



BASIC GUIDELINES: Letter to Parents

Only consider writing a letter if your child is beginning Kindergarten or first grade, or new to the school system. The older the child gets the less they need parents to handle situations that occur in a natural classroom environment. It is important for children to develop self-advocacy skills.

Instead of going into details about EB, use this letter to explain your child's abilities and times they need assistance. You want other parents to get to know your child, not their medical history. Understandably, other students may have questions. Be sure you are not sharing anything you have not already talked to your child about or anything that would make him/her uncomfortable discussing with other students. Ask the teacher to read your letter and supply your own copies for distribution if it is approved (most letters will need prior approval from the teacher or principal in order to be distributed among the entire class).

Include your name, number, and an email address in case parents have any questions.

SAMPLE LETTER

Dear Kindergarten Parents,

We are really excited about this school year. Our daughter, Jane Smith, will be in Ms. Teacher's class with your child. Jane has a rare genetic disorder called Epidermolysis Bullosa (EB) that causes her skin to be very fragile; it blisters and tears at the slightest friction. Her internal organs and body systems are also affected. Jane is not contagious and poses no danger to other students or faculty, but she does require special medical care to help heal wounds, keep her free of infection, and prevent new injuries.

We plan to explain a little about what EB is on the first day of class. We know other students may have questions, and don't mind answering them. Though EB limits Jane's physical abilities, she enjoys the same games and activities as other children her age. She is a little shy at first but loves making friends.

Jane wears bandages at all times to protect her skin, but things like being accidentally pushed or lifting heavy books can cause injury. Being aware and lending a hand makes a big difference. Jane will ask for assistance when she really needs it.

If you have any questions about EB or having Jane in class, please feel free to contact me at the email or phone number below. You can also reach out to debra of America to learn more about the disorder. Thank you and I look forward to getting to know you all better!

Best,
Judy Smith
Phone
Email

Dystrophic Epidermolysis Bullosa Research Association of America, Inc.

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