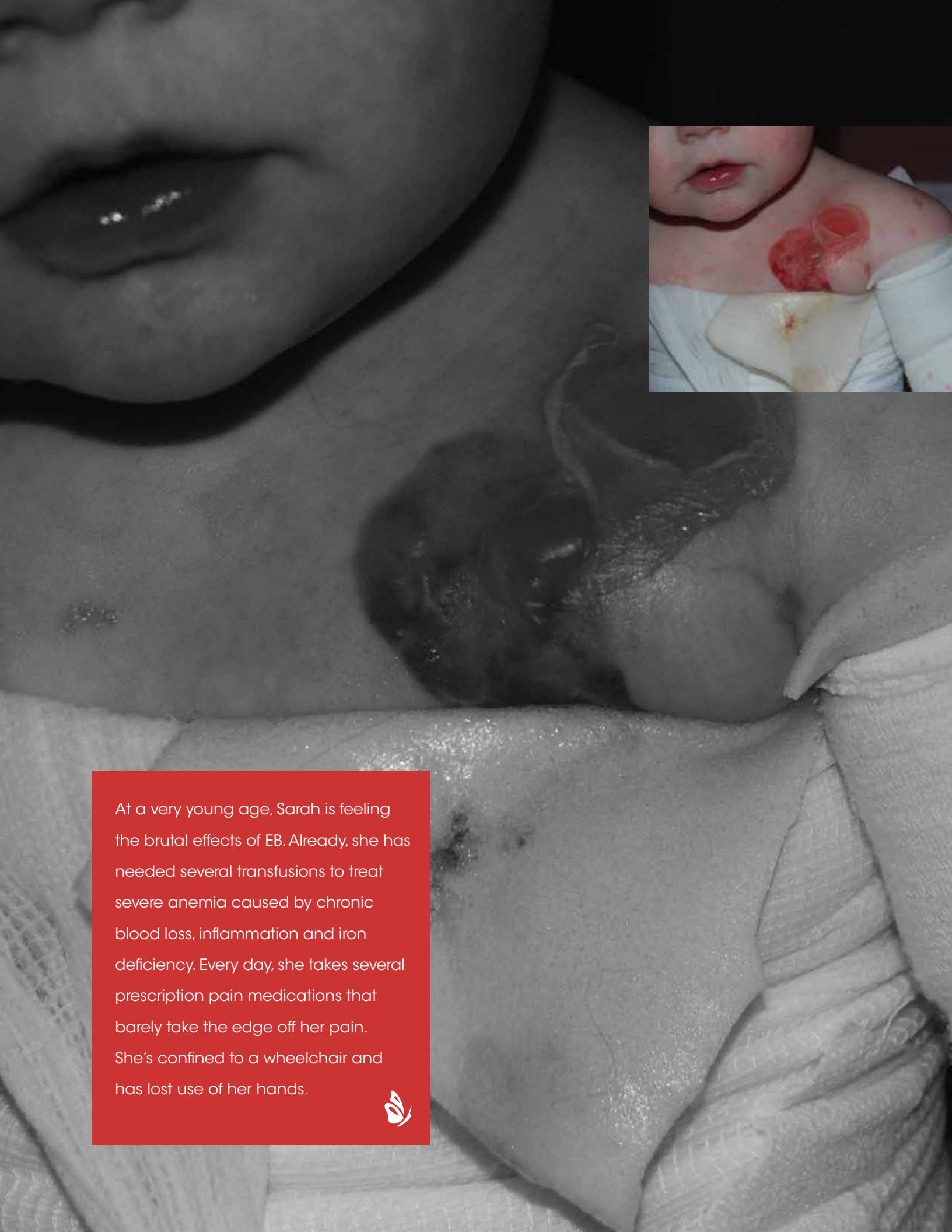


Because the cost
of doing nothing
is too great.

debra
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THE DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA



Epidermolysis bullosa, the worst disease you've never heard of.

Epidermolysis bullosa (EB) is a relatively unknown disorder that affects one out of every 20,000 live births. As of today, there is no cure or treatment—daily wound care, pain management and preventive bandaging are the only options for care.

