

UGAM CALLING....



UGAM - Victims of Childhood Cancer

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THE USAM FAMILY

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Patient Support Group

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Emcees

Ms. D.E. Sharma
Rs 5000, June 2009

Mr. J. R. Shetty
Rs 5000, June 2009.

Ms. Bhagyani Ramchandrabai Mubbi
Rs 500,500, March 2010.

Mrs. Nina Gupta
Rs 7000, April 2010.

Creative Eye Ltd.
Rs. 5000, June 2009

Mr. Sanjay Bano
Rs 5000, June 2009.

Mr. Santosh Khankholwal
Rs 5000, April 2010

It gives me a great pleasure to put down my thoughts for the launch issue of Ugam's newsletter.

Ugam is a voluntary support group which has been formed by Childhood Cancer Survivors from the ACT Clinic of Tata Memorial Hospital, inspired primarily by late Shobhit Kashani & survivors from across the globe with whom they interacted during the International Pediatric Oncology Society Meeting in October 2007. Ugam was formally launched on 7th June 2009, first Sunday of June celebrated as Cancer Survivors Day across the world.

I congratulate the enthusiastic members of Ugam for taking big strides in the first year of their existence & launching a newsletter on the first anniversary of Ugam.

UGAM means "Be Blunt", underlining the discrimination of childhood cancer survivors, to rise above all obstacles in life & be **VICTORS**. The dream of such a support group was seen by a childhood cancer patient, late Shobhit Kashani, who was a budding & very talented painter-poet. He held his first & only art exhibition in March 2009 while fighting a losing battle with cancer & succumbed a month later. Shobhit, through his courage and indomitable spirit, touched the lives of so many people during his own short life. He fought cancer on his terms, never giving up and was full of hope and a fiery spirit right till the end. He left behind his fighting spirit, strength and vision to start the support group that will help millions of childhood cancer survivors. His dream of providing the best possible helping hand to the survivors, to build up their life from ground zero & live life like normal human beings. He left behind his passion to carry his dream to a new high.

UGAM is the youngest unit of the oldest & most prominent NGO, Indian Cancer Society (ICS) under its mentorship programme. ICS has been involved in the crusade against cancer for more than 55 years and is recognized by the Indian Government as the premier Non-Profit Organization for cancer in the country.

Mission:

1) Self-empowerment of the young survivors

- Fulfilling their dreams that were put on hold while they were battling this tormenting disease and the hardships of the treatment.
- Helping in overcoming social fears and inhibitions.
- Overcoming their physical and mental disabilities and moving ahead despite them.
- Educational and career related assistance and guidance.
- Reestablishment and moving ahead in the desired direction in the future life and pursuing their careers.
- Recreation and fun in their present life.
- Creating awareness regarding the late-effects-of the treatment and spending the needed resources.
- Reinstating the confidence and power in the survivors.
- Uniting other such survivors and organizations from around the world and working with them.
- Facilitating assistance from the government and other local and regional bodies.

2) Helping Children with Cancer undergoing treatment:

- Young patients undergoing treatment can be helped in overcoming their fear, anxiety and uncertainty by bringing them in touch with those who have survived.
- Helping them to understand and accept the sudden changes happening around them.
- Building up their confidence and faith.
- Educating them about the disease and the treatment from the non-medical point of view.
- Arranging therapeutic and recreational activities for them.

2) Social awareness and re-bonding with society:

- Involving the survivors with society and helping them re-establish themselves.
- Spreading information and knowledge about the survivor group and emphasizing the survival rate of childhood cancer.
- Growth of the group and getting affiliated and collaborating with other such national and international groups.
- Creating awareness programmes for youngsters and involving them with the group.

UGAM has been set up with an aim to provide a helping hand to the survivors of childhood cancer & become the ambassador of the message "Childhood Cancer is Curable" to society. Ugam has been a trail blazer and a pioneer with many firsts to its credit since its inception.

Our plans for the future

As the strength of Ugam increases in the form of survivors as volunteers, we plan to organize social activities like blood donation camps, fund raising events, organizing interactive competitions (deals, morning sessions, group dances etc.) in association with premier entertainment television channels, for cancer patients & survivors.

Message:

With their hope, the family from West Bengal had brought their daughter all the way to the TSH in Mumbai, praying for a miracle that might just save her life. I watched them closely as they listened to the lady tell them in Bengali how she herself had fought cancer years ago, and survived. Deep in the eyes of the parents, I saw the veil of despair and fear fall away, to be replaced by courage and the determination to rise above what they suddenly had been struck with.

