

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.

\$1.06 MILLION

The total value of supplemental wound care supplies that debra of America sent in 2018 to families that didn't receive enough bandages from their insurance company.

113,173

The number of pieces of wound care supplies sent to families across the country in 2018.

\$83,464.17

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

75%

The percentage of the body that may be covered in bandages due to EB.

CONNECT WITH US



/COMPANY/DEBRA-OF-AMERICA



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WE FIGHT

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


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

Photo Credit: Ari Espay, 2016

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 researchers are making tremendous strides in developing therapies. As of today, there are 4 gene therapy clinical trials in progress.

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 develop and execute programs with free services for the EB Community in the U.S., and fund the most innovative research directed at symptom relief and a systemic cure.

In 2018 alone, debra of America spent \$3 million on our direct-to-patient programs + services and research, a 30.4% increase from the year before.

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
- **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!

THROUGH OUR PROGRAMS + SERVICES, WE...

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.