

Pompe disease included in Rare Disease Fund

The inherited neuromuscular disorder, which affects 1 in every 40,000 live births, can incur more than \$500k in medical expenses each year

YUENSIN

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 and SingHealth Fund in July this year. It combines community donations and government-matched contributions to provide aid for Singapore citizens with specific rare diseases, and it has approved two applications for financial support so far.

One of the beneficiaries is Mr



Mr Geoffrey Toi and Ms Amelia Teng with their son Christopher, who suffers from primary bile acid synthesis disorder.

PHOTO: LIANHE ZAOBAO

Geoffrey Toi, 35, a public servant whose three-year-old son Christopher suffers from primary bile acid synthesis disorder.

The condition interferes with the production of bile acids and if untreated, can lead to liver failure.

BLESSING

The fund covers a larger portion of Christopher's medication costs, which is currently about \$6,250 a month, as compared with Medifund Junior, which had 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 Temasek and the Tsao Family Fund.

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 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 more than \$200,000 for beneficiaries of the fund. The sum includes three-to-one government matching.

yuensin@sph.com.sg