

# 26 health

DISEASE HAS 'HIDE-AND-SEEK' SYMPTOMS THAT COME AND GO

## Lupus more severe when it afflicts younger sufferers

*Children more susceptible to potentially life-threatening organ damage than adult patients, says doctor*

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**SINGAPORE** – The immune system normally protects the body by fending off germs and infections. But that is not the case for 15-year-old Lau Ling Jie,

who was diagnosed with the autoimmune disease lupus, or systemic lupus erythematosus, at the age of 11.

Her immune system turned on itself, producing inflammation in various parts of her body and even causing damage to her kidneys.

She initially experienced repeated episodes of nosebleeds, fatigue, vomiting and rashes across her nose and cheeks — symptoms which baffled several doctors at first.

By the time they figured out what it was, her kidneys had already begun



Lau Ling Jie, 15, was diagnosed with the autoimmune disease lupus at the age of 11. She is still on regular follow-up doctor's visits and takes 18 pills every day. PHOTO: LAU LING JIE

### THE RIGHT TREATMENT CAN LIMIT DAMAGE

“While there is currently no cure for lupus, advances in treatment mean that what used to be an untreatable disease is now considered a chronic condition. The right treatment can protect the organs from being permanently damaged, and more than 80 per cent of patients are able to live a normal lifespan, said Dr Ooi Pei Ling, associate consultant at NUH's Division of Paediatric Allergy, Immunology and Rheumatology.

to fail and she was referred to the National University Hospital (NUH), where she was warded in an intensive care unit (ICU). She also required dialysis then.

“Initially my mum and I thought it was just some random infection and I would recover quickly from it, but who knew it would be so serious?” said Ling Jie, who was hospitalised for about two months.

“At one point in time, I didn't want to continue living because of the pain. I literally lay on the hospital bed all day and night, hooked up on machines, not knowing night from day.”

Lupus tends to affect older women, whose risk of developing the disease is 10 times higher than men, but children are not spared either.

According to Dr Elizabeth Ang, consultant at NUH's Division of Paediatric Allergy, Immunology and Rheumatology, the disease starts in childhood or

### ⚠ WARNING SIGNS

According to NUH's Dr Ooi Pei Ling, children with lupus often have at least two of the following symptoms:

- Fever, fatigue, weight loss and increased hair loss
- Joint pain or swelling (arthritis)
- Mouth or nose ulcers
- “Butterfly rash” on the cheeks or other rashes on the body
- Fluid around the heart or lungs
- Seizures or other nervous system problems (which can manifest as severe headaches or changes in behaviour)
- Kidney problems (blood or protein in the urine)
- Problems with the blood cells, such as low white blood cell levels and anaemia (which causes the patient to look pale) and low platelet counts (easy bruising)

adolescence in up to one-fifth of all lupus sufferers. In Singapore, it affects about 120 to 150 children.

● CONTINUED ON PAGE 27

● CONTINUED FROM PAGE 26

## CHILDREN AT GREATER RISK OF ORGAN DAMAGE

While lupus can strike across all ages, younger patients like Ling Jie often face very different challenges compared to adults. In children, the disease tends to be more severe at the beginning, and more active or aggressive throughout life, said Dr Ang.

As such, they are more susceptible to developing potentially life-threatening organ damage than adult patients, especially to the kidneys, nervous system and brain.

NUH sees about 80 to 100 children and teens with lupus, in particular, the more complex cases with severe kidney disease.

“An earlier onset of the disease also means that a child with lupus has more time to accumulate damage in any organ. A child who is diagnosed at 10 years old has many years of life ahead compared to an adult who develops the disease at 40,” said Dr Ang.

It is unclear what causes the body’s immune system to go rogue. What is known, according to Dr Ang, is that it involves a complex interaction between a person’s genes and environmental factors, such as infections and sunlight which can also trigger a flare-up in patients with the disease.

“The younger a child when he gets lupus, the more likely there is (to be) a genetic component to the disease. Even so, multiple genes contribute to the likelihood of getting the disease, so it is difficult to predict if or when a family member will develop lupus just because another relative has it,” she added.

Its hide-and-seek symptoms (see Warning Signs), which may appear similar to those of other illnesses, may delay early diagnosis and treatment.

“The symptoms can come and go, and vary from person to person. This makes the diagnosis challenging and can result in a delay in the diagnosis,” said Dr Ooi Pei Ling, associate consultant at NUH’s Division of Paediatric Allergy, Immunology and Rheumatology.

## TREATMENT ALLOWS PATIENTS TO LEAD NORMAL LIVES

While there is currently no cure for lupus, advances in treatment mean that what used to be an untreatable disease is now considered a chronic condition. The right treatment can protect the organs from being permanently damaged, and more than 80 per cent of patients are able to live a normal lifespan, said Dr Ooi.

According to her, nearly all patients require at least one medication, and many will need several. The number of medications can be gradually reduced once the disease is in remission.

“The aim of treatment is to keep the disease under control or in remission, with no flare-ups. This is possible if the child or teen takes the prescribed medication faithfully, leads a healthy lifestyle, and attends doctor’s

visits regularly,” said Dr Ang.

That said, sticking to a daily medication routine for years can sometimes be challenging for young patients.

“Sometimes as part of teenage angst, some of them stop taking their medication. This can be a difficult period for the family, emotionally and physically. The psychological impact of having a chronic disease is equally hard to bear. The family plays a vital role in such cases,” said Dr Ang.

With aggressive treatment, as well as a dose of luck, Ling Jie eventually recovered her kidney function and no longer requires dialysis.

She is still on regular follow-ups and takes a total of 18 pills every day, inconveniences which she gladly follows through to keep the disease under control. She also takes precautions against flare-ups by applying sunblock on her skin.

Today, nothing can stand between her and her love of sports, particularly

rhythmic gymnastics, and she leads a happy and active life.

Her mother, Madam Joyce Loh, 50, said Ling Jie has come a long way since her ICU days in 2012, where explosive temper tantrums were a common affair due to her frustration at having to deal with the painful symptoms.

“She’s so much more positive now. Going through this disease with my daughter has been an eye-opener for me; we should never take life for granted,” said Mdm Loh.

## SEVERAL MEDICATIONS

● Nearly all lupus patients require at least one medication, and many will need several. The number of medications can be gradually reduced once the disease is in remission.