

Does your child or student have mitochondrial
disease or complex medical needs?
Do you know how to help?

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“Energy for Education”
*IEPs, Health Care Plans and school
survival tips for kids with complex
medical conditions*

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Kids come in lots of unique flavors

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Mitochondrial disease is linked to many other medical conditions

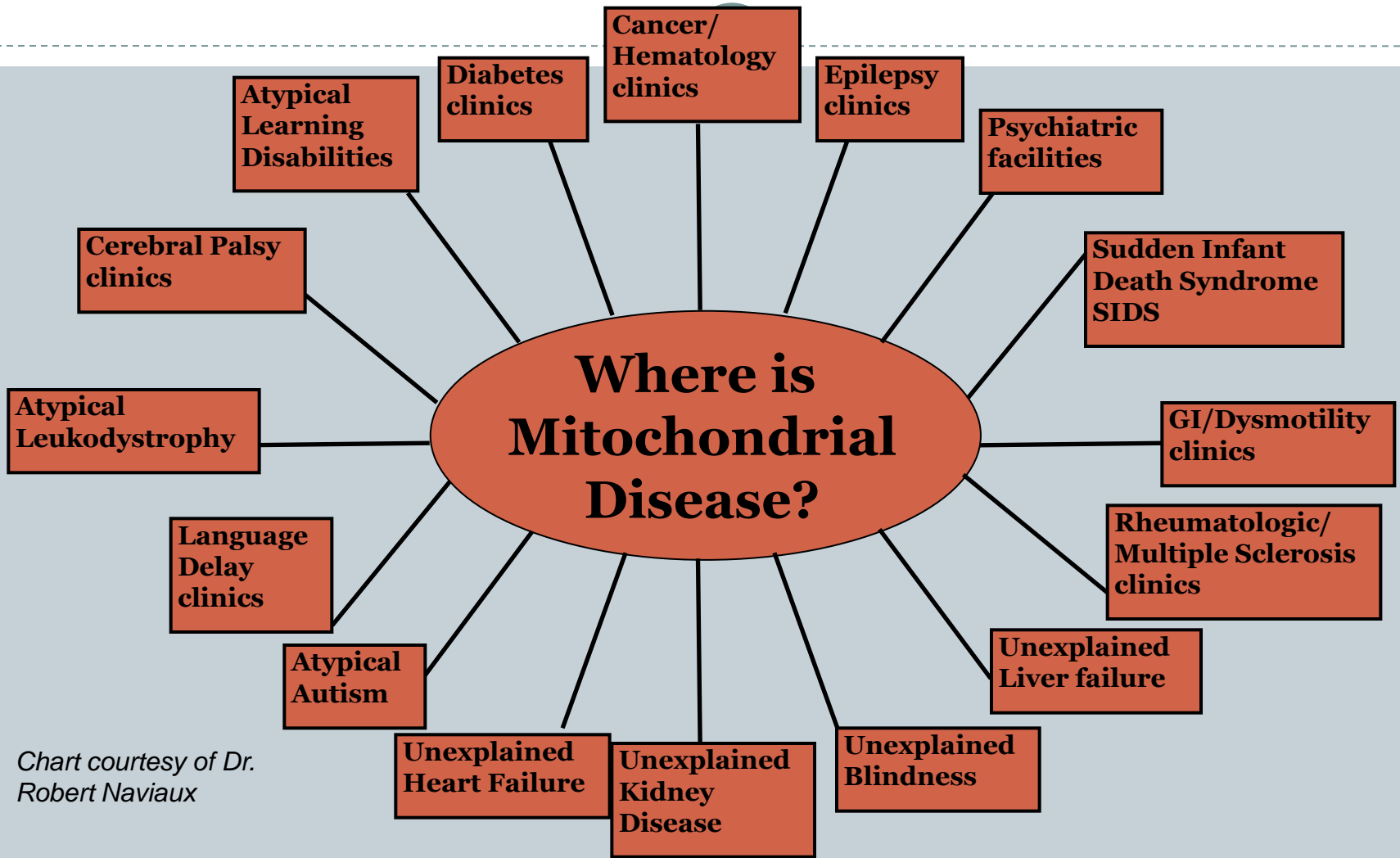


Chart courtesy of Dr. Robert Naviaux

What is Mitochondrial Disease?

