Edting Sample - Not for Publication

Excerpt from
"Siliently Seizing: Autism's Hidden Syndrome"

Introduction

A World Turned Upside Down

I felt motivated to write this book based upon my experience as a mother on the front lines of autism for more than 20 years. In my estimation, and with the agreement of some expert physicians, my beautiful son likely suffers with difficult-to-recognize seizures along with his autism diagnosis. On this journey I have gathered valuable information that might improve the outcome for the estimated 50 children who are being diagnosed with autism every single day.[1]

I hope this information finds its way into the hands of every parent facing an autism diagnosis in their child, especially those with a recent diagnosis who can benefit the most from the help.

My son Josh was diagnosed at age of two years and 10 months, and all of his odd behaviors were deemed just a part of this perplexing condition. Many of Josh's abnormal behaviors -- screaming, pulling his hair out in clumps, staring spells, and speaking gibberish -- were misinterpreted as the "self-stimulatory" behavior typical of autism. We were just supposed to grieve the loss of the normal child we would never have, accept it, and move on.

What we know now, but did not know then, is that these behaviors can also be signs of a partial form of epilepsy -- a seizure disorder -- that can be difficult to recognize and easily misdiagnosed.

My intention in writing this book is to let parents know that many of the troubling behaviors they're witnessing in their children, such as staring, head banging, spitting, screaming and aggression to name a few, are generally categorized by the medical community as symptomatic of autism, but they may also be caused by "stealth" seizures which are easily treated. Once these seizures are treated, the brain can function more effectively, and the patient can function at a much higher level. Left untreated, these seizures can cause brain damage, which can lead to serious harmful effects such as self-injury and psychosis later in life. Therefore the seizures *must* be recognized and treated early to preserve the function of the developing brain. If your child is older and has become self injurious or psychotic, it's not to late for intervention. There is a protocol of medicines described in this book that worked for my son and other children so

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[1] http://www.child-autism-parent-cafe.com/a-child-with-autism.html

effectively that the episodes were almost completely extinguished. Some children are getting treated early and actually losing the diagnosis all together.[2]

It is my greatest wish that other parents of autistic children will find this book and be spared some of the suffering and confusion that we, and our precious children, have had to endure. I hope my experience will inspire parents to do their own research educate themselves thoroughly about their children's diagnoses, rather than to just accept what is told to them. It is important to dissect and analyze the child's behaviors so that they can be accurately described to the doctor and diagnosed as seizure-related. If an unrecognized seizure disorder turns out to be the culprit then treating it can produce a miracle of healing.

Chapter One

Josh's Story

When Josh was placed in my arms moments after he was born, I gazed into his beautiful blue eyes. I recall feeling that life does not get any better than this. I thanked my lucky stars for this perfect little blessing. When the nurses shouted out "*hypospadius*" as they assessed his every nook and cranny, the delivery room doctors and nurses reassured me that the condition, an abnormal opening of the penis, is "fixable." Relieved, I returned to bathing in the bliss created by the arrival of my sweet angel. They brought him to me swaddled in a blue and yellow polka-dotted cotton blanket and tiny knitted yellow cap. He was the sweetest sight, as he looked around wide-eyed at the marvel of new beginnings.

Josh's early childhood seemed normal, but between 18 months and two years, those few coveted words he had acquired... "stop," "up," "ball" and "juice," were uttered less and less frequently. It was as though a water faucet was being turned off in slow motion. Instead of flowing out of him, language appeared to be flowing away. I began to notice that for seconds to minutes at a time, my beautiful toddler would stare off in a distant, hypnotic gaze. For the duration of the spell, nothing I said could penetrate his gaze or divert his attention.

We began to have Josh tested by a series of different medical professionals. First we went to an audiologist, wondering if maybe he was losing his hearing. Josh sat in a chair in a cold, sterile soundproofed room with an enormous pair of black headphones on his tiny head. As sounds beeped on one side and then the other, he clearly seemed annoyed by the noises. He could definitely hear. Once he exited the room, he smiled and giggled, as he often did, in response to all sorts of different stimuli unseen to the rest of us. It made me wonder what he was thinking about. I longed to understand him.

