

Education Matters is a guide for parents and teachers specifically about educational and other classroom-related issues for young men with Duchenne muscular dystrophy (Duchenne). Written by Parent Project Muscular Dystrophy (PPMD), it offers practical information on Duchenne as it relates to a young man's educational experience and specific advice on helping him succeed in the classroom.

Education Matters offers parents:

- Helpful tips on how to talk about Duchenne
- Issues to be aware of at school
- An Individualized Education Plan (IEP) overview
- Sample scenarios and suggested ways to respond

Education Matters offers teachers:

- A practical overview of Duchenne
- Classroom accommodations
- Suggested inclusive school activities
- What to be aware of regarding treatment/medications
- Confidentiality/sensitivity concerns

Parent Project Muscular Dystrophy

LEADING THE FIGHT TO END DUCHENNE

OUR MISSION

To improve the treatment, quality of life, and long-term outlook for all individuals affected by Duchenne muscular dystrophy through research, education, advocacy, and compassion.

Parent Project Muscular Dystrophy

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an introduction to education matters

for parents

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Muscular Dystrophy

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Version 2, September 2010

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A note to parents

Dear parents and families,

With its complex nature and extensive scientific terminology, Duchenne muscular dystrophy (DMD) can be overwhelming for newly diagnosed families to wrap their heads around, much less explain to others.

Parent Project Muscular Dystrophy (PPMD) created *Education Matters* to help you communicate with your son's teachers and other school staff about DMD. It's important for you to knowledgeably explain your son's needs in the classroom and suggest ways the school can help him have as rewarding and independent an educational experience as possible.

Inside this booklet, you'll find:

- Tips for talking to teachers and school administrators
- Guidelines on how to talk about DMD
- Sample scenarios and how you may respond

Additionally, we hope that one of your greatest resources to help inform your son's teacher about DMD is the booklet included in this binder called *Education Matters: A Teacher's Guide to Duchenne Muscular Dystrophy*. Written by PPMD especially for teachers, the guide should be passed on from parent to teacher, ideally in a face-to-face meeting before the beginning of the school year.

We hope this serves you well, and, above all, we wish your son a rewarding and educational school year filled with friendship, fun and a future of possibilities.

Sincerely,

A handwritten signature in black ink, appearing to read "Pat Furlong". The signature is fluid and cursive, with a large initial "P" and "F".

Pat Furlong, Founding President & CEO
Parent Project Muscular Dystrophy

Talking to teachers & school administrators

Request a kick-off meeting

One of the best things you can do at the start of the school year is to request a meeting with your son's teacher and other key school staff. This kick-off meeting is the perfect time to form a collaborative team of teachers and other professionals within your school to ensure your son's needs are met by a group—not just one individual—throughout the year.

For instance, this is a great time to candidly and openly discuss any confidentiality concerns you may have, as well as classroom accommodations your son requires and what treatments or what therapies he is receiving.

It's important to keep in mind that this may or may not be the first time your son's teacher has had a student with Duchenne muscular dystrophy in his or her classroom. Either way, be prepared to give them information and guidance at a level you are most comfortable with.

Use our teacher's guide to touch on various topics

One way to start a conversation with your son's teacher is by giving him or her the booklet in this binder called *Education Matters: A Teacher's Guide to Duchenne muscular dystrophy*. Depending on your son's age, he will have different needs and require different accommodations in the classroom. The teacher's guide covers everything from the basics of DMD and its progression to specific classroom accommodations. For instance, a youngster who is newly diagnosed may need help getting up from a seated position, while a teenager requires more help with mobility and lifting heavy objects.

Form a collaborative relationship with your son's school

Remember, it's important to be open and engaging about the topic of DMD and disability at the level you feel most comfortable. Especially with very young boys, sensitivity to how and how much to discuss DMD is paramount. By forming a collaborative relationship with the teacher, you can help him or her feel comfortable coming to you with questions, concerns or observations throughout the year (and vice versa!).

An easy, non-threatening way to introduce DMD to teachers, other parents and your son's peers is BrainPOP's short animated video about DMD. It's developed specifically to help foster a young child's understanding of DMD, but could be a helpful way to start a conversation with adults, too. For more information, please visit www.parentprojectmd.org.



