罕見疾病立法

20th Anniversary of Legislation for Rare Disorders in Taiwan

20週年專輯

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昂首邁向更美好的未來

《罕見疾病防治及藥物法》2020 年立法施行 20 週年，從立法之前的個別病友必須自行奮力爭取生存，到今天罕見疾病的照護已經成為傲人台灣之光當中的一道亮眼光束。這些政策與福利並非憑空得來，謹以此書紀錄這個美好法案從草擬、提案、遊說、修正、立法、執行一路上所經歷的風雨與成果。

個人從醫 30 多年以來，始終抱持著不愧對《日內瓦宣言》的信念：「准許我進入醫業時：我鄭重地宣誓自己要奉獻一切為人類服務，將病人的健康與幸福作為我的首要顧念」。而自

踏入兒童遺傳科的領域，面對許許多多難以確診或有效治療的病情，因著人道關懷與對醫療專業的執著，我與遺傳學科的夥伴們選擇走在一條「堅定守護」的鋼索上，兢兢業業為遺傳疾病尋找可能的活路。當年每在出國開會前夕，總會想方設法將無法在國內確診的病人檢體帶到國外檢驗，只為了讓病人能儘早得到明確診斷，並及早接受適當的治療；要回國之前又要絞盡腦汁帶回國內沒有的「救命藥」，以及相關的重要訊息。孑然行走在似乎沒有盡頭的黑夜裡，有時不禁會抬頭問老天爺：「這些父母承擔了照顧孩子的沉重責任，難道政府忍心遺棄他們嗎？」

命運掌握在自己手中，問蒼天不如採取積極有效的行動。1999 年基金會甫成立，便馬上成立立法小組擬定草案，並四處奔走遊說凝聚多元共識，幸賴行政部門、立法委員、政府官員、社會企業、醫療人員與無數夥伴們畢精竭思、無私義助，《罕見疾病防治及藥物法》奇蹟似地僅花了 40 多天的時間便獲得通過，並在隔年的 2000 年開始施行，讓長久以來孤立無援的罕病患者及家庭終於獲得了法源保障。爾後歷經 3 次修法，敦促政府健全罕病通報制度，陸續推行罕藥認定以提供健保給付重要參考，取得維生特殊營養食品及提供營養諮詢、緩和醫療及相關醫療照護與補助等等重要政策。在政府肩負法定責任下，罕病家庭得到應有的照護及幫助，也讓台灣擁有目前

世界上涵蓋面最為周延的罕病立法與制度，同時也呼應了世界衛生組織（WHO）在 2016 年第 69 屆大會中揭櫫的「一個都不能少（Leave No One Behind）」的精神。

在跨越 20 週年里程碑的當下，也是重新審度當前罕病政策並使之更加完善的重要契機。本書邀集跨領域的各方先進賢達一同回顧，並深入審視罕病立法施行 20 年以來對於罕病患者的影響流變，期待能夠得到社會各界的關注，將耀眼國際的台灣罕病制度推向一個更新的階段、更前瞻的層次，以持續性、制度化與合理化的支持陪伴，成為保護罕病家庭的方舟，繼續邁向更美好的未來。

罕見疾病基金會
董事長　林炫沛

20 Years of Devotion- Onto a Better Future

This year marks the 20th anniversary since the Taiwan Rare Disease and Orphan Drug Act (TRDODA) was enacted. Along the way, there have been countless ups and downs, from the time patients had to fight on their own due to the lack of rule of law to this day when healthcare for people with rare diseases has become one of the many achievements that Taiwan takes pride in. These regulations and the benefits they bring just do not come easy. For this reason, I would like to dedicate this book to every person that supports us for everything we have been through and achieved, so that we could witness the birth of this phenomenal Act from its drafting, proposal, lobbying, amendment to enactment and implementation.

