Pediatric Hematology
and Oncology Chapter
Indian Academy of Pediatrics

PHO Vibes

Third Edition August 2025


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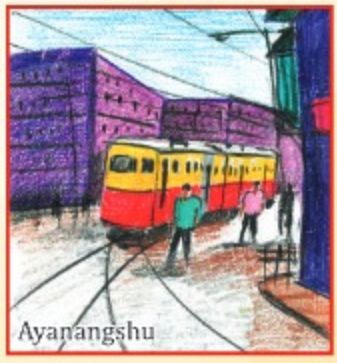
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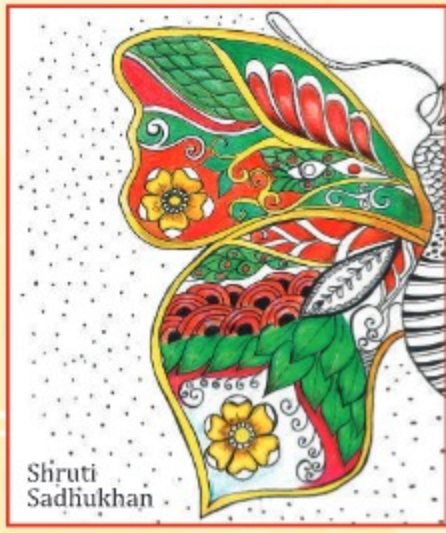
Shruti Sadhukhan

This Edition

Note from PHO Chairperson

Dear Friends and Colleagues,

Greetings from Paediatric Haematology Chapter of Indian Academy of Paediatrics (PHO-IAP).
It gives me immense pleasure to present to you the third edition of "PHO-Vibes", the newsletter of our PHO Chapter of IAP, during the occasion of our 10th midterm CME 2025 in Noida. This Publication gives us an opportunity to disseminate details of activities that have been conducted by our community during the previous six months as well as share with you the milestones achieved by our society during that time.

The PHO community in India is growing at a healthy speed, with nearly 50 trained paediatric haematologists / oncologists being added to this community every year. In addition, many other allied specialists are also joining our PHO community like paediatric surgical oncologists, paediatric radiation oncologists, paediatric nurses, NGO's, etc. The number of members of the PHO Chapter of IAP is expanding every year. Along with the PHO Chapter of IAP, we also have other Groups like Indian Paediatric Haematology Oncology Group (InPHOG), which is involved with Research activities of our community; and the Indian Childhood Cancer Initiative (ICCI), which is the arm involved with guiding the Indian government with making policies in regards childhood cancer care for India. All these have helped to increase the scope of work of our PHO community and at the same time help improve access to care for the patients, which will lead to improvement of the outcomes of children with cancer and haematological diseases in India.

With the publication of hundreds of journals, there is lot of scientific material already available on the internet. Therefore, this PHO-Vibes is not to give you additional knowledge to diagnose or treat patients with cancer or blood disorders. Articles published in PHO-Vibes are personal stories – cases - involved in the day-to-day activities of the members of the chapter, which gives an emotional and personal touch these articles! These are stories that one can relate to; these are articles / case reports, which are much closer to our heart – similar to the places where we practice - that makes it more special. There are success stories; stories which may not have the ending that we desired, but they are ours! PHO-Vibes also covers news of various activities that have taken place over the last few months. There are many photographs of our colleagues, ourselves, which will bring a smile on your face! Please take out time and read the entire issue.

I take this opportunity to thank all the contributors not only of this edition, but also of the previous editions. I once again would like to thank Dr. Shobha Badiger & Dr. Sunil Jondhale for doing a great job of being the editors-in-charge of the previous editions & Dr. KS Reghu who has taken great efforts to get this issue of PHO-Vibes to be published on time.

I wish you all a great 10th Midterm Meeting of PHO CME 2025 in Noida. Hope to meet you all again soon with the next edition of PHO-Vibes during the Annual PHOCON Meeting in Manipal. Keep on working hard for the children with cancer and blood disorders until then.

With personal regards,

Prof. Shripad Banavali, MD
Chairperson, Haematology Oncology Chapter
Indian Academy of Paediatrics
banavali-2000@yahoo.com

Note from Honorary Secretary

Dear PHO Members,

As the honorary secretary of the Pediatric Hematology Oncology (PHO) Chapter of the Indian Academy of Pediatrics, it is my pleasure to present this edition of our newsletter, skilfully crafted under the editorial leadership of Dr. Reghu. His hard work has truly resulted in a versatile and informative publication that I am proud to highlight.

I am thrilled to share that our chapter received the "Second Best Chapter of the Indian Academy of Pediatrics award during the 62nd annual PEDICON conference, held last year in Hyderabad. This recognition is a significant achievement for us. Our chapter has been actively promoting a range of initiatives aimed at improving the care and quality of life for our young patients with blood and cancer-related problems. In the last year, a key focus has been on empowering our nursing community. Soon, we will formally establish a dedicated nursing group in our country that will work collaboratively to enhance pediatric hematology-oncology nursing services, academics, and research. This development promises to strengthen the support available to our children and families.

In line with our mission to raise awareness about childhood cancer, we have initiated the program titled "12 Mahine 12 Poster," which underscores critical aspects of pediatric cancer care. I am excited to announce that during this midterm CME in Noida, we will launch a poster dedicated to bone marrow transplant awareness—an essential step in our ongoing educational effort. Our academic endeavours have been robust, featuring both monthly international and national speaker programs. The fantastic attendance and positive feedback from our peers in India and abroad are a testament to the value these programs deliver. Recently, our collaboration with AIIMS to organise a "Master class" in New Delhi was immensely successful, providing invaluable experience for students and professionals alike. Through partnerships with organisations like INPHOG and ICCI, we aim to strengthen advocacy, awareness, and research in childhood cancer, continuously making a positive impact on the lives of affected children. We have been conducting our flagship program - NTPPPO workshop across the country for many years. Last year, under the leadership of Dr. Anand Prakash, we revamped this program, creating a contemporary slide set that enhances the learning experience and added a digital pretest/ post-test to the existing format. Now onwards, we will be actively collecting feedback to further improve this signature project of the PHO Chapter.

I encourage all our members to take pride in our chapter and develop a sense of belonging, and actively contribute to its future. With over 80 new pediatric oncology and hematology trainees joining us annually, these are indeed exciting times. The potential these bright minds carry is truly unfathomable. Let us unite in our efforts to bring a positive change in the lives of children facing blood and cancer disorders. Together, we can make a profound difference!

Warm regards,

Dr. Manas Kalra
Honorary Secretary
Pediatric Hematology Oncology Chapter
Indian Academy of Pediatrics

Message From Editor

Dear PHO Friends and Fraternity,

It is with great pride and excitement that I present to you the third edition of PHO Vibes, the official newsletter of the Pediatric Hematology Oncology (PHO) Chapter of IAP. With each passing edition, PHO Vibes continues to grow as a platform that unites our community, celebrates our achievements, and shares the invaluable insights and experiences of those dedicated to the care and cure of pediatric hematological and oncological disorders. The previous two editions of the newsletter brought out by Dr. Shobha Badiger and Dr. Sunil Jondhale set the tone for the PHO Vibes format which has continued with the current edition.

This edition is a testament to the collective efforts of our vibrant PHO family. From doctors and transplant physicians to nurses, medical social workers, NGOs, and ancillary staff, each of you plays a vital role in shaping the future of Pediatric Hematology and oncology. Your dedication and passion inspire us to keep pushing boundaries and striving for excellence.

I would like to take this opportunity to express my heartfelt gratitude to Dr. Manas Kalra, our Honorary Secretary, for his unwavering support and guidance, and to Dr. Sripad Banavali, Chairperson PHO for his invaluable contributions to our field. Their leadership and vision continue to be a beacon of inspiration for all of us.

In this edition, you will find a recap of recent events and initiatives that have shaped the PHO Chapter vision for the year . The touch of creativity and joy with which artwork and contributions have come from both patients, PHOites and the support community has been extremely encouraging.

I extend my sincere appreciation to all contributors for their valuable insights, updates, and creative submissions, which have made this edition truly special. A special thanks to the entire PHO board for their continued support and encouragement in bringing this newsletter to life.

As we move forward, let us continue to work together, learn from one another, and make a meaningful difference in the lives of the children and families we serve. Thank you for being an integral part of this journey and enabling this humble endeavour.

Warm regards,

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27TH PEDIATRIC HEMATOLOGY AND ONCOLOGY CONFERENCE – PHOCON 2024, NOVEMBER 22-24, JAMMU

INTERNATIONAL CHILDHOOD CANCER DAY, 2025 CELEBRATION - VARIOUS CENTERS ACROSS INDIA

Dr. (Col) A T K Rau, MD, DHA, FAMS
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The Heroine

It was late on a very cold December night in the small army cantonment in a remote valley in the Northeast, a hundred miles north of and eight thousand feet above the Assamese town of Tezpur. From my small window in the improvised one room officer's mess, I could clearly see the twinkling lights of Bomdilla, the district headquarters, to the north and high in the towering mountains above. The icy wind tore through the rafters making a curious wailing sound that only those who have spent a winter in the Himalayas will remember. Jagmeet Singh, my trusted aide, was long gone to his quarters, the flames of the small log fire he had started, dancing amazing patterns against the wooden wall on which was pinned my favourite poster of Pink Floyd. Settling down for the night, I reminisced about my life as a Medical Officer, on temporary duty from the Military hospital in the plains at Hathiwadi, to an active army field formation high in the hills. All of twenty-four years of age, six months after a fascinating internship in the premier medical college of the Indian Armed Forces in Poona, I bored out of my mind, craving for some excitement and feeling terribly sorry for myself, as the blaze slowly ebbed away.

