The Spectrum of Medical Child Abuse and
What is Happening Across the Country?

Link to Slides

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About The Speaker:

Richard G. Boles, MD

Mitochondrial & Molecular Medicine

Pasadena, CA

Dr. Richard G. Boles completed medical school at UCLA, a pediatric residency at Harbor-UCLA, and a genetics fellowship at Yale. For over two decades, Dr. Boles' clinical and research focus has been on changes in genes involved in energy metabolism, and more recently ion channels, and their effects on the development of common functional disorders. Examples include autism, pain syndromes, chronic fatigue, cyclic vomiting, intestinal dysmotility/failure, and depression. Dr. Boles practices the "bedside to bench to bedside" model of a physician-scientist, combining an active clinical practice with basic research into the underlying genetic predispositions leading to the same conditions. He has over 80 published papers, mostly in mitochondrial medicine. For 20 years, Dr. Boles was a faculty member at the Keck School of Medicine at USC and a practicing medical geneticist and metabolic specialist at Children's Hospital Los Angeles. He was a Medical Director of Lineagen and Courtagen, which are/were genetic testing companies.

Dr. Boles became involved in genetic testing in order to facilitate the translation of the vast amounts of acquired genetic knowledge into applications that improve routine medical care. Dr. Boles has an active private practice in Pasadena and Aliso Viejo, CA. About half of the patients he currently sees as a physician have one of more functional conditions, especially cyclic vomiting syndrome, other forms of complex migraine, and/or chronic fatigue syndrome. Most of the other half have an autistic spectrum disorder or related condition. His clinical practice is devoted to using information, including genetic testing, to guide options for therapy. His care philosophy, practice, and types of patients he accepts are discussed at http://molecularmitomd.com. A telemedicine practice has just started at https://cnnh.org. Dr. Boles also does legal consulting, especially for those with multiple functional conditions that others are considering factitious disorder/Munchausen-by-proxy/medical child abuse. Finally, he is the primary designer of SpectrumNeedsTM, a nutritional product with 33 active ingredients designed for individuals with autism or other neurodevelopmental disorders, with an emphasis on assisting mitochondrial function (https://www.neuroneeds.com).

MaryBeth Hollinger introduces Dr. Boles.

Slide 1:

Thank you very much for that great introduction, and thank you again for giving me the opportunity to speak to your audience. On the first slide here, if any of you felt that you were looked at or felt like the woman in the right hand corner, then maybe you have been here. A lot of my patiences, actually over half of my patients have been in this situation where somebody somewhere has thought that they may be contributing to their child's disease. It may have been just a look or an accusation, it may have actually gone to court, most of them are just a look or an accusation or just a feeling that they are not believed.

But this is an area that has a lot of opinions and the opinions are very strong and it is also an area that is not spoken about very much and to be quite honest with you physicians are quite afraid to do this. Not only because they are afraid of getting a bad reputation but they are also afraid of what will happen to them if they get a bad reputation. Hospitals do not want doctors to talk about this. I was in that situation as well but I told them that there was a first amendment, and that did not go over very well with the CEO, but be that as it may, I am now in private practice, and I now work for a great company over in New Jersey, CNNH, which I will go into a little bit more. I can talk about this and give you my opinions, and yes there are a lot of opinions on this and unfortunately there is very little fact because nobody has really studied this, nobody really writes about it.

So I am going to show you three different cases that I have seen, these are real, I changed the names, and I changed a couple of the things like where people are from, but these cases are actually exact pretty much. To give you an idea of what the spectrum is across this. So first of all, the first slide that you can see, that is what the social workers, or some of the doctors, or certainly the state if they are investigating they see, and it is again, when we talk about munchausen or factitious disorder it is almost always the mother that is accused.

Slide 2:

What I hope to do is to take knowledge, yes the DNA sequence is a major part of knowledge, and to make a diagnosis to make it clear, and you can think about it not necessarily a get of jail free card but a validation that there is an illness, this is real, and there is a treatment.

Slide 3: Disclosure: Dr. Boles wears many hats

MaryBeth went through this a bit, I just wanted to mention that I look at this from many different perspectives. I have been the director of companies, building products, for 20 years at USC and a clinician seeing patients at Children's Hospital Los Angeles, I am now in private practice in Pasadena, CA and I also do telemedicine through CNNH that is based in New Jersey but I am still in California. I see this perspective from many different places but primarily I am a clinician and seeing patients with mitochondrial disease forever, even before we knew what it was. I have been interested and active in this area for a quarter century now, which is a long time. I am also an expert witness in legal cases. The cases I am going to show you, two of them were my own patients and one of them I was an expert witness and they came to me later, so all three are patients that I follow.

- Clinician treating patients
  - Primary interests in functional disease (autism, cyclic vomiting)
  - Past: Geneticist/pediatrician 20 years at CHLA/USC
  - Present: Director, CNNH NeuroGenomics Program (https://cnnh.org/cnnhservices/neurogenomics-program)
  - Present: In private practice in California (http://molecularmitomd.com)
- Chief Medical & Scientific Officer of NeuroNeeds LLC
  - Present: The company that produces SpectrumNeedsTM (https://neuroneeds.com)
- Medical Director for DNA Sequencing Companies
  - Past: 5 years at Courtagen Life Sciences; 6 months at Lineagen
  - Present: Loose affiliations with some companies
- Expert witness in legal cases
  - Present: Medical child abuse, child neglect and custody cases (drboles@molecularmito.com)
  - Vaccine Court, malpractice cases
- Researcher with prior NIH and foundation funding
  - Past: USC faculty for 20 years
  - Present: Study sequence variation that predispose towards neurodevelopmental and functional disorders

Slide 4: Case Report 1 Alejandro – early 1990s

1. 3-year-old boy, he came to me with mild developmental delay, hypotonia (floppy muscles), and muscle weakness. We did a large workup for metabolic problems. There were biochemical markers that suggest this was mitochondrial dysfunction.
2. Probable mitochondrial disease diagnosis based on phenotype, biochemistry, apparent maternal inheritance, and apparent clinical improvement with cofactor therapy

7 siblings and mother all with some degree of developmental delay

3. Mother was disowned by her own mother and she and her kids were cut off from the extended family. The grandmother was the matriarch of the family and controlled access to everyone. The family was disowned from this large extended family that was giving them support.
4. Soon thereafter Child developed episodes of hypernatremia (high blood sodium/salt), alkalosis (opposite of acidosis, where you have a high PH instead of a low PH) , and vomiting blood.

