SMA, MD & other Neuromuscular Disorders *at a Glance*

Neuromuscular disorders are conditions that affect some part of the neuromuscular system. The neuromuscular system includes the muscles, the peripheral motor nerves (in arms, legs, neck and face), and the "neuromuscular junction" where the nerves and muscles meet the muscle-controlling nerve cells (motor neurons) in the spinal cord.

Neuromuscular disorders can be inherited in many different ways. Some are inherited in an X-linked recessive manner meaning they will mainly affect males. Others are inherited in an autosomal recessive or autosomal dominant manner, meaning both males and females are affected equally. All neuromuscular disorders are progressive and all result in muscle weakness and fatigue. Some disorders begin at birth, some in childhood, and others begin during adulthood.

When muscle deteriorating occurs it can cause cramping, stiffness, joint deformities, chronic aches and pain, and sometimes the tightening and freezing of joints (contractures).

Many children with neuromuscular disorders have normal intelligence, however, muscle weakness and fatigue can make it hard for students to write, complete assignments, and/or organize materials. Children with these conditions do have an increased susceptibility to life-threatening respiratory infections, which may cause them to miss many days of school. A few neuromuscular disorders are associated with an increased incidence in learning disabilities and intellectual disabilities.

Life expectancy varies by disorder and severity. Heart and breathing problems, which are caused by muscle deterioration, are often the reason for death in individuals with neuromuscular disorders.

Learn more about common physical characteristics of neuromuscular disorders:

Heart

Poor circulation may cause:

- Fatigue
- Lethargy
- Swelling in the legs and feet
- Cold arms and legs

- Digestive problems

Nutrition

- Muscles used in swallowing and chewing may be weakened causing
    - Dehydration
    - Malnutrition
    - Inhaling food, which can cause choking or respiratory infections
    - Inhaling liquid into the lungs (aspiration).
- A feeding tube (gastrostomy tube or g-tube) may be needed
- Constipation may be an issue from lack of moving, which in turn may lead to decreased appetite.

Learn more about specific neuromuscular disorders:

Charcot Marie Tooth disease (1 in 3,300)

- Characterized by weakness and breakdown of muscles and nerves
- Typically affects from elbows down and the legs from knees down
- Other complications:
    - Foot deformities
    - Numbness
    - Ankle spasms
    - Muscle cramps
    - Burning nerve pain

Treatment and assists:

- Leg braces
- Wrist braces
- Wheelchair or other assistive devices

Dystrophinopathies (1 in 4,700)
(Duchenne Muscular Dystrophy (DMD) or Becker Muscular Dystrophy (BMD)

This refers to a range of progressive muscle disorder only affecting boys, which is caused by a change in a gene on their X chromosome. The skeletal muscle is affected and death is usually caused by cardiomyopathy.

Duchenne Muscular Dystrophy (DMD)

- Presents in early childhood with delayed milestones
    - Delays in sitting and standing

    - Proximal muscle weakness causes waddling gait and difficulty climbing
        - Proximal muscles are the ones closest to the center of the body
    - Boys may have trouble walking and be unstable
- DMD is rapidly progressive with boys typically being wheelchair dependent by age 12
- Cardiomyopathy (disease of the heart muscle) typically occurs in the late teen years
    - Shortness of breath
    - Fluid retention in the feet and lower legs

Becker Muscular Dystrophy (BMD)

- BMD has a later onset of muscle weakness
- Individuals can usually walk into their 20s
- Some boys will experience activity induced muscle cramping

Treatment (applies to both):

- Anti-congestive medications may help
- Prednisone may be used to improve strength and motor function.
- Annual flu and pneumococcal shots
- Balanced diet rich in vitamin D and calcium to improve bone density and reduce risk of fractures
- Weight control to avoid obesity

Emery Dreifuss Muscular Dystrophy (EDMD; prevalence unknown)

- Characterized by weakness and wasting of shoulder, upper arm, and shin muscles
- May also have
    - Joint deformities
    - Heart complications

Friedreich Ataxia (1-2 in 50,000)

- Characterized by slow progressive ataxia
- The onset is 10-15 years of age
- Cognitive skills
    - Cognition not usually slowed
    - Motor and mental reaction time may be impaired
    - Intelligence profile characterized by
        - Concrete thinking
        - Poor capacity formation
        - Visuospatial reasoning with reduced speed of processing

