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**Press Invite** 

## 11th NATIONAL CHILDHOOD CANCER EXCELLENCE AWARD PROGRAM 2019

An event to celebrate excellence & achievement of children fighting with cancer

New Delhi, 29th September 2019

## September is International Childhood Cancer Awareness month. And this September ----

CanKids....KidsCan, National Society for Change for Childhood Cancer is organizing its 11th Annual National Childhood Cancer Excellence Awards 2019 on September 29th at Sri Sathya Sai International Centre and school, Lodhi Road, New Delhi.

## Chief Guest for the program Mayor of SDMC Delhi, Ms Sunita Kangra.

Ms Sunita Kangra, Bharatiya Janata Party (BJP) Councillor from Madipur ward, has been elected as the new Mayor of South Delhi Municipal Corporation (SDMC). She is a graduate from Delhi University and an active member of the BJP for the last two decades, Sunita Kangra had assumed the position of secretary in the Delhi Mahila Morcha and at the district level. Besides, she was elected from Madipur ward as BJP nominee in 2017 elections.

#### Other Guests of Honor include

- Dr Gampo Dorji, from WHO South East Asia Region Office NCD & Environmental Health Division,
- Dr Mamta Manglani, President IAP, Pediatric Hematology Oncology Chapter (Video message)
- Prof Dr Navin Dang
- Monika Arora, Senior Advocate Supreme Court of India,
- Blossom Kochhar, Chairperson, Blossom Kochhar Group of Companies
- Amar Prasad from PTC Foundation (on behalf of CMD PTC Deepak Amitabh)
- Anup Mudgal, IFS, Former High Commissioner, Mauritius,

The Annual awards for Childhood Cancer Excellence honour children with cancer who have either survived the disease or are undergoing treatment and applaud their achievements even in the face of adversity.

In the past years, over 8000 childhood cancer patients and survivors have participated in the Awards, where each have received a medal and a certificate, and 157 children have received the Excellence awards.

This year, we have received 1400 applications from 33 cancer centers across the country. All our applicants who have participated will receive medals and certificates. 27 of them have been selected for

their outstanding achievements in academic, creative and extracurricular activities by our eminent panel of judges from academics, oncology and public life and will travel to Delhi to receive their awards. Awardee families are travelling in from Mumbai and Punjab, as well as many hospitals of Delhi.

The Award function will be attended by childhood cancer patients and families, our donors and well-wishers, medical and pediatric oncology fraternity and other health professionals, and media.

## Also partnering this year are -

- a. Svatanya Foundation (<a href="www.svatanyaindia.com">www.svatanyaindia.com</a>) which empowers which is giving handcrafted soft toys to all the children coming to the program, SVATANYA is a social initiative that aims to empower underprivileged women by training them to make handcrafted products by up-skilling them to become financially independent and self-reliant. Founder: Deepa Pant
- b. Rasoi on Wheels Foundation (www.rasoionwheels.com) mobile kitchen service that is providing healthy, nutritious, tasty, wholesome, hygienic packed meal boxes which are served to the less privileged section of our society. Founder:
- c. Pathways International School
- d. DPS Gurgaon
- e. Sinchita Creations
- f. Blossom Kochar
- g. Jolly Sapra of La Sunila Apartments





## Objectives of Awards:

- To advocate "Right to Education" for the health impaired child with cancer.
- To recognize the indomitable courage and bravery of children faced with cancer that have either survived the disease or are still undergoing treatment.
- To motivate and encourage those children who have fought cancer and emerged as winners.

- To honor and award the children who show exceptional will and determination to succeed and excel, despite their battle with cancer.
- To bring a strong message to society that cancer is a disease which can be tackled with a positive attitude and spirit.

#### Right to Education for the health impaired child with cancer-

Last September, during the Xth award program, 110 Childhood Cancer Survivors from Kidscan Konnect, Teenage and Young Adult Childhood Cancer Survivors group of Cankids has submitted a petition for Right to Education for the Health Impaired child with Cancer to Sh Vinod Paul, Member, Health, Niti Ayog on 9<sup>th</sup> September 2018 during the 4<sup>th</sup> National Childhood Cancer Survivors' Conference in New Delhi. Over 100 survivors from all over India presented him with a petition for Right to Education for Children with Cancer and/or Survivors.

