



養和醫院

Hong Kong Sanatorium & Hospital

For immediate release

## **HKSH Village Volunteers Join Hands with Children's Thalassaemia Foundation to Bring Hope of Cure for Young Patients**

(7 April 2019 – Hong Kong) Over 200 staff and friends of Hong Kong Sanatorium & Hospital today took part in the 11<sup>th</sup> Walk For A Vision organised by HKSH Village Volunteers and raised a total of HK\$500,000 for the Children's Thalassaemia Foundation.

The donations will be used to sponsor two Thalassaemia major patients to undergo Haploidentical Hematopoietic Stem Cell Transplantation (Haploidentical HSCT), an advanced treatment introduced in Hong Kong more than one year ago for the treatment of Thalassaemia major and has since then brought new ray of hope for cure among Thalassaemia patients. The treatment promises to bring a full recovery, relieving patients from regular blood transfusion and chelation therapy.

It was the second time for the Foundation to be named as the beneficiary in the Hospital's annual fundraising event. Thalassaemia major is a fatal form of hereditary blood disorder, where patients cannot produce enough haemoglobins. Patients have to receive blood transfusions every month as well as daily injection of chelation therapy for survival.

For many years, Hematopoietic Stem Cell Transplantation (HSCT) is known to be the only treatment for patients with Thalassaemia major but the challenge always lies in the search for a HLA-matched donor, either a sibling or an unrelated donor. Recent advances in treatment have enabled Thalassaemia major patients to undergo HSCT from donors with "half-identical" HLA (haploidentical), and the outcome is comparable to those from HLA-matched donors.

**Dr. Joseph CHAN Woon Tong, Deputy Medical Superintendent of the Hospital cum Chief Volunteer of HKSH Village Volunteers** said, "We supported the Foundation seven years ago and donations were made to procure syringe driver and disposable needles in thala set. Today, with the advancement in medicine, we are happy to see that with the new Haploidentical HSCT technology, the hematopoietic stem cells donated from either one of the parents can provide cure for Thalassaemia major patients, thus overcoming the difficulties of searching for HLA-matched donors and bringing new hope to patients and their families. It is such a meaningful experience for HKSH Village Volunteers to walk with Thalassaemia patients again, and help them make their dream of a full recovery come true!"



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**Dr. Edmond MA Shiu Kwan, Director of Clinical Pathology & Molecular Pathology Division of the Hospital cum Chairman of Children's Thalassaemia Foundation** added, "At present, there are about 350 Thalassaemia major patients in Hong Kong, and we are all very excited by the promising outcome of the new treatment. As there is an age limit for patients to receive the treatment with lower risks of complications, the new treatment is now applied to patients under the age of 12. We are eager to help the patients waiting to be treated and are grateful for the support from HKSH Village Volunteers. We also would like to appeal to others in the community to extend their helping hand to patients in need, while the Foundation will continue to promote disease awareness through public education, including the importance of pre-marital and pre-natal checkups for case prevention."

**Dr. CHEUK Ka Leung, Clinical Associate Professor of Department of Paediatrics and Adolescent Medicine of the University of Hong Kong Li Ka Shing Faculty of Medicine**, who performed Haploidentical HSCT on several Thalassaemia major patients said, "Haploidentical HSCT was put into clinical service in Hong Kong in August 2018 for Thalassaemia major patients and this technique has brought hope to patients who are unable to find a HLA-matched donor. By infusing hematopoietic stem cells donated by either parent, patients can regain normal blood cell production ability with a success rate of 70-80%. Following the treatment, patients will go through a period of immunosuppression, requiring the intake of anti-infection drugs. Other than that, patient's quality of life will be greatly enhanced without the need for blood transfusion and chelation therapy."

About 12.5% of the total Hong Kong population carries the gene for Thalassaemia, representing a total of 87,000 carriers. **Dr. Joseph CHAN, who is also the Head of Department of Women's Health and Obstetrics of the Hospital** said, "If both the father and mother carry the gene, there is a 25% chance that their offspring will inherit Thalassaemia major. Pre-marital and pre-natal checkups are the key for prevention. For the gene-carrier couples, they can adopt pre-implantation genetic testing for monogenic diseases (PGT-M) and select the normal embryo for implantation, minimising the chance of giving birth to a Thalassaemia major baby. While for the natural pregnancy, 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."

10 year-old **Chun Ho** will be one of the patients to be benefitted from this year's donation. He was diagnosed with Thalassaemia major when he was 8 months old. Since then, monthly blood transfusion and daily chelation therapy are required. Both mother and son are looking forward to receiving the treatment. "Chun Ho's situation has been complicated by the fact that there are signs of enlargement of his liver and spleen. Furthermore, his age is close to the limit of Haploidentical HSCT treatment and that



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is why we are particularly grateful for HKSH's support which helps relieve the financial burden of the family and provides a timely treatment for Chun Ho," his mother said.

