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捐款方法：

- (1) 劃線支票【支票抬頭請註明「香港罕見疾病聯盟有限公司」】
- (2) 直接存款【中國銀行(香港) 戶口號碼：012-740-2-010764-4】

Donation methods:

- (1) Crossed cheque 【payable to “Rare Disease Hong Kong Limited”】
- (2) Direct deposit 【Bank of China (Hong Kong) A/C no : 012-740-2-010764-4】



香港罕見疾病聯盟
 RARE DISEASE HONG KONG

關於我們

About Us

香港罕見疾病聯盟¹為政府認可的註冊慈善團體(註冊編號：91/16233)，成立於2014年12月，是全港首個由跨類別罕見疾病病人和照顧者組成，並得到有關專家學者支持的病人組織。

我們代表患者和照顧者，致力透過與持份者協作，提升對罕病的認知，共同推動改善罕病政策和服務，令罕病患者的醫療、社會支援、教育、生活等各項基本權利與其他所有市民一樣得到尊重和保障。

Established in December 2014, Rare Disease Hong Kong (RDHK)¹, formerly known as the Hong Kong Alliance for Rare Diseases, is a charitable institution recognized by the government (ref. no.: 91/16233). It is the first patients' group in Hong Kong comprising cross-rare-disease patients and their families with the support of experts and academics in the field.

We represent patients and caregivers, aiming to improve related policies and services, promote public education on rare diseases, and strengthen the community's support for patients in order to ensure equal respect and protection for patients in terms of fundamental rights such as healthcare, social support, education and daily needs.

¹ 香港罕見疾病聯盟是香港社會服務聯會及香港復康聯會會員機構。 Rare Disease Hong Kong is a member of The Hong Kong Council of Social Service and The Hong Kong Joint Council for People with Disabilities.



政策倡導
Policy Advocacy

我們的核心工作
What We Do

公眾認知
Public Awareness

能力建設
Capacity Building

什麼是罕見疾病？

What is a Rare Disease

罕見疾病泛指患病率偏低的疾病，涵蓋大部分先天遺傳疾病，和一些非常罕見的傳染病，自體免疫疾病及罕見癌症。全球約有7,000種罕見疾病²。根據估計，每15人中就有1人可能患有罕病，全球罕病患者約4億人³。

Rare diseases are generally referred to as low-prevalence diseases, which cover most of the genetic disorders, rare infectious diseases, autoimmune disorders and rare cancers. About 7,000 rare diseases are discovered so far². It was estimated that one out of 15 persons and 400 million people worldwide could be affected by a rare disease³.



² 資料來源：立法會秘書處 資料研究組IN07/16-17
Source of information: Legislative Council Secretariat Research Office IN07/16-17

³ 資料來源：世界衛生組織 Priority Medicines for Europe and the World 2013 Update
Source of information: World Health Organization—Priority Medicines for Europe and the World 2013 Update

罕病的定義

Definition of Rare Diseases



美國：全國患者少於20萬人的病症
United States: Condition that affects fewer than 200,000 people



歐盟：每1萬人少於5宗個案
EU: Affecting less than 5 in 10,000 people



台灣：每1萬人少於1宗個案
Taiwan: Affecting less than 1 in 10,000 people



日本：患者人數少於人口0.1%的病症
Japan: Less than 0.1% of the population being affected



香港：政府沒有界定準則
Hong Kong: No definition by the government



罕見疾病的特點

Characteristics of Rare Diseases

- 慢性和退化性，並可能引致殘障及危害生命
- 難以診斷及治療
- 病例及臨床數據稀少
- 醫護人員認知不足
- Chronic and degenerative, some may be disabling and life-threatening
- Difficult to diagnose and treat
- Limited cases and clinical data
- Insufficient awareness among health professionals

罕病患者及照顧者面對的挑戰

Challenges Encountered by Patients with Rare Disease and their Caregivers

- 患者身體各器官功能均可能出現日漸衰退現象，最終變成永久殘障。
- 大部份罕病是無法治癒的，藥物只能舒緩患者的病癥。
- 罕病藥物價格高昂，為患者及其家庭帶來沉重的經濟負擔。
- 照顧者長期承受身心壓力，卻缺乏社會支援。
- The function of various organs of the patients may gradually decline and eventually become permanently disabled.
- Most rare diseases are incurable, and medications can only relieve symptoms.
- The high drug prices lead to heavy financial burden for patients and their families.
- Caregivers have to face chronic physical and emotional stress, but lack social support.

