



Results of 2008 Family Survey

Parents Reflect on Their Birth Experience

In 2008, the DSAGC conducted an on-line survey of families who had given birth to a baby with Down syndrome between January 2003 and March of 2008. Two surveys



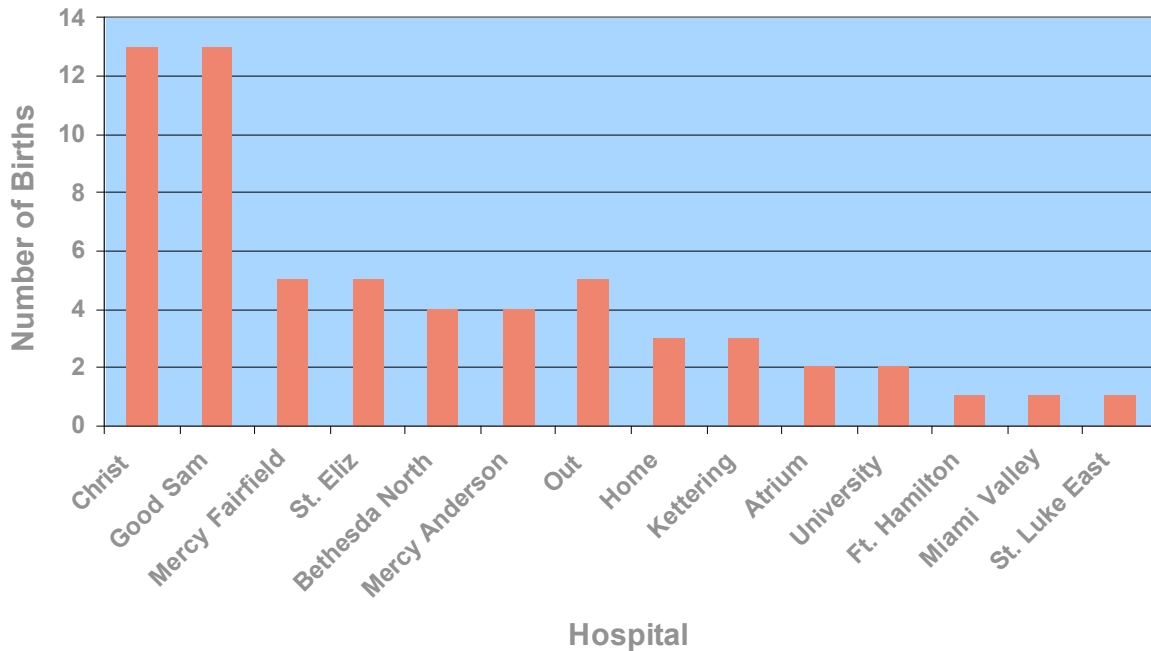
were created: one for prenatally diagnosed parents and another for those who received their diagnosis of Down syndrome postnatally. Forty-eight families completed the postnatal survey and 14 families completed the prenatal survey for a total of 62 families. This represents approximately 36% of the total number of births in that time period. The purpose of the survey was to gain insight into the birth experience of our families in order to assist healthcare professionals in their future interactions with families of babies with Down syndrome. In addition, basic information regarding babies' health was also gathered. This survey is by no means scientific, yet it does provide an opportunity to view the experience from a parental perspective and develop a deeper understanding of the emotional response of learning that your baby has a disability. Please note that in some cases the percentages do not total 100. This occurred when families had more than one response to a question.

Basic data

The average age of mother at time of birth in our survey was 34 years 1 month. The national average for this statistic is 28. This number reflects a significantly higher age for mothers in our sample. At the time of the survey, the current average age of child of the respondents was 3.25.

