



National Down Syndrome Society

Legislative & Advocacy Initiatives

The mission of the National Down Syndrome Society (NDSS) is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome by advocating for federal, state, and local policies that positively impact people with Down syndrome across the country. NDSS accomplishes this by doing the following:

- Works with Congress and federal agencies to develop and improve laws, regulations and other policies by executing a comprehensive legislative agenda supporting people with Down syndrome
- Trains and educates parents, self-advocates and others to advocate on the local, state and national levels to positively impact the lives of people with Down syndrome
- Organizes and participates in national coalitions that support and help advance the Down syndrome legislative agenda in DC
- Leads a state-of-the-art national and statewide advocacy program

The NDSS legislative agenda spans the life experience of individuals with Down syndrome from birth through adulthood and range in issue from healthcare to asset development. These priorities have been shaped by self-advocates, families, affiliate leaders and others under the direction of the NDSS Board of Directors.

- **Improving Health Outcomes & Quality of Life for People with Down Syndrome:** When it comes to improving the health and quality of life for people with Down syndrome, there are two important aspects that NDSS strives to address legislatively, creating and maximizing research opportunities for Down syndrome, and improving the quality of healthcare provided to people with Down syndrome.
- **Improving Education Opportunities for People with Down Syndrome:** The first years of life are an important time in a child's development. All young children go through the most rapid and developmentally significant changes from birth to age five. Children with Down syndrome typically face delays in certain areas of development, so quality early intervention (beginning any time after birth) and pre-school experiences are critical to the development of children with Down syndrome.
- **Increasing Opportunities for Adults with Down Syndrome:** NDSS recognizes that after high school, and even postsecondary education, the opportunities for adults with Down syndrome are limited. NDSS has always focused on creating opportunities for adults with Down syndrome through federal legislation, programs, and other key initiatives.
- **Creating an Economic Future for Individuals with Down Syndrome:** People with Down syndrome face several challenges that prevent them from gaining access to meaningful employment opportunities, economic and financial planning, and independent living. As people with Down syndrome are living longer, it's important for individuals with Down syndrome and their families to have access to meaningful employment, financial freedom, and a living environment of their choosing.



Down Syndrome Research Policy Initiatives

Down Syndrome Research Funding

NDSS works to create and maximize federal research funding opportunities across the federal government. The largest funder of biomedical research is the National Institutes of Health (NIH). NDSS is actively working to increase research funding for Down syndrome at NIH, and other federal departments and agencies. The fiscal year 2012 annual NIH budget for Down syndrome is \$22 million. NDSS commends NIH, especially the Eunice Kennedy Shriver National Institute for Child Health & Human Development (NICHD), for its leadership and ongoing efforts to implement the NIH Down Syndrome Research Plan, which is supported through funding efforts by NIH, and the current federal efforts underway to build research infrastructure (i.e., a patient registry and biobank) and capacity for Down syndrome across the country.

People with Down syndrome have an increased risk for certain medical conditions, including far higher rates of childhood leukemia, heart defects, severe digestive tract issues, and sleep apnea. Moreover, research indicates the incidence of Alzheimer's disease in people with Down syndrome is estimated to be three to five times greater than that of the general population, which according to the Alzheimer's Association is now estimated to be 5.4 million people. In light of the exciting research being done on Down syndrome and other associated medical conditions, NDSS is pleased that NICHD leads and convenes the NIH Working Group on Down Syndrome and NIH Down Syndrome Consortium to collaborate and convene the various NIH Institutes and Centers doing Down syndrome research.

Trisomy 21 Research Legislative Package

The Trisomy 21 Research legislative package is aimed at strengthening the research infrastructure for Down syndrome and improving the translational research opportunities for Down syndrome. This legislation is known as the Trisomy 21 Research Package, which includes the *Trisomy 21 Research Resource Act* and the *Trisomy 21 Research Centers of Excellence Act*, which will be reintroduced later this year.

The *Trisomy 21 Research Resource Act* would expand and intensify Down syndrome programs of the NIH and the Centers for Disease Control and Prevention (CDC) to create an infrastructure of Down syndrome tools, including a Down syndrome research database and Down syndrome biobank. The bill does not require any additional cost (i.e., appropriations) to the federal government. These research tools will further strengthen the research being conducted on Down syndrome across the country and better equip our research community with the tools necessary to facilitate their research.

The *Trisomy 21 Research Centers of Excellence Act* would require the Director of the NIH to expand and intensify NIH programs with respect to research and related activities concerning Down syndrome. Additionally, the bill requires the Director of NIH to publish a research plan on Down syndrome and update it every five years. Moreover, the legislation would require NIH to award grants and contracts to public or nonprofit private entities to pay all or part of the cost of planning, establishing, improving, and providing basic operating support for centers of excellence regarding translational research on Down syndrome.

Down Syndrome NIH Consortium

In September 2010, the National Institutes of Health (NIH) joined with NDSS and other organizations interested in Down syndrome to form a consortium that will foster the exchange of information on biomedical and biobehavioral research on the chromosomal condition. The NIH Down Syndrome Consortium is focused on the implementation of the NIH Down syndrome research plan, which set research goals for Down syndrome, based on previous research accomplishments and the need for research in areas in which evidence is lacking. The consortium meets two to three times a year.