PHO Vibes

Second Edition: November 2024

Pediatric Hematology and Oncology Chapter
Indian Academy of Pediatrics

Care

Jammu - 2024
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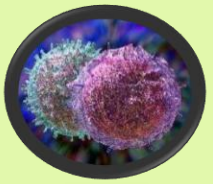

Thrive

NTPPPH

HOPE

NTPPPO

This Edition

Future

- Sangwari and KASH Foundation
- Musings of a pediatric oncologist
- Palliative Care in Pediatric Oncology
- Journey of Pediatric oncology ward Assistant
- Dr Yellapragada Subbarow: contribution for cancer care
- Running for Resilience
- Success stories
- Central Venous Access Devises (CVAD) in Children with Malignancy
- Chemotherapy Practice Points!!
- HLH or Not HLH
- PHO Accolades
- Scenario of Pediatrics Oncology in Kashmir
- Upcoming PHO academic extravaganza
- Edutainment and ARTi-Facts
- NTPPPO & NTPPPH
- Snapshots of Childhood Cancer Awareness Celebration month
- Let's Talk about Cancer

& MUCH MORE

Pediatric Hematology Oncology Journal

INPHOG
Indian Pediatric Hematology Oncology Group

All pictures at the end of each page are hand drawn paintings and sketches collected from various pediatric hematology centers all over the country.
Names are not mentioned to maintain confidentiality (requested by a few children) and also because some of the names were not known.
Diwali celebration photos shared by respected Dr Sangeeta Mudaliar with permission.

Cover page designed by Dr Sunil Jondhale

Newsletter Editor Team

Dr Manas Kalra

Dr Shobha Badiger

Dr Raghu KS

Dr Sunil Jondhale

Foreword Message from the IAP President

Dear Fellow PHO Members,

It is with great pleasure and pride that I congratulate you on the latest edition of the Pediatric Hematology Oncology Chapter's newsletter, *PHO Vibes*. As the President of IAP, it is my privilege to write for such a dynamic subchapter, one that is close to my heart, where passion meets purpose in the care of children with blood disorders and cancer.

I am particularly proud to see this newsletter celebrating unsung heroes like Dr. Yellapragada Subbarao and the NGOs supporting pediatric cancer and hematological diseases. These stories inspire and remind us of the extraordinary efforts being made to improve the lives of children facing such difficult challenges.

Every year, thousands of children face the unimaginable battle of cancer. But with every challenge comes a story of resilience and hope. The fight against childhood cancer is one of innovation, determination, and unwavering commitment. When this battle involves our youngest warriors, it takes on a profound significance, touching the hearts of all who bear witness to it.

The role of our pediatric community in this fight cannot be overstated. Whether through volunteering, raising awareness, or advocating for more research funding, every action contributes to the collective effort to eradicate pediatric cancer.

Together, we can make a significant impact and help light the way toward a brighter, healthier future for all.

I wholeheartedly congratulate everyone involved in this wonderful piece of work and offer my best wishes for a successful PHOCON 2024 Conference in Jammu.

Dr G. V. Basavaraja
National president IAP, 2024

Note from PHO Chairperson

Dear Friends and Colleagues,

It gives me immense pleasure to introduce the second edition of *PHO Vibes*, the newsletter of our Pediatric Hematology Oncology Chapter, at the occasion of the 27th PHOCON in Jammu. This publication is a significant milestone, not only because it brings together the latest in our field but also because it symbolizes our commitment to continuously evolve, share knowledge, and strengthen the bonds within our community.

As we move forward in this era of scientific innovation and rapid advancements in pediatric cancer care, it is crucial that we remain adaptive, engaged, and collaborative. The challenges we face in pediatric hematology and oncology are complex and multifaceted. However, I firmly believe that we are equipped, as a community, to rise to these challenges and continue to make a profound impact on the lives of children and their families.

Our journey in pediatric hematology and oncology is not just about pushing the frontiers of science; it is also about nurturing an ecosystem of learning, compassion, and support. The PHO Chapter is not merely a professional network—it is a community of caregivers, researchers, and advocates who are united by a singular purpose: to transform the future of pediatric cancer care in India and beyond. Each of you plays an integral role in this transformation.

The resurgence of *PHO Vibes* in the recent months, starting with the successful relaunch during the Mid-Term CME in Nagpur, has been a reaffirmation of the strength of our collective spirit. It is heartening to witness how this newsletter has become an important platform for exchanging ideas, sharing clinical experiences, and learning from each other's work. The response to the first edition was overwhelmingly positive, and I am confident that this second edition will continue to build upon that success.

I would like to take this opportunity to thank Dr. Sunil Jondhale, our diligent editor, and all those who have contributed to the content of this newsletter. Your efforts reflect the very essence of what we aim to achieve together: to educate, inspire, and collaborate for the greater good of our patients.

As we look ahead, the road before us is full of promise. With each passing year, new treatment modalities, technological advancements, and clinical trials provide hope for better outcomes. But we cannot afford to rest on our laurels. The future of pediatric hematology and oncology depends on the next generation of caregivers, researchers, and advocates. As leaders in this field, it is our responsibility to continue to innovate, to foster new partnerships, and to ensure that every child who needs our help receives the very best care possible.

I am excited to be part of this vibrant community, and I look forward to what we can collectively achieve in the years ahead. Let this newsletter serve as both a celebration of our progress and a reminder of the work still to be done.

Thank you for your unwavering dedication, and I wish everyone a fruitful and inspiring experience at PHOCON 2024.

With warm regards,

Dr. Shripad Banavali
Chairperson, Pediatric Hematology Oncology Chapter,
Indian Academy of Pediatrics
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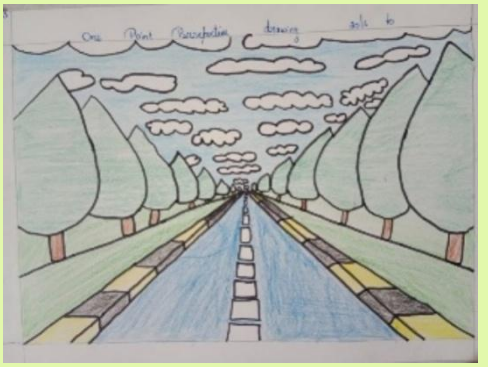


Note from Honorary Secretary of IAP

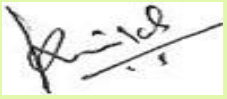
Dear Reader,

I extend my warm greetings to the entire PHO Chapter and the “PHO Vibes” newsletter team for bringing out this informative and celebratory mini-academia. I would also like to acknowledge all the contributors for sharing their valuable insights, artwork, and informative articles.

As we navigate the vast landscape of pediatric blood and cancer, we are continually inspired by the indomitable spirit of the children and families who face this challenge with remarkable courage and resilience. While this journey is fraught with difficulties, it is also illuminated by the extraordinary advancements in medical science and the unwavering support of communities around the world.

Every step forward in pediatric blood and cancer research brings us closer to a future where cancer no longer casts a shadow over childhood. Through continued efforts and unwavering hope, we strive to transform despair into determination and sorrow into triumph.
Let us all join hands in this journey, supporting and celebrating the indomitable spirit of children facing blood and cancer diseases. Together, we can illuminate their path with hope, strength, and unwavering support.

Congratulations and heartfelt thanks to PHO chapter and everyone who has contributed to these remarkable achievements. Best wishes to all for a successful academic endeavor at PHOCON 2024 in Jammu



Dr Yogesh Parikh
Secretary General – 2024 & 2025
Indian Academy of Pediatrics

Note from Honorary Secretary of PHO

Dear Colleagues and PHO Enthusiasts,

It is with great pleasure and a deep sense of pride that I present to you the second edition of our *PHO Vibes* newsletter, being unveiled at the 27th National Conference of Pediatric Hematology Oncology (PHOCON) in Jammu. This publication marks a significant moment in the life of our chapter—not just as a means of sharing knowledge, but as a celebration of the unity, dedication, and shared purpose that defines our community.

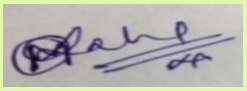
As we come together in this beautiful temple city to engage in discussions, exchange ideas, and inspire one another, I am reminded of the tremendous journey our field has undertaken. Over the years, we have seen incredible strides in pediatric hematology and oncology—breakthroughs in treatment, advances in research, and an ever-growing support network for both patients and their families. But as we all know, there is still much to be done.

The relaunch of this newsletter earlier this year during the Mid-Term CME in Nagpur was a testament to the resilience of our community, as we once again sought to engage, inform, and inspire. The response was overwhelming, a reflection of our collective drive to stay connected, share our experiences, and continue to grow. This second edition continues that momentum and serves as a reminder that our shared knowledge and experiences are not only vital to the growth of our field but essential to the children we serve.

Through *PHO Vibes*, we aim to highlight the individuals and initiatives that are shaping the future of pediatric hematology and oncology—whether through research, inspiring patient stories, or innovative community-driven efforts. This edition includes articles, artwork, and reflections from many of you, and I extend my heartfelt thanks to all the contributors who have made this possible. The versatility of the newsletter is its signature. As we embark on PHOCON 2024, let us remember that our work, while challenging, is not done in isolation. It is through the shared strength and expertise of each member of our community that we continue to make a difference. Together, we can bring about meaningful change, provide hope, and transform lives.

In closing, I wish to express my deepest appreciation for the continued efforts of everyone involved in the PHO Chapter and the *PHO Vibes* team especially the editor of this edition Dr Sunil Jondhale. May this newsletter inspire you as much as it has inspired me, and may our collective work continue to shine a light of hope for every child battling hematologic and oncological diseases.

Looking forward to a productive, enriching, and inspiring PHOCON 2024!



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Note from "PHO VIBES" Editor

Dear PHO Friends and Fraternity

After successful launching of our Newsletter PHO Vibes at Nagpur with a great pleasure I hereby introduce you to the second edition of "PHO Vibes" the official newsletter of pediatrics hematology oncology (PHO) chapter of IAP.
This newsletter dedicated to all pediatrics hemat-oncologist, Pediatrics transplant physician, all ancillary supporting faculty members, nursing staff, supporting staff, medical social workers and NGOs who are involved in caring and cure of pediatric hematological and oncology disorders. I personally thank you for sharing insights, experiences, and updates within the realm of pediatric Hemat oncology.

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.

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

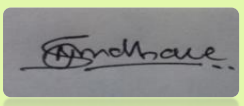
In the spirit of fostering creativity and camaraderie, we've included a "Fun Section," featuring artwork from both patients and PHO fraternity.

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. Special thanks to Dr Shobha Badiger for helping to design and contributing beautiful pictures of arts.

I would like to express my sincere appreciation to the entire PHO team for entrusting me this responsibility and their unwavering support in bringing this newsletter to fruition. Last but not least I would like to extend my gratitude to Dr Anil Kumar Goel, Hod Pediatrics AIIMS Raipur for unwavering support.

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

Warm regards,



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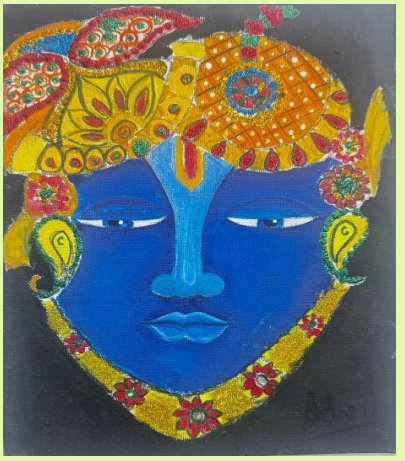

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Improving Care for Sickle Cell Disease in Chhattisgarh: Journey of Sangwari

Dr Yogesh Kalkonde
Public Health Practitioner and Researcher,
Sangwari-People's Association for Equity and Health

Sangwari is a not-for-profit organization registered as a section 8 company under the Companies Act 2013 in India (www.sangwari.net). It is formed in 2020 by a group of like-minded healthcare professionals who are interested in improving the health of rural and Adivasi people. Each one of these professionals has 5-20 years of experience working in underserved rural regions of the country. The mission of Sangwari is to improve the health and well-being of Adivasi and other rural communities by way of medical care, community engagement and mobilization, capacity building, research, and advocacy.

Surguja Sickle Cell Jan Swasthya Sammelan

Sangwari works in the Surguja division in northern Chhattisgarh which has a population of about 5 million. The division abuts Jharkhand on the east, Madhya Pradesh on the west, Uttar Pradesh on the north. This region is economically underdeveloped and has weak public as well as private health care services due to shortage of trained personnel and lack of adequate healthcare infrastructure. It can be easily described as a 'medical desert' and the closest tertiary medical care is available 300 kilometers afar. Close of 50% of the population of this region is Adivasi or tribal. Multiple Adivasi communities inhabit this region including Urao, Kawar, Gond, Majhi, Majhwar, Saota, Korwa and vulnerable tribal groups like Pahari Korwas and Pandos. The team has one pediatrician, three family medicine specialists, one internist, one anesthesiologist and pain specialist, one public health specialist and one neurologist cum public health specialist. There are community nurses, pharmacists, social workers and community health workers. The activities of the team are ably supported by an administration and accounts team. Collectively about 100 individuals are co-travelers in this journey.

Right from its inception, Sangwari has actively engaged with the public health system in the division as well as at the state level through training, clinical care, help with operationalizing care for selected diseases, care coordination and advocacy.

Home visit by Sangwari team

Sickle cell disease in Chhattisgarh

Sickle cell disease is a public health challenge in Chhattisgarh. Close to 10% of the population in the state are carriers and 1-3 individuals per 1000 population suffer from sickle cell anemia. However, the care of patients with sickle cell disease largely remained disorganized and very few patients were receiving hydroxyurea regularly.

In order to address this challenge, Samngwari first started a sickle cell unit at an Urban Primary Health Centre (UPHC) in Ambikapur town. This facility is now providing care to more than 500 patients with sickle cell disease. These joint efforts were awarded by the Health Minister of Chhattisgarh. Buoyed by the success of this initiative, Sangwari provided technical support to establish sickle cell disease units and OPDs in two districts (Surguja and Surajpur) in the Surguja division. The primary care doctors in the public health system found it challenging to prescribe hydroxyurea. Sangwari developed a simple weight-based treatment algorithm for prescribing and monitoring hydroxyurea which was accepted by the Health Department of the state and the National Health Mission for state-wide scale up. The patients in these districts are supported by a team of care coordinators. These care coordinators help in identifying patients, enrolling them in a registry and counselling.

Patient peer-support group meeting

They also help patients navigate the busy public. health system and ensure active follow up through phone calls and home visits. The initiative is providing care to more than 1500 patients of sickle cell disease in the public health system and is probably one of its kind in the public health system in India. After initially supporting the care at the district hospitals now the team is working to decentralize care to community health centre in these districts. To improve patient's awareness Sangwari is organizing patient peer-support group meetings and has also started a novel initiative of "Surguja Sickle Cell Jan Swasthya Sammelan" to build capacity of patients and promote collective problem-solving efforts. The Sammelan has panel discussions on frequent health issues faced by patients, challenges regarding disability certificates and issues related to skilling and livelihood among patients. These interventions have led to 40% decrease in blood transfusions and hospitalizations over a short span of 1 year.

