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Pittsburgh Parent

FREE

You know your child best

Holiday Happenings & Gifts

You Know Your Child Best. Period. End of Story.

By Kristi Wees

My pre-child life as a research chemist seemed as far from "motherhood" as one could get, but I'm not so sure it was. Far gone are my days of mixing chemicals, and donning a respirator to take a gas sample to the lab. My days now have been replaced with similar investigative science…let me explain.

The test tubes were replaced with baby bottles (complete with little brushes and tiny parts, thanks to Dr. Brown), the stinky lab chemicals were replaced with stench-filled diapers (that nearly peeled the paint). Oh, and those samples that I once collected and sent to the lab, they have now been replaced with repeated blood draws, hospital visits and urine collections from a toddler. I promise you, these duties are some that not even the most seasoned "chemist" wants to experience with their own child.

My new job title that I hesitantly accepted, after the birth of my second child, became: "Advocate." Why was I hesitant, you may ask? Because all my life I have been a "rule follower," a do-gooder and sometimes even a leader, but always a "by the book" kind of gal! But this time, following the rules, and trusting those who were supposed to be able to give me answers, didn't get my daughter the help she needed.

When our littlest struggled with colic, reflux, chronic diarrhea, violent tantrums, developmental delays, regressions, food intolerances and breastfeeding elimination diets, I found few "books" that could have prepared me for ALL of this. Although I read *What to Expect When You are Expecting* from cover to cover, I was not reading then to prepare to have a child with special needs. I don't know many parents who set out to prepare for that. I surely did not prepare myself to be my child's strongest advocate, until I realized I was the only one who was qualified to fill that role. As a person who played by the rule book, I had put much of my faith in "the system" to help me raise my child to be the "healthiest kid on the block." What took me longer to realize (longer than I wish to admit), was that it was time I began thinking for myself, and advocating for my children's health.

We visited more than 15 specialists…doctors, pediatricians and therapists. Some doctors told us that they could find nothing medically contributing to our baby's 14+ hours/day of crying, or that crying was "normal" for a baby. Then, some specialists at the other end of the spectrum informed us that our child was suffering from a "rare" disorder called mitochondrial disease. I, as a mother, did not know where to turn, whose "expert opinion" to believe or what to do to help my sweet baby girl… until I had no other choice than to listen to that tiny voice from within — my mother's instinct.

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Here are the five (+1) rules of the "rule-book" that I have re-written over the last ten years as a mom. For this once "rule-following momma," these are just a start for the "wish I would have known then what I know now" chronicles:

1

You know your child best. Period. End of Story.

That means you know them better than any doctor, therapist, or specialist that you are sitting in front of who may spend a few minutes with your child. YOU have spent months and years caring for them. You know them intimately; do not be afraid to be confident in that fact.

2

If something feels wrong to you regarding your child, something probably is wrong, go with your gut, but never stop asking questions and thinking for yourself.

If you voice your concerns and are repeatedly told you are just worrying too much or have "first time mom" syndrome, seek a second opinion and talk with other parents. If your health care provider is not committed to an improved quality of life for your little bundle of joy (and you), then it is time to look elsewhere. Ask other parents for recommendations, continue seeking the right fit for your child until you find the team that can help you navigate your way to a healthier child. Do NOT squelch your concerns until you have dug deeper, for the sake of your child's health.

3

Use technology to your advantage, and to the advantage of your child's health.

You have the power of information at your fingertips. USE IT! That may mean looking up medical journals on PubMed (http://www.ncbi.nlm.nih.gov/pubmed/) Even if you have to Google every word you do not understand until you have "interpreted" it into something you can digest, it will be worth it for your child's health. Connecting with other parents via Facebook, Twitter and local support groups to compare notes and share advice, can be truly helpful. In today's world, we have no excuse NOT to be informed, and this goes for all aspects of parenting — including what food we put in our baby's mouths to the chemicals we allow them to be bathed in, rubbed on and injected with.

4

Every medical intervention, procedure, pharmaceutical and injection has a risk, which varies from child to child and person to person.

Do not let anyone convince you that "perfectly safe" and "no harm" are possible in the world of medical science. They are not. Read the fine print, including the package inserts on all treatments and preventatives and make an informed decision for your child after you have done your own research (including digging into your and your partner's family health history).

5

Listen to and trust your instincts above all else .