A persistent hammering at the gate of the mess shook me out of my somnolence as I forced myself to the door. A heavily clad young infantry soldier with a lantern in his gloved hand yelled over the howling wind, "Jai Hind Sahab, General Sahab ne aapko yaad kiya hai," which when translated, roughly meant that the big boss, the General Officer himself, was calling and wanted me now. Wondering why on earth he wanted to see the doctor in the middle of the night (the sun sets much earlier in the eastern part of our subcontinent), I swathed myself in the issued warm clothing and got into the 4 wheel drive military ambulance and reluctantly made my way up the steep snow covered mountain road to the General's residence, quite expecting to see that huge bear of a man with an upset stomach due to his periodic and legendary indiscretions at dinner.

A distraught General and his near to tears wife waiting behind the door rushed me into an adjacent room where I beheld a lovely statuesque teenager, whom I immediately realised was the boss's daughter, in a state of total disarray, shouting and screaming and best of all, trying to tear off all her clothes, one by one, from her rather fetching exterior, in theatrics reminiscent of the female lead in a recently released Bollywood movie. A quick history revealed that she was a final year graduate in one of the leading lady's colleges of Lucknow and had come along with her mother the previous day, to visit her doting father on a short sojourn to the hills during the autumn break.

There was no past history of any such ailment earlier or that of habituation to a drug or intoxicant in the past and indeed, the mother swore that her 'darling Bitiya' had never even seen a doctor in all of her nineteen years of life. Perplexed, I carried out a detailed clinical examination observing for fever, paleness, jaundice, cyanosis, respiratory distress, neck stiffness and whatever else I could remember from the latest edition of Hutchinson's clinical methods that I had cheerfully thrown away after the final examinations just a few months ago. I could find nothing, other than feel the tip of an elusive spleen, which to my inexperienced mind appeared to be a normal variation, so I resorted to asking vague but medically sounding questions (Has any one in your family also tried to take off their clothes in public? Has anyone in the family now or ever been admitted to a mental hospital, etc, etc) buying time, keeping the Bear and his wife at bay and the daughter from removing all her clothes. When the situation appeared to be slipping out of control, and the boss began hurling aspersions on my competence coupled with dire threats and ultimatums, I decided to give the lass 10 milligrams of intravenous diazepam (the only anxiety relieving medication available then), knocked her out and rushed with her to the very basic field hospital two miles away on the next hilltop, where another solitary, terribly bored and somnolent medical officer, my immediate senior from college, decided that rather than losing his precious sleep on a hysterical teenager, it would be better for all concerned to shift her to the Base Hospital (BH) in the plains immediately.

"Five hours," said the boss, "it will take at least five hours to reach the hospital by road Doc. Do you think she'll make it?"

Looking at the indecision on my face and at her beautiful but now fully supine daughter, the mother burst into tears. "Kuch Karo ji," she pleaded with her husband. "Aap toh General ho, jahaz mangwa lo. (Do something, you are a General - call for an aircraft.)"

The Bear now swung into action and surrounded by his staff officers, who had been summoned soon after he had 'remembered' me, contacted the duty officer at Air Command. "For whom?" Asked the laconic and sleepy Air Force duty officer and became wide awake when told. Rather officiously, he replied, "I hope you know CAS-EVAC (Casualty Evacuation) is only for the men and women in uniform. I'll speak with boss tomorrow if you want but rules are rules." Hearing this, the lady let out a wail of disappointment and the general's aides got into furious chatter. "What the hell does he mean? Quoting rules to us," said one. "As if the Air Force belongs to his father," said another loudly in support, currying the boss's favour as the annual performance reports are usually written in the January of each year, now just a few months ahead. A second call higher up the ladder at Air Command also drew a blank despite the personal entreaties of the distraught father and his agitated staff. By now, the lissom teenager, despite her mother's pleas, had managed to remove some more of her clothing and clearly resembled an enlightened tourist on a secluded beach in Goa.

I had also had enough of the ensuing midnight family drama in real life and was never more overjoyed when the call to one of my younger colleagues posted in an Air Force station nearby was picked up almost immediately.
"Bhattu!" I yelled over the faint trunk call. "I'm in a spot. I need your help to transfer a patient to the BH by air." Bhattu was a close friend in college but more importantly his father happened to be a senior officer in the very same Air Command.

"Why me? Speak to Command," he replied. "Already did but they won't pick up the girl."
"Girl? What girl?" He shouted back. "The patient, dammit. She's the boss's daughter," I roared over the trunk line and gave him the sketchy details. "How old?" He asked. "Nineteen." There was a pregnant pause followed by a mischievous, "Is she pretty?"

"Yup" I replied, "very"

"Okay, I'll see what I can do. Will call you back," he said and rang off. He called at four in the morning when dawn was just breaking over the eastern horizon. "There is a supply drop planned for today. You'll have an inbound around zero eight hundred. They've cleared her on the return as an emergency. Bung her in and go with her. Best of luck." However, by the time the large helicopter arrived and the unloading completed, it was well past ten in the morning and the young lady in question was showing signs of coming out of the haze that I had induced earlier and she began to scream and shout again, which lasted for all of the of 40 minutes of flight time to the base helipad, much to the consternation of the Bear and the two dashing young pilots of the Air Force.

The landing ground of the cantonment is about five miles or 45 minutes away by the creaky military ambulance sent to fetch her but en-route to the hospital, lo and behold, a miracle unfolded and 'Bitiya' regained consciousness and her composure. In perfectly cultured and measured tones, she asked her visibly flummoxed father where she was and why she was lying supine in a rusty old ambulance with a rather sheepish looking doctor in attendance. By the time we reached the ICU of the hospital, she was as normal as she could be and the attending physician, trained in a college other than mine, began commenting loudly to anyone within earshot, about the dismal fall of standards in medical education and how scarce national resources like helicopters were being wasted on the whims and fancies of half-baked doctors!

Well, to cut it short, 'daughter precious' was admitted for observation, blood samples were taken and she was discharged the next day when, other than mild anaemia, her lab reports were all found to be normal. Affording considerable relief to her now bemused parents, who, after failing to get a diagnosis from the base hospital and the nikamma (inexperienced) Medical Officer (i.e. me!) decided to go back to Lucknow and consult one of the famous doctors in the city to get treated properly and get their daughter ready to re-join her classes after the eventful holiday. Yours truly went back to his unit in the high valley, amidst much teasing and bawdy jokes from his unforgiving colleagues in the Army and the Air Force, to hide his head in shame for probably the rest of his life. Despite all this, however, I still felt that I had missed something in this patient.

Nine days later, I got a telephone call from the base hospital pathologist, Major Murali, very excited and equally

anxious. "Hey, Kris (my seniors in the army used to call me Kris as they still do now!), Where's your heroine? The girl you brought to us last week?" Recollecting, I replied, "Back home, Sir, safe and sound in Lucknow."

"Do you, by any chance, know if her parents were related before marriage?"

"C'mon Sir, how will I know and frankly Sir it will take a braver man than I to ask the old man?" (By the way, all bosses in the Army are called 'the old man'). "Well, buddy, you just may have to go and find out and let me know – it's urgent."

"Why?" I asked and over the faint line he said, "I was reviewing her blood smear slides that were pending after her discharge today and I think I found something quite interesting."

I called up the Bear's office and made a rather timorous appointment. "2 o'clock today and not a minute later," said his big moustachioed Brigade Major who certainly wasn't my fan after the fiasco with the Airforce and the helicopter ride and I found myself at 1:50 PM sharp outside the Bear's den. "Come in," he boomed and asked me to sit, watching me all the time as if I was a fly on the wall waiting to be swatted.

Rather timidly, I asked him, "Sir, were you and your wife related before marriage?"

I half expected the giant of a man to sweep me, chair and all, out of the window into the thousand feet deep gorge conveniently situated next to his office (there were rumours that many an unfortunate enemy spy or other undesirables had often had to find their way out of the gorge after their sudden and unforeseen descent into it) but he just gaped at me and asked "How the hell did you know?" Before I could reply, he continued, "This is about Bitiya, isn't it? I told my wife that we should have told the doctor in the base hospital." Finally, after looking out of the window for ten long minutes, he blurted out, "Yes, my wife and I are first cousins. Our parents did not want us to get married but we went ahead anyway."

I conveyed this to MM, who shouted out his grateful thanks and promised to call again later. It was late in the evening when he did. "Hey Kris, guess what?"

"What?" I asked.

"Your heroine has Sickle Cell disease."

