

INDIAN CHILDHOOD CANCER INITIATIVE (ICCI)

NEWSLETTER, 2025, ISSUE 2

Welcome to Issue 2 of 2025,
ICCI's newsletter. 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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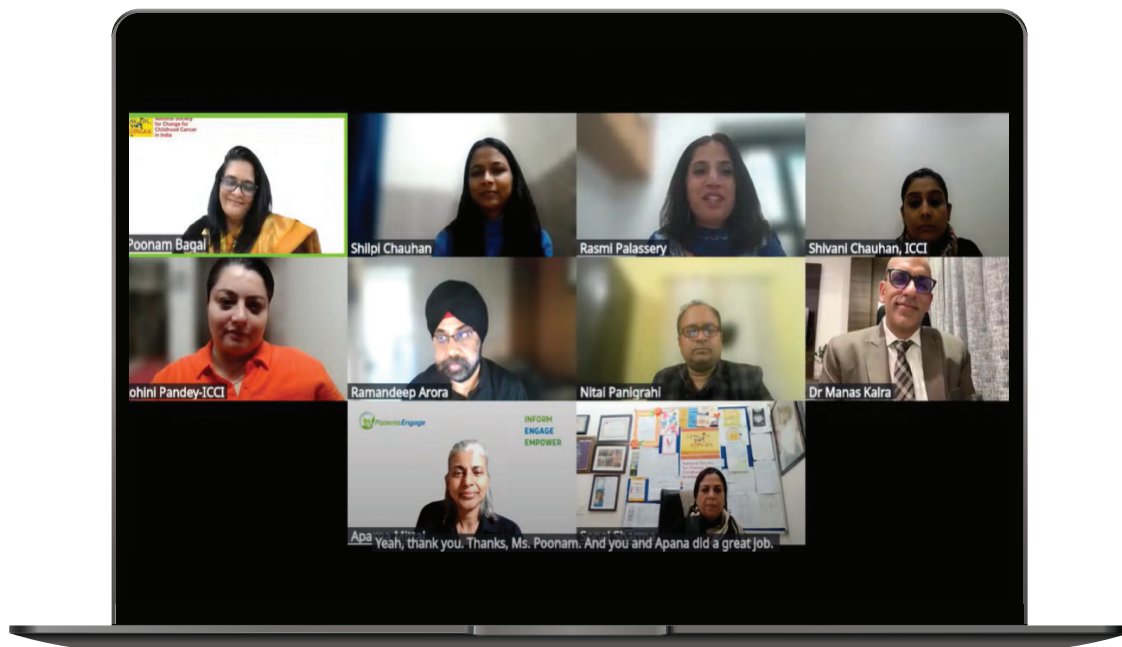
ICCD 2025 Webinar: Mapping the Road Ahead



On February 15, ICCI hosted a national webinar titled **“Developing a Roadmap for Childhood Cancer Service Delivery in India”** to mark International Childhood Cancer Day.

Key Highlights:

- ✓ Invited speakers from Govt. of India, WHO, civil society, childhood cancer survivors, and parents
- ✓ Aimed to raise awareness, educate stakeholders, and strategize improvements in pediatric oncology services
- ✓ Live-streamed on YouTube to expand reach



Webinar discussion on developing a roadmap

Next Steps:

Plan for National Cancer
Survivor Day (June 2025)

Amplify survivor stories
via social media

Pediatric Cancer Registry Data Meeting and CRC Workshop 2025



ICCI facilitated a landmark two-day workshop held in Chennai on January 31–February 1, 2025 to strengthen pediatric cancer data management and research coordination in India. It brought together expert clinicians, data managers, cancer registry staff, and clinical research coordinators (CRCs) from across the country to address key gaps in data quality, coordination, and usage for research and care.



Key Highlights:

- ✓ The preliminary Population-Based Cancer Registry (PBCCR) report for Chennai was presented and released, alongside the inauguration of Tamil Nadu's PBCCR and the INPHOG HBCCR—marking a milestone in state-level cancer surveillance.

Pediatric Cancer Registry Data Meeting and CRC Workshop 2025



- ✔ To ensure consistent and high quality data entry, Clinical Research Coordinators (CRCs) from across centers were trained on:
 - > Study protocols (Neuroblastoma, B-NHL, APL, LCH, cHL)
 - > Ethical consent, documentation, and follow-up standards
 - > Redcap database usage for efficient data capture & coding
- ✔ Experts presented updates on ongoing national studies and discussed barriers to high-quality data collection, with a focus on harmonizing standards across institutions.



The workshop reinforced best practices, encouraged institutional collaboration, and enhanced India's readiness for high-quality pediatric cancer research. This was a step forward in strengthening ICCI's mission of building a cohesive and future-ready cancer registry network to inform national policy, research, and care delivery.