Your mommy gut, inner voice, gut instinct, whatever you want to call it… is there for a reason. I believe this is one reason we have nine months of pregnancy to hone in on our "inner voice" literally — the little life growing within us. So once the baby arrives, keep this connection and whenever you feel that pit in your stomach that something just isn't ok… LISTEN TO IT… it comes from a place deep inside you where your child once lived!

BONUS

Make sure your baby has received their NEWBORN SCREENINGS (NBS)!

When you bring your baby into this world, a lot of the first few days are going to be a blissful blur, but it is crucial to give your baby a healthy start from day one, that you ensure that your baby has their FIRST TESTS… newborn screenings. I knew so little about this test with both my kiddos, and really wish I would have known more (now that my daughter is suspected of a metabolic disorder that was not detected by NBS). These tests screen for conditions that a perfectly healthy appearing baby can have, they are treatable conditions, that when caught early, lead to healthy lives, but when not detected, can result in autism, developmental delays, mental impairment, and even sudden death.

What are Mitochondria?

- Mitochondria are tiny organelles found in almost every cell in the body.
- They are known as the "powerhouse of the cell."
- They are responsible for creating more than 90 percent of cellular energy.
- They are necessary in the body to sustain life and support growth.
- Mitochondrial failure causes cell injury that leads to cell death. When multiple organ cells die there is organ failure.

What is Mitochondrial Disease?

Mitochondrial disease is a chronic disorder that occurs when the mitochondria of the cell fails to produce enough energy for cell or organ function.

Mitochondrial disease can be of genetic or non-genetic origin. Non-genetic disease can result from factors such as environmental, cosmetic, or other lifestyle-related exposures.

The incidence about 1:3000-4000 individuals in the US. This is similar to the incidence of cystic fibrosis of caucasian births in the U.S.

There are many forms of mitochondrial disease.

Mitochondrial disease presents very differently from individual to individual.

What are the symptoms of Mitochondrial Disease?

The most common symptoms are:

- Poor Growth
- Loss of muscle coordination, muscle weakness
- Neurological problems, seizures
- Autism, autistic spectrum, autistic-like features
- Visual and/or hearing problems
- Developmental delays, learning disabilities
- Heart, liver or kidney disease
- Gastrointestinal disorders,

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severe constipation
- Diabetes
- Increased risk of infection
- Thyroid and/or adrenal dysfunction
- Autonomic dysfunction
- Neuropsychological changes characterized by confusion, disorientation and memory loss.

What other conditions are linked to Mitochondrial Disease?

Other disorders and diseases have been found to have defects in mitochondrial function including:

- Autism
- Type 2 diabetes
- Parkinson's disease
- Atherosclerotic heart disease
- Stroke
- Alzheimer's disease
- Cancer

In addition, many medicines (both prescription and over the counter) can injure the mitochondria.

What is Newborn Screening?

Newborn screening is the practice of testing every newborn for certain harmful or potentially fatal disorders that aren't otherwise apparent at birth.

Source: mitoaction.org and J Child Neurol, Wallace, K., 2014, PMID: 25008905

What does Pennsylvania Screen Newborns for?

All newborns in Pennsylvania are screened for six mandated conditions.

They include:
- Congenital adrenal hyperplasia (CAH)
- Congenital hypothyroidism (CH)
- Galactosemia (GAL)
- Maple syrup urine disease (MSUD)
- Phenylketonuria (PKU)
- Sickle Cell Disease and other Hemoglobinopathies (HGB)

In addition the state of Pennsylvania follows up on 24 additional conditions.

A listing of those can be found on the state website at http://www.portal.state.pa.us under newborn screening, and the screening legislation link.

Two additional follow-up conditions were added in 2013 that do not appear on the list, CCHD (heart disease/defect) and SCID (immune condition).

