



### 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](mailto:info@ugamcalling.org)

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



# Ugam Calling...

7<sup>th</sup> Anniversary Issue - 2016

International Childhood Cancer Survivor's Week

*What defines us is how well we RISE after falling*



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Convener, Ugam & Hon Director, Cancer survivorship Programme

**Dr. Vandana Dhamankar**

Mentor Ugam & Asst. Director, Cancer Survivorship Programme

**Shekhar Jha**

Executive Administrator Ugam

**Savita Goswami, Dr. Maya Prasad, Dr. Nikita Shah**

Mentors, Ugam

**TMH**

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Dept of Medical Social Worker  
Dept of Psycho Oncology

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Lalitha Nair (Director ICS)  
Ulka Bangui,

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**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**

Convenor Ugam

Hon Director

Cancer Survivorship Programme

Indian Cancer Society

**The Greetings from Ugam on 7TH Anniversary Celebrations!**

journey of Ugam continues in seventh year with its **seven year itch!**

That supposed urge for infidelity after seven years of marriage is the meaning for this phrase, is now often extended to refer to **an urge to move on from any situation.**

Launched in 2009 on the first Sunday of June celebrated as Cancer Survivors Day across the world as a mark of celebration of life, **UGAM** has become a role model for Cancer Survivorship Programme of Indian Cancer Society(ICS). **Project PICASSO (Partnership in Cancer survivorship Optimization)** has been launched by ICS in partnership with HES Infra Pvt Ltd under corporate social responsibility with objective of

- Delivering high quality survivorship care to enhance survivors' long term health by managing concerns related to cancer treatment and survivorship.
- To assist oncologists all over India to implement such programs within their practice.

As a first step towards this goal, Dr R.A. Badwe, Director, Tata Memorial Centre and Mr Navin Kshatriya, Hon Secretary, ICS, have mutually agreed to collaborate and launch this pilot project in Tata Memorial Hospital( TMH)

Aims of this pilot project are-

- Consolidate existing After Completion of

Treatment (**ACT**) clinic for survivors of childhood cancers(0-15yrs at diagnosis) and scale it up as a full time service .

- Expand the services to survivors of Adolescent & young adult(AYA-16-30yrs at diagnosis) cancers on similar guidelines.
- To create model & standard operating procedures which can be replicated at various other cancer institutes to implement the survivorship program.

For the first time, there will be structured survivorship program as an important component of Cancer Control Continuum.

We thank HES Infra Pvt Ltd for generous financial support to make it possible to attain this historical milestone.



We also thank Dr Badwe for agreeing for the collaboration on occasion of Ugam's 7th Anniversary during platinum jubilee year of TMH.

As of now, there is no national or state level policy that addresses employment and health insurance problems faced by survivors. We intend to give thrust to this unmet needs.

Starting last year in June, Childhood Cancer International (**CCI**) members all around the world celebrated International Childhood Cancer Survivors Week or Day. As active CCI member, UGAM merged this event with our existing Anniversary Day celebrations.

**“Together – Stronger” is the theme for 2016 & 2017**

CCI encourages survivors to send stories around the themes mentioned below, to [togetherstronger@mail.com](mailto:togetherstronger@mail.com) which will be shared on social media.

- **REMARKABLE ACHIEVERS.** Childhood Cancer Survivors who are change makers and have made significant contributions to the development of their organization , communities, country. This work may or may

not be related to childhood cancer.

• **MODELS of COURAGE.** Childhood Cancer Survivors, who after conquering cancer, have created new lives for themselves, reshaping their dreams and goals in life, discovering new talents, exploring new potentials, skills and abilities, expanding their horizons.

• **STARS of HOPE.** Childhood Cancer Survivors and their families, who have undergone tremendous difficulties and yet, emerged victorious and triumphant over cancer.

Let us continue to **DO MORE** for survivors. Let us go out of our way this June to show our survivors how much we care for and appreciate them. Let us create special and memorable moments for them and their families.



**Dr. Shripad D. Banavali**

MD (Med; Bom), BC(Ped; USA)),  
BE(Hem-Onc; USA)  
Professor & Head, Department of Medical & Pediatric Oncology

**My dear members & friends of UGAM,**

Congratulations and best wishes for the 7th Anniversary celebrations of UGAM!

UGAM, a voluntary group formed by childhood cancer survivors (mostly treated at Tata Memorial Hospital), celebrates its anniversary on every first Sunday of June. This day is celebrated worldwide also as “Cancer Survivors Day” and UGAM has been ambassador of the message that “**Childhood Cancer is Curable**”.

The mission of this group of “**VICTORS**” is the self-empowerment of the young cancer survivors as well as to help, especially emotionally & intellectually, the children

currently undergoing cancer treatment. Since its formation as a unit of Indian Cancer Society, UGAM has been a trailblazer and a pioneer with many firsts to its credit and has impacted the lives of many children with cancer as well as their families.

Though UGAM means “To Rise”, UGAM also means “**The Beginning**” and in this respect UGAM has helped many childhood cancer survivors to begin a new life after cancer treatment, to make them aware that there can be & is a “normal Life” after winning the battle with cancer.

