INPHOG

Indian Pediatric Hematology Oncology Group

ANNUAL REPORT

2025

INDIAN PEDIATRIC HEMATOLOGY ONCOLOGY GROUP

Legal Name:

- Inphog Research Foundation

Registered Address:

- B-181, Raheja Atlantis, Sector 31, Gurgaon, Haryana – 122001

Correspondence Address:

- Ras Vilas, 501 & 501A, Salcon Rasvilas, District Centre, Saket, New Delhi – 110017

Section 8 Company CIN:

- U73100HR2021NPL100092

PAN Number:

- AAGCI4622R

CHAIRPERSON'S MESSAGE

Improving outcomes of children with cancer and blood disorders lies at the heart of what the Indian Pediatric Hematology Oncology Group or INPHOG does. We firmly believe that collaboration in delivery of care, measurement of outcomes, and in scientific enquiry, ultimately improves survival and quality of life for children.

With 26,088 children impacted in 164 hospitals in India since 2015, INPHOG is now considered a model for similar efforts in India and other low- and middle-income countries. This journey has been possible because of the vision of those who conceived INPHOG, and because of the work and support of our colleagues, our supporters, our leadership and our staff. Ultimately all this is given meaning by the difference we are able to make in the lives of these children and we are blessed to have this opportunity.

It is with great pride and sincere gratitude we present our first Annual Report. This inaugural report marks a significant milestone in our journey and reflects a shared commitment to advancing evidence-based care and improving outcomes for children with cancer and benign hematological disorders across India.

Read Share Enjoy

Ramandeep Arora
Chairperson, INPHOG
Pediatric Oncologist, Max Healthcare

CANCER & BLOOD DISORDERS IN CHILDREN IN INDIA

Pediatric cancers and blood disorders are illnesses that affect children from infancy through adolescence. Unlike adult cancers, childhood cancers arise from changes in rapidly growing cells, not from lifestyle or environmental factors. In India, the most common childhood cancers are **blood cancers,** especially **leukaemia,** followed by **lymphomas** and solid tumours such as brain and bone cancers.

Blood disorders are conditions that impact how blood is formed and how it functions. Children in India are commonly affected by conditions such as **thalassaemia, haemophilia, aplastic anaemia, sickle cell disease,** and other **bone marrow failure syndromes.** These illnesses often require specialised care, long term treatment, and, in some cases, bone marrow transplantation.

Every year, **India reports over 75,000 new cases of childhood cancer,** with leukaemia being the most common. Childhood cancers make up about **4% of all cancers,** with **leukaemia contributing nearly 35%** and **lymphomas another 10–15%.**

While childhood cancers are highly treatable, survival in India remains **30–50%,** compared to **85% in high-income countries.** This difference exists not because the disease is different, but because access to **clinical research, clinical trials & standardised treatment protocols** is limited.

This reality gives rise to a painful truth: **For many children, survival is decided by where they are born, not by the treatability of their illness.**

Pediatric cancers and blood disorders **can be cured,** yet many children in India still lose their lives simply because access to research driven treatment is uneven. INPHOG works to change this through **collaborative clinical research,** bringing together pediatric cancer and hematology centers across the country to develop standardised protocols, conduct multicentre studies, and generate evidence that improves care for every child.

By strengthening India's research ecosystem, INPHOG is helping ensure that **every child, regardless of where they are born, gets an equal chance to live.**

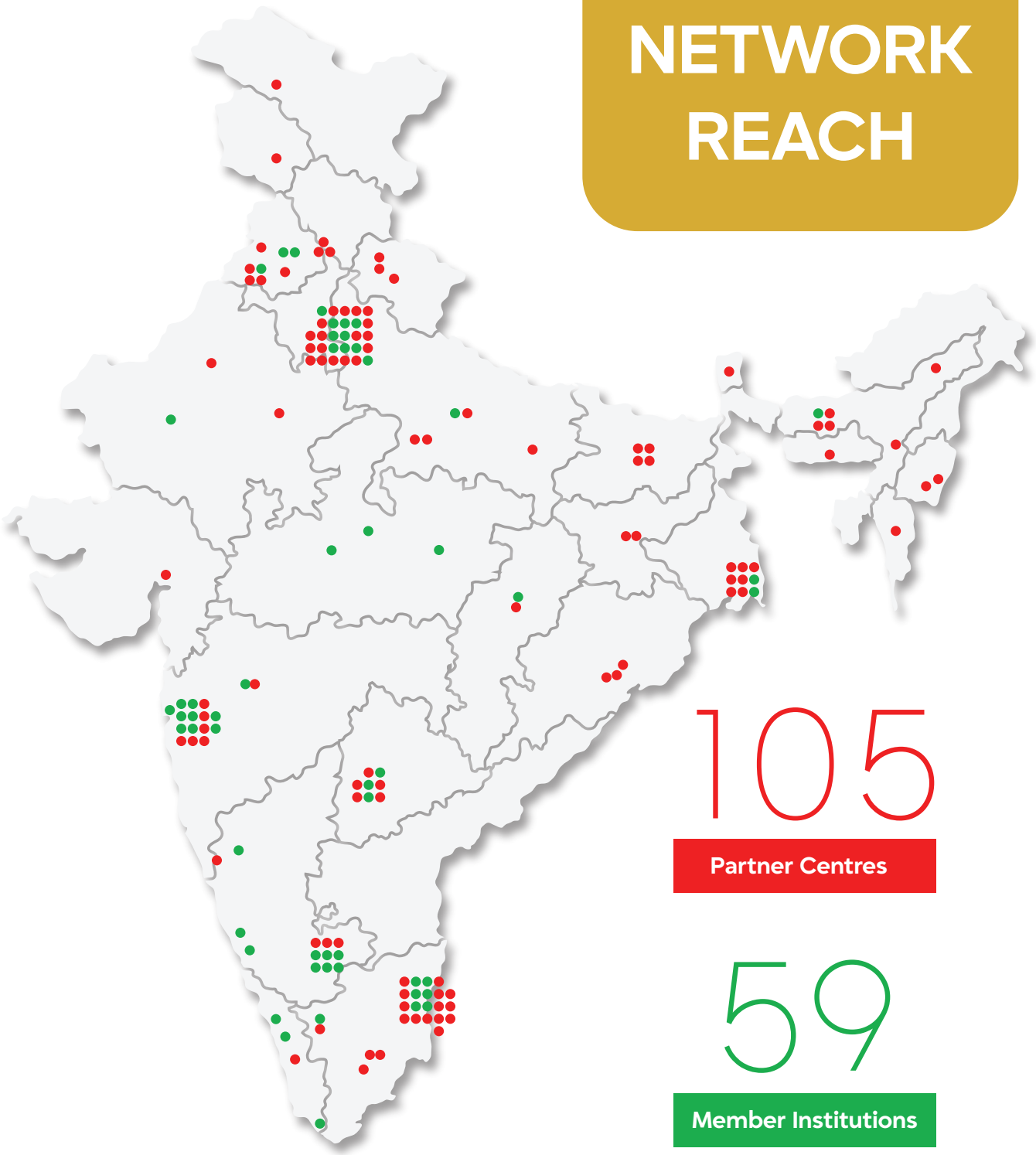
MISSION

Improving outcomes of childhood cancer and blood disorders in India through collaborative research

PURPOSE

Accelerate the development of prospective multicenter childhood cancer clinical trials in India to achieve our mission

INPHOG NETWORK REACH



105

Partner Centres

59

Member Institutions

AT A GLANCE

26,088

CHILDREN IMPACTED

Benefitted from INPHOG's work over the past 11 years. Our efforts have improved access to advanced treatments, enhanced survival, and supported brighter futures.

