



ICCI
Indian Childhood
Cancer Initiative

Indian Childhood Cancer Initiative (ICCI)

Newsletter 2025, Issue 3

We are excited to share with you
the ICCI meetings and a summary of
the key projects undertaken
by our eleven taskforces.

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Contents

Training Session to Recognize the Early Signs of Childhood Cancer	3
Psychosocial Guidelines Group Workshop	5
Estimating the Cost of Childhood Cancer Care in India	7
Identifying Priorities in Research for Childhood Cancer in India	9
Participated in Survivorship Core Committee Meeting	11
Participated in the 4th National Paediatric Oncology Nursing Conference	13
Workshop on Infection Prevention Control: Train the Leaders	14
Created an Emergency Fever Card for Childhood Cancer Patients	15
ICCI Launched on Major Social Media Platforms	16
Gold September 2025 Campaign	18

Training Session to Recognize the Early Signs of Childhood Cancer

On September 6, 2025, an **Early Recognition Training on childhood cancer** was held at CHC (old DHH) in Bargarh District, Odisha. The session aimed at strengthening **early identification of children with cancer in Odisha**. The training brought together 53 participants, including the CDMO, CHC superintendents, CHC and PHC Medical Officers and some paediatricians.

The event was organized in collaboration with Fighters Group, Bargarh Cares, and Umeedein Odisha, CANKIDS, UISCF, Dhanwantari Trust, Lions Club Lotus, Rotary Club Smile, Mahimas, and Sanyog.



Training Session to Recognize the Early Signs of Childhood Cancer

It was a half day program where the training were conducted by these faculties

Prof. Dr Saroj P Panda

Pediatric Oncologist,
SUM Hospital

Prof. Dr Nirmalya Deo Pradhan

Pediatric Oncologist, Bagchi Sri Shankara
Cancer Center & Research Institute

Prof. Dr. Palash Das

Hematology, KIMS Hospital

Asst. Prof. Dr Debasish Sahoo

AIIMS Bhubaneswar

Next Steps:

- ✓ A refresher session will be organized in Bargarh district, along with the distribution of IEC materials.
- ✓ Kalahandi district has been identified as the second site for the first round of early recognition training.
- ✓ The first round of training in Kalahandi district is scheduled to take place between the last week of October & mid-November.



Psychosocial Guidelines Group Workshop



The Psychosocial Support Taskforce of Indian Childhood Cancer Initiative (ICCI) began the work on Psychosocial guidelines with a two-day foundational meeting held on 5th–6th September 2024 at Radisson, New Delhi, which was attended by 50 participants.

The meeting included extensive group discussions and breakout sessions focused on psycho-oncology services, leading to the identification of three focus areas:

1 Evaluation/Triage/Referral

2 Interventions

3 Manpower and Training

Building up on the previous work, on 3rd August, 2025, ICCI held its Psychosocial Guidelines Group Workshop at Narayana Health, Bangalore, bringing together the working group for guidelines.

The workshop focused on the review of the drafted first three chapters—Evaluation, Interventions, and Manpower.

Psychosocial Guidelines Group Workshop



> > > > > > > > > Next Steps > > > > > > > >

The next step is to finalise these chapters and circulate them for feedback to guide the development of national psychosocial care guidelines for children with cancer.

Estimating the Cost of Childhood Cancer Care in India

The ICCI Finance & Policy Taskforce has launched a landmark study in India using the **CC-BRIDGE tool** (Childhood Cancers Budgeting Rapidly to Incorporate Disadvantaged Groups for Equity).

Developed by St. Jude researchers, this tool helps estimate the costs of childhood cancer care and has been successfully applied in countries like Zimbabwe and Uganda.

This is the **first time such a study is being conducted in India**, aiming to generate representative health economics data from public and charitable hospitals across the country. The findings will support advocacy with the Government of India to include pediatric cancer in the **National Cancer Control Plan**.



Two training workshops have already been conducted in **February (7 centres) & July 2025 (23 centres)**, where participants were introduced to the tool, trained in data collection, and engaged in practical breakout sessions. All participating centres are government or trust hospitals. Dr. Vasudev Bhat from Kasturba Medical College, Manipal; Nancy Sobhy Bolous from St. Jude Global & Anita Pickard, PhD student from the University of Sydney were also in attendance.

