

PERSONALITY FOCUS



**DR JAMALIA
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In the spectrum of childrens' eye diseases from glaucoma and cataracts to cases in neuro-ophthalmology, Dr Jamalia Rahmat has observed that key positive developments have been made in the treatment of retinoblastoma (RB), the rare malignant tumor of the retina affecting young children.

In the past, radiotherapy posed a higher risk of the child potentially developing second cancers in adult life. That was followed by the rise of chemotherapy which is generally given intravenously to cancer patients. What is available now is intra-arterial chemotherapy, the advanced localised application of the treatment directly onto cancer cells in the eye.

"In the past, we administered chemotherapy by giving the drug via IV. This makes the patient vulnerable to side effects as the drugs may well become absorbed elsewhere in the body, giving complications such as kidney and liver toxicities, bone marrow suppression and hearing loss. Now chemotherapy can be given straight into the eye," says Dr Jamalia.

HKL began this highly skilled intra-arterial treatment with the help of interventional radiologists at the end of 2015, and results from the RB centre have been very encouraging. "If we can continue to use this technique, there is no need for the child to undergo surgery or lose the eye."

However, HKL has its limitations as there are very few interventional radiologists who are skilled in the injection techniques of this treatment. "It is a highly skilled technique with a steep learning curve. The artery itself is small and you are injecting toxic chemicals so there is always the risk of the blood vessels going into spasm."

One of the constraints faced is the difficulty to recannulate these small vessels for repeat treatment, although they are working to overcome this limitation.

"So although we do have this service, we are limiting it to cases that are suitable, which includes for a baby who is more than 3 months old, and for unilateral RB that is not very big in the eye."

Based on the intra-ocular stages A-E, stage A is where the RB is very small and can be treated with lasers. At stage E, the RB is almost growing out of the eye, so intra-arterial chemotherapy may not be delivered accurately.



The Paediatric Ophthalmology team in HKL (L - R) Dr Nor Akmal Bahari, Dr Jamalia Rahmat, Dr Sunder Ramasamy, Dr Norazah Abdul Rahman

“We usually perform it when at stage B, C or D, where the RB is usually at the centre of the eye. There is no point if the RB is extra-ocular, and we will prescribe systemic chemotherapy in that case.”

EARLY DIAGNOSIS, LATE TREATMENT

Retinoblastoma (RB) is also known as childhood eye cancer, and the nationwide RB registry details more than 238 patients nationwide since 2004. The worldwide incidence is 1 case for every 20,000 live births so Malaysia gets an average of 25-30 cases each year. It usually strikes children who are less than 5 years of age, and the global mean age is 1-2 years.

“It is a problem of the developing retina. If it is treated early, it is one of the cancers with a 98% cancer survival rate. However, if it is diagnosed or treated too late at the extra-ocular stage, the survival rate of 98% plummets to 10%, and it also spreads very fast. Once it spreads from the eye to brain the usual lifespan is within a year.”

The problem with RB is that parents do not want treatment at first. When RB is first discovered, it is usually by signs of poor vision, or by the level of white reflex in the eye indicating the RB has occupied more than half the globe. “One of the treatments, which is curative, is to surgically take out the eye, but the minute you mention this to parents, they run away. They think the child is still alright because they believe the other eye is not defective, but they don’t realise that this thing is still growing. They only come back when it becomes more serious.”



“Parents even shy away from chemotherapy, because they look at the outward or temporary side effects of the treatment like fever, nausea, weight-loss and hair-loss as negative signs, rather than look at the positive side of the tumour getting smaller.”

Dr Jamalia laughs when recalling how she used to coax parents to come in for their child's treatment. “When they don't turn up, we would call them up.” She admits that it has been difficult, as Malaysia does not have a drastic law like in other countries where parents or caregivers can be charged with neglect or a form of abuse if they refuse medical treatment to a child, enabling the state to take over the right to consent for treatment.

“Parents have a lot on their plate. One thing they don't want to do is to make a decision for the child that might backfire on them in the future. They are also wary of facing the doctors if they default in the treatment process. But we always try to keep close rapport with them, we keep an open channel and tell them they can always come back at any time.” She adds that currently, with better communication and support groups linked together on WhatsApp, the job of discussing and assisting is made so much easier.

FIRST FELLOW

Having served for 20 years, RB is one of Dr Jamalia's main purviews once she became a paediatric ophthalmologist. After undergoing the usual one year housemanship plus three years as a general medical officer, she became eligible to specialize in ophthalmology. Following a four-year long Masters in Ophthalmology, Dr Jamalia qualified and started practicing, serving all over the country including Kuala Terengganu for 3 years, and then in Seremban.

“There were very few paediatric ophthalmologists at that time, and the service needed to develop that subspecialty further. So from 2004 onwards, there was a structured programme set up by the government.” She enrolled to become the first fellow in Paediatric Ophthalmology of the 3-year inaugural Ministry of Health (MOH) fellowship program, and spent the final year in Calgary, southwest Canada - after which she became certified as a paediatric ophthalmologist in 2007. She has since been attached to HKL.

Dr Jamalia speaks greatly of the late Dr Joseph Alagaratnam who trained in Edinburgh and started the pediatric ophthalmology unit from a single person under Ophthalmology in HKL. She was fortunate enough to work under him as his fellow, and the unit grew to become the biggest paediatric eye department in the country.



“Paediatric Ophthalmology is both very interesting and challenging. You are handling the whole spectrum of ophthalmology, but in paediatric patients. The whole ophthalmological approach is different.”

For instance, in treating a child with cataract, the ophthalmologist’s role is not only to remove the cataract, but also to help to develop the child’s full visual system and to train the brain to see.

“This is because a child’s eye is not the same as an adult eye – it is a growing structure. The most important period for a child’s vision is the first 1-3 months of the first year in terms of building up an internal visual system. However, the plasticity remains up to 7 years of age,” she adds.

“So if there is a problem with the eye, and if the child does not have access to care until he or she is much older, this can result in visual deprivation, where a lot of things are being missed in terms of developing a full visual system. In a child with cataract, the visual system certainly has not fully developed yet.”

PLAYING AT WORK

“The best thing about Paediatric Ophthalmology is being able to channel your inner child without anyone saying anything!”

In Dr Jamalia’s experience, the child will dictate how much examination you can do, so there will be a lot of playing and singing with the child and the clinic is never mundane. It is noisy, busy and is a lot of fun.

“But of course, it can be a bit difficult, as you need to handle the child. Both parents and child are impacted by anxiety and sometimes one parent can be difficult. But at the end of the day, you see them growing right before your eyes. The thing about children is you cannot discharge them completely, they are long term patients and will be under your care for a longer period than adults.”

“Children make it easy for you to keep in touch with your youth and to stay young at heart. This is important in any job you have, and makes it much easier to balance family life, work and friends.”

