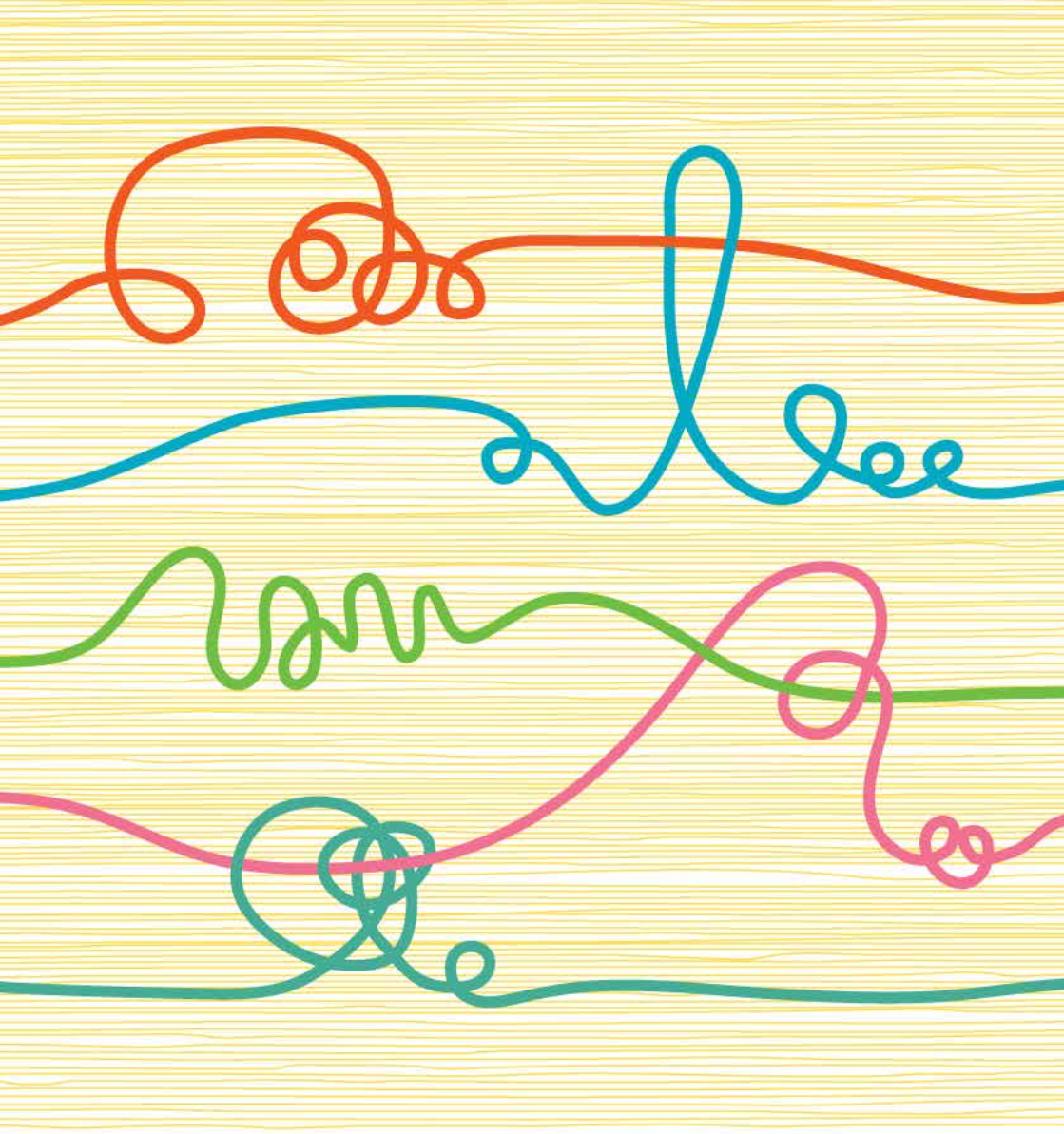


Rare Journey

Rare Disease Patients' Stories of Struggle


Rare Journey
A Bbluesky caring project

Preface

In the past, most of the rare genetic diseases were incurable. Medical advances have created medications one after the other. However, the high cost of the medication makes it impossible for ordinary families to afford it. Last year, our government has put those medications under the Hospital Authority's Drug Formulary, allowing patients with rare genetic disease to receive appropriate treatment.

Rare Journey is a book chronicling the disease-fighting experiences of 10 patients with rare genetic diseases, describing their family and school life, the major and minor operations and treatments. The patients face their lives positively and with indomitable spirit and optimism. Readers would be touched by their lives well lived.

I hope this book can raise the public's awareness towards patients with rare genetic diseases. I want the patients to know that they are never alone. Apart from family and friends, there is also the support from professional healthcare teams and the whole society. I wish all patients a healthy and fruitful life.

Mrs. Selina Tsang

Preface 2

It is my pleasure to write a preface for this book. To know each "little giant" is a blessing. I'm very lucky to be able to work and walk with them, their family and friends. I have learnt the meaning of life from them. Like Joe Lai said, "Do not blame others, but live wonderfully and meaningfully, so that I would not waste the life God has given me." I have also felt the greatness of love. The brother of Chun Ho once gently said, "Donating my white blood cells to my brother is totally fine, but it would be better if it brought me less pain.".

Five years ago, in the book *Little Giants—Dreams of Braving MPS,* the little giants said, "Little giants are like little beans. They absorb nutrients, gain energy under the sun, and exercise every day, hoping to grow up. But the little giants never grow tall." Five years later, not only did they grow up, they also achieved their dreams one after the other by their own effort. Their journeys were filled with unimaginable bitterness, unparalleled perseverance, endless love and many people's selflessness. I was touched to hear their feelings and wishes told so humbly.

Joe, through his determination and effort, has enrolled in a university faculty he likes. He hopes to find an administrative job and become self-reliant. Chun Ho, one of the last candidates sitting for the Hong Kong Advanced Level Examination, hopes to complete his surgery and go back to school soon to prepare for the examination. He wishes to study music in university and compose a song for his mother. Jay is a year three student in a Higher Diploma course. He wishes to study product engineering in university. He wants to find a job after graduation to feed himself and

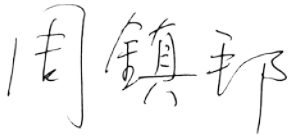
his parents. Jocelyn has finished university amidst the torments of different operations. She now frequently joins different international conferences on MPS, hoping to provide data for research institutions to develop enzyme replacement therapy for MPS type IV patients.

Karen, who loves visual arts, had wanted a brother to take care of her mother, as she cannot do it herself. She has two brothers now, who not only take care of their family, but also take care of her. Karen Kong, who lives in Tin Shui Wai, wishes to study tourism in university. She wants to tell others about the beauty of Tin Shui Wai. Terry, a former student union president, hopes to run an internet company after completing his computer course. He hopes to live out his dreams and contribute to the society at the same time. Mavish was short in the past. She has grown tall and is looking better after receiving medication. She wants to be a teacher for Pakistani children. John, who is studying at the Hong Kong Red Cross John F. Kennedy Centre, wishes to study multimedia arts at the Hong Kong Institute of Vocational Education and work in the creative industry. As for Johnny, who has lost his eyesight and his sister, he was not discouraged by the events. He has become more energetic after receiving medication; even his skin has improved. He wants to work in a sheltered workshop after graduating from form six so as to be self-reliant.

All these may seem ordinary and simple to the healthy. But to the patients, the hardship they have to endure to achieve these modest undertaking is unfathomable to outsiders. Their performance and achievement are worth

our learning and recognition. I'm glad to see the support given to them by healthcare professionals. As Joe said, "Illness is not a personal failure, but a test from God." Honestly, this is also a test for healthcare professionals. We shall not miss this chance to work with these brave warriors and let them hold a guiding light for the others.

Finally, I hope this book would allow people to know more about MPS. I also hope that readers can show their acceptance, love and appreciation towards the patients by contacting, befriending and supporting them. I wish our society can be enriched by their touching experiences and become more positive. Let us give the patients and their families a round of applause to thank them for their efforts in bringing a richer life and hope to themselves, their family and the society.



Dr. Chow Chun Bong
HKMPS Advisor

Preface

I am holding a just-published copy of *Rare Journey* in my hands. I think about life's journey when I look at the coloured lines on the cover. Different people living different lives, having different experiences, dreams, failures and happiness. Life is like those coloured lines. They radiate to various directions. Sometimes they mess up and twist. Sometimes they are straight. And sometimes they meet and form different shapes and patterns. The life of patients with rare genetic diseases is like that of the healthy, in that they are always changing and every person has his/her own story. In each story in the book, there are different characters walking alongside the main character. They appear at different times and places, providing care and encouragement to the patients. They also bring challenges and opportunities. At the same time, those patients light up and enrich their companions' lives.

Rare Journey is the fourth book published by HKMPS. *Little Giants—Dreams of Braving MPS* was the first book that introduced us to the public. *Little Giants·Great Letters* was filled with the creativity of our patients and the artists. It also recorded how we fought for the medication for our patients. The third book, *Rare Parents,* shifted the focus from patients to their parents. The book talked about the ups and downs of the "rare" parents. When we were planning to write the fourth book, we invited some patients to talk about their thoughts and feelings, as we would like people to understand their feelings. The results are gratifying. By reading the 10 articles, we can learn more about the inner world of MPS patients. We also know more about their ambitions and wishes. As their families and teachers, we no longer only care about their

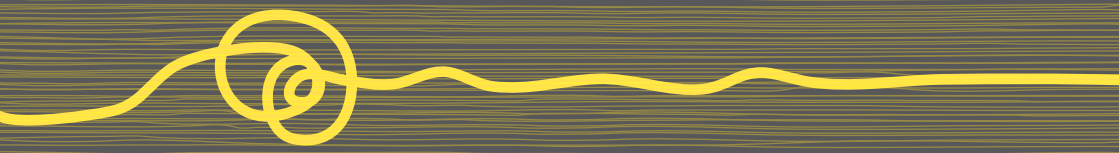
physical condition, but also appreciate their ambition and enthusiasm.

I would like to thank Mrs. Selina Tsang, and Dr. Chow Chun Bong for writing the meaningful prefaces for this book. As the wife of the Chief Executive, she must be tied up by her duties. Nevertheless, she cares about us and is concerned about the treatment of our members. Dr. Chow Chun Bong is our good friend. He always cares about us. He even serves as our advisor voluntarily. On behalf of MPS and all of our members, I would like to express our gratitude to Mrs. Tsang and Dr. Chow for their love and support.

In February 2011, HKMPS organised the First Hong Kong Rare Children Award to recognise outstanding, talented children who bring positivity and raise awareness towards MPS in our society. The winners, including Wong Yue-ching and Lau Kin-chi, awards ambassador Winki Wong, singers Abella Leung and Louis Cheung all came to cheer for the patients. Thank you for your support!

We are in charge of making our life journey. Let's work hard together!

Mrs. Ellie Ching
Chairperson of HKMPS



Everyone has a pair of wings — faith. As long as you trust your own capability, you will be able to fly.

We are all unique individuals in the world. Learning to appreciate our own strengths can add brilliant colours to our lives.

It doesn't matter what other people think. Stick to your own goals, and success would not be far away.

