



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

#### Mission

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

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

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#### **Indian Cancer Society**

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# Ugam Calling... 13<sup>th</sup> Anniversary Edition

" सबसे बेहतरीन रिश्ते वो है जिसे हम खुद बनाते है। "



#### **Indian Cancer Society**

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#### **Organizing Committee UGAM Anniversary 2022**

Organizing Chairperson: Dr. Purna Kurkure

Organizing Secretary: Dr. Vandana Dhamankar, Col. Abdul Khadar

Joint Secretary: Preeti Phad, Bhairavi Gawde

#### **Newsletter Committee:**

Narendra Shetty, Arun Kumar Nadar, Shweta Chawre, Ekta Rawat

#### **Registration Committee:**

Gopesh Chilveri, Priyanka Jadhav, Uzair Sakhi

#### **Cultural Committee:**

Ms. Savita Goswami, Shalaka Mane, Aishwarya Nikale, Sushant Bane

#### **Co-ordination Committee:**

Nirav Chotalia, Ritika Maurya, Vanchinathan, Vivek Pandey

#### **Workshop Committee:**

Divya Rajkumar, Juhi Sharma, Priya Dixit, Lynette Francis, Sadaf Wani

Song of Hope -Main Lad Lunga (Song by Amit Trivedi)
Motivational Video released by ICS. 135,281 views on YouTube
Link: <a href="https://www.youtube.com/watch?v=kQbavhGhfkE">https://www.youtube.com/watch?v=kQbavhGhfkE</a>

\*We are grateful to Yashwantrao Chavan Pratishthan for providing us the auditorium.

\*We are grateful to all Ugam friends, donors, volunteers for their generous support and Display House for technical support.

\*We acknowledge support from Marketing, Admin Survivorship & Rehabilitation Vertical Team of ICS.











#### **UGAM PROFILE**

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



#### WHAT WE DO?

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



Dr. Purna Kurkure

Convener, Ugam
Trustee In charge,
Cancer Survivorship & Rehabilitation
Indian Cancer Society
Chairman, Oncology Collegium
Narayana Health (NH) Group
Head Division of Pediatric Oncology & BMT
NH SRCC Children's Hospital, Mumbai

Welcome to the 13th Anniversary of UGAM - Celebration of Life!

Today, we have gathered at Yashwantrao Chavan Pratishthan Auditorium, in person after hiatus of 2 years of difficult time of pandemic. We are grateful to Yashwantrao Chavan Pratishthan for welcoming us to this beautiful & new venue, to join thousands of cancer survivors for an annual, treasured Celebration of Life that is held in hundreds of communities nationwide, and around the world, on the first Sunday in June which also marks birthday of Ugam- Childhood Cancer Survivors Support Group launched in 2009 under umbrella of Indian Cancer Society(ICS), a first & premier Not for Profit organisation in cancer space in India.

Project PICASSO (Partnership in Cancer SurvivorShip Optimization) is thriving well & has Pan India presence in major cities like Delhi NCR, Chennai, Bangalore, Varanasi, Srinagar at 11 After Completion of Therapy (ACT) clinics. Cancer Survivorship efforts to bring the survivors in network have been very fruitful & gratifying. Ugam with active& enthusiastic Mumbai based

survivor membership of more than 400 will now inspire survivors in these ACT clinics across country to form Ugam chapters to nurture solidarity & become advocates for childhood cancers at all Governmental & Non-Governmental platforms. We will be holding workshop of representative stakeholders from all these ACT clinics on 6th June2022 at ICS to initiate this process. We acknowledge cooperation & hard work of our partners & generous financial support & involvement of corporate donors for creating a platform for childhood cancer survivors to create a societal impact.

The first phase of infrastructure development in survivorship programme which was envisaged when we began our journey is almost getting crystallised now. It will go into replication & expansion mode as we find more partners. The time is ripe now to start working on the second phase of survivorship programme which is professional education & public awareness. We work towards this goal & make inroad into study curriculum of Oncology professional training, Psycho-Oncology training & also mass media training for public awareness. These efforts will provide springboard for research in cancer survivorship in India.

We have kept theme of this year celebration as **Rishtey (Relationship)** 

During the difficult time we valued the support & encouragement we received from each other & established this unique relationship which will always keep us together &stand by us in adversity.

हर किसी को नहीं सिखाती है ये ज़िन्दगी बड़ी मुश्किल से मिलती है रिश्तों की बंदगी रिश्तों की कदर कर लेनी चाहिए क्या पता कोन कब कहा मिल जायेगा!!

" सबसे बेहतरीन रिश्ते वो है जिसे हम खुद बनाते है। "

#### HOW CAN YOU CONTRIBUTE

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

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

Financial assistance for educational program for survivors

Financial assistance for the late effects of treatment



Dr Vandana
Dhamankar
Deputy Director
General,
Medical affairs
Director Survivorship
& Rehabilitation
Indian Cancer
Society

Congratulations to Ugam on completing thirteen years of inspiring journey!

Ugam has now inspired many more survivors to come together and get organized to form support groups in different cities. Ugam has been a role model in conceptualizing project PICASSO (Partnership in cancer survivorship optimization)

#### **Project PICASSO**

Taking inspiration from experience of an existing ACT Clinic in pediatric disease management group functional since 1991 at TMH,& support group (Ugam) which emerged & was established in 2009 under the umbrella of ICS, Survivorship & rehabilitation vertical of ICS has developed projectPICASSO (Partnership In CAncerSurvivorShipOptimization)

PICASSO is holistic rehabilitation module being implemented in partnership with pediatric cancer units. The objective is to facilitate the cancer institutes to start hospital based ACT (After Completion of therapy) Clinic for holistic (Medical& Psychosocial) care of survivors of childhood cancer to improve their quality of life and to decrease the lost to follow up cases.