Forty-two percent of our families delivered their babies at either Christ Hospital or Good Samaritan Hospital with 13 births at each site. The following chart reflects the number of births at other hospitals:

Number of Births Per Hospital



Overall health of baby

The national statistic for babies born with Down syndrome is that 40% will have a heart defect. In our survey, 51.5% of babies had a heart defect and 34% of those had more than 1 defect. Additional medical concerns occurred at the following rate:

Hirschprung disease occurred in 3%

Duodenal atresia was diagnosed in 4%

Gastroesophageal reflux was diagnosed in 54% of our babies.

RSV 14%

Nationally, 10 to 12% of babies with Down syndrome have intestinal defects which require surgery.* Our sample experienced this at a lesser rate although reflux was extremely common.

Prenatal Testing

Participants were asked to provide information regarding their experience with prenatal testing. Forty percent of respondents in both the prenatally diagnosed and postnatally diagnosed categories reported that it was recommended that they undergo testing to determine the health of their fetuses. Interestingly, 40% of the prenatal group felt that this testing was "strongly recommended," while only 9% of the postnatal group were strongly recommended to undergo testing. 49% of the postnatal group received no recommendation from their physician for testing. Ninety-seven percent of the total sample reported that they understood and were aware of the purpose of this type of testing. 80% of the prenatal group elected to undergo testing while only 42% of the postnatal group was tested.

The Birth Experience

Many of the questions in our survey related to the actual birth experience including, attitude of hospital staff, being informed of their babies' diagnosis and emotional reactions. In the prenatal group, almost half of the respondents were given their babies' diagnosis by the obstetrician and 27% receiving this information from a geneticist/genetic counselor. In the postnatal group, only 25% learned of the diagnosis from either an obstetrician or nurse. The remainder (76%) were informed from a geneticist/genetic counselor or other healthcare provider.

- *American Academy of Pediatrics Committee on Genetics. Health Supervision for Children with Down Syndrome. Pediatrics, volume 107, number 2, February 2001, pages 442-449.*

When asked if they received the diagnosis alone or with a partner present, 53% of the prenatal group stated that a spouse or significant other was present while 85% of the postnatal group had this support present. This may be due to the fact that oftentimes, a prenatal diagnosis is confirmed over the phone whereas the postnatal diagnosis is made shortly after delivery in the hospital.

Of those families who received a prenatal diagnosis of Down syndrome:

- When the diagnosis of Down syndrome was delivered in person, 100% reported they strongly agreed or somewhat agreed that the diagnosis was delivered in a sensitive manner.
- When given the diagnosis over the telephone, 0% reported they strongly agreed that their diagnosis was delivered in a sensitive manner.
- The highest level of satisfaction in how the diagnosis was delivered was from those who received the diagnosis in person **and** with their partner present.

Within the postnatal group, 70% felt that diagnosis was delivered either somewhat sensitively or very sensitively, while 32% felt strongly that this information was not presented sensitively. Which hospitals did the best job? According to our families, based on a 4 point scale with 4 being the highest score, hospitals were ranked in the following way:

1. Good Samaritan Hospital	3.3
2. Bethesda North Hospital	3.0
3. Mercy Anderson/St. Elizabeth South	2.8
4. Mercy Fairfield Hospital	2.5
5. Kettering Medical Center	2.0
6. Christ Hospital	1.8

Hospitals with fewer than 3 births were not included in this ranking.

When asked to share their emotions upon learning of the diagnosis, both groups described their reactions using similar terms: fear, terrified, devastated, sadness, shock, hopeless, depressed, etc. Two parents reported that the genetic counselor asked if they wanted to schedule an appointment for termination. Many questioned whether God was punishing them by giving them this baby and others reported that the doctors made them feel as if it were somehow their own fault for not having prenatal testing performed during their pregnancy. They were made to feel as if they were being scolded for attempting to conceive later in life. One mother was asked if she had taken drugs or smoked during her pregnancy. Four families reported that the doctors whispered, poked, prodded their baby, avoided eye contact and would not directly address them.

These anecdotal reports highlight the importance of those who interact with mothers and fathers at this sensitive time of diagnosis to refrain from offering an opinion or attitude which reflects judgment. Nothing can be accomplished by causing the parents to feel guilt or somehow responsible for their baby's extra chromosome.

