



生命小戰士會通訊



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Little Life Warrior Society Newsletter

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互助互勉走人生 Encouragement Along the Journey of Life



陳慧恩
計劃協調員
Brenda Chan
Programme Coordinator

陳慧恩姑娘(右一)與
骨瘤康復者真誠分享
Ms. Chan (1st right)
shares her feelings
with bone cancer
survivors.

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1 Little Life Warrior Society Newsletter

面對癌病，人生彷彿突然遇到風暴，令人不知所措；即使康復了，前路似乎仍有很多未知之數，好像歌詞中所寫：「每次看到風暴漸臨，烏雲天空聚雨雲，曾在暗暗自憐，恨這憂鬱氣氛……」。然而，支持小組可以成為暫時的避風港，縱然內心仍感到憂慮、孤單等複雜的情緒，但透過在充滿安全感的氣氛下分享，面對同樣經歷的組員可以舒解情緒、感覺被關懷及了解。

組員之間除了情緒心理上可以互相支援，還可以有實質的支援，包括交流面對疾病帶來的困難及處理方法；分擔實際問題；互相交流資訊，使組員更能適應患病時的生活；一起學習新知識等。每當看見參加者至真至誠的分享、組員的微笑及積極的參與，鼓舞了自己籌辦更多不同的支持小組，讓更多的病童、康復者和家人可以凝聚一起，亦可以在他們的身邊為他們打氣。盼望你也一起參與支持小組，經歷一起與人同行的奇妙感覺！

The lyric of the song says it all. "Every time I see a storm coming and the black clouds gathering, I feel sad about this dark mood" ...

These words poetically describe how everyone feels about cancer. When it comes, it can hit us like a nasty storm. But now, with the establishment of the support group, those who are caught in this storm can find refuge from loneliness and anxiety by sharing with other members.

There is a practical aspect to the support group other than its psychological and emotional effects. Group members can exchange information about their illnesses and medical treatments. Such knowledge can usually help ease their anxiety and raise their hopes.

The active participation of members has encouraged me to continue the effort in organising activities for the support group with the hope of benefiting more child patients, survivors and their family members. I hope you will join us in the support group and experience a feeling that can be nothing short of miraculous!



不一樣的社交 An Exceptional Gathering

我覺得「急淋支持小組」對病童家長很有用，因為除了可以互相支持，更可以重溫一些醫療知識和交流治療心得。即使家住深圳，長途跋涉來參加聚會的金錢及時間花費很大，我也會繼續支持這項活動。

偉宏母親

I found the ALL support group very useful. We could share our experience in patient care. Even more importantly is the encouragement we give each other to ease the anxiety during our ordeals. I live in Shenzhen, but I think the group is worth my continuous support even though it means that I have to spend lots of time and money on traveling to Hong Kong to join the group.

Mother of Wai Wang



偉宏(中)
辭勞苦來
Wai Wang
think it's w
a handing
group.



參加者
We are
family!



仲賢(右一)三母子同來參加小組
Jacky (1st right) and his family members join the group.

仲賢接受完治療後，我們希望知道更多醫療知識，幫助他順利康復。參加「骨癌支持小組」的感覺很好，除了可以認識更多科技新資訊，更可以透過分組討論，互相幫忙。

仲賢母親

Although Jacky's course of treatment has been completed, I feel there is a need for me to learn more about patient care to help him recover. I feel so pleased about joining the bone cancer support group because in the group discussions I can obtain the latest information about cancer care.

Jacky's Mother

錯過
獲邀參加
為可以對
資訊。戚
的知識，
及家長獲
預留時間

I was interested in bone cancer support group but I was too busy with my schoolwork to attend the second meeting. This time I joined because it was a group support meeting for us to learn more about the disease and cancer relapse. Dr. Chik gave us a lot of information and we can understand. Hope that you can join the gathering that you should.

活動 Gathering

一家三口，不參加聚會。
and his family
well worth while
the all support

感覺就像一家人
e just like a big

參加者都非常珍惜交流的機會
It's great to have the
opportunity to
exchange opinions.



能夠與病友及家長分享辛酸史，不但感到份外親切，更有「感同身受」之感。聚會時，家長可以分享烹調湯水的心得，互相瞭解；另一邊廂，病友們熱烈地談論最想吃東西、最想去的地方……。知道自己並不是孤單地作戰，還有很多人在為你打氣，真是好嘞！

奕舒

Through sharing and discussion I have become intimately close with other patients and parents who have gone through the same experience. I can feel their emotions when they tell their stories. In the support group gatherings, parents comfort each other and exchange ideas about looking after their children with cancer, while child patients talk about their thoughts and dreams. It is so comforting to know that you are not fighting the battle alone, and that there are many people out there cheering you on!

Katherine

了第一次「胃癌支持小組」，當我第二次聚會，便決定非來不可，因為這種病有更深入了解及獲得相關的新其感醫生講解有關食物營養及複雜內容充實、深入淺出，令一班病友受益良多。盼望下次的聚會，你也能出席！

偉航

the topic of the first meeting of the up but failed to attend because I was work. Fortunately I was invited to the e, I made up my mind to go regularly set up especially for us and can help e illness and the latest treatments. useful and interesting talk on nutrition explained so clearly that we could all ou will join the next meeting. This is a n't miss!

Stanley



雖然功課繁重，偉航仍望更多參與。

Stanley makes time to attend the support group because he finds it so helpful.



敏卿(左)與奕舒(右)都是支持小組的骨幹
Peace (left) and Katherine (right) are active members of the support group.

參加支持小組可以增加有關知識，對自己的身體情況加深認識，對突然而來的身體變化認知，及早知道身體有什麼毛病。同時，更可以認識不同時期的病友，分享患病的經過和心得。這不但是個普通的社交活動，還使康復者增加自信，真是很有意義。

敏卿

From the support group, I have learned much about bone cancer. I have met other child patients and we share our experiences. The group meeting is much more than a social gathering. It is a very meaningful event that helps to boost the morale and self-confidence of child cancer patients.

