



# InPOG Newsletter



**Sep-Dec 2019, Vol 5, Issue 3**

## InPOG Executive

Sripad Banavali (Chair)  
Revathy Raj (Co-Chair)  
Ramandeep Arora (Sec)  
Amita Mahajan  
Girish Chinnaswamy  
Nita Radhakrishnan

## 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	Hari Sankaran
Surv& Late Eff	Rachna Seth
Palliative	Gayatri Palat
Can Genetics	Nita Radhakrishnan

Dear Friends,

September 2019 saw PHOCON at Varanasi and results of several InPOG studies (on CML, Hodgkin Lymphoma and B-NHL) were shared with the attendees. Also there was a change in some of the Subcommittee Chairs with Ramya Uppuluri as new chair of Histiocytosis, Sujata Mushrif as new chair of CNS tumours, Sonali Mohapatra as new chair of GCT and Revathy Raj as new chair of the HSCT subcommittee. The GBM at PHOCON also approved InPOG to be registered as a separate body, which would allow it to take greater responsibility and also raise funds. This process is expected to take a year. InPOG's central role in research and clinical trials would continue to compliment the PHO IAP's role in education and advocacy.

We are delighted to share that the first publication with results from an InPOG study (InPOG-ACC-16-03) came out in December 2019 <https://www.ncbi.nlm.nih.gov/pubmed/31791308>. Congratulations to all the participating centres and investigators. The InPOG-AML-16-01 (Randomized Phase III Study Comparing DA (3+7) Versus ADE as Induction Chemotherapy in children with Acute Myeloid Leukemia) is now closed to recruitment. The InPOG-ALL-19-02 (Registry study for relapsed childhood acute lymphoblastic leukaemia using protocol ALL-R1) is now recruiting and interested centres can contact the PI. InPOG-RB-17-01 (A Prospective Collaborative Study for Newly Diagnosed patients with Retinoblastoma) and the InPOG-HIST-19-03 (Prospective Collaborative Study for pulse dexamethasone and lenalidomide in Relapsed / Refractory Langerhans cell histiocytosis (LENDEX-LCH study)) invite interested centres as they will begin to recruit soon. Details of the above studies are attached in the accompanying email.

We wish you all a Merry Christmas and a Happy New Year. SIOP Asia 2020 beckons and promises to showcase the best of Asian and Indian work. We look forward to seeing you all there

Warm wishes

InPOG Executive

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

Email address for all InPOG communication is [inpodexec@gmail.com](mailto:inpodexec@gmail.com)

## Study Summary Portfolio (Total 28)

Subcommittee	Provisional Registration (9)	Full Registration (4)	Recruitment Ongoing (8)	Recruitment Complete (7)
ALL			InPOG-ALL-15-01 InPOG-ALL-19-02	
AML				InPOG-AML-16-01
ChMyelop Dis				InPOG-CML-16-01
HL	InPOG-HL-19-03		InPOG-HL-17-02	InPOG-HL-15-01
NHL				InPOG-NHL-16-01
Histiocytosis	InPOG-HIST-18-02	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-16-01
Soft Tissue Sarcoma				
Germ Cell Tumours				
Rare, Epithelial			InPOG-RARE-17-02 InPOG-RARE-17-01	
HSCT				
Access to Care			InPOG-ACC-16-02	InPOG-ACC-16-01 InPOG-ACC-16-03
Supportive Care	InPOG-SUPP-19-01			
Epidemiology				
Late Effects		InPOG-LE-17-02	InPOG-LE-16-01	
Palliative Care	InPOG-PALL-18-01			
Cancer Genetics				

## **InPOG Studies - Recruitment Complete (7)**

### **InPOG-HL-15-01**

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

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

### **InPOG NHL-16-01**

**A Retrospective Multi-centric Study of Contemporary Epidemiology & Outcome of Childhood B-NHL in India**

<b>Principal Investigator</b>	Dr Amita Trehan
<b>Registered with InPOG</b>	October 2016
<b>CTRI Registration</b>	No
<b>Patients recruited</b>	323
<b>Recruitment Closed</b>	April 2018
<b>Centers study open in</b>	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)**

<b>Principal Investigator</b>	Dr Ramandeep Singh Arora
<b>Registered with InPOG</b>	August 2016
<b>CTRI Registration</b>	CTRI/2016/11/007492
<b>Patients recruited</b>	402
<b>Recruitment Closed</b>	November 2017
<b>Centers study open in</b>	15 centres

### **InPOG-ACC-16-03**

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

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

#### **Publications**

1. 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.

