



InPOG Newsletter



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InPOG Executive

Sripad Banavali (Chair)
Revathy Raj (Co-Chair)
Ramandeep Arora (Sec)
Amita Mahajan
Girish Chinnaswamy
Nita Radhakrishnan
Mamta Manglani (PHO IAP)
Sunil Bhat (PHO IAP)

Subcommittee Chairs

ALL	Shekhar Krishnan
AML	Smita Kayal
Ch Myelop	Tulika Seth
HL	Amita Mahajan
NHL	Manas Kalra
Histiocytosis	Ramya Uppuluri
CNS	Sujata Mushrif
NBL	Vikramjit Kanwar
Retino	Santosh Honavar
Renal	Sirisha Rani
Liver	Sandeep Agarwala
PNET	Sandeep Jain
Osteo	Ashish Gulia
STS	Arpita Bhattacharya
GCT	Sonali Mohapatra
Rare, epith	Harsha Prasad
HSCT	Revathy Raj
Acc to Care	Shruti Kakkar
Supportive	Maya Prasad
Epidemiology	Ramandeep Arora
Surv & Late Eff	Rachna Seth
Palliative	Gayatri Palat
Can Genetics	Nita Radhakrishnan
Hbpathy/RBC	Jagdish Chandra
Plat & Coag	Vandana Bharadwaj
BM Failure	Santanu Sen

Dear Friends,

As we stepped in 2021, we were cautiously optimistic that things were turning around and we were looking ahead to being “normal” again. Current events have shown that we were sadly mistaken. All of us have patients, family and friends who have been affected by the COVID infection. During such time our focus is and should be on navigating the pandemic for ourselves and for those around us. We also continue to fulfil our professional responsibilities delivering uninterrupted care to our patients as much as possible.

Even in such difficult times, collaborative research is at the front of solving the problems of prevention and treatment of COVID-19. Shared experiences of our colleagues globally on COVID in childhood cancer patients has allowed us to learn valuable lessons in a short period of time and offer better evidence based care to our patients. A couple of InPOG studies relate to this. The InPOG-ACC-20-04 which looked at the impact of COVID-19 pandemic on care of children with cancer in India has found that approximately two out of three children with cancer were impacted during the onset of the pandemic and lockdown last year. This study is now complete and is under review for publication.

We also recently published the progress InPOG has made since 2015. We are sharing a couple of figures on the next page from that publication and attaching the manuscript as well.

Please stay safe and stay well. We look forward to seeing you all soon at the other end of the pandemic.

Warm wishes,

InPOG Executive, inpogexec@gmail.com

<https://goo.gl/forms/HTUnL6wZyYEVbhHF2> for InPOG membership

Publications Related to InPOG

- Arora RS, Bakhshi S. Indian Pediatric Oncology Group (InPOG) – Collaborative research in India comes of age. *Pediatr Hematol Oncol J* 2016 May;1(1):13-17.
- Pediatric Hematology Oncology Chapter of Indian Academy of Pediatrics (PHO IAP), Indian Pediatric Oncology Group (InPOG), Cankids Kidscan representing Civil Society & Patient Groups. WHO Global Initiative for Childhood Cancer – India Responds *Pediatr Hematol Oncol J* 2020. Oct 1;5(4):145-50.
- Arora RS, Raj R, Mahajan A, Radhakrishnan N, Chinnaswamy G, Banavali S. Collaborative cancer research: progress report from the Indian Pediatric Oncology Group. *Lancet Child Adolesc Health*. 2021 Apr;5(4):239-240. – **NEW**

