



A Mother's Story...

Raising and Being Raised by Two Sons with Developmental Disabilities

The following was written by Jayelle Sargent, the mother of two individuals served by Community Interface. We asked her to share her family's story to gain a greater understanding of the experiences of individuals and families with disabilities. The story is very personal and extremely moving, and we thank her for revealing so much of herself and her family for the benefit of others. With her permission, we are making copies available in the hope that others will get as much out of her words as we have.



Dawn

In all honesty, when Judy, one of the supervisors at Community Interface Services, asked me to share this story, I jumped at the chance. I have told it many times, usually verbally, which does not need a form, spelling, really much thinking anymore. Just tell how we lived it, remembering to find the high points and laughter. Above all, the laughter. Writing it is a very different experience. To do it justice, it would have to be a novel. Since this is not, I'll attempt the art of brevity.

There are few things in life that of which we can be certain. One for sure, that each new day begins at dawn. Personally, I am equally as certain that on any given day I will be presented with at least one sign reminding me that I am a loved wife, a successful business woman, and the mother of four grown sons, one beautiful daughter-in-law, one maybe daughter-in-law, and "where is the other sock" memories in a pear tree. It might be a visit from Alexander, my nine-year-old grandson, who's presence instantly catapults me back thirty some years to the time when his father, Brad, my first born, was but a mere pup. Now, at thirty-nine, that same pup, married to his high-school sweetheart, Alanna, (whose inner beauty is elegantly framed by her outer loveliness), is a captain for American Airlines. Or a "just to say hi" cell phone call from Matthew, my second born, now thirty-six, whose career in the film industry keeps him on the go, and with him, his love Kristy, whose presence in his life brings joy to this mother's heart. Depending on which day of the week it is pretty much determines my interaction with Greg, thirty-five, and Darren, thirty-one. This story is primarily about the earlier years of both these men, and their separate journeys toward the independence that came so naturally to their two older brothers.

Before launching forward, I would also like to comment on the notion that with age comes wisdom. I am not at all certain that applies to everyone. I have learned, if wisdom is in part realizing how little we truly know, I accept that I am nearly wise beyond my years. What a joy, and relief, to at last be wise enough to consciously know how little I know. Ah,

but there is a caveat. Besides the dawn of a new day, there are a few things I do know. After remaining single for sixteen years, seven years ago, I blessed myself into a second marriage. Not without fighting myself all the way to the altar...fear does that you know.

My husband, also named Brad (no blood relation, but it certainly raised Freud jokes among my family), has taken his place in a family just waiting for someone of his spirit to grace us all. And so he does, daily.

I know the privilege it is to be invited by each one of my four grown sons to participate in their lives in such diverse ways. Each brings with them their individuality, their special brand of living, their special gifts. I know what it means to be in a family where two members are developmentally disabled. You see, Greg and Darren are those two men. I also know that being the mother of two men with brain damage seems foreign to me now. I also remember, it has not always been that way.

As a young mother (I was barely thirty at the time), not a day passed that I didn't suffer from a rare heart condition...broken. Every sign of intellectual or physical advancement that was made by either Greg or Darren was generally elevated to a larger than life event, while every day without was another day filled with hope, wishful thinking, and generally some tears. Mine were not the only tears. Larry, the boys birth father, was, in his own way, an amazing pillar of strength and caring during those years, I have read and heard from many sources that often times the father of a disabled child leaves home, each for his own reasons. In some ways, Larry did leave us. Where his physical commitment to his family never faltered, nothing that I could say or do could stop the wall he was building around his emotions. Today, with the gift of time and healing, those days are far behind all of us now. And yet, I admit, as I write this, I feel my body wanting to cry again. Cry for all the things I didn't know. Cry for my two older sons, for Larry, cry for our entire family. Cry for some relief from it all.



Greg

There did not seem to be a specific diagnosis for Greg's symptoms. Over a period of years, he was individually labeled with, shall we say, "the flavor of the day", medically speaking. Let's see, there was autism, childhood schizophrenia, brain damage, and damage to the central nervous system. Why is that? Why do doctors think in terms of labels? Sounds like cruising the aisle of a supermarket, looking for just the right label...completely forgetting the content of the package. Grrrr

July, 1996, Greg was two years old. By then, I had had many encounters with doctors who might well save lives. But I am here to testify that in the process, there were a few that seemed to destroy all signs of hope, let alone finding joy in the parenting of a disabled child. One such pediatric specialist, after performing a routine examination on Greg, gave me this ditty; " You have two normal sons, a husband, the chance for a good life. This boy will only drag you down. And then, after all that is done, he will never make it on his own. My suggestion to you is to institutionalize him now. It will be better for all concerned". Hard to believe? Believe it. Brevity precludes the entire story. It's probably just as well, given the expletives deserved. The fact remains, the insensitivity and disgust I experienced at the hands of this and other pediatric "specialists" became the igniting force, lighting the fire in the belly of this beast. I was on the path of redemption. My son was to become the best retarded * kid you have ever met. Little did I know at the time that two years later Greg would have a younger brother competing for the same title.

