



脊髓肌肉萎縮症慈善基金有限公司

Families of SMA Foundation Limited

Annual Report
Year Ended 31 December 2024

年度報告
截至 2024 年 12 月 31 日年度

	Contents 內容
Basic Information 基本資料	
Year of Establishment 成立年份	1998
Registration Type 註冊類別 (Reference Number of the Certificate 註冊證書編號)	Charity 慈善機構
Tax Exempted Charitable Institute? 是否獲豁免繳稅的慈善團體?	YES IR : 91 / 17214
Organization address 機構地址	Room 1402, 14/F, SUP Tower, 83 King's Road, North Point, HK 香港北角英皇道 83 號聯合出版大廈 14 樓 1402 室
Telephone No. 電話	2811 1767
Fax 傳真	2510 7199
Email 電郵	info@fsma.org.hk
Organization's Website 機構網址	www.fsma.org.hk
No. of Service Centers/Units 服務中心/單位總數	One 一位
No. of Staff 員工總數	Three 三位

Corporate Governance 機構管治	
Vision, Mission and Values 願景、使命、價值觀	Families of SMA Foundation (Formerly known as Families of SMA Charitable Trust) ("FSMA") was founded in 1998 by parents of a SMA severe type child, professionals from various business sectors and concerned parents of SMA children who understood so profoundly the sufferings and needs of SMA victims and their families. Spinal Muscular Atrophy (SMA) is a genetic neuromuscular disorder that causes progressive muscle weakness and loss of movement. This may lead to serious difficulties in feeding and breathing, and can be life threatening. Many victims are young children who are severely disabled / medically fragile and require specialized medical care and advanced medical equipment.

Our Mission is in the “To help in the relief of hardship and suffering of patients afflicted with Spinal Muscular Atrophy (SMA) and their family members”

Objectives:

- i) To provide practical and emotional support to patients with SMA and their family members in order to facilitate proactive health management as well as aggressive medical intervention to save lives;
- ii) To provide support services, donation and/or free loan of medical equipment and other para-medical items to needy SMA patients and their families so that they can continue to seek proper medical help and be able to face challenges associated with SMA;
- iii) To manage a Central Registry in Hong Kong of SMA patients for the enhancement of co-operation with health sectors and to serve as a research base to find further treatment strategies and cure;
- iv) To promote public awareness, understanding and education of SMA and the plight of afflicted patients & families.

脊髓肌肉萎縮症慈善基金（“FSMA”）成立於 1998 年，旨在提供創新和直接援助、醫療和輔助醫療設備以及相關療法，以減輕患有 SMA 和他們的家人的痛楚。SMA 是一種神經肌肉疾病。許多患者是嚴重殘疾/身體虛弱的幼兒，需要專門的醫療護理和先進的醫療設備。

我們的使命是“幫助脊髓肌肉萎縮症 (SMA) 患者及其家人舒緩該病所帶來的苦難和痛苦”

目標：

- i) 為 SMA 患者及其家人提供實際和情感支援，以促進積極的健康管理以及醫療以挽救生命；
- ii) 向有需要的 SMA 患者及其家人提供服務、捐贈和/或免費借用醫療設備和其他輔助醫療用品，以便他們能夠繼續有適當的醫療幫助，並且能夠應對與 SMA 相關的挑戰；
- iii) 在香港管理 SMA 患者的中央登記處，以加強與衛生部門的合作，並作以尋找進一步的治療策略和治愈方法；
- iv) 促進公眾對 SMA 以及患者和家人的困境有所認識、理解和教育。

Name and Title of Trustee and Executive Committee Members	Name 姓名	Title 職銜
受託人和執行委員會成員之姓名及其職銜	Ms. WAN Mei Yuk, Ruby 尹美玉女士	Board of Director 董事會成員
	Ms. TONG Wai Oi, Wanda 唐慧愛女士	Board of Director 董事會成員
	Ms. CHOW Fung Kay, Mavis 周鳳姬女士	Board of Director 董事會成員