UGAM's mission is to carry the message that childhood cancer is curable to every family with a child caught unaware by this disease, and to provide them with credible evidence that they too can rise with determination to fight it; that the child can survive, and go on to lead a full and fulfilling life. Doctors, expensive medication, ray guns, breakthrough new forms of treatment, all have important roles to play. But without the will to rise and fight, the recipe for success is incomplete.

On the occasion of this Survivors Day I am writing to send you my thanks and love. The work you do is of vital importance to your shared group, and to all those families in whom you carry your message. You are the wind beneath their wings.

Nihal Karimane CBE
Chairman, Indian Cancer Society

Journey of Ugam

- **12 September 2008: World Leukemia Awareness Day;**
To mark this day as an Awareness Campaign, Ugam organized a Fashion Show & a dance competition where in all the participants were Cancer survivors. The event was graced by the presence of Bollywood actor, **Sulman Khan** who was the guest of honor.
- **3 October 2009; NGO Mela;**
Indian Cancer Society organized a pre Diwali mela with the participation of other NGOs and artists. This Mela aimed at providing a solid platform for all NGOs to showcase their talent. UGAM was the youngest & newest NGO to join this fleet. Ugam participated in the mela by showcasing products made by it's members like specially made Greeting Cards, designer light fans, flower pots, pen stands made from brass , paintings and UGAM T-Shirts designed and made by our own Ugam members. All profits and donations received are being used for our forthcoming social activities.
- **14 November 2009; Children's Day at Tata Memorial Hospital;**
Children's Day is always special at Tata Memorial Hospital since many cancer patients are children. To encourage them to be cheerful & happy, Ugam members spent a day with them & entertained them with some interactive games. We also distributed some goodies.
- **December 2009; New Year Greetings to Children;**
When the entire world is celebrating & exchanging good wishes for the New Year, Ugam decided to celebrate the same with the Cancer patients at Tata Memorial Hospital as they felt that they deserved it the most since they were battling this dreaded disease. Ugam members wished the upcoming year would usher in good health & prosperity. Special handmade Greeting Cards were distributed to the patients.
- **HOPE 2010; Tata Memorial Hospital;**
HOPE 2010 was the first program of the Year 2010. The program was organized by the Pediatric Oncology Division of Tata Memorial Hospital and hosted by the noted Bollywood actor, **Ranbir Kapoor**. This was more of a get-together program with lots of fun activities like dancing & singing performed by Cancer Survivors for Cancer Patient undergoing treatment at Tata Memorial Hospital. Ugam members tried to deliver a strong message of HOPE to fight cancer and encouragement to lead a happy and productive life after cancer.
- **February 2010; 1st National Childhood Cancer Survivor Conference;**
Ceskids, an associate of Indian Cancer Society, Delhi organized the 1st National Childhood Cancer Survivor Conference. This four day long conference gave a platform for some expert panel discussions on different types of Cancers and the problems faced by patients during and after treatment of the same. Ugam members utilized this

opportunity to showcase our performance as a NGO with the help of a power point presentation on the working and inspiration behind UKAM. These kinds of national conferences give the members good exposure to the workings of similar childhood cancer NGOs and the mission ahead of them becomes that much clearer. It gives our members a better scope to spread the UKAM network as well as helps us in expanding and reaching our message to the masses who require it.

• **Founder's Day Celebration of Indian Cancer Society, Taj Hotel**

Ugam participated in the Founder's Day celebration of Indian Cancer Society held on 19th February 2010 at the Taj Palace and Hotel, Mumbai. The children of UGAM put up a lively dance showing their spirit and enthusiasm for living life long size after treatment of Cancer. They received an ever-whispering response from the guests present that night.

• **Art Workshops... APRIL 12th to 15th, 2010**

Madhya Pradesh Gosh artists taught a select few members of Ugam the art of making Gosh Paintings. This workshop was organized by Ms. Urmila Jain, a volunteer with Indian Cancer Society, Mumbai. The artists came all the way from Madhya Pradesh. The Ugam members made the most of it by participating in this workshop along with Dr. Parag Kulkarni. The artists not only taught us how to paint but also gave a different approach towards life which can be as colorful & beautiful as those paintings.

