



## DS MedPress

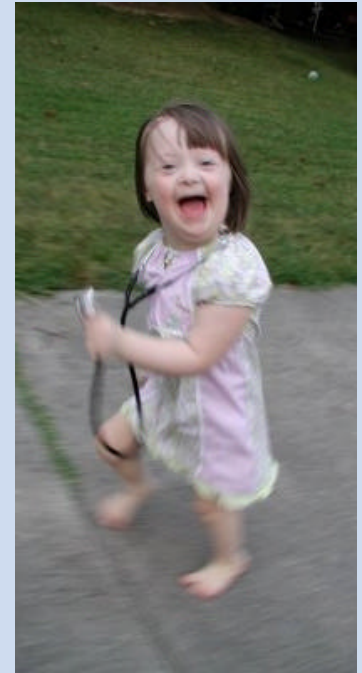
### A NEWSLETTER FOR HEALTHCARE PROVIDERS

Welcome to the DS MedPress, a publication of the Down Syndrome Association of Greater Cincinnati. Our purpose 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.

### DSAGC OFFERS SUPPORT AND INFORMATION FOR NEW FAMILIES

Parents who have just learned that their baby has Down syndrome can find themselves in a world of uncertainty, mixed emotions and confusion. The DSAGC provides new and expectant parents the help they need in the early days following the diagnosis. Our Family Support Coordinator will provide:

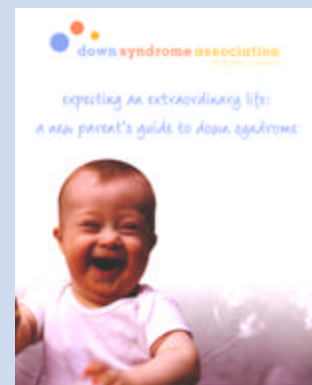
- . Parent To Parent Mentoring
- . Personal Visits
- . New Parent Magazine: Expecting an Extraordinary Life—A New Parent's Guide to Down Syndrome
- . DVD— The Journey Ahead
- . Welcome Basket containing gifts for baby and books for parents.



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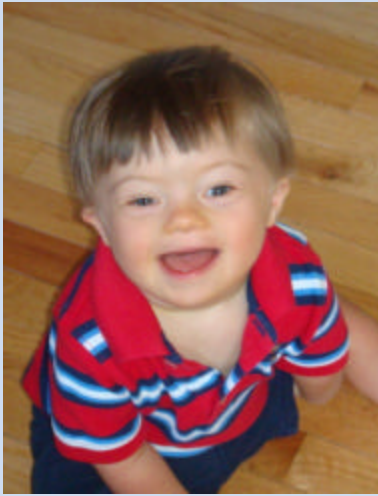
#### INSIDE THIS ISSUE

Family Support .....	1
New Research on DS...	2
Survey Results.....	2



**Available at no cost to area hospitals.**

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## DOWN SYNDROME OPENS NEW WINDOW ON CANCER

Although people with Down syndrome are at increased risk for leukemia, they rarely develop solid tumors, such as tumors of the breast or colon. According to Sandra Ryeom, a researcher at Children's Hospital in Boston and author of a study published online in *Nature*. In this study of 17,800 people with Down syndrome, the mortality rate from cancer was less than 10% of what is expected in the general population.

The answer to the mystery lies on chromosome 21. People with Down syndrome have three copies instead of two. Researchers suspect that the extra chromosomes may protect them indirectly by

preventing tumors from growing new blood vessels. Tumors need blood supply so they can grow beyond a microscopic clump of cells.

In experiments in mice and in human cells in lab dishes, Ryeom found 2 genes on chromosome 21 that block the process called angiogenesis. Interestingly, angiogenesis is not involved in leukemia, the cancer of white blood cells more common in Down syndrome.

Pediatric oncologist at Seattle Children's Hospital, Jessica Pollard believes more human studies are needed.

*Chicago Sun-Times, Liz Szabo, 6/4/2009*

***“The excellent TLC that I received from both Christ Hospital’s maternity staff and the CCHMC transport team made a very scary and tense situation less stressful.”***

### HOW DO PARENTS RATE HEALTHCARE PROVIDERS?

In general, the prenatally diagnosed group had a more favorable opinion of all the professionals who interacted with them. The most positive impression was made by the pediatrician followed closely by the obstetrician.

In the postnatally diagnosed group, the most favorable impression was also made by the pediatrician and the most unfavorable impression was made by the hospital nurses.

***“Nurses and doctors need to be joyous for all births and not so solemn when the baby has a disability.”***

**Contact the DSAGC to arrange a presenter from our Speakers Bureau who can offer tips and strategies on helping new families.**

### RESULTS OF DSAGC FAMILY SURVEY

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 sample of a few of the results of our survey.

Participants were asked to evaluate the treatment they received from a variety of healthcare professionals. The following chart reflects the percentage of favorable opinions.



#### Percentage of Favorable Opinions

	Prenatal	Postnatal
Obstetrician	99%	84.5%
Pediatrician	100%	91.5%
Geneticist/Counselor	92%	79%
Nurse	92%	76%
Social Worker	94.5%	90%