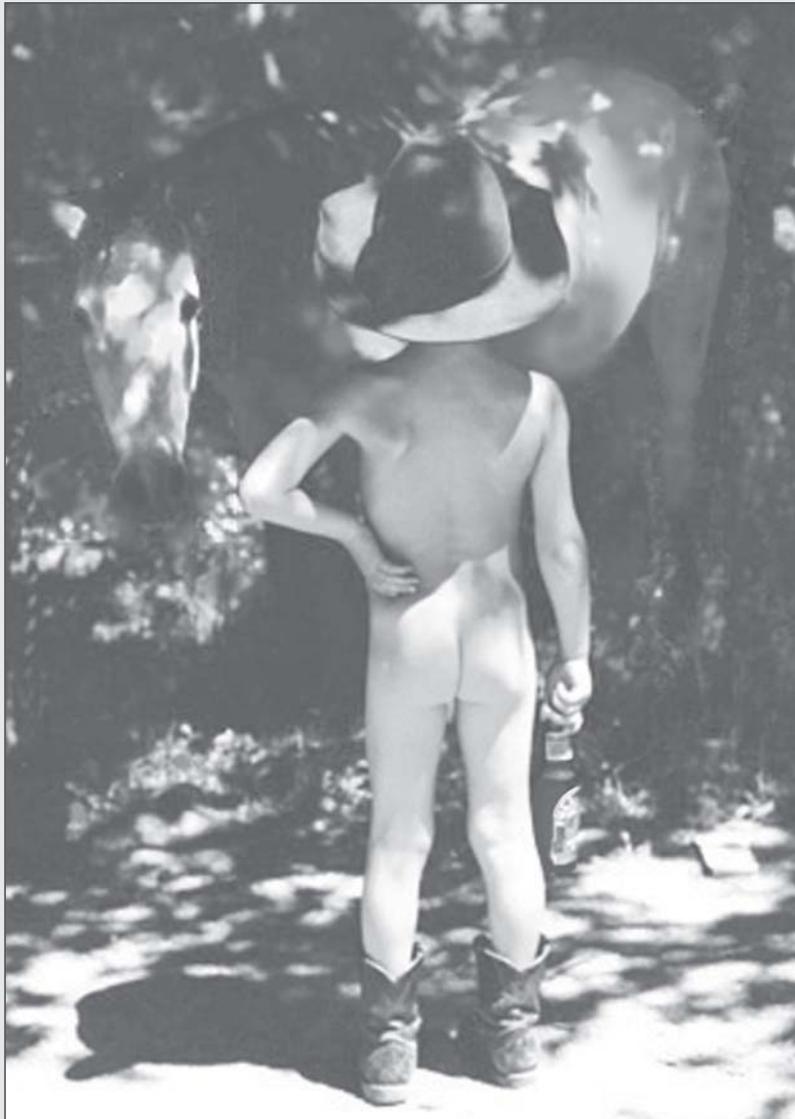


Chapter Two: Marley Up!



Marley, age five, frustrated with his horse, Nike.

Photo: Jennifer

Letter sent to my family

May 16, 1989

SPEECH! SPEECH!

Dear Family,

Here's some news for you! Another family member is on its way. A girl, this time, we hope. Yes, a baby...a Christmas baby (actually she's due December 7th).

The reason I'm writing is to let you know what's going on with our firstborn. Marley's now four years old and is a beautiful, bright boy. He's into horseback riding in a big way. He and Drew have been taking daily hour-and-a-half long rides. He goes to preschool and gymnastics class and even has a girlfriend (our neighbor, Brianna). Marley is a high-energy kid, filled with loads of common sense and a great imagination. He's not like other kids in a unique way...he doesn't speak the English language.

He communicates with a variety of sounds, great expressions, and a fairly large "vocabulary" of hand signs (American sign language). He fully understands everything, it just doesn't come back out with verbal words. Strange! Anyway, we've been to four doctors, a psychic, and several specialists. We've had his hearing tested twice and his oral motor capabilities tested; apparently there's nothing wrong with his hearing or the shape of his mouth, or the way he uses his tongue. He can make sounds, but he cannot put them together to form words (other than "mama," "dada," "pop," "yeah," "help," and "boom"). He never did the baby chatter that you commonly hear one-year-old kids do, although he makes lots of beautiful sounds when he sings.

