

#### Vision

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

#### Mission

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

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

## **CONTACT**

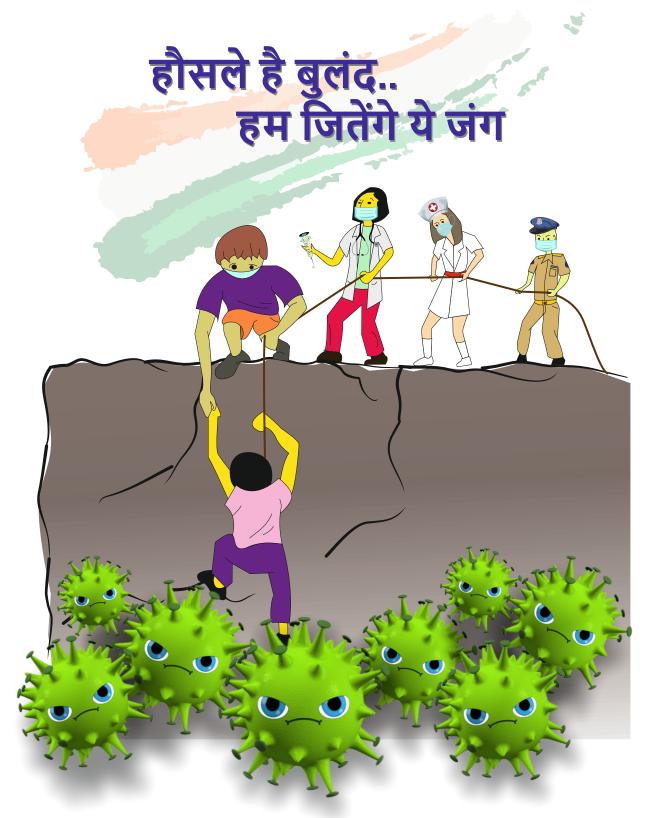
<ul> <li>Dr Purna Kurkure – Convener, UGAM</li> <li>Trustee In Charge, Cancer Survivorship</li> </ul>	E-mail: purna.kurkure@gmail.com
<ul> <li>Dr Vandana Dhamankar</li> <li>Director, Cancer Survivorship</li> </ul>	E-mail: vandana@indiancancersociety.org
• Ms Savita Goswami - Mentor	E-mail: savitata@yahoo.co.in
• Ms Preeti Phad- Member	Ph no : 9702488007 E-mail: preeti@indiancancersociety.org
• Ms Ekta Rawat – Co-ordinator Ugam	Ph no : 08805267800 E-mail: ugam.mumbai@gmail.com
• Mr Shekhar Jha - Member	Ph no : +91 9699975276 E-mail: jhashekhar56@gmail.com

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

ugam.mumbai@gmail.com / info@indiancancersociety.org

www.indiancancersociety.org





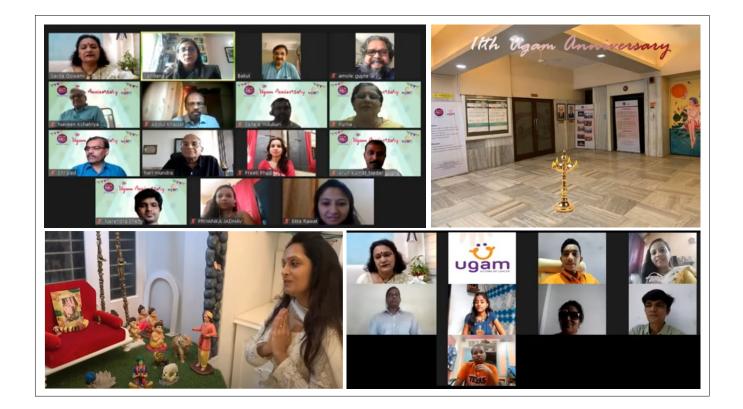
**Indian Cancer Society** 74, Jerbai Wadia Road, Bhoiwada, Parel, Mumbai - 400012 (India) ugam.mumbai@gmail.com / info@indiancancersociety.org www.indiancancersociety.org

Victors of childhood cancer

DISPLAY HOUSE DESIGNED BY:

Edited by: Dr. Purna Kurkure / Arun Kumar Nadar / Narendra Shetty Illustration by: Gopesh Chilveri

# **Ugam Calling...** 12<sup>th</sup> Anniversary Edition



#### Organizing Committee of the e-event, UGAM Anniversary 2021

Organizing Chairperson: Dr. Purna Kurkure

Organizing Secretary: Dr. Vandana Dhamankar, Mrs. Savita Goswami

Joint Secretary: Ms. Preeti Phad

**Newsletter Committee:** Ekta Rawat, Arun Kumar Nadar Narendra Shetty

**Creative Committee:** Gopesh Chilveri, Shalaka Mane, Priyanka Jadhav

**Registration Committee:** Ravi Sharma, Anita Kamble, Tushar Khillare, Shekhar Jha

**Co-ordination Committee:** Nirav Chotalia, Aishwarya Nikale, Kajal Dave, Divya R., Ritika Maurya

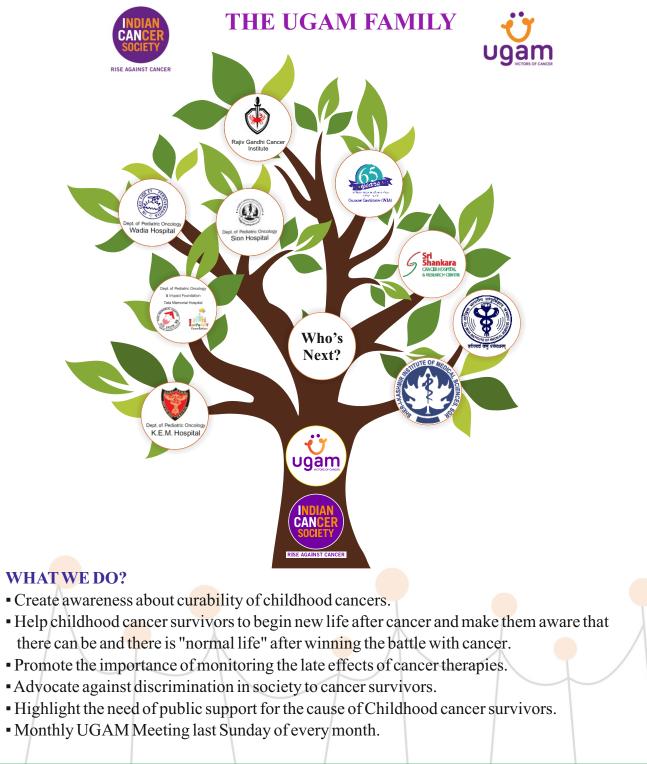
-We are deeply thankful to Mr. Rajesh Sharma (Manage Health Foundation) for providing the Digital Platform

-We are grateful to all UGAM friends, donors and volunteers for their generous support and Display House for technical support.

-We are thankful to Col. Abdul Khadar D.D.G. of ICS and grateful to board of trustees and the national managing committee of ICS for their unconditional love and support.

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.

to Ugam



#### WHAT WE DO?

Victors of childhood cancer

# **UGAM PROFILE**

Total no. of Ugam members 369, Due to the pandemic situation last year new members were not added



Dr. Purna Kurkure

Convener, Ugam

Trustee In charge, Cancer Survivorship & Rehabilitation Vertical

Indian Cancer Society

Chairman, Oncology Collegium Narayana Health Head, Division of Pediatric Oncology & BMT NH-SRCC Children's Hospital, Mumbai

Treasurer, Indian Academy of Pediatrics

Welcome to the 12th Anniversary of UGAM -Celebration of Life!

Today, we join thousands of cancer survivors and supporters around the world who are celebrating life after cancer on the Cancer Survivor's Day which also marks birthday of Ugam- Childhood Cancer Survivors Support Group launched in 2009 under umbrella of Indian Cancer Society, a first & premier Not for Profit organisation in cancer space in India.

We are back on digital platform for second year due to ongoing ravage created by COVID 19 pandemic. Last year we looked at online encounter as "Unique experience" in the journey of Ugam. We were excited & enjoyed it thoroughly not only for the anniversary celebrations, but through entire year with online activities well summarised in this issue. This kept Ugamites connected & energised through this difficult period. However, COVID 19 has turned out to be mystery which is still evolving & is here to stay with us before the hurly burly is over & our social isolation comes to an end.

This year digital platform is being kindly provided pro bono by Mice Ideas through its CSR arm Manage Health Foundation. We are grateful to Manage Health Foundation & Mr Rajesh Sharma for this kind gesture.

