

# Alana Patricia Drablos

Alana Patricia Drablos is my first born 23 year-old daughter. I was 26 and my husband, Scott, was 29 on February 8, 1985, when she arrived six weeks early weighing 4 pounds, 11 ounces. We learned she had a heart defect when she was two days old, and a group of doctors told us she had Down syndrome four days later when the definitive test results were in hand. My delivery was a Caesarian because Alana was breech and premature. She actually did very well and breathed on her own from birth, but needed to stay in the hospital for 16 days to establish a pattern of gaining weight.

Our doctors were well intentioned, but poorly informed in many ways. The lead neonatologist assured us that Alana would walk and run and play, for heaven's sake! Granted this was more than 20 years ago and times have changed, but it is almost silly to think of it given what Alana has accomplished and all that she can and will do in the future. Our shining star at the time was Alana's pediatric cardiologist, Damaris Wright, who is passionately attached to her patients with Down syndrome and a high energy super positive happy individual. Dr. Wright went through all of Alana's heart issues with us including successful surgery at 10 months.

Scott and I were referred to the Down Syndrome Guild of Dallas. We met other families with children with Down syndrome. I read everything I could find that seemed relevant trying to understand what it really meant to have Down syndrome. Alana was a perfect baby, easy going and very attached to her dad. She started home based therapy at six weeks. I became an advocate for full inclusion of people with Down syndrome in all communities, including the public schools. I became a board member of the Guild. Our family grew. Her sister Katie was born, then her brother, Thomas, and finally, her second sister, Maeve. All four children attended Montessori school in Dallas and then public school in Fairview, where we had moved when Alana was entering fourth grade.

Alana accomplished almost all the typical childhood milestones, just at a slower pace and in her own way. In grade school she was in an Indian Princess tribe, took dance and gymnastics lessons, played the piano, was in a Girl Scout troop, played basketball on a team Scott coached, sang in the church children's choir, and was fully included in typical classes at Lovejoy elementary.

Middle school and high school in Allen brought new challenges and enriching experiences. Alana managed girls basketball teams, was a staff photographer for the



yearbook and newspaper, took trips with the photography department to national conferences without her parents, and was very much a part of the school community with good friends and supportive teachers. She was assisted by peer tutors in some of her academic subjects where curriculum was modified. Alana herself was able to be a peer tutor for a student in a wheelchair her senior year. She was very active in the Life Teen program at our church.

After graduation from Allen High school Alana received a Special Services Certificate in Office Skills from Eastern New Mexico University in Roswell, New Mexico, upon completion of a one year program of study there. She lived in a college dormitory away from her family and came home more confident and independent. She has been successfully and very happily employed as a courtesy clerk at Kroger since she was sixteen. She is now taking one class a semester at Collin County Community College in their office technology division and working about 30 hours a week. She has a cute boyfriend, Chad Turner, who she met in Roswell and sees about once a month. He has Down syndrome as well, and lives on his own in Colleyville.

Alana loves her family and friends, the Dallas Mavericks (especially Dirk Nowitzki), Broadway musicals, sushi, playing cards and keeping score, the television show "Friends", purses, texting her siblings from her iPhone, listening to music, working out to her Denise Austin tape, babies in the checkout line at work, and helping out, among many other things. Her sophistication in some areas is amazing. She reads very well, balances her own checkbook, and knows as much about sports as any typical avid fan addicted to Sports Center on ESPN. At the same time she can be very sweet and innocent. Her siblings adore her. She makes all of us smile. She teaches us patience and determination and is a terrific example of good self esteem.

The path we have traveled from February 8, 1985, to the present has sometimes been very hard and challenging. It has been full of surprises, successes, and setbacks. Often, perhaps ironically, Alana has been my easy kid. Please know that the Guild exists to support your family in your journey, wherever it may take you. Give yourself time to adjust. Ignore the well intentioned but poorly informed. Come meet us when you are ready. You are most welcome.

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# Katie Longworth



Hi, we are the Longworth's – Greg, Elizabeth and Katie Longworth. Katie, our daughter, is a delightful, sassy, impish 7 year old! Katie loves to go down the slide, head-first, laughing all the way. She has a wonderful smile that lights up the room and a twinkle in her eyes I pray she never loses. She gives the best hugs and loves to laugh. She loves her friends, family and music. Katie loves school and has great friends. You can usually find her at school outside running around with the boys. She's taken swimming lessons, horseback riding and music classes. What a joy and blessing she is to all who know her. I can't

imagine what our life would be like without her. By the way, Katie has Down syndrome and mild-moderate hearing loss.

We found out Katie had Down syndrome through amniocentesis. We had heard the statistics, but we really didn't think that applied to us. The results of the amnio were not going to change anything for us – we just wanted to be prepared or if there was something that could be done prenatally to help – we would do it.

After receiving the news, we were stunned, probably shocked and scared is more accurate. How had the world suddenly turned upside down?? How were we going to face this? Handle this? What do we do?? That night as Greg and I lay holding each other in bed, I remember wondering if we would ever laugh again – what was our life going to be like? What was ahead for our daughter??

We were very blessed to have wonderful doctors, friends and family who were very encouraging and supportive. I was induced 2 weeks early and Katie spent 3 weeks and 5 scary days in NICU. Katie struggled with various issues during her stay in NICU – some mysterious, some frightening and others more mundane. How well I remember pumping in NICU and at home so she would have her breast milk! Katie was prenatally diagnosed with a serious heart defect and we met with the pediatric surgeon to discuss the problem and when they would repair her heart. After delivery, her heart was fine. She had some minor heart issues, but nothing requiring surgery. She was born with a cleft palate –which should have been an indication of her personality!! The little imp – full of surprises! Because of the lower muscle tone and hole in the roof of her mouth, she couldn't suck well – so she had a g-button put in her stomach so that she could get nourishment.