#### **Developments**

- \* Standardization of psychosocial follow up is on the verge of completion.
- \* Work on health insurance of survivors is in progress
- \* Outcome so far from 2017 to May 2022
- \* No of ACT clinics in India 11
- \* No. of ACT Registered Cases 1759
- \* No. of ACT Follow-up cases 1932
- \* No. of cases supported with Educational & Vocation Fund 300
- \* No. of Reapplications Approved 392
- \* Amount Distributed Rs. 13,948,027
- \* No. of cases received Career Counselling 170

- \*No. of survivors Achieved e d u c a t i o n a l milestones 70
- \* Late effects fund started which offers support for following investigations and treatment
- A. Fertility Treatment
- B. Hormone replacement therapy
- C. Dental Treatment
- D. Hearing Aid
- E. Prosthesis
- We are thankful to our advisors for guiding us and approving applications for late effects funding Dr Sudha Rao (Endocrinologist), Dr Manish Agarwal (Onco Orthopedic surgeon, Dr Dholam (Onco dental surgeon) have been helping us with advising on the applications received from the



#### - Partnership with Sangeet Niketan

An initiative of Indian Cancer Society in association with renowned music institute by Padmashri Shri. Suresh Wadkar Ji's Acharya Jialal Vasant Sangeet Niketan & Music Heals Foundation initiated a free online music courses in Hindustani Classical Music & Light Music (Sugam Sangeet) course for 1 year duration for cancer patients & victors of cancer. 1st batch consisting of 15 students each commenced on 10th October 2021

#### - Partnership with Byjus

ICS Ugam acknowledges Byju's for providing wider access to the Byju's Products to survivors in the ICS network free of cost.

There is a long way to go till survivorship program is recognised as an important component in cancer care continuum and ICS Ugam will strive to reach this goal..

ICS is grateful to donors for supporting the Survivorship & Rehabilitation Activities

Bharat Petroleum Corporation Ltd (BPCL), HES Infra, WPP India Foundation,

Navneet Foundation, UTI, Raymond, Geltec, Igarshi

## Ugam Journey During the Pandemic

#### **Events Organized by Ugam**

There were no physical events this year again due to the pandemic, however the reach was wider due to the online nature of events.

**UGAM's 12th Anniversary Celebration (June 2021)** 



Ugam has been celebrating its anniversary for past 11 years. This year too, despite the COVID-19 pandemic, Ugam celebrated its 12th Anniversary on 6th June 2021.

Ugam's 12th Anniversary was based on the theme, "Hausle Hai Buland Hum Jitenge Ye Jang" which indicated the unstoppable enthusiasm of Ugam members in the difficult time of COVID-19. Since social distancing was followed throughout the nation it seemed challenging to conduct the 12th anniversary physically, however the team brainstormed and came together with the idea of utilizing digital platform to conduct this event. Although it took more efforts for the team to collaborate and execute the event online, the dedication and hard work paid off after the successful event.

All the eminent oncologist from partner hospitals, Mr. Amol Gupte, ICS Trustees along with enthusiastic Survivor's attended the event.

The event was attended online -live by more than 300 attendees. The event has nearly 1.2k viewers on Youtube currently. We thank Mice Ideas, Mr. Rajesh Sharma for providing the platform for the event.

https://www.youtube.com/watch?v=gE0OG wIWoSE

## Childhood Cancer Awareness Month (September 2021)





On the occasion of Childhood Cancer Awareness Month. With the help of BPCL CSR funds, ICS through project PICASSO (partnership in survivorship optimization) partnered with Shankara Hospital - Bangalore & SKIMS Hospital - Jammu & Kashmir to set up ACT Clinics for organizing Survivorship Care.





ICS through project PICASSO (partnership in survivorship optimization) partnered with Mazumdar Shaw Hospital-Bangalore and inaugurated ACT clinic on 3rd March 2022

#### **Counselling session by Ugam members**

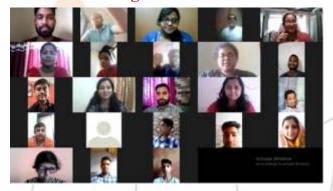
UGAM members, regularly attend the parent support group meetings held at St. Jude India Child Care Centers Cotton Green & Kharghar-for parent counseling. Sharing experiences and answering queries of active patients (children) & parents is an activity in which Ugam members are involved throughout the year. Due to the pandemic, counselling sessions were held online which allowed Ugam members to cover PAN India centers of St. Jude's. Several queries and doubts of anxious parents pertaining to Cancer treatment and care post treatment were answered by Ugam Victors. Appreciating the good work that Ugam members do, one of the staff members of St. Jude's narrated a poem for Ugam victors.

Amrapali Abgad (St Jude center Officer and a Teacher)

"ना डर ऐ मुसाफ़िर ऐ सफर भलेही कठिन है, सोच, तेरी ऐ एक जंग है राह आसान हो जाएगी 'उगम' हमारे संग है।



#### **Ugam Series**



Ugam series was a psychological workshop conducted by ICS psychologist for Ugam members. Interactive sessions on topics like – Self Development, Assertiveness, Team Building, Stress Tolerance, Decision making, how to control Anger were covered in the session.

#### **Ugam Monthly Meeting**

After Lockdown first Physical meet took place this year on 23rd April 2022, which was attended by Ugam Members and friends. 70 members were present to Plan and discuss Ugam Anniversary and Cricket match.



**Ugam Friendly Cricket Match** 





To commemorate the 13th anniversary of Ugam, Friendly Cricket Match organized by Ugam. At Mahim Juvenile Sports Club on 29th May 2022. To spread the message "Childhood Cancer is Curable" in society. Mr. Pravin Tambe (IPL-Cricketer) graced the event as a Chief Guest & motivated the prayer

#### **Participation at ICS Events**

#### **Relay For Life**

Indian Cancer Society has been licensed as nodal agency for RFL in India from 2014.

