

## Brain Interrupted: The Story of John's Traumatic Brain Injury

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Video Link: <http://www.brainline.org/content/multimedia.php?id=993>

**Dr. Wayne Gordon:** Few experiences are as difficult for a parent as seeking help for a child and being denied the help that they were seeking. The story you are about to hear is that of a mother asking time and time again for help from diverse professionals and being told time and time again that her son's ongoing and worsening symptoms were the result of poor parenting, bad behavior or an attention deficit disorder. In fact, Patricia's son, John, was struck on the side of his head by a swing at the age of 3. And although he experienced no loss of consciousness and no obvious or observable signs or symptoms of having sustained a concussion at that time, his radically changed behavior was actually the result of a traumatic brain injury or TBI. John's brain injury resulted from a playground accident but assault on the street or while playing sports. Details about the causes and consequences of TBI differ from individual to individual. But hearing the experiences of this boy and his mother may help you become more aware of TBI and its consequences so that you consider the possibility of traumatic brain injury when you are trying to account for the changes that are observed in others. Early identification and diagnosis could have helped John and his mother cope with the life long challenges of traumatic brain injury at home, at school and in all the contexts of life. There is help for individuals who sustain a TBI but only if the TBI is identified. I will return at the end of John's story to review the major points of this presentation.

**Patricia:** Hi John.

**John:** Hi mama.

**Patricia:** Mama has camera, that's right. Oops [laughter] bunk on the noggin.

**Grandma:** On the head. Right on the head. Right on the head. Yeah, right on there.

**Patricia:** Hey, there. Oh.

[ Laughter ]

**Grandma:** Give it to grandma. Right on the head for grandma. Wee.

**Patricia:** John, how old are you now?

**John:** 2.

**Patricia:** 2, 2.

**John:** 2, hello.

**Patricia:** And the swing, just as he ran behind it, came back and just clocked him. He never lost full consciousness. He was dazed and didn't cry, which was odd I thought. He did not have a mark on him. We called immediately and reached the pediatrician, and because he was conscious, because there wasn't a mark on him, and his eyes were equally dilated, the pediatrician who was unavailable to see said, "Do not take him." He was very specific about it. Do not take him to an emergency room because they won't do anything for you. He said, "Take him home and watch him for 24 hours for signs of concussion," which is exactly what I did and there were none.

The first change that I remember is that he went from being completely laidback, affable, easily redirected to an extremely highly anxious demeanor. And he refused to go to bed at night. He would hold on to my leg going into nursery school. That was the first and the greatest change and it was immediate.

I mentioned to the pediatrician that he had just so dramatically changed since the time he was struck in the head. And the pediatrician said, he laughed and he said to me, "Have you never heard of the terrifying 3's?" And I said, "Overnight?" And he said, "Well, you're just a first time mother. What do you know?" He didn't make the connection between the strike on the head and the immediate behavioral changes, didn't make any connection at all.

That May prior to the accident, the conference with the teacher when something like this, John is right on target. He is a pure delight, he's docile, affable, he does well with all the other children, they love him. And by early October, maybe several weeks into the school year I got a call from the same nursery school teacher and she said, "Your child is showing signs of abuse. What is happening in your household?" Which completely floored me and I said, "Nothing, there's nothing happening." I didn't know what to do. I did tell her that he had been struck on the head in the summer and that he's behavior had changed dramatically at that point and was continuing. And she just--she didn't pick up on that at all.

John's behavior did not improve. It--the agitation level, the anxiety level remained remarkably high and he did not seem to connect actions with consequences. I still remember drilling whether it was manners or tying a shoelace, how to do something or how--what not to do and crossing the street. Look both ways. Don't dart out into the street. He didn't get it and it took enormous efforts and repeated efforts and John would continue to fall back. And then when I would say to him, "John, what are you doing?" and he would look at me with such sadness. "Why are you mad at me, mom?" And so that disconnect between action and consequences lasted his entire life.

