

Letter for the school

No man can be perfectly free until all of them are, Herbert Spencer

Every man is diverse, different from others, ineffable, unique, and absolutely personal Giovanni Papini

INFORMATION FOR THE SCHOOL

Dear Teachers and _____ School Staff:

_____ has a growth problem called achondroplasia. Although we have all ever seen a «dwarf», very people are aware of how this lack of height can affect a life. Achondroplasia is not well known, both from a clinical and social standpoint and, therefore, we've decided to fulfill the following observations and a minimum information, that attempt to answer many of the questions that both, you as your students can have.

Children, both at school as at home, surely will show curiosity; is good that when they made questions or comments about _____ height, you answer them in an open, direct and honest way.

Achondroplasia is the most common form of dwarfism. It is a bone disorder of chromosomal origin wherein all the long bones are shortened symmetrically, with a normal length of the spine, which causes a disharmonic growth of the body. Achondroplasia is due to a change in the genetic information received by the growth factor receptor of fibroblasts, cells that makes bones grow along. This produces a malformation in the cartilage development, with an accelerated calcification which prevents a normal bone growth. People with achondroplasia have a normal-size-torso, short limbs and a slightly larger head, well as other phenotypic characteristics more or less regular.

The gen that causes achondroplasia has been discovered and the advances in the research are increasingly encouraging. Many researchers around the world are working to make the treatment possible.

There are about 200 different types of congenital dwarfism currently established. It's a dominant genetic disorder, but approximately 90% of children with achondroplasia have no history of it in their families, appearing as spontaneous mutation, which occurs by accident in 20,000 births.

Adults with achondroplasia are between 1.20 m and 1.35 m high, but nowadays bone lengthening surgery can improve greatly their quality of life. The

surgical interventions are performed at puberty or adolescence, and can increase the height considerably. For now, it is the only unquestionable method that exists, to make the bones grow, and these are complex and difficult surgeries. There are medications for hormonal growth disorders (for example, the pituitary), but not suitable for achondroplasia or, at least, not unanimously accepted. It has also begun a study of a treatment protocol of alternative medicine, but lacks the evidence of a sufficient large database.

Life expectancy and IQ of people with achondroplasia are the same as those of people of typical size, although children with this problem tend to have slow motor development as infants due to the body's proportions. There are number of medical problems associated with achondroplasia, throughout life, such as frequent ear infections, spinal problems, bowed legs, sleep apneas..., but the quality of children's life may be improved with an appropriate medical management.

From a social point of view, people with achondroplasia coexist always with a variety of problems due to the existence in our society of stereotypes, cultural and historical prejudices that persist still today. A "comedian" or "cirquesque" aura is around achondroplastic people, which can be painful and can bring serious life problems for all of them. The school, as the first formation place for all the people, should be especially careful with everything that is concerned with ethical awareness and must instill inside the children a respect and tolerance feeling toward different people. In this context, we wish to make a series of reflexions or advices that can make much easier the coexistence and the adaptations of the achondroplastics children.

In the first place, the word "dwarf" is hard to use, despite being the most clear and descriptive, for all its connotations; there are other terms to refer to them that may sound less contemptuous, as "a person with growth problems" or "little person", that achondroplastic people preferred for not having the "dwarf" negative charge.

Adults tend to be overprotective and to treat as babies the kids that look like little children, and sometimes they are less demanding with them than with other children of the same age. Faced with adults, a child with shorter stature often behaves in a more own the age that seems than the age which really has, and acts as he/she were smaller, because it's a good way to avoid quarrels and responsibilities and to receive more attention. This behavior, eventually, may cause significant problems in his/her development: lack of assertiveness, parents' dependency, a negative self-image...

If there are any special treatment we would want for _____, is that you attempt, in all possible situations to treat him/her according to his/her age and not by his/her height; both teachers and parents must be aware of the effect that _____ size can have in their relationships with him/her, and should avoid to become in the pet of the class, or that his/her expectations be lower.

In general, as also as a summary, we would like you to have in mind the following points when dealing with _____:

Remind the other children to treat him/her according to his/her age and not by her/his height.

