

Testimonials and Inspiration

Here you will find testimonials and inspirational words from DSAF members, their families, and from others dedicated to assisting individuals and families affected by Down syndrome.

Congratulations! You have a precious new baby!

Most likely this is the most difficult time of your life. You are probably asking, why? Why me? Why our baby? Why our family? That, we can't answer with complete certainty. But we can tell you for certain that you have been given a blessing. All babies are blessings, even the ones that look imperfect to the human eye. Our Megan has filled our hearts and so many others with warmth that is indescribable. We trust that your baby, like our Megan, will give you a greater understanding of life and love.

We found hope in the fact that other families worked through the same feelings of devastation. The words "your baby has Down syndrome" may bring days drenched with tremendous sorrow and days filled with great hope. You are no different than any other natural parent of a new baby with Down syndrome. Allow yourself to feel however you need to feel. Allow those close to you to do the same with their own emotions. Allow yourself to mourn the loss of the baby you thought you would have. You need to do this to heal and lovingly accept and bond to your new baby. Lean on your spouse and surround yourself with people who can provide love and acceptance of your child.

Our second daughter, Megan Anne, was born into this world on October 31, 2001. Her name was given to her in utero, because of its meaning...*great pearl* and *gracious*. We all have disabilities of our own in one way or another. Our hope is that Megan, along with your child, will help the world understand that we should accept one another for the love we have to share, and not to judge solely on ability or appearance.



Yes, your baby has Down syndrome, but he/she snuggles like a baby, smells like a baby, and will give you endless unconditional love. Seek out the facts. Learn as much as you possibly can. Meet other parents with children of all ages. Welcome to Holland! Enjoy the journey!

Enjoy your beautiful baby!



March 10th, 2000, the day my daughter, Rebecca, was born and the day my life changed forever. After an uneventful pregnancy and normal delivery, you can imagine my shock when my daughter was born and I was informed that she most likely had Down syndrome and that she was so sick that she might not be able to come home, ever. I remember the fear I felt, wondering if she did die, what would be stronger, the feeling of sorrow or the feeling of relief?

It rained the day after Becca was born. I knew it was because the whole world was crying with me. I cried for my son, who's childhood would be cut short by the seriousness of having a very ill, disabled sibling. My son, who's adulthood would be filled with the responsibility and burden of caring for his sister. My son, who instead of the companionship of a sibling, would have to fight for the attention of parents who would be forever filled with sorrow.

I cried for my daughter. For the dreams I had for her that were now gone. For the life I knew she would never have. For the struggles and prejudices she would face. For the pain she was experiencing and the heartache that would fill her future.

I cried for everyone and everything. I cried until I thought I was empty and then I would cry some more. I was feeling so much yet, I was numb. It was like my world stopped but somehow the rest of it kept turning. I felt inadequate, scared, and defeated. I thought I would never laugh or know joy again. I was lost.

Friends and relatives called with messages of "I'm sorry", "You can do this", and "It will be ok." Not one "congratulations" in the bunch. I was told that only "special people" received "special children", I didn't feel very special. I was informed that "we never get more than we can handle" which made me wonder why the expectations were set so high and even if I could handle it, why did I have to prove it?

Four months and two surgeries later, Becca's medical condition had stabilized. One day I looked at her and was utterly amazed. For the first time, I saw Becca, not the characteristics of Down syndrome, not the surgery scars, I just saw my little girl. I have since realized that what I thought was a burden, is actually a wonderful blessing. Time had a way of healing her body and my spirit. Struggles that I was so overwhelmed with weren't "Down's issues", they were parent issues. I still have to fight to resist the urge to blame things on Down syndrome. Two year olds are stubborn, Down's or not. It is hard to balance your time as a parent, even when there isn't a disability involved.

My son, who was 2 $\frac{1}{2}$ when Becca was born, has never seen her as anything other than his sister, Boo-Girl. Now a mature 5, he is the only kid in his preschool class who knows the difference between speech and physical therapy. People often comment on how caring and kind he is, traits I like to think his sister taught him. I have overheard him tell a friend who was struggling with something, "That's ok. Everyone learns at different times."

Becca, well, she is wonderful. She has touched lives in ways I would have never thought possible. She brings joy wherever she goes. She has tremendous determination. She has strengthened my friendships, my faith, and my family. She makes everyone she meets better people than they were before they knew her.

And me, I still feel the sorrow sometimes but it is different. When I think back to the overwhelming grief and fear that consumed me when she was first born, it almost feels like I am thinking of someone else's story. I am learning to accept her limitations but refuse to put limits on her. I imagined I would spend all of my time teaching her the skills needed to live her life. Instead, she has taught me some of life's most important lessons. Life isn't a race. Perfection is overrated. Celebrate life's little victories and ignore its little problems. Different does not mean bad. Most importantly, ability does not equal value. She means the world to me...both my kids do. I am proud to be their Mom.

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So you have just been told that your baby has Down syndrome...

I remember the day we were told that Jimmy might have Down syndrome very well. We had our daughter in October of 2002. We had tried for years to have another little bundle. I remember waiting on the ultrasound chair to find out what we were having. I wanted a little boy so bad. Someone to be mama's little man, who would play with trucks, track dirt in and be named after the best man I have ever met...his Daddy. And there it was, the tech pointed it out on the screen, without a doubt I would finally have my little man. I was so happy and smiley I thought my face would break. All those dreams would come true.

Then suddenly she got so serious, and after what seemed like an eternity she explained to us that our son *may* have Down syndrome. Suddenly all my happiness was torn away. Every dream I had was stolen. Would he be able to live? Would he still love us? Would he be able to do *anything*? I cried all the way home. I couldn't believe this was happening to my son. After trying to have him for over 6 years, this just wasn't fair.

