Rare Love

Rare Love

Hong Kong Mucopolysaccharidoses and
Rare Genetic Diseases Mutual Aid Group

Illustration and Comic Competition

Introduction

Mrs. Ellie Ching

Chairperson, Hong Kong MPS & Rare Genetic Diseases Mutual Group

From the day they are born, patients with rare diseases face difficult life paths. Pain, endless doctor visits, physical disability, organ failure, surgery after surgery–these are all experiences shared by rare disease patients. For them, death could come any moment. Making plans today does not mean getting to carry them out tomorrow. Many patients pass away before they turn 20.

Yet our patients are not defeated. They never despair. Life may be short, but they work hard to make it meaningful. With whatever time they have, they strive to learn, to give back to society, to make the most out of life.

Over the past few years, we have published four books about rare disease patients and have received encouraging responses from the public. This year, we organised the "Rare Love" Illustration and Comic Competition to allow more young people to learn about us. We hope today's youngsters, who live a life of abundance, will be inspired by the patients' perseverance and courage. We hope the youth will be inspired to live constructively, and equip themselves to become learned, compassionate and responsible members of society.

I am delighted that the competition was well-received by Hong Kong's higher-education and secondary school students. The quality of the works has exceeded our expectations. We have selected 13 works from hundreds of entries and compiled them into this book. We hope these outstanding illustrations and comics will touch your hearts and bring love to your lives.

Introduction

Dr. Joannie Hui

HKMPS Advisor
Senior Medical Officer, Department of Paediatrics, Prince of Wales Hospital

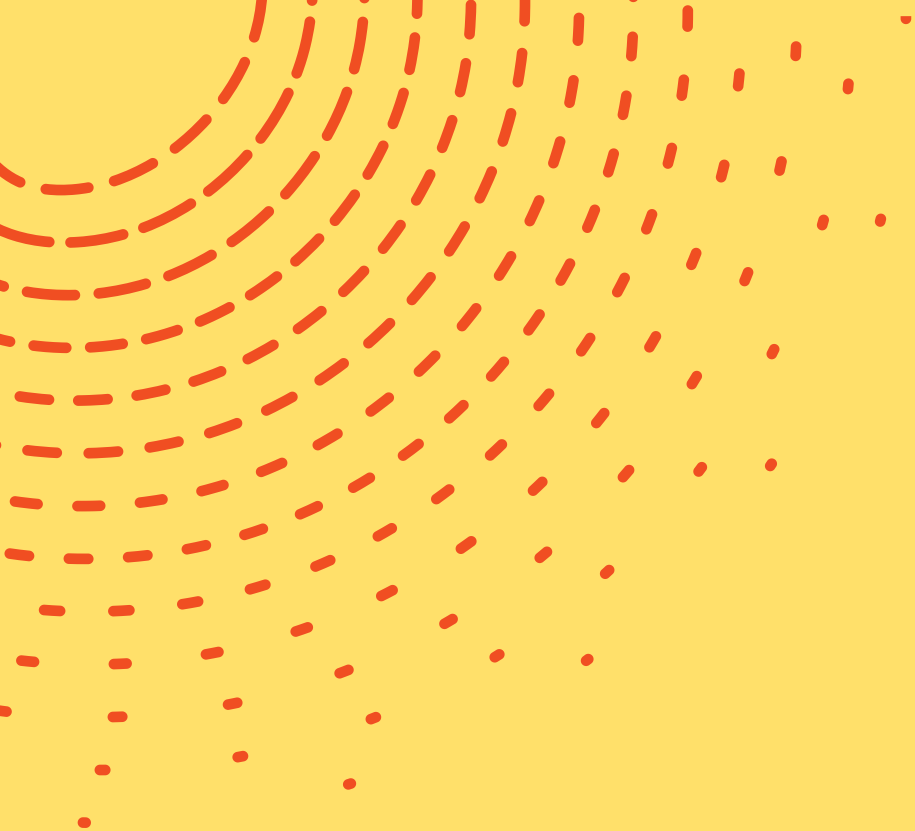
My interest in MPS began soon after I became a paediatrics student. The multifaceted nature of MPS makes it an excellent subject through which to learn about metabolic syndromes and other organ diseases. Despite its rarity, MPS was also a hot topic in paediatrics exams. After I started my career, I had the opportunity to treat some MPS patients. I soon realised how little doctors could do for them. The disease is incurable, and there is little to do in palliative care. All we could do was watch the patients deteriorate in health and mobility. We could refer the patients to different specialists and fill out the many forms for them, but that was it.

In the past decade or so, many medical journals have started mentioning bone marrow transplant as a way to treat MPS. This is an excellent development, as the transplanted bone marrow could produce the missing enzymes in the patients, and expand what doctors can do beyond palliative care. Scientists later discovered that they could manufacture drugs that produce these enzymes, and have successfully used these drugs to treat patients. I was at first doubtful about bringing such new treatment to Hong Kong, as efficacy takes time to prove and the drugs are very expensive.

Thanks to the work of different parties, the Hospital Authority finally agreed to set up an expert panel to look into the feasibility of this enzyme injection therapy, and look out for other medical proof of treatment efficacy. I am even more thankful for the patients' perseverance. The expert panel has been set up for five years already, and over 10 patients have benefited from this new treatment. As a doctor, there is nothing more delightful than seeing patients improve and discovering new, effective treatments. This is what drives healthcare professionals and scientists around the world to continue their research. I hope that newer, better, more effective drugs will continue to emerge.

This book contains many snippets of the MPS patients' daily lives. The young comic artists who took part in the competition used vibrant colours and lively brushstrokes to introduce these "warriors" and their families to us, vividly portraying each patient's will to live every day to the fullest with emotion and love, regardless of their physical condition. The works are all distinctive in style and content, and they all show the artists' understanding about and empathy for the patients. It is a lesson about love, about life, and about treasuring our health, mobility and freedom to learn.

I hope you will be touched by these works like I did—that you will understand the patients' situations, difficulties and needs, and appreciate their optimism and love for life. Please enjoy these amazing comic works by a group of talented young artists who have infused them with their love and empathy.



Rare Love

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我想長大

夏天到了，園子裏的豆豆落到地上
等待發芽。可是醣豆豆一直沒有
長高。每晚她做著同一個夢...

I want to grow up

Summer has come. Beanie falls to the ground, waiting to sprout. But she does not grow up.
Every night, she has the same dream...

夏天到了，豆豆們落到
泥土上吸收陽光和水份
長高長大。可是，
醣豆豆一直沒有長高。

只有自己一直小小的
醣豆豆感到很傷心，
因為一直小小的便不能
保護心愛的家人。

When summer arrives, little beans fall to the ground to absorb sunlight and water. All the little beans grow, except Beanie.

Only Beanie remains the same size. She is sad as she is too small to protect her beloved family.

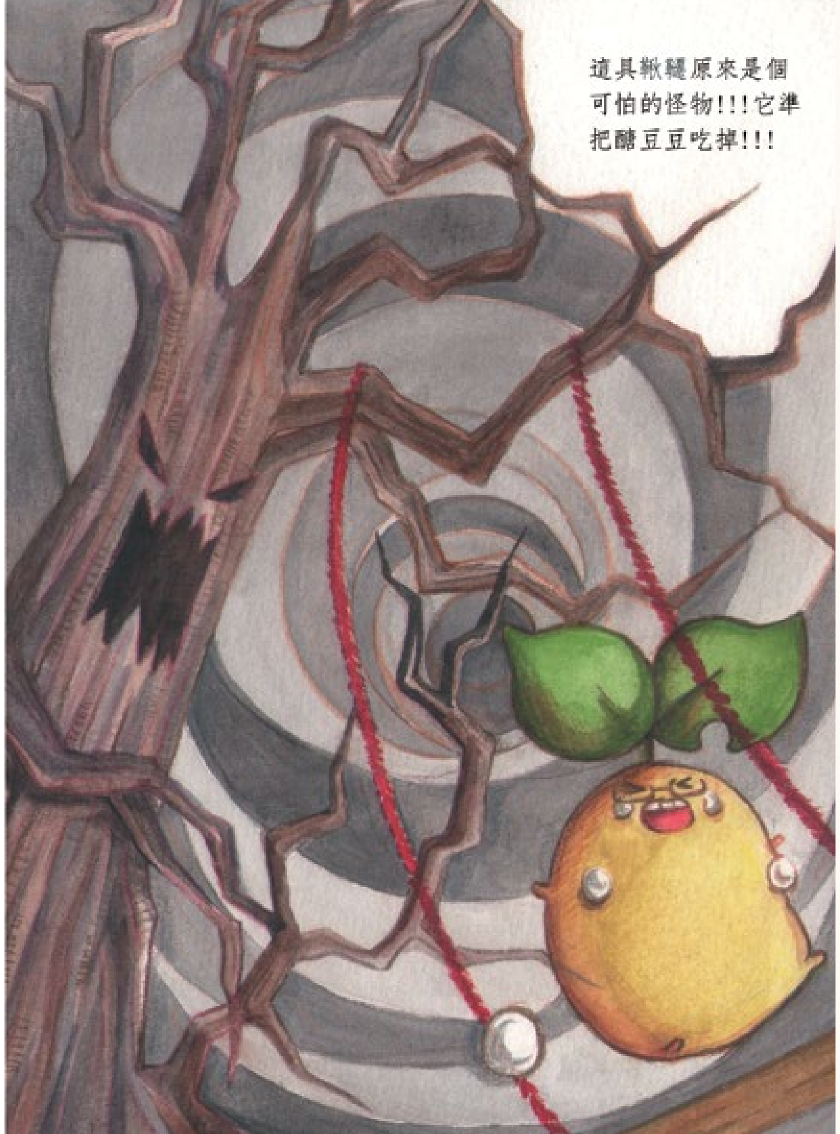
因此，醣豆豆每天都向神許願。
而且每天都努力向前走，
希望可以找到長大的方法。

就是這樣，
醣豆豆走過了一年又一年。
雖然走得很吃力，但她沒有放棄。

So Beanie prays every day.
She keeps living positively, hoping
to find ways to grow bigger.

Years pass.
And no matter how hard it is,
Beanie never gives up.

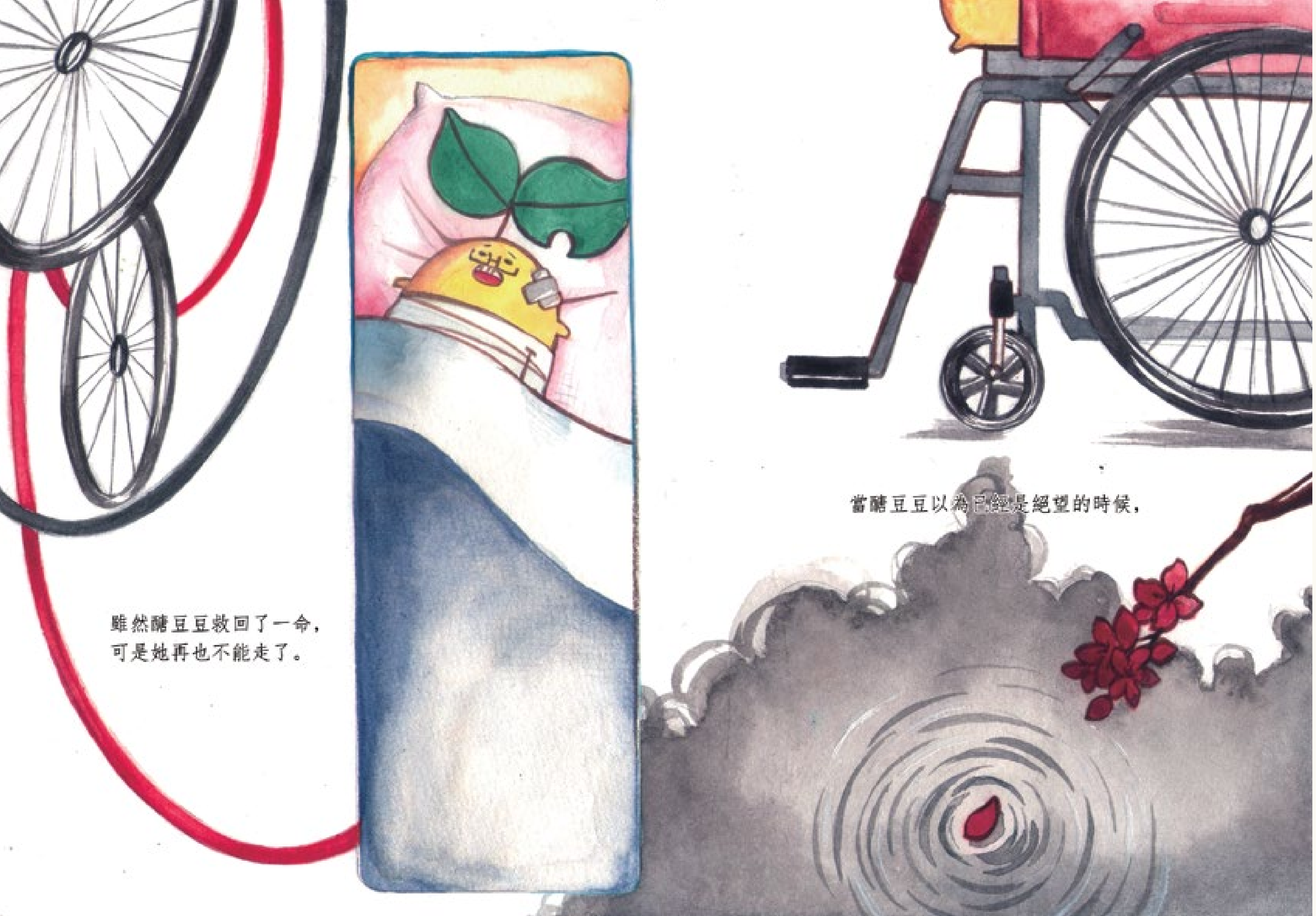
有一天，醣豆豆眼前出現一具鞦韆，
醣豆豆感到很好奇，於是坐了上去。



這具鞦韆原來是個
可怕的怪物!!!它準
把醣豆豆吃掉!!!

One day, Beanie sees a swing in front of her. Feeling curious, she sits on it.

But the swing turns out to be a horrible monster. And it is going to swallow Beanie!



雖然醣豆豆救回了一命，
可是她再也不能走了。

當醣豆豆以為已經是絕望的時候，

Beanie is saved, but she can
no longer walk.

Just as Beanie thinks all
hope is lost,

A pair of gentle and warm hands wraps around Beanie. It is Mum and Dad. “You’ve already worked very hard,” they say.

“No matter how you look, we just want you to be happy and healthy, my silly child.”

It is Beanie’s loving family that has been supporting her.

我好想長大，
好想長大。
好想長大。

“I want to grow up,”
Beanie says to herself again and again.

看！我已經長得那麼高！
那麼大！我終於可以成為你們的庇蔭！
我終於可以保護你們！

每晚，醣豆豆做著同一個夢。

Look how tall I am!
I am strong enough to be
your shelter!
To protect you!

Every night, Beanie has the
same dream.

Beanie's Dreamy Diary

我是醣豆豆...　　2007年10月30日　晴
我的世界有着不一樣的顏色。
在某一個角落有着只屬於自己的地方，
雖然患病，但我仍然生活得滿足。

30.10.2007
Sunny

My name is Beanie,
My world has different colours.
Living in a small and private corner
of the world,
I live a happy life, even though
I suffer from MPS.

2010年 10月30日 晴

我從小就與人不同,
我只會維持小朋友的高度,
我只有90cm多高,
衣服也很難找到合身的
所以在生活中遇到很多趣事!

30.10.2010
Sunny

I have been different from the others ever since I was small.
I have remained the height of a little child, I am only about 90 cm tall.
I find it hard to buy clothes that fit .
That's why I have encountered many interesting things in my daily life.

2020年2月3日 陰

那天妹妹突然無聲無息的離開了我們
經常也掛念她，想起她的笑臉，
想起她的聲線，想起她的夢想。

不知道她現在過得怎樣，在天國是否看着我？
希望她過得開心，在天國能夠做到自己
想做的事。

3.2.2020
Cloudy

My sister has left us quietly.
I miss her all the time, her smile,
her voice and her dream.
I wonder how she is doing in heaven.
Is she looking at me at the moment?
I hope she is happy, and can do
whatever she wants in her new home.

2035年3月10日 晴

回想起妹妹有很多夢想，現在妹妹不在，我要為妹妹努力，為妹妹享受生活，我不斷想自己能做什麼，最後我想到了，我想把快樂帶給別人。

10.3.2035
Sunny

I remember my sister had many dreams. Now that she is no longer here, I need to work hard for her and enjoy life for her. I have been thinking what I can do. Now I know: I want to share my happiness with everybody.

