



香港黏多醣症暨罕有遺傳病互助小組
**Hong Kong Mucopolysaccharidoses &
Rare Genetic Diseases Mutual Aid Group**

一個黏多醣症暨罕有遺傳病病友及家屬的自助組織
A registered support group for MPS &
other rare genetic diseases patients and families

To: Editors of News, Supplements, Features, Parenting, Family, Community, and Health sections

For Immediate Release

**2009 Asia-Pacific MPS Conference: Our Right To Treatment
International Support for HK Patient Group's Petition to Chief Executive**

May 14, 2009, Thursday, Hong Kong – On May 14, 2009, the day before the “**International MPS Day**”, delegates from Mucopolysaccharidoses (MPS) patient support groups in the Asia-Pacific region gathered outside of the Hong Kong Government House to pledge for and sign the world's first **Joint Declaration on MPS Patients' Right to Treatment**, initiated by the **Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group** (the Hong Kong MPS Group), urging for government action to provide immediate therapy to all MPS patients.

Support from the international society has been overwhelming. After learning about the Joint Declaration, MPS patient support groups from Mainland China, Taiwan and New Zealand have contacted the Hong Kong MPS Group and have provided their signature as tokens of support.

“World says: Right to Live for MPS Patients” as delegates from MPS groups all around Asia Pacific, including Korea, Malaysia, the Philippines and Australia, joined local patients and representatives to call for the provision of immediate therapy to MPS patients, and to support MPS patients to enjoy their basic human right and opportunity to treatment. Together with a petition, the signed Joint Declaration was presented to **Donald Tsang**, Chief Executive of Hong Kong by two young children with MPS. Both were received by a representative of the Hong Kong Government House.

Mr Stephen Ma, Vice Chairman of the Hong Kong MPS Group, said during the petition, “For years, although the Hong Kong Government has formed a special Expert Panel on using Enzyme Replacement Therapy (ERT) for patients with rare genetic diseases, no MPS patient has ever received approval to use ERT.”

“We urge the government to proactively and immediately evaluate all patients for the use of ERT, rather than waiting for families to submit their cases one-by-one for review. This will allow them to obtain the most appropriate treatment and so they can live a longer life,” he added.





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Consultant of the Hong Kong MPS Group, **Mr Fernando Cheung**, expressed that he has reflected the urgency of the problem to the government many times. “Since the financial year 2008-09, the government has allocated an additional recurrent funding of HKD \$10 million to the Hospital Authority for sponsoring ERT for patients with rare genetic diseases. However, the government has been ignoring these MPS patients and have never utilized the funding to benefit MPS patients, based on the reasons of cost effectiveness of ERT and fairness in using public funds,” Cheung said.

The overseas support groups have also joined the 2009 Asia-Pacific MPS Conference initiated and hosted by the Hong Kong MPS Group on May 12-14, 2009. Embracing the theme of “**Our Right to Treatment**” and in observance of the **May 15 “International MPS Day**”, they have shared experiences about their challenging journey toward receiving treatments and attaining quality of life for MPS patients in their countries/regions.

To download photos of today’s event, please visit:

http://www.bbluesky.com/bblue2/MPS_Conf09_20090514_Photos.zip

- 01** The Hong Kong Mucopolysaccharidoses and Rare Genetic Diseases Mutual Aid Group Vice Chairman, Stephen Ma (left), together with the Consultant of the group, Dr Fernando Cheung (right), appealed to the Government to provide proactive and immediate evaluation for ERT of all Hong Kong MPS patients.
- 02** Hamza Shahid (left) and Johnny Yeung (right), two teenagers with MPS, presented to the Hong Kong Government House a petition letter together with the Joint Declaration signed by all Asia-Pacific countries/regions.
- 03** Delegates from MPS patient support groups all around the Asia-Pacific region came to Hong Kong to support each and every MPS patient to have their basic human right and opportunity to treatment.

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Notes to Media:

Names of the Mucopolysaccharidoses (MPS) patient support groups present:

Patient Support Groups:

Mucopolysaccharide & Related Diseases
Society Australia Limited

Korea Organisation for Rare Disease

Malaysia Metabolic Society

Philippine Society for Orphan Disorders

Hong Kong Mucopolysaccharidoses &
Rare Genetic Diseases Mutual Aid Group

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Rare Genetic Diseases Mutual Aid Group

Representatives:

Mr David OLIVER (President)

Mr Hyun-Min SHIN (Chairman)

Ms Chok Yen SIAH (Member)

Dr Sylvia ESTRADA (Director and
Corporate Secretary)

Mrs Ellie CHING (Chairperson)

Mr Stephen MA (Vice Chairman)

Mr Fernando CHEUNG (Consultant)

About the Hong Kong MPS Group and its challenges:

At our 4th anniversary this year, the HK MPS Group is an NGO formed by people and families living with Mucopolysaccharidoses (MPS) and other rare genetic diseases. According to our understanding, there are currently 22 people diagnosed with MPS and another 12 people with other rare genetic diseases in Hong Kong.

MPS are a group of rare hereditary metabolic disorders caused by a defect of certain enzymes in the body, resulting in the body not able to break down glycosaminoglycans (i.e. a type of glycogen, or complex sugar, that are important for structural growth) and their widespread accumulation in the body, damaging multiple organs, hearing and vision over time. Patients with MPS are usually born normal and remain short in height with enlarged heads and abdomen (due to enlarged liver and spleen), crawled fingers, fragile joints and, in some cases,





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mental impairment. Their physical and mental health will only decline if the cause of the disorder remains untreated. Most MPS patients are children diagnosed at an early age and very likely cannot live beyond their teenage.

Although MPS is still not curable, targeted treatments such as enzyme replacement therapy exist and have already gone through clinical trials and the stringent reviews of the Food and Drug Administration (FDA) in the USA and the European Medicines Agency (EMA) in Europe, as well as rigorous efficacy assessments in many Asian countries. Many governments, including Korea and Macau, have already approved and funded treatment for MPS patients, while the road is still quite long for some that are in the process of doing so for their sons and daughters with MPS. The ultimate outcome ties with the public health system of each country/region and, of course, the patients and families themselves.

To date, the Hong Kong Government has still not approved using these therapies for MPS patients in Hong Kong.

Visit our website <http://www.hk-mps.com/en> for more details, and you can read more about our difficulties at this URL: <http://www.hk-mps.com/en/difficulty.html>

