



HKU Knowledge Exchange Project

Little People Care Alliance

「小個子，大作為」關愛行動

LKS Faculty of Medicine | March 2017

School of Biomedical Sciences

Prof. Danny Chan

Dr. Wilson Chan

Dr. Vivian Tam

Department of Paediatrics and
Adolescent Medicine

Dr. Brian Chung

Department of Orthopaedics
and Traumatology

Dr. Michael To

External partner:

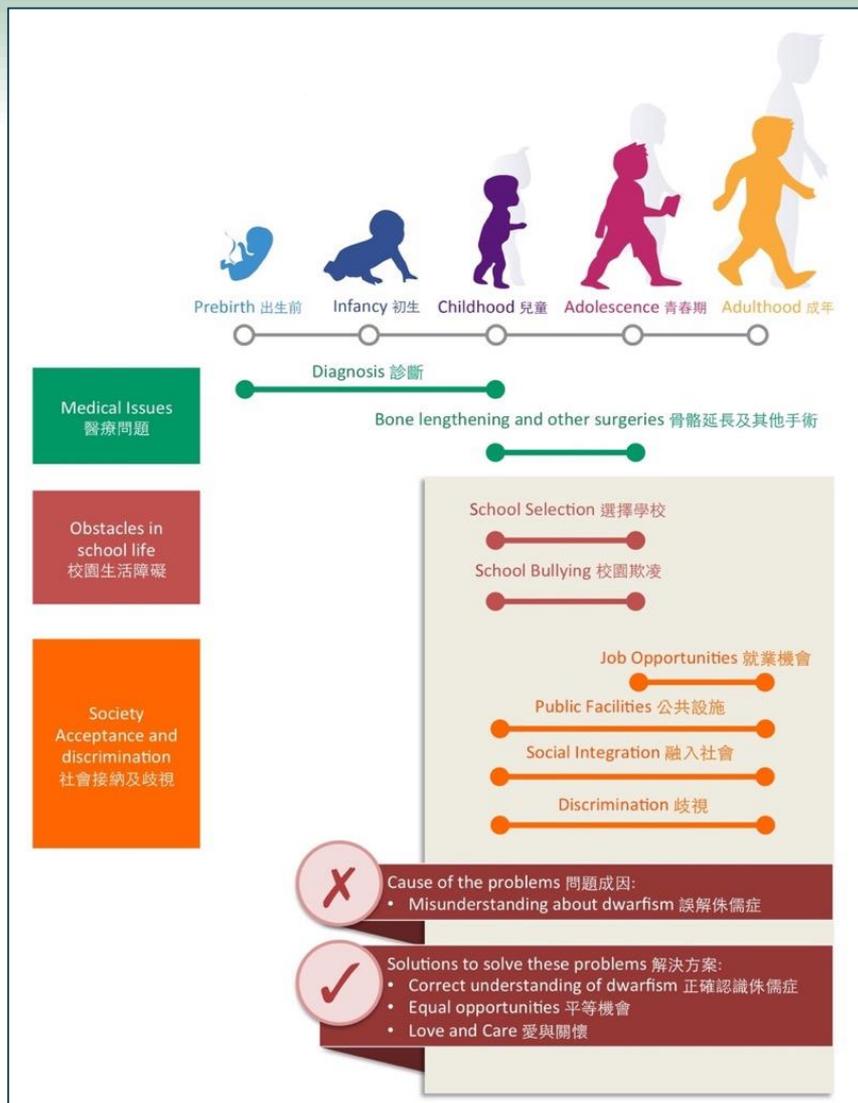
Little People of Hong Kong

Ms. Serene Chu



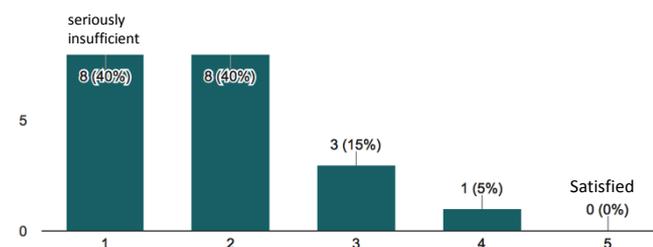
INTRODUCTION

Individuals with different forms of rare bone diseases (little people) face many difficulties because of a lack of awareness and public misconception



Do you think the general public understand enough about dwarfism?

