

Summary - Becoming an Advocate Dr. Mark Korson and Maggie Orr

Becoming an advocate - for yourself or a family member who has complex medical needs like mitochondrial disease is not really a choice - it is a necessity. There is no special training for this difficult process. Patients and family members need help to become the best advocates they can be in order to get the best care and results for themselves or family member. Two experts from Boston's Floating Hospital for Children, Dr. Korson and Maggie Orr, share three scenarios which can help demonstrate the role of advocacy for those with Mitochondrial Disease.

Scenario 1: Newly diagnosed patients

When an adult patient or parent of an affected child receives a new Mito diagnosis there may be initial relief because there is finally a name for the diffuse and complex symptoms. The caregiver needs to remember that this is just the beginning of a journey - "a marathon, not a sprint". The emphasis must be on taking care of yourself in order to take on the long-term role of advocate. *Don't underestimate the value of getting some exercise, having a routine, eating well, laughing, taking deep breaths to relax, and surrounding yourself with positive people.* While important for anyone, these "little things" are actually critical for those of us who struggle to find a "normal" life while dealing with mitochondrial disease. Those little things can also be the *most difficult* to obtain for any family affected by mitochondrial disease. However, as much effort should be placed on figuring out how to improve your quality of life as is on something more tangible, such as fighting for disability, school services or insurance coverage.

The focus following a new diagnosis is typically about "What do I do now?" When you have a medical appointment, you (parent/patient/caregiver) know best what the current symptoms are and you must start there. Try to:

1. Separate the urgent from the non-urgent symptoms.
2. Don't take on all of the possible symptoms that might crop up in the future; concentrate on what is important now.
3. Discuss an ongoing issue that has not yet been addressed or a time-sensitive issue like up coming surgery.

Ideally, you can determine in writing daily goals and weekly goals and link those with appointments that are already set up; that way when you see clinicians, you can discuss your concerns. In this age of accessible information, you are expected to and should educate yourself about your condition/symptoms, but you don't have to learn everything at once. Approach the information as a giant cookie that you can bite off one piece at a time. Some patients take notes so they can ask their healthcare providers specific questions. Use examples whenever possible to describe symptoms or provide a reason for the question.

The internet is a tremendous resource - do go on the web to search for information but limit your time online. There is a tendency when there is a new diagnosis be online for

literally hours and hours to research everything that has ever been published. Dr. Korson and Maggie Orr agree that this is not the best approach. Research, but keep a balance. Don't become overwhelmed. Connect with others offline who can discuss the diagnosis with you.

Scenario 2: Overwhelmed

Once patients and families have moved past the initial diagnosis (and the intensive and very medically-oriented process of obtaining a diagnosis), they often become overwhelmed. Most patients with mitochondrial disease have complex issues...multiple symptoms, variable presentation of the symptoms, and fear about progression of the disease. There always seems to be so much to know - understandable since the disease is so complex and affects many organs/systems in so many different ways. Yet there is still much we don't know about the disease and many questions may go unanswered. Also, because Mito is a fairly "new" disease, providers may not agree on treatment options. This puts you, the patient/advocate, right in the middle. In other words, what *should* happen, doesn't always happen.

Remember this is a lifelong journey. Parents, caregivers: take care of yourself *and* your child or spouse. If you do not, you really will not be able to care for others.

Dr. Korson shares an analogy. In the spoof on hospitals called *A House of God*, there are a series of rules. The first rule for a new physician to follow is that when faced with a person in cardiac arrest, the first pulse that the physician should take is his or her own! This rule applies to anyone in the role of advocate (even a self-advocate); take time to rest and self-assess or you will burn out! In times of crisis, is it perfectly ok to go "all out"; this is a short time frame, a "sprint". When the crisis is over, go back to pacing yourself. Patients with Mito must learn to pace themselves - and advocates should do the same.

Learn to prioritize. You do not have to deal with all the issues all the time. Very few decisions actually have to be made immediately. Mitochondrial disease is a chronic condition. In most instances, there is time to consider all options. For example, when receiving expected mail from a clinic or school, you do not need to run to the mailbox and open the letter right there. You can set the letter aside and pick it up again later. Take the time to sit down, have a cup of tea, relax...then face the news calm and focused.

