



關於我們ABOUTUS

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、費助手術器具、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; counseilling, liaising with averseas surgeons; provides professional psychological counseilling and therapies; and organizing regular educational and developmental and supporting programmes.



回郵地址

兒童心臟基金會 Children's Heart Foundation

服務中心 Service Centre

九龍灣臨樂街19號南豐商業中心821室

Room 821, Nan Fung Commercial Centre, 19 Lam Lok Street, Kowloon Bay



服務中心:九龍灣鹽樂街19號南豐商業中心821室 Service Centre: Room 821, Nan Fung Commercial Centre, 19 Lam Lok Street, Kowloon Bay



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NEWSLETTER

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Voices Of The Children with CHD

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(所有内容皆為中英對照。)

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

FDITOR'S NOTE 編者…的話

兒童心臟基金會繼輯小組

蓄键德醫牛、梁敬成先牛。 盧宇軒先生、葉明慧女士

鄭凱欣、Emma Fitzgerald、羅鎂華 李婉文、Sylvie Loparoi、潘詠琳、 譚嘉茂、譚敏瑤、崔婧怡、陳俊祺、 單字顧、黃樂恒

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因為生命有限時,所以才更渴望無限放大夢想;相信堅持,必定能夠成就一個個的小故事。

15/

每一個小孩都有權利去爭取屬於他們的夢想,先天性心臟病童亦不例外。心童常在保護傘下成 長,外界亦很不自覺地為他們的能力作出標籤。然而,他們有著很多心願,期望有天能夠踏出 舒適區,展栩上騰。

今期《心訊》以〈夢想飛翔〉為題,記載了面對不同困難的心童和家長,如何在逆風中前行, 勇敢面對人生的故事。同時,《心董有話兒》以全新形式出版,歡迎心童或家長透過投稿,和 其他會員分享日常生活及心路歷程,一起在成長路上互相扶持。

—— 公共傳訊事務委員會

Life is limited, but we are eager to pursue our dreams infinitely. Perseverance can definitely lead to a small legend.

Every child has the right to fight for their dreams, even the children with congenital heart disease. They often grow up under a protective shield, and it is common for the outside world to put labels on their abilities. However, for them, there are many things they want to accomplish and hope that one day they can step out of their comfort zone.

The theme of this issue is "Soaring Against the Wind", which covers few stories about how children and parents face different difficulties, and how they are bravely facing them. At the same time, "Voices Of The Children with CHD" will be published in a new way, children and parents are welcome to submit their daily stories and experiences to share with other members.

---- Publicity and Publications Sub-committee

專題 ·· 故事 Feature Story

逆風飛翔日誌

A JOURNAL OF SOARING AGAINST THE WIND

「老鷹媽媽教小鷹學習飛翔,但小鷹很害怕,總是在 原地撲騰幾下翅膀。老鷹媽媽看到了,直接把小鷹 趕到巢外·跌落懸崖。小鷹驚恐極了,眼看著要撞 到岩石上,本能的開始張開翅膀,奮力的拍打著。 就這樣拍著翅膀,慢慢的有了自己的感覺,從停止 下落到慢慢翱翔-----1

Janice在一個月大時,已確診先天性心臟病。由於只有單 心室可以正常運作,以及出現大動脈與肺動脈異位的情況, 因此她較一般人容易缺氧、氣喘,其心肺功能及抵抗力亦較 弱。儘管經歷多次開胸手術、身體狀況並沒有限制了 Janice的夢想,她決心遠赴台灣升學。「心童不能永遠在 温室内成長,我們終要學習獨立,走出屬於自己的路。」數 年來, Janice也在外地經歷週不少起伏, 跌碰過, 再慢慢 摸索自己的方向

'Mother Eagle teaches Baby Eagle to fly. Baby Eagle is very scared; she always flaps her wings simultaneously. Mother Eagle sees it and drives her away from the nest. Baby Eagle falls off from a cliff. She is very afraid, seeing the rocks are right in front of him. She instinctively opens her wings and flaps as hard as she can. She starts to flap her wings and slowly gets her feelings. From stopping falling, to slowly soaring...."

When Janice was one month old, she was diagnosed with Congenital Heart Disease. Due to only one of her two ventricles being able to function normally and the transposition of her great arteries and pulmonary arteries, she is more susceptible to hypoxia and asthma. Her cardiopulmonary function and immunity are also weaker than ordinary people. Even though she has undergone multiple thoracotomies, it did not restrict her dream - to study in Taiwan. 'Kids with heart disease cannot stay in the comfort zone forever. We need to be independent and find our ways.", Janice said. In these few years, Janice has experienced different ups and downs. When she falls, she stands up again





專題 · · 故事 Feature Story

堅定的決心

於就讀中二時及完成第三次手術後,Janice情況漸趨穩定, 只需要每天吃藥和定時覆診。於高中時的一次校內升學講 座,成為改變Janice人生的轉捩點。「我聽完講座後就產生 了想到外地讀書的想法,原因是很想嘗試雕閒家人生活,訓 練自己獨立。」由於台灣與香港距離不遠,加上當時身體狀 況十分穩定,所以Janice認為自己足以應付到外地升學。

當然,這只是Janice個人想法,其父母並不支持。「父母最初是完全不支持的,一方面很要應我的身體能否應付,另一方面亦擔心我自己能否獨立處理日常生活的大小事務。」由申請到放榜,足足經過了一整年的時間。「得知取錄的那刻,我高興得在家中尖叫,但當時父母仍是不支持的。」及後,父親決定踏出第一步,主動去嘗試了解Janice所讀科目,以及在台灣升學的資訊。「爸爸衡量過後都放心了一點,認為應該放手讓我去嘗試,當時媽媽卻依然希望我可以留港讀書,我們選因此冷戰了。」平靜過後,兩母女坐下互訴心聲,最後媽媽亦答應了。「她不想因為過度的保護,剝奪了我想去過零夢想的權利。」