2049年 8月10日 晴

雖然我經常要入院做治療，要飲苦藥，也要做拉筋運動，真的很辛苦，有時也很累，但為了我的夢想，我會堅持，我也不怕辛苦。

10.8.2049
Sunny

I frequently need to go to the hospital for treatment, take bitter Chinese medicine and do painful stretching. Life is hard and tiring, but I never give up. To pursue my dream, I will persevere, I am not afraid of anything.

2050年 2月6日 晴

其實我的夢想很簡單，或許只做一個小職員也覺得很開心也很滿足，我會用盡我全力做好它，只要每天能带快樂給別人就夠了。

6.2.2050
Sunny

Actually, my dream is very simple. I would feel happy and satisfied just being a minor staff. I would do my best at the job because I just want to share my happiness with the others every day.

2060年 12月 25日 晴

要是可以退休後去環遊世界，到世界每一個角落去看看，想必退休後的生活一定很多姿多彩，乘飛機也是我的夢想。

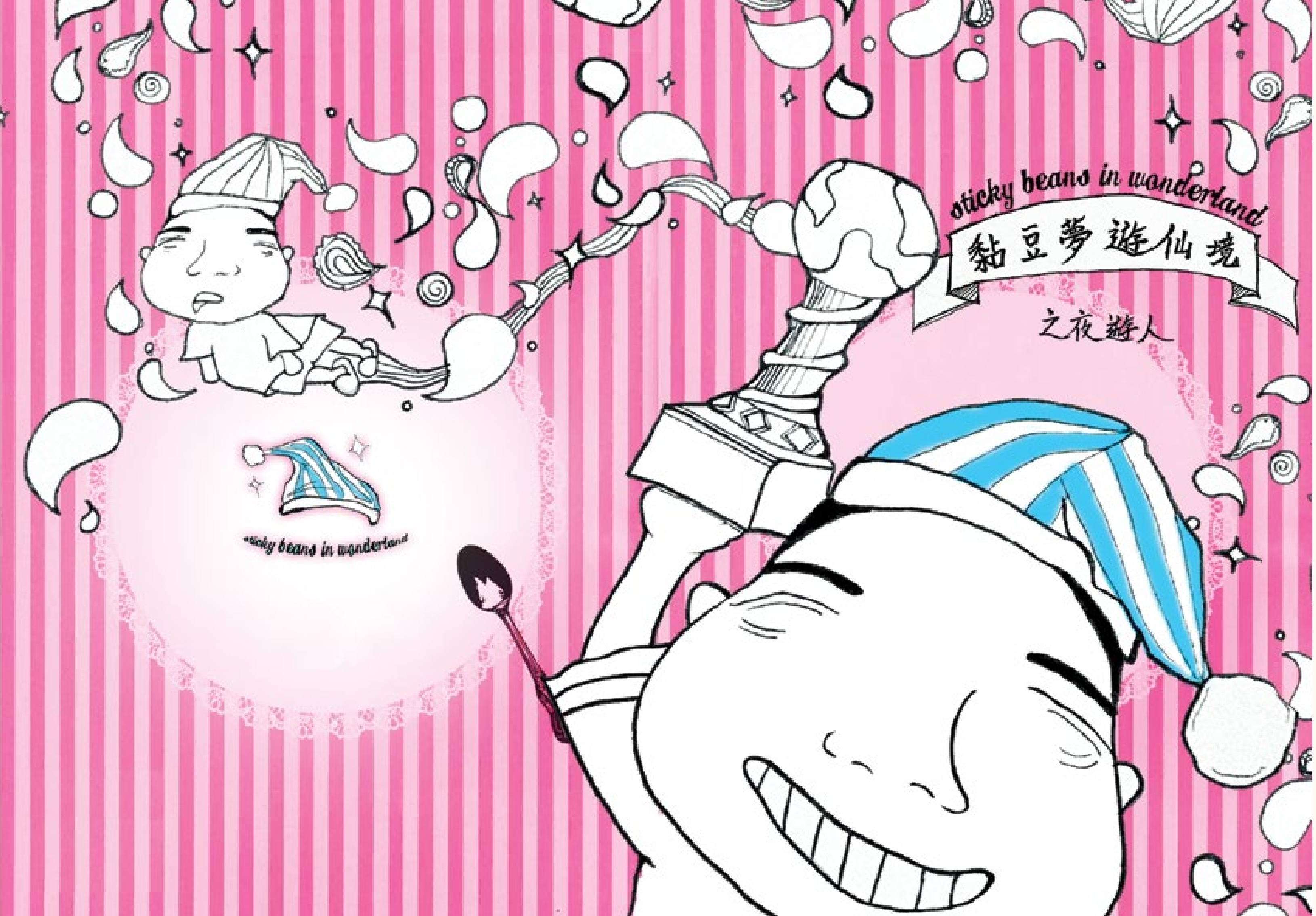
25.12.2060
Sunny

If I could travel around the world after I retire, to see different parts of the world, I think it would be a colourful retirement. I also dream to fly on a plane.

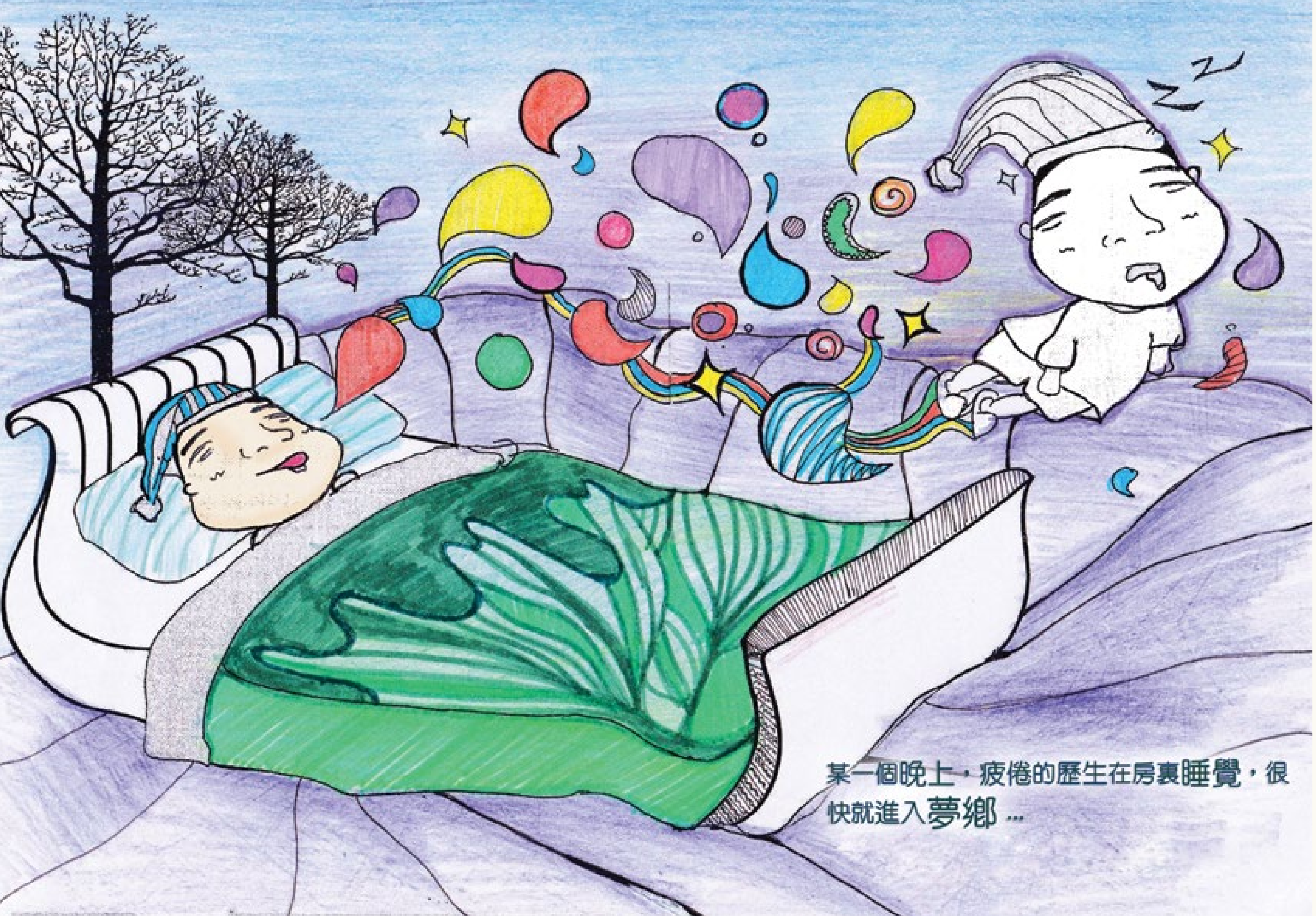
2080年 10月30日 晴
將邁向我的 80大壽了，我還相信我
往後的日子會更精彩，我是最年輕的老人。

30.10.2080
Sunny

My 80th birthday is coming! I think my life is going to be more wonderful. I'm going to be the youngest old woman in the world.



Sticky Beans in Wonderland



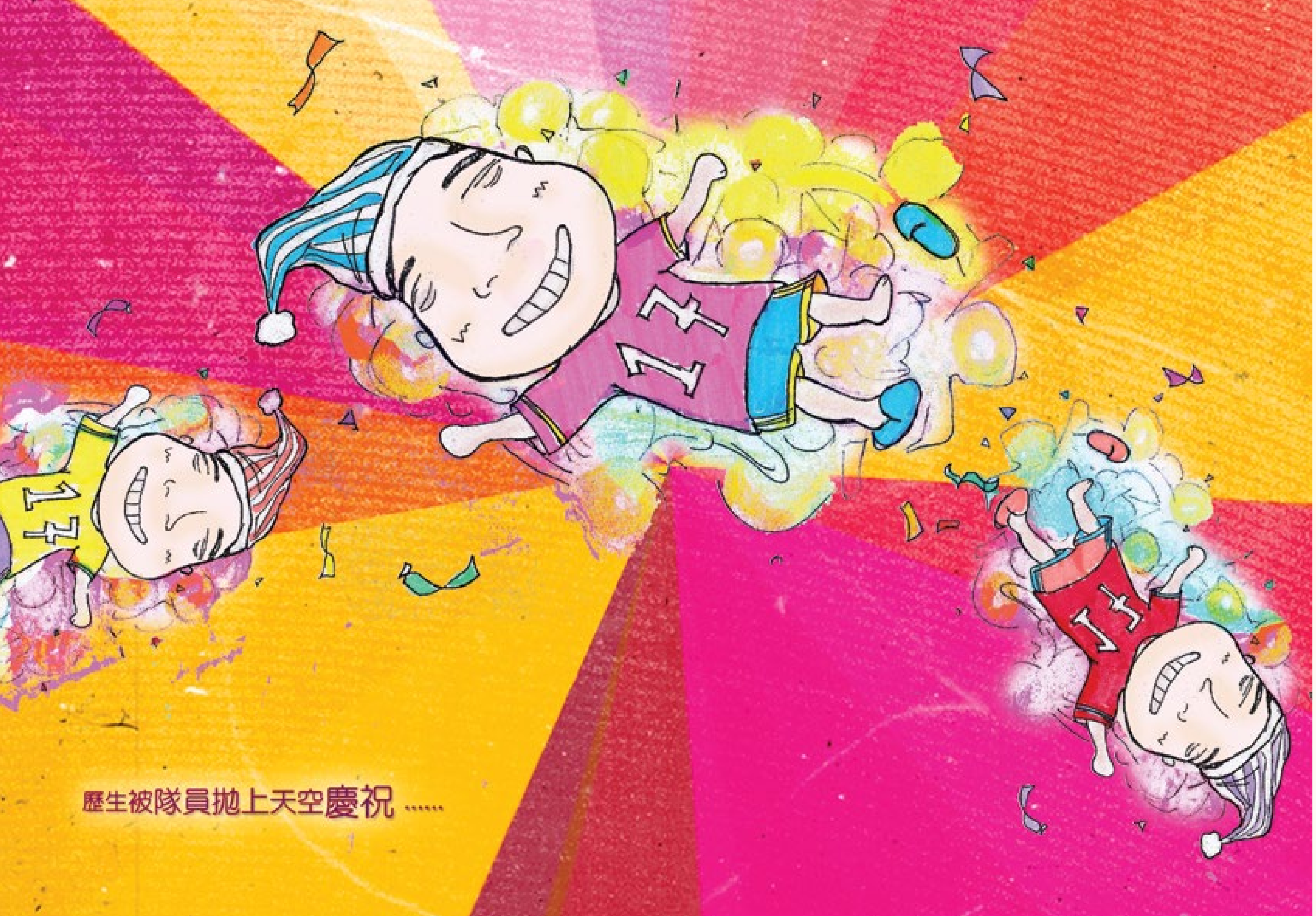
某一個晚上，疲倦的歷生在房裏睡覺，很快就進入夢鄉 ...

One night, tired Eric is lying on his bed. He soon falls asleep...

A big stadium appears in front of him. He can hear people cheering inside, and many football players are waving at him.

歷生的夢想實現了，得到世界盃的他和隊員
一起露出勝利的笑容！

Eric and his teammates have won the World Cup. They wear big smiles across their faces. Eric's dream has come true.



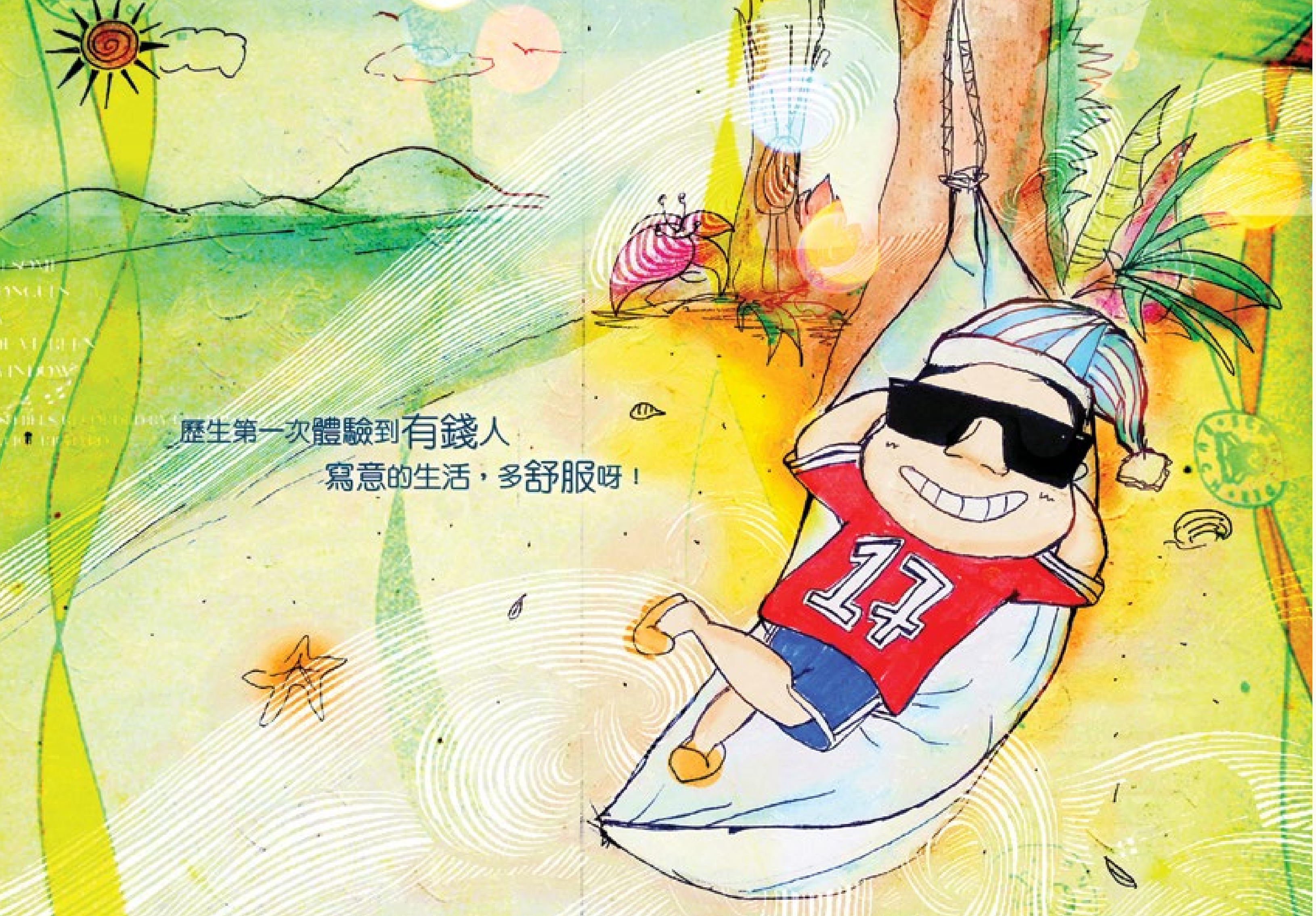
歷生被隊員拋上天空慶祝……

Eric's teammates throw him into the air to celebrate.

