

## Chinese Red Cross Foundation initiates Rare Disease Care Movement

04 July 2019 | News

**Rongxiang Xu Regenerative Life Non-Profit Fund Joined the movement and launched "Butterfly Baby Rescue Plan" to set up a special relief fund for 30 to 40 Epidermolysis Bullosa (EB) patients**



On July 2, 2019, Chinese Red Cross Foundation initiated the "Rare Disease Care Movement" in Yinchuan City, Ningxia Hui Autonomous Region, China. Rongxiang Xu Regenerative Life Non-Profit Fund joined the movement and launched its "Butterfly Baby Rescue Plan." Under this plan, a special relief fund will be set up for 30 to 40 patients with Epidermolysis Bullosa (EB). Meanwhile, the Fund will call for society to give special care to "butterfly babies" and popularize relevant knowledge about EB, spreading awareness about this rare genetic disease. Greater awareness will help improve the quality of life for this very vulnerable group.

The term "butterfly baby" comes from the extreme fragility of a sufferer's skin, similar to the wings of a butterfly. Minor trauma such as scratching or rubbing can cause severe blisters--even blood blisters--and even a light touch can be extremely painful, greatly detracting from the quality of life.

Until now, there has been no significant treatment modality for this disease. Worse still, EB--as a congenital disease--requires lifelong treatment. This creates a catastrophic financial burden for patients and their families, leaving many of them to struggle in stark poverty.