Estimating the Cost of Childhood Cancer Care in India

Encouragingly, **all centres have now started collecting data, with many already sharing their inputs. Analysis of the data will begin soon.** This collaborative effort will build a critical evidence base to demonstrate the **cost-effectiveness of investing in childhood cancer care** and ensure children with cancer are represented in national health policies.



Identifying Priorities in Research for Childhood Cancer in India

Childhood cancer in India faces challenges distinct from high-income settings viz. late diagnosis, fragmented healthcare access, high treatment-related toxicity, and substantial financial burden on families. Research that is driven only by academic or pharmaceutical interests may not always address these patient-centric gaps. Hence, there was a strong felt need to identify India-specific, stakeholder-driven research priorities.

To address this, the ICCI Task Force on Research & Clinical Trials in partnership with INPHOG started the Priority Setting Exercise (PSE). The goal is to systematically capture the perspectives of patients, families, survivors, clinicians, and civil society to inform future research directions.

Work Completed so far

1

Conducted a review of international priority-setting exercises (UK, Canada, James Lind Alliance).

2

Compiled a comprehensive list of **167 research questions** relevant to childhood cancer in India. Developed survey tools and methodology tailored to the Indian context.

3

Round 1 completed: Inputs were collected from the core team (clinicians, nurses, allied HCPs, survivors, parents, civil society, policy, and research stakeholders). In addition, **117 free-text responses** were received.

4

Data was analyzed, merged, and restructured, resulting in a **refined list of 60 questions**.

Identifying Priorities in Research for Childhood Cancer in India

Ongoing:

- ✔ **Round 2 survey:** The 60 refined questions have now been translated into English and Hindi. Both versions are being uploaded on SurveyMonkey and circulated to a wider audience of ~500 respondents (50% HCPs and 50% patients, parents, survivors, civil society, policy, and research stakeholders).
- ✔ This round will help shortlist 25–30 research priorities.

> > > > > > > > **Next Steps** > > > > > > > >

Round 3: The Final in-person meeting of the core team and stakeholders is planned to be held during **PHOCON/PHOSSCON, Manipal (28–30 November 2025)**.

This meeting will bring together **researchers, clinicians, survivors, parents, civil society**, and policymakers to finalize the **Top 10 research priorities** for childhood cancer in India.

Participated in Survivorship Core Committee Meeting

The Survivorship core committee met on 22nd August 2025 at AIIMS, New Delhi, to review progress and **address key challenges in long-term childhood cancer survivors care**. This meeting was led by Dr. Rachna Seth.



Key Highlights:

- ✔ **C2S Study:** The group discussed the future of the Childhood Cancer Survivorship (C2S) registry, currently expected to follow ~8,500 survivors by 2029. A sustainable in-house database coordinated from AIIMS is being explored to continue beyond that.

Participated in Survivorship Core Committee Meeting

- ✔ **Data Quality & Security:** Issues like missing data, portal gaps, and data confidentiality were raised. The team agreed to strengthen checks, create clear SOPs, and ensure patient data safety.
- ✔ **Survivorship Clinics & Resources:** Work is underway to create a national directory of survivorship services, alongside recommendations for structured clinics across India.
- ✔ **Role Clarity:** ICCI will focus on advocacy, while INPHOG will lead on research and guidelines, with joint efforts in capacity building.



Participated in the 4th National Paediatric Oncology Nursing Conference



To strengthen paediatric oncology nursing care in India, the 4th National Paediatric Oncology Nursing Conference was organized at ACTREC, Tata Memorial Centre in Mumbai on 17th, 18th and 19th of September, 2025 to celebrate World Childhood Cancer Awareness Month and International Pediatric Hematology Oncology Nurses Day. It aimed to empower nurses and allied professionals with cutting-edge knowledge, compassionate care strategies, and multidisciplinary collaboration.

Key Highlights:

- ✓ Under PHO IAP, the Pediatric Oncology Nursing Association was launched.
- ✓ Designed a competency based pediatric nursing curriculum



This initiative plays a vital role in addressing the growing demand for skilled pediatric oncology nurses across India, ensuring that children receive safe, effective, and compassionate care.



