

Navigating the Healthcare System while Attempting to Meet the Needs of a Child or Adult with Complex Medical Issues

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How did I end up here?

- RN, MSN (Pediatric)
- Family touched by Mito
- Mito411 Volunteer
- Mito411 Coordinator
- Advocacy Task Force



But my involvement can feel more like:





Trying to help.



To Comfort.



To Educate.

To keep families together.



- <http://www.thekinglink.com/guidedogpuppies.jpg>

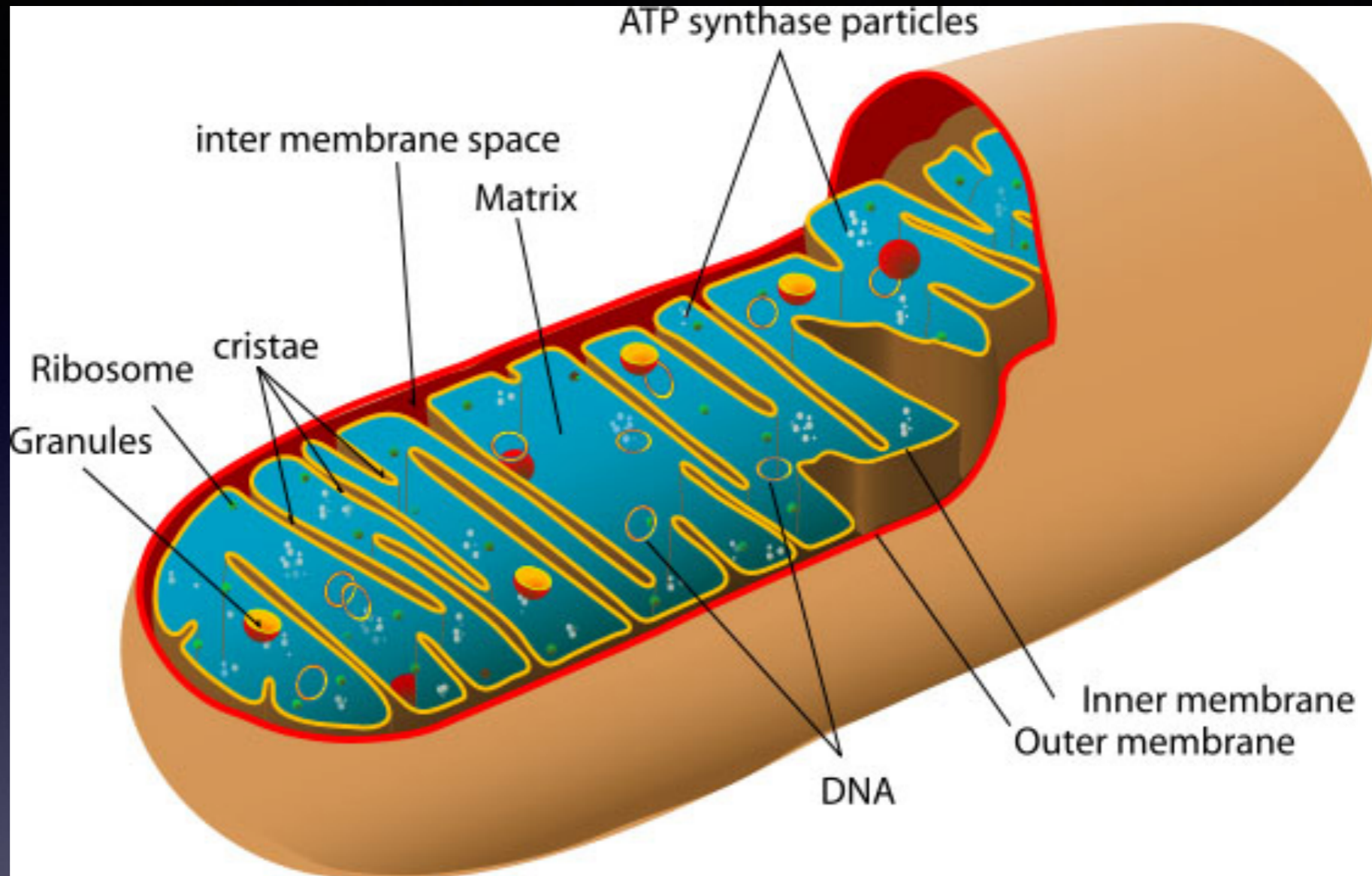
Goals

- 1. Increase understanding of the challenges that medical professionals and families face when caring for medically challenging, chronically ill child or adult.**
- 2. Increase understanding of the factors that contribute to allegations of Munchausen Syndrome, Munchausen by Proxy (MBP), Medical Child Abuse (MCA), somatoform or factitious disorder.**
- 3. Learn strategies to help communicate, instead of alienate, thus fostering better care.**

Objectives

- 1. Review challenges medical professionals and families face today which may impact the medically complex family and the care they receive.**
- 2. Review relevant literature to note trends, including current medical school and law enforcement training.**
- 3. Discuss common red flags for labels of MCA, Munchausen Syndrome and MBP and how families's voices can be heard, but not suspected.**

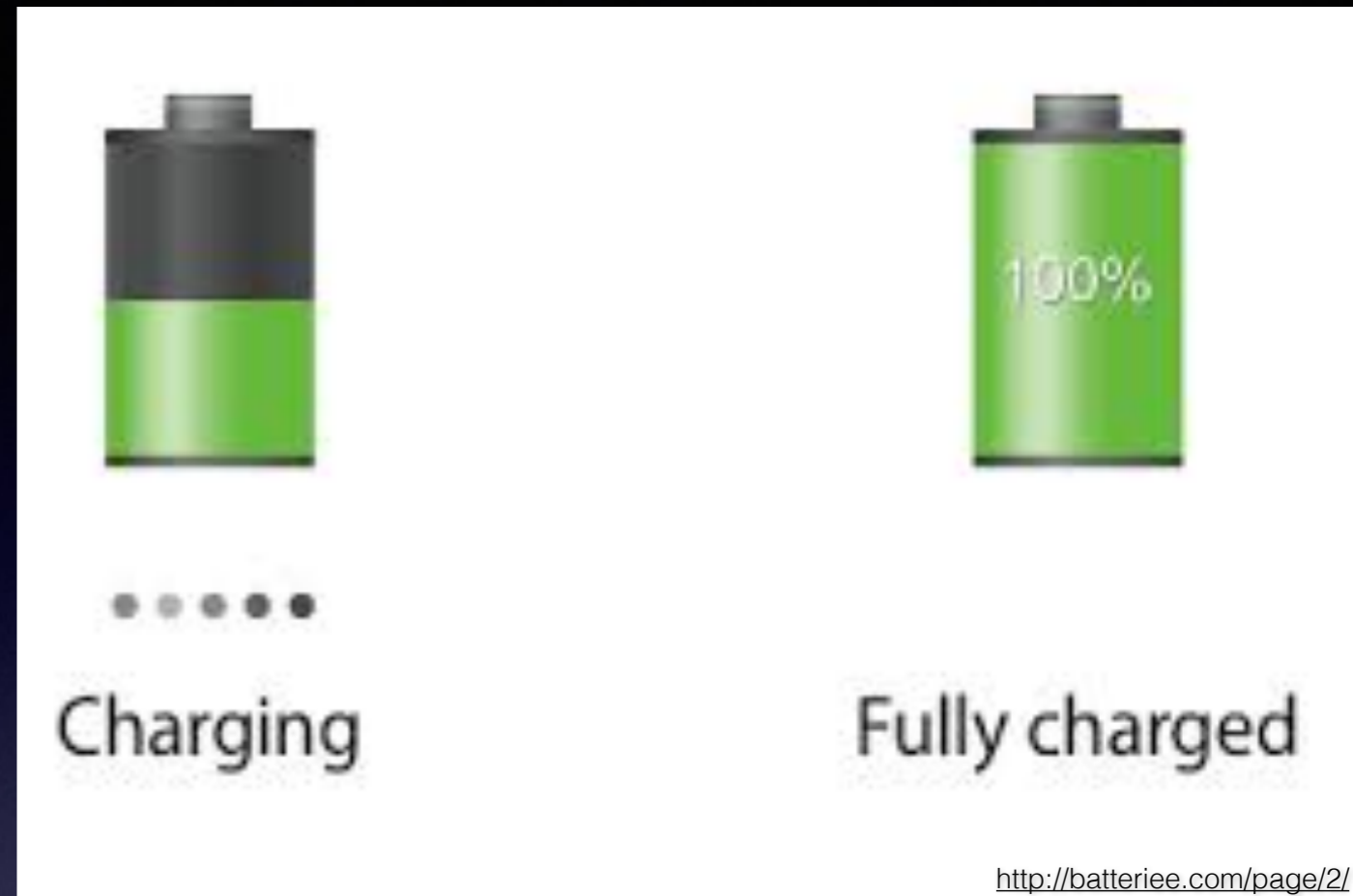
What is Mitochondrial Disease?



