香港罕見疾病聯盟
RARE DISEASE HONG KONG

會務報告 2023
ANNUAL REPORT

機構使命：尊重差異、確保權利

核心業務：政策倡導、提升認知、能力建設

發展策略：廣結網絡、共謀協作

管理哲學：善用資源、成效為本

管治原則：開放透明、誠信問責

Our mission:
To respect differences & ensure rights

What we do:
Policy advocacy, public awareness & capacity building

Development strategy:
To maintain and enhance networks and collaborative partnerships

Management philosophy:
Optimal resource utilisation & outcome-oriented approach

Governance principles:
Openness, transparency, integrity & accountability

香港罕見疾病聯盟有限公司 2023 年會務報告

(2024 年 2 月)

Rare Disease Hong Kong Limited Annual Report 2023

(February 2024)

經過三年多的新冠疫情，全球在 2023 年全面復常。香港罕見疾病聯盟（下稱「罕盟」）積極恢復各類實體活動，與各方持份者攜手協作。在多方共同努力下，各項核心業務均取得豐富成果。

After more than three years of the COVID-19 pandemic, the world has got back to normal in 2023. Rare Disease Hong Kong (RDHK) has fully resumed its physical activities and has been actively engaging and collaborating with various stakeholders. With the joint efforts of all parties, remarkable results were achieved in different aspects of work.

1 政策倡議

1.1 成功開啟溝通之門

罕盟自 2022 年第六屆香港特區政府新班子上任後，先後五次致函邀約醫務衞生局（醫衞局）會面，以了解香港各項罕見疾病措施的最新進度和現屆政府對罕見病的取向。2023 年 8 月 3 日，罕盟獲邀到政府總部，與醫衞局副局長、醫院管理局（醫管局）聯網服務總監等合共九名代表進行會面交流，成功開啟溝通之門。同年 12 月 1 日，醫管局再次與罕盟進行線上會議，就極昂貴藥物支付方式、病人名冊計劃、罕病跨專科覆診和其他醫療服務需要、中港兩地醫療合作等議題作具體解說和正面回應。

在兩次交流中，醫管局表示樂意與罕盟保持定期溝通，而當局在持續

1 Policy advocacy

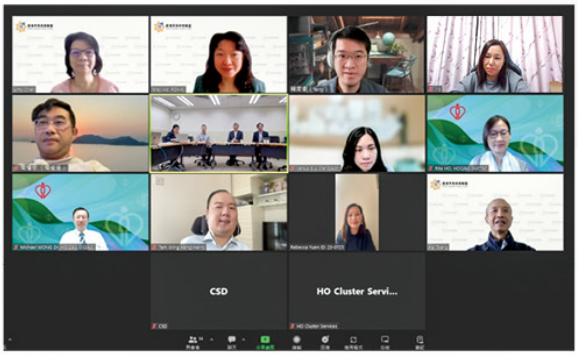
1.1 Opening the door to communication

Since the inauguration of the new leadership of the sixth-term HKSAR Government in 2022, RDHK has sent five invitation letters to the Health Bureau (HHB) requesting for a meeting in order to learn about the latest progress of various rare disease measures in Hong Kong and the current-term Government's approach to rare diseases. On 3 August 2023, RDHK was invited to the Central Government Offices to meet with a total of nine representatives, including the Under Secretary for Health, HHB and the Director (Cluster Services), Hospital Authority (HA). On 1 December of the same year, the HA held another online meeting with RDHK to give specific explanations and positive responses on topics such as payment methods for ultra-expensive drugs, patient registry scheme, multi-disciplinary follow-up consultations and other medical service needs for rare diseases, and medical co-operation between the Mainland and Hong Kong, etc.

During the two exchanges, the HA expressed its willingness to communicate with RDHK regularly. In

優化醫療服務的思維、策略和發展方向均與罕盟的建議類近。相信只要醫患雙方能保持這種務實和真摯的交流，日後定可為罕病社群和大眾市民帶來更多佳音。

fact, the authorities concerned and RDHK share similar thoughts in terms of thinking, strategy and development direction for continuous improvement of healthcare services. It is believed that if pragmatic and sincere communication between the health authorities and patients can be maintained, the rare disease community and the general public will benefit more in the future.



1.2 就《施政報告》公眾諮詢提交意見書

罕盟一直主張以官、商、民協作應對罕病挑戰，而政府在當中的角色尤其重要。罕盟就《2023 年施政報告》公眾諮詢提出下列六項建議：

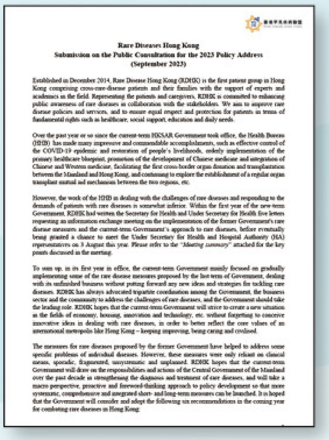
a. 政府主導，組成跨界別罕病策略協調機制
b. 就訂立本地罕病定義展開研究
c. 為罕病患者提供人性化的臨床服務
d. 拆牆鬆綁，優化和完善罕病藥物可及性機制
e. 就罕病診治開展與大灣區協作
f. 將帶狀疱疹疫苗納入疫苗接種資助計劃

掃瞄下載中文版　掃瞄下載英文版

1.2 Submission on the 2023 Policy Address public consultation

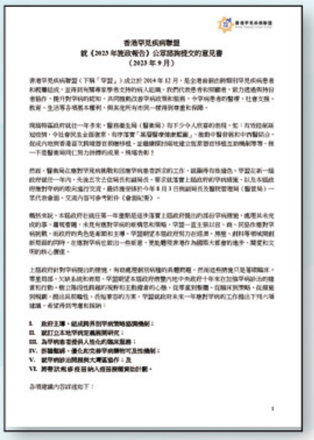
RDHK has been advocating for tackling the challenges of rare diseases with tripartite collaboration among the government, the business sector and the community, whereas the government plays a critical role. RDHK put forward the following six recommendations in the submission on the 2023 Policy Address public consultation:

a. To form a government-led cross-sector coordination mechanism on strategy for rare diseases
b. To commence a study on the local definition of rare diseases
c. To provide rare disease patients with humanised healthcare services
d. To optimise and improve the access mechanism for orphan drugs by cutting the red tape
e. To collaborate on rare disease diagnosis and treatment in the Greater Bay Area
f. To include Herpes Zoster vaccination in the Vaccination Subsidy Scheme



Rare Diseases Hong Kong
Submission on the Public Consultation for the 2023 Policy Address
(September 2023)

Established in December 2014, Rare Disease Hong Kong (RDHK) 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. Representing the patients and caregivers, RDHK is committed to enhancing public awareness of rare diseases in collaboration with the stakeholders. We aim to improve rare disease policies and services, and to ensure equal respect and protection for patients in terms of fundamental rights such as healthcare, social support, education and daily needs.