164

HOSPITALS

Engaged to coordinate data collection, strengthen treatment protocols, conduct collaborative research, and improve overall care.

38

INPHOG PROJECTS

Across all types of cancers and blood disorders in children with additional focus on epidemiology, access to care, supportive care, palliative care and survivorship.

TESTIMONIALS

Dr. Kathy Pritchard Jones
Professor of Paediatric Oncology
UCL Great Ormond Street Institute of Child Health, University College London

INPHOG has been instrumental in improving childhood cancer care and survival chances across India. Working together as a national network, INPHOG provides access to innovative treatments and addresses many important research questions. I feel privileged to be among their international advisors, helping them achieve their mission to give every child with cancer in India the best possible outcome.

Mr. Nihal Kaviratne
Founder – St. Jude India ChildCare Centres

At the high end, the remaining gap between childhood cancer survival rates in the developed world versus India is really hard to bridge. INPHOG's programme is sharply designed to enable that, and it is a privilege to lend my experience to helping them as an Advisory Board Member.

TESTIMONIALS

Dr. Carl Allen
Vice-Chair for Research, Pediatrics, Baylor College of Medicine
Milton and Allene Nerkin Chair, Pediatric Oncology
Professor, Baylor College of Medicine
Chair, SIOP Programme to Advance Research Capacity

"The mission of SIOP is to improve the lives of children and adolescents with cancer through global collaboration, education, training, research and advocacy. INPHOG is one of the first institutions supported by a PARC grant, with greatly accelerated clinical trial capacity development and impact on patients. INPHOG's accomplishments are a model for pediatric oncology research."

Dr. Scott Howard
CEO
Resonance

Mr. Chandan Kumar
Senior Project Manager
Resonance

Ms. Jennifer Lowe
Chief Research Officer
Resonance

Mr. Samik Samaddar
ECRF specialist & clinical data analyst
Resonance

"50 years of childhood cancer research have led to an 85% cure rate in high-resource healthcare settings, which leaves 15% more cures to find through continued research. In lower-resourced settings we have additional challenges to overcome, including incorrect/incomplete diagnosis, abandonment, toxic death, and excess relapses. INPHOG is critical for both research goals: getting to 100% and getting everyone to 100%. Once all pediatric cancer centers in India have joined, INPHOG will be the largest childhood cancer research network on the planet. It is already one of the most efficient and impactful. We at Resonance are delighted to support INPHOG's work to accomplish our shared mission of curing every child with cancer."

WHO WE ARE

BOARD OF DIRECTORS

Dr. Ramandeep Singh Arora
Pediatric Oncologist
Max Hospital

Dr. Amita Mahajan
Pediatric Oncologist
Indraprastha Apollo Delhi

Dr. Revathi Raj
Pediatric Hematologist
Apollo Hospital Chennai

Dr. Gauri Kapoor
Pediatric Oncologist
Rajiv Gandhi Cancer Institute
& Research Centre Delhi

Dr. Venkatraman Radhakrishnan
Professor and Head of Department
Medical Oncology, Cancer Institute
Chennai

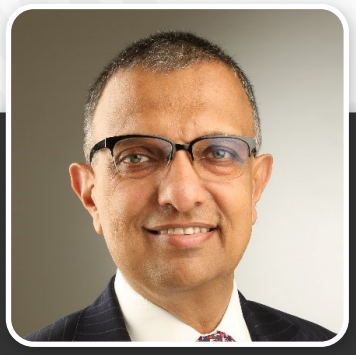
ADVISORS

Kathy Pritchard Jones
Professor of Paediatric Oncology
UCL Great Ormond Street Institute of Child Health
University College London

Carlos Rodriguez Galindo
EVP and Chair, Department of
Global Pediatric Medicine
St. Jude Children's Research Hospital

CS Pramesh
Director at Tata Memorial Hospital (Mumbai)
Professor and Chief, Thoracic Surgery
Department of Surgical Oncology

Nihal Kaviratne
Founder
St. Jude India ChildCare Centres



Nachiket Mor
Visiting Scientist
Banyan Academy of Leadershipin
Mental Health

TECHNICAL MENTORS

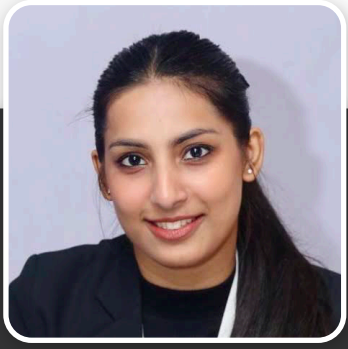
Meenakshi Devidas
Director, Global Analytics
St. Jude Children's Research Hospital
Memphis Metropolitan Area