And then it all came back to me – the consanguinity, the disorientation and the abnormal behaviour due to the lack of oxygen to the brain in high altitude, the just felt spleen, her mild anaemia and her miraculous recovery on reaching sea level along with the classically delayed diagnosis (it takes a while for the sickle cells to show up on the smear), was truly a text book description of the milder forms of the disease. I was also thrilled that I had been vindicated and made sure the surly physician at the base hospital quickly learnt the fascinating details about "my heroine". He was certainly not amused.

I rang up the Bear to convey the gist of my conversation with the pathologist. He grunted in reply but his wife snatched the phone. "What does it mean, doctor sahab?" she asked anxiously, "I am so worried. The doctors in Lucknow also didn't say a word about her illness and she is going to be engaged next month."

"Nothing much, madam," I replied in my most professional voice. "Instead of asking for the boy's horoscope, ask to do his Haemoglobin Electrophoresis!" And before she could reply, I added, "And madam, please tell our dear Bitiya to stay off mountains for the rest of her life."

(The events described above occurred 40 years ago when the author was posted to the North-east of the country as a young doctor in uniform)

" This article by Dr (Col) A T K Rau, former chairperson of the PHO chapter, appeared in his book "Yesterday's Train to Nowhere" first published in 2021 by Inkfeathers publishers, New Delhi . It is available for sale on Amazon"

Dr. Arpita Bhattacharyya
Senior Consultant
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The Classroom

I turn up at the classroom daily
My teachers are wise, funny
Wicked sometimes.
They tolerate me and my ignorance with unimaginable grace.

One takes a class on fortitude
She is six.
I see her smilingly put her arm out for the needle,
Keeps smiling even as a tear rolls down
Gives the phlebotomist uncle a kiss as she slides off the chair too big for her.
I am sure to fail this class- no matter how hard I try.

The next class is on patience.
The nine-year-old curls up for a lumbar puncture.
His doctor is not ready yet,
But the boy does not move.
He knows it will hurt when the needle goes in
He knows that his mother lies to him each time she says it does not hurt.
But he is patient.
How shall I ever measure up to him?

I always like the art class.
She uses her small hands to fashion tiny figures with modelling clay.
The colours are vibrant, reds greens and yellows
To compensate for the complete absence of colour in her own life.
Never went into remission - we have all but given up
Yet her colours go on.
How shall I ever embellish with colours like her?

The next class is on philosophy.
The senior teacher is all of fifteen.
He is full of banter and smart comebacks
Beckons me close when his mum's back is turned.
I do it all for her, he whispers
Otherwise she will be crying all day.
Smart Alec, I tell him
Philosophy isn't really my subject - I don't get how he does it all.

I have been a student for close to two decades now.
The chances of passing out of this school seem remote
I guess I'll have to quit at some point
While there will be younger, better students
Maybe they will complete all the courses with honours,
Philosophy, colours, patience, fortitude,
Life.

Sarbani Chowdhury
Deputy General Manager
Treatment Support Programme
Cankids Kidscan

Cankids' Holistic Approach towards Nutrition during Childhood Cancer Treatment

Founded in 2004 by cancer survivor Poonam Bagai, CanKids KidsCan partners with 141 hospitals and 8 state governments giving a coverage across 22 states and 60 cities to provide holistic support to underprivileged children battling cancer.

Under our YANA (You Are Not Alone) programme, we are providing comprehensive care to children with cancer and their families. This includes the Cannourish model which offers specialized nutritional care for children up to 19 years and continuing support for Childhood Cancer Survivors. The programme team has 25+ skilled professionals annually supporting more than 7500+ children for their nutrition related concerns. Our core mission is to understand and perceive the unique needs of children undergoing cancer treatment, reducing the financial burden on families. An essential part of our program is a personalized approach to nutrition. We meticulously assess each child's nutritional status, implement targeted dietary interventions, and then analyze the impact & barriers ensuring the best possible outcomes.

Collaborating closely with clinical and multidisciplinary teams allows us a deep understanding of each child's overall condition. We recognize that assessments for complex cases with growth failure, amputation, Down's syndrome, tumor burden and fluid load demand tailored assessment and interpretation of nutritional status. Our experience consistently shows that baseline evaluation for all children and frequent follow-ups with nutritionally affected or at-risk patients significantly improve their status.

Effective and engaging counseling through clear communication and audiovisual aids better address the primary concern of families for procedure related fears, poor adherence, and misconceptions. Age-specific counseling is crucial for achieving targeted nutrition. Knowing the right time to transit a child's feeding route often prevents malnutrition, especially given challenges like Chemotherapy-Induced Nausea and Vomiting (CINV), Neutropenic Enterocolitis (NEC), Surgeries, Radiation Therapy (RT), Critical illness, Gut mucositis etc.

Our program also provides ration support or supplementation, hot meal services, and the Poor Patient Support Assistance program, offering general and customized nutrition delivery to those in need.

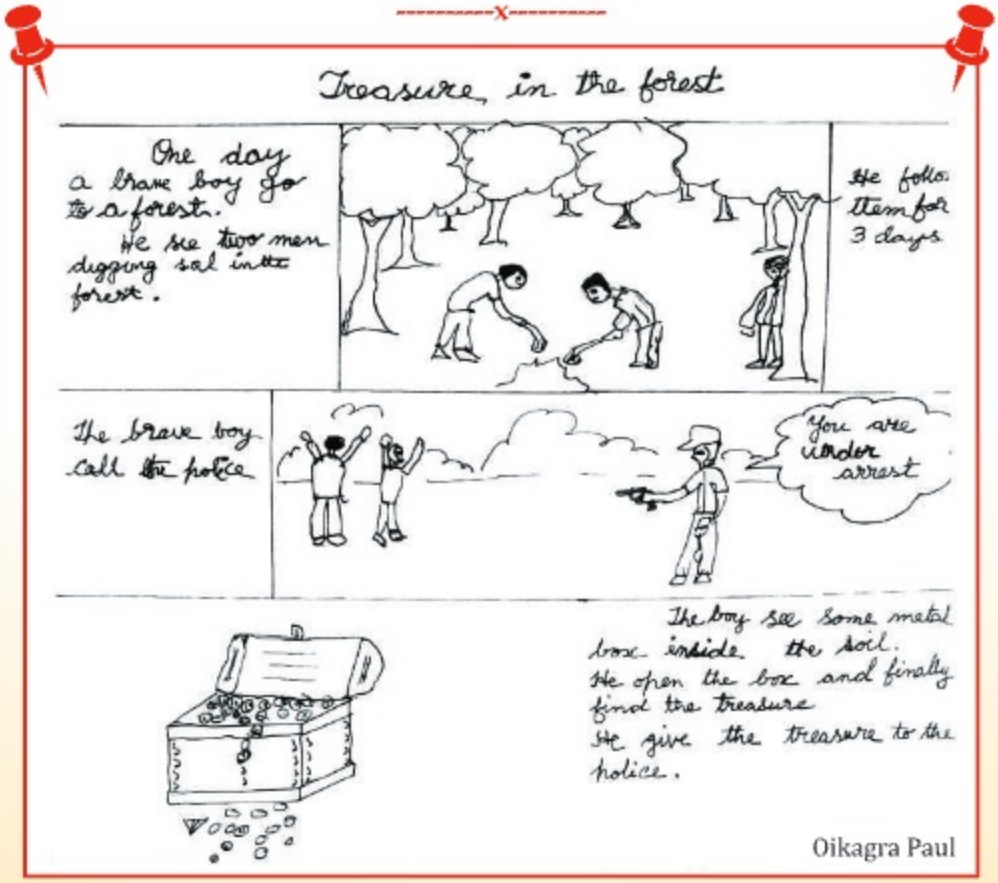
The work extends beyond active treatment with the Survivor Nutrition Programme. This vital component addresses post-treatment challenges such as undernutrition, overnutrition, failure to thrive, persistent dietary restrictions even after completion of treatment, and concern related to impact of treatment on fitness goals among young survivors. It signifies our unwavering commitment to children long after their treatment ends ensuring they have the support and resources needed for healthy growth and development into adulthood.

But sometimes, a patient's nutritional journey isn't about a complex, disease-specific diet, but rather about the fundamentals. Seven-month-old Dharitri (name changed) is a perfect example. Diagnosed with bilateral retinoblastoma, she began her chemotherapy regimen, but a more immediate concern quickly arose during our baseline assessment, shifting our focus from cancer-specific nutrition to basic. Her family was unknowingly offering her solids that posed a significant choking hazard for a baby at her age. Educating her family about weaning and ensuring her diet was age-appropriate and safe, was the primary intervention for us. Every aspect mattered – the correct quantity, texture, and frequency of food. Additionally, we addressed their hygiene practices, which were observed to be poor, and emphasized the importance of avoiding food sharing, especially crucial for an immunocompromised child. To effectively re-establish her weaning process, multiple counseling sessions, both in person and over the phone, were crucial, as the family's misconceptions and habit of adhering to old unscientific customs were a significant obstacle.

