



香港弱能兒童護助會

The Society for the Relief of Disabled Children

二零二一年冬季會訊

2021 NEWSLETTER WINTER ISSUE

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COVID-19 對住院患者生活的隔離影響 The Isolating Impact of COVID-19 on In-Patient Life

黃鎮滔 Wong Chun To (Wind)

我對醫院病房並不陌生。

我在小時候就經歷了肌肉無力和運動發育受限。在我五歲的時候，便由東區尤德夫人那打素醫院轉送至大口環根德公爵夫人兒童醫院(DKCH)接受治療。在這裡，我已經度過了十八年的時光。

由於我的肌肉無力，不能走路，甚至不能站立。抵抗力也比常人差，容易患病，會有發燒和喉嚨痛的情況出現。醫生最初懷疑我患有脊髓性肌萎縮症(SMA)，這是一種影響神經系統和隨意肌肉運動的遺傳性疾病。SMA有多種形式，患者可能會出現多種症狀，但它通常以常染色體隱性遺傳模式遺傳，並涉及脊髓中神經細胞（稱為運動神經元）的喪失。正因如此，SMA主要影響最靠近身體中心的肌肉，而我的治療正是針對這種情況。

直到大約六年前進行的基因測試，醫生才發現事實上我並不是患有髓性肌萎縮症(SMA)，而是一種稱為肌小管病變的罕見神經肌肉疾病。與 SMA 一樣，肌管肌病會導致肌肉無力，程度從輕微到嚴重，但一般都是嚴重的。對我來說，這會導致進食和呼吸困難，因為參與吞嚥和呼吸的肌肉會逐漸減弱。

肌小管病變是由MTM1基因突變引起的，並作為X連鎖隱性疾病遺傳，因此主要影響男性。MTM1是一種編碼為肌管蛋白的蛋白質，它對肌肉組織的正常功能發育和維持最為重要。這種情況通常需要對每個病人的症狀進行加強性治療。我現在是需要用電動輪椅代步，和用呼吸機幫助呼吸。

雖然每天都要在醫院進行呼吸練習和物理治療以改善和保持肌肉力量，但我仍然可以過一些有規律的生活，日間亦可以離開病房到香港紅十字會甘迺迪

I am no stranger to hospital wards.

Experiencing muscle weakness and limited motor development at a young age, I was admitted to the Duchess of Kent Children's Hospital at Sandy Bay (DKCH) to help treat my condition when I was five years old.

Because of my muscle weakness, I could not walk or even stand. I also got sick easily, constantly dealing with fevers and sore throat. My doctors initially suspected I had spinal muscular atrophy (SMA), a genetic disorder affecting the nervous system and voluntary muscle movement. There are several forms of SMA, and patients can display a variety of symptoms, but it is generally inherited in an autosomal recessive pattern and involves the loss of nerve cells – known as motor neurons – in the spinal cord. Because of this, SMA mostly affects the muscles closest to the centre of the body, and I was prescribed treatments targeted towards this condition.

It was not until a genetic test performed six years ago that my doctors discovered that I did not actually have SMA, but a rarer neuromuscular disorder called myotubular myopathy. Like SMA, myotubular myopathy causes muscle weakness that can range from mild to profound, but is typically at a severe level. For me, this results in feeding and breathing difficulties, as the muscles involved in swallowing and breathing are also weakened.

Myotubular myopathy is caused by a mutation to the MTM1 gene and is inherited as an X-linked recessive condition, thus predominantly affecting males. MTM1 codes for a protein known as myotubularin, which is critical in developing and maintaining normal function of muscle tissue. This condition usually requires intensive medical intervention to treat the symptoms. I myself need to use an electric wheelchair to move around and a ventilator to support breathing.

Although I would have to stay in the hospital to do daily breathing exercises

中心上課。在中學時期我認識了我的女朋友 Gladys，我們都有相近的興趣和經歷，所以和她在一起時並不會感到有任何壓力。我們無所不談，跟她傾訴心事或談論一些憂慮時，她總會給予我很多鼓勵，偶爾也會到病房探望我。每逢周末或假日，我都可以回家或出外吃飯，亦可跟Gladys與朋友們共度一天。

在二零二零年初COVID-19疫情開始後，這一切都發生了變化。

為防止病毒傳播及保障病房病人的健康和 safety，醫管局宣布所有住院病人必須留在病房內，不得離開。隨著疫情的惡化，探病也受到限制，外來訪客不能進入我們的病房。為了幫助住院患者與親人保持聯繫，DKCH的工作人員每週都會為每位患者安排視頻通話，以便與家人和朋友見面。