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Mitochondrial disease is a chronic, genetic disorder that occurs when the mitochondria of the cell fails to produce enough energy for cell or organ function.



- The incidence is more common than *cystic fibrosis in the U.S. (at least 1:4000 – some say 1:500)*
- Mito can occur in infancy, or develop in childhood or have adult onset in previously healthy individuals
- May be inherited or develop “spontaneously” from an unknown origin.
- Clinical presentation can be very different from individual to individual.

What are some common symptoms of Mitochondrial Disease?

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- FATIGUE and energy depletion
- Poor Growth
- Loss of muscle coordination, muscle weakness
- Neurological problems, seizures
- Autism, autistic spectrum, autistic-like features
- Visual and/or hearing problems
- Developmental delays, learning disabilities
- Heart, liver or kidney disease
- Gastrointestinal disorders, severe constipation
- Diabetes
- Increased risk of infection
- Thyroid and/or adrenal dysfunction
- Autonomic dysfunction
- Neuropsychological changes (confusion, disorientation and memory loss)

IDEA: Individuals with Disabilities Education Act

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- **Ensures all children get a free public education despite any mental or physical disabilities.**
- Includes education as well as speech therapy, occupational therapy, psychological services ,early intervention, and rehabilitation counseling.
- Helps with behaviors or physical issues that impede a child's ability to learn.
- The students cannot be discriminated against due to their disability and are to be given proper accommodation to help them with the learning process.

Meeting UNIQUE Individual Needs

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- IDEA requires that children with unique individual needs receive specially designed instruction
- NCSER meets this promise by systematically exploring how to best design instruction to meet the needs of each child with a disability
- Through rigorous, scientifically valid research, NCSER fulfills the Department of Education's pledge to promote the **highest levels of achievement for all children.**

Institute of Education Sciences, U.S. Department of Education
ncser.ed.gov National Center for Special Education Research

IDEA 2004

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- The IDEA instructs the team to allow the student to begin at highest level of academic achievement and modify down, not vice versa.
- Special education: Proactive vs. reactive?
- An IEP contains accommodations AND modifications to the child's curriculum

NPT, IEP, 504, OHI, IHCP...OMG!

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- Neuropsychological Testing (NPT)
- Individualized Education Plan (IEP)
- Section 504 Plan (504)
- Other Health Impaired (OHI)
- Individualized Health Care Plan (IHCP)

All children, even those with complex medical conditions, deserve the opportunity to thrive in school!

Neuropsychological Evaluations

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- ARE A MUST!
- Should be done prior to aging out of IFSP (early interventions) by age 3
- Carries more weight than medical testing and results shared will substantiate need
- Suggests accommodations and modifications specific to your child's learning style
- Incorporates how daily living activities (DLA) will impact your child's ability to retrieve, retain and repeat educational material

Neuropsychological Testing (NPT)

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- Most importantly, the neuropsych eval is viewed from schools as evidence of the items that are most necessary for the student to succeed academically.
- Parents have a right to third party evaluation *if school and parent do not agree* on testing results done by school.
- Normally repeated every three years or if significant change in medical stability

Neuropsychological Testing (NPT)

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- The testing is either requested by the parent or recommended by a teacher. Initially, the school completes the testing (if parent consents).
- Then, upon the results being reviewed, if the parent is not in agreement with the school's finding a private 3rd party neuropsychologist can be requested at some or no cost to the family (depending on state regulations).
- Getting insurance coverage for NPT testing depends on HOW and WHO submits the test

IEP - Individual Education Plan

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- An IEP is...acronym for Individual Education Plan
- **An IEP is a document that is designed to help a disabled child receive a quality education that he or she would not otherwise receive.**
- **The Individuals with Disabilities Education Act (IDEA)**, established in 1990 (rev. 2004), states that an **IEP** must be established for any child that qualifies for special education services. The [IDEA](#) applies to children between the ages of 3 and 21, and eligibility is decided through an evaluation.

