

Removed both kidneys at 10 months old

Received mum's kidney at age 5

Primary 2 pupil Hannah Phoa was born with a rare disorder, but gets a new lease of life with organ transplant

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Seven-year-old Hannah Phoa was put on dialysis when she was just 10 days old.

A rare disorder detected shortly after she was born signalled the imminence of kidney failure.

Her two kidneys were removed when she was 10 months old. For the first five years or so of her life, her body could not produce urine.

She endured dialysis for up to 14 hours a day and had to be tube-fed. Dialysis is a treatment to remove waste products and excess fluid from the blood when the kidneys malfunction.

As soon as she could, her mother donated one of her kidneys to Hannah in January 2021, when the child was five.

Ms Leong Wei Yee, 39, says: "It was an automatic decision. It would give Hannah a better quality of life. Like other parents in similar situations, it's a privilege to give my kidney to her, not so much a sacrifice."

The public health researcher adds: "A transplant had always been the goal. It was just a matter of when — she needed to gain enough weight for the surgery."

In fact, both Ms Leong and her husband, teacher Desmond Phoa, 40, were found to be suitable kidney donors for their eldest child.

To decide who should donate a kidney to Hannah, the couple — who have a four-year-old son and another daughter aged three — weighed considerations such as how much recovery time was needed after the transplant.

Ms Leong's work would be less affected, as she was working part-time then. She was glad that Hannah did not have to wait nine years for a transplant, which is the average waiting time for patients who received a kidney from a deceased donor in

2022, according to statistics published by the National Organ Transplant Unit. June 6 is World Transplant Day, which calls attention to persons who live with transplanted organs or are waiting for transplantation. Even while Hannah, now a Pri-

Hannah Phoa and her mother Leong Wei Yee (both left), who donated her kidney to Hannah in 2021.

mary 2 pupil, was in the womb, her kidneys were not working properly. When Ms Leong was seven months pregnant with Hannah, she was hospitalised after a routine ultrasound scan showed unusually low levels of amniotic fluid.



Hannah Phoa when she was around five months old. Like most babies with kidney failure, Hannah had to be tube-fed to meet her nutritional needs. PHOTOS: EUGENE TAN, COURTESY OF LEONG WEI YEE

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HANNAH PHOA, on the time she was sick and needed between 10 and 14 hours of dialysis daily

"The decreased amniotic fluid suggested that something may be wrong in the kidneys because less urine was being produced," says one of Hannah's doctors, Associate Professor Ng Kar Hui. She is a senior consultant at the paediatric kidney transplantation

programme at National University Centre for Organ Transplantation (NUCOT), the specialist centre for both adult and paediatric organ transplantation under National University Hospital (NUH).

Hannah had a swollen appearance after she was delivered prematurely at 34 weeks of pregnancy.

Genetic testing found that she has Denys-Drash syndrome, where scar tissue forms throughout the tiny blood vessels in the kidneys that filter waste from blood. The rare condition is characterised by kidney failure, typically before the age of three, and, in most cases, Wilms tumour, a type of kidney cancer.

"Every 10 years, we see three to four cases of Denys-Drash syndrome of varying severity," says Professor Yap Hui Kim, another of Hannah's doctors.

She is the medical director and emeritus consultant of the paediatric kidney transplantation programme at NUCOT, where Hannah's transplant took place two years ago.

Like most babies with kidney failure, Hannah had to be tube-fed to meet her nutritional needs, as well as to administer her medicines. Being tube-fed gave her an aversion to food. "As she matured after the transplant, this has improved with time," says Ng.

In Hannah's early childhood, blended food sustained her via a gastrostomy tube inserted into her stomach. She only occasionally had a bite of certain foods, with the help of a feeding therapist.

Around two weeks after her transplant, she tried some cheese-flavoured Cheetos snacks for the first time. "When I started eating cheese, it was so good," says Hannah, who has since developed lactose intolerance and now avoids dairy.

Most of her dialysis was done at home using a machine, for between 10 and 14 hours daily.

The dialysis machine worked during the night as she slept, as well as during some of her waking hours, where she was largely kept occupied by her iPad. Prolonged screen time was not ideal, but difficult to avoid under the circumstances, says her mother.

Hannah has had numerous trips to the hospital and more than seven surgical procedures, including the transplant. But she is still scared of needles. She keeps a hand towel with her, which serves as a security blanket whenever she has to undergo yet another procedure.

"I feel much better when I go to Physcape, where there's a big Peppa Pig house," she says, referring to a space for children at NUH that is filled with books and toys and is used by therapists, hospital staff and child patients.

Ms Leong says: "It sounds like there are a lot of logistics involved in caregiving, but it became a routine. When there's a routine, it gets a bit better. As long as the child is out of the hospital, that is already something that we're happy with." She and her husband eventually got so used to caring for Hannah that they once tube-fed her on an excursion to the zoo.

Post-transplant, Hannah has to continue taking medication and lead a healthy lifestyle.

She and her parents also receive psychosocial support from the multidisciplinary team at NUH caring for Hannah.

Prof Yap says: "Kidney rejection is always a risk. If it happens, she has to go back to dialysis. This is a lifelong journey. The child eventually needs to own the disease and manage her health, rather than the parents."

Hannah seems to be taking developments in her stride. When she entered Primary 1 in 2022, she went to the toilet every two hours because of her higher fluid intake. Her teacher even got her to tell her classmates about her

condition. "Kids are very resilient," notes Ms Leong.

Mr Phoa says his ideas about parenting have been overturned. "When you are expecting a child, you may think that you want your child to excel in certain areas. When we had Hannah, all of that changed. We want her to be healthy and happy."

"Our approach is interest-driven, rather than chasing after excellence. It's about doing your best and not giving up."

Hannah recently took up ballet and wushu.

Reflecting on the past, she says: "My kidneys weren't working well that time. My mum was very generous and gave me one of her kidneys."

She fondly remembers the day when the home dialysis machine was returned to the hospital.

She says: "I was jumping around. I didn't need dialysis any more. I was so excited. When I felt all better, I said, 'Bye bye, dialysis!'"

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