



From left The iC2 crew: Mary, Jason, Natasha, Jamuna, Beng Ti, Audrey, Lay Hong and Sangeetha

iC2 PrepHouse

– Solutions for Low Vision

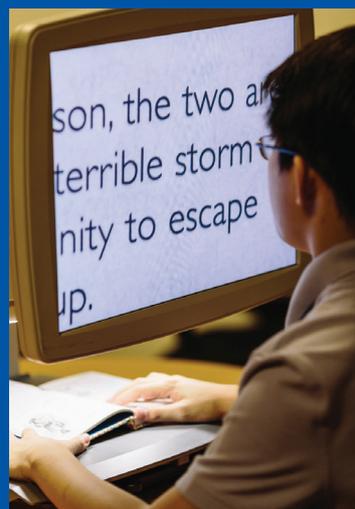
Text by Dr Audrey Looi
Photos by iC2 PrepHouse

“JAMES, please stop fooling around. The sooner we get this done, the sooner we can head to the funfair,” I urged impatiently. It was a Saturday morning, and I had stopped by Singapore National Eye Centre (SNEC) to get my then eight-year-old son’s refraction done. Both his Mandarin tutor and sister had been commenting for a few weeks that he tended to read with his books really close up. My initial presumption was that he needed glasses to correct myopia, a common enough problem among Singaporean children. I was not at all expecting to deal with a more serious diagnosis. As it turned out, his slowness in response to the optometrist’s queries heralded a tough time for our family – which surprisingly, led my husband Beng Ti and me to discover a public-spiritedness that we never knew we had.

The electroretinography tests conducted that morning confirmed the clinical suspicion of a cone rod dystrophy. A visiting expert later refined the diagnosis to Stargardt’s macular dystrophy, an autosomal recessive disorder that

is characterised by gradual progression of bilateral visual loss. I doubt I will ever be able to describe the devastation I felt that day. As an ophthalmologist, I knew immediately the grave prognosis. There is, to date, no widely recognised treatment for this condition. Sure, there is current research into gene therapy and stem cell therapy. But the work is rudimentary and no clear treatment looks to be available any time soon.

As there was nothing to be done, we proceeded on to the funfair in a bit of a daze, and took refuge in the comforting words of friends we met there. Over the next few weeks, we looked around desperately for the specialised support that James would need to cope with his macular dystrophy. Given his single disability and level of low vision (completely blind children learn through Braille and may be better supported in a school for the blind, or in designated schools with resource teachers who teach in Braille), he could and should continue to study in a mainstream school. We also



needed to understand how the support would change as his vision worsened with time. So we checked with the existing institutions in Singapore that dealt with visual impairments, and were shocked to find that there were no professionally structured programmes designed to assist children with low vision. I am no psychiatrist but am sure I was depressed for a short while back then. We even thought of emigrating to the UK.

The turning point

Thankfully, things got better after I met two very inspiring individuals. The first was Lee Lay Hong, a teacher who studied for her Master in Special Education (specialising in visual impairments) in Sydney to better support her two children who both have a similar condition as James. She had to embark on this further education as she had made the painful realisation that there was no one in Singapore who was formally trained to support children with low vision. She had also suffered the suspicions and irritation of teachers and principals who did not understand how a parent could not properly discipline a child who professed not to see well, yet was able to go outside and play catching! This is easily explained by the fact that in some children with low vision, there is mainly central visual loss with relative sparing of

peripheral vision. What this translates into, functionally, is that while their reading is affected early on, orientation and mobility can remain relatively intact for a long time.

Lay Hong's journey had begun a decade earlier. By the time I met her serendipitously through an informal support group that she had set up, she had become quite an expert in both the specialised assessments designed for children with low vision, as well as in the customised instruction of affected children. You can only imagine the load that came off my shoulders when I realised that with Lay Hong's aid, we would finally be able to help James manage his disability.