John would, out of the blue, just his hands would close into fist and he would just shake. And that lasted anywhere from a couple of seconds to maybe 10 seconds. And we had a neighbor that lived down the road who's had a son John's age and they used to play together once in a

while. And this woman was a nurse and she said to me, "I don't know what this is but I can tell you it's biological because it just comes from out of the blue." And it continued from age 3 to age 6, 6 and a half. And I certainly mentioned it to the pediatrician who said that John is just excitable, he is highly intelligent, he is highly imaginative and he's just gonna be the next Steven Spielberg. Let it go, there's nothing wrong.

It was always a flag to me that, you know, when a child would put himself to bed and when he was 4, on his fourth birthday, my mother, she invited a lot of the family over and so it was a lot of external stimulation. And he walked up her stairs and I said, "Hi, where are you going?" and he said, "To bed." And I said, "Honey, come on. Come join your party." He said, "I'm going to bed, mom, I'm tired." And he did. And so it reminds me that we had one meaningful Christmas with John and that was when he was 2 and a half. And it was a pure delight, it was everything you might expect of a child at 2 and a half the memories are wonderful and I will hold them forever. And after the accident, we had to actually wake John, you know we would wait until 9 or 9:30 in the morning even though we would go back and awaken him and my husband would pick him up and John would just bury his head in his dad's shoulder. And I think again it had to do with the stimulus around him. He didn't know what to expect from it. He didn't like a lot of sensory stimulus. Halloween was another one. He hated Halloween for many years.

His first attempt at kindergarten failed after 2 weeks. He did beautifully with the pre-kindergarten testing. They handed me--they called me in for a conference 2 weeks in the school, handed me his backpack and said, "He's going home today, try again next year. We think he's psychotic. That he doesn't really know he's John because he plays Batman all the time." And he was getting all A's and he could listen well in a classroom. So he did--academically he did fine but the report cards invariably would say, "Socially he is wanting to do very well and he's making strives but he's not quite there." I don't think that his empathic abilities were as strong as maybe someone else's could grow. So I don't think he was aware of other people's facial expressions or when--so that social impact was difficult. But academically he did well for that first--first 5 grades.

I can still remember learning soccer and the children would be on and they looked so cute, maybe 5 or 6 running back and forth on the field and John gleefully, like Tigger, running up and down the field. Great enthusiasm, he had no idea there was a ball or what the purpose of the game or why he was out there. There was no focus. There was no getting the point--the overall picture like a stone. It continued with baseball. If he made it on to a base, he would forget why he was there and he wouldn't get down into the dirt and start making castles in the dirt and the coaches would call to him when someone else would get ahead and he just did not hear him. And so the coaches would just tell the other children just run around him.

And when he turned 6, I took John on my own with no referral, with no recommendation, to a pediatric neurologist because the shaking of the fist was continuing, the agitation, the anxiety was continuing and the pediatric neurologist asked him to touch his fingers to his nose and walk a straight line, both of which John could do it quite well. And he then pronounced John

neurologically sound. Being struck with the swing did absolutely nothing to him. However, he is impulsive, he is anxious, and he looked at him. He said he's running all around this room. He says a behavioral problem. And on my way out the door, he leaned against the door and this is something I will never forget and he said, "You just need to be a better mother."

Maybe John was 8 or 9, John said to me, "Mom, what color are your nines?" "Well my nines are--they're blue and my fours are green." "What color are yours?" I had no idea what he was talking about. And this went on for a couple of months and I again asked the pediatrician and he said, "Well, I've been telling you," he said, "John will be the next Steven Spielberg. He's just so highly imaginative."

At one point, maybe when John was 9 or 10, maybe even a little older. He said, "Mom, I have noises in my head." He said, "It's like there are 5 televisions going at once and I don't know how to turn them off." And again, another trip to the pediatrician [laughs] you know or a phone call actually. I think this was the second time John told me that, and again I got the same response that he was just highly imaginative. By 5th grade, his teacher--I was a class mom that year and I went in about March and this woman said to the class, "Oh class, shall we tell John's mom what we say everyday?" And I looked at her and she said, "John, he's tapping on his--tapping with his pencil again class. There he goes again class tapping with his pencil." And I walked right up to her and I said, "Please do not ever say that again."