Abella Leung

I will live wonderfully

Joe Lai

My brother has a scroll with a motto about striving hanging on the wall: “People have to strive in their life; only through striving can one succeed”. And I wondered, “Can striving alone bring us success?” I decided not to agree with the motto. To be successful, besides striving, one may need the right time, the right place and the right people. As the saying goes, “Man proposes, God disposes”, I think the motto is not entirely correct. Rather than interpreting "striving" as "fighting", I would prefer to consider it as a “proactive, self-conscious” attitude. Because to do something well, we have to set a target first, then be determined to accomplish the goal no matter what difficulties lie ahead. Throughout the whole journey, the most important thing is proactivity and self-consciousness. Lacking them and without a target, one can never even begin to strive. My experience may be a little bit different from the other teenagers in Hong Kong, but I hope I can share with you the story of my life, my striving experience and my opinion on people and things around me.

Set a target for life

I was diagnosed with Pompe Disease (Type II) when I was 13 years old. A year later, not only did I have to wear a ventilator at night, I also developed scoliosis. The condition worsened and parts of my spine began pressing against my right lung, seriously affecting my breathing. I had to undergo surgery. The doctor said to me: “If you do not do this surgery, you will need to stay in bed all day, unable to stand or walk, for those actions will seriously affect your heart and lung functions!” This was a major operation with considerable risk, and failure was probable. My parents were stunned hearing this, but after they calmed down, they agreed to give surgery a

try, because they did not want me bedridden for the rest of my life and to have to be cared of by others at all times. However, as I was no longer a child, they allowed me make the decision myself. I was 14 years old then. Faced with a life and death decision, I was overwhelmed. I was craven and unaccustomed to bearing risks, not to mention such an important decision! But I did not want to be nailed to the bed my whole life, facing four pale walls, just because I dared not undergo the surgery. That was not a way to live. Finally, after weighing the pros and cons, I decided to sign the consent form, hoping to survive.

I trusted the doctors (they were the best orthopaedic surgeons in Hong Kong), anaesthetists, and healthcare professionals. I believed their expertise and experience would ensure a smooth surgery that would save my life. But during the operation, the anaesthetist, who was supposed to inject the anaesthetic into the vein in my neck, accidentally injected it into my artery, and resulted in a massive blood loss. Immediate blood transfusion was needed to keep me alive. I knew that the anaesthetist was not the one to be blamed, as my neck was tilted and twisted towards the right, making it difficult to distinguish arterial blood vessels from venous ones. It was not entirely the anaesthetist's fault. Fortunately, with the concerted efforts of all healthcare professionals, the surgery was completed successfully. I was placed in the intensive care unit. Since the surgery used quite a lot of morphine as anaesthetic, my lungs had accumulated a lot of sputum. When I woke up, I found breathing extremely difficult. The doctors and other nurses rushed into the room immediately and resuscitated me. At that time, I was found to be in cardiac arrest. They used the defibrillator to bring me back to life. And I regained consciousness. After I woke up, I found my chest painful, as if I was beaten up. Later on, my mother told me about the harrowing episode

that happened after I passed out. I realised that I was still alive because of the concerted efforts of the healthcare professionals. They may have been exhausted from having to treat my illness and the problems arising from it, but they never gave up on me. And I was deeply touched by it. From this operation, I understood the importance of having "the right people". I learnt to cherish life, and not to idle around, wasting time. In the first two years after the diagnosis, I was not able to accept my misfortune, I was upset and grumbling, and walled off myself. I talked to no one, and those two years were totally wasted. After the surgery, I reviewed my attitude in the past. I should not live that way! So I made up my mind: I should live wonderfully and meaningfully, so that I would not waste the life God has given me.

Stride forward with a strong will

In order to live wonderfully and meaningfully amidst my physical problems, I have devoted myself to my studies. I hope that, through academic success, I

can contribute to the community, so as to realise my wish. There was a time when failure in academics frustrated me. As I failed the English subject in the Advanced Level Examination, I was not eligible for university admission. I was depressed and had no idea about the road ahead, but those feelings only lasted for few days. I figured that life is never easy; we do not always get what we want. Everyone has their bad times. Failure is not the most terrible; being struck down by failure, downhearted and unable to cheer up are. I've experienced those feelings during the first two years of morbidity. I was depressed for two years. I was disheartened. I was transferred

to another school. Fortunately, the principal, teachers and students accepted and supported me. I remember that every time I passed by the school office, if the principal was there pacing or chatting with students and teachers, he would approach me when he saw me, and ask about my health and studies. The teachers would often encourage me to participate in extracurricular activities, like encouraging me to participate in the Chinese Society. Joining the society was not only to learn some folk customs and other knowledge, it was also a chance for me to know students from different forms, so as to widen my social network. My classmates would take the initiative to chat with me when they had time. Some of them would even take me to churches, where the Christians would chat and share with me, relieving my gloom. Also, if I came across anything I did not understand in any subject, as long as I asked them, my classmates would happily answer, especially in mathematics, my weakest subject. Encountering difficult maths questions, they would not only help me solve the problems, but also teach me some tips solving those questions. I learnt a lot from them. Because of their enthusiasm and love, I determined to cheer up and overcome the difficulties, which were mostly a result of my negative thinking and decadent soul. For I have experienced death, the failure of a test was no big deal. Maybe God has given me a new test, moulding me in my growth. I decided to repeat Form 7 and take the Advanced Level examination again. And once again I overcame the problems, successfully enrolled into the university, and studied in the department I liked. I've learnt that a strong mind plays a key role, for it determines one's success or failure.

For my medical condition, I am also resolute in facing challenges. So long as I can still stand up, I will keep training myself by holding on to the handrail and closet and standing up every day after meals. I

hope I would not deteriorate so fast that I could no longer stand with my own strength, but have to rely on a wheelchair. Leaning on something, I could keep standing for about an hour. The longest has been two hours. Although my arms and legs would numb because of that, it was still worth doing it. Because of the hard work and persistence, the deterioration of my legs had slowed down. I could still hold onto something and stand for a while, or even walk several steps. These could be attributed to my previous workouts. Later on, as my head kept bending backwards, if I stood for more than three or four minutes, my blood would rush to my head, followed by dizziness. And this forced me to stop the training.

The power of a strong mind was also applied to our recent plead for medication. My current physical condition is no longer eligible for drug testing, and doctors believe my application would have no chance of success. But I believe that "Man proposes, God disposes". Whatever we face, we should try our best first. So I looked for help, begging doctors to write recommendation letters to the expert panel to increase my chance of success. While doing so, something unexpected happened. Many people knew about my case, and they cared for and supported me and my brother. They organised themselves and fought for my treatment from the Hospital Authority. (Special thanks to the teachers and students from the Lingnan University and Council of the Church of Christ Yenching College.) My family was not alone going on this rare journey. While fighting for the medication, a lot of acquaintances—and even people I had never met—supported us silently. We deeply felt their love and care. On the day of the expert panel meeting, the doctors who fought for us called us immediately after the meeting, and told us that the panel had approved both my medication and my brother's . The news cheered my family up. After waiting for so many years, here came a new therapy

that could stabilise our condition and gave us the hope of surviving again. We would like to thank the people who had supported us. Without their help, our application would not have been so smooth.

The key is "the right people"

Looking back at my experience, whenever I faced difficulties, I had a lot of people helping me out at every critical moment. This is what I call "the right people". Without the help of those people, I would not be able to solve all these problems by myself, no matter how hard I try. In the matter of applying for medication, I would like to thank everyone at the Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group and all the staff of Bbluesky Kids. If they did not tell us that there were medications for my illness, and that there were children in Hong Kong trying the medication and achieving good results, I would not know that there were medications suitable for us. They brought hope to our survival. In the process of fighting for medication, without their help searching for relevant information and submitting it to the expert panel, we would not be able to try the medication. Thank you very much! I think the help from the patient group had been crucial to our success. I would also like to thank the doctors who had fought for the medication for us. Without their providing adequate medical data and writing reports to the expert panel, without their persuasion, our application for the medication would not have been so successful. Thank you!

My wish

Having taken medication several times, I feel that my lungs have improved. I do not choke during eating and I do not notice any side effects. Generally speaking, I am getting better. Now I would like to focus on my studies and my health. For my studies, I would like to get better results so as to graduate as scheduled. For my health, I hope I could exercise

more, and with the aid of therapy, improve my physical condition. I would also like to focus on the book's publication, so that I can share with the public my experience in illness and study, and inspire others to treasure life.

In the medium term, if my physical condition improves—say, if I do not need to use the ventilator for most parts of the day—I would like to travel more. In the previous five to six years, I needed to use the ventilator all day long. Because of that, and that the battery would run out in 4-6 hours, I could not travel far. I could only stay at home if there was no reason to go out. And that limited my opportunity to contact the things and people outside. All I knew about the world was from newspapers, television and books, and I did not have a full picture of things happening out there. I felt I was separated from the world, for I could only see the surface of things and I was forced to be narrow-minded. For that reason, I would like to broaden my horizons, change my perspectives and enhance my thinking through travelling. I hope to travel to Taiwan. I had heard about Taiwan's vibrant publishing industry, especially in Chinese literature and foreign classics translation, which is ahead of Hong Kong and Mainland China. Many books and papers that I used and read in the course were from Taiwan. However, those books from Taiwan are one-third to a half more expensive in Hong Kong than buying in the local stores in Taiwan. If I get the chance to travel to Taiwan, I would surely purchase the books I need and enjoy them when I come back to Hong Kong. There is another reason why I am so eager to travel to that place—genetic researches in Taiwan are more advanced than Hong Kong. The medication I am currently receiving is developed by Professor Yuan-Tsong Chen, the director of the Academia Sinica. There are around 30 people suffering from the same disease and receiving the same medication as I in Taiwan. I hope I could

pay the professor a visit, and learn more about the medication, the optimising measures and the direction of development. I also hope to talk to those who have taken the medication for several years, and ask them about their condition after treatment, such as the degree of recovery, so as to prepare myself and not have any unrealistic thoughts.

In the long term, I hope to find an administrative job and be self-reliant. I wish I do not need to be supported by my parents or the government. I do not want to be a burden to others. So I have to equip myself by learning more to prepare for my future career. Due to my limited mobility, I may not be as efficient as the normal person. However, I still want to try my best to find a suitable job, accumulate work experience and have a taste of "every grain is the fruit of hard work". Contributing the society is my wish. At least I want to be able to care for myself and be self-reliant. I never want to become a parasite in the society, waiting for financial assistance. I would work hard in this direction and find a suitable job. I would also like to spend more time on voluntary work, to further contribute to society. I would especially like to use my experience to encourage chronic patients who are at the edge of death, feeling helpless or discouraged. By caring and loving them, I hope they would realise that there is still love around them and they are not alone. More importantly, I want to spread the message that birth, old age, illness and death are processes every human must go through. Therefore, illness is not a personal failure, but a test from God. I hope that everyone understands that "everyone is gifted". Cheer up! By passing through different tests and challenges, you will develop a strong mind and lead a wonderful and brilliant life!

Karen

Words from the bottom of my heart

Karen Chau

Due to MPS (Type IV), my arms, legs and body did not develop normally, so I cannot move around like the others. I can hardly do any daily activities without my family's assistance. My mother is my legs and arms. Not only does she stay with me every day, taking care of me, but she also is my mental companion. I would share with my mum my thoughts and my mind. Every morning, when I open my eyes, the first figure in my eyes is my mum. She will assist me putting on my uniform and sending me to school.