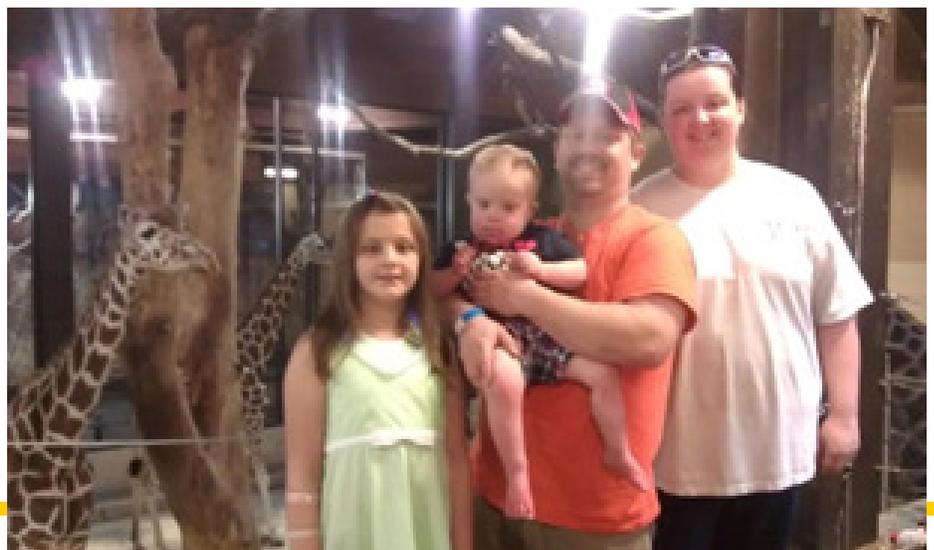


I went home and researched everything I could find on Down syndrome. I looked through hundreds of web pages, tried to get every fact I could. For me the scariest of them all was heart problems. Since my husband has heart issues we went ahead and decided to get our unborn son checked. Sure enough he had some holes in his heart, and one looked like it would have to be fixed, open heart surgery. And again my thought, why my son? What did we do? We didn't cause this to happen. Couldn't stop it or prevent it.

Jimmy has since been born. He spent ten days in the NICU with some breathing issues. At three months old he had his heart surgery. He came through it. His muscles are delayed, we work with them and they are building.

He is EVERY dream I ever had about my son long before I ever heard the words Down syndrome. He loves trucks, he is fearless, he is determined, he is happy, he loves his mama and so much more that just can't be put into words.

Having Jimmy has brought so much love and patience into our house. He has taught us not to sweat the small stuff and love with all your heart.



Through a Mother's Eyes



We were all moving along so quickly. Quickly going to and from work and school.... quickly going along life's journey. We had a plan. I always liked having a plan, setting goals and doing everything possible to accomplish them. We had married young and had spent ten happy years together. My husband and I were both working, my husband as a computer programmer/analyst, while I was going to school... forever going to school. We realized that the "right time" to have a child would never really arrive ("life is what

happens when you're busy making plans") and so we decided to start a family. The pregnancy was wonderful and relatively uneventful. I state relatively because in about the seventh month our doctor was listening to our baby's heart and noticed some irregularity in the heartbeat. We went in for a level two ultrasound and wouldn't you know...the baby was turned away from the ultrasound device. They told us that everything seemed fine and not to worry. I'm so glad they did.

Three weeks early and in a hurry, Elissa was born. A baby girl! I wanted to ask the typical questions, "Does she have all of her fingers and toes?" and "How much does she weigh?" Within three minutes our doctor said, "She has several signs that lead me to believe she has Down syndrome." To this day, I am happy we did not find out Elissa had Down syndrome until after she was born. We were able to enjoy the pregnancy without having to worry unnecessarily. We were able to see her first as a new baby-a new baby girl - the first girl on my husband's side in several generations. The fact that we knew her first as a baby has been important for so many reasons. She is indeed so much more than some label. We realized early on that she is a unique individual who also happens to have Down syndrome. This realization has propelled me to passionately promote person-first language with family, friends and professionals. We want everyone to know her first as we do, a child.

The first days in the hospital were unforgettable. My husband and I are both readers and researchers. My motto - if a challenge comes up in life, read as much as you can about it. Information has always been comforting to me. When I have information, I feel empowered. Fortunately, I was a school-teacher and already had many wonderful experiences with children who had Down syndrome.

We knew the news would be difficult to share with our families because we wanted them to also know her first as our beautiful new baby. I didn't spend much time feeling anger. Grief, yes, but not anger. I grieved for the loss of the image of the baby I thought would come to be. Little did I know, she would be so much more and would bring out in the lives of those around her unconditional love, understanding, unbelievable pride, an appreciation and respect for diversity, and knowledge of God's love for all of humanity. I still sometimes grieve. Not for Elissa or for ourselves, but for the world that is still untouched by someone so small, yet able to teach us such intangible things.



Those first days seem so distant now. We are grateful for supportive people who are in our lives. Elissa is now four years old and is an amazing little person. She is very much the big sister to her brother Hayden. She has benefited greatly from excellent medical care, including open-heart surgery when she was four months old. She has also benefited from early intervention services including occupational therapy, physical therapy and speech therapy. We have been blessed to encounter so many people who have invested so much time and energy to her happiness and development. Elissa is very independent, always wanting to "do it myself". She is our constant reminder to value the right things, to appreciate the beauty in creation and to savor our time here on this earth. Life is not a race.

Through An Aunt's Eyes

I always knew that the baby my sister was carrying was going to be special. I knew it because every one of my nieces and nephews are special, and my own children are unbelievably special. But I couldn't believe my eyes when I first saw her. She was such a special baby.

When my older sister told me that my niece had Down syndrome, I was concerned for my younger sister and her husband, yet I knew they would be celebrating the birth of their child, and that is just what we all did when we first saw her. Rhonda and DEan taught me right away that Elissa was a baby first and foremost. They didn't get angry and blame God; rather they accepted it as His will for their lives. She was a gift and the fact that she had Down syndrome didn't make it any less of a celebration.

Elissa melted my heart on that day just as she does every time I see her.

"Karie's here!" she cries out as she sees me come into her house. Her eyes sparkle; she drops what she's doing to give me a hug and kiss. She knows how to make me feel special too. "More music!" she says and will spend time on my lap singing the songs of my own childhood. She has taught me so many things already in her 4 years of life. She taught me how to be a better teacher by looking at the individuality of the students in my classroom and focus on their gifts not their downfalls. She is still teaching me to be patient. If I would wait just a little longer, she can do it all by herself. If I show her how to do it just one more time, she can get it right. She is a very typical 4 yr old, who loves to play with her friends, gets mad when she doesn't get her way, and LOVES to go to Karie's!

