# After Rain There's a Rainbow- After a Storm There's Calm

By Lin Shuan-Pei, Chair of Taiwan Foundation for Rare Disorders

Thirty years ago, I started my practice in pediatric genetics, and Taiwan was still inexperienced in diagnosing and treating genetic diseases. Later, I had the opportunity to study in the U.S. for two years and brought back valuable experiences. At that time, rare disease patients in Taiwan had little access to medical resources, thus patients' survival fell on the shoulders of medical professionals. Doctors could only face the music when there was nothing they could do about a disease. It was not until 1998 that everything changed, as Ms. Serena Wu, the founder of Taiwan Foundation for Rare Disorders (TFRD), spoke up to the government and the public for Hsiao Ren-hao, who suffered from Gaucher's disease. That was the start of campaigns for healthcare for rare disease patients, making Hsiao the first case where orphan drugs received payments from national health insurance. Enzyme replacement therapy (ERT) was performed for the first time in Taiwan on Hsiao at MacKay Memorial Hospital. After the treatment, Hsiao's liver, which used to be enormously enlarged due to the sickness, slowly returned to normal size. When I saw this boy, who had no idea what it felt like to run and jump, taking large firm steps, no words could describe that excitement in my heart. Twenty years later, I can still feel the same rush, as if it just happened yesterday.

After TFRD was founded in 1999, followed by the enactment of the Rare Disease Control and Orphan Drug Act, the rights of rare disease patients and families have been protected through government legislation. In addition, TFRD establishes a comprehensive service system regarding welfare policies, patients caring, and long-term care. Through all kinds of propaganda, labels on rare diseases can be removed gradually, so that a safe and patient-friendly environment can be built. Although it is often hard to diagnose and treat rare diseases, patients can still have quite an achievement in life once they obtain proper care; some even shine on the world stage eventually. At TFRD, we believe that fireflies that do not glow can still spread seeds of goodness, just as water droplets can one day form a large stream.

In the blink of an eye, TFRD has been established for twenty years. I cannot express my gratitude enough to the donors, social enterprises, medical professionals, volunteers, and countless help who have paved the way for patients with sunshine. I would like to give special thanks to WANG JHAN-YANG Charitable Trust Fund under Formosa Plastics, the main sponsor to TFRD since 2011. Over the past eight years, over 6,300 patients have benefited from its support. With love from everyone, TFRD is able to grasp the light of hope in the valley of shadow, courageously marching through difficulties alongside with thousands of patients and their families.

*Rare and Precious Life* tells about all the ups and downs that rare disease patients and families have been through in the past twenty years. Living with rare diseases, patients can be helpless sometimes, and there have been moments where difficulties ad solutions meet, while sorrow and joy are also found. At places that seem to be dead ends, I see a silver lining with warmth and comfort; thus, people start looking forward to the future. Because of this, I believe that someday, a beacon light of hope will shine on the world, leading everyone to the meaning of life as well as true happiness and freedom.