

The Vision

October 2006

A Children's Hospital for Hong Kong

A Children's Cancer Foundation Initiative



Aiming for World-Class Standards

There is no doubt that our city's paediatricians are among the finest and most dedicated in the world. But few of the facilities in which they work are designed and built to the same world-class standards. This imbalance between "software" and "hardware" leaves Hong Kong lagging far behind other world cities when it comes to providing the best possible healing environments for children and their families.

Most of our hospital wards for children and other facilities were not designed with today's children in mind. Worse still, paediatric wards and the specialists who work in them are spread out over 13 public hospitals across the city, making it difficult for multidisciplinary medical teams to cooperate, and this creates inconvenience for parents and their seriously ill children who are forced to shop around for specialists and treatment in different hospitals.

This current fragmentation of specialised services does not provide clinicians with the critical mass of patients in one place to facilitate the development of safe and effective clinical skills across the whole range of paediatric subspecialties. In the long run, this will restrict the future growth of paediatrics in Hong Kong.

Last year, one of the world's leading research companies, Synovate, conducted a stakeholder survey in Hong Kong on the proposed Children's Specialist Hospital. The survey included young

patients and their parents, children's charities, senior academics, over 250 paediatricians and other doctors in public and private practice, 117 nurses, allied health professionals and 1,200 parents in the general population with responsibility for their children's health care needs.

Almost three quarters of paediatricians working in the public sector who responded said they would be willing – assuming the same terms and conditions as they currently enjoy - to transfer to, or work on secondment at, the proposed children's specialist hospital; a similar number of all doctors and nurses who responded believed that such a hospital would enhance the world-class quality of medical treatment and create a more child and family friendly environment.

While these frontline medical staff expressed concern that the proposed specialist hospital would be inconvenient for parents and lack good geographical coverage, 90% of parents interviewed in the general population said that it would improve the quality of existing healthcare for children and adolescents. Only 9% said it would be inconvenient, and 27% saw it as an obvious place to go for specialist treatment and care.

All the parents of seriously ill children who were interviewed in the survey, and the teenage patients themselves, saw that a concentration of patients and medical expertise in one dedicated specialist hospital would offer a one-stop service for best treatment, allow patients and families to support

each other, facilitate medical professionals to share experience and knowledge among themselves, improve efficiency in resource allocation and offer more choice. While recognising that having only one specialist hospital would be inconvenient to some, this group of parents considered that the quality of services provided could outweigh the inconvenience.

Some parents expressed their concern over what they observed as the government cutting back on existing services and worried that a dedicated children's specialist hospital could further drain away resources, negatively impacting the services they currently enjoy.

There is one subject on which all stakeholders agree - that government and society should focus more attention on children's health care issues. Our shrinking child population makes this even more important. We need to be sure that Hong Kong's future workforce – today's and tomorrow's children – grows into healthy adults, capable and motivated to provide economic support for a rapidly ageing society. A dedicated children's specialist hospital has a vital role to play in ensuring this vision of the future.

Copies of CCF's proposal and Synovate's survey report can be downloaded at www.hkchildren.org ■

“Survey reveals the problems and helps show the way”



Leading the promotion of genetic health for all in Hong Kong

The Vision talks with Dr. Stephen Lam

The establishment of a children's hospital would definitely have a positive impact in fulfilling the vision of the Clinical Genetic Service Centre, says Dr. Stephen Lam, a Consultant Clinical Geneticist, and Head of the Clinical Genetic Service Centre operated by the Department of Health.

He proudly presented his vision for the centre, "Leading the promotion of genetic health for all in Hong Kong."

The Clinical Genetic Service Centre, where genetic diseases and rare disorders are investigated and diagnosed, was set up in 1981 and is the only place in Hong Kong offering services to paediatricians on diagnosis. The centre also runs neonatal screening programmes and provides counseling services to patients and families.

Most genetic diseases can be detected in the early stages of a person's life, but some may take a longer time to show. According to Dr. Lam though, some diseases may not develop at all if the patient were given good advice on nutrition and lifestyle.

He said, "Genetic diseases can be prevented. In

the coming years, public health education on genetic diseases will become a key focus for the centre."

