



Journey out of Autism

Breaking Through

A Mother's Story

Rebecca Ferguson
Author, Regarding Caroline

I stood with my fellow classmates and exchange students in Berlin, chiseling pieces of brick and mortar, bringing down the wall.

It was covered in graffiti. Some of it was in German, a lot was in English, some of it was just pictures, of flags, of cars, of people both famous and not, people like me, full of dreams. I was 16.

I was changing the world, one tiny chunk at a time, filling my pockets with pieces of stone.



Back home, I handed out pieces of the Wall to my friends, my family, with a heady sense that I had been part of something, made history, but I had the idea that I wasn't done, that I wanted to make more. I would be a world traveler. I would build sky scrapers. I would help the poor, heal the sick. I would leave my mark on the world.

The next Christmas, I remember watching “It’s a Wonderful Life,” a movie I’d seen a million times. This time, though, George Bailey’s words took on a new urgency:

"I'm shakin' the dust of this crummy little town off my feet and I'm gonna see the world. Italy, Greece, the Parthenon, the Colosseum.

Then, I'm comin' back here to go to college and see what they know. And then I'm gonna build things. I'm gonna build airfields, I'm gonna build skyscrapers a hundred stories high, I'm gonna build bridges a mile long...

I want to do something big and something important."

My aspirations, like George's, were as big as they come, the way they can only be when you're 16 and the whole world is laid out before you. And above all else, I wanted to be someone. Someone unique. Someone irreplaceable.

I went to college and designed expansive bridges and towering buildings. I went to law school. I travelled the world. And yet, even after all of that, I didn't feel like I'd made my mark. I felt a little like someone else could come along, do what I was doing— and just replace me.

And then, on a sultry night in June, 5 pounds and 15 ounces of sweet baby Caroline came into the world, and I began to wonder. I'd been looking high and low for meaning in my life. I'd been to Italy, Paris, Tahiti and the Colosseum. I still hadn't truly found it.

Was it possible that she was my purpose? Nursing this tiny creature in the small hours, as the night sky softens just before dawn, I certainly felt closer to being irreplaceable than I ever had before. This, this rush of love, this primal connection, this love like no other, was this what I had been searching for all along?



Say the word “milestone” to many parents, and they might think of sitting up or walking, and then their thoughts might drift to something else—what to make for dinner, say. Or that they need to return a library book.

Say the word to an autism parent, though, and you can see the pain flash across their face, thinking about the milestones their children never hit—the ones that meant there was something wrong. Or worse, the ones they hit, and then lost.

Caroline was 12 months when she stopped speaking, when she started avoiding eye contact. She became unhappy, irritable, introverted. She lost interest in other people. “She must just be tired,” people would say when they couldn’t engage her. She began to demand a sameness in our routine that became debilitating. Leaving the house without her toy rubber duck, resulted in tantrums so severe we’d return home and not leave again until the next day.

I must have cried a million times. What had happened to the baby I'd fallen in love with? Where was she? Because this child, this was a different child. This child didn't even call me mama.

"Good morning, Caroline," I would sing to her every day. And where once she would have held out her arms to me, babbling her sweet baby sounds, now she wouldn't even look at me.

And suddenly, everything fell away. Whatever I was before this moment was gone. I gave it all up— my job, my frequent flyer miles. My passport hasn't seen the light of day in six years.

I'll give it all up, I prayed. To God, to whomever would listen. Just fix her. I'll never ask for one thing more.

I just wanted my daughter back.



We immersed her in therapy, hours and hours during the day and into the night, trying to put the pieces of our daughter back together again.

Speech therapy. Occupational therapy. Physical. Developmental.
Speech again.

“Mama,” I would say. “MMMMMMMMMMMM. Mama.”

Caroline still wouldn’t look at me.

“Come on, sweetie. MMMMM. Mama.”

She was in there somewhere, that bubbly baby I’d known. I had to find her. But with each passing day, she was farther and farther away.

At Christmastime the year we got her diagnosis, we sat down to watch "It's a Wonderful Life" again. This year, though, we were tired, worn out from fighting an enemy that locked our daughter out of reach. The holiday season, always one of my favorite times of the year, had lost all luster. Or maybe it was me.

I watched the older, utterly defeated George. Broken. Taunted by Mr. Potter. Feeling he could do nothing right and all hope was lost.

On his knees, he prays:

"Dear Father in heaven, I'm not a praying man, but if you're up there and you can hear me [begins crying] show me the way... show me the way."

Completely forlorn, I was right there beside him, praying on my knees. Show me the way out of autism.

I cried watching George try to paste the petals back on Zuzu’s flower, knowing just how he felt. I tried and tried but couldn’t bring her back to us.