Subsequent to that, we have met and presented our petition to:-

- Ms Rina Ray, Secretary, Department of School Education and Literacy Ministry of Human Resources Development.
- Ms Preeti Sudan, Secretary, Ministry of Health and Family Welfare, and
- Ms Shakuntala D. Gamlin, Secretary, Department of Empowerment of Person with Disabilities.

The petition is about the right to education for children with cancer and/or survivors of childhood cancer. Our core demands are summarized below:-

- 1. We want children with cancer to be recognized as children with special needs for education both during treatment and as survivors.
- 2. We want ongoing school in hospital and through home schooling and individualized education programs (IEPs) during treatment.
- 3. We want the ability to take important examinations in hospitals and authorized centers along with additional time as needed.
- 4. We want that no child or survivor should be penalized in their examinations or promotion due to lack of attendance during the school year.
- 5. We want that no child should be denied admission to a school or competitive examinations because of their cancer treatments.

#### WHO Global Initiative on Childhood Cancer

Additionally, In September 2018 WHO announced a new effort- the WHO Global Initiative for Childhood Cancer – with the aim of reaching at least a 60% survival rate for children with cancer in LMICs by 2030, thereby saving an additional one million lives. This new target represents a doubling of the global cure rate for children with cancer.

Cancer is a leading cause of death for children, with 300,000 new cases diagnosed each year among children aged 0-19 years. Children with cancer in low and middle-income countries are four times more likely to die of the disease than children in high-income countries. This is because their illnesses are not

diagnosed, they are often forced to abandon treatment due to high costs, and the health professionals entrusted with their care lack specialized training.

## WHO Global Initiative on Childhood Cancer- CanKids Responds!

To focus attention on "Childhood Cancer" and to discuss the World Health Organization (WHO) Global Initiative on Childhood Cancer, a stakeholder meeting was organized on 24<sup>th</sup> June 2019. There was representation from the pediatric oncology community- Pediatric Hematology Oncology (PHO) Chapter of Indian Academy of Pediatrics (IAP) and Indian Pediatric Oncology Group (InPOG) as well as civil society CanKids KidsCan. The town hall was held at Max Super Speciality Hospital, Saket and sponsored by CanKids.

Furthermore to fulfil the WHO mandate and Cankids' vision, our cancer survivors across 17 states are celebrating childhood cancer awareness month. To mark this, Cankids launched a campaign "Haq Ki Baat" where our 2 Cancer Survivors leaders from Uttar Pradesh (resident in Maharashtra) Sandip Yadav, 24 years old- an Ewing's Sarcoma Survivor- and Vikas Yadav, 22 years- Eye cancer Survivor- accompanied with other survivors from Lucknow drove 1400 kms to our Hon'ble Prime Minister, Shri Narendra Modi's constituency - Varanasi who's popular talk show "Mann Ki Baat" reaches out to the people of India - "Mr. Prime Minister – Why does my birthplace have to decide whether I survive or not?".

The survivors also asked the Pediatric Oncology community which gathered at Varanasi for the 4th PHOSSCON Pediatric Hematology Oncology Support Services Conference and 23rd PHOCON - Pediatric Hematology Oncology Conference, to ensure that quality treatment to be provided to children with cancer.

The recent Government of India initiative 'Fit India' Prime Minister "Mann Ki Baat" monthly address, where he spoke about how 10 childhood cancer survivors beating all odds brought glory to the country when they won medals nationally and internationally, gives us hope that now the government in the state will no longer ignore the quality of childhood cancer treatment in the state and come together to build partnership with Pediatric community and civil society to close the gaps.

#### **ABOUT CANKIDS KIDSCAN**

CanKids Kidscan is a not for profit National Society dedicated to Change for Childhood Cancer in India.

Cankids Kidscan – country's only Civil Society Organization, that works across the spectrum of childhood cancer (0-19 years of age) to enable best standards of treatment, care and support, is committed to work with international, national and regional Pediatric Oncology Community and the Government to achieve this goal.

