



生命小戰士會通訊



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青年康復者的呼喊 A Young Survivor's Cry

陳奕舒 Katherine Chan



奕舒(中)向各國康復者分享心得
Katherine (Centre) with survivors from different countries



戰勝病魔的共同經驗將種族、言語的隔膜溶化了。
Sharing similar experiences in fighting cancer breaks down all race and language barriers.

我對參與2005年溫哥華的國際兒童癌症家長協會(ICCCPO)會議，抱著很大期望；除了想對兒童癌症有更多認識，更希望吸取各地建立青年組的經驗，幫助香港的青少年康復者。大會結束後，同行的參加者都深受感動，希望為一班兒童癌症中心的康復者成立小組。

我們現正籌組「生命小戰士青年組」，盼望透過各種活動，服務13歲或以上，曾患癌病、嚴重血病或接受骨髓移植的青少年，讓大家可以互相支持以促進個人成長；並發揮助人自助精神，服務正在接受治療的病童。17歲以上的康復者，若有興趣參與策劃工作，願意付出時間每月開會一次，便可成為核心小組成員。這個屬於大家的小組現仍處於起步階段，期待著你的積極參與。

I looked forward very much to participating the International Confederation of Childhood Cancer Parent Organisations (ICCCPO) Vancouver Conference. Besides getting to know more about childhood cancer, I wanted to learn more about youth groups from overseas delegates so as to help our local young survivors. All the Hong Kong participants were deeply impressed and became convinced that we should start a youth group for the survivors of the Children's Cancer Centre.

Immediately after returning from the conference we started to work on "The Little Life Warrior Youth Group". Our aim is to serve all youngsters aged 13 or above, who have once had cancer or a severe blood disease and those who have received bone marrow transplants. Through organizing different activities, we hope to bring them together so that they can support each other. It is also our aim to care for younger patients who are currently receiving treatment.

Survivors over 17 years old can join as core members by attending the monthly planning meetings. This youth group, which belongs to everyone, is just at the initial stage. It needs your active support to help it grow and become as effective as possible.



這次交流令錫熹(後排右一)獲益良多
A rewarding experience for Shek Hei
(right, 2nd row)



ICCCPO 交流事件簿 A Journal of My ICCCPO Trip

胡錫熹

Wu Shek Hei

溫哥華的ICCCPO之旅，讓我有機會與不同國籍的人溝通，使我明白生命的意義，懂得如何面對癌症的折磨。

會議的第一天，懷著既緊張又興奮的心情步入會場。不同國籍的康復者親切地提供幫忙，他們主動、活潑和良好的溝通技巧，真不像曾經患病的人。起初，我們彷彿「雞同鴨講」，但透過遊戲和活動，大家的友誼增進不少。

第二、三天主要是參加講座，而第四天的兩項活動，令我最刻骨銘心。第一項活動是康復者表演有關病人和醫院的短劇。起初我害怕英語欠佳影響全組表現，但組員都鼓勵我自由發揮。於是我鼓起勇氣出場，扮演一名病人，以淺白的英語對答，居然贏得全場掌聲。我對自己說：「成功了！以後用不著輕看自己。」

那天下午，另一個更艱鉅的挑戰是單獨以英文作演講。我硬著頭皮走上台，台下的聽眾都很細心聆聽，給予我很大的支持。晚上，我們乘坐郵輪，大伙兒高歌熱舞，不分彼此，這是既難忘又開心的一天。

五天的會議就像閃電般快速過去，令人回味無窮。這次的交流，令我的英語、溝通技巧和做事態度都有明顯進步，盼望將來有更多會員也可以參加這種擴闊眼光的活動。



全球兒童癌症康復者及家長濟濟一堂
Childhood cancer survivors and parents from around the world gathered together.

I met a lot of people from different countries during my trip to Vancouver. By sharing with each other we gained more insight into the meaning of life and how to fight against cancer.

I was very excited on the first day of the meeting. The survivors, from many different countries were very friendly and helpful. I could hardly believe that they had once been cancer patients with the very good communication skills they possessed, and their outgoing and energetic personalities.

At first, it took us some time to understand each other. The organizer had been kind enough to prepare some games in between seminars and these helped us to get to know each other and made the programme more interesting.

On the second and third days of the conference, we attended seminars with the parents. The programme on the fourth day was quite different. It was an unforgettable experience for me.

The first session required all survivors to prepare a role play about hospital life. I was worried that our team's performance would be marked down because of my poor English. However, my teammates were very supportive, they encouraged me to perform spontaneously. When I got on the stage I plucked up all my courage. I spoke simple English to play the role of a patient. The place was filled with applause and cheers. Then I told myself, "You did it! Be confident in yourself."

Another great challenge came up that afternoon. This time I had to give a short speech in English. I calmed myself down and went up onto the stage again. Once again, I was encouraged by the attentive audiences. That night, we cruised on a boat, dancing and singing. What a wonderful day!

The fifth day ended too quickly. The journey has greatly improved all my communication skills as well as my working attitude. I hope that more members will attend international conferences in the future to broaden their horizons.





難忘的旅程 My Unforgettable Journey

黃景勳
Wong King Fan

對我來說ICCCPO 是一個非常陌生的名字，但參加完這個組織 2005 年的年會，我對它的印象深刻。因為在會議中，認識了很多不同國家的兒童癌症康復者。起初因言語障礙，不敢跟外國人交談；但大家都很努力溝通，很快便可以融洽相處。

在加拿大的幾天，最難忘是遊船河和最後一天的活動。傍晚時我們登船遊覽，在船上用完晚膳後，音樂隨即響起，大家便開始跳起舞來。有些康復者拿著拐杖也盡情跳舞，玩得非常開心，這個美麗的回憶已烙印在我的心裡。

會議最後一天的晚上，我跟其他國家的康復者前往溫哥華康復者平日開會的地方參觀。我們到達時，當地的康復者邀請我們簽名及留下電郵地址。之後，他們送給我們每人一個花環和信封。不一會兒，他們把開會的地方變成小型賭場。原來信封內放著一些道具金錢，讓我們試試運氣，以換取獎品。大家都玩得愉快，最後，大伙兒捧著很多獎品，依依不捨地拍照留念。

經過這趟難忘的旅程，令我學會很多做人處事的技巧，也明白英文的重要性。我會多閱讀英文報紙和收看英文電視台，以提升語文能力，好讓日後可以主動與其他國家的康復者交往。

I had never heard about "ICCCPO" until I attended its annual conference in 2005. Since then, I have been impressed by this organization, especially after I met childhood cancer survivors from different countries. At first, I didn't feel comfortable about speaking English. The problem was quickly forgotten and we got along very well.