Today, we take a stand for cancer survivors. We make a commitment to lessening the burden of cancer survivorship. We use our voices to call for more resources, research, and legislation to improve the quality of life of cancer survivors. Ugam & Project PICASSO (Partnership in Cancer SurvivorShip Optimization) are testimony to these efforts & provide a model to create network of Cancer Survivorship units at Pan India level. We are grateful to our corporate donors for supporting this project and provide fuel to our burning desire of making Cancer Survivorship a societal movement. We are hopeful that our partners in project PICASSO will join this movement and nurture support groups & strengthen hands of Ugam.

#### Today, we also celebrate.

We celebrate the personal milestones of cancer survivorship, no matter how small. Our support to eligible survivors through DJ Jussawalla Educational & Skill Development Fund to achieve career milestones to get back to mainstream in society & related victor's stories in this issue exemplify this point. Our revamped Rehabilitation centre with state of Art facility for rehabilitation of cancer survivors physically & psychosocially in holistic way, formally launched on 26th January 2021 adds one more feature to survivorship care. Our vision to take care of medical late effects through financial support for specialised medical care is on our priority list.

We celebrate the research programs, the medical breakthroughs, and the treatment advances that are allowing cancer survivors to live longer, healthier, more active lives than ever before.

Today, we celebrate life. Though it may be unpredictable, it may be complicated, and even difficult at times, life after cancer can also be beautiful, inspiring, and profound.

" हौसले है बुलंद... हम जितेंगे ये जंग "

"Nothing can stop us."

# 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 Mentor-Ugam Director. Survivorship & Rehabilitation Indian Cancer Society

Congratulations to Ugam on completing twelve years of extraordinary journey!

I am very happy to see the togetherness growing despite the Covid 19 pandemic . Consecutive two years Ugam has been celebrating the anniversary online and we salute to the spirit of Ugamites!

It is important to spell out important milestones as 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 paediatric 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 project PICASSO (Partnership In Cancer SurvivorShipOptimization)

PICASSO is holistic rehabilitation module being implemented in partnership with paediatric 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.

Bharat Petroleum Corporation Ltd (BPCL), HES Infra, WPP India Foundation, Navneet Foundation, UTI, Raymond, Geltec, Igarshi

#### **Developments (from 2017 till date)**

- There are nine partners in five cities (As shown in Ugam family tree) involved in medical & psychosocial care of survivors.

- Phase two of the project has started in Tata Memorial Hospital where the AYA ACT clinics are started with the respective Disease Management Groups on specific days of the week.

- The psychosocial advisory groups consisting of experts from social sector as well as psycho oncology field are established. Regular meetings with them on specific agenda has been very helpful for further development of the psychosocial module. We thank our volunteers

- Prof Rukaiya Joshi (Ex Chairperson- Centre for Education in Social Sector, SPJIMR), Ms. Shailaja Muley (Senior Teacher Counsellor), Dr. Mira Desai (Faculty Member ,SNDT Women's University, University Department of Extension Education) Asha Banu Soletti Ph.D Professor Centre for Health and Mental Health School of Social Work. Dean, Office of Students' Affairs Tata Institute of Social Sciences Dr Savita Goswami (Clinical psychologist, Tata Memorial Hospital), Dr. Surendran (Psycho-Oncologist, Cancer Institute Adyar)

Ugam's future roadmap is clear- continue increasing the membership and motivate more survivors to do the voluntary work and sharing experience with other survivors from PICASSO project partner hospitals to expand the network which will enable formation of similar support groups.

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



#### Usha Thorat

Former RBI Deputy Governor, ICS Trustee, Trustee in Charge for CCF



Dr. Girish Chinnaswamy

MD (Peds); MRCP (UK); MD(UK),Professor & Head, Department of Medical & Pediatric Oncology, Tata memorial Hospital.

Anniversary!

The medical treatment of childhood cancer is only part of the journey and integrating back to society is what makes the journey complete.

UGAM has played a crucial role in this journey and has always been a ray of hope for every childhood cancer survivor. They have inspired many children to enjoy and lead a life with pride after fighting the deadly disease.

The survivorship programmes have supported huge number of children in their battle of cancer. I wish UGAM continues and reach out to each and every childhood cancer survivor and show them the right direction in life. UGAM can very well be defined by saying that "UGAM is by, of, and for the childhood cancer survivor"



Dr. Rachna Seth Professor Division of Pediatric Oncology Chair, InPoG Late Effects subcommittee Department of Pediatrics, AIIMS, New Delhi. India

Best wishes to UGAM, the support group of childhood cancer survivors of the Indian Cancer Society, as they celebrate their 12<sup>th</sup> anniversary. Advances in management strategies for childhood cancers has resulted in a growing population of childhood cancer survivors. Over 80% of children diagnosed with cancer will be cured and will emerge as long-term childhood cancer survivors! Survivors of childhood cancer and their families often have unique needs and concerns and this has led to the emergence of a Survivorship program which is essentially an 'Off therapy' care that helps patients / families navigate life after cancer.

As survivors age, they may experience health problems years or decades earlier than their peers: 'premature aging'. Psychosocial issues and post traumatic stress disorder often require attention. Late effects which are unrecognized toxicities that are absent /subclinical at end of therapy and manifest months/years later are an important concern of survivorship. The spectrum of late effects can be varied ranging from psychosocial and neurocognitive deficits to impairment in growth and development, reproductive dysfunction, organ specific deficits like cardiac dysfunction, endocrine dysfunction, metabolic syndrome etc. One needs to be aware of late effects.

Understandably more time needs to be dedicated Oncology at Sher-i-Kashmir Institute of Medical to survivorship care that requires integration of Sciences, Soura is privileged to be connected with multidisciplinary domains. This led to the ICS. establishment of the after treatment completion (ACT) clinics which serve as a platform for Since our long association, innumerable patients providing care to children having completed have benefited in terms of getting financial cancer treatment. At the All India Institute of assistance for the treatment of various cancers. Medical Sciences, (AIIMS), New Delhi we run a The support that holds on its shoulders the weekly survivor clinic where children after responsibility to wipe out all the red flags and treatment are registered and provided roadblocks in the way of treatment, is what comprehensive care comprising continued energizes even us as doctors to give in our best. evaluation for remission status of primary disease, evaluation of possible late effects, growth SKIMS has been associated with ICS, and AKITF monitoring, counseling for healthy lifestyle, and UGAM by ICS, and we honor this association handing of treatment summary via the and hope for it to continue lighting up the lives of indigenously designed after treatment patients battling Cancer completion card (ATCC) which also carries information on survivorship. Focus is on education, appropriate vaccination and integration of child into the society: ultimate cure! We have initiated the InPoG first nationwide childhood cancer survivor registry in India and invite centers to participate. We are happy to partner with ICS via the PICASSO project wherein the primary focus will be evaluation of neurocognitive deficits ,one of the most worrisome late effect of childhood cancer survivors. ICS and UGAM will help many cancer treating centers to set up survivor clinics which are an emerging need.

For all childhood cancer survivors : You can lead normal lives. You just need be aware of late effects which are the result of your successful treatment. Most late effects can be tackled. Ensure a healthy lifestyle and pursue your dreams and passions! Stay safe and take the COVID vaccine if you are eligible.

I will never forget my first encounter with the Heartiest Congratulations to UGAM on its 12th significance and meaning of UGAM for its members - or cancer victors as we like to call them

It was a play at ICS Founders Day- it was about a teenager stricken with cancer, who is so depressed that she takes to bed and refuses to meet anyone. Her mother is distraught and extremely worried about her daughter.

A group of youngsters then walk in -all cancer victors from UGAM. Over the next ten minutes of the play, they engage in such a realistic, nonjudgmental, pragmatic conversation with our teenage friend that by the end of it, she gets up and joins the others in their cheery songs and dance! The need for emotional support at a time when one feels one's world has ended and questions of "why am I being punished?" or "is there a God?" plague one is so critical and this is what the play illustrated. UGAM provides and remains an emotional support and friend for life.

Cancer Cure Fund CCF provides financial support for underprivileged cancer patients and so far supported more than 2600 children for Rs.36 crore through 16 empanelled hospitals throughout the country. This is of huge help to the family as very often the cost of treatment can drive a family into utter poverty. However, emotional support is equally important for recovery and post treatment progress. CCF has now linked with Ugam so that young patients who have been or are being supported by CCF can become part of the UGAM network and spread the message of UGAM to all those affected by cancer. This can be aided by whatsapp groups, zoom calls and other virtual ways we have learned to connect so that distance and language are no longer barriers!

I wish UGAM the very best on its 11th Anniversary and many many more !

Victors of childhood cancer



#### Dr. Faisal Guru

Assistant professor Department of Medical Oncology (Pediatric Oncology) SKIMS Srinagar.