As we were going through the process of getting the cleft palate repaired, we discovered that she had mild to moderate hearing loss. We were quite devastated at this news, but as

usual, Katie was undeterred, and then so were we! Katie had her cleft palate repaired at nine months and followed with hearing aids. What a challenge to keep the hearing aids in!! I used to call them the most expensive chew toys!!

The double edge sword of modern technology was that we were able to find out while I was pregnant that Katie has Down syndrome. It gave us the time to read and best prepare and plan for her. The scary part was that I didn't yet have my baby to hold and that beautiful little face to look at me – I could only imagine. After 9-11, as we all were scared and uncertain of what lay ahead, I'll never forget holding Katie on our couch and looking at her. I had just finished tube feeding her and was so scared. I really wondered what kind of world had I brought her into?? She looked up at me and just smiled and her eyes gave me the look that said – “Mommy, what's the problem?? Everything will be okay - I'll be fine, we'll be fine.” And a peace came over me and I knew we all would be fine together.

Katie is such a blessing to our family! When I look back at the hurdles we encountered, cleft palate, g-button, hearing loss – that seems so long ago. As parents, we just did what we needed to do for our daughter. The cleft palate was repaired at nine months, she was off the g-button by age 2, finally wearing her hearing aids without tossing them by 3ish – ok maybe longer!! Yes, it was painful at first, because we didn't know what to expect – not that you can know what to expect from a typical child either! And yes, it was scary, but she was our baby and depended on us. We would do everything we could to give her the best advantages – early therapy, the best doctors, great nutrition, love and most importantly, setting high expectations. We treat Katie just like we would if she were a typical child – lots of love, discipline and high expectations. As I have said to many a legislator when advocating, we are raising Katie to be a happy, productive, fulfilled, voting tax payer, not a tax burden.

Katie reminds us what is truly important in life – love, joy, family and friends. It's valuing life's little accomplishments and wonders, along with the big. Slowing down to treasure the enormous hug that your daughter decides you need. Katie has made me a better person, more compassionate and understanding of differences, truly looking at the bigger picture. She sees true joy and revels in it. I do believe there is a higher power who blessed us with Katie – and in that blessing an obligation to advocate for her and others and to hopefully, help make the world a better, kinder place.

And back to that original fear, would we ever laugh again??? Yes, oh how we laugh!!! Yes indeed, our life is so much richer with Katie!

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# Austin Davenport

## About a self advocate

Our son, Austin, just had his thirtieth birthday.

It was one of those events that we didn't think about the day he was born. We probably didn't think about it on his fifth birthday either, or even his fifteenth. It is unlikely at times such as those that we would imagine any of our children with Down syndrome having birthdays as significant as that. Our minds just don't go there.

To our surprise though, the years continued to plow by and our youngest had sixty of "his closest friends" for dinner and dancing to the music of his favorite DJ a few weeks ago.

It's funny that even though we never imagined Austin having a thirtieth birthday, we did imagine him growing up and being on his own. Once we got over the initial surprise of who he was when he was born, we never kept our eyes off that goal of his independence. Occasionally, a well-meaning teacher or a friend or a relative or a doctor unintentionally tried to discourage us. This was usually with the thought of protecting Austin from the world or protecting him from failure. Sometimes Austin himself discouraged us when he did something or could not do something that appeared at the moment to be a dead end to a life with independence as a goal. At times like that we wanted to take him and hide him and protect him.

We always came around though to asking the questions:

*How will he ever learn about the world without being constantly in it?*

*How he will ever learn how to overcome failure without experiencing it?*



So Austin struggled his way through growing up, with his family and friends occasionally picking him up and dusting him off. He gradually learned what worked for him to live life in the world with peers who allegedly don't have learning difficulties. If he found an insurmountable obstacle (often a person), we simply helped him find a way to go around it. It was seldom easy, and it was a long road.

And it's a road he is still on. Although he has lived almost completely independently for eight years—working full time, living

in his own place—life constantly throws in his path new things to learn. At this stage, that object is almost always a relational issue.

As a result we are SO glad we insisted that he be fully included with his more-able peers in school and church and scouts and life. We did not accept token inclusion. If we had, he would never have had the tools to sort out the intricacies of challenging relationships. He would never be planning, as he is right now, how he is going to pay for a wedding ring set for the girl he has loved for four years. He also would never have gathered together a few weeks ago such the delightful group of close friends of all ability levels with whom to dance.

*---Dick and Nancy Davenport*



# Casey Jane O'Brien

## What is Different, Anyway?

Casey Jane loves to copy her big brother, say 'no' to mom, and sing every song she's ever heard. She's 4 □ going on 14. Her favorite color is pink, she gets timeouts at school for erasing the calendar board, and does a mean punch-and-front-kick combo in Tae Kwon Do. She is a far different little girl than the one I pictured as I held her for the first time, hours after she was born, while they told me she had Down syndrome. I can't even write down what I thought she would be like – a mother is not supposed to have those thoughts about her child, especially on what is supposed to be a joyous day. Yet I did, and still bear a little guilt about it 4 □ years later. But one thought I still have and probably always will. That day, the day she came into our lives, our family became “different.”



I know that “all families are special.” Maybe it's just my need to feel 'extra-special,' or to counter the self-pity that sometimes creeps into my bones when I watch her lick the window at her gymnastics class in front of all the other parents. But the truth is, we are different now. We are going through life experiencing something most people never will. Our daughter has a disability. One look at her face and people immediately know. For us, the experiences that have come with raising Casey have resulted in changes to our family that neither my husband nor I would have ever predicted.

I once caught my dad, Casey's beloved PopPop – the tough, non-emotional, corporate executive – comforting her after a fall. He had swooped her up before I could even get near her. I heard him whispering little sweet nothings in her ear and that he would always be there to protect her, no matter what. I don't think my dad has ever whispered those words before or since. My husband and I, both brought up to “follow the job” and “keep your options open” left our wonderful house, beloved neighborhood, and comfortable job in Maryland to move to Dallas, only because we finally recognized the value in having our kids grow up around grandparents, aunts, uncles and cousins. We followed no job, just our hearts.

