



Set Feet On the Ground

By Wu Yen-Ping



“The surgical wound hurt so much that I almost cried. I held it back in though. As soon my wound recovers, with some rehabilitation, I’ll be walking again. I want to go to the bathroom on my own!” The solidarity in her message is clear. These are the words, typed out on a smart phone with her trembling hands, of a 25-year-girl who recently underwent corrective ankle osteotomy, tendon transfer, and myofascial release. Her name is Xiao-Hui, a patient suffering from Wilson’s disease, a rare genetic disorder. After onset, she gradually lost the ability to speak, and has to communicate her thoughts via her smart phone.

An Unexpected Assault

Xiao-Hui, a girl with a bright personality, was a nursing student in a college of technology. During her internship as a sophomore in 2010, she began to experience a series of symptoms, which she mistook for a flu and did not pay much attention. During her internship as a senior in 2012, she experienced tremors in her arms and legs, smaller handwriting, slurred speech, drooling, loss of appetite, and frequent choking. Her internship partner realized something was wrong and informed

the school teacher right away. The teacher notified Xiao-Hui's parents and recommended Xiao-Hui to take some time off school for a full check-up at a hospital.

Xiao-Hui's symptoms such as difficulty swallowing and walking grew worse by the day. A DNA test confirmed that Wilson's disease was the culprit. While hospitalized in a medical center, she joined inpatient participation groups to learn more about her condition. In the meantime, her symptoms continued to exacerbate. Her confidence began to crumble. She responded passively to treatments. After a while she simply decided to leave the center and went

home. At first, Xiao-Hui's mother could still take her out for walks. In time, walking became too much for her. She could barely leave the house. Eating, too, became a challenge. She had to rely on enteral feeding through nasogastric tube to survive.



Xiao-Hui's inward ankle deformity prior to surgery.



Rehabilitation specialist Chiu Chia-Yi teaching Xiao-Hui on rehabilitation exercises.



Tzu Chi's Home-visit Shedding Light on Potential Recovery

Watching her body wildly out of control, Xiao-Hui felt depressed. That signature smile of hers was gone. "I wanted to speak my mind, but the words just came out wrong; I wanted to pick something up, but my trembling hands were too clumsy; I hoped to stand firmly up straight, but my legs simply failed me," she said. She felt like a monster. She isolated herself from rest of the world. Negative thoughts began to eat her up from inside.

Thanks to the timely intervention

of the Tzu Chi volunteers, Xiao-Hui eventually reacquainted with her optimistic self...

Xiao-Hui's grandmother was a Tzu Chi recycling volunteer in Ruifang, Keelung, who collect recyclables from the neighborhood and deliver them to a local Tzu Chi recycling station. Many years ago she broke her leg in an automobile accident. Because the prosthetic limb she installed limited her mobility, and that her body was not as capable due to old age, she unwillingly retired from her recycling work. Xiao-Hui's mother had been a Tzu Chi member for more than a decade. Because of her long standing relations with Tzu Chi, when her



Neurologist Chen Kuei-Chuan injected Xiao-Hui with Botox to release the excessive tension in her muscle.

daughter was incapable of leaving the house due to her conditions, she thought of Tzu Chi right away. “I was concerned that she may get depression from staying at home too long, so I invited Tzu Chi volunteers home to keep her company. Among them were Sister Huang Shu-Chun, Lin Ching-Ju and Chen Se-Ching. I am very grateful to them. They came by quite often to talk to Xiao-Hui, and were genuinely concerned with how we were doing.”

In April 2017, Supt. Chao You-Chen led Taipei Tzu Chi Hospital medical team and TIMA Taiwan Northern Branch members on an outreach in Ruifang. The team took advice from local volunteers and visited Xiao-Hui at her home. That fateful meeting changed her life forever.

