

## INDIA IS FIGHTING RETINOBLASTOMA

A vigilant grandmother noticed a white cat's eye in her 15 day old granddaughter, Sampada, and brought her to Delhi from Nepal for treatment. Sampada's mother had eye cancer which was detected late and she lost all vision.

Little baby Sampada is being treated at Dr Shroff's Charity Eye Hospital and getting her chemotherapy at Indraprastha Apollo Hospital with funding support from national society for Change for Childhood Cancer in India – Cankids Kidscan.

Retinoblastoma (RB) – eye cancer, typically affects young children under the age of 5. Its incidence is low with not more than 7000-8000 new cases each year worldwide, but it is not distributed equally, with over 90% in low and middle income countries (LMICs). India alone accounts for 21 to 25% with 1500- 1800 new cases each year.

Practically 100% children survive this cancer in USA. But in our country due to late detection and diagnosis, children often present with very advanced metastatic disease and distressfully bulging protruding eyes which means the eye needs to be taken out (enucleated), the child loses vision permanently and there are low chances of survival.

*Timely diagnosis and proper treatment is the key.* In a unique stakeholder initiative - FIGHT RB INDIA - RB Centers across the country, specialists in the field of ophthalmology/ocular oncology, pediatric oncology, pathology and radiology, RB survivors and parents, CanKids and other NGOs, have joined together to fight against RB in young children – *to Save Life, Save Vision and Save Eyes.*

Vision 2020 is the roadmap to get there, authored by Internationally renowned ocular oncologist Dr Santosh Honavar, at the behest of the NGO under its Sajeev-Cankids Awareness, Advocacy and Patient Support project for Retinoblastoma.

“25 partnering RB Centers (ophthalmology + pediatric oncology) have come together with NGOs and civil society. “There are no leaders and each member has an equal voice,” says Poonam Bagai, Cancer Survivor and Founder Chairman of Cankids, that has served as a facilitator since the launch of the initiative in 2014. “It is only together we can make a difference and make a Change for Retinoblastoma in India, in the finite timeframe we have set for ourselves”

In a study by Drs Bhavna Chawla and Rachna Seth at AIIMS New Delhi, which treats 200-250 cases of retinoblastoma each year, it was pointed out that delayed presentation is a matter of concern. The successful management of the disease depends on the ability to detect it while it is still inter- ocular (within the eye).

Retinoblastoma education and public awareness campaigns have been shown to increase referrals, decrease rates of advanced disease and improve survival in other low middle income countries (LMICs).

With World RB Awareness Week from May 14<sup>th</sup>, the Fight RB India group has geared itself up. Says Dr Honavar, Director National Retinoblastoma Foundation and Director Medical Services Center for Sight, as well as the Cankids key RB Advisor. “The level of awareness of the first contact health provider in identifying the problem and making the referral is critical. The lack of knowledge by the physician first contacted by the parents is a key barrier. We have to identify the primary health care provider – the pediatrician or the ophthalmologist, educate them for early detection and ensure they know where to refer the child for immediate diagnosis and quality treatment.”

“Every year we send out awareness material and posters to all Regional Institutes of Ophthalmology (RIOs) and Regional Cancer Centers,” says Cancer survivor and Awareness Officer Kapil Chawla. “This year we are also doing an Online Branding campaign on Google, Facebook and Youtube,” added 19 year old survivor, Abhishek Mishra, also part of the Awareness Team. Many RB specialists are running education programs for the doctors in different parts of the country.

“We are hoping to rope in an important celebrity couple as ambassadors and to launch a national TV awareness campaign as much to encourage parents to be vigilant about the white cat’s eye, as for doctors to Know the Glow and a Red Eye Reflex,” says Dr Savari Desai at Hinduja Hospital Mumbai, a passionate crusader for the cause.

Parents and 1<sup>st</sup> contact physicians must know where to go for RB treatment, and once they get there families must get full support. “Our Fight RB India Helpline number is 1800 123 6272, the Access to Care Map provides full details and contacts at partnering RB Centers where the family will be met by a Social Support team member. NGOs like ours provide funding support for diagnostics, treatment, accommodation, travel and artificial eye prosthesis,” assures Dr Haresh Gupta, Head of Cankids Medical Support Program. “We also provide RB centers with social support team members and this year we are hoping to provide equipment support for better diagnosis and treatment standards like Retcams, for collaborating centers.”

More and more centers across the country, private – like the Shankara and Narayan Nethralayas Aravindas , Apollos and Center for Sight, as well Government and autonomous like AIIMS in Delhi and Tata Medical Hospital Mumbai are gaining expertise and offering intravenous, intra-arterial, periocular, and intravitreal chemotherapy as per the need along with focal treatments such as cryotherapy and transpupillary thermotherapy. On April 18<sup>th</sup> this year, Plaque Brachytherapy, a form of local radiation delivered to the eye via a radioactive device, is now also available at AIIMS making it the 4<sup>th</sup> Center in the country to offer this state of the art intervention.

The Retinoblastoma Working Group of InPOG (India Pediatric oncology group) of the PHO Chapter of the Indian Academy of Pediatrics is gearing up to do multi – center collaborative researches on retinoblastoma management and genetic counselling and testing championed by WG Dr Amita Mahajan Chair Cankids Medical Advisory and Sr Consultant Pediatric Oncologist, Indraprastha Apollo Hospital Delhi and Dr Rajeev Sarin, IN Charge Cancer Genetics Unit, TMH Mumbai respectively.

“Whatever best there is in the world is now also available here in the country,” says Honavar, who shows international results of 94% survival in the 1014 children he and his teams have treated in the last 5 years, with 90% eye salvage and 96% vision salvage.

Retinoblastoma Cancer Survivors & Ambassadors, Pankaj Yadav 22, Akanksha Gupta, 20, Shivam Dubey 18, and Rahul Nagar, 16, are celebrating all these advances and calling upon you to pledge your support and join them to Fight RB – India. “If you are an alert parent, a pediatrician, an ophthalmologist, a photographer, or just civil society – call on 18001236272 or email [fightrbindia@gmail.com](mailto:fightrbindia@gmail.com) - help us to Fight the White. Help us get our children with eye cancer to an RB cancer center on time!”