

(Translation)

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

**moved by Dr Hon Fernando CHEUNG  
at the Council meeting of 23 January 2019**

**Motion as amended by Prof Hon Joseph LEE and Dr Hon Elizabeth QUAT**

That as rare disease patients in Hong Kong have all along suffered neglect of their well-being, they have to face numerous difficulties in their living; 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;
- (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;
- (7) establishing a dedicated medical team and stepping up health care training to centralize the handling of suspected rare disease cases and expedite the testing and diagnosis of rare diseases, thereby raising the cost-effectiveness of health care; and
- (8) establishing an inter-disciplinary group to provide support for promoting the physical and mental health of rare disease patients and their families;

and the Government should also allocate additional resources for introducing genetic tests in the public health care system, including the provision of free prenatal non-invasive fetal trisomy testing services to pregnant women for early identification of the risk of rare diseases in foetuses, so that appropriate treatment can be provided as early as possible, and provision of preconception trisomy testing services to those who wish to have children, such that they can understand the risk of giving birth to babies suffering from rare diseases and the treatment required, thereby making appropriate decisions on childbearing.