Have been practicing medicine for over 30 years, there is not a single day that I forget the values stipulated in the Geneva Declaration: “At the time of being admitted as a member of the medical profession, I solemnly pledge to consecrate my life to the service of humanity, and the health of my patient will be my

first consideration." Since the first day of my practice in pediatric genetics, I have seen countless conditions that are difficult to diagnose or treat effectively. Due to the commitment to humanism and the values of the medical profession, my fellow geneticists and I choose to take the high-wire walk, despite all difficulties, with the shield that guards the patients' well-being, striving to find different ways to treat genetic diseases. Back in the day, some conditions were hard to diagnose in Taiwan, so we tried every means to bring the patients' specimens to a foreign country for examination every time we travel abroad for meetings. It was the only and fastest way we could give them proper diagnoses and treatments. Bringing back life-saving drugs and any information that were not available in Taiwan was also a task for which we went to great lengths. Walking alone in the seemingly endless night, sometimes we whisper to the sky, "The parents of people with rare diseases have shouldered the heavy burden of caring for their children. Can the government really bear to leave behind these families?"

We believe we make our own destiny, so we may as well take action, instead of praying to God for help. Upon the foundation of TFRD in 1999, a focus group was established to draft regulations

and spared no effort to lobby and bring together people that share the same view. Thanks to the wholehearted dedication and the strength from the administration authority, legislators, government officials, social enterprises, health professionals, and countless partners that fight side by side with us, TRDODA took only 40 days to pass and went into effect the next year. Since then, people with rare diseases and their families who used to fight alone finally have the protection of the laws. To his day, TRDODA has been revised three times. There are changes made to urge the government to improve the reporting system for rare diseases cases and facilitate orphan drug designation as the reference for health insurance payments. There are also amendments that regulate the acquisition and use of special formula as well as the provision of nutrition counseling services, palliative care, and subsidies. As the government fulfills its legal responsibility, people with are diseases can receive proper health care and assistance; Taiwan, because of this, has the most comprehensive framework of laws and regulations in place in the world when it comes to rare disease. This achievement is also in line with the goal of "leaving no one behind" proposed in the 69th World Health Assembly (WHA) in 2016.

As we mark the 20th anniversary of the foundation of TFRD, it is an opportunity to review the current policies and regulations so that they can better meet the needs of people. This book gathers stories from all walks as an in-depth retrospect of the changes of TRDODA and the impact it has on people with rare diseases since its enactment 2 decades ago. It is hoped that these voices can attract attention from different fields, which in turn, take the regulatory framework regarding rare diseases, which is already the pride of Taiwan, to a whole new level that is even more visionary. In this way, we can continue to support and care for these people and their family in ways that are systematic and reasonable, as all the efforts and dedication become the Ark that shields the families and sets sail for a better future.

Shuan-Pei Lin
Chairman, Taiwan Foundation for Rare Disorders (TFRD)

罕病法 20 年有成

感謝罕病基金會在陳莉茵女士、曾敏傑先生等創辦人持續不懈的努力下，結合民間團體、政府立法及行政部門共同協力，在民國 89 年催生《罕見疾病防治及藥物法》（罕病法），成為全世界第 5 個立法的國家，這部專法結合罕見疾病防治與適用藥物，堪稱世界首見。

本人非常關心罕病病人醫療權益，在 91 年擔任立委時，為協助罕病患者獲得國際醫療資源救治，曾提出罕病法修正草案並獲 45 位委員連署支持。嗣罕病法於 93 年在立法院三讀通過修正，簡化罕病國際醫療合作的申請程序，降低罕病病友就醫的障礙。

為擴大罕病病人照顧與保障，政府持續檢視修正相關法令，俾完善及支持罕病病人的醫療照護和家庭需求。罕見疾病已列入全民健保重大傷病範圍，免除病人就醫的部分負擔；對於罕病病友所需的罕藥與醫療費用，更提供健保給付以及罕病醫療補助的雙重安全網。另外，《兒童及少年福利與權益保障法》、《身心障礙者輔具費用補助辦法》亦將罕見疾病納入保障範圍，使罕病患友在醫療與社會福利上得到更完整照顧，也開啟我國醫療人權新頁。

欣見罕病法立法 20 年有成，並出版紀念專輯，記錄 20 年來政府政策推動落實，以及社會各界協助罕病病友與家庭的珍貴歷程。未來期盼罕病基金會能穩健發揮民間組織力量，協助政府持續完備與推動罕病防治與照護相關政策，以嘉惠更多病友及家庭，讓愛不罕見！

