

## Love in My Tummy

My son Mason was born July 11<sup>th</sup> of 2004. In September of 2004 he was diagnosed with a rare brain disorder called Lissencephaly (smooth brain), this condition greatly affects his cognitive and physical development. He is unable to walk or talk and has very limited voluntary movement and control of his body. By March of 2006 he had limited ability to suck and swallow and had a feeding tube placed with the intent to supplement his oral feedings with formula. He continued to decline in his ability to eat by mouth and was soon after entirely fed through the tube. Over the next four years with a diet consisting entirely of a complete meal in a can, he would vomit nearly every time he was fed. Our house had a constant and lingering vanilla scent that we grew to loathe. Mason would show agitation at the mere sight of a syringe due to the discomfort and vomiting that would soon follow. Mealtimes were not a pleasant time but merely another medical procedure that was performed every four hours in our home. It never dawned on me that I could be feeding him REAL food. I had the impression that tube=formula. As a family we eat very healthy and I can recall so many times thinking "this is the only one of my children that will eat whatever I give him and yet I feed him the worst". In early 2009 a bronchoscopy and endoscopy verified our fears; he was aspirating frequently from his vomiting and reflux and had caused severe irritation to his esophagus. He wasn't a candidate for surgery and his doctor appointments had become less about prevention and shifted focus onto "how can we keep him comfortable for what time he has left".

One day I was venting my frustrations to Mason's speech therapist and she replied with these sweet words of freedom "Have you ever thought about doing blended diet with him?" WHAT?!? Why was this such a difficult concept for me to grasp? Why had I never considered this myself? He is just a child like any other child who needs proper nutrition to grow and learn, his tube is merely an alternate route to his stomach and what I put into it shouldn't be any different than what any other child needs to grow healthy and strong.

It didn't take but a moment to ponder this new revelation before I was setting up a meeting with Marsha Dunn Klein to get us started in the right direction. Even

after understanding the concept that real food vs. formula was certain to be healthier on every level, I was still nervous about starting. What does his body need? How many calories? How much iron? How much protein? For the past four years my motherly intuition had been clouded by the idea that this highly processed, vanilla flavored, thick, liquid in a can had everything a body could possibly need. The thought of planning it all out myself seemed overwhelming to me.

I read the Homemade Blended Formula Handbook from front to back, did many Google searches on different foods and their health benefits, wrote down what I believed he needed and took my information and excitement to Mason's dietician. The master plan was to add in a new puree of baby food every week or so, just as you might introduce an infant to new foods, slowly transitioning him off of formula and onto real food within six months to a year.

My plan fell short after the first few days as he was already holding down more of his meals than he ever had before, each time I added more food and less formula the vomiting decreased. Within two weeks he was completely transitioned onto real food and the changes that came with it were nothing short of amazing! His pale color changed, his level of alertness increased, his focus and eye control became stronger, his muscles were strengthening, his vomiting had stopped completely, his reflux had decreased, he was feeling good and happy and I was feeling a new sense of empowerment!

As a parent it is our natural instinct to want to stop a child's hurt, to comfort their fears and make things all better but as a parent of a child with special needs there is a significant level of helplessness watching your child suffer and not being able to provide them any relief.

What an amazing accomplishment as a mother to be able to provide relief for something that has for so long caused misery and discomfort! I now felt as though I had taken back some control over his health and wellbeing. I now have the ability to bring him comfort and address the issues that are causing him

discomfort. Mason's meals are made up specifically for him and his needs and they change accordingly. Taking dairy out of his diet decreased his reflux dramatically, as did adding in apple cider vinegar. His secretions can be managed now through cardamom and cranberry. I can give him ginger tea when has an upset stomach and coconut water when he needs extra electrolytes, If he has been sick I can vary the amount and variety of foods that I give him based on how well he is tolerating and digesting it. There is so much more control and flexibility with real food vs. formula.

I walked out of his most recent GI and pulmonology appointments with a new sense of hope, gratitude and pride. They were in awe of the little boy before them and the unexpected changes they saw in him. The doctor who only months before was helping me set up a "do not resuscitate letter" and increasing medication to comfort him was now asking for tips to tell other parents and left me with this bit of expert advice "keep doing what you're doing".

A swallow study done a year after starting the blended diet showed that he was no longer aspirating and is now able to take small bites of puree by mouth, something we never thought he would be able to do again.

Mealtimes are no longer a medical procedure but a time of bonding and comfort. I feel good about what I'm putting into his body and instead of preparing for the inevitable consequences of the meal with towels and suction machine within arm's reach I am singing "Yummy Yummy Yummy I've Got Love in My Tummy" as I feed him. And I can say that I truly do LOVE doing homemade blended formula, I LOVE what it has done for Mason, his quality of life and for our family as a whole.

**By Sarah Robinson, Mason's Mommy**