

TOP STORY

No sweat

Born with a rare disorder, Loh Yihang has no sweat glands and only three teeth, but as mother Janice Chuah tells Theresa Tan, that doesn't stand in his way at all.



THREE TEETH? NO SWEAT: Loh Yihang is just four but he will need dentures in a few years. And he lives in danger of heat stroke as he can't sweat. [In full](#)

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Born with a rare disorder, Loh Yihang has no sweat glands and only three teeth, but as mother Janice Chuah tells Theresa Tan, that doesn't stand in his way at all.

Teacher Janice Chuah, 32, blogs about her life and times with her children Yihang, four, and Yixiang, 10 months old.



Unable to perspire, Yihang knows how to cool himself down by spraying himself with water or lying on a marble floor.

Her blog (www.parentsphere.com) offers readers an honest and witty look inside the world of a mother of a special needs child.

Yihang, her first-born, was conceived three weeks into her marriage to Mr Loh Tian How, a corporate planning and business development manager, now 32.

'At birth, the first thing that caught our attention was Yihang's bald, round head,' recalls Madam Chuah.

His parents also noticed that he had an unusually hoarse, raspy voice like that of an 'old man'.

There was darkening and wrinkling around the eyes, which he could not open because of infection. His skin was red, peeling and very thin, revealing surface blood vessels. Little did they know these were the telltale signs of a very rare genetic disorder.

According to the United States-based National Foundation for Ectodermal Dysplasia (NFED), the ectodermal dysplasia (ED) syndromes are a group of about 150 inheritable disorders that affect the ectoderm, the outer layer of tissue in a developing baby.

The ectoderm contributes to the formation of many parts of the body, including the skin, sweat glands, hair, teeth and nails. During embryonic development, these may fail to develop normally. ED is caused by either a gene mutation as a baby is forming, or is passed down from a carrier mother to her son. Girls do not show signs or symptoms of ED but may be carriers.

Madam Chuah started noticing that Yihang was slow in reaching physical milestones such as crawling and sitting. He also had persistent eczema and excessively thick mucus. At five months old, he was grossly underweight.

Her mother's instinct kicked in and she sought the advice of a number of paediatricians, most of whom told her she was 'paranoid' and that Yihang would outgrow his symptoms.

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But one noticed that Yihang had disturbing physical features such as low-set ears, absent eyebrows and a prominent forehead. Madam Chuah says: 'We were referred to a geneticist, who confirmed that Yihang (then eight months old) was affected by a type of ED known as hyperhydrotic ectodermal dysplasia (HED).'

It was hard news to take. 'I cried inconsolably. Although devastated, my spouse wiped away my tears and told me that we have to be strong.

'We did not dwell on the issue for too long. We accepted his condition and talked openly to family and friends about Yihang's condition,' she says.

They also began researching the condition. There is no known support group or centre for ED in Singapore, but they came across the NFED and e-mailed it for information.

They also joined an international online support group for ED sufferers, which is where they now go for encouragement and answers.

Sparse hair aside, Yihang's physical challenges include having only one cone-shaped front incisor (he broke the other one in a fall) and two molars.

'He will need dentures in a few years' time,' says Madam Chuah. 'Teeth implants will come later.'

Yihang's thin dry skin is prone to eczema. He is not able to perspire, which could cause his temperature to spike and lead to heat stroke.

But this doesn't mean his parents don't let him play in the sun. 'We believe in teaching him to cope with the heat,' says Madam Chuah. 'He's a bright and independent boy who is able to take care of himself - like spraying himself with water when he gets 'overheated'!

Yihang, who turned four in April, is a cheerful boy who has developed healthy self-esteem. His mother describes him as a social creature, who's always invited to birthday parties.

'We went to a party once and we had parents who came up and said, 'Oh, I've got to meet Yihang because my girl has been talking about him every day!' '

HED largely does not affect the intellect. Yihang started attending a Montessori school when he was two and a half.

Says Madam Chuah, whose second son Yixiang does not have ED: 'We found a school where he is accepted and well-loved by not only the teachers, but also his peers. He's generally very happy in school.

'I started my blog as a record of snippets of my sons' childhood and our parenting journey.

'When they are older and able to read, we hope the entries will help reiterate our love for them, explain the fears we encounter, tell of the tears we shed, convey the hope we have for them and thank them for the joy they brought us.

'Yihang is intelligent, witty, mature and sensible; like most parents, we are committed to help him achieve his fullest potential and do well in life,' she says. 'But above all, we want him to be a well-adjusted, confident and happy individual who will contribute positively to society.'

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WHERE TO GET HELP

- Hunnybunz Blog: www.parentsphere.com
- National Foundation of Ectodermal Dysplasia: www.nfed.org
- International support group for families and individuals living with ED: health.groups.yahoo.com