



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.

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(All content is written in both Chinese and English.)

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編者 .. 的話

兒童心臟基金會編輯小組

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人生總會遇到不同的困難，對於先天性心臟病童來說，他們一出生便需要面對改變一生的難關。有不少患者，可能一直都沒有發現自己的病況，原本平穩的生活，隨時因為突然其來的消息而掀起巨浪。

本期《心訊》記錄了港隊泳將在準備轉為全職運動員時才發現患有先天性心臟病的故事，以及他如何克服一切困難，重新踏上泳手之路。同時間，隨著疫情穩定，醫院服務亦重新回歸實體，基金會亦開展了新的醫療相關計劃。

跨越界限後重新啟航，盼所有心童都能乘著微風，像拍翼鳥般悠逸。

—— 公共傳訊事務委員會

Life is always difficult, and for the children with congenital heart disease, they are born with a life-long hurdle. Some of the patients may never find out about their condition and illnesses throughout their development period, their lives that had been so stable could be rocked by sudden diagnosis.

This issue included a story of a Hong Kong swimming representative who discovered his congenital heart condition when he was about to become a full-time athlete, and how he overcame all the obstacles to get back to the track.

At the same time, as the epidemic stabilised, the hospital services returned to the fold, an introduction of our services and new medical-related programme has been included.

We hope all the children can ride on the breeze and soaring high like a bird after crossing the boundary.

—— Publicity and Publications Sub-committee

港隊「飛魚」曾憂夢碎 破浪重生游出自我

RISING FROM THE WAVES: THE HONG KONG FLYING FISH'S JOURNEY OF REBIRTH



有人說：「夢想，應該是當你快要停止呼吸的時候，仍然覺得一定要做的事。」如果有一天，你一直堅持的夢想，與你的生命安全產生衝突，你又如何取捨？

突如其來的消息 體內的計時炸彈

港隊泳將何肇倫為100米自由泳、50米蝶泳香港青年紀錄及6項學界紀錄保持者，在學界有「霸王」的稱號。肇倫自幼稚園開始習泳，小學階段已每星期練水四天，身體一直沒有特別感到任何不適。「疫情時學校停課，泳池亦關閉，為了可以繼續練水，因此想申請轉為香港體育學院（體院）全職運動員，結果在做心臟超聲波檢查時才發現患有先天性心臟異常。」

「情況就好像體內有一個計時炸彈，做高強度運動時隨時會因為不夠血而有生命危險。」肇倫所患的是心臟冠狀動脈出口位置異常，血管較一般人幼，導至體內傳送血液的情況不理想。「當時都問過不少醫生，大部份醫生對我的情況都比較負面。」除了手術風險很大，醫生們亦表示肇倫有機會手術後的體能會比以往更差，但如果不做手術，肇倫就注定以後只能游「健康水」。「記得當時最直接的反應是和家人抱著哭了很久，事情好像一支炮彈突然打在我身上，十多年來的堅持一下子化為烏有。」幸好，後來體院給肇倫轉介了主診醫生，對方為他提供了四個手術的方案，並給予他很大的信心。起初，家人亦不贊成肇倫做手術，然而他們知道游泳除了是肇倫的夢想，亦是所有生活的重心。平衡一切因素後，加上學校和校友的手術資助，肇倫於2021年正式接受了開胸手術。



Someone once said, "Dreams should be something that you feel you must do even when you're about to stop breathing." If one day, pursuing your dream would conflict with your safety, how would you choose?

The Sudden News and A Time Bomb Inside His Body

Hong Kong swimming athlete Ho Siu Lun, Frank, who holds the title "Backstroke King", setting the Hong Kong youth record for the 100m freestyle and 50m butterfly events, as well as six records at the Hong Kong Schools Sports Federation (HKSSF). Frank started learning to swim in kindergarten and had been training four days a week since elementary school. He had never felt any discomfort until the school and swimming pool were closed due to the pandemic. In order to continue training, he applied to become a full-time athlete at the Hong Kong Sports Institute (HKSI). However, during a heart ultrasound, he discovered that he had a congenital heart abnormality.

