



education matters: adaptive physical education

A PE teacher's guide to
Duchenne muscular dystrophy

Parent Project
Muscular Dystrophy

LEADING THE FIGHT TO END DUCHENNE



education matters: adaptive physical education

A PE teacher's guide to
Duchenne muscular dystrophy

Parent Project
Muscular Dystrophy

LEADING THE FIGHT TO END DUCHENNE

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.

Copyright © by Parent Project Muscular Dystrophy
Version 2, September 2010

ParentProjectMD.org

Contents

	Introduction by Pat Furlong	iv
	<i>Founding President & CEO, PPMD</i>	
1	An overview of Duchenne muscular dystrophy	
	What is Duchenne muscular dystrophy (Duchenne)?	3
	Progression of Duchenne	4
	Treatments for Duchenne	6
2	Duchenne in the classroom	
	What is Adaptive PE?	11
	Four things every teacher should know	12
	Talking to your class about Duchenne	14
3	Challenges & ways you can help	
	Cognitive development	19
	Behavioral issues	20
	Confidentiality concerns	21
4	The basics of working with an IEP	
	Introduction	25
	IEP team	26
	Goals	27
5	Adaptive PE in action	
	A note on progress	33
	What to look for in the classroom	34
	In general	36
	Activities	38
	Equipment alternatives	40
	Peer mentoring	42
	Extracurricular sports	43
6	Summary	
	Why your help is so important	47
	PPMD's top three take-away points	48
	Conclusion	49
7	Resources for teachers	
	A note to my substitute	53
	Top recommendations	54
	About Parent Project Muscular Dystrophy	56

A note to PE teachers

Dear teachers,

For the teacher, the PE class environment presents its own set of unique and sometimes formidable challenges, focusing as it does on a child's physical development at the same time Duchenne is affecting it. Through no fault of their own, most PE teachers in our schools don't appear to have a standard, readable resource to turn to for strategies and activities geared toward the student with Duchenne.

In creating this guide our hope is that, by collecting and presenting advice and strategies from experienced PE teachers in the field, we can keep other teachers from having to start completely from scratch.

As always, the best way to get familiar with your student's diagnosis and his particular needs is to meet with his parents. You may, however, consider this booklet a resource to refer to throughout the year for guidance and advice.

Inside you'll find information about the following:

- Duchenne muscular dystrophy and its progression
- Physical, learning, and behavioral challenges
- Alternate PE activities and equipment
- Individual Education Program (IEP) issues
- Teacher tips and resources

While Duchenne slowly steals muscle function and independence, what remains strong is a child's desire to learn, grow, and have fun. With your positive, informed guidance and support, you can make that a reality in the PE class every day.

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

1

An overview of Duchenne muscular dystrophy



What is Duchenne muscular dystrophy?

Duchenne muscular dystrophy (Duchenne) is the most common fatal genetic disorder diagnosed during early childhood. A progressive muscle disorder that causes loss of muscle function and independence, Duchenne affects approximately one out of every 3,500 boys and 20,000 babies each year worldwide. Duchenne is not contagious, and it mostly affects boys. It knows no other boundaries and touches all races and cultures.

Parent Project Muscular Dystrophy (PPMD) estimates that there are approximately 15,000 young men with Duchenne alive today in the United States. Duchenne muscular dystrophy can occur during any pregnancy regardless of family history. To date, there is no cure or treatment to stop the progression of Duchenne.



Progression of Duchenne muscular dystrophy

Typically, Duchenne muscular dystrophy is diagnosed in boys between the ages of three and seven. Throughout the school year, your student's muscles will weaken progressively, affecting his physical capabilities. While the rate of progression and severity of symptoms are different for each student, there are four stages usually associated with Duchenne.

1 Early phase (diagnosis through age 7)

Many times, the very first signs of Duchenne involve a speech and language delay and other cognitive learning problems. Physically, your student's movements will be slower or more labored than those of his peers. He may appear clumsy and fall a lot. During this early phase, his calves may be enlarged or appear overdeveloped. This is not muscle, but fibrous tissue, which is formed from degenerating muscle cells. Jumping from a standing position may be nearly impossible for him. Although it may not be apparent, many boys with Duchenne will start to have early heart issues and may need to take medication, which can cause drowsiness or lack of energy.