Post pandemic, this was the first RFL organized by Singapore International School.



Retinoblastoma day celebration & Screening program for prosthesis at NH SRCC Hospital



As May Month is celebrated as "Retinoblastoma Awareness Month"
A Workshop was conducted by ICS in collaboration with SRCC Hospital on 27th May 2022.

## Participation in Conferences by Ugam members

#### PHOSSCON 2021



Ugam members attended the 5th PHOSSCON meet conducted virtually co organized by ICS-Ugam. 140 participants and 32 organizations participated in the conference. Dr. Vandana, spoke on the topics related to Late effects of treatment, Survivorship-ICS Initiatives

Ugam member Preeti Phad participated in Panel discussion, Patient Voice -Importance of survivor and parent participation led advocacy for NGOs

#### **TYACAN 2021**

Ugam members attended 10th National Conference on Teenage and Young Adult Cancers Conference (TYACON) held (Virtually) from 24th to 26th September 2021



Sanaya

CANCER WAS ONLY A CHAPTER IN MY LIFE, NOT THE WHOLE STORY!



I was always the skinny kid. Always told to "eat more, you need to gain weight etc." It never bothered me ever though. It was November 2008 and I was falling ill more than ever. I was paler and thinner. And all these remarks grew more than ever. I was having discontinuous fever for more than 6 months now and had a terrible pain in my legs that made me cry at nights. My parents began to worry even more. My family doctor advised a few tests and there it was the big truth behind all my suffering- CANCER. I was suffering from Acute Lymphoblastic Leukemia. My family was shattered into pieces but little did I know what was going on. I was just told its some blood infection and I need to take off from school for 2 months. I was an optimistic kid and took my illness positively. Days passed. Hospital, painful tests, chemotherapy became my life. And one day someone told me "you have pretty hair but you will start losing them soon" and it hit me. I was devastated. I started crying and told my mom "I don't want be treated anymore, I can't lose my hair". She comforted me and explained me "my hair is not greater than my life". I came to know about my illness through a newspaper advertisement where a kid needed money for his treatment and along with my disease name was written cancer in big bold letters. I never said anything to my parents and accepted my illness. I have seen my parents crying behind my back and acted like the strongest people in front of me. So I decided I am going to be strong for them and fight cancer like a true warrior.

But then something happened and for the first time I lost all the courage. A blood clot went to my brain and paralyzed half of my body twice. But

there was no turning back I had to win this battle. I didn't let let any of this break me. My doctor used to call me a true soldier. In February 2010 I was all set to go back to my school. But cancer doesn't just end with the end of the treatment. Some scars are left behind. I had this short hair, chipmunk face and some scars on my body. I saw students – who used to be my friends talk behind my back but in a few days everything got normal. I gave my final exams and passed 5th standard with flying colors. My parents and friends' support, my doctors' hard work and my determination to prove some negative people wrong made me fight cancer. Finally, I was cancer free in December 2011. I am writing this journey because we all are going to face hardships in life. They can come in any form be it cancer, loss of a loved one, failure, heartbreak but we always need to remember that to see the rainbow we need to pass through the storm, so anyone who is reading this its just a bad day my friend, not a bad life.

#### Saksham

It takes time and experience to alter a stigma or perspective relating to an understanding. Cancer is a disease that Society perceives as a pathway to death due to lack of knowledge.



The primary struggle for a Cancer Patient is generally not his treatment but the stage after. Being an example of getting through the battle myself, I can proudly say that my journey of 1.5 years fighting Cancer was virtually painless. The real war was still to be fought after.

Cancer as a disease has two impacts on an individual's life- Physical and Emotional. We all talk about the complications of Surgeries, reactions to Chemotherapy, allergies from radiation, etc. But what we do not talk about is the emotional burden or the brawl that the survivor must go through. Your identity drastically changes from what you were pre and post this phase. I have a new identity as a Saksham Katiyar who has undergone cancer treatment. There was a phase where I felt an existential crisis relating to

finding myself. Being diagnosed at the beginning of my Teen years, a lot was about to happen, and I had to learn to build my personality and foundation for what I have forthcoming in my life. When you are about 12, friends and friendship have a relatively different meaning; even though the relationships were not mature back then, they are emotional and dependable. The information regarding dropping the school was somewhat a nuclear bomb but dealing with it patiently was the need of the hour. To avoid the pressure and discomfort of friends and classmates going a year ahead, I planned on dropping from school while keeping in contact with my close ones.

In his early years of teen undergoing treatment for 4th Stage Cancer, a Boy must suffer attacks on multiple fronts from society. All of this leads to highly negative results on a positive mindset. From my life experiences, I can conclude that people who have had hard struggles tend to become more mature, understanding, and patient than others.

The lack of proper knowledge and information is evident in Society. My personal experiences with people have shown me how informing them about my Diagnosis was news of my demise. As a country, we might have failed to generate ample awareness regarding Cancer, the public's equation is still stuck at 'Cancer=Death.' I had all sorts of reactions to my diagnosis from the closed ones. The mindset was very harsh/negative, relating to the result. At the same time, some of them were over-sympathetic. My School Classmates still don't know about my survivor story because I am uncertain about their reactions and their long-term effect on my relationship with them. We, as survivors, require a neutral response from Society since we have fought and won our war and are ready to face the world with detention. Our experience has made us capable enough to tackle future barriers efficiently.

Hence, standing inch-close to life and death situations took me no time to believe that life is extremely precious. The concept of revenge and hatred holds no value in my life. Positivity and willpower played an essential role in getting me through my treatment. In life, I have been a very out-spoken person who stands up to speak for right when no one does. This trait has failed me to make deeper connections, but this was all about to change.