1. 你認為大眾對侏儒症的認識足夠嗎？ (20 responses)



What are the positive effects if awareness of dwarfism is raised in the general public?

2. 你認為增加大眾對侏儒症的認識有什麼正面影響？ (20 responses)



(Patients/family survey conducted by Little People Care Alliance in Mar 2017)

SUMMARY OF THE IMPACT

- There is general lack of understanding of rare diseases and public may have misconceptions about little people and people with other rare diseases and discrimination may occur at school and work opportunities.
- This project aims to raise awareness among the general public that little people and other rare disease individual are fully capable of achieving a meaning life, just like everyone else, despite their differences.
- We believe that promoting awareness and the importance of respect in the community and the future generation will build a positive foundation that will make a difference.



UNDERPINNING RESEARCH, TEACHING & LEARNING

Quality of the knowledge

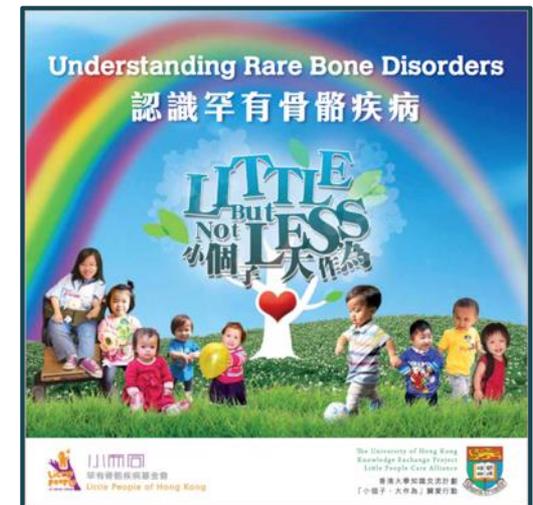
- This project harnesses the knowledge of medical professionals who work in the field of rare bone diseases, serves as a platform for interaction with all stake holders of the patient group, and brings forward open discussion forums with the education sector and the general community
- Through direct interaction with little people, the project provides mentorship and knowledge exchange about rare bone diseases, with direct positive outcomes in people and institutions
- A project in Feb 2017 to promote the international rare disease day theme of “Research brings Hope”.



UNDERPINNING RESEARCH, TEACHING AND LEARNING

Relevance of information

- A major outcome of this project is a 80-page bilingual booklet “Little But Not Less: Understanding Rare Bone Disorders”
- This booklet contains relevance information gained through laboratory research, and experience in genetic counseling and surgical treatments freely available online.
<http://www.lphk.org/RBDbooklet.pdf>
- It is written in layman’s terms for ease of understanding the genetics and biology of rare bone diseases, the implications to the affected individuals (little people), and the possibilities from positive thinking and attitude by patient groups and the community.
- 3000 Printed booklets delivered to Schools and relevant education sectors in Hong Kong

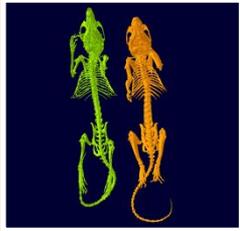


UNNERPINNING RESEARCH, TEACHING & LEARNING

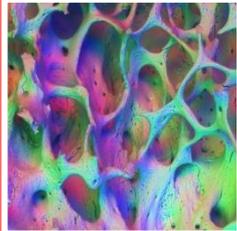
Innovativeness of the knowledge

HKU team

Generate innovative knowledge through research on Rare Bone Diseases



Mouse Genetics
and Basic Sciences



Human Genetics



Surgical Management



Understanding
Patho-mechanisms

Establish better assessment
and treatment methods

Provide accurate
genetic counseling

Allowing patients and the community to gain a clearer understanding of rare bone diseases

