



生命小戰士會會訊

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Little Life Warrior Society Newsletter 11/2003

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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 Child-
hood Cancer Parent Organisations
(ICCCPO).

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週年聯歡會花絮



生命小戰士會會訊
1 Little Life Warrior Society Newsletter

因沙士關係順延至8月23日舉行的週年聯歡會，共有 275 人參加。很多康復了十年、二十年的病友和家長，知道聚會有一個「向阮教授致意」的環節，都紛紛扶老攜幼出席，爭相跟阮文賓教授拍照留念，場面非常感人。

正如大會司儀鄧藹霖所說，這個聯歡會跟一般活動的氣氛不一樣，參加者彷彿出席溫馨的家庭聚會。對病友和家長來說，的確是加入了對抗兒童癌症的「大家庭」，能夠藉著每年一次的聚會，與多年來並肩作戰的病友、家長和醫護人員互相問好，歌頌生命有價，真是一件非常美妙的事情！





★ Highlights of the Annual Gathering ★

The annual gathering was rescheduled to 23 August because of the SARS epidemic. The event attracted 275 participants. On hearing that there would be a session dedicated to Professor Yuen, many patients who had recovered ten or twenty years ago joined the event, along with their parents. Many of them wanted to have their photographs taken with Professor Patrick Yuen. Their show of respect and affection towards Professor Yuen was most touching.

Ms Blanche Tang, the Master of Ceremonies, commented that the atmosphere of this gathering was noticeably different when compared to other events. To many participants, it was like attending a family gathering because they are all members of the "big family" of cancer fighters. The annual gathering is a wonderful opportunity for the patients, their parents and the medical staff to gather together to celebrate the preciousness of life!



擦亮香港大行動的召集人葛珮帆博士(後排右二), 多謝小戰士們將他們繪畫的圖畫製成電子卡。
Dr. Elizabeth Quat (back row, 2nd from right), BrightenHK Campaign Convener, thanks the Little Warriors for drawing the eCards.



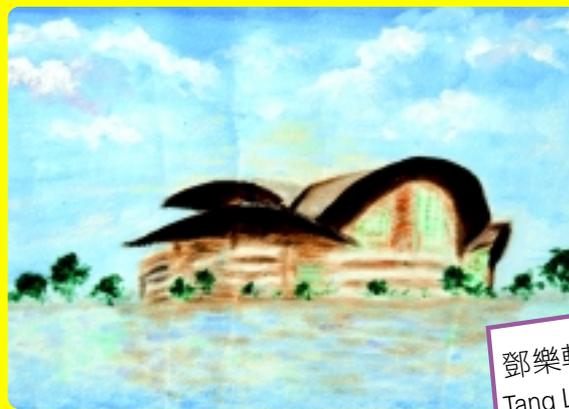
馬昕 4歲
Jenice Ma Age: 4



如欲欣賞更多可愛的電子卡, 可瀏覽 www.brightenhk.org.hk。
If you want to see more lovely eCards, please visit the website: www.brightenhk.org.hk.



余穎嫻 9歲
Yu Wing Han Age: 9



鄧樂軒 14歲
Tang Lok Hin Age: 14





你有沒有見過CCC的醫生和護士玩遊戲可以那麼投入?
Have you ever seen doctors and nurses at the CCC play so hard?

常司儀詢問會徽設計比賽得獎者蘇雪盈(中)的創作經過。她直言部分靈感來自《燃點希望》一書封面的彩虹。 Kwong Suet Ying (centre), winner of the Society's emblem design competition, says that the idea for her winning entry came from the rainbow on the cover of the book "Light in the Life Battle".



從前在病房不曾玩得那麼愉快，現在倒要盡情一點了。
Group games are not allowed in the ward but you can play now!



智樂兒童遊樂場協會的Dr. Bibi為小朋友帶來不少歡樂。
Dr. Bibi, the magician from the Playright (Children's Play Association) brings lots of fun to the children.



由醫生、護士及病童攜手演出的話劇《我在CCC的日子》非常精彩，贏得全場最多掌聲。
The audience applauds the performance of the doctors, nurses and child patients, in the play "My Days at the CCC".





由康復病童組成的合唱團除了將一曲《祝福您》衷心獻給阮教授，更帶領參加者唱出《生命有價》。

The choir sings songs dedicated to Professor Yuen on his retirement.



張黃希鸞女士(右)除了教導孩子唱歌，還帶領他們向阮文賓教授(左)獻花。

Candice Cheung (right) teaches the kids how to sing and leads them to pay tribute to Professor Patrick Yuen (left).



1998年前的病友快來開心心跟敬愛的醫生來個大合照。Many of the patients diagnosed with cancer before 1998 have recovered. How happy they look in this group picture with their doctors.



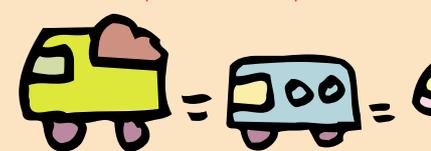
吳家榮(左)以前是骨癌病人，現在是中醫學院學生；他與病魔搏鬥的故事很能振奮其他病童的心。

Gary Ng (left), who has recovered from bone cancer, is now a medical student at the Chinese University of Hong Kong. His story of fighting the disease has brought hope to many child patients.



這次聚會得以順利舉行，全賴各位威爾斯親王醫院、愛心童樂營同工及台前幕後義工的努力。

The gathering could not have been so successful without the help of all staff and volunteers, including those from the Prince of Wales Hospital and Camp Quality Hong Kong.





馬陳嘉賢(左)不但跟著名DJ鄧藹霖(右)主持聚會非常合拍,更是「幕後黑手」之一,無論彩排、撰寫劇本、構思大會主題和集體遊戲,都有份參與。
Stephanie Ma (left) not only works well with celebrated DJ Blanche Tang (right), but she has also has a hand in planning the event, writing the scripts and organizing the games.