### **InPOG-PNET-16-01**

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

<b>Principal Investigator</b>	Dr Bivas Biswas
<b>Registered with InPOG</b>	June 2016
<b>CTRI Registration</b>	No
<b>Patients recruited</b>	40
<b>Recruitment Closed</b>	August 2018
<b>Centers study open in</b>	2 centres

### **InPOG-CML-16-01**

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

<b>Principal Investigator</b>	Prof Deepak Bansal
<b>Registered with InPOG</b>	Feb 2018
<b>CTRI Registration</b>	No
<b>Patients recruited</b>	171
<b>Recruitment Closed</b>	January 2019
<b>Centers study open in</b>	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**

<b>Principal Investigator</b>	Dr Venkatraman Radhakrishnan
<b>Registered with InPOG</b>	April 2016
<b>CTRI Registration</b>	CTRI/2014/11/005202
<b>Patients recruited</b>	150
<b>Recruitment Closed</b>	Nov 2019
<b>Centers study open in</b>	5 centres

## **InPOG Studies - Recruitment Ongoing (9)**

### **InPOG-ALL-15-01**

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

<b>Principal Investigator</b>	Prof Vaskar Saha
<b>Registered with InPOG</b>	July 2015
<b>CTRI Registration</b>	CTRI/2015/12/006434
<b>Recruitment commenced</b>	Oct 2016
<b>Currently patients recruited</b>	1687
<b>Target patient recruitment</b>	2240
<b>Centers study open in</b>	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**

<b>Principal Investigator</b>	Dr Rachna Seth
<b>Registered with InPOG</b>	May 2016
<b>CTRI Registration</b>	
<b>Recruitment commenced</b>	June 2016
<b>Currently patients recruited</b>	1618
<b>Target patient recruitment</b>	At least 500 (desirable 1000)
<b>Anticipated duration of recruitment</b>	5 years
<b>Centers study open in</b>	14 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
- 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

**InPOG-HIST-17-01**

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

<b>Principal Investigator</b>	Dr Mukesh Desai
<b>Registered with InPOG</b>	July 2017
<b>CTRI Registration</b>	Ongoing
<b>Recruitment commenced</b>	Yes
<b>Currently patients recruited</b>	20
<b>Target patient recruitment</b>	300
<b>Anticipated duration of recruitment</b>	5 years
<b>Centers study open in</b>	8 centres

- Apollo hospital, Chennai
- BJ Wadia Hospital, Mumbai
- Indira Gandhi Institute of Child Health, Bangalore
- Kanchi Kamakoti Childs Trust Hospital, Chennai
- Max Smart Super Specialty Hospital, Saket, New Delhi
- Max Super Specialty Hospital, Saket, New Delhi
- Max Super Specialty Hospital, Patparganj, New Delhi
- National Institute of Immunohaematology, Mumbai

**InPOG-HL-17-02**

**Prospective Collaborative Study for Relapsed/Refractory Hodgkin Lymphoma**

<b>Principal Investigator</b>	Dr Amita Mahajan
<b>Registered with InPOG</b>	May 2018
<b>CTRI Registration</b>	Ref/2019/03/024719
<b>Recruitment commenced</b>	Yes
<b>Currently patients recruited</b>	12
<b>Target patient recruitment</b>	115
<b>Anticipated duration of recruitment</b>	3 years
<b>Centers study open in</b>	11 centres

- Apollo Hospital, Chennai – **NEW**
- 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 – **NEW**
- 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**

<b>Principal Investigator</b>	Dr Anirban Das
<b>Registered with InPOG</b>	October 2018
<b>CTRI Registration</b>	
<b>Recruitment commenced</b>	Yes
<b>Currently patients recruited</b>	1
<b>Target patient recruitment</b>	50
<b>Anticipated duration of recruitment</b>	5 years
<b>Centers study open in</b>	1 centre

- Tata Medical Centre, Kolkata

**InPOG-RARE-17-01**

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

<b>Principal Investigator</b>	Dr Maya Prasad
<b>Registered with InPOG</b>	July 2017
<b>CTRI Registration</b>	CTRI/2019/02/017851
<b>Recruitment commenced</b>	Yes
<b>Currently patients recruited</b>	34



<b>Target patient recruitment</b>	250
<b>Anticipated duration of recruitment</b>	3 years
<b>Centers study open in</b>	7 centres

- All India Institute of Medical Sciences, New Delhi
- BJ Wadia Hospital, Mumbai
- Cancer Institute, Chennai
- Indraprastha Apollo Hospital, New Delhi
- King George’s medical University, Lucknow
- Tata Medical Centre, Kolkata
- Tata Medical Centre, Mumbai