Research shows that peers are less likely to tease and more likely to defend their classmate when they are armed with accurate knowledge about DMD.

Guidelines for talking about DMD

Parent Project Muscular Dystrophy has compiled the recommendations below to help you better communicate about DMD with teachers, school staff and even other kids' parents.



Negative adjectives & phrases to avoid

- Suffers from
- Terrible, debilitating disease
- Afflicted with
- Wheelchair bound/
Confined to a wheelchair
- Disease (viral)
- Fatal / terminal
- Crippling or crippled



Positive adjectives & phrases to use

- Diagnosed with
- Progressive muscle disorder
- Affected by
- Needs the assistance
of a wheelchair or scooter
- Disorder (genetic) / condition
- Devastating / life-limiting
- Progressive muscle disorder

Talking points on Duchenne muscular dystrophy

- Duchenne muscular dystrophy (DMD) is the most common lethal genetic disorder diagnosed during childhood. It is a progressive muscle disorder that causes loss of muscle function and independence. To date, there is no cure.
- DMD affects 1 in 3,500 boys. Approximately 20,000 children are born with DMD each year worldwide.
- Because the DMD gene is found on the X chromosome, the disorder manifests primarily in boys. It knows no boundaries; it affects all races and cultures.
- Approximately 35% of all DMD cases are the result of random spontaneous genetic mutation that can occur during any pregnancy, regardless of family history.



Tips for day-to-day interactions

It is very hard to come to terms with the diagnosis of DMD. It's likely that teachers, your son's classmates and his classmates' parents will have questions. Although there is no right or wrong way to deal with these interactions, experts recommend the following:

- When children ask questions about DMD, answer them as honestly as you can, in age-appropriate terms that will be easy for them to understand
- Remember that your son is an individual, made up of more than just a DMD diagnosis. Encourage others to see him this way also
- Do not blame yourself. The fact that your son has been diagnosed with DMD is not your fault
- Lay heavy emphasis on activities and hobbies that your child *can* do and encourage him to do the things he wants to do. Children with DMD often find creative and alternate ways to participate in activities they're interested in
- Treat your child the same as you would your other children by providing love, support, discipline, responsibility and love (it bears mentioning twice)
- Encourage your son to maintain a level of independence and try not to overprotect him



Tips for day-to-day interactions (continued)

- Create an open forum for discussions within your family, so no one is afraid to ask questions or talk about what's on their mind
- Plan family vacations and other family activities. Remember, where there's a will there's a way: You can do just about anything
- Exercise patience when dealing with family issues related to the disorder, and respect one another's way of coping with these issues
- Try to delegate the responsibilities of caring for your son so you have some time for yourself
- Live for the day by not letting the future control your lives
- Rely on friends, family and your support system. That's what they're there for, and they want to help. Realize that you are not alone in this
- Don't be too hard on yourself. Give yourself credit for being able to handle things as well as you do
- There will be good days and bad days. Enjoy the good while it's happening and deal with the bad as it comes up



Individualized Education Program (IEP) overview

Your son may need assistance with physical activities and access only, or he may require additional accommodations and modifications to help him complete regular assignments and standardized tests, develop speech and language skills, or specialized instruction to address learning disabilities. This is where an Individualized Education Program (IEP) comes into play.

An IEP is the blueprint to your son's education program. It's designed to help him benefit from the classroom curriculum and participate as much as possible with his peers. This plan is developed by an IEP team, in which you play a critical role together with teachers and other school staff.

We use the term IEP; however, schools in different states may use the term PET (Pupil Evaluation Team), MDT (Multidisciplinary Team), or ARD (Admission Review and Dismissal Team) to describe the group that convenes for this purpose.

For more IEP information

The needs of a young man with DMD may be very different from those of other children who receive special education. Areas of concern for students with DMD include physical education, physical therapy, occupational therapy, speech/language therapy and adaptive accommodations.

Find in-depth information on developing an IEP and federal laws regarding special education in your state at www.parentprojectmd.org/educational/states.



