

# DOWN SYNDROME:

*A new parent's guide*



## CONGRATULATIONS

*on the birth of your baby. We wish you, the new arrival and your entire family the very best!*

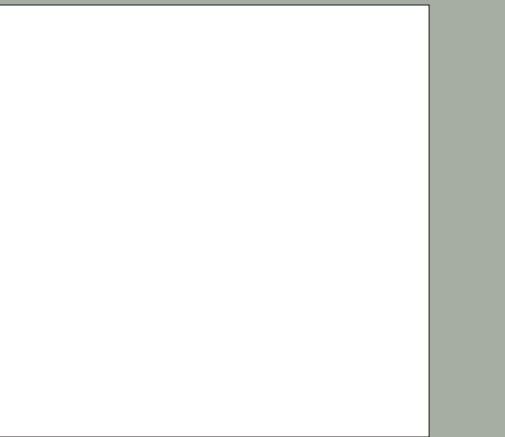
We understand that, with this wonderful event, has come some news you may not have expected – your new family member has Down syndrome.

We do not know how you may be taking that news, but sincerely welcome you to a large, warm and caring community.

You have a lot on your mind, so we do not wish to intrude. In this brochure, however, you will find some basic information on Down syndrome.

For now, take care of yourself, enjoy your baby and get to know each other.

When you are ready – when you feel you want to know more or connect with other parents who have been exactly where you are – please give us a call.





Even if you are the world's leading expert on something, all you know started with a few basic facts. As the parent of a child with Down syndrome, you will learn all kinds of lessons – and yes, there is every reason to believe your child will learn right along side of you. For right now, however, here are the basics:

## **DOWN SYNDROME is *a condition* –**

a set of symptoms and features common among people with Down syndrome.

*Importantly, few people with Down syndrome have all; many have few.*

## **Your child is *your child* –**

*more like his or her parents, siblings and other close relatives than anybody else.*

Those two facts make your child a distinct individual – a person who will grow to have a unique personality and capabilities. We can't tell you who or what your child will become. Nobody can or should even try to predict. It is just so for all newborns – all we can say for sure is you have a baby. Congratulations!

**DOWN SYNDROME** is a human chromosomal variation affecting the twenty-first chromosome.

*There are three types:*

#### **TRISOMY 21**

in which there is an extra copy of the twenty-first chromosome in all cells, is by far the most common and occurs at conception.

#### **MOSAIC DOWN SYNDROME**

is relatively rare and occurs sometime after conception when some cellular division has taken place. As a result, most but not all cells have an extra twenty-first chromosome.

#### **TRANSLOCATION**

in which an extra copy of the twenty-first chromosome adheres to another chromosome, is the rarest form and the only inherited type.





## A few additional facts you should know:

- **DOWN SYNDROME** is the result of extra chromosomal material.  
Nothing you did or did not do caused it. It is nobody's fault.
- **DOWN SYNDROME** is a factor in about 1 in every 733 live births, making it the most common genetic variation. There are about 350,000 to 400,000 people with Down syndrome in the United States.
- **DOWN SYNDROME** affects people of all economic, educational, cultural, ethnic and racial categories.
- The chance a baby will have **DOWN SYNDROME** increases with the age of the mother, however, 80 percent of babies with Down syndrome are born to women 35 years old and younger simply because women in that age group have the most babies.
- **DOWN SYNDROME** causes developmental delays and, typically, mild to moderate cognitive impairment. Both, however, range across a broad span and the degree of delay and impairment is highly individual.
- Children with **DOWN SYNDROME** can and do learn. They are often avid students and learn to read, write, do math and more alongside their typical peers. They commonly graduate from high school and, increasingly, pursue post-secondary educational opportunities.

## TWO FINAL FACTS:

*Being a parent is challenging, regardless of the capabilities of the child.*

We will not attempt to mislead you – this is also true for children with Down syndrome.

Few of us who are parents of children with Down syndrome consider it a burden.

Our lives are full, happy and rich. Our children – both with and without Down syndrome – are cherished.

*Finally, as you may have guessed, you are not alone.*

You are now part of a large, caring community whose hallmark is our ability to reach out to each other.

To laugh and cry, to share information and help each other along a road that, at times, seems impossibly long and hard, but is mostly wonderfully rewarding.

When you are ready,

we invite you to get in touch with us –  
it is always nice to make new friends.

*For additional information and to contact a Down syndrome organization near you, please call the*

**NATIONAL DOWN SYNDROME CONGRESS**

*at 1-800-232-NDSC (6372) or visit [www.ndsccenter.org](http://www.ndsccenter.org)*

*Special thanks to Karen, Todd, and Dylan*



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