2 Transitional phase (6 – 12 years)

During this time, your student will typically have trouble walking because his quadriceps (muscles in the front of the thighs) have grown weaker. This tends to keep him off balance as he attempts to shift his weight and walk. He may walk on the balls of his feet or on his toes with a slight, rolling gait. In order to compensate for a weak trunk, young men with Duchenne will stick their bellies out and throw their shoulders back to keep their balance as they walk. When asked to stand up, he will

put his rear end up in the air first and then use his arms for supports by “walking” his arms up his legs with his hands until he is standing (the medical term for this is Gowers' Maneuver).

3 Loss of ambulation (8 – 14 years)

By about 12 years old, most boys with Duchenne need a wheelchair. Your student's weakened muscles will cause him to tire easily. The teen years bring a continuous progression of weakness. After loss of ambulation, this progression becomes more apparent. Activities involving the arms, legs, or trunk of the body will require assistance or mechanical support. Most young men retain the use of their fingers through this phase, and can generally still write and use a computer.

4 Adult stage (15+ years)

In the teen years, life-threatening heart and respiratory conditions become more prevalent. Major symptoms include increased fatigue, inability to cough, and an increased risk of pneumonia. Typical signs of heart failure—shortness of breath and swelling of the hands and feet—are not obvious because the young men are not mobile. Young men with Duchenne usually die in their second or third decade due to heart and respiratory failure.

Treatments for Duchenne muscular dystrophy

When a student with Duchenne muscular dystrophy is placed in the PE environment, it's important to be aware of the treatments he's undergoing, what medications he might need during the day, and what side effects to expect. Although there is no cure for Duchenne, accepted treatments and therapies can lessen symptoms and improve a young man's quality of life.

Prednisone is the steroid most widely used to treat Duchenne muscular dystrophy. It slows muscle loss and dramatically improves strength for most boys. On the other hand, it can cause irritability and some psychological side effects, which may affect a student's behavior and academic performance. His appearance could be altered as well, including weight gain and facial changes. Psychological side effects include difficulty concentrating, sleeping, and controlling emotions. There's also a chance that impairment in thinking, reading, and coping skills can lead to depression or aggression.



Checklist

To keep track of what treatments and therapies your student uses, use the checklist below. If you aren't sure, contact your student's parents.

Therapy

- Physical therapy
- Occupational therapy
- Speech and language therapy
- Psychological counseling

Medications

- Prednisone
- Deflazacort
- Heart medications
- Alternative medicines
- Nutritional supplements

Mobility support devices

- Leg braces (sometimes called Calipers)
- Wheelchair or scooter

Surgery

- To straighten spine due to scoliosis
- To treat contractures (loss of elasticity in the tendons, namely the ankles, knees, and hips)

2

Duchenne in the classroom

openly discuss your student's capabilities and limitations with his parents



What is Adaptive PE?

Adaptive PE is the term for a Physical Education program that has been tailored for a student with differing abilities from his peers. It uses alternative forms of common activities, and alternate equipment, as well as strategies for including the student with Duchenne in activities to the fullest of his abilities. This program is developed as part of an IEP (Individualized Education Program) by a team comprised of administrators, medical professionals, parents, and you. The Adaptive PE program is the result. More information about IEPs follows in a few pages.

There are many things you can do for a student with Duchenne muscular dystrophy to ease his transition into the PE environment. The best way to start is to have a meeting with your student's parents and all involved teachers prior to the first day of school to openly discuss his capabilities and limitations. This will also help you talk to your student and his parents throughout the year more comfortably and confidently.

This “kick-off” meeting is the perfect time to form a collaborative team of teachers and other professionals within your school to ensure the student's needs are met by a group – not just one individual – throughout the year.

Before we delve into specific PE matters, here are a few overarching topics applicable to all teachers – and students – affected by Duchenne muscular dystrophy.



Four things every teacher should know about their student with Duchenne

1 Young men with Duchenne often experience some learning problems.

Most learning problems are related to the slower speed at which your student processes information, such as verbal instructions. For elementary students especially, it's important that you speak clearly and concisely, and repeat the information to ensure he has grasped it. For older students, this learning issue does not get worse, and many young men often overcome it. In fact, many young men with Duchenne have above-average intelligence. Their visual skills and creativity are often excellent, which is perhaps why many become very good artists. Together with an independent evaluation by your school, a conversation with your student's parents will help you gain a better understanding of his current level of ability and particular needs.

