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GLOBAL RESEARCH REVEALS SHORTCOMINGS IN HOW PHYSICIANS DELIVER NEWS OF DOWN SYNDROME DIAGNOSIS

Study Offers Multi-point “Prescription” to Help Improve Methods

BOSTON, MA—A survey of more than 9,000 mothers residing in Spain and the United States revealed that physicians, both domestically and internationally, were insufficient and, at times, offensive when delivering the diagnosis of Down syndrome to new parents. Mothers from both countries claimed that physicians rarely talked of the potential for individuals with Down syndrome and did not provide enough up-to-date printed materials or referrals to support groups comprised of parents of children with the condition. The study, noted as the most wide-reaching survey on how physicians communicate a postnatal diagnosis of Down syndrome, was supported by the Tim White Fund from Children’s Hospital Boston and a part-time research grant from Harvard Medical School.

Completed by Brian G. Skotko, who co-authored the national award-winning book, *Common Threads: Celebrating Life with Down Syndrome* (Band of Angels Press) and has a 25-year-old sister with Down syndrome, the research has also fostered bipartisan Federal legislation (Senators Kennedy and Brownback), proposing that \$25 million be appropriated so that mothers who receive prenatal test results for conditions like Down syndrome receive accurate, up-to-date information, and referrals to support groups. Skotko is currently a joint-degree student at Harvard Medical School and Harvard’s John F. Kennedy School of Government and sits on the Board of the Massachusetts Down Syndrome Congress.

Research reaches beyond the U.S and reveals global shortcomings

Down syndrome is the most common chromosomal condition worldwide. 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. Estimates suggest that around 350,000 families in the United States have a member with Down syndrome. Similarly, in Spain, about 1 in every 1,000 children is born with Down syndrome, suggesting that more than 32,000 people with Down syndrome currently populate the country.

To capture mothers’ perspectives on how they received the diagnosis for their child, Skotko mailed an 11-page survey to nearly 3,000 mothers belonging to Down syndrome parent support organizations in California, Colorado, Massachusetts, North Carolina, and Rhode Island, and more than 6,000 mothers affiliated with Down syndrome organizations in Spain.

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Of the 1,751 responses received, more than 1,300 were from mothers who had received the Down syndrome diagnosis after giving birth. Approximately 87 percent of mothers in the U.S. and nearly 99 percent of mothers in Spain who have children with Down syndrome learned of the diagnosis postnatally, as it is a rare event for a woman to continue a pregnancy if they learn of the diagnosis prenatally.

Mothers from both countries rarely reported that the birth of their child with Down syndrome was a positive experience, indicating feelings of fear and anxiety as well as shared frustrations about their physician's inability to explain positive aspects, attributes, and the potential for individuals with Down syndrome. The study notes that mothers with the best experiences had physicians who talked positively about Down syndrome.

"While statistical differences emerged between Spain and the United States, the differences ranged between terrible and bad. Clearly the worldwide community of pediatricians has now received a mandate for improvement. The feedback from mothers indicates that a diagnosis of Down syndrome need not be a gloomy affair," Skotko notes.

Multi-point "prescription" offered to physicians to improve delivery of Down syndrome diagnosis

Based on the international response from mothers, Skotko offers a 9-point "prescription" for physicians on how best to communicate a diagnosis of Down syndrome:

- The person to deliver the diagnosis should be a physician.
- The physician should deliver the diagnosis with both parents together, whenever possible.
- The physician should deliver the diagnosis in a private setting.
- The physician should convey the diagnosis as soon as he or she suspects it.
- The physician should use sensitive language. Instead of saying "I'm sorry" or "I have some bad news to share," physicians should first congratulate parents on the birth of their child.
- The physician should include the positive aspects of Down syndrome when explaining the diagnosis.
- The physician should not share his or her personal opinion.
- Parents should be provided with up-to-date printed materials.
- The physician should offer the contact information of a local support group.

Skotko published companion papers in the January issue of *Pediatrics*, summarizing the responses from women who received postnatal Down syndrome diagnoses in the United States, in the June issue of *Mental Retardation*, analyzing the perspectives of mothers in Spain who received postnatal diagnoses, and in the March issue of *American Journal of Obstetrics and Gynecology*, describing the responses from women in the U.S. who received prenatal diagnoses. The final installment of the research findings incorporates the results of an international poll, and will be published in the December issue of the *Italian Journal of Pediatrics*.

Note to editors: To arrange an interview with parents of children with Down syndrome willing to share their personal experiences, contact the Massachusetts Down Syndrome Congress (617-851-3426; Wendy Bulawa, Media Relations), the National Down Syndrome Society (1-800-221-4602; Suzanne Elliott Armstrong, Director of Communications), or the National Down Syndrome Congress (1-800-232-NDSC; David Tolleson, Executive Director).

About Massachusetts Down Syndrome Congress

Established in 1983, the Massachusetts Down Syndrome Congress (MDSC) is a non-profit organization dedicated to education about and awareness of Down syndrome. MDSC was founded to provide information, resources and support for families, while advocating for the inclusion of individuals with Down syndrome into all aspects of the community. Additionally, the organization gathers and disseminates the most accurate and timely news relating to Down syndrome to educate the public, while actively and aggressively addressing social policy and legislatively-driven issues alongside state and local human service agencies. More information about MDSC can be found at www.mdsc.org, or by calling 781-224-3991.

About National Down Syndrome Society

The National Down Syndrome Society is a nonprofit organization with more than 200 affiliates nationwide representing the more than 350,000 Americans who have this genetic condition. NDSS is committed to being the national leader in supporting and enhancing the quality of life, and realizing the potential of all people with Down syndrome. We demonstrate this commitment through our education, research and advocacy initiatives that benefit people with Down syndrome and their families.