Brain Tumour Society seeks to set up Singapore registry

Group hopes to gather and unify data to aid research on the condition in the Republic

SINGAPORE – Bianca Lai has spent more than five of her 10 years alive battling a rare brain tumour that has affected her ability to control her hunger, impulses and behaviour.

In the past six years, she has undergone more than 10 brain operations since being diagnosed with craniopharyngioma, a tumour located near the pituitary gland and hypothalamus, which produce hormones vital to body functions.

She also suffered a stroke that paralysed the right side of her body. It left her unable to walk or control her movements properly for six months at the age of five, after she underwent surgery to remove the tumour for the second time.

It recurred in the same spot 10 months after it was removed.

Bianca survived the ordeal, but the worst was not over.

The aftermath, said her mother, Mrs Karen Lai, 41, was where the real struggles started.

“When your kid is lying at death’s door, all you can do is pray and trust in medical care,” said Mrs Lai, a senior communications director, who has two other children aged seven and 12.

“But what we truly struggled with were the changes to her behaviour after she returned home from the hospital. The doctors couldn’t give any indication if she’ll eventually get better.”

Mrs Lai said Bianca’s tumour type is so rare among such patients that she did not know who or where to turn to for support in Singapore.

Her quest to connect with other local families facing a similar situation came to a dead end. She eventually sought support from the Brain Tumour Society (Singapore) (BTSS) and overseas support groups.

She has only heard of three other local cases of craniopharyngioma.

“There aren’t many surviving patients’ families on our tiny island to swap war stories with,” said Mrs Lai.

“Not much research has been done on these tumours either so there isn’t much information about it, especially about the recovery stage. To me, that was the hardest part.”

Patients like Bianca are why the BTSS is pushing for a brain tumour registry in Singapore. The non-profit society, established in 2014, provides support services to its members.

To gain more objective insights into the impact of brain tumours here, the BTSS is conducting a quality-of-life survey open to all brain tumour patients and caregivers, including those who are not members. Recruitment of participants will close on Sept 30.

BTSS president Melissa Lim said there is currently no known data here on the emotional and financial needs and challenges that brain tumour patients and their caregivers face.

Neither are there formal statistics to track the number of people with brain tumours, which encompass a wide spectrum of over 120 different types, said Dr David Low, head of Neurosurgical Service at KK Women’s and Children’s Hospital and consultant neurosurgeon at the National Neuroscience Institute.

“Each hospital keeps its own data on patients for their records and research. This data is also variable and there is no unified database due to reasons of patient confidentiality, ownership of the database and cost issues. In order to have a proper registry, this will have to be done at a national level,” said Dr Low.

Brain tumours are the second-most common cancer in children under the age of 18, after leukaemia. They have surpassed leukaemia to become the top cause of cancer deaths in children worldwide, as cure rates for the latter are better.

The trend appears to be similar in Singapore, where about 40 to 50 operations are carried out on children with brain tumours at restructured hospitals every year, said Dr Low.

An official registry, such as what countries like the United States and United Kingdom have, would offer greater insights into the disease and help support organisations respond better to issues faced, said Ms Lim.

It will also provide more information for further research and analysis of the disease, added Dr Low.

“Based on our ongoing interactions with the younger patients and their families, we know that they struggle to cope with mainstream studies during and after their treatments. Their problems are often compounded by teachers and peers who do not understand their situation,” said Ms Lim.

Different tumours respond differently to treatments. Some may have a better prognosis while others may be more challenging to treat, with poorer outcomes, said Dr Low.

According to him, the mainstay of treatment in most cases is surgery to remove the tumour.

Other treatments include radiotherapy and chemotherapy to target areas of the tumour that surgery is unable to remove.
Both benign and malignant brain tumours can have significant neurological consequences. The treatments may also cause side effects, particularly in young patients.

Children under the age of 10 are more prone to neurocognitive effects due to the immaturity of the brain and nervous system, said Dr Miriam Kimpo, consultant at the Division of Paediatric Haematology-Oncology at the National University Hospital.

But newer treatments, such as precision drugs that target gene mutations seen in certain brain tumours, may potentially reduce side effects, she said.

In the case of craniopharyngioma, which makes up about 5 to 10 per cent of all childhood brain tumours, many patients will suffer some degree of long-term issues with the pituitary gland and require lifelong hormonal replacement, said Dr Low.

Their behaviour, control of hunger and satiety, temperature regulation and fluid balance in the body may also be affected when the tumour enlarges and presses on the hypothalamus, which is adjacent to the pituitary gland, he added.

Without her daily cocktail of medication, which costs about S$2,000 per month, Bianca would be unable to grow properly or regulate basic body functions like blood pressure, metabolism, temperature and urine control.

Damage to the brain has caused her to feel perpetually hungry. She would eat non-stop if her parents do not portion her food. She also developed obsessive compulsive tendencies and began having frequent meltdowns during which she becomes aggressive and hits people.

“She’ll hit me, then cry and apologise for doing it because she can’t control herself. Then she’ll hit me again and cry. When people see her having a meltdown in public, they ask me why I’m not disciplining her and give us dirty looks. They don’t see her pain and all that she has gone through,” said Mrs Lai.

The Lais gave mainstream education a shot but it did not work out. After a term in Primary One, Bianca had to be transferred to a special needs school.

With Bianca’s teenage years approaching, Mrs Lai is uncertain if the growth hormones she is currently taking can help her hit puberty.

Mrs Lai said her daughter is unlikely to live a “normal life” any more. “When she was diagnosed, my concerns were whether she could get better. Now, I worry about the future: Will the tumour recur, and how is she going to cope with the medical bills when my husband and I are no longer around?” she said.

Mrs Lai is thankful for the support of the BTSS and other craniopharyngioma survivors living overseas.

She said: “Bianca is no longer the same girl she used to be, but I am immensely thankful that she is still alive. Right now, she is more settled than she ever was post-surgery. I’m still learning to accept the new normal.”