It is always a pleasure to see these Victors of cancer interacting with each other, as well as with other children undergoing cancer treatment and how with “team -approach” one can overcome any obstacles. These Victors have helped to create awareness regarding childhood cancers; regarding the late effects of cancer therapies; regarding discrimination in the society against cancer survivors; as well as, regarding the need of public support for the cause of childhood cancers. All this will help us better take care of children with cancer and together we can not only improve the outcomes of children with cancer, but also bring them back in the mainstream of society and make sure that these young childhood cancer victors of today can contribute in a big way back to the society in the future.

I wish UGAM the best and hope that we continue to work together in the future also for improving the outcomes of children with cancer.



**Naveen Kshatriya**  
Managing Trustee & Hon. Secretary  
Indian Cancer Society

This year 5th June is the National Cancer Survivors Day & 7th Anniversary of Ugam

On this day a Celebration of Life is held in

communities around the world, on the first Sunday in June every year in honour of cancer Victors!

It is a

- **CELEBRATION** for those who have survived,
- an **INSPIRATION** for those recently diagnosed
- a gathering of **SUPPORT** for families, and
- an **OUTREACH** to the community.

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.

This day provides an opportunity to those living with a history of Cancer, to connect with each other, friends, family and healthcare professionals. Celebrate milestones and recognize those who have supported them along the way.

It is also a day to draw attention to the ongoing challenges of cancer survivorship in order to promote more resources, research, and survivor-friendly legislation to improve cancer survivors' quality of life.

We come here today to celebrate the day with UGAM on its 7th Anniversary

UGAM is a voluntary support group, which has been formed by Childhood Cancer Survivors from After Completion of Treatment (ACT) clinic of Tata Memorial Hospital. UGAM is the youngest unit of the oldest & most prominent NGO, Indian Cancer Society( ICS) under its Survivorship programme

Launched on 7th June 2009 UGAM means “To Rise”, underscoring the determination of childhood cancer survivors, to rise above all obstacles in life & be **VICTORS**.UGAM has been set up with an aim to provide a helping hand to the survivors of childhood cancers & become the ambassador of the message “Childhood Cancer is Curable” in society.

Today we have about 2000 young survivors registered. We want to bring in lot more in this fold with the help of the enhanced

survivorship program being developed collaboratively by TMH and Indian Cancer Society.

Our mission in the next one year is to create a model Cancer Victor Program, to enhance the quality of life of children and young adults who have bravely fought and survived Cancer. Our Vision is to roll this model program out across the country across all the 56 hospitals of National Cancer Grid by 2020.

These survivors – need to be a productive and active part of our society, need as much warmth, encouragement and love as would all of us. Let us come together and help them find their wings, so that they can successfully fly to their desired goals and destinations.



**Dr. Vandana Dhamankar**

Mentor Ugam  
Assit. Director Survivorship Program ICS

Heartiest Congratulations to Ugam on 7th anniversary. It is with immense pleasure that I am writing in this newsletter today! I have witnessed the foundation of Ugam on 7th June 2009..Little did I know then that it is going to be such a wonderful survivors support group!

Ever since I started working in ACT Clinic in TMH; I always felt a strange connection with the cancer survivors ;now called Victors, and wanted a comprehensive and co-ordinated uniform care across India for the survivors. Thanks to ICS which has taken an initiative in this aspect, with plans to collaborate with premier cancer institutes like TMH, this dream is turning into reality.

For this to happen we need to make a good strategy and set realistic goals and work as a team to achieve the same. Ugam has proved time and again that it is an excellent team and I would like to see them continue to stand united to make this survivors group one of the best in the world! I am proud to be associated

with Ugam. Not only have they successfully executed various events on the home front but also represented the group internationally! Kudos to Ugam members for their zeal for life despite having to face a unique set of challenges as cancer survivors! I will be happy if I am able to optimally use all the resources available to us to make life after cancer the best it can be.

I wish them all the very best for future endeavors..

Badhte hi jana hai Ugam.....



**Savita Goswami**

Mentor Ugam

Clinical Psychologist

Tata Memorial Hospital

**Dear Ugam Congratulations.....We have reached our 7th anniversary.**

Over seven years Ugam has really grown up in strength, maturity and awareness about own responsibilities. Since year 2015 Ugam has taken up the mission of capacity building and educational empowerment of childhood cancer survivors and planned various programs to achieve the target.

Communication skills training workshop, education and vocational guidance (EVG) program were conducted during year 2015-16.

This year Ugam was more focused and structured about planning EVG program. We prepared a data bank of Mumbai based Ugam members who need educational and vocational guidance and then in continuation of last year we had organized **“Ugam-Educational and Vocational Guidance Program for Adolescents and Young Adult (AYA) Survivors of childhood Cancers on 16th of April 2016”**. This was a one day program which was attended by 60 children and their parents. Objectives of this program were a) Identifying challenges faced by AYA

survivors in achieving educational/vocational goals b) Addressing need for educational/vocational support/ interventions for improving QOL of AYA survivors c) Career Information & Career Planning d) Identifying available resources and their optimum utilization for empowerment of AYA survivors e) Create new resources to meet their requirements.