	Name and Title of Agency Head 機構主管姓名及職銜	Mei Ling Fok, Ph. D 霍陳美玲博士 Founder & Chairman 創辦人及主席
	Description on Organizational Structure 機構組織架構說明	<p>Founder & Chairman: Dr. Mei Ling Fok (Qualified Lawyer)</p> <p>Board of Directors:</p> <p>Ms. Ruby Wan (PR & Marketing Professional)</p> <p>Ms. Wanda Tong (Qualified Lawyer/ Legal Adviser)</p> <p>Ms. Mavis Chow (Retired)</p> <p>Board of Advisors:</p> <p>Ms. Catherine Cheung (Qualified Accountant / Treasurer)</p> <p>Ms. Maria Wong (Retired Special Needs School Principal)</p> <p>Medical Advisor:</p> <p>Dr. CHAN Hoi Shan, Sophelia</p> <p>Dr. CHUNG Hon Yin, Brian</p> <p>Dr. LEE So Lun</p> <p>Dr. LUK Che Chung</p> <p>Dr. NG Kwok Keung, Daniel</p> <p>Dr. PANG Yin Yu Shirley</p> <p>Prof. LAU Yu Lung</p> <p>Prof. WONG Chun Nei, Virginia</p>

Annual Report on Major Activities 年度主要會務及活動報告

	Report from Chairperson and/or Head of Organization 主席及/或機構主管工作報告	<p>Needless to say, with a continued challenging economic situation in Hong Kong, it is even more important for charities to step up their services. However, in reality it is a tall order because in this environment, we face increased fund-raising competition and dwindling income. Furthermore, with other global issues like climate change, aging demographics, poverty etc. many corporate and family foundations benefactors are also inclined to help and donate towards these equally pressing needs instead of just funding rare diseases like SMA.</p> <p>Nevertheless, we adhere to our mission to relieve hardship and suffering caused by the disease as much as we can. I am proud to report that none of our services have been affected nor curtailed and although we could only raise \$2.93 mil, we spent \$3.22 mil with a deficit of only \$290,931 for the year ended 31 Dec 2024. That said, rest assured that our charity' s financial health remains robust as we had planned ahead to weather economic storms.</p> <p style="text-align: right;">Dr. Mei Ling Fok Founder & Chairman</p>
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List of Activities (including donations made for charitable services) Year ended 31 December 2024

Medical Equipment, Medical Supplies and Disposables and Wheelchairs

For those unable to breathe independently, we provide or subsidize the rental of all necessary respiratory-related medical machinery. Given the patients' minimal or absence of muscle control, optimal postural support is crucial to prevent severe scoliosis and mitigate pain; therefore, we donate specially designed baby buggies and a range of manual and power wheelchairs.



Home-based Rehabilitation Program

Owing to SMA patients frequently experiencing progressive muscle weakening and limited mobility, to preventing painful joint contractures and calcification, we sponsor free home-based physiotherapy for those patients need it critically.



High Nutritional Supplements

Maintaining adequate nutrition and strong immunity is a major challenge for SMA patients, often compromised by poor or absent swallowing abilities, which can lead to malnutrition. Since the high-nutritional supplements prescribed by dietitians and doctors are costly and pose a financial burden on many families, we actively mitigate this risk by donating these essential high-nutrition supplements and free to our patients to maintain their health and immunity.



Home Tutorials & Interest Classes

To ensure that the educational standards and overall quality of life are maintained for SMA children and young adults, we actively support their learning and personal development. We achieve this by sponsoring home tuition and interest classes, to help SMA children to continue their education and young adults to explore their personal interests, we sponsor home tuition and interest class to support their learning and personal development so as to promote a better quality of life.



Wheelchair Taxi Transportation

To ensure the safe and barrier-free transfer of medically fragile SMA patients—who rely on special buggies or wheelchairs—for their essential medical appointments, we sponsor complimentary free wheelchair taxi services. This crucial logistical support helps eliminating stress and physical hardship during transportation for both the patients and their dedicated caregivers.



SMA Drug Home Delivery Programme

In close collaboration with the Pharmacy Departments of Queen Mary Hospital and the Hong Kong Children's Hospital, we sponsor a free and seamless door-to-door delivery service for SMA medication (Risdiplam in glass bottles). This programme is vital, as it obviates the need for patients to endure long waits in hospital pharmacies, thereby significantly reducing the risk of possible infections and minimizing physical strain on medically vulnerable patients and their caregivers.



Emergency Home-help

We recognize that the task of caring for a chronically ill child who requires 24/7 attention is incredibly demanding and stressful for caregivers. To alleviate this burden and prevent burnout, we provide essential support by sponsoring part-time home-helpers.



Seminars, Workshops, Medical Conferences, Free Outdoor & Social Activities

We ensure continuous improvement in patient care by organizing medical seminars, conferences, and workshops to provide essential medical updates for caregivers and professionals. Furthermore, we actively combat the loneliness and isolation often experienced by patients and their families by sponsoring free outdoor and social activities. These events allow patients and their caregivers to meet, share experiences, and build a supportive peer network.



