

# The Vision Comes True!

A Children's Hospital for Hong Kong

February 2009

A Children's Cancer Foundation Initiative



## HKSAR GOVERNMENT PLEDGES TO CREATE NEW CHILDREN'S HOSPITAL

With those official words the vision set out for a Children's Specialist Hospital for Hong Kong by the Children's Cancer Foundation in 2003 began to come true.

The Policy Agenda, detailing the items outlined in the Policy Address, expanded further on the Chief Executive's speech, committing government to "exploring the establishment of multi-partite medical centres of excellence in paediatrics (and neuroscience), which would raise professional standards and enhance patient care through cross fertilisation of expertise, enhanced research and training."

Earlier in 2007, Secretary for Food and Health York Chow had outlined his vision for such a facility in a speech to the Hong Kong Paediatric Society, in which he asked for cooperation between public and private healthcare sectors and the universities, and proposed the establishment of a new non-profit foundation to operate the new centre of excellence in paediatrics.

Good to its policy agenda promise, in March 2008, the government's Food and Health Bureau formed a Steering Committee on the Centre of Excellence in Paediatrics comprising key stakeholders from public and private healthcare sectors, academia, children's charities and other interested parties. Two working groups were also formed, one to look into Clinical Services, Research, and Training; and the other to examine the Institutional Arrangement and Finance Model

**October 2007:**

*"We will also study the establishment of medical centres in paediatrics and neuroscience to upgrade our health care services."*

Chief Executive Donald Tsang, Policy Address 2007

for the proposed Centre of Excellence. The work of the Steering Committee and the Working Groups is progressing rapidly.

The Policy Agenda in October 2008 went even further, beyond the previous year's promise of "exploring" to state that government was now "preparing for the establishment of multi-partite medical centres of excellence in paediatrics and neuroscience to improve the quality of clinical services to patients suffering from complex and serious illnesses as well as to enhance the standards of research and training in the two respective medical disciplines.



To contribute to the long-term development of paediatrics and neuroscience, the Centres will bring together medical professionals in the public, private and academic sectors from both within and outside Hong Kong, and partner with major international medical centres in professional collaborations, research and training."

four-year lobbying campaign – we present some of the views put forward by leading academics and medical professionals during the lobbying process, as well as talk to patients and parents about their vision for a children's specialist hospital for Hong Kong – what will eventually become known as the Centre of Excellence in Paediatrics. There is also a special contribution from Children's Cancer Foundation Founder Chairman Miami Wu – herself the mother of a child cancer patient, now fully-recovered – who has quietly yet resolutely driven the campaign from behind the scenes.

Previous editions of *The Vision*, as well as CCF's original proposal to the HMDAC and the stakeholder research that was undertaken to support the proposal are available for downloading at [www.hkchildren.org](http://www.hkchildren.org). ■

**October 2008:**  
*"[Government is now] preparing for the establishment of multi-partite medical centres of excellence in paediatrics and neuroscience..."*

Chief Executive Donald Tsang,  
Policy Agenda 2008

In this final edition of *The Vision* – published as part of the Children's Cancer Foundation's



# BOUNDING OVER BRICK WALLS

**Miami Wu, Founder Chairman of the Children's Cancer Foundation writes about the difficult but rewarding four-year journey CCF has faced in helping to make the vision come true**



2004 - the CCF Task Force and consultants meet for the first time

**I**n Randy Pausch's "The Last Lecture", he said something very true of brick walls:

*"They're not there to keep us out. The brick walls are there to give us a chance to show how badly we want something."*

*"Just wishing for something is only the first step towards obtaining it. In pursuing a dream, one is bound to run into difficulties; these are the brick walls, no matter how hard one pushes, they do not seem to give in."*

The Children's Cancer Foundation (CCF) is a happy charity – we plan the services, the public

gives us the funds to implement them; patients and parents are happy because of the upgrade in treatment facilities and improvement in quality of life; donors are happy because their money has been put to best use; and CCF is happiest because everyone else is happier because of our hard work.

In October 2003, the CCF council members and staff held a 6-day Visioning Workshop where we felt that the time had come for us to extend our services to other children with serious and chronic illnesses. We wished for a children's hospital, and, lo and behold, no sooner had the Task Force set to work than a gigantic brick wall

suddenly loomed out of nowhere. We were aghast with shock after shock after shock...

With hindsight, perhaps we should have seen it coming. Why is it that, since 1970, four initiatives to build a children's hospital had failed to be taken up by the government? Why is it that Hong Kong, recognized internationally as one of 20 'alpha world cities', is the only one that does not have a children's hospital, whereas on the mainland, there is already one in almost every major city?

This is especially mind-boggling when we know for a fact that each paediatrician with whom we have come to be acquainted in the five major public hospitals that we serve is a loving and caring doctor. Every single one of them is like a father to his patients and has the best interests of his children at heart.

As time passed and we learned more, it became clearer to us that territorialism and professional insecurity are the main components of this massive brick wall. Paediatric services are spread over 13 sites, and each of these departments in its respective hospital is a sovereign power unto itself where no knowledge needs to be shared or incidents reported to anyone other than those in the same domain. This silo mentality is not incomprehensible. In the same vein, the word 'specialist' could be particularly intimidating since it is not a

## Our special thanks to all who have supported The **Vision**

**I**t is impossible in this small space to thank everybody for their support in this long journey to making the vision come true, but there are a few whom we must single out for special mention. Dr John Yu, Australia's leading paediatrician, for his insights, guidance and professional expertise; Dr Leong Che-hung for his belief in the possibility and astute mentoring; Professors John Wong, Paul Tam and Lau Yu-lung of the University of Hong Kong, and Professor Fok Tai-fai of the Chinese University of Hong Kong for their unfailing support and help in navigating the political landscape; Professor Louis Low and members of the Hong Kong College of Paediatricians, Dr Chan Chok-

wan and members of the Hong Kong Paediatric Society, and Gloria Luk and members of the Hong Kong Paediatric Nurses Association for opening their doors, their minds and their hearts; members of the Health and Medical Development Advisory Committee who received and read our proposal; the Food and Health Bureau and its committed staff, particularly Secretary York Chow and Permanent Secretary Sandra Lee for sharing our vision and helping it come true; Wilfred Wong, Hilton Cheong-Leen and Dr Henrietta Ip, who, in 1970, 1978, and 1982 respectively each took up the challenge on behalf of Hong Kong's children and to those readers of *The Vision* who wrote in with their suggestions for naming the hospital.

*We will forever be grateful to the family of the late P.E. Nash, without whose generous financial support, given in his memory, this initiative would never have got off the ground, let alone come to fruition.*

*Finally to all the patients, parents and those committed members of children's charities and advocacy groups who have stuck with us against overwhelming odds in our quest to finally see the establishment of a world-class facility to care for the future needs of children with serious and life-threatening illnesses, a centre of excellence of which Hong Kong can be justifiably proud. ■*

# IN PURSUIT OF A DREAM!

standard to which every doctor is able to attest in the true sense of the word. On top of this is the historical rivalry between the two medical teaching universities—an issue that dates back to tradition and is not easily resolved. Further into the horror, we were even asked whether we could build three children's hospitals—one for the HA and one each for the two universities!

While we recognized that those brick walls were not going to simply disintegrate by themselves, we also discovered an effective weapon that might destroy them. It is called passion—a force that embraces not only strong emotions and determination, but most necessarily and importantly, also a great sense of sacrifice—a sacrifice of self, of time, energy and resources. It dawned on us that this was the one factor lacking in the previous initiatives, and one that not only CCF possesses but, very fortunate for us, is shared by our appointed consultants as well. We realized then that this must be our vision-turned-mission – one which, if it failed, would probably never be resurrected again for Hong Kong.

The list of people whom CCF and its consultants approached from 2004 to date is miles long. We did extensive research and needs analysis; came up with a 350-page proposal that established a platform for discussions; commissioned a comprehensive Stakeholder Survey; organized various forums for doctors, nurses and allied health professionals to express views and share opinions; published 5 editions of *The Vision*; strategized a lobbying roadmap and knocked on the doors of every person of influence who could help with the realization of this dream.