### InPOG-ACC-16-02

#### Accessing Childhood CancEr Services in INDIA (ACCESS INDIA)

<b>Principal Investigator</b>	Dr Ramandeep Singh Arora
<b>Registered with InPOG</b>	Sep 2018
<b>CTRI Registration</b>	Applied For
<b>Recruitment commenced</b>	No
<b>Currently patients recruited</b>	641
<b>Target patient recruitment</b>	6000
<b>Anticipated duration of recruitment</b>	12 months
<b>Centers study open in</b>	64 centres

- Aadhar Health Institute, Hisar
- Advance Cancer Diagnostic Treatment & Research Centre, Bhatinda
- Aligarh Muslim University, Aligarh
- All India Institute of Medical Sciences, Hematology, New Delhi – **NEW**
- All India Institute of Medical Sciences, Pediatrics, New Delhi – **NEW**
- All India Institute of Medical Sciences, Patna
- Apollo Gleneagles Cancer Hospital, Kolkata – **NEW**
- Army Hospital Research and Referral, New Delhi – **NEW**
- Asian Institute of Medical Sciences, Faridabad
- Assam Medical College, Dibrugarh
- Banaras Hindu University- Institute of Medical Sciences, Varanasi – **NEW**
- BL Kapur, New Delhi – **NEW**
- Cachar Cancer Centre, Silchar – **NEW**
- Chittaranjan National Cancer Institute, Kolkata – **NEW**
- Christian Medical College & Hospital, Ludhiana – **NEW**
- Command Hospital, Kolkata
- Dayanand Medical College and Hospital, Ludhiana

- Dharamshila Narayana Superspeciality Hospital, New Delhi – **NEW**
- Dr. Bhubaneswar Borooah Cancer Institute, Guwahati – **NEW**
- Dr. Ram Manohar Lohia Hospital, New Delhi – **NEW**
- Gauhati Medical College & Hospital, Guwahati
- Guru Gobind Singh Medical College and Hospital, Faridkot
- HCG Regency Oncology Healthcare Pvt. Limited, Kanpur – **NEW**
- Himalayan Institute Hospital Trust, Dehradun
- Indraprastha Apollo Hospital, New Delhi
- Institute of Child Health, Kolkata – **NEW**
- Institute of Hematology & Transfusion Medicine, Medical College & Hospital, Kolkata – **NEW**
- Institute Rotary Cancer Hospital, AIIMS, New Delhi
- Jawaharlal Nehru Institute of Medical Sciences, Imphal – **NEW**
- Kamla Nehru Memorial Hospital, Allahabad
- King George’s medical University, Lucknow
- L V Prasad Eye Institute, Bhubaneswar – **NEW**
- Lok Narayan Jai Prakash Hospital, New Delhi – **NEW**
- Max Super Speciality Hospital, Bathinda – **NEW**
- Max Super Specialty Hospital, Deharadun – **NEW**
- Max Super Specialty Hospital, Mohali – **NEW**
- Max Super Specialty Hospital, Patparganj, New Delhi – **NEW**
- Max Super Specialty Hospital, Saket, New Delhi – **NEW**
- Max Super Specialty Hospital, Vaishali, Ghaziabad – **NEW**
- Medical College & Hospital, Kolkata – **NEW**
- Mizoram State Cancer Institute, Aizawl – **NEW**
- Naga Hospital Authority, Kohima
- North East Cancer Institute, Jorabat – **NEW**
- North Eastern Indira Gandhi Regional Institute of Health and Medical Sciences, Shillong – **NEW**
- Pt. BD Sharma Post Graduate Institute of Medical Sciences, Rohtak – **NEW**
- Parvati Devi Hospital, Amritsar
- Punjab Cancer Centre, Bhatinda
- Postgraduate Institute of Medical Education, Chandigarh – **NEW**
- Purshottamdas Savitridevi Cancer Care Research Centre, Agra-**NEW**
- Rajendra Inst of Medical Sciences (RIMS), Ranchi – **NEW**
- Rajiv Gandhi Cancer Institute and Research centre, New Delhi – **NEW**
- Ramjanam Sukakshana Pandey Cancer Hospital Cancer Hospital, Ranchi – **NEW**
- RCC Jammu / Government Medical College, Jammu – **NEW**
- Regional Institute of Medical Sciences (RIMS), Imphal – **NEW**
- Royal Cancer Institute and Research Centre, Kanpur
- Safdarjung Hospital & Vardhman Mahavir Medical Collage, New Delhi – **NEW**
- Saroj Gupta Cancer Centre and Research Institute, Kolkata – **NEW**