Mercy Medical Management (“MMM”) Programme

Mercy Medical Management (“MMM”) Programme is a medical specialist-led inter-disciplinary outreach team to provide a “hospital-at-home” service to technology-dependent patients requiring long term mechanical respiratory support. MMM programme generally seeks to ensure patients are well cared for to prevent unnecessary hospitalizations.



“The Power of Perseverance” Picture Book Campaigns

To combat the loneliness and feelings of despair often experienced by the sick and disabled during challenging times, we created “The Power of Perseverance” picture book series in partnership with a large pharmaceutical company. This initiative comprises a set of four appealing and inspirational picture books. The books recount the stories of four young and multi-disabled patients suffering from SMA who, to everyone’ s amazement and admiration, managed to navigate life’ s toughest obstacles and beat all the odds.

One of the book’ s protagonists was invited by a primary school to share "The Power of Perseverance" with the students. Enthusiastic students actively engaged with the speaker, learning how patients with rare diseases manage difficulties and internalize the crucial message that "there are always more solutions than difficulties." We have donated hundreds of sets of these story picture books to different schools for use as complimentary teaching materials and giveaways.



Conclusion

We shall continue to strive our best to achieve our mission “To help in the relief of hardship and suffering of those afflicted with Spinal Muscular Atrophy (SMA) and their families” especially in such a difficult world today and the challenging days ahead.

Future Plans and Development 未來計劃及發展

One of our innovative and unique programme, called Mercy Medical Management (MMM) which delivers medical services to the homes of the chronically ill patients who depend on mechanical ventilation for their survival has not only been appreciated by many affected families but also caught the attention of the Hospital Authority. We are currently in close discussions with the relevant doctors and healthcare officers to see if this programme can be expanded to help more patients in the same health predicament.

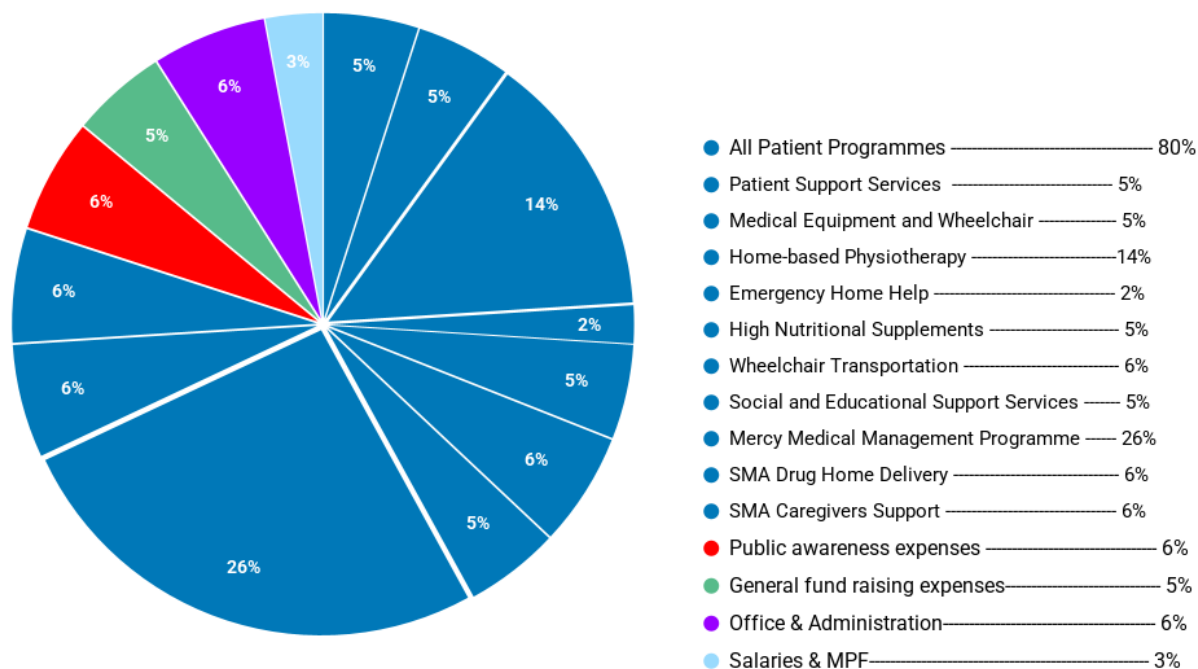
The government through the Community Care Fund will soon allow SMA patients above 25 years old to access Risdiplam, a SMA treatment drug. Our existing programme where we make door-to-door free deliveries of these expensive drugs will be extended to all you have been approved for the treatment. This delivery is 100% sponsored by our charity and we have successfully already made 111 deliveries directly from hospitals' pharmacies to patients' homes to the end of 31 Dec 2024. This programme is continuing and will be expanded in 2025 and beyond.