香港罕見疾病聯盟
就《2023年施政報告》公眾諮詢提交的意見書
（2023年9月）

1.3 脊髓性肌肉萎縮症（SMA）患者生命質量調查

為取得真實數據以加強政策倡議工作，罕盟於2021年11月委託香港中文大學賽馬會公共衞生及基層醫療學院進行為期一年的追蹤調查，後因疫情影響和受訪者人數增加而延長調查期，並加入質性調查。截至2023年12月為止，量性調查總共有28名成人患者和20名兒童患者的家屬受訪，預計2024年年中完成訪談及發表報告；質性調查於2023年年中完成，總共專訪13名SMA三型成人患者，了解他們的患病經歷、日常生活、疾病負擔及與健康相關的生命質量。

8月23日，罕盟召開新聞發佈會，發表香港SMA患者的生命質量與疾病歷程調查結果，透過17家媒體合共32篇紙媒和網媒的報導，呼籲政府撤銷資助用藥的年齡限制，讓25歲以上的SMA患者也獲資助用藥。10月初，罕盟分別致函醫衞局和勞工及福利局，分享

1.3 Survey on the quality of life of patients with Spinal Muscular Atrophy (SMA)

To collect real-world data to strengthen the policy advocacy work, RDHK commissioned the the Jockey Club School of Public Health and Primary Care in November 2021 to conduct a one-year research study. But due to the impact of the epidemic and the increased number of respondents, the survey period has been extended and a qualitative survey was added. As of December 2023, a total of 28 adult patients and 20 family members of paediatric patients have been interviewed in the quantitative survey. The interviews and reports are expected to be completed in mid-2024. The qualitative survey, aiming to understand patients' disease experience, daily life, disease burden and health-related quality of life, was completed in mid-2023, with a total of 13 adult patients with SMA type 3 interviewed.

On August 23, a press conference was held to announce the results of the survey on the quality of life and disease course of SMA patients in Hong Kong. RDHK called on the government to remove the age limit for subsidized medication through a total of 32 print and online media reports from 17 media outlets, so that SMA patients over 25 years old can also receive subsidized medication. In early October, letters were sent to the HHB and the Labour and Welfare Bureau to share the report on the

SMA 三型成人患者的病患旅程簡報，並提出回應 SMA 患者需求的建議。

patient journey of adult patients with SMA type 3 and to make suggestions for addressing the needs of SMA patients.

1.4 更新香港罕病及罕癌藥物清單

罕盟根據醫管局和 MIMS Hong Kong 網上提供的資料，於 2022 年編整了《香港罕見疾病藥物參考清單》和《香港罕見癌症藥物參考清單》，並於 2023 年 1 月更新和上載罕盟網頁（https://rdhk.org/others），以供各持份者參考和下載。

1.4 Updating the drug lists for rare diseases and rare cancers in Hong Kong

Based on the information provided by the HA and MIMS Hong Kong, RDHK compiled the "Drug List for Rare Diseases in Hong Kong" and "Drug List for Rare Cancers in Hong Kong" in 2022. The two drug lists were updated and uploaded to the website of RDHK (https://rdhk.org/others) in January 2023 for public reference and download.

請掃瞄二維碼，以查閱及下載
《香港罕見疾病藥物參考清單》
《香港罕見癌症藥物參考清單》

1.5 加速罕病藥物可及性

❖ 阿哌奧諾基

得悉有望根治 SMA 的基因療法已在香港註冊後，罕盟於 2023 年 4 月致函醫管局，請求儘快把新藥「阿哌奧諾基」（Onasemnogene abeparvovec）納入藥物名冊和安全網。同年 12 月，醫管局公佈，於 11 月首次應用「阿哌奧諾基」治療一名 SMA 一型男嬰，並納入「關愛基金極度昂貴藥物」項目資助範圍，估計引入藥物後每年約五名 SMA 患者受惠。

1.5 Accelerating to access to orphan drugs

❖ Onasemnogene abeparvovec

Having learned that the gene therapy for SMA had been registered in Hong Kong, RDHK sent a letter to the HA in April 2023 requesting that the new drug onasemnogene abeparvovec be included in the drug formulary and safety net as soon as possible. In December of the same year, the HA announced that onasemnogene abeparvovec was used for the first time in November to treat a baby boy with SMA type 1, and was included in the ultra-expensive drug category of the Community Care Fund (CCF). It is estimated that the introduction of the drug will benefit about five SMA patients per year.

❖ 布羅索尤單抗

繼 2022 年成功爭取把用作治療性聯遺傳型低磷酸鹽佝僂症 XLH 的新型藥物「布羅索尤單抗」（Burosumab）納入醫管局藥物名冊後，罕盟於 2023 年年初舉行傳媒小組訪問，讓一名 XLH 患童和照顧者分享其診治經歷和傳統治療方案的流弊。在多方共同協作下，醫管局在同年 5 月把「布羅索尤單抗」納入關愛基金資助範圍。

❖ Burosumab

After successfully advocated for the inclusion of the new drug burosumab in the HA Drug Formulary in 2022, RDHK held a media group interview in early 2023, in which a paediatric patient with XLH and her caregiver shared the experience of diagnosis and treatment and the drawbacks of traditional treatment. With the concerted efforts of various parties, the HA included burosumab in the list of drugs supported by CCF in May of the same year.

醫管局藥物名冊
HA Drug Formulary

撒瑪利亞基金

關愛基金

1.6 其他倡議工作

2023 年 11 月舉行罕病研討會後，罕盟把嘉賓講者席上發表的重要資訊、觀點和建議記錄下來，總結和整理後連同倡議書函一併呈交醫衞局，促請政府參考內地的作為，結合香港在醫療體系、科研、人材和國際聯系等方面的優勢，加強政策力度，主導官、商、民罕見病全方位協作網絡。函件內容可於罕盟網站 (https://bit.ly/rdhk_submissions) 下載。

1.6 Other advocacy work

After the Rare Disease Symposium held in November 2023, RDHK recorded, summarized and collated the important messages, views and suggestions delivered by the guest speakers, and submitted them to the HHB together with a proposal letter, urging the government to make reference to the Mainland's doings, leverage on Hong Kong's edge in the healthcare system, scientific research, human resources and international connections, strengthen policies, and take the lead in building a collaborative network which involves the government, the business sector and the community to tackle rare diseases together. The letter can be downloaded from the RDHK's website (https://bit.ly/rdhk_submissions).

