Whispers of Hope

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Forward

Hope is the thing with feathers
That perches in the soul.
And sings the tune
Without the words,
And never stops at all.

— *Emily Dickinson*

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Reneé

"Happiness depends more on the inward disposition of mind than on outward circumstances."

— Benjamin Franklin

It was early on a Saturday morning that I went into labor, two weeks earlier than planned. Less than six hours later, our beautiful baby girl came into the world at seven pounds, eleven ounces. I had a normal pregnancy and delivery; I had the blood test done at 15 weeks to determine if anything was out of the ordinary. Everything came back normal, and because of my age I was not asked to do an amniocentesis.

Two days later, as I was about to leave the hospital with my new little bundle of joy, I was told by the doctor that Renee might have Down syndrome. I was completely shocked! My husband and my 16-month-old daughter Ashley had not even arrived yet, so there I was, all alone. I had never felt so alone. I was left to tell my husband that our new baby girl could have Down syndrome. I didn't believe it! I wouldn't believe it! Was I to blame for this? Why my baby? Why? Why? We had so many questions while we waited the four days for the test to come back. I will never forget that phone call. I knew right when the phone rang, and by the way my husband answered and ended the phone call. I knew.

I fell to the ground and broke down. I felt as if I would never overcome this feeling inside. I felt, "I can't do this! I can't! It's going to be too hard!"

Or was it? We had no idea what to expect. We barely knew anything about Down syndrome. All we could think of was the future. Would Renee be able to do the things our other daughter could do? Would she laugh? Would she ever ride a bike? Would she ever be accepted?

Now, about a year later, we know she will be able to do all of the things her big sister can do, and we will never make excuses for her or put limits on what she will be able to do. Renee has already surprised us in so many ways — more than what was imaginable in those early days that feel so distant now. Having Renee has most definitely changed our lives — she has truly enriched our lives and has taught us the true meaning of life. She has taught us to look at everybody as an individual, and that everyone in the world has a place, and a meaning to be here, and to not be judged.

I cannot say it will always be easy; there will be bumps in the road, but as in anything, there are rough times and we somehow get through them. I know all we have to do in those times is look at Renee, and it all makes sense.

— Nicole Besoyan

Courtney

"People are about as happy as they make up their minds to be."

— Abraham Lincoln

Courtney Ann Cambridge was born at home on December 19, 2002 in a water-birthing tub. She was our first child. When we had her, Aaron and I had been married for five years.

Courtney's birth was a wonderful and perfect experience. I had finished my finals in my classes at the community college on Tuesday; I finished my Christmas shopping on Wednesday; and that night, the contractions started. Courtney was born on Thursday. When Courtney came out, she had a handful of loving family members around her to welcome her into the world. Aaron, my mother, my sister, my mother-in-law (who was also one of my midwives) and her partner (my other midwife and a dear friend), and I were all circled around the tub as she emerged from the water. We were all especially excited about having a girl.

Right away I wanted to bring Courtney close to me. I thought she was the most beautiful thing I'd ever seen and was immediately in love. Several hours later we did her newborn exam. It was then that I mentioned her squinting eyes to my mother-in-law and asked why they looked like that. She explained that Courtney had come with an extra gift. That is how and when we found out she had Down syndrome. Both Aaron and I thought, "Okay, now what?"

For us, there was no disappointment or sadness with finding out Courtney had Down syndrome. We did experience the spinning questions of wanting to know what this would mean for our little girl, what it meant for us, what needed to be done differently—all the questions and thoughts that flood your mind when you find out your child has Down syndrome. Looking back, what I love

was that we were never scared or concerned. The midwives simply assured us that she was wonderful and healthy and needed to be loved and taken care of.

As we filled the next few days with unplanned doctor appointments and a consultation with a lactation specialist, we were emotional, but never upset or frustrated. My biggest concern was for Courtney's emotions: What would other children think? Was she going to be made fun of? My husband was concerned with Courtney's health, and with the discovery of some holes in her heart. Eventually, they all closed on their own, so she never had to have surgery.

When sharing our situation with family and close friends, we were met with an immediate response of love, excitement, concern for her health, and research on how to make Courtney's life as good as possible for her. Through the time, knowledge, help and love of friends and family, Courtney is enjoying life to the fullest.

My mother-in-law put it best when, after Courtney's arrival into our lives, she threw her a birthday party. She was only 5 days old and there was a cake and gifts and all of my husband's family was there. The cake had a train on it with candles. As my mother-in-law lit the candles, she explained that because Courtney had come to our family with such a special gift, we had all begun a journey on a train. The train ride would be a new one for all of us, and we would go where the train took us. It may take us on unexpected adventures, but we will all enjoy the ride.

— Marcy Cambridge

Mya

"We must be willing to get rid of the life we've planned, so as to have the life that is waiting for us."

— Joseph Campbell

My daughter Mya has taught me a lot about myself and my outlook on life. I have learned that life does not always go as expected, and you cannot always be prepared for the hurdles that are thrown your way; however, you can always make it over them.

I was 22 and my husband Aaron was 24 when we found out we were expecting a child. During my pregnancy we would talk about the dreams we had for our little Mya and how her life would be. Neither one of us had a clue that Mya would be our special little angel.

The day I went into labor, emotions were high. As labor progressed, concerns arose. Soon, the urgency to get Mya out was apparent. I had to have an emergency C-section because Mya was not handling the stress of labor. Because of delays with the anesthesiologist, I had to be put under completely. Sometimes I am sad because I did not hear that first cry, but I think in the long run, it was better for me.

When I awoke, Aaron was by my side. He told me that Mya would be okay, but she had Down syndrome. My first response was,"Okay, let me see my baby."I couldn't wait anymore to see my precious baby. My first view of Mya was not what I expected. She had so many wires and a huge oxygen hood covering her little body. I looked past all that and saw the most precious baby.

I was in denial about Mya's diagnosis, but it started to hit me when the doctors told me of her other

conditions. Mya had a TEF, which meant her throat was not attached to her tummy. This was something that needed to be fixed right away. She also had a heart defect, which could wait for repair until she was six months old.

