## Eye Cancer

In April, LVPEI's Kode Venkatadri Chowdary (KVC) campus in Vijayawada made history by performing the first-ever intra-arterial chemotherapy (IAC) procedure in the state of Andhra Pradesh. A four-year-old girl with bilateral retinoblastoma, a life-threatening eye cancer, had a recurring tumour in one eye even after completing 12 intravenous chemotherapies (the first line of treatment). This prompted Dr Anasua Ganguly, Head of the KVC Campus and an ocular oncologist, to treat the young girl with IAC.

The call to offer IAC is not an easy decision. It is a delicate and complex procedure where a concentrated dose of cancer-inhibiting medication is delivered into the patient's ophthalmic artery, the primary source of blood to the eye. IAC is particularly effective in treating retinoblastoma, but it requires precision, skill, and the support of a multidisciplinary team. This form of chemotherapy is popular in the West, but its adoption in India is hindered by the cost and limited medical infrastructure. Anasua collaborated with experts from various hospitals, including Rainbow Children's Hospital and Pioneer Anaesthesia Group, Vijayawada; Life Neurovascular Hospital, Guntur; and Apollo Cancer Hospital, Hyderabad.

Anasua says, "This achievement holds personal significance for me, as it represents the culmination of years of perseverance. Despite initial reluctance and a lot of resistance from the interventional radiologist to initiate IAC services in Vijayawada, we remained steadfast in our commitment to providing comprehensive care locally. Through collaborative efforts and determination, we were able to overcome obstacles and successfully perform the procedure for the first time in Andhra Pradesh."

## A rare childhood cancer

Retinoblastoma is the most common eye cancer in children. Every year, about 8000 to 9000 new cases are detected worldwide. In India alone, about 1000 to 1500 new cases are diagnosed every year. The Operation Eyesight Universal Institute for Eye Cancer at L V Prasad Eye Institute sees about 200 to 250 new retinoblastoma cases every year across our network. OEU IEC is a Center of Excellence and Global Resource Centre, established in September 2015 with generous support from the Canada-based Killam family.

Early detection and prompt treatment are crucial for the management of this eye cancer. Timely management not only saves lives, but with modern treatment strategies, we can save the eye and the sight of these young children. Unfortunately, a lack of awareness and the consequent delay in bringing the child to a specialist makes the job of ocular oncologists challenging. To raise the profile of this condition, and to spread awareness, "Retinoblastoma Awareness Week" is celebrated worldwide in the second week of May every year. Six years ago, in 2018, we began organizing 'Whitathon', a running event open to the public to raise awareness and funds for children with retinoblastoma.

Dr. Swathi Kaliki, Head of the Operation Eyesight Universal Institute for Eye Cancer LVPEI, says, "With no prior experience in organizing running events, we were uncertain about logistics or participation but knew it would work if done right. As the saying goes, like-minded people attract each other, and we succeeded in finding our tribe – we found our technical partner in Hyderabad Runners, who have been our partners to this day."

On 19th May 2024, Swathi successfully led the sixth edition of Whitathon in Hyderabad, along with the third editions in Bhubaneswar, Vijayawada, and Visakhapatnam. In Hyderabad, we were honored to have the Deputy Commissioner of Police, Madhapur, Dr Vineeth G, as our chief guest. He also ran in the 10 km run! At the University of Hyderabad campus, amidst its natural beauty and a refreshing drizzle, a sea of purple tee-shirted participants ran, danced, and cheered on, reaffirming their commitment to treating retinoblastoma. I would like to thank all the runners, the Hyderabad Runners Society, and all the supporters who joined us in the Whitathon. Their support adds to our commitment to reach every child with eye cancer and offer timely care.

The key to this commitment is LVPEI's pyramidal model, which facilitates identifying and referring children with potential retinoblastoma. Very young children with a white reflex (the 'white' in Whitathon comes from here) are encouraged to visit our vision and secondary centres. If confirmed, they are referred to our tertiary centres, each of which is fully equipped to manage children with retinoblastoma. If any complicated procedure is required, they are referred further to the centre of excellence. The best care is offered to all children with retinoblastoma with an aim to save their vision, their eyes, and their life. For every child with retinoblastoma who has walked through our doors, we were able to save their life 95% of the time. In 75%, we were able to save their sight.

## The Change We Want to See

In low and middle-income countries (LMICs), the survival rate for children with retinoblastoma is 50% or lower. Swathi is working with various global organizations on the global effort to tackle retinoblastoma. She has contributed a policy brief on Retinoblastoma Policy for the WHO's <u>Global Initiative for Childhood Cancer</u>, along with similar briefs for a few LMICs. The oncology unit of L V Prasad Eye Institute is also part of the Global Retinoblastoma Network and plays a crucial role in global retinoblastoma research, advocacy, and capacity building. It also mentors retinoblastoma specialists in Africa and South-East Asia through quarterly multidisciplinary team meetings.

Consider the numbers here. In India, about 25 million children are born every year, and about a thousand or so develop retinoblastoma. We need a referral network that is robust and sensitive enough to catch these rare cases--and get them to care early. When they come into the care facility, we must offer them the best treatment possible irrespective of location or cost. This is an ambition that most countries in Asia, Africa, and Latin America can only aspire to, today.

Swathi and Anasua are showing us that this ambition is indeed feasible. Anasua's example shows us that even outside India's big cities, we can offer these children the best care they need. Swathi, through her expertise and leadership, is taking our experiences to many others who can benefit from them. In their spirit, we re-affirm our commitment to work with all those involved in the endeavor to save the sight and the lives of children with retinoblastoma.