中華人民共和國香港特別行政區政府總部食物及衞生局
Food and Health Bureau, Government Secretariat
The Government of the Hong Kong Special Administrative Region
The People's Republic of China

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2 January 2018

Ms Maise LAM
Clerk to Panel
Panel on Health Services
Legislative Council Complex
1 Legislative Council Road
Central, Hong Kong
(Fax: 2185 7845)

Dear Ms Lam,

Panel on Health Services

Follow-up to the meeting on 11 April 2017

During the discussion on policy on and drugs for uncommon disorders at the special meeting of the Legislative Council Panel on Health Services held on 11 April 2017, Members requested supplementary information relating to the allocation of resources and drug expenditure for treatment of uncommon disorders. The requested supplementary information is provided in the ensuing paragraphs.

2. The Hospital Authority ("HA") makes use of the recurrent funding from the Government (including designated funding for financing enzyme replacement therapy), the Samaritan Fund and the Community Care Fund ("CCF") Medical Assistance Programmes to provide sustainable, affordable and optimal care for all patients, including those with uncommon disorders. Under the highly-subsidised public healthcare system, all patients attending public hospitals have equitable access to appropriate public healthcare

services. HA clinicians would make diagnosis in the light of patients' clinical conditions and provide appropriate treatments according to the established operation guidelines.

Total Drug Expenditure

3. The Government's recurrent funding caters for around 90% of HA's total operating expenditure. HA would also deploy its own income and internal resources to meet the rising demand for hospital services and improve the quality of patient care. With the Government's recurrent financial provisions of $51.5 billion in 2015-16 and $53.4 billion in 2016-17, the HA's total drug consumption expenditure amounted to $4.6 billion and $5.0 billion in 2015-16 and 2016-17 respectively to cater for drug treatments for different types of diseases including uncommon disorders in public hospitals.

Designated funding for patients with lysosomal storage disorders for receiving enzyme replacement therapy

4. The HA has an established mechanism to evaluate, through an independent expert panel, the suitability of individual patients with lysosomal storage disorders for receiving enzyme replacement therapy in the light of their clinical conditions and the benefits and risks of undergoing such therapy. In 2015-16 and 2016-17, $75 million had been designated each year to support enzyme replacement therapy for patients with lysosomal storage disorders in the HA. The total drug expenditure on enzyme replacement therapy provided for specific patients at standard fees and charges amounted to $48.3 million in 2015-16 and $52.8 million in 2016-17, involving 20 and 22 patients respectively. As the amount of drug expenditure depends on the body weight of the concerned patients and patients may gain weight over the years, and there may be additional patients with lysosomal storage disorders who are suitable for enzyme replacement therapy every year. It is anticipated that the drug expenditure will continue to grow in the coming years.

Samaritan Fund

5. Over the years, the HA has included self-financed drugs which are proven to be of significant clinical benefits but extremely expensive for HA to provide as part of its standard services in its safety net provided through the Samaritan Fund. The Fund was established without endowment but operates on a rolling account basis, relying largely on donations, government grants and reimbursement under the Comprehensive Social Security Assistance Scheme. A one-off Government grant of $10 billion was approved in 2012-13 to support the continued operation of the Fund. The Samaritan Fund has covered various self-financed drugs for treating different diseases, including uncommon disorders. The approved drug subsidies for specific self-financed drugs covered by the Samaritan Fund amounted to $317.5 million and $332.4 million in 2015-16 and 2016-17 respectively.

Community Care Fund Assistance Programmes

6. Since August 2011, the HA has administered various CCF Medical Assistance Programmes to cover specific self-financed drugs for treating different diseases such as cancer and uncommon disorders. Drug subsidy would be provided for needy patients who require these drugs and pass the means test. In August 2017, the HA has rolled out a new CCF Programme – *"Subsidy for Eligible Patients to Purchase Ultra-expensive Drugs (Including Those for Treating Uncommon Disorders)"* to provide patients with subsidy to purchase ultra-expensive drugs. Initially, Eculizumab for treatment of Paroxysmal Nocturnal Haemoglobinuria ("PNH") was included in the Programme for suitable patients. In November 2017, the Commission on Poverty endorsed the recommendation to include an additional clinical indication for the drug to cover Atypical Haemolytic Uraemic Syndrome ("aHUS"). It is estimated that about 11 to 19 patients with PNH or aHUS will apply for subsidy under the Programme to use Eculizumab in the first 12 months. The estimated maximum amount of the subsidy for the first 12 months is around $76 million.

7. The Government and the HA will continue to provide drug subsidies for the purchase of ultra-expensive drugs by needy patients through various subsidy programmes. It is anticipated that expenditure on

drug treatments for patients with uncommon disorders will also continue to increase in the coming years.

8. To provide more assistance for patients with uncommon disorders, the Chief Executive has announced in the 2017 Policy Address that the Government and the HA will extend the scope of the new CCF Assistance Programme to provide patients with subsidies for specific drug treatments according to individual patient's special clinical needs. The HA will expedite the review of the patient's co-payment mechanism under the CCF Assistance Programme in order to alleviate the financial burden on patients requiring long-term ultra-expensive drug treatment. The HA will complete the review in the first half of 2018 and propose improvement measures.

9. The Drug Management Committee under the HA and the relevant committees will monitor more closely the research developments and accumulation of medical scientific evidence of new drugs, and include new drugs and indications in the HA Drug Formulary when appropriate, with the aim of providing early treatment for financially-needy patients who require the use of ultra-expensive drugs, including patients with uncommon disorders.

Yours sincerely,

(Miss Clarissa Wan)
for Secretary for Food and Health

c.c. Chief Executive, Hospital Authority
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