



Michael's Story





Hi, my name is Michael and I am 7
years old. I was born with
Epidermolysis Bullosa.

That can be a bit tricky to say so most
people call it **E.B.** for short.

This means my skin is very fragile
and can get hurt easily.



Lots of people call children like
me “butterfly children”
because our skin is as fragile as
a butterfly’s wings.

I wear bandages to help protect my
skin. You might see bandages on my
arms, legs, or other parts of my body.



In school, I must be careful when I
am in the classroom so that I don't
bump on desks or chairs and I
must be careful at recess so I do
not fall.



I can still have lots of fun
throughout the day! I love to learn
new things, make art, build with
blocks, read books, and play with
my friends.



Outside of school, I love painting,
playing with my dinosaurs, and
going to the movies.

I live at home with my Mom and
Dad, my sister and my puppy Rex.

Sometimes, people look at me because
they don't understand E.B., and this can
make me sad.

But having E.B. is just one thing about
me.

It doesn't stop me from learning,
laughing, and being a good friend.





Even though my skin is a little
different, I learn and play just like you.

So, come say hello to me, get to know
me, and let's be friends!

Learn more about EB

Epidermolysis Bullosa (EB) is a group of rare genetic disorders that cause the skin and mucous membranes to be extremely fragile. Even minor friction, heat, or trauma can result in painful blisters and open wounds.



For more information about Epidermolysis Bullosa (EB), resources for schools, and support for families, visit debra of America at debra.org

About this booklet

Special thanks to DEBRA Ireland, who originally created and developed this booklet to help children with EB share their story. Adapted by debra of America.



Disclaimer: This booklet has been adapted from a concept originally conceived and developed by Debra Ireland (debra.ie). Debra Ireland does not assume any responsibility for the content, direction of use, or outcomes associated with this booklet.