The term Western medicine is using to describe this handicap is *Developmental Apraxia*. Which basically means the connec-

tion in the brain to the speech center is “turned off,” thus he cannot get the information from his master computer to tell his tongue and lips how to work to form consonant sounds or to put more than one group of sounds together. The word “help” is a big one (take a minute to sound it out and break down the different movements of your tongue and lips.) It takes Marley major concentration to form this word.

There seems to be no apparent cause. The cure? They say there is a chance for him to learn to speak with therapy (taking anywhere from 3 to 10 years). It may or may not ever sound “normal,” although technology has devised many ways of helping these folks communicate with computer aid.

Alternative medicine has a slightly different twist. We were told “Mars Bar” has a lot of psychic energy, and he uses this to communicate with. They said, for reasons with an unidentified purpose, he has chosen not to use the “normal” ways of verbally communicating. In other words he has “turned off” this ability, but is also able to “turn it on” when he feels it is necessary to communicate with words.

I think they both said about the same thing, except the non-traditional view sees Marley in control of when speech will occur. This has been my sense for a long time; that it’s not just a rebellion, “I won’t talk,” but “I can’t talk now.”

So what do we do? We checked out a special school for the language impaired. None of us liked it but the concept was okay. At least the staff all used sign language. The idea of Marley finally being understood by other people was extraordinary to us. But they run the program with such limited brain power and imagination that we decided to reject it. We’re looking into hiring a private therapist.

I would like to ask all of you to consider learning sign language. It’s a wonderful second language to have under your belt, and it may be the only way you and Marley will be able to communi-

cate. Until now, I don't think our family has ever encountered a handicap other than dyslexia. It's time to think about what you're willing to do in order to communicate with your nephew, cousin, or grandson. Learning a different language can take some time, so don't wait until the last minute if you choose to give it a try.

We appreciate your love and support and thank you for considering working with us on this project. For those of you who haven't yet met Mars, I think you will find him a loveable, delightful, funny little boy who wants to play ALL THE TIME! I hope you will meet him soon—his little sibling-to-be, too!

With joy and much love,
Jennifer

*“The problem is not that there are problems.
The problem is expecting otherwise and
thinking that having problems is a problem.”*

—Theodore Rubin



Marley on Nike and Drew on Star

The Butterfly Effect

GRADE SCHOOL SPEECH

by Selene Foster (age 11)

If you see an elf running around with a sonic wave device hanging on his ear, don't call the Marines, it's Marley, my cousin, the subject of my speech. Actually, I think of him more as the little brother I never had. To explain my opening line I'll have to say that Marley is special. The sonic wave device is really just a piece of skin on his ear that's been there all his four-year-old life. The doctors say that it doesn't do anything, but I'm not sure they're right.

First of all, I'll tell you a little bit about Marley. He has blond hair, blue eyes, he is sweet, sensitive, outgoing, and very intelligent, despite his handicap. That's another thing I need to tell you about, his handicap. But, I really wouldn't call it that because it doesn't seem to slow him down any or bother him much, it just gets frustrating sometimes and he does have temper tantrums because of that frustration. Specialists say that there is a little part of his brain that doesn't work. This means that he'll probably never be able to talk. This also means that he'll probably never be able to go to a regular school or lead a normal life. However, I don't believe it. He says some words, so I think he just doesn't want to talk. At least I did think that, but now I realize that he really does have a problem. He taught me that. He knows he is different. I overheard him telling his mom that he really wants to go to a speech therapist.

He and I have a special relationship and it grows every time I see him. Right now I am looking forward to the next time I can visit. I always am. My aunt tells me Marley always asks her when I will come for a visit and that he continually asks how I am. This makes me one of the happiest people alive. When I do come to visit, he immediately latches on to me, and insists that he tell me everything new that has happened. Then he shows me all the new

animals he has gotten. I love it.

When I say he “tells me,” I mean he signs. Signing has been a big part of his learning, and I am now in the process of learning how to sign so that I can understand him more easily. He is so good at signing that he now surpasses his mom.

I have a horse that recently died. After I told my aunt on the phone, she told Marley. She said he cried for twenty minutes and was worried about me. When I hear things like that, it brings me to tears and I want to tell him how much I love him.

