PHO Vibes

Pediatric Hematology and Oncology Chapter
Indian Academy of Pediatrics

Opening Edition:July 2024

Care
Connect
Learn
Thrive










This Edition

PHO-INPHOG-milestones
Medical Chronicles
Future and Past Pulse
Crosswords and Quiz
Words of Wisdom
Paintings by the Fighters of PHO

All pictures at the end of each page are hand drawn paintings and sketches collected from various pediatric hematology centres all over the country.
Names are not mentioned to maintain confidentiality (as requested by a few children) and also because some of the names were not known.

Cover page design using AI by Dr Shobha Badiger

Note from PHO Chairperson



Dear Members,

We are thrilled to announce the release of the inaugural edition of our PHO newsletter, PHO VIBES.

Since our formation in 1987, the Pediatric Hematology Oncology (PHO) Chapter has flourished remarkably, now boasting a membership of thousands of dedicated individuals. Throughout the years, we have organized numerous impactful activities, ranging from commemorations of World Thalassemia Day to International Childhood Cancer Day. Our commitment to education is unwavering, evident through the multitude of workshops, Continuous Medical Education (CME) sessions, and fellowship programs that continuously enrich our knowledge base.

Each of these events is marked by an unparalleled enthusiasm across the nation, as we strive to raise awareness among both medical professionals and the public about childhood cancer, thalassemia, and hemophilia and several other haematological conditions. While our WhatsApp group and official website have served as valuable communication channels, the introduction of PHO VIBES fulfils the need for a centralized platform to compile our achievements and keep abreast of ongoing events.

PHO VIBES embodies a unique blend of informality, entertainment, and information. It is designed to serve as a conduit for sharing your achievements, job vacancies, meetings, and celebrations, while also disseminating valuable insights through experiential articles.

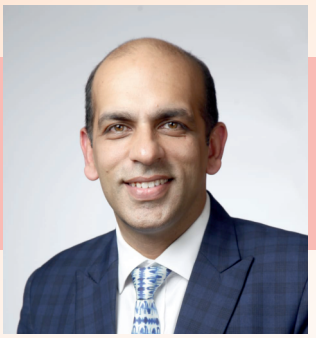
I invite each of you to contribute to the success of PHO VIBES by actively participating in its content creation and dissemination. I also take this opportunity to request all the Members to attend both Mid-Term as well as PHOCON, so that we can meet each other and strengthen our bonds. Together, let us leverage this newsletter to strengthen our community, celebrate our accomplishments, and advance our mission of creating a healthier future for all.



With warm regards,

Prof. Shripad Banavali, MD
Chairman, PHO Chapter
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Note from Honorary Secretary



Dear Esteemed PHO members and Stakeholders,

It is with great pleasure and pride that I welcome you to the latest edition of our Paediatric Haematology Oncology Chapter's newsletter. As the Honorary Secretary, it is my privilege to present to you a glimpse into the dynamic world of our chapter, where passion meets purpose in the care of children with blood and cancer disorders.

Within these pages, you will find a reflection of our collective efforts, achievements, and future endeavours. Through this newsletter, we aim to not only inform but inspire – showcasing the dedication and excellence that define our vibrant community.

Together, we stand as a beacon of progress, activity, and unwavering commitment to the well-being of our young patients. Let this newsletter serve as a testament to the remarkable work being done within our chapter, and may it reinforce our shared vision of making a difference in the lives of those we serve.

A special thanks to our executive board members who have taken on this task to regularly publish a newsletter. Kudos to Dr Shobha Badiger who is the person behind bringing out this issue for the outstanding efforts. She has set a high standard for the future editions.

I invite you to immerse yourself in the stories, updates, and milestones shared within these pages, as we continue our journey of compassion, knowledge, and innovation in paediatric haematology and oncology.

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Message From Editor



Dear PHOites,

It is with great pleasure that I introduce to you the inaugural edition of "PHO Vibes," our official newsletter dedicated to sharing insights, experiences, and updates within the realm of pediatric hematoncology.

In this edition, we aim to offer a glimpse into the diverse perspectives of our members, ranging from doctors to nurses to NGOs, who tirelessly work towards the care of pediatric patients. From heartfelt anecdotes to informative messages, each contribution reflects the passion and dedication within our community.

In this newsletter, you will find a recap of the events that have shaped PHO, along with a preview of upcoming initiatives. Additionally, our "Awards and Accolades" section celebrates the remarkable achievements of our members, showcasing their dedication and excellence in their respective fields.

In the spirit of fostering creativity and camaraderie, we've included a "Fun Section," featuring artwork from both patients and PHOites, as well as engaging puzzles and humor to lighten the mood.

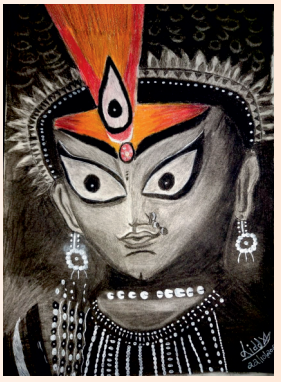
I extend my heartfelt gratitude to Dr. Manas Kalra, our Honorary Secretary, for entrusting me with the role of the first editor. I am deeply grateful to all contributors for their valuable insights, artwork, and event updates, without which this newsletter would not have been possible.

Last but not least, I would like to express my sincere appreciation to the entire PHO board for their unwavering support in bringing this newsletter to fruition.

Thank you all for your continued dedication to the mission of PHO. Here's to many more editions of "PHO Vibes" and the meaningful connections they will foster within our community.

Warm regards,

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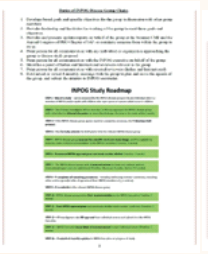


EB MEMBER SOUTH
Dr. Shobha Badiger



EB CENTRAL
Dr. Sunil Jondhale

PHO – INPHOG: Milestones, Growth & Development



1992 - 2007: Early Years

In 1992, SIOP under the banner of PODC SCHOLARSHIPS granted more than 25 scholarships for Indian pediatric oncologists to participate in the SIOP Congress at Hannover hosted by Dr Hansborg Rheim. It was the first time that the Indian diaspora was exposed to leaders of collaborative research from all over the world: CCG, SIOP, NWTS, IRS, CCLG, BFM, UKALL, etc. Seeds were sown in the young Indian minds to explore collaborative research and networking in India for the benefit of children with cancer.

In 1995, this same group under the banner of PHO Chapter of IAP (& the support of SIOP) set up the INTP- PPO, Indian National Training Project in Practical Pediatric Oncology: to educate pediatricians all over the country in basics of pediatric oncology. This program, then led by Dr Bharat Agarwal, resulted in early referrals and facilitated shared follow up of children with cancer; it continues until date. A significant fall out of this project was the networking opportunity it afforded to the existing pool of pediatric oncologists in India. This "collaboration for education" combined with other significant initiatives of the PHO Chapter particularly: organization of SIOP Asia Congress (2002), SIOP Congress (2007) and the launch of Fellowship training in PHO (2007) ultimately resulted in the formal setup of **INPOG in 2008**. The primary objective was to carry out collaborative research nationwide to answer specific questions that were relevant for our country. The PHO Chapter nominated **Dr Anupam Sachdeva & Dr Purna Kurkure to lead this initiative in 2008.**

2008 – 2021: Establishment & Growth

1st Business Meeting, New Delhi, August 2008

A very enthusiastic gathering of about 30 pediatric oncologists discussed & formulated steps to establish a national network for pooling efforts for children with cancer. It was agreed to initiate a few epidemiological studies in the coming year.

2nd Business Meeting, New Delhi, August 2010 & 3rd Business Meeting, New Delhi, August 2013

The formalities regarding the registration, constitution and the MOU of INPOG were discussed extensively during these meetings held in Delhi in Aug 2013. ICMR provided funds to organize these meetings. Due to administrative & financial restrictions progress was very slow.

4th Business Meeting, Mumbai, July 2014

To earnestly push forward the agenda the **4thINPOG Business meeting** was organized by **Drs ATK Rau, Amita Trehan and Santanu Sen on 19 July 2014** on the premises of the Kokilaben Dhirubai Ambani Hospital in Mumbai. This was combined with a scientific discussion on collaborative research and the 1st Mid-term CME of the PHO Chapter. The following **27** members attended: Dr Anupam Sachdeva, Dr Bharat Agarwal, DrPurna Kurkure, Dr L Appaji, Dr P Kusumakumari, Dr Jagdish Chandra, Dr Mamta Manglani, Dr Praveen Sobti, Dr ATK Rau, Dr Madhusmita Sengupta, Dr Gaurav Narula, Dr Satya Yadav, Dr Shailesh Kanvinde, Dr Tulika Seth, Dr Sameer Bakhshi, Dr Gauri Kapoor, Dr Amita Trehan, Dr Amita Mahajan, Dr Leni Mathews, Dr Deepa Trivedi, Dr Siddharth Laskar, Dr Sangeeta Mudaliar, Dr Archana Swami, Dr Manas Kalra, Dr Anand Prakash & Dr Vibha Bafna.

Dr Anupam Sachdeva, Chair & Dr Purna Kurkure, Co - chair of INPOG stepped down from their respective positions held since it's inception six years ago in 2008.

During the scientific proceedings of INPOG during this important meeting, initially **six working groups** of INPOG were formed:

1. Acute Leukemias,
2. Wilms Tumor,
3. Rhabdomyosarcoma,
4. Non-Hodgkins Lymphoma,
5. Hodgkins Lymphoma and
6. Neuroblastoma.

