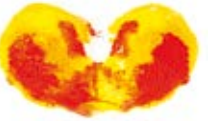

Little Giants Dreams of Braving MPS

About Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group

Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group is a group formed by people who have Mucopolysaccharidosis. Assisted by The Hong Kong Society for Rehabilitation Community Rehabilitation Network, our Group was registered as a non-profit organisation on 23 March 2005. Our purpose is to gather the people who have MPS disorders and other rare genetic diseases, share daily life experience, medical and other useful information that can help and support the families who have members with MPS disorder and other rare genetic diseases.

Please visit our website www.mps.org.hk/en or contact us info@mps.org.hk for more information about us and about rare genetic diseases.

Little Giants  Dreams of Braving MPS

This picture book is a part of the public awareness and fund raising campaign of Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group

A caring project by bbluesky

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bbluesky

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"The joints of his limbs would grow stiff, which may one day confine him to bed.
His intellect could be affected, and he would not live past the age of 20."

Such was the doctor's preliminary medical diagnosis for my child, and it shattered all the great hopes I had for him.

It was 11 years ago, when we did not have the kind of access to information we have today. Nor was the Internet widely available. Added to this was the very nature of Mucopolysaccharidoses (MPS) – a rare genetic disease which even doctors knew little about back then, not to mention an ordinary father like me. My friends from the church found me a medical dictionary, but it only gave descriptions in medical terms at best. I was totally helpless in coping with this disease of my son.

I spent a year in fear. And then I came across an interview of the late Chan Man-fong, a member of our mutual aid group, in Ming Pao Daily. Please excuse my figure of speech but I had to say I was happy I read it. To finally find someone going through the same experience was a big morale boost. We became acquainted and her parents gave me guidance on how to take care of my son. I later met more MPS patients. We felt that we needed to get together regularly, for sharing and mutual support. Five patient families joined our first gathering in 1999 and our group has grown. We now have 36 families today. Apart from MPS patients, our mutual aid group also welcomes fellow patients of other rare genetic diseases.

Exactly because they are rare, most rare diseases are without a cure. If such a cure exists, it may easily cost more than a million dollars a year. This book invites the public to learn more about rare diseases and our predicaments through sharing cases of several of our fellow patients. We are not able to include all the stories of our members here but we do hope that this book is just the first and more will come.

I would like to express my thanks to Chan Man-fong, Wong Wing-kan, Osmond Ching Ying-yu, Karen Chau Hiu-yin, founding members of our mutual aid group; Eric Ma, John Li, Leung Ka-po, Alan Chim, Mavish Sultana, Hamza Shahid, Tang Wai-man, Tang Wai-chi, Johnny Yeung and Annie Yeung for sharing their stories in this book; Anna Koo Wing-yee and Eunice Lai Wing-ngar of the Hong Kong Society for Rehabilitation - Community Rehabilitation Network; and our consultant doctors Dr. Chow Chun-bong, Dr. Joannie Hui Chung-ni, Dr. Stephen Lam Tak-sum, Dr Robert Lee Shing-yan. Closing with a high note, I would like to salute each and every one of our members. Your positive attitude in facing these impossible diseases is an inspiring example for us all.

Stephen Ma
Chairman, Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group

We Are All the Same

We are all the same.

Mucopolysaccharidoses is a genetic disease, and owing to its genetic nature, it is attached to patients as their limbs to their bodies, in-born and inseparable. It affects their physical conditions and daily lives.

But we are all the same because we all have dreams. MPS patients hope that life would go on as usual, and others treat them as anybody else. Recorded in this book are some patients' dreams. Some are special and fascinating; others are common like ours...

We are born in the same world as one family. With this in mind, I believe and hope that you will give your support to the Hong Kong Mucopolysaccharidoses and Rare Genetic Diseases Mutual Aid Group, to help patients fulfill their dreams.

Don Li
Ambassador of Mucopolysaccharidoses and Rare Genetic Diseases

You Can Help Contribute to What They Need

There are lots of self-pitying people in this world.

There are women who complain that their legs are not long enough, men who complain that they are not wealthy enough, and children who complain that they are not intelligent enough.

They never think they have already a lot.

What would you want to have most, if you were physically disabled and mentally deficient, had poor eyesight and had difficulty breathing?

I am grateful that the Hong Kong Mucopolysaccharidoses and Rare Genetic Diseases Mutual Aid Group has given me a chance of meeting these strong little warriors of life. Their passion about life deeply impresses me, and that is comprehensible to readers of this book, I believe.

We may not be able to buy what we desire, but we can give them support and help give them what they need. Let us lend a hand and give them hope, by supporting the charity sale of this little book, from which the proceeds will be used to help MPS patients.

Mandy Chiang
Ambassador of Mucopolysaccharidoses and Rare Genetic Diseases

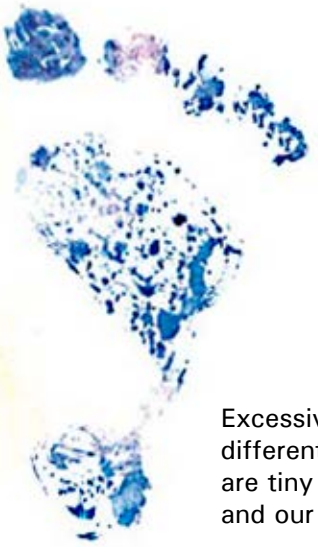
It is summer. All beans are ready for the landing.
They are to grow on new soil.

Beanie works hard every day.
He eats. He sunbathes. He exercises.
And he dreams of growing up,
as every other bean does.

But Beanie
remains little.

He dreams the same dream,
every night.

Most stories about
Mucopolysaccharidoses
start like this.



Excessive mucopolysaccharide starts accumulating in our bodies. We don't know when. That makes us different from others. We have short limbs and stiff joints, making it hard for us to move around. We are tiny and have rough hair. Mucopolysaccharide damages our eyes, ears, teeth, respiratory systems, and our intellect.

Doctors say we will not live past 20, but we never give up and always strive to move on.