後感

馬陳嘉賢

自從答應參與8月23日聯歡會的籌備小組之後,不時萌起「退出」的念頭。對於我們幾個毫無經驗的「師奶兵團」來說,這實在是又大又難的事;因為我們從未試過撰寫劇本及司儀稿、編排歌舞和設計遊戲。可是看見各委員的熱誠投入,加上神賜我排山倒海的創作意念;雖然愈做愈辛苦,但卻愈做愈興奮。

最初的構思只是新舊康復者的週年聚會,後來演變成主題是「生命有價」的聯歡會;以往只有幾位康復者參與表演和玩遊戲,今次所有人都有份參與。初時只想創作一個令大家有共鳴的話劇,後來加入了梁迪嘉和吳家榮激勵人心的見證。起初只計劃唱一首歌祝福阮教授榮休,後來考慮成立「生命小戰士合唱團」以回饋社會……。這些充滿創意的意念,都是我們從包黃秀英女士兒童癌症中心的會議室孕育出來的。

回想集體創作劇本時,我們經常被自己設計的對白,弄至捧腹大笑。可是當感到疲乏時,也曾懷疑為什麼要做得那麼辛苦。現在我終於明白了,不是為病童、不是為醫生,而是為了自己。能夠認識「生命小戰士會」的委員,與她們合作,我感到很榮幸;且讓我感到自己的生命比想像中更有價值,誠如今次的主题——「生命有價」一樣。

原來付出時,得益的永遠都是自己。

Epilogue

Stephanie Ma

The idea of quitting the 8.23 gathering organizing committee often came to me after I had agreed to join it. It was a daunting task facing us because we did not have any previous experience in organizing such events. We had never written any scripts, staged performances, or planned games. However, as time went by, I became increasingly excited about my involvement in this committee; I felt inspired by the enthusiasm of the other members. Despite my inexperience, I began to realize that God had given me the power of creativity.

We came up with so many great ideas during those times in the CCC meeting room. At first, the 8.23 gathering had no specific purpose — it was just a reunion of recovered cancer patients. Eventually, it developed into a gathering with the theme of "Life is Precious". We wanted everyone in the gathering to take part in the performances and games.

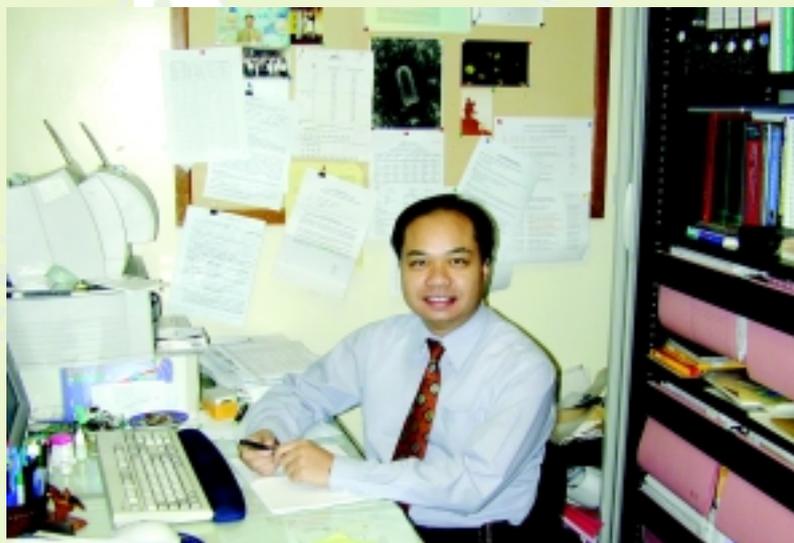
The biggest planned event was to be the play. Originally we only intended to put on a simple play and hoped that it would touch the hearts of the audience. However, as the planning developed, we decided to include the stories of Wendy Leung and Gary Ng because they were so moving. We also planned to express our gratitude to Professor Yuen on his retirement. That idea led us to setting up the Little Life Warriors Choir, which will be active in community service.

We had so much fun when we were writing the script. We could not stop laughing at some of the lines we had written! However, it is fair to say that during those times when I felt really tired, I did sometimes question why I had chosen to take on the responsibility. I now realize that I did this not just for the patients and the doctors, but also for myself. I am so honored to have worked with the organizing committee. My life has become more meaningful and rewarding than I've ever thought it could be. I feel that the theme for this gathering is a reflection of my own belief — Life is Precious. If you sometimes think that you have given out a great deal to help others, you will discover that you are the one who benefits the most.



病毒學家怎樣幫助癌症病童？

「沙士」一役，令香港中文大學醫學院微生物學系的陳基湘醫生和他的同袍頓成炙手可熱的「紅人」。原來全港現有的臨床病毒學家並不多，他們不單在疫症肆虐期間為市民服務，更是追查各種病毒元兇的幕後功臣。陳醫生跟包黃秀英女士兒童癌症中心（簡稱CCC）的關係密切，究竟他的專業可以怎樣幫助孩子對抗病魔？



陳基湘醫生 Dr. Paul K. S. Chan

病毒學家究竟做什麼

「如果社區沒有爆發如禽流感或沙士等大型疫症，普通人可能不會留意我們的工作。簡單來說，我的工作包括四方面：第一是學術研究，第二是病毒化驗服務，第三是臨床斷症治療，第四是教學工作。」

「以沙士為例，我跟同事要在實驗室培植從病人身上找到的病毒，以電子顯微鏡進行分析研究。然後，要為病人進行傳統或快速測試，以確定病人是否患上非典型肺炎，幫助前線的醫生斷症落藥。由於疫症期間，工作量大增，所以教學及其他非緊急性的工作和會議只好暫停。」

為何要跟 CCC 合作

「我跟傳染病科、兒科和CCC的合作比較多，因為這幾個部門對病毒診斷及研究有較迫切的需要。例如，我經常與CCC的醫生舉行定期會議，原因是癌症病童的免疫系統較差，特別是剛接受完骨髓移植或化療的小孩，很容易受到病毒感

