

Duke Dementia Family Support Program

Caregiver Connections

An Educational Webinar Series With The Experts

The presentation will begin shortly.
Thank you for your patience!

dukefamilysupport.org

919-660-7510



NC Registry for Brain Health



Advances in the Prevention and Treatment of Alzheimer's Disease

*Presenter: Kathleen A. Welsh-Bohmer, PhD,
ABPP*

Professor of Psychiatry & Neurology

Duke Clinical Research Institute

NC Registry for Brain Health &

Duke / UNC Alzheimer's Disease Research Center

October 17, 2023

Affiliation and Disclosures

Dr. Welsh-Bohmer directs the Coordinating Center for the NC Registry for Brain Health at Duke University.

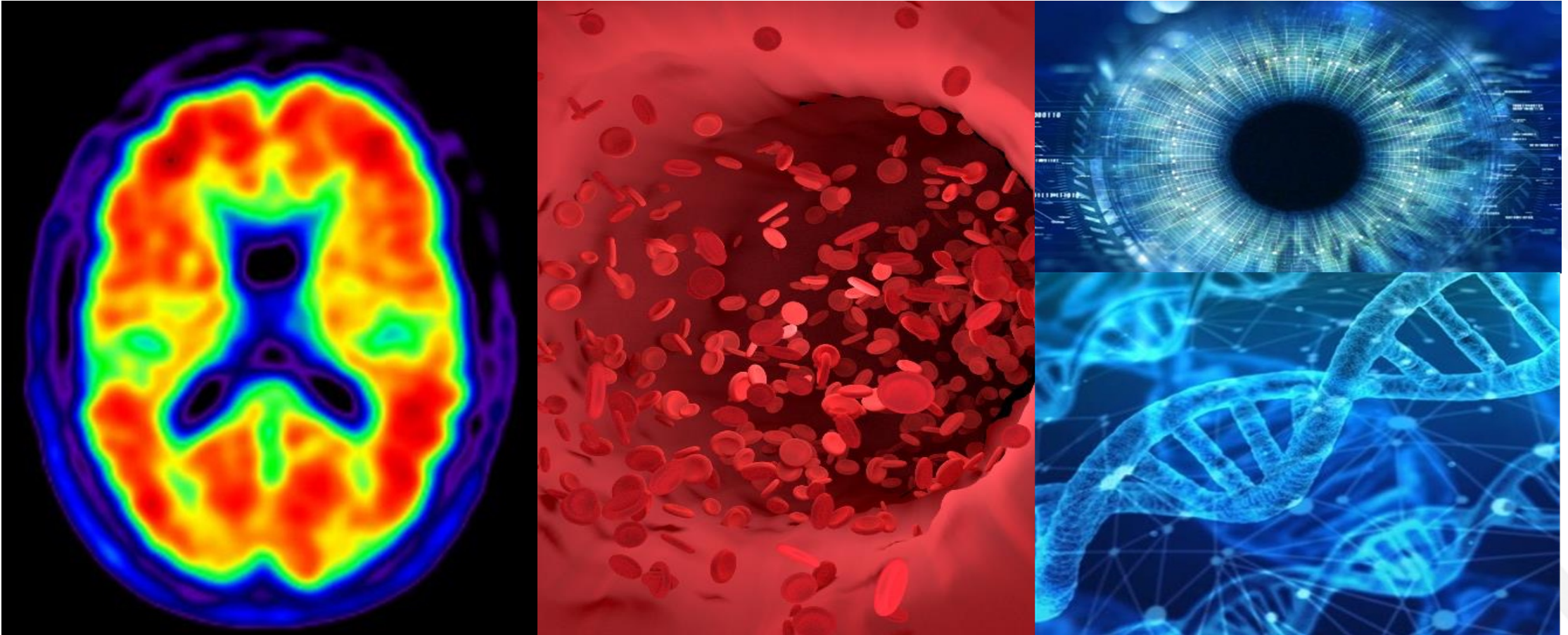
She consults with pharmaceutical companies, including Roche/Genentech and Biogen.

And she has a contract with the biotechnology company WCG-VeraSci to assist in the development of technologies for clinical trials of Alzheimer's disease



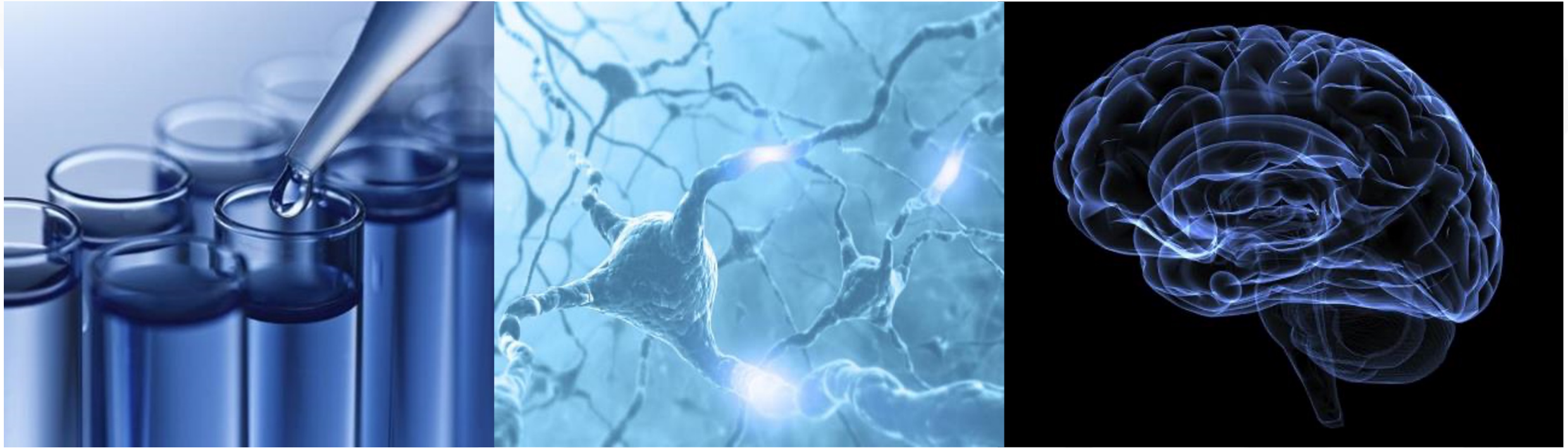
NC Registry for Brain Health

2023 EXCITING ADVANCES- ALZHEIMER'S RESEARCH



Brain imaging, fluid biomarkers, retinal imaging, & genetics allow enhanced detection of disease

New treatments target the underlying cellular mechanisms and slow the disease progression



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Where we are today

Bad News

- There is no cure for Alzheimer's disease once the disease has started
- No treatment that allows us to prevent the disease from occurring

Good news

- **Have disease biomarkers allowing earlier diagnosis**
- **New treatments that slow disease progression in brain**
- **Evidence based approaches to lower risk and promote healthy cognition**



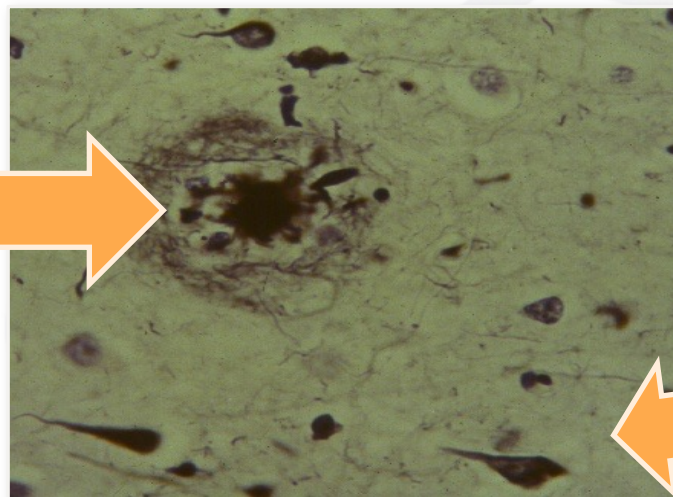
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Biomarkers for early detection



Alzheimer's Disease: Two Problems

Amyloid Plaques and Neurofibrillary Tangles



Amyloid “plaques”
(β amyloid protein)

*Brain immune response
inflammation/glial cells*

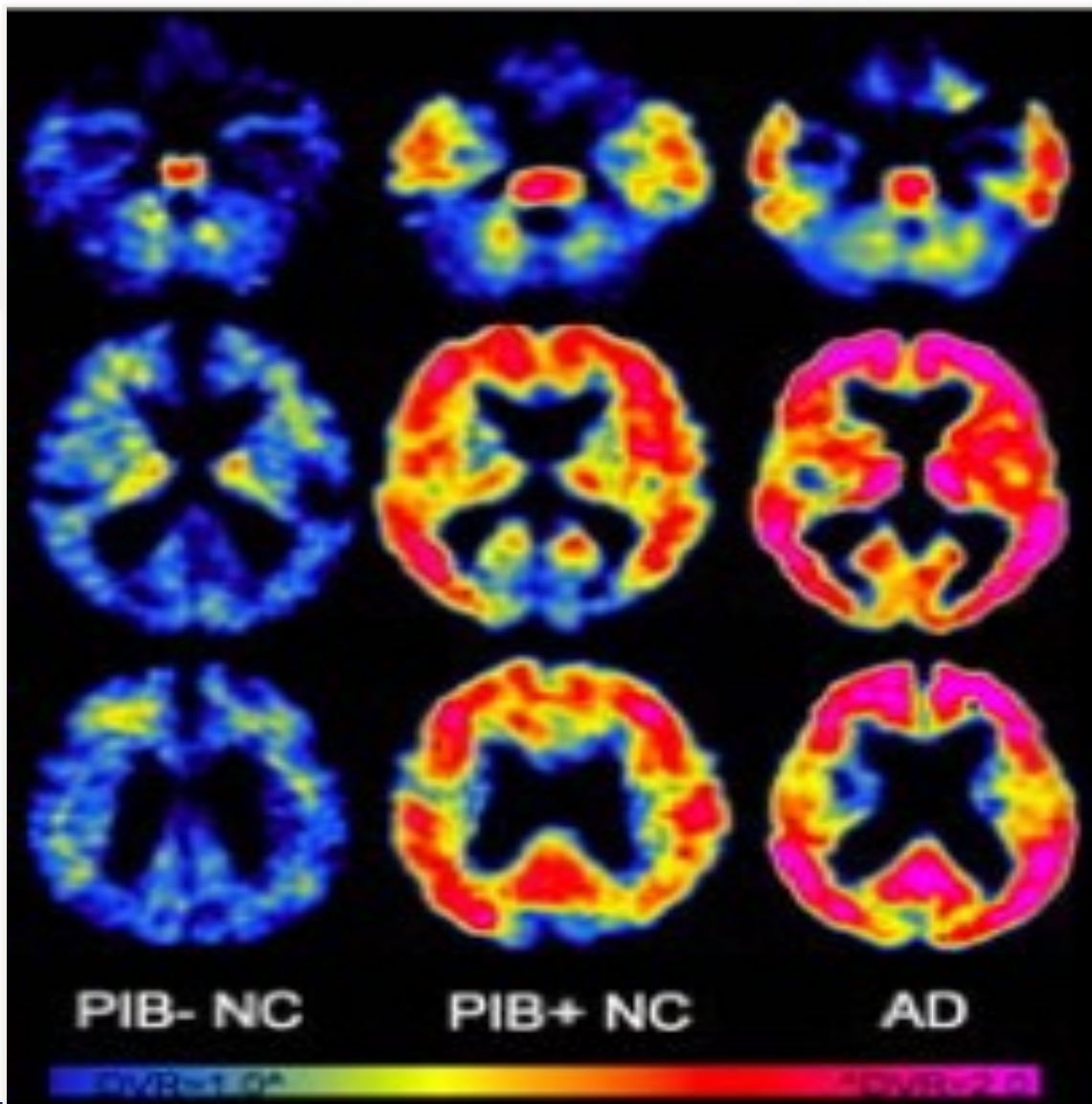
Cell loss “neurodegeneration”
Atrophy

Neurofibrillary Tangles
(*p-Tau protein*)



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Biomarkers of Alzheimer's Disease- Amyloid



- Measure abnormal amyloid and tau in cerebrospinal fluid (CSF)

— and —

- Amyloid and tau brain imaging using Positron Emission Tomography (PET)

Amyloid or tau is tagged with a fluorescing imaging agent, F18 florbetapir seen here

Doing this allows us to then visualize areas of high accumulation on imaging with PET

Three different agents FDA are approved for detecting abnormal levels of brain amyloid.

