

Green light in the darkest of nights awakens the rising sun

By Shih-Chung Chen, Minister of Health and Welfare

Green light is a special light that can be seen a split second before dawn or after sunset. It is so huge and dazzling. In fact, patients with rare diseases are like this admirable green light. I deeply understand that when they are on the road with rare diseases, the courage and perseverance required along the way are far beyond our imagination. Although they have to endure the suffering from illness, they have the love, care and companionship of their family and friends, which are important factors for them to keep moving on.

In 2000, Taiwan made Prevention of Rare Disease and Orphan Drug Act goes into effect and became the fifth country that established the law in the world. The content of the law is very unique, which could be said as the first in the world. So far, 223 rare diseases, 107 orphan drugs and 40 special nutritious foods for rare diseases have been announced. In addition, rare diseases are also included in major illness of National Health Insurance, which can reduce the financial pressure on the patients. As to medical expenses, we provide health insurance payment and subsidy for rare diseases, which stand for a dual safety net. Besides, 13 rare disease genetic testing bodies and 14 genetic counseling center have been approved. Now, we are also promoting genetically related reproductive and physical health services, including subsidy of prenatal genetic diagnosis, genetic disease screening and counseling, and metabolic disorders in neonatal screening.

In this book, we can see that the situation of rare diseases in Taiwan changed from having no treatments to having payments by National Health Insurance. It is like a silver lining for patients in the long dark nights. In the past, finding the right diagnosis is like looking for a needle in a haystack. Now, we can provide accurate diagnosis for patients and make them get a new lease of life. From prevention to treatment, newborn screening can be regarded as the first line of defense for babies. Our government wants to give every child the best start in life. In this book, I also find the selfless contribution and companions of members from the foundations, patients' family members, and volunteers. Just like one of the patients Yi-ting said in the book, "Because of my boyfriend's companionship, I feel that everything is not that difficult. I choose to take it easy and become more positive." This year marks the 20th anniversary of the establishment of Taiwan Foundation For Rare Disorders (TFRC). I must express my gratitude in particular to the founder of TFRC, Ms. Serena Wu, who has the most valuable tears in Taiwan. Her tears provoked a strong reaction among public, allowing more people to see the need for patients with rare diseases. From raising money in traditional markets to donating money or invoices in convenience stores, this green light in the darkest of nights awakens the rising sun, and the sunshine is so warm and strong.

What touches me the most is how these life fighters make the most out of life. I would like to express my admiration for their perseverance. In the future, we will also take resolute and quick actions, and provide comprehensive diagnosis and care for rare disease patients in a better way. I am very grateful for everyone's support, and I would also like to thank the members from TFRC. They accompany the patients and their family members and the government to deal with, to accept and to treat rare diseases together. We will never give up when encountering any difficulties in life. A blind alley is not bound to be a dead end, and there can still be delivery from desperation. Ultimately, the green light will surpass the darkness.