

**Epidermolysis Bullosa, or EB, is a rare genetic disorder. It is not contagious. It affects people of both genders and every ethnicity throughout the world.**

About one in 17,000 people are diagnosed with some form of EB. Approximately one in 500 are “carriers” of one of the defective genes that cause EB.

Doctors who work with EB patients have been quoted as saying that *EB may be the most painful disease known to man*, because of its many daily challenges.

**EB's characteristics:**

Recurring wounds occur from minor trauma, shearing or rubbing, and blisters are similar in appearance and effect to those from a 3rd degree burn;

The skin's dermis and epidermis are missing the anchor filaments that connect the layers, or the anchors are damaged, leading to separation of the skin and chronic wounds;

In severe types, scarring results in “mittening” deformities of hands and feet, and loss of body fluids and esophageal scarring leads to anemia and malnutrition, and impedes normal growth;

The only “treatment” for EB is bandaging to protect the skin from damage, and the cost of wound care supplies is often not covered by insurance or government subsidy.

**Every day is filled with the fear of contracting an infection, and the continual burden of physical, emotional and financial challenges.**

*“Walk a Mile in My Shoes” is the name of a global unified campaign recognizing **International Epidermolysis Bullosa Awareness Week**. The campaign is so named, not for a particular activity, **but to signify our compassion**.*

*This remarkable week is an opportunity to educate and enlighten others about EB during the last week of October, every year in perpetuity.*

*This special awareness campaign began in the United States in 2007, and in 2009 became endorsed by DEBRA International and all DEBRA groups around the world, along with EB Medical Research Foundation.*

*This year, and in future years, the focus is on **local community events** such as walkathons to raise EB awareness, and fundraising for our nonprofit **Community Partners** to fund EB research. In 2007, these partners were DEBRA of America and the EB Medical Research Foundation. In 2008, they are joined by DEBRA Canada and DEBRA Mexico.*

**Now, our objectives are international, and ALL EB advocates everywhere are welcome to participate!**

*Please contact any of the following and donate, referencing **IEBAW** in your donation, through the following websites:*

**[www.debra-international.org](http://www.debra-international.org)**  
to find the website for ANY of the DEBRA groups

**[www.ebkids.org](http://www.ebkids.org)**  
EB Medical Research Foundation

Please... the power is in YOU!  
Unleash the voice of your inner advocate, and help us create awareness to improve the lives of all people with EB!

Some years ago, the term “butterfly children” was coined in the U.K. This expression has come to symbolize people with EB, due to the remarkable fragility of their skin, similar to the delicate wings of a butterfly. The “butterfly road” insignia shows our “butterflies” leading the way... for they are at the heart of **all** we EB advocates do!



**TO HELP:**

**Please ask your local policy-makers for a proclamation of International EB Awareness Week; support fundraising/awareness events near you;**

**participate in the Second Life EB Benefit at [www.secondlife.com](http://www.secondlife.com) (contact “Caeleigh Lamington” in SL); or simply make a donation to one of our nonprofit Community Partners.**

**IN EB RESEARCH,  
EVERY DOLLAR COUNTS!**

**If you have any questions, please contact Gena Brumitt Gruschovnik at [gena@mywalkamile.org](mailto:gena@mywalkamile.org)**