

About EB

(Epidermolysis Bullosa)

“Butterfly Children”

With skin as fragile as a butterfly's wing, kids with EB are often called Butterfly Children. These kids CAN & DO enjoy many of the same activities as those without EB.



EB is a rare genetic skin disorder. It is not contagious.

Our skin has proteins and anchoring fibrils that look and act something like **Velcro or special glue to keep the layers together. This is one way that our skin helps keep us healthy and safe from getting** open wounds/**boo boos too often.**

In those who have EB, the protein (Velcro or special glue) is either missing or broken. This is why sources of friction, like rubbing, scratching itches or sweat, cause frequent blisters which can turn in to open wounds/**boo boos.**

The stickiness of adhesives/band-aids create another source of friction. This is why those with EB are wrapped in non-adhesive layers, like **gauze or different bandages, to keep** wounds/**boo boos healthy.**

(Note: To explain EB to your child, consider reading just the bolded text above.)

FAQs

- Q: Can I/my child catch EB?
A: No. It is genetic, not infectious or contagious.
- Q: Does it impede ability to participate in every day activities?
A: Whether mild, moderate or severe in form, EB does NOT impact intelligence. Some with EB might find certain activities more difficult, and require accommodations.
- Q: Why do those with EB need to be wrapped in special dressings?
A: Like a band-aid used for your cut, these dressings keep those with EB safe from bacteria and germs that you and I carry on our bodies every day.

To learn more about EB, visit www.IRefuseEB.org.
Please feel free to e-mail me your questions: sooann@gmail.com.