I think what has changed most about our family though, is our determination. Casey pushes herself to figure out how Lego's fit together, how to draw shapes, and how to get her shoes on without Mommy's help. Those things just don't come naturally to her like they do to her brother or her typical friends. This fighting spirit in her is what pushes me

to bring her to every one of Danny's soccer games, even though I spend most of the game chasing her around the field, just so that she can cheer when her brother scores a goal. It pushes me to sign her up for karate and gymnastics with her typical peers even though she might be the smallest and the slowest. It pushes my husband to show tremendous patience as he teaches both kids how to make pancakes every weekend. It even pushes Danny to practice the piano more often just because he knows Casey enjoys hearing his music so much. Seeing how hard she fights, makes us fight harder to make sure she is included and successful in whatever she does.

We are not the same family as before. We are different. We have evolved. We are better than we once were. So, while I strive everyday to teach Casey to do things that make her 'more normal' like everyone else, I secretly cherish the thought that I, as her mother, am made special; that our family is forever different, because of her.

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# Eric Edward Ford

## From an Aunt's Perspective



One of the biggest mistakes I ever made was on August 14, 1999, when my sweet baby nephew was born. I tried to encourage and assure my rock of a sister that everything would be okay after the birth of her son Eric, with Down syndrome, and said all the wrong things. I told her he would someday be a divine gift, a blessing, a wonder to everyone he met, but my timing for those words – though well intentioned – was bad.

Immediately though it seemed my assurances became reality as my sister Anita, her husband Ed and daughter Mandy recognized the true miracle of Eric. His demeanor, smile, and development were infectious, motivating and exciting. It wasn't long before everyone considered our little "Eric the Incredible" just a normal little boy. Don't get me wrong . . . though he is a remarkable young man, he is today who he is and capable of being because of his family. They never gave up, complained or fell short of providing every benefit, opportunity or resource for Eric's advancement. He is adored everywhere he goes and never hesitates to tackle anything. He is one amazing gift.

He wasn't voted captain of "Eric's Incredibles" for nothing:

- ❖ He loves adventure and trying new things
- ❖ He does it all with a smile on his face and seldom fails
- ❖ He never forgets a name or a face; he's never met a stranger
- ❖ He has every characteristic of a future politician or Rock Star, because he shakes hands with everyone he meets, with a smile on his face and a "My name's Eric."
- ❖ He gives a mean massage!
- ❖ He has excelled at every game or activity he has ever tackled. Do you have any idea how frustrating it is to be beat by him at Wii bowling? He bowls a 222 or higher!
- ❖ He performs a mean Rap, takes interesting photographs, loves to do "rabbit ears" over others' heads in photos and enjoys tickling
- ❖ He dresses purely GQ and struts when he's looking fine
- ❖ He is becoming quite the Tae Kwon Do student and can shoot a water pistol further than anyone
- ❖ He never waivers in his "inclusive" classes at school and has more girlfriends than most boys could handle

- ❖ He loves his family with a huge heart, greets everyone with a hug and challenges those around him to be their very best . . .

And he does it all with a giggle. Infectious – that’s what he is. Today he IS that divine gift, a blessing and a wonder. His future is bright and his potential is impressive. If you haven’t yet met young Eric Ford, you’re missing out.



Aunt Angela Knapp

# Yousef Malallah



Who would have imagined life could be so great? It was 18 years ago and we awaited the birth of our son. We had a daughter already and my husband had adopted my children from a previous marriage. He was a very successful CFO for an international airline, which provided us an exceptional lifestyle with many benefits. The school year was spent overseas and the summers in Dallas, my previous home and where my husband had completed some post-graduate work.

Christmas 1989, we came to Dallas for the holidays. The kids and I arrived first mid-month, followed by my husband (who only had a short time with us – 7 days to be exact). We arrived to a flooded house – a pipe had frozen and broken.... We should have known this trip would be more eventful than usual! We celebrated Christmas and Bader returned to Kuwait. I stayed behind to finish the repairs on the house. Then the real Christmas present: a baby was coming!!!

It had been a rocky pregnancy to say the least. I was stranded in Dallas because my doctor considered the pregnancy “high risk”. At the age of 38, I was pressed hard by my OB doctor to have amino; I had some breakthrough bleeding and extremely low progesterone (which was combated with daily injections). I opted not to have the amino – what difference would it make? I wouldn’t have eliminated a baby we wanted so much. We had been through a lot though. After 2 failed marriages, I had my tubes cauterized; then married the perfect man (who had never been married and no children of his own), I felt compelled to have his children. So, I underwent tubal repair, which was unsuccessful. Off to England to the best IVF doctor in the world: Patrick Steptoe. Pregnant the first time with triplets, one was born – our daughter Manal. IVF attempts (7 to be exact) were unproductive – now, no IVF or any other infertility intervention, certainly unexpected, I get pregnant! God wanted us to have this baby. So, we waited.

Our plan? I was to spend the summer of 1990 in Dallas like always; get ready for the next school year; baby due in September; October/November go back overseas to Kuwait where life would resume. Then it was the beginning of change, when the phone rang late on August 2, 1990. It was my husband calling from London; he was there on a business trip. He said, “Iraq invaded Kuwait.” I was standing by our bed, still up late, taking advantage of the long summer nights. I remember so well, holding the phone with what must have been the strangest look on my face, because I had no idea what that meant for us. I just stood there, saying, “So, what does that mean?” That was the start of another new chapter in our lives.