Excellent faculty from varied fields of education, counseling and vocational rehabilitation besides expert oncologists participated in this workshop and emphasized the importance of educational and vocational guidance and need for rehabilitation and support for empowerment of survivors.

Physical and cognitive disability, psychosocial issues, financial constraints makes the path of AYA survivors more challenging. Unfortunately survivorship care and empowerment continues to be neglected by oncology care-givers and the society. To stream line a support network for survivors rehabilitation we have created a data bank. Each participant of this program has given a detailed profile about their educational qualifications, area of interest, area in which they need guidance, financial support or any other resources. This profile will help in categorizing their major barriers in achieving education and employment and mobilization of need based resources for support. During the program Career guidance expert explained about role of aptitude test in selecting appropriate career. Many students and parents had shown keen interest in doing aptitude test but they felt it may not be affordable due to high fees for testing. Ugam has taken initiative and arranged aptitude test in collaboration with Disha Counselling centre on 8th June 2016 for interested AYA survivors at affordable cost.

In future Ugam and Indian Cancer Society has a plan to expand this program as one of the most important component of full-fledged survivorship program. We believe that **“Education is the most powerful weapon which can be used to change the world of the AYA survivors of childhood cancers”**.

My best wishes to Ugam on this great occasion.

## No Tobacco day 31st May 2015 SAY NO TO TOBACCO



Tobacco is one of the leading causes of cancer deaths in India. This year, to mark the occasion, Indian Cancer Society had set-up an awareness campaign at Marine drive in which Ugam members volunteered in large numbers. Our role was to increase awareness among people about the ill-effects of Tobacco. During the drive many people approached our Members and expressed their interest in joining Ugam and asked us about our activities. Members also distributed Ugam News letters to the people present and appealed not to consume Tobacco related products in any form as it may cause Cancer. An effigy of Cigarette was displayed to write messages on it and people actively participated in writing messages! The response received during the campaign was good as people responded positively and many of them congratulated Ugam members for their work, which was motivating.

## 6th Anniversary Celebrations of UGAM 7th June 2015



As we have been doing for the last 5 years, this year too we celebrated the annual survivor's day function, 6th Anniversary of UGAM – the victors of childhood cancer on 7th June 2015. Ugam, as we all know, is a voluntary support group of childhood cancer survivors, which was started on first Sunday of June 2009. On Sunday, 7th June 2015 the event was held at Tata Memorial Hospital to mark the 6th

anniversary of Ugam. The response was very good this year. About 450 survivors, active patients with parents attended the program of which 150 were Ugam members. The program started with a prayer by Ugam Members led by Mrs. Savita Goswami. Everyone in the auditorium observed silence remembering departed Ugam friend, Vaibhav Shinde who was a source of inspiration and strength to all Ugam members.



All Ugam members were dressed in Bihari attire which embodied the theme very well. Ugam members & friends under able guidance of Dance teacher Mrs Mahua Roy presented Bihari dance performances like Kajari, Chhath and Holi (Jogira) with Shekhar Jha explaining Culture of Bihar in an audio visual show which included a very fruitful presentation about world renowned Nalanda University and Bodhgaya festival. Honourable guests, Famous Chef Mr. Sanjeev Kapoor & Member of Parliament Mr. Manoj Tiwari, Mr Ranjan Kapur, Vice Chairman, Indian Cancer Society, along with Ugam Family members lighted the traditional inaugural lamp & released 6th Newsletter of Ugam. Our young achievers who had made an impact academically and professionally in life post their cancer treatment were felicitated by the guests present. Mrs. Savita Goswami made a power point presentation summarizing various activities undertaken by Ugam during the year 31st May 2014 to 31st May 2015.

Our young survivors Aakansha and Upahaar danced magnificently in their respective solo performances. Ugam member Mohd. Ali showcased his exceptional singing talent which enthralled everyone present in the auditorium. Ugam members and friends also enacted a skit which highlighted the current scenario of educating a girl child in our society. It was concluded by singing of Ugam's theme song composed & conducted by Emmanuel

one of the active Ugam member. The programme ended with a vote of thanks & dancing with DJ. 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 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. As 1st week of June is also celebrated as International Childhood Cancer Survivors week, Ugam had organized ' Vocational Guidance and Communication skills' for young survivors so that they benefit by getting relevant information, practical options & suggestions in education, training and career planning and 'Communication skills training workshop' to empower Ugam members in communication, decision making and problem solving. We received a very positive response as more than 100 members benefited with these workshops.

### Educational Program at Taj Mahal Hotel : 27th July 2015



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. dance performances were the entertainment for the day. Ugam members presented a Dance performance which was enjoyed by the

children and also appreciated by chief guests, actress Mrs. Renuka Shahane. Young survivors were also felicitated by her and were given need based scholarships based on their performance in exam. The event ended with Ugam's theme song.