2 提升認知

2.1 罕病研討會 2023

罕盟每年都舉辦大型研討會，就不同罕病議題作深入探討和提出建議。2023 年的罕病研討會於 11 月 11 日以線上線下模式同步舉行，主題為「健康中國，一個都不能少：香港如何趕上內地罕病政策步伐」，旨在瞭解近年內地罕病政策發展和實踐成效、探討香港如何有效借鑒內地的進展，積極主動應對罕病挑戰和促進內地與香港罕病診療的互聯互通。罕盟十分榮幸邀得北京協和醫院院長張抒揚教授和中國罕見病聯盟執行理事長李林康先生擔任主講嘉賓，並感謝田北辰議員、李小羿博士、李立業醫生、杜啟峻醫生和董咚教授擔任討論嘉賓。登記線上或現場參與研討會的總人數超過 300 人，出席率達七成。歡迎到罕盟網站的「影視廊」(https://bit.ly/RDHK-videos) 重溫研討會片段。

2 Public awareness

2.1 Rare Disease Symposium 2023

RDHK organises a large-scale conference annually to discuss and make recommendations on different rare disease topics. The Rare Disease Symposium 2023 was held in hybrid mode on 11 November, with the theme of "Healthy China, leaving no one behind: how Hong Kong can keep up the pace of the Mainland's rare disease policy". It aimed to understand the development and implementation outcomes of rare disease policies in the Mainland in recent years, to explore how Hong Kong can effectively learn from the progress of the Mainland under the framework of one country, two systems and proactively address the challenge of rare diseases; and to promote mutual access of rare disease diagnosis and treatment in the Mainland and Hong Kong. RDHK is honored to have Professor Zhang Shuyang, President of Peking Union Medical College Hospital, and Mr. Li Linkang, Executive Director of China Alliance for Rare Diseases, as keynote speakers, and thanked Hon Michael Tien, Dr. Benjamin Li, Dr. Larry Lee, Dr. Michael To and Professor Dong Dong as panelists. The total number of participants who registered for the seminar online or in person exceeded 300, and the attendance rate reached 70%. The symposium videos can be viewed at the "Galleries" of RDHK's website (https://bit.ly/RDHK-videos).

2.2 罕病公眾教育項目

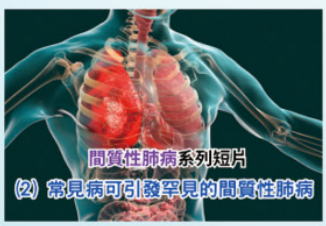
罕盟在 2023 年舉辦了多元化的公眾教育活動，以個別罕病為主題的包括特發性多發性卡斯爾曼氏症、間質性肺病、轉甲狀腺素蛋白類澱粉沉積心肌病變、脊髓肌肉萎縮症和性聯遺傳型低磷酸鹽佝僂症；形式包括短片、傳媒小組訪問、新聞發佈會、新聞稿、專欄文章、患者分享和電視特輯等。

鑑於「健康公平」的概念與醫療資源分配和醫療可及性利害相關，罕盟藉著 2023 年世界罕病日推出為期一年的「健康公平全接觸運動」，先後在多家媒體發表專文，並製作解說「健康公平」理念和落實「健康公平」對患者和社會帶來改變的短片，在多個社交媒體平台發放，以提升大眾對「健康公平」概念的認知和理解，使有關當局明白適當和公平分配醫療資源對罕見病患者的重要性。

2.2 Public education programmes on rare diseases

In 2023, RDHK organised a wide range of public education programmes on individual rare diseases, including idiopathic multicentric Castleman disease, interstitial lung disease, transthyretin amyloid cardiomyopathy, spinal muscular atrophy and x-linked hypophosphatemia, in the form of video clips, media group interviews, press conferences, press releases, op-eds, patient sharing, TV specials, etc.

In view of the stakes associated with the concept of "health equity" in the allocation of medical resources and access to healthcare, RDHK launched a one-year "Health Equity Campaign" on the occasion of World Rare Disease Day 2023. The Campaign included the publication of articles in various media outlets and production of short videos explaining the concept of "health equity" and the changes that the implementation of "health equity" will bring to patients and society. The articles and videos were distributed on various social media platforms to enhance public awareness and understanding of the concept of "health equity" and to enable the authorities concerned to understand the importance of appropriate and fair allocation of medical resources for rare disease patients.




為進一步提升廣大市民對罕見疾病和相關議題的認知和關注度，罕盟首次與報社合作，於 2023 年 4 月推出長達一年的《「罕罕」而談》專欄，內容包括罕病的介紹、最新的診治方法、罕病政策討論、罕病患者和照顧者的故事等，以淺白易明的方式向公眾傳遞訊息。相關文章除刊登於《東方日報》的港聞醫健版外，也在罕盟的網站和社交媒體平台發佈，平均每篇文章的觸及人數超過 5,000 人。

In order to further raise the public awareness of issues relating to rare diseases, RDHK cooperated with the newspaper for the first time to launch a year-long column in April 2023 to convey information to the public in an easy-to-understand manner. The column includes different topics such as introduction of various rare diseases, the latest diagnosis and treatment methods, discussion on rare disease policies, stories of rare disease patients and caregivers and so on. In addition to being published in the Health Section of Oriental Daily News, the articles were also published on RDHK's website and social media platforms, reaching an average of more than 5,000 people for each article.

2.3 真人圖書館

「真人圖書館」是一個讓罕病患者和照顧者走進社區的項目，透過真實故事的分享，向受眾傳遞尊重生命、逆境自強和關愛共融等正面訊息，同時讓更多人了解罕病社群面對的各種挑戰，以及罕病議題如何與大眾息息相關。在過去一年，罕盟總共為 10 間機構舉辦合共 24 場講座或輔導課，受眾人數約為 1,740 人，對象包括中、小學生、大學醫學院學生和商業機構。

2.3 Human library

The "Human Library" is a project that connects rare disease patients and caregivers with the community. The objectives are to convey positive messages such as respect for life, overcoming adversity, love and inclusion, etc., as well as allow more people to understand the challenges faced by the rare disease community and how rare disease issues are relevant to the public. In the past year, a total of 24 seminars or tutorials were held for 10 organisations, addressing an audience of about 1,740 people, including primary and secondary school students, university healthcare students and commercial organisations.

2.4 網頁

罕盟網頁自 2021 年 4 月優化後，內容豐富，圖文並茂，每年均有過百萬點擊率。2023 年的獨立訪客量高達 52,296 人，總瀏覽次數接近 72,000。

2.4 Website

Since its optimisation in April 2021, RDHK's website has become rich in content, including abundant information, images and videos, with over one million hits every year. In 2023, the website attracted 52,296 unique visitors achieving nearly 72,000 page views.