Elissa teaches me to celebrate uniqueness. What does special mean? Uncommon, Noteworthy, Individual, and Unique.

That definitely defines Elissa, and I wouldn't want it any other way.



People with
Down syndrome
can learn how to
read & write
just like others.



Images for a lifetime
jessicagardner.com

Through a Father's Eyes

How does anyone put into words the emotions and thoughts regarding the birth of one of their children? This is especially true of a first child, without a previous well of experiences. My wife and I had roughly 9 months of major prep time. We purchased a lot of books, received much advice, took a Natural Childbirth class, took an infant CPR class, accumulated quite the load of baby stuff, amassed several well organized bags for the hospital trip - all pretty typical first time parent activities. Living in Kansas City, Missouri, we had many Baby Superstores to make sure we had everything on the checklists. We decided to let the sex of the baby be a surprise, especially due to the fact that our chances of having a girl were slim.



2 $\frac{1}{2}$ weeks prior to our due date, two good friends and their newborn daughter visited us for the weekend. My wife states that the lunch at KC Masterpiece barbeque started labor on that Sunday. Our friends left, and we did what most people probably do in early labor - panic! We tried to clean the house, clean the car, load the new baby seat, time all contractions with a stopwatch (I have the logs to prove it), etc. Around midnight, after doing some fast cramming on my Doula training that I was behind on, Rhonda told me to go to bed. Before long, I was showering and loading the car.

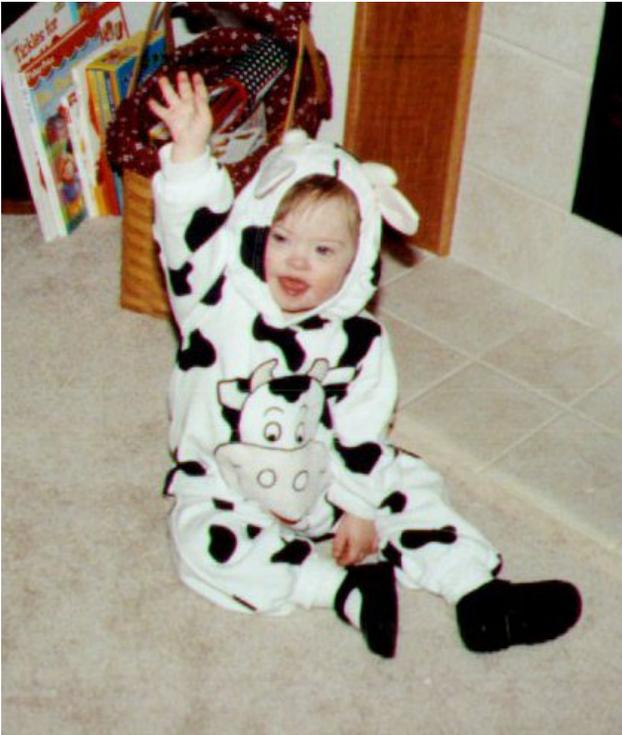
We drove to the hospital at 3 a.m. Monday morning, with contractions at 3 minutes apart, had the standard "do you really need to be here yet" monitoring, walked around an hour until contractions strengthened, had another monitoring session, and finally were admitted quickly to our birthing suite. By the time

I hauled the rest of the luggage to the room, things were really moving. It only took 3 $\frac{1}{2}$ hours until the blessed moment. A man cannot understand the emotions and pain endured during labor and delivery, especially when your wife has no medication. I, however, can say that I have never had more admiration and pride for my wife than in those 3 $\frac{1}{2}$ hours. At 9:53am, I acquired the first glimpse of a baby's head. A few seconds later, the doctor announced that it was a girl. My father's side of the family had not had a girl for over 4 generations, so the surprise was overwhelming. I am man enough to say that I broke down and cried. Two minutes later while they were taking all my daughter's vitals under the warmer, the doctor came back over and informed us that Elissa appeared to have Down syndrome.

Looking back, I know that in my now "enlightened" state, I would have liked to have had different responses to many things over the next few minutes, days, and weeks. Not that it would have made a difference, but I am thankful that we welcomed our daughter into the world first - then received information about her diagnosis. First and foremost, she was our child that we had eagerly anticipated meeting for the last 9 months. She was a beautiful, perfect creation from God. Her medical diagnosis did not alter our love for her or her love for us. We needed each other, and I feel privileged that God chose us for each other. He knew that a mere medical condition would not define our daughter, who would grow, crawl, walk, talk, laugh, cry, sing, and read just like other kids - but at her own pace and with our loving direction. He knew Rhonda and I could handle this little challenge.

Now, with my "enlightened" statements above, I can also be honest. Was I in shock at the news two minutes after my daughter was born? Yes. You don't know how to react to that type of news at that moment in your life.

For starters, my wife and I were not in a position to sit down and discuss with each other much about this news - as we were new parents with nurses and doctors bustling about the room. We also had no family present on that day, as we lived 3+ hours from the closest relative, and my Dad's mother passed away that weekend and my side of the family was all attending the funeral. So - our immediate support network was comprised of my wife and I, God, and two wonderful birthing nurses.



That evening, Rhonda's family trekked down to Kansas City to see our new family. The next day, one of our nurses gave us a packet of information from the Kansas City Down Syndrome Guild. It was an older, very small New Parent Packet, but it did give us a list of current literature to obtain. I journeyed several blocks away to Barnes and Noble to find the first book on the list: Babies with Down Syndrome - A New Parents Guide. Our knowledge and confidence grew through reading, getting to know our daughter, prayer, networking, and wonderful medical personnel and therapists that plugged us into what we needed to know, who we needed to see, and when we needed to do things.

I remember two defining events the day of Elissa's birth. I saw that our main nurse Elizabeth was going to give Elissa her first sponge bath, and I asked if I might watch closely to learn. She told me "No", that she was going to just let me do it myself (with some guidance).