Cankids works in partnership with69 cancer centers treating children with cancer, reaching out to 97 cancer centers in 42 cities and 22 States of India, It also has Change for Childhood Cancer in India - State projects in 10 States with MOUs with Government of Punjab and Maharashtra — as their knowledge and technical partner for childhood cancer.

#### In Retrospective

## Haq Ki Baat

## **Childhood Cancer Survivors Raise their Voice -**

# Why should I not have access to the right medicines, right doctors & hospitals and right treatment just because of where I was born?

September is the International Childhood Cancer Awareness month.

Gold is the color of Childhood Cancer and the Gold ribbon honors children with cancer and their families fighting this dreaded disease. The colour embodies strength, courage and resilience of all the children diagnosed with cancer and their families.

This September ---

Sandip Yadav, 24 years old, an Ewings Sarcoma Survivor and Vikas Yadav, 22 years an Eye cancer Survivor whose families had to relocate to Mumbai from Uttar Pradesh in their childhood, for their cancer treatment, at the country's premier cancer center Tata Memorial Hospital are joined by APML survivor Jishnu Mullick originally from West Bengal and Bhumi a >...survivor from Gujarat, as they journey from Mumbai to Lucknow and then drive with other survivors to Varanasi - a journey of 1488 kms to raise their voice for Childhood Cancer to be a Child health priority in the War against Cancer in India.

From the constituency of the Honorable Prime Minister of India Sh Narendra Modi, they are asking the PM – who's popular talk show Mann kiBaat reaches out to the people of India "Mr Prime Minister – Why does my birth place have to decide whether I survive or not?"

Childhood Cancers are considered from 0-19 years of age. A newborn baby can be born with cancer. For each child who survives cancer, on average, 71 yrs of life is saved. Childhood Cancer is rare. Even in India it accounts for 4-5% of all cancers. There are 16 different types of Childhood Cancer.

50-70% Children with cancer do not survive the disease. Worldwide there is estimated to be around 300,000 new cases of childhood cancer. In India, the estimate is 78,600 new cases each year, which is an unacceptably high percentage of the global childhood cancer burden. While the survival rates of children's cancers are 70-90% in developed countries, in India, the survival rate can be as low as 30-50%.

Low treatment & survival rates are due to: Lack of awareness · Stigma · Poor access to care · The high cost of treatment · Lack of supportive care · Lack of infrastructure, health professionals, good protocols, quality drugs & Diagnostics

Sandeep and Vikash are team leaders of Kidscan Konnect – the Teenage and Young Adult Childhood Cancer group of Cankids Kidscan – a National Society for Change for Childhood Cancer in India – the country's only NGO that works across the country and across the spectrum of support for children with cancer and families in India.

Cankids works in partnership with 69 cancer centers treating children with cancer, reaching out to 97 cancer cetners in 42 cities and 22 States of India, It also has Change for Childhood Cancer in India - State projects in 10 States with MOUs with Government of Punjab and Maharashtra — as their knowledge and technical partner for childhood cancer.

Last year the Survivors worked very hard to GO GOLD Maharashtra. They spread Childhood Cancer Awareness, Lit up Gold monuments like Chatrapati Shivaji Terminal, Gateway of India, Bibi ka Makbara in Aurangabad and Shanwarwada in Pune. They led an Access to Care Car Rally across 1100 kims in 4 Divisions of Maharashtra and asked people to take the pledge that childhood cancer should be a child health priority in our War against Cancer in India. They succeeded in their mission. In February 2019, Cankids signed an MoU with the Government of Maharashtra; because of which now we are working with the Government of Maharashtra and in all cancer hospitals treating children with cancer in Mumbai & Maharashtra.

This year Vikash and Sandeep are now off on another journey.

They are going from Mumbai to Lucknow and then from there to Varanasi. Uttar Pradesh is the focus for Change for Childhood Cancer. Uttar Pradesh has the highest childhood cancer incidence in the country – at over 14500 new cases each year it accounts for almost 20% of India incidence of 76800.