6-7 members joined each working group. More PHO chapter members were invited to join and contribute to these working groups. Dr. Vaskar Saha proposed that the already active "ALL Group" under the Banner of "ICICLE" be adopted as the "ALL Working Group" of INPOG. All the members stressed upon the need for INPOG to become self-sufficient with regards to funding for various projects and in this regard suggested that the next executive committee explore the possibility of obtaining funds from DST, DBT and the ICMR.

5th Business Meeting, Chennai, November 2014

The new executive committee of INPOG was elected during PHOCON 2014 in Chennai for a tenure of 3 years from **2015 to 2018:**

Chairperson: Dr. Sameer Bakhshi Co- chairperson: Dr. Amita Trehan

Hon Treasurer: Dr Brijesh Arora

Executive committee:

1. Dr. Deepak Bansal
2. Dr. Venkatraman Radhakrishnan
3. Dr. Tulika Seth
4. Dr. Ramandeep Arora

During this meeting under the active leadership of Dr Sameer Bakhshi 20 INPOG Disease Groups were established; their Chairs were nominated and duties assigned. Members of each Disease committee were enrolled and steps to start INPOG Studies were laid down.

6th to 15th Business Meetings, were held at various venues with the PHO Chapter Mid- Term CME's & PHOCON's from 2015 to 2019 on a regular basis. The first quarterly INPOG Newsletter (Vol 1; Issue 1, Jan to Mar 2015) was released in Jan 2015; and since then the newsletters have been published regularly with the 10th edition released in 2024.

In 2018 a new team of Executive was elected by the PHO Chapter for the next Term of 3 years from **2018 to 2020:**

Chairperson: Dr. S. D. Banavali

Co – Chairperson: Dr. Revathi Raj

Secretary: Dr. Ramandeep Singh Arora

Executive Members:

Dr Amita Mahajan

Dr. Girish Chinnaswamy

Dr. Nita Radhakrishnan

The term of this Team was extended by a year until December 2021 due to the unforeseen circumstances as a result of the Covid pandemic. By now, until 2020 INPOG had already been a great success with 224 members; 31 studies under the umbrella of INPOG; 7 completed recruitment; 15 recruiting; 2 already completed recruitment, and 7 in development. **More than 10,000 patients were recruited and 111 centers have already participated in the various studies.** The data from these studies resulted in many international and national publications (5 publications under the banner of INPOG). In 2019 during the PHOCON GBM at Varanasi, it was decided to add benign hematology in the research group and register the same as Section 8 company. Accordingly **three benign hematology subcommittees** were added in 2020.

2021 – 2023 : Consolidation

229 members had joined InPHOG and total 29 studies were registered, 10 of which had been completed, 14 ongoing, recruitment to commence in 1 study and 4 under development. **INPHOG RESEARCH FOUNDATION was registered as Section 8 Company on 22nd Dec 2021.** On 18th Nov 2022 during PHOCON, New Delhi, first INPHOG AGM was held with 28 Member Institutions, Board of Directors was constituted with an Advisory Board. The website (www.inphog.org) & logo of INPHOG was launched.

Following the registration of INPHOG as a Research Foundation & a Section 8 Company in December 2021 & as per the AOA & MOA a new Executive was installed with the following 4 Directors:

Dr Ramandeep Arora, Dr Amita Mahajan, Dr Gauri Kapoor and Dr Revathi Raj

The PHO Chapter would like to wish the new leaders of INPHOG to carry on with the legacy of "collaboration" established slowly but steadily over the past 30 years by the PHO community. It's definitely a reason to cherish and celebrate our achievements!

Authors - Dr Shripad Banavali and Dr Manas Kalra

Acknowledgments- Dr Bharat Aggarwal and Dr A T K Rau

Obituary

Dr. Praveen. C. Sobti



5th August 1953 - 11 June 2024

Dr. Praveen C. Sobti, a remarkable pediatrician known for her dedication and compassion, passed away on June 11, 2024, leaving an irreplaceable void. Born on August 5, 1953, in Jammu to Sardar Gurdial Singh Chabbra and Sardarni Mohinder Kaur, she was one of nine siblings and excelled in her studies from an early age. Dr. Sobti attended St Mary's Presentation Convent School and later Government College for Women, Jammu, where she pursued pre-medical studies under a National scholarship. She earned her MBBS and DCH degrees from Government Medical College in June 1981, impressing her mentors with her diligence and clinical skills.

Married to Bharat Bir Singh Sobti, a lawyer, on October 12, 1980, she was affectionately called Veena by her beloved husband. Her devotion extended to her children, Maninder and Damanbir Singh Sobti, whom she cherished deeply. Taking a five-year break to care for them, she emphasized the importance of balancing personal and professional life. Dr. Sobti was a pillar of her joint family, caring lovingly for her centenarian parents-in-law and grandchildren.

A pioneer in pediatric hematology-oncology, pediatric environmental health, and adolescent pediatrics, Dr. Sobti established Punjab's first pediatric hematology oncology unit in 1999. Even after retirement, she expanded services at Dayanand Medical College and Hospital and Christian Medical College and Hospital, Ludhiana. Known for her advocacy in adolescent health, she transformed Guru Teg Bahadur Charitable Hospital as its Director, undergoing extensive training in hospital management and NABH accreditation.

Her impact extended beyond medicine; Dr. Sobti was admired for her eloquence, often integrating heartfelt Shayari into her speeches. She meticulously organized conferences and events, ensuring every detail was flawless. Honored with numerous awards for her service, Dr. Praveen C. Sobti received the Award of Honour from Shaheed Memorial Sewa Society, Ludhiana in April 1997, the Award of Honour from Inner Wheel Club of Ludhiana in July 1998, and the Award of Honour from Rotary Club of Ludhiana Mid-Town in March 2000. She was also awarded the Parman Patra by the Government of Punjab on Independence Day in August 2004 for her outstanding work in thalassemia care. In July 2011, she received the Bhaskar Woman of the Year award from the Governor of Punjab, among other accolades.

Dr. Praveen C. Sobti has left behind a legacy of compassion, wisdom, and a unique blend of art and science that touched countless lives. Her personality would never be adequately described in words. Her profound impact and enduring spirit will surely find a place in the hearts of all who knew her.

- By Dr Shruti Kakkar

Medical Chronicles

THE BOY WHO PLANNED HIS OWN FUNERAL

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I was awakened by the ping on my phone on a pleasantly warm Sunday morning of September 2023. As I flipped through the notifications on my phone, an email caught my eye. It was from my patient from more than 10 years ago, who was sent to a hospice as he wasn't expected to make it till the Christmas of 2013. Rushingly, I opened the email that was sent with an attachment -there he was standing up tall, a very handsome 24-year old young man bearing a beautiful smile, next to his mother who had a shocking pink short hair, leaning on him with a grin on her face. Easily one of the most beautiful pictures of my patients I have seen lately. As I read through the email where he mentioned that he was working in a Celebrity Kitchen in London as a Sous Chef which he thoroughly enjoys working in, I couldn't be more prouder and a flood of memories rushed through my mind.

It was Jan 2013, when our BMT team got a phone call from Addenbrooke's Hospital at Cambridge about this 13 year old boy with a history of T cell acute lymphoblastic lymphoma (T-ALL) diagnosed in 2011. He developed recurrent tonsillitis and was noted to have a tonsillar enlargement during his maintenance treatment. Excision biopsy of the tonsils revealed Langerhans cell sarcoma (same IHC as primary diagnosis)- extremely rare incidence of subsequent LCS that develops following ALL therapy. His bone marrow was MRD negative and PET/CT was clear. Following detailed discussion amongst the BMT experts across the country, the consensus was to offer HSCT for the best survival outcome. Further, he underwent a 9/10 HLA A-mismatched donor transplant in March 2013 with us. A back-up bone marrow harvest wascollected and cryopreserved as he was receiving a mismatched donor HSCT.

Although he engrafted quite swiftly, he developed early adenoviraemia and mild to moderate skin GVHD, mostly settled with topical steroids and short course of low dose oral steroids. He was treated with Cidofovir for a few weeks. His adenoviral load was significantly high that we were unable to discontinue Cidofovir and his acute skin GVHD kept flaring with every little niggle of the dose of immunosuppression. Things from then, started to tumble down like a pack of cards.



Over the next 6 months, blood counts and graft started to dwindle away and he remained transfusion dependent. He had progressive worsening of donor chimerism (<20% donor chimera and no evidence of bone marrow relapse). With lack of any other attractive therapeutic options available, his autologous back up was administered in graded aliquots with no to very minimal conditioning three times, but in vain. He remained on Cidofovir as his adenoviral load was still significantly high. He then started to develop painful blisters of his lips and fingertips on both hands -HSV derived. The boy who filled his time and maintained his sanity throughout this period in the hospital by playing Playstation (PS) was unable to manoeuvre the joystick due to the infection on his fingertips and according to him was considered the most unfortunate complication of his HSCT. As his parents watched him lose weight and fade away with necrotic tissues on his fingertips and blackened lips or oral ulcers that limited his oral intake, he had a very modest request to us that he wanted his fingertips pain-free so that he could keep playing his Playstation.

At that point, he was 9 months post his first HSCT and >54 days following his last autologous stem cell rescue, with no signs of count recovery. He had >3 viral infections. Although there was no relapse, we could have no hope of recovery. We had multiple, daily, extremely difficult and disheartening conversations with the family and the boy himself, about the fatality of this situation, having lost his graft and unable to recover his counts with increasing infection risk. Family wanted to hold back any aggressive medical interventions including antibiotics, total parenteral nutrition (TPN), antivirals and would rather focus on improving his quality of life. They wanted to visit one of our hospices to be able to check if that seemed like a more appropriate place to be able to spend enough time as a family, when he was counting his last days of life.