I love school life

I am a Form 3 student from the Hong Kong Red Cross John F. Kennedy Centre. My favourite subject is visual arts and I am fond of 3D sculptures. My teacher often shows us artworks from different places to broaden our sight. In school, I have six close classmates. We chat and laugh and the classes are over soon. I am fortunate as I met a lot of good teachers in this school. The most impressive one was Miss Cheng, whom I met in primary school. Miss Cheng loves travelling, she would travel overseas on every vacation. She would miss us during her journeys and would send the whole class postcards from around the world. My mum would collect those postcards for me, and I enjoyed putting them all over the table and reading them one by one. Miss Cheng was also concerned about our academic performance. I remember that some years before I almost failed my mathematics test. Miss Cheng brought other students who needed special guidance to my home and served as our private tutor. Sometimes, she would visit me and dine out with me. Now that I am studying at the secondary level, I have fewer chances to meet Miss Cheng, who teaches at the primary level. But every time she sees me on campus, she would ask after me.

I also like going on field trips. One time, we visited a household exhibition named "Green Living". I was deeply impressed by that visit. The exhibition demonstrated automated household life. Using a remote control, or even voice control, we could control all the appliances and furniture at home. If my home were equipped with such facilities, I would not have to trouble my mum so often.

I am afraid of surgeries

My mum has done a lot for me since I was little. She told me that when I was three years old, I fell from a swing in a park. I could not move the right side of my body. At first, the doctors examined my bones and found that the fourth cervical vertebra was deformed and the nerves were compressed, so that my body could not move properly. They took a little piece of bone from my pelvis, and used it as a pad to support my neck bone. After the surgery, the doctors suggested me to go to Hong Kong Red Cross John F. Kennedy Centre and arranged social workers and therapists to follow up my case. At that time, I was not diagnosed with MPS yet, as the examinations were mainly focused on my bones. But after a series of checking, they found that I have such a rare disease. When I was a primary school student, my legs started to bend inward and my knees were worn. The doctors performed a surgery on me to straighten my legs. After the operation, I could walk, but the situation worsened later on. My legs were lacking in strength and I could not walk anymore. I could only go around in a wheelchair. My blood vessels are narrower than a normal person's, so I would suffer greatly every time I have my blood taken or have a saline drip. Speaking of surgeries, I once told my mum, if it is not necessary, I would rather skip it.

Knowing the world through the internet

Every day after school, I will spend more than two hours on my homework and after that is my free

time. I love surfing the net and Facebook is my favourite website. I now have more than 300 friends on Facebook. Most of them are my classmates and brothers and sisters in church. Apart from Facebook, I like browsing different news websites, reading news from different parts of the world. Recently, I was astonished by the news of the Japanese earthquake. I was very worried about the Japanese. The disaster triggered the nuclear radiation crisis. The nuclear radiation is contaminating the crops. Without the crops it means food shortage. Food shortage decreases the income of the people and livelihoods would be impaired. As for the panic purchase of salt in Hong Kong and Mainland China, it seems foolish to me. "It had done us no good but raised the price of salt. As the nuclear power plants were so far away from us, we have nothing to worry about," I told my mum.

Mother, I would like to have a little brother

Since I am not capable of taking care of my mum, I have been afraid that no one would look after her in the future. That's why a few years ago I told her I wanted a little brother. I knew that my mother had been struggling for a long time on my request. Provided that MPS is a genetic disease, if my mum was pregnant, there was a 25% chance that the infant would carry the disease. My brave mother was finally pregnant with a healthy baby when I was 12. I have a brother. Together with the newly adopted one, currently I have two younger brothers. I am relieved, because they can take care of mum when she gets old. Although they are naughty occasionally—disturbing my computer and my stuff—they already know how to protect their sister. Once in

the park, I sat in an electric wheelchair while my two lovely brothers went to play. Suddenly a few naughty children wanted to play with my wheelchair. And my siblings immediately ran back and protected me. Not only do they protect me, they also take care of me. They would even feed me. I feel relieved having them take care of mum in the future. Brothers, please look after our parents! I am counting on you!

Father, you are amazing

I can still remember how my father looked when I was small. Now, his hair has turned grey and he always walks around carrying a tired body. Father has really grown old. Without even realising it, father has already taken care of me for 17 years. He is a telecommunications technician who is always busy at work. Apart from working hard every day to feed a family of five, he also helps mum with our household chores. He is the first to rise each morning and the first to get to work. He would clean the patio, cook our breakfast and help me prepare the things I need for school. By 7am, he would leave for work. When he comes home in the evening, he would take some time to attend to personal matters and help cook our dinner, set the table, put up the block-out curtains in my room and do the laundry and hang dry them... Beside going to work and helping with household chores, father also takes me to the doctor for return visits. Although father is not as familiar with my daily routine as mum, he has always worked tirelessly for me, giving me his all. For that I am very grateful. Father has never given up on me and has done his most to ensure that I have the best care. Father, thank you for all that you have done for me, you are amazing.

John

If I knew magic

John Li

Ap Liu Street in Sham Shui Po is a well-known market, selling electronic devices and audio-video products. Because of my mobility problem, I have never asked my mum to take me there. So when teachers in my school planned to take us there, I was eager to join the trip. I am a Form 4 boarding student from the Hong Kong Red Cross John F. Kennedy Centre. Our teachers regularly arrange field trips for us. We have visited the village in the New Territories and saw a lot of monuments. This time, our first stop was Tsuen Wan Citistore. We had our lunch there and we set off to Sham Shui Po. We stayed in Ap Liu Street for about two hours. I put my focus on different types of headphones there because we often do our homework with headphones. I have also seen a lot of neon lights on the street. In fact, I was satisfied with the visit, walking around, looking at interesting things I like. In the past, I had to undergo different surgeries every year and spend most of my summer holidays in the hospital. Comparing to those days, the high school life I am having these few years has been pretty good.

Spending summer holidays in the hospital

Because of MPS, I underwent my first surgery when I was six. My bones had grown abnormally, and my collarbone was compressing my nerves. So the doctors took out a small piece of bone from my pelvis, ground it into powder, and used the powder to cushion my neck bone to prevent it from compressing the nerves. After the surgery, I had to wear a skull holder for a long period of time. Before I had my surgery, I really enjoyed playing football, and I often dreamt about being a football player someday. But because of the disease, I slowly understood and accepted the fact that I am incapable of playing football. I told myself, "Although it is my misfortune having this disease

and not being able to play football with the others, I could do nothing but accept it." In the summer two years later, I had orthopaedic surgery on my legs. Luckily, my optimistic personality kept my spirits high, and cartoons and Gundam models became my best playmates in the hospital.

Boarding school life

I have been studying at the Kennedy Centre since 2003. In 2005, I used a computer for the first time, and the computer immediately become a daily necessity of mine. With the computer, I can play different types of computer games, look up information from the internet, and listen to my favourite music. My mum said I was addicted to the machine, but for me, someone who cannot go around freely, computers let me live my dreams. For example, in the computer world, I am no different from the others, and I can move around freely. When I play computer games, I can jump anywhere, or even fly as I wish. I can also control every move on the computer. Such satisfaction keeps me devoted to computers and computer games. But boarding school life is very regular. Every day I can only use the computer and play computer games within a limited time. After school, 15:45 to 17:30 is the time for bathing. During this time, we can play computer games in turn. Everyone is allowed to play for five minutes only. We have our dinner from 17:30 to 18:45, and we would have our homework done before 22:00. During that period, we can also use the computer. We have to go to bed before 23:00. Fridays after school and holidays, I'll go back home. And it is my free time to play on the computer!

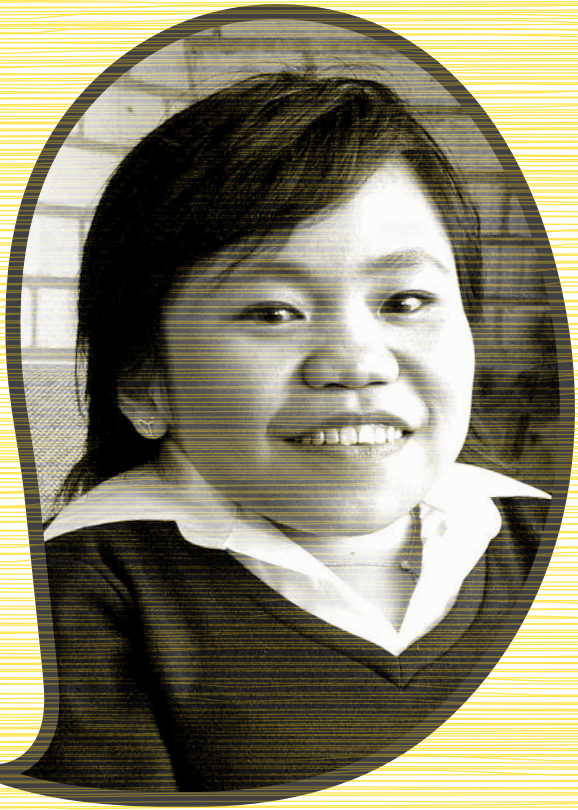
Multimedia art

We do not have much homework. I fear maths most, for I hate reciting formulae. I always think that my memory is not very good. Not sure if it is related to my disease. Under the 334 Scheme, Hong Kong's new academic structure, we can pick one elective subject. According to my interests and abilities, and considering my future career, I've taken the multimedia art course offered by the Hong Kong Institute of Vocational Education (IVE). I hope that after the completion of high school, I can continue my study at the Hong Kong Institute of Vocational Education, taking multimedia courses, and work in related fields in the future. In 2009, when HKMPS pleaded for government-funded medication, I drew a picture on the computer for our plea. The government finally granted our request; I think I might claim a little credit for that too!

Medication

Although the government has agreed to pay for our medication so that we can receive treatment, the drugs for MPS type IV are still in the testing phase. If all goes well, the drugs will be available in two or three years. But my respiratory function has been deteriorating and I have to use a ventilator at night—I could die without that machine. I also have a lot of concerns regarding medication. For example, I am worried that having medication will affect my studies at IVE, as well as the side effects of the drug. If it can really control my condition, so that I can live a normal life, I will definitely give it a try. But without the medication, my illness could worsen, and I may die. I am not afraid dying. Everyone has to face it eventually. I have told my mother not to waste money on my funeral ceremony if I die. I do not fear death, I do not even think about it. In my free time, I'll read a book and daydream. My favourite series is *Harry Potter.* Apart from Harry Potter, I also like Dumbledore, because he often offered help to Harry. If I knew magic like Harry Potter, I would make myself a lot of Gundam models and cure myself!


HONG KONG



Jocelyn

Bittersweet

Jocelyn Wong

MPS type IV is a rare disease. In the US, only one in 250,000 people has this disease. As information exchange in the past was not as convenient as nowadays, the disease did not catch many people's attention.

