# **PHOSSCON 2025 - Consolidated Report**



# Theme: Integrating Cure and Care 28-29 November 2025 | Manipal, Udupi

The 9th Pediatric Hematology Oncology Support Services Conference (PHOSSCON 2025) happened over two days with one clear purpose, bringing together the science of cure with the humanity of care. The theme, Integrating Cure and Care, shaped every discussion, reflection and interaction, ensuring that civil society and clinical leaders worked side by side toward a unified vision for childhood cancer care in India.

### **Background and Purpose**

Initiated in 2016 as a joint platform alongside PHOCON, PHOSSCON aims to strengthen dialogue between clinicians and the civil society organisations that work every day with children with cancer and their families. Over the years, it has evolved into the national convening space for shared learning, capacity building, and collaborative advocacy for childhood cancer care.

### The 2025 edition aimed to:

- Deepen collaboration between doctors and NGOs.
- Highlight patient-centred care models.
- Build research literacy and policy partnerships.
- Showcase innovations in palliative, psychosocial and survivorship support.

### **Day 1 - 28 November 2025**

# **Opening Session**

The conference opened with warm words from Dr. Haresh Gupta, Organising Secretary, and Ms. Poonam Bagai, Chair, Standing Committee of PHOSSCON. In her address, Ms Poonam Bagai traced the journey of PHOSSCON from its first edition in Mumbai in 2016 to its ninth in Manipal reflecting how more and more organisations have joined hands over the years to make childhood cancer care inclusive and holistic.

She reminded the audience that "integrating cure and care" means not just improving medical outcomes, but ensuring dignity, empathy and support at every step of a child's journey. With 41 organizations and more that 150 participants represented, the hall carried an energy of collaboration and shared purpose.

### **Session 1: Civil Society Presentations - Models of Care and Compassion**

The first session showcased the breadth of NGO work across India, from palliative care to psychosocial support.

Speakers included:

- Pallium India (Sunanda Samal): presented the 'DEF model' (Demonstration, Education, Facilitation) and emphasised community-led palliative care.
- Hope Child Cancer Care Foundation (Amir): spoke on holistic family support through Hope Homes and the "No Child Loses Childhood to Cancer" mission.
- YRG Care (S.K. Satish): introduced Camp Rainbow, a psychosocial intervention offering residential camps for children with long-term illnesses.
- V-Care Foundation (Divya Poojari): shared their 30-year journey of empowering families through patient navigation, nutrition, prosthetics for retinoblastoma, and education for children in treatment.
- Priyanka Jariwala Memorial Foundation (Sandip Jariwala): reflected on building partnerships that sustain paediatric oncology services across states.
- Garia Welfare Society (Pradeep Maity): highlighted cancer awareness and HPV vaccination efforts in schools in West Bengal.

The session set the tone for the conference, a living testimony that care is not charity, but collaboration.

# Session 2: "Not About Me, But With Me" - Patient-Centred Care (PCC)

Moderated by Mr. Nitai Panigrahi and Mr. Nirbhay Singh, this session was one of the most moving segments of PHOSSCON 2025.

Opening with the story of Pooja, a 13-year-old who lost her hand to cancer surgery, the session urged participants to reflect on how children and families often face treatment journeys filled with confusion, fear and isolation and how communication and inclusion can change that.

Ms. Poonam Bagai's keynote on 'Civil Society's Role in PCC' underlined that NGOs must not only deliver services but advocate for systems that respect the child's voice. The panel 'Real Voices, Real Care' brought together clinicians and advocates including Dr. Suresh Sunder, Dr. Amrit Varshani, Ms. Priti Rastogi, Ms. Ritu Bhalla, and Ms. Preeti Phad, exploring how empathy, inclusion and shared decision-making strengthen outcomes.

The takeaway of the session was Patient-centred care is not just a model, it is a mindset.

In a defining moment of the conference, the session concluded with a shared pledge, a symbolic act bringing together clinicians, civil society and survivors on a unified platform. Clinicians including **Dr. Sripad Banavali**, **Dr. Manas Kalra**, **Dr. Vasudeva Bhat**, **Dr. Sameer Bakhshi**, **Dr. Amita Mahajan and Dr. Shruti Kakkar** joined hands with NGOs and survivors to reaffirm their collective commitment to patient-led decision making and holistic care.

This marked the **first time** at PHOSSCON where healthcare teams and civil society publicly pledged together reinforcing that patient-centred care is not only an ideal, but a shared responsibility. The pledge goes as follow;

### **Advocacy for Patient-Centred Care**

We, the civil society organisations working in hematology and pediatric oncology, together with the pediatric oncology community of clinicians, pledge toward patient-centred care for every child with cancer and every family in India. This is our shared commitment; this is advocacy.