Workshop on Infection Prevention Control: Train the Leaders

ICCI Supportive Care Taskforce, in collaboration with St. Jude Children's Research Hospital and Tata Medical Center, Kolkata, organized a 2.5-day workshop on Infection Prevention and Control (IPC) from 11th–13th September 2025 in Kolkata. It was led by Dr. Miguela Caniza, Dr. Maya Prasad, Dr. Vasudha Rao, Dr. Arpita Bhattacharya, Dr. Maysam Homsy and Dr. Tanya Paes.

The workshop was aimed to bring together multidisciplinary teams from pediatric oncology centers across India, each represented by a pediatric oncologist and an oncology/infection control nurse.



Key Highlights:

- ✔ Built a strong leadership capacity in IPC, equipping teams to implement best practices, strengthen infection control systems, and train others at their centers.
- ✔ With this workshop, a key step is taken towards improving supportive care for children with cancer, ensuring safer treatment environments and better outcomes nationwide.

Created an Emergency Fever Card for Childhood Cancer Patients

At the ICCI's Supportive Care Core Group meeting in July 2023, members emphasized the urgent need for practical tools to improve early recognition and timely management of fever.

Building on these discussions, a Fever Card was developed that is a simple, patient-friendly tool designed to guide families and healthcare providers during fever emergencies. The card was circulated among experts for feedback, with 33 responses received. Recommended changes were carefully reviewed and incorporated.

FEVER CARD

This may be an Oncological Emergency!

Patient Name: _____
Patient ID / Reg. No.: _____
Diagnosis: _____
Consultant / Unit: _____
Treating Hospital Emergency Contact / Helpline: _____

To the Attending Doctor:

This child is undergoing **chemotherapy for cancer** and may have low immunity.

If the child presents with:
Fever >100°F
Or any signs of systemic illness (breathing difficulty, abdominal pain, vomiting, loose stool, drowsiness, rash)

Treat as FEBRILE NEUTROPENIA until ruled out.

URGENT MANAGEMENT NEEDED


Please initiate the first dose of **IV Antibiotic Therapy** immediately and perform a **Complete Blood Count (CBC)**, If possible.

Refer patient immediately to _____ hospital after giving first dose of antibiotic and stabilisation.

Antibiotic – Igi _____ gram in 100 ml of normal saline over 1 hour

(One dose of this antibiotic is available with the patient)


Direction for parents/guardians



- In case of fever > 100°F, report to your hospital immediately within 1 hour. Depending on the child's condition, you may need to do blood tests and start on IV antibiotics (antibiotic injections).
- In case you have been advised to start on oral antibiotics at home or antibiotic injections at a hospital or clinic near your home, please do so before going to your primary hospital.
- Do not wait at home for the fever to come down. Do not give paracetamol at home without going to hospital.
- In any case of fast breathing, vomiting, loose motions, fits/convulsions, bleeding, drowsiness even without fever, please take the child to hospital immediately.

माता-पिता / अभिभावकों के लिए ज़रूरी निर्देश

- अगर बच्चे को बुखार **100°F** से ज्यादा हो जाए, तो तुरंत अस्पताल जाएं। बच्चे की हालत के हिसाब से खून की जांच और एंटीबायोटिक का इन्वेन्शन शुरू करना ज़रूरी हो सकता है।
- अगर डॉक्टर ने पहले से कहा है कि घर पर दवा शुरू करनी है (जैसे सिरप या गोली) या पास के किसी क्लिनिक में इन्वेन्शन लगवाना है, तो पहले वही करें, फिर अपने बड़े अस्पताल जाएं।
- बुखार के ठीक होने का इंतज़ार मत करें। घर पर खुद से पैरासिटामोल (बुखार की दवा) न दें। पहले अस्पताल दिखाएं।
- अगर बिना बुखार के भी बच्चे को ये लक्षण दिखें — तेज़ सांस चलना, उल्टी, दस्त (लूज मोशन), दौरे (फिट आना), खून निकलना, या बच्चा बहुत सुस्त हो — तो बच्चे को तुरंत अस्पताल लेकर जाएं।



> > > > > > > > > **Next Steps** > > > > > > > > >

The final version of the Fever Card will be shared with hospitals for distribution to patients & caregivers, ensuring timely action in critical situations and helping reduce treatment-related complications.

