



# InPOG Newsletter



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## 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	Revathy Raj
CNS	Anirban Das
NBL	Vikramjit Kanwar
Retino	Santosh Honavar
Renal	Sirisha Rani
Liver	Sandeep Agarwala
PNET	Sandeep Jain
Osteo	Ashish Gulia
STS	Arpita Bhattacharya
GCT	Girish Chinnaswamy
Rare, epith	Harsha Prasad
HSCT	Satya Yadav
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,

We bring to you Volume 5 Issue 1 of the newsletter – which implies that this is the 5<sup>th</sup> year of our very exciting journey. New studies continue to join the fold (five studies have been provisionally registered in the last four months including three on CNS tumours). Another notable progress is the three studies on relapsed/refractory childhood cancers including Hodgkin lymphoma (currently recruiting) and those on LCH and ALL under development.

Congratulations to Dr Deepak Bansal and Dr Sidharth Totadri for completion of the retrospective study InPOG-CML-16-01 *Study of treatment and outcome of chronic myeloid leukemia in children and adolescents in India*. They collected information on 171 children with AML from 9 centres. We look forward to their results in the upcoming meetings.

Warm wishes

InPOG Executive

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

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## Study Summary Portfolio (Total 29)

Subcommittee	Provisional Registration (13)	Full Registration (3)	Recruitment Ongoing (7)	Recruitment Complete (6)
ALL	InPOG-ALL-19-02		InPOG-ALL-15-01	
AML			InPOG-AML-16-01	
ChMyelop Dis				InPOG-CML-16-01
HL			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-16-01 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				
Epidemiology	InPOG-EPI-16-01			
Late Effects		InPOG-LE-17-02	InPOG-LE-16-01	
Palliative Care	InPOG-PALL-18-01			
Cancer Genetics	InPOG-CANGEN-16-01			

## **InPOGStudies - Recruitment Complete (6)**

### **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>	409
<b>Recruitment Closed</b>	February 2018
<b>Centers study open in</b>	27centres

### **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-PocketExpenditure 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

### **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, Dr Sidharth Totadri
<b>Registered with InPOG</b>	Feb 2018
<b>CTRI Registration</b>	
<b>Recruitment commenced</b>	Yes
<b>Currently patients recruited</b>	171
<b>Target patient recruitment</b>	150
<b>Anticipated duration of recruitment</b>	8 months
<b>Centers study open in</b>	9

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

### **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>	999
<b>Target patient recruitment</b>	2240
<b>Centers study open in</b>	5centres

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

### **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>Recruitment commenced</b>	July 2014
<b>Currently patients recruited</b>	119
<b>Target patient recruitment</b>	700
<b>Anticipated duration of recruitment</b>	5 years
<b>Centers study open in</b>	4 centres

- Cancer Institute, Chennai
- Institute Rotary Cancer Hospital, AIIMS, New Delhi
- JIPMER, Puducherry
- MNJ Cancer Hospital, Hyderabad

### **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>	1262
<b>Target patient recruitment</b>	At least 500 (desirable 1000)
<b>Anticipated duration of recruitment</b>	5 years
<b>Centers study open in</b>	14centres

- 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>	8centres

- 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>	
<b>Recruitment commenced</b>	Yes
<b>Currently patients recruited</b>	1
<b>Target patient recruitment</b>	100
<b>Anticipated duration of recruitment</b>	3 years
<b>Centers study open in</b>	6

- BJ Wadia Hospital, Mumbai
- Indraprastha Apollo Hospital, New Delhi
- Kalawati Children’s Hospital, New Delhi
- Mahavir Cancer Sansthan, Patna
- Max Smart Super Specialty Hospital, Saket, New Delhi
- Rajiv Gandhi Cancer Institute, 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>	DrAnirban Das
<b>Registered with InPOG</b>	October 2018
<b>CTRI Registration</b>	
<b>Recruitment commenced</b>	Yes
<b>Currently patients recruited</b>	0
<b>Target patient recruitment</b>	50
<b>Anticipated duration of recruitment</b>	5 years
<b>Centers study open in</b>	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**

<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>	8
<b>Target patient recruitment</b>	250
<b>Anticipated duration of recruitment</b>	3 years
<b>Centers study open in</b>	5

- Cancer Institute, Chennai – **NEW**
- BJ Wadia Hospital, Mumbai – **NEW**
- Indraprastha Apollo Hospital, New Delhi – **NEW**
- Tata Medical Centre, Kolkata – **NEW**
- Tata Medical Centre, Mumbai – **NEW**

## **InPOG Studies Granted Full Registration (3)**

### **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>	NA

### **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>	
<b>Recruitment commenced</b>	No
<b>Currently patients recruited</b>	NA
<b>Target patient recruitment</b>	6000
<b>Anticipated duration of recruitment</b>	6 months
<b>Centers study open in</b>	NA

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

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

<b>Principal Investigator</b>	DrVikramjit 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 Studies Granted Provisional Registration (13)

1. **InPOG-EPI-16-01 (P)**. Association of gender and childhood cancer registration in India. **PI: Hari Sankaran**
2. **InPOG-WT-16-01 (P)**. Indigenously developed Wilms Tumor Protocol. **PI: Sameer Bakhshi**
3. **InPOG-CANGEN-16-01 (P)**. Evaluation of underlying genetic predisposition for acute myeloid leukemia in children and young adults. **PI: Tulika Seth**
4. **InPOG-RB-17-01 (P)** A Prospective Collaborative Study for Newly Diagnosed patients with Retinoblastoma. **PI: Santosh Honavar**
5. **InPOG-NB-18-02 (P)** Indian Non-high risk Neuroblastoma Study. **PI: Vikramjit Kanwar**
6. **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**
7. **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**
8. **InPOG-WT-18-02 (P)** Clinico-Pathological, Treatment And Outcome Measures Of Wilms Tumor – A Multi-Centric Study. **PI – Sirisharani Siddaiahgari**
9. **InPOG-CNS-19-01 (P)** Registry study on epidemiology of medulloblastoma in India. **PI – Manas Kalra– NEW**
10. **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– NEW**
11. **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– NEW**
12. **InPOG-HIST-19-03 (P)** Prospective Collaborative Study for pulse dexamethasone and lenalidomide in Relapsed / Refractory Langerhans cell histiocytosis (LENDEX-LCH study). **PI – Ramya Uppuluri– NEW**
13. **InPOG-ALL-19-02 (P)** Registry study for relapsed childhood acute lymphoblastic leukaemia using protocol ALL-R1. **PI – Vaskar Saha– NEW**