Based on the success of this model, the UNICEF has supported to replicate this model in the Jashpur district. Recently, Sangwari has also started implementing this model in the Durg district. A distinct feature of this model is to build the capacity of patients and their care givers to face this chronic disease and improve patient outcomes. The work done by Sangwari is awarded in the recent Pediatrics Hematology Oncology Conference in Nagpur.(Pic Below)

A Decade in the Pediatric Oncology Ward: My Journey as a Ward Assistant

Kanaiyalal Pimple
Senior ward assistant, Ward 37
Pediatric Hematology & Oncology ward
LTMMC &GH, Mumbai

Forty years ago, I stepped into the pediatric Hematology with Dr. MR Lokeshwar Sir to start the pediatric hematology Laboratory Assistant. After my Retirement from Municipal service, I continued to work with the same department as ward assistant. Since last Ten years, I am associated with patient care through an NGO. Being closely associated with pediatric cancer care, I was selected to work as ward assistant even after my regular superannuation. It was a leap into the unknown, filled with both uncertainty and hope. Over the years, I've witnessed the full spectrum of human experience—sorrow, resilience, joy, and profound connections

The First Day: A New Beginning

I remember my first day vividly. The ward was alive with sounds—machines beeping, the soft murmur of nurses, and the laughter of children. I felt overwhelmed, but as I met the young patients, their courage inspired me. I knew then that I was exactly where I needed to be.

Learning the Ropes

In the beginning, my duties were straightforward—assisting with daily tasks, helping nurses, and ensuring the children felt comfortable. But I quickly learned that my role was about more than logistics; it was about building relationships. I helped the trainee doctors to do Bone marrows as make proper slide spread with my due experience with the same for almost 40 years. The residents too and the faculty around would relax saying, don't worry when Kaniyalal is around to assist you for the procedures. Even the electrical and Air conditioning units were checked by him. Being familiar with the hospital functioning and all the engineers of the hospital, It was very smooth sailing to get the work done even at the government run Hospital. Every smile I shared, every story I listened to, helped me connect with the children and their families.

The Weight of Sorrow

As I grew accustomed to the rhythms of the ward, I also encountered heart-wrenching moments. I've held the hands of parents in distress and comforted children who were scared and in pain. Each loss carved a deep mark on my heart, reminding me of the fragility of life. But in those moments of sorrow, I found strength in community—colleagues, families, and even the patients themselves rallied together, supporting one another.

Celebrating Triumphs

Equally, I've celebrated countless victories. From ringing the bell after the last treatment to spontaneous dance parties in the play-area, these moments of joy were transformative. Each child's progress became a personal victory for me. I realized that even in a battle against illness, there are moments of pure joy worth cherishing.

The Bonds We Build

Over the years, I've forged bonds with patients that transcended the clinical setting. I've shared laughs during play therapy sessions, comforted them during tough treatments, and celebrated birthdays that, against all odds, became milestones. These relationships have enriched my life in ways I could never have imagined.

Personal Growth

This journey has also been one of deep personal growth. I've learned to be present, to embrace uncertainty, and to find beauty in small moments. Each child's spirit has taught me resilience, patience, and the importance of kindness. My perspective on life has shifted; I now approach challenges with a newfound appreciation for the present.

A Community of Care

I've been fortunate to work alongside an incredible team of professionals—doctors, nurses, social workers, and fellow support staff. Together, we've created a community that prioritizes compassion and understanding. The collaborative spirit in our ward makes the toughest days manageable and the good days unforgettable.

Looking Ahead

As I reflect on this decade, I'm filled with gratitude.
In this pediatric oncology ward, I've found my calling—a place where love, resilience, and humanity intertwine. My journey may have started with uncertainty, but it has blossomed into a profound and rewarding experience that I wouldn't trade for anything.

"And as the years pass, the bonds never fade,
Each child a bright star in the memories made.
Though the ward may be heavy, his heart remains free,
A ward assistant, forever a part of the sea."

Musings of a pediatric oncologist

Dr Prakruthi S Kaushik, Associate professor,
Department of Pediatric Oncology, Kidwai Memorial Institute of Oncology

Sometimes it makes me wonder, how did I end up being a pediatric oncologist! During post-graduation, I began the search about what next? Neurology had cerebral palsies and neurodegenerative diseases. The endless toils of a mother were depressing. Neonatal and PICU was too "intensive" for my taste. With the constant adrenaline rush, I would definitely age faster! Endocrinology wasn't my cup of tea. Despite attending infinite CMEs, I never got a hang of it. Nephrology was good but Hematology won my heart.

After post-graduation, Mumbai became my second home for a couple of years (husband was pursuing his MCh at Tata Memorial Hospital). I tried for a senior residency post at King Edward Memorial hospital, but was unsuccessful. As fate would have it, got selected as senior resident in the Department of Pediatrics at Lokmanya Tilak Municipal General Hospital headed by Dr Mamta Manglani, a doyen in Pediatric Hematology Oncology. She remains a dynamic personality, visionary and a source of inspiration to us all. Her anecdotes in life continue to resonate even to this day. The first thing ma'am asked me was whether I would be interested in doing a fellowship in Hematology. I denied saying I was not sure if I would like it. One month of rotation in PHO subdivision rekindled my love. Then there was no looking back. I successfully completed 2 years of fellowship.

We relocated to Bangalore in 2018. I am currently working as an Associate Professor in the Department of Pediatric Oncology at Kidwai Memorial Institute of Oncology. Every day is a challenge, to see the sheer numbers of children suffering, to see them getting admitted to the hospital for treatment rather than spending their precious childhood in school. But their smile and resilience are inspiring. It inspires us to do our best, motivates us to strive for better and reinstates courage and a "never lose hope" attitude.

They remind us to live fully even though the heart feels heavy.
To find beauty in every moment, to rise with grace, for resilience lies in the heart of our journey.
What made me choose this specialty?
Was it my father's wish to see me as a doctor?
Was it Robbins who made me fall in love with Hematology?
Were my teachers instrumental?
I know not.
But I love what I am right now. I see the same spark in all my colleagues and juniors.
More power to us all!

Successful Management of Multiple Biventricular Cardiac Rhabdomyomas in a Neonate using Everolimus

Dr Vidya K*, **Saurabh Pradeep Jain, Lalit M. Malviya, Shruti Pandey, Monica Lazarus**

** Assistant Professor, Department of Pediatrics, NSCB Medical college, Jabalpur*

Cardiac rhabdomyomas (CR) are the most common benign tumors of infancy with an incidence of approximately 0.1%, often presenting as multiple echogenic masses within the myocardium (1-2). These tumors are frequently associated with tuberous sclerosis complex (TSC) but may also occur in isolation. CRs typically regress spontaneously during early childhood; however, they can lead to significant hemodynamic disturbances including arrhythmias, ventricular dysfunction, and obstructive symptoms based on their size and location (5). Recent literature has explored the use of Everolimus, an mTOR inhibitor, in managing CR associated with TSC, demonstrating promising results in tumor regression at doses ranging from 4.7 to 5.6 mg/m²/day (6,7). Despite its efficacy, the use of Everolimus in neonates is limited due to a lack of comprehensive pharmacological data.

Case Report

A term male infant, born vaginally with a birth weight of 2.1 kg, presented at day 3 of life with respiratory distress and feeding refusal. Physical examination revealed tachycardia (heart rate 172/min), respiratory rate of 72/min with nasal flaring, chest retraction, and prolonged capillary refill time. Peripheral pulses were weak, and auscultation showed normal heart sounds without murmurs. The liver was palpable 4 cm below the costal margin. The infant was placed on CPAP support and treated according to NICU protocols.

Echocardiography revealed multiple echogenic masses in both ventricles and the interventricular septum (Figure 1). A particularly large mass in the interventricular septum was compressing both ventricles, affecting cavity size and causing systolic and diastolic dysfunction, though without inflow or outflow obstruction. Additionally, the infant had multiple hypopigmented macules on the trunk, suggestive of Tuberous Sclerosis Complex (TSC), though genetic testing was not performed due to financial constraints.

Given the severity of the infant's condition and the infeasibility of immediate surgical intervention, oral Everolimus therapy was initiated with informed parental consent. The starting dose was 0.1 mg/kg/day. The infant's condition gradually improved; oxygen support and inotropes were tapered and eventually discontinued. A repeat echocardiogram after 6 weeks demonstrated significant reduction in mass size, increased left ventricular cavity size, and improved biventricular function. Cranial and abdominal ultrasounds, as well as ophthalmologic examinations, were normal.

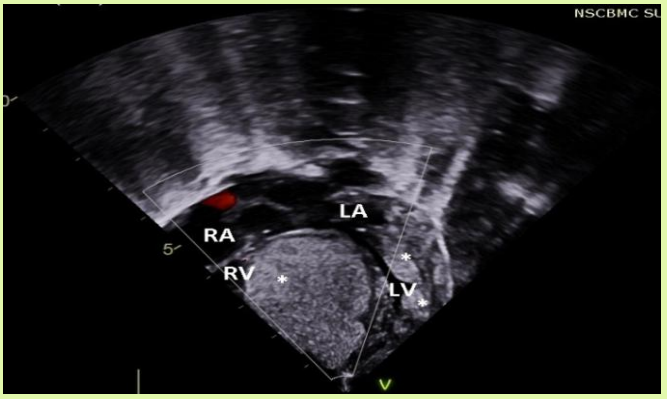

Fig 1 – Echo Showing large rhabdomyoma mass in interventricular septum compressing the ventricles, also in left ventricular free wall

At discharge, the infant was feeding well and stable. However, follow-up at 4 weeks revealed pancytopenia (Hb 7 gm/dl, TLC 3900, platelet count 99,000), indicative of bone marrow suppression, a known side effect of Everolimus. The medication was temporarily discontinued, allowing for recovery of the bone marrow. Once blood counts normalized, Everolimus was reintroduced at half the initial dose.

Follow-up echocardiograms after 5 months showed further mass reduction and continued good biventricular function (Figure 2). The infant continued to follow up with satisfactory weight gain and developmental progress.

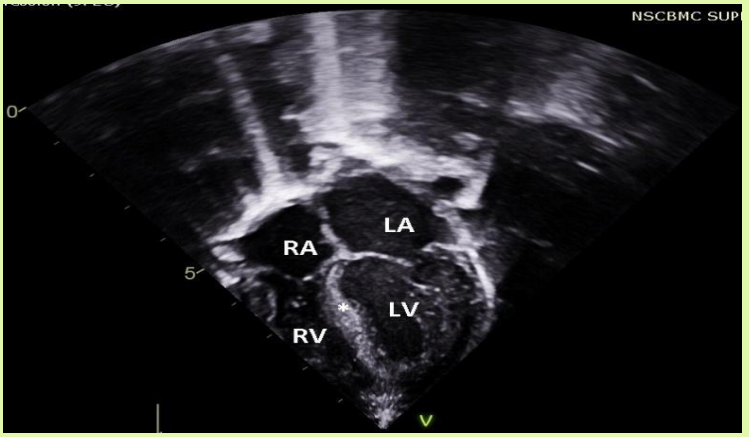

Fig 2 – Echo showing near complete resolution of mass after 5 months of treatment

Discussion

Cardiac rhabdomyomas often regress spontaneously due to diminishing effects of maternal estrogens. More than 70% of cases resolve without intervention, particularly when asymptomatic. Surgical intervention is generally reserved for cases with significant cardiac outflow obstruction, persistent arrhythmias, heart failure, or cardiogenic emboli (8). However, surgery may be impractical due to tumor size, location, or comorbidities.

In this case, the large mass in the interventricular septum led to systolic dysfunction and heart failure, making immediate surgical intervention unfeasible. Everolimus, an mTOR inhibitor, was chosen as a therapeutic alternative. Though there is limited literature on dosing and toxicity in neonates, our case demonstrates that low-dose Everolimus can be effective in reducing rhabdomyoma size with manageable side effects.Adverse effects of this drug include leukopenia, anemia, thrombocytopenia, susceptibility to infections, stomatitis, skin rash, hypercholesterolemia, hypertriglyceridemia, hyperglycemia, hypophosphatemia, hyperuricemia, and bone marrow suppression (9)Everolimus has been reported to cause anemia, neutropenia, and thrombocytopenia in patients under 2 years (10), but we found pancytopenia in our case which is not reported earlier in a neonate. Bone marrow suppression, the primary dose-limiting toxicity, resolved after a temporary discontinuation of the drug, allowing for reinitiation at a reduced dose without further significant adverse effects.

This case report contributes to the growing body of evidence supporting the use of low-dose oral Everolimus as a potential treatment for cardiac rhabdomyoma in neonates, either as an alternative or bridging therapy prior to surgical intervention.

Conclusion: Everolimus appears to be an effective treatment option for managing multiple biventricular cardiac rhabdomyomas in neonates, especially when conventional therapies are insufficient. This case highlights the potential of targeted therapies in improving outcomes in complex cases of cardiac tumors

References:

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"KOI APNA SA HO"
KASH FOUNDATION
NGO for Sickle Cell & Thalassemia Patients across India

Kajal Sachdev, Founder and Director,
Koi Apna Sa Ho (KASH) foundation, Raipur, CG

Koi Apna Sa Ho (KASH) foundation is a registered (reg no 12201968118) Non-Profit organization founded in 2016, representing mainly by a small group of patient's parents, doctors, well-wishers, philanthropists, etc. KASH foundation provides best treatment and management to patients suffering from Thalassemia and Sickle Cell Anemia. Key members of foundation include founder Mrs. Kajal Sachdev, director Mr. Suresh Sachdev and secretory Mr. Sandeep Kukreja.

Founder, Kajal Sachdev, and Director Suresh Sachdev's son was born with thalassemia Major, which required him to undergo blood transfusions every 15 days since birth. Unfortunately, no one in their family was a bone marrow match for son Suransh. This situation left Kajal Sachdev feeling extremely sad for a long period of time. However, she eventually made the decision to help other underprivileged children in similar situations. Mr. Suresh Sachdev, the Director of the KASH Foundation and the father of Suransh Sachdev, played a vital role in establishing the foundation. As a parent of a child with thalassemia, Suresh Sachdev understood the since 2001. Sandeep's personal experience with thalassemia major, suffering from it since birth, inspired him to join forces with Mrs. Kajal Sachdev in her noble cause. His qualification as a Master of Computer Application to provide technical expertise and dedication that have greatly contributed to the success of the foundation's initiatives. The foundation was registered in 2016 but has been providing its services. Since its genesis, foundation have expanded its operation from Chhattisgarh to pan India level. importance of the cause and made the decision to help other children who were suffering from thalassemia, leukemia, and sickle cell anemia.

