

Summary - Get More From Every Doctor's Appointment!
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Introduction: Today's discussion is led by two professional women who are quite experienced with mitochondrial disease. Kathy Rivers is a pediatrician, who has mitochondrial disease, and a mother of three children who also have Mito. Cristy is a nurse and author of Living Well with Mitochondrial Disease, whose daughter, Eva, has Leigh's Disease, one of the many specific mitochondrial disorders. (slide 2)

The need for an effective working relationship with health care providers is vital to good medical care. Patients need doctors for diagnosis and management of care, and doctors need patients to provide accurate information. Most Mito families average 2-3 complex doctor appointment per month with each requiring an extraordinary amount of time and energy to simply get ready for the appointment, let alone the visit itself - the drive, the parking, the waiting, the anxiety, communicating with various professionals, and answering of many complex questions (slide 3). Doctors are a vital part of a health care team, especially with families facing complex, chronic medical needs.

Mitochondrial disease is a frustrating disease with multiple symptoms, complex diagnostic paths, regressions, and often a lack of progress, ultimately rendering coordinated care difficult for both the family and the doctor. Planning medical appointments and ongoing care of a single Mito patient, adult or child, can become overwhelming, yet often multiple family members may be affected with Mito, intensifying the fatigue levels and number of complex medical appointments.

Today's Health Care Climate has changed dramatically over the past 10 years (slide 4). When working with families, Cristy noted a discord between what was possible to be done for the mito community and what was actually being done to provide the best care, fueling her motivation to work tirelessly to improve care for these patients. Awareness and advocacy for mito has increased, but, unfortunately, changes in the medicine hinder continued progress for all with complex medical needs. The new health care reality places incredible productivity pressure on providers - pressuring and shortchanging the time required to carefully consider all the ramifications of a disease and its symptoms.

Physicians today can be compared to car salespeople - being required to treat more and more patients each day regardless of the complexity of the cases and with punitive measures in place if the required number is not met. Funding for nurses and other support staff continues to be cut. Mito specialists are few in number and are overwhelmed by the numbers of new patients. Mitochondrial disease patients have complex needs that often can fall to the bottom of the pile because no easy solutions exist. Patients and families, therefore, need to take better charge of health care and get the most out of each medical appointment, without laying blame in one area. Becoming that advocate can be especially hard for adult patients who must deal with their own fatigue and symptoms, yet still be the "office manager" for their complex care in order to get the most of out of physician interactions (slide 5).

Most people who have Mito or a child with Mito have no medical background, but very quickly are forced to become the experts on living with mito, at times knowing more about the disease than most physicians. The goal to be a partner with the doctor, bringing valuable information to the table, can be tiring, difficult, time consuming, and expensive.

Steps to enhance communication and get the most from medical appointments:

1. **Get organized** - Make medical appointments as worthwhile as possible (slides 6-8).
 - Prioritize based on doctor specialty, taking different concerns to a Mito doctor as compared to a GI doctor, for example. Stay focused on the physician's specialty or expertise. The GI doctor may not be as interested in, nor have the best treatment options, for cardiac symptoms and time would be wasted exploring options outside the specialist's area.
 - Ask: What is one goal I want to get out of this appointment? Write down that goal so it's not forgotten during the appointment. Keeping that goal as a focus leads to a better result.
 - Make a list of symptoms, organized by priority.
 - Make a list of questions, also in priority order, highlighting 3-4 questions that are most important. Make a copy of this for the doctor and take a few minutes at the beginning of the appointment jointly deciding which questions need to be discussed first. The doctor may also have his/her own list of concerns (new labs, test results).
 - Realize that a second appointment may be necessary to address all questions and concerns.
 - Consider asking for an extended appointment when many concerns need to be discussed. Scheduling appointments for the beginning or end of the work day may give the doctor more flexibility with time, but expecting an hour discussion during a 15-minute time slot will likely not meet everyone's needs gracefully.
 - Do not go to the appointment until both parties are ready (Slide 9), having gathered all the information needed for success (referrals, lab results, transfer of records, etc.). Ask what is needed and also follow up to be sure all has been gathered or sent and received before the day of the visit.
 - Be willing to reschedule for "bad days." Low energy days hinder getting thoughts out as well as processing new information. Illness and associated medications may change typical presentation, clouding the doctor's assessment of how best to treat. Dr. Rivers recalled a visit to an orthopedic specialist after giving her daughter Valium for severe seizures. Valium altered her daughter's tone, making baseline spasticity impossible to evaluate and the entire appointment a waste of time for all involved.
 - Ask for a cancellation appointment to possibly get an appointment more quickly.
 - Avoid Emotional Responses - Step back and try to remain calm and non-emotional when getting ready for and during your medical appointment. Viewing appointments more like a business meeting allows the patient to detach from some of the emotions. Play the role of being "hired" to get this job done - the job of planning and executing the medical visit for yourself or your child. Medical appointments are difficult because patients may be exhausted by just the process of getting to an appointment and emotions suddenly just flood out, especially when forced to face complex, unsettling

matters. Advanced preparation will help guard against unwanted emotional responses.