Pooja Sharma
Founder
APAR Health

Durga Gadgil
CR&D Director
vWyeth

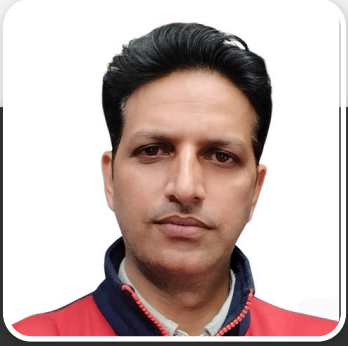
OPERATIONS TEAM

Harish T G
Lead - Fundraising
INPHOG



Tanya Dhawan
Research Manager
INPHOG

Nikita Patel
Biostatistician
INPHOG



Prakash Tiwari
HR Consultant
INPHOG

Vinita Upadhyay
Volunteer
INPHOG

CLINICAL RESEARCH COORDINATORS

STAFF

MEMBER INSTITUTES

S.NO.	NAME OF THE HOSPITAL	STATE	CITY
1	DR. BHUBANESWAR BOROOAH CANCER INSTITUTE	ASSAM	GUWAHATI
2	VEDANTA MEDICAL RESEARCH FOUNDATION (BALCO)	CHHATTISGARH	RAIPUR
3	RAJIV GANDHI CANCER INSTITUTE AND RESEARCH CENTRE	DELHI	NEW DELHI
4	SAFDARJUNG HOSPITAL	DELHI	NEW DELHI
5	MAX SUPER SPECIALITY HOSPITAL	DELHI	NEW DELHI
6	APOLLO HOSPITAL	DELHI	NEW DELHI
7	ALL INDIA INSTITUTE OF MEDICAL SCIENCES (AIIMS)	DELHI	NEW DELHI
8	SIR GANGA RAM HOSPITAL	DELHI	NEW DELHI
9	ATAL BIHARI VAJPAYEE INSTITUTE OF MEDICAL SCIENCE & DR. RAM MANOHAR LOHIA HOSPITAL	DELHI	NEW DELHI
10	HEMATOLOGY ONCOLOGY CLINIC, VEDANTA HOSPITAL	GUJARAT	AHMEDABAD
11	PANDIT BHAGWAT DAYAL SHARMA POST GRADUATE INSTITUTE OF MEDICAL SCIENCE	HARYANA	ROHTAK
12	SHER-I-KASHMIR INSTITUTE OF MEDICAL SCIENCES (SKIMS)	JAMMU & KASHMIR	SRINAGAR
13	MAZUMDAR SHAW CANCER CENTER, NARAYANA HEALTH CITY	KARNATAKA	BENGALURU
14	ST. JOHN'S MEDICAL COLLEGE HOSPITAL	KARNATAKA	BENGALURU
15	KASTURBA MEDICAL COLLEGE	KARNATAKA	MANGALURU
16	JAWAHARLAL NEHRU MEDICAL COLLEGE, BELGAUM (JNMC)	KARNATAKA	BELAGAVI
17	KASTURBA MEDICAL COLLEGE	KARNATAKA	MANIPAL
18	SRI SHANKARA CANCER HOSPITAL AND RESEARCH CENTRE	KARNATAKA	BENGALURU
19	RAINBOW CHILDREN'S HOSPITAL	KARNATAKA	BENGALURU
20	KIDWAI MEMORIAL INSTITUTE OF ONCOLOGY	KARNATAKA	BENGALURU
21	M. S. RAMAIAH MEDICAL COLLEGE	KARNATAKA	BENGALURU
22	MVR CANCER CENTRE AND RESEARCH INSTITUTE	KERALA	KOZHIKODE
23	REGIONAL CANCER CENTRE	KERALA	THIRUVANANTHAPURAM
24	MALABAR CANCER CENTRE	KERALA	THALASSERY
25	CANCER CENTRE, SRI AUROBINDO INSTITUTE OF MEDICAL SCIENCES	MADHYA PRADESH	INDORE
26	NETAJI SUBHASH CHANDRA BOSE MEDICAL COLLEGE	MADHYA PRADESH	JABALPUR
27	ALL INDIA INSTITUTE OF MEDICAL SCIENCES (AIIMS)	MADHYA PRADESH	BHOPAL
28	TATA MEMORIAL HOSPITAL	MAHARASHTRA	MUMBAI
29	BAI JERBAI WADIA HOSPITAL FOR CHILDREN	MAHARASHTRA	MUMBAI
30	MCGM COMPREHENSIVE THALASSEMIA CARE, PHO & BMT CENTRE	MAHARASHTRA	MUMBAI
31	BHARATI VIDYAPEETH HOSPITAL AND MEDICAL COLLEGE	MAHARASHTRA	PUNE
32	MAHATMA GANDHI MISSION MEDICAL COLLEGE & HOSPITAL	MAHARASHTRA	AURANGABAD
33	LOKMANYA TILAK MUNICIPAL GENERAL HOSPITAL (SION)	MAHARASHTRA	MUMBAI
34	DEENANATH MANGESHKAR HOSPITAL	MAHARASHTRA	PUNE
35	NARAYANA HEALTH – SRCC CHILDREN'S HOSPITAL	MAHARASHTRA	MUMBAI
36	KOKILABEN DHIRUBHAI AMBANI HOSPITAL	MAHARASHTRA	MUMBAI
37	NATIONAL CANCER INSTITUTE	MAHARASHTRA	NAGPUR
38	SIR H. N. RELIANCE FOUNDATION HOSPITAL	MAHARASHTRA	MUMBAI
39	JAWAHARLAL INSTITUTE OF POSTGRADUATE MEDICAL EDUCATION & RESEARCH	PUDUCHERRY	PUDUCHERRY
40	DAYANAND MEDICAL COLLEGE & HOSPITAL	PUNJAB	LUDHIANA
41	ALL INDIA INSTITUTE OF MEDICAL SCIENCES (AIIMS)	PUNJAB	BATHINDA
42	CHRISTIAN MEDICAL COLLEGE (CMC)	PUNJAB	LUDHIANA
43	MAHATMA GANDHI MEDICAL COLLEGE & HOSPITAL	RAJASTHAN	JAIPUR
44	ALL INDIA INSTITUTE OF MEDICAL SCIENCES (AIIMS)	RAJASTHAN	JODHPUR
45	CANCER INSTITUTE, ADYAR	TAMIL NADU	CHENNAI
46	APOLLO HOSPITAL	TAMIL NADU	CHENNAI
47	KANCHI KAMAKOTI CHILDS TRUST HOSPITAL	TAMIL NADU	CHENNAI
48	SRI RAMACHANDRA MEDICAL COLLEGE AND RESEARCH INSTITUTE (SRMC)	TAMIL NADU	CHENNAI
49	G. KUPPUSWAMY NAIDU MEMORIAL HOSPITAL	TAMIL NADU	COIMBATORE
50	MEENAKSHI MISSION HOSPITAL & RESEARCH CENTRE	TAMIL NADU	MADURAI
51	BASAVATARAKAM INDO-AMERICAN CANCER HOSPITAL & RESEARCH INSTITUTE	TELANGANA	HYDERABAD
52	RAINBOW CHILDREN'S HOSPITAL	TELANGANA	HYDERABAD
53	LITTLE STARS AND SHE CHILDREN'S HOSPITAL	TELANGANA	HYDERABAD
54	KING GEORGE MEDICAL UNIVERSITY (KGMU)	UTTAR PRADESH	LUCKNOW
55	MAX SUPER SPECIALITY HOSPITAL, VAISHALI	UTTAR PRADESH	GHAZIABAD
56	HOMI BHABHA CANCER HOSPITAL	UTTAR PRADESH	VARANASI
57	SUPER SPECIALITY PEDIATRIC HOSPITAL & PG TEACHING INSTITUTE	UTTAR PRADESH	NOIDA
58	TATA MEDICAL CENTER	WEST BENGAL	KOLKATA
59	CHITTARANJAN NATIONAL CANCER INSTITUTE (CNCI)	WEST BENGAL	KOLKATA