What impressed me most were the cruise and the entertainment on the last day. We boarded the boat in the evening and after dinner the music began and we danced. Some survivors on walking sticks also joined in. That wonderful memory will always stay in my mind.

On the last night of the conference, the other delegates and I visited the meeting place of the Vancouver survivors. The local survivors asked for our autographs and our email addresses. Then they gave each of us a garland and an envelope. In no time at all, the place was turned into a small casino. We were told to try our luck to win some prizes by using the tokens inside the envelope. We had a wonderful time there. In the end, we won a lot of prizes and we took a lot of photos of each other.

During this very special trip, I learnt how to improve my interpersonal skills. My experiences also made me realize how important it is to master English so from now on I will work hard on improving my language skills by reading more English newspapers and watching more English TV programmes.

鳴謝：國泰航空公司贊助四張前往溫哥華的來回機票
會員如欲參加 2006 年 ICCCPO 會議，可致電 2632 1262 查詢「申請機票贊助」詳情。

*Acknowledgements: Cathay Pacific Airways Ltd for donating 4 round trip tickets to Vancouver
If our members want to join the 2006 ICCCPO conference, please call
2632 1262 for information about "Air Ticket Sponsorship".*





作者(後排左二)在溫哥華與上海、香港的醫生及家長喜相逢
In Vancouver Stephanie Ma (2nd left, back row) greeted the Shanghai doctors, and parents and doctors from Hong Kong.



邁向自助精神 Towards the Goal of Self Help

馬陳嘉賢(家長)
Stephanie Ma (parent)



前往溫哥華參與ICCPPO 年會，令我眼界大開。除了與不同國家的家長交流，印象最深刻的是認識了一班充滿熱誠幹勁的外國青年康復者。他們一起籌辦活動，不但使人得益，從中也學習成長，建立了深厚的友誼。於是覺得香港的青年康復者，也需要成立一個屬於他們的小組。

成立「生命小戰士青年組」

香港的兒童癌症康復者日漸長大，他們需要空間發揮所長。因此盼望曾參加ICCPPO 會議的康復者可以組織起來，並鼓勵其他青少年康復者，一起幫助其他病童、服務社群，互相扶持及快樂成長。

義工發展計劃

目前本會的義工人數不算太多。因此，有系統的義工發展計劃，可能是本會未來的發展方向。首先鼓勵一些較成熟和有責任感的家長成為義工，是較快捷的方法；也可以依靠其他途徑訓練有心的家長及康復者，給予他們更多支持。

網上學習計劃

在這次會議得悉一項名為“Cyberkids”的計劃，就是由青年康復者攜帶手提電腦進入病房，透過電腦督導病童學習。倘若我們籌集到足夠資源和康復者，這個計劃不妨一試。

會員積極參與

最後，知道外國很多成功的家長組織，都是由家長或康復者「全職」參與。相信「過來人」的感受，非一般專業社工或醫護人員可以完全體會的。盼望本會會員能夠積極參與，邁向「自助」的目標。

Besides exchanging ideas with many parents of childhood cancer patients, what impressed me most about this ICCPPO annual conference, was the passion and boundless energy of the survivors from other countries. They care about other people and are willing to contribute to society. They learn from each other and build up close ties through organizing various activities. I was convinced that the local young survivors should set up a similar group after my return to Hong Kong.

The Youth Group

In Hong Kong, many childhood cancer survivors are growing up and they need the opportunity to develop their potentials. I really hope that those who attended the ICCPPO conference will become the core members of the youth group. They could encourage other young survivors to join in and work for the benefits of the child patients and the community.

Volunteer Training

Our Society has a limited number of volunteers. Therefore, we should think about a more systematic volunteer development programme. Our top priority should be training up volunteers and retaining them. One of the short cuts is to encourage more mature parents to become volunteers. We could also train up enthusiastic survivors and their parents and give them more support and recognition.

The Cyberkids

I came across a practical program called “Cyberkids” in the conference. The program encourages young survivors to tutor cancer children by using computers. Survivors can bring their notebook computers to the hospital ward and give tuition to the child patients. We should certainly try this programme once we have the necessary resources.

Active Participation

Lastly, I found many overseas successful parents' groups had "full-time" volunteers. We believe that even the professional social workers or medical staff cannot understand the feeling of child patients as well as parents and survivors can. We hope that more of our members will actively participate in our Society, to work towards the goal of self help.

俊裕(前排右一)深感參與本會工作令他獲益良多
After participation in volunteering, Chun Yu (1st right, front row) feels that he has matured a lot.



我們需要你 We Need Your Help

張俊裕 Cheung Chun Yu

「如果沒有各位家長的努力，又何來肥肥白白的小朋友呢？我想藉著這個機會代表小朋友向各位家長致以衷心謝意。」說畢這番話，我們三位康復者便一起鞠躬，之後全場響起熱烈掌聲。2005年週年會議中這一幕情景，到現在仍歷歷在目，因為這是全場對我們真實經歷的認同，彼此的心靈交流。

我們每一位生命小戰士都有著奇蹟般的過去。以我為例，發病時只有三歲，對於當時的情況印象模糊，但轉眼間已是精力充沛的年輕人。從家人和其他家長的口中，聽到大家的奮鬥故事，心裡不禁激起了助人之心，希望可以盡力幫忙。

當初我並不主動參與本會的義務工作，是由別的會員邀請加入。在這次的週年會議中，由籌備到現場控制，我都有份參與，對我來說是一個難得的經驗。透過參與，我曉得大會的成功是大家的努力成果，可說得來不易。

跟各家長相處了差不多兩個月，內心產生微妙的變化，待人處事開始變得有分寸。青年人做事都不禁心浮氣燥，今次的彼此磨合，正好給予我一個改變的機會，更懂得與人合作，令我得益不少。當天曾被贈一顆糖果，至今仍令我感動不已。

最後，呼籲大家支持生命小戰士會的活動，今年8月27日週年聯歡會的籌備工作現已展開，極需更多新力軍加入我們的行列。盼望你也可以透過積極參與，讓生命變得更豐盛！

"We wouldn't be living as happily now if it hadn't been for our great parents. On behalf of the children here, I would like to thank all parents from the bottom of our hearts."

After having said that in unison on stage, we three childhood cancer survivors bowed amid loud applause from the audience. This was a scene in the annual gathering 2005. I can still remember this moment because it summed up all our past experiences and was a moment of total communication with the audience.