My emotions finally caught up with me when they wheeled Mya to the operating room. I cried for at least an hour because I finally realized that the dreams I had for Mya would never come true – I would have to come up with new ones. There were times when I felt guilty, as if I had done something wrong. I thought, "Why is this happening to me? Why did I have to be chosen to go through this?" And then it hit me, I was chosen because I am the right one for the job. Some people find faith in religion, but I found faith in myself. I realized that it didn't matter that my daughter had Down syndrome; I was going to love her with all my heart. I decided to focus on Mya, rather than myself, because she needed a strong mommy.

Mya came out of her surgery just fine, but we were unable to hold her for five days. When we finally got to hold her, it was hard to put her down. We were anxious to take Mya home, but it was five long weeks before she was eating adequately. Having her home was amazing and we actually felt like a normal family. The only difference was that Mya had to take medicine regularly for her heart condition.

The months went on and we thought we were in the clear until Mya's heart surgery, but we were wrong. When Mya was four months old, she got sepsis from an infection unrelated to her Down syndrome. She was in the hospital for three weeks and suffered permanent brain damage. We now had to deal with the fact that Mya was going to be more developmentally disabled. This has not been easy, but I remind myself every day that I am very lucky to have such a beautiful little girl.

Three weeks after her discharge, Mya had heart surgery. Aaron and I were terrified to send our little girl into that operating room. After four long hours, Mya was out of surgery and doing well. She went home five days later. I was so proud of her for being such a trooper.

Soon we started Mya's therapies and contacted our local support group. Talking with people that were going through the same things was one of the best things we ever did. I wish I had done this sooner.

I have learned that if I am strong, I can make it over any hurdles that are thrown my way. If I find myself getting down, I just pick up my special little one and hug her tightly to make all of my problems disappear.

— Krisine Riley

It was Monday, December 16th, 2002 — exactly 23 years and 10 days since I was the one in labor and welcomed my beautiful daughter into this world. Now the tables were turned as I watched Krissy beginning the journey of motherhood. Krissy had quite a cheering section with her that day in me, her stepfather, mother-in-law, father, stepmother, and of course, Aaron, Mya's daddy. We anxiously awaited the birth of our first grandchild, a little girl named Mya Noel.

Things would not be so simple though, as Mya came to us by emergency C-section. I was fortunate enough to be with Aaron as they whisked Mya by us to the nursery. She was pink, naked, and had a head full of bushy black hair. But the thing that struck me most was what I called her little piggy nose. Oh, she was beautiful. That moment is forever etched in my mind. My daughter had given birth to a beautiful little angel.

About 20 minutes later, our world would change forever, with the uttering of two words: "Down syndrome." All of us grandparents were together as we shared our shock and grief. It was an intense grief that shook me to the core. Then, realizing the selfishness of that moment and that my daughter needed me, Aaron needed us, and most of all Mya needed us, we quickly gathered ourselves together. We formed a "grandparent brigade" as we dried our tears and marched to the nursery. It was late at night now, and we were basically the only ones there. The halls were empty, with the exception of this now determined group.

The next thing we saw melted my heart and made us realize that everything was going to be okay. As we all peered into the nursery window, there she was — our little angel with her very proud Daddy, who had so much love in his eyes and the biggest smile on his face. That was the deciding moment for me. My tears were quickly replaced by an incredible sense of peace and love. And thus, we began this journey.

We have met so many wonderful people, and I cannot imagine my life without them. We are involved in Down syndrome activities as often as possible. I am proud to be an advocate for Mya and other people with Down syndrome. I feel so honored to be one of the ones who "get it" — one who understands, one who is now accepting. We are now members of this special club.

Over the past two years, Mya has taught us more about life than anyone ever has. She has welcomed us into her world of acceptance and unconditional love, of intense emotional bonds that are forever forged by her existence. The incredible love that flows from this child is at times overwhelming. Sometimes when I look into her eyes, I feel so small. How could one so tiny, be so powerful?

I now celebrate every day, and I am ever so grateful to be part of my little "grand angel's" life. I have learned not to take anything for granted. I am honored even more to be the mother of an incredible young woman, Mya's mommy, Kristine. My enormous sense of pride for Krissy is rival only to my immense love for Mya.

Finally, I would like to share with you the words of Mya's Grandpa Manny, my husband, "Mya is the golden thread that has sewn our hearts together." Congratulations on the birth of your own little "golden thread. "You have an incredible journey ahead of you.

— Sally Dominguez

Blake

"Change your thoughts and you change your world."

— Henry David Thoreau

Blake is one of three boys in our family. With two older brothers, he is the youngest by just a few minutes. Yes, he is a twin. When the twins were born, we experienced double the fun and double the work, as all parents with multiples do. The pregnancy was short. Slow growth in one of the twins concerned doctors, so they came at 32 weeks. Although examinations are available that could have detected or alerted us of Blake's disability early, we declined them. Early birth brought concerns for lung development, nursing issues, jaundice and low birth weight, which seemed to be the focus of hospital staff.

As we tended to the needs of the boys in the Neonatal Intensive Care Unit (NICU) our discussions anxiously centered on how we were going fit into our future all the sporting events, cultural arts, church, school, dances, dating, cars and motorcycles. For two weeks, we spoke of what we imagined would be our future with three healthy boys. The hospital staff had not yet made us aware of the condition of one of the twins, as they were not sure themselves. When Blake was born, we knew he was not an identical twin, so the fact that he didn't look like his brother was not out of the ordinary. Because he only weighed three pounds, four ounces, the typical physical characteristics associated with Down syndrome were not easily recognized.

We went to the hospital for every feeding we could. One morning, we walked into the NICU and the nurse told us that some of the staff wished to meet with us. We optimistically went to the meeting, anticipating that it was a prep-talk for the release of our twins. Both showed good growth and aggressive eating habits. We entered the conference room. The two staff members already there told us what we truly least expected. One of them asked us if we had recognized the additional needs of Blake — his low muscle tone, slight thrusting of his tongue, and his more labored eating habits in comparison to his twin. She said that it was due to Down syndrome. Time seemed to stop for just a brief moment. I am not sure I actually heard the next few things the people around me were saying. My mind wanted to wander but did not know where.

At some time they explained that the"typical signs" of an infant with Down syndrome were not strongly pronounced. Yet it was no mistake. The blood work had been done and the additional chromosome was present. I knew it wasn't a joke, and I guess I trusted that the doctors couldn't make a mistake on something like this. The next few minutes I spent in that room were as the part of a "husband. "I gathered my emotions and did my best not to let them surface. I tried to listen to what the doctor had to say and observed how my wife was dealing with the news. Somehow, we both made it through that meeting.