染。很多與人類共存的病毒對普通人並沒有影響，但卻可以令這些病童有生命危險。能夠成功找到癌症與某些病毒的關係，是從事這項專業的最大樂趣之一。」

你如何幫助癌症病童

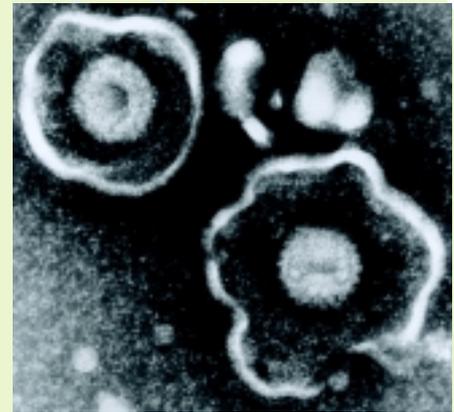
「自從1996年我開始跟CCC的醫生合作進行各種有關病毒的研究。比較近期的研究包括：測試某種新感冒藥是否對曾接受化療的小孩有效、可否服用抗肝炎藥以消除地中海貧血病童的丙型肝炎病毒等。」

「最成功的例子，要算是我們首先發現疱疹七型病毒對骨髓移植病童的威脅。倘若他們不幸受到病毒感染，會引起腦炎，甚至有生命危險。*因此，現在所有剛接受骨髓移植的孩子，每星期都要接受血液檢查，以測試有否感染疱疹病毒。如果發現有任何感染，醫生將會及早使用特效藥物，以保障孩子的健康。」

* 有關研究論文可參閱 www.childcancure.org.hk/publications/

How do Virologists Help Cancer Children?

The outbreak of the SARS epidemic in Hong Kong has made instant stars of Dr. Paul K. S. Chan and his colleagues at the Department of Microbiology, Faculty of Medicine of the Chinese University of Hong Kong. In Hong Kong there are less than a handful of clinical virologists. When the SARS disease was raging in Hong Kong, these clinical virologists had not only help in patient management, they had also worked behind the scene to track the culprit virus, and to provide diagnostic services. Dr. Chan has a close relationship with the Lady Pao Children's Cancer Centre (CCC). How did he apply his expert knowledge in helping the children fight the disease?



電子顯微鏡下的疱疹七型病毒
The electron micrograph for Herpesvirus 7

What does a clinical virologist do?

According to Dr. Chan's personal account:

"If it hasn't been for the outbreak of a serious epidemic like SARS, most people wouldn't have cared much about what we do. Simply speaking, our job covers four main areas: academic research, teaching, viral testing, and advice on management of viral diseases.

"Take SARS for example. My team had to detect the virus from patient's sample using various means including traditional method such as electron microscopy to see and to identify the virus, also modern methods such as molecular techniques and gene sequencing to further characterize the virus. These tests are essential in helping doctors to correctly diagnose SARS cases and administer the appropriate treatment and infection control measures. Because of the huge increase in workload during the outbreak of the epidemic, we had to put aside other routine duties, such as research on other viruses, teaching of medical students and other non-urgent work including our regular clinical meeting with CCC."

Why was there a need to cooperate with CCC?

"I usually work closely with the department of infectious diseases, pediatrics and CCC, because these units have a more pressing need for viral diagnosis and research. For example, I frequently meet with doctors of the CCC. The main reason is that cancer can greatly weaken the immune systems of the child patients. This is especially true for

children who have undergone bone marrow transplant operation or chemotherapy. They are particularly susceptible to viral infections. Many viruses that normally have no effect on healthy people can cause life-threatening diseases to cancer children. My major research interest is on elucidating the role of viral infections in human cancers. These research work is always my source of job satisfaction."

How do you help cancer children?

"I've been working closely with the doctors at CCC on research projects relating to viral infections in immunocompromised children since 1996. One of our recent project was on the evaluation of a new drug for treating common cold. Our aim was to find out if this new drug can be effectively and safely applied in children who have undergone chemotherapy. Another recent project was to examine the efficacy of a new combination of drugs for treating hepatitis C infection in Thalassaemia children.

"The most successful example over the past few years is that we were the first to discover a new disease association human herpesvirus 7. We have confirmed that the newly identified human herpesvirus 7 is able to cause fatal encephalitis in children who had received hemic stem cell transplant. * To follow this discovery, we have set up a rapid diagnostic test to identify these cases, so that immediate treatment can be given to the child."

*The Abstract of "Case report: Human herpesvirus 7 associated fatal encephalitis in a peripheral blood stem cell transplant recipient" can be found in: www.childcancure.org.hk/publications/



永遠的生命小戰士

廣桓父母



鮑廣桓兒童慈善基金標誌

Logo of Pau Kwong Wun Charitable Foundation

可愛的廣桓
Brian, the
lovely child

舊事舊物

今天是星期天，有空清理家居雜物，這是五年來首次收拾廣桓的遺物。太太很想扔掉已生鏽的單車，最後我還是把單車的響號及坐位拆下來保留，因為它曾經陪伴兒子度過許多歡樂時刻。我再將一個放滿另類療法藥物的膠箱扔掉，細看每個貼上來源及日期的盒子，一幕一幕四出奔跑的記憶再次湧上心頭。

1991年3月廣桓患上血癌，在威爾斯親王醫院接受完第一階段的化療，還趕得上在九月到幼稚園上學。直到1995年，我們的生活大致很愉快，全家都非常珍惜相處在一起的時間。1995年10月，廣桓的病復發。七歲的他知道這個壞消息，並沒有驚惶失措，反以堅定的目光看著我，默默地點頭；不一會與病友玩耍，笑容又出來了。多麼堅強的小戰士！