Albeit that the prospect seemed daunting, as we spoke to more and more people, we became convinced that there were enough people in the community, from the top echelons down, whose hearts were in the right place but who needed only to be brought together by one strong unwavering force. This force we found in Dr. York Chow, a visionary whose priorities in life are first to be a person with values that make him a responsible and humane leader, then a doctor who adheres to the Hippocratic oath with as much dedication and commitment as he did when it was first taken, followed by the politician required of him in his job only as a distant third.

*“ We wished for a children’s hospital, and no sooner had the Task Force set to work than a gigantic brick wall suddenly loomed out of nowhere. We were aghast with shock after shock after shock...”*

Even as we first talked to Dr. Chow about our plans in February 2004 when he was Chief Executive of the Queen Mary Hospital, he left us with the impression that a children's hospital was indeed something he felt in his heart - an ideal that he embraced with ardour. We met again in November 2004, soon after Dr. Chow became Secretary for Health, Welfare & Food. It was then that we received the greatest encouragement: the Secretary had made his intentions clear, that the proposed children's

hospital would be 'different'. At the same time though, our task was made no easier since the Secretary was not in a position to offer us a mandate that would give us the credibility we

paediatrician who could help us shape it and Dr. John Yu, former Chief Executive of the New Children's Hospital at Westmead in Sydney, came highly recommended to us. Dr. Yu was very glad to offer his expertise, but only on the condition that this hospital would be built to a world-class standard, along the guiding principles which he had set out and to which we all agreed—a hospital built to 2020 evidence-based design, where family-centred care in a purpose-created environment is a fundamental concept and intense attention to detail, vital. This would be a major opportunity for change. We should design a hospital unique to our Hong Kong community, making it a powerful statement that is both special and different.

Next in line was a Stakeholder Survey for which we took advice from our Patron, Mrs. Anson Chan, who cautioned us that our research would have to be watertight; hence we went to considerable lengths to make sure



2006 - Presenting the Stakeholder Survey results to doctors and nurses

needed, yet it was with a renewed passion that we walked away from his office that day.

To answer a question most frequently asked, the first person CCF approached on the feasibility of this project was then Chairman of the Hospital Authority, Dr. Leong Che-hung. Dr. Leong was, in no uncertain terms, an advocate and a staunch supporter of our cause. However, he was only too aware of what we would be up against and cautioned us on all the pitfalls. He was an astute sounding board and one of the few to whom we constantly returned for his wise counsel.

We gave ourselves six months to write the proposal. We needed a world-renowned

*“...we knew that CCF’s vision-turned-mission, in one way, was over; yet in another, the task had just begun.”*

that it was robust, professional and impartial. We received a positive response to the main points of our proposal from most. While many parents expressed concern about the effect the new hospital would have on current services, some diehard doctors focused only on the politics. A few private practitioners shocked us too, in asking for money to participate in the survey!

Then came the lobbying part—an experience that I had never imagined to be; one which not only caused my emotions to fluctuate wildly between excitement and disappointment, but also one through which I have come to learn a lot about how Hong Kong really works. It took a great deal of persuasion before our leading tycoons believed that all

we wanted was a half-hour of their time and not their money, but when we did manage to secure an appointment, it was comforting that all gave affirmative responses and showed their eagerness to help. Most members of the Legislative and Executive Councils listened very attentively, although some could not help but display a certain degree of skepticism as they weighed the odds against the political viability of such a project. Of the rest of the population lobbied, there were quite a few, of notable status, who vouched that this was such an impossible feat that it would never happen. But all in all, I should say that we had more gratifying days than otherwise.

Interviewing people for *The Vision* was a rather different and spiritually uplifting matter. As the newsletter, with a wide circulation to all stakeholders, served as a platform for lobbying, participants all took the interviews very seriously and we managed to gather quite a good collection of constructive opinions and suggestions. For the purpose of this newsletter,

*“While we recognized that those brick walls were not going to simply disintegrate by themselves, we also discovered one effective weapon that might destroy the walls. It is called passion...”*

public and private practice, and in particular, the two universities, to come under one roof where the best one-stop service could be offered to all children requiring tertiary care. This unanticipated piece of action took everyone by surprise and, to some, by storm. Later in October, a statement appeared in the Chief Executive's Policy Agenda to the same effect and that was when we knew that CCF's vision-turned-mission—our 4-year journey peppered with aggravation and pain—in one way, was over; yet in another, the task had just begun.

CCF presently has one seat on the government's Steering Committee for the CEP project as well as one each in the Clinical Services, Training & Research working group and the Institutional Arrangement & Finance Model working group. While we will ensure, as far as possible, that the CEP will be built as a world-class facility that is true to Dr. John Yu's guiding principles, we wish also to assure all CCF donors and supporters that government is truly and totally committed to the project.

We have indeed come a long way in fighting this battle and have spared no effort in paving the way for government to realize its vision as well as ours. Today, as CCF steps into its twentieth year of operation, this dream is about to come true. We are very proud to have been the initiator of something that the children, parents and medical professionals deserve—just as other cities have done for many years. We told everyone that we would not go away until our mission was accomplished. We stuck to our word. Bricks walls have buckled; bridges are being built. And we are still here, but so very glad that we are now all building the same bridges together.

On behalf of the Children's Cancer Foundation, my gratitude goes to all who helped make this happen. You know who you are. You have played an important part in the lives of those children and their families who, in the not too distant future, will be able to heal in greater comfort and in a much welcomed environment that is made possible only because of you. ■

**Miami Wu**  
 Founder Chairman  
 Children's Cancer Foundation



CCF consultant Dr. John Yu meets Ms. Winnie Lee, DOM Tuen Mun Hospital, Professor Fok Tai-Fai, and Dr. Chiu Man-Chun (left)

in November 2006, CCF and the Hong Kong Paediatric Society (HKPS) jointly organized a forum for the paediatricians with Dr. John Yu as the guest speaker. It was exactly four months later at the AGM dinner of the HKPS, in March 2007, that Dr. York Chow made his first public announcement about government's intention to build a Centre of Excellence in Paediatrics (CEP) for Hong Kong and called for all paediatricians, both in

It required not only great conviction on the part of the senior officials (in the likes of the Permanent Secretary, Miss Sandra Lee, who heads this project) but also an honesty and a sincerity, to know and feel in their hearts, what we, as a caring society, should be doing for our children. This, at the end of the day, constituted the unstoppable underlying force that finally cut through all the politics and had everyone sitting around the same table to begin discussions.

## Vision Facts

### WHAT ARE "SPECIALIST SERVICES"?

Care of a highly specialised nature typically provided as an inpatient in a centre of excellence, where there is a concentration of senior experienced doctors, nurses and allied health professionals.

Conditions for which children require specialist services may include cancer, severe renal, heart and neurological diseases, plastics, burns and vascular surgery.

Many specialist services are interdependent, such as renal services and vascular surgery; certain types of oncology and surgery; or muscular dystrophy and orthopaedics.

In keeping with the latest medical thinking, concentrating specialist services for seriously ill children will enable the best possible treatment by increasing doctors' expertise as they will see more patients in their chosen speciality.

# CALL FOR SELF-HELP PARENTS GROUP:

## A key factor in creating a positive outlook for families



**M**r. Benson Pau is a very hard-working, energetic and successful business man. He founded the Pau Kwong Wun Charitable Foundation in 1998 in memory of his son, Kwong-wun, the youngest of his three children, who succumbed to leukaemia after seven years of battling with the illness.

Both Mr. Pau and his wife, Ammy, have a very positive outlook on life. Instead of burying themselves in sorrow, they set out to try and help other parents go through the difficulties in coping with the trauma of seeing their children suffer from cancer. Their aim was to form a self-help parents' organization. Although they fully advocate professional help, they firmly believe that there is still a void that can only be filled through parents coming together and pouring their hearts out to each other in an unencumbered way. Despite their enthusiasm and determination, Mr. & Mrs. Pau soon experienced a set-back as

they discovered their limitations in physically gathering the parents together. "I guess I just don't have the same credibility that hospitals and charities like the Children's Cancer Foundation enjoy," says Mr. Pau ruefully.

