



### **BASIC GUIDELINES: Letter to Teachers/Administrators**

Let your child's teacher(s) and any relevant school administrators know that he/she has EB. Explain how EB affects your child and what his/her limitations are. Think of anything that might make the school day harder for your child (physical activities, needing time in between activities, etc.) and then give some ideas or strategies you use at home to help with these types of situations. If your child uses any adaptive equipment (doctor prescribed or otherwise) briefly explain what they are, how they're used, and why they are beneficial to your child.

Keep in mind that the beginning of the school year is a busy time for school staff. Try not to make demands, but instead offer suggestions. Be sure to include your contact information and the best way and time to reach you.

### **SAMPLE LETTER**

Dear (Teacher),

My child Jane Smith will be joining your kindergarten class this September. She has a rare genetic disorder called Epidermolysis Bullosa (EB) that causes her skin to be so fragile it blisters and tears at the slightest friction. Her internal organs and body systems are also affected. At any time Jane could have painful wounds, and she wears bandages at all times to protect her skin. Jane is not contagious and poses no risk to yourself or other students/faculty, but she sometimes needs extra time or assistance to complete tasks.

One of the areas where Jane has difficulty is participating in physical activities. Moving for extended periods of time causes painful blisters. At home when Jane's siblings are playing outdoors, we have her participate by being scorekeeper, or give her an indoor activity such as an art project. Jane also has some difficulty writing, due to scar tissue on her hands. We have seen an Occupational Therapist who provided adapted writing utensils, which Jane will bring to class, but it would also be helpful if she had some extra time to complete written assignments.

If you have any questions about Epidermolysis Bullosa or having Jane in class, I can be reached at the contact numbers below. You can also contact debra of America for information about EB and having a student with EB in your class.

Best,

Judy Smith  
Home/Work phone (times available)  
Email

debra of America  
Office: (212) 868-1573  
EB Nurse: (866) 332-7276  
staff@debra.org  
www.debra.org

#### ***Dystrophic Epidermolysis Bullosa Research Association of America, Inc.***

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