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Fort Pitt Museum Open daily, 10am-5pm, Point State Park • 412-281-9284

Friendship Hill National Historic Site Tours, special events, Junior Ranger Program for ages 6-12, Point Marion • 724-725-9190

Pittsburgh Zoo & PPG Aquarium Visit the Kids Kingdom and the PPG Aquarium, 9am-5pm, adults-$15; 60 plus-$14; Ages 2 thru 13-$13; under age 2 & Zoo Members-Free; parking is free, Highland Park • 412-665-3640

Please submit Info for our December Calendar by November 1
724-898-1898
Fax: 724-898-1877

ICE SKATING

Brady's Run Park Ice Arena • 724-770-2060
Center Ice Arena, Delmont • 724-468-1100
Lynch Field, Greensburg • 724-834-4880
Mt. Lebanon Ice Center • 412-561-4363
North Park • 724-935-1280
Schenley Park • 412-422-6523
South Park • 412-833-1499
The Ice Castle • 412-561-9090

SKIING

OH
Alpine Valley • 440-285-2211
Mad River Moutain • 800-231-SNOW
Ski Clear Fork • 419-883-2000
Snow Trails • 800-OHIO-SKI

MD
Wisp • 301-387-4911

NY
Holiday Valley • 716-699-2345
Kissing Bridge • 716-592-4963

PA
Blue Knob • 800-458-3403
Boyce Park 724-733-4665
Mystic Montain • 800-422-2736
Ski Denton • 814-435-2115
Whitetail • 717-328-9400
Willowbrook •724-929-2294

WV
Alpine • 570-595-2150
Canaan Valley • 800-622-4121
Snowshoe • 877-441-4386
Timberline • 800-776-9464

Too much tech *... continued from page 11*

social platform that lets kids express themselves, feel included and showcase their talents. "Social networking and role-playing games can have a social benefit, especially for inhibited kids who aren't socially adept in person," says Osit.

Techno-balance

Simply yanking kids' electronic access isn't a workable long-term option for most families, so parents need to strike the right balance for tween screen use. Though the American Academy of Pediatrics recommends limiting kids' screen time to two hours of "recreational" use per day, each family needs to define what flies in their household, says Rembold.

She encourages an open-door policy for screen use: kids need to have the door open when using technology in their bedroom. When kids turn in for the night, devices should power down, too. Bedroom electronics, including televisions and smartphones, are linked to sleep problems in kids and teens.

Harsh parental mandates may spark rebellion instead of compliance, so ask tweens to contribute to the dialogue about screen use and set media limits together. According to a study published in *Journal of Adolescent Health*, when parents and kids agree on screen time limitations, the rules are more likely to be effective.

Libby Boggs won't be loosening up Drake's media limits any time soon. A well-rounded life includes time for entertainment media along with lots of other pursuits, she says. "We want him to be creative and to be able to have fun in any situation—not just online or in front of a TV." ■

Malia Jacobson is an award-winning health and parenting journalist and mom of three. Her latest book is Sleep Tight, Every Night: Helping Toddlers and Preschoolers Sleep Well Without Tears, Tricks, or Tirades.

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Even though follow-up conditions are not mandated, the health department requires any birthing facility that is screening for them must also provide them with the data on those conditions.

Lastly, although hearing screening is not mandated it is highly recommended for newborns. ■

Source: Correspondence with the PA Dept of Health and www.health.state.pa.us/newbornscreening

Author Kristi Wees is a former chemist and scientific sales manager who temporarily traded test tubes for toddlerhood. She currently blogs at www.babyfoodsteps.com about taking baby steps each and every day to a happier, healthier family all while navigating the twists and turns of the metabolic/mitochondrial disorder that her daughter is suspected of having. She just relocated to Pittsburgh from Houston, Texas.

This article originally appeared on the website What To Expect (WhatToExpect.com) on August 7, 2013.

Adoption and *... continued from page 17*

rewarded with a fantastical black sheep family story. Such information provided me with history that fascinated me and helped me to understand her, and appreciate the fortitude of my family.

• *I see myself reflected back in the shared physical characteristics of my brothers, nieces, nephews, and son born to me.* People have always shared how they can pick us out of a crowd. I know that my dimples, curly hair and ruddy complexion come from my father and my stature, smile and eyes are gifts from my mother, who I resemble more and more as I age. I share left-handedness with my maternal grandfather, who died when my mom was just two-years-old.

• *I know my medical history, what issues and diseases occur frequently within our family gene pool.* I know what my mother, brother and grandparents died from. I know about the fertility and female health of the women in my family. I can provide answers in confidence when asked by my physicians.

• *I am not wary of others when they inquire about my family.* I am not concerned about being judged by the moral or political biases others hold about adoption, my birth mother/parents, birth country or culture of origin.

• *I do not wonder whether I should share my status = adopted.* I am not asked a

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