NIA-AA Research Framework: Toward a biological definition of Alzheimer's disease (Jack et al 2018; Alz & Dementia) & Blood Based Biomarkers of Alzheimer's Disease (Zetterberg 2018; Journal of Neuroscience Methods); Tian et al Eur J Nucl Med Mol Imaging.

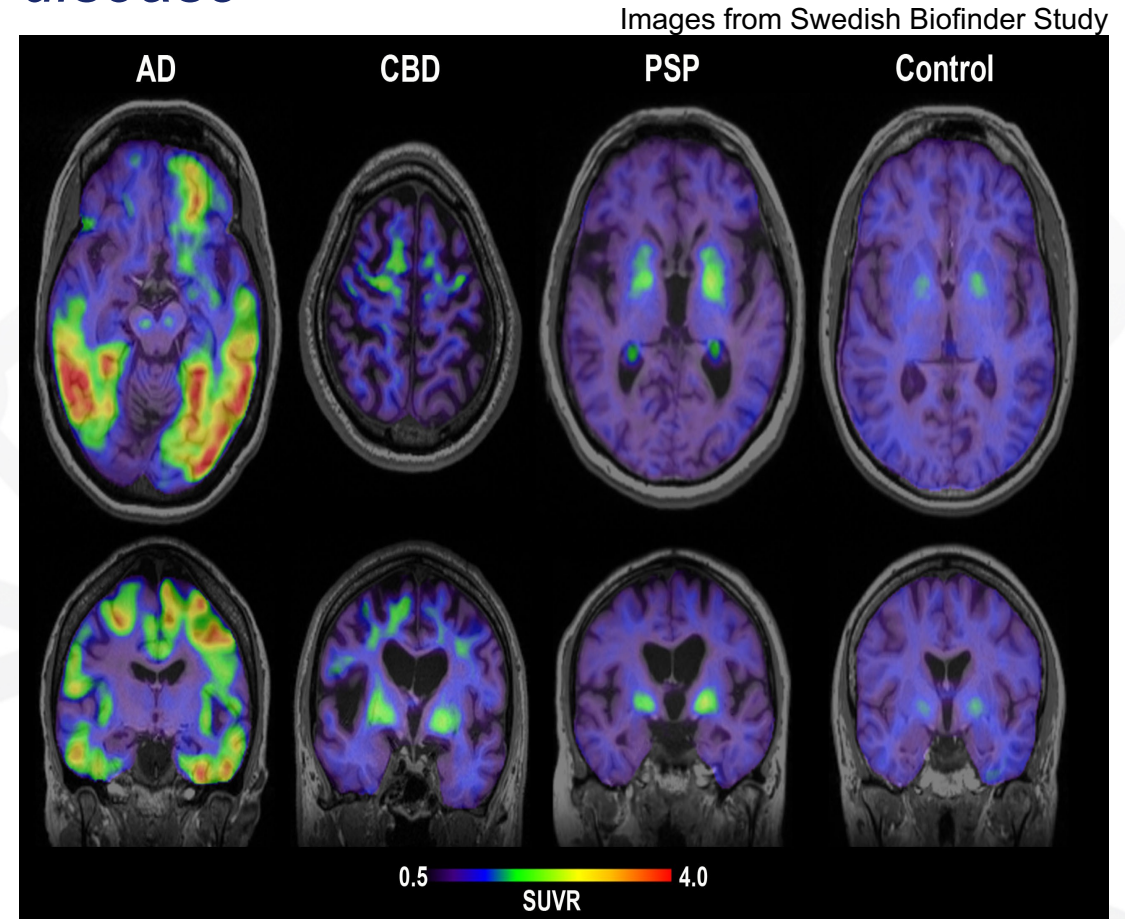
Increased Precision with Combined Biomarkers

Confirm & stage disease

- Large prognostic study with prospectively collected data (clinical and imaging) from 8 cohorts of AD, MCI, healthy controls from South Korea, Sweden, and the US (n=1431)

Showed

- Abnormal amyloid points to a diagnosis of Alzheimer's disease
- Tau abnormalities in the context of abnormal amyloid points to greatest risk for decline
- Together this information can be used to guide therapeutic decisions in early stages of silent disease (i.e., when to start therapy)



Ossenkoppele et al.(2021). Accuracy of Tau PET as a Prognostic Marker in Preclinical and Prodromal Alzheimer Disease. *JAMA Neurol.* 78(8):961–971

Blood Biomarkers- Improving Accessibility for All



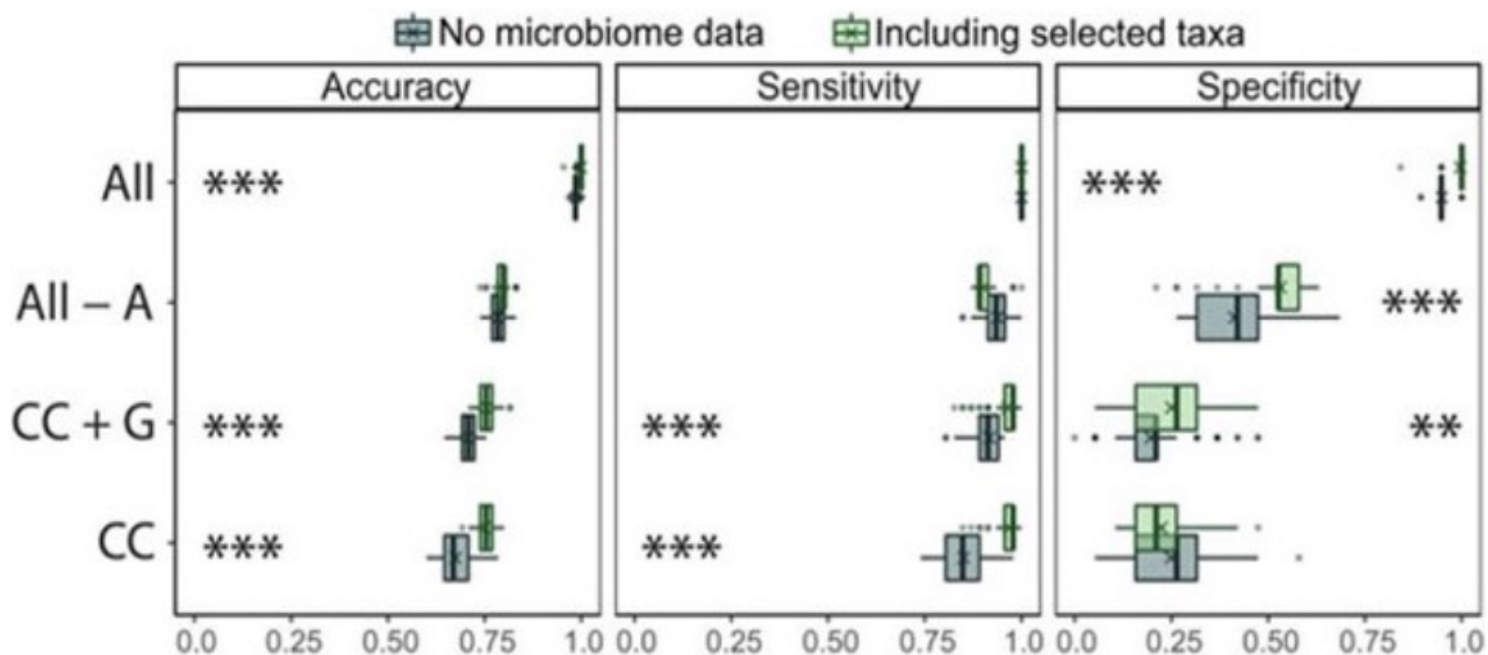
- Research suggests that a form of tau called p-Tau217 is very specific to Alzheimer's and, when measured in the blood, is highly accurate in distinguishing Alzheimer's from other neurodegenerative disorders.
- Advantages of convenience and cost
 - Starting to be used to screen for disease
- Disadvantages in accuracy compared to PET imaging & CSF methods
 - Not yet covered by insurance

Teunissen CE et al. (2022) Blood-based biomarkers for Alzheimer's disease: towards clinical implementation. . Lancet Neurol.21(1):66-77

New Breakthroughs- Gut Microbiome & Brain AD pathology

Novel biomarker improves accuracy in disease detection

(Ferreiro et al. *Science Translational Medicine*, June 14 2023)

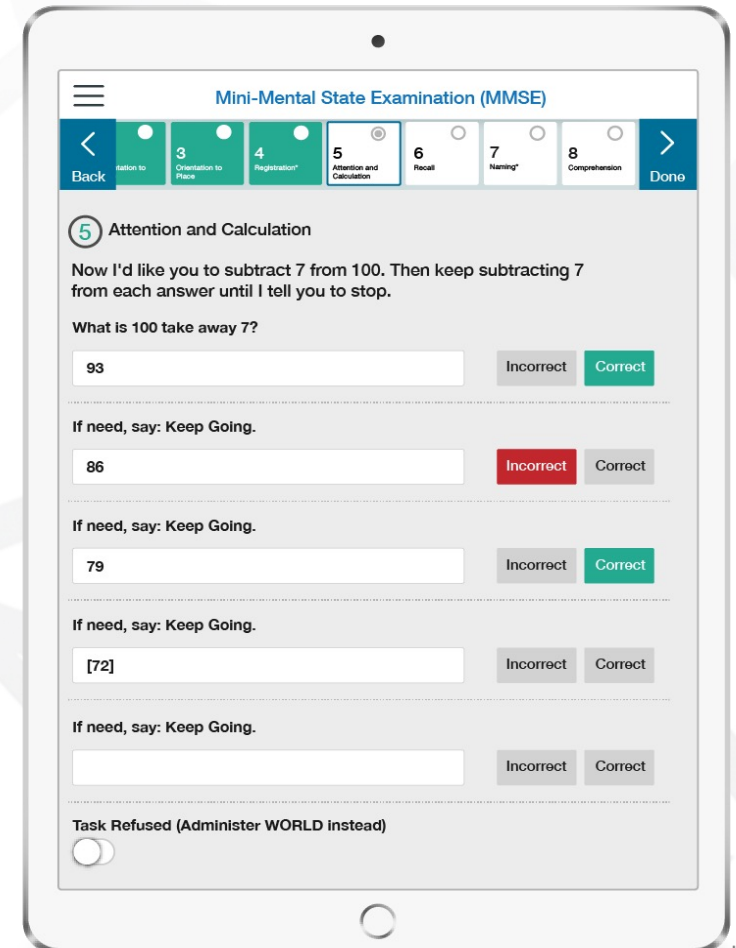


Improving Diagnostic Accuracy. Including the prevalence of certain gut bacteria (green) improved the accuracy of most models used to diagnose preclinical AD, including clinical variables only (CC), clinical information plus polygenic risk score and ApoE4 status (CC + G), those plus biomarkers of neurodegeneration, tau, and amyloid (All), or all the markers minus Ab (All - A). [Courtesy of Ferreiro et al., *Science Translational Medicine* 2023.]