Peace





預防感染有辦法

戚其威醫生、張瑞心護士

無從入手。因此如廁、咳嗽或打噴嚏後；處理食物及進食前；處理糞便、嘔吐物或呼吸道分泌物染污的物件後；為幼童或病人更換尿片後；以及護理導管前後，都應洗手。無論病童或照顧病童的人，都要互相鼓勵一起做。

星仔很高興可以戰勝惡菌，於是告訴其他小朋友要保持個人衛生，勤洗手，防惡菌。衛生大使也提醒各位住院的小朋友及家長其他有效預防感染的方法——就是減少攜帶大量個人用品入院，方便病房進行消毒及清潔工作。病童不應分享飲食，而探訪者絕不應在病房內進食，以防交叉感染。探訪者應使用醫院內的公廁，切勿使用病童的洗手間。已隔離的病者及其家人亦不可接觸其他病童。

星仔希望各位小朋友可以減少併發症，順利完成療程，開開心心地生活。

星仔整天肚痛、腹瀉、食慾不振，還有輕微發燒。媽媽立即帶他去看醫生，醫生要他留院觀察。於是病房孖生大使出動，希望查出星仔得病原因，想辦法對付致病的惡菌。

終於有大發現。原來星仔吃東西前及如廁後都沒有洗手。他經常借用別人的物件、玩具，用後也沒有洗手。照顧星仔的姐姐處理食物時，沒有將雙手洗乾淨，有時也沒有將食物完全煮熟。星仔喜歡與其他人分享食物，所以惡菌經由雙手進入口中，在肚子搗蛋。

於是衛生大使跟星仔商量，想出了幾個對付惡菌的秘密武器：

食嘢前洗洗手，細菌唔會走入口。

遊戲後洗洗手，細菌唔會帶埋走。

如廁後洗洗手，快D將細菌冲走。

星仔想了一想，又問衛生大使，入住醫院後是否毋須再怕惡菌作怪？衛生大使連忙搖頭說不，反倒要他特別注意清潔，還邀請了姐姐和媽媽一同細聽原因。惡菌可以在任何地方透過空氣及接觸媒介傳播，如果用正確方法洗手，病菌便

讓愛飛揚

本會的「聯歡會暨週年議會」將在8月28日(星期日)下午3時至7時，於香港中文大學醫學院深造中心(公共衛生學院)舉行；敬請會員及家屬預留時間參加。

Let Love Fly

Our Annual Gathering and the AGM will be held on 28 August (Sunday) at 3 - 7 pm at School of Public Health Building, Faculty of Medicine, the Chinese University of Hong Kong. Please come and join us!



Ways to Prevent Infection

Dr Chik Ki Wai & Nurse Cheung Sui Sum



Sing has felt ill all day. He's had pains in his tummy and has had diarrhea too. He doesn't want to eat and has a fever. His mother eventually decides to take him to a doctor, who arranges

to admit him to hospital for further observation. There, the Infectious Disease Specialist carries out an inspection in the hope of finding out how Sing has got sick and how to treat his illness.

Soon, after asking Sing a lot of questions the Specialist finds out something really worrying. He learns that Sing almost never washes his hands before he eats or after using the toilet. Also, when Sing borrows toys from other playmates he doesn't wash his hands after playing with those toys. His housemaid, doesn't wash her hands before she starts to cook and sometimes the food is not fully cooked. Sing likes to share his food with his friends so bacteria get into his tummy from his hands and make him sick.

The Specialist then tells Sing about a secret weapon that can destroy the bacteria. He tells Sing:

Wash your hands before you eat, so bacteria won't get into your body;

Wash your hands after games, so bacteria from the games equipment won't cling to you

Wash your hands after using the toilet. By doing so, you will also wash away the bacteria.

Sing thinks for a while, then he asks the Specialist

if he can forget about the threat of the Bacteria once he is admitted into hospital. The Specialist shakes his head immediately and warns Sing that everyone has to pay extra special attention to hygiene when they are in hospital. He also invites Sing's mother and housemaid to listen to what he says. He tells Sing and his family that bacteria can be spread by air and can exist on any surface. Therefore, if you wash you hands properly, you can prevent infection.

So, wash your hands after using the toilet, coughing or sneezing; before handling food or eating; and after coming into contact with faeces, respiratory or other body secretions; after changing diapers for children or patients; or before and after giving injection into the catheters. Whether you are the patient or a health care provider, you should always be fighting the war against Bacteria.

Sing is very happy when the bacteria that has made him so ill has been defeated, so he starts telling his friends that they too should pay attention to personal hygiene by washing their hands frequently. The Infectious Disease Specialist also reminds other child patients in the ward and their parents that another effective measure of preventing infection is to avoid bringing too many personal belongings into the hospital so that complete sterilization and cleaning of the wards can be done more effectively. Also, child patients should not share their food with others, and to avoid cross-infection visitors should not bring food into the wards. Visitors should use the public toilets in hospital, not the ones in the wards. Quarantined patients and their family members must always stay away from other child patients.

Sing hopes that everyone will remember these simple rules so that the recovery of patients will not be made any harder than it should be, and that their treatment will progress as smoothly as possible.