一個人在途上

「很慶幸的是,當時主診醫生向我提供了一些台灣成人先天性心臟病科醫生的資料,省卻了不少搜集資料的時間。」由初次自行去掛號登記,一直到熟習當地雙診模式,Janice都在學習自行處理。到埗半年,Janice便遇到身體不適,其中一次於無預兆下暈倒入院,幸好最後發現只是普通低血壓及中暑。「當時媽媽要立即「飛」過來,我跟她說:『放心,只是小事。假如你過來,於到達時我可能已經出院了。」這次對話令她相信自己會自己處理到。」

好景不常,於就讀大學三年級、回港接受恆常心導管檢查 時,醫生發現我接受第三次手術的血管出現狹窄,需要排期 再次接受開胸手術。在等待做手術期間,Janice再來在台灣





Janice's Determination

After her third surgery in Form 2, Janice's condition has stabilized and she only requires daily medication and regular check-ups. In her senior secondary year, a life planning seminar at school was the turning point that changed her life. The seminar brought me the idea that I shall study overseas. I wanted to experience a life without my family, and to train myself to be independent.", Janice said. Since Taiwan is not far from Hong Kong, and with her stable health condition, she believed that she could give it a try.

Of course, this was only thought of Janice. Her parents disagreed with that, 'My parents opposed to this plan. They were worried about my physical condition. Also, they were afraid that I could not handle my daily life.", Janice said. The journey was long, from school applications to getting a result. It took about a year. 'When I knew the school accepted me, I was so excited that I shouted at homel But it still did not change my parents' minds.' Later on, Janice's father started to know more about Janice's school subject and more information about studying in Taiwan, "My dad started to change his mind. He thought it would be a good chance to let me go and try by myself. But my mum still wanted me to stay in Hong Kong. We had a cold war because of that.' After calming ourselves down, Janice and her mother shared their worries and thoughts. Eventually, Janice's mother said "Yes". 'She did not want to over-protect me and restrict my opportunity of chasing my dream.", Janice said.

Solitude On Her Way

"I am fortunate that my attending doctor gave me some information about the Adults' Congenital Cardiologists of Taiwan in advance. It saved my time on searching." From the first time to register at the hospital to be familiarised with the follow-up procedures; Janice learned to handle them all by herself. Just half a year after Janice's arrival, Janice felt unwell again. Once, she fainted without reason and was sent to the hospital. Forfunately, it was only hypotension and heatstroke. "My mother wanted to come to Taiwan immediately at that time. I fold her, "No worries, mum. By the time you arrive, I will be out of the hospital." I let her know that I can handle it by myself.", Janice said.

Unfortunately, when Janice had the routine cardiac catheterization in Year Three, the doctor discovered her blood vessel was narrowed. She needed to schedule another thoracotomy. When Janice was waiting for the subsequent surgery, she was sent to the hospital in Taiwan again. 'I felt a little parting and chest fightness that day. I visited the outpatient clinic, but my attending doctor was on leave that day. By that night, I felt

不適入院。「其實我當天已經感到有點氣喘和胸悶,原本正打算去掛門診,但剛好主診醫生當天休息,結果當晚就感受到心臟有一下刺痛,於是凌晨便入了急症室。」因著過去幾年的經驗,Janice學會冷靜處理,她更預先致電回港,告訴父母自己準備去看急症。「媽媽叫我到達醫院後,有消息再打給她,我相信過往的經歷,讓她不會再過份擔心。」

行動證明一切

手術後的Janice重回台灣繼繼學業,現在更開始在醫院進行 實習課程,距離「呼吸治療師」的夢想邁進一步。疫情下, Janice於接近一年沒法回港,然而她在台生活多年,早已習 慣了在當地覆診,因此並沒有太大影響。「以往在香港,媽 媽每次都會陪我到醫院覆診,現在去了台灣,她反而學會了 放手,我亦可以多點和醫生溝通,了解更多自己的病況。當 然,之後當我能夠回港覆診時,我猜她還是一樣會繼續要求 陪我去。」Janice笑說。

鉄碰過,經歷過,Janice認為一個人在外地必須好好照顧自己,了解自己的限制和情況,適到問題就立即求醫。「我相信要讓父母放心,最好的方法便是用行動證明,讓他們看到你的自理能力,他們便會日漸增加信心。」Janice亦會和室友分享自己的情況,提早讓他們有心理準備,亦教導他們當出現突發情況時,該如何處理。



逆風飛翔

温室長大的孩子,成長路上長期受到保護,所以對於很多事情都不敢主動嘗試。「父母的保護罩部份可能源於對我們的 愧疚,同時亦因為他們擔心和緊張我們的生命:但其實父母 總有一天會難開我們,他們沒可能陪伴我們一輩子,所以我 們總要學習獨立自處。」

「只要身體容許,我都會盡力去實踐想做的事。正因為成長中曾經歷的,反而造就我可以有更強大的內心。」Janice並認為心擊並不一定比一般人弱,相反,心童亦可以擁有屬於自己的路,勇敢地為夢想飛翔。



a fingling in my heart, so I went to the A&E.' With the experiences throughout the years, Janice learned to calm down. She called her parents and notified them that she would go to the hospital. 'My mother told me to call her if I have any news. I guess the previous experiences could let her be at ease a bit.'. Janice said.

Action Speaks Louder Than Words

After the surgery, Janice went back to Taiwan and continued her studies. She now has a placement at the hospital, one step closer to her dream of being a Respiratory Therapist. Due to the epidemic, Janice has not returned to Hong Kong for almost a year. As Janice has lived in Taiwan for several years, she regularly sees the doctor there. It was not a big problem for her. When I was in Hong Kong, my mother went to follow-up sessions with me every time. When I am in Taiwan, she learns how to let me go. I can communicate more with my doctor and know more about my situation. But I guess she still wants to go with me when I am back.' Janice laughed.