本會獨特且創新性的恩慈醫療計劃 (MMM)，旨在為依賴呼吸機維生的患有慢性疾病患者提供專業的居家醫療服務。此計劃不僅獲得了眾多受助家庭的讚賞，亦引起了醫院管理局的高度關注。目前，本會正與相關醫生及醫護人員進行密切溝通，積極探討擴展計劃的可能性，以期能將這項服務幫助更多有面臨同樣健康需求的患者。

政府即將通過關愛基金的安排，擴大 SMA 治療藥物 Risdiplam 的資助範圍，允許 25 歲以上的 SMA 患者也能獲得藥物。本會現有的免費藥物上門送遞計劃將會全面延伸，服務所有獲批接受該藥物治療的患者。這項送藥到家服務由本會慈善全額贊助，截至 2024 年 12 月 31 日，我們已成功完成 111 次將藥物從醫院藥房直送至患者家中的服務，我們承諾在 2025 年及往後有進一步的擴展。

Financial Situation (Refer to the latest available audited Annual Accounts or Financial Statements)
財務狀況(參考機構提供最近年度的經核實之周年帳目或財務報告。)

Year Ended 31 Dec 2024 FSMA Patients Services Expenditure



Above figures are based on financial statements for year ended 31 December 2023, audited by external certified accountant Messrs. Albert S. C. Young & Company.

以上數據截至 2024 年 12 月 31 日止年度的財務報表，本基金賬目由楊少銓會計師事務所核實。

Acknowledgements & Thanks

Individual & Corporate	
Arrow Asia Pac Limited	Smart Select Limited
Asia Step Limited	Pak Hiu Fei
Lai Wing Chung Edward	Wong Tat Pui
Tam Man Ki	Sun Bui Limited
Wong Hiu Wai Ide	Joyous Health Concept Limited
Mei Ling Fok	Sin Wing Fung
Cheung Tin Chung James	DAA Services Limited
The Shamdasani Foundation	Chan Foon Hang Florence
Tse Wing Yuen	Leung Suk Fong
Wong Tse Kwan	Joyous Health Concept Limited
Wong Yuen Kwan	Dr. Chow Sze Fu Joseph
Hui Yau	Liu Yin Ling
Tam Man Ki	Hui Lai Yi
Tse Chuen Sum	Joyful Life (Hong Kong) Company Limited
Tai Chiu Yee Susan	楊炳洪
Fung Yin Fun	Leung Wai Sum
Wong Pui Wa	Iu Yam San
Chiu Chun Keung	Pong Kin Yee
張雅梅	Roche Hong Kong Limited
Fong Chi Ming	Kwong Kim Hung
Ng Kam Wah Webster	Lee Chi Hung
Nigel Stuart Winchester	Lau Tsz Yan
Ng Siu Kai	The Wing On Company Limited
蘇呂惠珍	Mr. Lo Kam Wing Barry
Hong Kong Baptist Hospital	Ip Sze Wai
Wong Wai Hon	Li Kwok King
Wong Yuen Ping Maria	Mui Ho Man
Fong Chi Ming	Ho Yu Yee
Lau Yan Kit	Chan Yu Kwan Clinic
朱靄風	Wong Suk Man
Hon Shuen Company Limited	The PPJL Foundation
Lee Tak Shing Dickson	Pauline Lung
Benjamin Lai	Poon Siu Lun
David Au	Bridgewater & Coulton Ltd
Winnie Lee	Edith Cheng
Stella Chan	Chan Pak Kiu
Venky Wong	Chan Kwok Kuen