The experience of shaking hands with the Devil was fruitful after all, and I learned to choose my

company. The world has become Toxic and hurtful on extreme levels, and you must ensure that you don't fall into a sandpit that pulls you into bad habits. One good friend is better than a handful of them. These relationships are not made on a give-and-take basis but on mutual understanding where you must put in similar efforts as to what you expect from the others. From my experience, I can say that building a likeminded community of people and ensuring contact with them has worked in my favour.

Cancer was undeniably a roller-coaster ride with ample twists and turns, but the experience overall was vast learning and a blessing for me. From the day I completed my treatment, I promised not to devote a single moment of my precious life to negativity.

#### Risha

It started in October 2016 when I woke up one morning with a small lump behind



my right ear. When I told my mother, she thought that someone might have punched me in a playful manner so we brushed it off. I was a happy-go-lucky girl who had everything planned in her life ahead. I was excited about my college life, but who would have known that everything was about to change. The swelling became worse within a two-weeks and I went for X-rays and ultrasounds but the reports didn't show anything. We were worried, so we consulted with two of the famous doctors in Delhi where they asked me to go to for MRI and FNAC, a needle test. The FNAC was really painful as the swelling (lump) was so hard that the needle couldn't go inside, but after a few attempts, they took the samples. Even the FNAC couldn't tell anything and doctors suggested me to not to worry about it and go

for a surgery to remove the lump. By the time this was going on, Diwali arrived and we went to our hometown, Dehradun, and this visit changed everything. One of my uncles is a cancer surgeon there and during the Diwali party he observed my face and I explained everything to him and he asked me to visit him to the hospital the next day for the routine checkup. I guess his experiences paved the way and was telling him that something is wrong. He ran several tests like x-ray, FNAC, MRI, ultrasound, but nothing came in the reports and at last, he went for a high-level test but we had to wait for 5 days to get the reports. In the meantime, I went through surgery and the lump was removed and the biopsy was taken and it showed that I have a cancerous cell in my body. Well, after 4 days reports came and it was diagnosed that I have Acute lymphoblastic leukemia (ALL) which is a type of blood cancer. My chemotherapy kicked off immediately and later treatment got little extended due to many side-effects. My diwali break turned into full time hospital visits. When the chemotherapy started, I was very positive about it because I didn't want to give up and I had to be strong for my family, so I never showed them my sadness and the first two months of treatment went well and I was positive that whole treatment would be easy but as chemo sessions were going on I started getting side effects and chemo sessions were often postponed.

For 2 months, I was under chemotherapy session every alternate day—I lost all my hair and lost awful amount of weight - approximately 17 kgs. But the worst part was that I couldn't go to college or see my friends. I've always wanted to pursue law, but couldn't prepare for the exams & had to give up that dream. I was shattered.

One of the incidents... was just before chemotherapy, I developed high fever and my blood counts dropped drastically. I was on the verge of death because the counts were severely lower than the normal value and the bone marrow wasn't generating the blood; The reports were haemoglobin-3, WBC-700 and platelets 30,000; I started having blood clots coming in urine and I went for 3 days of blood transfusion. The chemotherapy side effects were:- I got UTI, Anal fistulas, hemorrhoids, nausea, drastic weight change, hair loss, severe constipation, etc. I won't deny that there were times when I used to cry alone and used to question God, that out of million people why it has to be me. Often, I used to get sad because of the unbearable pain of injections and side effects I was going through. I was missing out on my college, life and career which was at stake but I always had one thing on my mind that to cure myself, I have to be positive because even medicines can't do anything if we don't have the will power or the positive mind. When I was most upset, my mom made me believe I'd get through it. I knew I had to fight, so I focused on my mindset. I watched TED talks & read positive books. I appreciated that I was alive & stopped covering my head. I felt like a phoenix during this transformation. That's the thing about cancer-it's an excruciating process that teaches you so much. Over the 13 months that I couldn't attend college, I began valuing every little thing-from home, food, to friends taking notes for me or making me laugh, to the support of my family. My friends even did my assignments & that year, on my birthday-they threw me a party. Never before had a simple cake & balloons meant so

So that's how I battled cancer, took my exams & got into my dream school in Bangalore.

Still, life had other plans for me—I didn't have the clearance to travel, but after all that I'd been through, I took it with a pinch of salt. I took up Spanish & classical dance, I started feeling healthy & now, I'm going to give my MBA entrance exams—this time I'll make it happen.

Honestly, I could sulk about the cancer and how hard the journey has been, but it's given me so much that I can't complain. Cause if it wasn't for the cancer, I wouldn't value life so much, I wouldn't be so positive even when things don't go my way—I wouldn't feel this invincible.

The treatment journey was a long road which took a toll on my physical health and appearance, but what kept me going was the WILLINGNESS TO LIVE LIFE ONCE AGAIN AND BATTLE THROUGH THE DISEASE.

Arya

I was six years old when I was diagnosed with Acute Lymphoblastic Leukemia. I used to get low grade fever frequently. It used to get better with



medication, but after few months my parents observed me having difficulty in breathing. My health was deteriorating day by day, there were few lumps in my neck & nose. No medication was helping. One of the doctors suggested to get few tests done, and the results were indicating the possibility of me having Blood Cancer. My parents were told that it is curable and suggested to visit Rajiv Gandhi Cancer Institute & Research Centre, Delhi. Being from a middle class family it was not easy for my parents to take treatment form a private hospital. They were told to save money for my younger siblings, who were 4 year and 2 months old at that time, rather than spending for such expensive treatment because according to their perception, cancer cannot be cured. It was a tough call for my parents, and they decided "Not To Give Up".