Providing a realistic assessment of possible treatments and long term outcomes

UNDERPINNING RESEARCH, TEACHING & LEARNING

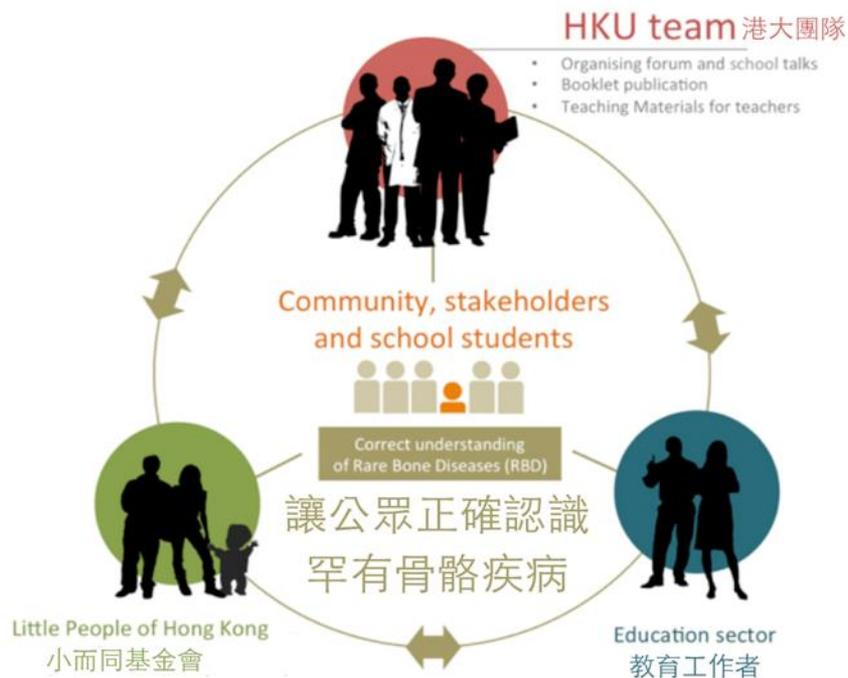
Significance of the key insights

- Direct interaction with the patient groups and the community provided the reality touch to our research programmes which study rare diseases of the skeleton
- The activities helped us to realized the “real goals” that need to be achieved from our research; the need for little patient groups and the community to understand the problems, and the importance of professional genetic counseling

ENGAGEMENT

Hand in hand with members of the education sector, we aimed to dispel public misconceptions for a better community understanding of the needs of the “little people” through dialogues, workshops and a specialized information booklet .

External Partner: Little People of Hong Kong



KEY ACTIVITIES

- 1 **FEB15**
RARE DISEASE DAY EVENT
- 2 **MAR15**
HIGH TABLE TALK
- 3 **APR15**
PUBLIC SYMPOSIUM
- 4 **APR-MAY15**
EXHIBITION
- 5 **SEP15**
PUBLIC LECTURE
- 6 **FEB16**
PUBLICATION OF A BOOKLET
- 7 **OCT16**
VIDEO FOR DWARFISM AWARENESS MONTH
- 8 **NOV16**
SCHOOL TALK
- 9 **FEB17**
HKU LABORATORY VISIT

1

FEB15
RARE DISEASE DAY EVENT

Targets: Patients and general public



Prof. John Leong, Chairman of Hospital Authority, gave an opening speech



Adult patients shared their experiences with other LP families



Patients and families making handprint blossoms for the Little People Care Alliance Vision Tree



Group photo of Honary guests, HKU Little People Care Alliance Team, HKU student volunteers, Little People patients and families in front of the Vision Tree – promoting awareness of Rare Diseases to the public

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MAR15
HIGH TABLE TALK

@ St. John's College "A Long and Winding Road in Dignity" delivered by adult patients with dwarfism
Targets: HKU students and staff



Little people Jacqueline and Edmund shared their school life experiences

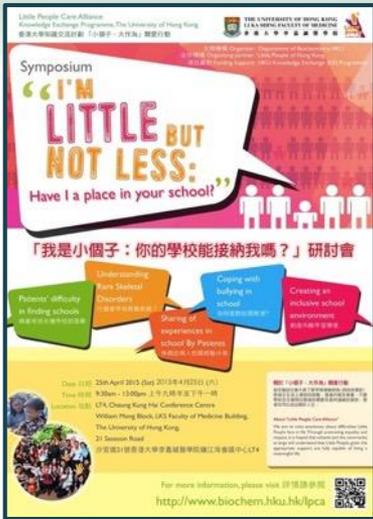


Local and foreign students were actively involved in question time

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APR15
PUBLIC SYMPOSIUM

Symposium "I'm Little but not Less, have I a place in your school?"
Targets: Educators, school teachers and medical professionals