The boy, in the meantime, was planning his own funeral and dyed his hair pink in a mohawk style.He stated he wanted to look good in his coffin. He discussed how he wanted everyone of us to be dressed up as at his funeral, as though it was a fancy dress competition. He was a real trooper!

As per his request, several discussions with pain team, ID team and plastics/orthopods were held about the best possible way to relieve him of pain from his fingertips and to be able to move them and use it. An option of a median neurectomy was suggested, which the surgeons had never attempted in a live patient before and was moderately certain to help him get relieved of his pain. Holding back tears, this was discussed with the 13 year old himself, who surprisingly was excited that he could have it done and has a chance to use his fingers without pain. In the meantime, we stopped all his anti-infectives and TPN -preparing him to be sent to the hospice which is what the family wanted. He finally underwent a median neurectomy and voila! -he could play games on his PS again with no pain. We all were delighted with what we had achieved with his symptom control.

My 13-year old young man was transferred to our paediatric hospice in the region for comfort care in early December 2013. He was told that he may need to have an early Christmas as we were not expecting him to live through then. The family loved the care delivered at the hospice whilst working on his bucket list. He met a lot of celebrities, drove a few fancy cars, even had a sip of his dad's favourite beer, baked cakes, was on stage with a stand-up comedian where he shared his life story -he ticked off all his bucket list and was running out of ideas.They celebrated his Christmas on the 16th December 2013 and we were his guests for an early Christmas dinner at the hospice. He then lived through a second Christmas in the same year and also wished us for a lovely new year in 2014.



Our frequent visits to the hospice only made us suspicious of his wellness throughout -his lip lesions disappeared, oral lesions improved and appetite greatly improved; he started to gain weight. End of January 2014, he surprised us by showing his fingertips, which looked near to perfect and his sensations improving and no longer required dressing change.



We couldn't keep our growing suspicion to ourselves. We finally did some blood count at the hospice.
Lo and Behold! His counts started to improve and he was just over D+120 from his last autologous infusion. We had to rush back to the hospice to share this lovely news to the family. It was all hail and glory and we had hence named him "Lazarus"! The boy who had been planning his own funeral, now was planning his discharge from the hospice, back to the community.

This was the beginning of an unusual scenario which we have never dealt with before. This youngman was struggling to cope with the thought and the reality that he was no longer dying and he is doing so well and needed to reintegrate into main stream of normalcy. Numerous counselling sessions with him and his family, helping his parents find a job again closer to home, getting him back to school and readapt to a "typical" teenage school life and readjust to what is normal for his age wasn't an easy task. We saw the family move between countries to find a place of solace and finally settled in London for his further education and work.

Looking at his contagious smile from picture on the email that day which I opened feeling so proud of what he is capable of doing with his fingers as a Sous-Chef now, I am not even debating anymore about the worth of getting him through the transplant and beyond or even questioning the transplant in the very first place. I have learnt my lesson.

"When you think you are winning or have won – you probably haven't. When you think you have lost – you haven't always, particularly if not dealing with relapse"

CENTRAL LINE ASSOCIATED BLOOD STREAM INFECTIONS IN PEDIATRIC ONCOLOGY – A MAJOR CHALLENGE

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Let us start with an illustrative example. A 4-year-old child – a case of acute myeloid leukemia (AML) on D10 of induction chemotherapy with 7+3 regimen, with an ANC of 90/mm^3 developed high grade fever and shock. There was no obvious focus of infection. He had a central venous catheter (CVC) on his right cubital fossa. Serum CRP and procalcitonin were elevated and blood cultures were sent. He was started on parenteral antibiotics as per the unit policy (antipseudomonal penicillin + aminoglycoside + vancomycin). *What would be the ideal antibiotic in this situation*? There is no clear answer. The treating team usually decides on an escalation or de-escalation policy depending on their antibiogram.

Since there is no other clinical focus of infection, this is possibly a central line associated infection. Hence, an antimicrobial lock solution was instilled into the CVC. Twelve hours later, Microbiology department informed that there is a Gram-negative growth from both central and peripheral samples and the antibiotic susceptibility profile shows that it is a multidrug resistant organism (MDRO) – MDR Klebsiella - sensitive only to Colistin and Tigecycline. *What do we do further*? The antibiotics will be escalated based on the antibiotic susceptibility pattern and vancomycin would be discontinued. *But do we need to remove the CVC or can we salvage it?* The recommendation would be to remove the PICC line. But in this patient with profound neutropenia on antibiotics, inotropes, blood product transfusions and other supportive care needs, this is a very difficult decision. We would remove the line, continue the antibiotics, and secure another central line.

At this point there is a need to stress on the infection prevention aspects as well. All standard and contact precautions must be taken to prevent the spread of infection. The entire team should be alerted – clinicians, nursing staff, infection control team and housekeeping staff – regarding the precautions to be taken. We should revisit our infection control practices and strengthen them.

What has been described above is a very common scenario in any Pediatric Oncology scenario. CVCs are very commonly used in pediatric oncology settings, more commonly than in general pediatrics setting. CVCs have the advantage that they provide a reliable intravenous access especially in emergencies, aid in the administration of chemotherapy and other supportive medications (especially when prolonged infusions and hydration are required), for administration of total parenteral nutrition and repeated blood sampling. The commonly used central lines are peripherally inserted central catheters (PICC), tunneled catheters and implantable ports. These catheters are retained for long durations spanning from months to a few years. Hence, they are very prone to infections. Central line associated blood stream infection (CLABSI) is usually defined based on the NHSN criteria. Though this is a surveillance definition, this is relevant because it gives us an idea regarding the burden of infections in our unit. CLABSIs increase the morbidity and mortality, the costs of health care and duration of hospital stay. Adding to this problem is the fact that there is a higher prevalence of multidrug resistant organisms (MDROs) as illustrated in the case. An intriguing question to the Pediatric Oncologist is regarding the salvage of CVCs in these situations. They are more likely to have septic shock and thrombocytopenia which makes reinsertion of CVCs difficult in this group of patients. Though different methods of CVC salvage have been attempted like use of antibiotic lock solutions (with or without addition of other agents like EDTA and ethanol), data on the salvage of CVCs are very limited especially in the pediatric population.

An important concept that has evolved in recent years and must be considered important in oncology is mucosal barrier injury associated laboratory confirmed blood stream infection (MBI-LCBI) which is based on the concept that in patients on intensive chemotherapy with prolonged neutropenia or in post HSCT patients (especially with GVHD), there can be translocation of the gut microorganisms to the blood stream. These may not be catheter related but may get included in the definition of CLABSI. The traditional methods of CLABSI prevention may not be effective in this situation.

A major concern is the high prevalence of Carbapenem resistance reported from various centers in our country. The rates of Carbapenem resistance ranges from around 20% to as high as 60% in some reports. The sensitivity to Colistin is also decreasing over the past few years with colistin resistance reported in up to 25% of isolates. The only solution to this problem is by implementation of good antimicrobial stewardship programs in all oncology centers and in the community. Antibiotics should be deescalated whenever possible. Awareness regarding antimicrobial use among primary care physicians is important. The misuse of antibiotics in the veterinary sector should also be strongly discouraged. The policy makers are now becoming more aware of these problems and good AMS programs are being implemented in various states.

Can we reduce the prevalence of CLABSI in oncology settings? Effective infection control practices need to be implemented in all centers treating pediatric cancers. Strict adherence to hand hygiene, asepsis during insertion and maintenance of CVCs, implementing bundle checklists and strict adherence to flushing and dressing guidelines is important. Awareness sessions should be provided to all staff (doctors, nurses, cleaning staff, food handlers) caring for cancer affected children and caregivers. Policy makers should also be involved in these discussions.





NON-IMMUNE HYDROPS FETALIS WITH NEONATAL ANEMIA

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A 1.5-month-old female baby born by emergency LSCS at 36 weeks' gestation to a presented to us with complaints of pallor and refusal to feed over the past one month. The conception was spontaneous and there was no history of consanguinity. Mother developed severe anemia in the second trimester of pregnancy for which she received a blood transfusion. There was a history of intrauterine death in the previous pregnancy. Emergency LSCS was done in view of increased peak systolic velocity (PSV) in middle cerebral artery (MCA) on antenatal doppler sonogram suggestive of hydrops fetalis. The birth weight was 2.9 kg. The infant was intubated immediately after birth due to increased respiratory rate and work of breathing. She received packed red blood cell transfusions on day 1 and day 8 of life. Baby and mother's blood group were O positive and A positive respectively. She was extubated after 8 days and discharged on day 17 of life from the neonatal intensive care unit. The timeline for the case is shown in figure1.

On presentation, the baby had pallor, icterus, pedal edema but no cyanosis or lymphadenopathy. The liver and spleen were palpable 1cm and 2 cm respectively beyond the costal margin. The weight and length were at 3rd centile. The infant had a hemoglobin of 5.8 gm/dl, parents were advised admission for further evaluation and management, however, they refused admission on the first visit. Examination of both parents was done as well. Father, 27 years old, had no history of anemia, his examination revealed mild icterus with no organomegaly. Mother, 27 years old, had moderate to severe pallor with mild icterus on examination along with splenomegaly of 6 cm below left costal margin. Both parents were investigated along with the baby (Table 1). Baby was transfused with packed red cells (10 ml/kg) due to refusal to feed. Parents returned a week later for further management. At this visit, hemoglobin of 7.5 gm/dl, RBC count of 2.77 x 10^6/uL, PCV of 23.5%, MCV of 84.8 fL, RDW of 14.9% and Reticulocyte % of 0.16. Peripheral blood film was suggestive of a predominantly normocytic normochromic red blood cell picture with normal white blood cells and platelets (Table 1). Due to the rapid fall in hemoglobin over one week and the presence of splenomegaly, we investigated the baby for hemolytic anemia. The workup was insignificant for immune mediated hemolysis with negative Coombs test in both the infant and her mother. The osmotic fragility testing was also negative in both. Hb HPLC of parents revealed Hb A2 of 3.4 in mother and 2.9 in father.

