

# INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE (INCLUDE) Project Update

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Planning, and Strategic Initiatives

NIH ACD Meeting  
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2005

## The NIH Down Syndrome Working Group

- Formed in late 2005 to coordinate DS research
- Original members: NICHD (chair), NCI, NHLBI, NIA, NIAID, NIDCD, NIDCR, NIDA, NIMH, NINDS, OD
- Tasked to develop a research plan for DS focused on cognition and dementia



NIH Down Syndrome Working Group, 2019



2011

# The Down Syndrome Consortium

- Created in 2011 as a public-private partnership to meet regularly to discuss DS research
  - 13 NIH ICs
  - 17 professional organizations, advocacy groups, and foundations
  - 3 Self-advocates
- Provided critical input into the DS Research Plans and Registry



## The Down Syndrome Consortium

- ### NIH ICs
- National Institutes of Health  
*Down Syndrome Working Group*
  - [National Cancer Institute \(NCI\)](#)
  - [National Heart, Lung, and Blood Institute \(NHLBI\)](#)
  - [National Human Genome Research Institute \(NHGRI\)](#)
  - [National Institute on Aging \(NIA\)](#)
  - [National Institute of Allergy and Infectious Diseases \(NIAID\)](#)
  - [Eunice Kennedy Shriver National Institute of Child Health and Human Development \(NICHD\)](#)
  - [National Institute on Deafness and Other Communication Disorders \(NIDCD\)](#)
  - [National Institute of Dental and Craniofacial Research \(NIDCR\)](#)
  - [National Institute of Diabetes and Digestive and Kidney Diseases \(NIDDK\)](#)
  - [National Institute of Mental Health \(NIMH\)](#)
  - [National Institute on Minority Health and Health Disparities \(NIMHD\)](#)
  - [National Institute of Neurological Disorders and Stroke \(NINDS\)](#)
  - [National Center for Advancing Translational Sciences \(NCATS\)](#)

### Professional organizations, advocacy groups, and foundations

- American Academy of Pediatrics
- aaidd
- ontg
- DSMIG-USA®  
Down Syndrome Medical Interest Group
- GLOBAL  
DOWN SYNDROME FOUNDATION
- FOUNDATION Jerome Lejeune  
research, care, advocacy
- AUCD  
ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES  
THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK
- International Mosaic Down Syndrome Association
- national down syndrome society  
ndss.
- alzheimer's association
- DSDN  
DOWN SYNDROME DIAGNOSIS NETWORK
- NATIONAL DOWN SYNDROME CONGRESS
- Lumind
- idsc  
DOWN SYNDROME FOUNDATION
- Special Olympics
- t2i  
RESEARCH SOCIETY
- DSi Down Syndrome International
- dsaia  
Down Syndrome Affiliates in Action