During the home visit, Xiao-Hui’s mother recounted her daughter’s life ever since her first onset at 17, the helplessness she experienced when her symptoms worsened despite treatment, and the nervousness that hovered over her brothers and sisters in fear that they might be next. Dr. Chiu Chia-Yi, a rehabilitation specialist, conducted her preliminary diagnosis, and taught Xiao-Hui some rehabilitation exercises and abdominal breathing. Supt. Chao gave the mother his promise that Taipei Tzu Chi Hospital would do all they could to help Xiao-Hui.

Wilson’s disease is an autosomal recessive, rare genetic disorder that

occurs in about 1 in 30,000 people. The mutation to the gene coding (ATP7B) on chromosome 13 leads to abnormal copper metabolism, causing copper to build up in liver, brain, cornea, and heart, resulting in systemic symptoms. The culprit behind Xiao-Hui’s slurred speech, difficulty swallowing, tremor, writing problems, and walking abnormalities is the excessive accumulation of copper in her brain. Although Wilson’s disease had left her with many irreversible neurological deteriorations, what modern medicine can do for her is to inhibit the abnormal copper metabolism and reduce her symptoms. Supt. Chao assembled medical experts from the department of hepatobiliary and gastroenterology, pediatrics, rehabilitation, neurology and orthopedics for an interdisciplinary evaluation on potential treatment options, hoping to elevate Xiao-Hui’s life quality through appropriate health care.

The abnormality of Xiao-Hui’s copper metabolism had led to excess muscle tone, rigid joints, and an inward rotation of her right ankle. As result, she was unable to walk and spent three years on a wheelchair. Neurologist Chen Kuei-Chuan injected her with Botox to address the involuntary muscle tone in her feet; TCM practitioner Chen Pei-Shan applied acupuncture to ease the discomfort brought about by her excess muscle tone; and the rehabilitation team recommended the use of corrective tools



The family meeting before Xiao-Hui's surgery.

to adjust her right ankle deformity with splint-cast combination. Approximately one month after the splint-cast was applied, Xiao-Hui's leg developed severe pressure sores. The medical team terminated the splint-cast correction, and decided to instead perform a corrective surgery when her skin recover from the sore. However, Xiao-Hui rejected surgery, which brought her treatment to a halt.

Both Feet on the Ground

Four months later, it became harder and harder for Xiao-Hui to visit bathroom on her own as her functional capacities continued to degenerate. She realized that she could continue living like this. After pondering on the

matter, she decided to comply with the doctors' recommendations on surgically correcting her deformed foot, allowing her to stand firm on the ground once again and access the bathroom on her own.

She was hospitalized on Nov. 15, 2017, evaluated by orthopedic surgeon Wang Chen-Chie for corrective surgery. On Nov. 18, a family meeting was convened, during which Dr. Wang explained the evaluation and the success rate of the corrective surgery to Xiao-Hui, her mother, Vice Supt. Shyu Rong-Yaun, and the medical team. The surgery would help Xiao-Hui to improve the range of her physical functions.

"From the topography, it is confirmed that Xiao-Hui has clubfoot, a deformity

common in certain patients with Wilson's disease. The aim of this hospitalization is to evaluate the three-dimensional structure of her ankle and to observe the organization of her bone structure," Dr. Wang explained during the family meeting. "Clubfoot is a deformity caused by imbalanced neural activities that lead to strong peroneal and tibialis posterior tendon and weak tibialis anterior muscle. The first step of the surgical plan is to release the strong peroneal and tibialis posterior tendon and tendon sheath." "Depending on the condition, parts of the strong tendon may be removed and transferred to the opposite side to

balance the tension, the most important step is to rearrange the bone structure through a specialized corrective osteotomy, realigning the seven tarsal bones in the back of the foot, and fixate them with steel nails and plates. Some of the bones may be damaged due to prolonged deformity. We will use donated bones from our silent mentors to fill in the gaps to improve recovery, so we don't have to use other parts of her bones. Bone and tendon transfer procedures have low rejection rate, so no anti-rejection drugs are needed."

