

# AGING, DEMENTIA, AND DOWN SYNDROME

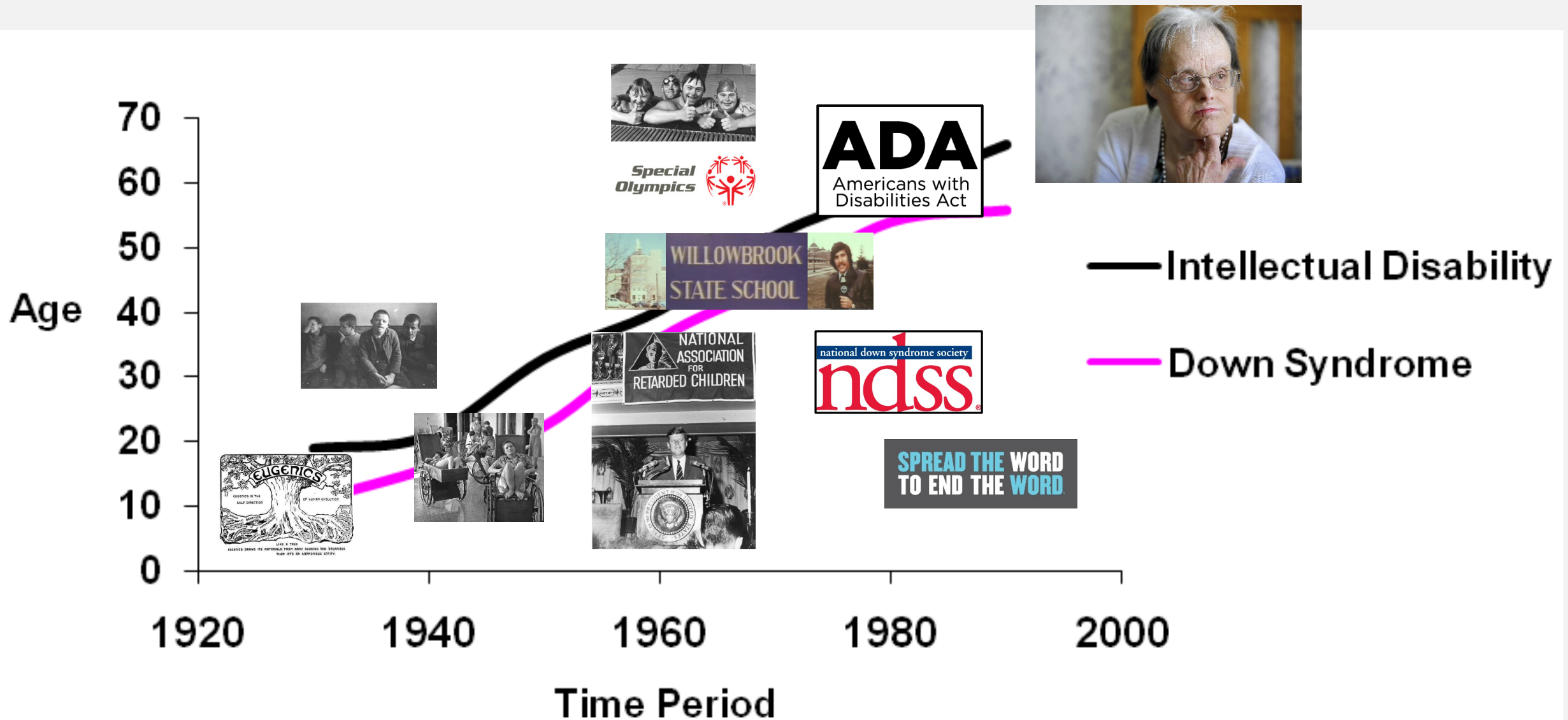


Seth M. Keller, MD  
Past President AADMD  
Co-Chair NTG  
Chair Adult IDD Section AAN