That's when he also started the need for divergent thinking and multiple multitasking and that's where the holes in the mortar of his education really started. And by 6th grade, book reports and the teacher--his English teacher would say he was, "He's just slow to mature and if you would please just work with him. Help him to complete them. He'll catch on." And he never did. And it wasn't for lack of trying, you could tell that he really wanted to do well in the school, but he just didn't know how.

By 6th grade he began to withdraw. The enthusiasm part of him waned completely and he went in the opposite direction. He had a couple of friends but he was mostly shunned by everyone else.

He had difficulty reading all along, and we asked in 7th grade for an assessment. She asked John to read aloud and he did. And he read faster than I could have probably. And the problem is that she never asked him what he read. So she proclaimed to my husband and I that John reads as well as you or I and to--that he was lazy and manipulative and don't let him get away with it because he's gonna try to get away with doing as little as he can. And that did not ring true with me at all, not at all. But I didn't know that they hadn't asked him what he read.

So we went to a parochial--boy's parochial school and it was a jock school. He came home from school everyday and seemed more dejected than the day before. He got it out and I learned later that his French teacher everyday called him an idiot. He said to me in June, the

last day of school, "Mom, I made it through," but he said, "I developed a motto after about 2 weeks of school, get tough or die."

For sophomore year he reapplied to the boarding school and was accepted and it was a very good fit overall. He--there were 10 kids in the classroom and homework was well overseen and everything was structured.

However, we would still get calls. John has forgotten his homework again. He does not come to class prepared. He isn't working with teams on projects. He's doing alright if he just listens in class. He also doesn't take notes. John takes no notes. He doesn't research. So it's all those multitasking things again.

I had taken him to another pediatric neurologist at the encouragement of a friend whose son had ADHD. And this doctor tested for that and he said, "Your son has 9 and a half out of 10 criteria for ADHD and on top of that I'm picking up a strong language processing component."

So he started to school of junior year with the understanding of the school that he had ADHD, and that language processing was very difficult for him. Wanting to be a physicist, this was his first year to take physics and he was very excited about it. And the teacher was a very new immigrant from Russia and I could not understand her, my husband couldn't understand her. I did ask his counselor if he could be--if he could change teachers for physics and the teacher responded, "The other children are adapting. John needs to do what the other children are doing. We don't adapt to him he needs to adapt to us."

So November first of his junior year, he started the public school, and about every day a phone call would come. I would pick up the phone, it would be another teacher saying John's head is on his desk the whole period. He is not engaged. He's not focused. He's not listening, he doesn't come to class prepared, at least do what you can at home which of course we continue to try to do until it became very, very difficult watching him not only fall straight down the chute academically but take behavioral risks socially, that take my breath my away, you know, looking back, and I couldn't stop him.

As a senior, he came to me that September and said, "Mom, I can't read. I know all the words so I can read them individually, but it's that I have to read it 5 or 6 times to understand how they fit together." First I took him to the high school as a public high school at this point and they said he is way too old, we can't do a thing for him and this is not the time when you work on reading skills. And so I took him to a private tutor. They didn't wanna work with him either and I begged them. I said please just 4 weeks, just 4 times. So they did and by the second visit I got a call from the tutor saying that John needed more help than most of the 6 year olds she was working with, and she said, "And did you know that John reads in color. John told me that every letter of the alphabet has a different color association and it overlays everything he reads." And I thought back to that time when he was 8 or 9 asking me about the colors of his numbers. And she said, "I tried to trick him. I thought it would be fairly easy to

trick him up." But she said, "Every time I ask him, it just pops right out. My R's are orange red and my A's are purple, whatever it was." And she said, "I'm very concerned about it." So we went to the high school again and we talked with the principal and at that point he knew that we were very serious and that maybe there was a problem here and that maybe they should look at it. So they've asked for a psychiatric assessment. One of his tutors referred us to a doctor who had written a book, well respected, nationally known book about ADHD kids. He was very empathic and worked with John and he did the evaluation and he said this is definitely ADHD and this is how you could work with him. The school ended up putting John in pull out classes basically for kids who were not making it. And they dummed down all the material which further depressed John. We talked about holding him back and redoing senior year. He wanted his high school diploma so badly because he grasped onto that notion that if I get a high school diploma I've made it, I can go on.