Psychological and financial support,

inclusive of not just the patients but the caregivers as well, is a quintessentially integral part of the treatment of cancer. ICS has been a great patron in this direction. The Department of Medical

Victors of childhood cancer

#### **Events organized by UGAM**

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

#### UGAM's 11<sup>th</sup> Anniversary Celebration (June 2020)

#### **Counseling session by Ugam members**

Sharing experiences and answering queries of active patients (children) & parents from St Jude's Centre (Cotton Green Centre) is a regular activity in which Ugam members are involved throughout the year. Three sessions were conducted this year



Ugam's 11th Anniversary was based on the theme, "Hum Har Nahi Manenge" which indicated the unstoppable enthusiasm of the Ugam in the difficult time of COVID-19. Since social distancing was followed throughout the nation, it seemed challenging to conduct the 11th anniversary physically. But Ugam accepted the challenge, The event has nearly 2.5K viewers on YouTube (https://youtu.be/G7fza22tXSM) Because of online nature, more survivors from all over India could view and enjoy the program with family & friends!! We thank Digital IAP for providing the platform for the event.





Due to the online nature of the sessions, interactive Question Answer session were held across 9 St. Jude's centres all over India covering 80-100 families in each session. Several queries and doubts of anxious parents pertaining to Cancer treatment and care post treatment were answered by Ugam Victors.

**Childhood Cancer Awareness Month** (September 2020)

1. Workshop For Ugam Members

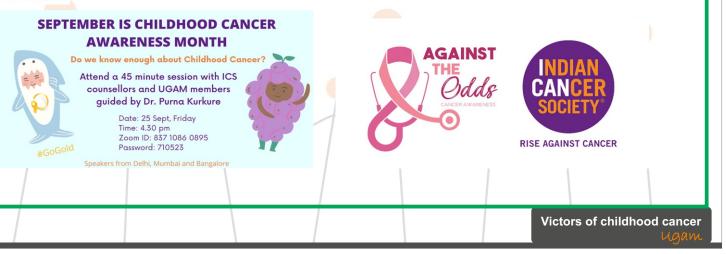




Ugam members share stories of hope and motivation with children undergoing treatment, it has been useful to the parents as well .A workshop was organized for Ugam members to upgrade their counselling skill. Several Psycho-social and medical aspects were explained by the experts during the discussion. It was attended by more than fifty survivors.



2. Seminar for ICS Branches **Under ICS One** 



Victors of childhood cancer





It was an internal capacity building session. Dr Purna Kurkure gave an overview of childhood cancers followed by an interactive session with ICS counselors and Ugam Members on practical issues faced by survivors. Counselors from Mumbai, Delhi & Bangalore branches interviewed the survivors.

It was attended by more than 65 attendees from ICS including NMC members.

#### **Creating Awareness with ICS** awareness team

1. In October 2020, ICS in collaboration with BIG FM 92.7 radio channel (58 stations and 6 cities in India) had conducted a campaign #TogetherAgainstCancer to spread awareness about Childhood Cancer. Dr. Purna Kurkure, Convenor-Ugam, Mrs. Savita Goswami -Psycho-oncologist from TMH, Amisha & Divya - Clinical Psychologist and Rajesh Savla - Ugam member were interviewed.

2. Childhood cancer Awareness - Oberoi International School social media campaign This year due to the pandemic, Relay for life could not be conducted in schools However, in November 2020, Ugam members participated in an awareness campaign organized by Oberoi International school to spread awareness about cancer & its care. Ugam members shared their cancer experiences and motivated others

https://www.instagram.com/tv/CGh2 -VHA\_Z5/?utm\_source=ig\_web\_copy\_link https://www.instagram.com/tv/CGb4zXAA1Jt/ ?utm\_source=ig\_web\_copy\_link https://www.instagram.com/tv/CGZU5wiAUSa /?utm\_source=ig\_web\_copy\_link

**Sanjeev Kumar** – He is an Ugam member and well qualified artist. His paintings were put up for Exhibition on Their Instagram page, has reached more than 6000 viewers with around 1000 likes.

#### **Programs organized for Ugam members during the pandemic**

Art of living online Workshop – July 2020



To make Ugam members stronger mentally during the pandemic and to cope up with the stress, Art of living workshop was conducted for Ugam members. It was spread for 4 days wherein, participants were enlightened about the importance of meditation for physical, mental and emotional health. Twelve members were benefitted from the advanced course whereas many more attended the one day program,

#### **Live Panel Discussion** (Covid 19 Vaccine Concerns of Young Cancer Survivors)



On  $1^{st}$  may 2021, The Govt opened the next phase of vaccination from 18 - 45 years age group, which created a lot of anxiety in survivor's minds. A panel discussion was organized to address the Covid-19 Vaccine concerns of young survivors. We thank our Picasso Project partners, Dr Gauri Kapoor (RGCI), Dr Venkat (CIA), Dr Maya Prasad (TMH) for their valuable contribution as Panelists. The session was fruitful as many doubts and myths related to vaccine were cleared. The session was attended by more than 450 attendees

### Participation in Conference by Ugam Members

#### TYAcan 2020 – Sep 2020



UGAM Members Participated in 9<sup>th</sup> National Conference in Teenage & Young Adult Cancers Conference (Virtual) was held on 12<sup>th</sup> & 13<sup>th</sup> September 2020.

**Theme** – Adversity to Opportunity A group of Ugam members were interviewed by Mrs. Savita Goswami on **How to become a friend of a Young Cancer Patient?**  The below questions were discussed on the live panel discussion held regarding vaccination concerns on 01st May, 2021. For full video and details about this discussion, please visit the following link https://www.youtube.com/watch?v=lYVbbAJmgDg on our ICS Youtube channel

**Q.1)** Can Survivors take Covid vaccine? **Ans.** Currently, vaccines in India are available to those above 18 years of a survivors above 18 years can (and shou the vaccine.

Q.2) I was a corona positive but now I am good, can I take Vaccine? Ans. Yes, after 3 months of recovery.

Q.3) Which Vaccine should take (Covishield or Covaxin)? Ans. Both the vaccines are equally effective, and you can take the vaccine, w more readily available.

**Q.4)** Can pregnant and lactating women take vaccine?

**Ans.** The government has recently allowed pregnant and lactating women to get vacci walk-in appointments.

Q.5) Can women take vaccine during their menstruation cycle? Ans. Yes

**Q.6)** Can I get Covid even after being fully vaccinated?

Ans. Yes, even fully vaccinated people may get COVID infection. However, vaccinated reduces the severity of Covid, a very rare to see severe covid, ICU admiss deaths in patients who have been vaccinate vaccine does not always prevent infectimost patients who have the vaccine have mild form of infection.

Q.7) How many days gap should there be be first and second dose of vaccine?Ans. The government has extended the between two doses, and it is now 12-16 week

Q.8) What is the common side efficiency vaccination?

Ans. Both vaccines are overall safe. The co side effects include mild fever, mild pain at of injection and weakness. Rarely, individuals may develop high fever or complications.

ge, and ld) take	<ul><li>Q.9) Can covid recovered patients donat blood and platelets?</li><li>Ans. A person who has totally recovered from active Covid infection can donate blood and platelets. If you are a cancer survivor who has received Chemotherapy and Radiation, you should follow survivors guidelines related to blood donation.</li></ul>
	<b>Q.10)</b> If somebody has got covid after 1st vaccination, when should they take second dose? <b>Ans.</b> Approximately after 3 months.
vhich is	<ul><li>Q.11) Can I take Covaxin as a second shot if I have taken Covishield for the first short and vice versa?</li><li>Ans. No, both doses should be from the same brand of vaccine.</li></ul>
ine with	Q.12) Can patients post- bone marrow Transplant
r	take vaccine? Ans. According to American Cancer Society, patients who have undergone bone marrow transplant can take vaccine after a gap of 3 to 6 months from transplant, after consulting with their doctors.
, being and it is sions or ted. The ion but e a very	<b>Q.13)</b> Should survivors need to come at ACT clinic during this pandemic situation? <b>Ans.</b> ACT clinic have risk based follow up. Intermediate risk and low risk survivors can do follow up on telephone and zoom. For high-risk survivors we can decide whether they need to come or not on our video consult depending upon the situation.
between he gap eks.	Q.14) Can vaccine cause Thrombosis? Ans. Yes, Covishield may rarely cause thrombosis. In case of history of Thrombosis, you need to consult doctors before going for vaccine.
fect of	<b>Q.15</b> ) What should I eat to prevent covid? What kind of life style should I follow? <b>Ans.</b> Take a healthy life style. Avoid smoking,
ommon the site , some r other	exercise daily, take a healthy and nutritious diet and. Most importantly, continue to follow social distancing, strict use of mask and good hand hygiene.