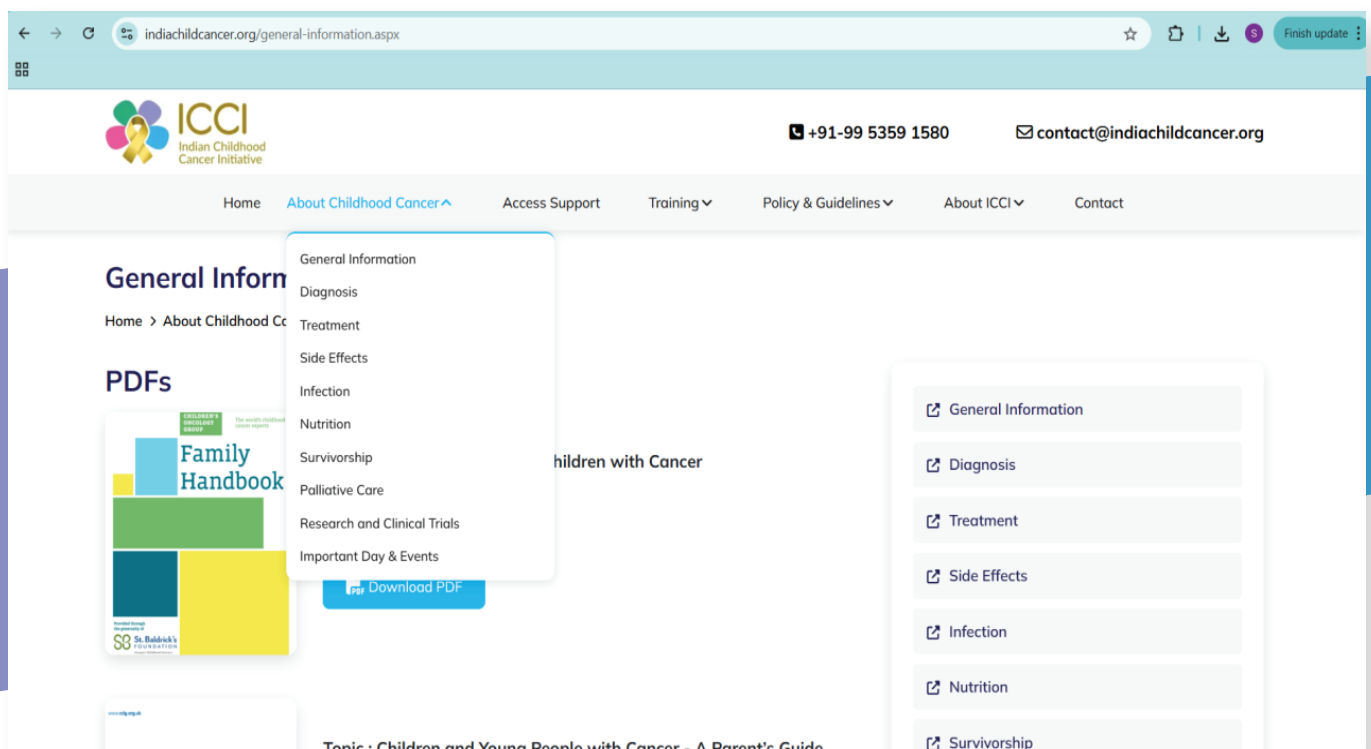
ICCI Website Update: New Information & Training Resources Live



About Childhood Cancer

This section is for anyone who wants to better understand childhood cancer.

As part of the IEC material development process, relevant videos, documents, and links are carefully selected and curated to ensure they align with the topic **“About Childhood Cancer”**, and then uploaded for easy access.



ICCI Website Update: New Information & Training Resources Live



IEC Material Development

As part of its IEC material development effort, ICCI undertook a rigorous review of content from **43 national and international sources**, identifying **459 materials** in various formats and languages. After expert screening and stakeholder scoring by a survivor, parent, and ICCI team member, **64 high-quality materials** were approved.

