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MEDICINE

November 18, 2023

Dear Journey to Hope Participant:

Welcome to the 16th Annual Journey to Hope Conference on Memory Loss. We have a great line up of speakers and participants including Johns Hopkins University faculty members, memory care experts, community leaders, and Memory Center families.

Below are details regarding the event logistics, we hope you find this information helpful.

1. **Please turn off/silence all cell phones.**

2. **Recording devices are prohibited: tape recorders, video recorders, and cameras are not allowed.**

3. **Restrooms are located on the left hand side behind the double doors on the 1st floor.**

4. **Free parking vouchers will be given out to each driver at registration.**

5. **Event Packets include:**
   - Event Agenda
   - **Event Evaluation form - please return evaluation forms to a volunteer staff person at the end of the conference. Your comments are very important to us and helps us in planning next year's event**
   - Speaker PowerPoint handouts
   - Information on Alzheimer's disease/memory loss
   - List of Exhibitors
   - List of abbreviations
   - Patient Family Advisory Council (PFAC) form
   - Research form

6. **During the break, please visit our exhibitors for information on health resources.**

7. **Please give the following to a staff member or PFAC member:**
   - ☐ **Research and PFAC forms**
   - ☐ **Event Evaluation forms**

Sincerely,
The Journey to Hope Planning Committee

Agenda

8:30 a.m. — **Registration & Continental Breakfast**

9 a.m. — **Welcome: Conference Overview and Goals**

Constantine Lyketsos, M.D., MHS
Director, Johns Hopkins Memory & Alzheimer's Treatment Center;
Director, Department of Psychiatry and Behavioral Sciences, Johns Hopkins Bayview

Introduction of Patient-Family Advisory Council & Exhibitors

Andrea Nelson, RN, MSN
Director, Memory Care Programs, Johns Hopkins Memory & Alzheimer's Treatment Center
Director, Patient-Family Advisory Council

9:15 - 10:15 a.m. — **Keynote Presentation: New Treatments for Alzheimer's**

Paul Rosenberg, M.D.
Co-director, Johns Hopkins Memory & Alzheimer's Treatment Center
Professor of Psychiatry and Behavioral Sciences, Johns Hopkins School of Medicine

10:15 - 10:30 a.m. — **Gaga Gentle Movement Chair Flow**

Mica Saunders, *Senior Enrichment Specialist and Body Chemist*

10:30 - 11 a.m. — **Break**

11 - 11:10 a.m — **Presentation of 2023 Trailblazer Award**

Emily Kearns, *Coordinator, Dementia Friendly Baltimore, Baltimore County Department of Aging*

11:10 - 12 p.m. — **Panel Discussion – Coordinating Care Near and Far**
Moderated by Andrea Nelson, RN, MSN, Director, Memory Care Programs

Janet Michel, *Member, Patient Family Advisory Council*
Jane Marks, *Associate Director, Johns Hopkins Geriatric Workforce Enhancement Program*
Marina Nellius, LCSW-C, *Social Work Manager, Mid-Atlantic South, Landmark Health*
Jessica Young, BS, CDP, *President/Aging Life Care Manager, Ferretto Young Care Management Consulting*

12 - 1 p.m. — **Lunch**

1 - 1:10 p.m. — **Presentation of 2023 Pioneer Award**

Cass Naugle, *Executive Director, Alzheimer's Association, Greater Maryland Chapter (1986-2020)*

1:10 - 1:55 p.m. — **Ask the Expert with Constantine Lyketsos, M.D., MHS**
Moderated by Andrea Nelson, RN, MSN

1:55 p.m. — **Call to Action**

Russell Kempner and Karen Paide, *Patient-Family Advisory Council Members*

Closing Remarks

Constantine Lyketsos, M.D., MHS, & Andrea Nelson, RN, MSN

New Treatments for Alzheimer's disease (AD)

Journey to Hope

November 18, 2023

Paul B. Rosenberg, M.D.
Professor of Psychiatry and Behavioral Sciences
Division of Geriatric Psychiatry and Neuropsychiatry
Johns Hopkins University School of Medicine

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Disclosures

- Research support
  - Lilly, Eisai, National Institute on Aging, Alzheimer's Association, Functional Neuromodulation (FNMI), Alzheimer's Disease Cooperative Study (ADCS), Alzheimer's Disease Trials Research Institute (ATRI), Alzheimer's Clinical Trials Consortium (ACTC), Richman Family Precision Medicine Center of Excellence on Alzheimer's Disease
- Consulting/advisory boards
  - Acadia, Biogen, ExpertConnect, GLG, Guidepoint, HMP Global, Leerink, Lundbeck, Medalink, MedaCorp, Medscape, Novo Nordisk, Noble Insights, TwoLabs
- DSMBs,
  - Synaptogenix
- CME presentations
  - Neurology Week
- No royalties, patents, stock

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Agenda

- What is Alzheimer's disease (AD)?
- Diagnosis and symptoms of AD
- What can **you** do to prevent cognitive decline?
  - Lifestyle strategies
- Medications for Alzheimer's
  - Old
  - New
  - On the horizon
- Social determinants of health and cognitive decline

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Impact of Dementia

- Dementia currently afflicts 6.2 million in USA
  - 18-20 million worldwide
- Projected to increase to 13.8 million patients by 2060
  - In Asia, prevalence will increase 10-fold or more
- Between 2000 and 2019, deaths from stroke, heart disease and HIV decreased, whereas reported deaths from AD increased more than 145%. This trajectory of deaths from AD was likely exacerbated in 2020 by the COVID-19 pandemic.
- Annual U.S. costs of ~$355 billion annual health care costs for treatment of dementia and ~$256 billion in unpaid care by > 15 million family members
- If we can delay onset by 5 years we can cut prevalence and health burden **by half**

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How can I tell dementia from normal cognitive changes of aging?

Normal aging

- Occasional trouble finding words
  - Particularly words less commonly used
- Occasional difficulty learning new names
- Slower processing speed
- Occasional problems learning to use new electronic devices
- **No change in functional abilities**

Dementia

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks
- Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood, personality and behavior

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Causes of dementia

Etiology	Prevalence
Alzheimer's Disease	60-70%
Vascular Dementia	10-15%
Mixed Dementia	10-15%
Dementia with Lewy Bodies	5-10%
Frontotemporal Lobe Dementias	5-8%

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WHAT IS ALZHEIMER'S DISEASE?