# The session had an impactful Survivor Leadership Pledge

We stand here today because someone held our hand when cancer tried to take everything away from us. We survived because care reached us... at home, in hospitals, and in the hardest moments. We are here because our voices were heard, not ignored.

We are patients... people with dignity, dreams and rights. No child should suffer because of distance, poverty or lack of awareness. No parent should face cancer alone.

We are living proof that care and compassion save lives. We survived so that every child will receive the same chance we received.

We, the survivors of India, pledge to make childhood cancer care patient-centred, compassionate and accessible. **Not about us, but with us.**For every child, in every state... until no child is left behind.



**№ Pledge Videos from PHOSSCON 2025** 

#### Session 3: Access to Clinical Trials and Research in India

Led by Dr. Pooja Sharma (APAR Health), this session demystified research access for patients. It introduced PACER, an initiative to make clinical trials more transparent and accessible. The practical workshop guided NGOs and social workers on how to navigate CTRI, India's clinical trial registry.

Ms. Khushboo Sharma demonstrated how to search disease-specific studies, encouraging patient advocates to act as information bridges between families and researchers.

# Session 4: Research Priorities for India - Workshop on Advancing Childhood Cancer Care

Dr. Ramandeep Singh Arora and Ms Tanya Dhawan facilitated a participatory workshop to identify priority research questions for India's childhood cancer ecosystem.

Breakout groups discussed:

- 1. Setting national priorities for collaborative research.
- 2. Planning next steps for dissemination and stakeholder buy-in.

  The emphasis was on co-creation, moving from isolated studies to shared frameworks for action.



# **Session 5: Formal Inauguration**

The formal inauguration, held jointly with PHOCON 2025, featured eminent guests including:

- Chief Guest: Dr. Avinash ShettyGuest of Honour: Dr. Raj Warrier
- Special Addresses: Dr. Vasudeva Bhat (Organising Chair, PHOCON) and Dr. Archana M.V.

The inauguration reaffirmed PHOSSCON's position as the civil society arm of PHOCON where scientific advancements and human support meet on the same platform.



# Meet & Greet: Strengthening Relationships Beyond the Agenda

The Day 1 ended with a beautiful Meet & Greet. The session was more than a fun social interaction, it served as an intentional space for sharing, connecting and building trust among participants. It created a warm environment where CSOs, survivors and programme teams could engage beyond formal sessions, deepening understanding and strengthening alignment.

Conversations that began during presentations continued here, transforming ideas into meaningful dialogue and, in many cases, the early stages of partnership. This gathering enabled

organisations to share experiences, challenges and models of care in an open and supportive setting reinforcing a sense of collective ownership of the childhood cancer mission. For many, this space became the bridge between conversation and collaboration where relationships grew, networks expanded, and individuals found common purpose. The Meet & Greet highlighted the importance of community in this ecosystem, demonstrating that progress is not only driven by strategy and science, but also by the human connections that make shared action possible.

### **Day 2 - 29 November 2025**

### **Session 7: Funding the Fight - Models that Work**

This session explored sustainable funding and partnership models:

- 1. Institutional Partnership ABCF (Mr. Gopal Kumar)
- 2. Collaborative & Research Partnership ALSAC (Ms. Priya Tummalapalli)
- 3. Beneficiary Support Model Indian Cancer Society (Dr. Guru Suhas)
- 4. Association-led Advocacy Model Thalassemia Society of India (Ms. Shoba Tuli)

The discussions highlighted transparency, partnership equity, and storytelling as the backbone of trust-based fundraising.

### Session 8: Bridging the Gap - Palliative Care in Pediatric Oncology

Chaired by Dr. Shweta Pathak, this session called attention to gaps across levels of care. Speakers from across India, Dr. Amita Mahajan, Dr. Ramandeep Arora, Dr. Vinay M, Dr. Veronique Dinand, Dr. Seema Rao, and Dr. Philomena D'Souza shared ground realities and integration models. Dr. Krithika S. Rao presented the Manipal experience in building paediatric palliative care services.

The message from the session was, Palliative care is not an afterthought, it is a continuum of cure.

### Session 9: Improving Survival Outcomes of ALL in India

The session featured a keynote by Prof. Ajay Vora (UK) and insights from Dr. Sameer Bakhshi (AIIMS) on lessons from global research and India's roadmap. They also explored how India can accelerate progress in Acute Lymphoblastic Leukemia outcomes. Panelists including Mr. Ajay, Mr. Sandeep Jariwala and Mr. Nitai Panigrahi discussed the power of collaboration and data-sharing in improving outcomes.

Lessons from global research, combined with India's emerging collaborations, highlighted how standardised care, shared data and stronger networks can significantly improve survival rates nationwide.