Despite our dedicated efforts, Dharitri's side effect of onco-treatment took a severe toll. She lost weight, dropping more than 10% of body weight, and began refusing food. We initiated enteral nutrition support via nasogastric (NG) tube to ensure she met her daily nutritional needs. A customized nutritional care plan keeping cost concern in mind was given with pictorial inputs for better understanding. Sourcing natural foods and low-cost nutritional formulas that could pass through an 8 FR size tube was a challenge however we could manage.

A significant part of our commitment to Dharitri's family involved breaking down language barriers. We understood that effective communication was primary for their adherence to the nutritional plan. All nutritional advice, IECs (Information, Education, and Communication materials), and diet charts were translated into their regional language. This extra effort, though time-consuming but extremely fruitful in the long term for their full understanding and cooperation.

Thanks to this comprehensive approach—addressing basic weaning practices, providing aggressive nutritional support, and diligently breaking down language barriers—Dharitri has made remarkable progress. She has now regained her lost weight and is tolerating both oral and NG tube feeds comfortably. Her case beautifully illustrates that sometimes, the most effective nutritional intervention is a blend of clinical expertise, patient-specific tailoring, and a commitment to a family's unique needs.



Manjusha Nair
Associate Professor, Division of pediatric Oncology, Regional Cancer Center
Meera Nair
Clinical Psychologist, Regional Cancer Center

The Silent Echoes of Children's Minds - Are we listening?

In the pediatric oncology department, amidst the busy OP with anxiously waiting parents, soft lullabies and playful chirps of children intermixed with restlessness of waiting, a father walks through the door on the first week of every month, to the place that bears the loss of his beloved son, a crisp envelope clutched in his hand. It isn't a mere another month of donation, but in his hands he carries a chance at life for another child, a legacy left behind by his son who, in his own way, showed us that child is the father of man.

This is the story of a 6-year-old boy who was diagnosed with Burkitt's leukemia, an aggressive childhood cancer that demands swift and intensive treatment. Like many others, the diagnosis of cancer came as a brutal shock to the family as the child was admitted into the ward, so small, so frightened, and unaware of the disruptions that lay in the long road ahead. But what he left behind in this world was not just the memory of a young life lost, but a legacy of compassion, hope and grace that we as adults struggle to understand.

His father tells this story, the story that lies behind each donation that he brings and delivers to the hospital without fail, his voice trembling but proud.

One evening, his son was resting in bed after a round of chemotherapy, his tiny hand connected to the IV drip, and through the thin partition between the beds came a muffled sob. Though tired after his chemo, with childish inquisitiveness he peered sidewards, noticed the girl admitted in the next bed crying quietly, and asked her gently, "Why are you crying?"

The girl looked at him with pain in her eyes and replied with sadness and hopelessness : "Why has God given us this illness? My father doesn't have enough money to buy the medicine for me."

The boy turned his head slowly towards his father and asked, "Father, do you have money for my treatment?"

His father nodded, wondering why his son was asking the question and uncertain of what was coming next.

The boy paused, as if to gain some strength. Then, with a clear voice, he said, "Father, please don't give that money to mother. Instead, give it to the girl's father so she can buy her medicine."

Minutes of silence followed. The father was overwhelmed, not only by the generosity of his son's request, but by the conviction with which he said the words in the midst of his own suffering. Tears in his eyes, he hugged the child, who, in the midst of his own battle for survival, was thinking of another.

But the story didn't end there.

A few months later, the boy relapsed. His condition deteriorated quickly. The same vibrant eyes now struggled to stay open, his breathing became labored and his chirpy voice became silent. His parents were heartbroken and watched helplessly as their son slipped away, each moment painfully reminding them of hope lost. One night, barely able to speak, he turned to his father and said, "Father, you should save one lakh rupees for me...there are other children like me who are suffering with this disease...you should help them"

He passed away a few days later.

And we are left with questions that reverberate louder than any medical report or clinical statistic:

How can a 6-year-old child develop empathy at such a young age?
How can this small child think with so much purity and foresight in the presence of such pain and suffering? How can he be emotionally so mature as to feel another's pain and suffering without prejudice or judgement, and feel the urge to give?

What were the little bubbles of thoughts that caused him to think of other children like him even when he was struggling to keep his eyes open? How much those thoughts would have impacted him that even during his final days all he asked was to help others?

And if this is the story revealed to us, how vast must be the landscape of unspoken stories quietly unfolding in a child's inner world?

As healthcare professionals, parents, and caregivers, we often focus, rightly, on survival rates, protocols, labs, and regimens. But stories like these remind us that the mental and emotional landscapes of our patients are just as vast and in need of care. These children are not only the bodies that we see, but they are humans with minds and emotions stronger and bigger than their own little bodies. They are thinking, observing, and reflecting on life and suffering in ways we can hardly imagine. They are worried not just about themselves but about the child in the next bed. About their parents. About a future they may not live to see.

The question we must ask ourselves—Are we LISTENING? Don't their emotions and feelings need to be SEEN?

Are we giving them the emotional and psychological support they so deeply deserve ? Pediatric psycho-oncology, though emerging, is still not available in many cancer centers. We need more trained counselors, child psychologists, and safe spaces where children can process their fears, hopes, and questions. Because as this story shows, children do carry these thoughts, even if they may not always voice them. Talking to children is a totally unique skill, which we as pediatricians hardly learn or practice during our training. Pediatric palliative care is an emerging specialty that offers a unique opportunity to develop the sensitivity and skill required to gently enter the complex inner world of children living with serious illnesses. Their perceptions, emotions, and experiences are profoundly different from those of adults—and they will only allow us a glimpse into that private universe if they trust us.

We often assume childhood is a time of innocence, shielded from the world's harshness. But illness strips that away far too quickly. And yet, in that stripped-down space, we sometimes find wisdom, empathy, and courage that adults can barely grasp. This small child's wish—that no other child should suffer for lack of resources—echoes beyond the ward, beyond his short life, and into every clinic, home, and heart that hears it. His story is a call to action, a reminder to see beyond the illness and into the interior world of the child. To acknowledge their emotional lives, not as secondary to treatment, but as part of healing itself. To support those silent echoes within.

Let us honor his memory not only with our tears, but with action. Let us commit to caring for not just the bodies of our young patients, but their minds, their hearts, and their beautifully complex, untold thoughts.

---------x---------

Srinika Chatterjee

Sreehari Ravindranath
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Life Skills Researchers, Dream a Dream
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The Bracelet That Said 'You Matter' : Fostering Holistic Healing in Teen Oncology

When Aanya*, a spirited 15-year-old, was diagnosed with leukemia, her life changed instantly. Her schoolbag was traded for hospital gowns, and her vibrant days were replaced with IV drips and whispered consultations.

While her medical care was swift and responsive, what remained unanswered was the emotional upheaval she faced—confusion, isolation, and loss of control. This unseen emotional toll is one of the greatest challenges for adolescents with cancer.

As pediatric oncology teams, we are trained to save lives. But how often do we pause to ask how our young patients feel about the life they're fighting for?

Adolescents and the Emotional Landscape of Cancer

Adolescence is a time of identity-building and emotional intensity. A cancer diagnosis disrupts this journey, often leaving teens feeling lost in a system that treats their disease, but not always their distress. Many experience:

- Disrupted social relationships
- Anxiety about appearance and identity
- Isolation during extended hospital stays
- Unspoken emotional turmoil: *"Why me?"*, *"Will I ever be normal again?"*

These aren't peripheral concerns. Research—including a 2008 study by Klassen et al.—confirms that adolescents with cancer experience higher emotional distress than their healthy peers. The impact can persist long after treatment ends.

Holistic Healing: Beyond Symptom Management

"Holistic healing" means recognizing that recovery is not just physical—it's emotional, psychological, and social. It is relational. It's about treating the person, not just the condition.

In our work with youth across India, we've seen how small, human gestures—what we call life skills in action—can create emotionally safe spaces, even within clinical settings. These aren't new protocols. They're acts of mindful presence.

Examples include:

- Naming emotions: *"It's okay to be angry. You don't have to be brave right now."*
- Restoring agency: *"Would you like music on during this procedure?"*
- Encouraging creative release: *"Here's a sketchpad. No pressure—just yours if you want it."*
- Simple check-ins: *"What's been the toughest part of today?"*

These moments humanize care. They offer emotional scaffolding, allowing teens to process grief, fear, and frustration—rather than bury it.

Aanya's Bracelet: Healing Through Connection

Aanya once received a handmade bracelet from a fellow patient, Devika*, with colored beads representing different emotions. *"Wear it when you're scared,"* Devika said. *"It means you're not alone."*

That bracelet did what medicine couldn't—it anchored Aanya in empathy and connection. Even after Devika passed away, Aanya wore it every day. It was a quiet, enduring reminder that her feelings mattered.

Practical Ways to Foster Emotional Support

Clinicians often ask: *How do we embed this into our care*? The answer isn't more time—it's a change in approach.

Evidence-informed practices include:

- Emotional check-ins: A simple, "*How are you—really?*" can reshape a clinical moment.
- Creative corners: Quiet areas with crayons, journals, or music as emotional outlets.
- Peer connection: Even brief contact with other teens can reduce loneliness.
- Empathy training: Helping care teams recognize and respond to silent distress.
- Family support: Coaching caregivers to offer presence without needing to "solve" everything.

