

# Overcoming lupus to become a mum to baby boy

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Ms Nur Amalina Norraimi was 15 when she began to get unexplained fever and headaches almost every day for months.

Once an avid netball player at Hillgrove Secondary School, she found herself taking frequent rest breaks because “my body was very weak”. Rashes would appear on her face and arms if she went out in the sun without sunscreen.

Over-the-counter paracetamol did not help and the general practitioners she visited were puzzled, with some suspecting she had dengue fever.

After an episode of 39.8 deg C fever that did not subside despite medication, her parents took her to Bukit Batok Polyclinic, where the doctor immediately called for an ambulance. Doctors at the National University Hospital (NUH), where she was warded, finally found the cause of her illness – she had systemic lupus erythematosus (SLE).

More commonly known as lupus, SLE is a chronic autoimmune disease in which the body’s immune system mistakenly attacks healthy tissues, such as the skin, joints, kidneys, brain and other organs.

Symptoms typically include fatigue, joint pain and swelling, skin rashes, fever, hair loss, kidney problems, sensitivity to sunlight and mouth ulcers. There is no cure.

Lupus is in the news after American singer-actress Selena Gomez recently revealed that is one reason she cannot have kids. The founder

of Rare Beauty, a make-up and skincare line, was diagnosed with the disease in 2015 and underwent a kidney transplant two years later.

“I haven’t ever said this, but I unfortunately can’t carry my own children,” Gomez told Vanity Fair magazine in a new interview published on Sept 9.

“I have a lot of medical issues that would put my life and the baby’s in jeopardy. That was something I had to grieve for a while.”

Gomez did not reveal the details of her medical issues in the interview, but said she was considering adoption or surrogacy.

Other celebrities with SLE include American singers Toni Braxton and Halsey.

Women make up about 90 per cent of lupus patients and the condition often develops during their childbearing period of 15 to 45 years old, says Professor Anselm Mak, a senior consultant at NUH’s Division of Rheumatology in the Department of Medicine.

Certain ethnic populations, such as Asians and African Americans, seem more predisposed to lupus, compared with Caucasians.

Prof Mak cites a 2001 study from Tan Tock Seng Hospital, which estimated that the prevalence of SLE was about 40 per 100,000 people in Singapore. “This figure is likely to be higher today due to increased awareness and better identification of the condition,” he says.

Medical experts do not know exactly why lupus affects women more than men, although the higher levels of oestrogen in women’s bodies, along with genetic and en-



Lupus patient Nur Amalina Norraimi with her son, Shayaan Aniq Syaifulbahari, who was born in January. She had worried that her condition might not allow her to start a family. ST PHOTO: JASON QUAH

vironmental factors, are thought to play a part, Prof Mak says.

Ms Amalina, now 28, says her lupus diagnosis came as a shock. In her teen years, she had to give up her thrice-weekly netball training sessions and was in and out of the hospital at least five times a year.

“I couldn’t do anything my friends did and I spent a lot of time in the hospital. Not many people were aware of what lupus was then, so I just told them that I was

sick and couldn’t attend school activities,” she says.

One of the four medications she took then was costly – \$500 for a month’s supply – which was financially painful for her father, who worked for a transport operator, and her mother, who worked in manufacturing. No one else in her family has the condition. She has a younger brother, now aged 20.

At one point, her family sought help from a medical social worker

to relieve their burden. Her medication was later changed to one costing one-tenth the price.

Her condition improved enough for her to sit the N-level examinations in 2012, following which she studied at the Institute of Technical Education and worked in food and beverage roles. In 2017, she pursued a part-time diploma in business practice (hospitality management) from Republic Polytechnic.

She says her husband, civil servant Syaifulbahari Asfar, 30, has been quietly supporting her since they met in 2018, accompanying her to medical appointments before she married him at age 26 in 2022.

Through it all, she wondered if lupus would prevent her from becoming a mother. “I was quite worried that I couldn’t get pregnant and, that if I got pregnant, there would be something wrong with the baby,” she recounts.

Patients with lupus face a higher risk of pregnancy complications, including having their water bag breaking early, preterm delivery, poor foetal growth and pregnancy loss, says Associate Professor Chan Shiao-Yng, a senior consultant at NUH’s Division of Maternal Fetal Medicine in the Department of Obstetrics & Gynaecology, who is part of the team that looks after Ms Amalina.

Women who have kidney function impairment because of lupus are also at risk of pre-eclampsia, a potentially dangerous high blood pressure condition of pregnancy, adds Dr Chan Gek Cher, a consult-

ant at the Division of Nephrology in NUH’s Department of Medicine.

Ms Amalina’s condition seemed under control with no flare-ups, and she has been in remission since 2022. After consulting with Prof Mak and Dr Chan, she was given the green light to try for a child in April 2023.

In June 2023, she took a pregnancy test on a whim. To her surprise, she saw double lines. She confirmed that she was about three to four weeks pregnant the next day at a polyclinic.

Her pregnancy was smooth sailing with mild morning sickness, and her son, Shayaan Aniq Syaifulbahari, was born in mid-January.

The most dramatic part of her pregnancy was waiting 48 hours for Shayaan’s birth after being induced at 38 weeks because of her condition – she eventually had to have a caesarean section.

“I’m thankful that he was born healthy,” she says, adding that she plans to breastfeed him until he turns two. She is open to having another child later and now takes three types of medication, including a pregnancy-safe one.

Having had lupus for almost half her life, Ms Amalina is grateful for her family’s support, such as reminding her to take her medication and accompanying her to medical appointments.

“Having lupus is not easy and many people are aware of it. By sharing this, I hope that more women out there who have lupus will know that you can get married and have a baby,” she says. “Just don’t give up.”