A month later my husband was still in London, trying to hold together the national airline and to keep the symbolic Kuwaiti logo at the forefront of the news. Everything was going to be all right?? My husband was going to be here in just 2 days so that he would be present at the scheduled C-section. Then, as unexpected as our future, my water broke! As I was wheeled off to the delivery room, I said to my cousin standing there for support, "Please don't let him have IT!" The fear of Down syndrome had haunted me for the last nine months. My worst fear: Having a child with DS. Don't ask me why the fear was DS, it just was!!!! About 1 hour later, a baby was born. The news hummed in the delivery room; since I had eaten earlier, there was no general anesthetic, so I was semi-awake during the section. I could hear people muttering, but nothing specific. Then, I heard something, "...symptoms of Down syndrome." OH MY GOSH! MY GREATEST AND ONLY FEAR – A baby with Down syndrome? This could NOT be happening to me! What had I ever done to deserve this? My girlfriend (the replacement for my husband's absence), holding the new baby, squealing with delight said, "Here don't you want to look at him?" There in my face screaming DOWN SYNDROME, my girlfriend held a baby, unlike any I had given birth to prior! I thought, "Who does that baby belong too?" How could I have imagined what greatness lay in front of me?

And that was the beginning of a new life. Our Yousef, our light, the freshness of every, single day had arrived. I had yet to accept this greatness....After a few weeks had passed, I was still uncertain about our future; I hesitantly opened the DSG New Parent packet. Still shaken by the events in my husband's homeland (Kuwait) which was under siege and occupation, I felt semi-unconscious, sinking into quick-sand: a new baby; Down syndrome acceptance and "what now" questions.

When Yousef was about 6 weeks old I finally faced the reality of having a baby with Down syndrome; it happened at a DSG New Parents Coffee. I asked my girlfriend to go with me; it was a club that I wasn't keen on being inducted into, but had faced the inevitable reality... it was time. Again, a new chapter. Nervous to the point of sweat pouring down my back, I was so surprised and overcome with emotion by what I saw: toddlers, walking, talking and they LOOKED like their parents and their siblings! So, you mean Yousef who has DS looks like our family?? Everything changed from that moment – the blindness was taken from my eyes and my heart opened and embraced this loving infant who was mine.



Now 17 □ years later, Yousef is a brother, uncle, cousin, son and companion. He has traveled through the school system in Coppell and is currently a junior at Coppell High

School. He has more friends than the most popular cheerleader and football star combined! He plays snare drum in the band, which proudly marches 350 band students. He is a history buff who would die to meet Benjamin Franklin. He knows more about The Alamo than I do! He attends as many Dallas Stars hockey games as he can, always willing to contribute his Kroger earnings for tickets. He hates vegetables and loves hamburgers with lots of French fries. He loves travel to anywhere and is set on going to Kuwait this summer on his own. He wants to go to college and move to an apartment. He has been playing TOPS soccer since he was 6; swimming on his own since he was 5, plays Special Olympics basketball, cooks, cleans, does his chores, hates homework as much as any 17 year old boy, has several girlfriends (all typical), goes to the movies and dinners with his peers, travels on band trips and spring getaways, oh and did I mention, **LOVES THE PRETTY GIRLS!**

Someone asked me “How’s puberty going for ya’ll?” Oh that’s funny, I thought! Puberty is as complicated as it is with any other teen! I knew we were in trouble one day, when one of my friends was at the house, attractively wearing a form fitting t-shirt. Never shy Yousef greeted her with his friendly smile and handshake, “I L-O-V-E your t-shirt!” My friend replied, “Oh thank you, Yousef.” Then we both laughed when I said, “Yousef, look at her eyes, look at her eyes!” Need I say more about puberty?!

So what is the secret to Yousef’s success? The only thing I can attribute it to is being treated like any other kid! It’s simple. Why have different expectations for him, just because he has Down syndrome? He’s a typical teenager! Oh, did I mention that he just happens to have Down syndrome? Down syndrome is a condition – it doesn’t define who Yousef is! That is **THE** number one message we have lived by – it’s the message our family, his teachers, his friends, his co-workers, everyone who is around Yousef hears. **HAVE EXPECTATIONS!** Wow, what a unique concept: having expectations! I believe that combined with Yousef’s unique personality and ability, Yousef has surprised even the most doubtful.

Did someone say this has been easy? I wouldn’t say difficult, so it must have been pretty easy. I learned early on, it’s about being an advocate – knowing the law, making sure educators are aware of your expectations of your child and what expectations you have of them. Our daughter, Emily, who is a successful Occupational Therapist said to me a long time ago, “You, Mom, you have to make it happen for Yousef. The teachers aren’t going to be the ones who are going to be responsible for him at the end of school; it’s you and dad. It’s what you want for Yousef – to be as independent as possible.”

Yousef, by far, has given us more pleasure than anything we could have ever done for him. He has been the “giver” and us the “receiver.” We have learned more from him than any book or educator could have ever taught us. He is celebrated by everyone in our family and all of our friends. He is supported with kindness from his high school peers and band members. His teachers adore his politeness, genuine kindness and his eagerness to participate, contribute and learn.

If it's already been 18 wonderful years, I can only imagine how wonderful the next 18 will be with our Yousef!

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By request; written for the Down Syndrome Guild of Dallas  
Phyllis A. Malallah, May 1, 2008  
Not for reproduction elsewhere w/o approval

# Kallen Chase

## From a Big Sister's Perspective

I was an only child until I was 13, and had desperately wanted a sibling my whole life. When I found out that my wish had finally come true, it came with a twist. The little sister I had always hoped and dreamed for was going to have Down syndrome. I didn't really know what to think of it at the time...I was sort of indifferent to the situation because I didn't know what to expect. I never could have imagined what Kallen and her spirit would bring to my life or how she would touch me so completely. I never expected that she would mold my perceptions of different people and situations to teach me the true meaning and importance of acceptance. I never expected that one, young life could not only make me appreciate the difference in people, but see it as a blessing. Having a sibling with Down syndrome has been one of the most eye-opening experiences of my life. It has showed me that the simple things in life are often our greatest joys and that there is nothing better in the world than selfless, unconditional love. Although I have helped Kallen take her first steps, speak her first words, write her name, and everything else on the endless list of things people teach children to do, no amount of what I have taught her can even compare to what I have learned from her. Kallen has taught me that patience really is a virtue, and that the longer you have to wait for something to happen, the sweeter it is when it finally does happen. She has helped me realize the amazing power of encouragement, support and love. She has shown me what it truly means to be a family because no matter how many mistakes I make, she loves me with reckless abandon. She has taught me so many important virtues that I fear I would otherwise be without, and for that I think she has made me a better person. Although she has helped me realize so many of the things that make someone a "good" person, the one and constant thing that I know has made me a better person is her love. I cannot properly express with words how it makes me feel to hear her say, "Goober, I love you", to see her sweet smile when I walk into a room, or to get a big hug from her. It is my great hope that she will touch others lives even a fraction of the way she has touched mine, and that people will be able to grow with and learn from her as I have.

