

#### 關於我們 ABOUT US

兒童心臟基金會成立於1994年，致力服務先天性心臟病兒童及家人。基金會的服務包括提供經濟援助、贊助手術器具、購置醫療設備、安排海外醫生到訪進行醫學交流、為病童及家長提供情緒治療及心理輔導支援和定期舉辦各項教育及發展性活動等。

Children's Heart Foundation was established in 1994 to support children and their families affected by congenital heart disease. The CHF provides a wide range of services such as financial support; purchasing medical equipment; counselling, liaising with overseas surgeons; provides professional psychological counselling and therapies; and organizing regular educational and developmental and supporting programmes.



| 回郵地址 |

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# 終身的挑戰

Lifelong Challenge

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## 心童 · 有話兒

Sharing

「來回地獄又折返人間」的三月



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(所有內容皆為中英對照。)  
(All content is written in both Chinese and English.)

## EDITOR'S NOTE 編者..的話

### 兒童心臟基金會編輯小組

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先天性心臟病是一種常見的兒童先天性疾病，每一千名新生嬰兒中就有六至八個患有不同程度的先天性心臟病。患者從出生開始就需要定期到醫院進行追蹤檢查、手術和治療。在他們成長的過程中，患者和家人都必須面對各種困難，包括醫療、經濟、心理和社交發展方面的挑戰。

本期《心訊》記錄了兩位最近需再次面對手術的先天性心臟病成人患者的故事，他們分享了自己的手術過程，以及如何樂觀面對長久的醫療經歷。同時間，面對此症帶來的終身挑戰，我們都期盼醫學的進步，可以為心童帶來更多希望。是次會訊亦邀請了兩位心臟科醫生，一同分享新的醫療技術如何改善病患的生活。

—— 公共傳訊事務委員會

Congenital heart disease is a common condition found in children, impacting six to eight out of every thousand new-borns at different levels. Starting from birth, patients need ongoing hospital visits, surgeries, and treatments. As they grow, patients and their families encounter a range of challenges encompassing medical, financial, psychological, and social aspects.

In this issue, we document the stories of two patients with congenital heart disease who recently underwent surgery again. They share their surgical experiences and how they maintain a positive outlook despite their prolonged medical journey. At the same time, in the face of the lifelong challenges posed by this condition, we all look forward to advancements in medicine that can bring more hope to individuals with congenital heart disease. This newsletter also features two cardiologists who discuss how new medical technologies can improve the lives of patients.

—— Publicity and Publications Sub-committee

# 十九歲的天空 成人禮的「考驗」

先天性心臟病是常見的兒童先天性疾病，每一千個初生嬰兒，就有六至八個患有不同程度的先天性心臟病。此症是一個終身的疾病，患者由出生起，便一直需要定期到醫院覆診或接受手術及治療。在他們的成長路上，患者與其家人皆需要面對不同的困難，包括醫療上、經濟上、心理上、以及社交發展上。

今年十九歲的成成，自出生起已接受超過十次大大小小的手術，「我在懷孕時已得知他患有先天性心臟病，當時醫生說不會是很嚴重的的心臟病，但是出世後，就預料不到是他患有心房間隔缺損、心室間隔缺損、肺動脈閉鎖和剝離。」成成媽媽說道。成成出生後隔天，就需要用氧氣箱送到香港瑪嘉烈醫院進行手術，足足過了半年後才可以出院。

成長的過程中，成成很多時也在醫院渡過，需要一直定期覆診或接受治療，當中包括一次「搭橋」手術，兩至三次開胸手術，以及無數次心導管手術，身上的數道疤痕，成為了他的生命印記。「印象最深刻的一次是八歲進行心臟矯正手術，手術之前常常都會感覺到身體比較辛苦，例如走樓梯時一直在喘氣。記得手術當日我真的十分害怕。由被推上瑪嘉烈醫院心臟科手術室就開始哭，一直到下麻醉藥都還在哭。」成成說。



Congenital heart disease is a common congenital condition in children, with six to eight out of every thousand new-borns affected by varying degrees of the condition. It is a lifelong disease, and patients require regular hospital check-ups, surgeries, and treatments from birth onwards. Throughout their journey of growth, patients and their families face various challenges, including medical, financial, psychological, and social development difficulties.