EB is a rare connective tissue disorder with many genetic and symptomatic variations. Yet, all forms share the prominent symptom of extremely fragile skin that blisters and tears from minor friction or trauma. Children with EB are often called butterfly children, because their skin is as fragile as a butterfly's wings. And like butterflies, their lives are often short.

For infants with EB, a necessity like wearing a diaper causes blisters and skin tears. Even an everyday event, like taking a bath, is a painful ordeal. Many will be confined to a wheelchair early in their lives and lose use of their hands and feet by the age of 10. Others will develop a deadly form of squamous cell carcinoma by age 15.

EB is always painful, is often pervasive and debilitating and, in some cases, is lethal before the age of 30. It affects both genders and every racial and ethnic background equally.

\$1,200 – helps to pay for the doctor and prescription copays for one child for one year.

To donate, visit www.debra.org/donate or call toll free, 855-CURE-4-EB.

At a very young age, Sarah is feeling the brutal effects of EB. Already, she has needed several transfusions to treat severe anemia caused by chronic blood loss, inflammation and iron deficiency. Every day, she takes several prescription pain medications that barely take the edge off her pain. She's confined to a wheelchair and has lost use of her hands.





Living with the secondary illnesses and complications caused by EB is an everyday reality.

Butterfly children with all forms of EB experience painful blisters and open wounds, and those affected with the milder forms of EB can lead long, productive lives. However, those with more severe forms are subject to disfigurement and disability early in life because of the secondary complications. Unfortunately, others lose their battle quickly — sometimes in the first few months of life.

The list of secondary complications is long and requires multiple interventions from a range of specialists. In spite of this fact many still refer to EB as a skin disorder, but it is significantly more. It affects bodily systems and internal organs, as well as the eyes, nose, mouth, throat and anus. Secondary illnesses and complications run the gamut from anemia to zinc deficiency. Monthly blood transfusions or iron infusions are a way of life to treat anemia. Many are diagnosed with a disease of the heart muscle called cardiomyopathy, which is heart failure. Squamous cell carcinoma, a usually curable skin cancer in the general population, is particularly virulent in those with EB. In fact, it proves fatal within five years to 80 - 90% of those diagnosed.

alopecia • anemia • anxiety • cardiomyopathy • colitis • constipation • corneal abrasions • dehydration
depression • esophageal strictures • growth retardation • infection • joint contractures • melanoma
nutritional deficiencies • osteoporosis • premature tooth decay • pruritus • squamous cell carcinoma • etc.

\$1,500 – the average retail value of a box of wound care supplies that debra sends out every day.

To donate, visit www.debra.org/donate or call toll free, 855-CURE-4-EB.

By the tender age of five, Rafi has already undergone five esophageal dilatations to widen her throat just so she can swallow her own saliva. She was also diagnosed as suffering from cardiomyopathy, osteoporosis, anemia, frequent infections, pseudosyndactyly of the hands and feet (mitten deformity), growth retardation, constipation and acute anxiety.



Imagine your child needing a daily dose of methadone just to get through the day. The pain is so severe that even prescription drugs like morphine can't alleviate it.



Learn the facts about EB:

- About 25,000 people in the U.S. suffer from one of the various forms of EB.
- Blisters and wounds, prone to life-threatening infections, can cover more than 75% of their bodies.
- Some children get at least one corneal abrasion a month and can't open their eyes for up to four days.
- The itching from healing wounds, infections and heat is a constant battle, but scratching can rip the skin.



5:15 am

Even though school doesn't start until 8:30 and it's only a half-mile away, your day begins. Anxiety is your morning coffee, as you hope your child's eyes haven't dried up and stuck to the lids, ripping the top layer of the cornea first thing upon opening.

On a good morning, the pajamas haven't stuck to the dried blood of a new wound, formed simply by moving around in bed at night. This would result in the painful removal of skin along with fabric. For now, you focus on preparing the bandages you'll need to replace the dirty ones.

7:00 am

You've just spent 20 minutes holding your child's hands during a painful visit to the bathroom. The constant constipation finally gave way, but not without a price. There is blood in the toilet.

8:20 am

Thankfully, only one area was stuck, requiring an extra ten minutes to the morning routine to soak it off. The soiled bandages have been removed and you've popped and drained several new blisters with a thick hypodermic needle. Another piece of your heart breaks as you apply the new bandages for the day.