- Begin with **TODAY** when feeling overwhelmed (slide 10). Do not think about all the past issues, symptoms, etc., but rather start the visit with what is going on NOW and the current needs and then work backwards. Going through an entire complicated history from day one may both exhaust the patient and overwhelm the physician. Mito symptoms are always changing, so stick to what is important today. Use tools to help organize symptoms, diet, medications, etc. Last year, a graduate student developed a free Mito App for Apple devices that allows day-by-day symptom tracking which can then be emailed or can be made into a chart (<https://itunes.apple.com/app/mitoaction/id527800830?mt=8>). Tracking symptoms shows trends that may otherwise go unnoticed.

2. **Medical Information Sheet & Medical Binder:** (Slides 11 - 13)

A) Develop a personal “elevator speech” or a short, 15-second paragraph that explains mitochondrial disease and most relevant individual symptoms or issues. Write it down, then practice saying it. A simple example could be: “I have mitochondrial disease, which is a genetic defect that hurts my ability to turn food and fluids into energy, therefore, I suffer from fatigue and muscle weakness. Keep it simple, yet also have supplemental materials at hand. MitoAction’s web site offers an abundance of quick print information as well as the Clinician’s Guide. Print out just one page at a time, only printing pages that are relevant to personal symptoms

B) The **Medical Information Sheet** allows you to document all of your relevant data, and avoid the need to recall the information during an appointment or emergency. This template, as well as the template “Effective Appointment Handout,” are available on the MitoAction website in Word:

(http://www.mitoaction.org/files/Handout%20Effective%20Appointments_0.pdf and <http://www.mitoaction.org/blog/get-more-every-doctors-appointment>), so a patient can type directly into these documents and update as needed. Dr. Rivers calls this tool: “Emily in a nutshell.” Keep it brief, updated, and organized, carrying a copy at all times - in your purse, briefcase, backpack, or diaper bag.

- **Demographic data** - Name, date of birth, contact information, emergency contacts, insurance information and date last updated.
- **Diagnosis** - List in order of priority and severity. Add a sentence or two to include significance of each diagnosis to the patient. Simple is key as more information can be supplied when requested. For example, name the Mitochondrial Disease, important deficiencies, and genetic defects if known.
- **Current medications** - In order of importance, list daily doses of medications with exact dose and frequency, including as needed medications. Also group medications together by listing all anti-seizure meds together, all GI meds together, for example.
- **Allergies** - Drugs, food, latex and/or others.
- **Recent hospital/ER visits and surgeries.**
- **Anesthesia protocols, code status, and immunizations.**
- **Most recent vital statistics** such as height and weight.
- **Note:** Special diets, fluid requirements, TPN, ports, size of any tubes, oxygen flow rates, or other technology required or special equipment.
- **Vitamins and minerals** taken, especially mito cocktail, again with doses listed.

- **Recent and significant labs**, including muscle biopsy results.
 - **Upcoming medical appointments**, even if no appointment dates have been finalized, indicate: "Cardiac follow-up due in June 2013."
 - **ALL physicians**, including name, specialty, phone number, fax number, and address.
 - **Support agencies contact info** - pharmacies, nursing agencies, DME suppliers, etc.
- C) **Medical Binder** (slide 14) with tabs for sections to help organize (family history, lab results, etc.)

Section One and Two - Basic Information

- Contact list for all current physicians
- At least three emergency contacts
- Current insurance cards - front and back

Section Three - Medications (slide 18)

- Current medications, kept up to date, including med name, dose prescribing doctor and formulation

Section Four - Diagnosis

- Recent and comprehensive physician letter summarizing history and diagnosis, including diagnosing physician.
- Discharge summaries from any hospitalization provide a synopsis of what happened during the hospital stay.
- Prioritize and summarize.

