

NO BABY BLISTERS STATEMENT OF PURPOSE

To save EB babies from blisters, skin loss, extreme pain, and death.

WHAT IS EB?

EB (Epidermolysis bullosa) is a genetic blistering skin disease that causes a baby's skin to blister and peel off, creating extreme pain and, in its most severe forms, leading to death. EB is caused by a genetic mutation that creates a very weak bond between the baby's skin layers in the epidermis and dermis. Friction, pressure, and heat on the skin causes blisters and skin loss. Even a hug from mom or dad can cause life-threatening blisters and skin loss, and extreme pain that can't be controlled even with our best medicines. EB affects both genders and ethnicities equally so it is a global, neglected problem.

WHY IS IT CALLED "THE WORST DISEASE YOU HAVE NEVER SEEN"?

EB babies are called Butterfly Children because their extremely fragile skin is like a butterfly's wing. It easily blisters, peels off, and then becomes infected, causing inflamed, very slow-healing wounds that may never heal. The wounds can grow deeper causing greater pain and life-threatening infections and dehydration. EB babies often fail to grow and thrive because blisters on the lips and inside of the mouth make eating extremely painful. Severe EB creates constant extreme pain for the baby whose life is often tragically cut short—many babies born with EB do not see their first birthday celebration.

It is hard to know how to treat EB. The wounds—which can cover large areas of the baby's tiny body—require dressings but changing those bandages can rip off additional pieces of skin and worsen the wound by making it deeper and larger. Even under the best conditions, changing dressings on these precious children is extraordinarily painful and unavoidable. EB babies can even start to cry when mom or dad enters the nursery room because the baby quickly identifies the parents as the "torturers" because of the painful bandage changes. It is heart breaking.

Parents who want to love and protect their precious children are submerged in a situation where they must inflict constant pain on a body that is already suffering. But it's even worse. Blistering and infections of the fingers, toes, and nails can require repeated partial amputation surgeries to stop the infection from spreading. Every amputation causes terrible post-surgical pain. The raw unhealed skin between adjacent toes and fingers can fuse together creating "clubbed" hands and feet. Without fingers and toes, crawling, walking, and picking up a toy becomes impossible.

EB babies can spend most of their painful lives indoors wrapped in bandages like a butterfly's cocoon — instead of crawling, running, and playing outside with their family and friends. Simple things like sitting in a grandparent's lap or eating ice cream or exploring the backyard are unknown to these poor children. They won't walk or go to school or run through a sprinkler or enjoy the sort of childhood their families so want to give them.

Babies born with less severe forms of EB who live into young adulthood suffer extreme pain, scarring, itching and bullying because of their skin's appearance. EB also causes deadly skin cancer in many of these young adults.

Parents suffer an unbelievable emotional burden because their EB baby is constantly crying tears of unrelenting pain. Imagine the heartbreak and devastation of not being able to stop the pain of your precious baby. These parents often feel guilty because EB is a genetic disease usually inherited from one or both parents. Besides the emotional devastation caused by EB, EB families can easily go bankrupt because one parent has to stop working and stay home full-time to care for the baby combined with the high medical costs of special bandages, doctor visits and surgical procedures. Not everything these EB babies need is covered by insurance.

Over 500,000 humans around the world are suffering or dying with EB right now. EB not only separates the baby's skin but also separates the baby from the parents' loving hugs. Hugs shouldn't hurt so we will

work tirelessly until we fund and find a cure to stop EB's blisters, skin loss, extreme pain, and death.

Yes, EB is the worst disease most people have never seen.

WHAT CAN WE DO RIGHT NOW TO HELP EB BABIES?

First--we need to stop the pain and deaths of hundreds of thousands of babies and children with EB by donating to our Fast Cure Plan. Your donations are tax deductible. Rare genetic blistering skin diseases do not receive the same funding from the medical establishment as do more common lifestyle diseases like heart disease and smoking. Tragically, EB babies are routinely neglected by modern medicine research funding while their parents can only watch them suffer excruciating pain and death.

It is time for the neglect and injustice in medical funding to end.