Eric Ma, 14, MPS VI

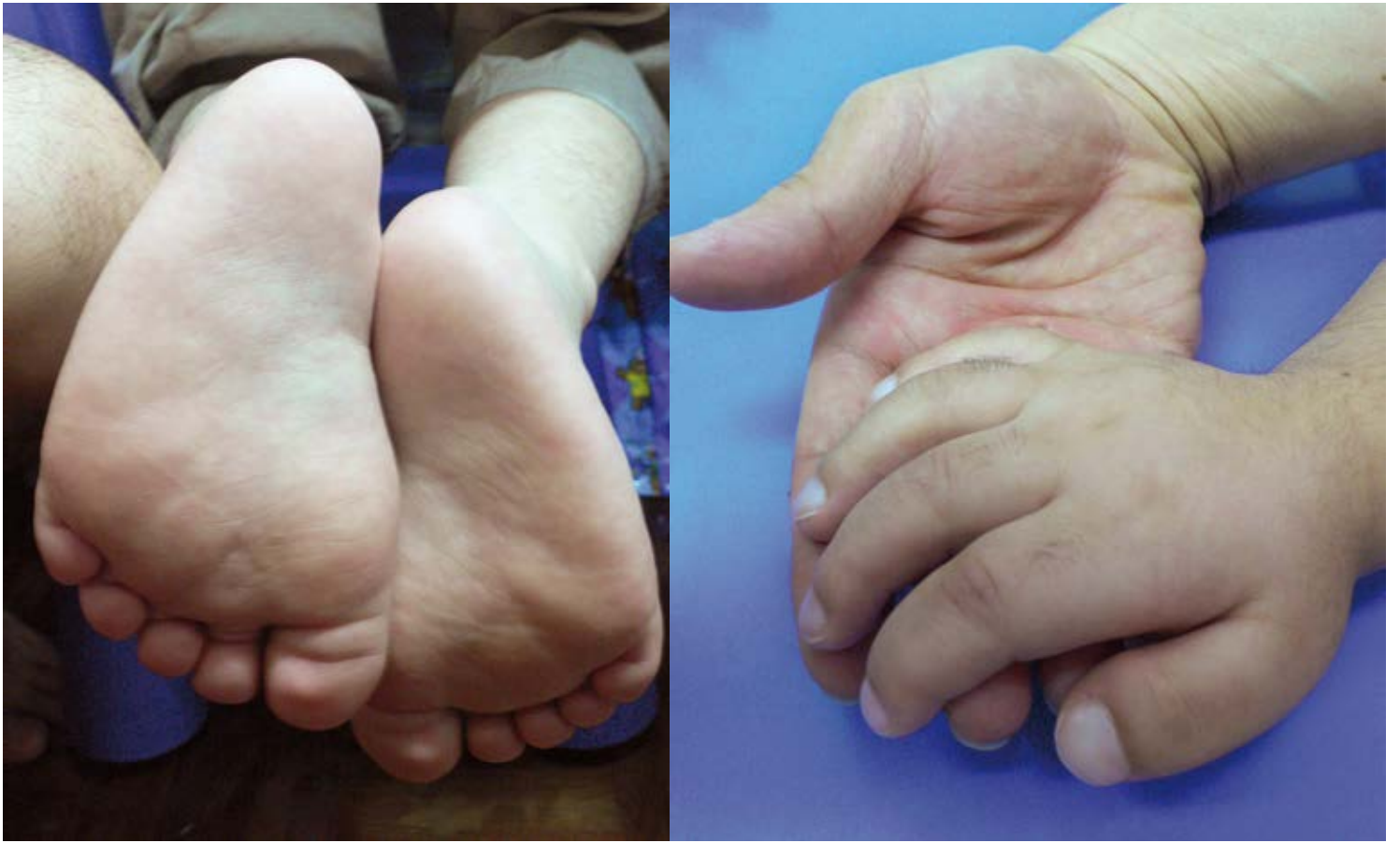
He goes to a regular secondary school. He wants to be richer than Li Ka-shing, play football better than Ronaldinho and wake up alive. But he has never played football in a field. He has only cheered players from off the field.

I’m Only Three Feet Tall

“It’s alright!” “It’s alright!” This is my pet phrase.

People always stare at me in the street. Once, a kid tried to roar at me like a tiger. Sometimes other children make faces at me. I can never get used to these but then it is no big deal. “It’s alright!”

I have never thought about wearing special high-heels. I have never thought about doing jumping exercises to make myself taller. Because it does not matter how tall I am.



It’s Alright – Because I Already Have a Lot

I easily get tired from walking. My father would not only walk with me. He would also carry me for the rest of my journey I cannot finish on foot.

Because I am small, I can sit on my mother’s lap when I watch TV. She is my throne.

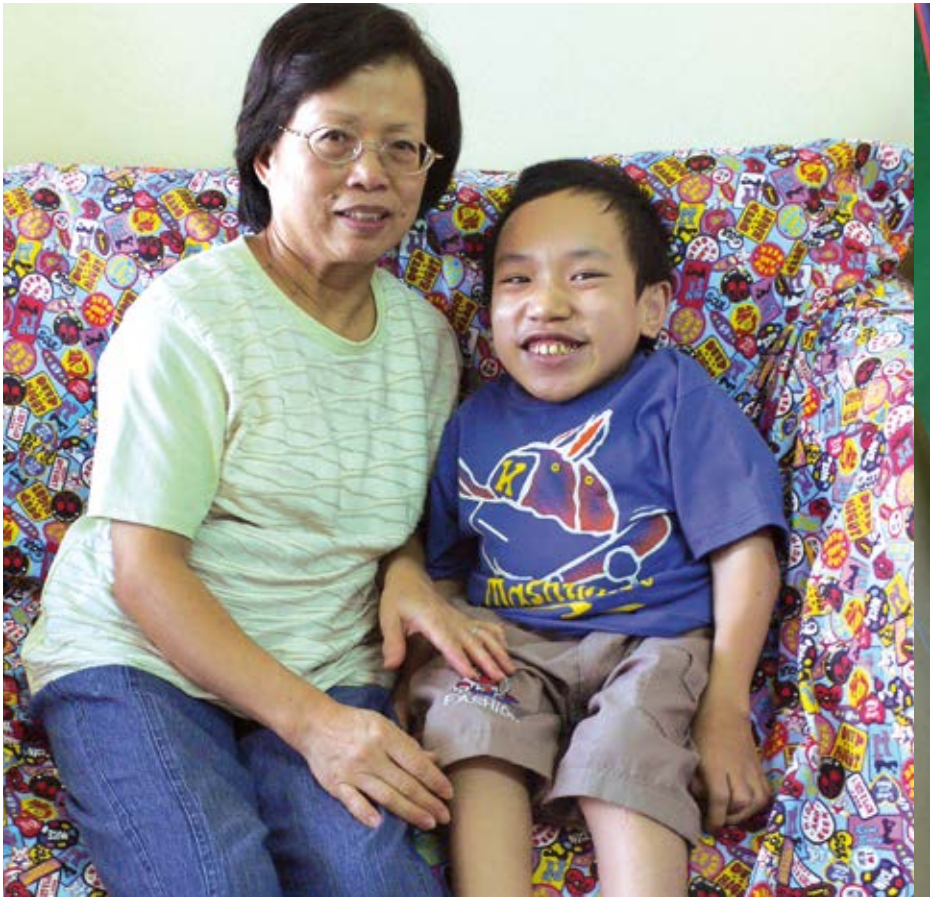
I am happy every minute of my life because I breathe freely every day. I know I will not live to be 20 but I am not afraid.





