

**NEWSLETTER
DEC 2024**

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Amita Mahajan
Revathy Raj
Gauri Kapoor

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NBL	Yamini Krishnan
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Renal	Shalini Mishra
Liver	Vimal Kumar
PNET	Vasudev Bhat
Osteo	Akshay Tiwari
STS	Reghu KS
GCT & Rare	Sonali Mohapatra
HSCT	Ponni Sivaprakasan
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Can Genetics	Badira CP
Cell & Gene	Gaurav Narula
Hbpathy/RBC	Bhavna Dhingra
Plat & Coag	V Bharadwaj
BM Failure	Mukul Agarwal

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Milestone Achieved: 20,000 Patients Recruited

20,388

We are delighted to share that we have surpassed the milestone of recruiting over 20,388 patients across our studies! This milestone is a testament to the dedication of our member institutions, researchers, and CRCs. Together, we continue to pave the way for a brighter future in pediatric cancer care and research.

This accomplishment underscores our commitment to improving outcomes for children with cancer and hematological disorders in India.

CSR REGISTRATION

We are proud to share that INPHOG has achieved another significant milestone by obtaining the **CSR (Corporate Social Responsibility) certificate**. This accomplishment reinforces our commitment to making a meaningful impact in pediatric hematology oncology research and care. With this certification, we are better positioned to collaborate with corporate partners and enhance our initiatives to improve outcomes for children across India.



GOVERNMENT OF INDIA
MINISTRY OF CORPORATE AFFAIRS
OFFICE OF THE REGISTRAR OF COMPANIES

Dated : 25-11-2024

NOTE - THIS LETTER IS ONLY AN APPROVAL FOR REGISTRATION OF THE ENTITIES FOR UNDERTAKING CSR ACTIVITIES.

To,
INPHOG RESEARCH FOUNDATION , B-181, Raheja Atlantis, Sector
31, Gurgaon, Gurgaon, Haryana, 122001

PAN : AAGCI4622R

Subject: In Reference to Registration of Entities for undertaking CSR activities

Reference: Your application dated 25-11-2024 (SRN-N19521608)



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MEMBERSHIP UPDATE

NEW MEMBER INSTITUTION



**NSCB Medical College
Jabalpur**



**Kidwai Memorial Institute
Bengaluru**



**Little Stars & She
Hospital Hyderabad**

INPHOG STAFF

Today, our company employs fifteen members: one research manager, one communication manager, 12 clinical research coordinators, and one HR professional.

CRC Name	Centre Name	Designation
Nichila Mary Philip	Cancer Institute, Adyar	Clinical Research Coordinator
Shikha Kumari	AIIMS Hospital, New Delhi	Clinical Research Coordinator
Nisha Kumari	Safdarjung Hospital	Clinical Research Coordinator
Khushi Jha	Rajiv Gandhi Cancer Institute, New Delhi	Clinical Research Coordinator
Aishwarya Siddhi	DMC Hospital, Ludhiana, Punjab	Clinical Research Coordinator
Anjana Joseph	MVR Cancer Research Institute, Kozhikode	Clinical Research Coordinator
Kenson Alex	St Johns Medical College Hospital	Clinical Research Coordinator
Sandhiya	Apollo Chennai	Clinical Research Coordinator
Rwiti Clara Biswas	TMC, Kolkata	Clinical Research Coordinator
Mohammad Ashraf Rather	SKIMS, Srinagar	Clinical Research Coordinator
Peketi Sai Soumya	Indo-American Cancer Hospital, Hyderabad	Clinical Research Coordinator
Usmaan	King George Medical University, Lucknow	Clinical Research Coordinator
Aishwarya Nair*	TMH, Mumbai	Clinical Research Coordinator
Kulvant Singh*	HBCH, Varanasi	Clinical Research Coordinator
Malobika Deb*	BBCI, Guwahati	Clinical Research Coordinator

*Hired by Tata Memorial Hospital



STAFF TRAINING

We are pleased to share that a two-day training and discussion meeting for all INPHOG CRCs working on the C2S study was successfully held on August 2–3, 2024, at AIIMS, New Delhi.

The first day of the training meeting was held at the INPHOG office, where the focus was on CRF training, and technical challenges related to the Resonance software were addressed.



The second day, held on August 3, 2024, at AIIMS, New Delhi, was dedicated to discussing the status and preliminary results of Phase I of the C2S study.

This two-day meeting was a significant step forward in advancing the C2S study, and we appreciate the active participation of all CRCs in making it a success!



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We are also excited to announce our upcoming annual meeting in January 2025, to be held in Chennai. Stay tuned for more details!

TECHNICAL ADVISORS

We are delighted to welcome Dr. Durga, Research Consultant at Tata Memorial Centre, Homi Bhabha National Institute, Mumbai, as a new technical advisor to INPHOG.

With extensive expertise and experience in the research field, Dr. Durga's mentorship will be invaluable in guiding our efforts.



INPHOG Presentations

INPHOG STUDIES in PHOCON 2024



INPHOG-RARE-17-01 Clinical Course, Pathological Spectrum and Outcomes in Paediatric Rare Tumours in India: A Multicentric Observational Study



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<https://www.linkedin.com/in/inphog/>

INPHOG STUDIES in PHOCON 2024



INPHOG-RB-19-01 A Prospective Collaborative Study for Newly Diagnosed Patients with Retinoblastoma



InPOG-LE-16-01 Retrospective Cohort Study of Late Effects in Long-term Survivors of Childhood Hodgkin Lymphoma