### Launch of the ALL Maintenance Guide

During this session, Dr. Amita Mahajan released the ALL Maintenance Guide, a practical tool to support families through the critical maintenance phase of ALL treatment. Designed as a for parents, teenagers and young adults and treating doctors, the guide helps monitor adherence, understand home-based challenges and ensure continuity of care beyond the hospital.



**Sessions 10-12: The Way Forward** 

### **Session 10: Roadmap towards GICC Goals**

Led by Dr. Cherian Verghese, the session examined India's progress toward the Global Initiative for Childhood Cancer (GICC) goals, 100% health coverage, 100% access, 60% survival. Discussions focused on capacity building, advocacy and partnership with WHO.

# Session 11: Continuity of Care - Survivorship

Dr. Purna Kurkure and Ms. Poonam Bagai led this forward-looking discussion on survivorship and neurocognitive testing. Survivors shared lived experiences, reminding the group that healing does not end with remission.



# Session 12: NGOs in ACT Clinics and Beyond

Representatives from AIIMS, ICS, CanKids and partner organisations discussed psychosocial support, patient navigation and the role of civil society in long-term survivorship clinics.

The concluding discussion explored the role of NGOs in ACT Clinics and long-term care, re-emphasizing the indispensable role of psychosocial support, survivorship navigation and patient advocacy.

# **Final Day Reflections:**

The second day of PHOSSCON 2025 began on a thoughtful and energised note, as participants shared reflections from the previous day's discussions. Many expressed deep appreciation for the strong alignment with the conference theme, "Integrating Cure and Care," noting how every session had managed to stay rooted in patient needs, lived experiences and system-wide collaboration.

A recurring highlight was the emphasis on survivor voices. One participant remarked,

"What I really liked was the Survivors' Pledge and the way we kept the patient-centric approach at the centre of discussions. Sometimes conferences drift away from their theme, but PHOSSCON stayed absolutely on-track. Well done, survivors."

Participants also commended the research-priority-setting session led by Dr. Amita Mahajan and her team, which many felt expanded the role and vision of NGOs in the research landscape. As one participant shared,

"NGOs often don't think from a data or research perspective. The session on priority setting helped us expand our thinking in that direction and it is absolutely welcome."

The reflections then shifted to patient rights and communication, reinforcing the importance of honest, compassionate dialogue with families. One powerful observation was,

"Yesterday's discussion on whether treatment details should be shared with patients was very stimulating. My view is that we should share everything openly. The entire medical team, doctors, nurses, everyone involved should communicate clearly and reassure the patient that we are with them for their betterment."

Survivorship groups contributed practical suggestions to strengthen peer-led advocacy and leadership. Their reflections carried a sense of continuity and collective responsibility: "Earlier we used to have multiple sessions on survivorship where survivors participated actively, learned, and spread awareness. With so many CSOs present, each organisation should aim to bring at least two survivors into these sessions. This builds leadership, encourages volunteering, and strengthens survivor-led advocacy."

There was also a clear acknowledgment that the scientific quality of discussions had risen significantly this year. As Mr Sandip Jariwala mentioned, "The discussions this year were at a much higher level compared to last year. We engaged with WHO priorities, GICC frameworks and other advanced topics which made the sessions more impactful. It felt elevated, and it can lead to much more meaningful outcomes."

A final collective suggestion from many participants focused on strengthening patient advocacy systemwide, "Since all of us, directly or indirectly, contribute to patient advocacy, it would be extremely beneficial to develop an online course on patient-centred care and advocacy. This would help standardise knowledge and empower both NGOs and survivors."

These reflections captured the spirit of Day 2 enthusiastic, aligned and deeply committed to advancing patient-centred, research-informed and survivor-led childhood cancer care across India.



# **Closing Remarks:**

PHOSSCON 2025 ended not with a conclusion, but a collective commitment, to cure more, care better, and collaborate deeper. As Ms. Poonam Bagai reminded participants, "Cure is what doctors aim for. Care is what keeps it human. Integrating the two is what keeps it whole."

From research to respite, from advocacy to access, this ninth PHOSSCON reaffirmed one thing...Together, we can defeat childhood cancer, not just medically, but humanely.

# **Action Points:**

- Integrate cure and care throughout the entire treatment journey, ensuring psychosocial support, navigation and palliative care begin at diagnosis and continue through survivorship.
- Strengthen survivor voice and leadership by increasing participation and positioning survivors as co-creators in programmes, advocacy and policy.
- Improve communication with patients and families through transparent, empathetic and consistent sharing of treatment information across the entire care team.
- Build NGO capacity for research, data collection and clinical trial literacy, enabling civil society to contribute to national research priorities and guide families accurately.
- Deepen partnerships between civil society organisations and clinical teams to create a unified ecosystem that supports children and families seamlessly.