“Mitochondrial diseases result from failures of the mitochondria, specialized compartments present in every cell of the body except red blood cells. Mitochondria are responsible for creating more than 90% of the energy needed by the body to sustain life and support growth. When they fail, less and less energy is generated within the cell. Cell injury and even cell death follow. If this process is repeated throughout the body, whole systems begin to fail, and the life of the person in whom this is happening is severely compromised. The disease primarily affects children, but adult onset is becoming more and more common.”

[http://www.umdf.org/site/c.8qKOJ0MvF7LUG/b.7934627/k.3711/What is Mitochondrial Disease.htm](http://www.umdf.org/site/c.8qKOJ0MvF7LUG/b.7934627/k.3711/What%20is%20Mitochondrial%20Disease.htm)

I have Mito- What Disease?



Failure of cells to make enough energy to
fully power a body.



<http://blogs.intel.com/freepress/files/2013/09/Critical-Battery.jpg>

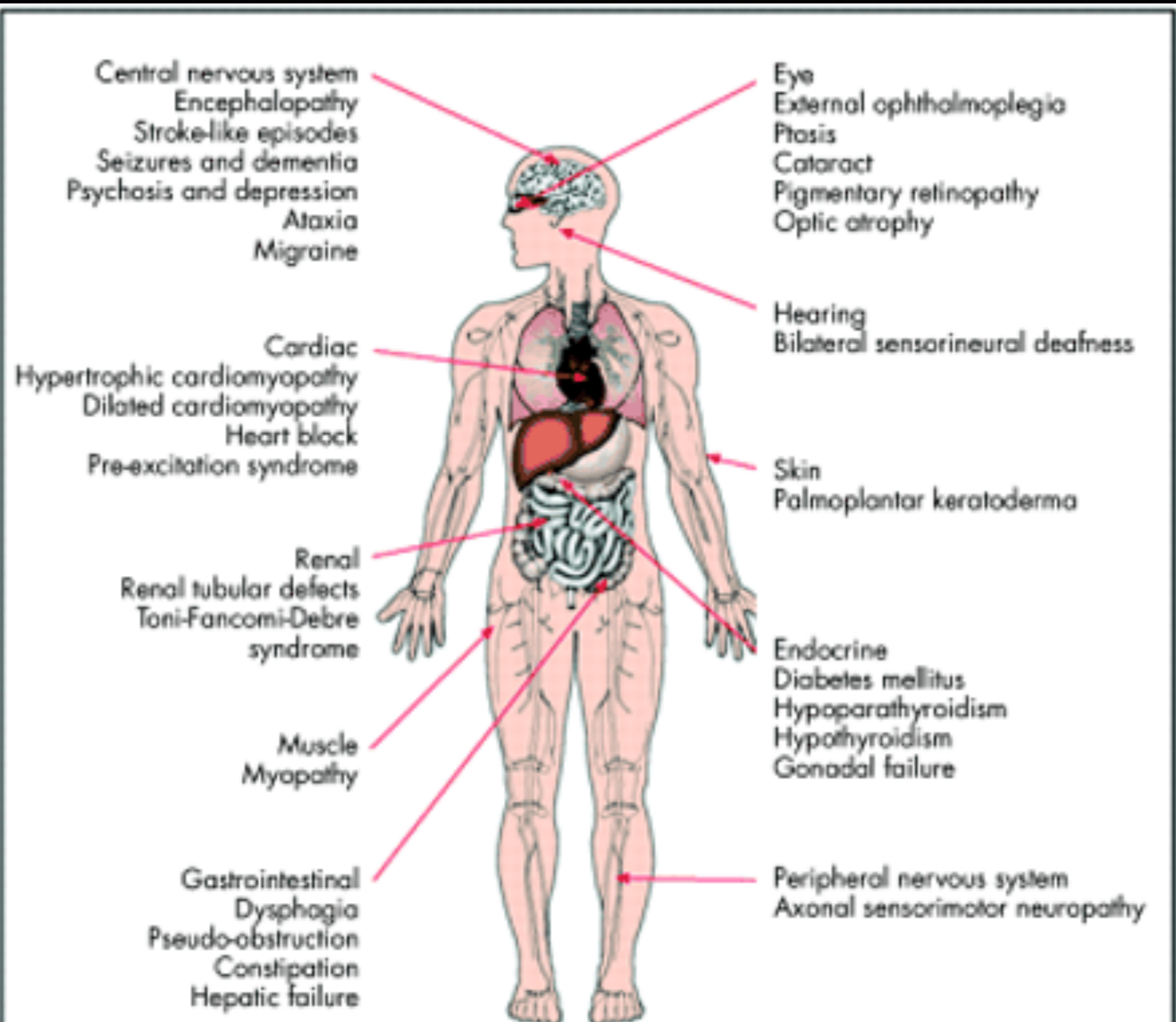
When energy runs critically low, body systems may begin to show signs and symptoms of stress and/or failure.

All systems
(apps) can be
affected.



<http://thegeek.com/2013/06/>

Your body's "Apps"



The Confusing Part:



Any system, any time.

Mitochondrial Disease

- any disease manifestation
- any degree of severity
- any age of onset
- any mode of inheritance

With symptoms that can vary day to day....

And even minute to minute!