Possibilities kept were hereditary spherocytosis/membrane disorders, enzyme deficiencies, unstable hemoglobin disorder. The following investigations were planned:

- Enzyme assays: G6PD was done at birth and found to be normal. Other enzymes could not be tested.
- Bone marrow aspiration and biopsy was not performed.
- Next generation sequencing was sent to arrive at a final diagnosis. It revealed a heterozygous missense variant in the exon 19 of the SPTA1 gene that results in amino acid substitution of glutamic acid for alanine. It is associated with Spherocytosis type 3 and is inherited in an autosomal recessive fashion.

Management:

Baby received 2 transfusions at our institute and was started on folic acid and B12 supplementation. Mother was also given oral B12 and folate supplements. Baby has been transfusion independent since June 2023 and maintained Hb > 9 g/dL.

HERPES SIMPLEX VIREMIA INDUCED SECONDARY HEMOPHAGAOCYTIC LYMPHOHISTIOCYTOSIS AND ESOPHAGEAL STRICTURE IN A PEDIATRIC ACUTE LYPMHOBLASTIC LEUKEMIA PATIENT

Dr. Ngangbam Sonamani, Dr. Monisha Chandrasekeran
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4 years old male child diagnosed as B cell Acute Lymphoblastic Leukemia, Standard risk, CNS Status - 1, normal cytogentics was started on BFM ALL 2009 protocol.End of induction MRD was negative and he started maintenance therapy from Jan 2023.

Herpes Simplex Viremia induced Secondary HLH

On May 2023, during his maintenance therapy, he was admitted in the hospital with the complaints of fever with multiple oral ulcers, spreading to lips and cheeks, for which he was treated with injectable antibiotics (meropenem, teicoplanin, metronidazole) and antifungal(fluconazole). With persisting fever spikes, antimicrobials were upgraded to Colistin and antifungal to Amphotericin. Chest X ray was clear and revealed no abnormality. Serial blood cultures yielded no growth. Urine culture also demonstrated no growth. Culture from throat swab, oral ulcer showed no growth. Fever spikes persisted and he became increasingly pancytopenic. Further workup showed elevated transaminases, hyper-ferritinemia, splenomegaly, pancytopenia and florid hemophagocytosis in bone marrow examination. Diagnosis of secondary HLH was considered. He had no signs and symptoms suggestive of CNS involvement and his CSF analysis was normal. Blood for viral RNA PCR came positive for HSV1 with 28116 copies and he was started on inj Acyclovir and ulcers were managed with local antibiotics and saline compressions and gradually his lesion over the lips improved. For secondary HLH, he was started on HLH 2004 protocol and received Dexamethasone, Etoposide and Ciclosporine, given for 8 weeks. A repeat Bone marrow examination revealed mild hemophagocytosis with marrow in remission and negative MRD. Following the treatment, his fever became defervescent and CBC normalisnormalised. Two weeks later, repeat HSV 1 was negative. In view of difficulty in swallowing, parenteral nutrition was initiated followed by Ryle's tube feeding was continued. How ever he was taking solids and liquids via oral route minimally. His fever, odynophagia and oral ulcers began to improve and he was discharged home, maintained on prophylactic oral acyclovir .

HSV induced Esophageal stricture

One month later, he was brought with the complaints of difficulty in taking solid foods, however he was taking liquids well. On evaluation, Contrast Esophagogram with esophagoscopy was performed. Stricture at T1 level was found with 6 French RT could not be negotiated. Contrast was seen flowing across the stricture. Edematous oropharynx and aryepiglottic fold with multiple oral ulcers were also noted. For nutrition, Stamn's gastrostomy was performed and feeding continued through gastrostomy tube along with orally allowed. Oral ulcers were healed, acyclovir continued. Definitive surgical management for Stricture was planned and he is now under management for the same. He is currently under maintenance therapy for Acute Lymphoblastic Leukemia.

Description

Hemophagocytic lymphohistiocytosis is an aggressive and sometimes fatal disease, which mimics sepsis and autoimmune disorders. Incidence of HLH is more among children than adults. Childhood HLH is strongly associated with underlying genetic disorder in contrast to HLH in adults. HLH is occurs due to lack of perforin dependant cytotoxicity secondary to impaired function of cytotoxic T cell and NK cell. Diagnosis of HLH is made using 2009 HLH diagnostic criteria. Use of this protocol has drastically reduced the mortality associated with HLH. The most common infectious trigger for HLH is viral infection. However in children, HSV causing HLH was rarely reported. In our case, timely diagnosis and treatment with immunosuppression and treatment of the causative agent resulted in favourable outcome for HLH.

Primary HSV infections are common in childhood. The peak incidence of clinical disease is at 2 years of life, with gingivostomatitis the most common expression. Patients with severe herpes gingivostomatitis or pharyngitis may have unrecognised esophagitis. Males are commonly affected than females with a ratio of 3.4:1. HSVE usually presents with odanophagia and dysphagia. Severe symptoms and complications like esophageal stenosis, perforation or bleeding are much more frequent in immunosuppressed patients.

We have not been able to isolate HSV from the esophageal tissue in our patient, probably because of the preceding antiviral therapy, but the clinical history, presence of typical cold sore on his lip, typical endoscopic findings and HSV1 copies identified made a probable diagnosis of HSVE. HSVE is usually self-limited with a favourable outcome in the majority of immunocompetent patients. In our patient with immunosuppressed state and febrile neutropenia might have resulted in formation of stricture. How ever with the prompt initiation of acyclovir therapy in our patient resulted in the healing of ulcer and control of infection.

Conclusion

Hemophagocytic lymphohistiocytosis is a potentially life threatening but treatable condition if recognised early. It mimics sepsis and is triggered by a number of infections, autoimmune conditions and malignancies. HSV induced HLH in children are found rare in literature. In our case with initial difficulty in diagnosing the cause of HLH, high index of suspicion and prompt initiation of therapy resulted in improvement in patient's condition.

HSV– Herpes Simplex Virus
HLH- Hemophagocytic Lymphohistiocytosis
VAHS- Virus Associated Hemophagocytic Syndrome
HSVE-HSVEsophagitis



CARING FOR BODY AND MIND:

THE PIVOTAL ROLE OF PSYCHO-ONCOLOGISTS IN COMPREHENSIVE PEDIATRIC ONCOLOGY CARE

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In the challenging world of pediatric oncology, where young warriors battle against formidable adversaries, the importance of a multidisciplinary approach cannot be overstated. Among the many heroes of these teams are the psycho-oncologist, a professional who specializes in understanding and addressing the psychological and emotional aspects of childhood cancer (Kazak et al., 2015; Pai et al., 2021). Integrating a psycho-oncologist into the pediatric oncology team brings numerous benefits, enhancing the overall care and well-being of young patients and their families.

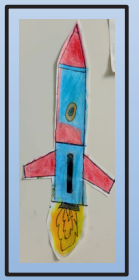
Childhood cancer is not only a physical battle but also a psychological and emotional one. The rollercoaster of emotions, anxiety, and stress that children and families endure throughout the treatment journey can be overwhelming. This is where the expertise of a psycho oncologist becomes invaluable. They provide emotional support, coping strategies, and a safe space for families to express their fears and concerns. These emotional concerns often get left unattended in by primary treating teams due to high workloads and focus on medical aspects of cancer treatment. However it is important to ensure that children and parents are emotionally well as this is known to have an effect on treatment adherence, quality of life, adjustment to treatment, coping and other physical aspects such as sleep, eating etc. These factors may directly impact treatment and its tolerance.

Recent studies continue to highlight the positive impact of psychosocial support on the overall well-being of pediatric cancer patients (Kazak et al., 2015; Pai et al., 2021). A study by Pai et al. (2021) emphasizes the critical role of psycho-oncology services in improving mental health outcomes for children undergoing cancer treatment. The presence of a skilled professional who understands the unique challenges of pediatric oncology adds a layer of holistic care that goes beyond treating the disease using evidence based practice is therefore crucial.

The psycho-oncologist also often serves as a bridge between medical teams and families, fostering effective communication. They help families comprehend complex medical information, aiding in shared decision-making and promoting a sense of control in a situation often dominated by uncertainty. Effective communication is paramount in ensuring that families feel heard, understood, and involved in the treatment process.

Another critical role of the psycho-oncologist is identifying and addressing mental health issues that may arise during and after treatment (Pai et al., 2021). Children facing cancer may experience symptoms of anxiety, depression, or post-traumatic stress disorder and other neurocognitive problems. Early detection and intervention can prevent these issues from escalating, ultimately contributing to a healthier and more resilient post-treatment life.