2 Duchenne muscular dystrophy has no association with a particular personality type.

Many parents suggest, however, that their sons exhibit some traits similar to those in obsessive-compulsive disorder. Like all students, some young men with Duchenne are quiet and reserved, some are outgoing, and others misbehave. Also, like all students, they should be expected to follow school rules and procedures. It's important to hold them accountable for their actions.

3 Boys with Duchenne may experience emotional or behavioral problems.

Some of this may stem from steroids that are known to cause aggressive behavior. Other emotional issues arrive from the undue stress that a fatal, independence-robbing disorder puts on a child and his family. As a teacher, you can help him adjust by being supportive, understanding, and consistent with your words and actions.

4 Confidentiality is a great concern for many parents of children with Duchenne muscular dystrophy.

Parents often struggle with what, when, and how much to tell their son about his fatal disorder. It's critical to make no assumptions about what your student knows about his diagnosis. Meet with your student's parents before the first day of school to discuss their wishes for confidentiality.

Talking to your class about Duchenne

Because the Duchenne child's ability to take part in PE activities will differ (sometimes greatly) from the abilities of his peers, his classmates will naturally have questions about his changing appearance and abilities. In addition, since many activities may need to be modified to accommodate his needs, the other students' experience of PE class will be affected.

The key is communication. Research shows that peers are less likely to tease and more likely to defend when armed with accurate knowledge about Duchenne. From the outset, be frank about what is going on (following parents' confidentiality wishes, of course), and encourage discussion. All children react to social settings differently, so be sensitive to the Duchenne child's needs. Your student may wish to be part of an open discussion about his condition, whereas a more private child may not enjoy the attention. In some cases it may be best to have the discussion on a day when the child is absent. In general, be as open and engaging about the topic of Duchenne and disability as the family will allow.



It's important not to lose sight of the needs of all your students in your efforts to accommodate the student with Duchenne. From early on, involve your class in making decisions about how to include their friend with Duchenne muscular dystrophy in all activities. Have brainstorming sessions. When other students feel involved in helping their classmate, the social bond is deepened, and the possibilities of resentment from 'special treatment' are vastly reduced. In preparing this book, the teachers we talked to were unanimous in their experience of how positively their students' peers responded to the opportunity to be part of the solution.

With its complex nature and extensive scientific terminology, Duchenne muscular dystrophy can be difficult to comprehend fully. We've compiled some recommendations below to help you better communicate about Duchenne with other teachers, your class, your student, and his family.



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
- Disorder (genetic) / Condition
- Devastating / lethal, Genetic
- Progressive muscle disorder

The overwhelming majority of the Duchenne population is male. Because some will survive into adulthood, it may be appropriate to describe them as 'young men' rather than as 'boys' or 'children.'

Words like 'normal,' 'fulfilled,' and 'productive' should be used carefully so the sentence does not imply that those affected by Duchenne aren't 'normal,' 'fulfilled,' or 'productive.'

3

**Challenges &
ways you can help**

Cognitive development

Processing issues are typical in boys with Duchenne and are considered related to the disorder. Many times this presents as an expressive communication difficulty. Your student may not be able to process a lot of information or series of instructions at one time. As a result, it may be very difficult for him to organize and respond appropriately. It's important to remember that this is not necessarily laziness or diminished mental capacity, but a language-processing problem. Cognitive abilities of boys with Duchenne range from mild diminished mental capacity to normal, and all the way to superior.

Behavioral issues

Physical limitations can be challenging for anyone. Physical limitations for a young man with Duchenne only increase over time, which can cause frustration and embarrassment, even among the youngest students. These frustrations may, for some students, be acted out through their behavior. While your sensitivity and support is critical, students with Duchenne should be held accountable and responsible for following the same class and school rules as other students.

After the age of 10, your student may experience symptoms such as headaches, mental lapses, difficulty concentrating, or staying awake during the day due to respiratory difficulties. These may affect his demeanor in class. The cause of these symptoms may be breathing problems at night. If you observe any of these symptoms, they should be mentioned to the parents in case they have not noticed them at home.