Sometimes the clinics have staff that can also assist you. While at your appointment, ask whom you could contact if you have an issue that needs support before your next visit. For example, if you have an issue with scheduling appointments, ask for help from the administrative staff. If you are concerned with care coordination and getting multiple plans working together, ask if there is an opportunity to speak to the nurse. Prioritize and discuss urgent medical issues with the physician. The goal in this process is to seek support from many resources and to try to get help. Whenever possible, try to anticipate areas which you may need support before you are in a crisis...for example, if

you know that your child might need a surgery for tubes in her ears in a few months, let the nurses and doctor know well in advance that you are hoping that they can connect with your primary care doctor to help you advocate about the best protocol to follow for the surgery.

Talk to those you trust and surround yourself with positive people, and trust yourself. You will always find others who have used treatments or options different from those you have chosen to use - do not second guess yourself!

Scenario 3: Overly Aggressive

With Mitochondrial Disease advocates do need to be assertive; providers often do not agree, sometimes do not respond, and sometimes do not do what you need to have done in a timely manner. Assertiveness can mean getting better care because that means you actually go after what you need. Because there are so few clinics that deal with Mito patients, those that do are overwhelmed.

But, when advocates (and patients) become frustrated, this assertiveness can become abusive and this abuse is often misdirected toward staff, nurses and doctors. It is understandable that families get frustrated, but try not to burn your bridges. These same people at the clinics are the ones who ultimately will be there to help you.

Some parents bring reams and reams of articles to their doctor and ask that the provider read it all. Truly, this is an unreasonable expectation. MitoAction's [Clinicians Guide to Mitochondrial Disease](#), written by Dr. Korson and Margaret Klehm RN NP, is purposefully NOT published in book form or in a journal. Available online and searchable by chapter, the clinician's guide is organized so that patients can look at just the section they need, print off just that section and bring that to your physician (and guide him/her to the site). For example, if GI symptoms are your main concern at this visit, then print out just that section. If you or your child has an upcoming procedure, then refer to that section of the guide. It is much more likely that a provider will actually look at and read just a few pages relevant to the issue at hand.

Unfortunately, sometimes even advocates with the best intentions can bring negative attention to themselves or their family. Because you may use multiple providers and different hospitals, the patient or parent (often the mother) becomes the central source, or "gatekeeper", of all information. Some providers may wonder or question why this information is always coming from the parent rather than another physician. They may not understand and question why you, the advocate, are so knowledgeable and why you focus only on certain symptoms. Providers cannot always tell the true accurate, informed advocate from the distraught, uninformed parent. To guard against this, Dr. Korson has a few simple recommendations. Keep a journal and bring it with you to appointments. Document the highs and the lows in a typical day and week in order to help demonstrate when and how symptoms occur, and that they may be variable or difficult to detect. The MD sees the patient for only 1/2 hour at most, so get other independent observations if you can. Written observations/reports from teachers, OT, PT, coaches or others who see your child and lots of other children on a regular basis will be very helpful. For example, "this child is really different from the others his/her age - he/she gets tired and cannot keep up with the others." This kind of information

helps to validate the advocate's observations and removes any perceptions of "suspicion" about an anxious and over-concerned caregiver.

As an advocate, you probably know at the beginning of a process what needs to or should be done, yet you may find that the more you push, the worse the results may be. One way to accomplish your goal (rather than demanding that something be done) would be to sit down with the provider(s) and discuss all the potential options. Go slowly and discuss carefully why certain options will not work and why others will. Hopefully, this will lead to the option for care that you want - and the health care provider will "own" the idea with you.

Always be thinking about the long-term value of developing relationships with physicians, schools and others. Nurture these relationships. Of course, you have legal rights, but remember, these rights are moderated by people. It is always better if plans are a team decision rather than a reluctant response to a demand. Give the team the benefit of the doubt and believe that everyone is working hard and trying their best. The saying you "catch more flies with honey than with vinegar" requires patience and thoughtful approach by the person/patient who is in the role of advocate. Some parents or patients interpret this approach as "giving up", and feel that if they are not "fighting" for better care then they will be defeated. In fact, the advocate who is an active and valuable part of their or their child's/family member's team is the true leader and likely to be more successful in getting the best possible care and outcomes. Being patient, thoughtful, and encouraging in those relationships with the people and healthcare providers (who are often the source of frustration and bad news!) is a challenge but is so critically important.