As he flies in the sky, he finds
a long ladder.

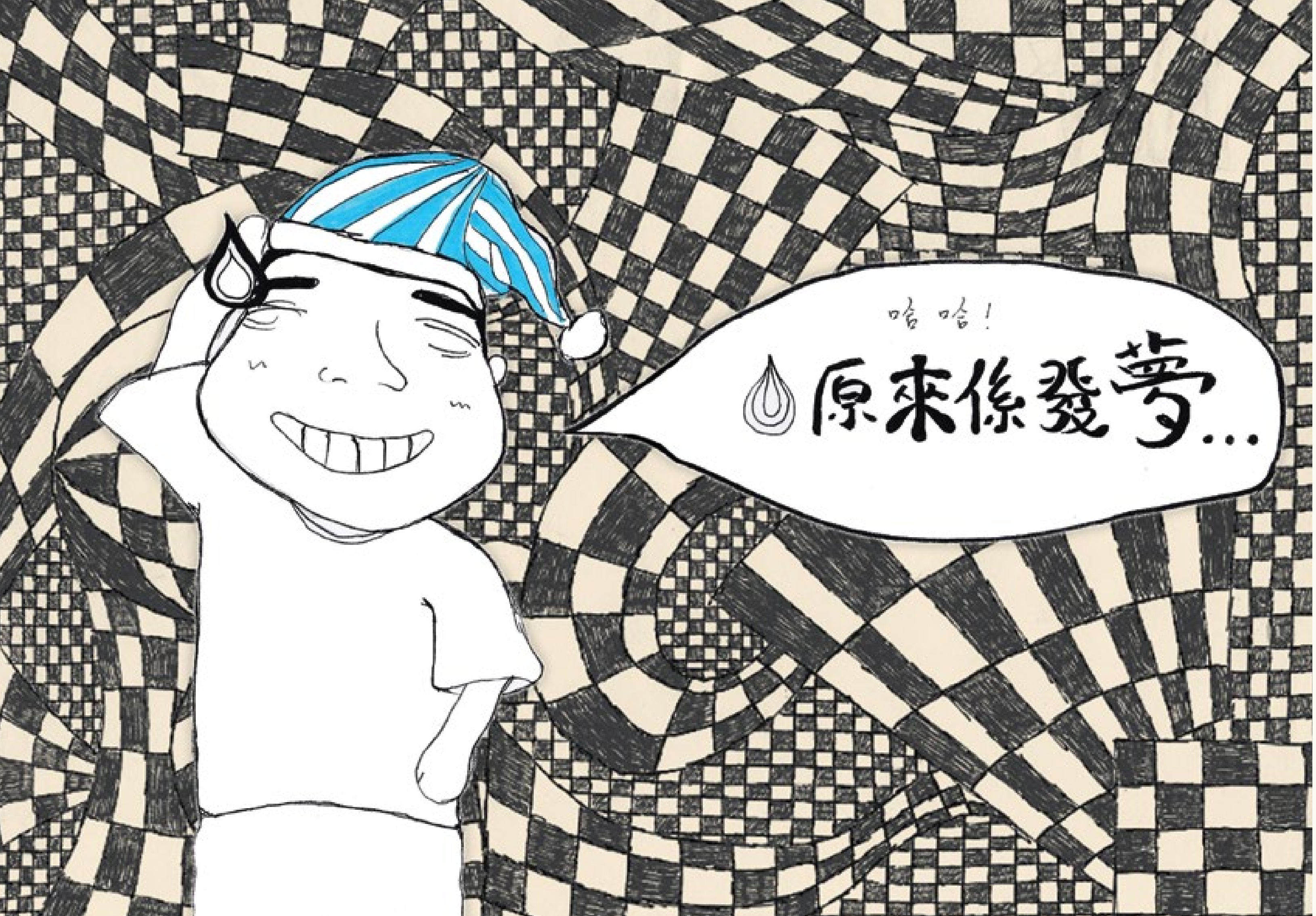
爬上長梯後，歷生發現了
一個美麗的小島！

Climbing to the top of the ladder,
Eric discovers a beautiful islet!



It is Eric's first time enjoying the life of the rich. How relaxing and comfortable!

While the idea of comfort is still lingering in his mind, Eric falls off the bed.



Haha! It is just a dream...

A Joyful Beanie Life

A Joyful Bean Life
Tsang Wai Yin

樂豆人生

我是馬歷生，

小時候的我跟一般小孩沒分別，

但沒想到

我卻和他們大大不同。

A Joyful Beanie Life
I'm Eric Ma. When I was small, I was just like the other kids.

But I never thought we were actually worlds apart.

When I grew up, I discovered that
I was not growing taller with them.

The other kids would grow taller and
taller, but I remained three feet tall.
I guess I must have forgotten to eat
the Grow Up Mushroom.

But I soon realised that it was
a disease that has stopped me
from growing.
I received many people's care and
help in my daily life. But...

I was more eager to do whatever
I wanted by myself.

The city was so big and scary, to a point that I couldn't live a normal life.

Walking, going up stairs all challenged me one after another.

Hiking and playing basketball were things I could only dream about.

The disease deteriorated me gradually. My strength waned, my eyes became covered in ink.

Light was taken away from me, and I had to face a life of endless darkness.

This ink brought darkness upon me. I lost the things I cherished, and I couldn't see the people I loved.

But this darkness also allowed me to feel the warmth of the people around me more vividly.

To those of you who care about
me, even though I can't see you,
I can still feel you.

I have been tortured by the disease
for 20 years, and soon my body
will no longer be able to take it.
But it doesn't matter, I know you
are still with me.

Because of you, I am no longer afraid.

A Wish

從四歲後，我的世界…

Since I was four years old,
my world…

改變了…

has changed…

People are looking at me
this way again.

I am just someone who
can't grow tall, who has
shorter limbs...

體內有過多黏多醣，
一個患有罕有病症的人。

who has too much
mucopolysaccharides
in the body, who has a
rare disease.

My parents love me.

My little sister, my friends who grew up with me, are all much taller than me.

但我不灰心，
每天可以醒過來，
和家人一起度過每個早上，
和妹妹一起上學，

But I am not disheartened.
As every day I can wake up,
spend every morning with my
family and go to school with
my sister.

I'm sorry.

對我來說，
每一刻都非常珍貴。

只是…

要承受藐視的目光還有嘲笑，
果然還是覺得很難受。

Every moment is precious to me.

Just that...

I still feel bad being despised and ridiculed by the others.

He is my best friend in class.
We have grown up together.

Although he doesn't speak
much, he is the only person in
class who would accept me.

Sometimes, my sister and he
would wait with me as my
parents come to take me home.

Even though it is a bit self-willed,
sometimes I wish that
“I want go home by myself.”

Like ordinary people,

I want to walk my own way.

The doctor says that apart from not being able to grow taller, my eyes, ears, teeth, respiratory system and other organs are going to deteriorate gradually.

“I’m so sorry…”

I may even lose my intelligence…

And I…

Might only live till my twenties.

I have only little time,
but there are still a lot of things
that I would like to experience.

Walking isn't easy for me.
But I want to try my best to
keep going...

until the day I collapse.

"I'm sorry..."

It is really, really hard to be an ordinary person.

"You just have to..."

"You just have to stay alive. Nothing else matters."

Did you know that?

Actually, I have many wishes...

希望能活著，

希望能稍微再長高少少，

偶爾也好，
希望能照顧自己、
照顧身邊的人，

To be alive.

To grow a little taller.

To take care of myself and those
around me, even just occasionally.

A Wish
Man Wing Yi

I wish the people around me could be happy.

這個世界能有再多一點的包容和愛。

And my biggest wish, is that
the world could be a bit more
compassionate and loving.

MPS Bean and Dream

It is not only in our dreams that we can help people!

我從一出生已患黏多醣症，
不能長高，更沒法子
照顧自己，總要依靠別人。

所以，我一直有個心願就是不再
依靠別人，而是可以去幫助別人吧！

I have been suffering from
Mucopolysaccharidoses (MPS) since
I was born.

I can't grow tall and I can't take
care of myself, so I always need to
depend on the others.
That's why I always have this wish,
that I would no longer need to
depend on the others, but could
help them instead!

有一天，一片白雲飄浮在天空，
他請求我助他救回公主，還說，
病魔囚禁了她。

我呆呆地說：不可能吧！
連日常生活也要別人幫忙的我，
如何有能力打敗病魔呢？

One day, a floating cloud comes to me and asks me to save the princess, who has been imprisoned by some illness devils.

"That's impossible! Even in my daily life, I need other people's help. How can I defeat the illness devils?"
I say, dully.

白雲說：不用擔心了，我會給你
戰衣和黏多醣疫苗，
讓你能戰勝病魔。

於是，我便答應了他的請求。

“Don’t worry,” the cloud says. “I’ll give you a costume and an MPS vaccine so you can beat the devils.”

So I agree to the cloud’s plea.

當我踏入城堡後，病魔立即
向我展開攻擊，
我使出了絕招–黏多醣疫苗，

疫苗使病魔失去作戰能力，
最終，病魔眼見大勢已去就速速離去了。

As soon as I set foot in the castle, the devils start attacking me. I launch my weapon—the MPS vaccine.

The vaccine incapacitates the devils! And the devils, seeing that they have lost, flee.

我戰勝了病魔
便馬上去救出公主。

她看見我來救她後，由
原來絕望的神情,
頓時，變得充滿了笑容。

After I have defeated the devils,
I set off to rescue the princess.

When she sees me coming to
save her, her glumness turns into
a big smile.

我對公主說：我要離開了！
公主很感激的對我說謝謝。

她還送贈貴重的皇冠給我，
而我也不好意思地收下了這份禮物。

"I have to go now," I say to the princess.
The princess is very grateful, and thanks me repeatedly.

She also offers me her precious crown as a gift, which I accept out of courtesy.

我回到了現實，原來這只是一場夢。

我們不是在夢裡才能幫助人！

When I return to reality, I find that what has happened was only a dream.

It is not only in our dreams that we can help people!

From That Year On

From that year on,
I stopped growing tall.

我每走一小段路，
已經累極了。

所以，
我從沒有試過登山，
這只不過是妹妹想像出來的。

4th March,

Dad and Mum take us hiking.

I always get tired after only a short walk.

So we've never really hiked.

This is just my baby sister's imagination.

這是我家附近的小花園。

這是尖沙咀海旁。

這是九龍公園。

無論看到的影像多朦朧，
我仍能記得。
只怕，
未來看到的都是漆黑一片。

This is a small garden near my home.

This is Tsim Sha Tsui waterfront.

This is Kowloon Park.

I can remember all the images,
no matter how blurred they are.
I am just afraid that all I can see in the
future is darkness.

我不是在玩捉迷藏,

而是

沿地下紅、黃線穿梭於醫院間。

I am not playing hide and seek, I am just following the yellow and red lines on the floor at the hospital.

今天，媽媽叫我起床

說天亮了，
但我仍在黑暗中，

我知道
我再看不到這個世界了。

這一刻我沒有害怕，只有失望。

Today, mum wakes me up,

she says the sun has risen,

but I am still in the dark.

I know I can never see the
world again.

I am not scared, only
disappointed.

於是，我走到九龍公園，
奏起〈小星星〉。

我仍能
記得孔雀的顏色，
記得家人的樣子，

而他們的樣子
永遠都是那麼年青！

So I go to Kowloon Park,

and I start playing the song “Twinkle
Twinkle Little Stars”.

I can still remember the colours of the
peacock, the faces of my family,
faces that are always so young!

幸好，

一直有這麼一陣風，
吹著我，

叫我不要放棄。

Luckily, there is always a breeze
urging me not to give up.

慢慢來，

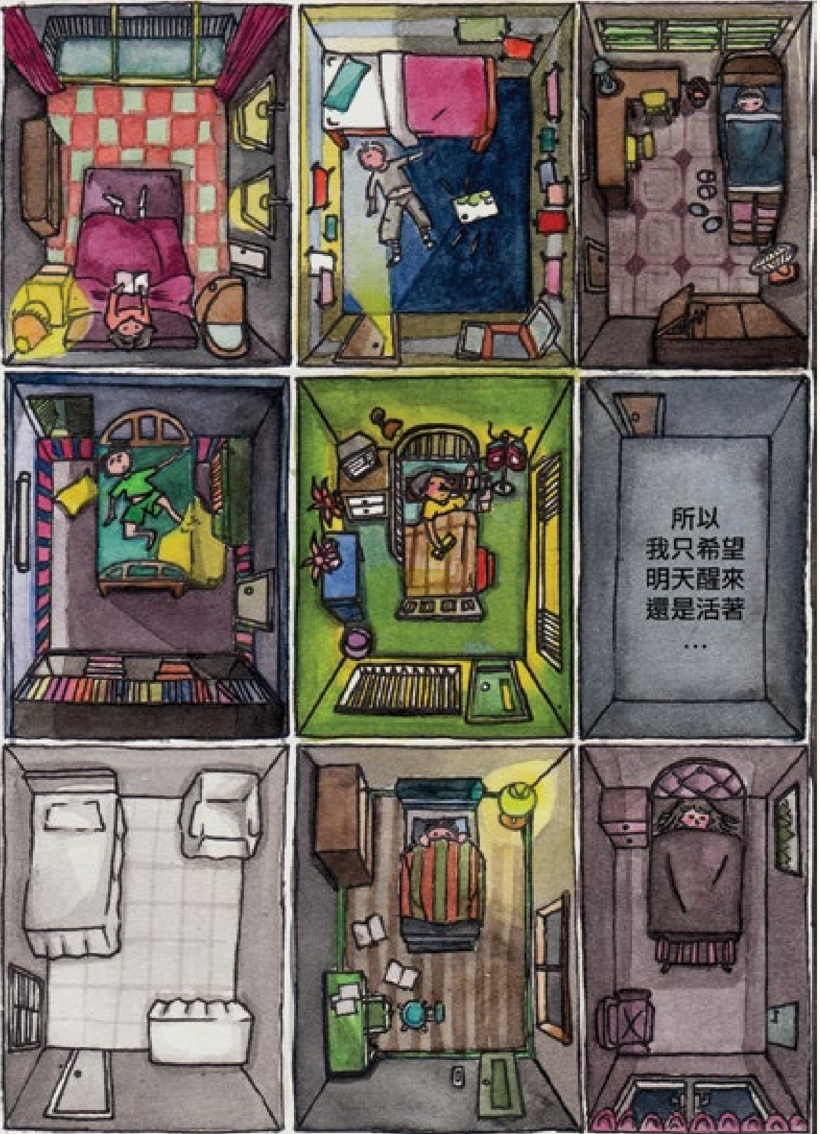
不要急。

無論未來的生活是怎樣，
我都一定會努力。

Take your time,

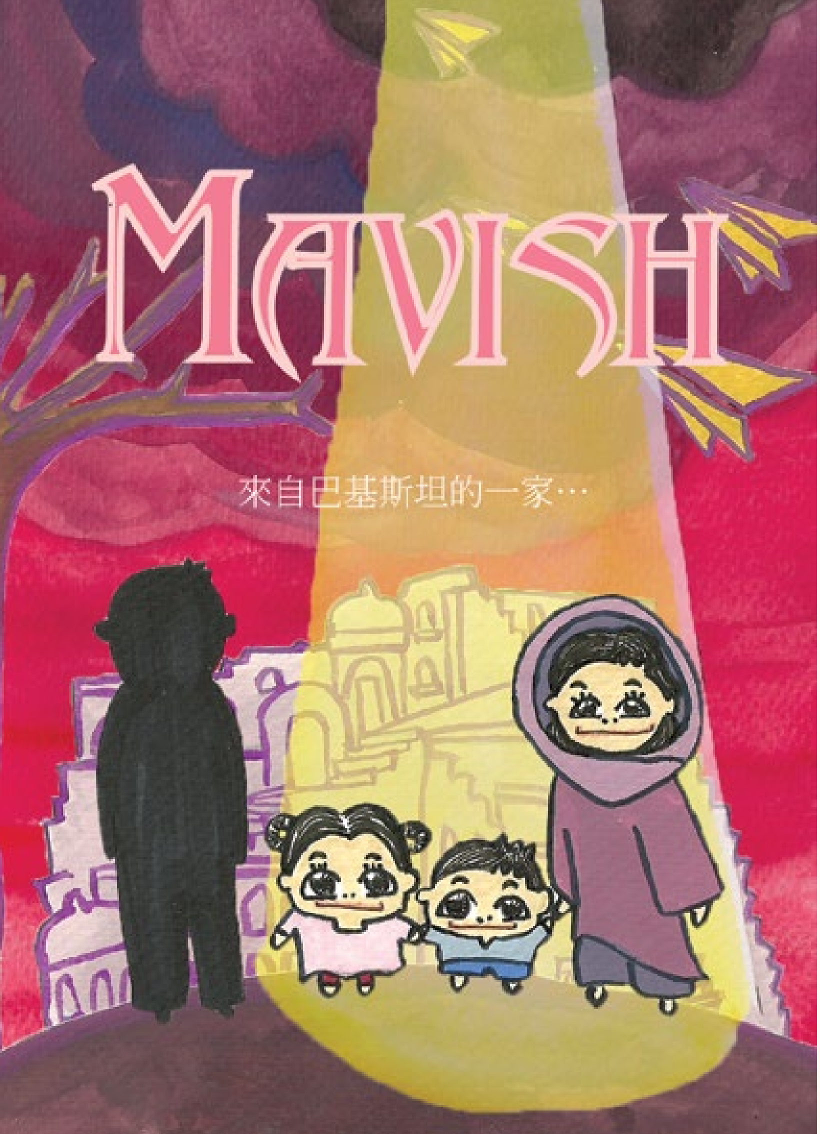
There is no need to rush.