In addition, your student will most likely be taking medications designed to slow the symptoms of Duchenne and improve strength. Prednisone is a steroid widely used, but may produce severe physical and psychological side effects, which may affect a student's appearance, behavior, and academic performance.

A teenager with Duchenne has a unique set of concerns that can affect his behavior in school. Physical, emotional, and social 'growing pains' affect all students in this vulnerable time of moving into adulthood. It's important to remember that it's just as difficult—and arguably even more so—for a young man with Duchenne muscular dystrophy. The changes he's experiencing can be frustrating. While his friends are gaining more independence, he is facing less independence, more severe health conditions, and a future cut short by something he's been living with since he was a young boy.

Confidentiality concerns

At earlier ages, when your student is newly diagnosed (and still too young to understand the diagnosis fully), it's safe to assume that his parents may have only told him a limited amount of information, if any, about Duchenne muscular dystrophy. The only way to find out for sure is to meet with the student's parents. They will be able to give you guidance regarding what or how much they'd like you to discuss with their child, his peers, other parents, and other teachers.

The older your student with Duchenne, the more likely it is that he knows a reasonable depth of information about his diagnosis. It's best not to assume, however, this is always the case. It's a great idea to meet with his parents to find out what your student does and doesn't know about Duchenne muscular dystrophy.

While it's imperative to honor the parents' wishes, it's important overall to maintain open, honest, and sensitive communication about Duchenne. It will make the student and everyone involved more comfortable to share information, ask questions, and address any issues that arise.

4

**The basics of working
with an Individualized
Education Program (IEP)**

you can play a critical role in developing an IEP for your student

Introduction

Every child has a legal right to PE class. Federal Law #94142 states that all children, regardless of handicap & condition, are entitled to free and appropriate education. In fact, Physical Education is the only specific school subject mentioned in the text of the law.

A young man with Duchenne may only need minimal assistance with physical activities and access, or he may require additional accommodations and modifications to help him take an active role in his education. This is where an Individualized Education Program (IEP) comes into play.

An IEP is the guiding blueprint that delivers your student's special education program. It's designed to help your student benefit from the PE curriculum and participate as much as possible with his non-disabled peers. This plan is developed by an IEP team made up of several members. As his PE teacher, you will play a critical role, since you are in a position to be one of the closest observers of the student's cognitive and physical abilities.

Other members of the IEP team will be the student's parents, school administrators, an adaptive PE consultant, and a licensed Physical Therapist. The PT should be expected to consult on the recommended plan of action so that the PE teacher is not responsible for making medical decisions.

Schools in different states may use the term PET (Pupil Evaluation Team), IEP (Individual Education Program) Team, MDT (Multi Disciplinary Team), or ARD (Admission Review and Dismissal) Team to describe the group that convenes for this purpose. In this booklet, the term IEP Team will be used.

IEP team

An IEP Team must include the child's parents or guardians, at least one regular education teacher (assuming the child will be in the regular education environment), at least one special education teacher, and a school representative who is qualified to provide or supervise special education services and who is knowledgeable about both the school's general education curriculum and the school's available resources. In addition, parents and school are each entitled to bring others who have knowledge about the child or special expertise. At least one member of the Team must be able to interpret the educational implications of the evaluations the Team is to consider.

Goals

An IEP outlines measurable annual goals detailing what your student is expected to learn and achieve in the coming school year. These goals must be designed to meet your student's current needs resulting from his disability to enable him to be involved in and make progress in the general education curriculum. Updates of measured progress should be provided to parents periodically through the school year, at least as often as reports are given on the progress of his non-disabled peers.

The IEP is a flexible document and may be amended from time to time as necessary to help ensure appropriateness and student progress. It must be reviewed at least once each year, and the child's needs must be reevaluated at least once every three years. Because of the progressive nature of Duchenne, parents should have ongoing communication with teachers and administrators at the school, and the student's changing physical needs should be evaluated every six months.



