

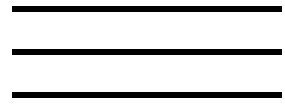


**Down Syndrome
Connection**
OF NORTHWEST ARKANSAS



FIRST STEPS

A Magazine for Parents of Individuals with Down Syndrome

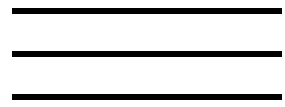


Place
Stamp
Here



**Down Syndrome
Connection**
OF NORTHWEST ARKANSAS

1200 W Walnut St. Suite 1424
Rogers, AR 72756



Place
Stamp
Here



**Down Syndrome
Connection**
OF NORTHWEST ARKANSAS

1200 W Walnut St. Suite 1424
Rogers, AR 72756

DSCNWA

1200 W Walnut St. Suite 1424 | Rogers, AR 72756
479-282-3639 | www.DSCNWA.com | info@dscnwa.com



Table of Contents

Letter from the DSCNWA Staff & Board of Directors.....1

What is Down Syndrome2

Health Issues3

Everything Will Be Alright.....4

Breastfeeding.....6

How Do I Tell the Kids?7

Questions About Early Intervention8

Where to Start9

New Parent Tribe.....10

Personal Stories:

Bradley11

Nate12

Sofia13

Brooks14

Bentley15

An Unexpected Birth16

Welcome to Holland18

The Down Syndrome Connection of Northwest Arkansas19

Step Up for Down Syndrome Event20

Just Like You Down Syndrome Video20

Spanish:

¡Felicitaciones!21

Historia de la Familia Sofia22

Bienvenidos a Holanda.....23

El Síndrome de Down24

La Organización DSCNWA25

Early Intervention and Therapy Providers.....26

National Down Syndrome Resources28

A special thanks to DSG for letting us use some content and model our magazine after their New Beginnings Magazine designed by Trudi Nelson.



Raphotocompany.com

First Things - Person First

When describing your child's condition, you should say he/she has Down syndrome and not that he 'is a Down's child,' or that he has Downs. Describe him as 'a child with Down syndrome,' rather than 'a Down syndrome child.' He is a child first and foremost. The fact that he has Down syndrome is of secondary importance.

Adopted from the book "Down Syndrome - The Facts" by Mark Selikowitz



Down Syndrome Connection
OF NORTHWEST ARKANSAS

The DSCNWA is a non-profit 501c3 organization whose mission is to provide support and resources for individuals with Down syndrome, their families, and the professionals who serve them.

The DSCNWA seeks to provide the entire community with information and education to broaden awareness and foster positive attitudes regarding people with Down syndrome.

DOWN SYNDROME CONNECTION OF NORTHWEST ARKANSAS

1200 W Walnut St. Suite 1424
Rogers, AR 72756
479-282-3639
www.DSCNWA.com
info@dscnwa.com

Program Director

Lindsay Dover

Director of Operations

Nicole Terry

Magazine Editors

Bethany Rine & Danielle Pezely
updated December 2003

Cover Photo: Logan Gillham Photography

- Please send me a complimentary copy of the book "Babies with Down Syndrome" to the address below.
- Please add my name to the DSCNWA Email List so I can begin receiving information about upcoming programs.
- Please contact me to schedule a parent-to-parent visit.
- Please have someone contact me so I can learn more about the programs and support available.

PARENT'S NAME _____

CHILD'S NAME _____

CHILD'S BIRTHDATE _____

ADDRESS _____

CITY, STATE, ZIP _____

PHONE _____

EMAIL _____

- Por favor envíeme una copia gratuita del libro "Bebés con síndrome de Down" a la dirección que figura a continuación.
- Por favor de incluir mi nombre en a la Lista de Correo Electrónico de DSCNWA para que yo pueda comenzar a recibir la información para las actividades futuras.
- Por favor de contactarme para coordinar una cita de padres a padres.
- Por favor que alguien se contacte conmigo para que yo pueda aprender sobre programas que se llevan acabo para apoyar a las familias y soporte disponible.

NOMBRE DE LOS PADRES _____

NOMBRE DEL NIÑO _____

FECHA DE NACIMIENTO _____

DIRECCION _____

CIUDAD, ESTADO, CODIGO POSTAL _____

TELEFONO _____

CORRERO ELECTRÓNICO _____

DSCNWA

1200 W Walnut St. Suite 1424 | Rogers, AR 72756
479-282-3639 | www.DSCNWA.com | info@dscnwa.com

National Resources

Morgan Emery Photography



Founded by a parent of a child with Down syndrome in 1979, the National Down Syndrome Society (NDSS) gradually expanded to become one of the largest organizations in America focusing on intellectual disabilities. The mission of NDSS is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome.

- The NDSS National Policy Center strives to protect the rights and remove barriers for all individuals with Down syndrome. The policy center works with Congress and federal agencies to develop and improve legislation.
- NDSS leads a national network of over 375 affiliate groups across the country, consisting of local parent support groups and other organizations.
- The Goodwin Family Information and Referral Center offers a toll-free helpline and e-mail service that can be accessed in over 150 languages. The NDS website, www.ndss.org is a comprehensive and up to date resource for families, professionals, affiliates and others and includes extensive Spanish translation.
- NDSS created the Buddy Walk®, a national program that promotes acceptance and inclusion of people with Down syndrome and raises funds for local and national initiatives that support people with Down syndrome and their families.
- Through public awareness, NDSS works to ignite a new way of thinking about people with Down syndrome. NDSS proactively reached out to national media to secure editorial content and monitors all forms of media, 365 days a year. The My Great Story campaign honors and celebrates the great stories of the 400,000 Americans living with Down syndrome by showcasing these stories into a national public service announcement which has been featured in national and local media outlets across the country.

For more information, contact:

**THE NATIONAL
DOWN SYNDROME SOCIETY**
8 E. 41st Street, 8th Floor
New York, NY 10017
Tel. (800) 221-4602
www.ndss.org
info@ndss.org



The National Down Syndrome Congress is the country's oldest national organization of self-advocates, their families, and the professionals who work with them. Over the years, the NDSC has become known for its unflinching advocacy in promoting the rights of and opportunities for individuals with Down syndrome. Additionally, the Congress is recognized for the personalized care it gives to families. Each year, the NDSC National convention brings together speakers and participants from throughout the United States and the World to learn and share in a giant "family reunion" setting.

MISSION

The Mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down Syndrome.

For more information, contact:

**NATIONAL DOWN
SYNDROME CONGRESS**
30 Mansell Court, Suite 108
Roswell, GA 30076
Tel. (800) 232-NDSC (6372)
www.NDSCcenter.org
info@ndscenter.org

CONGRATULATIONS!

Dear New Parent,

The Down Syndrome Connection of Northwest Arkansas (DSCNWA) seeks to provide support and resources for individuals with Down syndrome and their families. You are facing many emotions right now and we are here to support you!

If you are like most new parents, you have little idea what Down syndrome will mean to your child and your family. Some impressions you have may be bleak or very inaccurate. You will be advised by the professionals that you encounter not to read anything about Down syndrome written more than five years ago, as new information and therapies are rapidly being discovered and refined. Also, searching on Google can be overwhelming and inaccurate. A large network of sophisticated services and specialists are available to assist your family and your child - most at no cost to you. Your child has a very bright future!

DSCNWA has consolidated key information about Down syndrome in this magazine, including information on local services and resources available to you. We suggest that you read the section titled "Health Issues" while in the hospital and then look at "Where to Start" section. Select from the rest whenever you are ready.

Your child's diagnosis may seem overwhelming right now. As you learn more about Down syndrome, it will lose its place as a defining feature of your child - your wonderful, adorable, how-did-I-possibly-think-life-was-good-before-him child.

Congratulations on your new baby!

DSCNWA STAFF & BOARD OF DIRECTORS

Please reach out to DSCNWA! We would love to connect. We want to make sure you know the resources and support available. We can add you to our email list so you know what events are coming up so you can join if and when you're interested and ready. We are here for you, in whatever way is best for you and your family.



Christa Henson Photography



Bethany Blair Photography

What is Down Syndrome?

Down syndrome is the most commonly occurring genetic condition at 1 in every 800 births. Down syndrome occurs in people of all races and economic levels. More than 250,000 people in the United States are living with the condition.

In every cell in the human body there is a nucleus, where genetic material is stored in genes. Genes carry the codes responsible for all of our inherited traits and are grouped along rod-like structures called chromosomes. Typically, the nucleus of each cell contains 23 pairs of chromosomes, half of which are inherited from each parent. Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21.

This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome. A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm - although each person with Down syndrome is a unique individual and may possess these characteristics to different degrees, or not at all.

People with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses. Children with Down syndrome learn to sit, walk, talk, play and do most other activities, though somewhat later than their peers without Down syndrome.

People with Down syndrome should always be referred to as people first. Instead of "a Down syndrome child," it should be "a child with Down syndrome." Also avoid "Down's child" and describing the condition as "Down's," as in, "He has Down's." People have Down syndrome, they do not suffer from it and are not afflicted by it.

Quality educational programs, a stimulating home environment, good health care and positive support from family, friends and communities enable people with Down syndrome to realize their aspirations and lead fulfilling and productive lives. People with Down syndrome attend school, work and contribute to society in many wonderful ways.