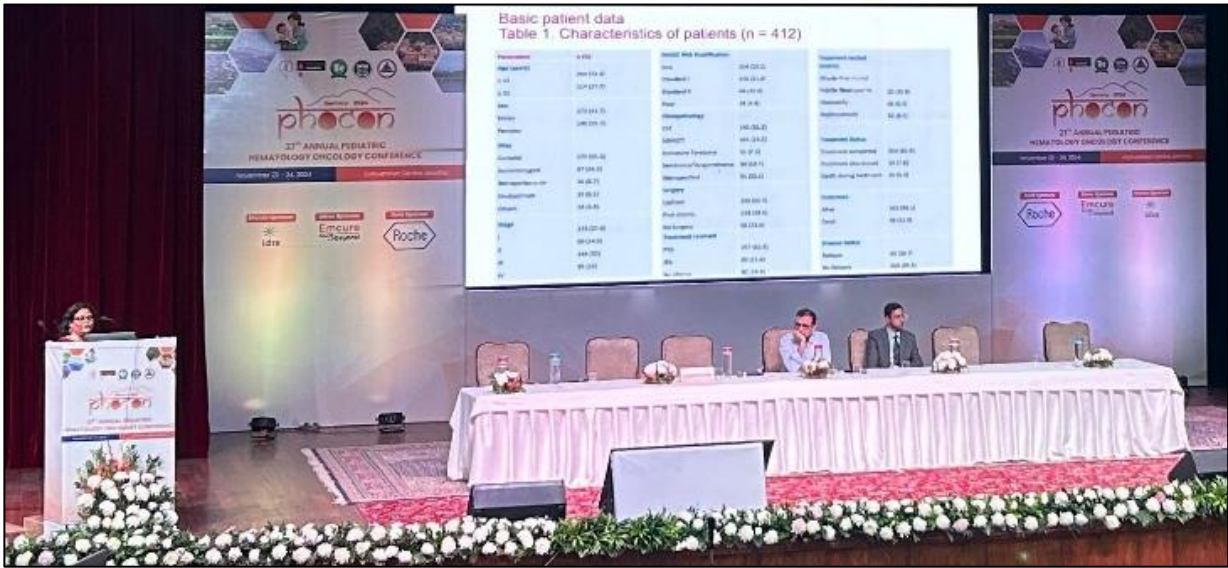

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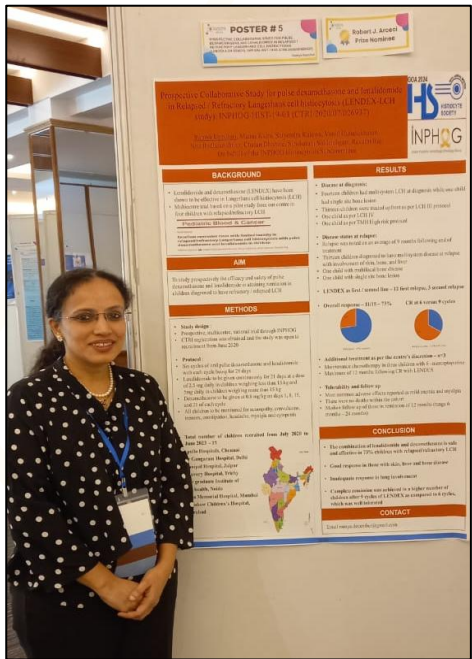
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INPHOG STUDIES in PHOCON 2024



INPHOG-GCT-22-01 Integrated Clinico-pathological and Treatment Outcome Analysis of extra-cranial Malignant Germ Cell Tumors in Children and Adolescents in India

INPHOG Study Awards



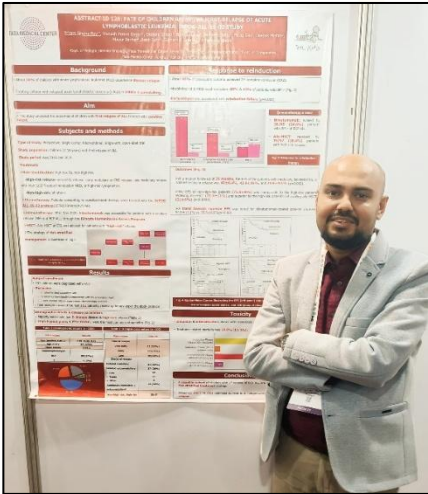
We are thrilled to share that Dr. Ramya, an esteemed member of INPHOG, received a prestigious award for her outstanding research on histiocytic disorders. Her **InPOG-HIST-19-03 (LENDEX-LCH study)** study was recognized for its significant contribution to the field and was honored during her presentation at the 40th Annual Meeting of the Histiocyte Society in Nov 2024.

Congratulations to Dr. Ramya for this well-deserved recognition!



Also, we are delighted to announce that Dr. Pritam and Dr. Prag Das received recognition at PHOCON for their outstanding work on the INPHOG ALL studies. Their contributions were honored with a special award, highlighting the impact of collaborative research in advancing pediatric hematology oncology.

Congratulations to both for this remarkable achievement!



InPOG-ALL-19-02 Fate of children after the first relapse of acute lymphoblastic leukemia: InPOG-ALL-19-02 study and the **InPOG-ALL-15-01** presentation on a shorter induction corticosteroid reduces acute lymphoblastic leukemia induction deaths in the icicle-all-14 randomized trial



Subcommittee	Provisional Registration (7)	Full Registration (4)	Recruitment Ongoing (12)	Recruitment Complete (21)
ALL			InPOG-ALL-19-02 INPHOG-ALL-24-03	InPOG-ALL-15-01
AML			INPHOG-AML-23-02	INPOG-AML-16-01
Ch Myelop				InPOG-CML-16-01
HL			InPOG-HL-19-03 INPHOG-HL-24-04	InPOG-HL-15-01 InPOG-HL-17-02
NHL	INPHOG-NHL-PROV-01		INPHOG -NHL-24-01	InPOG-NHL-16-01
Histiocytosis			INPHOG-HIST-24-04	InPOG-HIST-17-01 InPOG-HIST-19-03
CNS		INPHOG-CNS-24-01		
Neuroblastoma	INPHOG-NB-PROV-01	InPOG-NB-23-02		InPOG-NB-18-01
Retinoblastoma				InPOG-RB-19-01
Renal				InPOG-WT-18-02
Liver				
Osteosarcoma			INPHOG-OST-23-01	
PNET				InPOG-PNET-16-01 InPOG-PNET-19-02
STS				
Germ Cell Tum			INPHOG-GCT-22-01	
Rare, Epithelial				InPOG-RARE-17-01 InPOG-RARE-17-02
HSCT	InPOG-SCT-20-02			
Access to Care				InPOG-ACC-16-01 InPOG-ACC-16-03 InPOG-ACC-16-02 InPOG-ACC-20-04
Supportive Care	INPHOG-SUPP-PROV-01	INPHOG-SUPP-23-04	INPHOG-SUPP-22-03	
Epidemiology		INPHOG-EPI-24-04	INPHOG-EPI-22-03	InPOG-EPI-20-02
Late Effects			InPOG-LE-16-01	
Palliative Care	INPHOG-PALL-PROV-01			InPOG-PALL-18-01
Cancer Genetics				
Hbpathy/RBC	INPHOG-RBC-22-01			
Plat & Coag				
BM Failure	INPHOG-BMF-PROV-01			



INPHOG Studies - Recruitment Complete (21)