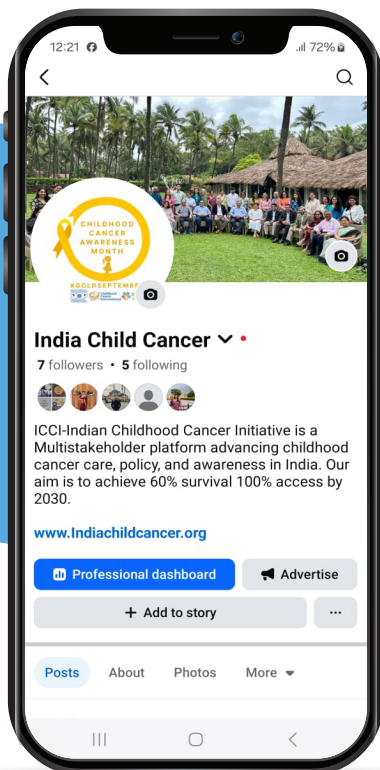
ICCI Launched on Major Social Media Platforms



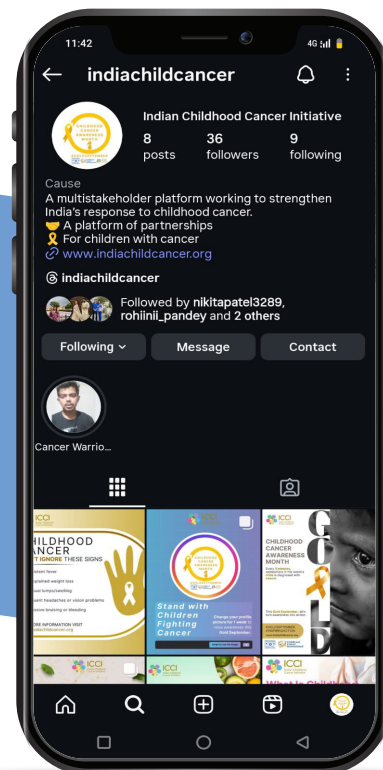
ICCI officially launched its social media presence on Instagram, Facebook, LinkedIn, and X to raise awareness on childhood cancer and direct audiences to trusted resources on the ICCI website.



@India Child Cancer



@indiachildcancer



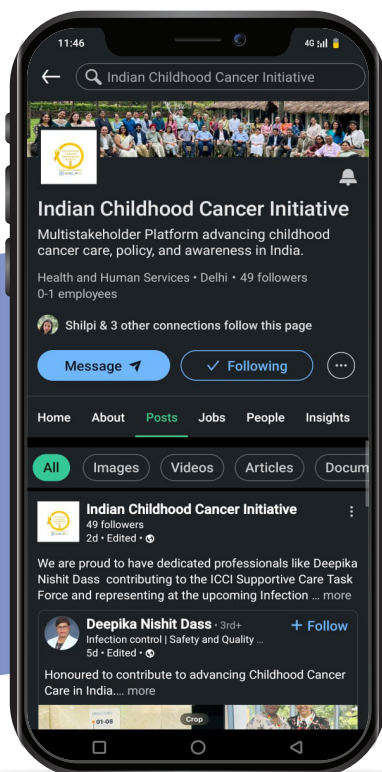
ICCI Launched on Major Social Media Platforms



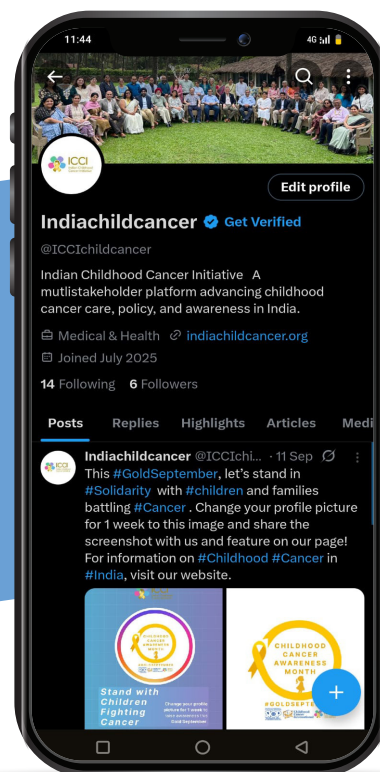
All content is carefully reviewed and verified by experts to ensure accuracy and reliability.