I have many other stories. Just the other day, he went up to my aunt Jennifer, and “said” that the door needed to be closed, (usually he would have just closed the door himself). Jennifer told him he could go ahead and close it, but he didn’t. Instead he signed to her that she needed to do it so that his ten piglets wouldn’t get out. After Jennifer told my mom this story my mom asked when they had gotten the piglets. Jennifer said they hadn’t, but apparently Marley thought so! He is always surprising someone with something.

Another thing Marley is famous for are girls. I know that you might think that he would be shy, and sometimes he is. But, when it comes to girls, he’s a tiger. At the pool, at the arcade, it doesn’t matter where, if Marley’s around, you’ve got to watch out. Many a time he has gone up to a girl, grabbed her hand, kissed her on the cheek, and dragged her around until it was time to leave.

There is so much else I could say about him, but I don’t know how to put it into words, so I’ll end by telling you what he has taught me. He has taught me patience, courage, how to accept things as they are, how to get the most out of everything, and most of all—how to love. I hope that one day he will be able to read this and fully appreciate and realize how much I really do love him.

Thank you for taking the time to listen to me speak.
Good night.

COWBOY TROUBLES

Horsing Around

One thing I am truly amazed at is how few times Marley really hurt himself. He was taken to the emergency room only once until he tangled with cancer at 15 years old. That's mind-boggling, considering how active and daring he was.

When Marley was five years old, he tried to load his pony in the horse trailer alone. Our trailer was the old fashioned kind, sporting a ramp rather than the swinging door that was later proven safer. The ramp was fivefeet square, made of steel and thick planks of wood, designed to support 1,000 pounds of bucking horseflesh. Marley must have thought he was much stronger and taller than he was, because his plan included lowering this heavy ramp.

From what would be a block away in city terms, Drew and I heard Marley's bloodcurdling scream. We ran up the gravel drive to find his leg pinned between the ramp and the dirt road, with a three-inch bolt embedded in his calf. After patching the hole and stabilizing his broken leg, we calmly endured the 25-minute drive to Ashland's hospital. I knew there was something strange about this kid because he, too, was remaining calm, like this was another adventure—a field trip to the ER!

It was then that I learned his pain threshold was abnormally high. A few days later, he was good to go, ready to show off his fancy, painted cast. Why slow down when you can have fun? Having a cast didn't stop him from riding horses, running, climbing, wrestling, or getting into mischief. I had to fight the urge to protect this little kid who talked without saying any words—but there wasn't much I could do to stop him.

*“When a great ship is in harbor and moored,
it is safe, there can be no doubt.
But that is not what great ships are built for.”*

—Clarissa Pinkola Estes

August 3, 1990

UNCONDITIONAL LOVE

Dear Marley,

I just want to tell you how much I love you! You are five and a half years old. What an age! Sometimes you drive me crazy, but through it all you are my best friend. We are with each other all day long, every day. We've been busy this summer going to summer camp at the YMCA and to speech therapy in Medford. Even when I'm a real crankcase, you're always there for me in the end. I don't know how you put up with me and still try so hard to please me.

Your sister, Catie, is eight months old and she loves you so much. You're a great big brother. Thank you for letting me watch how you look at her when she sleeps. Such adoring, I've never witnessed, only felt. For a rough-and-tumble guy, you sure know how to be gentle and sweet. I am amazed by the way you, the one who takes such pleasure in pulverizing rocks, are so incredibly tender with your baby sister, handling her with the perfect combination of strength and care.

Your ever lovin' Mom



Mars with his baby sister, Catie
(Note the polyp or "sonic wave device"
on his ear. At his request, it was
removed when he was seven.)

PASSING THE TEST

It's Elementary

Before Marley could enter the public school system, he needed to be assessed for eligibility for special education services. When he was five and a half years old, Janet, the Speech Language Pathologist for our district, was asked to do an evaluation. She visited him at his preschool summer camp and, as a part of his assessment, wrote:

“During the informal speech/language observation, Marley displayed age-appropriate play skills. He participated with other children, but only communicated with gestures and noises. He appeared to have no interest in verbalizing. He displayed the functions of asking, showing, telling, and requesting at a pre-linguistic level. It was apparent Marley used direct eye contact while communicating and was understanding questions asked of him and directions given.”