SUBCOMMITTEES

S.NO.	SUBCOMMITTEE	CHAIRS
	HEMATOLYMPHOID NEOPLASMS	
1	ACUTE LYMPHOBLASTIC LEUKEMIA	DR. VENKATRAMAN RADHAKRISHNAN
2	ACUTE MYELOID LEUKEMIA & CHRONIC MYELOPROLIFERATIVE DISORDERS	DR. SMITA KAYAL
3	HODGKIN'S LYMPHOMA	DR. PAYAL MALHOTRA
4	NON-HODGKIN LYMPHOMA	DR. NIRMALYA MOULIK
5	HISTIOCYTOSIS	DR. RAMYA UPPULURI
	SOLID TUMOURS	
6	CENTRAL NERVOUS SYSTEM TUMOURS	DR. VIKRAMJIT KANWAR
7	NEUROBLASTOMA	DR. YAMINI KRISHNAN
8	RETINOBLASTOMA	DR. AMITA MAHAJAN
9	WILMS' TUMOUR	DR. SHALINI MISHRA
10	LIVER TUMOURS	DR. VIMAL KUMAR
11	PNET (PRIMITIVE NEURO-ECTODERMAL TUMOUR)	DR. VASUDEV BHAT
12	OSTEOSARCOMA	DR. AKSHAY TIWARI
13	SOFT TISSUE SARCOMA	DR. REGHU K. S.
14	GERM CELL TUMOURS & RARE TUMOURS	DR. SONALI MOHAPATRA
	TRANSVERSAL	
15	HEMATOPOIETIC STEM CELL TRANSPLANT	DR. PONNI SIVAPRAKASAN
16	ACCESS TO CARE	DR. SHRUTI KAKKAR
17	SUPPORTIVE CARE	DR. GARGI DAS
18	EPIDEMIOLOGY	DR. RAMANDEEP ARORA
19	SURVIVORSHIP & LATE EFFECTS	DR. RACHNA SETH
20	PALLIATIVE CARE	DR. VERONIQUE DINAND
21	CANCER GENETICS	DR. BADIRA C. P.
22	CELL & GENE THERAPY	DR. GAURAV NARULA
	BENIGN HEMATOLOGY DISORDERS	
23	HEMOGLOBINOPATHIES & RED BLOOD CELL DISORDERS	DR. BHAVNA DHINGRA
24	PLATELET & COAGULATION DISORDERS	DR. VANDANA BHARDWAJ
25	BONE MARROW FAILURE	DR. MUKUL AGARWAL

OUR SUPPORTERS

Over the past year, INPHOG has had the privilege of collaborating with and receiving support from a wide network of organizations and partners, partners who share our mission to improve childhood cancer and blood disorder research and outcomes.

Some of our valued supporters include:

APARhealth

CANKIDS KIDSCAN

artizen

ICCI Indian Childhood Cancer Initiative

Leukemia Crusaders
An Initiative of BansiVidya Memorial Trust

UNIFI FOUNDATION

Pediatric Hematology and Oncology Chapter
Indian Academy of Pediatrics

resonance
amplifying health

STOP PARC Programme

St. Jude Global

Mission Samriddhi
SOCIAL IMPACT ENTERPRISE

ANNUAL RETURN 2024-25

INPHOG RESEARCH FOUNDATION
(A Private Company under Section 8 of Companies Act, 2013)
CIN NO. U73100HR2021NPL100092

(All amounts in Hundreds)

BALANCE SHEET AS ON 31st MARCH 2025

Particulars	Note No.	As at 31-3-2025	As at 31-3-2024
EQUITY AND LIABILITIES			
Shareholders' Funds			
Reserves and surplus	3	16,343	4,461
Current liabilities			
Short Term Borrowings	4	3,000	-
Other Current liabilities	5	3,272	3,967
TOTAL		**22,615**	**8,428**
ASSETS			
Non Current Assets			
Fixed Assets			
Tangible Fixed Assets	6	1,561	2,957
Other Non Current Asset	7	200	100
Current Assets			
Cash and cash equivalents	8	15,122	3,006
Other Current assets	9	5,732	2,365
TOTAL		**22,615**	**8,428**
Significant Accounting Policies and Notes on accounts	1-22		

As per our report of even date.
For S.P. Gupta & Associates
Chartered Accountants

Preeti Parasrampuria
Partner
Membership No 131204

Place: Mumbai
Date: 05.09.2025

For and on behalf of the Board of Directors
For INPHOG Research Foundation

Dr. Ramandeep Arora
Director
DIN: 09445611

Dr. Amita Mahajan
Director
DIN: 07316636

Place: Gurgaon
Date: 05.09.2025

WHAT WE DO

InPOG-ALL-15-01

An Indian Childhood Collaborative Leukemia Group multicenter national standardization study for newly diagnosed acute lymphoblastic leukemia

Dr Vaskar Saha

Dr Shripad D Banavali

The Indian Collaborative Childhood Leukaemia (ICiCLe) group was established in 2012 to improve outcomes in childhood acute lymphoblastic leukaemia (ALL) in India. Six centres – two in Delhi (both at the All India Institute of Medical Sciences) and one each in Chandigarh (Postgraduate Institute of Medical Education & Research), Mumbai (Tata Memorial Hospital), Chennai (Cancer Institute) and Kolkata (Tata Medical Center) – collaborated to design a modern, risk-stratified treatment protocol. Treatment intensity was tailored using clinical features, leukaemia genetics, and early response assessments. A preparatory phase (2013 to 2018) demonstrated feasibility of a uniform, risk-adapted treatment across all centres. Around 10% of 2700 patients died from treatment-related toxicity, mostly in the first 100 days, lower than reported previously. Subsequently the ICiCLe-ALL-14 randomised trial (InPOG-ALL-15-01; CTRI/2015/12/006434; 2016-2022) tested two interventions to lower toxicity and relapses: shortening corticosteroid exposure during induction for younger, non- high-risk patients; and an alternative anthracycline during the delayed intensification treatment phase for all. In over 2,500 patients, treatment-related mortality declined further.

Children under ten years were identified as particularly vulnerable to treatment-related toxicity. The shortened induction steroid regimen substantially reduced deaths without compromising cure rates. Results from the anthracycline randomisation await more mature follow up***. ICiCLe studies show that a collaborative, data-led approach can deliver modern, risk-adapted care for patients with ALL in India, reducing mortality and treatment costs.*** Outcomes remain inferior to those in high-income countries, likely reflecting variability in diagnostics, drug quality, and outpatient maintenance care. The initiative has attracted support from non-governmental organisations and catalysed efforts to standardise laboratory tests, drug administration and treatment practice. ***The programme has expanded to 21 public hospitals through the ISCALL study (Improving Survival in Childhood ALL, CTRI/2023/12/060828)*** and a new randomised trial ICiCLe-ALL-24 (CTRI/2024/07/069839), with the shorter induction steroid now incorporated into subsequent protocols.

InPOG-HL-15-01

A collaborative study for newly diagnosed childhood Hodgkin's lymphoma patients in India

Dr. Jagdish Chandra

Dr. Amita Mahajan

Developments in treatment strategies, in large part, depend upon the results of clinical studies to address questions regarding appropriate treatments for a particular condition. For a long time, we in India followed the western guidelines based on the results of studies in their patients. This study aimed to look at the strategies for treatment of Hodgkin Lymphoma (a type of cancer of lymphatic glands) in Indian settings.

We were able to enrol a large number of patients (one of the largest studies in the world on Hodgkin Lymphoma in children) from nearly 30 centres across the country. Thus, a uniform strategy of treatment of Hodgkin Lymphoma is now adopted. Our results are quite encouraging and comparable to the best from the developed countries. This has led to the belief of doability of such clinical studies in our country.

The first collaborative effort from India highlighted key differences in epidemiology: lower median age (9%< 5 years) and striking male preponderance. Patients with early-stage disease achieved satisfactory results with 4 cycles of ABVD and radiation limited to sites of bulky disease and inadequate response at early-interim assessment. This approach (with 6 cycles) yielded suboptimal results in advanced-stage disease. Use of PET-CT was associated with reduction in patients requiring radiation .

InPOG-RB-19-01

A Prospective Collaborative Study for Newly Diagnosed Patients with Retinoblastoma

Dr. Santosh Honavar

Dr. Amita Mahajan

Dr. Sima Das

This prospective multicentric collaborative Indian study analysed diagnostic and treatment lag time in 1120 retinoblastoma children, focusing on delays at the parental and healthcare system levels and their association with disease stage and sociodemographic factors.

