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DEBRA International and DEBRA of America Launch EBCare.org, the International Patient Registry for Epidermolysis Bullosa (EB)

First Database Collecting Patient-Reported Information Designed to Improve Understanding of Rare Genetic Disease and Accelerate Development of Novel Treatments

Vienna, Austria and New York, New York – February 29, 2012 - DEBRA International and DEBRA of America today announced the launch of EBCare.org, an online, international, comprehensive registry for patients with all types of Epidermolysis Bullosa (EB). EB is a set of rare genetic disorders characterized by the presence of extremely fragile skin and recurrent blister formation, resulting from minor mechanical friction or trauma. Secondary complications can include infections, anemia, oral ulcerations, dental decay, esophageal blistering, corneal erosions, osteoporosis and psychological trauma. There is currently no cure or treatment except for palliative care and preventative bandaging. An estimated 1 out of every 50,000 live births are affected with some type of EB. The disorder occurs in every racial and ethnic group throughout the world and affects both sexes equally.

"We are excited to launch this international patient registry, fulfilling a long-standing goal of DEBRA," said Rainer Riedl, President of DEBRA International. "We encourage all patients diagnosed with EB to participate fully as the registry will help us build the most comprehensive and valuable collection of data about EB. To reach the greatest number of patients, the registry is currently in English and will be available shortly in additional languages. Our hope is that this increased level of access and information will enable the acceleration of development and commercialization efforts for new, safe and effective treatments for EB."

Information gathered from the registry will provide researchers with additional insights into EB symptoms, prevalence and the severity of the disorder. This information will help guide the design of new clinical studies, provide data on the quality of life of patients with EB and help better quantify the costs associated with EB treatment, which could enable more streamlined reimbursement.

"The registry is a significant step forward for the EB community as it offers the only opportunity for patients from all over the world to provide much-needed, first-hand information about their diagnosis, symptoms, medical care and the social and financial burden of living with EB," said Brett Kopelan, Executive Director of DEBRA of America. "Because there has been no single repository of patient-reported EB data, this registry is expected to help researchers and clinicians better understand EB from a patient's perspective and enable us to improve our advocacy efforts and, through education and the sharing of de-identified data, have a greater impact on patients' lives."

EBCare.org will be managed by Innolyst, Inc., which has developed patient registries for more than 200 diseases. The development and maintenance of the registry is supported by grants from Lotus Tissue Repair, Inc., a company that is developing a proprietary recombinant collagen type VII (rC7) technology as a treatment of dystrophic EB (DEB), one of the genetically inherited forms of EB.

About EB
Epidermolysis Bullosa (EB) is a rare genetic disorder characterized by the presence of extremely fragile skin and recurrent blister formation, resulting from minor mechanical friction or trauma. Secondary complications can include infections, oral ulcerations, dental decay, esophageal blistering, corneal erosions, osteoporosis and psychological trauma. This condition is not contagious. An estimated 1 out of every 50,000 live births are affected with some type of EB. The disorder occurs in every racial and ethnic group throughout the world and affects both sexes equally.

About Lotus Tissue Repair, Inc.
Lotus Tissue Repair, Inc. is developing its proprietary recombinant collagen type VII (rC7) technology as a treatment for dermatologic conditions in which rC7 may play an important role in accelerating wound healing. The company's lead program is the first and only protein replacement therapy for the treatment of dystrophic epidermolysis bullosa (DEB), a devastating orphan disorder with no currently approved treatment options other than palliative care. Lotus Tissue Repair is a private company launched in 2011 by a proven team of biotechnology entrepreneurs, the world's leading experts in rC7 therapy for chronic skin wounds and Third Rock Ventures. For more information, please visit http://www.lotustissuerepair.com.

About DEBRA International
DEBRA International is the alliance of national Epidermolysis Bullosa (EB) patient groups, currently working in over forty countries worldwide. Amongst other actions, DEBRA International coordinates research strategy on behalf of the member groups and manages research grants made by its members, including centralised peer review. For more information contact John Dart at john.dart@debra.org.uk or visit http://www.debra-international.org.

About DEBRA of America, Inc.
Based in Manhattan and incorporated more than 30 years ago, DEBRA is the only national not-for-profit organization that supports the research initiatives for a cure or treatment for Epidermolysis Bullosa (EB), while also providing services and programs to those who suffer from or care for those who have the disorder. DEBRA distributes $500,000 of wound care supplies annually, offers financial aid to families for unreimbursed medical expenses, provides

on call nurses, manages a new family advocate program and organizes annual patient care conferences where families can meet, share and learn more about EB. DEBRA's programs and services truly make a difference in the lives of people with EB and they define our dedication to alleviating the inherent daily stress of living with the "worst disease you never heard of." For more information, please visit http://www.debra.org.

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