"It's as if there's a time bomb inside my body, and I could be in danger of losing my life at any time when I do high-intensity exercise because of insufficient blood supply." Frank's condition is an abnormal location of the coronary artery outlet, and his blood vessels are thinner than average, leading to poor blood flow in his body. "At that time, I consulted many doctors, and most of them had a negative view of my situation." In addition to the high risk of surgery, doctors also said that Frank's physical fitness might be worse after surgery. But if he didn't undergo surgery, he would only be able to do leisurely swim in the future. "I remember I cried with my family for a long time immediately, it felt like a cannonball hit me suddenly, and my more than ten years of perseverance suddenly went in vain." Fortunately, the HKSI referred him to another doctor who provided him with four surgical plans and gave him great confidence. At first, Frank's family did not agree to the surgery, but they knew that swimming was not only his dream but also the focus of his life. After weighing all factors and with the surgical sponsorship from the school and alumni, Frank underwent an open-heart surgery in 2021.



漫長的康復路程 渴望追上進度

手術一覺睡去，肇倫醒來後迎來的除了是胸前多了一條長長的疤痕，還有漫長的復康過程。「做完手術後一直發燒，傷口亦好痛，加上身上插了很多喉管導至不能動彈，好幾天都沒法入睡。」出院後，肇倫初期依然需要食藥和定期覆診，以及重新學習呼吸。「有一個呼吸訓練儀器是需要我吹起三個波，以前我是十分輕鬆的，手術後初期，我只能勉強吹到一個波到一半。」醫生建議至少需1-2個月後才可以慢慢輕量運動，亦要避免上胸過多肌肉拉扯。「記得手術後第一次游泳是在酒店「宅渡假」，當時依然隱約感受到胸口輕微痛，雖然只能慢慢地游，但都已經很開心。」

隨著身體慢慢恢復，肇倫開始重回醫院練習，然而，不管在體能上，還是心理上亦承受著不少打擊。當隊友在密集性訓練時，他只能自己在旁邊慢慢游，教練亦不讓他操練太多。「自己都會心急，好想快點追上以往的水平，成日都問教練可否讓我嘗試衝下。」由一開始沒法游背泳和蝶泳，只能游自由式；由參加比賽成績未如理想，到後來重新游出個人最佳紀錄。歷時一年半，肇倫終於可以再次代表港隊出戰，踏上國際比賽舞台。

生命的印記 盼以正能量感染他人

談及手術後重新出戰的感受，肇倫坦然最大的分別是他人的目光。他憶述當時比賽於熱身池一除下外衣時，其他選手看到他的疤痕都不期然會驚訝，大家亦會很好奇他的經歷。畢竟游泳界比較少這樣的個案，即使遇到他的情況，可能也會選擇了放棄運動員生涯。「這個疤痕像是我生命的一個獎盃，印證著我成功打贏過一像硬仗。」肇倫亦言，這個患病經歷讓他有不同機會可以和其他人分享自己的故事，「社會上可能有很多人都有類似的問題，希望可以利用自己的經歷，以及運動員的身份，鼓勵到他們。」

乘風破浪 從游泳中得到動力

現時肇倫在加拿大升學，依然過著日復日不斷練習游泳及操練體能的運動員生活。事過兩年，肇倫坦然因為心肺功能不如前，至今仍然未能返回200米比賽戰場，但願隨著適當訓練，有天可以重回這個項目。「游泳是我生命的一切，成就了現在的自己。每當碰到氣餒的時候，想起曾經有可能失去游泳的時刻，就會有動力堅持下去。」

