



# 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	Venkatraman Radhakrishnan
Rare, epith	Harsha Prasad
HSCT	Satya Yadav
Acc to Care	Shruti Kakkar
Supportive	Maya Prasad
Epidemiology	Hari Sankaran
Late effects	Rachna Seth
Palliative	Gayatri Palat
Can Genetics	Nita Radhakrishnan

Dear Friends,

It is our pleasure to bring to you the next InPOG newsletter summarizing the current status on InPOG studies. Five studies have completed recruiting patients and are in the process of data collection, data analysis, and dissemination of results through presentations and publications. Many of these will be presented at the forthcoming SIOP and PHOCON. Below are those selected for presentation at SIOP 2018 at Kyoto.

- *Initial Report On InPOG-HL-15-01- A Risk-Stratified Response-Based Collaborative Protocol For Newly Diagnosed Childhood Hodgkin Lymphoma Patients In India*
- *Exploring Barriers To Accessing Care For Childhood Cancers In India: A Qualitative Study (INPOG-ACC-16-03)*
- *The Indian Childhood Cancer Survivorship Study (C2S Study): After Treatment Completion Registry Of Childhood Cancers - Phase -I. An INPOG-LE-16-01 Study*
- *Families Of Children Newly Diagnosed With Cancer Incur Significant Out-Of-Pocket Expenditure For Treatment – Report Of A Multi-Site Prospective Longitudinal Study From India (INPOG-ACC-16-01)*

We would like to congratulate the InPOG-LE-16-01 team led by Dr Rachna Seth and Dr Gauri Kapoor. This study now has recruited over 1000 children on the study (in just over 2 years after start of study). Also worth noting are the new study on relapsed/refractory Hodgkin's disease led by Dr Amita Mahajan which is now enrolling patients, as well the proposed study on demographics and end-of-life symptoms and treatments in pediatric cancer being developed by Dr Gayatri Palat.

Recently we have made progress on identifying a potential cloud-based database which can also work as a clinical trial management system and is likely to be free. We hope to soon have this option available to InPOG members allowing them to accelerate development and conduct of their studies. The program for PHOCON 2018 to be held at Bangalore is taking shape. We are grateful to the organizers for providing dedicated time for individual InPOG subcommittee meetings (on 30<sup>th</sup> Nov morning) as well as the InPOG report (30<sup>th</sup> Nov evening).

<https://goo.gl/forms/HTUnL6wZyYEVbhf2> is link to join as a full/associate InPOG member, while link to join as a trainee InPOG member (those currently working as trainees/fellows) is <https://goo.gl/forms/kjDHLxiGv0TSfw972>

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

## Study Summary Portfolio (Total 22)

Subcommittee	Provisional Registration (8)	Full Registration (4)	Recruitment Ongoing (6)	Recruitment Complete (5)
ALL			InPOG-ALL-15-01	
AML			InPOG-AML-16-01	
Ch Myelop Dis			InPOG-CML-16-01	
HL			InPOG-HL-17-02	InPOG-HL-15-01
NHL				InPOG-NHL-16-01
Histiocytosis			InPOG-HIST-17-01	
CNS				
Neuroblastoma	InPOG-NB-18-01 InPOG-NB-18-02			
Retinoblastoma	InPOG-RB-17-01			
Renal	InPOG-WT-16-01			
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			

## **InPOG Studies - Recruitment Complete**

### **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>	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

### **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 Studies - Recruitment Ongoing**

### **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>	644
<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-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>	99

**Target patient recruitment** 700  
**Anticipated duration of recruitment** 5 years  
**Centers study open in** 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**

**Principal Investigator** Dr Rachna Seth  
**Registered with InPOG** May 2016  
**CTRI Registration**  
**Recruitment commenced** June 2016  
**Currently patients recruited** 1056  
**Target patient recruitment** At least 500 (desirable 1000)  
**Anticipated duration of recruitment** 5 years  
**Centers study open in** 14 centres

- All India Institute of Medical Sciences, New Delhi
- Apollo Hospital, Chennai – **NEW**
- 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 – **NEW**
- 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**

**Principal Investigator** 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>	6
<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 – **NEW**
- 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 – **NEW**

#### **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>	71
<b>Target patient recruitment</b>	150
<b>Anticipated duration of recruitment</b>	8 months
<b>Centers study open in</b>	10

- All India Institute of Medical Sciences, Bhubhaneshwar – **NEW**
- AIIMS, New Delhi (Pediatric Oncology unit, Dept. of Pediatrics and Dept. of Hematology) – **NEW**
- Christian Medical College, Ludhiana – **NEW**
- Kidwai Memorial Institute of Oncology, Bengaluru – **NEW**
- Institute of Medical Sciences, Benares Hindu University – **NEW**
- Lady Hardinge Medical College, New Delhi – **NEW**
- Lokmanya Tilak Municipal Medical College, Sion, Mumbai – **NEW**
- MVR Cancer Centre and Research Institute, Calicut – **NEW**
- PGIMER, Chandigarh – **NEW**
- Tata Medical Centre, Kolkata – **NEW**

### InPOG-HL-17-02

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

Principal Investigator	Dr Amita Mahajan
Registered with InPOG	May 2018
CTRI Registration	
Recruitment commenced	Yes
Currently patients recruited	0
Target patient recruitment	100
Anticipated duration of recruitment	3 years
Centers study open in	2

- Mahavir Cancer Sansthan, Patna – **NEW**
- Max Smart Super Specialty Hospital, Saket, New Delhi – **NEW**

## InPOG Studies Granted Full Registration

### 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	
Recruitment commenced	No
Currently patients recruited	NA
Target patient recruitment	250
Anticipated duration of recruitment	1 year
Centers study open in	NA

### InPOG-LE-17-02

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

Principal Investigator	Dr Maya Prasad
Registered with InPOG	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 – NEW**

**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>	13000
<b>Anticipated duration of recruitment</b>	4 years
<b>Centers study open in</b>	NA

**InPOG-RARE-17-01 – NEW**

**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>	No
<b>Currently patients recruited</b>	NA
<b>Target patient recruitment</b>	50
<b>Anticipated duration of recruitment</b>	5 years
<b>Centers study open in</b>	NA

## **InPOG Studies Granted Provisional Registration**

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: IC Verma**
4. **InPOG-RB-17-01 (P)** A Prospective Collaborative Study for Newly Diagnosed patients with Retinoblastoma. **PI: Santosh Honavar**
5. **InPOG-NB-18-01 (P)** India Neuroblastoma Registration and Biology Study. **PI: Vikramjit Kanwar**
6. **InPOG-NB-18-02 (P)** Indian Non-high risk Neuroblastoma Study. **PI: Vikramjit Kanwar**
7. **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 – NEW**