



ICCI
Indian Childhood
Cancer Initiative

INDIAN CHILDHOOD CANCER INITIATIVE (ICCI)

NEWSLETTER, JUNE 2024

Welcome to the second edition of ICCI's newsletter. We are excited to share with you the updates and key work done in the last three months. In this newsletter, we are sharing an update on the ICCI meetings and a summary of the goal statement and key focus areas of our ten taskforces.



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ICCI, LOGO



The logo for ICCI, was finalised on the **12th March 2024**, after sharing three drafts with the all the members of ICCI taskforces.



What does the logo mean?

The four petals in the flower, similar to periwinkle, which is the most commonly used cancer drug for children, signifies the four important partners involved in the journey of child suffering from cancer



The golden ribbon is the child suffering from cancer, who is the centre and the most important stakeholder.



ICCI Governance Council & Taskforce Chairs Meeting

📅 29th & 30th April 2024

📍 Novotel, Mumbai



First Governance Council meeting on 29th April 2024 in Mumbai

We conducted the first in person meeting of the Governance Council members on 29th April in Mumbai. The meeting was a great opportunity for the Governance Council members to meet, interact and work together on strengthening the council. It was also an ideal platform to apprise the council on the work done by ICCI in the last one year.

The topics of discussion in the meeting were:

- 🗨️ ICCI – Summary and progress so far
- 🗨️ ICCI – Structure and Processes
- 🗨️ ICCI – Funding and Budget
- 🗨️ ICCI – SWOT analysis
- 🗨️ Summary on Strategy and Roadmap based on SWOT Analysis
- 🗨️ Governance Council SOPs, TOR, Members



ICCI Governance Council & Taskforce Chairs Meeting

📅 29th & 30th April 2024

📍 Novotel, Mumbai



Governance Council and Taskforce Chairs meeting on 30th April in Mumbai

- ✔ It was the first meeting where the Governance Council met the Taskforce chairs.
- ✔ Day 2 of the meeting was dedicated for the taskforces, where the taskforce chairs presented their key focus areas, ongoing projects, potential targets and projects about to initiate.
- ✔ The individual budget for each taskforce for July 2024 to June 2025 was also discussed.
- ✔ Feedback on the work planned and the budget was taken from the council and other taskforce chairs and core members.
- ✔ A summary of the Governance Council meeting done a day before was shared with the taskforce chairs.
- ✔ The chairs who couldn't make it to the meeting physically, presented their session online.

SUPPORTIVE CARE



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76

members



39

hospitals



11

civil societies &
other organizations

Goal statement

To provide timely and standardized optimal multidisciplinary supportive care.

Key Focus Area

- 🕒 To develop consensus guidelines/SOPs for nutrition assessment & management
- 🕒 To optimize management of fever and febrile neutropenia
- 🕒 Template for febrile neutropenia management
 1. Fever Registry
 2. Quality Improvement initiative
 3. Implement and test PEWS
- 🕒 Implement infection control bundles/ WHO Hand Hygiene



**Supportive Care
taskforce meeting
on infection control**

25th May, Bengaluru

RESEARCH AND CLINICAL TRIALS



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Cancer Initiative



64
members



42
hospitals



05
civil societies &
other organizations

Goal statement

To increase the utilization of protocols and the percentage of children on trials/Aims at promoting research related to childhood and adolescent cancer

Key Focus Area

- Developing and delivering training and research content for patients, caregivers, CRCs, and research staff to enhance cancer registry management and patient engagement
- To do the Childhood Cancer Research Priority Setting Exercise (PSE) by a collaborative effort to identify research priorities and develop protocols for childhood cancer research
- Creation of a Clinical Trial Unit dedicated to Childhood Cancer with Human and Other Resources

RESEARCH TRAINING RESOURCE

(III) For Researchers and Clinical Investigators



Annual Biostatistics and Clinical Research Methodology Course

Source - TMC Kolkata

Link - <https://tmckolkata.com/in/biostatistics-clinical-research-methodology-course-2023/>