副總統　賴清德

愛不罕見　生生不息

感謝罕見疾病基金會，讓國內小於萬分之一的罕見疾病病人和家屬，在與罕見疾病共處的生命過程中，得到最完整的照護，讓罕見不再視而不見。

為防治罕見疾病發生，及早診斷罕見疾病，加強照顧罕見疾病病人，我國於 2000 年立法施行《罕見疾病防治及藥物法》。迄今（2020 年 8 月）公告 225 種罕見疾病、114 種罕見疾病藥物、40 項罕見疾病特殊營養食品及 85 項罕見疾病國內確診檢驗項目；將罕見疾病納入全民健保重大傷病範圍，罕見疾病病人在保險有效期間，可依全民健康保險法規定免醫療部

分負擔；另外，簡化罕見疾病藥物專案進口流程，簡化許可證申請應檢附之資料與查驗登記規費，以提供罕見疾病病人更好的醫療與照護。

未來，政府將持續與民間團體攜手落實罕見疾病之預防與照護，更期盼社會大眾持續參與罕病病人照護、研發與改進，以嘉惠更多病人及家庭！

衛生福利部
部長 陳時中

每個罕見疾病者都是人間的天使

22 年前，二位創辦人陳姐和敏傑兄找我倡議，希望成立基金會幫助罕病者及其家屬解決面臨的困境，此機緣促成我成為罕病之友的契機，並讓我和基金會結下深厚因緣。基金會成立後，為制度化照護罕病者而推動制定專法的過程中，我要求政府在預算、健保給付及罕病用藥等政策，須符合罕病者的需求，也積極整合理念相同人士、協調各方意見，終於順利地在 2000 年完成《罕見疾病防治及藥物法》的立法。罕病雖罕見，但卻彰顯生命處於逆境時所展現的堅韌和喜悅、感恩和珍惜等

人生修練的生命價值，是上天所給的一份特殊禮物。儘管罕病立法已獲得相當成果，但更完善的友善、接納環境，仍有長路要走，罕病者需要且值得你我持續的支持、關愛與呵護，因為－每個罕見疾病者都是人間的天使！

立法院
秘書長　林志嘉

在別人的需要上看見自己的責任

罕見疾病多會出現嚴重的病徵，為病患生活造成重重障礙。病友們不但在個人的日常生活需要各式協助，其實更需要來自國家社會群體的理解與友善對待。然而，罕病太少見且病況嚴重，社會大眾普遍不了解他們的困境何在，更遑論提供協助。最終，使得這一群在人類社會裡最需要幫助的朋友，除了自身疾病的苦痛，還必須承受不被理解、不被認識，被邊緣化的痛苦。

自 101 年起我有幸與楊玉欣委員一起共提許多弱勢族群的修法與立法，其中罕病修法案是我印象深刻難以忘懷的。此案讓我更深度地認識了這個族群的醫療生存、生活照顧與長期身心壓力的折磨是怎樣的無助，也更深刻的了解到罕病病友難以言說的尊嚴、經濟與自我價值的挑戰苦痛。或許可以說：認識愈多，心中的不捨愈劇烈。我深深體認到作為一個立法委員，我們還需更努力為罕病病友創造更友善的制度。

有句話說：「在別人的需要上，看見自己的責任」，我期許自己，不是修法完成我的任務就結束了，相反的，這是嶄新階段的啟航。我會持續與罕見疾病基金會一起努力，改善罕病族群的生存環境，這是我的福氣與責任。感謝罕見疾病基金會 20 年來的貢獻，你們是台灣社會最美麗的風景。祝願台灣早日邁入更實質平等、友善的進步社會。

立法委員　劉建國

罕病法 20 年
讓我們攜手繼續向前

一晃眼，《罕見疾病防治及藥物法》已經立法 20 載，如果是個孩子，都已經成年了。也還好罕見疾病基金會在 20 年前有推動這個法案的三讀，幫許多罕病患者及其家庭減輕許多痛苦和沉重經濟負擔。

《罕見疾病防治及藥物法》自 2000 年立法以來有過 3 次修正，陸續地強化罕病病友的各項服務機制，包括：1. 將罕病患者進行國際醫療的主體性回歸病友；2. 要求政府應編列給罕

病政策預算的最低額度；3. 將罕見疾病相關團體納入政府的獎勵範圍；4. 強化罕病病人就學、就業或就養等協助機制的法源；5. 保障罕病患者之用藥權益等。

感謝所有的罕見疾病病友和家屬、醫師及基金會工作同仁人員的努力。因著大家的努力，台灣對於罕見疾病的整體照顧體系才能夠持續前進，更在聯合國佔有一席發言的空間。

20 年，是有法案時間，罕病以前就存在，現在還是存在，未來還會有“更多”的存在。針對罕病相關制度的建立和進展，我們還要繼續攜手，陪伴著罕病患者及其家庭一起往前走。

