

ds medpress

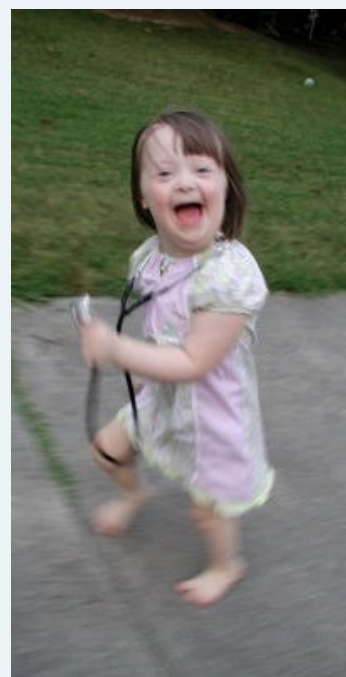
A NEWSLETTER FOR HEALTHCARE PROVIDERS

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.

LOCAL OBSTETRICIAN GRATEFUL FOR DSAGC MATERIALS

*"The Down Syndrome Association of Greater Cincinnati information kit is an invaluable resource for patients and families. It provides current information and personal insights regarding Down syndrome. It is particularly useful to have accurate information to send home with the patient after my discussion." **Teresa J. Schutte, M.D., F.A.C.O.G.***

Please contact our offices at sally@dsagc.com or 513-761-5400 to receive these information kits for your patients. There is no cost for these materials.



**Fall, 2009
Volume 1, Issue 3**

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. Help your staff learn the preferred ways to support new families.

Contact :
sally@dsagc.com

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Down Syndrome and Hirschprung's Disease

- Around 2% incidence in children with DS.
- 50% present after one month.
- Early diagnosis important.
- Careful neonatal surveillance is required.
- Surgical outcome variable.

HIRSCHPRUNG'S DISEASE

Hirschprung's disease is due to failure of migration of the ganglion cells to the submucosal and myenteric plexuses of the large bowel. The affected segment can vary in length. It is important to remember that the affected area has a risk of stasis, infection, enterocolitis and perforation. This is one reason why early diagnosis is important. A newborn exam should include:

- An examination for imperforate anus in the delivery room in order to ensure this has been excluded.
- Active observation of when meconium is first passed.
- Consideration of Hirschprung's following late passage (24 hours) of meconium in a child with Down syndrome.

Establishing a diagnosis involves abdominal x-ray, contrast enema, rectal biopsy and anorectal manometry.

Dr. Charlie Charlton—Down Syndrome Medical Interest Group (DSMIG) and Cincinnati Children's Hospital

'People with Down syndrome are going to college, getting jobs, living independently and even getting married. He is a miracle and a blessing. Down syndrome is only part of who he is.'

Parent of a newborn baby



Down syndrome is the most frequently occurring chromosomal condition affecting all ages, races and economic levels. Down syndrome occurs in 1 out of every 733 births.

RESULTS OF 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 narrative account from a parent who reported the **sensitive, compassionate manner** in which her physician delivered their baby's diagnosis:

*"The doctor sat at the side of the bed with us and held the baby while she told us and showed us why they thought our baby had Down syndrome. She said they were confident that this was the diagnosis but that it would be confirmed by bloodwork. She also notified Children's Hospital and a physician from genetics came that evening to talk to us. Our memories of that day are bittersweet. We were devastated by the news but still in awe of our precious new baby...I will always hold a special place in my heart for the medical professionals that cared for us during this time. They relayed the news in a compassionate manner, allowed us privacy to cry and grieve, gave us information verbally but also sent home the same information in written form. **Most importantly, they never treated our baby differently than any other newborn on the floor.**"*