

Current and Future Changes in Healthcare Policy for People Aging with IDD and Dementia

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Past President AADMD
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Arc of New Jersey Mainstreaming Medical Board



DEMENTIA (Neurocognitive Disorders)

Alzheimer's Disease

- Early - Young Onset
- Late Onset (LOAD)

Vascular Dementias (Multi-infarct)

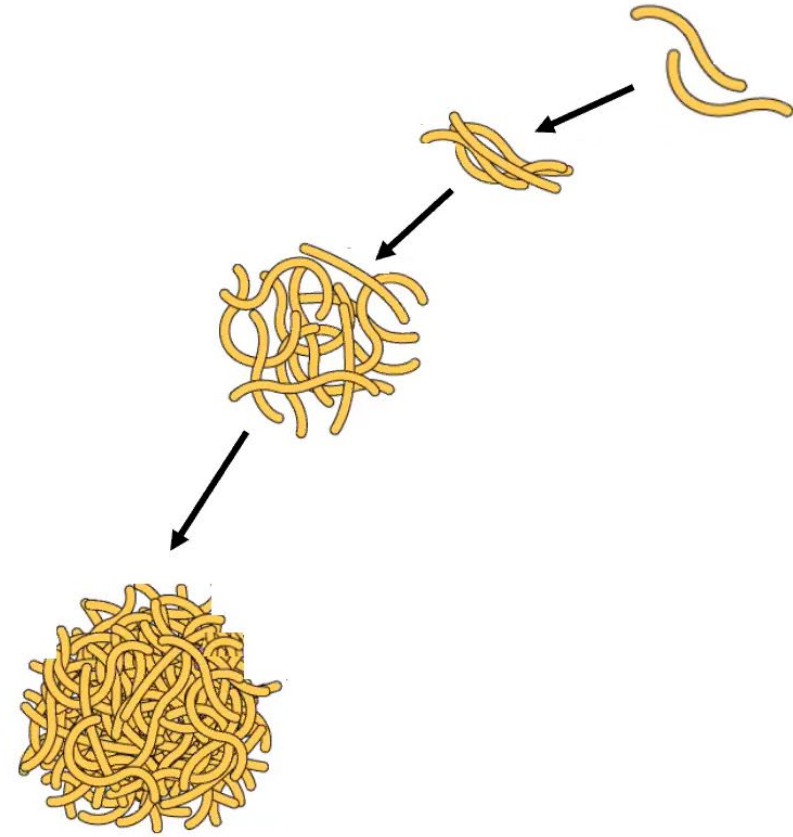
Lewy Body Dementia

Parkinson's Dementia

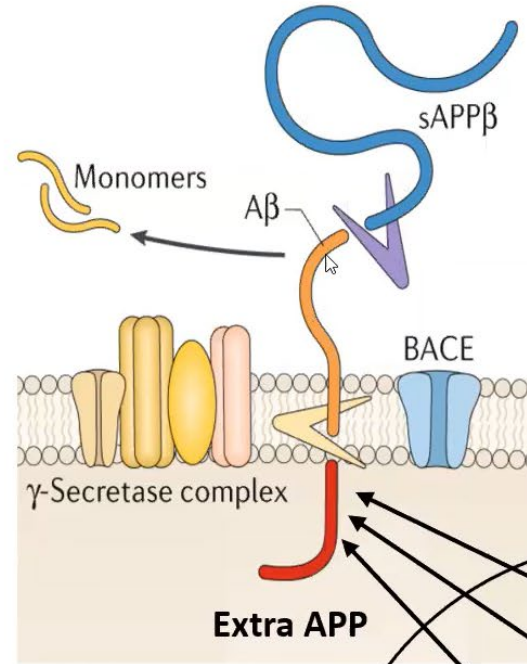
Fronto-Temporal Lobe Dementias

Other Dementias

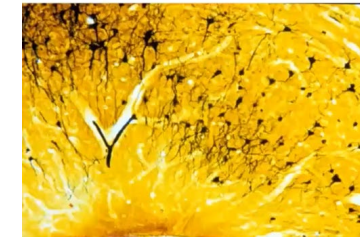
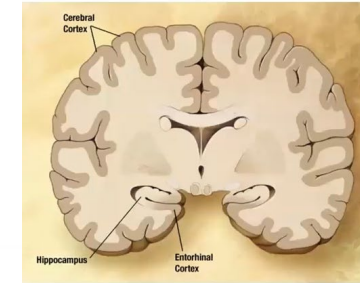
- Genetic syndromes
- Metabolic abnormalities
- ETOH related
- Drugs/toxin exposure
- White matter diseases
- CTE
- Depression(?) or Other Mental conditions
- Infections – BBB cross
- Multiple Sclerosis
- NPH