Definitions

- Münchausen Syndrome by Proxy
- Münchausen Syndrome
- Somatoform
- Medical Child Abuse

Munchausen Syndrome by Proxy

- Applied to parent who purposely harms a child for external gain.
- Child's health improves when removed from parent(s).
- **Rare** form of child abuse that usually involves the mother, where both
 - the child suffers from unnecessary medical procedures and treatments or direct injury by the perpetrator
 - the adult perpetrator is mentally ill, carrying the diagnosis of factitious disorder imposed on another

Incidence of MBP

Exceedingly Rare

- UK studies report 0.5 cases per 100,000 (age birth to 16 years)

<http://www.ncbi.nlm.nih.gov/pubmed/11468037>

- New Zealand studies report 1 case per 100,000

<http://www.ncbi.nlm.nih.gov/pubmed?term=8813872#sthash.wHjHuyNj.dpuf>

Munchausen Syndrome

- Type of factitious disorder, or mental illness, in which a person repeatedly harms his or herself but presents for care for physical illness. MS is caused by an inner need to be seen as ill or injured.

www.clevelandclinic.org/health/diseases_conditions

Somatoform Disorder

- Diagnosis given when a patient displays psychological stress with physical manifestations, such as pain.
- Presenting symptoms have no clear medical reason.
- Two Types:
 1. Factitious Disorder - fake or exaggerated complaints for internal gain (subconscious).
 2. Malingering - intentionally exaggerating or faking symptoms for external gain.

Medical Child Abuse

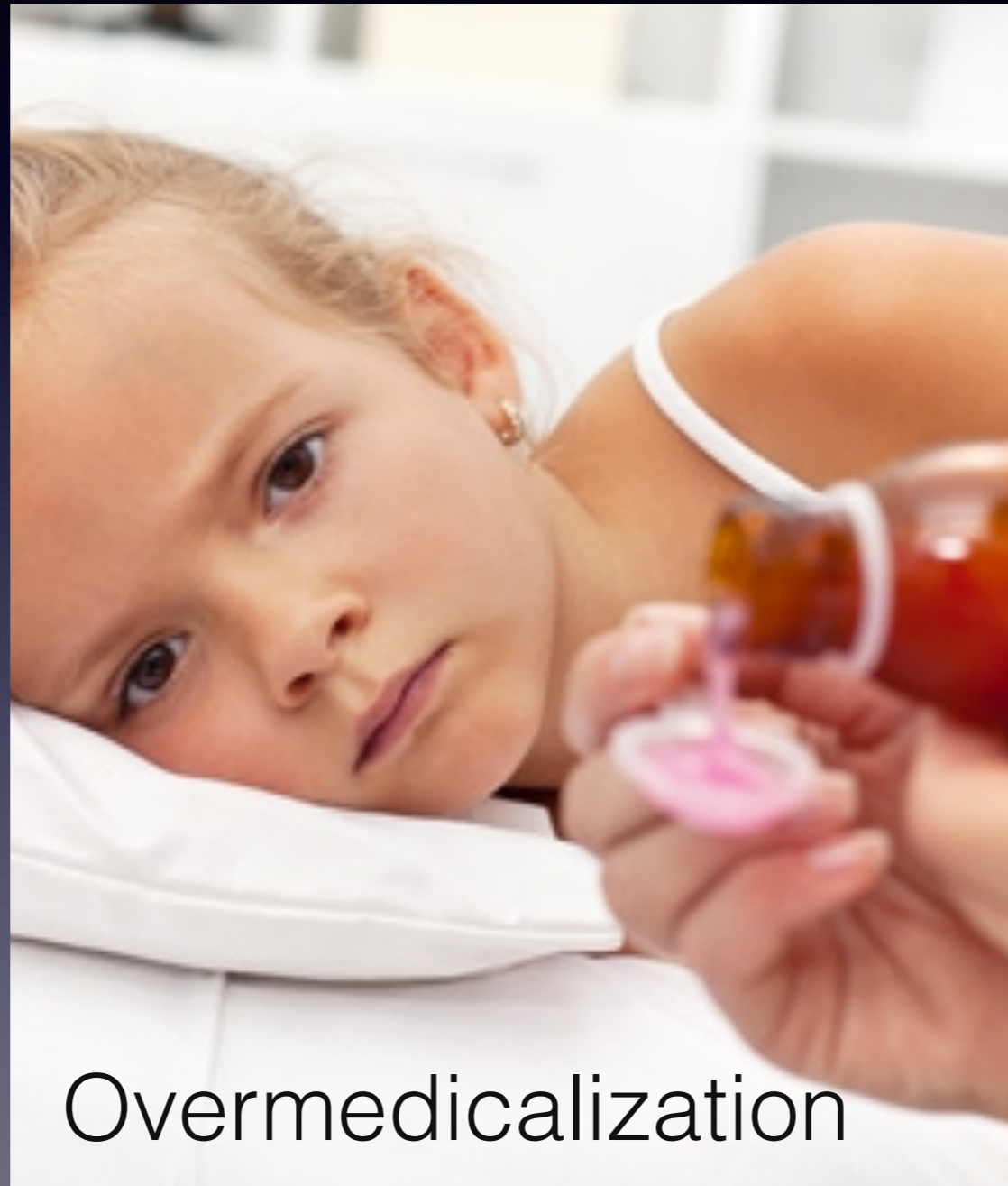
- **A game changer !**
- **A “shift in terminology”**

MCA

- Focus on the victim (child)
- INTENT is no longer considered!

American Academy of Pediatrics, Visual Diagnosis of Child Abuse on CD-RoM, Third Ed.

Child receives harmful or potentially harmful treatment and/or procedures at the “instigation” of the parent.