Also present at the walkathon was **Cheuk Laam**, a 12 year-old patient who has been gradually recovering from the disease after treatment. She was diagnosed when she was 30 months' old. She underwent Haploidentical HSCT successfully in August 2018 and she is now free from blood transfusion and chelation injections. She was prescribed with anti-infection drugs for a short period of time following the treatment and has been in a stable condition. Her mother is relieved with joy and said, "She used to get chelation injections every night for 12 hours, with the needle pierced on her belly overnight. Monthly blood transfusion was necessary to keep her alive, and she would become weak in the third week of the month. Her academic performance and daily life had been severely impacted. When I learnt about the new treatment, we decided to give it a try as Cheuk Laam was already 11 years old at that time and we had to grasp the last chance. I hope to share our experience and give support to other patients and families."

Walk For A Vision is an annual charity event organised by HKSH Village Volunteers, supporting medical-related institutions and projects with a noble cause. Starting from the Hospital, the 8-km walkathon route passes through Sing Woo Road, Blue Pool Road, Wong Nai Chung Gap Road, and Violet Hill hilltop and finishes at the Hospital.

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#### Supplementary information

#### Haploidentical hematopoietic stem cell transplantation (Haploidentical HSCT)

Thalassaemia is an inherited genetic blood disorder. Thalassaemia major patient's body cannot produce normal haemoglobins. Regular blood transfusion and chelation therapy is essential to sustaining their lives. Hematopoietic stem cell transplantation is the only way to cure Thalassaemia major. In the past, transplantation was only feasible if the hematopoietic stem cells were donated from a HLA-matched donor. The new Haploidentical HSCT can achieve comparable treatment outcome with a related donor who is haplotype identical to the recipient but not completely HLA-matched, and in this regard the potential donor could be extended to the patient's father or mother.

#### 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.



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### **About HKSH Village Volunteers**

Established in April 2009 and became an approved charitable organisation in July 2018, the HKSH Village Volunteers, which consists of HKSH staff members, doctors, nurses, nursing students, alumni of the School of Nursing and retired staff, has taken part in various community and fundraising activities to promote the health and wellness of people in Hong Kong through care and love. Two main fundraising events are the annual “Walk For A Vision” and “HKSH Christmas Party in Benefit of OSC”. In recent years, more volunteer programmes and services have been developed, i.e., “HKSH Health Buddies”, “HKSH Health Talks”, “HKSH Caring Friends” and “HKSH Trekkers”.

### **About Children's Thalassaemia Foundation**

Established in 1993, the Children’s Thalassaemia Foundation (CTF) is a charitable organisation that receives no subvention from the Government or Community Chest of Hong Kong.

Over the years, CTF has worked towards advancing clinical care, facilitating research and enhancing public awareness of Thalassaemia. CTF finances patients to purchase iron removal devices, supports them to undergo novel stem cell transplantation procedures to cure the disease, and provides funding for their employment training and academic studies. CTF also increases public awareness to prevent severe Thalassaemia in Hong Kong.

The aim of CTF is to ensure that Thalassaemia major patients can grow in a healthy and happy environment, and to ultimately eradicate Thalassaemia major in Hong Kong.

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## Photos

1. About 200 staff and friends of Hong Kong Sanatorium & Hospital join in the annual fund raising event for Thalassaemia major patients.



2. At the cheque presentation ceremony: Dr. Joseph CHAN, Deputy Medical Superintendent of the Hospital and Chief Volunteer Leader of HKSH Village Volunteers (third from left), Ms. LOK Wai Kwan (second from left) and Ms. CHUNG Po Kuen (first from left), Sub Group Leaders of HKSH Village Volunteers, present the cheque of pledged donation of HK\$500,000 to Dr. Edmond MA, Chairman of Children's Thalassaemia Foundation (fourth from left), Dr. YEUNG Chap Yung, Honorary President of the Foundation (third from right), Ms. Stella LEE, Vice-Chairman of the Foundation (second from right) and Mr. Ken HUNG, Children's Thalassaemia Foundation Ambassador (first from right).



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3. (From left) Dr. Joseph CHAN, Dr. Edmond MA and Dr. CHEUK Ka Leung, Clinical Associate Professor of Department of Paediatrics and Adolescent Medicine of the University of Hong Kong Li Ka Shing Faculty of Medicine, share latest update of the disease.



4. Thalassaemia major patients Chun Ho (fifth from right) and Cheuk Laam (sixth from left) can say good bye to regular blood transfusion and chelation therapy following the new treatment. Mr. Ken HUNG, Children's Thalassaemia Foundation Ambassador shows support to Thalassaemia patients.



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