

The Standard



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Incurable 'Orphan - Disease' could affect hundreds

Patsy Moy

Friday, December 04, 2009

Hundreds of children in Hong Kong could be suffering from a rare, difficult to diagnose and incurable disease that leads to multiple organ failure and death.

But they have been abandoned by the pharmaceutical companies - who deem it too expensive to search for a cure - leading to the degenerative disorder being called "Orphan Disease."

The condition is one of a group that comes under the umbrella of mitochondrial diseases.

Mitochondria provides human cells with energy but due to inborn faults in the metabolism of sufferers, the mitochondria fail to do their job and the body cannot maintain its normal functions.

University of Hong Kong pediatrics professor Virginia Wong Chun-wei says Queen Mary Hospital and The Duchess of Kent Children's Hospital have seen only 23 known sufferers since 1985, eight of whom have died.

But it is estimated there could be as many as 1,400 sufferers, many of whose deaths will have been misdiagnosed.

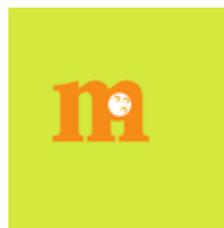
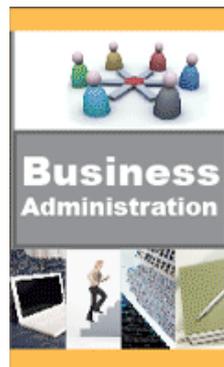
The youngest case was a newborn who died within four days.

There are is no known cure and patients have to rely on a mega-vitamin cocktail and energy therapy. Early symptoms can be so insignificant that parents and doctors can easily miss them.

"Early diagnosis is important. We can try to prevent strokes. A patient's condition deteriorates with every stroke," Wong said.

Among her patients was Hong Kong- born Joshua Hellmann who died of multiple organ failure in October 2007 aged 15. He appeared to be healthy until Christmas Day 2002 when he suffered a severe headache and was admitted to hospital.

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His mother, Christina Hellmann- Ipsaryaris, said Joshua suffered a second stroke in 2003 when the family moved to Switzerland.

In all, he suffered 10 strokes as well as bouts of epilepsy and convulsions.

The mother launched a global search for help, including flying a Japanese expert to Hong Kong to see her son.

But Joshua became blind, deaf, dumb and bed-ridden before he died.

She has set up a charity fund in memory of her son to help sufferers.

Families can contact the Joshua Hellmann Foundation on 2297-2484.

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