3 episodes were life-threatening; sent to ICU, 2 went into full arrest, 1 where the heart and lungs stopped and had to be resuscitated

Several milder episodes that mostly led to bloody diarrhea

When these events happened, the extended family rallied around and supported the mother

5. No apparent medical cause was identified.

6. This was about 20 years ago and a much-younger Dr. Boles was the attending physician.

Slide 5: Case Report 1 Alejandro – early 1990s

Nobody could figure out what was going on with this, it didn't make any sense at all.
7. Blood testing via indwelling catheter every 4 hours revealed normal findings just prior to a life threatening event, in which case the blood sodium and bicarbonate levels were extremely elevated. This was done to identify when these things are happening. What happened was the blood was normal, normal, normal, normal, sky high and the kid is in the ICU. And that happened more than once. So then I said ok, maybe these are seizures.
8. Video-EEG was ordered. This was 20 years ago, this camera was no some small thing. This camera is as large as a television, huge and pointed right at the bed. The video-EEG consult was about 8 feet high, 4 by 4 feet and it was wheeled by a few people in the room. This was not a subtle thing, no camera in the mirror or anything like that. No further events occurred. The child was having episodes every day or so and now nothing happened for like a week.
9. The monitor was turned off, but the camera was left on.
So I ordered that the camera be turned off, we turned everything off, all the lights all the beeps, everything went off, it looked black, but the camera was still recording.

Slide 6: Case Report 1 Alejandro – early 1990s

9. The monitor was turned off, but the camera was left on. Within a day we had video of the mother with a large syringe, looking around to make sure nobody was there, filling it up with a liquid, a nurse walks in and she shoves it under the bed, looks around, nurse walks out, she goes to the G-tube and she pushes it into the G-tube and then the child got sick.
Video showed mom mixing a substance and injecting into the G-tube through a very large syringe (60cc).
10. Security found empty Alka-Seltzer tins in mom's purse, and the large syringe.
Alka-Seltzer is sodium bicarbonate and aspirin. Aspirin can cause stomach ulceration with bleeding.
11. Mother charged with attempted murder, pleaded guilty, and sentenced to hard time.
12. The episodes stopped. Child stable several years later.
Still with same degree of developmental delay and hypotonia and mitochondrial disease but has no more life threatening episodes. The child has been in care of the father ever since and doing well.

Slide 7: Case Report 1 Alejandro – early 1990s

This is on the spectrum remember, I am going to show you the spectrum of medical child abuse.
1. Some people really do abuse their children. There is a point to the child protective agencies. As a pediatrician at busy inner city children's hospital for over 20 years,I can tell you for sure even though I can not explain it emotionally and it still sickens me, this happens, and these people in these services are needed to protect the children.
2.. A pediatrician is charged with both protecting his patient (the child) and in protecting the family.
- When these are in conflict, the child takes precedence, the child is the patient.

3. Most cases of medical child abuse (MCA) occur in children who have a real underlying medical condition. This is something that people forget all the time. Is this child abuse or is this a medical condition, it is not an either or. It is not a question of necessarily of if you have a diagnosis that it is not child abuse. The question is, does the diagnosis explain what is going on?
4. Actually having mitochondrial disease, or any other condition, even if one can prove it, does NOT negate the possibility of MCA.
5. The key is to whether mitochondrial disease, or other diagnosis, can account for the issues that are of concern. That is the important thing here, does the diagnosis account for what is going on and that is not easy, because these diagnoses can do a lot of different things, they are very complex and few people understand them. It is a really big problem.

Slide 8: Case Report 2 Bailey – early 2010s

This was several years ago instead of 20 years ago, things have changed.

1. A previously-normal, intelligent, early-adolescent girl suffered from multiple functional symptoms that started following an apparent stomach flu at age 10 years:
Severe dysmotility, which has required long-term TPN (could eat almost nothing)
Chronic fatigue syndrome (the chief complaint, the thing that borrowed her more than anything else.
Chronic pain in multiple locations (very severe)
Unexplained tachycardia (high heart rate)
2. Probable mitochondrial disease diagnosis based on phenotype (the tachycardia the TPN, the dysmotility, the pain, and the onset with the stomach flu), biochemistry, apparent maternal inheritance, apparent clinical improvement with cofactor therapy (Q10, riboflavin, carnitine, the usual things), and a variant of uncertain significance in the mtDNA thought to be disease related. The pedigree in this family was suggestive of maternal inheritance, of course that doesn't prove anything but it is suggests that there a mitochondrial DNA component. I knew perfectly well that this was no the cause of all her problems, but because the other people in the family were not

nearly as severe. They had pain, fatigue, depression, dysautonomia, but they were functional, they weren't going to the hospital they weren't homeschooled, they weren't on TPN, they were normal people with a lot of aches and pains and other concerns, and they may be on a few medications but they weren't really what you would think of as sick. The maternal inheritance may be the mitochondrial DNA variant but there was obviously more to it then that. Everything was going along okay, we had a probable mitochondrial diagnosis maybe even a variant that suggests part of it, but then she started getting anemia.

3. Additional features developed:

Anemia (very severe) requiring multiple transfusions

Severe dysautonomic reactions often mimicking septic shock with negative cultures (shock syndrome), she would really be out of it, blood pressure would go way down, heart rate would get way up, she would get very clammy and pale. It looked like she was about to die of infection, it looked like she was septic. She would go to the ICU and they never able to find out what it was, it always went away.

4. Local physicians (somewhere in the midwest, she flew once a year to California to see me) could not identify an apparent medical cause for neither the severe anemia nor the life-threatening episodes of shock. They weren't believing that this was all mitochondria because why would it look like that in their mind. They thought that these events were life threatening and were going to kill her because it looked like she was dying and it required transfusions that had a lot of side effects. They felt that they had to intervene and they could no describe it.

Slide 9: Case Report 2 Bailey – early 2010s

5. Suspected MCA was reported, munchausen, factitious disorder, whatever you want to call it.

The family traveled to another state for expert evaluation by a mito doctor, many of you would recognize the name.

Suspected MCA was reported again.

This time, the patient, then in her mid-teens, was held against her will in the hospital for several months in which the parents had limited if any ability to see her.

The mitochondrial cocktail was discontinued.

The parents were not allowed to contact her during much of the time.

The hospital and physicians did not attempt to communicate with her previous medical providers. The only reason I knew it was going on is because the parents contacted me. When I tried to contact the doctors that were involved they would not return my calls or my emails.

Slide 10: Case Report 2 Bailey – early 2010s

6. The patient's condition deteriorated throughout the time of separation. She got a lot worse in many areas.

Under increasing legal pressure, the family was allowed to transfer the patient to the care of a local physician in a state adjacent to where they live.

The mitochondrial cocktail was reestablished.

The patient improved dramatically.

7. At this point exome sequencing became available. Exome sequencing revealed mutations in:

A mtDNA gene, likely accounting for mitochondrial dysfunction (previously identified)

A connective tissue that appears to be a mutation in the Ehlers-Danlos gene was found, likely accounting for dysautonomia which are the episodes that look like septic shock.