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Alzheimer's Disease: Pathophysiology

- AD has a complex neurobiology
- Changes in amyloid beta-protein (Aβ) are the first detectable changes
- Tau protein changes are associated with brain atrophy and cognitive decline
- Inflammation and oxidation appear to have important roles in AD

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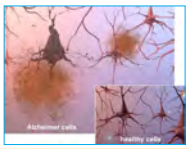
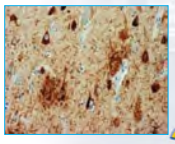
Plaques and Tangles: Hallmarks of Alzheimer's Disease

The brains of people with AD have an abundance of 2 abnormal structures:

Beta-amyloid plaques, which are dense deposits of protein and cellular material that accumulate outside and around nerve cells



Neurofibrillary tangles, which are twisted tau fibers that build up inside the nerve cell



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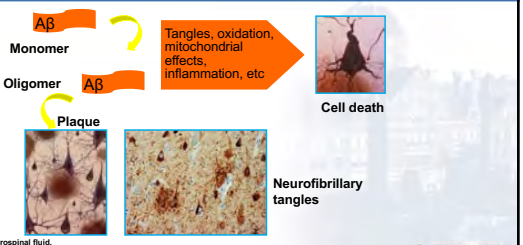
Amyloid Initiates a Complex Cascade of Events



Aβ = amyloid-β; CSF = cerebrospinal fluid.
Reitz C. *Int J. Alzheimers Dis.* 2012;2012:369808; Serrano-Pozo A et al. *Cold Spring Harb Perspect Med.* 2011;1:9006189. ©J Cummings. 2012.

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Risk factors for AD

- Age (by far the strongest risk factor)
  - 65-74 years 5.3% prevalence
  - 75-84 years 13.8%
  - > 85 years 34.6%
- Less education
- ApoE4 allele
  - Increases risk but not causative
- A long list of new candidate genes
  - each adds a small amount of risk
  - many involved with inflammation and cell-cell signaling
- Less exercise
- Higher BMI, cholesterol, BP (midlife)
- Hearing loss

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DIAGNOSIS AND SYMPTOMS OF AD

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AD Clinical features

- Time course
  - Pre-clinical, early clinical (MCI), dementia
  - Gradual onset, slow progression
    - Often not so slow and with fits and spurts
- Characteristic signs and symptoms
  - Tends to start with memory problems
  - Moves on to problems with language, recognizing things and people
  - Functional decline
  - Neuropsychiatric symptoms
    - Depression
    - Agitation
    - Apathy
    - Anxiety

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Cognitive changes in AD

- Episodic recall
  - What happened minutes, hours, days ago
  - Very different from remote memory
  - Requires *encoding*, then later on *retrieval*
  - AD starts with deficit in encoding
    - Probably associated with hippocampal damage
    - Which can *sometimes* be seen on MRI
- Aphasia
  - Problems with word-finding
- Agnosia
  - Not recognizing things, places or people
- Apraxia
  - Problems with coordination

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Loss of function (IADLs)

- Driving
  - Getting lost
  - Poor judgment
  - Tickets
  - MVAs
- Bill paying
  - Problems balancing checkbook
  - Problems tracking bills
- Cooking
  - Losing track of time, sequence
  - Wrong ingredients
- Appointments
  - Use of notes, calendar, Post-it Notes, smartphone
  - Have to remember to use the aids!
- Work

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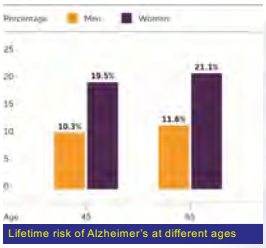
Alzheimer's more prevalent in women



Lifetime risk of Alzheimer's at different ages

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AD more common in Nonwhite Americans

- Black Americans' risk of dementia about 2X that of White Americans
- Hispanic American risk about 1.5X greater
- The differences most likely due to social determinants of health such as access to quality health care and healthy diet
- Genetic influences are different in blacks and amyloid less common
- Drives home the importance of controlling cardiac risk factors

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Caregiver burden

- "Caregiver is the customer"
- Huge burden on families
- Emotional
  - Frustration
  - Guilty
  - Loss of independence
- Financial
  - Unpaid time
  - Loss of work
  - Long-term care
- Health
  - Caregivers delay care

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Who are the caregivers?

- Approximately two-thirds of dementia caregivers are women.
- About 30% of caregivers are age 65 or older.
- Over 60% of caregivers are married, living with a partner or in a long-term relationship.
- Over half of caregivers are providing assistance to a parent or in-law with dementia.
- Approximately 10% of caregivers provide help to a spouse with Alzheimer's disease or another dementia.
- Two-thirds of caregivers are White, 10% are Black, 8% are Hispanic and 5% are Asian American.
- Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers — meaning that they care not only for an aging parent, but also for a child.
- Well over half (57%) of family caregivers of people with Alzheimer's or other dementias living in the community had provided care for four or more years

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WHAT CAN YOU DO TO PREVENT AD?

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Healthy lifestyle may prevent cognitive decline

There's good evidence for all the interventions listed below!

- Exercise (especially aerobic)
- Diet (Mediterranean)
- Brain training
- Cardiac health
- Leisure activities
  - Have a variety of activities that include socialization
- Treat depression
- Pay attention to hearing
- Music!
- I've shared a summary/handout in your folders

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Exercise

- Aerobic exercise associated with lower risk of incident dementia in many epidemiologic cohorts.
- Also associated with *increased* hippocampal volume
- Clinical trials results are mixed to date
- The data more point towards the value of **aerobic exercise** rather than strength training or stretching
- Evidence for benefit of T'ai Chi and it's easy for older persons to engage
- Sedentary people seem to benefit the most
- **So get up from the couch and take a walk!**

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Diet

- Most dementia is actually 'mixed' Alzheimer's-vascular
- So the same interventions that work for heart health probably will work for brain health
- Mediterranean diet (see handout) is a low-saturated-fat diet
  - Substituting olive oil, chicken, fruits and vegetables for beef and butter
  - Shown to reduce cardiac mortality
  - And there is evidence for preventing dementia
- MIND diet (see handout) is basically Mediterranean diet with more antioxidants
  - Berries, especially blueberries