Every Little Life Warrior has a miracle-like past. For example, I got cancer when I was three. I can't really remember what it was like then. Now I have become an energetic youth and have learnt about our brave fight against cancer from my own family and from parents of other survivors. These stories have motivated me to make an effort in helping others.

I was not very active in volunteering at first. What changed my attitude was a member's invitation to help out at the annual gathering 2005. This gave me an excellent opportunity to get involved in every part of the event, from preparation to on-site control. I learnt from my participation that everyone's effort counts for the success of the programme. It was a fairly steep learning-curve!

I also think my personality has changed a little too. Working with other parents and survivors has helped me learn to control my temper and work with others as a team. When I was given a candy that day at the gathering, I could not have felt happier. Even today, I can still remember the joy I felt.

Lastly but certainly not the least, I would like to invite everyone to help in events organized by our Society, especially the preparation work for the annual gathering on August 27. We can help a lot, even if we contribute only a little of our time.



給長期康復者的話

Anthony Penn 醫生
前ICCCPO 康復者小組主席
布里斯托皇家兒童醫院兒童癌病研究員



故事還未完結

我是Anthony Penn，現正於英國接受兒童癌病的專科訓練。過去五年，我有幸當上國際兒童癌症家長協會(ICCCPO)康復者小組的主席。還記得一切由小學畢業那年7月的膝痛開始，及後出現胸口痛，直至同年11月，我的身體已經變得非常虛弱而需倚靠輪椅活動。我更開始經常嘔吐，體重下降了三分之一。

我不停接受抽血化驗，見過大批專科醫生，都無法找出病因。最後，一群聰明的醫生（當然是兒童癌症的專科醫生）決定抽取骨髓作活組織檢查，才被診斷出患上急性淋巴白血病，那時我只有13歲。

記得當時感覺彷如放下心頭大石，因為經過五個月的煎熬，醫生終於找出病因。另一方面，亦感到相當沮喪，因為我很喜歡運動，但以後卻不能參加籃球活動了。我和家人面對患上癌病，並沒有想像中那麼徬徨。傑出的醫護人員幫了很大的忙，衷心多謝他們的悉心照料和鼓勵。

經過三年的化療及電療，於深切治療部醫治嚴重肺炎三星期，及一項切除左肺胸膜手術，我終於可以跟癌病及恐怖的療程說再見，可是故事還未完結……



成長與互諒的機會

癌病對每人的影響不同，有好有壞。對於我和家人來說，那是一段非常困難、充滿挑戰及結果難料的日子，但也是一次成長和幫助家人互相體諒的機會。癌病經驗雖未致於界定我是誰，但將永遠成為我的一部分。

完成療程之後，我開始參與一個南非志願組織CHOC的工作，為患上癌病或血病的兒童及其家長提供支援。這次經驗推動我積極參與ICCCPO 康復

者小組事務的決心。

2001年，首個為康復者籌辦的國際會議於盧森堡舉行。自此，這個由癌病康復者主持的週年會議成了ICCCPO年會的一部分，為世界各地的康復者提供了一個互相交流的機會，除了分享有關癌病的資訊，更會探討就業及困擾康復者的保險等問題。我們希望為全球康復者建立一個平台，讓他們可以在一個親切的環境與其他康復者分享經歷。第一次會議以分享治療過程的個人經驗為主，現在我們已演變成一個關心長期康復者的組織，特別關注那些較小規模的長期康復者組織。

2005年溫哥華的ICCCPO康復者會議，共有51名來自東西歐、北美洲、紐西蘭、中東及亞洲

19個國家的15至34歲康復者出席，人數打破過往記錄。其中10名來自發展中國家的康復者獲岩士唐基金贊助，讓不同社會經濟背景的人士可參與其中，可謂真正的全球性會議。

大部分參與會議的康復者以自己的國家或地區兒童癌症組織代表的身份出席，有些人更希望於自己的國家成立康復者小組。當然，我們於開會之餘亦樂在其中；最高興是可以認識很多新朋友。

2006年ICCCPO會議將於9月16日至21日在瑞士日內瓦舉行（請瀏覽網頁www.iccpo.org/），我們盼望可以繼續與全球的兒童癌症康復者分享及交流經驗。



左起：黃景勳、Anthony Penn、馬陳嘉賢、胡錫熹，攝於溫哥華。
(From left) Wong King Fan, Anthony Penn, Stephanie Ma & Wu Shek Hei in Vancouver

Inspiring the Long Term Survivors

Dr Anthony Penn
Former Chairperson, the ICCCPO Survivors' Group
Paediatric Oncology Research Fellow
Bristol Royal Hospital for Children



Not the End of the Story

My name is Anthony Penn, and I am training to become a paediatric oncologist in Bristol, England. I have also had the honour of being chairperson of the International Confederation of Childhood Cancer Parents Organisation (ICCCPO) Survivors Group for the last 5 years.

It all started in July of my final year of primary school with excruciating knee, and later chest-pain. By November I was confined to a wheelchair, too weak to walk and crippled with pain. I'd also begun to vomit profusely and had lost nearly a third of my body weight.

I had had blood tests and other diagnostic procedures, as well as seeing a host of specialists. Finally, a very clever group of doctors (paediatric oncologists of course) decided to perform a bone marrow biopsy, and at the age of thirteen, I was diagnosed with acute lymphoblastic leukaemia (ALL).

I remember at the time being relieved that finally a cause of my illness had been found, but extremely upset that I would not be able to play rugby as a result (I was a very keen sportsman at the time). The thought of having cancer did not frighten my family and me as much as one would expect. The excellent doctors and nurses taking care of me at the time, and their positive and encouraging attitude helped a lot.

Three years of chemotherapy, radiotherapy, a three week stint in intensive care for very severe pneumonia, an operation to surgically remove the pleura of my left lung and I was finally rid of the cancer and its horrible treatment. This is not the end of the story.....



Opportunity for Growth and Understanding

Cancer affects people in many different ways, both good and bad. It was a difficult time for me and my family, full of challenges and uncertainty, and as a result, an opportunity for growth and understanding. My cancer experience, though not defining who I am, will always be a part of me.

A few years after completing treatment I became involved in CHOC, a South African voluntary organisation providing support for children with cancer and other blood disorders and their parents. It was this experience which ultimately led to my involvement with the ICCCPO survivors group.