壓不碎的夢想，毫不畏懼去突破自我，破浪後依然敢於去劃屬於自己的領海。未來，肇倫依然視游泳為生命中最重要一環，展望可以繼續代表香港參加更多國際賽。



A Long Road to Recovery, A Desire to Catch up

After the surgery, Frank woke up with a long scar on his chest and a long recovery process. "I had a fever after the surgery, and the wound was very painful. I also had many tubes inserted into my body, so I couldn't move, and I couldn't sleep for several days." At the beginning after being discharged from the hospital, Frank still needed medication and regular follow-up visits, as well as relearning how to breathe. "There is a breathing training device that requires me to blow three waves. I used to find it very easy, but after the surgery, I could barely blow one balloon." The doctor recommended that he should not do any exercise for at least one to two months to prevent excessive stretches in the upper chest. "I remember the first time I swam after the surgery was during a staycation, I still felt a slight pain in the wound, and although I could only swim very slowly, I was already very happy."

As his body gradually recovered, he returned to training at the HKSI, but he experienced many setbacks both physically and mentally. While his teammates were training intensively, he could only slowly swim by himself, and the coach did not let him practice too much. "I was impatient and wanted to catch up with my previous level as soon as possible. I asked the coach if I could try to swim faster all the time." From not being able to swim backstroke and butterfly strokes, he could only swim freestyle, to reaching his personal best after participating in competitions with unsatisfactory results. After a year and a half, Frank finally represented Hong Kong in international competitions again in September 2022.

A Seal of Life: Spreading positive energy through experiences

Talking about his feelings of returning to the competition after the surgery, Frank said that the biggest difference was other people's gaze. He recalled that when he took off his jacket in the warm-up pool during the competition, other athletes were surprised to see his scar, and everyone was curious about his experience. After all, such case is rare in the world, and even if others encounter similar situation, they may choose to give up their athletic careers. "This scar is like a trophy of my life, proving that I have successfully won a tough battle." Frank also said that this experience of illness gave him the opportunity to share his story with others. "There may be many people in society who have similar problems. I hope to use my experience and my identity as an athlete to encourage them."

Riding the Waves: Motivations from swimming

Currently, Frank is studying in Canada and still lives the life of an athlete who practices swimming and fitness every day. Two years have passed, Frank frankly said that because his cardiopulmonary function is not as good as before, he has not been able to return to the 200-meter competition arena, but he hopes that with appropriate training, he can return to this event someday. "Swimming is everything in my life and has made me who I am now. Whenever I encounter frustration, I think of the moment when I could have lost swimming, and it gives me the motivation to persevere."

A dream that cannot be crushed, fearlessly breaking through oneself, and still daring to create one's own territory after breaking through the waves, in the future, Frank still regards swimming as the most important part of his life and looks forward to representing Hong Kong in more international competitions.

醫院探訪回歸實體 提供最適切服務

HOSPITAL VISITS BACK TO OFFLINE, PROVIDING THE MOST APPROPRIATE SERVICES

重新開展每星期的探訪服務

醫院往往是其中一個最常接觸到心童家庭的地方，在過去的兩三年，基於疫情的關係，醫院一般不容許家屬以外的探訪。儘管基金會仍然嘗試透過網上平台提供服務，希望將愛與關懷分享給心童家庭，但始終難以提供最適切的服務。

自2023年1月起，香港兒童醫院逐漸開放病房及門診探訪，目前只有機構職員可以進入範圍並提供有限度服務，以實體形式，如：病房探訪、舉辦發展性活動、以及在專科門診設立流動服務站，從而接觸心童家庭，了解他們的需要並提供支援。

為配合服務，基金會社工預備了各式各樣的遊戲和手工包，務求讓每星期的探訪服務都能夠陪伴住院心童和家長，在手術前後得到放鬆，以及抒緩照顧者的壓力。社工月亮姐表示：「網絡雖然帶來方便，亦可以有其效用，但以往只能透過屏幕看到心童及家長，有些亦會因為電子疲勞而未能接觸到，效果遠遠不及面對面來得直接。」