The mean time from symptom onset to treatment initiation was 4.2 months, with parental delay accounting for the largest share (44%), followed by diagnosis and treatment delays. ***Longer lag times were significantly associated with extraocular disease, lower socioeconomic status, lower maternal education, greater travel distance, younger maternal age, and first consultation with non-specialists.*** One-quarter of children presented with extraocular or metastatic disease. Zone-wise analysis showed higher rates of extraocular disease in Northern and Eastern India, regions with poorer socioeconomic indicators and higher maternal illiteracy, compared to predominantly intraocular presentation in Southern India.

The study identifies key targets for intervention—targeted and zone-specific community awareness, maternal education, early screening, and training of all healthcare providers—to enable earlier diagnosis, improve survival, and increase chances of eye and vision preservation.

INPHOG-EPI-22-03

Establishing the first dedicated Population-Based Childhood Cancer Registry (PBCCR) and network of Hospital-Based Childhood Cancer Registries (HBCCRs) in India.

Dr. Venkatraman Radhakrishnan

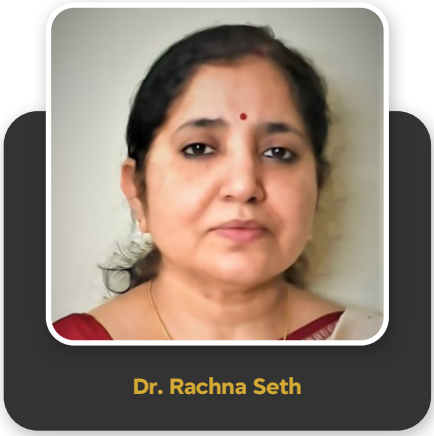
Registration of patients is the starting point for understanding disease burden. This is best exemplified by cancer registries which provide valuable information on cancer control efforts. Although cancer registries capture information & childhood cancer as well, this data has deficiencies and comprehensiveness, quality and detail.

This has been address by the **establishment of the first dedicated population based childhood cancer registry in Chennai, India in October 2022.** Registered 241 pediatric cancer cases for individuals aged 0 to 19 years within the Greater Chennai corporation limits. The reported 2 years survival of 70% represents a stepping stone on the way towards 60% survival at 5 years from diagnosis, which is at 2030 global target of the WTO global initiative for childhood cancer.

This effort is now being expanded to the entire state of Tamil Nadu which will provide us coverage of approximately 5% of the Indian population. This data generated will support policy level decision making and will monitor the impact of local interventions.

InPOG-LE-16-01

The Indian Childhood Cancer Survivorship Study (C2S study): After treatment completion registry of childhood cancers – Phase 1



Dr. Rachna Seth

About Study:

There is very limited data on the prevalence of late effects in childhood cancer survivors from LMICs, including India. With a large number of adolescent & young adults getting cured, there is an unmet need for establishing comprehensive nationwide childhood cancer survivor registry and a survivors' cohort in India to evaluate & improve their long-term health.

The INPHOG survivorship and late effects subcommittee in 2016 launched the first study on survivorship 'Childhood Cancer Survivorship (C2S) Study' InPOG-LE-16-01, was envisaged in two phases with distinct objectives Phase one of the study was designed to establish a multi-center registry and form the Indian Childhood Cancer Survivorship Cohort for children completing treatment for childhood cancer. Phase two would focus on in-depth studies that will be directed at providing evidence on the strength and direction of the association of late effects with exposures on the Indian C2Scohort and would attempt to generate guidelines for follow-up of childhood cancer survivors in India.

What did we find?

5419 survivors enrolled from 20 geographically diverse centers across the country was analysed in December 2024.The study provides a detailed description of the cohort characteristics, treatment exposures (chemotherapy, radiotherapy, surgery), and systematic follow-up. The outcomes (survival, relapse, lost to follow up) was available for the cohort via the registry. Acute leukemia was the most common diagnosis. The 5-year overall survival (OS) and event-free survival (EFS) rates for the entire cohort after they entered the study 94.5% (95% CI: 93.7-95.3%) and 89.9% (95% CI: 88.8- 91.0%), respectively. It also highlights the strengths and challenges of collaboration across public and private sector institutions.

How has it impacted/will impact patients?

The cohort would form a denominator for the future multicentre research on childhood cancer survivorship in the country, as differences in exposures warrant local adaptations of the international guidelines in the regional context, with due consideration to the regional evidence. It would serve as a model for similar resource-limited settings, to engage in collaborative research in survivorship and to help in capacity- building for better post-treatment care to improve quality of life and reduce long-term morbidity/mortality in childhood cancer survivors.

EVENTS

Strengthening Research Capacity Through Staff Training

To ensure that collaborative pediatric cancer research in India is implemented with consistency and quality, INPHOG invested in intensive staff capacity building through a ***two-day Pediatric Cancer Registry Data Meeting and CRC Workshop held in Chennai in January 2025.***

The focus of the training was not only on understanding study protocols, but on translating them into day-to-day clinical research practice. Participants worked through real-world challenges related to documentation, informed consent, follow-up, and protocol adherence. Ongoing INPHOG studies including Neuroblastoma, B-NHL, APML, and Hodgkin Lymphoma were used as practical examples to demonstrate how standardised approaches can improve data quality and patient outcomes across centres.

The second day shifted attention to the backbone of collaborative research: data systems and registries. Through hands-on engagement with REDCap and registry workflows, CRCs strengthened their skills in data entry, validation, and quality control. Ethical compliance & inter-centre coordination were emphasised, reinforcing the role of CRCs as key drivers of reliable, high-quality research data within the INPHOG network.

Investing in the Backbone of Research: CRC Training at PHOCON 2025

Clinical Research Coordinators play a central role in making multicentre research possible, and INPHOG's CRC Training Program at PHOCON in Manipal in November 2025 was designed to recognise and strengthen this role. Held alongside the national pediatric oncology conference, the two-day program brought together CRCs and investigators from across the country to deepen skills, share experiences, and build a sense of community.

The training blended scientific updates with practical learning. Participants engaged with ongoing INPHOG studies, explored challenges in trial implementation, and gained exposure to biostatistics, data management, and peer review processes. Interactive sessions encouraged CRCs to see their work not just as operational support, but as a critical contribution to scientific rigor & research integrity.

The second day focused on strengthening coordination across centres. Sessions on monitoring, data quality, and REDCap usage were complemented by direct interaction with INPHOG leadership, reinforcing transparency and shared ownership of research goals. By the end of the program, CRCs were better equipped to support complex multicentre studies and contribute confidently to India's growing pediatric oncology research ecosystem.

In Summary

Across trainings, workshops, and stakeholder engagement, INPHOG's efforts during this period focused on one core goal: building a strong, connected, and data driven research community that can improve outcomes for children with cancer across India. Each meeting strengthened skills, fostered collaboration, and laid the groundwork for research that is both scientifically robust and deeply relevant to the needs of patients and families.

