



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	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,

As we bring this newsletter to you, we are faced with an unprecedented healthcare scenario, which has percolated all aspects of our lives. Its ramifications are not only on the health of the individual and the country but also on our social fabric and our economy. Not surprisingly its impact is felt on InPOG studies as well, some of which have either suspended recruitment or are seeing a significant decline in patients being recruited.

At the same time, COVID-19 has led to an explosion of clinical research. As of 26th Apr 2020, there are 6754 “COVID-19” articles on Pubmed and 424 on “COVID-19” AND “Cancer”. There are 1528 COVID-19 clinical trials registered onto the WHO International Clinical Trials Registry Platform. We at InPOG have also initiated a couple of studies. Dr Revathy Raj has launched a very simple mobile/computer based link <https://forms.gle/yqxM3bzCsALNMoN77> for registering and tracking COVID19 in children in cancer in India. This will allow us to get immediate and real-time valuable data while the formal study, **InPOG-EPI-20-01 (P) Epidemiology Of COVID-19 In Children With Cancer In India**, which is currently under peer-review is up and running. Also provisionally registered, and currently under peer-review is the study **InPOG-ACC-20-04 (P) The impact of COVID-19 pandemic on care of children with cancer in India**.

Additionally, two new studies have now completed all formalities and are now available for participation and enrollment of patients. These are the **InPOG-HIST-19-03** on relapsed/refractory LCH by Dr Ramya Uppuluri (ramya.december@gmail.com) and the **InPOG-NB-18-01** on neuroblastoma by Dr Vikramjit Kanwar (vikramjit.kanwar@gmail.com). We would encourage you to contact the respective Principal Investigators to get more information.

We would like to end by wishing all of you, your families and your patients to be safe and well. These are challenging times and we draw strength and inspiration from each other.

Warm wishes, InPOG Executive, inpogexec@gmail.com

<https://goo.gl/forms/HTUnL6wZyYEVbHf2> for InPOG membership

Study Summary Portfolio (Total 31)

Subcommittee	Provisional Registration (10)	Full Registration (4)	Recruitment Ongoing (10)	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-17-01 InPOG-HIST-19-03	
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				
Access to Care	InPOG-ACC-16-04		InPOG-ACC-16-02	InPOG-ACC-16-01 InPOG-ACC-16-03
Supportive Care	InPOG-SUPP-19-01			
Epidemiology	InPOG-EPI-20-01			
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

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

1. 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. *Pediatr Hematol Oncol J* 2020. In Press

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

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

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 Studies - Recruitment Ongoing (10)

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	1979
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	
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	15 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
- Tata Memorial Hospital, Mumbai – **NEW**

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	Ongoing
Recruitment commenced	Yes
Currently patients recruited	20
Target patient recruitment	300
Anticipated duration of recruitment	5 years
Centers study open in	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

Principal Investigator	Dr Amita Mahajan
Registered with InPOG	May 2018
CTRI Registration	Ref/2019/03/024719
Recruitment commenced	Yes
Currently patients recruited	19
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	1
Target patient recruitment	50
Anticipated duration of recruitment	5 years
Centers study open in	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**

Principal Investigator	Dr Maya Prasad
Registered with InPOG	July 2017
CTRI Registration	CTRI/2019/02/017851
Recruitment commenced	Yes

Currently patients recruited	70
Target patient recruitment	250
Anticipated duration of recruitment	3 years
Centers study open in	9 centres

- All India Institute of Medical Sciences, New Delhi
- 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-ACC-16-02

Accessing Childhood CancEr Services in INDIA (ACCESS INDIA)

Principal Investigator	Dr Ramandeep Singh Arora
Registered with InPOG	Sep 2018
CTRI Registration	
Recruitment commenced	No
Currently patients recruited	1427
Target patient recruitment	6000
Anticipated duration of recruitment	12 months
Centers study open in	71 centres

- Aadhar Health Institute, Hisar
- Acharya Tulsi Regional Cancer Centre, Bikaner – **NEW**
- Advance Cancer Diagnostic Treatment & Research Centre, Bhatinda
- Aligarh Muslim University, Aligarh
- All India Institute of Medical Sciences, Bhubaneswar – **NEW**
- All India Institute of Medical Sciences, Hematology, New Delhi
- All India Institute of Medical Sciences, Pediatrics, New Delhi
- All India Institute of Medical Sciences, Patna
- Apollo Gleneagles Cancer Hospital, Kolkata
- Army Hospital Research and Referral, New Delhi
- Asian Institute of Medical Sciences, Faridabad
- Assam Medical College, Dibrugarh
- Banaras Hindu University- Institute of Medical Sciences, Varanasi
- BL Kapur, New Delhi