After experiencing falling in Taiwan, she thinks it is essential to take good care of herself by knowing her restrictions and situations. Once she feels unwell, she will go to the doctor immediately. 'I believe my actions is the best way to set my parents' mind at rest. By letting them see that we can look after ourselves, they will become more confident in us day by day.' Janice also shares her situation and ways to help her with her roommates, if she has an emergency condition, her roommates will not be too panicked and know how to help her.

Soaring Like An Eagle Against The Wind

The farmers always protect Flowers that grow in a greenhouse. Same as children who are always protected by others. It is hard for them to try and experience actively. The protection from our parents may be because of their sense of guilt to us, and they are worried about our lives. We have to know that they will leave us one day. They will not be able to accompany us forever, so we need to learn to be independent.". Janice said.

'As long as my body allows, I will try my best to achieve my goals and chase for my dreams. Maybe because of what I have experienced, it trains me to have a stronger heart and mind.' Janice does not think that children with heart disease are necessarily weaker than others, instead, they can all find their ways and soar bravely for their dreams.

◆ 會員週年大會 Annual General Meeting

會員週年大會順利舉行,由主席周啓東醫生代表匯報年度工作報告,並邀請會員共商會務

The Annual General Meeting was successfully held with the Chairman, Dr. Adolphus K.T.Chau, reporting on the annual report and inviting members to discuss the affairs of the Foundation.



◆「學業獎勵計劃」頒獎禮 Academic Award Scheme 2020/2021

雖然於疫情下未能舉行實體頒獎禮,但即使喝著屏幕,我們亦能感受到得獎心童的喜悦和努力。

Although the award presentation ceremony could not be held in person due to the epidemic, we could still feel the joy and efforts of the winners through the screen.



1. 莊韻婷 2. 江日葵 3. 張晉浩 4. 何志誠 5. 沈卓妍 6. 林進健 7. 林映希 8. 馮朗維 9. 曾康兒 10. 梁穎琛

小學組學術卓越獎:

1. 陳樂琛 2. 呂承康 3. 李泓浠

得獎名單如下(排名不分先後):

中學組學業進步獎:

中學組學術卓越獎:

1. 林瀬君 2. 丘子琦

特別鳴謝: 滙業財經集團贊助是次活動



Academic Excellence Award - Secondary Session : 1. You Tsz Kei 2. Lam Ho Kwan

The list of winners is as follows (in no particular order)

Academic Improvement Award-Primary Session:

1. Chong Wan Ting 2. Kong Yat Kwal 3. Cheung Chun Ho 4. Ho Ching Shing Derek 5. Shum Cheuk Yin 6. Lam Chun Kin

7. Lam Ying Hei 8. Fung Irwin 10. Leuna Wina Sum

9. Tsang Hong Yi

Academic Excellence Award - Primary Session : 1. Chan Lok Sum 2. Lui Shing Hong 3. Li Wang Hei Ethan

Academic Improvement Award - Secondary Session : 1. Cho Hei Tuna

Special Thanks: Delta Asia Financial Group sponsored this event

◆ 中秋活動 Mid-Autumn Festival Activity

月餅食得多,自己整又試過未?

Try to make your own mooncake with parents.



◆ 心連心慈善運動日

一衆蹇賓在導師及運動大使陳安立帶領下,完成運動環節,一起身體 力行去支持心童及提升對心臟健康的關注。

現場更有氣氛火熱的迷你慈善音樂會,表演者透過不同演唱去分享個



Heart-to-Heart Charity Sports Day

The guests were led by the instructor and the Star of the Sports Day, Mr. Brian Chan, to complete the exercise session and join in the physical effort to support children with congenital heart disease and raise awareness of heart health.

A mini charity concert was held in the venue, with performers sharing their personal stories and voices for the children with CHD through a variety of songs.



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◆ 活著便好 先天性心臟病童慈善相展

一趟與心童交織的生命之旅,相片像時光機一樣,可以留住生命的瞬間, 亦可以撫慰心靈。

 Charity Photo Exhibition -Living In The Moment – Journey Of The Children with Congenital Heart Disease

This is a life intertwined journey of the children with congenital heart disease. Photos are just like a time machine in which we can keep our memories of the past and soothe the soul.



■電影活動:《失靈腦朋友》

家長同小朋友一起在電影中,尋找自己於未來世界的朋友仔。

Movie Time 1.0: "Ron's Gone Wrong"

Parents and children found their own future buddy together during the movie time.



◆ 兒童醫院聖誕手工班 Christmas Activity in HKCH

一齊整屬於自己的聖誕老人禮物袋! Let's DIY the Santa gift bag of your own!



聖誕聯歡會

基金會為心童帶來冰上嘉年華,一起歡度聖誕!溜冰場有聖誕老人、 又有聖誕太太、更有不同的公主和卡通人物,一起參與。 聖誕太太和聖誕老人的表演及派禮物環節,更令心童們樂而忘返

Christmas Party

The CHF held an ice carnival for the children with CHD to celebrate Christmas together! There were Mr. and Mrs. Santa Claus, different princesses and cartoon characters on the

Mr. and Mrs. Santa Claus performed and handed out gifts to keep the children joyously



預告 Upcoming Events

作為心量家長,可能都會對心量成長發展有好多顧慮,我們將會舉辦一連串有關 心童成長的講座,邀請物理治療師、言語治療師及營養師等為大家講解照顧心重 上的小技巧,大家記得密切留意我們的社交平台,掌握最新的活動報名資訊!





As a parent of a child with a congenital heart disease, you may have many concerns about the development of your child. We will hold a series of seminars on child development, inviting the physiotherapists, speech therapists and dieficians to give you some tips on caring for your children. Remember to keep eyes on our social media platforms for the latest event registration information!

