

香港弱能兒童護助會

The Society for the Relief of Disabled Children

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由一位長期病患者成為未來的醫生

相信大部分人都從未聽聞XLA這個簡稱。然而,因為親身經歷,讓余卓斐很早就明白到這幾個字母的真正涵義。五歲時,卓斐在基因測試中得悉自己患有「X-連鎖丙種球蛋白缺乏血癥」(XLA, X-linked Agammaglobulinemia)。XLA 的患者缺乏產生特定抗體的能力。卓斐把大部分的童年時光花在和細菌感染反覆搏鬥。縱使屢勝,他仍要承受頻繁入院治療的痛苦。可幸的是,他現已成為一名醫科學生,今年畢業後,將會成為一名醫生,投身杏林。

XLA 是一種人類原發性免疫缺陷病 (PID - Primary Immunodeficiency)。PIDs 通常被認定為罕見病,因為部分免疫系統未能正常運作而引起。PIDs 的患者比其他人更易受到感染。如果他們沒有得到適當的治療,便容易生病、變成殘障、器官永久受損,甚至死亡。

由於 XLA 的患者缺乏產生特定抗體的能力,因此可能患上鼻竇感染(鼻竇炎)、眼部感染(結膜炎)、耳部感染(耳炎)、鼻部感染(鼻炎)、肺氣道感染(支氣管炎)或肺部感染(肺炎)。胃腸感染是個相當棘手的問題,特別是當患者同時感染一種寄生蟲 — 賈第鞭毛蟲的時候。賈第鞭毛蟲能引致腹痛、腹瀉或發育不良,患者亦有可能失去血清免疫球蛋白,如丙型球蛋白。一些 XLA 患者亦會有皮膚感染的問題。

在成長過程中, 卓斐每個月都會有反覆的不常見細菌感染, 因此, 醫生很快便斷定他的病況異常。不過, 他們卻一直未能準確地判定問題所在。接受治療之前, 卓斐被病魔折磨至身心俱疲, 令他無法好好享受童年。因為要長期住院, 更令他無法在學校或遊樂場和其他小朋友嬉戲互動, 圍繞著他的是醫生、護

From chronic patient to future doctor

XLA is an acronym which most of us would have never come across. But Geoffrey Yu learnt the actual meaning of these letters early, by life experience. Geoff was diagnosed at 5 years of age with XLA (X-linked Agammaglobulinemia) through genetic tests. Patients with XLA lack the ability to produce antibodies. Geoff has fought and conquered recurrent infections and endured frequent hospitalizations for the majority of his childhood. He is currently in his final year of studies to become a medical doctor.

XLA is a specific type of Primary Immunodeficiency "PID". PIDs are generally recognized as rare disorders, caused when some components of the immune system do not work properly. Patients with PIDs are more prone than others to infections and if they are not properly treated, the patients are exposed to illness, disability, permanent organ damage or even death.

As they cannot produce antibodies, XLA patients may have infections that involve the sinuses (sinusitis), the eyes (conjunctivitis), the ears (otitis), the nose (rhinitis), the airways to the lung (bronchitis), or the lung itself (pneumonia). Gastrointestinal infections can also be a problem, especially with the parasite Giardia. Giardia may cause abdominal pain, diarrhea, poor growth or loss of serum proteins like gamma globulin. Some patients with XLA also have problems with skin infections.

Growing up suffering from repeated episodes of uncommon infections every month, doctors were quick to detect Geoff as an anomaly. However, they were unable to pinpoint his exact condition. At that time, Geoff's physical and psychosocial life deteriorated to the point that he lost the ability to enjoy his childhood. Instead of interacting with other children at school or at the playground, Geoff spent extended periods of time in hospital surrounded by doctors, nurses and last but not least, his family. The severity of his condition disrupted Geoff's childhood and greatly impacted his loved ones. However, they supported each other and worked through Geoff's difficult medical obstacles with great fortitude.