My parents took me to RGCI & RC, where I met the second Hero of my life "Dr. Gauri Kapoor".

After careful clinical examination, she counselled my parents about my disease and treatment. Her words gave hope and reassurance. I was admitted to the hospital for treatment and our battle began. I used to get high fevers, became weak, started losing weight and hair. Food became tasteless and irritation peaked. My parents used to counsel me patiently about the side-effects and encouraged me to do what I could do during the treatment. I couldn't understand everything that my parents said at that time but their body language always communicated what needs to be done to get better soon. We stayed in Delhi, away from our home, which is in Bihar, for the next six months. I was allowed to travel back home with precaution and continue schooling, during my maintenance therapy.

I was demoted to previous class which broke my heart, but my new friends and teachers were very supportive. Gradually I started feeling comfortable and did well in both academics and co-curricular activities. By the end of 2002, my treatment also ended. RGCIRC's Department of Pediatric Hematology & Oncology became like a family to me. The journey was not easy at all but I won and with me, my loved ones won too. I was Cancer free. And now, Cancer is just a chapter of my life. Today, I am happily married and living a beautiful life. I have recently completed my Masters in Computer Applications and have applied for PhD. I dance, travel, play and I am also, one of the team leaders of "Childhood Cancer Support Group- Aashayein" which was formed by the department of Pediatrics of RGCIRC..

When I look back, I realize that Cancer in return of all our sacrifices, has given me & my family a new vision towards life. It has given me mental strength, positivity, patience and strong determination. I am grateful to each and everyone who stood by my side in this journey. I am proud Childhood Cancer Warrior. Just because of Cancer, today I am strong enough to face any challenge that life has for me with no fear of losing because I know, I have already won the biggest battle of my Life and I have the power to conquer anything that challenges me.

I am Pravin kumar. M, I am 19 years old now. I am doing first year in B.sc Biotechnology. I hail from Trichy, Tamilnadu. I was raised by my mother who is a single parent. We do not get any support from my father due to family issues. I have an

elder brother also. My mother works as maid in a hospital and she managing to take care of me and my brother studying.

With the existing family scenario and poor financial condition my mother managed to admit me in the college. I joined my Under graduation course with lots of dreams.

But I did not ever think that I will be discontinuing my college soon.

In February 2019 I had large tumour in my neck and I did know that it was cancer. I was later admitted in ESI Hospital, Coimbatore. Doctors did completed all tests for me. After which I came

Pooja

Acceptance -Stepping stone to Success

As a teenager busy shaping my life,

Mixed Germ Cell Tumour of the Ovary seemed to be a dead end. My family looked anxious on hearing about cancer and chemotherapy, but I stood blank. The efficient oncology team explained the process and convinced us that all changes will be temporary. Now I was anxious, but my family took it in the right spirit and stood by me as pillars of strength. We stepped into the unknown, with faith. Anticipating the changes, with a sunken heart I got my tomboy haircut. Post first cycle - a touch and my tresses were in my hands. Soon I resembled my bald childhood photos. As my family and team at the hospital did not treat me differently, I soon came to terms with it and diverted my mind. I had nausea which made me averse to any food. I was also losing weight and my new bony look in the mirror ran a chill down my spine.

As my six-month treatment came to an end, I

grew hopeful yet anxious. It had just dawned upon me that regrowth of hair post therapy was not a miracle. As a solution we were guided to Marchers- the wigmakers. Hoping he would give me my old look, I met him with all enthusiasm. After working on me when he finalized the bob cut hair, my smile vanished. It took a lot for him to convince me with his idea of the new me. The questions from my friends on cutting my long tresses were on my mind. With hope and anxiety, I joined back school. The new look was a hit but my classmates were uncomfortable. Gradually I realized it was due to their lack of awareness.

In this process of settling down socially, I learnt the importance of self-acceptance and the role of feeling good for looking good. It gave me the courage to carry the new look. Also, the importance of encouragement and warmth from people who matter to us – our parents, family, friends, teachers etc. acted as a fertilizer in re-establishing myself and moving ahead in life.

Almost all cancer warriors would have faced similar body image issues. Our acceptance and belief help us to cope with the new normal. This process is also influenced by how people close to us react and support us. This is possible when they also accept and take it in the right spirit. We also understand that all this is indeed a temporary phase in life.

This experience inspired me to do a survey in Rajiv Gandhi on 'Psycho-social impact of childhood cancer on children and their families' as part of my 12th standard biology project. Dr. Gauri Kapoor encouraged me and gave me an opportunity to present this at PHOCON-2009 at Chandigarh. It was here that my aversion to become a doctor became a passion.

Victors of childhood cancer

I had a fascination for the Sanskrit language from childhood. I opted for Ayurveda and completed my BAMS Degree as a rank holder from Amrita Vishwa Vidyapeetham. Then I was blessed to work with The Arya Vaidya Pharmacy, Coimbatore contributing in the field of clinicals, research, marketing and teaching. My interest in teaching and research is making me pursue my masters in Ayurveda currently from a reputed institute in Karnataka.

Today as a doctor myself I am able to connect to people and help them cope with their challenges because I have also been in their shoes. On looking back at those unpleasant days, I realize that I am stronger. Acceptance and hope helped me tide over challenges. We imbibe gratitude, empathy, spirit of a warrior and learn to celebrate every moment of life. So always ask 'What next?' And not 'Why me?'

Dr. Pooja Neelakantan, 30 years Survivor of Germ Cell Tumour Off therapy since 2004

Aditya

I was diagnosed with Ewing's Sarcoma in the beginning Of 2018



at the age of 14 and I got cured by the end Of 2018 which drained me and my family emotionally and financially.

I was given a back support by receiving Dr. D J Jussawalla Education Scholarship for my education which Really Motivated Me To Move Forward And Continue My Studies With Same Energy And Still Had Me Focused To Achieve My Dream of Becoming A Commercial Pilot.