- Seven types of bacteria found in gut are correlated with AD pathology in preclinical AD
 - Suggests that bacteria in the gut and our exposures over our lifetime can influence what is happening in the brain
- Adding microbe data to all types of biomarkers nudges up accuracy in diagnosis
 - Could be used to screen people to identify those who should go on to have a lumbar puncture or PET scan
 - And could help physicians in the future personalize medicines to prevent disease based on our unique biology & health history

ADVANCES IN DIGITAL TECHNOLOGY: TOOLS FOR COGNITIVE ASSESSMENT & MONITORING EVERYDAY FUNCTION

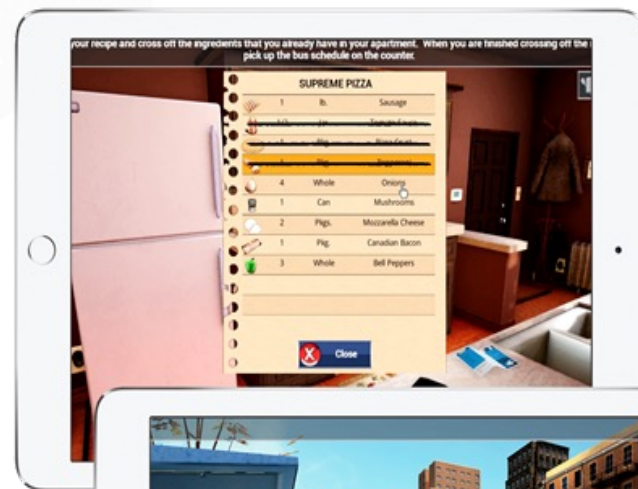
- Digital tools, including wearable devices, increase the reliability of measuring cognition and highly nuanced changes in behavior
 - Discrete measures that can be repeated over time
 - Can be used to help clinicians detect subtle changes in real time to guide management decisions; &
 - Potentially some forms of this could be used for people to self-monitor their everyday function to know how well interventions are helping



Gold M, et al. (2018) *Digital technologies as biomarkers* *Alz & Dementia*, 4:234–242;
Germine L, et al. (2019) *Digital neuropsychology*; *Clinical Neuropsychologist*, 33:2, 271-286.

DIGITAL TECHNOLOGY: DUKE/UNC ADRC DRIVING NEW INSIGHTS IN NEUROCOGNITION

- Virtual Reality Functional Capacity Assessment Tool (VRFCAT)
 - Used to detect subtle changes in function in the preclinical stage of Alzheimer's disease
 - performance based instrument
 - assesses the ability to complete instrumental activities associated with a shopping trip
 - normed (18-85) & sensitive to subjective cognitive complaints and MCI



Atkins A et al (2018). Assessment of IADL funding in older adults with Subjective Cognitive Decline using the Virtual Reality Functional Capacity Assessment Tool (VRFCAT) J Prevention of Alzheimer's Disease (JPAD), 5(4): 216-224



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A photograph of a woman with short grey hair and glasses, wearing a white polka-dot shirt, sitting on a blue couch. She is holding a wooden-handled microphone. This scene is displayed on the screen of a laptop. At the bottom of the screen, there is a video call control bar with icons for video, audio, chat, and a red 'X' to end the call. The laptop keyboard is visible in the foreground, and a person's hands are seen typing. The background behind the woman on the screen is a bright, indoor setting with a green plant.

**Technology can
enable broader
access to services
and facilitate
accuracy/ clinician
insights by linking
electronic health
records**

Treatment Advances



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Medications approved for symptomatic treatment of Alzheimer's disease

Drug	Class & Indication	Mechanism of Action	Common Adverse Effects
Donepezil (FDA approved 1996) – Aricept	Cholinesterase inhibitor prescribed mild/mod AD	Prevents breakdown of transmitter acetylcholine (ACh) in brain	Nausea, vomiting, diarrhea
Galantamine (FDA approved 2001) – Razadyne	Cholinesterase inhibitor prescribed mild/mod AD	Prevents breakdown ACh and stimulate receptors to release more Ach	Nausea, vomiting, diarrhea, appetite, weight loss
Rivastigmine (FDA approved in 2000) – Exelon	Cholinesterase inhibitor prescribed mild/mod AD	Prevents breakdown of ACh and butyrylcholine	Nausea, vomiting, diarrhea, appetite, weight loss, muscle weakness
Memantine (FDA approved in 2003) - Namenda	N-methyl-D-aspartate antagonist prescribed to treat mod/severe AD	Blocks toxic effect of glutamate and glutamate activation	Dizziness, HA, confusion, constipation

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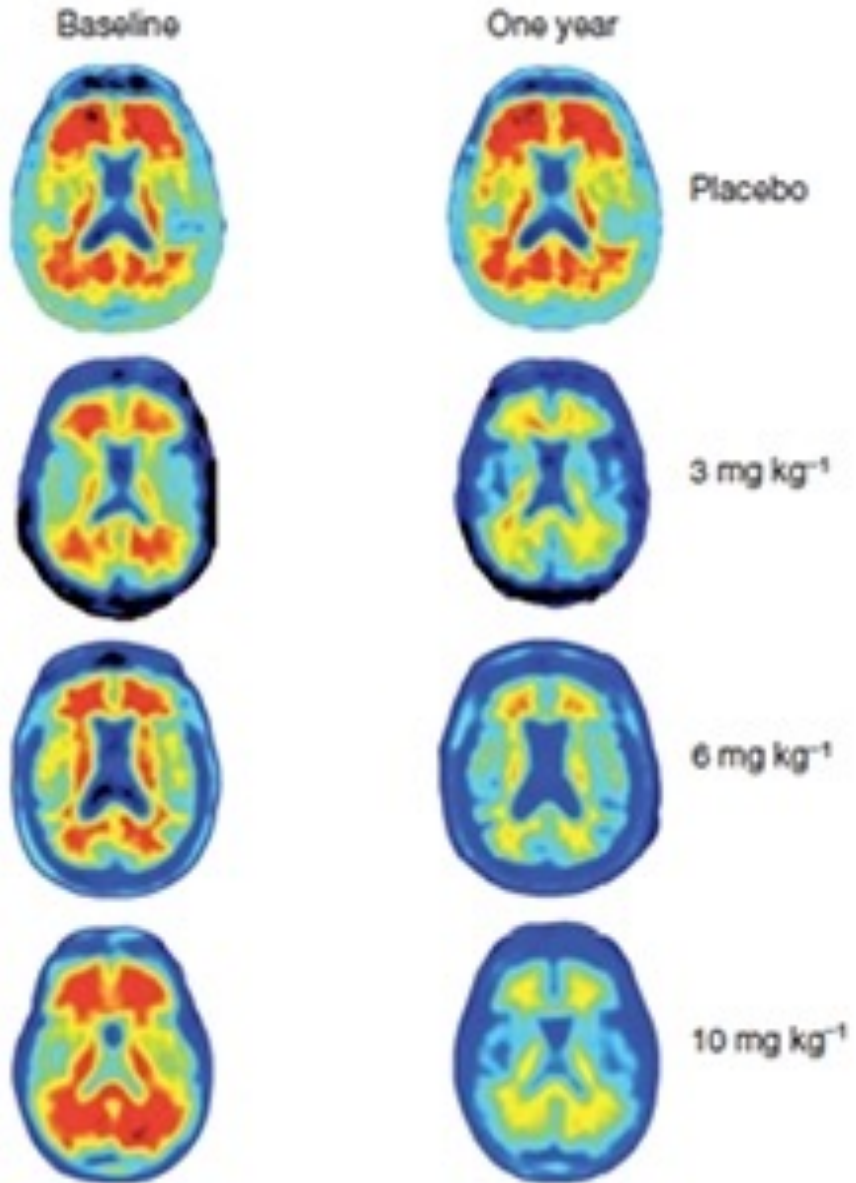
- Provide symptomatic relief
- Do not change the underlying disease course
- Latest AD drug approval occurred in 2003

DISEASE MODIFYING TREATMENTS

“Amyloid” Directed Immunotherapy

- Monoclonal antibodies aimed at lowering toxic forms of A β (protein found in amyloid plaques).
 - Typically these drugs involve monthly infusions in order to reduce the aggregation of amyloid plaques in the brains of treated patients, as shown here with the first generation drug, Aduhelm
- Goal is to not only lower amyloid in brain but to, of course, also improve patient function and cognition

Budd Haeberlein S et al (2022). Two Randomized Phase 3 Studies of **Aducanumab** in Early Alzheimer's Disease. *Journal for the Preventionth of Alheimers Disease*. 2022;9(2):197-210.