No matter how hard life is,
I will keep on fighting for it.



I only hope that I am still alive when
I wake up tomorrow...

From That Year On
Leung Yee Ting



A Pakistani Family

Mavish和Hamza約五歲和四歲時，
膝蓋突然異常疼痛，
把腳跟放在地上也不行，
唯有四處打探病因。

確診第一型黏多醣症後，
被爸爸拋棄了...

One day when Mavish and Hamza were five and four, they felt an intense pain in their knees. They were not even able to put their heels on the ground. So they asked around about the cause of the disease.

When they were diagnosed with MPS1, their father abandoned them...

香港的天氣、
醫療設施和教育系統都適合Mavish一家，
但對單親家庭來說，
生活也不容易。

透過社工，
認識有相關經歷的家庭，
也更認識黏多醣症。

Hong Kong's weather, medical facilities and education system suit Mavish's family. But as a single-parent family, life is not easy for them.

Through social workers, they meet other families that share their experience and learn more about MPS.

Mavish有視力問題，
Hamza則有呼吸問題，也不能長時間站立和走動，
在互聯網上，媽媽看到黏多醣症是有藥可醫的。

為了Mavish和Hamza能接受酵素替代治療，
改為有更大機會成功安排用藥的醫院，
學校也在附近，非常方便。

Mavish has eyesight problems; Hamza has respiratory problems, he can't stand or walk for extended periods. Their mother has found on the internet that MPS is curable.

In order for Mavish and Hamza to receive Enzyme Replacement Therapy, they switch to a hospital that has a higher chance for granting medication. The school is also nearby so it is very convenient.

從第一次基因測試中，
得知媽媽和Hamza的基因病理十分相似，
卻沒有發病。

媽媽為了身體健康，開始練習瑜伽，
她會幫助Hamza練習，提高身體靈活性，
而Mavish則能自己洗澡和做功課。

A genetic testing has found that
mother's genetic pathology is very
similar to Hamza's, only that her
disease never developed.

Mother started practicing Yoga
for health.
She helps Hamza to practice Yoga
too, to keep his body nimble.
And Mavish is trained to bath herself
and do homework by herself.

二零零九年十一月中旬，
Hamza答應參加巴基斯坦親戚的婚宴，
但在當地家中走路時摔倒，
與世長辭…

誰能相信這個事實呢？

In mid-November 2009, Hamza attends a relative's wedding in Pakistan. But he falls at home, and passes away.

Who would believe it?

政府批准用藥！
因此，
Mavish的健康情況比以前
穩定了很多，
長高了！
面容也變得更正常了！

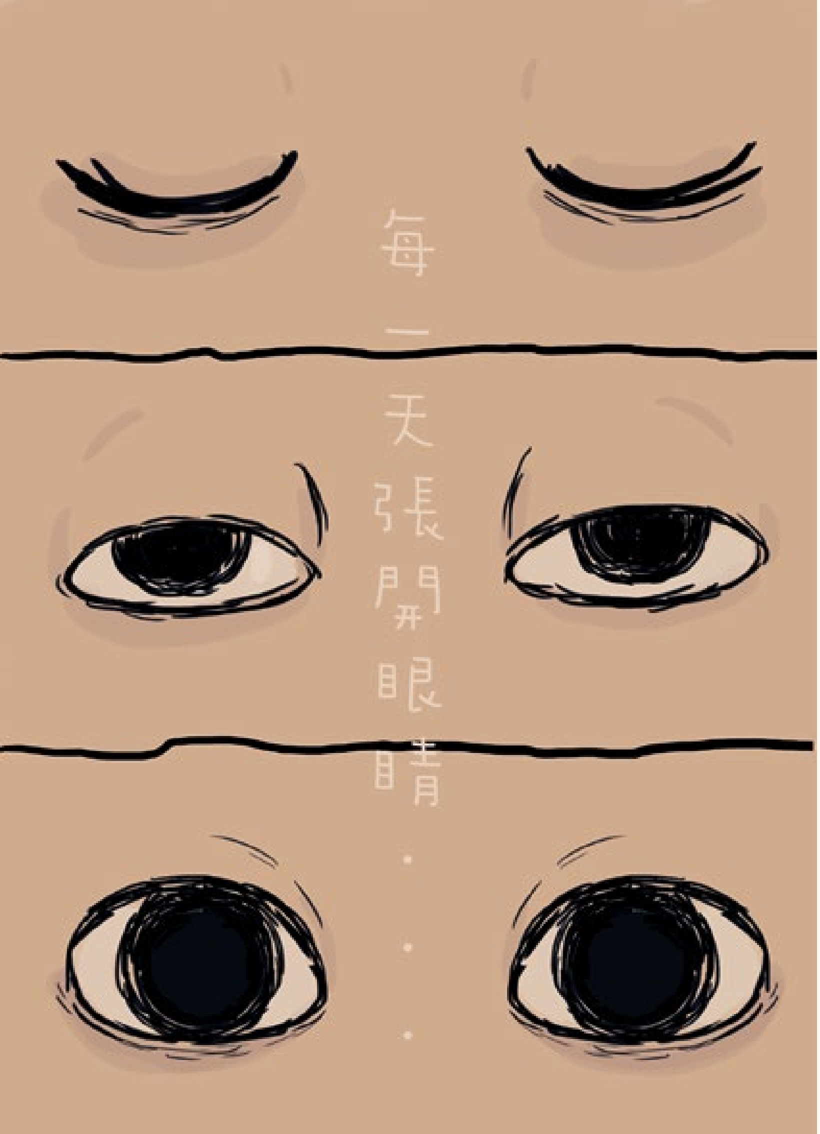
Mavish和媽媽相信，
Hamza只是先到天堂，熟悉好環境，
將來會在那兒笑著迎接大家！

The government has approved Mavish's medication! Her health has stabilised as a result. She has grown taller and her appearance has become normal too!

Mavish and mother believe that Hamza is going to heaven first to familiarise with the environment He will meet them there in the future.

小時侯，Mavish希望成為醫生，
但醫生實在太繁忙，
黏多醣症病人則需要多些私人時間，
現在，Mavish希望成為教師了！

When Mavish was small, she wanted to be a doctor But doctors are too busy and MPS patients need more private time. Now, Mavish wishes to be a teacher



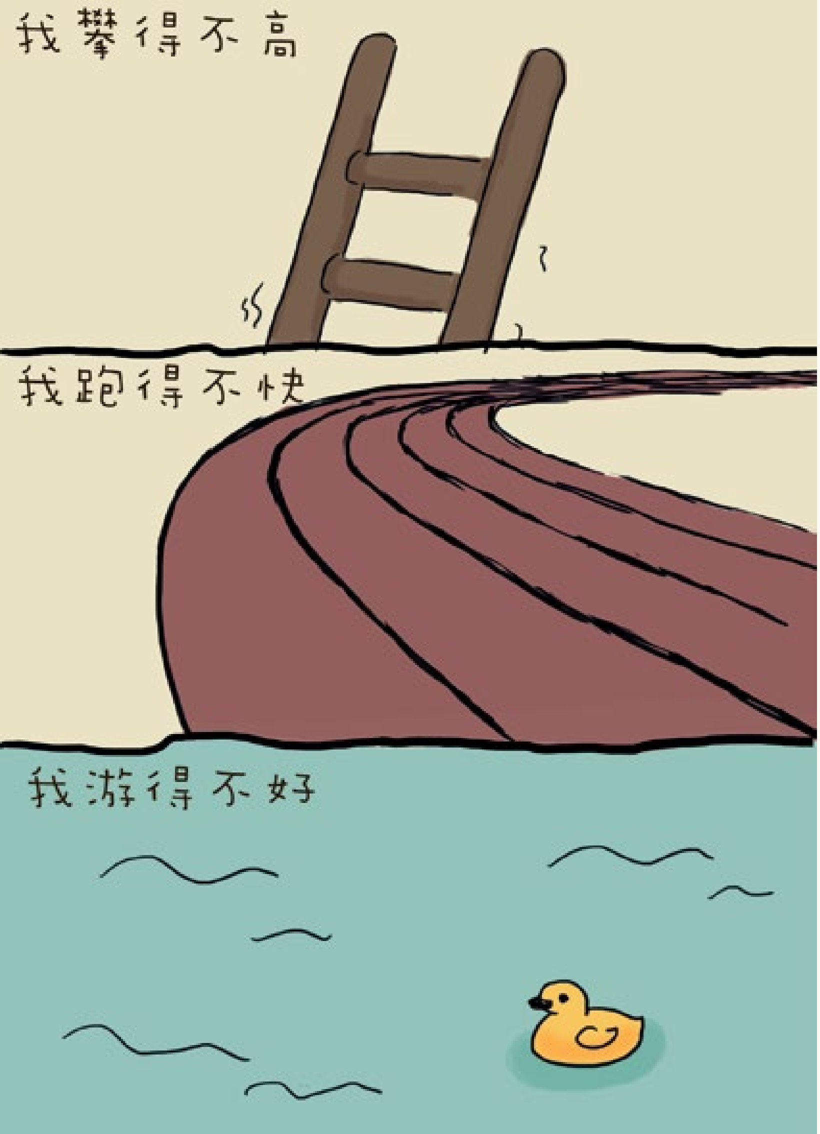
But...

Every day when I open my eyes

I look at my tiny hands and feet.

They have not grown any bigger.

What have also not changed are that



I am still unable to climb high,

I am still unable to run fast,

I am still unable to swim well.

但是...

But...

我擁有世界上最偉大的愛，

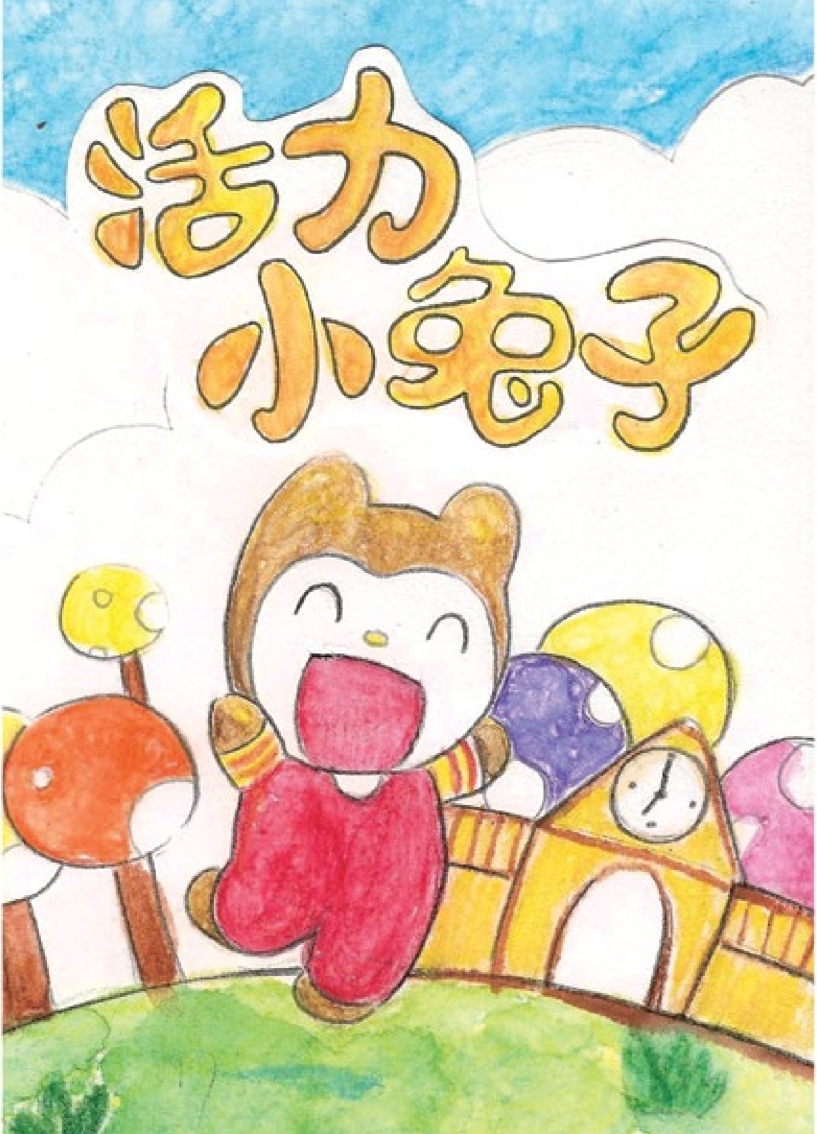
I have the greatest love in the world.

My mother’s care.

My father’s encouragement.

My brother’s company.

Isn’t love all around me?



Energetic Bunny


小小很喜歡上學，每天總是最早回到學校的學生。

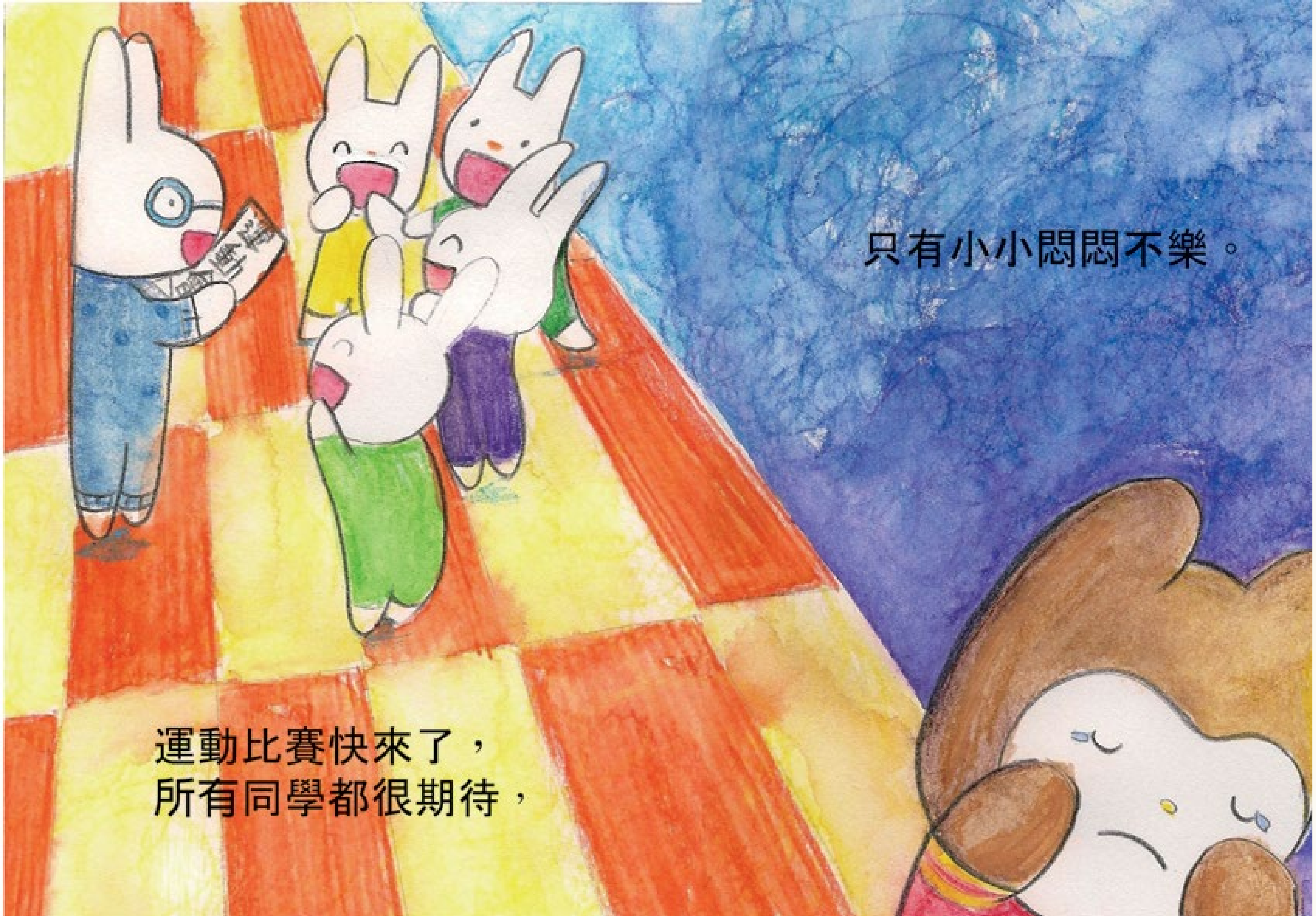
Tiny likes going to school.
He is the student who arrives at
school the earliest.

