

Annual Report  
Year Ended 31 December 2020

年度報告  
截至2020年12月31日年度

## Families of SMA Charitable Trust

脊髓肌肉萎縮症慈善基金



Field Name 資料名稱	Contents 內容
<b>Basic Information 基本資料</b>	
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
Tax Exempted Charitable Institute? 是否獲豁免繳稅的慈善團體?	YES IR : 91 / 5292
Organization addresss 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



## Governance

### Corporate Governance 機構管治

Vision, Mission and Values  
願景、使命、價值觀

*Families of SMA (Spinal Muscular Atrophy) Charitable Trust ("FSMA")* was established 22 years ago in 1998 to provide innovative and direct assistance, medical and para-medical equipment, as well as related genetical therapies to relieve hardship of patients suffering from SMA and their families. SMA is a form of neuromuscular disease. 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 "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。



## Governance

	Name 姓名	Title 職銜
<p>Name and Title of Trustee and Executive Committee Members 受託人和執行委員會成員之姓名及其職銜</p>	<p>Ms. WAN Mei Yuk, Ruby 尹美玉女士</p> <p>Ms. TONG Wai Oi, Wanda 唐慧愛女士</p> <p>Ms. WONG Yuen Ping, Maria 黃婉冰女士</p> <p>Ms. CHEUNG Kit Yim, Catherine 張潔艷女士</p> <p>Mr. CHUNG Chin Pang, Peter 鍾展鵬先生</p>	<p>Trustee 受託人</p> <p>Executive Committee Member 執行委員</p> <p>Executive Committee Member 執行委員</p> <p>Executive Committee Member 執行委員</p> <p>Executive Committee Member 執行委員</p>
<p>Name and Title of Agency Head 機構主管姓名及職銜</p>	<p>Dr. Mei Ling Fok, Ph. D 霍陳美玲 博士</p>	<p>Founder &amp; Chairman 創辦人及主席</p>



## Organizational Structure

Description on  
Organizational Structure  
機構組織架構說明

### PATRON

Professor Sophia CHAN Siu Chee,  
JP

Secretary for Food and Health  
HKSAR Government

### FOUNDER

Dr. Mei Ling FOK, Ph.D

### TRUSTEE

Ms. Ruby WAN Mei Yuk

### EXECUTIVE COMMITTEE MEMBERS

Ms. Catherine CHEUNG Kit Yim

Ms. Wanda TONG Wai Oi

Mr. Peter CHUNG Chin Pang

Ms. Maria WONG Yuen Ping

### MEDICAL ADVISORS

Prof. Virginia WONG Chun Nei

Dr. Sophelia CHAN Hoi Shan

Dr. LEE So Lun

Dr. Brian CHUNG Hon Yin

Dr. Daniel NG Kwok Keung



**Annual Report on Major Businesses & 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

A Pandemic-stricken 2020 was indeed a difficult year for everyone. Those of us, lucky to still be considered somewhat healthy, nevertheless woke up to the sobering thought of our own human fragility and mortality. Imagine those who need to live with a life-threatening condition called Spinal Muscular Atrophy (SMA) and who are severely disabled and immune-compromised, especially children. They live in constant fear of imminent infection which, in their case, can easily prove fatal. Patients and their caregivers face untold stress and isolation.

Globally, businesses stopped, shops & restaurants closed, airplanes grounded and for a period, the world stood eerily still. With social distancing, plummeting profits and looming uncertainties, corporate CSR initiatives were curtailed, fund-raising activities cancelled and individual donors slashed their charity budgets. Small charities such as Families of SMA felt the brunt at a time when our patients need the most help. It was quite ironic.





However, every cloud has a silver lining and we found that reputable Hong Kong family charitable foundations proactively tried to help. We were lucky to have receive a grant from The Kadoorie Charitable Foundation to enable us to operate all our modest services for a year without disruption. In the following pages, you will see the different categories of direct assistance accorded to those in need.

Going forward, we hope 2021 will present a more optimistic future for all of us. I look forward to my next report, which I hope will be rosier than this one. Meanwhile, my sincerest thanks and gratitude to all donors, sponsors, volunteers and supporters who also contributed in a myriad of ways to ensure we continue to contribute to society's weakest and underprivileged.

Mei Ling Fok, PhD  
Founder & Chairman

Report from Chairperson  
and/or Head of Organization  
主席及/或機構主管工作報告

## Events and Projects



### Brief Description on Major Service, Events and Projects 主要服務、計劃及活動簡報

#### *List of Activities (including donations made for charitable services) Year ended 31 December 2020*

##### Medical Equipment, Wheelchair & Special Baby Buggies

For those unable to breathe independently, we donate all necessary respiratory-related medical machinery. With little or no muscles, proper seating is important to prevent severe scoliosis and pain. We donate specially designed baby buggies and wheelchairs.