EVENTS

Advancing India's Role in Global Data Collaboration: DaSH Workshop

INPHOG's participation in the India Data Sharing & Harmonization (DaSH) Workshop marked an important steptoward integrating Indian pediatric oncology research into global data ecosystems. Organized in collaboration with the University of Chicago, the workshop brought together Indian and international experts to explore how large-scale data sharing can accelerate discovery while respecting ethical and regulatory frameworks.

Discussions began with a focus on governance, ethics, and trust critical elements for responsible data sharing. International examples from initiatives such as the Pediatric Cancer Data Commons (PCDC) illustrated how harmonised datasets enable large, meaningful analyses that no single centre or country could achieve alone. These conversations helped contextualize how INPHOG could evolve from a national collaborative group into a platform that supports disease-specific consortia and international partnerships.

As the workshop progressed, attention turned to practical implementation. Sessions explored data models, harmonised staging systems, and real-world applications of registry linked research. INPHOG's own registries and trials including ICiCLe, Hodgkin Lymphoma, HBCCR, and Low-Grade Glioma were highlighted as examples of how standardised, high-quality data from Indian centres can contribute to global knowledge.

The workshop reinforced INPHOG's growing leadership in data-driven pediatric oncology research and led to Dr. Ramandeep Arora being invited to represent INPHOG on the PCDC Scientific Advisory Committee, strengthening India's voice in global collaborations.

EVENTS

Listening to the Community: Setting Research Priorities for India

Recognising that impactful research must be guided by real needs, INPHOG partnered with the Indian Childhood Cancer Initiative (ICCI) to launch a national Priority Setting Exercise for childhood cancer research in India. This initiative was designed to move beyond investigator driven agendas and instead reflect the perspectives of clinicians, researchers, patients, and caregivers.

A structured and transparent process was developed, beginning with the creation of a comprehensive list of 167 research questions spanning diagnosis, treatment, survivorship, access to care, and health systems. With ethics approval in place, the exercise is now underway and will progress through multiple rounds of stakeholder engagement.

Through successive surveys, the long list of questions will be refined into a set of national research priorities. The final outcome will be a ranked list of the top 10 research areas that matter most to children with cancer and their families in India. These priorities will guide future INPHOG studies, funding decisions, and collaborations, ensuring that research efforts are aligned with the country's most pressing needs.

PUBLICATIONS IN 2025

Articles

Risk stratified treatment for childhood acute lymphoblastic leukaemia: a multicentre observational study from India

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Summary

Background Overall survival rates of children with acute lymphoblastic leukaemia (ALL) in high-income countries approach 90%. Treated on the same protocols, outcomes in India, were ~65%.

Methods The Indian Childhood Collaborative Leukaemia (ICiCLe) group used genetics and measurable residual disease (MRD) to categorise B-cell precursor (BCP) ALL as standard (SR), intermediate (IR) and high-risk (HR) to receive increasing intensity of therapy. T-ALL were treated uniformly. Data on risk stratification, deaths and relapses were collected annually.

Findings 2695 patients aged 1–18 years were enrolled between January 2013 and May 2018. Induction deaths were significantly lower in SR patients ($p = 0{\cdot}002$) compared to others. At a median 61 (59–62) months, the 4-year event free and overall survival was 76% (72–79%) and 88% (85–90%) in SR; 70% (66–74%) and 80% (77–83%) in IR; 61% (51–64%) and 73% (70–76%) in HR; and 69% (62–75%) and 77% (70–83%) in T-ALL patients ($p < 0{\cdot}001$). For BCP-ALL, regression analyses showed age, white cell count, bulky disease, high risk genetics and treating centre as independent prognostic variables. The cumulative incidence of treatment deaths (TRD) and relapses at centres varied from 2% (1–5) to 13% (10–17) ($p \leq 0{\cdot}001$); and 21% (17–26) to 45% (39–51) ($p \leq 0{\cdot}001$) respectively with significant differences in proportion of BCP-ALL patients with MRD $\geq 0{\cdot}01\%$ ($p = 0{\cdot}0007$) and time to relapse ($p = 0{\cdot}001$).

Interpretation Risk stratified directed reduced intensity treatment and collaboration decreases treatment deaths and relapses. Standardisation of genetic and MRD tests across centres and access to high quality drugs will lead to further improvements in survival.

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Original Article

Lag time for diagnosis and treatment in 1120 retinoblastoma children: Analysis from InPOG-RB-19-01

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Setting: Increased lag time for diagnosis and treatment is a key determinant of adverse retinoblastoma (RB) outcomes. Analysis from INPHOG-RB-19-01, a prospective, multicentric study of newly diagnosed RB with regard to lag time and its correlation with various variables, is presented. **Patient or Study Population:** All newly diagnosed RB patients treated at the participating centers during the study period were enrolled. **Observation Procedure:** Lag time was subdivided into parent-lag time (symptom onset to first consult) and system-lag time (including diagnosis lag time, defined as first consult to diagnosis, and treatment lag time, defined as diagnosis to treatment initiation.). Multivariate logistic regression analysis was used to assess factors predictive of increased lag time. **Main Outcome Measures:** In all, 1120 patients from 20 centers were enrolled over a 36-month period. Extraocular or metastatic disease was present in 25.2% of patients at diagnosis. The mean lag time from symptom onset to treatment initiation was 4.2 months (range 0.5–61.6 months). Parental, diagnosis, and treatment lag time contributed to 44%, 26%, and 31% of the total lag time, respectively. Increased lag time had significant correlation with the stage at presentation ($P < 0.05$), lower socio-economic status ($P = 0.006$), increased distance from treating center ($P = 0.001$), younger maternal age at pregnancy ($P < 0.05$), family history of cancer ($P = 0.031$), and first consultation with a non-specialist ($P = 0.001$), and showed a negative correlation with improved maternal education. Parental lag time is the major contributor to the cascading delay in RB diagnosis and treatment initiation. Efforts for earlier diagnosis, therefore, need to be directed towards community awareness and routine screening during contact with healthcare professionals, such as at immunization.

Key words: Extraocular, lag time, parental lag time, retinoblastoma, time to diagnosis

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Retinoblastoma (RB) is the most common intraocular malignant tumor in children. Worldwide, increased awareness and advances in management have facilitated early diagnosis and improved survival. Survival rates reported from high-income countries (HIC) range from 88% in the United Kingdom to 93% in the United States.[1,2] In India, Nepal, Africa, and South American countries, the prognosis is significantly inferior, with a higher proportion of these children presenting at an advanced stage. Orbital RB has been reported to be 18% in Mexico, 36% in Taiwan, and 40% in studies from Nepal, and ranges from 9%–45% in studies from India.[3-10] Ocular salvage and preservation of vision are essentially dependent on early diagnosis, and several studies have been conducted to identify the factors leading to delayed diagnosis at presentation.[11-13] Survival is dependent on the geographic location and the economic status of the country; the Global Retinoblastoma Outcome Study reiterated that children from low- and middle-income countries (LMICs) have significantly inferior (50%) 3-year survival compared to almost 100% survival in those from HICs.[13] Delay in diagnosis in RB has been associated with lower chances of globe salvage and higher mortality.[14,15] Studies from South America have noted prolonged time to diagnosis to be more associated with extraocular disease at presentation.[16,17] Reduced lag time to diagnosis has been associated with less advanced RB, as found in the Swiss

