**Report of the 8th Pediatric Hematology Oncology Support Services Conference (PHOSSCON 2024)**

***Venue: Convention Center, Jammu, India***

***Dates: November 22-23, 2024***

***Organized by: Pediatric Hematology Oncology Chapter (PHO), Indian Academy of Pediatrics (IAP)***

***Conference Theme: "Advocating for Change in Childhood Malignancy and Hematological Disorders"***

**Day 1: Friday, November 22, 2024**

**Session 1: NGO Presentations on Hematology and Oncology**

*Chair: Dr. K. Saroja (Medical Officer, Thalassemia and Sickle Cell Society, Hyderabad)*

*Co-Chair: Shobha Singh (Hon. GM, Bihar Cankids)*

This session featured presentations from various organizations working in the fields of hematology and oncology. The organizations shared their initiatives, research, and work aimed at improving the care and outcomes for patients, particularly in the areas of sickle cell disease, thalassemia, cancer care, and related support services.

**1. Ms Payal - St. Jude Child Care Center:** Presented the work of St. Jude Child Care Center in providing comprehensive support for children with cancer and their families.

**2. Dr Baidyanath Debnath - Divisional Coordinator, Sangwari** - People’s Association for Equity & Health, Ambikapur, Chhattisgarh: Focused on addressing health disparities through patient-centered care, highlighting the Sangwari model, an initiative aimed at improving care for sickle cell patients in northern Chhattisgarh.

**3. Mr Lalit Kishor Pargi - Founder, Sickle Cell Saksham Rajasthan Foundation;** Executive Member, National Alliance for Sickle Cell Disease Organizations (NASCO); Nursing Incharge, Center of Excellence for Sickle Cell Disease (CoESCD) Udaipur; State Sickle Cell Disease Committee Member, Rajasthan: Shared the success journey of Rajasthan in managing sickle cell disease, emphasizing the role of the Sickle Cell Saksham Rajasthan Foundation and its impact on the state’s public health approach to sickle cell disease.

**4. Mr Aanish - Hope Child Cancer Care Foundation:** Presented the work of the Hope Child Cancer Care Foundation in providing critical care and support services to children battling cancer by showing a video.

**5. Mr Gautam Dongre - Secretary, National Alliance of Sickle Cell Organizations (NASCO);** Board Member, GASCDO: Provided insights into the patient experience of living with sickle cell disease, drawing from his personal experiences and his role as a secretary of NASCO.

**6. Ms Karishma Pavaskar - Clinical Psycho-Oncologist & Expressive Arts Therapy Practitioner, Cancer Patients Aid Association, India:** Discussed her work as a clinical psycho-oncologist, offering insights into the mental health aspects of cancer treatment and support for patients and their families.

**7. Mr Ravi Yadav - DigiSwasthya:**  Introduced DigiSwasthya, a digital health initiative aimed at improving access to healthcare services, particularly in remote areas.

**8. Dr Vandana - ICS Ugam:** Shared the mission and activities of ICS Ugam in improving healthcare accessibility and care for marginalized populations affected by hematological and oncological conditions.

**9. Ms Shobha Tuli - Secretary, Thalassemics India:** Discussed the HSCT project under the Thalassemia Bal Sewa Yojana, an initiative aimed at providing critical care and treatment options for children with thalassemia.

**10. Ms Roslina Digai - Umeedein:** Presented the work of Umeedein, an organization focused on providing support and hope to children and families dealing with cancer.

**11. Ms Ratnavali Kottapalli - Vice President, Thalassemia and Sickle Cell Society (TSCS):** Shared her insights as Vice President of the Thalassemia and Sickle Cell Society, discussing the society’s work in raising awareness and supporting patients with thalassemia and sickle cell disease.

**12. Mr Bal Kalne - Aarambh Palliative Care:** Introduced Aarambh Palliative Care, an organization dedicated to providing palliative care services to patients with life-threatening conditions, focusing on quality of life.

**13. Ms Kajal Sachdev - Founder, KASH Foundation:** Talked about her journey from being a thalassemia mother to the founder of KASH Foundation, an organization focused on achieving a thalassemia-free Chhattisgarh and supporting thalassemia patients.

**14. Dr Haresh Gupta - CanKids KidsCan:** Presented the work of CanKids KidsCan, a PAN India organization providing comprehensive support services for children with cancer and their families.

The session concluded with a rich exchange of ideas and experiences from the various organizations, underscoring the importance of collaborative efforts in addressing the challenges in hematology and oncology care, particularly for marginalized and underserved populations.

**Session 2: Gaps and Challenges in Patient-Centric Care in Pediatric Oncology & Hematology**

*Chair: Dr. Shruti Kakkar (Professor, Pediatrics, Consultant Clinical Hematology, CMC Ludhiana)*

*Co-Chair: Dr. J.S. Arora (General Secretary, National Thalassemia Welfare Society)*

This session addressed critical challenges in pediatric oncology, hematology, and patient care, with a particular focus on childhood cancer, sickle cell disease, and thalassemia in India. The discussion highlighted the gaps in healthcare services, awareness, and support systems, especially for economically disadvantaged populations in rural and remote areas.

**1. Thalassemia Care, Cure & Control: Challenges and the Way Forward by Ms Shobha Tuli (Secretary, Thalassemics India):** Ms Tuli discussed the Coal India project and the Thalassemia Bal Sewa Yojana (TBSY) for Bone Marrow Transplant (BMT). She also emphasized that Ayushman Bharat coverage should be expanded to include all states and districts without restrictions.

**2. Role of Support Services for Patients and Families by Dr. Aditya Gupta (Consultant Pediatric Oncologist):** Dr Gupta outlined the challenges faced by childhood cancer patients, including neurocognitive deficits, nutritional issues, limited access to treatment, and geographic barriers. He recommended expanding access to nutritional support and educational services, improving the availability of pediatric oncologists and cancer drugs in rural areas, and integrating psychological and social care into cancer treatment.

**3. Patient Perspectives on Treatment Challenges and Solutions:**

**i. Sickle Cell Anemia**

Key Challenges discussed: Late diagnosis, stigma, and misunderstanding of sickle cell disease were discussed. Awareness about Hydroxyurea, a repurposed cancer drug used to treat sickle cell disease, is limited.

Potential Solution discussed: The need to train healthcare professionals, promote public awareness, reduce stigma, and address financial and logistical barriers was emphasized.

**ii. Thalassemia Challenges and Solutions:**

Key Challenges discussed: Inadequate blood transfusion protocols, limited access to iron chelation therapy, and lack of affordable BMT facilities.

Potential Solution: Solutions proposed included improving blood transfusion protocols, expanding access to iron chelation, and raising awareness about early diagnosis and genetic counseling.