士,當然還有最重要的家人。他的情況嚴重得摧毀了他的童年,亦影響到他的親人。然而,他們互相扶持,堅毅不屈地與卓斐一起,合力渡過這醫學難關。

幸運的是, 卓斐接受了基因測試, 在幼年時已得以 確診為患上了 XLA。對於 PID 的患者來說,及早 確診和治療至關重要, 因為這可以降低感染和併發 症的風險, 並改善治療效果。雖然目前並沒有方法 能治癒 XLA, 但要控制病情, 病人可注射缺乏的抗 體,把抗體直接注入血液 (靜脈注射)或是皮膚下 (皮下注射)。卓斐每個月都要到醫院接受一次 靜脈注射抗體的治療(又稱為靜脈注射免疫球蛋 白, IVIG)。現在, 他每次接受這種治療, 都歷時約 五小時, 卓斐聽說有些病者更會長達十二小時。接 受治療之後,卓斐受感染的情況開始減少,生活質 素大大改善。卓斐解釋道:「雖然 XLA 會令人極 度虛弱, 但配合適當的治療, 有助改善病情, 所以, 要重申對病人來說,及早確診和治療的重要性。」 接受定期治療後, 卓斐重獲健康, 能把精力集中在 學業上, 並跟家人和朋友共度閒餘時光, 告別醫院 的陰霾。



身為 PID 患者過來人, 卓斐娓娓道來患病帶來的感悟:「健康真的很重要,是任何東西都無法取代的。沒有健康, 不但自己的生活受到影響, 連家人的生活也會受到影響。」家人, 醫生和其他醫療專業人員對卓斐毫無保留的支持和關愛, 激發他從小立志成為一名醫生。卓斐很感恩可以與家人和兒科醫生游日新醫生並肩打這場漫長的仗。「正是游醫生的熱誠,以及我的童年經歷, 培養了我對醫藥的濃厚興趣, 亦令我非常崇拜醫生這種職業。醫學結合了科學和人類的互動。」

這次,卓斐不單以病人的身份,亦以醫科生的身份再次踏進醫院。 現在他的目標是激勵和啟發其他人。當我們問他要成為一位醫生 須具備什麼必要條件時,他這樣回 答:「我認為,同理心是極為重要 的。當與病魔經歷了漫長而痛苦 的抗爭後,游醫生讓我知道,醫生 的理解與關心可以帶給患者多大

的安慰, 激勵患者與他們的親人勇往直前。我時常 提醒自己, 不要忘記初衷, 不要忘記我為何選擇成 為一個醫生。」

在醫學院, 卓斐成為劉宇隆教授的學生。劉教授是世界知名的兒科免疫學和傳染病專家。在過去十年, 劉教授與同區域的四十多間醫院合作, 幫助疑似患有 PID 的兒童。這種緊密的合作促成了亞太

Fortunately, Geoff undertook a genetic test and was diagnosed at a young age with XLA. Early detection and treatment is crucial for PID patients to reduce the risk of infections, complications and to improve outcomes. Currently there is no way to cure patients who have XLA. However, they can be given some of the antibodies that they are lacking, directly into the blood stream (intravenously) or under the skin (subcutaneously). Geoff has been receiving monthly intravenous antibody infusion treatment (also referred to as IVIG) at the hospital. Normally, each session takes about 5 hours for him but he has heard other patients spending 12 hours per session. Since then, Geoff's susceptibility to infection has been greatly reduced and his quality of life improved significantly. 'Although XLA is a potentially debilitating disease, appropriate management can make a huge difference; and this truly emphasizes the importance of early diagnosis and treatment', Geoff explained. After receiving regular treatment, Geoff regained his health and was able to shift his efforts onto his studies, enjoy leisure time with family and friends, and step outside the bleak hospital environment.

Geoff reflects on his personal experience with PID and noted, 'health is a very important and irreplaceable thing. Without it, not only will one individual's life be affected, but also the lives of his/her family.' Inspired by the unwavering support and love from his family, doctors and other medical professionals, Geoff's passion since childhood was to become a doctor. Geoff expressed his gratitude to have fought this long battle alongside his parents and Dr. YS Yau, his paediatrician. 'It was Dr. Yau's passion, combined with my childhood experience that fostered my fascination with medicine which combines science with human interaction, as well as a resolute admiration for the medical profession.'

