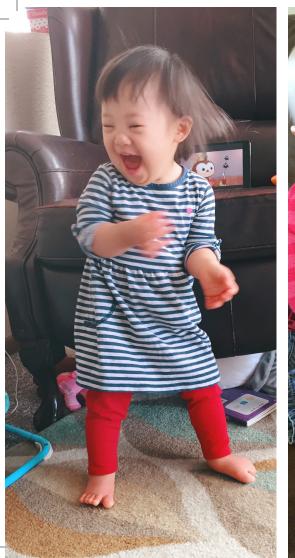




dsafnebraska.org

# A BOOK OF STORIES













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05/2020



# 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 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.



# GRANT

SEL

8

RAPK & FIELD

### 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 Mom

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 DS, 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 DS. 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. Ok." 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 nonjudgmental 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. 13

#### by Emma's mother



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.



# by Lily's Mom

I wish I could go back in time and give myself a pep talk when I was a scared and worried expectant mom sitting in the fetal maternal specialist office. I was swallowed up by what I thought was devastating news that our unborn daughter had Down syndrome. I didn't realize at the time that I had actually just been given the greatest news of all time. News that would forever change the course of my life for the better.

If I get a hold of that magical time machine this is what I would tell myself:

I know this news is unexpected and you are in shock and disbelief and can barely see through your tears. That is a normal reaction when the life path you are on suddenly changes directions. You have to take a deep breath and allow yourself to be open to a bigger, brighter plan around the corner. I will be honest; it will take some time. After you grieve the family you thought you wanted, you will start to celebrate the family you needed. Your family will be changed in ways you never thought possible.

Go ahead and allow yourself to enjoy your pregnancy. Agree to have a pink princess baby shower for Lily instead of declining one because you don't want anyone to feel awkward. Believe me you will regret that later.

Go ahead and meet your new neighbors on your new street. Not only will they support you, but one will be the first nurse to greet your daughter in the NICU.

I know it is impossible believe all of this as your well-meaning fetal maternal specialist bumbles through trying to explain what Down syndrome is with random stories of all the people he knows with an extra chromosome. The only saving grace from this appointment will be the big, white binder from some local organization called the Down Syndrome Association for Families of Nebraska. Sure, some of your legitimate worries and challenges will come true – an all-or-nothing lifesaving heart surgery at nine weeks, oxygen for a year, airway and feeding issues, hypermobile joints, and leg braces. But let me tell you, those medical complications will resolve, and the challenges will make the accomplishments so much sweeter. Many of the irrational fears running through your head will not come true and in fact will have the opposite outcome.

Don't worry that Lily will be shunned and snickered at in public. The biggest challenge in your public appearances will be controlling the mobs of fans and remembering the names of everyone who knows her. You will wonder sometimes if you need to hire an agent for your star. No one will remember your name. From now on, you will only be known as "Lily's mom." A title that will mean much more to you than the doctorate you earned.

Don't lose sleep about Lily not being able to walk for over two



(Lily Continued...)

years. Sure, it will take a bit longer, but in in a couple of years you will find yourself chasing after Lily in Target thinking to yourself, "That physical therapy worked a little too well."

Talking? Don't worry about that Lily either. Lily walks up and talks to everyone she meets. And when she gets sassy and demands Barney on the kindle, you also question the Catch 22 of the excellent speech therapy.

School? Not a problem. She will run out to the bus and barely look back to say bye as you are crying about her maturity and independence. Don't waste your time and tears worrying if your daughter will be able to learn. Lily will come home from Kindergarten after the first week and tell you she is bored with learning preschool stuff.

I know you love taking Jayden to music and swim class, the zoo, and museum, and you assume this is not in cards for your unborn daughter. You are convinced Lily won't be able to do the things your typical child is able to do. What an unbearable thought. Shhh. I've got a secret to tell you. The child you are carrying with that extra-talented chromosome will not only participate in music and swimming, but she will sign up for cheer, dance, t-ball, and theater. In six years, you won't be heartbroken because of the lack of activities. vou will be heartbroken because there are not enough days in week for all the activities.

And don't think about giving up family vacations. By the time Lily is five, she will have a couple stamps in her passport taking her on journeys to swim with



dolphins and sea lions. Something you didn't do until you were in college.

Friends you say? Lily will have friends of all ages, races, and beliefs. She makes friends and melts hearts wherever she goes. I will challenge you to find a more extroverted child than Lily.