He added, "For example, if a new-born child suffers from diabetes as a result of a deficiency in genes, the child may need to be advised on diet and lifestyle issues so as to prevent the development of diabetes in later life. The same will apply to young patients who have high blood pressure and genetics-related cancer."

Dr. Lam has visited many overseas children's hospitals, including the Great Ormond Street Hospital for Children in London and the Children's Hospital in Auckland. What impressed him most was the availability of world-class expertise in related areas within an individual hospital, thus facilitating collaboration of different disciplines.

If a children's hospital is to be set up, Dr. Lam believes that related expertise and resources will be more readily available, which will facilitate the offer of better service. He also expects that the paediatric department will be pro-active, out-reaching, and have frequent interaction with medical experts in different disciplines.

The Clinical Genetic Service Centre will celebrate its 30th anniversary this year. Dr. Lam said that the centre deals with cases referred by clinicians, mostly paediatricians. There are on average 1,000 new cases referred each year, which covers about 700 different types of genetic diseases.

The centre is operated by a team of 5 experts, all paediatricians. Dr. Lam said that in-service training is important in training up genetic experts and the proposed children's hospital will definitely provide more training opportunities for those medical professionals who want to develop their expertise in paediatrics. ■

ision Facts **THE LONG JOURNEY**

The need for a dedicated children's hospital has been debated in the Legislative Council four times in the last 35 years - 1970, 1978, 1982 & 1983.

A hospital where I have access to internet

Anthony (Siu Chun) has lived with thalassaemia, an inherited genetic defect of red blood cells, since he was born, but he did not know much about the disease until he grew up. However, he was fully aware of the difference between himself and other normal children because he was required to stay in hospital one day each month for blood transfusions and needed regular check ups and clinical treatment. Luckily, Anthony has a cheerful personality so he was not too bothered by this difference. Now at the age of 17, he just accepts it as a fact of life.

Anthony lived in Toronto for 4 years and returned to Hong Kong to study when he was 5. When asked how he found the local hospital environment, he made use of his experience in Canada as a reference. He commented that the hospital he went to in Hong Kong was not spacious enough when compared with those he saw in Canada,

and the design was just too boring. "You can see the hospital is white everywhere, but I prefer something more colourful," he said.

He proposed that the children's hospital should offer more entertainment to the kids. His suggestions include providing internet access for young patients. "Teenagers like me always go on line. It is the only way to keep track of what's happening, which is essential for sick kids," he said. Other than internet service, Anthony said that it would also be good to have areas where patients could watch television and read quietly.

Apart from the hospital setting and facilities, Anthony also appreciates the services he received in hospital. He said that the doctors and nurses had been very nice and that had meant a lot to him because he feels that what is more important to a patient, is to have the love and care that hospital staff could offer. ■

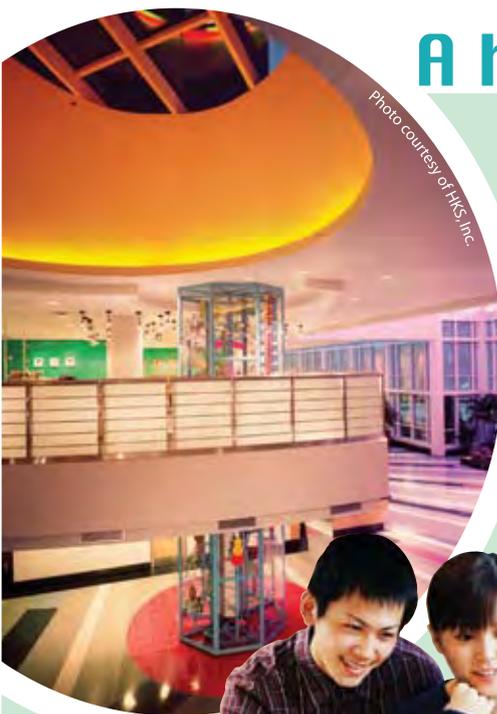


Photo courtesy of HHS, Inc.



Photo courtesy of HKS, Inc.