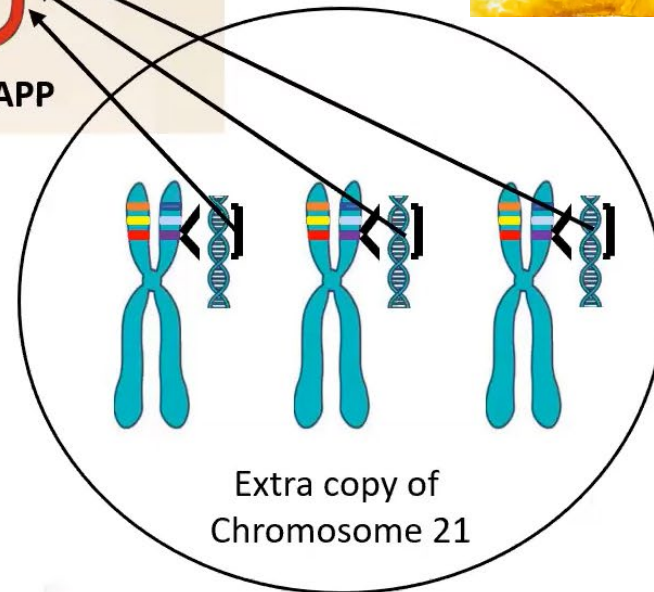
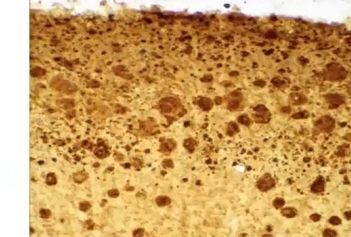
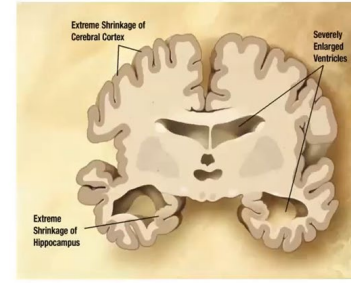
Fibrillar Amyloid plaques