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Brain Training

- There is some evidence that brain training helps cognition in older persons with intact cognition
- Less convincing in early AD
- Many companies making money selling "brain training"
  - Lumosity shares results with researchers
  - BrainHQ has some promising results
  - More info in your handout
- Fits in with education being protective

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Cardiac Health

- As above, 'what's good for the heart is good for the head'
- **Midlife** cardiac risk factors increase risk of dementia in **late life**
  - High blood pressure
  - Smoking
  - Obesity
  - Elevated cholesterol
- Lowering blood pressure in **late life** also slows down cognitive decline
  - Note that a few years ago the recommendations for blood pressure went down to < 120/80
  - Lower cardiac mortality and probably reduced risk of dementia

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Leisure activities and socialization

- Both associated with lower risk of dementia
- Broader/wider social network
- Having a variety of leisure activities that involve **socialization**
- Volunteer work
- Activities that combine mind/body activities
- Dancing (!)

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Depression

- Many people have depression and anxiety as a precursor to AD
- But does treating depression and anxiety prevent AD?
  - Verdict still out
  - One study reported antidepressants appeared to prevent dementia
  - I'm doing a clinical trial of psychotherapy in MCI + depression
- No prevention trials to date

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Hearing and vestibular function

- A very promising target!
- Hearing loss associated with incident MCI and dementia
- Hopkins is doing research on hearing aids (for hearing) and physical therapy (for balance and vestibular function) to improve cognition
- Hearing aids now available OTC and therefore much less expensive (see handout)

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Music

- Full disclosure: I'm biased because I play jazz piano and love it
- People with dementia often retain the ability to process and appreciate music even if they've lost some of their language skills
  - Different parts of the brain (left-sided = language, right-sided = music)
- But also evidence that listening to music can improve cognition in cognitively normal adults
  - Might work for prevention
- Evidence that **playing an instrument** may be especially helpful

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Sleep

Behavioral
- Sleep hygiene
  - Calm, quiet, dark environment
  - Minimize caffeine
  - Daytime exercise
  - Minimize naps (if extreme)
    - Daily nap is normal
- Look for medical cause

Medications
- Antipsychotics if "sundowning" and agitation associated with insomnia
- Trazodone 25-50 mg
- Mirtazapine (Remeron) 7.5-15 mg
- Ambien 5 mg (watch for delirium, ataxia)
- Suvorexant
  - Orexin antagonist

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Nonpharmacologic interventions for psychological symptoms of dementia

- Reassurance
- Redirection
  - Fundamental intervention is distraction
- Pleasurable activities
  - Music
    - Listening
    - Playing music
  - Socializing
  - Games
  - Videos
  - Telling stories
  - Visiting with family
- Therapeutic Activity Program (TAP)
  - Other Occupational Therapy interventions
- Art Therapy
- Cognitive Interventions
- Animal-assisted therapy
- Physical Therapy
- Multi-sensory/Snoezelen
- Aromatherapy
- Reminiscence
- Virtual Reality

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MEDICATIONS FOR AD

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Overview of current FDA-approved medications for AD

- I use **cholinesterase inhibitors** at all stages
  - **Donepezil** (Aricept), **rivastigmine** (Exelon), **galantamine** (Razadyne)
  - Little to choose between them
  - Buys 6-12 months' delay in cognitive decline
  - Notable idiosyncratic positive responses!
  - Consider Exelon patch to minimize GI side effects
  - Safety issues are becoming clearer:
    - wary of bradycardia, falls, fractures
  - May be useful for neuropsychiatric symptoms
- **Memantine**
  - Different mechanism
  - I use only in moderate-severe AD

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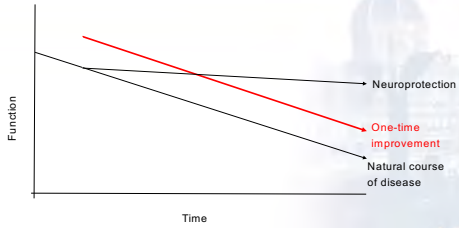
Neuroprotection vs. one-time improvement



We are still looking for our first neuroprotective agent for AD!

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Anti-amyloid antibodies for AD

- Studied in humans for 15-20 years
- Several early failures
  - Solanezumab (Lilly), gantenemurab (Roche), crenezumab (Genentech)
  - Along with failure of amyloid enzyme inhibitors (gamma-secretase and BACE inhibitors)
- Newer antibodies target plaques, not monomers
- **Our first effective disease-modifying treatments for AD**
- Very efficiently remove amyloid
  - To the point where amyloid is 'gone'
- Concomitant clinical improvements
  - But not nearly as impressive as the amyloid removal
- Concomitant side effects
  - ARIAs (amyloid-related imaging abnormalities)

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Lecanamab
Brand Name: Leqembi (Eisai)

- Antibody that binds to amyloid plaques
- Very effective in removing amyloid
  - 50% of patients have no amyloid left after 1 year of treatment
- Pivotal trial (CLARITY) showed clinical benefit in several ways
  - Cognition
  - Daily function
- But the benefits must be weighed against the risks
- FDA approved 7/6/23
- Medicare says they will cover the costs
  - But still many details to be worked out

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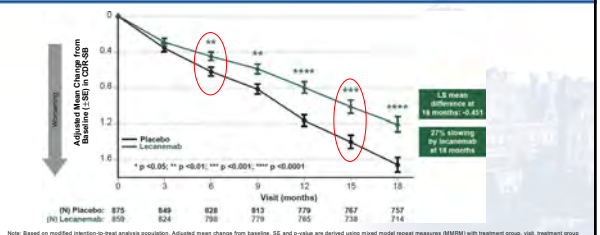
Leqembi slowed rate of functional decline



Note: Based on modified intention-to-treat analysis population. Adjusted mean change from baseline, SE and p-value are derived using mixed model repeat measures (MMRM) with treatment group, visit, treatment group by visit interaction, clinical subgroup, use of Alzheimer's disease symptomatic medication at baseline, ApoE4 carrier status, region, baseline value by visit interaction as fixed effects, and baseline value as covariate. CDR-SB, Clinical Dementia Rating, sum of boxes; LS, least squares; SE, standard error.

