

FROM ANAPHYLAXIS TO BUTTERCREAM

THE AMAZING STORY OF HOW ONE MOTHER
HELPED HER DAUGHTER WORK THROUGH
LIFE-THREATENING FOOD ALLERGIES

Holli Bassin, MBA, Health Coach

ACCEDE CORPORATION PUBLISHING

Boston, Massachusetts

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www.yourfoodallergycoach.com, www.hollibassin.com

Cover photography and design by KasZucker Design and Marketing.

Cover image courtesy of Treat Cupcake Bar.

Interior design by Amanda Filippelli.

Edited by Melissa Caminneci.

Hardcover ISBN 978-0-9985630-2-2

Paperback ISBN 978-0-9985630-0-8

E-Book ISBN 978-0-9985630-1-5

Library of Congress Control Number 2017930484

Printed in the United States of America.

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While all the experiences in this book are true, some names and identifying details have been changed in deference to the privacy of the people involved.

Acknowledgments

I'd like express my love and gratitude to my daughter, Rachel for her intelligence, perseverance, nonchalance and ability to think outside the box. I'd also like to thank my daughter Iris for her never ending smile and ability to always see the positive in anything and everything we ever do.

Loving thanks to my husband, Ed for his unyielding emotional support and enthusiasm throughout this process. His reasoning, intellectual perspective and positive outlook will always keep me buoyant!

Most of all I want to express my utmost respect and gratitude to Alexis. Without her knowledge, experience, dedication, perseverance, love and guidance we would not be living a normal allergy-free life today.

Honorable appreciation goes to the School of Integrative Nutrition for enlightening me about nutrition, immune system health, and coaching. This education

has changed my and my family's life for the better in so many ways.

Exceptional thanks to my editor, Melissa Caminneci for her amazing hard work, professionalism, dedication, expertise, and guidance. I give her kudos for willing to work with me as a first time author and taking lead of the overall process.

Gratitude and special appreciation to Wendie Trubow for her expertise and leadership. And extraordinary thanks to Jenny Berk for her mentorship and passion for life!

Others to thank...

Scott Buquor, Deborah Elbaum, Nicole Crossman, Joseph Lipchitz, Jillian Erdos, Jean Sharry, Elizabeth Lee, Cissie Klavens, Debra Bruckner, Lena Goodwin, Holly Palli, Robin Zucker, Melissa Patz, Rebecca Young, and Sharon Goodfriend.

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*In loving memory of my Grandmother Miriam, my mentor
and inspiration.*

Goblin Free Treats

OCTOBER 31, 2015

It's Halloween and my two girls, Rachel, 12 and Iris, 10 are going trick or treating with respective friends. Two things are unusual about this particular event. First, Rachel is free to be at a neighbor's house for dinner and subsequently with her friends for the rest of the evening without any dietary restrictions, and second Rachel is actually allowed to eat *milk chocolate* anytime she wants.

Three years ago, Rachel would have had an allergic reaction to anything that contained eggs, dairy, or mustard. If she had ingested even a morsel of any of these foods, she could have gone into a life threatening state of anaphylactic shock, a severe allergic reaction. Initially after ingestion, she might have had a runny nose or skin rash. But within 30 minutes or so, she would have begun to feel nausea, tightness in her chest, itching, hives, swollen or red skin, tightness in her throat and trouble breathing. Without an immedi-

ate injection of epinephrine (adrenaline) to reduce the swelling she could have died.

Needless to say, I was always on guard and never more than 30 minutes away from her with an antihistamine and EpiPen in my purse, unless another adult was present who could administer the necessary protocol and call 911. In previous years, either my husband or I always went trick or treating with Rachel to be certain she didn't accidentally ingest anything that contained, or was made in a factory with eggs, dairy or mustard.

Some children who have only one or two food allergies can outgrow them. But children like Rachel who develop multiple food allergies rarely outgrow them. Rachel was only able to go from *anaphylaxis to buttercream* because I consistently analyzed and questioned the medical community's training and conventional wisdom of avoiding all allergens. As a result, we changed our mindset and opted for systematic desensitization, a non-conventional, holistic alternative method of allergy elimination that is managed with the guidance of a certified nutrition and health coach. In this therapy, once the immune system is balanced, the allergic client is given a precisely measured introduction of the allergenic food. The dosages are gradually increased until the food can safely be consumed without an allergic reaction. And it worked!

Here's Rachel's life changing story.

PART ONE

DISCOVERING FOOD ALLERGIES



Our Bundle of Joy

Ed and I were married in the fall of 2001. Being on the mature side for a newly married couple, we wasted little time starting a family, and after nine months of marriage, I became pregnant. We were overjoyed when our healthy bouncing baby girl, Rachel was born on Red Sox opening day, 2003. We named our daughter after Ed's grandmother Rose, a Jewish tradition.