Figure 1 Trend of InPOG Studies, Participating Centres, and Patients Recruited

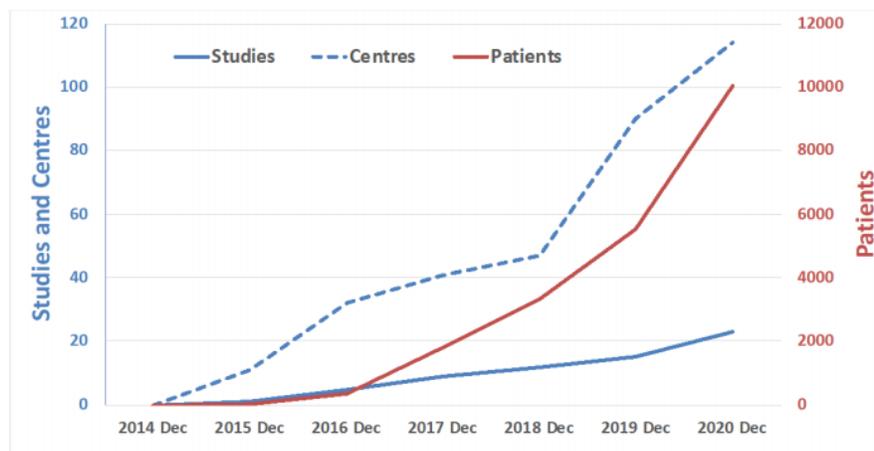
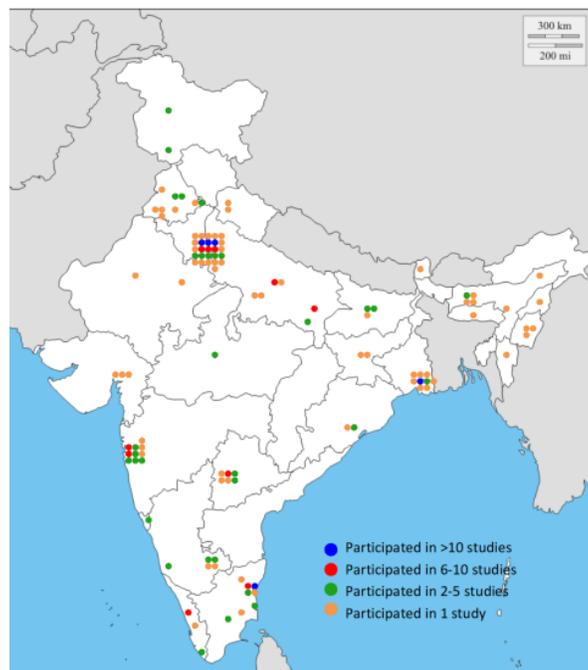


Figure 2 Distribution of Centres in India participating in InPOG Studies



Study Summary Portfolio (Total 29)

Subcommittee	Provisional Registration (4)	Full Registration (2)	Recruitment Ongoing (13)	Recruitment Complete (10)
ALL			InPOG-ALL-15-01 InPOG-ALL-19-02	
AML				InPOG-AML-16-01
Ch Myelop Dis				InPOG-CML-16-01
HL			InPOG-HL-17-02 InPOG-HL-19-03	InPOG-HL-15-01
NHL				InPOG-NHL-16-01
Histiocytosis			InPOG-HIST-19-03	InPOG-HIST-17-01
CNS	InPOG-CNS-19-01 InPOG-CNS-19-02 InPOG-CNS-19-03			
Neuroblastoma		InPOG-NB-18-02	InPOG-NB-18-01	
Retinoblastoma			InPOG-RB-17-01	
Renal			InPOG-WT-18-02	
Liver				
Osteosarcoma				
PNET		InPOG-PNET-19-02		InPOG-PNET-16-01
Soft Tissue Sarcoma				
Germ Cell Tumours				
Rare, Epithelial			InPOG-RARE-17-02 InPOG-RARE-17-01	
HSCT	InPOG-SCT-20-02			
Access to Care				InPOG-ACC-16-01 InPOG-ACC-16-02 InPOG-ACC-16-03 InPOG-ACC-20-04
Supportive Care				
Epidemiology			InPOG-EPI-20-02	
Late Effects			InPOG-LE-16-01	
Palliative Care			InPOG-PALL-18-01	
Cancer Genetics				
Hbpathy/RBC				
Plat & Coag				
BM Failure				

InPOG Studies - Recruitment Complete (10)

InPOG-HL-15-01

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

Principal Investigator	Prof Jagdish Chandra
Registered with InPOG	June 2015
CTRI Registration	CTRI/2016/03/010916
Patients recruited	410
Recruitment Closed	February 2018
Centers study open in	27 centres

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 Multicentre Prospective Clinical Trial in Childhood Cancer in India. *Pediatric Hematology Oncology J* 2020. Oct 1;5(4):166-70.

