



Tyler's Gift

By Linda Jones, Tyler's Mother, and edited by Catherine Bailey

Tyler,
From Harvard to Heaven all in one leap,
Your memory is ours to cherish and keep
Living with autism you had much to endure
Now through your precious gift you will be part of the cure
By Helena Clancy

The daily living with an autistic child can be filled with challenges and triumphs. Then the worst and unexpected happened, our family has had to cope with the sudden death of our 16-year-old autistic teenager.

Tyler's journey began as one of twin boys born in October 1992. In November 1994 our twins were diagnosed with autism. One son recovered and Tyler maintained a diagnosis of severe autism. Supported by Birth to Three Resources Tyler started an Applied Behavior Analysis (ABA) program with Rutgers University supervised by Dr. Mary Jane Weiss.

Dr. Weiss emphasized the need to teach as many academic skills as possible since the social piece of going to school would be the most difficult skill to master. Our family was fortunate enough to be a part of an early ABA program offered in Connecticut for a limited number of six children. Tyler received intensive one-on-one training seven days a week learning *how to learn*.

Tyler struggled with learning academics such as the alphabet, basic coloring skills, and counting. He simply could not understand what we were trying to teach him. In 1995 very little information was available regarding autism. For months we sought answers from various professionals but no one had the answer of what to do for a low functioning autistic child. We persevered with home schooling, public school, a residential program for a year, and specialized schools. Each transition into a different system of education had its own problems and adjustments.

Our home program behavior analyst, Dr. Robert Murphy, taught us the concept of *functional* ABA. In 2002, for a year my husband and I worked alone with Tyler using this approach. This included taking Tyler into a public school for approximately an hour a day. The routine was to transition Tyler into the school with pictures, do some chores, work with an OT and a SLP for 15 minutes each, and work for a few minutes on a computer. Tyler mastered using a mouse on the computer to match shapes. A wonderful accomplishment after so many practice sessions!

One of the hardest days was when I took Tyler to school to practice our typical schedule. It was clear from his noises and frustration level that he did not want to go. He got so angry when we pulled up to the school that he kicked the windshield of the car with his foot hard enough to crack it. He started scratching, pinching, and biting out of his intense anger. The school's SLP came out to help get Tyler into the classroom. After cleaning up my wounds and getting Tyler settled down, we moved through the schedule and came home. There was blood, tears, sadness and defeat at that moment.

In 2002 we started consulting Dr. Margaret Bauman, a neurologist specializing in autism from LADDERS in Massachusetts, for Tyler's medical concerns. Throughout his life Tyler suffered from chronic constipation. Dr. Bauman referred us to Dr. Timothy Buie, a gastroenterologist. The two year wait for an appointment was well worth it as Dr. Buie's input changed Tyler's life—medically and behaviorally.

Dr. Buie diagnosed gastric reflux also and both conditions were treated with medication. Many of Tyler's maladaptive behaviors were a result of the pain he felt from these medical conditions. Dr. Bauman diagnosed a mitochondrion deficiency in 2007 which was treated with vitamin supplements.

Tyler slowly started to learn with our practical approach to teaching in a quiet environment. In 2006, we added occupational therapy, music therapy, physical therapy and some speech therapy. We practiced daily living skills including dressing, packing a lunch, getting on and off the bus, doing laundry, vacuuming, changing the toilet paper, and so on. Everything had to be broken down and taught in real photo sequences. This was a significant turning point in Tyler's life.

In the summer of 2008, Tyler started a beading program and his jewelry business T.J. Designs was created. We started with random semi-precious stones that did not require a pattern and had Tyler put them on a piece of elastic using a needle. He was very good at it and it seemed to calm him. We progressed to a bead board having Tyler make preset designs on a left to right plan. At our first craft fair in October 2008 we sold approximately 150 bracelets! Tyler, two of his teachers, and I were tickled to tears when we realized our success. Tyler made an average of two bracelets per day over the next year.

Tyler learned through the use of a reward system. Smiley faces had meaning to him and at the end of the day he usually earned enough smiley faces to get a special reward of his favorite meal or a bath.

A picture exchange system (PECS) was used for many years. In 2008 Tyler was introduced to a talking PECS book known as ProxTalker from the founder Glen Dobbs. His first paid job was

for ProxTalker cleaning used computer chips. Tyler also started a program at the Newtown Youth Academy where he practiced various photo driven activities and chores. After completing these tasks he walked around the track and shot a few basketballs. He often worked for a snack that he received as his reinforcer.

On September 18, 2009 Tyler did not get up to go to school. He passed away from unknown causes. There are so many memories to record. He struggled to learn and to communicate but he never struggled to love. Tyler adored his twin brother and older sister. They spent time together playing basketball, listening to music, or playing instruments—his brother on the piano, his sister playing the violin, and Tyler drumming. His smile and gentle “butterfly” kisses let you know that no matter how bad his behavior he still loved you. Tyler loved to go to school and could hardly wait to walk down to the van in the morning. He loved to learn and he loved to make people proud of him.

One week after Tyler’s passing I took a walk in the condominium complex behind our house. Our family’s bridge of communication to Tyler, and Tyler to us, was through the use of pictures—pictures did the talking for everything. I wanted to take a photo “virtual tour” of the typical walk that Tyler and I took together so many times as well as the night before his death. During the stroll I took a picture of a small dog. The dog owner did not ask why I was taking pictures but simply said good bye after I took the photo. A few minutes later she came back to find me and asked, “Are you the mother of the boy that recently passed away?” I answered yes and she said “I just knew you were and I wanted to come back and talk with you.”

As we talked, I stated that we did not know what had happened to Tyler and that our family made the decision to contact the Harvard Brain Bank to donate Tyler’s brain to Dr. Bauman. After explaining everything this nice woman gave me a hug. She told me that Tyler was talking to me at that moment and that I should take a picture. The clouds immediately opened up and a large ray of sunshine peeked through the white and black fluffy clouds. I snapped the shot! I arrived home a few minutes later and put the pictures into my computer to view them. When I came upon this most beautiful picture I noticed the amazing balls of colors—red, blue, and green, with a touch of yellow—like the colors used in an autism puzzle piece. Tyler did talk to me that

afternoon—as it was when he was living and will always be in the future—through a picture...



Tyler’s life was a learning gift. We learned patience; we learned if Tyler could not learn something it was our responsibility to learn *how* to teach him; we learned to never give up. We hope that the donation of his brain will serve as a medical gift for all future generations.

Donations in Memory of Tyler Jones can be made to:

Autism Research Foundation
c/o Anatomy and Neurobiology, Dr. Margaret Bauman
Boston University School of Medicine
750 N. Albany Street
Boston, MA 02118

To view Newtown Bee’s article on T.J. Designs, go to newtownbee.com and click on the search tab; type in “Autistic Child’s Beads, Blessings Will Be His Legacy” The article was published on October 15, 2009.