RESEARCH TRAINING RESOURCE

(II) For Frontline Research Staff



This webpage offers a free National Cancer Grid Clinical Trial Network course. Simply create an account to start the self-paced

learning

Source - National Cancer Grid Clinical Trial Network (NCG CTN) by NATIONAL CANCER GRID

Year Created - 2018-2020

Link - <https://ncgeducation.in/course/index.php>

Glimpse of Research Training Document

INFORMATION AND AWARENESS



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Cancer Initiative



58
members



28
hospitals



14
civil societies &
other organizations

Goal statement

To spread awareness of childhood cancer and to involve patient & parent groups in awareness and decision making

Key Focus Area

- Develop and/or collate IEC materials in different languages and different mediums including on awareness of signs, symptoms, reducing stigma and myths, survivorship, etc.
- Create a One stop Web portal to disseminate IEC and all other ICCI generated information
- Create unified content calendar of relevant national and international events

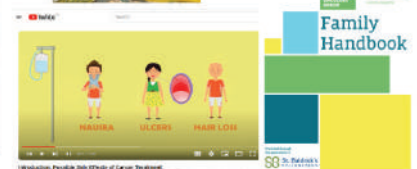
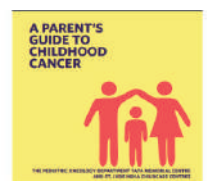
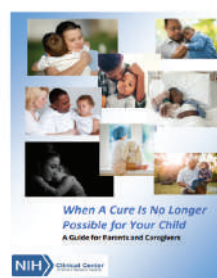
Unified Childhood Awareness Calendar

Childhood Cancer Awareness Calendar - Sourced from Cankids

January	February	March	April
26th - National Girl Child Day	4th - World Cancer Day 18th - International Childhood Cancer Day (ICCD)	8th - International Women's Day	7th - World Health Day 21st - AIDS, World Awareness Day
5th - World Hand Hygiene Day 6th - National Nurses Day 8th - Thalassemia Day 14th - TB - RD 21st - No Tobacco Day	1st - 7th - Survivor's Week 8th - World Brain Tumor Day 14th - World Blood Donation Day 19th - Stroke - Cell Day	1st - Doctor's Day September & Bone Cancer Awareness Month	Immunisation Month
Childhood Cancer Awareness Month - Russian Month (Russian Month) 4th - World Leukemia Day 19th - World Lymphoma Awareness Day (WLAAC) 17th - World Patient Safety Day 3rd Saturday - World Marrow Donor Day	2nd Saturday - World Palliative Care Day 18th - Global Hand Washing Day 2nd Thursday - World Sight Day	7th - National Cancer Awareness Day	12th - Universal Health Coverage Day