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 InPOG	October 2016
CTRI Registration	No
Patients recruited	323
Recruitment Closed	April 2018
Centers study open in	10 centres

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 InPOG	August 2016
CTRI Registration	CTRI/2016/11/007492
Patients recruited	402
Recruitment Closed	November 2017
Centers study open in	15 centres

InPOG-ACC-16-03

Exploring Barriers and Enablers to Accessing Care for Childhood Cancers in India: A Multi-centre Qualitative Study

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

Publications

- Faruqi 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.
- Faruqi 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 InPOG	June 2016
CTRI Registration	No
Patients recruited	40
Recruitment Closed	August 2018
Centers study open in	2 centres

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 InPOG	Feb 2018
CTRI Registration	No
Patients recruited	171
Recruitment Closed	January 2019
Centers study open in	9 centres

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 InPOG	April 2016
CTRI Registration	CTRI/2014/11/005202
Patients recruited	150
Recruitment Closed	Nov 2019
Centers study open in	5 centres

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 InPOG	July 2017
CTRI Registration	Not done
Patients recruited	20
Recruitment Closed	Feb 2021
Centers study open in	8 centres

InPOG-ACC-16-02

Accessing Childhood CancEr Services in INDIA (ACCESS INDIA)

Principal Investigator	Dr Ramandeep Singh Arora
Registered with InPOG	Sep 2018
CTRI Registration	
Patients recruited	2850
Recruitment Closed	Feb 2021
Centers study open in	71 centres

InPOG-ACC-20-04

The impact of COVID-19 pandemic on care of children with cancer in India

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

InPOG Studies - Recruitment Ongoing (13)

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 InPOG	July 2015
CTRI Registration	CTRI/2015/12/006434
Recruitment commenced	Oct 2016
Currently patients recruited	2961
Target patient recruitment	3056
Centers study open in	5 centres

- All India Institute of Medical Sciences, New Delhi
- Cancer Institute, Chennai
- PGIMER, Chandigarh
- Tata Medical Centre, Kolkata
- Tata Medical Centre, Mumbai

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 InPOG	May 2016
CTRI Registration	Not done
Recruitment commenced	June 2016
Currently patients recruited	1801
Target patient recruitment	At least 500 (desirable 1000)
Anticipated duration of recruitment	5 years (Project extended till 2025)
Centers study open in	16 centres

- All India Institute of Medical Sciences, New Delhi
- Apollo Hospital, Chennai
- Banaras Hindu University, Varanasi
- Cancer Institute, Chennai
- Indraprastha Apollo Hospital, New Delhi
- Kalawati Children's Hospital, New Delhi

- Kidwai Memorial Institute, Bangalore
- King George’s medical University, Lucknow
- Max Super Specialty Hospital, Patparganj, New Delhi
- Max Super Specialty Hospital, Saket, New Delhi
- Rainbow Children’s Hospital, Hyderabad
- Rajiv Gandhi Cancer Institute, New Delhi
- Regional Cancer Centre, Thiruvananthipuram
- SION Hospital, Mumbai
- Tata Medical Centre, Kolkata
- Tata Memorial Hospital, Mumbai

InPOG-HL-17-02

Prospective Collaborative Study for Relapsed/Refractory Hodgkin Lymphoma

Principal Investigator	Dr Amita Mahajan
Registered with InPOG	May 2018
CTRI Registration	Ref/2019/03/024719
Recruitment commenced	Yes
Currently patients recruited	31
Target patient recruitment	115
Anticipated duration of recruitment	3 years
Centers study open in	13 centres

- Apollo Hospital, Chennai
- All India Institute of Medical Sciences, New Delhi
- All India Institute of Medical Sciences, Patna
- Cancer Institute, Chennai
- BJ Wadia Hospital, Mumbai
- Indraprastha Apollo Hospital, New Delhi
- Kalawati Children’s Hospital, New Delhi
- Mahavir Cancer Sansthan, Patna
- Max Super Specialty Hospital, Saket, New Delhi
- Meenakshi Mission Hospital, Madurai
- MVR Cancer Centre and Research Institute, Calicut
- Rajiv Gandhi Cancer Institute, New Delhi
- Safdarjung Hospital, New Delhi

InPOG-RARE-17-02

Indian Childhood Advanced Nasopharyngeal Carcinoma Study (ICANaPS)

A multicenter, prospective, pilot study on 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 Anirban Das
Registered with InPOG	October 2018
CTRI Registration	
Recruitment commenced	Yes
Currently patients recruited	2
Target patient recruitment	50
Anticipated duration of recruitment	5 years
Centers study open in	1