開放後，社工能夠在病床旁直接關心他們當下的情緒，觀察他們的需要，例如協助調較病床高度等，行動也來得更有溫度。有些以往只能在電話聯絡的心童家庭，社工亦可以在門診服務時相認了，感覺像過了重重難關後，彼此終於看到曙光般。

醫療監測僱借用計劃 紀錄心律輔助監察

基金會致力推動有關先天性心臟病的研究，透過資助手術器具、購置醫療設備，發展治療技術來支援心童。隨著科技進步，基金會近期開展了「隨心計劃」，為患有心律不正的病童提供僱用心電圖監測儀器服務，讓病童能在心博時紀錄心律，輔助監察。

隨著推動可隨身攜帶的輔助裝置，讓更多病人於日常生活中，能夠提升自我監察心臟的意識。

Hospital Visits Back to offline, Providing the Most Appropriate Services

Hospital wards is often one of the places where we can approach the families of children with congenital heart disease directly. In the past two or three years, due to the epidemic, outsiders are generally not allowed for wards visit. Although the Foundation still tries to provide online services to the families, it is still difficult to provide the most appropriate service to them.

Until January 2023, the Hong Kong Children's Hospital gradually opened up its wards and outpatient clinics for visit. At present, only the foundation's staff can enter and provide limited services, for example: wards visits, developmental activities and mobile service station at the specialist out-patient clinics to reach out the families.

In coordination with the service, the Foundation's social workers have prepared a variety of games and craft kits for the children and parents during our weekly visit. We wish it could relieve the stress before or after the operation. "Although the internet is convenient and can be useful, we could only see the children and parents through the screen. Some of them were not easy to be reached due to digital fatigue. Screen time is far less direct than face-to-face." said Andress, the social worker.

With the opening of our service, the social workers were able to spend time with the patients at the bedside and care their emotion as well as observe their needs directly, such as helping them to adjust the inclination of the bed back. Some of the families who could only contact each other by phone in the past were able to recognize each other in person during the out-patient service.

Medical Equipment Loan Scheme for monitoring the electrocardiogram

The Foundation is dedicated to promoting research on congenital heart disease, sponsoring and purchasing medical equipment. With the advancement of technology, the Foundation has recently launched the Medical Equipment Loan Scheme, which allow the patients to borrow the monitor, so that they can record their electrocardiogram daily.

With the promotion of portable monitoring devices, more patients are able to increase their awareness of self-monitoring of their heart in their daily lives.



NEWSLETTER



九月 SEPTEMBER

◆ 會員週年大會

會員週年大會順利舉行，由主席周啓東醫生匯報年報。

◆ Annual General Meeting

The Annual General Meeting was successfully held and Dr. Adolphus K.T.Chau, Chairman, reported the annual report.



活動贊助：滙業財經集團贊助「學術卓越獎」
Special Acknowledgement: Delta Asia
Financial Group sponsored this event.

◆ 「2021/2022學業獎勵計劃」頒獎禮

兒童心臟基金會於2007年開始舉辦「學業獎勵計劃」，鼓勵先天性心臟病兒童於學業上取得佳績。當日一眾得獎者齊集頒獎禮，並分享自己的讀書方法。

◆ Academic Award Scheme 2021/2022

The Children's Heart Foundation started the Academic Award Scheme in 2007 in order to encourage children with congenital heart disease to achieve academic excellence. The winners gathered at the award presentation ceremony and shared their own learning styles.

十月 OCTOBER

◆ 港島童軍第十旅 X 兒童心臟基金會：人在野

秋季來臨，一眾心童家庭參加了非一般的戶外活動，一同原野烹飪、一同跳營火舞、一同體驗野外生活。

◆ Scout Hong Kong Island Region 10th Hong Kong Group X CHF: Outdoor activity

With the arrival of autumn, our members participated in an unusual outdoor activity, such as cooking in the wilderness, campfire dancing and experiencing the outdoor life together.



