



For Immediate Release
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Poll: Americans overwhelmingly support government programs and research for people with Down syndrome

Approval of fair funding contrasts with reality, as highlighted by New York Times Magazine [Article](#)

Denver, CO -- Despite tough economic times and concerns about government spending, a majority of Americans support funding for government programs and research for people with Down syndrome, according to a **first-of-its kind** national poll.

The recent telephone survey of 810 Americans, conducted by Kupersmit Research on behalf of the Global Down Syndrome Foundation, found strong backing for government programs that provide education and training for people with Down syndrome, support for their families, and research into the condition.

The poll demonstrates a disconnect between funding for people with Down syndrome, which has lagged over the last decade, and the widespread support for spending on the condition. *"I am encouraged to learn from this poll that so many Americans join us as advocates of the Down syndrome community,"* says U.S. Congressman Pete Sessions (R-TX), who co-chairs the Congressional Down Syndrome Caucus. *"With additional funding and research, we can continue to build on our quest to provide the resources individuals with Down syndrome need to achieve and reach their maximum potential."*

Down syndrome is the most frequent chromosomal disorder representing an estimated 400,000 Americans. However, federal research funding from the National Institutes of Health (NIH) for people with Down syndrome was a mere [\\$22 million in 2010](#), representing 0.0007 of NIH's

annual \$31 billion budget. Despite its frequency, Down syndrome research funding has dramatically shrunk, as a percentage of the total NIH budget since 2000. In some years Down syndrome had the largest decrease in funding of any single condition at the NIH.

A New York Times Magazine [article](#), published online on July 29, highlighted the disparity in funding for Down syndrome. It quotes U.S. Congresswoman Cathy McMorris Rodgers (R-WA), as saying, *“I find myself wondering how N.I.H. really sets their priorities.”*

Current scientific thinking supports the spending of research dollars on Down syndrome. Leading scientists believe increased funding would, within a decade, significantly improve the health of people with Down syndrome, while allowing them to live fuller and more productive lives. In addition to improving the health of people with Down syndrome, increased spending would positively affect other areas of research according to McMorris Rodgers. *“Because people with Down syndrome have many medical issues, research on the condition can yield important treatments for other conditions like Alzheimer’s or heart disease. Investing in this research will benefit millions of people who suffer from these common diseases.”*

Ninety-five percent of poll respondents agreed (73 percent strongly, 22 percent somewhat) with the statement that “programs and financial support can make a huge difference in what someone with Down syndrome can achieve for themselves and their whole family.”

Eighty-five percent agreed (61 percent strongly, 24 percent somewhat) with the statement: “We are all better off if government invests in improving the lives of people with Down syndrome.”

Among other findings:

- 96 percent supported (83 percent strongly, 13 percent somewhat) both education and training for people with Down syndrome, so they can learn job skills and training. Equally important was counseling and support to parents of children with Down syndrome.
- 91 percent believe funding for research about Down syndrome should be equal to or more than to the funding for research for other conditions like Fragile X or Autism. (85 percent believed it should be about equal while 6 percent believed funding for Down syndrome should be greater.)
- NIH research funding for Down syndrome in fiscal year 2010 equaled [\\$50 per each American living with the genetic condition](#). In contrast, NIH research funding for other conditions per each American with such conditions equaled:
 - \$137 for Autism
 - \$573 for Fragile X, a genetic condition that leads to developmental disabilities
 - \$2,867 for Cystic Fibrosis
 - \$322 for Multiple Sclerosis

Michelle Sie Whitten, executive director of the Global Down Syndrome Foundation, emphasized the need for support, “It was important for us to understand how mainstream Americans feel about programs and research for people with Down syndrome as we simply didn’t know. We are surprised and delighted by the overwhelming support,” Whitten said. “We are also pleased we

can now help funding agencies and Congress realize that increased funding for people with Down syndrome would be viewed as a fair move by voters.”

The survey was conducted April 5-11, 2011. The margin of error is plus or minus 3.4 percent at the 95 percent confidence level. Key portions of the survey are being released by the Global Down Syndrome Foundation to highlight specific areas of focus. The questionnaire and topline results to the questions referenced in this release, as well as demographic information about the respondents, are available [here](#).

For more information about polling, please visit <http://globaldownsyndrome.org/press/>.

About the Global Down Syndrome Foundation

The Global Down Syndrome Foundation is a public non-profit 501(c)(3) dedicated to significantly improving the lives of people with Down syndrome through research, medical care, education and advocacy. Formally established in 2009, the Foundation’s primary focus is to support the Linda Crnic Institute for Down Syndrome, the first academic home in the US committed to research and medical care for people with the condition. Fundraising and government advocacy that corrects the alarming disparity of national funding for people with Down syndrome is a major short-term goal. The Foundation organizes the Be Beautiful Be Yourself Fashion Show - the single largest annual fundraiser benefitting people with Down syndrome. Programmatically the Foundation organizes and funds many programs and conferences including the Dare to Play Football and Cheer Camps, Global Down Syndrome Educational Series, and Global Down Syndrome Multi-Language Resource Project. The Foundation is an inclusive organization without political or religious affiliation or intention.

About the Linda Crnic Institute for Down Syndrome

The Linda Crnic Institute for Down Syndrome is the first medical and research institute with the mission to provide the best clinical care to people with Down syndrome, and to eradicate the medical and cognitive ill effects associated with the condition. Established in 2008, the Crnic Institute is a partnership between the University of Colorado School of Medicine, the University of Colorado Boulder, and Children’s Hospital Colorado. Headquartered on the Anschutz Medical Campus, the Crnic Institute includes the Anna and John J. Sie Center for Down Syndrome at the Children’s Hospital Colorado. It partners both locally and globally to provide life-changing research and medical care for individuals with Down syndrome. The Crnic Institute is made possible by the generous support of the Anna and John J. Sie Foundation, and relies on the Global Down Syndrome Foundation for fundraising, education, awareness and government advocacy. It is a research and medical-based organization without political or religious affiliation or intention.

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