KASH Foundation's primary objectives include:

1. Arranging free medication and leukocyte blood filters for children suffering from thalassemia in Chhattisgarh through a collaboration with the government.
2. Advocating for government support and services for thalassemia and sickle cell patients.
3. Ensuring that the rights of these patients are upheld.
4. Organizing specialized OPD (Outpatient Department) sessions by inviting renowned hematologists to provide the best possible treatment for affected children in their respective cities. 5. Arranging HLA (Human Leukocyte Antigen) camps to facilitate bone marrow transplants when matching donors are found.
6. Assisting in managing the funds required for bone marrow transplants, During the COVID pandemic, we established a special assistance fund of 20 lakhs with the government to support families affected by thalassemia and sickle cell disease in raising funds for bone marrow transplants. This initiative aims to alleviate the financial burden and challenges associated with arranging funds for BMT procedures.
7. Conducting counseling sessions to educate and support individuals and families affected by thalassemia and sickle cell disease
8. Implementing prevention programs to raise awareness in society, with the goal of eradicating thalassemia and sickle cell diseases from their roots.

Dr Sunil Bhat (Pic 1) and Dr Vikas Duwa (Pic 2) in HLA and pretransplant counselling camp at Raipur, Chhattisgarh.

Key Activities of Foundation:

Awareness

Blood donation

Day Care

BMT Support

HLA testing

Counselling

Kash Foundation have successfully collaborated with the government to provide free CVS (chorionic villus sampling) tests, a prenatal test valued at 16,000 INR. This initiative plays a crucial role in the thalassemia and sickle cell prevention program, as it helps prevent the birth of new children with thalassemia and sickle cell disease. To date, foundation have facilitated 1000 free CVS tests and contributing to this important cause.

Till date foundation has arranged more than 1500 blood donation camps and provided 15000 blood transfusion to children with thalassemia and sickle cell disease. With Pediatrics transplant crusaders like Dr Sunil Bhat, Dr Vikas Duwa and Dr Dinesh Bhurani foundation have facilitated more than 155 transplants till date. Today, the KASH Foundation proudly serves over 460 thalassemic children in Chhattisgarh, providing them with necessary support and medical care.

Kash foundation has honored with 100+ national awards including the EOTY award presented by chief minister Shri Bhupesh Baghel, MYFM Jio Dil Se awards, Phalake Corona Worrier Award the Narayana Health center all over India counselling award, The Sindhu Ranta Award and many more award since 2016. Kash foundation's tireless efforts are aimed at improving the lives of thalassemia and sickle cell patients and eventually eliminating these diseases from society.

लोकमत समाचार

थैलेसीमिया शिविर का 100 मरीजों ने उठाया लाभ

माहेश्वरी मंडल, महेश सेवा समिति, रोटरी क्लब यवतमाल मिडटाउन का संयुक्त आयोजन

लोकमत समाचार सेवा

यवतमाल: निःशुल्क थैलेसीमिया शिविर का आयोजन माहेश्वरी मंडल, महेश सेवा समिति, इंडियन अकादमी ऑफ पेडियाट्रिक्स, रोटरी क्लब ऑफ यवतमाल मिडटाउन ने स्थानीय महेश भवन में हाल ही में किया. इसमें भरीजों को थैलेसीमिया है या नहीं, इसकी जांच की गई.

अंध फाउंडेशन रायपुर की संस्थापक काजल सवदेव के मार्गदर्शन में डॉ.विवेक वखाणे की अध्यक्षता में यह शिविर हुआ. इस समय थैलेसीमिया संगठन के जिलाध्यक्ष वुधम वाजड़ेने १०० मरीजों का पंजीयन किया था. मरीजों के परिजन भी इस समय उपस्थित थे.

सवदेव ने बताया कि, वे स्वयं और उनके पति, पुत्र इस बीमारी से ग्रस्त है. गत 15 वर्ष से वे यह शिविर ले रहे है. उन्होंने इस बीमारी की जानकारी दी. माहेश्वरी मंडल के अध्यक्ष विजय लाहोटी, रोटरी क्लब ऑफ यवतमाल मिडटाउन के अध्यक्ष घनश्याम वाणी, आईपीए के अध्यक्ष डॉ.गिरीश डबले, महेश सेवा समिति के अध्यक्ष चंद्रकांत वाणी आदि उपस्थित थे. शिविर का प्रारंभ भगवान महेश का पूजन और दीप प्रज्वलन से किया गया. मान्यवरों का स्वागत माल्यार्पण, शाल, स्मृतिचिन्ह देकर किया गया.

इस उपक्रम के प्रकल्प प्रमुख दीपक भूटड़, माहेश्वरी समाज के सदस्य, डॉक्टर, रोटरी सदस्य उपस्थित थे. संचालन माहेश्वरी मंडल के उपाध्यक्ष विजयमोहन राठी तथा आभार रोटरी क्लब ऑफ यवतमाल मिडटाउन की सचिव श्रद्धा गट्टानी ने माना. राष्ट्रगीत के बाद कार्यक्रम का समापन हुआ.

Bracing support beyond End-of-Life care: Early integration of Palliative Care in Pediatric

Dr Veronique Dinand
Head, Pediatrics Palliative and
Supportive care Unit
Bai Jerbai Wadia Hospital for Children,
Parel, Mumbai

"We are sorry, the chances of cure for your child's cancer are bleak as per medical science". This thought and the impact of this declaration on patient's family would haunt oncologists. 'I wish I had something more to offer to the patient, I wish I had spent more time understanding stresses families are going through, I wish I could do something to bring down physical and psychological pain of the child; are the thoughts that kept coming to our minds.

To address these challenges, we were blessed to have support of a dedicated palliative care unit in our hospital who have now become an indispensable part of the oncology team. Palliative care is an integral part of comprehensive care of oncology patients. Its role is even more vital in care of pediatrics patients who are more vulnerable than adults, higher possibility of therapy related complications and psychological support is warranted for both patient and parents.

Palliative care plays a significant role in alleviating symptoms, improve understanding of the disease and hand holding of families in case of unfortunate eventuality. [1] Guidelines published in ASCO journal in 2016 and in Palliative medicine journal in 2021 have recommended early referral to palliative care team, within 8 weeks of diagnosis of cancer, especially in advanced and aggressive cancers. [2]

Palliative care unit was conceived in our tertiary care pediatrics hospital in 2019 under the leadership of Dr Veronique Dinand. The team includes experienced doctors, nurses, counsellors, social workers, clown therapist and book & toy librarian. Over the past 5 years, 428 children with cancer have benefitted from palliative care services, not just within the boundaries of the hospital, but in home setting too. In many cases, palliative care team was a path breaker in achieving goals and providing comfort to the child and family. To mention a few, most referrals have been for emotional support (257), counselling to choose palliative or curative intent at the time of diagnosis (71), symptom management for pain or mucositis (167), end of life care and bereavement support (143) and home visits (19).

Case 1: ***Courage to deal with setbacks***

An 11-year-old girl having multiple joint pains being treated with multiple therapies and misdiagnosed as Systemic onset Juvenile Idiopathic Arthritis (SOJIA), presented to our department where she was diagnosed with Acute Lymphoblastic Leukemia. Such patients due to inappropriate therapy received and delay in diagnosis, have to bear higher brunt of disease and therapy related complications, hence we involved the palliative care team in the beginning. To our dismal, the child relapsed in maintenance therapy. The family had gone through a difficult time for more than a year already and it was difficult for them now to accept this news. Palliative and oncology care team counselled them and a decision to undergo transplant was taken by the parents. With constant emotional support, family sailed through the transplant successfully and now child is one year post HSCT and doing well.

Case 2: ***Strengthening Bereavement support***

A child diagnosed with Mixed Phenotype Acute Leukemia in a Bloom syndrome was counselled for upfront palliative care considering bleak prognosis and long-term outcome. However, parents insisted and treatment was started, on which he had multiple complications and ultimately put on oral metronomic therapy with palliative intent. He was doing well for a year and palliative team ensured he had a good time during his hospital visits and beyond. We lost him after a year, but the bereavement care provided by palliative care team helped the mother to deal with the loss. Palliative care was providing support to another child since diagnosis, whom we lost to a high-risk AML. Bereavement care plays a pivotal role in assisting families to grow out of grief and rebuild their life again with happy memories of the child. These two mothers from diverse religions

came together in palliative care department to share their life stories over a cup of tea. As a busy oncology unit, this wouldn't have been possible for us without the efforts of palliative care team.

Case 3: ***Consolidating broken families***

A doting couple to a child with Down's syndrome, presented to us with diagnosis of Acute leukemia in their child. They were financially drained taking initial treatment in a private hospital and wished to take further treatment for their son with us. Unfortunately, we lost the child to refractory disease. Palliative care team stood beside them to recover from the emotional and financial setback. With their encouragement, the parents gathered courage to learn the art of soap making and have found peace in making it their source of living in the memory of their adorable child who was very fond of colorful soaps.

Case 4: ***Mucositis/Pain management***

A 14-year-old child with osteosarcoma was receiving chemotherapy with highly emetogenic drugs (High dose methotrexate, cisplatin etc). We know incidence of chemotherapy induced nausea vomiting (CINV) and anticipatory vomiting is higher in adolescents. This child used to have severe bouts of vomiting during his chemotherapy and even for days beyond chemotherapy. He required multiple antiemetics to control vomiting. To worsen the situation, child used to get grade 3-4 mucositis post every chemotherapy. With constant assistance from palliative care team in providing pain control for mucositis and emotional support, we managed to pull through his chemotherapy.

Conclusion: Palliative care has only recently gained importance as a part of oncology, with still a deficient literature on its role in pediatric oncology. Holistic care of children with cancer is incomplete without the support of palliative care team and we are privileged to be one of first pediatrics centre to have dedicated palliative care services not just assisting us in oncology but also in non-oncology patients.

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FACTS HUMOR

What does your blood type say ABOut you?

A's
- Crave order and neatness
- Meticulous habits
- Incredibly self-controlled

AB's
- Rational and sensible
- Make excellent first impressions
- Often have paranormal abilities

B's
- Candid, forthright, non-conformist, absentminded, and thrive on the unusual
- May be poor team players and believe in their superiority
- Make great cooks

O's
- Crave power, leadership, and success
- Act as jealous guardians at work and in the family
- Are ideal presidents, heads of corporation, and captains of sports teams.

Running for Resilience: A Perspective on Marathon Running and Medicine

Dr. Sunil Bhat
Vice-Chairman Oncology Collegium,
Narayana Health Group of Hospitals
Director and Head of Pediatric Hematology Oncology and BMT
Narayana Health City Bangalore

When people ask me about my life outside the hospital, they're often surprised to hear about my love for marathon running. As a pediatric hematology oncology and bone marrow transplant specialist, my workdays are intense and emotionally charged. I witness children and families navigate some of the most challenging experiences, and I'm privileged to be a part of their journey. Yet, outside the hospital, I lace up my shoes and head out for a run. Running marathons has become a vital part of my life—not just for physical fitness but also for the mental clarity and resilience it brings.

Training for marathons is not easy. It demands discipline, resilience, and the ability to push through discomfort—all qualities that are also crucial in medicine. But more than that, running makes me feel good. There's something about the rhythm of my feet hitting the ground, the surge of adrenaline, and the release of endorphins that lifts my spirit. This "runner's high," as many call it, is a unique sense of euphoria that brings me immense joy and a deep, almost meditative calm. It's a feeling that reminds me why I keep going, step after step, mile after mile. Of course, sometimes oftentimes have aching muscles and bruised toes but that's all a part of it!

Beyond the local runs, I've found great fulfillment in traveling to different places and taking on challenging marathons, like the one in Ladakh. Running at such high altitudes, where the air is thin and every breath is a conscious effort, adds another level of challenge and excitement. These difficult marathons have taught me that even in the face of physical limitations, the mind has an incredible capacity to push forward. The breathtaking landscapes remind me of the beauty of resilience—both of the human spirit and of the natural world.

In a high-stakes field like pediatric oncology, self-care often takes a backseat. But I have found that prioritizing my physical health through running makes me a better physician and a better person for my patients and their families. Running is my way of managing stress, and I believe that when I'm physically fit, I'm better equipped to handle the demands of my role. There's something grounding about connecting with my body through physical exertion—it brings me back to a place of strength and resilience that I can carry into my work.

For those in our field, finding a way to destress and recharge is essential. Whether it's running, hiking, or any other activity, I encourage everyone to discover what brings them peace. Medicine is a marathon of its own, with its own set of hurdles and long stretches, but I am reminded with every step that endurance, persistence, and a focus on well-being are key to navigating both the marathon tract and the hospital corridors

Central Venous Access Devises (CVAD) in Children with Malignancy

Dr Purvaja Kubde
Associate consultant, PHO
Deenanath Mangeshkar Hospital, Pune

"Just as a seed needs sunlight and water to grow, Children with cancer needs a hope for nurturing and support"

INTRODUCTION

The use of central venous access devices for children undergoing treatment for cancer is almost universal and has greatly improved their quality of life. A CVAD makes the administration of drug and supportive therapy safer and easier. Children with Cancer Need Secure Central Venous Access Devises (CVAD) due to small vein, frequent prick leading to treatment phobia, risk of extravasation injury due to spillage of drugs in subcutaneous site and for emergency care of sick children on treatment.

USES

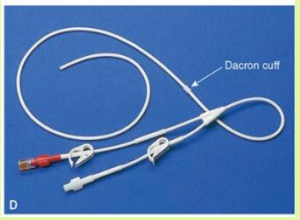
CVAD can be used for administration of highly osmotic or caustic fluids or medications, frequent administration of blood and blood products, total/partial parenteral nutrition, frequent blood sampling and administration of multiple therapies. Choice of CVAD is based on weight and size of the child, type and duration of therapy and frequency of CVAD access required.

>TYPES OF CVAD

- Skin tunneled catheters - Hickman™ line (single or double lumen)
- Implanted port - Portacath™ (single or double lumen)
- PICC -Peripherally inserted central catheter

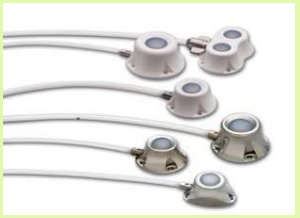
Portacath™ and Hickman™ lines are always inserted into children and young people in theatre under general anaesthetic by a surgeon. PICCs are occasionally inserted in the ward / PICU, but usually this procedure is performed in theatre by a doctor or anesthetist

- **Skin tunneled catheter - Hickman line**



A Hickman line is tunneled from the exit site on the chest wall, under the skin to the neck, where a small incision is made and the tip of the line is inserted into the superior vena cava with the tip usually sitting at the entrance of the right atrium. There is a Dacron cuff around the line which is designed to prevent dislodgement and form a barrier against infection through formation of a fibrous tissue around it

- **Implanted port - Portacath™ (single or double lumen)**



The Portacath is a totally implanted device which has a reservoir made up of titanium, stainless steel or plastic. The top of the reservoir, known as the septum, is the part that is closest to the skin's surface and is made of self-sealing silicone. A catheter is connected to the reservoir and is fed under the skin to a vein in the neck. There will be a small incision in the neck to place this catheter into the vein and position it just above the heart.