Things to consider

For most boys with Duchenne, the regular classroom is the ‘Least Restrictive Environment’ (LRE). The LRE is considered the educational environment where a child with disabilities can receive a free and appropriate public education designed to meet his education needs while being educated with peers without disabilities in the regular educational environment to the maximum extent appropriate. In some cases, however, the need for additional services may be important for the IEP Team to support because denying a particular service could result in the child being removed from the regular classroom.

A student with Duchenne may need the following and other related services:

- Transportation Services
- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Counseling Services
- Social Work
- Developmental and Corrective Services
- Assistive Technology



For more IEP information

Needs for a young man with Duchenne may be very different from those of other children who receive Special Education. For more in-depth information on developing an IEP and federal laws regarding special education in your state, visit our website at www.parentprojectmd.org/educational/states.

5

Adaptive PE in action

A note on progress

Although Duchenne's progress is generally broken down by age group, you may find that your student does not fit easily into the age categories. They may be significantly impaired at an earlier age, or fortunate enough to be less affected as they head toward their teens. In addition, their capabilities may vary widely from day to day.

Please bear this in mind when using the guide; use the activity that seems to be the best solution for your student's current ability level. Be flexible; communication, attentiveness, and patience are crucial to a rewarding experience for your student and for his peers.

**communication,
attentiveness, and
patience are crucial**



What to look for in the classroom

Pre-school & elementary school (ages 3 – 7)

Duchenne muscular dystrophy is typically diagnosed between the ages of three and seven. During this early phase, your student's movements may appear slower or more labored than other students. You may notice physical changes such as enlarged calf muscles and walking on tiptoes, due to a tightening of the heel tendons. He also may start to experience difficulty standing up from a sitting position due to muscle weakness in his legs. Even the youngest students with Duchenne will face challenges maneuvering within the school environment.

Elementary & middle school (ages 7 – 11)

At this age, your student is considered to be in the 'transitional phase' of Duchenne muscular dystrophy. His leg muscles will grow weaker, and he'll have trouble walking, standing, and maintaining his balance. He probably will not be able to climb any stairs and should not be encouraged to try.

Junior high & high school (ages 12+)

Typically, beginning at around 12 years old, a student with Duchenne muscular dystrophy needs the assistance of a wheelchair due to significant loss of skeletal muscle strength. His muscles will continue to weaken throughout his teenage years, considered the 'adult stage' of Duchenne. Activities involving the arms, legs, or trunk of the body will require assistance. Most young men retain the use of their fingers through their early teens, and can generally still write and use a computer. These tasks may become more difficult for an older student (15+ years).

Declining respiratory function makes breathing more difficult and can lead to symptoms such as headaches, mental lapses, and difficulty concentrating or staying awake during the day. Be understanding and mindful of symptoms, and, most importantly, understand that your student should be kept out of school during cold or influenza epidemics. His weakened muscles make coughing difficult, which allows a simple cold to progress quickly into pneumonia in a young man with Duchenne. Be aware that he needs to be taken to the physician if symptoms develop.

The wheelchair will, of course, have an effect on your student and may affect the entire PE class. Nonetheless there are still many ways to keep him involved, physically and socially.

In general

- Remember that these activities are designed to afford the Duchenne child the experience of succeeding, as opposed to simply being allowed to take part in a limited fashion. If you focus on making your student a real, integral part of the class, the results will speak for themselves.
- Don't allow the child to exert himself to the point of exhaustion. Focus on keeping muscles active, to maintain flexibility.
- Strength-building exercises can further damage weak muscles and should be discouraged for a student with Duchenne.
- Make sure he stretches his leg muscles regularly. As he weakens, he naturally will find it difficult to exert himself, which can lead to tightening of muscles and shortening of tendons, resulting ultimately in further loss of mobility. Work out a set of stretching exercises. Consider making an illustrated 'Goal Book' in which he can work through a set of stretches throughout the school year.
- Some typical stretching exercises of particular importance to a student with Duchenne include stretching the foot and ankle (the Achilles tendon), the knees (hamstrings), and hips (IT bands).
- Avoid stairs. It is unsafe and puts stress on the muscles. Use an elevator or a ramp instead. Better yet, choose activities that don't require students to change floors.
- Since the student with Duchenne will likely be slower than his classmates, one way to make sure he's not being left behind is to make him a line leader, allowing him to set the pace, or conversely, a caboose (one which must stay attached to the line).
- Getting up from the floor, or any seated position, is very hard for a student with Duchenne. Have a chair or other raised seat available for his use. Other students can be made responsible for making sure the seat is there when he needs it.
- Please do not let your student with Duchenne walk long distances. If extra time is needed, make it an honor or reward to be assigned as the child's 'buddy' and get to leave class a little early or come in a little late.
- In some cases, it might be a valuable learning experience for your other students to experience some of the challenges faced by the student with Duchenne. Have them do running and jumping activities with ankle weights, or while dragging a hula-hoop with their foot.