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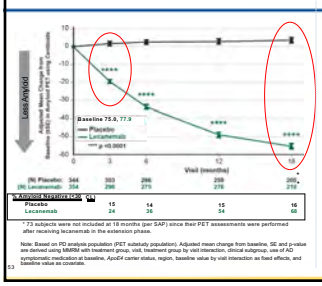
Leqembi removed amyloid very effectively



* 73 subjects were not included at 18 months (per SAP) since their PET assessments were performed after receiving lecanemab in the extension phase.

Note: Based on PD analysis population (PET substudy population). Adjusted mean change from baseline, SE and p-value are derived using MMRM with treatment group, visit, treatment group by visit interaction, clinical subgroup, use of AD symptomatic medication at baseline, *ApoE4* carrier status, region, baseline value by visit interaction as fixed effects, and baseline value as covariate.

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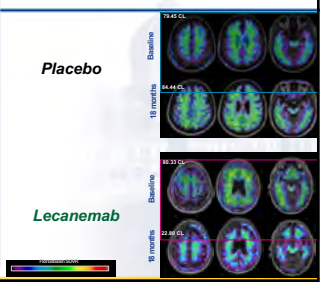

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Leqembi's effects (continued)

- Leqembi similarly slowed decline in cognitive measures and decline in activities of daily living (ADLs)
- But the **clinical effects** are not nearly as strong as the **biochemical effects**
- Removing amyloid slows but does not stop decline
- 'Early' Alzheimer's is probably **too late** to have strong effects
- Need to go earlier for prevention

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Risks

ARIAs (Amyloid-related imaging abnormalities)

- Brain swelling and microhemorrhages (bleeds) due to amyloid removal
- Occurred in about 15% of participants in CLARITY
- Most had no symptoms and could only be detected on MRI
- ~1/5 had mild symptoms
  - Headache, confusion, unsteadiness on feet
- 3% had serious reactions and some had to go into the hospital
- 3 deaths in ~1500 patients
  - All on blood thinners
- ARIA risk increased in patients with two ApoE4 alleles (genetic subtype)

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Implementing Leqembi

- Proof of amyloid positivity
  - LP or PET
  - CMS says it will cover PET, we're awaiting details
- Enrolled in CMS Registry
  - A loose observational study
- IV infusions every two weeks
  - Probably for 18 months, duration to be determined
- MRI scans for monitoring for ARIAs
  - 3-4 MRIs in first six months
- We are in the process of setting up this workload in the Bayview Memory Clinic
- **It's a lot of burden on patients/families and also adverse effects need a lot of monitoring**

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Exclusions to using Leqembi

- Blood thinners (Eliquis and similar drugs)
  - Anti-platelet drugs such as aspirin and Plavis are fine
- Two ApoE4 alleles
  - Requires genetic testing prior to starting treatment
- Contraindications to MRI
  - Especially pacemakers

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Donanemab (Lilly)
(No brand name yet)

- An antibody which targets a similar but slightly different target on amyloid plaques
- Similar effects to lecanamab
  - The company argues that the effect is 'stronger' but I think the differences are small
- **Given monthly (vs. every 2 weeks for lecanamab)**
- **More ARIAs (!)**
- FDA will make its decision 1st quarter 2024
- Most experts (including me) think they will approve
- Probably **won't** exclude patients on blood thinners
- But otherwise implementation will likely be similar to Leqembi

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The puzzle about Leqembi and donenamab

- Robust reduction of brain amyloid burden
  - ¾ of patients on donenamab had *no amyloid* at 18 months
- Modest clinical efficacy
  - Is the glass 1/3 full or 2/3 empty?
- ARIAs are *mostly* asymptomatic but are severe in about 3% of cases
- *Is the clinical benefit enough to make a difference in patients'/families quality of life and functioning? Is it worth the risks?*
- Decision needs to be collaborative between clinician and patient/family
- There is a real range of views in the field and within Hopkins

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WHO'S ELIGIBLE FOR LEQEMBI?
NEED (+) BIOMARKERS OF AD

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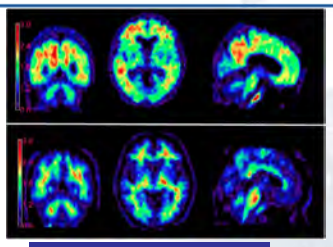
Amyloid PET imaging

4 amyloid PET and one tau PET tracer approved by FDA

Mild AD
77 years
MMSE 24/30



Normal
82 years
MMSE 30/30

CMS denied florbetapir coverage 2013

CMS agreed to cover (2023)

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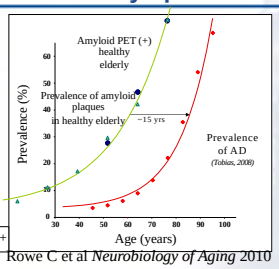
Amyloid brain accumulation starts ~15 years before first symptom



aibl

Rowe C et al *Neurobiology of Aging* 2010

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New developments in blood-based AD biomarkers

- Looking for markers that are less expensive than PET and less invasive than CSF
- It's been a long project but finally plasma-based biomarkers seem to be working
- Plasma p-tau$_{181}$ correlates well with tau-PET and CSF p-tau
- Also predicts dementia incidence AND is associated with brain amyloid burden in early disease (!)
- Plasma p-tau217 and p-tau231 may be even better early markers
- All excellent for distinguishing AD from non-AD dementias
- **We are close to having blood tests to detect early Alzheimer's, but not quite there yet**

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Take-home lessons

- AD is the commonest cause of dementia and causes a great deal of burden to patients, families, and society
- Lifestyle modification offers a great deal of promise for slowing down progression of AD and is something you can do right now!
  - Get off the couch and take a walk!
  - Get up and dance!
  - Listen to music or play music!
  - Take care of your heart
- We may soon have blood tests for Alzheimer's (!)
- We have a new class of medications for early AD that truly slow down decline
- But these medications are a lot of trouble to take and have significant side effects
- **The question remains whether the benefits are worth the risks**

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Acknowledgements

Thank you!

- Andrea Nelson
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  - R01AG050515
- Richman Family Center of Excellence for Precision Medicine in Alzheimer's Disease

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Questions?

