Push for Kawasaki

Parents band together to raise awareness of this rare early childhood disease. Joan Chew finds out more

When Ms Sunita Sue Leng’s son was five months old, he came down with a bout of fever which did not go away after three days.

By the fourth day, Jun Kai, now 2 1/2 years old, also had red eyes.

Later, at Raffles Hospital, the baby developed red lips, a rash and swelling of the lymph nodes in the neck. This prompted the paediatrician, Dr Chu Hui Ping of Raffles Children’s Centre, to diagnose him with Kawasaki disease.

Ms Sunita, a 46-year-old freelance writer, said: “I remember staring at her in shock and thinking, ‘There’s a disease named after a motorcycle?’ I had never heard of it.”

Today, she has gone one step further by forming a new support group for caregivers of children suffering from Kawasaki disease.

The rare condition, which has no known cause, gives rise to inflammation of the small- and medium-sized blood vessels throughout the body, which can sometimes lead to problems in the coronary arteries of the heart.

When Jun Kai was hospitalised, Ms Sunita tried to read up as much as she could about Kawasaki disease online, but the information was mostly from the United States.

“At that time, I wished there was someone here whom I could speak to about this disease. I searched for a support group in Singapore, but couldn’t find one,” she said.

She and five other mothers are now plugging this gap by offering to share their experiences with other families whom they hope to link up with via their doctors and other medical professionals.

Back then, Jun Kai was treated with antibiotics, namely intravenous immunoglobulin, to relieve the acute inflammation and resolve his fever.

This medication, which is usually given once, also reduces the risk of someone with Kawasaki developing coronary aneurysms from over 25 per cent to no more than 5 per cent, said Dr Chu. A coronary aneurysm is when part of the artery that sends blood to the heart dilates abnormally.

This is the main danger of the disease, Dr Chu warned, as an aneurysm can block blood flow to the heart or rupture, either of which would cause death.

Jun Kai was found to have a mild dilatation of his left coronary artery. He was given aspirin to reduce the risk of a clot forming there. For several months, Ms Sunita had to crush the pills to mix them in his milk. Thankfully, further tests have shown that the problem has resolved, so he no longer requires medication.

RAISING THE ALERT

Looking ahead, the group hopes to reach not only parents but also more importantly, general practitioners to be alert to the disease.

Of the seven mothers who responded to Ms Sunita’s Facebook page in 2013, one later lost her 23-year-old son to a heart attack. It was caused by a coronary aneurysm, said Ms Magdalene Tan, 43. Her son, the oldest of three children, was diagnosed with Kawasaki disease when he was an infant. While he had undergone angioplasty procedure last year to widen the affected blood vessel, it narrowed again and caused the fatal heart attack.

“Although it was a tragic end for him, I hope something good comes out of our efforts with this support group,” said Ms Tan, who works as a physiotherapist.

“We want parents to know that the condition can be reversed if it is detected and treated early,” Ms Sunita said, who held its first meeting last month at Suntec City mall, also wants to promote discussions on issues related to raising children with heart problems from Kawasaki disease.

These include questions on whether such children can take part in competitive sports, if the boys can go on to do national service and the types of insurance plans parents should get for these children.

As Ms Tan put it in a message on the group’s Facebook page: “No parent should ever have to bury or cremate his child.”

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For more information about the support group, go to: facebook.com/KawasakiDiseaseSupportGroupSingapore

Blood vessels on fire

The inflammation of the blood vessels in Kawasaki disease is more like having them on fire. The longer the fire is allowed to burn, the greater the risk of damage to the vessels, said Dr Terence Lim, a consultant at the division of paediatric cardiology at National University Hospital (NUH).

“No one knows exactly why this fire starts, why it happens in children only and why it happens most often to Asian children,” he said.

Boys get Kawasaki disease more often than girls; and in Singapore’s population, Chinese children are at greatest risk.

According to the latest study by NUH and KK Women’s and Children’s Hospital, the incidence of Kawasaki disease in Singapore is estimated at 51.4 per 100,000 children aged five and under, said Associate Professor Tan Teng Hong, head and senior consultant at the cardiology service in the department of paediatric sub-specialties at KK Women’s and Children’s Hospital (KKH).

The blood vessels supplying the heart with blood are most vulnerable to damage, so treatment is focused on reducing the risk of damage to the coronary arteries with antibodies, a procedure called intravenous immunoglobulin.

Aspirin is also used as an adjunct treatment, said Prof Tan.

High doses of aspirin are given in the acute phase, then reduced to low doses once a day in the later phase of the disease, he said.

At KKH, about 30 per cent of the Kawasaki disease patients develop coronary abnormalities. Most of them fall under mild dilatation of the coronary artery.

When a coronary artery becomes very dilated over time, there is a higher risk of it narrowing, which raises a patient’s risk of a heart attack, said Dr Lim. This is because the body repairs itself by growing scar tissues, which narrow the vessel.

Of greater concern to Prof Tan is the 5 per cent of patients who develop coronary aneurysms, which can weaken the heart, block blood flow and lead to abnormal heart rhythms or sudden death.

Dr Chu Hui Ping, a specialist in paediatric medicine and a consultant at Raffles Children’s Centre at Raffles Hospital, said the disease usually presents with high fever lasting more than five days.

The child may also develop a rash, conjunctivitis (red or sore eyes), red lips or tongue, swollen lymph nodes in the neck, swollen and red hands and feet, and in the illness, peeling skin on the fingers and toes, she added.

Dr Lim said Kawasaki disease is difficult to diagnose as it appears to be like any other childhood infection.

“Fever and rash are very common in young children and the vast majority of cases are due to viral illnesses, which most children recover from in four to seven days,” he said.

But one should suspect Kawasaki disease if the child’s fever and rash is accompanied by red eyes.

“Parents who are well-read can remind their doctors about this,” he said.