- Sarojini Naidu Medical College, Agra – **NEW**
- Sher-i-Kashmir Institute of Medical Sciences, Srinagar
- Shroff's Charity Eye Hospital, New Delhi
- Sir Thutob Namgyal Memorial Hospital, Gangtok
- Sri Sankaradeva Nethralaya, Guwhati
- Tata Medical Centre, Kolkata
- Tata Memorial Hospital, Mumbai – **NEW**

**InPOG-ALL-19-02 – NEW**

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

<b>Principal Investigator</b>	Vaskar Saha
<b>Registered with InPOG</b>	Jun 2019
<b>CTRI Registration</b>	CTRI/2019/10/021758
<b>Recruitment commenced</b>	No
<b>Currently patients recruited</b>	NA
<b>Target patient recruitment</b>	220
<b>Anticipated duration of recruitment</b>	5 years
<b>Centers study open in</b>	1

- Tata Medical Centre, Kolkata – **NEW**

## **InPOG Studies Granted Full Registration (4)**

### **InPOG-LE-17-02**

#### **Cross-Sectional Study of Late Effects in Long term Survivors of Childhood Hodgkin Lymphoma**

<b>Principal Investigator</b>	Dr Maya Prasad
<b>Registered with InPOG</b>	Nov 2017
<b>CTRI Registration</b>	
<b>Recruitment commenced</b>	No
<b>Currently patients recruited</b>	NA
<b>Target patient recruitment</b>	300
<b>Anticipated duration of recruitment</b>	1 year
<b>Centers study open in</b>	No

### **InPOG-NB-18-01**

#### **India Neuroblastoma Registration and Biology Study.**

<b>Principal Investigator</b>	Dr Vikramjit Kanwar
<b>Registered with InPOG</b>	Nov 2018
<b>CTRI Registration</b>	
<b>Recruitment commenced</b>	No
<b>Currently patients recruited</b>	NA
<b>Target patient recruitment</b>	500
<b>Anticipated duration of recruitment</b>	5years
<b>Centers study open in</b>	NA

### **InPOG-HIST-19-03**

#### **Prospective Collaborative Study for pulse dexamethasone and lenalidomide in Relapsed / Refractory Langerhans cell histiocytosis (LENDEX-LCH study)**

<b>Principal Investigator</b>	Dr Ramya Uppuluri
<b>Registered with InPOG</b>	Aug 2019
<b>CTRI Registration</b>	
<b>Recruitment commenced</b>	No
<b>Currently patients recruited</b>	NA
<b>Target patient recruitment</b>	50
<b>Anticipated duration of recruitment</b>	3 years
<b>Centers study open in</b>	NA

**InPOG-RB-17-01 – NEW**

**A Prospective Collaborative Study for Newly Diagnosed patients with Retinoblastoma**

<b>Principal Investigator</b>	Dr Santosh Honavar
<b>Registered with InPOG</b>	Sep 2019
<b>CTRI Registration</b>	
<b>Recruitment commenced</b>	No
<b>Currently patients recruited</b>	NA
<b>Target patient recruitment</b>	330
<b>Anticipated duration of recruitment</b>	3 years
<b>Centers study open in</b>	NA

## **InPOG Studies Granted Provisional Registration (9)**

1. **InPOG-NB-18-02 (P)** Indian Non-high risk Neuroblastoma Study. **PI: Vikramjit Kanwar**
2. **InPOG-PALL-18-01 (P)** The Demographics And End-Of-Life Symptoms And Treatments in Pediatric Cancer Patients at Various Pediatric Oncology Centers In India. **PI: Gayatri Palat**
3. **InPOG-HIST-18-02 (P)** A multicentric phase III randomized trial to evaluate the efficacy of an early response-based treatment algorithm for children diagnosed with Hemophagocytic Lymphohistiocytosis. **PI Nita Radhakrishnan**
4. **InPOG-WT-18-02 (P)** Clinico-Pathological, Treatment And Outcome Measures Of Wilms Tumor – A Multi-Centric Study. **PI – Sirisharani Siddaiahgari**
5. **InPOG-CNS-19-01 (P)** Registry study on epidemiology of medulloblastoma in India. **PI – Manas Kalra**
6. **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**
7. **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**
8. **InPOG-HL-19-03 (P)** 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. **PI – Gaurav Narula**
9. **InPOG-SUPP-19-01 (P)** A Prospective Open-labeled Randomized Control Trial of Proactive Enteral Nutrition Versus Standard of Care in Children with Cancer and High Nutritional Risk. **PI – Maya Prasad**