A Blackfan-Diamond gene, likely accounting for severe anemia

Once we got exome sequencing, it accounted for all of her disease problems. She was treated appropriately.

8. Six or seven years later:

Bailey is clinically stable.

Has a few (one or two) hospitalizations each year for blood transfusions because that is still a problem and she gets line infections occasionally.

Attending university full-time, she is doing well at the university, she is pretty much a normal student in all respects except for TPN.

All legal action against the family was dropped after quite a bit of a battle.

Slide 11: Case Reports 1 and 2 Analysis

I know that that was difficult, that is the spectrum, one end in which the mother is caught on videotape doing it, and on the other end, where they didn't understand the disease and they jumped to a conclusion that there was something wrong there, but eventually figured out what it was and she is getting better and it is clearly not abuse at all. While they have very different outcomes, and obviously these cases are very different as to what is going on, these cases started off the same way. Non specific clinical findings, pain, fatigue, nausea, developmental delay, hypotonia, hundreds of different things can cause each of those.

1. While very different outcomes, both cases had similar beginnings:

– Non-specific clinical findings

– A clinical diagnosis of mitochondrial disease that was not proven, and was challenged by some physicians. Does that sound familiar? If you are in that situation, that is the normal.

– Later development of severe life-threatening intermittent manifestations

– An inability of the physicians to medically account for these later developments

- Dysautonomic reactions can occur, but are not usually this severe.
- Anemia can occur, but is not usually this severe.

That is really the issue here, you have somebody where nobody knows what the problem is for sure, that you can not prove it. You have the following situation. You have a clinical diagnosis of mitochondrial disease that can't be proven and was challenged. They don't know for sure and some people really don't believe it. The child may die, there are life threatening events, people that are filing do not understand and can not account for. So when you have a child who is not doing well at all, and they can't account for what is going on, some people will say 'Well, I don't know what it is is, but maybe it is this", and some people will say 'It has to be this this' because they don't understand and they don't realize that they don't understand everything and that is sometimes a major problem.

Slide 12: Case Reports 1 and 2 Analysis

The cases were very similar in terms what went through the doctor's mind, I have a sick kid, the kid might die, this is very severe, and I don't know what is going on.

2. How are the cases different? One was a poisoner and one was a completely blameless family.

What was missed in the second case?

Slide 13: Case Reports 1 and 2 Analysis

These are the things I see over and over again:
– There was no communication with previous physicians. In fact they cut off communication completely because they felt the previous physicians were complicit in the diagnosis that was wrong, that the physicians were leading them astray. Even they were idiots, or wrong or evil, I don't know what they thought at that point about me, but probably all of the above.
– There was no attempt to order additional testing. In some cases that is reasonable and other cases it is not. Like the would not do whole exome sequencing even though I told them over and over again they should it.
– Even in the face of continued deterioration, (like when they took them off the cocktail and the condition continues to deteriorate) the hospital continued with its assessment and plan.

So these are the things that I see were the mistakes of the second hospital and the second set of doctors.

Slide 14: Case Reports 1 and 2 Analysis

3. Were the rights of the patient and/of family violated in either case? If so how? What would you suggest should have been done instead?

I will give some answers later but it is something to think about on this.

- Case 1
- Case 2

Slide 15: Case Report 3 Caitlyn – early 2010s

Again, names have been changed to protect the innocence or at least all the children are.
This was also several years ago.

1. 6-year-old girl with:

- Intestinal pseudo obstruction (very severe constipation)

When it gets to the point where you have to do a lot of measures, a lot of treatments, and it is severe enough that it requires hospitalization than often you get pseudo obstruction, pseudo meaning there is not like an actual block, you can't remove it surgically, nothing is moving but it is not because there is a block it is because the intestines aren't working right.

- Chronic pain syndrome (in the gut, hands, head, everywhere) including somatic and visceral hypersensitivity
- Generalized dysautonomia, including unexplained tachycardia
- ADHD - Normal IQ

2. Probable mitochondrial disease diagnosis based on phenotype, apparent maternal inheritance (looked like it might be mitochondrial DNA), muscle biopsy, (the other two cases never went to biopsy) and apparent clinical improvement with cofactor therapy

This is really common you have a probably mitochondrial diagnosis, many of you probably have that. Why is it probable? That is because there is not an absolute mutation that people can say 100% that is what it is. But as best as we can figure it out it is mitochondrial disease. So it is a probable diagnosis, this one is even based on muscle biopsy.

3. Caitlyn presented to the ER multiple times and her care continued to escalate:

- Feeding tolerance worsened so that she was on tube feedings, TPN, and frequent additional IV fluids on top of TPN
- Multiple hospitalizations for fever and/or tachycardia, ruled out line sepsis

Occasionally the line showed problems but rarely. Most of these hospitalizations were because there was an increase of this temperature, in other words a fever, the heart rate was high, and they said 'ok it looks like it is line infection' and we need to put them in the hospital for antibiotics, and the cultures were negative and she was discharged three days later.

- BiPAP (breathing mask) and supplemental oxygen
- IVIG because of multiple infections
- The pain eventually led to narcotics, heavy duty things that have a lot side effects.

4. Presented to another facility. That is a major red flag, going to another facility.
They couldn't figure out in their mind was caused her problems. They could not justify the escalation in her care, which had gotten a lot worse in the past year. They did not see anything objective to account for her escalation of care. No apparent medical cause was identified to justify the escalation in care management. They filed for medical child abuse.

Slide 16: Case Report 3 Caitlyn – early 2010s

5. Suspected MCA was reported.

– The child was held in the hospital against her mother's will for months.

– Limited and supervised visitation was instituted.

– The hospital and physicians had limited communication with her previous providers, including one who was known mito doctor, not me.

– She was successfully weaned off of several aspects of her previous medical care, including narcotics, BiPAP, supplemental oxygen, IV fluids, TPN, tube feedings, and IVIG. All of those things that were added in the last year were taken off.

– The diet was expanded to pretty much normal.

– The mitochondrial cocktail was discontinued.

– She remained in good condition throughout the admission and weaning process.

So they said, 'these things are not necessary this is medical child abuse". They took her off of all of those things, and the child did great, no problems.

Slide 17: Case Report 3 - Analysis

Did that mean that the child was victim of medical child abuse? Did the mother make this up? No. Both of those are not true.

1. Again this case has similar beginnings to the previous cases:

– Non-specific clinical findings

– A clinical diagnosis of mitochondrial disease that was not proven, and was challenged by some physicians.

– Later development of severe life-threatening intermittent manifestations.

– TPN, a line, IVIG, and particularly narcotics all have severe risks, they can kill you, especially narcotics.