A child who needed holding

When I was young, I was no different from the others. I could walk when I was one year old. I loved moving around, I was an active baby. Even though I was often sent to the hospital because of respiratory diseases like bronchitis and shortness of breath (there was a period that I had to see the doctor three times a week, for I got high fever and had to have bone marrow examinations), my family had never thought that I was a child with a rare disease. When my relatives heard the news of my illness, they attributed the misfortune to the pills my mum took during her pregnancy or the pathological change during my bone marrow examinations. My parents were under great pressure back in those days. When I was two, my legs bent inwards. I visited many doctors because of this, but they told me that it was commonly seen among kids my age and the problem would go away when I grew up. Back then, my parents would take me and my sisters out every week. In winter, we would go hiking, cycling in Sha Tin or have fun in the country park. In summer, we would go swimming at beaches. We have been to every beach in Hong Kong. To other kids, they may yearn for such a life, but it was kind of hard for me. Because of the bandy knees, I did not have much strength and was easy to tire. I would ask my dad to hold me and he thought that I was lazy and wayward. My mum and sisters could not bear to have me walking with hardship so they would hold me and bear with me as I wished. My

situation was not getting better; quite the contrary, it was getting worse, so was my physical strength. The doctor referred me to The Duchess of Kent Children's Hospital at Sandy Bay for medical treatment. At that time, the doctors did not know what had happened to me. I had to stay in hospital for one to two weeks almost every month that year. After many tests, including intelligent testing, electroencephalogram (EEG), blood and urine tests, everything was shown to be normal, apart from the bending of my legs. Having X-rayed different parts of my body, by the time I turned five, I was diagnosed with MPS type IV.

Two large school bags on my sister's back

The doctors did not explain much, only saying that it was a genetic disease. We were only told that it was due to the bad genes that both my dad and mum carried, that it would not affect my intelligence, that I would no longer be able to walk when I entered my teens, and that I could only live until twenty something. As my intelligence was spared, my parents insisted on sending me to a mainstream school. MPS type IV generally does not cause a large impact on patients when they were young, so I was in the same school as my sisters and I did not encounter great hardship at school. Apart from physical ability and eyesight, I was no different from others. Being a short girl did not trouble me either. I am over 20 right now, standing at 100 cm tall. It was not uncommon for my schoolmates to laugh at my height, especially when I was in Hong Kong. Yet, my mum told me, "They would laugh at you just because they are curious. If they keep making fun of you after you explain to them, it only means they have no manners and are disrespectful. We do not have to care about them." When I was very young, I had eyesight problems. I could not see clearly the words on bus stops or the numbers on buses. But my family thought that it was due to my short stature and young age. After I was confirmed to be an MPS patient, I

was sent to have an eye test. However, the doctor said it was too late as the shape of my eyeballs were set, and the mucoploysaccharides had accumulated on my cornea, so I would not have a clear vision. Nothing could be done to help, not even glasses. I cannot clearly see objects from a long distance, but my sight is good enough to fulfil basic needs, such as reading and watching TV. Soon after I was diagnosed with MPS, the situation of my legs became serious. They would easily tire and hurt. The doctor was afraid that it would affect my growth in the future; so I had my first surgery when I was five—an operation on my knee valgus. After the surgery, my legs were in casts, only my toes were spared. It was Chinese New Year. And my cast became a popular spot for people who visited me to sign. It was a pity that the cast was not kept. I was young, so I have forgotten the pain I suffered. Before the surgery, my family briefly told me it was the problem with my knees and I might not be able to go to school for a while. I bet every student would consider it good news. My second sister and I studied in the same primary school. Thanks to her, she carried my homework and the school circulars for me. And by the time I went back to school, it was she who carried my school bag for me—and school bags were commonly heavy those days. She had to bear hers and mine, two large school bags.

Precise leg straightening surgeries

As my legs grew, the problems we solved a few years ago reoccurred. When I was 11, my doctor found from the X-ray that the problem with my bandy knees was pretty serious and my hip joint was displaced. He suggested that I have another operation. After considering for a month, my parents agreed with the plan and I was sent to the operating theatre. As a party concerned, I did not have much disagreement. I remembered saying goodbye to my parents with a smile before I entered the operating room. “Not many patients are like you,” the doctors

and nurses said, surprised. In the surgery, my legs were inlaid with steel plates and nails and put in casts. Due to the hot weather, the wound where those steel nails were laid inflamed. So after those casts were removed, the nails had to be taken out. I should have received general anaesthesia, but I requested for a local one, because every time I had my whole body anaesthetised, I would be nauseous and I would vomit and not be able to eat or drink for two to three days. Those who knew I had an extra operation were sympathetic to me, even my grandmother asked my father the reason for the operation. Looking back, without the two surgeries, I might not be able to walk today. Doctors in America said the operations I received were done well. Both of my shanks are about the same length, meaning the doctors in Hong Kong had a very precise calculation before the surgeries.

A new life in the United States

Soon after graduating from primary school, I went to the US to study. It really broadened my horizon. As I had studied in a mainstream school in Hong Kong—although I knew I was different from others—it seemed to me that everyone was unique. I did not pay much attention to my difference. In the US, I learnt the word "disabled", and I realised that I belonged to this group. American high schools have a "class floating system". Students need to go to different classrooms for different lessons, and not staying in a fixed classroom. Concerning my safety, the school allowed me to leave the classroom five minutes before the end of each lesson so as to avoid colliding with others and allowed me to walk around the campus with my school bag, which was forbidden by the rules. The school also prepared me two sets of textbooks, a set to put in the classroom, the other at home. The teachers knew about my poor English, and let me start with vocabularies in English lessons. Knowing that I was good with

numbers, my mathematics teacher gave me questions without words. Every day I borrowed a lot of English books from my teachers, but as I adapted the life in America, I read Chinese books instead. At my graduation ceremony, it was announced, without prior notice, that my excellent results had won me the President's Award's Best Progress Award. It was really surprising, because I had only been to the US for three years, and my English was not very good. My language could only be used for basic communication. I had to rely on the textbooks together with a dictionary to understand the teacher's lectures. The teachers even allowed me to use an electronic dictionary during examinations.

With full scholarship and a hearing aid, I became a university student

In high school, my classmates were all taller than me. My school hired a special assistant to help me take my bags and jot notes for me. They tailor-made a ladder for me in the activity room so that I could use the sink during cooking classes and art lessons. My hearing began to decline, which led to articulation problems, but the doctor said hearing aids were not necessary since the situation was not serious. In fact, hearing aids were expensive, costing from US$800 to US$8,000. Because I was small in size, many of my belongings had to be custom-designed. The medical supplies I needed were thus more expensive, and so I did not buy hearing aids. When I graduated from high school, my excellent academic performance earned me a scholarship from the *New York Times.* I heard that the sponsor knew that my hearing would affect my learning, so they bought me a pair of hearing aids. In the same year I also received a

notice of university admission and a full scholarship. As Mother's Day was approaching and my parents were still working in Hong Kong, I made a phone call to my parents and told them the good news. It was midnight in Hong Kong. My mum doubted if I had read the letter clearly! The next day I told the teachers and the principal the news and they were all very surprised.

The scholarship included four years of university tuition and accommodation fees, which allowed me to live in the dormitory alone. My family was very much against the idea. My mum even quarrelled with me about this every week during our long-distance calls. Fortunately, my second sister mediated and finally my mum compromised. My second sister went to the university open day with me. She persuaded our mum to let me try, as the scholarship was enough to cover accommodation. The university had also made a lot of changes for me. They assigned me a single room with a sink in a lower position installed. They installed a lower clothes rail and put a small chair in the laundry room. They gave me a higher chair in the classrooms. The teachers prepared me another set of textbooks, so that I did not have to go around with heavy textbooks. The first day I moved into the dorm, the president went back to school especially for me to meet me and introduce me to all the staff and security guards. He told them to help me whenever I needed, and I was permitted to call the security guards to drive me to the train station.

Although the school had done a lot of changes for me, university was a place for students to learn to be

independent. It was not possible for the university to take care of the students like in secondary schools. Fortunately, as my schoolmates knew that I needed help, they would often lend me a hand. For example, when I ate at the school cafeteria, my schoolmates would help me get a tray and the drinks. In classrooms, they would lend me their notes. In the dorm, my schoolmates would help me change the sheets. One time, my hearing aids ran out of battery, and a schoolmate immediately drove to a shop to buy me replacements. We also frequently went shopping and had fun together, we shared a strong bond.

The orthopaedic surgeon who knew patients the most

My hands' numbness had been bothering me since high school. An MRI scan found that the cervical degeneration had caused cervical instability, but the problem was not too severe, and surgery was not necessary at the moment. In my sophomore year, I received a phone call from my orthopaedic doctor. He told me that my cervical spine problem had worsened, and I needed to have a cervical fusion surgery in the short term. Without surgery, minor injuries on the cervical spine could cause paralysis or even death. My parents and family were very opposed to the surgery, but I trusted this doctor. Doctors generally rely on textbooks and clinical experiences to make a diagnosis, but this doctor has an additional skill—a first person experience. He suffers from achondroplasia, a very common form of dwarfism, so he knew the patients' feelings and needs. I have full confidence in him. I was glad that I had made the decision of taking a one-year break after the surgery. I had to wear a halo, which was a head and neck holder. The holder was used to fix and support the head. But wearing the halo, I could barely move. The halo looked a bit scary, but I was used to it after a few days. The most awful thing was the woollen

sweater inside the holder. I had to wear the holder for five months! In summer, air conditioning had to be turned on all day at home, for otherwise I would not have been able to bear it. Three months after the removal of the holder, I went back to school and resumed my classes.

I moved back to the dorm, and my family did not oppose this time. They learnt that the class schedule in university was not the same every day. The school was located far away from our home, so it was not possible for my family to drive me to school every day. My cervical spine surgery had postponed my graduation, and I did not want to further delay it. So I decided to ignore the suffering and endure the pain until I completed my studies. My physical condition had been poor after the surgery. I often felt tired easily. In the two years after I returned to school, I had a fall and hurt my head. Compounded by the stress I had, a migraine developed. I was sent to the emergency room several times. Fortunately, none of those was a big deal. I graduated in 2007. Finally graduated! At the graduation ceremony, I was relieved.

In 2008, being unable to bear the pain, I had a total hip replacement. I heard that this surgery was not common for MPS type IV. My body size was small, so were my joints. That increased the difficulty of surgery. Before deciding to undergo the operation, I talked to a lot of doctors, and even e-mailed MPS experts from different parts of the world. Finally, I chose to believe in my orthopaedic doctor. The result of surgery was as expected—the degree of pain reduced from eight to four.

Participating in clinical evaluation programme

In the past two years, I was lucky to be sponsored by HKMPS to attend medical seminars about MPS

around the world. The meetings allowed me to see the many people supporting and researching this rare disease around the world. The associations and groups in all the regions are composed by patients and their families. Most of them have their own jobs, and even more of them are bereaved parents, but they still continue to work hard for patients who suffer from MPS. During the meetings, associations and groups from different regions would share their experience on organisation management and persuading the government to provide healthcare and education support. We also learn more about our disease, the latest research and treatment methods. MPS patients can raise questions during these meetings, so that medical professionals and researchers can answer our questions and understand our difficulties and needs. Recently, I participated in a clinical evaluation of MPS type IV A in the United States, in an assessment programme called MorCAP (Morquio A Clinical Assessment Program). The programme aimed to understand the physiological state of the patients, so as to further study this rare genetic disease. I sincerely hope that the research will run smoothly and there will be enzyme replacement treatment for patients of MPS type IV A, so that patients can be relieved from the disease and live a better life.