Though I was nauseous beginning at week seven of my pregnancy and the nausea didn't subside until sixteen weeks, I muddled through by eating crackers to help with the nausea. Otherwise, the pregnancy proceeded smoothly and I gained the appropriate weight.

At five months, I felt that first funny fluttery feeling-- a gentle kick from my unborn fetus. And at sixteen weeks I had an amniocentesis, a prenatal test to detect abnormalities that involved removing a small amount of fluid from the amniotic sac surrounding the fetus. The results reassured us that everything was fine. A huge sigh of relief!

THE “BIRTH”

At my 40-week appointment, the day before my due date, my OBGYN was concerned about decreased fetal movements. On that day, she did some tests in her office, but my kick counts were still too low, so she asked me to get an ultrasound. I picked up Ed, who was in a meeting with a client near the local hospital and together we went for the ultrasound.

During the ultrasound, the technician went into the adjacent office to call the doctor on the phone. The next thing I knew, my husband was on the phone with the doctor who was instructing him to take me straight into the Boston hospital for an induced delivery. Apparently the baby’s amniotic fluids were at a dangerously low level.

My level of concern was less than that of the obstetrician. I had been participating in an online community with hundreds of other expectant mothers since the time of my conception. We formed our own support group and experienced each stage of our pregnancies together. There was a lot of information posted about pregnancies and subsequently deliveries where Pitocin, a synthetic oxygen used to induce labor was given for no reason except for the doctor’s convenience, or to prevent liability issues. I was leery about having Pitocin. From my research, I knew that Pitocin made the contractions more painful and could result in an unnecessary cesarean section. I wanted my labor to come naturally and was convinced that our baby was not ready to come out.

Ed followed the doctor's instructions. But when we arrived at the hospital, I still refused the Pitocin. As I expected, the staff was unwilling to break my water because I was not in labor. Eventually I relented. They gave me the maximum dosage of Pitocin, but I still did not go into labor. Then they broke my water anyway. Despite all of the last-minute panic, my first labor and delivery was completely normal and natural, except for the epidural to alleviate pain.

Once she was in my arms, I enthusiastically began nursing my daughter in the delivery room. With the help of a lactation consultant my new baby girl latched on well. My milk however, did not come in for several days. I supplemented with Similac, and Rachel was voiding and stooling well.

First Allergy Signs

The first sign that Rachel was in trouble happened when she was five months old. On a perfectly beautiful warm sunny day in September 2003, I seated my daughter in her Blue Evenflo stroller so we could go for a walk into town. At five months old she was sitting unsupported, an important developmental milestone; alongside her was a multi-colored huggable plush toy. In motherese I told her about the trees that had not yet started turning their brilliant New England fall colors. In response, she babbled away – “da, da, da, da.”

Decked out in a short sleeve cotton pink and white striped onesie with a white bib decorated with whimsical flowers, a buzzing honey bee and the words, “Thank Heaven for Little Girls,” with a pair of plastic kiddie sunglasses resting on the bridge of her nose, she was the living picture of the cutest thing ever! A beautiful, long, lean and curious baby, she had a twinkle in her hazel brown eyes and short baby peach fuzz hair that barely blew in the faint breeze. I loved being her mother and spending time with her.

Once we arrived in the town center, I stopped in the local ice cream store to buy a cup of black raspberry frozen yogurt. We crossed the street to the green park area so we could sit and enjoy the frozen treat. As Rachel had recently started eating solid foods, I didn't see any harm in giving her a little taste of the frozen yogurt.

Suddenly, her face and lips swelled and she developed hives. I had no idea what to do. I had never seen anything like this before. I panicked.

"Look at my baby!" I exclaimed to another mother in the park.

"Is this your first child?" she asked.

"Yes." I responded. She told me that she needed some Benadryl (antihistamine). I had very little idea of what Benadryl was. Luckily the local commercial pharmacy was right across the street and we rushed in.

"What should I do?" I asked the pharmacist in a trembling voice.

Calmly, he called the pediatrician's office to find out how much antihistamine to administer. I gave Rachel this dosage, purchased the bottle of liquid antihistamine and walked out of the store with my baby. Still shaking and numb, I didn't yet know that Benadryl would become as much a routine part of our lives as diapers, safety seats, Elmo, and Baby Einstein. While we walked home, Rachel fell asleep in the stroller, prob-

ably from the antihistamine. I felt baffled, traumatized, and scared.

The minute I walked in the door of my house, I called my husband who was on a business trip. Optimistic and not easily ruffled, Ed was his usual calm self. I was a wreck. He wasn't there to witness the experience. I told him it was like when the girl turned into a blue blimp in *Charlie and the Chocolate Factory!*

How could this be? What happened? Was it the black raspberries? It couldn't be the yogurt...or could it? At this point we just didn't know. And then, two months later we had another terrifying incident.