2:30 pm

Hopefully, there was no incident at school that required new bandages. Just being bumped in the hallway, in the lunchroom or on the stairs can cause a painful, bleeding wound. You get ready for your child's afternoon bath and bandage change. Preparing the bandages and gauzes takes about an hour.

4:00 pm

With 70% of the body covered in open wounds, your child must soak in a bath of diluted bleach, or worse yet, vinegar, to fight the life-threatening infections. The initial sting of the water is unbearable, causing tears. You never get over seeing your child cry or hearing their sobs. The sting then turns into a throbbing that even prescription pain medications can't alleviate. Imagine torturing your child like this for two to three hours on a daily basis.

8:00 pm

Worn down by the fear, pain and drugs, your child finally falls asleep. Hopefully, there has been time for homework and dinner first. And hopefully, you both will sleep through the night tonight—before starting the process over again tomorrow.

\$2,500 – the cost for debra to send an experienced caregiver to train new parents on how to care for their EB infant.

To donate, visit www.debra.org/donate or call toll free, 855-CURE-4-EB.



A lack of awareness adds to the debilitating effects of EB.

Because fewer people are aware of EB, it receives less attention than many other rare diseases like cystic fibrosis and ALS (Lou Gehrig's disease). But while EB may not be as well recognized, its effects are no less debilitating.

EB kids are dependent upon others because they can't dress themselves, tie their shoes or hold a pencil. Because many school districts are unable or unwilling to accommodate the needs of an EB child, many have to be home schooled, making it difficult for their parents to hold a full-time job.

Adding to this burden, the highly specialized, non-adherent bandages and wound care supplies often cost in excess of \$10,000 per month. Most insurance carriers, if they pay for the medical equipment at all, have a cap of \$1,500 per year. When you factor in the cost of hospitalizations, co-insurance, deductibles, doctor and prescription drug co-pays, and lost time from work for the parents, EB steadily drains a family's finances.

Two-income families quickly become one-income families—often living at or below the poverty level. Many rely solely on Medicare, Medicaid and Social Security Disability Insurance. Funds are badly needed to help these families, as well as to find more effective treatments and, ultimately, a cure.

"My despair hasn't reached suicide level again, but it comes close. Dependency is a curse I wouldn't wish on anyone. I loathe not being in control of my life...unable to give myself an Advil because I'm alone and can't open the cap...staring at my deformities in mute despair."

Kate, a 13-year-old with EB



\$7,500 – the monthly cost of an available nurse to deal with the thousands of calls and emails.

To donate, visit www.debra.org/donate or call toll free, 855-CURE-4-EB.

"Daisy uses breathing equipment and her feeding tube up to 16 hours a day. When the electricity goes off, as it frequently does in central Florida, Daisy is at risk. I was terrified that she was going to stop breathing. debra helped us with a propane generator that takes over when our power fails."

Dana, mother of Daisy



Until there's a cure, there's debra.

debra of America is the only national not-for-profit organization that supports the services, treatment and research for this rare disease. While the search for a cure moves forward, debra provides a number of programs to alleviate the inherent daily stress of living with this horrible disease.

New Family Advocate Program – This vital program sends care packages to all new families afflicted by EB. The packages contain wound care products and medical supplies as well as practical information on wound care and the many medical issues caused by EB. We also send an experienced caregiver to train the new family on how to care for the newborn with EB.

Wound Care Clearinghouse – Wound care supplies for those with EB can run more than \$10,000 per month. In many cases, private insurance has a \$1,500 yearly cap. debra steps in to fill this gap by sending wound care supplies to those who can't afford them, distributing more than \$350,000 worth of supplies annually.

Family Crisis Fund – Financial assistance extends to expenses related to the care and treatment of someone with EB, including their insurance deductibles, co-insurance and co-pays. We also purchase equipment related to care. See Daisy's story above.

Nurse Educator Program – Our nurses are usually the first point of contact for new families faced with EB. Available by telephone or email, they discuss treatment options, palliative care, wound care and clinical trials currently underway for those challenged with this illness. Nearly 30% of the calls fielded by the Nurse Educator Program are from the professional medical community asking for care advice.

National Referral Network – Our nurses compile and update a national referral network of physicians who specialize in particular areas of care related to EB.

