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Medical Mysteries is a series that spotlights rare diseases or unusual conditions.

MIRACLE BABY

S'pore girl with 1 in 100 million brain stem tumour survives and thrives against all odds

Given the aggressive cancer tumour located at her brain stem, little E should have died within weeks of her birth. Instead, the girl, who is now two years old, is not just alive but also well and behaving like any other toddler her age.

Doctors at the National University Hospital (NUH) say she is truly a miracle baby.

While her parents do not want her to be identified, E may well be the only child in the world to survive an aggressive congenital cancer in her brain stem. At the very least, she is the first such documented case, said Dr Vincent Nga, who heads neurosurgery at NUH.

It is extremely rare for an infant to be born with a tumour in that highly critical part of the brain which controls all the body's major functions, such as the ability to move and even to breathe. The odds are one in 100 million.

Her mother's pregnancy was normal, as was her birth in January 2022. But shortly after E was born, doctors knew she had a problem.

She had difficulty swallowing on day one. Then the right side of her face drooped within days of her birth, as though she had suffered a stroke.

Doctors at KK Women's and Children's Hospital where she was born did a scan, which identified a brain tumour. They told her parents the infant would not survive, and suggested they give her the best possible care to reduce her suffering.

Said her mother, Mrs Lee: "It was heartbreaking. When we asked the doctor what can be done, we were told, 'Nothing; mortality is 100 per cent within the year.'"

Her husband, Mr Lee, added: "They gave up on her. They didn't even give my daughter a chance. It made me very angry."

The Lees refused to give up hope on their baby girl, their second child. Instead, they turned to both the private sector and NUH to get a second, and even a third, opinion.

Mrs Lee, who works in the pharmaceutical industry, called on her contacts for a doctor who might be able to help. They suggested Dr Yeo Tseng Tsai, a neurosurgeon at NUH, who brought together a team, including several international experts, to explore if anything could be done.

Dr Nga said that while the tumour in E, who was only a week old, was fairly diffuse – meaning it had an odd shape, having worked its way into various crevices – they could still make out the outlines.

"There was no possibility of removing a good portion of the tumour without causing significant harm," he said, but "we had the impression that the tumour might not be that deadly".

They were wrong. But that knowledge came later.

The multi-disciplinary team of doctors, including cancer and radiation specialists, suggested doing a biopsy, and the Lees agreed. The purpose was to find out if it was an aggressive tumour that would likely double in size within months or a slower-growing one which might give the infant a chance for treatment.

At just a few days old, an infant is too fragile, with too little reserves, to undergo surgery, chemotherapy or radiation treatment – all of

which could possibly be done when the child was at least several months old. A biopsy would also allow doctors to know if there is targeted therapy for the cancer, which would give her a better chance of survival.

They explained the risks to the parents. Doing the biopsy could kill her. But without treatment, she would die within months.

Said Mr Lee: "The NUH doctors did not want to commit to anything, but also did not give E a death sentence. We knew the risk (that she could die) but biopsy was the only recourse. I was assured (by the knowledge) that if anyone had the experience, it had to be that circle of doctors."

Doing a biopsy of the brain tumour was a fairly complex procedure. First, part of her skull had to be removed – in this case, roughly 2cm by 2cm. Then, the doctors needed to ascertain if the part of the tumour they wanted to remove



Baby E may well be the only child in the world to survive an aggressive congenital cancer – a high-grade glioma – in her brain stem. At the very least, she is the first such documented case, said Dr Vincent Nga, who heads neurosurgery at the National University Hospital. ST PHOTO: SHINTARO TAY



Baby E's multi-disciplinary team of doctors (from left): neurosurgeon Vincent Nga, paediatric haemo-oncologist Miriam Santiago Kimpo and senior radiation oncologist Balamurugan Vellayappan. ST PHOTO: DESMOND FOO

NECESSARY RISK

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MR LEE, E's father. Without treatment, she would have died within months.

for the biopsy was near any critical function areas.

They did this by sending electric currents to different areas of the tumour. Said Dr Nga, the neurosurgeon in charge: "Fortunately, the tumour was fairly near the surface."

They removed about 1cm by 1cm of the tumour. They needed that much because they had been discussing E's case with international experts and wanted to send part of the tumour for testing at the Hospital for Sick Children (SickKids) in Toronto, which calls itself Canada's "most research-intensive hospital and the largest centre dedicated to improving children's health".

Both NUH and SickKids found the tumour to be a high-grade glioma, an aggressive cancer. The decision by the NUH team then, in consultation with experts from SickKids, was to give the infant the best possible care and to wait and hope.

Even after going home slightly more than a week following the biopsy, baby E had to be tube-fed till she was almost a year old, which was when she was able to swallow her food without problem.

At three months, a miracle happened. A scan showed no change to the size of the tumour, which was unusual.

High-grade cancerous tumours should be doubling every few months, but E's was "not behaving like cancer", said Dr Nga.

Dr Balamurugan Vellayappan, a senior radiation oncologist at the National University Cancer Institute, Singapore, who was part of the team, said: "The fact that the tumour didn't double in size or didn't even grow in three months was already unusual."

Said Dr Nga: "While it is not possible to be conclusive, we believe that the tumour regression, in this particular case, is related to the biopsy that was performed."

He explained that surgical stimulation could have attracted immune cells and activated local immune responses – which means her body was now fighting the cancerous tumour.

Six months after the biopsy, the tumour had shrunk by half. Dr Vellayappan said: "The space around the brain stem had started to open up. Previously, it was squashed. Now at two years-plus of age, the tumour has, kind of like, just stabilised."

As a result, the pressure on the brain stem has eased. E no longer has trouble swallowing and her facial droop has disappeared. Aside from needing to do brain scans every few months, she is typical of toddlers that age – bright-eyed and cheery, going to childcare, and fighting with her older sister over toys.

Through the biopsy, doctors also discovered potential targets for treatment, should the tumour start growing again. Doctors are hoping that it will not, but should it happen, they hope E will be old enough to undergo treatment.

Mr Lee said the past two years have taken an enormous emotional toll on him and his wife. But now, "it feels great that she is doing well".

He added: "The reality is that the tumour is still there. But she could grow up with it there. If there are no medical issues, there is no need to fix something that ain't broke."

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