***“In many nations and medical centres, parent-family and volunteer associations have formed to help one another and the medical staff ... these associations are uplifting examples of the expression of collective caring energy and solidarity.”***

International Society of Paediatric Oncology (SIOP) report

Undaunted, Mr. and Mrs. Pau decided to learn more about how parent groups in other countries help each other. They joined the International Confederation of Childhood Cancer Parents Organization (ICCCPO), a great advocate of therapeutic alliance where both medical staff and parent volunteers help one another to relieve some of the psychosocial side effects of cancer. The Pau Kwong Wun Charitable Foundation has since become a full member of ICCCPO and Mr. Pau has only very recently taken up the Chair of the Executive Committee.

Having linked themselves to the global front, Mr. & Mrs. Pau are now aiming to help parent groups on the mainland with their Foundation serving as a medium for parents of children

with cancer to come together and support each other.

"We hope there will be facilities for parent support group activities in the future children's hospital." Mr. Pau said, "With the centre acting as a platform, the present child cancer parent groups could be extended to include parent groups of children with life-threatening and chronic diseases."

Both Mr. Pau and his wife firmly believe that a children's specialist hospital in Hong Kong would yield some best results of therapeutic alliance. To elaborate further, Mr. Pau quoted from a report of the working committee of the International Society of Paediatric Oncology (SIOP) who works closely with ICCCPO: "Everyone must work together towards the common goal of minimizing the medical and psychosocial side-effects of serious illnesses. In many nations and medical centres, parent-family and volunteer associations have formed to help one another and the medical staff in this work. These associations are uplifting examples of the expression of collective caring energy and solidarity."

"At each stage of treatment, there must surely be common needs between different support groups of various childhood diseases to share resources and knowledge under one roof," Mr. Pau commented emphatically. "I just hope that the new hospital will take the initiative in forming self-help parent groups so that there will be sort of a fellowship among parents, not only to help themselves, but also be the volunteers that the hospital needs them to be," he continued, "I am sure that with some proper training, parents can be a huge asset to the medical professionals since they know better than anyone else what their children's needs are."

"One last thing—I really wish that palliation will become a full-blown service in the new hospital with its own unique environment, facilities and specially-trained carers," Mr. Pau concluded hopefully with his one final wish. ■





# Meeting the needs of children is the top priority

## The new hospital will be a centre of excellence

*The Vision talks with Professor Paul Tam*

Professor Paul Tam is Pro-Vice-Chancellor (Research) and Chair Professor of Paediatric Surgery at the University of Hong Kong. With many years of experience in the United Kingdom—including as a Consultant at Liverpool’s renowned Alder Hey Children’s Hospital and later as Director and Reader in Paediatric Surgery at the University of Oxford—he returned to Hong Kong in 1996 to take up his present position.

Expressing his views on why we should have a dedicated children’s hospital Professor Tam goes beyond comparing Hong Kong to other world cities. “If you look at the States, if you look at the UK, if you look at Australia, even China, every big city has a children’s hospital.”

He believes that a children’s hospital must be for the children and not just because Hong Kong is a world city. “The primary reason is to give the children a specialist hospital where we provide the best possible healthcare; where expertise is concentrated; where the right environment exists; where modern needs—such as multidisciplinary care—are the norm rather than the exception for children with complex problems. These can only be served well in the setting of a children’s hospital,” Professor Tam stressed.

Professor Tam pointed out that children are unable to speak for themselves, and that those who have major health problems often come from disadvantaged groups. “To some extent the moral fibre of society is defined by how well it cares for this disadvantaged population,” he said, adding that the establishment of a children’s hospital is an

important statement by any society, irrespective of government fiscal or policy considerations that it cares for its children.

In addition to world class medical care and treatment, research and training are two key elements integral to any centre of excellence, and Professor Tam stressed that staying at the cutting edge is critical for a children’s hospital to succeed. “Firstly that drives you to the forefront of excellence—and you want to offer your children excellent healthcare. Second is the possibility to retain talent and attract young

people into the different specialties,” he said. “In a children’s hospital you are continuously trying to improve further and

make contributions that can be translated across the world. Your findings, the treatments you propose, not only affect local people, but affect every child with the same problem elsewhere.”

Collaboration between researchers around the world also helps medical professionals to get the latest information about how to manage their patients. “If you’re well-connected with professors in other parts of the world, you can call upon these people as your friends and equals. It makes a lot of difference.” Professor Tam also noted that networking between children’s hospitals around the world is particularly strong. “We can learn from them, call upon their expertise, exchange staff, have training programmes and so forth. It can be very beneficial.”

The model for the children’s specialist hospital proposed by the Children’s Cancer Foundation, which was echoed in the government’s Policy Address this year, calls for the establishment of a Centre of Excellence in Paediatrics which brings together medical professionals in the academic sector. This would require a high degree of collaboration between the rival medical teaching schools of the University of Hong Kong, and the Chinese University of Hong Kong.

Professor Tam doesn’t see this as a major issue. “Modern trends are that people have to work together and there’s no reason why the two universities can’t work together, absolutely none,” he said.

In fact, Professor Tam believes that collaboration between the two universities should be a motivating factor for the establishment of a children’s hospital and the development of a system which is transparent, fair, collaborative and merit-based. “We already collaborate, we share students and things are happening, particularly in research,” he said, citing the possibility of making funding available for collaborative projects as an incentive.



*Nine-year-old little artist Annie drew this picture while receiving treatment at the Tuen Mun Hospital for brain cancer*

On the benefits of concentrating paediatric cases in specialist units such as at the new Centre of Excellence in Paediatrics, Professor Tam notes that patients and their parents have an increasing level of expectation and a growing knowledge of the range of treatment options available. They are also more likely to question a doctor's credentials and experience to seek out those with the most experience and highest success rate. Concentrating caseloads in one place, rather than scattered around Hong Kong's network of public hospitals, not only puts the best medical professionals under one roof, but also gives confidence to patients and parents to challenge the old paradigm of doctors as authority figures not to be questioned. According to Professor Tam, 'patient power' is one of the characteristics of a different society, and as people become more educated, more sophisticated, they realize what they deserve.

"As they get to know more about the desired and achievable standard, they're not going to settle for second best simply because it is available next door. They go on the Internet, they see this is a procedure that has a success rate of 90%, has a complication rate of say 10%. They see the team is good at it, has done more than 50 procedures, and you need to keep your skills up by doing more than 5 procedures a year. These sorts of metrics are now freely available, so when people look at their own doctor's credentials they will discuss it very openly."

While some question the need for a children's hospital in light of Hong Kong's shrinking child population, Professor Tam noted that actually the birth rate is quite steady. "Treatment is no longer directly related to just the birth rate, because a lot of conditions now occur after birth and also some of the conditions which were not treated previously can now be treated."

He added another factor—additional sources of patients beyond the control of our public healthcare



*“The establishment of a children’s hospital is an important statement by any society, irrespective of government fiscal or policy considerations.”*

system. “You have to cater for them when they come from China. It’s a good thing that we can offer them better healthcare too,” he remarked.

Professor Tam believes that in Hong Kong, patients, parents, the media and the community in general lack an acute awareness of the shortcomings of the existing specialist healthcare system for children because they haven't experienced living abroad and don't know what opportunities there are for improvement. “If it is possible in other world cities, if it can be done in China, if it can be done in the United Kingdom or North America, Hong Kong must have the talent, must have the people with the management skills to work it out.”

Professor Tam concluded with words of praise for the Children's Cancer

Foundation and offered his thoughts as to why this time around the government has taken up the initiative to establish a Centre of Excellence in Paediatrics, a children's hospital for Hong Kong. “As a group, the advantage is that it takes away personalities and it's less threatening than if you are just one person doing this,” he concluded. ■

## Mission Facts

### THE 4 “D”S OF CHILDREN’S HEALTH CARE

**DEPENDENCY** – Children are dependent on others, most often their parents.

**DEVELOPMENT** – Children and their health care issues change rapidly with time because childhood is a period of rapid growth and development.

**DISADVANTAGE** – Children are disproportionately poor, in a minority, and unable to speak for themselves.

**DIFFERENT EPIDEMIOLOGY** – Children are generally healthier, but when sick, tend to have a wider array of rare conditions than do adults.