        - Problems with attention and working memory
- Other characteristics findings:
    - Muscle weakness
    - Dysarthria (a motor speech disorder affecting muscles in the mouth and face)
    - Spasticity in lower limbs and/or absent lower limb reflexes
    - Scoliosis
    - Bladder dysfunction
    - Loss of position and vibration senses
    - Sleep apnea
    - Shaky movements
    - Lack of coordination
    - Poor balance
    - Slurred speech
    - Dysphagia (difficulty swallowing)
    - Hearing loss
    - Loss of visual acuity

Treatment:

- Walking aids
- Wheelchairs
- Speech therapy
- Occupational therapy
- Physical therapy for strength and balance
- Orthotic interventions for scoliosis, and/or foot deformities
- Hearing devices for hearing loss
- Address vision issues
- Dietary modifications and/or G tube for dysphagia
- May need insulin and/or dietary management for diabetes
- Psychological support counseling
- Ataxia:
    - Avoid areas that may put individual at risk for falling,
    - Excessive use of alcohol can increase ataxia

Limb Girdle Muscular Dystrophy (LGMD 1 in 14,500-123,000**)**

- There are more than 20 different subtypes, which vary in progression, severity, and age of onset
- This is a group of disorders affecting voluntary muscles: mainly hips and shoulders

- Muscle weakness and atrophy lead to limited mobility and an inability to raise arms and shoulders
- Intellect is not affected
- Cardio/pulmonary issues may occur later in disease

Myotonic Dystrophies (1 in 20,000)

- Is a multisystem disorder that affects skeletal and smooth muscles
- It ranges from mild to severe
- Most symptoms of myotonic dystrophy begin after 20 years of age
- This condition causes an inability to relax muscles
    - It typically affects the following:
        - Face
        - Feet
        - Hands
        - Neck
- The eyes, heart, endocrine, and central nervous system may also be affected
- Minor intellectual disability is present in some individuals
- Lack of facial expression may misrepresent intelligence
- Anti-social behavior may be found
- Possible behavioral characteristics
    - Avoidant
    - Obsessive compulsive
    - Passive expressive personality
    - Anxiety
    - Depression
- May have sleep apnea and day time sleepiness

Learn more about the different forms of Myotonic Dystrophy:

Mild form of myotonic dystrophy

- Includes cataracts and mild myotonia (sustained muscle contractions)

Classic form of myotonic dystrophy

- Muscle weakness and wasting
- Myotonia
- Cataracts
- Cardiac conduction abnormalities
- Adults may be physically disabled

Congenital form (present at birth)

- Hypotonia (low muscle tone)
- Severe generalized weakness at birth
- Respiratory insufficiency and early death
- Intellectual disability (50-60%)
- Autism spectrum disorder
- Mood/anxiety disorders
- Impaired attention
- Abnormal visual spatial abilities
- Low visual acuity, farsighted, astigmatism

Treatment (depends on the individual's specific diagnosis):

- Ankle and foot orthotics
- Wheelchairs and other assistive devices
- Pain management
- Cardiac evaluation
- Cataracts removed
- Physical therapy

Spinal muscular atrophy (SMA; 1 in 10,000**)**

SMA is a disease that progressively weakens individual's physical strength by affecting the motor nerve cells in the spinal cord. This affects the ability to walk, eat, and/or breathe. It is the number one genetic cause of death for infants. Cognitive function is not affected.

- There are four primary types of SMA: type I, II, III, and IV. The type of SMA is based on age of onset and the highest physical milestones achieved.
- Those with SMA may also have:
    - Poor weight gain
    - Sleep difficulties
    - Scoliosis
    - Joint contractures
    - GI issues
        - Constipation
        - GI reflux
    - Incontinence
    - Pain

Treatment and other assists:

- Physical therapy
    - Stretching
    - Range of motion activities
- Occupational therapy
    - Modified written assignments
    - Computer technology
    - Fine motor strengthening
- Orthotic interventions for scoliosis, and/or foot deformities
- Dietary modifications and/or G tube for dysphagia
- Cough assist, bi-pap and/or other respiratory interventions
- Ensure safety on playground, in hallways, in the class
- Adaptive physical education
- Walking aids, wheelchair, and other assistance in getting around the classroom

For more information on SMA generally and SMA in the classroom visit:
http://www.curesma.org/support-care/living-with-SMA/daily-life/at-school/

Things to think about

1. Medical / Dietary Needs

What you need to know

- Certain muscular dystrophies have special diets or dietary restrictions. It is important to discuss dietary needs of the child with the parents. If there isn't a special diet required for an individual, a well-balanced diet is important.

