

# **Jackson Gabriel Silver Foundation and Heal EB Announce Merger**

## ***New organization named the EB Research Partnership***

### ***Creates Largest Non-Profit Dedicated To Finding a Cure for Epidermolysis Bullosa***

### ***Pearl Jam's Eddie Vedder and Wife Jill Vedder among Founding Board Members***

**NEW YORK, October 1, 2014** – The Jackson Gabriel Silver Foundation and Heal EB announced today a merger of their organizations to form the EB Research Partnership (EBRP), creating the largest non-profit organization dedicated solely to funding research to cure Epidermolysis Bullosa (EB).

EB is a group of devastating life-threatening genetic skin disorders impacting children that is characterized by skin blisters and erosions all over the body. For a child with EB, even the most delicate touch can cause the skin to tear apart, blister and shear off the body. There is currently no cure, and treatment often comes in the form of wound care, intensive bandaging and managing debilitating pain and infection.

EBRP, which utilizes groundbreaking venture philanthropy funding models to support leading research institutions such as Stanford University and the University of Minnesota, has set their initial fundraising goal at \$5 million dollars per year to exclusively fund research and find a cure for EB.

Eddie Vedder, founding board member of EBRP said, “My wife Jill and I are thrilled to be able to support the brilliant work of leading doctors and researchers committed to identifying better treatments, and ultimately a cure for this cruel disease. Our close family friends have a young son with EB and we want to do everything we can to ensure a better quality of life for him and all children living with these types of genetic disorders.”

“As families impacted by rare diseases know all too well, it is difficult to access sufficient research dollars to make a true impact on the development of new treatments and cures. As a combined organization, EBRP can command the scale to fund aggressive research and accelerate a cure for EB,” commented Alex Silver, Chairman of EBRP. “We are thrilled to join forces with Jill and Eddie Vedder and Heal EB – founded by Heather and Ryan Fullmer and Jill Vedder – with the goal of finding a cure for EB and bringing hope to thousands of children who suffer from this horrific condition,” added Silver.

EBRP is pleased to announce that Jessica Scheer will serve as Executive Director. She will oversee day to day leadership of the organization and will be responsible for its financial development. Scheer brings more than a decade of experience in non-profit leadership, including her work with DoSomething.org and Lady Gaga's Born This Way Foundation.

### **Microsoft Employee Giving Campaign**

Kicking off an initial push towards their \$5 million fundraising goal, EBRP is teaming up with Microsoft during the month of October during the Microsoft Employee Giving Campaign, including a grassroots movement “Heal EB: Cause the Wave” to raise awareness about EB and create a ripple effect of support. Some of the money raised during this year's

campaign will go to fund the work of Dr. Jakub Tolar at the University of Minnesota who is working to advance gene and cellular engineering research, efforts which have the potential to drastically transform the quality of life for individuals with EB.

Commenting on the opportunities presented by this campaign, Dr. Tolar states, "Funding from the EB Research Partnership can shorten the time from the lab to the clinic by more than 50%, which helps those most in need. In addition, this type of treatment is potentially the key to treating not just EB, but 5,000+ other genetic disorders."

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### **About the EB Research Partnership**

EB Research Partnership (EBRP) is the largest 501(c)(3) nonprofit dedicated to funding research aimed at treating and ultimately curing Epidermolysis Bullosa, a group of devastating and life-threatening skin disorders that affect children from birth. EBRP was formed in October 2014 through the merger of Jackson Gabriel Research Foundation and Heal EB. To learn more about Epidermolysis Bullosa and to donate to research for a cure, please visit [www.ebresearch.org](http://www.ebresearch.org).

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