The scene was set, and I was probably as determined and out of control as any stage mother you would ever want to avoid. We tried special private school, Special Ed. in public school, YMCA, the list is endless. Finally, by the time Greg was ten years old, this beautiful, emotionally healthy youngster began to withdraw. "Mommy, why don't the other kids like me? Why do they make fun of me, and beat up on me?" Is there a parent that has not

heard that, at one time or another, from all our children? Yes, it is cruel, insensitive, and mean. (And don't you sometimes just want to be equally as mean right back at them?) Even though I do believe it is in part one of the ways that children learn about their feelings, try explaining that to your ten-year-old son, who incidentally, can shoot the basketball better than most. He just can't get the concept, but he doesn't know that. He just knows that he's better at shooting baskets than the other kids, and they still don't want him. Observing my child's emotional pain, which of course, by now was becoming my own, forced me to open my mind to a recent suggestion from Greg's social worker, " Perhaps he could live away from home, in a school setting, or group home, with children like himself." I did say open my mind, but my heart was still in charge, "NO! NEVER! NOT OPEN FOR DISCUSSION", until the day I realized that Greg was now pulling away from everyone, and everything. Although we, as a family, were there for him, we could no longer fill one of the primary needs of every child. The need for peers. The need to belong in your own world.

Greg's social worker did a brilliant thing. He arranged for Greg's dad and I to visit several group homes. I can't tell you exactly what they were like. I can tell you that I was extremely nervous, extremely kind, for the first few minutes of each tour. I don't think it was my imagination that each place we visited seemed to go down in quality, rather than get better. Finally, it was the smell of urine soaked mattress that sent me running like a screaming banshee, "No! No! No! This is not a good idea. Greg doesn't wet the bed. Why should he have to live with a rolled up mattress? He has a red, white, and blue bedspread that looks like a car! Forget it! There has to be another way". Fortunately, there was. St. Vincent's School for Disabled Children, Santa Barbara. The social worker had intentionally sent us there last.

What I can share here is that St. Vincents School was the only place we visited that had children

*The word retarded was still being used at that time, and had not been replaced by the phrase developmentally disabled.



playing freely outside, with pets by their sides. Horses out back, waiting to be ridden. Yes, four to six beds to a room, but there was a time, in our home, when all four of our sons slept in one large loft style room. There were tablecloths on their tables. This was not an institution. It was a large home for children who needed to be together. Perhaps Matthew, who was eleven at the time, best described St. Vincent's. We took the entire family to visit the place where Greg was going to be

living...for awhile. On the way home, Matthew went on a funk tangent; "Why can't I live there too? Why does Greg always get all the good stuff?" Those words were probably the final blast both Larry and I needed to go home and begin packing Greg's things. It was September, 1974. He was ten years old. He graduated twelve years later, at the age of twenty-two. That period of Greg's life, as you can imagine, is an entire chapter in itself.

Darren

Darren's early childhood was as unique and confusing as Greg's. It's true that they each had very special needs, albeit very different ones. Sometimes the fact that they were brothers, and both disabled, made it seem like it would be easier the second time around, you know, like that Sinatra tune. Certainly not the case. What they did have in common were the same parents, the same older brothers, same family pets, and a bedroom with twin beds, and yes, matching red, white, and blue bedspreads designed to look like a car.

September, 1968: Where Greg's birth was full term and easy, Darren was two months premature. Weighing less than four pounds, he was not expected to make it through the night of his birth. The nurses nicknamed him, "Tiger", commenting that he never stopped fighting like a tiger, never gave up for a moment. They were amazed how this tiny little being was able to turn himself completely around in his isolette, head to toe.

Darren was a bright-eyed, delightful, beautiful baby. We nicknamed him, "Pixie Pete" in that he had many of the same characteristics of an elf. His miniature ears were still slightly pointed, while his nostrils were shaped like the tiniest of stars. Aside from his endearing appearance, there was something very special about Darren. I could write ten pages, and more, about what I mean, and probably never be able to identify the exact way in which he was special. I know, I'm just his Mom, and

we Moms know how we are about our babies. But I assure you, those that know Darren today will attest to the sweetness of spirit that this man carries with him at all times.

If you were to ask me what was the most difficult part of being the mother of four young boys, I would tell you it was the chronic ear and respiratory infections. All except Matthew, who escaped the plague. Of the other three, Darren was by far the most affected. If it wasn't a nearly bursting eardrum, it was pneumonia. For a period of months, it was not unusual for Darren to wake the entire household, in the middle of the night, with a pitiful cry, and a temperature soaring beyond the safety zone. It was on those nights that we were more than grateful that UCLA Medical Center was only blocks from our home. I can still remember the first time they placed Darren's overheated body on a bed of ice to lower his temperature. (After writing that last sentence, I hesitated for a moment, checking my inner vision of memories. All intact. I can still see it all. I also discovered that I am also holding my breath. Even though thirty years have passed since these events, it seems quite real that our bodies, much like a computer, have stored all this data. Another Grrrr.)