- **PICC -Peripherally inserted central catheter**

PICC lines are fine, flexible catheters, made from silicone rubber or polyurethane. The external tubing of a PICC line is narrow and is inserted through an introducer, similar to a cannula, into the cephalic, median cubital or basilic vein in the antecubital region of the arm. The line is inserted until the tip reaches the superior vena cava. The introducer is then removed and the line is secured with a suture and / or a STATLOCK® device and dressing

- **Routine care of central venous access devices (CVAD)**

Regardless of the type of CVAD used, the principles of care for the device remain the same:

- To prevent infection adhering to principles of (Aseptic) Non-Touch Technique
- To maintain a patent device
- To prevent damage to the device and associated equipment.

- **Complications and care of CVAD: As below**

	Cause	Signs	Management
Infection	Poor insertion technique and CVAD management	Redness, Swelling at site Pain, Pyrexia Infected exudates from exit site	-Swab site for bacteriology. -Blood for culture and sensitivity from the CVAD and peripheral. -Possible catheter removal if sepsis unresolved following antibiotic treatment.
CVAD Migration	adequate securement not pulled	Reduced infusion rate. Signs of extravasation (pain) and Swelling	Ultrasound of the jugular vein can indicate malposition in the vessel before an X-ray.
Thrombosis	. An SVC (superior vena cava) thrombus is caused when the catheter rubs against the wall of the SVC	No blood return from the catheter. Reduce flow, Pain, Dema and Discoloration of the limb,	-Constant assessment of the function of the catheter. -Venogram to diagnose -Thrombolytic therapy (Urokinase). -Oral anticoagulants. -Catheter removal.
CVAD Fracture	-Due to a faulty VAD set -Not clamping at the correct position -Nicking of the catheter when removing sutures. -Over screwing of the cap on to the hub	-Catheter damage can occur at different points along the catheter: -The catheter hub Internal fracture Above or below the catheter hub	Prevention is key when caring for CVADs. -Use 10ml or large syringes. -Avoid the use of small syringes wherever possible. -Immediate management is to clamp the catheter and assess the damage. -Catheter repair can only be performed for external catheters.
Catheter occlusion	There are two main types of occlusions: Persistent withdrawal occlusion (PWO) or total occlusion.	No withdrawal of blood from the catheter. The catheter may or may not flush.	-Prevention key: -Correct flushing procedure Utilising a volumetric pump for infusion management

- **To maintain a patent device**
  - Ensure IV drip is always running when a CVAD is accessed
  - Minimal infusion for maintenance:
  - Port Cath : 21 mls/ hr (12.5 mls/hr for fluid restriction) Table 2:
  - Hickman line: 12 mls/hr (LL), 5 mls/hr (SL)
  - PICC: 5 mls/hr (each lumen)

Flushing-Flushing schedule as per **Table 2**

Device	Locking agent	Volume	Frequency
Hickman Line	Heparinized Saline (10U/ml)	5 ml	Weekly
Port-a-cath	Heparinized Sodium (100 U/ml)	10 ml	Monthly
PICC	Heparinized Saline (10 U/ml)	3-5ml	Daily

- **Line handling- Nurses Responsibility**

- Change IV tubing: every 6days
- Gripper needle change: every 6 days
- Microclave change: every6days
- StatLock® device: Once a week
- TPN and lipid tubing change: Daily
- Tubing used for blood transfusions to be removed once transfusion is completed

Patients teaching: Parental teaching on how to keep CVAD clean and dry at the exit site where it comes out and also at the end where the bung is attached is important as following complication are expected

Conclusion

CVADs are the cornerstone of modern oncologic practice. Blockage and Infections are common problems, hence establishing best practices for catheter management in children with cancer is essential to optimize care in children with malignancy. CVAD needs patient motivation, counselling and regular care. Cost may be prohibitive if not supported.

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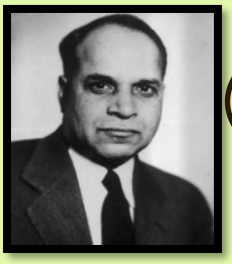

Dr Yellapragada Subbarow: Indian-American Doctor with Profound Contribution for Cancer Care

Dr Sunil Jondhale, *Additional Professor, Pediatrics, AIIMS Raipur*

Born on January 12, 1895, in Bhimavaram, Andhra Pradesh Yellapragada Subbarow was an influential Indian-American doctor whose work has had a lasting impact on medicine. But sadly, he is still an obscure historical figure in India and the current generation of learners are almost unaware of this founding father of modern Indian scientific research particularly tremendous contribution to cancer treatment.

Early life and education

Subbarow's journey from humble beginnings to a pioneering biochemist is a testament to his relentless determination and intellectual prowess. Born into a modest family, Subbarow faced numerous challenges throughout his career and struggled financially to pursue his education. He had to work hard to secure scholarships and support himself through school and college. Subbarow's academic journey was fraught with challenges. He struggled in school, flunking out of two high schools before finally passing his matriculation examination on his third attempt at High School in Madras. His interest in science, particularly mathematics and chemistry, blossomed during his intermediate studies at Madras Presidency College. After completing his studies, he enrolled at Madras Medical College in 1915 and earned Licentiate in Medicine and Surgery (**LMS**) degree. There he developed a keen interest in medical research, motivated by the tragic deaths of his brothers from tropical sprue. He sailed for the US on October 26, 1922, and took admission in the Harvard School of Tropical Medicine.

Professional and personal Struggles

After completing his studies, he joined Harvard as a Junior Faculty member. He left this job in 1940 and took up a position with Lederle Laboratories. As an Indian immigrant in the United States during the early 20th century, he faced significant racial and cultural discrimination. This made it difficult for him to gain recognition and secure positions in academia and research.

His first tryst with success came with the discovery of the Fiske-Subbarao method, which helped estimate the amount of phosphorous in body fluids and tissues. Despite his groundbreaking discoveries, Subbarow often did not receive the credit he deserved. Many of his contributions were overshadowed by his colleagues, and he faced challenges in getting his work published and recognized. Subbarow suffered from poor health throughout his life, which sometimes hindered his ability to work. Despite these setbacks, he continued to make significant contributions to science and medicine. Even though his work had a profound impact on medicine, he never received a Nobel Prize or the level of recognition that many of his peers did. This lack of acknowledgment was a significant challenge and disappointment for him. Despite these obstacles, Subbarow's perseverance and dedication to science led to discoveries that continue to save lives today.

His story is a testament to the power of resilience and determination.

Major scientific contributions

Subbarow's contributions to chemotherapy have had a lasting impact, he saved countless lives and improved the quality of life for many patients. His work exemplifies the profound difference that scientific research can make in medicine. Followings are his notable scientific contribution

- **ATP:** He contributed in discovery of the role of ATP s powerhouse of cell. This discovery has become a cornerstone in biochemistry, influencing countless studies and applications in cellular biology
- **Methotrexate**: He developed this chemotherapy drug, which is still used today to treat cancer and rheumatoid arthritis. Subbarow, along with Dr. Sidney Farber, developed methotrexate, one of the first chemotherapy agents. Methotrexate was revolutionary because it provided a targeted approach to cancer treatment. It was one of the first drugs to induce remission in childhood acute leukemia, marking a significant milestone in oncology. **S**ubbarow's work laid the foundation for the development of other chemotherapy drugs. His research on folic acid analogs paved the way for further advancements in cancer treatment.
- **Diethylcarbamazine (DEC)**: Dr Subbarow was also involved in biochemical research for the US military during the 2nd world war. But naturally, the details of that research ware classified. However, his discovery of Hetrazan (Diethylcarbamazine) was one of the results of that military-cantered project. This drug has saved the lives of millions all over the world in next six decades. He discovered this drug, which is the only effective treatment for filariasis.

- **Folic Acid**: His work was pivotal in isolating folic acid to treat nutritional deficiencies, particularly tropical sprue, which affected many individuals in his native India. He synthesized folic acid, which is crucial for DNA formation and is used to treat tropical sprue.

- **Tetracycline:** Subbarow also led the research at Lederle Laboratories, where his team discovered chlortetracycline, the first tetracycline antibiotic. This discovery was crucial in developing antibiotics that effectively combat bacterial infections. Tetracycline antibiotics have profoundly impacted treating a wide range of bacterial infections, making them essential tools in medical practice. Subbarow's contributions to antibiotic research have saved countless lives and continue influencing antibiotic therapy today.

Collaborations with Notable researcher

Yellapragada Subbarow collaborated with several researchers throughout his career, particularly on the development of methotrexate. One of his notable collaborators was **Dr. Sidney Farber**, a pioneer in pediatric pathology. Together, they worked on the development of antifolate drugs, which led to the creation of methotrexate. Their collaboration was instrumental in advancing the understanding of how folic acid analogs could be used to treat cancer. Dr. Farber's clinical expertise combined with Subbarow's biochemical insights made their partnership particularly effective. This teamwork was crucial in demonstrating the potential of chemotherapy to induce remission in childhood leukemia. Subbarow's ability to work collaboratively with other scientists was a key factor in his success, allowing him to contribute significantly to various fields of medicine.

Dr Subbarow had authored over 100 brilliant research papers. Some nucleotides discovered by him had to be rediscovered by other western scientists years later (according to Dr George Hitchings). Surprisingly, he never filed patent claims for any of his discoveries. Subbarow died on 8 August 1948 in New York due to cardiac arrest. Despite his significant contributions, Subbarow did not receive a Nobel Prize, but his work continues to benefit millions of people worldwide. His journey from a small town in India to the forefront of biomedical research showcases not only his intellect and dedication but also his unwavering commitment to improving human health through science. By honoring Yellapragada Subbarow's legacy, we not only pay tribute to a pioneer who transformed medical science but also inspire future generations to recognize and celebrate the diverse array of contributors who shape our understanding of health and disease.

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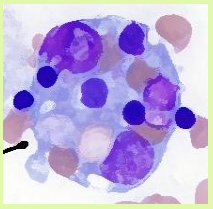

HLH or Not HLH – Diagnostic Dilemma!

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Case Review

A nine-year-old boy with T cell ALL and mediastinal mass had a stormy course since initial diagnosis. He had culture positive sepsis before the commencement of treatment, developed pyogenic myositis in mid induction. Clinical condition improved with IV antibiotics and supportive care. Induction with Icicle high risk protocol for T Cell ALL completed in time and End of Consolidation MRD was negative. Just at the end of consolidation he again presented with high grade fever and ANC of 0. Clinical examination was unremarkable with mild mucositis. Broad spectrum antibiotics, antifungal and GCSF were started. Fever remained unresolved after 5 days of IV antibiotics. All investigations including serial blood cultures, urine culture, X ray chest, CT Chest, USG abdomen, blood Galactomannan, 2 D ECHO were normal. Screening for Malaria and Dengue was negative. He had pancytopenia, enlarged liver with mild elevation of transaminase and serum bilirubin. Spleen was not palpable. Other biochemistry was normal RFT, hypoalbuminemia. Fasting serum Triglyceride and S. Ferritin were raised to 300 mg / dl and 558 ng/ ml respectively. CSF was normal and Bone marrow aspirate was negative for malignancy, occasional Haemophagocytes were seen. CD 25 count, Fibrinogen level and viral panel to evaluate fever cause could not be sent due to financial constraints. On Day 14 WBC count improved post GCSF, while Hb and platelet remained low in a clinically unwell child with persistent high-grade fever of unidentified focus. Secondary HLH was considered as partial 4/8 (HLH 2009) diagnostic criteria were fulfilled. IV Dexamethasone 10 mg/ m2 /day was started. Surprisingly, following the 2nd dose of dexamethasone, fever resolved completely, clinical condition improved dramatically, platelet count raised and was discharged home on oral dexamethasone.

Discussion points

This creates a diagnostic dilemma whether or not it was early secondary HLH with partial 4/8 diagnostic criteria met and whether to continue treatment with dexamethasone in our case? Was it improving WBC count with unidentified cause for fever or just 2 days of dexamethasone for HLH did the magic? Supportive criteria to consider early HLH were persistent high-grade Fever > 2 week with unidentified cause, pancytopenia, Raised Triglycerides and S. ferritin. Hepatomegaly with mildly raised transaminase and hypoalbuminemia. Response in clinical condition with IV dexamethasone.

Dilemma remains as the essential 5 /8 diagnostic criteria were not fulfilled. Trigger for HLH was not identified. Post GCSF WBC count had improved. Fever resolved after only two doses of dexamethasone. There was no splenomegaly. Ferritin level though in diagnostic range was only marginally raised. Bone marrow showed occasional Haemophagocytes. No specific treatment was given for viral cause if any.

Description

Hemophagocytic Lymphohistiocytosis (HLH) is an under-recognized hyper inflammatory disorder, which mimics sepsis. It is a potentially life threatening but treatable condition if recognized early. Patients usually present with high fever, cytopenia, hyperferritinemia, and hepatosplenomegaly. Disease process ranges from mild to fatal multiorgan failure. Hemophagocytosis in a tissue specimen is a characteristic feature of HLH however, might not be identified in the initial stages of disease. HLH can be triggered by underlying infections (especially viral), hematologic malignancies or autoimmune triggers. In some cases, an underlying trigger will not be identifiable.

Conclusion

Diagnosing HLH accurately is challenging and difficult in critically ill patients because most of the clinical and laboratory features are nonspecific. Delay in diagnosis leads to significantly worsened outcomes. Is this HLH? The diagnostic criteria should be evaluated and reevaluated in the suspected case. HLH is a progressive disorder, and if the diagnostic criteria cannot be reached today, then they may be reached tomorrow. Waiting for all criteria to be met may result in a grave outcome. One of the duties of the practicing pediatric hematologist/ oncologist is to raise the profile of this diagnosis to consider it in a timely manner. High index of suspicion and early initiation of treatment after appropriate investigations is required. When in doubt, diagnosis need to be revisited with clinical judgement whether or not to continue treatment for HLH.

Defying The Odds: A Story of Hope in The Battle with Ewing Sarcoma

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Cancer begins and ends with people. In the midst of scientific abstraction, it is sometimes possible to forget this one basic fact. . . . Doctors treat diseases, but they also treat people, and this precondition of their professional existence sometimes pulls them in two directions at once.

-June Goodfield

In May 2023, an 11-year-old female child was diagnosed with primary Ewing sarcoma of the proximal right tibia, which had already metastasized to the lungs. The child was treated with VAC based chemotherapy. In the initial treatment plan, the treating team opted not to administer lung radiation and instead provided definitive radiotherapy to the primary tumor as local therapy. The post-treatment PET scan was normal, and the child was closely monitored. However, in June 2024, she presented with symptoms of raised intracranial tension (ICT) and was subsequently diagnosed with metastasis to the brain, bone marrow, lungs, and bones.

