




National
Down Syndrome
Adoption Network
planning for a loving future

A Loving Choice... *Adoption as an Option*

A PROGRAM OF THE DOWN SYNDROME ASSOCIATION OF GREATER CINCINNATI

WHAT IS THE NATIONAL DOWN SYNDROME ADOPTION NETWORK?

The National Down Syndrome Adoption Network is a *connection point* between expectant and birth families, and adoptive families who want to adopt a child with Down syndrome.

We are here for you. We will answer any questions you have about parenting a child through the lifespan, and send you current and accurate information on Down syndrome. If you decide to parent, we will connect you with your local parent group.

If you decide to make an adoption plan, we have a registry of families who want to adopt a child with Down syndrome. They have been licensed and approved to adopt.

The mission of the National Down Syndrome Adoption Network is to ensure that every child with Down syndrome grows up in a loving family.

That family may be an adoptive family or that family may be you. We are here to help you walk this journey.

They wanted us with her right away so she would never be alone, and so we were waiting in the hospital in the NICU during her C-section.

Once she was stabilized and in her room we were able to see her and to hold her, even though she was so small. And though she was small, she was strong.

We spent a month with her in the NICU and she was released to come home at a tiny 3 pounds 14oz! Her adoption became official when she was 4 months old, and she had a successful open heart surgery at 6 months old.

Faith is the light of our lives. Her three older brothers adore her and would do anything for her. She is so loved by all who know her. Not a day goes by that I don't look into her sweet face and feel SO thankful that her first family chose to give her life, and chose us to be the ones to watch her live it. She is a gift, and such a blessing.



I Adopted a Child with Down Syndrome

Adoption has always been a part of our lives. Both Matt and I have younger siblings who were adopted, so it just felt like a natural way to build our family. While we were in college we talked a lot about how our family would end up looking and how we had thought that adoption would be a part of it. During this time, I had worked with a little boy who had Down syndrome, and from then on I knew in my heart that one day a child with Down syndrome would be a part of our family.

Fast forward 10 years, and after having three biological children we felt like the time was right to add a much anticipated, much longed for, and loved child to our family through adoption. Two of our boys have varying degrees of special needs so we felt even more confident that our home would be a perfect fit for a child who had some extra needs. We completed our home study and registered with the National Down Syndrome Adoption Network as a waiting family. We were hoping for a little girl who had that extra special chromosome.

We were contacted about a little girl, yet to be born, who had Down syndrome and a heart condition that would need to be repaired a few months after she was born. That was the beginning of our journey with Faith, she is our best Yes!

Faith Noelle was born on New Year 's Eve weighing a whopping 2 pounds 12 ounces and only 14 inches long. Her biological family felt like they could not give her the life that she needed, so they chose and trusted us to be her family.

WHAT IS DOWN SYNDROME?

Down syndrome is a genetic variation that may affect physical, intellectual, or language development. The exact causes of the genetic variation are unknown, and it is not related to race, nationality, religion, or socio-economic status.

Down syndrome may cause an increased risk of medical issues with the heart or digestive tract. Most of these issues are correctable with surgery.

Individuals with Down syndrome benefit from loving homes, early intervention, inclusive education, and appropriate medical care.

In adulthood, many persons with Down syndrome hold jobs, live independently, and enjoy recreational opportunities in their communities.

There are excellent resources to learn more, via Google:

Down Syndrome Association of Greater Cincinnati

Global Down Syndrome Foundation

International Down Syndrome Coalition

National Down Syndrome Congress

National Down Syndrome Society



Let's Talk About Getting that Diagnosis

A lot of families refer to this as a “flashbulb” moment. This is an unforgettable moment that you will carry with you for a lifetime. Some of you may get a prenatal diagnosis; I received a post-natal diagnosis. I still remember when the doctor told me my son had Down syndrome. I had my son at 7am, and the House Pediatrician woke me up to tell me the news.