十一月 NOVEMBER



◆ 2022 心連心慈善運動日

今年活動以小型運動會為主題，首次加入運動競技比賽，包括三人足球、地板冰壘及障礙跑賽事。活動同時加入不同運動體驗，更有攤位遊戲及充氣城堡等。活動元素豐富，當日超過六百人齊集，身體力行為心童籌款。

◆ Heart-to-Heart Charity Sports Day 2022

This year's event was themed as a mini-sports day, included three challenges: 3-person football match, floor curling and obstacle run. The event also included different sports experiences, booth games and an inflatable castle. Over 600 people gathered to raise funds for the Foundation.



十二月 DECEMBER

◆ 香港地質岩石保育協會 X 兒童心臟基金會：龍虎山生物多樣性

一眾心童家庭在香港地質岩石保育協會的義工帶領下，一同去行龍虎山。沿路除了可以欣賞到不同生物的生態，還一齊去了參觀龍虎山環境教育中心，親親大自然。

◆ Association for Geoconservation, Hong Kong X CHF: Biodiversity of Lung Fu Shan

Families went to Lung Fu Shan with volunteers from the Association for Geoconservation, Hong Kong. Along the way, they could appreciate the ecology of different creatures and also visited the Lung Fu Shan Environmental Education Centre to learn more about the nature.



◆ 聖誕聯歡會

一眾心童家庭一齊觀賞電影《Puss in Boots: The Last Wish》，在義工帶領下參與不同類型的工作坊、享受聖誕大餐、還有聖誕太太表演及派禮物等等，令心童們樂而忘返。

◆ Christmas Party

Families enjoyed watching the movie "無敵貓劍俠：8+1條命"，participating in various workshops led by volunteers, enjoying a Christmas lunch, watching Mrs. Santa Claus' performance and handing out gifts together.



遊出我心途 音樂的自療與治療

JOURNEY INTO YOUR HEART MUSIC AS SELF-HEALING AND THERAPY

| 文章 周穎賢 音樂治療師 NICOLE CHOW (MUSIC THERAPIST)

「發生緊急情況時氧氣面罩會自動脱落，如果您是與兒童相鄰而坐，先戴好自己的面罩，再幫兒童戴上面罩...」

這是我們耳熟能詳的飛行前廣播；其中的邏輯，放諸心理健康範疇上亦適用。要實踐這愛己及人的道理，卻殊不簡單；當中牽涉到自我覺察的修練。透過音樂，我們或能嘗試以一種較純粹和具創意的去探索這種由自愛到愛人的學習。

我也曾是孩子，也曾面對成長的困頓和身心靈的磨練。今天，我還好嗎？我有讓音樂成為我的鼓勵、我的資源嗎？當我說要去學習以某種方式來「治療」孩子，我有沒有先讓自己獲取被治療的經驗？我對自己此刻的狀態敏感嗎？

今天我們所談及的「音樂治療」，是指由第一、二次世界大戰後慢慢發展出來的一套有系統、有訓練框架、以臨床實踐為基礎的「音樂心理治療」；是一種十分個人化的介入，當中尤其看重治療師與治療對象的關係。然而，「以音樂作治療」卻一直存在於人類歷史中；不同文化的古醫學文獻均不乏以音樂帶來治療效果的記錄。

並非所有人也需要接受音樂治療，但我們往往能透過欣賞音樂、參與音樂活動或創作來調節自己的內在狀態。前提是，我洞悉自己的內在狀態嗎？我有聆聽身體的提示嗎？有時候身體的毛病或崩緊都是一些信號，呼喚我們多加留意自己的狀態。坐下來，靜靜聽一首我喜歡的歌（不一定是柔和的慢歌！），觀察我此刻的身體有哪些感覺；告訴自己：這刻，我在（慢慢呼吸）。

音樂加上皮膚的接觸，也可以是照顧者與孩子之間另一種愛的傳達。【**來做三文治**】是一首可以加入觸感手法的歌曲，讓家長和孩子透過音樂和肢體接觸加強連繫。在輕柔而實在的結連中，我運用對自己內在狀態的敏銳去感受孩子此刻的狀態；透過身體說：這刻，我在。



▶ VIDEO



在照顧孩子前，別忘記先為自己戴上氧氣面罩。
Before taking care of children, don't forget to put on your oxygen mask.