Elise Kennedy Photography

Northwest Pediatric Therapy Services (ST/OT)

Fayetteville 479-521-7337
www.nwpedtherapy.com

Post Pediatric Therapy (PT/OT/ST)

Cave Springs 479-631-7678
Rogers 479-631-7678
www.posttherapies.com

All Aboard Pediatric Therapy (PT/OT/ST)

Rogers 479-445-6800
Springdale 479-445-6800
allaboardpediatrictherapy.com

Kids for the Future Rogers, Inc. (PT/OT/ST)

Rogers 479-986-5150

Mercy Therapy Services - Highway 102

Rogers 479-986-6084
www.mercy.net/practice/mercy-therapy-services-highway-102/

Playstrong Pediatric Therapy

Centerton 479-224-2362
Rogers (479) 246-0101
www.playstrongtherapy.com

Friendship Pediatric Services Of NWA (PT/OT/ST)

Lowell 479-770-0744
Siloam Springs 479-524-2456
www.fccare.org

Holly Street Physical Therapy (PT/OT)

Siloam Springs 479-524-8028
hollystreetpt.com

Cassady Children's Center (PT/OT/SP)

Springdale 479-419-9911
www.cassadychildrenscenter.com

Jarvis Pediatric Therapy, Inc. (PT/OT/SP)

Rogers 479-367-2806
Springdale 479-750-7778
www.jarvistherapy.com

Kids Spot (PT/OT/ST)

Springdale 479-259-2339
www.kidsspotllc.com

Physicians Therapy Group (PT/OT/ST)

Springdale 479-750-3535
www.ptgtherapy.com

Thera Play Pediatrics (PT/OT/ST)

Springdale 479-856-6400
www.thera-play.com

The Therapy Spot (PT/OT/ST)

Springdale 479-595-0599
www.therapyspotllc.com

Early Intervention & Therapy Providers

Early Intervention

Arkansas Department of Human Service First Connections

800-643-8258

dhs.arkansas.gov/dds/firstconnectionsweb/#fc-home

Elizabeth Richardson Center

Fayetteville, Huntsville and Springdale

479-872-7450

www.ercinc.org

NWA Education Service Cooperative (3-5)

479-267-57450

www.starfishnw.org

Therapy Providers

Children's Therapy TEAM (PT/OT/ST/DT/ABA)

ABA Clinic 479-282-1506

Bentonville Aquatic Center 479-657-6272

Fayetteville 479-521-8326

Siloam Springs 479-521-8326

www.childrenstherapyteam.com

Emerge Therapy

(PT/OT/ST/DT/Psych and Mental Health)

Bentonville 479-250-4355

www.emergenwa.com/contact.html

Fusion Therapy Center (PT/OT/ST)

Bentonville 479-252-3321

www.fusiontherapycenter.com



Sunshine School & Development Center

Rogers 479-636-3190

www.nwasunshineschool.org

Kids First

Springdale 479-750-0130

https://kidsfirst.uams.edu/locations/springdale/

Imagine Pediatric Therapy Inc (PT/OT/ST)

Bentonville 479-795-1260

www.imaginepediatrics.com

No Limits Pediatric Therapies (PT/OT/SP)

Bentonville 479-250-9838

www.nolimitstherapies.com

Cross Therapy Services (PT/OT/ST)

Fayetteville 479-582-2740

www.crosstherapyservices.com

Pediatrics Plus (PT/OT/SP)

Rogers 479-346-5459

pediatricsplus.com

Health Issues



to address at the hospital or soon after birth

Children with Down syndrome are often at increased risk for certain health problems. Congenital heart defects, increased susceptibility to infection, respiratory problems and obstructed digestive tracts occur with greater frequency among children with Down syndrome. Fortunately, advances in medicine have rendered most of these health problems treatable.

As with all children, you must take an active role in ensuring the best health care for your child. Some steps that we recommend be taken soon after birth include:

- **Obtain an echocardiogram.** It is important that all children born with Down syndrome, even those who have no symptoms of heart disease have an echocardiogram in the first 2 of 3 months of life. Symptoms may present themselves as heart failure, difficulty breathing or failure to thrive. The symptoms may not be apparent at first. Most hospitals have the capability to perform an echocardiogram. It is often most convenient to take care of this before leaving the hospital.
- **Obtain a hearing test before leaving the hospital.** Some children with Down syndrome have hearing loss. With new testing procedures this can be detected easily in newborns.
- **If your child has any feeding difficulties, consult a feeding specialist.**
- **Ensure that the diagnosis of Down syndrome is confirmed via chromosomal karyotyping.**
- **Obtain a vision test.**
- **Obtain a TSH test.** Thyroid hormone levels can be too low in newborns and need to be checked. Thyroid hormone imbalance can cause a variety of problems that might not be easy to detect without a blood test.
- **Obtain a CBC blood test.** After birth, white and red blood counts can be unusually high in infants with Down syndrome.
- **Look for developmental services.** It is not too early in the first month of life to start to look for the developmental services (sometimes called "Early Intervention") that will be very important in early childhood. The state of Arkansas has many benefits available to support families. See the "Where to Start" section. Ask the social worker at the hospital or contact our office for questions.



Deserae Stewart Photography

(Please note: This non-exclusive list is not meant to replace the care and advice of a qualified physician.)

Everything Will Be Alright: Our Story



It's a boy! We were ecstatic!

We'd just found out that our second child was going to be a boy and we had already narrowed names down. Our 2 1/2 year old son, Hudson, was just as excited to have a little brother as we were to have two boys.

Come July 26th, Jessica knew he was on his way. We calmly prepared, checked into the hospital, and were ready to rock. When our beautiful baby boy arrived, he came with a head full of blonde hair. We named him Anderson Grant.

Shortly after he was born, I was impressed by how calm he was. He was so chill; arms and legs spread out, unafraid, not crying, just kind of looking around. This was much different than how I remembered our first son acting after birth and was my first clue that something might have been...different.

Nurses swarmed him. I heard one talking with a trainee and saying "...these guys usually have a deep upper palette...see, you can feel it." I asked what she meant by "these guys" and she said "uh...babies." It was not a convincing response but I just wanted to admire my son so I let it go.

Early the next morning the pediatrician mentioned, "You might have noticed that your baby has some physical traits associated with Down syndrome."

....We did not.

We stared blankly. It startled us. It felt like a gut punch. How? The prenatal testing said everything was normal. How could this be?

"It's okay though, give him a chance!"

We didn't need to be told that, but appreciated the attempt at...whatever that was.

She wasn't awful or anything, but she offered no help other than "give him a chance!" I needed some sort of playbook!

I don't even remember anything else the doctor said after that and she was in the room with us a solid 15 minutes.

I think we were both really upset, because one of us asked if it was possible he didn't have it. She said it was indeed possible but could only be confirmed with special testing. We exhaled. We denied it. We were convinced they made a mistake.

I took a walk. We barely talked about it for a while, both still in denial. We studied him. I sent pictures to my cousin, who is a NICU nurse and she said it looked to her like he had Down syndrome but she immediately pivoted to congratulating us. She gets it.

At some point it all added up in my head. The chill behavior, the nurses' comments, the general mood of the room, the pediatrician's weird approach, my cousin's response...

I went back to the hospital room and for 8 straight hours, I immersed myself in it. There was no sleep. Meals and restroom breaks were ignored. I consumed everything I could about Down syndrome. I tried to find the cause and, bizarrely, a cure.

Mostly, I just learned how ignorant I was about it. I felt resolute. It was a mission now, a task. In many ways nothing changed - I still have a child to raise. And so far, it's been about like you'd expect. He has a different pace on things but he gets there.

Now, Anderson has bad days like any other 3 year old, but he is a beacon of joy for everyone he encounters. He's a game changer. He loves so hard. He knows people. He hears people. He feels people. He talks. He ponders things. He IS. And we thank God for him. He's perfect! He's happy and thriving! And huge! I am grateful for this child. I hold him close and make sure he knows how much he is loved. He's happy to return the favor.

There was no one in my life that even knew anyone with Down syndrome.

DSCNWA Servicios y Programas



Christa Henson Photography

Revista para Padres Nuevos

La revista "First Steps" está diseñada para educar y reconfortar a padres nuevos de niños(as) con Síndrome de Down. Esta revista está llena de información útil y correcta y de listas sobre recursos para familias de individuos con Síndrome de Down. Este recurso es provisto de forma gratuita a hospitales locales para ser diseminada a nuevos padres y futuros padres.

Canasta para Padres Nuevos

DSCNWA provee paquetes de bienvenida con información sobre Síndrome de Down y regalos de bebe para familias que han recibido un diagnóstico.

Desayunos Trimestrales de Soporte

Padres que son nuevos al diagnóstico están invitados a acompañarnos una vez al trimestre para un evento social para compartir recursos y establecer contactos.

Red de Contactos de Padre a Padre

Padres con experiencia ofrecen soporte, amistad, e información a padres nuevos que han recibido un diagnóstico.

Biblioteca de Recursos

Libros, folletos, y visualizaciones sobre el Síndrome de Down están disponibles para ser prestados de forma gratuita.

Conferencias, Seminarios, y Talleres

DSCNWA ofrece seminarios y talleres durante el año para educar a miembros del DSCNWA y a toda la comunidad. Oradores locales y nacionales son invitados a compartir información pertinente sobre las mejores prácticas con relación al soporte de individuos con Síndrome de Down.

Todos los Eventos Sociales de las Familias del DSCNWA

DSCNWA patrocina varios eventos cada año, incluyendo la búsqueda de huevos de pascua, eventos sociales con helado, y celebraciones de días festivos para que todos los miembros se reúnan y compartan intereses y valores en común. Las familias utilizan estos eventos como una oportunidad para crear redes de contacto y compartir información y recursos uno con el otro.

Grupo de Facebook del Down Syndrome Connection of Northwest Arkansas

Un gran recurso para mantenerse informado sobre los próximos eventos del DSCNWA, conocer a nuevas personas, y hacer preguntas y obtener respuestas rápidas por parte de familias locales.

Grupos del Programa DSCNWA Tribu de Nuevos Padres:

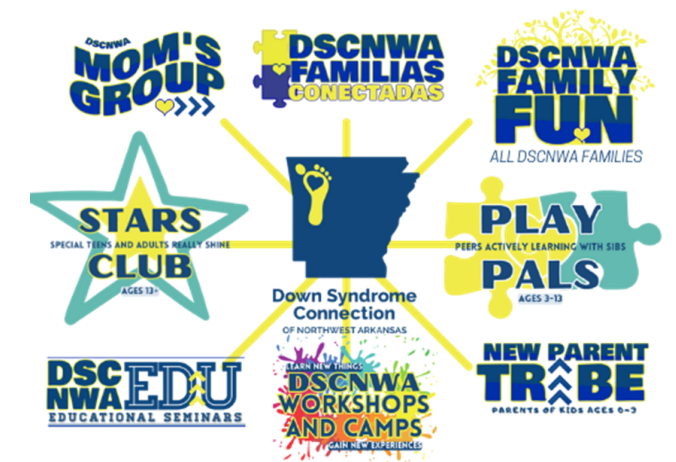
Grupo para padres de niños con Síndrome de Down entre las edades de 0-3 años. Este grupo ofrece reuniones sociales que permiten a padres de niños pequeños hacer nuevos amigos, hablar de preocupaciones, compartir alegrías, y desarrollar nuevos apoyos.

Play PALS: (Compañeros Aprendiendo Juntos Activamente):

Este grupo está diseñado para niños con Síndrome de Down, sus hermanos, y papa de edades de 3 años a 12 años. El grupo ofrece oportunidades para que los niños hagan amigos, trabajen en sus habilidades sociales, sus habilidades verbales, sus habilidades motrices, y que se diviertan. Se solicita que los padres se mantengan en la ubicación durante el programa.