Will her siblings like her? Jayden and Brynn adore, protect, and help Lily on the bus, at school, search for glasses she lost for the hundredth time, tuck her in at night, and watch her perform in front of 2,000 people at the Lied Center. They will laugh and play, and be better people because of Lily.

I assure you every day will be a gift and a joy. You will grow as a person, mom, advocate, and friend. Right now, you don't think you can be a parent of a special needs child, but that will all change when you open that white DSAF binder and make that first call. The uncertain pregnant mom you feel like today will quickly be transformed into a proud, fierce Mama Bear. Your grief will resolve and your heart will be full. You will never look back at the tears of sadness you feel today. You will only look forward to the tears of joy you will feel tomorrow.

Hang on, you are in store for a wild ride!

# CAMDEN

### by Camden's mom

We found out that our son Camden was going to have Down syndrome halfway through our pregnancy. On ultrasound, it was discovered that he had duodenal atresia (a blockage in the duodenum, or first part of the small intestine). We were told that about one-third of infants born with duodenal atresia will have Down syndrome. At that point we had to know, so an Amniocentesis was performed.

I will never forget waiting for the call that Saturday morning. The phone rang. I was terrified to answer, knowing that in an instant I would be extremely happy or completely devastated. I picked up the phone and answered with my husband Blake sitting by my side.

I was told the news I had feared so much. Our son was going to have Down syndrome. We felt hopeless. Hopeless for what our son's life would look like, hopeless for what parenthood would be like, and hopeless for what our family would be like – different from the one that we imagined. The dreams that we had for our son felt completely shattered.

Camden arrived on July 3, 2018, at 9:58 PM. I got to hold him for a quick picture and then they took him straight to the NICU. Camden went into surgery on July 4, 2018. Surgery went well and we were in the NICU for 2 weeks while he recovered.

Early on, we contacted the Down Syndrome Association for Families of Nebraska for support. It has been amazing to receive the support from other families and to see these families happy and flourishing. I have built strong relationships with the families in the community. We all have a special bond with each other. We call ourselves "The Lucky Few" for a reason.

Blake and I have had several high points this past year that Camden has been in our lives. Watching him grow and develop, getting to know his amazing personality, and seeing his smiles and laughs that melt our hearts over and over again. He has brought us a greater sense of purpose that has enriched our lives.

It does take a little more work for Camden to reach his milestones; but the extra effort makes every milestone a cause for celebration. We utilize the Early Childhood Development program through Lincoln Public Schools. As a team, we set goals and interventions so that Camden may reach his fullest potential.

I've been reflecting on our life before Camden and how humbling it has been to learn from him. One thing Camden has taught me is to accept and see the beauty in everyone. He has changed my perspective about people with unique differences and abilities. I now see immense beauty in differences, whereas before I may have thought the differences to be more of a flaw. He has taught us how to accept people as they are, regardless of their abilities and differences. **23** 

#### (Camden continued...)

This past year we have fallen completely in love with Camden. Down syndrome has quickly become background noise. All that matters is that our child is happy and healthy. We finally realized what everyone was telling us the entire time to be true – that he is just our child. He is not the Down syndrome child; he is Camden.

If I could go back in time and relive one moment, I would go back to the day I heard the words "your child has Down syndrome". I would want to replace that anxiety, sorrow, and anger with different emotions; hopeful ones. I wish I would not have cried all those tears, however, I do feel it was necessary to grieve the loss of the child we thought we were going to have.

To the new Moms or Dads facing the diagnosis of Down syndrome, I want you to know that in the end your child will "just be your kid". You will love them more than you think you could love someone and you will embrace them for who they are. They will make you see life in a new beautiful way, I promise.

Try not to fear the unknown. I remember fearing all the "what if's" and I let the fears consume me. "What if he never leaves the house?" "What if he wants to have a child someday?" "What if his peers don't accept him?" And the list went on and on. Most of the fears that I had dwelled on, have completely faded away. Don't waste your time fearing the unknown. Have faith that life will be better than you could ever imagine.

Camden, every day I am thankful that we were chosen to be so abundantly blessed to learn from you. How you have helped us grow! You are much more than I could have imagined prior to knowing the Down syndrome diagnosis. I am blessed to call you my son.





# by Brigg's Mom

I wish I would have known that forced smile on my face would soon be a smile I can't wipe away. I wish I knew those little eyes would turn blue and stare at me to tell me it's okay. I wish I knew that palmer crease on your left hand would soon grip my finger at every feeding telling me I'm needed. I wish I knew all that hair would soon go in a ponytail and make your brothers laugh until they fell to the ground. I wish I knew that despite all the unknowns and scares with a diagnosis, you would make us better people. I wish I knew how many friends we would soon make and have by our side every step of the way. I wish I knew how much life would change for the better.