### Dahi Handi celebration on 5th sep. 2015



This is another regular event of Ugam Calendar, Ugam members were invited to Celebrate Dahi Handi on 5th Sep. 2015 at Pali Talav, Thane, by Mr. Rajan Vichare, a Member of Parliament, Thane, Maharashtra. More than 15 Ugam Members participated in the event. One of the Ugam member Priti, who was "Govinda" on that day, broke the Handi. We also raised the fund, They created awareness about cancer in the community through this event.

### आज की रात है जदिगी ( AKRHZ)

#### UGAM's Stint with Mr. Amitabh Bachchan

We were thrilled to receive an invite from Start India Pvt. Ltd to participate in the finale of show called आज की रात है जदिगी (Aaj Ki Raat Hai Zindagi), an immensely popular show engaged with highlighting the unnoticed social work done by individuals/groups across India and anchored by none other than Bollywood legendary Mr. Amitabh Bachchan.

Finally on 4th December 2015, as per schedule we were asked to reach well before event so that we could be briefed about the show in terms of code of conduct, time constraint clause according to which we need to describe the UGAM work which was a sort of dress rehearsal of finale. When we reached to Film City, we were amazed to see the hard work put in by these behind the camera team. From those hustle bustle view to the actual set of AKRHZ, we were taken to make-up room

where entire team was present including Dr. Kurkure, Ms. Savita & the UGAM dance team who were all set to share the stage with Mr. Bachchan & popular comedian Bharti Singh.

Mr Bachchan, Big B as he is popularly known, came walking from the descending stairs, his current age still carries that refreshing energy & the enthusiasm in spite of the fact that he was shooting for the show from the morning 8 am. No other reason why he is a true legendary for his commitment & the passion for his profession.



Ugam team was first introduced by Mr. Bachchan himself followed by a group dance by UGAM troop with Bharti Singh. Mr. Bachchan did remember our UGAM spirit Shobhit who met Mr. Bachchan in March 2009 at his residence on personnel invitation of Mrs Jaya Bachchan after his solo art exhibition in gallery where she was invited as chief guest. We not only amazed with his sense of acknowledgement but want to applaud his sharp memory of UGAM. After the dance segment, Mr. Bachchan interviewed our Ugam convener Dr. Kurkure to let the world know what UGAM is all about. It was now turn of Ugam members to speak directly with Mr. Bachchan. We did spoke confidently knowing the fact that we were facing the live camera for the first time & that too in front of someone legendary.

The show was finally concluded at 12:30 am which was the last episode of the show too. It was such an enthralling experience for all of us. Last but not least which we really didn't want to miss was a group photo with Mr. Bachchan for which he agreed spontaneously. This was such a mesmerizing experience & we thoroughly enjoyed it. UGAM got platform to connect with people who are looking for help & second to see Mr. Amitabh Bachchan in person who too wished all the very best for our journey ahead.

### Cancer Shero Trek- Pinkathon 5th Dec. 2015



Ugam was invited for a trek cum walkathon arranged by United Sister's Foundation at Naga trail, Vasai on 5th Dec in which Ugam members participated. This was to motivate Cancer survivors that they too can live a normal life after winning over Cancer. United Sister's Foundation is a Foundation to motivate and empower women especially who are Cancer Survivors. Ugam members were felicitated at the end of the trek. Lots of Thanks to 'United Sister's Foundation and their mentor Rishita, the trek expert who were really helpful all the time.

### HOPE : 12th December, 2015



HOPE is the biggest Annual Event at Tata Memorial Hospital organized by department of pediatric oncology. This year's theme was DANCE. The event was attended by more than 350 cancer children and parents. Extraordinary performances by dancers and artists not only thrilled the kids but also entertained everyone presented in the auditorium. Celebrities like actor Neel Nitin Mukesh, Bollywood comedy star Jhony Lever and notable choreographer Bosco 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 volunteered for the event. Ugam members participated in dance performances and also took part in distribution of gifts and food.

### Relay for Life ( RFL) : 16th Jan, 2016 / 1st April 2016

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 16th Jan 2016 & 1st April 2016 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.

**A new chapter in RFL called Rural relay for life, The program was held in Virar**

**Shirleywadi Our Lady of Lourdes Church on 31st January 2016. It was a beginning to expand RFL in the Rural areas. This was an important day for us as Mr. Adam Schwartz , lead volunteer for Relay for life from the American Cancer Society graced the occasion.**

### Mumbai Marathon on 17th January 2017



17th January, 2016 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 various charity organizations. Ugam got an opportunity to participate in this event as a unit of survivorship programme of Indian Cancer Society . On that day, 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 had 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.

