

DARREN'S SMILE

(A MEMOIR OF DARREN BARTLETT ROSE)

(Written by his Dad)



PROLOGUE

Our Son died not long ago. Part of us died with him. The sun doesn't shine so brightly anymore. The laughs don't come so easily....and there is a hole somewhere deep inside that nothing can fill. But if I can, I want to tell you a little about this son that altered our lives so profoundly.

It is hard to write about Darren, because Darren, you see, was what many call developmentally disabled. People like him used to be called retarded, until that term fell out of favor....its meaning bastardized at the hands of boorish people. I wonder what will be the next term used to describe those of us unlucky enough to be brain damaged? Whatever it is, inevitably, it will soon be abused by those who find some strange satisfaction in derisively comparing their peers to individuals unable to function normally.

EARLY CHILDHOOD

Darren was born on a warm, early June day, in 1970. It was a totally uneventful birth. Mother and son did well and were soon home from the hospital.

The most noteworthy thing about the newborn was his beaming smile which came so effortlessly. He was just an all around happy baby.....perhaps, just a little too happy. Darren wasn't as alert as his older sister, Laura...he didn't cry so lustily and he was certainly not as adventurous. He didn't crawl on schedule. But he did eventually scoot around and he did begin walking at 16 months...not too far off, but none the less, delayed. And yet, there was always his smile.

By the time our son was 24 months of age, it was obvious he had a significant problem. He was not playing as to be expected. His language was limited and hard to understand. And most worrisome, he had little curiosity about the world around him. Contradicting what we observed in his behavior was an appearance that shouted all American Boy. Historically, all males with the Rose surname are born with blond hair. So it was with Darren...blond hair, blue eyes....a Rose child through and through. But this child was not much a part of the world around him.

We watched and we waited but with each passing month, it became obvious we had to do something....but what? We were little more than kids ourselves. We had married when I was 23 and Glenda was 21. Even now, she was barely 30 years old. Our marriage, without our knowledge, had entered a crucible. The tribulations ahead would either burn it up or forge it into an inseparable union that most marriages never attain.

As Darren neared his fourth birthday, we made a decision to take him for several days of testing at Children's Hospital in Birmingham, Alabama. Because I was a young engineer with demanding professional responsibilities, Glenda took him to the appointment without me. It was traumatic from the outset and culminated with me having to go extricate them both from the Hospital bureaucracy. The memories, even today, are vividof both Darren and Glenda crying as I demanded the nursing staff release my wife and child. They finally agreed but not before we endured the darkest doctors' consultation of our young lives. They told us that our child was functioning at about 35 per cent of normal. They informed us that he would never be normal, that he would never graduate

from high school, much less college...that he would never be able to marry or have a family. And on and on they went, each declaration landing like a sledgehammer to our souls.

I managed to get Glenda and Darren to the auto and we departed Birmingham as quickly as the speeding laws would allow. Glenda sat beside me in the front seat crying softly, but inconsolably. Looking in the mirror to check on Darren in the back seat, I found him looking at me with a broad smile. I told him reassuringly, "Hang in there, Buddy." He giggled, and began to laughingly repeat exactly what I had just said over and over. It dawned on me that all the terrible things they had said might be true, but the fact remained that the sweet kid in the back seat was just the same. None of the predicted tragedies had altered him, and hopefully, would not for a long time to come.

As we made the three hour trip home, we discussed over and over what our options were. It always came back to the same dilemma. There was something terribly wrong with our son, and nobody in the medical profession seemed to know what it was. But it wasn't just Darren we were concerned about. His perfectly normal, beautiful sister, Laura, also needed love and attention. It was imperative that in our efforts to do the right thing for him, that she not be neglected. Eventually, as we neared our Dothan home, we made a pact with each other. We would live our daily lives endeavoring to make our family as normal as it possibly could be. We would not be dominated by Darren's deficiencies, but instead, would work around them. We would include him in all that he could manage, and for that which he could not, we would obtain outside assistance care that would enable the remaining three of us to proceed with the business of living our lives. Fortunately, because we had an unbelievable support structure of friends and relatives, we were able to do just that.