Healthy Brain



AD Brain

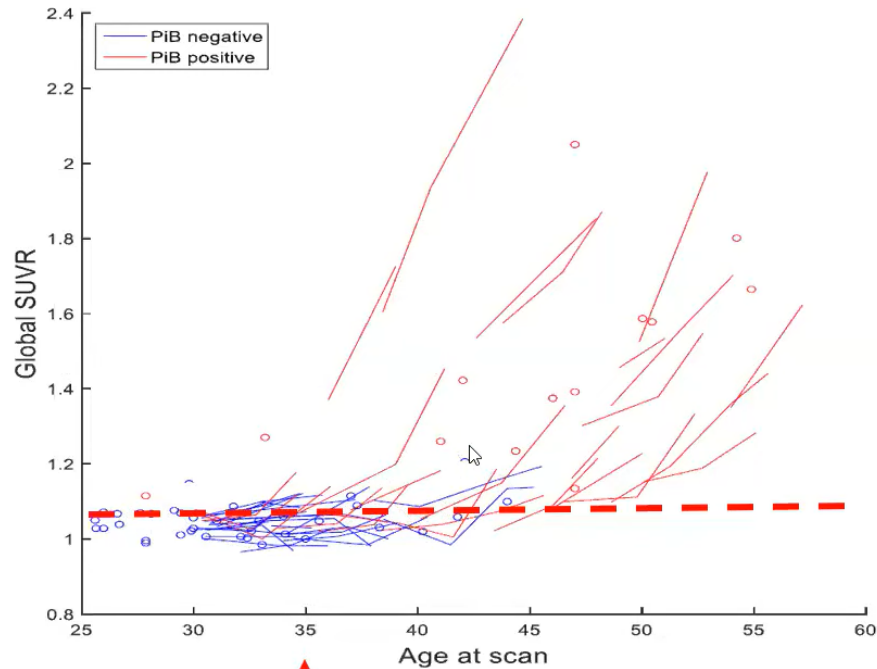


APP duplication is basis for AD in DS

- Partial trisomy
- APP Dup mutation
- Protective mutation

Brain Amyloid in People with Down syndrome

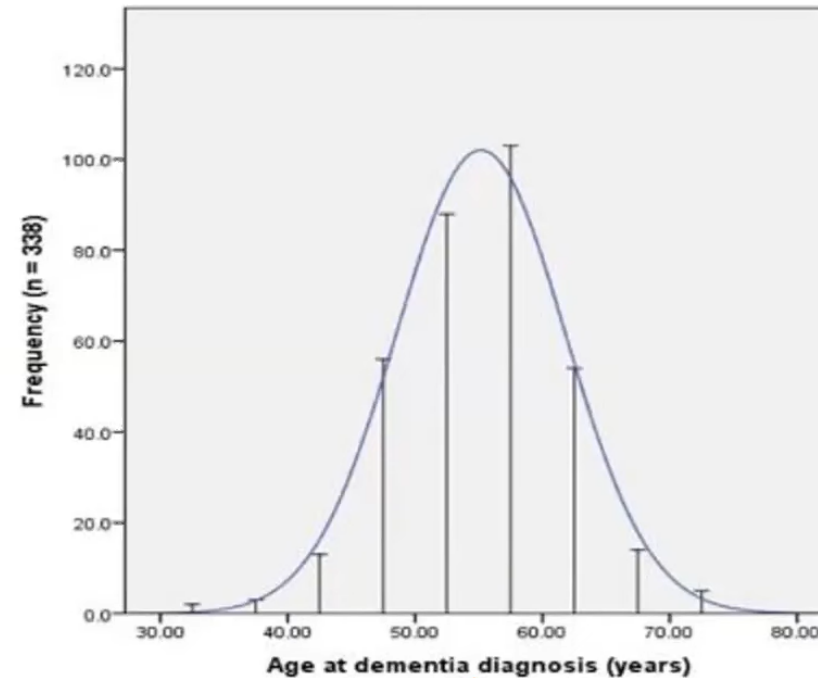
Longitudinal Amyloid PET Imaging



Lao et al, 2018

Amyloid PET positive