After a thorough explanation, Xiao-Hui and her mother grew confidence in



Concerned with Xiao-Hui's recovery, Vice Supt. Shyu Rong-Yaun and Rehabilitation specialist Li Kun-Chang visited Xiao-Hui's at home two weeks after her discharge.



the surgery. Dr. Wang reminded them, “The first three months after the surgery is critical in bone growth. After the stitches are removed and the bones are stable, we will need assistive devices that can fixate your leg from top and bottom. Three months later, when the bones have healed to a certain degree, you can start practicing walking wearing protective gear.”

Team Work Makes the Dream Come True

To build up Xiao-Hui’s confidence, a day before the surgery, the hospital supervisors, social workers and hospital volunteers held a party for her to pray for a smooth surgery. On the day of the surgery, Supt. Chao and rest of the team cheered her up. With all the love and care, the surgery was a success. A week later, the pain gradually subsided, and the pain medicines were removed. On Dec. 4, Xiao-Hui was discharged with overwhelming love and prayer.

Discharged, Xiao-Hui eagerly waited for her wound and the bones to heal so she could rehabilitate. Two weeks later, she returned to the hospital to remove the stitches. In the follow-up appointments, Dr. Wang found out that her bones healed particularly well, and thus permitted her to begin rehabilitation, starting with standing and slow walking.

On April 22, 2018, the eve of

Mother’s Day, Supt. Chao and Vice Supt. Shyu visited Xiao-Hui’s home in a TIMA medical outreach, with a cake for her as a Mother’s Day gift for her mother.

With months of practice, Xiao-Hui gradually gained the ability to walk with the assistance of a walker, fulfilling her wish to be independent in her bathroom visits and to walk up and down the stairs on her own. Before the surgery, she, 172cm in height, had to rely on her father to carry her up and down the house. “I don’t think I can carry her much longer,” her father once said. Since she can walk on her own, it is the best gift for her parents.

Optimism for the Future

Wilson’s disease relentlessly altered Xiao-Hui’s life. She did not have the right to say no. Her optimism, though, supported her through the darkest time and lifted her above her suffering. Especially when the Taipei Tzu Chi medical team worked collaboratively to fulfill her wish to walk on her own in those bathroom visits, she grows more optimistic by the day in the face of this rare and irreversible disease. It’s all possible because she has a medical team rallying behind her.

With her wish came true, Xiao-Hui types on her phone one letter at a time, “I can walk and stand better than ever before. I know now that efforts beget

rewards.” Looking back at the days, she writes, “When the Wilson’s disease first started, I could still walk on my own even with my arms and legs shaking. I even took buses to the hospital and the clinic for rehabilitation. To correct my deformed feet, my dad took me to the hospital to make who knows how many corrective shoes. No matter how many they make, I’ll wear them out pair by pair.”

“Because it became harder and harder for me to walk, I had to start using a wheelchair, and I rarely went out. During that time mom and dad took me to the zoo twice. When we went to a shopping mall and we were on an escalator, my personal aide did not know to control the wheelchair properly, and I fell on the escalator. Mom screamed so loud, and dad hit the stop button saving my life. I stayed at home ever since,” Xiao-Hui types her thoughts and experience after her illness one letter at a time. “Because of the disease, I spent all my time at home, practically isolated from the world. I felt like I was a monster. I did not like any outside contact. Mom was scared that I would have depression, so she started introducing me to Tzu Chi. After that, I started to interact with people and grew happier and happier.”

She was to become an angel in white, taking care of those in need, but as fate would have it, just when she completed her studies and was in line to join the rank of nurses, Xiao-Hui became



Xiao-Hui begin to walk firmly on solid ground with the help of a walker.

a patient who needed care. “At first I thought my disease was untreatable. But with my bravery and Dr. Wang’s skills, I can now walk again! For that I have to thank the medical team of Taipei Tzu Chi Hospital, who worked so hard in treating me and taking care of me. Furthermore, I would like to thank my mom and dad for their love and care throughout my sickness,” Xiao-Hui shows me the text on her phone, and gives me a smile as bright as sunshine.