• **Chatal Clinic, Tata Memorial Hospital**

The Chatal clinic is the latest addition to the work being carried out by the Ugam members. The Chatal clinic provides emotional support to the parents of children suffering from Cancer who are unaware of the latest treatment modalities of cancer disease. We inaugurated and launched this program on May 8, 2010 by the hands of Mrs. Poozari Bagal, head of CanKids India, a unit of Indian Cancer Society. We intend to continue this program every Saturday which will be co-managed by two rotational Ugam members.

• **Personal Counseling of Survivors & Parents**

Along with the above periodic activities, Ugam members have a pre-scheduled program which is organized every Tuesday at the ACT Clinic (After Completion of Therapy) at Tata Memorial Hospital. This activity is conducted by two of Ugam's members on a rotational basis. These two members are present at Tata Memorial Hospital every Tuesday where cancer survivors come for their routine check up. Most of them are adolescents and they require proper guidance in terms of their educational and personal social problems & further follow up. Regular follow up is very important and hence we always emphasize on the same.

Dear AJ,

I was born on 17th June, 1982. I remember I was very naughty & used to trouble everyone right from my nursery teacher to my neighbors & mother. Despite this, everyone loved & cared for me because I was an innocent child. There were my childhood days spent with my father, mother, sister & brother. AJ was going fine with me till the age of six.

One fine day my father was walking holding me in his arms & he suddenly felt something wrong at the right side of my lower stomach. He took me immediately to a doctor who could not find anything at first & said everything was okay & normal. But he referred it with a specialist doctor who then confirmed it to be a kind of stomach cancer. To the best of my knowledge no one in our generation even knew about Cancer. My parents were shocked to know about it but did not lose their belief that cancer is curable if treated in time. They took me to Mumbai & admitted me to Tata Memorial Hospital. And honestly that was the beginning of my journey with cancer. I don't know why but I was never afraid of the disease called cancer for the obvious reason that I was not aware what this disease is all about & also because for me I got the opportunity to travel to Mumbai which was a dream city to visit that too by train. So for me it was fun until my treatment actually started but at the same time I was clueless why my parents were so worried & I used to bombard them with so many questions about the disease. I did undergo various treatments like chemotherapy which made me bald. I used to take high power tablets & medicines which left burn marks on one side on my stomach & a dark spot below my chin.

Broadly speaking cancer has left many marks in my life known, but...but...but does not mean I should stop living a Happy Life. Thanks to my parents & my friends/relatives who have guided me through, who have always given me a ray of hope & supported me while I have been suffering from cancer. Today I have recovered from Cancer & am living a happy life since the past 22 years after cancer treatment. During this tenure I completed my schooling, college & a post graduation from a reputed university. I started my career with a reputed IT company called Infosys & am now working with Wipro. In these five years of my career I have seen many highs & lows and achieved remarkable progress. On a business trip, I have travelled to my all time dream destination London & Scotland. Moreover, in the current phase of my life, I am getting married to a girl who is also a cancer survivor from Tata Memorial Hospital & who is also leading a normal & successful life like me. What else can I ask from life? Looking back I don't think I have any regrets. I must say I am really happy now for what life has currently in store for me. I really want to be an example to those who are losing their hope to lead a normal life due to Cancer & I want to say, "Guys, Life is Colorful, just live to enjoy it."

In this journey of my life I have never missed a single follow up at Tata Memorial Hospital where every year I used to undergo a medical check up. This medical check up was not only a physical check up that the doctors used to keep a record of, but a thorough record of my growth as a person in life. They used to organize a lot of interactive programs between those who survived Cancer & those who are currently under treatment. As a result of this, today we have a year old NGO called Ugam which is collaboratively set up between Tata Memorial Hospital & Indian Cancer Society in Mumbai. Ugam's formation has been inspired by one of the cancer victims, late Shobhin Kumbhar, who dreamt of helping all those who were suffering from Cancer. Unfortunately he lost his battle to cancer & we all decided to carry his dream forward. Cancer has shown us all the dark side of life as well. Slowly & gradually patients and their parents are being made more aware of Cancer through UGAM's activities & we are witnessing many young children joining us in this social cause. On the front note, today Ugam is being successfully getting a round of applause which is encouraging & branding our efforts; however all Ugam members think that we have a long way to go and need to do a lot of social work. This is just a beginning.

Three Cheers for our UGAM... Hip Hip Hurray!!! Hip Hip Hurray!!! Hip Hip Hurray!!!