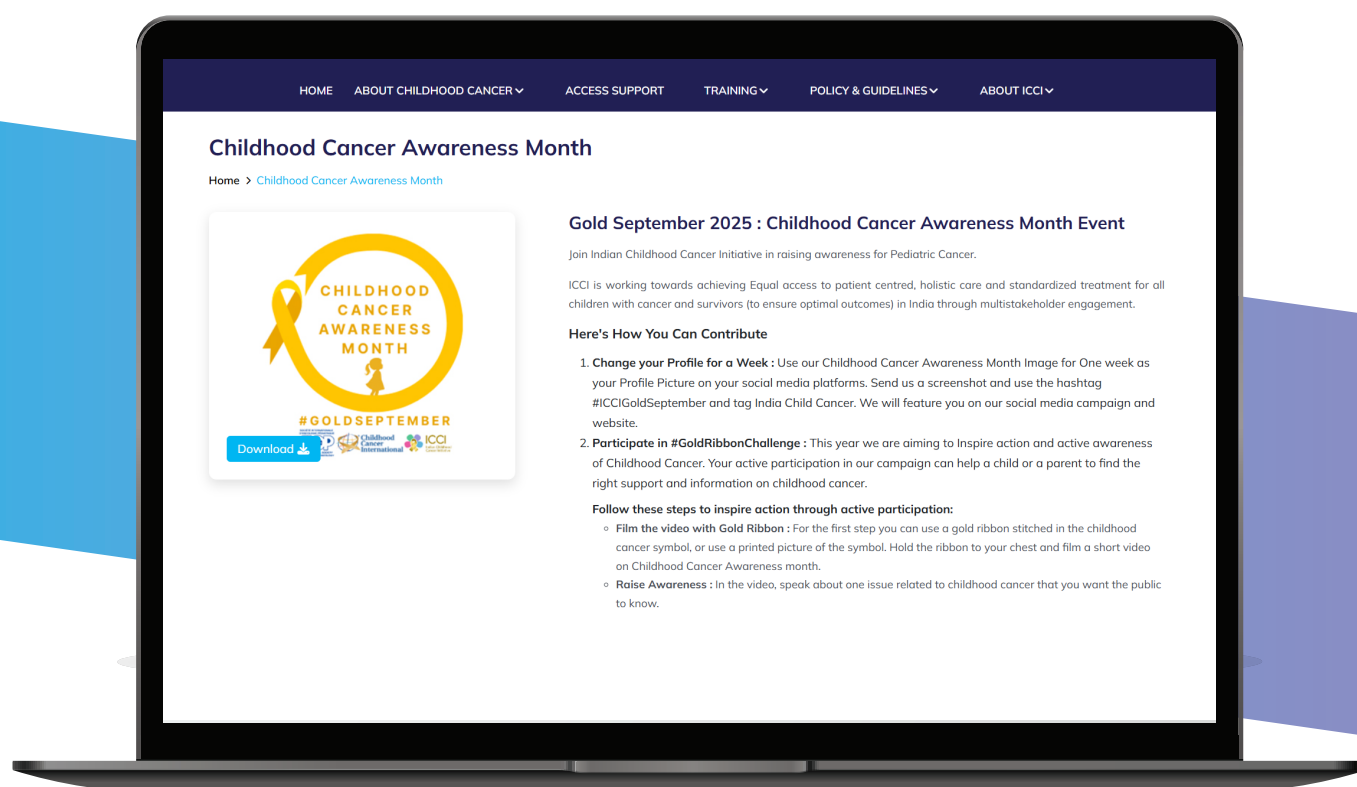
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To mark Childhood Cancer Awareness Month, ICCI launched its first national social media campaign. Supporters were invited to show solidarity by changing their profile pictures with ICCI's Gold September image and by joining the #GoldRibbonChallenge, sharing short videos with the gold ribbon symbol to raise awareness on childhood cancer.





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