永不言棄

廣桓血癌復發後，為了不錯過任何有可能幫助廣桓的方法，我開始到世界各地尋找各種另類療法和藥物。我曾拜訪中國的名醫和到過美國和墨西哥的另類療法醫院參觀。由於廣桓對院方的治療方案反應良好，所以並未採用其他治療。1997年10月，很不幸地廣桓的病再度復發。在這嚴峻時期，我每晚也會致電外國的醫療中心，請教世界各地的白血病專家，以了解我兒的醫療選擇。今天扔掉從未用過的另類藥物，都是這段時期找回來的。

雖然藥物已無法幫助廣桓，但是我夫婦倆卻絕不放棄。另一方面，我們也得預備最壞一刻的降臨。如廣桓的狀態良好加上天氣許可的話，便做一些他喜歡的事情，例如打籃球、吃下午茶、到海洋公園和郊遊等。

愛的轉化

1998年4月的一個清晨，廣桓終於離我們而去。雖然我們共同生活只有短短十年，卻留下很多精彩片段。七年治療期間無數的記錄和生活片段，都成了我們珍貴的回憶。之後，我參加了一個國際性會議，一位美國教授談到如何處理女兒病逝後的哀傷情緒，她主張「轉化」取代「忘記」。

我們決定實行這個主張，成立一個以廣桓命名的慈善基金，1998年底正式註冊為非牟利慈善團體。除了為紀念愛兒，主要是希望召集更多家長，幫助有需要的病童及提升他們的生活質素。盼望醫護人員、志願機構和病童家長，可以各展所長，以不同形式幫助這些生命小戰士和家人渡過難關。

欲閱讀詳盡的全文，請瀏覽網址：

www.childcancure.org.hk/chinese/cured_stories/
若希望對「鮑廣桓兒童慈善基金」有進一步的認識，可致電(852) 2796 0818或以電郵 info@pkwfoundation.org 查詢。

Eternal Little Life Warrior

Parents of Brian Pau Kwong Wun

Memorable Events and Memorable Belongings

Today is Sunday so there's time to do some domestic chores. This is the first time in the past five years that I have thrown away something belonging to Brian — a bicycle with rusty wheels, which my wife had been asking me again and again to throw away. However I'll still keep the bell and the seat. The bicycle was one of the many things that gave Brian happiness and provided him with his most joyful moments. I also got rid of a plastic box labeled "Brian's alternative medicine". I looked at the labels affixed on each

box, memories of those heart wrenching and anxious days came flooding back into my mind.

It was March 1991 when Brian was diagnosed with leukemia. After months of chemotherapy treatments in the

Prince of Wales Hospital, he started his kindergarten in September. Before 1995, other than some anxious moments, everything went fairly well.

We appreciated every moment that was ours over those years. In October 1995, Brian suffered from a relapse. I told him, "the bad cells are active again so you'll have to go through chemotherapy treatment again." He was only seven then but probably knew it was a bad news. However he showed no fear and didn't cry. Instead, he looked straight at me and firmly nodded his head twice. What a strong Little Life Warrior! Not long after he finished his cardiac test he returned to the ward and started playing with other children — he had a broad smile on his face again.

Never Give Up

After his second series of chemotherapy in 1995, I started to spend every spare moment looking for alternative medical treatments to help Brian in his battle against leukemia. I investigated every source of information to determine the applicability of any new treatment methods. I visited a lot of places. In Sichuan PRC, I met with Chinese professors. I also visited the alternative treatment clinics in New York, USA and Mexico. I really did not want to miss any possible treatments that could help Brian to recover. However, since Brian had reacted positively to the local

hospital's treatment, we did not use other alternative treatments. In October 1997, Brian suffered a second relapse. We were greatly agonized by this news. In the midst of this critical moment, I contacted other hospitals and cancer treatment centers in other parts of the world to seek their opinion on my son's present situation and chances of survival. What I discarded today was mainly the medicines I collected during this period.

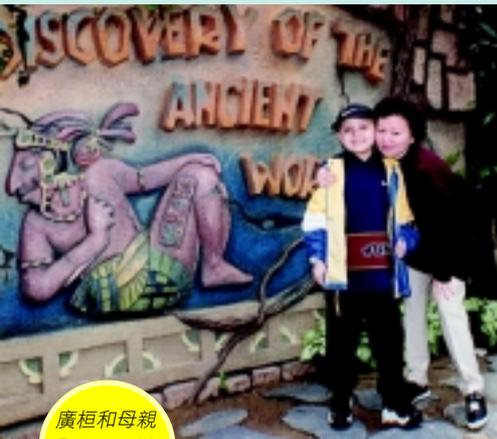
In early February 1998, we were told that no medicine could help Brian. However we still hoped for a miracle. It should be the time for him to relax. We would not give up hope for any second. On the other hand, we prepared for the worst. We took a proactive approach and made our best effort to ensure our beloved son enjoyed life as much as possible. If Brian felt good and the weather was nice, we would go to places and do the things Brian loved. During that time, we often went to play basketball, enjoyed having afternoon tea, visited Ocean Park and went on picnics.

Transformation to Love

On a breezy sunny morning in April 1998, Brian departed. With us now are a lot of memories of Brian and the medical records we kept of his seven-year treatment. We also recorded all the episodes in our daily lives, which becomes the most precious things left.

In September 1999, I attended a national conference held in England. I was greatly impressed by a US professor who advocated "transformation" rather than "forgetting". We then adopted her suggestion and transformed our past experience into a force to assist children suffering from leukemia. At the end of 1998 we set up a charitable foundation in Brian's name (Pau Kwong Wun Charitable Foundation). We aim to offer and provide emotional and psychological support to child cancer patients and their families. We hope that medical staff, charities and parents will work hand in hand in support of these Little Life Warriors.

(With sincere gratitude to Miss Kammy Yuen for translation of the English version.)



廣桓和母親
Brian with
his mother



This is an extract from the original article. To read the whole article, please visit the website:

www.childcancure.org.hk/english/cured_stories/

If you wish to obtain more information about Pau Kwong Wun Charitable Foundation, please call (852) 2796 0818 or e-mail info@pkwfoundation.org.