John Li, 14, MPS IV

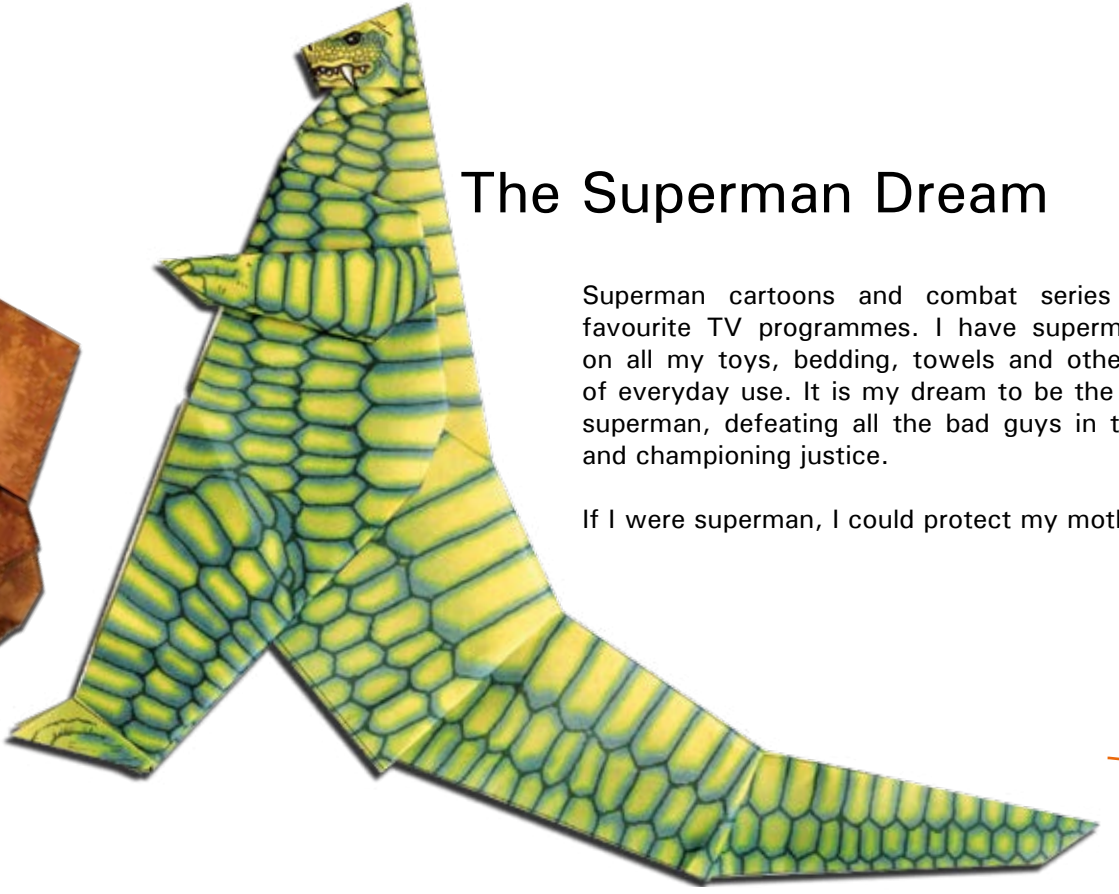
A student of The John F. Kennedy Centre. Had three operations because his doctors feared his crooked legs would affect his movements. John can no longer walk now and moves around in a wheelchair. John comes from a single-parent family and is looked after by his mother. His wish is to become superman, a champion of justice.



My Mother

My legs began to bend inwards when I was three and I was sneered at by a lot of people. When I was five, I was diagnosed with MPS. Every time people give me the sneer, I squeeze my mother's hand, and she would walk faster and lead me away. Both of us would feel so miserable. At school, "bullies" would snatch my new stationery, food, even my pocket money. I have been cursed for moving slow and being "in people's way" for so many times I have lost count of them.

I remember once when I was out with my mother I was hit by a schoolmate. My mother rushed forward immediately to protect me. That "bully" could only give my mother a vicious stare. Her anxious look in protecting me has remained a deep burn on my mind all these years.



The Superman Dream

Superman cartoons and combat series are my favourite TV programmes. I have superman icons on all my toys, bedding, towels and other articles of everyday use. It is my dream to be the immortal superman, defeating all the bad guys in the world and championing justice.

If I were superman, I could protect my mother.

Karen Chau, 13, MPS IV

Had had operations done on her neck, thighs and hipbone before she turned four. Her worst fear is to have her blood tested. She moves around in a wheelchair but she is an ardent volunteer to help elderly people. She hopes she can take care of her parents and herself.

You Made Mom a Different Person

Karen, now thirteen, is often in hospital. She had operations on her hipbone, her neck and her thighs between two and four. Her doctor was unable to diagnose her with MPS then. The operations only made her worse. She walked awkwardly, often making her the victim of stares. I found that hard to bear and used to carry her so that she would not be stared at. We used to stay home to get away from it all.

"Mom, it doesn't matter the way people look at me," said little Karen to me.

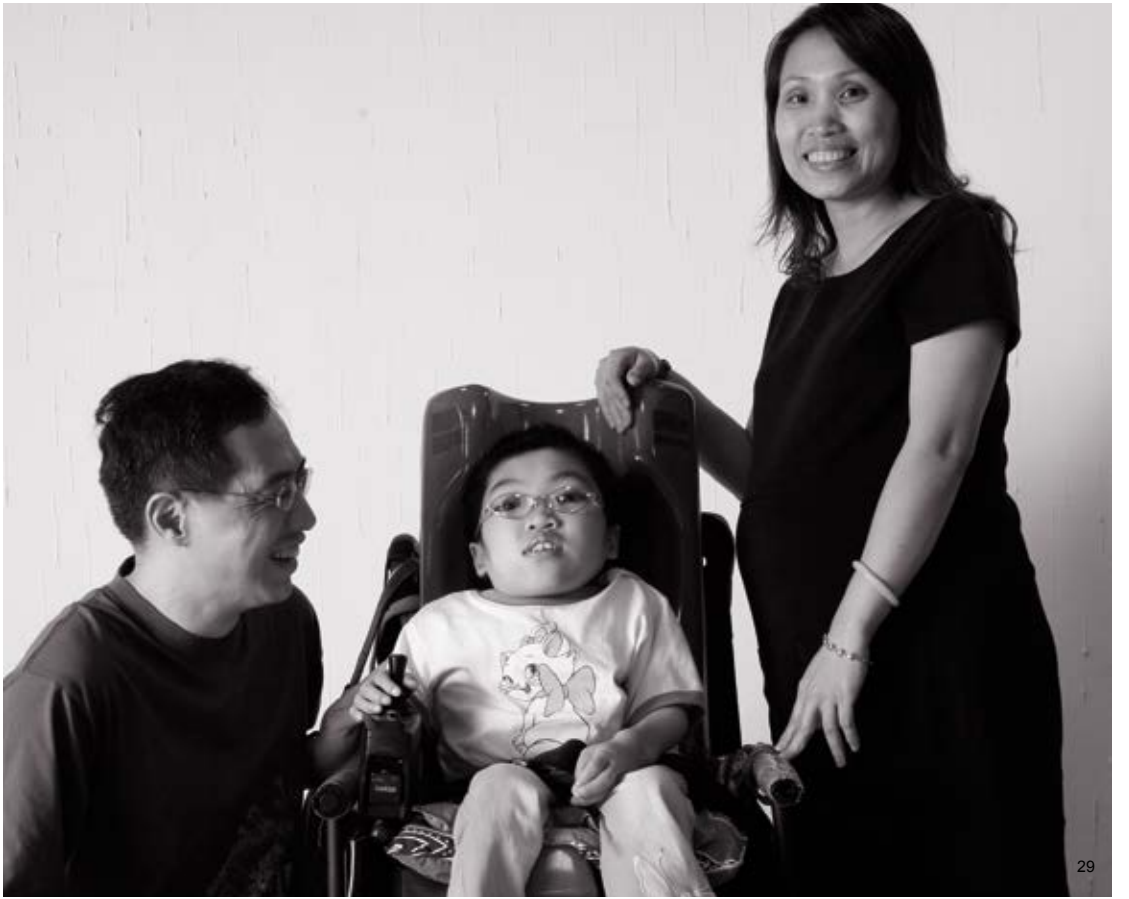
Her words made me brave.