Activities

- Swimming is a terrific activity for the student with Duchenne; not having to fight against gravity allows him to use more of his strength to propel himself. It improves pulmonary ability and it's also a great opportunity for him to horse around with his friends without having to worry about losing his balance.
- In earlier stages, a kick scooter or even a tricycle can be an effective way for your student to keep pace with his classmates.
- A smaller field of play can make a big difference in the strain placed on your student with Duchenne. Baseball, soccer, kickball, etc., can all be modified to greatly reduce the distances traveled, allowing your student to compete more meaningfully.
- At each stage, try to partner your student with a rotating cast of 'buddies' to assist and keep an eye on him. Many students will take to this naturally (be sure that no single student is the buddy all the time; distribute the responsibilities).
- Breaking the class into smaller teams or groups with changing membership will enable every student to have the opportunity to take part in modified and unmodified activities.
- Scooter boarding is very popular with kids. Other students can take turns pushing the student with Duchenne. Because his legs are weak, great care should be taken when pushing him. If your scooter boards attach, use two of them, so that he has a place to rest his legs.
- Even after your student has reached the wheelchair stage, he should still be able to participate. Wheelchair soccer is a terrific sport. A cage or open box may be attached to his wheelchair to capture and direct the ball. A hockey stick attached to his wheelchair can also keep him involved and active.
- The student with Duchenne can also act as 'helper' in a variety of activities, such as freeze tag, where he can be the 'unfreezer.' Keeping score, refereeing, serving as announcer, and other non-physical roles are other ways for the student to participate. Make sure that ground rules for his authority are in place if he is a referee. And be sure that he feels included, not isolated, in his role, whatever it may be.

Equipment alternatives

As long as the student with Duchenne is able to take part in modified versions of PE activities, alternate forms of equipment will make his involvement much more fulfilling. You can certainly come up with more ideas, but here are some that have proven to work well in the classroom. Again, be sure to encourage ideas from all of the students. You never know what they may come up with, and it invests in them the idea of responsibility to their classroom community.

- Instead of baseballs and softballs, try a whiffle ball, which is lighter, slower, and easier to spot. For volleyball, soccer, or any game that requires a larger ball, a beach ball is light, easy to throw and kick, and won't hurt if the catch is fumbled.
- In place of regular bats, whiffleball bats, made of light plastic, may be used, as can foam bats. Foam noodles, cut down, make swinging much easier as well.
- Bowling ramps can be used, both for bowling and for pitching a kickball; these are incredibly easy to use, and are simply adjusted for aim.
- A Frisbee® can be used in place of a ball for alternate versions of soccer, baseball, bowling, golf, etc. A wide variety of sizes and weights are available; some are even made of cloth or foam.
- A ball attached to a rope that has been looped around a line stretched across an open space is an excellent adaptation for throwing and catching games. The ball travels more directly to the student, and he can throw or hit it back with more accuracy and without having to fight gravity as much.

- Using a batting tee, or suspending an object to be struck, will help the student by allowing him to take his time and really set up his swing.
- EZ Rope™ is a way to jump rope without having to actually jump in time with the swinging motion. It's simply a jump rope with the middle cut out, so that the child can swing it and jump at his own pace, or just swing it and not jump at all. His heart rate and breathing will still increase, without having to put strain on his muscles.

i

Equipment resources

There are, happily, an increasing number of resources for alternative sports or PE equipment geared toward the differently-abled child. The two sites below are recommended by the majority of the PE Teachers and Physical Therapists we talked to in preparing this booklet.

www.flaghouse.com

www.abilitations.com

Peer mentoring

Another highly effective approach in working with the student with Duchenne is peer mentoring. Simply put, a classmate, a student (often older) from another class, or even from a neighboring school, makes themselves available to assist the student with Duchenne, focusing on him during the duration of the class. Contact schools in your area, as well as your own school administrators. Many times a program such as this can be created if none exists. You will find that many students will be delighted to make a difference in another child's life.