I Am Really Thankful To The Counseling Provided By Indian Cancer Society Which Solved My Education Queries And Showed Me A Better Path, ACT Clinic Which Solved And Made My Personal Life Smoother And Easier... Attending All The Events In Which One Of Them Is Ugam Gave Me A New To Meaning for Enjoying Life and Learning Things from other victors Of Cancer. I Am So Glad That I Was Helped By These Many Things Which Helped Me To Move On Not Just Me It Goes Same To My Family Too. I Feel Blessed To Be Helped By Others In My Worst Part Of My Life, So I Have Decided That I Am Going To Help Someone Like Me To Fulfill Their Life Too Like ICS Did To Me...Once I Am At My Success Place.

Ishan

My Self Ishan Kaluniya,I am 11 Year's Old.I M Studying In 6th Std. In St Columbo



Public School, In New Delhi. I Have Scored 98.7% In 5 Th Std. And I'll Try To Give My Best And Always Score Good Marks. I Have Always Participated In All The Competition Held By The School And Have Always Performed Well. The Best Of My Performance Till Now Are The Role Of Krishna From Mahabharata And The Role Of Sita From Ramayana After I Played The Role Of Krishna. All Of My Teachers Praised Me And I Felt Good To Hear That. I Am Very Good At My Studies My Teachers And My Mum Help Me If Ever Have Any Doubts. I Get Financial Support To Pay My School Fee By ICS. I Am Always Thankful To Them. Apart From S Studies I Like Skating, Yoga, Dance, Listening To Music And Reading Books. I

Want To Become An \*IAS\* And Make My Parents

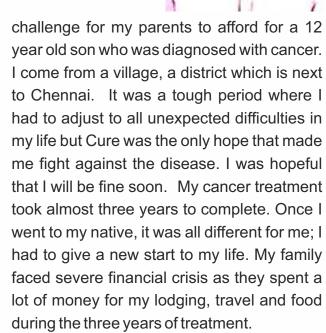
Proud I Want To Give Them All The Happiness Because I've Seen Them Struggle A Lot For Me..

From Chennai (Divya Shared)

I was diagnosed with Ewing's Sarcoma in the beginning Of 2018

Nithish

Hi, I'm Nithish!
On August 2,
2 0 1 3 I w a s
diagnosed with
cancer (ALL). It was
a big shock and



After completing treatment, I was really worried about my future - how would I be able to take care of my health, how can I afford studies after 12th.

I visited "After completion therapy" clinic at the Cancer Institute (WIA), Adyar. In the primary assessment, I ventilated all my worries and uncertainties regarding my future. After completion therapy clinic has given me all support to fulfil my dreams. Dr. D J Jussawala education scholarship was my support to pursue studies, helping me improve my financial background as well. With the help of DJ fund I was able to complete my graduation successfully. I wanted to prove myself, to my community that I can make it. Now, I can proudly say that I'm a survivor of Cancer.

Ajay Kumar

I am Ajay Kumar, I am 20 years old. I come from a village in Salem which has no major medical facilities. I was



diagnosed with cancer in the year 2014 when I was just a 12 year old boy who was just busy of normal life with my family and friends. Cancer diagnosis was a sudden break to my daily routine and life. I stopped schooling; I had to visit the hospital for 2 years for treatment. I had to travel to Chennai for my Cancer treatment. My father is a Cooley and my mother is housewife. Though I was able to get free treatment for myself from Cancer Institute Adyar, it was still a difficult period for my family because they spent a lot of money in stay, food and travelling for three years in Chennai. Somehow, I managed to complete my treatment. As I come from a literate family, I want to study well and bring a change in my family condition. Financial crisis was one the huge barriers in my family which made me think whether to continue my education after 12th std. One day on regular follow up visit to Cancer Institute, I was made to go to ACT clinic. It was the day that changed everything. I felt I can achieve my dream. I met a Psychologist at the ACT clinic who counselled me on cancer survivorship. I got an opportunity to open up about my dreams and the financial barrier that I had in life. I was informed about the Dr. DJ Jussawala education Schlorship for academic support. The same year I applied for the fund and I was able to take up the Visual communication course in reputed college. Now I am a graduate on B.SC Visual Communication. I am proud to say that I am a Cancer survivor. No one should fear cancer, there is a cure and there is life after cancer. I could fight Cancer only because I had the support from parents and proper guidance from the psychologist at the ACT Clinic.

#### Karthickeyan

I am Karthikeyan; I come from a very normal family from o u t s k i r t s o f Chennai. My father is a daily wage



earner and mother is housewife. I am the first son for my parents. I was diagnosed with cancer (Rhabdomyosarcoma) at the age of 10. I was studying in 5th std. The cancer diagnosis was big shock to my family. My parents were devastated but they did not lose hope. They admitted me in Cancer Institute Adyar and I started treatment. It was like a sudden change in my life where I could not understand what was going in my life except the fact that I am ill. But I told myself that things will be okay. I completed my treatment in a year and I continued my school. When I felt that all the issues are over, my family was in a major financially crisis because of my treatment and they had a tough time to pay my school fees. Somehow, I was able to complete my schooling. This was the time I was sent for my follow up check ups at the hospital (CIA). It was the ACT Clinic. It was a new experience to me. I found there is holistic care given at the clinic. I was clinically interviewed by a psychologist who actually

changed my life. It was place where I found my true potential being a cancer survivor. I gained good confidence about my future. I was informed about the DJ fund academic scholarship (ICS) by the psychologist at the clinic. I came to the clinic as a 10th std student, now I am student who completed Diploma in Mechanical Engineering. I was able to complete my diploma only because of major funding support from Indian Cancer Society. Psychologist at ICS was my biggest support throughout these three years till I completed my diploma.