Questions from listeners:

What is the best way to inform physicians who may not know very much about Mitochondrial Diseases?

There are very few mitochondrial specialists, so it is probable that your physician will not know a lot about Mito. When you are looking for a physician, look first in large academic medical centers - it is more likely that these health care providers will have at least a familiarity with Mito. Then look for (and ask for) a provider who likes to think before he/she speaks, who likes complex cases, and who will not mind if the patient is seen/cared for by several different physicians, not just one. When you first meet the physician, explain the use of lots of providers again - and explain why. Use the clinician's guide that was referred to earlier, but only small sections at a time.

Specialists are seen infrequently by advocates and patients. There is never enough time to discuss all the "saved up" issues. How do you prioritize?

Prepare a BRIEF summary (one-page maximum) before you go and give it to the physician. Even better, prepare it ahead of time (a few days or a week), and give/send to physician or nurse so they can review it before your visit. This gives them a "heads up" on the issues you are most concerned about and can shorten the time it takes for

them to take a history. Make this a quick update - nothing lengthy - but something that will allow the physician to focus and understand the patterns of the medical issues that are most troublesome. Avoid emotional statements in this summary. Avoid venting and listing all the reasons that you feel that the symptoms are present. If the summary goes on for 5 or 6 pages, then it is too long. Be concise; even just listing the topics can help focus the visit.

What if your clinic/physician is not open to this?

Then write this summary for your own use before the visit and hit only the important points. If being an advocate were your job and the patient (even yourself) were the company, then you are the CEO. Prepare for the meeting as you would for a meeting of great importance in the corporate world. Direct questions to the appropriate sub-specialist whenever possible. Always ask for help.

How do you handle diplomatically telling a doctor what to do or not do for the patient? For example, certain medications are not recommended for patients with Mito.

If you know this is going to be an issue, bring up the point and provide written information from the guide or some other source. You can also ask that the specialist to call the Mito MD to "double check".

When there are multiple physicians involved who are in close proximity to each other (same building), yet still do not talk to one another, how does the advocate ensure the best treatment for the patient?

This can be difficult, especially if they are not doing it now. Perhaps at the time of the visit you can ask the physician to check the record right there on the computer in front of you. It would be a good idea for you to have a copy of the relevant pages of the record yourself if possible and to keep and have a journal with you. You can then point out, "This is what Dr. J. said..." This may still not improve communication, as this is nationwide one of the greatest challenges for all patients.

Another suggestion would be to use a coordinated care team or a palliative care team. This then takes the advocate out of the middle of any controversies. It also decreases the stress for the advocate. Many hospitals have these kinds of teams available - just ask. A social worker, child life specialist, or even a chaplain can be an important relationship and player on the team as well.

Many people think that palliative care is only for those with end of life issues, but that is often not true. Palliative care is about providing quality of life for diseases which have no cure, and Mito certainly falls into this category. If this is not available, try to find others at your clinic/hospital who can be your patient's champion so that you are not the only person who is aware of what is going on. Share the advocate role! Even if you don't see the immediate value in these relationships, it is very important that there are many people who know you and your family and feel invested in your care.

Sometimes in the inpatient setting multiple specialists offer different (and opposing) treatment options. What do you do about this?

Ask for a team meeting where essential components are all brought together and a decision is hammered out so that you, the advocate, does not have to decide or the attending service does not have to choose. Don't allow others to put you in a position where you have to be the gatekeeper or make decisions between conflicting advice. Use "I" statements that reflect your discomfort with this position, such as *"I don't think I can be the one to make this decision alone and I don't feel like I have the strength to call all of the doctors and figure this out. I need help with this."* Here's an important clarification that relates back to the idea of bringing people together as a team to advocate for the patient. You may feel that you DO have the strength, skills, knowledge, etc. to make the decisions, and to coordinate the doctors! Great! You will be a great advocate. BUT you must bring others into the decision making process and DO NOT let yourself ever be put in the position of being the sole gatekeeper of all of the information. This puts you and your family at risk for misinterpretation of your role and your intentions, and could be detrimental to the relationship and trust that you need to have with the team.