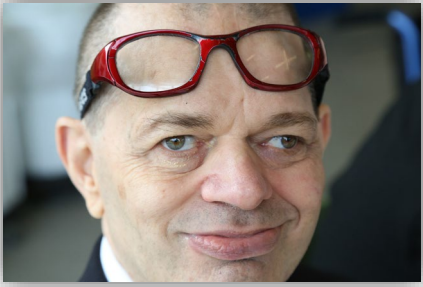
Nov 15, 2019



# LIFE EXPECTANCY



Carter & Jancar, 1983, Janicki, Dalton, Henderson, & Davidson, 1999



# Aging Persons with Intellectual and Developmental Disabilities (IDD)

- Individuals with IDD are living longer and some experience age-related functional and/or cognitive decline
- Normal aging vs pathologic aging
- Syndrome specific aging concerns
- Change in interests
- Aging support networks; siblings and parents
- Younger support networks not adapted to seniors
- Direct support staff/agencies not trained in recognizing the changes of aging nor trained in most age-related conditions including dementia care and support
- Participation in competitive physical activity-based sports may become more difficult as one gets older
- Adults with IDD often drop out of Special Olympics as they get older
- Aging and health promotion is not routinely a part of most programs



# **Cognitive Changes with Aging In those with Down Syndrome**

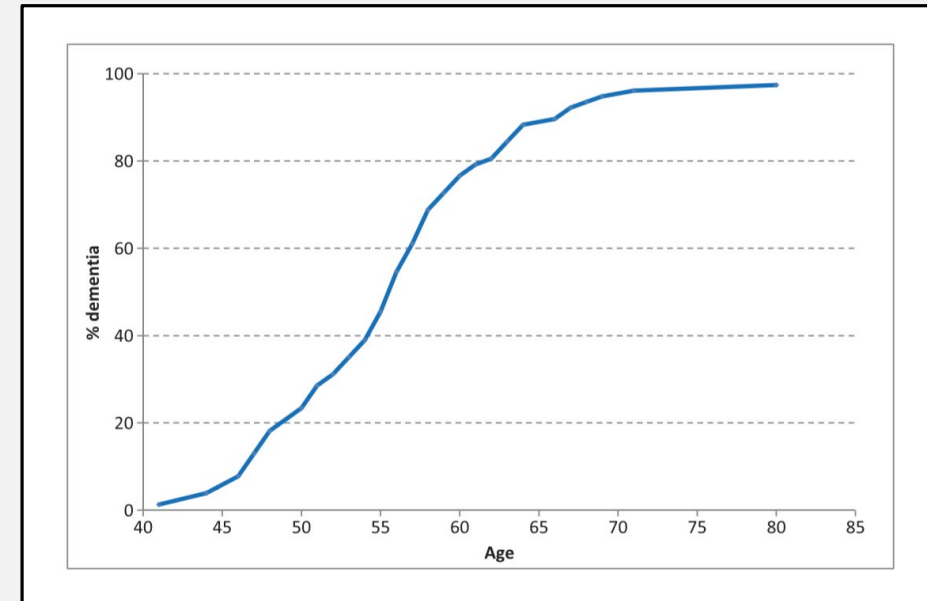
## **Who I Am: My Stories, My Memory, My Life History**

- Regression
- Medical
- Psychological
- Normal Aging
- Mild Cognitive Impairment
- Dementia (Alzheimer's)

# ALZHEIMER'S DISEASE IN DOWN SYNDROME

- Women with Down's syndrome are more at risk of developing Alzheimer's disease than men in the 40 to 65 age group
- People with Down's syndrome who develop Alzheimer's disease live, on average, 4-10 years from first symptoms; median 7 years
- Rapid decline can occur
- Sensory impairments (vision: 93.3%; hearing: 61.3%) were evident in adults with dementia
- Late onset seizures were evident in 73.9%; with epilepsy dx at mean age of 55.4, and interval of about 1/2 year following dx of dementia.