- Tata Medical Centre, Kolkata

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 InPOG	July 2017
CTRI Registration	CTRI/2019/02/017851
Recruitment commenced	Yes
Currently patients recruited	150
Target patient recruitment	250
Anticipated duration of recruitment	3 years
Centers study open in	10

- All India Institute of Medical Sciences, New Delhi
- Apollo hospital, Chennai
- BJ Wadia Hospital, Mumbai
- Cancer Institute, Chennai
- Indraprastha Apollo Hospital, New Delhi
- Kasturba Medical College, Mangalore
- King George's medical University, Lucknow
- Rainbow Children's Hospital, Hyderabad
- Tata Medical Centre, Kolkata
- Tata Medical Centre, Mumbai

InPOG-ALL-19-02

Registry study for relapsed childhood acute lymphoblastic leukaemia using protocol ALL-R1.

Principal Investigator	Vaskar Saha
Registered with InPOG	Jun 2019

CTRI Registration	CTRI/2019/10/021758
Recruitment commenced	Yes
Currently patients recruited	19
Target patient recruitment	220
Anticipated duration of recruitment	5 years
Centers study open in	1

- Tata Medical Centre, Kolkata

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 InPOG	Aug 2019
CTRI Registration	CTRI/2020/07/026937
Recruitment commenced	Yes
Currently patients recruited	5
Target patient recruitment	50
Anticipated duration of recruitment	3 years
Centers study open in	8

- All India Institute of Medical Sciences, New Delhi – **NEW**
- Apollo Hospital, Chennai
- Indraprastha Apollo Hospital, New Delhi
- Rainbow Children's Hospital, Hyderabad
- Sri Aurobindo Institute of Medical Sciences, Indore
- Sri Ramachandra Institute of Higher Education and Research, Chennai
- Tata Medical Centre, Kolkata
- Tata Memorial Hospital, Mumbai

InPOG-NB-18-01

India Neuroblastoma Registration and Biology Study

Principal Investigator	Dr Vikramjit Kanwar
Registered with InPOG	Nov 2018
CTRI Registration	CTRI/2020/01/023088
Recruitment commenced	Yes
Currently patients recruited	2
Target patient recruitment	500
Anticipated duration of recruitment	5 years
Centers study open in	6

- Apollo Multispecialty Hospital, Chennai, Tamil Nadu
- Apollo Indraprastha Superspecialty Hospital, New Delhi
- CIMS Hospital, Ahmedabad. Gujarat
- Deenanath Mangeshkar Hospital, Pune, Maharashtra
- Indo-American Cancer Hospital Hyderabad, Telangana
- MVR Cancer Centre, Calicut

InPOG-EPI-20-02

Indian COVID-19 Childhood Cancer Registry

Principal Investigator	Dr Revathi Raj
Registered with InPOG	May 2020
CTRI Registration	CTRI/2020/05/025221
Recruitment commenced	Yes
Currently patients recruited	258
Target patient recruitment	1000
Anticipated duration of recruitment	3 years
Centers study open in	31

- AIIMS Pediatric Delhi
- American oncology institute
- Apollo cancer centre, Chennai
- Asian Cancer Institute, Mumbai
- BJ Wadia, Mumbai
- Cancer Institute, Chennai
- CMCH, Vellore
- Comprehensive Thalassemia BMT Center, Mumbai
- Dayanand Medical College, Ludhiana
- Goa Medical College and Hospital, Goa
- Hematology oncology clinic, Ahmedabad
- Holy Spirit hospital, Mumbai
- Indraprastha Apollo Hospitals, New Delhi
- Institute of medical sciences, Varanasi
- Kanchi Kamakoti Childs Trust Hospital, Chennai – **NEW**
- KGMU Lucknow
- Max Hospital Vaishali
- Max Super Specialty Hospital, Saket, New Delhi
- MCGM, Mumbai
- Mothers Care Children Hospital , Imphal
- MVR Cancer Centre
- Narayana Health City, Bangalore

- Rainbow Children's hospital, Hyderabad
- S.L. Raheja Hospital, Mumbai
- Safdarjung Hospital, New Delhi
- SRCC Narayana, Mumbai
- Sri Aurobindo Institute of Medical Sciences, Indore
- Sri Ramachandra, Chennai
- SSPHPGTI, Noida
- St John's Medical College & Hospital, Bangalore
- Tata Memorial Hospital, Mumbai