In my personal experience and as a specialized psycho-oncologist focusing on pediatric oncology, my role encompasses the management and support of children and their families throughout the entire spectrum of care, from pre-habilitation to rehabilitation. This entails providing psycho-oncology services starting from the initial diagnosis and extending through survivorship, and in some cases, until the end of life. Day-to-day challenges sometimes involve addressing the reluctance of patients and families to accept psychological support, often due to misconceptions associating it with 'mentally ill' or feeling 'weak' for seeking help. However, by building strong rapport and fostering healthy therapeutic relationships, we can readily overcome these hurdles and guide patients through their cancer journeys. We often serve as confidants for patients and families, acting as a bridge between medical and non-medical aspects. Additionally, our involvement extends to preparing children and families for procedures, managing anxiety, and addressing other psychological concerns.

In conclusion, the inclusion of a psycho-oncologist in pediatric oncology teams is not just an option but a necessity. Their expertise in addressing the psychological and emotional dimensions of childhood cancer complements the medical care provided by oncologists, ensuring a more comprehensive and compassionate approach. As we continue to advance in pediatric oncology, acknowledging and appreciating the role of psycho-oncologists is crucial for the holistic well-being of the young warriors and their families facing the daunting battle against cancer.

References:

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- Pai, A. L., Mages, K. C., Mullins, L. L., Suris, J. C., Alderfer, M. A., Ewing, L. J., ... & Barakat, L. P. (2021). Systematic review and meta-analysis: Strategies for optimizing psychosocial outcomes for children

A Nurse's Journey in Healing and Compassion

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NURSE stands for Noble-Understanding-Responsibility-Sympathy-Efficient. With this, nursing encompasses all aspects of promoting health, preventing disease, and providing care to the sick, afflicted, and dying.

Nursing is a highly rewarding career. It is a respectable profession with a decent paycheck. Every day, nurses get numerous opportunities to save lives and help people in need. nursing is an extremely taxing job, both physically and emotionally.

As the scope of pediatric hematology and oncology nursing expands, nurses are challenged with staying current in the evidence guiding their practice.
I've had the honor of working in the pediatric hematology and oncology & Bone marrow transplant unit department at Narayana health city Bangalore.I'm so thankful to be where I am in life.

A pediatric hematoncology nurse is a health care individual who specializes in nursing care of children with cancer and hematological problems. They typically work in the hematology or oncology department in a multispeciality hospital, though some work in standalone facilities.

In my experience, I can't forget the job of caring one patient named Rima (name changed) 16yrs old girl who came from Oman for bone marrow transplantation for Thalassemia major. Initially she was doing well, but after discharge she got admitted 4 times with transplant related complications. Day by day her condition worsened. She developed severe hip joint pains, autoimmune complications requiring steroids. She then developed severe myositis. As if this were not enough her thigh bone got infected with osteomyelitis. She was not able to get out her bed because of severe pain. Prolonged hospitalization made her extremely anxious. She would shout and scream at the nurses who were taking care of her.

She had gained weight due to steroid medications, and any movement was extremely painful due to the bone infection. She demanded to be taken care of by only select nurses, would refuse to eat, demanded to be taken to the wash room despite the pain and would not allow us to check her vitals. Rima had new problems every day. The nurse who was taking care of her was tired physically of lifting and cleaning her and was also emotionally burnt out. Her father was also emotionally exhausted and would scream at the nurses. It became the nurse's job to balance between the patient and her father. Several counselling sessions to Rima and her father hardly made any difference. We as nurses were at the receiving end of Rima and her father's emotional outbursts. Convincing the allocated nursing staff to take care of her was a difficult task for me. The day would start with unspoken pain while going to Rima's room. But the determination to do our job as nurses kept us going.

As the nursing incharge the allocated nurse's stress level was as important to me as the patient's pain and emotional problems. Talking and counselling the nurses daily several times was the only way we could continue with Rima's care with a smiling face.

After nearly 6 months of stay in the hospital Rima was finally discharged - although yet to fully recover, but fit enough to travel and be rehabilitated at home. Now she is going to school. All the struggles Rima and her family went through and the struggles we as nurses went through are now all in the past. We only remember the smiling face of Rima that she sends us by whatsapp. Rima's success is our success too and makes the entire nursing team proud.

Pediatric hematoncology nurses have specialized training to care for cancer patients undergoing treatment such as chemotherapy, surgery , radiotherapy and bone marrow transplants. They are also prepared for the unique emotional challenges that families face when a child undergoes critical complications during the treatment. Since each cancer has distinct symptoms and affects patient health differently, these nurses work with a wide range of medical conditions and needs.

They help patients prepare for and recover from surgery, conduct radiation and chemotherapy sessions, organize rehabilitation schedules and monitor vitals. They have to be extremely careful every time while handling these patients as they are highly immunocompromised. They also update medical charts and update doctors about a patient's condition.

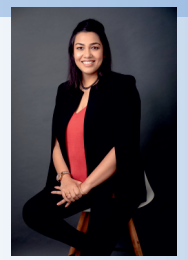
A nurse is not allowed to become sick, as her absence not only brings down the manpower but also causes a sense of loss or anxiety among patients like Rima and her family.

Unlike older patients, children might be too young to understand what cancer is or its implications. They also cannot make their own health care decisions, requiring additional coordination between the doctors, nurses, patients and families.

Observation skills enable pediatric oncology nurses to process sensory information, analyze it and draw conclusions that improve job performance. All nurses rely on observation skills, which are even more important when working with children since children might be unable to verbalize how they feel physically and emotionally.

Emotional intelligence skills help pediatric oncology nurses manage their own emotions and interpret and respond to the emotions of others. Working with children who have life-threatening illnesses can be an intense emotional challenge. Counselling and their own Emotional intelligence enables pediatric oncology nurses to grieve personally and with families and prepare to help the next patient who requires care.

Cuddles Foundation:
Nourishing Children in Their Fight Against Cancer



"Together, we can turn the tide against childhood cancer."

"A child's smile is the most powerful cure in the world."

"Nourishment is the foundation of hope for children battling cancer."

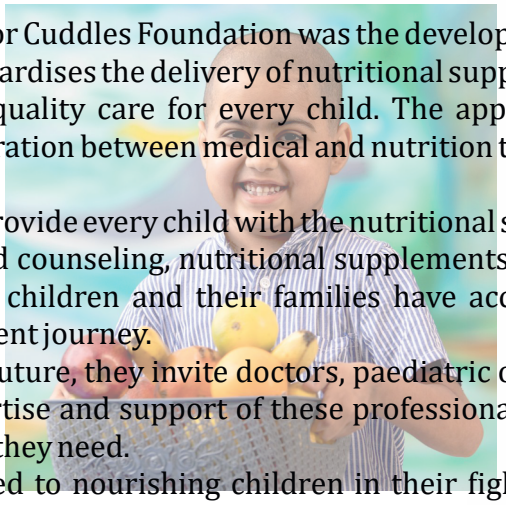
Purnota Dutta Bahl's journey from corporate leader to social entrepreneur is a testament to the power of compassion and action. After over a decade of managing and leading brands for companies like Hindustan Times and Shaadi.com, Purnota's life changed when she visited Tata Memorial Hospital in Mumbai in 2012. Witnessing the dire need for nutritional support among children battling cancer, she was inspired to take action.

In 2013, Purnota founded Cuddles Foundation with a simple yet profound mission: to support children fighting cancer by providing essential nutritional care. Cuddles Foundation partners with government and charity cancer hospitals across India, ensuring these young warriors receive the nutritional support they need to combat their illness effectively. The organisation's vision is to give every child fighting cancer in India a fair chance at recovery and a brighter future.

Cuddles Foundation operates in over 40 hospitals across 14 states in India. Last year alone, they conducted more than 203,000 counseling sessions and supported over 18,000 children. Through their child-centric approach, 82% of patients improved or maintained their nutritional status despite cancer therapy like chemotherapy or radiation, and 96% of children followed up* on their treatment plan when nutrition was a part of it. This impact reflects the foundation's dedication and the effectiveness of its programs.

Paediatric onco-nutrition is not typically covered in standard nutrition curriculums. To address this gap, Cuddles Foundation is dedicated to educating nutritionists nationwide on this critical subject, fostering a more child-centric approach to care. By empowering parents and children with the knowledge needed to manage cancer-related nutritional challenges, the foundation ensures that the best nutritionists from across the country work in its partner hospitals. Cuddles Foundation collaborates with doctors to help manage treatment side effects, providing comprehensive nutritional care that supports the overall treatment plan and enhances the child's quality of life.

A significant milestone for Cuddles Foundation was the development of the FoodHeals® App in 2017. This innovative tool standardises the delivery of nutritional support across all partner hospitals, ensuring consistent and high-quality care for every child. The app automates clinical nutritional functions and enhances collaboration between medical and nutrition teams, making it a crucial part of the foundation's efforts.



The foundation's mission is to provide every child with the nutritional support they need to fight cancer. By offering personalized counseling, nutritional supplements, hot meals and monthly ration bundles, Cuddles ensures that children and their families have access to the essential resources required for a successful treatment journey.

As the foundation looks to the future, they invite doctors, paediatric oncologists, and nutritionists to join in their mission. The expertise and support of these professionals are crucial in reaching more children and providing the care they need.

Cuddles Foundation is dedicated to nourishing children in their fight against cancer because they believe #FoodHeals. Join them in their mission to ensure all children across the country fighting cancer get a chance at cure with the right nutrition. Please write to uma@cuddlesfoundation.com to partner with them.

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*follow-up treatment rate: Patients who returned for a second visit or continued treatment when nutrition was a part of it.

