



# **NEWS NEWS NEWS NEWS NEWS NEWS**

## **EMBARGOED NEWS FOR RELEASE:**

Monday, January 3, 2005, 12:01 a.m. ET

### **Contacts:**

Mary-Ellen Shay, Children's Hospital Boston, 617-355-6420,

[mary.shay@childrens.harvard.edu](mailto:mary.shay@childrens.harvard.edu)

John Lacey, Harvard Medical School, 617-432-0442, [public\\_affairs@hms.harvard.edu](mailto:public_affairs@hms.harvard.edu)

## **Mothers Speak: Physicians Often Fall Short When Delivering a Down Syndrome Diagnosis**

### ***10 Specific Recommendations Offered***

BOSTON, MA—A survey of mothers in the January issue of *Pediatrics* found that physicians remain overwhelmingly negative in communicating a diagnosis of Down syndrome in newborn infants. Mothers reported that the majority of physicians were uninformed about the positive potential for children with Down syndrome, and rarely provided an adequate, up-to-date description of the children, printed information, or telephone numbers of other parents. By nearly all ratings – including explaining Down syndrome, the timing and setting of the news, and the language that was used -- physicians fell far short of making the birth a positive experience.

The study was done by Brian Skotko, a student at Harvard Medical School (HMS) and Harvard's John F. Kennedy School of Government, and supported by the Tim White Fund from Children's Hospital Boston (where Skotko did his pediatric rotation) and a part-time research grant from HMS.

Skotko mailed an 11-page survey to nearly 3,000 members of five Down syndrome parent organizations in California, Colorado, Massachusetts, North Carolina, and Rhode Island. Of the 1,250 responses, nearly 1,000 were from mothers who had not undergone prenatal testing and received the Down syndrome diagnosis after delivery. Very few reported that the birth of their child was a positive experience.

Mothers were frequently advised to put up their child for adoption, or chided for not having prenatal testing, the survey found. Some mothers received the news too soon, such as while having episiotomies stitched up. While the worst reported instances came from the 1980s and earlier, and physicians improved over time, mothers still described insensitive comments as

recently as the late 1990s and early 2000s. A mother in 1997, for example, heard a doctor refer to her newborn as an “FLK” (“funny-looking kid”); another who gave birth in 2000 reported, “The doctor flat out told my husband that this could have been prevented or discontinued at an earlier stage of the pregnancy.”

“Doctors have gotten better over time, but it’s been a very slow change, and they’ve really gone from terrible to just bad,” says Skotko, who has a 24-year-old sister with Down syndrome and co-authored the award-winning book, *Common Threads: Celebrating Life with Down Syndrome* (Band of Angels Press). “Finding out a diagnosis of Down syndrome does not have to be a horrible process. In fact, the mothers in this study explain how physicians can make it a positive experience. We hope this paper will be a catalyst for increased dialogue among doctors.”

Dr. Allen Crocker, Skotko’s faculty advisor on the project and director of the Down Syndrome Program at Children’s Hospital Boston, says that the survey findings echo his nearly 40 years of experience working with families. “Physicians have consistently been inadequate and incomplete, and, on occasion, offensive,” he says. “This study is the most searching review of parents’ experiences of postnatal presentation of a diagnosis of Down syndrome ever published, and it has been done with considerable statistical care. It is clearly a case of families teaching physicians.”

Skotko notes that mothers with the best birth experiences had physicians who talked positively of Down syndrome. Examples include: “Your child is going to bring great richness and warmth to your family and community”; “Your child should be loved just like any other child”; “Your child will teach you and others life lessons”; “Your child will be a beacon of what humanity is supposed to stand for.”

Based on the mothers’ comments, Skotko offers a 10-point “prescription” for communicating a diagnosis of Down syndrome:

- The person to communicate the Down syndrome diagnosis should be a physician.
- Obstetricians, neonatologists and pediatricians should coordinate their messages.
- The diagnosis should be delivered as soon as a physician suspects the diagnosis, but only after the mother is settled.
- Parents should receive the news together, in a private setting.
- The physician should first congratulate the parents on the birth of their child and not forget to talk about the positive aspects of Down syndrome. They should not begin the conversation by saying, “I’m sorry.”
- Health care professionals should keep their personal opinions to themselves.

- Mothers should be provided with up-to-date printed materials – at a minimum, a bibliography listing the most current resources for new parents.
- Parents should be put in touch with other families who have children with Down syndrome.
- After the diagnosis or suspicion is shared, parents should be offered a private hospital room.
- All physicians should educate themselves about the educational and social potentials of children with Down syndrome.

Skotko will soon publish a companion paper in the *American Journal of Obstetrics and Gynecology* summarizing responses from women who received the Down syndrome diagnosis prenatally. He also has conducted the same pair of studies in Spain to get a cross-cultural perspective.

Approximately one of every 1,000 children in the U.S. is born with Down syndrome, meaning that approximately 5,000 parents receive the diagnosis for their child each year. Despite the widespread use of prenatal testing, the majority of families who have children with Down syndrome do not learn of their child's diagnosis until after they are born.

To identify parents of children with Down syndrome who are willing to be interviewed about their experiences, contact the National Down Syndrome Congress (1-800-232-NDSC; David Tolleson, Executive Director), the National Down Syndrome Society (1-800-221-4602; Suzanne Elliott Armstrong, Director of Communications), or local Down syndrome support groups (a directory is at [www.ndss.org](http://www.ndss.org)).

### **CHILDREN'S HOSPITAL BOSTON**

Children's Hospital Boston is the nation's leading pediatric medical center, the largest provider of health care to Massachusetts' children, and the primary pediatric teaching hospital of Harvard Medical School. Children's provides pediatric and adolescent health services for patients from birth through age 21. In addition to 325 inpatient beds and comprehensive outpatient programs, it houses the world's largest research enterprise based at a pediatric medical center. More than 500 scientists, including eight members of the National Academy of Sciences, nine members of the Institute of Medicine and 10 members of the Howard Hughes Medical Institute comprise Children's research community. For more information about the hospital visit: [www.childrenshospital.org](http://www.childrenshospital.org)

### **HARVARD MEDICAL SCHOOL**

<http://www.hms.harvard.edu/>

Harvard Medical School has more than 5,000 full-time faculty working in eight academic departments based at the School's Boston quadrangle or in one of 47 academic departments at 18 Harvard teaching hospitals and research institutes. Those Harvard hospitals and research institutions include **Beth Israel Deaconess Medical Center, Brigham and Women's Hospital, Cambridge Hospital, The CBR Institute for Biomedical Research, Children's Hospital Boston, Dana-Farber Cancer Institute, Forsyth Institute, Harvard Pilgrim Health Care, Joslin Diabetes Center, Judge Baker Children's Center, Massachusetts Eye and Ear Infirmary, Massachusetts General Hospital, Massachusetts Mental Health Center, McLean Hospital, Mount Auburn Hospital, Schepens Eye Research Institute, Spaulding Rehabilitation Hospital, VA Boston Healthcare System.**