



Hong Kong Mucopolysaccharidoses &  
Rare Genetic Diseases Mutual Aid Group

## Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group

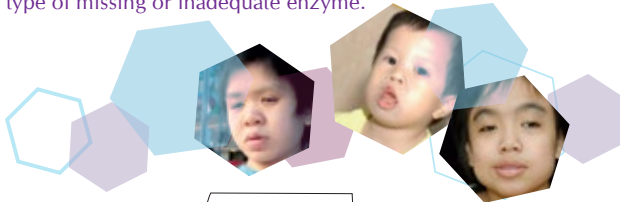
The Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group was originally formed by patients of Mucopolysaccharidoses (MPS) and their families for mutual support and encouragement. With the assistance of The Hong Kong Society for Rehabilitation's Community Rehabilitation Network, the Group later registered as a charitable organisation on March 23, 2005. Apart from MPS, we also have members who are diagnosed with Mucopolipidosis, Glycogen Storage Disease, Multiple Sclerosis, Gaucher's Disease, Pompe Disease, Hereditary Epidermolysis Bullosa, Phenylketonuria (PKU), Glutaric Aciduria Type I, Sotos Syndrome, Urea cycle disorder, Fabry disease and Aarskog Syndrome . All patients with other rare genetic diseases are welcome to join our Group as well. To know more about these rare genetic diseases, please visit our website at [www.mps.org.hk/en](http://www.mps.org.hk/en).



## What are Mucopolysaccharidoses?

Mucopolysaccharidoses (MPS) belongs to a group of rare inherited metabolic diseases known as storage diseases. The disorder is caused by the deficiency of specific enzymes needed to break down mucopolysaccharides, which are long chains of sugar molecules used in building body tissues and organs. Such deficiency results in harmful amounts of mucopolysaccharides accumulated in the body and progressive damages to various organs.

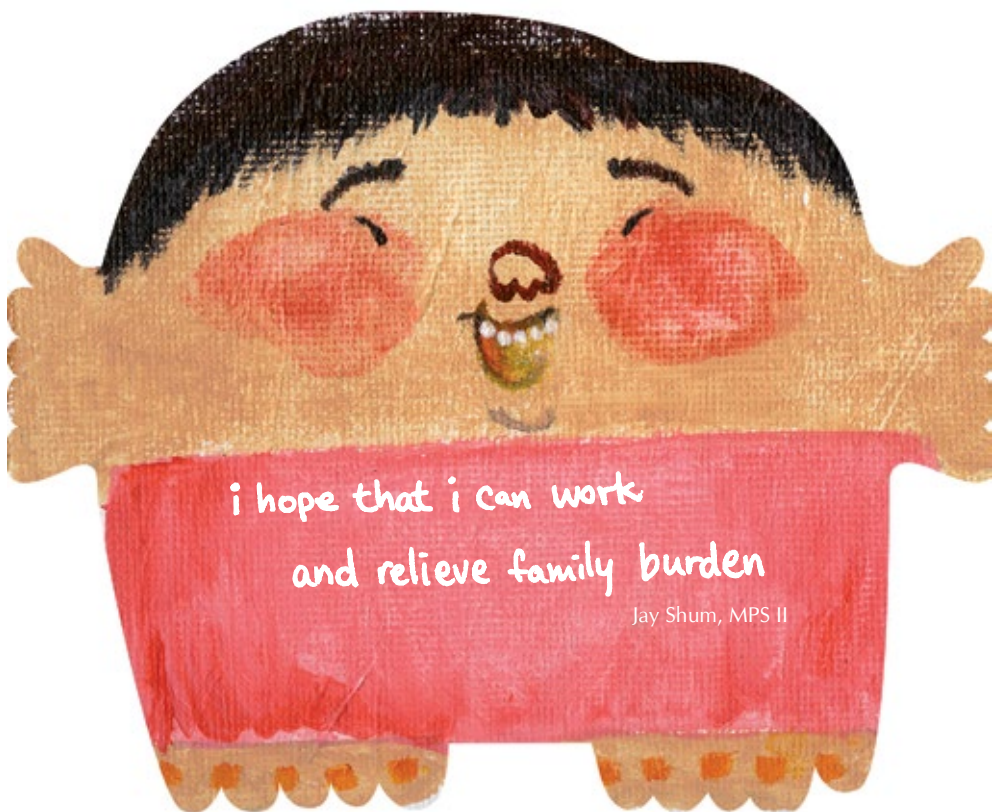
MPS is classified into 7 types (Type I,II,III,IV,VI,VII and IX) according to the type of missing or inadequate enzyme.





While the disease may not be apparent at birth, signs and symptoms develop with age as more mucopolysaccharides accumulate:

As the patients age, accumulated mucopolysaccharides may affect their appearance and damage their intelligence, internal organs, bones and joints. Affected individuals often share symptoms such as coarse hair and cloudy corneas. In severe MPS cases, patients may even suffer from mental retardation, language disorder, distended abdomen, enlarged joints, spinal deformity, stiff fingers with contracture, impaired physical mobility, and sight and hearing loss. As the airway passage gradually narrows with increased and thickened secretions, patients are prone to bronchitis or pneumonia infections.



i hope that i can work  
and relieve family burden

Jay Shum, MPS II

A hand-drawn illustration of a girl with a brown face, black hair, and purple dress, holding a sign with text. The girl has large blue eyes, a red smile, and orange cheeks. She is wearing a purple dress with a scalloped hem and colorful dots at the bottom. The text on the sign is written in a white, cursive font.

I hope that I could play,  
I could chat and  
enjoy everything.

