

# HOW TO BUILD YOUR MITOCHONDRIAL MEDICAL HOME

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# I WAS ONCE ALL NEW TO THIS...

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- In the beginning I was LOST.
- I had a miserable baby GIRL. I had a strong mother's instinct that something was WRONG. And within the first few years, we had over 20 medical professionals from pediatricians to occupational therapists, from neurologists to nutritionists involved, who had NO answers.
- Going from appointment to appointment trying to make sense of it all was exhausting and overwhelming.
- Medical Record Misery
- Who is the Quarterback of this team?



# SINCE THEN I HAVE LEARNED A LOT AND CONTINUE TO LEARN DAILY!

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- Bachelors degree in Chemistry Penn State University
- Masters degree in Chemistry UCLA
- Consumer Taskforce, Baby's First Test, Newborn Screening Education
- Member of MitoAction's Advocacy Task Force
- Mountain States Regional Genetics Collaborative, Social Media Coordinator
- Former Parent Advisor for Pennsylvania American Academy of Pediatrics Medical Home Initiative
- Author, writer, blogger ([www.babyfoodsteps.com](http://www.babyfoodsteps.com)) and above all Advocate
- Patient Advocate with Empowered Medical Advocacy: [EmpoweredAdvocacy.com](http://EmpoweredAdvocacy.com)

# DISCLAIMER

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- The medical information in this presentation is provided as an information resource only, and is not to be used or relied on as medical advice, or for any diagnostic or treatment purposes.
- I am not a doctor and therefore will not be able to answer questions specific to medical treatment or diagnosis.

# WHAT IS A MEDICAL HOME?

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- When I first heard the term...
- Per the National Center for Medical Home Implementation:

**A medical home is not a building or a place.**

It is an approach to providing comprehensive primary care that facilitates partnerships between patients, clinicians, medical staff, and families.

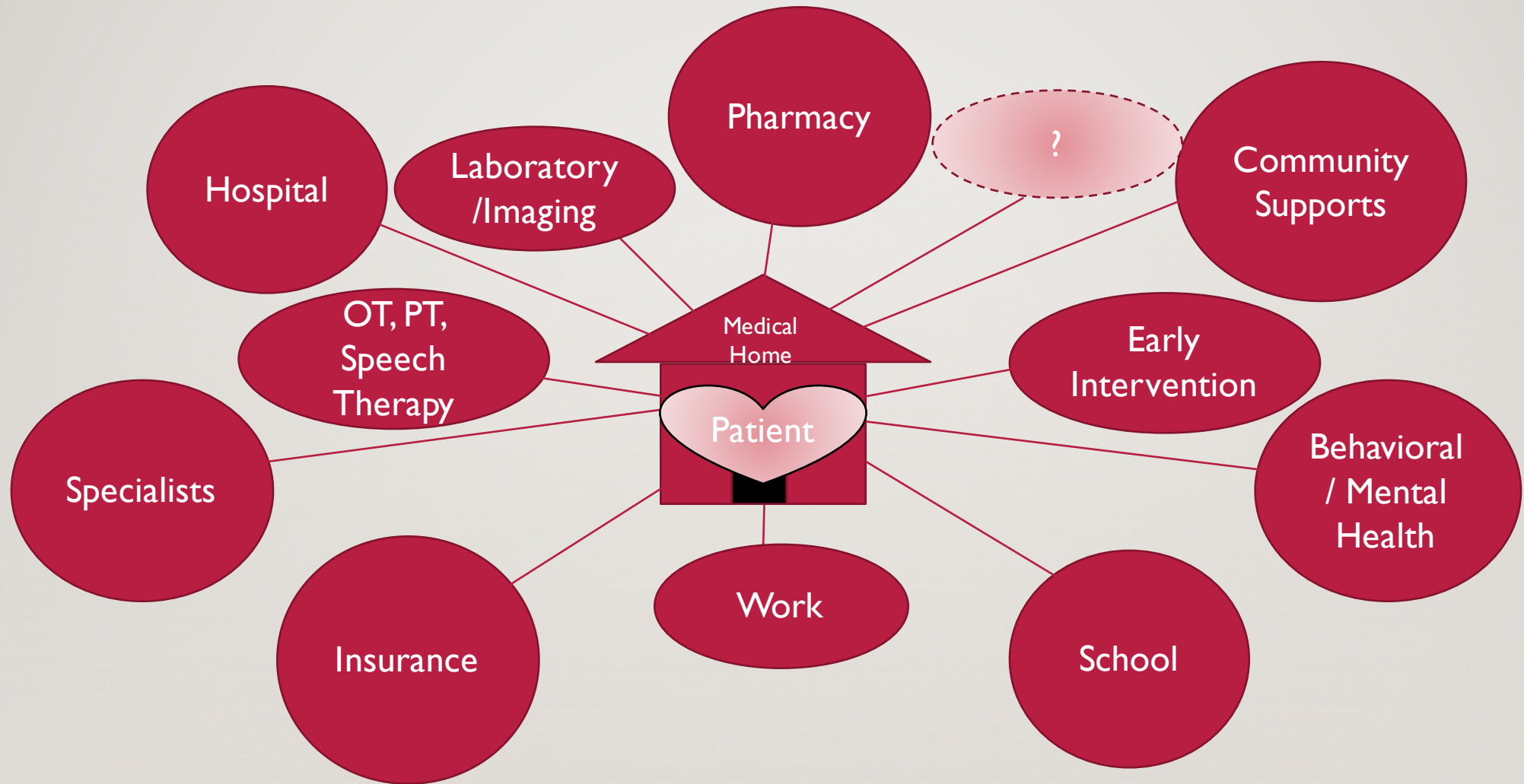
- Also known as Patient Centered Medical Home (PCMH), Health Home,