"When an emergency occurs, the oxygen mask will automatically drop down. If you are sitting next to a child, put on your mask first, then help the child with their mask..."

This is a familiar pre-flight announcement, and its logic can also be applied in the realm of mental health. Putting this principle of self-love and love for others into practice is not easy; it involves the cultivation of self-awareness. Through music, we may be able to explore this learning journey from self-love to love for others more purely and creatively.

I was once a child, and I faced the struggles of growing up and the challenges to my physical, mental, and emotional well-being too. Today, am I okay? Have I made music my source of encouragement and resource? When I say I want to learn to "heal" children in a certain way, have I first experienced being healed myself? Am I sensitive to my current state?

Today, we are discussing "music therapy", a systematic, trained and clinically tested "music psychotherapy" developed gradually after World War I and II. It is a highly personalized intervention that emphasizes the relationship between therapist and client. However, "using music as therapy" has always existed. Ancient medical literature from different cultures is full of records of the therapeutic effects of music.

Not everyone needs to undergo music therapy, but we can often regulate our inner state by listening to music, participating in activities, or creating music. The premise is, do I have insight into my inner state? Do I listen to the signals from my body? Sometimes, physical discomfort or tension is a signal that calls on us to pay more attention to our state. Sit down, listen quietly to a song I like (not necessarily a soft, slow song), and observe the sensations in my body at the moment; tell myself: at this moment, I am (taking slow breaths).

Music, combined with touch, can also be another way for caregivers and children to express love. "Let's Make a Sandwich" is a song that incorporates tactile techniques, allowing parents and children to strengthen their connection through music and physical contact. In the gentle and practical connection, I use my sensitivity to my inner state to feel the child's current state; through my body, I say: at this moment, I am.



家長如何協助心童戒掉偏食癮？

HOW CAN PARENTS HELP CHILDREN WITH CONGENITAL HEART DISEASE (CHD) QUIT DIETARY BIAS?

| 文章 張卓軒 註冊營養師 MR. ANTHONY CHEUNG (REGISTERED DIETITIAN)



你知道先天性心臟病童偏食的原因嗎？

不少兒童在成長發展階段，都希望自己能夠自主，加上對食物的陌生，例如相幼、軟硬度、味道都較敏感，很多時都比較難接受陌生的食物。而先天性心臟病兒童在進食時所出現的身體狀況，亦會為他們帶來不適感而導致偏食，例如以下情況：

- 由於心臟跳得比一般人快，因此需要攝取更多才能供給身體所需，身體的代謝也比一般人還要快，但心臟的缺陷卻會帶給身體壓力，令心臟病童會更容易感覺疲憊。
- 進食緩慢
- 出汗增加
- 開胸時氣促或呼吸困難
- 容易嘔吐

家長如何協助心童戒掉偏食癮？

- 餐前**
 - 正餐前2小時不要讓孩子吃零食
 - 安排10分鐘時間，讓孩子從其他活動中收拾心情預備進餐

- 準備食物時**
 - 讓孩子有選擇，包括孩子喜歡或不抗拒的食物和一些新食物
 - 邀請孩子參與準備食物的過程，如洗蕃茄和擺放餐具
 - 顏色鮮艷的菜式和形狀小巧的食物均能引起孩子對食物的興趣
 - 改變煮食的方法使食物弄成容易接受的質感
 - 如孩子不吃焗蛋，可嘗試蒸水蛋或煎蛋
 - 如不喜歡焗軟的菜，可嘗試剪碎的炒菜