In 2001 the first international survivors meeting took place in Luxembourg, and has been part of the ICCCPO conference ever since. This annual meeting, run by survivors, for survivors provides an opportunity for people from all over the world to meet and learn about issues related to their disease and its treatment. Such issues include late effects, second malignancies, and other problems including difficulties related to employment and insurance which continue to be a problem for some childhood cancer survivors well after the primary cancer has been treated. Our intention was to create a forum for survivors from all over the world to share their experiences in a friendly, unthreatening environment. The first meeting focused on sharing individual experiences while undergoing treatment for cancer. We have now evolved into an organisation primarily concerned with issues faced by long-term childhood cancer survivors, and more particularly, long-term survivor groups.

The Vancouver 2005 ICCCPO Survivors Conference had the largest attendance to date with 51 survivors from 19 countries attending. The age of survivors ranged from 15 to 34 years and there were representatives from Western and Eastern Europe, North America, New Zealand, the Middle East and Asia, making the Vancouver survivors meeting a truly global one. A generous donation by the Lance Armstrong Foundation allowed ten survivors from developing countries to attend the conference, ensuring representation from a wide range of socio-economical backgrounds.

Most survivors at the meeting were representatives of their own national or regional childhood cancer groups, or were interested in starting up new survivor groups in their countries.

However, our meetings are not all hard work. We also have a lot of fun. The conference is a great place to meet new friends and have a good time, and there are always social events in conjunction with the meetings.

The next ICCCPO survivors meeting will be held on 16th to 21st of September, 2006, in Geneva, Switzerland. Please consult the ICCCPO website for more details closer to the time (<http://www.icccpo.org/>). We look forward to the continued sharing of ideas and experiences with other childhood cancer survivors all around the world.



農村小孩治病記

在經濟條件比較差的中國農村，小孩子得了白血病，很多父母都無法負擔沉重的醫藥費，只好放棄治療。廣東省雲浮市郁南縣連灘的國樸是其中一個幸運兒，他的家人、親友、師長、同學和醫護人員都對他不離不棄，讓他可以重獲新生……



右起：黃俊琳醫生、曾國樸、家長曾福榮及潘冬永主責醫生
(From right) Dr Huang Junlin, Zeng Guoliang, Zeng's father &

雨過天晴人歡笑

曾國樸

我是個活潑的男孩，家中的摯愛。2003年夏天，突然感到腳趾關節疼痛，大腿出現瘀血；接著開始發高燒，臉色蒼白，精神疲倦。爸爸帶我到連灘人民醫院就診。經過多天診治，病情仍沒有好轉，醫生建議轉往一級醫院作詳細檢查。後來廣西桂東人民醫院的醫生確定我患的是白血病。

這個晴天霹靂的消息嚇呆了父母，他們立刻背著我偷泣起來。那時我病得有氣無力，不知道他們為什麼會傷心。經與醫生詳談，爸爸很快便面對現實，讓我開始接受抗癌注射。我康復得很快，現已完成四個療程，正進行維持治療，可以返回校園學習。

現在親人看到我的學業成績不俗，又可以像其他小孩那麼活潑，也就破涕為笑了。能夠有今天，真要感謝醫護人員的悉心照顧和家人的關懷支持，使我可以樂觀地去戰勝病魔。我決定努力地生存下去，好好地度過每一天。

幸獲新生

曾福榮(父)

我一家五口，以耕種為生。2003年夏天，兒子國樸患上急性淋巴細胞性白血病，我頓時感到天昏地暗。廣西桂東人民醫院黃俊琳主任不但給予安慰，更鼓勵我們設法籌措醫藥費，為兒子治愈惡疾。

於是鼓起勇氣跟家人及親友商量，他們都很支持我們。學校校長把國樸的病情向鎮教辦主任反映，他與鎮領導商量後，發動各中小學生捐資，得人民幣6,500元及救助基金3,000元；讓國樸能夠順利完成首兩個療程。可是錢還是不夠支付以後的三個療程，於是想到向農村信用社貸款，及找朋友代貸，卒之籌足了費用。

接受治療期間，為了減輕兒子的痛苦，我常給他講一些頑強奮鬥的英雄故事與開心的事情，鼓勵他戰勝病魔。我每天都弄點他最喜歡吃的食譜，幫助他調理身體。經過醫護人員及家人的一番辛勞，孩子的病終於好轉；現已回校上課。非常感謝桂東醫院的醫護人員，給予孩子新生。

How Could a Poor Farmer's Son Get Cured

Dr Pan Dongyong

Sunshine After Rain Zeng Guoliang

I am an energetic boy, truly loved by my family. In the summer of 2003, I started to feel pain at my toe joints and bruises were found on my thighs. I had a persistent fever and I felt very tired. My father took me to the Liantan People's Hospital for treatment. However, my condition did not improve and the doctors suggested that I transfer to a better equipped hospital for a thorough examination. The doctors at the Guangxi Guidong Hospital diagnosed that I had acute lymphoblastic leukemia.

My parents were shocked and they wept over my illness. At that time I was very ill and I did not understand why they were so sad. After talking to the doctor, my father quickly recognised that he had to face reality and he allowed me to receive the treatment. I have now completed four phases of treatment and have been recovering fast. I have been allowed to go back to school.

I do quite well at school and I am as energetic as other kids. My parents' tears have finally turned to laughter. I am really grateful to my family and the medical staff. Their care and support have helped me a great deal in this battle. I am determined to make the most of my life.



关爱儿童健康 2005.5.22

2005年廣西桂東醫院舉辦「關愛兒童健康」活動，邀請難治的病童外出聚餐及聯誼，彼此打氣。

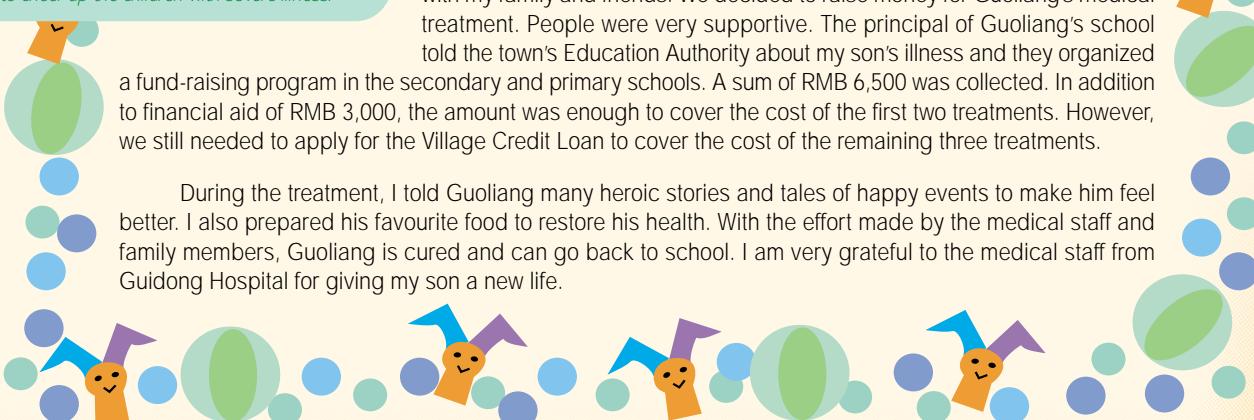
"Caring for the Children's Health" was a special event organized by the Guidong Hospital in 2005 to cheer up the children with severe illness.