IEP: Individualized Education Plan

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- The purpose of the IEP is...to make an agreed upon educational process/contract by which the student can meet grade level expectations (GLE) with accommodations and modifications to the necessary academic requirements to attain grade level achievements.

Key words: accommodations and modifications-know the difference!

IEP: Individualized Education Plan

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- **The IEP contains:**
 - Child/Student Data
 - Summary
 - Accommodations
 - Modifications
 - Goals.



What else does the IEP do? Ensures the child:

- Is placed in the Least Restrictive Environment (LRE)
- Is able to appropriately access the curriculum

TEAM IEP: Individualized Education Plan

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- Who is the “team”?
 - Director of special education
 - Student’s classroom teacher
 - Parent(s) AND the student if over the age of 14
 - Other therapists, school nurses, advocates, medical professionals, etc. can be included but are not necessarily VOTING members of the team
- Parents rights as team members – parents are VOTING members of the team
- At every IEP meeting, your parental rights and safeguards should be shared with you (state and federal guidelines may change)

Do's and Don'ts of IEP Meetings

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- **Do make a list of 10 items to discuss**
- **Do prioritize and plan to address only 5 of those items**
- **Do consider OHI for eligibility**
- **Do consider a HCP if you have a OHI**
- **Don't go to the meeting with your child's entire medical record**
- **Don't expect everyone to meet your demands**
- **Don't switch to a 504 once an IEP is in place**
- **Remember that “do-overs” can be a positive way to obtain what is necessary for your child**

Do's and Don'ts of IEP Meetings

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- **Do leave emotion outside the meeting**
- **Do type up your IEP responses before the meeting and send to the team at least a week prior**
- **Do separate needs from wants**
- **Don't assume that funding exists for everything your child needs (initially)**
- **Don't expect teams/teachers to come up with all of the accommodations and modifications without your help**

Do's and Don'ts of IEP Meetings

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- **Do spend some time doing your homework and learning special education law**
- **Do solicit outside help when you are overwhelmed**
- **Do have your child participate in a neuropsychological evaluation**
- **Don't forget to provide real-life examples relevant to your child as part of their IEP and HCP**
- **Don't proceed without also collaborating with your child's physician**

Section 504 Plan

- A Section 504 Plan is normally a short term list of accommodations dealing with mobility, transitioning, and access to school activities and buildings in the event of a minor injury or permanent impairment that impedes the child's ability to gain access or attend school classrooms for instruction.

Section 504 Plan

<http://learningdisabilities.about.com/od/df/g/disability504.htm>

Section 504 of The Rehabilitation Act:

is a civil rights law that covers the rights of all individuals with disabilities, not just school-aged children. It prohibits disability discrimination by any program or activity that receives federal funds. For example, it applies to public schools, colleges, and vocational programs. State and local government agencies and programs, public services, are also covered. Section 504 has significant differences from the Individuals with Disabilities Education Act (IDEA).

Section 504 Plan

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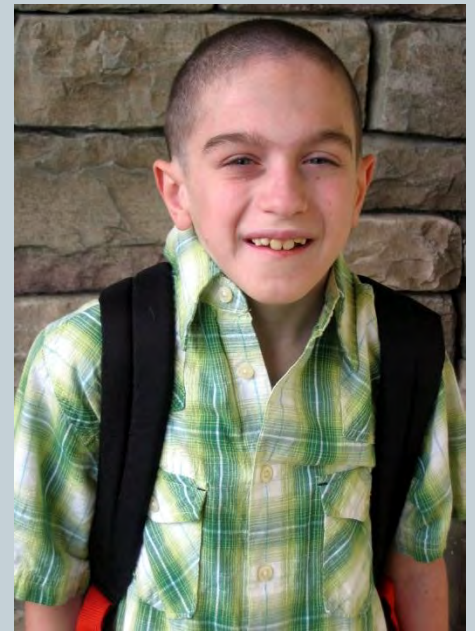
Example:

- A short term example would be a fractured hand on the dominant writing arm.
 - Suggested accommodations would include a scribe to write for the student until the fracture is healed.
 - Long term would be a permanent injury to a limb which limits the child access and ability to write and intake educational material
- The key difference between an IEP and a 504 is the lack of **MODIFICATIONS** to the curriculum. In other words, accommodations only!

OHI - Other Health Impairments

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Other health impairments, known collectively as **OHI**, is an umbrella term that covers several impairments or **disorders that limit a student's ability to learn** in or access an educational environment.



OHI: Other Health Impairment

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- OHI can be used as an eligibility criteria for medically fragile children who will also be served by an IEP
- Why is OHI important for medically fragile children?
 - The OHI dictates the importance of the interference of daily living activities and how they will impact the educational journey for the child that is medically fragile.

Other Health Impaired (OHI)

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- *Developmental delay* is one of the most common placement categories for children with complex medical conditions
- If a child has complex medical needs and IS NOT developmentally delayed, should that child have an IEP?
- YES, because the child is “*other health impaired*” due to his or her medical diagnosis which requires significant accommodations and modifications to make the curriculum accessible to the child in the least restrictive environment possible

OHI: Other Health Impairment

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FROM IDEA:

Other health impairment means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—

- (i) Is due to **chronic or acute health problems** such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; and
- (ii) **Adversely affects a child's educational performance.**

<http://nichcy.org/disability/specific/ohi>

OHI: Other Health Impairment

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- The health impairment must affect the student's educational performance;
- When a child is found to be eligible for special education, he or she will also be eligible to receive related services in school:
 - **medical services**, which are provided for diagnostic and evaluative purposes only, and which are defined as "...services provided by a licensed physician to determine a child's medically related disability that results in the child's need for special education and related services." [34 CFR §300.34(c)(5)]
 - **school health services and school nurse services**, which are defined by IDEA as "...health services that are designed to enable a child with a disability to receive FAPE as described in the child's IEP. School nurse services are services provided by a qualified school nurse. School health services are services that may be provided by either a qualified school nurse or other qualified person." [34 CFR §300.34(c)(13)]

Do's and Don'ts of OHI

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- **Do research the IDEA OHI requirements**
- **Do insist on parent, school nurse and teacher input**
- **Do request an OHI if appropriate (parents)**
- **Don't be afraid to request a change in eligibility to OHI**
- **Don't expect an OHI to be a "free pass"**

Do's and Don'ts of OHI

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- **Do prioritize your child's medical needs and symptoms based on potential severity**
- **Do reflect carefully on how your child's symptoms affect his or her academic abilities**
- **Don't forget to detail your child's symptoms with real-life examples**
- **Don't proceed without also collaborating with your child's physician**

HCP: Health Care Plan

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A health care plan is similar to an IEP as it offers the students data, diagnosis, possible medical side affect, mode of handling the medical issue, and who is responsible for the child to reach the pre-set medical goal.

- Sample Health Care Plan (handout)



HCP (Health Care Plan)

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- For children who have or are at risk of having developmental, emotional, behavioral or chronic physical conditions and require extensive health and other related services
- The **HCP** can help to ensure that a child's medical requirements are properly met during a school day.
- Contains pertinent information regarding the child's health and health needs.
- Includes people who are responsible for the monitoring of any special health needs whether during transportation to and from school, while at school or during field trips, after school care or at other after school activities, sports or clubs.