By the time Darren was eighteen months old, he had been in and out of the hospital as many times as he was months old. Finally, his pediatrician referred us to an ENT doctor, who suggested Darren have a bi-lateral myringotomy, "drainage tubes in his ears".



We agreed. Hope and healing were on their way. Not yet. That was also the same day I lost it in the doctor's office. Poor guy, he didn't know who to care for, Darren or me.

Upon hearing that this little bundle had to have another major surgery, I also knew that meant, not just his pain, but our entire family once again displaced by an absentee mother. The doctor did not hesitate one second before handing me a prescription for Valium.

Little did any of us know this act was to alter my life for a few years to come. Once again, that is another whole chapter. What I will share about it here is, as difficult as it was to stop taking a drug that I had become addicted to, I will ever bless the relief that it gave me, and indirectly, that of my children. In many ways during that period of extreme stress and anxiety, it did help me to hold onto my sanity, or some semblance of it. Of course, those who knew me then, and now for that matter, may tell a different tale.

It was during one of Darren's hospital stays that a team of doctors were making their rounds. Larry and I overheard the resident in charge tell them that "this little guy will probably never walk without long leg braces...cerebral palsy." Once again, what a way to get information. Our pediatrician had chosen "not" to tell us this yet. He felt that with all we had to deal with, it might cause us to let fear get in the way of normal, loving care of an infant. The memories of Greg's earlier days flooded my heart. I was seriously beginning to wonder how much more of this emotional battering any of us would be able to take.

Shortly after his second birthday, we enrolled Darren at the UCLA Preschool for children with

cerebral palsy. A time to breathe. Although Greg's schooling was still random, there were at least days when all four boys were away for several hours. God is good, as were the friends who supported us during those days. Without the loving support of so many people, I cannot imagine how differently all of our lives would have been, then and today. Special note-Judy Louderback Alton. Judy was a nurse at UCLA at the time. She came to live with us for two years. A reciprocal arrangement. She wanted to go back to school and get her master's degree in nursing; we needed help. A new member of our family was born. Thank you God..and Judy. Another "I know". We would never had made it without you!

By now, Darren had enjoyed several wonderful and uplifting years at UCLA preschool. He was four years old, the limit age for the school. Fortunately there was a nursery school at the nearby Presbyterian Church, where several of our friends' little ones attended. The school agreed to take Darren. The teachers there were so positive and loving that Darren's disabilities were hardly noticed. Then came kindergarten. He made it, barely. Then came first grade and his first step into Special Ed. It was miserable. Darren was miserable. Here we were again, our school-aged child, with no appropriate classroom for him. We were determined that Darren benefit from what we had learned during our years of wondering, and wandering, in search of a safe, appropriate school for Greg. We also knew we would never risk subjecting this sweet child into the same school arena that has caused his brother such pain and humiliation. Deciding to have Darren leave home at the tender age of seven was both a nightmare and a relief.

Beginnings and Endings

July 1975, Darren moved into St. Vincent's . Greg had been there a year by then, and to some degree, had adjusted into his surroundings, which included friends. By that time, I was emotionally and

physically drained. The energy that it takes to care for a family of six people is extraordinary. Ask any mother who is doing it. The children's activities alone-Little League, Cub Scouts, YMCA, school work



and homework for the two oldest, and then throw in speech therapy, physical therapy, Social Workers, Regional Center, etc, etc. All of this had taken its toll. (A saint, I am not). But I will admit, sometime in my very private thoughts, I hear, "if this were someone else's life, I would stand in awe of it." And I do. God handed our family quite a "big life". And yes, I believe our family, as any family that is asked to serve one of their own, in extraordinary ways, is closer to sainthood than any of us knows. (Did you hear that, God?!?) Now, go ahead, ask me, would I want this life again? You didn't really expect me to answer that, did you?

Perhaps one of the greatest losses of all was happening during the years leading up to Greg and Darren leaving home. Larry and I had seen the signs that our marriage was sorely in need of attention. How could it not have been? For us, the "adversity brings people closer" theory turned out to be a myth. It certainly seemed true at the onset of our having a family. We were both very passionate people. But when the fire that brought us together spread out to

include not only the ordinary needs of our children, by the extra-ordinary needs of two of them, the death in early infancy of our actual second born son, (another chapter), the fire got lost, smothered, died out from lack of tending. Simple as that. We tried, off and on, for the next couple of years to rediscover our individual selves, as well as each other. It never happened. Left with embers, nothing we knew how to do, including marriage counseling, seemed to re-ignite the fire of our marriage. It was over. We divorced a year later. Nothing I can say here could honestly express the torture of that time. Nothing. Well, yes, there is something. Faith. Not the self-righteous, holier than thou kind. I stumbled around in that pit for so many years. It no longer served my needs. I needed to yell, and scream at God. To let him/her know that enough was enough. Go pick on someone else for awhile. I had had it. Here I was, thirty nine years old, divorced, mother of four sons, two at home, two living in a school for disabled children, and...and...now what?