# Retinoblastoma Survivors and family meet – Sep 2020

This was organized by Abigail Wagh Foundation. 10 RB survivors from Ugam participated in the Panel discussion and shared their experience, stories to motivate others.

### CCI ( Childhood cancer International ) ASIA – Mar 2021



3 Ugam members Preeti Phad, Shweta Chawre & Ravi Sharma participated in the annual CCI Asia conference that was held virtually. Clinical psychologist Amisha gave oral presentation in the conference

#### NCD Meet-Nov 2020



Ugam was invited by ICS-Delhi to be a part of Healthy India Alliance (HIA). HIA invites people living with NCDs to be a part of a series of Virtual Community Dialogues and a National Digital Signature Campaign, to strengthen their voices. Preeti & Narendra represented Ugam at the virtual meet. There were talks on the surge pricing of NCD medicines by pharma companies at the time of COVID. Health Insurance issues of people living with NCDs were talked on as Insurance companies are reluctant to cover people living with NCDs



Awareness activities and spreading hope

about curability of Childhood cancer

Gokulashtami / Dahi Handi Event – Aug 2020

"Dhoom Virtually on Zoom". Ugam has been celebrating Dahi handi and spreading awareness messages through this platform over last 10 years (2010). Mr. Nitin Landge (Yuvasena President & Ugam Friend) represented Mr. Rajan Vichare MLA of Thane.32 survivors attended the virtual event.

## Participation in ICCD campaign – Feb/Mar 2021

ICS Ugam is an Associate member of CCI (Childhood Cancer International). International Childhood Cancer Day (ICCD) is organized every year with an objective of raising awareness about childhood cancer and to express support for children and adolescents with cancer, the survivors and their families. Ugam members participated in ICCD campaign by posting motivating messages online for others survivors across globe. They were awarded with certificates as a token of appreciation.





जब नाम ही उगमहैंतो...

ही बनी हैं।

ये हौसला कैसे झके, जीने की आरज् कैसे रुके,

मंझिल मश्किल तो क्या..धंदला साहिल तो क्या।

मरीर अलीँजी की ये पंक्तिया मानो जैसे उगम के लिए

महामारी और तालाबंदी के इस पुरे दौर में भी उगम ने अपना जज्बा नहीं खोया।जून २०२० को उगम ने अपनी

११ वी और पहली वर्चअल वर्षगाँठ मनाई। एक नया

अनभव था मगर सबने अपना अपना योगदान देकर उसँ दिन को संस्मरणीय बना दिया और उस साल के हमारे "हम हार नहीं मानेंगे" इस ब्रीद वाक्य को साबित

करके दिखाया। देखते देखते एक साल बीत गया सबको

बडी उम्मीद थी के सब जल्द ही पहले जैसा हो जायेगा पर नहीं हआ। मुसीबतों के बादल कुछ ज्यादा ही गहरे हो गए। कुछ मंबर्स और उनके परिवार को कोरोना का

सामना करना पड़ा, तो कुछ लोगोंने अपने क़रीबिजनोंको खो दिया, कुछ मेंबर्स की नौकरी खतरे में आ गयी,

पढ़नेवालों की पढ़ाई रुक गयी। इतनी सारी मुश्किलें है मगर हौसलों को बलंद करके इस साल भी उँगम परी तयारी के साथ अपनी बारवी वर्षगांठ मना रहा है। इसबार उगम के प्री-इवेंट सेलिब्रेशन का प्रमुख आकर्षण है।

उगम क्विज कॉन्टेस्ट और उगम फोटो कैप्शन चैलेंज।

उगम क्विज कॉन्टेस्ट में २१ मेंबर्स ने भाग लिया था। पहले राउंड में तीन ग्रुप बनाकर क्विज खेला गया, हर ग्रुप से

तीन विजेता चुने गएँ, जिनके साथ सेकंड राउंड खेला गया

और उनमें से तीन जो अच्छा खेले उनके साथ तीसरा

उगम फोटो कैप्शन चैलेंज में उगम की स्थापना से लेकर ग्यारवी सालगीरा तक जो भी तस्वीरें थी उनमे से कछ

तस्वीरों को चून कर उन्हें अनुरूप (suitable) एक वॉक्य

इस एक्टिविटी का मक़सद पुरानी यादों को ताज़ा करना तो था और साथ ही नए मंबर्स को फोटो के जरिये कछ

गैभीर परिस्थितियों को सहज बनाना, हँसते खेलते हौंसलों को बलंद रखते हए आगे बढना, उगम की खासियत हैं

और इसी तरह अपँनी रफ़्तार को बरक़रार रखते हए उगम

और फाडनल क्विज राउंड खेला गया।

या एक शब्द का शीर्षक (caption)देना।

परानी बातों की जानकारी देना भी था।

आगे बढ़ता रहे यही हमारी मनोकामनाहै।

Mrs. Savita Goswami Mentor - Ugam Psycho-Oncologist Tata Memorial Hospital

जिंदगी कभी लगता है तुमसे हुँ वाकिफ, तो कभी लगता है अभी भी हुँ मैं तुमसे अनजान हर मकाम पर चौकाया हैं तुने और लिए नये इम्तहान ..

लोग साथ चल रहे थे मेरे और मंजर भी थे तब सुहाने कुछ साथ छुट रहे है अब, मंज़र भी कहा वो नजर आते हैं पुराने..

तेरी राहें खिलखिलाती थी कभी अब हो गई है बड़ी सुनसान तु चाहें जितने भी ले इम्तहान हम हार नहीं मानेंगे जब तक है जान..

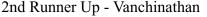
सविता गोस्वामी



"Hum Jha Khade Hote Hai Line Wahi Se Shuru Hoti Hai"



"Hum Sath-Sath Hai"





"Khana Khakr Hi Jana Hai apko"





"Meri Aawaj hi Meri Pehchan Hai"





"The job of feet is walking but their hobby is dancing"

Victors of childhood cancer





Winner : Shalaka Mane





1st Runner up : MD Belal Anwar





2nd Runner up : Ritika Maurya



# **DR D. J. JUSSAWALLA EDUCATION & VOCATIONAL SKILLS FUND** Beneficiaries who completed milestone









Parvez Shaikh

Sonu Sinah



Aiinkva Dhondiram Shewale

Amit Gupta





edika Suresh Kol



Rahul Pande







no reimbursements), Vocational course fees, career guidance & individualized Education

guidance

Education Fund-

Victors of childhood cancer

email: kajal@indiancancersociety.org School & college fees (directly to the institutes / Ms. Shabana Shaikh -

Ph: 8591406582 email: shabana@indiancancersociety.org









Surbhi Paswar



Dr. Ritesh Kuma



Pankaj Tiwari







Shruti M





Jav Patil





Juned Basheer Shaikh









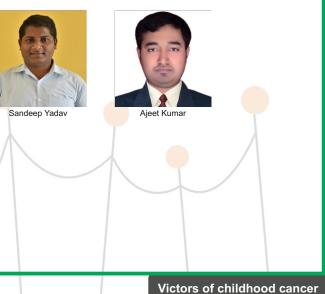
Gunian Jotka





Rohit Naidu





# **Ugam Victors Story**

#### **Rupja Banerjee**

Myself Rupja Banerjee. When I was Six I was diagnosed by ALL-Acute Lymphoblastic Leukaemia, at my home town Kolkata in the year 2006. As soon



as I was detected, without thinking of anything, my father took the decision to relocate at Mumbai for my better treatment at TMH – Tata Memorial Hospital. My treatment went on for 3 years (2006 Nov – 2009 Oct). It was so painful treatment which is indescribable. I strongly believe that without my parents sacrifice, love, care, energy, nothing was possible. Whatever, wherever I am standing right now all the credit goes to them.

At present, I am completing my graduation- first year. Beside everything, my hobbies are dancing, painting and crafting. Also I love to click pictures and to innovate recipes and cook them.

Being a childhood cancer survivor I feel very proud as I can serve the other fighters to fight and survive properly and feel proud as I do.

Beside all of the above, there is another vast family that came in my life when my parents started to feel lonely-Ugam. Ugam stands beside us like mentor.

With the touch of Ugam I started to feel very fortunate because it started to increase my courage. We got opportunity to cater joy and fun to others through some social and cultural programs organised by Ugam. Not only the mental support but also we get financial support too from Dr. DJ Jussawala Fund.

Therefore, I do want to thanks to Doctors, Nurses and last but not the least Ugam & ICS.

You will face many hurdles from the society but some are going to be helpful and some not, as

people have different opinions. Therefore, do believe in yourself and keep the urge of living because everybody can leave you but not your parents.