小小最喜歡上體育課，
目標是成為一名運動
員。

老師和同學都稱讚
小小有運動天份。

Tiny likes PE class the most.
He wants to become an athlete.

Teachers and classmates say Tiny
is talented.



運動比賽快來了，
所有同學都很期待，

只有小小悶悶不樂。

Sports Day is coming soon.
All the students are looking
forward to it.

Only Tiny feels unhappy.

幾年以來
手短腳短

又沒長高

令小小非常自卑，
晚上偷偷哭起來。

His arms and legs have remained
short for years.
He has not grown any taller.
Tiny feels inferior.

He would cry secretly at night.

甚至以生病為借口，好幾天都不上學。

He would even pretend to be sick so he can skip school for a few days.

小小的朋友都好擔心，
所以決定放學一起去探
望小小。

Tiny’s friends are worried about him, and decide to visit him after school.

小小很感動，知道自己不應該逃避，更不想要好朋友難過。

Tiny is touched. He knows he should not hide, and he should not upset his good friends.

在大家的鼓勵下，
小小鼓起勇氣，和
朋友一起上學了。

At his friends' encouragement, Tiny determines to go back to school with them.

運動比賽終於來到了，

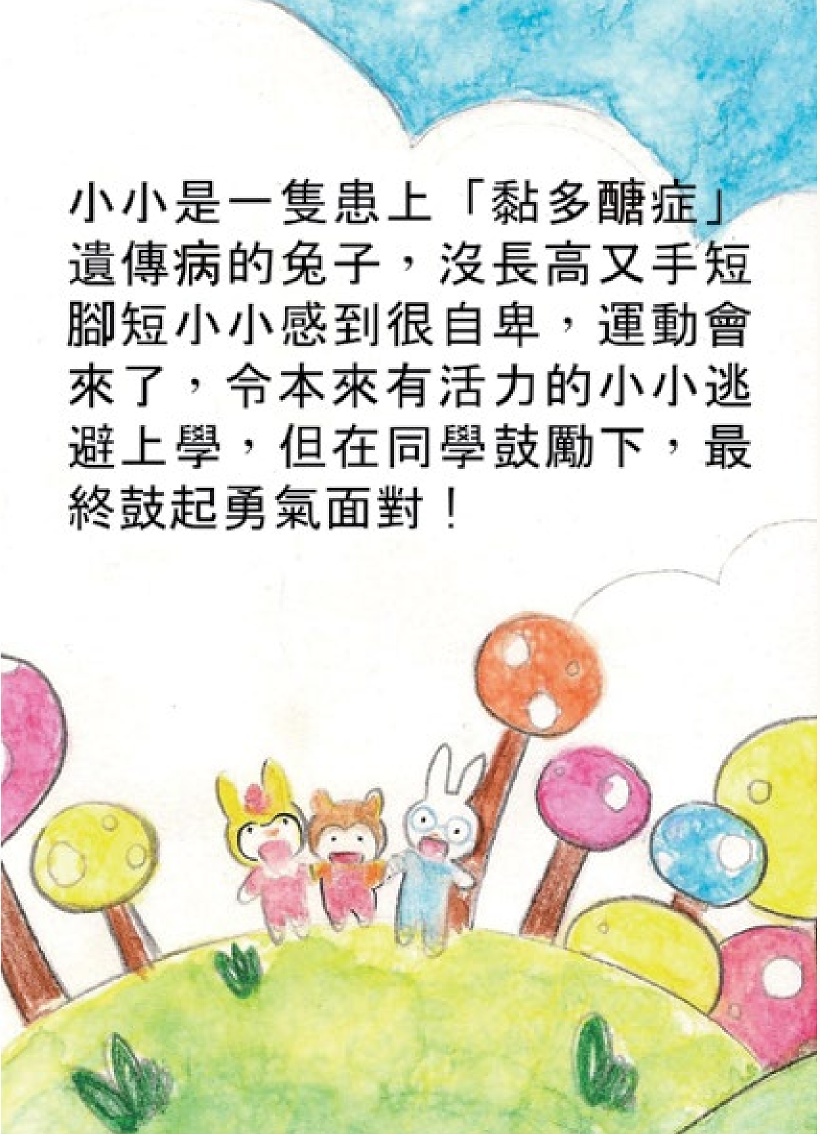
同學們都熱烈地為小小打氣，令小小充滿自信。

Sports Day has finally come.

Tiny’s schoolmates all cheer for him, giving him confidence.

小小最後不負眾
望，還成功衝刺
第一名呢！

At last, Tiny does not disappoint and wins the race!



小小是一隻患上「黏多醣症」遺傳病的兔子，沒長高又手短腳短小小感到很自卑，運動會來了，令本來有活力的小小逃避上學，但在同學鼓勵下，最終鼓起勇氣面對！

Tiny is a bunny that suffers from a rare genetic disease called MPS. He cannot grow tall, and his limbs are short. He feels inferior because of that. As Sports Day comes again, the once-lively Tiny decides to skip school. But his schoolmates keep supporting him, and Tiny finally decides to face life with courage.

Annie, Johnny and the Magical Crayon

今天，
丹丹的父母送給她一份特別的禮物。
從這刻開始，
小鳥有了「德德」這個名字。

她們總是形影不離。
這天，丹丹告訴了德德
神奇蠟筆的秘密：
「它能將畫出來的東西都變成真啊！」

Today, Annie receives a special gift from her parents. A bird, which she calls Johnny.

They are always together.
This day, Annie tells Johnny the secret of the magical crayon:
“It can turn what it draws into reality!”

弱小的翅膀令德德未能自由地飛翔。
黏多醣症令丹丹不會長高；
她們都發現彼此有一個很相似的地方。
逐漸，

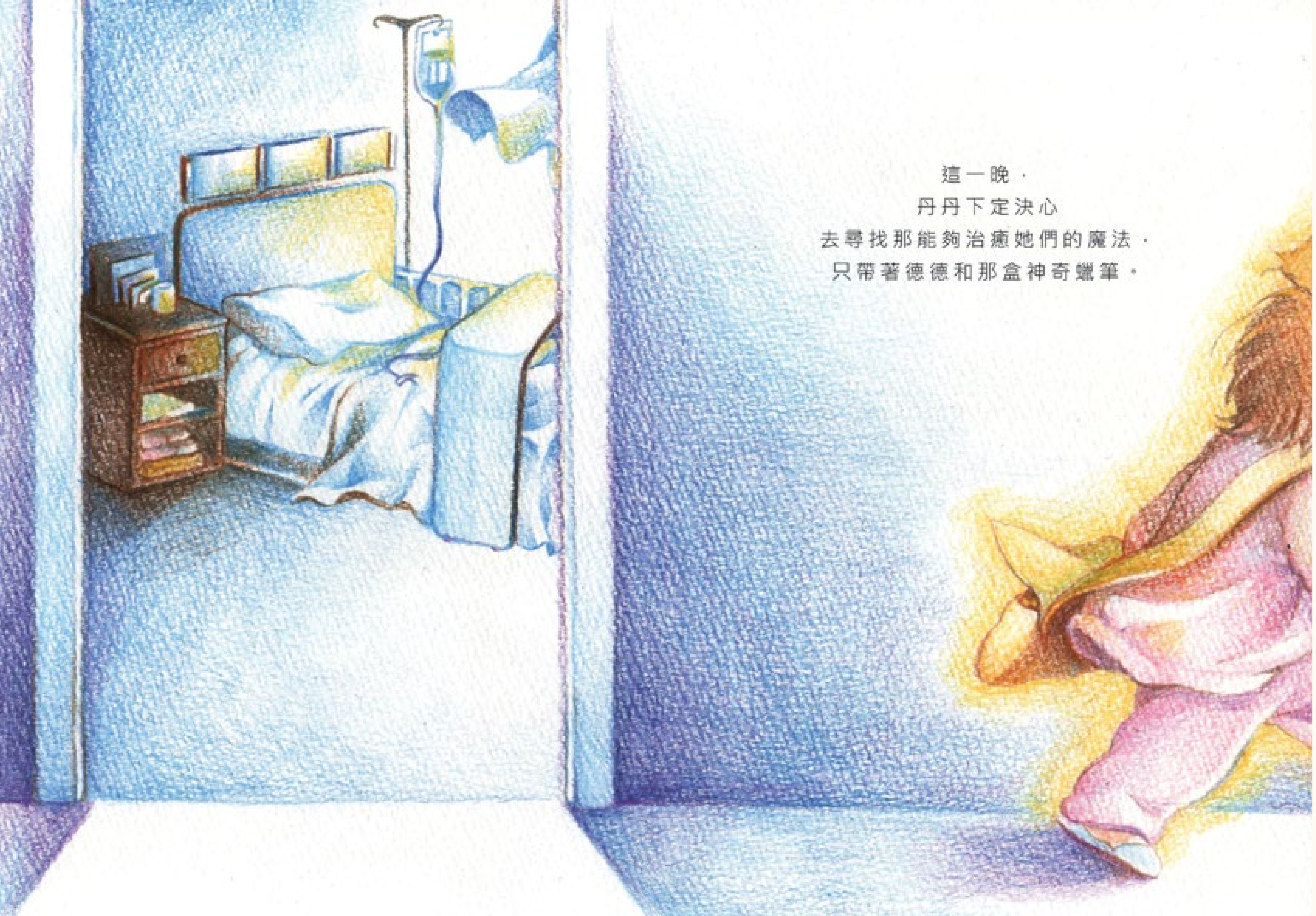
不同的治療，
偶爾讓丹丹面上露出了痛苦的表情，
偶爾讓丹丹像被下了魔咒般沉睡，
但德德卻從來沒有看到她流過一滴眼淚。

Weak wings have kept Johnny on the ground. MPS has kept Annie from growing. The two find that they are similar.

Because of the various treatments, Annie sometimes has a painful look on her face. Sometimes Annie sleeps like she was cursed. But Johnny has never seen Annie cry.

在精神較好的日子，
她們會一起看書；一起說故事；
一起分享彼此的願望。
丹丹：「我希望將來成為畫家…」

On better days, they would read together, tell stories together, and talk about their wishes. Annie says, “I want to be an artist in the future.”



這一晚，
丹丹下定決心
去尋找那能夠治癒她們的魔法。
只帶著德德和那盒神奇蠟筆。

Tonight, Annie decides to seek the magic that can cure her and Johnny. She only brings Johnny and that box of magical crayons.

月亮和星星的光很柔和，
路邊的野花很美，
所有的景物是如此的新奇。

The moon and stars are soft.
The flowers along the road are
beautiful. Everything is new to them.

第一次走這麼遠的路
丹丹感覺很疲累，
她用神奇蠟筆畫了一個小帳篷，
還有豐富的美食，
與德德在星空下享受著屬於她們的時間
但她們並不知道，

醫院中的護士正慌張地大叫，
一連串的騷動延續了好幾小時。

It is the first time that they have walked so far. Annie feels tired. She uses the magical crayon to draw a tent and a feast. And they enjoy their time under the starry sky.

What they did not know is that the nurse in the hospital is shrieking in panic. The commotion lasts for several hours.

一個發光的小帳篷為父母引路，
他們很快找到了丹丹，
就在離醫院不遠的海邊。
短短的黑夜冒險就這樣結束了。

丹丹對德德說：「你去追尋自己的夢想吧！
我亦會為實現願望而努力，不會輕言放棄！」

A beaming tent shows Annie's parents the way. In no time they find Annie at the seaside near the hospital. And their night adventure ends.

Annie says to Johnny, "Go after your dream! I will also fight for my dream and never give up!"

丹丹用了僅餘的蠟筆，
為德德畫了一雙又強壯又美麗的彩色翅膀。

德德拍動雙翅：
「吱吱吱…」
和丹丹道別，然後愈飛愈高了。

With what is left of the crayon, Annie draws a pair of strong, beautiful and colourful wings for Johnny.

Johnny flaps his wings and chirps to say goodbye.
Then he flies higher and higher.

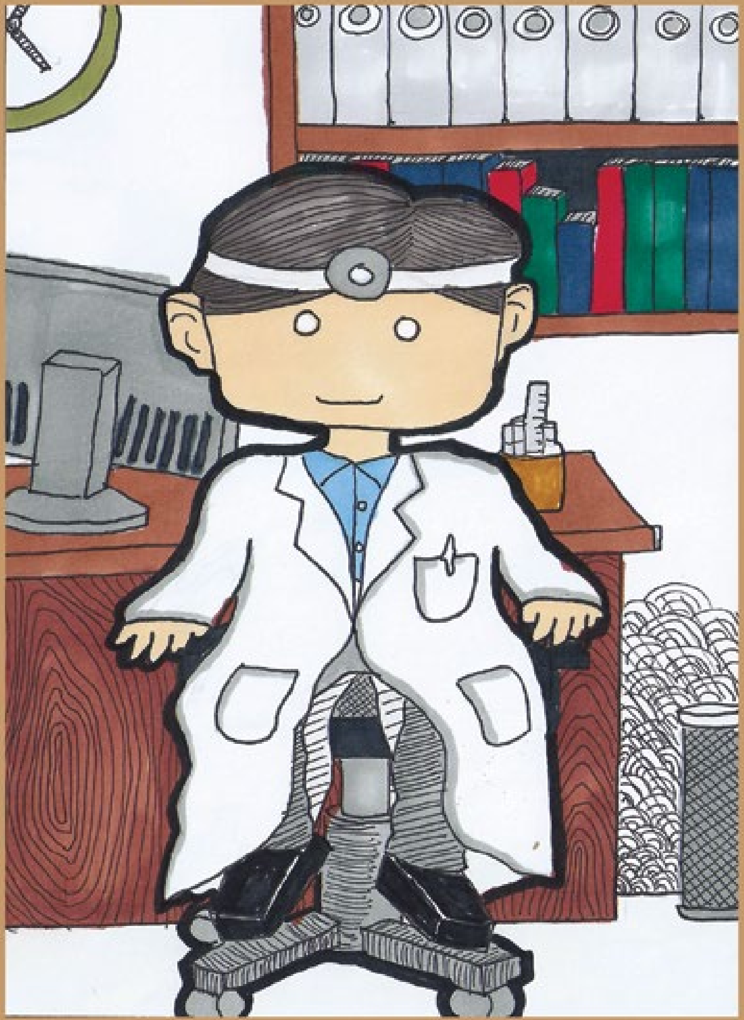
My Position

My Position
Chan Ho San

我一直在尋找屬於自己的位置。

I have always been looking for
my position.

這個位置可能是醫生。



但是我的眼睛不太好，不能替病人打針。

This position may be a doctor.

But my eyesight is bad so I cannot give injections.

這個位置可能是律師。

但是我的身高不夠高，大家都看不到我。

This position may be a lawyer.

But I am not tall enough and no one can see me.

My Position

Chan Ho San

這個位置可能是理髮師。

但是我的手不夠靈活，不能替客人剪髮。

This position may be a barber.

But my hands are not nimble enough to cut hair.

這個位置可能是隧道收費員。

但是我的手不夠長，收不到錢。

This position may be a tollbooth cashier.