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# Shelby Strawn



On the morning of July 13, 2006, my wife Paige was almost 8 months pregnant. As I was getting ready to run out the door for an early appointment, she told me that she didn't feel right. She said that the baby hadn't moved since the night before, and she had a bad feeling. After getting us in quickly to a Perinatologist the doctor saw that the flow in the cord was very little, there was little amniotic fluid and recommended that our doctor deliver the baby as soon as possible. He also said that he saw a possible heart defect, but the main thing was to get the baby out as soon as possible. About an hour later we had our baby girl, Shelby Kate Strawn. I thought that she was beautiful and tiny. Other than her being little, I didn't see anything different about her. However, Paige knew that she had Down syndrome immediately. I think they call this a mother's intuition. They took her into the NICU and that is

where we would spend the first two weeks of her life. During that first day we learned that Shelby had a VSD, and that she did have Down syndrome. By the luck of the draw we found Dr. Kao who would become our cardiologist, and a couple of months later her VSD was repaired by Dr Mendelhoff, at Medical City.

After her surgery, Shelby really began eating and growing faster. She also began to develop her personality, which is a combination of standup comedian and a demanding actress. We have also had her in a lot of physical, occupational, and speech therapy. Almost from the start her fine motor skills and speech have been good. However, she has had a more difficult time with gross motor skills. In July, Shelby will turn two and she is very close to walking on her own. She feeds herself and even uses a spoon and fork some of the time. She loves trying to get into the bathroom and pull all the toilet paper off the roll. Although Sesame Street is her favorite show she enjoys watching sports with her Dada on the couch. But when times are tough she always opts for her Mama.

Shelby also has a very close relationship with her big brother, Turner. They are truly best friends and love to play and dance together. Their relationship seems different than most siblings, at this point in their lives. Almost from the time we brought Shelby home, her brother has known that there is something different about her. That he needed to watch out for her and help take care of her. I believe that God gave us a son like Turner, because he knew Shelby would come along later.

We are blessed to have many friends and family. All of them will tell you that they have a special relationship with Shelby, because that is the way she makes you feel. The other kids in the neighborhood love her and always want to hang out with her. She also has Casey, Chloe, Brittany and Grover that are her buddies, and they have Down syndrome as well. It has been a big help to us, to have their families in our lives.

I know that there will be many times that we have to fight for Shelby, and that she will need our support for the rest of our lives. But there is something that makes you feel very special to be the parent of a child like Shelby.

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# Bennett Redden

“Mom, I feel like God is trying to tell me something.” “What dear?” “I feel like my baby may have some sort of special need.” “Oh Polly, don’t worry sweetie, everything will be just fine. I think you are just nervous.” Little did I know that only 24 hours later, I would get God’s message loud and clear. This was a conversation between my mom & me one day before I went into labor with my son. We were at the State Fair of Texas and I could not keep my eyes off every person I saw with some sort of special need. I knew deep down that my life was about to change.

You could have heard a pin drop when the on-call pediatrician delivered the news later that cool October day. Bennett Peoples Redden was born only a couple of hours and was having trouble breathing. He was in the special care nursery as Ross & I were resting in our room. We were exhausted from over 20 hours of labor that lasted throughout the night. “What?” I said. “Your son shows signs of Down syndrome.” I literally sat there with my mouth wide open for no telling how long. What in the world was this lady talking about? Who was she? I hated her at that moment. She certainly didn’t seem to be bothered by the news she was delivering to us – coming in waking us up, tossing her purse ever so carelessly on the floor, invading our room and privacy. The NICU doctor was with her and he began to give us an update on Bennett. I have no idea what words were coming out of his mouth. I was in shock. I could hear him speak but I was already gone to someplace else. I had to then make the dreaded phone call to my parents, which was one of the hardest calls I’ve ever made.

I knew when I first laid eyes on Bennett that something was wrong. I felt it from the very beginning. Ross & I declined any prenatal testing offered to us simply because we agreed that whatever the results, we would not end the pregnancy. I second-guessed my decision once we declined but quickly decided to let it go. That was probably the best decision I ever made. I enjoyed my pregnancy and chose not to worry about anything. I laughed, sang, read and talked to Bennett while he was growing inside me. I always tell people that my hell lasted only a few hours because I didn’t find out early on. To me, that is much better than months of knowing.

Bennett was admitted into the NICU before the afternoon was over and immediately put under a halo, which is an oxygen tent. He was sleeping ever so peacefully when my sweet husband wheeled me downstairs so I could see him. It was at that moment that I fell in love with him. He was my son and I loved him dearly no matter what the doctors told us. Before the morning, he was



put on a CPAP, which gave him more oxygen than the halo. We were assigned a primary care nurse and told he would be given the first round of tests to see if he was positive for DS. Several days later we received what we prayed would be negative results but turned out to be positive. What a coincidence being that Bennett has brought so many positives to our lives since he was born.

I can't tell you the number of people who have said to us, "I'm sorry" when we've told them Bennett has Down syndrome. Our comeback is always the same, "please don't be, we aren't." He is still a little boy, with big bright blue eyes and a smile and laugh that will tattoo itself on your heart.