Social Graces and St. Vincent's School

If there is one thing that stands out, as a result of Greg and Darren's years at St. Vincent's School, it is their understanding and use of social graces. Not one of my friends keeps their unused hand on their lap while eating, or their elbows off the table, or always cleans their plate. I do not mean to infer that much of what was learned during their individual twelve years at SVS is not evident, or has been lost. On the contrary, those years, in and of themselves could be chapter upon chapter of stories. For this story, I am referring to table manners since eating is a daily event, making these habits a bit more noticeable to an outsider. I would be remiss if I failed to add the compassion Greg and Darren harbor for those less fortunate. Many of the children they grew up with at St. Vincent's were far more disabled, physically and mentally, hence their ability to accept their fellow man without judgement. Certainly patience. Always, and I do

mean always, they are patient, no matter the circumstances. Several years ago, Greg and I were having a discussion about our lives, as such. He commented, "The main reason I wish I didn't have brain damage is so I could drive. It feels awful to have to always have to ask someone to take me somewhere, or wait for them to pick me up, or go where they want to go". It was a statement that really made me take notice. Greg and Darren do spend extraordinary amounts of time having to wait, for the bus, for their ride, for their mother to get in the car when she says, "Let's go!" They never complain. They never exhibit any sign of anger or restlessness, least of all impatience. I continue to learn from them, about this gift of patience. It also inspires me to work, with diligence, on my very undesirable habit of tardiness. Thanks guys!



St. Vincent's was the answer to this family's prayers. I am not so certain that Greg, or Darren would agree. They have since told us that they were not happy there. Darren claims that it was too noisy. Greg; too strict. I would not dare to disagree with anything they tell us about their days there. It was never meant to replace home. It was more a place of belonging for them, as well as a respite time for the rest of the family.

Greg was one of the higher functioning children at St. Vincent's, Darren one of the sweeter. Each of them stood out among the crowd. This was a general consensus, not just Mom's observation. I used to wonder if possibly they were held back in their development, for some of the above-mentioned

reasons. That thought haunted me for years. Fortunately, the haunting is over. Now, just as then, they were exposed to new ways of learning, new ways of communicating, new ways of just about everything, and anything. And still, for the most part, the basic concepts of most subjects eluded them. Please do not misunderstand me, they did learn then, and continue to do so now. However, whomever is on their support team must understand fully the thin line between supporting them, and giving them cause for embarrassment by expecting them to grasp what might appear to be a very simple concept. I dare say, it is a fine dance. Yet, they live, and like the rest of the population, continue daily to practice their individual dances with new teachers.

Journeys to the Outside

St. Vincent's was designed to serve students through the age of twenty-one. Greg stayed until he was nearly twenty-two. Prior to his leaving in June 1986, Greg made it clear to all that would listen; he was determined to try independent living. We, the "we" group in his life, parents, counselors, social worker, were in complete agreement that this was not a good idea. St. Vincent's, like any boarding school, had a staff that pretty much handled the daily living needs of the students. Greg insisted he wanted to try. We supported him all the way. Unfortunately, it didn't work. He wasn't ready, but neither was the program he entered. Greg had only been there for several months when the calls started coming from the administrators about how unruly Greg was, etc. etc. I would drive up to Santa Barbara, only to find everything seemingly in perfect order, except Greg. He was unhappy, grumpy, and negative. Part of the difficulty for me was that these were not necessarily new behaviors. I would leave, knots in my stomach, feeling completely undermined, and overwhelmed. Here we were again, trying to find a place where he would fit, feel some success, be happy. It got so I didn't know whom to believe. Administration complaining. Greg cursing. Me crying, cursing, and

complaining. Finally, it got handled. Greg called me on the telephone. His speech was so slurred that I could barely understand him. He begged me to come and get him. I was scared to death as to what was happening. I did not call for help. I jumped in my car and raced to Santa Barbara. Although it had only been two weeks since I had seen him, I truly do not think I would have recognized him on the street. He was waiting on the curb, sickly thin, emaciated, matted hair, hollow eyes, and drooling. Even on his worst day of teething, Greg had never drooled like this. One thought obsessed me, "How could this have happened so quickly"? We were packed and heading home before the sun set on that particular day. For the next couple of weeks, Greg and I stumbled through detox hell, me forcing the herbs and detox program down his throat, while he ranted and raved hourly that he was going to run away. At one point, having had enough, I told him , to go ahead, not before encouraging him to check with the homeless people living on the beach, several blocks away, and see if they wanted him as a neighbor. He did leave,for about an hour, after which he stopped threatening me. Sadly, he sunk into depression.