**iii. Cancer Care Challenges: Umeedein NGO by Nitai G Panigrahi**

Key Challenges discussed: The lack of awareness, long travel distances to treatment centers, psychological stress, and gaps in palliative care were highlighted. A specific case of a child, Amrita, struggling with PTSD after treatment was shared.

Solutions: Better communication systems for healthcare workers to help families navigate the cancer journey, and collaboration with NGOs to provide mental health support were identified as critical needs.

**Panel Discussion:**

The session transitioned into a panel discussion, where experts shared insights on how to address the gaps in patient-centric care:

- Ms. Ratnavali Kottapalli (Vice President, Thalassemia and Sickle Cell Society, Hyderabad) : She emphasized the importance of integrated counseling for patients and families at every stage of treatment. She described a multi-disciplinary approach, where patients receive counseling from doctors, nurse counselors, and social workers.

**Action Point:** Standardize patient care protocols and integrate a holistic care model across centers to ensure comprehensive support for both patients and families.

- Dr. J.S. Arora (General Secretary, National Thalassemia Welfare Society): He defined patient-centric care as involving patients as active partners in their treatment journey. He highlighted the importance of empathy, listening to patient concerns, and offering treatment choices.

**Action Point:** Encourage healthcare providers to foster open communication with patients, empowering them in their healthcare decisions and ensuring that patients' voices are heard.

- Kajal Sachdev (Founder, KASH Foundation): She addressed the issue of resource constraints, particularly in rural areas where blood supplies and medications are insufficient.

**Action Point:** Develop localized solutions for blood donation drives and collaborate with government bodies to ensure essential supplies and treatments are available for pediatric cancer patients in underserved regions.

- In large academic institutions with high patient volumes, providing individualized care becomes challenging due to overcrowded OPDs, long wait times, and limited doctor-patient interaction was also discussed.

**Action Point:** Explore strategies like telemedicine, task-shifting, and increased involvement of allied healthcare professionals to optimize time management and improve patient flow in busy hospitals.

- Ms Ratnavali on Integrating Counseling and Psychological Support: She highlighted the necessity of psychological support alongside medical care. She described a model where patients receive family counseling and access to mental health professionals.

**Action Point:** Advocate for the inclusion of mental health professionals in every pediatric oncology center to provide critical psychological support.

- Dr. J.S. Arora on the Role of Communication: He emphasized the importance of two-way communication between healthcare providers and patients, ensuring that patients feel empowered and involved in their treatment decisions.

**Action Point:** Establish regular feedback systems to improve understanding of patient concerns and continuously enhance care delivery.

**Overall Action Points from Session 2 for Improving Patient-Centric Care:**

**- Integration of Multi-Disciplinary Support:** Develop standardized care protocols that integrate psychological, nutritional, and social support alongside medical treatment. This approach should be implemented at all treatment centers to ensure a holistic care model.

**- Enhancing Communication and Empowerment:** Foster an environment where patients are actively involved in their treatment journey through open, empathetic communication. Regular feedback loops should be established to ensure that patient concerns are addressed effectively.

**- Addressing Resource Constraints Locally:** Build local capacity for blood donation, provide adequate resources in rural areas, and ensure affordable access to medications and treatments. Collaboration with government bodies, NGOs, and community organizations is essential to bridge gaps in healthcare access.

**- Optimizing Care in Overburdened Centers:** In institutions with high patient volumes, explore the use of telemedicine, task-shifting, and expanded roles for allied healthcare professionals to optimize care delivery, reduce wait times, and enhance the overall patient experience.

**Session 3: Compliance for CSR, FCRA, and Taxation**

*Chair: Mr. Arvind Kumar (Hon. President, Varsha Foundation)*

*Co-Chair: Mr. Aniket Kotkar (CRMCO, Cankids)*

*Speaker: CA Dr. Subhajit Sahoo*

This session provided an in-depth overview of key financial and compliance aspects that NGOs must adhere to, along with strategies for effective fundraising and maintaining transparency.

Dr Sahoo began the session by discussing the difference between charitable work done individually and that undertaken collectively through registered organizations such as trusts, societies, and NGOs.

**i. Tax Exemptions & Compliance**

Dr Sahoo highlighted the importance of proper registration and compliance for NGOs to qualify for tax exemptions under Section 12A and 80G of the Income Tax Act.

- 12A Registration is necessary for NGOs to receive tax exemptions. Failure to comply with this requirement can result in the withdrawal of these benefits.

- 80G Registration is crucial for ensuring that donors can avail of tax exemptions for their contributions.

He also pointed out that both *12A and 80G registrations now require regular renewal every three years, with compliance checks. Previously, these registrations were valid for a lifetime, but recent amendments necessitate periodic renewal.*

**ii. Compliance with Government Regulations**

**Income Tax & FCRA Compliance:** The FCRA registration is mandatory for organizations that wish to receive foreign funds. *To qualify for FCRA, organizations must be at least three years old and have a minimum of ₹15 lakh in program expenses.*

**Documentation & Reporting:** *NGOs must file annual income tax returns and submit audited reports by September 30 each year.* They are also required to maintain detailed records for every donation, including receipts and expenditure reports.

**iii. Fundraising & Financial Transparency**

Dr. Sahoo emphasized the importance of thorough due diligence when accepting donations. NGOs must verify the legitimacy of donors, particularly when receiving foreign funds, to avoid funding from blacklisted or non-compliant sources.

**iv. Social Security Compliance**

Dr. Sahoo also covered employee welfare and social security compliance: NGOs must adhere to statutory regulations related to employee benefits, such as EPF, gratuity, minimum wages, and professional tax. These must be accounted for in the organization’s HR budget to ensure compliance with labor laws.

**v. Social Sector Activities and Exemptions**

Dr. Sahoo highlighted several tax exemptions available for NGOs involved in specific social sector activities: Exemptions are available for organizations working in environmental protection, old-age care, and education for marginalized groups. *Preventive health activities, such as thalassemia awareness,* also qualify for tax exemptions. NGOs must ensure that their projects are properly classified to benefit from these exemptions.

**vi. Fundraising Strategies and Diversification**

Dr. Sahoo emphasized the importance of diversified fundraising. Relying solely on one funding source, such as CSR, can be risky. NGOs should diversify their fundraising efforts, including individual donations, grants, and partnerships with other NGOs.

**Overall Action Points and Recommendations from Session 3:**

**i. Review and Update Compliance:** Ensure the organization’s 12A and ATG registrations are in place and up to date. Review FCRA registration for eligibility and maintain compliance with documentation and reporting requirements.

**ii. Improve Fundraising Practices:** Ensure all donations are received through compliant channels, including bank accounts and online payment systems. Perform due diligence on donors to ensure the legitimacy of funds received, especially foreign donations.