護士也會流淚

李傲霜

我在醫院工作多年，對針藥抽血已經習以為常。可是，眼見被注射抽血的是自己的女兒，實在心如刀割……

母女被不幸選上

1992年的春天，一件令我畢生難忘、不幸的事情發生在我的兩歲女兒——慧慧的身上。初時她出現一些傷風感冒的徵狀，面色蒼白，經常渴睡，跟一般健康活潑的小孩完全兩樣。經過抽血檢驗後，我帶着報告送她入院，心知情況不妙。

入院後第二天，慧慧被證實患上血癌，醫生告訴我女兒將要面對的療程。當時就像世界末日即將來臨，無論在病房、乘車途中、上班時或在家中，我都不能自制地流淚。身為護士，我很難接受女兒患此重病。我不但明白這個病可以致命，也了解到女兒將會面對一連串艱苦的療程，怎能不心痛！

慧慧被送進手術室，植入希克文導管，未幾就開始抗癌藥的注射。我在醫院工作多年，對針藥抽血已經習以為常。可是，眼見被注射抽血的是自己的女兒，實在心如刀割，如果可以的話，真想代她受這些苦。

初時慧慧經常嘔吐，而且脾氣很壞。每天除了上班之外，其餘的時間我都會留在病房陪伴她。父母全力支持我，在我返工時，在病房陪伴女兒。每天到病房帶東西給女兒吃、陪她玩、替她洗澡，已成為我的習慣。

當慧慧的情況穩定下來，她亦習慣了病房的生活。不竟她年紀小，相比大人，她所受的痛苦在皮肉之上多於精神之上。我亦得到很多人的支持，包括病房的

醫生、護士及其他病童家長，心裏也覺得沒有那麼絕望。

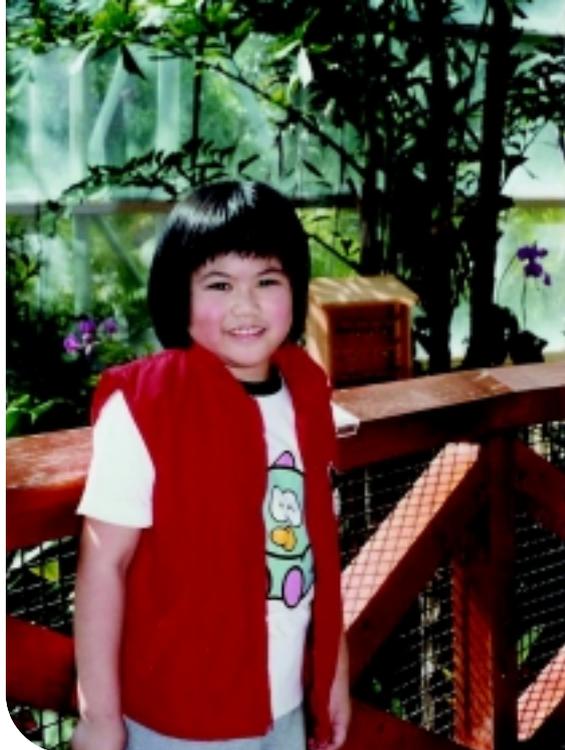
一切得來不易

慧慧完成了初期的療程，終於可以出院，真的十分開心。完成了多個療程，女兒面色開始紅潤，體重增加，我亦比較放心，開始為她籌備入學。看見她在學校開開心心地學習，感到非常欣慰，覺得以前所付出的努力很值得。

記得在完成療程後的一年，我很少帶她到人多的地方，怕她受到感染。第一次帶她到海洋公園，是她六歲的那年，我們都十分興奮，那種心情不能以筆墨形容。普通人看是簡單的事，對於我們來說是得來不易。

不經不覺，慧慧已經十四歲，是個中二學生。她長得比我還高，擁有自己的理想，跟她閒談，感覺她真的長大了。我開始給她更多自主權，但依然十分留意她的健康。

能夠有今天的日子，不單是我個人的努力，真的十分感謝醫生及護士的幫助，也非常感激父母給予我的幫忙和支持。最慶幸是女兒能夠在最艱難的情況下，努力地生存下去，使我們現在能夠一起度過未來的每一天。



第一次到海洋公園
Our first time to Ocean Park



Nurses Cry Too

Geneva Lee

I've been working as a hospital nurse for many years and have become accustomed to the hospital environment and medical procedures. Yet I couldn't bear the sight of my own daughter having blood taken and receiving injections.



再到海洋公園時，身體已健康了。
Wai-wai has become really healthy when we visit Ocean Park the second time.

Misfortune Fell Upon Us

In the spring of 1992, my two-year-old daughter, Wai-wai, started on a traumatic journey that I will never forget for the rest of my life. At first, Wai-wai only showed symptoms of a cold. Then she became very pale looking and got tired easily. She didn't look like a normal kid of her age. After several medical checkups, she was admitted to the hospital. I knew at that time that her condition was not good.

On the day after her admission, the doctor told me that my daughter had leukemia and explained to me the treatment program that my daughter would have to go through if she was to have any hope of recovery. It felt like the end of world. I could not hold back my tears whenever I thought about it — whether in the hospital ward, on the bus, at work or at home. Being a nurse myself, I understood that this disease could be fatal and I couldn't accept the fact that my daughter had it. The very thought of the painful treatment she must endure upset me greatly.

Wai-wai was immediately sent to the operating theatre for a Hickman catheter implant. Soon after that, she started receiving injections of anti-cancer drugs. Although I've been working in hospital for many years and have seen much pain and suffering, I couldn't bear the sight of my

own daughter having blood taken and receiving injections. I really wished I could take my daughter's place in enduring the pain and suffering.

At the beginning of the treatment, Wai-wai often threw up and got irritated very easily. I spent all my free time with her in the hospital ward. I was very grateful for the support of my parents for looking after my daughter while I was at work. It had become our daily routine to bring food to Wai-wai, play with her and bathe her in the ward.

Wai-wai, too, got used to the hospital environment when her condition began to settle down. Luckily she was still young and the pain she suffered was more physical compared to the mental anguish that was torturing those of us who loved her. However, the psychological support from the doctors, nurses and other childhood cancer parents helped to strengthen my spirits.

It Doesn't Come Easy

I was very happy when Wai-wai completed the first stage of treatment and could finally be discharged from the hospital. She gained some weight and looked healthier than before the treatment. I felt very relieved and began making preparation for her schooling. Now, whenever I see her studying happily at school, I know that our efforts in fighting the disease together were truly worth it.

