Light of Miracle

by Huei-Jyun Yang, Planner of *Rare and Precious Life*

I was born on the day when mankind took the giant leap on the moon. My other often speaks of that evening when news at the clinic was all about the huge event, and she is grateful to Neil Armstrong for distracting her from the pain during labor. For every mother, I believe, they can always name something miraculous on the day they gave birth to their child, but what they did is actually the most miraculous thing- bringing a new life to this world. They rarely talk about it only because they just do not want to flatter themselves.

No child is born without their mother experiencing enormous pain, which then turns into joy in a family. Mothers with rare disease children, however, is another story, as the pain still lingers after the childbirth and onwards into their life. People may imagine that in the bottomless pit of pain are only endless tears, but looking at the past twenty years, families with rare disease patients have in fact conquered challenges one after another like climbing mountains where the roads to the top are steep and rough.

Twenty years ago, as a junior medical journalist, I wrote news stories about hyperglycinemi, urea cycle disorder, leucine metabolic disease, Gaucher's disease, spinocerebellar Ataxia, Huntington's Disease, maple syrup urine disease, and so on. For the first time in my life, I realized that there are challenges in life that may be impossible to conquer. I wrote stories one after another, which kept me going for more. At the same time, I often thought to myself, "Are these kids gonna grow up safe and sound as long as they receive the drugs and necessities they need? Is it enough that they go through early childhood screening, before they and the family live happily ever after? Even if everyone on earth advocates for social justice, will life do them real justice as well?

It goes without saying that deep down I still feel a sense of guilt, in a way that I am blessed with a path different from the patients', yet there is nothing much I could do for them. When "rare disease" was made an official medical term, Dr. Lin Shuan-Pei, now the Chair of Taiwan Foundation for Rare Disorders (TFRD), was still a young doctor. I said to him then, "The risk of giving birth to a rare disease baby is unpredictable. It's really alarming!" Dr. Lin replied, "That probability is one in 10,000 for any expectant mother, but it is already 100% fact for families with rare disease babies. In that sense, these families are actually helping reduce the odds for babies to come in the future. That's why when I meet these patients, I have been grateful and always will be."

That was the reason that got me to write and to look into related issues. That being said, I still feel like an outsider, who can do nothing but to keep cheering for those rare disease children and family, whose hard work so far has been worth a big round of applause.

20 years ago, when Tseng Min-Chieh borrowed a critical orphan drug to save his son's life from Serena Wu, a mother of a child with another rare disease, the case set a precedent for rare disease patients who have been fighting non-stop to this day. Tseng and Wu always refer to themselves as the *Taoyuan Duet*, who single-handedly founded TFRD. They both have lived in the U.S. for a period of time, yet none of them turned to the States for help when it came to saving their child. Instead, they chose to stay in Taiwan, fighting alongside with other families facing the same challenge. It was such "rare" mindset and unstoppable courage that gave rise to a momentum that drives future generations to devote themselves wholeheartedly. Starting from two persons to two families, then tens of thousands of patients and families; from lack of medicine to enacted legislations, and the development of new drugs; from unpredictable odds of conceiving rare disease babies to the next-generation newborn screening; from eternally staying indoors to being able to study abroad.

In addition, people will start to realize that *miracle* is not an abstract word. As long as a door of opportunity slides open, those who keep marching forward will continue to make breakthroughs through their wills. As their world fall apart in hardship and challenges, it only gives them a reason to build a new one.

Examples can be found on Hsiao Ren-Hao, who suffers from Gaucher's disease with a swollen abdomen and hunchback like an old man. Hsiao was determined at a young age that he would not live longer than five years before he joined his brothers in heaven. Yet, Hsiao has now entered his thirties, alongside with his mother, who used to appear rather aged due to all the troubles, but now she looks rejuvenated with her face glowing upon seeing her son living his life to the fullest.

The same spirit is also seen on the Wu siblings, Yi-Hsin and Yi-Nuo, who both have Niemann–Pick type C, usually with a life expectancy limit of only 20 years. It was frustrating for the parents to learn that both of their children are sick, yet there was a silver lining found upon discovery of new drugs. Yi-Hsin has now entered her twenties and even set her foot onto continents as far as Africa and Europe; not to mention the touching story where she and her mother both got admitted into the same graduate institute and now go to school together.

The same is true of Rose Yang, a news anchor diagnosed with distal myopathy. Although the disease symptoms continue to worsen, it never stops Rose from making the most of her life. At first, she fights for her own life; after she becomes a legislator, she fights for rare disease patients by enacting and implementing related regulations. However, these wonderful moments are nothing compared to the day she put on her wedding gown and married the love of her life.

The same wonder works on Chen Chun-Han, who has spinal muscular atrophy. Despite all difficulties, Chen obtained a degree of Master of Laws from Harvard University and

passed the New York State bar examination. What's more, Chen started choirs, painting classes, and writing lessons for rare disease children by bringing together teachers and parents who believe in the possibilities they see in these children.

Last but not least, let's not forget all the sung and unsung heroes who have answered the call of Serena Wu along the way by providing financial supports and assistance of any kind. 86% of the fund received at TFRD is small donation below US$33. There is not a penny from the government, and therefore a record is set as a nationwide fundraising is supported entirely by regular citizens and citizens only. It is the most touching and realistic devotion that all Taiwanese people are proud of.

With a closer look, it is not hard to see that people who seem to be only cheering for rare disease patients on the sidelines are in fact all in this together.

Auroras are the result of collision between the particles in solar wind and the atoms in the atmosphere. This meteorological phenomenon is indescribably beautiful, yet it arises from ferocious storms. Some people see auroras as the light of happiness, as such a breathtaking scene is only possible when the stream of light interacts with the particles and atoms, just as the way rare diseases are intertwined with our society.

The momentum that stands against rare diseases has been accumulating over the past 20 years. Now it has led us all to a "humane revolution" where ideas collide and within the collision rise the purpose of life, breakthroughs in healthcare, and changes in the social system. If seen in this way, the birth of every child with rare disease is definitely a "miracle" in the world.