Next Josh was evaluated by a speech pathologist. I brought him there on a rainy November afternoon. She did a litany of tests without me in the room, despite Josh's protests. When Josh emerged, he looked sleepy, and he was clutching his little blanket along with a new label... "speech delay of one year." It was a label we adjusted to, taken on like a heavy new sweater we would dutifully wear. I felt I could deal with it.

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[2] http://abcnews.go.com/Video/playerIndex?id=4883944

There were so many things I wanted to know. Why didn't he respond when I called his name? Why did he like to lie so close to the wall, facing it for hours on end while laughing? Why did he take me by the hand to the pantry and throw my hand up to the cabinet to get me to open door? Why didn't he wave bye-bye or want to play peek-a-boo? Why did he drop to the floor periodically and just scream? Why did he love to spin in a circle until dizziness hurled his tiny body to the floor? Why didn't he point to objects in an attempt to learn about the environment, like every other kid his age? Why didn't he sleep at night instead of jumping on his bed, endlessly giggling until the sun rose?

Could Josh's Behavior Be Caused by Seizures?

I was also very worried about Josh's continual staring spells, up to 50 or more in a given day. Each lasted 15 to 30 seconds and, although they were brief, they were very intense. I finally took Josh to a neurologist. He was two years and eight months old. Dr. Ingrid Taff, a well-respected neurologist in Great Neck, New York, performed a standard test for epilepsy, called an *electroencephalogram*, commonly called an EEG. This test measures and records the electrical activity of the brain through sensors (electrodes) attached to the outside of the skull and hooked up to a computer. The computer records the brain's electrical activity on the screen or on paper.

Josh pulled the electrodes off as quickly as we tried to put them on, but we prevailed with the test, and his EEG result was normal. In retrospect, this *did* make sense, since he was not having one of his staring spells during the test itself. Still the doctor felt strongly that the spells were compelling enough to warrant a trial of anticonvulsant drugs. She suspected "absence seizures," which are a type of seizure caused by a "misfiring" of electrical impulses deep in the temporal lobe; the portion of the brain where much of language development originates. The doctor believed that the EEG could fail to pick up these seizures. Once Josh was stable on a proper dose of an anti seizure drug, such as carbamazepine (Tegretol), Dr. Taff believed he would begin to speak and learn.

The words "speak" and "learn" were like honey slowly pouring over me. I drank them in desperately and prayed that the doctor was right that Josh had a seizure disorder. Imagine, hoping and praying for that! That is how devastating some of the alternatives felt. If Josh had something that could be treated with medications, we could move forward with a more normal life. Yes! That would be wonderful! I could feel the burden slowly lifting as she spoke. I had some renewed hope.

One Step Forward, Two Steps Back

Josh was prescribed Tegretol (carbamazepine) to control his suspected absence seizures. Unfortunately, within 24 hours of taking his first dose he developed a head-to-toe, welt-like rash, and we took him off the medication immediately. The next day, by coincidence, he had a long-awaited appointment with a neuropsychiatrist who was, we were told, an expert on developmental disorders.

The doctor pointed out that Josh made very limited eye contact and made no appropriate response to any requests. During the exam Josh moved about the room singing a few words from the songs he had memorized from his favorite Raffi tape, "baby

Beluga la-la-la." He really seemed to be tuning out the world that day. As we watched the scene unfolding before us, the doctor asked us about Josh's difficulty attending to any one specific task. He told us that typically children at Josh's age (he was two at the time) would use sentences to communicate, and that typically they understand even more language than they use.

Watching Josh with what I thought was a measure of objectivity, I surmised that he must be very tired, a bit cranky from the itchy rash, and maybe feeling a tad stubborn. The doctor had a different take on it. He told us simply and clearly: *Your son Josh is autistic.*

I will never, ever forget that day. I could barely see the doctor's impassive face through my cascading tears. As they fell in torrents on my shirt, I looked over at my then-husband, who was looking pained. The diagnosis was searing in its honesty.