– An inability of the physicians to medically account for these later developments

2. What are the medical and legal teams not considering herein? What are they missing? What are they not considering?

Slide 18: Case Report 3 - Analysis

– The mother never misrepresented herself, although her assessments regarding the child's discomforts were likely off, exaggerated in that the child was probably not in as much pain as the mother portrayed. She was very anxious herself. Probably the child did not have as much nausea. But the mother never lied, she never misrepresented herself, her child was pain, her child was nauseated, her child had a fever, she told it as she saw it, although her assessment were a bit exaggerated based upon her anxiety and her fear, her fear that her child had a severe mitochondrial disorder, and would likely not survive, she believed that. She felt that the child did not get to the hospital and immediately be put on antibiotics that she would die of line sepsis. But, the mother did not order the IVIG, or the narcotics, she did not place the line.

– Each and every escalation was performed by medical professionals. Every single one was done based upon what the medical professional felt at the time was the right thing to do.

– All of the providers were aware of what other providers had done, or should have been, it is all in the chart. When I went through the chart as the medical expert, everybody was talking about everything else, these providers that had done were aware of what was going on.

3. Who is responsible for the unnecessary escalation of care in the absence of fraud? I am going to make a couple of assertions here, first of all, the escalation of care was unnecessary because she was taken off of it and did fine. The doctors made a mistake. There was no fraud, I know I have not gotten to that point yet, but the mother never misrepresented herself, never lied. The only reason she went to the second facility is because the first facility was closing down for insurance reasons, I can't remember exactly but she wanted to continue but was unable to. I think it was an insurance issue, the insurance companies stopped paying for it so she had to go to another facility.

Slide 19: Case Report 3 - Analysis

I was brought into the case, I read all the records, it was obvious to me that the mother was very anxious and that when the child had a fever, of course the child was tachycardic it was dysautonomia. The fever was dysautonomia. If you take the temperature all day long which was done in the hospital the temperature frequently would go over 101. The child is that way every single day of her life. The people in the emergency room would say, this is our algorithm. If you have a fever, if you have tachycardia, you have line sepsis, not just a possible line diagnosis, but that sepsis because for a non mito kid, that is right. Tachycardia with line means line sepsis more often than not. They often put the kid in the ICU because the vital signs were crazy, it was dysautonomia and they didn't understand that.

The child really did have visceral hypersensitivity, normally you can feel when you eat something, but when you eat too much you have nausea. It is Thanksgiving and you pig out you have nausea. But what if all of your nerves are exaggerating what they get, that is hypersensitivity, when it happens in the gut it is visceral hypersensitivity, so a little food in the abdomen, a little bit of food in the stomach causes severe nausea. A tiny bit of sensation on the skin, causes severe pain. This child had chronic pain, visceral and somatic due to the nerves constantly firing exaggerating signals. That led to TPN, because if you put any food in the kid the kid became nauseated. And it led to morphine and other narcotics to try and control the pain.

There are just some things you are not going to be able to make normal. This kid can eat, but is going to feel some nausea. This kid can be off narcotics but is going to feel some pain. Eventually, with the right medications, that work on neuropathic pain we were able to reduce the pain and the nausea to point that it was really quite mild. But you still have to say ‘ok, it is mild but we are not going back to TPN, we are not going back to narcotics. The kid really quite clinically stable, just understanding the dysautonomia the child doesn’t require ER visits unless she unstable and her mental status drops and she become lethargic.

4. Following my testimony, the child was returned to the family under the legal responsibility of the maternal grandparents regarding medical care, but with no further restrictions on mom’s Involvement.

– Child is clinically stable and requires no ER visits.

– Still has functional symptoms related to some residual pain and fatigue.

– No care is now provided other than medications for ADHD (that didn’t do very well when that was discontinued), dysmotility (she does have this but it is just not bad enough for TPN) and neuropathic pain, we can treat it with a lot better drugs than narcotics.

– Regular diet without supplementation.

Slide 20: Case Report 3 - Analysis

5. What can we learn regarding what happened in this case?

It is a case where there was an escalation in care which was drive by the anxiety of the mother and the ignorance of the physicians. Because of insurance issues, and others, there was not good continuity of care. But who is responsible for the unnecessary escalation of care in the absence of fraud? Unfortunately, the blame was placed on the mom. She contributed to it no doubt because she would come in saying ‘My kid is doing again, the fever is 102, the heart rate is really high’ and the emergency room would overreact, but she did not do any these things. She did not lie. So what can we learn regarding what happened in this case?

Slide 21: Case Report 3 - Analysis

Can a good parent be contributing to harm even if they always had the best intentions and never lied?

Yes. This case is in the middle. This case is not a poisoner, this case is not a situation in which it is all medical and everything was appropriate nobody did anything wrong the doctors just didn't understand. This is a case in which a child was harmed, though not seriously and not irreversibly, because bad things could have happened but didn't for the narcotics and the others. But the child was harmed and the harm could have been worse because of an overreaction of the family, of the mother, and of the medical team.

It is always a different person, mitochondrial disease involves many different tissues, everything needs energy, so you go to the cardiologist, you go to the GI, you go to the neurologist, you got to the pediatrician, you go to the surgeon for the lines and on and on, a pain specialist, a developmental specialist and you can go on and on. Some people have ten different specialists or more. Everytime you go to the hospital it is a different person taking call for each and every one of those. It is a setup for disaster, eventually one of those is going to be a denier of mitochondrial disease or have a bad day or something else. It is a setup.

Slide 22: Analysis of Cases 1-3 and About One Hundred Others

Now to get into the meat of the matter I have set up the situation and now I am going to try and go through this to kind of discuss the various situations. I tried put everything on this slide here, we have already gone over it before. This is the layout of the majority of the cases that I do and I am a medical expert whose taking cases all across the country. I am currently involved three different cases that I am expert on and three different states, none in California.

Another family of mine was sent to the social worker and the Department of Children's Services for that, maybe one a month or so, for my patients because I have the most severe and complicated ones it seems like. It is an ongoing issue, but what is almost always, this is sort of the menu for disaster.

- Non-specific clinical findings
  - GI failure on tube feedings or TPN (common)
  - Multiple hospitalizations with fever and tachycardia, rule/out sepsis (particularly if they have a line)
  - Organ failure, especially bone marrow with anemia and multiple infections

When they get to the stage that somebody is thinking munchausen often you have one, two, or three of those. But there are exceptions, there are some that don't have any of those.

- A controversial diagnosis in the absence of proof - Unfortunately if you are a MitoAction most likely there is at least a consideration of mitochondrial disease in you or your child, it is a controversial diagnosis and usually there is no proof.
- Severe, even life-threatening, intermittent manifestations

– Protean

Different forms, mitochondrial disease can look like gut failure, it can look like anemia, autism, chronic fatigue, depression, tachycardia you name it, it can show up in all different ways.Why? Because every tissues requires energy, neurological predominantly because the nerves are electrical and require a tremendous amount of energy.

