



For Immediate Release

The Fourth “Walk for Vision” Raises over HK\$ 570,000 Leo Ku Shows Support for Thalassaemia Patients

(March 26, 2012 – Hong Kong) Led by Village Volunteers of Hong Kong Sanatorium & Hospital (“HKSH”), the fourth Walk for Vision held yesterday proved to be a resounding success. As part of the major celebration of HKSH’s 90th anniversary, the event attracted about 300 people, including members of hospital staff, their families and charitable supporters. The event raised HK\$575,000 for Children’s Thalassaemia Foundation, which will go towards funding the purchase of auxiliary medical equipment for local Thalassaemia patients, and supporting public education of the disease. The Foundation’s Ambassador, Mr. Leo Ku, was present at this year’s walkathon to share his experience as the Foundation’s Ambassador, showing support to the patients and their families.

The kick-off ceremony was officiated by Dr. Walton Li, Medical Superintendent of HKSH, Dr. Joseph Chan, Deputy Medical Superintendent of HKSH and Chairperson of Village Club, and Dr. Kathleen So, Vice-Chairman of Children’s Thalassaemia Foundation. “This year marks the 90th anniversary of Hong Kong Sanatorium & Hospital. Over the past decades, it has always been our mission to serve the public and provide quality healthcare and total patient experience. At the same time, we are committed to giving back to the community and raising the standard of community health through supporting health-related charitable events and non-profit organizations,” stated Dr. Walton Li in his welcoming speech. It is the very vision that is shared by Children’s Thalassaemia Foundation, prompting its collaboration with HKSH to raise the bar in public health. “Children’s Thalassaemia Foundation is coming to its 20th anniversary. With our tireless effort and generous donations from all walks of life over the years, in the public consciousness ‘Thalassaemia’ has transformed from an almost unknown disease to one which is widely recognized. Yet we cannot afford to relax, and we hope that there will be more charitable organizations and individuals like HKSH in the community to support the Foundation in research, promotion, education and patient assistance,” said Dr. Kathleen So, Vice-Chairman of Children’s Thalassaemia Foundation. “We will continue to strive toward our goal of ‘zero’ new cases.”

According to figures published by the Children’s Thalassaemia Foundation, about 380 patients are now suffering from Thalassaemia major and put on treatment. As their bodies cannot produce normal haemoglobins, over the course of their whole lives, they need to undergo blood transfusion once every four weeks at the hospital and receive chelation injections in order to avoid complications arising from iron accumulating in the body due to long-term blood transfusion, which include heart disease, diabetes and liver fibrosis. Without chelation therapy, the life expectancy of a Thalassaemia patient would

be under 20 years.

“I have had to undergo chelation therapy since I was two,” remarked Fu during the sharing session, a 21-year-old patient with Thalassaemia major. “It takes 12 hours every night to rid my body of iron, which means basically I can participate in none of the extra-curricular activities, and need to rush home right away for my injections. I could hardly get a good night’s sleep from worrying about the tip of my needle coming off at night. My daily life is nothing like that of a normal person. Fortunately, Children’s Thalassaemia Foundation has provided us with continuous support and guidance, giving me the courage and strength to face these difficulties.”

“I hope that everyone can join HKSH staff members and me to support Thalassaemia patients through monetary aid and action,” expressed Leo Ku, Children’s Thalassaemia Foundation Ambassador. Leo understands the effect of the illness on the patients’ quality of sleep, social life and psychological development. “I hope that through more extensive promotion and education, we can enhance the public understanding of Thalassaemia patients as well as encourage more people to test for the Thalassaemia gene, thereby reducing the incidence of Thalassaemia major.”

Presently in Hong Kong, one in every 11 people carries the gene for Thalassaemia. If both the father and mother carry the gene, there is a 25% chance that their offspring would inherit Thalassaemia major. As Dr. Edmond Ma, Director of Clinical Pathology & Molecular Pathology of HKSH and Governor of Children’s Thalassaemia Foundation points out, “Thalassaemia is a genetic blood disorder disease. As carriers of the Thalassaemia gene exhibit no visible symptoms, we advise couples to undergo premarital checkup before planning to have a baby. If both parents are carriers of the gene, the mother-to-be can undergo chorionic villus sampling (CVS) test in the tenth week of pregnancy, to confirm whether the fetus suffers from Thalassaemia major, and if so, the couple has the right to know, and hence decide whether to terminate pregnancy.” Dr. Ma adds that with medical progress and research development, there has been a rise in the medical standard of the prevention, diagnosis and treatment of Thalassaemia. With the introduction of new generation sequencing system, prenatal tests for Thalassaemia major may be conducted non-invasively through gene sequencing, thereby avoiding the risks of CVS tests.

