ugam volunteer Sophie Ahmed.

Victor's Stories:



Chandan Behra

Hello friends, my name is Chandan Behra. I am a Childhood cancer survivor. When I was three years old I got Wilm's tumor in my right kidney. After 2 years of treatment I got completely cured. I was attending ACT clinic for my follow up at Tata Hospital. Later on I have joined Ugam-Childhood Cancer Survivors support group. It is really a great platform for us, the cancer survivors. It encourages us a lot in many aspects so that we can lead life like normal individuals. I am very happy to be in such an amazing support group and the doctors who are very helpful and kind.



Shahbaz Baig

I am Shahbaz Baig. I was born in the cotton city of India i.e. Akola in State of Maharashtra. Ugam is a group of people rendering help to cancer patients. I am Childhood cancer survivor and I am really very Happy/Proud to be a part of such a group.

I intend to share the pain I have undergone in my childhood. I was born in 1992 and I had completed 12 years in 2005. I had high fever and I was feeling tired/exhausted. My parents consulted various doctors in Akola but unfortunately they were not able to diagnose the reason of high fever and exhaustion. Moreover I was feeling weak. Lastly my parents took me to Dr. Sadik and he advised me to do various tests including CBC. Dr. Sadik called for the report and I was diagnosed with Acute Lymphocytic Leukemia (a type of blood cancer)..

Entire family was shattered. It was the most difficult period of my life when I found my friends playing various games and I had to go to various hospitals for treatment. My parents consoled me that they will give me the best treatment and encouraged me to be positive.

Dr Sadik advised my parents that I should be taken to Tata Memorial Hospital for treatment in Mumbai. We went to Mumbai and I was under the care of Dr Brijesh Arora. I had to undergo Chemotherapy & Radiation therapy. Subsequently I met Dr Brijesh Arora and he advised me that I am fine and should go for further follow up in ACT clinic.

I completed my graduation in the faculty of Commerce in the year 2012 from Sant Gadge Baba Amravati University, Maharashtra. I joined the Akola District Central Co- Bank Limited, Akola in August 2012. I gained

experience in dealing with customers and finishing the task assigned to me within the time frame allotted to me. I completed the job in Feb-13 because it was on contract basis.

I wanted to pursue post graduation in finance and I decided to move to Mumbai. I joined Topwheelz Automotive Private Limited as an Accounts Executive with help of Mr. Navin Kshatriya from ICS. I was recognized as the most efficient employee in the duration of six months. I am studying MBA (Finance) part time & also working to support myself & my family.

I Express my heartiest thanks to the Ugam team and doctors for giving me a new life.....



Priti More

Hello Friends, My name is Priti More. I am 17 years old, I am a childhood cancer survivor and now working with Ugam.

In November 2000, when I was 3 years old I was detected with Retinoblastoma a type of eye Cancer. I was very young to understand what had happened but my parents were very shocked. With lot of courage I started with my treatment, I had my operation and started with chemotherapy. At that same time my mother took my admission in the school. My father and other family members opposed her decision. Only because of her I didn't drop out of school. Apart from undergoing my treatment in Tata Memorial Hospital, I was also attending my school but fewer days. I had to endure 12 cycles of chemotherapy and few sessions of radiation therapy. My treatment lasted for one and half year. After completion of my treatment I am concentrating on my studies. Now after 14

years of my treatment I am perfectly fine and healthy. I completed my S.S.C. with first class and have currently passed my HSC exams with 80% marks. I wish to do graduation in Accounts & Finance. I am a part of Ugam for the past 2 years and have actively participated for the last one year. I am very happy to be a part of it. Ugam has helped me to gain my confidence and also have provided me a platform to show my talent. I thank all the Ugam members, doctors and my friends from bottom of my heart. Thank You.



Rahul Raj Sharma

Hello Friends, My name is Rahul Raj Sharma and I am a childhood cancer survivor and active member of Ugam family. In 2003 I was suffering from a major disease ALL, a type of blood Cancer. At that time I was just 9 years old, I didn't understand what happened to me. I faced a lot of pain and difficulties in my life.

