

# Appendix A: NIH-Led Down Syndrome Activity Groups

## Down Syndrome Consortium

In 2011, the National Institutes of Health (NIH) joined with governmental and private organizations interested in Down syndrome to form the Down Syndrome Consortium. The goal of the Consortium, led by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) with other NIH institutes and centers in the NIH Down Syndrome Working Group, is to encourage the exchange of information about Down syndrome research and healthcare among Consortium members, including (in alphabetical order):

- Alzheimer's Association
- American Academy of Pediatrics
- American Association on Intellectual and Developmental Disabilities
- Association of University Centers on Disabilities
- Down Syndrome Affiliates in Action
- Down Syndrome International
- Down Syndrome Medical Interest Group
- Global Down Syndrome Foundation
- International Mosaic Down Syndrome Association
- Jerome Lejeune Foundation
- Linda Crnic Institute
- LuMind IDSC Down Syndrome Foundation
- National Down Syndrome Congress
- National Down Syndrome Society
- NIH Down Syndrome Working Group
- National Task Group on Intellectual Disabilities and Dementia Practices
- Self-Advocates
- Special Olympics
- T21 Research Society

## **NIH INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE) Project Group**

(\* Also part of the NIH Down Syndrome Working Group)

- *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)\*
- Fogarty International Center
- National Cancer Institute (NCI)\*
- National Center for Advancing Translational Sciences (NCATS)\*
- National Center for Complementary and Integrative Health (NCCIH)
- National Eye Institute (NEI)
- 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)\*
- National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)
- 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 Environmental Health Sciences (NIEHS)
- National Institute of General Medical Sciences (NIGMS)
- National Institute of Mental Health (NIMH)\*
- National Institute on Minority Health and Health Disparities (NIMHD)\*
- National Institute of Neurological Disorders and Stroke (NINDS)\*
- National Institute of Nursing Research (NINR)
- NIH Office of the Director
  - Environmental influences on Child Health Outcomes (ECHO) Program
  - Office of Research Infrastructure Programs