What I'd Like to Say to My Parents

First of all, "Thank you for standing by me."

Time was I had to go to hospital several times a week. Mom had to work so that we could pay the medical bills and she often had to take leave to take me to hospital. I know she has suffered a lot at work because of me.

I have to move around in an electrical wheelchair but few public vehicles have wheelchair access. So I have this wish. It is for me to own a car. Because of my wish, my Mom has managed to get a driver's licence. We do not have a car though. But Mom, I want to thank you for everything you have done for me.



Leung Ka-po, 17, MPS III

Being able to consume purees only, Ka-po has to rely on her mother to take care of all aspects of her life. Like all other MPS III patients', Ka-po's condition will only deteriorate. What is left of her IQ now is equivalent to a one-year-old's.

Mom Is by Your Side

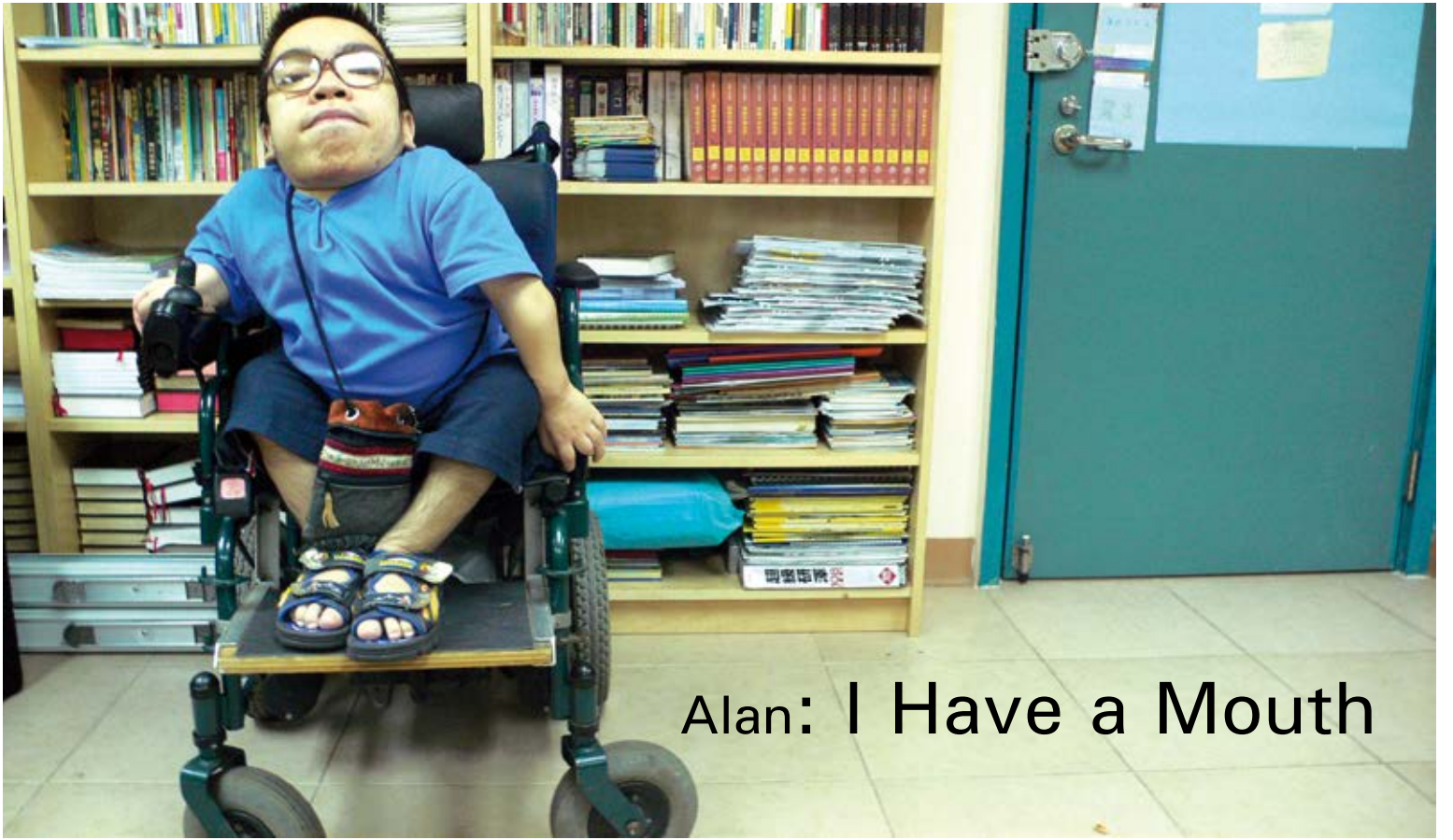
Ka-po's name means the family's treasure. Her papa gave her the name.

Ka-po has just celebrated her 17th birthday. As a child, she was below the normal curve in intellectual development. She looked no different from other children. Not until she turned four was she diagnosed with MPS. Her intellect is comparable to that of a one-year-old only. Ka-po's condition would get worse with each passing day. The only thing I can do is to be a dutiful mother and stay by her side.

When we go out, Ka-po would stretch her hand out to touch everything she sees. At the market, she would try to catch fishes at a seafood stall, or she would try to take vegetables away. I have to apologise every time. I remember dozens and dozens of occasions when people shouted at me for failing to discipline my child.

It is incidents like these that have left me disheartened. But every time I hear Ka-po call me "Mom" in her muffled little voice, I find renewed strength.

I do not care if the whole world turns its back on her. I would always stay by her until the very end.



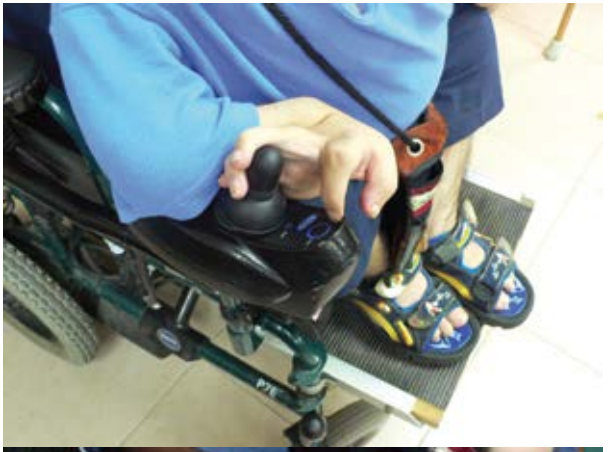
Alan: I Have a Mouth

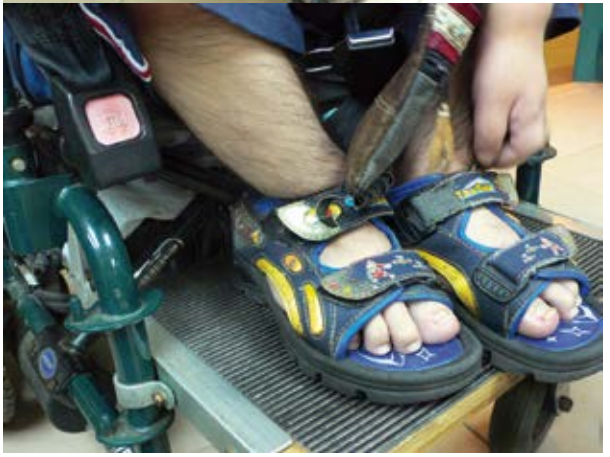
Alan Chim, 24, MPS IV (Deceased)