The best way to describe my feelings at that meeting is that an emotional dam was placed in my path. It was as if everything we had anticipated, planned or hoped for had just been abruptly stopped. We gathered ourselves and made our way to the NICU. I remember even discussing just heading home, as we knew we had missed the morning feeding. I guess it was at that moment the emotional dam began to weaken. I realized that, regardless of a condition that society has labeled, Blake would live a rich and full life. He was still that special baby boy I saw in that first ultrasound. I remember looking at him that morning as he lay in the crib, co-bedded with his brother, and thinking that I needed him just as much as he needed me.

— Bill Duffield

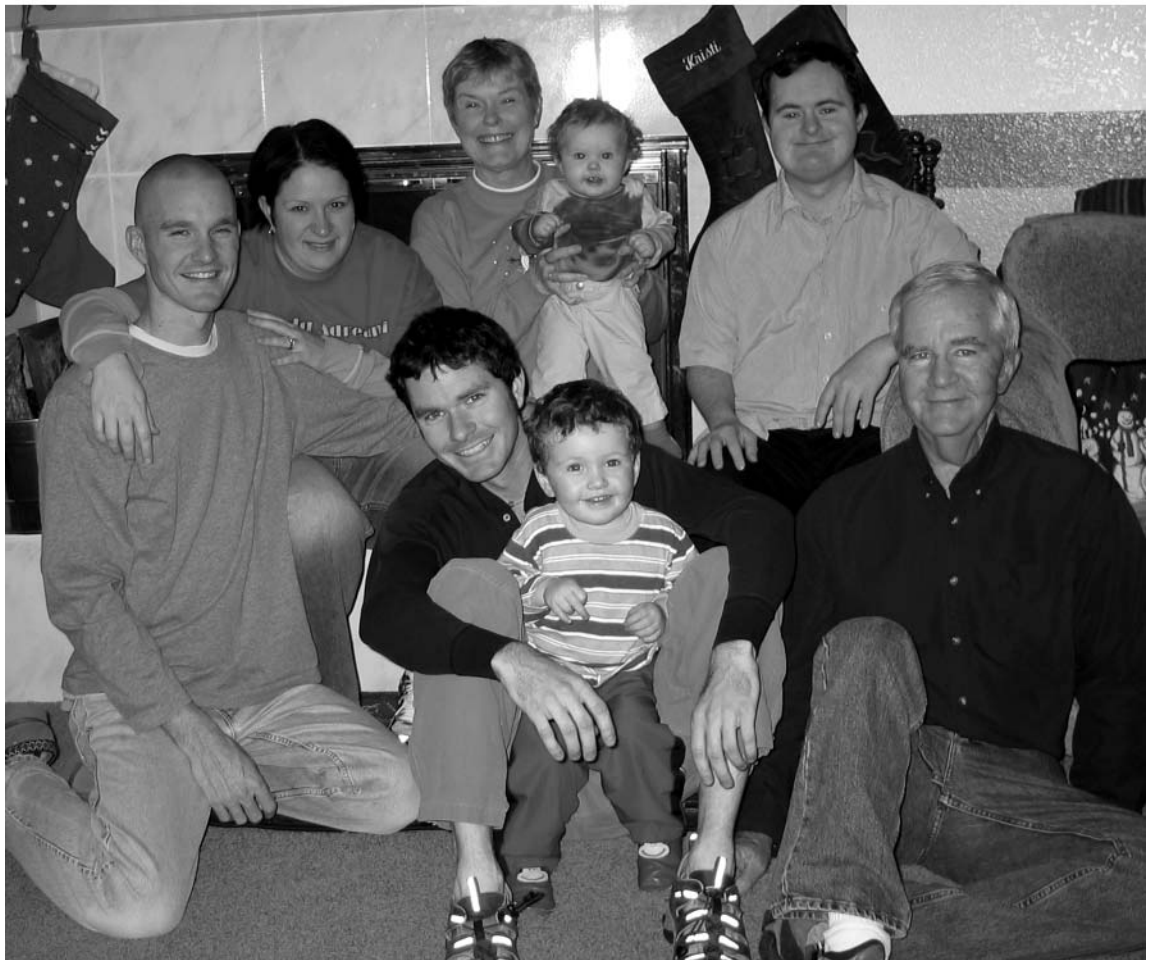
John

"Never doubt that a small group of thoughtful citizens can change the world.

Indeed, it is the only thing that ever has."

— Margaret Mead

DISNEYLAND



My husband Mike was 27, I was 26, and we were finally going to be first-time parents. By way of a C-section, we had our beautiful baby boy, who we named John, after his grandpa. The next day, we were told something might be wrong with John. A month later, the genetic testing report came back positive for Down syndrome. It was 1973, Mike was a park ranger at Lake Isabella, and information on raising a child with disabilities was not available in the mountains. In an effort to remedy my depression, the so called experts in nearby Bakersfield presented us with papers to institutionalize John at Porterville State Hospital. Instead, through my husband's calm and loving support, we moved back to Sacramento to be with our family and friends and raise a happy, healthy, beautiful son.

It was with family and friends that we knew we would receive loving acceptance for everything, but we received even more. From thoughtful and helpful resources in the community, we learned about Down syndrome and what it involved. We learned from each other and joined together to plan for our children's futures. Our children with disabilities and their siblings played together and grew up with a strong bond.

When John turned three and it was time for him to start preschool, there were none available. So, a group of strong-minded parents, with the help and support of Alta California Regional Center, started a class for our children with disabilities. Our class had its own specially trained teacher to support our kids with extra gross and fine motor activities, but it was otherwise fully integrated with the rest of the preschool for most activities.

All too soon, it was time for elementary school. Contemporary practices placed children with disabilities in schools consisting entirely of special education students, or in self-contained classes on regular campuses where John would be separated from the "normal" students, so he could "learn at his own pace," so we were told. Since we knew how important socialization had been in John's growth, behavior, and acceptance into the community we chose a different journey. At 5, we placed John in a Special Day Class (SDC) at our home school, Oakview Elementary, where he was mainstreamed into kindergarten for reading and social time. The school psychologist was against mainstreaming since, at that time, instructional assistants were not hired to add support to integrate students with special needs. Thus, our pursuit of "Please, try it for a few weeks before making a final judgment" began. A couple of weeks later, the psychologist admitted that if she hadn't known there was a child with special needs in the class, she would not have noticed. What a compliment!

