



March 11, 2024

The Honorable Cathy McMorris Rodgers  
2188 Rayburn House Office Building  
Washington, D.C. 20515

The Honorable Diana DeGette  
2111 Rayburn House Office Building  
Washington, D.C. 20515

The Honorable Tom Cole  
2207 Rayburn House Office Building  
Washington, D.C. 20515

The Honorable Rosa DeLauro  
2413 Rayburn House Office Building  
Washington, D.C. 20515

The Honorable Pete Stauber  
2136 Rayburn House Office Building  
Washington, D.C. 20515

The Honorable Eleanor Holmes Norton  
145 Cannon House Office Building  
Washington, D.C. 20515

Dear Representatives Rodgers, DeGette, Cole, DeLauro, Stauber and Norton:

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 (H.R. 7406), 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*

*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 (alpha):*

*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*  
*Rueckert-Hartman College for Health Professionals, Regis University*  
*United Coalition for Down Syndrome (alpha):*  
*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*