InPOG-HL-15-01

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

Principal Investigator
Registered with INPHOG
CTRI Registration
Patients recruited
Recruitment Closed
Centers study open in

Prof Jagdish Chandra
 June 2015
 CTRI/2016/03/010916
 410
 February 2018
 27 centers

Publications

- Arora RS, Mahajan A, Dinand V, Kalra M, Jain S, Taluja A, Mandal P, Chandra J. InPOG-HL-15-01 - Challenges and Lessons Learnt in Setting up the First Collaborative Multicenter Prospective Clinical Trial in Childhood Cancer in India. Pediatric Hematology Oncology J 2020. Oct 1;5(4):166-70.
- Mahajan A, Singh M, Bakhshi S, Jain S, Seth R, Verma N, Kumar A, Radhakrishnan V, Mandal P, Kapoor G, Arora RS, Dinand V, Kalra M, Sharma A, Phulkar S, Arora A, Chandra J. Treating Early-Stage Hodgkin Lymphoma in resource-limited settings: InPOG-HL-15-01 Experience. Pediatric Blood & Cancer. 2021 Jul 22: e29219.
- Jain S, Bakhshi S, Seth R, Verma N, Singh M, Mahajan A, Radhakrishnan V, Mandal P, Arora RS, Dinand V, Kalra M, Sharma A, Chandra J. Risk-based and response adapted radiation therapy for children and adolescents with newly diagnosed advanced Hodgkin lymphoma treated with ABVD chemotherapy: A report from the Indian Pediatric Oncology Group study InPOG-HL-15-01. Leuk Lymphoma 2021 Dec 9:1-8
- Mahajan A, Bakhshi S, Singh M, Seth R, Verma N, Jain S, Radhakrishnan V, Mandal P, Arora RS, Dinand V, Kalra M, Kapoor G, Sajid M, Kumar R, Mallick S, Taluja A, Chandra J. Empirical antitubercular treatment for lymphadenopathy: Are we missing lymphoma? Indian J Pediatr. 2022 Jun 23.
- Mahajan A, Bakhshi S, Seth R, Verma N, Mandal P, Singh M, Jain S, Radhakrishnan V, Kanvinde S, Arora RS, Dinand V, Kalra M, Taluja A, Mallick S, Kumar R, Chandra J. Hodgkin lymphoma in children under 5 years: Do they behave differently? J Pediatr Hematol Oncol. 2022 May 1;44(4):186-190.
- Kalra M, Bakshi S, Singh M, Seth R, Verma N, Jain S, Radhakrishnan V, Mandal P, Mahajan A, Arora RS, Dinand V, Kapoor G, Sajid M, Kumar R, Taluja A, Mallick S, Chandra J. Response assessment with Positron Emission Tomography-Computed tomography as compared with contrast-enhanced computed tomography in Childhood Hodgkin Lymphoma can reduce the need for radiotherapy in low- and middle-income countries. Pediatr Blood cancer 2022; e 30091.
- Banwait DK, Arora PR, Mahajan A, Dinand V, Jain S, Kalra M, Chandra J, Arora RS. Barriers to Accessing Fertility Preservation in Adolescents with Hodgkin Lymphoma in India. Pediatr Hematol Oncol. 2023 Jun 2:1-6.



InPOG NHL-16-01**A Retrospective Multi-Centric Study of Contemporary Epidemiology & Outcome of Childhood B-NHL in India**

Principal Investigator	Dr Amita Trehan
Registered with INPHOG	October 2016
CTRI Registration	No
Patients recruited	323
Recruitment Closed	April 2018
Centers study open in	09 centers

Publications

- Rahiman EA, Bakhshi S, Deepam Pushpam, Ramamoorthy J, Das A, Ghara N, Kalra M, Kapoor G, Meena JP, Siddaigarhi S, Thulkar S, Sharma MC, Srinivasan R, Trehan A. Outcome and prognostic factors in childhood B non-Hodgkin lymphoma from India: Report by the Indian Pediatric Oncology Group (InPOG-NHL-16-01 study). *Pediatr Hematol Oncol*. 2022 Jan 3:1-15.

InPOG-ACC-16-01**Multi-site Prospective Study to Determine Household Out-of-Pocket Expenditure Incurred by Families of Children Newly Diagnosed with Cancer in India (HOPE Study)**

Principal Investigator	Dr Ramandeep Singh Arora
Registered with INPHOG	August 2016
CTRI Registration	CTRI/2016/11/007492
Patients recruited	402
Recruitment Closed	November 2017
Centers study open in	15 centers

InPOG-ACC-16-03**Exploring Barriers and Enablers to Accessing Care for Childhood Cancers in India: A Multicenter Qualitative Study**

Principal Investigator	Dr Ramandeep Singh Arora
Registered with INPHOG	May 2017
CTRI Registration	No
Patients recruited	34 patients + 27 healthcare
Recruitment Closed	January 2018
Centers study open in	7 centers

Publications

- Faruqui N, Joshi R, Martiniuk A, Lowe J, Arora R, Anis H, Kalra M, Bakhshi S, Mishra A, Santa A, Sinha S, Siddaiahgari S, Seth R, Bernays S. A health care labyrinth: perspectives of caregivers on the journey to accessing timely cancer diagnosis and treatment for children in India. *BMC Public Health*. 2019 Dec 2;19(1):1613.
- Faruqui N, Bernays S, Martiniuk A, Abimbola S, Arora R, Lowe J, Denburg A, Joshi R, Access to care for childhood cancers in India: perspectives of health care providers and the implications for Universal Health Coverage. *BMC Public Health* 2020 Dec;20(1):1-1.