My dream to continue education after cancer was fulfilled by the ICS funding. Now I can proudly say that I am diploma holder in Mechanical Engineering. I can support my family and I can stand as independent individual in a society. I am a proud cancer survivor. I thank ACT Clinic of Cancer Institute and ICS for the continuous support.

**Juned Khan** 

My name is Juned Shaikh from taluka Umarkhed, district Y a v a t m a l Maharashtra, I have been lucky



and blessed enough for having such wonderful people, around me to uplift my spirits at all, difficult times. For me happiness comes in small packages even, a, warm, hug can make, me the happiest person on the earth. I too have a story of struggle I never thought that I would pull through a journey in one piece, But I did and I'm stronger as being strong was the only choice I had and I made it. I had my share of hideous and low days there have been sleepless nights when I used to cry in pain and there were days I felt very comfortable. It

wasn't easy at all but, I had to gather my

strength. Because I always used to say cancer cannot take my life I may die in a road accident but not with cancer. I have to live for myself and for my family but first for myself so after all investigations have been done and it has shown that I have OGS in left leg. In 2015 I was diagnosed OGS in left leg at the age of 20 . I completed my treatment in Tata Memorial Hospital. Thanks to doctors and all other staff members, and specially my family. During treatment I faced many challenges with hard experience of life. Thanks to Indian Cancer Society for helping me in completing my Bachlors degree through the Dr. D J Jussawalla Education Vocational Skill fund. I have also completed my Post graduateion degree and currently I'm pursuing another degree in Post graduation.

I believe there is always a good way behind our troubles, whenever we see the closed gate, God opens another way for us. But you have to fight against those trouble. So you always fight against this deadly disease with fully potential. Now I'm in teaching profession conducting lectures on Chemistry in Junior college as well as Science and English at High school in my hometown. And it makes me very happy that I am able to encourage & motivate people those who suffer from disease.

Yes Yes I am a cancer victor and I'm proud of Cancer Victors.

#### **Sumit Dhir**

I'm Sumit Dhir, I was diagnosed with Non M e t a s t a t i c Osteosarcoma of the left femur at the age of 18 in 2018. When I first found



out that I was diagnosed with cancer. I couldn't believe it. I was afraid, my parents

were shattered and devastated but they stood by me very bravely. I suffered a lot, I was in a lot of pain. I'm from Odisha, so the doctors referred me to Mumbai. Mumbai was totally new for me and my parents. We are a middle class family and staying here was very difficult. In 2018 I went under treatment: 8 chemotherapies and a knee replacement surgery at Tata Memorial Hospital, Mumbai. After one year of treatment I completed my Diploma in computer science from KIIT, BBSR. Again after 3 years in 2021, I was diagnosed with metastatic osteosarcoma in my lungs but still I didn't break down, I never lost hope. Again I went under 10 chemotherapies and surgery. My parents and doctors gave me the motivation to fight against cancer. I never stopped my education during the treatments. I always think that Cancer is just a chapter of my life. Now I'm fully recovered and a Cancer Survivor. I'm very thankful to the Indian Cancer Society, Mumbai for providing me facilities for my studies, caring for me and giving me financial and emotional support. Currently I'm doing my B. Tech in Computer Science from Centurion University Of Technology & Management, Bhubaneshwar. I want to become a Software Engineer. I want to associate with the Indian Cancer Society in future. Lastly I have a message for all the cancer fighters that we have to defeat cancer through proper medication, treatment, regular medical and psychosocial follow up and a healthy lifestyle. Thank you.

#### Nandani

I'm Nandani Maurya, a survivor living in Mumbai, Maharashtra. My treatment started in 2020 when I was 16



years old at Tata Memorial Hospital, Mumbai. My family financial condition was not stable and poor for many years & When I fell sick I was unable to understand what was going on with me. Every day my family prayed to my doctor to help me and my family with their treatment and many thanks to my best friend for supporting me and motivating me. Taking counseling also helped me a lot. By God's grace I completed my treatment successfully in March 2021.

Now I'm studying in 12th Science. I'm very thankful to Ugam for giving me social support and Indian Cancer Society for helping me financially in my education and also in my career growth. Thank you Mohit Suraj Gupta Hello, I'm Mohit Suraj Gupta I was diagnosed with Pre-B-ALL in April 2016 and my treatment got completed in October 2018. From this note I want to share my experience with cancer Which is both good and bad. When I heard that I have Cancer I didn't know what it was. I thought it was a fever-like thing. When I was admitted to Wadia Hospital on 9th April 2016

I cannot ever forget that day because from that day my life was changed from that day, I was faced with a lot of pain physically, mentally and emotionally.

My 3 years of childhood went under that treatment. I faced many side effects at that time and today also. I was admitted many times and I felt like I will not survive and I lost hope. But whenever I had this thought, I looked at 3 faces around me: first my mom, Second my dad and third myself. My mother always used to say that Lord Krishna said, "Yeh time bhi beet Jayega".

With the help of my mom and my dad today I survived and fought with blood cancer. I want to say to my friends who have fought this disease.

I was 11 years old at that time and passed the

Std 5th exam. Now I have completed the SSC exam in 2021 and took admission in Thakur Polytechnic for Diploma in Information Technology course for which Indian Cancer Society helped me a lot financially and for social support. And I want to thank the Indian Cancer Society for it.

Dear friends always remember

- 1) You are valuable for your parents and your loved ones.
- 2) Though the treatment journey has many ups and downs but see the faces who loves you. Life is really beautiful.
- 3) Remember we are warriors and Cancer is our enemy.
- 4) Eat good healthy food which gives you a positive attitude towards life.
- 5) My sister said to me, "Mohit, education has lots of power, if you focus on it, life changes, so focus on studies and work hard.
- 6) Friends story to sab ki hoti hai but hum warrior ki story to hamare bache bhi sunkar proud feel karenge
- 7) Again, never lose hope. Positive person ko aas paas rakho.
- 8) Always remember the line "Yeh waqt bhi beet jayega".