Chen Li

An enzyme-lacking drummer

Chun Ho Wong

I belong to the last generation of students who took the Advanced Level Examination. In my leisure time, I like playing pop music with my classmates. I am the drummer in my band, together with two guitarists, a bassist and a pianist. Joining my classmates who shared the same interest, playing music together bring me great satisfaction. It is my dream studying music in university. In the coming year, I will be taking the last Advanced Level Examination. If the results of the exam were not good enough, I would have to repeat Form 5 under the new education curriculum (334 Scheme), which implies that I have to spend two more years in order to enrol in a university. That's why, after a string of surgeries, I yearned to get back to my studies as soon as possible, to catch up to my fellow classmates.

Cord blood of my baby brother

I have been suffering from MPS type 6 since I was born. My height stopped growing when I was two. So my mum took me to the doctor and I was confirmed to be the victim of the disease, which was incurable at that time. Four years later, Dr. Huen Kwai Fun came up with a plan of treatment. At that time, my mum was pregnant with my little brother. The stem cells in my sibling's cord blood became my hope. I received chemotherapy to restrain my blood production, to allow the stem cells from my infant brother to produce blood in my system. Such a treatment was certainly risky, as my immunity was very weak during the treatment. In case of infection, it could be fatal. My mum said it was the only solution, and so I had to take the risk. After the treatment, 70% of my blood was from my brother and my health greatly improved. This little being was just born and immediately became a part of my body. We have

helped each other since childhood. For instance, on Mother's Day, I am responsible for buying presents for our mother; while in ordinary days, he would help me get things from high places. Helping each other out has become routine between us.

A series of surgeries that is too difficult to withstand

Since the cord blood transplant 12 years ago, my condition has been stable. I just have to take a blood sample every year to see if the enzymes in my body functioned properly (the cause of MPS is the absence of enzyme which dissolves mucopolysaccharides). In 2010, my mum noticed that my situation had worsened. I could not walk steadily and I started having difficulty in breathing once in a while. We told the doctor about those symptoms and my blood sample was sent to Australia and Taiwan for assay. The test results came back: there were not many enzymes left in my blood. Dr. Joannie Hui, a medical practitioner at the Prince of Wales Hospital, spared no effort in my case. She followed up my case attentively and arranged examinations for me. In January 2011, something happened to my cervical vertebra—the nerves were compressed, and I had to receive surgery. The operation left me in pain. Every time I could not stand it anymore, my mum would call Dr. Hui, who would care for me and the pain would subside. After the surgery, I had a fever and threw up. My case MO thought that it was just a cold. Yet, seeing Dr. Hui two weeks later, I was recommended to be hospitalised. I was found having hydrocephalus and had to receive surgery immediately. In the surgery, a duct was inserted into my brain as a way of leading flow, but the duct was blocked, which brought me another operation. Facing a series of surgeries, I found it difficult to withstand. Because of MPS, I cannot be anesthetised. So every time I was intubated, the surgeon could only spray some anaesthetic on my throat. It is not hard to image the pain each surgery brought. And it was not only me

who suffered, my mum also suffered with me. Her eyes revealed her worries. Looking at her face, feeling pain throughout my body, the only thing I could do was to soldier on.

Mother, I will write you a song

Between January and February 2011, my younger brother donated his white blood cells to me. The extraction of white blood cells had to be done in three separate stages. My brother is usually afraid of pain, but he allowed the doctor to extract the cells again and again. "Donating my white blood cells to my brother is fine, but it would have been better if it brought me less pain." Hearing him, I did not know how to respond but to thank him in my heart. Once again my brother's blood flowed into my veins. I hope the treatment works, and my system can generate enough enzymes so that my brother does not have to suffer for me again. And I hope I can recuperate and return to school as soon as possible, so I can focus on my studies and perform well in the Advanced Level Examination, and enrol in a university to study music. My dear mother, after I receive musical training, I will write a song for you someday. Please wait for that day patiently, would you?

Editor's Note:
Chun Ho passed away on 15 June 2011, just as we were editing this book. Chun Ho's mother has this to say about Chun Ho's passing, "Chun Ho was a good child. Although God did not give him a healthy body, Chun Ho never gave up on himself. He cared about everyone around him. We are sad about his passing, but our family will stay strong and pull through. There is no need to worry about us. I thank everyone for their love and care for me and my family."

Morish

I'm tall

Mavish Sultana

This is my first year in high school. Suffering from MPS type I, I am a little short and I often rely on magnifying glasses because of my blurred vision. Despite all that, I am very happy to be able to study in a regular secondary school. I have four good friends at school. Together we play in the park during lunch, shop, do silly things and laugh. I love going to school because of them. Besides playing with me, they help me a lot in class too. I could not read the notes written on the blackboard by the teachers because of my poor vision, and they would jot down the main points for me to read back home. I thank them for their help, but quite frankly, I don't like the feeling of being dependent or different. I wish I could be able to handle things just like the others, but I often require people's help because of the disease, and I could only thank them.

I love my motherland Pakistan,
but I love my mother more

Although there are a lot of good people around who are willing to help me, I just cannot help but think that some people see us Pakistanis differently, perhaps because I am a minority. They do not actually bully us in any way, but they often look at us in a funny manner and sometimes judge the way we dress.

I spend most of my time at school. I am of course happy to attend school with my friends, but I would also feel bored and lonely after school ends. That is why I love going back to Pakistan, my hometown. My beloved granny lives there, and I have a lot of cousins to play with. I cannot always go back because of my disease, but I really wish I could spend more time with my granny.

There is luckily Facebook in Hong Kong, allowing me to chat and play online games with my friends and learn about their daily lives. Besides my friends and relatives, my mother is probably the most important person in my life. She has never given up on me, always supported me, and I could say our hearts are joined. I look a bit different from others because of my disease, and it is her who always encourages me to accept the disease and myself. Under her guidance, I am slowly capable of tackling the problems in life with a positive attitude. With her by my side, I would not think I am different. I am who I am! Mum, you are the best!

A different wish

Over the years, I have grown older but not taller because of the disease. I love wearing fashion pieces designed for teenage girls. But I could not buy them at all, and I could only seek clothes from the children's section because of my height. But I have absolutely no interest wearing those pink princess dresses!

As my understanding about my disease deepens, I have a different wish. When I was small, I wanted to become a doctor to help Pakistani patients. But as I spend more time with doctors and nurses treating my disease, I have come to understand that they have a heavy workload. I know I would need more personal time because of my disease, and being a doctor would not be the best job for me. But now I have a different wish—I hope I can be a teacher one day, to pass on my knowledge to other Pakistani children.

Someday we'll meet again

In November 2009, my brother Hamza, who suffered from MPS like I do, passed away suddenly while he was attending a wedding in our hometown. I still remember my mother chatting with him on the phone that morning, and we received the unfortunate news

that very same night. We could not believe it. Hamza was like an angel to us. He was always happy and he always influenced people around him to be happy as well. Whenever I think about my brother lying there motionlessly, I would wonder if it is only because of the phlegm affecting his breathing, and he would wake up again soon, jumping around and living his life happily again. I know I have to accept that my brother is no longer alive, although I still feel his presence from time to time. Our religion tells us that good people go to heaven after death. My mother and I both believe that Hamza is in heaven already. He is there to get used to the environment and prepare for the arrival of my mother and me. When that happens, I will not be afraid because he would be there to welcome me with his smile! We will live there happily ever after!

Medication

After the government approved the medication funding for MPS patients, I started a weekly intravenous drip infusion treatment at a hospital. The drip allows my body to absorb the medicine. This weekly treatment takes up most of the day, and every time my mother would be there with me and take care of everything. This has become our regular date. My health condition has stabilised after medication and I have grown taller since! I look more normal too! My mood has improved. I do not complain about my look to my mother anymore, and I have a more positive view towards life!

Jay

It doesn't take much to be happy

Jay Shum

Like other MPS type II patients, I am constantly in and out of hospitals, and I have undergone multiple surgeries. The scar on my wrist is a mark from the surgery on my arm tendon. I am very lucky, although I am suffering from this disease, I can move freely, take care of myself and even cook to feed myself whenever I'm hungry. I am studying at the Tuen Mun campus of the Hong Kong Institute of Vocational Education (IVE). I am one year from graduating from the high diploma of Product Testing. I have a bunch of good friends at school and I enjoy my life now, unlike three years ago, when I was worried about my studies and how to make friends. Now that I look back, I figured I would not have been able to change the school and find a discipline I am passionate about without the help of social workers and my parents.

A favourable turn

The first person who thought I might be ill was my cousin. My mother had taken care of her when she was small, and she was especially close with my mother. She cares for me and loves me a lot too. When I was about two or three, my cousin found my palms to be unusually hard. She told my mother about it, who then took me to the hospital. I do not recall the details of tackling the disease or undergoing surgeries anymore, but only the questions my mother asked the doctors and the tears she had all over her face.

I could not take PE lessons with my classmates when I was in primary school. When I grew older, I found that I was not as tall as the others. These, together with my condition, made me sad sometimes; but the blues often faded away after a good sleep. I studied six subjects for the Hong Kong Diploma of Secondary

Education Examination. I was most terrified by mathematics and history, but I successfully got into IVE, studying Property Management at the Morrison Hill, Wan Chai, campus at first. It was probably the lowest point of my life—I was not interested in what I was studying, and I was having lunch alone all the time because I did not get along with my schoolmates.

Luckily, a very nice social worker at school gave me a thorough analysis after I explained my situation to her. She said property management might not be suitable for me as I am introverted, and the job requires communicating with others. She suggested studying Product Testing at the Tuen Mun campus, which is closer to my home and requires fewer meetings with strangers. I further discussed the matter with my parents, who weighted the pros and cons of changing subjects with me like good friends. They were worried that I might encounter various difficulties studying this science-based subject given my arts and business background. But they left the decision to me and I chose to change the school.

It turns out that a change can also be an opportunity. I managed my studies fairly well and made very good friends. We even hang out after class.

Being a leader

My schoolmates and I went travelling in Macau not long ago. I was more familiar with the roads in Macau because I had been there before with my family. I became the little tour guide of the trip, bringing my friends to The Ruins of St. Paul, to eat around and even to the casinos. It felt great to be the tour guide, and I felt accomplished bringing them to

the destinations and walking the right paths. I am usually the follower, and I am already happy leading my schoolmates once in a while. Indeed, I enjoy the simplest form of happiness: gossiping, eating, shopping with my friends and reading comic books.

Beyond words

I have two sisters, one six and one seven years older than me. They are sometimes stricter than my parents, and would sometimes lecture me for playing but not helping out. That said, I would always save them something delicious. As for my parents, I am certain that they love me a lot, but as a boy, it is difficult for me to express my love. It is not always the case though. I can still recall I bought my mum a box of masks when I got my first pay cheque because she never spends a dime on skincare products, and we shared the set together. I also bought her a box of local pastry the time I went to Macau, with a special note on the box dedicating the gift to her. For my dad, I recently gave him my savings for investment, and we study the market trends every day now.

