

## EB in Numbers

**200**

The number of children born with EB every year in the US. This equates to 1 in 20,000 births. Both sexes and all racial and ethnic backgrounds are affected.

**75%**

The percentage of the body that may be an open wound. It can take 6+ hours to set up and perform a bath and bandage change.

**\$83,464.17**

The average monthly cost of wound care supplies for an 11-year-old child with Recessive Dystrophic EB, a subtype of EB.

**115,000+**

The average number of wound care supplies sent each year to 500+ families in 48 states. Unfortunately, many families are underinsured or don't have coverage for these medically necessary items.

**130**

The average number of unique families that our EB Nurse supports per month, providing expert advice and education on EB care and management.


## Our Impact


- **100%** of program participants reported that our New Family Advocate Program reduced their stress.
- **94%** of program participants reported that our EB Nurse allowed them to better care for themselves or their loved one with EB.
- **95%** of program participants reported that our Wound Care Distribution Program either provided support during, or prevented, a crisis.

## Get in Touch

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We Fight  
**Epidermolysis  
Bullosa (EB)**

debra of America is a 501(c)(3) nonprofit organization.  
Contributions are deductible to the fullest extent allowed by law.  
Tax ID: 11-2519726

# What is Epidermolysis Bullosa?

Epidermolysis Bullosa (EB) is a group of rare disorders caused by a mutation in one of 18 genes. People with EB share the lifelong challenge of extremely fragile skin that blisters and tears from minor friction or trauma. The list of medical complications EB causes may be long and often requires multiple interventions from a range of medical specialists.

There is no cure for EB, but there are treatments that help alleviate some of the debilitating symptoms of certain types of EB. debra's work led to the historic U.S. FDA approval of three treatments for EB in three years.

## What does debra do?

Our mission is to improve the lives of those impacted by Epidermolysis Bullosa (EB) — "The Worst Disease You've Never Heard Of"

We integrate direct-to-patient programs and services, education, advocacy, close partnership with treatment developers, and research funding to foster meaningful change for those living with EB.

Each year, debra spends an average of \$1.5 million on direct-to-patient programs and services to provide immediate relief to thousands of families across the country.

## What can you do?

- **Make a tax-deductible gift.** A gift from you directly impacts families with EB. For more information about your gift's impact and to donate today, please visit [debra.org/donate](https://debra.org/donate) or scan the QR code below.



- **Attend or host an event.** In addition to attending our debra-hosted events, many of our supporters host their own fundraisers to help raise awareness and critical funds. These Supporter Led Events come in all shapes and sizes. We're here to guide you every step of the way to your fundraising goal!
- **Fundraise online.** Start an online fundraiser with our easy-to-use DIY fundraising platform or with Facebook Fundraisers.
- **Join #TEAMDEBRA.** Calling all walkers, runners, and cyclists! Join our charity endurance team in iconic races around the world.

## Our Programs and Services

### Free Medical Supplies

#### Wound Care Distribution Program

debra fills the coverage gap for people living with EB, providing essential wound care supplies free of charge. Specialized EB bandages can cost over \$80,000 per month—we make sure no one goes without.

### Expert Guidance

#### EB Nurse Educator Program

Our EB Nurse is available by phone or email to answer questions, refer doctors, and offer compassionate guidance to families, the public, and the medical community.

### Support for New Families

#### New Family Advocate Program

When we hear of a newly diagnosed person, we send wound care samples and educational materials on insurance, daily care, and treatment options—so families know help is here from day one.

### Advocacy

#### Legal Aid Program

We educate the U.S. FDA and legislators on the nuances of EB to ease the regulatory burden and to promote the best policies and legislation that affect the EB Community. We also empower patients and families to advocate with insurers and schools.

### Moments of Joy

#### Smile Fund Program

We fulfill mini-wishes with the goal of bringing joy to those living with this taxing disease.

### Peer Mentorship

#### Mentorship Program

We offer mentorship opportunities for people living with EB, as well as parents and caregivers.

### Learning & Connection

#### DCC & Meetups

Our biennial debra Care Conference (DCC) is the world's largest EB Community gathering—four days of education, connection, and empowerment. In off years, Regional Meetups keep the community connected.

### Education & Community

#### EB Connect

EBConnect.org is a private, online platform for the global EB Community. Membership is free.