A 2022 review by Pardo et al. affirms that such psychosocial interventions enhance emotional outcomes and improve treatment cooperation.

Redefining Care: From Surviving to Thriving

Teenagers in oncology care are not just patients—they're individuals navigating one of the most defining chapters of their lives. They are shaping identities, clinging to dreams, and seeking meaning in the midst of disruption.

To help them not just *survive* but *thrive,* we must extend care beyond clinical procedures—to compassion, connection, and emotional grounding.

Supporting their healing doesn't demand new infrastructure. It starts with pausing. Listening. Being human.

Because sometimes, the most powerful medicine isn't a procedure or a pill—but a moment of presence, a gesture of kindness, or a bracelet that says, "*You're not alone.*"

**All names have been changed to protect the privacy and dignity of the individuals involved.*

Interested in integrating life skills and emotional support into your pediatric oncology program?
Write to us at: *dr.sreehariravindranath@gmail.com* or *amit.k.cse@gmail.com*

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Ayanangshu


Anjali Kumari

Rewanth Vinuthne
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A Fly and a Fish : Tiny Warriors in the Fight Against Cancer

When you think of cancer research, your mind likely conjures images of high-tech labs, cutting-edge machines, and clinical trials involving human patients. But what if I told you that some of the most groundbreaking insights into cancer—spanning everything from tumor genetics to drug discovery—are coming from creatures as small as a fruit fly or as slippery as a zebrafish? These unassuming organisms have been quietly revolutionizing oncology for decades, and their contributions are nothing short of extraordinary.

Let's take a deep dive into the fascinating world of *Drosophila melanogaster* (the humble fruit fly) and *Danio rerio* (the common zebrafish familiar to aquarium enthusiasts) to explore how these tiny creatures are helping us tackle one of the most complex diseases of our time.

The Fruit Fly : A Century of Genetic Gold

A Historical Perspective

The fruit fly has been a geneticist's best friend since the early 1900s, thanks to the pioneering work of Thomas Hunt Morgan. Morgan's experiments with *Drosophila* melanogaster in the early 20th century laid the foundation for modern genetics. By studying inheritance patterns in these tiny flies, Morgan discovered the concept of linked genes and earned a Nobel Prize in 1933. Since then, *Drosophila* has become a staple in labs worldwide, and for good reason.

Fruit flies are genetic powerhouses. Despite their simplicity, they share about 75% of the genes associated with human diseases, including cancer. They're also cheap, reproduce rapidly, and have a short life cycle—perfect for rapid experimentation. Over the years, *Drosophila* has been used to study everything from embryonic development to neurodegenerative diseases. But its role in cancer research is where it truly shines.

Fruit Flies in Cancer Research

The fruit fly's genome is surprisingly similar to ours—about **60% of human genes** have a counterpart in *Drosophila*, including many of the genes involved in pediatric cancers. Even better, *Drosophila* develops quickly (egg to adult in about 10 days), making it an ideal model for studying how genetic mutations affect development and lead to cancer.

And let's not forget the ethical and practical advantages. While studying cancer in children is obviously limited by ethical considerations, *Drosophila* provides a fast, cost-effective, and ethically sound way to model pediatric cancers in the lab.

Neuroblastoma : A Fly's Eye View

One of the most common pediatric cancers is **neuroblastoma**, a tumor that arises from immature nerve cells. Neuroblastoma is notoriously tricky to treat, especially in high-risk cases, and researchers have long struggled to understand its underlying biology.

Enter *Drosophila*. Scientists have used fruit flies to study the ALK (anaplastic lymphoma kinase) gene, which is mutated in many cases of neuroblastoma. By engineering flies with ALK mutations, researchers have been able to study how these mutations drive tumor growth and test potential therapies.

In fact, *Drosophila* models have been instrumental in identifying drugs that target ALK mutations, some of which are now being tested in clinical trials for neuroblastoma. Not bad for a bug that lives on rotting fruit.

Leukemia : Tiny Flies, Big Insights

Leukemia, the most common cancer in children, has also benefited from *Drosophila* research. Flies have been used to study genes like **NOTCH1** and **JAK/STAT,** which play key roles in leukemia development.

For example, researchers have created *Drosophila* models of T-cell acute lymphoblastic leukemia (T-ALL) by overexpressing NOTCH1 in fly blood cells. These models have helped scientists understand how NOTCH1 mutations drive leukemia and identify potential drug targets.

But it's not just about understanding the biology of cancer. Fruit flies are also being used to screen for new cancer drugs. High-throughput drug screening in *Drosophila* models has already led to the identification of compounds that target specific cancer pathways. These compounds can then be tested in more complex models, such as zebrafish or mice, before moving on to clinical trials.

The Zebrafish : A Transparent Window into Cancer

While fruit flies have been a staple of genetic research for over a century, zebrafish are relative newcomers to the field. The use of zebrafish in biomedical research began in the 1970s, thanks to the work of George Streisinger, who recognized their potential as a model organism. Zebrafish are small, easy to breed, and have transparent embryos, making them ideal for studying development and disease.

Like fruit flies, zebrafish share a significant portion of their genome with humans—about 70%. But what sets zebrafish apart is their vertebrate biology. Unlike fruit flies, zebrafish have a backbone, making them more similar to humans in terms of anatomy and physiology. This makes them an invaluable tool for studying complex diseases like cancer.

Zebrafish in Cancer Research

Zebrafish have become a go-to model for studying cancer for several reasons. First, their transparent embryos allow researchers to observe tumor growth and metastasis in real time. By injecting human cancer cells into zebrafish embryos, scientists can watch as the cells proliferate, invade surrounding tissues, and even spread to distant organs. This provides a unique window into the dynamics of cancer progression.

Second, zebrafish are highly amenable to genetic manipulation. Using techniques like CRISPR-Cas9, researchers can create zebrafish models that carry the same genetic mutations found in human cancers. For example, zebrafish models of melanoma, leukemia, and glioblastoma have been used to study the genetic drivers of these diseases and to test new therapies.

One of the most exciting applications of zebrafish in cancer research is the development of patient-derived xenograft (PDX) models. In these models, tumor cells from a cancer patient are implanted into a zebrafish. This allows researchers to test different drugs on the patient's tumor cells and identify the most effective treatment. Zebrafish PDX models are particularly valuable for studying rare cancers, where clinical trials are often limited.

Why Fruit Flies and Zebrafish?

You might be wondering: why not just use mice or other mammalian models? While mice are undoubtedly valuable in cancer research, they come with significant limitations. They're expensive, time-consuming to breed, and not as genetically tractable as fruit flies or zebrafish. Moreover, the complexity of mammalian models can make it difficult to tease apart the basic mechanisms of cancer.

Fruit flies and zebrafish, on the other hand, offer a unique combination of simplicity and relevance. They're cost-effective, easy to manipulate genetically, and capable of modeling key aspects of human cancer biology. For example:

- **Genetic Similarity :** Both fruit flies and zebrafish share a significant portion of their genome with humans, making them ideal for studying the genetic basis of cancer.
- **Rapid Reproduction :** Their short life cycles allow researchers to conduct experiments quickly and efficiently.

- **Scalability :** Both models are well-suited for high-throughput drug screening, enabling the rapid identification of potential cancer therapies.

The Future : Tiny Models, Big Impact

Of course, no model is perfect. While fruit flies and zebrafish offer many advantages, they also have limitations. For example, the simplicity of fruit flies means that they can't fully replicate the complexity of human cancer. Similarly, while zebrafish are more similar to humans, their immune system differs significantly from ours, which can complicate studies of immunotherapy. The contributions of fruit flies and zebrafish to cancer research are a testament to the power of model organisms. They've already given us invaluable insights into the genetic and molecular mechanisms of cancer, and their potential is far from exhausted.