The doctor went on to say, "Most of these children have a lifelong developmental delay and have great difficulty adjusting socially. Most children with autism have mental intellectual impairment, and only about 20 percent have normal or above-average intelligence." He felt Josh had varying degrees of cognitive ability, with memory being one of his strengths.

This doctor said that he thought the staring spells were likely an integral part of Josh's autism rather than a separate or treatable entity. We took his advice, discarding the idea of treating Josh's 'invisible' seizures. In hindsight, I believe this was a tragic mistake.

Many years later as I began to put together the pieces of our puzzle, I realized that Josh had a seizure disorder all along. As it progressed, its manifestations went well beyond staring spells. Josh's more severe seizures produced vicious rage, undirected horrific violence and self-mutilating behavior, including bites that have left his skin forever scarred. Knowing what I know now, I agonize over a wish that I could somehow go back in time and change the choices I had made.

Questioning Authority

We trust that medical professionals have great understanding of the many human afflictions, and we trust them with our lives. Yet there are those times when it's difficult to obtain a clear, definitive diagnosis. Many human conditions still remain a mystery as to the cause and thus, a viable treatment. Autism certainly falls into this category.

Parents and caretakers of children with autism need to arm themselves with as much knowledge as they can possibly glean from those who have made an in-depth study of this perplexing disorder. It is so important to work with a team of experts who have the background to understand and treat the complexities of this autism.

The lovely actress Jenny McCarthy trusted her instincts when she realized that her son Evan, who was diagnosed with autism, also had additional underlying medical problems. In 2007, McCarthy published the book, *Louder than Words: a Mother's Journey into Healing Autism,* about her son Evan. She described the terror she felt when witnessing her son's seizures, finding him in his room "barely breathing with his eyes opened but not focusing, while his whole body was convulsing, he was fighting to breathe." Unfortunately, this was not an isolated event, and she would endure many more similar moments on her journey. McCarthy became increasingly frustrated and realized that Evan had many issues yet to be discovered by the testing. She knew there was more to the story, and she told her son's doctors, "Guys, I feel like we might be missing something."

So often we rely on inexact science to tell us what is wrong with our children without questioning that science. This can sometimes lead to the erroneous assumptions we all make as to why a child lashes out, screams, or becomes violent, but the truth is we really don't always know. The reason we don't know is that most of these children cannot answer the basic question, "What's wrong?"

How many of us really have the tools we need to try to dissect the behavior of our autistic children? When we are told by experts, "this is just the way they are," we believe it, because we, as parents and average people, don't have the tools to look further. So we grieve the loss and go on with our lives, accepting without question that our children bang their heads for no reason, walk on their toes, cling to a wall in fear, cover their ears and stare into space. We believe that this is all just a part of autism, a disorder for which no existing remedy can significantly alter the course.

What we, and most of our doctors, may not recognize at this point in time is that these behavioral traits are also common manifestations of *temporal lobe* or *frontal lobe* seizures in children. Untreated, temporal lobe epilepsy predisposes children to developing the similar types of behavioral disturbances -- self-injury, aggression, and psychosis -- seen in many cases of autism.

When Seizures Are Silent

An "absence seizure" (formerly known as a *petit mal seizure*) is a sudden loss of consciousness in a person with epilepsy. The person appears to "blank out" and may not remember the brief episode later. I had an opportunity to witness this type of seizure first-hand years ago. My college roommate's sister had epilepsy and numerous times a day she would stare into space blankly for periods of 15 to 30 seconds. At the time I found it strange and interesting as she simply "zoned out" and then, blinking her eyes, suddenly came back in less than a minute. I could have assumed she was day dreaming but she shared her medical history with me, so I knew what was happening.

The memory of that experience came rushing back to me when Josh began his episodes of staring out at nothing, at nobody, into some unreachable alternate universe beyond my reach and immune to my love. I recalled seeing my roommate's sister do the same thing, where she would simply stop and stare out into space at nothing. Although she was deemed normal in every way, she was visited multiple times a day by these "silent seizures."