PATTERNING

Though she had struck out in Birmingham, Glenda continued to search for something that might offer hope for Darren. One day in our local library she came across a novel entitled, "Todd". Upon perusing it, she found out that it was about a treatment procedure used on a developmentally disabled boy. The headquarters for the treatment method was in Philadelphia and the treatment itself was administered at home by the parents. The more we read about it, the more we thought it might help Darren. So, we went to Philadelphia, where we were given a week long course on how to go about the whole thing. Upon arriving back at Dothan, we began immediately.

Basically, the idea behind the protocol was that brain damaged children miss out on certain very necessary activities as babies....things such as crawling, brachiation, and sensory stimulation. The structure of the program was to provide the child extensive practice in all these activities through out the day.

An exercise called "patterning" had been developed which utilized three adults to actually guide the child through the mechanics of crawling while the child lay on a table specially made for that purpose. There was also an exercise for spatial relationship training wherein the child was suspended upside down by a strap connected to the ceiling. He then was spun round and round, back and forth, for several minutes. This was repeated four times a day. We put the strap beside Darren's bedroom window so he could see outside while spinning, which was good for him, but Lord, we got some real "looks" from people passing by.

There were 10 minute crawling periods in which Darren actually crawled all over the house while supervised. In addition there were baths in warm water that allowed him to be continuously and vigorously rubbed with a bath cloth. On top of all that were educational activities designed to improve and develop the memory.

All together, the program consisted of about 10 hours of intense activity for child and mother. In addition, it was necessary to bring in friends from all over the city to help with the "patterning".

The regimen described above went on for 7 days per week with no breaks and no holidays. Glenda, with the assistance of me and many others, maintained this grueling grind for over a year. It was then that I realized that this woman would march through Hell, itself, for someone she loved. But the most amazing thing of all was that Darren willingly did it every day without complaint. They made it into a game and strangely enough, this afflicted home, with all its weird rituals of exercise and teaching was a place of joy and love.

But nothing so demanding can go on indefinitely, and as we neared the 14th month of continuous patterning, it was obvious that all involved were nearing the point of exhaustion. We believed that Darren exhibited some improvements, but truthfully, the results were not as hoped. So, we made the difficult decision to discontinue the program. It was time for everyone to rest. And it was time to take Laura to Disneyworld.

CHILDHOOD

We settled into a routine of letting Darren be Darren. He listened to music, played with his toys in his room, and cavorted with his older sister, as long as it was inside the house. The cleverness of our damaged son continually amazed us. It was so hard to reconcile his deficiencies with the ingenuity he demonstrated when he chose.

On a cold rainy day in January, I walked by his room and saw that he had raised the bedroom window, and thrown a half dozen of his toys out in the rain. I closed the window and latched it, then went outside, retrieved the toys, dried them off, and put them back in his room. Some 15 minutes later, I walked by the door again, and realized he had unlatched the window, raised it, and thrown the toys out in the rain again. I went through the same procedure, except this time, after latching the window; I got some nails and drove them into the jamb on each side of the lower window, making it effectively impossible for a 4 year old to raise it. A half hour passed, and I went by his room again. Lo and behold, the toys were out in the rain again. He had taken a chair, climbed up on it so he could reach the latch for the top window, then released it, and lowered the top window enough to take each toy and toss it in the rain. I stood there with my mouth agape. I have a masters' degree in engineering and I had been outsmarted again by a kid who was supposedly unable to learn anything of note.

Standing at the door to his room that day, I knew something that I would never forget. Darren was in there somewhere. Beyond all the mysteries, somewhere inside his brain, was the child he was meant to be. This was not a stupid individual, rather, he was an individual who for reasons we did not understand, could not relate or properly function in the world around him.

His relationship with his sister, Laura, was surprisingly close. There were many road trips that their interaction in the back seat made it hard to tell one of them was abnormal. As we drove to the beach one day, I listened to Laura read him his favorite story of "Brer Rabbit". It was difficult to tell who was enjoying it more. But then Laura made a big mistake. She asked him what his favorite color was. "Green!" came the quick reply. He absolutely loved the sound of that word. Then he proceeded to repeat it over and over and over for the next 30 miles. Finally, I had enough, and yelled at him, "Darren! If you say Green one more time I am going to spank your bottom." (We all knew that wouldn't

happen, but my voice did sound authoritative.) Everyone went totally silent for about a minute. Then from the back of the car, came a very small muffled voice, "Green." We all collapsed into laughter which inspired him to repeat it for the next hour.