### World cancer day 4th Feb. 2016



Indian Cancer Society celebrated the day by organizing a friendly cricket match between ICS and UGAM. The match was played at Shivaji park ground. It was a friendly match but both the team played competitively. The support for the teams were great and it was well organized and the main purpose was to show the world that we can be normal and play a sport which is a religion in India. We are hopeful about more members join us in celebrating world cancer day

### Interaction with childhood cancer patients and their parents



One of Ugam's missions is to help children undergoing treatment for cancer by counseling at the same time bring social awareness among the masses that Cancer is curable. As a group of Childhood Cancer survivors Ugam Members are always ready to share their experiences with cancer patients to motivate them and help them in fighting Cancer. When Ugam was given the task of counseling the patients and parents of St. Judeat childcare center at Kharghar it was not less than a challenge! Most of the Ugam Members are either working or studying so they take time out from their routine, take turns to go to St Jude at Kharghar, once in every three months for counseling and are often confronted with tons of questions not from the patients but their parents who sometimes get surprised to know that the person to whom they are questioning is a Cancer survivor himself so they immediately bond with us! Some parents also ask medical, treatment related questions to our members where our members honestly tell that they are not the experts and encourage parents to speak to experts. We note down those questions and discuss in our Monthly meetings with Dr. Purna Kurkure and Mrs. Savita Goswami. Ugam Members feel that interaction with

parents and patients give them a lot of insight and strength about their own life.

On 20th march 2016 Ugam members interacted with parents and patients in the pediatric ward at Tata Memorial Hospital. These biscuits which were given by Vandana Cancer trust due to the kind efforts of our Ugam Member Tushar Khilare. It was a pleasure to see the happiness on the faces of those small children as our Ugam Members made them forget their pain for a while. Ugam would like to thank Vandana Cancer trust for the generous donation.

### National Park Trip on 3rd April 2016



Mr. Richard Ramos who is a Nurse in a hospital at California visited Tata memorial Hospital for one of the pediatric Oncology training program for nurse specialists. Mr. Richard also visited ACTclinic and actively listened to the experiences of childhood cancer survivors and expressed that he would like to spend some more time with young survivors informally either on a trip or trek which he was ready to sponsor for more interaction and to understand survivors perspectives because that is his area of work and interest. Mrs. Savita Goswami organized the trip and Ugam members were taken to Sanjay Gandhi National Park. Mr. Richard was keen in doing something good for the survivors while he is doing his research. He interacted with Ugam members on various topics like their cancer journey, fight with cancer, their education and further interests. All of us strolled across Kanheri Caves ,also enjoyed the Tiger Safari which was followed by Lunch . Mrs. Reena Nair nurse at TMH also accompanied and spend some quality time with Ugam members. All Ugam members enjoyed the field trip and sharing experience.

## Ugam-Educational and Vocational Guidance Program For Adolescents and Young Adult Survivors of Childhood Cancers 16th April 2016

The educational and vocational guidance program for Adolescents and Young Adult Survivors of Childhood Cancer received an overwhelming response of more than 62 Survivors with their parents. All the sessions held during this program were really insightful for parents and young survivors. First session was panel discussion on "Addressing need for educational/vocational support interventions for improving QOL of AYA survivors". Panelist were Dr. (Col) Prakash Chitalkar (Founder of TYA Cancer Foundation, Director Sri Aurobindo Cancer Institute, Professor of Medical Oncology), Dr Purna Kurkure (Convener Ugam), Dr. Girish Chinnaswami (Pediatric Medical Oncologist), Dr. Laskar (Radiation Oncologist), Dr. Jalali (Neurooncologist), Dr. Jayita Deodhar (Psychooncologist), Dr. Vandana (Mentor, Ugam). Panelists made the session very interesting by addressing important issues in simple manner and in Hindi language.

Dr. Rajendra Badwe (Director, Tata Memorial Centre) and Mr. Ranjan Kapoor ( Vice chairman of Indian Cancer Society) inaugurated the function and addressed the audience.



The next session was about career planning and career information by Disha counseling centre (DCC) by Ms. Sheetal Ravi the Director & Counseling Psychologist of DCC, Ms. Sheetal gave a detailed information on the various courses which can help children to choose their educational stream or vocational courses. DCC also displayed exhibition in the auditorium foyer on educational and vocational courses so parents and children can see majority of options and also clarify doubts

with the DCC experts.

Afternoon session started with panel discussion on "Identifying educational Vocational Support inventions and resources for empowerment of AYA survivors" experts participated in this session were Dr. Neela Dabir (Director B.voc, TISS), Mrs. Ulka Bangui (Director of awareness and detection at ICS), Mrs. Shalini Jatia (Secretary, ImPaCCT foundation, TMH and Mrs. Sheetal Ravi (Counseling Psychologist, DCC) Dr. Dabir spoke about Work Integrated Training Programme (WITP). This Vocational Educational Programme is being implemented for the first time in India with a focus on job-specific skills rather than providing only a broad based education, where students learn the skill by engaging in on-the-job training at real shop floor of the industry/company. Both the panel discussions were proceeded by Mrs. Savita Goswami a Clinical Psychologist at TMH, she made the sessions more interactive by asking the panelists relevant and important Questions which proved to be a great help for many parents and survivors who attended this session.

## ICS founders day: 1st May 2016



Indian Cancer Society's 65th Founders' Day was celebrated on May 1, 2016. Shri Piyush Goyal, Minister of State for Power and New and Renewable Energy was the chief guest at the function. Ugam members participated in the function.

