

A BOOK OF STORIES

brought to you by DSAF



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a forward....

Congratulations on your new or expected baby! Here are personal messages written for you by people who have been in your shoes. We hope, through these sincere and heartfelt stories, you can see the outlook of what life is like with a loved one with Down syndrome. What lies ahead, is a life full of love, hope, and happiness.

This collection was created for you by members of the **Down Syndrome Association for Families of Nebraska** (DSAF). We are an organization of parents and family members who have been brought together by our loved ones who have a little something extra.

by Henry's father



My wife and I had our first child, Henry, on St. Patrick's Day. Little H was beautiful. This was our boy, made of the same flesh and blood as you and me, yet the world tells me he is going to be "different".

Confusion and anger were two emotions that flooded my mind when we heard the diagnosis. We had no pre-screening and no ultrasound that gave any indication of anything "different", so naturally my wife and I were taken aback by the diagnosis.

Regardless of the challenges we were told Henry will face throughout his life, we still knew he was a gift delivered straight to us from the Lord's own two hands. So we took Henry home, loving him up every second we had.

The days turned into weeks and our boy started to smile. He smiles with every inch of his face. The type of smile that feels like you are looking God right in the eyes and he is telling you not to be afraid anymore.

Weeks turned into months and our prince grew and grew. Each passing day he became more and more curious of his surrounding world. As months turned into a year, we watched our boy learn to talk, walk, run, play catch, do sign language, do puzzles and of course, use an iPhone.

Three years have passed and now we watch Henry teach his little brother how to learn about his surroundings. Henry has brought joy to more people than I can count with his infectious laughter and hugs that make you feel like you're being wrapped in sunshine and happiness. Turns out Henry was never developmentally different. He is developmentally distinct. I wouldn't change him for the world. I would like to change the world for him.





The sunshine was warm and bright on a September day in 2015, when my husband and I were at his Peace Corp reunion. However, the day soon changed, when we received a voicemail from our son, saying he needed to speak with us right away.

We wondered about the urgency in his voice. Was something wrong with him, our daughter-in-law, or our three year old grandson? Such was not the case. Instead, he told us something might be wrong with the baby girl he and our daughter-in-law were expecting in five months. We felt overwhelmed when our son said she could have Down syndrome. The next day a final test confirmed the diagnosis.

I was extremely concerned about what a Down syndrome diagnosis would mean for our son's family. But from the beginning, my husband, our daughter, and a good friend were very positive and kept telling me, "It will be okay." I held that hope in my heart every day and began to really believe it when our son said something that pretty much changed my outlook. He told me, "She's ours and we will take her however she comes." From that point on, I became more positive about the wellbeing of the precious girl who would enter the family.

Our son and daughter-in-law tackled the situation by learning all they could. They knew they would receive strong support from some of the Down syndrome groups in Lincoln. I researched Down syndrome extensively, too. I had been an Early Intervention Coordinator for young special needs children and was glad to know what kind of services would be available to our granddaughter and her parents.

During the rest of the pregnancy, I thought about heart problems, low birth weight or a premature birth that may occur in Down syndrome babies. Thankfully, our daughter-in-law's check-ups were good throughout and in February our entire family welcomed delightful little Mia, who was born at full-term, at a good weight and with no heart problems.

Mia quickly had the hearts of all of us and has continued to do so. Now at almost a year old, she laughs and giggles a lot, goes from one end of the house to the other, teases her brother and demands her share of attention.

There are over a thousand miles between Mia's house and ours. Even so, I have been able to see her several times. This last time was at Christmas and I learned a lot from watching her with her mother, dad, brother, and extended family. I now know that for our family, Mia is perfect just the way she is.