每一天都是美好的

如果剛出席完本年度的「生命小戰會週年聯歡會」，大家應該對分享個人經歷的迪嘉並不陌生；不過若錯過了這個盛會，你也必定希望認識這個性格堅強和樂於助人的少女。

第一回合：暫勝骨癌

十一歲那年的暑假，迪嘉的右膝蓋起了一片小腫塊。母親帶她看門診，醫生懷疑她患上骨癌。她記得很清楚，是在9月1日開始抗癌之旅，那天她到了包黃秀英女士兒童癌症中心，接受詳細的身體檢查。

起初迪嘉對化療反應欠佳，腫瘤面積仍不斷擴大；改用藥性較強的藥物，才成功令腫瘤縮小。完成了化療，骨科醫生又著手為她進行換骨手術。雖然從此不能夠跑跑跳跳，但能夠保存整條腿，她還是非常慶幸的。

回想當時年紀太小，迪嘉不曉得自己可能有生命危險，後來才知道事態嚴重。不過，病中可以看漫畫、玩遊戲機，還有親友千依百順的照顧，她覺得住醫院並不是那麼糟糕的。

第二回合：難防復發

停了藥兩年多的初夏，迪嘉再次感到不適，連續咳嗽超過兩個月，有時甚至呼吸也感到困難。醫生看過肺部的x光片，告訴她癌細胞已轉移至肺部，要開胸切除腫瘤和再次接受化療。

迪嘉跟其他癌症復發的病童一樣，非常抗拒再次接受治療。後來得到家人和醫護人員的鼓勵，才慢慢接受現實，並開始學會珍惜每一天。

養病期間，紅十字會的義工到家裡為她補習；但因沒有正式升讀中一，尋找中學升讀中二



迪嘉(左二)攝於「黃寬洋青少年進修獎學金」頒獎典禮
Wendy (2nd from left) in the Felix Wong Youth Improvement Award Ceremony

曾遇到不少困難。幸好她最終可以重返校園，更在2002年7月成為「黃寬洋青少年進修獎學金」的得主，以表揚她勇於面對人生逆境的精神。

第三回合：小心肺炎

2003年迪嘉應該很快樂，因為她的生活非常充實。她的病情穩定，學校成績不俗，認識了很多好朋友，參加了不少課外活動，還成為「燃點希望大使」一份子，為其他病童打氣。

不過，來勢凶凶的非典型肺炎蔓延全港，打亂了她原有的生活節奏，曾令她和家人感到提心吊膽。由於左右兩邊肺都被切去一部分，萬一不幸被病毒感染，後果必定很嚴重。由於威爾斯親王醫院曾接收不少非典型肺炎病人，每次返醫院覆診，母女都必定戴上口罩和手套，做足所有防禦措施。現在她的心願是疫症不會捲土重來，讓她可以好好地呼吸一口自由清新的空氣。

只要有一天生命，每一天都是美好的。
—— 迪嘉

Every Day is a Beautiful Day

If you attended the Little Life Warrior Society's 2003 annual gathering, you should remember Wendy, the girl who shared her experience with us. If you missed the chance, you might want to know more about this brave and helpful girl.

First Round: Against Bone Cancer

During the summer holiday when she was 11 years old, Wendy noticed that there was a small swelling on the kneecap of her right leg. Initial diagnosis showed that she was afflicted with bone cancer and required immediate treatment. On September 1, Wendy was admitted to the Lady Pao Children's Cancer Centre (CCC), Prince of Wales Hospital. Her long struggle against cancer began. The memory of those early days is still vivid in her mind.

At first, Wendy did not respond very well to chemotherapy. Her doctors tried stronger drugs on her and the tumor shrank. After chemotherapy, the doctors immediately conducted the bone transplant operation on her. Although she could not run or jump like other children and had to use a crutch when she walked, Wendy knew she was lucky that she had not lost her leg.

Thinking back, Wendy thinks that she was too young to know the seriousness of her illness. At the time, she did not think it was too bad to be hospitalized as she could read comic books and play video games there, and was always under the care of her relatives and friends.

Second Round: The Relapse

During the summer, just two years after she had stopped her medication, Wendy did not feel well again. For a period of two months, she was coughing frequently and sometimes found it hard to breathe. A radiogram was taken of her lungs. Cancer was found. An operation to remove the tumor and another round of chemotherapy were required.

Like other child patients who have experienced a cancer relapse, Wendy became resistive to the treatment. However, the care and encouragement of her family and the hospital staff enabled her to face reality and live each day wisely.



迪嘉在週年聯歡會分享經驗。
Wendy shares her own experience in our annual gathering.

During her recovery, Wendy was tutored at home by volunteers from the Red Cross. Subsequently, she gained a place in a secondary school. At first, she did not get along too well with her classmates. However, her teacher explained about Wendy's illness to her classmates and she was then well accepted. In July 2002, she became the winner of the Felix Wong Youth Improvement Award, for her valor in face of great adversities.

Third Round: Beware of SARS

Wendy should be very happy in 2003. Her cancer has stabilized, she does well at school and has made many good friends. She has also participated in the School Music Festival and entered a drawing competition. Joining the "Ambassadors of the Light in the Life Battle" programme has enriched her life. She finds visiting child patients at the CCC very fulfilling.

However, the spread of the SARS epidemic has not only disrupted Wendy's life, it has also caused her family great concern about her health. It would be very serious indeed if Wendy became infected with the virus as she has had part of both sides of her lungs removed. Her mother makes sure that Wendy wears her mask and gloves every time she visits the hospital. Now, Wendy wishes that the virus has disappeared forever, so that she can enjoy the fresh air unhindered by a face mask.

When there is life, every day is a beautiful day.