##### Home-based Rehabilitation Program

With no movement and muscles gradually weakened, it is important to prevent painful contractures and calcification of joints. We provide free home-based physiotherapy in home-based rehabilitation program and benefits patients with serious disabilities.



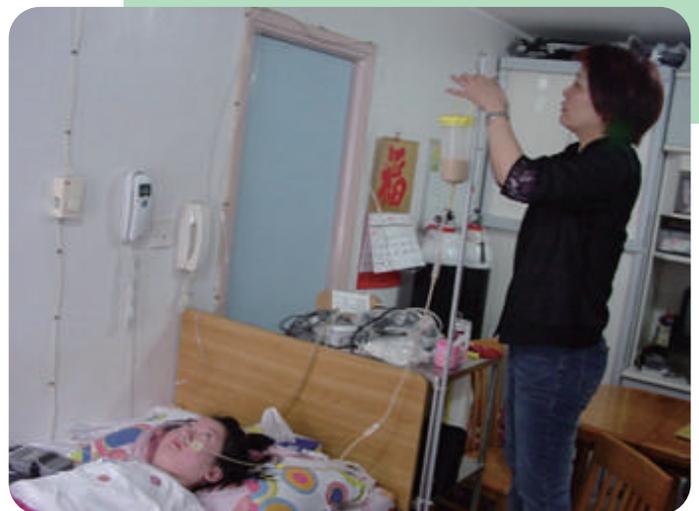
### Music Therapy & Social & Educational Support

Ensuring that quality of life and educational standards are maintained for these sick children, we provide home-based Music/Play/Art Therapies and Home Tuition to enable these sick children to catch up with their education.



### High Nutritional Supplements

With poor or no swallowing abilities, maintaining proper nutrition and good immunity poses a big challenge and often leads to malnutrition and poor immunity. High nutrition supplements recommended by dietitian and doctors are expensive and some families may not afford. We provide free high nutrition supplements to ensure patients remain healthy.



## Events and Projects



### Wheelchair Taxi Transportation

To ensure safe passage and transportation of these medically fragile children and patients for their medical appointments, we provide free wheelchair taxi transportation.

### Emergency Home-help

Understanding that, without help, it is impossible for a mother to look after a chronically ill child who needs 24/7 care, we sponsor domestic & emergency part-time home help.



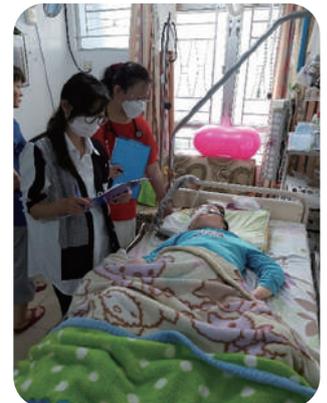


### Seminars, Workshops, Medical Conferences, Free Outdoor & Social Activities

For proper medical updates and collaboration with medical professionals, we organize medical seminars, conferences and parents' workshops. To prevent loneliness and isolation, sharing notes and meeting peers with like-minded are important. We organize free outings and social events. However, difficulties brought on by months of continued social unrest culminating in the emergence of life-threatening Covid-19, most social activities were cancelled. Instead, we organized a medical treatment webinar online for patients with updates from medical doctors as our guest speakers.

### Mercy Medical Management (“MMM”) Program

In response to pandemic and to relief some burden on the hospital system, this new and innovative project called MMM Programme seeks to deliver multi-disciplinary professional medical teams of ventilator technicians, physiotherapists, nurses and doctors. Their services target on both online telemedicine and on-site home visits, depending on patients' needs. The project not only directly benefits SMA patients but also relieves some stress on the part of the carers. Further we assist in ensuring that preventable medical problems can be identified.



## Events and Projects



### Home Visits

Where possible, our volunteers and staff visit the homes of patients and their family members to show concern and extend help, where necessary.



### Picture Book Campaigns

During difficult times, especially in a pandemic, loneliness abound and many, especially the sick and disabled, feel like giving-up. We started a campaign to raise awareness of "The Power of Perseverance" in the face of challenges. Through sponsorship by a large pharmaceutical company, we created a specially commissioned and beautifully painted picture book set. It consists of 4 separate booklets depicting the lives of 4 young and multiply disabled patients suffering from SMA who, to everyone's amazement and admiration, managed to navigate life's toughest obstacles and beat all the odds. In so doing, they not only help to raise awareness of this SMA disease but are happy individuals. We distributed about 1000 sets of Picture books to primary schools, special schools, child development centres, children with rare diseases, certain NGOs, sponsors, SMA patients and also on social media.