LAS VEGAS: NOVEMBER 2003

Rachel was 7 months old when the two of us accompanied my husband on a business trip to Las Vegas. Ed traveled often for business. He was the owner of a software company, and his clients were all over the country. This was our first time going together as a family.

While we were in Vegas, Rachel became fussy and began rubbing her body all over. Her skin turned a bright, blotchy red. Even her eyelids were red and puffy with eczema. As her eyelids were never swollen and red like that before, I knew she was having an allergic reaction. But to what? Then it hit me. Yogurt. I had been eating a lot of yogurt on the trip to try and combat what I thought was the start of a yeast infection.

What happens in Las Vegas, stays in Las Vegas, but all of this was not funny. I was still nursing and so she was ingesting whatever I ate. Ed was concerned about me because even though I was nursing, and it was hot in Vegas, I was drinking an excessive amount of water-- probably two gallons a day. So I began eating a lot of yogurt. Yogurt is fermented and contains probiotic gut flora to eat up the yeast.

What should I do? Clueless, I called the pediatrician. He told me to give her Benadryl. This relieved the immediate allergic reaction, but we wanted to understand the big picture.

CHANGE MY DIET?

Once we got home from Las Vegas, I asked Rachel's physician if I should change my diet. I suspected that Rachel may have been reacting to the yogurt, or more precisely to all milk products. The physician said it was unnecessary. Foolishly, I initially ignored my own instincts and listened to his advice. After all, doctors have years of education and training, so they should be knowledgeable and respected, right?

But a few days later, Rachel's eczema got so bad that I went ahead and changed my diet to see what would happen. I ate my cereal in the morning with either water or water mixed with a small amount of cow's milk as I wasn't aware of any other kind of milk at the time. Not very nutritious for me or for my breastfed baby, but just an experiment.

Lo and behold, in about three days I noticed a slight improvement in my daughter's eczema, something she had been suffering with since she was a newborn. Holy cow! She must be allergic to cow's milk! Should I change my own diet? What could I eat? Was she allergic to anything else? We just didn't know.

HYDRONEPHROSIS

Soon after Rachel was born, she was diagnosed with hydronephrosis or vesico-ureteral reflux. Hydronephrosis is a congenital condition of the urinary tract system that causes a swelling of a kidney due to a build-up of urine. Because of a blockage or obstruction, urine cannot drain out from the kidney to the bladder. The doctors put Rachel on prophylactic antibiotics to treat her condition.

All this rang a familiar bell. As a child, I had the same medical condition, which we were told was hereditary. My mother took me to some of the best New York urologists for treatments: Dr. Coleman and Dr. McGovern. I was constantly on Macrochantin, an antibiotic to prevent me from getting urinary tract infections, until at thirteen years old I finally outgrew the condition. I was told that I had high fevers as a child, and I was also on tetracycline which discolored my teeth. Subsequently, for years I had constant yeast infections.

And so, while I was always concerned about Rachel's eczema, at the time I was more concerned about the hydronephrosis and thought she might outgrow the eczema issues.

When I got back to Boston, I asked Rachel's pediatrician what to do. This doctor also told me not to change my diet. Though skeptical, I listened because I had no one else to go to who I trusted or from whom I could receive helpful advice.

Who could help me figure out what to do differently? I didn't know what questions to ask or why I should ask them. I did not know what foods were affecting our diet. It was very unclear.

I was fearful of giving Rachel anything new, but at the same time I was still in denial. "My daughter couldn't possibly be allergic to foods; that's silly." When I was growing up, children were occasionally allergic to nuts, but I had never seen an allergic reaction such as the one Rachel had experienced. I may have heard that someone got sick from eating a bad piece of shellfish, or someone may have had a peanut sensitivity, but literally turning pink with hives was completely foreign to me. I wanted to protect my daughter from ever having this happen again, yet at the same time I wanted her to live a normal life. And I was a new, inexperienced mother.

I begged the pediatrician to send us to an allergist for testing, but he thought it was unnecessary.

I was so confused and frustrated. I knew something wasn't right. Why did the doctor not see it? Finally, I chose to listen to my own intuition and eliminated all dairy products from my diet.

In the meantime, I began to wonder if the antibiotics that Rachel was on for the hydronephrosis might have something to do with her milk allergies that we first observed at five months and then at seven months old. Later I found out that they did indeed. They were killing the good flora in her gut, thereby weakening her immune system and natural defenses to foreign pathogens. Good gut flora is essential to kill bad, disease-causing bacteria in the gut and to keep us healthy. In fact 70% of our immune system is in our gut; our immune systems are dependent on good bacteria greatly outnumbering bad bacteria. But I didn't learn this until much later when I started to educate myself about the cause of Rachel's allergies.

