The founding of Little People of Hong Kong

Ms Serene Chu, Chairperson

How we began

It all began with a documentary produced by TVB Pearl Report in August 2013, in which several children with skeletal dysplasia and their families were filmed for a programme titled “Orphan Diseases”. Nathan, my 3-year-old son with achondroplasia, was one of them. The programme touched the hearts of many who love children.

The programme did not only promote public awareness of dwarfism and other rare skeletal disease but also drew together a few passionate doctors, professors and our family who want to do something for these children. With a dauntless attitude, we embarked upon an unprecedented journey – setting up a foundation for “little people”. It was unprecedented in the sense that there has never been any organisation or support group in Hong Kong for “little people” even though there is a sizeable population of patients in the community.

Our values and mission soon attracted a group of volunteers who contribute their expertise to help build the foundation. In June 2014, we were granted the “charitable organisation” status by the government.
He is our Happy Boy

Laura (Jayden’s mother)

Jayden was sent to the Neonatal Intensive Care Unit right after birth. He just reached 35 weeks that night and weighed only 1.06kg with body length of 34.5cm, similar to the size of a newborn kitten. In fact, Jayden’s growth rate was found to be slow during prenatal check up and even very experienced gynecologist could not explain the cause. After staying in Neonatal Intensive Care Unit for two months, Jayden reached 4lbs which is the minimum required weight for discharge. His face did not have the standard features of a baby while his head, hands and legs were obviously small. Since there were no similar cases in Queen Mary Hospital, doctors could not make a diagnosis. I searched online day and night frantically for all possibilities, only to find that the problem was related to bone growth.

When Jayden was 9 months old, his trachea was found to be just 1mm wide and would suffocate anytime. Doctor suggested tracheostomy, a high-risk surgery. As parents, we struggled because we just want Jayden to spend his life, albeit short, happily. We ended up not going for the surgery but Jayden had to start living in the hospital for easier checkup. He was born a happy and sociable boy, often drawing people’s attention by his laughter. It was a weary battle visiting him after work every day but his positive and optimistic character always cheered us up.

When Jayden reached 1.5 years old, we lost the battle. Jayden was sent to Intensive Care Unit due to parainfluenza and would die if he did not undergo surgery. This was the first time we wept aloud at the hospital. After about three hours, we finally saw our little baby coming out from the operation room. The incision wound was large compared to his body size. Every kid, especially those who are sick, is stronger than what we imagine. Two days after the surgery, he was laughing happily like there was no wound at all. His strength and perseverance touched our hearts. I always tell Jayden, “You are so good at picking and you picked us as your parents. You know how much we love you!” Indeed we are very grateful to have this little boy - an angel - coming to teach us how to “love”. He united our family and reminded us to treasure our loved ones.

Jayden was diagnosed with MOPD II at the age of 2 years and 4 months, which is a rather serious and rare type of dwarfism, and there are only about 50 patients globally. According to diagnostic prediction, this “little man” will have an adult height of around 100cm. People will make frivolous remarks on his appearance but his heart is no different from that of other kids. He may not be physically fit but he can also live a normal life given appropriate trainings and facilities.

I am really glad to learn about the establishment of “Little People of Hong Kong” (LPHK) which supports patients with dwarfism and other rare bone diseases and their families. Through sharing experience and supporting each other, I hope every patient family can have a positive attitude towards life. I also hope that LPHK can raise public awareness of rare bone disease, so that patients will no longer be embarrassed by stares. LPHK’s motto “We are little, but not less!” echoes my heart.