STARS: Special Teens Achieving Real Success (Adolescentes Especiales Logrando Éxito Verdadero):

Este programa ofrece un entorno social seguro para que adolescentes y adultos mayores de 13+ años con síndrome de Down interactúen entre sí y con sus compañeros voluntarios típicos. Oportunidades para hacer nuevos amigos, trabajar en valiosas habilidades para la vida y fomentar la independencia, aumentar la confianza en uno mismo y la autodefensa. Los padres no se quedan durante los programas.



Para más información sobre Down Syndrome Connection of Northwest Arkansas (DSCNWA) contacte a nuestra oficina al 479-282-3639 o por correo electrónico a info@dscnwa.com, o visite nuestra página en www.dscnwa.com

El Síndrome de Down

DEFINICIÓN

El síndrome de Down es la más común y fácil de reconocer de todas las condiciones asociadas con el retraso mental. Esta condición (antes conocida como mongolismo) es el resultado de una anomalía de los cromosomas: por alguna razón inexplicable una desviación en el desarrollo de las células resulta en la producción de 47 cromosomas en lugar de las 46 que se consideran normales. El cromosoma adicional cambia totalmente el desarrollo ordenado del cuerpo y cerebro. En la mayor parte de los casos, el diagnóstico del síndrome de Down se hace de acuerdo a los resultados de una prueba de cromosomas que es suministrada poco después del nacimiento del niño.

INCIDENCIA

Cada año en los Estados Unidos, nacen aproximadamente 4,000 niños con síndrome de Down. Se podría decir que uno en cada 800 a 1,000 niños nace con esta condición. Los padres de cualquier edad pueden tener un niño con síndrome de Down. Aunque no importa si los padres sean jóvenes o mayores, la incidencia es mayor entre las mujeres sobre los 35 años de edad. Las formas más comunes del síndrome generalmente no ocurren más de una sola vez por familia.



CARACTERÍSTICAS

A pesar de que hay más de 50 síntomas reconocidos del síndrome de Down, es raro encontrar una persona con todos o una gran cantidad de éstos. Algunas características incluyen:

1. Falta de tono muscular
2. Ojos alargados, con el cutis pliegado en el raballo del ojo
3. Hiperflexibilidad (la habilidad de extender excesivamente las coyunturas)
4. Manos chicas y anchas con una sola arruga en la palma de una o ambas manos
5. Pies anchos con los dedos cortos;
6. El puente de la nariz plano
7. Orejas pequeñas, en la parte inferior de la cabeza
8. Cuello corto
9. Cabeza pequeña
10. Cavidad oral pequeña
11. Llantos cortos y chillones durante la infancia

Los individuos con síndrome de Down típicamente son más pequeños que sus compañeros normales, y su desarrollo físico e intelectual es más lento.

Aparte de un distintivo aspecto físico, los niños con síndrome de Down

frecuentemente experimentan problemas relacionados a la salud. Por causa de la baja resistencia, estos niños son más propensos a los problemas respiratorios. Los problemas visuales, tales como los ojos cruzados y la miopía, son comunes en los niños con síndrome de Down, al igual que la deficiencia del habla y del oído.

Aproximadamente una tercera parte de los bebés que tienen síndrome de Down tienen además defectos en el corazón, la mayoría de los cuales pueden ser corregidos. Algunos individuos nacen con problemas gastro intestinales que también pueden ser corregidos, por medio de la intervención quirúrgica.

Algunas personas con síndrome de Down también pueden tener una condición conocida como Inestabilidad Atlantoaxial (Atlantoaxial Instability), una desalineación de las primeras dos vértebras del cuello.

Esta condición causa que estos individuos sean más propensos

a las heridas si participan en actividades durante las cuales pueden extender demasiado o encorvar el cuello. A los padres se les pide una examinación médica en este respecto, para determinar si al niño se le debe prohibir los deportes y actividades que puedan dañar el cuello. A pesar de que esta desalineación puede ser una condición seria, un diagnóstico correcto podría ayudar en la prevención de las heridas serias.

En muchos casos los niños con síndrome de Down son propensos a subir de peso con el tiempo. Además de las implicaciones sociales negativas, este aumento de peso amenaza la salud y longevidad de estos individuos. Una dieta controlada y un programa de ejercicio podrían presentar una solución a este problema.

Consulte la página 3 para obtener más información para discutir con su médico.

Comfort came from seeing how different life is these days compared to how it was when I had limited exposure to people with Down syndrome in my younger years. I found the Down Syndrome Connection of Northwest Arkansas which was a crucial lifeline for me mentally. I met with the President of the organization, who gave me all the time I needed and answered every question he could. He kickstarted my desire to be an advocate and not just a parent. A parent-advocate is a strong force, a real agent of change. That's who I strive to be for my son and others in the community.

But my biggest takeaway from him: This isn't a club we asked to join. It's true. It isn't. We never wanted this. But there we were, going to events with strangers.

It's sometimes weird if it feels like friendships are forced only because of the common thread that has nothing to do with your personalities or life experience. But let me tell you - I've learned a huge lesson about people. No one is without value. And there is huge value in community.

We've made some life long friends just because our kids have Down syndrome. We're all just regular people that got lucky enough to have someone join our life that reminds us daily how joyful it can and should be, and that ended up connecting us with other enlightened folks.

DSCNWA does a great job connecting people to important resources. One of the most important resources is someone to talk to who's been through it. Someone like you, perhaps, that had an otherwise charmed life and suddenly found their world rocked one day. It can take you to some dark places. It's normal. You're not alone. You are loved. There is help. There are shoulders to cry on, ears to listen, people to advise, and friends to be made. We have felt it. We know what's on your heart.

When we are able to have fellowship with other parents via DSCNWA events we never regret it. It's a fantastic organization led by a diverse, incredibly talented team representing a good cross section of NWA. And they're no slouches - this group works hard. Many have advanced degrees but are out there sweating it out making the events happen. They are servant leaders in the truest sense.



Look, parenting is really hard. Accepting what you believe to be very bad news about your child is possibly harder. We all get it. In the beginning it's particularly hard to digest the words people throw at you. "They're so happy! They've come a long way! You hit the jackpot!" It all feels a little disingenuous even though they have the best of intentions. They aren't the experts, after all. They certainly don't know what happens behind the scenes. And they haven't a clue just how messed up your schedule is and how hard you have to work just to get through each day. Those are teachable moments - relish them.

I can promise you this - it does get easier. It helps to be around others and see children and even adults with Down syndrome. Talk to them. You'll be surprised! I know I was! It gives me hope and optimism to be around other families with positive outlooks and children that are thriving.

At some point you'll begin to have days where you won't even think about Down syndrome. Yes, that's right - it won't always consume your entire life! That's just your child, it's not your child with Down syndrome.

You will find therapists that love your child and help him/her thrive, and you'll regularly be impressed with small victories. Let your child be your child first. Don't lower expectations.

When all other advice is junk, just remember this - that is still your flesh and blood. You're equipped to handle this. It will stretch you but it will make you a better parent and person. And the joy you get to share when you celebrate every win is worth the difficulty and then some.

And because you need to hear it, and because it is true - everything will be alright!

Anderson's Dad - Ron Miller



Breastfeeding & Your Baby



The best advice your pediatrician can give you is to take your new baby home and shower him with love, warmth, security and personal attention that the family unit can provide. This helps your baby develop to his fullest potential. The majority of babies with Down syndrome are happy, playful, and a delight to the whole family. Though the child is developmentally delayed, he is capable of expressing his emotions. He responds readily to love, and returns it enthusiastically to those around him.

Please be aware that other mothers have gone through the emotions that you are feeling right now. You are not alone. These parents will be happy to share their experiences and the information they have gathered that will help you nurse your new baby successfully.

Can a baby with Down syndrome learn how to nurse and be strong enough to nurse successfully? The answer is YES! Sometime it takes a little longer for the baby to learn how to suck well. It might take longer even for an experienced nursing mother to learn the particular "trick" to help your new baby with Down syndrome to nurse successfully.

Breastfeeding not only strengthens the maternal-infant bond, but it is also a major contributor to the baby's nutritional well being. The advantages of breastfeeding take on added significance for the baby with Down syndrome. They have a greater susceptibility to infection than other infants so the immune factors present in colostrum and breast milk are especially valuable. Recent research shows that breast milk contains lactoferrin and transferrin, which prevent the growth of harmful bacteria in the intestinal tract. The bifidus factor (contained in breast milk) also promotes the growth of friendly bacteria in the intestinal tract. Further protective action is gained from lysozyme found in breast milk that attack and break down bacteria. Antiviral factors, such as interferon, are also present in human milk. These are just a few examples of why breast milk is the best food for the baby. Of special interest is the high level of tryptophan (an amino acid) and lactose found in breast milk. These two nutrients have been found to be essential for growth in early infancy and especially for brain development.

Many pediatricians tell their new mothers that nursing is the very best thing for new infants with Down syndrome. It is the perfect food for their immature digestive systems and it provides good tongue thrust and jaw development.

When the baby is born with Down syndrome, there are varying degrees of concerns. The baby may be a little sleeper and have a poor sucking reflex, while others may have respiratory problems and more serious difficulties. If your baby is weak at birth, he may experience some difficulty in learning to suck and swallow, so you will need to be calm and patient while he learns.

Babies with Down syndrome are often more prone to respiratory infections and digestive upsets. Breastfeeding lessens the incidence of both of these problems and probably reduces the severity of them if they should occur. Babies with Down syndrome are often placid and sometimes have poor muscle tone and generalized weakness at birth. Therefore, the mother will have to learn to be a clock watcher, picking the baby up frequently and offering the breast, rather than waiting for him to cry to be fed. The baby should be encouraged to nurse about every two hours during the day and several times during the night.

Sometimes mothers have trouble getting the baby's tongue down from the roof of his mouth. To help with this concern, insert the tip of your finger between the roof of the baby's mouth and the tongue in an upside-down position, then turn the finger over, to condition the sucking reflex, the procedure could be repeated four or five times before each nursing, starting with the finger at the front of the baby's mouth and pushing it slowly into the baby's mouth so the baby will think he is drawing in.

When you get home from the hospital it is important to remember to take care of yourself. You need to rest and to watch your nutrition, just as you did when you were pregnant. To assure yourself of these things, a mother's helper is a wonderful asset — someone to care for you while you care for your baby.

