



Leading Genetic Researchers Partner to Find Treatments, Cures Faster for Epidermolysis Bullosa (EB)

Scientists from Stanford, Columbia and Colorado Universities share research to cure EB, a debilitating disease affecting children worldwide



Drs. Anthony Oro, Angela Christiano and Dennis Roop. Photography by Eliza Donley Nolte

NEW YORK CITY, N.Y.—August 1, 2016—The EB iPS Cell Consortium announced its formation today to fight the rare and debilitating genetic disease Epidermolysis Bullosa (EB), affecting thousands, many of whom are children, across the U.S. and worldwide. This consortium is jointly funded by [EB Research Partnership](#) (EBRP) and [EB Medical Research Foundation](#) (EBMRF). EBRP's support is in partnership with The Jillian M. Neubauer and Lawrence A. Neubauer Foundation and the Mario Batali Foundation. This collaborative team approach is meant to produce faster results through partnership and shared resources.

The newly formed EB iPS Cell Consortium is a unique partnership that includes research teams led by Dr. Angela Christiano from Columbia University Medical Center, Dr. Anthony Oro from Stanford University School of Medicine and Dr. Dennis Roop from University of Colorado Anschutz Medical Campus. These scientists will work together to find new treatments for EB on an accelerated timeline using an iPS Cell approach to gene therapy. iPS stands for “induced pluripotent stem” cells whereby cells from a patient are modified, reproduced and given back to the patient. The first year of the EB iPS Cell Consortium will focus on comparing and contrasting various approaches of iPS cell therapy to determine the most commercially viable approach.

“EBRP was founded on the principle that partnership is the cornerstone to success in healing and curing EB,” said Alexander Silver, co-founder and Chairman of EBRP. “This first-ever iPS Cell consortium will allow three leading EB research teams to come together to find a treatment or cure faster than any individual research approach we’ve seen. When time is the most precious resource of any child or adult living with EB, progressive collaboration like this is increasingly important.” Paul Joseph, CFO of EBMRF, added “EBMRF believes that by encouraging collaboration amongst researchers, we can help push life-changing treatment on a faster track, and that is a critical part of our mission to find a cure for EB. We are encouraged by the team’s commitment to research and the groundbreaking progress they are making with our support.”

Drs. Christiano, Oro and Roop jointly released the following statement: “We are delighted to co-found the EB iPS Cell consortium and excited to work together to help those living with this devastating disease. With the support of our institutions, we look forward to contributing our knowledge to create sustainable iPS Cell therapies that can be commercially viable for a global population.”

EB is a group of devastating and life-threatening genetic skin disorders that affect children through adulthood. Often referred to as “butterfly children,” individuals with EB lack a critical protein that binds their layers of skin together causes severe blistering both internally and externally. EB affects 1 in 50,000 people; currently, an estimated 30,000 people live with EB in the U.S and 500,000 globally.

The consortium inaugural meeting was held at the University of Colorado on July 22nd.

Members of the Inaugural iPS Cell Consortium:



Photography by Eliza Donley Nolte

About EBRP

The EB Research Partnership (EBRP) is the largest nonprofit funding the most medical research for a cure and meaningful therapies for EB. EBRP takes concepts from venture capital investing and applies them toward achieving philanthropic goals: when it takes a traditional donation to a research project, it retains the added upside of generating a recurring donation stream if the therapy or product is commercially successful. It then uses this revenue to fund additional EB research. To date, EBRP has raised more than \$10.5 million for research grants and has been instrumental in securing an additional \$35 million for critical EB research. Find it online at www.ebresearch.org.

About EBMRF

The Epidermolysis Bullosa Medical Research Foundation (EBMRF) is dedicated to finding a cure for EB by funding the best of cutting edge and innovative research and seeking out new researchers and scientists at America's top institutions. It also raises awareness and provides outreach through the media and various fundraising programs. The EBMRF was founded in 1991 and is currently headed by The Joseph Family in Los Angeles. To date, EBMRF-Los Angeles has funded over \$5 million in research. www.ebkids.org.

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