



August 14, 2025

The Honorable Mike Johnson  
Speaker  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Hakeem Jeffries  
Democratic Leader  
U.S. House of Representatives  
Washington, DC 20515

Dear Speaker Johnson and Leader Jeffries:

On behalf of our Down syndrome community, with the support of our esteemed colleagues listed below, the Global Down Syndrome Foundation (GLOBAL) is writing to express our strong support for the DeOndra Dixon INCLUDE Project Act of 2025 (H.R. 3491), which would authorize the INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE) Project at the National Institutes of Health (NIH). We urge Congress to pass this lifesaving legislation before the end of the year.

Congress had long recognized Down syndrome as “a fertile area for research investments” and “an ideal candidate for a trans-NIH initiative”; but for two decades, Down syndrome was one of the least funded genetic conditions at NIH. On October 25, 2017, House Appropriations Labor, Health and Human Services, and Education Subcommittee Chairman Tom Cole (R-OK) and Ranking Member Rosa DeLauro (D-CT) held the first ever hearing on Down syndrome research. The hearing increased awareness that people with Down syndrome, compared to the general population, are highly predisposed to certain diseases like Alzheimer’s disease and autoimmune conditions, yet are highly protected from others like solid tumors such as breast cancer or prostate cancer. The hearing also raised serious questions about the fact that for decades people with Down syndrome were excluded from lifesaving clinical trials research.

Thankfully, this landmark hearing catalyzed the establishment of the INCLUDE Project, the trans-NIH Down syndrome funding program under the Office of the Director, which is advancing science that will improve the lives of people with Down syndrome as well as individuals without Down syndrome.

Over the last seven years the NIH INCLUDE Project increased Down syndrome research funding from \$35 million in fiscal year 2017 to an estimated \$88.8 million in fiscal year 2024 and \$434 million in funding for all projects over the last 7 years towards 575 unique awards from 18 different institutes. Today there are now 13 clinical trials specifically for people with Down syndrome including treatments for Alzheimer’s, multiple autoimmune diseases, cognition deficit, and Regression Disorder.

This trans-NIH structure for Down syndrome research ensures that major crosscutting issues and opportunities are identified and will allow multiple NIH institutes to collaborate on a coordinated research plan that harmonizes planning, funding, and the sharing and disseminating research results. Named in memory of GLOBAL's most beloved and accomplished self-advocate, DeOndra Dixon, who tragically passed away in 2020 at the age of 36, this legislation honors her and all individuals with Down syndrome.

Enacting this legislation to formally authorize this program will be a message to our dedicated current and future researchers that the government will continue its support for their important work to reduce health disparities, elongate life, and improve health outcomes. Authorizing the program beyond an annual congressional report language will ensure that people with Down syndrome are not left behind when it comes to participating in clinical trials; it will improve health outcomes and improve their quality of life; and it will send a strong message that our society values and wants to invest in the future of our children and adults with Down syndrome and their families.

The Down syndrome community is grateful for your support on this matter.

Gratefully,



Michelle Sie Whitten  
President & CEO

Esteemed Colleagues and Supporters:

*Adult Disability Medical Healthcare, Inc.*

*Adult Down Syndrome Clinic, Denver Health*

*Alzheimer's Association*

*Alzheimer's & Cognition Center, University of Colorado*

*Alzheimer's Impact Movement (AIM)*

*Anna & John J. Sie Center for Down Syndrome, Children's Hospital Colorado*

*Arc Thrift*

*Bellucci Translational Hearing Center, Creighton University*

*BioFrontiers Institute, University of Colorado Boulder*

*Black Down Syndrome Association*

*Boys Town National Research Hospital*

*Bringing Up Down Syndrome*

*Cardiovascular Research and Exercise Lab, University of Nevada, Las Vegas*

*Club 21 Learning & Resource Center Inc.*

*Down Country*

*Down Syndrome Advocacy Foundation*

*Down Syndrome Association of Atlanta*

*Down Syndrome Association of Central Florida*

*Down Syndrome Association Central Kentucky*

Down Syndrome Association of Central Texas  
 Down Syndrome Association of Connecticut  
 Down Syndrome Association of Delaware  
 Down Syndrome Association of Greater New Orleans  
 Down Syndrome Association of Greater Winston-Salem  
 Down Syndrome Association of Memphis & Mid-South  
 Down Syndrome Association of Middle Tennessee  
 Down Syndrome Association of Northeast Indiana  
 Down Syndrome Association of Northern Virginia  
 Down Syndrome Association of West Michigan  
 Down Syndrome Association of Wisconsin  
 Down Syndrome Center of Puget Sound  
 Down Syndrome Clinic and Research Center, Kennedy Krieger Institute  
 Down Syndrome Connections Nevada  
 Down Syndrome Diagnosis Network  
 Down Syndrome Indiana, INC.  
 Down Syndrome Medical Interest Group-USA  
 Down Syndrome Network of Montgomery County  
 Down Syndrome Program, Boston Children's Hospital  
 Down Syndrome Neurology Program, Children's Hospital Los Angeles  
 Down to Defend  
 Fun Coast Down Syndrome Association  
 GLOBAL Membership Advisory Board (alphabetical):  
     Down Syndrome Alabama  
     Down Syndrome Alliance of the Midlands  
     Down Syndrome Association of Central Oklahoma  
     Down Syndrome Association of Greater Cincinnati  
     Down Syndrome Association of Greater St. Louis  
     Down Syndrome Association of Jacksonville  
     Down Syndrome Association of Minnesota  
     Down Syndrome Association of Northeast Ohio  
     Down Syndrome Connection of the Bay Area  
     Down Syndrome Guild of Dallas  
     North Carolina Down Syndrome Alliance  
     Rocky Mountain Down Syndrome Association  
 Grays Peak Speech Services, LLC  
 Inspired to Learn  
 International Mosaic Down Syndrome Association  
 Jane and Richard Thomas Center for Down Syndrome at Cincinnati Children's Hospital Medical Center  
 Linda Crnic Institute, University of Colorado Anschutz Medical Campus  
 NTG  
 Perfect Harmony Health  
 Rock Life, Slippery Rock University of Pennsylvania  
 Rueckert-Hartman College for Health Professionals, Regis University  
 Sharing Down Syndrome Arizona INC.  
 Stand Up for Downs  
 University of Kansas Medical Center, Adults with Down Syndrome Specialty Clinic  
 United Coalition for Down Syndrome (alphabetical):

*Down Syndrome Affiliates in Action*  
*GiGi's Playhouse Down Syndrome Achievement Centers*  
*LuMind IDSC Foundation*  
*National Down Syndrome Congress*  
*National Down Syndrome Society*