

## Regional Paediatric Oncology forum

CanKids...KidsCan, a not for profit family support group for children with cancer and their families, is a National Society, dedicated to a **Change for Childhood Cancer in India**. CanKids was set up in January 2004 in Delhi under the umbrella of Indian Cancer Society. In June 2012, it registered as an independent National Society working in over 37 cancer centers across the country which treats over 10000 new cases of childhood cancer each year. It is a grass-root level field organization of over 230 people (volunteers, survivors, parents of children with cancer and employees).

**Cankids Vision is to enable global standards of survival, between 70-95%, for childhood cancer in India.** Cankids programs, projects, activities, support and advocacy are aimed at enabling best possible **treatment, care and support.**

It works collaboratively with paediatric oncology professionals and organizations, hospital administrations, industry, national and international organizations and families of children with cancer to study and research, make the change and to fill the gaps.

It has been decided that an important part of CK advocacy program is to encourage Doctors of a region/city to interact, discuss and collaborate

- To standardize care
- To encourage best practice
- To adopt common protocols
- To review impact
- To encourage studies, research and publication.
- To share new developments worldwide SIOP & PODC.
- To foster better relationships between Doctors of a region for shared care.
- To focus on important aspects of supportive care and psycho-oncological support.
- To encourage younger doctors and fellows to learn, interact and present their problems.

In addition, it would give Cankids and other NGOs the opportunity to more formally share the work we are doing as well as to advocate on a common platform.

- CK will be most willing to
- Serve as the secretariat.

Currently we are having three regional forums and one stakeholder's forum

North India Paediatric Oncology Forum

East India Paediatric Oncology Forum

Tamilnadu Pudduchary Paediatric Oncology Group

RB Stakeholders forum

## **Change for Childhood cancer in States**

With health being a State subject in India, in the last 3 years Cankids has started working on

### **CHANGE FOR CHILDHOOD CANCER - STATE WISE**

It aims to ensure:

- The development of appropriate infrastructure
- Pediatric oncology centers of excellence
- Access to care networks and referral pathways
- Pediatric oncology health professionals
- Appropriate and adapted regimens of treatment and diagnostics
- Quality and affordable drugs
- Focused disease specific interventions and
- patient, family and civil society engagement in a participatory approach

## **Cankids Interventions**

1. Set up Cankids programs and services in Cancer centres and start providing services through our Cankids Hospital Support Units (CHSUs) and Cankids Care Centres(CCCs)
2. Expand services and programs to other Centres treating children with cancer in the State.
3. Advocate to the Government to focus on making childhood cancer a healthy priority in the State, creating a childhood cancer control plan.
4. Partner, to help improve infrastructure, to enhance manpower and capacity, provide supportive care– social support services, social Support teams, information
5. Create awareness about childhood cancer in the State,
6. Improve Access to Care
7. Build capacities of health professionals and social support teams for delivery of pediatric oncology services
8. Undertake and promote research and impact studies.

Currently we are having Seven Change for Childhood Cancer in states project

- A) Punjab
- B) Uttrapradesh
- C) Delhi NCR
- D) West Bengal
- E) Tamil Nadu
- F) Rajasthan
- G) Maharashtra

## **CK-JDF Model for PEDIATRIC ONCOLOGY OUTREACH -**

**Background:** In India, the paediatric oncology services are still at an infancy stage. By a rough estimate, India generates nearly 50,000 new cases of cancer in children who are under age of 18 years. These children are treated either in dedicated paediatric oncology units belonging to various regional cancer centres, or in various medical colleges (Government sector). In the private sector, they are either treated at corporate hospitals situated in various metro cities, or private hospitals run by charitable trusts. But the problem is the availability of qualified and experienced paediatric oncologists in all these hospitals.

Why do we need a dedicated paediatric oncology unit /service

**Establishing paediatric Oncology Unit (POU), also referred to as a Paediatric Cancer Unit (PCU)** is the first and most important step is the first step towards improving the care of children with cancer which will lead to a cure for more and more children, and eventually to most children, with cancer.

- The most vital component of the PCU is the **paediatric oncologist**, who is either a physician formally trained in paediatric oncology or a paediatrician with at least two years of experience in treating such children, usually with some guidance from formally trained physicians.
- In addition, a **dedicated paediatric inpatient ward and an outpatient area and a Day Care** are essential infrastructure,
- The Paediatric Oncology ward should be staffed by adequate nursing staff (with one nurse taking care of no more than 6 patients)
- Additional members of a PCU would include social workers, data managers and whenever possible more supportive staff such as child-life specialists and nutritionists

### **How to improve survival in Paediatric Oncology:**

1. Establishing a Paediatric Cancer Unit in Medical College Hospitals, Cancer centers, large tertiary care hospitals (corporate or Trust) with strong paediatric dept and a medical oncology unit and radiation therapy facilities
2. Improving the quality of treatment: The best way to improve the quality of treatment is to appoint qualified paediatric oncologists in all those hospitals where children with cancer are being treated. But it is not easy because of various technical and bureaucratic reasons.
3. Reduction in abandonment: This can be done through various means. Cankids through its huge network has helped thousands of children and their families, and has successfully reduced the abandonment rate in all those hospitals, where they have presence.