## THEIR JOY WAS NOT TO BE HAD FOR LONG

“His eyes were so bright and crystal clear. He seemed to be able to look through my mind and understand my thoughts,” said Mrs. Lau as she recalled the joy that Nok-hang’s arrival brought to the family, her face softening as she remembered her son’s birth.

It was a pity that the joy was not to be had for long.

“All new-born babies are like dough. They’re so fluffy and good to hug. We didn’t realize anything unusual until he was a month old. We found that his muscles were too weak. The doctor suggested some blood work and a DNA test,” the mother said.

“Then he had blood in his stool. We had to take him to Emergency at the North District Hospital. All the while, we worried a lot. When he was two months old, the paediatrician at Pamela Youde Nethersole Eastern Hospital finally came back with the most shocking news. Nok-hang had spinal muscular atrophy (SMA) and his prognosis was none too good.”

Mrs. Lau remembered the devastating discovery. “Heaven crumbled, just as his papa said, ‘All our stakes were gone.’ It was as if we had lost all our wealth and possessions in one single game.”

Despite their low spirits, Mr. and Mrs. Lau took it upon themselves to gather information about the disease, contacting the SMA charitable foundation to find out more. Gradually, they tried to pull themselves together and make mental adjustments.

At three months, Nok-hang took a turn for the worse. He was in and out of the hospital frequently, needing the support of medical equipment. Thanks to the SMA charitable foundation, the Laus were able to acquire a blood-oxygen monitor and a mucus suction machine to keep their son at home.

“The first horrifying experience was when he had low oxygen level in his blood while he was in the Nethersole Hospital for a week. His condition deteriorated and he had to be kept in the Intensive Care Unit. The hospital advised us to prepare for the worst, saying he had heart problems and his condition was critical. Although he pulled through that time, we began

to understand the true state of his illness.”

“In such a case, what parents can do is to try their best and pray for a good turn so that they can take their children home as often as possible. But when Nok-hang came home, we had to make a lot of preparation. He had breathing problems and difficulty swallowing saliva. There were so many homecare procedures to be learned. We had to pay special attention.”

“Despite my aching heart and my weariness, I had to work hard to keep his trust. Whenever I looked into his eyes and caught that tranquil and innocent expression, which seemed to be telling me that he had trusted his whole self to me for shelter, I was filled with renewed energy. During his illness, I tried my best to keep in good health so as not to infect him.”

The remaining days saw Mrs. Lau in hospital most of the time. She counted herself lucky for being able to access more resources and managing to make ends meet. However, she had to work hard to keep her spirits up and maintain a good state of mind.

While looking after her child at the hospital, she wanted desperately for him to be taken good care of. But she understood that the hospital was understaffed and that paediatric nurses were scarce, especially during the nightshift. She dared not bother them. If she was depressed, she bottled up her emotions.

Oftentimes, Mrs. Lau wanted very much to have someone lend a helping hand and to talk to for support. And when she stayed overnight at the hospital, there was no bed for her. A solitary chair was all she had. There was no place for her to do her toiletry. That was simply not the place for a parent to stay. Yet she worried about being exhausted and not having the energy to look after her son.



“We were very concerned about the shortage of staff. We had to learn first aid and how to clear his airways of mucus. I had come across so many good doctors and nurses, but they had too many patients on their hands. When we had questions for the medical people, we had to prepare a list of the questions and know when to broach the subject, or else we missed the chance of getting hold of them.”

“Nok-hang was one of those chronically-ill patients. We felt that he needed a different setting and different equipment in a medical institution. As for us parents, we needed long-term psychological and spiritual support.”

“Sometimes I felt very lonely and unhappy. I felt as if I were locked up in a room with Nok-hang. Nobody would come to us if there were nothing wrong. We could have gone home more often, if only there were homecare services. That would be a much better arrangement for the patients, their families and even the hospital.

If someone could offer us relief services, we might have felt less pressurized and frustrated. But we had no choice!”

“The first time Nok-hang’s condition turned critical, we took the initiative to approach the hospital chaplain. We learned how to face death. Thinking back, that helped us a lot, even though it was very painful. But then, we wanted to find out. If people do not have the knowledge, if they let their emotions overwhelm them, if the families are more inward-looking, they would not be able to build up this relationship and get support.”

**“Nok-hang had spinal muscular atrophy (SMA) and his prognosis was none too good.”**

**“When [the mother] stayed overnight at the hospital, there was no bed for her. A solitary chair was all she had.”**

“To me, it is very important to have a professional worker who would be able to assess the needs of families with serious and rare illnesses like Nok-hang’s and link them with the appropriate information resources and various supporting agencies. And when a patient’s condition deteriorates and when the parents go through the stage of facing death, practical and emotional support is very important.”

*“We felt that he needed a different setting and different equipment in a medical institution. As for us parents, we needed long-term psychological and spiritual support.”*

“Nok-hang passed away in July last year. He had no need of those support machines anymore. I had also left that empty hole of the medical ward. But the gentle and tranquil look of his eyes has never left me. His life might be short, but it was filled with infinite love. While we gave him the best we could, he gave us something in return—truth, charity and beauty.”

“We wish that he was never embittered by the physical pain he suffered. Because he was born out of love and he passed away in the embracing love of his family.”

“For all those sick children and their families, I sincerely wish that, unavoidable as all the suffering and pain might be, they, supported by the loving care of their families and medical people and the right hospital setting, are not only comforted, but can also mitigate their feeling of bitterness to the minimum.” ■

## MUSIC AND A GARDEN WOULD MAKE HOSPITAL LIFE SO MUCH BETTER



Dilys stands next to young artist Ho Suet Hei's vision for the new children's hospital

there! Peer support is very important during treatment. I enjoyed the time I learnt and played with my friends in hospital.”

“I hope the hospital can have a big play area, and also a big garden. I always imagined that I could play or walk under beautiful sunshine when I was lying on my hospital bed.”

“I also hope the hospital can have a music room and a resident music teacher, so that patients can learn piano and other musical instruments when they feel better.”

“Finally, calendars and newspapers should be everywhere, so that we can have a better idea of time and date—then we know we are not abandoned and our life in hospital can be better tolerated.” ■

*“We want to know the date and time when we are in hospital.”*

Dilys is a very cheerful girl.

Dilys was diagnosed with leukaemia when she was only three years old. After eight years of treatment, she has recovered at last. Looking back on her life while in hospital, she has a few suggestions for the proposed children’s specialist hospital.

“A designated children’s specialist hospital is a very good idea, since all the child patients will be centralized in one place, and that means I can have more friends

## Mission Facts

### THE DEMAND FOR SPECIALIST SERVICES

There are around 1.4 million children (0-19 years old) in Hong Kong. That’s roughly 20% of the total population.

Hospital admissions for this age group total around 150,000 each year.

Of these admissions, around 25% are for children requiring specialist treatment.

Source: Census & Statistics Department; Hospital Authority ICD-10 Data

# WINNIE'S UNUSUAL ROUTINE

Meeting special education needs is essential for new hospital



It is hard to believe that nineteen year old Winnie—beautiful, radiant, and on the surface not unlike many other girls her age—is afflicted by an illness which requires her to go for a blood transfusion at the hospital every other day.

“I have a type of blood disease called Factor VII Deficiency. It affects my body’s ability to produce blood. My family tells me that I have had to go in for blood transfusion ever since a month after I was born. I also have frequent epileptic fits and am on constant medication. The dosage is difficult to get right and it has been adjusted many times. I do beg your pardon, because my memory has also been affected by my illness and there are many things I just don’t remember. I attend a special school on account of my poor memory and need to make frequent visits to the hospital.”

Despite constantly having to go in and out of hospital, the disruption of her studies, changes to her medication, having to adjust to countless doctors and nurses, seeing friends pass away—Winnie is unshaken, and handles these afflictions with an almost childlike innocence and grace. It is as though she is a veteran in the battlefield against disease; there is nothing she has not seen and nothing fazes her.

“The thing I hate the most, though, is putting on the heparin block. I used to have a central line, but I had an infection so they took it out. If the

doctor is good at what he does, then the day goes by quickly, but if it takes him many tries to get it right, I panic and it is the worst feeling imaginable. I wish they had one designated person for the procedure. For example, the designated person who draws my blood every time, and not only is she good at it, she has become a friend to me and it makes the whole ordeal less stressful.”