Of course you will be in close contact with your doctor who will continue to evaluate your baby's progress. Because some babies with Down syndrome don't gain weight as well as they should, doctors sometime suggest solids earlier than usual. Let your doctor's advice and the baby's needs be your guide. Many babies with Down syndrome are slow, leisurely nursers, so long feedings are to be anticipated. You'll both thrive on these quiet times; this can be a cozy, relaxing time.

The rewards of nursing your baby are well worth the extra effort, so don't be discouraged if you encounter problems. A good knowledge of breastfeeding is helpful. *The Womanly Art of Breastfeeding* can be obtained from the local La Leche League and can offer excellent information and encouragement. Lactation specialists are also available through most hospitals and WIC (Women Infants and Children) programs to offer encouragement and support and to help you and your new baby learn together the art of breast-feeding.

New parents often don't realize that children with Down syndrome can have nearly normal social and emotional development. Babies with Down syndrome thrive on the stimulation, attention, and the tender, loving care that all children need. They return love one-hundred fold.

For more information find the book:

Breastfeeding & Down Syndrome - A Comprehensive Guide for Mothers and Medical Professionals by Ella Gray Cullen

Author - Unknown

Bienvenidos a Holanda

por Emily Pearl Kingsley

A menudo me piden que describa lo que es la experiencia de criar a un niño con una discapacidad. Para ayudar a entender lo que esta experiencia única significa, a aquellos que nunca la han tenido; para poder imaginar lo que se siente, dejenme decirles que es algo parecido a lo siguiente...

Cuando se va a tener un bebé es como planificar un viaje de vacaciones fabulosas a Italia. Se compran un montón de guías turísticas y se hacen planes maravillosos: el Coliseo, el David de Miguel Ángel, las Góndolas de Venecia. Uno se prepara incluso para aprender algunas palabras en italiano. Es muy emocionante.

Luego que se han pasado meses en expectativa, finalmente llega el esperado día. Horas más tarde, el avión aterriza. La aeromoza se acerca y anuncia: "Bienvenidos a Holanda".

"Holanda?!" se pregunta uno. "Como que Holanda?!" Mi vuelo era para Italia! Se supone que debía estar en Italia. Toda mi vida he soñado con ir a Italia.

Pero, ha habido un cambio en el plan de vuelo. El avión aterrizó en Holanda y debe quedarse aquí.

Lo importante es que no le han llevado a un lugar horrible, desagradable y sucio, lleno de pestilencia, hambre y enfermedad. Es sólo un lugar diferente.

Así es que usted debe salir a hacer compras y adquirir nuevos mapas y guías. Y debe aprender un nuevo idioma. Y conocerá a un montón de gente que nunca habría conocido.

Sólo que es un lugar diferente. Con un ritmo un poco menos ajetreado que el de Italia, menos bullicioso y aparatoso. Pero, luego de estar allí por un tiempo, una vez que la agitación ha pasado, usted mira a su alrededor y comienza a darse cuenta que Holanda tiene los molinos de viento, y Holanda tiene los tulipanes. Holanda incluso tiene los Rembrandts!

Pero todo el mundo está muy ocupado yendo y viniendo de Italia, y todos se ufanan de las maravillosas vacaciones que han pasado allí. Y por el resto de su vida, usted se dirá "Si, allí es donde yo debía haber ido. Eso es lo que tenía planeado".

Y ese dolor nunca, nunca jamás se irá, pues la pérdida de ese sueño es una pérdida muy significativa.

Pero, si usted se pasa la vida lamentando el hecho que no llegó a Italia, nunca tendrá el espíritu libre para disfrutar lo más especial, lo más precioso de Holanda.



Christa Henson Photography

Sofia

Mi nombre es Jessica, mi esposo es Ricardo y tenemos cuatro hijas, Idaly, Michelle, Sofia, y Mary. Sofia tiene síndrome de down. Mi embarazo de Sofia fue muy normal. Ibamos a las citas de doctor y nos decía cada vez que todo parecía ir muy bien. En ningún momento sospeché el doctor que tal vez Sofia nacería con síndrome de down. Sofia fue prematura, naciendo a las 36 semanas. Al nacer Sofia, estuvimos internados en el hospital durante 3 días. El primer día entró la pediatra del hospital a nuestro cuarto para hablar con mi esposo y conmigo. Su primera pregunta fue: Saben que es el síndrome de down o conocen a alguien que lo tenga? Nuestra respuesta fue "no." Yo no conocía sobre esto ni tenía algún conocido con síndrome de down. Solo me acordaba de haber escuchado sobre este tema alguna vez cuando iba en la escuela. La pediatra luego nos dijo "Su bebé tiene características de una bebé con síndrome de down, pero por el momento no le podemos asegurar que este sea el caso, le tomamos muestras de sangre a su bebé y los resultados llegarán dentro de dos semanas." Mi esposo y yo nos quedamos confundidos y ofendidos a la vez, pues, pensamos en como podía ser capaz la doctora de insinuar que algo tenía nuestra bebe recién nacida, si para nosotros era tan perfecta y hermosa. Decidimos no decirle a nadie lo que estaba pasando, mas que nada por que no sabíamos si Sofia tenía síndrome de Down o no y no sabíamos realmente que era el síndrome de down.

Después de tan solo un día en casa, Sofia tuvo un chequeo con su pediatra y de nuevo fue internada debido a deshidratación por dos días. Estando en el hospital paso un pediatra nuevo y le pregunté: "Doctor usted cree que mi niña tenga síndrome de Down?" Su respuesta fue sencilla: "No se puede saber hasta que no regresen los resultados de la muestra de sangre." Nos aconsejo que no buscáramos información en internet hasta que nos llegaran los resultados. Sofia tenía citas con su médico cada tres días para revisar su peso y asegurarse de que estuviera subiendo de peso. Cada tres días le preguntaba al doctor que si ya había recibido los resultados. Nada. Fue tan difícil para esperarnos. Desde un principio decidimos poner todo en las manos de Dios. Para nosotros Sofia estaba bien de salud y es lo que mas nos importaba. Pensamos que si los resultados eran negativos, seguiríamos adelante nuestra vida normal con nuestras hijas. De igual manera, si los resultados regresaban positivos, le pediríamos a Dios que nos diera las fuerzas, conocimiento, y paciencia para darle la mejor vida que se le pudiera dar a Sofia. A las dos semanas le toco cita a Sofia con su doctor. La cita fue igual que todas. La enfermera le tomó el peso, y nos pasó a un cuarto a esperar el doctor. Entro el doctor, dijo que todo parecía perfecto, se despidió como todas las veces anteriores y ya iba de salida. Lo detuve y le pregunté, como todas las veces, "disculpe, pero todavía no sabe nada sobre los resultados de sangre?"

Christa Henson Photography



Tomó asiento de nuevo el doctor, me miró a los ojos firmemente y me dijo "no recibió una llamada la semana pasada? Fue positivo." Sentí que se me quebró el corazón. La única pregunta que me salió preguntarle, de las cientos que pasaban por mi mente, fue "Qué sigue de aquí?" Como nos había mencionado antes, nos recomendó no buscar información por internet. Nos dijo que Children's Hospital se iba comunicar con nosotros.

Dentro de una semana recibimos la llamada de Children's Hospital. Esperábamos que nos dieran información sobre el Nuevo diagnostico de Sofia. Solo nos llamaron para agendar una cita con un médico de genética cuando Sofia cumpliera seis meses. Nos sentimos impotentes. Aún no le habíamos dicho nada a la familia por que en realidad ni nosotros sabíamos aún lo que significaba tener síndrome de Down.

Cuando Sofia tenía 4 meses le comenté a una amiga que Sofia había nacido prematura. Nuestra amiga es terapeuta infantil y nos recomendó que lleváramos a Sofia a su consultorio. Nos dijo que le beneficiaría mucho recibir terapias. En ese momento le comenté que también tenía síndrome de down. Al instante su tono de voz cambio por uno más serio y compasivo, me dijo "no tienes idea lo importante que es para tu bebé recibir terapias. Es lo mas importante que tú le puedes dar a tu niña para ayudarle a vivir una vida normal." Me sentí con esperanza y motivada. Al final de cuentas, lo que una quiere para sus hijos es lo mejor. Lo hablamos mi esposo y yo, pensamos, nos esperamos a su cita y luego la llevamos? O si es tan importante por que no lo había mencionado el doctor? Decidimos llevarla al lugar de las terapias. Aún sigue siendo una de las bendiciones más grandes que hemos recibido. Los terapeutas nos educaron sobre síndrome de down y nos conectaron con otras familias en nuestra área que tenían hijos o seres queridos con síndrome de Down.

Se siente lejano aquel día que recibimos la noticia del diagnostico de Sofia, pues ahora tiene cuatro años, es una niña muy alegre y sociable. Le gusta cantar, bailar y convivir con la gente. Sin embargo, llegar hasta donde estamos hoy no fue fácil pues cuando recibimos el diagnóstico aunque tratamos de mantenernos positivos, si pasamos días difíciles. Días de no saber si estábamos tomando las mejores decisiones para ella y días que nos sentíamos abrumados. Pero al final del día, logramos mantenernos positivos y aprender a ser mejores padres para Sofia y no cambiaríamos ni un momento, ni un recuerdo, ni un cromosoma.

La mamá de Sofia - Jessica Nieves



It was actually easier to tell my children that their new baby sister had Down syndrome than it was to tell other family and friends. Adults have preconceived ideas or remember old stereotypes. Their first instinct was to be sad. I spent a lot of time comforting them, and explaining that times have changed and our child has a promising future.

Children, however, are so accepting and if they are already in school, they have probably had more experience with people with special needs than most adults. Their new sibling is either the best new playmate they could ever ask for, or she's an intruder that is demanding a lot more of mom's time than they are willing to give up. Well, what newborn doesn't fall into one of those two categories?

I've always told my children that what makes them different is what makes them special. They understood this long before we brought home their new sister. "Oh, so Kathryn is special because she has Down syndrome. Well, I'm special because I'm the fastest runner in my class," my older daughter simply stated. "Yeah, and I'm super special because I am the only brother in our family," added my son. "That is true, and as Kathryn gets older we'll learn more about her special talents and gifts just as we learn more about you as you get older," I explained.

How Do I Tell the Kids?



