

“because the cost of doing nothing is too great”

**200**

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

**50%; 6 hours**

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.

**\$4.6 million**

The total value of wound care supplies shipped over the past five years through our Wound Care Distribution Program.

**500,000+**

The number of pieces of wound care sent to families across the country through our programs and services in the past five years.

## OUR 2022 IMPACT

**93%** reported an improvement in health over the year for their loved one with EB due to our programs + services.

**100%** said that the New Family Advocate Program reduced their stress.

**94%** said that our EB Nurse Educator allowed them to better care for themselves or their loved one with EB.

**95%** of families said that the Wound Care Distribution Program either provided support during or prevented a crisis.

## GET IN TOUCH



[www.debra.org](http://www.debra.org)



833-debraUS



[staff@debra.org](mailto:staff@debra.org)



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Suite 300  
NY, NY 10004



WE FIGHT

**THE WORST  
DISEASE  
YOU'VE  
NEVER  
HEARD OF.**

## CONNECT WITH US ON SOCIAL



@debraOfAmerica



@wefighteb



/company/debra-of-america

**BECAUSE THE  
COST OF DOING  
NOTHING IS  
TOO GREAT.**

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

**debra**  
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## WHAT IS EPIDERMOLYSIS BULLOSA?

**Epidermolysis Bullosa (EB)** - The Worst Disease You've Never Heard Of - is a rare connective tissue disorder with many genetic and symptomatic variations. All forms of EB share the prominent symptom of extremely fragile skin that blisters and tears with any friction. The list of complications and secondary illnesses can be long and requires multiple interventions from a range of medical specialists. There is no treatment or cure for EB, but there have been tremendous strides in therapy development.

### WHAT DO WE DO?

“Because the cost of doing nothing is too great” is an axiom that defines our mission and directs all that we do. We are dedicated to improving the quality of life for those living with Epidermolysis Bullosa (EB). To achieve our mission, we do two things in parallel: we provide **free programs and services** to the EB Community in the United States and fund the most **innovative research** directed at symptom relief and a systemic cure.

In 2022 alone, debra of America spent \$1.7 million on our direct-to-patient programs + services and research.

### WHAT CAN YOU DO?

- **Make a tax-deductible gift.** A gift from you directly impacts individuals and families. For more information about your gift's impact and to donate today, please visit [debra.org/donate](https://debra.org/donate)
- **Attend or Host an Event.** In addition to attending our debra-hosted events, many of our supporters host their own fundraisers to help spread awareness and raise funds. 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. 100% of proceeds go towards our mission.
- **Join #TEAMDEBRA.** Calling all walkers, runners, and cyclists! Join our charity team in endurance events around the world.

### Provide Wound Care Supplies

#### WOUND CARE DISTRIBUTION PROGRAM

debra of America bridges the gap in coverage for individuals with EB by providing supplemental wound care supplies, free of charge, to those in need. Specialized bandages for EB can cost \$80,000+ per month!

### Answer & Refer

#### EB NURSE EDUCATOR PROGRAM

Our nurse is available by phone or email for EB families, the public, and the professional community to answer questions, refer doctors, and provide guidance.

### Welcome New Families

#### NEW FAMILY ADVOCATE PROGRAM

When we learn of a newly diagnosed person with EB, we provide a free care package containing an assortment of wound care products and informational materials to help as soon as possible.

### Advocate

#### LEGAL AID PROGRAM

Has your health insurance denied you coverage for your wound care supplies or your local education system not provided your child with the assistance he/she needs? We can help.

### Spread Smiles

#### SMILE FUND PROGRAM

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

### Advise & Support

#### MENTORSHIP PROGRAM

debra of America offers mentorship opportunities for people living with EB, as well as parents and caregivers.

### Educate & Connect

#### DEBRA CARE CONFERENCE

One of the largest gatherings of the EB Community worldwide! This biennial multi-day conference brings the EB Community together to access the latest information, discover new ideas, and connect with other EB families.

### Find Community

#### EB CONNECT

EBconnect.org is a private, online platform for the global EB Community. Membership is FREE.

through our programs + services, we...