That event really bonded Elissa and I as father and daughter. The second event was the call to Rhonda's parents to tell them we were parents. They had wondered why we weren't home, and they figured we must be at the hospital. The phone in our birthing room was ringing several times during delivery, which must have been my in-laws. I answered the phone sometime the first hour after Elissa's birth, and had the pleasure of telling my mother-in-law of our great news. I found that in trying to tell the first person about our daughter's birth, I was unable to speak.

The medical issues that surrounded Elissa did make life more interesting for the first 6 months (as it still does at times), but it made Rhonda and I STRONGER people. A friend of mine spoke a phrase that I have now taken to be my own: I am a better person today because of my daughter. This is not a haughty statement. I know that I value family more, I value the little achievements more (like shedding a tear when your daughter walks up the stairs without the railing for the first time), I value my responsibility to raise-the-bar for my daughter at every step of her life, I value my role as an advocate for my daughter, and I value my passion for spreading awareness to the community and others about Down syndrome. A very wise Physical Therapist, Jenny, once told us that we were very lucky parents, because Elissa would walk, talk, read, and do all the typical things in life - just with a little extra help.

Little Miss Emery

I guess when you get near a certain age and have children that are married, you start wondering, silently, when you'll become a grandparent. Over the past ten years or so prior to my granddaughter being born, I knew the time would come, purposely not thinking too much about it all along. You see, I was too young or thought so, as most of my children's friends' parents were older than we were and fit the stereotypical mold of grandparents. It wasn't until my daughter Kristen got pregnant that I had to come to grips with the fact that my wife and I were going to be grandparents.

The pregnancy went well. My daughter was becoming a mom, and my wife was becoming uncontrollable (baby items needed bought). It's at this point that I discovered a true relationship between birth of a grandchild and golf handicap deterioration. That's another story that I dare not get into in this open forum.

March 13, 2009, Kristen had her checkup and she'd been having some contractions and really wanted to have the baby. As she was getting ready to leave from her checkup, her water broke and she was admitted. My wife had left already to be with her in the delivery room and I stayed at work waiting for the "2-hr" warning so I could get to the hospital in time. That call finally came late in the afternoon, so I closed up the office and picked up my other daughter and son and we headed off to the hospital to meet our new family member.

The time came. The hospital plays a lullaby in the waiting room when a new baby is born. My daughter became a mom, and my wife and I became grandparents. My wife came out to tell us all the particulars and then returned to be with Kristen. I remember everything about each of my three children's birth and knew this would be another day to add to my memory banks.

My son nicknamed the baby half-pint since she was born on the half hour was 19 $\frac{1}{2}$ inches long and weighed 7 $\frac{1}{2}$ lbs. My wife eventually came out to the waiting room and asked me to come into Kristen's room. When I entered there was quiet, no crying baby. I looked at my wife and daughter and they were obviously upset so I went to see what the nurses were doing at the warming table. At that point I realized my granddaughter has Down syndrome. It was like a sledge hammer had just been slammed into my chest and I began to understand the magnitude of life. It's at that moment that I understood what a grandparent was and more importantly why God put me here.

There is not a lot of information available regarding grandparents and their actions during and after a grandchild is born with Down syndrome. Some have actually indicated that grandparents grieve twice when they get the news about their grandchild having Down syndrome; once for themselves and once for their child. I don't know if that is true, but I honestly believe that I didn't grieve at all. Grieve is too harsh a word to describe the wonderful gift my daughter and son-in-law, our family, had just received. Yes, almost immediately, we knew she had Down syndrome and



there was sadness in the room, but as my wife so eloquently put it, "this baby couldn't have been born to a more loving family'. I think the word that I'd like to attribute to my granddaughter's birth is love. From the minute that I saw her, I knew that she was going to be a special child in my life. As a first time grandparent, I will always have a unique spot for her. I don't want to call her my favorite grandchild, as I'm sure there will be plenty more and that would not be fair, but she's the first and holds that status for ever.

Her name is Emery and it comes from Old English meaning "home strength", "power" and "bravery". This name has proven to be very insightful as she continues to grow and develop into a powerful force.

There were some uncomfortable and unnerving moments when we had to listen to doctors tell us that she has a heart defect and may eventually need surgery, but the bravery this little girl is showing and her daily accomplishments are amazing. At close to seven months, I watched her with all her might pull herself up to sit and soon thereafter force herself to stand while holding on to my fingers, all the while just laughing away. This made my day each and every time I got to be with her.

March 13, 2011 Miss Emery turned two. According to her she is five. Although delayed somewhat, she says about 10 or so words but knows upwards of 30 sign language words. Although her original heart issues have faded the doctors still think she'll need to have heart surgery to repair a leaking valve. She doesn't walk just yet but can manage three-four steps before she realizes she's on her own and then slowly sits down. I have faith in her that she'll do the things she needs to do when she wants to.

My daughter and son-in-law recently visited and I observed them intently watching Emery as she played with her toys and stood walking around holding onto the furniture, then sitting there talking to her baby doll. I asked what they were thinking and they commented on how independent she was when she visited grandma and grandpa's house. I told her that, as with them, when they were growing up, we treat her just as we did with them. Although I didn't say it to them, but I believe her independence is achieved through her exploring. As a child with Down syndrome she has a different way of dealing with things around her and must explore those things. Again with her namesake, she's a brave girl, not really afraid of anything. As a grandparent of a child with Down syndrome, we have to learn a different way of sharing our knowledge to not only our child but to our grandchild. We have to explore as well. There are numerous web sites that address Down syndrome; however, there are not a lot of resources available for grandparents. My wife and I read a lot and even co-founded a local grandparents group to be able to discuss and share our thoughts and experiences. The biggest thing I can say that helps is the ability to talk with others in the same situation. Seek out other grandparents and explore with them. I guarantee you'll be better for it.

My life has changed so much for the better since little Miss Emery was born. These last two years I wouldn't trade them for anything. As a grandparent to a child with Down syndrome, both my wife and I have learned that love is truly a gift from God; ask Emery, she'll smile and say so.

"Experience is not what happens to you. It is what you do with what happens to you."

-Aldous Huxley

December 19th 2004 changed my life forever. It was the day I became a big sister for the second time. It was the day my baby brother Sean was born.