by Mia's grandmother



by Grant's best friend



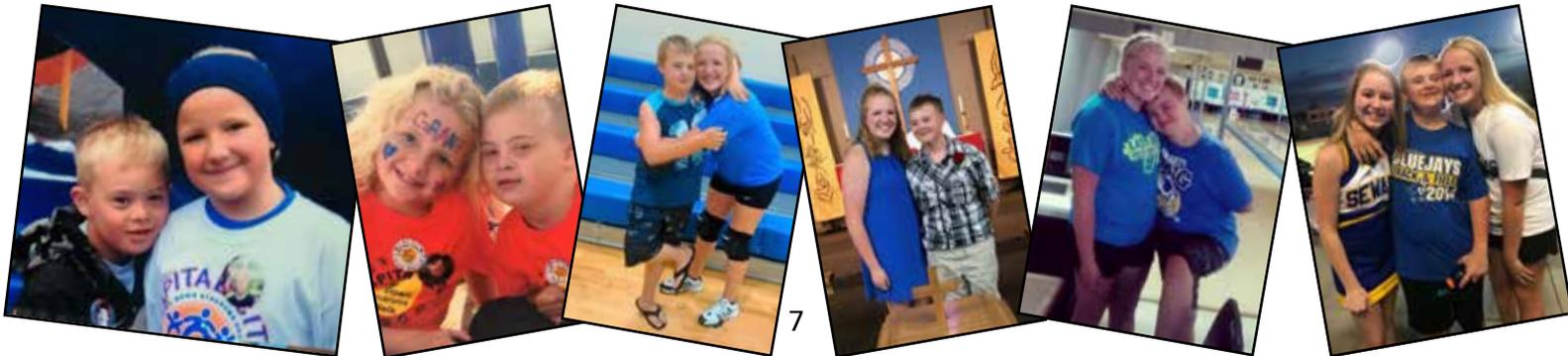
Best friends don't count chromosomes. They don't look at Down syndrome as a disability. A person is not Down syndrome, they are a person, just like you and me. They can do the same things everyone else can do, you just have to be a little more patient. When someone has Down syndrome, it doesn't change your friendship at all.

Grant and I have been best friends since we were about three years old. Since then, my life has been filled with nothing but happiness. One thing about having a friend with Down syndrome is that they will never leave your side. Grant sticks with me no matter what. He is a loyal person that I can always trust. The bond between him and me is not any different because he has Down syndrome. In fact, it is more special.

Grant and I do things together and have a regular friendship just like others do. We go to the movies, go bowling, go out to eat, go swimming and so much more. Grant and I always support what the other person likes or wants to do. He comes to my volleyball games and is the loudest cheerer out there and I go to his baseball games or other events. Grant and I even go to each other's houses. He sometimes rides the bus home with me and we will hang out. Grant is capable of doing most anything that he puts his mind to.

As far as communication between us two goes, we can have conversations just as I do with my other friends. Just recently, Grant and I have been starting to text and Facetime a lot. Before Grant had an iPad he could text on, he would sneak his mom's phone and text me. It started off with him just typing random letters. Now he sends me messages such as "Good morning, Beth" or "Hi, Beth." When I see him in the halls at school, we carry on a conversation. I think it is awesome that Grant and I can talk so much now.

Grant and I go out, text and always have a good time together. Down syndrome does not affect anything at all. Grant has so many wonderful abilities and such a great personality and those are the qualities I look for in a friend. Grant is my best friend and nothing can change that.



by Ruby's mother

Our Ruby just celebrated her sixth birthday. Six years of growth and milestones and love. When we found out Ruby had Down syndrome, we, like other parents in the same boat, were shocked. I had prenatal testing done because I was in my 40s. When the genetic markers showed a likelihood of Down syndrome, I then had an amniocentesis.

During the time between the blood test and the amniocentesis, I experienced a mixed bag of emotions. I went through denial, anger, bargaining with God, and even contemplated aborting the baby ... for about 1.2 seconds, anyway. I look back on it now and think, "Why? Why did I stress out about this so much?"

Also during this period of waiting, my family went bowling. There was a girl on the lane next to us who had Down syndrome. She



was probably about 10 years old. I found myself watching her as she had so much fun with her parents. As I watched, I kept saying a silent prayer, "Please God, no."

I never had eye contact with the girl but as she was leaving, she came over to me. She gave me a quick little hug and whispered, "It'll be okay." And off she ran. It was a very powerful moment. Definitely a turning point in my way of thinking. It would be okay. It has been okay. It is okay.

I haven't told anyone this story because I was ashamed of how I felt before this encounter. Don't be ashamed. Everyone doubts. Everyone wonders. Everyone is scared. But we have been blessed beyond reason with this little spunky, beautiful, awesome, life-changing little girl. And we wouldn't have it any other way.



by Andy's grandparents



The day we became grandparents, a little over seven years ago, brought us a joy that coursed through our being. Our first grandson, Simon, was a little ball of love and we enjoyed every moment with this new little person. And when we were told another little boy would join our family a few years later, we were just as thrilled and excited. We watched as all the preparations were made to welcome this little one and all signs seemed to be normal for his delivery.