Shri Naveen Kshatriya, Hon Secretary, ICS shared the vision and mission for the coming years. He emphasized on the need for people from all walks of life to participate in the Rise against Cancer movement which will make a difference to millions of lives in our country. ICS will launch this movement with giant steps in cancer awareness, early detection, treatment support, rehabilitation,

survivorship, research and learning.

The energy and spirit of the Ugam members, who performed dances, touched the audience emotionally. Ranjana Saha gave a light classical music performance. Auditors, Lawyers and others who do pro- bono work for ICS were felicitated for their long term assistance. The event was attended by more than 250 people from the corporate world, who have been staunch supporters of Indian Cancer Society.

## SelfV HCG Survivors Campaign



'Healthcare Global Enterprises Ltd HCG 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 youtube and facebook and they managed to rope in some excellent reviews. Audience in the social media were inspired and awestruck with the massive valor. Out of the 245 Cancer Survivors who had participated all over India, Narendra Shetty & Shekhar Jha's Selfv's were shortlisted in the top 10 inspirational videos. Narendra was ranked 3rd and Shekhar was ranked 9th. The SelfV campaign was not only a gigantic accomplishment to Ugam members but also to cancer survivors all over the country.

## Race of Hope



Race of Hope is an Annual Fund Raising Event of the Indian Cancer Society of which Ugam is an integral part. This year's race of hope was organized as a Two day Carnival show. Ugam participated on the 2nd day where we distributed souvenirs to guests and helped in the fund raising activities.

## The World's Children Winners game Russia



Children of Tata Memorial Hospital represented India by participating in the World Children's Winners games held in Moscow every year.

This grand event is more than a mere athletic event.

These are

celebrations for those children who have won their main victory over illness. "Winning is not the main thing" taking part in a competition is just as important. The greatest accomplishment end glory for them is the ability to feel free, to move around, to participants in sports. They were deprived of these abilities for such a long time during their treatment. All these young participants have faced life-threatening disease at some point in their lives.

The first Children's winners games took place in Moscow in 2010 and are being held every year since. This was the second time India was invited to participate. The Games were organized by a non-profit organization 'Gift of Life' and second club Locomotive and were held in the Locomotive stadium, This year 500 children from 14 countries, including India, participated in six different games viz table tennis, swimming, football, supported walk/ running, chess and rifle shooting. Every team had a slogan. The Indian team's Slogan was 'MINDS WITHOUT FEAR'

The Indian team was represented by 10 childhood cancer survivors from ACT Clinic of Tata Memorial Hospital. The team came back with flying colors, managing to get 8 medals in all (3 Gold, 1 Silver, 4 bronze)

## Victor's Story



**Gunjan Jotkar**

I am Gunjan Jotkar, I am studying in std 12th science in K. J. Somaiya college of science and commerce. In June 2015 from 26 June to 28 June I had participated in sixth international world children's winners games held in Russia through impacct foundation. I had participated in rifle shooting, football and running. I got gold medal in running and silver medal in football in Moscow Russia. The race was held between cancer patients of different countries. I found n made new friends there. This was the best experience for me and my parents. I achieved the prizes only because of the support of my parents n doctors. Dr. Tusshar and ameeta mam were our guiders n supporters in our games. I want to thank the doctors who made me reach my goal. Only because of their support I have overcome my problems and today whatever I am is the struggle, love and support of my parents and thanks to tata memorial hospital for making me capable of this opportunity.



**Preeti Phad**

I am Preeti Phad, 28 years old woman, and this is my story. At a young age of 8 years I was diagnosed with cancer of my left eye (retinoblastoma) resulting in loss of the eye. I underwent treatment of surgery, Chemo and radiation. The treatment got over and was successful, but when I stepped out into the society and world where "Normal" people live, my fear creped in. Low on confidence, morale, feeling lonely in every moment, that is

how I lived. I managed to finish my schooling and First year B.com smoothly. But during my Second year in college, the young adult period, I feared to interact with my peer group due to artificial eye, which doesn't blink and looks weird, making me conscious. At this time "UGAM" was formed and I became its founder member. Ugam members made me feel special and unique. Ugam gave a turning point to my life.

Being a part of ACT clinic and the Ugam Family, the circle of friends, supports of doctors, social workers and psychologists gave me a platform where I could share, express myself and interact which boosted my self-confidence and morale. This platform made me feel comfortable and definitely put my worries and that "weirdness" on the back burner. With this confidence I became NEW NORMAL & completed my graduation and also pursued further with Masters of Social Work from Nirmala Niketan University.

My journey after being a part of Ugam family and completing my MSW motivated me to give back to the society and I decided to help & support cancer patients in any way I can to see that they complete their treatment. This opportunity was given by Gunvati J. Kapoor Foundation where I am presently working as coordinator placed at TATA Hospital as Medical Social Worker giving counseling and other support to patients that will motivate the patients to complete the treatment. Along with this I work in After Completion of Therapy (ACT) Clinic for the childhood cancer survivors who come for follow up from all over India, understanding their difficulties/problems, achievements and provide them motivational counseling.