- When the muscles used in swallowing and chewing are weakened, there's a risk of dehydration, malnutrition, choking, or respiratory infections caused by inhaling food or liquid into the lungs (aspiration).
    - Gastrostomy (G-tube) tube may be required
    - If acid reflux is present, allow child to keep antacids in nurse 's office

- It is important to discuss the nature of the student's condition and implications for school activities. The child's physicians will determine the student's permitted activities and levels.

- School age children with neuromuscular disorders may have multiple doctors and specialist visits to monitor medical conditions.

- In almost everyone with a neuromuscular disorder, bladder and bowel control are normal, although students may need help in the bathroom as their physical abilities weaken.

- If diabetes is present, follow care plan for that student.

What you can do

- A yearly check-up and studies as needed should occur in the child's Medical Home.

- Be aware of any changes in behavior or mood that seem unusual and notify the parents.

- Be aware of any academic changes. Contact parents when any differences are noticed.

- Accommodate students who may need to visit the nurse to take medications during school.

- Be aware that the student will often have increased susceptibility and life threatening consequences of respiratory infections:

    - Yearly administration of pneumococcal vaccine and influenza vaccination
    - (RSV) vaccine should be considered.
    - Any infection should be treated promptly before it progresses to a serious illness.
- Ensure exposure to sunshine and a balanced diet rich in Vitamin D and calcium to improve bone density and reduce the risk of fractures.

- Know the signs and symptoms of heart failure and or breathing difficulties.

- Be aware of how to support a student who has diabetes (if the child is diagnosed with diabetes)

2. Education Supports

What you need to know

It is important to have high expectations for children who have neuromuscular disorders. Some students will need physical or learning supports, based on their particular condition and stage. It is important to discuss the child's individual needs as a team. Many of these conditions are progressive. It is important to have high but realistic expectations for each child.

Even with normal intelligence, individuals can have muscle weakness and fatigue. This can make it hard for students to keep up with physical demands of handwriting, completing their assignments, and organizing materials.

This may affect learning to read, understanding math and different concepts. Unlike muscle weakness, cognitive effects usually are not progressive over time.

What you can do

Consider therapists and specialists to consult and support classroom teacher.

Physical therapy

- Help ease the side effects of neuromuscular diseases by keeping the body flexible, upright, and mobile.
- Help prevent contractures or "freezing" of the knee, hip, feet, elbow, wrist, and finger joints by employing range-of-motion exercises and stretches.
- Swimming pool exercises are often effective, especially in a warm pool.
- Safe transfers of non-ambulatory students is critical. Aides, teachers, and other caregivers should receive appropriate training.
- Ensure the student has appropriate musculoskeletal support and on-going treatment for prevention of scoliosis related complications.

Occupational therapy

- Ensure child has special feeding utensils and cups as needed.
- Hand splints keep the wrists and fingers in a good position.
- Work on dressing and daily skills to keep independent.
- Adapt play, environment, routines as needed.

Speech therapy

- Encourage use of assistive technology such as tape recorders
- Alternative communication system may be needed.
- Assistive/augmentative devices for communication may be needed.

Assistive Equipment

- Communication devices
- Computer adaptations and software
- Tools to help with everyday tasks:
    - Special feeding utensils and cups
    - Straws
    - A foam rubber cylinder for grasping pens and pencils
    - Tape recorders
    - Slanted desk top
    - Trays, may need sides
- Standing frames allow non-ambulatory students to continue to bear weight on their legs which promotes:
    - Healthy bones
    - Better circulation
    - Straighter spine.
- Transfer boards and mechanical lifts make it easier and safer to move a non-ambulatory student.
- Walkers, wheelchairs, and foot, ankle and leg braces keep children safely mobile and enables them to interact and play with their peers.