John became the first fully mainstreamed student in the San Juan School Unified District by attending full-time kindergarten in the mornings and his SDC class in the afternoons. For first and second grades, John

attended a regular class all morning and his SDC class in the afternoon. After that, he continued his SDC placement, and also went into an age-appropriate classroom for art, music and P.E. We had become mainstreaming pioneers. In 1991, John walked across the stage with his graduating class at Mira Loma High School. Could a family be more proud?

The huge benefits John gained from the main-streaming were matched only by the benefits his classmates received. They accepted him not just as another kid, but as another friend, inviting him to birthday parties and play dates. He was a member of our neighborhood Cub Scout den and played on a regular baseball team.

Being a part of John's life has enriched our family members' lives beyond comprehension. Both of John's brothers have coached Special Olympic teams since they were teens. His brother Matt and his wife Kristi are special education teachers in the Elk Grove Unified School District. My husband Mike has coached Special Olympic teams for over 20 years and still can't get enough of it. I am retired from Orange Grove School for Adults with Disabilities and get my "fix" by chaperoning out-of-town sports trips and by being involved with the Sacramento Association for the Retarded (SAR).

And John? For the past ten years he has found there really is a good and full life after the "yellow school bus stops." He has worked for eight years at the Orangevale Community Center with a work group consisting of four friends and a job coach. He also square dances weekly, golfs on a team at Haggin Oaks Golf Course, and is on the Orange Grove Special Olympics team where he bowls, plays floor hockey, basketball and bocce ball. And his most important joy of all? Being Uncle John to Abe and Ella. Truly, life is good!

— Ginny Petrinovich

Sarah

"The journey of a thousand miles must begin with a single step."

— Lao Tzu

My wife and I moved our family of six children from Little Rock to St. Louis just before our daughter Sarah started school. Sarah has Down syndrome. She also has a condition identified as "selective mutism" or "social phobia," which means she is usually terrified of new situations. Some of the physical characteristics of Down syndrome cause her to have a problem communicating with others. These two things combined often make things difficult for Sarah. We have learned to set "short-term" targets, a lesson that carries over to all areas of our life.

On the first day of school, I walked with Sarah to the bus stop. As we approached the other children, she gripped my hand with a "death grip." We had pre-arranged for her to get on the bus with the help of three girls from our neighborhood with whom she had become friends. The friends had taken a liking to Sarah, and wanted to help.

When the bus came, she wouldn't get on, and wouldn't let go of my hand. So I walked onto the bus, essentially dragging her on. I knew from experience that we already had a major victory. She was on the bus, and wasn't screaming! (Victory #1)

I assumed that she would get off the bus when it got to the school. About 15 minutes later, the phone call came. She didn't get off the bus, and I knew she wasn't getting off that bus for anyone except me!

I headed to the school, walked onto the bus, smiled, extended my hand out to her, and she popped right up and walked off of the bus with me. Her teacher was there, and I attempted to make a "hand-off." No dice. I had to walk her all the way to her desk. She was very scared.

That afternoon, Sarah walked from her classroom to the bus with her teacher and got on the bus with the teacher's help. She arrived home at the bus stop, and

got off, holding the hand of one of her three friends. She seemed happy about her first day. (Victory#2)

The next morning, I walked with Sarah to the bus stop. This time, she got on without my help, holding on to one of her friends. She proudly waved to me as they drove away. (Victory#3)

I followed in my car and watched from a distance. At school, the three girls tried, unsuccessfully, to coax her off the bus, so I went and helped her off. But this time she let go of my hand, grabbed the teacher's hand, and walked inside without me. (Victory #4)

The following day, we maintained status quo. No progress, but we didn't lose any ground! (Victory #5)

The next day, I was sitting behind the bus, and it looked like I was going to have to help her again, but something "clicked" inside her, like it usually does. She grabbed her friend's hand, got off of the bus, and walked in with her teacher. (Victory #6)

The following day, once again, she got off just fine, and transferred from her friend's hand to her teacher and walked in. (Victory #7)

The next day I stayed in my car, but I worried because the teacher wasn't there. I watched in amazement as she walked off the bus and into the school with the help of all three of her friends. She saw me sitting in the car, and waved as she walked by! (Target Achieved) I called my wife on the phone and we had a celebratory cry as I drove away from the school.

When life throws a curve…Set a Target…Take Baby Steps…Enjoy the journey! Don't let the little victories go by without stopping to celebrate! Look around in the world and be a friend to someone else who needs help. Those three girls got a lot of satisfaction from the help they gave to Sarah.

— Alan Hardwick

A long time ago, before I was born, my sister Sarah was born. Sarah was not any ordinary kid. She was born with an extra chromosome. My sister has Down syndrome. I did not know what it was exactly, until a couple of years ago when I had to choose a topic for a school report. I chose Down syndrome because I wanted to learn more about my sister. Lots of kids in my class chose the same topic I did, including some of my friends who knew my sister. They said they chose the topic because they knew Sarah. That makes me feel glad that my friends wanted to learn about Down syndrome.

Sarah is a very bright, funny girl who loves doing stuff kids without Down syndrome like to do. She loves horseback riding, Saddle Club, movies, ice-skating and many more fun things. Sarah is the second child out of six kids. She was home-schooled until the 4th grade. At age 18, she learns very well. She even won a special award at her high school for making a difference in her class.

My life is sometimes difficult with Sarah but no matter what, I still love her. Knowing my sister makes me think differently about people with disabilities: No matter what they look like on the outside, it is what is inside that counts. Sometimes I wish she had been born without Down syndrome, and sometimes I say it does not matter if she has Down syndrome – she is still my sister.

I like to do stuff with kids with Down syndrome. Someday, I will probably become a special education teacher and adopt kids with DS. This year, I did the Buddy Walk, which raises money for Down syndrome awareness. I think the Buddy walk is something everyone should do. I am so proud of my sister because she can make a difference in the world.

