

## LCQ7: Supporting patients with classic phenylketonuria

Following is a question by Dr the Hon David Lam and a written reply by the Secretary for Health, Professor Lo Chung-mau, in the Legislative Council today (November 27):

Question:

Classic phenylketonuria (PKU) is a rare amino acid disorder. Patients with PKU can only consume special formula food and supplements for the whole life, as eating ordinary food will result in serious complications and even death. However, some carers of PKU patients have relayed to me that, as Hong Kong does not produce any special formula food for patients with PKU, these patients can only purchase imported food from individual suppliers, yet the prices for such food products have surged exorbitantly in recent years. For example, the price of a brand's tinned formula milk powder increased by folds from \$93 per standard tin in 2022 to \$430 in 2024, while another brand's formula milk powder can even cost as much as \$860 per tin with a net weight of 500 grams. It is learnt that, currently, patients in some jurisdictions (e.g. the United Kingdom) are subsidised by their governments for the purchase of special formula food. In this connection, will the Government inform this Council whether it will consider including special nutritional formulas which are essential for PKU patients in the Hospital Authority Drug Formulary, or otherwise subsidising patients for purchasing special formula food and supplements; if it will, of the details; if not, the reasons for that?

Reply:

President,

In consultation with the Hospital Authority (HA), the reply to the question raised by Dr the Hon David Lam is as follows:

Classic phenylketonuria (PKU) is a rare but treatable amino acid metabolism disorder, which is an inherited metabolic disorder. To prevent the excessive build-up of phenylalanine in the body, patients with PKU need to take a special nutritionally balanced and low-phenylalanine diet including the use of specified dietary products (e.g. disease specific formula, other supplement products, specially formulated low protein products, etc). Child patients have to limit their intake of high protein food such as general infant formula milk powder, meat and dairy products so that just small and sufficient amount of phenylalanine would be consumed to maintain a healthy body as well as normal growth and development. According to the HA's records, the number of PKU patients is 21.

Where special nutrition and special dietetics products are indicated clinically for relevant patients during their stay in public hospitals,

relevant costs are covered by their in-patient fees. As for out-patient services, if patients are prescribed with special nutrition and special dietetics products based on the assessment of clinical teams, they may purchase the relevant items at their own expense in the community. Patients or families with financial difficulties may approach the Medical Social Services Unit of hospitals or clinics for application for Comprehensive Social Security Assistance Scheme or Disability Allowance. For these patients with financial difficulties and unique clinical conditions, medical social workers will also assist in soliciting other financial assistance (e.g. donation) to subsidise their additional nutritional needs. At present, Hong Kong Children's Hospital also administers fund-raising activities for children suffering from rare diseases to support their relevant expenses.

The Hospital Authority Drug Formulary (HADF) has been implemented with a view to ensuring equitable access by patients to drugs prescribed based on their needs through standardisation of drug policy and drug utilisation in all public hospitals and clinics. Only registered pharmaceutical products (or commonly known as drugs, which are used for prevention and treatment of diseases) in Hong Kong that are cost effective as well as of proven safety and efficacy are covered by the HADF. It is not appropriate to include in the HADF any food or supplements such as special formula milk powder or special food products that are beyond the scope of drugs. The HA will continue to closely monitor the supply and usage of relevant special nutrition and special dietetics products or nutrition supplements, and maintain communication with suppliers regarding the supply situation for Hong Kong patients to address patients' needs.