The blood transfusion takes up an entire day, and so Winnie has had to learn to entertain herself for long periods of time. If the medical facilities, designed especially for young adults, are equipped with internet access, music, and even a library of books and comics—it will make the endless wait more bearable. Although the friendliness and encouragement of the medical staff has been a great help to Winnie, her constant need to be in hospital has caused her studies to suffer too. She has to be absent from school every other day, and as a result, her academic progress is in need of improvement.

“I go to a special school, and because the curriculum is different from the school at the hospital, I cannot attend classes when I am at the

hospital. Is there a way for the school at the hospital to communicate and collaborate with my school, so that I can still continue with my studies even when I am at the hospital? Wouldn’t that be a more efficient use of time?”

Winnie also wishes there was some forum in which young patients like herself can come together for mutual encouragement and support especially during difficult times.

Winnie chuckles, in her youthful exuberance, “Well, I’d have to ask for my mother’s permission before I can join!” ■

**“... Internet access, music, and even a library of books and comics will make the endless wait more bearable.”**

**Vision Facts**

**RESPECTING THE SPECIAL NEEDS OF CHILDREN**

*How a hospital manages pain is a benchmark for how it manages all forms of distress in suffering children.*

*A children’s hospital should be a place where all children are happy to come for treatment. Children will be actively involved in their treatment, and parents will be included in the health care team as ‘experts’ in understanding their children’s pain and helping them to deal with it.*



## Putting experts in one place will create a paediatric hub

*The Vision talks with Dr. Dawson Fong*

Based at Tuen Mun Hospital, Dr. Dawson Fong is the Chief of Service and Consultant Neurosurgeon for the Department of Neurosurgery in the New Territories West Cluster of the Hospital Authority. He has a special interest in paediatric neurosurgery.

HKSAR Chief Executive Donald Tsang argues that the city deserves to be on a par with New York and London, and a children's specialist hospital is one thing that we deserve, according to Dr. Fong.

"We do need one," he said, "because now the services are truncated and separated, and there are 41 hospitals each trying to be an acute hospital on its own."

Dr. Fong believes that for parents of seriously ill children the best expertise may not be available in a local hospital. Gathering all the experts in one place creates a hub where 'everything is meant for paediatrics.'

"In the end," he said, "the most important thing is the culture...the culture for children. Facing children you need a different mindset. That is the thing that Hong Kong doesn't yet have."

According to Dr. Fong, modern medicine demands a new approach, one based on teamwork, pooling the best experience available and sharing information.

"Things are getting complex," he noted. "We are no longer dividing patients by age group, but by the specialties, and within those, the subspecialties. As you go in that direction there needs to be a venue where you can put the experts together so that they are cooperating on a single case."

One of the issues surrounding the establishment of a children's specialist hospital is the effect that a new concentration of specialties and subspecialties will exert on existing paediatric services and departments in the major hospitals. For parents the choice might be obvious. "Better to get my child to the specialist hospital rather than staying here," Dr. Fong suggested.

So for the paediatric units in those major hospitals who stand to lose all the complex cases to a new children's specialist hospital, he believes

they will have to scale back their scope of work if the new facility is going to be a success. "But if the door is open for them to remain involved in those cases further, then I think demand will shift," he said, adding that the opportunity will be there for all paediatricians to refer cases and to be involved.

Dr. Fong believes that a children's specialist hospital will also provide paediatricians with an opportunity to develop themselves in subspecialties; an opportunity which doesn't exist in the current framework. "For example, if you want to be an endocrinologist, how can you be sure that you will see enough cases working in a small paediatric unit in a general hospital?"

Even in his own specialty area of neurosurgery, which is divided into seven departments across Hong Kong, Dr. Fong experiences the same problem. "What good cases do they have," he asks, "in terms of quantity or quality?"

Concentrating complex cases in one place brings benefits to the medical profession as well as to young patients. Citing Sick Kids Hospital in Toronto as an example, Dr. Fong notes "they have paediatric everything—paediatric pathologists, paediatric neuropathologists, paediatric anaesthesiologists, paediatric

neuroanaesthesiologists. What's the difference? You get immediate, appropriate treatment, from a tip-top team."

Long-term follow-up is another important area which benefits from a multidisciplinary approach with a team that works under the same roof, especially for children. "Children have a much longer follow-up period than that with adults—not really just for 6 months after surgery. I prefer 60 years," he said. "So I don't think we should just look at the results at the exit door of the operating theatre; I need to look at how they fare afterwards. If I've done what I thought was a total excision of a tumour, and yet the patient remains dumbfounded for the rest of his life—that's not good surgery."

Children often have trouble fitting back into school after an illness or trauma, or between treatment sessions. This may only come to the attention of an education expert or at best a development paediatrician. Dr. Fong questions how, in the current system, these problems will come to the attention of the entire medical team.

"So I always tell my students that it's how you look at the results, not at the fact that they simply survived surgery or that the tumour was completely removed. The important thing is to know how the patient recuperates, and that's where we need others, where team work comes into play," he added.

In conclusion, Dr. Fong was delighted that the Children's Cancer Foundation has worked hard to ensure that Hong Kong will finally have a world-class children's specialist hospital, and pledged his support to making it the best possible by adding "if you need me to sit somewhere and hold a placard..." ■

*"The most important thing is the culture...the culture for children. Facing children you need a different mindset."*





## A PLACE NEEDED FOR PARENTS TO REFRESH

### A 'rest station' while we wait for our children's treatment would be a godsend

**M**rs. Lai was startled by the sounds of very loud breathing and woke up in a fright. She ran straight to Yan's bed to find her suffocating daughter's face turn a ghastly shade of blue. She immediately lifted Yan's head up, making it possible for her to resume breathing properly. It was not until her daughter's complexion returned to a normal shade that Mrs. Lai's heart, sick with anxiety, began to beat again at its regular pace.

Ever since her daughter's first coma four years ago, Mrs. Lai has not had a single night of sound and care-free sleep. As she turned her thought on Yan's condition, she looked out the window and saw the first light of daybreak. They had made it again. It's a new day today!

Mrs. Lai has had to endure the devastating effects of her daughter's fight with brain cancer. Yan had initially recovered from her brain tumor and had resumed a normal life, but soon after a brain infection put her into a coma on three separate occasions. Yan was finally diagnosed with infection of the brain arteries, which began to

have serious effects on her health.

Mrs. Lai witnessed the deterioration of her daughter from a girl once so vibrant and passionate to a sickly bed-ridden girl incapable of speech and in need of constant medical attention. As a mother, her grief and pain is unfathomable. Nobody can understand her feelings of emptiness and helplessness.

There are days when Yan's condition would seem to improve, giving her mother a moment of happiness and respite. But there are other days when her daughter suffers from convulsion, which causes great pain in the mother's heart

***"We take it one day at a time! Frankly it has been very exhausting; there is no rest at all."***

"We take it one day at a time! Frankly it has been very exhausting; there is no rest at all. Our financial situation does not allow us to hire a domestic helper, and our relatives have not been much help, either. Even a follow-up examination is a big hassle. The taxi fare is several hundred dollars. The routing of the Rehabus is too long. Even when we are at the hospital, I need to be by her side because of her condition. I won't even have a place to sleep or wash up. I often have a

headache back home after visiting her."

"The biggest help to me will be a parents' support station at the hospital. It is like a rest area in a long journey that allows people to unwind and energize themselves. The hospital is a familiar environment for a patient, and with the care of the health care professionals, we can get a few hours of sleep at the station. We also have the space to attend to other matters. My husband and I haven't dined tête-à-tête for more than four years now!"

Mrs. Lai does not only have her own physical fatigue to contend with, she must also deal with the emotional trauma of her daughter's being transferred between different medical departments due to the complexity of the illness. On one occasion, she chanced to overhear a conversation between a non-pediatric specialist and the attending doctor:

"There is not much that can be done for this patient. Perhaps they should consider placing her in a health care home where she can grow old and return to the hospital only when her condition worsens."

