



Sample Letters

Date: _____

To: _____

Our son, Johnny, attends _____ grade in Mrs. _____ classroom. We are writing this letter because Johnny has hypochondroplasia, a form of dwarfism, and we have found that it is quite common for both children and adults to have questions about his condition. Even though your child may be older or younger than Johnny, they will likely meet in the classroom, on the playground or at another school event. Our family and friends have found it helpful to have a little information about dwarfism.

Basic facts about dwarfism

- There are over 200 distinct types of dwarfism. Johnny has hypochondroplasia, which is a bone growth disorder that affects the long bones of the arms and legs.
- Johnny's hypochondroplasia is a non-recessive 'spontaneous mutation'.
- There are no 'cures' for Johnny's type of dwarfism. HGH (Human Growth Hormone) does not have an impact on hypochondroplasia. Some people have tried limb-lengthening procedures, but this is a controversial, complicated & painful surgical procedure that would happen during and after puberty.
- Over 80% of all people with dwarfism have average-height parents and siblings, as is the case in our family.
- Johnny's adult height will be somewhere around 5', about the height of an average-height 5th grader.

Terminology

- *Midget*: The word "midget" is considered to be a derogatory, slang-word amongst the short-stature community and is not used anymore. In our home, we use the terms "little person", "short-stature" or "having dwarfism".
- *Dwarf*: The word "dwarf" is technically the correct term for someone with a dwarfing condition, although we rarely use it when speaking about a person.
- *Average-height*: We use the term "average-height" as opposed to "normal-height". Everyone has their own opinion about this, but for us, people with dwarfism are just shaped differently, not 'abnormally'. Johnny's height *is* normal for a person with hypochondroplasia – in fact, he's a little tall!

Johnny knows he is a little person and is pretty good at explaining it when asked. He usually says "My bones don't grow the same way as yours, and that's what makes me short" or words to that effect. If you are asked by your children why he is short, that may be a good way to explain it to them. Children are naturally very curious and notice differences, especially in peoples' physical characteristics. Those observations can sometimes turn into teasing, but we hope by learning a little about dwarfism and Johnny, your children will quickly 'see' Johnny for what he is: a wonderful, sensitive boy with a great sense of humor who happens to have a dwarfing condition.

We hope this information is helpful. The Montessori community has always acknowledged and welcomed the differences in each human being; we each have our own 'uniqueness', some just carry it on the outside. I think we've all found that once we know and understand someone, we are far more accepting and often forget that they are different.

We truly appreciate all of the great people we have shared time with through Woodinville Montessori; the whole WMS community has been wonderfully enriching for all of us for the last eight years and we look forward to another great year.

If you have any questions at all, please don't hesitate to contact Janet or me!

Warm regards,

Date _____

Dear Parents:

Our Son, Johnny, is enrolled in Kindergarten at Washington Elementary, alongside your son/daughter. We would like to take this opportunity to “introduce” Johnny to you. Johnny was born with a form of dwarfism known as Achondroplasia. We have often found, children and adults alike who are new to Johnny’s condition are “curious” and interested in increasing their understanding of dwarfism. With this in mind, we have gathered the following information which should answer many of the most frequently asked questions that we receive about Johnny.

- Johnny’s growth disorder, Achondroplasia, is the most common form of dwarfism. It is a dominant genetic bone disorder that affects the long bones of the arms and legs, the spine, and some small bones in the head. Achondroplasia affects one child in 40,000 births.
- 80% of children born with dwarfism are a first generational phenomenon, which means that neither parent is a dwarf nor is there a history of dwarfism on either side of the family. First generation dwarfism (as is Johnny) is a spontaneous gene mutation that is presently unexplainable; no cause has yet been found.
- Johnny’s adult height will be approximately 4 feet 10 inches. His life span should be equivalent to “average-height” people.
- Dwarfs are not mentally handicapped in any way. The median I.Q. for dwarfs is, in fact, slightly higher than the median for “average height” people.
- The difference between a dwarf and a midget has to do with physical proportions. Midgets are perfectly proportional, short-statured individuals (and because of medical advances-no longer exist). Dwarfs have average sized torsos, shortened limbs and slightly larger heads. Many people with dwarfism find the word “midget” highly offensive. The word midget stems from the late 1800’s during the circus era, when dwarfs were displayed for entertainment purposes. This word is no longer used to describe people with dwarfism. The term “little person” or “person with dwarfism” is perfectly acceptable. Some individuals do refer to themselves as “dwarfs” and this also acceptable and not offensive. However, we prefer that Johnny is called “Johnny” ☺.

In talking about Johnny, the best route to take is to be open, honest and direct. For example, if your child comments that, “Johnny looks like a baby” or “there is a baby in our class”, tell him or her, “Yes, Johnny is a little smaller than most kids, isn’t he? People come in all shapes and sizes, and Johnny’s bones grow slower than yours!” We are confident Johnny will be able to accomplish anything he wants in life, he may just have to do it “differently” to achieve his goal. To us Johnny is just "Johnny" he may be little ~ but we go about our crazy daily life just like any other family, except we have a few more doctor appointments than the average family.

If there is any special treatment that we would like for Johnny, is that he be treated according to his age and not his height. We celebrate Johnny’s differences and the opportunity he provides us to teach our community about differences. Please feel free to approach us with any questions you may have.

Thanks!

Hello Little League Coaches and Families,

I would like to introduce you to Johnny Harris. He will be playing farm baseball with your kids. When you first meet Johnny, you will quickly notice that he is very different than the other kids playing baseball. Johnny has the most common form of dwarfism called achondroplasia. Although Johnny stands 6-12 inches shorter than his teammates, he loves to play baseball every bit as much as they do.