However, there are cases when parents reported that doctors and other hospital staff got it "just right:"

"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."

In contrast other parents had this to say:

"One of my biggest disappointments was that they did not send the

photographer to take a picture of my beautiful baby. It broke my heart. .. I just wanted her to be treated like all the other babies."

"A neonatologist came in and proceeded to spill a plethora of information on Down syndrome, telling us what may or may not happen over the years. She went on for half an hour telling us everything that could go wrong until a nurse in the room finally told her to stop. She had the right intentions but it was WAY too much information to try and process."

Interestingly, in spite of describing their reactions to receiving the diagnosis of Down syndrome with words such as devastating, shocked and numbing, 93% of the prenatal group and 72% of the postnatal group reported that their birth experiences were generally positive. This may be due to the fact that although the news is very difficult to hear, in retrospect i.e. 3 years post delivery, the pain of hearing the diagnosis is lessened by the joy that raising the baby has brought.

After the Birth

Ninety-seven percent of our sample was offered information on Down syndrome from the healthcare professionals, while almost 96% sought to further educate themselves on the subject. When asked specifically if they were provided with the DSAGC Yellow Hospital packet of information, 69% reported yes while 6% were uncertain. In order to learn more about Down syndrome, 83% turned to the internet and 71% sought help from the DSAGC. When asked which source of information was most helpful, 64% said the DSAGC was most helpful, 31% said personal contact with a family who had a child with Down syndrome helped them the most and 29% received the best information from books and the internet. A large percentage, 78% reported being connected to a parent mentor and 89% scheduled an appointment with the Thomas Center for Down Syndrome at CCHMC. 100% reported that they received early intervention services although 2 parents described Help Me Grow services as "useless" and "terrible."