How do you negotiate school concerns and/or the college admissions process when the student/applicant has Mito? How and when do you discuss health concerns?

For students entering college, go to the College's Disabilities Services Office. This can be done even while you are in the application stage. There are legal rights that students have to accommodations - so find out just what these are and what you need. The intermittent nature of Mito symptoms can be difficult to describe, but try to give them an idea of whether the symptoms occur several times in a day, once daily, once a week, or once a month. Do not give them the entire list of Mito symptoms - just what the current active symptoms are or the symptoms/issues that will affect their ability to access the curriculum. Give them details on these, however, because the more they know, the more they can help.

In addition, there are extensive and excellent, practical resources on [MitoAction.org's](http://MitoAction.org) [education section](#) (for example, you can find a sample IEP, letters, daily health checklists, templates for school health plans, explanation of the laws, etc).

SEE THE BOTTOM OF THIS PAGE FOR MORE USEFUL WEBSITES!

The following article was written by Theresa Couture, MitoAction co-founder & Chairperson Emeritus

Just when I think I am getting a firm handle on my life, another medical issue hits and knocks me off my feet. I can't seem to regain or maintain any balance in my life!

When you and/or your child learn about the diagnosis of Mitochondrial Disease, it can be extremely frightening. As time goes on you will begin to develop some perspective and distance from the initial shock of your diagnosis. Bills will need to be paid, laundry done, birthday's celebrated, holidays respected - in other words life will go on. For patients or parents who are dealing with this for the first time this may be hard to imagine but ask a "Mito" veteran and assuredly it is true. This is when the questions about, "how do I live with Mito" begin to get asked. "How do I get off this roller coaster called my life?" To some extent, the ups and downs can't be avoided, but there are some things you can do to gain some control and lessen the disruptions caused by these ups and downs. It may take some work but it will be worth it.

The following three strategies can be effective in reducing the degree of disruption caused by the ups and downs of living with mitochondrial disease. Even doing just one of them can allow you to step off the rollercoaster or at least control the brake pedal!

Control your information flow

Control your responses

Control the quality of your life

Control your information flow

Choose how you want or need to receive non-emergency medical information. This is usually never considered but can become essential in developing quality in your life. Here is one example about a parent but adults can relate to it as well:

A mother of three children affected by Mito disease begins her day, not your ordinary day, but a Mito-ordinary day! Just when she thinks things are under control and she is getting the hang of it, the phone rings and the neurologist tells her that the EKG (electrocardiogram-a tracing on paper that shows the electrical activity of the heart) from one her children's sleep studies showed an enlarged left ventricle. The mother has 101 questions, and the neurologist cannot answer 50 of the 101 questions. He tells her he will need to call the other doctors to gather more information, and suggests she make an appointment with a cardiologist. Mom agrees, hangs up the phone and understandably panics! Her thoughts become consumed by this new information. She calls her husband and tells him what has occurred and he asks her 102 questions.

Anxiety and some panic takes over and they begin to research articles, they go on-line to search "enlarged left ventricle" and on it goes...crisis mode kicks in! She forgot about the shopping she was supposed to do, oops! She forgot the therapy appointment for one of the other kids, never made it to the bank, you get the idea. This is the roller coaster of mitochondrial disease.

This is how most of us receive our medical info but it doesn't have to be this way. Quite

a few people were out of the loop in this verbal exchange: the primary doctor, the metabolic specialist, the cardiologist. By creating a rather formal method of information dissemination the parents can help to control the non-emergency ups and downs that go along with having a mitochondrial disease. The goal is to give your primary doctor the opportunity to become an expert along with you in your mitochondrial disease.

When you become the case manager and the only expert in your care, the primary care doctor is left out of what is their primary role. They are busy, but there are many doctors who've really want to take the initiative and learn about mitochondrial disease but have felt out of the loop. If they receive information about your abnormal EKG reading from you, it leaves them at loose ends as to what they can do to help you.