- Paul B. Rosenberg, M.D.
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- prosenb9@jhmi.edu

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LIFESTYLE STRATEGIES FOR PREVENTING MEMORY DECLINE

There are many observational studies suggesting that lifestyle is associated with risk of memory decline. This is of course a very attractive prospect, because it offers the hope that healthy living will lead to long-lived brain health. Who wouldn't want this? But lifestyle interventions are innately difficult to study scientifically and few have been tested in well-designed trials. This document therefore will review lifestyle interventions in the spirit of cautious optimism, knowing that their effectiveness is not yet proven.

Websites for further information:
https://www.nia.nih.gov/alzheimers/publication/preventing-alzheimers-disease/search-alzheimers-prevention-strategies

http://www.helpguide.org/articles/alzheimers-dementia/alzheimers-and-dementia-prevention.htm

https://www.alzu.org (this is an excellent website from Dr. Richard Isaacson at Weill-Cornell Medical Center covering many aspects of Alzheimer's prevention reviewed in this handout)

Lifestyle strategies for preventing memory decline			
Lifestyle area	Potential mechanisms	Examples	Comments
Exercise	Improved blood flow to brain Enhance hippocampal neurogenesis Reduce depression and stress Reduction in inflammation and oxidative stress	Aerobic exercise Walking Swimming Tai Chi	Abundant epidemiologic evidence Many exercise programs currently being studied Aerobic aspects seem important Feasibility in frail elderly remains to be proven

Lifestyle strategies for preventing memory decline			
Lifestyle area	Potential mechanisms	Examples	Comments
Cognitive interventions	Cognitive reserve, strengthening brain circuits Improve brain plasticity (biological compensation) Improve compensatory strategies (behavioral compensation)	Many approaches to 'brain fitness' Commercial packages: Lumosity, BrainHQ, Things you can do yourself: reading, crossword puzzles, wordsearch, Sudoko Continuing education Paid or volunteer work	Education highly protective in epidemiologic studies Many strategies being studied in research But it has been difficult to show that “brain training” has significant real-world effects
Leisure activities	Mix of mechanisms above	Hobbies Social clubs Paid or volunteer work Playing games Crafts Computer use Social activities	Having a variety of leisure activities appears protective Two important themes appear to be socialization and verbal/intellectual stimulation Difficult to “prescribe” however
Diet	Reduction of atherosclerotic disease (i.e., “what's good for the heart is good for the brain”) Antioxidants	Mediterranean diet Fruits, vegetables, and juices Maintaining healthy weight Preventing diabetes	Compelling rationale for extension of well-validated interventions for heart disease But difficult for people to implement and evidence quite weak to date

Lifestyle strategies for preventing memory decline			
Lifestyle area	Potential mechanisms	Examples	Comments
Stress reduction	Prevent depression Improved brain connectivity	Psychotherapy Meditation Exercise Antidepressant medications	Late life depression and anxiety frequently linked to increased AD risk Interventions have been shown to alter brain connectivity No evidence from trials to date
Improving sleep	Reduce amyloid deposition	Sleep hygiene	Laboratory evidence that poor sleep enhances amyloid deposition and vice versa

Exercise: There are many observational studies reporting that older persons who do not develop dementia are more likely to exercise than those that do. The strongest evidence is that physical activity in *midlife* prevents dementia in *late life*, and there is similar evidence for the benefit of midlife cognitive activity as well. There are many potential mechanisms why exercise might prevent AD (https://doi.org/10.1016/j.arr.2020.101108): 1) Improved brain blood flow. In community samples dementia is most often a mixture of Alzheimer's and vascular pathology, and thus it is possible that exercise targets the latter. 2) enhancing formation of new brain cells in the hippocampus, a region of the brain crucial for memory. In one recent study older persons who did aerobic exercise actually enlarged their hippocampus vs. loss of volume in a control group who performed stretching exercises. 3) The prevention and reduction of depression and stress (see below). It is known that exercise is as effective a treatment as antidepressant drugs in mild depression. 4) The reduction of neuroinflammation and oxidative stress which are two mechanisms that may contribute to brain damage in late life. 5) Exercise releases two chemicals (irisin and cathepsin B) that may improve brain function. There is a recent meta-analysis reporting the benefits of exercise for memory, mood and daily function (https://doi.org/10.1016/j.arr.2021.101479).

While many clinicians encourage exercise for prevention of memory loss as having the solidest evidence base, it remains unclear what forms of exercise are best or what is the minimum “dose” required. The epidemiological evidence points to walking at least half an hour a day which for many older persons would be “moderate” intensity. The experimental evidence points more to aerobic exercise which means exercise that increases a person's heart rate, but there is increasing evidence for the benefit of strength training (i.e., weight training). In clinical practice, exercise recommendations are best based on patients' tolerability and interest. Tai Chi combines aerobics,

stretching, and strength training and is often well tolerated by formerly sedentary adults. There is evidence that even very elderly and frail adults can start new exercise regimens at an advanced age, and there is one such trial (LIFE) underway. But there are questions about whether the overall effect of exercise can be large enough to have a clinically significant effect.

Websites for further information:
https://go4life.nia.nih.gov/exercises. The section on "Endurance" covers aerobic exercise, and I think should be the priority for memory prevention. But the other sections ("Strength", "Balance", "Flexibility") are also important in maintaining health and well-being as we age.

Cognitive interventions: It seems logical that cognitive exercises should improve cognition but the evidence has been less clear than for physical exercise. Three possible mechanisms have been suggested: 1) Cognitive reserve and strengthening brain circuits. Education has been found to be pretty consistently protective in epidemiologic studies, in that persons with more education are less likely to develop dementia. This (and other evidence) has led to the concept of *cognitive reserve*: persons with more education have developed "stronger" brain circuitry underlying cognition, and thus are more resistant to pathologic processes such as Alzheimer's. It is possible that practicing cognitive tasks of increasing difficulty strengthens these circuits, and this hypothesis is the concept behind many interventions; 2) Improving brain plasticity: another mechanism for adapting to neuronal loss and dysfunction is to recruit more intact parts of the brain to fill in. For example, persons with MCI can frequently perform cognitive tasks well but MRI studies show that they activate specific brain regions more widely than normal to perform these tasks. This is a form of "plasticity" or brain adaptation; 3) Improving compensatory behavioral strategies: at a practical, non-biologic level one mechanism of adapting to memory problems is the use of aids, lists, reminders, etc. Contemporary digital devices (i.e. smart phones) can help similarly to low-tech strategies such as lists and calendars.