General Accommodations for Neuromuscular Dystrophies:

Consider these ideas in supporting children who have muscular dystrophy:

General Ideas

- Special transportation
- Physical and occupational therapy
- Minimize exposure to infection
- Curriculum modifications (as needed)
- Aides and note takers
- Tutoring
- More time on tests
- Adapted keyboards, software and calculators
- Adaptive physical education
- Rest time
- Bathroom assistance

- Field trip assistance
- Extra time to pass between classes
- An extra set of textbooks to keep at home to minimize carrying a heavy load
- Classroom and school campus accessibility modifications
- Assistance in making friends and maintaining social relationships
- Alternative ways to demonstrate understanding of a concept
    - Oral report instead of a written report
- Peer supports and using computer-assisted learning
- Using special education strategies for:
    - Learning
    - Memory
    - Language-processing difficulties
- At-home instruction for children who miss school due to illness, etc. requires:
    - Consistent support
    - Communication between school and home
    - Follow-through and high expectations
    - Inclusion of students with disabilities in social and extracurricular activities
- Allow children as much independence as possible
    - Especially for those in middle school and high school, but for all ages
    - Make sure they have chores like everyone else
    - Allow individuals to develop emotional and social independence while physical dependence may be decreasing.

Specific educational supports for Duchenne MD/ Becker MD

Boys with DMD have an increased chance for developmental, cognitive, learning, and behavioral problems. Boys with BMD may have cognitive impairment however it is not as common or as severe as in DMD. They often have difficulties with active working memory and executive memory.

Characteristic learning problems:

- Difficulties due to short-term verbal memory
- Deficits in visuospatial as well as verbal auditory
- Generalized deficits in cognition and adaptive functioning
- Problems with planning and organization
- Difficulty with understanding complex verbal information
- Expressive language delays

- Difficulty with goal orientated behaviors and lack of mental flexibility
    - Get stuck on one idea and have a hard time shifting thinking away
- Dyslexia
- Dyscalculia (math disorder)
    - A weakness in math reasoning ability
        - Hard time with math concepts
        - Difficulty estimating amounts
        - Hard time with understanding value, greater than, less than, or understanding abstract math concepts
        - Hard time with math because memory for math operations is challenged
            - Difficulty remembering number fact (i.e. multiplication fact) steps in solving equation
            - Hard time computing in head
- Dysgraphia: (disorder of written expression)
    - Requires many skills to be integrated
    - May be related to deficits in language skills
    - Executive functions difficulties
        - Hard time starting, planning and organizing written projects
    - Problems with short-term memory (working memory)
    - Weakness in phonics
    - Rate of dyslexia is increased
    - Problems with motor planning that are separate from muscle weakness. This can lead to:
        - Clumsiness
        - Incoordination
        - Poor hand eye coordination
    - Sensory processing disorder

<u>What you can do:</u>

- Help to keep up with classwork/homework
- Be clear and concise
- Have clear expectations
- Provide supportive seating
- Raised desktop
- Special pencil grips
- Note taking
    - Have helper

    - Allow more time
- Allow extra time between classes
- Peer supports to help with books etc.
- Be aware of fatigue
- May have difficulty paying attention and concentrating
    - Break down new information into small chunks
    - Summarize information
- Transitions may be difficult
    - Provide advanced warning of upcoming transitions
- Address math and reading difficulties and provide support
    - Use same strategies as other children with dyslexia
    - Use real life examples
    - Practice memorization techniques with the student
    - Help by allowing lots of space for work if needed
    - Allow use of calculator and/or number line
    - Reduce the number of questions
    - Give small amounts of information at a time
    - Introduce one concept at a time
- Provide opportunities to participate in classroom activities
- Provide help with social skills and facilitate peer relations.
- Ensure the physical accessibility of the school paying particular attention to:
    - Doorway widths & weight (e.g. heavy doors)
    - Stairs
    - Heavy doors
    - Water fountains
    - Distances between classes
    - Aisles between desks
    - Accessible bathrooms

Ages 4-7

- May need help getting up from seated position
- May lose balance when:
    - Bending down to tie shoes
    - Picking something up from the floor
- Can't walk long distances and should avoid stairs
- Steroid treatments may cause rapid weight gain and facial changes

- Psychological effects of steroids
    - Difficulty concentrating
    - Sleeping
    - Controlling emotions
- May have difficulties with language processing
    - May struggle learning to read