Nineteen-year-old Alex, has undergone more than ten surgeries since he was born. "The doctor discovered his congenital heart disease during my pregnancy, and at that time, the doctor said it wouldn't be a serious heart condition. But after birth, we didn't expect him to have Atrial Septal Defect, Ventricular Septal Defect, Pulmonary Atresia, and Patent Ductus Arteriosus," Alex's mother said. Alex needed to be transferred to the Grantham Hospital for surgery the day after his birth and stayed in the hospital for six months.

Throughout his growth, Alex has spent a lot of time in the hospital, requiring regular check-ups and treatments, including one Coronary Artery Bypass Surgery, two to three times of Open-Heart Surgeries, and numerous Cardiac Catheterization procedures. The scars that mark on his body have become a testament to his life. "The most memorable one was the surgery at the age of eight. Before the surgery, I often felt physically exhausted, such as asthma when climbing stairs. I remember on the day of the surgery, I was extremely scared. I cried from the moment I was pushed into the operating room at Queen Mary Hospital until I was given anesthesia," Alex said.



由於媽媽需要經常出入醫院照顧成成，遙遠的車程是她的一大負擔，「最初他住在香港葛量洪醫院，我從天水圍出發，來回都需要三小時。有時候因為要照顧他，都需要留守到晚上十一至十二時。」媽媽說。因此媽媽在醫院的介紹下認識了兒童心臟基金會，並入住基金會的「愛心之家」，直到後期兒童心臟科及「愛心之家」搬遷到瑪麗醫院，媽媽亦有再次入住。而治療的過程中，他們所需要支付的「自資醫療項目」費用亦不菲，因此他們也受惠於基金會的「醫療資助項目」。及後隨著成成的成長，基金會一直陪伴左右，見證著他由嬰兒到長大成人，由受助者到身體力行成為青年義工。



Because Alex's mother needed to frequently visit the hospital to take care of him, the long distance was a significant burden. "He stayed at Grantham Hospital, and I had to travel three hours back and forth from Tin Shui Wai. Sometimes, I had to stay until 11 or 12 at night to take care of him," his mother said. Therefore, through the hospital's referral, Alex's mother got to know the Children's Heart Foundation and stayed at the Foundation's "House of Heart" until the later relocation of the Paediatric Cardiology Department and the "House of Heart" to the Queen Mary Hospital, where she stayed again. During the treatment process, they also incurred substantial expenses for "self-financed medical items," and they benefited from the Foundation's "Medical Sponsorship Program." As Alex grew up, the Foundation has been with him, witnessing his journey from an infant to an adult, from a beneficiary to an active young volunteer.



雖然成成現時已長大成人，然而，他依然需要持續接受治療。在剛過去的四月，已成年的他，又迎來一次「考驗」。「這次是進行心導管手術，比起小時候的我，這次手術就沒那麼害怕了，始終做了這麼多次，都習以為常了。」成成說。面對未知的未來，他和媽媽由最初的驚恐與擔憂，已變成習慣和接受。「隨遇而安吧，現在我對着他這個病，已經是隨遇而安的心態。他有一天在這裡，我就當已經是多賺了一天。」媽媽說。

Although Alex is now an adult, he still requires ongoing treatment. In April, he faced another "test". "It was a cardiac catheterization procedure. Compared to when I was a child, I wasn't as afraid this time. After so many surgeries, I've become accustomed to them." Alex said. Facing an uncertain future, he and his mother have transitioned from initial fear and worry to acceptance and adaptation. "We take it as it comes. Now, I have a mindset of accepting his condition. As long as he's here for another day, I consider it as gaining an extra day," his mother said.

「希望透過我的故事分享，可以讓更多人知道患有先天性心臟病的小朋友，甚至是成年後的患者，其實生活都不容易。」

"I hope that by sharing my story, more people will understand that children and even adult patients with congenital heart disease face challenging lives."



觀看更多成成的故事：  
Watch more about Alex's story:



◆ **流體龍工作坊**

以龍年公仔配合流體藝術創作而成，一眾心童發揮創意，製作獨一無二的流體小龍吊飾及儲錢筒，每一隻都用上他們最喜愛的顏色配搭。



◆ **Fluid Art Workshop**

The children showcased their creativity by making unique fluid art dragon key chains and money boxes, using their favourite colour combinations.