Be very clear that mentoring is a voluntary act. If the mentor is one of the student's classmates, make sure that they do not shortchange their own education by focusing too exclusively on the student with Duchenne. By fostering an atmosphere of tolerance and inclusion, you will increase the likelihood of multiple volunteers, ensuring that the responsibility for helping does not fall to only one person.

Extracurricular sports

Some students will want to take part in extracurricular sports. While this may seem at first to be counterintuitive, we found examples of students with Duchenne playing golf, baseball, flag football, and even skiing. It should go without saying that this should only be entered into with full communication between all parties who may be affected by the student's participation.

6

Summary

**you can have a
tremendous impact
on your student's life**



Why your help is so important

When it comes to the PE experience of a child with Duchenne muscular dystrophy, you can have a tremendous impact on your student's life. Whether he's starting his first day of school or heading into high school, he will need your informed guidance and support. There are many ways you can help enhance his physical capabilities, protect his muscles, and encourage social interaction, especially at the start of the school year.

If you found this guide helpful or have suggestions on how we might improve it, we'd love to hear from you.

Please contact Parent Project Muscular Dystrophy at info@parentprojectmd.org or 800-714-5437. For more information, visit www.parentprojectmd.org.



Top three take-away points

- 1 Partner with your student's parents. To get familiar with your student's diagnosis and his particular needs, meet regularly with his parents. They are the best source of information for what he does or does not know about his diagnosis, his current level of ability, and specific treatment(s) he requires during the school day.
- 2 Involve your class in making decisions or accommodations about how to include their friend with Duchenne muscular dystrophy. From finding an active role for him in PE class to giving him extra time for note-taking, there are many things you can do for a student with Duchenne muscular dystrophy to ease his transition into the PE class.
- 3 Be as open and engaging about the topic of Duchenne muscular dystrophy/disability as your student's family will allow. Due to the nature and rapid course of Duchenne, sensitivity and confidentiality is critical to many parents. While it's important to respect the wishes of your student's family, it's also important to have informed, open and honest discussions with your class.

Conclusion

Remember that these activities are designed to afford the Duchenne child the experience of succeeding, as opposed to simply being allowed to take part in a limited fashion. If you focus on making your student a real, integral part of the class, the results will speak for themselves.

With your consistent support and understanding, a student with Duchenne muscular dystrophy can have a fun and rewarding school experience, which is often the highlight of his young life.

Thank you for striving to enrich the life of your student.

For more information, visit www.parentprojectmd.org.

7

Resources for teachers



Please use or adapt the following sample letter if you have a substitute filling in for you:

A note to my substitute

Welcome!

There's something about my class you should be aware of.

One of my students has Duchenne muscular dystrophy.

His name is _____
and he's _____ years old.

Because he has muscle weakness, he might need to take part in alternative forms of the regular PE activities. He may also need alternate forms of equipment. We have developed several activities that allow all of the students to participate. Please ask the other students, or refer to the Adaptive PE booklet.

He also has a buddy/aide to help him with these things.

His/her name is _____ .

I hope this helps. If you have any questions or concerns, please contact the principal.

Have a good day, and thanks for your help!

Sincerely,

Here are a few of our top recommendations:

Parent Project Muscular Dystrophy (PPMD)

parentprojectmd.org • A national nonprofit organization founded in 1994 by parents of children with Duchenne muscular dystrophy. For an extensive list of links to educational resources we've compiled, go directly to <http://www.parentprojectmd.org/resources/index.html>

Muscular Dystrophy Association (MDA)

mdausa.org • A voluntary health agency dedicated partnership between scientists and concerned citizens aimed at conquering neuromuscular diseases that affect more than a million Americans.