They will always be one step behind where you need them to be. The medical system is extremely challenging to navigate: the more complex the care, the more difficult the navigation. One way to have your physician become a partner with you and your family is to schedule a meeting to talk to them (this can be on the phone or it can be face-to-face). Explain to your physician that you would like receive non-emergency medical information and results through them: the who, what, where, when and how. Have a pad of paper to write down what's being told to you. This will give you something to refer back to when questions come up. Sometimes as patients or parents, we become anxious about the information that's being given to us and we may only hear one quarter to one half of what the medical profession was telling us. Having something to refer back to will help to control any anxiety you may have over thoughts that sudden pop into your head.

In the case above, the pediatrician could have spoken with the neurologist, received a copy of the test results, and contacted the metabolic specialist about what cardiologist was working with the mitochondrial clinics. They then would make their recommendations to you based on a review of the information. This allows the pediatrician to become increasingly knowledgeable about mitochondrial disease and about your child specifically. Patients and parents do become the experts in their or their child's disease. BUT they shouldn't be the only expert.

To take this from a more altruistic point of view, when your doctor becomes more knowledgeable about one child, it expands the professional's knowledge about how mitochondrial disease can impact the lives of other children that might be in their practice. Having a little-known disease, like mitochondrial disease, can be a lonely place. By involving more of the professionals that are involved in the care of you and/or your child you expand the circle of support that your family will receive and, like a pebble in a pond, the ripples will extend far beyond just you and your child. If you are fortunate to have a physician/pediatrician who is willing to get involved in the care of your child, encourage them to become empowered and to become a partner in care with you. If your physician/pediatrician is not willing to work in a partnership with you, you may need to consider finding one that will.

Control your responses

When you hear new information one of the things you can ask yourself, "is anything bad happening right now.", "is there anything I can do to fix this situation right now?"

If the answer is no, then go forward with your day. If you had planned to take your child to the park, go to the park. If you had plans to go to dinner with your husband, go to dinner with your husband. If you planned to go out with friends, by all means go. This is obviously not as easy as it sounds. Over time, you will get better at this. These very steps will help you ensure that you have quality in your life.

Long-term stress can have a tremendous consequence on your own personal health, on the health of your child and the health of your family unit. In the Mito world, never underestimate the effects that psychological stress can have on a person's fatigue and symptoms. You have a choice and must choose to not function in your everyday life as if every situation was a crisis.

Control your quality of life

Another strategy that may help is to teach yourself is how to compartmentalize through visualization new and overwhelming information. As an example, begin with closing your eyes, imagine a filing cabinet, see yourself pulling open the drawer of the filing cabinet and placing inside it a visual picture of this new information, see yourself closing the filing cabinet drawer. Then imagine a to-do list entitled filing cabinet. Imagine writing down what you put in that filing cabinet. This will give your mind control over the information you receive so it won't become engulfed by the information. Of course, at some point you will need to open that filing cabinet and take the information out, look at it, study it and see how it fits in with your family and see what you have to do with it and if there are things you can do to address it. There will be times when you will be able to cope with that new information and there will be times when it needs to be put aside to be coped with at a time that you are better able to deal effectively.

USEFUL WEBSITES

National:

- www.ada.gov/ The federal government's ADA website: everything you ever wanted to know about the Americans with Disabilities Act.
- <http://school.familyeducation.com/special-education/ada/38436.html> **Attorney Robert Crabtree's Special Ed Advocacy: Nine Rules of Thumb**
- Massachusetts:
 - www.fcsn.org Federation for Children with Special Needs, umbrella organization of groups working to improve the lives of children with special needs in MA. FCSN is also MA's parent training and information center. Excellent website; advocates available to answer questions about school issues. FCSN offers advocacy workshops and training for parents. Dynamite conference in Boston every March.

- www.mass.gov/dds The state Department of Disability Services' website. Information about agencies that work with DDS and services available.
- www.mass.gov/masshealth Information about Massachusetts Medicaid. Be sure to ask about CommonHealth, the program for people with disabilities, and MSCPA, premium assistance for people on CommonHealth who also have private insurance.
 - <http://massfamilyties.org/index.php> Family TIES of Massachusetts provides parent-to-parent support, information and referral services, and workshops to ensure that parents feel confident in caring for your children with special needs. Produces an annual resource directory that is a must have if you live in MA and have a child with special needs.