Geoff re-immersed himself into the hospital environment; this time not only as a patient but also as a medical student – and now he aims to influence and encourage others. When asked what qualities he thinks are essential for a doctor to possess, Geoff answered, 'Empathy is extremely important, Dr. Yau showed me the comfort that doctors can bring to a patient after a long, hard struggle with diseases, as well as their impact on both the patient's life and their loved ones. I always remind myself not to forget where I came from and why I have chosen to pursue this aspiration.'

In medical school, Geoff became a student of Professor YL Lau, a world renowned expert in paediatric immunology and infectious disease. Over the past decade, Prof Lau has worked with some 40 hospitals in the region to help children suspected of PID. This strong alliance formed Asian PID Network, to which SRDC has rendered funding for PID molecular testing for numerous patients in the last six years.

In 2013 Geoff, Prof. Lau and Dr. Pamela Lee worked collaboratively to initiate the "PID League", Hong Kong's first and only PID patient group. The aim of PID League is to provide a platform to connect PID patients, their family members, immunologists and other healthcare professionals, and raise awareness locally. Through this platform, Geoff and over 50 other patients have created a community to provide mutual support, share their personal experiences and

exchange updated information, such as new research or treatment methods. As Vice-President of the PID League since the group was established two years ago, Geoff has witnessed the growth of the PID community and the impact it can make collectively as a group. Geoff and other patients can assist the newly diagnosed patients sharing their own personal experience.

Geoff and the many other PID patients have pushed through numerous obstacles.



PID 網絡。而在過去六年,香港弱能兒童護助會一直為此提供資金,為眾多患者進行 PID 檢測。

此外,在二零一三年,劉教授,李珮華醫生與卓斐合作啟動了「勉逆歷」,香港首個,也是屹今唯一一個 PID 患者組織,其宗旨是提供一個平台去連繫 PID 患者、患者家人、免疫學家以及其他醫療專業人士,並提升大眾對這種疾病的認識。透過這個平台,卓斐與其他五十多名的患者組成了一個群體,互相扶持,分享個人經歷,並交換最新資訊,例如新研究或新治療方法。自「勉逆歷」兩年前成立以來,身為副會長的卓斐見證著 PID 群體的發展,也目睹了群體努力為社會帶來的可喜改變。這證明了卓斐與其他患者可藉助自身經歷幫助同行者。

卓斐和其他 PID 患者一起克服了許多困難。卓斐表示, 他在將來「會致力提高醫療專業人士、決策者和大眾對 PID 的關注, 以便患者能儘早確診, 接受早期治療, 從而取得最好的療效。就我個人而言, 我希望透過我的自身經歷和醫學專長, 去扶持和影響其他人, 並鼓勵正受病魔折磨的人。這會是一個全新的挑戰, 但是我已經準備充足、蓄勢待發!」

及時的診斷讓 PID 患者回歸社會、作出貢獻, 活出充實的人生。 為了實現願景, 香港弱能兒童護助會承諾為疑似患童提供免費的 檢測, 重燃他們對生命的希望。您願意慷慨捐助, 與我們一起幫助 像卓斐一樣的患者, 為他們塑造美好的未來嗎?

Photo credit: Dino Zarafonitis / amacod.com

As for the future, Geoff said, 'I aim to continue raising awareness on PID among healthcare professionals, policy makers and the general public; so that diagnoses can be made as quickly as possible, and treatments can be prescribed at an early stage in order to achieve the best outcome for patients. And from a personal standpoint, I hope to inspire and influence others with my experience and medical skills to encourage those who are suffering from ailments – this will be a new challenge but I am ready for this!'

With prompt diagnosis, patients with PIDs can still be contributing members to society and live their lives to the full. To make this happen, SRDC has pledged to support free tests for children suspected of the disease. Would you like to join us in shaping a bright future for patients like Geoff by donating generously?



活動回顧 ACTIVITIES & NEWS

醫院探訪

一直以來,不少嘉賓均親臨大口環根德公爵夫人兒童醫院參觀,切身了解敝會工作。

於三月三十日,Mrs. Amanda Buckingham 和 Ms. Olivia Buckingham 親臨兒童醫院探訪,敝會深感榮幸。她們的先祖 Mr. Noel Croucher 為人低調, 是位福澤人群的大慈善家。他的捐助促成兒童醫院的建立。直至現在,醫院的舊入口仍然聳立著紀念他的奠基石。得悉她們來訪,敝會的主席李偉文、前主席黃匡源及兒童醫院代表李素輪醫生歡迎她們,讓兩位更了解敝會和醫院的工作。敝會十分感謝 Mrs. Amanda Buckingham和 Ms. Olivia Buckingham 支持敝會的工作。

蒙特梭利國際學校的師生及 Morgan Stanley 的義工分別於五月二十四日和六月三十日到兒童醫院進行探訪。

Hospital Visits

Hospital tours enable visitors to better understand our work.

