

# Fund for rare diseases now covers Pompe

Citizens can get help with medical costs for neuromuscular disorder and 3 other illnesses

Yuen Sin

The Rare Disease Fund now covers Singaporeans with Pompe disease – a rare inherited neuromuscular disorder where patients can incur medical expenses in excess of \$500,000 each year.

The committee overseeing the fund announced yesterday that citizens can now apply for financial aid to help with their medical expenses for the disease, which affects about one in every 40,000 live births.

With the addition, the fund now covers four conditions, including primary bile acid synthesis disorder, Gaucher disease, and hyperphenylalaninaemia due to tetrahydrobiopterin deficiency.

The fund was launched by the Ministry of Health (MOH) and SingHealth Fund in July. It combines community donations and

government-matched contributions to provide aid for Singapore citizens with specific rare diseases, and has approved two applications for financial support so far.

One of the successful applicants was public servant Geoffrey Toi, 35, whose three-year-old son Christopher has primary bile acid synthesis disorder. The condition interferes with the production of bile acids and, if untreated, can lead to liver failure.

The fund covers a larger portion of Christopher's medication costs – currently about \$6,250 a month – than Medifund Junior, which previously subsidised part of his medical fees.

“It was a blessing when this fund was announced,” said Mr Toi.

Senior Minister of State for Health and Law Edwin Tong yesterday said the fund recently received significant support from Singapore investment firm Temasek and the Tsao Family Fund.



Public servant Geoffrey Toi and his wife, Straits Times correspondent Amelia Teng, watching as their three-year-old son Christopher interacted with Senior Minister of State for Health and Law Edwin Tong at the Punggol carnival organised by Mount Alvernia Hospital in support of the Rare Disease Fund yesterday. Christopher, who has the rare primary bile acid synthesis disorder, is a beneficiary of the fund. PHOTO: LIANHE ZAOBAO

It has grown from \$70 million in July to about \$90 million, with the Government matching community donations by three to one.

Mr Tong said he hopes more companies, community groups and individuals will support the fund.

“As more funds are raised, the Rare Disease Fund can be expanded further to cover even more types of treatments and more patients in the future,” said Mr Tong, who was attending a community carnival organised by Mount Alvernia Hospital in support of the fund.

The carnival in Punggol raised over \$200,000 for fund beneficiaries. The sum includes three-to-one

POTENTIAL TO HELP MORE PATIENTS

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The MOH defines rare diseases as conditions that affect fewer than one in 2,000 people, and are mostly genetic and often surface during childhood. In some cases, effective treatments are available and the medicines can substantially increase patients' life expectancy and improve quality of life. However, these medicines can be very costly, and patients often need to take them for the rest of their lives.

Pompe disease is caused by a defective gene that results in a deficiency of an enzyme.

It results in the excessive build-up of a substance called glycogen, a

form of sugar that is stored in a specialised compartment of muscle cells throughout the body.

Mr Kenneth Mah, whose 10-year-old daughter Chloe has Pompe disease, cheered the move to have the fund cover the disease.

While insurance now covers much of Chloe's treatment cost, which exceeds \$40,000 a month, it may not be enough in the future as she gets older and needs more medicine. “(The fund) gives us greater peace of mind,” said Mr Mah, 49, who is co-founder of the Rare Disorders Society Singapore.

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