

# Communicating Effectively with your healthcare providers

Also known as

Getting what you need from  
those hours of appointments!

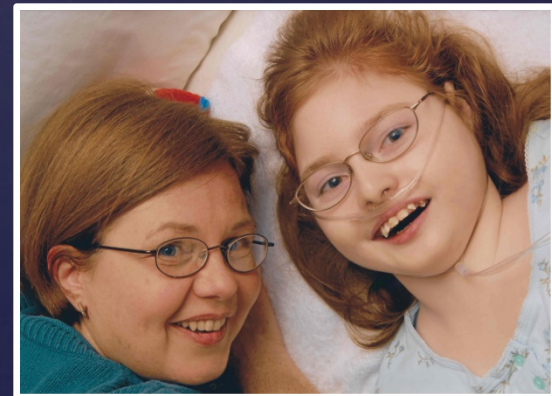
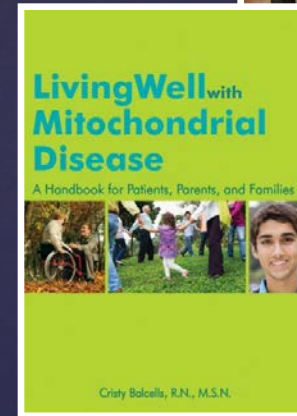
# About Us

Cristy Balcells, Executive Director MitoAction

- ⌘ RN and MSN Public Health
- ⌘ Mito Mom of 3 kids, including Eva age 8
- ⌘ Self-imposed advocate who gets little sleep
- ⌘ Author of “Living Well with Mitochondrial Disease”

Kathy Rivers MD

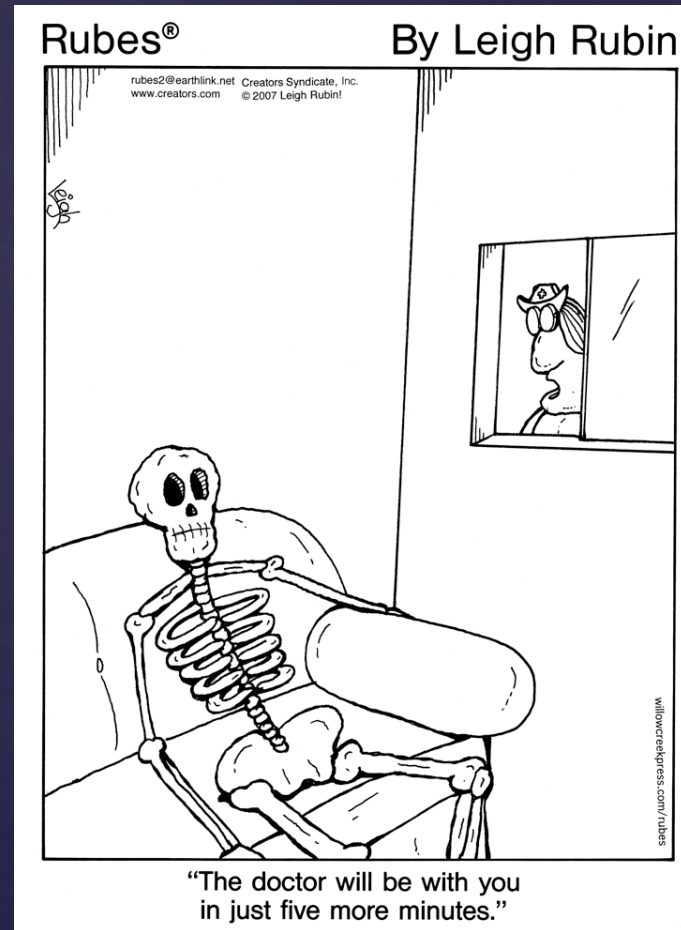
- ⌘ Former Pediatrician, current day nurse for bedridden daughter Emily, age 21
- ⌘ Mom of 3 kids, all of us living with Mitochondrial Disease
- ⌘ Special interest: Mito-Autism



# Why this topic?

On average, Mito patients and families have 2-3 appointments per month!

- ⌘ We spend a lot of time with and waiting for healthcare providers
- ⌘ We lean heavily on our doctors for support
- ⌘ We need help from clinic staff for things like school letters, insurance issues, referrals, etc.
- ⌘ We are often frustrated by the lack of progress or lack of coordinated care
- ⌘ We are often tired and overwhelmed





# Behind The Scenes: The New Healthcare

## Doctors overextended

- ⌘ Productivity expectations
- ⌘ Limited funding for support (nurses, genetic counselors)
- ⌘ Mito Specialists overwhelmed by new patients
- ⌘ Little time for follow-up
- ⌘ Desire to help overwhelmed by external pressures



# Patients & Parents in a Tough Spot

- ⌘ Patients, parents, families expected to advocate yet often feel powerless
  - ⌘ Put in a difficult position when expected to be advocate and care coordinator yet dependent on healthcare providers
  - ⌘ Often overwhelmed and exhausted by the demands of Mito on energy levels, time, financial resources, all while being frontline caregivers
  - ⌘ Need and want to learn all they can about Mito and how to manage Mito, but haven't been to medical school themselves – yet often become the experts on living with Mitochondrial Disease!