Laura Powers Photography

Of course how much your child understands about Down syndrome depends on their age and sometimes their personality. My six-year-old daughter wanted to know all about therapy. Most kids play house or doctor. Mine played therapist. She became an authority on the subject among her school friends and enjoyed educating them about her sister and the best teaching techniques. My four-year-old son, on the other hand, just wanted to know when she would be ready to wrestle. As far as he was concerned, telling him his sister has Down syndrome was like telling him she has blue eyes. "Yeah, yeah, yeah. But does she like Spiderman better, or Batman?"

I frequently point out to my children other individuals with Down syndrome. They learn a lot from observing, asking me questions, or talking with the person. It is comforting for them to see that the world is full of some pretty great people who just happen to have Down syndrome.

I have discovered that no matter how old your children are, telling them about Down syndrome is an on-going process. At first they just need to know that for the most part their baby is going to be like any other baby. She'll just need some extra help. As the kids mature, new experiences will invite further discussions. Maybe they notice some unique features and so we launch into a discussion about how each of us is made differently...hair, eyes, skin and so forth. Maybe a friend has a question and together we find the answer. As parents, we learn what we need to about Down syndrome each time we approach a new phase. It is exactly the same for our kids.

You'll be amazed how much your children figure out for themselves and can even teach you.

A wonderful way to introduce Down syndrome to kids is by reading the book 47 Strings: Tessa's Special Code. Available for free checkout at the DSCNWA library and included in our new parent baskets.

47 Strings: Tessa's Special Code is a children's picture book that explains what Down syndrome is in a kid-friendly way that is easy to understand. 47 Strings also encourages children to embrace differences in their peers, and it expresses the belief that different does not equal less.

Questions About Early Intervention

What is Early Intervention, and what is its purpose?

The concept of “early intervention” is quite simple. If a child with a developmental delay receives proper help early on, problems in the future may be minimized. A child, his/her family, and the educational system will benefit by the reduced need for long-term intervention throughout the child’s school years.

How much does it cost?

There may be fees associated with these services depending on which state you live in and your household income. Please ask your early intervention provider about fee schedules.

What kinds of things will my child with Down syndrome do in Early Intervention?

Your child will participate in a variety of activities planned by licensed therapists, teachers, and nurses. The setting for these activities—which are designed to provide physical, occupational, and speech therapies as needed—may include regularly scheduled home visits, play group activities, individual therapy at home, daycare or hospitals, or other combinations that work for your family. Your child’s record will be kept confidential.

Will I have any say regarding my child’s participation in any of these therapies?

Absolutely! After eligibility is determined (and most children with Down syndrome usually qualify), the Individualized Family Services Plan (IFSP) is written with help from the parent(s) and services begin.

When should my child start Early Intervention Services?

Some families choose to enjoy their babies and adjust to life with a new little one before jumping in. Others choose to start therapy right away. Ideally, a baby would start therapies within the first 8 weeks of life if that works in your family schedule.

Is there an age limit to receiving Early Intervention services?

The age limit is newborn to three years.

PT, OT, and Speech Therapy

Pediatric Physical Therapy (PT) is the treatment of children with physical disabilities by a licensed professional physical therapist who is educated and trained in the diagnosis and treatment of children with physical disabilities. The goal of PT is to improve care and provide a treatment program to obtain or restore the highest level of independence and function in quality of movement, walking, strength and endurance, gross motor skills, posture, positioning for functional skills, coordination, and mobility for the child with the disability.

Pediatric Occupational Therapy (OT) is the treatment of children with physical, emotional, and/or intellectual disabilities age birth to 21 by a licensed occupational therapist educated in a variety of diagnoses and therapies for such children. The goal of OT is to help make learning possible by helping children develop the underlying skills that will lead to independence in personal, social, academic, and vocational activities. This includes remediation of difficulties the child may encounter with ADLs (Activities of Daily Living) such as dressing, grooming, feeding, etc.

Pediatric Speech Therapy addresses the child’s complete communicative needs. This often begins with the development of non-verbal communicative skills such as attending to the speaker and the activity, taking turns, and making appropriate eye contact. It is designed to help with speech disorders, often referred to as articulation or phonological disorders—problems with the way sounds are made or how sounds are sequenced to form words; oral-motor problems resulting in difficulty producing speech sounds; and delays in feeding skills. A speech-language pathologist is a specialist in the normal development of human communication. The Certificate of Clinical Competency (CCC) assures you that a speech-language pathologist has been qualified to provide clinical services by the American Speech-Language Hearing Association (ASHA).

Purple Heart Photography



¡Felicitaciones!

Querido Nuevo Padre,

Como padre de un niño con Síndrome de Down, quiero presentarle a una organización de voluntarios sin fines de lucro fundada por padres de niños con Síndrome de Down. El Down Syndrome Connection of Northwest Arkansas (DSCNWA) busca proveer apoyo y recursos para individuos con Síndrome de Down y sus familias. Como un padre amigo, yo sé que está pasando por muchas emociones ahora mismo.

Si usted es como muchas personas, tiene un poco de idea de lo que el Síndrome de Down significará para su niño y su familia. Las impresiones que usted tiene han de ser probablemente sin esperanzas e inexactas. Usted será aconsejado por los profesionales que encuentra a no leer nada sobre Síndrome de Down escrito hace más de cinco años atrás, ya que nueva información y terapias están rápidamente siendo descubiertas y perfeccionadas. Una gran red de servicios sofisticados y especialistas están disponibles para ayudar a su niño y a su familia- la mayoría sin costo para usted. ¡Su niño tiene un futuro muy brillante!

La revista DSCNWA incluye información sobre servicios locales disponibles para usted. Le sugerimos que lea la sección titulada “Primeras cosas” mientras que esté en el hospital. Elija del resto en cualquier momento que esté listo.

Junto con esta revista, nos gustaría ofrecerle una copia complementaria del libro “Bebés con Síndrome de Down”. La información en este libro provee una actual y clara introducción al Síndrome de Down. Por favor contacte nuestra oficina para pedir su copia gratis de este libro, una cesta de regalo y coordinar una cita para los padres nuevos.

El diagnóstico de su hijo puede parecer abrumador en este momento. De todas maneras, a medida que usted vaya aprendiendo más y más sobre el Síndrome de Down, este llegará a ser una característica definida de su niño- su maravilloso, adorable, cómo-pensé-que-la-vida-era-buena-antes-de-él ...niño.

¡Felicitaciones por su nuevo bebé!

DSCNWA STAFF & BOARD OF DIRECTORS



Christa Henson Photography

Step Up for Down Syndrome Event

Each year members of the Down Syndrome Connection of Northwest Arkansas (DSCNWA) gather their family and friends to take part in the Step Up For Down Syndrome Event.

This event is the main fundraiser for the DSCNWA, and it enables us to continue to grow the programs and services that we offer to our local families throughout the year for free. The Step Up For Down Syndrome Event takes place on a Saturday in October during an away game for the Razorbacks.

For more information on the Step Up Event, making a team, sponsor and volunteer opportunities visit dscnwa.com > Events & Programs > Step Up Event or email us at info@dscnwa.com



Just Like You - Down Syndrome



JUST LIKE YOU -- DOWN SYNDROME - a 13-minute youtube video that explores the life, hopes, challenges and dreams of three kids living with Down syndrome. Elyssa, Rachel and Sam share personal stories to help viewers better understand their condition and why they wish to be treated just like you. Each of our stars has their own talents, characteristics, strengths and challenges. Down syndrome is just one part of who they are and this film identifies how to handle and accommodate differences while celebrating the many similarities our friends with Down syndrome have with their peers.

There have been over 550,000 views on YouTube! Schools and Down syndrome organizations across the US are hosting screenings. The film is offered in Spanish, Portuguese and Icelandic.

"This is the very best video I've EVER seen explaining Down syndrome to ANYONE - it is appropriate to show children as young as Pre-k, Elementary, Middle School, High School - and yes even those ignorant adults we all know and sometimes love (some are friends, some are merely acquaintances, some are FAMILY members) . . . THEY ALL NEED TO WATCH THIS VIDEO!!"

"This film should be shown in every school around the world to help children and adults better understand what it means to live with Down syndrome and how you can provide respectful support."

"I watched this film with tears streaming down my face as I know it will open the doors to friendships. My 12 year old daughter with Down syndrome said, mom they have Down syndrome like me!"

WWW.JUSTLIKEYOU-DOWNSYNDROME.ORG

Where to Start

Arkansas State Programs

These are listed on DSCNWA's website for easy access at DSCNWA.com



Arkansas Department of Human Services, Division of Medical Services

The state of Arkansas has many benefits available to support families. However, navigating these benefits can be challenging. We would encourage you to visit the websites listed below for more information. Apply for TEFRA or SSI. Submit within 90 days of birth to have birth-related expenses covered.

TEFRA-Tax Equity & Fiscal Responsibility Act

Is a Medicaid program for children under the age of 19 years old with a disability. Premiums are based on a sliding scale and pick up charges after primary insurance has paid. It is very beneficial because most insurances have caps on therapies, such as (PT) physical therapy, (OT) occupational therapy & (SP) speech-language pathology.

Contact Information: humanservices.arkansas.gov/about-dhs/dms/tefra
Benton & Washington counties: Amanda Bunch 870-423-3351

SSI- Supplemental Security Income Benefits

Disability benefits for 0-18 year olds, dependent on income requirement.
Contact Information: www.ssa.gov/benefits/ssi or call 800-772-1213

Medicaid Waiver

A division of the Medicaid program that allows your loved one to remain living at home or in the community with support staff instead of in an institution. FYI: there is a long waiting list and some families have been waiting for years (10+ years).

humanservices.arkansas.gov/divisions-shared-services/developmental-disabilities-services/ces-waiver/
Children's Contact Information: 501-682-2277 Adult Contact Information: 501-683-5687

PASSE-Provider-led Arkansas Shared Savings Entity

When enrolled in TEFRA and Medicaid Waiver you will be assigned PASSE and Optum will come out for an independent assessment and your child will be assigned a care coordinator. The PASSE is responsible for paying the medical claims.

Contact Information: www.passe.arkansas.gov or call 833-402-0672

Early Intervention (0-3) under Part C of the Individuals with Disabilities Education Act (IDEA) is First Connections

The Department of Human Services, Division of Developmental Disabilities Services is the "lead agency" with administrative oversight. First Connections provides supports and services for families and their children, birth to age three who have special needs. They serve infants and toddlers birth to age three with certain levels of developmental delay or a diagnosed condition likely to result in developmental delay and their families. Participation in early intervention is at no cost to families with an eligible infant or toddler.