He had been given two labels, *Apraxia* and *Aphasia*, but both were deemed inaccurate. Because no one could come up with a better label to afford him the services we knew he needed, we found a loophole: percentages. The final report stated that Marley demonstrated severely limited oral expressive language development, scoring a 67 percent delay. That percentile was good enough for the state's requirements. Marley could go to school! The following year, when he entered kindergarten, Janet began her role as Marley's speech therapist for the next eight years.

During an interview with Janet ten years later, she was asked if she remembered the first time she met Marley. A warm smile spread across her face as she said, “Oh yes! I went to observe him when he was five years old. He had been told I was coming, and I was expecting him to be shy and withholding. But as soon as I entered the room, he ran up to me smiling, gave my legs a hug, and took my hand. I was instantly his friend and he wanted to show me everything.” For the rest of his days, Marley adored Janet, and honored her for his ability to speak.

Letter written to my clan
New Year's Day, 1991

HOLIDAY UPDATE

Dear Ones,

It was a wonderful Christmas! We spent this holiday wrapped in warmth and love in our ever-expanding home, nestled in the mountains. Santa was very generous and Marley was a great receiver, taking his time, exploring each gift with interest and thanks. A remote controlled cement mixer actually brought tears of joy to my boy! Because of my children, for the first time as an adult, I'm actually looking forward to next Christmas.

For two weeks, the temperatures have hovered around twenty degrees. Oregon is simply not prepared for these temperatures. The electricity, gas, and water went out for much of Ashland during this Arctic freeze, and many have been residing in the gymnasiums of our local schools. Fortunately we weren't so badly hit because we use wood for heat, propane for most utilities, and a generator that provides electricity to pump our well water and to charge the 12-volt system used for lights. Unfortunately, our water pipes *did* freeze. So we are carrying water from town in many 5-gallon containers to supply water for thirsty animals and our household needs.

Before the freeze hit, Drew had nearly completed a new extension; an office and a bathroom with a compost toilet. Yes, folks! No more midnight runs to the outhouse in the snow. We're moving up in the world. Another lifesaving addition this year has been a large covered front porch. Now there's a place to stack firewood, kick off mud covered boots, and a place to be outside while the skies cry. A true blessing.

I have found a beloved friend who is a godsend in my life.

Friends of this quality and depth don't come along every day! Cindy lives in Ashland with her husband and two daughters. Vanessa is a year younger than Marley, but they are both in the same preschool class, which is how we met. Laura is just ten months older than Catie, and both pairs of kids adore each other. Laura and Marley even share the same birthday!

Drew is now a farrier, shoeing horses, a perfect career choice for his rare personality type. It's dangerous and exciting, it's hard work and rewarding, and it's ever-changing and flexible. A demanding job not many can withstand but, then again, we're talking about Drew (Doo da loo, as Marley calls him). When Drew's not shoeing horses, he's adding on to the house, redesigning the existing system, taking long horseback rides in the mountains with Marley, or curled up reading a never ending supply of western novels. A true cowboy. His fantasy is a 100-acre ranch with lots of horses and cattle to roundup.

Marley will be six years old in February. He has grown tall and beautiful. His words, limited to five last January, have rapidly multiplied. He now uses full sentences, one right after another. (Currently his speech is at about a three-year-old level.) He still uses sign language and/or sounds for words he doesn't know or cannot manage. Imagine, it's the first time I can listen to my son without having to always be within eyesight!

Last January, just after Catie was born, Marley had PE tubes placed in his eardrums due to repeated ear aches. This procedure equalized the pressure and allowed for adequate drainage. It was a 20-minute out-patient surgery done in the local hospital. We're not sure whether it was the surgery or Catie's birth that influenced his desire and/or ability to speak, but regardless, we're thrilled about the shift.

Marley is an amazingly bright and loving boy whose zest for living and learning seems to far outweigh the pain he has had to live with. Not only has he dealt with intensely painful earaches

and the frustration of not being able to communicate with others without my help, he has also had an acute and chronic stomach disease.

After ten doctors, thousands of dollars, and two and a half years of pain, we took Marley to Stanford Medical Center for two days of tests, climaxing with two surgical procedures; a *bronchoscopy* (a camera tube snaked down his throat) and a *colonoscopy* (the same but from the other end). He made us very nervous when he stayed under the anesthesia much longer than expected. But in the end, a diagnosis was made: He had a bacteria called *Urcenia* and a parasite called *Blastycis Hominus*. Both are extremely microscopic and rarely seen, apparently the reason our local doctors and lab technicians were unable to explain the cause of pain.