立法委員　吳玉琴

創辦人的愛心、耐心、毅力終於達標

20 年後的今天，回憶起《罕見疾病防治及藥物法》的立法過程，特別令人悵觸萬端，不勝感慨！

立法初期，經常在立法院看到創辦人陳莉茵女士穿梭在各委員辦公室進行立法的遊說，由於永權時任國民黨立法院黨團工作會主任（黨鞭），負責立法的協調工作，陳莉茵女士每天都到黨團辦公室向我說明罕見疾病的困境，這是永權第一次深入用心認識罕見疾病，恍悟才知罕見疾病的認定須達萬分之一，實屬非常少見，在尚未立法前，罕見疾病病友需面對醫藥

資源取得不易的問題，甚或面臨無藥可醫的無助感。

永權被陳女士的用心及毅力所感動，尤其初期無人理會，到最後獲得立委們的支持，耐心的與朝野黨團協調，並且在專業人士的支持下，終於在 2000 年 1 月通過《罕見疾病防治及藥物法》。

立法院
前副院長　曾永權

Happy 20th birthday to the Taiwan Rare Disease and Orphan Drug Act

It's my honor to write something for this book celebrating the 20th anniversary of Taiwan's legislation, the "Taiwan Rare Disease and Orphan Drug Act", as well as the support organization the "Taiwan Foundation for Rare Disorders". I am genuinely moved to say that many countries all over the world have enacted orphan drug legislation, but Taiwan's law appears superior in many ways including the United States where it all began in 1983. The American

law addresses only financial incentives for research and manufacture of pharmaceuticals and biologics, whereas Taiwan's law creates a comprehensive Medical Network for people with rare disorders, it specifically includes rare disorders in Taiwan National Health Insurance program (the United States does not yet have a national health insurance program), provides subsidies for medical costs, subsidizes the supply of special nutrient foods for patients with congenital metabolic abnormalities, provides pre-natal diagnosis for high risk pregnancies, makes genetic counseling centers available and psychological support services for patients and their families.

Importantly, the Act also provides subsidies in support of rare disease patient organizations. For 25 years I was the President and CEO of the American support organization, "National Organization for Rare Disorders" (NORD). It was necessary to spend much of my time fund raising just to keep the organization functioning, time that would have been better spent talking to patients and families. Taiwan is wise to help rare disease support organizations provide the services that families desperately need.

I became involved in this unusual area of public health after one of my sons was diagnosed with a rare disease. Because I knew nothing about public health, I had to learn everything including the

political issues affecting all people with rare disorders, wherever they are. Today my son is almost 50 years old and he is doing well. But I wish I had better answers for the many people I talk to with hopeless diseases that have no treatments. I can only advise that our answers will come from RESEARCH. Research must come from scientists working mostly in academic laboratories, and when they find something hopeful they will need a company to scale up the manufacturing process so appropriate supplies will become available to patients. Clinical trials are essential for all medical research and that is when people with the target disease are needed. You cannot sit back and hope other patients will volunteer. When a disease is rare every one of us may be called to serve the needs of all of us.

Happy Birthday TFRD, and happy 20th birthday to the Taiwan Rare Disease and Orphan Drug Act!

Abbey Meyers
Founder, National Organization for Rare Disorders (NORD)
Past President (retired)

台灣《罕見疾病防治及藥物法》二十週年生日快樂！

我很榮幸能替這本為慶祝由「台灣罕見疾病基金會」所推動的台灣《罕見疾病防治及藥物法》（以下簡稱罕病法）立法20週年而出版的冊子寫點我的感想。我真的很感動全世界許多國家都頒布了孤兒藥物法，但我必須說，比起這些國家，包括於1983年立法的美國，台灣的罕病法，在許多方面，看得出是令人稱羨的。美國法律僅有針對藥物和生物製劑研究和生產給予財務上的獎勵，而台灣的罕病法則為罕見疾病患者創建了一個全面性的醫療網。罕病法明確地將罕見疾病納入台灣全民健康保險（美國尚未建立全民健康保險），提供醫療費用補貼，對先天性代謝異常的患者給予特殊營養食品的補貼，提供高危險妊娠者產前診斷，可以尋求遺傳諮詢中心協助，罕病法還針對罕病患者及其家人提供心理方面的支持服務。