Through the Valley of Death Zeng Furong (Father)

I am a farmer. There are five people in my family. In 2003, we were devastated by bad news about my son, Guoliang. He was diagnosed with acute lymphoblastic leukemia.

With the encouragement of Dr. Huang Junlin of Guangxi Guidong Peoples Hospital, I discussed how we could pay for my son's medical fees with my family and friends. We decided to raise money for Guoliang's medical treatment. People were very supportive. The principal of Guoliang's school told the town's Education Authority about my son's illness and they organized a fund-raising program in the secondary and primary schools. A sum of RMB 6,500 was collected. In addition to financial aid of RMB 3,000, the amount was enough to cover the cost of the first two treatments. However, we still needed to apply for the Village Credit Loan to cover the cost of the remaining three treatments.

During the treatment, I told Guoliang many heroic stories and tales of happy events to make him feel better. I also prepared his favourite food to restore his health. With the effort made by the medical staff and family members, Guoliang is cured and can go back to school. I am very grateful to the medical staff from Guidong Hospital for giving my son a new life.





最嚴峻的考驗

別人很難明白先天性代謝異常疾病(簡稱代謝病)令這家人嘗盡多少苦頭：兩個兒子先後離世，幼子子昕正在康復中。他們並沒有被命運打倒，反倒相親相愛地對抗嚴峻的挑戰。

沉重的喪子之痛

經歷一次骨髓移植治療已令人嚇破膽，三個兒子先後接受移植手術，簡直匪夷所思。

1999年，七歲的次子仲昕手腳動作開始不協調，寫字歪歪斜斜，上落樓梯有困難。經威爾斯親王醫院的專家評估及將血液樣本送往美國化驗，證實患上「腎上腺腦白質缺乏營養症」。這種罕見的遺傳病*是X染色體出了問題。通常女性是隱性帶因者，健康不受影響；男性患者若於兒童或青少年的高峰期發病，壞細胞擴展至腦部，將難以治愈。骨髓移植不能阻止病情迅速惡化，幾個月後仲昕因肺炎感染不幸離世。

2001年，十三歲長子浩昕腦部陰影有擴大跡象，醫生建議接受骨髓移植以防患未然。手術非常成功，但兩年後卻出現胃痛及嘔吐等腸排斥現象。當時正值沙士瘟疫蔓延，家屬嚴禁進入隔離病房，心急如焚的父母只能每天靜待主診醫生來電報告病情。完全禁止進食，只靠打針吸收養份，浩昕日漸消瘦，最終藥石罔效。

2004年，子昕腦部組織出現少許變化，醫生建議進行臍帶血移植。經歷兩次喪子之痛，父母最終決定承受醫療風險，讓幼子接受目前唯一可治這種病的療法。目前子昕正在康復中，在家接受紅十字會的功課輔導服務。

對哀傷默然無聲

原本熱鬧的家庭遭逢巨變，身為隱性帶因者的母親，內心有一絲絲歉疚。不過在哀傷過後，她仍默默地承受命運的挑戰，堅強地陪伴兒子渡過艱辛的療程。

當然沒有明白事理的丈夫及親友的支持，這條孤單的路並不好走。丈夫不但從沒有埋怨妻子，反倒經常安慰對方。「既然要做的已經做

了，大家盡了力，結果不成功也不用埋怨。」是互相支持的金石良言。

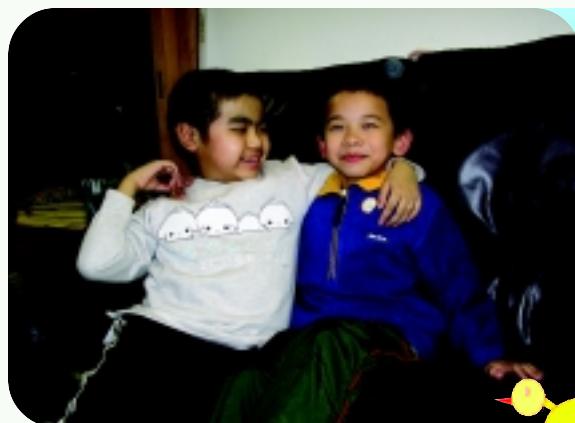
嚴重疾病患兒的父母很易受悲傷及焦慮等情緒困擾，究竟他們怎樣舒緩沉重的精神壓力？原來「遠親不如近鄰」，充滿人情味的街坊給予他們一家最大的支持。

當最小的兒子入院接受治療，母親總會在中午出外用膳減壓；只要致電邀約，相熟的街坊總會義不容辭，聆聽她的傾訴。

最難得同學健源和他的媽媽的實質支持。他們得悉子昕因接受治療而停學，便經常慰問對方。當子昕出院在家養病，他們每逢假日都會到訪；健源是最佳玩伴，媽媽是臨時保母。這種單純而無私的付出，不單為這家人帶來不少歡樂，更溫暖了他們哀傷的心。



子昕(前)與哥哥手足情深
Tsz Yan was very close with his brothers.



健源(右)令子昕不再寂寞
Tsz Yan likes to spend time with Vincent (right).

*由2005年開始，本會服務對象已擴大至兒童癌症、嚴重血病及曾接受骨髓移植的病童、康復者及家長。

The Ultimate Challenge

It is beyond someone's imagination how a rare genetic disorder (one kind of metabolic disease) could be so tragic to a family: two sons passed away because of this disease. The youngest son, Tsz Yan, fought a hard battle against it and, fortunately, survived and is slowly recovering. Almost miraculously, the family has held together and kept its spirit throughout the ordeal and never lost hope in the struggle against the toughest challenges.

The Pain of Losing Beloved Sons

It is terrifying just to undergo a bone marrow transplant. Yet all three sons in this family had to endure this treatment at different times. It is hard to imagine how they could have gone through this.