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 InPOG	Apr 2020
CTRI Registration	CTRI/2021/01/030770
Recruitment commenced	Yes
Currently patients recruited	254
Target patient recruitment	300-500
Anticipated duration of recruitment	Not applicable - Retrospective
Centers study open in	9

- Apollo Hospital, Chennai – **NEW**
- Indraprastha Apollo Hospital, New Delhi
- Max Super Specialty Hospital, Saket, New Delhi
- Rainbow Children's hospital, Hyderabad
- St John's Medical College and Hospital, Bangalore – **NEW**
- MVR Centre, Kozhikode – **NEW**
- HCG, Bangalore – **NEW**
- Hemato-Onco clinic, Ahmedabad – **NEW**
- Tata Medical Centre, Kolkata – **NEW**

InPOG-RB-17-01

A Prospective Collaborative Study for Newly Diagnosed patients with Retinoblastoma

Principal Investigator	Dr Santosh Honavar
Registered with InPOG	Sep 2019
CTRI Registration	CTRI/2020/09/027846
Recruitment commenced	Yes
Currently patients recruited	93

Target patient recruitment	600
Anticipated duration of recruitment	3 years
Centers study open in	15

- AllIMS, New Delhi - **NEW**
- BHU, Department of Pediatrics
- Center for sight, Hyderabad
- GMCH Chandigarh
- HV Desai eye Hospital Pune
- KGMU Lucknow – **NEW**
- LVPI Bhuvneshwar
- NH Bangalore
- PGI Chandigarh – **NEW**
- RIO MCK Hospital Kolkata
- Sankara Eye Hospital, Bangalore
- Shroff's Charity Eye Hospital, New Delhi
- SMS Hospital, Jaipur – **NEW**
- SRCC Mumbai
- Sri Sankaradeva Nethrayala Hospital, Guwahati

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 with Treated with a Standard of Care Intensified Chemotherapy Regimen.

Principal Investigator	Dr Gaurav Narula
Registered with InPOG	Feb 2020
CTRI Registration	CTRI/2020/08/027495
Recruitment commenced	Yes
Currently patients recruited	22
Target patient recruitment	700
Anticipated duration of recruitment	5 years
Centers study open in	1

- Tata Memorial Hospital, Mumbai

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 InPOG	Sep 2020
CTRI Registration	CTRI/2020/12/029960
Recruitment commenced	Yes
Currently patients recruited	40
Target patient recruitment	780
Anticipated duration of recruitment	Not applicable - Retrospective
Centers study open in	6

- Cancer Institute, Adyar, Chennai
- Max Super Speciality Hospital, Saket, New Delhi – **NEW**
- Malabar Cancer Centre, Thalassery – **NEW**
- MNJ Institute of Oncology, Hyderabad
- Pain Relief and Palliative Care Society, Hyderabad
- Sri Ramachandra Medical Centre, Chennai – **NEW**

InPOG Studies Granted Full Registration (2)

InPOG-NB-18-02

Indian Non-high Risk Neuroblastoma Study

Principal Investigator	Dr Vikramjit Kanwar
Registered with InPOG	Sep 2020
CTRI Registration	
Recruitment commenced	No
Currently patients recruited	NA
Target patient recruitment	Not specified
Anticipated duration of recruitment	Not specified
Centers study open in	No

InPOG-PNET-19-02 – NEW

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 InPOG	May 2021
CTRI Registration	
Recruitment commenced	No
Currently patients recruited	NA
Target patient recruitment	Not specified
Anticipated duration of recruitment	Not applicable - Retrospective
Centers study open in	No

InPOG Studies Granted Provisional Registration (4)

1. **InPOG-CNS-19-01 (P)** Registry study on epidemiology of medulloblastoma in India. **PI – Manas Kalra**
2. **InPOG-CNS-19-02 (P)** A collaborative protocol for newly diagnosed Indian childhood medulloblastoma patients above 3 years of age with standard risk disease. **PI – Manas Kalra**
3. **InPOG-CNS-19-03 (P)** A collaborative protocol for newly diagnosed Indian childhood medulloblastoma patients above 3 years of age with high-risk disease. **PI – Manas Kalra**
4. **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**