AWARDS AND ACCOLADES

Dr Mamta Mangalani and Dr Banavali awarded the Lifetime Achievement Award at the 47th Annual Conference,
Mumbai Haematology Group (MHG) and
Essence of ASH- Dec 2023 held at Mumbai on 26th to 28 th January 2024





PHO chapter was awarded the "Best Chapter Award of IAP " at Pedicon 2023

Dr Venkataraman Radhakrishnan was awarded the " Hans Peter Wagner Prize-2023 Winner" in recognition for his work in the less resourced settings





Dr Rashmi Dalvi delivered SIOP statement at the 77th session of World Health Assembly





Prof. Dr. Shripad Banawali and Prof. Dr. Anupam Sachdev conferred PHO Guru Dronacharya Award during PHO Gurukul on B- ALL at Amrita , Faridabad





India's first CAR-T cell therapy developed through collaboration between the Indian institute of technology Mumbai and TATA Memorial Hospital, Mumbai with the Industry partner ImmunoACT was recognised and awarded by the Honorable President of India Smt Droupadi Murmu at the Rashtrapati Bhavan, New Delhi

Past Pulse: Recaps of Recent Events

International Childhood Cancer Day Celebrations
February 15,
Unveiling Challenges
















World Thalassemia Day: May 8

Empowering Lives, Embracing Progress: Equitable and Accessable Thalassemia Treatment for All





















Video link for Thalassemia awareness released by The Ministry of Health and Family Welfare:
https://www.youtube.com/watch?v=H__bidXcanE

NTP-PPH Workshop





24 Feb Apollo Hospital New Delhi by Dr. Anita Mahajan and Dr. Meenakshi Bansal





30 March at Bharati Vidyapeeth Hospital,Pune organized by Dr. Vibha Bafna and Dr. Sandeep Bartakke Delegates: 87



7th April, SS Medical College Rewa, Dr. Gaurav Tripathi Delegates 50

NTP-PPO Workshop





4th feb at AIIMS Bhatinda by Dr. Prashanth Chabra and Dr. Amita Trehan
Delegates 50





10th Feb, AIG Hospitals Hyderabad by Dr. Anisha Panda and Dr. Sunil Bhat
Delegates 100



17th Feb, KIDWAI Memorial Hospital by Dr. Prakruthi Kushik and Dr. Shirisha Rani
Deligates 40

NTP-PPO Workshop



30 March, TMC Kolkata by Dr. Arpita Bhattacharya and Dr. Munlima Hazarika
Delegates 108



27 April, NSCB Medical Jabalpur by Dr. Shweta Pathak and Dr. Sunil Bhat
Delegates 108



26 May, By Dr Abhilasha and team from KLE Belgaum
Delegates 61



31 May, at PGICH, Noida, By Dr Nita Radhakrishnan
Delegates 89

Past Pulse



3rd SACT- An Asia Pacific Cell Therapy Conference on 1-3rd February 2024 at TMH, Mumbai



World Hemophilia awareness day activity at Hemophilia treatment centre(HTC), Hyderabad chapter



5 th annual meeting of ISBMT, 3-5 May ,2024, Hilton Convention Centre, (Manyata Business Park) Bengaluru

International

- 50th annual EBMT Meeting: Glasgow UK: April 14 to 17, 2024
- 6th Emirates Pediatric Hematoncology Oncology Conference, May 4-5,2024, at Grand Hyatt Hotel, Abu Dhabi
- 10th annual Retiniblastoma group (EURBG) meeting: May 31 to June 1, 2024: Athens
- SIOP Africa 2024 Congress: June 4-8, 2024: Johannesburg: South Africa
- 21st International Symposium on Pediatric Neuro-Oncology (ISPNO 2024) Philadelphia, PA, from June 28 – July 2, 2024

Future Pulse

International

1. Malaysian Society of Pediatric hematology and oncology (MASPHO) - Childhood T cell leukemia/AML/ AML in Downs syndrome and Oncofertility, 3-4th August 2024,Nursing Masterclass 3rd August 2024, Everly Hotel, Putrajaya, Malaysia
2. SIOP 2024: October 17-20, 2024, Honolulu, Hawai, USA
3. 51st Annual Meeting of the EBMT in the city of Florence from March 30 to April 2025
4. Asia-Pacific Blood and Marrow Transplantation Group (APBMT) Annual Meeting 2024 from 10th October to 13th October 2024 at Singapore.

India

1. 27th annual PHOCON 2024, from 22 November to 24 November 2024 at Convention Centre, Jammu City
2. Ongoing PHO Classes on ECHO platform:
   -2nd Thursdays Pho National training program
   -3rd Thursdays - Nurses training program
   -4th Thursdays - International speaker program
3. International Histiocytosis Meeting, 5-9 November 2024, Goa
4. Hematocon 2024, at Nagpur from 7-10 th November with state and zonal level quizes (Karnataka State level quiz on 24 August 2024 in Mangalore. last date to register 15-7-2024. Contact Dr. Sidarth Totadri)

GOA 2024 — 40TH ANNUAL MEETING — HISTIOCYTE SOCIETY

April 5, 2024 - Early Bird Registration, Abstract Application and Travel Scholarship Application open
May 6, 2024 - Nominations open (Members only)
June 27, 2024 - Abstracts and Scholarships close – Date has been extended to July 7, 2024
July 7, 2024 - Abstracts and Scholarships extended closing date
July 8, 2024 - Nominations due (Members only)
August 16, 2024 - Abstract author and travel scholarship notifications sent on or about this date
August 23, 2024 - Early Bird registration closes
September 9, 2024 - Late Breaking Abstracts open
October 7, 2024 - Late Breaking Abstracts close – No Extensions
October 21, 2024 - Late Breaking Abstract author notifications sent on or about this date
October 23, 2024 - Standard Registration for in-person attendance closes
October 30, 2024 - Virtual Standard Registration closes

PHOCON 2024
27th Annual Pediatric Hematology Oncology Conference
22 Nov'24 : Pre- Conference Workshops
23 & 24 Nov'24 : Main Conference
CONVENTION CENTRE JAMMU

Important Dates
Last Date of Early Bird Registration: July 31, 2024
Last date for submitting abstracts: August 31, 2024

Program Highlights
Pre-conference workshops on November 22, 2024.
Main conference on November 23 & 24, 2024
Plenary lectures
Debates
Oral paper presentations & poster presentations
Panel discussions
Cultural Program & Conference Dinner

Conference Secretariat
PHOCON 2024, Jammu
Department of Pediatrics, SMGS Hospital, Jammu - 181205
E: admin@phocon2024jammu.com
To submit your abstracts,visit: phocon2024jammu.com/abstracts/
To register & confirm your participation visit:
phocon2024jammu.com/registration/

EDUTAINMENT AND ARTiFACTS

THOU ART SHALL LIVE



Paintings by The Fighters Of PHO

PHOmor

"Why did the pediatric hematologist become a comedian? Because they were tired of everyone saying they had a 'bloody' serious job!"

WOW Words of Wisdom

The Seven Steps To Multiplying Joy And Dividing Sorrow – The Essence Of Team Work

Dr Revathi Raj,
Senior Consultant, Pediatric Hemato- oncology
Apollo Cancer Center,
Chennai
revaraj@yahoo.com

The field of Paediatric Haematology and Oncology in India is now at its threshold with exciting new therapies and curative options and pioneering work being done in our country. I have counselled many young paediatricians about pursuing a career as an Oncologist or as a Transplant physician. The essence of several conversations has now been condensed into this article and they truly represent my experiences and my deepest thoughts.

India is home to 444 million children with a significant proportion with blood disorders and cancers. It was in the early 2000s that the concept of paediatricians treating children with these conditions was first introduced in the country when a few pioneers who had trained abroad came back to establish centres of excellence. The last two decades have seen the fruits of the seeds laid down by these individuals and we now have state of the art training available in our own country.

The first question is why PHO? Would you choose this path if given the choice all over again? The answer without a doubt is yes again and again. We are given a unique opportunity to make a difference in the lives of children with lethal disorders. Every day work involves meticulous attention to little details and consistent service delivery to ensure an optimal outcome. The difference in the outcome of a child treated by a team lead by a PHO physician has been published in several journals. As a PHO physician, we need to follow protocols and guidelines, review the response, and connect with the child and their family for a life time and I totally treasure this bond!

The second question is about how can I handle the emotional roller coaster? Our training does not entirely prepare us to deal with “failures” and honestly the “successes” too. If a child is in remission, we let our hearts soar only to fall from a great height if the child relapses. If we understand and accept that we are part of a journey in the life of our patient and not personalise these events, the fear and stigma associated with our service can be removed. Once we accept that we are not super heroes but a trained physician performing their duty to the best of their ability, then the highs and the lows of the job are easier to navigate.

The third question is where should I work in India? The service in India comes from both public and private sector hospitals and the first choice a young PHO physician needs to make is which sector to choose from. Every system has its unique challenges and the most important step is to build a team and invest in every member of the team. The essence of team work is to trust in each other, allocate individual roles and ensure that the collective result provides for all the needs of an individual child and their family under our care. We need to find the deficits in the system in which we work and fill the gaps.

The fourth question is should I settle down abroad? The systems in any of the high-income countries ensures that the service delivery is as a team and never linked to an individual and is seamless. This is the system that we need to replicate in India. The model for personal space, growth in a unique area of interest, trained nursing personnel, para-medical staff, data managers and staff to help in the psychosocial well-being of the family has been perfected for decades. This ensures 24x7x365 service delivery without the need for an individual’s presence at all hours and prevents stress and burn-out. These models can now be replicated in our country the local community benefits immensely from this service.

The fifth question is if I am interested in research can I still work in India? We are just beginning to understand that high quality bench work must be integrated with patient service units. We have been islands of excellence so far and must learn to work hand in hand to understand the gaps for our patients and fill them with innovative low-cost technology. Make in India is possible as demonstrated by the IIT Mumbai and TMH Mumbai team who have produced low- cost CAR-T from our own country.