Second—partner with us. No Baby Blisters is global movement of loving people who have joined together to save EB babies. We invite you to join us today. Your love and financial help can put an end to EB babies' pain, suffering and death. These precious babies with their skin blistering off are fighting to stay alive and urgently need our help. Take a moment and imagine what your donation can do.

- Imagine your baby in extreme pain and there is nothing you or your doctor can do to help stop it.
- Imagine knowing that your baby may not live to celebrate the first birthday, or her/his teenage years due to infections or skin cancer.
- Imagine the painful daily bandage changes over large areas of your baby's body.
- Imagine your baby crying every time you walk into the room because you are the one causing more pain with every bandage change.
- Imagine not being able to hold and hug your baby – because it could cause blisters, skin loss, extreme pain and infections.
- Imagine your baby not being able to crawl, walk or pick up a toy because the partial amputations and fusions of toes and fingers.
- Imagine the hungry cries of your baby, who cannot eat or drink enough due to blisters in the mouth, leading to malnutrition and slow physical development.
- Imagine your lack of hope because EB research is not being properly funded.

Third—make a commitment. EB babes have a terrible future unless we choose to end the neglect and injustice in medical funding. We are already making a difference in many lives and with more committed partners, we can help today's patients and cure this awful disease tomorrow. Our goal is to find fast, efficient research strategies that will lead to real cures that will be made available either free or at affordable prices for these suffering families. Imagine EB babies escaping their cocoons of pain, suffering and death! With our Fast Cure Plan, we imagine a cure and great future is close. We are funding smart researchers at top hospitals:

1. Who have FDA regulatory experience needed to get a cure approved.
2. Who have intellectual property rights to what they are studying so our research money is not wasted on dead ends that can't be made available to EB babies.
3. Who are studying affordable or free cures so everyone suffering with EB can be saved.

Finally—educate yourself and your family and friends. Even if EB does not touch your life directly, we should all be moved by the suffering and hopelessness of the thousands of EB babies in the world. There are other organizations working on EB. Unfortunately, many potential treatment studies funded and conducted by other groups and researchers subject EB babies to added pain and risk. Their research includes harvesting live stem cells that require sticking these children with needles and taking skin samples; exposing EB babies to potential cancer-causing viruses; and, using cancer-causing gene editing techniques like CRISPR that create even more mutations. Bone marrow transplant studies to reset the skin were halted for safety reasons due to early deaths of the EB babies. All of these potential cures would cost hundreds of thousands of dollars to millions per treatment that insurance likely would not cover. We

believe a cure should be affordable or free for all 500,000 EB sufferers and future EB babies. There are other ways to approach EB—with compassion—that can lead us to an affordable cure.

OUR URGENT PLEA FOR YOUR LOVE, YOUR COMPASSION, AND YOUR TAX-DEDUCTIBLE SUPPORT TODAY

EB babies should not suffer excruciating pain and early deaths. Their families should not be destroyed and bankrupted trying to get them help. They should grow, live, love and play like other children. BUT PLEASE HURRY. Every day is another day these babies must suffer and their parents must watch. We are asking for your tax-deductible donations to finalize our Fast Cure Plan. We need your love and financial help to:

- **Find fast cures for EB**, ways to provide life-changing and life-sustaining medical help that will stop their pain and suffering and allow them to grow up as normal children
- **End the despair and suffering of EB parents** who can do little besides watch their children suffer and die ... sometimes before their very first birthday
- **End the injustice in medical funding** that often overlook so-called “orphan diseases”
- Help us **create a cure that is safe, effective, and affordable** so that no child with EB needs to suffer
- **Fund the right researchers**—those who own the intellectual property rights to create affordable cures that we can distribute (without going through big companies)
- Commit to our goal of **finding free or affordable treatments** so that no family is bankrupted by EB treatments (that do not even cure the disease)
- Support all of us fighting the war against EB—smart scientists, dedicated researchers, avid fundraisers, parents, physicians, nurses, caregivers. **This is a battle we can win**, if we fight together!

Will you love and financially help EB babies? Please join No Baby Blisters to save EB babies from blisters, skin loss, extreme pain, and death today. Donate now at www.nobabyblisters.org