Success 1: Aducanumab “Aduhelm”



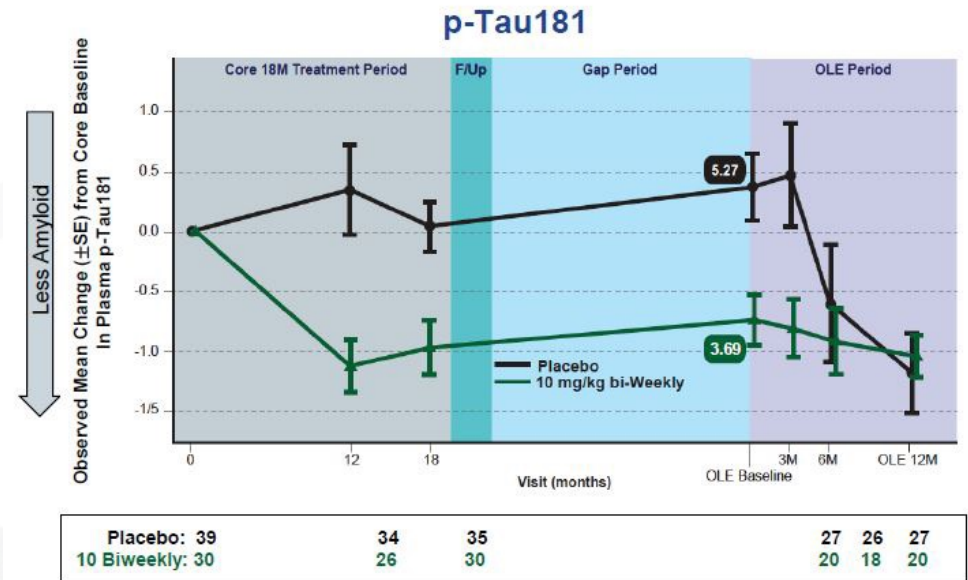
- FDA granted early “accelerated” approval to the anti-amyloid drug Aduhelm in June 2021
- Controversial decision because of the drug’s mixed results in two large studies and mistakenly ending the study early
- Limited availability rarely used but paved the way for accelerated approval for future AD drugs



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Continued Treatment Breakthroughs 2022-2023

- Phase 3 “Clarity” trial tested an experimental amyloid-targeting antibody, **lecanemab** (BAN2401) in mild stage Alzheimer’s disease (n=1795)
 - significantly slowed the progression of dementia symptoms among people with early Alzheimer’s disease
 - slowed the rate of cognitive decline by 27% over 18-months
 - reduced blood biomarkers of progression (pictured)
 - adverse events (microbleeds) 17.3% on treatment compared to 9.3% on placebo. 12% had brain swelling (edema) on drug.
 - ~25% of the U.S. participants were Hispanic and African American



Changes in plasma p-tau181 in people taking lecanemab mirror those previously reported for amyloid plaque clearance. [image courtesy of Eisai.]

van Dyck CH et al (2023). **Lecanemab** in Early Alzheimer's Disease. *New England Journal of Medicine* 388(1):9-21. doi: 10.1056/NEJMoa2212948. Epub 2022 Nov 29. PMID: 36449413.

Success 2: Lecanemab or “Leqembi”



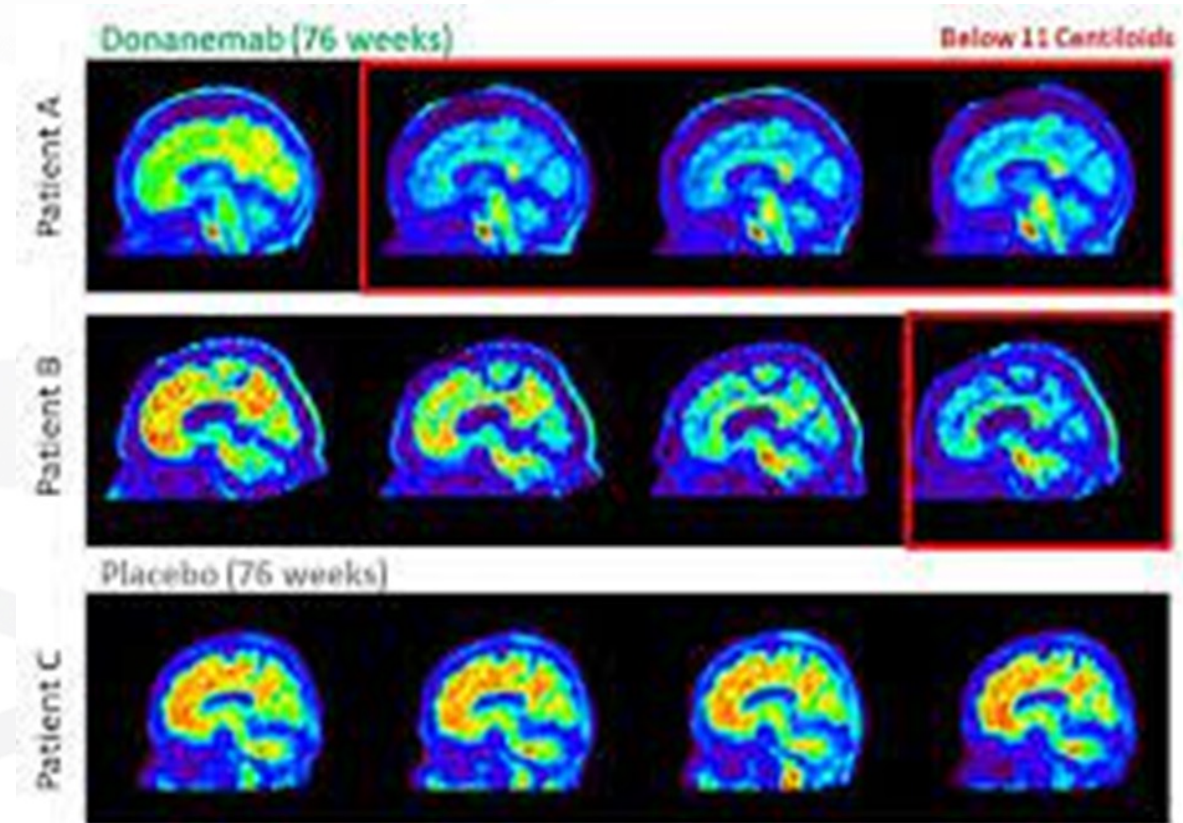
- U.S. Food and Drug Administration (FDA) granted “accelerated approval” January 6th 2023
- July 2023 the drug received full FDA approval for use in mild AD
 - Significant adverse reactions in 20%+ patients treated;
 - High costs for treatment and medical procedures;
 - Medicare coverage provided for qualifying patients.



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Success 3: Within Reach

- May 3, 2023 Phase 3 donanemab trial results released.
 - Demonstrated a 35% slower decline in memory, thinking, and ability to perform daily activities
 - Reduced brain plaque associated with Alzheimer's disease (shown here)
 - Like the other immunotherapies, donanemab carries significant adverse risks for brain edema (swelling) and micro-bleeds that can be managed
- Moving forward towards traditional FDA approval with additional data for patients on drug for 12 months



“Trail Blazer 2” Study recruited 1736 patients with either MCI or mild Alzheimer’s disease who also had abnormal levels of *both AD proteins: amyloid and tau*



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CONCERNS - AMYLOID THERAPIES

SAFETY

- ARIA-e: Brain edema/ swelling detected on MRI imaging
 - 47% aducanumab (vs 5% control)
 - 27% donanemab
 - 12% lecanemab
- Typically asymptomatic and occurs in first 3 months & resolves
- Monitor closely
- If asymptomatic, discontinue dosing until resolves

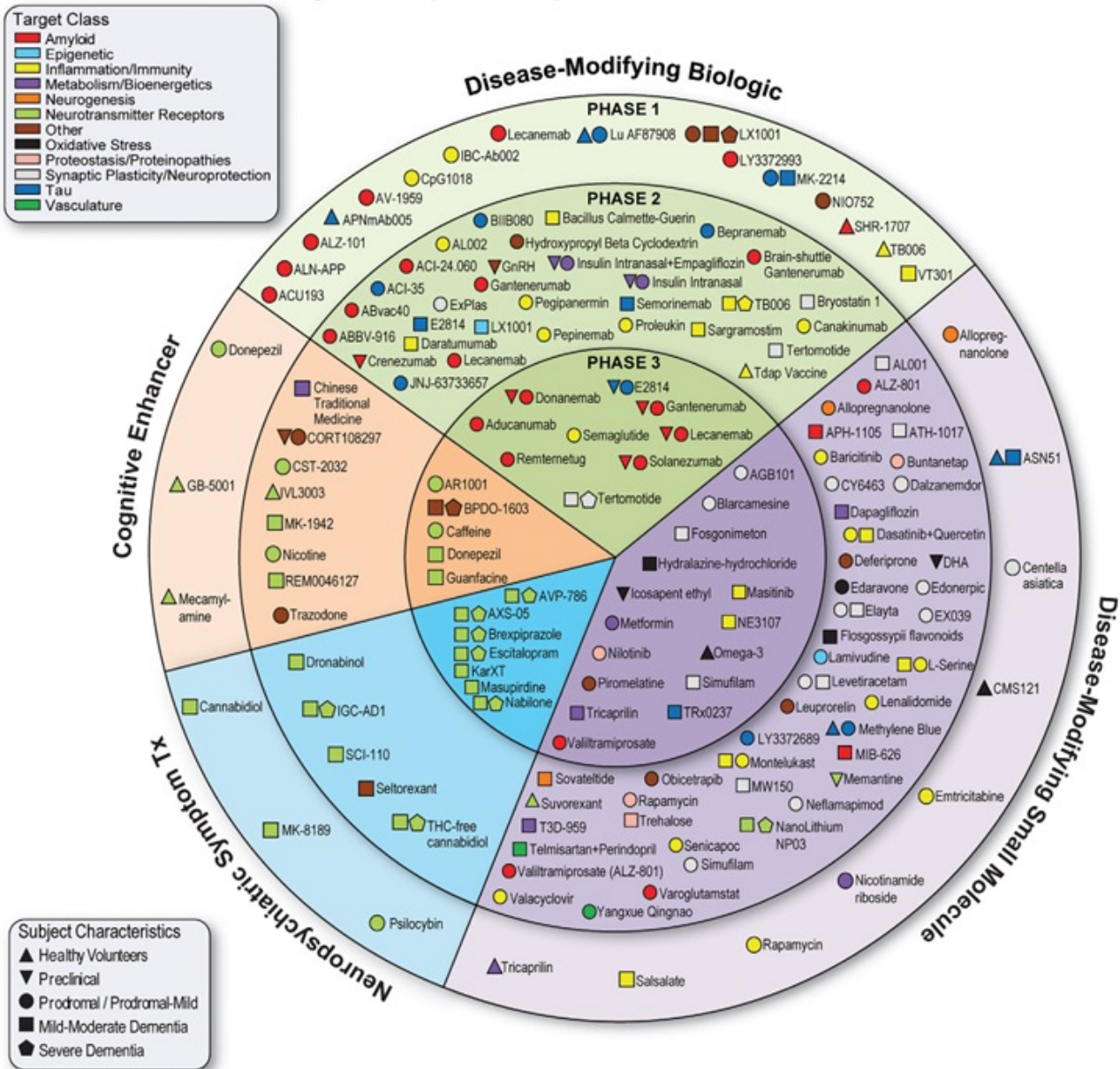
FEASIBLE/ AFFORDABLE/ ACCESSIBLE

- Typically administered with monthly infusions for 18 months or much longer
- Costly at ~\$27,000 per year
- Medicare coverage contingent on physicians entering treatment and outcome data into an electronic database



