

Enhancing Down Syndrome Research

Down syndrome is the most common genetic cause of mild to moderate intellectual disabilities and associated medical problems, affecting nearly 400,000 Americans. To ensure that research for Down syndrome advances at the same rate as research for other genetic conditions, U.S. Sens. Sherrod Brown (D-OH) and Susan Collins (R-ME) today introduced two pieces of legislation aimed at enhancing Down syndrome studies, including a bill that would create national research databases and another to recognize six centers of excellence that would conduct evidence-based and clinical research.

“Virtually all of us know someone—a friend, a family member, or a colleague—that has been touched by Down syndrome. Yet despite its prevalence, research on Down syndrome has failed to keep pace with the research for other common genetic conditions, like autism and epilepsy,” Sen. Brown said. “These two bills will help expand and coordinate federal support for Down syndrome research and leverage resources through the National Institutes of Health to spur medical innovation. We owe it to the thousands of Ohioans and Americans living with Down syndrome to support research that will advance better therapies and treatments.”

Despite its frequency of occurrence, research for a Down syndrome treatment and cure has lagged behind research for other medical conditions. In 2000, Congress passed the Children’s Health Act, which amended the Public Health Service Act by including a number of provisions addressing the research and surveillance needs of numerous disabilities and conditions such as autism, juvenile diabetes, asthma, epilepsy, Fragile X, and traumatic brain injury. However, the amendments in this landmark piece of legislation did not include Down syndrome.

To address this disparity, Sens. Brown and Collins introduced the Trisomy 21 Research Resource Act of 2011 (S.1841) and the Trisomy 21 Centers of Excellence Act of 2011 (S.1840). The Trisomy 21 Research Resource Act of 2011 would establish three research databases that would provide the research community with access to information that has otherwise been difficult to acquire. The bill would also authorize ongoing efforts by national patient advocacy organizations in collaboration with the National Institute of Child Health and Human Development to create such a resource. There is no additional funding associated with this bill, and it is budget-neutral.

The second bill, the Trisomy 21 Centers of Excellence Act of 2011, recognizes six centers of excellence nationwide that will be committed to conducting and coordinating translational research on Down syndrome. These centers of excellence will be key in conducting rigorous evidence-based and clinical research and in focusing on accelerating the development and delivery of new, effective patient therapies. This legislation authorizes \$6 million in yearly research funding for Fiscal Years 2012 through 2017.

The extra chromosome (known as “trisomy”) occurring in individuals affected with Down syndrome causes varying degrees of intellectual disabilities and physical abnormalities. Therefore, individuals with Down syndrome often suffer from a variety of medical, neurological, and psychological conditions, such as Alzheimer’s disease and autism. Consequently, the research underway stands not only to benefit those with Down syndrome, but millions of others who are also suffering from other conditions and diseases.

In March, Sen. Brown delivered remarks to the Down Syndrome Association of Central Ohio’s observation of World Down Syndrome Day. Photos from that event can be seen [here](#) .