In 1999, 7-year-old second son, Chung Yan, was found to have problems with limb coordination. He could not write properly and had difficulty in climbing up and down stairs. Specialists at the Prince of Wales Hospital found out, after sending Chung Yan's blood sample to a laboratory in the United States, that he had adrenoleukodystrophy (ALD)*. ALD is a rare, genetic disorder caused by mutation in the X-chromosome. The disease only affects males. Females are always recessive carriers. The disease is most severe when the onset happens during childhood. It is very hard to cure if the cell damage has progressed to the brain. Because a bone marrow transplant failed to stop the quick progression of the disorder, Chung Yan died of pneumonia a few months after his operation.

In 2001, a shadow was found in 13-year old Ho Yan's brain scan. Successive scans showed that it was expanding. Doctors recommended a bone marrow transplant for treatment. The operation went very well. However, two years later Ho Yan suffered from persistent stomach-ache and vomiting because of rejection.

He was admitted to hospital for further treatment. At that time, visitors were not allowed to enter the hospital wards because of the SARS outbreak. Ho Yan's parents could only wait for the daily telephone report from the attending doctor. Ho Yan could not eat. He could only absorb nutrients from a drip. Slowly, his body weakened to the stage that made all attempts to save his life impossible.

In 2004, brain tissues of the youngest son, Tsz Yan, were found to show abnormal signs. The doctor suggested an umbilical cord blood transplant. His parents had no choice but to take the risk. They agreed to allow their son to undergo this treatment because the doctors told them there was no other way. The treatment has proved effective. At present, Tsz Yan is slowly recovering. He is also receiving tuition at home from Red Cross teachers.

Silence Towards Grief

The mother, being a recessive carrier of the disorder, felt grievously sorry to have brought such tragedies to the family. But she has borne her grief in silence and has remained strong in accompany her son through the difficult treatment.

Of course, she would not have gone through this without an understanding husband and the support from friends and relatives. Her husband never put the blame on her, but, rather, he tries all the time to comfort her. Their motto of support is: "No matter what the outcome, we have already done our best and we have tried everything."



未接受臍帶血移植前的滑雪之旅
The skiing trip just before the umbilical cord blood transplant

Parents of children with serious illness can very easily be overcome by grief and anxiety. So how did Tsz Yan's parents find solace under such pressure? The answer is that they were lucky to have received much generous support from their neighbours. When their youngest son was receiving treatment in hospital, the mother always had her lunch outside to relieve her pressure. Her neighbours were all very willing to accompany her to lunch and shared her worries.

The family has been most grateful to Tsz Yan's classmate, Vincent, and his mother, who have shown great concern for Tsz Yan. Now that Tsz Yan has returned home, they always visit him during holidays. Tsz Yan has a lot of fun spending time with Vincent, and Vincent's mother is the best nanny. Their unselfish support has brought lots of happiness to the family, as well as warmth to their hearts.

* Since 2005, the service of our Society has expanded to patients with childhood cancer, serious blood disease and those who had received bone marrow transplant, as well as survivors and their parents.



罕見難治的代謝病

許鍾妮醫生

會否想過一些外貌有異、毛髮粗糙、智力受損的小孩，可能正受著代謝異常疾病(簡稱代謝病)之苦？威爾斯親王醫院兒科的許鍾妮醫生，剖析這些不幸的孩子及家庭所面對的困難——除了未必可以治愈，還可能因歧視而得不到應有的體諒。



許鍾妮醫生(右一)攝於病人活動
Dr. Joannie Hui (1st right) in an activity for the patients

🍎 「代謝病」是什麼？

代謝病的種類多達數千種，泛指身體的新陳代謝出了問題。例如較常見的代謝病——「黏多醣貯積病」，因身體的遺傳基因細胞缺少了能分解黏多醣的酵素，當細胞內的黏多醣無法新陳代謝時，便會在體內細胞堆積，損害各個器官。

🍎 這些怪病是否遺傳？

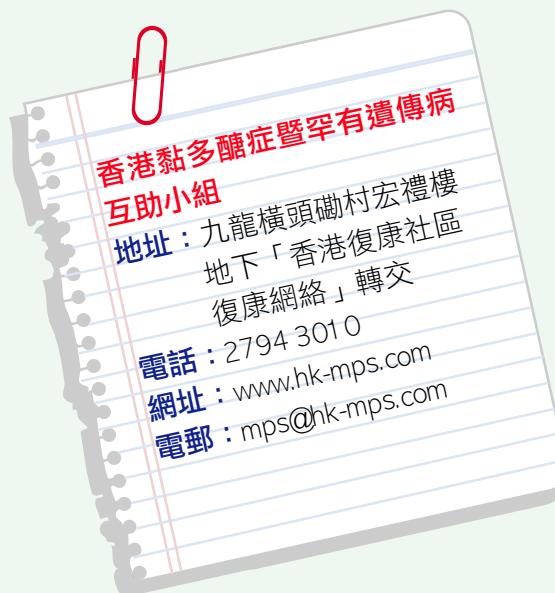
部分代謝病是自體發病，但很多時患者的父母親各帶一個造成疾病的隱性不正常基因；父母健康不受影響(即隱性基因攜帶者)，若孩子遺傳到兩個有病的隱性基因就會發病。子昕及兩位兄長(請參本刊第10頁)所患的「腎上腺腦白質缺乏營養症」情況有點不同，是X-性聯隱性遺傳；有病的基因來自母親的X染體，兒子有一半的機率會得病。

🍎 「代謝病」有何病徵？

有害物質的堆積是漸進過程，孩子在剛出生時並無異樣。隨著年齡增加，堆積在體內的物質可能損及病童的外貌、智能、內臟及骨骼關節，造成面容毛髮粗糙、腹部突出、關節變形、脊椎變形、手指屈曲僵硬、行動不便、視力或聽力障礙；甚至呼吸道會變窄，引起肺炎等併發症。由於每種代謝病的病徵不盡相同，醫生必須像偵探般仔細推敲，再經過複雜的檢查，方可確診。

🍎 病童得到什麼幫助？

這些罕見疾病的嚴重程度不同，但大多隨著年齡增加而逐漸惡化。部分患者可在發病早期進行骨髓移植，以減輕病情及延長壽命。部分病人可接受「靜脈注射酵素治療」以減輕病情；但由於費用高昂(每年約需數十萬元)，目前並不普及。威爾斯親王醫院的「代謝病門診」會為病人的親屬作遺傳諮詢，盡量減低同類病發生的機會。這些病人和家屬的經濟和心理負擔都非常沉重，極需要社會大眾的關心和支持；若希望關懷這些病童，可先從認識他們的需要開始。





黏多醣症病童及家屬郊遊樂

Outing for the Mucopolysaccharidoses patients and family members

The Rare and Intractable Metabolic Disease

Dr. Joannie Hui

Has it ever occurred to you that some mentally retarded children with abnormal facial features and coarse hair could be suffering from a metabolic disease? Dr. Joannie Hui of the Pediatric Department of the Prince of Wales Hospital tells us about the difficulties faced by patients suffering from these diseases and also the stress encountered by their parents. The disease itself can be life-threatening. What makes it even more unbearable is that some of these patients may be subjected to discrimination by the public.