As we begin the baseball season, we want to equip you with information and resources to be able to talk to your kids about Johnny. As a family, we understand that kids are curious and don't often know exactly how to articulate their curiosity. Here's a few things that might want to share with your kids prior to them meeting Johnny for the first time.

- Johnny is just like your kids except his bones grow slower than other kids
- His brain works exactly the same as every other kid
- He loves sports of all kinds and wants to play hard, have fun and win baseball games just like every other kid playing baseball
- Since Johnny's legs are shorter than other kids, he can't run as fast or as far as most kids but he can run the bases with all his might
- Everyone in Johnny's family is regular height. He is the only one in our family that is a little person
- Johnny doesn't like to be pointed at, laughed at, stared at, called names especially little or baby
- The word Midget is considered derogatory but little person or dwarf is ok.... But mostly he just likes to be called Johnny.

There are lots of kids playing baseball this year. Some are tall, some are short, some have red hair, and some have black hair. Some kids have light skin, and some have dark skin. Some have played baseball a long time and can hit the ball way far in the outfield and some have never played before and have to work hard to get their first hit. No matter what they look like or how they play all the kids are there for the same reason.... To have fun. That is exactly why Johnny is there too.

Below are a few online resources if you should wish to have further discussions with your kids about dwarfism or any kind of difference. I encourage you to spend some time with your child looking at the information offered. Our family is dedicated to inform, educate and inspire our community about dwarfism and we are always open to answering questions or offering information. If you or your child has any questions, please feel free to contact me via email at youremailaddress@yahoo.com or by phone at xxx-xxx-xxxx.

We look forward to a fun and exciting baseball season.

Play Ball!

Johnny's Mom

Little People of America www.lpaonline.org

Understanding Dwarfism www.udprogram.com

Little People of Puget Sound <http://littlepeoplepugetsound.com>

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 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 sample letters; one for the staff, and one for the families of the students in the school.

September 7, 2015

To: The Staff at Main Street Elementary School

This week our daughter, Mary, began second grade at Main Street in Mrs. Smith's class. Mary 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 Mary and her safety.

1. Please advise the other children, as necessary, that Mary 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 Mary 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. Mary 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 Mary. Although tempting during play, a hard fall can be very serious for her.
4. Mary will often feel warm to the touch, and is usually comfortable in cooler weather.
5. Because her arms and legs are short Mary 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 Mary 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 we want her to participate fully in the classroom and in P.E. we don't want her to dread games like these. Perhaps for now it is best to follow Mary's lead as to her comfort level of participation.

8. Mary'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.

Mary can be quite strong-willed and funny. We sincerely hope you will enjoy having her in your class and at Main Street Elementary. 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 Mary'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 7, 2015

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, Mary, is attending second grade this year at Main Street. We are writing this letter because Mary 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 Mary, 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 400 distinct types of dwarfism. Mary has achondroplasia, the most common type of dwarfism, which is a bone growth difference 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". Mary's form is not recessive. In other words neither myself, my husband nor Mary's brother carry the gene. It was just a simple genetic mutation that occurred. Mary, 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 Mary's type of dwarfism, although limb-lengthening has been used on some people. Limb-lengthening is a controversial and painful procedure. 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.
- Mary's adult height will be some where around 4' 2", about the height of an average- height first or second grader.

•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". Mary has a 6 year old average-height brother.

Mary 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 Elementary 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

Dear Parent(s),

As parents of a child attending (school name), we are sure that you are as excited and somewhat nervous as we are. This year our daughter (or son) (name) will be attending (school name) with your child. You and your child may realize a difference in (child's name) compared to some other children in her class. The only difference is that (child's name) is shorter than the "average" classmate because she has a form of dwarfism called Achondroplasia.

It is our hope that the parent(s) of (child's name) classmates will take a few minutes and explain to their child about children with differences. For example, some children are smaller, taller, skinnier or heavier than the next child. Some children have different color skin, hair or eyes. Some might even speak differently or some might not speak at all. Even though some people look different or act differently, that they are all people and should be treated as such.

We also ask that you mention to your children that pointing and staring are inappropriate and will make others feel uncomfortable. This is an important life lesson that we are teaching our daughter (or son) and a good one for all children so that they all learn to respect one another.

If your children ask about (child's name), you can tell them that she (or he) is a Little Person or that she (or he) has dwarfism. We ask that you remind them that she (or he) is the same age as your child and should be treated that way. For instance, she (or he) should not be called names...for example, the word "baby" because of her size. We have explained to (your child's name) that people are all different. This is who she (or he) is and her (or his) differences are what make her unique and special.

In our home, we refrain from using the word "normal" and have substituted it with the word "average" when referring to others...since what is normal? Also, please mention that (child's name) does not like to be patted on her head and should not be picked up or be pulled by her (or his) arms because this can cause a very serious injury to her (or him).

(Child's name) does realize that she (or he) is a Little Person. We know that throughout her (or his) life she (or he) will have plenty of times that people will point, stare and make her (or him) feel uncomfortably different. We hope that the time we share in (school name) will spare her (or him) some of these burdens in life. If you have any questions regarding (child's name) please do not hesitate to give us a call. It is our job to educate and our hope for people to listen.

Attached is a post card with basic facts on dwarfism. If you or your child would like to learn more about dwarfism, you can visit our web site: www.understandingdwarfism.com

Look forward to building great friendships during this school year!

(your name)

(your number) home (your cell) cell

LIKE US on Facebook: <http://www.facebook.com/understandingdwarfism>