

# Down Syndrome

## A New Parent's Guide



EASTERN IDAHO  
**DOWN SYNDROME**  
FAMILY CONNECT



# Meet the Murrays



Our son Eli is 5 years old. He loves music, reading books, and popcorn. We got his diagnosis of Down syndrome while 20 weeks pregnant. He had many intense medical issues in utero and at birth, but with medical care and therapy, he is doing amazing. He is currently in Pre-K at a local private school and is fully included in the regular education classroom. His older sister Ali and younger brother Kian love to sing and play silly games with Eli.

# Meet the Larsens



BrynnLe is the light of our family! Her outgoing, spunky personality keeps us smiling and on our toes everyday. She loves Sophia the First, music, and tortilla chips! We found out at birth that she had Down syndrome. It was a very big surprise and overwhelming at first, but now we couldn't imagine life any other way. Currently, she is 7 and is in kindergarten at our local elementary school in a regular education classroom. She talks in full sentences, runs, jumps, climbs, and enjoys life to the fullest. She gives the best hugs to everyone she meets and has four older brothers who adore her!

# 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.

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.



# More About Down Syndrome

Down syndrome starts at conception and nothing the mom or dad did or did not do causes Down syndrome. There are three types of Down syndrome: trisomy 21, translocation, and mosaicism.

Trisomy 21 is the most common type with 95% of people with Down syndrome having this type. This means that every cell in the person's body has an extra 21st chromosome. This type is not inherited, it is sporadic and happens by chance just as if someone won the lottery.

The second type is translocation. This accounts for 4% of all people with Down syndrome. Translocation means that a full copy or part of a copy of the 21st chromosome breaks off and attaches to another chromosome in the body (most commonly it attaches to the 14th chromosome). This means each cell only has the regular 46 chromosomes, but due to the extra 21st chromosome linking with another chromosome in the body, the characteristics of Down syndrome are present. This type can be inherited but that is not always the case.

The third type, and least common, is mosaicism. Only 1% of all people with Down syndrome have this type. In mosaicism only some of the cells have the extra 21st chromosome. This can mean that the person has fewer characteristics of Down syndrome but is not always the case. Just as the first type trisomy 21 is random and sporadic (not inherited) that is true of mosaicism as well.

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.

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\*information gathered from the National Down Syndrome Society, National Down Syndrome Congress, and Global Down Syndrome Foundation print and website materials

# 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.

Getting a diagnosis of Down syndrome for your child can be overwhelming and full of questions. 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.

Please contact us and join our beautiful family of love and support.

Phone: 208-716-6504

Email: [info@easternidahodownsyndrome.org](mailto:info@easternidahodownsyndrome.org)

Website: [www.easternidahodownsyndrome.org](http://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**

National Down Syndrome Society- [ndss.org](http://ndss.org)

National Down Syndrome Congress- [ndsccenter.org](http://ndsccenter.org)

Global Down Syndrome Foundation- [globaldownsyndrome.org](http://globaldownsyndrome.org)

Down Syndrome Pregnancy- [downsyndromepregnancy.org](http://downsyndromepregnancy.org)

Lettercase- [lettercase.org](http://lettercase.org)



[www.easternidahodownsyndrome.org](http://www.easternidahodownsyndrome.org)