What Is Metabolic Disease?

Metabolic disease refers to disorder in the body's metabolism. There are many types of metabolic diseases. For example, mucopolysaccharidosis, a common metabolic disease, occurs when there is a deficiency of specific enzymes needed to break down mucopolysaccharides (a kind of sugar molecules) in the genetic cells. When mucopolysaccharides cannot be metabolized and are stored up in the body damage will occur in various organs of the body.



Is the Disease Inherited?

Some of the metabolic disorders aren't genetic. But in most cases, the disease is caused by inheriting abnormal genes from both parents. While both parents remain normal, the child who receives one mutated gene from each parent will be affected.

The adrenoleukodystrophy (ALD) that has been affecting Tze Yan and his brothers (Please refer to P.10) is slightly different from the metabolic disease described here. ALD is an X-linked recessive inherited disorder. A male child born with the mutated gene carried on one of his mother's X chromosomes will get the disease.



What are the Symptoms of the Disease?

The affected child may look normal at birth because it takes time for the noxious substances to accumulate in the body. When the child gets older, the substances in the body may cause damage to the child's facial features, mental ability and the functioning of various organs and joints. This may result in rough hair, hernia, stiff joints, curvature of the spine and vision and hearing impairment. It may even cause complications such as the narrowing of the respiratory tract or pneumonia. Since the symptoms for each metabolic disease are different, doctors have to make an extremely careful search for clues from the patient's medical history, physical examination and together with a series of complicated investigations before confirming the actual diagnosis.



What Kind of Support do Patients Get?

These diseases could become very serious. In most instances, the condition of the patient deteriorates with age. Some of them can receive bone marrow transplantation at the early stage of the disease to reduce its damage and prolong their lives. Some may be treated by intravenous injections of the missing enzymes which are being manufactured artificially by the drug companies. This however is not a common treatment as it is only limited to a few diseases. Also it is a very expensive treatment costing up to a few hundred thousand dollars a year for each patient. In addition to diagnosis and treatment, the Joint Metabolic Clinic of the Prince of Wales Hospital also provides consultation on genetic issues to families with metabolic diseases with an aim to help reduce the risk of passing on the disease in future pregnancies through counselling and prenatal testing.

These patients and their families have to face serious financial and psychological challenges. They need your support and concern. If you want to show that you care, you can start with understanding their needs .





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治療先進 減少復發

本院血液腫瘤科原名「小兒白血病研究組」，創建於1972年，是國內最早成立的專攻兒童白血病、淋巴瘤等血液系統惡性疾病的科室。2001年新病房啟用，改名為血液腫瘤科。該科由血液腫瘤專科病房、專科門診以及專科研究室組成；經過近30年的努力，已成為一個集臨床、科研、教學為一體的有機整體。

除一般常規檢查外，專科研究室採用嶄新的技術為常見及疑難血液腫瘤性疾病的診斷帶來便利，使臨床診斷能快速、客觀、準確地進行，對早期診斷及治療起到了非常重要的作用。臨床治療主要採用聯合化療為主的綜合治療方法，輔以免疫治療以及造血幹細胞移植。血液腫瘤患兒在治療過程中，採用免疫學（流式細胞儀）、細胞遺傳學（染色體檢查）以及融合基因（RT-PCR）檢查，對白血病微小殘留病（MRD）進行實時監測，及時調整治療方案，避免過度治療造成重要臟器的嚴重損害或治療不足而導致白血病復發。

建立了嚴格的專科門診隨訪制度，堅持長期、規則、強烈和交替的化學治療，診療水平不斷提高，取得了可喜的成績；兒童血液病、淋巴瘤的治療效果顯著改觀，白血病、淋巴瘤已經可以徹底治愈。五年無病生存率已達到了國內最先進水平：兒童ALL完全緩解率97.9%，標危組ALL五年生存率為84.3%，高危組ALL五年存活率為52.8%。兒童AML初次緩解率為72.5%，五年存活率為45.6%。1999年本院首先從事器官移植，開展了親緣或非親緣外周造血幹細胞、臍血幹細胞移植治療白血病、淋巴瘤的工作，成為全國兒科較早開展造血幹細胞移植的單位之一。

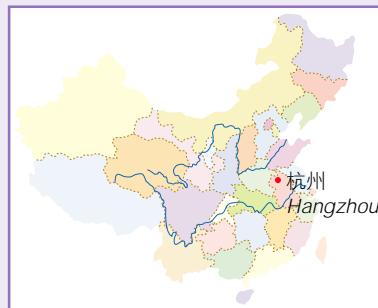
抗體研究 備受重視

為了不斷提高診療水平，該專科非常注重科研與臨床的緊密結合，專科研究室擁有先進儀器從事

血液惡性腫瘤性疾病的科學研究，曾獲國內多項贊助及獎項，並在國內外權威雜誌上發表多篇科研論文。自行研製了30餘種抗人白血病細胞的單克隆抗體，並有20個抗體已得到國際鑒定和CD命名，為白血病的免疫學診斷以及體外淨化、導向治療奠定了良好的基礎。目前，在國家自然科學基金的資助下正從事自製抗體的人源化基因改造研究，以便使它們儘快進入臨床治療。

為了保持最先進的診療技術，該專科經常邀請各國專家來華講學，進行信息交流和分享經驗，並派遣專業技術人員出國進修，吸取國外先進的臨床經驗與科研技術，為患兒服務。

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人口：7百萬（25% 為兒童）
景點：西湖
工藝：絲織
Population: 7 millions (25% of children)
Scenery: West Lake
Handicraft: Silk products



住院大樓

The resident hall of the hospital

An Introduction to the Department of Hematology Oncology

The Children's Hospital of Zhejiang University School of Medicine

Professor Tang Yongmin

Director of Department of Hematology Oncology

The Children's Hospital of Zhejiang University School of Medicine



Advanced Examination Techniques

Following its establishment in 1972, the Department of Hematology Oncology of the Children's Hospital of Zhejiang University School of Medicine was originally named the "Pediatric Leukemia Research Group". It was the nation's first laboratory specializing in pediatric malignant hematology diseases such as leukemia and lymphoma. New wards came into operation in 2001. Since then, the research group is now officially named the "Department of Hematology Oncology", comprising the Hematology Oncology wards, an outpatient care centre, and a research laboratory. Over the past 30 years, the Department has been developed into an institute of pediatric hematology oncology, combining clinical, research and teaching as one unit, with contributions made by many specialists, professors and medical research teams.