在疫情開始時，大家都過著自我隔離和與社會保持距離的生活，彼此都飽受著精神壓力。但是你能想像這對被限制在病房裡的病人的影響嗎？

我不能回家，因為在一般家庭中的設施，無法令我的父母安全地照顧我，我需要醫院的設施來妥善管理肌小管病變。多年來能夠去上課並自由地與家人、女友和朋友們共度時光的情景已經不復再現，我的生活完全改變了，因為實際上我只能躺在床上或坐在輪椅上，每天只能上課和通過視頻通話與親人交談。

回想之前只是早晚需要留在病房，更讓我覺得自己被困在了自己的處境中。自從疫情開始以來，我每天都按照醫院的節奏過著同樣的生活。不能見女朋友和家人，也不能出去。過去一年半的日常生活，都是在醫院裡度過。

在病房內這段淒涼而孤獨的時期，我特別感謝我們的病人服務助理李家霖先生，他從我第一次入住DKCH起就一直在我的病房裡工作。他對每一位病人都表現出無限的善意，非常關心我們，病房裡的每個人都很敬重他。他在今年較早時候轉到另一家醫院工作，我們都感到非常不捨，祝願他今後的工作一切順利。

目前，我在香港都會大學就讀工商管理榮譽學士學位課程。今年夏天，我透過 Care in Education and Recruitment (CareER) 申請在香港弱能兒童護助會 (SRDC) 實習，CareER是一個慈善工作匹配平台，旨在幫助殘疾人士和特殊教育需求者的職業發展。我計劃將來會申請公房，這樣我就可以更加獨立，隨時都能夠跟家人、朋友和女朋友見面。

對於SRDC的支持者，我希望在閱讀本時事通訊後，您可以了解 COVID-19 在此期間對住院患者的生活和心理健康的嚴重影響。我也希望醫管局可以考慮在不久的將來放寬一些限制，因為在過去的一年半，我們一班病人都只能困在病房裡生活，其實是非常痛苦的。



and physical therapy to improve my muscle strength, I was still able to live a fairly regular life and could leave the ward during the day to attend classes at my secondary school, where I met my girlfriend, Gladys. We had similar interests and experiences, so I did not feel any pressure when I was with her. We could talk freely about worries or concerns, and she always cheered me up, sometimes visiting me in the ward too. Whenever it was a weekend or a holiday, I could return home or go out for meals and spend the day with Gladys and my friends.

This all changed after the COVID-19 pandemic began in early 2020.

To prevent the spread of the virus and protect the health and safety of patients living in the wards, the Hospital Authority announced that all in-patients were required to stay in our wards and were not allowed to leave. As the pandemic worsened, visitation was also restricted, preventing outside visitors from entering our ward. To help in-patients stay connected to their loved ones, the staff at the DKCH arranged weekly video calls for each patient to see their family and friends.

The world has collectively experienced the mental strain while living a life of self-isolation and social distancing, especially at the beginning of the pandemic. But can you imagine the effects on the patients confined to the hospital ward?

I could not return home because it would take a toll on my parents to monitor me continuously, and I needed the facilities in the hospital to properly manage the myotubular myopathy. After years of being able to go to class and freely spend time with my family, girlfriend and friends, my life completely changed as I was effectively bed-bound, only being able to attend classes and speak to loved ones over video calls.



Thinking back to the life I had before, where I only spent the mornings and evenings at the ward, made me feel even more trapped in my situation. Since the beginning of the pandemic, I have lived the same life every day. Following the rhythm of the hospital, I was unable to meet my girlfriend and family members, nor could I go out. I felt that I was missing out on normal life being stuck in the hospital for a year and a half.

Through this bleak and lonely time in the ward, I was especially thankful to our personal care assistant, Mr. Lee (李家霖), who has worked in my ward since I was first admitted to DKCH. He has shown immeasurable kindness to every patient and cares for us very much.

Everyone in the ward respects him a lot. He transferred to another hospital earlier this year, so while we were all sad to see him leave, we wish him all the best in his future endeavours.

Right now, I am pursuing a Bachelors of Business Administration in Business Management with The Metropolitan University of Hong Kong. I was accepted for an internship with the Society for the Relief of Disabled Children (SRDC) this summer through Care in Education and Recruitment (CareER), a charitable job matching platform to assist the career development of people with disabilities and special education needs. In the future, I plan to apply for public housing so that I can be more independent and freely meet with my family, friends and girlfriend again.