Dr Brian Chung
Department of Paediatrics and Adolescent Medicine, The University of Hong Kong

Microcephalic osteodysplastic primordial dwarfism type II (MOPD II) is a condition characterized by short stature (dwarfism) with other skeletal abnormalities (osteodysplastic) and an unusually small head size (microcephaly). This condition is caused by the gene change in PCNT gene and is inherited in autosomal recessive manner. Each of the individuals has 2 copies of PCNT gene. The diagnostic difficulty in Jayden is we can only find 1 mutation by DNA sequencing. Finally we need to do protein analysis to confirm the diagnosis. Affected individuals with MOPD II have slow growth before and after birth. On average, final adult height is about 100cm and affected adult head circumference is comparable to a 3 months old’s. Other skeletal abnormalities include abnormal development of the hip joints, thinning of the bones in the arms and legs, scoliosis, and dental anomalies. However, most affected individuals have normal intelligence development. Other health-related issues are found in older affected individuals with onset at or before puberty, including far-sightedness, truncal obesity, type 2 diabetes and vascular problems. Appropriate follow-up in different disciplines are needed.
**LPHK NEWS**

**Education, Policy & Public Awareness**

**JAN2014 | Education**
LPHK Chairperson Serene Chu spoke at the commissioned program “Clinical Genetics & Genetic Counseling for Nurses” organised by the Hospital Authority and Institute of Advanced Nursing Studies.

**FEB2014 | Policy Awareness**
Vice-chairman Prof Danny Chan and Chairperson Serene Chu attended the “Roundtable on the Development of Rare Disease Policy in Hong Kong” organised by the Hong Kong Alliance of Patients’ Organizations.

**JUN2014**
LPHK was recently granted the charitable organisation status by the HKSAR government. We can begin to raise important funds to host more public seminars, workshops and patient activities.

**Family & Patient Support**

**FEB2014 | Chinese New Year Party**
In support of Rare Disease Day, we made a large-scale handprint collage at the party to raise social awareness of rare bone diseases.

**JUN2014 | Education**
The Rare Bone Diseases Seminar delivered by Prof Danny Chan, surgeon Dr Michael To and patient parent Ms Win Choi was held at The Queen Elizabeth Hospital.

**APR2014 | Art Therapy Workshop**
Registered art therapist Grace Chan taught the children how to use simple shapes to express their feelings in artwork.

**ARP2014 | Caring Family Party**
LPHK exhibited a booth at the CECES “Caring Family” event to raise public awareness of rare bone diseases through various art and craft activities.

**JUL2014 | Music for Everyone Concert**
LPHK families attended the “Music for Everyone” Concert organized by the Music Children Foundation.

**APR2014 | Bone lengthening Seminar**
Surgeons Dr Michael To and Dr Evelyn Kuong spoke about the limb lengthening procedure while Ms Annie Ng and Ms Kennis Ha discussed the post-operation recovery process.
UPCOMING EVENTS
LPHK has partnered with The University of Hong Kong to organize the "Little People Care Alliance" program which aims to promote a better community understanding of the needs of "little people", with a particular emphasis on school-aged children. Through a mentorship program, dialogues, workshops, social activities and a specialized information booklet, we will work with teachers and students to promote understanding of and acceptance for others who are different.

HKU x LPHK Knowledge Exchange Project
- Publication of a bilingual booklet on rare bone diseases
- Public forum and workshops

Big Brother Big Sister Mentorship Project
- Cookery workshop
- Ocean Park visit
- Music therapy workshop
- BBQ Fun Day

SUPPORT US
You can help make a difference!

JOIN US!
If you would like to become a LPHK friend or volunteer, please visit http://lphk.org/ to download the application form. Email your completed form to info@lphk.org or post it to Little People of Hong Kong, 2/F, Third Wing, St John's College, 82 Pokfulam Road, Hong Kong.

DONATIONS
You can also support us by donating to the Little People of Hong Kong.

By Cheque
Please make a crossed cheque payable to "Little People of Hong Kong Foundation Limited" and send to The Little People of Hong Kong Head Office, 2/F, Third Wing, St John's College, 82 Pokfulam Road, Hong Kong.

Please send the crossed cheque along with your name, address and contact email or telephone number to the foundation.

By Direct Bank Deposit
You can deposit your donation into our account - Bank of East Asia: 015-514-68-013177

Please send the deposit slip along with your name, address and contact email or telephone number to the foundation by fax at +852-28175624, by email to info@lphk.org or by post (address as above).

An official receipt will be issued for donations of HK$100 or above.

Thank you! We appreciate all your support!!