**Unified Childhood
Awareness Calendar**

Samples of available IEC material



**Samples of available
IEC material**

PSYCHOSOCIAL SUPPORT



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36

members



14

hospitals



11

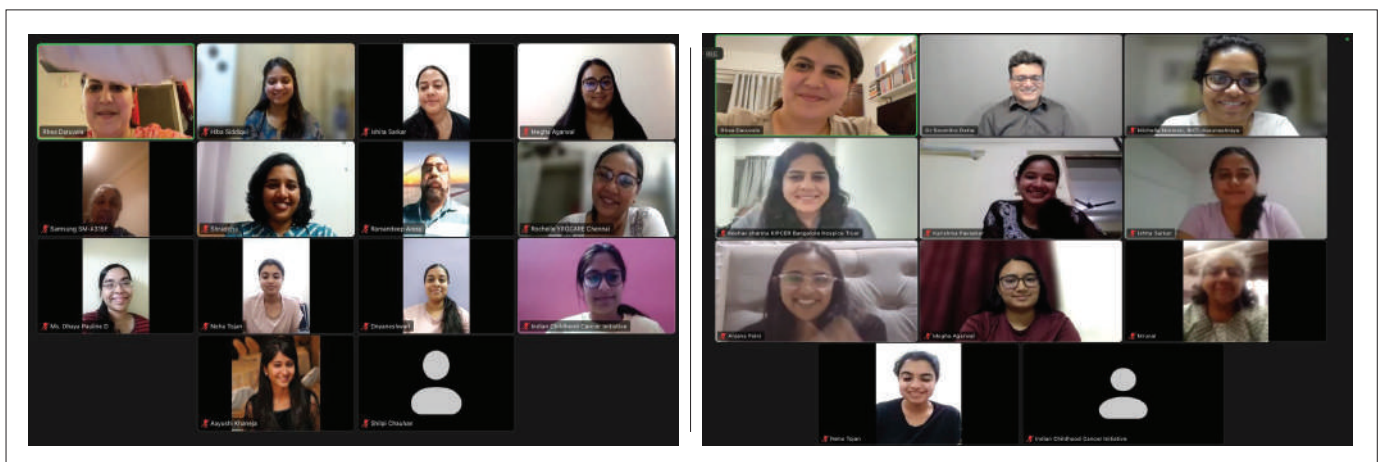
civil societies &
other organizations

Goal statement

Every child & their families with cancer should have the assessment of their social & psychological needs and access to holistic social support as per their needs

Key Focus Area

- 📍 Publish a position statement on psychosocial support
- 📍 Creation of special interest group for paediatric psycho oncology
- 📍 Mapping - Food/ Nutrition, psychology services, social workers etc.
- 📍 Develop and implement standardized psychosocial assessment tool/ pathways/processes, including education and training



Monthly discussion meetings by the Special Interest Group of Paediatric Psycho Oncology (SIGPPO)

FINANCING AND POLICY



ICCI
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Cancer Initiative



40
members



19
hospitals



08
civil societies &
other organizations

Goal statement

To achieve quality & timely care through structured/ strategic plans & adequate resources

Key Focus Area

- ❖ Create a comprehensive resource document for all the funding – Govt, NGO, CSR, Crowd Funding and increase visibility
- ❖ Make a list of NGOs for all hospitals and the support they provide
- ❖ Country Collaboration for Childhood Cancer Control (C5) Tool consists of 5 modules and provides a platform for sustainably improving childhood cancer outcomes in low- and middle- income countries. We plan to do two modules of c5 tool, c1 – National Context and Indicators and c2 – Mapped Institutions, Organizations & Roles in the next six months.
- ❖ Undertake a costing exercise to determine cost of cancer treatment

Govt Funding available in Kerala

Prime Minister National Relief Fund

Important Facts

- Any cancer patient can apply
- Only available for government hospitals and certain listed hospitals
- No reimbursement of medical expenditures already incurred
- One-time financial assistance – Maximum amount available: Rs three lakhs
- Applicable in all states

What documents do I need to apply?

- Original Estimate Certificate
- OPD Card Protocols
- Charter Income Certificate/Income affidavit up to one lakh rupees
- Proof of family permanent address
- Patient Photo
- Member of Parliament recommendation letter
- Request letter from the family addressed to the Prime Minister

Reference Website

- <https://pmsf.gov.in/about/private-hospitals>

Rashtriya Arogya Nidhi (RAN)

Important Facts

- AAN Ration cardholder's holder can apply.
- Any cancer patient can apply.
- Reimburse functional
- No reimbursement of medical expenditure already incurred.
- One-time financial assistance.
- Applicable in all states.
- Those who are not being treated in Govt. Hospitals can't apply.

What documents do I need to apply?