Here's what you'll find:

- 1 Basic information about childhood cancer
- 2 How it's diagnosed and treated
- 3 Tips for managing side effects and infections
- 4 Guidance on nutrition, survivorship & palliative care
- 5 Details on clinical trials and important awareness days

Whether you're a parent, teacher, social worker, or just want to know more about childhood cancer, this section can be helpful

ICCI Website Update: New Information & Training Resources Live

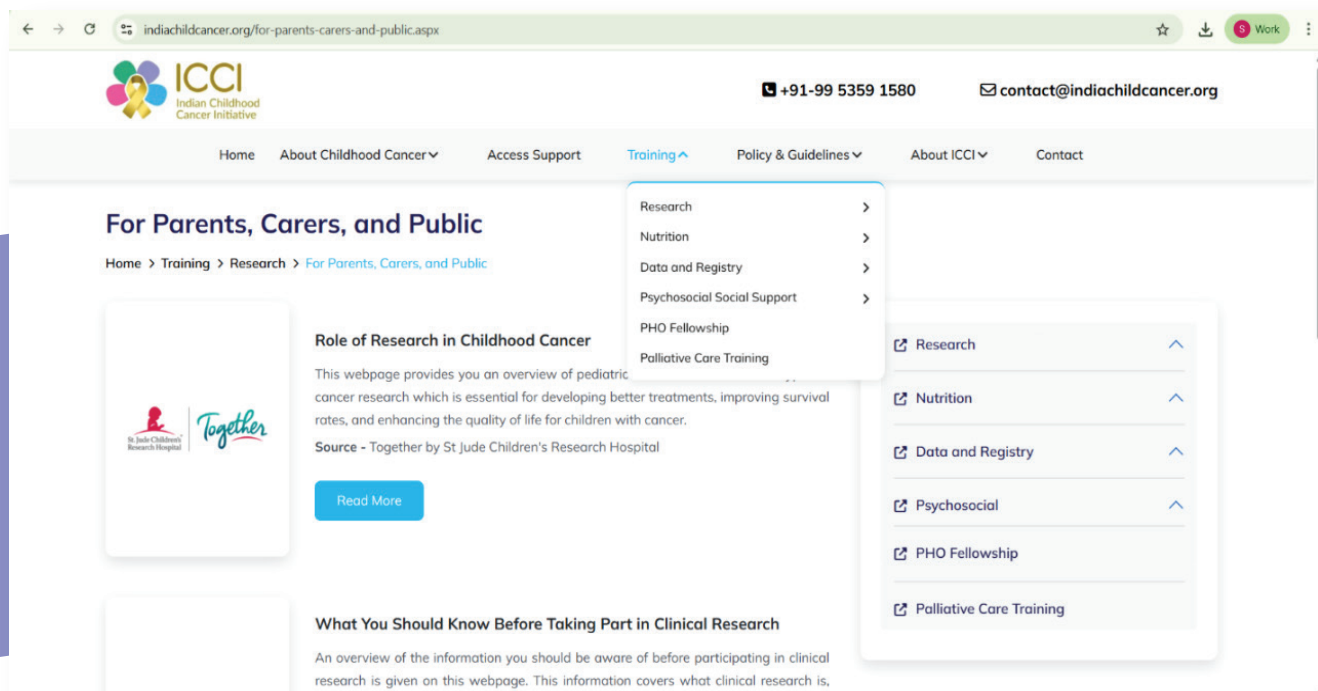


Training

We're pleased to share that the "Training" section on the ICCI website has grown. In addition to the existing content, we've now added three new focus areas:

PALLIATIVE CARE | **PHO FELLOWSHIP** | **NURSING**

These materials are meant to build confidence and skills for anyone involved in a child's care.



www.indiachildcancer.org

Explore the new sections and share them with someone who might benefit.

Early Recognition and Referral Pathway



In April 2025, ICCI hosted a two-day in-person workshop focused on strengthening early recognition and referral systems for childhood cancer in India—an essential step toward improving timely diagnosis and access to care for every child.

The event brought together over 90 participants, including government representatives, WHO officials, paediatric oncologists, frontline health professionals, NGOs, and civil society partners. The gathering provided a collaborative platform to develop, review, and refine the national framework for early cancer detection and referral pathways.

Day 1

Early recognition manual

Day 2

Mapping exercise



Early Recognition and Referral Pathway



Brief on Proposed Document on Early Recognition

We discussed the documentation we worked on for 2 months with the present stakeholders in various breakout groups. The participants were divided into breakout groups based on key symptom categories.

The 8 Key Symptoms are:

- | | |
|--|---|
|  Anemia |  Bleeding |
|  Abdominal Distention |  Eye Symptoms |
|  Lymphadenopathy |  Limb swelling |
|  Genitalia abnormalities | |
|  Headache and other neurological signs and symptoms | |

Key Highlights:

- ✓ Identification of children needing urgent referral.
- ✓ Documentation was to train the medical officers on red flags/early warning signs
- ✓ Listing symptoms and creating a practical algorithm.

Early Recognition and Referral Pathway



MAPPING – METHODS AND RESULTS

Key findings from the national hospital mapping initiative highlights gaps and variations in paediatric cancer services across India. During this session a breakdown of private & public hospitals was done.