遊出我心途

與未發展語言的寶寶情感結連

JOURNEY INTO YOUR HEART CONNECTING EMOTIONALLY WITH YOUR CHILD NON-VERBALLY

文章 蕈類章(心理輔導員) AUTHOR MS. KAREN CHUM (COUNSELLOR)



初生寶寶由媽媽的肚子誕生到世上,對新世界有很多未知 和探索的地方。要幫助寶寶順利融入新環境,父母或照顧 者續當著重要的角色。父母除了滿足寶寶生理的需要,與 寶寶親子互動所建立的情感連結,會大大提升他們的安全 感,對他們日後的情緒發展與人際關係有很大益處。

1. 獨排

父母溫柔地觸碰寶寶的小手小腳與皮膚對他們身心的成長非常 重要。銀哺母乳固然可以讓寶寶和媽媽近距離接觸,未能進行 銀哺母乳的嬰兒都需要觸摸媽媽的肌膚,聆聽和感受媽媽心跳 及呼吸均有助穩定寶寶的情緒。

2. 情感回應

父母可用溫柔的語調、關懷的言語去反映寶寶的情緒和狀態。例如:寶寶開心時:「寶寶在微笑,(媽媽)見佢好開心!」 哭鬧時「寶寶有區舒服嘅地方・(媽媽)宜家嚟睇吓佢有咩需 要,係咪肚餓?還係覺得悶要陪伴呢?」

緊記每個實寶的成長與氣質都是獨一無二的,作為父母, 透過多觀察、關注與互動,就能夠更深了解實寶向你表達 的信息。

遊出我心涂計劃

以多元的手法,為患有先天性心臟病的兒童及家長,提供全面 的心理支援服務,如:遊戲或創意藝術活動,或家長心理輔 導,從而協助表達內在的情緒,提升他們的的家庭精神健康。 When a newborn baby is born into the world from their mother's womb, there are plenty for them to learn and explore about the world. Parents and caregivers play a crucial role in aiding their babies to integrate smoothly into this new environment. In addition to satisfying the physical needs of the baby, the emotional connection between parents and their baby will greatly enhance their sense of security, which will be of great benefit to their emotional and interpersonal development in the future.

1 Touch

The gentle touch of parents on their baby's hands, feet and skin is very important for their physical and emotional development. While the act of breastfeeding allows close interactions between the mothers and babies, it is also vital that babies that are not breastfed to be able to touch their mother's skin, to listen to their heartbeat to aid in stabilizing their emotions.

2. Emotional response

Parents should use gentle, caring words to reflect their baby's emotions. For example, when a baby is happy, their parents could say "Baby is smiling, we are so happy to see him!". On the contrary, if the baby is feeling unwell, one could say "if baby is not feeling well, we should come and see if he wants food? Or does he need someone to accompany?"

Each baby's development and temperament are unique to themselves and by meticulously observing and interacting with them, you can gain a better insight into the message your baby is expressing.

Journey Into Your Heart

The concept of the program is to provide comprehensive psychological support for congenital heart disease children and their parents through games, creatives art activities and counselling, help them to express their deep inner emotions and improve their family's mental health.



CHINESE MEDICAL PRACTITIONER'S HEALTH ADVICE IN SPRING

文章 陳思霖 (註冊中醫師) AUTHOR MISS CHAN SZE LAM

(REGISTERED CHINESE MEDICINE PRACTITIONER)

一年之計在於春,一日之計在於晨。

春天是陽氣初升,萬物開始生長的季節。在中醫五行角度 上,春屬木,肝亦屬木,是肝氣較旺盛的季節。若肝氣無節 制而旺盛太過,木剋土,會令脾土功能受損,所以健脾胃是 很重要,未病而先防。

春節是新一年的開始,香港人慶祝新年,大多選擇盆菜、火 鍋、年糕、糖果甜吃等,容易多了大魚大肉、肥甘厚膩,吃 太多便易引致消化不良、胃氣胃痛、嘔吐、便秘泄瀉的情 況:或吃多了油炸乾果瓜子,容易出現"上火"。

心童體質、氣血雖然相對可能較其他人弱,但小朋友和春天 一樣,處於生長發育快速的階段,所以仍有機會容易出現燥 熱上火的。而小孩子五臟六腑尚未完全成熟,脾胃運化相對 成人薄弱,飲食不節的話較易生病,變化亦快。

陳醫師給心童及家長的春季小建議:

1) 少吃太威、太甜及難消化食物:多吃蔬果 盆菜、火鍋經過一段時間炆煮後,十分美味濃郁,但其實鹽油 含量不少,增加重心腎脾胃的負擔:朱古力、糖果、糖冬瓜等 等質年食物含糖量高,吃太甜的食物有機會增加胃脹、胃酸的 機會:少吃難消化的食物例如芋頭、花膠、鮑魚、糯米。 "Plan your year in spring and your day at dawn."

In Chinese culture, spring is the season of birth and everything begins to grow. From the stance of Chinese medicine and its core five elements, the concept of Qirevolves around important organs in the body, especially the liver in the spring season.

As Chinese New Year is the beginning of a new year, most Hong Kong people celebrate it by consuming Poon Choi (a traditional meal composed of several layers of ingredients in a large bowl) and the increasingly popular hotpot. As well as this, many consume traditional glutinous rice cakes and candies. As a result of this, many people are prone to eat excessive fatty and greasy foods, potentially leading to indigestion, stomach pain, vomiting, constipation and diarrhoea.

From the perspective of Chinese Medicine, children's physique and Qi may be relatively weaker than adults. As well as this, children's internal organs are not fully matured yet. In particular, their spleen and stomach are weaker and hence more prone to illnesses if they do not eat appropriately.

Here are some health tips from Dr Chan about diet during spring.

1. Eat less salty, sweet or indigestible foods; instead, opt for more fruits and vegetables

Although Poon Choi and hotpot are quite delectable dishes, they contain a lot of salt and oil, which increases the burden on kidney, spleen and stomach; Chinese New Year sweets, such as chocolates, candies and sweetened winter melons are high in sugar. These treats may increase the chance of stomach bloating: Reduce the consumption of foods that are relatively difficult to digest, such as taro, fish maw, abalone, and glutinous rice.