When I got an opportunity to present my abstract in front of the world; on topic "To Understand the Importance of a Support Group in Survivor's Life" at the 47th Congress of the International Society of Pediatric Oncology (SIOP) held from 8th October to 11th October 2015 in Cape Town, South Africa, I felt elated. With the guidance of Dr. Purna Kurkure, Ms. Savita Goswami and Miss Bhavisha Sanadhya, I could send my abstract, travel to South Africa and present my study

findings to the world. This research portrays on how Ugam aims at providing a helping hand to survivors of childhood cancer. The support group helped its member significantly to bring about a positive change in their perspective and identity as a survivor. This counselling not only helped the little cancer patients reduce fear, anxiety, but also increased the self-confidence and self-esteem thus emphasizing on impact of support group which plays an important role in psychosocial rehabilitation of young adult survivors. My presentation was applauded with a standing ovation from the audience.

All this was possible due to Ugam family who supported me at every step. My confidence and self motivation made me travel abroad; present my abstract, live alone in an unknown country & bring back glory to Ugam. I think I have lived up to the opportunity given to me. Thank you UGAM & the entire team who stood by me throughout.



**Shalaka Mane**

My association with Ugam is since it was just a dream. It was in 2007 in SIOP where survivors across globe came to India for a survivors programme in which I participated. There I met many survivors from India and one name I cannot forget is 'Shobhit' who wanted to bring Survivors under one roof for a noble cause. This dream of Shobhit was fulfilled by Dr Purna Kurkure and Ugam was born in 2009 but the sad part was that Shobhit was not in this world to see his dream come true.

I am associated with Ugam from the day it was born and this year Ugam will step into its 7th year. After fighting with Cancer for two times me and my family hardly had any strength to fight the 3rd battle of Panipat with an unseen enemy like Cancer when my mother too was diagnosed with Uterus Cancer. We did not give-up but decided to fight back and we won.

Friends, Cancer taught me two things in life 1) never give-up and 2) try until you succeed. Ugam taught me many things. It has taught me- How can you make your life beautiful, How can you live your life not only for yourself but for the one who loves you more than yourself, for the one who needs you more than yourself. Ugam gave me my Identity and I thank Ugam for that. If you too want to do something good for yourself or for Cancer survivors and for Cancer Patients come join us.



**Vanchinathan**

Hi..... I am back with my story. Last time (2 years back) my story would have put a smile on your face, joking about my marriage life. Only I know what was the consequences once my wife came to know about the story. So no more jokes please. This time I will tell you about my other family, my "UGAM FAMILY".

I became member of Ugam 5 years back. Ugam changed my way of thinking. I was always stressed thinking about my future. After getting in Ugam, the members made it easy for new member like me. The first survivor I met was Preeti Phad. The first time we met, we talked about serious and matured matters. This kind of matured talking group consists of Shalaka, Sampada and Arun with whom sitting in a room will look like a professional meeting room. The next group with whom I can share my personal things in my life are Narendra, Shekhar, Sachin and they share their personal things too. We share our opinion and experiences. The next group which makes me feel like a youngster (I am nearing 40!) talks about their college life, fun & It consists of Vishal, smruti, shifa, Aishwarya, Harsh. Then there is the best group with whom I can become like a child doing silly things, pulling their legs taunting them dominating them and it consists of



Bhaves, Bhaskar, Taha, Inzmam, shahzad. The main reason for putting you through stress of reading this big para is just to show how heterogenous this group is. There is unity in diversity & we have complete package in Ugam members. One can be always happy while in this group and can have interaction with anyone group according to their mood. (Special thanks to whats app)

And above all there is Kurkure mam, Savita mam and Vandana mam from whom I can take guidance in whatever I do. so big thanks to them.

The main reason for me joining Ugam was to create awareness about cancer in my area and with Ugam I feel I have created a little bit awareness which is a small step and it has encouraged me to be brave and talk about cancer to anyone and debate with them that cancer is not the end of the world.

On personal front I was in a lean period not knowing how to deal with the situation but constant support of Ugam members has helped me a lot. That is what Ugam can do for you. By actively participating in most of the events of Ugam, I don't feel that I am getting older while being in constant touch with young survivors. So this prescription is free any one can avail without any charges.

Tried hard to keep this story on serious note !!



**Aakash Kadam**

My name is Aakash Kadam. I am studying Banking and Insurance (SYBBI). I live at Ulhasnagar. In July 2010 I had blood cancer. I was treated in Tata Memorial Hospital, my treatment lasted for about 1 year. After that I was perfectly fine, Today I am a member of Ugam, I learned so many things after joining Ugam. Today I am a guide to other cancer patients. Ugam has given me the confidence to move forward in life. Today I am living a good and normal life. I want to give advice to other cancers patients that now cancer is not any fatal disease, It can be completely cured. All

you have to do is to increase your confidence

and always have to think positive in your life. Thank You.