Contact information: firstconnectionsar.org/services or call 800-643-8258

ARHIPP-Arkansas Health Insurance Premium Payment Program

A free program offered to those with employer-sponsored health plans or COBRA. This program may pay part or all of your insurance premium. Must be enrolled in TEFRA to be eligible.

Contact Information: myarhipp.com or call 855-692-7447

US Social Security Office is located at 2153 E Joyce Blvd- Suite 101, Fayetteville, AR 72703. 877-694-5493

New Parent Tribe

“After my child was born with Down syndrome, it became exhausting to deliver this news to my family and friends. I was very proud of my new baby, but felt like I had to stay extra upbeat when I talked to any of them. Through the New Parent Tribe program, I contacted another parent of a child with Down syndrome. It was nice to talk to someone else who had been in my shoes. He was able to talk to me with empathy, not sympathy. As a parent of a child with Down syndrome, he found it easy to focus on my new child as a child first and assured me of the positive future for my child and my family.”

As new parents of a child with Down syndrome, you probably have many questions. One of your best resources for assistance is a fellow parent of a child with Down syndrome.

The New Parent Tribe has quarterly gatherings, allowing parents to meet fellow parents, meet new friends, discuss concerns, share joys and develop new supports. Gatherings are intended for expectant parents and parents with children ages 0-3.

When you receive a diagnosis, contact DSCNWA and we will deliver a basket full of baby items and resources about Down syndrome. If wanted, we would like to schedule a visit with a member of our organization at your convenience. We also try to connect you to a family with similar experiences as your own. If you would like to have a new parent visit and/or be matched with a family, contact DSCNWA at (479) 282-3639 or info@dscnwa.com. We know you may experience a lot of feelings and emotions when you receive a diagnosis and we are here to offer support and celebrate your new baby with you!



NEW PARENT TRIBE
PARENTS OF KIDS AGES 0-3



DSCNWA Services & Programs

New Parent Magazine “First Steps” magazine is designed to educate and comfort new parents of a child with Down syndrome. The magazine is filled with useful and accurate information with helpful lists of resources for families with individuals with Down syndrome. This resource is provided free to local hospitals to disseminate to new and expectant parents.

New Parent Basket DSCNWA provides welcome packages with Down syndrome information and baby gifts for families that receive a diagnosis.

Quarterly New Parent Gatherings: Parents new to the diagnosis and with young kids are invited to join us once a quarter for a networking and resource sharing mixer with the rest of our New Parent Tribe.

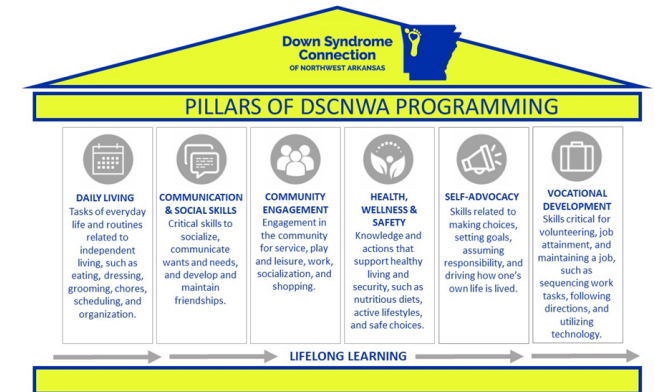
Parent to Parent Network Experienced parents offer support, friendship and information to new parents upon receiving a diagnosis.

Resource Library Books, brochures, and visuals about Down syndrome available on loan at no cost.

Conferences, Seminars and Workshops DSCNWA offers seminars and workshops throughout the year to educate DSCNWA members and the community at large. Local and national speakers are invited to share pertinent information on best practices related to supporting individuals with Down syndrome.

All DSCNWA Families Social Events DSCNWA hosts several events each year including an Easter Egg Hunt, Ice Cream Social and Holiday Party for all members to come together and share common interests and values. Families look forward to these events as an opportunity to network and share information and resources with one another.

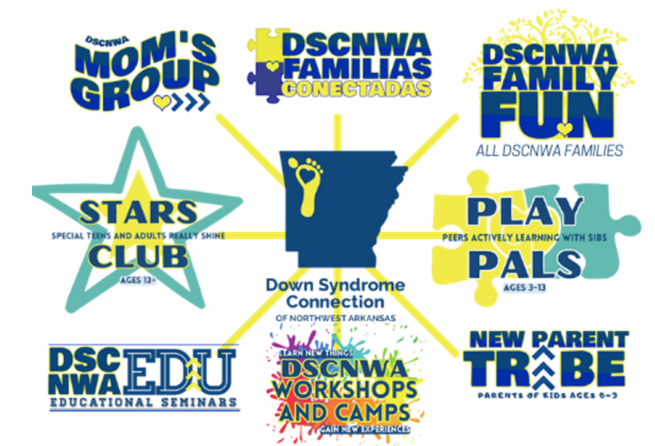
DSCNWA Facebook Group A great resource to stay informed with upcoming DSCNWA events, meet new people, ask questions and get quick responses from local families.



New Parent Tribe For parents of children with Down syndrome ages 0-3. Social gatherings that allow parents of younger kids to make new friends, discuss concerns, share joys and develop new supports.

Play PALS (Peers Actively Learning With Siblings) Designed for kids ages 3 to 12 with Down syndrome, their siblings and parents. Offering opportunities for kids to make new friends, work on social skills, verbal skills, independence, fine motor skills and to have fun.

STARS Club (Special Teens & Adults Really Shine) This program offers a safe social environment for teens and adults ages 13+ with Down syndrome to interact with each other and typical peer volunteers. Opportunities to make new friends, work on valuable life skills and foster independence, increase self confidence and self advocacy. Parents do not stay during programs.



For more information about the Down Syndrome Connection of Northwest Arkansas (DSCNWA) contact our office at 479-282-3639, via email at info@dscnwa.com, or visit our website at www.dscnwa.com

Welcome to Holland

by Emily Pearl Kingsley

I often am asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this . . .

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, Michaelangelo's David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland, and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you never would have met otherwise.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills.

Holland has Rembrandts.

And Holland has tulips.

But everyone you know is busy coming and going from Italy, and they're all talking about what a wonderful time they had there.

And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely, things about Holland.

Our nickname for Abby was "Holly." We ordered tulips for her.



Christa Henson Photography

K Wilder Photography



Bradley

Full of Surprises

Four years ago, I was pregnant with a baby boy due to join our family soon after Christmas. Bradley was full of surprises right from the start. He decided to come a month before his due date! We spent his birthday cuddling him and introduced him to his enamored big sister. In the evening while his sister was visiting, the pediatrician on-call came into our hospital room and while we wrangled our two-year-old, she kindly but nervously told us our son had some physical attributes that made her suspect he had Down syndrome. I was holding Bradley, trying to process what she'd just told us, and clearly remember attempting to smile reassuringly, while tears rolled down my face.

I was stunned. We had so many questions about what that meant for him, for his future, for our future... Would he have friends? Would others tease him? Would he play sports? Would he have a first kiss? Would he get to marry his best friend? Would he have a best friend? What health issues would he have... or already have?

As we searched the Internet, we had more and more questions... and more and more fears.

One difficult aspect of getting his diagnosis is that we instantly started worrying about his future--- 5, 10, 50 years ahead. With all your kids, you worry for the future, but for the most part you take those on one time period at a time. First, worry about sleeping through the night and feedings...then the first time you leave them with a babysitter, the first day of kindergarten, etc. The night he was born we started worrying about us dying before him and EVERYTHING until then.

In just weeks after Bradley was born, we experienced a hospital stay with RSV, IVIG transfusions, a leukemia scare, and a dependency on oxygen. We realized to a greater extent how precious life was- his life, our lives and our lives with him in it! One thing we continue to learn is to slow down and be in the present. Yes, plan for the future, advocate now, and push him to learn good habits and skills to help him later, but our focus should be more about right now. A friend wisely advised us to never let the fear of the future rob us of the joy of today.

Gina from the local Down syndrome group came to visit us when Bradley was about 3 months old. She brought up future potential difficulties but reminded us what

mattered today and reassured us we were exactly who Bradley needed. She gave us resources and told us about early intervention. She reminded us what he needed most right now was someone to love him, to feed him, and change his diapers. She told us not to limit Bradley, to set high expectations, and that we'd need to fight for him. She told us he'd surprise us over and over again. She validated how we felt (and we had every single feeling you can imagine...moments of peace, sadness, guilt, anger) and she left us with hope and someone to turn to that understood.

Soon after Gina's visit, we moved to Arkansas and learned about the DSCNWA. We were able to connect with other new and seasoned parents. We learned more about Down syndrome, what programs were available in Arkansas, and how to plan appropriately for Bradley's future. Having this tribe to turn to has been amazing. It's insightful to talk to parents ahead of us on this journey and to know other individuals with Down syndrome that have passed milestones and get advice from their parents. It's refreshing to talk to friends with kids Bradley's age that relate to our triumphs and struggles.

Bradley is full of surprises: his early arrival, his diagnosis, his stubbornness, how discerning he is, and how many strangers he can draw in. We wouldn't change one thing about him- even the extra chromosome! That extra chromosome might mean more doctor appointments, therapy, and different challenges than we once envisioned... but it's just a tiny part of who Bradley is. He is our cuddliest kid and a master of mischief that likes to make messes hourly and loves to play catch. He is silly, spunky, funny, sweet, and just happens to have Down syndrome. Because of a tiny extra chromosome, we see things a little differently than we once did, and these lenses are often wonderful. One extra chromosome will shape all of my kids and how they educate and include others. Because of a tiny extra chromosome, we celebrate tiny accomplishments we may have once taken for granted. Because of that extra chromosome, we have been so blessed to add a team of amazing therapists to our family and make life-long friendships with people we might not have been lucky enough to meet. One in every 800 babies is born with Down syndrome. We definitely hit the jackpot! We wouldn't change one chromosome in him!

Bradley's Mom - Danielle Pezely



In the summer of 2008, we were moving for a new job. My wife, Jenny, and I were expecting our third child, a boy. My wife has high-risk pregnancies due to a blood clotting disorder, which requires frequent monitoring with ultrasounds and stress tests throughout her pregnancy. With every test came good results, a healthy baby boy.