This is an important one here:

- An inability of the physicians to medically account for the issues of concern

They may or may not buy the fact that mitochondrial disease is the cause of what is going on. Even if they do buy that, remember that doesn't mean that there is not munchausen going on, because in the first case, the real one I showed, that was a mito kid, but things happened on top of that from poisoning. So how do you know if mitochondrial disease can account for it when mitochondria affect every cell and every tissue because energy is needed for every biological process? That is a very difficult question.

– In part due to extreme biological and clinical complexity

In the first case, it was poisoning, and I was the doctor that filed, I could not account for it any other way, and eventually it got proved. I filed after I got the videotape. In the second case, they couldn't explain the anemia, and they couldn't explain the episodes of dysautonomia. The episodes of dysautonomia were related to ehlers-danlos and related to mitochondrial disease and the episodes of anemia were due to the black fan diamond mutation. So it is very complex, so it is not like 'Oh they should have known that.' I couldn't explain the anemia either until I got the black fan diamond mutation.

– In part due to a failure of the Western Medical Model

The Western Medical model does great, there is no better model out there out there anywhere in the world that anyone has ever come up with. But it has its problems like any model, it is not perfect. It assumes that there is a problem, a diagnosis, something that you can find, something that you can explain, even if we can't treat it. This is controversial, but I am going to say this because I truly believe, this is what I see in my own patients. Most of you, most of your children, do not have a diagnosis, you do not have a single cause. You have contributing factors. Most of you have multiple factors, each and every one of them contributes towards disease, predisposes towards it, but none of them cause it by themselves.

Most human disease, whether it is asthma, or diabetes, depression, heart disease, or mitochondrial, is multi factorial, many different genes, many different environmental components. In particular as a geneticist I look predominately at the mitochondria, at the genetics. I showed you the exome sequencing, it took three mutations to explain what was going on in the second case. And I am sure there are other mutations that I am not recognizing that are either right in front of me or in the parts of the DNA we didn't sequence at the time. So it is complicated, so it is like 'I want a diagnosis, I can't find it, maybe it is munchausen', but remember in the first case it was mitochondrial disease and munchausen, is this is complex. Mental health issues, the brain is electrical, consciousness itself is involved in the electrical conductivity through the network of brain. The higher parts of the brain require a tremendous amount of energy, it would be a shock to me if mitochondrial disease did not cause higher brain issues. People say 'okay, it causes autism, it can cause migraine, it can cause stroke, it can cause mental retardation, it can cause seizures'.

People accept that but anxiety and depression, those are mental issues, those are brain. Of course it can cause anything with brain, and brain problem it can cause requires electricity, but people see anxiety and depression and they start thinking down another road. Not that, 'Well they have a disorder of energy metabolism and they have other neurological problems, why not anxiety and depression?' Since mitochondrial disease inherited in most cases, not all but in most cases, in most cases it is genetic from a mutation or more likely mutations or variants in many different genes, it often comes from the mother at least the maternal component, the mitochondrial DNA. Remember the three cases that I mentioned, all three of them had maternal inheritance. The mother was affected to some degree, in all three cases. And in all three cases, the mother had some sort of mental health issue, anxiety, and or depression but always had anxiety.

- Mental health issues, including anxiety and/or depression, in the child and other family members.
  - Especially anxiety and/or depression in the mother

So you have a situation in which again, you have a child who is not doing well, it could be life threatening, no-one can explain it, it doesn't make any sense, and the mother appears to have a lot of anxiety and depression. That is the perfect storm, that is what causes these cases, over and over again. That is what triggers it. Eventually, somebody, one of the people rotating through one of those many services, says something and reports, and you start the whole ball rolling.

Often there is a trigger in addition to that, sometimes there is not, but most of the time there is.

- A breakdown in communication, respect, and/or support between the family and one or more care providers.

Sometimes that starts because one or more of the physicians are outwardly contemptuous, maybe it is the things they say or maybe it is just the tone of their voice and the way their eyes roll or something. The family, usually the mother, reacts by hostility. Hostility can be firing a doctor, you have the legal right to do so, and sometimes the doctor needs to be fired, but just so people know, firing a doctor is often a trigger for a munchausen accusation, even if you are in the right, and have the right, just be aware of that. A lack of respect, this could be started by the doctor not knowing anything about the disease, asking questions that you have heard 20 million times before, or maybe the doctor really is stupid. Sometimes they are, and the mother, the family, doesn't show respect, and says 'You don't know anything, just like the rest of them. You know nothing, I don't want you involved in this.' or something. That is often what it is, there is no communication. It is like, well the child keeps getting admitted because of fevers and keeps getting normal cultures, maybe we should change the temperature which is automatic admission? Maybe evaluating in the emergency room, maybe get a blood culture and BBC but not admit if the child is not lethargic or looking sick and eating okay? Or tolerating the tube feedings okay? Communication, the mothers are often thinking this and talking through it to the person who is staring at them with contempt, there is a breakdown.

– In most of these cases, there are MULTIPLE care providers given the number of specialists referred and the rotation of services.

• Often times there is a presentation to another medical facility, for a "second opinion", procedure, or emergency. A lot of the cases I've been involved with the family went for another opinion, or went for a better opinion and crossed state lines to find a doctor who is an expert, or on vacation. Controversial again but I tell you there are some places in this country you perhaps shouldn't have vacations in, because if you go to that main facility, you will be accused. I'm not going to name any names now, you guys can talk amongst yourselves, you probably where you are anyway. It is unfortunately a reality, there are some places that are lightning wrong to this and that can be a problem.

Slide 23: What Can You Do? Pre-Allegation

Now that I have broken you down I want to build you up, so what can you do? What can you do now, you are saying 'Okay this sounds really horrible, nobody has accused me yet, how can avoid that?' Well, here are my suggestions, there are my opinions, there is no research behind this, because nobody has done research and nobody writes about this. These are my opinions based upon talking to many many other mito doctors, many moms and dads and kids, some of them have since grown up and also reading the literature and talking to the child abuse experts. Again, these are my opinions. The most important thing is you need a team leader.

A team leader – one person who runs the show

If a bunch of cooks are in the kitchen doing things and nobody is a team leader, nobody knows what is going on, nobody takes responsibility for it until a child abuse person comes up there and grabs everybody and throws everybody out of the room that doesn't agree with him or her. You need a team leader who will stand up and say 'No, you were wrong, the patient has the following laboratory results, they could not have been faked. The patient has the following symptoms that you say are unexplained but this is how you explain it. Yes there is a problem here, perhaps there has been too much done, perhaps we should take off the narcotics, perhaps we should reduce the TPN, this is our plan but this is not munchausen.' That is what you need, you need a team leader. Someone who will stand up for you. Usually that is the pediatrician, it can be a mito doctor as well, somebody who understands the situation.

