



Empowering families.
Fighting Duchenne.

TOOLS FOR SCHOOL

Dear Teacher,

We recently received some life-changing news that we need to share with you.

Our child, _____ has Duchenne muscular dystrophy. Most people cannot tell by looking at him that he has a condition because at this early stage the disease has had limited visible impact. Over time, his muscles will start to weaken and he will eventually lose the ability to walk. We as a family are still coping with this diagnosis and are trying to best understand and learn what our child will need.

We want to make sure that he has the proper support in the classroom and want to work closely with you to provide him and his classmates with the best experience possible. Luckily, Jett Foundation, a leading non-profit in the Duchenne community, has developed a guide to help better assist you and our son throughout this school year.

Included in this packet is more information about Duchenne, a children's book and lesson plan that introduces children to Duchenne that you may read to the classroom, and some of the top things you should know about my child.

For more information or ways you can help, please visit www.jettfoundation.org.

We would love to chat more about how we can develop a strong support network at school for our son and ways that we can work together to fight Duchenne.

Thank you so much for your understanding and support during this difficult time. Please feel free to contact me if any other questions.

Name: _____

Phone: _____

Email: _____



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Things to Know in Working with a Student Impacted by Duchenne

- Standing up from sitting on the ground/floor is more difficult for him than other children. When possible, if he can be offered a chair or stool (which it is OK for him to decline if he wants) that would be appreciated.
- He will be slower than other children. He can run, but not very fast, and when walking longer distances (i.e., across the field) he should not be expected or asked to keep up with the rest of the students.
- Going up and down stairs is particularly difficult for him and he needs a railing or a hand on stairs with more than just a few steps. Going down stairs, running downhill, squatting and jumping are particularly damaging to his muscles. While he doesn't need to be forbidden from these activities, he should not be required to do them (as part of a game or activity, for example). When possible, modifying active group games so he can more easily participate is very much appreciated.
- Carrying heavy objects such as a pile of books or his lunch tray may be difficult for him. Offering assistance if he is struggling would be appreciated (OK if he declines).
- He may (or may not) tire more easily than others. On some days he may be very active and on other days he may need more breaks. It is important to allow him to rest when he asks or when it is clear he needs to.
- He can participate in most activities, but may need extra help depending on the activity.
- He is at risk to fall more easily. While he can climb on play structures, he is easily knocked off balance or may lose his grip or stumble. He should have an adult watching him closely while he is on a play structure or climbing equipment, particularly while other children are in proximity.
- If he complains that his legs are sore, drinking water and sitting down often helps. Side note: his calves appear strong and developed because they are compensating for weak hip/thigh muscles.
- Extra supervision during lunch and recess is recommended. Please offer help opening food containers as needed and be mindful that certain aspects of the playground may not be accessible. Stationary games, such as, sidewalk chalk or bubbles, are a great alternative to a more strenuous activity during recess.
- An emergency evacuation plan should be in place in the event of a fire or lockdown procedure. This may require the usage of adaptive equipment to ensure he can evacuate quickly and safely.
- Conserving energy throughout the day may be achieved by using adaptive equipment, such as a motorized scooter or power chair for classroom transitions. Special transpiration may be needed for field trips for transporting adaptive equipment.

Please feel free to contact us using the information below if you have any other questions about Duchenne or about our child!

Name: _____

Phone: _____

Email: _____

FREQUENTLY ASKED QUESTIONS ABOUT DUCHENNE

What is Duchenne muscular dystrophy?

Duchenne (pronounced Du-Shen) is the most common form of muscular dystrophy. It is a progressive neuromuscular disorder that causes a loss of motor, pulmonary, and cardiac function, and ultimately, premature death. Children with Duchenne are born seemingly healthy and decline over time, typically losing their ability to walk around the age of 12 and succumbing to the disease in their early to mid-twenties. There is no cure but treatment can help extend and improve quality of life.

How is Duchenne caused?

It is caused by a mutation in the gene that encodes for Dystrophin, a lubricating protein supports muscle fiber strength. When dystrophin is missing in the body, muscle cells are easily damaged, since it is essential for maintaining cell structure and function. Without it, muscles cannot repair themselves properly, which causes progressive muscle weakness in the entire body.

How does someone get Duchenne?

The Duchenne gene is found on the X-chromosome and therefore affects mostly males; however in rare cases it affects females. Duchenne can be inherited from the mother, but approximately 35% of cases occur because of a random spontaneous mutation. In other words, Duchenne can affect anyone.

How common is Duchenne?

It affects approximately 1 in every 3,500 live male births. There are approximately 15,000 patients diagnosed with Duchenne alive today in the United States.

What is Jett Foundation?

In 2001, Christine and Stephen McSherry started the Jett Foundation after learning the devastating news that their then five-year-old son Jett had Duchenne Muscular Dystrophy. The McSherry family was determined to save Jett and the thousands of boys like him by establishing a foundation dedicated to funding DMD research that will ultimately cure this deadly disease.

Since then, Jett Foundation's efforts have raised over \$16 million dollars for promising biomedical Duchenne research and transformational direct service programs. Jett Foundation offers educational workshops across the country for families to learn more about Duchenne; run Jett Giving Fund, a matching gift program for families raising money to purchase accessibility equipment; and put on Camp Promise, a free week-long camp for kids, teens, and adults with select neuromuscular disorders across three national locations. Jett Foundation also serves as an advocacy leader, which led to FDA approval of the first drug for Duchenne. We as a community grow stronger everyday in our fight against this disease.

Jett Foundation has a proven track record of influence and connect with and meet the needs of affected families from every city and town regardless of location, financial situation, or capabilities. We aim to reach every patient and family in the Duchenne community, and invite you to engage with us as we realize a world without Duchenne.