Now, after two weeks of being on two different antibiotics, Marley has only had five bad days. I'm skeptical about the cure, due to the fact he's been on so many antibiotics for his ear troubles. I wonder sometimes if the cure for the ears wasn't possibly the cause of the stomach disorder. At least we are relieved to know there's really something in there and it's not all in his head.

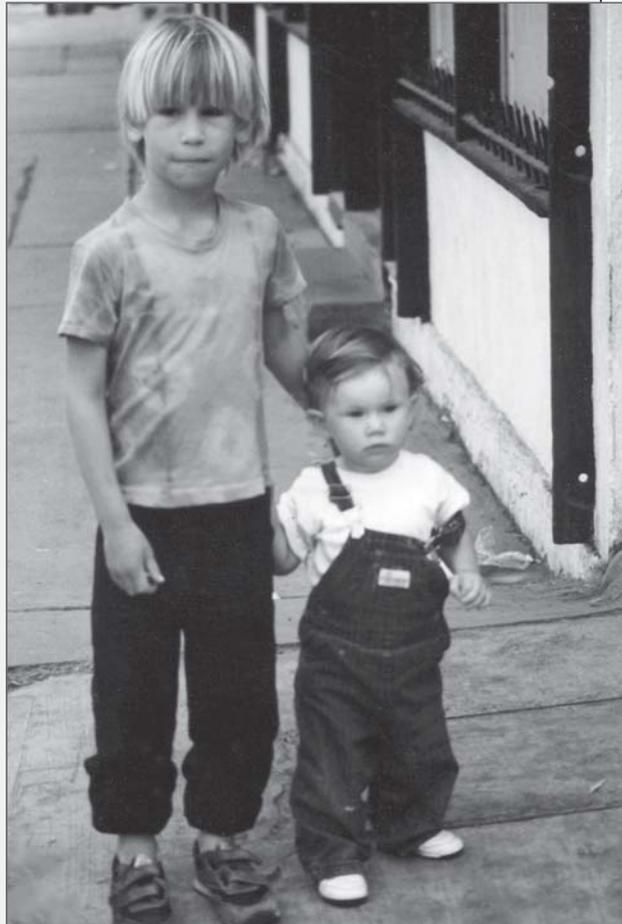
It's been very hard to see my boy in such pain and not be able to find a solution. This stomach problem has been the cause of Marley's hyperactive behavior (he says he had bees in his belly and moving fast was his solution). It's been really nice to have my boy back now that he's feeling better. Keep your fingers crossed!

Catie just had her first birthday. She's a pretty little "knee leech" that loves to dance. She's always happy and loves wrestling with her brother, whom she adores. Marley is the best big brother in the world—it's so cool the way he loves her. We just got an Olympic-sized trampoline, and Catie squeals with delight as Marley endlessly bounces her on it.

The animals still fill our lives. We presently have three horses, one dog called Sage who faithfully sticks close to the kids at all times, and two cats. Pretty Kitty helps pay the bills, producing continual crops of Himalayan kittens, which we sell for \$20 each. We also have a bunch of laying hens, one mean rooster that we're all scared of, and a very funny guinea pig that roams free but is faithful to the homestead.

We hope you come to visit soon. You're always welcome. You'll probably want a four-wheel drive vehicle to get down our driveway. When you do come, remember to watch out for Marley's trucks frozen in the puddles, and don't worry about Sage; she barks but she doesn't bite. Our guest house is small but has a really comfy featherbed and a shower. (Well, that won't do you much good 'til the pipes thaw.) Hell, forget about visiting until springtime—we just decided to pack up and go to Baja for awhile! Yahoo!

We love you,
Jennifer



Marley and Catie in San Felipe, Baja

PLEASURES AND PITFALLS

Responsibility

From parenting, I learned the ability to respond—even when I didn't want to. I had felt the joys of love from parents, siblings, friends, and mates, but no one could have prepared me for the utter bliss of smelling a newborn, the incomprehensible butter softness of new skin, and the intimacy that's not only allowed, but required. The most amazing thing was understanding, on a cellular level, that this little human will die...DIE...if it's not cared for, and it will pay the price later for negligence now.