**iii. Training for Staff:** Provide regular training on compliance with 12A, 80G, FCRA, and other financial and regulatory requirements.

**iv. Ensure Employee Welfare Compliance:** Factor in statutory employee benefits such as EPF, gratuity, and minimum wage in the HR budget to comply with labor laws.

**v. Submit Returns on Time:** Ensure that annual returns and audited reports are submitted on time to avoid penalties or cancellation of registrations.

**vi. Update Donor Communication:** Clearly communicate to donors the tax exemptions available for their donations and ensure transparency in the organization’s compliance status.

**Session 5: Formal Inauguration of PHOSSCON 2024**

*Chief Guest: Shri B.R. Sharma (IAS 1984), State Election Commissioner, Jammu & Kashmir UT*

***Inaugural Speakers:***

*Dr. Shripad Banavali, Chairperson, PHO Chapter IAP*

*Dr. Manas Kalra, Honorary Secretary, PHO Chapter IAP*

*Dr. G S Saini, Organizing Chairperson, PHOCON 2024*

*Dr. Sanjeev Kumar Digra, Chief Organizing Secretary, PHOCON 2024*

- Dr Haresh took over the inauguration. He acknowledged the importance of collaboration between hospitals, social support organizations, and government bodies in pediatric cancer care. He also noted the growth of PHOSSCON 2024, with over 100 registered attendees from 39 organizations.

- He mentioned the expanded focus of the conference, now including pediatric hematology and oncology disorders, including conditions like Thalassemia. Welcomed key organizations and advocates, including Shobha Tulli (Thalassemia advocate) and JNK Thalassemia Association.

**Remarks from Shripad Banavali, Chairperson PHO, Chapter IAP**

**-** He thanked the collaborative efforts; the number of children treated at Tata Hospital has increased from 1,000 to 3,000, showcasing the impact of coordinated support.

- Stressed the importance of continued financial and social support to improve cure rates and treatment options for children with cancer.

- Called for a goal similar to St. Jude’s, where no child should die of cancer due to lack of support.

**Remarks from Ms Poonam Bagai and Dr Sanjeev Kumar Digra**

**-** Shared thoughts on the importance of capacity building, treatment infrastructure, and the need for increased awareness around pediatric hematology and oncology.

- The challenges in areas like access to specialized care, lack of hematologists in certain regions, and the need for specialized training and fellowship programs were discussed.

**Session 4: Challenges and Diversified Fundraising Strategies for NGOs**

*Chair: Ms. Poonam Bagai, Founder, CanKids KidsCan*

*Co-Chair: Mr. Sandip Jariwala, Founder, Relief From Cancer, USA*

**i. ALSAC & St. Jude Global Alliance Fundraising Strategies**

**Speakers:**

Mr Sri Kankarla - Senior Regional Liaison for India

Ms Priya Tummalapalli - Global Coordinator

Ms Paola Cassana - Sr. Advisor Global Education

A dedicated session on fundraising was introduced, with a team from ALSAC & St. Jude Global Alliance Fundraising Strategies present to discuss collaborative efforts to raise funds and resources for pediatric cancer care.

- Mr Sri Kankarla introduced ALSAC’s critical role in supporting the mission of St. Jude Children's Research Hospital, focusing on fundraising, marketing, and awareness-building to support global efforts in fighting childhood cancer.

- Ms Paola shared ALSAC's 60 years of experience in fundraising and awareness efforts, emphasizing their unique model of supporting St. Jude with 87% of the hospital's budget. ALSAC employs various strategies, including direct marketing, monthly donor programs, corporate partnerships, and media outreach.

- Notable achievements include major media partnerships, raising over $220 million annually, and 12 million active donors. *The focus on data analytics and targeted campaigns has been critical to ALSAC's success.*

While digital tools are increasingly vital, grassroots efforts like walks, dinners, and community-based events could be a starting point for engaging local donors and building long-term relationships. The team highlighted the need for a diversified approach to fundraising. Rather than relying on a single source of income, organizations must explore multiple channels for revenue generation. This includes individual donations, corporate partnerships, grant funding, and events. Diversification reduces financial risk and ensures a steady flow of support, even when one revenue stream faces challenges.

- Ms Priya discussed how ALSAC has transitioned from print to digital, acknowledging the shift towards digital fundraising, especially with younger audiences. Despite this, print remains effective with older audiences (ages 47–65) in the U.S.

- In regions like India, where mobile usage is high, digital fundraising methods (e.g., social media campaigns, digital ads) should be prioritized, but traditional methods like grassroots events may still be effective for building relationships.

- Ms Priya shared the success story of the Lifeline Foundation in Ghana, which has grown significantly through ALSAC’s support. Lifeline focused on building staff capacity, organizing events like golf tournaments and marathons, and raising funds for the creation of a pediatric oncology ward.

- Lifeline was able to raise over $1 million for a new pediatric oncology ward through strategic fundraising events and dedicated training.

Mr Sri Kankarla emphasized the importance of collaboration, noting that ***"if you want to walk far, walk with others."*** *He called for continued partnership and collective action in the fight against childhood cancer.* The ALSAC team encouraged all attendees to take the lessons learned and apply them in their respective regions to enhance fundraising efforts and strengthen the St. Jude mission.

The session then shifted to discuss strategies for diversified fundraising, a critical topic for organizations of all sizes.

**ii. This session focused on the challenges faced by NGOs of varying sizes - small, new, and large,** along with an in-depth discussion on diversified fundraising strategies.

The participants were grouped according to the size of their NGOs and asked to discuss and document their challenges, proposed solutions, collaboration strategies, sustainability plans, and the external support they utilized within the context of their organization's size.

**Small NGOs Group**

**Challenges:**

- Manpower: Limited volunteers.

- Documenting and Reporting: Difficulty in managing and reporting data accurately.

- Securing Donor Data: Challenges in storing donor information securely.

- Social Media Strategy: Need for a focused approach to online outreach.

**Solutions:**

- Successful campaigns.

- Good online presence (website and Facebook).

- Strong community awareness and involvement.

- Expanding Partnerships: Success in cultivating corporate partnerships.

**Opportunities for Collaboration:**

- Sharing resources

- Technical collaboration for patient continuity of care.

- Sponsoring joint events, such as fundraisers or galas.

**Sustainability Strategies:**

- Focus on cultivating long-term partnerships with current donors.

- Building a strong volunteer network that stays engaged and upskills over time.

**External Support Needed:**

- Government support

- Access to new opportunities like the social stock exchange.

- Employee Engagement

- A formal directory to connect NGOs with necessary services.

**Middle-sized NGOs Group:**

**Challenges:**

- Lack of Resources: Insufficient trained professionals and donor fatigue.