When I went back to the medical community seeking answers to my questions about the possible relationship between Josh's condition and a seizure disorder, initially I was met with staunch resistance and closed doors. Josh had started slipping away into brief dreamy episodes too numerous to count, and by age 12, these episodes had an additional facet of uncontrollable aggression. It was a kind of madness in which strange, acrid smells lingered in his perception and odd voices screamed at him from inside his head. He told me he heard potato chip crunch sounds, and covered his ears often. However, no one in the medical community listened to my theory that many years of brief *partial* *seizures*[3] had morphed into a pattern of *complex partial seizures*[4], possibly underlying and exacerbating my son's autism.

And thus I began my quest to understand the seizure connection as it relates to the diagnosis of autism.

Why didn't the doctors want to believe that Josh could be suffering an underlying syndrome of silent seizures? Why were they so willing to discard Dr. Taff's earlier assessment of a seizure disorder? Was it simply the lack of clinical proof causing a disregard of what seemed to be so obvious?

EEGs were ordered for Josh by various epilepsy experts, and all showed normal results. But results of EEG, MRI (magnetic resonance imaging) and other tests used to detect seizures can sometimes be completely normal despite a true diagnosis of epilepsy. Many experts agree that the diagnosis has to be made "clinically," that is, based on a description of the person's symptoms and the patterns in which they occur. This is how Dr. Taff diagnosed Josh years earlier.[5]

"Please Fix My Brain, Mom!"

Back in the world of autism, many professionals who consulted on our case labeled Josh's odd behaviors (facial grimacing, eye blinking, and fluttering) as "stims," a short term for *self-stimulatory behavior*. His habit of staring for brief intervals throughout the day was given the euphemism of "light gazing." Once, as he was observed staring off into space, eyes transfixed for about 30 seconds, a behavioral therapist surmised that this was his way of internally stimulating himself. She was taught that this staring behavior is purposeful and has some benefit to him. She did not take into consideration the possibility that these stims could be manifestations of seizures.

The doctors told me that when he reached puberty, my son's behaviors could "get much worse," but nobody ever dared to detail what that might look like, so I was not at all prepared for what was coming. Since conventional tests still did not register any signs of seizure activity, Josh's doctor suggested that he probably suffered from a "mood disorder with psychotic features."

Josh was then treated with high doses of anti-psychotic drugs, including Risperidone (Risperdal), which was supposed to help relieve his "mood disorder." But the drugs made him much worse, and this should have been a tip that something else was behind his out-of-control behavior. At times, Josh was capable of being happy, gregarious, and loving. In contrast, a person with a diagnosis of psychosis (such as schizophrenia or severe depression) would be completely lacking in emotional connection with others and appear out of touch with reality.

> *Josh has been on his bed watching TV. Suddenly, he calls out profanities as he rudely asks someone, a hallucinated entity, to leave him the f*** alone.*

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[3] Partial seizures occur in specific area of one side of the brain. In a *simple partial seizure* the person is fully conscious (www.epilepsyfoundation.org/answerplace/Medical/seizures/types/partialSeizures).

[4] In a *complex partial seizure*, the person either loses consciousness, or consciousness is impaired (www.epilepsyfoundation.org/answerplace/Medical/seizures/types/partialSeizures).

[5] (Panayiotopoulos; The Epilepsies: Seizures, Syndromes, and Management, 2005)

> *I run, trying to negotiate the stairs two at a time, so I can try to keep him from hurting himself.*
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> *His body is shaking, his pupils enlarge, and his shrill screams fill the air. His eyes glaze over as if possessed by some demon. "My eyes aren't working, my eyes aren't working, Mom!" he screams. Then the staring. No movement for about 30 seconds, eyes widened, as he is seemingly transported to a far-away place. "My brain is broken!" he bellows as he repeatedly taps his head.*
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> *Then his fear turns a dark corner. He becomes enraged. He lunges at me and in a second, his hands are suddenly around my neck. I try to extricate myself from his grip as his anger intensifies. In the seconds that follow, he throws a punch with such force it hurls me backward on to the floor. I clutch my face in pain and disbelief. My blood is everywhere.*
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> *"The Ninjas have guns," he growls. He begins to kick into the air while making combat type sounds.*
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> *After a few more excruciating moments, the ninjas retreat. He is panting and seems to settle down. He looks at the devastating scene of smashed objects, blood, and broken glass. He sees me holding my face and sobbing. He surveys the mess with profound confusion and sadness. He asks me, "What happened, Mom?" Just then, my precious son, now 18-years old, who was diagnosed with autism at the age of 2 years and 10 months, actually apologizes. "I am so very sorry, Mom. Can you please give me a hug?"*
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> *I am reluctant in that moment out of fear, and I sheepishly refuse. He begins to sob with his head in his hands. He pleads with me, "Please, fix my brain."*