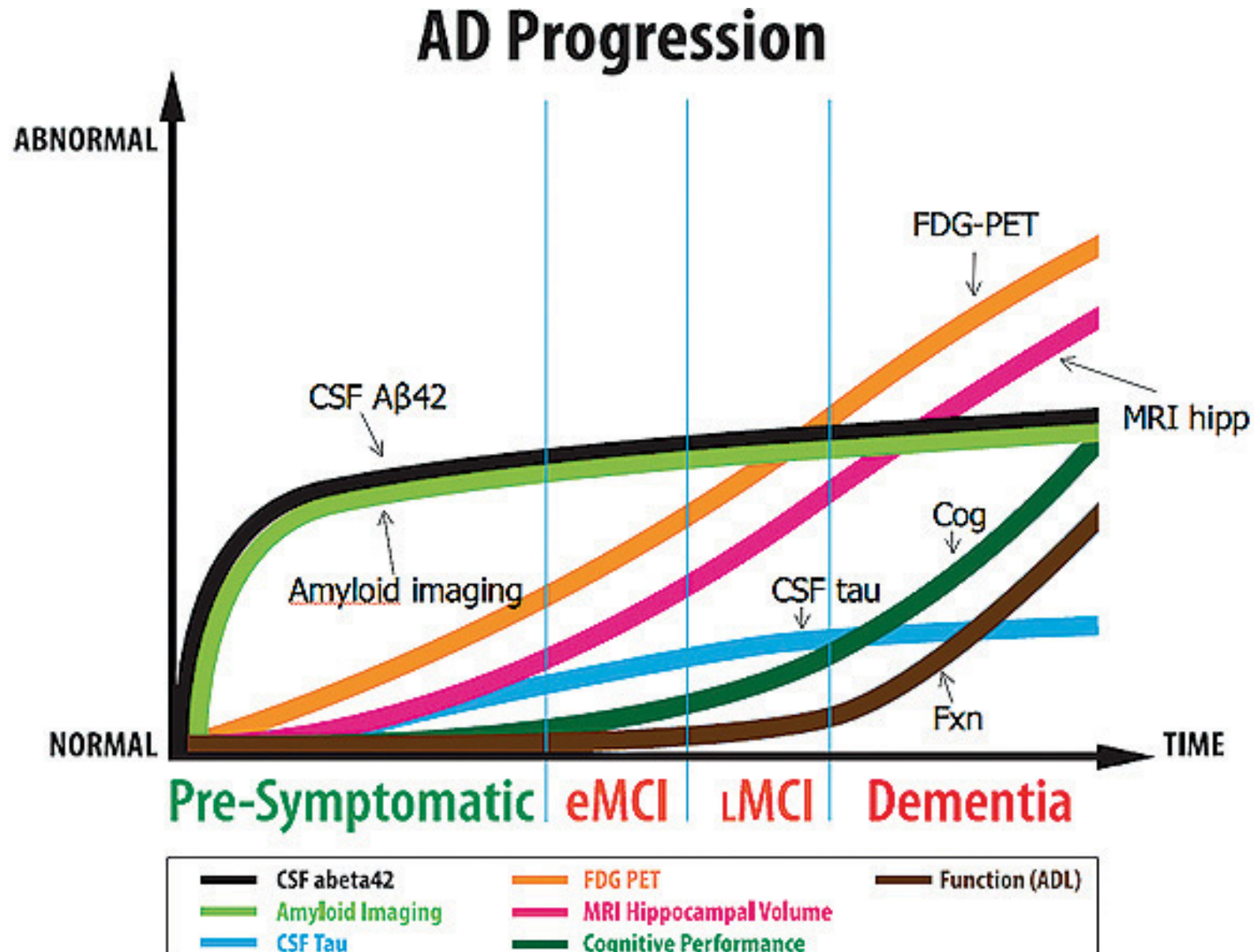
95% Lifetime Risk for AD Dementia



Strydom et al, 2017

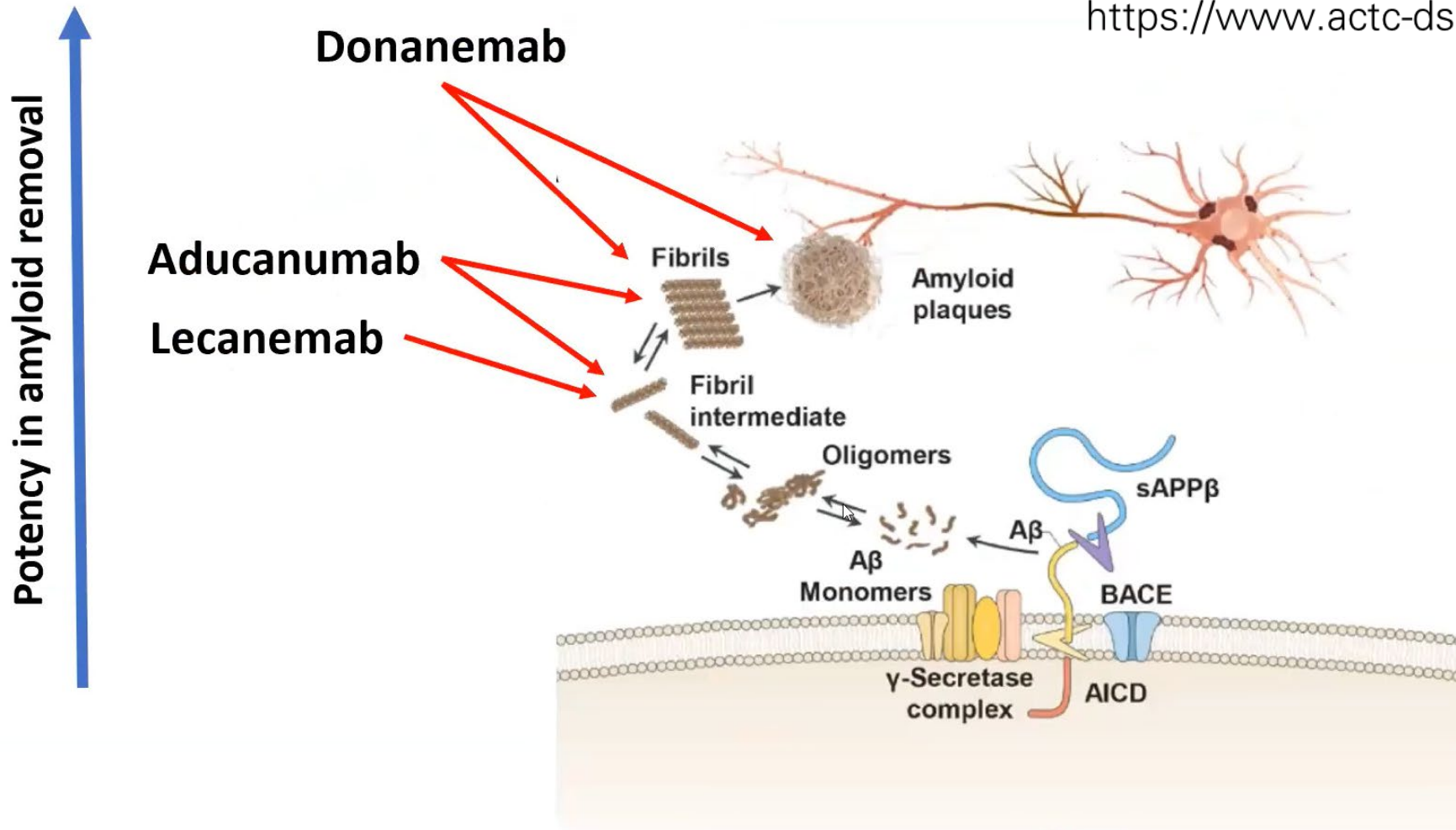
Dementia diagnosis

Alzheimer's Disease Biomarkers



Amyloid-Lowering Monoclonal Antibodies

<https://www.actc-ds.org/>

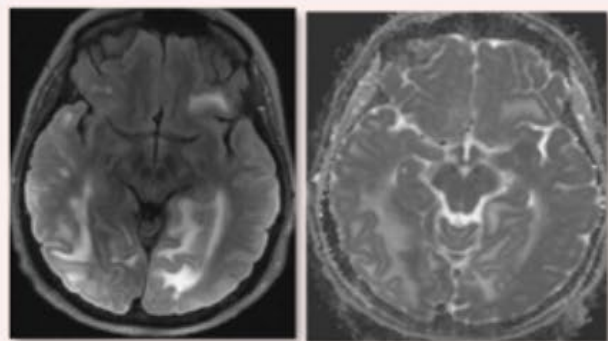


36% reduction in cognitive decline. 40% ARIA mostly asymp.