The MPS disease causes his bones to grow abnormally. He now has to move around in a wheelchair. He once worked as an operator after he had finished secondary 6. But most of all he hopes to become a missionary and spread the message of reconciliation. For him, the most important thing is to listen and to share. He hopes his family will come to terms with his sickness.

“My limbs are far from agile. I need help when I dry my towel, get dressed or unscrew the cap of a bottle. But I still have a mouth,” Alan, confined to a wheelchair since 18, declares proudly.

“My mouth is my instrument to experience this world.”





Passing the HKAL　Looking for Work

It was no easy task for Alan to pass his HKAL. Each word was written slowly with tremendous effort. Alan was afraid that if he wrote fast his teacher could not read his handwriting and he would get low grades. He finished his HKAL course with much sweat.

His childhood dream was to become a doctor. He decided that he should become a disc jockey after he had won a first runner-up at the Hong Kong Schools Speech Festival. This dream vanished after he had started working. Alan was an operator for a few months. The frustration of not having any listener who would answer his questions was too much to bear.

I Am a Lucky One

Alan has never complained about his sickness which makes it difficult for him to move around. He is outgoing and jumps at the chance to join different activities. His weekly schedule is fully packed with Putonghua classes and volunteer work, which allows him to help cheer up his fellow patients. “Once I was at a party with patients suffering from spasm. Their brains were already damaged by the sickness. I could not help but feel that I am a lucky one for having mine still functioning fine,” said Alan.

Mavish Sultana, 11, Pakistani born in Hong Kong, MPS I

She may be short but her intellect is developing fine. She speaks fluent English, and what she would most want to say to her mother is, “My mother is the best in the world.”

Hamza Shahid, 10, MPS I (Deceased)

Younger brother of Mavish. Their father left after learning that his children were diagnosed with MPS. They have therefore been looked after by their mother. Hamzor hopes that he would grow stronger when he is older, so that he can take care of his mother and sister.

Everyone Is Different

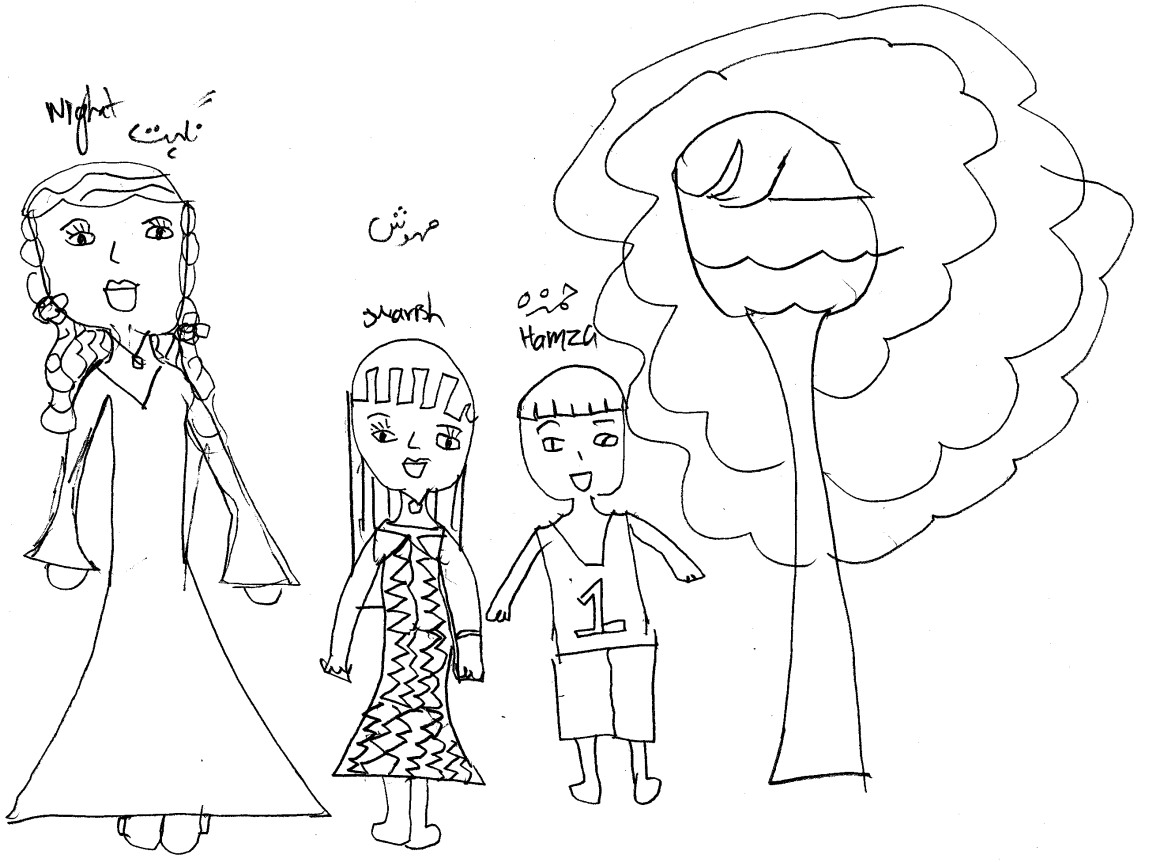
Mavish and Hamza are a funny pair. They would keep saying “I have no idea what you are saying” when in fact they can understand Cantonese.

But they have a sad story.

Their mother recalled that when Mavish was little she looked no different from other children. One day she cried, “Mother…I cannot move, mother…” That frightened her parents. Later they found that both their children had bulging backs and tummies. Around the age of four, they were diagnosed with MPS.

Mavish started to notice that she was shorter than her friends her age. She would ask her mother, “Why am I so small? Other children are always staring at me. I want to be taller.”

And her mother would tell her, “Everyone is different. Some are tall, some are short, some are fat, some are thin.” So the child learnt to accept herself for what she is, “We may be a bit different but we can play and live happily.”


Night
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حمزہ
Hamza
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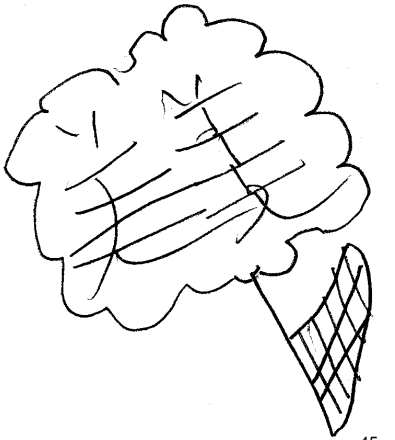
What Is Your Wish?