Overmedicalization

Easier
diagnosis
to make

Straight
forward
definition

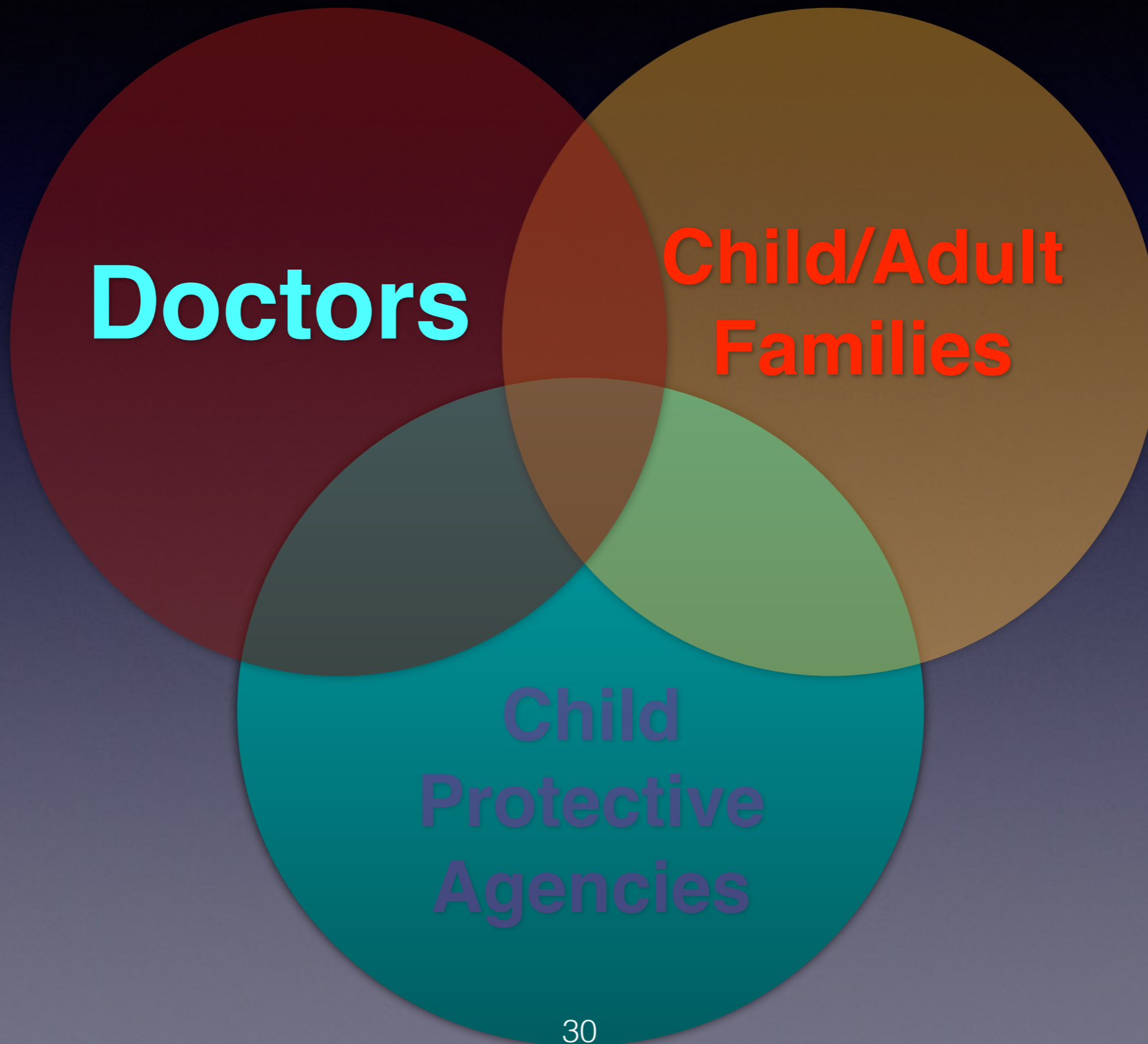
No parent
motivation

“Logical diagnosis as the
counterpart to medical
neglect at the opposite end
of the spectrum”

No need to
assess if
symptoms
resolve with
separation
from parent

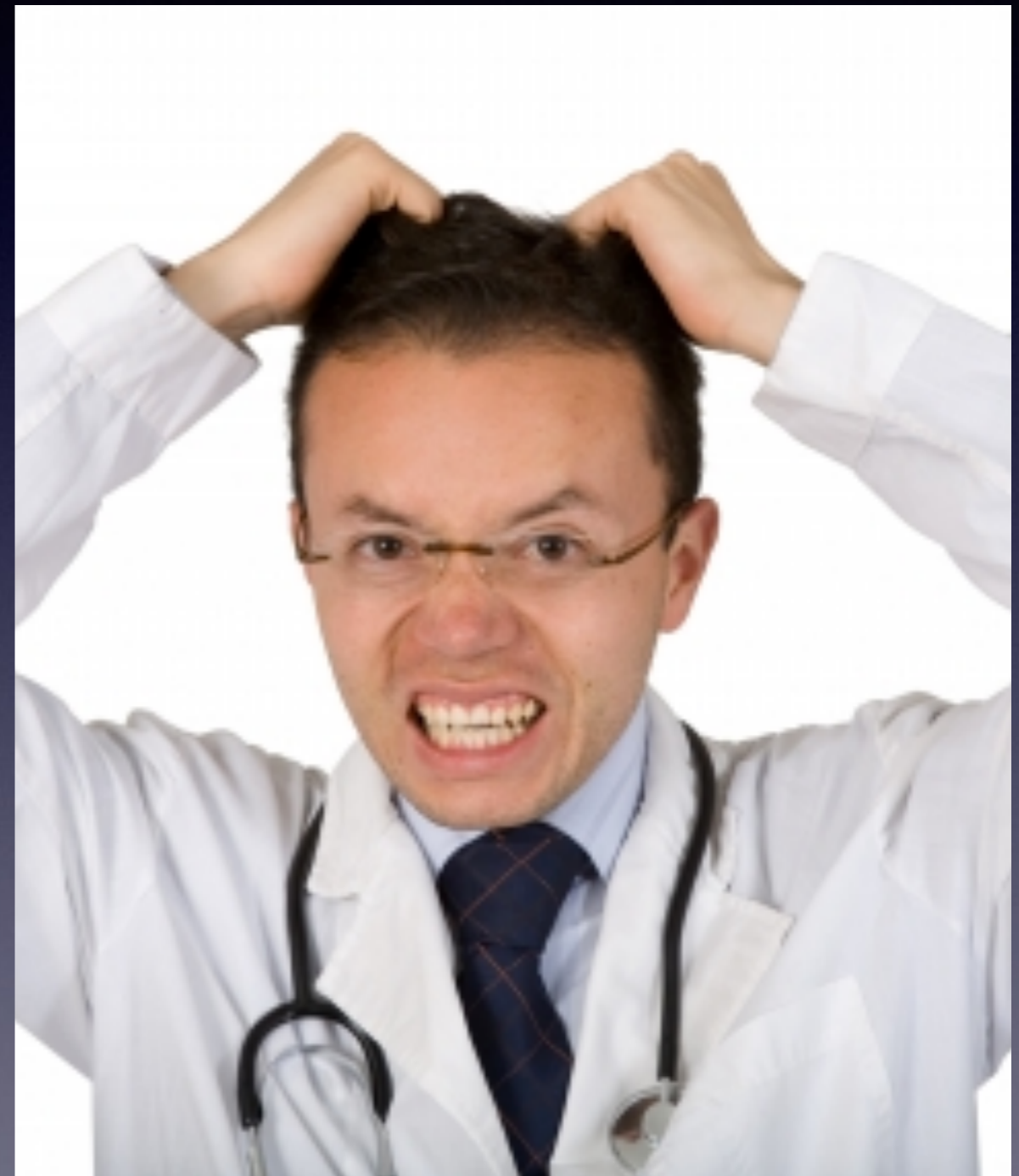
More
inclusive

How does Mitochondrial
Disease begin to look like
MBP/MCH/Somatoforn/MCA?



Doctors

- Time constraints - too busy
- Insurance pressures - \$\$
- Science driven knowledge base
- Sees patient in the moment
- Complex patients - Progressive
- Human - frustration, anger, sadness
- Communication skills
- Mito Knowledge base is often poor
- Personality - understanding vs. arrogant



