



down syndrome association
of greater cincinnati

ds medpress

A NEWSLETTER FOR HEALTHCARE PROVIDERS

2011 Family Survey

The DSAGC has just completed a follow-up survey of the families giving birth to a baby born with Down syndrome in the Greater Cincinnati area from 2008-2011. The purpose was to repeat a survey that was conducted of those who had given birth from 2005-2008. Results of the 2008 survey revealed some areas in which families felt that perhaps their birth experience could have been more positive. From 2008 to 2011, through a generous grant from the Charles H. Dater Foundation, the DSAGC set out to alleviate some of the distress that new parents may encounter by emphasizing the importance of increased sensitivity and careful selection of language used with new parents. These strategies were shared with area medical professionals.

The goal of this outreach to the medical community was to provide information to help create a more positive experience for newly diagnosed families. To assess the effectiveness of our efforts, the same online survey was completed by families whose child was born between 2008 and 2011.

What did we learn? Did our efforts make a difference?

The answer is yes! See page 2

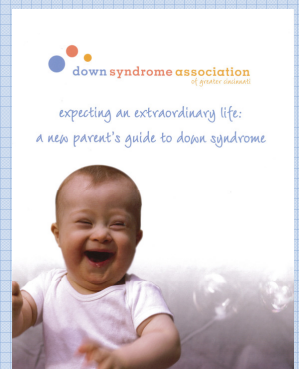


Fall, 2011

New Parent Guide

The DSAGC provides this guide to area hospitals at no cost to offer information to new parents in the early days following a diagnosis.

Please contact sally@dsagc.com to request a supply for your hospital.



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Alzheimer's and Eyes

A team of researchers has discovered that the protein that forms plaques in the brain in Alzheimer's disease also accumulates in the eyes of people with Down syndrome. The new findings show that the toxic protein, amyloid- β , that causes Alzheimer's pathology in the brain also leads to distinctive cataracts in the eyes. The discovery is leading researchers to develop an innovative eye test for early detection of Alzheimer's pathology in both disorders (Down syndrome and Alzheimer's)

"The results are striking," says David Hunter, M.D., Ph.D., Ophthalmologist-in-Chief at Children's Hospital Boston. "We have known that these cataracts are prevalent in people with Down syndrome and are sometimes even seen at birth, but we never knew how they were related to the disorder—now we know. These distinctive cataracts appear only in people with advanced Alzheimer's disease and much earlier in Down syndrome."

Lead researcher, Lee Goldstein, M.D., Ph.D. says, "We are developing an eye scanner to measure amyloid- β in the lens. Effective treatments are on the horizon and early detection is the key for successful intervention."

www.healthcanal.com/brain-nerve May 25, 2010



PARENTAL WORDS OF WISDOM

"I think the healthcare community needs to see more images of children with Down syndrome to see beyond the first traumatic year of health concerns to the vibrant, meaningful future. What parents need to hear is that their new baby can have a purposeful, wonderful life. The healthcare community is in a position to plant the seed of optimism at the time of the diagnosis, but they can only do that if they too feel optimistic about people with Down syndrome." **Mother of newborn, Family Survey 2011.**



FAMILY SURVEY RESULTS

Each issue of **ds medpress** will contain highlights from the survey results. For a copy of the complete survey report, please contact sally@dsagc.com.

- There is a significant increase in parent's positive perception of how they were treated by both their OB and nurse, 12% and 17% respectively.
- In the 2011 survey, the number of families reporting a very negative overall birth experience was only 4. This means that the remaining 36 families (90%) had a satisfactory experience or better vs 77% who reported a satisfactory experience or better in 2008.
- In 2011, families reported **many** more positive and hopeful comments made by the healthcare professionals regarding the baby's arrival and no reported expressions of sorrow and pity. In the 2008 survey, very few positive statements of this nature were made by the healthcare professionals.

Thank you to the Charles H. Dater Foundation for their support of our project.