# WHAT DOES PATIENT CENTERED MEAN?

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- *Patient centeredness* refers to health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they require to make decisions and participate in their own care.
- **Institute of Medicine *Envisioning a National Healthcare Quality Report (2001)***

# WHAT DOES IT LOOK LIKE?



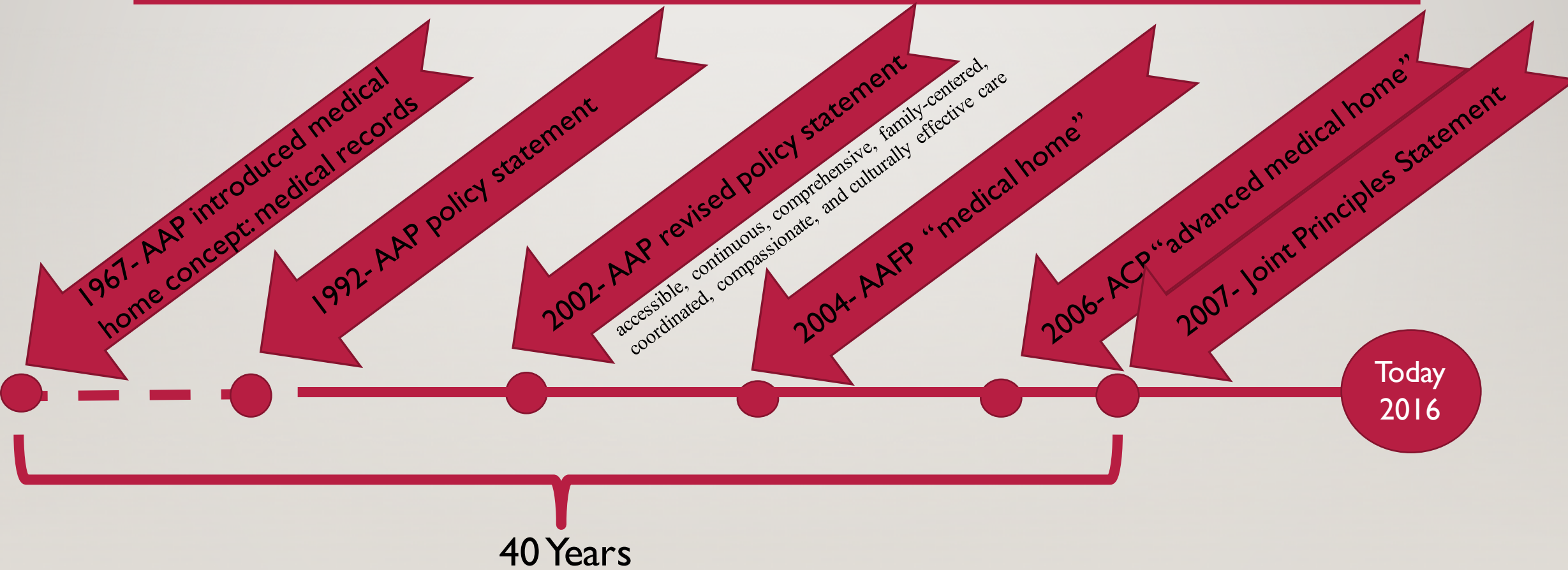
# WHY MEDICAL HOME?