Mrs. Lai thought to herself, "How can a doctor be so insensitive towards a patient? My daughter is barely over ten years old! Even if there is no cure for her in the present, how can they give up on her? The doctors at the pediatric ward would never speak in this way. They always try to think of ways to help us; they are mindful of our problems and are sensitive to our feelings. Why aren't the other doctors more like them? The patients' parents are so vulnerable already. We need doctors to be more than merely physicians. We who are parents need their encouragement and moral support to keep going. I hope those who are training to be practitioners of medicine will also learn to care for our emotional well-being!" ■

## **ision Facts**

### **FAMILY FACILITIES**

*At children's hospitals around the world, family facilities include fully-reclining chairs next to all beds, kitchen facilities, lounge areas (with access to computers and Internet connections) and bathroom facilities.*

*Private spaces, such as family consulting rooms and resource centres provide comfort, convenience and sanctuary. Play, educational and work support spaces provide a continuity of lifestyle during the hospital stay.*



# I can't wait to see my dream come true!

## Hospital will improve service quality in treating children

*The Vision talks with Ms. Winnie Lee*

**T**he idea of building a specialist hospital for the children of Hong Kong excites me!" said Ms. Winnie Lee, Department Operations Manager of the Paediatrics and Adolescent Medicine service at the Tuen Mun Hospital. "To advocate for the welfare of sick children, a specialized hospital is a must. As a sophisticated society with excellent medical technology, Hong Kong has been waiting too long for that to happen. I simply can't wait to see my dream come true!"

Being the founder president of the Hong Kong Paediatric Nurses Association in 2000, Ms. Lee has a determined vision for Hong Kong to have its own specialist hospital for children requiring specialist care.

Ever since the completion of her basic nursing training at the Queen Elizabeth Hospital in the 80's, Ms. Lee has all along devoted her career to looking after children with illnesses. After her basic training, Ms. Lee went on to obtain her midwife qualification and subsequently travelled to England for an 18-month in-depth training in Paediatric Cardiac-Thoracic Nursing, a specialized course in caring for children with heart and lung problems.

"I am fond of working with children and their families, so I decided to become a paediatric nurse long ago," smiled Ms. Lee as she recalled the early days of her career. "I shall never forget the great times I spent with my patients and their family. There are loads of memories that I cherish even after years."

"I can remember vividly how the children in the oncology ward were exhilarated by the celebrities' visit; and how I and my colleagues would celebrate seeing the children recover from critical illnesses," she continued. "In facing the death of some children, we mourned



together and cared for each other while giving psychological support to the parents. All the experiences were so valuable and unforgettable in my career."

Before serving at the Tuen Mun Hospital in 1994, Ms. Lee spent a few years working in the Paediatric Department of The Prince of Wales Hospital and The Royal Alexandra Children's Hospital in Sydney (now the Children's Hospital at Westmead). After three decades of diversified service in paediatric nursing, Ms. Lee is truly an expert in the area.

According to Ms. Lee, the design of the children's specialist hospital must provide a 'child-friendly' atmosphere to all. "Children become anxious coming to an unfamiliar place for their medical treatment, so it is important that we do our best to relieve their psychological stress while attending to their physical problems," Ms. Lee pondered for a while before going on to describe her ideal children's hospital.

"A playground or garden in front of the soft-coloured buildings would just be great. There should be creative themes on the interior walls, lift doors, and corridors. Huge paintings of the ocean or the sky would definitely make the children and visitors feel calm, too! To enhance the sense of liveliness, we can also install artificial plants and hang some indoor ornaments, like model aeroplanes and birds, in the lobby," Ms. Lee continued, "All in all, it would be most important to make the children, parents, and visitors feel as comfortable as possible."

The traditional structure of the hospital building limits the layout of the paediatric wards, making it unfeasible to set up special designs for children. "There are too many constraints when transforming the traditional layout of a general hospital according to the children's needs – we often run out of space," said Ms. Lee as she envisioned the future setting of the children's specialist hospital. "Designing the new children's hospital from scratch, we want to offer spacious rooms for the children and their visitors. Ideally it should have no more than 24 beds in each ward, and we will have sufficient space to set up special rooms for the children to enjoy different activities while being admitted."

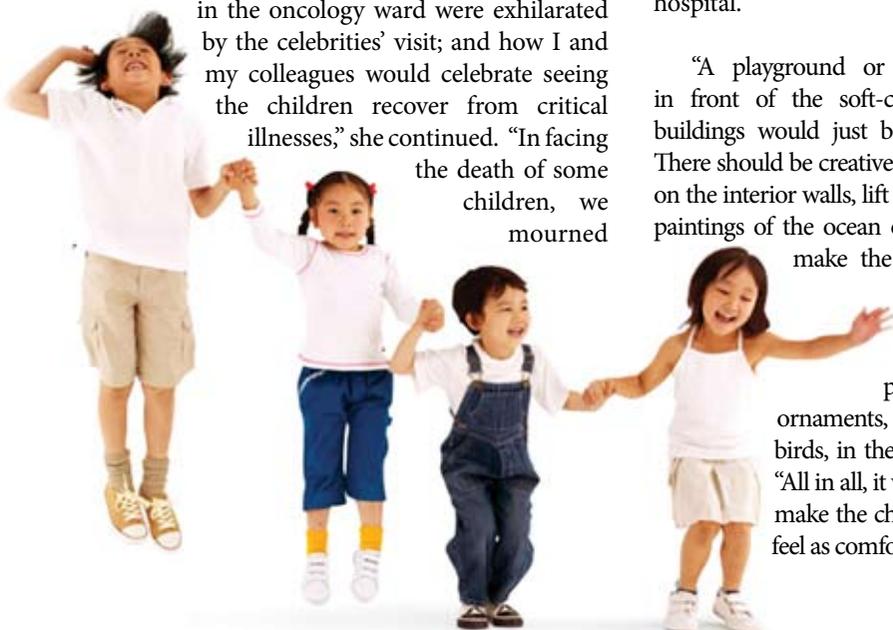
A specialist hospital for children does not only provide a better place for children with long-term illnesses to stay, it also allows the gathering of medical and nursing expertise to improve the overall service quality in paediatric medicine.

Regarding collaboration with the present paediatric services, Ms. Lee believed a specialist hospital for sick children will coordinate well with the traditional children's wards in giving

the parents more options on treatment for their children.

"We should never see the children's hospital as a competitor with the current services provided by various paediatric departments. A hospital for children merely helps to excel the standard of local paediatric medicine," Ms. Lee gave an end-note with a confident smile, "As an advocate for children's welfare, I shall spare my every effort to support and promote the idea of building a children's hospital for Hong Kong." ■

***“All in all, it would be most important to make the children, parents, and visitors feel as comfortable as possible.”***





## DAY-BY-DAY BATTLE IS A PARTNERSHIP BETWEEN FAMILY AND MEDICAL STAFF

### A story of hope and commitment

**L**Y's mother emerged from the children's bone marrow transplant ward after keeping her son company for 48 hours. Now that Grandma took over the watch, she could finally take leave from the hospital. There was no rest for her, however, since she had to first sanitize her son's clothing and then attend to other duties like updating the child's blog for people who care so much about them.

"I wish there was a hospital dedicated to treating children in Hong Kong. It would have saved us several months of worry, waiting, fear, and emotional stress. And perhaps LY could have been diagnosed sooner and begun his treatment earlier," remarked the mother.

She recalled his ailments, "At least then he would have had a chance to see and be treated by a paediatric specialist. Unfortunately, three months after LY was born and after he was weaned of mother's milk, he began to suffer from frequent cold, flu and developed a cough. We took him to a number of doctors. He was given various medications but his condition did not improve."

"From that time onwards, he continually suffered from low grade fever, so we took him to the casualty ward at Queen Elizabeth Hospital. They found he had tuberculosis. His father and I also had to be examined but we had to wait for three months."

"LY stayed in the hospital for a month. After he was discharged, he had another bout of fever. He had fungus infection and pneumonia. It was the third time within a short period."

"In this time, we had to make separate trips to the Eye Hospital in Kowloon and a skin clinic in Yau Ma Tei because there isn't a hospital for children. LY had a fever and we were both worried and helpless because we felt like we were running around, wasting our efforts, wondering if we could make good use of our time by visiting a one-stop medical establishment"

It was only at the beginning of March that LY was officially diagnosed with a very rare disease, called Severe Combined Immunodeficiency (SCID).