- 進餐時**
 - 在輕鬆的環境下進餐，避免分心的物件如電視或玩具
 - 先給孩子分較少量食物，之後再加添
 - 以不同感官去認識食物，如摸、嗅、舔或品嚐

- 親子溝通**
 - 讚賞做得好的地方
 - 切勿以甜品或零食為獎勵哄他多吃
 - 孩子拒吃時切勿批評、責罵
 - 孩子一般會在15-20分鐘內吃飽；當限時過了，便收起食物和餐具，不加入任何批評

兒童接受新食物需時，很多時可能需要重複多達10-15次。要改善孩子的偏食行為，家長必須有耐心！

你了解高熱量高蛋白飲食方法嗎？

這是一種可提供比一般飲食所含蛋白質及熱量為高的飲食，目的就是為了提供足夠熱量和蛋白質，以因應特殊生理或疾病需要或是要預防疾病所造成的體重減輕及組織耗損，使其恢復至正常的營養狀態。

- 飲品/甜品：高熱量營養奶粉配方、乳酪、布丁、燉蛋
- 三文治：花生醬、果醬、沙律醬、芝士、牛油果、雞蛋、三文魚、吞拿魚
- 主食：雞肉、牛肉、豬肉、碎肉、蔬菜、豆腐、肉鬆、果仁及種子類、紅豆、扁豆、豆腐類製品

Do you know the reason behind dietary bias among children with CHD?

During development, many kids would like to make decision by themselves. Due to CHD, children are very sensitive towards the texture of the food, such as its thickness, hardness, and taste etc. This makes it more difficult for them to accept unfamiliar food. Furthermore, the body condition during eating brings discomfort to children, for instance:

- Children with CHD have a higher heart rate and metabolic rate, so they need to intake more energy for body mechanisms. However, defects in the heart bring stress to the body and make CHD kids more prone to tiredness.
- Children with CHD eat slowly
- While eating, they may experience shortness of breath or difficulties in breathing
- Increased sweating
- Easier to vomit

How can parents help children with congenital heart disease (CHD) quit dietary bias?

- Before meal**
 - Do not allow kids to eat snacks 2 hours before meal
 - Reserve 10 minutes for kids to calm their mind after other activities and be ready for the meal

- Preparing meal**
 - Allow kids to choose the types of food, including those they like, dislike and new kinds of food
 - Invite kids to participate in the process of making food, such as washing tomatoes or setting the tableware
 - Try to cook dishes with different colours and use food of tiny shape, which can arouse kids' interest to the food
 - Change the cooking method to make the texture of the food more acceptable to kids
 - If kids do not eat boiled eggs, try steamed eggs or fried eggs
 - If kids do not like boiled soft vegetables, try chopped stir-fried vegetables

- During meal**
 - Eat in a relaxing environment, avoid distraction such as television or toys
 - Give small amount of food first, add more afterwards
 - Use different senses to know more about the food, such as touching, smelling, or tasting

- Parent-child communication**
 - Appreciate the things that kids did well
 - Do not use dessert or snacks as reward to encourage kids to eat more
 - Do not criticize or condemn kids when they do not eat the food
 - Normally kids will be full within 15-20 minutes; after that, take away the food and tableware without any criticism

It takes much time for kids to accept new food, and it often takes as many as 10-15 times to accomplish that. To alleviate the problem of dietary bias, parents need to be patient.

Do you know any diets with high calories and high protein content?

Below provides a diet with higher calories and protein content compared with normal diets. This is for suiting special physical or disease needs, or prevent weight loss and tissue wearing problems caused by diseases, eventually restoring a normal nutritional status.

