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***Study: Family, Siblings, Etc. Find Down Syndrome to be Positive in Their Lives***  
*News comes as thousands prepare to celebrate 15<sup>th</sup> Annual Buddy Walk for Down syndrome*

Burlington, MA —Three related surveys led by a physician at Children's Hospital Boston suggest that the experience of Down syndrome is a positive one for most parents, siblings and people with Down syndrome themselves. The results, published in three reports in the [October issue](#) of the *American Journal of Medical Genetics*, may serve to inform expectant parents and clinicians providing prenatal care.

"New prenatal tests for Down syndrome are set to come out as early as the end of this year," says Brian Skotko, MD, MPP, a clinical fellow in genetics at Children's Hospital Boston. "Many more women will then learn about the diagnosis prenatally and will need to grapple with very personal pregnancy options. In [previous surveys](#), mothers have reported receiving inaccurate, incomplete and occasionally offensive information about Down syndrome from their healthcare providers."

Skotko and collaborators Susan Levine, MA, CSW, of Family Resource Associates (Shrewsbury, NJ) and Richard Goldstein, MD, of the Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, sent surveys to 4,924 households on the mailing lists of six nonprofit Down syndrome organizations around the country.

Among the findings:

- 79 percent of parents or guardians felt their outlook on life was more positive because of their child. Only 5 percent felt embarrassed by their child.
- 94 percent of siblings age 9 and older expressed feelings of pride about their sibling. 88 percent said they felt they were better people because of their sibling with Down syndrome. Only 4 percent said they would "trade their sibling in" for another.
- 99 percent of people with Down syndrome said they were happy with their lives. 97 percent liked who they are and 96 percent liked how they look. Only 4 percent expressed sadness about their life.

"As international discussion is mounting over the new prenatal tests, family members have now had their say about life with Down syndrome," says co-author Levine. "And, more importantly, the people with Down syndrome themselves have clearly stated that they consider their lives valuable."

This news comes just as thousands of family, friends and self-advocates prepare to gather at Lake Quannapowitt in Wakefield on Sunday, October 9, for the Massachusetts Down Syndrome Congress's 15<sup>th</sup> Annual Buddy Walk & Family Picnic, presented by VERIZON.

"We invite the entire community to come and walk with us to celebrate the lives of individuals with Down syndrome and how they contribute to our families and communities in so many ways," said Maureen Gallagher, Executive Director of the Massachusetts Down Syndrome Congress.

The MDSC is at the forefront in providing parents, people with Down syndrome, educators, health care professional, and the community-at-large with providing information, networking opportunities, and advocacy for and about Down syndrome. Through Buddy Walk events, the MDSC continues to educate, raise awareness, and promote the positive contributions of individuals with Down syndrome to deliver a more accurate and realistic portrayal of Down syndrome and those living with it.



Event registration opens at 11:00am with the three-mile walk kickoff starting at 1:00pm. Registration includes event t-shirt, kids' activities, pre-walk entertainment with Grammy Nominee Brady Rymer of the Little Band That Could, walk kickoff with emcee Erin O'Malley of Mix 104.1, lunch, and post-walk tunes by Ayla Brown, recording artists and *American Idol* Season 5 semifinalist. All funds raised directly support vital MDSC programs and services including Parents First Call, Advocates in Motion (AIM), Teacher Partnership Network, Educator's Forum, Annual Conference, and Legislative Advocacy efforts.

To make a donation, register to walk, or volunteer, visit <http://mdsc.kintera.org/buddywalk2011>. Your support of this event will help the MDSC ensure individuals with Down syndrome are valued, included, and given opportunities to pursue fulfilling lives in the community.

For more information on the Children's Hospital Boston study, visit here.  
<http://www.childrenshospital.org/newsroom/Site1339/mainpageS1339P766.html>

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#### **About MDSC**

*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](http://www.mdsc.org), or by calling 781-221-0024.*

#### **About Buddy Walk**

*The Buddy Walk® was established in 1995 by the National Down Syndrome Society to celebrate Down Syndrome Awareness Month in October and to promote acceptance and inclusion of people with Down syndrome. Today, the Buddy Walk program is supported nationally by NDSS and organized at the local level by parent support groups, schools and other organizations and individuals.*

#### **About Children's Hospital Boston**

*Children's Hospital Boston is home to the world's largest research enterprise based at a pediatric medical center, where its discoveries have benefited both children and adults since 1869. More than 1,100 scientists, including nine members of the National Academy of Sciences, 11 members of the Institute of Medicine and nine members of the Howard Hughes Medical Institute comprise Children's research community. Founded as a 20-bed hospital for children, Children's Hospital Boston today is a 396 bed comprehensive center for pediatric and adolescent health care grounded in the values of excellence in patient care and sensitivity to the complex needs and diversity of children and families. Children's also is the primary pediatric teaching affiliate of Harvard Medical School. For more information about research and clinical innovation at Children's, visit: <http://vectorblog.org>.*