InPOG-PNET-16-01

Evaluation of clinicopathological characteristics, prognostic factors, and treatment outcomes in patients with PNET of Kidney: An InPOG study

Principal Investigator	Dr Bivas Biswas
Registered with INPHOG	June 2016
CTRI Registration	No
Patients recruited	40
Recruitment Closed	August 2018
Centers study open in	2 centers

InPOG-CML-16-01

Study of treatment and outcome of chronic myeloid leukemia in children and adolescents in India

Principal Investigator	Prof Deepak Bansal
Registered with INPHOG	Feb 2018
CTRI Registration	No
Patients recruited	171
Recruitment Closed	January 2019
Centers study open in	9 centers

InPOG-AML-16-01

Randomized Phase III Study Comparing DA (3+7) Versus ADE as Induction Chemotherapy in Children with Acute Myeloid Leukemia

Principal Investigator	Dr Venkatraman Radhakrishnan
Registered with INPHOG	April 2016
CTRI Registration	CTRI/2014/11/005202
Patients recruited	150
Recruitment Closed	Nov 2019
Centers study open in	5 centers

Publications

- Radhakrishnan V, Bakhshi S, Kayal S, Thampy C, Batra A, Shenoy PK, Kumar H, Rajaraman S, Chaudhary S, Bisht R, Dubashi B, Ganesan TS. Two-drug versus three-drug induction chemotherapy in pediatric acute myeloid leukemia: a randomized controlled trial. Blood Cancer J. 2022 Sep 6;12(9):131. doi: 10.1038/s41408-022-00726-1. Erratum in: Blood Cancer J. 2022 Sep 27;12(9):139. PMID: 36068213; PMCID: PMC9444698



InPOG-HIST-17-01**Indian Hemophagocytic Lymphohistiocytosis Registry (I-HLH): Establishment of a nationwide prospective web-based registry for patients diagnosed with HLH**

Principal Investigator	Dr Mukesh Desai
Registered with INPHOG	July 2017
CTRI Registration	Not done
Patients recruited	20
Recruitment Closed	Feb 2021
Centers study open in	8 centers

InPOG-ACC-16-02**Accessing Childhood Cancer ServiceS in INDIA (ACCESS INDIA)**

Principal Investigator	Dr Ramandeep Singh Arora
Registered with INPHOG	Sep 2018
CTRI Registration	Not done
Patients recruited	2850
Recruitment Closed	Feb 2021
Centers study open in	71 centers

InPOG-ACC-20-04**The Impact of COVID-19 Pandemic on the care of children with cancer in India**

Principal Investigator	Dr Ramandeep Arora
Registered with INPHOG	May 2020
CTRI Registration	CTRI/2020/05/025219
Patients recruited	1146
Recruitment Closed	Feb 2021
Centers study open in	30 centers

Publications

- Sharma J, Mahajan A, Bakhshi S, Patil V, Verma N, Radhakrishnan V, Singh A, Kayal S, Seth R, Pushpam D, Arora RS. The impact of COVID-19 pandemic on access to treatment for children with cancer in India and treating center practices. Cancer. 2022 Feb 1;128(3),579-86.

InPOG-ALL-15-01**An Indian Childhood Collaborative Leukemia Group multicentre national standardization study for newly diagnosed acute lymphoblastic leukemia**

Principal Investigator	Prof Vaskar Saha
Registered with INPHOG	July 2015
CTRI Registration	CTRI/2015/12/006434
Patients recruited	2516
Recruitment Closed	Aug 2022
Centers study open in	5 centers



Publications

- Das N, Banavali S, Bakhshi S, Trehan A, Radhakrishnan V, Seth R, Arora B, Narula G, Sinha S, Roy P, Gogoi MP, Chatterjee S, Abraham B, Das P, Saha V, Krishnan S. Protocol for ICiCle-ALL-14 (InPOG-ALL-15-01): a prospective, risk stratified, randomized, multicentre, open label, controlled therapeutic trial for newly diagnosed childhood acute lymphoblastic leukemia in India. Trials. 2022 Jan 31;23(1):102.

InPOG-HL-17-02**Prospective Collaborative Study for Relapsed/Refractory Hodgkin Lymphoma**

Principal Investigator
Registered with INPHOG
CTRI Registration
Patients recruited
Recruitment Closed
Centers study open in

Dr Amita Mahajan
 May 2018
 Ref/2019/03/024719
 69
 SEP 2023
 13 centers

InPOG-NB-18-01**India Neuroblastoma Registration and Biology Study**

Principal Investigator
Registered with INPHOG
CTRI Registration
Patients recruited
Recruitment Closed
Centers study open in

Dr Vikramjit Kanwar
 Nov 2018
 CTRI/2020/01/023088
 311
 SEP 2023
 13 centers

InPOG-EPI-20-02**Indian COVID-19 Childhood Cancer Registry**

Principal Investigator
Registered with INPHOG
CTRI Registration
Patients recruited
Recruitment Closed
Centers study open in

Dr. Revathi Raj
 May 2020
 CTRI/2020/05/025221
 659
 JUL 2023
 37 centers

Publications

- Raj R, Uppuluri R, Parambil B, Dhariwal N, Totadri S, Mathew LG, Radhakrishnan V, Charan A, Yadav SP, Mahajan A, Mudaliar S. Outcomes of COVID-19 in children with cancer–Report from the Indian Pediatric Oncology Group (InPOG) COVID-19 registry in India. Pediatric Hematology Oncology Journal. 2022 Jun 1;7(2):34-7.



InPOG-PALL-18-01

Patterns of End-Of-Life Care in Children with Cancer in India – A Multicentre Retrospective Study

Principal Investigator	Dr Gayatri Palat
Registered with INPHOG	Sep 2020
CTRI Registration	CTRI/2020/12/029960
Patients recruited	384
Recruitment Closed	JUL 2023
Centers study open in	17 centers

InPOG-WT-18-02

Pattern of care and survival of renal tumors in children in India - Multi-center study

Principal Investigator	Dr. Sirisharani Siddaiahgari
Registered with INPHOG	Apr 2020
CTRI Registration	CTRI/2021/01/030770
Patients recruited	443
Recruitment Closed	JUL 2023
Centers study open in	17 centers

InPOG-HIST-19-03

Prospective Collaborative Study for Pulse Dexamethasone and Lenalidomide in Relapsed / Refractory Langerhans Cell Histiocytosis (LENDEX-LCH study)

Principal Investigator	Dr Ramya Uppuluri
Registered with INPHOG	Aug 2019
CTRI Registration	CTRI/2020/07/026937
Patients recruited	15
Recruitment Closed	DEC 2023
Centers study open in	07

InPOG-RARE-17-02

Indian Childhood Advanced Nasopharyngeal Carcinoma Study (ICANaPS) A multicenter, prospective, pilot study on the use of platinum-based chemotherapy for pediatric nasopharyngeal carcinoma and exploration of the role of plasma Epstein-Barr virus (EBV)- DNA PCR titers in predicting relapse

Principal Investigator	Dr Reghu
Registered with INPHOG	October 2018
CTRI Registration	
Recruitment commenced	Yes
Patients recruited	2
Centers study open in	1



InPOG-RARE-17-01

Clinical Course, Pathological Spectrum and Outcomes in Paediatric Rare Tumours in India: A Multicentric Observational Study

Principal Investigator	Dr Maya Prasad
Registered with INPHOG	July 2017
CTRI Registration	CTRI/2019/02/017851
Recruitment commenced	Yes
Patients recruited	384
Centers study open in	10 centers

InPOG-PNET-19-02

Evaluation of clinic-pathological characteristics, prognostic factors, and treatment outcomes in patients with ESFT in children and young adults.