◆ **荷花幼兒成長展覽攤檔**

基金會參與了為期三天的「荷花幼兒成長展覽」，一眾義工積極向公眾介紹基金會的工作。



◆ **Toddler Growth Exhibition**

The Foundation participated in a 3-day toddler growth exhibition. The volunteers actively promoted the Foundation's work to the public.

◆ **「心活希望」慈善市集**

以「心活希望」為主題乃基金會三十週年的首個活動，象徵著為孩子們帶來希望。市集充滿熱鬧與歡樂，除了準備了多個有趣的工作坊，還邀請了各式各樣的表演團體，市集上的產品全都是精心製作並且十分多元化。

特別鳴謝：

利東街及如新善的力量基金會香港分會及利東街全力支持是次活動



◆ **Living Heart of Hope Easter Charity Market**

This event marks the Foundation's first activity for its 30th anniversary, themed "Living Heart of Hope," symbolizing bringing hope to children. The market was filled with excitement and joy, offering various engaging workshops and performances by different groups. The products at the market are diverse and meticulously crafted.

**Special Acknowledgement:** Special thanks to Force For Good Nu Shin Hong Kong Chapter and Lee Tung Avenue for supporting the event.



◆ **基金會X Picasso Creative Arts Gallery: 吉祥物設計畫班**

在兩位專業導師帶領下，一班心童充滿創意和熱情地製作吉祥物。導師不但分享了吉祥物設計的技巧、理念和靈感源頭，同時，也與心童一起探索吉祥物的創作過程。大家用不同的方式詮釋吉祥物的形象，見證了各人的驚人設計才華和創作能力。



◆ **CHF X Picasso Creative Arts Gallery: Mascot Design Drawing Class**

The professional mentors shared techniques, concepts, and sources of inspiration for mascot design, and together with a group of children with congenital heart disease, they explored the creative process of designing a mascot. Everyone interpreted the mascot image in different ways, witnessing each other's astonishing design talent and creative abilities.



活動 · 預告 Upcoming Events

◆ **三十週年吉祥物設計比賽**

作為「兒童心臟基金會三十週年」的其中一項活動，我們希望透過心童的創意展現對其他路人的支持。這個吉祥物亦有機會成為基金會三十週年的象徵，並在各種活動和宣傳中使用。

詳情請參閱：

<http://www.childheart.org.hk/TR/EventsPage.asp?EID=180&EType=RightContent>

◆ **30th Anniversary Mascot Design Competition**

As part of the "30th Anniversary of the Children's Heart Foundation" event, we hope to showcase the creative talents of children and express their support for other children who are suffering from congenital heart disease. This mascot also has the opportunity to become a symbol of the Foundation's 30th anniversary and be used in various activities and promotions.

For more detail, please refer to the website below:

<http://www.childheart.org.hk/en/eventspage.asp?eid=180&etype=rightcontent>

◆ **基金會X羅氏香港: 健康飲食煮藝班**

今次烹飪班準備了全新的健康菜式，讓一眾心童連同義工學習製作「鳳梨大蝦芝士薄餅」，一齊享受烹飪的樂趣。

◆ **CHF X Roche Hong Kong: Healthy Food Cooking Class**

In this cooking class, a brand new healthy recipe has been prepared for the members' and volunteers to learn and enjoy together. They will be making a "Pineapple and Shrimp Stuffed Crust Pizza," exploring the joy of cooking.

\* 稍後將會有更多不同的暑期活動，記得密切留意基金會會員資訊群。如有任何查詢，歡迎聯絡基金會職員。

Stay tuned for more summer activities and make sure to keep an eye on the Foundation's member information group for updates. If you have any inquiries, please feel free to reach out to the Foundation's staff members.



## 治療上的新進展

# 肺動脈瓣倒流患者的新希望

### THE INTRODUCTION OF TRANSCUTANEOUS PULMONARY VALVE REPLACEMENT (TPVR) WITH SELF-EXPANDABLE VALVES

文章 陳義舜醫生 (香港兒童醫院兒童及青少年科 (心臟科中心) 顧問醫生)

DR ROBIN HAY-SUN CHEN (CONSULTANT, CARDIOLOGY CENTRE, DEPARTMENT OF PAEDIATRICS AND ADOLESCENT MEDICINE, HONG KONG CHILDREN'S HOSPITAL)

阮嘉駿醫生 (瑪麗醫院心臟科副顧問醫生)