The audience included local and international school principals, teachers, students, and medical professionals who were actively involved in the discussions



Dr. York Chow giving the opening speech about Equality

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APR-MAY15
EXHIBITION

Exhibition "Little but not Less: Better care for Patients with Rare Bone Diseases"
Targets: Faculty members and medical students



Little People Care Alliance Vision Tree
(created by patients and volunteers together)
and exhibition boards



Honorary Guests, Executive committee of LPHK,
Patients and HKU Little People Care Alliance team

Public Lecture @ Hong Kong Central Library
Targets: General Public



兒童及青少年的健康

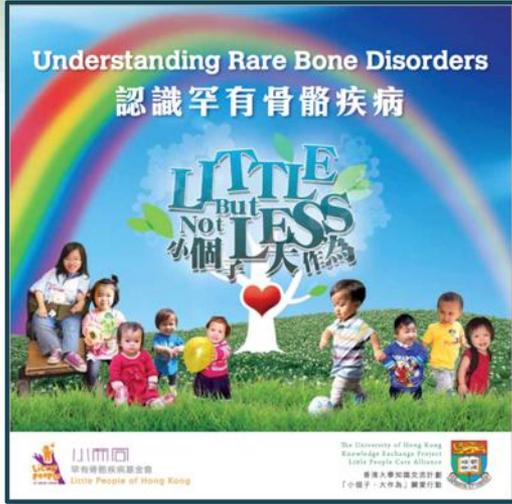
日期/時間: 2015年9月12日 (星期六) 上午10時至12時
地點: 香港中央圖書館 (地下演講廳)
講者:
鍾傑宜醫生 (香港大學李嘉誠醫學院兒童及青少年科學系臨床副教授)
杜焯焯醫生 (香港大學李嘉誠醫學院燒傷及創傷外科系臨床助理教授)



"Little People Care Alliance" Team

Drs. Brian Chung and Michael To gave talks about Genetic Rare Bone Diseases to the general public

“Understanding Rare Bone Disorders” Book Launching
Targets: Schools, Hospitals, Social Workers, Corporations and General Public



3000 copies of this 80-page bilingual booklet have been distributed to schools, hospitals, companies and government departments



Over 130 participants including patients, families and volunteers joined the book launching event

Basic Science about dwarfism



Advances in treatments



Clinical Cases



Patient stories

A "little giant" on the ball



If you ever had the pleasure of reading the news about a basketball player that is a very unique individual, you are not talking about his physical appearance that makes him different from others, but the personality and spirit that makes him stand out from others. An energetic and active young man who always has a heart-winning grin on his face. The words of an IT department at a financial company in Hong Kong are just like any one of us. At the right, he transformed into a member of the Hong Kong basketball team that serves clubs and other represents Hong Kong in international basketball competitions.

A patient who struggles to balance his life and enjoying his social network, participation in recreational activities and enjoying his well-being and care for patients with rare diseases. There is no doubt that there is great support for patient groups in countries other than Hong Kong. The support when meeting other members greatly helps with disease

Broadcasted in HKU UVision and campusTV for a month and uploaded to youtube
Targets: HKU Members and public

Video link:
<https://uvision.hku.hk/playvideo.php?mid=20486>



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NOV16
SCHOOL TALK

Dr Michael To, LPHK member Katy & Chairperson Serene gave a talk about rare bone disease to Baptist Lui Ming Choi Secondary School

Targets: Secondary School Students and Teachers



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FEB17
HKU LABORATORY VISIT

Laboratory tour for LPHK members in response to the theme of this year's Rare Disease Day "Research Brings Hope". We showed the recent researches relating to skeletal disorders and stem cells in HKU to patients and their families.

Targets: Patients and families



HKU STUDENTS AS VOLUNTEERS

This project was co-funded by “We Are with You” (WAY) Fund, CEDARS, HKU



Big Brother Big Sister Mentorship Project 「同步成長」大哥哥大姐姐計劃

The programme was co-organised by HKU Little People Care Alliance and LPHK. Through participation in a series of activities, junior patients benefited not only from academic and social guidance from HKU students (“big brothers and sisters”), but also developed confidence and a positive attitude towards life. On the other hand, HKU students learned how to express love and care for the underprivileged as well as become socially responsible leaders. The programme aimed to build long-term friendships between the junior patients and HKU students.

