



March 20, 2024

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 2024 (S. 3981), 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. It 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 556 unique Down syndrome awards from 18 different NIH institutes and there are now at least 12 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 Down Syndrome Clinic, Denver Health

Advocate Medical Group Adult Down Syndrome Center

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

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

Down Syndrome Clinic and Research Center, Kennedy Krieger Institute

Down Syndrome Diagnosis Network

Down Syndrome Medical Interest Group-USA

Down Syndrome Program, Boston Children's Hospital

Down Syndrome Neurology Program, Children's Hospital Los Angeles

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