Section Five - Emergency Protocols

- Current protocols, with physician signature, which can provide protection during an emergency
- Protocols can be individually written by a physician or a template can be found on both the MitoAction and UMDf websites (dehydration, anesthesia, vomiting, etc.):
- <http://www.mitoaction.org/files/protocol-fever-and-infection.pdf>
- <http://www.mitoaction.org/files/protocol-vomiting.pdf>
- <http://www.mitoaction.org/files/protocol-general-surgery-eating-disrupted.pdf>
- <http://www.umdf.org/atf/cf/%7B858ACD34-ECC3-472A-8794-39B92E103561%7D/Metabolic%20Precautions%20and%20ER%20Letter.pdf>

Section Six - Notes from Physicians (Slide 20)

- summaries of diagnostic tests
- most recent clinical notes, including summary and follow up letters
- create a tab for each specialist, with contact info.

Section Seven - Hospitalizations

- Copy of discharge summary, including reason for hospitalization, recommended next steps, etc.
 - Organize by date
 - Include names of all doctor's instrumental in providing care
 - **Keep good organized records** (slide 17)
1. SORT - By year, then by type of information, then chronologically by month. Keep summary notes, (HPI) History of present illness (HPI) and SOAP (Subjective, Objective, Assessment and Plan) notes separate.
 2. CONSOLIDATE - Create a binder snapshot copy to keep track of how symptoms progress, test results change, noting trends.

3. **PRIORITIZE AND SUMMARIZE** (slide 19) A rolling filing cabinet is not needed and a stack of printouts will never be read during an appointment.

Key Points in preparation for appointment: (Slide 14)

- Bring binder to each appointment, keeping information up to date and organized.
- Request needed medical records (lab and test results) soon after an appointment and well before the next big appointment to have time to organized all the information.
- Compile and print a detailed family history - all doctors want this information!
- Bring copies of a few pertinent papers that the doctor may want to keep. Do not leave the doctor your only original copy!

D. Mito “Survival Kit” (Slides 15) Medical appointments zap energy!

- Always carry fluids (with electrolytes), snacks, and needed medications.
- Expect delays, packing an extra of everything!
- Bring books, electronics, blanket, or favorite item to keep kids amused.
- Likewise, bring computer, book, paperwork, craft, etc. to keep adults occupied.
- Rest at first sign of fatigue. Pay attention to the child’s cues too. Ask for a break when needed, either for the adult patient or for the parent to tend to a child’s needs.
- If possible, bring a second adult to the appointment primarily so that adult provides a second set of ears to listen, take notes, and process information. Especially when news is upsetting, the option to remove the child from the room or to use that extra adult to take notes of exactly what is being said can be most helpful. A second support adult is equally valuable for the adult patient. Asking to record an important appointment so that a spouse or significant other hears first hand information is another helpful option.
- Be as patient as possible, knowing that delays may occur.

E. Key Points during the appointment! (Side 16)

- Make sure doctor’s instructions are understood before leaving the appointment.
- Take notes, making a “to do” list of what needs to be done after the appointment.
- Don’t let the binder or paperwork take over - keep it simple and summarize, but provide more details when asked.
- Form a strong bond with the staff - bring in a food item, be polite and sincere, and say “THANK YOU!” Be remembered, but for the right reasons!
 - Remember the Four Ps!
 1. Perspective - Keep it real!
 2. Patience - Take deep breaths.
 3. Planning - Anticipate roadblocks!
 4. Persistence - Gets you where you want to go!

All of this seems overwhelming and cannot be accomplished overnight, but it is important. There are too few physicians who know enough about Mito for you to not have this organized information readily available.

Moving Forward: Awareness of mitochondrial disease has increased over the past 5 years due to grassroots efforts from parents, patients and health care providers. One simple way to increase awareness might be to ask to post a postcard about Mito on the bulletin board in the office or clinic you visit. Finding physicians who are knowledgeable about Mito can still be challenging, and patients and their families should not shy away from requesting coordinated care meetings between PCPs and specialists. Also, asking nurses in an office or clinic which physicians are interested in caring for more complex

patients can help you find the "right" provider. Social media and word of mouth can also provide help in finding the right physician for a complex patient.

Additional Reading:

<http://www.mitoaction.org/blog/advocating-for-yourself>

<http://www.mitoaction.org/autism/communicating-your-health-care-provider>

<http://www.mitoaction.org/mito-navigator-communication>

<http://www.mitoaction.org/blog/becoming-great-advocate-advice-parents-adult-patients-complex-needs>

<http://www.mitoaction.org/blog/advocating-responsibly-and-communicating-effectively>