Why didn't the doctors tell my mother to give me probiotics to replenish the good gut flora destroyed by the antibiotics? Likewise, why didn't the doctors tell me to give my baby probiotics along with antibiotics? Good question. Perhaps physicians are unaware of antibiotic's effect on the microbiome of the gut, or they know but ignore the implications. Whatever the reason, few bother to inform their patients upon dispensing antibiotics to also take probiotics or, if they do know, they don't emphasize the importance of doing so.

First Food Allergy Signs

While Rachel had full blown allergy reactions at five months and then again at seven months, there were signs of potential allergies even earlier. At the time I was not educated to recognize these warning signs.

During our first pediatrician visit, when Rachel was four days old, the doctor discussed thrush with me as Rachel had some “baby acne.” Thrush and yeast are related, but at this time I had no idea what was to come and so I didn’t see this as a red flag. With the need to increase my milk supply, exhaustion from too little sleep, and Rachel’s hydronephrosis, I had enough to worry about.

When Rachel was four or five weeks old, she had a rash on her chest and crusty ears. The pediatrician put her on Amoxicillin, an antibiotic. Around this time, we took a six-week Baby and Me class at Great Beginnings

in Brookline, Massachusetts. During our very first class, the instructor pointed out that Rachel had eczema on her face. This instructor was also a registered nurse, lactation consultant, and mother/baby nurse educator.

We had also recently noticed baby acne on our daughter's face, but it seemed to be clearing up on its own and I didn't feel concerned. After all, I assumed the pediatrician was on top of it. Little did I know that that "baby acne" was a sign of food allergies that would soon consume our family's life and put my baby's life at peril, something the doctors had missed.

Still, the question of why she had a rash on her chest at all nagged at me. Why would there be an issue with her immune system? After all, I was breast feeding; I assumed she was getting all of the immunity and antibodies she needed from my milk.

INCREASING ECZEMA: SEPTEMBER 2003

By the time Rachel was 5 months old, I started to have real concerns about the eczema, which was getting worse. At this time, she also started to commando crawl. As she started crawling, she would rub her little itchy, rosy-cheeked face on the rug to scratch it. The eczema on her body got so bad that my husband started nicknaming her "little bunches of O's and P's with eczema behind her knees."

SOLID FOODS

It was also at around 5 months of age that we started introducing solid baby foods such as squash and rice

cereal. We were advised by our pediatrician to try one food for a few days before we tried the next. This would isolate any possible incidents or allergic reactions as had happened with the tiny bit of yogurt. We were still nursing and I had no idea what “safe foods” were or what she or I should or should not eat.

At six months of age, our precious daughter was now sitting up, giggling, and laughing. She was a happy baby and a joy to be with. She was mamma’s girl. In fact, until this time I was the only one who could feed her because she refused to take a bottle. My husband used to call me “mommy milk cow,” but at 5 months we started feeding her solid foods; baby cereal made with pumped breast milk which created constipation. Then we eventually graduated to store bought, jarred baby food including fruits and veggies. Apples and avocados seemed to be the only two foods she would suck on. My friend Karen had recommended that we try giving Rachel avocado, as avocados and breast milk had similar essential fatty acids. So I started buying the frozen pre-peeled avocados from Trader Joe’s. This became one of her first “go-to” foods. For breakfast, she would eat carrots, rice cereal and avocado.

She also had trouble sleeping and a constant tummy ache; sometimes she would go three days without a bowel movement. But I had no idea why. As these were common problems in babies-- no one seemed concerned.

At six months, we tried working on sleep training. But Rachel didn't sleep through the night until she was nine months old. I would get up in the middle of the night, every night to nurse her. It was easy to just take her out of her crib and bring her in bed with me. That way everyone got a good night's sleep.

She also took the shortest naps in all creation! I used to call it the 42-minute nap.



Rachel with eczema, 11 months old

And the eczema didn't go away. At this point, Ed and I suspected that the eczema indicated some type of allergy. But what allergens and what triggers? We didn't have a clue.

Ed had environmental allergies, so he suspected that her eczema could be from the chemicals in our laundry detergent or dust in the house. We changed our laundry detergent from Tide to a scent free, dye free brand, but it didn't help. We suspected she might be allergic to the pink rug in her room. It had been left there by the

Review From an Allergy Free Kid

After two years of lovingly and meticulously writing, re-writing and editing this manuscript, I forwarded a copy to Rachel, my eighth grade voracious reader for her review. She read some then looked up and said “Mom, it’s really good. Honest! But these are your issues. I’m over it.”



Gotta love that kid!