

立法會
Legislative Council

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Tel : 3919 3300

Date : 10 January 2019

From : Clerk to the Legislative Council

To : All Members of the Legislative Council

Council meeting of 23 January 2019

Motion on
“Enacting legislation to protect the rights and interests of
rare disease patients”

Dr Hon Fernando CHEUNG has given notice to move the attached motion on “Enacting legislation to protect the rights and interests of rare disease patients” at the Council meeting of 23 January 2019. The President has directed that it be printed in the terms in which it was handed in on the Agenda of the Council.

(Dora WAI)
for Clerk to the Legislative Council

Encl.

(Translation)

Motion on
“Enacting legislation to protect the rights and interests of
rare disease patients”
to be moved by Dr Hon Fernando CHEUNG
at the Council meeting of 23 January 2019

Wording of the Motion

That quite a number of countries have laid down definitions, enacted legislation and formulated evidence-based and regularized long-term policies on rare diseases as early as the 1980s, making it more convenient for rare disease patients to apply for approval of drugs, subsidy, and so on, and enabling them to receive more efficient and more proper treatment and care; and the United States, member states of the European Union and the neighbouring countries and regions of Hong Kong, such as Singapore, Japan, Australia, Taiwan and Korea have long laid down definitions of rare diseases, formulated support policies, established a database of rare disease cases, etc.; however, the Hong Kong Government has yet to lay down any definition and formulate any concrete policy on rare diseases to provide support for rare disease patients; in this connection, this Council urges the Government to enact legislation on rare diseases, in order to protect and promote the rights of rare disease patients and enable them to receive proper diagnosis, treatment and care, thereby fulfilling the requirements of the United Nations Convention on the Rights of Persons with Disabilities; the relevant contents include:

- (1) establishing a policy committee on rare diseases to advise on a strategic development direction for a policy on rare diseases, monitor the implementation of the policy on rare diseases by government departments and statutory bodies, report on the implementation of the policy on rare diseases, etc.;
- (2) establishing an evaluative committee on rare diseases to evaluate whether a disease meets the definition of rare diseases;
- (3) defining a disease which affects no more than 1 in 10 000 individuals in Hong Kong and is clinically definable as a rare disease;
- (4) introducing a registration system for rare disease drugs whereby rare disease patients, medical practitioners and pharmaceutical companies

can apply for the inclusion of new drugs in the list of drugs for rare diseases;

- (5) introducing a subsidy system to ensure that rare disease patients will receive safe, quality, effective and affordable drugs and treatment, instead of laying emphasis only on cost-effectiveness; and
- (6) introducing a rare disease information system which contains a list of rare diseases and their prevalence rates, the demographic information of patients and usage statistics of rare disease drugs.