Principal Investigator	Dr Sandeep Jain
Registered with INPHOG	May 2021
CTRI Registration	Applied for
Recruitment commenced	Yes
Patients recruited	1600
Centers study open in	09

InPOG-RB-19-01

A Prospective Collaborative Study for Newly Diagnosed Patients with Retinoblastoma

Principal Investigator	Dr Santosh Honavar
Registered with INPHOG	Sep 2019
CTRI Registration	CTRI/2020/09/027846
Recruitment commenced	Yes
Patients recruited	1120
Centers study open in	20



INPHOG Studies - Recruitment Ongoing (12)

InPOG-LE-16-01

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

Principal Investigator	Dr Rachna Seth
Registered with INPHOG	May 2016
CTRI Registration	Not done
Recruitment commenced	June 2016
Currently, patients recruited	4682
Target patient recruitment	At least 500 (desirable 1000)
Anticipated duration of recruitment	5 years (Project extended till 2030)
Centers study open in	26 centers

- All India Institute of Medical Sciences, New Delhi
- AIIMS, Jodhpur
- Apollo Hospital, Chennai
- AIIMS, Bhubaneswar, **New**
- Banaras Hindu University, Varanasi
- BJ Wadia Hospital, Mumbai, **New**
- Cancer Institute, Adyar Chennai
- DMC, Ludhiana, **New**
- Indraprastha Apollo Hospital, New Delhi
- Indo-American Cancer Hospital and Research Institute, **New**
- Kalawati Saran Children's Hospital, New Delhi
- Kidwai Memorial Institute, Bangalore
- King George's Medical University, Lucknow
- Kasturba Medical College, Manipal
- Max Super Specialty Hospital, Patparganj, New Delhi
- Max Super Specialty Hospital, Saket, New Delhi
- MVR Cancer Centre and Research Institute
- Post Graduate Institute of Child Health, Noida
- Rainbow Children's Hospital, Hyderabad
- Rajiv Gandhi Cancer Institute, New Delhi
- Regional Cancer Centre, Thiruvananthapuram
- RML Hospital, New Delhi, **New**
- Safdarjung Hospital, New Delhi
- SION Hospital, Mumbai
- Tata Medical Centre, Kolkata
- Tata Memorial Hospital, Mumbai



InPOG-ALL-19-02**Registry study for relapsed childhood acute lymphoblastic leukemia using protocol ALL-R1.**

Principal Investigator	Vaskar Saha
Registered with INPHOG	Jun 2019
CTRI Registration	CTRI/2019/10/021758
Recruitment commenced	Yes
Currently, patients recruited	102
Target patient recruitment	220
Anticipated duration of recruitment	5 years
Centers study open in	1

- Tata Medical Centre, Kolkata

InPOG-HL-19-03**Response-adapted management of Childhood Classical Hodgkin Lymphoma (cHL) and Early Response Assessment by Positron Emission and Computerized Tomography (PET-CT) to allow Omission of Radiotherapy in Indian Children Treated with a Standard of Care Intensified Chemotherapy Regimen.**

Principal Investigator	Dr Gaurav Narula
Registered with INPHOG	Feb 2020
CTRI Registration	CTRI/2020/08/027495
Recruitment commenced	Yes
Currently, patients recruited	277
Target patient recruitment	1500
Anticipated duration of recruitment	5 years
Centers study open in	10

- Apollo Cancer Centre, Chennai
- Bai Jerbai Wadia Hospital, Mumbai
- Cancer Institute (W.I.A) Adyar, Chennai
- Homi Bhabha Cancer Hospital, Varanasi
- Indraprastha Apollo Hospital, Delhi
- Kasturba Medical College, Manipal
- Max Super Specialty Hospital, Saket, New Delhi
- Malabar Cancer Center, Kerala
- Rajiv Gandhi Cancer Institute & Research center, Delhi
- Tata Memorial Hospital, Mumbai



INPHOG-SUPP-22-03

Anti-Emetic Prophylaxis for Chemotherapy-Induced Vomiting Without Dexamethasone for Children and Adolescents Receiving Highly Emetogenic Chemotherapy: Investigator-Initiated, Open-Label, Multi-Center, Non-Inferiority, Phase III Randomized Controlled Trial

Principal Investigator	Dr Venkatraman Radhakrishnan
Registered with INPHOG	June 2022
CTRI Registration	CTRI/2022/08/045009
Recruitment commenced	No
Currently, patients recruited	193
Target patient recruitment	300
Anticipated duration of recruitment	3 years
Centers study open in	5

- AIIMS, New Delhi
- Apollo Hospital, New Delhi
- Cancer Institute, Chennai
- JIPMER, Puducherry
- Max Hospital, New Delhi

INPHOG-GCT-22-01

Integrated Clinico-pathological and treatment outcome analysis of extra-cranial malignant germ cell tumors in children and adolescents in India.

Principal Investigator	Dr Sonali Mohapatra
Registered with INPHOG	March 2023
CTRI Registration	Applied For
Recruitment commenced	Yes
Currently, patients recruited	380
Target patient recruitment	400-500
Anticipated duration of recruitment	18 Months
Centers study open in	17

- AIIMS Bhuvneshwar
- AIIMS, Bhopal
- AIIMS, New Delhi
- Apollo, Chennai
- BHU, Varanasi
- Cancer Institute (WIA), Adyar
- Dayanand Medical College & Hospital, Ludhiana
- Indraprastha Apollo Hospitals, New Delhi
- Kasturba Medical College, Manipal
- KGMU, Lucknow
- MVR Cancer Centre, Kozhikode
- Rajiv Gandhi Cancer Institute & Research Center, Delhi



- Rainbow Children's Hospital, Hyderabad
- SKIMs, Jammu and Kashmir
- St Johns Medical College Hospital, Bangalore
- SGRH, New Delhi
- Tata Medical Centre, Kolkata

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.

