

CLASSROOM ACTIVITIES FOR UNDERSTANDING DUCHENNE



In this packet are some age-appropriate classroom exercises that can be done either by you (the parent) or by your child's teacher to educate students about Duchenne and some of the challenges your child faces on a daily basis. They are easy and can be done in one class period or as part of a larger group gathering, such as an assembly. Involve your child as much as he/she is comfortable and in a way that reflects how you discuss Duchenne at home.

In addition to these activities, PPMD offers **BrainPOP**, a brief and informational 4 minute video geared toward children and young adults to help them understand Duchenne. BrainPOP is available in both [English](#) and [Spanish](#).

Chocolate Chip Cookie Presentation

1ST – 3RD GRADE

This presentation is usually set up as a mock-cooking demonstration that includes three main points/questions that we answer. Also included is a sample letter that was sent from a school when one of our PPMD community's families worked with the school to have the Chocolate Chip Cookie presentation conducted as an assembly at their child's school. The school's guidance counselor took the initiative to send the letter – and the day was a tremendous success! Of course, you can tailor it however you wish.

What is Duchenne?

- Talk about how we are all made from lots of different recipes: recipes for our eye color, height, hair color, skin color, etc.
- Talk about how things that are in our recipe (in our genes) are not contagious.
- Ask for some examples of things that are contagious, so that we can distinguish.
- Talk about how our muscles are made from a recipe, too.
- Ask the class to name something that they like to help their parents make at home...
- Take answers until someone says "chocolate chip cookies". Then the fun begins...

Make chocolate chips cookies... sort of...

- Have the student (with Duchenne) come up to be your assistant, and have him select a few friends to help.
- Each selected student adds another dry ingredient to the bowl while he stirs. You only do a few ingredients (this is just for show): salt, sugar, brown sugar, flour, baking soda, baking powder...
- Then talk about what key ingredient is missing... the Chocolate Chips! Ask the class whether you could make a cookie without chocolate chips and still have a good cookie – yes, of course (sugar cookies, etc). But that it won't be exactly what we wanted – chocolate chip.

How does someone get Duchenne?

- Talk about how having muscular dystrophy is like having had an ingredient left out of the recipe for our muscles... Alex still has muscles... and they work... they just are missing an ingredient which makes them work differently from how our muscles work.
- At this point, ask the student (Alex) to talk about some things that are difficult for him. What makes him tired, etc. (acknowledge Alex for being so brave and honest).
- Then, ask the class to list some things that Alex is very good at. You can write those up on chart paper. This works well because the kids don't know whether you really know the student and usually come up with a GREAT list of talents and strengths. The student is usually beaming by the end of this.
- Let the student select some classmates who have questions and, together, answer those questions. Things that are frequently asked: Does it hurt? Do you take medicine? Do you get sad? Do you have a pet? Can I give you some of my muscle?

How should we treat someone with Duchenne?

- Talk about how we all have strengths and weaknesses.
- Ask the class "How do you think we should treat someone with Duchenne?" Kids usually says things like, hold the door open (to which you can reply, wouldn't you like someone to do that for you?), help him up when he falls (again, 'wouldn't you like someone to do that for you?'), etc., etc.
- Eventually a student gives the exact answer you're looking for: You treat someone with Duchenne just like you want to be treated. We should all treat each other the same.

Sample Letter to Accompany the Chocolate Chip Cookie Presentation

Below is a sample letter that was sent from a school when one of our PPMD community's families worked with the school to have the Chocolate Chip Cookie presentation conducted as an assembly at their child's school. The school's guidance counselor took the initiative to send the letter – and the day was a tremendous success! Of course, you can tailor it however you wish.

#####Begin Letter Template#####

Dear 1st grade Parents:

I am writing to inform you of a 1st grade presentation that took place today. One of our 1st grade students is diagnosed with Duchenne Muscular Dystrophy (Duchenne), which is a genetic progressive muscle disorder. The purpose of the presentation was to familiarize the students with Duchenne at an age appropriate level. It covered what Duchenne is and how someone gets Duchenne. The presentation explained that children with Duchenne have an ingredient missing from their muscles that makes their muscles work differently and get tired more quickly. We drew the comparison to chocolate chip cookies and what happens if they are missing an ingredient like the chocolate chips. We get a different cookie like sugar cookies, but those are awesome too! The children also learned how peers should treat children with Duchenne. Children with Duchenne may need the door opened for them, just as any student would like done for them. Children with Duchenne may need help of some sort, just as any student may need help from peers too. Simply put, the students should treat children with Duchenne the way they want to be treated.

Experts say that children can best interact with a peer with a medical condition if they are appropriately informed about the condition. We would caution you and your family regarding the importance of keeping information about complex medical conditions at an age-appropriate level and would request that any discussions at home regarding Duchenne be limited to the information provided above. We carefully considered how to present the information in an age-appropriate way that would be beneficial and understandable for the children.

We were pleased to have the opportunity to inform the students about Duchenne. Please feel free to contact me at _____ if you have any further questions. Thank you!!

End Letter Template#####

Firefighter Boots

PRESCHOOL – 2ND GRADE



The goal of this exercise is to help students understand what it feels like to have muscles that may not be as strong as theirs, and to facilitate a discussion about being empathetic and helpful to someone who has Duchenne.