<http://ryanocomedy.files.wordpress.com/2010/07/doctor20angry.jpg>

Hospitals

- Complex, huge
- Disorganized
- Poor communication between doctors
- Problems magnified between multiple institutions
- Insurance pressures



http://media.bizj.us/view/img/215751/albany-medical-center*304.jpg

Child/Patient/Family with Mito

- Multiple medical problems - many systems, many doctors
- Variable symptoms & variable intensity of symptoms
- Some with strong knowledge base, many with much mito experience with self/child.
- Scared, angry, frustrated, exhausted, hostile, lonely
- Multiple family members may be affected
- Search for Mito friendly doctors (“doctor shopping”)



www.google.com/search

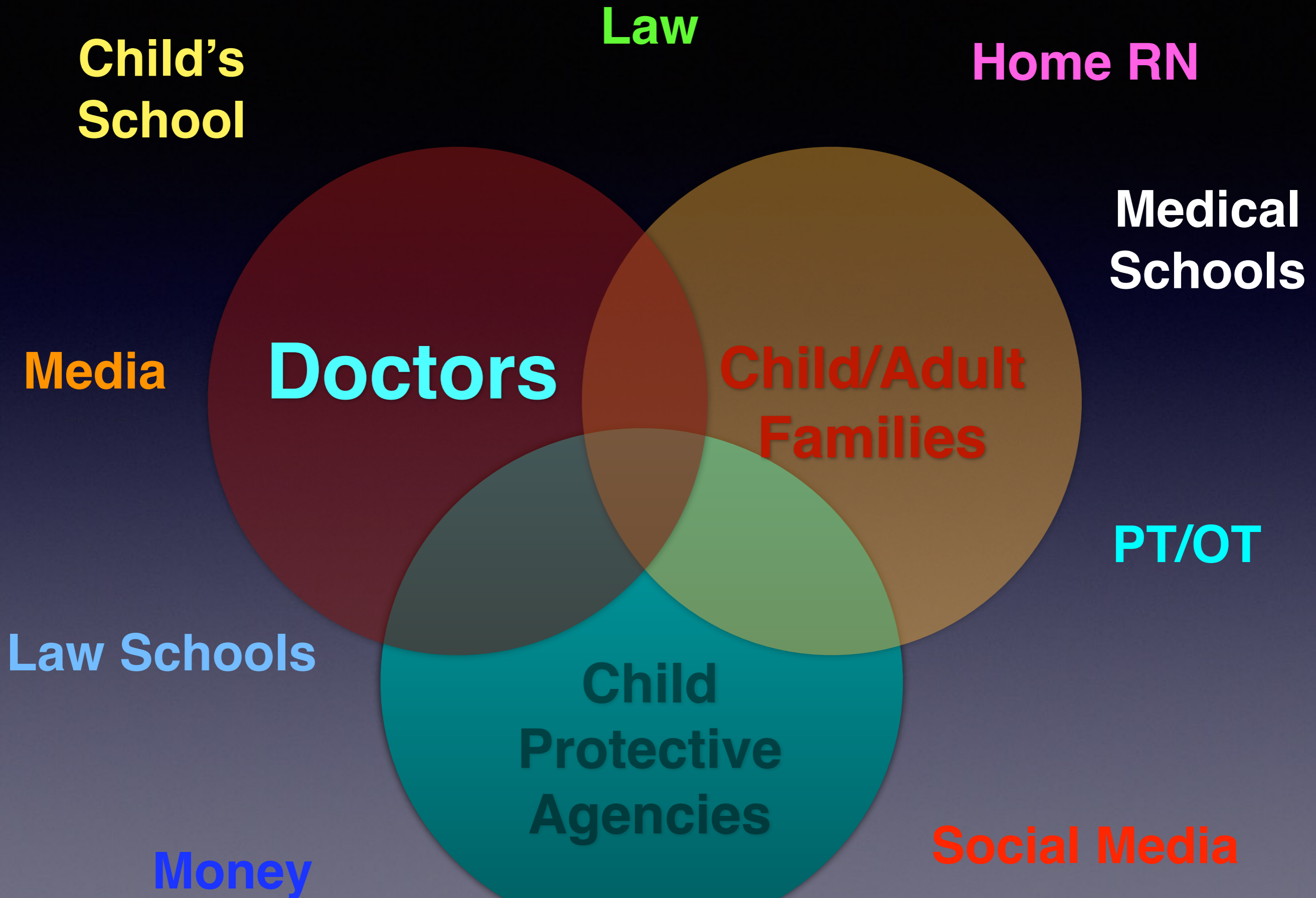
Helicopter Moms



<http://thenextfamily.com/wp-content/uploads/2012/11/helicopter-parents-4.jpg>

Child Protection Agencies

- Overworked, understaffed
- Do not understand mito
- No review/hearing before a child is removed
- Courts and CPS agencies take doctor's word over parent's word



Medical Schools & Post Graduate Articles

- MCA, MS, MBP, Somatoform definitions
- Physician Profile
- Perpetrator Profile
- Child or Adult presentation

Physician Profile

- Fooled, tricked or hoodwinked by mother
- Trusting
- Unknowing

Perpetrator Profile

- Primary Care Giver (99% female) - usually single mother
- Educated, middle class
- Friendly with staff
- Knowledgeable, may be in health care field
- Multiple doctors and facilities
- Multiple symptoms that do not fit known diseases
- Unexplained sibling death
- Child improves in absence of caregiver
- Demands specific care (IVs, medications, etc.)
- Block proposals to stop treatment

Perpetrator Profile

- Child has received a work up for Mitochondrial disease.....
- Yet: “Psychologists have described that the population of patients and parents of children with Mitochondrial Disease are much more vulnerable to a false Munchausen's by proxy accusation simply due to the nature of the disease.” -Dr. Alex Flores

• <http://www.mitoaction.org/blog/munchausens-proxy-accusations-mitochondrial-disease#sthash.QRcEjYfa.dpuf>

- AAP instructs doctor to ask: “Have you ever worried that your child might not be normal or that you might lose them?”
- If yes, then instructed to “ask ***mother*** (emphasis mine) how much of the child’s symptom result from her anxiety vs. a medical problem.”

“We suggest a more rigorous approach to Munchausen syndrome by proxy, with explicit acknowledgment that it is abuse and that the medical system is critical to its genesis.”

Donald, T, Jureidini, J. *Pediatr Adolesc Med.* 1996;150(7):753-758. doi:10.1001/

Law Enforcement

- Medical Child Abuse = Child Abuse
- Obtain extensive social history from defendant (crime scene)
- Interview those with contact with defendant or victim
- Neighbors, family, friends, employers, church members



Law Enforcement

- Social Media - “One of the most important aspects of medical child abuse investigations”
- Prior to speaking with defendant, find FaceBook profile, Blogs, Twitter, Instagram, Web Groups, and other social media profiles.
- Obtain Preservation Requests to all social media sites
- Obtain Search Warrants for private messages
- Use Social Media to seek out more witnesses to abuse

- Common blog themes:
 - Distortion Patterns
 - Escalation Patterns
 - Attention seeking Patterns
 - Exposure of the Child to Public Viewing
 - Attitudes toward Medical Professionals
 - Fundraising and Charity

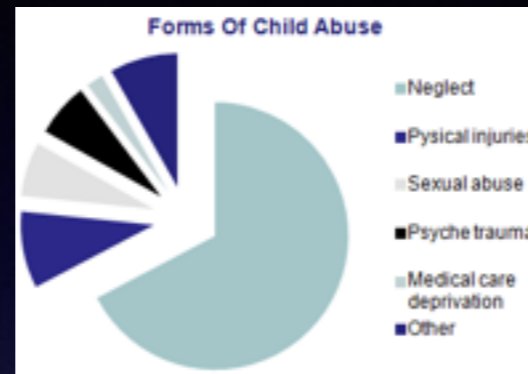
Law Enforcement

- Williamson v. State - First Court of Appeals upheld the verdict that gastric feeding tube placement constitutes serious bodily injury
- Parents are believed to have “hoodwinked” the physicians

Media



- News Articles
- Books
- TV shows
- Exaggerate the incidence of MBP - drama



<http://www.childhealth-explanation.com/images/childabuse-forms.png>



“TEEN AT CENTER OF MEDICAL ABUSE LEGAL WRANGLE RETURNS TO KC, BUT NOT TO HIS MOM”

-THE KANSAS CITY STAR 09/20/2014



“Are Hospitals And Child Protective Services Conspiring To Kidnap Children?”