Step One:

Get focused, Get organized!

Approaching healthcare  
like a business – with a  
plan!

# What makes for a successful and productive office visit?

- ⌘ How should I prepare for a visit to my doctor?
- ⌘ How do I organize the data?
- ⌘ How do I present my child's problems in as clear and concise a way as possible?
- ⌘ How do I prioritize my concerns?
- ⌘ How do I make the best use of a short time?
- ⌘ How can I be an active participant in my health care?
- ⌘ How do I become a partner with my health care provider?



# Prioritize for the appointment based on the specialist

“What can you do for me, baby?”

- ⌘ Stay focused on the specialist’s area of expertise.
- ⌘ What is your ONE goal?
- ⌘ Write it down!
- ⌘ Make a list of your symptoms (in priority order)
- ⌘ Make a list of your questions, again in priority order. Highlight the 3 or 4 questions that are most important to you.
- ⌘ Print out these lists, and give a copy to your doctor.
- ⌘ Consider spending the first few minutes of your appointment deciding with your provider which things are most important and need to be discussed first. This way, you are more likely to cover your priority list, even if you run out of time and other issues need to be discussed later.

# Ask for more time - Don't go until you're ready

- ⌘ Ask how long the appointment is – and ask for an extended appointment if you have a lot to discuss
- ⌘ Make a list of priorities
- ⌘ Tell yourself what you need MOST from the appointment
- ⌘ Don't go until you have the information necessary for the decisions you need (charts, labs, etc.)
- ⌘ Know what you need to bring (referrals, copay, medical records)
- ⌘ Be willing to reschedule if it's a “bad day”





# There's too much going on and I feel overwhelmed – how do I even get started?

- ⌘ Start with today!
- ⌘ Write down what is happening today – problems, diet, meds
- ⌘ It's okay to start small and add more information as you go on – getting started is usually the hardest part!
- ⌘ There are tools to help you get organized, or you can make up your own
- ⌘ MitoAction iPhone app
- ⌘ Medical Information sheet





Step Two:

Get focused, Get organized!

Get your elevator pitch and  
quick reference info ready

# Medical Information Sheet

- ⌘ It can be very helpful to provide your health care professional with a brief, organized overview of your medical status. Once this sheet is made, it can be updated before appointments.
- ⌘ Include name, date updated, DOB, contact information, emergency contacts and insurance information.
- ⌘ List your diagnoses by name, very briefly but including the most important information (a sentence or two each). Start with your Mito diagnosis (include genetics if you have it), and list your diagnoses in order of priority and severity. Keep it short and simple! You can always provide more information when requested; the purpose of this is to provide an overview.
- ⌘ List dates of important surgeries and hospitalizations (not every one!).
- ⌘ List drug allergies, anesthesia precautions, code status and immunization status. Include food allergies.
- ⌘ List most recent height, weight and vital statistics.

# Medical Information Sheet (continued)

- ⌘ Daily medication list (prescription and OTC) – names, dosages, how many times a day taken; listed in order of importance.
- ⌘ PRN (as needed) medication list – names, dosages, when to take and how often.
- ⌘ List special diets (medical formulas, TPN); list fluid requirements if necessary.
- ⌘ Add technology requirements (G-tube size, type of central line, etc.)
- ⌘ Consider listing the amounts of vitamins and minerals taken per day, especially those important in the Mito cocktail (CoQ10, Carnitine, Creatine, etc.)
- ⌘ Recent and significant labs
- ⌘ Upcoming appointments
- ⌘ Physician contacts (Specialty, Name, Address, Phone, Fax); you can include pharmacies, DME suppliers, nursing agencies, etc.



# Organize your medical records

- ⌘ Get in the habit of requesting your medical records. These can be organized in paper form in a binder or electronically.
- ⌘ These include copies of doctor's letters, lab and radiology results, testing and evaluations.
- ⌘ Arrange either in chronological order or by specialist or test.
- ⌘ Compile a family history and keep it updated.
- ⌘ Bring to the appointment, just in case information is needed, but don't expect the doctor to look through the whole thing!
- ⌘ Make copies of pertinent information before your appointment to give to the doctor.
- ⌘ If you allow your originals to be copied, make sure you get them back before you leave the office!