Living the moment

I am in the third year of the higher diploma programme, and I will be graduating very soon. I wish to further continue my studies. The most ideal would be getting into The Hong Kong Polytechnic University majoring in Product Testing. I hope I can find a job and support myself and my parents after graduation. I wish to learn how to drive and have my own car, and to travel around Hong Kong, or even the world. I have been to different places with my family and cousin, like Thailand, Australia and some cities in China. But the

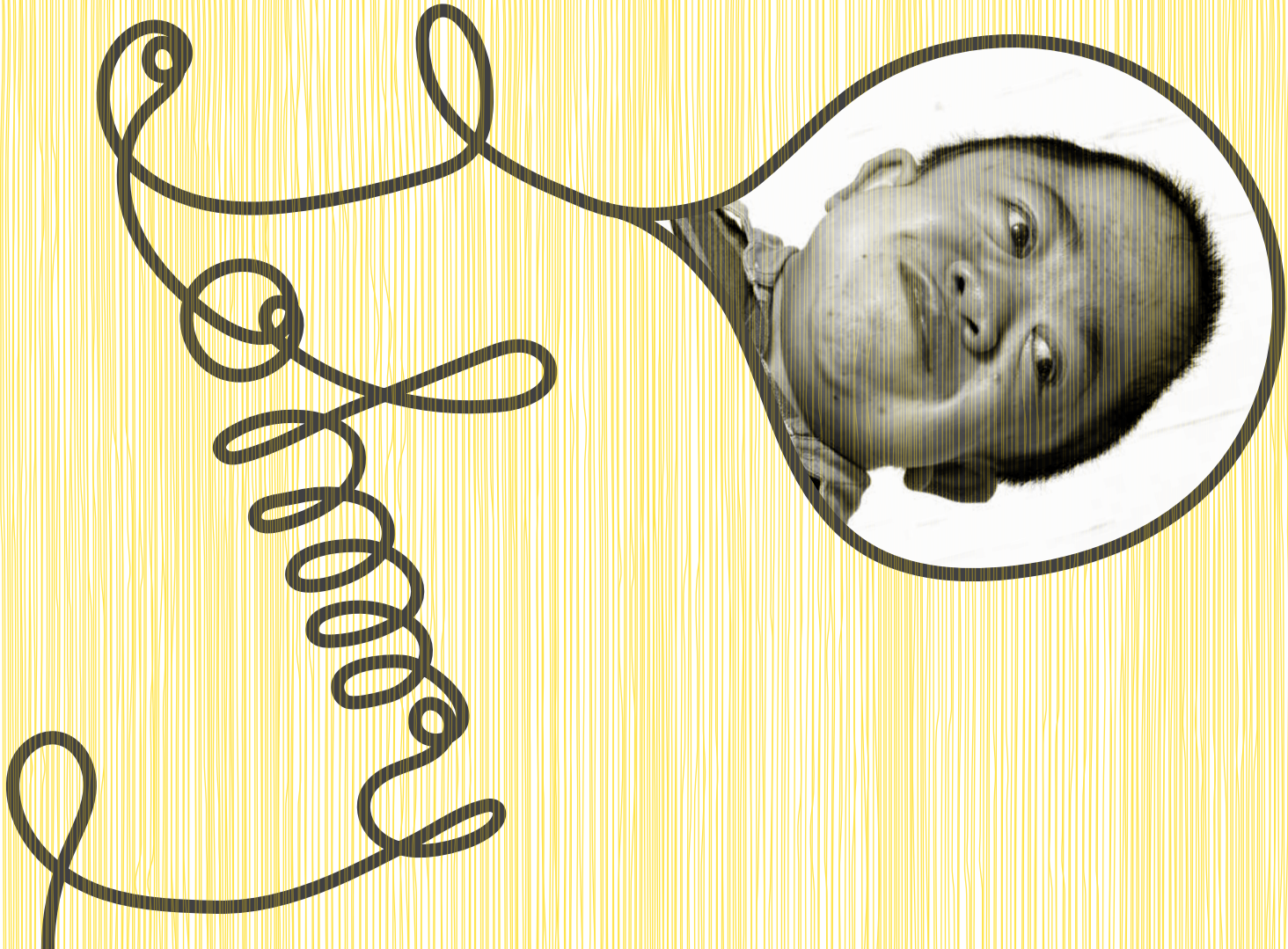
places I want to visit the most now are Japan and the UK; the former for shopping, especially since I am such a huge fan of Japanese comics, and the latter for the mystic nature of the country.

I may live a shorter life because of my disease, but it is never my concern. The most important thing is to live the moment and enjoy life every day. I do have a darker side, where I constantly compare myself with others and feel bad about the differences. I may ask questions like “why am I different?”, “why do others perform better?”, or “why are others treated better?”. I may sometimes split hairs and feel bad, but I am very fortunate to have a very good friend to comfort me and provide me with psychological guidance whenever I need. This friend has helped me a lot on my thoughts and relationships. To all my friends, I truly wish that we could be friends forever from the bottom of my heart.

Medication again

Thanks to HKMPS’s fight for our medication, I have been allowed to receive enzyme replacement therapy since July last year. However, my cardiac rhythm has become uneven due to the side effects, and the treatment has to be paused. The doctors said they have already enquired the pharmaceutical company and is following up the case. I hope the treatment could be resumed soon, so that the disease could be controlled and I could be free. I have recently found a part time job tutoring primary students. I hope to earn a bit more to lessen the burden on my family.

PowerShot G10
Canon



Reborn

Johnny Yeung

25 April 2011 is the date of my reborn. I was baptised in front of all my relatives, friends and fellow Christians. I have encountered numerous difficulties and challenges because of MPS since birth. In the past, I would blame myself and ask if I had done anything wrong from time to time. But not anymore. Now that I have believed in God, I know that God would lead me on a bright path, and to Heaven at last. There I would no longer be blind, and I would see my sister Annie again. In Heaven, there is no MPS, but only happiness.

Waking at eight, it was totally dark

Due to the lack of some enzymes, my body is unable to digest Glycosaminoglycan. Different problems have appeared since I was three or four. I have a bigger head, shorter and fatter fingers and clumsier joints unlike the other children my age. My mother took me to the doctor and I was diagnosed with MPS after undergoing numerous tests. I became an elder brother when I was three, when my sister Annie was born. She was diagnosed of MPS a couple of years later too. I think I understand how she felt more than others, because we were facing the same difficulties and challenges.

I moved from my grandmother's house in China to Hong Kong to live with my parents and Annie. I can still recall we lived in To Kwa Wan at that time. My mum brought me to Tsim Sha Tsui to apply for the children's ID and we went to Kowloon Park afterwards.

One night, I suddenly vomited and had a headache, and I rested in bed after taking the medicine. I woke up at eight the next morning, and found it was all

dark outside. I asked my sister for confirmation but she said it was all bright. It turned out that my disease had caused necrotic lesions of my eyes' nerves. I would never see again.

In spite of that, I can still remember the bright coloured peacock we saw in Kowloon Park and the

appearance of my parents and Annie; they will forever look young! I simply accepted my sight loss because of my optimism, as, after all, there is a silver lining in every cloud. At least I would not have to be afraid of seeing the sufferings of people around the world. There is no point over-thinking the incident after it happened, and there is no point blaming myself. The only thing I should do is to live my life happily every day.

Unexpected death

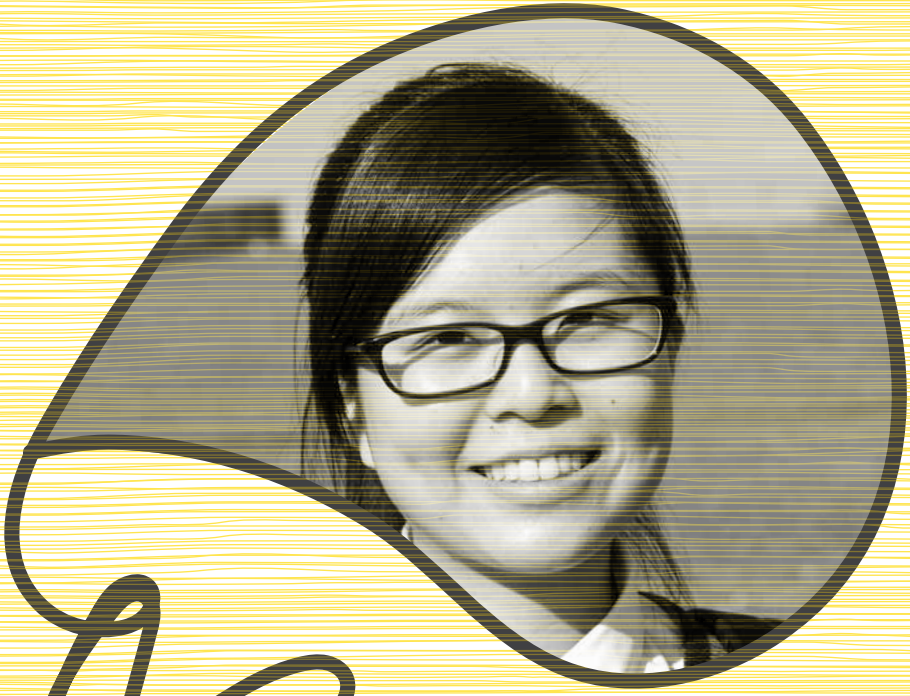
With the help of my family and Annie, my life remained the same after blindness, except I no longer have to read my textbook, write, or be afraid of being punished by teachers to write lines. I was relaxed and happy, and I never thought about death. Just that death was around the corner all along.

One morning, Annie and I wanted instant noodles. For some reason, my mother was particularly accommodating that day and agreed right away. We were eating happily and Annie ate faster than me. She went to the bathroom after eating. Suddenly, we heard a thud in the bathroom. We were worried, but getting in and out of hospitals are normal routines for us. My mother therefore suggested that my father accompany me to the school bus first and she

would go to the hospital in the ambulance with my sister. Just before I got on the school bus, my father received my mother's phone call, saying that Annie had passed away.

I could not accept her death at that time. I did not understand how easily people die. But what has happened has happened, and I can only accept it. She has left us for more than two years now. I still miss her from time to time and think about the memories of her when she was still home, but I know we would meet again in Heaven someday. I will not be sad simply because we cannot see her temporarily. Her death made me understand that death often comes unexpectedly, but I shall not be afraid because God is with me to guide me and protect me. Even if I leave the world while my parents are still alive, I would not be worried because we are one big family in HKMPS and we would support one another. My mother has also believed in God and He would watch over her too. I would pray for my dad to believe too, so that we could all gather again in heaven in the future.

Even my skin improved after medication!
The government has finally agreed to sponsor the expenses of our medication after HKMPS fought hard for it. I have been receiving medical treatment in hospital every week since 2009 and I am feeling better. When I walk, I no longer get easily short of breath as before. And I could do more without feeling tired. My digestive system and my skin condition have improved too. The medication, however, has to be injected into my blood vessels, and it is getting harder and more painful to find them. But there is no other way other than to bite the bullet and man up! I am now a full time Form 6 student and my wish is to work in a sheltered workshop to support myself.



Roger

A rule-abiding foodie

Karen Kong

I have never liked meat. It was probably my body's defence mechanism. My body lacks an enzyme to break down proteins, resulting in Urea Cycle Disorder, a problem with the metabolism of amino acids. I do not quite understand the biochemical principles involved, but only the fact that I cannot have too much protein, or else I would look dull or distant, followed by a fever and nausea. If it gets serious, it may even be life threatening.