Ages 7-11

- Leg muscles grow weaker
    - Trouble walking, standing and maintaining balance
    - Often can't climb stairs
    - Needs help getting up
    - Assistance in restrooms
- Breathing may become more difficult. This may lead to
    - Headaches
    - Mental lapses
    - Difficulty concentrating or staying awake
- Executive skills may be delayed. This may cause problems with:
    - Planning
    - Organization
    - Initiation of tasks
    - Self-evaluation
    - Processing large amounts of information or instructions
    - Responses to questions
    - Verbal expression
- Supportive ideas:
    - Allow oral testing
    - Dictate responses into tape recorder
    - Condense assignments
    - Verbal report instead of a written report
    - Explicit, concrete and specific instructions
    - Minimize written work

Ages 12+

- Children are typically using wheelchairs.
    - Allow extra time to travel with wheelchair

- Problems with complexity or work, and keeping track of assignments

3. **Behavior and Sensory Support**

What you need to know

A few types of muscular dystrophy may present with a psychological complication. It is important to discuss the child's individual issues with the team and treat the child according to the plan developed.

Psychological and psychosocial difficulties

- Fatigue and pain may make psychological problems worse.
    - Fear of pain and joint instability may lead to avoidance behavior.
        - This may make the dysfunction and disability worse.
    - Psychological distress may increase pain.
- Children may be self-conscious of physical differences
- Depression is often associated with chronic pain and disabilities
    - Individuals may feel misunderstood and/or alone
- Other possible psychological problems
    - Anxiety
    - Low self-confidence
    - Negative thinking
    - Hopelessness
    - Desperation

Other considerations:

- Misconceptions of abilities can cause insecurity and anxiety in social situations.
- Physical limitations can cause frustration or embarrassment.
- Medications may have side effects that impact behavior and/or school.

Specific Behavior Concerns for boys with Duchene muscular dystrophy

- Increased incidence of
    - Impulsivity
    - ADD
    - Autism
    - Oppositional/defiant behaviors

    - Aggression
    - Obsessive-like features
        - Difficulty with mental flexibility
    - Depression and anxiety
        - Physical signs
            - Headaches
            - Stomachache
            - Sensitive
            - Changes in appetite
        - May be due to awareness that this is a fatal disease

Other considerations:

- Difficulty concentrating, and controlling emotions
- Poor coping skills
- Rigid and lack of flexibility in thinking
    - Can lead to non-compliance or arguing
- Difficulty with transition
- Emotional moodiness
- Social problems due to:
    - Physical limitations
    - Cognitive delays
    - Social deficit
    - Difficulty identifying and interpreting facial features
    - Lack of practice with social skills
- May be on steroids
    - May make boys more emotional and more active than normal

What you can do

Children who have both muscular dystrophy and psychological complications may benefit from:

- Counseling and support for pain
- Behavioral supports
- Meditation and yoga
- Antidepressants
- Help with adaptation and acceptance of issues and potential limitations
    - Be supportive

    - Understanding
    - Consistent
- Some individuals need support for social skills development

Supportive ideas:

- Make eye contact to help ensure attention
- Be clear and concise
- Provide routine and structure
- Clear boundaries
- Transitions
    - Provide advanced warning of change
    - Visual cues

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4. Physical Activity, Trips, Events

What you need to know

Physical Education:

- It is important for a child with muscular dystrophy to have an opportunity for physical activity to optimize physical and mental health.
- Certain syndromes will have very specific recommendations regarding physical exercise and restrictions.
    - Exercise is important and should be encouraged
    - Individuals may be able to exercise but not participate in contact sports
    - All ambulatory children should participate in gentle exercise to avoid contractures and muscle wasting.
    - Activities can include a combination of swimming pool and recreation-based activities.

- Individuals with muscle pain during or after exercise activity should be monitored for myoglobinuria (myoglobin in the urine).
    - Muscle pain within 24 hours after exercise indicates overexertion leading to rhabdomyolsis (rapid destruction of skeletal muscle)
- Strengthening exercises may cause damage to fragile muscle cells if done too vigorously.
- Moderate and light exercise or standing exercises, undertaken under the guidance of a physical therapist (PT) or doctor is important.
    - This may help maintain muscle tone and flexibility
    - This may help combat obesity and bone thinning.
- Boys with DMD and BMD should not:
    - Lift weights
    - Do push ups and/or pull ups
    - Abdominal crunches