Mrs. Amanda Croucher Buckingham and Ms. Olivia Croucher Buckingham the granddaughter and great-granddaughter of Mr. Noel Croucher, visited DKCH on the 30th March. An influential but discreet philanthropist, Mr. Croucher made generous donations to enable the establishment of the convalescent home, later known as DKCH. The foundation stone commemorating his contribution is still erected at the old entrance of DKCH. Our chairman, Mr. Vivian Lee, past chairman, Mr. Peter Wong and the representative of DKCH, Dr. SL Lee, welcomed our guests and showed them around the hospital. They were very moved to witness the development of the hospital and congratulated us on our work.

On 24th May and 30th June, some students from The International Montessori School and volunteers from Morgan Stanley also visited us.







免費門票

承蒙 Lifewire 的善心, 送出【歲月無聲 2.0 誰伴我闖蕩】 慈善音樂劇五月四日的門票, 讓敝會的病童可以觀看精 彩的舞台劇。其後 Lifewire 再次送出門票, 讓病童可以 在八月二十及二十一日參觀景賢里。

Free Tickets from Lifewire

Thanks to Lifewire, our patients were able to enjoy a charity musical on the 4th of May and visit King Yin Lei on the 20th and the 21st of August.

自發籌款活動

The Crayon Society 樂善好施, 特意為敝會籌款。這個籌款活動尤其特別, 籌款團體會熔掉收集了的蠟筆, 然後製造新的蠟筆作義賣, 既環保, 亦可行善。他們亦親臨兒童醫院, 把新的蠟筆送贈病童, 敝會由衷感激。

The Crayon Society

The Crayon Society, in a thoughtful effort to help children with disabilities by remoulding old crayons, initiated a fundraising campaign for SRDC. They also visited our hospital with new crayons as gifts to our patients. We thank The Crayon Society for their willingness to serve.

暑期實習生

今年暑假, 敝會有四名實習生。首先, 我們很高興上年的 實習生麥禮衡回歸我們的大家庭。另外一個高中實習 生是他在西島中學的同學 Philippe de Manny。另一 個高中實習生是陳健欣,來自英國。最後是就讀於倫敦 政治經濟學院的陳筠朗。他們在實習期內努力學習,致 力為弱能兒童的福祉服務,為我們的辦公室注入不少活 力。

Summer Interns

This summer, we had four interns. Colin Mak from West Island School, who participated in our intern program last year, joined us again this year with his classmate Philippe de Manny. With them is another high school intern Florence Chan from the U.K. and Gwen Chan, a university intern from The London School of Economics and Political Science. They were all on board to assist our efforts in bettering the lives of children with disabilities. They also injected youthful energy into our working environment.









迪士尼義工聚會

於七月九日, 敝會帶領參加了「迪士尼賞義工行動」的 義工前往迪士尼樂園。當日風和日麗、陽光普照, 是遊 玩的好天氣。義工均玩得不亦樂乎。他們於過去一年裡 竭力幫忙, 貢獻良多, 功不可沒, 敝會感激萬分。

Disney Volunteering Gathering

On the 9th of July, SRDC took our volunteers on a free trip to Hong Kong Disneyland under the 'Give a Day, Get a Disney Day' Scheme. On this sunny and beautiful day, our volunteers had great fun. We would also like to take this opportunity to thank our volunteers for their help and dedication throughout the years.



慈善獎券活動回顧

今年的慈善獎券活動經已完滿結束。敝會非常感謝大家 的支持。我們一起來分享各位得獎者的快樂時刻吧!

Charity Raffle 2016

Our Charity Raffle ended on a good note. The event wouldn't have been successful if not for the support of our generous donors, keen raffle buyers and enthusiastic volunteers. Let's share the happy moments of the winners!