- Fundraising: Difficulty in securing funds and finding reliable donors.

- Legal Policies: Issues with navigating legal frameworks.

- Education Facilities

- Funding Donors

- Knowledge gap

**Solutions:**

**-** Technology Integration: Use of technology and data-driven approaches for fundraising (e.g., reverse engineering successful campaigns).

Training: More focus on specialized training for teams and volunteers.

- Projects

- References Networking

- Management System

- Donor Connecting Programs

**Opportunities for Collaboration:**

- Sharing resources and knowledge with aligned NGO partners.

- Engaging corporate support and voluntary participation from employees.

- Government support for permissions and shared resources.

- Replicating

- Reverse Engineering

**Sustainability Strategies:**

- Emphasis on the importance of diversifying funding sources and not relying solely on one partner (e.g., CSR contributions).

- Building donor relationships: Understanding donor cycles and engagement strategies. Avoiding depending too heavily on large corporations and ensuring a balanced approach to fundraising.

- Volunteer Network

**External Support Needed:**

- Activities with Govt. Support

- Stock Market/ Social Stock Exchange

- Employee Engagement

- Directory

**Large NGOs Group:**

**Challenges:**

- Awareness, Fundraising and Diversity

- Lack of awareness on how to raise funds

- Low fund support for adult patients

- Manpower crisis

- Difficulty in raising funds for investigations

- Fund crisis

- Reaching out to Corporates for CSR

- Untimely release of CSR Funds

**Solutions:**

- Increase in Volunteers/Manpower

- Collaboration/Networking

- Skilled employees

- Relationship building

- Transparency

**Sustainability Strategies:**

- Regular Donors

- Patient-Donor meet

**External Support Needed:**

- Resources

- Family support and counselling

- Donor management in terms of building relationships

- Events

- Showcasing of our work

- Awareness

- New projects (finding new CSR)

- Existing projects to be duly completely

- Transparency

**Overall Action Points and Recommendations**

Address Challenges Based on Organizational Size: Small NGOs should focus on building credibility and networking within their local communities. Medium-sized NGOs should prioritize establishing a proven track record, with a clear impact narrative to attract funders. Large NGOs must focus on maintaining transparency, optimizing resource management, and staying adaptable to donor trends.

Diversify Fundraising Approaches: Explore multiple fundraising channels, including individual donors, corporate sponsorships, events, and online campaigns. Build long-term relationships with donors and communicate the impact of their contributions regularly. Leverage technology to engage donors and simplify donation processes.

Learn from Successful Models: Study successful fundraising models like those used by ALSAC-St. Jude to understand how to build a sustainable, diversified revenue stream. Implement best practices for donor engagement, transparency, and impact reporting to foster trust and loyalty.

**Session 6: Fundraising Competition**

*Judging Panel: ALSAC Jury*

**Best Campaign of the Year**

- Awarded to: Digiswastya

- Raised approximately 1 crore rupees and launched a mobile medical unit.

**Best Individual Giving of the Year**

- Awarded to: CanKids KidsCan

- Individual Donors - Sirpal were recognized for their ongoing efforts and impact in the field of Retinoblastoma with CanKids.

**Best CSR Project of the Year**

- Awarded to: Cancer Patient Aid Association

- Recognized for their HPV vaccination campaign targeting girls aged 9-14 years across Maharashtra, aiming to eliminate cervical cancer.

**Most Innovative Fundraising Idea of the Year**

- Awarded to: CanKids KidsCan

- Awarded for their innovative cycle initiative for fundraising - Cycle For Gold

*Conference Adjourned at 6:30 pm*

**Day 2: Saturday, November 23, 2024**

**Session 7: Importance of Supportive Care Services**

*Chair: Haris Kattakath (Chairman, Hope Child Cancer Care Foundation)*

*Moderator: Dr. Pratibha Arun Chandekar (Professor, V. V. Patil Foundations College of Nursing)*

**i. Nutrition: Ms Sripriya Venkiteswaran, Ms Juna Dhungana**

- Global Incidence & Pediatric Cancer: Ms Sripriya discussed that nearly 400,000 children are diagnosed with cancer annually worldwide, with 80% of cases occurring in low- and middle-income countries. Despite this high incidence, there is a significant lack of accessible education and care in these regions.

- Importance of Nutrition in Treatment: She emphasized the critical role of nutrition in cancer treatment. Malnutrition, whether undernutrition or overnutrition - can significantly impact cancer outcomes. Well-nourished children tend to have better survival rates, while poor nutrition exacerbates treatment side effects like nausea, vomiting, and gastrointestinal issues. Post-treatment nutrition is also vital in preventing long-term complications such as osteoporosis and cardiovascular diseases.

- Dr Neelima inquired whether RUTF is suitable for children with cancer. Ms Jhuna responded that RUTF is highly recommended for children with severe malnutrition even in cancer, as it helps provide the necessary nutrients. For other children with cancer, however, a regular home diet can typically be continued, with RUTF being an option to help boost calorie intake if needed.

- Challenges in Pediatric Cancer Nutrition: The discussion highlighted the challenges in providing adequate nutritional care, such as the shortage of skilled pediatric oncologists, nutritionists, and healthcare professionals trained in cancer-specific nutritional care. A lack of standardized nutritional guidelines, especially in low-resource countries, was identified as a key barrier.

**Solutions:**

- Building Nutritional Capacity: The need for building nutritional capacity in pediatric oncology was discussed, with suggestions to:

- Train healthcare professionals, especially pediatric oncology nutritionists, to bridge gaps in specialized education.

- Standardize nutrition guidelines across regions to ensure consistent care.

- Foster collaboration between nutritionists, oncologists, psychologists, and caregivers to ensure holistic care.

- Integrate technology to monitor children's nutritional progress and improve care.

**ii. Psychological Support: Ms Rhea Daruvala, Ms Hiba Siddiqui**

Ms Hiba discussed the vital role of psychosocial support not only for the child but also for their family.

- Children’s Right to a Normal Childhood: Experts emphasized that a child’s right to a normal childhood should be prioritized, even during cancer treatment. Psychological support should be tailored to the child’s developmental stage, and Child Life Specialists should help children navigate emotional challenges related to treatment.

- She also discussed the need to include the family in psychosocial support strategies, as the well-being of the child is deeply interconnected with the emotional state of the parents and caregivers.

- Psychological Impact on Families: The psychological implications of a cancer diagnosis on families were discussed, particularly on parents and siblings. The tendency of some families to hide the diagnosis from extended family members was noted, which can lead to feelings of isolation. Early psychological counseling for parents was highlighted as a key strategy to manage their emotional response and support their child’s treatment.