What you can do

- Encourage academic, social, and artistic activities
- Allow child to help with coaching or team management if there are physical restrictions.
- Consider 504 Plan in school for physical activity modifications if appropriate
- Instruct in self-monitoring techniques so child learns to judge his/her own fatigue level during exercise.
    - Provide opportunities for practicing self-monitoring
    - Instruct in relaxation techniques, safety, and breathing
- Consider adapting PE program
    - Downsize equipment – i.e. smaller bat
    - Have a designated runner
    - If activity can't be modified to be safe, have child be a scorekeeper, umpire etc.
- Occupational therapy evaluation may help with accommodations and modifications
- Some individuals may need additional time to get to class

<u>Field Trips:</u>

- If there is to be a lot of walking on the field trip it is important to be aware that it may take the child more time and they may be tired
    - Consider cutting down on walking when possible
    - Use alternative forms of transportation
- Assistive devices are available to improve accessibility and independence in the home, school, automobile and workplace.

5. Absences and Fatigue

What you need to know

Absences:

- A child with muscular dystrophy may be absent due to surgery, illness and/or medical appointments.
- The increased susceptibility to and life-threatening consequences of respiratory infections may cause students to miss many days of school.

Fatigue:

- Medications, may cause drowsiness or lack of energy
- Fatigue may be a symptom of a condition or may be a side effect from lack of sleep
- Fatigue is a symptom of muscle disease
- May fall more and get injured when tired

What you can do

- Help to make transitions in and out of school as seamless as possible
- Allow extra time for assignments and/or provide make up work as needed.
- Make accommodations for resting or taking a break
- Have peers share class notes
- Monitor work so that it is challenging, but ensure goals are attainable and realistic
- Plan for absences and consider tutoring
- Communicate with parents in order to successfully meet these challenges

6. Emergency Planning:

What you need to know

- There should be a plan for an emergency evacuation in children with physical limitations.
- Be aware that some children with neuromuscular disorders may have diabetes.

What you can do

- Develop an emergency plan if necessary, depending on the needs of individual children.
    - For example, the child may have diabetes and need a care plan
- Develop a plan to assist the student with an emergency exit.
    - If possible plan to use an alternative exit to avoid crowding by the other students which creates a potential for injury
    - Assign someone as a back-up to help the student if the primary staff member is out

7. Resources:

Muscular Dystrophy Association

http://MDA.org
An organization dedicated to finding treatments and cures for muscular dystrophy

http://mda.org/publications/teachers-guide
A Teacher's Guide to Neuromuscular Disease

Education Matters (for Duchenne muscular dystrophy)

http://www.parentprojectmd.org/site/DocServer/EdMatters-TeachersGuide.pdf?docID=2403
A Teacher's Guide to Duchene Muscular Dystrophy

http://www.parentprojectmd.org/site/DocServer/EdMattersAdaptivePE.pdf?docID=2401
Adaptive Physical Education – a PE Teacher's Guide for Duchenne muscular dystrophy

The Cooperative International Neuromuscular Research Group

http://www.cinrgresearch.org/aboutnd/diseases.cfm
Information about Neuromuscular disease ongoing research

EndDuchenne.org

http://www.parentprojectmd.org/site/PageServer?pagename=Care_educational_edmatters#sthash.GrB6pZeJ.dpuf
Provides information and ways to connect for families of newly diagnosed, as well as those caring for individuals with Duchenne muscular dystrophy over time
This is a product of the Parent Project / Muscular Dystrophy.

Articles

http://www.biomedcentral.com/content/pdf/1471-2431-10-55.pdf
Physical training in boys with Duchenne Muscular Dystrophy: the protocol of the No Use is Disuse study is an article featured in Bio Med Central (BMC) Pediatrics, 2010.

http://www.muscular-dystrophy.org/assets/0002/6398/Schools_-_DMD_L_d_Behaviour.pdf
Duchenne muscular dystrophy - learning and behavior was written in 2011 by the Muscular Dystrophy Campaign / For Professionals.

