

Rare Disease Hong Kong Pilot Scheme of Subsidy for Healthcare Needs <u>Application Notes</u>

1. Introduction

1.1. Objective

The Pilot Scheme of Subsidy for Healthcare Needs (hereinafter referred to as "the Subsidy Scheme") aims at providing transitional funding for nursing materials and services that are not covered by the current public healthcare and social welfare services but needed by patients with rare diseases. In the long run, we hope to collect evidence-based information from the Subsidy Scheme in order to urge the authorities concerned to improve the coverage of the safety nets to benefit more patients.

1.2. Duration

The implementation dates of the Subsidy Scheme are from 1st June 2023 to 30th June 2026.

1.3. Types of subsidised goods and services

- Subsidies will be provided for the following 3 categories of materials in the first phase:
 - (i) Silver-containing or non-adherent dressings Note1
 - (ii) Phenyl-Free food powder and supplements Note2
 - (iii) Soft meals supplied by social welfare organisations Note3
- Subject to availability of funds and manpower, other nursing materials and services will be covered under the Subsidy Scheme.

2. Applicant eligibility

- 2.1. Must be a full member of Rare Disease Hong Kong (RDHK).
- 2.2. Must produce a copy of the most recent prescription (or relevant supporting documents) issued by a healthcare professional, dietitian or speech therapist stating that the applicant needs the relevant nursing materials or services due to designated rare disease(s).
- 2.3. *To declare that when submitting the application, the applicant has not been granted the Comprehensive Social Security Assistance, or similar financial assistance offered by other funds or organisations; and
- 2.4. Each applicant may apply for only one type of goods or services.

* In the period from the submission date to the approval date of the application, the applicant should notify RDHK at once if any similar subsidy is granted by the government or non-government organisations, or the content of prescription issued by the healthcare professional, dietitian or speech therapist has been changed.

Note1 Item (i) refers to the dressings suitable for patients with Epidermolysis Bullosa.

Note2 Item (ii) refers to the food powder and supplements suitable for patients with Phenylketonuria.

Note³ Items (iii) refers to the soft meals provided by social welfare organisations for patients with neuromuscular disorders who have chewing and swallowing problems.



3. Subsidy limits

	Subsidised items	Maximum subsidy per individual per quarter (HKD)
i.	Silver-containing or non-adherent dressings	80% of the total actual expenses or \$8,000 (whichever is less)
ii.	Phenyl-Free food powder and supplements	80% of the total actual expenses or \$8,000 (whichever is less)
iii.	Soft meals supplied by social welfare organisations	80% of the total actual expenses or \$1,800 (whichever is less)

4. Application and approval

- 4.1. Complete the application form and return it to the office of RDHK together with the documents required by email (<u>info@rdhk.org</u>) or by post (Room 101, G/F, Lai Suen House, Lai Kok Estate, Cheung Sha Wan, Kowloon).
- 4.2. For applicants under 18, the application form must be signed by a parent or guardian.
- 4.3. Upon receipt of each application, the RDHK staff will contact the applicant for an interview to further understand his/her health and family conditions. Then a report will be prepared and submitted together with other application documents to the RDHK Task Force for vetting.
- 4.4. Application results will be sent to the applicants by email. The validity period of each successful application is from the notification date of the application results until 30 June of the following year, after which the applicant may submit another application.
- 4.5. Applicants found to have knowingly made false statements, misrepresented or concealed any information to obtain subsidies will be disqualified and required to fully refund the subsidies disbursed.

5. Subsidy disbursement

- 5.1. Successful applicants may complete and return the "Disbursement Request Form" together with the original receipts of goods or services purchased to RDHK by post on or before the 5th of March, June, September or December.
- 5.2. After verification by the RDHK Task Force, the applicants will be granted 80% of the total value of the receipts, but not exceeding the subsidy limit for each category of goods or services.

6. Amendments and additions

- 6.1. RDHK will review the terms and conditions of the Subsidy Scheme from time to time and will make amendments and additions if necessary.
- 6.2. In case of any dispute regarding the content of the Subsidy Scheme, RDHK reserves the right of final decision, including suspending, amending and deleting the terms and conditions of the Subsidy Scheme at any time without prior notice.



7. Important notes on provision of personal data

- 7.1. Rare Disease Hong Kong (RDHK) will use the personal data collected in the application forms for the following purposes:
 - a. To handle all matters related to the applications for the "Pilot Subsidy Scheme on Nursing Materials".
 - b. To facilitate the contact between RDHK and the applicants / the issuer(s) of the documents submitted by the applicants.
- 7.2. In accordance with the Personal Data (Privacy) Ordinance (Cap. 486) of the laws of Hong Kong, applicants have the right of access and correction with respect to personal data. The right of access includes the right to obtain a copy of the personal data provided in the application form.
- 7.3. For any enquiries regarding the personal data collected in the application form, including access, correction and updating of information, please contact the Secretariat of Rare Disease Hong Kong (Rm 101, G/F, Lai Huen House, Lai Kok Estate, Cheung Sha Wan, Kowloon).

8. Enquiries

By phone: (852) 5528-9600 By email: info@rdhk.org