- AAN Ration Card
- Income Certificate/Charter
- All India Declaration Form
- OPD Card

Reference Website

- <https://ran.north.gov.in/?major-programme=poor-patients-financial-assistance/rashtriya-arogyo-nidhi>



C5 Template | Module Overview



Country Collaboration for Childhood Cancer Control Tool (C5)



A Tool Supporting National Priority-Setting, Cancer Control Planning, and Collaborative Systems Change through Partner Engagement and Systems Science

An example of how the information on available government schemes will appear on ICCI website

Country Collaboration for Childhood Cancer Control (C5 Tool)

ACCESS TO CARE



ICCI
Indian Childhood
Cancer Initiative



74

members



34

hospitals



12

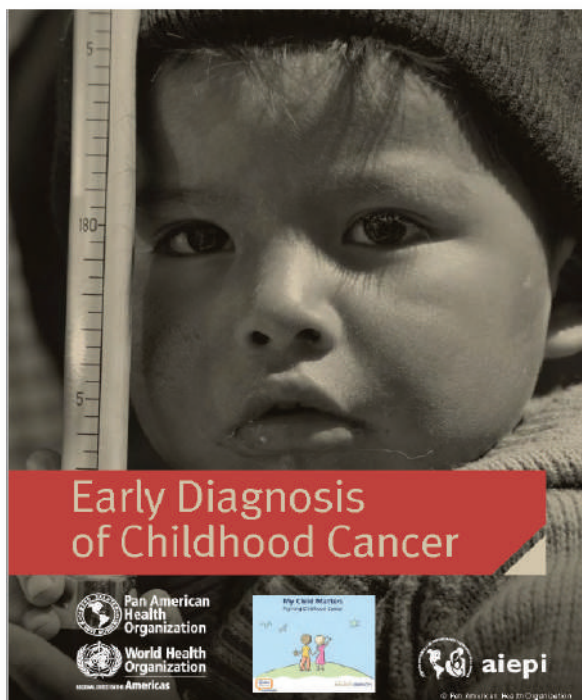
civil societies &
other organizations

Goal statement

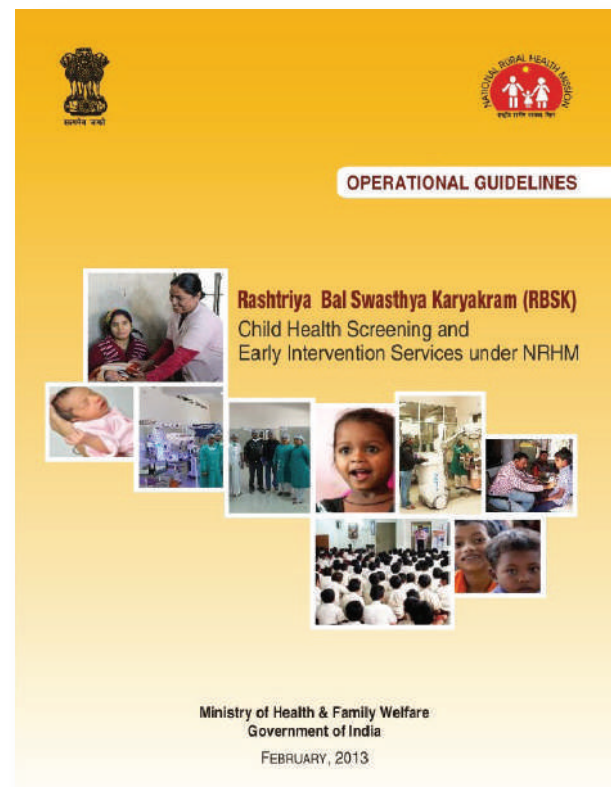
To develop well defined referral pathways, networks and linkages in each state

Key Focus Area

- Map all the centers across the country
- Develop the IEC material for use at grassroot level (PHC, CHCs etc.)
- Define guidelines for pediatric cancer centers
- Setting pediatric oncology standards
- Update the NTP-PPO



**Module on Early Diagnosis of
Childhood cancer by PAHO**



**Operational guidelines of RBSK on
Child Health Screening and
Early Intervention Services**

WORKFORCE AND TRAINING



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Cancer Initiative



60
members



33
hospitals



12
civil societies &
other organizations

Goal statement

To develop and implement training and accreditation of all verticals of pediatric oncology workforce

Key Focus Area

- ❖ Create Nursing Apex body and decide priorities
- ❖ Expanding and scaling up the available courses and to do need assessment & identify gaps in training
- ❖ To do need assessment and identify gaps including workforce mapping