I never wanted kids. That was supposed to be my sisters' job. They were supposed to have the kids, and I was to be the best auntie known to humankind. I believed I didn't need kids to know what responsibility was, because I was an adult orphan responsible for myself in a way none of my peers or even siblings were. (That's a complicated story, I'll explain later, I promise.)

When the going got tough, most folks my age had at least one parent to fall back on. Yet, for me, the rite of passage from individual to parent was the very lesson I needed. I was, for the first time, responsible for someone else, and I knew what commitment meant: 'til death do us part, for better or for worse, for richer or for poorer, in sickness and in health.

Commitment Sample, Part I

Many of us throw around the term "commitment" with relative ease. I really had no concept of what it meant until I had a baby. At 17 years old, I married a man I had loved since I was 13. Yet after nine years of loving him, we divorced because I wanted to feel free. Vows...whatever! Things change.

My role models were confusing. On one hand, I had my parents (here comes that complicated story I promised you). My mother, Virginia, was married to Phil, and they had four kids; Tip, Ric, Julia, and Constant. My father, Alden, was married to Liz, and they had four children; Andrea, Meredith, Martha, and Tim. (Both sets of kids were approximately the same ages.)

Phil and Virginia had built a new house on the hill above the one they lived in, and Alden and Liz bought their old house. We're talkin' a rural small town—Wayzata, Minnesota, in 1958. To make a long story short, Mom and Dad fell in love and so did Phil and Liz. Both couples divorced and, days later, married their new loves. Phil and Dad packed their belongings, and each moved into the house of his new wife and legally adopted her four kids. Constant, for example, went to kindergarten that morning with one last name and returned home that afternoon to a new last name and a different dad. Meanwhile, just to make things a little more complicated—Mom was nine months pregnant. Eleven days after Mom and Dad were married...ta da...I was born! Nine months after that, Jay was born to Phil and Liz.

Poor Phil had to move back into the house he had just moved out of, so he and Liz built another one on the other side of the hill. The two families lived next to each other for eight years until Phil and Liz and their five kids moved to California. Mom, Dad, Constant, and I moved to Miami. Tip and Ric, adults with independent lives, stayed in Wayzata, and Julia remained at college.

Commitment Sample, Part II

On the other hand, I had Gladyce and Phil (another Phil) as the example of an old-fashioned, farm-style, 'til death do us part kind of marriage. Mom and Dad went on their honeymoon two weeks after I was born, and left me in the highly capable hands of Gladyce, who helped both Liz and Mom with domestic chores. Gladyce and Phil lived on a dairy farm that I considered my second home, as Mom and Dad traveled a lot. Gladyce and Phil are now both in their 90's and have been married longer than most people live.

I'm thankful I had examples of two very different life styles available to me. I felt what two very different brands of motherly love felt like. When it was my turn to mother, my technique fell somewhere between Mom's pioneering style of the future and Gladyce's old-fashioned style.

History Repeating Itself

My parents weren't the only couple with a complicated love scenario. I had to ask myself why we sometimes create situations that mirror circumstance of the past, as this soap opera story became even more absurd. (Some things are just too weird to ignore.)

Marley and Vanessa were in preschool together—that's how I met Cindy. She had a babe in arms (Laura) and I had a babe in the oven (Catie). We became inseparable friends for the next three years. Cindy, her husband Marlo, and their two kids would hang out with us for BBQ's, waterskiing, etc. Everybody got along, especially the four kids.

Marley and Vanessa adored each other. One night when we were at Marlo and Cindy's, the kids announced that they were going to get married. A few weeks later, Drew and Cindy realized they had fallen in love with each other.

After ten stormy, emotional months, both marriages were dissolved. Drew moved up on the hill above our property and started courting Cindy. Had Marlo and I connected, it would have been exactly the same type of switch that my parents had made thirty years earlier.

In the end, Drew and Cindy got married, so Laura and Vanessa became Marley and Catie's stepsisters, which suited them just fine. Marlo and Cindy set up the same schedule for the kids that Drew and I had—two weeks on, two weeks off. And everyone lived happily ever after. Tra la la!

Even though I never wanted to have children, I know that becoming a mother was the most important gift the spirits ever gave me. It is my children that taught me about commitment and about being alive—about really living! I always hoped to repay their gifts by being a great parent, helping them to love, live, and die well.