When I was told I was going to have another younger brother, I wasn't exactly thrilled. At that time, I already had one other younger brother. Hunter was two years younger than I and lets just say we did not get along. We both got on each others' nerves and I dreaded having another one of him running around. But Sean was different, for one he was much cuter than Hunter and two, Sean had Down syndrome.

I can still remember when my dad first told me that Sean had Down syndrome. It was some months after Sean was born. We were downstairs in the basement and Sean was playing with some of his toys. My dad asked me if I noticed anything different about my brother and I didn't even hesitate when I told him no. To me, Sean was just like any other baby. He then told me that Sean had Down syndrome and he explained to me what Down syndrome was. I started crying, I didn't want my brother's life to be difficult and filled with drawbacks. I wanted him to be like everyone else. I wanted him to have a normal life and do normal things. But most of all I was scared, I didn't know how to be around a person with Down syndrome. I use to think they were so weird. I had no idea how to act around them. I didn't think I would be able to be a good big sister to my brother.

I soon realized that the rest of my family was in the same predicament I was in. We all had to learn about Down syndrome and how to help Sean. My family and I joined the DSAF(Down syndrome Association for Families). We met other families who were like us and had a member of their family with Down syndrome. We would go to special events and helped with their annual fundraiser, the Buddy Walk.

Having a little brother with Down syndrome really changed my attitude. Before Sean was born I, like most other teenagers, used the word retarded. I can't even remember where I heard it from, but I always used it, as did all of my friends. After I learned that Sean had Down syndrome, I felt so horrible for all the times I had used that word. And it took me nearly a year to finally stop using it. I still have to remind some of my friends not to use the "r" word.

Then one day came where I was truly thankful for Sean. It was my sophomore year and in my choir class there was a boy with Down syndrome. I was assigned the seat next to him and I immediately turned my head, smiled and said "Hi" to him. He smiled and said "Hi" back. Everyone in the class would always stare at him like he was some sort of anomaly. They would always ask questions about how he looked and why he acted the way he did. I tried being understanding with them since I knew what it was like to not understand. I always answered their questions about Down syndrome and tried encouraging them to be nice to him. As the year went on they got used to Jamie's eccentricities and soon everyone just acted like normal around him and no one stared. By the time the year was over, the entire choir, and most of the school were friends with Jamie. He became the most popular guy in school and everyone would stop and say hi to him in the hallways.

I learned through my experience with Sean as a brother how to look at each individual and see a person no matter how different they are. I can now stand up to people like those that were in my choir class. I can teach them how everyone should be treated with love and respect. And the only way I would have ever been able to do all that is by being a big sister. I am so thankful to have my brother in my life.



**Siblings of a child
with Down syndrome
tend to be more
compassionate
& better adjusted
than their peers.**



Announcing the Birth

By: Nancy J. Murray, MS and William I. Cohen, MD

Source: When Your Baby Has Down Syndrome

Most importantly, your baby is a baby first and secondly, a baby who happens to have Down syndrome.

It is generally suggested that parents not wait to tell friends and family members about their baby having Down syndrome. Even though telling family members and friends about your child having Down syndrome will be one of the most difficult things you face, don't be afraid. Most parents who have a new baby want others to be happy for them and to extend best wishes.

Generally, the longer an announcement is put off, the harder it may be. Most people know very little about Down syndrome, so education is important. Some people will think back to people with Down syndrome that they knew as children. Their thoughts will tend to be out-dated, because today society is more accepting of people with disabilities. Children born with Down syndrome today have available to them more inclusive educational and community opportunities than children born even a decade ago. For some people, it may be extremely difficult to accept your child. That will be their problem and misfortune if they choose not to be a part of your family's life.

Generally family and friends will follow your lead. Most people will want to sincerely share your experience in a supportive and encouraging way as with the birth of any child. It may also be helpful to share your child's accomplishments throughout his or her life so that friends and family can continue to share developmental and educational milestones. On the other hand, it will also be helpful to share any difficult times, such as an illness or surgery.

Oftentimes, a child with Down syndrome will cause others to reflect and find new, different and deeper meanings in their own life.



Molly Elizabeth

June 23, 2010 5:34pm

6lbs 3oz 20in.

Dear Family and Friends,

We would like to introduce you to the latest addition to our family! Molly Elizabeth arrived June 23rd weighing 6lbs 3oz and 20in. God has made Molly very special and chosen us to be her parents. Molly was born with Down Syndrome. We wanted to send this news so you wouldn't feel the need to have an immediate response.

We want you to know that we are very happy and proud of our brand new baby girl. We want everyone to see her as we do, a beautiful and happy little girl. We also want everyone to treat her like any other baby, please congratulate us; we have a brand new addition to our family! This is not a sad moment, we understand that sorrow may be a natural first reaction that people have, please understand that we are not sorry. We encourage you to call us or come by and see her.

If you have questions, please ask us and we will answer them the best we know, we are still learning about Down Syndrome as well. Molly is a very healthy baby girl who sleeps, eats, cries, and dirties diapers just like every other baby, she's just got an extra chromosome!

With love,

Rob, Carrie, Maggie + Molly

Birth Announcement Note

We included the following note in Tarenne's birth announcements:

Dear friends and family,

As many of you know Tarenne was born with Down syndrome. We want to thank all of you who helped us with prayers and support during our pregnancy. We are so blessed that she is a very healthy little baby.

We want everyone to be comfortable enough to ask us questions. We have learned a lot in the past five months, but before we found out about Tarenne we didn't know much about Down syndrome either. We are doing everything we can to provide her with the best start. That will only be possible with the love and understanding of our family and friends. So please don't hesitate to ask us anything, or share information you have heard.

Tarenne's name sounds like Karen, after Joe's mother, and is spelled like Nicole's maiden name Turenne. She is doing really well, except is having a hard time learning to eat because she is often very sleepy. But when she is awake, she is very alert and sweet. Everyone who has held her has been touched by this special angel- and she can't even talk yet. We can't wait for all of you to meet her.