### **Model for outreach services for technical support:**

1. A qualified and experienced paediatric oncologist (called expert), who is associated with NGOs like Cankids will meet the team which are treating children with cancer. Most important aspect in this model is the willingness of the team to learn from the expert.
2. The expert will discuss the existing facilities available in the hospital, the beds available, the nursing staff training etc.
3. He will discuss the existing protocols being followed in treating children with cancer. The expert will tell them about existing protocols being followed in various centers of excellence across India. He will discuss the feasibility of running those protocols with some minor modifications.
4. He will also discuss the minimum investigations which are needed to be done before, during and after completion of treatment. All these will be properly documented and saved as soft copies as well as hard copies.
5. Since the treatment of various solid tumors is a multi modality treatment, involving surgery, radiation and chemotherapy, proper sequencing of these modalities is very important.

6. Arrangements for these will be made at a centre if the treating team perceives the need for the same and the management is fully supportive.
7. The structure/ format of these clinics/visits is designed to be decided mutually by the Paediatric Oncology representative from Cankids and the treating team at the centre in a way that best meets the needs of the children at that centre.
8. These visits will usually be in the form of clinics where patients will be seen jointly by the Paediatric Oncologist and the Treating Physician. However, the logistics at some centres, especially governmental setups may not permit this arrangement. Under these circumstances, it may be better to constitute a tumor board so that individual patients or treatment plans can be discussed.
9. The endeavour would be to treat all children as per standardized protocols.
10. Efforts will be made to collect data prospectively so that it can be appreciated whether progress is being made in reducing outcomes and improving outcomes.
11. If there are elements of treatment such as radiation/ pediatric surgery that are not available at that centre, Cankids will make efforts to coordinate this with other centres.
12. The frequency of these clinics/ tumor boards is usually months but may be less or more frequent depend on local needs and feasibility and decided mutually.
13. The travel costs of the Paediatric Oncologist can be borne by the hospital or Cankids.
14. It is also expected that as visited Paediatric Oncologist also consolidates the Cankids team at the centre and addresses their training needs and motivates and supervises them
15. He will be available on phone, through email, or skype to guide the center on case to case basis and during emergencies.
16. Expert will conduct regular teaching programs for the doctors at the hospital premises during his / her monthly visits.

#### Commitments from Cankids and JDF:

Altruistic service to make CCC – enable best treatment, care and support.

Social Support Teams and Services

Training and Capacity Building

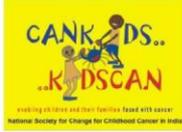
Research and Studies

Infrastructure and Equipment

#### Impact Assessment - Baseline and annual evaluation

Currently we are running three outreach clinic through our Medical Advisors at Mahavir Cancer Sansthan Patna, Safdurjung Hospital Delhi and Advance Cancer Center Bhatinda.

One of our abstract showing impact of outreach clinic at MCS Patna was also selected for oral presentation at SIOP in 2016.



# MAKING A CHANGE FOR CHILDHOOD CANCER IN PATNA INDIA AGAINST ALL ODDS - A MULTIPRONGED APPROACH

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## Background

CanKids...KidsCan is a support group committed to making a Change for Childhood Cancer in India.

Our focus areas are creating awareness, advocacy and providing holistic support

- Started working in Cancer Centers in 2004 in Delhi, India
- Vast majority of children that we support belong to low income families
- Our 1<sup>st</sup> outreach centre was in 2008 in Patna which has 1 pediatrician and an overburdened Medical Oncologist

### About Patna, Bihar (India)

Patna is the capital of Bihar (India's 3<sup>rd</sup> most populous state where 85% live in rural areas and over 50% live in Poverty)  
The life expectancy here is lower than other Indian states and India as a whole  
Bihar ranks 5<sup>th</sup> highest in terms of death of children below 5yrs of age



Mahavir Cancer Sansthan is a not-for-profit cancer hospital in Patna

Observations over 2008-15 :

- Concerns regarding lack of improvement in key indices
- Abandonment approx. 50%
- High Treatment Related Mortality (TRM) over 30%
- High Rates of Relapse
- Poor long term outcomes e.g. ALL data: 23% survival

## Aims

To attempt to improve outcomes, reduce abandonment and TRM with focused interventions

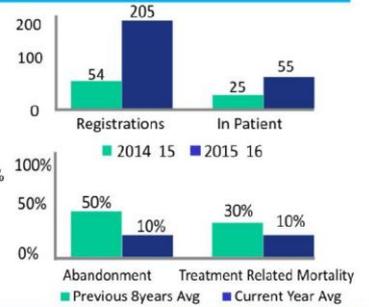
## Interventions

### March 2015, decision to set Pediatric Oncology Outreach Clinic

- Root cause analysis was done to improve outcomes and a number of factors were identified.
- Each of these factors was systematically addressed in collaboration with hospital management
- Interventions included
  - A monthly outreach clinic by a visiting Pediatric Oncologist
  - Setting up of new adapted protocols for treatment and supportive care
  - Enhanced support for drugs and diagnostics
  - Blood Bank Support
  - Increased facilitation from governmental and non-governmental institutions
  - Nutritional support
  - Providing a playroom and teacher

## Results

- Enhanced Registrations by **380%**
- Previous 8 years: 345 Registrations
- Preceding Year 2014-15 : 54 Registrations
- Last year 2015-2016: 205 (Leukemia 73) Registrations
- Average number of number of InPatient at any given time increased from 25 to 55
- Reduced Abandonment from >50% to <10%
- Treatment Related Mortality from >30% to <10%
- Inter-hospital collaboration for procedures not available in that hospital
- Contributing 2<sup>nd</sup> highest number of patients to the 1<sup>st</sup> nation wide collaborative study for Childhood Hodgkins Lymphoma



## Conclusion

- Interventions based on Root Cause Analysis led to increased patient registration, reduction in TRM and reduced abandonment
- Further analysis on long term outcome will determine whether these interventions will achieve improved cure rates