*“Our children change us...
whether they live or not.”*

—Lois McMaster Bujold

GROWING PAINS

Square Hole, Round Peg

Marley spent two years in kindergarten and was seven years old by the time he was ready to start first grade. I had fought hard to get him into a school that would adapt to his special needs, rather than trying to make him fit their curriculum. His elementary school was amazing. During the years he was in kindergarten, this school helped students learn sign language and began to implement an old-school concept: blended classes.

Marley's first blended class consisted of both first and second graders. A wondrously creative woman named Pat was his teacher for both years. It was a brilliant plan that let the kids learn at their own pace. The kids also had time to learn how to communicate with Marley while he slowly learned to speak our language.

For the next two years, Tim was Marley's teacher for a third and fourth grade blend. Most of his classmates had graduated with Marley from Pat's class to Tim's class. Being with the same bunch of



Marley ready to fly, age 7, Nags head, NC

kids was his saving grace. They had already learned to accept Marley for who he was and had the patience to help teach him social skills without stomping on his self-esteem in the process.

It became apparent that Marley simply didn't understand the

abstract nature of symbols. Seeing letters and trying to match a sound that related was incredibly confusing and frustrating for him. Whenever the class focused on English, Marley would go with Janet, who helped him with his speech. It was the same with numbers. When the class studied math, Marley would go to Nancy, his special-ed teacher, for one-on-one help.

An example of how Marley's brain worked: If Nancy was teaching math skills and asked him what two plus two was, he wouldn't know. But if she asked him how many tires a truck needed, he'd ask, "What kind a tfwuck? A semi or one like my dad's? My dad's tfwuck needs fouda tiyas." And he'd launch into a story about the time his dad almost rolled his truck off a cliff. He was so animated, it was difficult not to fall completely in love with him.

"I never let schooling interfere with my education."

—Mark Twain

Throughout his elementary education, Nancy was a master at inventing ways to teach Marley. She incorporated "life skills" into Marley's special curriculum. For many years, Marley had two jobs; one in a nearby plant nursery and the other in the school cafeteria. He especially loved working in the kitchen because he got second helpings for his effort.

Going Psycho

When Marley was in the third grade, it was time for him to be retested for continued special education. It took Don, the school district's psychotherapist, several months and a wide variety of tests to determine if Marley was officially handicapped. It was the responsibility of this one man to give Marley an effective label that would allow Marley special services until he graduated from high school. When his report was complete, a meeting was called. Tim, Pat, Nancy, Janet, the principal, Drew, Cindy, and I all gathered to read the report aloud.

Don's nine-page Psycho-Educational Report was either going to make or break Marley's future in education.

“Initial Contact: Ordinarily during the initial period, there is some tension as the examiner and the child ‘adjust’ to each other and to the evaluative situation. In this case, Marley accompanied me quite willingly and did not show any undue signs of distress or tension. Marley was a delightful but low-functioning student who warmed up rather quickly to me. It takes a while to understand Marley’s verbal output, but after one becomes used to his language it is much less of a problem.”

Before Don explained the details of all the tests, he did a “Summary of Report” that really worried us.

“Current testing indicates Marley is classified as being in the Borderline and Intellectually Deficient (mildly mentally retarded) range. There were, however, some definite indicators that exceeded these global scores. Clearly Marley presents a difficult diagnostic problem. He has many of the traditional signs of mental retardation and yet there are sufficient strengths that would, in my opinion, make a determination of mental retardation erroneous.”

We all moaned, fearing that Don’s confusion would mean Marley might face a bleak future without special aid. But in the end, Don’s final summary gave us what we needed.

“From my numerous interactions with Marley, I will state that he does not appear to me to behave like a ‘typical’ retarded child. He has some areas of strength that approach the average range. I have to say, as well, that when it comes to the very abstract nature of ‘learning,’ that his scores are quite like that of a mildly retarded student. He is much what I think of as a boy who is ‘retarded between 9 A.M. and 3 P.M.’—i.e., primarily for the purposes of learning academics. His breadth of knowledge in interest in things outside of ‘book learning’ are much stronger, and I think it would be a disservice to Marley to label him mentally retarded, though he is, functionally, when it comes to school-

ing in academics.”

That was that! We all cheered. We had Don’s label, (which he purposely put in quotes) to put on Marley’s documents. Once signed by all of us, Don’s assessment would not be challenged.