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- In the past the “fee for service” model has been in place, but this model rewards QUANTITY not QUALITY of care.
- Providers get paid regardless of clinical outcome, with no differentiation between effective and ineffective encounters.
- Healthcare spending is on the rise.
- There is a move from a model of productivity (more patients) to a model focused on improved outcomes (health).
- Section 2703 of the Affordable Care Act (ACA) provided for the care of chronically ill patients through “Health Homes”.



# A LITTLE HISTORY~ MEDICAL HOME...



# “JOINT PRINCIPLES” OF THE PATIENT-CENTERED MEDICAL HOME MARCH 2007

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- American Academy of Family Physicians (AAFP)
- American Academy of Pediatrics (AAP)
- American College of Physicians (ACP)
- American Osteopathic Association (AOA)

# WHAT ARE THE JOINT PRINCIPLES?

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- Personal physician
- Physician directed medical practice
- Whole person orientation
- Care is coordinated and/or integrated
- Quality and safety
- Enhanced access
- Payment

# IN 2007...JOINT PRICIPLES

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- “This model is an aspiration that is not currently found in most clinical practices and is unavailable to most people in the US. This important evolution of care will require active demonstrations, change facilitation, and a business plan that can either survive in the current payment environment or that is specifically financed.”
- ***Robert Graham Center 2007 report on Patient Centered Medical Home***

# ALMOST 10 YEARS LATER... WHERE ARE WE NOW?

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- Still Implementing!
- Medical Homes are being set-up across the nation but is still a process and does not happen overnight.
- For the pediatric population, evidence shows an association between access and utilization of a medical home to the following:
  - Decreased hospitalizations, including days spent at the hospital
  - Decreased visits to the emergency department
  - Less out-of-pocket spending from families, particularly those with public insurance

Source: <https://medicalhomeinfo.aap.org/overview/Pages/Evidence.aspx>



# MEDICAL HOME ACCREDITATIONS

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- Medical Home accreditation often is required to obtain an **increase in reimbursement from a health plan.**
- These Accreditations may or may not impact you directly as a patient
- searchable databases available
- National Committee for Quality Assurance (NCQA): **Patient-Centered Medical Home**
- Joint Commission : **Primary Care Medical Home**
- Accreditation Association for Ambulatory Health Care (AAAHC): **Medical Home On-site Certification**
- Utilization Review Accreditation Commission (URAC): **Patient Centered Health Care Home**
- Some programs have been criticized for being too administratively focused, “check the box”, and not focusing on bigger picture: the patient.

# CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN) OR (CYSHCN)

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- The Maternal and Child Health Bureau definition: children birth to age 21 who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.
- CSHCN: DOES NOT ONLY encompass those children who have complex disorders or who require technology; children who have attention-deficit/hyperactivity disorder, diabetes, emotional disorders, and autism ALSO can be INCLUDED in CSHCN definition.
- CSHCN are estimated to comprise 13% of the pediatric population and account for 70% of pediatric health-care expenditures.