The other amazing individual was Wong Meng Ee. I first knew him as the chairman of the Retinitis Pigmentosa Society Singapore – a support group for patients with retinitis pigmentosa which held regular meetings at SNEC. He was kind enough to share with me his personal experience. Like James, he had begun losing his vision in primary school; and now, in his 40s, he had lost most of his vision. Despite that, armed with the requisite skills that he acquired in the UK where he received his post-primary education, he had gone on to become an assistant professor in special education at the National Institute of Education. If that was not enough to impress, I have to mention that he is also a regular marathoner and biathlete!

So, really, although the disability is severe, if others have the strength of character and steadfastness to work through the difficulties and achieve much, then the least I could do was to cheer up, roll up my sleeves and work on providing the necessary support to James, with Lay Hong's help.

Her weekly instruction in using the video magnifier/closed-circuit television and the Braille lessons led to a warm friendship between the two families. It really is a small world – her husband turned out to be an endocrinologist whom my husband knew. I was truly grateful for her expertise and could not understand why there were other parents who had complained of the nominal fee she charged (approximately \$30 to \$40 per hour, mainly to cover transport costs). This woman knew her stuff yet she was being questioned not only by some parents, who felt her support should be provided free, but also by school authorities because they viewed her as an overly anxious parent instead of a trained professional.

Taking the plunge

One day, Lay Hong asked if I would help her set up a school or centre that would better cater to the needs of children with low vision. I remember telling her right away that what she envisioned could not be provided by an education centre but by a charity proper. How else could one cover the overheads when families, already grappling with the disability in their children, are unwilling to pay for specialised assessments and instruction? As we discussed what needed to be done, I have to confess that I struggled between taking the easier way out of just carrying on with Lay Hong's support, and the more difficult job of setting up and running a charity. I had heard of charities that were poorly run and was concerned whether we had the wherewithal to make this succeed. My husband had his reservations as well. His neurosurgeon duties and research work leave him little time as is for the family. But, our personal painful experience could not allow us to turn away from a job that needed to be done.

Thus, we took the first leap of faith and met up with then Minister for Community Development, Youth and Sports, Dr Vivian Balakrishnan, who, as luck would have it, was my ex-medical director at SNEC. He was aware of the local low vision scene and kindly pledged his support. He introduced us to the folks at the National Council of Social Service and we began our journey to set up iC2 PrepHouse. We formed a board comprising Meng Ee as chairman, Beng Ti and myself. We later roped in Lynette Shek (our old friend and an associate professor in paediatrics) and Jennifer Chia (recommended by another wonderful and supportive old friend Stefanie Yuen-Thio; both Stefanie and Jennifer are

corporate lawyers with TSMP Law Corporation and have provided tremendous legal and governance support for iC2). Lay Hong came on board as a vision teacher, and we also were fortunate to recruit another passionate teacher, Mary McPherson, who had approached me for a position when she heard through the grapevine that we were setting up iC2.

Looking back, I am constantly amazed by how all the pieces came together neatly like a jigsaw puzzle. To cut the long story short, I am glad to report that since its official opening in November 2012, iC2 has reached its two-year milestone and supported over 50 families. We have also started training more vision teachers, to ensure that there will always be a local pool of professionally trained instructors who can support children with low vision in Singapore to achieve their maximal potential in mainstream schools. James, incidentally, performed well in the Primary School Leaving Examination two years ago and is now studying at Anglo-Chinese School (Independent), supported by iC2.

In conclusion, I would like to share my personal opinions about work and of giving back to society. I have always been grateful for the myriad opportunities to help our many patients. Nothing beats the delight one experiences with good clinical outcomes, especially when dealing with challenging diseases. All doctors are familiar with that feeling. Not all of us, however, have experienced the joy and satisfaction of giving back in other ways. The first step is the most difficult, given the unfamiliar territory and the necessary demands on one's time. But I would encourage you to do so. There are many charities that could do with a doctor's healing touch. ■

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