There is a great deal of research on a variety of cognitive interventions. Many focus on practicing memory tasks and enhancing behavioral compensatory strategies. Others focus on alternative mechanisms such as enhancing central auditory processing of speech. Many are available commercially and are being studied to various extents; most of these focus on enhancing memory, speed of processing, and the ability to change cognitive set (executive function). Examples of commercially available programs include Lumosity and BrainHQ but there are too many to mention; nor, given the sparse evidence, can we recommend any one over the other. There are many cognitive activities you can do on your own that are likely equally beneficial, and I recommend looking for activities that you genuinely enjoy. They should involve language and they should be active, i.e., not just watching television. Examples include crossword puzzles, wordsearch, Sudoku, and simply reading, but there are too many potential activities to list. Another form of cognitive intervention is volunteer work which combines cognitive and social stimulation (see below "Leisure activities"). For example, a group of older adults were trained for one week to tutor at-risk schoolchildren; the tutors improved cognitively over one year of volunteer work.

The caveat is that there are similar concerns as with exercise about the size of the effect of cognitive interventions, and thus far the effects appear relatively small.

There is considerable interest in combining web-based data collection and intervention for maximum dissemination of dementia prevention. The references include

a website for the Brain Health Registry which is an academic-industry collaboration in this area.

Websites for further information:
Given the many products available and limited data we cannot strongly recommend any one product, but here is a list of websites:

- www.memoryzine.com
- www.sharpbrains.com
- www.lumosity.com
- www.brainist.com
- www.fitbrains.com
- www.happy-neuron.com
- www.brainhq.com
- www.memorymagic.com

With the same cautions as above, here are several apps available for tablets and smartphones:

- Lumosity Mobile
- Elevate-Brain Training
- Fits Brains Trainer
- Peak-Brain Training
- Memorado
- CogniFit Brain Fitness
- NeuroNation
- Memory!
- BrainHQ
- Here is a website with brief descriptions of several apps, several of which are listed above: https://lonestarneurology.net/blog/mobile-apps-for-dementia-patients/

Leisure activities: There is considerable epidemiologic evidence that having a diverse range of leisure activities may prevent dementia. The details are still being worked out but important aspects appear to include: 1) having a variety of leisure activities; 2) engaging in activities that include socialization; 3) experiencing verbal and intellectual stimulation. In clinical practice this is a challenging “prescription” but the recommendations should be based on the persons' individual interests, characteristics, strengths, and life history.

In a recent analysis of cognitive normal persons in the Mayo Clinic Study of Aging (https://www.ncbi.nlm.nih.gov/pubmed/28135351), leisure activities associated with good cognitive outcomes included playing games, engaging in craft activities, computer use, and social activities. Persons who engaged in these activities were about 25-30% less likely to develop mild cognitive impairment. This is not likely to be an exhaustive list but serves as a useful set of examples for leisure activities that may help preserve cognition in older adults.

Websites for further information:
https://www.nia.nih.gov/health/publication/participating-activities-you-enjoy

Diet:
Heart-healthy diet: One approach to dietary intervention is that “what's good for the heart is good for the head.” The best evidence for this claim is available for the “Mediterranean” diet, which focuses on substituting unsaturated for saturated fats,

limiting beef intake and emphasizing fish, chicken and vegetarian alternatives, and substituting complex for simple carbohydrates. Recent trials of the Mediterranean diet show decreased mortality from heart disease and some limited evidence for improved cognitive outcomes. Consumption of fruits, vegetables, and 100% fruit juices has improved cognition in some laboratory studies. Maintaining a healthy weight similarly may be associated with improved cognition, although in advanced dementia lower weight is associated with poorer functioning. The mechanisms likely include improved vascular health, less body-wide inflammation, and prevention of late-life diabetes.

The National Institute on Aging has an excellent post summarizing the results of dietary interventions (January 2020):

https://www.nia.nih.gov/health/what-do-we-know-about-diet-and-prevention-alzheimers-disease?utm_source=NIA+Main&utm_campaign=796b792d04-20200107_ADEARdietAD&utm_medium=email&utm_term=0_ffe42fdac3-796b792d04-7503093

Antioxidants: There is evidence that in the development of Alzheimer's disease there is an increased amount of what is called “oxidative stress” in the blood and brain. These mechanisms are better-established for the eye disease macular degeneration in which increased consumption of the antioxidants **lutein** and **zeaxanthin** may help prevent the disease. The evidence for preventing Alzheimer's is still quite modest and there is one trial of adding antioxidants that did not prevent cognitive decline. Still, this area of dietary change is worth exploring:

Best sources of antioxidants lutein and zeaxanthin: kale, collard greens, spinach, turnip greens, brussel sprouts, and orange bell peppers. **Other sources:** broccoli, squash, peas, corn, tangerines, persimmons, eggs

Websites for further information:
https://www.nia.nih.gov/health/publication/healthy-eating-after-50. An excellent publication on general principles of healthy eating for older persons, with specific recommendations for DASH diet for treating high blood pressure.

http://www.mayoclinic.org/healthy-living/nutrition-and-healthy-eating/in-depth/mediterranean-diet/art-20047801. A user-friendly introduction to the Mediterranean diet.

http://www.alzheimers.net/4-8-15-mind-diet-alzheimers-prevention/ The MIND diet is a variant on DASH and Mediterranean diets with early data suggesting that it might be useful in prevention of memory loss.

Stress reduction: Late-life depression and anxiety are higher in people who go on to develop dementia. There may be a causative link, but it seems more likely that these mood symptoms are actually be early symptoms of dementia. Analogous to cognitive MCI, the concept of “Mild Behavioral Impairment” has been proposed to describe late-life mood changes that represent the earliest symptoms of dementia. If this concept is validated it will be an attractive area for dementia prevention as the interventions (treatment of depression, anxiety, and stress) are already indicated as targets for symptom relief. Interventions being study include: 1) cognitive-behavioral psychotherapy, which has been adapted for older persons with memory complaints; 2)

meditation and exercise, both of which improve symptoms of depression; 3) antidepressant medications. Possible preventive mechanisms include 1) improvement in mood leading directly to improved cognition, in that people who are less preoccupied think more clearly and efficiently; 2) improvements in brain connectivity which have been observed with all three interventions. It is important to note, however, that to date there is very little evidence that our treatments of stress, depression, and anxiety improve cognition or prevent dementia.