2018

# Congress Established INCLUDE



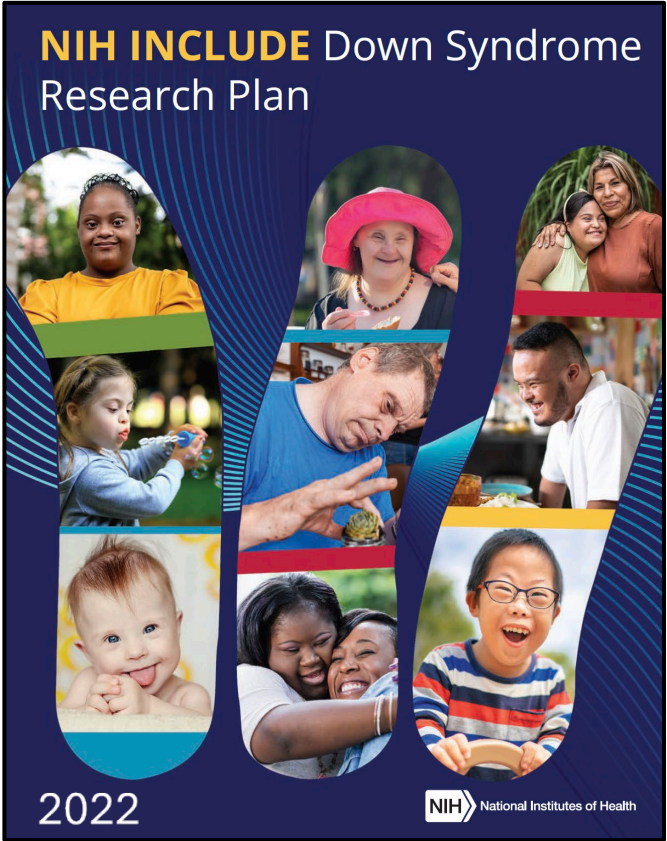
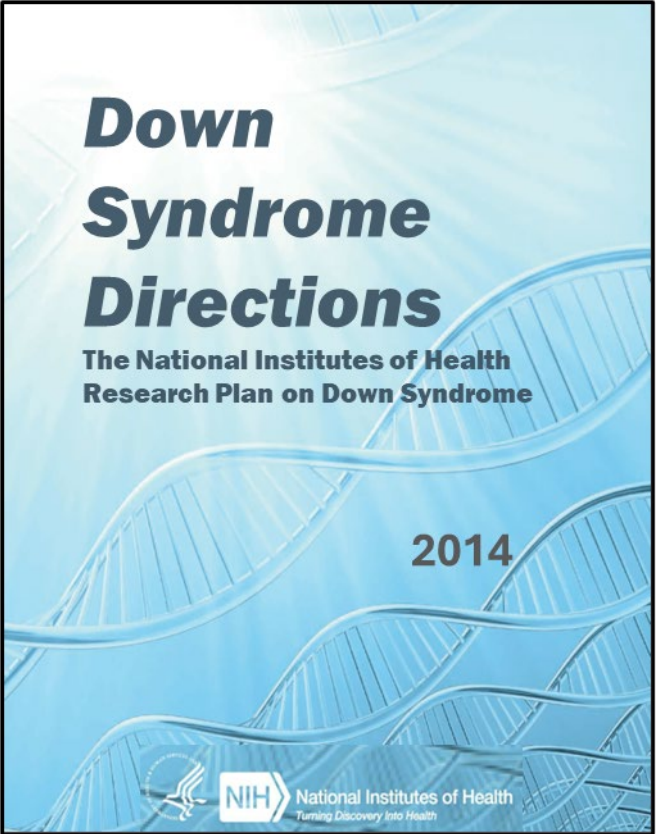
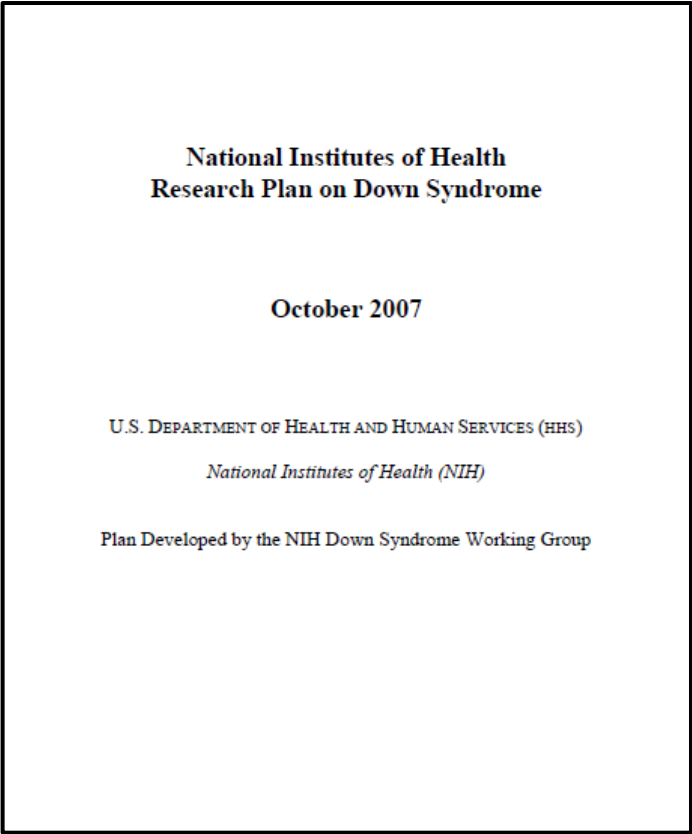
# INCLUDE

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# NIH Down Syndrome Research Plans Across the Years



Available for download on the [INCLUDE Project Website](#).



# INCLUDE Investigators Meeting

- Investigators Meeting hosted more than **250 researchers** on the NIH campus on April 15-16 to discuss research updates, fostering collaboration, and how NIH can help advance the next 5 years of Down syndrome research.
- Received over 75 poster abstracts and funded an additional 18 posters given the quality of abstracts received (**total of 68 posters were displayed**)
- 29 presenters, including **3 self-advocates**
- **Supported travel** for 97 presenters and an additional 14 trainees who expressed a need for financial support to participate



***“Being healthy is a goal for every person on this earth including individuals with Down syndrome.”***

-David Egan, Down syndrome research advocate

Thank You!