重要的是，該法案還提供了補助金，資助罕見疾病的病友組織。25年來，我一直擔任美國的一個支持性組織「全國罕見疾病組織」（National Organization for Rare Disorders, NORD）的主席兼執行長。我必須花很多時間去籌集資金，以保持組織的正常運作，因此，應該花在多與患者和家屬交談的

時間就減少了。台灣資助罕見疾病組織，提供患者家庭急需的服務，這種作法是明智的。

在我的一個兒子被診斷出患有罕見疾病後，我參與了公共衛生當中這個罕見的領域。起初，我對公共衛生一無所知，所以我甚麼都得學，包括影響到所有罕見疾病患者權益而必須和政府及政黨交涉的各種議題。如今，我兒子快 50 歲了，他過得不錯。但是，我與許多位無藥可醫的患者交談後，我多麼希望我能提供他們有效的解方。我只能告訴對方我們的解方將來自「研究」。罕病的研究一定是寄望於大多數時間都埋首在學術實驗室研究的科學家們，當他們找到有希望治癒的藥物時，他們需要一家可以將之擴大生產的公司，如此才能為患者提供適量的供給。臨床試驗對於所有醫學研究都是必不可少的，也就是說，當科學家們需要對特定疾病進行實驗時，你要採取行動，而不是坐等其他患者自願參加。當一種疾病很少見時，為了解除所有患者的困境，我們每個罕病患者可能必須站出來。

祝「台灣罕見疾病基金會」生日快樂，並祝台灣《罕見疾病防治及藥物法》20 週年生日快樂！

Abbey Meyers

美國「全國罕見疾病組織」創辦人
前主席（已退休）

Taiwan Rare Disease and Orphan Drug Act is a model of innovative and patient-centered rare disease policy

The Asia-Pacific Economic Cooperation (APEC) Rare Disease Network joins TFRD and the Ministry of Health & Welfare to celebrate the 20th anniversary of the Taiwan Rare Disease and Orphan Drug Act. The 5th of its kind in the world at the time of promulgation in 2000, the Taiwan Rare Disease and Orphan Drug Act was and

continues to be a model of innovative and patient-centered rare disease policy from which all APEC member economies can learn. The APEC Rare Disease Network thanks Ms. Serena Wu, Dr. Min-Chieh Tseng, Dr. Shuan-Pei Lin, Ms. Ruth Kuan-Ju Chen, and many others at TFRD for their commitment to regional cooperation on rare diseases in the Asia-Pacific region.

Eric Obscherning
Secretariat, APEC LSIF Rare Disease Network (RDN)

罕病法是以患者為中心及創新的罕病政策典範

亞太經濟合作組織罕見疾病網絡攜手台灣罕見疾病基金會，以及衛生福利部共同慶祝《罕見疾病防治及藥物法》實施20週年。台灣於2000年頒布該法之時，是全球第5個制定這類法案的國家。罕病法是以患者為中心的創新法案，是制定罕病政策的典範，所有APEC成員經濟體都可以從中吸取經驗。亞太經濟合作組織罕見疾病網絡非常感謝陳莉茵女士、曾敏傑教授、林炫沛教授、陳冠如女士，以及台灣罕見疾病基金會的工作人員，對亞太各國攜手對抗罕見疾病所做出的承諾與貢獻。

Eric Obscherning
亞太經濟合作組織生命科學
創新論壇罕見疾病網絡秘書長

Congratulate the great success of rare disease policies in Taiwan

On behalf of Asia Pacific Alliance of Rare Disease Organisations, I would like to congratulate the great success of rare disease policies in Taiwan and especially for the implementation of the Taiwan Rare Disease and Orphan Drug Act for 20 years. As a regional rare disease alliance, we truly understand how supportive policies and regulations can enhance the experiences and quality of life for rare disease communities. The Taiwan Foundation for Rare Disorders (TFRD), founded by Mrs. Serena Wu and Professor

Min-Chieh Tseng, has been a pioneer in the work of co-creating and influencing government policies to advance the cause of rare disease patients. As a partner in the healthcare initiatives of Taiwan, TFRD forms a critical bridge and a role model for the rare disease organisations in the Asia Pacific. We at APARDO hope to partner with TFRD in sharing their success stories and experiences with younger national and regional rare disease organisations so we may collectively affect policies for better health outcomes. With this shared vision and stronger partnerships, we move forwards with the UN spirit of 'leave no one behind'!