Reader, be aware, I do not share this story because of its elements of drama, of which, there are many. Instead, I am using it as an example of the damage created by a very poorly run independent program. It was a horrible experience. We lived. We learned. We all learned well. Greg recognized he was not ready for independent living. I learned never, ever, again to relinquish the complete care of my sons to any organization, no matter how highly recommended they come. No matter the services they offer. No matter how much I need the break. The flip side of this, (here's that boundary dance again,) how do we parents stay one hundred percent involved, and as invisible as possible, while supporting the needs of our children? Get involved yourselves. Stay involved with whatever organization supports your child. There are wonderful programs available for people with disabilities. For the past two years, we have been affiliated with two such programs; Community Interface Services, for whom I have written this story, and Partnerships With Industry. Both organizations are well aware of my presence. and it works! So far, they have welcomed my concerns, and my support. Teamwork...works!

Darren's departure from St. Vincent's came in January 1989. Although his official graduation was held in June of that year, his social worker told us of an immediate opening at a group home just two hours north of Santa Barbara. More importantly, Darren was anxious and ready to leave St. Vincent's.

Chestnut House was every bit as engaging as its name. Nestled in the small town of Paso Robles, it sat squarely on a corner lot, surrounded by grass, trees, and its own vegetable garden. It was truly a scene from "Leave it to Beaver." Two-storied, yellow and white, plenty of windows. Nothing spoke of special needs. Everything inside and out spoke of home. I remember the first time I visited; there was a banner across a beam separating the kitchen from the dining room, which read;

"God, grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference." I

was familiar with the Serenity Prayer. The rest of it read; "Help me, while others learn, to help me do it on my own." There it was, a truthful bid for patience and independence.

Darren had been living at Chestnut House for about one year, when Greg came to join him, leaving behind the group home where he had been living in Pasadena. He had tired of the city, and after visiting Darren one weekend, he let us know that he would like to move into Chestnut House. In all their years at St. Vincent's, Greg and Darren never shared a room due to their age difference. Once they were both at Chestnut House, and in their twenties, they were given the choice to be roommates. Each declined.

Chestnut House was a warm haven for the next four years. All was well there. It was here that both Greg and Darren began to develop the basic skills for independent living. Each resident participated in the grocery shopping, housekeeping, cooking, etc. I remember being there one day when the shopping crew came home with more bags of food than I could imagine. Within sixteen deep breaths, all foodstuffs were put away, hands washed, and everyone got whatever tools they needed to start preparing dinner. Currently, Sundays are our family day with Greg and Darren. Generally, we cook as a group, which often times warms me to the memory of Chestnut House, especially when Darren comments, "Everyone works at their station", and Greg hums, "This is nice. This is family".

If you were to ask why I think Chestnut House worked, I would tell you it was because the families of the men and women living there were happily involved. The couple who ran it had a twenty-two-year old son living there. His sister was a volunteer there. Several women from the neighborhood worked there. The staff was equally committed. I don't know, maybe it also had something to do with the community. Paso Robles is a small town. Oddly enough, it is also known for its' redneck attitudes, but when it came to the residents of Chestnut House, all were as welcome as royalty. Parent participation was high. I probably lived the furthest away, so my



participation was done in different ways. But I made sure that I was there, as well as close friends, and family for birthday parties, Christmas parties, and

one time, much to Darren's delight, I even made it to the Paso County Fair...the year it rained.

A Different Rein

It was 1993 and times were a changing. The financial cutbacks imposed by the government were substantial. Large group homes, such as Chestnut House, were being closed down in favor of four and six bed residences. Independent apartment living was heavily encouraged. I of course, at the time, felt more like it was being forced upon us rather than encouraged. Nevertheless, it appeared that it was time. Six of the older residents, Greg among them, were excitedly moving into a smaller residence, still under the guidance of Chestnut House, along with one counselor, who was to serve as a twenty-four-hour live in. This was to last six months. It was designed to prepare these young people for the next step of independence, their own apartment. The following year, 1994, under the auspices of CSLA (Community Supported Living Arrangement), Greg, bravely seeking his independence, along with his new roommate, moved into a two bedroom apartment at the nearby Branch Creek apartments. This time, he made it.

Does anyone out there know of a perfect situation? I doubt it. Hence, bear with me when I say this new apartment situation was not perfect, by any matter of means. I worried about his diet. His addiction to television. His diet. His laundry. His vitamins. The windows were always closed. The blinds drawn. You name it, I worried about it. And what did that get me? Well, it got Greg to not return my phone calls, or even come to the phone when his roommate told him "it's your mom again!" , it got me not being invited to come up for his birthday; his not wanting to come home for holidays, or, shall I continue? Finally, I realized something had to change. Writing my list of pro's and con's, it became clear, very quickly, what, and who, had to change. No real surprise. It was Mom! Fortunately, I

knew some of the other local parents from Chestnut House. That was a comfort. But what was more comforting to me was getting to know the head of the independent living program, as well as Greg's resource counselor. First of all, I am of the opinion, in order for a counselor to help, they need to know as much as possible about their charge. Having done that, I could support Greg differently. He was able to live his life, his way, and I had my spies letting me know that he was, at least, healthy. Some might consider this a bit sneaky. I don't. One of the biggest drawbacks in all these types of programs is the turnover of support players. It's not something easily acknowledged, or talked about out loud, but sorry to say, it's true. If for that reason alone, it is imperative to me that anyone who plays a major role in my son's lives is going to have to account to me. You see, when these people leave Greg and Darren's lives, as they will continue to do, it is my husband and I who are the continuing caregivers.