DR UN, KA-CHUN TIMOTHY (ASSOCIATE CONSULTANT, DIVISION OF CARDIOLOGY, DEPARTMENT OF MEDICINE, QUEEN MARY HOSPITAL)

在先天性心臟病患者中，右心室流出道功能異常是常見的問題，在對於曾接受法洛氏四聯症修補手術後的病人尤其普遍。手術一般於幼兒時期進行，隨後肺動脈瓣會長期處於倒流狀態，該情況會隨時間漸趨嚴重，當患者進入青少年或年輕人階段，便需要作出治療。傳統上，儘管存在一定的風險，再度開胸及肺動脈瓣置換一直是主要的治療方案。

作為先天性心臟介入治療專家，我很高興今天能夠分享這類疾病治療上的新進展：在香港引入了自我擴張瓣膜的經皮肺動脈瓣置換 (TPVR)。自從引入了這項微創技術，它已經徹底改變了這種病患的治療選擇，為患者提供了一個除了開胸手術以外可行的替代方案。這個技術期望能減少患者要進行開胸手術的次數，並減少再度開胸手術相關的風險及能縮短復原時間。

Dysfunctional right ventricular outflow tract is a prevalent issue in the congenital heart community, particularly in individuals who have undergone repair for congenital heart diseases like tetralogy of Fallot. Long-term complications arising from pulmonary regurgitation, where the valve guarding the arteries to the lungs is leaky or absent, often affect adolescents and young adults. Traditionally, open-heart surgery and valve replacement have been the go-to management options, despite their associated risks.

As a congenital interventional cardiologist, I am excited to share a significant development in the management of this condition: the introduction of transcatheter pulmonary valve replacement (TPVR) with self-expandable valves, available right here in Hong Kong. This technique has revolutionized the management of the condition and offers patients a viable alternative that potentially improves their long-term care by reducing the need for multiple open-heart surgeries throughout their lifetime.

一直以來有幸獲得兒童心臟基金會的慷慨支持，自 2023 年 12 月以來，我們已經能夠向患者提供這一類突破性的替代治療選擇。TPVR 手術包括在肺動脈內放置一個新的瓣膜，而無需進行開胸心臟手術。這些瓣膜是被縫製到一個能夠自我擴張的鍍鈦合金記憶金屬支架上，可通過在腹股溝或頸部靜脈的導管傳送裝置運送到心臟。當 X 光下定位正確，瓣膜就會被釋放出來，並自我擴張至原來的大小，完全替代原有失去功能的瓣膜。

TPVR 有各種優點：患者在手術後明顯感到更少的傷口痛楚，並能縮短術後復原時間，他們通常能夠比傳統開胸手術更快地恢復日常活動。此外，較低侵入性的 TPVR 手術亦減少了與開胸手術相關的風險，包括傷口感染、出血、使用人工心肺機以及較長麻醉時間相關的併發症。

對於我們的年輕患者及其家人而言，TPVR 不僅代表著醫學上的進步，也為他們帶來新希望。這一個選項能夠縮短住院時間，減少對學業或工作的影響，並能更快地返回正常的生活。

我們的團隊在兒童心臟基金會的支持下，致力確保能繼續提供這種創新的治療方法給有需要的病患者。我們堅信，每一個患者都應該可以擁有健康的心臟功能以及能夠過著正常的生活。

我們衷心感謝兒童心臟基金會一直以來的贊助，能將這項改變生活的技術帶給先天性心臟病患者。我們呼籲各位繼續邀請親朋好友，攜手支持基金會的工作。每一分鼓勵都至為重要，對患者術後的生活產生了關鍵的改善，並為患有肺動脈瓣倒流的患者帶來治療的新希望。

Thanks to the generous support from the Children's Heart Foundation, we have been able to offer this ground-breaking alternative to our patients since December 2023. The TPVR procedure involves placing a new valve in the heart without resorting to open-heart surgery. Instead, these valves, being sewed onto a self-expandable nitinol stent (a form of memory metal), are collapsible and can be delivered to the heart through a delivery device inserted via veins either in the groin or neck. Once correctly positioned, the valve is being released and conforms to its original configuration with a fully functional valve in place.

The benefits of TPVR are substantial. Patients experience significantly less discomfort and enjoy a quicker recovery after the procedure. They can often resume their daily activities sooner compared to traditional surgery. Furthermore, the less invasive nature of the procedure reduces the risks associated with open-heart surgeries, including infections and complications from extended anesthesia exposure.