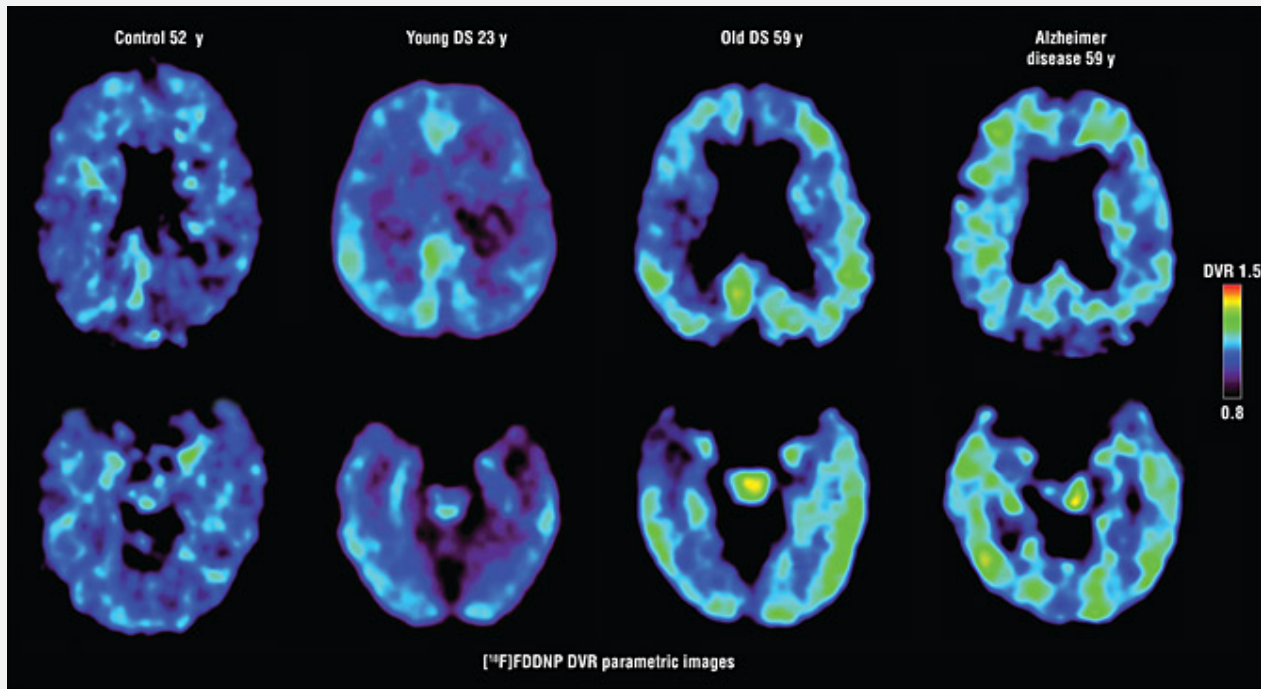
McCarron et al., (2017). A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome  
Journal of Intellectual Disability Research Sep;61(9):843-852



Percentage of people with Down syndrome who develop dementia at different ages:

30's	2%
40's	10-15%
50's	20-50%
60's	60-90%



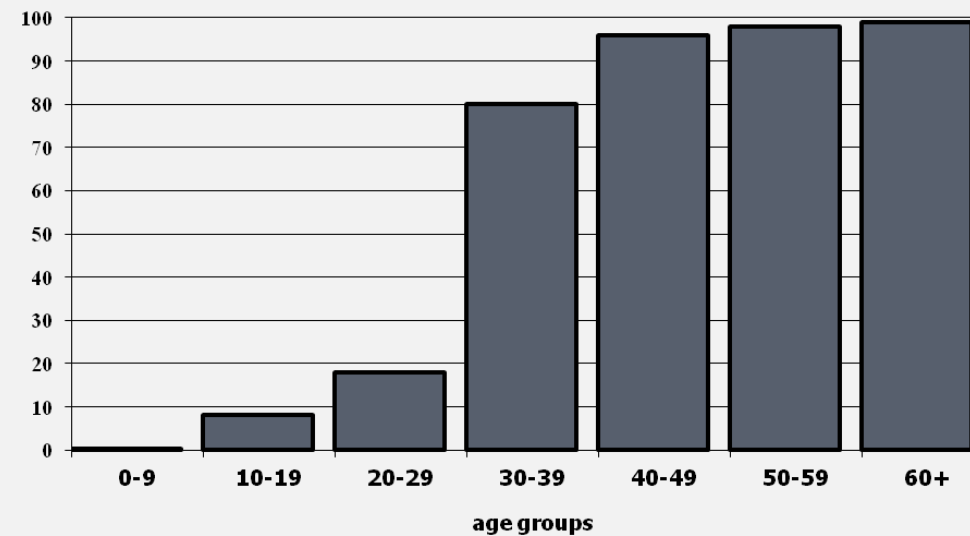


## Representative Amyloid Scans in DS and AD

Nelson, L. D. et al. Arch Neurol 2011;68:768-774.

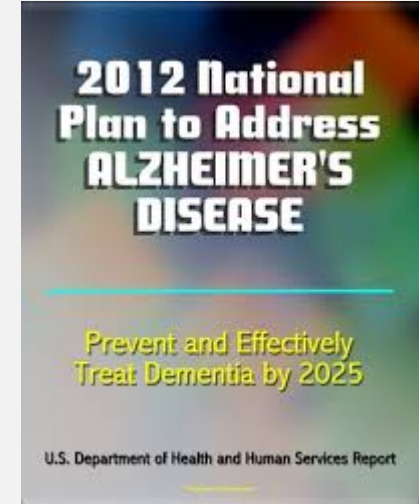
Percent persons with Down syndrome showing evidence of neurofibrillary tangles (NFT) and senile plaques (SP) at autopsy

Mann, D.M.A. (1993). Association between Alzheimer disease and Down syndrome: Neuropathological observations. In J.M. Berg, H. Karlinsky, & A.J. Holland (Eds.), Alzheimer disease and Down syndrome and their relationship (pp. 71-92). Oxford University Press



# NATIONAL TASK GROUP ON INTELLECTUAL DISABILITIES AND DEMENTIA PRACTICES

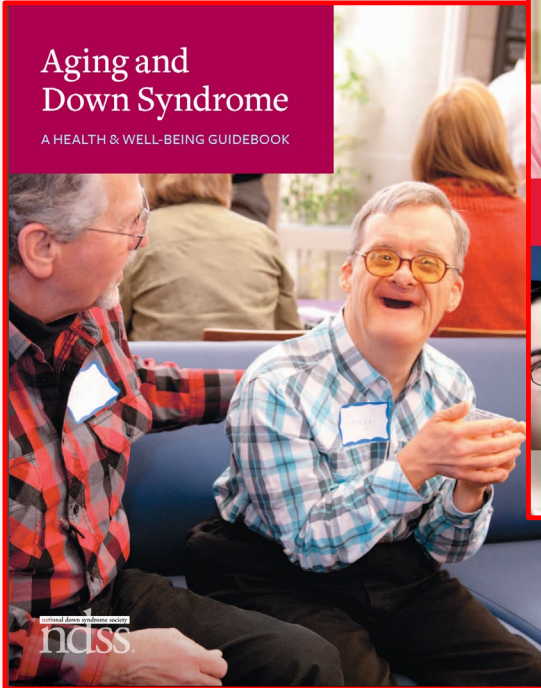
- An affiliate of the AADMD, the 'NTG' is a coalition charged with ensuring that the interests of adults with intellectual and developmental disabilities who are affected by Alzheimer's disease and dementias – as well as their families and friends – are taken into account as part of the [National Plan to Address Alzheimer's Disease](#).
- Advocacy and policy
- Staff education and training; workshops, webinars
- Healthcare provider supports
- Assessment tools; NTG-EDSD, SAFD Project
- Forming partnerships and building networks
- Support grantees