— Wendy



兒童骨髓移植概觀



陳嘉華醫學博士*

兒童骨髓移植的歷史

利用骨髓治療血病的概念早於1900年經已存在。當時的病人被餵服骨髓，但效果並不理想，而這項技術亦漸漸被人淡忘。第二次世界大戰後，這項治療因核武及核電的發展而再次被醫學界重視。

早期透過血管將骨髓移植到人體內的成敗參半，大多數移植都被排斥，只有少數白血病人的病情獲得輕微改善。其他病人均有出疹、肚瀉、黃疸等可致命的症狀，醫學界對骨髓移植研究的熱情亦因此而於六十年代開始冷卻。

當時已發表有關移植組織的排斥和組織(人類白血球抗原，簡稱HLA)配合的遺傳學，自此醫生可以替病人找尋及挑選出最合適的骨髓捐贈者。第一次成功的骨髓移植個案始於1968年，一位天生缺乏完整免疫系統的嬰兒成功接受親兄弟的骨髓移植，並於35年後仍然保持健康。之後，有更多類似的成功個案，而病者都是患有再生障礙性貧血及急性白血病。至1986年，全球已有超過200間移植中心，每年進行多達5,000宗的移植手術。

與此同時，醫學界發現有製造血球細胞功能的幹細胞可以隨意活動於骨髓及血液之間，這情況在化療後的康復期最為明顯。此外，向病者輸入一種叫集落刺激因素(G-CSF)的蛋白質，有助增加幹細胞的活動。1990年中期，很多移植中心除了使用骨髓外，還採用從外周血收集的血幹細胞。有的甚至以幹細胞取代了骨髓，這個程序叫外周血造血幹細胞移植。

胎盤血又稱臍帶血，是最後被發現跟骨髓一樣，擁有大量的幹細胞。1988年，法國研究人員成功為一

位Fanconi氏貧血病童移植從他胞弟出生時採集到的臍帶血。自此，患有白血病、嚴重再生障礙性貧血或其他血病的病童，得以成功接受臍帶血移植。由於臍帶血的血幹細胞數目不多，因此只適用於兒童或身材較細小的成人。目前醫學界正在研究能否擴大臍帶血幹細胞的數目，讓更多成年人可以受惠。

很多需要接受骨髓移植的病人，都不能從親屬當中找到合適的骨髓。1973年，第一宗非血緣骨髓移植在紐約完成。這次移植成功導致世界各地紛紛成立骨髓捐贈者登記處，美國更於1986年成立全國骨髓捐贈計劃。直至現在，全球已儲存了超過七百萬自願捐髓者的資料，並有超過20間臍帶血庫正在收集和保存初生嬰兒的臍帶血。國際之間還發展出相互合作的機制，以促進辨證、測試及獲得所需幹細胞作移植用途。

幹細胞移植的類型

骨髓是骨骼中的海綿組織，內含幹細胞。幹細胞可以製造血液中各種具有不同功能的血液細胞：減低感染的白血球、將氧氣運往身體各組織的紅血球和控制出血現象的血小板。

倘若幹細胞受疾病影響，骨髓不能正常運作，將會產生過多不正常或未成熟的血細胞(如地中海貧血和白血病)，又或產生過少血細胞(如再生障礙性貧血)。當診斷出這種情況時，以健康捐髓者的幹細胞替換病人的骨髓，進行異基因造血幹細胞移植或可治愈。幹細胞移植亦是治療實體腫瘤的方法之一。為了讓病人接受較高劑量的化療以去除腫瘤，病人原有的幹細胞會首先被提取及冷藏，待完成化療後再次輸入已儲存的幹細胞以作補充。這種以病人本身健康的骨髓或血幹細胞移植的治療方法叫自體幹細胞移植。

幹細胞移植過程

進行移植前，病人要先接受高劑量的化療、或化療加上電療，把不正常的骨髓完全清除。同時，病人的免疫系統亦要先被去除以防止排斥。這個通常為期五至十天的療程叫準備性或條件營造療程。

提取幹細胞的程序會因應骨髓移植所需細胞而有分別。捐髓者先接受全身麻醉，醫生會在手術室使用針筒從捐髓者的盤骨刺皮抽取骨髓。由於每一下骨刺都



佩殷(右)是全港首位接受骨髓移植的病童。(手術於1991年2月在CCC完成)

Gloria (right) is the first child patient who received bone marrow transplant in Hong Kong. The transplant was performed at the CCC in February, 1991.

Overview of Pediatric Bone Marrow Transplantation

History of Pediatric Bone Marrow Transplant

The idea of using bone marrow to treat blood disease is not new. In the early 1900, patients were given marrow orally. Obviously this did not meet with success and interest faded. After the Second World War, this treatment strategy was re-evaluated due to the development of nuclear weapon and generators.

Early attempts to transplant bone marrow into humans via blood vessels were met with mixed success. While a few leukemia patients had transient improvement of their disease, most transplants were rejected. Other patients developed a clinical syndrome of skin rash, diarrhea, and jaundice, which was mostly fatal. The enthusiasm waned in the 60's.

Around this time, the genetics of graft rejection and tissue (called HLA) matching was described. For the first time, physicians were able to match and select the most suitable marrow donor for the patient. The first successful bone marrow transplant of the modern era was performed in 1968, when an infant born without an intact immune system received a transplant from a sibling. This patient remains healthy 35 years later. Similar success was soon reported for patients with severe aplastic anemia and acute leukemia. By 1986, more than 200 transplant centers worldwide were performing 5,000 transplants annually.

Around this time, it was discovered that stem cells (which produces subsequent generations of blood-forming cells) move freely between the bone marrow and the blood stream. This exodus of stem cells into the circulation is most evident during the recovery phase after chemotherapy. It can be also enhanced by the administration of proteins called colony-stimulating factors (G-CSF). By the middle of the 1990's, many transplant centers were using stem cells collected from peripheral blood instead of, or in addition to, bone marrow. Such a procedure is called peripheral blood stem cell transplantation.

