FOR PARENT SUPPORT GROUP NEWSLETTER

Mothers Have Spoken: Physicians Need to Do a Better Job in Delivering a Postnatal Diagnosis of Down Syndrome

By Brian Skotko

Two years ago, I asked 2,945 mothers who have children with Down syndrome to participate in a research study that examined how doctors deliver a diagnosis of Down syndrome. Your responses poured in, and your stories were poignant and sensitively honest. I am happy to report that you now have a voice in a national medical journal. The results of your opinions—and your frustrations—have been published in the January issue of *Pediatrics.*

This research study asked mothers to reflect on a central question: How could medical support have been better when you received the diagnosis of Down syndrome for your child? To answer this, mothers completed an 11-page survey, which included a variety of topics: How did your physician deliver the diagnosis? Were the verbal explanation adequate, the setting appropriate, the language sensitive, and the printed materials helpful? What was it like to receive the diagnosis?

Five parent support groups—the Massachusetts Down Syndrome Congress (Massachusetts), the Mile High Down Syndrome Association (Colorado), the Triangle Down Syndrome Network (North Carolina), the Down Syndrome Association of Los Angeles (California), and the Down Syndrome Society of Rhode Island (Rhode Island)—distributed copies of the research survey to all of the mothers on their mailing lists. In total, 1,250 responses were received, making this the most comprehensive and robust study on the topic, to date.

The majority of mothers reported being frightened or anxious after learning of the diagnosis, and very few rated the overall experience as a positive one. Among the words that were used were *shocked, angry, devastated, overwhelmed, depressed, stunned,* and *helpless.* The statistics revealed that mothers were more apt to be fearful and anxious if their physicians emphasized the negative aspects of Down syndrome when first delivering the diagnosis. Physician behaviors did improve with time, although very slowly. Definitively positive comments did not seem to be included in mothers' responses until the late 1990s and 2000s. Mothers were most optimistic when their physicians talked about the positive aspects of Down syndrome and provided them with up-to-date printed materials.

Through their collective responses, mothers have called upon physicians to adopt 10 recommendations when delivering a postnatal diagnosis of Down syndrome:

(1) **The person to deliver the news should be a physician**. Mothers in this study received the diagnosis from a variety of health care providers: pediatricians, neonatologists, obstetricians, genetic counselors, nurses, and in two cases, the lactation specialist and the candy-striper volunteer. Mothers felt that a physician was the person most knowledgeable to present the diagnosis.

(2) **Obstetricians need to coordinate their messages with neonatologists and pediatricians**. In many hospitals, mothers suggested that there was confusion and, at times, disagreement over which physician was responsible for delivering the news. Physicians from various specialties need to work collaboratively.

(3) **The news should be delivered once the mother is settled and as soon as a physician suspects the diagnosis**. Some mothers were upset that they received the news immediately, particularly while episiotomies were still being sutured. Most mothers, however, were worried during what was described as a silence period, where no health care professional would give them an honest answer about what was going on. A physician should not wait until a diagnosis is confirmed through karyotyping; mothers prefer to be aware of the physicians' thought process, no matter how difficult the news might be.

(4) **Whenever possible, the physician should make the announcement with both parents present, in a private setting**. As the diagnosis of Down syndrome is just as novel to the father as it is to the mothers, physicians should not expect that fathers should be the ones to share the news with the mothers.

(5) **When delivering the news about Down syndrome, the physician should first congratulate the parents on the birth of their child**. Mothers have recommended that physicians include the positive aspects of Down syndrome in their first descriptions of the condition. Many mothers mentioned that the best words used by their physician during this initial explanation were, "Love your child like any other child."

(6) **Health care professionals should keep their personal opinions to themselves**. Mothers have asked physicians to offer sound medical advice based on up-to-date information, but not personal opinion.

(7) **Mothers should be provided with up-to-date printed materials**. Most new parents were frustrated at either receiving outdated information or no information at all. Mothers requested receiving complimentary copies of books on Down syndrome that

included positive imagery; or, in the cases where hospitals were financially unable to do so, a bibliography listing the most current resources for new parents.

(8) **Parents should be provided access to other families who have children with Down syndrome.** First call programs—that is, support programs in which a parent of a child with Down syndrome visits or phones one of the new mothers—were mentioned as invaluable sources of help to the new parents. Hospitals and parent support groups should work collaboratively to provide this requested outreach to new parents.

(9) **After the initial diagnosis or suspicion is shared with parents, they should be offered a private hospital room.** As mothers respond to the diagnosis with a variety of emotions, many requested that they have a private space to express those emotions.

(10) **Physicians should be cognizant of the realities and possibilities of growing up with Down syndrome.** Simply put, Down syndrome is not just what was taught in medical school. Mothers considered it the responsibility of doctors to stay informed about the educational and social potentials of children with Down syndrome.

The time for change is long overdue. These recommendations offered by mothers are by no means revolutionary and could be easily implemented by all physicians responsible for delivering diagnoses of Down syndrome. You can continue to effect change by sharing the full study with the hospitals in your surrounding area. (The complete report is available online at <<list parent support group web page>>.)

Also of note: Many of the mothers who responded to the survey received the diagnosis of Down syndrome through prenatal testing. These results were analyzed separately and will be published in an upcoming issue of the medical journal, *American*

Journal of Obstetrics and Gynecology. I will be sure to submit to you another report when I am able to release these results.

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