Sample scenarios & suggested ways to respond

This section contains difficult information for parents to read. (It may even break your heart.) So, take a deep breath and remember that the more prepared you are, the more you can help your son have a wonderful school experience. Keep in mind one of the best things you can do is to partner with your son's school. Establish a friendly relationship with the entire staff at the school. Even if you feel scared, sad, and overwhelmed—or like you don't need or want help—please let your son's school know that you need their help. In our experience, when parents ask schools to work with them, they will do their best.

You may encounter one or more of the following scenarios at your son's school. The corresponding responses are suggestions designed to help newly diagnosed families cope with this difficult diagnosis.

Scenario: The teacher says, "Your son has started falling down frequently, and he seems to be weaker and more tired at the end of the day. What should I do?"

Response: "Thanks for bringing this to my attention. My son's disorder causes muscle weakness. It will get tougher for him to stand and move around on his own. Where is he falling? How often? If he's falling during daily activities, please ensure he remains seated and can do activities at his desk as much as possible. If it's during class changes in the hallways, please allow him extra time to get from place to place. Let's meet to further discuss classroom strategies to lessen his falling."

Scenario: The teacher says, "Your son's behavior has been frustrating me. He's stubborn, strong-willed, compulsive about many things and has a hard time staying on the same schedule as the rest of his class."

Response: "Thanks for bringing this to my attention. Kids with DMD can have behavioral or social problems as a result of cognitive weakness tied to their diagnosis. They may have problems being flexible in their thinking, and, as a result, may get stuck on an idea, appear oppositional or have difficulties with transitions. They may have difficulty interpreting another's perspective or reading body language. Can we meet soon so that we can discuss your concerns and help find ways for you to address them in class?"

Scenario: The teacher points out that your son has a waddling gait and accidentally bumps into people at school, many of whom get frustrated because they don't understand this is due to DMD muscle weakness. He often gets flustered and doesn't know how to respond.

Response: "My son walks this way because his muscles are weak. Kids with DMD may walk with a wide stance and with arms stretched out because their body is naturally seeking added stability. My son is not always focused on who else is around, but is focused on trying to stay upright. Additionally, due to cognitive weakness tied to DMD, he may not interpret others' frustration or realize he is supposed to say 'I'm sorry' if he bumps into them. Please continue to talk to me about what you observe, and let's continue to meet about ways we can address it."



Sample scenarios & suggested ways to respond (continued)

Scenario: Your son's class is taking a field trip.

Response: Speak with your son's teacher beforehand to discuss any accommodations of which he or she needs to be aware. For instance, even if your son doesn't need the assistance of a wheelchair, he should not walk long distances on a field trip. If your son is in a wheelchair, confirm with the teacher that the field trip location and transportation are wheelchair-accessible.

Scenario: Your son's classmate calls him "clumsy" and makes fun of him for falling down.

Response: Ask your son's teacher if you can speak to the class without your son present. (If you don't feel comfortable doing this, consider asking a family member or a close friend who understands the diagnosis to volunteer.) At a level you are comfortable, explain to the class that your son has weak muscles. He may need help standing up, walking or picking up his pencil, for instance. By engaging the class, you raise their awareness and make them advocates, so to speak. Especially with younger students, we suggest using phrases like "Being different is okay" and "I need your help with this."

Another easy and effective way to raise the topic of DMD to young students is through BrainPOP's short animated movie about DMD. It's specifically written and designed to help foster a young child's understanding of DMD. For more information, visit www.parentprojectmd.org.

Scenario: Participation in P.E. class & recess

Response: "Due to my son's weakening muscles, he will not be able to participate during all P.E. and recess activities. Let's meet to find other ways he can actively participate, such as games that don't require physical strength."

In some states, schools require adaptive-P.E. teachers so that all children can be accommodated in P.E. class.

Scenario: The teacher asks, "Does your son have any learning disabilities due to DMD?"

Response: "I recently received this diagnosis, and here's a guide to DMD that contains information specifically for teachers. For instance, there are behaviors and learning issues often found in young men diagnosed with DMD. Please keep me informed if you notice these behaviors in my son."

A parting thought

Welcome to Holland—by Emily Pearl Kingsley

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel.

It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. Michelangelo's David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away, because the loss of that dream is a very, very significant loss.

But, if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.