When I first met the family, the most logical medical recommendation, given the early relapse and widespread metastasis, was to shift to a regimen that minimized hospital visits and focused on symptom control, possibly incorporating oral metronomic therapies. This approach is often advised in such multifocal, disseminated cases as it prioritizes quality of life and symptom management. However, the determination to treat was fueled by the child's unwavering resolve to face the challenging course ahead, which included frequent hospital visits for chemotherapy. This was what she wanted. I wondered: Should I believe in the slim chances of survival, or should I believe in this child's incredible strength and determination to overcome the arduous treatment?

The parents, devastated, yet determined, were not ready to give up. They understood that the chances of their child surviving with curative therapy were bleak, but that slim hope was enough to fuel their resolve. As an oncologist, I find myself constantly grappling with the balance between medical science and the profound human desire for miracles. The question often arises: in such cases, where the prognosis is so bleak, should we still offer definitive intravenous salvage chemotherapy regimens, even when the odds are staggeringly low?

In this case, we chose a course of irinotecan and temozolomide, although the standard approach would have been to minimize hospital visits. The medical literature is clear, yet sometimes in oncology, it is not just about the data; it is about the human element—the hope of a miracle.

Interestingly, the child responded well to the treatment, and all her bony lesions disappeared miraculously within a few weeks of treatment. Watching the progress unfold, no matter how incremental, was heartening. The small victories we saw were celebrated not just by the family but also by me. For now, the child is doing well, and that in itself feels like a gift.

Still, I find myself reflecting on the challenges in such cases. Was it right to take the path of aggressive treatment when everything was pointed in the other direction? Did I make this choice because I believed there was still something left to fight for? As doctors, these are the questions we continually face. The boundaries between science and hope blur, and we are left wondering if our decisions are guided more by data or by the sheer will to give our patients and their families a chance—however small.

`During my training period in pediatric hemato-oncology, attending counselling sessions for palliative treatment was challenging. Parents often struggle to comprehend or accept the goals of the therapy, making these sessions emotionally taxing.

Working in a daycare chemotherapy center that primarily serves adult oncology patients and attending numerous CME sessions on adult cancers have provided me with valuable insights. I observed that many adult patients receiving palliative care were able to fulfil significant lifetime goals during their treatment, such as celebrating the birth of a grandchild or their 50th wedding anniversary, thanks to ongoing sessions of monthly IV immunotherapy. This experience highlights a key difference for pediatric patients: their goals often have more immediate time constraints. While my young patients may not have the option of lifelong immunotherapy, the goal remains to enhance their quality of life and provide the joy of living as pain-free as possible for as long as they can. Everyone deserves the opportunity to experience joy and meaningful moments regardless of their prognosis.

The path ahead for this child remains uncertain. The possibility of another relapse is high, and definitive treatment is challenging. However, for now, we have a moment of relief—a moment where hope and science converge, even if just for a while. The joy, the smile on the parents' faces, and the child's strength in this fight are treasures that I will never forget.

Scenario of Pediatric Oncology in Kashmir

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The pediatric oncology unit at Sher-i-Kashmir Institute of Medical Sciences (SKIMS), Soura, stands as a pioneering institution and the only dedicated pediatric oncology facility in a tertiary care hospital in Jammu and Kashmir. Established in the year 2008, the unit began with only a couple of beds, driven by a mission to provide specialized cancer care for children in the region. Despite facing numerous challenges, it has evolved into a fully functional 15-bed unit, delivering comprehensive, patient-centered care and serving as a symbol of resilience and dedication for families affected by pediatric cancer across the state. This unit treats a wide array of childhood cancers, with a focus on both common and rare forms.

The diseases treated include leukemia (such as Acute Lymphoblastic Leukemia (ALL), Acute Myeloid Leukemia (AML), Chronic Lymphocytic Leukemia (CLL), and Chronic Myeloid Leukemia (CML)), lymphoma (including Non-Hodgkin's Lymphoma (NHL) and Hodgkin's Disease (HD)), and solid tumors such as Neuroblastoma, Ewing's Sarcoma, Retinoblastoma, Wilm's Tumor, and Round Cell Tumor, among many others. By encompassing a broad spectrum of cancers, the unit ensures that children across the valley receive access to advanced, targeted treatments within their own community.

The journey of establishing this unit and making basic to advanced necessities accessible to patients and their caregivers were inspired by a deep recognition of the barriers faced by the economically weaker sections of society. Many families, despite their determination to pursue treatment, were hindered by financial and logistical constraints. This often led to high rates of treatment abandonment, which posed a serious threat to successful outcomes. To counteract this, the unit focused on building a support system that would reduce these barriers. Today, the availability of essential resources and financial support has significantly decreased treatment abandonment rates, allowing children from all backgrounds to complete their full course of therapy.

The unit's dedicated team of oncologists is deeply committed not only to treating the diseases but to caring for the patients in a comprehensive way that recognizes their individual struggles. The medical team extends beyond physicians to include a diverse care unit composed of dietitians, psychologists, and social workers. Dietitians work closely with each patient to address nutritional needs, while psychologists provide essential mental and emotional support. Social workers assist families with logistical and financial concerns, ensuring they have the guidance necessary to navigate the complexities of the healthcare system. These efforts aim to care for the whole child—physically, emotionally, and socially—creating a supportive environment for both the patients and their caregivers. Further enhancing the supportive atmosphere, the unit maintains collaborations with various NGOs, whose contributions are crucial to its day-to-day operations. These partnerships provide financial aid, medicine procurement through affiliated pharmacies, nutritional supplements, academic financial aid, and other essential services. Additionally, the unit has established a toy library for young patients, creating a child-friendly space that helps ease the emotional burden of treatment. This initiative, coupled with efforts to keep the ward's ambiance warm and welcoming, creates a supportive and less intimidating environment for the children One of the initiatives is also the provision of rations through partnerships with NGOs, which has been instrumental in supporting caregivers. With children undergoing cancer treatment facing elevated nutritional needs, this provision of food ensures that they receive adequate nutrition in both quality and quantity.

Such support helps caregivers fulfill the dietary requirements that play a critical role in the recovery and strength-building process, allowing families to focus on the treatment journey without the added stress of food insecurity.

The unit's Corporate Social Responsibility (CSR) engagements have also played an integral role in expanding its capabilities. Esteemed organizations like Jammu and Kashmir Bank have offered significant financial contributions, such as funding for PRP (platelet-rich plasma) kits, which are crucial but often costly for families. These CSR collaborations ensure that even advanced medical necessities remain within reach, irrespective of a family's financial limitations in building a strong sense of community, the unit regularly organizes events that invite current patients, survivors, and their caregivers to share their stories. These heartfelt narratives of resilience, struggle, and triumph provide inspiration and a sense of solidarity to families currently navigating treatment. For new patients and caregivers, hearing the journeys of those who have endured similar challenges fosters a powerful connection, instilling hope and reinforcing the notion that they are not alone in their fight. The unit also celebrates various festivals and special occasions, organizing activities, decorations, and gift distributions to bring moments of joy and normalcy to the children. This attention to festive observances helps children experience the joy of celebration despite their circumstances, creating a sense of belonging and reducing the emotional impact of prolonged hospital stays.

In conclusion, the pediatric oncology unit at SKIMS, Soura, is not merely a medical facility but a holistic support system that addresses the full spectrum of patient needs—medical, nutritional, emotional, and financial. This commitment to the well-being of each child and their family has solidified the unit's role as an irreplaceable part of Kashmir's healthcare landscape. Through its compassionate approach and collaborative efforts, the unit provides a crucial lifeline for pediatric oncology patients and stands as a testament to how healthcare can be transformed through empathy, innovation, and community support.

Spectra of Pediatric Palliative Care: Still Seeking Existence

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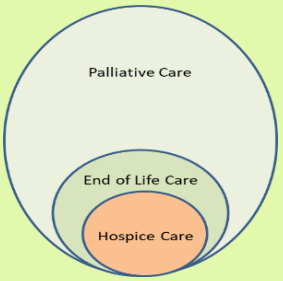
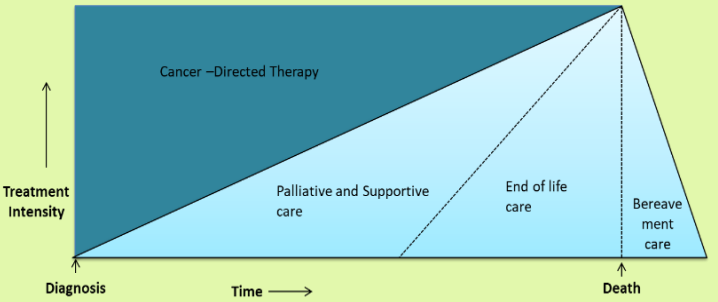
The field of Pediatric oncology is one of the biggest success stories in history of medicine, where cancers which were deemed incurable have achieved high cure rates, especially when diagnosed early.
LMIC's still struggle for cure rates similar to western world, owing to diversity and extreme variation in patients population (Education, awareness, financial status) and resources at treating centre – Availability of a dedicated Pediatric oncologist or a team, infrastructure, supportive care, multimodal therapies, availability of advanced/novel therapies, doctor: patient ratio and last but not the least –abandonment during therapy.
This scenario precludes the importance of palliative care, which is thought synonymous with end-of-life care
In a country where the Pediatric oncologist fights for basic needs to treat a child, where awareness to childhood cancer even amongst pediatricians remains blur, and infrastructure is still shaky at most places, palliative care struggles to make its place.

What is palliation?

Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. ***Eric Cassel, M***

The term "palliative care" is often incorrectly used as a synonym for end-of-life care, or "hospice care". However, palliative care does not require a terminal diagnosis or proximity to death.PPC relies on the comprehensive and multidisciplinary management of the child and the family's physical, psychological, spiritual, and social needs. Importantly, PPC begins at the diagnosis of incurability, or supposed incurability, and continues regardless of whether the patient receives any oncological treatment. As such, PPC is a general approach continuing over the entire disease trajectory, which includes, but is not limited to, end-of-life care.





Scope of palliative care :

As Olmsted commented in 1970: "Death for children no longer comes quickly and mercifully."

Pediatric palliation care (PPC) was introduced globally in late 1960's, much later to heroic developments in Pediatric oncology per se. The decade of the 1970s became known as the "pivot of change". It was in this decade that the children's hospice movement began to develop as an entity separate from the general hospice movement and a great deal of the early development was in the United States.
Remarkably, however, PPC has not been seen as a priority around the world. A 2011 study found no PPC services in 65.6% of countries. Where services do exist in LMICs, they typically are available in only one or a few institutions and are not integrated into health care systems.

Globally, cancer constitutes only 5.2% of the palliative care needs in children. 90% of children with cancer live in LMIC, (84% global burden of childhood cancers and palliative care in pediatric oncology remains relevant in LMIC due to low cure rates and high death rates
First guidelines on integrated palliative care in pediatric oncology were published in 2013 and mandated creating a specialist interdisciplinary team that can provide collaborative multi-modal care across all settings. The purpose was to provide support to children and their families whilst ensuring the child's quality of life and safety. It advocated for child and family participation during communication and decision making

Can we decide who needs it: Risk stratifies need for PPC at the start?

Despite excellent cure rates of childhood cancer, there will be some, who ll have a very high symptom burden or shall have a guarded prognosis right from the start and also, even if none of former exist, there may be excessive disease burden or psycho social factors which may complicate the course of disease. (Table 1)

Who needs Palliative Care?
Patients with Hematologic malignancies: ✓ With high symptom burden or refractory symptoms ✓ Hospitalized for allogeneic stem cell transplantation ✓ With significant psychological distress ✓ With difficulty coping with their illness ✓ With complex family and social needs ✓ With significant and/or persistent misperceptions about illness trajectory and overall prognosis ✓ Who may have a poor prognosis and limited life expectancy (i.e., you would not be surprised if they die within 1 year

Challenges unique to PPC: Do they exist, or are just in our minds?

- ✓ Available resources designed for the care of adults with life-threatening illness do not fit the needs of dying children.
- ✓ Insurance / finances for palliative care do not exist
- ✓ Who will do the palliative care: Logistic issues (Admitted under pain specialist / oncologist / ICU specialist).
- ✓ Also, despite recent increases in interest in adult palliative care and hospice philosophy, a parallel increase in pediatrics has not occurred—80 percent of children dying with cancer in this country are still suffering, and their symptoms are not being adequately palliated
- ✓ Extrapolation of adult-derived pharmacokinetic and pharmacodynamics data is often inappropriate and sometimes dangerous for children.
- ✓ Referral to an end-of-life program may be seen as abandoning hope, which may interfere with good communication and clinical care
- ✓ Finally, the death of a child -most significant psychological stressors a person may ever face- Acceptance / denial

Who will do palliative care?

Teams may vary by hospital, but common palliative care team members include physicians, nurse practitioners, nurses, social workers, Dentist, Pain team, ICU intensivist, chaplains, and child life specialists. Each of these team members has special training and a common focus of addressing suffering and coping

The perspective then and now (From 1977 to 2024): Where do we stand?

In 1977, the Pediatricians' Manual included one of the first sections on this topic, a letter written by a dying child am a 13-year-old boy. I am dying. I write this to you who are and will become nurses and doctors in the hope that, by sharing my feelings with you, you may someday be better able to help those who share my experience. But no one likes to talk about such things . . . The dying person is not yet seen as a person and thus cannot be communicated with as such. He is a symbol of what every human fears and what we each know. . He ends his letter with a plea: "Don't run away. Wait. All I want to know is that there will be someone to hold my hand when I need it. I'm afraid."

Way forward: Changing the perspective

Short term Goals:

· Assessment of current status of PPC in India (available facilities, man power, challenges and solutions) [Through questionnaire/surveys among PHO fraternity]

· Sensitization of pediatric Oncologists/ centers about PPC: Dedicated session in annual and midterm conference, part of NTP-PPO workshop.

· Sensitization of State/ central Government: Creation of national guidelines, PHO chapter statement and recommendation to concerned authorities

· creating a training module of specialized pediatric palliative and hospice care programme for all PHO trainees.

Long term goals:

· Annual dedicated conference on PPC involving all stakeholders

· Multicentric Research projects to address various aspects of PPC in India

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AWARDS AND ACCOLADES

Senior Pediatric Oncologist Dr Appaji L from Kidwai Memorial Institute of Oncology being felicitated with Life Time Achievement award at the ISMPO Conference. held at INDIA Habitat Centre, New Delhi.

Dr Anupam Sachdeva felicitated with Life Time Achievement Award in ISMPOCON 2024.

Dr Dipti Jain
conferred HAM WASSERMAN LECTURE in ASH 2024
in San Diego on December 7 at ASH International congress.
She received this prestigious award in
recognition of her work in the field of Sickles cell disease.

PHO Journal has reached Hawaii USA!!!
Current and future editor-in-chief
(**Dr Deepak Bansal and Dr Vikramjit Kanwar**)
of PHOJ at the journal's stall at SIOP, Honolulu.

Dr. Ramya with In PHOG study 'Lendex' poster won the 1st prize 'Robert Arceci award' at the 40th Annual Meeting of the Histiocyte Society held in Goa from6-9th Nov 2024.