Let him/her do as many things by himself/herself as possible. We must encourage him/her to be totally independent. He/she will often find a creative way to get somewhere or to perform some task. It can be as simple as pull up a step. It's important that he/she does these things without help. Encourage also other children to allow him to do things alone; they always try to help, and don't realize that in many cases that's not good for the other person.

A simple way to avoid back problems is to add a horizontal bar between the front legs of the chair so the child may rest the feet. If not, have his/her feet dangling may painfully affect his/her back.

Don't let other children pick him/her up; this is one thing they do often, because they find it funny to follow a colleague as small and that they can raise him/her up. Furthermore, he/she will not only be more "baby", but it can be dangerous: kids with achondroplasia can injure the spine more easily than other children and could get hurt if they let him/her fall.

If you do form in a row to up or down stairs, make sure not to put _____ ahead. The steps are higher for her/his legs and take longer to go up and down. Children often push themselves and he/she could harm himself/herself.

Children with achondroplasia sweat more than others and need to expel the body heat, so tend to drink more water.

_____ probably will take more time to undress and to use the toilet.

As their limbs are shorter and the head is large and heavy, they often tend to fall. Except for more than scraping, is not cause of concern.

Children with low growth often experience obesity problems, so it's important that as children develop right habits at the time to eat; even though children are more active and burn more calories, the amount that _____ needs for his/her physical development is slower than the children (boys/girls) of his/her age.

We would appreciate you to see if he/she needs help to do things that the children at this age do independently; if there are physical activities, at the playing times or work in class, which are limited due to his/her size or if his/her visual field in the class is adequate. Some problems are easily solved with a sturdy box, stools or a stepladder. Remember that there are physical obstacles which, nevertheless and not to be significant, can be overcome with a little bit of ingenuity and resource capacity.

Any child needs to feel safe in the places where passes his/her time, whether if it is at home, at day care, at school, and finally, in the world. If there are teased or victims of verbal attacks that go beyond of what is normal among the children or are related to _____' condition, teachers or concerned adults would have to be informed; the supervision of an adult can usually break the battles and the teasing before they become big.

When in the texts appear references about "dwarfs" or "little dwarfs", beware that this will not cause for laughter, teasing or ridicule, that there not be identification between _____ and the character of the tale.



Keep in mind, when you observe, perhaps, an excessive chatter that is not uncommon for these children in the attempt to develop, as a compensation mechanism, close relationships with friends, and a social aspect that for them is much more important than the pedagogical.

We believe that it would be desirable that _____ before beginning the class, to have an explanation in every classroom about this child that will be a partner and who has a birth problem that causes him to grow differently than the rest. Tell them that he/she is typical in everything else, a girl/boy like them, who was born this way as others may be born not hearing (which are called "deaf") or without sight (which are called "blinds")... Explain to them; briefly, what is a disability. That this child "is not sick", but he/she is this way, different in the height, but like them in all else. We believe that these talks could avoid the initial shock and problems that might arise later on through an oversight and which should be more difficult to solve later.

We all know that our society tends to judge people by their physical appearance and that not match with the cultural patterns about the good or the bad or the beautiful or the ugly can be very painful. Make children aware that there are more important values such as honesty, courage, friendship, or kindness, which are enriching, not only for the different children but for all children. Encourage them to develop their talents at different fields, those skills into which they stand out, tell them that everyone can do something for others, is as important as that is to learn the multiplication table. Promote the self-esteem, the realistic appreciation of his/her possibilities, make independent human beings, happy and well adjusted, is a task, that is performed along a series of subtle details, in a constant work, day by day, every day. It may seem, to intend as a goal, a task beyond our reach, maybe "so are we, the humans" would be the temptation that we all have when we want to change the world. But for one person, and one person is a world of happiness or sadness when she/he feels, this succession of signs and attempts, may be essential. To act in the playground, in the classroom, is to act in the whole world. It's the beginning...

We'll thank you from this moment all the interest and the desire to cooperate that you've shown and all, all those little moments and daily acts into which you will teach to our children to be better human beings.

P.S. This introduction letter about achondroplasia for schools is a general model written by ALPE ACHONDROPLASIA Foundation, and to them we refer you for any consultation.

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Fundacion ALPE ACONDROPLASIA (ALPE Achondroplasia Foundation)

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