Near-death feeling

I was born in Shenzhen. But I cannot recall much of the things that happened when I was young. The only thing I can remember is being admitted to Alice Ho Miu Ling Nethersole Hospital right after crossing the border when I was five. I was transferred to Prince of Wales Hospital later when I attended kindergarten, and I have been receiving treatment there ever since. There I met Dr. Joannie Hui, who introduced me to the Hong Kong Mucopolysaccharidoses and Rare Genetic Diseases Mutual Aid Group. It was only after meeting the members of the group that I realised that there are a lot of rare genetic disease patients in Hong Kong too. The members and their families help and support one another, and share their experience in dealing with the disease. I perceive myself as one of the lucky ones, as my physical and mental developments are normal and my condition only worsens if I eat too much meat.

The last time I ate too much meat was in 2008, when my cousin came to Hong Kong to visit my family. We had hotpot together and I ate too many beef slices and cheese-balls without noticing. The symptoms occurred the following day. I looked dull and distant, and started vomiting. My mother sent me to the

hospital immediately. The blood test showed that I had had too much protein and I had to be treated in the Intensive Care Unit. I never thought about death under normal circumstances, but this was my first close encounter with death. It was indeed terrifying, because I did not know where I would end up after death.

Meeting the best nurse

Apart from staring death in the face, I was lucky to meet a very nice nurse during that stay. Although I have forgotten her name, her love and care remained in my heart until today. When I missed home and cried, she did not only comfort me gently, but also chatted with me about the content of the magazines to keep me from boredom. If everyone working in the medical field could take care of patients whole-heartedly like her, I am sure many suffering patients would feel better.

I am also relatively lucky when it comes to the use of medicine, because there is medication for my disorder and it is affordable for my family. The government doctors transferred me to the Division of General Medicine in Tuen Mun Hospital when I was 18, and my case is now being followed by a different doctor every time because of the system. They treat my case like a new one every time, never reading my records ahead, and always requiring me to explain to them my situation. It is very inconvenient. I hope government hospitals can improve their administration by assigning doctors to patients with serious conditions, because we would always miss out important notes if we are asked to tell the doctors our disease every time.

My love for the Tin Shui Wai District

I have lived for quite a while in Tin Shui Wai. I even study here. I can be regarded as one of the earliest students studying under the new curriculum. I am

a Form 5 student at Queen Elizabeth School Old Students' Association Tong Kwok Wah Secondary School. Besides Chinese, English, mathematics and liberal studies, I am also studying history and tourism and hospitality studies.

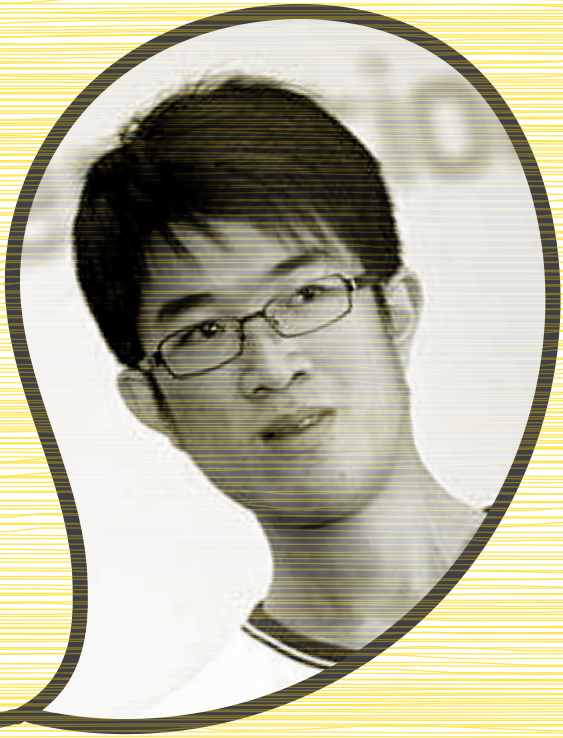
I enjoy surfing the Internet and watching movies in my free time, and what I enjoy most is playing with my puppy. Speaking of movies, I suddenly recall two movies directed by Ann Hui, namely *The Way We Are* and *Night and Fog.* I live near where *Night and Fog* was filmed, and I often pass by the bridge where Simon Yam likes to walk with his two daughters in the movie. The Tin Shui Wai district that I know is in fact not as described in this tragic movie. There are of course youth problems in the district, as well as some low-income families with relatively poor living conditions, and there are also couples with various problems because of their age differences. But I believe there will always be problems in different districts, and these are not limited to Tin Shui Wai alone! To me, the movie created a labelling effect, and it neglected all the good people and good things in the community.

This district is, on the contrary, very pretty. When the school was suspended in 2003 because of SARS, I rode the bicycle every day around the district to enjoy the quiet scenery. It gave me a peace of mind. I may try to design some routes to re-introduce Tin Shui Wai to the general public, applying what I have learnt in my tourism and hospitality studies.

Carefully calculate to eat more!

I am studying tourism, and I also like to go travelling. In 2007, I went travelling in Japan with nine relatives, including my mother. It was amazing! I even tried the Red King Crab there. This spring, I joined a tour to Taiwan with a friend, with my mother's consent. She was worried about me travelling alone at first, but

she later realised she didn't have to, as I was very careful and I packed all the essentials and medicines days ahead. I paid for the trip with my savings, and during the trip I went to the flower exhibition and visited the famous Shilin Night Market. I hope I could visit Taichung one day to see its views and try its cuisine. Trying out new food and experiencing foreign culture are perhaps the must-dos for many tourists. But for me, good food is not only important during travels, but also during everyday life. I am in fact a foodie. I always pay attention to food advertisements on newspapers, and I share where to find good food with my friends on Facebook. When I encounter a recipe that appeals to me, I would cook it myself after buying all the ingredients needed, and my mother would be the "lucky one" to try my dish first. She would occasionally give me tips on cooking too. However, I must always carefully calculate the amount I can consume before eating delicacies, otherwise I would be in big trouble if I have too much protein!



Jerry

With life there is hope

Terry Lai

"One would only succeed by fighting hard; there is no other way in life" is a motto printed on a scroll hanging at my home, which has accompanied me as I grew up. Now that I think about it, what does it actually mean by fighting hard? Literally it means waging a war and fighting as hard as you can. But in the modern world, there is not much chance of fighting a war, and the meaning of the word should be changed according to the environment.

Handing my homework over to the dwarf

I would regard myself as an optimistic person who has always been curious about everything nearby. I am quite "nosy" in some sense and I enjoy exploring. Maybe that is the reason why I do not excel in any particular field—I was simply being "fair" to everything. I have never fought hard for anything specific, and you could regard me as someone with no fighting spirit.

If you insist on discussing this topic, there are a few memory fragments I can talk about. During my childhood, my fighting spirit only arises when I was focusing on winning and when playing cards with my family during Chinese New Year. There are also memories of me competing against my friends and schoolmates. What a shameful thing to say!

If you ask for examples of me being lazy, there would be, on the other hand, loads. Back when I was studying in kindergarten, I was deeply touched by the acts of the seven dwarves after reading the story of *Snow White*. I have decided to leave the dwarfs with the sacred mission of completing my homework for me, and go to sleep right away. You all know how the story goes. I was astonished when

my mother reminded me about these incidents years later, unable to believe how I had developed these thoughts at such a young age. The fact that I have this clever excuse for my laziness probably proves the "true nature" of being human.

I entered my primary school years with this personality. I did not fight hard at all, and I did not put any effort into my schoolwork. I read my textbooks, paid attention in class, but I seldom studied after school, and most importantly, I hated doing homework. My parents at that time were both working to support my family, and my brother was studying in a whole-day school unlike me in an AM school. No one was there to supervise me from noon to 5pm every day. My mother would cook my lunch before she went to work and keep it in the rice cooker. I would have it after school ended. I would arrive home at around the same time every day from Primary 1 to 3, and I would have my lunch while watching educational television programmes, regardless of what grade they were for. I watched the programmes over and over in those three years; so much that most of the knowledge of primary school was embedded in my head. The knowledge became handy at examinations. Though I was not the best student, I was always among the top five or ten.

Of course I became bolder as I grew older. I would always hang out with my schoolmates after school. I would "process" the food at around 4pm before my brother came home to act as if I had already eaten and was very full. And I would spend all my mealtime playing and doing sports! Primary school life was great. It was always my personal time, except

when I was punished by teachers to write lines, stay afterschool, work on the homework that I did not do, or when I trained with school teams or worked as a school librarian. I could visit shopping malls and parks, and play sports like football. I did all sorts of things: eat, drink, have fun, whenever I wanted to, but never "fighting hard". How shameful! Yet changes can happen in a split second; you can never dodge or hide. This may be fate, the force over everything.

Unknown disease hitting all of a sudden

When I was around nine, the time when I was studying in Primary 5, a great change befell my family. It was not financial, but my brother was diagnosed with an unknown disease. He became feeble after a fever, and his muscles became weak. The disease was not recognised even after asking many. We could only wait for the test results from the hospital: blood tests, extracting muscle tissues, DNA checks... We tested basically everything we could, and after about a year, my brother was finally confirmed to be suffering from Pompe Disease, a rare genetic disease.

This disease brought great changes, not only financially, but also to my parents' emotions. More importantly, I may suddenly develop the disease in the future as well. My test results came back fine, but many indexes were on the borderline. This worried my parents even more—who would ever thought that both their sons, healthy since birth, would be suffering from this "strange disease". This struck us speechless like a time bomb about to explode at any moment.

The disease was incurable then and there was nothing doctors could do to help. They could only provide us with vitamin supplements and physiotherapy sessions, then monitor and record our situation. I witnessed a drastic downturn on

my brother's condition. He became weaker and breathing became harder and harder for him. His spine twisted to the side, and was forced to undergo surgeries to fix his spine. He started using breathing machines, sitting on wheelchairs, and I would be lying if I say we were not worried.

At that moment, the thought of "fighting hard" came to me. I wanted to change my destiny with my own hands. I wanted to prove to my parents that I was healthy and was able to be their support. I hoped to reverse the negative emotions in the family and lessen my parents' worries and burden. That is why I started doing sport, in hopes of prolonging the degrading process of my body. I played basketball most, for one or two hours every day after school. It was sometimes shooting exercise and sometimes dribbling exercise. I tried to keep my body exercising.

Sadly, the disease still struck. I was a lot weaker than others in my junior secondary school years, and the difference became quite obvious. When I was in primary school, I was able to convince myself that even if there was a difference between my schoolmates and I, there were still those who are less talented in sport to make it less intolerable. However, that difference became unbearable starting from Form 3. I used to be in several school teams in primary school, but I was not as good as my old teammates , and I even dropped to the last place. I was very sad about it.

Failed gaining confidence from video games

I experienced physical downgrading during that period. My muscles became weaker, my spine twisting, and it was even hard for me just to walk with my back straight. My psychological bearing was also heavier, partly because of the future of our family, and partly because of my experience in

school. I can still recall being laughed at since Form 3 because of the changes that had happened to my body. My schoolmates talked about me during recess or lunch, and some would even walk beside me again and again, mimicking my posture just to tease me. Silly as I was, the thought of escaping gradually seeded. I slowly gave up playing sport and turned to video games, because I thought I could regain my confidence there. Gradually I did not want to go to school anymore because I did not want to see my schoolmates. I escaped school every day. I left home with my school bag, but I called in sick outside home, and went to arcades until school was over and headed back home. I know it was crazy looking back now, but I really did not want to go to school, to be boycotted by schoolmates, to be teased again and again. This, however, only lasted for one week, until my parents found out about it. My mother even went to school in person to explain my situation to my teacher. This has brought me new thoughts and inspiration.