Congratulations to TFRD and may we grow even stronger together!

Ritu Jain
President, Asia Pacific Alliance
of Rare Diseases Organisation

賀台灣罕病政策的傲人成就

我謹代表亞太罕見疾病組織聯盟，祝賀台灣罕見疾病政策取得傲人的成就，更要祝賀台灣實施《罕見疾病防治及藥物法》20 週年。身為區域性的罕見疾病聯盟，我們深刻了解支持性政策和法規是可以改善罕病患者的生活經驗和品質。由陳莉茵女士和曾敏傑教授所創立的台灣罕見疾病基金會，一直是足以影響政府政策以促進罕病患者權益的先驅者。作為台灣醫療保健革新的一員，台灣罕見疾病基金會為亞太地區的罕見疾病組織建立了重要的溝通管道和學習的典範。亞太罕見疾病組織聯盟希望與台灣罕見疾病基金會合作，與年輕的全國性或地區性的罕病組織分享台灣罕見疾病基金會的成功經驗，進而打造出更好的衛生政策。讓我們本著聯合國「不放棄任何人」的精神，透過共同的願景和牢固的夥伴關係，繼續向前邁進！

祝賀台灣罕見疾病基金會，願我們共同成長茁壯！

Ritu Jain

亞太罕見疾病組織主席

Celebrate the 20th anniversary of the Taiwan Rare Disease and Orphan Drug Act

ASrid (Advocacy Service for Rare and Intractable Diseases' multi-stakeholders in Japan) sincerely celebrates the 20th anniversary of the Taiwan Rare Disease and Orphan Drug Act in Taiwan.

Taiwan is a very close country to Japan, and we have been actively working together in the area of rare disease patient advocacy. We are very proud of this collaboration.

We completely understand that the approach to the enactment of the Taiwan Rare Disease and Orphan Drug Act and the history since then has been a wonderful history of TFRD's activity.

Although Japan enacted the Outline of Measures against NANBYO (rare and intractable diseases) in 1972, it took 42 years for the NANBYO Act to be enacted. We are well aware of the importance of such lobbying efforts. And we dearly admire TFRD as a patient advocacy organization for its involvement in this legislation since its enactment and the benefits it has provided to patients and families.

We heartily salute Ms. Serena Wu, Prof. Min-Chieh Tseng, Dr. Shuan-Pei Lin, and Ms. Ruth Kuan-Ju Chen for their leadership of TFRD over the years. We would also like to express our sincere wishes for the further development of your organization.

ASrid will continue to work hand-in-hand with the TFRD to advance the field of rare diseases in Asia.

Yukiko Nishimura

President, NPO ASrid, JAPAN

恭賀台灣《罕見疾病防治及藥物法》立法 20 年

Asrid（日本稀少及難治性疾病倡議組織）誠摯地祝賀台灣《罕見疾病防治及藥物法》立法 20 週年。台灣不只地理位置與日本相臨，在罕見疾病領域中，我們更是一起工作和倡議的好夥伴，為此我感到非常榮幸與驕傲。

我們與台灣罕見疾病基金會結緣多年，我很清楚台灣制定罕見疾病防治及藥物法的過程，而這一路上所經歷的風雨都已成為甜美的果實，為罕病基金會留下美好的一頁。

雖然日本在 1972 年便宣示了《罕見及難治症措施綱領》的理念，但這項法案真正通過立法卻花了 42 年的時間，我們深知努力遊說是多麼地重要。正因為如此，我們非常讚賞台灣罕病基金會作為一個病患倡議組織，自成立以來便深入參與罕病法立法，為病患及家屬爭取權益。

我們衷心向陳莉茵女士、曾敏傑教授、林炫沛醫師和陳冠如女士致敬，多年來他們引領著罕病基金會邁步向前，在此也為罕病基金會獻上誠摯的祝福。未來，Asrid 將繼續和罕病基金會攜手合作，齊心推動亞洲罕見疾病更光明的道路。

Yukiko Nishimura
日本 ASrid 主席