#### Rohit Balkrishna Chilka

I'm Rohit Balkrishna Chilka, living in Mumbai, survivor of blood cancer (ALL). My treatment started in 2008 when I was 7 years of age under Dr. Mamta Mangalani at



LTMG Hospital (Sion Hospital). My family's financial condition was poor. Since I was just a child, I was unable to understand what was going on with me. Every day my mother prayed for me. Doctors helped me and my family with their treatment and counselling. By God's grace I completed my treatment successfully in 2010.

Now, I'm pursuing my BSC IT 2nd year. I am very thankful to Indian Cancer Society (I.C.S) and Ugam for helping me financially in my education and also in my career growth. Thank You

Raj The Tonsil's Tale

My life was quite regular until 17<sup>th</sup> March 2008 evening when I had pain in my tonsil, felt as if a rope was tightening my throat. I could barely whisper as my



throat had an unbearable pain. Despair darkened me, choked me. My body was all numb and my soul was overpowered. I wanted to scream so loud that the clouds would burst open with showers of love pouring down, but I couldn't.

I was rushed to the hospital and the fear on my parents face horrified me. I was rushed into the I.C.U. For a fraction, I gagged and I couldn't breathe as I kept puking. It hurts I kept saving, tossing & turning, gasping for air. I became unconscious and woke up with syringes pierced,

oxygen pipe running through my nose, and pulse oximeter on my finger. I felt the gentle caressing of my mom whilst watching my dad gulp down his fear and anxiety.

My parents were terribly shaken when they were informed by the Doctor that I was suffering from Throat Cancer. They became restless and started sweating and shivering in an air-conditioned room. I was unaware of the gravity of my disease as I was just 7 years old and all I knew was that I am ill and I am going through a bad phase. I felt like watching my favorite show and then someone played something really very horrid and threw away the remote.

After 2 weeks or so I was shifted to a well-known Cancer hospital. It looked like a new home where I spent almost 8 months in bed with nurses and doctors piercing me with several syringes throughout the day. My body went through a lot of weird machines throughout the day which made me feel like a lab-rat. Majority of times as I laid my head on my wet pillow, I wondered about the many stories racing in my head. So many folks lying down on their own in a dark room waiting for the silver lining to knock at their door. So many eyes were waiting for the good news to soothe them with every passing minute. I knew my story and there was more to it, more pain and tears.

Luckily it had been just 8 months and I was finally home. People visited me as if I had won a war for my country. Bouquet of flowers, biscuits and lots of sympathy from my loved ones. It was like a rainbow appearing after the storm. I had a wrong prediction that the bad days are over. Visiting the hospital 3 times a week was my routine. I had a few friends who eventually left me but the syringes and machines still didn't.

After a vacation at home I was taken back to the hospital. It literally felt like a rehabilitation center. I didn't speak to anyone for several days, I used to get mad at things, threw things in air, I frequently used to get mad at myself, why me I kept asking. I'd watch all the images and videos in my gallery and spend the day. Not a single day passed without my parents motivating me. I had my first Radiation therapy . I was too young but I kept telling myself - you've come so far and hope is the last thing to lose right now.

I woke up on a Sunday morning and was interrupted from having my breakfast. My early morning roller coaster ride ended up at 'Minor OT' with a team of doctors in front of me and one of them pierced me. I wasn't in my senses due to anesthesia and went completely numb all I could barely see were those docs. I could see everything for just 4/5 seconds but couldn't say or do anything.

Later when I came back to my senses, I was in my room and I got a panic attack due to which they had to take me back to the OT. I literally thought I'm on some drugs, having weird hallucinations. When I was completely back to normal I couldn't feel my body for the next 8 hours. Having oxygen pipe running through my nose, surrounded with TV screens which showed weird signs of an earthquake, the beep-beep sound sounded like a running tap, saline running through my veins, and the unbearable pain made me feel like a living corpse. I suffered the whole night inspite of all the painkiller injections they gave me. I wanted to meet my family but it wasn't possible until morning, I had only one option left, wait...

Next day as I woke up I wanted to pee so I got up and fell due to weakness with all the saline strings pulled down, syringe out of my fist spurting out blood as there was a black out in front of my eyes. It was like 'ay shit here we go again'. Doctors added some more medicines to the saline and I was back to normal. A week later I was discharged with lots of medicines as my reward and was asked to take complete rest. After few weeks I could sit, walk and eat on my own. I know these are like basic things but never in my life I thought I'll be thankful for doing these normal movements.

I am not ashamed of putting it out here because I survived and made it through the dark tunnel. I am never going to take simple things in my life for granted and on a serious note I'm grateful for the life I'm living right now. All I am m asking y'all is just to be gentle with yourself and others. And all I wanted to do now, as I ponder on the lives of the survivors is to hold them tight through my closed eves and hug them. Hug them till I hear the serene voice of their body calming them. To all the voices, broken dreams, and lost souls, I hear you. I see you struggling. I feel the tears rushing down your cheeks like pearls of dew. It hurts, its hard, its dark but I can see the ray of light way ahead

waiting for you to dance freely in its warmth. There are these people wearing green, blue and white with stethoscope around their neck who won't give up on you. Just keep going eventually it's just phase and this too shall pass.

#### Pankaj Tiwari

नमस्कार दोस्तो. मेरा नाम पंकज तिवारी है, मुझे पैर में 15 साल की उम्र में बोन सॉफ्ट टिश्यू का कैंसर डाइग्नोस हुआ। 2011 में मेरा इलाज टाटा



हॉस्पिटल मे शुरू हुआ पूरे एक साल तक मेरा इलाज चला इलाज के समय मुझे बहुत सारे परेशानियों का सामना करना पड़ा मुझे 8 कीमो लगें 21-21 दिनों के अन्तराल मे और 2 बार सर्जरी हुई अंत में मैंने कैंसर जैसी बीमारी को मात दे दी।

इन्डियन कैंसर सोसाइटी से मुझे उगम के बारे में पता चला और मैं उगम ग्रूप से जुड़ गया। उगम से जुड़ने के बाद मुझे डॉ. डी. जे जस्सावाला एज्युकेशन फन्ड के बारे में पता चला वही से मुझे एज्युकेशन के लिए मदद भी मिली और मैने हार्डवेयर नेटवर्किंग का कोर्स पूरा किया, जिससे मुझे काफी फायदा हुआ उसके बाद मैंने अपनी पढ़ाई पूरी की पर ऐसा नहीं है कि यहा मेरी परेशानियां खत्म हो गई। 2019 मे मैं गिर गया और मेरे पैर का रॉड खिसक गया था। डॉक्टरों ने कहा दोबारा ऑपरेशन करना होगा और खर्च काफी ज्यादा होगा। 3 महीने तक मै टोटल बेड रेस्ट पर था, काफी उदास हो गया था और उस समय मुझे फाइनेंशियल, इमोशनल, मेन्टल सपोर्ट की बहत जरूरत थी।

उस वक्त मुझे इण्डियन कैंसर सोसाइटी की तरफ से फंड दिलाया जिससे मेरा इलाज जल्द से जल्द हो जाये। इस सपोर्ट के लिए मैं आई.सी.एस और डॉ. वन्द्रना मैम का आभारी हैं।

तभी उस वक्त उगम ग्रुप के लोगों ने मेरा बढूत साथ दिया। डॉ. सविता मैम ने मुझे फोन पे भी कॉउन्सलिग किया मैम ने मुझे मेन्टली रूप से बहुत सपोर्ट किया। और सर्जरी के बाद मुझसे वार्ड में मिल<mark>ने भी</mark> आई थी। मुझे कभी ऐसा फिल नहीं हुआ की इस कठिन परिस्थिति में मैं अकेला हूँ, मुझे बहुत अच्छा महसूस हुआ कि मेरे साथ इतने लोग खड़े हैं। और आज मैं जो जीवन व्यतीत कर रहा ह। उसमें उगम और इण्डियन कैंसर सोसाइटी का महत्वपूर्ण योगदान है। किंतु मैंने जीवन में कभी हार नहीं मानी

क्योकी मेरे पास अपनो का साथ था ऐसे बुरे समय मे मेरा परिवार और उगम हमेशा से मेरे साथ था। इन सभी परेशानियों के बाद भी मैंने डिप्लोमा इन कम्प्यूटर का कोर्स किया अभी मैं पम्प चालक के रूप में नौकरी करता हूँ। अब मैं आत्मनिर्भर हूँ।