By the third week of the reading program, the tutor called and she said, "I want you to take John for another neurologic assessment. This child, there is something wrong." So I called a neurologist, got an appointment and dropped John off. He was over 18 at this point. And so I went to pick him up and the doctor called me in and he said, "Tell me a little bit about John's history." So I did and I danced around the swing incident a little bit because I didn't wanna go there again. But I thought, alright let's just, you know, put it all on the table and I said, and he was struck in the head with a swing when he was 3 years old and changed dramatically after that. And I expected him to say, "Oh, that would mean nothing." But instead he said, "I knew it." He said, "I want you to take John immediately to see a cognitive neurologist." I made the appointment, took John to a major teaching hospital and this doctor sat with us for an hour and a half and just took the history. John slept through the appointment. And he said to me at the end of it, "I'm going to send you for 2 scans of John's brain," which had never been done before, he said, "and they will come back negative because they normally don't pick up a mild injury but don't think for a moment that this is not a brain injury." He said, "And the biggest clue for me is the disparity between John's IQ and his failure to achieve." He said, "I don't know how this was missed all these years."

When the cognitive neurologists showed me the picture, it was a SPET scan picture that he showed me and I saw, I actually saw the lack of blood flow in the area of the brain where John had been struck which was the right frontal temporal area. And he said, "So this is not a really mild injury and I don't know how your son has made it as far as he has." So I said, "Well, what do we do now? Where do we--what, okay, let's just get into motivation gear. What do we do now?" And I'll never forget this. He looked right at me and he said, "Oh, he said, there's nothing you can do now. Your son's life is over. It's way too late for him." And but how did we come to this point, we finally know what's wrong and he's gonna tell me that there's nothing you can do and I didn't believe him. And I drove home and picked up the phone and started calling the tutors that we were working with and one of them gave me a name of a director of a brain injury program in New York and he had worked with him 25 years earlier. He wasn't even sure he was still in the business.



I called and this man picked up the phone and I began to tell him about John's story and he said, "Let me describe your son for you." And he did. He said, "He wasn't socially adept. He didn't succeed academically. He thought he was a screw up, he didn't--he just didn't make it in any way meaningful in life and he's depressed and he has withdrawn, and he is defiant, and he is obnoxious. Did I hit that right?" he said. I said, "You certainly did because by this point, the behavioral manifestations were unlivable." He was screaming at us for the least little thing, calling his father names, calling me names. It was very, very difficult on the family dynamics.

We asked John if was willing to take a thirteenth year after high school, and going he was tested for 4 days and he showed a lot of temporal frontal lobe deficits. And he began the program but just as quickly as he began it, it almost ended for him because he chose to cut class one day. A friend was visiting and he wanted to be with the friend and so he did what John did and he cut the afternoon of class. And from that point on, John was handled as life had handled him. He was told that he was hanging by a thread in the program and then if he did one more thing wrong, he would be asked to leave. And that hanging by a thread phrase kept repeating itself and I appreciate that they were trying to pull him in to the ranks and make him follow a pattern. For John, unfortunately, it was the same message he had gotten on through life. So John just folded it up, he basically said, "Well, I've already failed, I might as well not even go anymore." At which point--pretty helpless at that point, we knew we couldn't just bring him home. I didn't want him out and just walking the streets of New York which he had taken off a few times at night after the program and I didn't know where he was and he wouldn't come home, and it was a pretty scary time.

And so we interviewed with a residential program out of state and it was supposed to be a dual diagnosis so that they would talk with him about the dangers of using substances which is, you know, the percentages are enormously high for people with brain injuries and using substances to self medicate, and also the cognitive training. And John went to that program and he started off in an environment where he was in a building with 3 people, it was wonderful, it was a wonderful set up. But he abused the system and he opened his window at night and took off and walked 2 miles to a 24-hour drug store and picked up cold medicines that could make him high and he was eventually found out and was put in a lockdown area. And he told me many times after that that he just felt like he lost his mind there and that was--there was no recovery after that.

