

“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.

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.

115,000+

The average number of wound care supplies sent each year to 400+ families in over 42 states. Unfortunately, many families are underinsured or don't have coverage for these medically necessary items.





130

On average, our EB Nurse supports more than 130 unique families per month, providing expert advice and education on EB care and management.

OUR IMPACT

- 93%** of program participants reported an improvement in health over the year for their loved one with EB due to our programs and services.
- 100%** said that the New Family Advocate Program reduced their stress.
- 94%** said that our EB Nurse allowed them to better care for themselves or their loved one with EB.
- 95%** said that the Wound Care Distribution Program either provided support during or prevented a crisis.

GET IN TOUCH





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WE FIGHT

THE WORST DISEASE YOU'VE NEVER HEARD OF.

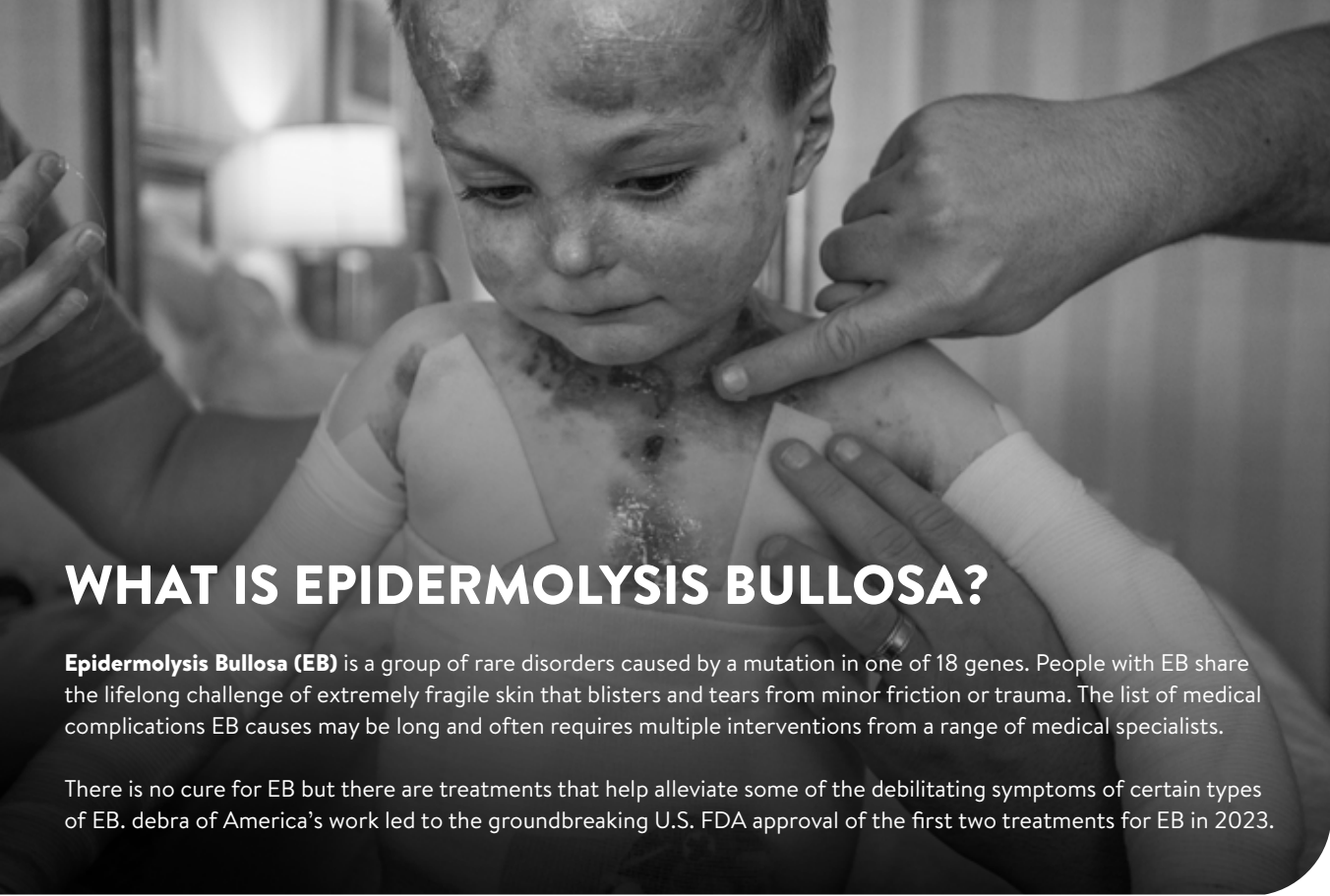
CONNECT WITH US ON SOCIAL

-   @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





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 of America's work led to the groundbreaking U.S. FDA approval of the first two treatments for EB in 2023.

WHAT DO WE 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 of America 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 individuals and families with EB. For more information about your gift's impact and to donate today, please visit debra.org/donate or scan the **QR Code on this brochure.**
- **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. 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 team in endurance events around the world.

through our programs and services, we...

Provide Wound Care Supplies

WOUND CARE DISTRIBUTION PROGRAM

debra 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.

Support New Families

NEW FAMILY ADVOCATE PROGRAM

When we learn of a newly diagnosed person with EB, we send informational and educational materials covering everything from insurance needs to care trends, as well as a sampling of wound care products.

Advocate

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 instruct patients and families on the best ways to advocate for themselves with insurance companies and school boards.

Spread Smiles

SMILE FUND PROGRAM

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

Advise & Empower

MENTORSHIP PROGRAM

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

Educate & Connect

DEBRA CARE CONFERENCE

Drawing 700+ guests, this biennial conference brings the EB Community together for four days of education, connection, and empowerment.

Build Community

EB CONNECT

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