Much love, Joe, Nicole, Darrah and Tarenne

Dear friends and family,

As many of you know Kelly was born with Down syndrome. We want to thank all of you who helped us with prayers and support during our pregnancy. We are so blessed that she is a very healthy little baby.

We want everyone to be comfortable enough to ask us questions. We have learned a lot in the past five months, but before we found out about Kelly we didn't know much about Down syndrome either. We are doing everything we can to provide her with the best start. That will only be possible with the love and understanding of our family and friends. So please don't hesitate to ask us anything, or share information you have heard.

She is doing really well, except is having a hard time learning to eat because she is often very sleepy. But when she is awake, she is very alert and sweet. Everyone who has held her has been touched by this special angel- and she can't even talk yet. We can't wait for all of you to meet her.

Much love, Michael, Anna, and Kelly

Dear Family and Friends,

Lora Grace Harrington entered quickly into the world on August 2, 2002 at 8:30pm. She weighed 6lbs 2oz and was 19 inches long. Lora is a very special baby, and the birth announcement can't possible say it all. God has made Lora special and chosen us to be her parents. We feel blessed. Lora was born with Down syndrome. We hope you feel the same way as we do, we are happy and proud. We would like you to see her as we do, a beautiful, healthy baby girl. We also want you to treat her just like any other baby— Congratulate US! We have a baby, we are a family now. This is not a sad moment, PLEASE do not apologize, we are not Sorry! We are still gathering information on Down syndrome and so we probably won't be able to answer most of your questions for a while. We would like to encourage you to call and visit us. She sleeps, eats, cries, and dirties her diapers just like every other baby, she just has an extra chromosome.

With Love, Jerime, Cory and Lora

Sample Birth Announcements

This is the birth announcement that we sent out to our family and friends shortly after our daughter, Elissa, was born. We also included the "Welcome to Holland" poem by Emily Kingsley.

Elissa is a very special baby, and the birth announcement can't possibly say it all. We are excited about our new family addition. She is a precious baby girl - the first Fuelberth girl in several generations. Elissa also has a few health challenges. She was born with Down syndrome (named after John Langdon Down - an English physician who discovered the condition). We want to give you time to adjust to the news, so you won't feel you need to give an immediate response. We hope you feel the same way we do - we're happy and proud. We would like you to see her as we do - a beautiful baby girl! We also want you to treat her like any other baby. CONGRATULATE US! Please do not apologize - we are not sorry. We are still gathering information on Down syndrome and won't be able to answer a lot of questions right away.

A challenge accompanying Elissa's condition is a congenital heart defect commonly called an AV Canal. In "real people" terms this means she has two holes - one between the upper two chambers and one between the lower chambers of the heart. These cause her heart to work harder than usual. Elissa will need to have open-heart surgery sometime between four and six months of age. The prognosis for recovery is excellent and should require no additional future surgery. We are confident in Children's Mercy Hospital and their cardiology staff. Please keep us in your thoughts and prayers as she undergoes this procedure.

We hope this letter finds you well. Elissa looks forward to meeting everyone soon! What a miracle life is!

Megan Anne Calhoun

born into the world

October 31, 2001 at 6:55 PM

weighing 6 pounds 8 ounces

stretching 19 $\frac{1}{4}$ inches.

Her name was given to her on June 25,

because of its meaning...

"great pearl" and "gracious".

We all have disabilities of our own in one way or another. Our hope is that Megan will help the world understand that we should accept one another for the love we have to share, and not to judge solely on ability or appearance. Thank you for your love, support and prayers, especially through the pregnancy and Megan's first days. Please continue to pray for our family, as we will be praying for yours. We wish you a very blessed holiday season.

All our love,

Anna, Charlie, Elyse and Megan

"Our Lord and God! You are worthy to receive glory, honor, and power. For you created all things, and by your will they were given existence and life." Revelations 4:11

"Be glad and rejoice forever in what I create." Isaiah 65:18

"I know what you are thinking. You need a sign. What better one could I give than to make this little one whole and new? I could do it; but I will not. I am the Lord and not a conjuror. I gave this mite a gift I denied to all of you-eternal innocence. To you she looks imperfect - but to me she is flawless, like the bud that dies unopened. She will never offend me, as all of you have done. She will never pervert or destroy the work of my Father's hands. She is necessary to you. She will evoke the kindness that will keep you human. Her infirmity will prompt you to gratitude for your own good fortune...More! She will remind you everyday that I am who I am, that my ways are not yours, and that the smallest dust mote whirled in the darkest space does not fall out of my hand...I have chosen you. You have not chosen me. This little one is my sign to you. Treasure her!"

The Clowns of God, Morris West

Aidan's Gift

By Valle Dwight

I think it's serendipitous that my second son's birthday is so close to Mother's Day. When Aidan arrived, I had already been a mother for more than three years. My first son, Timmy, a strong-willed, inquisitive boy, had taught my husband, Phil, and me many things — like how to survive on four hours' sleep, the best ways to navigate through a tantrum, and how to hide vegetables in chili. But I don't think I came face to face with the true range of what motherhood means to me until Aidan entered our lives 18 months ago.

It was the first day of spring when Phil and I checked into the hospital. Shortly thereafter, Aidan came into the world looking very much like his brother, howling, arms and legs flailing, a mop of wild red hair matted to his head. But when the midwife handed him to me, I looked right into his tiny face and stopped for just one instant. Hmm, I remember thinking, his eyes look a little strange.

I quickly rejected that thought — no, everything's fine — and turned to Phil. We reveled in the afterglow of what had been an easy birth, and talked about how lucky we were. We were filled with gratitude for the beautiful family we had created, and looked forward to getting home and starting our lives together.

Then the nurse arrived to tell us that she needed to send the baby to the nursery because he was a little cold and they wanted to warm him up. She took him away, and we began to call family and friends to share the good news about our 8-pound, 13-ounce newborn son. But when Aidan still hadn't been returned an hour later, I had a nagging feeling that something was wrong. I didn't want to ruin the moment — or lend weight to my fears — so I said nothing to Phil.