# Your Mito “Survival Kit”

## Pack and Plan Ahead

- ⌘ Always carry fluids (with electrolytes) and a snack. Don't forget your meds! Plan to be there longer than you think.
- ⌘ Plan ahead, expect delays, and pack extra everything! Bring amusements for the kids (electronics, books) and for yourself.
- ⌘ Rest at the first sign of fatigue, and pay attention to your/your child's cues. Ask for a break if you need one; take care of your child's needs.
- ⌘ If you can, bring another adult – to be another set of ears, help carry things, distract the kids so you can talk (and listen) to the doctor, maybe even go to the bathroom!



# KEY POINTS

- ⌘ Be able to use descriptive phrases, such as “Typically my lactate is around 3, but can be much higher when I’m not well”
- ⌘ Don’t let the paperwork and details take over - keep it simple whenever possible and summarize
- ⌘ Generalize in most cases, until detail is necessary. Keep in mind the focus of the provider at hand!
- ⌘ Take notes. Make a “to do” list of what you need to do after the appointment. Make sure you understand the doctor’s instructions!
- ⌘ Say THANK YOU!



# Your Mito “Survival Kit”

## ⌘ Keep Good Records:

### ⌘ Step One: Sort

- ⌘ Sort by year, then type of information, then chronologically by month.
- ⌘ Keep summary notes (HPI & SOAP) separate from everything else.

### ⌘ Step Two: Consolidate

- ⌘ Create a medical binder and/or electronic snapshot copy to keep track of how symptoms progress, how test findings change, and trends in symptoms.

# Your Mito “Survival Kit”

Get the details straight:  
Your Medical Binder

- ⌘ Sections One & Two: Basic Information
  - ⌘ A contact list including all current physician info
  - ⌘ At least three emergency contacts
  - ⌘ Current insurance cards, front and back
- ⌘ Section Three: Medications
  - ⌘ Current medications, kept up to date, including medication name, prescribing doctor, dosage, and formulation



# Your Mito “Survival Kit”

## Prioritize and Summarize Contents of Your Medical Binder

### ⌘ Step Four: Diagnosis

- ⌘ Recent and comprehensive physician letter summarizing history and diagnosis, including who made the diagnosis
- ⌘ Ask for “Intake H&P”

### ⌘ Step Five: Emergency Protocols

- ⌘ Current protocols, with physician signature
- ⌘ Protocol samples, templates, and letters available at [www.MitoAction.org](http://www.MitoAction.org) and [www.umdf.org](http://www.umdf.org)



# Your Mito “Survival Kit”

## Prioritize and Summarize Contents

- ⌘ Step Six: Notes from Specialists, Including Summaries of Diagnostic Tests
  - ⌘ Most recent clinical notes (summary, follow-up letter)
  - ⌘ Create a tab for each specialist, with contact info
- ⌘ Step Seven: Hospitalizations
  - ⌘ Ask for “Discharge Summary”, including reason for hospitalization, recommended next steps, etc.
  - ⌘ Organize by date
  - ⌘ Include the names of all doctors who were instrumental in caring for you/your child.

# Your Mito “Survival Kit”

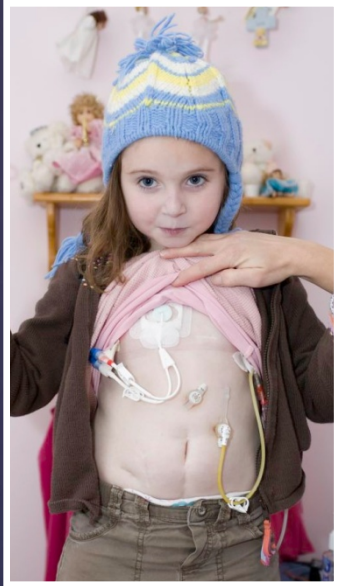
## ⌘ Maintain the Four Ps

- ⌘ Perspective: Keep it real.
- ⌘ Patience: Take deep breaths.
- ⌘ Planning: Anticipate roadblocks!
- ⌘ Persistence: It gets you where you want to go.





# Mito is COMPLEX



Yet, few people are familiar with it and unlike other equally devastating diseases, there is no long list of corporate sponsors or a marketing machine leading the charge to find a cure, treatments or to FIGHT MITO!

Use clinic visits to help raise awareness and share support materials.





- We have to explain mitochondrial disease and speak when our children cannot... a lot.
- We are strong.
- We are tired.
- We could care less about your kid's handwriting problems or soccer team politics.
- We have the number for the insurance company on speed-dial.
- We know the number to the pediatrician by heart.
- The local hospital ER knows our names.
- We are worried. And scared. And resilient.
- We need help.