The world would be brighter if you let go

I figured that a person's worth is not defined by the thoughts and views of others, but by the promise and affirmation you make to yourself. As long as you see your own value, there is no need to fear of others' opinions, and you would not be disturbed and lose direction. I started letting go after that incident, and gradually started to accept the fact that I am sick. I still did not explain to my schoolmates what I am going through, but I can take their jokes about my body as a topic in our conversations, and I did not try to avoid it ever since.

It is funny that after I let go, my schoolmates lost their interest and stopped bullying and teasing me like they used to before. My grades in Form 3 were always lingering at the bottom because I was avoiding school all the time. I was even the student

with the worst results once, so I was forced to study arts in senior form.

I became hardworking in Form 4 and 5, and my results went back to average. I caught up with many of my studies, and even though the results of my public examinations were not perfect, I was still happy that I did not give up and rediscovered myself.

After repeating Form 5, I proceeded to Form 6 successfully. I have studied in a total of three secondary schools throughout my school years, and this allowed me to make more new friends and trained my social skills. I felt like having gained another life when I entered a new school, and I longed to try something I have never done before and to explore my path. My "curiosity" stroke again. I wanted to grasp this opportunity and to fight for something.

The start of the school year also meant it was time for elections for different school positions. I decided to get a post in the student union. This was not an easy task, because the school I enrolled in consisted mostly of students having studied from Form 1, and transferred students consisted only a very small population. In order for me to be elected, I must gain the support from the original students. Most importantly, I must find the right schoolmates to form a cabinet and serve the student body.

From choosing the right people, naming the cabinet, outlining our platform, to designing the slogan, posters, and promoting, everything had to be done after thorough thinking, discussion and the agreement of the whole cabinet. After deciding the direction of the student union and identifying the key areas for development, we planed every detail of the events and welfare items of the upcoming

year to ensure we could keep our promise in the future.

I still remember the student union in my Form 2 year clearly because the student president had too many directions and plans in his head. He made too many promises and his plans were too big. Listening to him in the playground, I had the impression that this student president did not plan well, and there was a great chance that the plans would not be executed, and they would end up being an irresponsible cabinet. After that time, whenever I saw him at school, I could not help but lay my eyes on him because of this deep impression. Learning from the past, I understood that I have to avoid making promises too big at elections.

There was another cabinet, which consisted of mostly girls from this school, running against mine. In that election month, my members and I went into classrooms every day to promote and canvass for our cabinet during lunch breaks and recesses. Luckily, students from junior to senior years responded positively to our promotion after all those recesses and lunchtime sacrificed. There were two huge debates later on, which sparked intense discussion between the cabinets. Both the cabinets have worked hard to be elected to serve the student body.

At last, the cabinet I led won by about a hundred votes. It all felt so unreal when I became the president of the student union. It was yet the reality, and the upcoming year would be the start of another “fight”.

The start of another fight

My main duty during my term of service was to handle administrative work. The student union was another department at school, separate from the teaching and administrative staff. It was our job to coordinate students from different sectors, to assemble them and to ensure that they were delivering things that they were supposed to do. I still remember we had at least two to three new activities every week on average, some recreational, some welfare or entertainment related, and some concerned the communication and discussion with the school. We would hold meetings regularly for people to express their opinions, and vote to decide on the main direction. My role was to eliminate first the infeasible options to narrow down the choices for greater efficiency. I would also integrate different opinions and combine them to see if there was a better way of working and even to assign the most suitable persons to the jobs.

Throughout that year, I learnt a lot on how to work as a team and some basic communication skills like how to deal with different opinions. I also learnt to analyse the pros and cons of a project impartially. These all benefitted me a lot. I often talked to the teachers till late in the evening during this time and it posed great burden to my physical condition. I was lucky that it only took two to three minutes to walk back home, so I could reach home quickly to buy time to rest.

I tried many new things during this period. For instance, I always needed to give speeches and announce the student union's activities in front of all the teachers and students at school. At first I was always nervous and my legs would shiver. Coupled with my standing posture, sometimes I could not even hold my notecards steadily. I was very shy. Yet I slowly got used to giving speeches,


本門

and established a style, controlling my tone and tempo, and I was even able to improvise a little. There was once when I was giving a speech at a sports day's closing ceremony when the students started to jeer because it was almost time to leave. My speech was interrupted and so I said, "Please stay calm and you would be allowed to leave after the speech is done." The crowd calmed down at once, and my speech ended smoothly. I did not know if my schoolmates paid attention, but I truly had a sense of accomplishment at that moment. The headmaster and teachers even praised my public speaking techniques and how I reacted. This not only gave me a sense of achievement, but also greatly increased my confidence.

Happiness after suffering

I continued my studies after the preparatory course. My family had slowly recovered because, after all, it had been 10 years since we were diagnosed with the disease and we have slowly accepted it. There had been many negative emotions in between, but my parents are getting better as we are very fortunate to have the support, encouragement and comfort from friends all around. My brother has also joined numerous social organisations and patient groups to give speeches, attend seminars, district talks and support group meetings to learn how to face the future positively and to contribute to the society as much as he can.

The phrase "happiness after suffering" may simply be a self-comforting line to many, but I can really feel that my family and I are slowly getting back in shape in the recent two to three years. We are actively getting rid of negative emotions and trying hard to let go. We have met many guardian angels and have encountered a lot of invaluable opportunities.

When my brother was first diagnosed with the disease, there was nothing the doctors could do but to say “Don't give up! There would be medication someday!” The wait of this “someday” lasted until 2006. I was searching online about my disease one day (when there was still no official name for it) and I discovered the name “Pompe Disease”. After studying closely, the symptoms described were very similar to that of my brother’s. What was more exciting was that, in that same year, a Taiwanese scientist developed an enzyme treatment that was more effective in combating the disease.

I was very happy because I knew that a new medicine would be launched in the very near future, and it may be developed specifically for the disease we were suffering from! I also thought it was all along the same disease but simply with a different name. We sought the opinion from the doctors in multiple occasions but their answer was always “There is no such news that they have heard of.” Of course I respected their opinion because they were the experts in the field.

The hospital finally renamed our disease as “Pompe Disease” in 2010, but they were still uncertain if there was medicine to treat our disease. My brother and I then searched for more information from the Internet and handed them to the doctors, hoping that they could handle it faster. We had no time to lose. If we did not treat it, our situation would only get worse. My brother’s physical condition had worsened quickly in one or two years’ time, and it was threatening his life. We had to be proactive.

When we were searching for information on the internet, we came across the Hong Kong Mucopolysaccharidoses and Rare Genetic Diseases Mutual Group and found that there were other

people suffering from Pompe Disease. Some of them had even received treatment for a few years! With the help of the group, we further learnt about the application process for receiving medication. The application and processing procedures lasted almost half a year, and my brother and I could finally receive treatment! I am really grateful to the group, the school, the teachers, our friends, and even the general public who have been supporting our family. You have given us the chance to receive treatment, and the chance of a brighter future.

With life there is hope

Starting from today, I will step up my fight. I have to settle down, take good care of myself and then find a chance to repay and contribute to society. I would first finish my studies and then plan my career. I have always dreamed of starting a company. With the Internet's rapid development, my dream could easily come true, because I can deal with the paperwork on the computer. With technology, I can easily set up my own website. I am now learning website development and e-commerce, working towards my dream.

On the other hand, I would like to participate in more community activities like holding talks, giving speeches, travelling and doing voluntary work. Through spending time and learning about other patients, I hope to help those who are also suffering from diseases. I hope everyone would be inspired to persevere after listening to what I have been through—because there is always hope. At the same time, I would also like to encourage everyone to care about and support those who are undergoing difficulties, and to be with them as they overcome challenges and headwinds.

Lastly, I wish everybody good health. It is the greatest treasure. With a healthy body, we can achieve everything we want and live happily.


第一屆
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頒獎典

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全面關懷 以人為本

"我們大多是新移民，很多更是單親媽媽以及領取綜援的，實在無法負擔請私人補習老師，幸好中電義工三年來每星期義務替我們的子女補習，實在十分感激。"

仁愛之家 補習學童家長
江太

"中電義工幫替我檢查所有電線、插蘇的，損壞的電線全都更換了，令家裡更安全及清潔。"

獨居長者
黃伯伯

"在這五年的夥伴關係中，我們見到中電義務導師對同學的個個善誘，深深感受到中電對年青人及香港未來傳遞的關懷。信任企業精神全賴管理層積極推動，以及中電員工的鼎力支持。"

國際成就計劃香港部
行政總裁
劉少坤女士

"中電多年來的贊助及參與，不但令更多傷健人士受惠，更協助推動「傷健融合」概念，使傷殘及健全人士能不分彼此，在無障礙環境下並肩合作，共同締造「傷健共融」的和諧世界。"

香港傷健協會 總幹事
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"中電多年來一直為銀行者活動提供電力裝置服務。每年，中電為這個活動鋪設的電纜超過三萬公尺，還在沿途安裝超過四千個燈泡，照亮每個檢查站。銀行者是樂施會在港最大型的籌款活動，我們感謝中電的幫助，使每年活動得以順利進行。"

樂施會 總裁
施日君

我們深信，為市民提供穩定而可靠的電力之餘，更應多行一步，積極關心社群，為社會上有需要的人士獻上關懷。中電感謝每位員工的熱誠支持及參與，使中電連續七年榮獲香港社會服務聯會的「商界展關懷」標誌。

我們將繼續努力，為社會發光發亮。

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CLP 中電

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.

Support Us

1. By cheque
   The cheque should be made payable to "Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group" or "H K M & R G D Mutual Aid Group"

2. By direct deposit
   Please deposit the funds into our Bank of East Asia account
   015-246-40-426130 or 015-246-10-37986-7
   and obtain a deposit receipt.

3. By online donation
   Please visit the following website for details:
   www.mps.org.hk/donation.html

Please mail your cheque or deposit receipt to our office. If you need an official receipt from us, please specify your name, mailing address and contact phone number.

Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group
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Kowloon, Hong Kong
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email: info@mps.org.hk
website: www.mps.org.hk/en

HKMPS Publications

HKMPS publications are also available in electronic version, please visit our website for details: www.mps.org.hk/en/publish.html

Rare Parents

Publication Date: May 2010 (First edition) |
Publisher: Bbluesky | Language: English | Pages: 128 |
ISBN: 978-988-99703-0-7

Little Giants—Dreams of Braving MPS

Publication Date: September 2006 (First edition) |
Publisher: Bbluesky | Language: English | Pages: 80 |
ISBN: 988-98181-7-5

罕有人情 *(Rare Love)*

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Languages: English, Traditional Chinese, Simplified Chinese | Pages: 144 | ISBN: 978-988-19578-6-3
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HKMPS

Rare Journey contains not just our stories of struggle, but also that of our many "fellows" — including our parents, siblings, friends, schoolmates and healthcare professionals. With this book, we wish to thank all those who love us. It is you who have made our stories of hope and aspiration possible.