

How to share the news that a baby has Down Syndrome

"Before I could even see or hold my baby, the doctor looked at us and told us our daughter had Down syndrome. She quickly left the room and my husband was forced to tell the rest of our waiting family. We were overwhelmed..."

"...We were overwhelmed by all the negative messages the doctors and nurses gave us. They made it seem like Down syndrome was a horrible thing."



Talk to the families promptly!

Families want to hear such concerns from a doctor they are familiar with as soon as possible after suspecting the diagnosis.

- Before talking with the family, make sure that the mother has support in the room (spouse, significant other or family).
- Be seated when talking with the family.
- Encourage the mother and/or father to hold the baby while talking.
- Address the newborn by his or her name... never as a Down's baby.
- Allow time to discuss your concerns and hear theirs.
- Most families will want some written information on Down syndrome and local resources such as support groups.
- Families want to hear only the present concerns. Do not forecast the child's future (e.g. child will never play sports, finish school, etc.).



celebrating extraordinary lives



A simple narrative to help start your conversation...

"Hello, Mr. & Mrs. Smith...Congratulations on your new baby. Have you chosen a name for your daughter? Jasmine! Jasmine is a lovely name. Jasmine is the reason I asked to speak with both of you. Please take a seat. You may have noticed that Jasmine has some distinctive facial characteristics. The nurses and I have also noticed this and based on these concerns, we feel that Jasmine may have Down syndrome. We are not sure at this time, but let me tell you a little about Down syndrome and what we plan to do for Jasmine..."

Why is this important?

The words that you choose to deliver the diagnosis to a new family will echo in their minds forever, so it is very important to choose your words thoughtfully. Parents need to know that although this is a difficult time, no one knows what the future holds for any newborn baby. They should maintain high expectations for this baby just as they would for any child. This child is a baby first and the birth should be cause for celebration.



Leave the family with concrete plans as to how to proceed from this point. These plans should include the following:

Confirming a Diagnosis

- Chromosomal study: Consider an evaluation by a clinical geneticist.

Evaluations Needed Now or in the Near Future

- Echocardiogram

Follow-up Plan

- Home nurse visitation
- Breastfeeding support if needed
- Early weight checks
- Clinical genetics evaluation
- Cardiology evaluation
- Support group

Most importantly, let the parents know who to call with questions and concerns. Let them know the DSAGC is available to support them, and they can be contacted at: (513) 761-5400 or at www.dsagc.com.

Additional Resources

The Down Syndrome Association of Greater Cincinnati

Supporting families of individuals with Down syndrome for over 25 years, the DSAGC can offer a wide variety of programs and services to educate, inform and support. Contact them at (513) 761-5400 for more information.

Children's Hospital Medical Center

3333 Burnet Ave., Cincinnati, OH 45229

The Jane and Richard Thomas Center For Down Syndrome

Conducts research and offers interdisciplinary evaluations and interventions for all individuals with Down syndrome. They can be reached at (513) 636-0520.

Division of Human Genetics

Provides comprehensive clinical management and diagnostic services to patients and families affected by birth defects and chromosomal disorders. For more information contact (513) 636-4760.



The mission of the DSAGC is to empower individuals, educate families, enhance communities and together celebrate the extraordinary lives of people with Down syndrome.

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