HKU Knowledge Exchange Project
Little People Care Alliance
「小個子，大作為」關愛行動
LKS Faculty of Medicine | March 2017

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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. 當前對侏儒症的認識足夠嗎？(20 responses)

<table>
<thead>
<tr>
<th>Response</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seriously insufficient</td>
<td>6 (30%)</td>
<td>30%</td>
</tr>
<tr>
<td>Insufficient</td>
<td>6 (30%)</td>
<td>30%</td>
</tr>
<tr>
<td>Satisfied</td>
<td>3 (15%)</td>
<td>15%</td>
</tr>
<tr>
<td>Satisfied</td>
<td>1 (5%)</td>
<td>5%</td>
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</tbody>
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What are the positive effects if awareness of dwarfism is raised in the general public?

2. 你認為增大眾對侏儒症的認識有何正面影響？(20 responses)

- Prevent Bullying and discrimination: 19 (95%)
- Correct understanding of the disease: 17 (85%)
- Equal opportunity in education and employment: 18 (90%)
- Increase medical resources and public facilities: 18 (90%)
- Other: 0 (0%)

(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.
Narratives of illness provides a framework for approaching a patient's problems holistically, and may uncover diagnostic and therapeutic options.
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 stakeholders 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

Understanding Patho-mechanisms

Human Genetics

Establish better assessment and treatment methods

Surgical Management

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
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 realize 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
1  
**FEB15**  
**RARE DISEASE DAY EVENT**  
Targets: Patients and general public

![Image](image1.png)

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

![Image](image2.png)

Adult patients shared their experiences with other LP families.

![Image](image3.png)

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

Group photo of Honorary 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.

2  
**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

![Image](image4.png)

Little people Jacqueline and Edmund shared their school life experiences.

![Image](image5.png)

Local and foreign students were actively involved in question time.
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

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

Exhibition “Little but not Less: Better care for Patients with Rare Bone Diseases”
Targets: Faculty members and medical students
Public Lecture @ Hong Kong Central Library
Targets: General Public

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

“Little People Care Alliance” Team
“Understanding Rare Bone Disorders” Book Launching
Targets: Schools, Hospitals, Social Workers, Corporations and General Public

Basic Science about dwarfism
Advances in treatments
Clinical Cases
Patient stories

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

FEB16
PUBLICATION OF A BOOKLET

OCT16
VIDEO FOR DWARFISM AWARENESS MONTH

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
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

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
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: 你的學校能接受我嗎？」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。希冀藉著香港大學「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

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

(20 responses)

- 0 (0%)
- 2 (10%)
- 5 (25%)
- 13 (65%)

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

- Information is useful
- Patient Sharing is useful
- Can increase the awareness in the public
- I will recommend this book to others
IMPACTS ACHIEVED
Raise awareness among the general public – Media coverage of this KE project

Radio interviews

TV programmes
IMPACTS ACHIEVED

Raise awareness among the general public – Media coverage of this KE project...
Our sustainability goal

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

Educate the next generation and the community