

Down Syndrome

Waiting for a Diagnosis



EASTERN IDAHO
DOWN SYNDROME
FAMILY CONNECT 

Meet the Moncurs



Our sweet Briella is 4 years old. She is so fun, energetic, and full of love. We got a Down Syndrome diagnosis while 20 weeks pregnant. Briella had two holes in her heart when she was born and had a surgery to close one at 10 months old. She has been doing so good ever since! She loves to play pretend, dance to music, and clean! She is also enjoying preschool. Briella loves spending time with her siblings and they adore her so much!

Meet the Phelps



Little Adeline is 3 months old. She is the most social little infant you will meet. She can't even talk yet, but still manages to carry a conversation with whomever will listen. She loves to listen to music and sit up so she can see everything happening around her. Since she was born, she has had her eyes wide open and ready to take on the world. We were told that Addie would have an 85% chance of having Down syndrome at 19 weeks pregnant, they also found a hole in her heart. Once Adeline was born, the doctors could not tell by her appearance if she had Down Syndrome. We were ready to know and asked for a genetic test. Adeline was diagnosed with Mosaic Down syndrome. Addie is a rare little ray of sunshine, she touches the hearts of everyone she meets. Her Mom and Dad cannot imagine life without her, and her comforting spirit.

Waiting for a Diagnosis

Waiting for a diagnosis for your baby can be a very stressful. There can be so many thoughts and fears running through your head. Things are uncertain about your baby's future which leads to worry and concern. However, find comfort in knowing that if your baby has Down syndrome, only he/she will determine what his/her strengths and limitations will be in life. Each person with Down syndrome is an individual and can reach great potential. There will be challenges along the way, but through therapies, medical care, support, and encouragement people with Down syndrome can live happy and fulfilling lives.

We want you to know we are here to help. We have families that have been in your shoes who are ready to support you. Call 208-716-6504 to be connected with a mom or dad from Eastern Idaho that can relate to your feelings and help you process what you are going through.

In this booklet we give you a brief description of Down syndrome, the resources we provide as a non-profit Down syndrome support organization in Eastern Idaho, and some national resources. We have plenty more resources we are happy to share. Just give us a call and we can get you more information.



Basic Facts About Down Syndrome

Down syndrome occurs when an individual has a full or partial extra copy of the 21st chromosome. Typically, a person has 46 chromosomes in the nucleus (center) of each cell in his/her body. With Down syndrome a person has 47 chromosomes in the nucleus of each or some of his/her cells. Down syndrome occurs in approximately one of 700 live births.

Due to the extra 21st chromosome, each person with Down syndrome can have varying health, learning, and physical differences. Some of the most common medical issues with Down syndrome are heart, vision, intestinal, thyroid, and ear, nose, and throat issues. Down syndrome can cause low muscle tone which can make fine motor, gross motor, and speech more difficult. However, with therapy and diligent medical care, many of these issues can be resolved or significantly improved.

People often have misconceptions about Down syndrome from stereotypes in the past. However, we are happy to inform you that babies, children, and adults with Down syndrome are able to live fulfilling and meaningful lives. Current medical advancements and therapy opportunities have left the sky as the limit for individuals with Down syndrome. People with Down syndrome can walk, talk, go to school, work, vacation, and enjoy many other parts of life. People with Down syndrome write their own stories and can live inclusively in their communities.

The chances of having a baby with Down syndrome does increase as the mother's age increases, especially after the age of 35. However, mothers under the age 35 can have babies with Down syndrome as well



Eastern Idaho Down Syndrome Family Connect

We are a nonprofit organization that provides support for individuals with Down syndrome and their families in Eastern Idaho. We also provide education to our community, ages preschool through adult, on Down syndrome and how to include people of all abilities in life.

We have several programs that help us accomplish our goals. We are here to support and help you, so please reach out to us and let us be here for you.

With over 100 families in our organization we have moms, dads, siblings, grandparents, and our wonderful self advocates (individuals with Down syndrome) ready to guide you and answer your questions.

Below are all the ways you can reach out to us:

Phone: 208-716-6504

Email: info@easternidahodownsyndrome.org

Website: www.easternidahodownsyndrome.org

Facebook: Eastern Idaho Down Syndrome Family Connect



Our Programs

BrynnLe's Baskets

We supply all local hospitals with newborn baskets for parents when they have a baby with Down syndrome. The baskets are filled with welcome gifts and educational information.

First Call

Receiving the news that your baby has Down syndrome can be filled with many emotions. We are here to help. Parents with a new diagnosis can call us at 208-716-6504 for support and guidance.

NICU Assistance

Many babies with Down syndrome have intensive medical needs at birth and spend time in the NICU. We provide funds to help the families.

Grants

We give grants to families to help cover costs of medical and adaptive equipment, guardianship fees, and other expenses.

Down Syndrome Awareness Lessons

We have lesson plans and kits to teach kids and adults about Down syndrome.

Dash for Down Syndrome

This is our annual fundraiser in August. Come participate in the 10K, 3.21 mile, or 1 mile fun run/walk and enjoy a fun celebration of Down syndrome.

Social Events/Gatherings/Play Groups

These provide safe and supported environments for our families to bond.

Educational Panels and Classes

We host a variety of presentations to help educate the parents and caretakers of individuals with Down syndrome.

Mom's and Dad's Retreats

Moms and dads who have kids with Down syndrome can attend these retreats to gain knowledge and skills while bonding with other parents.

Grandparent Support Group

We support grandparents through educational and social gatherings.

Gifts from Gracen

This is a resource for families to help cover funeral expenses when loved ones with Down syndrome pass away.

See The Ability



National Down Syndrome Resources

Down Syndrome Pregnancy- downsyndromepregnancy.org

Lettercase- lettercase.org

National Down Syndrome Society- ndss.org

National Down Syndrome Congress- ndscenter.org

Global Down Syndrome Foundation- globaldownsyndrome.org



www.easternidahodownsyndrome.org