

Appendix E: Congressional Directives on Down Syndrome Research Since 2018

Fiscal Year 2018: House Report 115-244

Trisomy 21. The Committee continues to recognize that the presence of a third copy of human chromosome 21, which causes Down syndrome, predisposes individuals to significant immune system dysregulation. This dysregulation is associated with the occurrence of Alzheimer's disease as individuals with Down syndrome age and the high incidence of autoimmune disease as well as protections against most solid tumor cancers and cardiovascular disease. These findings present a rich research opportunity and, based on the NIH's recently released report on the Feasibility of a Multi-Year Study on Trisomy 21 in Humans, the Committee encourages NIH to pursue a multi-year, trans-NIH research initiative examining immune system dysregulation and trisomy 21, with the aim of yielding scientific learnings that could significantly improve the health of individuals with Down syndrome as well as millions of typical individuals.

Fiscal Year 2018: Senate Report 115-150

Trisomy 21. The Committee recognizes that the presence of a third copy of human chromosome 21 may be linked to significant immune dysregulation and Alzheimer's disease, while protecting against most cancers and cardiovascular disease among individuals with Down syndrome. The Committee strongly encourages NIH to pursue an initiative on this topic that will yield scientific learnings that could significantly improve the health of individuals with Down syndrome as well as millions of typical individuals.

Fiscal Year 2019: House Report 115-862

Trisomy 21. The Committee applauds the NIH for significantly increasing its investment in Down syndrome research and for the NIH Director's leadership in advancing the trans-NIH initiative the Committee included in the fiscal year 2018 appropriation. The Committee directs NIH to continue to make new investments in Down syndrome research that prioritize funding for both new research grants that will significantly expand the current pipeline of Down syndrome research, as well as the implementation of the new trans-NIH initiative. In addition, the Committee

encourages NIH to prioritize funding for research to improve the health and neurodevelopment of individuals with Down syndrome and typical individuals at risk for immune system dysregulation, Alzheimer's disease, cancer, cardiovascular disease, and autism.

Fiscal Year 2019: Senate Report 115-289

Trisomy 21. The Committee applauds the NIH for significantly increasing its investment in Down syndrome research and for the NIH Director's leadership in advancing the trans-NIH initiative the Committee included in the fiscal year 2018 appropriation. The Committee directs NIH to continue to make new investments in Down syndrome research that prioritize funding for both new research grants that will significantly expand the current pipeline of Down syndrome research, as well as the implementation of the new trans-NIH initiative. In addition, the Committee encourages NIH to prioritize funding for research to improve the health and neurodevelopment of individuals with Down syndrome and typical individuals at risk for immune system dysregulation, Alzheimer's disease, cancer, cardiovascular disease, and autism.

Fiscal Year 2019: Conference (House) Report 115-952

Trisomy 21. The conferees applaud the NIH for significantly increasing its investment in Down syndrome research and for the NIH Director's leadership in advancing the trans-NIH initiative the Committees included in the fiscal year 2018 appropriation. The conferees direct NIH to continue to make investments in Down syndrome research that prioritize funding for both research grants and early-stage investigators that will expand the current pipeline of Down syndrome research, as well as the implementation of the new trans-NIH initiative. In addition, the conferees encourage NIH to prioritize funding for research for emerging scientific opportunities to improve the health and neurodevelopment of individuals with Down syndrome and typical individuals at risk for immune system dysregulation, Alzheimer's disease, cancer, cardiovascular disease, and autism.

Fiscal Year 2020: House Report 116-62

Trisomy 21. The Committee commends NIH for its support of the Investigation of Co-Occurring Conditions Across the Lifespan to Understand Down Syndrome (INCLUDE) Initiative. The Committee includes no less than \$60,000,000 within the Office of the Director for the INCLUDE Initiative, an increase of \$22,000,000 above the expected fiscal year 2019 funding level. The Committee expects that this multi-year, trans-NIH research initiative may yield scientific discoveries that could

significantly improve the health and quality of life of individuals with Down syndrome as well as millions of typical individuals.

Fiscal Year 2021: House Report 116-450

Trisomy 21. The Committee commends NIH for its continuing support of the INvestigating Co-occurring conditions across the Lifespan to Understand Down syndromE (INCLUDE) Initiative. The Committee includes no less than \$65,000,000, an increase of \$5,000,000 above the fiscal year 2020 level, within the Office of the Director for the INCLUDE Initiative. The Committee expects that this multi-year, trans-NIH research initiative may advance scientific discoveries that will dramatically improve the health and quality of life of individuals with Down syndrome as well as millions of typical individuals. The Committee requests the Director provide a plan within 60 days of enactment of this Act that includes a timeline description of potential grant opportunities and deadlines for all expected funding opportunities so that young investigators and new research institutions may be further encouraged to explore research in this space. This plan should also incorporate and increase pipeline research initiatives specific to Down syndrome.

Fiscal Year 2021: Conference Report 116RCP68-JES-Division H

Trisomy 21. The agreement commends NIH for its continued support of the INvestigating Co-occurring conditions across the Lifespan to Understand Down syndromE Initiative. The Committee includes no less than \$65,000,000, an increase of \$5,000,000, for this initiative. The agreement reiterates the directives under this heading in House Report 116-450. In addition, the agreement encourages this project to consider complementary and integrative health approaches to address co-occurring conditions in individuals with Down syndrome, such as traditional Chinese medicine on development, and Applied Behavioral Analysis and Applied Verbal Analysis on development and language acquisition.