2.5 社交媒體平台

經過多年深耕，罕盟臉書粉絲專頁的追蹤者已超過 6,300 人。2023 年總共發佈了 166 則貼文，總觸及人數接近 1,200,000 人。為進一步接觸到不同年齡和背景的和覆蓋，罕盟去年 2 月底增設 Instagram 和 LinkedIn 專頁。在短短十個月內，兩個平台合共吸引超過 900 人追蹤和關注，貼文的總觸及人數超過 670,000 人。

2.5 Social media platforms

After years of efforts, RDHK's Facebook fan page has more than 6,300 followers. In 2023, a total of 166 posts were published, reaching nearly 1,200,000 people in total. To further reach people of all ages and backgrounds, RDHK created an Instagram page and a LinkedIn page at the end of February last year. In just 10 months, the two platforms attracted more than 900 followers, and the total reach of posts exceeded 670,000 people.

2.6 罕情

《罕情》是每年1、4、7、10月出版的季刊，兼備印刷版和網上版，內容包括國際和本地的重大罕病政策、罕盟及其他罕病團體的活動消息、罕病診療和藥物資訊等，讀者對象包括政府官員、議員、醫護人員、罕病社群、罕盟的合作伙伴和社會大眾，歡迎到罕盟網頁(https://rdhk.org/RareCare)下載閱讀。

2.6 RareCare

RareCare is a quarterly newsletter published in January, April, July and October every year, with both electronic and print formats. It covers major international and local policies on rare diseases, various activities of RDHK and other rare disease groups, and information on rare diseases, orphan drugs and so on. Readers include government officials, District or Legislative Council members, healthcare professionals, rare disease communities, RDHK's partners and the general public. The public is welcome to download the newsletters from RDHK's website (https://rdhk.org/RareCare).

3 能力建設

3.1 鼓勵會員走出靜默圈

在過去一年，罕盟成功發掘了6名「新星」，協助他們把自己的疾病簡介和個人經歷編整為PowerPoint簡報，在不同場合分享。此外，我們也邀請不同病類的會員參與短片拍攝、擔任電台節目分享嘉賓、在病人焦點小組會議發表意見、接受傳媒、學院及機構訪問等，目的是鼓勵會員面對公眾，

3 Capacity building

3.1 Encouraging members to break the circle of silence

In the past year, RDHK identified 6 "new stars" and helped them recount their disease profiles and personal experiences with PowerPoint slides for sharing on different occasions. In addition, members with different diseases were also invited to participate in video shooting, radio interviews, patient focus group meetings, and be interviewed by media, colleges and institutions, etc., with the aim of encouraging them to express themselves in front of the public, enhance their presentation and communication skills, enhance their self-confidence and self-esteem, and at the same

勇於表達自己，提升他們的表達技巧和溝通能力，增強自信心和肯定自我價值；同時，也讓大眾對罕病社群有更多的認識和關注。

time, let the public learn more about the rare disease community.

3.2 專題講座

去年罕盟主辦或與其他機構合辦了多個專題教育活動，包括間質性肺病健肺運動及教育講座、神經纖維瘤一型病友支援課程、香港小胖威利症家長大會、基因治療講座，總參加人數接近 200 人。

3.2 Subject talks

Last year, RDHK hosted or co-organised a number of seminars on topics such as education seminar and exercise for patients with interstitial lung disease, practical workshop for patients with neurofibromatosis type 1, Prader-Willi syndrome parent meeting and seminar on gene therapy. The total number of participants was about 200.

3.3 社交及消閒活動

為促進會員之間的互動交流，從而結認同路人和舒展身心，罕盟不時舉辦不同類型的消閒聯誼活動。2023 年舉辦的會員活動包括禪繞畫基本圖樣工作坊、逆向而生園藝活動、樹葉紋袋工作坊、中秋扭扭汽球花燈工作坊、壽司製作體驗班和間質性肺病病友分享會。此外，罕盟亦協助派發「舞創新篇章 2023」入場門票及「國際復康日」免費海洋公園門票予有興趣的會員。上述各項活動均深受會員歡迎，總參加人數超過 200 人。

3.3 Social and leisure activities

To promote exchange among members and provide them with chances to gain peer support and relax, RDHK organised various social and leisure activities from time to time. Member activities held in 2023 included Zentangle Workshop for Beginners, Gardening Workshop on Hanging Plants, Workshop on Leaf Print Tote Bags, Mid-Autumn Festival Lantern Making Class, Sushi Making Class and Interstitial Lung Disease Patient Gathering. Additionally, RDHK assisted in distributing tickets for "Dance a New Chapter 2023" and free Ocean Park tickets on "International Day of Persons with Disabilities" to interested members. All the above-mentioned activities were well received by the members, with a total of over 200 participants.

3.4 義工培訓

罕盟去年總共為 10 名來自港大和中大醫學院的醫科生和公共衛生學生、3 名護士和 5 名公眾人士提供義工培訓，並為其中兩名公共衛生課程學生分別提供 100 小時和 120 小時的實習機會。義工們主要的任務是參與各項會員活動和家訪，透過親身接觸、體驗和交流，增加他們對罕病社群的認知和關懷；其他的義工服務包括問卷調查分析、文章翻譯、賀咭設計等。

3.4 Volunteer training

Last year, RDHK provided volunteer training for 10 students from the Faculty of Medicine from HKU and CUHK, 3 nurses and 5 members of the public, and two of the public health students were provided with 100 and 120 hours of internship respectively. The main tasks of the volunteers were to participate in various member activities and home visits, which aimed to increase their awareness of and care for the rare disease community through personal contact, experience, and communication. Other volunteer services included survey analysis, article translation, and greeting card design, etc.

3.5 境外交流活動

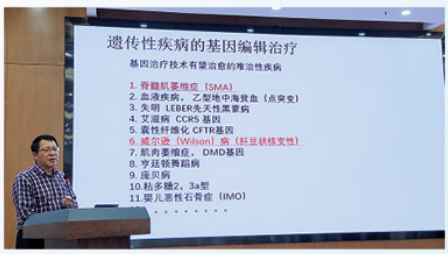
各地區和國家都有不同的應對罕病方式。因此，罕盟鼓勵病友和同事到境外交流，以增廣見聞、擴闊視野。去年罕盟資助了 13 名會員參與 9 月於湖南長沙市舉行的「2023 第十二屆中國罕見病高峰論壇」，了解內地罕病政策和服務的發展；10 月派代表到安徽省合肥市參加由香港威爾遜氏症協會舉辦的學習考察團，參觀一所有數十年研究和

3.5 Exchange activities outside Hong Kong

Different regions and countries have different ways of coping with rare diseases. Therefore, RDHK encourages patients and staff to go overseas for exchanges to broaden their horizons. Last year, 13 members were sponsored to participate in the "2023 The 12th China Rare Disease Summit" held in Changsha, Hunan Province in September to learn about the development of rare disease policies and services in the Mainland. In October, RDHK representatives participated in a study tour organised by the Hong Kong Wilson's Disease Association, to visit a hospital in Hefei, Anhui Province. which has been researching and treating

治療威爾遜氏症的醫院，並與當地病友組織交流；11 月安排多名罕盟理事和職員參觀香港大學深圳醫院，了解其醫療服務、硬件設備、就診和配藥操作流程等；罕盟同事還先後到新加坡和廣州出席與罕病相關的會議和交流，分享香港的運作和吸收境外的經驗。

Wilson's disease for decades, and to interchange with the local patient organisations. In November, a number of RDHK council and staff members visited the Hong Kong University-Shenzhen Hospital to learn about its medical services, hardware equipment, procedures for medical appointments and dispensing, etc. Some RDHK staff also went to Singapore and Guangzhou to attend conferences and exchange activities relating to rare diseases, sharing experiences and learning from others.