Smile Fund – Similar to wish granting, the Smile Fund selects one EB applicant every month to grant a mini wish. These wishes are typically for items like webcams or iPads.

Patient Care Conference – debra hosts a free biennial conference where families can meet with clinicians who specialize in EB, as well as the researchers working on its cures and treatments. These forums also provide an opportunity to connect with other families facing problems similar to their own.

\$12,000 – Twelve smiles for twelve children provided by the Smile Fund.

To donate, visit www.debra.org/donate or call toll free, 855-CURE-4-EB.



Your gift gives hope.

More than 25,000 people in the U.S. currently live with little hope of a cure for this painful disease. But promising new research may soon change this. A treatment and a cure are at hand.

debra of America is providing financial grants for some of the most innovative, practical and exciting basic science and translational research to date. Our funding has led to the discovery of the genetic basis of EB, the development of the mouse model to test therapies and a national registry to capture data about the burden of illness. With our funding, researchers have corrected the gene that causes one of the more severe forms of the disease.

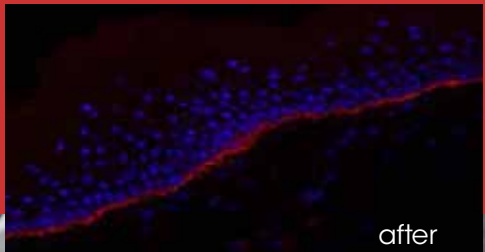
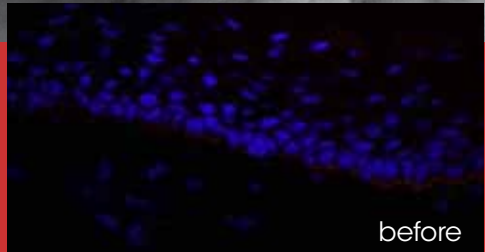
In 2012, debra of America, along with debra International, allocated more than \$4 million to research projects globally. Clinical trials in cell therapy are underway while trials in protein replacement and gene therapy are under development.

Even though there are more researchers and companies working diligently to ease the pain and debilitating symptoms of this rare disease than ever before, we still have a great deal more to do. Please give generously to push this new research forward, because hope is the greatest gift you can give to those who live with "the worst disease you've never heard of."

\$20,000 – the monthly cost of an early-stage research project

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These before and after photos show the promising results of a new clinical trial that helps develop Collagen VII, a vital protein that is the primary building block of the connective tissue and structure of the skin. The red line in the after treatment photo shows the increase in Collagen VII production in the skin of a little girl with a severe type of EB.





The cost of doing nothing is too great.

Please help us fund the exciting research and provide the vitally important programs and services these children and their families. Your generous support will make an immediate impact on the lives of thousands.


debra will continue to pursue its mission of alleviating, and eventually eradicating, the inherent daily stress of living with EB. Our goal is to find not only commercially viable treatments, but a cure that will be available to all.

Visit www.debra.org/donate to learn more about EB and the many ways to get involved or make a donation. You can also contact the office directly by calling toll free, 855-CURE-4-EB, or mail a check payable to debra of America to:

debra of America
75 Broad Street
Suite 300
New York, NY 10004

The time to act is now.

- As of June 2013, 16% of those born with EB in 2012 are no longer with us.
- 32% of those born with EB in 2009 have succumbed.
- Studying a five-year time period, 73% of those born with junctional EB have lost their battle.



To donate, visit www.debra.org/donate or call toll free, 855-CURE-4-EB.

About Debra

debra of America was founded in 1980 by Arlene Pessar, whose son was born with Epidermolysis bullosa (EB). Frustrated with the lack of available medical information on the disease, Arlene hoped to fill the large gaps in knowledge about the cause, diagnosis, treatment and cure of EB. Today, the debra newsletter is mailed to approximately 13,000 families, health professionals, corporations and public officials. Throughout its 30 years, debra has remained committed to funding research toward a cure, while responding to the increased need to provide direct services to patients and their families.



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**To donate, visit www.debra.org/donate or
call toll free, 855-CURE-4-EB.**

The Dystrophic Epidermolysis Bullosa Research Association of America, Inc., is a registered 501(c)(3) organization with the Internal Revenue Service. All donations are tax deductible to the fullest extent allowable by law.