- One of the chair members asked about peer intervention, to which Ms Rhea explained that it involves showing a child who is about to undergo a procedure, like a chemoport insertion, another child who has previously gone through the same experience. The psychologist counsels the child and parent, sharing this peer experience to help instill confidence and ease any anxieties, reassuring both the child and the parent about the process.

**Solutions:**

- Address the mental health needs of both parents and siblings, who often face emotional challenges during the child’s treatment.

- Train healthcare professionals, particularly nurses and social workers, in providing psychological support to both children and families.

- Establish support groups for parents, facilitated by trained psychologists, to help them cope with the emotional burdens of raising a child with cancer.

**Action Points:**

- Integrate family-based counseling as a central part of pediatric oncology care.

- Develop educational materials to help families navigate the psychological aspects of cancer diagnosis and treatment.

**iii. Infection Control: Dr Scott Howard**

The high morbidity and mortality associated with infections in pediatric cancer patients, especially during chemotherapy, were discussed by Dr Scott. Early detection and intervention in infection management were stressed as critical for preventing life-threatening complications, such as sepsis.

Role of Nutrition in Infection Control: It was discussed that proper nutrition can play a vital role in preventing infections and mitigating the severity of side effects from chemotherapy. Malnutrition increases vulnerability to infections, making nutritional support even more important during cancer treatment.

**Solutions:**

- Infection Control Measures: The panel emphasized the importance of strict infection control protocols in pediatric oncology settings, particularly:

- Hand hygiene to prevent cross-contamination between patients and staff.

- Early diagnosis and intervention in infections, especially in the critical "golden hour" following the onset of fever or any other symptoms.

**Action Points:**

- Strict adherence to infection control protocols, including hand hygiene and isolation of infected patients.

- Train healthcare professionals in early detection and treatment of infections to reduce mortality from sepsis and other infections.

- Implement fever cards to enable parents and healthcare providers to act swiftly when a child develops a fever.

- Support research into infection control protocols in pediatric oncology, particularly in low-resource settings.

**Overall Action Points for Supportive Care in Pediatric Oncology from Session 7**

1. Develop and implement global, standardized guidelines for nutrition, psychosocial support, and infection control in pediatric cancer care, with a focus on low-resource settings.

2. Enhance training for healthcare professionals in nutrition, psychological support, and infection control to ensure a comprehensive, holistic approach to pediatric cancer care.

3. Incorporate family-based support into the pediatric oncology care model, providing emotional, psychological, and practical support for both the child and their caregivers.

4. Leverage technology to standardize care protocols and monitor the progress of supportive care services, particularly in regions with limited healthcare infrastructure.

5. Foster global collaboration to share knowledge, research, and resources aimed at improving the overall quality of pediatric cancer care worldwide.

**Session 8: "Say No to Financial Hardship – Roadmap to 100% Financial Protection by 2030"**

*Chair: Mrs. K. Ratnavali (Vice President, Thalassemia and Sickle Cell Society, Hyderabad)*

*Co-Chair: Aneesh Kumar M (CRMO, Hope Child Cancer Care Foundation)*

The session was hosted by Mr Vishwajit and Mr Chandan Kumar, and began with a brief overview of the workshop's objectives, which focused on financial hardship and financial protection for families with children diagnosed with cancer. The goal of the meeting was to deepen understanding of financial issues, particularly financial access and protection, as well as to explore solutions that could better support affected families.

They engaged with Participants on the following:

**i. What do you understand about financial hardship in treatment?**

- Lack of Job Opportunities for Parents: A key issue discussed was the loss of income due to the inability to work, with many parents unable to secure jobs because they are focused on caring for their sick child. This is particularly critical when a family’s primary income earner is forced to stop working for long periods. The discussion emphasized that while there is support for some treatment costs, indirect costs such as transportation, nutrition, and missed education for siblings remain largely unaddressed.

- Treatment Expenses and Reimbursement: Parents whose children receive reimbursement for treatment expenses under government schemes (e.g., those working in government jobs) are less impacted by financial hardship. However, the majority of families face significant out-of-pocket expenses, which is a significant burden. *Suggestions were made to raise awareness among families about reimbursement policies and ensure broader access to financial assistance programs.*

- Insurance Challenges for Children with Cancer: Many families face challenges obtaining health insurance for children diagnosed with cancer. Insurance providers often require the parent to have coverage before the child can be insured, but many parents themselves do not have adequate insurance. It was noted that only about 20% of children are insured, and awareness efforts need to focus on both parents and children to improve coverage rates.

- Challenges with Genetic Blood Disorders: Some insurance providers are hesitant to cover children with genetic blood disorders, even though these conditions may require costly treatments. There is a need for advocacy to expand coverage to include these cases.

**ii. Financial Access vs. Financial Protection:**

The discussion highlighted that while some families may have access to treatment, the broader financial challenges, such as loss of income, out-of-pocket expenses for transportation, food, and other necessities, are not always covered by insurance or government schemes.

**iii. Universal Health Coverage:**

WHO Definition: Universal Health Coverage (UHC) ensures that all individuals have access to the full range of quality health services without facing financial hardship.

UHC includes three dimensions:

-Access to essential health services (treatment, prevention, rehabilitation).

- Protection from financial risk when seeking care.

- Ensuring that the quality of services is adequate and effective.

It was pointed out that, while treatment is often covered by insurance or government schemes, additional expenses such as food and nutrition for children undergoing treatment are often overlooked. Adequate nutrition is critical for the recovery of the child and should be included in support schemes.

Following this, the participants were encouraged to split into groups of five and to engage in the upcoming workshops, share insights from their own experiences through case studies, and work together to strengthen financial protection systems for children with cancer.

**Workshop:**

**Group 1: Represented by Mr Nitai and Team**

**NGOs Involved:** Aroh, ICS, Umeedein

**Financial models of these NGOs:**

**- Need Assessment and Financial Support:** Appointing counselors to evaluate patient needs, provide estimates, and approve financial assistance quickly.

**- Diagnostics and Treatment Support:** Providing support for critical diagnostics (e.g., chemoport) and other treatments.

**- Holistic Support:** Offering additional support services, including nutrition, accommodation, and emotional support.

**- Donor Linkage and Fundraising:** Facilitating connections with donors and facilitating crowdfunding efforts. Collaboration with government schemes, NGOs, and High Net-Worth Individuals (HNIs) to secure funding.

**- Community Involvement and PRI Engagement:** Engaging local Panchayati Raj Institutions (PRI), village leaders, and community donors to support families.

**Case Study: 3-Year-Old Retinoblastoma Patient**

Background: From a poor and illiterate family.

Steps Taken:

- Arranged accommodation and food through a local NGO.

- Assisted with government scheme liaison and crowdfunding for treatment costs.

- Engaged PRI members, local businesses, and small donors to provide financial support.