Cup Cake Fun Day

(for Dwarfism Awareness Month 2015)



Ocean Park Visit



Rare disease Day



IMPACTS ACHIEVED

Positive feedback from our community partner - Little People of Hong Kong, patients, families and volunteers

I am very grateful for Little People Care Alliance in organizing this series of activities. Understanding is the first step in eliminating prejudice. The Alliance has been successful in laying down the foundations for understanding rare skeletal conditions among people from different backgrounds.

Miranda Chiu

A mother of a 3-year-old girl with achondroplasia



Children with dwarfism are often subject to stares, teasing, isolation or even bullying. The series of activities organised under the "Little People Care Alliance" project have successfully raised awareness among schools, the younger generation and the general public. I believe this will make a difference to the lives of Little People and help promote acceptance, equality and diversity in society. My deepest gratitude to the HKU team for everything they have done for Little People.

Serene Chu

Chairman of Little People of Hong Kong
A mother of a 6-year-old boy with achondroplasia



My active participation in the activities organized by Little People Care Alliance, allowed me to further understand the difficulties little people face on a daily basis. I found this to be a very rewarding and enriching experience as a 'big brother' volunteer, and that it greatly complemented my own research projects on clinical diseases.

Steven Pei

Volunteer, PhD candidate,
Paediatrics & Adolescent
Medicine, LKS Faculty of
Medicine



有平等的機會進入良好的學校生活, 對每位侏儒症患者及他們的家長都很重要, 參與「我是小個子: 你的學校能接納我嗎?」研討會, 讓我看到聽到幾位對教育有熱誠的校長及老師那份「有教無類」的大愛精神, 他們真的可以帶給病人家庭無限的幫助及支持。希望藉著香港大學「小個子·大作為」關愛行動舉辦的活動, 令香港的教育機構與及這個社會能提供更多的平等機會予侏儒症患者。

Manda Chan

侏儒症患者

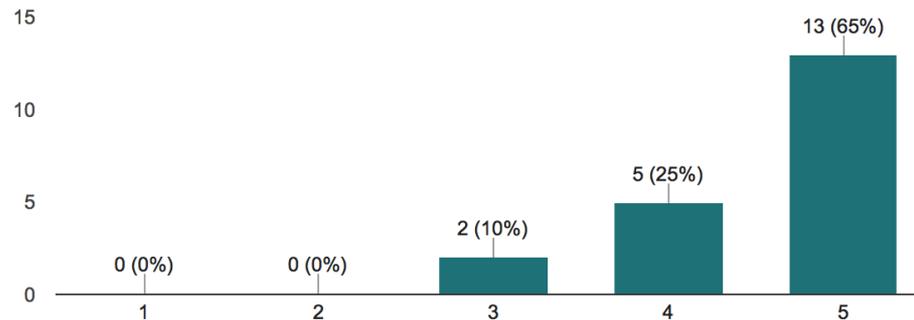


IMPACTS ACHIEVED

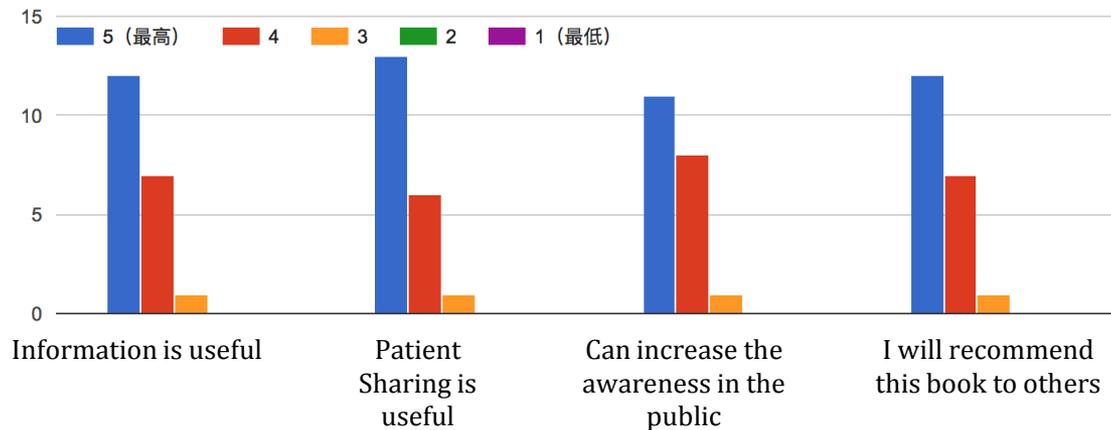
Positive feedback from our community partner - Little People of Hong Kong, patients, families and volunteers

