



September 15, 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.

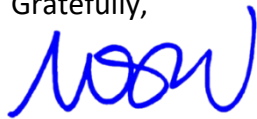
Over the last seven years the NIH INCLUDE Project increased Down syndrome research funding from \$35 million in fiscal year 2017 to an estimated \$88.8 million in fiscal year 2024 and \$434 million in funding for all projects over the last 7 years towards 575 unique awards from 18 different institutes. 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 for Families of Nebraska

Down Syndrome Association of Atlanta

Down Syndrome Association of Brevard

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 Maryland
 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 South Georgia
 Down Syndrome Association of Southern Kentucky
 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 Arizona
 Down Syndrome Network of Montgomery County
 Down Syndrome Partnership of North Texas
 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
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 Down Syndrome Connection of the Bay Area
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 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.

SMILE on Down Syndrome

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

Virginia Down Syndrome Association

National Down Syndrome Society