4 其他工作

4.1 周年大會

罕盟第四屆會員周年大會於 2023 年 6 月 17 日舉行，總共有 62 人出席。會後安排了有獎集體遊戲和聯誼茶聚，促進會員之間的交流。

4 Miscellaneous work

4.1 Annual general meeting

The fourth Annual General Meeting was held on 17 June 2023, with a total of 62 attendees. There were games, prizes and tea gathering after the meeting, to promote interaction among members.

4.2 護理物資及服務資助先導計劃

罕盟根據會員調查報告的結果，制定了「護理物資及服務資助先導計劃」，目的是對現有公共醫療及社會福利服務未有妥善處理的罕病患者所需的護理物資和服務提供過渡性資助，從中收集政策倡議的實證資料，推動完善安全網，惠及更多患者。資助計劃於 2023 年 5 月推出，直至年底為止，總共收到 4 份申請，其中 3 宗申請獲批，其餘一宗因未能配合審批程序而自願撤銷申請。

4.2 The Pilot Scheme of Subsidy for Healthcare Needs

RDHK established the "Pilot Scheme of Subsidy for Healthcare Needs" based on the results of a member survey, to provide transitional funding for nursing supplies and services that are not covered by the current public healthcare and social welfare services but needed by rare disease patients. Empirical data will be collected from the subsidy scheme in order to urge the authorities concerned to improve the coverage of the safety net to benefit more patients. The subsidy scheme was launched in May 2023. As at the end of the year, a total of 4 applications were received, 3 of which were approved, and one was voluntarily withdrawn due to non-compliance with the approval procedure.

4.3 與其他病友組織交流

病友組織之間的交流，有助互相學習和互相支持。罕盟在過去一年分別與 16 個本地罕病組織的代表會面，了解個別組群的近況和可合作的機遇，並就成立社團或慈善機構、開立銀行戶口、撰寫倡議函件、籌辦活動等事宜，為多個有需要的病友組織提供支援，例如提供建議、實用資訊、資助和協助宣傳等，發揮團結互動精神，務求一同為罕病社群謀福祉。

4.3 Interchange with other patient organisations

Exchange among patient organisations facilitates mutual learning and support. In the past year, RDHK met with representatives of 16 local rare disease organisations to understand their current situations and opportunities for collaboration. RDHK also assisted a number of patient organisations in need with such matters as setting up associations or charities, opening bank accounts, writing advocacy letters, organising activities, etc. by providing advice, practical information & funding, assisting in publicity, and so on. It is expected that all the patient groups are united and stand by each other to strive for betterment of the rare disease community.









附錄一、會員及所涵蓋病種

截至 2023 年年底為止，會員總人數為 761，其中：

1. 普通會員（關注及支持罕病患者人士）數目：82
2. 基本會員（罕病患者或家屬）數目：679
   a) 個人會員數目：670
   b) 團體會員數目：9

Appendix I – Members and types of diseases

As at the end of 2023, the total number of members was 761, among which:

1. Number of ordinary members (those who care about and support rare disease patients): 82
2. Number of full members (rare disease patients or families): 679
   a) Number of individual members: 670
   b) Number of organisational members: 9

（按英文名稱排序）
(In alphabetical order)

- 牽手同行協會
  Hand in Hand Association
- 香港平滑肌肉瘤基金會有限公司
  Hong Kong Leiomyosarcoma Foundation Limited
- 香港神經纖維瘤協會
  Hong Kong Neurofibromatosis Association
- 香港雷特氏症協會
  Hong Kong Rett Syndrome Association
- 香港小腦萎縮症協會
  Hong Kong Spinocerebellar Ataxia Association
- 香港威爾遜氏症協會
  Hong Kong Wilson's Disease Association
- PNH 病人權益關注組
  PNH Concern Group
- 勉逆歷協進會有限公司
  Primary Immunodeficiency League Association Limited
- 香港視網膜病變協會
  Retina Hong Kong