Bennett is among the percentage of children born without a heart defect. So we consider ourselves very lucky. We spent a total of 21 days in the NICU at Presby Dallas and made lifelong friends with other families, nurses, and doctors. We love to stop and visit when we are close by.

Ross told me early on that we had 2 choices to make, either we could feel sorry for ourselves or take this opportunity and be joyous about it. After all, we have been given a "child for life" and doesn't that make us among the luckiest people of all? What a joy Bennett is to our family. Little sister Hattie Grace joined our family in March of 2008 and Bennett already brings smiles to her face. Thank you God for the journey we are on!

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# Abby Munn

## Play, Learn, and Grow Together An Analysis of the Benefits of Inclusive Education for Children with Down Syndrome

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4/17/2008

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### **Introduction:**

Abby is my sister by all but biological means. From day one, Abby and I have been best friends and have grown up side by side. Over the years, we have spent holidays together and gone on vacations. Together, we were Indian princesses, Brownies, and Girl Scouts; we were in choir and on sports teams, but most importantly, together we went through our first thirteen years of school.

Abby was born with Down syndrome and her parents were immediately faced with decisions and difficulties that they had not experienced with their other two children. After advice and insistence from their four and six year olds, Abby's parents decided that she would attend school with her peers, that inclusion was the way to go for their family. In making this decision, Abby's parents believed they were providing her with a better learning environment and a place to grow socially; but what her parents did not realize at the time was the impact that Abby would have on every classmate, friend, and teacher that she encountered.

Through her inclusive education, Abby became the epitome of independence. At an orientation before the first day of middle school, I told Abby I would help her find her way around our new school. She was appalled at my offer. She took my face in her hands and let me know that she knew as much about the school as I did and did not need my help. Instead of accepting my offer, she studied a map of the school to prove to me that she could do it on her own. It was at that point I realized that Abby *could* do it on her own, that she did not need my help, and that the only thing she needed was my friendship. I realized that Abby was no different from my other friends. Yes, I might have to explain something an extra time, or watch my language for fear of being scolded, but Abby is not my inferior; in fact, in many aspects Abby is my role model.

Abby has taught me not to take anything as a disadvantage. She has taught me to put a smile on my face through the hard times. Abby is always there to give me a hug when

she knows I am feeling down, or to yell at me when she thinks I am acting inappropriately. Abby faces every challenge in her life with confidence and has taught me, as well as many of our peers, to do the same. Abby has taught us all that anything is possible, given the right attitude.

Abby graduated from high school with me last May and now attends a community college close to home. Though Abby does not have her driver's license, she goes by herself to class every day, independently taking a bus and a train. Abby would not have the independence that she has today, and I would not be the person that I am today, if she had not been an integral part of my education.

### **An Assessment of the Benefits of Inclusive Education**

As more public school systems begin to adopt inclusive methods of education, experts and parents are becoming skeptical, often questioning whether the benefits of inclusive classrooms really do outweigh the consequences. Inclusion is defined as establishing an educational system in which all students, including those with disabilities, are educated together, in a general education classroom, for the entirety of the school day. Inclusion is different from mainstreaming because all students remain in the general education class for the whole school day, instead of only participating for specific subjects.

Much of the adoption of this teaching method is due to the Individuals with Disabilities Education Act (IDEA) of 1990 which states that, "each state must establish procedures to assure that, to the maximum extent appropriate, children with disabilities... are educated with children who are not disabled and that special education, separate schooling or other removal of children with disabilities from the regular educational environment occurs only when the nature of the severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily" (NDSS 2). Following the ideals set forth by the IDEA, many children, including those with Down syndrome, who would at one time have been put in separate special education classrooms, are being placed into general education classrooms.

Though the IDEA and many other similar acts and initiatives exist, many critics, teachers, administrators, and especially parents still resist inclusive methods of teaching. Inclusion critic and former president of the American Federation of Teachers, Albert Shanker, has argued that "requiring all disabled children to be included in regular classrooms is both unrealistic and downright harmful to the children themselves" (Peltier 1). Teachers worry about whether they will be able to give the extra attention and spend the extra time necessary to execute an effective inclusion program. Administrators worry about having to ensure extra funding for aides, or extra training workshops. But most of all, parents of non-disabled students often worry about inclusive education having a negative impact on the learning and classroom opportunities of their children. It is common for these members of the education community to have the belief that, "accommodating the needs of a few may place at risk the learning opportunities of the majority" (Peltier 1). After doing research on this topic, I believe that not only is an inclusive education environment

not detrimental to other students, but that it is beneficial to all involved, including the teachers, parents, peers, and special needs students.

Inclusion, particularly the inclusion of pupils with Down syndrome, promotes a successful learning environment for those involved, causing teachers to adjust their classroom methodology in ways that are positive for all students, promoting extra help in the classroom, and promoting more teacher and parent fulfillment as all students noticeably benefit from the program.

A study done by Gloria Wolpert showed that in order for inclusive education to be entirely successful, a teacher needed to be prepared for and flexible to formatting curriculum to address the special needs of a Down syndrome child. While adjustments to the classroom curriculum instigated by the presence of a Down syndrome student sound as if they would be detrimental to the learning of the other students, they have actually proved to be beneficial (Banerji, Dailey 511-521; Davis, Farrell, Fox 188-189; Johnson 27-29; Peltier 1-4; Wolpert 1-20). Many teachers undergo special training and/or workshops in order to better prepare themselves to teach in an inclusive environment. I believe that this extra training also helps to keep teachers up-to-date with all teaching methods and modern student problems. Many schools with successful inclusion programs allow more time for teachers to plan out classroom activities and to assess work, as well as to facilitate teacher communication about students (Banerji, Dailey 512). With the extra planning and training for inclusive educators, they are more prepared to teach all children in the classroom and to create a positive learning environment (Banerji, Dailey 518; Wolpert 5-11).