When the call came that we were to head to the hospital for his delivery, we were up and out in a flash and sat in the waiting room anxiously waiting for the little nursery song to play, announcing that our darling little Andrew had entered our lives. We remember that it seemed to be taking a little longer than usual after we knew he had arrived and there was some worry. It wasn't until Kathryn's mother, who was sitting with us, and a registered nurse, was called to come back to the delivery room that we really felt something was not right. When we finally got to see our son, he told us that the doctors were thinking our little grandson might have Down syndrome.



We had never dealt with anything like this before and our minds went all different places. What were the health implications for Andy? What did this mean for our son, his wife, and our other grandson? What did this mean for us? What kind of tests do they run? What would Andy's future be like?

When we were first able to see our little one, we knew that the possibility of Down syndrome was accurate. I could see the concern and questions in our son's eyes. "One day at a time," we told him. "Don't plan the rest of Andy's or your lives at this moment. It will unfold, one day at a time." Yet, we too fought the voices of concern in our heads. Perspective was badly needed.

When we told a couple of our younger sons that Andy was born with Down syndrome, their response was simply, "Oh. Okay." You see, unlike our generation, they've grown up with children with special needs as an everyday part of their lives. Children today sit along side them in many of their classes at school. Our sons' honest, calm, and non-judgmental response was just what we needed to hear.

Every day with Andy is an adventure, a new and exciting adventure. We have learned that this little boy will achieve many of the same milestones all children do but in his time and his way. Andy won't be put in a box – his achievements will come when they are appropriate for him. Guidelines and benchmarks don't mean much to Andy and take on a whole new meaning to us. When he accomplishes something, his joy is equaled by the family's joy for him. We've learned that Andy has a wide variety of emotions. Andy can get angry and sad and frustrated. But mostly, Andy gets extremely, enthusiastically happy. And so do we. If you're having a ho-hum day, be ready to have that changed the minute Andy comes in the room, as his joy for life is contagious.

It's encouraging to see all the services (and kind people) that were and still are available to help Andy grow and develop. All of this has helped him become a successful little kindergartener. Andy loves baseball, soccer, Husker football and all things sports, especially riding his Strider Bike. Not to mention he likes to help cook. A chef in the making. We are so encouraged for his future and to see just what Andy will continue to achieve. He loves to learn and watch videos of kids at waterparks sliding down giant slides on the "hi"pad.

Our hearts are twice as big because of the love this little guy gives us. We couldn't imagine it any other way! Who could have known? And now we do. And we are better because of it.



I still remember the day that I got the call from my OB that told me Emma was diagnosed with Down syndrome. My palms and feet were freezing for almost five minutes because of the shock. My husband and I were in our early thirties, and we were expecting our first child with such an excitement in our heart. As aliens here, we don't have our extended family nearby. So this was like a bomb dropped in our life.

Very soon, Emma came into our life. She was so fragile but tough and had a strong will. We were not able to bring her home until she was 80 days old. The amazing doctors did the surgery on her heart and she came home without needing supplemental oxygen.

The journey continued from there. Because Emma is our first kid, we have all these expectations and anxieties about her development. There were days that my husband and I fought really badly about her vomiting episodes and her unreasonable fevers. There are moments that I would have to run out of the house and be in the chilly air to calm me down.

I screamed inside my heart numerous times when Emma was in the neonatal intensive care unit (NICU) but this was different. This was about a mom who has an exception to her kid, her first kid. We had to go through a process of acceptance. I knew Emma had Down syndrome but I couldn't really settle down and accept this very fact. I couldn't stop comparing her with other kids around us who were at her age. Until one day, she started to recognize me as her mom and wanted only me to hold her. Not her dad, not



her grandma, but her mama. I held her in my arms tightly and cried and whispered to her “Mama loves you, Emma and I am sorry, Emma.”

At that moment, I realized that she is just my daughter. Not more, not less but just my daughter. The very important point is she loves me so much that she doesn't even need to use words to tell me. After that, I forgot to record when she learned to crawl or walk, because those things were not important to me anymore. The thing about Emma was she couldn't comprehend the world in a sophisticated way, and this made her very pure and simple. She runs to you for a sense of security when strangers are in the house. She comes to ask for a hug when you get home from work and she gets really mad if you don't do that. She needs your eye contact for proof of your love if you walk past her, otherwise you will get a tantrum from her. What else can I ask for? She is full of love and she loves me with all her heart. Maybe not piano classes or math class but she loves watching her little video programs and dances like nobody else is there.