At six years of age, Darren entered the public schools system of Dothan, Alabama. It quickly became clear that he would be placed in special education classes. His appearance at this time in his life continued to be that of a perfectly normal child which made it even harder to accept the inevitable labels and disdain that came with being placed in special education. But it was not an optional situation. He just could not function in a regular classroom environment. Darren, being Darren, quickly adapted to the special ed classroom and was happy to get on that bus every day to go to school.

We continued to search high and low for anything that might explain or help our son, but it was a futile process. The medical establishment saw him as damaged goods and could offer no explanation as to why. They also had nothing to suggest that might improve his intellectual capabilities. The years passed, and as they did, Darren's appearance changed. He slowly began to exhibit the distorted body and facial characteristics that go with retardation. His situation gnawed at us daily but Darren did not seem affected by any self awareness of being different. He found friends and allies everywhere he went, and somehow, always made special contacts that watched out for him at every turn. It was never more evident than in pre-school. The teachers at Kindercare were kind enough to let Darren come everyday, although he created many extra problems. One of his favorite routines was flushing his socks down the commode. We had a large budget item for socks and Kindercare soon had a rather large monthly plumbing bill.

Years later, we found out that at nap time each day, when the rest of the children were asleep, a teacher would take Darren up the street to the convenience store for ice cream.

We witnessed such acts of kindness and love through out his childhood and marveled at how someone so damaged could get into people's hearts so easily. But we later came to know, it was Darren's smile. He might not say very much, but his smile said more than a thousand words ever could.

REVELATION

During Darren's fourteenth year, the mystery of his affliction would be unraveled. In reading a newspaper article describing the discovery of a previously unknown cause of mental impairment, Glenda realized that our son might suffer from the described condition. That condition was identified as Fragile X syndrome.

She immediately began a detective hunt to get an appointment set up to have Darren evaluated. After considerable research and effort, we were scheduled to visit the University of South Alabama Genetics Clinic in Mobile. As fortune would have it, our appointment was at the exact time that an Australian fragile X expert was to be at the clinic. He agreed to see Darren.

A few weeks later we arrived at the clinic with Laura and Darren in tow. We were all escorted in to meet with the kind, gentle, man who actually knew what was wrong with our son. He looked at Darren, and smiled and said, "Well Hello, Mr. Fragile X." Darren grinned and said "X". He briefly examined Darren and then asked an assistant to accompany both of our children to a playroom while we talked.

He asked us many questions that day about our families, our education level, our cultural background, and how we related to Darren. Always, he was polite and warm with his questions and responses. We answered them all as best we could.

He listened intently, and when all the answers were given he paused. Then in calm, reassuring voice, he said, "Let me begin by telling you both that neither of you bear the slightest responsibility for what has happened to your son. Nor does anyone else, for that matter. I can tell you, by my brief physical exam, that Darren is almost certainly affected by Fragile X syndrome. We are talking about a genetic problem that we do not yet fully understand. I can tell you that it appears that sometimes the problem is inherited and at other times it seems to be a new genetic mutation in the person affected. We will want to take blood samples from all four of you and after those samples are analyzed, we can state for certain that Darren is Fragile X."

Glenda could remain silent for no longer, "Is there anything that can be done for him?"

“I am sorry, no. We do not yet understand the processes going on his brain due to the syndrome and there is no means of intervention. Please keep in mind that the syndrome itself has only been identified for a few years. I personally believe that one day in the future this problem will be solved, but likely not soon enough for your son.”

“So”, I said, “There is nothing that we can do to change the outcome of what he is facing in life?”

“Not really. From my interview with you both it appears to me that you have given Darren a home environment that is the absolute best that he could have. And he appears to be an outgoing, happy child. You are to be congratulated for that. What about Laura? Do you feel she has been short changed by the demands placed on both of you by Darren?”

We looked at each other. Then Glenda responded, “We have gone to great lengths to keep her life as normal as possible, but there is no question that living in a household with Darren presents challenges for everyone. We pray that she is not significantly affected by all this.”

In a soft voice, the old gentleman responded, “Darren is now in the puberty years and these years are often the most difficult for dealing with a fragile X child. It could become appropriate to place Darren in domiciliary care outside the home at some point just to give your daughter a chance to develop free of all the strains that he places upon you all. If that happens I want you both to promise me that you will do what is best for the family and do it without guilt.” Neither of us responded. Institutional care for Darren was something we had never considered.