"When we found out about this, we were at a loss as to how to deal with it. On one hand, we finally had a clear diagnosis, but on the other hand, we now face a tremendous challenge since there is no incidence of this disease for people of his age in Hong Kong."

"The doctor suggested a bone marrow transplant, and we didn't know if we could handle it. I was very unhappy and felt extremely stressed; I wish there had been qualified professionals who would take the initiative to look after and support us, especially in the early stage. In the past few months, friends and relatives have been most supportive, but at times it was very much a solitary battle for us. I wish there were some professional caregivers

who would spend time with us, talk with us, and care for us."

On the 26th of March 2007, LY was admitted to Queen Mary Hospital to await a bone marrow transplant. Over 400 people – family members, relatives and friends – registered to be a bone marrow donor for LY. Touched by the overwhelming support, LY's mother, together with LY and his father, vowed to fight this disease to the end no matter what.

"The comforting attitude and encouragement of the medical staff gave us a lot of faith. They were attentive and accommodating to our needs, and gave us no small relief during what was a very anxious time. I didn't mind the

location of the hospital, so long as the hospital staff was willing to communicate and discuss things openly with us. I was also referred to social workers and psychologists for follow-up consultation."

May 23rd is a day LY's parents would never forget - LY was to have his bone marrow transplant from a Taiwanese donor! However, each passing day after the procedure was a challenge. LY had had recurrent fever and infections, requiring around-the-clock parental care. The most important thing for the mother was to collaborate with the medical staff by updating them on her son's progress and reporting any changes she observed. At times she would make suggestions which the staff would be happy to accommodate. She felt she had such an important part in her son's treatment.

*"A dedicated  
Children's Hospital  
would have saved us  
several months  
of worry, waiting,  
fear, and emotional  
stress."*

LY's mother has some personal observations and insights that she would love to share with all regarding the need to support the parents of sick children.

"We wanted very much to remain healthy ourselves while we were taking care of LY, but the hospital facilities were highly inadequate. For example, we did not have a bathroom for washing up. We were very concerned about hygiene because we did not want to infect LY but there were no facilities for washing and sanitizing our clothes. It is even worse for visitors from out of town, they had to use a public washroom and do the laundry. It was so exasperating! It would be great if the hospital had a guest house and a laundromat!"

LY stays in an isolated room at the hospital for an extended period of time. Other than his mom, dad, and grandmother, who come to take care of him, the only people in LY's small world are the masked medical staff who attend to him.



"Would it be possible to have a family room, with hyperfilter, which enables people who care about him, for example, his grandfather, to visit him occasionally? The adults would be relieved, and LY can get to know his relatives! As well, LY is growing older by the day, and is in need of educational enrichment. I would appreciate it if the hospital could help me and provide guidance on these issues."

Because LY's case is the first in Hong Kong, his mother has been searching the web for information about the disease. She also hopes that LY's treatment can lead to further medical research that will benefit other children with the same health problem.

While each day finds her dead tired, LY's mother has never given up. She faces each day with a determination to do her best for her son. ■



## LULU'S WISH LIST

"There should be a very big play area. I loved the play area in hospital, although it was very small. I made lots of friends there, and the arts and crafts activities gave me the only feeling of satisfaction when I was in hospital."

"I suggest that the hospital should have classrooms and a shopping mall, so that we can go back to our normal lives when we feel better. I also suggest that patients should be able to leave the hospital for a few hours from time to time, so that their family can take them out to for a meal or even to watch a movie!"

When she was nine years old, Lulu was hospitalized for more than a year because of leukaemia. Mature, imaginative and talented, Lulu gave *The Vision* some creative ideas on what a children's hospital should be like.

"Drawing is a very effective way for us to express our feelings and so I would like to suggest that there should be a wall for children to draw on, so that the hospital can change its interior design constantly. No wall paper will be needed in the hospital, and the paintings can cover the boring and scary white walls."

"I also suggest that there should be windows all around the ward, so that we can look out and see what other ordinary people are doing. It is no fun at all to be hospitalized for a long time, and having a glimpse of the outside world will give us energy for a faster and better recovery."

"Finally, the children's specialist hospital should have a big television, but not for watching cartoons or TV programmes. I believe children in hospital do miss their families, and I hope with this big television they can have virtual meetings with their families when they feel lonely and need support." ■



Lulu and her little sister Sin-yi

## Vision Facts

### RESPECTING THE SPECIAL NEEDS OF CHILDREN

Wherever possible, patients at a children's hospital should be grouped in inpatient units according to their age and condition. That way, teenagers can be surrounded by those their own age, and likewise for younger children, toddlers and infants. It also allows for easier contact between the multi-disciplinary teams at the hospital when a variety of specialists and health care experts may be treating infants, children and adolescents with similar conditions.

A children's hospital should be a nurturing and gentle environment for young patients and their families – a place where art, colour and open space are more common than white hospital coats.



## “Who wouldn't want to work in a centre of excellence in one's own dedicated field?”

The Vision talks with **Dr. Ellis Hon**

**D**r. Ellis Hon is Associate Professor of Paediatrics with the Chinese University of Hong Kong. He is an American board-certified paediatric intensivist, who completed an intensive care fellowship and has served as the Chief Resident of the paediatric training programme at the Miami Children's Hospital in Florida.

Dr. Hon's special interests are paediatric intensive care and dermatological diseases; although he is quick to admit that he has not been properly trained in the area of paediatric dermatology.

Dr. Hon is very enthusiastic about the idea of Hong Kong having its own children's hospital. “Preferably, it should be in a district central to where most children live”, he suggested, “like the old Kai Tak airport site.” Being a man who advocates quality before quantity, he is of the opinion that, rather than debating the issue of how many children's hospitals or how many subspecialties there should be, we should simply “get on with it and prioritize the establishment of sub-specialties according to the availability of resources.”

Haematology/oncology is first on his list, followed by psychiatry, cardiovascular surgery, renal, neurology, metabolic diseases and others. Dr. Hon is emphatic that all specialists must live up to the standard of having been properly trained with recognized postgraduate subspecialty qualifications and adequate experience in the relevant fields. “Of course, being kind and caring as well is a much welcomed bonus”, he added.

There are two areas where Dr. Hon would like to see more emphasis and improvement being placed in the new hospital – psycho-social support and hospice care. He believes that Hong Kong is world-class in saving lives and treating physical ailments, but “shouldn't we also put some resources into looking after patients' mental, emotional and spiritual needs?” he asked.

Dr. Hon also has a diploma in aviation



medicine, and so the subject of transporting trauma cases and critically ill babies and children from outlying services to the intensive care units in the proposed children's hospital is one of great interest to him. He is confident that Hong Kong is more than able to take up this challenge by putting together a well-equipped neonatal/paediatric transport team.

Being an academic, Dr. Hon is naturally interested in teaching and research. He strongly regards cooperation between the teaching hospitals as imperative for breakthroughs in research and that, if the universities could work together, there would be no end to how much more Hong Kong could excel in medical excellence. “Hong Kong is too small to be so divided; perhaps the

second tier of younger doctors could see a way to help resolving this to fruition,” Dr. Hon mused hopefully.

Dr. Hon believes that the proposed children's hospital should attract the interest of many renowned paediatricians who would take on the role of visiting consultants to share their expertise in respective sub-specialties. “Who wouldn't want to work in a centre of excellence in one's own dedicated field? It is such a rewarding thought and a morale-booster even just thinking about it. I fervently hope that it will happen in my lifetime!”

“Oh, by the way, I have a suggestion for the name of the hospital—I am not concerned whose name it may bear, but I would really like to see it followed by ‘Children's Hospital of Hong Kong’ – is that possible?” Rubbing his hands together with great enthusiasm, Dr. Hon concluded the interview with this thought. ■

*“Shouldn't we also put some resources into looking after patients' mental, emotional and spiritual needs?”*



# HOPE LIVES ON

*"Mummy, mummy ...it hurts, it hurts ..."*

Waking from her nap, 27-month-old Yan began to cry and refused to get out of bed. For a few days, she cried whenever she got out of bed and insisted on walking on tiptoe only. It did not look like anything was wrong with her, except that her little hands were a little swollen and she had a low fever of 38C. Because Yan's brother was a leukaemia patient, her mother was frightened, so she hastened to call her relative for advice.