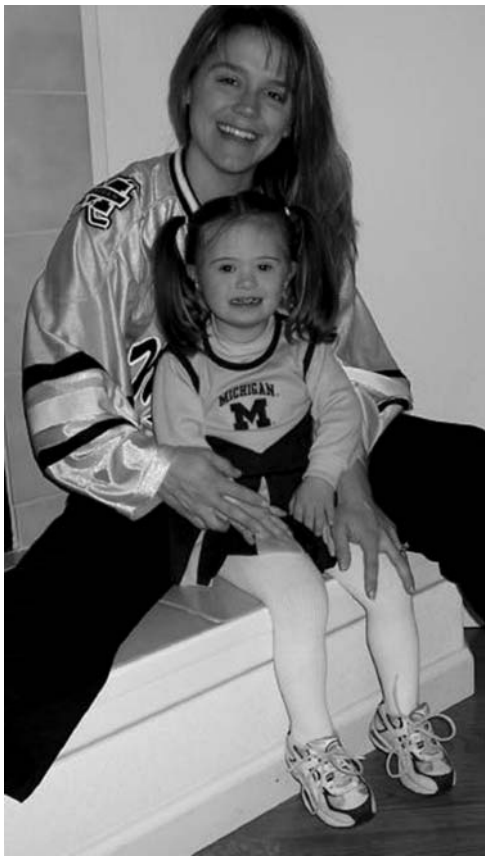
— Leah Hardwick

Abigail

"The thing always happens that you really believe in; and the belief in a thing makes it happen."

— Frank Lloyd Wright

Abigail's life began when I was 31 years old. I had been married to Joe for 5 years, and we had been trying to get pregnant for over a year. My pregnancy was unremarkable. All the tests came back normal (even the AFP). No worries or concerns entered our minds. We were expecting a happy, healthy and normal baby.



Abi was born at Folsom Mercy Hospital on April 6, 2001. My labor was long and full of complications. All I heard was, "It's a girl!" I was overjoyed!

After the delivery, Joe and I hugged, and I immediately turned and asked, "What are her Apgars?" I was met with silence. They took Abi from the room quickly and Joe was sent to watch over her. Our doula was with me when our doctor came back in looking serious. He said they suspected Down syndrome and possible serious medical complications. I just stared at him thinking, "Is he kidding? This has got to be wrong!" I don't remember responding to the doctor, but the minute he walked out, I disintegrated physically and emotionally. I am a speech therapist who has worked with children with varying diagnoses, including Down syndrome and Autism, so I had an idea of what was in store. My dreams and hopes for a happy and healthy family were crushed. I wanted to see Abi. I wanted to hold Joe. Was I going to be a good mother to a child who has disabilities?

Shortly after, Joe came to get me with a wheelchair. We embraced and cried. Folsom does not have a Neonatal Intensive Care Unit (NICU) so they had arranged for our daughter to be "life-flighted" to the UC Davis Medical Center in Sacramento immediately. They only let me hold her hand. She looked terrible. She had a tent over her head and a bluish tint, and was struggling for every breath.

The nurses brought Abi in to see us before they left. I erupted into tears. Approximately 1 hour after her birth, she was taken away from us. I never had a chance to hold her. After they took her away, I demanded to be immediately discharged and the doctor complied. We arrived home without our baby roughly 3 hours after she was born. I kept thinking that she must be scared without us.

Joe and I didn't sleep very much that night. We wanted to see our baby. At this point, she did not have a name because we wanted to hold her and meet her

before we named her.

We were at the hospital early to talk to the doctors and review all the tests that had been done. Entering the NICU I had an overwhelming urge to get her out of this place NOW. I wanted to pick her up, put her on my bare chest and tell her everything was going to be fine and she was coming home. The nurses were friendly and gave her to me to hold for the first time. I embraced her with all my heart, and rocked her and hummed to her.

The doctor told us there was a major problem with Abi's heart. He reviewed all the procedures and the completed tests. The cardiologist explained the problems with Abi's heart and drew pictures to help us understand. Our baby essentially had two chambers in her heart instead of four (AVSD), and there was also a problem with her pulmonary valve. This was later diagnosed as Tetralogy of Fallot. Heart defects are not uncommon among people with Down syndrome but having two was highly uncommon. The doctor described all the medical warning signs then dropped the bomb: Our infant would need to have open-heart surgery within 6 months, perhaps earlier. The thought of this was gut-wrenching!

Abigail Grace came home from the hospital ten days after she was born. She had to see the cardiologist every week and be weighed almost every day by the pediatrician. Soon Abi began therapy with an in-home infant stimulation therapist.

Abi thrived at first but when she began to show signs of heart failure at three months we were forced to prepare for surgery. I began to have nightmares about the surgery.

I finally made a deal with God: If He intended to take our daughter back to Heaven with Him, He could have her while she was in the hospital. If she made it home, she was ours to raise and love.

Much to our joy, Abigail returned home exactly one week after the surgery was completed with no complications, no illness or infections. She was still swollen and required many medications and appointments but she was home! Abi resumed therapy and began reaching developmental milestones within "normal" ranges. She sat up at 7 months — just in time for Christmas — walked at 16 months and signed her first word at 12 months (book). She began physical therapy around 6 months and attended playgroups until she was 3.

Abigail continues to amaze us, and the professionals, with her energy, joy and skills. Her cardiologist says she will need another open-heart surgery before she turns 5. We wait and watch her progress. I try not to think of her going through another surgery. I want very much to help her reach her potential and love her each and every precious moment. She is our miracle!

— Luann Kuzniar

Gabriella

Just when you think you have learned what you need to know in life,

someone truly special comes into it and shows you just how much more there is.

In October of 2001, we were newly married and busy building our lives together. I was an executive manager for Target stores and Jorge had just been hired as a commercial airline pilot with Continental Airlines. We were also expecting our first baby. Our life was picture-perfect.

On October 29, 2001, I went into labor and 39 hours later I gave birth to our daughter, Gabriella. In our hospital room, there were no cries of "It's a girl!" — only questions like "Did you have an Alpha Fetal Protein Test?" as they whisked her away. The doctor told Jorge that our daughter had Down syndrome and later, they both informed me. We cried and screamed and just wanted to hold her.

The nurse wanted to take Gabby to the nursery for a bottle, and I explained that I wanted to breastfeed. The nurse said, "Honey, babies with Down syndrome do not breastfeed." Our daughter wasn't even 2 hours old, and already we were being told of things she would never do. Over the next 5 days in the hospital as Gabby underwent screenings for heart defects, kidney abnormalities and therapy for jaundice, we worked at breastfeeding.

