Satish

Satishwaran Ahrumugam
23 June 2003 - 30 November 2005

Why meeting was 'pointless'
Dead soldier's uncle tells court family members walked out five minutes into hospital meeting as they were not allowed to ask questions.
PAGE H5

HOME
THE STRAITS TIMES THURSDAY JUNE 23, 2005

Baby with rare gene disease can't eat

›› Needs intravenous feeding ›› Twice at death's door ›› Disorder never documented: US doc

BY TRACY SUA

SATISHWARAN Ahrumugam turns two today. But there will be no cake for the birthday boy.

Satish either throws up everything he eats or it goes right through him. The only "food" that he can keep in his body is rice water and a special nutrient-filled milk formula.

Since his birth, he has spent only about 30 days outside a hospital, as his low immunity level makes him prone to infections.

He fell sick so often — he had chest infections, high fever, fits, liver cirrhosis — that doctors thought at first that he might have contracted pneumonia or liver cancer or even the Aids virus.

But it turned out that he is afflicted with a congenital disease so rare his parents have not been able to find a doctor to treat him.

Madam Dhevaki Sokkalingam, 32, a housewife, and Mr Ahrumugam Valaitham, 39, a buyer with a computer company, were at their wits' end watching their youngest of three children constantly at death's door.

What starts out as diarrhoea usually leads to something more serious. In May last year, he contracted septicemia and collapsed from septic shock with high fever.

Blood had accumulated in his stomach and he was given 24 hours to live.

Recalled Madam Dhevaki: "We kept thinking, 'What is wrong, what did we do wrong?' and we kept wondering why this is happening."

But Satish pulled through, celebrated his first birthday, went to National University Hospital for some tests to determine what he was suffering from — and ended up near death again.

His liver was like that of an alcoholic, doctors found.

His parents alternated between despair and frustration. Despair over their inability to save their child and frustration that nobody knew what was ailing him.

But again, he pulled through.

His blood samples were sent to Australia and the United States.

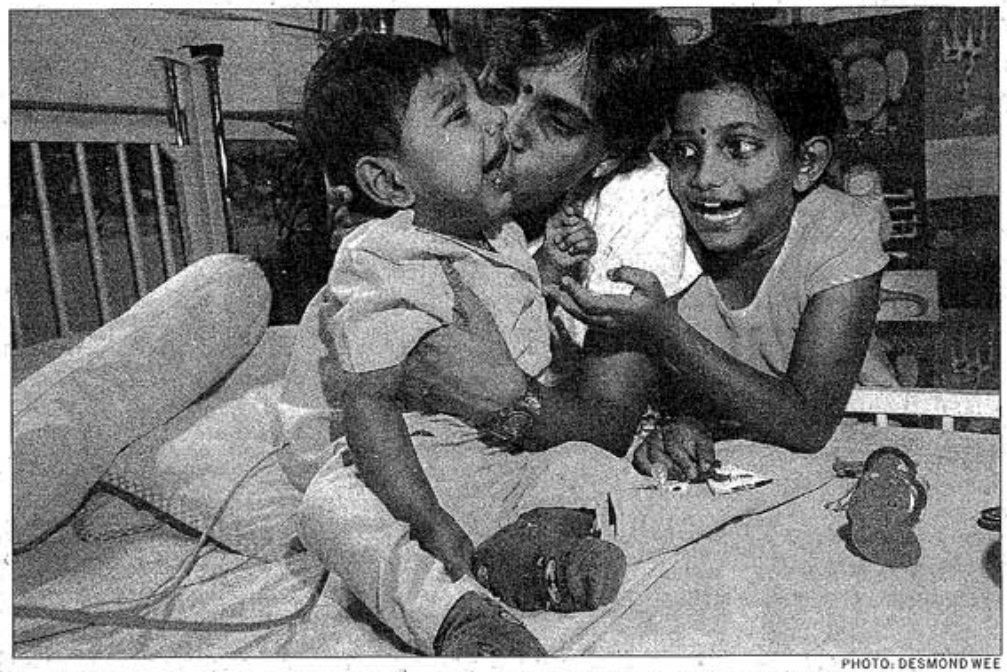


PHOTO: DESMOND WEE

Last October, scientist Dr Hudson Freeze from The Burnham Institute in California found that Satish is suffering from a metabolic disease that affects many different organ systems including digestive and immune systems.