– Assemble a team that works with the leader and with each other.
– Work collaboratively with the leader and team, but let them take the heat.

A team that can work with a leader and yourself, and to a lesser degree with each other. You are never going to find a team where everybody on the team is buddy buddy, that's not really necessary but they are at least cordial to each other and they work collaboratively, and they have a good working relationship to the leader and people that you can trust.

– Do not doing anything important without the input of the team leader.

Forget about munchausen for a second, you don't want somebody who doesn't know what is going on saying that you need to have your child in the ICU or you need a tube or you need a surgery. They may be wrong. The team leader needs to be involved in that, and the team leader is usually the pediatrician then the mito doctor needs to be involved as well if it is severe. That is that is the best way to inoculate yourself against an accusation.

'This is my doctor, this is the leader of my team, I don't do anything until he/she says it okay, because I am the mother, this is the person leading the team, what you say seems reasonable, or maybe I disagree with it, but regardless, you have to talk to this person.'

That is the way to handle a situation like that.

– Have the important information with you at all times.

There is what we call in medicine, positive binder signs, you go in there with a bunch of notebooks and things, yes that can be a problem, but also going in there not knowing the name of the diagnosis can also be a problem, but going in with all of the information available on your phone if you need it, and going in with a few key documents and a letter from a mito doctor, and some telephone numbers and emails to call, that is the best way to do it.

Slide 24: What Can You Do? Pre-Allegation

Be very careful regarding presenting at other facilities, I can not emphasize this enough. If you feel that the people who are taking care of you are bogus clowns, and some of them are, they don't know what is going on and you want to go to somebody else, then by all means, do that. But, going to another facility, like and emergency room or medical center, without having been sent there but your doctor, by your team leader, is dangerous.

– Clear it first with the team leader, or at least with a team member.
– By very careful while traveling.

Slide 25: What Can You Do? Pre-Allegation

Insist on DNA testing, at least including exome and mtDNA. We are going through the genome where you sequence all of it fifty times more than exome, but at least exome and mtDNA, and insist that a mito specialist read that exome, because otherwise it can be missed. Okay these things are expensive, but they are not as expensive as you think. You can get an exome and a mitochondrial DNA on your child, for under a thousand dollars cash now. So if insurance company says forget it we are not paying for it, I'm not saying that that is pocket change, but we were talking about a few years ago something like 10,000 or more. It has come down, there are several companies that will work with your insurance company, and if your insurance pays for it, great, and many companies will only take insurance and will tell you exactly what you owe and there are no billing, like it will be $100 and later insurance sends you a $5,000 bill, that happened in the past. There are companies that don't do that anymore. They say 'This is how much you owe and no more, here is a contract, you can't possible owe a dime more.' And you can decide, and if it is too much, then maybe the cheapest way is to do cash, sometimes it is cheaper to do cash then what the insurance has you pay even if you cover it.

Slide 26: What Can You Do? Pre-Allegation

Avoid breakdowns in communication and respect - even if you are right.

Even if the doctor is absolutely wrong, and even if you feel that the doctor is being, pardon my language, a total asshole. You have to communicate respectfully and you have to keep communication open, because this is your child's life. You have more at stake.

– A*lways treat the medical team with respect, especially if they do not deserve it.*

Respect is something that is easy to give when it is deserved and hard to give when it is not deserved. Respect is most important when it is not deserved because that is the person that you could get into trouble with.

– *You do not have to agree with the doctor; you do not have to comply*, in fact I suggest that you don't if you don't think that it is right, get your team leader involved, if the team leader talks to them and they agree, then that is probably something that you can agree with, but you don't have to agree and comply with every resident in ever emergency room, or every attending or every specialist, but you must keep an open line of communication.
of communication.

– *Let your team leader take the heat.*

I had a couple years ago through another organization we had some workshows on this, with people were having difficulty on that and we did some play acting. I would pretend to be the real jerk doctor, I have seen enough of them I know how to act that part really w

They have to say 'I'm sorry that you feel that way, I don't really agree with you, it is really complicated, none of us understand it completely, this is my team leader, this is the doctor I trust, this is the one who is in charge of all of the team, everybody has agreed that the team leader has to be involved in all of these decisions, you have to call the team leader, here is her number, this is the one who is in charge of all of the team, come up with a plan with the two of you, and then present it to me.'

That way you don't take the heat for saying 'I don't agree with you, you are an idiot, I'm not going to do that, you don't know anything about mito.' Let the team leader education them about mito. They probably need it.

Slide 27: What Can You Do? Pre-Allegation

If you are affected, and half of you are and half of you aren't playing the average from what I have seen, you need to get treated. Taking care of a kid with mito disease is very very hard, even if you are in perfect shape. It is not easy to get treated there is very few adult doctors, I know you are afraid to go in and get a diagnosis of mental health disorder and that it will make things even worse, but you really need to take care of your own health so you can take care of your child's health. If you have anxiety or depression those are easily treatable, anxiety and depression for mitochondrial dysfunction, I treat that all the time in my patients, teenagers young adults I see as well, it is very easily treatable and it makes a big difference.
– Especially regarding anxiety and/or depression in the mother
– You cannot adequately advocate for your child if you are not healthy yourself.

Slide 28: What Can You Do? Post-Allegation

Don't panic!
This is post-allegation. The worst thing happens, somebody said something to somebody, it is either whispers in the hall or the way they look at you or you actually have a court order. So the first thing to do is not to panic, which is unfortunately what most people do.

Slide 29: What Can You Do? Post-Allegation

What happens when they call in the social worker?
– *Tell the truth.* And I mean all of the truth. Explain why you are anxious. Explain what you want. Be honest and open with them. Honest and open is much more likely to get you where you want to be then being close minded and lawyered up. What do you want? You want your mito doctor to be able to talk to to the doctor. You don't want to discontinue something abruptly. You want to wean it off and to watch. Explain what you want and why.
– *Be in problem-solving mode.* At this point, unfortunately it is no all your decision. They have to agree with you, so you have to work with somebody that may be very hostile towards you and

you may hate, you think is evil and wrong and everything else, but you need to work with them in problem solving mode. Because again, this is your child, and you need to work it out.