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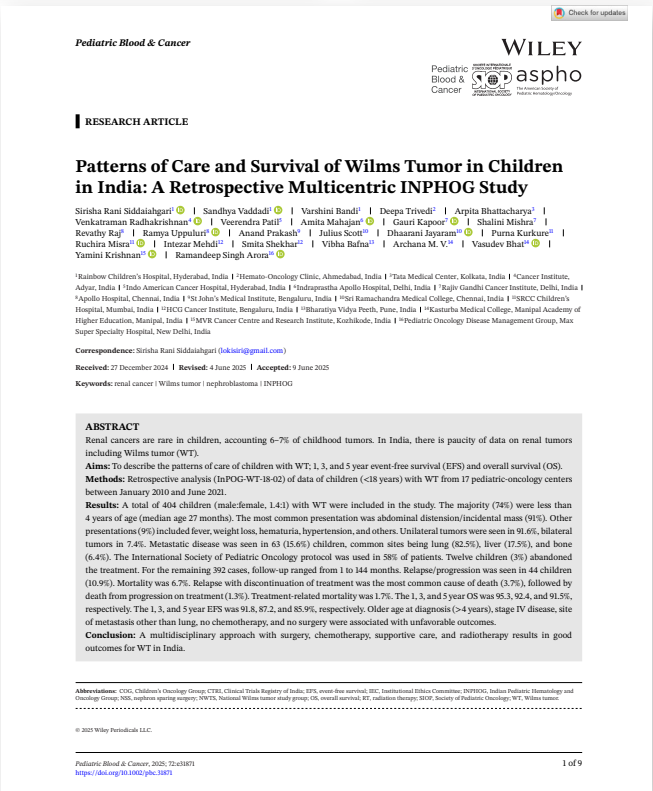

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RESEARCH ARTICLE

Patterns of Care and Survival of Wilms Tumor in Children in India: A Retrospective Multicentric INPHOG Study

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Keywords: renal cancer | Wilms tumor | nephroblastoma | INPHOG

ABSTRACT

Renal cancers are rare in children, accounting 6–7% of childhood tumors. In India, there is paucity of data on renal tumors including Wilms tumor (WT).

Aims: To describe the patterns of care of children with WT; 1, 3, and 5 year event-free survival (EFS) and overall survival (OS).

Methods: Retrospective analysis (InPOG-WT-18-02) of data of children (<18 years) with WT from 17 pediatric-oncology centers between January 2010 and June 2021.

Results: A total of 404 children (male:female, 1.4:1) with WT were included in the study. The majority (74%) were less than 4 years of age (median age 27 months). The most common presentation was abdominal distension/incidental mass (91%). Other presentations (9%) included fever, weight loss, hematuria, hypertension, and others. Unilateral tumors were seen in 91.6%, bilateral tumors in 7.4%. Metastatic disease was seen in 63 (15.6%) children, common sites being lung (82.5%), liver (17.5%), and bone (6.4%). The International Society of Pediatric Oncology protocol was used in 58% of patients. Twelve children (3%) abandoned the treatment. For the remaining 392 cases, follow-up ranged from 1 to 144 months. Relapse/progression was seen in 44 children (10.9%). Mortality was 6.7%. Relapse with discontinuation of treatment was the most common cause of death (3.7%), followed by death from progression on treatment (1.3%). Treatment-related mortality was 1.7%. The 1, 3, and 5 year OS was 95.3, 92.4, and 91.5%, respectively. The 1, 3, and 5 year EFS was 91.8, 87.2, and 85.9%, respectively. Older age at diagnosis (>4 years), stage IV disease, site of metastasis other than lung, no chemotherapy, and no surgery were associated with unfavorable outcomes.

Conclusion: A multidisciplinary approach with surgery, chemotherapy, supportive care, and radiotherapy results in good outcomes for WT in India.

Abbreviations: COG, Children's Oncology Group; CTRI, Clinical Trials Registry of India; EFS, event-free survival; IEC, Institutional Ethics Committee; INPHOG, Indian Pediatric Hematology and Oncology Group; NSS, nephron sparing surgery; NWTS, National Wilms tumor study group; OS, overall survival; RT, radiation therapy; SIOP, Society of Pediatric Oncology; WT, Wilms tumor.

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RESEARCH ARTICLE

Assessment of Barriers and Enablers for Implementing a Population-Based Childhood Cancer Registry in Chennai, India

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Keywords: cancer registry | epidemiology | pediatric cancer | population-based childhood cancer registry

ABSTRACT

Background: Despite most childhood cancer cases being diagnosed in low- and middle-income countries, there is a significant deficit of population-based childhood cancer registries (PBCCRs) in these regions. To address this critical gap, we established India's first dedicated PBCCR in Chennai on October 4, 2022, covering children aged 0–19. This study aims to identify the barriers and enablers to implementing the Chennai PBCCR.

Procedure: Between April 2023 and March 2024, a sequential explanatory mixed-method study was conducted across 10 of the 16 centers in Chennai that agreed to support the PBCCR. A total of 25 professionals agreed to participate in the quantitative phase utilizing a structured questionnaire. For the qualitative phase, in-depth interviews were conducted with 23 participants, including 16 from the quantitative phase, two stakeholders, and five caregivers. The interview guide was constructed, and the responses were analyzed using the Consolidated Framework for Implementation Research.

Results: Themes from the qualitative analysis revealed technological constraints, poor record-keeping, insufficient details captured in case records, and inadequate human resources as impediments. At the same time, factors such as knowledge, belief in sharing high-resolution data, the requirement and advantages of implementing a childhood cancer registry, professional self-efficacy, work infrastructure, and collaborative networks emerged as facilitators to the successful implementation of PBCCR.

Conclusion: Our experience and the findings of this study serve as a model for successfully implementing and operating PBCCRs in India and other countries. Registry data are vital to improving the understanding of childhood cancer burden and offer hope to children and their families.

Abbreviations: CFIR, Consolidated Framework for Implementation Research; EMR, electronic medical records; GICC, Global Initiative for Childhood Cancer; ICCC-3, International Classification of Childhood Cancer—version 3; ICMR, Indian Council of Medical Research; ICC-3, International Incidence of Childhood Cancer—version 3; LMICs, low- and middle-income countries; MMTR, Madras Metropolitan Tumor Registry; MRD, Medical Records Department; NGO, non-government organization; PBCCR, population-based childhood cancer registry; WHO, World Health Organization.

Nickhill Bhakta and Swaminathan Rajaraman are the joint senior authors.