2023 Drug Development Alzheimer's Disease

2023 Alzheimer's Drug Development Pipeline



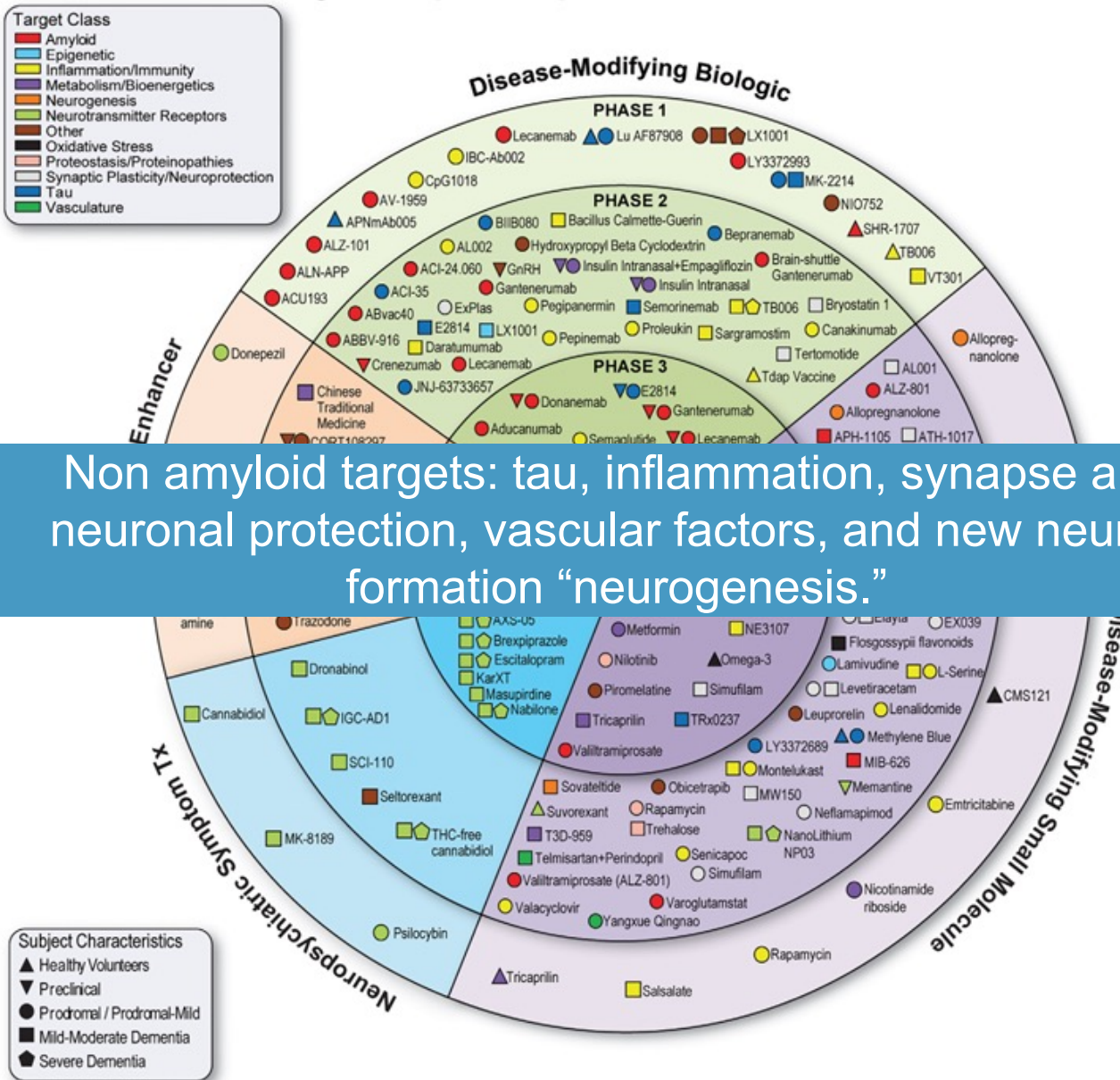
141 unique agents
187 clinical trials
36 in Phase 3 studies

Published March 14, 2023
 Cummings, J, Zhou, Y, Lee, G, Zhong, K, Fonseca, J, Cheng, F. Alzheimer's disease drug development pipeline: 2023. *Alzheimer's Dement.* 2023; 9:e12385. <https://doi.org/10.1002/trc2.12385>



2023 Drug Development Alzheimer's Disease

2023 Alzheimer's Drug Development Pipeline



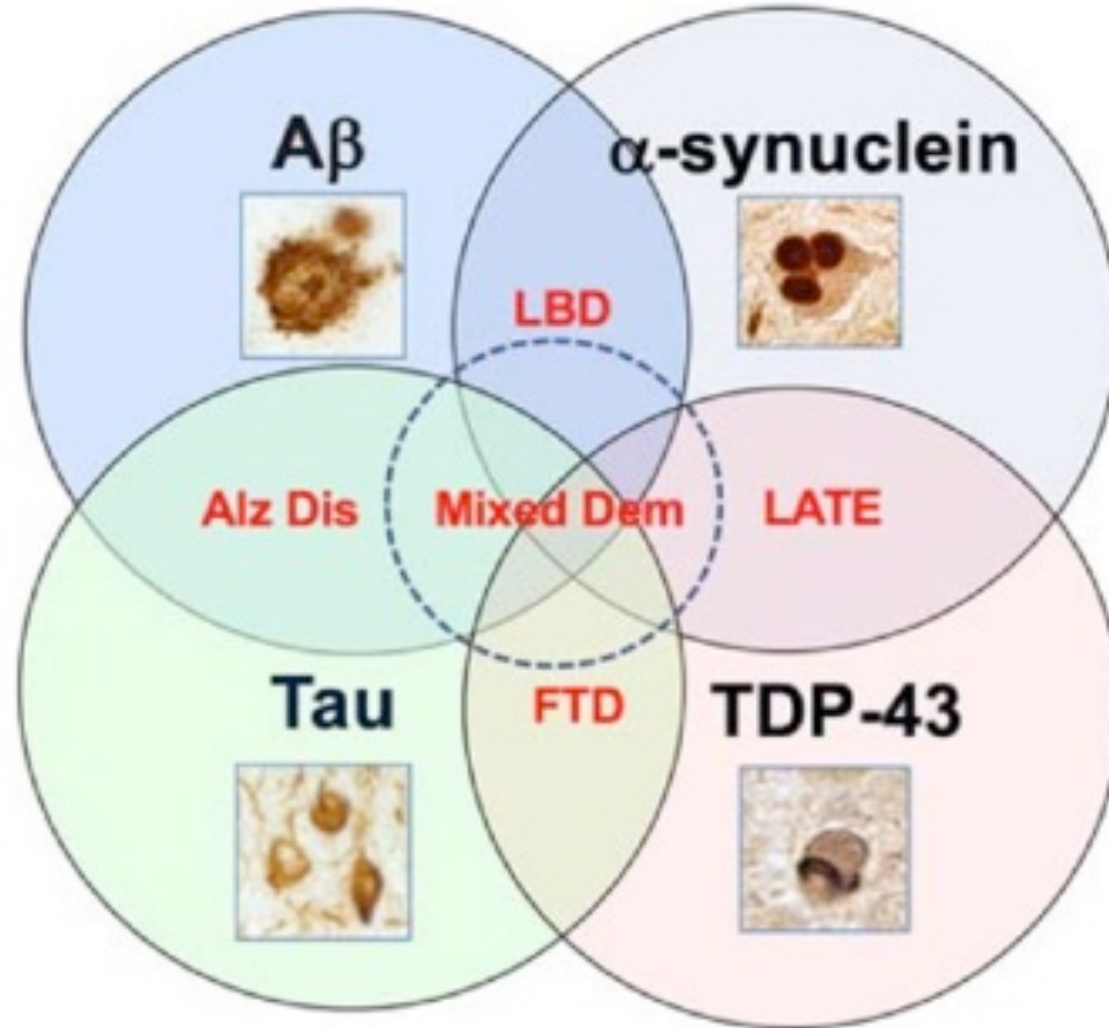
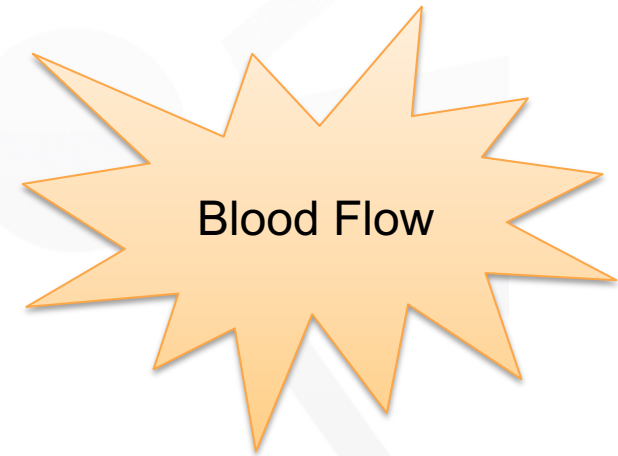
141 unique agents
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Non amyloid targets: tau, inflammation, synapse and neuronal protection, vascular factors, and new neuron formation “neurogenesis.”

Published March 14, 2023
 Cummings, J, Zhou, Y, Lee, G, Zhong, K, Fonseca, J, Cheng, F. Alzheimer's disease drug development pipeline: 2023. *Alzheimer's Dement.* 2023; 9:e12385. <https://doi.org/10.1002/trc2.12385>



Not all dementias are Alzheimer's diseaseor due to Alzheimer's disease only



Mix of pathologies that overlap lead to cell injury and cell death



Developing Effective Treatments for All

Improving Diversity in Clinical Trials

- As new therapies are developed, it is important experimental therapeutics are available to all
- And, that it is clear that these drugs will be safe and effective in all populations.
 - African Americans are two times more likely to develop Alzheimer's compared to whites. And, Hispanics are at 1.5 times higher risk than non-Hispanic whites.
 - Less than 10% of participants in most clinical trials are African American (Flores et al 2021)¹



1 Flores LE et al. (2021) Assessment of the Inclusion of Racial/Ethnic Minority, Female, and Older Individuals in Vaccine Clinical Trials. JAMA Network Open;4(2):e2037640



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Diversity in Clinical Trials

- Reasons for the imbalance and lack of population diversity within clinical trials are complex (Franzen et al 2022)²
- Health inequities, limited access to research, reluctance, historical trial injustices leading to mistrust, and rigid study designs that create obstacles to participation.
- FDA (April 2022) now requires all companies doing clinical trials to have a plan for increasing diversity before they start the work.



2 Franzen S et al. (2022). Diversity in Alzheimer's disease drug trials: The importance of eligibility criteria. Alzheimers & Dementia 18(4):810-823.