For our young patients and their families, TPVR represents not just a medical advancement but also a beacon of hope. It offers the prospect of shorter hospital stays, less time away from school or work, and a faster return to normal life.

Our team, supported by the Children's Heart Foundation, is dedicated to ensuring that this innovative treatment remains accessible to those in need. We firmly believe that every patient deserves a healthy heart and the freedom to live life to the fullest.

We extend our heartfelt gratitude for your continued support, which has played a crucial role in bringing this life-changing technology to our community. Together, we are making a tangible difference in the lives of our patients.



## 「來回地獄又折返人間」的三月

A TOUGH JOURNEY IN MARCH

文章 露露媽媽 EUNICE'S MOTHER



過去我們一家經歷了「來回地獄又折返人間」的三月……

女兒突然在家暈倒，入院後醫生建議盡快接受手術安裝植入式去顫器 (ICD)，一切都是難以接受。當下聽到醫生建議，一家人心中都出現了無數的擔憂、疑慮、徬徨無助。

經歷了幾天的沉澱後，女兒和我們都靜靜接受了，接着便疲於奔命去了解不同廠商的去顫器及了解如何申請資助。過程中感恩我們遇上了「兒童心臟基金會」，透過基金會安排，讓我們認識了同路人，不但幫助女兒了解手術後有機會遇上的情況，更溫馨地提示她很多手術後要注意的事情。而且基金會亦在我們急切的情況下，於手術前兩天成功為我們安排了資助。

回首「寒天飲雪水，點滴在心頭」，基金會中各人的關懷的確是雪中送炭。如沒有遇上基金會，女兒或許不會知道手術後如何減輕痛楚；如何令傷口癒合得更好……感謝你們的幫忙！

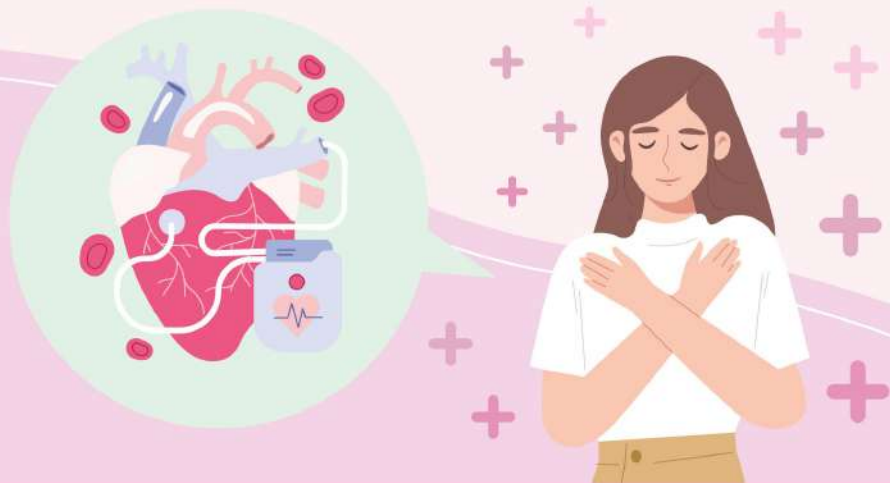


In the past, our family experienced a "tough journey" in March...

Our daughter suddenly collapsed at home. Upon admission to the hospital, the doctor recommended that she proceed the implantation surgery of an Implantable Cardioverter-Defibrillator (ICD) as soon as possible. It was really difficult to accept the sudden. Upon hearing the doctor's advice, countless worries, doubts and feelings of helplessness arose within our family.

After a few days of reflection, our daughter and we silently accepted the situation. We then rushed around, exhausted, to understand different manufacturers of Defibrillators and how to apply for financial assistance. Throughout the process, we were grateful to know the "Children's Heart Foundation". With the Foundation's assistance, we met a few fellow members who not only helped our daughter understand the potential situations she might encounter after the surgery, but also kindly reminded her of many things to pay attention to during the recovery stage. Moreover, the Foundation successfully arranged the financial assistance for us two days before the surgery in view of our emergency needs.

Looking back, the care shown by everybody within the Foundation was indeed a great help during our difficult times. Without acquainted with the Foundation, our daughter might not have known how to alleviate the pain after the surgery and how to promote better wound healing. Your assistance is highly appreciated!