After the diagnosis was made for John in April of his senior year and we had, just recently within that year, gone to see this nationally known psychiatrist. I called him, I called the doctor to tell him that the diagnosis of brain injury had been made and was backed up with these scans and he denied it. He said he does not have a brain injury, he has ADHD. And I said, "But doctor, he does and I even saw the scans and could see the damage." And he said, "He does not have a brain injury."

There was another neurologist actually when we were in New York that we were sent to--who on the first visit he didn't have John's records in front of him and he said--well he said, "I

don't know why you're here." He said, "Your son does not have a brain injury."

And I just looked at him. There we were attending a brain injury program and most his PET scan clearly showed and then all of the criteria, you know, that had been missed all that that--that difference between his intelligence level and his achievements and his failure to achieve really and all the signs, the--the shaking of the fist which they now realize were seizures. The fatigue, the inability to react--interact with people as he should have, all of the signs were indicative and this man said, "Well, I dropped my daughter on her head when she was 6 months old and she is perfectly fine. There is nothing wrong with your son neurologically." He subsequently looked at the scans and did apologize to me, but you know I think it's just rampant. I think there's just a lack of awareness of what the signs are of a closed head traumatic brain injury.

Basically, he and I did this alone without the help from the medical community or the educational community, the professionals whom we contacted for assessment and--we're rejected. Family and friends did not buy the picture. They did not trust to believe that there was anything wrong with John. I believed so much in John and I knew there was something wrong and we have 3 family members who are in the medical profession and they didn't get it either, but I really believe you can't get what you're not taught and I--my guess is that medical and nursing students are not taught about brain injury awareness. I would contact family members for help particularly as John got older looking for networking and I would say, "There is something wrong with John. Please help me to find someone to network with through to find the help that John needs." And invariably the answer came back that they didn't think that there was anything wrong with John, and that--that was very difficult. So, being isolated, I felt very isolated. I imagine John did as well, and in the end John--the person that had been with him and believed in him the most, he turned against me. I'm sure he just he didn't know what to do and look--had looked to me and I couldn't help him.

I wish that people had recognized the immediate change in John. I wish that schools of medicine had better information about what a closed head injury looks like. I wish that this shaking of the fist were known and recognized to be signs of seizure. I wish that school systems would--would be trained to know that when a child has a high IQ and it's obvious and it's measured and then they fail to achieve, that children are not born lazy, they're not born wanting to fail, and to please look into the reasons and the causes for what might be causing this child such failure when they're working very hard to achieve and to succeed. And I wish that families and friends would not judge. I wish that physicians would not judge without knowledge. I wish that teachers and school counselors would not judge. I think the injury itself had it been diagnosed, John could have found a way in this world and--and could have made a way for himself. I think the psychological damage from the judgment and the isolation that went with it is really in the end what killed John.

The wishes just expressed by John's mother, Patricia, say it all. Physicians and educators need better information about brain injury and how to recognize it. At Mount Sinai's TBI research



center, we are working to educate the medical and educational communities as well as the general public about TBI. Other research institutions and medical personnel throughout the country are engaging in similar work. The goal is for symptoms of brain injury to be as well known as the symptoms of cancer or of heart attack, and for TBI to be as openly discussed as other medical conditions. A blow to the head often has no long term consequences; however, all too often it results in sustained major changes in behavior and cognitive function like the ones experienced by John. Patients and family members must be aware of the possibility of traumatic brain injury following a blow to the head, pay attention to its symptoms and seek help. Medical and educational professionals must learn, listen, and take action. Awareness of the symptoms of TBI is the essential for a step in its identification and its diagnosis. The first step will enable patients and their families to get the treatment and the support that they need.

If you or a member of your family is experiencing sustained behavioral changes following a blow to the head that resulted in a period of confusion or loss of consciousness, my best recommendation is for you to your contact a state-affiliated brain injury association of America for referral to a specialist. If you are a medical or educational professional, please review and be aware of the signs and symptoms of TBI so that you will prepare to identify it in your patients and students. Your awareness is the first step in helping to save a life.