The midwife arrived. She told us that there was a possibility our baby had "chromosomal problems." I refused to let it sink in. Oh, a chromosomal problem, I thought. I'm sure they can fix it. Although my mind hadn't registered her meaning, my body must have because a chill ran right to my neck. Phil was silent. Maybe one of us asked what she meant exactly. Maybe she spotted our look of obvious misunderstanding. So she spelled it out: "The nurse thinks he may have Down syndrome."

From where I sit now, I can split my life in two. There's the time before we heard those words, and the time after. Before, we were probably like most people. We knew we were lucky. We were healthy. Our little boy, Timmy, was funny and strong and happy. We had jobs and a loving family. But until we were hit with those words, I don't think we had any idea how fragile that luck can be.

I knew nothing about Down syndrome, but I had lots of frightening preconceptions. My first thought, even as I nursed him in the hospital, was "How will he get a job?" My instinct right from the start was to hold him tightly against a world that seemed irreversibly changed.

I thought back on my pregnancy, which had been uneventful. Because I was over 35, my doctor had advised me to have an amniocentesis. So I'd made an appointment for the prenatal test that was to determine whether my baby had a chromosomal abnormality or spina bifida. I got as far as the ultrasound. Just before the doctor started the test, I changed my mind. I told the doctor I didn't want to risk a miscarriage.

"Well, your chance is one in one hundred that you'll have a baby with Down syndrome," she said. "I've had ninety-nine other women in here this month and none of their babies had Down syndrome. You might be the one."

I had been ambivalent about the amnio from the start. Driving to the appointment, I'd told Phil that I didn't want to terminate the pregnancy no matter what the amnio revealed, and he'd agreed. We'd planned to have a second child, and there was no going back.

"Even if the baby has Down syndrome," I told the doctor, "I won't terminate the pregnancy, so what difference does it make?"

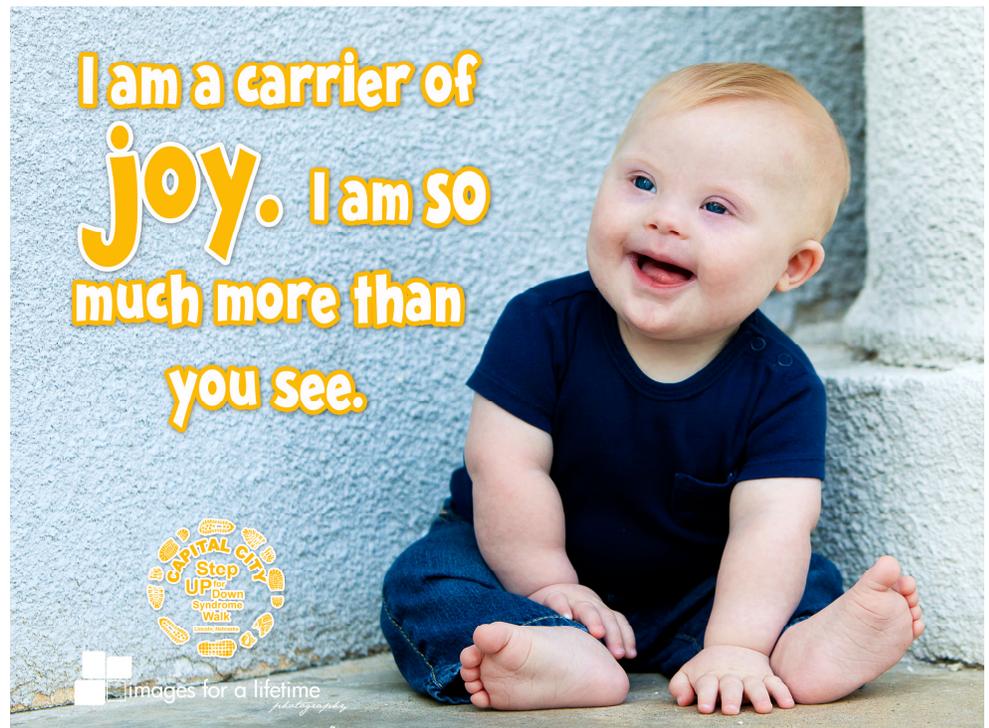
"Well, that's what everyone says," she told me. "But they change their minds when they get the test results."

I was offended by her flip attitude toward my baby. "Well, I'm not changing mine." And we left, clutching the ultrasound photos of our beautiful baby.

Now here I was five months later, holding my blue-eyed baby who suddenly seemed so distant. We took Aidan home and waited a week for the blood test that would tell us for certain whether the doctors' suspicions were correct. Meanwhile, we stared at him, wondering. We compared him to pictures of Timmy as a baby. And we went back and forth with each other: Did he look the same or different? And were the differences we saw a result of Down syndrome, or because he was a different person? I kept thinking about the moment he was born, when I'd noticed something odd about his eyes. But other times I'd reassure myself that he was no different from Timmy, that everything would be fine. It was an agonizing period.

By the time the results were in, I thought I'd resigned myself to the worst. But the news sent me reeling. I cried for two days. I was grieving for the baby we had expected, the only one we thought we were prepared for.

When the tears dried, I began the long learning process that will continue, I imagine, for the rest of my life. Having resolved to find out everything I could, I went online, I read books, I talked to people. I was surprised to discover that everyone in the world, it seemed, was either related to, went to school with, or grew up next door to someone with Down syndrome. Everyone but me. I discovered an Internet support group for parents, and at the urging of one of them, I posted a message announcing Aidan's birth. The fact that he had Down syndrome was understood. These parents wanted to know the truly important things, like our baby's height, weight, and hair color, and their interest put things into perspective for me.



Within days we had received more than 50 congratulatory notes — not one "I'm sorry" among them. Our spirits soared. Friends and family had been very supportive, but, let's face it, they knew as much about Down syndrome as we had. And they were all a little sad, too. But these other parents weren't sad at all. They felt that their children were a great gift, Down syndrome or no.

As I pored over the books and talked with these other parents, I found the factual side of Down syndrome fairly easy to piece together. Also called Trisomy 21, it is caused when a person is born with three of the 21st chromosome rather than the usual two. This extra chromosome, and all its associated genes, alters the development of the body and brain. What this would mean for Aidan specifically would be hard to say, but he would be developmentally delayed to some degree (most people with Down syndrome fall in the moderate to mildly mentally retarded range) and would have low muscle tone. This would make it tougher for him to crawl, walk, and talk. The list of the other potential problems was daunting: heart defects, hearing loss, vision problems, small airways making children prone to upper respiratory infections, and on and on.