I didn't watch much of the movie after that, I was cutting tags out of her clothes, something I learned made her so uncomfortable she would scream like a thousand fire ants were crawling up and down her body.

Caroline's doctors weren't any help. "There's no cure," they said over and over. "Early intervention is your best option."

But early intervention wasn't working, and if that was our best option, there was no hope.

But there was also a rustling, a whisper traveling from parent to parent, those of us sitting in waiting rooms and searching the internet for something—anything—we could do. Diets. Treatments. Special doctors who were bucking the system. There were rumors of recovery.

"It's not possible," her doctor said. "There is no cure."

I looked at my daughter, the light gone from her clear blue eyes, eyes that used to dance with laughter, sparkle with life.

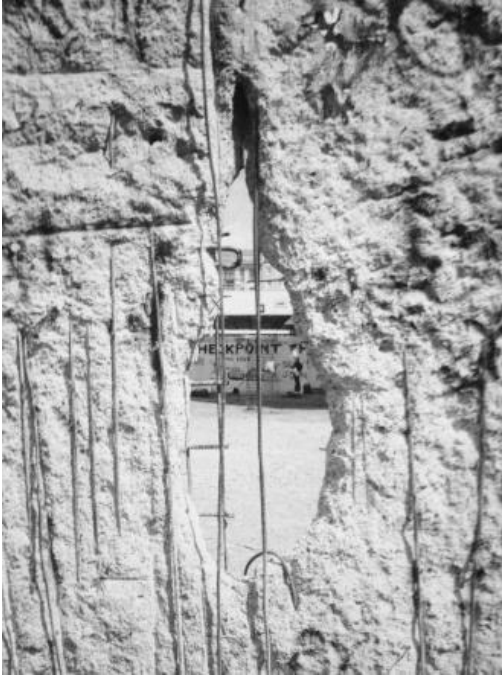
I decided to throw my lot in with the renegades offering ideas. Answers. Hope. Maybe it was a wild goose chase. Maybe it was alchemy, snake oil.

But it was worth a try. I felt a galvanizing sense of energy, of hope. It was worth a try. The worst thing I could do was nothing, look back on my daughter's life and wish I could have done more.

Here it was. More.

And suddenly, I was 16 again.

I had a wall to tear down.



I started to do some research. There were doctors interested in immunity. Doctors interested in the gut. I read every paper and article I could find. I was up well into the night, long after my husband and daughter went to sleep. I ignored the toy explosion, the strewn papers, the empty fridge.

“Come to bed,” my husband would mumble.

“One more page,” I would answer. How could I sleep when the key to unlocking my daughter might be right here in front of me?

And over and over, the same two factors kept appearing: vaccines and immunity.

Vaccines and immunity.

Vaccines.

And immunity.

Her pediatrician said no. Unequivocally. There's no way that vaccines caused this. Vaccines are safe. Autism just happens. We don't know why. And the immunity? An immune disorder? We put our faith in science. The science just isn't there.

Except that it was. It was!

It was right there. We had to heal her. We had to undo the damage that the viruses and the metals in the vaccines did to my baby, my bright, bubbly baby, and if her pediatrician wasn't willing to research the answers, well, I was more than up to the task. I read until I understood, until I could go toe-to-toe with any expert, I read until I saw the path—the one that would heal Caroline.

We began supplementing high doses of vitamins, omegas and more. We started a gluten and casein free diet. The one all the doctors told us wouldn't work. But it did, there was change. There was more awareness, more engagement and attempts to speak!

“MMMMMMMMMMMM. Mama. MMMMMMMMM,” I'd say.

And then, one day, “MMM,” she said.

“MMMMM. Mama.”

When it happened, finally, more than a year after we lost her, after the

light went out in her eyes, when she looked at me and said, “Mama,” it was Christmas. It was my birthday. It was the freaking Fourth of July.

It was my chisel finding purchase in that wall.

“Mama,” she said. “I’m coming!” I exclaimed, wrapping her in my arms, I was crying and laughing at the same time. I held her until she began to push me away.

Caroline toddled back to her puzzle. Did she have any idea what a miracle that one word was? It was so hard to know back then what she knew, as we tried to penetrate her world. My friends’ children were asking “wh” questions, and here I was crying over a simple “mama.”

It was an energizing force, though, this breakthrough. And with it, simple things like putting her in her car seat without a meltdown or a successful trip to, well, anywhere, began to happen.

Before we started trying to heal her, these things were impossible.

“Is that diet really worth it?” a friend asked me, as I declined yet another lunch invitation. Finding something that Caroline could eat was just too hard.

“Hi, Sweetie,” I said to Caroline.

“Hi, Mama,” she said.

Oh yes. Yes it was.

I rolled up my sleeves. We hadn’t even begun to fight.