Straight From a parent's Heart

Mr. J.S. Kaurw

"**CANCER**" the most feared word or to be more precise a sentence-which has a complete meaning in itself and for a common man it means the end. But is it so? Or is it a misnomer? Have people interpreted the word wrong? I will say, not five decades ago-it was the fact, but not today, with the advance of science and technology it is possible if detected at the right time and treated it's not only small medicines and good doctors but the willingness to fight and face it and moreover the determination to survive. There are examples where people have overcome and won against disease by their strong will power.

Why do usually children survive more than adults? If they both receive proper and right treatment, it is because children have a strong will, but often times their hope easily, even though there are some biological aspects associated with it.

My daughter, Hita Kaurw was detected with the disease at the very young age of 5 yrs. She had two-massive lumps on the right side of her neck, she was given medicines, for time being it subsided, but after a week it reappeared. Our family doctor just expressed doubt that it may be due to T.B., hearing which my wife fainted on the spot because it got her knowledge it was a fatal disease and secondly she was not prepared for it. But at the later stage when it was detected cancer after the biopsy report, she was just cool because in the mean time she had prepared herself for it and just asked me "What Size?". Our family Dr. Mr M.G. Kaurw guided us to Tata Memorial Hospital where her treatment began under the guidance of Dr.P. Sarkar and Dr. Advani. Now I will not begin to thank each and every staff of Tata hospital for their courteous behaviour.

During the period of her treatment, she was in class III, her studies were in no way affected by the treatment. As most of the parents think I was not an exception, I did not inform about her treatment to any of my relatives and even my neighbors excluding one or two-of my best friends. Even till few years before she was too conscious of it I took her for routine check-up, but did not participate in any of the functions or programs arranged by Tata Hospital despite of getting invitations. This was all due to fear of society and the after reaction of others.

But few years before when my daughter became aware of all her treatment, she attended the conference of "IROP" an International Conference of Childhood Cancer. She then decided to work for cancer patients and motivate them for undergoing the treatment and under the guidance of Dr. Kaurw and with the help of the other survivors started conducting the cancer survivors retrosome for their follow up at ACT (After Completion of Therapy) clinic at Tata Memorial Hospital Today all my relatives and friends know about her and all appreciate her for the work she does, none of them discuss her on any basis. Today I feel sorry for keeping her away from other functions and attending the fact from others, but then I cannot change the past. I am proud of her today when I read and listen about her.

I will also inform you that even she is getting married and the groom is also a survivor. I am very happy not only for her marriage but as the boy knows all about her and we don't have to explain or convince him about anything.

It is said that there is no lock manufactured without a key. So when God gives no problem He also gives a solution and the courage to face it. I will ask all the cancer survivors, patients and especially the parents of the patients to think positive and not give up without a fight. As we consult doctor for fever, migraine and other problems in the same way we should treat the patient for cancer. Consult the doctor and the guidance you can seek help of the group "UJAM" the group of Childhood Cancer Survivor since they can guide and explain you better about it.

Dear friends cancer is not a end-of-life, there is always a wonderful life after cancer. Live life with more confidence because "nothing succeeds like surrender". So all the survivors come together work together for a common cause and you will find a whole new world in Ujam, where all your needs and wants will be met with honor.

THE IMMORTAL GUIDING LIGHT THAT HE IS...

SHOBHIT KAUSHAL

Shaohank John

"That's the difference", he continued, "You will have time my friend". I had not known what impact those words were to have on me in days to come, but I excuse myself by thinking that I had not known my friend Shobhit Kaushal enough to know what he really meant by those. He was referring to the short films I had made, which I could not complete. It angered him that it was not complete because he wanted to see it, more importantly he wanted to see me making a film. Before he could and the conversation with the final words, I remember telling him that I would make it in my free time.

It angers me now to not have completed that film. It could have well been my final gift to my best friend, Shobhit.

We fail to realize that unlike a tree, we have all the time in the world!

Shobhit Kaushal, in that inspiration that was mothered by a man of the same name and grew up to be a guide to all those who at whichever stage of life discovered the being in this immortal human.

A little boy of 19, when I met him first, had a vague idea of what the world outside the drapes of the hospital had become during his treatment at the TATA cancer memorial hospital, a place, he said to be responsible for keeping his body strong so that he could realize those colorful dreams that he saw lying down with tubes inserted all over his body.

