

EB Research Partnership Forms Scientific Advisory Board

NEW YORK – MAY 18, 2015 – EB Research Partnership (“EBRP”), the largest nationwide organization focused on funding research to cure epidermolysis bullosa (“EB”), announced today the formation of its first Scientific Advisory Board. The advisory board, made up of esteemed medical professionals in dermatology research and genetic diseases, will apply its collective scientific expertise to advise on the dissemination of grant funding for research initiatives likely to treat, heal and cure EB.

“The formation of our scientific advisory board is an important milestone for the EB Research Partnership and the EB community because it brings together top medical experts in a truly collaborative way. Our grant-based strategy to promote research to cure EB will greatly benefit from their knowledge of this very challenging goal,” Heather Fullmer, Co-Founder and West Coast COO.

The Scientific Advisory Board is chaired by Dr. Alfred Lane, emeritus Professor of Dermatology and Pediatrics at the Stanford University Medical Center, where he led the university’s longstanding commitment to treating and finding groundbreaking therapies for EB.

Commenting on his involvement in the formation of the Scientific Advisory Board, Dr. Lane said, “I am honored to work with the EB Research Partnership as part of its Scientific Advisory Board as it works to cure this extremely rare and highly debilitating disease. We saw an opportunity to bring together the best minds in medicine to help find treatments and cures in an efficient way.”

The inaugural EBRP Scientific Advisory Board includes:

- **Greg Barsh, M.D., Ph.D.** - Barsh runs the Barsh Lab at the Hudson Alpha Institute for Biotechnology in Huntsville, AL. The Barsh lab studies the genetic mechanisms of morphologic variation, and looks for new insights on basic biology and human disease. He has a M.D. and Ph.D. in pathology from the University of Washington, Seattle.
- **Steven Buchsbaum, Ph.D., MPIA** - Buchsbaum is Deputy Director of Discovery & Translational Sciences at the Bill & Melinda Gates Foundation. In this capacity, he leads the team’s efforts to expand the Grand Challenges family of grant programs and associated partnerships to enhance their impact. Dr. Buchsbaum earned his Ph.D. and MPIA at the University of California, San Diego. Dr. Buchsbaum will serve as an advisor to the SAB.
- **Suephy Chen M.D., MS** - Chen is Associate Professor of Dermatology and Emory Program in Cardiovascular Outcomes Research and Epidemiology (EPICORE) and Director of the Dermatology Clinical and Outcomes Research Unit. She attended medical school at Johns Hopkins University School of Medicine.
- **Alfred Lane, M.D.** - Dr. Lane is emeritus Professor of Dermatology and Pediatrics at the Stanford University Medical Center. Dr. Lane and his team led

the first stem cell based gene therapy trial for recessive dystrophic EB (RDEB) in the world and achieved the first sustained genetic correction for this disease in human beings. He earned his medical degree from The Ohio State University.

- **David Russell, M.D., Ph.D.** - Russell is Professor of Medicine for the Division of Hematology and Adjunct Professor of Biochemistry at University of Washington School of Medicine. He has a medical degree from Cornell University Medical College and a Ph.D. in Genetics from Rockefeller University.
- **John R. Stanley, M.D.** - Stanley is Professor of Dermatology at University of Pennsylvania. He has been recognized by Best Doctors in America for the past ten years. He has clinical expertise in epidermolysis bullosa and the epidermal and dermal proteins associated with EB. Dr. Stanley received his medical degree from Harvard Medical School.

EB Research Partnership will commence its first formal and global RFP process for funding this spring. Grant applications will be accepted from July 1 – 15, 2015. To support its broad mission, the EB Research Partnership is committed to funding research that will lead directly to commercially feasible products and therapies for treating and/or curing EB. Grant awards will be announced by September 15, 2015. Information on the grant application process and forms can be found at www.ebresearch.org.

For questions regarding the grant application process, please contact Heather Fullmer at heather@ebresearch.org.