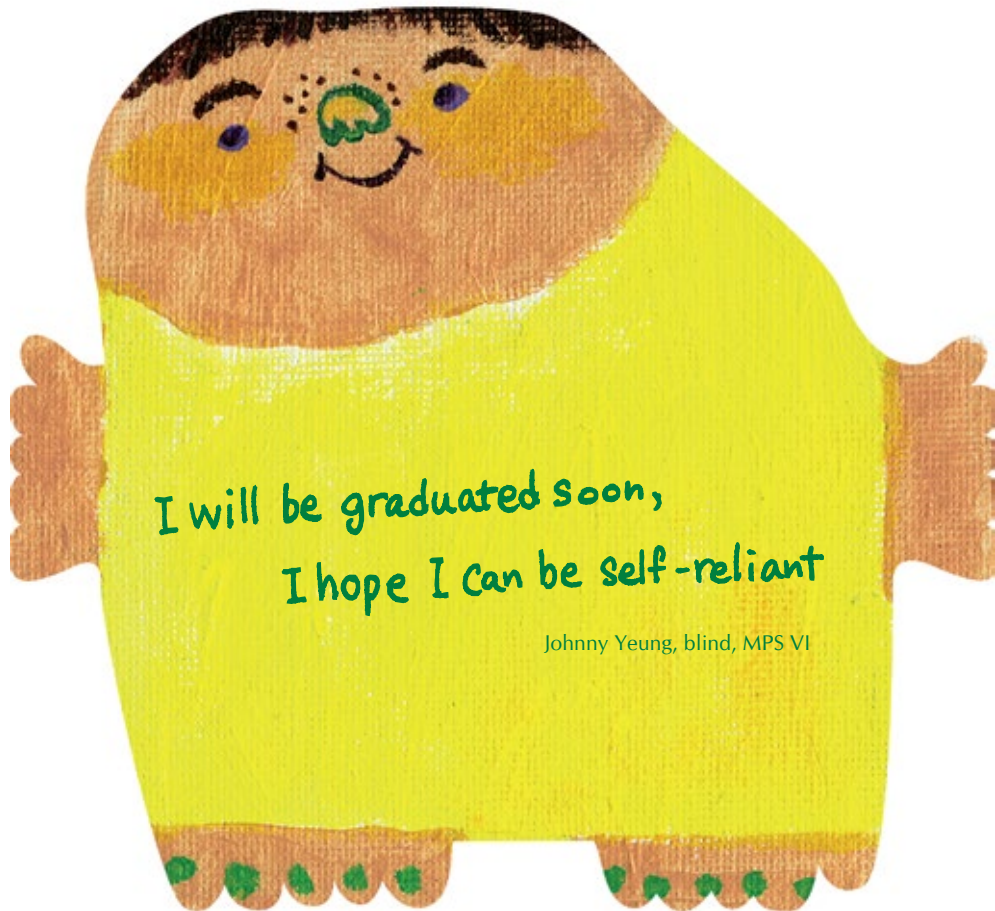
Mavish Sultana, MPS I



## **Treatment: Bone Marrow Transplantation and Enzyme Replacement Therapy (ERT)**

Bone marrow transplantation can help MPS I and VI patients at an early stage to ease symptoms and prolong their lives.

At present, ERT for MPS I, II and VI have been successfully developed and is being used on patients. However, as the intravenous enzymes cannot cross into the brain, ERT does not address the neurological symptoms experienced by these patients. To supplement or replace the deficient enzyme, a patient should regularly and continuously receive ERT without any pause.



I will be graduated soon,  
I hope I can be self-reliant

Johnny Yeung, blind, MPS VI





I hope that I can get  
the medicine to cure me.

John Lee, MPS IV

## Funding and Address

The Group receives no regular funding from the government. Our operational expenses are mainly covered by annual membership fees and donations, whereas individual activities are supported by funds from different charitable foundations.

The Group does not have a permanent address. We borrow venues from the Hong Kong Society for Rehabilitation for meetings, gatherings and letter collecting.

## Donation Methods

- 1) By cheque      The cheque should be made payable to  
"Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases  
Mutual Aid Group" or  
"H K M & R G D Mutual Aid Group"
- 2) By direct deposit      Please deposit the funds into our Bank of East Asia account  
015-246-40-426130 or 015-246-10-37986-7  
and obtain a deposit receipt.
- 3) By online donation      Please visit the following website for details:  
[www.mps.org.hk/donation.html](http://www.mps.org.hk/donation.html)

Contact Tel: +852 2794-3010

Contact Address: G/F, Wang Lai House, Wang Tau Hom Estate, Kowloon, Hong Kong

Website: [www.mps.org.hk/en](http://www.mps.org.hk/en)

Email: [info@mps.org.hk](mailto:info@mps.org.hk)

## The Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group Donation Form

Your donation will be crucial for us to better support the patients.

Donations of HKD100 or above are tax-deductible with official receipt.  
(Inland Revenue Department File Reference: 91/8375)

Name/Name of Organisation: \_\_\_\_\_

Contact Person: \_\_\_\_\_ Email Address: \_\_\_\_\_

Tel: \_\_\_\_\_ Fax: \_\_\_\_\_

Address: \_\_\_\_\_

If you would like a different name to appear on the receipt, please specify:

\_\_\_\_\_

Date: \_\_\_\_\_



To join us, please contact us at email [info@mps.org.hk](mailto:info@mps.org.hk) or 2794-3010

Seventh Edition, 2011

The production of this leaflet is sponsored by Genzyme Asia Limited.