On July 29th, we excitedly arrived at the hospital to welcome our son into the world! Everything seemed to be going as planned. However, with one of the first pictures I took, my wife's face showed some concern. She said, "He looks like a Down's baby." "No," I replied, "he looks like our nephews that have beautiful almond-shaped eyes". The room seemed quiet that day, much more so than with the deliveries of our previous children. No one really gave us much eye contact, and no one spoke much other than to give us facts about what they were doing with Nate.

Later, we were joined by a doctor in my wife's recovery room, who said that he suspected that our son had Down syndrome. The doctor proceeded to tell us all the things that our child would never do, including breastfeeding, which devastated my wife. He explained that there were resources to help us out and that they would order a genetic test to be sure. He left the room without much more than an "I'm sorry..." We were shocked.

That afternoon, we went to the nursery to see our son. When the nurse laid him next to my wife she asked, "Would you like to try to nurse?" "But the doctor said I couldn't," lamented my wife. "Forget the doctor!" retorted the nurse. With tears in her eyes and doubt in her heart, we all watched in amazement as Nate nursed. He performed his first act of defiance. He proved the doctor wrong!

During our hospital stay, we were visited by the parents of one of my former students, John and Mary. They also had a son with Down syndrome.

They came to give us hope and told us that all the feelings we had were perfectly normal, even the ones that made us sad or mad. They cried with us; they prayed with us. We will be forever grateful for their visit and friendship that day.

Fast forward to October 2008, we had heard about the Down Syndrome Guild of Kansas City and decided to join them for their annual Step Up for Down Syndrome Walk. We were completely overwhelmed by it all, but, in a way, it was comforting. We were surrounded by many individuals who had Down syndrome and all of those who loved and supported them. It gave us hope!

Our little Nate had a hole in his heart that required surgery at 4 months of age. During our time in the hospital, we got a visit from a parent member of the Down Syndrome Guild of Kansas City. We were not expecting it, and it was wonderful. She gave us resources, listened to us, and told us about programs at the DSG.

Several years later, we moved to Northwest Arkansas. We had heard about the Down Syndrome Connection of Northwest Arkansas, and we knew that the benefits of the DSG in Kansas City were significant, so we knew we would get involved with the DSCNWA. The first event we attended was the annual Christmas brunch. There we met Danielle Pezely, who was the President of the Board of Directors for DSCNWA. She was so wonderful and told us all about the great things being done here in Northwest Arkansas.

Over the course of the next year, we attended a few events, but we didn't "commit." Over time, we decided that we needed to take the steps to be more involved in the DSCNWA because the benefits to us, our son, and to others were so great! We put together a team to attend the Step Up for Down Syndrome Walk. We attended some other events, and I even did an IEP presentation for the DSCNWA. When I was asked to join the Board, I immediately knew this was the perfect way to give back to this wonderful organization that helps so many in Northwest Arkansas.

We are firmly planted here in Northwest Arkansas. Our son, Nate, has proven the doctors wrong at every turn! He is nearly fully included in the general education classroom at his school, and he is making great friends. We are invested in the DSCNWA because we know that there is great value in the programming, support, friendship, and encouragement that is provided. The statistics tell us that 1 in 800 children are born with Down syndrome, so we count ourselves as one of the "Lucky Few", and we are doubly blessed to be joined with others through the Down Syndrome Connection of Northwest Arkansas!

Nate's Dad - Brian Herndon

I just remember happiness. From everyone. All of the blessed souls in that room celebrated as if there was nothing but joy. Everyone knew...and there were a few puffy eyes, but mostly, it was pure happiness. More friends trickled in. More smiles. More toasts. And hugs with no words...hugs like I've never felt. And Brett, well, he never left our girl's side. He was quiet through this all, and I'm not sure I'll ever know what he felt, but I know the daddy of our babies, and I know he knows nothing but to love them with all his heart. And he did from the very start.

I remember arriving to our room and being told our older daughter, Lainey, was on her way. And I cried new tears... I hadn't even thought about how this would impact Lainey. What she would think...how her life would be different...how every beautiful vision I had of two sisters growing up together, grown phone calls, advice-giving, cooking together, shopping...everything would be different. Numbness started leaving my heart and sheer pain started settling in.

Don't cry. Don't cry. Don't cry when Lainey gets here and then I'll never forget her face...her cute outfit someone put her in, her eyes when she walked into that room, and the way she tried to hide her excitement with her shy smile. I will never forget the day my girl became a big sister. I will never forget the moment her little sister was placed in her arms. I watched in agony... in tears...in admiration as my little girl taught me how to love. She showed me what unconditional love looks like...what the absence of stereotypes feels like...she was....proud. That was one of the most beautiful moments of my life. I needed that.

As darkness set in that night and people started trickling out, I felt paranoid. So completely afraid because I knew with darkness, with the absence of everyone celebrating, the grief would come. I could feel it coming and it hurt so, so, so very bad. I think I cried for seven hours straight. It was gut-wrenching pain. I held Nella and I kissed her but I literally writhed in emotional pain on that bed in the dark with our candles and my friends by my side until the sun came up. I remember trying to sleep and then feeling it come on again and I'd

start shaking, and they'd both jump up and hug me from either side, Nella smooched between the four of us.

I can't explain that evening. And I suppose it's horrible to say you spent the first night your daughter was born in that state of agony, but I know it was necessary for me to move on to where I am today. And, knowing where I am today and how much I love this soul, how much I know she was meant for me and I am meant for her, knowing the crazy way our souls have intertwined and grown into each other, I can say all this now. It's hard, but it's real, and we all have feelings. We live them, we breathe them, we go through them and soon they dissolve into new feelings.

I cried out that I wanted to leave her and run away. I wanted to take Lainey and my perfect world and this perfect love I had built with my two-year old and our cupcake-baking days and our art projects and our beautiful bond and I wanted to run like hell. I wanted to be pregnant again. wanted to be pregnant so bad. I wanted it to be the morning she was born again when I was happy and excited. I wanted to go back. I moaned in pain and through it all, this little breath of heaven needed me. I cried while I nursed her, while I held her, while I pulled my nightgown off just so I could lie her body on my naked skin and pray that I felt a bond. I literally writhed in emotional pain for hours. And then morning came, and with it came hope.

Over the course of the next several days, things just became beautiful. I cried, yes, but they soon turned to tears of joy. I felt lucky. I felt happy. And so, we came home...happy. In fact, walking out of the hospital with our new baby girl and our proud new big girl, all crowned up, gripping the handle of the car seat with Daddy, it was just how I had imagined it.

Life moves on. And there have been lots of tears since. There will be. But, there is us. Our Family. We will embrace this beauty and make something of it. We will hold our precious gift and know that we are lucky. I feel lucky. I feel privileged. I feel there is a story so beautiful in store and we get to live it. Wow. The story has begun...



To read the full story visit: www.kellehampton.com

An Unexpected Birth...

This is probably the hardest thing I've ever had to write in my entire life. The hardest and yet the most beautiful. The story of our daughter's birth. I knew the minute I saw her that she had Down Syndrome and nobody else did. I held her and cried. Cried and panned the room to meet eyes with anyone that would tell me she didn't have it. I held her and looked at her like she wasn't my baby and tried to take it in. And all I can remember of these moments is her face. I will never forget my daughter in my arms, opening her eyes over and over. She locked eyes with mine, stared and bore holes into my soul. She seemed to say love me, love me. I'm not what you expected, but oh, please love me. That was the most defining moment of my life. That was the beginning of my story. I don't remember a lot here. My friends have filled me in, but I feel like I was in a black hole. I know I held her. I know I kissed her. I know I begged every power in the world that this wasn't happening, that she was normal, but I knew in my soul exactly what this was.

She was scooped off my chest and taken to the warming bed where nurses nervously smiled as they checked her over. I wanted someone to tell me what was going on...I kept asking if she was okay, and they told me she was fine. She was crying and pink and just perfectly healthy. I wanted to say the words, but couldn't. I kept crying and asking, "Is there something you aren't telling me?" And they just kept smiling.



When I think about this time later, I have cried and cried wondering what I did. Did she feel love? Did I kiss her? Did I hold her and tell her 'happy birthday' and smother her with happy tears? My friends in the room smile when I ask this and promise me I did. They said I couldn't stop kissing her. And while I held her, the room went on.

I remember feeling....nothing. As if I literally left my body for a bit. But they said I kissed her. They said I loved her. They said I was a mama. I remember my pediatrician suddenly walking in and my heart sank a bit I knew. "Why is she here?" I asked. And they told me she was just checking the baby out. Which she did. And then the room grew quiet and everyone was asked to leave. I started shaking. I knew it was coming. The tears. The twisting in my stomach that they were about to rock my world.

Brett stood behind me, stroking my hair and my nurse friends, Dot and Katie, stayed on either side of the bed. And it happened. My pediatrician snuggled Nella up in a blanket and handed her to me and she knelt next to my bed so that she could look up at me, not down, and she never took her eyes off mine. I need to tell you something...and I cried hard. "I know what you're going to say." She smiled again and squeezed my hand a little tighter. The first thing I'm going to tell you is that your daughter is beautiful and perfect...and I cried harder....but there are some features that lead me to believe she may have Down Syndrome.

Finally, someone said it. I felt hot tears stream down and fall on my baby's face. My beautiful, perfect daughter. I was scared to look up at Brett, so I didn't. I just kissed her. And then, Dr. Foley added.....but, Kelle....she is beautiful and perfect. The hallway was still filled with everyone who was waiting. I held my baby and told them all, crying, what we had been told. I knew there was a stream of friends ready to come and celebrate and I wanted them all to be told before they came in. I couldn't emotionally handle telling anyone and yet, strangely, I wanted people to know as soon as possible because I knew I needed the troops...I

was falling, sliding, tunneling into a black hole and I needed as much love as possible to keep me up.

Sofia



My name is Jessica and me and my husband Ricardo have four girls, Idaly, Michelle, Sofia, and Mary. Sofia has Down Syndrome. My pregnancy with Sofia was just like all the others. At all of our doctor's appointments they would say everything was going great. Even after her diagnosis he said that he never had a reason to suspect she had Down syndrome. Sofia was born at 36 weeks and considered premature. While in the hospital, the pediatrician on duty entered our room to speak to my husband and I. Her first question was "Do you know what Down syndrome is, or do you know anybody that has Down syndrome?"

I didn't know anyone with Down syndrome and I briefly recall having heard about Down syndrome in school once. The pediatrician continued with "Your child shows some characteristics of Down syndrome and blood work has been submitted. We should have the results in a couple of weeks." My husband and I were left confused and offended. Who was this lady? How dare she come and insinuate something could be wrong with our beautiful newborn baby? We decided it would be best to not share this with our family. Mostly because we didn't know if Sofia had Down syndrome or what Down syndrome really was.