Shobhit Kaushal was diagnosed with cancer at the age of 14. Born and brought up in Kanpur, Uttar Pradesh, his family decided to shift to Mumbai for helping him in handling the disease. But fate had to run its own game. He wanted to become an artist.

Even though he was diagnosed with rarer cancer 3 times, he did not let it come in his way. He continued painting. And as his teacher made strokes on his canvas, he made his own destiny, consistently proving that nothing in the world could ever stop him from realizing his dreams.

"I believe in magic", he said to me, after he was diagnosed with the disease the final time. I am sure magic believed as much in him. Whenever he got rarer from area, which had become a vital necessity, he would paint, or write. His poems were as beautifully infectious as were his paintings. He wrote about cancer, his people, and his dreams. He expressed his life as a wonder and always pointed that there was a reason why he had to go through such trials and tribulations.

Few are those, on this planet who suffer not just their own miseries but create a magical plan for those in whose fate it is written to suffer, so that their suffering could be empowered by their survival.

He had some contribution in the creation of Ugam, Victims of childhood cancer, along with other survivor friends and his doctors. He continued, with great zeal and felt deeply for the cause of childhood cancer and childhood cancer survivors. To survive, he thought was like winning a battle and therefore wished to replace the word 'survivors' with 'Victims'. Ugam's logo was inspired by his artwork. He had a vision for Ugam, and to him the rehabilitation of Cancer-ridden families was a dear task.

His first solo art exhibition was the day in March 2009, in the Gallery art and soul, Work, Mumbai. He was affected by the fame and success and volitionally contributed half of his earnings for charity.

I had never seen him happier. It was his day! Though his body was stuck to the compulsory wheelchair, his dreams wandered in his paintings and immortal verses. His work was immensely appreciated by the masses and the masses. He was joined by the glitterati of the glimmer world who were so fascinated with his work, his spirit and his enthusiasm, that they were speechless, some with tears in their eyes, while others too lost in the magical equation of his art.

He was a master of his own destiny, a loving son and brother. I consider myself fortunate to have met him in life and truly feel the same for those like you, who may not have met him, but know about him or have read about him.

We, the Vectors and friends, miss Shakti deeply and are determined to take forward his plans for the establishment of our cause.

We know you are watching us Shakti as we work in accordance with what you had written for us.

Love,

Mumbai.

IMPOSSIBLE IS NOTHING

-Mrs. Lolita Salovey

The name Ugam, chosen by the Vectors of Childhood-Cancer survivors of the Tata Memorial Hospital could not have been more significant, for "Ugam" means "To Rise". This group of survivors is indeed a bunch of enthusiastic youth who have ventured into a pioneering path of counselling cancer children and their parents who are now treading the path they have walked, years ago. The members of Ugam have so much to give, they may be young, but they are mature – they have already seen and experienced so much in life. The passion with which they work is astounding and I feel passion rebuilds the world for the youth. It makes all things alive and significant.

Lisa Helen Keller once wrote, "It is not possible for civilization to flow backwards while there is youth in the world. Youth may be handicapped, but it will advance it's allotted length."

These young groups of budding talia makes me want to touch the stars, walk on the moon and fly high in the sky... Things you may think are impossible but then you learn from them...like the Adidas advertisement says, "Impossible is nothing".

The American Poet, H. W. Longfellow once wrote "For age is opportunity no less than youth itself, though in another dress, and as the evening twilight fades away, the sky is filled with stars, invisible by day."

I wish all the Ugam members all the best in their future endeavors.



VICTORS OF CHILDHOOD CANCER

We are the victors of childhood cancers,
For us the skies did create the definitions,
Nor did the rays of the sun enlighten our paths,
Also did the oceans rejoice in a chorus with us,
Yet we are determined, determined to our cause,
It's ours; let the steps be slow and steady,
And our hands join each others', let the situations be ready,
It's ours; let the achievements remain unclear,
The process that nurtures within to the life they are dear,
So, let the skies remain calm, we'll stir them on our will,
Let the sun do his job, we'll surmise be our prism,
And let the oceans remain blue and deep,
For we shall traverse limitations and the treasuries unseen.

(Bhupendra Kaulshal)



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

- 1) Self-empowerment of the young survivors
- 2) Helping Children with Cancer undergoing treatment
- 3) 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 & sent to:

Indian Cancer Society,
T4, Jeeba Media Road,
Parel, Mumbai - 400 012.
Tel. No: 022-26161876/2413944661.

Please visit our Website: <http://www.indiancancersociety.org>

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