Summary - Mitochondrial Medical Homes
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In the beginning of Kristi's medical journey with her daughter, she felt lost. Kristi had a miserable baby girl and had a strong mother's instinct that something was very wrong with her child. Pursuing that instinct, her baby saw over 20 medical professionals in the first years of her life, including pediatricians, occupational therapists, neurologists, and nutritionists, yet still had no answers. Going from appointment to appointment, trying to make sense of it all, was exhausting and overwhelming. After asking, "Who is the quarterback of this team?" and wading through years of "Medical Record Misery," the concept of finding a medical home to better coordinate the care her child received from multiple specialists became Kristi's focus (slides 1-3).

Disclaimer -- 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.

A **medical home** is not a building or a place, but rather an approach to providing comprehensive primary care that facilitates partnership between patient, clinicians, medial staff, and families (slide 5). A medical home is also known as Patient Centered Medical Home (PCMH) or Health Home. (National Center for Medical Home Implementation). 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) (slide 6). Specialists, OT, PT, speech therapists, hospitals, schools, work, insurance companies, among others, work to keep patient needs in the center of care (slide 7).

Why do we need a Medical Home?

- 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.
- Health care spending is on the rise, which has helped to 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 though "Health Homes" (slide 8).

History -- Medical Homes began in 1967 as a concept for special needs children to decide where their medical records should be housed (slide 9).

- 1992 -- American Academy of Pediatrics (AAP)released a policy statement on Medical Homes.

- 2002 -- AAP revised the statement to include accessible, continuous, comprehensive, family-center coordinated, compassionate, and culturally effective care.
- 2004 – American Academy of Family Physicians (AAFP): Paper about Medical Home used.
- 2006 – American College of Physicians (ACP): Advanced Medical Home.
- 2007 -- **Joint Principles Statement on Patient Centered Medial Homes:** *American Academy of Family Physicians (AAFP), American Academy of Pediatrics (AAP), American College of Physicians (ACP), and the American Osteopathic Association (AOA) (slide 10)* came together and agreed upon joint principles that covered areas of excellence in medical homes (slide 11)*:*
- --*Personal physicians* -- each patient has an ongoing relationship with a personal physician trained to provide first contact, continuous and comprehensive care.
- --*Physician-directed medical practice* -- personal physician will lead the team of individuals at the practice level to collectively take responsibility for the ongoing care of the patient.
- --*Whole-person orientation* -- personal physician is responsible for providing all the patient's health care needs or taking responsibility for appropriate care with other qualified professionals, including all stages of life from acute care to chronic care, to preventative services, and even end of life care.
- --*Care is coordinated and/or integrated* -- encompasses coordinated care across all elements of complex health care systems, including subspecialty care, hospitals, home health care agencies, nursing homes, and the patient's community, including family, public, and private-based services. Care is facilitated by registries, information technologies health information exchange, and other means to assure that patients get indicated care when and where they need and want it in a culturally and linguistically appropriately manner. The American Academy of Pediatrics defines coordinated care as the deliberate organization of patient care activities between two or more participants, including the patient, involved in the care to facilitate the appropriate delivery of health care services, including: medical, social, and behavioral professionals; the educational system; payers; medical equipment providers; home care agencies; advocacy groups; needed supportive therapies/services; and families (https://medicalhomes.aap.org/Pages/Coordinated-Care.aspx).
- --*Quality and safety* -- focuses on quality improvement, with patient actively providing feedback so that actions can be implemented.
- --*Enhanced access* -- being able to access care when you need it and where you need it, via open scheduling, extended office hours, new options of communication between patients and their physicians, such as patient portals.
- --*Payment* -- should reflect the value of physician's and non-physician staff's extra time and expertise that would fall outside of face-to-face visits and should also support provisions to support communication access such as email and telephone calls.*"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 (slide 12). http://www.graham-center.org/dam/rgc/documents/publications-reports/monographs-books/rgcmo-medical-home.pdf

- After 10 years, Medical Homes are still in the implementation phase and are being set up across the nation, but the process takes time.For the pediatric population, evidence shows an association between access and utilization of a medical home and:

- 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 (slide 13)

Medical Homes Accreditations

- Often required to obtain an **increase in reimbursement from a health plan**.
- May or may not impact you directly as a patient
- Have 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 (slide 14).

Children with Special Health Care needs (CSHCN) or (CYSHCN)

- 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. (McPherson, M., et.al. "A New Definition of Children With Special Health Care Needs." Pediatrics 102.1 (1998): 137-39. Print.)
- Does not always 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 the CSHCN definition.
- Estimated to comprise 13% of the pediatric population and account for 70% of pediatric health-care expenditures (slide 15). Streamlined, efficient care lowers costs (side 15).
- Examples are listed on slide 16 and can be found: https://medicalhomeinfo.aap.org/practices/Pages/Promising-Practices-Archives.aspx

- Healthcare is in a transition phase. Medical homes do exist all over the country: Organic and Accredited. If a medical home is not available certain areas, the patient or family may have to build their own medical home (slide 17).

How to Build a Medical Home

- Start with the PRIMARY piece, the foundation, or "quarterback," of your Medical Home. Primary Care Doctors can be Medical Doctors (MD) or Doctors of Osteopathy (DO). DOs receive special training in the musculoskeletal system, the body's interconnected system of nerves, muscles, and bones.
    - Primary care physicians include: Family Physicians, Pediatrician/Developmental Pediatricians, Internal Medicine Doctors, General Practitioners, Geriatricians (65 and older), Med/Peds (Dually trained in Internal Medicine & Pediatrics), or Functional Medicine/Integrative Doctors (slide 18).
- Use word of mouth referrals to find Mito-friendly providers.
- Ask others in the medical profession, especially nurses, therapists and specialist's staff, for recommendations.
- 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 -- find out which doctors are speaking in your town, local library, parenting classes and go listen to them as that encounter is great way to see what a provider is like before on the exam table.
- New Parent/ New Patient consults --15-20 minutes free consult may be offered (slide 19).
- When you call:
    - Be polite and courteous: "I am calling to find out if Dr. Quarterback is taking new patients?" "I was referred to her and would like to speak 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 see multiple specialists?"
    - What to ask of your potential new team member … ask the questions that are important to you!
        - 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 patients? (slides 20-21)

First few visits:

- Consider bringing an advocate to take notes and be another set of ears!
- Be prepared to share your health history *concisely*.
- Have medical records available, but do not bombard the provider.
- 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 when …?
    - Child has been vomiting for 24 hours?
    - Child has not eaten for a day?
    - Muscle weakness has lasted for a week and no improvements?
- Ask about preferred 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 (slide 22).

Resources for your team

- **MitoAction's A CLINICIAN'S GUIDE TO THE MANAGEMENT OF MITOCHONDRIAL DISEASE: *A Manual for Primary Care Providers***
- **MitoAction's Podcasts**-- 114 podcasts on many topics
- **Cristy Balcells's Book- Living Well with Mitochondrial Disease**
- **UMDF's** Annual Symposium archive of talks

Sick visits

- Very important to see your medical home provider in good times and bad as doctors 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 specialists are usually the ones to write these letters,

but be sure your Medical Home has a copy and that you have discussed plans with them and how they can help

Ongoing Communication

- 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 (slide 25).

Advocates

- 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 patients 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.
- ADVOConnection -- Advocate directory (slide 26)

Medical Home Care Initiatives

- 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 (slide 27)

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