春日飲食健康建議

CHINESE MEDICAL PRACTITIONER'S HEALTH ADVICE IN SPRING

2) 按合谷穴



每次按壓1分鐘, 休息10秒,再按 图1分鐘,重覆 2-3次。可左右交 替按摩。

合谷穴位於虎口位置,將食指拇指合起來,如同山谷最 高點的地方就是。按壓時會有痠、脹、麻的感覺。常按合谷穴功 效:健胃行氣止痛,幫助消化。

* 孕婦避免,或先諮詢中醫師建議。

3) 春日茶飲湯水

杭菊花甘草茶





用熱水泡燭出味

適合吃太多煎炸食物而有咽痛、口乾舌燥、眼垢黃多等熱氣症狀

蘋果無花果湯

健脾消食,益氣生津(性質平和,2-3人量)

蘋果	2個	蜜棗	1-2粒
麥芽	30克	陳皮	1/4片
無花果乾	4-6粒	瘦肉/豬腰	250劳

將凍水及材料放入煲中,大火煮滾後,轉細火煲約1小時

如有疑問、有飲食限制或病情嚴重的心童,請先諮詢心臟兒科 醫牛或中醫師意見

2. Massage the He Gu point

Press the He Gu point for 1 minute at a time. Rest for 10 seconds before pressing the He Gu point again for 1 minute. Repeat this 2-3 times. You can also alternate between left and right hand.

The He Gu point is located in the drawing below. When pressed, you will feel slightly pain, swelled and numbness. By regularly applying pressure on He Gu point, this will strengthen the stomach and promote the flow of Qi, hence relieving pain and aiding digestion.

* Avoid: if you are pregnant, seek advice from a Chinese medicine practitioner first.

3. Spring Tea / Soup / beverage

Chrysanthemum Liquorice Tea

Dried Chrysanthemum	3 Grams
Liquorice	1-2 Slices

Soak them in hot water to bring out the flavour.

This is suitable for people who suffer from sore throat, dry mouth, yellow eyes and other symptoms faced after eating too much

Apple and Fig soup (Portion for 2-3 people)

Apples	2 Pieces
Malt	30 G
Dried Figs	4-6 Pieces
Dried Honey Dates	1-2 Pieces
Dried Tangerine Peel	1/4 Slice
Lean Pork or Pork Shank	250 G

Soak them in hot water to bring out the flavour,

This is suitable for people who suffer from sore throat, dry mouth, yellow eyes and other symptoms faced after eating too much fried food

*Should one have any questions regarding dietary concerns and serious heart disease, please consult a cardiologist or Chinese medicine practitioner.





傷感的九月,希望的十月:

一個法絡氏四聯症病患少年的生死感受

"SORROWFUL SEPTEMBER AND OPTIMISTIC OCTOBER" -LIFE AND DEATH A TEENAGER WITH TETRALOGY OF FALLOT

文章 單字麒 AUTHOR MR. ANDREW SIN

給每一位如我的病童的希望 給每一位如我心力交瘁父母的病童家長的希望

十月四日,我回到兒童醫院覆診。

當我見過醫生,做了X光和心電腦,預約了接下來的一系列醫 療日期,走出兒童醫院大門,在陽光下看著蔚藍的天空,我心 中充滿了感激:感激翁德璋醫生、感激周啓東醫生、感激匆匆 的美麗護士、感激兒童心臟基金會的社工。

我是一個心臟病病童,自胎兒階段就被診斷患有嚴重的先天性 心臟病一法洛氏四聯症,這是一種尚未出生就像被上帝判了死 刑的病症。今天,剛剛過了十七歲生日的我還能走在陽光下, 呼吸著地球的空氣,因為我出生在香港,香港醫生高超的醫術 多次將我從死神的手中搶了回來。

一直以來,我都知道最大的鬼門關在等待我闖過去。儘管我在 幼兒時做了搭橋手術及心臟整形手術,可是,由於心臟缺失了 心瓣膜,血液倒流的情況日趨嚴重,右心室日益增厚,一步步 走向心臟衰竭。三年前在瑪麗醫院做了核磁共振,診斷心臟功 能下降,數值已達到了醫學設定的心臟衰竭最大值,我必需排 期接受人生中最複雜的心臟手術。

尚在童年懵懂期,我一邊如正常孩童般生活、學習、玩樂,一 邊隱隱感受著死神的來臨。但我是樂觀的,因為翁德璋醫生在 我嬰兒時期、生命最危險的時刻,作出準確診斷,並果斷決定 立刻施行手術,把我從鬼門關抱了回來;又因爲周啓東醫生一 直如守護天使般監察著我心臟數值的走向,多次幫我做「通波 仔」治療,讓血液在我心中順暢流動;還有,兒童心臟基金會 的社工們陪伴著我成長,在我徬徨時伸出雙手幫助我,給予及 時的安慰和信息。

在新冠疫情肆虐的一年多,我們自覺守在家中,靜靜地等待手 術時間的到來。然而,媒體於2021年9月16日就一則港間的廣 泛報導,令我宛如請天霹靂:〈兒童醫院心胸外科顧問醫生羅 冠中離港辭職,全港僅12人同級,難以填補,恐影響複雜手 術〉。羅冠中醫生就是被安排做我這次手術的主刀醫生

我看著母親每天偷偷流淚,如一個迷失的羔羊般,天天打電 話,四處求助而不得其門。我亦悄悄上網試圖尋找豬冠中醫生 的 跡,我想活下去!我想為愛我及我愛的親人、為我的理 想、為我著迷的科學和鋼琴 為所有的美好活下去!

Hope for Every Patient Like Me Hope for Every Struggling Parent of a Patient Like Me

October 4th, returning to the Children's Hospital for a follow-up consultation.