Our conversation with this brilliant and understanding physician continued for at least an hour and a half. When it was over, they drew the samples and promised to call with the results as soon as possible.

We gathered up the kids and set off back to Dothan. It was a journey full of relief. We finally knew what was wrong with our son. We went thru the drive thru at Hardee’s in Bonifay and everyone got a hamburger, French fries, and a coke. Darren was in the front seat with me. He wolfed his hamburger down and then the fries. He looked at the empty box, and then grinned at me. With a backhand toss, he threw the box over his shoulder at Laura in the back. There was an ensuing protest from both Laura and Glenda, but no real harm done. Then he finished his coke. Again he gave me a sly grin, and threw the cup into the back. This time there was an indignant uproar. He just chuckled.

Some three years later after additional research, it was determined that the damaged gene was passed from Darren's granddad, through Glenda, and on to Darren. The arrival of that knowledge was probably one of the worst days of Glenda's life. It is a tragic, horrible thing for a mother to know that her son's disability is a direct result of something that came from her. But Glenda is no ordinary woman. She is the lady I married. And just like she always had before, she dug way down deep inside and somehow found the strength to deal with the situation and move on with her life. And there was a silver lining....testing showed that Laura was not a carrier of the affected gene.

DUVAL HOME

As Darren entered his middle teens, the problems of adolescence got worse. He was now six feet tall and 180 pounds. It was no longer feasible or appropriate for Glenda or Laura to supervise his bath. Yet, on many occasions I was out of town at night. I was the only authority figure that he paid much mind. Outside of a stern admonishment from me, there was no other way to discipline him.

Laura, by then, was an active teenager, with a life of her own. But Glenda and I became more and more isolated because Darren could never be left alone.

After much agonizing consideration, we made a decision to place our son in the Duval Home for the Developmentally Disabled at Deland, Florida. This decision was made under the caveat that we would take it month by month, and if we didn't like the way things went, we would bring him home. We made an initial visit to the facility with Darren. He appeared comfortable there. Returning home, we told Laura that we had made the decision. She tried to talk us out of it but to no avail. It was something that needed to happen.

We moved Darren down to Deland some two weeks later. It was among the toughest days of my life. We got him settled in and then started for home. Twice, I stopped the car, and turned around to go get him, and twice, Glenda talked me through my doubts, and we turned around for home again. Finally, about one hour out of Deland, we pulled over to the side of the road and both wept uncontrollably until the tears would not come. When all the tears are gone, there is nothing to do but march forward, and that is what we did. We went to visit him as often as practical, and he seemed to do well in his new environment. We were particularly impressed with his new school. It was all special education students, and the staff was excellent. Darren loved it.

Several years passed. Laura graduated from high school and began her studies at Auburn. It was obvious that she was well on the way to becoming a young lady. Then, at age 21, Darren graduated from his special studies school in Deland. We all went to his graduation. Upon receiving his diploma, he put on a big production of waving it in the air while dancing down the aisle and out of the auditorium. At that moment, it was clear that there was a lot of my long deceased brother, Wilson, in my son.

Shortly after Darren's graduation day, we received a distressing call from his foster grandmother. She told us that he had been placed on a low cholesterol diet and it just broke her heart to see the other kids eating what they wanted while he got none of what he wanted.

That was more than we could bear. Nobody was going to deny our son the foods he loved. We left immediately to go get him. It was a spur of the moment decision and we had no idea what we would do long term. While we considered our options, he lived with us for another year. It was extremely difficult but we made it work.

One morning, as Glenda made coffee, Darren calmly walked into the kitchen, sat down on a bar stool, and announced in perfect diction, "Momma, I want bacon and eggs for breakfast." Again, we were both stunned. This declaration, in perfect form, tense, and verb, had come from someone who seldom said anything, much less a complete sentence. I actually found myself wondering if he had been "putting us on" for all these years. How could he, on occasion, enunciate his most specific thoughts with such clarity, but yet be unable to do so when called upon? The answers would not come until some twenty years later when genetic research finally revealed the biologic processes of Fragile X syndrome.