At the time of my treatment I was just counting the injections which were injected to me , "ohh!!!.. its 14, ohh!!!.. its 21st today" After some days I couldn't remember counting my injections , but I had to believe that I could win the fight against cancer . In 2006 my treatment was over and I conquered cancer. My health is good now and I am enjoying my college life . Now I will be completing my graduation in commerce. In 2011 I joined Ugam family. After joining Ugam I started participating in lots of events. I talk to many cancer survivors who are my friends now, many doctors are also good friends and we are enjoying every moment together . I am happy to be a part of Ugam family .

Thank you Ugam, Thank you all.



तुषार दत्ताराम खिल्लारे

नमस्कार दोस्तों , मेरा नाम तुषार दत्ताराम खिल्लारे है। मुझे बचपन में ALL (Blood Cancer) हुआ था. २००६ में मुझे बिमारी का पता चला और टाटा मेमोरियल हॉस्पिटल में मेरा इलाज चला। २००८ तक मेरा इलाज चलता रहा, इस बीच मुझे बहुत से परेशानियों को झेलना पड़ा, और उन सब परेशानियों को झेलते हुए अंततः मैंने Cancer पर विजय प्राप्त किया। २००९ में मेरी दवाई बंद कर दी गयी। उसके बाद मैंने B.Com की पढ़ाई पूरी की। अभी मैं काम भी करता हूँ और पूरी तरह से ठीक हूँ। इस सफर में मेरा साथ देने वाले मेरी माँ और पिताजी का मैं हमेशा ऋणी रहूँगा। मैं हॉस्पिटल के सभी डॉक्टरों , सिस्टरों, सोशल वर्करों का भी आभारी हूँ जिन्होंने मेरी और मेरे जैसे ही अन्य कर्क रोगियों की हर तरह से मदद की है और उन्हें एक नया जीवन प्रदान किया है। इस सफर में एक बहुत महत्वपूर्ण बात सीखी है - Never Give Up .



इंजमाम

हेलो फ्रेंड्स, मेरा नाम इंजमाम है। मैं एक कैसर सर्वाइवर हूँ। मैंने अभी १२ वी की परीक्षा दी है। और मैं आगे शेफ बनना चाहता हूँ। जब मैं डेढ़ साल का था तभी मुझे wilms tumor हुआ था। उस समय मुझे जो परेशानी उठानी पड़ी उसका मुझे एहसास नहीं है, लेकिन मेरे माता पिता को बहुत परेशानी उठानी पड़ी थी। उस वक़्त मुझे इस बिमारी का मतलब भी नहीं पता था। जब पांचवी में था तब मुझे बिमारी के बारे में पता चला। उस वक़्त मैं बहुत निराश हो गया था। मैंने समस्या अपने दोस्तों को बतायी। उसके बाद वो भी मुझसे थोड़े दूर दूर रहने लगे। मुझे किसी भी खेल में शामिल नहीं करते थे। इसके कारन मैं और निराश रहने लगा। दसवी की परीक्षा के बाद जब मैं टाटा हॉस्पिटल अपने followup के लिए आया तभी मुझे उगम के बारे में पता चला। मैं उगम के सदस्यों से मिला तो मुझे बहुत अच्छा लगा और मैं फिर Regular meeting attend करने लगा। Activities में भाग लिया जिससे मुझमें एक आत्मविश्वास जगा। आज उगम में मेरे बहुत सारे दोस्त हैं जिनके साथ मैं बहुत खुश हूँ। Thank You Ugam.



We Remember.....

Vaibhav, a true brave heart and a warrior, was born on the 18th of April, 1991. Having completed his schooling and higher secondary education from Yavatmal, Vaibhav was all set to commence his graduation studies in Bachelors Of Science (BSc). It was then that he was diagnosed with Acute Lymphoblastic Leukaemia (Blood Cancer). Frequent hospitalization at the Tata Memorial Hospital in Mumbai meant that he couldn't attend regular college, and had to take a year off. Determined as he was, he secured admission the next year, but unfortunately, his health demanded him to move