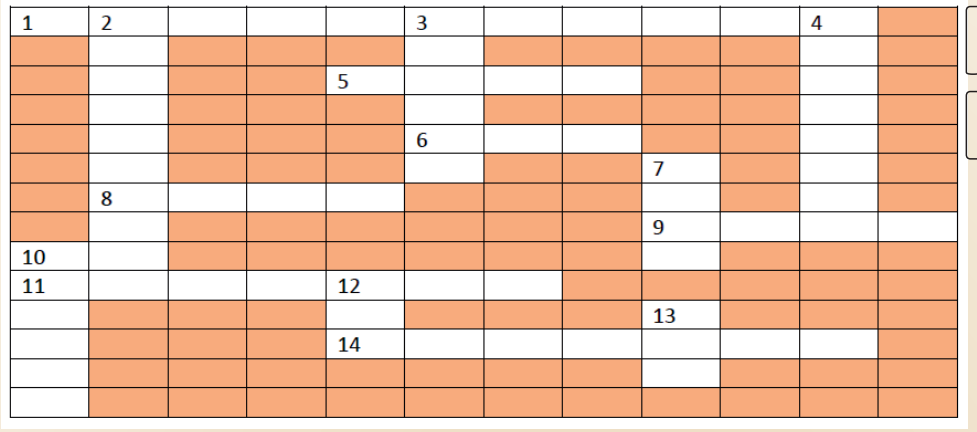
The sixth question is how should I work on access to care? The most important challenge for a physician is to ensure adequate funding is available to deliver treatment for every single child that they treat. India has seen an amazing improvement over the last decade with several government and non-government schemes available for every individual child to avail of the treatment to save their lives. A team to work on funding helps remove the stress from the treating physician on making the right decision for an individual child and their unit. India has wealth within the country to help perform miracles for little lives and this needs to be tapped appropriately.

The seventh question how should I manage my personal finance and does this job pay well? It is important to plan personal finance very early in life. Our income from the primary job does not have to cover all our expenses. A well-balanced approach to long term finance eliminates pressures from the management to work beyond our capacity resulting in stress and ill health.
A PHO physician in India is now set to change the world by working together as a team, at a unit level and national and international level. Working groups and teams can now connect virtually to discuss the way forward for a particular child and at the highest level recommend government policies. The public are now engaging with us to do their part for the community with blood donation camps, volunteering, and crowd funding. Artificial intelligence will come to our aid in difficult situations. The time is right to work in this field, enjoy what we do as a team and find that together with our mentors, nurses, social workers we can make a difference with human touch and compassion and enrich our lives and that of every one we meet in our daily lives! We only need to continue connecting…..





CROSSWORD

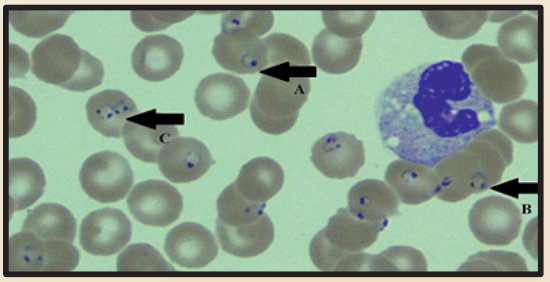


Across	Down
1: I drain your hue to a pallid veil, Organs overwhelmed as I assail. Thirsting for their blood, my silent plea, Lifelong agony, my grim decree. Yet in donors' grace, a lifeline found, To quell the suffering, and heal the profound. (11 letters) 5: I toil relentlessly, yet breed only harm, From birth, a crimson glow, a silent alarm. Bowels loosen, defences frail, No vaccine triumphs, in this microbial tale. Trivial germs wield fatal might, Self-loathing festers, sparing no plight. Innocence lost, in the cradle's keep, But hope persists, in your stem cells, to leap.(4 letters) 6: I devour bones, swell liver and spleen, Skin left ravaged, cells bizarre, but seen. A puzzle to research, this enigma's code, Find and treat me, lighten this load.(3 letters) 8: From my absence, growth's pace does wane, Common culprit: poor nutrition's chain. Solution simple, yet oft forsaken, Bright minds dim, agility shaken. Unaware until blood's hue pales, Absence speaks in silent tales. (4 letters- clue deficiency) 9: No production, no destruction in my stead, Blood runs pale, no crimson spread. Born of marrow's impoverished plight, Dependent on supply to sustain the fight. Grant me the graft, this vital seed, To awaken the factory, fulfill my need.(4 letters) 11: Harmless to thee, yet your child may suffer, Beware your lineage, it's not a buffer. Test your betrothed, ensure their health's clear, Lest your offspring bear the burden severe.(7 letters) 14: I may grace the nose or monthly cycle's dread, My presence uncertain, where I tread. Less dire than my ominous kin, Some find solace in sticky blood's thin spin. For some, a graft may be the only lure, In this enigma, solutions obscure. (7 letters- first word of the disease)	2: I flow like an unyielding tap, With or without a forceful rap. Once a tale of royal bloodline pride, Now a commoner's fate doth abide. One shot, the only pause to see, Yet halt not, if freedom you plea. (9 letters) 3: I bend, I block, I bring pain's hush, Turning pale or yellow with my touch. Yet some remain untouched by my spell, In genes, future hopes may tell. For now, capsules and donors' cells cast their spell, To ease the suffering in this lifelong dwell.(6 letters) 4: Factory idle, niche diseased, marrow barren, Fat overflows, red and white forgotten. Bleed unceasing, a relentless flow, Why falter, the root cause unknown. Urgent need for replacement dire, Resolve sought, no matter the mire.(8 letters) 7: Stones form, a painful foe, Eyes turn yellow, a warning's glow. Beans forbidden, boys take care, Scarce enzymes, a burden to bear.(4 letters) 10: Sailor's lore speaks of woes at sea, Blood in mouth, foul odor, not free. But in citrus' tang or sweet embrace, Lies the cure, this ailment's saving grace.(6 letters) 12: Beneath my skin, my army turns foe, Brief skirmishes, but they come and go. Yet some battles need support to last, Through sneezes, coughs, a shadow cast.(3 letters) 13: What's in a name Said the poet But my name tells a tale of riot Infection it seems But it's all in the defective gene Causing chemical explosion Severe disruption Know my name Learn my game Only then will thou explore and find All the riot and its mind Hurry there is no time to roll Miss the sign you lose control(3 letters)

Created by Dr. Shobha Badiger

Quiz !

Q1 A 10 years old boy comes with history of fever and altered mental status. On examination has splenomegaly. Complete blood count - Hb 11g/dl, WBC: 15 x 10^3/uL and platelet count: 59 x 10^3/uL. Peripheral smear picture as below. What are the arrows in the smear showing?



Q2. 15 years boy was diagnosed with mixed germ cell tumor of the right testis. AFP was 206ng/ml. He was treated with chemotherapy and underwent orchidectomy. His disease was in remission and all the follow up scans were normal. After 2 years on a regular USG - Lymph nodal mass in abdomen was found. CT abdomen showed soft cystic mass lesion in the infrarenal aortocaval region. AFP and HCG were normal. He underwent laparotomy with excisional biopsy of retroperitoneal lymph node. Histopathology was suggestive of Mature teratoma . What is your diagnosis?

Q3: Osteosarcoma and rhabdomyosarcoma are associated with germline p53 mutations as part of the Li-Fraumeni familial cancer syndrome. Germline Rb mutation is associated with retinoblastoma and secondary sarcomas, which are predominately osteosarcomas. Germline RECQL4 mutations are associated with a predisposition to osteosarcoma but not rhabdomyosarcoma. PAX3 mutations are associated with Waardenburg syndrome and not specifically with cancer. Germline LOH at 11p15.5 is associated with Beckwith-Wiedemann syndrome and a predisposition to rhabdomyosarcoma but not osteosarcoma

Answers

Quiz : 1- Trophozoite of Plasmodium Falciparum, 2- Growing Teratoma Syndrome (GTS), 3- E

Q2: Definition (all three parameters to fulfill)1. Enlarging or new masses despite appropriate chemotherapy for nonseminomatous germ cell tumors; and
2. Normalization of serum tumor markers, alpha fetoprotein, and human chorionic gonadotropin
3. The exclusive presence of mature teratoma in the resected specimen.

Q3: Osteosarcoma and rhabdomyosarcoma are associated with germline p53 mutations as part of the Li-Fraumeni familial cancer syndrome. Germline Rb mutation is associated with retinoblastoma and secondary sarcomas, which are predominately osteosarcomas. Germline RECQL4 mutations are associated with a predisposition to osteosarcoma but not rhabdomyosarcoma.PAX3 mutations are associated with Waardenburg syndrome and not specifically with cancer. Germline LOH at 11p15.5 is associated with Beckwith-Wiedemann syndrome and a predisposition to rhabdomyosarcoma but not osteosarcoma

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Crossword : Across - 1. Thalassemia 5. SCID 6. LCH 8. Iron 9. PRCA 11. Carrier 14. Platelet
Down- 2. Hemophilia 3. Sickle 4. Aplastic 7. G6PD 10. Scurvy 12. ITP 13. HLH

DID YOU KNOW

The Infamous Infected Blood Scandal

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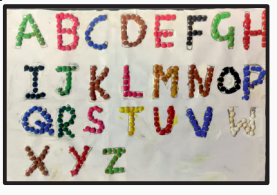


In May 2024, the final report of a statutory public inquiry conducted in the United Kingdom (UK) was published which brought to light an upsetting incident involving thousands of people with hematological disorders.[1] In the 1970s and 1980s, several thousand people with bleeding disorders such as hemophilia were administered clotting factors and blood products that were contaminated with HIV and hepatitis viruses. A 6-year public inquiry initiated in 2017 examined the reason behind how 30000 people with hemophilia became infected with HIV and hepatitis C viruses. Hemophiliacs were found to have received factor concentrates from the United States of America, which were prepared from blood donations from high-risk populations such as prisoners and people living in poverty. The UK government is planning a comprehensive compensation scheme for the affected individuals.