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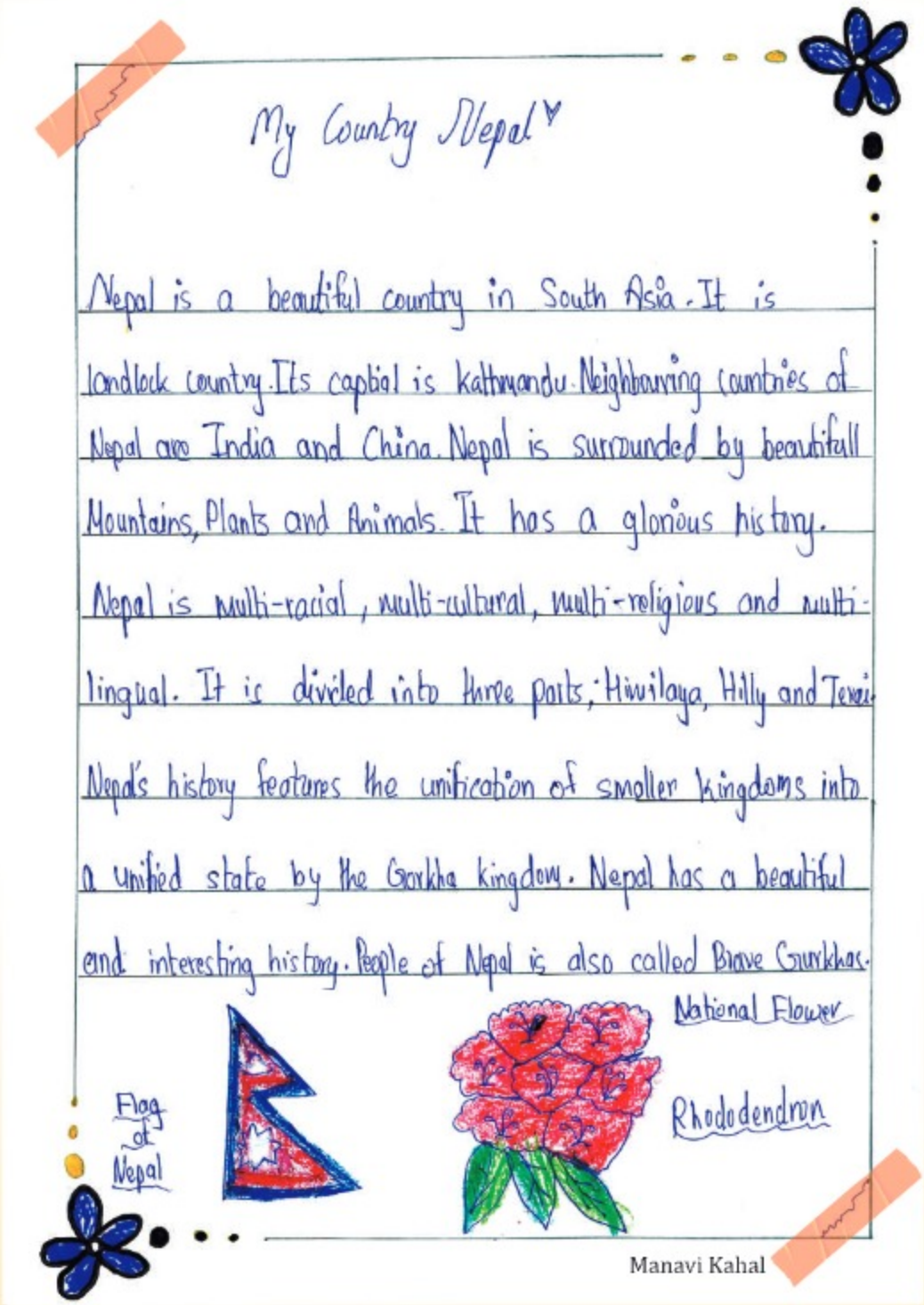

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Endocrine surveillance in childhood cancer survivors - Keeping hormones in harmony

It's beyond doubt that advances in cancer diagnostics and therapeutics have dramatically improved long term survival rates of most of the paediatric cancers over years leaving the survivors at risk of longterm health consequences from various modalities of anticancer therapy particularly affecting the endocrine glands. It is estimated that almost 50 % of the child hood cancer survivors (CCS) suffer from at least one endocrine dysfunction in the long run. Hormone deficiencies in the most critical periods of physical growth and development leads to compromises in final height, pubertal maturation, reproductive health as well as bone and metabolic disease risks. Early detection and appropriate therapeutic intervention of these disorders improves the quality of life of these young survivors.

Hormone disorders in cancer survivors

Table 1 shows the various endocrine late effects in paediatric cancer survivorsy

Table 1 : Endocrine disorders in childhood cancer survivors
Hypothalamopituitary dysfunction
Thyroid dysfunction
Obesity
Short stature
Gonadal dysfunction
Diabetes and metabolic syndrome
Reduced bone densit

Hypothalamopituitary dysfunction

Hypothalamus and pituitary are the master regulators of endocrine system. Hypothalamic releasing and inhibiting hormones regulate release of tropic hormones namely growth hormone (GH), thyroid stimulating hormone (TSH), corticotropin (ACTH), gonadotropins (LH and FSH) and Prolactin (PRL) from the anterior pituitary. In addition posterior pituitary gland stores and releases antidiuretic hormone (ADH) and vasopressin (Oxytocin) upon appropriate stimulus. Tumours in close proximity, intracranial surgery, cranial irradiation and newer anticancer drugs like tyrosine kinase inhibitors and immunomodulators can disturb the anatomy and/or physiology of these glands leading to various health consequences as summarised in table 2.

Table 2 : Hypothalamopituitary dysfunction in CCS		
Affected cells	**Affected Hormones**	**Clinical presentation**
Somatotropes	GH	Short stature, poor growth
Thyrotropes	TSH	Central hypothyroidism
Gonadotropes	LH, FSH	Precocious puberty, delayed puberty
Corticotropes	ACTH	Central adrenal insufficiency
Neurohypophysis	ADH	Central Diabetes Insipidus

Growth hormone deficiency is the most common pituitary hormone deficiency observed in cancer survivors, followed by gonadotropins, TSH and ACTH together or in succession depending on the extend of damage to HP axis. Direct tumour invasion or surgery leads to early occurrence of endocrine dysfunction. Radiation induced damage takes years to manifest and depends on age of the child, radiation dose, number of fractions and duration since treatment. Table 3 shows radiation sensitivity thresholds for various HP hormones.

Growth hormone deficiency is the most common pituitary hormone deficiency observed in cancer survivors, followed by gonadotropins, TSH and ACTH together or in succession depending on the extend of damage to HP axis. Direct tumour invasion or surgery leads to early occurrence of endocrine dysfunction. Radiation induced damage takes years to manifest and depends on age of the child, radiation dose, number of fractions and duration since treatment. Table 3 shows radiation sensitivity thresholds for various HP hormones.

Table 3 : Hypothalamic dysfunction and radiation dose

HP dysfunction	Radiation dose
GH deficiency (GHD)	> 18 Gy
Central Precocious Puberty (CPP)	> 18 Gy
Hypogonadotropic Hypogonadism	>30 Gy
Central hypothyroidism (CH)	>30 Gy
Central Adrenal Insufficiency (CAI)	>30 Gy
Hyperprolactinemia (HPL)	>40 Gy
Hypothalamic Obesity	>20 Gy

The PENTEC comprehensive review reports 20 % risk each for GHD, CH and CAI in children with a median age of >5 years who receive a median dose of 21 Gy, 22 Gy and 34 Gy in 2 Gy fractions to HP axis respectively.

Clinical clues to HP dysfunction

Most common clinical manifestation is growth failure. Both GHD and Central hypothyroidism affects linear growth in children and adolescents. In addition, delayed pubertal onset and progression affects the physical maturation and attainment of final adult height. Regular growth checkup and appropriate growth chart plotting helps early identification of such children warranting further tests including growth hormone stimulation studies and thyroid function tests to confirm before instituting appropriate therapeutic interventions. Benefits and safety of growth hormone therapy in childhood cancers survivors has been reassuring.

Normal pubertal development commences at 9-13 years in girls and 10-14 years in boys with onset of breast development (thelarche) and testicular enlargement (gonadarche) respectively. Over next 3-5 years pubertal development progresses to menarche in girls and other secondary sexual features in boys. Thelarche before 8 years of age or menarche before 10 years of age is considered precocious and needs evaluation. Absence of thelarche by 13 years of age or menarche delayed by 15 years of age warrants evaluation for delayed puberty. In boys testicular enlargement before 10 years is precocious while puberty delayed beyond 14 years of age is considered delayed. Pubertal development at appropriate ages is crucial not only for physical maturation but utmost essential for emotional and psychosocial wellbeing as well as bone health. Hypothalamic pituitary dysfunction can lead to either central precocious puberty or hypogonadotropic hypogonadism (low LH, FSH). Premature growth spurt classically described in CPP may be absent due to concurrent GH deficiency. Timely identification of either of these conditions enable appropriate therapeutic intervention. Precocious puberty can be arrested with use of Gonadotropin analogues while delayed puberty can be corrected using appropriate hormone preparations to mimic normal the physiology.

Glucocorticoids are important stress hormones in our body secreted from adrenal glands under the control of CRH/ACTH from HP adrenal axis. Central adrenal deficiency produces subtle clinical symptoms ranging from fatigue, low blood pressure, low blood glucose to vomiting, abdominal pain and shock. A low cortisol of <3 ug/dl in morning 8 am sample or <18 ug/dl in ACTH stimulated sample confirms the diagnosis and needs to start the child on glucocorticoid replacement with appropriate stress dosing.

Central hypothyroidism (CH) is a condition often diagnosed late in many situations. Unlike in primary hypothyroidism where goitre and or elevated TSH levels make diagnosis early and easy, in CH absence of goitre and normal or low TSH levels often leads to clinical miss. A strong clinical suspicion together with low total/free T4 clinches the diagnosis. Before starting thyroxine in a subject with CH, cortisol deficiency has to be ruled out lest it will precipitate life threatening adrenal crisis. Glucocorticoid has to be replaced before thyroxine replacement.
Hyperprolactinemia is rarely seen as a consequence of HP damage. Children and adolescents can present with gynecomastia and/or galactorrhoea and hypogonadism or secondary amenorrhoea. Serum prolactin levels will be elevated. Some case require dopamine agonists for a variable period of time.