Once home, we struggled with many things. We made the decision that I would not return to work. We struggled with how to tell our friends and family. We spent a lot of time crying, afraid for Gabby's future, wondering how hard everything would be for her. Our family's only reaction was "We still love her."

We were numb. Of course we loved her, that wasn't the issue at all. We were worried about her. What about everything we talked about when we talked about the future of our children? Nothing was the same anymore.

Gabby had a hard time nursing at first. I pumped breast milk for her for three months; at that point, she was able to nurse like a champ. Other than that, things seemed to be "normal." We enjoyed all the things you do when you have a new baby — the smiles, the coos, playing with toys. We quickly settled into our new routine, although our new routine involved new people and therapists. I remember feeling very, very fortunate to have all these great people in our lives. As Gabby got older, we got busier with more appointments, but Gabby seemed to love her therapists and that made it all much easier.

Once in a great while, all those feelings rush over us — the fear, the disappointment, the feeling of "This can't be happening to us." It's odd how those

feelings come and go, and come again. One of the most frequent questions we get asked by other parents of children with Down syndrome is, "When will these feelings go away?" We try so hard to explain that they really don't go away. But they surely don't surface as often after a while. They are often replaced by this awesome, all-empowering love that we have for this child who was meant for us. Daily we are in awe of her — of how quickly and diligently she works to learn something new and her sense of pride for an accomplishment.

In December of 2003, Gabby's little sister was born. Never once were we worried about having another baby with Down syndrome. To be honest, we were scared of having a "normal" baby who cried all the time and didn't sleep through the night. One of our favorite memories is the day after we had Lucy, and Jorge brought Gabby to visit. I had never spent the night away from Gabby and my arms ached for her. She crawled into bed with me and Lucy, and she just held her baby sister. Gabby looked like she couldn't be happier.

Gabby started preschool in August 2004. Words cannot express our feelings when we see the kids rush to the door to greet her. Or when we pick her up and the teachers tell us that the other kids were fighting over who got to sit by her. She has this magic about her. You can't help but smile when you see her. She is smart, funny, sneaky, and so very, very sweet. She takes such great care of her younger sister by going to get her books, or by holding her hand as we walk to school.

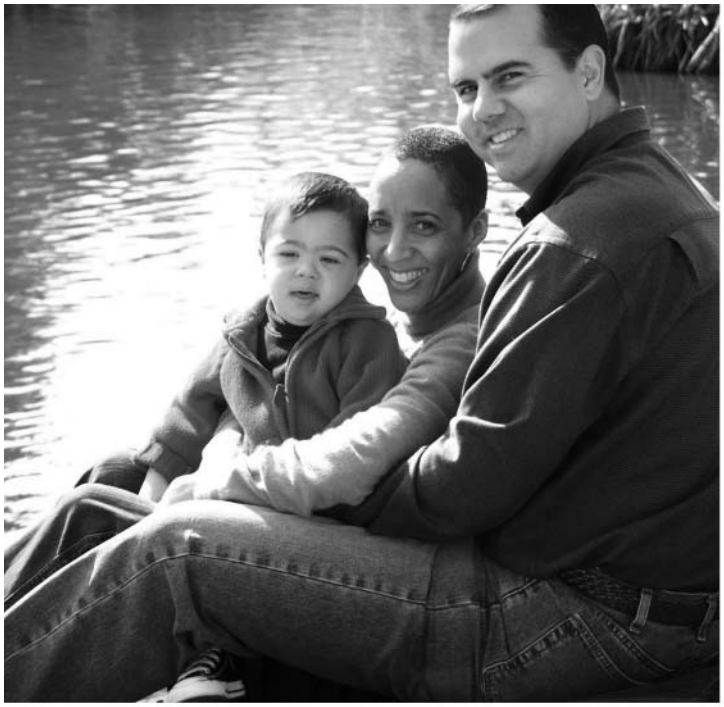
There is a quote we heard right after Gabby was born: "Just when you think you have learned what you need to know in life, someone truly special comes into it and shows you just how much more there is." It does a good job of summing up how we feel. God knew exactly what He was doing when He chose us to be Gabby's family. She has such a purpose for our lives. Gabby has, by far, taught us much more than we could ever teach her. In the last four years, we have learned many things, the most important of which is that we want our children to grow up to be happy and fulfilled people, and as their parents, we will do whatever we can to help them succeed.

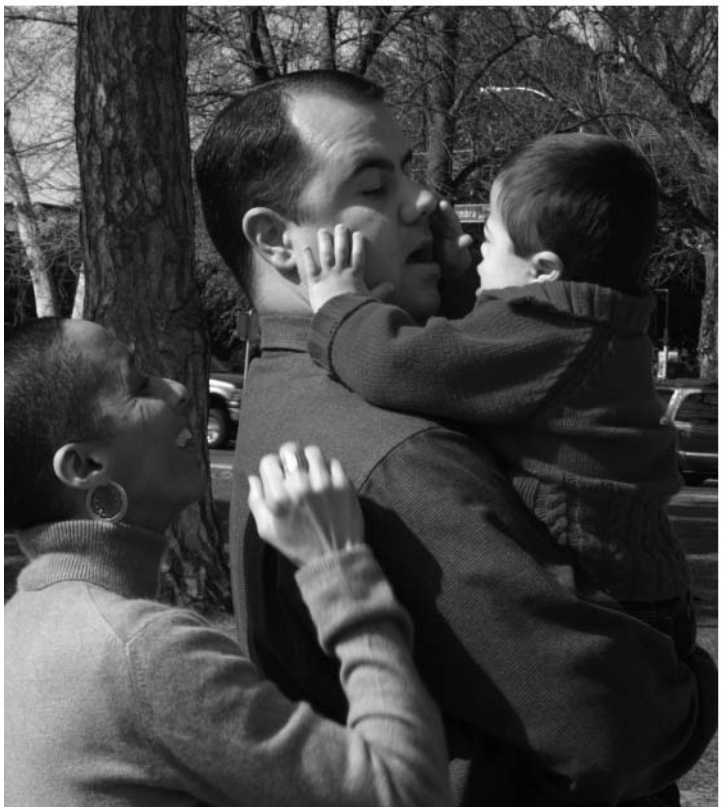
— Heather Prieto

Jackson

"Things turn out best for people who make the best of the way things turn out."