With the doctor's arrangement, I had a series of X-ray scan, electrocardiogram and other examinations, then made an appointment for further follow-ups. I stepped out of the main entrance of the hospital, with the warming sun in the blue sky and comforting breeze brushing my face, I owe my heart-felt gratifude towards Dr. Yung Tak Cheung, Dr. Chau Kai Tung, kind-hearted and beautiful nurses, and all the helpful social workers from the Children's Heart Foundation.

Seventeen years ago, I was born with congenital heart disease, and have later been accurately diagnosed with severe Tetralogy of Fallot, a disease that has been sentenced to death by God before birth, Today, just after my seventeenth birthday. I can still walk in the sun, breathe the air of the atmosphere, play my favourite piece on my piano, all because I was born in Hong Kong, fortunately privileged with superb medical infrastructures and dedicated medical practitioners, which have more than once rescued me from the sickle of Grim Reaper.

All along my life thus far, I knew that the biggest gate of hell was waiting for me. Although I have had bypass and correction surgeries when I was a child, however, due to the lack of a normal heart valve, conditions aggravated and the backflow of blood became more and more severe over the years. the wall of the right ventricle became thicker, which could gradually lead to heart failure. Three years ago, I underwent a MRI examination at Queen Mary Hospital, which suggested a decline in cardiac function. The functional data were approaching critical heart failure values. I was then put on the waiting list for the most complex heart surgery, hence greatest challenge in my life.

In the ignorance of my childhood, I went to school, carried out physical activities, learned piano and enjoyed life like any other normal child, vaguely felt the approaching of death. On the other hand, I have been optimistic because Dr. Yung Tak Cheung accurately diagnosed me at the most dangerous moment of my life as a baby, decisively arranged to pursue surgery immediately, and brought me back from the verge of death. Dr. Chau Kai Tung has been monitoring my heart conditions like my guardian angel, Social workers of the Children's Heart Foundation accompanied me and saw me through my growing up, reached out to me timely whenever I felt hesitant and lost, and offered warm and comforling consolations and constructive information.

Then came the rage of COVID-19 pandemic, forcing us to consciously stay at home and patiently wait for the surgery. On September 16, news media reported widely that "Dr. Barnabe Antonio Rocha, a cardiothoracic surgery consultant at the Children's Hospital, was leaving Hong Kong, There were only 12 cardiothoracic surgeons in Hong Kong at this level of seniority including Dr. Barnabe Antonio Rocha, This will affect patients who require complex surgeries." It was like a bolt from the blue to patients like me and their parents.



小童··有話兒 Voices Of The Children with CHD

好友們提出了各種意見和建議,例如去美國找好的醫院做手 術、追隨羅冠中醫生去他國做手術、介紹了許多香港私家心臟 科醫生……一次又一次的碰壁,我見到擁有博士頭銜的母親哭 腫了雙眼, 迅速消瘦, 失去了曾經的華麗和優雅。我默默地忍 受著心臟衰竭帶來的一切痛與累,以及手術何夫何從的無奈。 在母親如瘋了般打了各種求助電話之後,得到了各方的來電, 快速安排我提前覆診。

今天,我又見到翁醫生,他儒雅的笑容讓我們緊張的神經也得 鬆弛了下來。翁醫生詳盡地分析了我的病情,肯定地告知我手 術在去年已經進入了排期程序。他說兒童醫院流失了優秀的羅 醫生的確非常遺憾,但是,兒童醫院依然有優秀的外科醫生: **區醫生、張醫生,以及優秀的醫生團隊。我的手術可以順利進** 行,不必渦於擔心。

最後,我想將心聲寫給你們:

寫給翁德璋醫生:感謝您能夠站在病童的立場耐心講解,您 溫和的笑容是我沉重的心恢復跳動的動力。

寫給新聞媒體:在報導新聞時,請不要過於渲染悲觀的一 面,更不要單面打擊病人求生之心,只為追求吸引眼球的效 果,要找出積極的一面,立體全面報導。

寫給醫院管理局:感激醫管局接到求助電話,立即安排覆 診,讓病人得到及時的醫療訊息,解救我即將崩潰的神經。然 而·醫管局公關部能否在一邊倒的新聞報導出來時·立即安排 醫院聯繫媒體,介紹醫院優秀的外科醫生,明確表態能夠勝任 面對複雜的小臟手術,並目給病人家中開一個求助之門呢?

寫給各位如我的病童和家長:不要徬徨,家人要積極聯繫醫 院,可以及時了解病童的病情以及醫院的安排,可以求助兒童 心臟基金會的幫助,不要讓自己陷入一個悲觀無助的漩渦中。

雖然我不能像「小鐵漢」那麼幸運,馬上得到安排羅冠中醫生 進行手術,目圓滿成功,我衷心祝福他;雖然我依然不知道何 時、哪位外科醫生替我做手術,可是,今天見過翁醫生,走出 醫院大門,我對著陽光舒展了緊鎖十幾日的眉頭。有香港優秀 的醫生團隊和護士,以及幫助我們的社工,我相信我會活下 去!我相信如我的心童亦能活下去。

送走哀傷的九月,走進希望的十月。



I watched my mother grieving and weeping every day. We felt so lost and helpless, and we tried calling everyone begaing for help. We even resort to going online to trace Dr Barnabe Antonio Rocha. For the first time in my life. I wanted so eggerly just to be alive! Hove my parents, my feachers, my friends, Hove science and piano, and I need more time to achieve my goals in life!

Friends around us offered different suggestions, such as going to the United States to find a good hospital for surgery, following Dr. Barnabe Antonio Rocha to wherever he goes for surgery, and even searching for other private practicing cardiologists in Hong Kong.