Mavish's answer is prompt. "First, I hope that there would be a cure for my sickness. Second, I hope to return to Pakistan sooner because no one would do silly things and talk to me here. Third, I hope to become a beautiful and intelligent girl. I also want to become a doctor because there are a lot of sick people in Pakistan. I can study medicine here and go home to cure people."

Hamza's wishes vary from time to time but one wish remains unchanged, which is "to become stronger because I can take care of my sister and mother when I am bigger".

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PHILIPS

Tang Wai-man, 43, diagnosed with MPS II recently

The eldest of the four children in his family, Wai-man often thinks of his late father. His greatest wish is for his family to be healthy and happy.

Tang Wai-chi, 40, diagnosed with MPS II recently

The third son of the family. His employment portfolio includes food packing worker, messenger and security officer. After his father's death, he started helping out his elder brother at the family hardware store. He used to care about nothing except money. But now, like his elder brother, he believes health is most important.

Brothers of Different Temperaments But Like Hearts

Both brothers were diagnosed with MPS five years ago. The elder brother is now 43, the younger three years his minor. They are as different as any two persons can be. The elder brother is quiet. He enjoys farming and keeping poultry. He believes the key to good health is doing exercise, having quality sleep and looking at green plants. He is never angry at people's unfriendly stares. The younger brother is an active person. He loves night life, drinks and smokes. He would snap back at people's stare with a bold "Are you done yet?"

The brothers may be of different temperaments but they share the same voice: “We are now past 40 and have lived much longer than everybody expected.”

Sacrifices Made by the Family

Both my younger brother and I were born in the sixties when this disease was quite unknown in the medical circle. The only way for our parents to deal with our sickness was to come up with their own cure. I still recall vividly how I would stand at the side of the playing field and watch people play basketball, afraid of being laughed at. My father would look at me in my face and say, “You need more exercise to have more agile joints and to stay healthy. Don’t bother yourself about how people look at you.” He could be dead tired after work but he played basketball with us every day. Sundays we went swimming. We can keep doing exercise because of our father’s encouragement and support.


PYLOX

As the younger brother, I could feel most acutely the never-failing love of our mother. She would go to great lengths to answer our needs. We might have been a poor family but she always found a way to let us eat better, dress better. She spent all she could spend to provide the best for us both.

Our other brother and youngest sister do not have this disease. They have never abandoned us. Our sister went all the way to Taiwan to try to find us a cure. It was only after many years that we found we had MPS.

We are indeed a blessed pair to have our family's love and support.


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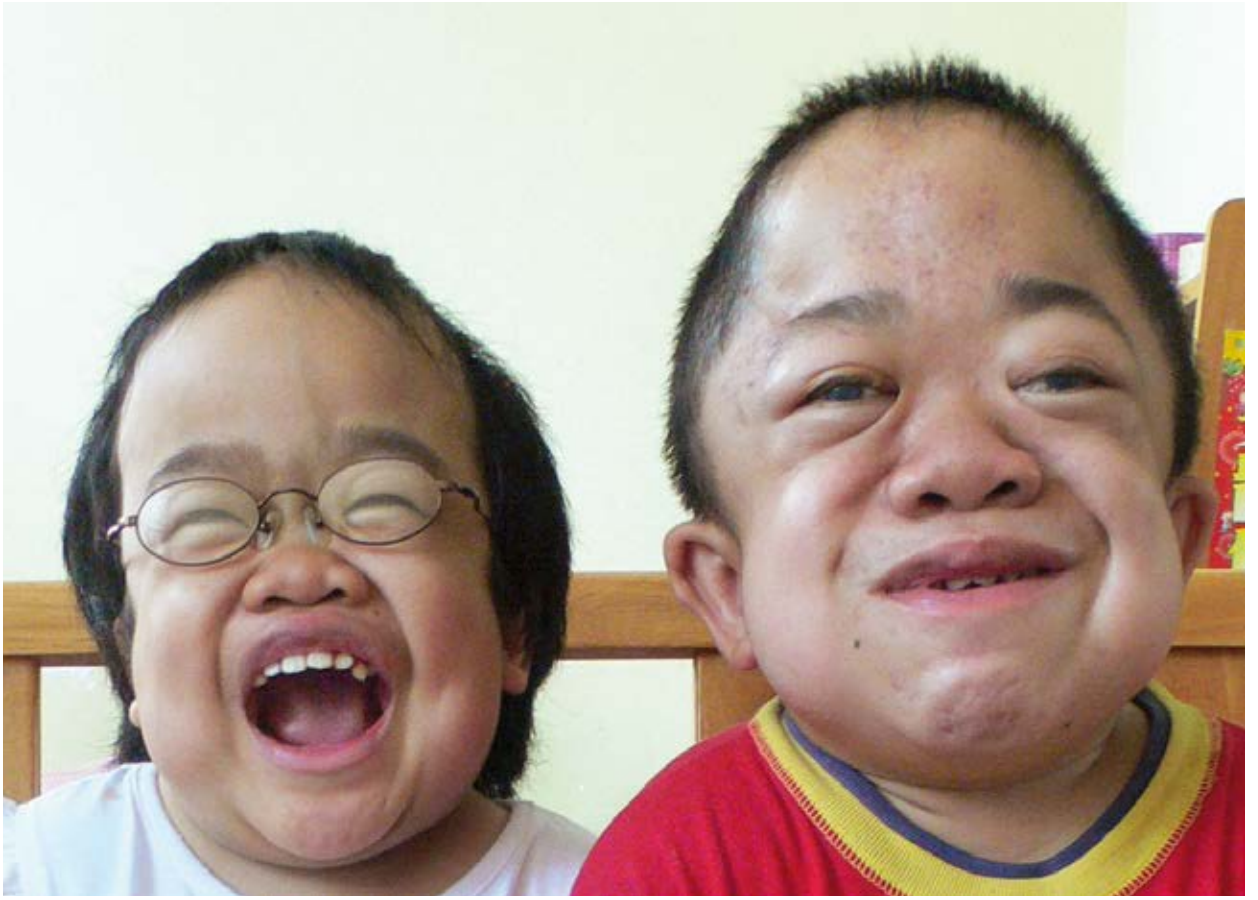
Johnny Yeung, 14, MPS VI

Born in Guangzhou. His eyesight was seriously affected by the illness. He went completely blind when he was 11 and now has to move around in a wheelchair. He studies at a school for children of special needs. His fluent Putonghua won him the first-ever prize of his life–the second runner-up in the Hong Kong Putonghua Recital Competition.

Annie Yeung, 11, also has MPS VI, like her brother (Deceased)

Her father donated his bone marrow to her two years ago on medical advice, in the hope that it would help revive her body's ability to make the badly-needed enzymes. She is still under medical observation. Annie is a lively child, always wearing a bright smile and loves to express herself with pictures.