Two are FDA approved, 3rd expected in 2024 for Early AD

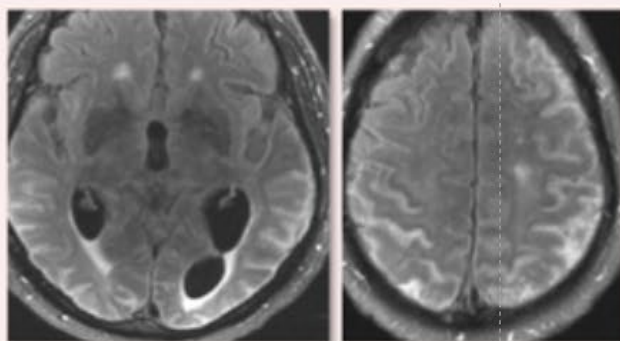
Amyloid-related Imaging Abnormalities in Alzheimer Disease Treated with Anti-amyloid- β Therapy

Amyloid-related imaging abnormalities (ARIA)

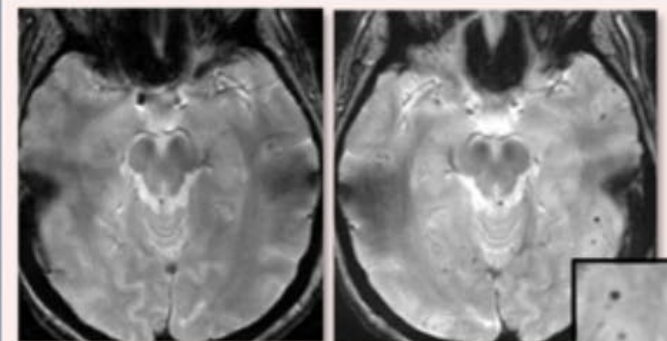


ARIA-E (edema)

ARIA-E is characterized by parenchymal edema and/or sulcal effusion.
This is the most common side effect of monoclonal antibodies.



ARIA-E (effusion)



ARIA-H (microhemorrhage)

ARIA-H is characterized by parenchymal microhemorrhages and/or superficial siderosis.

Increased vascular permeability forms the basis of both ARIA-E and ARIA-H.
Therefore, both entities can occur concurrently.

Agarwal A et al. Published online: August 31, 2023
<https://doi.org/10.1148/rg.230009>

RadioGraphics

Down syndrome families' fight for access to Alzheimer's trials, treatments

By Julie Steenhuysen

October 10, 2023 6:10 AM EDT · Updated 4 months ago



Equitable Access to Alzheimer's Disease Therapeutics for Adults with Down Syndrome



Sep 10

by Matthew P. Janicki, Ph.D., Hampus Hillerstrom, and Richard Fisher, Ph.D.



Don is living with Down Syndrome in Colorado. Photo Credit: Rick Guidotti for Positive Exposure.

<https://www.reuters.com/business/healthcare-pharmaceuticals/down-syndrome-families-fight-access-alzheimers-trials-treatments-2023-10-10/>

<https://helenjournal.org/september-2023/equitable-access-to-alzheimers-disease-therapeutics-for-adults-with-down-syndrome>

ADAPTING ELIGIBILITY CRITERIA FOR
PRESCRIBING FDA APPROVED ANTI-
AMYLOID IMMUNOTHERAPEUTICS FOR
ADULTS WITH DOWN SYNDROME
WITH EARLY-STAGE ALZHEIMER'S
DEMENTIA

An Advisory and Consensus Statement of the Working Group
on Criteria for Access to Alzheimer's Therapeutics for Adults
with Down Syndrome

Product of the LuMind IDSC Foundation, Burlington, Massachusetts, and National Task Group
on Intellectual Disabilities and Dementia Practices (www.the-ntg.org)



States and other payers adopt the proposed:

- DS-focused equivalency criteria as soon as possible; and Phase 4 clinical trials in adults with DS be undertaken with similar urgency so that clinicians gain information on the safety of this class of drugs for adults with DS.
- The working group recommends a series of wording changes to reflect equivalencies in the prescribing criteria, offers substantiation for such changes, and calls upon relevant organizations to provide education to prescribers, and for professional associations to issue protocols for guiding prescribers in the use of this class of AD drugs

<https://www.the-ntg.org/lumind-drug-equivalency>

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

U.S. Department of Health & Human Services

NIH National Institute on Aging

HEALTH INFORMATION | RESEARCH & FUNDING | NEWS & EVENTS | ABOUT NIA

Home / Research & Funding / 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.