उगम ग्रुप से जुड़े हुए मुझे 4 साल हो गये हैं। मैं सभी एक्टिविटी में हमेशा हिस्सा लेता हूँ हर बार कुछ ना कुछ नया सीखने मिलता रहता है। मैनें लॉकडाउन के दौरान एक यूट्यूब चैनल की शुरुआत की हैं जिसका नाम टेविनकल पण्डित जी है इस चैनल पर टेक्नोलोजी से रिलेटेड वीडियो बनाता हँ।

एक बात जरूर कहगा जाते जाते-देर लगेगी मगर सही होगा हमे जो चाहिए वो ही होगा दिन बुरे है जिंदगी नही

#### Shubham Mali

नमस्ते दोस्तो, मेरा नाम शुभम माली है और मैं मुंबई का रहने वाला हूँ! दो साल के उम्र में मेरे घर वालो को पता चला कि मुझे ब्लड कैंसर है। वो इस बात से



हैरान थे। 22 सितम्बर 2002 को मेरे इलाज की सुरुवात वाडिया हॉस्पिटल में हुई। इलाज के दौरान मुझे कीमोथेरेपी भी लगाई गई और तो और मेरे रीड की हड़डी से कई बार सैंपल भी लिए गए। ये सब मेरे लिए पीड़ादायी था। पर कहते हैं ना बुरा समय ज्यादा दिन नही रहता है। तीन साल काफी मुश्किलों के बाद २ जून २००५ को मुझे होस्पिटल से छुट्टी मिल गई। इलाज के बाद मैंने अपनी पढ़ाई पूरी की और एक दिन मुझे उगम के बारे में पता चला और मैं 2015 मे उगम में सम्मिलित हो गया।

मैंने पहली बार उगम की 8वीं एनिर्वसरी अटेन्ड की और मैं उगम के परिवार का हिस्सा २०१५ में बना, शुरवत में मैं बोहोत शांत रहता था, धीरे धीरे में आगे बढकर बात करने लगा.. मुझ में ये कॉन्फिडेंस उगम से ही आया है। उगम द्वारा आयोजित सभी प्रोग्राम में मैं हिस्<mark>सा ले</mark>ने की कोशिश करता <mark>हु औ</mark>र मुझे बहुत अच्छा लगता है। और मेरे लिए सबसे महत्वपूर्ण बात की मैं कैंसर पेशेन्ट और उनके परिवार वालों से मिल कर मैं उनको motivate करता हूँ, ऐसा करना मुझे बहत अच्छा लगता है।

में अभी अपने पापा के साथ फिश का बिजनेस सिखता हूँ और आगे मैं मेरा खुद का बिजनेस बढ़ाना चाहता हूँ।

थैंक यू, शुभम माली।

#### Amit Kesarwani

Mera naam Amit Kesarwani hai aur mai sion, Mumbai me rehta hu, me 20 sal ka hu. Mujhe garv hai ke me Cancer Survivor hu



#### Ye baat 2005 ki hai Jab

mai 4 saal ka tha tab mera bike se accident hua tha. Us accident me mujhe bike ka handle laggaya mere aakh ke pass. Us waqt meri aakh halki si laal hui thi. To mujhe mere parents doctor ke pass leke gaye, doctor ne bola darne ki koi baat nahi hai. But uske 15 din baad achanak meri aakh halki si choti aur tedi dikhne lagi to mujhe sion hospital me dikhaya, unhone sab checkup kiye aur unhone bola kuch serious problem hai tum Tata hospital check up ke live jao. Jab mere sab report Tata hospital me hue to pata chala ki meri aakh me khoon ki gath jam gai hai mujhe cancer ho chuka hai, us aakh ke cancer ko Retinoblastoma kehte hai.Us baat ko sunkar mere mummy papa ko jaise vishwas hi na ho rha ho. Us waqt doctor ne bola ki jitna jald se jald ho utna jaldi aakh nikalna padega warna ye cancer dusre aakh me bhi ho jaayege. Us waqt to mujhe kuch knowledge hi nahi tha mere saath kya hone jaa raha hai. To jab mera operation hua aur mai operation theatre se bahar aaya tab mujhe pata chala ki meri aakh nikal di gai hai. Us waqt mujhe rona sa aagaya ki ye mere saath kya hogaya hai. Shayad se wo meri life ka sabse bada kharab din tha.

Aur jab bade hone ke baad pata chala ki ek aakh se bhi normal zindagi jiya ja sakti hai. Tb me khush rehne laga, kyun ki ek aakh se sab kuch dekh sakta hu aur normal logo ki tarah jindagi bita sakta hu.. Me thankful hu ki mera operation itne acche Tata hospital me hua, Kyuki yaha ke sabhi doctors friends jaise rehte hai.

Operation ke baad mujhe sabhi ne himmat di aur maine apni study bhi chalu rakhi. Me ab SIES College me 3rd year BMS(Bachelor of Management Studies) ka student hu.

Tata Hospital, ACT clinic me jab mai follow-up ke



live gaya tb waha mujhe Shekhar sir mile, unse mujhe Ugam ke bare me pata chala. Maine 2018 me Ugam join kiya. Wahi par mujhe Dr. DJ Jussawala education fund ke bareme pata chala or wahi se mujhe mere studies ke live last 3 years se financial help mil rahe hai, jisse me apni study continue kar pa raha hu. Iske liye me ICS-Ugam ke sath hi ye fund se mujhe help karne ke liye thankful hu, kyunki ye support agar nahi milta to me apne study continue nahi kar pata.

Aur me Ugam ke baare me kehna chahunga ki Ugam group mera sabse favourite group hai. Because, Ugam sabse supportive group hai aur Ugam ek aisa group hai jaha sabhi Survivours, Doctors Patients Parents ko ek saath engage karke rakhta hai. And I am very thankful that I had joined the Ugam group.

Last me yahi kehna chahunga ki. Agar Aap Me Himmat hai To Aap Badi Se Badi Bimari Ko Maat De Sakte Ho To Bas Khudpar Bharosa Hona Chahiye.

Thank you....

#### **Pravin kumar**

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

to that I was diagnosed with Cancer. So I am supposed to shift to a Cancer Hospital where I have get treated for the disease. Later we have reached Chennai and I was admitted in Adyar, Cancer Institute. With the help of funding from Indian Cancer Society, I could able to complete taught me so many my chemotherapy treatment at the hospital. We lessons and it stayed in Chennai for almost 10 months to take continues teaching treatment.

I was sad when I had to miss my two year college but I did not lose hope, I stayed positive that I will win over Cancer. Before cancer, I had normal goals like going to job after finishing a degree like others in the society. But after cancer diagnosis I decided to set an example for others by winning over cancer and lead a successful life. Yet life was not so easy after my cancer treatment, I had financial burden in my family because of which I could not able to continue my education which made me feel low.

It was the time I was offered a special counselling session at the Cancer Institute where I was enrolled in After Completion Therapy Clinic. I was given motivational counselling and psychological support at the clinic which really helped me to gain more strength as well. The psychologist also introduced me about the academic scholarship for pediatric cancer survivors provided by Indian Cancer Society. I applied for scholarship with Indian Cancer Society. I also availed the scholarship from ICS. Now I am doing my first B.SC Biotechnology. I am happy that I am able to continue my education after cancer treatment. My dream is to specialise oncological research and also help the kids who are suffering from cancer. I am very much thankful to Indian Cancer Society who helped me to complete my treatment and also supported me to continue my education further.

The concept of After Completion Therapy Clinic has made a change in my life and also brought back my dreams alive.

After treatment I visit act clinic. I learned about their understanding of cancer and the DJ fund, a scholarship for cancer survivors. I also applied for a dj fund and my first year scholarship was donated by the Indian cancer society. It evokes the desire to achieve more while regretting having missed two years of education. I look forward to success as soon as possible. "Cancer is not a curse! It is a gift".

#### Vedharam

"Everyone has their story to share. As life is the best teacher, it me. From a Cancer survivor. I turned into



#### a Chartered Accountant (CA),"

"I belonged to a traditional middle-class Tamil Brahmin family who was born and brought up in a village. My time was spent reciting shlokas, accompanying my father for poojas at the temples and following strict food habits. When I was about 7 years my monotonous life changed when I started feeling a sharp pain in my stomach which made me roll from one end of the floor to the other. At the hospital, they operated and cut 8 inches of my intestine and sent it for biopsy and the report tested positive for Cancer. I got admitted to Cancer Institute WIA-Adyar, Chennai

On insistence of my family they did a bone marrow test twice ( A Bone Marrow Biopsy can establish the spread of the disease. This involves the insertion of a needle into bone to obtain bone marrow) and confirmed beyond doubt that it was early stage of Non Hodgkin Lymphoma. I was advised to take two cycles of Chemotherapy

During chemotherapy, all my hair had fallen but my COURAGE was intact. I knew I had to build my own confidence. My immunity hit a low and I could not strain myself physically. I could not do the things others my age were doing. It was then that I took solace in books. I started to concentrate on activities involving mental work rather than physical. Books and journals became my friends. I did my schooling in a Government School in Tamil Medium.

