

200

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

\$2.44 MILLION

The amount that debra of America spent on direct-to-patient programs and services and research in 2019.

110,753

The number of specialized, non-adherent bandages sent to families across the country in 2019.

\$83,464.17

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

75%, 6 HOURS

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

## OUR 2019 IMPACT

92% 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.

93% said that our EB Nurse Educator allowed them to better care for themselves or their loved one with EB.

96% of families said that the Wound Care Distribution Program either prevented, or provided support during, a crisis.

## CONNECT WITH US



@DEBRAOFAMERICA



@WEFIGHTEB



/COMPANY/DEBRA-OF-AMERICA

## GET IN TOUCH



www.debra.org



staff@debra.org



(212) 868-1573



75 Broad Street  
Suite 300  
NY, NY 10004

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WE FIGHT

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



debra

because the cost of doing nothing is too great

# 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. As of May 2021, one treatment for EB is on the verge of approval and 3 gene therapies are in the final stages of development.

## WHAT DO WE DO?

**"Because the cost of doing nothing is too great"** is an axiom that defines our mission and directs all of debra of America's actions as an organization. We are dedicated to improving the quality of life for those living with EB. To achieve this, we do two things in parallel: we provide free programs and services for the EB Community in the U.S., and fund the most innovative research directed at symptom relief and a systemic cure.

In 2019 alone, debra of America spent \$2.4 million on our direct-to-patient programs + services and research.

## WHAT CAN YOU DO?

- **Make a gift.** A gift from you directly impacts individuals + families. For more information about your gift's impact and to donate today, please visit: [debra.org/give](https://debra.org/give)
- **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 + raise funds. We're here to help guide you through every step of the process!
- **Join a Committee.** Have a hands-on role in planning and executing initiatives to advocate and raise funds for the EB Community.
- **Volunteer.** Make an immediate impact in the fight against EB!

## PROVIDE WOUND CARE SUPPLIES

### WOUND CARE DISTRIBUTION PROGRAM

debra of America bridges the gap in coverage for individuals with EB by providing supplemental bandages to those in need. Specialized bandages for EB can cost more than \$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.

## SPREAD SMILES

### THE SMILE FUND

In partnership with Grace Peshkur's family and friends, debra of America grants mini-wishes for people with EB. These smiles not only benefit the recipient, but they also create priceless memories.

## INFORM + EDUCATE

### DEBRA CARE CONFERENCE (DCC)

The largest gathering of the EB Community worldwide! The DCC is a biennial conference where EB individuals, families, and the professional community come together to access the best information, discover new ideas, and connect with each other.

## WELCOME 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 after a diagnosis.

## ADVOCATE FOR THE COMMUNITY

### GOVERNMENT AFFAIRS + LEGAL AID PROGRAMS

We work at all levels of government to educate legislators about important laws, regulations, and policies that will benefit those with EB. Our Legal Aid Program is designed to help people with EB, and their families, best advocate for themselves when issues arise.

THROUGH OUR PROGRAMS + SERVICES, WE...