Contact your local fire department and let them know you are doing an awareness activity for muscular dystrophy; most will be happy to support you. Ask if you can borrow two pairs of fire fighter boots (or if they can come to the school and bring them). Do the exercise in one classroom or gather several classes together, whatever works best within your school.

Start out by asking questions:

- How many kids like pizza (raise your hands)? How many kids like baseball?, etc. The object is to ask questions that show similarities and differences between kids.
- Once you've asked a few questions, finish with: How many of you have noticed something different about (child's name)? This is not an effort to single out your child and make him/her feel badly, but rather an opportunity to share the child's experience with their classmates.
- Go on to say something like: That's right, (child's name), has different muscles. They work differently than some of yours. But did you notice

that (child's name) likes pizza, just like you? Have you ever seen (child's name) have to sit and rest? How many of you want to know why?

Next, ask for two volunteers. Line up half the class behind these two students. Then take the rest of the class across the room and line them up in two lines. Starting with your two volunteers, help them put the firefighter boots on. Then ask them to walk as quickly as they can (safely) to the other kids across the room. They'll take the boots off and hand them to the next two students, who will walk back. Repeat this until everyone has had a turn.

After everyone has had a turn, sit them down again and have a discussion about their experience. Start with questions like: Was it hard to run? Were you frustrated when you fell? Did you feel left behind? Explain that that's how it feels to have special muscles like (child's name). Then start a discussion about ways that students can help (child's name).

We also have age-appropriate books available to help kids learn about Duchenne:

- [DMD and Me](#)
- [Welcome To My Street: A Popping Wheelies Picture Book](#)
- [What Did You Do Today: A Popping Wheelies Picture Book](#)

Weights or Chain Exercise

3RD GRADE – 5TH GRADE



Do the same exercise as above but you can also do it in gym class. Instead of firefighter boots, use VERY heavy leg weights. Borrow a set of weights from a friend or the school gym/athletic department.

Try to keep your information very clear and simple.

- Every cell in your body is made up of genes – your eyes, your hair, your skin, and your bones! Genes also make up all of the parts of your muscles.
- A “mutation” is a change in a gene. Some mutations make genes stop working. (If you want to explain how a mutation in the gene makes the gene stop working, line kids up and have them all hold hands and do the wave with their hands sending a ripple down the chain. Then go in and take a kid or two out of the chain, when the ripple comes to the break (or the missing exon) the message can’t keep going.
- Duchenne is caused by a “mutation” or change in the “dystrophin” gene. When the

dystrophin gene stops working, it does not make “dystrophin.” Dystrophin is the “glue”; it protects the muscle from damage and helps keep the muscle strong and working. When a person has Duchenne, the dystrophin in the muscle is missing. Without dystrophin, the muscle becomes damaged and weaker.

- Duchenne is not contagious (you can’t catch it from anyone) and you cannot get Duchenne later when you grow older. People with Duchenne are born with it.

If students ask questions, try to keep your answers very simple, clear and honest. If someone asks you an uncomfortable questions (i.e., “can you die from Duchenne”), stay calm and say that scientists, researchers, and doctors are working very hard right now to find a cure for Duchenne. Ask if anyone in the class wants to be a scientist, researcher or doctor – maybe you the person who will find a cure for Duchenne is right here in this classroom!

Spaghetti Experiment

MIDDLE SCHOOL/JUNIOR HIGH/HIGH SCHOOL



The experiment is designed to give students a hands on look at how Duchenne affects muscles. It requires a few inexpensive supplies and some preparation. We recommend preparing the spaghetti the night before so the glue has time to dry overnight.

Supplies:

- Spaghetti noodles (2 packs)
- 2 big bowls
- Big container of Elmer's glue
- Wax paper
- Blue food coloring
- Large fork

Directions:

The night before the presentation, boil both packages of noodles. Take one package of boiled noodles and put in a bowl of water overnight. Take the second package of boiled noodles and put in a bowl. Pour in a container of Elmer's glue and 3-4 drops of blue food coloring. Mix until all the noodles are covered in blue glue. Spread out on the wax paper to dry overnight.

Classroom Script:

How many of you know how when you work out you tear down muscle and then you get sore and then it builds back stronger? The reason you are able to build it back stronger is because you have a protein called dystrophin that helps to repair your muscles. It works very much like glue. When someone has Duchenne, it means their muscles are missing that glue. When they tear down their muscles from

exercise or even regular movement, instead of repairing themselves, their muscles turn into scar tissue.

Put the fork in the bowl of blue spaghetti. It will be clumped and dry now so when you lift it up, the

whole chunk will stay together. Explain this is their muscle and it has the blue glue (dystrophin) holding it together.

Now put the fork in the regular spaghetti (you can spill the water out now, you only needed it to keep them soft). Try to pull the noodles up and watch them fall apart. This is a muscle without the glue.

Pass both bowls around or invite the kids up to check out the two bowls for themselves. At this age many people with Duchenne can do this presentation themselves, which can be very empowering. At the end, if there are questions, answer the questions with clear, simple answers. If the teacher is in the room, they may refer to lessons that the class has covered previously to help explain the answers.

If anyone asks something uncomfortable about the life timeline of Duchenne (because some kids are smart enough to ask), stay calm and confidently answer that medicine is changing so fast with new research and treatments, we just don't know the timeline of Duchenne. That's why we hope some of you grow up and invent the science that will help us to treat, and hopefully to cure, Duchenne. And leave it at that, on a positive note.