- > **Mapping analysis on 108 cities.**
- > **Treating estimated number of 13722 per year.**



Early Recognition and Referral Pathway



Dr. L. Swasticharan, Additional Deputy Director General of Health Services, MoHFW, joined the meeting virtually, along with representatives from various state governments, International faculty, **WHO and NHSRC**.



Dr. L Swasticharan



Dr. Paola Friedrich



Dr. G.K. Rath

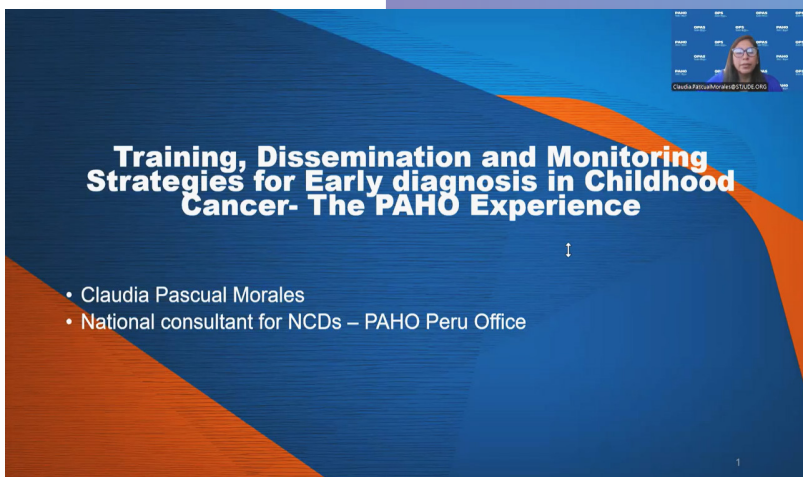


Dr. Bishnu Giri

Early Recognition and Referral Pathway



A virtual session on “PAHO MODEL OF EARLY DIAGNOSIS OF CHILDHOOD CANCER” was lead by Liliana Vasquez, Childhood Cancer Consultant, PAHO/WHO.



Claudia Pascua; Morales, MD, facilitated a virtual session on “Training, Dissemination and Monitoring Strategies for Early Diagnosis in Childhood Cancer– The PAHO Experience”



Paola Friedrich, MD, MPH, Assistant Member, St. Jude Faculty, lead the session on “How Do We Know If a Change is an Improvement?”.

Stakeholder Engagement in Childhood Cancer Care in Odisha



ICCI, along with government bodies, hospitals, and civil society partners, convened a key stakeholder meeting to strengthen childhood cancer care in Odisha on April 26th, 2025.

Key Highlights:



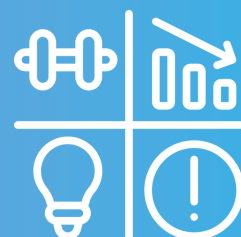
6 hospitals highlighted their institutional service capacities, and challenges in treating pediatric cancer

Various representation from 19 NGOs were made, highlighting the gap in childhood cancer treatment they have identified while working in specific areas concerning childhood cancer.



Various senior government officials expressed their strong commitment to strengthening pediatric oncology services

In-depth SWOT analysis and breakout sessions were organised to identify key challenges and action points



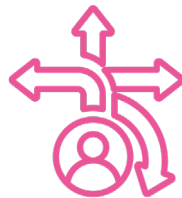
Stakeholder Engagement in Childhood Cancer Care in Odisha



Top five strategic priorities identified:



Raising public awareness
and reducing stigma



Creating clear
referral pathways



Strengthening early
detection & diagnosis



Expanding training across
health worker levels



Prioritizing childhood cancer
in state health policies



The meeting marked a strong step forward in building a coordinated, inclusive framework for childhood cancer care in Odisha.

ICCI Leadership Meeting 2025, Goa



ICCI convened its Governance Council, taskforce chairs, key members, WHO representatives, and external experts for a two-day strategic leadership meeting to review progress and chart the course for 2025–2026.



Key Highlights:

- ✔ **Taskforce Presentations:** All taskforces shared updates on completed activities, ongoing initiatives, and future goals.
- ✔ **Workshop on National Childhood Cancer Policy (NCCP):** Led by external experts to initiate structured policy development.
- ✔ **Financial Review:** Council reviewed 2024–2025 utilization and approved the proposed 2025–2026 budget.
- ✔ **Operational Planning:** Discussed evolving the governance and operational framework for scale-up.
- ✔ **Networking & Recognition:** ICCI Awards were presented, and participants engaged in cross-stakeholder discussions to strengthen collaboration.

This meeting reaffirmed ICCI's commitment to inclusive leadership, transparent planning, and evidence-driven pediatric cancer policy advocacy.



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Indian Childhood
Cancer Initiative

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