Principal Investigator	Dr Venkatraman Radhakrishnan
Registered with INPHOG	Sep 2022
CTRI Registration	CTRI/2022/06/043526
Recruitment commenced	Sep 2022
Currently, patients recruited	630
Target patient recruitment	1000
Anticipated duration of recruitment	Continuous
Centers study open in	18

- Apollo Specialty Hospital, Chennai
- Cancer Institute (WIA), Adyar
- Dr. Rela Hospital, Chennai
- Dr. Mehta's Hospital, Chennai
- Global Hospital, Chennai
- ICH Government Hospital, Chennai
- Kauvary Hospital, Chennai
- Kanji Kamakoti Child Trust Hospital, Chennai
- Kumaran Hospital, Chennai
- Rajiv Gandhi Government Hospital, Chennai
- Rainbow Children's Hospital
- Royappa Pettah Government Hospital, Chennai
- Sankara Nethralaya Eye Hospital, Chennai
- SIMS Hospital Chennai
- Sri Ramachandra Medical Centre, Chennai
- Standely Government Hospital, Chennai
- Tamil Nadu Multispecialty Hospital, Chennai
- VS Hospital Chennai

INPHOG-AML-23-02

Indian Childhood Acute Promyelocytic Leukemia Study (I-CHAMPs)

Principal Investigator	Dr Smita Kayal
Registered with INPHOG	March 2023
CTRI Registration	CTRI/2024/04/065353



Recruitment commenced	March 2024
Currently, patients recruited	25 (Retrospective)
Target patient recruitment	100-200 Annually
Anticipated duration of recruitment	6 years
Centers study open in	13

- AIIMS, New Delhi
- Apollo Hospital, New Delhi
- Apollo Specialty Hospital, Chennai - **New**
- ABVIMS & Dr RML Hospital, New Delhi
- Cancer Institute (WIA) Adyar, Chennai- **New**
- Dayanand Medical College & Hospital, Ludhiana
- Dr. Bhubaneswar Borooah Cancer Institute
- JIPMER, Puducherry
- KGMU, Lucknow
- MVR Cancer Centre and Research Institute, Kozhikode
- Postgraduate Institute of Child Health, Noida
- St Johns Medical College Hospital- **New**
- Safdarjung Hospital, New Delhi- **New**

IMSOS OS 01/INPHOG -OST-23-01- **New**

Evaluation of Clinicopathological characteristics, prognostic factors, and treatment outcomes in patients with osteosarcoma in children and adults treated in India"

Principal Investigator	Dr Akshay Tiwari
Registered with INPHOG	OCT 2023
CTRI Registration	CTRI/2023/05/053100
Recruitment commenced	Yes
Currently, patients recruited	622
Target patient recruitment	Not specified
Anticipated duration of recruitment	10 years
Centers study open in	07

- AIIMS, New Delhi
- KGMU, Lucknow
- Apollo Hospital, New Delhi
- Bai Jerbai Wadia Hospital, Mumbai
- TMC, Kolkata
- Dayanand Medical College & Hospital, Ludhiana
- V Care Hospital



INPHOG-ALL-24-03- **New**
**Improving Survival in Childhood Acute Lymphoblastic Leukemia in India (ISCALL):
 ICICLE Implementation Study."**

Principal Investigator	Dr Venkatraman Radhakrishnan
Registered with INPHOG	Apr 2024
CTRI Registration	CTRI/2023/12/060828
Recruitment commenced	May 2024
Currently, patients recruited	421
Target patient recruitment	-6300
Anticipated duration of recruitment	3 years
Centers study open in	27

- AIIMS, Bhopal
- AIIMS, New Delhi
- AIIMS, Jodhpur
- AIIMS, Bhatinda
- AIIMS Rishikesh
- AIIMS Nagpur
- AIIMS Bhuvaneswar
- AIIMS, Pediatrics, New Delhi
- Cancer Institute (WIA) Adyar, Chennai
- Dr. Bhubaneswar Borooah Cancer Institute, Guwahati
- Govt. Medical College Jammu
- Government Medical College, Aurangabad
- Homi Bhabha Cancer Hospital, Varanasi
- Homi Bhabha Cancer Hospital and Research Centre, Visakhapatnam
- Jawaharlal Institute of Postgraduate Medical Education & Research, Puducherry
- Lady Hardinge Medical College & Kalawati Children's Hospital, New Delhi
- National Cancer Institute, AIIMS- Jhajjar Campus
- Nizam's Institute of Medical Sciences, Hyderabad
- PGIMER, Chandigarh
- PGIMS Rohtak
- Regional Cancer Centre, Trivandrum
- St. John's Hospital, Bengaluru
- Safdarjung Hospital and VMMC, New Delhi
- Tata Memorial Centre, Mumbai
- Tata Medical Center, Kolkata
- Vardhman Mahaveer Medical College & Safdarjung hospital, New Delhi



InPOG-HL-24-04- **New****Immunotherapeutic strategies in children and adolescents with Hodgkin lymphoma**

Principal Investigator	Dr Amita Mahajan
Registered with INPHOG	Mar 2024
CTRI Registration	CTRI/2024/11/076407
Recruitment commenced	Yes
Currently, patients recruited	07
Target patient recruitment	Not specified
Anticipated duration of recruitment	6 years
Centers study open in	04

- Apollo Hospital, New Delhi
- Apollo Specialty Hospital, Chennai
- Rajiv Gandhi Cancer Institute Delhi
- SKIMS, Jammu & Kashmir

INPHOG-HIST-24-04 - **New****A multicenter, retrospective study on demography, presentation, treatment, and outcome of Langerhans cell histiocytosis in India**

Principal Investigator	Dr Ramya Uppuluri
Registered with INPHOG	AUG 2024
CTRI Registration	CTRI/2024/12/077952
Recruitment commenced	Yes
Currently, patients recruited	NA
Target patient recruitment	150
Anticipated duration of recruitment	10 years
Centers study open in	NA

INPHOG-NHL-24-01- **New****A prospective multi-centric study on practice, clinical outcomes, and toxicities in children with mature B-cell non-Hodgkin lymphoma treated with a Rituximab-based chemotherapy regimen**

Principal Investigator	Dr Nirmalya Roy Moulik
Registered with INPHOG	AUG 2024
CTRI Registration	CTRI/2024/12/078641
Recruitment commenced	No
Currently, patients recruited	NA
Target patient recruitment	150
Anticipated duration of recruitment	3 years
Centers study open in	NA



INPHOG Studies Granted Full Registration (4)