Besides conducting regular tests, the research laboratory has introduced advanced technologies for fast, objective and accurate hematology oncology diagnosis. Such improvements are very crucial to the early stage cancer diagnosis and treatment. Joint chemotherapy is the major application in clinical treatment, complemented by immunotherapy and hematopoietic stem cell transplantation. During treatment, patients will undergo leukemia minimal residual disease (MRD) real time regulation through various examination methods of immunology (Flow CytoMeter), cytogenetics (chromosome analysis) and fusion gene (RT-PCR). Treatment will be adjusted accordingly to ensure the dosage used is small enough to

avoid damages to internal organs but sufficient enough to minimize the chances of relapse.

With the establishment of a strict outpatient follow-up system and the perseverance in adopting, alternately, regular strong long-term chemotherapies, the hospital has obtained very good results in childhood cancer treatment. The goal of 100% cure rate in leukemia and lymphoma is no longer just a dream. The hospital has reached the highest levels in the 5 year disease-free survival rates within the country. The complete response rate (CR rate) of pediatric ALL has reached 97.9%, the 5 year survival rate of standard risk ALL is 84.3%, while the rate for high risk ALL is 52.8%. The first CR rate of pediatric AML is 72.5%, while the 5 year survival rate is 45.6%. In 1999, the hospital became the first to implement organ transplantation in the country. It was also among the first batch of hospitals to develop the skill of peripheral blood stem cell transplantation and umbilical cord blood transplantation in treating leukemia and lymphoma.

Megaphone icon indicating a key point or announcement.

Research on Leukemia Antibodies

To further improve the cancer treatment, the hospital places great emphasis on combining research with clinical practice. The Department is also equipped with the most advanced instrumentation to conduct researches on hematology oncology malignant diseases. It has received many awards. It has published more than 80 essays in national and international medical journals. In addition, it has developed over 30 kinds of leukemia cell monoclonal antibodies, 20 of which are verified and coded by an internationally approved institution. The newly developed antibodies are serving as a strong base for the immunotherapy, purging and targeted treatment. At present, under the sponsorship of the National Natural Science Foundation, the Department is researching into the genetic engineering of those antibodies. It is hoped that the antibodies could be applied to clinical treatment in the near future.

The Department has also invited overseas specialists from the United States and Japan to host seminars in order to keep up-to-date on global advancements in medication and the latest changes in international standards. Medical professionals have also been sent to developed countries for further studies on modern clinical practice and research techniques.



病童獲贊助吃美式快餐

Patients enjoying American fast-food offered by a sponsor



1月19日陳慧琳小姐及麥潤壽先生與病童及家屬同度愉快時光
Ms Chen Wei Lam, Kelly and Francis Mak had a nice time with the child patients and their family members on January 19.



- 1 本會與東華三院賽馬會沙田綜合服務中心合辦「心靈音樂盒」計劃，參加者於12月29日暢遊音樂農莊，在1至2月學習樂器，並於2月18日舉行表演及嘉許禮，共24位病童及其兄弟姊妹參加。
- 2 1月21日「義工日」工作坊共32位會員出席，內容包括：遊戲、探病技巧、與病童及青少年溝通技巧及小組經驗分享。
- 3 2月4日第四次骨瘤支持小組的主題是：「介紹適合骨瘤病童及青少年進行的運動及需注意地方」，由物理治療師姚慧琴女士主講，共22位參加者出席。
- 4 2月25日第三次急性淋巴細胞性血癌支持小組的主題是：「急淋兒童如何有效攝取足夠營養」，由營養師林智君小姐主講，共20位參加者出席。
- 5 3月8日香港迪士尼樂園的巴斯光年及義工探望兒童癌症中心的病童。
- 6 4月16日青年組第一次聚會內容是互相認識、分享參加ICCCPO會議經驗及探討未來路向。
- 7 合唱團定期練習於每月第二個星期六舉行(5月13日、6月10日)，時間：下午2:30-4:30，地點為包玉剛爵士癌症中心三樓，歡迎參加。

繼續祝福你們

由於缺乏經費，計劃協調員這個職位即將取消，故此，我亦會於五月離任。雖然離別感覺依依不捨，但我仍會紀念各位小戰士，及繼續為你們祝福和打氣。本會將需要會員義互協助處理會務，如有興趣，請致電2632 1144查詢。

陳慧琳

Farewell

I am very sorry that due to the shortage of funding I will be leaving in May. I will miss all the Little Life Warriors and will remember you always. Our Society desperately needs your help so that we can carry on with our work. To find out how you can help us, please call 2632 1144 for further information.

Brenda Chan
Project Co-ordinator

我們需要您的支持

本會是由兒童癌症中心的醫護人員、病人及病童家長組成的互助組織，服務包括探訪、支持小組、病房茶聚、週年聯歡會、合唱團、出版通訊及書籍、閱讀計劃、與國內醫院交流和資助會員參加國際會議和義工訓練等。

如欲支持本會工作，歡迎致電2632 1262查詢。捐款可以劃線支票寄交香港沙田威爾斯親王醫院兒童癌症中心閣樓G15室。支票抬頭請寫「香港中文大學」，並指明款項捐贈「生命小戰士會」，捐款\$100或以上可憑收據申請減免稅項。

We need YOUR support

Our Society is a mutual help organization, with membership derived mainly from the medical staff, patients and their parents from the Children Cancer Centre. Our work includes visits, supportive groups, hospital ward tea parties, an annual gathering, choir, publication of books and newsletters, English activities, exchange visits with the hospitals in China, sponsoring our members to attend international conferences and volunteer training.

If you want to support our work, please call 2632 1262 and ask for further information. Donations can be made by crossed cheque made out to "The Chinese University of Hong Kong". Please write on the back of the cheque that the donation is for the sponsorship of "The Little Life Warrior Society" and post it to Rm. G15, The Children Cancer Centre, Prince of Wales Hospital, Shatin, Hong Kong. Donations of over HK \$100 can be claimed as tax deductible.

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本會為國際兒童癌症家長會協會會員
Our Society is a full member of the International Confederation of Childhood Cancer Parent Organisations (ICCCPO)
網址 Website: www.icccpo.org