Before long, my heart aches seeing my mother, who holds a doctorate title, having her eyes swollen from crying, substantially losing weight due to sleepless nights, losing her former beauty and grace, I silently endured all the pain and tolerated the fatigue caused by heart failure, as well as the helplessness of where to go for the surgery, because I cannot bear melancholy seeing my mother worry and suffer further. After my mother made various calls for help, we eventually got a reply and quickly arranged for me to return to the clinic on an earlier date. That reply came like a faraway shore I see after drifting helplessly in the cold ocean for an infinitely long time.

Today, I saw Dr. Yung again. His elegant smile gave us tremendous consolation. He painstakingly analyzed my condition in great details and assured me that the surgery had entered the scheduling procedure. He said that it is really regrettable that the Children's Hospital is losing the excellent Dr. Barnabe Antonio Rocha, but the Hospital still has other excellent surgeons, such as Dr. Au. Dr. Cheung, and an excellent team of doctors and health care workers. We were assured that my surgery can go well without working too much.

Finally, I want to express my deepest gratitude.....

To Dr. Yung Tak Cheung: Thank you for being able to explain patiently from the standpoint and perspective of a sick child. Your gentle smile is the essential driving force for my broken heart to recover.

To the news media: When reporting news, please do not overplay the pessimistic side, please understand the patients' desire to survive, and please also report the positive aspects rendering a well-balanced and comprehensive coverage of news.

To the Hospital Authority: I am extremely grateful that the Hospital Authority received our call for help, immediately arranged a follow-up visit so that I could receive timely medical information, and allowed me to relieve my nerves that were about to break down and collapse.

However, can the Public Relations Department of the Hospital Authority immediately contact the media whenever there are one-sided news reports, and use every means to reach out to the general public publicizing the hospital's excellent surgeons, medical-care team, and state-of-the-art facilities, and hence absolute competency for all complex heart surgery, and open a door for help for all patients in the Territories?

To all fellow patients like me and their family members: Don't be hesitant to actively contact the hospital so that you can keep abreast of the patients' conditions and the hospital's arrangements, understand the help that are offered by the Children's Heart Foundation, and never allow yourselves to fall into a whirlpool of pessimism and helplessness.

Although I was not as lucky as Kansas (a.k.a. "Little Tough Guy"), who was immediately arranged for Dr. Barnabe Antonio Rocha to perform the surgical operation before leaving Hong Kong, I still want to sincerely wish him best of luck. Although I still don't know when and which surgeon will perform the surgical operation for me, but after seeing Dr. Yung today, I walked out of the hospital door with a lighter mood. With the excellent feam of doctors and nurses in Hong. Kong, the dedicated learn of the social workers, and the top-notch medical facilities and system, I have absolute confidence and faith that I will survive!

I will say goodbye to the Sorrowful September and enter the Optimistic October.

生命的價值 逆風中前行

THE VALUE OF LIFE

文章 AUTHOR MS LUCY CHRISTIE

Lucy的兒子Damain在出生時患有動脈幹,在出生10天時便 要接受手術,清據於三天後去世。儘管生命短暫,Lucy及她 的的家人在醫院時受到深切的關懷,因此他們希望可以為 Damain做一些積極和正面的行動,賦予回報。

1. 作為一個心臟病童的父母,你們面臨最大挑戰的是什麼?

種種外在壓力和對病情的不確定性是最難處理的。由於 Damian的情況在懷孕期間並未能準確地診斷出來,這讓我們 一直擔心不已。隨著Damian的出生,醫生便確認了動脈幹的 診斷,這為我們過往的不確定性和擔憂打開了一道大門:到底 Damian什麼時候需要進行手術?接受手術的最佳年齡和體重 是多少?我們應該嘗試等待更長時間,還是這樣只會增加心臟 衰竭的風險?由於動脈幹是十分罕見的病症,尤其香港只有很 少病例,這令我們難以判斷哪種做法才對Damian是最好的。

2. 你們如何克服這種種挑戰與悲傷?

Damian去世後, 我們感到無盡的痛苦和迷茫。我們希望為 Damian的去世做出一些正面的行動,將悲傷和哀痛轉化為積 極的行動確實對我們有很大的幫助。許多家人和朋友都很關心 我們,希望為我們提供幫助,但同時,他們其實亦不太知道該 說什麼來安慰和幫助我們。我們想到Damian肯定也會希望幫 助其他小朋友,特別是同樣生長於香港的小朋友,因為這 是 他出生的地方,因此我們決定為兒童心臟基金會籌集資金。我 們相信在積極幫助其他孩子生活的同時,也能為了共同的目標 團結我們的家人和朋友。

3. 為什麼你選擇兒童心臟基金會作為受助組織?

在Damian患病時,我們很慶幸可以得到兒童醫院的幫助,於 疫情之下,其股施和服務更見優良。作為父母,我們因防疫措 施而無法陪伴在Damian左右,這對我們更為煎熬。及後,我 們詢問了各醫生和護士,哪個機構最為可靠和可信,幾乎所有 的心胸科醫生都告訴我們,兒童心臟基金會是香港兒童心臟科 慈善機構中的領頭羊。

(編者按:兒童心臟基金會在此衷心感謝Lucy及丈夫將慰問金 掴贈予本會,延續了Damian的愛。)

4. 惚想與其他有相同經歷的父母分享些什麼?

我們希望與其他經歷過無法想像的傷痛的父母分享:這份痛苦 確實會隨著時間而減輕的,可能我們不能在短時間内感覺到任 何變化,但這種體會將增強你內心的力量,慢慢地讓你學會如 何面對。還有,請記著微笑!當事情變得真的很艱難和悲傷 時,你身邊的人可能覺得你會一直沉溺在痛苦中,但其實我們 也可以擁有快樂。別忘記積極面對人生,學習欣賞四周的美好 和幸福,享受生活!



Damian, Lucy and Eamon's son, was born with Truncus Arteriosus. He had to have surgery when he was 10 days old. Unfortunately, he passed away when he was 13 days old. To celebrate Damian's life, Lucy and Earnon organised a fundraising campaign for CHF.