If One Day
You Needed Me

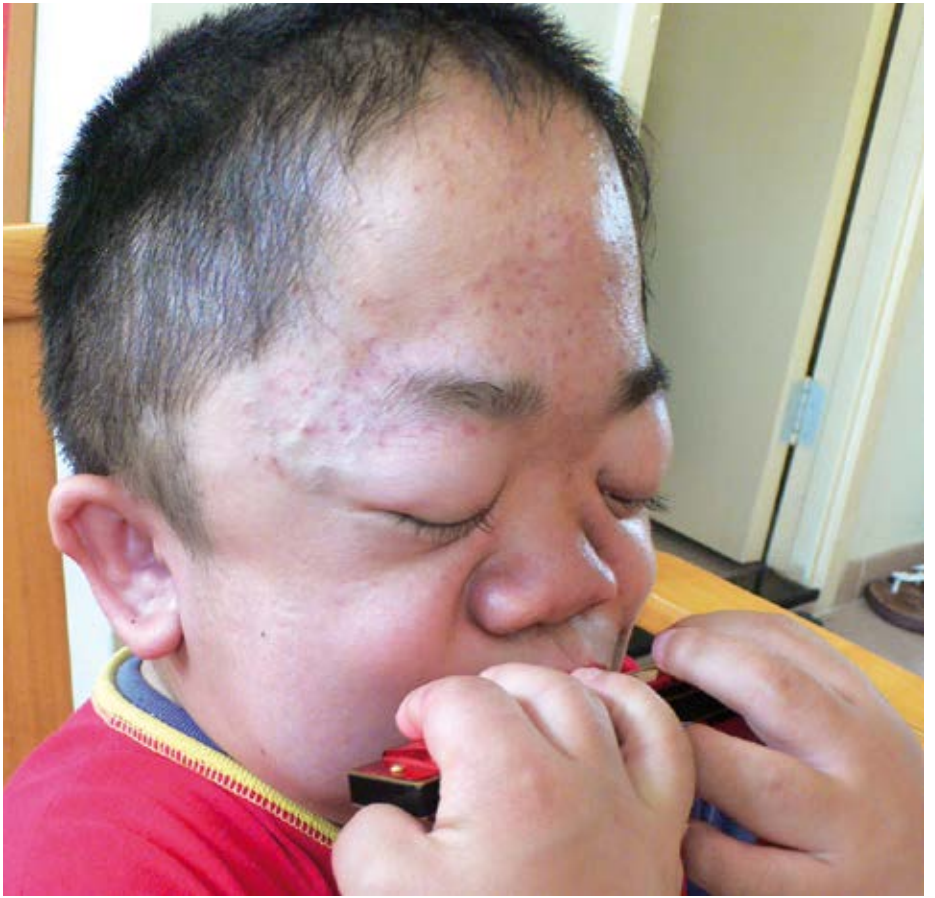
The brother is 14 and the sister, 11. Both born and educated in Guangzhou. Settled in Hong Kong in 2003.

When they went to school in Guangzhou, they were the subject of constant bullying and abuse. Johnny recalled once a young friend of his called him “three eyes” and suddenly came up and spat on him. He could but hold his temper. Annie was nicknamed “big head” and felt miserable about it. She would run home to their mother and tell her about it in tears. “I don’t look like a pig at all. Why would my classmates call me pig-nose?” She could never understand such bullying.

Johnny believes that people are all equal and should not be discriminated against. “You feel miserable if people discriminated against you. Imagine that if you were sick one day and you were discriminated against because of it, you would be miserable too.” He believes that one day, he too may be able to help you.

It Should Be a Bright Day, Isn't It?

Why Does It Look Like Rain to Me?



Johnny has MPS VI, which severely impaires his eyesight. The journey is like walking from a colourful world into a pitch dark desert. “People told me it was a bright day but I saw only a cloudy sky, and it looked like it was going to rain. Then one day my mother told me that it is already daytime and I should get out of bed. But what was around me was complete darkness. I knew I could never again see this world. I was disappointed but I was not afraid.” Johnny then took out his harmonica and played Twinkle, Twinkle Little Stars. He hopes that one day he would be able to see the stars.

“Actually there could be good things in not being able to see,” said Johnny with a grin. “I cannot see the look on people’s faces. And I would only need to take oral exams. My teacher would write down my answers so I always get the words right and get higher marks.”

I Would Like to Become a Painter

Annie loves drawing pictures but has had no opportunity to learn doing so. She likes to draw things she imagines. Because of the disease, she has stiff joints and needs tremendous effort and a lot of time to make each brushstroke. But she persists in drawing things she imagines with all her heart. “I would like to become a painter,” Annie would say so all the time.

This is a wish that has come true with the help of “Make-A-Wish Foundation”. Each guest was only allowed to bring along one companion for the helicopter ride. But the staff in charge let my mother and brother took the ride with me, which made me so happy. I sat in the middle and I could not see anything but I was so thrilled. It felt wonderful.

I have never gone up a hill.
I imagine this is what it would look like.

Let's help them fulfill their dreams and have happiness...