Hoei, a 10-year-old recovered patient who used to suffer from Thalassaemia major, participated with her parents in the sharing session. They were all initially shocked and frustrated upon learning about Hoei’s illness, trying out countless measures in the hope of curing Hoei. They even considered IVF, which could provide an opportunity for bone marrow transplant from a close relative, but to no avail. It was in 2010 that suitable bone marrow was finally found overseas, and with the financial aid from the Children’s Thalassaemia



Foundation, Hoi completed the bone marrow transplantation. “It was heart-wrenching to see Hoi go through the torture of unending transfusion and chelation injections,” said her parents. “I hope that all couples would undergo a preliminary blood test before having babies.” During recovery, Hoi contracted acute myocarditis and nearly lost her life. She fought for 14 long days, ultimately conquering the illness. The details of this experience, along with the journeys of her fellow patients, are chronicled in the educational book set published by the Foundation with HKSH’s support. The series will be distributed to all the public libraries, universities libraries, hospital libraries and patient resource centres, in the hope that the heart-lifting stories of unrelenting fighters can exude positive energy to the public, while reducing the misunderstanding and prejudice against Thalassaemia patients.

At the closing of the event, Dr. Joseph Chan, Deputy Medical Superintendent of HKSH and Chairperson of Village Club said, “We owe the event’s success to the generous support of all members of the hospital. As medical practitioners, we not only want to save lives within the confines of the hospital, but to step into the community and make good use of our professional knowledge in other sectors of society to extend our care for the greater benefit of all. We shall build on our efforts in minimizing the risk of complications in Thalassaemia patients to strive towards the goal of ‘zero’ new cases, and realize our mission of providing total patient care.”

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About Hong Kong Sanatorium & Hospital

Hong Kong Sanatorium & Hospital is one of the leading private hospitals in Hong Kong. With the motto “Quality in Service Excellence in Care”, the Hospital is committed to serving the public as well as promoting medical education and research.

About Village Volunteers

Established in April 2009, the Village Volunteers, which consists of HKSH staff members, doctors with HKSH privilege, nursing students and alumni of the School of Nursing has taken part in various community activities, such as visiting the home of the elderly and institutions for the mentally handicapped and the physically disabled, and other fund-raising activities, e.g. the annual Walkathon “Walk for Vision”.

About Children’s Thalassaemia Foundation

The Children’s Thalassaemia Foundation is a charitable organization, which was established in June 1993 by parents, doctors and charitable members of the community. The Foundation receives no subvention from government. Over the years, the Foundation has been inspired to work towards improving clinical care, supporting medical research and enhancing public awareness of Thalassaemia. This is to ensure that children born with Thalassaemia major can grow up in a healthy and happy environment.

Photos:

1. Dr. Walton Li, Medical Superintendent of HKSH, Dr. Joseph Chan, Deputy Medical Superintendent of HKSH and Chairperson of Village Club and Dr. Kathleen So, Vice-Chairman of Children's Thalassaemia Foundation officiate the kick-off ceremony of Walk for Vision.



- The Fourth Walk for Vision organized by the Village Volunteers of HKSH raised a total HK\$575,000 for the Children's Thalassaemia Foundation. (From Left) Dr. Edmond Ma, Director of Clinical Pathology & Molecular Pathology of HKSH and Governor of Children's Thalassaemia Foundation, Dr. Yeung Chap Yung, Specialist in Paediatrics of HKSH and Honorary President of Children's Thalassaemia Foundation, Dr. Kathleen So, Vice-Chairman of Children's Thalassaemia Foundation, Mr. Leo Ku, Ambassador of Children's Thalassaemia Foundation, Dr. Walton Li, Medical Superintendent and Dr. Joseph Chan, Deputy Medical Superintendent of HKSH and Chairperson of Village Club at the cheque presentation ceremony.



- The educational Thalassaemia book sets sponsored by HKSH will be distributed to all public libraries, university libraries, hospital libraries and patient resource centres to raise public awareness on Thalassaemia.



- Part of the raised fund will be used to sponsor the purchase of syringe driver (left) and disposable needles in thala set (right).



- Thalassaemia Major patients Fu (first from right) and Hoi (second from left), along with Hoi's mother (second from right) share their experiences in fighting against the diseases and the difficulties they are facing.



- Dr. Edmond Ma, Director of Clinical Pathology & Molecular Pathology of HKSH and Governor of Children's Thalassaemia Foundation, encourages couples to have premarital and prenatal screening to prevent giving birth to Thalassaemia babies.



- Mr. Leo Ku, Ambassador of Children's Thalassaemia Foundation shares his passion for Thalassaemia patients.



8. Dr. Walton Li, Medical Superintendent of HKSH receives souvenir from the Children's Thalassaemia Foundation.



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