I still remember that, for the first year after Wai-wai completed her treatment, I rarely took her to crowded places for fear that she would pick up an infection. It wasn't until she was six years old that I took her to Ocean Park for the first time. We were extremely excited at that time. The joy I felt could not be expressed fully in words. A trip to Ocean Park may sound common-place to most people, but it meant a great deal to us all.

Time passes so fast, and Wai-wai is now 14. She is in form-two and has grown taller than me! She has her own dreams and it is clear through talking to her that she has really grown up. I give her a lot of freedom although, at the same time, I continue to watch her health very closely.

Wai-wai and I live so happily now — not only because of our own efforts, but also those of the doctors and the nurses, as well as my parents. I thank my daughter for her courage in fighting this disease and for not giving up, even during the most difficult times. It is a blessing that we are still able to spend every day together.



希望將來開心地活下去
We wish that we will live happily ever after.





在兒童癌症中心的第五天，仍然笑容滿臉。
Fung still wears smile on his fifth day at the CCC.

無條件的愛

江丰家長

沒有人希望遇到苦難，但當你經歷過苦難，回望從前，便發覺所得的比失去的更多、更珍貴。

回望苦難

小兒江丰四歲，個子矮小，經常笑容滿臉。他討人喜愛的外表，包着一個飽受急性淋巴白血病折磨的身軀。也因為他獨特的經歷，叫我們一家人得到重生，學習到何謂無條件的愛。

丰兒生病前，我們夫婦各自忙於為事業奔波。他20個月時首次無故發燒，睡覺時呼吸異常。我們以為是小事，想不到檢查結果顯示他可能患上血癌。我們即時被嚇壞了，只好立刻把他轉往包黃秀英兒童癌症中心接受治療。

這個突如其來的打擊，頓使我們跌至人生最低點。傷心痛哭之後，我們祈禱及重新訂立目標，並把事情告知家人、同事及教會朋友。起初家人傷心不已，幸好得到各方安慰，心情才平伏下來。在家人及好友的協助下，我們很快便安頓下來；媽媽即時停止工作，專心照顧兒子；爸爸繼續上班，作後盾支援。

起初因對這個病所知不多，我們感到恐懼不安。我們終於決定積極面對，與醫護携手合作：細閱及翻查有關資料及研究、積極向醫護及社工提問、照顧丰兒細心專注、注意清潔衛生，以減低丰兒不適及受感染的機會。

好好保管天賜的禮物

我們視丰兒是神賜給我們的禮物，必須好好

保管，在能力範圍內給予他最好的。最好的東西並不是以前盲目地供應物質，而是世上最珍貴的，也是這次我們學習到的，那就是無條件的愛——先放下自己，多想別人的需要。

媽媽決定辭職，與兒子共渡難關。她緊記不要在兒子面前哭，多跟他笑，認同他的感受，跟他祈禱、唱歌、玩樂。曾有一晚上我們與其他的小朋友在走廊玩捉迷藏，笑過不停，真要多謝護理人員包容。

總算平安渡過落重藥的階段，進入維持治療，這時我們又要面對另一個難關——丰兒被診斷為整體發展遲緩。跟多方面了解及協商後，他獲派到一所合適的幼兒園，及接受一連串的专业治療。

我們仍在學習怎樣幫助丰兒克服困難，趕上同齡的水平。可喜的是他在兩年的治療過程中，培養出樂觀、開朗及關懷別人的性格。他知道人可以依靠甚麼，這對他的康復及成長奠下良好的基礎。

隨波逐流的生活會容易令人迷失，但當人尋到正確的依靠及方向，即使大浪湧過來，仍有力量、信心去繼續前路。苦難是一種磨練，讓我們有機會學習反省、忍耐、分享、寬恕、犧牲、珍惜，和接受別人愛的服侍。



Unconditional Love

Parents of Kong Fung

Nobody wants to face adversity. However, when you look back on your past sufferings, you will often realize that you have gained more than you have lost in the process, and that a terrible experience can be treasured as a precious one.

接受治療時，勇闖美國迪士尼樂園。
The family visited Disneyland Resort in California, USA when Fung was still under treatment.



Looking Back

Our son, Kong Fung, is now four years old. He is short and well known for his lovely smile. However, his smile seems all the more precious and endearing to those who know of the pain and suffering he endured when he came down with the dreadful disease, acute lymphoblastic leukemia. The battle we fought alongside him against the disease has made us understand what love really about. That experience has drastically changed our lives.

We were both busy in our careers that we did not spend much time for Fung before he became sick. When he was 20 months old, he had a fever and experienced difficulty in breathing when sleeping at night. At first, we did not pay much attention to the symptoms, thinking that they would go away. We were totally unprepared for the shock on learning that his medical report showed he could have leukemia. We immediately sent Fung to the Lady Pao Childrens Cancer Centre for treatment.

This unexpected news of his disease nearly broke our will. After all the grief and tears, we prayed often and prepared ourselves for the drastic changes that were going to affect our lives. We told our families, colleagues and friends from the church about the news. Our families were overcome with grief on hearing what had happened to Fung. It took every one quite a while to recover from the initial shock. With the supports of our friends and families, we came up with a plan to cope with the demanding task ahead. Mommy resigned from her job so that she could spend all her time taking care of Fung, while daddy back her up after work.

At first, we felt anxious and scared because of our

ignorance to the illness. But we resolved the situation by learning and working closely with the medical staff. We gathered as much information as we

could about the illness and kept asking the doctors, nurses and the social workers about the symptoms and processes we did not understand. In addition with that, we took great care of Fung to reduce his chance of infection.

