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

I remember everything about how my husband and I learned that our first-born child, Maren, had Down syndrome. It had been two hours since her birth and I had only briefly held her — Tim didn't do so at all — and then the hospital staff whisked her away to check her out. Tim and I had just agreed he was going to go to the nurse's station to ask for the baby to be brought to my room when a man we had never seen before came to the door. He introduced himself as a staff pediatrician and said he was sorry he had something to tell us about our baby. We got the news that our daughter — an intimate stranger — probably had DS and likely a serious heart condition. We learned this before we got to see what color her eyes were.

In retrospect, our story could have been far worse. We did get a packet of up-to-date information (provided by our local parent association). The next morning, the doctor did connect us with a family of a two-year-old boy with DS. However, the hospital staff seemed to actively avoid us (mind you, I was a patient!) and my husband still resents the fact that everyone in the delivery room knew what had happened — except us.

Brian Skotko is a joint-degree student at Harvard Medical School and the John F. Kennedy School of Government. He has a 23-year-old sister with DS and, along with former NDSC board member Cynthia Kidder, has co-authored the book, *Common Threads: Celebrating Life with Down Syndrome*. Brian, a leader of the NDSC's annual Brother/Sister Conference, recently surveyed nearly 3,000 mothers on how they learned that their new baby had DS and what support was provided with this diagnosis.

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? The results have been published in the January 2005 issue of *Pediatrics*, the journal of the American Academy of Pediatrics. A copy of the published study is available on the NDSC Web site, www.ndsccenter.org. Included below is a summary of the recommendations.

Skotko reports that through more than 1,200 collective responses, mothers have called upon physicians to adopt 10 recommendations when delivering a postnatal diagnosis of DS:

(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 DS 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 DS, the physician should first congratulate the parents on the birth of their child. Mothers have recommended that physicians include the positive aspects of DS 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 DS 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 DS. First call programs—that is, support programs in which a parent of a child with DS 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 DS. Simply put, DS 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 DS.

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 DS. You can continue to effect change by sharing the full study with the hospitals in your surrounding area.

You may be surprised at how grateful hospital staff is to get the information. The DSA of Minnesota sent copies to 125 hospital contacts across the state. The response?

“Thank you for the wonderful article and information on delivering a postnatal diagnosis of DS. I intend to share this much needed information with our birth center staff.”

“Thank you so much for the information. We have all been put in the situation where we have had to deliver specific news or let parents know of our suspicions. This article has just wonderful information in it that will be so helpful to us. I plan to share it with my staff.”

“The information is so valuable. We plan on presenting the paper at our grand rounds.”

Many of the mothers who responded to the survey received the diagnosis of DS 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*. Brian will share those results later this spring. (JA)

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