- The Inquisitor 10/20/14

Schools

- IEPs and 504 plans cost the schools money
- Many IEPs and 504 are not well received by school
- Need vs. helicopter parent
- Some allegations do come from schools



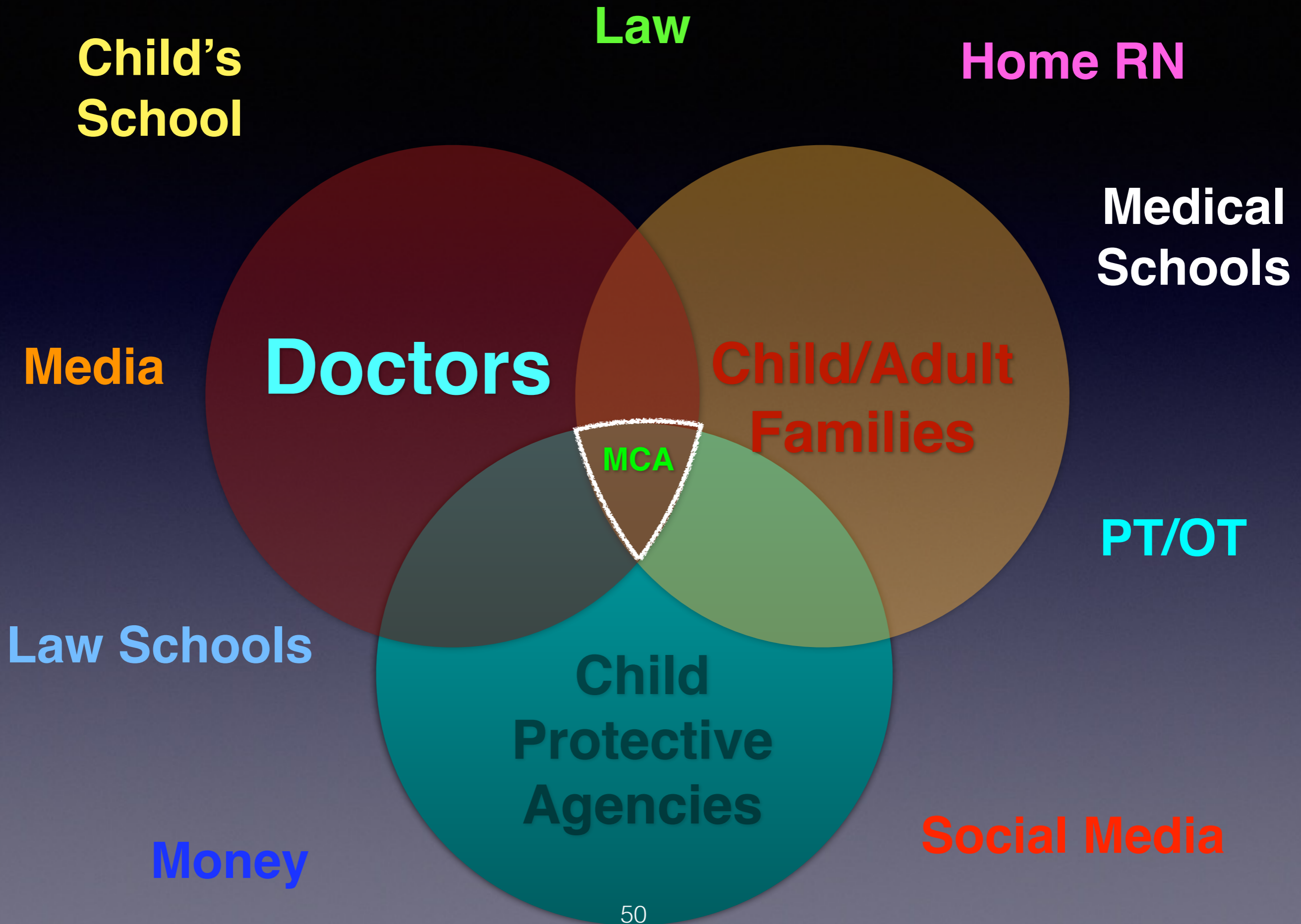
http://3.bp.blogspot.com/_SRT7VG7GMjA/TLeslkvDJyl/AAAAAAAAAkQ/mWoxkyM7jKk/s1600/Castellanos+Elementary+School+Opening+Oct+14-10+013.jpg

PT/OT and Home care

- PT/OT, home aides and RNs are often the parents biggest supporters.
- Spend the most time with the family.



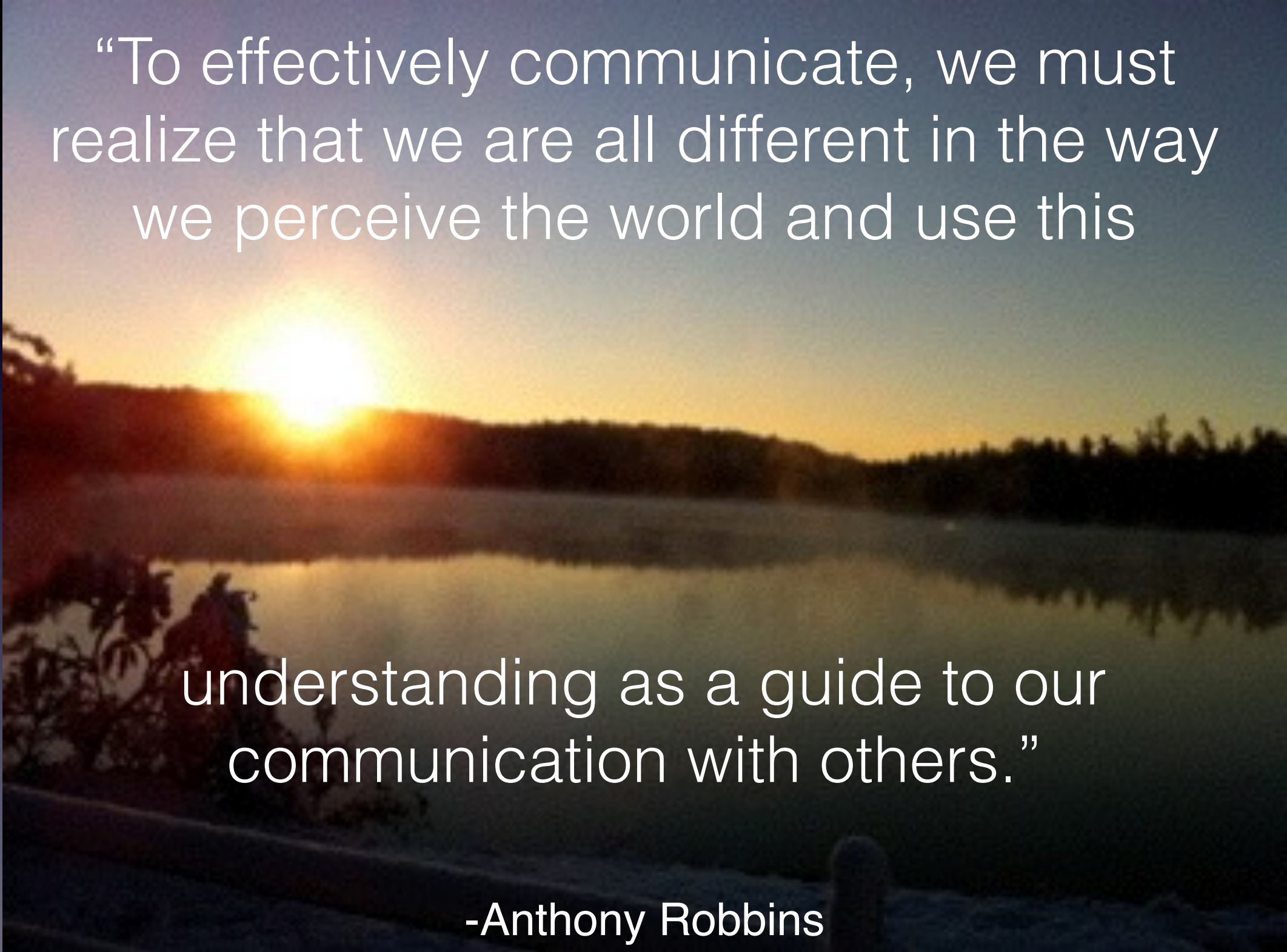
<http://peaktherapy.com/assets/images/pediatric-physical-therapist.jpg>