Slide 30: What Can You Do? Post-Allegation

This one, I have taken some flack for this, that is okay I have been honest with you so far.
Put yourself in their shoes
– *The child is very sick and they cannot seem to help.* Most of them are in this production because they want to help, particularly, in pediatrics. The want to help, they have a child that is sick and they don't know what to do. Usually they are doing this because this is the only thing they can think of.
– *If they have concerns that you may be part of the problem, they are legally as well as morally required to act.* I know that you may not believe this but they be ignorant of mitochondrial disease, we all are, we don't understand anything practically yet for where we need to be, but they are not evil, the vast majority of them are very well meaning people who have taken a very difficult road, believe me, I've done it, I have filed before, it is not easy. The easy way to do it is to not do it and ignore it.
– *They may be ignorant, but they are not evil.* They need to be educated, but not fought. The best way to educate them is your doctors that believe in you and believe in your child to educate them.

Slide 31: What Can You Do? Post-Allegation

Involve your medical team "early and often".

This is about, somebody in Chicago a long time ago a politician said you should vote early and often, fortunately things are better now. Your medical team needs to be involved early and often. Get them involved early, when things look like they aren't working out in the emergency room or during hospitalization. Keep them abreast of what is going on. Maybe it is daily emails, maybe they are not answered by your doctor but they are appreciated and they show what is going on.

Slide 32: What Can You Do? Post-Allegation

If a report is filed, get legal counsel.
– Insist on an expert witness if there is legal action.
If you lawyer up early, it is a red flag unfortunately. Sometimes that is the right thing to do, and sometimes it is not, there is no size fits all for that. When you are having trouble, it is best to take a step back, be nice but insist that your team work together with your existing physicians, and to let them take the heat. But once a report is filed, once there is legal action, then you need to get a

lawyer, then you need to get an expert witness. It doesn't make you look bad, because if you don't, it makes you look stupid to be honest. That is the time to do that.

Slide 33: Beyond the Metabolic Pathways

You can just glance you don't have to read this slide, but the point is, this really is complicated, and your doctors do not have to be poorly educated or that they never took a continuing education class, they don't have to be stupid, they just don't know. Nobody knows. This is really, really complicated.

- There are hundreds of known causes of mitochondrial disease
- There are perhaps more causes of Secondary mitochondrial dysfunction
- In most patients the underlying gene is not obvious even by an expert.
- The complexity lends itself to massive parallel sequencing = "NextGen sequencing".

Not on this slide:

  - Transcriptional elements
  - Translational elements
  - Chaperones
  - Glycosylation
  - Assembly factors
  - Other post-translational elements
  - Mitochondrial Import
  - Cofactor metabolism
  - Antioxidant pathways
  - Many others
  - Causes of secondary mitochondrial dysfunction
  - Ion channels
  - Peroxisomal biogenesis factors
  - Many others
  - Phenocopies

Slide 34: The functional symptoms elephant

Again, I love to show my elephant here, this is from the Indian proverb that if three blind men are feeling different parts of the elephant, think about it, a cardiologist, a gastoenteoligist, and an ENT, feeling different parts of your child, calling it different diagnoses. All of those diagnoses on there are functional diagnoses. These are the type of diagnoses that on top of the fact that they are actually impossible to prove, and they are subjective, a lot of people out there, forget about the mitochondrial world, a lot of people out there don't believe that they exist, they think they are a mental, but they do exist, they are real. If your child or you have a few of those, then these are the kind of things that are trouble.

- tinnitus
- depression
- autism
- migraine
- postural orthostatic tachycardia syndrome
- fibromyalgia
- functional abdominal pain
- irritable bowel syndrome
- interstitial cystitis
- restless legs syndrome
- complex regional pain syndrome

The elephant is lying down due to chronic fatigue

Slide 35: 20 "Functional" Disorders

There are many, many, many others.

- Attention deficit hyperactivity disorder
- Anxiety disorder
- Autistic spectrum disorders
- Chronic fatigue syndrome
- Complex regional pain syndrome
- Cyclic vomiting syndrome
- Depression (MDD)
- Fibromyalgia
- Functional abdominal pain
- Interstitial cystitis
- Insomnia (chronic, severe)
- Irritable bowel syndrome
- Migraine
- Panic disorder
- Post-traumatic stress disorder
- Postural orthostatic tachycardia syndrome
- Restless legs syndrome
- Temporomandibular disorder

- Tinnitus
- Vulvovaginitis syndrome

Slide 36: What Is Functional Disease? A poem by a 14-year-old patient

Here is a poem you can go back to and read by one of my patients who is an adult now but when she was fourteen she wrote this about functional disease. I think that it is a better description than an elephant or anything else.

I never know when its going to come back
This fatigue is an internal attack
It so easily cripples me
Only no one can see
Its so hard when you easily tire
And everyone around you thinks your lazy and a liar
They cant see so they don't know
I know in my heart its real though
Its a relief to get the answer and know you're not crazy
You can finally prove you're not just lazy
Its still not easy and never will be
But maybe some day the world will see

Slide 37: Don't Panic!

You may know where this is, that is a picture of a real car in orbit around the earth with a dummy in the seat, and it says *don't panic* on there. You are in a situation that, the vast majority of people would panic, just like a car revolving around the earth. That, by the way, is a real photo. That is not generated by a computer. That is probably the most important thing to learn from that is don't panic. There are options, there are things you can do to avoid, or at least decrease the likelihood of an accusation, and how to deal with one after it happened.

Questions:

MaryBeth Hollinger:

Thank you so very much, that was an awesome 'why it happens, how it happens, how it can sneak up you' and I so appreciate it and the don't panic advice. All the callers should know if you are accused or if you feel impending or you are getting too many of those hairy eyeballs, you can always call MitoAction, our mito411 line, or email me marybeth@mitoaction.org, and we can help start to sort things out as well as hook you up with people you may need to be hooked up with. I love your points, they are so on spot. I wondered if you could talk a little bit more about some of red flags that maybe you didn't mention. I know that you mentioned going to a new facility or multiple facilities and maybe the multiple doctors, but I know there are few others, females, even female little girls vs. little boys, single parents, when people get well well educated it seems on their child's illness it seems to set them up, and if there were any other red flags. You know people can't help what gender you are.

Dr Boles:

Unfortunately these are false flags, but they are real in that they are in the mind of the beholder. It has been show before that, if you look at old literature, even new literature about the munchausen mom, about how she wants to different facilities, and she doesn't believe this, and the way that she talks, and all that stuff, this is the way that people act if their child has a chronic illness. It is not a flag, it may be a flag for maternal anxiety, but it may be a flag for a child that has a lot of hospitalizations and nobody can figure it out, but it really has no predictive power for munchausen, unfortunately a lot of doctors were trained and they feel that is does. So, female sex definitely, it is almost always the mothers, there are exceptions, but they are extremely rare. Regarding the gender of the child, I didn't even know there was something there, I see boys and girls equally but maybe there is a false flag there as well. Oftentimes the mother are accused because they are overeducated, a lot of them are nurses, but a lot of times the mothers are very uneducated, and they get into this trouble because the medical system is so complex, and it is so ridiculously set up, that nobody can navigate through it well, but people who are less sophisticated and less educated have more issues, plus the fact that they are looked down upon perhaps by many in the medical team. So I see both of those.