Adriano Chao	Wong She Mei
Ricky Lam	Kung Lap Quin Kevin
Elizabeth Poon	Leung Man Yee Sylvia
Lo Kit Har Connie	Chiu Wan Man
Chow Sin Kei Vincent	Yau Wing Yi
Ho Kam Wah	Clement Kong
Tse Chuen Sum	Ng Hoi Man
Amy Shek	Chou King & Fu Siu Fong Charity Fund Limited
Lai Shuk Han	SF Supply Chain (Hong Kong) Limited
Parson Ng	Fieldful Limited
Kenneth Hon	Poon Siu Lun
Brian Leung	Poon Hoi / Ho Pui Sum
Poon Siu Fung	Ho Yu Yee
Genevieve Fung	Main Plan Limited
Sharon Cherk	Ku Ka Ki Kelvin
Bernie Tang	Wong Yuk Chi
Noel Chak	Poon Siu Lun
Au Hung On Adam	Ng Ka Man
Hau Kam Ping	Wong Wai Man
Regina Leung	Ho Yuk Fung
Chow Siu Ngan	Chow Chui Kwan
Lisa Lau	Chow Chui Kwan
Tse Tao Yan Agnes	Lau Yan Yee
Tsui Sin Mei	何仲儀
Lau Mei Yee	Fung Suet Ping
So Wing Chi	Poon Siu Lun
Chow Tuen Yi	Yip Wai Lun
Savio Lee	The American Women's Association of Hong Kong
Steve Wong	Foundation Limited
Ng Wai Man	Chan Kam Ming Clement
William Lau	Chan Kam Ming Clement
Gary Cheok	尚健國際有限公司
Edmond Chan	Mrs. Carrie Lam
Chau Kin Wai	Liu Chi Keung Ricky
Wong Lai Yin	Wong Sai Kit Joseph
Lettie Leung	忠誠的士管理有限公司
Michael Choa	Wong Tin Son
Chow Pok Yu Michael	Lo Kam Wing
Mei Ling Fok	Yip Kam Keung Alex
Sit Sou Chi	Chan Lai Har Kum Elizabeth

Chan Wing Kin	Zheng Ge Ru Foundation
Josephine Cheung	Iu Mei Ling
Leung Ho Kwan	Ng Yeuk Sze Joanna
Mimi Ho	Wan Shiu Yung
Louise and Ffion Ryan	Ng Siu Kai
Sylvia Leung	Philip K. H. Wong Foundation
Rainbow Law	Pauline Lung
Chan Hong	Chan Hoi Shan Sophelia
Yip Kam Keung Alex	Sin Wai Sum Virginia
Chan Lai Yin Maria	Choi Kit Ying
Kate Chan	Yeung Hip Wo Victor
Ian Siu	Poon Siu Lun
Siu Wai Kuen	Lui Shuk Yuen
Siu Wai Ling	Medflow Medical Services Limited
Ken Lau	Wong Yuen Kwan
Li Kit Ka	Annie Chen
Lee Kar Fay Phoebe	Poon Ho Shing Abraham
Lam Tin Chi Tania	Hon Wai Man Samantha
Chan Hei Yuk Carol	Lui Ting
Lam Mei Yi Olive	Ng Kwok Keung Daniel
Athena Lau	Poon Mak Sui Man
Chan Hong	Tsang Chik Kwai Tong Charity Foundation Fund Ltd
Joey To	Wan Shiu Yung
Alan Lee	Tong Wai Oi Wanda
Yau Wai Yin	Lam Yuk Yin
Lau Mei Chi	Mei Ling Fok
Chit Fung	Ottillie Kong
Cheng Chun Ho	Kwong Kim Hung
Remi Chan	Edward Yau
Joe Law	Ku Ka Ki Kelvin
Evan Wong	Medwell Healthcare Co. Ltd
Perry Lee	Kathleen Oi Kay Lo
Eric Kung	商業廣播有限公司
Yip Kam Keung Alex	Chow Yu Fat
Lee Kwan Ka Carly	Lam Wai Ting
Tong Pik Chui Irene	Lau Mei Yee
Tang Suk Ling	Tsui Wing Kei Vicky
Li Wan Chui	Shirley Yin Yu Pang
Chan Mei Yee Emily	Yip Kam Keung Alex
Li Kit Ka	Chao Wai Khean

Chan Pak Ho	Li Kwok King
Lai Tsz Hong	Poon Siu Lun
Tong Sheung Chi	Tsang Yu Chor
梁可君	Chan Yuen Han
Poon Siu Lun	李后輝
Leung Sau Shan	Chau Wai Man
Tse Chung Hei	Hon Kwok Chung Kennetg
Cho Pun Fan	Patrick Kwong
Tam Man Ki	David Yeung
Poon Siu Lun	Lee Kar Yee
Lai Yee Piu Billy	Lau Kin Chun Iris
Lee Sum Yee	Lawrence Lan
Wan Shiu Yung	詹楚生
Law Kwun Mei	So Wing Chi
Sing Boon Jon	Ho Fu Ho Jonathan
The Extra Mile Limited	Lai Moon Ping
Arnold Chan	Sharon Cherk
Brian Chan	Hui Yau
Benjamin Foo	Lau Yuen Hung
Catherine Cheung & Co	Chan Chi Yuen
Chan Wai Keung	Yu Kuen Ying Denny
DAA Services Limited	Rishabh Malpani
Crux Developments Ltd	Tse Wing Yuen
Lui Ting	Ng Teng Fong Charitable Foundation Limited
Wasabi Creation Ltd.	Wong Yan Yan Viola