

School Letters

A note to parents considering school letters: There seem to be two schools of thought on school letters. One is "My child would be mortified if I sent a letter out about her!" The other is "The more I can educate the people around my child the better, so the weight of "fitting in and explanation" does not fall entirely on her shoulders." We have personally found that kids new kids primarily have 4 or 5 basic questions they want answered about the child's difference, and then everyone seems to move on, but with a new level of understanding. Don't confuse quietness with acceptance or understanding on the public's part. The decision to use a school letter or not is purely individual and should be made after consideration of your environment and your child's personality.)

There are two letters; one for the staff, and one for the families of the students in the school.

September 7, 2000

To: The Staff at Main Street Elementary School

This week our daughter, Elizabeth, began second grade at Main Street in Mrs. Smith's class. Elizabeth has a form of dwarfism called achondroplasia, and there are a few things we thought may be helpful to pass on to you about her. We've enclosed the letter for the Main Street parents with the basic information for your review, but as teachers, we would like to give you some more detailed information relating to Elizabeth and her safety.

1. Please advise the other children, as necessary, that Elizabeth is the same age as other first graders (she will be 8 this month) and that she is not a "baby". Being called a "baby" is the one thing that can really irritate her.

Please remember, and remind others, to treat her as any other 8 year old child in your classroom, or the school.

2. Please let Elizabeth do as many things on her own as possible. We are encouraging her to be independent. This may mean finding a creative way to do something, or that a task takes a little longer for her to complete. Usually it involves standing on a chair or stool. Elizabeth has very good balance and will generally tell you when she can't reach something, or feels unsafe.

3. Please do not let other children pick up or carry Elizabeth. Although tempting during play, a hard fall can be very serious for her.

4. Elizabeth will often feel warm to the touch, and is usually comfortable in cooler weather.

5. Because her arms and legs are short Elizabeth tends to fall more than other children, usually on her stomach. Although it looks painful, she rarely gets hurt unless it's a fall from a

height or she hits her head. She usually just pops right back up and continues on with whatever she was doing.

6. One of the things that bothers Elizabeth is to be in the middle of a large group of kids, when she feels she may be hurt or not seen. She may feel more comfortable if you are able to encourage her to be near a teacher or special friend, where she may feel safer in a large group.

7. Games that involve running like Tag and Duck/Duck/Goose can be very frustrating for her. Although I want her to participate fully in the classroom and in P.E. I don't want her to dread games like these. Perhaps for now it is best to follow Elizabeth's lead as to her comfort level of participation.

8. Elizabeth's spine and neck are more susceptible to trauma than other kids so activities that put a strain on her neck, or any type of whiplash motion are to be avoided. She is not to do a somersault, although she can do a cartwheel. She will be instructed to stay off of the monkey bars and high climbing structures.

Elizabeth can be quite strong-willed and funny. We sincerely hope you will enjoy having her in your class and at Tustin. We certainly enjoy having her in our lives. If you have any questions, please do not hesitate to contact us. We'd also like to thank Mrs. French and her custodial staff for making Elizabeth's physical environment more comfortable. You don't know how much that means to her, and to us. Thank you!

Sincerely,

Jane and Joe Doe

September 12, 2001

To: Grade 1 - 3 Parents, Main Street Elementary School

Many of you received this letter last year, but with the increased growth of Main Street, we thought it would be a good idea to pass this out again.

Our daughter, Elizabeth, is attending second grade this year at Main Street. We are writing this letter because Elizabeth has achondroplasia, a form of dwarfism, and we have found it is quite common for both children and adults to have questions about her condition. Even though your child may be older or younger than Elizabeth, they may meet on the playground or at another school event. Friends have found it helpful to have a little information. The following are a few basic facts about dwarfism:

- There are over 200 distinct types of dwarfism. Elizabeth has achondroplasia which is a bone growth disorder that affects the long bones of the arms and legs.
- Some dwarfism types are recessive (carried within the parents' genes), others are what are called "spontaneous mutations at conception". Elizabeth's form is not recessive. In other words neither myself, my husband or Elizabeth's brother carry the gene. It was just a simple genetic mutation that occurred. Elizabeth, of course, does carry the gene, which may or may not be expressed when she has children of her own.
- There are no "cures" for Elizabeth's type of dwarfism, although limb-lengthening has been used on some people. Limb-lengthening is a controversial and painful procedure, which happens during puberty. HGH (human growth hormone) does not work for Achondroplasia.
- Over 80% of all people with dwarfism have average-height parents and siblings, as is our case.
- Elizabeth's adult height will be some where around 4' 2", about the height of an average-height first or second grader.
- It is extremely rare to have retardation in conjunction with dwarfism; only a few very rare types correlate to any type of mentally handicapping condition.

Terminology: the word "midget" is not used anymore among most in the short-stature community; it is seen as a derogatory, slang word. We use the terms "short-stature", "little person" or "having dwarfism" in our home. The word "dwarf" is technically correct although we rarely use it when speaking about a person.

We also use "average-height" as opposed to "normal-height". Everyone has their own opinions, but to us, people with dwarfism are just shaped differently, not "abnormal". Elizabeth has a 4 year old average-height brother.

Elizabeth knows she is a little person and is pretty good at explaining it when asked. She usually says "My bones don't grow as fast as yours, and that makes me short", or something to that effect. If you are asked by your children why she is short, that may be a good way to explain it to them.

The reason this letter is being sent is to help stop any teasing that may occur. We are looking forward to this year at Main Street and have been extremely pleased with the openness and cooperation we have received from Mrs. French and the Main Street staff. If you have any questions please do not hesitate to contact us.

Sincerely,
Jane and Joe Doe