— John Wooden





It was early in my pregnancy when my doctor suggested I see a geneticist because of my advanced maternal age. I was turning 40 just one month before the baby was due. So we went to the geneticist where an ultrasound was performed. Jason and I were ecstatic at the first chance to see our child. We laughed and joked with the technician until the tone of the room changed. We saw a wave of seriousness come over her face. Then she left the room only to re-enter with the geneticist. They exchanged mumbles, and then the doctor informed us that he wanted to perform an amniocentesis but he didn't make the reason clear to us.

Once the procedure was finished we met with the doctor to discuss his concerns. There were cysts in the baby's neck area. He wasn't certain about the cause of the cysts, but he had a few ideas, and among them were possible chromosomal disorders. He gave us four scenarios: 1) Trisomy 13, severe mental retardation with a high likelihood of other medical complications and a minimal life expectancy; 2) Trisomy 18, several deformities and medical issues with most children dying either at birth or by age 1; 3) Trisomy 21, Down syndrome; or 4) None of the above.

Of course the fourth is what every parent hopes for. However, based on his reaction, we concentrated on the other three. I think the doctor was more devastated than we were. A few times during our consultation he recommended termination, which was the furthest thing from our minds, especially since we didn't have a definitive diagnosis. The results from the tests would take two weeks. Our minds were racing, yet it seemed as though time had stopped. We called our families and explained the situation. As we expected, there was nothing but support from them. We all prayed and waited a difficult two weeks for the results.

The doctor's office called on a Monday night. Jason was out of town and I was home alone. The genetic counselor's voice was very solemn. She gave me what she called "sad news." The baby had Down syndrome.

My heart was racing and I blurted, "That's great!"

She said, "I said your baby has Down syndrome. Do you understand?"

"Of course I do," I said. "That is what we were praying for, given the high death rates of the other syndromes, we'll take Trisomy 21."

It was obvious that she couldn't begin to share in my excitement. The doctor wanted to see us the next

day for more "consultation." All he did was encourage termination. When he saw that we would have no part of that, he handed us pamphlets of information that was printed when Pete Wilson was governor. We left the office never to return. My obstetrician wasn't any more inspirational, as he too mentioned termination several times. It was unbelievable to discover that 94% of pregnancies are terminated if there is any indication of a disability/malformation.

I decided to be proactive. I contacted the Warmline and attended the Down syndrome support group meetings. Friends and relatives began sharing stories, newspaper articles and research materials. With an outpouring of interest, love, and support, we knew that we were blessed. All of this before the baby was born. WOW!

The doctors were very concerned about the baby's heart so they performed a fetal echocardiogram in search of an atrial septal defect. They used something that looked like the Doppler radar on the weather channel. We could see the blood flow and the chambers of the heart. Everything looked fine and there was a big sigh of relief from all of us. The technology was amazing, and the results were reassuring.

The pregnancy progressed and everything was going wonderfully. On August 6th, 2002, our beautiful baby boy Jackson Jacob Ross was born. Minutes after his birth, Down syndrome was truly the least of our concerns. Jackson was born with Leukemia. They really didn't expect him to live through the night. He obviously had other plans. Jackson was taken to the Neonatal Intensive Care Unit at Sutter Memorial Hospital. When we arrived, a social worker handed us a book on Down syndrome and that was the extent of her services. As a result of our bad experience, we are now involved with a group of nurses at Sutter Memorial Hospital as family/patient advocates for the Special Care Nursery in hopes of preventing such an experience for other families.

Jackson remained in the Special Care Nursery for 3½ months while undergoing four rounds of chemotherapy. His doctors were caring, diligent and unbelievably dedicated. All of our prayers and the endless hard work of the doctors and nurses, not to mention Jackson's resiliency, paid off and in December we took him home for good. Jackson has accomplished things that continue to amaze his doctors, nurses, therapists and certainly us. Everyone who meets him loves him. He's been an inspiration to many people. Last year we had a wonderful experience participating in the Buddy Walk. Also, a friend of ours ran a marathon in honor of Jackson and we raised over $9,000 to help support the Leukemia and Lymphoma Society. Jackson has touched more lives in his 3½ years than one can imagine. We are incredibly blessed and thankful to have him in our lives. We have no regrets with the decision that we made and would certainly do it all over again. He is truly our hero.

— Alva Toca

Christian

"The more you praise and celebrate your life, the more there is in life to celebrate."

— Oprah Winfrey

With great anticipation, I was told I was expecting our second child. Since I was over 35, my obstetrician recommended I have an amniocentesis. I agreed because if something was wrong, we wanted time to prepare. I remember feeling different with this pregnancy and praying to God to give me strength to handle anything. Two weeks after the amnio, my husband took the call from the genetic counselor. His face lost all of its color as he announced, "The baby has Down syndrome." I fell to the floor sobbing. That evening we had dinner with my parents who comforted us and gave us hope and encouragement.

The following day, the counselor called back with the phone number for the Down syndrome support group. The director of the group was compassionate and supportive and provided us with information and resources. I started attending the meetings and found them invaluable. While I found strength in talking to other parents, my husband handled our baby's diagnosis very quietly and privately. We sought the guidance of a counselor to help us through the grieving process. After thinking long and hard about what we wanted for our children, it boiled down to two things: We wanted them to be happy and loved.

Two months after receiving our baby's diagnosis, my mother was diagnosed with pancreatic cancer. About the same time our doctor recommended a high-imagery ultrasound to examine the baby's heart. However, if any abnormalities were detected, there was nothing they could do in-utero. We declined the ultrasound and concentrated on comforting my sick mother and preparing for our baby's birth.

Christian was born on September 25, 1996. At first, the doctor informed us that Christian was healthy;

however, within hours, this situation dramatically changed. Christian was transported to a Neonatal Intensive Care Unit where doctors ran numerous tests. We were told that Christian had three holes in his heart and might require open-heart surgery.

My mother passed away four days after Christian's birth. I think she waited to hear that Christian was born and doing fine. This was a difficult time, but with the support of our family, friends and our faith, we were able to carry on. A friend sent me Bruce Carroll's tape, *Sometimes Miracles Hide*, which reminded us that God had truly touched our lives and given us Christian, our hidden miracle.