街坊小子木偶劇場二零一六年週年聚 會及聚餐

「街坊小子木偶劇場」剛走過第二十一個年頭。 於八月二十七日當晚舉辦了週年聚會及聚餐,回顧 他們於推廣共融社會上的工作,義工亦分享了他們 的心得,和一些表演中難忘的經歷。新畢業的木偶 師亦初踏台板,為大家作一場表演。而壓軸抽獎把 氣氛推至高峰,大家盡興而回。



KOB Annual Gathering and Dinner

'Kids on the Block' is already in its 21st year. On 27th August, an annual gathering and dinner was held for members to look back on their work in promoting an inclusive community and to share their unforgettable experiences in past shows. Fresh puppeteer graduates had their first performance. The lucky draw was the climax of the evening, and all went home feeling contented.



儀器植入計劃 磁控延長棒

穎穎

她是一位九歲女孩, 不但曾因為雙邊高 弓足内翻畸形而動手術, 而且亦患有關 節攣縮和脊柱側彎。得到敝會的資助, 她接受植入磁控延長棒。植入磁控延 長棒能夠為穎穎帶來最佳的醫療功效, 不然她將要飽受多次手術之苦。在六 月廿三日, 她成功進行了手術。

手術前 Before Surgery

Wing Wing

MAGnetic Expansion Control Growing Rod

Implants Sponsorship

Wing Wing is a 9-year-old girl with Arthrogryposis, bilateral cavocrus feet with surgery done and scoliosis. With our sponsorship, she can have MAGnetic Expansion Control growing rod inserted, which is the best treatment plan available under her medical circumstances to prevent further deterioration and allow gradual lengthening without frequent surgeries. Her surgery on 23rd June was successful.

亞J/浠兒/莫浩翔/佩佩小朋友/俊俊

植入了磁控延長棒之後,亞J進行延長程序。三月七日至 現在, 他的延長棒左邊一共拉長了 2 毫米, 右邊則拉長 了 0.3 毫米。 浠兒也繼續進行延長程序, 康復進度十分良 好。她的延長棒左邊被拉長了 16.62 毫米, 右邊被拉長了 17.66 毫米。另一位小朋友莫浩翔, 他的螺絲鬆脫並導致 其體内的棒凸出。所以,雖然第二次植入的延長棒只用 了百份之七十一, 浩翔需要在六月六日做第三次植入手 術。至今他的延長棒左右各拉長了 2 毫米。在植入磁控 延長棒的兩年後,佩佩小朋友的延長棒左邊一共被拉長 了 30.13 毫米, 右邊則拉長了 31.67 毫米。

俊俊因神經肌肉狀況惡化而仍 在屯門醫院留醫, 並需要長時間 使用呼吸機。經過醫護人員的 努力, 他情況好轉, 並預計可於 十一月出院。



He has a total distraction of 2 mm on the left and 0.3 mm on the right. Hei Yee continues her distraction after rod insertion. Her total distraction on the left is 16.62 mm and 17.66 mm on the right. For Mok Ho-cheung, the right side rod appeared pulled out and right T3 screw appeared to be

Ah J has distraction sessions after his rods implant on the 7th of March.

Ah J/Hei Yi/Mok Ho-cheung/Little Pui Pui/Chun-chun

impinging against the right back subcutaneous region under CT scan. He had his third rod implant on 6 June when 71% of his second rods was used. Since then, he has a distraction of 2 mm on each side. Little Pui Pui has a total distraction of 30.13 mm on the left and 31.67 mm on the

right.

Chun-chun continues his hospitalization in Tuen Mun Hospital 'TMH' and relies on ventilator. Both medical professionals at TMH and DKCH have put in effort in offering him spinal care. He is recovering well and expected to be discharged from TMH in November.

中國病童計劃

欣欣

欣欣十三歲,來自福建。她患有成骨發育不全症(亦稱為 「脆骨症」)及脊柱側彎。自出生後,她有多處骨折。她 於七月四日在港接受手術,矯正向前畸形彎曲的脊骨。 手術順利進行,非常成功。她現已回家。



China Patient Project

Xin Xin

Our new China patient is a 13-year-old girl from Fujian. She is diagnosed with Osterogenesis Imperfecta, aka 'brittle bone disease', and scoliosis. She has multiple fractures since birth. We arranged surgery for Xin Xin on the 4th of July to regulate an abnormal forward curvature of the spine. The surgery was very successful and Xin Xin is now on the road to recovery.