HCP: Health Care Plan

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- A HCP is used often with medically fragile children as a tool for school nurses, teachers and physicians to appropriately communicate the day to day medical management of the student while attending school
- The HCP **MUST** be signed and approved by the child's physician, typically the pediatrician or primary care provider

Examples of Accommodations

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- Truncated day due to fatigue
- Enlarged fonts
- Scribes
- Transitional aids and class layout
- Assistive technology usage
- Food and drinks allowed throughout day
- Harder academic classes/therapies in morning
- Tutorial use as based on a certain number of days absent

Examples of Modifications

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- Limit unnecessary writing once concept is mastered
- Reduce number of math problems once concept is mastered
- Reduce length of written essays to convey necessary information
- Reduce curriculum to represent master of concept, as opposed to "busy work"
- Break larger projects into manageable sections
- Offer verbal responses as opposed to written for tests and quizzes

Assistive Technologies

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Assistive Technologies are “life useful” adaptive, assistive, educational, and tutorial devices that allow a person with special/medical needs and or learning disabilities to properly access information and perform tasks that they were unable to accomplish.

EXAMPLES:

Vision: magnifiers, vision software, screen magnifiers, readers, scanners, embossers, Braille accessories.

Learning: Readers, writing tools and accessories, visual learning cues, auditory learning software, teacher aides, kinesthetic objects, voice recognition typing software

Assistive Technologies, cont.

Hearing: Amplified phones, TDD/TTY's, amplification devices, alarms

Keyboards and Mice: Large print key boards, trackballs and joysticks, touch pads, one handed keyboards, scribes

Mobility: voice recognition, touch screens, Head/Eye supports, controlled input, word prediction

Ergonomics: Ergonomic mice, keyboards, chairs, keyboard mice and trays, leg stools for rest while sitting

Assistive Technologies, cont.

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Work areas in school: padded chairs, desks with changeable height, desk fans

How does someone request an Assistive Technology Evaluation? A simple written request to the special education liaison, or department of your school district that handles assistive technology requests on behalf of your child.

For more information on Assistive Technology Information Links please use these sites: The National Assistive Technology/Technical Assistance Partnership (NATTAP), [http://www.resna.org/Assistive Technology Quick Information](http://www.resna.org/Assistive%20Technology%20Quick%20Information) <http://trace.wisc.edu/resources/at-resources.php>

Energy In > Energy Out

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Recharging the Battery

$$2 + 2 = 3$$

Cornerstones to care:

1. Energy conservation
2. Hydration
3. Nutrition

Team approach to:

- Fatigue
- Preventing illness
- Managing stress
- Temperature Control





What does FATIGUE look like?

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- Not just sleepy!
- Can be manifested many ways:
 - Irritability
 - “Meltdown”
 - Avoids eye contact
 - Slurred speech, drooling
 - Difficulty communicating or responding
 - Ataxia, or other fine motor/gross motor issues

Temperature Control

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- Control the ambient temperature and humidity at school and at home
- Air-conditioning during the summer
- Do not overheat in the winter
- Avoid rapid fluctuations in temperature

Infection Prevention

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- Since infections are often associated with unusual weakness +/- lethargy, a prolonged recovery time, and/or serious symptoms:
 - Keep vaccinations up to date
 - Seasonal vaccinations
 - Common sense precautions (avoid exposures)
 - Regular hand washing
 - Caution with exposure to other children and large groups

Stress

Increased stress means extracellular work and higher energy demands

- Causes of stress
 - physical exercise
 - infection
 - fever, high ambient temperature/humidity
 - ***don't underestimate emotional stress***

Great resources for more info

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- www.MitoAction.org/education
- www.wrightslaw.com
- www.Specialnews.com
- www.nichcy.org

More resources online

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- Go to www.MitoAction.org
 - → School Advocacy
<http://www.mitoaction.org/tools-for-special-education>
 - → About Mitochondrial Disease
 - → Energy 4 Education DVD
<http://www.mitoaction.org/energy-4-education>
 - Speaker transcripts/podcasts →
www.MitoAction.org/blog and
iTunes podcasts (“MitoAction”)