in to Mumbai permanently. Vaibhav was one who never believed in the fact that an ailment or disease could win over one's positivity. His urge to serve people and support his family saw him join Sadbhavna Kendra, an NGO that guided cancer patients and families towards funding of treatment and accommodation through various trusts. The manager of the NGO was a big support to Vaibhav in many ways. Vaibhav faced enormous challenges, but never gave up. It was during this period at The Tata Memorial Hospital that he also met the members of UGAM, Victors of Childhood Cancer. The motivation and determination of the members of UGAM reinforced his belief that there was life after cancer. He found the best of his friends in UGAM and the bonding with them made sure that his spirits were always up. After having completed his treatment, Vaibhav secured admission for BSc IT (Information Technology) at a college in Mumbai. He believed that perseverance is the key to success. His quest to complete his education and carve a path towards success had begun. As he attended regular college, he continued working at Sadbhavna Kendra too. Halfway through the first year, he was diagnosed with a relapse of his disease. He was compelled to quit college once again. Through all this, Vaibhav never let any form of negativity affect him. Such was his determination towards completing his education that a newspaper article of his interview led to the Vice Chancellor of Yashwantrao Chavan Maharashtra Open University (YCMOU) herself come to Mumbai and announce distant education courses for those under treatment for Cancer. With this, he enrolled himself into the Bachelors in Computer Application (BCA) programme and restarted his education. Vaibhav had to face numerous challenges, be it financial, health or social, but nothing hampered his progress. He set an example for those who felt that their ailment stopped them from achieving what they aspired for. His family, who supported his endeavours and stood strong through all the tough times, were a source of his strength. His Never Say Die Attitude kept him going. With fun loving people at UGAM, a supportive family, helpful colleagues and the care of the doctors, Vaibhav believed that he could be a cancer survivor too. Anybody who ever met him would agree to the fact that he had a smile on his face that would never fade. In July of 2014, he was admitted to the Tata Memorial Hospital due to deterioration in health. Little did anyone know that he would be bidding farewell to the world at this young age. In spite of the pain that he was going through, he made sure that his visitors had a smile on their face when they met him, be it through jokes or any form of humour. On the 4th of July, 2014, Vaibhav bid final farewell to this world. He set an example of sorts. He spread happiness in all forms that he could. Till his last breath, he did not give up. Every individual that ever knew him took back tales of positivity and bravery. His memories shall always stay with us. It is extremely tough to document the greatness of such a soul. The best way to conclude is to quote him from his interview on IBN Lokmat, " Koshish Karne Waalon Ki Kabhi Haar Nahi Hoti". May his Soul Rest in Peace.



We are proud of you

My name is Shweta Chawre. I've been a bone cancer survivor for the past 6 years and an Animator by profession. I currently work as 3D Junior Animator at Prime Focus World Studio from December 2014. In September 2014, I had worked on a 3D short film "Hungroo" for MAAC Thane. Two months of patience, dedication and hardwork lead us to the "Best Character Animation" Award at the 24 FPS International Animation Award Festival. This was a very big Achievement for me and I'm thankful to all my mentors, doctors, my family

and all my friends who helped me through each and every dark phase of my life to see this beautiful day!

I got a golden opportunity to represent Ugam in "SIOP" Toronto (October 2014) an International platform for all similar NGOs and Childhood Cancer related Organizations to come together once a year and present their respective group. I represented Ugam, and spoke about "Education empowerment" in Childhood cancer survivors who were deprived of education due to the long treatments. It was a very successful conference, me being the youngest in the group of NGOs from all over the world. Thank you Ugam for providing me this opportunity!

What truly defines us is how well we RISE after falling, and with Ugam, we shall Rise like a Phoenix, from the flames!



We are proud to announce the success of our young survivors Shrinidhi Prabhu, Vansh Shah, Raj Singh, Likhith Desai and Anagha Gaikwad of ACT CLINIC and members of Ugam who had participated in 'The World Children's Winners' Games', Russia, Moscow (CSKA Stadium) June 19-23, 2014. Shrinidhi bagged Gold, Silver and Bronze medals. Vansh won Gold and Silver medals. Raj and Likhith were able to rope in Bronze medal each.

MESSAGE FROM THE VICE CHAIRMAN, INDIAN CANCER SOCIETY ON BEHALF OF BOARD OF TRUSTEES

May the Ugam family continue to thrive, to grow and to inspire us with their dedication and compassion towards children undergoing treatment for cancer. The Victors of Ugam are the torch bearers of hope and a true example of our belief that life after cancer is worth living. The Board of Trustees of Indian Cancer Society join me in wishing Ugam a very happy and rewarding sixth anniversary. May this be a fitting start to the Childhood Cancer Survivor Week of which Ugam is a proud participating member.

Ranjan Kapur

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 उमंगो से ये गगन
हम हैं उगम हम उगम

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

चल दिए हम लेकर अपना कारवाँ....