Landscape of paediatric oncology clinical trials in Asia

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Summary

In this second paper of a Series on childhood cancer in Asia, we provide an overview on the Paediatric Oncology Clinical Trials in Asia. Asia with a population of 4.7 billion constitutes about 60% of the world's population. The continent accounts for about half of the global paediatric cancer burden. Many Asian countries have consequently formed national professional societies in childhood cancer. Multicentre clinical trials are pivotal in advancing survival outcomes in paediatric oncology. The continent's diverse socioeconomic conditions may account for significant disparities in the development of such trials. However some countries with good financial resources are

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Abbreviations: ALL, Acute Lymphoblastic Leukaemia; AML, Acute myelocytic leukaemia; APHOG, Asian Pediatric Hematology and Oncology Group; APL, Acute promyelocytic leukaemia; CCCG, Chinese Children Cancer Group; CCLG, Chinese Children Leukemia Group; GICC, Global Initiative for Childhood Cancer; HIC, High-Income countries; ICICLe, Indian Collaborative Childhood Leukaemia group; IIT, Investigator-initiated trials; INPHOG, Indian Paediatric Haematology Oncology Group; JCCG, Japan Children's Cancer Group; LIC, Low-income countries; LMIC, Lower Middle-income countries; MRD, Minimal residual disease; MCCT, Multicentre Clinical Trial; PHO, Pediatric Hemandology and Oncology Group; SCCOG, South China Children's Cancer Group; SIOP, International Society of Pediatric Oncology; UMIC, Upper middle-income countries; WHO, World Health Organization

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The impact of the SIOP Programme for advancing research capacity on global childhood cancer research

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Childhood cancer survival exceeds 80% in high-income countries (HICs) but remains far lower in many low- and middle-income countries (LMICs), where most affected children live and where little research occurs. Applying HIC protocols may lead to poorer outcomes in less well-resourced institutions, underscoring the need for context-specific evidence. Systemic barriers – fragile cooperative groups, underfunding, limited personnel, and regulatory complexity – further constrain LMIC research. To address this, the International Society of Paediatric Oncology (SIOP) launched the Programme for Advancing Research Capacity (PARC) in 2022, initially supporting cooperative groups in Latin America, Africa, and India. By strengthening infrastructure, training, and sustainability, PARC advances equitable paediatric oncology research and fosters long-term improvements in survival worldwide.

Addressing research disparities in childhood cancer

The survival gap

While significant progress has been made in childhood cancer, global outcomes remain markedly inequitable. In high-income countries (HICs), overall survival for children with cancer now exceeds 80% due to advancements made over the last 50 years through collaborative clinical trials and multidisciplinary care *(1)*. However, this success is not uniformly distributed. Childhood cancer survival rates in low- and middle-income countries (LMICs) are substantially lower, creating a major public health disparity. This profound imbalance is underscored by the paradox that over 90% of the world's children live in LMICs but less than 10% of childhood cancer research is conducted there *(2)*. This disproportionate allocation of research resources has resulted in a critical gap in locally relevant evidence, which is essential for developing, building up, and implementing effective treatment strategies.

The direct application of treatment protocols developed in HICs can lead to poorer outcomes in resource-limited settings *(3,4,5)*. A compelling example is the case of Burkitt lymphoma, where higher intensity chemotherapy regimens, which led to improved survival in HICs, resulted in unacceptable fatal toxicity when implemented in some LMICs *(4,5)*. This is often due to a higher proportion of patients presenting with advanced disease, as well as comorbidities such as malnutrition and chronic infections, and lower availability of intensive care support, which influence a patient's tolerance for intensive treatment. These outcomes highlight the critical need for context-adapted treatment protocols and the generation of local evidence for their clinical effectiveness *(6)*.

Systemic barriers to childhood cancer research

In LMICs, paediatric oncology research faces systemic barriers that go beyond clinical expertise. Because childhood cancers are rare, multicentre and often multinational collaborations are essential *(7)*. But cooperative groups in LMICs are typically fragile, underfunded, and unable to sustain long-term, high-quality research *(8,9)*. This financial instability is compounded

TESTIMONIALS

Mr. K Sarath Reddy

Founder & Chief Investment Officer
Unifi Capital Private Limited

INPHOG is building the research foundation every child with cancer deserves; strong data, shared learning, and nationwide collaboration. Their work brings science closer to hope, transforming how care is delivered. We are proud to support a mission that strengthens outcomes for children and look forward to the impact this partnership will shape.

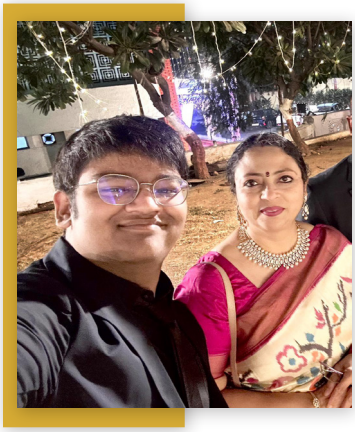
DR. Arpita Bhattacharyya

Senior Consultant Department of Paediatric Haematology Oncology
Tata Medical Center, Kolkata

Survival in childhood cancer has been one of the greatest contributions of the medical sciences to humankind. This has been possible through tireless laboratory research and clinical studies over the last six decades. Most of the progress has been in the high income countries until recently, but the need for quality research has been paramount in the low-middle income nations where the majority of these children belong.

Collaborative work and collective knowledge & experience is required for new ideas leading to new and better cures. InPHOG, over the last four years, has brought together clinicians and researchers in Paediatric Oncology from across the nation. As primary delegate of an INPHOG member institute, this collaboration has allowed us to be part of new cancer registries, new clinical trials and emergence of high-quality data. In the coming decades, InPHOG will continue to engage with the medical community for better and brighter horizons beyond India to the rest of the world.

TESTIMONIALS



Dr. Shalini Mishra & Mr. Shreyas Mishra

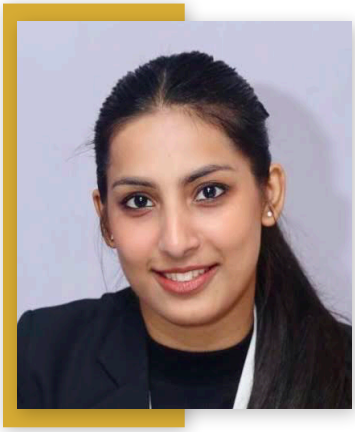
(Community Fundraisers & Supporters of INPHOG)

I see firsthand the impact INPHOG creates for children with cancer. This year, my son and I were proud to raise funds in support of their mission. Contributing together to a cause that brings hope and better care to families across India through research, has been truly meaningful. We're grateful to stand with INPHOG and continue supporting their incredible work.

Ms. Vinita Upadhyay

Volunteer

Being connected with INPHOG has been truly inspiring and fulfiling. Their dedication to advancing research in childhood blood cancers and other blood-related disorders reflects a deep commitment to improving children's lives. I'm proud to support an organisation doing such meaningful work.



Ms. Tanya Dhawan

Research Manager

Working with INPHOG as a Research Manager has been a truly fulfilling experience. INPHOG's strong collaborative research ecosystem, focus on quality multicenter studies, capacity building, and system strengthening has enabled meaningful contributions to pediatric oncology research in India. I'm proud to be part of an organization committed to equitable, evidence-based care and setting benchmarks in collaborative childhood cancer research.

Ms. Khushi Jha

Clinical Research Co-ordinator

Research begins with a question and ends with impact. On this Annual Day, we celebrate the passion, precision, and purpose that define our journey. United by ethics and innovation, we continue to turn data into discovery and discovery into meaningful change for patients and society. As a CRC, my role is to ensure that every study is conducted with integrity, accuracy, and patient safety at its core, bridging science and care.

CONNECTING WITH INPHOG

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