Sticking Together

By the time Marley was ready for fifth grade, for some mysterious reason Tim and Pat resigned their posts and joined forces to team-teach fifth and sixth grades. Pat primarily worked with the younger students while Tim focused on the older ones. This meant that for his last two years of elementary school, Marley would be able to float between two classrooms with the same two teachers and the same students he had had since the first grade.

Marley began to thrive in school when he was 11 years old. The following progress report describes Marley’s abilities during the last two years of his elementary education:

“Marley seems much more comfortable about approaching academic topics. Because he is now adding and subtracting, he can play many of the math games with other students in Pat’s room.

Marley is very adept at traveling between the rooms. He works in Pat’s class for some of the academics but feels more socially connected to the students in Tim’s. He is very independent but also interacts well with other students.

Marley is an incredibly dependable student. He is the person both classes rely on when something needs to be done just so and right away. More than any other student, he knows his way around the school and knows where things are and how they work.”

I was amazed Marley did such a great job of hanging in there with school. Sometimes it felt like a survival test, and I held my breath throughout most of those early years. But when the going got tough, he’d either find a way around the trouble or he’d cowboy up and keep trying.

THE GOOD, THE BAD, AND THE UGLY

Stuck in the Middle

When Marley was 13 years old he entered middle school. Most of his peers were one to two years younger than him, and were far superior academically. The combination could have been devastating, but he was placed in a “cross-grade” program that was similar to his earlier education. There were six teachers that worked as a team for both seventh and eighth grades. All classes were in one hall, which made it much easier for Marley to navigate in unfamiliar territory with new rules.

Marley loved his first year at the middle school. The special services were fairly limited at this school, so when the regular class focus was beyond his comprehension, he got to socialize one-on-one with the teachers and counselors. Two of his favorite people were the nurse, Beth, and a new counselor named Abdi. They ended up being Marley’s saving graces at the middle school. They were always there for him *and* they loved listening to stories about Marley’s wild adventures (some of which, I’m kind of sure, were true!)

The second year wasn’t as much fun for him. Nothing inspired him. I think it started to dawn on him that life wasn’t going to be easy without a few of the basic concepts he was missing. He tried to rely on his loving charm, but that wasn’t working with many of the girls. He was a romantic and would bring girls roses. Many of them loved his attention, but didn’t want to accept his favor for fear that their social status would be lowered by associating with the “odd kid.”

Marley looked and moved like a normal 14-year-old, but he talked in a strange way and he couldn’t read or write. He covered up how much he didn’t understand so well that we didn’t always know how much help he needed. For instance, sometimes after bathing, his hair still looked greasy. It took us years to figure out it was because he couldn’t tell which bottle was the shampoo and which was the conditioner. It was a 50/50 chance he would wash his hair with the conditioner. He started looking much better after

we taught him to recognize the word “shampoo.”

One of his teachers pointed out, “He has difficulty using the correct verb tense and seldom uses the past tense.” This, combined with not fully understanding the concept of numbers, made for some fascinating storytelling.

One example is when Marley told a teacher about an accident that Drew had as a youth. Marley made it seem like it happened yesterday, and the cliff Drew drove off wasn’t 600 feet, it was really only 6 feet. But to a listener, it all sounded possible. Fantastic but possible. Marley’s teacher was very concerned, and asked me how Drew was getting along after the accident. Huh? I listened to the re-telling of the story and understood the confusion. Another example is when Marley said, “That car could haul ass, it could rev up to 600,000 rpm in second gear!” I knew to translate that to 6,000 rpm. But when Marley referred to the cost of things, misunderstandings could get a little pricey.

For the first time, Marley was surrounded by peers who were unfamiliar with how he looked at life upside down. I think he was often misunderstood, made fun of, and accused of lying. Most of the time he just didn’t want to deal with trying and failing to make new friends. He was miserable. On most mornings that year, I would have to drag him out of bed, as he loudly complained about how stupid school was.

Catie loved school and would be furious at Marley for threatening to make her late. When she would start screaming at Marley to hurry up, his reaction was to move slower and then she’d start yelling at me! I hated those mornings. I hated fighting or having to be the stern, consequence-wielding parent. There were some mornings when he refused to get ready. After a verbal battle, I’d make Marley dress in the car after threatening to take all of his bikes to Goodwill. Many of the mornings during the first part of that year were a drag. We all suffered through Marley’s suffering. Little did I know what was to come.

“If you’re going through hell, keep going.”

—Winston Churchill