Treasure God's Gift

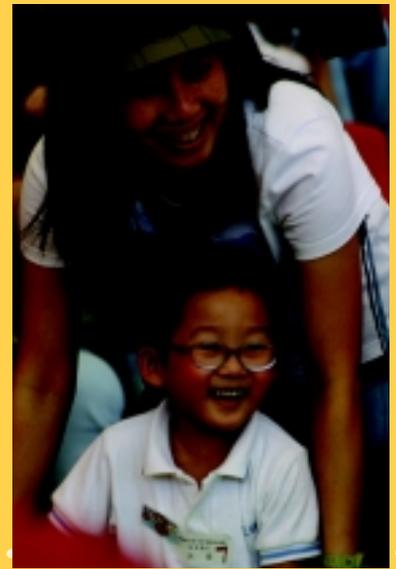
Fung is our precious gift from God and we want to give him the best. We have learned from this experience that the material things we gave him in the past were nothing compared with the unconditioned love we have for him. Because of this experience, we believe that we are beginning to understand the true meaning of to love not to be loved. It is, indeed, the most precious thing in the world.

Mommy decides to give up her career to find the time fighting the battle side by side with Fung. She never cried in front of him. Instead, she always tried her best to keep a smiling face all the time when he was around. She tried to share Fung's feeling and played, sang and prayed with him. Once, there was a night when we played hide- and- seek in the corridor. We were very happy at that time and could not stop laughing. We really need to thank the staff there who allowed us to have such a great time.

Fung got through the critical stage of treatment and entered a phase of maintenance treatment. Yet another problem was awaiting us as Fung was diagnosed with global developmental delay. Subsequently, he was referred to an early development center and was given courses of specialist therapies.

At present, we are still learning the techniques of helping Fung to overcome challenges and live like a normal 4 years old. We are happy to see that he has built up a cheerful, open and caring personality throughout his treatment. Now, he has learnt the things that he can rely on, and this is crucial to his recovery and growth in the future.

We all can become too preoccupied in our daily busy lives. However, when we have identified our own direction and sources of support, we can find the faith and energy to keep going even in times of great difficulties. Suffering is the kind of test that forces us to evaluate our past, endure the present and gain hope for the future.



完成治療後，母子同樂。
Mommy plays with Fung after he completed his treatment.





國際兒童癌症家長協會主席 暢談家長參與重要性



主持 ICCPCO 執行委員會會議
Chairing the Executive Committee of ICCPCO



與委員會成員攝於週年大會
Executive Committee members at the Conference

國際兒童癌症家長協會(以下簡稱協會)主席 Mr. Simon Lala 在 2005 年初路經香港，向我們介紹協會怎樣致力聯繫全球的兒童癌症家長組織，在沒有同工、沒有龐大財政支援的情況下，在短短十年間，發展成為共 76 個會員的國際性網絡。

五年仍然存活，可是全球的總生存率只維持在 20% 的低水平。這個數字顯示只有五分一的病童得到優良的醫療護理，超過二十萬發展中國家的病童未能得到適當治療。因此協會希望透過國際性的合作、訊息及經驗分享，讓全球癌症兒童，尤其是發展中國家的癌症兒童，得到更適切的支援。

家長參與乃成功秘訣

協會於 1994 年 5 月在西班牙城市華倫西亞成立，致力聯繫全球的兒童癌症家長組織；現時擁有 57 個國家共 76 個會員。來自五湖四海的義工，不但願意貢獻所長，每星期還得花幾小時，透過電郵與各地有關人士聯絡。此外，他們更要自掏腰包，支付各種行政及交通費用。例如，執行委員會的成員，除了間中召開會議，日常會務主要透過荷蘭家長組織的秘書處協助。

協會為會員提供多項服務，包括：基本支持、資料訊息、社會關注、援助發展中國家及向國際性機構爭取支持等。協會的收入來源主要倚靠會員費、企業贊助和其他較先進的家長組織的捐款，資金並不豐裕。協會愈辦愈成功，主要原因是所有義工都非常落力，大家的共同願望是為癌症兒童出一分力，令發展中國家的癌症兒童，得到更適切的支援。

Mr. Lala 盼望香港的病童家對協會有多認識，除了瀏覽網頁 www.icccpo.org，還可以抽空參加 9 月 20-24 日在加拿大溫哥華舉行的週年會議。

全情投入造福病童

Mr. Lala 是紐西蘭人，女兒在六歲時患上肝癌，自此他便加入了當地的癌症兒童家長組織。1999 年他成為協會的委員，四年後更被推舉為主席。他曾任紐西蘭兒童癌病基金主席六年，才成為協會的主席。自己是癌症兒童的家長，所以他非常明白其他家長的心情，願意全情投入兒童癌症家長的義務工作。

身為協會的主席，Mr. Lala 十分認同協會的兩個主要信念：(一) 無論癌症兒童的經濟環境、社會地位、種族、國籍如何，都應得到最佳醫療護理。(二) 每位兒童癌症家長都可以接觸所有有關兒童癌症的資料，好為孩子作最佳決定。

目前超過 70% 先進國家的病童在發病後



The Importance of Parents Participation

In early 2005, the Chairman of the International Confederation of Childhood Cancer Parent Organizations (ICCCPO), Mr. Simon Lala, introduced the ICCCPO to us during his visit to Hong Kong. He described the challenge of operating such a worldwide network without the benefit of either full-time staff or sufficient financial support. Despite these constraints, the ICCCPO has succeeded in establishing itself as a self-sufficient entity with 76 members and representatives from 57 countries.

Committed in Helping the Child Patients

Mr. Simon Lala is from New Zealand. When his daughter was diagnosed with leukemia at the age of six, he became an active member of a local childhood cancer parent organization. In 1999, he was elected to the ICCCPO executive committee and became its chairman four years later. He was the chairman of the New Zealand Child Cancer Foundation for six years before becoming the chairman of the ICCCPO. Being a father of a child with cancer, Mr. Lala understands the feelings of others who find themselves in the same situation. Through international cooperation, he wishes to offer support to childhood cancer patients and their parents in the developing countries.

As the chairman of the ICCCPO, he fully identifies with its two beliefs: 1. Every child with cancer, regardless of financial or social class, race or native origin deserves access to the best possible treatment and medical care. 2. Parents of children with cancer must have access to the information they require to make informed decisions about their child's treatment.