At first, I was a little nervous caring for Christian because of his heart condition. Fortunately, he continued to thrive and two of the holes in his heart closed. Visits started with the county's early intervention program and the regional center. We also attended massage therapy sessions and playgroups. Christian received music therapy to help his speech and motor development and, most importantly, he loved it.

Christian was diagnosed with hypothyroidism at 6 months. He began taking medication that he will most likely take for the rest of his life. At 9 months, Christian had heart surgery to repair the largest and only remaining hole in his heart. It was hard to have our little baby boy be taken from our arms into surgery.

At 3, Christian started preschool. His Special Day Classes provided a wonderful teacher/aide-to-child ratio and inclusion periods. He is going into third grade this year and he is reading, writing his letters and short sentences, spelling, and operating the computer. Our major challenges are Christian's speech and potty training. Christian's receptive language is excellent but his expressive language is delayed. However, he is able to convey all his needs and wants. Christian receives speech therapy at school and occupational therapy at a clinic.

Christian is like any other child. He just does things a little slower. He loves his sister, Rebecca, and brother, Daniel, but also exhibits typical sibling rivalry, like fighting over the remote control. He loves to read, swim, bowl, and play baseball and video games. Christian is a good problem-solver, and he has a wonderful sense of humor. He joined the Special Olympics this year and won a gold medal in bowling! He just started basketball and we look forward to a great season.

Christian has helped us realize how important it is to celebrate all achievements, regardless of how big or small. We have become more patient, compassionate and loving because of Christian, and we have grown stronger as we face the challenges of raising a child with Down syndrome. Although we don't know what the future holds, we will continue to provide Christian with every opportunity to grow to his full potential.

— Julie Wright

Toby

"Life is a field of unlimited possibilities."

— Deepak Chopra

Jake awaited the arrival of a new baby with great anticipation and trepidation. At 3, he knew that having a baby brother or sister would be a good thing, even though he didn't know what it meant. Jake's naiveté became a blessing when Toby was born with Down syndrome and a serious heart condition. He didn't know that all baby brothers weren't in the hospital for two weeks, or that all families didn't have to wash their hands constantly to avoid getting a cold. He thought it was normal that when a new baby arrived, nobody was allowed to visit or hold the baby because they might expose him to an infection. What Jake couldn't understand was why mommy was crying all the time.

What seemed to be a subconscious decision at the time turned out to be very deliberate later. We didn't sit Jake down and tell him his brother had Down syndrome. It didn't occur to us that we should. I didn't know it then, but looking back, I believe that was our first step in a very long journey towards acceptance. Subconsciously, we made the decision that we would not treat Toby differently from his brother.

Toby was what most would consider a "good" baby. He didn't cry much, he slept through the night and he was content to sit quietly and observe the world around him. Although we spent Toby's first months in a fog of anxiety, uncertainty, and fear, we decided that we would have the same expectations for both of our children. Just like Jake, Toby would be expected to try hard, have a positive attitude and strive for his personal best. As parents, our job would be to provide support, tools, structure and love.

We jumped in with both feet, taking early intervention to another level. Along with weekly home visits, we spent hours each day working with Toby through play to strengthen his

muscles, awaken his senses, and stimulate his mind. When he had sufficiently recovered from cardiac surgery at four months, he began clinic-based speech, occupational and physical therapy. Almost immediately, it became clear that Toby thrived with the challenges presented to him by his therapists. Soon Toby was sitting up, holding his own bottle, and babbling a little.

To some it may have appeared as though we were driving Toby too hard and not letting him "just be a baby." In reality, we were doing what every parent does: providing stimulating experiences in a loving environment for growth and development. Our approach was a bit more deliberate, but that is what Toby needed. As Toby develops we continue our commitment to teaching him the self-help, social, and other skills he will need to live in a society.

Jake still thinks his brother is pretty normal, although he wishes he could talk. Like most children, he complains that "it's not fair" when he is disciplined differently from his brother. But he knows that this "unfairness" is not because Toby has Down syndrome. It's just because they are two different boys.

We still have hard days – a lot of them. But what seemed insurmountable when Toby was born now seems possible because we have a shared vision. Toby has proven what most of us already know: people live up to the expectations placed on them. We expect a lot of our children – try hard, have a positive attitude and strive for your personal best – and we know that with our commitment, love and support, they will live up to these expectations.

— Elaine Linn

I have 2 wonderful grandsons. Jake was born on 9/10/99 and Toby was born on 8/15/02. Shortly after Toby was born, we were told that he had Down syndrome.

My daughter and I have always had a very close relationship. She told me before Jake was born that she couldn't imagine going through life without a child because she wanted to have a relationship with her children like she and I had.

With the news of Toby's diagnosis, along with all of the health issues that followed, I felt my daughter slipping farther and farther away from me. I searched for other grandparents who had grandchildren with Down syndrome. I read everything I could find. I needed to learn how to help my daughter.

In my pursuit for information and support, I told everyone I met that Toby had Down syndrome. Everyone I talked to had a nephew, a cousin, a sister, a friend, or a neighbor with Down syndrome. Everyone seemed to have a connection to someone with Down syndrome.

As I began to speak with people, I found that I could help my daughter by listening. I found that she didn't need me to give her advice – she needed me to listen. Sometimes she just needed to vent. Sometimes she simply needed me to be there.

I am still searching for other grandparents so we can help each other learn to help our children get through the task of being new parents of children with special needs. In the meantime, I continue to treasure both of my grandsons and know that they will both become fine young men who will do great things. After all….they are my boys!

— Barbara Comstock

Whispers of Hope is a compilation of stories from eleven families about their children and the joys, challenges and celebrations they have experienced. Each of these families is affected by Down syndrome.

"Become a possibilitarian. No matter how dark things seem to be or actually are, raise your sights and see possibilities – always see them, for they're always there."

— *Norman Vincent Peale*

Proceeds from the sale of this book will benefit the Down Syndrome Information Alliance, a 501c3 non-profit organization dedicated to improving knowledge for those affected by Down syndrome. The DSIA provides resources and support for those affected by Down syndrome while ensuring access to services, treatments and programs that enhance health, quality of life and productivity. For more information log onto www.downsyndromeinfo.org.

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