To the supporters of SRDC, I hope that after reading this newsletter you might understand the severe impact of COVID-19 on the lives and well-being of in-patients during this time. I also hope that the Hospital Authority can consider relaxing some restrictions in the near future, as this



SRDC努力幫助像鎮滔這樣的患者提高他們的生活質素，並很高興為他們的職業發展提供機會。如果您希望支持我們的工作，為我們住在大口環根德公爵夫人兒童醫院的住院患者爭取更好的治療、生計及福利，請考慮關注我們的工作及捐款支持SRDC。

翻譯鳴謝
香港中文大學專業進修學院
應用翻譯高級文憑課程
陳保潤同學



past year and a half have been particularly mentally draining for us stuck in the wards.

SRDC strives to help patients like Wind to improve their quality of life and is glad to provide opportunities to aid their career development. If you wish to support our work as we campaign for better treatment, livelihoods, and wellbeing of the in-patients in our care and at the DKCH, please consider following our work and making a donation to SRDC today.

項目更新 PROJECT UPDATES

儀器植入計劃 - 前椎體螺絲釘拴繫技術 新植入資助

敝會與大家分享植入前椎體螺絲釘拴繫技術(VBT)資助再有受惠者的好消息: 脊柱側彎受惠男童，十四歲的小銘已於六月三日進行手術，小銘胸椎至腰椎T11-L3弧度從手術前49.2°改善到14°，T6-11弧度改善到11°。十二歲的Iris於七月十三日進行了第一次VBT手術，隨後於七月二十九日進行了第二次手術。胸椎T6-12弧度從手術前56°改善到19°，而胸椎至腰椎弧度T12-L4從43°改善到10°。十三歲的男童00於八月三日進行了VBT手術，胸椎至腰椎T8-L1弧度從手術前49°改善到13.7°，而腰椎弧度L1-5弧度從手術前25°改善到14.5°。



手術前 before surgery



手術後 after surgery

Implants Sponsorship - Anterior vertebral body tethering (VBT) System

We are happy to share good news for our more implant sponsorship beneficiaries. 14 year old Siu Ming had his anterior vertebral body tethering (VBT) surgery on 3 June. Siu Ming's Cobb angle improved from 49.2° before surgery to 14° in T11-L3 and for T6-11, the Cobb angle improved to 11°. Iris, aged 12 had her first VBT surgery on 13 July followed by the second surgery on 29 July. Cobb angle of her spine (T6-12) improved from 56° before surgery to 19° while for T12-L4, improved from 43° before surgery to 10°. QQ, aged 13 boy had his VBT surgery on 3 August. QQ's Cobb angle of his spine improved from 49° before surgery to 13.7° in T8-L1 and 25° before surgery to 14.5° in L1-5.

街坊小子木偶劇場

街坊小子木偶劇場舉辦的2020-2021學年寫信填顏色比賽經已完滿結束，全年幼稚園組共收到351份作品、小學中文組及英文組各分別收到352及475份作品，經評審後，得獎名單已經公布！恭喜所有得獎同學及感謝評審們！

The Kids on the Block 'KOB'

The 2020-2021 academic year Kids Letter Coloring Contest, organized by The Kids on the Block was completed. We received a total of 351 entries from Kindergarten, 352 entries from Primary School Chinese group and 475 entries from Primary School English group. After review, the results were released. Please take a look at their beautiful work. Congratulations to the students and thanks to the judges!



實習生計劃

今年夏天，四名大學及一名高中學生包括姜嘉蔚、湯曉彤、廖嘉穎、何尚民、周瑋嫻參與了敝會的實習生計劃。他們被分派了不同的工作，包括辦公室行政、網站內容管理及籌款活動推廣資料。周瑋嫻亦於完成實習生計劃後，立即啟程前往英國為當地新學校生活做準備。我們祝願他們在將來的努力中一切順利和快樂，並繼續為社區和世界作出正面的改變。

Summer Intern

This summer, we had four university and one high school interns with us – Joanna, Alana, Eunice, Shirley and Adeline. They were assigned different tasks including administrative works, website content management and fundraising marketing materials. Adeline immediately set off to UK after her internship to prepare for her new school life there. We wish them all the best and happiness in their future endeavours and hope that they continue to create positive impacts to the community and the world.



慈善晚宴

麵麵俱到於七月一日將其開幕周的一日全數食物收益捐贈給敝會。新餐廳以潮流中式居酒屋作賣點。非常感謝麵麵俱到的慷慨和支持。

Charity Dinner

Mian Mian Ju Dao donated all the food proceeds of one of their opening nights 1 July to SRDC. The new restaurant boasts the latest trend of Chinese style Izakaya. Many thanks to Mian Mian Ju Dao for your kind support and generosity.