NATIONAL PEDIATRIC HAEMATOLOGY ONCOLOGY NURSING CONFERENCE 2024
*Transforming Practices to Reality:
Shaping the Future of Pediatric Oncology*

19th - 20th February, 2024
Venue: JLN Auditorium, AIIMS, New Delhi - 110029

Organized by
Indian Childhood Cancer Initiative (ICCI)
Workforce, Accreditation & Training Taskforce

CHAIR

Ms. Sindhu Nair Nursing Superintendent TMH, Parel	Dr. Vikramjit Kanwar Chief of Pediatric Oncology HBCH, Varanasi
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Engaging Partners
St. Jude Global Health & CanKids KidsCan

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E-mail: contact@indiachildcancer.org

**Flyer for The
National Pediatric
Haematology
Oncology Nursing
Conference**



**The National Pediatric Haematology Oncology Nursing Conference,
19th-20th February, 2024 at AIIMS, New Delhi**

DRUGS AND DIAGNOSTICS



ICCI
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Cancer Initiative



31
members



18
hospitals



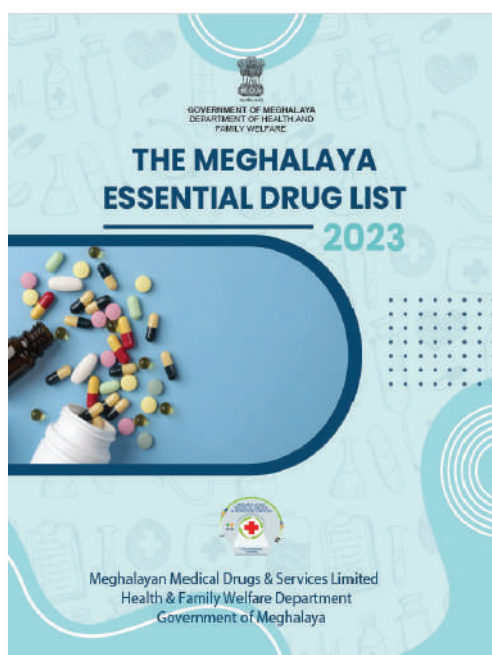
05
civil societies &
other organizations

Goal statement

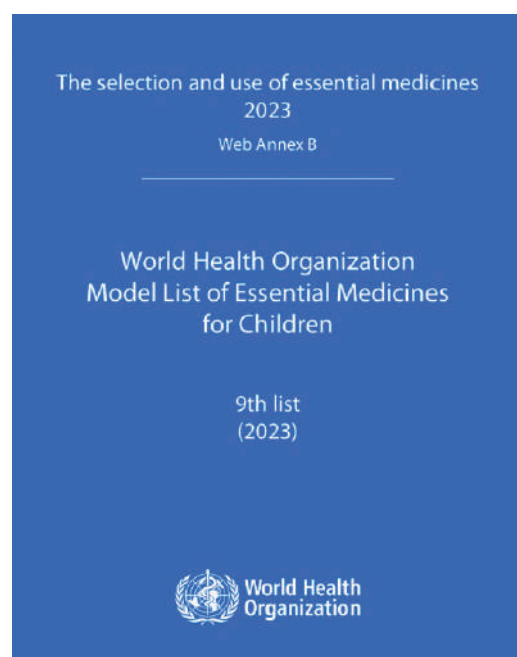
To generate recommendation for uninterrupted supply of good quality drugs and diagnostics

Key Focus Area

- ◉ Random testing for drug quality.
- ◉ Compilation of national essential medicine list- childhood cancers
 1. Compiling of all available states and UTs list of anticancer drugs is done
 2. Comparing of WHO EMLc with all states and UTs
 3. Final analysis will be done after the compilation



