



Affiliates in Action

FEB 25-28, 2009 IN WASHINGTON, D.C.



February 26, 2009

There are more than 400,000 people living with Down syndrome in the U.S., and about 5,000 babies, or one in 800, are born with the condition each year. Down syndrome occurs in people of all races and economic levels, and it is the most frequently occurring chromosomal condition.



As the mortality rate associated with Down syndrome continues to decline, life expectancy continues to increase dramatically – from age 25 in 1983 to age 56 today. As a result, the prevalence of individuals with Down syndrome is expected to double by 2013.



Advancements in the treatment of health problems have allowed people with Down syndrome to enjoy fuller and more active lives, and become more integrated into the economic and social structures of our communities. Unfortunately, while progress has also been made in public policies that enhance the lives of individuals with Down syndrome, barriers still exist, making it difficult for people to access adequate health care, housing, employment and education.

Linda Crnic Institute
for Down Syndrome

To address these challenges, the organizations that participate in Affiliates in Action look forward to working with our Members of Congress to advance public policies that promote the acceptance and inclusion of individuals with Down syndrome, and help them to achieve their full potential in all aspects of their lives. Specifically, we urge our Members of Congress to support the following legislative priorities:



I. IMPROVE THE QUALITY AND AVAILABILITY OF INFORMATION ABOUT DOWN SYNDROME

REQUEST: Sign the McMorris Rodgers letter to the House and Senate Labor-HHS-Education Appropriations Subcommittees in support of funding to implement the Kennedy-Brownback Act.

STATUS: On October 8, 2008, President Bush signed into law S. 1820, the *Prenatally and Postnatally Diagnosed Conditions Awareness Act*, which was sponsored by Senator Edward Kennedy (D-MA) and Senator Sam Brownback (R-KS). Effective implementation of the new law will require Congress to enact separate appropriations of \$5 million a year.

SUMMARY: The Prenatally and Postnatally Diagnosed Conditions Awareness Act seeks to ensure that pregnant women receiving a positive prenatal test result and parents receiving a postnatal diagnosis will receive up-to-date, scientific information about life expectancy, clinical course, intellectual and functional development, and prenatal and postnatal treatment options. It offers referrals to support services such as hotlines, Web sites, information clearinghouses, adoption registries, and parent support networks and programs specific to Down syndrome and other prenatally diagnosed conditions. The goal is to create

a sensitive and coherent process for delivering information about the diagnosis across the variety of medical professionals and technicians, who often provide conflicting and inaccurate information.

II. CREATE FINANCIAL SAVINGS ACCOUNTS FOR INDIVIDUALS WITH DISABILITIES

REQUEST: Cosponsor the Financial Security and Disability Savings Act by contacting the offices of Senator Robert Casey (Staff Contact: Bryn McDonough, 202-224-6324) or Representative Ander Crenshaw (Staff Contact: Dustin Krasny, 202-225-2501).

STATUS: In the coming weeks, legislation to create financial security accounts for individuals with disabilities will be introduced in the House and Senate. Similar legislation was introduced in the 110th Congress (S. 2743/H.R. 2370), but no action was taken prior to the adjournment of that Congress.

SUMMARY: The Financial Security and Disability Savings Act allows for the establishment of tax-exempt financial security accounts for individuals with disabilities to pay certain expenses of such individuals, including expenses for education, housing, medical care, and employment training. It provides tax incentives for cash contributions to such an account. It also excludes financial security accounts for disabled individuals in determining eligibility for Medicaid benefits, and for purposes of determining eligibility for certain means-tested federal programs. The legislation encourages persons with disabilities to save in order to live an independent and meaningful life while reducing their dependency on public benefits.

III. PROVIDE STUDENTS WITH DISABILITIES WITH A QUALITY HIGHER EDUCATION

REQUEST: Contact the Labor-HHS-Education Appropriations Subcommittee to urge support for funding to implement the provisions of the Higher Education Opportunity Act of 2008 with respect to model demonstration projects for students with intellectual disabilities and a coordinating center for these model demonstration projects.

STATUS: In August 2008, Congress passed H.R. 4137, the Higher Education Opportunity Act of 2008, which allows students with intellectual disabilities to be eligible for Federal grants and work-study jobs if enrolled in programs designed for them. It also establishes model demonstration projects for such programs and a coordinating center. Effective implementation will require Congress to enact separate appropriations of \$10 million a year for the model demonstration projects for students with intellectual disabilities and \$1.5 million for the coordinating center.

SUMMARY: The Higher Education Opportunity Act establishes a model demonstration project for comprehensive transition and post-secondary programs for students with intellectual disabilities. By awarding competitive grants to higher education institutions, models of best practice will be established as examples for the current "fledgling" system of programs that have popped up independently across the country and for the colleges and universities that want to create new programs. To ensure the integrity and success of these ground-breaking programs for students with intellectual disabilities, the new law also authorizes a coordinating center that can provide technical assistance, evaluation, and recommendations for the development of accreditation standards. For the first time, students with intellectual disabilities participating in inclusive postsecondary education programs will be able to qualify for Federal grants and work study jobs. Research shows that participation in these postsecondary programs leads to jobs and living more independently.

IV. DEVELOP A NATIONAL DOWN SYNDROME PATIENT REGISTRY

REQUEST: Contact the Labor-HHS-Education Appropriations Subcommittee to urge support for funding to establish a national Down syndrome registry at the Centers for Disease Control (CDC) to help identify the incidence and prevalence of Down syndrome in the U.S. and collect data which is urgently needed for Down syndrome research, disease management and the development of standards of care.