池昌旭香港池粉會捐款

池昌旭香港池粉會今年再次以池昌旭的名義捐款給敝會作為慶祝他在七月五日的生日，並由患罕見疾病的Chelsey接收支票。非常感謝池昌旭的愛心及香港池粉一直對敝會的支持！



Donations from Ji Chang Wook Hong Kong Wookies Club

Ji Chang Wook Hong Kong Wookies Club again donated to SRDC in celebration of his birthday on 5 July. Larsen Syndrome patient Chelsey received the cheque on our behalf. We thank Ji Chang Wook for his love and his fanclub for their kindness and support.

《COVID-19抗疫之路：香港醫護的心路歷程》

「縱使疫情帶來了對未知的恐懼以及失去生命的痛苦，但它也喚醒了我們潛藏在內心的無私大愛與堅毅不屈的專業精神。只要共同努力，必能渡過難關。」

《COVID-19抗疫之路：香港醫護的心路歷程》是由港島東醫院聯網醫護編著。敝會代表於七月十七日到書展支持快閃簽書會。

"The Road to COVID-19 Fighting the Pandemic: The Mental Health Journey of Hong Kong Healthcare Workers"

"Even though the pandemic has brought about the fear of the unknown and the pain of losing lives, it has also awakened the selfless love and perseverance hidden in our hearts. If we work together, we will be able to overcome the difficulties."

"The Road to COVID-19 Fighting the Pandemic: The Mental Health Journey of Hong Kong Healthcare Workers" was compiled by the medical and nursing staff of the Hong Kong East Cluster. Our representative went to the book fair on July 17 to support the book signing event.



防疫物資派發

衷心感謝所有慷慨的捐贈者，使我們在暑假期間可以再為有需要的病人提供新一輪防疫及開學用品。再次感謝鳳凰有限公司和香港獅子會主會贊助敝會的防疫用品。

Personal Protective Equipment (PPE) Giveaway

We are most grateful to all generous donors to allow us to provide new rounds of PPE and back to school giveaways to our needy patients over the summer. We thank again Phoenix Inc and Lions Club of Hong Kong (Host) for their kind donations of PPE.

二零二一慈善獎券

衷心感謝各位對敝會2021慈善獎券的支持，於八月三十日在大口環根德公爵夫人兒童醫院行政總監鄧錦成醫生監督下，由敝會主席張達棠太平紳士主持抽獎。敝會再次感謝捐款人、贊助商及參與者的慷慨捐贈，遺傳性疾病病童得到可以改善他們人生的機會，可盡快接受基因測試，早日找出病因。同時亦恭賀各位得獎者！讓大家一同分享他們的喜悅吧！

SRDC Charity Raffle 2021

We sincerely thank you all for your generous support towards SRDC Charity Raffle. The draw was officiated by our Chairman Mr Cheung Tat Tong, JP, and monitored by Dr Tang Kam-shing, HCE of DKCH on 30 August. A big thank you again to donors, sponsors and participants for your supports towards children with genetic conditions. Congratulations to all winners! Let us share the joy with all of them!



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捐利是表格 RED PACKET DONATION

在這個喜氣洋洋的春節，捐出一封利是，給有需要的人送上新春祝福。您的捐助可以讓有需要的病童得著適切的幫助。捐出一封利是，祝福他人亦祝福自己。

This Chinese New Year, send in a red packet to share the spring blessings with the needy children. The money you donate to The Society for the Relief of Disabled Children will help the differently-abled children.

☐ 本人 願意捐款港幣\$_____支持「香港弱能兒童護助會」。
I would like to make a donation of HK\$_____to "The Society for the Relief of Disabled Children".

☐ 本人 願意每月定期捐款港幣\$_____支持「香港弱能兒童護助會」。
I would like to make monthly donation of HK\$_____to "The Society for the Relief of Disabled Children".

本人以 電子 / 郵寄 / 毋需 收取收據。I would like an **e-receipt / paper receipt / no receipt**.

姓名 _____ 收據抬頭 _____
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本人同意 / 不同意 香港弱能兒童護助會使用以上簡單資料，透過不同渠道通知本人 貴會的各项活動、通訊及意見收集。

I agree / do not agree that The Society for the Relief of Disabled Children (SRDC) can use my above data to keep me posted of SRDC news, events and surveys through various communication channels.

簽署 Signature: _____ 日期 Date: _____

倘若日後閣下不想收到本會的宣傳推廣或最新消息，請以郵寄或電郵方式來信通知本會，本會將會停止使用閣下資料。如想多些了解我們，歡迎瀏覽我們的網頁 www.srdc.org.hk。謝謝！

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WINTER/2021

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