NEWSLETTER

1. What was the biggest challenge you faced as parents of a child with congenital heart disease?

The stress and uncertainty were the most difficult to deal with. Our diagnosis was not certain during pregnancy; and this left us in a state of constant worry. Then, following Damian's birth, once we confirmed the diagnosis of Truncus Arteriosus, we felt that opened the door to more uncertainty and worry - When would Damian need an operation? What was the best age and weight? Should we try wait longer or does this just increase the risk of heart failure? Since Truncus Arteriosus is so rare, and there are so few cases in Hong Kong in particular, it was so difficult to know what was the best thing to do for Damian.

2. How can you overcome the challenges and the sadness?

After Damian's passing, we felt quite lost and adrift. Turning our sadness and arief into positive action really helped us. Many family and triends asked what they could do to help; but at the same time, they were often lost for words and also felt awkward and didn't know what to say. We wanted some positive action to come from Damian's death. We knew Damian would want to help other children if he could, especially in Hong Kong, which was his home. By raising money for the Children's Heart Foundation in Damian's memory, we really felt that we were making a positive difference to the lives of other children, while uniting our family and friends for a common cause.

3. Why did you choose the Children's Heart Foundation as the beneficiary

We felt very fortunate that we were able to benefit from the Kowloon. Children's Hospital in Hong Kong. The facilities and quality of care there were excellent, given the circumstances, COVID-19 made our suffering much worse, as both parents were not allowed to be together with Damian at the same time due to the COVID-19 restrictions, From our discussions with the doctors and nurses there, we asked who or what would be the most valuable organization to contribute to, and most of the cardiologists said Children's Heart Foundation is the leading heart charity for kids in Hong Kong.

(Editor's note: The Children's Heart Foundation would like to extend heartfelt thanks to Lucy and her husband for continuing Damian's love by donating to support other children with congenital heart disease.)

4. What would you like to share with other parents who have experienced the same thing?

What we would share to any other parents aoing through the unthinkable is this: it does get easier. It might not feel like it today, tomorrow or next week, but this experience will strengthen you and it will get easier to manage, Also, it's okay to laugh! When things are really hard and sad, it can feel like there is an expectation from those around you to be miserable all the time, but it is okay and healthy to see the good and happiness around you. Don't forget to enjoy life!



CHF's activities only.

《心童有話兒》會員投稿專區

讓更多同路人或大衆更了解心童家庭的想法。

children with congenital heart.

MEMBERS ARTICLES - "VOICES OF THE CHILDREN WITH CHD

我們現正積極招募各位心童或家長,誠邀你們在《心訊》上投稿刊登文章,透過文字分享你的經歷或感受,

We are now recruiting children and parents members actively to submit articles for publication in our newsletter, sharing your experiences and feelings, so that more members or the public can better understand the thoughts of the families of the

我們認為創意不應該有任何限制:任何你想分享,或你認為心童家庭會感興趣的題材內 容均可。我們非常歡迎以下類別的内容:

We believe that there should be no limits to creativity; any content that you would like to share or that you think would be interested by the congenital heart disease kids' families are welcome. The content could be:

- 心童/家長生活日記或生活散文 Diary or essay of the daily life or thoughts of the congenital heart disease children/parents
- 創意文章、詩歌、書作 Creative articles, poems, paintings
- 電影分享、讀書分享 Movie sharing and book sharing
- 專業知識分享 Professional knowledges sharing



題材、字數、形式不限,語言需為中文或英文

There is no restriction on the topic, word count, or format. The language must be in Chinese or English.

- 電郵至 chf@childheart.org.hk Email to chf@childheart.org.hk
- 郵寄至兒童心臟基金會服務中心(地址:九韓澧隔樂19號南豐商業中心821室) 標題講註明「心童有話兒投稿」,並提供會員的真實姓名、會員編號和電話號碼以作參考。

Mail to the Children's Heart Foundation (Room 821, Nan Fung Commercial Centre, 19 Lam Lok Street, Kowloon Bay, Kowloon) Please put Members' Submission - "Voices Of The Children with CHD"" in the subject and include the member's real name. membership number and phone number for reference.

- *為表達對會員的支持,所有獲選刊章的投稿,將會獲贈精美紀念品/禮品一份。
- *基金會可能對投稿進行內容考證與修改,並刊載於本會訊中。來稿若未被採用,恕不奉覆及退稿。
- *請勿寄送任何原稿或無法取代之資料,基金會恕不退回投稿作品。
- * As a token of our gratifude, all submissions selected for publication will be awarded a souvenir/gift.
- * Submissions may be reviewed and revised for publication in our newsletter. No manuscript will be returned if it is not accepted.
- * Please do not send any original or irreplaceable materials, as the Foundation shall not return any submissions.

捐款表格 Donation Form

= 1
NEWSLETTER

我的支持 My Support 本人願意 | wish to | 毎月定期捐助 Dongte 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: 批計 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.) 若収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 銀行戶口每月自動轉賬 Bank account monthly autopay http://www.childheart.org.hk/TR/Doc/DDAF.PDF 語下載銀行戶口轉賜授權書。 Please download the Bank Direct Debit Authorization Form. 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 / 透過銀通或自動欄目機轉帳至渣打銀行 (香港) 有限公司「兒童心臟基余會」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 ☐ 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. 真附有回郵地址 Input a message remarks (e.g. Donation, Chan Tai Man, Tel: 2553 - 0331). 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), П 到 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/odf.asp 請將表格連同每月自動轉脹表格/銀行入數紙/支票電郵、傳真或郵寄至兒童心臟基金會。 兒童心臟甚余會是根據《稅務條例》第88條讓點發繳稅藥公共件暨的慈善團體。相款港幣一百元或以上可獲賴收據。 若閣下需要捐款収據,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 donatios 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攻據之用。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