

Overcoming the Odds When the Cards Are Stacked Against You

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The goal of this article is to demonstrate the effects of MNRI® and the changes that have occurred with my son, George Nameny, since starting this program. His situation is unique because he was introduced late to MNRI® and has a diagnosis of Fragile X.

George was born on February 25, 1996 a healthy 9.5 pound boy. He had difficulty at first latching on, sucking, and swallowing during breast feeding. This resolved on the first day after a lactation nurse intervened. I brought home a beautiful, content, and calm baby who slept through the nights. At two months of age he ran a temperature of 100-103° for three days and was admitted to the hospital with fears he had contracted meningitis. They poked and prodded him and did a spinal tap which was repeated 3 times before the doctor found the right spot. He was sent home with a diagnosis of reflux in his kidneys and was prescribed a maintenance dose of antibiotics. Until the age of five, George was on the maintenance dose of antibiotics until the reflux naturally resolved itself. The doctors also identified (with an ultrasound) that George had a horseshoe kidney. George's temperament changed during and after his hospital stay and he had to be held a certain way, he became extremely fussy, and was resistant to touch. He startled easily to lights, sound, and change in position.



Anna Nameny

The doctor said, with kidney reflux, George was more susceptible to infections because he was not circumcised. We took George in at 5 months of age for the simple outpatient procedure at our local Children's Hospital. We came home with unstoppable bleeding where the surgery had been performed. Several hours later, we returned for emergency surgery to resolve the bleeding. It was an extremely long day. George wasn't able to eat well, sleep, or be calmed. He cried constantly and it was very distressing to all of us.

George was tested by the school district when he was 25 months to see if he qualified for early intervention services. The school district identified developmental and language delays and began providing in home services. He also qualified for county services which provides a personal care attendant and respite hours in home for support. When George was young, I tried everything the traditional medical model offered but progress was slow and he kept slipping further and further behind his peers. We utilized private occupational, physical, and speech therapy. He was integrated in a regular education preschool and received individual special education services before class. I requested that the school include George in the regular education setting because I knew this was the best place for my son to learn new skills and model appropriate behavior by his peers in a natural setting.



George Nemeny in senior high school.

George was quite a handful. My life consisted of waking up every morning and ‘chasing’ George all day to keep him safe, redirect behaviors, and utilize every teachable moment for him. He and I both ‘dropped’ from exhaustion at the end of the day and some days this came earlier than others. George had severe separation issues and his activity level resembled someone who was always on the go, full speed with no brakes. He had many temper tantrums daily and only spoke a few words. His fine motor skills were obviously delayed but his gross motor development at the time appeared normal. Looking back, I now recognize there were huge red flags regarding gross motor skills where he developed a lot of compensations.

In 1999, George was given the diagnosis of Pervasive Developmental Disorder and met the criteria for Attention Deficient Hyperactive Disorder. He was taking the highest doses of medication recommended for his age and weight for anxiety, hyperactivity, difficulty focusing and attending, getting stuck, and impulsivity. In 2000, we began further addressing concerns for his anxiety and he was diagnosed with Anxiety Disorder, Not Otherwise Specified. In 2003 after genetic testing, he was diagnosed with Fragile X. In 2006, George was taking five different prescription medications for his symptoms but, by 2007, it was decreased to two prescriptions.

In 2002, George went to kindergarten. He had to be carried into the classroom because he wouldn’t walk through the doorway and he needed 1:1 adult support. George could not sit for circle time. His fine motor skills were delayed – he could barely hold a pencil or form letters or shapes, cut with a scissors, or write his name. His only writing ability was to scribble. George’s vocabulary was small and communication was limited to a few simple words. (It took until second grade before George could say a complete sentence.) At age 6, according to the Peabody Picture Vocabulary Test-3rd edition, George scored in the first percentile for auditory comprehension, expressive communication, and total language. Some of his common sentences were, “Where do you get?” “I want to play some toys” “I try this on?” His language was characterized as being literal and responding to the concrete. George was preoccupied by his own interests, not the classroom activities. He did best with structured and consistent routines; he did not handle change well because it confused him. Around this age he began to show an interest in his peers. He could play independently; however, he needed an adult for group activities to redirect his attention to the topic of discussion. In elementary, middle, and high school George has been in the regular education setting for a majority of the school day with a 1:1 support.

In February 2006 (at age 10), we began using Brain Gym® activities, especially cross lateral movements. At first I physically moved his body for the movements because he was not able to do the movements independently. Within a short time, he was able to do them on his own and his ability to complete tasks, his tolerance for touch, presence of mind, and verbal and non-verbal interaction increased or improved. George was able to do chores with one prompt and more complex tasks without step-by-step direction. He tolerated light touch even when approached from behind unexpectedly. He had a better understanding of time relating to days of the week and upcoming events, his eye contact improved, and his conversation and social skills increased.

For four years I used individual Pilates sessions for core strengthening with George. I used Rhythmic Movement Training with George in 2007 and noticed his hyperactivity, anxiety, and panic attacks decreased although it was obvious, when I stopped using it daily, the effects soon wore off.

I began using Pattern Learning, a very intense academic program in 2007. George made academic gains but it required extreme repetition and was a slow, time consuming approach. He had improvement in handwriting, telling time, reading, and identifying the value of coins. He learned his full name, birth date, address, and the phone numbers for himself and family members. George has been working with a tutor since 2009 using the Riggs program to help him complete homework and develop more reading skills.