In fact, it seemed that we spent the first few months of Aidan's life in the offices of endless medical specialists, most with titles longer than our baby's tiny body. By his first birthday, Aidan had seen a pediatric cardiologist, pulmonologist, ophthalmologist, audiologist, and an orthopedist, to name a few.

Of course, there was nothing in those reference books that could fully explain the other side of the story — the ups and downs of raising a child with Down syndrome in our society. That's what we've been learning from Aidan himself, and it's been a lesson filled with wonder. Aidan's life so far has been more complicated than Timmy's was. There are more ongoing appointments — he has physical therapy, a play group, and a teacher once a week. There have been challenging days and frustrating moments as we've all struggled to learn about each other.

But we've come to recognize that we've had trying times with Timmy, too — they've just been over different issues. Timmy never slept. Aidan goes to bed a 7:30 p.m. and wakes up laughing. Timmy threw tantrums to beat the band; Aidan definitely knows what he wants, but he's generally much less stubborn. We're learning, as all parents discover with the birth of their second child, that each child presents a unique set of challenges.

Aidan is actually more like other kids than he is different. He will learn to walk, talk, read, sing, and dance (you should see him rock to "Itsy-Bitsy Spider"), although he will have to work harder than most kids to reach those milestones. And we will have to slow down and allow him the extra time. Beyond that, he will have skills, talents, and quirks all his own. He already does. He scoots around the house using his bottom, two hands, and one foot faster than any crawler I've seen. He can find his Barney doll no matter how well we've hidden it. And he's already using sign language, predating his eventual use of words.

When Aidan was newly born, all I could think about when I looked at him was "Down syndrome." But now I see that the syndrome is just a small part of who he is and what he will become. Aidan has shown us that contrary to stereotypes, kids with Down syndrome aren't always sweet angels. When he does get angry, he can throw a tantrum to rival his brother's. When he doesn't want to eat, he sweeps his vegetables off the table with a stubborn flourish. And he hustles away with a backward glance and devilish giggle when he knows he's put something in his mouth that he shouldn't. Like the rest of us, kids with Down syndrome have a range of personalities, moods, and temperaments.

The future for people with Down syndrome is brighter than it has ever been, which makes me hopeful for my son's adulthood. Early intervention, medical advances, inclusive schools that educate all kids together, and new therapies have meant that people with Down syndrome can live longer, achieve more, and contribute to their communities in meaningful ways. Most of them graduate from high school, many live independently, marry, and have jobs. So while I wondered on Aidan's first day of life how he would even find a job, now I dream about the possibilities. Will he love the theater the way his father does? Maybe he'll want to work at a newspaper, as so many generations of my family have. Perhaps he'll be wiser than his parents and find work that actually makes money.

It has been only a short time since Aidan came into our world. To a degree, we're still on an emotional roller coaster. We have days of unadulterated joy over our family and what Aidan brings to us. And more wistful days when we wish that life was simpler, though these come less and less often. Sometimes I get sad about the might-have-beens, especially on the days when Timmy makes plans about things he and Aidan will do together, and I wonder which of those dreams will come true. Many days I feel guilty and unsure as to whether we're doing enough for Aidan. Would he be better off if we could afford this program, those vitamins, or that new therapy? And sometime I get scared about what's down the road, especially when I think of the struggles he may face making friends in those horrible junior high years, or making his way in a culture that places such high value on convention and looks.

But as we head into year two of Aidan's life, I've long since realized that our luck did not run out the day he was born. Not at all. In many ways, our lives have been transformed. We have found loving support from people who used to be strangers. We look at the world differently and consider ourselves lucky to be able to. We have an appreciation for a slower pace, we take greater delight in each small step. And we have a newfound understanding of the preciousness of all people.

Valle Dwight, an editor for Family PC, lives in Florence, Massachusetts. This essay first appeared in Family Fun magazine.



The Special Mother

by Erma Bombeck

Most women become mothers by accident, some by choice, a few by social pressures
and a couple by habit.

This year nearly 100,000 women will become mothers of handicapped children. Did you ever wonder how mothers of handicapped children are chosen?

Somehow I visualize God hovering over earth selecting his instruments for propagation with great care and deliberation. As He observes, He instructs His angels to make notes in a giant ledger.

"Armstrong, Beth; son. Patron saint...give her Gerard. He's used to profanity."

"Forrest, Marjorie; daughter. Patron saint, Cecelia."

"Rutledge, Carrie; twins. Patron saint, Matthew."

Finally He passes a name to an angel and smiles, "Give her a handicapped child."

The angel is curious. "Why this one God? She's so happy."

"Exactly," smiles God, "Could I give a handicapped child to a mother who does not know laughter? That would be cruel."

"But has she patience?" asks the angel.

"I don't want her to have too much patience or she will drown in a sea of self-pity and despair. Once the shock and resentment wears off, she'll handle it."

"I watched her today. She has that feeling of self and independence that is so rare and so necessary in a mother. You see, the child I'm going to give her has her own world. She has to make her live in her world and that's not going to be easy."

"But, Lord, I don't think she even believes in you." God smiles, "No matter, I can fix that. This one is perfect - she has just enough selfishness." The angel gasps - "selfishness? is that a virtue?"

God nods. "If she can't separate herself from the child occasionally, she'll never survive. Yes, here is a woman whom I will bless with a child less than perfect. She doesn't realize it yet, but she is to be envied. She will never take for granted a 'spoken word'. She will never consider a "step" ordinary. When her child says 'Momma' for the first time, she will be present at a miracle, and will know it!"

"I will permit her to see clearly the things I see...ignorance, cruelty, prejudice...and allow her to rise above them. She will never be alone. I will be at her side every minute of every day of her life, because she is doing My work as surely as if she is here by My side".

"And what about her Patron saint?" asks the angel, his pen poised in mid-air.

God smiles, "A mirror will suffice."

***Taken from Motherhood: The Second Oldest Profession*