Cure SMA (spinal muscular atrophy)

www.curesma.org
A national organization dedicated to the treatment and cure of spinal muscular atrophy

Classroom Accommodations for Students with Visual Issues

Classroom Accommodations for Students with Visual Issues is a resource from Boulder Valley Vision Therapy, P.C. (https://www.bouldervt.com/), in Boulder, Colorado. It describes a variety of variety of issues and offers strategies.
https://www.bouldervt.com/wp-content/uploads/sites/478/2015/12/227-Course-Handout-CCIRA-2016.pdf

Genetics Home Reference

Consumer-friendly information about human genetics from the U.S. National Library of Medicine

SMA
https://ghr.nlm.nih.gov/condition/spinal-muscular-atrophy

Myotonic Dystrophy
https://ghr.nlm.nih.gov/condition/myotonic-dystrophy

Duchene and Becker Muscular Dystrophy
https://ghr.nlm.nih.gov/condition/duchenne-and-becker-muscular-dystrophy

Note: *This printable version does not include the information found under the green button marked "Transitions" on the website. Those general pages may be printed separately.*

Meet a Child with a Neuromuscular Disorder

Believe in Bodhi

His big brown eyes took in the stranger joining him at the kitchen table, then, slowly, a beautiful smile spread across his face. He was soon chatting and trying to share his bagel and mandarin orange. When people meet Bodhi, says his mother Déodonné, he immediately engages them and makes people smile and laugh. "He is really observant and reads people's energy. What he lacks in physical strength, he makes up for in spirit!" Soon, another visitor entered and Bodhi clasped his hands together, bowed his head, and said "Namaste" to her.

Déodonné gets so much hope from his smile and listening to him chatter. When she feels overwhelmed by the future and the challenges it may bring, being with Bodhi brings her back to a hopeful place.

Bodhi. His name comes from the "tree of enlightenment" and speaks to his father's roots in Nepal. Friends and family have joined together to paint an intricate and beautiful mural of a Bodhi tree in his bedroom. Meeting him was such a true honor – his spirit is so full of something very brilliant.

At 18 months, Bodhi is a busy boy. In his early intervention program, he gets PT, OT, and aquatherapy. In addition, a nutritionist comes to his home. He also has a PT and nutritionist through his consultation from a large hospital's children's clinic. To ensure continuity and quality of care, his family coordinates the connections between providers and has organized Skype sessions between their hospital-based team and their local therapists.

Bodhi has started horseback riding on a friend's farm. He really connects to the horse and gently pats her as he rides with his mother. He is working on strengthening his core muscles as the horse shifts Bodhi's weight from side to side, mimicking the feeling of walking deep in his hips.

Bodhi was diagnosed with Spinal Muscular Atrophy (SMA), Type 2 when he was about 12 months old, after his gross motor skills seemed to plateau. SMA is rare, affecting around 1 in 10,000 births, and they know of only a couple of other SMA families in this state.

Bodhi's family has been very involved in his care and raising awareness of SMA. His eight-year-old cousin held a neighborhood bake sale and raised $400 for Cure SMA. Other family members joined the annual Cure SMA Walk & Roll and raised nearly $3,000 for the organization. Their team name was "Believe in Bodhi." They have become involved with raising awareness through both traditional and social media. Their state-wide newspaper featured Bodhi on its front page and the family even got their Governor to proclaim August as SMA Awareness Month.

Déodonné, who was wearing a shirt that read, "Never Give Up," offers some **Advice to Parents** that helped her when Bodhi was first diagnosed:

- **Take care of the breathing**. They use a cough assist machine (Mr. Coughy) every day, paired with tooth brushing. He uses a nebulizer when needed and uses an oxygen monitor for 1 hour/week in his sleep.
- Diagnosis is overwhelming. Take it one day at a time.
- Get involved with Cure SMA. When they reached out to the organization just after his diagnosis, they got a care package with a wagon, a swing, toys, etc. and the organization helped the family attend the annual Cure SMA conference. Although the conference was overwhelming, just after the diagnosis, they learned so much from the SMA specialists, researchers, and other parents.
- Going public is helpful for increasing awareness. "It was like a big weight was lifted," says Deodonne. She added that it is a way of "allowing others to show the best of them to you" as they offer support.

Déodonné offered some thoughts and **Advice for Teachers, Therapists and Professionals**.

- Assume competence in the children. What they lack in musculature, they make up for in their brightness and insightfulness. Assume he will be able to keep up. And don't judge people by how they present or look.
- Be knowledgeable about SMA and learn the methods for handling him to protect his bones during transfers. Partner with the parent to create training specific to that child.
- Respect his dignity and privacy. Allow him to do as much as possible. Ensure his safety from afar and don't insert adults into the mix as he forms relationships and friendships.
- Help him find the right balance, for example, between independence and fatigue.