

Suggested School Accommodations for the Child with Mitochondrial Disease

Scheduling

- Flexible scheduling
- Consider shorter school day/week, especially if ill
- Allow for frequent breaks if needed
- Extended school year maybe needed to prevent regression
- Homebound education may be needed at times

Physical/Medical

- Limit physical demands such as physical education/therapy, writing, and other sustained activities
- Ongoing communication between school and caregivers/medical team
- Follow diet guidelines of doctor/nutritionist
- Provide a private place for meeting hygiene and medical needs
- Provide a quiet, comfortable place for rest as needed
- Be forward looking in providing positioning, communication and other options, knowing the path disease may take (do not wait until the situation is desperate for a power chair, stand assist recliner, or AAC device before beginning to explore the options, especially for funding)
- Climate control is vital in all seasons, some students with mito cannot regulate temperature well
- Constant access to hydration, i.e. water bottle available through out the day (dehydration is an issue in mitochondrial disease)
- Medical devices as prescribed available at school (suction machine, oximeter, g-tube supplies/pump, glucometer and diabetes supplies)
- Student may require LPN or RN consultation, available in the classroom or 1:1 CNA, LPN or RN

Emotional

- Limit emotional stressors
- Work with student/family on stress management
- Be aware of psychological/psychiatric impact of the disease and the way the disease affects the student's and families life
- Provide a support system and counseling if needed
- Work through transitions carefully, the stress of a transition can be lessened if done slowly with appropriate interventions

Staff Training

- Train staff to look for changes in student affect and appearance that may signal an energy crisis or infection
- If student has seizures train all staff in seizure protocol
- Stress importance of universal precautions and caregiver hygiene with all direct care staff to limit possibility of spreading infection
- Limit the child's exposure to students and staff who are feeling ill; insist that sick children and staff stay home and that all members of the school/classroom community participate in hand washing and wear gloves and masks if ill and present in the classroom

Cognitive

- Provide multi-sensory learning supports, especially if there are hearing/vision issues
- Watch for signs of onset of dementia and/or memory loss and report to medical team
- Engage student in challenging but not frustrating educational work

Social

- Provide opportunities to interact with both typical peers and peers with disabilities/chronic illness
- Seek ways for the student to participate in general social events with accommodations as needed
- Direct Instruction (to the student, related to disease)
- Energy conservation strategies
- Self-advocacy
- Instruct others in providing for individual care
- Importance of healthy diet and plenty of sleep
- Transportation
- Student may need curb-to-curb or door-to-door transportation
- Student may need monitor or nurse on the bus or van
- Most students with mitochondrial disease will need a climate-controlled vehicle
- Student may need a limited time on transportation to prevent fatigue

Note: Provide accommodations for vision, hearing and motor challenges as you would for other students with these issues.

Helpful Web Sites:

- Site created by an educator: <http://www.k12academics.com/mito.htm>
- Sample letters to parents and teachers – [Fall/Winter 2001 #3 newsletter, pages 8 & 18](#) (must be an online member at either the free or paid level to view newsletters)
- Bubel/Aiken Foundation – <http://www.bubelaiken.org/Default.aspx?tabid=59>

- A child advocacy/education/IEP self-study course from the PEAL center in Pennsylvania – <http://www.partnersinpolicymaking.com/education/>
- Regional parent training & information centers and their contact info around the country. Helps “families obtain appropriate education and services for their children with disabilities.” – <http://www.taalliance.org/centers/index.htm>
- Some government IEP links – <http://www.ed.gov/searchResults.jhtml>
- Special education links – http://www.thearc.org/NetCommunity/Page.aspx?&pid=214&srcid=1386#special_education
- Educational advocacy links – <http://www.familyvillage.wisc.edu/education/advocacy.html>
- Government guide to the IEP program – <http://www.ed.gov/parents/needs/speced/iepguide/index.html>
- National Dissemination Center for Children with Disabilities - Includes state resources – <http://www.nichcy.org/>
- National Dissemination Center for Children with Disabilities, school issues. Numerous websites included. Learn how to make a video for your child’s IEP meeting by clicking on the link in the “Have you met Alex” paragraph. National Dissemination Center, “News You Can Use.” To view, <http://www.wrightslaw.com/info/iep.video.moody.htm>.