捐款表格 DONATION FORM

□ 本人 願意捐贈港幣\$	支持「 香港弱能兒童護助會 」。
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姓名	收據抬頭
Name	Name on receipt
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□ 直接過戶 (匯豐銀行 002 – 244416 – 003	或 恒生銀行 383 – 686516 – 001,請附上入數紙紀錄)
	02 or HANG SENG BANK 383 – 686516 – 001, please enclose bank-in-slip)
□ 繳費靈 [本會商戶編號9270。請鍵入賬員	怎 號 (閉下8位數值的雲話號碼) 1
	調弧 (格) では安国内 电台弧隔 / 」 e state the bill number (which is 8-digit telephone number)]
賬單號碼Bill number:	
□ 信用咭 Credit Card □ VIS	A
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(須於三個月內有效Should be valid for th	next three months)
授	權使用個人資料作推廣事宜 (只適用於新捐款人)
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newsletters, volunteer services and surveys to	collect donor opinions through various communication channels.
- 個人資料包括:姓名、電話號碼、傳 My personal data include my name.	頁號碼、電郵地址及通訊地址。 elephone number, fax number, email and mailing address.
- 使用的通訊渠道包括:郵遞、電郵、	圖文傳真、電話及電話短訊等。
Communication channels include di 口 本人不同意香港弱能兒童護助會使用本人的個人	ect mail, email, facsimile, telephone and sms. 資料作上述用途。
I do not agree the SRDC to use my personal of	
簽署 Signature :	日期 Date:
	,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!	
either by post or by email, the SRDC will cease to	marketing materials or updates from the SRDC in future, upon receipt of your written request, use your personal data for the above purposes. If you would like to know more about us,
you are welcome to visit www.srdc.org.hk Thank	
/#÷t Demovice:	

- 1. 請將支票、銀行入數紙或繳費靈號碼連同表格寄回「香港薄扶林大口環道12號香港弱能兒童護助會」收 Please complete the donation form and send it together with a crossed cheque, bank-in slip or PPS bill number to "The Society for the Relief of Disabled Children, 12 Sandy Bay Road, Pokfulam, Hong Kong."
- 2. 一年內累積捐款達港幣\$100或以上在香港可憑收據申請扣減稅款。
- Accumulated donations of HK\$100 annually or above are tax deductible with a receipt in Hong Kong. 3. 每月捐款正式收據將於每年四月寄奉,以便閣下申請扣減税款。 For monthly donation, an annual receipt will be issued in April for tax deduction in Hong Kong.

AUT/2016

未來動向 UPCOMING

第三十五屆大口環根德公爵夫人 兒童醫院賣物會

萬眾期待的兒童醫院賣物會即將舉行。每年, 賣物 會都有約一百個攤位, 吸引不少市民參與, 所籌得的 善款將全部撥捐兒童醫院, 作購置醫療儀器之用。 如此盛事, 您又豈可錯過?

賣物會資料:

二零一六年十一月五日(星期六) 時間:

上午十時至下午五時

地點: 大口環根德公爵夫人兒童醫院

The 35th Annual Sandy Bay Charity Fair at DKCH

The much loved Fair will be held very soon. Every year, the annual Fair showcases nearly 100 stalls and all of the funds raised will be used for purchase of medical equipment at DKCH. Don't miss this once-a-year activity!

Details of the event:

Time and date: Saturday 5 November 2016 at 10:00 -17:00 Location: The Duchess of Kent Children's Hospital at Sandy Bay

聖誕賀咭

香港弱能兒童護助會 The Society for the Relief of Disabled Children

聖誕賀咭現已發售,來買張為您的親朋好友送上溫 情的祝福吧!

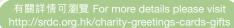


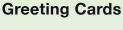












Lovely Christmas cards are available for sale. Don't miss the perfect chance to send the warmest greetings to your loved ones, at the most festive time of the year!





會訊印刷贊助

Daycraft

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