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DONOR OF THE DAY | By Melanie Grayce West

A Venture to Cure An Orphan Disease

The life-altering moment for parents Jamie and Alexander Silver came just hours after the birth of their son and with the removal of an ordinary adhesive bandage.

It was October 2007 and the Silvers—who first met in middle school and married in 2004—were celebrating the birth of their firstborn, Jackson Gabriel. Nurses at the hospital had applied a bandage to Jackson's foot, but when it was later pulled off, it removed all the skin on the infant's heel.

In the next few days, as Jackson stayed in the hospital's neonatal intensive care unit, the Silvers learned that their son had Epidermolysis Bullosa, better known as EB, a rare genetic disease without a cure.

People with EB have extremely fragile skin that is prone to blistering and tears from even the slightest trauma or movement, including something as simple as rubbing the eyelids.

Though there are multiple subsets of the disease, daily maintenance is usually the same for all and leads to a poor—and painful—quality of life. EB patients are usually wrapped daily in bandages, to reduce the chance of injury, and bathe with diluted bleach to help prevent skin infections. Disfigurement is common and blistering can occur internally.

Long-term prognosis for patients with EB is grim, with many developing skin cancer.

"There's nothing worse than feeling like you can't help your child," said Mr. Silver, a partner at the New York-based P2 Capital Partners. "I remember feeling that way when Jackson was born...I just sat there saying, 'How can I not help?' No parent should have to go through that."

Mr. Silver, now 37 years old, and his wife launched the Jackson Gabriel Silver Foundation about five years ago. To date, the New York-based organization has raised about $3 million toward EB research.

This week, the Jackson Gabriel Silver Foundation merged with a similar California-based group, Heal EB, to create a larger, national organization called the EB Research Partnership. The organization is focused on effective treatments and a cure for EB.

Alexander and Jamie Silver

The new organization employs a so-called venture-philanthropy model, where grant-making is linked to profit. The EB Research Partnership will receive a return on a research grant when the work leads to or develops into a commercial treatment. Those royalties funnel back to the foundation for future grant-making in biomedical research.

This strategy, which is becoming more popular, is followed by other disease-related charities including the Cystic Fibrosis Foundation and the Michael J. Fox Foundation.

Mr. Silver came to this approach from his professional life in venture capital, growth equity and private equity. Angel investors in the for-profit world, he said, provide early-stage funding, helping to lessen risk in the process in return for a reward. Why not do that in the field of rare diseases, he thought, where the risks and rewards can be greatest?

Unlike with many other rare (or orphan) diseases, scientists know what causes EB, leading to hope for a cure. Several U.S.-based universities are working on topical products and bone-marrow-transplant treatments.

"We have the ability to effect a change," said Mr. Silver. "It's just a question of how we do it and in what time frame."