Sleep: Sleep may be the "next frontier" in dementia prevention. Persons with dementia have poorer sleep quantity and quality; amyloid deposition in the brain is associated with poorer sleep; and there is laboratory evidence that poorer sleep in animal models is associated with amyloid deposition. This bi-directional relationship suggests that improving sleep could be beneficial for cognition and dementia prevention, although there have been no trials of this hypothesis to date.

Websites for further information:
http://www.alzdiscovery.org/cognitive-vitality/article/deep-sleep-may-be-a-key-to-prevent-alzheimers-disease

http://healthletter.mayoclinic.com/editorial/editorial.cfm/i/315/t/forgoodhealth,makesleepa priority/

Hearing: There is increasing evidence that poor hearing may impair your cognition and that improving your hearing may improve cognition. If you have any concern about your hearing ask your doctor for a referral to an audiologist who can help with a hearing aid prescription, if appropriate.

Hearing aids are expensive but the FDA has recently approved a new class of over the counter hearing aids. In the meantime, one inexpensive and effective way of approving communication are portable hearing devices, they look like an mp3 player with headphones and are readily available for < $100. We use this one in the clinic, for example:

https://www.amazon.com/SuperEar-SE5000-Directional-Microphone-facilitates/dp/B017ZQ68HK/ref=sr_1_5?crid=38EYD0Y7Q1RSC&keywords=super+ear+se5000&qid=1646142493&sprefix=super+ear%2Caps%2C132&sr=8-5

If you live in the Baltimore area there is an organization that helps not only with hearing evaluations but also with affordability of hearing aids:

https://www.hasa.org/

We Hear You Baltimore: Affordable hearing health care for older adults

Age-related hearing loss often goes undetected and untreated. But your hearing is a vital part of your well-being and maintaining your friendships and family relationships. Whether you are just starting out or are already on your hearing health journey, We Hear You Baltimore provides older adults with a hearing evaluation, hearing aids, over-the-counter hearing technology, and more. We Hear You Baltimore is your one-stop service for all of your hearing health needs.

Do I qualify? You qualify if you are age 50+, live in Baltimore or the surrounding areas, and have difficulty hearing or are experiencing hearing loss.

What will my hearing health care cost?

Your consultation and working with the Hearing Health Navigator is always free. If you have Medicaid insurance, you may be eligible to receive hearing aids covered by Medicaid. If you do not have Medicaid, other options include affordable over-the-counter hearing devices provided by Access HEARS, which cost $450 or less. Outside of the We Hear You Baltimore program, traditional hearing solutions costs $4700 on average. The Hearing Health Navigator will help you review all of your options and make sure that your option is the most affordable and best suited for your needs.

16th ANNUAL JOURNEY TO HOPE

LIST OF EXHIBITORS

November 18, 2023

Community Exhibitors

AARP

Alzheimer's Association

Baltimore County Department of Aging Caregiver Program

Dementia Friendly Baltimore County

Ferretto Young Care Management Consulting

Geriatric Workforce Enhancement Program (GWEP)

LifeBridge Health/ Levindale Medstar Center for Successful Aging

Johns Hopkins Exhibitors and Research Studies

Alzheimer's disease don-invasive biomarker study

Bakker Labs

Johns Hopkins Alzheimer's Disease Research Center (ADRC)
MEMORI Corps

Music therapy for autobiographical memory and neuropsychiatric symptoms in Alzheimer disease

The 16th Annual Journey To Hope Conference – 2023

List of Abbreviations

AD – Alzheimer's disease

ADRC – Alzheimer's Disease Research Center

ALF – Assisted living facility

CCRC – Continuing care retirement community

CIND – Cognitive impairment not dementia

DLB – Dementia with Lewy bodies

FTD – Frontotemporal dementia

GCM – Geriatric Care Manager

LTC – Long term care

MACAB – Memory and Alzheimer's Community Advisory Board

MATC – Memory and Alzheimer's Treatment Center

MCI – Mild cognitive impairment

POA – Power of Attorney

PFAC – Patient Family Advisory Council

SNF – Skilled nursing facility or nursing home

VD – Vascular dementia

SPEAKERS, PANELISTS, AWARDEES AND MODERATOR BIOS
16th Annual Journey to Hope Conference
Saturday, November 18, 2023

SPEAKERS

Constantine G. Lyketsos, MD, MHS, FACLP, FACPsych, FACNP
Conference host, Expert Speaker

A native of Athens, Greece, Dr. Lyketsos graduated from Northwestern University and Washington University Medical School in St. Louis. He completed residency and chief residency in psychiatry at Johns Hopkins, followed by fellowship in clinical epidemiology. He currently serves as Chair of the Department of Psychiatry and Behavioral Sciences at Johns Hopkins Bayview and as the Elizabeth Plank Althouse Professor in Alzheimer's Disease Research at Johns Hopkins University. An active clinician, teacher, and researcher Dr. Lyketsos' clinical and research work are integrated in the Johns Hopkins Memory and Alzheimer's Center, which he founded as a collaborative partnership between three departments to offer comprehensive evaluation and innovative treatment for a range of conditions that affect cognition and memory. A world expert in the care and treatment of patients with Alzheimer's and related dementias (AD), Dr. Lyketsos has carried out pioneering work on the epidemiology and treatment of AD. His team is developing biomarkers to accelerate treatment development for AD while designing and implementing innovative clinical trials. He leads efforts, as well, to ensure the provision of state-of-the-art dementia care for people with dementia in the community. Dr. Lyketsos is the recipient of multiple major awards including the American College of Psychiatrists 2018 *Geriatric Research Award*. He has authored over 350 peer-reviewed articles, as well multiple chapters, commentaries, and five books. Castle-Connolly has named Dr. Lyketsos as one of *America's Top Doctors* every year since 2001.

