

Sample CHOP Letter for MD School Modifications

Patient A is followed at The Children's Hospital of Philadelphia's Neuromuscular Program for the following diagnosis:

Muscular Dystrophy

This diagnosis is permanent and genetic in etiology and Patient A will not outgrow this.

Because of their muscular dystrophy, we recommend the following accommodations for school, gym, and physical activities:

- They should be allowed to participate in all activities, including gym class, as tolerated. They **should not be graded in gym class** based on physical ability or norm-based scores.
- They should avoid strength training with weights.
- They can exercise at sub-maximal level with focus on endurance type activities such as walking, biking, and swimming.
- They should avoid over-fatiguing muscles. If they are sore 2 days after exercise, they probably over-worked themselves.
- They should receive evaluations for PT and OT therapies at minimum every 6 months. They should also be actively receiving these services in school.
- They should be allowed to self-limit their activity based on symptoms of muscle pain and their own perception of their tolerance and skill level. Please allow them to rest as needed when they are tired and their legs are hurting. They cannot continue walking or going long distances if they say they need to rest.
- Please have the PT work with the gym teacher in advance of each gym unit to provide proactive modification of the gym activity to accommodate their need.
- They should have two sets of books, one for school and one for home. They should not carry a heavy book bag; please ensure that all of their textbooks remain in their assigned classrooms to ensure this.
- They should have access to the elevator.
- They should have access to a water bottle.
- They may need assistance with opening doors, toileting, and eating lunch/snacks.
- They should have a 1:1 aide with them at all times for assistance with ADLs. This designated person should be trained by the PT and OT.
- They should be permitted to leave class 5 minutes early and arrive 5 minutes late to avoid heavy traffic in the hall ways and provide them with enough time to get from class to class.

- They may miss an abnormal amount of school and work due to doctor's appointments and disease flares. These absences should be excused. Please allow flexibility for them to make up any missed work to minimize the risk of falling behind without penalty.
- Proper infection/virus protection is a serious concern, as viruses and infections can have dramatic consequences on their health. Therefore, proper infection precautions need to be taken, such as proper hand hygiene.
- Door to Door transportation in a handicap accessible bus.
- Jane Doe's parents may have additional requests. Thank you in advance for your assistance and please do not hesitate to contact us for additional information and documentation. If you have any questions, please call Social Worker. We will happily answer questions with **parental permission**.

Sincerely,