Are the “red flags” of MBP/MCA a result of the pressures and stress on the parents of a poorly understood, chronically ill child?

Summary of Red Flags

- Social Media
- G tubes and Ports vs. FTT
- Presentation not match with history given
- Multiples: Specialists, Hospitals, Medications
- IEPs and 504 plans
- Poor communication between doctors
- Hostile parents + arrogant doctors
- Mothers: single, educated, medical field, strong advocates
- Knowledgable parent - makes demands
- Make a Wish?



“To effectively communicate, we must realize that we are all different in the way we perceive the world and use this

understanding as a guide to our communication with others.”

-Anthony Robbins

Medical Professionals

- Continue to embrace the quest for knowledge
- Knowledge base for Mito is Poor
 - Medical Schools
 - Post Grad
 - Few Experts
 - Grand Round Impact is LOW

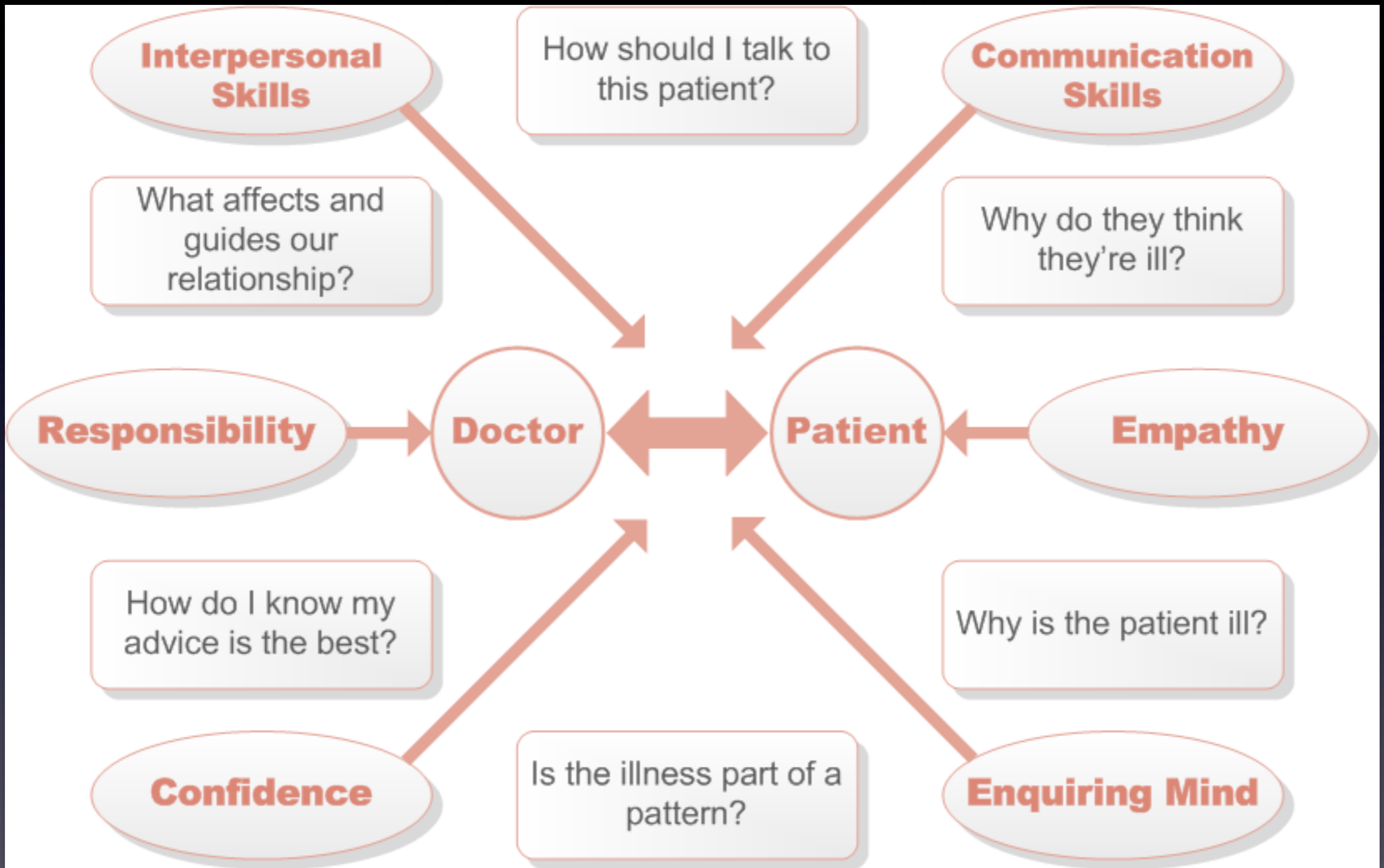
- Understand the Nature of the Disease
 - Variable symptoms and presentations
 - Many specialists, many medical problems
 - Many misconceptions with the disease

“I have never known a false case not sparked by conflict between a mother and a doctor.”

