



香港罕見疾病聯盟
RARE DISEASE HONG KONG

Code of Practice for Collaboration with the Business Sector



Effective from December 2021

Rare Disease Hong Kong Limited

Code of Practice for Collaboration with the Business Sector

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1. Preamble

Established in December 2014, Rare Disease Hong Kong Limited (hereinafter “RDHK”, formerly known as “Hong Kong Alliance for Rare Diseases”) is the first patient group in Hong Kong comprising cross-rare disease patients and their families with the support of experts and academics in the field. In 2020, RDHK was registered as a company limited by guarantee under the Companies Ordinance and became a recognised charity institute (#91/16233) under Section 88 of the Inland Revenue Ordinance.

The sources of funds for the day-to-day operations and long-term development of RDHK include charitable donations, grants, sponsorships, government project funding, membership fees, event fees, etc., with sponsorships and grants from the business sector accounting for a certain proportion. Therefore, RDHK has compiled a Code of Practice for Collaboration with the Business Sector (hereinafter referred to as “the Code”) with a view to reinforcing integrity management and internal controls, ensuring that all the money, goods and services from the business sector are lawful and ethical.

The Code applies to all RDHK staff^① and commercial organisations^② collaborating with RDHK.



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- ① RDHK staff refers to anyone who acts in the name of RDHK, e.g. council members, advisors, employees and volunteers, etc.
- ② Commercial organisation means any business entity that is working to earn profit and the profit is distributed among the owners of the business.

2. General principles

RDHK welcomes any form of financial support from the business sector, including donations, grants, sponsorships, services, goods, etc. However, the collaboration between RDHK and these businesses must be based on the following principles to avoid any potential conflict of interest:

2.1. Put patients' interests first

Patients' interests always come first when deciding whether, when and how to work with a commercial organisation. To avoid conflicts of interest, RDHK does not promote any specific product, brand or service, but rather supports the availability of the widest range of effective drugs, treatments, health services and technologies. Patients are encouraged to consult their healthcare professionals and make a fully informed choice of all available options.

2.2. Maintain the autonomy and independence of RDHK

The relationship between RDHK and commercial organisations is based on partnership, while preserving RDHK's autonomy and independence. To ensure a successful partnership, each partner must understand and respect each other's internal culture and external constraints, and must not influence in any way the policies, standpoints or decisions of RDHK, whether explicitly or implicitly.

2.3. No commercial transaction

Businesses are not supposed to conduct such commercial activities as product / service advertising, promotion or trading through RDHK's webpages, social media platforms, online or offline activities, publications, etc. Acceptance of commercial organisations' support should not be construed as an endorsement of their products or services by RDHK.

2.4. Transparency and accountability

The Code is publicly available. All commercial organisations working with RDHK are required to study and agree to comply with the Code.

3. Types of financial support by the business sector

Subject to the laws of Hong Kong, RDHK's Articles of Association and the "General principles" listed in subparagraph 2 above, RDHK may accept different types of financial support by the business sector, including but not limited to:

3.1. Restricted grants or sponsorships

Restricted grants or sponsorships from commercial organisations will be used to organise designated events or activities to support the core business of RDHK (i.e. "policy advocacy", "public awareness" and "capacity building"). For example:

- Rare diseases public awareness campaigns
- Symposiums
- Roundtable meetings
- Press conferences
- Networking gathering for patients
- Specialised talks or seminars
- Development and management of dedicated webpages for rare diseases
- Local and overseas training and empowerment activities for rare disease patient leaders

3.2. Unrestricted donations

RDHK may use the unrestricted one-off or regular donations for the activities listed in subparagraph 3.1. above, printing of publications, souvenir production, interest classes, assistance and welfare for patient members, administrative expenses and other operating expenses.

3.3. In-kind contributions

Commercial organisations are welcome to offer RDHK goods or services free of charge or at special rates, for example:

- Epidemic prevention materials
- Healthcare supplies
- Nursing and other allied healthcare services
- PR services
- Auditing services
- Legal advisory services
- Provision of drug information
- Genetic testing
- Genetic counselling
- Voluntary services
- Translation services
- Accessible transport services

4. Involvement in business sector activities

4.1. Activities that can be attended

RDHK may participate in business sector activities **without** commercial purposes (e.g. brand building, product or service promotion and sales). For example:

- Training activities related to the work of RDHK
- Seminars or specialised conference without commercial act
- Provision of staff training or talks to individual commercial companies by RDHK

4.2. Activities to avoid

To avoid conflicts of interest, RDHK staff should not engage in any product / service advertising or promotional activities, and it is not appropriate to participate in the decision-making of a commercial organisation or accept unreasonably frequent or lavish entertainment that is unrelated to the official business. For example:

- Product or service launch
- Annual banquets of individual commercial companies
- Internal meetings of individual commercial companies

5. Transparency

The project description, terms of cooperation, amount of funding, designated use, etc. of the collaboration between RDHK and the business sector must be documented in writing, and discussed & reported in the internal administrative meetings and council meetings in due course.

For restricted grants or sponsorships from the business sector, RDHK will enter into a cooperation agreement with the funders to ensure that both parties are aware of and agree to the terms of the partnership.

6. Process and documentation

6.1. Process of committing to a collaborative project

All collaborative projects with the business sector should be reported and discussed in the weekly administrative meeting. Projects that are handled for the first time or involving more human resources will be submitted to the Council for adoption before being formally launched.

6.2. Documentation

All letters of agreement, financial transaction records and supporting documents must be kept properly.

Under Section 51C of the Inland Revenue Ordinance, all business records of RDHK shall be kept for at least 7 years. If a staff member resigns, he/she should hand over all the relevant documents before leaving.

7. Implementation and monitoring

The Code is adopted and monitored by the Council of RDHK, and to be reviewed and revised every two years or as necessary.

All RDHK staff are required to act in accordance with the Code and to ensure that the commercial organisations working with RDHK are aware of and agree to comply with the Code.

RDHK staff may be subject to disciplinary action for breaching the Code. Any illegal cases will be referred to the law enforcement agencies.

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