Again, at the age of 12, I was affected by tuberculosis and was operated in my neck and undergone tough medication for 6 months. In spite of all this, I excelled in my studies. I got my education through my mother tongue Tamil. My dream was to study at IIT. But due to my health condition, I was not allowed to move to Chennai. I love maths so I choose B. Sc. Mathematics instead of engineering even though I scored 93 % in 12th Grade.

CA was introduced to me by one of my relatives. I promptly enrolled myself in CPT (1st level CA exam) coaching while still in college but failed 3 times due to improper coaching at my village. Post my graduation in Mathematics. (B.Sc., Mathematics), I switched to direct entry when it was introduced in 2012 and arrived in Chennai in 2013 with the support of my brother to pursue CA. I joined a mid-sized firm with the only expectation to become a Good Chartered Accountant.

I could not sit for more than 8 hours as it created a lot of physical strain on me. Though I cleared my CA Inter in 1st attempt, I failed CA Final in my 1st attempt. When I started preparing for my 2nd attempt, I fell sick. I got a severe pain in my stomach yet again. I had to undergo various tests to confirm whether Cancer has struck me again. In the process of all the tests and hospital rounds, I could not study and failed in my 2nd attempt as well.

However, in my 3rd attempt, I cleared CA Final with 60+ in 4 subjects. It was a great day for me. I always wanted to start my own CA Firm and get into CA Practice so that's what I did after becoming a CA. I had hesitation in marital life. After getting my doubts cleared from experts, I got married too. She is also a CA. My wife knows my complete medical history. Yet she didn't have a second thought of marrying a survivor. We are blessed with girl baby. We are happy family now. I always tend to help kids suffering from Cancer. Also, the real tough task is not winning the war against Cancer, it is The Post-Treatment Life with so many restrictions on food and activities that makes it tough. The moral support always supplements the treatment and speedy recovery. The psychological support for survivors and the counselling post treatment can bring lot of positive changes in the survivor's life that will drive the survivor towards a happy and meaningful life. In that way I am very gifted as well to receive the support and I am happy that cancer Institute is providing the psychological support for cancer survivors through After Completion Therapy Clinic.

To bring awareness that "Cancer is not the end of life, certainly there is a happy life after cancer" I shared my journey in various forum.

#### **Re-joining Ugam**

#### Madhuri Ramnath Bhaitandel

#### हैलो उगम फ्रेंन्डस,

उगम का मेंम्बर होना ये एक बेहद अमेजिंग फीलिंग है, और इसलिये मुझे लगता है कि फिरसे उगम जां ईन करनेका मेरा फैसता सही है....



शायद बहुत सारे लोग मुझे नहीं जानते होंगे, मेरा नाम माधुरी रामनाथ भाईतंडेल हैं। बहुत साल हो गये, मैं उगम से दूर थी पहले आप ही की तरह मैं भी उगम का एक हिस्सा थी। ये सारी एक्टिविटीस. फून और रिस्पांसबिलिटीस मेरे भी लाइफू का एक इम्पाः स्टन्ट हिस्साथा।

बेहद ही अच्छे दिन थे, बहुत सारे अच्छे मूमेन्टस एन्जा य भी किये। P.N.E.T के ट्रीटमेंट के बाद मैंने उगम ज्वाइन किया था। सब बहुत ही अच्छा चल रहा था, मेरा जॉब, बाकी एविटविटीस और उगम।

मेरे पर्सनल लाईफ मे कुछ ऐसै प्रां ब्लेंमस हुए की एक दिन बिना बताए मैंने उगम छोङ दिया.. मे कभी भी नहीं चाहती थी उगम छोड़ना। अगर किसी को बताती तो मुझे कोई भी उगम छोडने नहीं देता। उगम से मेरी जो अटैचममेंट थी और ऐसै मे इस तरह से उगम को ऐसै अलविदा करना मेरेलिये मुश्किल हो जाता .इसलिये बिना बताये उगम को छोङ दिया.सोचा पर्सनल लाईफ मे जो भी प्रा ब्लैम हुई है उसे तो मै सवार तू पर ऐसा कुछ भी नही हुआ.

मैने जो कुछ मेरे खुद से पाया था लाइफ में, सब खतम हो गया। लाइफ को कैसे सवारू समझ मे नहीं आ रहा था। उगम की बहत याद आती थी, कछ फ्रेंन्ड्स कॉल करके बोलते भी थे की वापस आ जाओ, पर समझ नहीं आ रहा था की मैंने जिस तरह उगम को छोड़ा था वापस कैसे जाऊ, कैसे सबको मना लू उतनी हिम्मत नहीं थ<mark>ी मुझमे</mark> सारे मेरे फ्रेंन्डर बहुत आगे भी चले गये थे, औ<mark>र म</mark>ै जहाँ थी उससे भी पीछे आ ग<mark>यी थी</mark>। बहुत ज्यादा डिप्रेशन था लाइफ में पर खुद को उससे सवार लिया और ये कर पायी क्योंकी उगम ने कभी हारना सिखाया ही नहीं, जो वक्त मैंने उगम के साथ बिताया था, मुझे जो मोटीवेशन, अपने जीद को पुरा करने की हिम्मत,ताकद जो दोस्तोंसे मिली थी उनको याद करके खुद को फिर से तैयार किया हर उस मुश्किल वक्त के लिए जो मेरे सामने थी। जो नहीं चाहिए था लाइफ में उस हर चीज को, हर इन्सान को लाइफ से दर किया।

बहुत बार मन मे आ रहा था की उगम रिजां इन कर लूँ। फाइनली सोच लिया गलतियाँ सबसे होती है, और अपने लोग माफ भी कर देते हैं, तो फैसला कर लिया उगम रिजा ईन करना है। अभी सबके मन मे शायद यही सवाल आरो की फिर से उगम क्यो ? सत्त कहुँ तो मुझे नहीं लगता इस सवाल का जवाब देना जरूरी हैं। आप सब लोग उगम की लाइफ जी रहे हो मुझे भी मेरे फैमिली मे वापस लौटना था। इसकी वजह ये हैं की यहाँ जो रिश्ते हैं वो एक दूसरे को सच्ची इज्जत और प्यार देना जानते हैं। जब तक उगम से दूर थी, सोसायटी की गलत सोच का बहुत निगेटिव इम्पैवट खुद पे होते हुये देखा। और इस अनुभव से ऐसा लगा की उगम के साथ होना ही अच्छा है। उगम जिसने मुझे हराना सिखाया, खुशी से जीना सिखाया। उगम ने मुझे मेरे लाइफ में बहुत कुछ दिया है। शायद अभी बहुत ज्यादा समय ना दे पाऊ क्योंकि फिर से लाइफ को झीरो से शुरू कर रही हूं। फ्रेंन्डरस शायद आप सबके सामने मेरी एचीवमेंट बहुत ही कम लगे। पर मैं ये यकीन दिलाना चाहती हं, की एक दिन मैं मेरी पहचान बना ही तूंगी। उगम मेरे लिए खास है क्योंकि उगम हमे बेहतर इन्सान बना कर जीना सिखाता हैं। एक प्युर सोल बनाता है। पॉजिटिव्ह सोच भरकर जीना सिखाता है एक सच्ची फैमिली की कोई डेफिनेशन एक शब्द में करे तो वो शब्द उगम है।

सॉरी फ्रेंन्डर जिस तरह से मैं उगम से चली गयी थी। और थैंक यू मुझे फिर से अपनाने के लिए। थैंक यू ऑल, स्पेशली उन्हे जिन्होने अभी-अभी बात की प्रिती, राजेश, नरेन्द्र और अरून।

आय लव्ह यु उगम फ मिली..... I Love You Ugam Family

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

#### Bhagyesh R Gupte

I am the childhood cancer survivor of Retinoblastoma where my treatment started when I was just 3 months old, I was undergone my first operation at the age of



5 months old under the supervision of Dr. Adwani and Dr. Kurkure where my left eye was enucleated at Sion Hospital.

As my retinoblastoma was bilateral my right eye was given radiation and 6 cycles of Chemotherapy because of which my optic nerve was damaged, and I have a low vision in my right eye. I have completed all my studies till my graduation in such conditions and afterwards I appeared for various bank exams for Government job. With God's grace and parents support I was selected in one of the nationalized bank with 100 % job security in the year 2010 and currently I am working as a an Assistant Manager in Bank Of Baroda.