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Genetics & Alzheimer's Disease Risk

Effect sizes of disease-associated gene variants can differ between populations

APOE

- AA: 1.93 (1.72-2.17)
- EUR: 3.32 (3.20-3.45)
- JAP: 5.5 (4.4-6.9)*

ABCA7

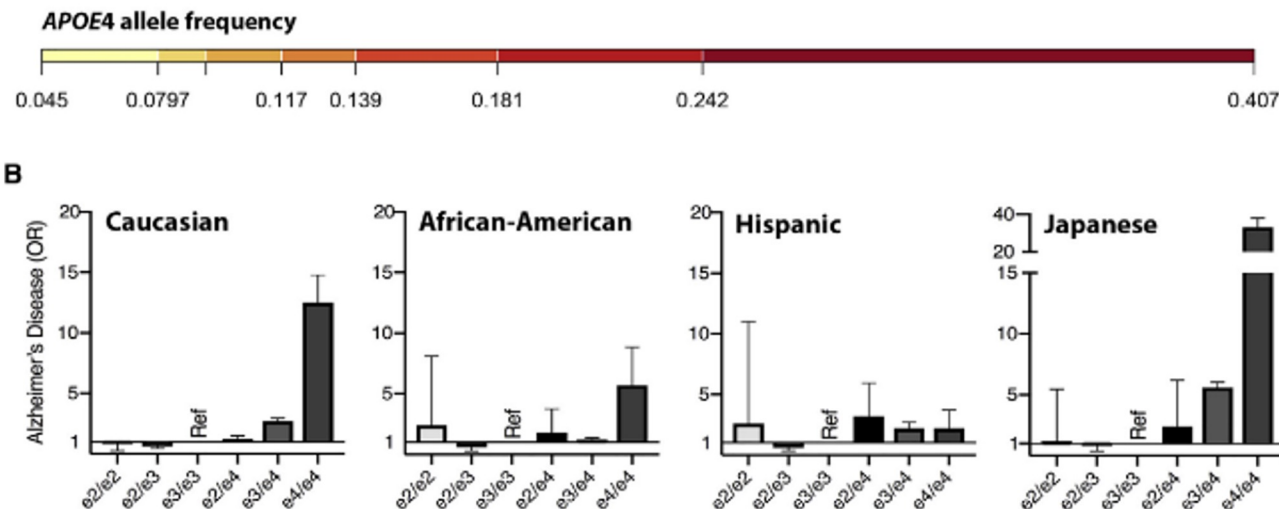
- AA: 1.41 (1.21-1.65)
- EUR: 1.13 (1.09-1.18)
- JAP: NS

SORL1

- AA: NS
- EUR: 0.81 (0.76-0.88)
- JAP: 0.75 (0.66-0.85)*



- Genes related to AD may operate differently across the world populations.
- Important to understand this as we attempt to personalize treatment.



Slide Courtesy -Alz Association: Dr Rebecca Edelmayer

Adapted from Shea Andrews and Alison Goate, Ichan School of Medicine, Mt Sinai

Preventing Alzheimer's Disease & Optimizing Brain Health



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What can we do now until there is a treatment?

Alzheimer's is a highly complex disease involving the demise of multiple brain systems, developing over a long period of time, the entire life course

As is true with other complex diseases, there is not one answer or one treatment that will be effective for all

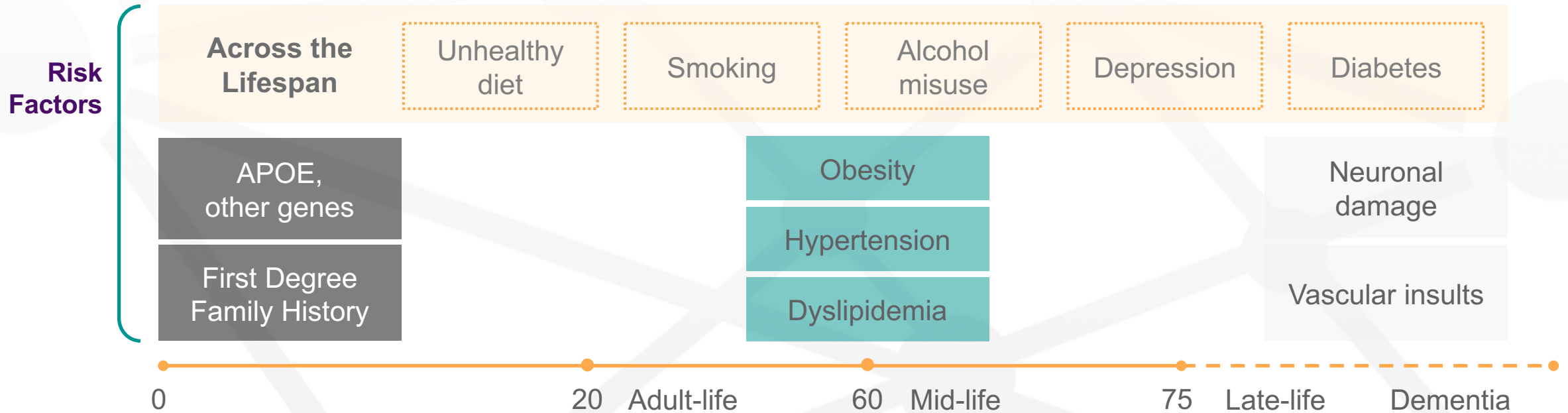
Protecting brain health is best when started early, but it is never too late to have a positive impact



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HEALTHY AND PATHOLOGICAL AGING?

Chronic Exposure
to Multiple Factors
Across the Lifespan



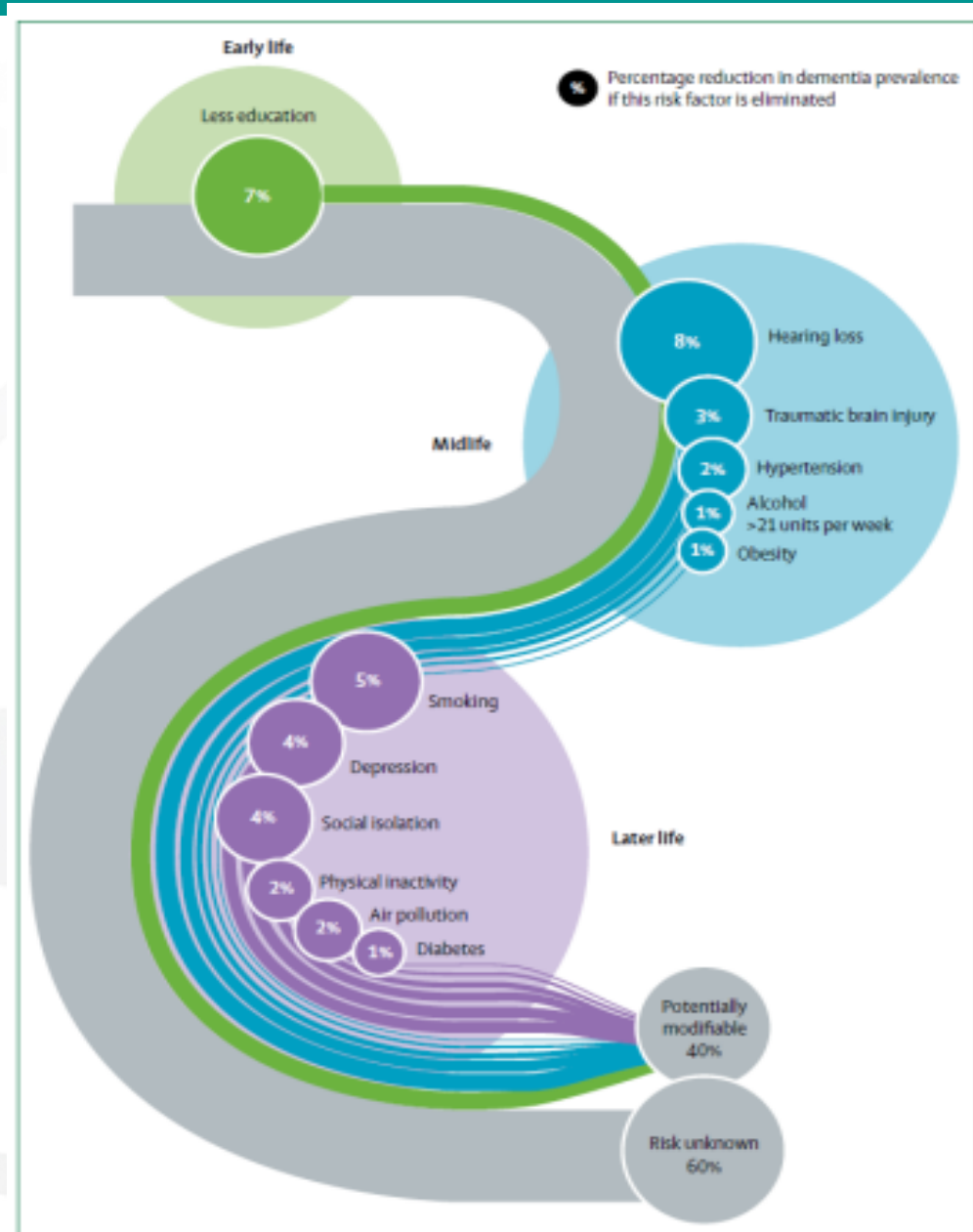
AD Risk: Genetics accounts for ~30% risk of developing AD

Non-genetic factors account for the other 70% risk. These factors impact neuron viability, inflammation, oxidative stress, glucose metabolism, endothelial cell damage, clearance of tau and b-amyloid from brain

Lancet Commission Report 2020

Modifying risk factors across
the lifespan can prevent or
delay up to 40% of dementia
cases.

Dementia prevention, intervention, and care: 2020
report of the Lancet Commission. *Lancet*. 2020 396:413-
446. doi: 10.1016/S0140-6736(20)30367-6



How do we implement changes to optimize brain health?

Seven things that can be done now to reduce risk of disease and potentially have a positive impact on memory decline & dementia progression



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Step 1: Change in Mindset- Positive & Take Control



- None of us are powerless as we age
- Responsibility to maintain health
 - Continued contributions (big or small) to the larger society, family, & friends. “Wisdom of age” and a life well-lived
- Cultural/ societal supports for active aging — Europe models
 - Delay exit from employment for those who want to work and encourage an active life following retirement

European Innovation Partnership on Active and Healthy Age (EIP-AHA). Green Paper on Ageing was adopted on 27 January 2021, COM (2021) 50 final



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Step 2: Treat What Can Be Treated



- Stop smoking
- Reduce alcohol consumption
- Management of medical conditions:
 - Heart disease & vascular risk conditions
 - Hypertension,* diabetes, high cholesterol
 - Thyroid disease
 - Sleep disorders (obstructive sleep apnea)
 - Pain, arthritis
 - Anxiety & depression
 - Sensory Impairments

Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet. 2020 8;396(10248):413-446.