Thank You so much.

#### Aniya Makroo

I am Aniya Makroo Student of class 9th Age 14 years old. At the age11 years, I was diagnosed with the disease known



as Ewing's Sarcoma it was the shocking news for all of us and I felt that now it is end of my life, when I came to SKIMS I got a ray of hope when my case was discussed with doctors. During my treatment I got positive approach from all doctors, dieticians, nurses, and psychologist.

I got firm belief on my Allah that he will help

me in this difficult path, I came to know that we don't alone achieve the things ,there is always another person behind us and I owe my life to Dr Faisal Guru , Dr Gul Mohd, Dr Saqib.

All my nutrition care was taken by dietician. After completion of two years disease free life, there was a ray of hope for my future that came from Indian Cancer Society, Mumbai. When Sadaf Maam, ICS's clinical psychologist registered me in ACT Clinic run by Indian cancer society in SKIMS where I received my annual fee for school and I was also able to board my school bus. I thank Sadaf ma'am and Indian cancer society. My message to all cancer patient is that hope

sustains life and this disease is curable if you

have positive approach towards life.

#### Mamtha M

Mamtha M, 13 yr old s u r v i v o r o f C a r c i n o m a o f parotid gland My name is Mamtha , I am studying in 8th



standard. About 3 years back one day I was playing in the rain, when suddenly my neck started paining, I told my mum about it. She then checked my neck and saw that there was a small ball like lump on it. My parents assumed it was an infection and told me it will go away, when the pain didn't subside. They then decided to take me to the hospital. There I was given some medicines and told to see if the lump dissolves, if not I was asked to come back. The lump remained, so at the hospital they decided to operate and test the bump. The report came back with a cancer diagnosis. I was then told to visit Kidwai and take treatment. In kidwai, I was given radiation for 29 days. The lump had dissolved

but it came back after 3 months, after which I was told to go to Shankara Hospital, there I was operated twice and the doctor's told me that cancer was gone. I was very happy that treatment ended. I started going to school. School turned out to be another problem. My eyes can't close fully because the nerve that makes the eyes close has been operated on during my treatment. My friends started making fun of me - asking me why my lips were lopsided, they started ignoring me, I was very hurt by this treatment. I started losing confidence, my self esteem was very low. Then my family noticed and they told me about how brave I was to have overcome cancer, and tried to boost my self esteem. I, was also going to follow up every 3 months to Shankara at this time, once while I went for follow up, I met the ICS psychologist, and took counselling, after 1 or 2 sessions, I slowly started understanding that it was not my fault that they weren't talking to me, I also realized that to be more kind to myself, and stop believing the comments my friends

Recently, we were struggling financially because of the pandemic. I wish to grow up and become a Doctor and help save children's lives just like my doctor's saved mine but our financial difficulties might have cut off my dreams in the bud. My parents were struggling to pay the fees of their 3 children, and ICS turned out to be the saving grace, they supported my education financially through the Dr. D J Jussawalla educational and vocational fund, and ensured that I received quality education. I'm deeply grateful to them for the support and encouragement.

#### **HAPPILY MARRIED!!!**

#### Ashraf Ali Chaudhary



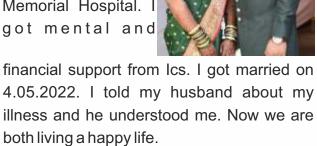
Harsh Baxi

We have been knowing each other from last 8 years and finally we got married in December 2021.



#### Vedika Lahu Vhatkar

After cancer, I thought it was an incurable disease, but I was treated at Tata Memorial Hospital. got mental and



#### **Madhuri Shreekant Deodhar**



Kabhi socha bhi nahi tha ki aisa hoga.. safar Me hamsafar miljayega..

#### **NOW PROUD PARENT!!!**



**Sudeep Das** 

#### WE ARE PROUD OF YOU



Dr. Ritesh Kumar

MBBS from Seth GS Medical College, Mumbai



Prathamesh Ravindra Jadhav

Won 1st Prize in Techno-Enhance 2022 Organized by EESA, Electronic Department, Government Polytechnic, Kolhapur.



Stood in top 5 graduates in Vivekanand College ofLaw



Samriddhi Rain (10yrs)

Scored 31/40 in National Science Olympiad, Science Olympiad Foundation.

International Rank: 83, Zonal Rank: 38, School Rank: 5 & Gold Medal Of Excellence.



Priti Nag

Std 10th Scored: 97.6%



#### Rohit Ramchandra Kanse

An Interior Designer, completed his studies from ITM institute of Design & Media (2018-

Now he is working as a Junior Interior Designer at Square 3 Design.



krishna Surywanshi

Completed D-Pharmacy

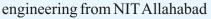
Victors of childhood cancer

Victors of childhood cancer



Vikas Maurya

Qualified JEE entrance exam in 1st attempt, Rank 233 from all over India. Pursuing computer science





Rupali Kurane

1st Professional Drama "Tidik"



**Prashant Jadhav** 

Joined National Institute of Virology as a Scientific Officer



Sonu Gupta

joined TCS, Varanasi



Anamika Soni

Got a Stree Shakti Award 2021 Award (Nari Shakti)



**Rahul Pandey** 

Received an award from CM Yogi for his support and guidance towards 65 cancer patients in Azamgarh.

### 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 सपनो को फिरसे उठाना है बढ़ते ही जाना है.... उगम

चल दिए हम लेकर अपना कारवाँ ...

Song Written by: Shashank Johri & Composed by: Immanuel