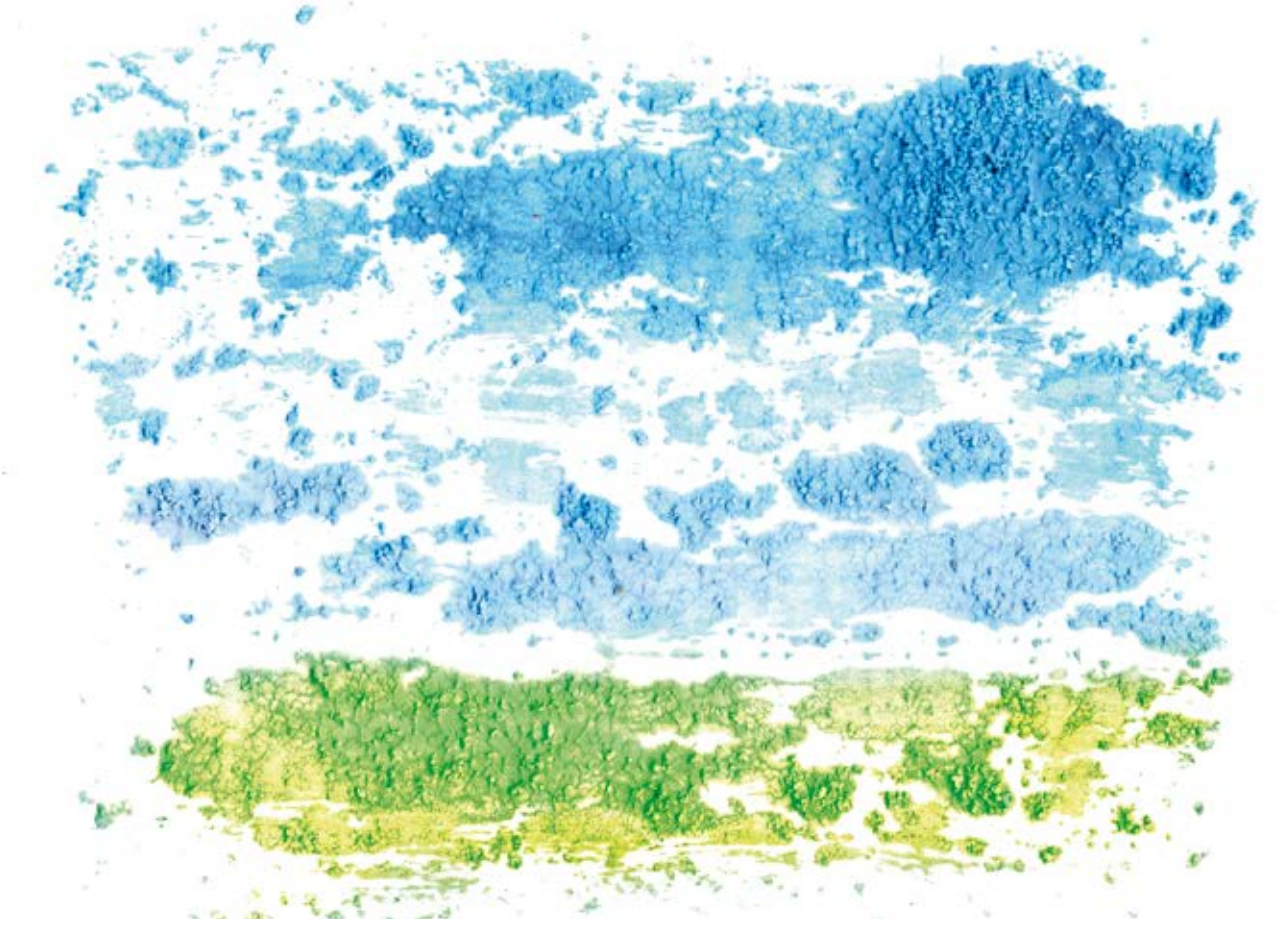


Photographed by Mandy Chiang

“So this is my dream,”
Beanie tells every little bean that has just arrived.

Every one of them begins dreaming
the same dream every night,
of growing up.

So much warmer each day now becomes.
The garden is turning green,
with all the beans happily growing.
The sky seems closer every day.



“I hope that I could play, I could chat and enjoy everything” Mavish Sultana

“I hope that my family could understand me” Alan Chim

“I hope that I will never be discriminated against” Johnny Yeung

“I hope that there would soon be a cure for our sickness” Annie Yeung

“I hope that my family would have good health” Tang Wai-man

What is MPS?

Mucopolysaccharidoses (MPS) are a group of rare inherited metabolic diseases known as storage diseases. Mucopolysaccharides are long chains of sugar molecules for building body tissues and organs. MPS are caused by the deficiency of specific enzymes needed to break down mucopolysaccharides. Because of enzymes deficiencies, excessive amounts of mucopolysaccharides accumulate in the body, causing progressive damage to many different organs.

Depending on which enzymes are deficient, MPS are subdivided into seven types (Type I to Type VII). Most patients with MPS are normal at birth. As they grow, because more and more mucopolysaccharides accumulate, the following symptoms may become evident:

1. short stature, big head, bushy eyebrows, increased hairiness, flat nasal bridge, thick lips, big tongue;
2. stiff joints with contractures, claw hands;
3. enlarged liver and spleen with a distended abdomen, umbilical hernia, cloudy cornea in the eyes etc.

Different types of MPS involve different organs. The above features with varying severity are present in many MPS patients. With regard to brain and IQ involvement, the severe Type I, II and Type III patients have severe mental retardation with progressive deterioration. Patients with mild Type I and II have relatively normal brain functions and IQ. Type IV and VI patients' IQ is usually unaffected by their diseases. Type IV patients have predominant bone involvement.

MPS diseases are hereditary. Other than Type II, most types of MPS are inherited in an autosomal recessive manner. Each parent is a carrier of an abnormal gene for the disease and they themselves are unaffected by the disease. If a child inherits two such abnormal genes, one from the mother and the other from the father, the child will get the disease. Type II is inherited in a X-linked recessive manner. The abnormal gene responsible for the disease is carried on the X chromosome, which is passed from a mother to her son. As girls have another X chromosome carrying the normal unaffected gene, they do not get the disease.

The key to curing MPS patients is to give them the missing enzymes. At this stage, this is done by two means: (1) haematopoietic stem cell transplant (2) intravenous infusion of synthetic enzymes.

Haematopoietic stem cell transplant provides the patient with the donor's haematopoietic stem cells which have the potential to produce the previously deficient enzymes. There is however definite risks involved with haematopoietic stem cell transplant. Donor availability is another major consideration. Enzyme replacement therapy (ERT) works by infusing synthetic enzymes into affected patients at regular intervals. At present, enzymes for Type I, II and VI MPS have been produced and are being used in patients with these conditions. As infused enzymes do not cross the blood brain barrier, ERT cannot improve brain functions in these patients. Also, this treatment must be continued for life.

In Hong Kong, there are 30 - 40 people with various types of MPS. Though they are a minority group, they definitely need society's concern, understanding, support and acceptance. Their desire for treatment is in no way different from that of other patients', as is their need for it. Many researchers in different parts of the world are trying to come up with cures that are better, more effective and with fewer side effects. We sincerely hope that breakthroughs will soon be made in this area and new cures will become available to all MPS patients in the near future.

Dr. Joannie Hui,
Consultant Doctor, Hong Kong Mucoploysaccharidoses & Rare Genetic Diseases Mutual Aid Group

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Dreams of Braving MPS

Book Title: Little Giants - Dreams of Braving MPS
Published by: bbluesky
Issued by: Leslie Ng
Edited by: the bbluesky creative team
Interviewed by: Leemaigo, Meh
Cases written and edited by: Meh
Story by: Loretta Chang
Photos by: Mandy, Ducky, Meh
Designed and Illustrated by: Meh
Release Date: 2006/9
ISBN: 988-98181-7-5
Price: HK$58

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Publication Date: September 2006 (First edition) |
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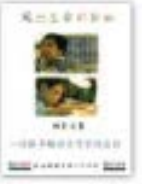

寫出生命的彩虹—一位黏多醣症女作家的自白

Author: 陳雯芳 | Publication Date: 1999 | Publisher: Metro Broadcast Corporation Limited | Language: Traditional Chinese | Pages: 105 |
ISBN: 978-962-85596-5-7

Beanie works hard every day. He eats. He sunbathes. He exercises. And he dreams of growing up, as every other bean does. But...

This is a story of a little bean, and a story of a little group of people.

“No growing, life’s ending” is what doctors prophesy about them. Like other rare genetic diseases, Mucopolysaccharidoses is hard to diagnose prior to pregnancy, and medical treatment is extremely costly. Many parents (of the patients) are racked by this. Is this a joke of their genes? Is this a test of resolution imposed by destiny?

They have small bodies, but their dreams are big, and never give up moving ahead. As parents or children, you will sympathise with the heros and heroines of the stories in this book.

“Mucopolysaccharidoses is attached to patients as their limbs to their bodies, in-born and inseparable. It affects their physical conditions and daily lives... But, we are all the same because we all have dreams.”
– Don Li, Ambassador of Mucopolysaccharidoses and Rare Genetic Diseases

“Their passion about life deeply impresses me... We may not be able to buy what we desire, but we can give them support and help give them what they need.”
– Mandy Chiang, Ambassador of Mucopolysaccharidoses and Rare Genetic Diseases

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