BACKGROUND | GOALS AND MEASURES | RECRUITMENT

STUDY SITES AND INVESTIGATORS | INFORMATION FOR PARTICIPANTS AND FAMILIES

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

Get More Information

Scientific Contacts for ABC-DS

NIA
Laurie Ryan PhD, ryanl@mail.nih.gov

NICHD
Melissa Parisi
PhD, 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 β 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
University of North Texas Health Science Center Fort Worth, TX	Sid O'Bryant, Ph.D., Site PI

Guiding an Improved Dementia Experience (GUIDE) Model

MODEL PURPOSE

Dementia takes a toll on not just the people living with the disease but also on their loved ones and caregivers in a way that almost no other illness does. About 6.7 million Americans currently live with Alzheimer's disease or another form of dementia, a number that is projected to grow by nearly 14 million by 2060. To help address the unique needs of this population, the GUIDE Model aims to:



Improve quality of life for people living with dementia by addressing their behavioral health and functional needs, coordinating their care for dementia and co-occurring conditions, and improving transitions between community, hospital, and post-acute settings.



Reduce burden and strain on unpaid caregivers of people living with dementia by providing caregiver skills training, referrals to community-based social services and supports, 24/7 access to a support line, and respite services.



Prevent or delay long-term nursing home care for as long as appropriate by supporting caregivers and enabling people living with dementia to remain safely in their homes for as long as possible.

To reduce disparities in access to dementia care services, the GUIDE Model incorporates policies to enhance health equity by ensuring that underserved communities have equal access to the model intervention

CMS Alternative Payment Model Model
Beneficiary Eligibility

Traditional Medicare Patients/Beneficiaries (Parts A & B)

Not enrolled in Advantage Plans, Special Needs Plans & PACE

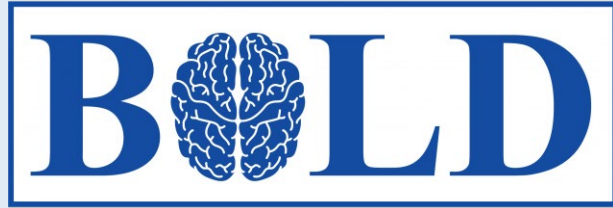
Beneficiary has a diagnosis of dementia, as confirmed by clinician attestation
Community Dwelling (Not residing in long-term nursing home)

Excludes Hospice Patients

8 Year Program (July 2024 – July 2032)

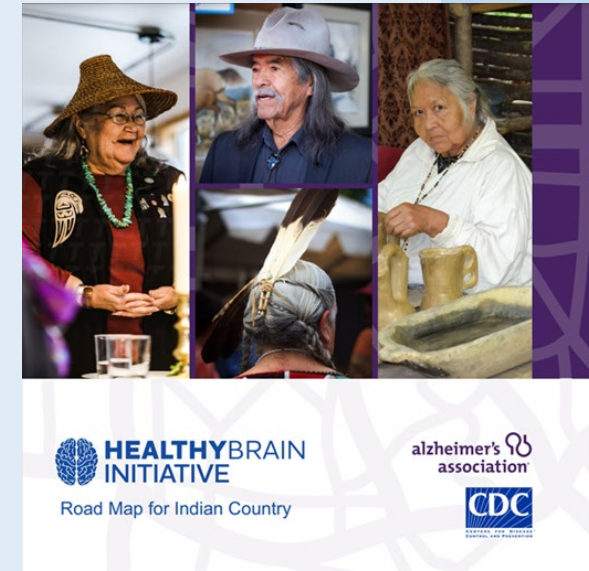
CMS will actively seek out the participation of eligible organizations that provide care to underserved communities for participation in the GUIDE Model.

BOLD Infrastructure for Alzheimer's Act



The BOLD Infrastructure for Alzheimer's Act directs CDC to:


- Establish Alzheimer's and Related Dementias Public Health Centers of Excellence
- Provide Funds to Support Public Health Departments
- Increase Data Analysis and Timely Reporting
- Passed into law on December 31, 2018



The Healthy Brain Initiative improves understanding of brain health as a central part of public health practice. The initiative **creates and supports partnerships, collects and reports data, increases awareness of brain health, supports populations with a high burden of Alzheimer's disease and related dementias, and promotes the use of its Road Map series: State and Local Public Health Partnerships to Address Dementia**



- The UIC HBI Project activities aim to 1) educate and empower people with IDD (with and without dementia) and their supports (paid and unpaid caregivers and stakeholders) about brain health; 2) mobilize partnerships to implement the Road Map and increase number of people reached; and, 3) embed evaluation into training and support programs to determine program accessibility, affordability, effectiveness, and impact.




**HealthMatters™
Program**

**ALZHEIMER'S DISEASE AND
RELATED DEMENTIAS**
People with Intellectual and Developmental Disability


PROMOTING BRAIN HEALTH EQUITY FOR ALL! | WWW.HEALTHMATTERSPROGRAM.ORG

- Approximately 6.5 million people in the United States have an intellectual disability (IDD). Approximately 1 - 3 percent of the global population has an intellectual disability—as many as 200 million people.
- Number of adults with IDD age 60 years and older may double from 641,860 in 2000 to 1.2 million by 2030 resulting in a need for more services.
- About 11,000 (6%) of the 180,000 older people with IDD will experience a form of Alzheimer's disease and related dementias (ADRDs) after age 60 (increases with age).
- People with Down syndrome have a higher risk, with about 2 in 3 people over the age of 60 developing dementia, usually Alzheimer's disease (AD), with a mean age of onset or diagnosis of AD at 53.