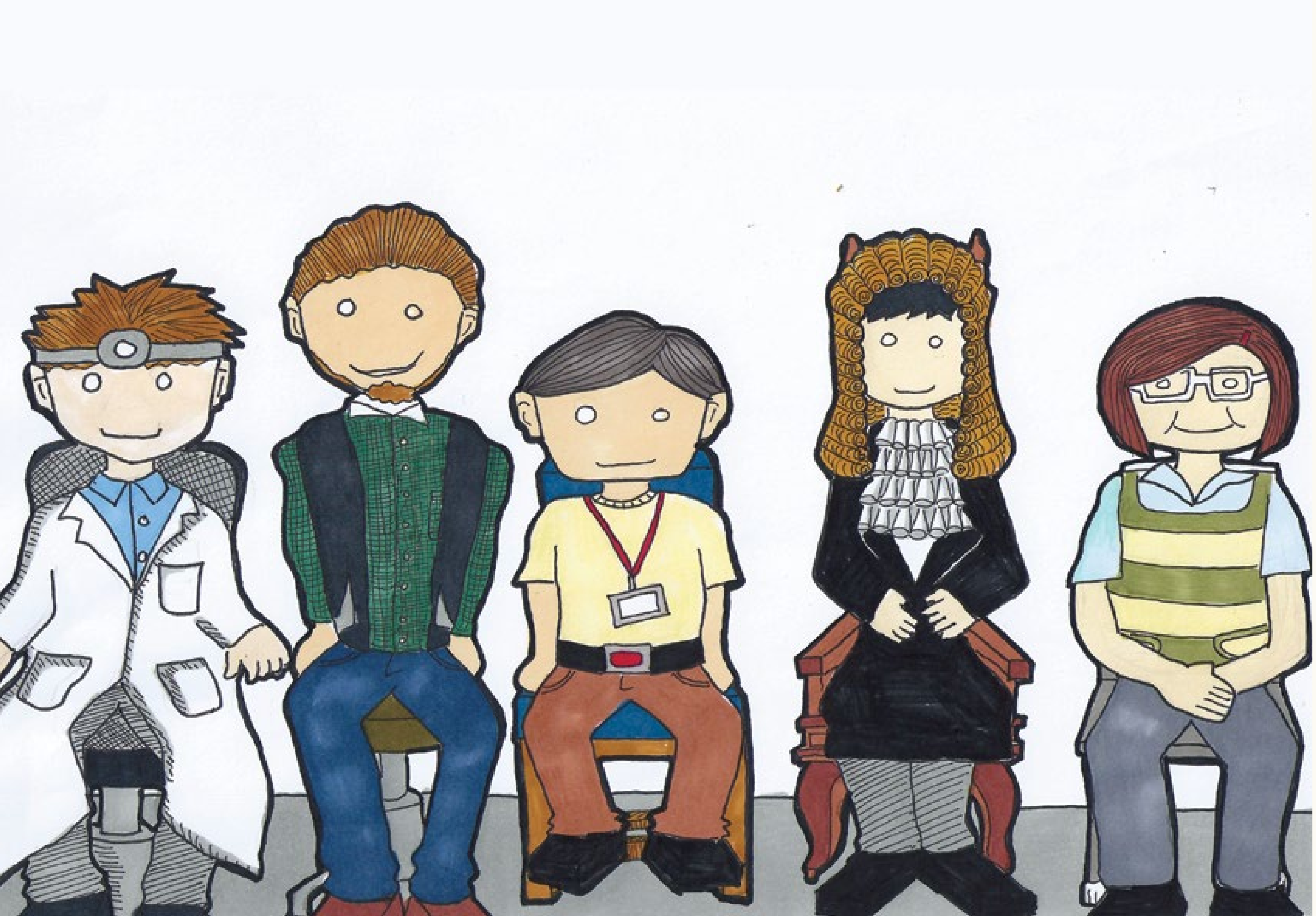
But my arms are not long enough to collect the toll.

我終於也找到自己的位置，原來我的位置是社工。

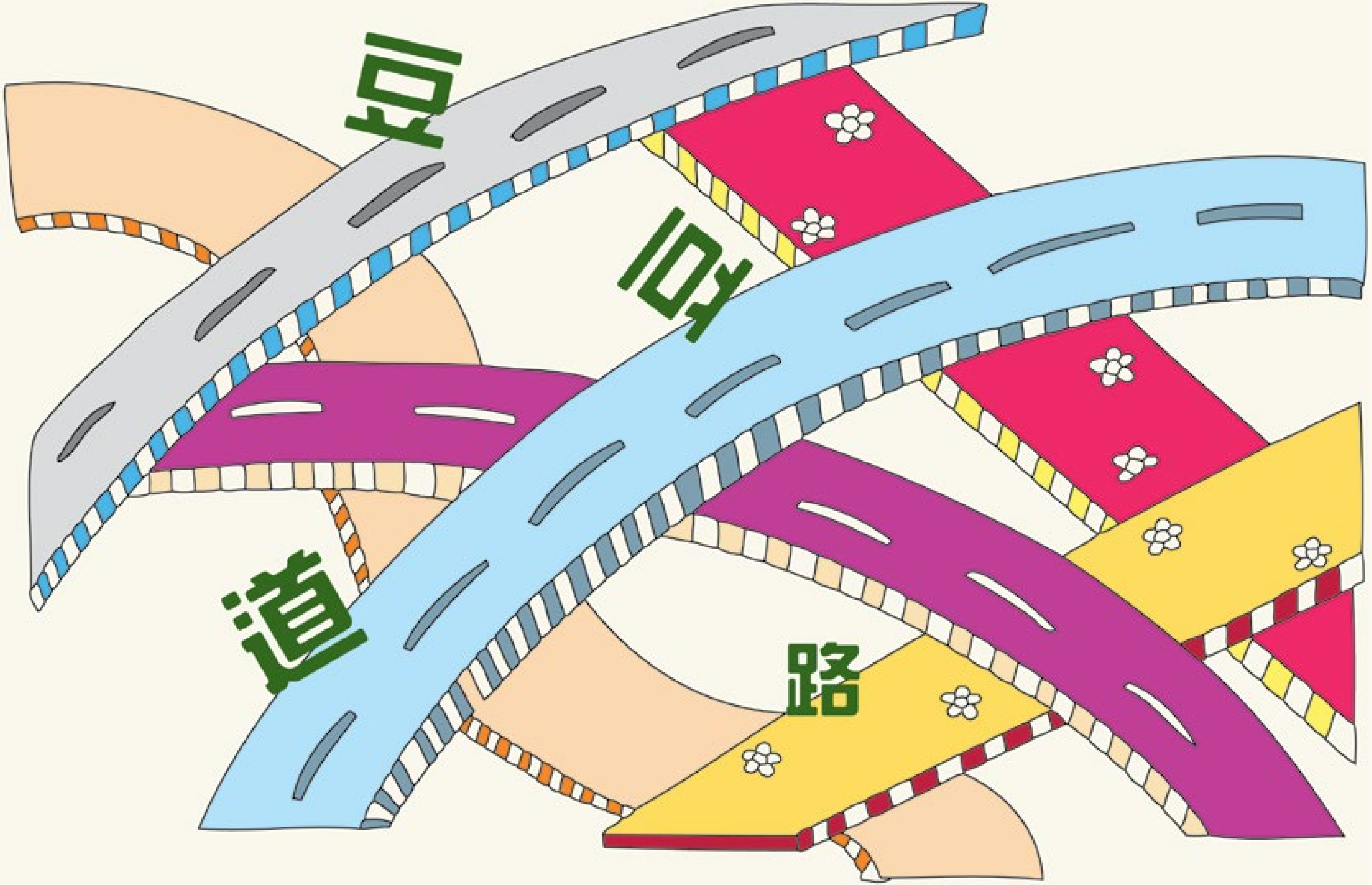
因為我的經歷能為大家打起精神。

I finally find my position, and it is a social worker.

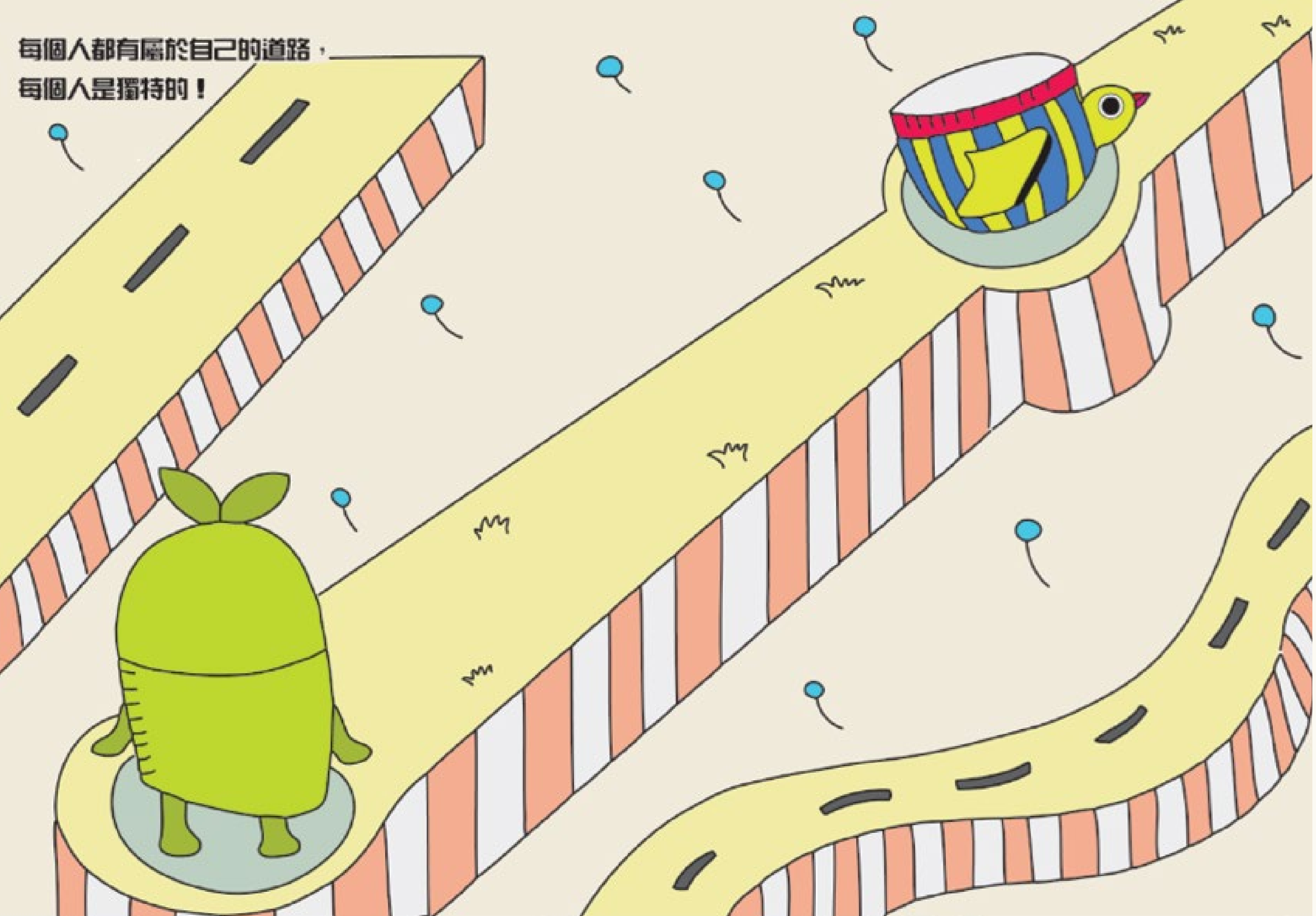
My experience can cheer people up.



My Position
Chan Ho San



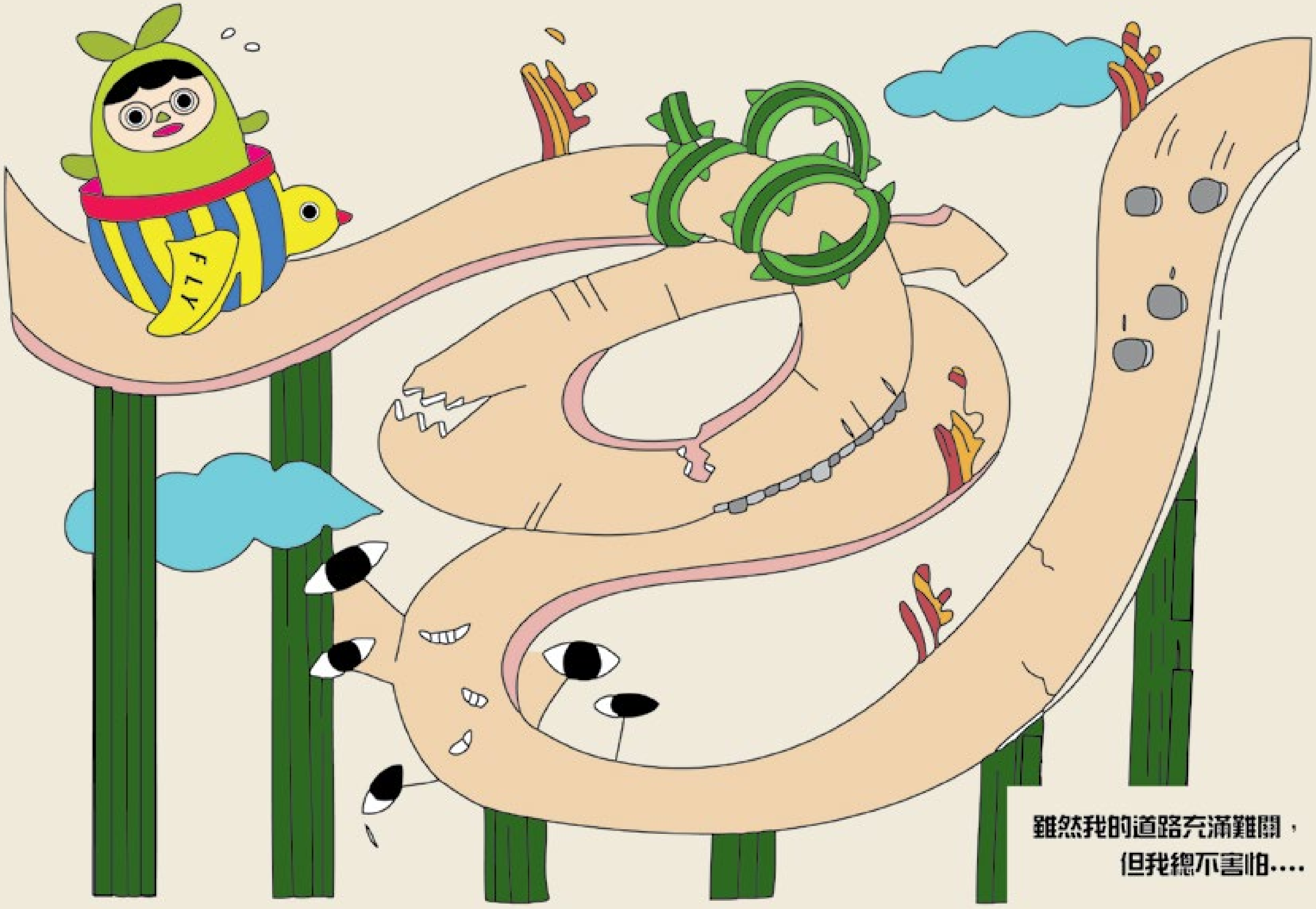
Beanie's Path



每個人都有屬於自己的道路，
每個人是獨特的！

Everyone has his/her own path.

Everyone is special!



Although my path is full of challenges,
I am never afraid.

Beanie's Path
Wong Ka Kit

Thank you, my friends, for teaching me that we do not need to care how others look at us.

I am grateful to my mother for being at my side, fighting the disease and tackling every surgery.