InPOG-NB-23-02- **New****Indian Non-high Risk Neuroblastoma Study**

Principal Investigator	Dr Yamini Krishnan
Registered with INPHOG	Apr 2024
CTRI Registration	CTRI/2024/10/075688
Recruitment commenced	No
Currently, patients recruited	NA
Target patient recruitment	150
Anticipated duration of recruitment	3 Years
Centers study open in	No

INPHOG-SUPP-23-04 - **New****Drug-induced Diabetes Mellitus management in children with Acute Leukemia (ALL) – A Phase-2 Open-Label Randomized Control Trial (RCT) comparing two treatment arms (Insulin alone Vs Insulin + Metformin)**

Principal Investigator	Dr. Kalashekhar V.S
Registered with INPHOG	May 2024
CTRI Registration	Applied For
Recruitment commenced	No
Currently, patients recruited	NA
Target patient recruitment	Not specified
Anticipated duration of recruitment	Not specified
Centers study open in	No

INPHOG-EPI-24-04- **New****ESTABLISHING THE INPHOG NETWORK OF HOSPITAL-BASED CHILDHOOD CANCER REGISTRIES (HBCCRs) IN INDIA**

Principal Investigator	Dr Venkatraman Radhakrishnan
Registered with INPHOG	Apr 2024
CTRI Registration	CTRI/2024/05/067345
Recruitment commenced	No
Currently, patients recruited	NA
Target patient recruitment	Not specified
Anticipated duration of recruitment	5 Years
Centers study open in	No



INPHOG-CNS-24-04- **New**

Multicentric Indian Pediatric Low-Grade Glioma Registry (IPLOGG): Epidemiology, Treatment Patterns, and Outcomes

Principal Investigator	Dr Shweta Bansal
Registered with INPHOG	AUG 2024
CTRI Registration	In Process
Recruitment commenced	No
Currently, patients recruited	NA
Target patient recruitment	Not specified
Anticipated duration of recruitment	Not specified
Centers study open in	No



INPHOG Studies Granted Provisional Registration (7)

InPOG-SCT-20-02 (P) A multicenter collaborative study for evaluating the outcome in children with high-risk neuroblastoma undergoing autologous stem cell transplantation (NBL-ASCT). **PI - Venkateswaran V S**

INPHOG-RBC-22-01 (P) A Cross-sectional study of children receiving regular red cell transfusions for primary non-malignant hematological conditions excluding thalassemia and sickle cell anemia– Assessment of disease burden and clinical profile. **PI - Stalin Ramprakash**

INPHOG-PALL-PROV-01 Caregiver Perspective for the care of children with cancer receiving end-of-life Care **PI – Dr Amita Mahajan**

INPHOG-NB-PROV-01 A multi-center observational study to evaluate the toxicity profile and outcomes of children and young adults treated for High-risk Neuroblastoma with anti-GD2 immunotherapy **PI – Dr Venkata Rama Mohan**

INPHOG-BMF-PROV-01 Frequency, Natural History, and Improved Diagnosis of Inherited Bone Marrow Failure Syndromes (IBMFS) in India: An Ambispective Multi-Centric Study **PI - Dr Ruchira Mishra**

INPHOG-NHL-PROV-02 Safety and Efficacy of Reduced Dose Chemotherapy in Children and Adolescents with high-grade Mature B Non-Hodgkin Lymphoma – A Prospective Multicenter Phase II Single Arm Study (RED X – B NHL Study)” **PI - Prasanth Srinivasan**

INPHOG-SUPP-PROV-01 Childhood Leukemia Antifungal Prophylaxis (CLAP) study: A Prospective, multi-arm multi-stage randomized phase III, open-label study **PI - Shyam Srinivasan**





CELEBRATING LIFE!



NEED OF NEWSLETTER



Dr Rachna Seth
Professor,
Department of Pediatrics, Division of Oncology

With improvement in diagnostics, advances in therapeutics and other ongoing research, the number of childhood cancer survivors continues to grow, offering hope and inspiration to those still fighting the disease. Survivorship is a concept that helps survivors and their families navigate life after cancer.

The conventional definition of survivorship care involves post-treatment care or addressing the health-related needs of patients who have “survived” a diagnosis and are no longer receiving active treatment. The goals of survivorship care are to anticipate, identify, monitor, and manage late effects and work towards the inclusion of survivors into the society.

INDIA’S FIRST CHILDHOOD CANCER SURVIVORSHIP COHORT!
Many countries have their own survivor cohorts. They help generate data on long-term morbidities of childhood cancer survivors. Recruiting participants into such studies is challenging, yet the work on this growing population is necessary to understand the prevalence and long term consequences of cancer treatment in Indian childhood cancer survivors

We wish to bring together the community interested in cancer survivorship with this newsletter. We thank INPHOG for accommodating us. We propose to showcase ongoing research on survivorship, publications from India and abroad, share stories of public-private partnerships and philanthropic organizations.

SURVIVORSHIP CARE IN INDIA

Dr Payal Malhotra

Consultant Department of Pediatric Hematology Oncology and BMT, RGCIRC, New Delhi.



Dr Gauri Kapoor

Director of Pediatric Hematology and Oncology, RGCIRC, New Delhi.



An estimated 52,366 children (0-14 years) and 76,805 children and adolescents (0-19 years) develop cancer every year in India. Research advancements in cancer prevention and treatment have helped pave the way towards establishing survivorship as a distinct phase in the cancer care continuum. It is estimated worldwide that 73% of survivors will have at least one chronic health condition 30 years after cancer diagnosis, with survivors 3.3 times more likely to have chronic conditions compared to their siblings and 9 times more likely than their siblings to have a severe or life-threatening condition (2). Various studies from India have also reported a high incidence of a spectrum of late effects with any disability (mild to severe) ranging from 23%-63%.

Even though the first survivorship clinic in India was established more than three decades ago in 1991 at TMH, survivorship care remains an underdog. Furthermore, increasing interest in survivorship care in India over the past few years has been limited to larger centres, primarily in metro cities....

[Read the full article here](#) ✨

SURVIVORSHIP SERVICES: HISTORY & IMPORTANCE

Dr. Purna Kurkure.

Head, Division of Paediatric Haemato- Oncology & BMT
SRCC Children’s Hospital Managed by Narayana Health



Introduction

As the number of individuals diagnosed with cancer increases and progress is made in successfully treating the disease, the population of cancer survivors will inevitably swell. The fact that the number of cancer survivors is growing annually and is expected to continue to do so in the future makes it critical to understand the unique needs of the survivor population.

Late Effects of Cancer Therapy

Cancer survivors and their family members face unique consequences of illness and treatment, with the issues grouped in three major categories.