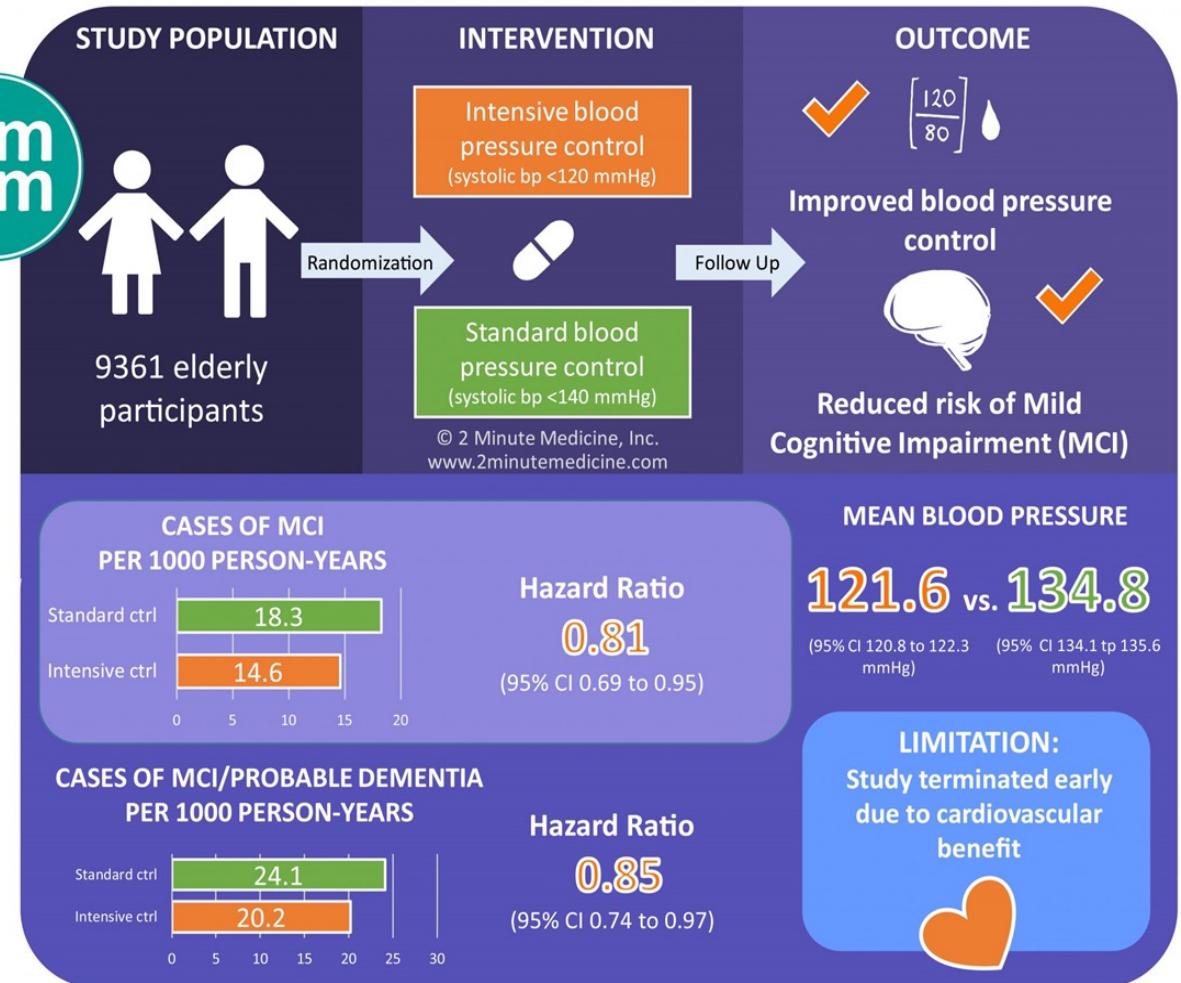
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Evidence that treating what we can treat works: Hypertension

- SPRINT & SPRINT-MIND trials
 - 9361 participants age 50+ with SBP > 130 + CVD risk factor
 - Randomized to
 - Standard BP control (target SBP <140)
 - Intense BP control (target SBP <120)
 - **Intense BP control over 5 years lowered risk of MCI/dementia by nearly 20%**



Effect of Intensive vs Standard Blood Pressure Control on Probable Dementia



SPRINT research group. JAMA. January 2019.

Step 3: Get Physically Active



World Health Organization 2020 guidelines on physical activity and sedentary behavior
Br J Sports Med. 2020; 54(24):1451-1462.

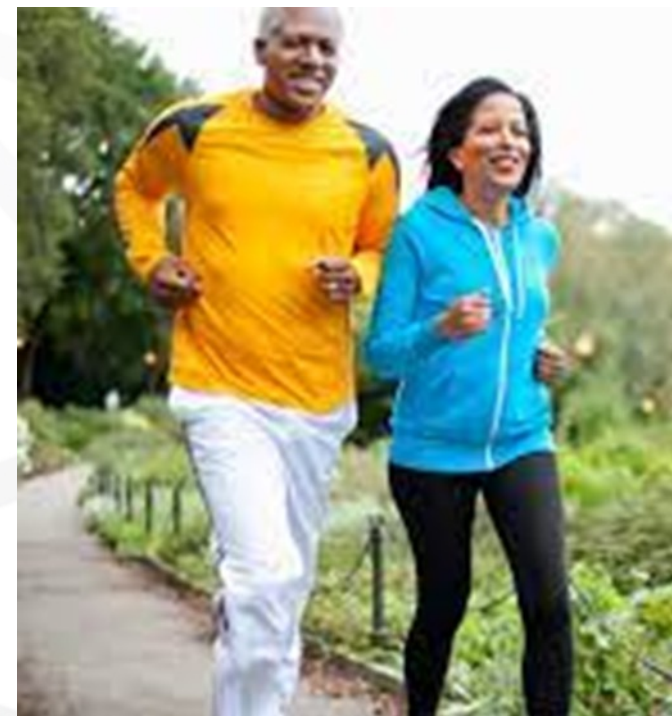
Senior Guidelines For Physical Activity	
Aerobic Exercise (walking, jogging, dancing, biking, swimming, etc.)	Older adults need moderate-intensity aerobic physical activity for a minimum of 30 minutes five days each week or vigorous intensity aerobic activity for a minimum of 20 minutes three days a week. (Moderate intensity is when you feel "warm and slightly out of breath," and vigorous is when you feel "out of breath and sweaty.")
Resistance Exercise (weight lifting, calisthenics)	Older adults will benefit from performing activities that maintain or increase muscular strength and endurance for a minimum of two days each week. It is recommended that eight to 10 exercises be performed on two or more nonconsecutive days per week using the major muscle groups.
Flexibility Exercise	To maintain the flexibility necessary for regular physical activity and daily life, older adults should perform activities that maintain or increase flexibility at least two days each week for at least 10 minutes each day.
Balance Exercise	To reduce risk of injury from falls, older adults with substantial risk of falls (for example, with frequent falls or mobility problems) should perform exercises that maintain or improve balance.



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Exercise & Dementia

- The World Health Organization named “physical activity” as the highest priority, non-pharmacological intervention with potential to **reduce dementia risk**
 - Meta-analysis of 19 studies (17 randomized clinical trials) concluded that exercise delays cognitive decline in people with MCI
 - Observational data from humans and animals point to mechanisms: improvements in:
 - brain structure
 - brain tissue function
 - biomarkers associated with dementia



Panza GA et al. J Am Geriatr Soc. 2018 Mar;66(3):487-495. doi: 10.1111/jgs.15241



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Exercise & Dementia

- Inconsistent evidence on whether it is possible to **prevent** MCI or dementia by exercising
- Meta-analysis of 5 RCTs found no significant effects
 - Strongest evidence for **aerobic exercise**¹
- Recent multi-site RCT in very mild MCI & subjective concerns (EXERT;18 months)²
 - Saw positive effects across both exercise arms
 - Biomarker data under analysis



¹De Souto Barreto, P et al., (2018). Exercise training for preventing dementia, MCI, and clinically meaningful cognitive decline: A systematic review and meta-analysis. J Gerontol A Biol Sci Med Sci.73(11):1504-1511

² Baker L, et al (2022) . Topline Results of EXERT: Can Exercise Slow Cognitive Decline in MCI? Presented at the Alzheimers Association International Conference.July 2022.



Step 4: Watch What You Eat!

- Many observational studies report lower dementia risk associated with diet types (e.g., Mediterranean diet & MIND diet) or specific nutrients
- Mechanism unclear but these diets confer broad health benefits that protect against brain injury:
 - Anti-inflammatory effects
 - High antioxidant properties
 - Pro-metabolic effects
 - Lower lipids
 - Offer protection from cardiovascular disease
 - Modulate intestinal microbiome in healthy ways



Singh et al (2014). *J Alzheimers Dis.* 2014;39(2):271-82;
Fu et al (2022). *Front Nutr.* 2022 Jul 28;9:946361

Diet & Dementia Risk

- Meta-analysis of 15 RCTs with dietary interventions found a significant effect on cognitive performance (*McGrattan et al 2018. Brit J Nutr*)
 - Supplements do not confer the same advantage (*Wengreen et al 2013 Amer J Nutr*)
 - Effect seen across cultures (*Moustafa et al 2022 JAMA*)
 - World Health Organization recommends vitamins and nutrients obtained from balanced diet, not supplements



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Step 5: Work Your Brain—Engage it in Novel Ways



- Learning new things creates new brain connections
- If it involves movement & activity with others, all the better!
- Protects brain, buffering against damage in the same circuits affected by disease

Peterson RL, et al.(2020). *Alzheimers Dement* (N Y). 6(1):e12047.

<http://doi.org/10.1002/trc2.12047>

Cognitive & Social Engagement and Dementia Risk

- Engaging with others is a natural way to cognitively engage
 - Social engagement taps multiple cognitive domains (e.g., attention, memory, planning, language) and can bring with it positive emotional elements
- Low social engagement and loneliness are both linked to dementia risk & cognitive decline.
- Groups at high risk include:
 - Widows, caregivers
 - People in rural settings
 - Individuals from groups that have been targeted or marginalized



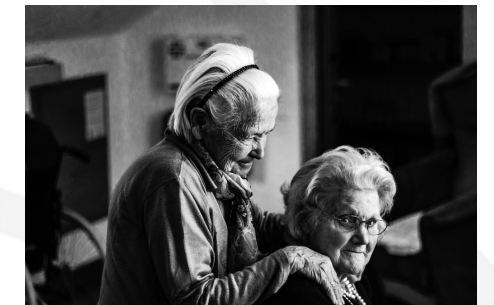
Fancourt D, et al (2020). Community engagement & dementia risk. *J Epidemiology Community Health* 74:71-77;
Marioni RE et al (2015) Social activity, cognitive decline, & dementia risk. *BMC Public Health* 15:1089.



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Step 6: Stress Reduction and Caring for Your Emotional Health

- Growing evidence from animal models that stress hormones contribute to risk of cognitive decline and dementia
- Sleep often affected by stress but is crucially important for reducing toxic molecules including beta amyloid
- Methods for reducing stress:
 - Social engagement
 - Outdoor activity
 - Pet therapy
 - Meditation/prayer
 - Yoga /mindfulness
 - Close personal connections/ support groups



Gothe et al 2013 Yoga trial in older adults. J Gerontol 9:1109.

Lucey BP et al. (2018) Effect of sleep on overnight cerebrospinal fluid amyloid β kinetics. Ann Neurol. 2018 Jan;83(1):197-204.

Step 7: Be a Part of the Solution—Participate in Research!