Early in 1994, Darren's social worker telephoned me with the message to say Darren had requested moving into his own apartment. "Are you kidding?" is probably some form of what I screeched into the phone. "No, Never. Ahh, No, and don't ask again"! Nice person huh! Wrong. When it is about Greg, that is one thing. Greg speaks his mind, and has the vocabulary to do so. Greg has been out in the world a bit more than Darren. On and on I went, in constant pursuit to protect my sweet, sweet Darren. I received many calls from the staff at Chestnut House asking me to at least consider giving it a try. The only response they got was, well, there is question as to whether we really did have an earthquake that night, or just another response from Jayelle on Darren's independent living request. Don't ask me how, why, when, or what it was that made



me change my mind on that day. Perhaps the same thing I do sometimes when the tennis ball is coming straight at me. I blink.

The expression on Darren's face the day that we hugged and told him, "what a great idea", is one that I had never seen before. I believe the angels might describe it as pure joy! It has been our good fortune to see that same smile, ever so slight, ever so

innocent, quite a few times in the years that Darren has been living on his own.

In September of that same year, at the age of twenty-six, Darren moved into the Branch Creek apartment complex, just six doors away from his brother Greg, both once again declining the opportunity to become roommates.

Random Order

December 31, 1991. My beloved Brad Sargent and I eloped to New Orleans. This superceded our original plan to get married sometime the following year, with our families in attendance. The change came about during a family dispute. Greg announced, "You guys, go ahead and get married. I'm happy for you, but I am not coming to the wedding. I like you, Brad. You are like a father to me, but, I was planning to come and live with mom someday". (This mother's version of what he didn't say; "I was planning to come and live with mom...and she could take care of me"). Why is that my version you might ask? As much as Greg cherishes his independence, he has an equal aversion to new situations. New jobs. New barbers. New toothbrushes, shoes, new anything. Change is not something he does with much ease. When he finds his spot, no matter how wonderful, or deplorable it may seem to the rest of us, he will endure it rather than change. He feels safe. Well, that part sounds pretty healthy to me, and equally unrealistic, unless one lives at home. And then, I ask you, how safe is that, all the time?

June 6, 1992. Six months after our elopement, Brad and I decided it was safe to have a wedding ceremony at our church, with our families and friends in attendance. We were joyfully ushered to the lakeside altar by my four sons. The dispute resolved, we were now all family. Which, speaking of, we invited the entire group from Chestnut House to attend. And attend they did. What a wellspring of joy they brought to our day...Greek dancing and all.

Brad and I had often discussed having Greg and Darren live near us. We also knew that we wanted to leave the Los Angeles area, but until we were certain where we would be, it made no sense to move the guys. And then there was our alone time together. We knew that it would change our lives. Our plans for learning to be together, now, as well as growing old together. But, it was when we talked about what we had to offer Greg and Darren that we both puffed up with excitement and gratitude. Who better to share our love and prosperity with than our family? This was all new for Brad. Never having been married before, my children became his only children. What an undertaking; along with his bride he received four/men sized stepsons, and the responsibilities of full time dad to Greg and Darren. His commitment is steady and solid. His performance, unparalleled.

November, 1992: Within two months of discovering paradise, the small, hamlet beach town of Leucadia, located about thirty miles north of San Diego, we also found a house, sold our home in Van Nuys, and made the move. We knew instantly that we were home. The major adjustments we needed to make had to do with our jobs. Both of us worked in Los Angeles, but because I own my own business, I was able to work part-time from a home office. Brad's job in the film industry often times requires him to be on location away from home. We decided to risk it all and make it work. It is exactly seven years this month, and working quite nicely. (Another, I know-ism, God keeps promises!)



Homeward Bound

November 27, 1997. We had just spent four days together in Las Vegas. It was Greg and Darren's turn to pick a place for our traditional, foursome Thanksgiving holiday. It would never have been my first choice. Surprise! We had a ball. We stayed in a time share apartment, off the Strip, and did whatever we pleased. Mostly played board games, as the weather was pretty nasty. We caught a couple of shows, Darren won a \$75 jackpot, and I amused myself by worrying about where they were when they got out of my sight. It's not easy to lose two 6' 3" men in a gambling casino, but in hindsight, I realized how much they were wanting to lose me. And why not, by then they had been living in their own apartments for how many years now? Oh well. The point of all this is, we realized, as an adult family, we genuinely liked each other, that we had stuff in common, and that we could help each other in many ways.