**Group 2: Represented by Mr Sandeep and Team**

**Case: Manisha Kumari, 14 years old, diagnosed with Sarcoma**

Background: Mother is a homemaker, and father is a farmer, with irregular income.

**Challenges:**

- Late Diagnosis

**- Financial Constraints:**

- The family did not have PMJAY or other insurance coverage.

- Borrowed ₹30,000 for initial treatment, but required ₹12,00,000 for surgery.

- Crowdfunding raised ₹3,00,000, but the family had to borrow ₹70,000.

- DigiSwathya provided ₹2,20,000 for treatment.

No Access to Affordable Diagnostic Centers: The family had no money for diagnostic expenses and struggled to find cheaper options.

**Proposed Solutions:**

**- Universal Medical Coverage:** Implementing a system for universal medical coverage that ensures every individual, regardless of financial status, can access critical health services.

**- Better Access to Government Schemes:** Ensuring all patients can access government schemes for diagnostic tests and treatment, especially for cancers and rare diseases.

**- Government Schemes Should Cover Diagnostics:** Expanding coverage to include diagnostic expenses, ensuring early intervention.

**Group 3: Represented by Dr Baidyanath and Team**

**Case Study:**

**Patient: A 3-year-old diagnosed with Acute Lymphoblastic Leukemia (ALL) from Wadia.**

- After completing treatment, the patient received education and ration support.

- The child is now a skilled artist.

**Challenges**:

**- Lack of Awareness and Access to Government Schemes:** Many families are unaware of available financial schemes and do not have proper documentation to access them.

**- No CSR Support for Out-of-Pocket Expenses (OOPE):** Many patients face substantial financial burdens due to high out-of-pocket expenses for treatment.

**- Expensive Treatment and Non-Systematic Government Schemes:** Existing government schemes do not cover all aspects of treatment, especially for rare diseases like ALL.

**- Lack of Psychosocial Support:** Absence of trained psychologists or social workers to provide mental health support for families.

**Proposed Solutions:**

**- Community-Level Awareness Campaigns:** Raising awareness at the grassroots level through local healthcare workers and community outreach programs.

**Government Mandates for Admin Costs:** Mandating that administrative costs for treatment support are covered under government schemes.

**Psychoeducation:** Incorporating psychoeducation into cancer treatment programs to better support families emotionally.

**Subsidies for Medicines and Investigations:** Encouraging partnerships between the government and pharmaceutical companies to reduce the cost of medications and diagnostic tests.

**Group 4: Represented by Dr Vandana and Team**

**Case Studies:**

**- Pooja Gupta:** Diagnosed with thalassemia at age 5, received full support from various organizations, and has since lived a successful life, supporting her elderly parents.

**- Cancer Survivor Story:** A young girl survived cancer, only to succumb to a second cancer later. This highlights the need for long-term care and monitoring for cancer survivors.

**Challenges:**

- Out-of-Pocket Expenses (OOPE)

**- Late Side Effects and Cancer Survivorship:** Late side effects from cancer treatment, including the need for vaccinations and other health interventions, are not always covered by insurance or government schemes.

**- Lack of Awareness about Long-Term Support:** Survivors often face difficulties in accessing continued care, especially for late effects and second cancers.

Proposed Solutions:

**- Inclusion of Middle-Class Families:** Expanding government health schemes to cover the "missing middle" families who are often excluded from BPL-focused programs but still face significant financial hardship.

**- Collaboration Across Sectors:** Emphasizing the need for collaboration between the government, NGOs, corporate sectors, and patients to create a more accessible and inclusive healthcare ecosystem.

**- Grassroots Awareness and Early Detection:** Training local healthcare workers to detect conditions earlier and educate communities about available financial support.

**Group 5: Represented by Mr Aanish and Team**

**Case Study:**

**- Patient: 7-year-old diagnosed with Acute Lymphoblastic Leukemia (ALL).**

- Family faced severe financial difficulties, with the mother selling her mangalsutra to raise funds for treatment. The father also lost his job, worsening their financial situation.

**Challenges:**

**- Cost of Diagnostics:** Diagnostic costs before treatment are not reimbursed by government schemes, leading to significant financial strain.

**- Late Diagnosis**

**Proposed Solutions:**

**- Employment Support for Parents:** Providing opportunities for employment or skill development for caregivers (especially parents) to generate a stable income.

**- Crowdfunding and Financial Assistance for Families:** Raising funds through crowdfunding to assist families with day-to-day expenses and medical costs.

- **Addressing Diagnostic Costs:** Advocacy for government schemes to include diagnostic expenses under reimbursement programs.

**Overall Action Points and Next Steps from the Workshop:**

**- NGOs and Government Coordination:** Work on improving communication between NGOs and government bodies to streamline access to financial aid, including diagnostics. Engage in discussions to expand government schemes to cover the "missing middle" and reduce out-of-pocket expenses.

**- Community Engagement:** Initiate grassroots awareness campaigns to inform rural populations and underserved communities about available schemes and treatment options.Strengthen PRI engagement and local leadership involvement in fundraising and community mobilization efforts.

**- Psychosocial Support:** Advocate for the inclusion of trained social workers and psychologists in the treatment process, ensuring families receive emotional and mental health support.

**Skill Development and Employment for Families:** Develop programs to provide skill training for parents and caregivers, ensuring families have the resources to support treatment and long-term recovery.

**Continued Monitoring and Long-Term Care:** Focus on long-term follow-up care for cancer survivors, including addressing late side effects and providing necessary vaccinations.

**Session 9: Status of Bone Marrow Transplant in India - Barriers and Accessibility**

*Chair: Dr. Vikramjit Singh Kanwar (Chief of Pediatric Oncology, Homi Bhabha Cancer Hospital)*

*Speaker: Dr Sunil*

- History and Evolution of Transplants, Challenges in BMT, Access to treatment, Financial Challenges in BMT were discussed.

- Dr Sunil mentioned that there is a significant gap between the number of patients who require BMT (estimated 200,000 annually) and the actual number of transplants performed (around 3,000-3,500 annually).

**Panel Discussion:**

**i. How CanKids address the BMT Challenges**

**Commented by Ms Poonam Bagai:**

- Access to Information and Support: Lack of accessible information about transplant centers and processes was highlighted as a major challenge for families. Not all transplant centers meet the required standards, and there is a risk of families seeking help at under-equipped centers.

- Financial and Psychological Support: Financial constraints are often the most significant hurdle. Families struggle to cover the costs of treatment, post-transplant care, and the necessary follow-up treatments. Psychological support is also critical for both patients and families, particularly as they navigate the complex and long treatment journey.

