

**Summary - Back to School Tips**  
**Annette Hines, Esq.**  
Special Needs Law Group of Massachusetts

*and*

**Cristy Balcells, RN, MSN**  
Executive Director of MitoAction

**What is Mito?** (slide 2)

- A concrete, working definition of mitochondrial disease to share with teachers, family and community members can help understanding, especially given that Mito has so many unique characteristics even within the same family. Basic Mito understanding can help others make sense of presenting symptoms and symptom variability.
- Fundamentally, Mito is an energy disorder, as mitochondria create energy for the entire body by converting food into energy.
- Any defect in the energy production process renders any system susceptible to symptoms of dysfunction or failure. Organ groups that require the most energy, such as muscles, brain, liver, GI, and neurological systems, tend to be most dramatically affected, but symptoms can manifest in any body system.
- Mito patients need to “plug in” and recharge more frequently and today’s discussion will help families explore ways for their children to do so at school.
- Energy conservation and avoiding overload is vital to planning for academic success.

**Reviewing the IHP -- Individualized Health Care Plan** (slides 3 - 6)

- IHP - Every child is entitled to an IHP, with the level of formality dependent on state and school district. The IHP addresses individual health care needs and is tagged with the IEP (Individualized Education Program) or 504 plan (child with disabilities receive accommodations to ensure academic success, a civil rights accommodation). If an accommodation has the ability to impact access to education, it should be on an IEP and IHP and not on a 504 plan. Medical needs often impact education in medically fragile children. An IHP can be requested by a parent by calling a formal team meeting. Typically, the plan is written by the school nurse. Some districts and/or states require a neutral party to develop this plan. A doctor may be required to sign off on certain safety features of the plan.
- An IHP is an agreement, or contract, that all involved with the child agree to follow. It may include medications, GT feedings, and frequent or prolonged absences, for example.
- The close of the summer is a good time to review changes over the past year, such as: change in classroom from contained to integrated, moving from elementary to middle school, or changes in the child’s health. Updating doctor and medication lists is important, especially when changing schools and staff, including school nurses.
- Resistance with school districts over parental advocacy on behalf of the child is not uncommon. It’s best to keep all involved informed and draw staff in so all are working toward the common goal of finding the best ways to foster learning and academic success.

- The IHP is a vision statement that all understand and accept -- in the ideal setting, the following plan would be implemented by all. Prevention of energy depletion is more helpful to learning than trying to recover a child who has exceeded his or her limits. Productive communication is vital and falls to the parent to keep positive and effective. Stop and choose the things that will most help your child succeed, from the simple to complex, such as:
  - Air-conditioned rooms.
  - Parent-supplied extra snacks and drinks that are with the child at all times. Set clear expectations at Day 1 for snacks and fluids, taking snack breaks on schedule.
  - Backpack with wheels or wheelchair use to save energy for learning. Be smart about converting energy. Explain in terms of a concrete “energy budget” so everyone can better visual how much certain activities cost the child, and how staff can work to save energy.
  - Communication plan -- RNs, teachers, therapists need a plan or location to communicate with parents and each other when needed.
  - Fatigue does not always mean sleepy! List individual child’s cues that staff can recognized as warning signs such as:
    - altered gait/coordination
    - altered speech patterns, including slurring, slowed speech, wording difficulties, volume changes, etc.
    - tantrums or other actions that may look like behavioral issues
    - tremors
    - eyes unable to focus
    - hyperactivity or withdrawal
    - lack of energy
    - cessation of communication
    - flushed cheeks, mottled skin, subtle changes in breathing
    - simply not acting normal for that child
    - Encourage the teacher check in with the child -- how are you doing? Green, red, and yellow lights or happy to frowned face spectrum commonly used for pediatric pain scales work well with children in the school setting. This check-in cues the child to tune in to his/her body and also cues the adult to assess the child.
  - Prioritize the plan -- A 10-page plan may just be too cumbersome for a busy teacher.

**Minimize exposure to illness -- IHP (slide 6)**

- Provide classroom with giant bottle of antibacterial, hand sanitizing gel, requesting that the gel be kept by the door so that everyone uses it as they go in and out of the room. Good hand washing is a must! Many school nurses will offer a hand washing campaign in the classroom.
- Provide bleach-based cleaning solutions to wipe down desks.
- Provide tissues for the class. Donations to the class indicate that the parent is a partner in helping to keep the class as healthy as possible.
- Avoid your child being seated in the middle of the classroom where exposure to germs is the greatest.

- Asked to be notified if there is a known contagious disease in the classroom. Most children with Mito have a difficult time recovering from illness due to the high energy demand illness carries.
- Conversely, a child with Mito may appear ill when he/she is not. For example, a child may vomit frequently due to reflux, or have an elevated temperature due to dysautonomia, yet not be sick and may be better served to stay in school that day, despite the school policies regarding vomiting and fevers.