會員所涵蓋的病種 *：212
Types of diseases among members *: 212

1 10q26 Microdeletion Syndrome (Genetic Disorder)
2 14q Deletion Syndrome (Genetic Disorder)
3 16q11.2 & q22.2 Deletion Syndrome (Genetic Disorder)
4 18q21.2x3 Deletion Syndrome (Genetic Disorder)
5 1p36 Deletion Syndrome (Genetic Disorder)
6 1q44 Deletion Syndrome (Genetic Disorder)
7 2q37 Microdeletion Syndrome (Genetic Disorder)
8 3q23 & 3q25 Deletion Syndrome (Genetic Disorder)
9 8p Inverted Duplication / Deletion Syndrome (Invdupdel(8p)) (Genetic Disorder)
10 Achondroplasia (軟骨發育不全症)
11 Acromegaly (肢端肥大症)
12 ACTA1-related Congenital Myopathy (Genetic Disorder)
13 Albinism (白化病)
14 Alexander Disease (亞歷山大症)
15 Allan-Herndon-Dudley Syndrome (AHDS) / MCT8 Deficiency (MCT8 缺乏症)
16 Alstrome Syndrome (AS) (阿爾斯特倫綜合症)
17 Alveolar Soft Part Sarcoma (肺泡狀軟組織肉瘤)
18 Amyloidosis (AL) (類澱粉沉積症)
19 Amyotrophic Lateral Sclerosis (ALS) (肌萎縮性脊髓側索硬化症)
20 Angelman Syndrome (AS) (天使綜合症)
21 Anomalous origin of Left Coronary Artery from Pulmonary Artery (ALCAPA) (肺動脈左冠狀動脈異常症)
22 Anti-MOG Associated Encephalomyelitis (抗 MOG 相關腦脊髓炎)
23 Anti-NMDA Encephalitis (自體免疫性腦炎)
24 Antisynthetase Syndrome (抗合成酶綜合症)
25 Apert Syndrome (亞伯氏症)
26 Aplastic Anemia (再生不良性貧血症)
27 Aromatic L-amino Acid Decarboxylase Deficiency (AADC) (芳香族 L- 胺基酸類脱羧基酶缺乏症)
28 Arthrogryposis Multiplex Congenita (AMC) (先天性多發性關節攣縮症)
29 ATAD3A Syndrome (Genetic Disorder)
30 ATR-X Thalassemia Syndrome (ATRX) (α 地中海貧血 X- 連鎖智力障碍症)
31 Atypical Hemolytic Uremic Syndrome (aHUS) (非典型溶血性尿毒症)
32 Autoimmune Insulin Syndrome (胰島素自身免疫綜合症)
33 Autosomal Recessive Spastic Ataxia of Charlevoix-Saguenay (ARSACS) (Charlevoix-Saguenay 型隱性痙攣性共濟失調症)
34 Behcet's Disease (BD) (貝賽特氏症)
35 Bilateral Perisylvian Polymicrogyria (BPP) (雙側西耳維厄斯周圍多小腦回畸形症)
36 Burning Mouth Syndrome (BMS) (口腔灼熱症侯群)
37 Cardiofaciocutaneous Syndrome (CFC) (CFC 症侯群)
38 Castleman Disease (CD) (卡斯爾曼氏症)
39 Central Core Disease (CCD) (肌中央軸空症)
40 Charcot-Marie-Tooth Disease (CMT) (進行性神經性腓骨肌萎縮症)
41 Chronic Hemolytic Anemia (慢性溶血性貧血症)
42 Chronic Inflammatory Demyelinating Polyneuropathy (CIPD) (慢性脱髓鞘性神經炎)
43 Chronic Suppurative Osteomyelitis (慢性化膿性骨髓炎)
44 Cockayne Syndrome (柯凱因氏症侯群)
45 Coenzyme Q10 Deficiency-7 (Genetic Disorder)
46 Collagen XII Myopathy (膠原蛋白 XII 缺失肌肉萎縮症)
47 Complex Regional Pain Syndrome (CRPS) (複雜性局部疼痛症) / Reflex Sympathetic Dystrophy Syndrome (RSD) (交感神經失調症)
48 Cone-rod Dystrophy (視幹細胞營養不良症)
49 Congenital Bile Acid Synthesis (CBAS) (胆汁酸合成障碍)
50 Congenital Glaucoma (先天性青光眼)
51 Congenital Insensitivity to Pain with Anhidrosis (CIPA) (先天性痛不敏感症合併無汗症)
52 Congenital Muscular Dystrophy (CMD) (先天性肌營養不良症)
53 Cornelia De Lange Syndrome (CdLS) (狄蘭氏症侯群)
54 Costello Syndrome (克斯提洛氏彈性蛋白質缺陷症)
55 Cri-Du-Chat Syndrome (貓哭症)
56 Crohn's Disease (克隆氏症)
57 CTNNB1 Syndrome (Genetic Disorder)
58 Cushing's Syndrome (CS) (庫欣氏症候群)
59 Cystic Fibrosis (囊腫性纖維化)
60 Dandy-Walker Syndrome (Dandy-Walker 氏症候群)
61 Ddx3x Syndrome (Genetic Disorder)
62 Dermatomyositis (皮肌炎)
63 DiGeorge Syndrome (DGS) (迪喬治症侯群)
64 DNM1-L Syndrome (Genetic Disorder)
65 Dravet Syndrome (DS) (卓飛症候群)
66 Duchenne Muscular Dystrophy (DMD) (杜興氏肌肉營養不良症)
67 DYRK1A Syndrome (Genetic Disorder)
68 Ectodermal Dysplasia (外胚層發育不良症)

69 Ehlers-Danlos Syndrome (埃勒斯 - 當洛二氏症)
70 Eosinophilic Granulomatosis with Polyangiitis (EGPA) (嗜酸性肉芽腫性多血管炎)
71 Epidermolysis Bullosa (EB) (表皮溶解水皰症)
72 Epithelioid Hemangioendothelioma (EHE) (上皮樣血管內皮瘤)
73 Erythromelagia (紅斑性肢痛症)
74 Fabry Disease (法布瑞氏症)
75 Facioscapulohumeral Muscular Dystrophy (FSHD) - Type 1 (面肩肱型肌肉營養不良症第 1 型)
76 Familial Amyloid Polyneuropathy (FAP) (家族性澱粉樣物多發性神經病變)
77 Fibrodysplasia Ossificans Progressiva (FOP) (進行性肌肉骨化症)
78 Floating-Harbor Syndrome (FHS) (Floating-Harbor 綜合症)
79 Fragile X Syndrome (FXS) (X 染色體脆弱症)
80 Glioblastoma Multiforme (GBM) (膠質母細胞瘤)
81 Glutamate Receptor, Ionotropic, N-Methyl D-Aspartate 1 (GRIN 1)
82 Glutaric Acidemia Type 2 (GA2) (戊二酸血症第 2 型)
83 Glycogen Storage Disease (GSD) - Type 1，G6PC Variants (肝醣儲積症第 1 型，G6PC 病變異)
84 Glycogen Storage Disease (GSD) - Type 1B (肝醣儲積症第 1B 型)
85 Glycogen Storage Disease (GSD) - Type 2 (肝醣儲積症第 2 型) / Pompe Disease (龐貝氏症)
86 Glycogen Storage Disease (GSD) - Type 6 (肝醣儲積症第 6 型)
87 Hereditary Angiodema (HAE) (遺傳性血管性水腫症)
88 Hereditary Spastic Paraplegia (HSP) (遺傳性痙攣性下身麻痺症)
89 Hirschsprung's Disease (HD) (先天性巨結腸症)
90 Huntington's Disease (HD) (亨丁頓舞蹈症)
91 Ichthyosis (斑色魚鱗癬症)
92 Idiopathic Intracranial Hypertension (IIH) (特發性顱內壓增高症)
93 Idiopathic Pulmonary Fibrosis (IPF) (特發性肺纖維化)
94 IgG4-related Chronic Sclerosing Sialadenitis
95 Interstitial Lung Disease (ILD) (間質性肺病)
96 Intravenous Leiomyomatosis (IVL) (靜脉內平滑肌瘤)
97 Jacobsen Syndrome (JS) (雅各森症候群)
98 Kallmann Syndrome (KS) (卡爾曼氏症)
99 KCNB1 Syndrome (Genetic Disorder)
100 KCNQ2 Syndrome (Genetic Disorder)
101 Kennedy Disease (甘迺迪氏症) / Spinal and Bulbar Muscular Atrophy (SBMA) (脊髓延髓性肌肉萎縮症)
102 KIF5C Syndrome (Genetic Disorder)
103 Kleefstra Syndrome (KS) (Kleefstra 綜合症)
104 Klippel-Trénaunay Syndrome (KTS) (靜脈畸形骨肥大綜合症)
105 Langerhans Cell Histiocytosis (LCH) (蘭格罕細胞組織球增生症)
106 Larsen Syndrome (顎裂 - 先天性脱位症候群)
107 Leigh Syndrome (Leigh 氏症候群)
108 Leopard Syndrome (豹皮症候群)
109 Linear Scleroderma (線性硬皮症)
110 Lipid Storage Myopathy (LSM) (脂質儲積性肌病)
111 Lissencephaly (平腦症)
112 Lymphangioleiomyomatosis (LAM) (淋巴管平滑肌增生症)
113 Maple Syrup Urine Disease (MSUD) (楓糖尿症)
114 Marfan Syndrome (MFS) (馬凡氏症)
115 McCune-Albright Syndrome (MAS) (纖維性骨失養症)
116 Medulloblastoma (髓母細胞瘤)
117 Melanomae / Eye Ciliary Body Tumor (眼睫狀體黑色素瘤)
118 Mesothelioma (間皮瘤)
119 Methylmalonic Acidemia (MMA) (甲基丙二酸血症)
120 Mitochondrial Cardiomyopathy (線粒體心肌病變)
121 Mitochondrial Disease (線粒體病)
122 Monoclonal Gammopathies (單克隆免疫球蛋白沉積病)
123 Mowat-Wilson Syndrome (MWS)
124 Mucopolysaccharidoses (MPS) - Type 2 (黏多醣症第 2 型)
125 Mucopolysaccharidoses (MPS) - Type 3 (黏多醣症第 3 型)
126 Mucopolysaccharidoses (MPS) - Type 4 (黏多醣症第 4 型)
127 Mucopolysaccharidoses (MPS) - Type 4A (黏多醣症第 4A 型)
128 Mucopolysaccharidoses (MPS) - Type 6 (黏多醣症第 6 型)
129 Multiple Epiphyseal Dysplasia (MED) (多發性骨骺發育不全症)
130 Multiple Pituitary Hormome Deficiency (MPHD) / Anterior Pituitary Hypoplasia (腦下垂體發育不全症)
131 Multiple Sclerosis (MS) (多發性硬化症)
132 Multiple System Atrophy (MSA) - Pakinsonian Subtype (多重系統退化症 - 非典型巴金森症)
133 Myasthenia Gravis (MG) (重症肌無力症)
134 Myhre Syndrome (Myhre 綜合症)
135 Nemaline Myopathy (桿狀體肌肉病變)
136 Neuroendocrine Tumor (NET) (神經內分泌腫瘤)
137 Neurofibromatosis (NF) - Type 1 (神經纖維瘤第 1 型)
138 Neurofibromatosis (NF) - Type 2 (神經纖維瘤第 2 型)
139 Neuromyelitis Optica (NMO) (視神經脊髓炎)
140 Nicolaides-Baraitser Syndrome (NCBRS)
141 Non-infectious Non-Anterior (NINA) Uveitis (非感染性非前段葡萄膜炎)
142 Noonan Syndrome (努南氏症候群)
143 Optic Neuropathy (視神經病變)