# CSHCN MEDICAL HOME, EXAMPLES

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- Dr. Renee Turchi : **The Center for Children and Youth with Special Health Care Needs, St. Christopher’s Hospital for Children: Philadelphia PA.**
- Dr. Daniel Felten and Dr. Karen Fratantoni: **Complex Care Program, Children’s National Health System: Washington DC.**
- Dr. Ebony Williams: **CHOSEN Clinic, UT Physicians : Houston, TX.**
- More examples: <https://medicalhomeinfo.aap.org/practices/Pages/Promising-Practices-Archives.aspx>

\*\* These are just examples of various programs across the country, but do not constitute specific recommendations for care.



# WHAT DOES THIS MEAN FOR ME OR MY CHILD WITH MITO?

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- Healthcare is in a “transition” phase
- There are medical homes that DO exist all over the country: Organic and Accredited
- BUT one of those may not be in your town or nearby
- If you do not have a medical home currently, you may have to “build” your own!

# HOW TO BUILD YOUR OWN MEDICAL HOME...



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- Start with the PRIMARY piece... the FOUNDATION of your Medical Home
    - The “Quarterback” of your medical team
    - MD= Medical Doctor
    - DO= Doctor of Osteopathy (DOs receive special training in the musculoskeletal system, your body’s interconnected system of nerves, muscles and bones.)
    - Family Physician
    - Pediatrician/Developmental Pediatrician
    - Internal Medicine
    - General Practitioner
    - Geriatrician (65 and older)
    - Med/Peds (Dually trained in Internal Medicine & Pediatrics)
    - Functional Medicine/Integrative Doctor

# WHERE TO FIND A QUARTERBACK?

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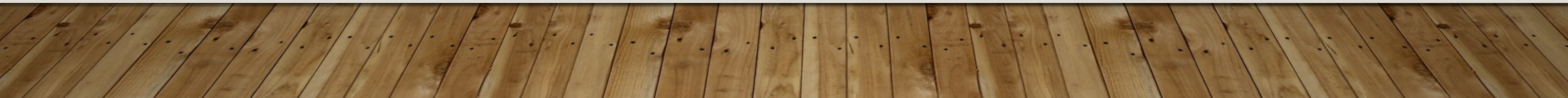


- Word of mouth referrals
- Asking others in the medical profession, especially nurses, therapists and specialist's staff
- Asking others who have complex conditions or chronic conditions in your community who their Primary Physician is and what their experience has been.
- Message Boards (buyer beware, one patient may have a great experience, another may have a horrible experience with the same practitioner)
- Community educational events, what doctors are speaking in your town, local library, parenting classes, go listen to them! A great way to see what they are like before you are on the exam table.
- New Parent/ New Patient consults | 5-20 minutes free consult.

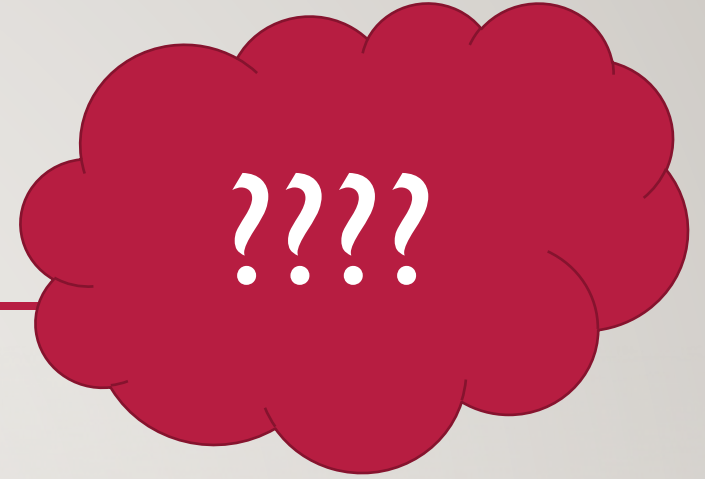
# WHEN YOU CALL...