Hospital.. a cradle of friendship

Hospital is not only a place for surgery, but also a cradle of friendship. In front of us are six cheerful and lively teenagers aged from 16 to 20. Who could imagine what hardships they have gone through in their young lives?

“I wish I could have a private washroom,” said Nathan, “I wish my parents who accompanied me overnight throughout the ordeal could sleep in a bed rather than an armchair.”

All of them also suggested the ward should have more windows as sunlight would make the ward appear warm and comfortable. “It will be great if we can have a library and a resource centre, since it is so boring to stay there for such a long time,” said Yin-yi. The suggested library should have lots of magazines, comic books, novels and storybooks in order to accommodate the wide-ranging interests from toddlers to teenagers. Television, VCD player, DVD player and Karaoke should also be provided in the resource centre so the kids can have more fun. This everlasting search for fun seems to be the source of energy for these kids when undergoing treatment and operations.

They all agreed that food quality should be improved in the new children's hospital, and that there should be a variety of special menus for kids. Presentation of the meal is also very important, and they suggested colourful plates and a colourful combination of food. Other

“I wish my parents who accompanied me overnight throughout the ordeal could sleep in a bed rather than an armchair.”

than just a main course, they want something more. “I suggest we should have dessert after each meal, ice-cream and pudding are definitely good choices,” said Suet-fei.

Since patients spend most of their time in bed, the teenagers suggested some improvements in this area too – including a softer mattress, and the ability to bring along their own bedding and clothes from home. “I don't like the uniforms provided by the hospitals, it makes me look like a prisoner,” said Nathan, who also reflected that he really was a ‘prisoner’ of his illness during his time in hospital.

Some spaces should also be reserved for outside organizations, which take care of other children's needs besides healthcare. These include art, play, reading, and even schooling. The purpose-built design of a specialized children's hospital can facilitate centralization

and sharing of these resources, and make access to them much easier.

Laughter and giggles could not conceal the maturity of these special young people. They are all pursuing their studies in different areas, and appear to be more understanding and caring compared with others of the same age, leaving you to wonder if their illness is a curse or a blessing. Their wish from the community is for a centralized and specialized children's hospital so that they, and other sick children, can all recover in a healthy and positive way. ■



Vision 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

A place like home warm and colourful



Photo courtesy of HKS, Inc.

One day at the age of ten, Connie was sent to hospital with acute kidney pains. For the first few days she was placed with other adult patients in a general ward but was then transferred to ICU when her situation deteriorated. It was later confirmed that she was suffering from kidney failure, a problem that could have cost her life. At that time, her primary concern was not only whether she would recover, but also the apprehension of a long stay ahead in such a foreign and scary place.

Now Connie is eighteen years old and will soon commence her university degree reading Chinese Medicine. Looking back, she recalled her initial feelings about the hospital where she stayed for nine months: "I saw another patient in the ward nearby who was connected to a lot of tubes and surrounded by a lot of medical equipment. It was a horrible sight. In my mind, the hospital was a place where people suffered."

When she was given the chance to undergo a kidney transplant four years ago, she got to experience first hand what she saw in that ward, being connected to lots of tubes and equipment herself. Now that she has regained her health, she is only required to go for routine follow-ups once every month.

Having lived through nine months of hospital life, Connie has strong comments on the effects a

hospital setting can have on adolescents. "The environment was terribly pale, and the bad odor in the ward made me feel sick," she said.

Her dream hospital is a place like home, where you get a warm feeling being there. She suggested that patients should have more space for keeping snacks, books and magazines, for displaying their artwork done in the hospital and for cards received from their friends. She believes that a warm atmosphere would encourage interaction among patients staying in the same ward which might make them feel more supported and less lonely. ■

What should a Children's Hospital for Hong Kong be called?

We invite you to send us your ideas on a suitable name for a children's hospital in Hong Kong.

Providing specialist care for infants, children and adolescents from birth to 19 years old, the proposed hospital could be named after a person, a place, or a fun idea. Children and parents want it to be a place of happiness and healing.

What do you think? Let us know your ideas, and we'll print some of the best in future editions of this newsletter and on our website - www.hkchildren.org.

Mission 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 specialty.

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