

Short Stature in Duchenne Muscular Dystrophy

This information sheet is about short stature in people with Duchenne muscular dystrophy. It is written for parents and caregivers. You might want to start by reading the Introduction to the Endocrine System Sheet, which introduces you to some basic topics.

What is “short stature”?

“Short stature” is defined as height below the normal range. Heights are compared to boys of the same age using a growth chart. Children whose heights are below the curve (less than 3rd percentile) on this chart are considered short. Having short parents is a common cause of being short. Being short does not affect your child’s health. In fact, shorter boys with Duchenne might get around better than taller boys. Some boys are not bothered by being short. However, it is possible that short stature may affect your child’s self esteem and relationships, and could lead to behavioral or emotional problems.

What causes short stature?

Short stature is common in boys with Duchenne. A main reason for short stature is that steroids cause slow growth. Steroids slow growth by affecting hormones and bones. Boys with Duchenne who are not on steroids may also be shorter than expected.

How is short stature monitored?

It is important that the doctor keep accurate growth records for your child. This will show if your child’s growth begins to slow. You should talk to your doctor about the possibility of slow growth before starting steroids. In general, concerns about growth do not prevent the use of steroids.

What tests need to be done?

If your child’s growth is slow, his healthcare providers will review his health and diet and check if he has started puberty. His doctor may do blood tests to make sure there aren’t other causes of slow growth. Another test is a “bone age” or hand X-ray to see how much time there may be before your child stops growing. Your child may be referred to an endocrinologist (hormone doctor).

What can we do about it?

It is normal for doctors to watch short stature without doing a treatment since short stature does not cause health problems. In fact, some doctors think that it is easier for your son to move around, be less tired, and for other people to help him if he is short.

Sometimes a doctor might talk to you about decreasing your son’s levels of steroids, but this may reduce your son’s strength.

Using growth hormone is not standard care for Duchenne. Growth hormone may have unwanted side effects. Based on the chance for side effects, the fact that we don’t have much information about the use of GH, and the fact that short stature does not cause any health problems, PPMD cautions families considering growth hormone to ask lots of questions to understand the possible benefits versus the chance for side effects.

Some boys are bothered about being short. If your son is concerned, psychological support can help your child adjust. You may want to share information about Duchenne and the resulting short stature with teachers and students in schools to encourage social inclusion and acceptance of others’ different abilities.

Summary & important facts to remember:

- Short stature can be a problem for boys with Duchenne, especially those who are on steroids.
- Measuring growth regularly is important.
- Talk to your doctor if you or your child are concerned about growth.
- Usually the doctor doesn’t need to do anything about short stature except for keeping an eye on growth.

(continues on back)

- Your child may be referred to an endocrinologist.
- When discussing therapy options be sure to ask about potential benefits and possible risks before making any decisions.
- Psychological support may be very helpful if your child is concerned about being short.

What resources are available and how can I learn more about it?

The Diagnosis and Management of Duchenne Muscular Dystrophy: A Guide for Families

http://www.parentprojectmd.org/site/DocServer/Family_Guide.pdf?docID=9321

Cincinnati Childrens Medical Center, Wong B, Rutter MM, Rose SR, Clark E, Hill B, et al. Best evidence statement (BEst). Growth hormone therapy in Duchenne Muscular Dystrophy. Cincinnati2009.

<http://www.cincinnatichildrens.org/assets/0/78/1067/2709/2777/2793/9198/b74ce8e2-84b7-4fbd-9b3f-c990358fd313.pdf>