Doctors, Pediatric Oncologists from all over the country are gathering for the 23<sup>rd</sup> PHOCON conference at BHU in Varanasi and at the same time NGOs who work on childhood cancer are meeting for 4<sup>th</sup> PHOSSCON on 7<sup>th</sup> and 8<sup>th</sup> September. Among other things they will deliberate on the WHO Global Initiative for Childhood Cancer that asks all LMICs to improve survival rates to 60% by 2030 thereby saving an additional one million lives. This new target represents a doubling of the global cure rate for children with cancer.

"India response is vital, and through both the Conferences the pedaitric oncology community of Doctors, researchers, Civil Society organizations, and patient groups, we will work out plans, next steps and working groups on all different aspects that will need to be addressed to make this happen, "said Dr Mamta Manglani, President of the Pediatric Hematology Oncology Chapter of the Indian Academy of Pediatrics.

In a video the Survivors have made, Childhood Cancer Survivors, Sandeep and Vikash had this to say, "We are going to our Prime Minister's constituency. On Mann kiBaat, our Prime Minister Shri Narendra Modi Ji speaks to the citizens of the country. We really like that the leader of the country talks so openly to all of us. So today we want to talk to him - HaqkiBaat - We want to talk to him about our rights.

## We want to ask:-

Why do only 15000 children out of 76000 children suffering from cancer in India reach hospitals? We ask that when I had cancer, why did I need to go to 22 hospitals?

Why isn't there enough knowledge of the right hospitals and treatment in public or even the doctors? By the time they reach the right place for treatment it is already too late....

Why is it that 90% of children survive cancer in developed countries but not in India?

Why should I not have access to the right medicines, right doctors & hospitals and right treatment just because of where I was born?

Why should anyone suffer from unnecessary pain or a child who is in the terminal stage suffer due to lack of morphine?

We have so many friends who lost everything due to cancer & its treatment and their families became even more poor & helpless than they were before. Why?

We want to talk to the Prime Minister and the Central and State Government about Our Rights – our Right to best treatment, better support and care. This is not just a Privilege - it is our Human Right."

Driving from Lucknow to Varanasi and back via Sultanpur and Jaunpur, the Survivors will Light up Gold King George's Medical University at Lucknow and Banaras Hindu University in Varanasi, lead a Walkathon, raise pledges of support and raise funds for children with cancer between 4<sup>th</sup> to 9<sup>th</sup> September.

Haq Ki Baat is a Childhood Cancer Survivor led Advocacy and Awareness Campaign to ensure that Childhood cancer becomes a child health priority in India which will engage all stakeholders including hospitals, nurses, parents, schools, colleges and govt. etc. The programs will include, survivor interactions, marathons, rallies, photography opportunities among others. The aim is to create large scale awareness, raise funds for cancer cure and engage stakeholders to formulate friendlier policies on Cancer Support for all kids. It may be noted that only 40% kids with cancer in India survive against survival rates of 90% in developed nations of the world.

#### **ABOUT CANKIDS KIDSCAN**

CanKidsKidscan is a not for profit National Society dedicated to Change for Childhood Cancer in India.

It is the only organization in India that works on all aspects that will drive this Change – from support services for families of children with cancer (age 0-21), to awareness, advocacy, stakeholder engagement, capacity building, quality care, research and impact. It works in partnership with centers treating children with cancer across the country, as well as with State Governments and all relevant stakeholders to improve Access to Care. Through the Go Gold India campaign it advocates for childhood cancer to be a child health priority in India.

Its YANA –You are Not Alone – signature program aims to provide holistic support to the child with cancer and his family, from moment of detection, through diagnosis, treatment and after - Offering medical and educational financial assistance, social and psychological support for diagnosis, treatment, nutrition, accommodation and other supportive care and education for the health impaired child with cancer and his family.

Cankids' Vision is — To enable global standards of survival, between 70-95%, for childhood cancer in

India. Partnering with Reach - To ensure Quality of Life and Holistic Care for the child with Cities Cankids cancer & his/her family through **Holistic Care Families** his/her cancer journey. **Cancer Centres** 1 / States Centres Supported +28 Outstation Centres - To secure the 5 Rights of **Team Cankids** Manpower to State Projects health impaired children with 1870+ hospitals Capacity & Skill cancer - To Health, To **Building Verticals** Parent & Survivor Social Support Staff Education, To Childhood, To **Members** 21 Research Studies Pain & Palliative Care & the 1505+ **Dedicated Nurses** 26 \* as on Aug, 2019 Right To be Heard.