Most children's cancers are curable. In developed countries, more than 70% of children with cancer are still alive 5 years after diagnosis. Unfortunately, only 1 in 5 of the world's children has access to advanced medical care. As a result, the world's overall survival rate is as low as 20%. This means that more than 200,000 children, mostly those in developing countries, die each year due to the lack of adequate treatment. Hence, the ICCCPO's mission is to share information and experience in order to improve access to the best possible care for children with cancer everywhere in the world.

Parents' Participation is the Key to Success

The ICCCPO was founded in May 1994 in Valencia, Spain. It is a worldwide network of organizations of parents of children with cancer. Currently there are 76 member organizations from 57 countries representing all continents.



Mr. Simon Lala (左) 參觀包黃秀英兒童癌症中心，與成明光醫生合照。
Visit to the Lady Pao Children's Cancer Centre (left) with Dr M K Shing

The organization's volunteers come from different parts of the world. Not only do they contribute their talents to helping the ICCCPO, they also spend a few hours of their time every week coordinating with other members around the world via email. They are self-financed, paying for their own transportation and myriad other expenses. For example, the Executive Committee is responsible for the managerial work. The Dutch Parent Organization in Amsterdam serves as the Secretariat to support the Executive Committee.

The programs offered to its members include: General Support, Information, Awareness, Support of the Developing Countries and International Representation. Its funding is reliant on membership fees, corporate sponsors and donations in kind from well developed parent organizations. With a growing membership, the finances of the ICCCPO stretched to the limit. The key to its success is the dedication of all its members to bringing comfort and support to the families of childhood cancer patients.

Mr. Lala encourages the parents of childhood cancer patients in Hong Kong to find out more about the ICCCPO via its website: www.icccpo.org. He also hopes that he can meet them in the ICCCPO Parents Meeting and Annual General Assembly in Vancouver, Canada on 20th-24th September 2005.





華西醫科大學 領導中國西部醫療發展

賈蒼松教授在華西醫科大學附屬第二醫院小兒血液 / 腫瘤科服務，曾於2004 年前往包黃秀英兒童癌症中心進行學術交流。通過病例討論、學術會議等活動，使他深深感受到兒童癌症中心醫護人員「學而不厭，誨人不倦」的敬業精神。然而，來自人傑地靈的天府之國——四川的他，怎樣形容他所在的這所中國西部的重點醫院呢？



華西醫科大學鐘樓
The Bell Tower of the West China University of
Medical and Science

西部重點醫院

華西醫科大學歷史相當悠久，始創於1910年，前身為美國、英國、加拿大的5個基督教會組織在成都創辦的私立華西協合大學。中華人民共和國成立後，更名為四川醫學院。1985年易名為華西醫科大學。

華西第二醫院位於中國西部地區人口最多的省份，是衛生部重點院校的附屬醫院之一，是集醫療、教學、科研、預防為一體的西南地區最大的婦產兒童專科醫院。1993年被衛生部、聯合國兒童基金會、世界衛生組織授予「愛嬰醫院」的稱號。

兒童血液腫瘤科

華西第二醫院兒童血液腫瘤科創建於1973年，是國內較早創建的兒童血液腫瘤專科，目前已發展成為國家衛生部臨床重點學科。開放病床43張，配有中央空調和24小時熱水供應系統，分為血液/免疫病室和兒童造血幹/祖細胞移植病室。

除收治四川省內的兒童血液腫瘤患者外，還接受重慶、雲南、貴州、西藏、新疆等省、市、區的轉診患兒。對各種兒童血液腫瘤疾病的診治均達到國內先進水平，近年尤其是急性淋巴細胞白血病五年無病生存率已達71%。對於缺鐵性貧血的診治居於國內領先地位，部分成果已達國際先進水平。在醫院大力支持下，裝備有國內一流水平的兒童骨髓移植病室，開放床位5張。從2000年開始，在西部地區首先開展造血幹細胞移植工作，首例接受臍血移植患兒已存活四年多。



華西第二醫院
The West China Second University Hospital



血液 / 腫瘤科醫師
Doctors from the paediatric haematology and oncology unit

兒童血液腫瘤科為福建泉州、雲南大理、新疆、河南等地培訓血液專科醫生多名，經常與國內外科研單位有人才培養、學術交流的聯繫。此外，兒童血液腫瘤研究室的設備裝置已達國內先進，目前已逐步發展成為開放性實驗室，被評為四川省重點實驗室。

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West China University of Medical and Science

The Best in the West

Professor Jia Cangsong, of the paediatric haematology and oncology unit of West China Second Hospital, visited the Lady Pao Children Cancer Centre in 2004. During the exchange programme, he deeply felt the dedication of Hong Kong's medical professionals in their constant pursuit of knowledge and tireless devotion to teaching. How does the man coming from Sichuan, commonly called the "land of heaven" rich in both natural and human resources, describe the key hospital in the west of China?



賈蒼松醫師深深體會香港醫護人員對病童的關愛
Dr. Jai Cangsong is deeply impressed by the care shown to patients by the Hong Kong's medical professionals.

The Key Hospital in the West

West China University of Medical and Science was formerly a private university established in Chengdu in 1910 by five Christian organizations from the US, Britain and Canada. Its name was changed to Sichuan Medical College soon after the establishment of the People's Republic of China. It acquired its present name in 1985.

West China Second University Hospital is part of West China University of Medicine and Science. It is located in the most populous province in the west and has been designated by the Ministry of Health of China as one of the key university hospitals. As the largest maternity and paediatric hospital in the southwest, it is a centre for health care, clinical research, medical teaching and disease prevention. In 1993, the Ministry of Health, the United Nation's Children Fund and the World Health Organization awarded it the title "Children Friendly Hospital".

Childrens' Haematology and Oncology

The paediatric haematological oncology unit of the West China Second Hospital was established in 1973 and was one of the earliest specialized centres for the treatment of blood diseases in China. Now, blood diseases have been designated by the Ministry of Health as a key subject for medical research. The paediatric leukemia ward of the hospital, divided into haematology and transplant sections, has 43 beds. It is equipped with central air-conditioning and 24-hour hot water supply.