"Bara Mahine, Bara Poster"

In honor of Childhood Cancer Awareness Month in September, the Pediatric Hematology Oncology Chapter of the Indian Academy of Pediatrics, in collaboration with the Central Body of the Indian Academy of Pediatrics, has launched an important new initiative titled "Bara Mahine, Bara Poster" (12 Months, 12 Poster). This initiative aims to address various issues related to childhood cancer and enhance awareness among pediatricians and healthcare professionals across the country

“Bara Mahine Bara Poster “
Second Poster

Childhood Cancer Awareness Campaign
“12 Mahine:12 Poster”

Pediatric Hematology and Oncology Chapter

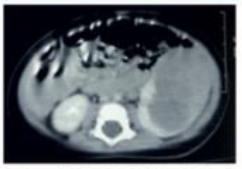
Mother Feels the Unknown: Discovering Unseen Tumor in Child’s Tummy

Abdominal Tumors constitute about **20%** of all Childhood Cancers

Differential diagnosis depending on age of presentation

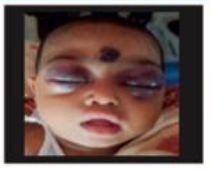
Newborn	Infants & Toddlers	Young children (<10 y)	Older Children & Teenagers
Hemangioma	Neuroblastoma	Neuroblastoma	Germ Cell Tumors
Adrenal Hemorrhage	Wilms Tumour	Wilms Tumour	Hematolymphoid
Neuroblastoma	Rhabdoid Tumor	Hepatoblastoma	Hepatocellular Carcinomas
Teratomas	Hepatoblastoma	Rhabdomyosarcoma	Renal Cell Carcinoma
Mesoblastic Nephroma	Hemangio-endothelioma	Hematolymphoid	Adreno-cortical Carcinomas

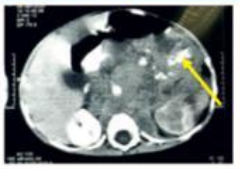
Wilms Tumor: Most Common Kidney Tumor



- Asymptomatic, incidentally detected flank mass
- Never miss to palpate abdomen in infants and toddlers during regular visits

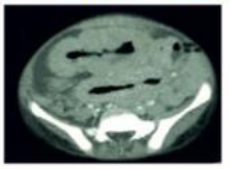
Neuroblastoma: A “whimsical” enemy





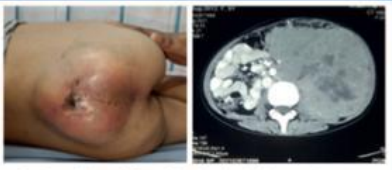
- Myriad presentations: abdominal mass, raccoon’s eye, bone pain or swelling, opsoclonus-myoclonus (dancing eye, dancing feet)
- CT abdomen: Intra tumoral calcifications, and vessel encasement

Burkitt lymphoma: A terror in the tummy



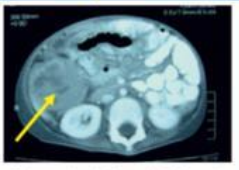
- A rapidly growing tumor, generally in older kids/teenagers
- Oncological emergency: High propensity for catastrophic tumor lysis syndrome & intestinal obstruction

Germ Cell Tumor: A midline monster



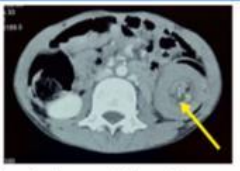
- Dealing with a midline abdominal/ pelvic/ sacral area tumor ovarian mass in teenagers - Don’t forget GCT
- Perform serum α-fetoprotein(AFP), β-HCG

Ileocecal mass: Not always tuberculosis!



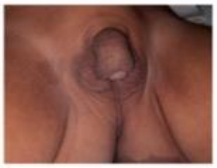
- We may be dealing with high grade Lymphoma

Intussusception: Premonition of NHL

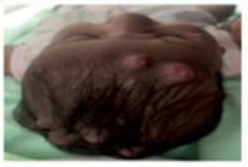


- Resected segment of the gut in a case of intussusception must be subjected to histopathological examination.

Tumor in tummy- Examine head to toe



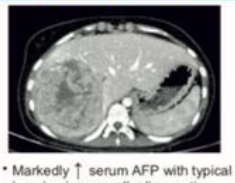
- Genital ambiguity and aniridia: Syndromic Wilms tumor



- Multiple skin nodules: stage MS neuroblastoma

- Left-sided varicocele: Wilms tumor with renal vein thrombus

Hepatoblastoma: Massive liver mass



- Markedly ↑ serum AFP with typical imaging is generally diagnostic

Initial investigations for a child with tummy mass: An outline

Investigation	Purpose / Rationale
Ultrasonography of abdomen (±Doppler study)	Assess the organ of origin, vascularity, tumor thrombus
Computed Tomography of abdomen	Precise 3D assessment of the extent of tumor, relationship with the great vessels, intratumoral bleed or calcification
Computed Tomography of chest	Screening for lung metastasis
Spot urine VMA	Aid in diagnosing neuroblastoma in appropriate clinical setting
Serum biochemistry: serum electrolytes, uric acid, renal function	Screening for tumor lysis syndrome, especially if Burkitt lymphoma is in consideration
Serum α-fetoprotein & β-HCG	Diagnostic tumor markers for malignant GCT, hepatoblastoma

Treatment of abdominal malignancies : In a nutshell

- Neoadjuvant chemotherapy followed by surgery is often a standard approach for many types of abdominal tumors, including Wilms tumor, neuroblastoma, malignant germ cell tumors and hepatoblastoma.
- In cases of high-risk disease, in terms of advanced stage or aggressive histology, some patients may require additional treatments such as radiotherapy, autologous stem cell transplant and immunotherapy in Neuroblastoma, liver transplantation in Hepatoblastoma
- High-grade lymphomas often respond well to chemotherapy, and chemotherapy is a primary treatment modality

Key messages
- Most abdominal malignancies in children are highly curable
- Early diagnosis and timely referral to a Pediatric Oncology centre is critical


Dr G V Basavaraja
National President 2024
IAP


Dr Vasant Khalatkar
President Elect 2025
IAP


Dr Upendra Kinjawadekar
IAM Past President 2024
IAP


Dr Yogesh Parikh
Secretary General 2024 & 25
IAP


Dr Atanu Bhadra
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Childhood Cancer Awareness Celebration: Month of September 2024

Lokmanya Tilak Municipal Medical College, Sion, Mumbai

B J Wadia Hospital, Mumbai

PGICH, Noida

HCG Hospital, Bangalore

Childhood Cancer Awareness Celebration: Month of September 2024

Celebration of Childhood cancer awareness month with a Flash Mob.
Dr Sunil Bhat
Narayana Health City, Bangalore

On the occasion of Childhood Cancer Awareness month team of Meenakshi Madurai Hospital (Dr Kasi, Dr Annapoorani, Dr Anitha and Dr Venkateswaran V S)

Childhood Cancer awareness month, Narayana hospital, Gurugram under aegis of IAP-PHO chapter organized NTP-PPO workshop on 15th September, 2024. Dr Purna Kurkure, Dr Mukesh Dhankar and Dr Manas Kalra were faculties

Childhood cancer awareness month celebration at AIIMS Bhubaneshwar. Dr Sonali Mahapatra coordinated event.

NTPPPH Workshops

Dr B R R Ambedkar state institute of Medical Sciences, Mohali. Dr Amita Trehan and Dr Shruti Kakkar were faculty

At Solapur under guidance of Dr Sujata Sharma and Dr Shweta Bansal. It was organized by

At Ahmedabad, 21st July by Dr Vaibhav shah. With more than 80 registrations and 17 faculties.

At Rewa, MP,
Dr Narendra Chaudhary was faculty.

Zulekha Yenepoya Institute of Oncology, Yenepoya Mangalore on 10/08/2024.The faculty included Dr Shweta Bansal, Dr Vasudev Bhat, Dr Vandana Bharadwaj. Dr Appaji L from Kidwai Memorial Institute of Oncology also blessed the event

NTPPPO Workshops

The Pediatric Oncology unit at Dr.RMLIMS Lucknow conducted the NTPPPO . Dr Manas Kalra, Dr Vinita Gupta, Dr. Anuj,Dr. Neeta,Dr Prakruthi and Dr Abhishek Jha were the faculty.

Childhood Cancer Awareness month by conducting NTP-PPO at Max Vaishali on 1st Sep 2024 by Dr Prachi Jain and team. Total attendance crossing 100.

=

GMC Gondia, Maharashtra by Dr Leena and Dr Sunil Deshmukh. Dr Pankaj Dwivedi, Dr Atish Bakane, Dr Ruchi Aujla and Dr Sunil Jondhale were faculties

At Bharati Vidyapeeth Hospital, Pune on Oct 13th, Sunday Dr Vibha Bafna. We had a vibrant and enthusiastic faculty Dr Sangeeta Mudaliar Dr Purvja Kubde etc and 53 delegates.

Past Pulse: Recaps of Recent Events

SMPOCON - Indian Society of Medical and Pediatric Oncology Conference 2024 took place in New Delhi over the weekend. Sir Ganga Ram Hospital served as the official host for this event Pediatric Oncology was prominently featured at the conference

1st MP state CME on Pediatric Bone Marrow transplant was conducted today at NSCB medical college, Jabalpur. Faculties-Dr. Shweta, Dr. Vidya K.S, Dr. Akshay Kamble, Dr. Rajesh Mahobia, Dr. Rajesh Jain

Interesting PHO panel in alien territory of fertility preservation specialists on Barriers to Onco-fertility programs for CAYA cancers at Hyderabad. Sept 2024

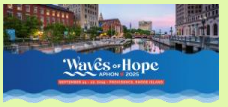
Indian delegation at International histiocyte society conference in Goa 5-9th Nov 2024.

Fantastic Midterm PHOCON at NCI Nagpur 12-14 July 2024. Dr Pankaj and team took it to next level.

Upcoming Academic Extravaganza

International

1. ASPHO 2025, May 7-10, 2025
   Kentucky International Convention Center
   Louisville, KY
   Abstract Submission Date: April 22 - July 25, 2024



2. Association of Pediatric Hematology/Oncology Nurses (APHON) Conference
   25-27 Sept, 2025, Rhodes Island

3. 2nd Edition of International Summit on Hematology and Blood Disorders, June 05-07, 2025
   Venue Address: NH Villa Carpegna, Roma RM, Italy

4. SIOP 2025, Amsterdam, Netherlands, October 20 - 23, 2025

National: India

1. International Symposium on Neonatal & Pediatric Transfusion Organized in association with the International Society of Blood Transfusion (ISBT)
   Registration link: https://forms.gle/Q3xhAjoegexGZLcY9
   Dates: 20th and 21st December 2024,
   Venue Address: 5th Floor Main Auditorium, PGICH, Noida

2. Pediatric Cancer Registry and Data Meeting, Cancer Institute (WIA) Adyar, Chennai 31st Jan and 1st Feb, 2025.

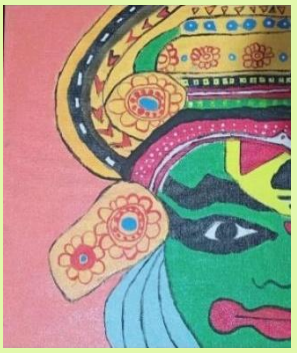
3. 6th Annual Congress of I-OSCICON (Immune Oncology Society of India) 2025, Bhubaneshwar, 31st Jan,1st& 2nd Feb, 2025.

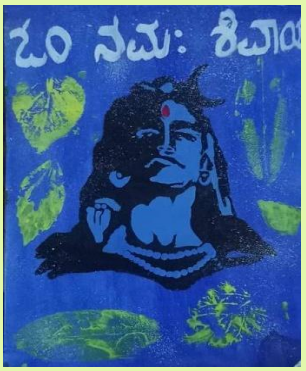
4. Molecular Basis and Mechanisms of Therapy Personalization in Pediatric Leukemia, February 5-8, 2025. Kolkata.

5. 10th Midterm PHOCON, PGICH, July 2025, Noida, Utter Pradesh

6. 28th annual PHOCON 2025, November 2025, KMC Manipal, Karnataka

THOU ART SHALL LIVE:
Paintings by The Fighters Of PHO





Cancer Chemotherapy in Children: Practice Points!!

1. Dr Swathi Krishna, Consultant Pediatrics Hemat-Oncology Mumbai Oncocare Cancer care and research centre Ghatkopar, Mumbai
2. Dr. Prasanthi Guna M.D(Pediatrics), Fellowship IAP PHO-BMT, Fellow Resident - Pediatric Hemato-Oncology / BMTU
3. Dr. Shobha B, Consultant - Dept of Pediatric-Heamto-Oncology / BMT, Mazumdar Shaw Cancer Center, Narayana Health City, Bengaluru.

Cancer chemotherapy is a modality of cancer therapy that involves the administration of chemical agents to destroy the cancer cells. The development of chemotherapy in the 1950s and 1960s resulted in curative therapeutic strategies for patients with hematologic malignancies and a small number of advanced solid tumors. Chemotherapy plays a vital role in the treatment of pediatric cancers, with the aim of eradicating malignant cells while minimizing harm to developing tissues. It is essential in both curative and palliative settings, with the goal of achieving long-term remission or managing symptoms to improve quality of life. Pediatric chemotherapy poses unique challenges owing to the need for age-specific dosing and careful management of long-term effects, such as organ damage, growth impairment, and secondary malignancies.

Tumor cells have poor DNA repair mechanisms. Normal cells can repair or replace themselves more efficiently. Intermittent chemotherapy damages both normal replicating cells and tumor cells but the tumor cells do not recover as quickly. DNA damage may prevent production of daughter cells or cause cell death – eg: through induction of apoptosis

Principles of Cancer Chemotherapy

1.1 Combination vs. Single-Agent Therapy

a) Enhanced Response Rates: Synergistic Combinations and Rational Sequencing

The selection of drug combinations is based on the principle of synergy, in which the combined effect of the drugs is greater than the sum of their individual effects. Cell Cycle-Specific (CCS) drugs are often administered after Cell Cycle Non-Specific (CCNS) drugs in treatment regimens. This sequence maximizes cell death by targeting the cancer cells at various stages of the cell cycle.

b) Dose Intensity Maintenance

Maintaining the dose intensity is critical for maximizing the tumor response while minimizing the risk of resistance. Drugs are typically administered at their maximum tolerated doses (MTD) to enhance their efficacy, particularly in intensive regimens. This approach is especially beneficial when treatment is initiated early in the disease process.

1.2 Tumor Growth Dynamics

a) First-Order Growth

Initially, tumor growth often follows first-order kinetics, indicating that it is exponential in early stages. Understanding this growth pattern informs the timing and intensity of treatment.

b) Slower Later Growth

As tumors progress, their growth may slow, necessitating different treatment strategies, such as prolonged maintenance therapy or the use of alternative agents to target slow-growing cells.

