



September 15, 2025

The Honorable John Thune
Senate Majority Leader
United States Senate
Washington, DC 20510

The Honorable Chuck Schumer
Senate Minority Leader
United States Senate
Washington, DC 20510

Dear Senators Thune and Schumer:

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 (S. 1838), 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 this 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.

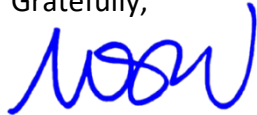
Thankfully, this landmark hearing catalyzed the establishment of the INCLUDE Project, the trans-NIH Down syndrome funding program under the Office of the Director, which is advancing science that will improve the lives of people with Down syndrome as well as individuals without Down syndrome.

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

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[Down Syndrome Association of Maryland](#)
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[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):
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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