**Essential Drug List of
Meghalaya, 2023**



**List of Essential Medicines for
Children by W.H.O, 2023**

DATA AND REGISTRY



ICCI
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Cancer Initiative



47
members



24
hospitals



12
civil societies &
other organizations

Goal statement

To facilitate the collection of high-resolution data on pediatric cancer

Key Focus Area

- Establish a REDCAP Database for collecting HBCR data and implement a Backup Server to ensure data security and integrity
- Training CRCs, Data Managers, and Cancer registry staff for accurate data entry and management in the HBCR database
- Increase centers contributing data to HBCR



REDCAP Server installed in Chennai

ESTABLISHING THE FIRST DEDICATED POPULATION-BASED CHILDHOOD CANCER REGISTRY (PBCCR) AND A NETWORK OF HOSPITAL-BASED CHILDHOOD CANCER REGISTRIES (HBCCRs) IN INDIA

DATA COLLECTION FORM

Patient Number:.....

A. Essential Information

(NOTE: this form may be completed on admission to reporting hospital)

SICARES ID: ...[auto-generated] First Name: Last Name:

Date of birth: Gender: Male Female Other

Are you attempting to report a second cancer in a patient who was previously registered?

Yes No

NOTE: if yes, these cases will now be linked in the Registry and a new SICARES ID will be assigned for the second cancer. Do you confirm this is accurate? Yes No

B. Demographics

(NOTE: this form may be completed on admission to reporting hospital)

National ID: Medical record number:

Usual residence address:

Address line 1: Address line 2:

City: State/Province: Country:

Race: (specify) or Unknown Declined to respond Not applicable

Ethnic group: (specify) or Unknown Declined to respond Not applicable

Parent/Primary Caregiver name:

Parent/Primary Caregiver Highest Education:

<input type="checkbox"/> None	<input type="checkbox"/> 1-8 years (grade school)	<input type="checkbox"/> 9-12 years (high school/O-level), but did not graduate
<input type="checkbox"/> Completed high school/GED/A-levels	<input type="checkbox"/> Trainings after high school, other than college (vocational/community college)	<input type="checkbox"/> College graduate
<input type="checkbox"/> Post-graduate level	<input type="checkbox"/> Unknown	

Parent/Contact information:

Best phone number: Best e-mail for contact:

C. Diagnosis

(NOTE: this form may be completed ~13 months post-admission)

Date of initial onset of cancer-related symptoms:

Date of First Medical Assessment for cancer associated symptoms:

Does the patient have a **confirmed** cancer diagnosis? Yes No (NOTE: if "No", data collection for this patient ends here)

Date of diagnosis:

Best method of diagnosis: (select the highest in the hierarchy if multiple diagnosis Methods were used. (lowest: Clinical exam, highest: Autopsy/Death certificate))

<input type="checkbox"/> Clinical examination
<input type="checkbox"/> Lab exams (including tumor markers)
<input type="checkbox"/> Imaging

Data Collection Form for
HBCR and PBCR in India

CONTINUITY OF CARE



ICCI
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64
members



23
hospitals



14
civil societies &
other organizations

Goal statement

To establish pediatric palliative care programs in all pediatric cancer centers.
To establish survivorship clinics in all cancer centers and develop guidelines for follow up care

Key Focus Area (Palliative Care)

- 📍 Map all existing pain and palliative care services in India
- 📍 Publish a position statement on palliative care
- 📍 Train and educate health care professionals on palliative care
- 📍 Develop guideline for palliative chemotherapy and palliative radiotherapy
- 📍 Develop SOPs on PPC services

Key Focus Area (Survivorship and Reintegration)

- 📍 Rehab introductory session for Patients, Survivors & Health Care Professionals
- 📍 Develop national surveillance/follow-up guidelines.
- 📍 Develop position statement on fertility preservation
- 📍 INPHOG C2S study expansion to capture national survivorship data
- 📍 Conduct research studies to understand the long term effects of childhood cancer treatments and survivorship outcomes in India
- 📍 Establish fertility preservation working group

Indian Childhood Cancer Initiative (ICCI)

📍 Nukleus, 501& 501A, Salcon Ras Vilas, Saket, New Delhi – 110017

✉ contact@indiachildcancer.org