Myotonic Dystrophy

Symptoms or Behaviors

Symptoms

- Muscular weakness and stiffness
- Easily fatigued
- Speech difficulties
- Tiredness after physical exercise
- Gastrointestinal problems
- Learning difficulties
- Facial weakness features
- Delayed fine motor movement
- Somnolence (sleepiness)
- Abnormal heart rhythm

Behavioral issues

- Apathy/lack of initiative
- Withdrawal
- Social problems
- Attention problems
- Depression
- Anxiety Disorders
- ADHD
- Oral fixation
- Spontaneous laughter
- Obsessive Bonding
- Little or no fear of strangers
- High voice

About the Disorder

What is Myotonic Dystrophy?

Myotonic Dystrophy is a rare disease with an incidence of about one in 8000. The incidence of the congenital form is 1/100,000. The symptoms vary from person to person, some being mildly affected and others severely affected. As a general rule, the earlier the disease is apparent or can be detected, the more severe the symptoms will be. The disease gets progressively worse with each generation affected.

Myotonic Dystrophy is known as a multi-systemic disease. Several different types of tissues and organs are affected. Thus, the disease may impact the eyes, heart and muscles. Individuals with the disease may have trouble staying awake and have low energy levels. They may have depression. There may be hair loss or digestive problems.

What causes Myotonic Dystrophy?

Myotonic Dystrophy is genetically based and inherited from one generation to the next. 50% of children inherit the disease from an affected parent, generally the mother.

How is Myotonic Dystrophy treated?

There is no specific treatment found for the muscle weakness and wasting. Ankle and leg braces can help to support muscles as weakness progresses. There are some medications that can relieve the myotonia. Heart problems, cataracts and other abnormalities associated with the disease can also be treated.

Minnesota Low Incidence Projects

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Educational Considerations

Myotonic Dystrophy can impact a student's participation in everyday school activities and schoolwork. It can affect the student's mobility, strength and endurance to perform daily tasks. Writing may be difficult as well as other fine motor tasks. Intestinal issues may cause the student to need increased time away from the classroom for restroom breaks. Excess fatigue may cause excessive absences. Learning difficulties are common.

Instructional Strategies and Classroom Accommodations

1. Treat the student, as much as possible, like other students.
2. Encourage participation in physical activities, but modify activities according to recommendations provided by the student's doctor for fatigue or muscle weakness or stiffness.
3. Make arrangements for assignments to be sent home when the student misses school because of his or her condition.
4. Extended time for written assignments/tests or allow oral responses.
5. Provide an extra set of textbooks at home.
6. Shorten or modify long written assignments.
7. Provide copy of teacher notes.
8. Provide a water bottle additional bathroom privileges for digestive issues.
9. An Individual Health Plan may be necessary.

Resources

International Myotonic Dystrophy Organization
P.O. Bx. 1121
Sunland, CA 91041
818-951-2311
e-mail: info@myotonicdystrophy.org
www.myotonicdystrophy.org

South West Thames Regional Genetics Unit:
St. George's Hospital Medical School
Cranmer Terrace, London, SW17 0RE
Tel:020 8266 6427 Fax 202 8725 3444

Myotonic Dystrophy Support Group:
A self help group, willing to provide support to families affected by Myotonic Dystrophy
Email: mdsg@tesco.net
Web: www.mdsguk.org

Muscular Dystrophy Campaign:
A charity funding medical research and support, including Family Care Officers for people with neuromuscular conditions
Email: info@muscular-dystrophy.org
Web: http://www.muscular-dystrophy.org

Muscular Dystrophy Association
National Headquarters
3300 East Sunrise Drive
Tucson, AZ 85718 520.529.2000
www.mda.org

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