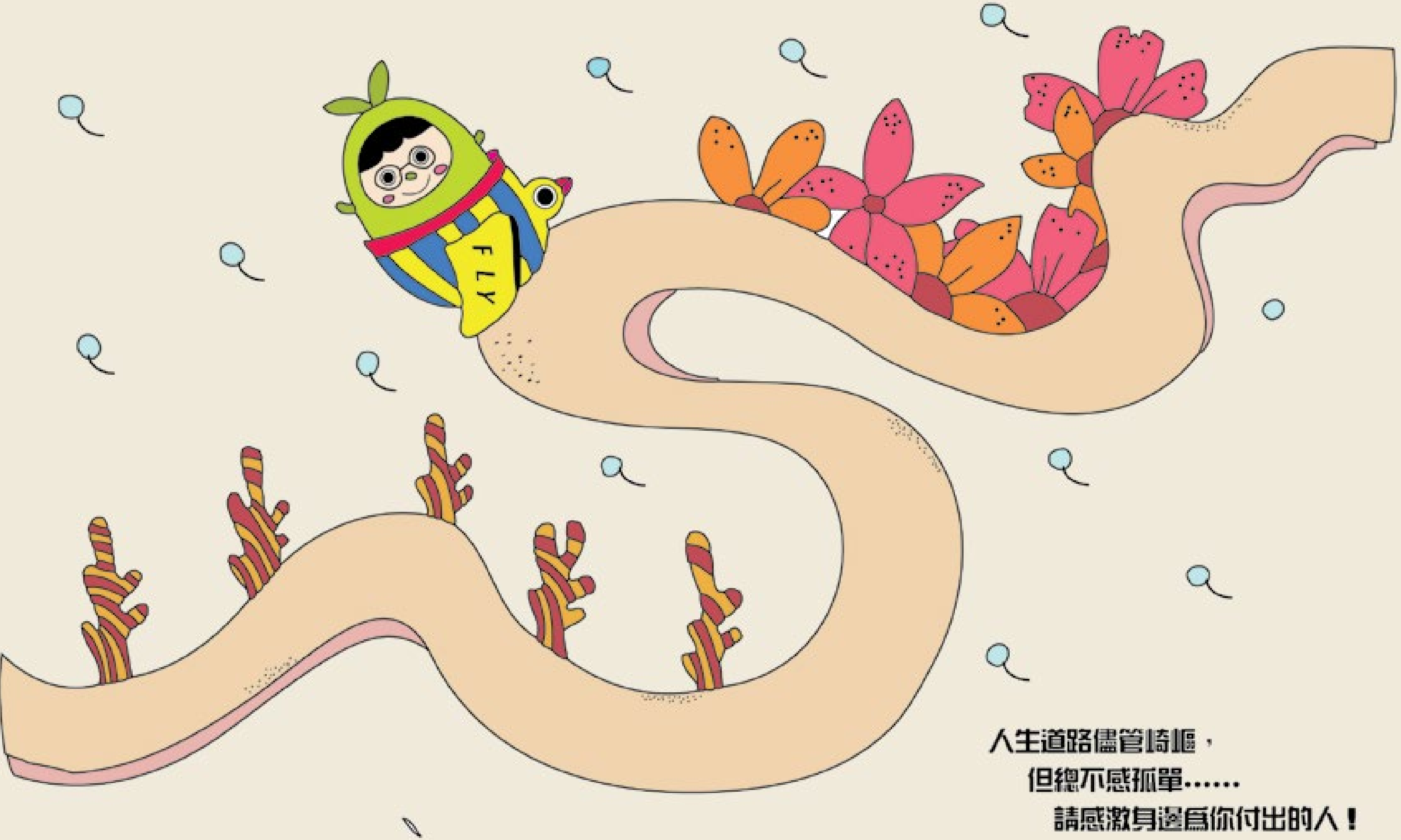
Beanie's Path
Wong Ka Kit

謝謝我的兩位弟弟，
讓我在人生路上
有快樂的光陰！

Thank you, my two younger brothers,
for cheering me up.

感激一家之柱，
看守著及照顧
　我的日常生活，
讓我有快樂的家！

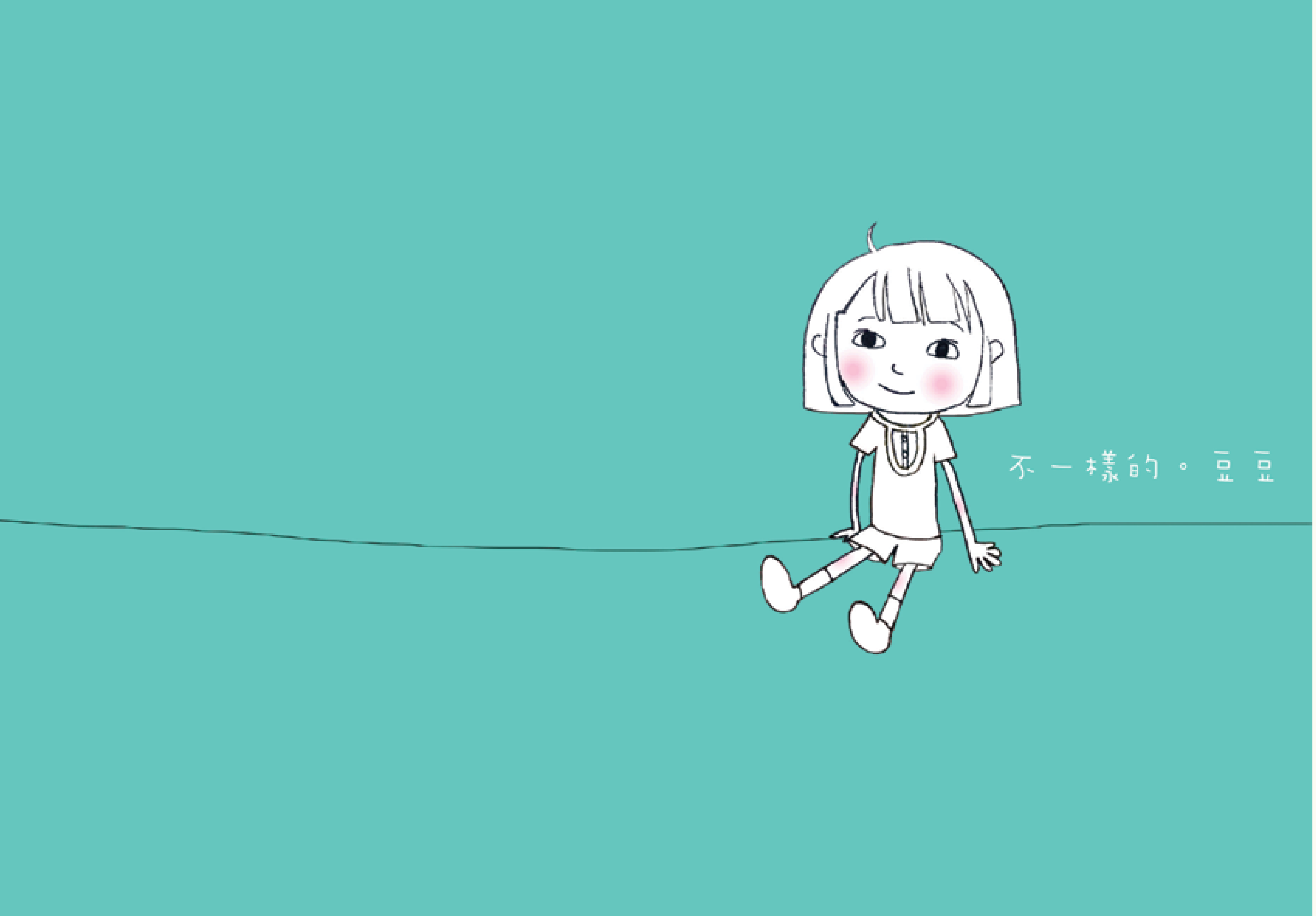
I am grateful to my father for looking after me every day and giving me a happy family.



人生道路儘管崎嶇，
但總不感孤單……
請感激身邊爲你付出的人！

Life's journey can be rugged but you will never be alone.

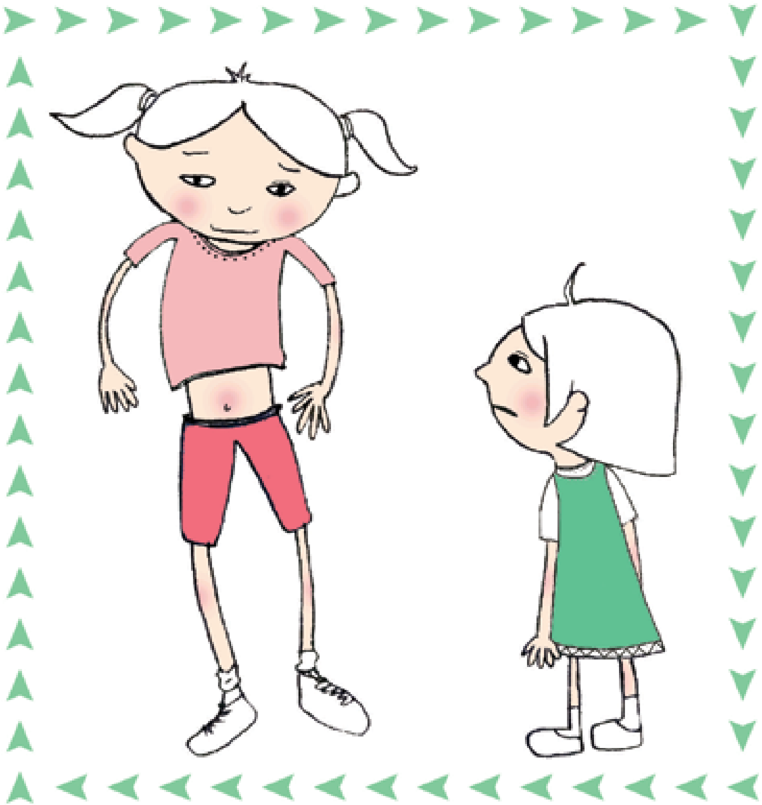
Please be grateful to the people who support you.



A Different Bean

豆豆是個黏多醣症的小孩，出生時並無異樣，但隨著黏多醣日漸堆積，會逐漸出現各種症狀；身材矮小長不高、頭顱變大、關節變形僵硬、手臂粗短彎曲、爪狀手、短下肢........等等多種問題。

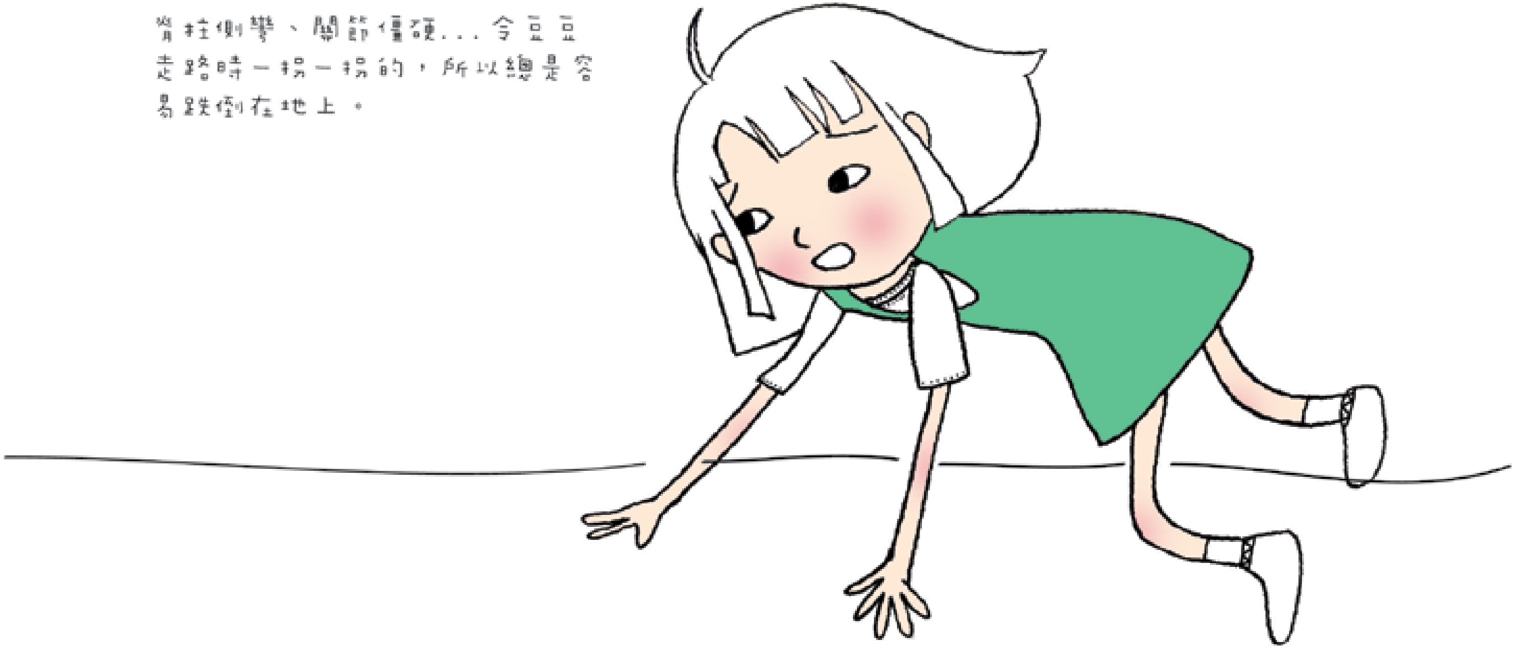
Beanie is a child with MPS. She seemed normal when she was born. But as MPS accumulated, different symptoms gradually appeared: Short stature, bigger skull, deformed joints, stubby and curved arms, clawed hands and short lower limbs.



豆豆身材一直矮小長不高；生長也比正常兒童顯著減慢。

Beanie doesn't grow tall and she grows significantly slower than normal children.