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- Polite, Courteous 😊
- “I am calling to find out if Dr. Quarterback is taking new patients?”
- Yes or No
- “I was referred to her and would like to speak with her about possibly being my primary physician”
- “Does Dr. Quarterback offer any new patient consultations or an opportunity to speak with her and ask a few questions, prior to a first appointment?”
- “If not, would it be possible to schedule an introductory appointment with Dr. Quarterback to speak with her about my medical concerns?”
- “Do you know if Dr. Quarterback is comfortable working with patients who have multiple specialists?”



# A FEW QUESTIONS...



- What to ask of your potential new team member...
- How does your office operate? Will I be scheduled with you each time?
- Who will I see when I/my child is SICK?
- How comfortable are you in working with complex care/chronic care conditions?
- Have you ever heard of mitochondrial disease? (not a deal breaker!)
- Most importantly...Are you willing to LEARN along side me, about MITO?
- What is your philosophy on being a primary care physician/pediatrician?
- What role do you feel the patient/or parent of patient plays on the care team?
- How do you facilitate communication with other members of a care team, both within and outside of your office?
- What hospital do you refer to?

# FIRST FEW VISITS

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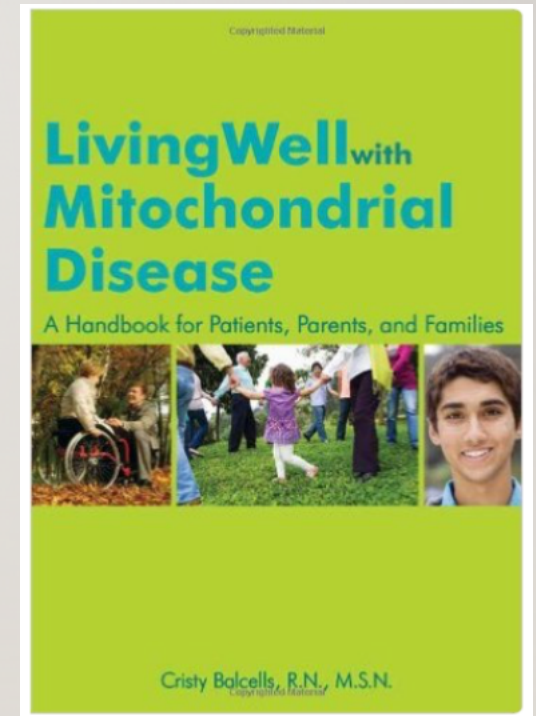


- Consider bringing an advocate
- Be Prepared to share your health history concisely.
- Have medical records available but do not bombard them.
- Set Reasonable Expectations for appointment length (8-15 minutes), unless you ask for more time when you scheduled the appointment.
- Write down ALL your questions but prioritize the top 3-5 that you would like answered
- Discuss situations before they become emergencies..
  - What do I do if, Who do I call?
    - Child has been vomitting for 24 hours?
    - Child has not eaten for a day?
    - Muscle weakness has lasted for a week and no improvements?
- Ask about communication methods and what you should expect if you would like to contact your doctor: Email, Patient Portal, Phone Calls: Nursing staff vs. Doctor directly.

# MITO RESOURCES FOR YOUR DOCTOR

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- **Mitoaction's A CLINICIAN'S GUIDE TO THE MANAGEMENT OF MITOCHONDRIAL DISEASE: A Manual for Primary Care Providers**
  - <http://www.mitoaction.org/guide/table-contents>
- **Mitoaction's** Podcast- 114 podcasts on many topics
  - <https://itunes.apple.com/podcast/audio-podcast/id290467730>
- **Cristy Balcells's Book- Living Well with Mitochondrial Disease**
  - available on Amazon
- **UMDF's** Annual Symposium archive of talks
- <https://vimeo.com/umdf>



# SICK VISITS

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- Very important to see your medical home provider in good times and bad
- They need to see you/your child at your baseline to know when you are not at your baseline
- If you are having a difficult time deciding if you need to seek more urgent care-
  - call your medical home FIRST, ask to be seen if the situation allows.
- Primary Care doctors can **CALL AHEAD** to the ER to let them know you are on your way and help advocate for your emergency care.
- Emergency Protocol Letters- have this discussion with your doctor before an Emergency! Mitochondrial Specialist are usually the ones to write these letters, but be sure your Medical Home has a copy and that you have discussed it with them and how they can help.