**The Mission** is to enable the best possible treatment, care and support for every child affected with Cancer & his family.

Pledge your Support & DONATE at www.cankidsindia.org

Go Gold India -for Warriors & Angels

I would like to pledge for Childhood Cancer to become a Child Health Priority in the War against Cancer in India

## **FACTSHEET for CHILDHOOD CANCER**

- A. A study released recently estimates that there was incidence of 3.97 lakh (+/- 20000) cases in the world of childhood cancer in the year 2015 (1)
- B. And 43% (1.72 lakhs)of childhood cancer cases were undiagnosed globally.
- C. Estimates that there was 76,800 (19% of world) incidence of childhood cancer in India based on IICC-3 incidence rate and India population census in 2011.( Incidence in Uttar Pradesh -highest at 14700)
- D. Only 30% (22-23 thousand) of childhood cancer cases are estimated to reach a tertiary cancer center in india
- E. It is estimated that 80000 children with cancer die annually worldwide.
- F. 46000 children are estimated to die in Asia every year (highest is the world)
- G. The most common categories of childhood cancers include leukemias, brain cancers, lymphomas and solid tumours, such as neuroblastoma and Wilms tumour.
- H. In high-income countries more than 80% of children with cancer are cured, but in many low- and middle-income countries (LMICs) only about 20% are cured (2,3)
- I. Childhood cancer generally cannot be prevented or screened.
- J. Improving outcomes for children with cancer requires early and accurate diagnosis followed by effective treatment.
- K. Most childhood cancers can be cured with generic medicines and other forms of treatments including surgery and radiotherapy. Treatment of childhood cancer can be cost-effective in all income settings. [2]
- L. Avoidable deaths from childhood cancers in LMICs result from lack of diagnosis, misdiagnosis or delayed diagnosis, obstacles to accessing care, abandonment of treatment, death from toxicity, and higher rates of relapse.
- M. Childhood cancer data systems are needed to drive continuous improvements in the quality of care, and to drive policy decisions.
  - 1. <a href="https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(18)30909-4/fulltext">https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(18)30909-4/fulltext</a>
  - Gupta S, Howard SC, Hunger SP, et al. Treating Childhood Cancer in Low- and Middle-Income Countries. In: Disease Control Priorities, volume 3. <a href="http://dcp-3.org/chapter/900/treating-childhood-cancers-low-and-middle-income-countries">http://dcp-3.org/chapter/900/treating-childhood-cancers-low-and-middle-income-countries</a>

3. Howard SC, Zaidi A, Cao X, et al. The My Child Matters programme: Effect of public-private partnerships on paediatric cancer care in low-income and middle-income countries. *Lancet Oncol.* 2018;19(5):e252-e266.

CANKIDS MASSI (Medical & Social Support Informatics) & QCRI ( Quality Care Research & Impact)

Depts

## Spokespeople

- 1. Poonam Bagai, Founder Chairman & Cancer Survivor Patient Advocate Member rep Childhood Cancer International- +91 9811525745 poonambagai@cankidsindia.org
- 2. Mukul Marwah, Vice Chairman & Regional Director CK West, Mumbai +91 99876 40550 mukulmarwah@cankidsindia.org
- 3. Dr Ramandeep Arora, Pediatric Oncologist, Max Hospitals, Honorary Head QCRI Cankids, EB of INPOG. SIOP member +91 83750 17305 <a href="mailto:childhoodcancer@gmail.com">childhoodcancer@gmail.com</a>

#### Survivors -

- 1 Sandeep Yadav, Ewings Sarcoma Childhood Cancer Survivor, KCK Leader, from Gorakhpur UP, settled in Mumbai +91 96283 21299
- 2. Vikash Yadav Retinoblastoma Survivor, KCK Leader, from Jaunpur, settled in Mumbai +91 7666 389207