**Sandeep Yadav**

My name is Sandeep Yadav, I am from Uttar Pradesh. Everything was going well. One day I suddenly had pain in my hand so I went to the doctor, after undergoing some tests I was diagnosed with cancer. I came to Mumbai, and took my treatment at the Tata Memorial Hospital. I am grateful to my family, doctors and social workers of Tata Hospital who equally contributed in helping me to complete my treatment successfully. I was completely cured. I continued further studies and I am doing BA. Recently I was selected for professional oncology care giver course which was jointly done by Tata Institute of Social Sciences(TISS) and Sanjeevani organization. Accomodation in Mumbai for the course was funded jointly by Ugam & Sanjeevani. I am very grateful to Ugam & Sanjeevani. It is my dream that I will do much more to help Cancer Patients. Now I am working with V care foundation and I am very Happy.

“Jindagi me kabhi udaas matt hona, kabhi kisi baat par nirash matt hona!

Jindagi sangharsh hai chalti rahegi, kabhi apne jine ka andaz matt khona”



**Bhaskar Pandey**

My name is Bhaskar Pandey, I live in Sangharsh nagar, Chandiwali, I had blood cancer in year 1999, At that time I was 4 years old, At that time I was taking my treatment in Uttar Pradesh, My first operation took place in Faizabad and then I was referred to Mumbai at

Tata Memorial Hospital. My family members were very upset. I was brought to Mumbai for further treatment. I got great help from Tata Hospital, I had lots of problem during treatment but my father always tried to keep me happy. My neighbors and my relatives always kept away from me. They felt if they came close to me, they will also get affected with the same disease. In 2012, I Joined Ugam. Ugam has helped me a lot, I made many friends .I have participated in so many events of Ugam. After joining Ugam many doctors know me personally, they all love me. I completed my 10th and 12th from Mumbai. I got 56% marks in 10th and 58% in 12th. Currently I am doing a job in D-Mart, I am very happy to be a part of Ugam Family.

## We Remember...



**Niranjan Parikh**

The children's wing at Tata Memorial Hospital may resound with squeals of laughing and playing kids, but the shrill whistles of their beloved 'daddu' are missing. Absence of the late 78-year-old Niranjan Parikh 'Daddu', is strongly felt in the long winding corridors of the hospital. After having served 22 years at the hospital selflessly, his silence will be noticed for ever.

Born on December 25 (no wonder he was the Santa for all the kids), Daddu wore many hats. He was a disciple of Vinoba Bhave and an active member of his Bhoodan Movement. At 72, he was a part of Indo-Pakistan peace march in 2005, conducted from Delhi to Multan, on foot.

For the past 22 years, Daddu worked for the

hospital without a break. His day would start at 10am but would end only when he felt 'all was done'. All day long, he would counsel patients and their patients. Taking initiative on working on 'how to improve the treatment and lives of patients' was a relentless goal. He was a creator of systems. He developed mechanisms to screen patients, identify the needy, raise funds and give psycho-social and financial support to child and adult cancer patients. He started creating social support groups by involving volunteers in paediatric oncology department and widened the realm of work in adult oncology divisions including bone and soft tissue, head and neck, thoracic, brain tumours and breast cancer.

His inspiration probably came from the 'smile' of the patients.

Although Daddu is missed by us all, his smile, inspiration and energy will always remain with us.

Daddu was associated with Ugam since 2009. He was very active person. He never said no to any work and would do everything he could do. Daddu was very helpful person and especially for Ugam members he always behaved like a friend than a senior member. He was like a strong Pillar for Ugam Family. He always actively participated in all the events of Ugam, let it be Cricket Match or any education programme he was always a star of the event. He was very supportive and a humble person and a great human. We Ugam members can never forget him. Ugam is incomplete without you Daddu.



## A big opportunity to meet The President of India



14 Pediatric Cancer Survivors from Tata Memorial Hospital had a lifetime opportunity to meet The President of India Shri. Pranab Mukherjee on Friday 17th July 2015. Apart from the memorable photograph moment with the President, we also took a tour of the Rashtrapati Bhavan where we were served tasty snacks (Thank you all the staff at the Rashtrapati Bhavan for being such a nice host who welcome children with gratitude and respect)...Children also enjoyed their two days Delhi sight-seeing and outing.

## We are proud of you

Aakanksha Gupta & Anita Gupta Received An Award from Rashtriya Shakti Foundation In Collaboration With CPAA (Cancer Patient Aid Association) & Parliamentarian Ms Priya Dutt. Aakanksha for fighting the disease and Pursuing her academics and Anita for her excellent work In the field of social work.



"WINNERS IN LIFE AWARD" Anita Gupta & her Daughter Duo Have Received An Award From Zee Media In Collaboration With CPAA For Being Winners In Life & For Being An Inspiration To others. Their Story Was Selected by renowned jury members amongst 200 stories .



Mihir Shailesh Danak won gold in softball game at special Olympics game 2015 At los Angeles U.S.A.

Shweta Chawre got victors award from Vcare foundation



Gunjan Jotkar won gold medal in running and silver medal in football in Moscow Russia at the sixth international world children's winners games

## 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 ....