## 捐款·表格 Donation Form

### 捐款表格 Donation Form



#### 我的支持 My Support

本人願意 I wish to  每月定期捐助 Donate on a monthly basis  一次性捐助 make a one-off donation of  
 HK\$100  HK\$300  HK\$500  HK\$1000  Others: HK\$\_\_\_\_\_

#### 捐款者資料 Donor's Information

姓名 Name: \_\_\_\_\_ (Mr./Mrs./Ms.)  
 機構 Corporate: \_\_\_\_\_  
 地址 Address: \_\_\_\_\_  
 電話 Tel: \_\_\_\_\_ 電郵 Email: \_\_\_\_\_

需要發出捐款收據 (適用於捐款 HK\$100 或以上) Donation receipt is required (For donations of HK\$100 or above.)  
 若收據抬頭與捐款者不同，請註明 Please state if receipt title is different with donor:

#### 捐款方法 Donation Method

- PAYME  
 請開啓PAYME手機應用程式，掃描以下二維碼進行捐款，並於訊息欄輸入參考資料  
 (例子: **Donation, Chan Tai Man, Tel: 25530331**)，以供識別。  
 Please scan the below QR Code through your mobile PAYME app.  
 Input a message remarks (e.g: **Donation, Chan Tai Man, Tel: 2553 - 0331**). 
- 以劃線支票捐款，抬頭請寫「兒童心臟基金會」。By a crossed cheque made payable to "Children's Heart Foundation".  
 支票號碼 Cheque No.: \_\_\_\_\_
- 直接存款 / 透過銀通或自動櫃員機轉帳至渣打銀行 (香港) 有限公司「兒童心臟基金會」之銀行戶口。  
 Direct deposit / through "Jetco" or "ATM" transfer to CHF bank account at Standard Chartered Bank (HK)  
 帳戶號碼 Account no.: **447-1-034943-5**
- 轉數快 Faster Payment System (FPS)  
 請開啓銀行機構的手機應用程式，輸入快速支付系統識別碼 (FPS ID) : **160893608**。  
 轉賬至: **CHILDREN'S HEART FOUNDATION**，並於訊息欄輸入參考資料  
 (例子: **Donation, Chan Tai Man, Tel: 25530331**)，以供識別。  
 Please insert FPS registered ID: **160893608** through your mobile banking app.  
 Transfer to: **CHILDREN'S HEART FOUNDATION**. Input a message remarks (e.g: **Donation, Chan Tai Man, Tel: 2553 - 0331**).
- 銀行戶口每月自動轉賬 Bank account monthly autopay  
 請下載銀行戶口轉賬授權書。 <http://www.childheart.org.hk/TR/Doc/DDAF.PDF>  
 Please download the Bank Direct Debit Authorization Form.
- 到 7-Eleven 捐款 Make donation at 7-Eleven  
 只需攜同以下捐款二維碼到全港任何一間7-Eleven，以現金捐款便可 (每次捐款金額最少為港幣一百元)。  
 Present below donation QR Code to any 7-Eleven stores in HK when making a cash donation to CHF.  
 The minimum donation amount is HK\$100 per transaction. 
- 透過信用卡捐款 By Credit Card <http://www.childheart.org.hk/TR/ocdf.asp> 

請將表格連同每月自動轉賬表格 / 銀行入數紙 / 支票電郵、傳真或郵寄至兒童心臟基金會。  
 Please return this form together with monthly auto-pay authorization form / bank-in slip / cheque to the CHF by fax/email/post.

\* 兒童心臟基金會是根據《稅務條例》第88條獲豁免繳稅屬公共性質的慈善團體。捐款港幣一百元或以上可獲發收據。  
 若閣下需要捐款收據，請同時附上您的姓名、地址及聯絡電話。  
 Children's Heart Foundation is a charitable institution of a public character exempt from tax under Section 88 of the Inland Revenue Ordinance. Receipts will be issued for donations of HK\$100 or above.  
 If you need an official receipt, please send the crossed cheque along with your name, address and contact telephone number.

\* 基金會將按上述資料與閣下保持聯絡，定期介紹基金會活動和發收據之用。一切資料，絕對保密。  
 Data collected will be treated strictly confidential and will be used for issuing receipt and sending information on CHF's activities only.

請將表格連同每月自動轉賬表格，請將表格連同每月自動轉賬表格。