As Josh's adolescence raged on, I continued to talk to anyone who would listen about the idea that Josh may be having seizures. By this time, I was certain that Josh's symptoms mirrored those of temporal lobe epilepsy. But sadly, I was starting to sound like a broken record. I began to be treated by the professionals as if I, too, had lost my sanity.

Affirmation at Last

After years of relentless research I eventually found a community of doctors and researchers who believed that seizures were likely causing the syndrome of autism in Josh and in many other children. I have talked with parents of autistic children who shared their belief that their children also suffer from invisible seizures. I have come to realize that many parents of autistic children are dealing with similar situations. I know that many more children like my son are out there, "silently seizing" because the scientific world has not yet fully embraced this perplexing connection. I resolved to find out as much as I could about the intersection of seizures and autism. I was fortunate to gain from the expertise and support of several top medical professionals in the field of autism.

One of the extraordinary doctors I have come to know is Fernando Miranda, MD, a respected neurologist who has held prominent positions at Johns Hopkins University and the University of Maryland. Dr. Miranda is the founder of The Bright Minds Institute[6], a groundbreaking organization dedicated to helping children with neurologic and learning disorders. He has locations in San Francisco and Los Angeles. Dr. Miranda speculates that as many as half of the children diagnosed with autism may actually be suffering from an undiagnosed, difficult to recognize seizure disorders, resulting in the set of behaviors and symptoms we have come to call "autistic." Dr. Miranda and a small number of other specialists are having impressive results treating these seizures in young patients diagnosed with autism.

I walked blindfolded through this maze of autism and seizure until very recently. Now as the parent of an older child, I feel compelled to share what I have learned and help to provide other families with a guiding light on this terrifying journey. I know and understand first-hand how devastating it is for a parent to be told that his or her beautiful child has an incurable, lifelong, neurodegenerative condition. Once the diagnosis has been made and the tears have lessened, I must tell you that there is tremendous hope.

In hindsight, I realize now that I missed an opportunity to diagnose and treat Josh's invisible seizures early on. By inadvertently allowing his brain to continue to silently seize, we robbed his brain of its ability to function normally. The brain is a miraculous organ that tries to find new neural pathways to help compensate for injury. Josh is an artistic savant, meaning that he has a special skill that surpasses the skills of others who are not savants.. His brain, in an effort to overcome the damage, became enhanced in its area that controls artistic talent.

If Josh had been treated as a baby for his underlying seizure disorder, I truly believe his outcome would have been different. I lost valuable time that can never be recovered, as Josh's brain is now irreparably damaged by years of uncontrolled, erratic electrical activity, yet he continues to make terrific strides.

Thankfully, my wonderful son and I are past the daily rages that once forced me, his devoted mother, to contemplate placing him outside the cocoon of a loving home. It took nearly ten years of trial and error, but finally the team found the right combination of medicines for Josh.

When children who are silently seizing are treated early with anti seizure medications, many of them begin to show amazing gains in expressive language and comprehension. Many *are* beginning to speak and learn, as described in this book. Even more importantly for some, an absolute miracle is occurring: they are losing their diagnosis of "autism."

Fortunately, we now live in a time when greater attention is paid to the baffling origins of autism spectrum disorders. There is much that can now be done to help these children once their underlying issues are fully understood.

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[6] www.brightmindsinstitute.com