I stood next to the baggage claim, panic seeping into the edges of my already frayed nerves. Where was that suitcase?

We had begun a new diet for Caroline, an intensive regimen called the Specific Carbohydrate Diet. SCD for short. Believe it or not, it's completely grainless. Yep. Grainless! No corn, no rice, no bread. No sugar. All this in addition to the rest of it.

The diflucan to combat the yeast her immune system simply couldn't control. The mb-12 injections that improve her methylation cycle and bring us more language. The hyperbaric oxygen chamber to supply more oxygen to her brain and strengthen connections. The list goes on.

Many days, since I learned about SCD, I wish I'd never heard of it. The idea behind it is that complex carbohydrates cannot be easily digested by people with damaged guts. Those undigested carbs feed harmful bacteria and inflame the intestines, causing a vicious cycle. If you starve out the bacteria, balance can be restored and inflammation halted.

We decided it was worth a try. So now, in addition to the endless therapies, the research, the sleepless nights, I began preparing every single morsel of food she ate, from scratch, every day.

It's a bigger task than it sounds really and if it wasn't responsible for more eye contact, more smiles, more words and greater health, I would've stopped long ago.

When friends tell me how at the end of a long day, they just go through the McDonald's drive-through, it feels like we live on a different planet.

On planet SCD, there are no drive throughs, no restaurants, no pre-packaged food of any kind. All of the food is made at home.

Special stews and vegetables. Unending parades of vegetables. It makes simply leaving the house a feat of planning and organization. I pack snacks and meals and must be prepared in case we get stuck in traffic or a waiting room. Going on vacation is madness.

Madness.

So as I waited at the baggage claim at the Orlando airport for the suitcases, I became more and more agitated. I'd packed my new tankini with the flattering side rutching. My jewelry, her Cinderella dress. But I didn't care about any of those things. It wasn't that suitcase I cared about. It was the other one.

The one full of food.



We knew Caroline's challenges couldn't be healed with food alone. Tests showed she had elevated levels of metals in her system. The average person has an amount of metal in their bodies just from living their lives—eating tuna, say or living in an industrial city.

Her levels showed that she was more than three times the amount considered “acceptable.” And they were killing her immune system.

Her body was so busy fighting battles that she was unable to function as a typical child might. To heal it we needed to remove the metals. According to my research, there was only one way to remove them.

Chelation.

Chelation is controversial. Our local paper ran a series of articles about it, calling it fraudulent at best, and at worst, downright dangerous.

But the more I read, the more specialists I talked to, the more and more I knew it was a clear choice.

Caroline was making steady gains on SCD, on mb-12, on the endless vitamin and supplement regime. The wall was coming down, one piece at a time. No way was I going to stop now.

The chelation method we chose is low dose and oral. Because it's so gentle, it requires dosing every three hours for three consecutive days each week, for two years.... TWO YEARS!

So every weekend we follow the protocol, the alarm clanging next to my bed at midnight. And again at 3 a.m.

The one at 6 a.m. often reminds me of the flu shot I was told I needed when I was pregnant, the one containing mercury. I sometimes wonder, if my daughter's ex-physician is awake, too, in the gray light of dawn after a sleepless night. "The vaccines are safe," she said. I wish *she* had to stay up all night to rid my daughter of the poison she injected. I'd love to call her. "I'm awake," I'd say. "Thought you should be too."

People ask me all the time how I do it. How I wake up in the night like I did with newborn Caroline. How I have the energy to blow-dry my hair. How I stay up on the latest research.

When Caroline started kindergarten last fall after being on the chelation regimen for 40 weeks, she was placed in a general-education classroom. She was speaking better, she was calmer. She had better eye contact and social interaction.

How could I wake up in the night?

How could I not?



When your child is diagnosed with autism, you are really left to fend for yourself. “There is no cure,” is the party line. Your pediatrician treats ear infections and strep throat, but not autism. That’s because they believe there is no cure. There’s a pill for strep. There’s no pill for autism.

Sorry, and have a nice day.

It’s the other parents who become your support. Those days where you have a setback, where your kid melts down at the grocery store or reverts to that inward state, it would be impossible to continue without the parent network.

Is your doctor able to tell you why your child is regressing? No? Ask the lady sitting next to you at the speech therapy appointment, she's likely to know more.

Along our journey, the parent network has often led to treatments we would never have come across had we been going it alone.

One such time happened last year when Caroline faced a sudden onset of tics, obsessive compulsive behaviors, regression, rigidity, I was devastated. Behaviors we'd left in the dust were back and much worse. We'd fought so hard. How can we be going *backwards*?

My fellow autism parents jumped to the rescue. They reminded me that healing does not occur in a straight line. Two steps forward, one step back (and sometimes three steps back) is too often a reality in this game. "You found your way once and will find it again," they told me.