After spending nearly ninety-six hours together, whether sleeping, driving, Las Vegasing, it was clear to Brad and I that we were ready to invite the guys to be neighbors. Having arrived home, we were getting our things out of the trunk of the car, when I asked, "How would you guys like to move to San Diego, and live closer to us"? It wasn't like they jumped up and down with joy. Rather, a more sedate, "How fast can you make it happen"?

Brad and I had prepared ourselves for this moment. We had already shared how important it is that we respect Greg and Darren's wishes in regards to their living arrangements. Initially we discussed the probability that they would want different apartments, with new roommates. It didn't take me long to realize what that really meant, and I knew there was no way Brad and I would be able to support them in separate residences. When we told them the only way it would work was if they lived together. We also thought they should take some time, discuss it, and get back to us. It was just short of delightfully, comical the way they went about their decision. They walked about three feet out of the garage, garbling something for maybe ten seconds,

then cheerfully announced they had decided, between them, that it would work.

Several months before Greg and Darren made the physical move to Encinitas, I felt like I had been transfused into a time warp. My days were suddenly filled with telephone calls to both Santa Barbara, and San Diego Regional centers, conversations with organizations that provide independent living services, as well as job development. On weekends, while slopping around in my jeans, looking at low-rent housing, something very invisible kicked me in the butt, while ringing in my ears, "Raise Your Standards," it shouted! Embarrassed as I am to admit this, it wasn't the first time I had heard this message. This is about my kids, and yet, that uninvited thought, "they won't know the difference" persisted for longer than I care to admit. What low thinking...and who's disabled here?

I decided in that moment, for now, and evermore, I would only accept things for them that I would accept for myself. The next time I went apartment hunting I was dressed as if I was going to Mrs. Astor's Grande Ball! They didn't exactly move into the Ritz, but it was certainly something my husband and I would have gladly accepted in our younger years.

March, 5 1998. For the first time since leaving their family home in 1974, and 1975, respectively, Greg and Darren were once again living together as roommates. Do you remember the Neil Simon film, "The Odd Couple", also a television series probably twenty-five years ago? Do you remember how they made it work...perfectly? Darren is Felix, Mr. anal, neat, and clean. Greg, although not completely Oscar, leans heavily in that direction. It is quite wonderful to observe their dance. They genuinely serve one another in their self-appointed roles. Where Darren is the homemaker, taking care of the inside needs, houseplants, trash, matching plates and silverware, Greg, (who used to eat Dinty Moore stew right out of the can,) continues to experiment with new ways of cooking chicken, pot roast, and steamed oatmeal. Also, since Greg is the more



assertive of the two, he generally deals with outside communication, anywhere from calling the landlord to encouraging telephone solicitors.

In Greg and Darren's daily lives, they have been closely aligned with two specific organizations designed to aid, and support the needs of people with disabilities. From Community Interface Services, they receive bi-weekly support from a resource counselor, without whom, this independent adventure would not be happening. Not only do these counselors help the guys with daily living needs, often they fill the roll of companion, friend, listener, trusted friend. One of those peoples who play a very important role in each of our lives. Socializing, outside their home, is still fairly limited for Greg and Darren, with the exception of being with us, or friends of ours who embrace them with the warmth and acceptance they deserve. Last Sunday they were invited to go sailing with a couple from our church...that is, "they" were invited, Mom and Dad next time. With the encouragement of their resource counselors, we hope to see the seeds of new friendships blossom sometime soon.

The other organization that we are affiliated with, as well as support, Partnerships With Industry, had job opportunities for Greg and Darren within two weeks of their moving to Encinitas. After eight months of working for the City of Oceanside, Darren asked PWI for their support in finding a job closer to home. It took awhile, but the wait was worth it. In August, 1998, PWI was offered a government-approved, two-year contract for a six-person maintenance crew, of which Darren is joyfully a member. (Mother's pride coming here.) Just this past August, Darren was voted one of the Employees of the Year for the City of Encinitas. He was cited for his hard work and positive attitude. To quote Darren, "Gotta do it! Somebody's gotta do it!" What he doesn't say is, not everybody does it with his attitude. But then, he wouldn't. He's much too busy

cleaning up whatever needs cleaning.

Where Darren finds his way through life with ease, Greg seems to struggle at every turn. Staying employed is difficult for Greg. His physical health presents him with challenges. His tendency toward depression haunts him. A while back, one of my older sons said to me, "Mom, sometimes I wonder if the torment in Greg's life has anything to do with his disability, or if he just came into the world with a tortured soul". There is no way to know that. We will never know. Knowing used to matter to me, just as it used to be easier to judge Greg, (and everyone else), to analyze his behaviors, (and everyone else's) to keep him stuck in our old ways of perceiving him. It used to be that way. These are past, bad habits. Some days I congratulate myself for overcoming them, other days, I want to stick my head in a vice hoping to squeeze all the old crap out, and make room for what my heart constantly lives. Someone once said, "The only failure is when we give up." I need to remember that more often.