Superior screening techniques such as NAAT (nucleic acid amplification testing) have significantly reduced the risk of transfusion-transmitted infections. Yet, in 2023 a single-center study from Lucknow demonstrated positive screening tests for HIV, HBSAg, and HCV in 1.3%, 0.78%, and 1.56% of 385 patients with hemophilia.[2] This reiterates the need to ensure safe blood products and factor concentrates for patients with bleeding disorders. Additionally, voluntary blood donation must be encouraged in our country, where there is a demand and supply gap of 2.5 donations per 1000 eligible persons.[3]

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Past shapes present, Present shapes future

Important dates and interesting facts in the History of Pediatric Hematology Oncology

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- 1674- first accurate description of RBC in Leeuwenhoek's publication
- RBCs are so minute that 100 of them placed side by side would still be smaller than the diameter of a common grain of sand
- Dr William Hewson, one of the Fathers of Hematology, described for the first time that RBCs were flat, that there were leukocytes and that coagulation occurred in the plasma
- 1882: Julius Bizzozero described platelets calling them "platchen"
- William Osler believed that platelets were infectious agents like the bacteria
- Bizzozero identified the bone marrow as the site of blood formation
- 1877: Paul Ehrlich developed staining of peripheral blood smears with aniline dyes. He was a medical student then
- 1925-1927: Thomas B.Cooley described a new hemolytic syndrome in a group of young children of Italian and Greek ethnicity and called it as Erythroblastic Anemia, later known as Cooley's anemia/Mediterranean disease
- Dr. Louis K. Diamond , called Father of American Paediatric Haematology, and who along with Blackfann described congenital hypoplastic anemia better known as diamond blackfann syndrome, spent six unpaid years in clinical and research training under the mentorship of Dr. Kenneth D.Blackfan in preparation for his career (unthinkable in today's time)
- 1944: Atlas of the blood of Children was published by Blackfan, Diamond (the principal force behind this remarkable book) and C.M Leister. The 70 illustrations of peripheral blood smears were hand painted color drawn by Leister
- Paediatric haematologists who were trained by Diamond were called Diamond Chips, there were a generation of them
- Dr Wolf W Zuelzer, who described megaloblastic anemia, was partly Jewish, fled from Germany in 1933, to escape elimination by Hitler for being a "non Aryan", served a year as an unpaid volunteer in Boston Children's hospital under Dr. Sidney Farber who became his adoptive father, mentor and role model
- 1960: Dr. Carl H. Smith, single authored Blood Diseases of Infancy and Childhood, long before word processors and electronic literature searches
- 1974, November 2: First certifying examination in Paediatric Hematology Oncology was given by American Board of Pediatrics simultaneously in Chicago, Philadelphia, and San Francisco. There were many senior candidates appearing for the exam, hence the slides were "moved up" for those with trouble focusing!
- 1964: Hypertransfusion in thalassemics was introduced by Dr Irving Wolman who showed that maintaining Hb above 8-9.9 g/dl resulted in better growth, less organomegaly and other complications. Before this, patients were chronically anemic with pretransfusion Hb of <4-6 g/dl due to the fear of iron overload
- 1950s: Use of Desferoxamine started. It was only after nearly 20 years that prolonged infusions of deferoxamine was introduced as more effective iron chelation by Dr Riichard Propper and associates in 1977
- The term Sickling Crisis was first used by Dr Virgil Sydenstriker who also described latent sickling in the parents of sickle cell disease
- Dr. Harvey A. Itano and Dr. Linus Pauling were responsible for the construction of electrophoresis apparatus to analyze the Hb and HbS in sickle cell disease. Pauling's interest in sickle cell disease started in an overnight train ride from Denver to Chicago with Dr William Castle from whom he learnt about sickling phenomenon
- 1916: Splenectomy as cure for chronic ITP was "discovered" as a result of removal of spleen in a young woman with severe thrombocytopenia by Professor Schloffer only on the persuasion of a medical student, Paul Kaznelson
- 1803: Hemophilia was described as "Bleeder's Disease" by Dr.J.C Otto. Severe bleeding, which was undoubtedly hemophilia, was recognized more than 2000 years ago in boys after ritual circumcision, in the Babylonian Talmud
- 1970: Entry of HIV virus in plasma derived Factor VIII concentrates, more than 75% of those who were transfused became HIV positive
- 1992: It took this many years for recombinant Factor VIII to be widely available
- 1897: A brief description on brain tumors, leulkemia and hodgkins disease in a six page section was the only attention pediatric malignancy received in the text book "The Diseases of Infancy and Childhood". It took 43 years for pediatric cancer to get a full publication by Dr Harold W. Dargeon with his publication Cancer in Children in 1940

- 1969: National Wilms' Tumor Study was organized and funded by the National Cancer Institute, by 1979 the studies showed that RT is not necessary in completely resected wilms tumor with multiagent chemotherapy
- 1955: Children's Cancer Study Group CCG and in 1968: SIOP were founded
- By 2000 Children's Cancer study group (CCG), Pediatric Oncology Group (POG), the IRSG and NWTS were merged to form Children's Oncology Group (COG)
- 1940: Average survival of children with ALL was less than 3 months , stated by Dr Dargeon. Only 71 children with ALL were found to have survived more than 5 years in the whole world
- 1948: Dr Sidney Farber and associates reported temporary remissions in ALL with aminopterin, making the beginning of modern era of leukemia. Biochemist Y. Subbarao synthesized aminopterin, but sadly, is name was not mentioned in the Farber's report
- Introduction of important chemotherapeutic drugs in ALL: 1953: 6 Mercaptopurin (Drs. Burchenal, Lois Murphy, and associates), 1961: L asparaginase, 1962: vincristine, steroids, cytarabine
- Synergistic action of Combined, simultaneous chemotherapy in leukemia was first demonstrated in animals by Dr H. Skipper, was aptly called Skipper model
- 1965: First drug combination in ALL – VAMP, showed better survival compared to sequential use
- 1960s: phases of ALL treatment became recognised as remission induction, intensification, CNS therapy and continuation (maintainance) therapy
- 1970s: Drs. R.J.A. Auer, D. Pinkel,and associates showed that Craniospinal radiation and intrathecal methotrexate (called it "total therapy") increased survival and prevented relapses in sanctuary sites (they called it leukemic meningitis)
- 1975: ALL is for the first time classified into subtypes
- 1998: researchers begin individualizing the dosage of chemotherapy to increase survival rates in children with ALL
- 1990s: cures in malignancies improved: from 5 to 80% in ALL, 30 to 90 % in Wilms, 10 to 60% in malignant brain tumors
- 1891- William Bradley Cooley, known as father of immunotherapy, first time used immune system - called "Cooleys toxin"- scientifically to cure bladder cancer, then several.other cancers.
- 1908- Paul Ehrlich confirmed Cooleys findings
- 1997- first monoclonal antibody - rituximab- was introduced
- 1995- significance of TREGs in cancer was recognised
- 1902- onset of CAR T and adoptive cell therapy era with autologous tumor cell vaccination by Blumenthal and E Von Leyden
- Mid 1990s- CAR T cells were described for the first time but failed to launch
- 2017- FDA approved CAR T therapy in pediatric ALL in 2018 in B cell Lymphoma
- 2018 Nobel Prize award to James Allison and Tasuku Honjo for their meticulous work on checkpoint molecules as potential therapeutic targets.

Reference-

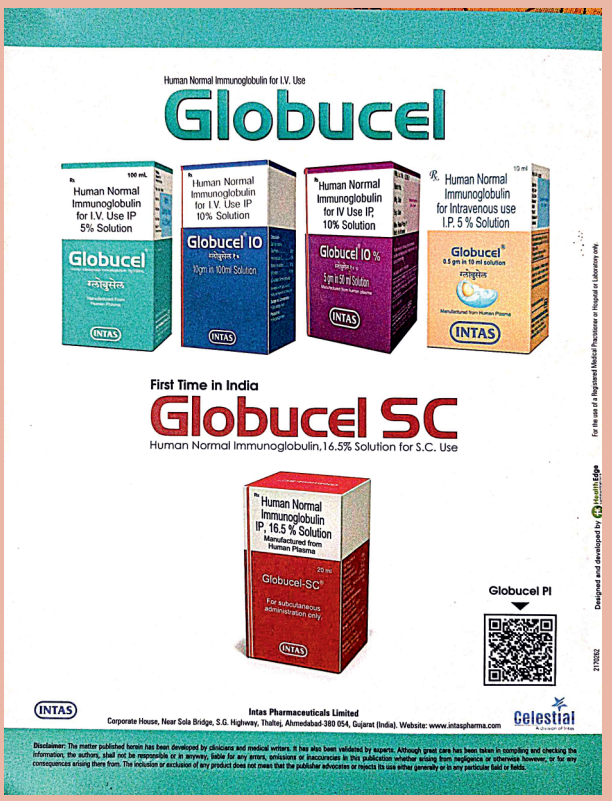
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