In such a pandemic situation, the other thing which was a turning point for me was I got married in December 2020. I found my life partner Bhagyashree who is also a working professional. She is very caring, supportive and a loving person with a kind heart. She has turned out to be the most awaited person in my life who has accepted me with all my flaws.We both are happily married and look forward to enjoy the rest of our lives together for lifetime

I am one of the founder members of Ugam but was not active. However, recently I have rejoined the group in the last year and am glad to see this group have widened with many active and enthusiastic members

#### "Double Dhamakaa"

#### Ummul

I can't stop looking at my boys and our priceless expression of joy. The phenomenon of giving the birth to two human being is unfathomable and divine. There's a god realisation that nothing is in our hand and control. These two Angels were meant to come in the 2020th year with all the blessings. So .... Yay I'm a 2020 mom



#### **Reshma Chikankar**



Victors of childhood cancer

## **Poems by Ugam Members**

Ashwini Chorge



#### हौसता

हारना तब आवश्यक हो जाता है, जब लड़ाई "अपनो" से हो। और जीतना तब आवश्यक हो जाता है, जब लडाई "अपने आप" से हो। मंजिले मिले, ये तो मुकदर की बात है। हम कोशिश ही न करे ये तो गलत बात है। किसी ने बर्फ से पुछा कि, आप इतने ठंडे क्यू हो? बर्फ ने बडा अच्छा जवाब दिया :-" मेरा अतीत भी पानी. मेरा भविष्य भी पानी... फिर गरमी किस बात पे रखू।

#### मित्र

घर जळाले तर विमा आहे स्वप्न जळाली तर काय?

ढग बरसले तर छत्री आहे डोळ्यातून अश्रू बरसले तर काय?

काटा टोचला तर काढता येतो शब्द टोचले तर काय?

वाघ आडवा आला तर पळता येतो अहंकार आडवा आला तर काय ?

शरीर आजारी पडले तर औषध आहे पण मनच आजारी पडले तर काय?

त्यासाठी लागतो...

एक चांगला मित्र गोळ्या औषधापेक्षा कमी नसतो।



**Manish Sase** 

बाप कैसे जीता हैं -

बाप नाम की शायरी हैं जो शायद दो शब्दों में बया नहीं कर सकते क्यूँकि उनकी जिंदगी बीती, हमारी जिंदगी बनाने में और हम कभी रोये ही नहीं अपने बाप के जमाने में।

बाप वो लम्हा होता है. जो हर पल अपनों के लिए जीता हैं हमारे लिए जीते-जागते। खुद का वो जीना तो पलभर की हर चाहत भूल जाता हैं।

#### सपने हम देखें

पुरा करने की जिद तो बाप ठान लेता है। तीन वक्त का खाना माँ ही देती है, लेकिन खाना लाने वाला बाप अक्सर बिना खाये ही सो जाता हैं।

हमारे पास सब ब्रांडेड होता है फिर भी शिकायत होती है। कभी बाप के करीब जाकर देखा है क्या ? पराने चीजों को जोड़-जोड़कर बाप खुद के लिए ज्यादा कुछ खरीद नहीं पाता है।

हर एक मौसम को अपना बनाकर उनकी मेहनत सच्चाई से लड़ता है। बेटा सीखे मेरा इस खातिर फटी चप्पल पहनकर शरीर के पसीने से खेती में खुद बारिश के बूँद जैसे बरसता है।

काश ! आपने देखा भी होगा बाप के अंदर प्यार का साया, ऊपर से कडवाहट होती है और दिल से अपनों पर निगरानी का काया।

जिम्मेदारियों की दिवाली में वो फटाके जैसे जलते हैं। फिर भी उनकी कैफियत का हाल हम कभी पूछा नहीं करते है। और आज भी... माँ बाप वृद्धाश्रम में दिखाई देते है...

#### अब तो

माँ एक बेटे के पास, तो बाप दुसरे बेटे के पास हम दोनों को हिस्सों में बाँट लेते हैं। गलती क्या हुई इतनी सी हम तो उन्हें अब डांट देते है|

वो तो खुद टूटा तारा बनकर हर सफर की उम्मीदें बरसाते हैं। हजारो ख़्वाबों की तलाशें बिना माँ- बाप की अधूरी होती है...

बाप की कहानी में लफज कम पड जाते है. जब यादगारी के लम्हे उनके पैरों की निशानी को ढूँढते हैं।

जिंदगी के सिलसिलों में अपना माँ-बाप से बड़ा कोई ताज नहीं होता है, क्योंकि कहते हैं ना बाप तो बाप होता है। और बिना माँ के हर घर सुना- सुना होता है।

@ मनिष ह.सासे

**Volunteers Speak...** 

**Sanjeev Sharma** 



#### Proud to be a part of UGAM'

I am always proud of being a part of Ugam... I still remember those earlier days when a small group of survivors came together and along with professional mentors form this group UGAM. My first encounter with this group was when coincidently once I have been to there monthly meeting where they were discussing about 1<sup>st</sup> Ugam anniversary. They had plan to do one Role Play. I also performed with them and I didn't realize when I became a part of the group and day by day the bond became strong. We worked together for activities like networking, fund raising for anniversary and all that was very satisfying for me.

Being in a group I could see the struggle of survivors and their parents, families even after completing their treatment. Survivors face lot of challenges coping with their disfigurement and losses. It impacts deeply on their self-image and self esteem and some also think "why me". Families face financial crisis and there is no back up of medical insurance.

The second very important thing I realized is when a survivor join Ugam he/she feels I am not alone loke me there are so many and if they can cope with it I can also. While being with them I learnt about their issues and realized that being young their priorities in life are different then I felt it's important to discuss about their friends, education, carrier, jobs. We also used to attend ACT clinic to understand needs of the patients and families to support if possible.

As Ugam grow older every year new members joined Ugam and number of Ugam members increased gradually. I think support group like Ugam is the most needed Platform for survivors and families to feel reassure, to get on-going support and guidance. I have witnessed many examples of survivors who transformed totally from being shy, introvert to more expressive and

Victors of childhood cancer

#### confident.

St Jude Sessions -- Many of these survivors interact with parents of peadiatric cancer patients who are staying at St. Jude children's center and I am so amazed to see their confidence, vocabulary and judgement when they deal with parents concerns and very thoughtfully answer even difficult questions. I remember when families ask questions related to treatment, survival, time frame they very sensibly tell them to ask those questions to their doctor, it just shows that they are aware of their limitations and boundaries, for which they are given training and supervision within the group. These interactions are very useful and hopeful for parents and patients who are on treatment.

Looking at the work of Ugam brigade I feel Ugam is really serving its purpose as support group.

I feel really very proud that I am part of Ugam throughout the beginning and to see that a small seed of hope has now grown as big tree.

Amita Bhatia



#### Me and Ugam

I joined Tata in 2003 as a volunteer social worker, But I am still a learner and my teachers are all my lovely Ugamites. So what did Ugam teach me... and us? Ugam always give us positive energy Ugam always tell us not to be afraid, be brave Ugam always teaches us how to fight and win Ugam always teaches us togetherness Ugam teaches us to be happy always, Ugam teaches us to be creative Ugam teaches us to give support So for me Ugam is a beautiful song with beautiful music For me Ugam and me is Teacher and student Mother and children Friend and friendship

# WE ARE PROUD OF YOU



# **Rahul Panday**

Working as a front line worker in this pandemic situation for Cancer Screening project at Indian Cancer Society

Vikash Mourya

percentile in JEE

MAIN exam in PWD

Scored 87.12

category



#### Sandeep Yadav

Started a telemedicine startup in UP called "Digi-Swasthya". Also successfully completed Big Gyan Tree Business plan competition in the category of healthcare. www.digiswasthya.org

#### **Rakesh Choudhary**

He is currently giving his service in Muzaffarpur, Bihar at HBCH&RC Muzaffarpur-a unit of TMC at the post of Patient Navigator

Shruti Nirmal Mhatre

Working in the front line as a Staff Nurse at Bhaktivedanta Hospital

## Arun Kumar Nadar

Started his Independent IT startup "Linkage Infotech Private Limited"

www.linkageinfotech.com



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 बिखरे उन सपनो को फिरसे उठाना है

बढ्ते ही जाना है.... उगम बढ़ते ही जाना है....उगम

Song Written by: Shashank Johri & Composed by: Immanuel

Victors of childhood cancer



### Anita Kamble

Appointed as Nurse at Covid Care Centre (Mumbai) to give service to all the patients till the Covid Care Centre is operational.

# **WE REMEMBER**

We convey our deepest condolences to the families whose loved ones have succumbed to COVID-19 infection.



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

चल दिए हम लेकर अपना कारवाँ