[July, 2000 – Authors update: It is eight months since I wrote this article. In fairness to Greg, I think it is important to note that with a new found purpose, and great diligence on his part, Greg has stepped onto the path of re-building his self-esteem. He now has an office job with A-1 Trophy, where he is learning many new skills. His bouts with depression are being curbed with the aid of St. Johns Wort. In his quest for a healthier body, Greg is committed to working out with a trainer 3 times a week. He never misses. Greg's determination to get what he wants, reminds me of something my tennis instructor said to me, "when you give up on the ball...it's like giving up on yourself". It is clear that Greg is finding his place on the court. For me and Brad, the honor is being a part of Greg's self-discovery. The reward is being allowed to walk with him as his courage outwits his fears.]



Thanksgiving

"and the greatest of these is Love"

St Paul, Corinthians – Chapter I

There is no question that the special needs of Greg and Darren keep them in the forefront of much of my life. My perspective on this? I have that many more lessons to learn from them. Earlier I mentioned that being the mother of two brain-damaged men is no longer foreign to me. What I mean is, these days, Greg and Darren's special needs are not much different than most folk's daily needs. Basically, what they are attempting is to live comfortably, be responsible, be kind, be productive at a job, or in their home, have some fun, eat fairly well, be as independent as possible, be respected, and sleep in clean sheets. Nope, scratch the clean sheets. That's a mom-ism. Truthfully, I don't think they care a damn about clean sheets. Well, maybe Darren does. I don't check anymore.

The tears I used to shed daily, thirty-five years ago when I began this journey with Greg and Darren, have reshaped themselves into smiles of pride, and genuine happiness. I am able, at last, to embrace these opportunities afforded to me, not just as their mother, but as a fellow traveler on this extraordinary road of life. But since I am their mother, I also rejoice that I have been given this opportunity to re-do some rather screwed up "mothering" of the past. (Don't we all wish we could go back and do some things differently. Yippee! I'm doin' it!)

A couple of weeks ago, I heard something come out of my mouth, that I swear I didn't think. You know, first a thought, then a word. Well, I was speaking with someone about the lessons that come from parenting, and without "thinking", my mouth said, "I feel so honored to be able to participate in Greg and Darren's lives. That they allow us this intimate privilege". That felt great. And a first. Usually, people are telling us how lucky Greg and Darren are to have us. And they are. But to turn that around. Wow!

Lest I forget, knowing there is always the other side, have I also mentioned the frustration,

exhaustion, and exasperation that goes with this gilded life? I never want to give the impression that this road is for the faint of heart. There is no quitting, no giving up. But then, I am of the belief that the role of a mother is the star of a woman's crown, no holds barred. Children come to teach. They come in all different packages. The difference now, besides my age, is that I have actually "lived" those many long and hard years. Wisdom has become my companion. No longer wishing anything to be different, I remind myself daily of the rewards in accepting each experience, each moment, with gratitude. To knowingly invite, not just my immediate family, but all whose lives touch mine, to be present to one another, so that together we might know what great teachers we are for one another. In the case of this mother, the patience and love that all four of my sons have showered upon me lifts me beyond any doubt that all is in Divine Order. I have not always made it easy for them.

November, 1999. Last week Greg and Darren celebrated their second Thanksgiving as residents of Encinitas, Ca. My older son, his wife and child, my mother, and one of my brothers were here to celebrate with us. Of all the gifts those members of my family shared with me, besides their physical presence, was how they experienced their time with Greg and Darren. Each one, save my grandson, who at nine is struggling with his discomfort in the presence of his uncles, commented on how they never expected either of them to reach the levels of "normalcy" at which they are now functioning. If there is anything I have prayed for over the years, is that my family would begin to see the wholeness of Greg and Darren, their abilities rather than their disabilities. What a joyous gift to receive on Thanksgiving Day. (God..also answers prayers.)

Brad and I remind each other and ourselves daily, that in life, we are all disabled. Not one of us knows what is really going on inside of the other. Not one of us truly knows what our roles on this earth are, and who, in the end are the teachers, and who are the students. What we do know is that we are all in it together. That we, the bigger we, are



family, in every sense. That we are here to "Love our neighbor, as ourselves." We personally thank God that for the past two and a half years, Greg and Darren, our three miles near our home, neighbors, have given us daily opportunities to practice the art

of unconditional love. We pray also, that we as a family, will have unknowingly reached out to others, so that they too, may be touched by love's mystical, and magical ways.

Thanks you. Thank You. Thank you.

Post Script

In the fall of 1984 Greg was in his early twenties, Darren his late teens, we participated in a research program designed for families, with two or more siblings, who had brain damage. It was no more than a month or so later that I received a letter from the research team informing me about the discovery of Fragile X Syndrome. For the first time, those of us that mattered in the lives of Greg and Darren,

mutually agreed that some of the behaviors, and physical characteristics manifested by Fragile X seemed closer than anything else we'd been offered over the years.

If any readers are interested in knowing more about Fragile X Syndrome, there is amazing information on the internet at www.healthlinkusa.net