MaryBeth Hollinger:

I find it is interesting that in our society, we are really forcing parents to take care of very ill children at home, and handle G tubes, cords, cecostomy tubes, flushes, all of these things that they are supposed to do without a blink, then when they gain their knowledge and may present it in the ER, the team feels very threatened by their knowledge and it is almost used against them. So we are putting parents in a very tricky spot, do we want them to know this stuff or not?

Dr Boles:

Many of my parents run ICUs at home. They have a lot of tubes, a lot of beds, they are taking vitals, they are basically running ICUs at home. They do a better job than the real ICU most of the time, but not everyone agrees upon that. They are there because they want their child at home, it is cheaper to have their child at home, and it is better for the child to be at home medically. So they are at home for really good reasons but it doesn't mean everyone agrees, and someone will think that they should not have been given that responsibility, or something like that, but you are right, it is a difficult situation.

There is also the fact that I think a lot of you know that but this is a controversial area in medicine, every new area is going to be controversial. Because, until it is all figured out there are going to be different opinions. That is good because if you all have one opinion and that is the doctrine, that is the dogma, it could be very wrong. You want there to be different opinions so that people think about it and check different things so that what eventually comes out of it is the truth. But with those different opinions, families can fall in the cracks, and that is where it is wrong. It is okay to go get different opinions, in fact that is probably a really good idea, because each of the doctors may have a fraction of the truth and they may, and each of the doctors might have come up with a treatment that might work based upon that fraction of the truth.

MaryBeth Hollinger:

Let me switch gears a little bit. If we could talk a little bit about social media and from my research because I do take quite a few medical child abuse calls as well, on a different level that you deal with them, but sort of the first line of attack, we always bring up the social media and how it really can be used against parents so I wanted to make sure that we mentioned it. I lectured and then followed up and spoke with a prosecutor in Texas and he had really hammered home that, that I was so right on to focus on social media, because it is literally considered the crime scene for many medical child abuse cases. So I just wanted to caution parents to just really be careful with how they use social media, how much information they divulge, it can't look like attention seeking, it has to look like a very balanced picture of child maybe on a bad day but as well as on a good day, and not just, 'here is a blog about all of the terrible things that have happened to my child,' as well the photographs. Anything that can be deemed embarassing or hurtful to the child when they are a teenager, so that picture with tubes and ports and things that may be a 15 year old girl may be embarrassed by later is considered abusive by the courts and many people don't know that.

Dr Boles:

Everybody is using social media to gather evidence, if you have active social media they will pick and choose what evidence they want to find out of it so do have to be careful. I have had many times in which the other side would say 'the mother is on this, and blogging on this or something like that' and I say 'this is something that mothers do with kids with chronic illness all together, there is no predictive quality regarding a munchausen accusation based on this, there is no studies that have shown an increase of likelihood, this is just something that communities do.' But being outside of the community, you are right, it looks wrong to them. They don't realize, each community has its own norms, what is considered acceptable and unacceptable and the things that are acceptable in the mito or other disease communities, are not necessarily to everyone who looks on there.

MaryBeth Hollinger:

Totally true. I want to just touch on adult manifestations, or even older child when they start using terms like somatoform and conversion disorder and how that plays into this picture. Do you have any feel for that?

Dr Boles:

Well, somatoform is a different opinion coming from a different direction but the same problem. The idea of somatoform is that the symptoms are not real, but they are very upsetting. Not real, meaning, look at pain, pain is the easiest thing to look at. You hit a toe with a hammer, you have tissues damage in the toe, the nerves are shooting pain signals to the brain and the brain is interpreting that as suffering. So you have the three components. If the nerves are firing pain signals, which you get in chronic pain, but there is no damage to the toe, you can have exactly the same pain, the brain gets the same pain signals, and comes up with the same suffering, it is not a mental illness. It is not a child who is a baby and can't tolerate the pain, it is not made up, it is not attention seeking, the brain is getting real pain signals, but the toe is normal. That is what most chronic pain is, it is wired that are getting crossed that are sending the wrong message.

Somatoform disorder is looking at, 'Okay, patient has a toe that hurts, it hurts a lot, but the toe is normal, the MRI shows you have done anything, there is nothing there.' That doesn't mean there aren't nerves that are firing, people have been dealing with somatoform ideas for a couple hundred years, there are drugs and treatments that will help on that, many of them work on chronic pain. I don't like the word, and I don't like the way people think about it because I think a lot of them are thinking it is in the brain, it is not in the nerves, and that the person is making it up or exaggerating because they want to get some gain from it or they can't handle the suffering because they are a baby with a low pain tolerance. But really it is the same as visceral hypersensitivity coming from another point of view. It is treated in the same way, because it is the same problem. Why is there somatoform disorder, well there is genetic and environmental reasons for that.

There is sort of a progression, if you are a school aged child, then the mother poisoned the child. If you are a children well the teenager isn't going to get poisoned, it is mental illness, it is somatoform disorder. The second you are eighteen you are a drug addict, going in there to the ER because you are drug seeking. So among the adults that is what I see most often, is that they go from being like 'the mother did it' to 'you are a drug addict.' None of which is true.

MaryBeth Hollinger:

I see also a lot of 'you have anorexia' instead of GI issues. I see that one often too. The final question that has come in is, and I do hear this a lot as well, what do you do when you meet that doctor and you say, 'call my team leader, call the primary, call the metabolic specialist', maybe you are in the ER or wherever and the doctors just refused to make that step and make that contact.

Dr Boles:

Go above that doctors head. Go above his head and and think about what you are going to say, be very respectful, and say, ‘there is a disagreement among the physicians, I am caught in the middle, my doctors have said ABC, these are the ones that I trust, these are my doctors I have chosen for my child, but you guys are saying XYZ, I want you two to talk, figure it out among yourselves and then both of you come to me and tell me what you think, because I can’t go left and right at the same time and I want to follow what my doctors say.’

MaryBeth Hollinger:

That is a great response, truly appreciate that. Dr. Boles I so appreciate you spending an hour with us this Friday, and I know that this recording will be listened to many more times in the future, because I think people stumbleupon medical child abuse when they are almost least expecting it and the allegations hit them pretty hard. One of the things I hear most often is ‘But I know I am a good mom, how on earth could this happen to me?’ because people are putting everything into their child. So I just thank you, I am so glad we can add this to our recorded presentations, for many more people to listen to if not today then whenever they get that chance, I so appreciate it.

Dr Boles:

Your welcome very much and thank you for this opportunity.