

Standing with Love- 20 Years of Work

By Ing-wen Tsai, President of Republic of China (Taiwan)

With the dedication and efforts of Ms. Serena Wu, the founder of Taiwan Foundation for Rare Disorders (TFRD), TFRD has walked side by side with rare disease patients and their families for 20 years. In the spirit of giving and caring for others, Ms. Wu brings the love and vitality into patients' life, and urges the government to take the initiative in providing patients with more comprehensive healthcare. Where there are challenges and difficulties, TFRD members and volunteers will travel across Taiwan, bringing warmth and hope to every corner. It is everyone's devotion that builds a life of quality and dignity for rare disease patients. The diseases and drugs may be rare, but love is still everywhere!

On the 20th anniversary, TFRD published *Rare and Precious Life*, a book of the life stories and touching moments of rare disease patients, showing the resilience in human nature and the progress of healthcare in Taiwan regarding diagnosis, treatment and rare disease prevention. Behind every story, readers see the strength and will from families and the society, as patient groups, social enterprises, and volunteers all devote themselves wholeheartedly. What is also seen is that no matter how rare the diseases are or how difficult they are to be diagnosed and treated, every patient stands as a peaceful warrior who spreads their love for life to others and never gives up.

To support families with rare disease patients and to uphold their rights, the Rare Disease Control and Orphan Drug Act was enacted in 2000. The act identifies a variety of diseases and drugs, facilitating the prevention and treating of rare diseases. It also helps patients obtain the medicines, prescribed nutritional supplements, and medical assistance by encouraging the supply and manufacturing of required drugs and food produce through incentives. It is without a doubt that as Taiwan's government continues to review and amend related regulations, better healthcare and support for patients and their families will be seen in the near future.

I cannot express my delight enough when I see everything achieved by TFRD over the past twenty years, as it works together with the government as an NGO in promoting policies regarding rare diseases. With continuous devotion, TFRD supports patients in so many ways, through which warmth and hope are carried on by every loving heart. It is hoped that through these stories, the will and perseverance of patients and their families can be seen, so that everyone can work together to raise the public's awareness and pay forward the love.