THE GROUP HOME YEARS

Glenda had maintained a presence with the local Association for Retarded Citizens (ARC) since Darren's childhood. During the year he was at home with us after Deland, she learned that the ARC was in process of building a new group home in Dothan. I suggested to her that we should meet with the Director to determine if Darren would qualify for residence. She was at first very hesitant, thinking that it would be for higher functioning people. But eventually I convinced her to give it a try. As the home was nearing completion we met with the Director and described our son to him. Much to our surprise, he said that it sounded like Darren would be a perfect fit.

When the group home opened, Darren became its first resident. It was a godsend for both him and us. He lived only two miles from our house. He came home to eat every Saturday, but always wanted to go back after a couple of hours. On Wednesday afternoons, it became a tradition for Glenda to take him to get French fries at McDonalds'. Occasionally, when she couldn't make it, I substituted. I recall one such trip with great fondness. We went through the drive by window, and he paid for his fries with his money. I gave them to him and he began to devour them with great relish. I looked at him hopefully, and asked, "Darren, give me a French fry." He looked at me like I had leprosy, and replied, "No!" I then really started my best begging, "Aw, come on, Darren, give me at least one." He stared intently at his fries....after some deliberation and searching, he chose the smallest fry he could find and handed it to me while grinning from ear to ear.

In addition to living at the group home, Darren attended school five days a week on the same campus, where they taught him much regarding the details of self-care. It was very comforting to know that his life was self-contained and independent of us.

We all settled into a comfortable routine. We were close to him, and so thankful that he was under the care of people we knew.

But life is not a fairy tale. It never concludes with "they all lived happily ever after." As Darren entered his middle thirties, significant health threatening conditions reared their ugly heads. He had to have cataract surgery due to a medication he had taken. He fell

and broke his leg, necessitating a cast for five weeks. He developed a rattle in his chest that never seemed to completely go away.

Then, out of the blue, he began to have seizures, each one requiring a trip to the emergency room. Though they were very frightening to us, he never remembered them, and he soon became a real pro at managing the ER visits. Upon being assigned a bed, he would sit there cross legged with a completely disgusted look. When a physician walked by, he would smile at the doctor and plaintively exclaim in an angelic voice, "Doctor, Come here!" No physician I ever saw could ignore this appeal. As the doctor approached, Darren would point to an imaginary watch on his left wrist and say, "Time to go." He would be out of there in five minutes.

His declining health took a serious turn for the worse when he inexplicably lost the ability to properly chew his food before trying to swallow it. We met with the administration at the Center and a directive was issued to his group home care staff that all his food must be pureed. But still, we knew that Darren was in danger. There was an instance at home where he aspirated while eating with us on Saturday. There was another instance of the same at the group home.

I told Glenda one night at our evening meal that if something didn't change, Darren was likely not to live a long life. I did not realize how quickly that grim prediction was to come true.

THE PASSING

It was a sunny Sunday morning in early November. Glenda had gone to Sunday school and I was headed out for a round of golf. As I drove to the course, I thought about Darren's visit with us on Saturday. He had watched his favorite Star Wars movie and with supervision from both of us had managed to eat his spaghetti without incident. When he was ready to go back to the group home, he gave us his usual, "Bye! See ya later!" His rendition of this universal valediction always cracked me up. It came across as something like, "I know it is a great loss to you all that I am leaving, but don't worry, I will be back soon." I pulled into the course parking lot and while getting my clubs out, my cell rang, "Mr. Rose, Darren has had a bad choking episode. They are on the way to the emergency room now."

Something in the staff member's voice told me this time it was different. I didn't ask any questions, just put the clubs back in the trunk and headed for the emergency room some three miles away. I decided not to try to reach Glenda until I knew more about the situation.

I beat the ambulance to the emergency room and nervously waited. They quickly arrived and when they unloaded his gurney, I knew my son was in deep trouble. He was unconscious, and there were tubes invading his body everywhere. Unlike previous visits, the EMT's said nothing. Just went about their jobs of getting him inside.

It was time to call Glenda, but I had to be careful not to say too much. She had to be able to get from the church to the hospital. So, I just told her that he had a choking episode and I was with him at the emergency room.

She arrived in minutes, and when she did, I still knew very little. All of the medical people were totally involved in trying to get his vital signs stabilized.