After our first few days at home, Sofia had a follow up appointment with her primary care physician. Shortly after, she was hospitalized for dehydration. During our stay in the hospital, a different pediatrician went to check up on Sofia. I asked the pediatrician, "Do you think she has Down syndrome?" His response was "it is very hard to be certain until we receive the results of her blood work." He did advise us not to look for information on the internet. After Sofia's discharge she had follow up appointments with her primary care physician every three days.

Every three days I would ask for an update on her results. Nothing. The wait for the test results was not a difficult one. We decided to put everything in God's hands. If the results came back negative, great! We could go on with our lives and raise our daughters. If the results returned with a positive diagnosis, we prayed God would give us the strength, patience, and wisdom to give Sofia the best life we could.

At two weeks, Sofia had her usual follow up appointment. The appointment went like all others. A nurse would check her weight and lead us to a room to wait for the doctor. Just like all other appointments, the doctor came in, said Sofia was doing great, and left.

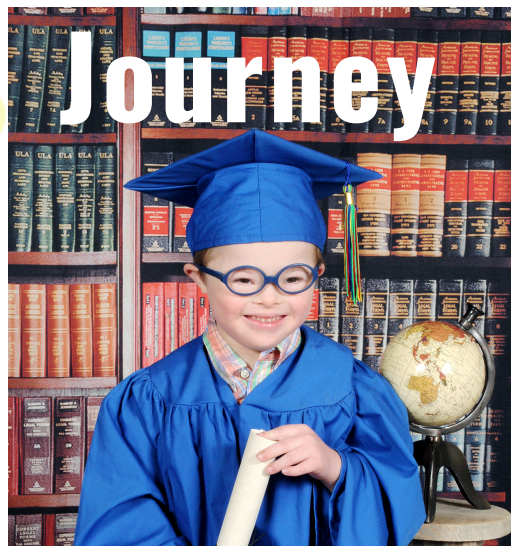
This time I stopped him and asked "Have you received the results on her blood work yet." He reentered the room, took a seat, looked at me and said "Did you not receive a call last week?" "Results were positive." As I felt my heartbreak the only question I could manage to ask, out of the millions running through my mind, was "What now?" He said we should expect to hear from the Children's Hospital soon.

Within a few days we received a call from Children's Hospital. We expected the call to consist of information about Down Syndrome and our child's new diagnoses. It did not. The call consisted of scheduling an appointment with a genetics specialist when Sofia was six months old. We felt discouraged. At this point we still had not told our families because we ourselves did not have any answer about Sofia's diagnosis.

When Sofia was four months old, I mentioned to a friend, who happened to be a pediatric physical therapist, that Sofia was born premature. She suggested I take Sofia to therapy. I then mentioned that Sofia has Down Syndrome. Her tone immediately changed to a more serious one, she said "you have no idea how important it is for her to receive therapy. It's the most important thing you can do for your child to give her as normal of a life as possible." I felt hopeful. At the end of the day we all want the best for our children. I discussed it with my husband. We debated on waiting to start therapy for Sofia's appointment. If it was so important, why had the doctor not mentioned this before. We decided to take her for an evaluation. It turned out to be one of the biggest blessings. Her therapist helped educate us on Down syndrome and they connected us with other families that had a child with Down syndrome.

Sofia is now four years old. She is a happy social butterfly. She enjoys dancing, singing, and being the center of attention. Not all days are sunshine and rainbows. Some days feel more overwhelming than others. At times we can only hope that we are making the best decisions for Sofia to give her the best life we possibly can. At the end of the day we would not change the moments, memories, or chromosomes.

Sofia's Mom - Jessica Nieves



On February 19, 2014, Brooks Foster McGrew came into the world 2.5 weeks earlier than expected and not breathing. Almost instantly, 15 doctors and nurses rushed in and surrounded Brooks. After five full minutes of CPR, Brooks finally took his very first breath. He was rushed to the NICU before I had the opportunity to hold him, but I quickly turned to my husband Josh and said "It's going to be okay; no matter what." Then we prayed. That was just the beginning of our journey as new parents.

After 26 long minutes, my incredible OBGYN, Dr. Dittmeyer came back into the delivery room. He explained that Brooks looked strong and was breathing on his own despite a large hematoma on his head and having a very low APGAR score. Then Dr. Dittmeyer went on to say something that would change our lives forever. In the kindest, most heartfelt way, he broke the news to us... Brooks appeared to have many "markers" for Down syndrome. He took the time to explain the diagnosis and how Brooks would be impacted by it.

Through the shock, I don't remember a lot from the conversations that day, but I do remember our doctor saying he knew of several people with Down syndrome that have gone on to lead very fulfilling lives and the more "normal" we treat him, the more "normal" he will become. We have never forgotten those words, and in many ways they have become our motto for Brooks. We treat him like we would any other child; although we probably push him a little harder. We didn't know any better...we were first-time parents and we had and always will, set high expectations for him.

Over the next several days in the NICU, the pediatricians walked us through the risks around Down syndrome, things to watch for, and blood tests he would need on a regular basis. We talked about therapy and the importance of early intervention. While we waited for the blood work to come back to confirm he had Down syndrome, we were consumed by Brooks' other medical needs but deep down we already knew the result.

Becoming parents of a child with special needs, wasn't something we had planned on. We were scared and nervous because this wasn't what we had dreamt for our child. Our world was completely turning on end, we didn't know what the future looked like- or how great it would be. We connected with our DSCNWA for support and guidance, which we received immediately. We have since been able to connect with other parents who are well into their journey and learn from them and others in the special needs community. DSCNWA was instrumental in our ability to quickly adapt to the heartbreaking news at his birth and then shift our focus to getting to know and falling in love with our tiny new guy.

Over the course of the last 5.5 years, Brooks has had his fair share of medical complications. From a floppy airway requiring us to thicken all liquids, to nearly cutting his tongue in half while learning to walk, and being diagnosed with chronic pneumonia, we've been in and out of the hospital more than we'd like to admit. But each time, our boy met challenges head-on, with courage and often a smile on his face. He is an inspiration to all of us and our guiding light. We are so thankful for the incredible medical teams we have, as well as the phenomenal team of therapists who continue to push Brooks past his comfort zone to meet new milestones. Despite all the challenges and obstacles, Brooks has come a long way.

Thankfully, the last year has brought more triumphs than heartbreak. Brooks continues to find his voice and uses an Augmentative Alternative Communication device to "talk" for him, when he can't find his words. With his little sister Harper talking more and more, it's really been helping Brooks to be more vocal. Harper is about 3 years younger than Brooks and about as sassy as they come. Brooks is an amazing big brother to her and they are truly the best of friends. He looks for her when he wakes up and looks for her when he goes to bed. I hope they always have that special bond. Brooks' other big accomplishment this year was graduating preschool and starting Kindergarten. We can't wait to see how he grows this year at his new school, and how he touches the lives of those around him.

We are so incredibly thankful for Brooks. Coming up on nearly 6 years into this journey, we can happily say without a doubt that Brooks is the best thing that has ever happened to us and we honestly wouldn't change one thing about him...not even that extra chromosome. He has shown us how to have a new perspective on life and not take anything for granted. We celebrate every accomplishment big and small. And how many people get to have their hero as their son? It's pretty neat. We consider ourselves one of the lucky few and are so very thankful to be on this journey with him.

Brooks' Mom - Angie McGrew




Bentley
Meme's Girl

Let me start off by telling you about my granddaughter... Bentley Bella Nicholas (aka Meme's girl, BeBe, Boo). Bentley is a bundle of joy with an infectious smile. She's spunky, loving, ornery, sweet, mischievous, and caring. Bentley's entry into this world was not as expected. My daughter, Candia, had a wonderful pregnancy and smooth delivery. On April 9th, 2004, my 3rd granddaughter was born.

In normal delivery fashion, Bentley was taken to the nursery for vitals. During this process a nurse noticed one of Bentley's ears was folded over, which is a common sign for children with Down syndrome. After closer inspection, the nurse found that Bentley had many characteristics of a child with Down syndrome. Bentley was then taken back to her parent's room with a hospital cap on.

All of Bentley's family were waiting outside the door to get their hands on this precious child we had waited for, for so many years. Then, we noticed the doctor closing the blinds in my daughter's room. Through a small crack in the blinds, I saw a single tear flow down my daughter's cheek. I knew that something was wrong. The doctor was telling my daughter and son-in-law their precious baby most likely had Down syndrome. (This was quickly confirmed with a blood test). Then the doctor opened the door and told our family we could enter Candia's room. With a concerned voice, my daughter told us Bentley had Down syndrome. It definitely caught everyone off guard, but luckily we were somewhat familiar with Down syndrome because our neighbor, Danny, had Down syndrome. Three days later, the doctor came in once again and told us Bentley had a serious heart condition called AV canal. Her heart would need repair once she gained some weight and was strong enough for surgery.

Three months later, she had open heart surgery. Bentley had a busy first two years of life. Following heart surgery she had eye surgery (twice) to repair her crossed eyes, tonsils and adenoids removed so she could breathe easier, a feeding tube placed so she could eat, plus many other minor surgeries. At age six, after many years of encouragement and feeding therapy sessions, Bentley learned to eat by mouth. Six months later, her feeding tube was removed. At seven years of age we found out that Bentley's heart was not working as well as it should be, so a pacemaker was placed.

Bentley is one of the strongest children I have ever been around and she's definitely a fighter. She has been fighting for life, since the day she was born. She comes by this naturally. My daughter has been fighting for Bentley to be included and accepted in every aspect of life. Bentley has been in the public schools, general education setting since kindergarten. My daughter works hard to make sure Bentley is ready for life in the "real" world. We credit family involvement and community & school inclusion for many of Bentley's successes. Bentley is a tomboy in every sense of the word. Her favorite things are her dog "Betty Davis", swimming and boating, Hip-hop dance, Miracle League Baseball, Young Life Capernaum Club, and playing on her school's Jr. High basketball team. Having a granddaughter with Down syndrome is the best thing that has ever happened to our family. She has opened our eyes to the truly important things in life and has taught us not to take anything for granted. Fast forward to today... Bentley Bella is like many other children her age, living and loving life as a teenager, with a bright future ahead of her.

Bentley's Meme - Brenda McCall