The hospital admits child patients from Sichuan as

well as those transferred from other neighbouring cities and provinces, including Chongqing, Yunnan, Guizhou, Tibet and Xinjiang.

The standards in this hospital for the treatment of child leukemia patients are among the highest in the country. In recent years, the five-year cancer-free survival rate has reached 71 per cent. Its treatment of anemia is the most advanced in the nation. Fully supported by the hospital, the paediatric haematology and oncology unit, with 5 beds, has the best equipped bone marrow transplant centre in the country. This centre was the first to conduct stem cell transplantation in the western region in 2000. Its first child patient is still alive for more than four years.

The paediatric haematology and oncology unit has already trained many specialist doctors for the neighboring provinces of Fujian Quanzhou, Yunnan Dali, Xinjiang and Henan. It has also established close training and academic relations with various research units within the country and Overseas. In addition, its research facilities for paediatric leukemia has already reached the nation's highest standard and it is developing as a reference laboratory in Sichuan.

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與腦外科醫生對談

今次的訪問是由兩位腦瘤康復者 May 和 Shirley 向與專責腦外科手術的潘偉生教授提問，盡釋病人有關手術風險和後遺症等疑團。



潘偉生醫生
香港中文大學外科學系 腦外科講座教授
Prof. Poon Wai-sang
Division of Neurosurgery,
Department of Surgery,
The Chinese University of Hong Kong

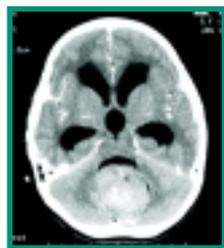
切除腦瘤手術是否風險很高？成功率有多少？

每種切除腦瘤手術的風險不同，其中以良性腦膜瘤的風險最低；與大腦幹接連的惡性腫瘤的風險最高，併發症較多及康復時間亦較長。以 May 的神經管細胞瘤為例，屬中度風險外科手術，風險比切除盲腸手術為高，危及生命的機會只為 1-2%。由於要完全切除，所以出現功能損害的機會為 5-10%，May 腿部便出現較難平衡的毛病，手術後亦要接受化療及電療。

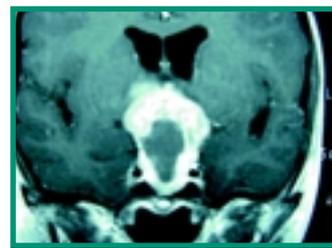
為患者大多是兒童，他們的父母都十分擔憂。作為外科醫生，要替病人切除 95% 以上的腫瘤，走進手術室必定戰戰兢兢。一方面怕切得太多，會損害病人身體功能；另一方面，又怕切得太少，可能會復發。

手術後有什麼後遺症？是否要長期打針服藥？

腦瘤的性質及生長位置不同，手術後遺症亦不盡相同，並不是每個病人都要長期打針服藥。以 Shirley 胚胎細胞瘤為例，腫瘤生長在腦下垂體頂部，要打開頭骨作部分切除，然後接受電療及化療，所以手術危險性不及 May 的高。不過，由於手術破壞了荷爾蒙分泌，必須長期服食甲狀腺素、女性荷爾蒙，及注射生長激素。



神經管細胞瘤的電子掃描
Imaging of a medulloblastoma similar to May's case



腫瘤生長在腦下垂體頂部的電子掃描
Imaging of a pituitary region tumour similar to Shirley's case

未來的腦外科手術將有什麼新的發展？

目前香港的腦瘤治療已經很先進，患上跟 May 一樣的腫瘤五年存活率是 50%，而患 Shirley 類型的腫瘤五年存活率是 90%。將來的趨勢是發展細胞治療及免疫治療，將藥物直接打入腦部患處，減少外科手術帶來的風險。目前這些治療方法仍在臨床研究階段，還未正式使用。

你曾為不少病人做手術，有什麼感受？

作為醫生，當然以病人的福祉為依歸。遇到 Shirley 情況的病人，心情比較輕鬆，因為毋須完全切除腫瘤，加上化療，根治機會很高。可是，若病人體內的鈉變化太大，情況會很危險，所以也不敢掉以輕心。

遇上 May 情況的病人，心情會較為複雜。因

後記

生病後，我常感到上天對我不公平。透過這次採訪，增加了腦瘤外科手術的認識。原來有些康復者要長期打針服藥；相對來說，我的情況已算幸運，只是腳部出現平衡問題，及要服食荷爾蒙補充劑。啊！做醫生真是殊不簡單！

May

原來腦瘤的性質及生長位置不同，其後遺症及康復時間亦有異。盼望日後科技進步，能減少後遺症，使痊愈時間加快。藉此感謝醫護人員的照料，使我可以早日康復。

Shirley



In Conversation with a Brain Surgeon

This interview was conducted by two brain tumour survivors, May and Shirley, with Professor Poon Wai-sang, who specializes in brain surgery. Professor Poon explains to us the risk and residual defects of brain surgery.

Is the operation to remove a brain tumour very risky? What about the success rate?

Each tumour resection carries different risk levels. The resection of a benign tumor carries the lowest risk, while resection of a malignant tumor connecting to the brain stem not only carries the highest risk but also entails a higher chance of complications, requiring a longer period to heal.

Take May's case, for example. Her medulloblastoma was an intermediate risk operation. Carrying a higher risk than an appendicectomy, there is a 98-99% chance of success. However, the surgery requires a complete resection of the tumor, with a 5-10% chance of causing functional damage. In May's case, she found it hard to balance on her legs after the surgery, chemotherapy and radiotherapy treatment.

Are there any residual defects after brain surgery? Does one need to take long-term medication after the surgery?

