



August 14, 2025

The Honorable John Hickenlooper
374 Russell Senate Office Building
Washington, D.C. 20510

The Honorable Jerry Moran
521 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Senators Hickenlooper and Moran:

The Global Down Syndrome Foundation (GLOBAL), with the support of our esteemed colleagues listed below, write to express our gratitude and unequivocal support for the bipartisan legislation you have introduced, the DeOndra Dixon INCLUDE Project Act of 2025 (S. 1838), to authorize the INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE (INCLUDE) Project at the National Institutes of Health (NIH).

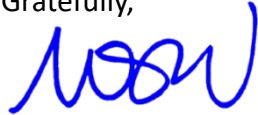
Congress had long recognized Down syndrome as “a fertile area for research investments” and “an ideal candidate for a trans-NIH initiative”; but for two decades, Down syndrome was one of the least funded genetic conditions at NIH. On October 25, 2017, House Appropriations Labor, Health and Human Services, 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 began a seven-year increase in Down syndrome research funding from \$35 million in fiscal year 2017 to an estimated \$143 million in fiscal year 2024. Based on the encouragement of the Congress, the hearing also led to the establishment of the INCLUDE initiative, a trans-NIH effort based in the Office of the Director, which is advancing science that will improve the lives of people with Down syndrome as well as typical individuals. To date, INCLUDE has provided 575 unique Down syndrome research awards from 18 different NIH institutes and there are now at least 13 clinical trials that include repurposed drugs to treat 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.

We deeply appreciate all your leadership to ensure that people with Down syndrome are not left behind but rather are provided the opportunity to live healthier and longer lives and therefore reach their true potential. Your efforts are transforming the lives of over 400,000 people with Down syndrome in the U.S. and potentially benefitting 60% of Americans who suffer from diseases that people with Down syndrome are highly protected or from or predisposed to. You are also sending a clear message that people with Down syndrome and their families are an important valued part of our society and world, and for that we are forever grateful. We urge Congress to quickly pass the DeOndra Dixon INCLUDE Project Act and look forward to working with you to achieve this goal.

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 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
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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