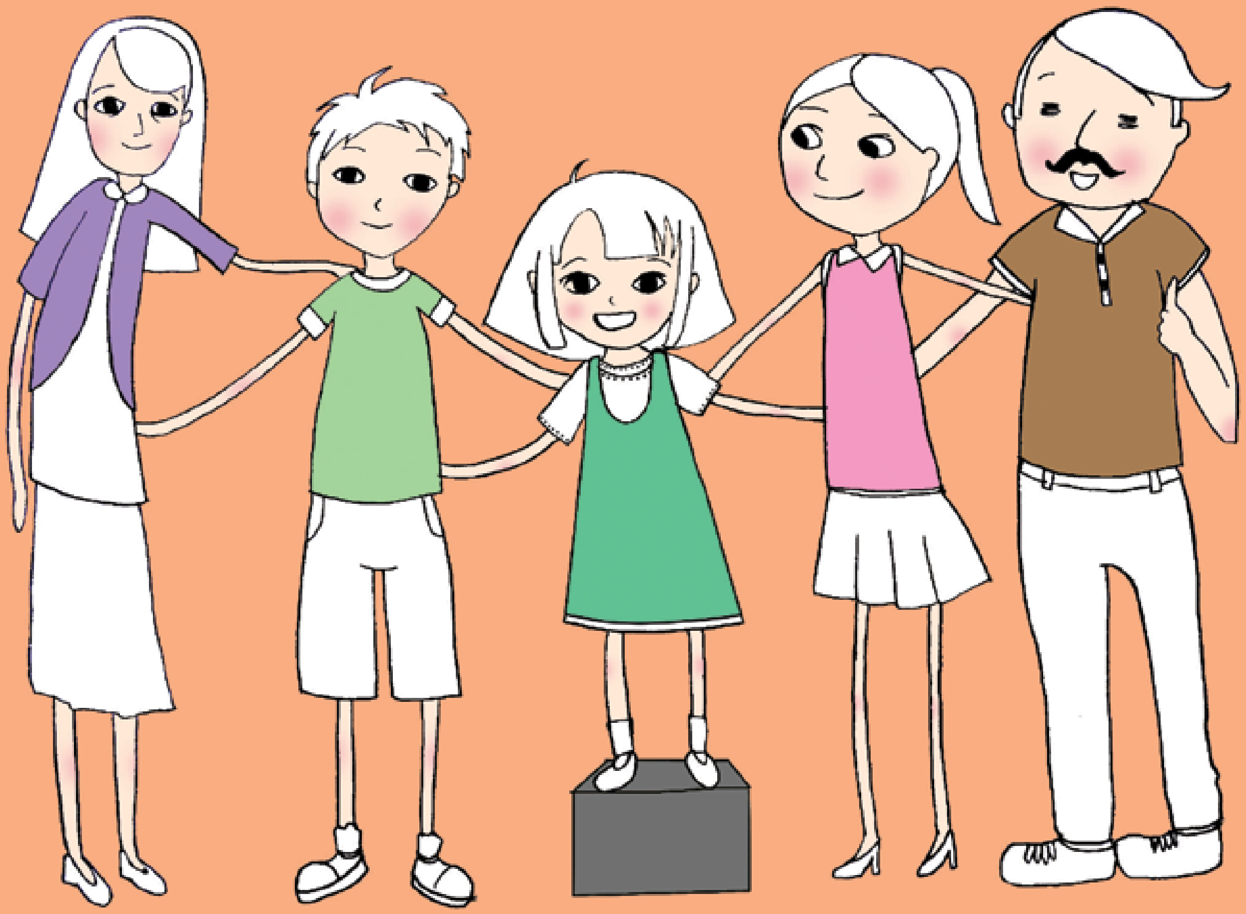
脊柱側彎、關節僵硬...令豆豆走路時一拐一拐的，所以總是容易跌倒在地上。



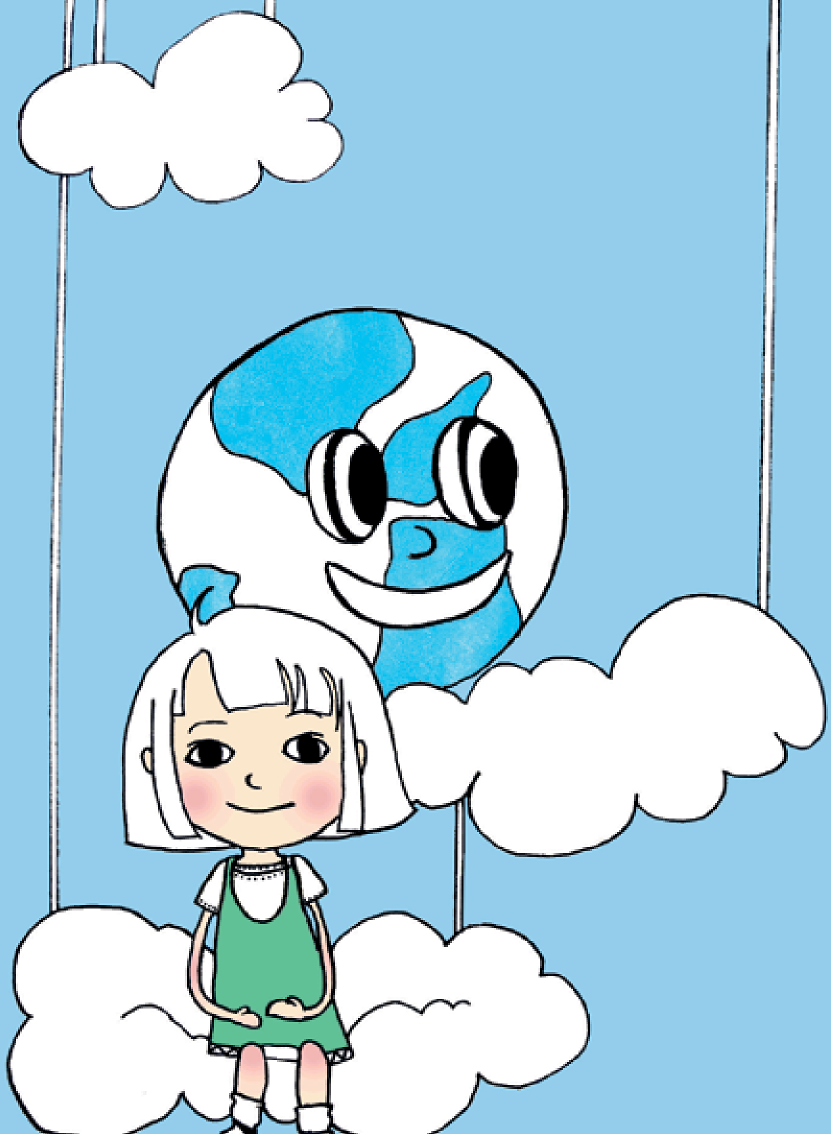
Bent spine, stiff joints... Beanie always staggers when she walks and she falls easily.

People always look at her curiously
on the streets.

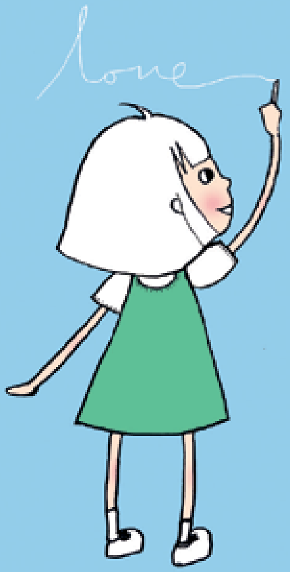
但是豆豆更多的是支持她的人，還有是家人的關心和照顧。



But there are more people who support Beanie, and her family cares about her.



豆豆的世界擁有着不一樣的快樂，所以她從沒有因此而放棄自己。而她所選擇的，是繼續以開朗、積極的心態生活。



In Beanie’s world, there is a different kind of happiness, that’s why she has never given up on herself

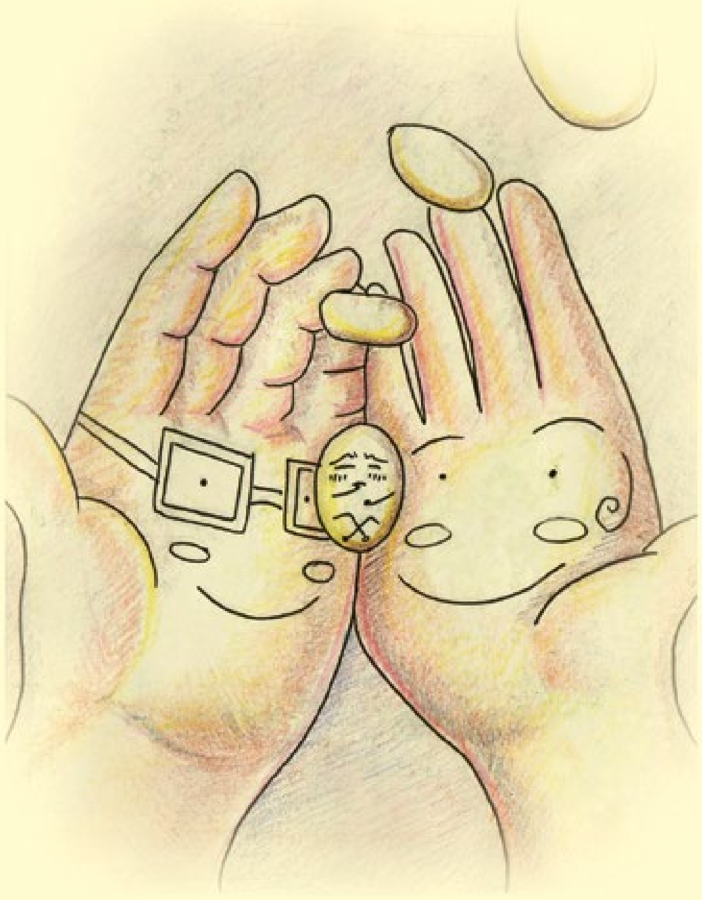
And Beanie chooses to live happily and positively.

Who Understands The Beanie Heart—

A Story About a Happy Bean

從前有顆住在天堂的開心果……

Once upon a time there was a Happy Bean living in heaven.



有一天,有顆開心果從天而降落在一對夫婦的手上,他們把開心果當作上天的禮物。

夫婦二人對開心果悉心照顧,每天都為開心果灌溉,但開心果沒有長高。

One day, Happy Bean falls from the sky, and lands on the palms of a man and his wife. They consider Happy Bean a gift from heaven.

The couple takes great care of Happy Bean. Watering him every day. But Happy Bean never grows.

他的高度引起了其他人奇異的目光與排擠
但開心果依然臉帶笑容。

這引起了上帝的好奇,上帝決定給予開心果進行考驗....

His height has attracted others' strange looks and rejection. But Happy Bean keeps a smiling face.

God becomes curious, and decides to give Happy Bean a test.

上帝把他的手腳變得腫脹,令他變得行動不便!*

把他的身體變的脆弱,容易受傷。

每次都不能與朋友們玩耍。

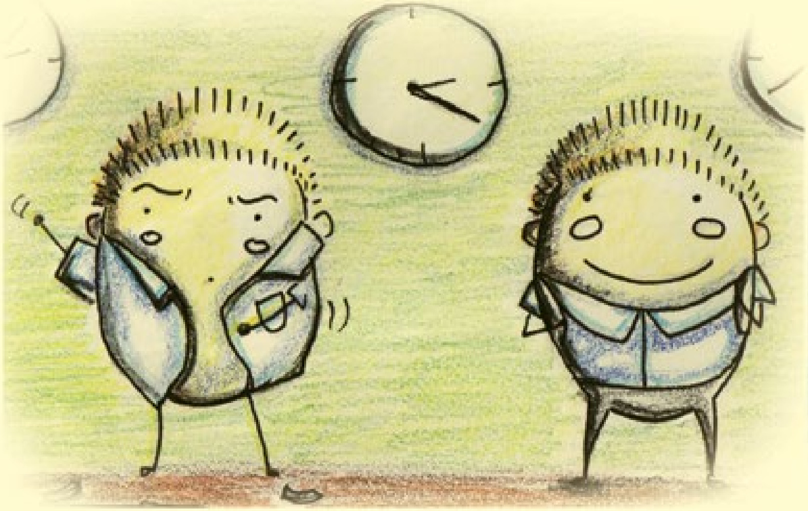
把他的呼吸變得困難,使他每走一步都變得辛苦易累。

God makes Happy Bean's limbs swollen, so that it is hard for him to move.

He makes his body weak and prone to injury.

Happy Bean can never play with friends.

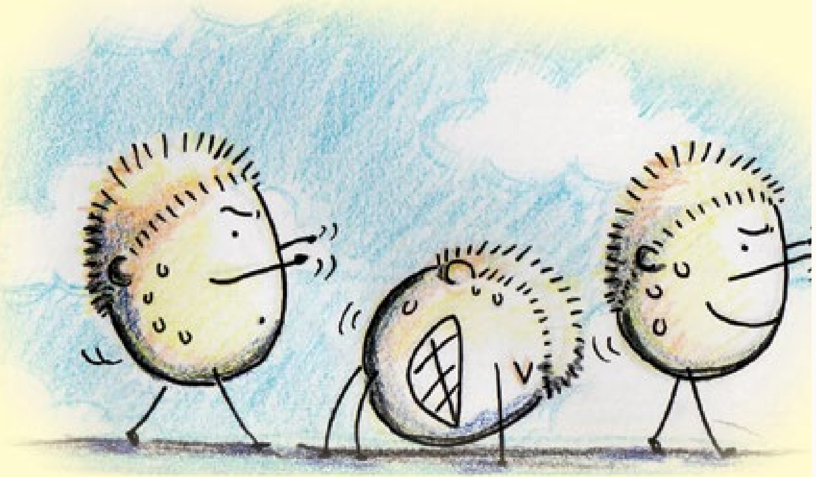
Happy Bean always has trouble breathing. And every step he makes tires him.



每天起床的時候,他都會靠自己梳洗更衣。

每次朋友玩耍時,他都會在旁邊打氣。

每次跌倒的時候,他都會自己爬起來。



每次累的時候,家人都會抱著他走完餘下的路程。

When he wakes up in the morning, Happy Bean always tries to brush and dress himself.

When his friends play, Happy Bean would cheer from the side.

When he falls, Happy Bean would stand up on his own.

When he gets tired from walking, Happy Bean's family would carry him.

上帝問他每天都忍受著痛苦與折磨,為什麼還可以笑著面對?

他說他雖然不可以做自己喜歡的事

但他每一刻都感到高興,因為每天都能夠自由自在地呼吸,他已經很滿足。

God asks Happy Bean, why he can endure such pain and suffering with a happy face?

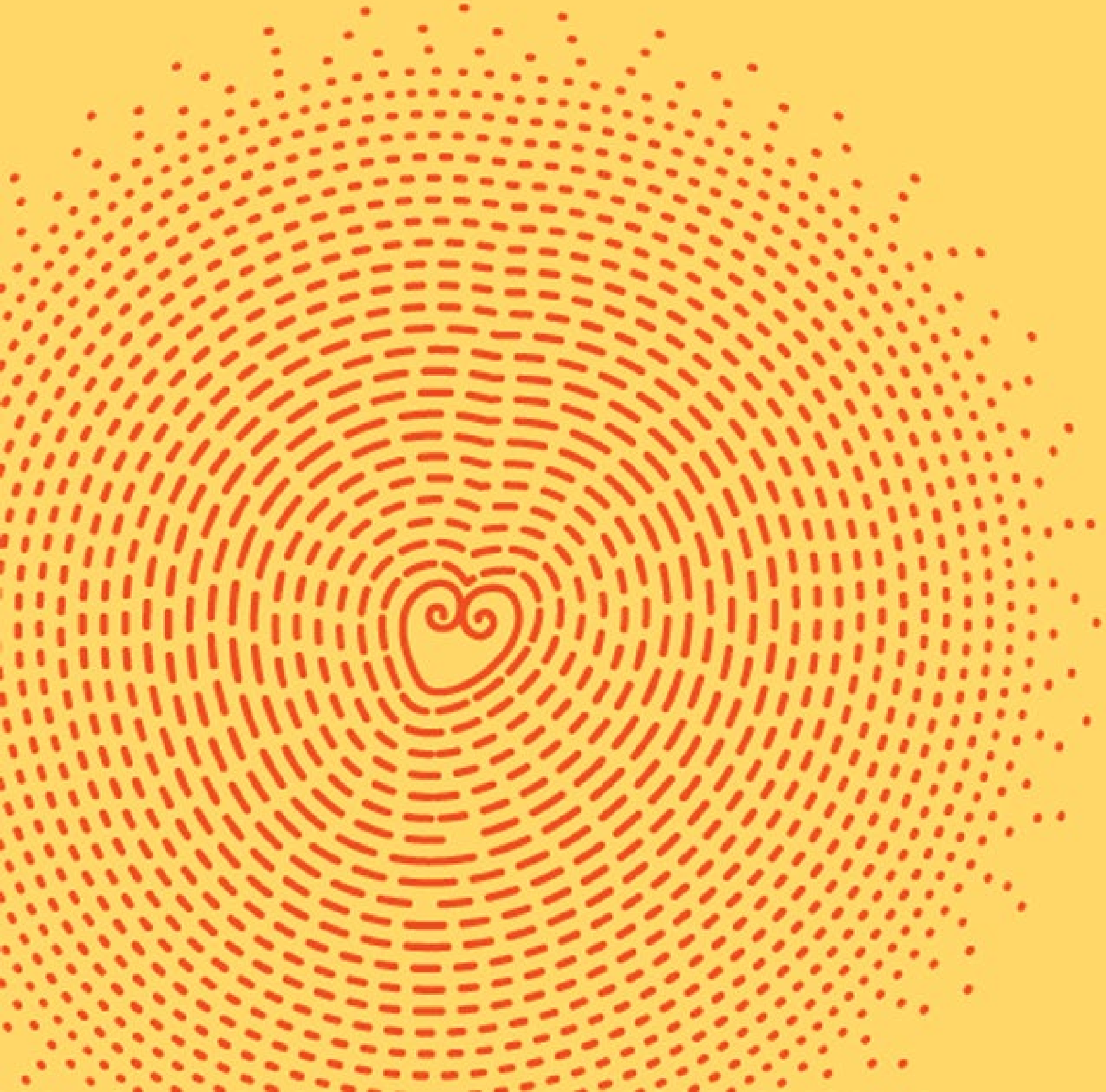
Happy Bean replies, even though he can't do what he wants, he feels happy all the time. He is glad to be able to breath freely.

上帝最後把開心果變成一個健康的小朋友。

從此開心果過著與普通人一樣的愉快生活……

God finally turns Happy Bean into a healthy young child.

And Happy Bean lives the life of an ordinary person ever after.



Winners of the "Rare Love" Illustration and Comic Competition

Champion

Leung Yee Ting From That Year On

1st Runner-up

Chan Nok Sze Annie, Johnny and the Magical Crayon

2nd Runner-up

Ho Hau Yi Beanie's Dreamy Diary

Merit Awards

Man Wing Yi A Wish
Wong Ka Kit Beanie's Path
Lam Kwun Tat Who Understands the Beanie Heart
Wu San Yee, Sandy I want to grow up
Chan Ho San My Position
Chan Wai Sze MPS Bean and Dream
Tsang Wai Yin A Joyful Bean Life
Wong Chiu Yan A Pakistani Family
Lau Yuen Que Energetic Bunny
Lau Yin Yee But...
Choy Po Yee Sticky Beans in Wonderland
Kwan Wing Yee A Different Bean

Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group

HKMPS was formed by patients and families living with rare genetic diseases for mutual support and encouragement. With the assistance of The Hong Kong Society for Rehabilitation's Community Rehabilitation Network, the Group later registered as a charitable organisation on 23 March 2005.

Apart from Mucopolysaccharidoses (MPS), HKMPS also have members who are diagnosed with Mucolipidosis, Glycogen Storage Disease, Multiple Sclerosis, Gaucher's Disease, Pompe Disease, Hereditary epidermolysis bullosa, Phenylketouria (PKU), Glutaric aciduria Type I (GA I) and Sotos Syndrome. All patients with rare genetic diseases are welcome to join as well.

The Group receives no regular funding from the government. Our operational expenses are mainly covered by annual membership fees and donation, whereas individual activities are supported by funds from different charitable foundations. The Group does not have a permanent address. We borrow venues from the Hong Kong Society for Rehabilitation for meetings and gatherings.

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.

Donation methods:

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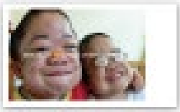

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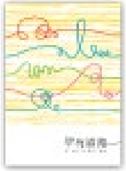

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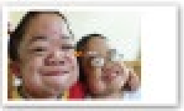

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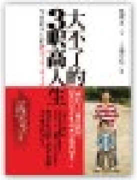

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