She is Emma and I am so proud of being her mom. Because of her developmental delays, I was able to slow down my pace as well and started to enjoy every day with her. I treasure every minute with her because I don't want to miss anything. Her pure need of me as her mother made me so happy and made me realize how much love a person can actually give instead take. She made me a better person!



by Dottie's grandmother



It is nearly impossible to put into words the gamut of emotions I felt, as both a grandparent and mother, when my daughter, Holly, and her husband, Larry, delivered the news after their 20 week ultrasound. The excitement I felt, when they revealed their unborn child was a girl, turned to concern, when I heard there would be further testing because of some anomalies that were seen. After ultrasounds, Fetal MRI, genetic testing and talking with a Maternal Fetal Medicine Specialist, we had the diagnosis their little girl was going to be born with Down syndrome.

I work in a hospital as a labor and delivery nurse. I know firsthand that things go wrong in pregnancy. I have sat for hours with grieving parents and family members over a premature birth, fetal loss, or admission into the neonatal intensive care unit (NICU).

This was different. This was my life, my daughter, my granddaughter and nothing could prepare me for the moment that changed all of our lives.

The news arrived at Christmas time and as part of the holiday decorations the hospital had displayed a picture of a newborn baby in a pink hat with the word “Joy” written in large letters over the top. I remember hardly being able to look at the picture. I was filled with hurt, anger and other raw emotions. The picture taunted me with what was not happening in our life. Why were other people given “Joy” while my family was given heartache?

My focus was to help Holly and Larry as they struggled through a difficult crisis. Further testing brought more devastating news. The baby had a severe heart condition, more complex than typically seen. She would need open heart surgery soon after birth.

After that day, all my efforts went into praying and worrying about my daughter and son-in-law. While they were anxious, grieving, and stressing over their baby, I was lamenting that something had been stolen from them: the happiness, the excitement, and the thrill that most couples experience



with their first pregnancy.

In the last trimester, Holly and Larry met with an amazing pediatric heart surgeon at Children’s Hospital in Omaha. Through all this, I expected to see this young couple collapse under all the devastating news. Instead, I glimpsed a side of this little family I had not pondered. Their sense of calm was inspiring. They devised a plan of what to do with their jobs and arranged for friends to watch their house and dog, during the time they would be away for their daughter’s surgery.

Together we waited until the day of birth, armed with a load of information, worry, and love for this baby. Holly and Larry were the ones that led everyone in the belief “We can do this.” I was fortified by their strength, yet suffered silently for their loss of “normalcy.”

Our beautiful granddaughter, Dottie, was born on St. Patrick’s Day. The first time I laid eyes on her she was lying in the NICU’s isolette, wearing only a pink hat, sunning her flawless beautiful body under the warming lights. I was taken aback how this beautiful sight looked like all other parents who have just had a baby. A little baby with her mommy and daddy, looking at her with unwavering love. During the previous months of stressed filled worry, what I had grieved most over, was Holly and Larry would not be able to have what most parents experience. In this brief moment, it might have been argued, they had more. They were armed with the knowledge that all of us, and Dottie, were in this together.

The first year, was an emotional roller coaster. There were several months of hospitalization after open heart surgery. The first twelve months were a busy mix of first smiles, feeding tubes, therapy sessions and learning to crawl and play. Dottie showed all of us her loving, happy, resilient little self. I marveled at Holly and Larry's medical vocabulary and abilities. They juggled difficult feedings, diaper changes, and kept family and friends up to date on Dottie's progress with a Facebook page they created in honor of their sweet little girl.

They became experts on Dottie. Like most parents, they knew their daughter best. They quickly learned to negotiate the foreign terrain of specialists, parenthood and advocacy. They watched Dottie with awe as she responded to each challenge with strength. I understood how they felt, having been filled with awe watching them work together as a team.

Today, just a few months from her third birthday, I see Dottie standing in her pink cowboy boots, holding a play phone, jabbering a million words an hour. Dottie can feed herself and Holly reports she's doing well with potty training. Intervention therapy has helped immensely. She continues to meet her milestones on time.

This girl can cast you a smile that will melt your heart. When she sees me, she flings her arms out wide, demanding the hug that I can't wait to give her. I love the way she wraps her arms around me, patting my back, nuzzling her head against my neck. She is just my sweet granddaughter, Dottie, who, by the way has Down syndrome.

St. Patrick's Day will always be our Lucky Day.





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