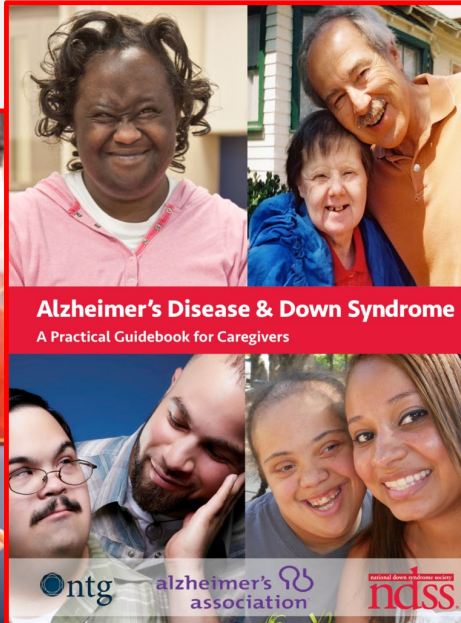
# PERSON/FAMILY CENTERED RESOURCES

## Aging and Down Syndrome

A HEALTH & WELL-BEING GUIDEBOOK



<http://www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-Syndrome.pdf>



[http://www.ndss.org/wp-content/uploads/2017/11/NDSS\\_Guidebook\\_FINAL.pdf](http://www.ndss.org/wp-content/uploads/2017/11/NDSS_Guidebook_FINAL.pdf)

## Intellectual Disability and Dementia: A Caregiver's Resource Guide for Rhode Islanders



Seven Hills  
Rhode Island

ontg  
National Task Group  
on Intellectual Disabilities  
and Dementia Practices

<http://www.sevenhills.org/uploads/SHRI-IDD-ADRD-Resource-Guide.pdf>

## Jenny's Diary



resource to support conversation  
about dementia with people who  
have a learning disability

Karen Watchman,  
Irene Tulfrey-Wijne, Sam Quinn

[www.learningdisabilityanddementia.org/jennys-diary.html](http://www.learningdisabilityanddementia.org/jennys-diary.html)



NATIONAL TASK GROUP  
ON INTELLECTUAL DISABILITIES  
AND DEMENTIA PRACTICES

## CAREGIVER NEWS

### A Message from the Co-Editor

Jadene S. Ransdell

On behalf of the National Task Group on Intellectual Disabilities and Dementia Practices, I want to apologize for the break in delivery of the Caregiver News. Due to some personal issues earlier this year, it was necessary for me to take some time off.

Although publication was interrupted, the newsletter was never far from my mind. With the support of the NTG Steering Committee we have made some changes that we believe will make this newsletter even better.

As you already noticed, we have a new layout, but that is just the beginning. We have added Rachel Grimm from the National Down Syndrome Society as a co-editor, and she has already proven to be a wonderful addition.



Rachel Grimm

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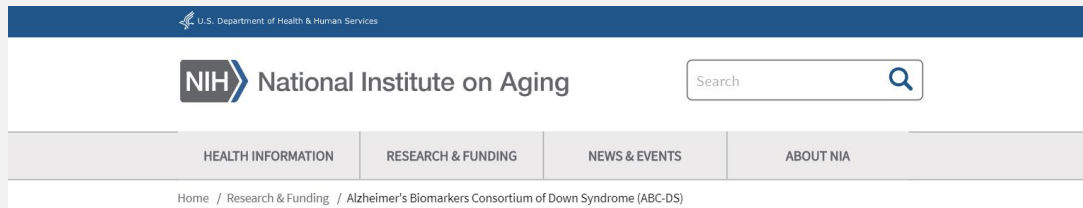
"In the USA, an estimated 9,000\* adults with intellectual disability may be affected by Alzheimer's or other dementia and this number is expected to triple in the next 20 years."  
The NTG Education and Training Curriculum on Dementia and Intellectual & Developmental Disabilities