### **Conserving the Battery - IHP (slide 7)**

- The smartphone's battery is a good, well-known visual to explain a child's energy levels with Mito. A low battery causes some of the higher energy-demanding apps to fail. When a smartphone indicates low battery, users tend to shut off Blue Tooth or close certain apps to conserve what little energy is left in order to prevent the phone from going dead.
- Develop a trusting relationship with the school team by offering effective, practical energy-saving steps. Explain what can happen if the child does not take a break, have scheduled snacks, or becomes ill.
- Schedule high-energy activities at the beginning of the day. PT at 2:30 p.m., for example, may not be productive most days.
- Allow ample time for transitions -- *Stable is more important than schedule!*
- Allow rest periods. Activity -- Rest -- Activity -- Rest (or other quiet activity).
- Schedule snack/water breaks at least every 2 hours.
- Environmental temperature is very important as a body expends great deal of energy in heating and cooling itself.
- Prioritize -- quality is more important than quantity as a goal.
- Shorter (to help with fatigue) or longer (to allow breaks) school days or extended school year are part of the IEP.
- Be flexible with your school district. Schools are challenged by constraints beyond their control. For example, PT may only be at the school between noon and 2 p.m. a few days per week. Both sides need to be flexible.

### **IHP Summary Checklist for Common Issues (Slide 8)**

- Fatigue -- Conserve energy with periods of rest. Allow time for transitions.
- Infection and Illness -- Good hand washing! Provide hand sanitizer.
- Muscle Weakness and Pain -- Use wheelchairs, strollers, or other assistive devices liberally. Hydrate and take breaks.
- Mental Fog -- Plenty of rest, snacks, and hydration.
- GI Issues -- Watch diet closely.
- Overheating -- Keep cool, avoid humidity, watch for abrupt temperature changes. Be flexible with gym or physical education class in the heat (or cold as well).

### **Changes over the summer -- Preparing for the New School Year (slides 9-15)**

- Families often schedule long appointments and specialist visits requiring extra travel time for the summer months. Evaluations, elective procedures, and testing during the summer may alter the IHP and IEP and changes should be communicated to the school team.

- Sharing medical information with the school can be difficult for some as pieces of the information are private, but it does offer the school insight to those working with the child. Medical information, by mandate, must be kept separate from the child's academic record. Medical information must be treated like any other protected medical information. Leaving simple printed material behind can be helpful.
- Sample IEP plans, letter templates, checklists, and protocols can be found on the "Tools for Schools" section of the MitoAction website ([mitoaction.org/education](http://mitoaction.org/education)).
- Share teacher, camp, or home progress notes.
- Update medical information -- give teachers and nurses a small card with all contact information. Allow them to call you at any time of the day with concerns.
- Note any new learning aid or technique that worked well for the child and integrate that tool into the plan for the child's maximum feasible benefit. Also share any techniques that did not work well for the child.
- Summer is a good time to meet the new school aide as the pressure is lower.
- Tour the school to look for obstacles or areas of concern, especially in terms of mobility issues. Are there refrigerators for medicines, stairs to climb, distances to cover between classes?
- Encourage any strides in independence gained over the summer to be reinforced during the next school year.
- Keep school staff informed by meeting with the school nurse and teacher to discuss the above information. The more comfortable the staff is with a child, the less conflict will arise during the school year. LIABILITY is the elephant in the room. Schools are getting sued and teachers and school staff are on edge, pushing some fragile children out of schools and districts due to concerns about safety. Most concerns arise when the child requires a one-one-one medical aide, which becomes a civil rights issues. Schools are more confident with educational issues and less confident with complex medical issues.
- Be prepared to discuss:
  - Accessibility of the school nurse and what the nurse is allowed to do.
  - When needed, advocate for and introduce a private nurse; also have a plan for when the private nurse is unable to attend school.
  - Some schools require a contract for liability with the home healthcare provider.
  - How information will be shared during the school year. Exactly who is doing what needs to be clear.
  - Daily checklists for easy communication work well.
  - Remind everyone that changes can happen quickly in a child with Mito.
  - Emergency procedures for the child in case of fire or other crises.
- Request a free copy of MitoAction's Energy 4 Education DVD, which also can be viewed here: <http://www.mitoaction.org/energy-4-education>.

### **When All Else Fails:**

- Request a team meeting as soon as tensions rise or needs are not consistently being met. Some situations require formality and to be on the record.
- Bring a support person to the meeting (spouse, friend, etc.).
- Ask medical staff to attend to offer their insight.
- Hire an advocate or attorney if needed.

The Back to School Checklist is summarized on the website ([http://www.mitoaction.org/files/back2schoolchecklist\\_0.pdf](http://www.mitoaction.org/files/back2schoolchecklist_0.pdf)).

### **Additional Reading**

[Educational Advocacy for families](#)

[Sample IEP, 504 Plans, Letters and more](#)

The mission of the [Energy 4 Education DVD](#) is to improve a child's success in school by helping parents and the education team to better collaborate and creatively support the child or teen with mitochondrial disease. To request a free copy of this presentation on DVD, email [info@mitoaction.org](mailto:info@mitoaction.org)

[Back to School Checklist that corresponds with this presentation](#)

[Top Ten Back to School Tips for Kids with Mito](#)

[School Tips with Kristen Casale and Cristy Balcells](#)

[Suggested School Accommodations for Kids with Mito - UMDF](#)