Not only did this supportive bunch boost my morale, they helped guide me to an additional diagnosis.

PANDAS.

Another autoimmune disease. So there I was, staying up until the wee hours of night, researching again. But this time I had friends as sounding boards. What should we do? How do we get started and what to expect?

I learned that with PANDAS, an autoimmune reaction to bacteria creates antibodies that attack the brain. Attack the brain? Sounds awful. Words like inflammation and basal ganglia damage are hard to swallow. Even worse, the areas controlled by those "ganglia" are motor control, learning, behaviors, the sleep/wake cycle and cognitive and emotional functions.

Isn't that *everything*?!

Caroline was hit hard by every aspect of PANDAS and her obsessive behaviors made everyday life beyond challenging. Her need to

complete an exact order of events before every single routine (eating, teeth brushing, getting dressed) made getting anywhere on time a rare occurrence. And anything not done in the right certain order or not lined up perfectly or tapped the precise number of times resulted in sheer, panic stricken meltdowns.

We listened to the PANDAS experts and started her on rounds of antibiotics. The tics calmed but were never completely gone.

It was then that I determined – with help from other parents - that we needed to stop the antibiotics and try natural treatments. Ironic, of course that after all we'd been through, I still even had the tendency to turn to mainstream medicine.

Perhaps the intensity of the tics or the doctor's warning of how serious PANDAS can be, made things scarier. I'll admit, I was afraid natural treatments wouldn't be enough and we'd lose the gains we saw with antibiotics. But we had no choice, the antibiotics were harming her gut. The same gut we were so intent on healing.

After weighing it in my mind, I had to trust the parents. They possessed something the doctors didn't have. Real life experience. They had been through it and knew firsthand.

I'll be forever in debt to one such friend who clued me in to the miraculous healing properties of camel milk. At first I couldn't believe she was serious. But, it's ability to deliver "mild IVIG" benefits, makes it ideal for PANDAS kids. That same friend also steadfastly stood by my side as I ditched the prescription antibiotics and lined up the herbs.

Within a week, the PANDAS symptoms were nearly gone. "Back to baseline" never felt like more of a victory.

And never did I feel so... irreplaceable! With each gain, no matter how small, I know I'm making a difference. A real difference in her world.



When Caroline began healing, I created a [video chronicling her progress](#). At first, it was just so we could record her challenges, to channel our frustration in the face of all of these burdens heaped on an innocent little girl. The video led to a website, and then a [blog](#). We talk openly of the challenges we've faced, the treatments we've tried. We now have followers from all corners of the earth.

There was a time I wanted to travel the world, and I gave up that idea to heal my daughter. Now, through our story, the world comes to us.

Helping ensure that other parents have an easier time getting started on their child's road to recovery is something I do every day. Caroline's healing story, although not yet complete, is giving hope to many.

I get heartbreaking e-mails all the time from people new to autism. They come to me with their own dreams rearranged in the face of what feels like a devastating diagnosis. I am always so, so sorry to open another e-mail and find out that another child is sick, but I am also so very, very grateful for the chance to reach out to them and help. "That happened to us and here's what worked," I'll say.

And it's the beginning of their own journey, and sometimes, the first time they've felt hope in some time.

I hand them their own chisel. Go get 'em, I think. Tear down that wall.



I had this idea long ago about the kind of mark I wanted to leave on this world. I wanted to build something grand, something that would touch the sky. Instead, I've done something much, much harder, and more ambitious. I'm healing a child with autism.

I still watch "It's a Wonderful Life" every Christmas. It's interesting to me how I relate to it differently as I live my own life. Before Caroline's diagnosis, I felt sorry for George, like he settled, like he missed out on his dreams.

But dreams change. Plans change. Life is messy and complicated, and also wonderful.

My dreams of leaving a mark on this world have come true. I'm somebody very important indeed. I'm Caroline's mom.

A girl who's recovering from autism.



This e-book is dedicated to parents everywhere fighting for their children and one stone at a time, changing the world.



Rebecca Ferguson authors the website Regarding Caroline. When she isn't blogging or researching, she's helping other parents in the community heal their children. The message that there's always hope is a pervasive theme in her articles.

www.regardingcaroline.com for Caroline's Story, Journey to Recovery Videos, Blog posts and more.

Facebook: [Regarding Caroline](#)

Twitter: [@reqcaroline](#).

[Click to subscribe to blog updates via email](#)



Copyright © 2012 Regarding Caroline
All rights reserved. This book or any portion thereof
may not be reproduced or used in any manner whatsoever
without the express written permission of the author.

Printed in the United States of America

AvantBooks | First Printing, April 2012

Originally published as e-book:

www.scribd.com/doc/91473446

www.regardingcaroline.com