**ii. Learnings/Experiences from Thalassemics from TBSY project:**

**Commented by Ms Shoba Tuli:**

Barriers to Increasing BMT Access and Awareness:

- Lack of awareness regarding BMT, particularly in rural and underserved areas, and the cultural mindset around the procedure (often seen as too complex or risky).

- Families are sometimes influenced by negative experiences of others (e.g., unsuccessful transplants).

**iii. Learnings/Experiences from TSCS Hyderabad:**

**Commented by Ms Ratnavali:**

Funding and Costing for BMT Procedures:

- Funding Challenges: There is a gap in providing full financial assistance for BMT procedures, with most organizations providing partial funding.

- The cost of transplants varies greatly, especially in private hospitals, with some treatment centers facing funding challenges despite having funds available from government schemes.

- Requested Ms Shoba Ji to make TBSY flexible and to add Haplo BMT into it as well.

**iv. Improving Donor Pool**

**Commented by Ms Sumati Misra from Datri Stem Cell Registry**

- Current Donor Registry Stats: India has 570,000 registered donors, but this is less than 1% of the population. The registry needs significant expansion to meet the needs of thalassemia and other patients requiring BMT.

- The probability of finding a match from the Indian registry is only 5-10%, much lower than for international patients.

**Action Points from Session 9:**

- Work on creating a comprehensive online portal or database listing certified transplant centers, financial assistance options, and counseling services.

- Advocacy and Counseling Programs: Create dedicated patient navigators to guide families through the transplant process, particularly in rural or remote areas.

- Increase Engagement with Peer Groups: Promote stories of successful transplants and ensure ongoing support from the community.

- Public-Private Partnerships: Approach CSR groups and corporate foundations for funding BMTs, using the example of the Coal India project as a template.

- Increase donor recruitment: Continue organizing awareness campaigns targeting younger, healthy individuals (18-50 years) in schools, colleges, and corporates.

- Targeted Drives: Focus on family members and friends of patients, especially those with thalassemia or sickle cell disease, encouraging them to donate to the registry.

- Prepare a document/proposal to submit to the Ministry of Health advocating for the inclusion of pediatric cancer patients under the TBSY Project through Ms Shoba.

**Session 11: Indian Childhood Cancer Initiative (ICCI)**

*Chair - Poonam Bagai Operations Lead ICCI, Chairman Cankids*

*Co-Chair - Dr. Ramandeep Arora, Operations Lead ICCI, Director INPHOG*

**Introduction and Overview of ICCI was discussed.**

The focus of the ICCI is on achieving 60% cure rates, 100% access to treatment, and improving the psychosocial and social care for children with cancer.

ICCI Task Force Updates took place.

**Psychosocial and Social Task Force by Dr Ruchira Mishra.**

- The Psychosocial and Social Task Force is focused on providing psychosocial support to children with cancer, their families, and caregivers.

- Over 380 members have been involved in various initiatives, with a focus on psychological support, parent support groups, and doctor support groups.

**Action Points:**

- Expand participation by inviting more NGOs, health professionals, and patient advocates to join the Psychosocial Task Force.

- Publish and distribute the position statement on psychosocial support.

- Continue identifying gaps in psychosocial support and create action plans for underserved regions.

**Information, Education, and Awareness Task Force by Ms Shilpi.**

- This task force is focused on raising awareness, disseminating accurate information, and engaging communities to support childhood cancer care.

- The task force has prioritized IEC (Information, Education, and Communication) material development, including collating existing resources and creating culturally appropriate content for families and communities.

- A web portal will be created as a one-stop platform for all cancer-related resources, making scientifically accurate and culturally relevant material available to families and caregivers.

- 452 IEC materials have been reviewed, and 241 materials were selected based on relevance and credibility, with further screening and scoring tests ongoing.

**Action Points:**

- Launch the web portal for sharing IEC materials and updates on childhood cancer care.

- Continue developing and updating IEC materials, ensuring they are culturally appropriate and scientifically accurate.

- Create and distribute a unified calendar highlighting important dates related to childhood cancer awareness and survivorship.

**Finance and Policy Task Force Updates by Ms Shivani**

Creation of a comprehensive resource document for funding available for childhood cancer care across India.

**Action Points:**

- Finalize the comprehensive resource document for state and central government schemes and NGOs supporting childhood cancer.

- Ensure all funding sources are captured and accessible on the ICCI website, organized by state.

- Engage hospitals to participate in costing exercises and help identify gaps in childhood cancer treatment funding.

**Survivorship Task Force Updates by Mr Chandan and Dr Vandana**

- Establish survivorship clinics in all cancer centers and develop a national guideline for follow-up care.

- Registry Study: Aiming to establish a comprehensive registry of childhood cancer survivors for future research and policy advocacy.

**Action Points:**

- Work towards the establishment of dedicated survivorship clinics in all pediatric cancer centers.

- Finalize the guidelines for survivorship care, engaging with survivors, parents, and civil society organizations during the second round of consultations.

- Fertility Preservation Group to continue its work on creating a statement and standard of care for fertility preservation in childhood cancer survivors.

**Question:**

- A participant asked about how organizations can join interest groups.

- It was clarified that organizations can join the task forces and represent their interests in the groups. There is an emphasis on individual participation, but hospitals and organizations are encouraged to engage as well.

- There was another query regarding the definition of "survivor" in the context of thalassemia. The response emphasized that thalassemia patients are lifelong caregivers and may not be considered "survivors" unless they undergo specific treatments such as a bone marrow transplant.

- A long-term care registry for thalassemia patients, akin to the cancer survivor registry, could be beneficial for monitoring their health, blood transfusion needs, and potential complications.

**Remaining Task Force Updates were presented:**

**i. Access to Care Task Force**

**Key Focus Areas:**

- Increase awareness among healthcare providers and the general public (parents, teachers) about the symptoms of childhood cancer.

- Development of educational materials (IEC) for physicians to help reduce diagnostic delays.

- Mapping of facilities for appropriate referrals when cancer is suspected.

**Action Points:**

- Collaborate with civil society organizations and NGOs to map healthcare facilities.

- Continue working with Dr. Anuprakash and Dr. Pratik on developing the IEC materials.

- Plan to implement the awareness campaign in the second phase to reduce diagnostic delays.

**ii. Supportive Care Task Force**

Key Focus Areas:

- Focus on medical aspects of supportive care, particularly virus infection control, fever management, and nutrition.

- Development of IEC materials for fever management and nutritional support.

- Work on transcription and survivorship guidelines.

**Action Points:**

- Continue developing fever management cards to distribute to parents and patients.

- Collaborate with private diagnostic centers for broader implementation of fever management protocols.

- Complete the nutritional guidelines by June of next year.

- Plan to address transcription management at a later stage.

**iii. Drugs, Diagnostics, and Therapies Task Force**

Key Focus Areas:

- Ensure availability, affordability, and quality of drugs and diagnostic services.

