



養和醫院

Hong Kong Sanatorium & Hospital

For immediate release

10th Walk For A Vision by HKSH Village Volunteers Raised Funds to Support Spinal Muscular Atrophy (SMA) Patients

(25 March 2018 – Hong Kong) More than 200 staff and friends of Hong Kong Sanatorium & Hospital (HKSH) today joined the 10th Walk For A Vision organised by HKSH Village Volunteers and showed their unwavering support to Families of SMA (Spinal Muscular Atrophy) Charitable Trust by raising over HK\$360,000 to help purchase medical equipment and wheelchairs for SMA patients.

Spinal Muscular Atrophy (SMA) is the most common genetic cause of death for children under 2 years old, affecting 1 in 10,000 newborns. SMA manifests in various degrees of severity, usually onset at an early age. SMA leads to progressive loss of motor neurons and muscles, while the patients' cognitive development remains unaffected. SMA causes weakness in limbs and neck, impacting the patients' ability to swallow and breathe. Conditions of SMA patients may get worse over time and eventually lead to death from respiratory failure.

SMA patients rely on intensive life-support systems including feeding tube and ventilator as well as physiotherapy, imposing huge financial burden on their families. "HKSH Village Volunteers are deeply impressed by the fighting spirit demonstrated by SMA patients. As our Walk for A Vision event is entering its 10th year, we find it extremely meaningful for hospital volunteers, families and friends to raise fund for SMA patients so that they can get the most needed life-support equipment," said Dr. Joseph CHAN, Deputy Medical Superintendent of the Hospital cum Chief Volunteer of HKSH Village Volunteers.

Dr. TSOI Tak Hong, Co-Director of Neurology Centre of the Hospital, explained that there are four primary types of SMA based on the age of onset and the highest achievable developmental milestones. "Type I is the most severe form of SMA. Babies of SMA Type I begin to show symptoms between 0 and 6 months of age, facing difficulties in head movement, swallowing and breathing. Type II usually has symptoms onset between 6 to 18 months of age. Some Type II babies can sit without assistance, but most of them require supporting aids for standing or a wheelchair to get around. Type III is a milder form of SMA, often diagnosed after the age of 18 months, and even into the teenage years. Type IV is rare and its symptoms surface in adulthood after 35 years of age." SMA patients have to rely on life-support systems for breathing and feeding until very recently, when gene therapy becomes available as a treatment option for SMA.



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Ms. Tina WONG, Chief Operating Officer of Families of SMA Charitable Trust expressed gratitude to HKSH Village Volunteers for its fund-raising efforts for the purchase of the life-sustaining equipment. “The donations are very important for allowing SMA patients to live longer and have a better quality of life before they can receive treatment using the new drugs. In the long run, we hope to call for public awareness of the disease, and there will be zero SMA case in the future.”

“SMA is a rare genetic disease, where statistics show that 1 in 60 people are carriers of SMA genes. Couples now have the option to receive carrier screening before or during pregnancy to assess risks of SMA in their offspring,” said Dr. CHAN, who is also the Head of Department of Women’s Health and Obstetrics of the Hospital.

Ms. Josy CHOW was diagnosed with the most severe SMA Type I at the age of one. She has lost all mobility except for two fingers, and needs assistance in breathing and swallowing. She was admitted by HKU to study English and Linguistics. Josy submitted a proposal to The Chief Executive Mrs Carrie LAM on 8 October 2017, urging the government to introduce Spinraza, the drug for SMA. Josy said at the ceremony, “We are deeply grateful for the support from the government and the community as a whole which have led to the early introduction of SMA treatment to Hong Kong.”

Another patient WONG Yui, who aged 1.5 years old, attended the ceremony with her mother. Yui was diagnosed with SMA Type II in March 2017. She stays at home with stable condition. Although she is unable to stand, she can sit straight when assisted. Yui is a happy and sociable kid, blessed by the dedicated care of her mother Ms. Lo. “We are thankful to Families of SMA Charitable Trust for support rendered to us. We feel a lot more hopeful for the future.”

Mr. TAM Wing Hang, aged 24 years old, who is also a SMA Type II patient. He can only move three or four fingers of his right hand. He lost motivation to study in the early years of secondary school, and gave up trying until he found his life purpose in the Christian faith. He achieved a score of 23 points in the Diploma of Secondary Education (DSE). Admitted by The Chinese University of Hong Kong, he is currently a year 4 student of Divinity School of Chung Chi College. He shares his experience as an occasional speaker at churches and secondary schools. He wishes to be a pastor in the future. “Though this disease has made a less independent person but it doesn’t deter me from exploring the world,” said Hang.

‘Post-90s’ Mr. LAU Shiu Fung, SMA Type II patient, has used wheelchair to get around since Form 3. He attained a Bachelor of Science in Computing from The Hong Kong Polytechnic University in 2013 and accomplished the MPhil programme last year. Fung was nicknamed “Stephen Hawking in Hong



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Kong”, he is contented with himself and his physical defects. He is the inventor of many computer learning software and applications, which assist the physically disabled and brought him several awards. He said, “I hope to use my knowledge for improving the quality of life of patients like me and for raising public awareness of the disease.”

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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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 HKSH Village Volunteers

Established in April 2009, the HKSH Village Volunteers, which consists of HKSH staff members, doctors, nursing students, alumni of the School of Nursing and retired staff, has been taking part in various community and fundraising activities in order to promote the health and wellness of people in Hong Kong through care and love. Its major fundraising events are the annual Walkathon “Walk For A Vision” and “Christmas Party in Benefit of OSC”. In recent years, more volunteer programmes and services have been developed, including “HKSH Health Buddies”, “HKSH Health Talks”, “HKSH Caring Friends”, and “HKSH Trekkers”. Partners include Ebenezer New Hope School, Ripple Action, Enlighten, and St. James’ Settlement.

About Families of SMA (Spinal Muscular Atrophy) Charitable Trust

Families of SMA Charitable Trust was established in 1998 to provide financial assistance, donation of medical and para-medical equipment to relieve hardship and patients suffering from an extremely debilitating genetical disease called Spinal Muscular Atrophy (SMA).

The Trust runs self-help programmes and outings for SMA patients and their family members to promote common support and understanding. It also supports top notch international medical research in finding treatment and an early cure for this terrible disease.

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Photos

1. The kick-off ceremony of “Walk For A Vision” organised by HKSH Village Volunteers is officiated by Dr. Walton LI, Medical Superintendent of the Hospital; Dr. Joseph CHAN, Deputy Medical Superintendent of the Hospital and Chief Volunteer Leader of HKSH Village Volunteers and members of the Clinical Governance Committee and Hospital Management Committee of the Hospital.



2. Dr. Joseph CHAN, Deputy Medical Superintendent of the Hospital and Chief Volunteer Leader of HKSH Village Volunteers (second from left), together with Dr. TSOI Tak Hong, Co-Director of Neurology Centre of the Hospital (right) show support to SMA patients.



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