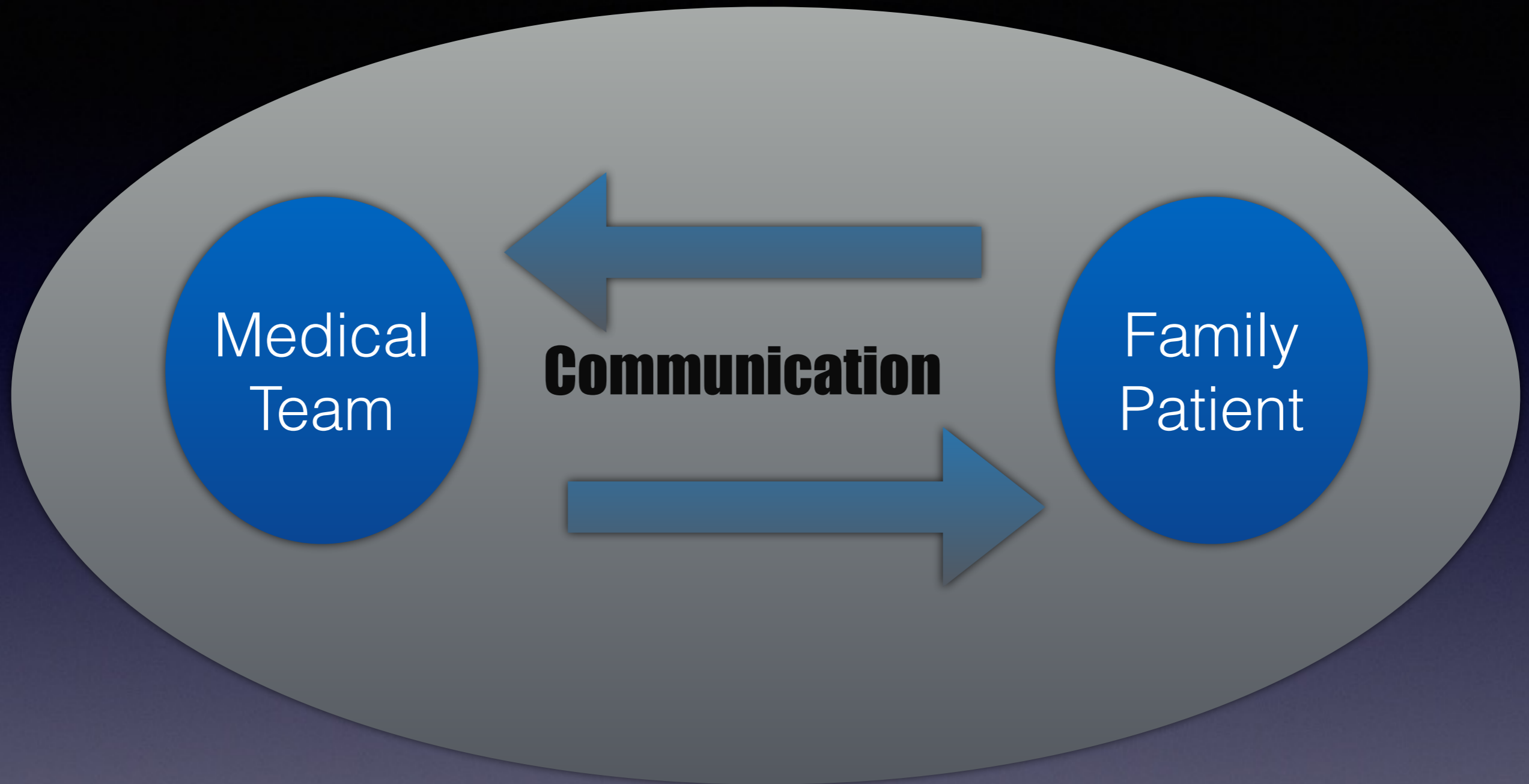
-Eric Mark, New Hampshire Psychologist

Medical Professionals

- Listen and respect the experiences of the family
- Empathy - understand the fears of the family
- Take the time to explain to the point of understanding
- Be constructive not obstructive
- Communicate more effectively with other doctors



Preventing and Facing Accusations



Parents/Patients have control too.

Medical Child Abuse ~ Munchausens by Proxy Plan of Action

- Retain a Lawyer
- Gather Supports
- Gather Medical Documentation
- Watch your Attitude!

Retain A Lawyer

- Only needed if facing allegations
- Lawyer who is well versed in child laws and who has worked with CPS cases
- Do not sign anything without lawyer approval
- Most states will appoint a lawyer if you cannot afford one
- Hospital and CPS vs. Mom or family - family will need legal help

Gather Supports

- Ask for letters of support from trusted people or groups
- Facilities may prevent employees from openly supporting the family, so it is important to gather supports quickly

Supports

Those who can verify that you are a good parent:

- Teachers
- Grandparents, family and friends
- Primary Care/Other Doctors
- RNs
- PT/OT, therapists and other home services
- Neighbors and coaches
- Church members or other community organizations
- Medical Insurance companies (approval for procedures/tests)

Gather Medical Documentation

- Past Medical History
 - Obtain past medical records to document when and why any tests and procedures were performed
 - Test, results, who ordered it, who performed and why
 - Obtain both doctor and nurse's notes
 - Medications - who ordered, why ordered, including date ordered

Keep meticulous current medical documentation:

- Who you spoke with
- What was discussed
- Who else was in attendance
- Plan if presented
- Date and time



PLAY NICE!

- AVOID:
 - Hostility, swearing, threats, aggressive statements or actions
 - Anger directed at staff members
 - Making unnecessary demands (medical or educational)
 - Constantly talking about child/self in a “sick role”
 - Vent to staff about doctors or other staff members
 - Complaining about small, unimportant things
 - Rigidity when it comes to new treatment plans

- Aim for:
 - Respect for all
 - Patience with new staff (ER, teachers)
 - Being open to new idea for treatment
 - Talking about your child/self as a normal child/self to the extent possible
 - Having a support person with you for doctor appointments and hospital rounds. Husband-wives, moms and dads, a medical partner, making every effort to attend all meetings and specialist appointment as a team



<https://www.google.com/search?q=doctor+patient+relationship>

Communication

- Report symptoms as honestly and accurately as possible
- Request a team meeting as soon as tensions begin to build
- Break down the issues into smaller pieces and try to address one concern at a time
- State feelings without accusations
- If you are firing multiple doctors, seek insight with a social worker, patient liaison, or other third party
- Advocate - Yes! Aggressive - No!

Advocate for you child/self!

- Parental instincts are vital. Parents know their children.
- Adult patients uniquely know their bodies.
- Understand your patient rights within each institution.
- Parents/Patients have the right to seek the best care for their children and themselves.
- Parents/Patients need to effectively advocate on behalf of their children and themselves.
- Faced with critical medical crises, parents do need to put. the best interest of their child first and speak up, even if it causes conflict

Be Mindful of all that is
Stated, Posted or Written

Social Media is often used against families



- Facebook

- Blogs



- Twitter



- Chat room, disease focused forums

- On line support groups



- Pictures displaying tubes, hospital, procedures vs. child participating in normal activities



- Be careful of how you portray your child among friends and within the community
- Make a Wish and other fundraising activities have been used to target families for MCA allegations
- Find a TRUSTED friend to confide in rather than seeking support via social media
- Know when you are at your limit and find someone to step in for you
- Seek help for anger management and/or stress management if needed
- Use stress reduction techniques

Prevention

- Work with a mito knowledgeable medical team
- Get a copy of medical records - communication log, documentation of each diagnosis, treatment and medication
- Don't speak for other doctors - force provider communication
- Avoid passing on other doctor's orders - Get ER orders in writing
- Second opinion for all major procedures (G tubes)
- Let others see your child sick

False Allegations

Child

- separated from loved one
- routines disrupted
- often become more ill (mito)
- PTSD

False Allegations

Parent

- Distrust/avoid medical professionals
- Fear ERs
- Doubt parenting, doubt themselves
- Socially withdraw
- Anxiety, fears, PTSD

Summary

- All parties involved are under tremendous stress
- Personalities and communication styles clash
- Communication is key

Parents need support rather than
punishment and/or suspicion

Compassion rather than Reaction

mito411@mitoaction.org