CHANGING THE MYTH


- People with intellectual and developmental disability (IDD) have healthy brains.
- ADRDs are NOT a natural course of aging for people with IDD.
- People with IDD like their nondisabled peers can optimize cognitive, emotional, psychological and behavioral functioning with or without dementia to cope with life situations.
- Healthy lifestyles among people with IDD can be supported by considering the impact of structural and social determinants on healthcare and health outcomes.



Know the Signs & Symptoms

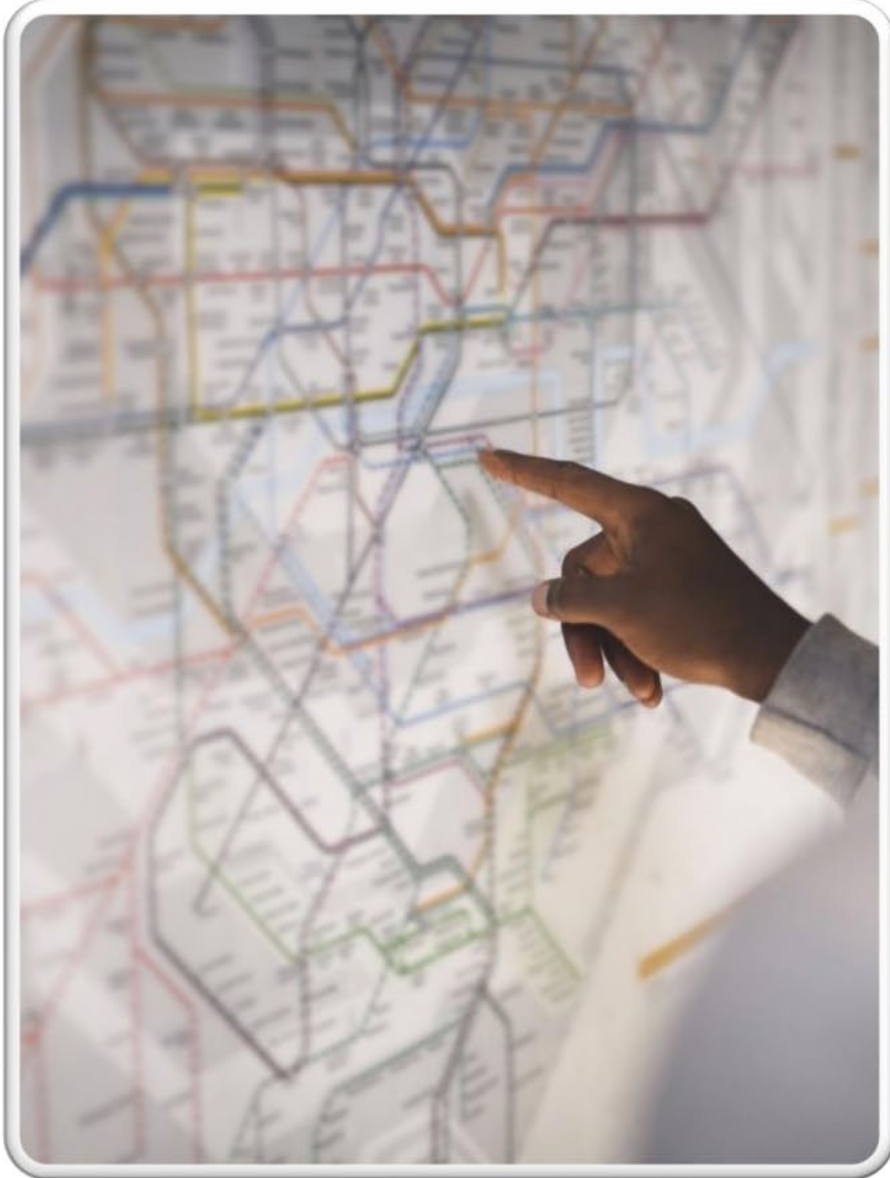
- Loss of daily living skills (difficulty with usual abilities, changes in daily routine, sleeping, or eating habits, inability to choose clothing)
- Changes in personality (withdrawal, frustration, increased aggression, unjustified fears, inability to focus, periods of inactivity, disinterest in activities previously enjoyed)
- Increase in stereotyped behavioral traits (most often stubbornness)
- Difficulties remembering names of people previously known

- Loss of language and other communication and social skills
- Changes in coordination (increased difficulty with visual/motor coordination or accidents and falls, difficulty learning new tasks)
- Development of seizures not previously seen
- Disorientation to time and place or getting lost in familiar environments
- Repeated choking incidents
- Changes in hearing and vision
- Hyperactive reflexes



SCAN ME

Addressing IDD Brain Health - Road Map Strategies



State Councils on Developmental Disabilities (DD and Bill of Rights Act)

- Required to have a strategic plan and enable coordination among state agencies
- Council membership by agencies, petitioning Council for underwriting risk reduction efforts
- **Influence:** state developmental disabilities agency, education agency, health agency, etc.

