Principle Non-profit Charitable Organizations
In Support of the Objectives of “Walk a Mile in My Shoes” Relay-Rally

Epidermolysis Bullosa is a painful, disfiguring, disabling, sometimes fatal, genetic disease that is characterized by skin so fragile, any friction causes painful blisters and wounds. Present at birth, this disease affects people throughout their lifespan. Sufferers may be mildly or severely affected. The following two non-profits work individually, but are unified in supporting the objectives of this campaign. As well, dEBra Canada plans to support the campaign in 2008, if efforts to pass a Canadian version of awareness legislation are successful.

Epidermolysis Bullosa Medical Research Foundation
8909 W. Olympic Blvd., #222
Beverly Hills, CA 90211
Website: http://www.ebkids.org
EIN/Tax ID: 94-3130081

The EB Medical Research Foundation was established in 1991 by Gary and Lynn Fechser Anderson at the request of Dr. Eugene A. Bauer, then Professor and Chairman of the Department of Dermatology at the Stanford University School of Medicine. His research team was making exciting progress in their study of EB but needed additional funding to realize their goals. The Andersons lost two children, Chuck and Christine, to EB. Chuck died of skin cancer (a side-effect of his EB subtype) as a young adult, and Christine died of heart failure at age 14.

The EBMRF is unique in that the Foundation pays no salaries. All work, including executive, legal, accounting, development and administrative, is done on a volunteer basis. It is the goal of the Foundation to keep operating costs at less that 1% of incoming donations so that a full 99% of contributions can go directly to the research program. EBMRF is a volunteer nonprofit foundation dedicated to the support of medical research of Epidermolysis Bullosa (EB), its causes, the development of successful treatments, and ultimately, its cure.

In 2005, the EBMRF expanded its efforts by adding the Joseph Family, whose son Brandon was born with RDEB in 2003, to its Board of Directors and opening Administrative offices in Los Angeles. Paul and Andrea Joseph and their immediate family are committed to raising funds for ongoing research as well as awareness through the media. EBMRF is an approved public charity of the Jewish Community Federation. EB research at Stanford has been made possible in part by EBMRF fundraising efforts for the past 16 years.

Dystrophic Epidermolysis Bullosa Research Association (DebRA) of America
5 West 36th St., #404
New York, NY 10018
Website: http://www.debra.org
EIN/Tax ID: 11-2519726

DebRA of America was founded in 1979 by Arlene Pessar. Arlene’s son, Eric, had RDEB Hallopeau Siemens – he died as a young adult of a kidney-related side-effect of EB.

DebRA of America Inc. sponsors research and provides programs and services for patients, their families, and medical professionals. An on-staff specialized Registered Nurse Educator maintains a toll-free hotline dedicated to patient health inquiries. A trained volunteer makes in-person visits and offers phone support to families with a newly diagnosed child through the New Family Advocate Program. Patient conferences are conducted at no cost to participants. The Wound Care Clearinghouse provides free emergency supplies of wound care dressings and non-prescription medication to registered patients who have difficulty acquiring materials because of financial or logistical limitations. A Family Crisis Fund provides emergency financial support for urgent medical needs. The new EB *En Espanol* Program provides access to medical information in Spanish. DebRA of America is one of “America’s Charities.”