After a half hour, a pulmonary specialist gave us an update. He said that Darren had aspirated on some doughnuts and had stopped breathing. He then went into seizure, followed by a heart attack. There was material in his lungs which they were trying to vacuum out. The doctor said Darren's prognosis was poor but that the next 24 hours would be critical.

And so began a four day ordeal that only now I can begin to talk about. Everyday Darren's condition worsened. He was having almost continuous seizures. They were trying everything but nothing helped. A test was run that demonstrated no reflexive response to anything below his waist. For two days, his eyes did not open, and when they did, they did not see. Darren was gone, yet his body was still alive.

Because they were medical professionals, the hospital staff continued to poke and prod him with everything they could find. When I came in on Thursday morning, the seizures were still racking his body. His blood pressure was 210 over 120. His temperature was 106 and his pulse rate was 160, and they were in there cutting his arm to insert another tube.

I called the duty nurse aside and asked her if we had any rights about stopping all the heroic life support efforts. She replied that we certainly did. That if we thought there had been enough; we should speak with the pulmonary doctor. She got him on the phone and he instantly concurred that it was time to give up the fight.

Glenda and I went out to the car in the parking lot and held each other while we both wept. After a time, we returned to the ICU and signed the necessary papers. We called Laura in Birmingham and she and her husband, Danny, were by our side within a few hours.

Soon, all of the grotesque medical paraphernalia was pulled off of him and he was moved to a private room on another floor. We stayed with him as his breathing became more and more labored. But they had begun a morphine drip and, other than the breathing, he was peaceful. Then, at about 11:50 p.m. on November 15, he took a final breath followed by silence.

He was gone.

Though he was gone, he forever remains a part of us. His life taught me so many things it is impossible to list them all. But certainly, I learned that love can be expressed in many ways...."verbally" is a very limited way and not really necessary. I found out that intelligence is a very difficult thing to measure. Just because one can do calculus, does not mean one can keep toys out of the rain. I discovered that there are good caring people everywhere, and sometimes we all need help. I learned that when you need help, you have to trust that others will do the right thing. You may sometimes be disappointed, but you still have to trust. Most of all, I learned humility. None of my resources or my

intellect could fix Darren. But Darren did a lot to fix me. I am so indebted to, and so grateful for my son.

We arranged for the visitation on Sunday afternoon, followed by the funeral on Monday morning. Glenda declared that she would give the eulogy. I honestly thought she had lost her mind. I told her that no mother could do that, especially one who had been through what she had. She countered, "It has to be done, and it has to be done by me. So, I will do it." I knew at that point it was time for me to shut up.

At the visitation, I was overcome by how many lives Darren had touched. I don't know how we survived the emotional upheaval, but with the help of Laura and family, we made it through it.

At the funeral Glenda delivered, without faltering, one of the most poignant eulogies I've ever heard. But I don't know why I ever doubted that she could. The signature of her life is that she always does what has to be done.

At visitation we saw our son for the last time. Though I despise the idea of an open casket, Glenda insisted that it be open for the benefit of the staff workers at the group home and other people who might not have seen him for a long time. I relented, and there were indeed many people who stopped by to see him at rest.

When the visitation was over, we were left standing alone with Laura and Danny. We each took turns for one last moment with Darren. Then the undertakers came in to put everything in order. As they lowered the lid on my son's casket, the last thing I saw was Darren's smile.

EPILOGUE

It is ironic that in the year of Darren's death, clinical trials were ongoing regarding new pharmaceuticals designed to lessen the effects of the fragile X gene. After much research by many world class scientists, it turns out that people who have the fragile X site on their chromosome actually manufacture too much of a natural protein called mGluR5. The excess of this protein in the body causes the synapses in the brain to not develop properly. This in turn leads to all the problems manifested by fragile X.

It is thought that within five years there will be FDA approved products in production which will greatly mitigate or eliminate the afflictions of fragile X.

Glenda and I have supported, and will continue to support, the fragile X research effort. There are too many lives hanging in the balance to stop now. Current studies indicate that fragile X is the second leading cause of retardation and autism, ranking only behind Down's syndrome.

Any memoir that discusses the life of Darren would be incomplete without an acknowledgement of the many people who blessed his time on this earth. We owe so much to all of you. It is a debt that can never be paid.