Successful inclusive classrooms often have a very positive atmosphere. Teacher praise, being the best motivator for a child with Down syndrome, becomes a prevalent part of the classroom. As quoted in Wolpert's study, one teacher states that "my children with Down syndrome soak up praise - the more they get, the more they want and the harder they will work to get it," but isn't this true of all children? "A child is a person first and their difficulties are add-ons which, although posing difficulties, can be overcome by a good teacher with... a positive attitude" (Johnson 22). The positive atmosphere is also promoted by the lack of "emotional outbursts and punishments" as methods of controlling inappropriate behavior, with the idea that "these cause bad feelings for everyone" (Wolpert 8). In this context, everyone can be interpreted to be not only students with Down syndrome, but those without, including teachers. More encouragement and less scolding create a supportive classroom, one that is conducive to the learning of all children.

Teachers also support more hands-on teaching methods because they are "reported to be highly successful catalysts of achievement for students with Down syndrome" (Wolpert 5). Personally, I believe that hands-on learning is advantageous for all students, keeping them active and interested in what they are learning. When teaching hands-on activities, as well as other activities around the classroom, teachers have the ability to slightly alter the assignment for the Down syndrome student, without noticeably setting them apart from the class. In Wolpert's study, "one teacher reported that while the rest of her first

grade class used Uniflex (small, colored) cubes for counting and adding, her student with Down syndrome sorted the cubes by color" (Wolpert 7). This active teaching approach is applied in testing and grading methods within the classroom as well. I agree with the idea that "performance in a workbook does not adequately reflect the knowledge and abilities of students," that instead, "teachers [have] found that daily physical performances or participation in class, and effort of the student [are] much better indicator[s] of learning or grades for students" (Wolpert 8). Here the teachers are speaking specifically of students with Down syndrome, though, from personal experience, I believe this to be true for all students, especially in elementary school. Another teaching method strongly advocated by inclusion supporters is group work and peer interaction. Having students work together helps everyone learn; top students help tutor needier students, while reinforcing their own knowledge. One parent in Wolpert's study said, "I love it that my son works with a top student in class. He tries to be more independent and do more on his own to be accepted by his peer tutor" (Wolpert 10). Sherri Munn, another parent of a child with Down syndrome, said that when her daughter, Abby, was in first grade, she was paired with a fellow student who was having trouble reading; after working together, Abby's partner, Brooke, gained confidence in her reading, while Abby learned how to read, which in the first grade is a major accomplishment for a child with Down syndrome (Munn). As both students gain academic knowledge, they are also learning social skills that will help them succeed throughout the rest of their lives. The teaching methods and environment of inclusive classrooms are opportune for students with and without special needs.

Often full inclusion calls for the presence of a special education supporter within the context of the general education classroom (Banerji, Dailey 512). An extra teacher available in the room can allow for more one-on-one activity with not only the student with Down syndrome, but with the other students as well. In a study done by Banerji and Dailey, the researchers found that, "all the students want[ed] to work with the [special needs] teacher...I think they think it is special" (Banerji, Dailey 518). The ability of the special needs teacher of making students feel 'special' rather than stigmatized is important in their ability to help out rather than to cause problems. There can be problems that stem from the presence of an aide, such as giving one-on-one attention to only the special needs child or in causing distractions in the classroom (Wolpert 4-9). In order to prevent these problems from occurring, aides and teachers need to communicate and work together well, working more as a team instead of as two individual teachers. The aide also needs to be aware of all of the children in the classroom, helping all students who are struggling with a lesson or assignment, so that no one student feels singled out. Despite complications that can arise because of the presence of a classroom aide, overall, the extra help in the classroom can help to relieve the stress of the teacher and to give each child more individualized attention.

Inclusive classrooms are not only beneficial for the students, they are also beneficial for the teachers and parents. Teaching in an inclusive setting does require more work from both teachers and parents, but both groups find the process to be more fulfilling and worthwhile.

Teachers report that inclusion causes extra work in areas of modifying homework, class assignments, tests, grading procedures and communicating with parents (Wolpert 7). They agree that, “the benefits [are] well-worth the extra effort” (Wolpert 11). In another study, teachers also reported positive experiences working in inclusive settings and even high levels of professional fulfillment (NDSS 9). Parents placing their children in inclusive education have the responsibility of being in greater communication with their child's teacher in order to facilitate learning outside of the classroom walls. Though there are extra demands, parents describe having positive attitudes about inclusion (Johnson 26; NDSS 5-6; Wolpert 5-11). From my experiences, I believe that the parental involvement that inclusion requires helps to promote a better relationship between the parent and child and a more conducive home environment.

Teachers and parents could be pleased by inclusive education because of the growth, personally and academically, that all students experience in an inclusive classroom. Students with Down syndrome placed in inclusive classrooms experience “increased self-esteem, independence in daily living skills, social interaction, speech and communication and academic achievement,” becoming more prepared to move forward with their lives and to find their places in a heterogeneous society (Wolpert 3). The students without Down syndrome show benefits from inclusion, including openness to human differences,

along with comfort and awareness of the physical and cognitive differences of people. They also experience improved feelings about themselves after helping classmates with severe disabilities. All students, through inclusion, improve their abilities to develop warm and caring friendships with both people to whom they are similar and with people with whom they have differences (Peltier 3).



As shown from the evidence above, inclusive education can be beneficial for parents, for teachers, and for all students. No student should be left out because of their disability, because of their differences. Every member of a classroom has something to bring that helps transform the class into a medley of personalities, talents, experiences, and abilities, an environment in which both academic and social personal learning are cultivated.

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# Alex White

*Written in 7<sup>th</sup> grade by Averi White (12 years old) who is currently a freshman at Pearce High School. Averi was selected to read 'Alex' at a 'prose and poetry' assembly while at Parkhill Junior High.*

I knew something was wrong...I could sense it, but little did I know that this feeling would soon turn out to be a reality, and this reality would soon turn out to be a nightmare.

