

MYTHS VS TRUTHS OF DOWN SYNDROME

MYTH: Down syndrome is a rare genetic disorder.

TRUTH: Down syndrome is the most commonly occurring genetic condition. According to the Utah Department of Health, one in every 580 births is a child with Down syndrome.



MYTH: Having a child with Down syndrome will be a burden on a family.

TRUTH: Children with Down syndrome have a variety of gifts and talents. They bring joy to their families and enhance the world around them. Many people seek to adopt children with Down syndrome because they feel that these children will enrich the lives of their families.



MYTH: All individuals with Down syndrome will have severe developmental or intellectual delays.

TRUTH: Most people with Down syndrome have cognitive delays that are mild to moderate. IQ is not an adequate measure of the functional status of people with Down syndrome. People with Down syndrome have great potential when given the opportunity to succeed.



MYTH: Individuals born with Down syndrome do not experience full and meaningful, productive lives.

TRUTH: Individuals with Down syndrome live at home with their families, in group homes, or in homes of their own. They are integrated into the regular education system and are active participants in the vocational, social, religious, and recreational activities of the community. Many individuals will go to college, work, and lead meaningful lives.



SHARING THE NEWS

How to Help Families Accept
Their Baby's Down Syndrome Diagnosis


UDSF
UTAH DOWN SYNDROME FOUNDATION

A baby with Down Syndrome is reason to celebrate!


UDSF
UTAH DOWN SYNDROME FOUNDATION

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SOME HELPFUL TIPS

- Celebrate the birth of the baby with the family and encourage them to think positively about their baby's future.
- Use people first language, e.g. "Your baby has Down syndrome," NOT: "A Down's baby."
- Give the diagnosis in a private setting as soon as possible.
- Both parents should be present for the initial diagnosis. In the case of a single mother, make sure a significant other, the birth coach or a family member is available to offer support.
- There are many different ways to understand, accept and cope with this information. Do not pass judgments or make assumptions about a family's reaction to the news.
- Ask the family if you may contact the Utah Down Syndrome Foundation as a step toward helping the family.



THE MEDICAL PROFESSIONAL'S IMPORTANT ROLE... As a medical professional you will be the first touch point for a family. Your attitude will have a strong effect on the family—they look to you as the expert.

Sharing positive and acute information helps your families accept their child's diagnosis and begin the bonding process with their baby.

Talking openly with the family will help them to deal with the diagnosis. What you don't say may be as powerful as the things you do say. If you are not sure what to say, let us help you! Please be sure to refer the family to the Utah Down Syndrome Foundation.

YOUR FIRST WORDS TO A FAMILY WILL HAVE A LIFELONG IMPACT

Try saying something along these lines...

Other parents tell us that meeting another family was their most valuable experience. Would you like me to contact the Utah Down Syndrome Foundation (UDSF) to request a parent-to-parent visit for you? The UDSF will provide you with a gift package full of resources on Down syndrome, put you in touch with other families and provide you support throughout your child's life. The social worker here at the hospital may be able to help you access resources.

You should contact your local early intervention program as soon as possible. They will help you set up a series of therapies to get your baby off to a great start! Contact utahbabywatch.org.



Congratulations on the birth of (use baby's name). **I have some information about your baby that I need to share with you. It looks as though your baby may have Down syndrome.** We'll do some tests and let you know the results as soon as possible. For now, I just want you to know your baby seems to be doing great. **I have some resources available for you about Down syndrome.** What information would be most helpful?

You may be feeling a whole range of emotions right now. Whatever you are feeling is normal. Many families tell us they are shocked, grieved, and were angry when first learning of their child's diagnosis. Be sure to talk about your feelings and express them openly. This will help you overcome any concerns you have and bond with your baby. No one can predict what your child's future will hold.