

**立法會**  
**Legislative Council**

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From : Clerk to the Legislative Council

To : All Members of the Legislative Council

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**Council meeting of 23 January 2019**

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

Further to LC Paper No. CB(3) 303/18-19 issued on 10 January 2019, Prof Hon Joseph LEE and Dr Hon Elizabeth QUAT have respectively given notice of their intention to move separate amendments to Dr Hon Fernando CHEUNG’s motion on “Enacting legislation to protect the rights and interests of rare disease patients”. As directed by the President, Prof Hon Joseph LEE’s and Dr Hon Elizabeth QUAT’s amendments will be printed in the terms in which they were handed in.

2. The President will order a joint debate on the above motion and the two amendments. To assist Members in debating the motion and the amendments, I set out below the procedure to be followed during the debate:

- (a) the President calls upon Dr Hon Fernando CHEUNG to speak and move his motion;
- (b) the President proposes the question on Dr Hon Fernando CHEUNG’s motion;
- (c) the President calls upon the two Members who wish to move amendments to speak in the following order, but no amendment is to be moved at this stage:
  - (i) Prof Hon Joseph LEE; and
  - (ii) Dr Hon Elizabeth QUAT;

- (d) the President calls upon the public officer(s) to speak;
- (e) the President invites other Members to speak;
- (f) the President calls upon Dr Hon Fernando CHEUNG to speak for the second time on the two amendments;
- (g) the President calls upon the public officer(s) to speak again;
- (h) in accordance with Rule 34(5) of the Rules of Procedure, the President has decided that he will call upon the two Members to move their respective amendments in the order set out in paragraph (c) above. The President invites Prof Hon Joseph LEE to move his amendment to the motion, and forthwith proposes and puts to vote the question on Prof Hon Joseph LEE's amendment;
- (i) after Prof Hon Joseph LEE's amendment has been voted upon, the Council deals with Dr Hon Elizabeth QUAT's amendment to the motion; and
- (j) after Dr Hon Elizabeth QUAT's amendment has been dealt with, the President calls upon Dr Hon Fernando CHEUNG to reply. Thereafter, the President puts to vote the question on Dr Hon Fernando CHEUNG's motion, or his motion as amended, as the case may be.

3. For Members' reference, the terms of the original motion and the marked-up version of the amendments are set out in the **Appendix**.

(Dora WAI)  
for Clerk to the Legislative Council

Encl.

(Translation)

**Motion debate on  
“Enacting legislation to protect the rights and interests of  
rare disease patients”  
to be held at the Council meeting of 23 January 2019**

**1. Dr Hon Fernando CHEUNG’s original 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.

## **2. Motion as amended by Prof Hon Joseph LEE**

*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; ~~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;
- (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.*

Note: Prof Hon Joseph LEE's amendment is marked in *bold and italic type* or with deletion line.

### **3. Motion as amended by Dr Hon Elizabeth QUAT**

That *in view of* quite a number of countries ~~have~~ *having* 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, *coordinate and* 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) *laying down a definition of rare diseases applicable to Hong Kong by, for instance, giving consideration to* 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 *designated* 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;

*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 fetuses, 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.*

Note: Dr Hon Elizabeth QUAT's amendment is marked in *bold and italic type* or with deletion line.