- Drink/ Dessert: high-calorie nutritional milk formula; yoghurt, pudding, stew egg
- Sandwich: peanut butter, jam, salad dressings; cheese, avocado; egg; salmon, tuna fish
- Main dish: chicken, beef, pork; minced meat, vegetables, tofu, meat floss; nuts and seeds; red beans, lentils; tofu products



積極面對挑戰 心童家庭的心聲

FACING CHALLENGES OPTIMISTICALLY, HEARTFELT VOICE FROM CHD FAMILY

文章 陳樂琛 AUTHOR LEONIS CHAN

大家好！我叫陳樂琛，今年十一歲。我出生時患有先天性心臟間隔缺損症（VSD）。這是甚麼？簡單來說就是心臟裡有一個洞。媽媽告訴我，當她知道這個消息後，馬上像「世界末日」一樣，因為她擔心我日後的成長。很感恩，我的身體並沒有太大影響，還成長得很好，亦不需要動手術。我還可以上體育課，所以在我一年級時就參加了花式跳繩課外活動課，我好厲害，可以完成三小時的訓練也不累，我也試過代表學校參加跳繩比賽，還拿了幾個獎。

因此，我在這裡鼓勵其他心童也不要因為患病而放棄囉！要積極面對挑戰，珍惜生命。

Hello! I am Leonis Chan, I am now 11 years old, I had ventricular septal defect (VSD) when I was born. In simple terms, there was a hole in my heart. My mum told me that when she knew this, it was like the doomsday to her. Mum was terribly worried about my future development with this disease. Gratefully, this disease did not cause much harm to my body. I grew up very well and did not even need to perform surgery. I could even attend PE lessons too. When I was studying primary one, I joined rope skipping as one of the extracurricular activities. Even undergoing 3 hours of practice, I was not tired at all. I also represented my school in rope skipping competitions and got several awards.

Therefore, I am here to encourage all other CHD kids: Please don't give up! Let's face our challenges optimistically, and cherish our life!



媽媽心聲：

經歷懷胎十月，由充滿期待去到生產的一日，突然被告知兒子患有先天性心臟病。對於這個病不太認識的我，當然只覺得好嚴重，不停想日後孩子要面對的，到底是一條怎樣的出路呢？

當時我不停上網查有關這個病的資料，但是愈看只會愈擔心。後來爸爸加入了「兒童心臟基金會」，我們從中了解到一些正面和正確知識，於是就立下決心，提醒自己不要想太多，只記著醫生說的話：「有不少心童日後都可以正常過活，心漏的部分亦有機會隨成長而慢慢癒合的。」之後的日子，除了每年定期覆診外，我們都沒有太在意兒子這個病。真的很慶幸，在他4歲那年，再做心臟超聲波時發現心漏的部分已經自然癒合了！

現在樂琛已經將近11歲，他有自己喜歡的興趣，亦能夠保持不錯的學業成績，看到他健康成長，已是我最高興的事。

Mum's voice:

Going through 10 months of pregnancy, till the day of giving birth, I was suddenly told that my son had CHD. Not knowing much about this disease, I thought it was a very severe condition. I could not stop thinking what my child needed to face in his future path.

I searched much information about CHD on the Internet, but the more I searched, the more worried I was. After Dad joined Children's Heart Foundation, we finally learnt some positive and reliable knowledge about CHD. I started to remind myself not to overthink, just remember what the doctor has said, "Many CHD kids can live normally, it is also possible that the heart leakage part can heal during child growth." Since then, besides regular annual clinical visits, we were not excessively concerned about this disease. Fortunately, when Leonis was 4 years old, cardiovascular ultrasound imaging showed that the heart leakage part healed naturally!

Now, Leonis is nearly 11 years old. He develops his own interest and can even attain a good academic result. It is always my greatest pleasure to see him grow healthily.



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 Direct deposit / through "Jetco" or "ATM" transfer to CHF bank account at Standard Chartered Bank (HK)
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