"It's probably just a flu, but it might be better to go to the hospital. We were advised to go to Emergency!"

After a long period of waiting, the doctor examined Yan and concluded that nothing was wrong. He felt that Yan's mother might be overly concerned about the situation because of her son's leukaemia. However, Yan's symptoms did not dissipate. And every day at the same time, she would experience pain and would run a fever. In order to secure an appointment with the paediatric department, Yan's mother brought Yan to Emergency every three days for an entire month until the hospital admitted her for further tests.

"If there was a specialized sick kids' hospital, especially staffed by experienced paediatricians, Yan could have been treated much sooner. Guangzhou has one. Why not Hong Kong?"

Yan's mother remorsefully and tearfully recalled a few occasions when Yan would refuse to put on her favourite clothes. She mistook Yan's complaints for a tantrum and scolded her for it.

"As it turns out she has Juvenile Idiopathic

Arthritis. She suffered great pains in her joints."

This diagnosis was not easy to come by. There was no incidence of this disease in such young age in Hong Kong. And Yan's condition was the first of its kind. Early on, no suitable medication was prescribed except pain-killers to relieve her pain. The only good thing was that she did not have to go to emergency each time, instead she went to the paediatric ward, where the paediatric doctors and nurses were kind and caring and put them at ease.

Prior to this, Yan's brother had just come off his medication, and Yan's mother was looking forward to some peace after two chaotic years. She never thought that she would have to face something like this so soon. Why did this happen? Was it because of something she did? It was difficult to have to deal with these issues but fortunately she had the counsel from a social worker she met during Yan's brother's illness.

"At that time, I really needed a lot of support. When your children are sick, it brings a lot of tension into the family and our marriage. And so it is also important to care for the parents. It has been hard to talk to other people about this because Yan is the youngest patient with this condition in Hong Kong."

After four months, Yan's diagnosis had been confirmed and she began her treatment. In addition to taking oral medicine, Yan also needed a year-course of weekly injections which her mother would administer at home. Each time Yan saw her mother make preparations for the injection she would become unsettled and

begged her mother not to go on with it. This broke her mother's heart.

"Why couldn't Yan have a play specialist prepare and play with her and calm her fears, like her brother did in the hospital? The needle jab is hurting as it is, and she also has to deal with the emotional stress! Since her condition is not likely to improve soon, her mental health for the long term is very important. She could use some child counselling support, just as her brother did."

After Yan's brother was finished with his treatment, he resumed his studies but had difficulty keeping up with the other children. It was difficult for Yan's mother to see his studies deteriorate, and the embarrassment it caused him. Fortunately, with some special arrangement by the Children's Cancer Foundation, an educational and psychological assessment was made in time, and a more suitable school was chosen for Yan's brother. Now Yan's brother is enjoying his studies much more. It can be seen that the follow-up care of a child patient after his treatment, especially in the area of education, can be a great relief to both the patient and his parents. "Without extra efforts and support, Yan's brother may not be willing to go to school!"

Having to take care of two children with rare illnesses is an indescribable nightmare. However, Yan's mother is thankful for the dedication of the medical staff, social workers, family members, and especially the parents of the other children in the ward, whose mutual support and encouragement were like a beacon(s) of light in a time of darkness and gloom.

"I am still in contact with those other parents. We share about what's going on and encourage each other to carry on!" ■

*"When your children are sick, it brings a lot of tension into the family."*

# HONG KONG'S CHILDREN'S CHARITIES GET BEHIND THE VISION

The Children's Cancer Foundation would like to thank those children's charities that have supported our efforts and helped to make the vision come true.

Together, NGO's provide accessible child and family-centric care where and when it is needed; they are a source of support and stability for families while other systems and people within those systems fluctuate; and they are integral partners to other service providers in the continuum of care by providing professional linkage between hospital, home, and community care.

Most important though, their dedicated staff and volunteers are advocates for the children and families they serve, who are often in a minority and unable to speak for themselves. Thank You. ■



## PARENTS ASK FOR DONATIONS INSTEAD OF GIFTS AT ARABELLA'S FIRST BIRTHDAY

In early December 2008, The Vision received the following email from Vivien Tham, a medical doctor in Hawaii:

Hi,

We are celebrating the first birthday of my little girl and wanted to ask our guests to donate to the Children's Cancer Foundation's children's hospital project in lieu of gifts. Should the cheques be made out to Children's Cancer Foundation? Do we have to specify which project it is for?

Thanks,  
Vivien Tham

Founder Chairman Miami Wu wrote back explaining that although the hospital was still several years away from being built, CCF would be delighted to hold on to the donation and pass it over to the new hospital foundation at the appropriate time. "Your daughter is the first baby donor to this worthy cause," she wrote. "We at the Foundation are not only touched but find the idea very cute as well. Perhaps circumstances permitting, we can ask Arabella to come to the ground-breaking ceremony when she is five or six years old?"

"A Centre of Excellence for Paediatrics is such an important project for the children of Hong Kong," Dr. Tham replied a few days later. "I commend you all on your hard work."

Here at The Vision we thought it would be good to put a face to a name and include a picture of Arabella at her 1st birthday party, which was held in Hong Kong on December 26th.

"That's a great idea," Dr. Tham wrote back. "Maybe we can inspire more people to donate to such a worthy cause."

On behalf of all those who share our vision, the Children's Cancer Foundation wishes to thank Dr. Tham for her thoughts and the generosity of her family and her guests. As you can see, little Arabella certainly had a joyful birthday, and in her own little way has added significant meaning to her very first birthday! ■



One year old and oh so beautiful  
周歲的頌欣長相多美

# 香港的兒童 慈善團體支持 建院計劃

兒童癌病基金謹向各兒童慈善組織致謝，它們支持本會倡議建設兒童醫院，幫助我們實現理想，我們心存感激。

各個志願慈善機構都共同為有需要的兒童及其家庭提供一般性或特定服務。即使福利服務界中人事或制度有變更，但是這些機構從來都是支援和穩定家庭的力量。在護理服務界，它們也是基本夥伴，與其它服務機構結合，以專業的方式，在醫院、家居和社區護理服務之間擔任搭橋的角色。

機構的職員和義工盡心盡力，為兒童病者和家人爭取權益，因為這些患者往往在社會勢單力薄，而且是沉默的一群，他們的服務精神，難能可貴，特此鳴謝。■



## 女兒頌欣周歲生日 父母懇請賀禮改為捐款

零八年十二月初，本刊收到家住夏威夷的譚慕冰醫生的電郵，她寫道：

你好。

我們在慶祝小女兒第一個生日，我們要告訴賓客，想送賀禮，不如給兒童癌病基金兒童醫院建院工程捐款。支票抬頭人應寫兒童癌病基金嗎？我們要不要寫清楚哪個捐款計劃？

謝謝！  
譚慕冰

兒童癌病基金創會會長胡逸雲回信給譚醫生時解釋說，兒童醫院工程需時，還要等好幾年，醫院才能建設。不過，兒童癌病基金樂意暫存捐款，在適當的時候代轉新設醫院基金。「您的女兒頌恩是第一個嬰兒善長支持醫院建院計劃，令我們感動之餘，更覺有趣。等到頌欣五、六歲時，也許情況配合許可，我們可以邀請她出席醫院工程動工禮。」

譚醫生幾天後回信：「對香港兒童來說，兒科卓越中心是個非常重要的建設計劃，你們艱苦努力，精神可嘉。」

本刊覺得讓讀者一睹頌欣的面目，很有意思，因而選登她去年十二月二十六日在香港慶祝生日的留影。

譚醫生回郵讚同：「好主意！這樣我們可能啟發更多人給兒童醫院捐款。」

兒童癌病基金謹代表所有支持建院者，感謝譚醫生、她的家人和賓客們的美意和慷慨捐助。我們都看得出，小頌欣顯然有個快樂生日，她以自己的方式，為第一個生日增添特別的意義。■



A beautiful cake for a fairy princess  
仙境公主的瑰麗蛋糕



Arabella's birthday garden  
頌欣的慶生花園