Central diabetes insipidus is usually seen as an acute presentation of HP damage following tumour invasion (craniopharyngoma, germ cell tumours, histiocytosis) or surgical procedure. It can manifest as polyuria, polydipsia, weight loss and electrolyte disturbance (in unconscious child). A dilute urine against a highly osmolar serum is diagnostic. In majority of cases, the condition is permanent and requires lifelong replacement with desmopressin preparations.
Targeted radiation therapy using proton beams reduces HP damage from spill over radiations.

Primary thyroid dysfunction

Direct thyroid gland involvement occurs from neck irradiation, scatter radiation from spinal or chest irradiation and newer chemotherapeutic agents particularly tyrosine kinase inhibitors, MIBG and immune modulators. It can lead to autoimmune thyroiditis, primary hypothyroidism, hyperthyroidism, thyroid nodules and cancers. Through regular thyroid palpation, thyroid function tests (TFT) and thyroid ultrasound these problems can be picked up early and managed appropriately.

Primary Gonadal failure

Alkylating agents are mainstay chemotherapeutic agents in many paediatric cancers. These agents cause gondaotoxicity leading to premature or primary ovarian failure in girls and testicular germ cell damage in boys both ultimately leading to infertility. In addition, TBI as part of conditioning regimen or abdominal/pelvis radiation also leads to gonadal dysfunction. Boys whose testes were exposed to radiation will remain small in size despite adequate hormone production and virilization. Suppression of pubertal process using GnRH analogues during chemotherapy saves gonads to some extent.

Obesity and Metabolic syndrome

The cause for obesity in cancer survivors is multifactorial. Although sedendary lifestyle and altered eating habits remain the major culprits, hypothalamic damage from radiation or surgery can aggravate the situation. Damage to the satiety centre leads to uncontrolled appetite and abnormalities in fat redistribution compounded by GHD and thyoid dysfuntion. Progressive obesity results in setting in of various metabolic dysfunctions namely Type2 diabetes mellitus, hypertension, dyslipidaemia and menstrual irregularities (in girls). Abdominal radiotherapy for solid tumours is another risk factor for development of dysglycemia and diabetes mellitus. Early identification of at-risk individuals and timely screening for metabolic complications reduces the burden of this potentially preventable health hazard.

Low Bone mineral density

Bone health is a growing concern in individuals who survived childhood cancers. Childhood leukemias, total body irradiation, prolonged high dose glucocorticoids, HSCT, osteotoxic chemotherapeutic agents and delayed or absent pubertal development, reduces the bone density in adolescents and young adults leading to fracture risk. Bone densitometry techniques like DEXA scan detects low bone mass. Ideal bone density report in children and adolescents should be matched against age, sex, height and pubertal stage to avoid underestimation of bone health. Serial DEXA measurements in at risk individuals and adequate calcium and vitamin D supplementation together with appropriate physical activity ensure healthy bones. Bisphosphonates are indicated in those with vertebral fractures and or long bone fractures due to low bone density.

Conclusion

Endocrine disturbances are unavoidable long term effects with the currently available cancer treatment strategies in children. However, they can be predicted, identified and treated early to improve the quality of life of the young survivors. Some of these ill effects can be prevented using appropriate lifestyle measures. Newer treatment modalities offer better hopes in term of reduction in long term health consequences.

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The Hands That Heal: An Occupational Therapist's Journey in Pediatric Oncology

In the world of pediatric hematology and oncology, where every day is a battle against the odds, the role of an occupational therapist (OT) often unfolds quietly in the background. We are not the ones administering chemotherapy or performing surgeries, but we are the ones helping children reclaim their lives—piece by piece, movement by movement, and hope by hope. Especially in the current age when survival outcome for childhood cancer has improved tremendously, dealing with disability in survivors is becoming very important. As an occupational therapist, my work begins where the medical interventions leave off. My role is to help children regain their independence, adapt to new physical realities, and rediscover the joys of childhood amidst the challenges of cancer treatment. It's a delicate balance of science and empathy, of understanding the intricacies of the human body while also holding space for the emotional and psychological toll of illness.

The Challenges of the Work

I see quite a few children undergoing treatment for brain tumors or bone sarcomas and is as rewarding as it is demanding. Pediatric brain tumors, often leaves children with significant neurological deficits post-surgery or radiation therapy. Many of my young patients struggle with ataxia, fine motor difficulties, and cognitive impairments. For children with bone sarcomas, especially osteosarcoma or Ewing sarcoma, the challenges are different but no less profound. Limb-sparing surgeries or amputations mean that these children must learn to navigate the world with prosthetics or adapt to altered mobility.

The physical challenges are only part of the story. The emotional weight these children carry is immense. Imagine being 10 years old and suddenly unable to run, draw, or even hold a spoon without assistance. Imagine the frustration of a teenager who once excelled in sports but now struggles to walk. As an OT, I am not just addressing their physical needs but also helping them process the grief of losing the life they once knew. The varying growth satges and developmental phases of children imposes additional challenges unlike adults

Stories That Stay With Me

There was Ridhika, a 7-year-old girl with medulloblastoma. Post-surgery, she had severe ataxia and could barely sit upright without support. Her parents were heartbroken, fearing she would never regain her independence. We started with the simplest of tasks—sitting balance exercises, hand-eye coordination games, and sensory integration activities. Progress was slow, but Ridhika;s determination was unshakable. I'll never forget the day she took her first unassisted steps in our therapy room. Her smile lit up the entire hospital, and her parents wept with joy.

Then there was Somnath, a 14-year-old boy with osteosarcoma who underwent a below-knee amputation. Somnath was a budding cricketer, and the loss of his leg felt like the end of his dreams. Our sessions focused on prosthetic training, but they also became a space for him to vent his anger and sadness. Slowly, Somnath began to adapt. I'll always remember the day he sent me a video of himself bowling with his prosthetic leg. "I'm not giving up," he said. "I'll find a way to play."

The Rewards of the Work

Moments like these are what make the challenges worthwhile. There is no greater reward than seeing a child regain their confidence, their independence, and their sense of self. It's in the small victories—the first time a child ties their shoelaces after months of therapy, the first time they climb a set of stairs, or the first time they smile after weeks of despair.

But the rewards go beyond the children. Working with their families is equally humbling. Parents often come to us overwhelmed and exhausted, unsure of how to support their child. As an OT, I become a part of their journey, teaching them how to assist with therapy at home, how to celebrate small milestones, and how to hold onto hope even in the darkest moments.

Supportive care in pediatric hematology and oncology is not just about managing side effects or preventing complications. It's about giving children the tools to live their lives to the fullest, despite the challenges of their diagnosis. As occupational therapists, we are privileged to be a part of this journey, to witness the resilience of the human spirit, and to play a role in helping children and their families find light in the midst of darkness.

----------x----------

Dr Pritam Singha Roy
Consultant
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QUIZ

1. Which of the following pertains to the PROPS trial?

a) Cotrimoxazole prophylaxis for children on therapy for acute lymphoblastic leukemia
b) Oral penicillin prophylaxis for patients with sickle cell disease
c) Azole prophylaxis for patients receiving autologous stem cell transplantation
d) Penicillin prophylaxis for splenectomized children with transfusion-dependent thalassemia

2. Pick the CORRECT statement on congenital neutropenia

a) The ELANE mutation is the most common genetic etiology of severe congenital neutropenia; it holds an autosomal recessive inheritance pattern
b) Schwachman-Diamond syndrome, a mitochondriopathy, is characterized by severe congenital neutropenia & exocrine pancreatic insufficiency
c) In HAX 1 deficiency, cells have a lower threshold to dissipate inner mitochondrial membrane potential, leading to cellular apoptosis
d) Reticular dysgenesis: A biallelic mutation of the adenylate phosphatase gene, which is associated with severe lymphopenia along with congenital neutropenia

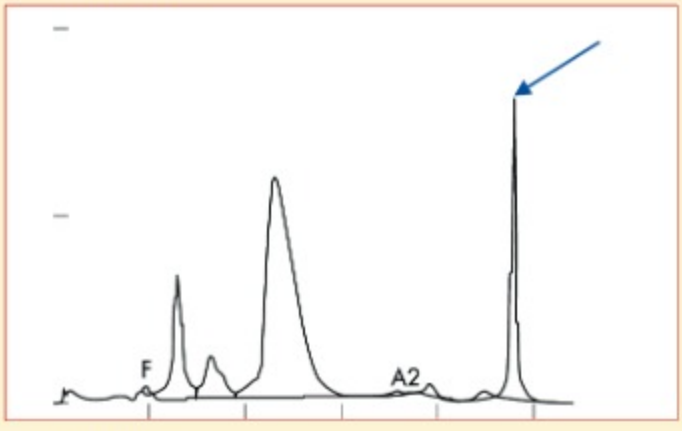
3. Which situation may lead to false-negative HPLC screening of beta-thalassemia carrier status?

a) CAP+1 A>C
b) -101 T>C
c) IVS2 854 C>G
d) All

4. Select the correct option regarding inhibitors in hemophiliacs:

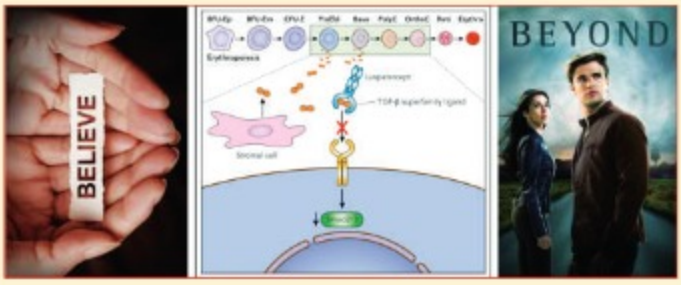
a) 1 Bethesda Unit of inhibitor neutralizes 5% of factor activity
b) Hemophiliacs with missense mutations in the factor VIII gene are at the highest risk of inhibitor formation
c) The finding of the SIPPET trial: patients exposed to plasma-derived clotting factor products are at lower risk of inhibitor development than those exposed to recombinant products
d) The risk of inhibitor formation is highest in the 2nd decade of life.