144 Osteogenesis Imperfecta (OI) (成骨不全症)
145 PACS1 Related Syndrome (Genetic Disorder)
146 Paroxysmal Nocturnal Hemoglobinuria (PNH) (陣發性夜間血紅素尿症)
147 Pemphigus Vulgaris (天皰瘡)
148 Persistent Hyperplasia of Primary Vitreous (PHPV) (持續增生性原始玻璃體症)
149 Peutz-Jeghers Syndrome (PJS) (黑斑息肉症候群)
150 Phakomatosis Pigmentovascularis (PPV) (色素血管性母斑症)
151 Phenylketonuria (PKU) (苯丙酮尿症)
152 Phosphatase and Tensin Homolog (PTEN) (Genetic Disorder) (磷酸酯酶與張力蛋白同源物) (基因病變)
153 Pierre Robin Syndrome (PRS) (皮爾羅賓症侯群)
154 Polymyositis (多發性肌炎)
155 Prader-Willi Syndrome (PWS) (小胖威利症)
156 Primary Ciliary Dyskinesia (PCD) (先天性纖毛運動障礙症)
157 Primary Immunodeficiency (PID) (原發性免疫缺陷病)
158 Progressive Pseudorheumatoid Dysplasia (PPD) (進行性假性類風濕性骨發育不良症)
159 Propionic Acidemia (丙酸血症)
160 PTEN Hamartoma Tumor Syndrome (PHTS) (PTEN 過誤腫症)
161 Pulmonary Alveolar Proteinosis (PAP) (肺泡蛋白質沉著症)
162 Pulmonary Hypertension (肺動脈高壓)
163 Pyruvate Dehydrogenase Deficiency (丙酮酸鹽脫氫酵素缺乏症)
164 Raynaud Phenomenon (雷諾氏現象)
165 Relapsing Polychondritis (RP) (復發性多軟骨炎)
166 Retinitis Pigmentosa (RP) (視網膜色素病變)
167 Rett Syndrome (RTT) (雷特氏症)
168 Rhabdomyosarcoma (RMS) (橫紋肌肉瘤)
169 Rubinstein-Tabyi Syndrome (RTS) (Rubinstein-Taybi 症候群)
170 Russell-Silver Syndrome (RSS) (羅素 - 西弗氏症)
171 Sacral Chordoma (骶骨脊索瘤)
172 Schaaf-Yang Syndrome (SYS) (Schaaf-Yang 症候群)
173 Schinzel Giedion Syndrome (SGS) (Schinzel Giedion 綜合症)
174 Sciatic Nerve Tumors / Schwannoma (坐骨神腫瘤)
175 SCN1A Syndrome (Genetic Disorder)
176 SCN2A Syndrome (Genetic Disorder)
177 SCN8A Syndrome (Genetic Disorder)
178 Short Bowel Syndrome (短腸症)
179 Smith-Magenis Syndrome (SMS) (史密斯 - 馬吉利氏症)
180 Spina Bifida (SB) (先天性脊椎裂症)
181 Spinal Muscular Atrophy (SMA) - Type 1 (脊髓肌肉萎縮症第 1 型)
182 Spinal Muscular Atrophy (SMA) - Type 2 (脊髓肌肉萎縮症第 2 型)
183 Spinal Muscular Atrophy (SMA) - Type 3 (脊髓肌肉萎縮症第 3 型)
184 Spinalcerebellar Ataxia (SCA) - Type 2 (小腦萎縮症第 2 型)
185 Spinalcerebellar Ataxia (SCA) - Type 3 (小腦萎縮症第 3 型)
186 Spondyloepiphyseal Dysplasia Congenita (SEDC) (先天性脊椎骨骺發育不全症)
187 Stiff Person Syndrome (SPS) (僵硬人症)
188 Succinic Semialdehyde Dehydrogenase Deficiency (SSADH) (琥珀酸半醛脫氫酶缺乏症)
189 Supernumerary Chromosome 8 Syndrome (Genetic Disorder)
190 Takayasu Arteritis (TA) (高安氏症)
191 Tetratricopeptide Repeat, Ankyrin Repeat and Coiled-coil containing 2 (TANC2)
192 TRIO and F-actin Binding Protein Syndrome (TRIOBP) (Genetic Disorder)
193 Tuberous Sclerosis Complex (TSC) (結節性硬化症)
194 Usher Syndrome (尤塞氏綜合症)
195 Vitamin D-Resistant Rickets (抗維生素 D 性佝僂病)
196 Waardenburg Syndrome (WS) (瓦登伯革氏症侯群)
197 Walker-Warburg Syndrome (WWS) (Walker-Warburg 綜合症)
198 WDR45 (Genetic Disorder)
199 Wells Syndrome (韋爾斯綜合症)
200 West Syndrome-Infantile Spasms (韋氏症 - 嬰兒痙攣症)
201 Williams Syndrome (WS) (威廉氏症候群)
202 Wilson's Disease (WD) (威爾森氏症)
203 Wolf-Hirschhorn Syndrome (WHS) (沃夫 - 賀許宏氏症候群)
204 Wolfram Syndrome (Wolfram 症候群)
205 Worster-Drought Syndrome (WDS)
206 WWOX Syndrome (Genetic Disorder)
207 Xeroderma Pigmentosum (XP) (著色性乾皮症)
208 X-linked Agammaglobulinemia (XLA) (X- 連鎖無丙種球蛋白血症)
209 X-linked Hypophosphatemic Rickets (XLH) (性聯遺傳型低磷酸鹽佝僂症)
210 X-linked Myotubular Myopathy (XLMTM) (肌小管病變)
211 X-linked Retinoschisis (XLRS) (Genetic Disorder)
212 X-linked Thrombocytopenia (XLT) (Genetic Disorder)