- Cachar Cancer Centre, Silchar
- Chittaranjan National Cancer Institute, Kolkata
- Christian Medical College & Hospital, Ludhiana
- Command Hospital, Kolkata
- Dayanand Medical College and Hospital, Ludhiana
- Dharamshila Narayana Superspeciality Hospital, New Delhi
- Dr. Bhubaneswar Borooah Cancer Institute, Guwahati
- Dr. Ram Manohar Lohia Hospital, New Delhi
- Gauhati Medical College & Hospital, Guwahati
- Guru Gobind Singh Medical College and Hospital, Faridkot
- HCG Regency Oncology Healthcare Pvt. Limited, Kanpur
- Himalayan Institute Hospital Trust, Dehradun
- Indraprastha Apollo Hospital, New Delhi
- Institute of Child Health, Kolkata
- Institute of Hematology & Transfusion Medicine, Medical College & Hospital, Kolkata
- Institute Rotary Cancer Hospital, AIIMS, New Delhi
- Jawaharlal Nehru Institute of Medical Sciences, Imphal
- Kamla Nehru Memorial Hospital, Allahabad
- King George's medical University, Lucknow
- L V Prasad Eye Institute, Bhubaneswar
- Lok Narayan Jai Prakash Hospital, New Delhi
- Mahavir Cancer Sansthan (MCS), Patna – **NEW**
- Max Super Speciality Hospital, Bathinda
- Max Super Specialty Hospital, Deharadun
- Max Super Specialty Hospital, Mohali
- Max Super Specialty Hospital, Patparganj, New Delhi
- Max Super Specialty Hospital, Saket, New Delhi
- Max Super Specialty Hospital, Vaishali, Ghaziabad
- Medical College & Hospital, Kolkata
- Mizoram State Cancer Institute, Aizawl
- Naga Hospital Authority, Kohima
- Nil Ratan Sarkar Medical College and Hospital (NRS)- Hematology & Pediatrics, Kolkata – **NEW**
- Paras Cancer centre, Patna – **NEW**
- North East Cancer Institute, Jorabat
- North Eastern Indira Gandhi Regional Institute of Health and Medical Sciences, Shillong
- Pt. BD Sharma Post Graduate Institute of Medical Sciences, Rohtak
- Parvati Devi Hospital, Amritsar
- Punjab Cancer Centre, Bhatinda
- Postgraduate Institute of Medical Education, Chandigarh

- Purshottamdas Savitridevi Cancer Care Research Centre, Agra
- Rajendra Inst of Medical Sciences (RIMS), Ranchi
- Rajiv Gandhi Cancer Institute and Research centre, New Delhi
- Ramjanam Sukakshana Pandey Cancer Hospital Cancer Hospital, Ranchi
- RCC Jammu / Government Medial College, Jammu
- Regional Institute of Medical Sciences (RIMS), Imphal
- Royal Cancer Institute and Research Centre, Kanpur
- Safdarjung Hospital & Vardhman Mahavir Medical Collage, New Delhi
- Sanjay Gandhi Post Graduate Intitute of Medical Sciences, Lucknow – **NEW**
- Saroj Gupta Cancer Centre and Research Institute, Kolkata
- Sarojini Naidu Medical College, Agra
- 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
- Valentis Cancer Care Hospital Pvt. Ltd., Meerut – **NEW**

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	5
Target patient recruitment	220
Anticipated duration of recruitment	5 years
Centers study open in	1

- Tata Medical Centre, Kolkata

InPOG-HIST-19-03 – **NEW**

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	In process

Recruitment commenced	Yes
Currently patients recruited	2
Target patient recruitment	50
Anticipated duration of recruitment	3 years
Centers study open in	2

- Apollo Hospital, Chennai – **NEW**
- Indraprastha Apollo Hospital, New Delhi – **NEW**

InPOG-NB-18-01 – NEW

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	0
Target patient recruitment	500
Anticipated duration of recruitment	5years
Centers study open in	6

- Apollo Multispecialty Hospital, Chennai, Tamil Nadu – **NEW**
- Apollo Indraprastha Superspecialty Hospital, New Delhi – **NEW**
- CIMS Hospital, Ahmedabad. Gujarat – **NEW**
- Deenanath Mangeshkar Hospital, Pune, Maharashtra – **NEW**
- Indo-American Cancer Hospital Hyderabad, Telangana – **NEW**
- MVR Hospital Kozhikode, Kerala – **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

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

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	
Recruitment commenced	No
Currently patients recruited	NA
Target patient recruitment	330
Anticipated duration of recruitment	3 years
Centers study open in	NA

InPOG-HL-19-03 – NEW

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	
Recruitment commenced	No
Currently patients recruited	NA

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

InPOG-WT-18-02 – NEW

Clinico-Pathological, Treatment And Outcome Measures Of Wilms Tumor – A Multi-Centric Study.

Principal Investigator	Dr Sirisharani Siddaiahgari
Registered with InPOG	Apr 2020
CTRI Registration	
Recruitment commenced	No
Currently patients recruited	NA
Target patient recruitment	300-500
Anticipated duration of recruitment	10 years retrospectively
Centers study open in	NA

InPOG Studies Granted Provisional Registration (10)

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-CNS-19-01 (P)** Registry study on epidemiology of medulloblastoma in India. **PI – Manas Kalra**
5. **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**
6. **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**
7. **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**
8. **InPOG-PNET-19-02 (P)** Evaluation of clinic-pathological characteristics, prognostic factors and treatment outcomes in patients with ESFT in children and young adults. **PI – Sandeep Jain – NEW**
9. **InPOG-EPI-20-01 (P)** Epidemiology Of COVID-19 In Children With Cancer In India. **PI – Revathy Raj – NEW**
10. **InPOG-ACC-20-04 (P)** The impact of COVID-19 pandemic on care of children with cancer in India. **PI – Ramandeep Arora – NEW**