NDSS Adult Summit  
May 7-9, 2020  
Scottsdale, Arizona  
ADULT SUMMIT  
See page 3 for information

"Worry never robs tomorrow of its sorrow, it only robs today of its joy."  
Leo Buscaglia, author, professor, motivational speaker



# ALZHEIMER'S BIOMARKERS CONSORTIUM OF DOWN SYNDROME (ABC-DS)



## Alzheimer's Biomarkers Consortium of Down Syndrome (ABC-DS)




### Exploring the Connection Between Down Syndrome and Alzheimer's Disease

The ABC-DS study is a joint study conducted by two groups of research collaborators—Neurodegeneration in Aging Down Syndrome (NiAD) and Alzheimer's Disease in Down Syndrome (ADDS)—and is supported by the National Institute on Aging (NIA) and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), both part of NIH.



## Get More Information

### Scientific Contacts for ABC-DS

NIA  
Laurie Ryan PhD, [ryanl@mail.nih.gov](mailto:ryanl@mail.nih.gov)   
  
NICHD  
Melissa Parisi  
PhD, [parisima@mail.nih.gov](mailto:parisima@mail.nih.gov) 

## Goals and Measures





The overall goals of this study are to:

- Identify sensitive neuropsychological measures of cognitive decline, imaging, blood-based, and genetic biomarkers associated with transition from normal aging to mild cognitive impairment to clinical dementia in adults with DS
- Identify critical factors that link cerebral A $\beta$  deposition to neurodegeneration and, ultimately, dementia
- Understand the relationships between biomarkers and pathways implicated in AD pathogenesis
- Provide rapid public access to all data, without embargo, and access to the biological samples by qualified scientific investigators

## Recruitment

The NiAD sites will recruit 180 adults with DS (10% with dementia) and 40 sibling controls, age 25 years and older. The ADDS sites will recruit 225-300 adults with DS, 40 years and older.

### Neurodegeneration in Aging Down Syndrome (NiAD)

Site	Investigator & Study Coordinator
University of Pittsburgh (Coordinating Center), Pittsburgh, PA	Ben Handen, Ph.D., Co-PI  William Klunk, M.D., Ph.D., Co-PI  Cathy Wolfe, Study Coordinator 
University of Wisconsin Madison, WI	Brad Christian, Ph.D., Co-PI  Renee Makuch, Study Coordinator 
Barrow Neurological Institute Phoenix, AZ	Marwan Sabbagh, M.D., Site PI  Sandy Quintanilla, Study Coordinator 
University of Cambridge Cambridge, UK	Shahid Zaman, M.D., Ph.D., Site PI  Concepcion Padilla, Study Coordinator 

### Alzheimer's Disease in Down Syndrome (ADDS)

Site	Investigator & Study Coordinator
Columbia University (Coordinating Center) New York, NY	Nicole Schupf, Ph.D., Co-PI  Deborah Pang, Study Coordinator 
Kennedy Krieger Institute/Johns Hopkins Medical Center Baltimore, MD	Wayne Silverman, Ph.D., Co-PI 
University of California, Irvine Irvine, CA	Ira Lott, M.D., Co-PI  Eric Doran, Study Coordinator  Alicia Hernandez, Study Coordinator 
Harvard/Massachusetts General Hospital Boston, MA	Florence Lai, M.D., Site PI  Diana Rosas, M.D., Site PI  Nusrat Jahan, Study Coordinator  Courtney Jordan, Study Coordinator 
The New York State Institute for Basic Research in Developmental Disabilities Staten Island, NY	Sharon Krinsky-McHale, Ph.D., Site PI  Deborah Pang, Study Coordinator  Coordinator 
University of North Texas Health Science Center Fort Worth, TX	Sid O'Bryant, Ph.D., Site PI 

<https://www.nia.nih.gov/research/abc-ds>

# Thank You!!



At every age a happy life  
is made up of little things

<http://aadmd.org/ntg>

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