### 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.*

## Future Plans and Development 未來計劃及發展

*Our charity does not have any government subvention nor subsidies and relies entirely on fund-raising and donations.*

Therefore, where a programme significantly confers benefit to our patients, we will continue to raise funds and expand our fund donors base to support the programme. Moreover, we would promote public awareness of this disease and the difficulties of SMA patients and their families via social media. We find that we can help the patients more by exploring their needs by organizing more social gatherings, events and patient activities. Our donors will then be more willing to continue to fund our charity on humanitarian and compassionate grounds.

**我們的慈善機構沒有任何政府資助或補貼，完全依靠籌款和捐款。**

因此，如果一項計劃顯著地使我們的患者可以受益，我們將繼續籌集資金並擴大本會規模得以支持該計劃。此外，我們將通過社交媒體提高公眾對SMA和 SMA 患者及其家人所遇到的困難的認識。我們發現可以通過組織更多的聚會、不同活動和患者互動來解決他們的需求，從而為他們提供更多幫助。我們的捐助者將更願意繼續以人道主義和富有同情心的理由為我們的慈善基金提供資金。



## Financial Situation

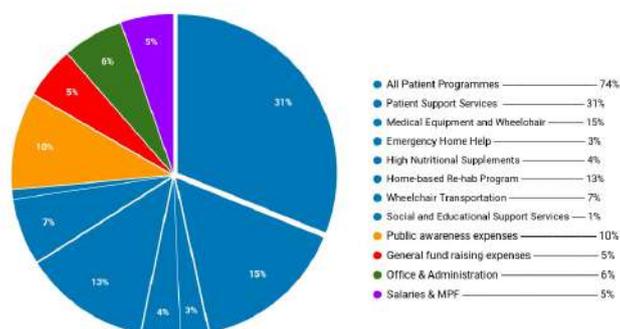


**Financial Situation (Refer to the latest available audited Annual Accounts or Financial Statements)**  
 財務狀況 (參考機構提供最近年度的經核實之周年帳目或財務報告。)

截至 2020 年 12 月 31 日 FSMA 會員服務開支



Year Ended 31 Dec 2020 FSMA Patients Services Expenditure



Above figures are based on financial statements for year ended 31 December 2020, audited by external certified accountant Messrs. Albert S. C. Young & Company.

以上數據截至 2020 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批核算

## Acknowledgements & Thanks

Corporate	Individual
Biogen 渤健公司	Annie Louie
Catherine Cheung & Co. 張潔艷會計師事務所	Ada Chan Tak Mee (陳得美)
Drs Richard Charles and Esther Yewpick Lee Charitable Foundation 利銘澤黃瑤璧慈善基金	Chan Choi Kam
Hasbro Far East Limited 孩之寶遠東有限公司	Chan Hei Tak Sunny
Hong Kong Exchanges and Clearing Limited 香港交易及結算所有限公司	Chan Ka Fai
Kadoorie Charitable Foundation 嘉道理慈善基金會	Cheng Wai Chun, Rocka
Lockton Companies 諾德保險經紀有限公司(香港)	Chiu Ngar Wing
MAST Industries (Far East) Limited 美國萬事達(遠東)有限公司	Chui Wue Yun, Vivian
Ng Teng Fong Charitable Foundation 黃廷方慈善基金	Chung Luen Tai
Ronald and Rita McAulay Foundation	Edmund Yeung
Roche 羅氏大藥廠	Gilbert Lau
Sino Group 信和集團	Ho Man Ching, Jennifer
Zindart (De Zhen) Foundation Limited 鑫達(德貞)基金有限公司	Ho Yu Yee
	Keung Kim Fan Elsa
	Kenneth Kong
	K T Sin
	Kwok Po Lan
	Mrs. Lau / Ms Lo Kit ching (Mandy)
	Liu Chi Keung Ricky
	Lo Kam Wing Barry
	Lui Pao Lock, Paul
	Maria Wong
	Mavis Chow
	Mavis Lui
	Ng Mien Hua Kikki
	Olive Lam
	Patricia Hayward
	Pong Kai Man Kevin & Ms Edith Pong
	Ronald Li
	Ruth Kuok
	Tang Kay Hwa
	Tong Wan Kei
	Wan Mei Yuk, Ruby
	Winnie Chan
	Wong Suk Man
	Wong Tat Pui
	Wong Tin Son
	Wong Wai Fun
	Wong Wai Keung, Dickson
	Wong Wai Man (黃慧敏)
	Yeung Ping Hung /
	Yeung Chow Chiu Ping, Kathleen
	張國光
	李振豪

(Listed in no particular order 排名不分先後)