



March 20, 2024

The Honorable Chuck Schumer  
Senate Majority Leader  
S-221, The Capitol  
Washington, DC 20510

The Honorable Mitch McConnell  
Senate Minority Leader  
S-230, The Capitol  
Washington, DC 20510

Dear Senators Schumer and McConnell:

On behalf of the Down syndrome community, Global Down Syndrome Foundation (GLOBAL) with the support of our esteemed colleagues listed below, write to express our strong support for the DeOndra Dixon INCLUDE Project Act of 2024 (S. 3981), 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 118<sup>th</sup> Congress.

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.

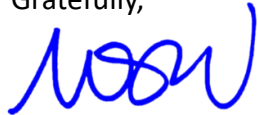
This trans-NIH structure for Down syndrome research ensures that major crosscutting issues and opportunities are identified and will allow multiple NIH institutes to collaborate on a coordinated research plan that harmonizes planning, funding, and the sharing and disseminating research results. Named 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.

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 directive 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 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*

*GLOBAL Membership Advisory Board (alphabetical):*

*Down Syndrome Alliance of the Midlands*

*Down Syndrome Association of Greater Cincinnati*

*Down Syndrome Association of Greater St. Louis*

*Down Syndrome Association of Jacksonville*

*Down Syndrome Association of Louisville*

*Down Syndrome Connection of the Bay Area*  
*Down Syndrome Guild of Dallas*  
*North Carolina Down Syndrome Alliance*  
*Intellectual and Developmental Disabilities Division, Colorado State University Prevention Research Center*  
*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*  
*Rock Life, Slippery Rock University of Pennsylvania*  
*Rueckert-Hartman College for Health Professionals, Regis University*  
*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*  
*University of Pittsburgh Adult Down Syndrome Center, University of Pittsburgh Medical Center*