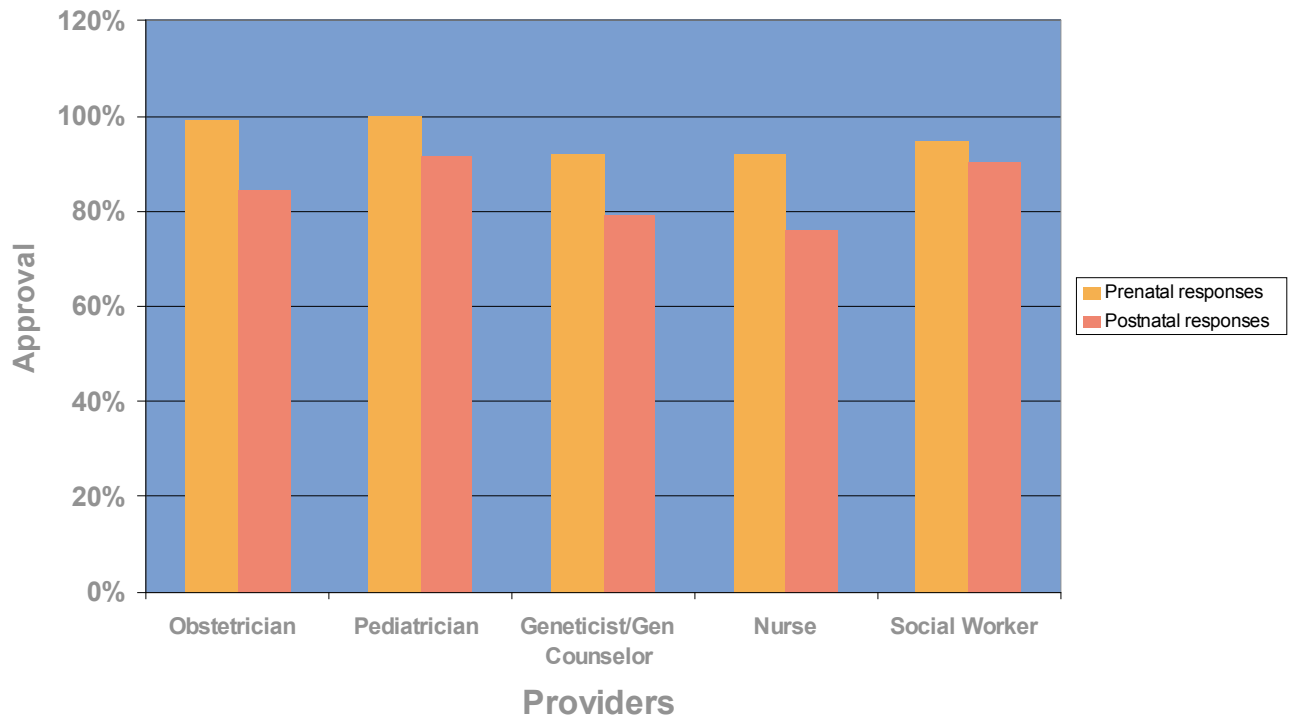
Impressions of Healthcare Providers

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

In general, the prenatal group had a more favorable opinion of all the professionals who interacted with them with the most positive impression of their pediatrician. In the postnatal group, the most unfavorable experience was with the hospital nurses and most favorable overall rating from both groups was earned by pediatricians.

Impressions of Healthcare Providers



When asked if the healthcare providers had an adequate knowledge of Down syndrome, only 56% of postnatally diagnosed parents said yes while 73% of prenatally diagnosed parents reported yes.

What Would You Like Your Doctor to Know About Your Baby?

Overwhelmingly, parents want to be congratulated on the birth of their child. Although the news is very difficult, they want the healthcare professionals to be happy for them and to let them know how much joy their baby will bring to their family. They feel that doctors underestimate their baby's potential and view their child as a burden while parents view them as a blessing.

As one parent said,

"She is a lovely person; she is spunky, hates vegetables and getting her hair combed. She loves ice cream and sliding and she is the best gift we have ever been given. Down syndrome is such a small part of who she is. Her personality is her own and not formed by an extra chromosome."

Another parent had this to say,

"The doctors had such outdated information and spoke almost as though I'd lost the baby, when I was so proud of the beautiful healthy boy that I had. I wish the medical community was more aware of the realities of DS. People with DS are going to college, getting jobs and living independently and even getting married. He is a miracle and a blessing. DS is only part of who he is."

What Does It All Mean?

As mentioned previously, this is not a scientific study, however we can make some generalizations about the birth experience of some of the families in our area.

It seems as if the healthcare community is doing some things well. They are doing a good job of educating parents on the purpose of prenatal testing and they are also doing a good job of offering more information on Down syndrome but they could do a better job of connecting them to the DSAGC. The overwhelming message for healthcare providers can be summed up in this way:

- Parents want to be congratulated on the birth of their baby.
- They want their baby treated the same as all the other babies.
- They want to be told the diagnosis but not lectured or over- informed.
- They want to learn more about Down syndrome **and** they want their doctors to know more about Down syndrome as well.
- Prenatally, parents feel the diagnosis is delivered much more sensitively when

it is given in person and not over the phone.

- They want privacy and time to grieve with a significant other or family member.
- They want you to know their child is a blessing.

The DSAGC would like to thank the **PNC Advisors** for their generous grant to help support this project. Our intention is to repeat the survey in three years after an intensive effort to increase our outreach efforts to the healthcare community in Greater Cincinnati. Most importantly, the DSAGC is very grateful to **Sarah Hartway, Healthcare Partnership Coordinator for the Mile High Down Syndrome Association in Denver, CO** for graciously sharing information which allowed us to benefit from all her efforts in the Denver community.

For additional information regarding this survey, please contact:

Sally K. Tilow

Outreach Coordinator

DSAGC

644 Linn St. Suite 1128

Cincinnati, OH 45203

513-761-5400

sally@dsagc.com