- Medical science has come a long way in the last 30 years
 - But still no cure for Alzheimer's disease and other dementias
 - And in all likelihood there will not be just one solution or one treatment
 - Different treatments for different stages of disease- early & late
- Preventing Alzheimer's disease and other dementias can only come with further research
 - Need help from everyone so that answers and treatments are based on the full population at risk of dementia
- Getting involved in clinical research is a proactive step to brain health



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DO ALL SEVEN THINGS!

MULTIDOMAIN INTERVENTIONS ARE EFFECTIVE TREATMENT



Ngandu, T., et al (2015) FINGER. *Lancet* 385: 2255–2263

○ US POINTER STUDY

- Builds off of study in Finland FINGER showing merits of combined approach
- 2 year lifestyle intervention trial targets simultaneously a number of risk factors to protect cognitive function
- 2000 older adults; completed enrollment in March 2023
 - Sites in Chicago, Rhode Island, Texas, California & NC (Wake Forest!)
 - Sub-studies include sleep, neurovascular, imaging, & microbiome



NC Registry for Brain Health

Getting Involved in Research



NC Registry for Brain Health

NC Registry for Brain Health (www.ncbrainhealth.org)



NC Registry for Brain Health

phone: 919.613.8633



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TOGETHER
We Can Improve Brain
Health and Defeat
Dementia



[Click Here to Join](#)



What is a research registry?

A registry collects information from people who ***might*** want to be in research studies or learn more about current research that they may be eligible for.



NC Registry for Brain Health

What is the NC Registry for Brain Health?

The “Registry” is a group of people across North Carolina interested in news to improve brain health and research to advance the treatment of dementias such as Alzheimer’s disease and other memory disorders.

Funded by the State to increase access to information and to research studies to improve brain health


FREE!!



NC Registry for Brain Health


Who We Are: Impact Across the State of NC

THE REGISTRY – PEOPLE AND PLACES




Wake Forest School of Medicine
WINSTON-SALEM, NC

Researchers at Wake Forest School of Medicine combine medical research with community engagement at the Maya Angelou Center for Health Equity.




Duke University
DURHAM, NC

Duke University partners are building on the Alzheimer's Disease Prevention Registry to create a new statewide registry.




NC A&T State University
GREENSBORO, NC

Researchers from NC A&T University link science and community at the Center for Outreach in Alzheimer's, Aging and Community Health (COACH).



UNC-Chapel Hill
CHAPEL HILL, NC

Our partners at UNC-Chapel Hill include the UNC Memory Disorders Program and the Carolina Alzheimer's network.



East Carolina University
GREENVILLE, NC

East Carolina University combines expertise in neurology and brain disorders with commitment to improving health for future generations.

Who's joined so far? (October 16, 2023)

Total enrollees: 11,314

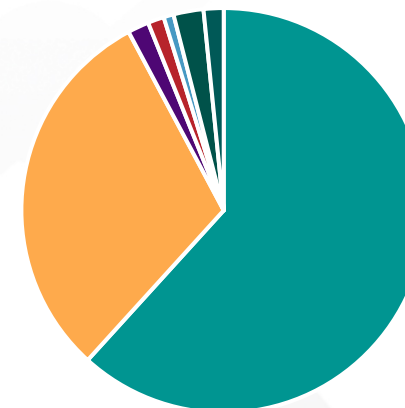
Race (check all that apply)

7177 (63.4%)	White
3293 (29.1%)	African-American/Black
205 (1.8%)	Multi-racial
193 (1.7%)	Unknown
146 (1.3%)	Asian
182 (1.6%)	Other
115 (1.0%)	American Indian/Alaska Native
4 (0.0%)	Native Hawaiian/Other Pacific Islander

Do you have any Hispanic or Latino Ethnicity?

10,083 (89.1%)	No
399 (3.5%)	Yes
605 (5.4%)	No response
227 (2.0%)	Don't know

Racial Demographics



■ White ■ AfrAm ■ Multi ■ Asian ■ Native Am ■ Unknown ■ Other

What is the highest level of school you have completed?

1998 (17.6%)	Unknown
3137 (27.7%)	Graduate degree
2715 (24.0%)	4-year college degree
2354 (20.8%)	Some college or Associate's
967 (8.5%)	High School graduate
168 (1.5%)	Less than HS diploma



NC Registry for Brain Health

Who's joined so far? (October 9, 2023)

Total enrollees: 11,314

Gender

8353 (73.5%)	Female
2923 (25.9%)	Male
14 (0.1%)	Nonbinary
13 (0.1%)	No response
2 (0.0%)	Transgender
2 (0.0%)	Transgender male
2 (0.0%)	Transgender female

Gender



Age (approximate)

23 (0.2%)	100s
315 (2.8%)	90s
1568 (13.8%)	80s
3297 (29.1%)	70s
3008 (26.6%)	60s
1275 (11.3%)	50s
707 (6.3%)	40s
403 (3.6%)	30s
263 (2.3%)	18-29s
455 (4.1%)	Unknowns

Age



18 - 29	30 - 40+	50's
60's	70's	80's
90 - 100+	Unknown	



NC Registry for Brain Health

Some Types of Studies

- Studies of how lifestyle change may reduce risk and slow down disease
- Clinical trials examining medications that might work to improve memory functioning or slow decline
- Studies of new technologies to help better identify early signs of disease



Duke/UNC Memory & Aging Study



THE DUKE/UNC ALZHEIMER'S DISEASE RESEARCH CENTER IS CONDUCTING A STUDY ON MEMORY AND AGING

We're especially interested in learning from people who have a parent or sibling with dementia that started before age 80.

You may be eligible to participate if you:

- are between the ages of 45 and 80, with or without memory loss.
- are willing to attend yearly visits that include brain imaging (MRI) and memory evaluations.
- have a study partner who knows you well and can answer questions about your memory and daily activities.
- are willing to provide a one-time spinal fluid donation. Watch our informational videos at <https://dukeuncadrc.org/join-our-study>.

You and your study partner will be paid for participating.

FOR MORE
DETAILS OR TO
FIND OUT IF YOU
MAY BE ELIGIBLE
TO PARTICIPATE,
PLEASE CONTACT:

(919) 668-0281

adrc@duke.edu

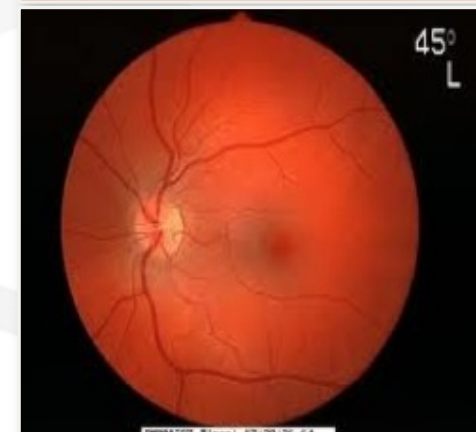
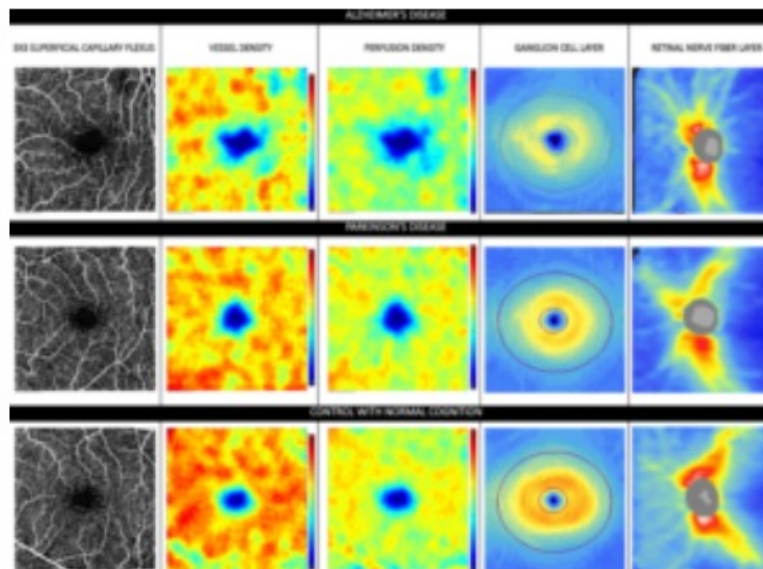


Duke Studies: Retinal Imaging to Detect AD

We are recruiting cognitively healthy adults over 18 years old for a study to take non-invasive pictures of the retina in your eyes. No X-rays and no eye drops. Compensation for time/travel.

You may be eligible for this research study if you:

- Do not have Alzheimer's, frontotemporal dementia, mild cognitive impairment, Parkinson's, Down syndrome, multiple sclerosis, PTSD, traumatic brain injury, or another dementia or neurodegeneration
- Have not had prior retina surgery
- Are willing to have some undilated pictures of your retina



NC Registry for Brain Health



Volunteers needed for the PACT research study to see if computerized training exercises reduce risk of Alzheimer's disease.

Study participation takes about three years and includes 3 study visits of up to 2 hours each. You will also complete 45 hours of computerized training exercises.

You may qualify if you:

- Are 65 years of age or older
- Do not have any neurological disorders
- Have not had a stroke or brain injury
- Do not have mild cognitive impairment or dementia such as Alzheimer's disease

Please contact the PACT study location nearest you for more information:

919.668.3154
Durham

www.PACTstudy.org

PI: Brenda Plassman, WIRB® Protocol #20182630



DukeHealth

Duke Study—“ PACT”

Preventing Alzheimer's with Cognitive Training



NC Registry for Brain Health

NC Registry for Brain Health- Challenges

- Mostly Women
- Mostly Educated
- Need more ethnically diverse populations
- Need to assure we are reaching rural, communities with disadvantage
- Those who successfully enroll in research are White - 89%
- Sex and Gender Minorities
- Indicate need for science of enrolling and recruiting into studies



NC Registry for Brain Health

CONCLUSIONS

After 30 years of investment, we now have

- **Diagnostic tools**, imaging & fluid biomarkers, opening up the opportunity for early identification of Alzheimer's disease and early intervention
- **Disease modifying therapies** to slow the disease once it has started and many more compounds in the pipeline targeting different biological mechanisms offering the potential to treat patients from early to late stage disease



NC Registry for Brain Health

CONCLUSIONS

○ Evidence based life-style approaches that we each can use to improve brain health

- Positive mindset & taking control of health; treat what can be treated; maintain healthy diet; get regular daily exercise; attend to stress reduction, emotional health & sleep; remain socially and cognitively engaged

○ Continuing research to accelerate a cure

- Partnering in research includes a need for everyone to get involved. With better diversity and inclusion in research, we will have scientifically well informed treatments positioned to benefit all people affected



NC Registry for Brain Health

**BE INFORMED
GET INVOLVED
JOIN THE NC REGISTRY FOR BRAIN HEALTH
GO TO [NCBRAINHEALTH.ORG](https://ncbrainhealth.org)**



NC Registry for Brain Health



THANK YOU
QUESTIONS AND
DISCUSSION

Duke dementia family support program

Caregiver Connections

An Educational Webinar Series With The Experts

Thank you for joining us today!

dukefamilysupport.org

919-660-7510



NC Registry for Brain Health