I was by myself; after what we thought was a successful labor, my husband and parents went home to rest while I slept. I remember every word the doctor said, I remember the feeling afterward. The feeling of someone coming in and turning your world upside-down. Time just stops and you are left with this diagnosis, and you don't know what to do with it.

First of all, it's okay to grieve. You've received life-changing news that your child will have a life-long, permanent disability. Allow yourself to feel the full range of emotions. Reach out to us for support, we have a list of families who have been through this experience, who would be honored to share their story and support you during this time.



There are some great resources to read during this time, and they are listed here, and can be found via Google:

- **Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome**
- **Down Syndrome Diagnosis Network**
- **Welcoming a Newborn with Down Syndrome**
- **Video, “Welcome to the Down Syndrome Community”**

At 39 weeks and six days, I finally got to hold my baby. Even with all the extra challenges I knew we would face, giving into our love for her and having what they call a “change of heart” and deciding to parent her would have been the easy thing to do. The day after I came home from the hospital, I already missed her more than anything in this world. In moments where I try to tell myself I should have raised my baby, I stop myself and remember how good it was to see her family holding her themselves for the first time. They already loved her just as much as I did. I may be sad, I may wish she could have come at a different time in my life where embracing her special needs would have been something I could do. But at the end of it all, I am proud I made the decision to give her the best life possible, even if it means watching her grow in the arms of someone else.



The NDSAN has a list of birth families who have either decided to parent, or decided to make an adoption plan, and they would be honored to connect with you, share their experience, and answer any questions you may have. Email us at stephanie@ndsan.org for more information.

I Made an Adoption Plan

I found out I was pregnant a whole three weeks in, unfortunately with a man whom I was just barely getting to know. We had a rocky start given the situation, but we were able to work things out to co-parent, and both be there equally for the baby. At 22 weeks pregnant, I was told my baby had an A/V canal defect. At 26 weeks, it was confirmed. She also more than likely had Down syndrome. To top it all off, at 27 weeks I was told termination was still one of my options, if that was what I felt was the right thing to do. I will never say a woman doesn't have the right to decide what is best for her situation, but hearing them offer that to me made me feel like my baby didn't matter.

All of a sudden, we weren't just bringing home a cute bundle of joy, we were going to be bringing home a cute bundle of joy who we knew would need so much more than we could ever provide. So at 30 weeks, we made an adoption plan to ensure that our baby would have the best chance at being as high functioning as possible. Some may think placing a baby with special needs is easier than placing a typical child. I beg to differ.



Placing your baby in the arms of someone else to love and cherish is the hardest thing anyone will ever do, but when you make the decision to place your baby with special needs, you are putting even more faith into their family that they will advocate and fight for that child in every way you would want. You are trusting they will make sure to be a part of early intervention and do everything they can to make sure the child gets all the therapies they may need, many not covered by insurance.

WHAT DOES PARENTING A CHILD WITH DOWN SYNDROME LOOK LIKE?

After you go through the grieving process, you will notice that your baby has needs like all babies...they will need to be fed, changed, held, nurtured, loved. With the increased risk of medical issues, your baby may require more appointments in that first year and quite possibly as he grows.

Early Intervention can start as early as 4-6 weeks of age, depending on your county.

At this time, specialists may assess him and begin therapies to help him meet his developmental milestones.

While therapies are important considerations for you and your family, they will not consume your lives and will soon become part of your normal routine. Your baby will grow into a toddler and you'll be trying to keep up with her! She will begin school, write her name, play soccer, learn to dance, or paint. He will grow into a teenager, join a club, and go to prom. She will graduate high school, possibly pursue secondary education, and you will help guide her into becoming an independent adult.



WHAT DOES MAKING AN ADOPTION PLAN LOOK LIKE?

You are reading this because you love your child. You have reviewed the information about parenting a child with Down syndrome, you have educated yourself on Down syndrome, and after many sleepless nights and heart wrenching talks with your family, you feel that the best choice for your child is a family who is ready, and who wants to adopt a child with Down syndrome.

