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Living with Morquio

By Jocelyn Wong

I was born as a healthy baby with 8 pounds 12 ounces in Hong Kong. I am the third child in my family and I looked alike with my unaffected sisters at that time. Difficult breathing was the only problem that I have since it is very common in infant. Thus, my parents never think I have serious disease.



5 Months Old



18 Months Old

The Initial Sign

I began to walk at a year old like other children. Everything seems to be fine. When I was about three years old, my parents noticed that I grew very slow and my knees bent slightly, but my doctor said it was very common in toddler and should be better when older.

But my knees got worse and I always fall and tired easily. My doctor referred me to a children's hospital. After multiple times of hospitalized for observations, multiple intelligence tests, electroencephalogram (EGG) test, blood test and x-rays, the doctors announced my diagnosis is Morquio by age four.

Experience of surgeries

I had have my first corrective knees surgery at five. After the surgery, I had a pair of long-leg casts which covered from my toes to upper thigh. Those became my “signature pants” for next six weeks. I was able to walk without aid after a month of physical therapy, but my knees had turned again two years later.



4 Years Old



*8 years old
legs had been turned*

My second corrective knees surgery had done when I was eleven years old. The procedure was similar to the one that I had before, but my legs have placed internal fixation which were plates on each thigh and pins in lower leg. The pins in the lower legs had removed after eight weeks of the surgery due to infection. I remember I persuaded my surgeon to let me have local anesthesia instead of general anesthesia when removing pins because I had have postoperative nausea and vomiting in my previous

experiences. I was prescribed to wear a pair of full leg braces for physical therapy and was able to walk without aid couple months later. The plates in my thighs had removed a year later under general anesthesia. I believe if I don't have corrective knee surgeries, I may not able to walk without aid today.



20 Years Old

My third major surgery was cervical fusion and had done with Dr. Ain at Johns Hopkins Hospital due to numbness on hands and stenosis at

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twenty years old I was grateful that I took leave of absence from college because I was required to wear halo brace for five months and a neck collar for six weeks. During the recovery, I spent most of my time in reading, watching TV and playing computer. I even learn how to type Chinese at that time.

After removing the halo brace, my hip pain had increased. My orthopedist told that it would be another surgery when I can't bear the pain. Finally, I had have my right hip replacement in 2008. I was glad I don't need to wear brace after THR, but I needed to get off my bed few days after the surgery. The hip replacement is work on me. It reduced my pain from 8 to 3 on pain scale. Even thought I still have pain on my hips and lower back but it can relieve from resting and regular pain killer.

Community with other MPS

Technology wasn't as convenient as today during the times I was born. Also caused of language barrier, there are very few MPS information are written in Chinese, my family and I didn't have a chance to understand Morquio and meet other MPS family when I was little.

Recently, I had attended several MPS conferences around the world. I impressed that there are many people supporting MPS and I had met some MPS families. It is amazing to know doctors and MPS families in person and some of them I even had talked via email for years.

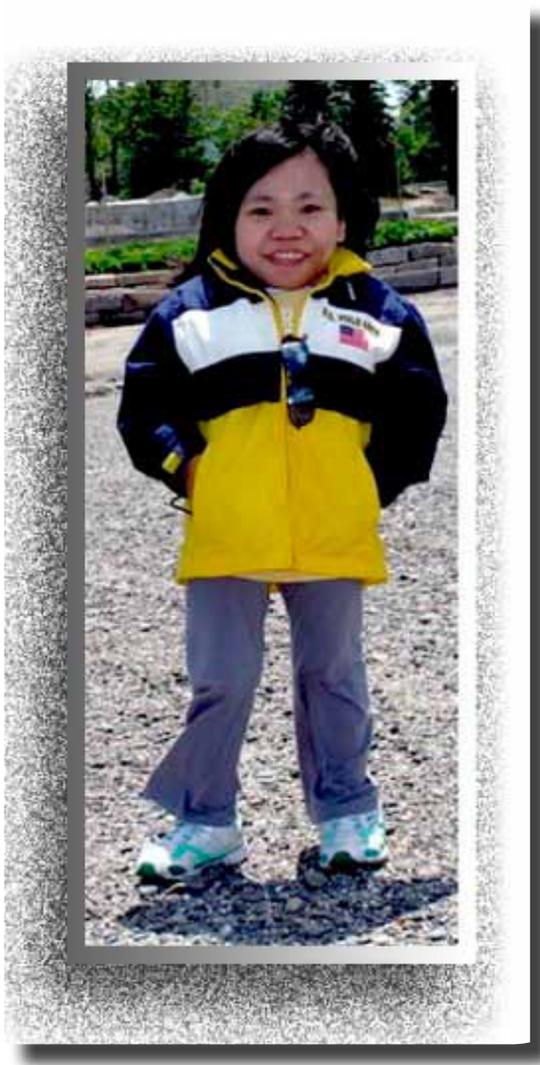
My Current Situation

I keep visit my family doctor, audiologist, ophthalmologist, cardiologist and orthopedist yearly. My hearing is getting worse and worse but I am still able to hear with hearing aid. Sometime, I think it is nice to have hearing loss because I can sleep whenever I want and wake up naturally without anyone bother. My vision also getting worse and the glasses is useless due to cloudy cornea, but I am grateful that I am still able to see even I can't drive. I am still

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connecting the world via internet and doing some art like origami (paper folding), beading, and graphic art.

As an adult Morquio, I believe I am blessing because there are many people who are suffered in Morquio or other diseases has more surgeries than I do and may not able to see, to hear and walk or move freely, but I am still able to do these today. Even though Morquio has limited my ability and affect my living, I have gained a lot, especially medical knowledge which I don't think I would know if I don't have it.



20 Years Old