The latest player in the field is placental blood. Like bone marrow, blood collected from the placenta (also known as umbilical cord blood) is rich in stem cells. In 1988, researchers in France transplanted placental blood collected from a newborn child to the baby's sibling — a

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child with Fanconi anemia. Since then successful cord blood transplants have performed on children with leukemia, severe aplastic anemia, and a number of other blood disorders. Due to the small number of stem cells in a placental blood collection, cord blood transplantation is currently only a suitable option only for children and, possibly, small adults. Research is underway to determine if cord blood cells can be expanded so that more adults can benefit from this therapy.

The majority of patients who could have benefited from a transplant do not have a brother or sister with matching marrow type. In 1973, the first unrelated marrow donor (matched for HLA tissue type) transplant was performed in New York. The success of this procedure led to the establishment of marrow donor registries around the world. In 1986, the National Marrow Donor Program in the US was created. Currently there is information on over 7 millions volunteer donors worldwide. Similarly over 20 umbilical cord blood banks are collecting and preserving placental blood from newborn infants. There is international cooperation to facilitate the identification, testing, and procurement of stem cells to be used for transplantation.

Types of Stem Cell Transplant

The bone marrow is a spongy tissue found inside bones. It contains stem cells, which divide and generate different kinds of blood cells in the circulation. The white blood cells fight infection; the red blood cells carry oxygen to body tissues; and the platelets control bleeding.

Diseases affecting the stem cells result in bone marrow malfunctioning: either by producing too many defective / immature blood cells (e.g. thalassemia and leukemia), or too few blood cells (aplastic anemia). When these conditions are diagnosed, replacement of the patient's marrow with stem cells from a healthy donor may lead to a cure. This type of transplant is called an allogeneic stem cell transplant. A stem cell transplant may also be part of





只能提取少量骨髓，所以醫生要在多個皮刺的部位提取足夠的骨髓。所提取的骨髓經過濾後，會即時灌輸入病人體內。若使用外周血幹細胞，捐髓者會接受三至五天的集落刺激因素，讓幹細胞從骨髓移動到血液中。醫生會使用特殊的針筒，從捐髓者手臂或腹股溝的大動脈把血液分流，再由一部由電腦操控的細胞分隔器把幹細胞抽出，而剩餘的血細胞則會回流到捐髓者體內。

骨髓移植通常於條件營造療程完成後的一至三天內進行。病人會透過導管輸入幹細胞，情況跟接受輸血相似，整個過程需要三十分鐘至兩小時。

骨髓移植的成功率

家長最常問的問題是：「移植中心醫治病童的成功率有多大？」除非能正確地理解移植中心所提供的數據，否則單談成功率是沒有意義的。

幹細胞移植成功與否有賴多個因素，其中最關鍵的是病人進行手術時的病情。病人的白血病若在手術前並未受到傳統化療的控制，即使進行幹細胞移植亦很難治愈，並且復發的機會亦較大。若病人的病情沒有好轉跡象，移植不但未能改善病情，病者更不適宜進行移植手術。還有，病人的健康狀況也是手術成功的重要因素，病人於條件營造療程後會較易受到疾病感染、器官功能減弱和身體變得虛弱，患上併發症的機會往往非常高。此外，捐髓者的類別亦會影響移植手術的結果。病人若接受親屬完全相合的幹細胞移植或自體移植，併發症的發病率會較低；而非血緣捐贈者及不全相合幹細胞移植則比較危險。

手術後的併發症

1. 移植物抗宿主疾病 (簡稱排斥)

由於捐髓者的骨髓未能與患者完全相合，當捐髓者的T細胞(白血球的一種)於受贈者體內識別出與己不同的細胞組織而進行攻擊時，便會引起移植物抗宿主疾病，簡稱排斥。若捐髓者和受贈者的基因構造差異較大，排斥的機會亦會較高。現在，平均有二至七成的骨髓移植病人會出現這個問題。當然，接受不全相合或非血緣幹細胞移植的病發機會也較高。

急性排斥多於移植後的數週內發生。發病初期，病人的面部和手會出現皮膚疹，後來會擴散至身體各部分及引起紅腫，像曬傷一樣出現脫皮及水泡的現象。還有，腸胃會感到不適，產生痙攣、作嘔及腹水等情況。若有黃疸症狀，皮膚及眼睛變黃，表示肝臟受到影響。急性排斥可以是輕微和短暫性的，但亦可足以致命，視乎有多少器官受到影響以及其嚴重性。

慢性排斥通常於移植後的三個月後發病，或從急性排斥演變過來。病人多會出現皮膚問題，如出疹、膚色變異及皮膚繃緊；還可能使病人的眼睛及口腔乾燥潰瘍，或肝臟出現不正常狀況及體重減輕。病人亦可能有皮膚疤痕及攣縮、脫髮、指甲剝落、吞嚥及呼吸困難的問題。

急性及慢性排斥均可用藥物抑制T細胞的活動能力，可是診斷及治療均會減弱病人的免疫系統，增加受感染的機會。

2. 感染

病人在整個移植過程中都有可能受到感染。於準備性療程中，高劑量的化療及輻射治療會破壞病人體內的骨髓，大大減少白血球的數量，使身體無法製造抗體。加上人體的前線防禦系統：皮膚、口腔及腸胃，也受到損壞，差不多每位病人均於移植後一至兩週內出現發燒症狀。若發燒由細菌性感染引起，則大都對抗生素有所反應。不過，有時發燒是因為經過漫長的抗菌療程由真菌引起的。

雖然病人體內的白血球數目通常於兩至四週後復原，但其免疫系統的功能仍未回復，受病毒、原蟲、寄生蟲及桿菌感染的機會仍然很高。在正常情況下，機體防禦需要六至十二個月才能完全恢復其功能，所以病人會因排斥及其治療而延誤了康復時間。

因此，病人接受移植後要謹防受到感染，必須養成良好的洗手習慣及避免跟其他病人接觸。嚴密的病情監控及使用預防性抗生素，均有助控制一些潛伏於病人體內的病毒再次活動。

總結

血液及骨髓移植已被確認為治療兒童癌病、血液及免疫系統失調的方案，現在每年有超過二千名病童接受此治療。移植是一項非常漫長又劇烈的療程，病者需要衡量成功的機會及移植會所帶來短期和長遠的副作用，方可決定是否接受此項治療。

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玉媛 (中) 是第 100 位在 CCC 接受移植手術的病童 (1998 年 1 月)
Yuk Wun (Centre) is the 100th child patient who received transplant at the CCC in January, 1998.

the treatment for patients with solid tumor cancers. In these situations, some of the patient's own stem cell can be collected and frozen. This allows a higher dose of chemotherapy to be given to kill the tumors, and the patient can be "rescued" by reinfusion of the previously stored cells. The use of the patient's own, otherwise normal, marrow or blood stem cells for treatment is called autologous stem cell transplantation.