1,.3. Treatment Timing and Scheduling:

a) Optimal Dosing Schedule

Drugs should be administered at optimal doses and consistent intervals to maintain therapeutic levels and maximize efficacy.

b) Short Treatment-Free Intervals

The time between cycles should be minimized to allow recovery of the most sensitive normal tissues, while ensuring that treatment is administered as early as possible

1.4 Importance of Early Intervention

Addressing micro-metastatic disease is crucial, as undetected cancer cells can lead to recurrence. Early treatment increases the likelihood of eradicating all malignant cells

1.5 Requirement for Cell Proliferation

1.6 Cancer Cell Dynamics

Understanding the dynamics of cancer cells and the limitations of chemotherapy are essential for the development of effective treatment strategies. Chemotherapy resistance, both primary and secondary, can arise from various factors, including tumor heterogeneity, adaptive responses to therapy, and changes in the tumor

microenvironment. These factors necessitate the exploration of novel therapeutic approaches such as targeted therapy and immunotherapy. The effectiveness of classical chemotherapy relies on cell proliferation. Indolent tumors, which grow slowly and have low proliferation rates, are often resistant to standard chemotherapeutic agents.

Modes of chemotherapy:

- **Primary chemotherapy**: It is used as the sole anti-cancer treatment in a highly sensitive tumor type Example – CHOP for Non-Hodgkins lymphoma, BFM-Leukemia
- **Adjuvant chemotherapy**: Given after surgery to "mop up" microscopic residual disease Example – Cisplatin, Etoposide and Bleomycin (PEB) for germ cell tumor
- **Neoadjuvant chemotherapy**: Treatment is given before surgery to shrink tumor and increase chance of successful resection. Example – Adriamycin, cisplatin for osteosarcoma
- **Concurrent chemotherapy**: Treatment is given simultaneous to radiation to increase sensitivity of cancer cells to radiation. Example – Vincristine and carboplatin for Medulloblastoma

2) Important practices in Pediatric oncology:

Chemotherapy Administration Safety and Precaution Guidelines in Pediatric Oncology (Table 2.1)

Category	Precaution	Description/Notes
Patient-Specific Dosing	Weight and Body Surface Area (BSA) Calculations	Ensure accurate height and weight for correct dosing (mg/m² or mg/kg). ✓ **For infants**, use the **Rule of 30** to estimate surface area (30 g = 0.1 m² of BSA). ✓ **Thumb Rule:** Below 6months-2/3rd dosing 6-12months-3/4th dosing >12months-Full dose ✓ **For amputees**, adjust BSA using the **Rule of Nines** to account for the reduced surface area. ✓ **For obese children** (BMI > 95th percentile), **adjust chemotherapy doses** using an ideal body weight formula or capped BSA dosing, as overestimation could lead to toxicity.
	Renal and Hepatic Function	Adjust dosing for impaired kidney or liver function as needed. Ex: **Vincristine & Vinblastine** - T. Bil 1.5-3.0 mg/dL or AST 60-180 IU/L: 50% of full dose - T. Bil > 3.1 mg/dL or AST > 180 IU/L: Omit dose Similar dose adjustments for Alkylating agents Platins and Anthracyclines as well.
Drug Verification	Double-Check Chemotherapy Agents	Verify that the prescribed drug matches the treatment protocol (trade names, generic names, dose forms).
	Cross-reference Protocols	Ensure prescription aligns with established pediatric oncology protocols (e.g., COG, SIOP).
	Specific Drug Precautions	Separate hazardous drugs like Vincristine from intrathecal medications to prevent fatal administration errors.
Cold Chain Management	Storage of Cold Chain Drugs	Maintain storage of chemotherapy drugs like Vincristine, L-Asparaginase, Bleomycin, Dacarbazine at 2-8°C until administration.
Drug Interactions	Check for Interactions	Review interactions with other medications the patient is taking, including antibiotics, anticonvulsants, etc.
	Nutritional and Supplement Caution	Warn parents about potential interactions between chemotherapy and over-the-counter supplements or alternative medicines.
Safety Mechanisms	Segregation of Chemotherapy and Intrathecal Medications	Ensure strict segregation of chemotherapy and intrathecal drugs to avoid wrong-route errors.
	Prescription Order Verification	Verify the prescription by another healthcare provider before chemotherapy is administered.
	Checklist for Administration	Cross-check patient ID, drugs, doses, and routes of administration before each chemotherapy session.
Monitoring	Baseline Investigations	Check recent blood work, liver, and renal function tests before prescribing chemotherapy.
	Infection Control	Ensure neutropenic patients are on appropriate prophylaxis (antibiotics, antifungals). Delay treatment if active infection.

Parent/Guardian Counseling	Explain Side Effects	Educate parents about immediate (nausea, allergic reactions) and delayed side effects (myelosuppression, mucositis).
	Drug Handling at Home	Provide instructions on safe handling and storage of chemotherapy at home (e.g., gloves for oral chemotherapy).
Documentation and Record-Keeping	Keep Detailed Records	Maintain thorough documentation of treatment rationale, dose calculations, and modifications.

Table 3:1 Laboratory checklist for chemotherapy drugs:

Drug	Laboratory check list	Precautions
Vincristine, Vinblastine, Vinorelbine	Blood counts	Monitor for peripheral neuropathy, constipation, and ensure no severe infections.
Daunorubicin, Doxorubicin	Blood counts, Screening ECHO	Check for cardiac function (baseline ECHO), monitor for neutropenia and mucositis
Cyclophosphamide Ifosphamide	Blood counts, Screening ECHO	Check for cardiac function (baseline ECHO), monitor for neutropenia and mucositis
Methotrexate	Blood counts, Renal function tests	Ensure hydration, monitor for hemorrhagic cystitis, renal toxicity, and signs of myelosuppression
Cisplatin Carboplatin	Blood counts, Renal function tests, Audiometry	Monitor for nephrotoxicity, ototoxicity, electrolyte imbalances (especially magnesium and potassium), and peripheral neuropathy
Bleomycin	Blood counts, Pulmonary function tests	Monitor for lung toxicity (baseline pulmonary function tests and chest X-ray)
Asparaginase (L-asparaginase, PEG-asparaginase)	Blood counts, Coagulation profile (PT, INR, Fibrinogen), Liver function	Monitor for coagulation disorders, pancreatitis, hyperglycaemia, and liver function abnormalities.

Toxicity prevention:

- ✓ Prophylactic anti-emetics
- ✓ Vascular access devices minimize extravasations.
- ✓ Adequate pre/post hydration,

- Growth factor support, prophylactic antibiotics, oral care, cytoprotectants / rescue agents.
  INJ G-CSF: Filgrastim 5 mcg/kg/day SC until neutrophil recovery. A reasonable starting point for GCSF is to start not less than 24 hours and not more than 72 hours after cytotoxic treatment is completed. Should be avoided in leukemia

Conclusion: In summary, the integration of combination therapies, timely interventions, meticulous dosing, proper precautions, effective management of side effects, and stringent protocols for drug handling creates a comprehensive approach to pediatric chemotherapy. This holistic strategy aims to enhance treatment efficacy and ultimately improve long-term outcomes and survival rates in patients

Reference:

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3.Hendrayana, T., Wilmer, A., Kurth, V., Schmidt-Wolf, I. G. H., &Jaehde, U. (2020). Anticancer dose adjustment for patients with renal and hepatic dysfunction: from scientific evidence to clinical application. Cancers, 12(10), Article 2913. https://doi.org/10.3390/cancers12102913

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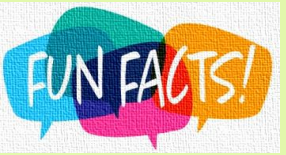

- **Blood donation:**
  Anyone in good health, at least 17 years old, and at least 110 pounds can donate whole blood every 56 days
- **Blood production:**
  The human body produces about 2 million red blood cells per second. In times of stress, the body can produce up to 7 times that amount
- **Blood vessels:**
  The human body has over 100,000 miles of blood vessels.
- **Mosquito and blood**:
  Mosquito's saliva is a powerful stuff. It makes blood vessels dilate, blocks the immune response, and lubricates the insect's proboscis.
  It would take about 1,200,000 mosquitoes, each sucking once, to drain a human of blood.
- **'Blood' word :**
  The word bloodbath is a compound of the words "blood" and "bath". The earliest known use of the word was in the 1810s, and the earliest evidence of it in print is from 1814 in a translation by R. Jamieson
  The word Blood appears at least once in Shakespeare plays
- **Rich blood:**
  You may also be surprised to know that blood contains small amounts of gold. The average human body contains about 0.2 milligrams of gold, which is mostly found in the blood. This trace amount of gold could be formed into a solid cube of purified gold that measures 0.22 millimeters
- **Longevity and Memory**
  While white blood cells have varying lifespans, some can survive for years. Memory B and T cells, generated during an initial immune response, provide long-term immunity. These cells "remember" specific pathogens they encounter, allowing for a quicker and more robust response upon re-exposure. This memory function is the foundation of vaccines, which exploit the immune system's ability to recall and mount an effective defe
- **O**
  Only 7% of the population has type O negative blood, while 38% has O positive blood
  Mosquitoes are more attracted to people with type O blood than other blood types
- **Little to more:**
  A newborn baby has only one cup of blood in the whole body, whereas, the healthy adult has about 1.3 to 1.6 gallons or 4.0 to 5.0 litres of blood circulating inside their body
- **Polysemous:**
  The word "immunity" has multiple meanings and can be used in a variety of contexts, including medicine, law, and other situations
  Plasma: Fluid part of blood, lymph, or milk, Charged particles, a display -such as a television screen, green quartz, protoplasm, whey
- **Blood recipe**: (used in movies)
  1 cup (237 ml) corn syrup (clear or dark), 2 tablespoons (30 ml) water, 2 tablespoons (30 ml) of red food coloring, 1 tablespoon (15 ml) chocolate syrup, 2 tablespoons cornstarch.
- **Blood Protect Against CO Poisoning:**
  CO binds to proteins in the body known as hemoproteins. Hemoglobin found in blood and cytochromes found in mitochondria are examples of hemoproteins. When CO binds to hemoglobin in red blood cells, it prevents oxygen from binding to the protein molecule leading to disruptions in vital cell processes such as cellular respiration. At low CO concentrations, hemoproteins change their structure preventing CO from successfully binding to them. Without this structural change, CO would bind to the hemoprotein up to a million times more tightly.

Dr Shobha Badiger: Senior Consultant,
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Mazumdar Shaw Medical Centre,
NH Health City Bangalore,
shobhapeds@gmail.com

Pediatric Hematology Oncology Training Courses Offered in India

Pediatric hematology oncology courses are quite popular amongst pediatrics trainee. In India training in this sub superspeciality is offered eighter as DM or fellowships. Following are Institutes or Hospitals who offer these courses:

1. DM Pediatrics Oncology:

Sr.No	Institute/Hospital Name	City	State	No of Seats	Head/Incharge
1	AIIMS New Delhi	New Delhi	Delhi NCR	2	Dr Rachana S
2	Tata Memorial Centre, Mumbai	Parel, Mumbai	Maharashtra	3	Dr Girish C
3	RCC Govt Medical College	Aurangabad	Maharashtra	4	Dr Arvind G
4	Kidwai Memorial Institute of Oncology	Bengaluru	Karnataka	2	Dr Arun Kumar
5	Regional Cancer Centre	Thiruvananthapuram	Kerala	2	Dr Priya Kumari
6	Sri Ramachandra Medical College & Research Institute	Chennai	Tamil Nadu	1	Dr Juliot S

2. DM Pediatrics Hemat-Oncology

Sr No	Institute/Hospital Name	City	State	No of Seats	Head/Incharge
1	AIIMS Bhopal	Bhopal	Madhya Pradesh	1	Dr Narendra C
2	AIIMS Bhubaneshwar	Bhubaneshwar	Odisha	1	Dr Sonali M
3	PGIMER	Chandigarh	Chandigarh UT	5	Dr Amita Trehan

3. ICP/IAP - Pediatrics Hemat-Oncology fellowship: (IAP changing to ICP next year)

SrNo	Institute/Hospital Name	City	State	No of Seats	Head/Incharge
1	Bharati Vidyapeeth Hospital	Pune	Maharashtra	1	Dr Vibha B
2	KMC Hospital	Manglore	Karnataka	1	Dr Harsha P L
3	Dinanath Mangeshkar Hospital,	Pune	Maharashtra	1	Dr Shailesh K
4	MCGM-CTC PHO& BMT Center,	Borivali Mumbai	Maharashtra	3	Dr Mamta M
5	RCC NH Children's Hospital	Haji Ali, Mumbai	Maharashtra	1	Dr Purna K
6	Narayana Health City	Bengaluru	Karnataka	1	Dr Sunil B
7	Medanta The Medicity	Gurgaon	Haryana		Dr S P Yadav
8	Kanchi Kamakoti Children's Hospital	Chennai	Tamil Nadu	1	Dr Arathi S

4. HBNI Fellowship: Pediatrics Oncology (2 YR)

Sr No	Institute/Hospital Name	City	State	No of Seats	Head/Incharge
1	Tata Memorial Hospital	Mumbai	Maharashtra	Varies	Dr Girish C

5. Fellowship of National Board (FNB) Hemat-Oncology

Sr No	Institute/Hospital Name	City	State	No of Seats	Head/Incharge
1	BJ Wadia Hospital	Parel Mumbai	Maharashtra	3	Dr Sangeeta M
2	Rajiv Gandhi Cancer Institute and Research Centre	Rohini, Delhi	Delhi UT	3	Dr Gouri K
3	Fortis Memorial Research Institute	Gurgaon	Haryana	1	Dr. Vikas Dua
4	Sir Ganga Ram Hospital	Delhi	Delhi UT	2	Dr Anupam S
5	NH Narayana Health City	Bengaluru	Karnataka	4	Dr Sunil B
6	Apollo Hospital	Chennai	Tamil Nadu	2	Dr Revathi R
7	St John Medical college	Bengaluru	Karnataka	3	Dr Anand P
8	Rainbow Children Hospital	Hyderabad	Telangana	1	Dr Shirisha R
10	Guru Teg Bahadur Hospital	Delhi	Delhi UT	1	Dr Pooja D
11	Indo-American Cancer Institute	Hyderabad	Telangana	1	Dr Veerendra P
12	Indraprastha Apollo Hospital	Sarita Vihar, Delhi	Delhi UT	2	Dr Amita M
13	Institute of Child Health and Hospital for Children	Egmore Chennai	Tamil Nadu	2	Dr Aruna R
14	Malabar Cancer Institute	Thalassery Kannur	Kerala	1	Dr Jithin TK
15	Medanta The Medcity	Gurgaon	HR	1	Dr S P Yadav
16	Shri Shankara cancer Hospital	Bangalore	Karnataka		Dr.Anand K C
17	Tata Memorial Centre	Kolkata	West Bengal	2	Dr Arpita B
18	The Gujrat Cancer and Research Institute	Asrawa	Gujrat	2	Dr Chinmay V
	LTMMC & Hospital	Sion, Mumbai	Maharashtra	2	Dr Sujata S
19	MVR Cancer Centre and Research Institute	Calicut	Kerala	1	Dr Yamini K
20	Christian Medical College	Chennai	Tamil Nadu	2	Dr Leni M