State Units on Aging (aging dept, elder affairs div, etc.) (Older Americans Act)

- Required to produce multi-year plan for receipt of federal funds
- Advisory councils help set framework
- **Influence:** state and local (AAA) efforts for targeting; funding initiatives

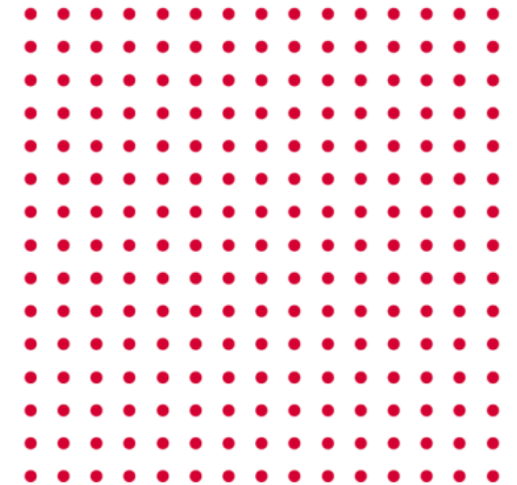
State health departments/agencies

- Required to address public health issues
- **Influence:** physical and brain health initiatives

Addressing SDOH to Build a Diverse and Skilled Workforce – Healthcare and Public Health

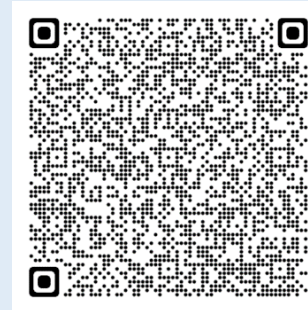
Healthcare providers need training on how to provide inclusive and accessible healthcare.

- **ENGAGE-IL (GWEP)**
Geriatric CEU Modules 27 Learning Modules
 - ✓ Healthy Brain Module 1: Health Advocacy
 - ✓ Healthy Brain Module 2: 6 Pillars of Brain Health for People with IDD
 - ✓ Address disability humility for people with intellectual and developmental disability
 - ✓ Identify SSDOH, 2) uproot systemic bias, and 3) illustrate Universal Design.
 - ✓ Topics: diagnostic overshadowing, complex health conditions, accessible healthcare (buildings, equipment, communication)



Obstacles to equitable and timely access to new Alzheimer disease diagnostics and treatments

- Lack of research for safety and efficacy
- Lack of awareness, education and training
- Lack of assessments
- Difficult conversations about the risks and how to best prepare



ntg National Task Group on Intellectual Disabilities and Dementia Practices

NTG-EDSD

v1/2018.2

The NTG-Early Detection Screen for Dementia, adapted from the DSQ/DSM, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.8 of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/screening).

⁽¹⁾ File #: _____ ⁽²⁾ Date: _____

Name of person: ⁽³⁾ First _____ ⁽⁴⁾ Last _____

⁽⁵⁾ Date of birth: _____ ⁽⁶⁾ Age: _____

⁽⁷⁾ Sex:

Female

Male

⁽⁸⁾ Best description of level of intellectual disability

No discernible intellectual disability
Borderline (IQ 70-75)
Mild ID (IQ 55-69)
Moderate ID (IQ 40-54)
Severe ID (IQ 25-39)
Profound ID (IQ 24 and below)
Unknown

⁽⁹⁾ Diagnosed condition (check all that apply)

<input type="checkbox"/> Autism
<input type="checkbox"/> Cerebral palsy
<input type="checkbox"/> Down syndrome
<input type="checkbox"/> Fragile X syndrome
<input type="checkbox"/> Intellectual disability
<input type="checkbox"/> Prader-Willi syndrome
<input type="checkbox"/> Other: _____

Instructions:
For each question block, check the item that **best applies** to the individual or situation.

Current living arrangement of person:

Lives alone

Lives with spouse or friends

Lives with parents or other family members

Lives with paid caregiver

Lives in community group home, apartment, supervised housing, etc.

Lives in senior housing

Lives in congregate residential setting

Lives in long term care facility

Lives in other: _____



A Companion to the GSA KAER Toolkit for Primary Care Teams:
Supporting Conversations About Brain Health, Timely Detection of Cognitive Impairment, and Accurate Diagnosis of Dementia



Thank You!!

<https://www.the-ntg.org/family-caregivers>

<https://www.the-ntg.org/training>

sethkeller@aol.com



Intellectual Disabilities and Dementia (the-ntg.org)