The NDSAN has a registry of families who are approved and licensed for adoption. These families currently have a home study – a document that verifies the family has passed background and fingerprint checks, medical evaluations, home checks, and referrals that were submitted on their behalf. These families are comprised of:

- Parents who already have a child with Down syndrome - Parents who work directly with children with Down syndrome
- Parents who are siblings, nieces, cousins, or other family members of someone with Down syndrome
- Parents who babysat, attended church with, went to school with, or were friends with someone with Down syndrome
- Parents who feel called to adopt a child with Down syndrome

These families reside within the US, all across the country. They are licensed to adopt within the United States.



We contacted the NDSAN just to see what our options were. We wondered if there truly were families out there that we might feel comfortable allowing to raise our boys. Long before we felt ready to make a final decision, we found out that adoption was a very real option. We really believed ours was not a black and white decision. Adoption is a wonderful gift for everyone involved. For the child, it demonstrates that he is loved enough for his birth parents to seek out what is best for him even though it may mean such pain for the parents. For the birth family it can provide peace knowing their child is being placed into the arms of a family who loves him as much as they do. For the adoptive family it is the fulfillment of a dream to parent a child they may not otherwise be able to have. Therefore the decision was even more difficult because the answer was not cut and dry. We wrestled and prayed and discussed until we had no strength left.

The turning point for me was when I realized I needed to let go of fear. It was fear that was ruling my thoughts and trying to rule my decisions. However, I know I had to go through that valley. I had to experience that pain, grief and loss because it's just normal. Life doesn't always go the way we plan and when we receive a diagnosis we never expected, it rocks our world! I'm so thankful that the

NDSAN was there for us and our potential adoptive family as well. They gave us the permission to experience all the ugly feelings and to work through them.

You can see our boys and how they have changed our world at:

www.facebook.com/charlieandmilo





I Decided to Parent

Our ultrasound at 11 weeks began to show some markers in our twin boys that we were familiar with, having recently been through an over-40 pregnancy. We tried not to let the measurements showing the abnormally thick nuchal folds get us too concerned. We chose to proceed with a new screening test that would tell us with remarkable accuracy if Down syndrome was present. We waited for the results with high hopes that we would receive a negative result and this would all just be a fire drill. Our doctor's call proved otherwise. Down syndrome was present.

The next several weeks and one heart wrenching experience with amniocentesis confirmed our worst fears. Not just one, but both babies had Down syndrome. Those next several days and weeks were a swirling blur of pain, loss, tears, and waiting to awaken from this bad dream.

We honestly didn't see how we could provide care for two boys - TWO - with Down syndrome. By this time I was 44 and my husband was 45. The fear was not so much a baby or even child with Down syndrome. The fear was a teenager, then adult with Down syndrome. How could we possibly care for two young men who would almost certainly outlive us? How could we put that burden on their siblings? How much time and resources would it take to raise two boys with Down syndrome? How could we rob our son of the care he needs as he grows because we have two other boys with special needs?

When a family wants to join our registry, their social worker must send their completed, signed, and updated home study to us. Then we send a registration form to the family. They tell us about their family, who provides us with information on their location, employment, faith, family life, etc.

After we have counseled with you on parenting a child with Down syndrome, provided you with updated, positive information on Down syndrome, and you have chosen to move forward with an adoption plan, we will honor your request and walk you through the process of connecting with an adoption agency, and connecting with families on our registry.

As you provide information on your child, we will create a query in our database that will generate a report of potential families who would be a best fit of what you may be looking for in an adoptive family. Families on the report will be contacted, and I will send you the profiles of families who wish to be considered for your situation.

A family profile will show you pictures of the family, and it will tell their story of who they are, why they want to adopt a child with Down syndrome, and what experience they have with Down syndrome.

You will review family profiles, and when you are ready, you will choose an adoptive family and the adoption agency will step in and take care of the legal aspects of the adoption.



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BIRTH PARENT LINE Call/Text: 513-709-1751
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