5. I'm an asymptomatic Hb variant with very long (approx.6 min) retention time on HPLC. How am I?



a) Hb D-Punjab
b) HbQ India
c) HbJ Meerut
d) HbE

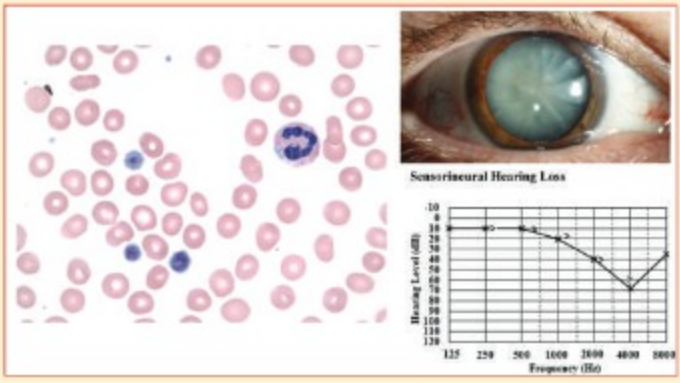
6. I am a new drug in the portfolio of thalassemia. Who am I?



7. Which of the following is true regarding the irradiation of blood products?

a) Irradiation reduces the risk of transfusion-related acute lung injury and CMV transmission.
b) Perioperative transfusion should be with irradiated products for children with DiGeorge syndrome undergoing surgery for congenital cardiac anomalies.
c) Marginally increases the risk of red cell alloimmunization
d) Granulocytes are nucleated cells, and hence, granulocyte apheresis products should not be irradiated

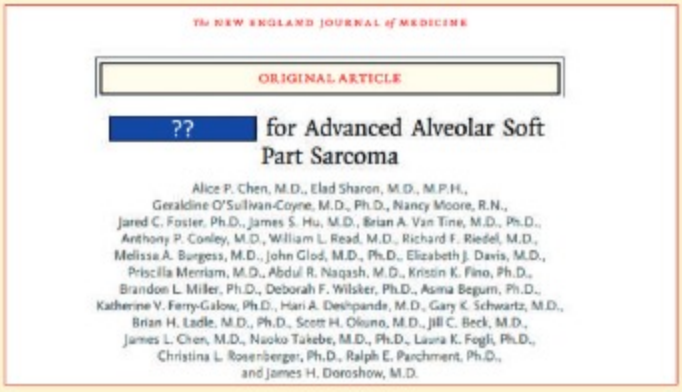
8. Identify the syndrome



a) May-Hegglin
b) Alport
c) Chediak-Higashi
d) Hermansky-Pudlak

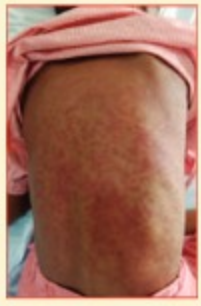
9. What is this collage referring to?

10. Name the PD-L1 inhibitor hidden in the study title.



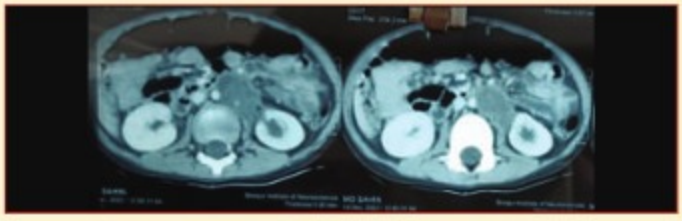
a) Durvalumab
b) Pembrolizumab
c) Atezolizumab
d) Ipilimumab

11. I'm a 1st generation, type II FLT3 inhibitor. My beneficial role in childhood AML has been tested in the COG AAML 1031 trial. Sadly, I often end up causing a horrible rash, as shown in the picture. Who am I?



a) Midostaurin
b) Quizartinib
c) Sorafenib
d) Gilteritinib

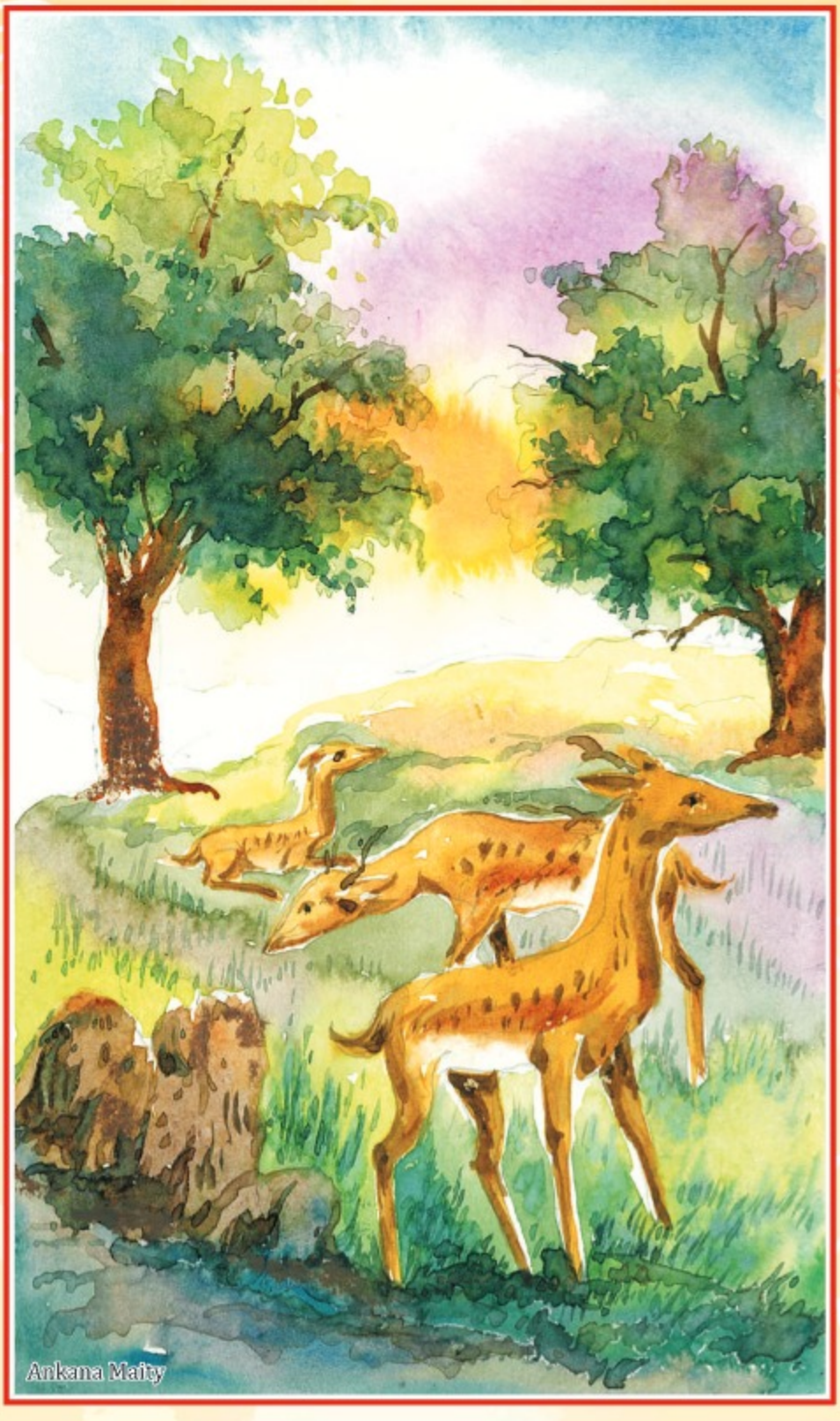
12. Attached are the staging CT abdomen images of a 4-year-old boy with testicular yolk sac tumor. He has undergone upfront high inguinal orchiectomy; the margin of the spermatic cord is clear. How would you define the stage and the MaGIC risk group?



a) Stage II, Sr1
b) Stage III, Sr1
c) Stage IV, Sr2
d) Stage III, Sr2

ANSWERS

1. B	**2. C**	**3. A**	**4. C**	**5. B**
6. Luspatercept		**7. B**	**8.A**	
9. CHIPS score		**10. C**	**11. C**	**12. B**



All pictures are hand drawn paintings and sketches collected from various pediatric hematology centres all over the country.

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