Just as the excitement of the newest edition of the White family began to stir it was quickly shot down by "***the news***" and left a state of depression hanging over my family.

My pop, (what we call our dad), tried to tell us as gently as possible- Alex has Down syndrome- the news pierced my heart. I felt unbearable pain for my brother, who had just been born a day earlier and I had yet to meet.

My pop tried to explain what Down syndrome meant. All we wanted to know was when we could see him...when or if we could hold him. My pop said we could go to the hospital that night to see mom and Alex but he was intensive care so we would only be able to stay a little while.

Mom needed a hug so I hugged really tight and told her not to worry because we would all help...we would all be there for Alex...she was not alone. He was so cute but we could not hold him because he had a lot of tubes and things hooked up to him. We all told him we loved him.

What I thought would be a nightmare has turned out to be what seems like a dream if you think about how lucky we are to have Alex. He is healthy and smart. There could have been tons of challenges for Alex- but there was only one besides Down syndrome. One of his eye muscles were extremely weak, he could barely focus on an object without one of his eyes straying away. The day he had surgery I cried, I was scared that he wasn't going to be okay. When I came home from school that day, his eyes looked bloody, but after awhile they cleared and he could see a lot better. He was a fighter.

Almost immediately after his surgery Alex began to crawl, slow or fast he crawled. The next thing I knew he started walking. I couldn't believe it, could this really be the little brother I used to cradle and hold in my arms? He was going to be able to do anything.

Despite everything that has happened to Alex, he still keeps going--he never gives up and he never will. We have learned so much from him.

I love Alex just the way he is. When I look at him he doesn't seem any different than any other child his age, but what I worry about is if someone tries to tell him he is different- I worry about the first time he feels hurt or pain.

I know that Alex will go through a lot of hard times in the future, but what ever challenge life brings to Alex I will be there for him...we all will. We love him very much and our family would never be the same without Alex.



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# Eric Ford

## Endless Possibilities

It is hard to believe that nearly a decade has passed since we were blessed with the birth of our Eric. It is even harder to believe that where we once were told not to expect much of Eric that we now see endless possibilities for him. It is our hope that this guide will not only give you the resources you and your family need to cope with the birth of your new born but that it will also give you confidence that there are limitless possibilities for your son or daughter as well.



Like many parents, we were not allowed the luxury of enjoying the birth of our new baby before we were hit with the news that our son had Down syndrome. Along with the news came some cold, hard, alleged facts about Down syndrome and what we could expect and not expect from our son. I can still remember a nurse telling me: "...And he will not be able to kiss you goodnight." Most of Eric's first year or so was spent searching for information about Down syndrome, sifting through piles of information and sorting what was helpful and what was rather misleading, in a quest to answer the many questions coursing through our brains. We were not fortunate to have a resource book at our fingertips or a support group to help guide us in the right direction. We felt lost and alone. And there were many family members and friends that wanted to help but didn't know how or what Eric and our family needed.

One day, a friend gave me the book *Another Season*. This book gave me a new perspective on Down syndrome and gave me the courage and hope that I could expect much more from Eric. The book is the story about Johnny Stalling, the son of the famous football coach Gene Stalling and his wife Ruth Ann, and the family's resiliency and fortitude to help Johnny overcome the many challenges of Down syndrome. As Johnny was born in 1962, there were virtually no resources or medical treatments available to support the Stalling family. Through love and perseverance, the Stallings pioneered a new path for people with Down syndrome and proved that there were options for Johnny and others. Today, there are more and more resources and possibilities for people with Down syndrome, especially in the medical and development fields. A research study conducted in 2002 showed that the life expectancy of individuals with Down syndrome nearly doubled from 25 to 49 years in the previous two decades.

While I did not specifically set out to find ways how to open up more possibilities for Eric, what *Another Season* encouraged me to do was to get involved in his activities, to seek support from others, and most of all, to love my son as I would any child of mine.

In Eric's early years, most of my time was spent finding out what interested him. Consequently, I spent many an evening watching "Veggie Tales", pushing the ball back and forth to each other and acting like "rock stars" while we played on his electric drums and guitar.

As Eric grew older, his interests turned to sports and other outdoor activities. We were fortunate to come across several sports programs for Eric in Lafayette, Louisiana: swimming, soccer and T-Ball. I was amazed at how many people wanted to help Eric and offered their knowledge and time without asking for anything in return. What I learned was that they did get a lot in return and it is what I get great satisfaction in seeing everyday – Eric's beaming smile when he accomplishes a new task no matter how small. In swimming, it was getting his face in the water. In soccer, it was stopping the ball with his foot. In T-Ball, it was running to first base by himself.



Over the past several years, Eric has progressed in his sports. He continues his swim lessons and is now diving under water for objects on the pool floor. In T-Ball, Eric had his first hit off a coach's pitch this season; his smile was a mile wide. Eric has traded in his soccer ball for a Taekwondo Gi; he is now working towards his red belt. He also has taken on many new interests and tasks. Eric and Dad have enjoyed two camping trips, the Pinewood Derby and selling popcorn as part of the Cub Scouts. Eric is also an avid PSP™ and Wii™ player and is many times the

champion for the night. He has also taken on more responsibility around the house and he routinely sets and clears the dining table including the cleaning of the glass tabletop.

In the next decade, we have visions of Eric graduating from high school, getting his black belt in Taekwondo, having a girl friend, driving a car, going to college and starting a work career. Isn't this what we would want for any of our children? It is only now, through the encouragement of the Stalling family story and with the resources and support from many wonderful people that these dreams are possible as well as all the other endless possibilities. With love, perseverance and support, anything is possible.

By the way, Eric is one of the best goodnight kissers that I know.

*It is not enough to give the handicapped life; they must be given a life worth living. – Helen Keller*

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**Sometimes the perfect person for you,  
is the one you least expect.**

**Unkown.**