Although there are about 20 types of this disease, Satish's congenital disorder has never been documented.

Dr Freeze told The Straits Times: "He is the pioneer and writing his own book.

"The downside is we don't have any other patients for comparison. We can't predict what lies ahead.

"We are trying to find the specific gene where he has a problem and if we discover that, it is the first necessary step to trying to find a rational treatment."

Recognising that their two other children, aged three and eight, also deserved their attention, Satish's parents moved him to KK Women's and Children's Hospital (KKH), which is closer to home.

The couple spent most of their free time there, with Mr Ahrumugam even working from a laptop by his son's hospital bed.

They estimated that they have spent about $25,000 on Satish's medical bills, so much so that their Medisave accounts have been depleted and they now owe KKH $20,000.

Satish cannot walk or talk. He weighs 8.6kg when children his age are about 10kg to 15.5kg and can form three- or four-word sentences and wear their clothes.

Dr Tan Ee Shien, registrar of the paediatrics department in KKH, said that Satish's main source of nutrition now is a milk formula fed to him intravenously. He is also on medication to boost his immunity.

Yesterday, he was in hospital still nursing an infection that set in after a device was implanted in his body to help control his feeds and extract blood samples.

MUM: I'LL KEEP GIVING 200%

"I'm giving 200 per cent no matter what, even though I know some day we have to face it that he may not pull through and may even die...

"I'm still halfway accepting the fact that the chances of me seeing him at 10 years old are slim.

"But I feel it is worth all the effort and time spent trying to find out what is wrong with him and the many hours spent by his bedside praying for him and being there for him."

MADAM DHEVAKI — with daughter Subethira (right), eight, and Satish — on her two-year-old son's condition.

Said Madam Dhevaki: "I'm giving 200 per cent no matter what, even though I know some day we have to face it that he may not pull through and may even die.

"So why not celebrate him when he is around and tell others about him.

"I'm still halfway accepting the fact that the chances of me seeing him at 10 years old are slim.

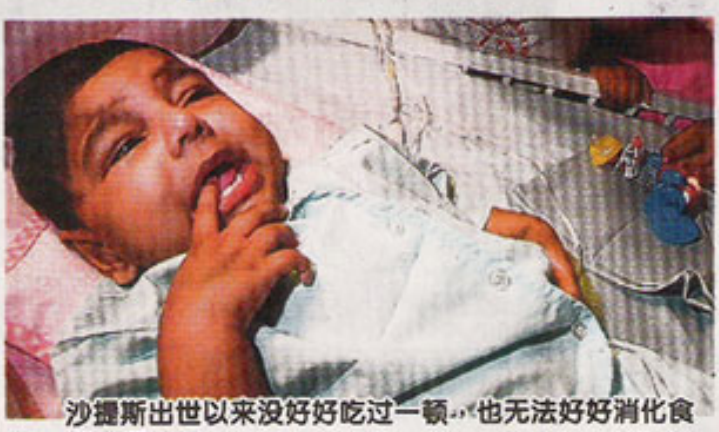
"But I feel it is worth all the effort and time spent trying to find out what is wrong with him and the many hours spent by his bedside praying for him and being there for him."