It depends on the nature and location of the brain tumour. For example, Shirley's germ cell tumor was located above the pituitary gland on top of the nasal sinuses. We only had to open her skull to remove part of the tumour and destroy the remaining part by radiotherapy. Therefore, the risk level of Shirley's surgery was not as high as May's. However, the surgery did cause damage to her ability to secrete hormones. As a result, she now takes long-term medication of anti-diuretic hormone, thyroxine and oestrogen, and receives regular injections of growth hormone.

What are the new developments in brain surgery?

Brain tumour treatment in Hong Kong is already very established. The 5-year survival rate for May's disease is 50%, while that for Shirley's is 90%. The latest technologies in brain tumour treatment include cell therapy and immunotherapy. These methods are designed to improve long term outcome. Instead, drugs are injected directly into the brain tumour. At present, the new therapies are still under clinical tests.

You have operated on many patients. What are your feelings towards them?

As a doctor, of course, I always place the well-being of my patients first and foremost. I feel more optimistic for

patients like Shirley as it is not necessary to completely remove the tumour. With the help of radiotherapy, the cure rate is very high. Yet, I'll always be watchful of the patient's condition. For example, a massive change in the body sodium level indicates a serious condition that can cause irreversible brain damage. With close monitoring, we can avoid this situation.

For cases similar to May's, it is very difficult to describe my feelings. Most of my patients who are diagnosed with that kind of disease are children and their parents are, understandably, very anxious about the treatment. Every time I go into the operating theatre, I am fully aware of the fact that it requires total concentration and great skill to remove over 95% of the patient's tumour in one operation. I have to take great care in removing as much of the tumour as possible without causing any damage to the patient's bodily functions.

Behind the Scenes

I always thought that it was so unfair for me to have got this disease. But my self-pity has now largely dissipated. I know that there are survivors who need to take medication and have injections for the rest of their lives in order to maintain the normal function of their bodies. Compared to them, I think that I was lucky to have only had a small problem in balancing that required relatively minor treatment. It is really not easy to be a doctor!

May

I didn't know that the residual defects and recovery time from brain surgery depends on the nature and location of the tumours. I hope that the advances made in medical science will further reduce the chances of residual defects and shorten the recovery time in the future. I wish to take this opportunity to thank the medical staff, whose support and help were crucial to my early recovery.

Shirley



- 1 3月15日第二次骨瘤支持小組，主題是「骨瘤的化學治療與如何識別復發」，由戚其威醫生主講，共有23位康復者、病童及家屬出席。
- 2 小童群益會上環青少年綜合服務中心的義工於3月26日與本會合辦復活節派對，與20多位會員歡渡佳節。



多采多姿的復活節派對
The Easter Party was great fun for everybody.

- 3 衷心多謝雷慧樺小姐對合唱團所作出的貢獻，指揮及司琴工作將分別由黃懷德先生及何志恆醫生接任。
- 4 主席成明光醫生於4月7日往廣州中山大學附屬第二醫院兒科及廣州南方醫院兒科，介紹本會工作及講解如何成立病人家長組織。
- 5 第四期英語活動小組已於5月23日至6月27日(星期一)，1:00 p.m. - 2:15 p.m.，在包玉剛癌症中心三樓活動室舉行。
- 6 6月25日第一次腦瘤支持小組，主題是「腦瘤的手術治療及最新發展」，由朱獻倫醫生主講。
- 7 7月10日合唱團被邀為伊利沙伯醫院癌症病人資源中心十週年慶祝作表演嘉賓，鼓勵病人活出積極人生。
- 8 7月23日將舉辦第一次骨髓移植支持小組，主題是「兒童骨髓移植」，由阮文賓教授主講。
- 9 合唱團練習日期為7月30日、8月20及27日、9月10日、10月15日、11月12日及12月10日(星期六) 2:30 p.m. - 4:30 p.m.，地點為包玉剛癌症中心三樓。
- 10 本會將資助四名康復者及家長於9月前往加拿大溫哥華，參加2005年國際兒童癌症家長會協會的週年會議。

- 1 The 2nd meeting of the Bone Cancer Support Group, held on March 15, was attended by 23 survivors, child patients and their family members. A talk on "Chemotherapy for Bone Cancer and How to Recognize a Relapse" was given by Dr Chik Ki Wai.
- 2 On March 26, our Society held an Easter Party with the help of volunteers from The Boys' & Girls' Clubs Association of Hong Kong Sheung Wan Integrated Service Centre for Children & Youth. More than 20 members enjoyed this special event.
- 3 We would like to express our heartfelt gratitude for the contribution made to our Choir by Ms Elaine Louie Wai Wah. From now on, Mr Walter Wong will be the conductor and Dr Assunta Ho will be the pianist.
- 4 On April 7, our chairman, Dr Shing Ming Kong, visited the pediatrics department of Guangzhou Sun Yat-sen University Second Hospital and Guangzhou Southern Hospital to introduce the work of our Society. He also gave a talk on how to establish a parents' association.
- 5 From May 23 to June 27, the fourth phase of the English Activity Group was held every Monday, from 1:00pm - 2:15pm, in the Activity Room on the 3/F of the CC.
- 6 The 1st meeting of the Brain Cancer Support Group was held on June 25. Dr. Zhu Xian Lun gave a talk on "Surgery on Brain Cancer and Its Recent Developments".
- 7 The Choir gave a guest performance at the 10th Anniversary of the Queen Elizabeth Hospital Cancer Patients' Resource Centre on July 10.
- 8 The 1st meeting of the Bone Marrow Transplant Support Group will be held on July 23. We are honored to have Prof Patrick Yuen Man Pan as our guest speaker on "Stem Cell Transplant in Children".
- 9 Choir rehearsals will be held on the 3/F of the CC, on July 30, August 20 & 27, September 10, October 15, November 12 and December 10 (Saturdays) from 2:30pm - 4:30pm.
- 10 We will sponsor 4 survivors and parent members to attend the ICCCP0 2005 annual meeting in Vancouver, Canada in September.



6月18日迪士尼義工與病童共度一個多采多姿的派對。
Disney VolunTEARS brought Disney magic to child patients in the party on

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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)
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