STATUS: A national, computerized database of confidential information about individuals with Down syndrome and their families who are interested in participating in research does not currently exist. Efforts to develop such a registry require significant time, expertise, and money to implement, and such an undertaking is difficult without the support of the Federal government, which has created a number of patient registries for people with diseases and conditions.

SUMMARY: An estimated 400,000 persons with Down syndrome live in the United States. Despite these relatively high numbers, researchers often have difficulty in attaining sufficiently large samples of patients for many different types of studies. The most effective way to address this problem is for the CDC to partner with non-profit organizations, the NIH, and other public and private institutions to develop a national, computerized listing of individuals with Down syndrome and their families who are interested in participating in research. The ability of researchers to translate biomedical research into therapies that will improve the lives of people with Down syndrome will be significantly enhanced by the development of a patient registry. A registry established by the CDC will ensure that studies of individuals with Down syndrome fairly represent the demographic and sociological make-up of the population of people with Down syndrome. The current indirect process of recruiting research subjects often leads to samples that under-represent families who are poor, non-White, less educated and from rural areas.

V. EXPAND MEDICAID HOME AND COMMUNITY BASED SERVICES

REQUEST: Encourage the Ways and Means and Energy and Commerce Committees in the House, and the Finance and HEALTH Committees in the Senate, to conduct effective oversight of the increased Medicaid funding in the economic stimulus package for the Medicaid Home and Community Based Services (HCBS) waiver program for persons with developmental disabilities.

STATUS: The economic stimulus bill recently passed by Congress includes increased Medicaid funding to address funding shortfalls in the states as a result of the economic downturn. In addition to providing health insurance to the poor, Medicaid funding supports services for persons with developmental disabilities. This is a unique opportunity to begin shifting the system of long-term support services from expensive institutional placements to a more cost-effective system that allow consumers and families to control the resources available for community living.

BACKGROUND: Currently, Medicaid provides the lion share of funding for adult support services needed by individuals with Down syndrome to create meaningful and independent lives in the community. These services are needed throughout their lives, particularly when parents are aging and unable to provide the support needed. However, current public policy promotes dependence on public benefits, discourages work and prohibits individuals from saving and developing assets. The Medicaid program promotes expensive institutional care while long waiting lists exist for the community-based support services that promote consumer choice, work and independence. Directing funds to HCBS makes economic sense for persons with Down syndrome and other developmental disabilities. It costs less than expensive institutional care and enables states to provide services to many of the individuals

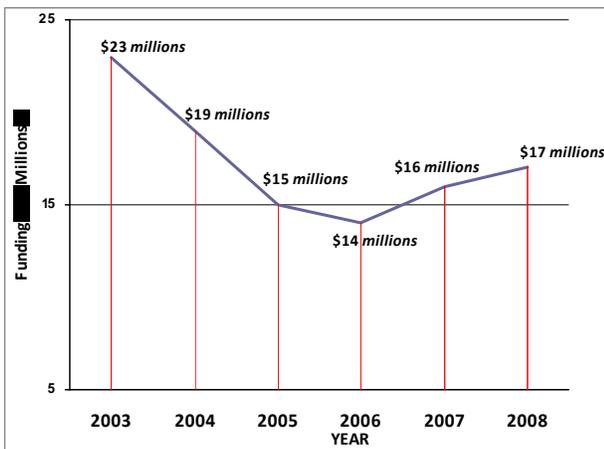
living with aging parents and relying on them as caregivers. It enables individuals with disabilities to have the dignity true choice and of a future in which they can be economically productive and a true part of society.

VI. STRENGTHEN NIH RESEARCH PLAN ON DOWN SYNDROME

REQUEST: Contact the Director of the National Institutes of Health to urge the NIH to devote sufficient resources to meet the short- and long-term objectives of the agency's strategic plan for Down syndrome.

STATUS: In January 2008, after consultation with the scientific research community and national organizations that focus on Down syndrome, and taking into account various congressional directives, the NIH Down Syndrome Working Group developed the NIH Research Plan for Down Syndrome. Because Congress does not earmark funds for specific diseases or conditions in its annual appropriations for NIH, efforts must be made to encourage NIH to adhere to the recommended goals of the report.

SUMMARY: The purpose of the research plan is to build upon on-going NIH-supported research to take advantage of emerging scientific opportunities and set the stage for possible future collaborations in this area. Although the plan was a welcome development, the resources that NIH currently dedicates to Down syndrome research are clearly insufficient to effectively accomplish the goals set in the plan. In fact, NIH funding for Down syndrome research has decreased significantly over the past five years and such research continues to be disproportionately under-funded in relation to other conditions. With sufficient resources, the plan has the potential to advance the translation and development of effective new treatments, particularly for cognition in Down syndrome. It will also encourage new therapeutic strategies involving secondary disorders affecting a significant numbers of individuals without Down syndrome, including Alzheimer's disease, atherosclerosis, cancer, and developmentally-associated cognitive impairment.



CONDITION	US POPULATION (est.)	2008 NIH FUNDING Millions \$	2008 NIH \$ per CAPITA AMOUNT
Cystic Fibrosis	30,000	90	3,000
Parkinson's	1,500,000	152	101
ALS	30,000	43	1,433
Huntington's	30,000	51	1,700
Multiple Sclerosis	400,000	169	422
Crohn's Disease	400,000	51	128
DOWN SYNDROME	350,000	17	45
Fragile X	17,000	26	1,529
Duchenne MD	45,350	22	485