1) Physical issues, 2) Psycho social issues, 3) Economical issues

After Completion Therapy (ACT) Clinic

Drawing inspiration from the model of care established at St. Jude Children Research Hospital, USA, a first follow-up clinic for long term survivors of childhood cancer was initiated at Tata Memorial Hospital in February 1991. This clinic was appropriately named After Completion of Therapy (ACT) clinic to emphasize that ACTs are needed beyond therapy to achieve CURE in its full dimensions. The aims of the clinic are.

To monitor growth, development & sexual maturation of survivors

To monitor late effects of therapy.

To address psycho-social problems of the survivors

Rehabilitation for useful productive adulthood

To provide feedback for future protocol modification to obviate/minimize late effects....

[Read the full article here](#) ✨

CHILDHOOD CANCER SURVIVORSHIP (C2S) STUDY



- The great leaps in childhood cancer survival seen in the west has not been replicated in LMICs.
- Overall 5-year survival: HICs: 80%, MICs 55% & 40% in LICs.
- Survivors are at a higher risk of reporting a severe chronic health conditions c/w age & sex matched siblings

India lacked a childhood cancer survivor registry and focus till now have been on improving cure rates and new therapies.

We proposed to establish the first multi-center registry & build the first national childhood cancer survivor cohort to determine the outcome of children completing treatment and the profile of late effects/chronic health conditions in Indian childhood cancer survivors.

C2S study is the longest INPHOG study with the largest number of participating and prospective centers. It is a prospective observational study and was started in May 2016. It is still recruiting centers and has recruited >4000 survivors.



Participating Centers: 26
Prospective Centers: 4

“WHERE THE BRAVE BELONG”

Namaskar! My name is Shivakumar K.M. I am presently working as a primary school teacher in Bhadravati, a taluk in Karnataka. I was diagnosed with cancer at 15 years of age in 1985. I was fortunate enough to be treated by able doctors like Dr Appaji L, Dr Aruna Kumari and Dr Madhumathi in the Department of Pediatric Oncology at Kidwai Hospital. I received chemotherapy and radiation.

After treatment they kept me under close follow up for five years and declared me cured. I believe it is most important to never lose hope and confidence. Being positive during testing times shall cure half the disease. I never worried about my diagnosis and carried out my daily activities. After treatment, I did not let the disease hinder my work. I have always lived with a positive attitude and mindset. Maybe this is the reason I am alive and happy at 55 years!

I am proud father of a 25 year old son and a 21 year old daughter. I keep myself involved and active, and this is another reason for my health and happiness. Healthy food in limited quantity is essential for a robust health. I am ever indebted to the care given by Dr Appaji and all the staff of Kidwai Memorial Institute of Oncology.



WHAT WE PUBLISH

Long-Term Outcomes in Survivors of Childhood Cancer: A 30-Year Experience From India

Authors: Maya Prasad MD, Savita Goswami MA, Girish Chinnaswamy MD MRCP, Shirod D Banerjee MD, and Purna A. Kurkure MD
Publication: JCO Global Oncology Volume 8 <https://doi.org/10.1200/JGO.22.009>

in survivors of childhood acute lymphoblastic leukemia

Silky Jain, Sandeep Jain, Gauri Kapoor, Anju Virmani, Ram Bajpai

First published: 26 September 2016 <https://doi.org/10.1002/pbc.26271> Citations: 12

Establishing childhood cancer survivorship clinics in India: A consensus statement

Rachna Seth^{a,*}, Maya Prasad^b, Gauri Kapoor^c, Gargi Das^d, Srinivasan Prasanth^d, Vandana Dhamankar^e, Purna Kurkure^f, M Melissa Hudson^{g,h}

Prevalence and Risk Factors Of Insulin Resistance and Impaired Fasting Glucose and Obesity among Pediatric Acute Lymphoblastic Leukemia Survivors in India

Nirmal G, Thankamony P, Guruprasad CS, Nair M, Rajeswari B, Shwetha S, Jagathnath Krishna KM and Pillai RK
Published on: 2023-10-24

Prevalence and Risk Factors for Metabolic Syndrome Among Childhood Acute Lymphoblastic Leukemia Survivors: Experience From South India

Garima Nirmal¹, Priyakumari Thankamony¹, Guruprasad Chellappam Sojmani¹, Manjusha Nair¹, Binitha Rajeswari¹, Prasanth Varikkattu Rajendran¹, Jagathnath Krishna K M²

Affiliations: + expand
PMID: 32516199 DOI: 10.1097/MPH.0000000000001856

Scan Me



NEWS & EVENTS

Psychologist's Conclave

27 Feb 2024

“Neurocognitive and psychosocial concerns in childhood cancer survivors”



- Understanding needs of Childhood Cancer Survivorship (CCS) beyond treatment.
- Case based discussion on approaches to neuro cognitive and psychosocial issues in CCS.
- Explored rehabilitation opportunities and services.
- Proposed “handbook for psychologists- Growing beyond Cancer: Neurocognitive & Psycho-Social Assessment.



3 rd International Symposium on Late Complications after Childhood Cancer (ISLCCC)

27 -29 June 2024.

Survivorship & Late effects Subcommittee Meeting

3rd and 4th August 2024



- Released newsletter of the Survivorship & Late effects subcommittee (INPHOG).
- Childhood Cancer Survivorship (C2S) study Results of Phase I.
- Proposed Prospective projects on Survivorship & Late Effects.
- Delphi Consensus Guidelines on ALL, AML, and CML.



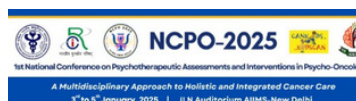
27th Annual Pediatric Hematology Oncology Conference

www.phocon2024jammu.com

November 22 - 24, 2024

Convention Centre Jammu

Upcoming Events



Register at: www.ncpo2025.in



Register at: <https://forms.gle/dNEkO7xtDEHy9nzcA>



ONGOING & UPCOMING PROJECTS OF THE SURVIVORSHIP & LATE EFFECTS COMMITTEE

- C2S study
- Bone health in Leukemia survivors
- Metabolic Syndromes

Newsletter Team: Dr Rachna Seth, Dr Vandana Dhamankar, Dr Gargi Das, Dr Prakruthi Kaushik, Dr Nivedita Pathak, Shikha Kumari, Priya Dixit

For further information and contributions to the newsletter kindly write to us at: survivorship77meeting@gmail.com

Look out for our next issue!