U.S. Department of Education, Office of Special Education Programs and Rehabilitative Services
ed.gov/offices/OSERS/OSEP/index.html

National Dissemination Center for Children with Disabilities (NICHCY)
nichcy.org

Centers for Disease Control and Prevention

cdc.gov • Connect directly to their Duchenne and Becker Muscular Dystrophy webpage at <http://www.cdc.gov/ncbddd/duchenne/index.htm>

BrainPOP

brainpop.com • Health, Science, Technology, Math, English Animation, and Educational Site for Kids, Parents and Teachers

The National Center on Physical Activity and Disability
ncpad.org

PE Central

pecentral.com • Connect directly to their adaptive PE webpage at <http://www.pecentral.com/adapted/adaptedmenu.html>

Family & Advocates Partnership for Education (FAPE)

fape.org • Helping Parents and Advocates Improve Educational Results for Children with Disabilities

Council for Exceptional Children (CEC)

idea practices.org • The voice and vision of special education

School Zone

geocities.com/Heartland/Plains/6097/special.html • A web site with an extensive list of links to special education resources

Childhood Learning Disabilities

learning-disabilities.org • The Internet Resources for Special Children (IRSC), global disABILITY resource

The Accessible Games Book, by Katie Marl
(available through Jessica Kingsley Publishers, www.jkp.com)

Quick-Guides to Inclusion: Ideas for Educating Students with Disabilities, by Michael F. Giangreco
(available through Paul H. Brookes Publishing Co., Baltimore: 1-800-638-3775)



About Parent Project Muscular Dystrophy

Parent Project Muscular Dystrophy (PPMD) was founded in 1994 by parents of children with Duchenne to offer the hope, support, and resources families may not find anywhere else.

Today, PPMD is the largest nonprofit organization in the United States focused entirely on Duchenne muscular dystrophy. No other organization works to secure more dollars for Duchenne research or lobbies the government more aggressively to provide increased support for the fight against Duchenne. Our mission is to improve the treatment, quality of life, and long-term outlook for all individuals affected by Duchenne through research, advocacy, education, and compassion.

Parent Project Muscular Dystrophy is proud to lead the Duchenne community. Our name reflects our grassroots origins and parent-led focus, which drive us to pursue strategies that will impact this generation of young men affected by Duchenne. In addition to funding critical research, we offer families the most up-to-date information available and create vital connections throughout the entire Duchenne community. For more information, visit www.parentprojectmd.org.

About Pat Furlong

Founding President & CEO of Parent Project Muscular Dystrophy

Pat Furlong is the executive director and one of the founding parents of Parent Project Muscular Dystrophy. Her focus and determination have helped to grow the organization from a small group of parents, who were frustrated by the lack of investment in Duchenne muscular dystrophy research, into the world's leading Duchenne authority.

In 2001, Ms. Furlong was invited to testify at a Senate Appropriations Hearing that focused on the introduction of the MD CARE ACT. Her testimony and her ability to mobilize a grassroots advocacy effort helped to speed the passage of the MD CARE ACT into law.

In February of 2002, Ms. Furlong was one of 25 individuals chosen by United Airlines as an “Everyday Hero.” This prestigious award was presented at the 2002 Olympics to honor her as a woman who carries a torch for so many families affected by Duchenne.

Ms. Furlong was recently appointed to serve on the Muscular Dystrophy Coordinating Committee of the U.S. Department of Health & Human Services. She will be one of approximately 15 committee members, appointed by the Secretary of Health and Human Services, who will develop a plan for conducting and supporting federal research and education on muscular dystrophy through the national research institutes.

It is through Ms. Furlong's determination that Parent Project Muscular Dystrophy continues to make strides not only in the muscular dystrophy research community, but also in the areas of care and treatment. Her goal is to help to impact this generation of boys diagnosed with Duchenne. And her perseverance is in honor of her two sons, Christopher and Patrick, whose own battles with Duchenne continue to motivate her efforts.

Credits and acknowledgements

Grateful acknowledgement is made to the following for their advice in preparing this booklet:

Laura Case, P.T., D.P.T., M.S., P.C.S.

Sue Hensler, PE teacher

Susan Parker, Pediatric P.T.

Barb Melaney, Adaptive PE Contact, Durham Public Schools

Education Matters is a series of guides 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 for talking 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
- A guide to adaptive physical education

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

T. 800.714.5437

ParentProjectMD.org