Briggs Barrington, I'm scared for our new life, but most importantly, I'm excited and confident we are going to have a great one.

Diagnosis day is no joke, but day by day, it becomes a smidge easier. #upsyndrome #lovemyhomie





### by Mia's mom

Mia was prenatally diagnosed with Down syndrome via amniocentesis. Besides possible medical complications, my biggest concern was her older brother, Nathan.

Nathan was 3 1/2 and had just started preschool. We had told him he was going have a little sister a few weeks prior to Mia's diagnosis. His biggest worry about being a big brother at that time - "where was she was going to sleep?" After her diagnosis, though, my biggest worry was if Nathan would know she was different. Would he even like her? What would their sibling relationship look like? Would he be able and willing to take care of her when we were gone? Would he defend her from others? How would we tell Nathan his baby sister would be different than his friends' baby siblings?

As part of the preparation for Mia's birth, I reached out to the Down Syndrome Association for Families (DSAF). I was placed in contact with a DSAF First Call mom who had a prenatal diagnosis with her second child as well. I met with her while I was still pregnant and after Mia was born. She supported me and gave me advice on how to prepare our family for life with Down syndrome. She suggested the book, "We'll Paint the Octopus Red," by Stephanie Stuve-Bodeen, as a way to tell Nathan about his sister's diagnosis.

We read, "We'll Paint the Octopus Red," to Nathan. He didn't understand what Down syndrome meant. He understood he was going to have a baby sister, though, and that Grandma was going to come stay with him while we were at the hospital. When asked for his opinion on what to name his sister, he said, "Devious Diesel." Diesel is the name of one of the characters in the "Thomas the Tank Engine" stories who sometimes tricks Thomas. Thomas and his friends include Diesel even though he is a diesel and they are steam engines.

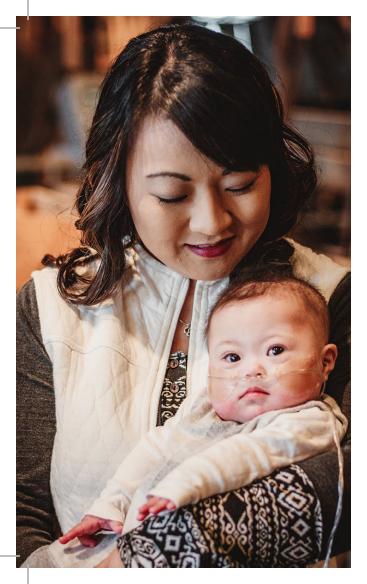
Mia was born on a Friday, she was cleared by the NICU team within 10 minutes of birth, and we left the hospital with Mia on Sunday. Nathan was most upset he didn't get to spend more time alone with Grandma.

From the moment we brought Mia home, her Nathan has been there for her. First, trying to figure out how to play with her. He built train tracks around her and would wait for "Hurricane Mia" to destroy them. Now, it's how to keep her out of his room.

As a mom, I have loved watching their relationship grow. When Mia was about 8 months old, I was wrapping Christmas presents. Nathan was diligently writing name tags. Mia wanted his attention. She rolled over and grabbed a wrapping paper tube and hit him with it. He yelled "Mia, stop!" She laughed. Then he smiled and laughed! In this one moment, my fears of their relationship disappeared. She was going to stand up to him, annoy him, play with him, and love him. He would do the same in return.

Now, Mia is a preschooler and has proven to be a strong, outgoing, and opinionated little girl. She tries to sneak into Nathan's room to play with his toys when he is not looking. She will convince him to dress up as a fairy ninja. She will persuade him to do what she wants with a smile and a giggle. Her favorite part of the day is picking Nathan up from school. She waits until she sees him come out the door and then runs up and hugs him. She high fives his friends and teacher. He then takes her by the hand and walks with her back to the car. She has her devious moments with him, but mostly they love each other. To Nathan, she isn't a sister with Down syndrome, she is just his sister. #JustASister







PO Box 57362 Lincoln, NE 68505-7362 www.dsafnebraska.org

For more information, contact: info@dsafnebraska.org | phone 402.421.1338 medicaloutreach@dsafnebraska.org

We have a closed group on Facebook Visit facebook.com/groups/dsafnebraska and ask to join!







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