无法消化食物 不断泻肚子

2岁男童口出血 指甲变蓝而死

他出世后就没有好好吃过一顿，他无法好好消化食物、不断泻肚子，最后指甲变蓝、嘴巴出血……

本地这名两岁男童患上了罕见的“代谢异常症”。美国专家说，这是一种医学上从来没有记录过的罕见遗传病，医生专家还找不到治疗的办法。小男孩已经在一个月前去世了。



沙提斯出世以来没好好吃过一顿，也无法好好消化食物，经常泻肚子。（图片/ST）

一出娘胎 就和病魔搏斗

这名两岁男童叫沙提斯，一出娘胎就和病魔搏斗，去年11月30日，他去世了。

他的母亲德瓦姬（32岁）接受《海峡时报》访问时，回忆孩子在世最后一天的情形：“到了半夜，医生告诉我们，他已经挣扎够了，必须让他慢慢的离开世界。”

德瓦姬和丈夫阿鲁穆甘（39）有3个孩子，沙提斯是老幺。

专家确定，沙提斯患上的怪病属于先天性糖基化失调症（Congenital Disorder of Glycosylation，简称CDG）。这种病共有20种，但沙提斯所罹患的这一种在医学上从来没有记载过。

先天性糖基化失调症侵袭人类的消化系统和免疫系统。所以，沙提斯从没有一次好好地消化过食物，而且经常出现严重腹泻、病毒感染和肝硬化，饱受折腾。

面对死神的他，进出医院如家常便饭，竹脚妇幼医院的65号病房简直是他的第二个家。

怪病阻止沙提斯成长，他无法像同龄孩童那样走路、说话。连“爸爸”“妈妈”都不会叫。直到他即将离开父母亲人的前几天，爸爸妈妈第一次听见他叫了“阿爸”“阿妈”……

罕见‘代谢异常症’ 医生毫无头绪

美国医学专家原本在为男童找药方，没想到男童来不及等到这一天，就不幸去世。

由于沙提斯的怪病太罕见，本地医生一直毫无头绪，直到前年4月，男童一岁的时候，狮城医生向美国加州著名的Burnham医学研究所求助，才总算有点概念。

有关研究所的科学家哈森博士（Dr Hudson Freeze）和研究团队发现，这个代谢异常症非比寻常，属于先天性糖基化失调症，但却和过去记载的20种类型都不一样。

哈森博士研究了男童的皮肤细胞，希望获知其中有何异常现象影响身体的其他组织。

他告诉《海峡时报》说，研究员已看到男童的血蛋白出现异常，但还必须进一步发现细胞内的异常现象，研究工作才能有突破性的进展。

但对沙提斯来说，这一切都太迟了。

男童微笑的照片，原是研究员最大的推动力，如今传来他去世的消息，积极研究药方的专家无不饱受打击。

哈森博士说，沙提斯的死给了研究团队很大的打击。“我们经常看着他妈妈寄来的他满脸微笑的照片，那对实验室里的大家是很好的充电器。”

在男童去世的两个星期后，哈森博士在小儿科期刊上发表了有关沙提斯的研究报告。“我们刊登他的个案，希望能警惕全世界更留意类似的病患，也希望这些病患能联络我们。”

哈森博士最近也与我国的分子与细胞生物学学院合作，希望能找到这种病症的根本原因，并尝试将正常基因引进细胞，从而纠正有缺陷的基因。

▲痛苦的离别：德瓦姬（右）仍然无法接受沙提斯已永远离开她。

安心走吧！我告诉孩子

男童等妈妈跟他说了再见，才安然去世。

在爱儿临终前，德瓦姬忧伤地抱着他，轻缓地摇晃。“我告诉他，停止搏斗，安心走吧，妈妈会好好活下去的。我的儿子战斗到最后一分钟，等着我说了OK才走，我真以他为荣。”

“我希望，别再有任何一个家长或孩子经历这一切。”说着，她已泪流满面。

德瓦姬是在11月底，最后一次送儿子进医院。自从沙提斯的怪病在去年6月刊登以来，他的父母得到广大公众的支持鼓励，令这家人感激不已。

经历丧子之痛后，德瓦姬准备报读辅导课程，帮助更多需要支持鼓励的家长。