



ds medpress

A NEWSLETTER FOR HEALTHCARE PROVIDERS

The purpose of ds medpress is to share the latest medical information regarding individuals with Down syndrome, present the variety of supports we can offer families and highlight the many wonderful professionals in the Greater Cincinnati area who are doing a great job of supporting our families. Please share this e-newsletter with others who may be interested. To receive a hard copy, please contact our offices.

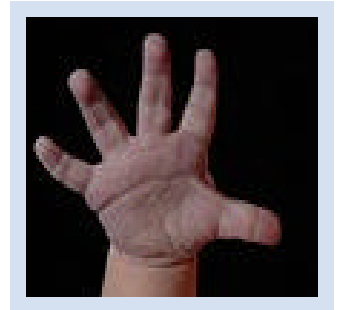
COMPASSIONATE NURSE COMFORTS FAMILY

In October, 2009 the Barber family welcomed a beautiful daughter to their family at Bethesda North Hospital. After a “textbook” pregnancy, they were surprised to learn their baby may have Down syndrome. The shock of this unexpected news was eased by the com-



forting words of the Labor & Delivery nurse, *Heather Evans*.

“Heather reassured us that the doctor suspected our baby may have Down syndrome but only a blood test would tell for sure. She told us to just love our beautiful baby while we waited to get the results. I was so thankful for her words. She put things into perspective for us. Breanna was diagnosed with Down syndrome but we think she is perfect and beautiful.”



Provided by Michelle Edwards

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SPEAKER'S BUREAU

The DSAGC is happy to provide information sessions for your staff provided by parent volunteers and staff. We can adjust the length of these sessions to fit your needs. Become familiar with all the ways we can help your patients.

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SHARING THE NEWS

Healthcare professionals who find themselves delivering a diagnosis of Down syndrome can receive tips in this valuable handout.

[Download the PDF](#)

Visit the Program tab on our website and click on Healthcare Provider for other resources.

www.dsagc.com



Heart Defects

40 % of babies born with Down syndrome have a heart defect. According to our 2008 survey, over 50% of babies born in our area had a heart defect.

DS AND TRANSIENT LEUKEMIA

Newborns with Down syndrome have an increased risk of having a condition called transient leukemia (also called transient abnormal myelopoiesis, transient blastemia or myeloproliferative syndrome). This condition resembles leukemia, but disappears on its own without treatment in just a few weeks or months. One researcher found that up to 10% of newborns with DS had evidence of transient leukemia on blood tests.

On the blood test, the number of white blood cells is greatly above normal and there are immature white blood cells ("blasts") present in the blood as well. While this condition resolves without treatment, the concern is that there is an increased risk of these infants to develop leukemia later in childhood. In one study of 85 infants with transient leukemia, 30% went on to develop a type of leukemia called nonlymphoid" (also called "myelocytic," or AML) within the next 3 years. The reason for the development of transient leukemia isn't understood, but is definitely linked to the extra 21st chromosome.

Written by Dr. Len Leshin www.ds-health.com

*Parents of newborns with Down syndrome want to be congratulated on the birth of their baby.
DSAGC Parent Survey, 2008.*

SMALL THINGS MAKE BIG DIFFERENCES TO NEW PARENTS

In 2008, the DSAGC surveyed families who had given birth to a baby with Down syndrome within the last 5 years. 63 families completed the survey. The following is a comment shared with us regarding a small detail which became a missed opportunity for one family.

"My biggest disappointment was that no one ever came to take my daughter's photo. That broke my heart. I was told by the hospital staff that they had no control of the pictures, but it seemed odd that we were there so much longer than all the other mothers but I was never even given the option of having her photographed. As a result, I have hospital photos of all my other children but her first professional photo did not happen until she was 2 years old after her heart surgery. You can never go back and take those newborn pictures again."