

# What is EB?

*Epidermolysis bullosa*, or EB, is a rare genetic disorder. The most prominent characteristic is extremely fragile skin that blisters and tears with the slightest friction. Internal organs and bodily systems can also be affected. The list of secondary complications is long, and requires interventions from a range of medical specialists. EB can occur in every racial and ethnic group, and affects both genders equally. As of today, there is no cure.

**EB is not contagious.** It is far more likely a child with EB will be accidentally harmed by their peers than inflict damage.

**EB is painful.** Wounds caused by EB heal slowly and are prone to life threatening infections.

**EB is debilitating.** Repeated injury and the resulting scarring lead to deformity and loss of function in the hands, feet and mouth.

**EB is pervasive.** It affects the internal organs as well as the eyes, nose, mouth, throat and anus. Some typical complications are: infection, anemia, growth retardation, inability to swallow, corneal abrasions, cancer, contractures, depression, anxiety, malnutrition, premature tooth decay.

## debra of America

is the only national non-profit dedicated to supporting research for a cure or treatment while providing programs and services to those who suffer from EB and their families.

Our mission is to alleviate the inherent daily stress of living with EB, because the cost of doing nothing is too great.



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## IS THERE A STUDENT WHO HAS EB IN YOUR SCHOOL?

### It's okay to touch.

EB is not contagious, so as long as other students are careful of their sensitive skin they can hold hands, hug, and play with EB children.

### Be careful of their skin.

Damage is caused by friction or trauma. Be careful not to snatch items from, bump, or grab an EB student.

### They may have dietary restrictions.

Children with EB may have difficulty swallowing because of blistering and scarring in the mouth and throat. It is best to offer them soft food options. Ice cream is usually a favorite!

### EB does not affect them mentally.

Though EB can have devastating physical and emotional impact, children with this disease have the same mental development as other students their age.

### They are the same as other children.

Children with EB may look different, but they have the same likes, dislikes, fears and hopes as other kids their age. It is important they are included as part of the group.