In August 2007, George saw a neuro-developmental specialist who suggested eliminating salt and nitrates from his diet to help decrease fluid retention and support his adrenal function. With these simple changes he

appeared less 'puffy'. We continue to avoid salt and nitrates to this day. The specialist also recommended certain movement activities for reflex integration with George. His understanding of verbal information increased along with an ability to sing along with songs on the radio, and his hyperactivity continued to decrease.

I was always searching for something to help George. Then in 2007 one of my professional friends mentioned that she had been invited to sit in on a MNRI® class in Minneapolis, MN. Dr. Svetlana was speaking and demonstrating a technique called Embrace Squeeze. My friend was only there a short time but left amazed. She shared what she had learned with me and I began asking around. Everyone I spoke with respected Svetlana Masgutova's work and held her in the highest regard. My burning desire became to meet Svetlana Masgutova and to learn more about her method and what she was giving to the world. I learned Svetlana was teaching two classes in Minnesota in the summer of 2008 and signed up for both. Our life has never been the same . . .

So in 2009 (at the age of 13), George attended his first MNRI® Family Conference. Immediately we noticed a change in his physical posture. Before the conference, all the muscles in his body were constantly tense and flexed and had been like this since he was 2 months old. After the conference his body appeared relaxed. His eyes were able to track naturally from left to right and back for the first time in his life. After several months of using our MNRI® Home Program, the doctor said he could discontinue the remaining prescription medications. We have used the MNRI® Home Program as recommended – 1½-2 hours a day, 5 days a week of MNRI® – for 1½ years. George has attended four MNRI® Conferences and two MNRI® Clinics since 2009. His social skills have continued to improve – he gives and takes in conversations with others. George has come so far! He played baritone (an instrument) from 6th – 9th grade in band. Academics have come slower but he continues to learn and make progress. He participates in regular school classes with the help of a 1:1 support and modified materials. He goes to his church youth group, school dances, the YMCA, and community events. He has so many wants and dreams including a desire to drive a car someday. I can't get George to quit talking now (and would never try)! He has a cell phone and calls family and friends daily. Sometimes he's on the phone with his Grandpa for hours. George has a positive outlook and is present and happy most of the time. His anxiety has decreased, he demonstrates good problem solving skills, his posture appears more natural, and his fine motor skills have improved drastically. He retains and understands verbal and written information better. There is measurable progress with his physical endurance and speed. Most recently, George stopped shredding his socks – behavior he has exhibited since he was a toddler!

George went through puberty between 2009 and 2010. It was a difficult time for all. He was very interested in the opposite sex and required increased supervision and redirection. The support of the MNRI® team during this time was priceless and I found the Masgutova Home Program very valuable. I was able to demonstrate appropriate touch and provide integrating movements. We survived!

George has had leaps and bounds of growth and development in the last five years. I attribute most of this progress to Masgutova Method®. In George's case, we were able to establish the correct primary reflex patterns



George on the football field.

and continued integrating them to the place where his body integrates naturally with regular exercise and physical activity. This is ultimately the desired results with reflex integration. Infants with normal circumstances and a typical environment can integrate their reflexes and live a healthy integrated life. I have now witnessed how it is possible for individuals with developmental and reflex challenges to naturally integrate on their own once the correct neurosensorimotor reflex patterns have been established. MNRI® is amazing! It is never too late to integrate with MNRI® but sooner is better. MNRI® empowers parents by supporting us with classes and further educates us by giving special opportunities at Conferences to hear about the method and individual techniques, see how reflex integration works, do the activities and movements with our children, and experience it in our own bodies. Parents, I suggest taking home what



George with his mother, Anna.

you've learned at MNRI® Conferences, on their website, from Core Specialists, and at MNRI® classes, and use this with your child and family.

Today (2014) George is 17 years old and is on the Elk River High School football team. Recently he was playing defense at practice and intercepted a pass thrown for the offense. He ran over $\frac{3}{4}$ of the field through the entire offensive line and kept going to the end zone for a touchdown. His team mates, standing on the sideline, were yelling and cheering for George! The further he got, the louder they yelled. Even the coaches joined in! When George reached the end zone, all the players ran out to where he was laying on the ground laughing and smiling, holding the football in the air. George got up and the players surrounded him in a huge circle

cheering and giving chest bumps to George and other players! The mood was exhilarating as if they had just won a Super Bowl! Later in the evening George said to me, "Did you see my touchdown, Mom?" I responded, "Of course, I did George! You were awesome!" I now realize how valuable even the practices are for George.

In late 2014 during George's senior year in high school, the *Minneapolis Star Tribune* carried an article about George and the Elk River football team titled, *Elk River Football Plays for Its Emotional Leader*. The article quotes George (who is the kicker) and many of his teammates relating their commitment to each other and their love for the game. The players and coach credit George for helping them keep committed to the game, keeping its relevance to their life in check, and always encouraging them to do their best and win. George has become an inspiration to many.

My family has had many challenges over the last 17 years supporting George through many struggles and teachable moments. I have come to cherish every precious moment past, present, and still to come. . . I believe George is in a better place today than I ever imagined possible because of MNRI®. I will continue to encourage George to learn and further integrate and give him as many opportunities in life as possible to reach his fullest potential.



George, your growth is amazing, your talents are so great! Thank you for using MNRI® as one of your main methods for reaching all this. Success, good health, and realization of your plans and dreams to you!
– The USA MNRI® Team Specialists