* 以上病種均由病人或其家屬於登記入會時提供。

* The above types of diseases were provided by patients or their families at the time of membership registration.

附錄二、理事會成員

會長：曾建平先生（患者，退休企業主管）
內務副會長：阮佩玲女士（患者家屬，產品代理）
外務副會長：黃耀文先生（患者，公司主管）
義務秘書：徐江琼女士（患者家屬，理財顧問）
義務司庫：梁七根先生（患者，自由工作者）
理事*：陳振勝教授（科學家）
陳蔚斯女士（患者，公共關係及市場推廣）*(2023 年 6 月到任)*
周權棣先生（患者家屬，執業護士）
朱嘉豪先生（患者家屬，電訊企業總裁）*(2023 年 3 月離任)*
賴家衡先生（患者，政策研究及倡議經理）*(2023 年 6 月到任)*
譚永亨先生（患者，傳道）*(2023 年 6 月到任)*
黃敏兒女士（註冊社工）
**按英文姓氏排序*

附錄三、秘書處成員

何翠薇女士（營運總監）
賴家衡先生（業務發展主任）*(2023 年 4 月離職)*
陳淑雲女士（服務統籌經理及護理顧問）
黃桂婉女士（活動助理）

附錄四、顧問

（按英文姓氏排序）
車錫英教授
陳麗雲教授，*太平紳士*
陳凱珊醫生
鍾一諾教授
許鍾妮醫生
陸志聰醫生，*太平紳士*
彭彥茹醫生
盛斌醫生
黃志基教授

附錄五、科學及醫療諮詢委員會

主席：　鍾侃言醫生
委員*：陳振勝教授
董咚教授
李雪教授
邵得志醫生
Dr. Sarah WYNN
**按英文姓氏排序*

附錄六、罕盟的本地及境外參與

罕盟是下列本地和境外機構的成員：
香港社會服務聯會
香港復康聯會
亞太罕見病聯盟
國際罕見病聯盟

鳴謝

（按英文名稱排序）
所有支持者、捐贈者和贊助商
義務公關顧問
社會福利署 - 殘疾人士 / 病人自助組織資助計劃
罕盟顧問
罕盟理事會成員
罕盟科學及醫療諮詢委員會成員
罕盟秘書處成員及義工
香港視網膜病變協會

Appendix II – Members of the Council

Chairman: Mr TSANG Kin Ping (patient, retired business executive)
Vice-Chairman (Internal Affairs): Ms Rebecca YUEN (patient's family, product agent)
Vice-Chairman (External Affairs): Mr Davy WONG (patient, company manager)
Honorary Secretary: Ms Helen TSUI (patient's family, financial advisor)
Honorary Treasurer: Mr Jackie LEUNG (patient, freelancer)
Council Members*: Professor Danny CHAN (scientist)
Ms Iris CHAN (patient, PR & marketing) *(took office in Jun 2023)*
Mr Ronald CHOW (patient's family, nurse practitioner)
Mr Jack CHU (patient's family, telecommunications director) *(quitted in Mar 2023)*
Mr Terry LAI (patient, policy research & advocacy manager) *(took office in Jun 2023)*
Mr Henry TAM (patient, preacher) *(took office in Jun 2023)*
Ms Amy WONG (registered social worker)
** In alphabetic order by surname*

Appendix III – Staff of the Secretariat

Ms May HO (Director of Operations)
Mr Terry LAI (Business Development Officer) *(quitted in Apr 2023)*
Ms Amy CHAN (Service Coordination Manager & Nursing Advisor)
Ms Pat WONG (Programme Assistant)

Appendix IV – Advisors

(In alphabetical order by surname)
Professor CHAIR Sek Ying
Professor Cecilia CHAN, *JP*
Doctor Sophelia CHAN
Professor Roger CHUNG
Doctor Joannie HUI
Doctor Che-chung LUK, *JP*
Doctor Shirley PANG
Doctor Bun SHENG
Professor Ian WONG

Appendix V – Scientific & Medical Advisory Committee

Chairman: Doctor Brian CHUNG
Members*: Professor Danny CHAN
Professor Dong DONG
Professor Shirley LI
Doctor Byron SHIU
Doctor Sarah WYNN
** In alphabetic order by surname*

Appendix VI – RDHK's local and overseas involvements

RDHK is a member of the following local and overseas organisations:
Hong Kong Council of Social Service
The Hong Kong Joint Council for People with Disabilities
Asia Pacific Alliance for Rare Disease Organisations
Rare Disease International

Acknowledgement

(In alphabetical order)
All supporters, donors and sponsors
Ernest & Donald Marketing Communications Ltd, honorary PR advisor
Financial Support Scheme for Self-help Organisations of Persons with Disabilities / Chronic Illnesses, Social Welfare Department
RDHK advisors
RDHK council members
RDHK Scientific & Medical Advisory Committee members
RDHK staff and volunteers
Retina Hong Kong

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RARE DISEASE HONG KONG

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Instagram: https://www.instagram.com/rdhk2014
Linkedin: https://www.linkedin.com/company/rdhk

Website　Facebook　Instagram　Linkedin

社聯 HKCSS 機構會員 AGENCY MEMBER