- Ongoing project to test the quality of drugs in different centers across India.

- Review of WHO and national essential medicine lists to identify gaps.

**Action Points:**

- Continue collaborating with Dr. Vikram Gupta on the drug quality testing project.

- Work with diagnostic labs to enhance the affordability and quality of diagnostics.

- Report any issues regarding drug shortages or quality to the task force for action.

**iv. Cancer Policy and Advocacy**

Key Focus Areas:

- Push for India to become a "focus country" in the WHO's Global Initiative for Childhood Cancer (GICC).

- Develop a national cancer plan, focusing on childhood cancer policy, advocacy, and financing.

**Action Points:**

- Work towards the government of India signing an MOU with the WHO.

- Increase advocacy efforts to ensure childhood cancer is included in national health policies.

**v. Survivorship, Continuity of Care, and Palliative Care**

Key Focus Areas:

- Survivorship and palliative care were discussed in the context of the increasing number of childhood cancer survivors.

**Action Points:**

- Prepare a post-conference session on survivorship, emphasizing continuity of care and the need for proper follow-up protocols.

- Ensure that the palliative care aspect is integrated into all care plans for childhood cancer patients.

**Session 12: Continuity of Care - Survivorship & Palliative Care**

*Chair : Dr Prachi Jain, Senior Consultant and Incharge Pediatric Oncology Hematology and BMT, Max hospitals, Delhi NCR*

*Keynote Speech on Survivorship: Dr Vandana Dhamankar (Deputy Director, ICS Ugam)*

**Panel Discussion:**

- The session began with a focus on the importance of survivorship in childhood cancer care.

- Dr Prachi highlighted the tight chance of survival for children with cancer, emphasizing how therapies, available sensors, and NGO support are crucial for these children’s survival and recovery.

- The session addressed the psychological and social aspects of survivorship, including the challenges children face in reintegrating into society post-treatment.

**Key Point: Long-Term Side Effects:** Survivors often face long-term side effects from cancer treatments, including physical issues like growth problems, fertility concerns, and psychological impacts.

**Survivorship - Medical Issues and Challenges**

Another Panelist discussed the medical challenges faced by childhood cancer survivors:

- Psychological impact: Many children are not told about their cancer diagnosis directly. This leads to emotional and social challenges once they re-enter society.

- Monitoring and Preventive Care: Survivors must be regularly monitored for issues like liver cancer in those who had Hepatitis B, fertility problems, and growth-related issues in children treated for brain tumors.

**Key Action:** Survivorship care needs to be individualized, with a focus on long-term monitoring and preventive care (e.g., liver function tests, fertility counseling, heart monitoring).

**Psychological Care and Support Groups**

A psycho-oncologist from the panel, shared insights on the importance of support groups for survivors:

- Survivors who are part of a support group experience better mental health outcomes and have lower distress levels. Survivors in support groups are more proactive in managing their post-treatment care, and often serve as advocates for other cancer survivors.

**Key Action:** Promote the establishment of survivor support groups in hospitals and treatment centers. These groups should be integrated into the care plan from the beginning of treatment.

**Building Survivor Empowerment and Advocacy**

- Survivors who are empowered to talk about their experiences become advocates for childhood cancer awareness. This empowerment fosters a sense of community and reduces the stigma associated with cancer.

- Dr Prachi emphasized the need for both psychological and social support to help children accept their condition and reintegrate into society confidently.

**Key Action:**  Encourage hospitals to create spaces for survivors to share their stories and educate others. This could include survivor-led awareness programs in schools and communities.

**Thalassemia and Cancer Survivorship - Common Challenges**

- Ms Shobha discussed the similarities between thalassemia and childhood cancer care, highlighting that both groups face challenges such as bodily changes, emotional distress, and societal stigma.

- Unlike childhood cancer, survivors of thalassemia may not be considered "cured," but they still experience significant emotional and social challenges similar to cancer survivors.

**- Key Point:**  The social stigma surrounding chronic conditions like thalassemia and cancer is a significant barrier to seeking support and treatment. There is a need for greater awareness to reduce stigma and improve acceptance.

**The Right to Forget - Challenges of Survivor Identity**

- A discussion took place about the concept of the "right to forget," with survivors having different desires regarding their experience:

- Some survivors want to move on from their diagnosis and not be reminded of their past experience. Others want to actively give back to society and share their journey to help others.

**Key Point:** It's essential to respect the survivor’s choice, some may want to forget, while others may feel the need to advocate and share their stories. There should be no pressure to engage in advocacy if the survivor isn’t ready.

**Key Action:** Develop flexible survivor programs that cater to both groups, those who want to forget and those who want to engage. The survivor's wishes should guide the direction of their post-treatment care.

**Palliative Care for Childhood Cancer - A Continuous Process**

- Mr Chandan emphasized that palliative care should begin from the day of diagnosis, not just at the end of life. Palliative care is crucial for ensuring quality of life and alleviating symptoms from day one of treatment.

- Palliative care includes not only physical but also psychological, emotional, and spiritual support.

**Key Action:** Integrate palliative care early into the treatment process for children diagnosed with cancer, ensuring it is a continuous part of care throughout the treatment and survivorship phases.

**Misconceptions About Palliative Care:**  Many people associate palliative care with "end-of-life care" and believe it accelerates death. There is also a misconception that palliative care is only for cancer patients, although it can support a range of conditions.

**Registry and Data Collection:** A significant gap in survivorship data was acknowledged. The creation of a comprehensive survivor registry is essential for tracking late effects and ensuring proper follow-up care.

**Improving Data Collection:**  The importance of establishing a national database of childhood cancer survivors was reiterated. Data will help improve research, track late effects, and guide treatment protocols for future generations.

**Educational Support for Survivors:**  Survivors were encouraged to pursue education and vocational training. Programs that offer financial support for schooling, along with counseling, are essential for their long-term success.

**Palliative Care: End-of-Life Considerations:** The importance of continuing palliative care, even when patients relapse or are at end-of-life stages, was discussed. Further training for healthcare professionals in pediatric palliative care was identified as a priority.

**Advocacy and Awareness:** Participants stressed the need for greater awareness and advocacy for both palliative care and survivorship. Palliative care should be integrated into national health policies, alongside cancer treatment and survivorship care.

**Action Point:** Creating a Survivorship Task Force: A task force was proposed to focus on the development of survivorship care pathways, including regular follow-ups, psychological counseling, and vocational support.

The session concluded with a call for action, emphasizing the need for collaboration across sectors to improve the quality of life for childhood cancer survivors and integrate palliative care into national healthcare frameworks.

*Conference Adjourned at 5:30 pm*

*This report was prepared by Ms Prathipa K and will be reviewed for approval.*