6 Institutional Fellowship/PDCC: Hematology/Oncology Fellowship:

Sr No	Institute/Hospital Name	City	State	No of Seats	Head/Incharge
1	AIIMS Jodhpur (Hemat)	Jodhpur	Rajasthan	1	Dr Siyaram D
2	AIIMS Raipur (PHO)	Raipur	Chhattisgarh	1	Dr Sunil J
3	BHU Institute of Medical Science	Varanasi	Utter Pradesh	2	Dr Vandana G
4	MCGM-CTC PHO& BMT Center, (MUHS)	Borivali East, Mumbai	Maharashtra	2	Dr Mamta M

7. Pediatrics BMT Fellowship in India

Sr No	Institute/Hospital Name	City	State	No of Seats	Head/Incharge
1	ACTREC	Navi Mumbai	Maharashtra	2	Dr Navin K
2	NH Narayana Health City	Bengaluru	Karnataka	1	Dr Sunil B
3	Fortis Memorial Research Institute	Gurgaon	Haryana	1	Dr. Vikas Dua
4	BJ Wadia Hospital	Parel Mumbai	Maharashtra	1	Dr Prashant H
5	Apollo Hospital	Chennai	Tamil Nadu	2	Dr Revathi R
6	MCGM-CTC PHO& BMT Center, (MUHS)	Borivali East, Mumbai	Maharashtra	2	Dr Mamta M

Compiled from: FNB brochures, INI & NEET SS Brochures and PHO website. Few online searches for BMT Fellowship. *Seat may vary years to years basis and Centers need.*

Compiled By Dr Sunil Jondhale, Additional Professor Pediatrics, AIIMS, Raipur

Dr. Sunil Jondhale
Additional Professor, Department of Pediatrics,
AIIMS Raipur

Interesting Facts about Sickle cell disease

Discovery:

Sickle cell disease has been known in Africa for thousands of years before it was discovered in USA. Traditional African names for sickle cell anemia reflect the painful symptoms of the disease. Among four African tribes, the disease was named "chwechweechwe", "nwiiwii", "nuiduidui", and "ahotutuo". The names mean "beaten up," "body biting," "body chewing," and "painful body". First Sickle disease patient Walter Clement Noel from Granada. He was studying Dental surgery at Illinois in US. Dr. James B. Herrick published an article about Noel's visits to his hospital in the November 1910 issue of the Archives of Internal Medicine. Herrick wrote, "because of the unusual blood findings, no duplicate of which I have ever seen described." Second patient was Anthony who worked as a cook and housekeeper who had recurrent infection and the third patient was a 21- year-old woman from St. Louis, Missouri, who had recurring skin ulcers and anemia. Verne R. Mason published a report about the fourth patient in 1922 and gave the new disease a name: ***sickle cell anemia****. Mason stressed that the disease was inherited. He was correct about that, but he incorrectly suggested that sickle cell anemia occurs only in people of African descent. This misconception lasted decades.*

First Molecular Disease:

The Caltech researchers published their findings in a 1949 Science paper entitled "Sickle Cell Anemia, a Molecular Disease." They had found an abnormality in the chemistry of a protein that seemed to cause a disease. In 1949, Harvey Itano and his coworkers announced that they had found a chemical difference between normal hemoglobin and sickle cell hemoglobin using the technique of electrophoresis. Sickle cell anemia has indeed become the first genetic condition to be characterized at the molecular level.

Malaria hypothesis

It is the advantage conferred by sickle cell trait in protecting against Plasmodium falciparum malaria in heterozygous individuals. Parasitized red blood cells have an increased (up to eight times) chance of sickling in HbAS than in HbAA individuals, which may enhance phagocytosis of infected red blood cells and, therefore, result in reduced parasitemia

Sickle cell disease in India *was first detected by Lehman and Cutbush in 1952 among the tribals from Nilgiris. India has been ranked the country with the second highest numbers of predicted SCD births.*

Treatment of SCD

- ***In 1960 blood transfusions*** *first used to treat sickle cell and it was only treatment available till 1990.*
- *During the early 1970s, a chemical called* ***urea*** *was thought to be a cure. In one very small study, urea appeared to restore a patient's sickled cells to the normal shape. Later studies failed to show this helpful effect. By 1974, scientists found that urea not only failed to offer a cure but was toxic.*
- ***Hydroxyurea Discovery and Approval:***
  Dr. Oswald Hoffman, a researcher at the National Institutes of Health (NIH), observed that hydroxyurea increased HbF levels in patients with sickle cell disease. Elevated HbF levels were known to reduce sickling of red blood cells. After Multicenter trials conducted in the US and Europe which demonstrated hydroxyurea's efficacy in SCD it became the first FDA approved drug for sickle cell disease treatment in 1998.
- *The* ***first stem cell transplant for sickle cell*** *is performed in 1984 representing the first curative therapy for the disease*

References

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Let's talk about cancer

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Aparajita had just turned 13 when her cancer was diagnosed. "So, my teenage will be fun!" she said wryly. And as her father and I tried to process the devastating news while packing a quick bag for her immediate admission to hospital, Aparajita – i.e. The Undefeated – was out the door like a shot. "Have to tell my friends before we go off!" she shouted. She came back smirking. "They said I'm half dead," she guffawed. At which I was ready to deliver her pals swiftly to that state themselves. Instead, I laughed out loud. So did Aparajita. "It's our theme music, guys," we would say for a long time afterwards, to people startled by sudden, inexplicable laughs by the mother-daughter duo, "our theme music – hysterical laughter!"
An hour later, on the way to the hospital, the phone calls and messages started pouring in. Apparently, Aparajita had changed her WhatsApp status to declare, "Hey, I have bone cancer!" The toughest journey of our lives had begun.

Learning that your child has cancer is a bit like being shot into space – you float alone, anchorless, mindless in an unreal world. Till you give the haze enveloping you a shape -- and the world shrinks into a dark, hard, clenched fist. You live inside that fist. That fist lives inside you.

And everything outside changes forever. Including friends and family. Cancer scares people. It reminds them of death, of their own mortality. People are even scared to say its name. In more Anglicized circles it's called 'The Big C'. Elsewhere, it's called nothing at all, it's a spectral presence, shrouded in suspense. Sometimes it is expressed through widened or narrowed eyes, heaving brows and a silent shaping of the word by mime-worthy lips. You may notice people hovering about, whispering around you, maybe flashing the awkward smile at you, before quickly moving away. As if a reminder of mortality is infectious, as if they might just catch it and drop dead.
In short, the possibility of death makes people uncomfortable. They can't talk or think about or be in contact with anything they believe may be touched by it. Interestingly, there are others too, those who talk about it perhaps a bit too much, a bit too excitedly. So if touched by 'The Big C', just for the sake of clarity, you could sort your friends, family and acquaintances into neat little piles.

1. Those Fleeing in Fright – these dear souls are genuinely scared of getting infected with death, or bringing misfortune upon themselves by mingling with those hit by misfortune. Terrified that our bad luck would rub off on them, they run for their life. Let them go.

2. Objective observers – In polite society, these are perhaps the biggest group of your friends, acquaintances or extended family. When you run into them, they are sheepish or righteous or both, announcing that they know everything. "I keep getting your news from XYZ," they will say. "Yes, I often ask XYZ about you and your child. I get updates." Don't ask, "Why? Are we a natural disaster that you need updates? Or an unfolding political drama? Or a love story in *filmistaan*? How does it help anyone – other than the curious cat inside you – for you to get 'updates'? And why on earth are you behaving like you have done me a favour!" Instead, you could gently tell them that it's okay to talk to you directly, you don't mind. Their objective observer status could very well be because they don't know what to say, or don't want to offend you.

3. Scintillating storytellers – those eager to know every miserable detail and in return tell you elaborate gory tales about others who are suffering from or have died due to terrible diseases. They appear to be masters at Chinese Whispers, and it's best not to play their game.
4. Rocks, big and small – these are your anchors. Friends and family who stand by you through your fears, tears, anger and hope. Those who keep in touch, hear you, sit with you, wait anxiously

for test results, pray for your child whatever their faith or language or politics, remember what's important to you or your child, make time in their lives for you and your child, share your fears and hopes

We need these rocks. Parents of a child with cancer may not show how terrified and fragile they are, they may not seem to need any support at all – but actually they do need their network of rocks to anchor them to reality and keep them sane as their world falls apart.

Aparajita has Ewing's Sarcoma, a rare and difficult children's cancer affecting bones and soft tissue. And although her father and I are with her practically all the time, we can only imagine what she – a bright, sensitive, uncompromising adolescent – is actually going through. Our cancer journey began when our friend and celebrated liver surgeon Dr Saumitra Rawat at Sir Ganga Ram Hospital sent us to the brilliant pediatrics surgeon Dr Satish Aggarwal, who recognized the monster at once and spoke to Dr Manas Kalra, pediatric oncologist, who arranged for Aparajita's treatment right away. Dr Kalra was very knowledgeable and caring, and had a great team of young pediatric oncologists.

Each one of whom had their share of desperately trying to get my incredibly self-willed daughter to abide by the rules of the hospital and her treatment. Dr Swati Bhayana, forever smiling and gentle, tried juggling carrots and sticks. Dr Srijib Mukherjee, shy, efficient and affectionate, tried big-brotherly reasoning and gentle cajoling. Dr Ayush Sopori, well-informed on a wide range of topics, chatted expertly on music and manga. They all had limited success. I remember the earnest conversation between Aparajita and Dr Saroj, who was explaining to her why she must be strapped to Ifosfamide and Etoposide infusions for five days every time as Aparajita tried to bargain it down to three days. "I can't take it anymore!" she kept saying, "not more than three days at a stretch!"
"Of course you can, Aparajita," insisted Dr Saroj gently. "Even little kids much younger than you can do it, and you are older and so much wiser!"

Aparajita stared at him. "Can you do cartwheels?"

"No," said the doctor, taken aback.

"Well, I can. And you are so much older and wiser than me. You see, age or wisdom has nothing to do with it. I cannot do five days of this chemo anymore!"

Meanwhile Sister Siji, in charge of the pediatric hematology-oncology ward, was running out of encouraging words and prayers from the Bible which were having no effect on my intractable child. But neither of them would give up. It was like the unstoppable force meeting the immovable object. As a final act of defiance, Aparajita looked Sister Siji in the eye and said, "Sister, I am an atheist." Softer souls like Sister Shiny, the one with the gentlest touch with needles and PICC lines, would give up at that point. But not the unwavering Sister Siji. "You are not an atheist," she said firmly, "you are only a child. And God loves you." And she swept victoriously out of the room.
Let's talk about cancer. It's not something to hide, not a shameful disease, not even an infection. And it is not a curse. Not the wages of sin. It's just a dreadful disease that could kill you. We need to see it as that, and fight it as hard and as long as we can. Some cancers are now completely curable, some are not, but could be one day. We need to hold tight and stay the course – and hope and pray like we've never hoped and prayed before. And through it all, we need our sense of humour – that's our torchlight to navigate the darkness. For Pratik, Aparajita and me, it's finding the absurd in everyday matters that keeps us going. And of course, our theme music – hysterical laughter.

Perseverance and Persistency is the Key

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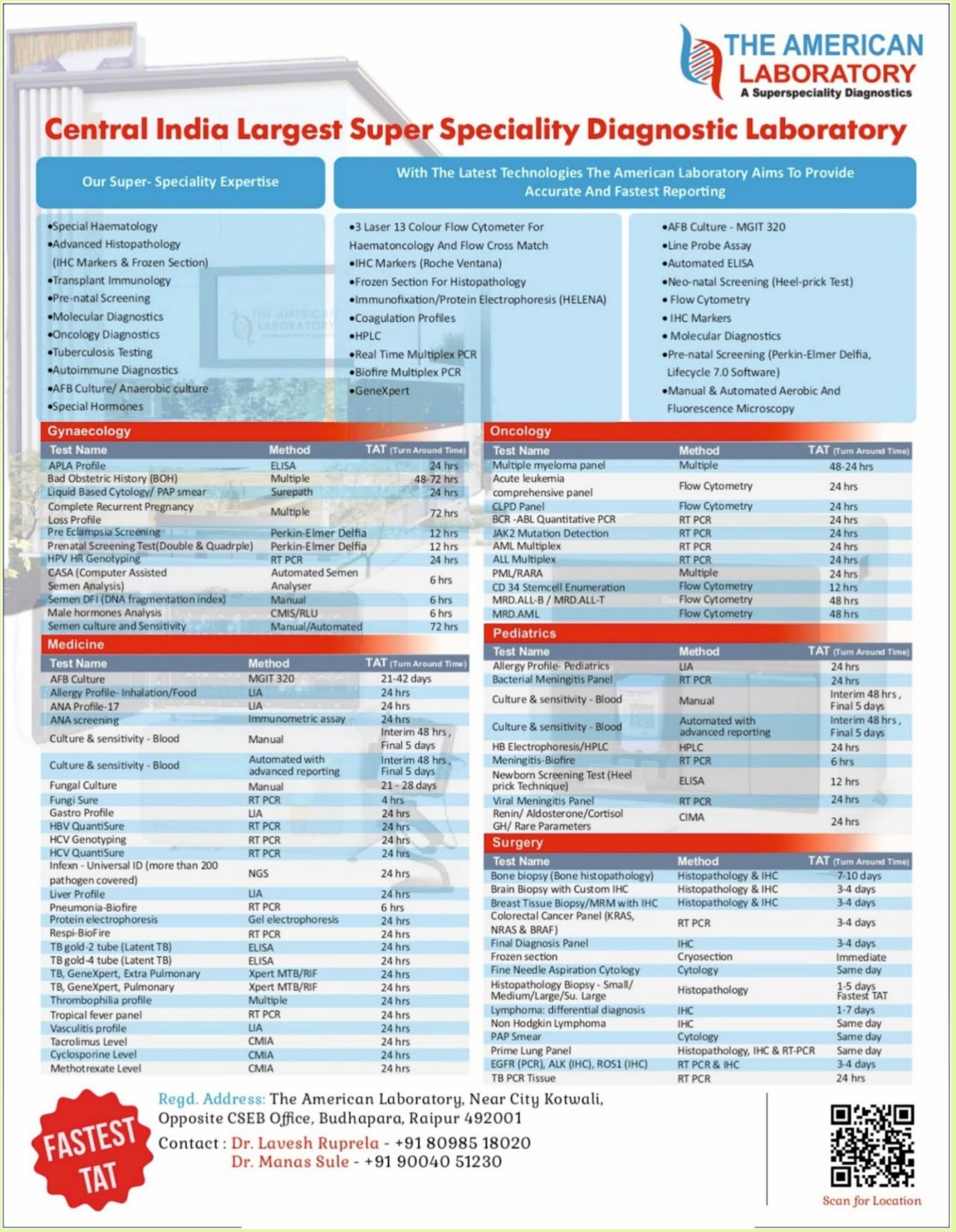

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