- Expand early and continuous integration of palliative care, ensuring symptom relief, psychosocial support, and family support are available at every stage of treatment.
- Strengthen survivorship pathways, including long-term follow-up, late-effects education, peer support, and NGO roles in ACT Clinics.
- Promote sustainable, transparent, and equitable funding models that emphasise dignity, trust and collaborative fundraising.
- Develop a standardised training platform or online course on patient-centred care and advocacy for NGOs, survivors and care teams.
- Consolidate PHOSSCON as a year-round platform for coordination, shared learning and collective action across India's childhood cancer support ecosystem.

# **Communications, Awareness and Media Outreach**

A coordinated communication effort ensured that the message and impact of PHOSSCON 2025 extended far beyond the event venue. The **Communication, Education, Public Awareness & Advocacy (CEPAA) Team** of CanKids played a key role in shaping public engagement and supporting partner organisations in amplifying the theme "Integrating Cure and Care."

Ahead of the conference, the team developed and shared:

- A national press release template for NGOs to customise and circulate to regional and local media
- Social media prompts to maintain unified voice and messaging
- Captions and hashtags to help partners post real-time updates

This enabled consistent storytelling across states and organisations, ensuring that every stakeholder from large national NGOs to local support groups could participate in shared communication efforts with confidence and clarity.

### **Media Impact Summary**

PHOSSCON 2025 received coverage across 39 media publications including 27 print articles and 12 online features spanning national, regional, English and vernacular platforms. Publications such as The Times of India, Deccan Herald, The New Indian Express, The Asian Age, Daijiworld and BW Healthcare World highlighted the conference's focus on integrating cure and care, survivor leadership and national collaboration. This extensive visibility ensured that the message of holistic, patient-centred childhood cancer care reached communities, institutions and stakeholders across the country.

### **Print Media Coverage**

A total of **27 print articles** appeared in leading newspapers across India, including:

#### • National dailies:

The Times of India, The New Indian Express, Deccan Herald, The Asian Age (Delhi & London editions), Deccan Chronicle (Chennai, Tiruchy, Madurai, Coimbatore)

# • Regional & language press:

Prajavani, Kannada Ratna, Kannada Prabha, Samyuktha Karnataka, Vijaya Karnataka, Hai Karavali, Tuluvaadu Varthe, Esanje, Amogha Vani, Sanjevani, Malenadu Isiri, Hosadigantha, Sanje Samachara, Global Connect, Vijaya Vani

Coverage highlighted themes such as:

- Childhood cancer survivorship
- The integration of cure and care
- National collaboration between doctors and CSOs
- Patient-centred care and advocacy

# Digital / Online Media Coverage

There were **12 online publications**, featuring PHOSSCON across national and sector-specific platforms, including:

#### • Mainstream Media:

IndiaTimes (Times of India online), Daijiworld, BW Healthcare World, ThisWeekIndia, TheHansIndia

### • Health and medical platforms:

Oncodaily, Kemmannu News, DMA Newsdesk, Tulunadu Varthe online

# • Regional language online portals:

kannadaprabha.in and others

### Online headlines focused on:

- Human impact stories
- Survivor leadership
- Advances in paediatric oncology
- The symbolic significance of pledges and national collaboration

# Why This Matters

This level of widespread media presence ensured that PHOSSCON 2025 was not only a closed-door conference, it became a national conversation.

The reach across metro, regional, print and digital platforms helped expand public awareness about:

- Childhood cancer challenges in India
- The need for psychosocial and palliative care
- Patient rights, advocacy and survivor involvement
- The shift toward integrated, compassionate, evidence-based care

#### PR - PHOSSCON 2025

### Acknowledgements

PHOSSCON 2025 Organising Committee thanks:

- PHO Chapter of IAP
- Manipal Academy of Higher Education
- All participating NGOs and clinicians
- Standing Committee Members
- Special thanks to survivors, parents and volunteers whose stories gave the conference its heart.

#### Social Media Posts so far:

https://www.instagram.com/s/aGlnaGxpZ2h0OjE4MTkwMjQ1NjI4MzQyMzk0?story\_media\_id =3775555284552078323 6060987464&igsh=dzdtb3p0OTg2YTNl

https://www.instagram.com/reel/DRy-p0eio3t/?utm\_source=ig\_web\_copy\_link&igsh=MzRlOD BiNWFlZA==

https://www.linkedin.com/feed/update/urn:li:activity:7401919182927413248

https://www.linkedin.com/feed/update/urn:li:activity:7401165743326781440

https://www.facebook.com/share/r/1Fsr1qAYpU/

https://x.com/CanKidsOfficial/status/1996154132454166984?s=20

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