How does Stem Cell Transplant Work?

Prior to transplant, the patient's diseased bone marrow has to be destroyed. This usually involves the use of a combination of chemotherapy drugs, or by a combination of chemotherapy and irradiation, given in very high doses. At the same time the patient's immune system is also eliminated to prevent rejection. This phase of treatment is called the preparative or conditioning regimen and typically lasts five to ten days.

The procedure to collect stem cells differs according to nature of the cells used for transplantation. Bone marrow is harvested in a hospital operating theatre. The donor is put under general anesthesia and a needle is inserted into the hipbone. Over several skin puncture sites repeated bone punctures are performed. A small amount of bone marrow is extracted each time and the total quantity of marrow is pooled, filtered, and transported to the patient's room for immediate infusion. If peripheral blood stem cells are to be used, the donor will receive three to five days of G-CSF to mobilize stem cells to move out of the bone marrow into the blood stream. A needle or special tubing is placed in a large vein either in the donor's arm or the groin. Blood flows into a computer-control machine called a cell separator, which will remove the stem cells and return the rest of the blood cells

back to the donor.

On the day of transplant, usually one to three days after the completion of conditioning, stem cells are passed into the patient through a catheter, much like a transfusion. Typically the infusion takes 30 minutes to two hours to complete.

Success Rate: Is It Worth All the Side Effects?

The question parents most frequently asked is, "What is the success rate of the transplant center in treating my child's disease?" It should be stressed that success rate quoted by centers is meaningless unless it is properly interpreted.

Many factors influence the success of a stem cell transplant. The most important element is the patient's status of disease at the time of transplant. Leukemia that is not under good control by conventional chemotherapy is very difficult to cure by a stem cell transplant. There is a higher chance of leukemia recurrence in these cases. When there is progressive disease a transplant will not help and should not be done. The health condition of the patient is also critical for the success of the transplant. Active infection, poor function of any organ system, and general debilitation are usually associated with a higher complication rate due to the effect of conditioning. Finally the donor type affects the transplant outcome. Autologous and matched sibling donor transplants have a lower complication rate whereas mismatched and unrelated donor transplants are generally more dangerous.

What Complications Should I be Aware of?

1. Graft-Versus-Host Disease (GVHD)

This condition is triggered by the T cells of the donor, which are a type of white blood cells that recognize and attack the body cells of another individual (that of the recipient). The larger the differences in the genetic makeup between donor and recipient, the higher the likelihood of GVHD. On the average 20 to 70% of transplant recipients may develop this problem, and as expected the incidence is higher when stem cells from an unrelated or mismatched donor are used.

The acute form of GVHD usually appears during the first few weeks after engraftment. The earliest sign is often a skin rash on the patient's face and hands. It may spread to other parts of the body into general redness, similar to a sunburn, with peeling and blistering of the skin. The stomach and the bowel may also be affected, causing cramping,

nausea, and watery diarrhea. Jaundice (yellow color of the skin and eyes) is a sign the liver is also involved. Depending on the number of organs affected and their severity, acute GVHD may be mild and transient or it may be severe and life threatening.

The chronic form of GVHD develops several months after the transplant. It may evolve from the acute form or it may present independently. Patients usually experience skin problems such as a dry itchy rash, color changes, and tightness. Dryness or burning of the mouth and eyes, liver abnormalities and weight loss are also common complaints. Less frequently, patients may suffer from skin scarring and contractures, loss of hair and nails, and swallowing and breathing difficulties.

Both acute and chronic GVHD are treated by medications that suppress the overactive T cells. Both the diagnosis and its treatment weaken the patient's immune system, so there is an increased risk of opportunistic infections.

2. Infections

Transplant patients are prone to infections during all phases of the procedure. With high dose chemotherapy and/or radiation during the preparative phase, the bone marrow is destroyed and the white blood cell count becomes very low. Antibody-producing cells are depleted. The skin and the lining of the mouth and intestine, the body's other first line of defense, are also damaged. The patient is almost certain to have fever in the first two weeks after transplant. Most of these episodes are responsive to antibiotics, suggesting the infections are bacterial in origin. Occasionally fungi may be the cause of the fever, especially after prolonged antibiotic treatment.

Even after the white cell count recovers, usually in two to four weeks' time, the function of the patient's immune system remained subnormal. The risk of unusual infections caused by virus, protozoa, parasite and mycobacterium remain significant. It takes 6 to 12 months or more for the



梓軒 (左) 是第 194 位在 CCC 接受移植手術的病患 (2003 年 7 月)
Kelvin (left) is the 194th child patient who received transplant at the CCC in July, 2003.

body defense to function at 100% efficiency. Recovery is delayed by GVHD and its treatment.

Extra precaution is necessary to prevent infection after transplant. Good hand washing and avoiding contact with others who are ill are of paramount importance. Close surveillance and prophylactic antibiotics may also be helpful to manage the reactivation of some viruses dormant in the patient's body.

Summary

Blood and marrow transplantation are now established treatment modality in the management of childhood cancer, blood and immune disorders. Each year over 2,000 children undergo this treatment. It is a lengthy and vigorous procedure. The decision to proceed with a transplant must be weighed between the chances of success against the short- and long-term side effects of transplantation.

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