



Photos of Life

Smiles they show while on arduous journeys



●Yan-fen, at 32, not becoming ill yet, bears a new mother's charm. (Photo provided by Xia Yan-fen)



●Six out of the seven siblings of the Zhu family. Except for their fortunate elder sister Sui-ping, the other six siblings are forced to carry the cross for genetically inherited disorders, having acquired Spinocerebellar Ataxia. At the time of this photo, two of Sui-ping's younger brothers (Sui-yong and Ke-ying) became ill. For financial reasons, Sui-ping is forced to bring her two brothers to stay with relatives on inexpensive mainland China.

A rare family photo from 1993, this was shot in front of their family grave in Taiwan prior to their first trip to the mainland. Uncertain of the future, Sui-ping wanted to bring Sui-Yong to see their other family grave on Mt. Kuanyin, worrying he would be the first sibling to rest here. Presently, Sui-yong and one of their younger sisters Ming-hua have already passed on. Their other siblings continue to fight for life.

Front row starting from the right: Ke-qin, Sui-yong, Ke-ying

Back row starting from the right: Sui-ping, Ya-pin, Yan-fen

(Photo provided by Zhu Sui-ping) (See Chapter One for their story)



●A Young and Handsome A-Jie, 20 years old, attends military academy.
(Photo provided by Song Jian-yi)



●Forever a youth at heart, A-Jie was attacked by Multiple Sclerosis on the eve of his 30th birthday, making him feel imprisoned for life. MS attacks range from mild to severe, sometimes triggering pain within certain nerves, tremors, and high fever. It's as MS patients say: "It creeps up on you slowly, and then quietly steals a part of your life."

This photo shows A-Jie after becoming ill, on one of the rare opportunities he took his dog for a walk. A-Jie already suffered from vision loss at that time.

(See Chapter Two for A-Jie's story)



- Hereditary Epidermolysis Bullosa patient called by the nickname “Bubble Bobble Dragon,” A-Ying (Liu Pei-jing) forms blisters all over her body, breaking and leaving scars. This beautiful fairy is cared for by her loving mother, making her enjoy warmth, optimism and a healthy, happy life. This photo shows A-Ying, 9 years old, playing in a park close to home. (Photos provided by Lin Jin-gui)



- A-Ying with her mother Mrs. Liu. Their struggle against sadness is aided by the many kind, caring people of southern Taiwan. In this picture, 12-year-old A-Ying is accompanied by her mother in Chang-Gung Memorial Hospital after the first time her head is shaved. A-Ying required a skin graft from her scalp to repair her arm.

(See Chapter Three for A-Ying's Story)



- In 1993, Li Tien-yu (back right) took his family to the US, forever changing the lives of his two sons with Duchenne Muscular Dystrophy. Here, Zhi-ren (front right) and Zhi-wei (front left) enjoy the rights deserved by all children in an effort to make up for nature's mishaps. Specialized care provided to them brings out spirits that, unlike their bodies, are disabled in no way. This photo was taken during Halloween in 1995 during the family's trip to a farm that grows pumpkins. Zhi-ren and Zhi-wei live their lives to the fullest with the encouragement of their parents along with their electric wheelchairs. (Photo provided by Li Tien-yu)



- In July, 2001, Li Tien-yu (center) held the second annual computer camp at National Taiwan Normal University for children with rare disorders. At the Department of Information and Computer Education, Professor Li eagerly provides technology to better the lives of disabled children. (Photo provided by the Taiwan Foundation for Rare Disorders)



- Xiao Ren-hao was 2 years old when diagnosed with Gaucher's disease. Treatment was found for him when he was 7 years old, but would not be available to him until 13. After the Taiwan Foundation for Rare Disorders held a press conference, the Eden Social Welfare Foundation lent NT\$2.6 million to purchase four to six months worth of medication. This photo was taken in April of 2000 in a hallway at Mackay Memorial Hospital. Swelling in Ren-hao's stomach has gone down considerably thanks to routine injections. Here he is shown supported by his mother while he awaits leg extension surgery the next day. (Photo provided by the Taiwan Foundation for Rare Disorders) (See Chapter Six for Ren-hao's story)



●Serena Wu and Professor Tseng Min-chieh worked together to found the Taiwan Foundation for Rare Disorders. These friends in need set out to do everything in their power for their children, Terry Wu (Urea Cycle Disorder) and Zeng Zi-fan (Disorder of Leucine Metabolism). Through countless sorrows but harboring no regrets, they seek a hope with a one in a hundred chance of success. Helping themselves by helping others, they provide more services to rare disorder patients by creating an oasis in Taiwan's barren desert of a healthcare system.

The foundation was established in June of 1999, not only sheltering patients from the storm, but also serving as the front in the battle against the system. With the combined pressure of their numbers, they are posed to open the way for expansion towards a greater social movement.

This picture was taken on December 10, 2000 at the opening ceremony for the "Taiwan Organization for Disadvantaged Patients." This resulted from the positive and constructive cooperation between the Taiwan Foundation for Rare Disorders and 22 other rare disorder associations.

Shown here are Taipei's Mayor Ma Ying-jeou (right) as he speaks with Professor Tseng Min-chieh (center) and Serena Wu (left) about the situation of rare disorder patients in Taipei.

(Photo provided by Taiwan Foundation for Rare Disorders)

(See Chapter Seven for their Story)



●An active, outgoing Zi-fan grows up under the care of his father (Tseng Min-chieh) and mother. Father and son, 6 years old, are photographed by Zi-fan's mother while on vacation in I-Lan, north-eastern Taiwan. (Photo provided by Tseng Min-chieh)



●Serena Wu and her son Terry, 8 years old, share a strong bond between mother and son. (Photo provided by Serena Wu)