Do you think “Little people care alliance” help to increase understanding of dwarfism in the general public? (1 Lowest-5 Highest)

(20 responses)



Please evaluate the KE booklet “Understanding rare bone disorders” (1 Lowest – 5 Highest)



IMPACTS ACHIEVED

Raise awareness among the general public – Media coverage of this KE project



TV programmes



Radio interviews



無線電視星期日檔案

日期: 2014年10月12日
 受訪者: 香港大學李嘉誠醫學院兒童及青少年科學系臨床副教授鍾傑富醫生
 內容: 罕見疾病: 侏儒症
 連結: <http://mytv.tvb.com/news/sundayreport/190247> (17:30 至 19:00)

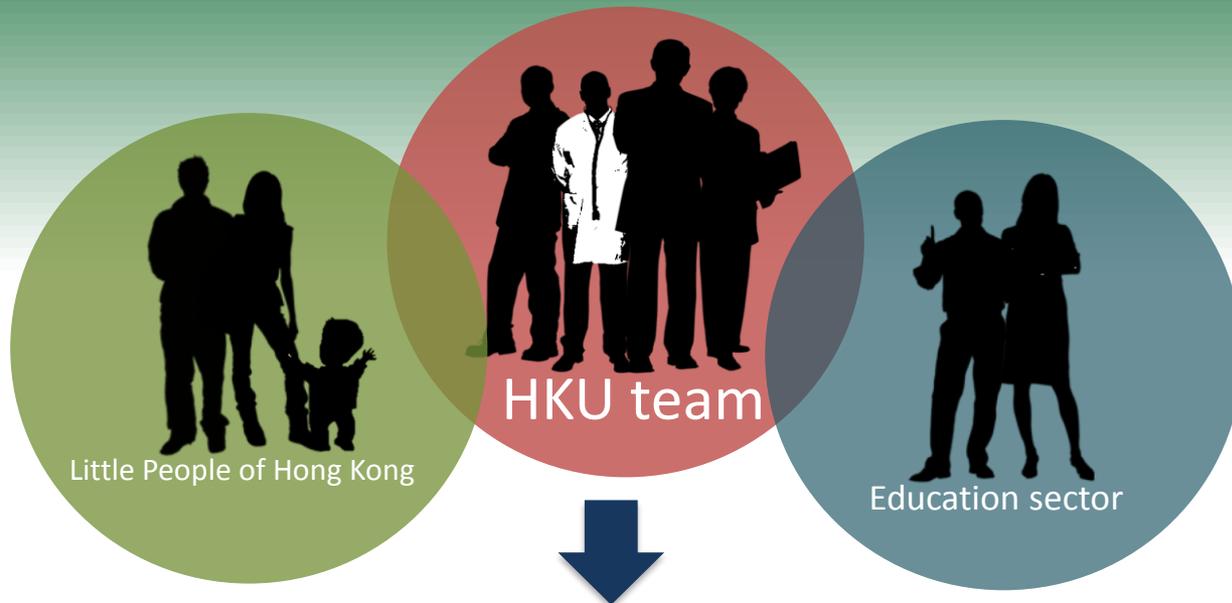


平等機會多元共融行動

主題: 認識侏儒症, 消除誤解, 以及介紹「小而同罕有骨骼疾病基金會」最近出版的書籍《小個人大作為》

嘉賓: 香港大學李嘉誠醫學院助理院長陳振勝教授
 香港大學生物醫學學院陳卓榮博士
 小而同罕有骨骼疾病基金會會長朱凱欣女士 (三位都是是香港大學知識交流計劃「小個人大作為關愛行動」成員)

Our sustainability goal



Educate the next generation and the community



Foster the attitudes of empathy, open-mindedness and acceptance to people with special needs in Hong Kong