# ONGOING COMMUNICATION

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- Sign ALL Medical Releases at ALL specialists for clinic notes to be shared with your medical home and a copy provided to YOU the PATIENT.
- Call ahead before your appointment and ask if all the clinic notes have been received from ALL other providers you have seen since your last appointment.
- When you see your Medical Home provider tell them who you have seen since your last visit and ensure they have the summary clinic notes from those providers.
- If not, provide them with your copy that can be scanned into your file.
- If they did not have copies, bring this up as a concern and ask how you can work together to make sure they are getting these communications in the future so that your care is complete.

# CONSIDER AN ADVOCATE

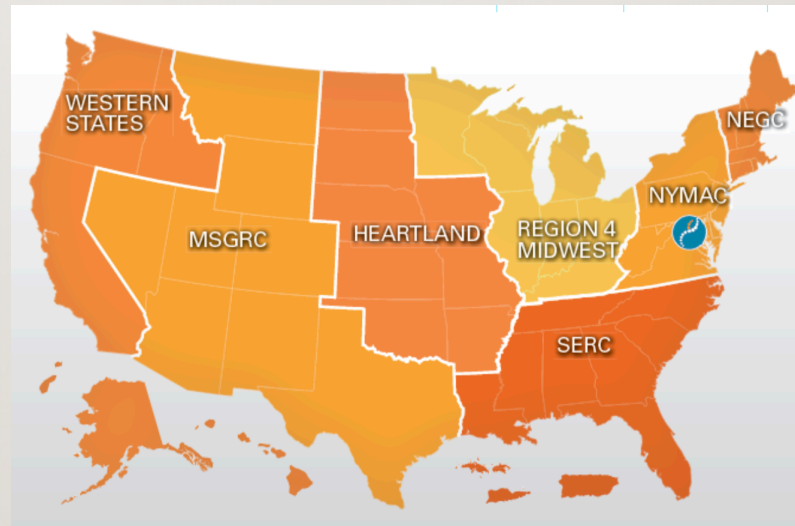


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- An advocate can be anyone from a friend or relative or a paid professional advocate.
  - Professional Advocates can be employed by a doctor's office, hospital, health insurance company, or **by the patient themselves**.
  - A private, independent patient advocate who is hired by a patient or patient's family can assist in navigating medical care for their loved one.
  - Advocates can help you locate options for “draft pick” Quarterbacks (and other members of your team) and communicate with them effectively.
  - ADVOCConnection- Advocate directory: [www.advoconnection.com](http://www.advoconnection.com)

# GETTING INVOLVED IN MEDICAL HOME INITIATIVES

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- Start locally. After you establish a primary practice, ask if they have any advisory boards or ways for patients to get involved with the practice.
- National Initiatives and opportunities for consumers/patients through the Regional Genetics Collaboratives.
- <http://www.nccrcg.org>



# ADDITIONAL RESOURCES

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- MitoAction Mito Navigator Toolkit
  - <http://www.mitoaction.org/mito-navigator-toolkit-overview>
- Mito411 - MaryBeth Hollinger is the Mito 411 Nurse Coordinator : **I-888-MITO-411**
- AAP National Center for Medical Home Implementation [www.Medicalhomeinfo.org](http://www.Medicalhomeinfo.org)
- Patient-Centered Primary Care Collaborative [www.pcpcc.org](http://www.pcpcc.org)
- Medical Home Video <https://www.youtube.com/watch?v=cZZdVpMsL6M>
- Book: Being an Empowered Patient: An Advocacy Guide by Erika Balfour, MD

# CONTACT INFO

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