Paul Rosenberg M.D.
Keynote Speaker

Paul B. Rosenberg, M.D., is Professor of Psychiatry and Behavioral Sciences at Johns Hopkins University School of Medicine, and Associate Director of the Memory and Alzheimer's Treatment Center at Johns Hopkins Bayview Medical Center. His research focuses on developing new treatments for Alzheimer's Disease (AD) especially neuropsychiatric symptoms and relevant biomarkers including sleep and circadian rhythms. Dr. Rosenberg is a 2008 Paul Beeson Scholar, chaired the NIA-N SRG at the National Institute on Aging, and served on the FDA Advisory Committee for Peripheral and Central Nervous System Drugs. He trained in Adult Psychiatry at Tufts University/New England Medical Center and Geriatric Psychiatry at McLean Hospital. He has over 130 peer-reviewed publications and has been the recipient of numerous NIH grants. He has served on the International Psychogeriatric Association task force revising the criteria for agitation in AD and the ISTAART-PIA task force revising the criteria for apathy in AD.

Mica Saunders

Mica Saunders is a Senior Enrichment Specialist and Body Chemist. She specializes in helping seniors keeping their mojo and assist caregivers with navigating through the journey of caring for someone with Alzheimer's or Dementia. Mica developed her passion for working with the aging population through caring for her grandparents. She was the secondary caregiver for two of her late grandmothers. Mica is a member of the MACAB Board and the owner of Moxie Movez. Mica is also the Fitness Director at Waxter Senior Center and owner of Moxie Movez.

PANELISTS

Janet Michel
Founding Member – Memory Center Patient Family Advisory Council (PFAC)

Janet lives in Havre de Grace, MD. She lovingly took care of her husband Kevin, who was diagnosed with Alzheimer's disease ten years ago and passed away in March 2023.
She advocates for learning about the disease, coping with the challenges, and utilizing the community resources available to all families. In 2020 she was interviewed by a panel from The National Academies of Sciences, Engineering, and Medicine discussing the role of caregiver for persons living with dementia.
Janet is an active, founding member of the Johns Hopkins Memory Center Patient Family Advisory Council. She is also involved with the Alzheimer's Association Harford County support group.
During the years as Kevin showed decline, Janet made sure to keep him as involved as possible in activities at home and within the community. They participated in Club Memory, the Harford County Alzheimer's Association monthly activities and socializing with new friends. For three years Kevin attended adult day programs which gave Janet some respite time. She knows first-hand the courage, love, respect and devotion one needs to care for a person diagnosed with Alzheimer's.

Jane Marks RN, MSN

Jane Marks RN, MS is the Associate Director for the Johns Hopkins Geriatrics Workforce Enhancement Program, a HRSA funded grant integrating geriatrics into primary care practices and promoting community outreach. Her work with the project extends across the state of Maryland working with various health care systems and agencies. She has been involved in providing and coordinating education for health professionals and caregivers regarding older adults. She participates in community activities and outreach to seniors as well. For the past 2 years, she participated with Maryland's Dept. of Aging and other organizations to create educational videos regarding dementia for Maryland Access Point Staff and other community-based staff. The goal of this effort is to promote Maryland as a Dementia Capable Community. Jane is involved with the Maryland Gerontological Nurse Group that

promotes nursing education regarding care of the older adult and recognition of the important role nursing assistants have in the older adult's care. Jane has been a nurse in the Division of Geriatric Medicine for over 35 years and worked in a primary care team with Dr. John Burton for older adults until 2018.

Marina Nellius LCSW-C

Marina Nellius, LCSW-C, is a passionate aging advocate, who views systemic barriers as opportunities for change. She is a clinical social worker with over 15 years of experience and has made a career of serving those who are underserved, "hard-to-reach," and most often, left behind. Currently, she is the social work manager at Landmark Health, a division of Optum Health and the nation's largest home-based medical provider. In her role, Marina oversees the Mid-Atlantic region's social care division. She acts as the clinical subject matter expert and supports the Maryland and Virginia markets with their implementation of best practices related to intensive case management, short-term solution focused therapy interventions, and palliative-focused engagement. Marina is the board president of the Maryland Gerontological Association and a two-term elected member of the American Academy of Home Care Medicine's board of directors. Most recently, Marina was appointed as a commissioner for Howard County's Commission on Aging.

Jessica Young

Jessica Young has been in healthcare administration for over 20 years. She has been an Executive Director in both the field of medical day services and assisted living. Jessica has extensive training in dementia care and uses this training and her real-life experience in providing dementia coaching and education to families. She has been an active member of many committees that help promote Alzheimer's awareness and the movement to find a cure. Jessica is now President/Owner of Ferretto Young Care Management Consulting, LLC. where she is able to provide families 1:1 eldercare coaching, education, and guidance. She is also a member of Aging Life Care Management Association. Jessica's passion is ensuring that families feel supported in their journey of caregiving.

AWARDEES

Cass Naugle - Pioneer Award Winner

Cass Naugle was the former Executive Director of the Alzheimer's Association, Greater Maryland Chapter. She was hired as the first executive director and served in this role from 1986 – 2020. During this time, she oversaw the growth of the organization from 1 staff person to 27 staff, and from a budget of $50,000 to over $5 million. Under her leadership, the chapter received numerous accolades, including grants and awards providing care partners with the opportunity for respite; initiating specialized programs including support groups for spouses, adult children people in the early stages of the illness and those with younger onset; and working with local researchers to promote opportunities for participation in Alzheimer's research studies.

Under her leadership, providing health care professionals with the most current information on Alzheimer's disease was a top priority. She developed a Medical and Scientific Advisory to help the chapter interpret research findings into clinical practice. In 1998, she initiated the Dementia Care Consortium, a quarterly networking meeting of professionals involved in dementia care. The chapter was one of the first in the country to develop a curriculum for training of people with a dual diagnosis of Alzheimer's and developmental disabilities. The chapter also collaborated with Hospice of Maryland to increase the use and availability of hospice services for people with dementia, as well as working with area hospitals to improve dementia care in acute care settings. Ms Naugle also oversaw the development of a state public policy committee, which has been a model for Alzheimer's Association chapters in the country. This committee assures that people with Alzheimer's disease and their families have a voice in all state policy issues that may impact them. Cass retired in 2020. She is enjoying time connecting with friends and long-time colleagues, traveling with her husband of 51 years and spending time with her three grandchildren.

Emily Kearns – Trailblazer Award Winner

Emily is currently the Coordinator for Dementia Friendly Baltimore County with the Baltimore County Department of Aging providing community-wide dementia education, resources, and care partner support. Emily was formerly the lead for Dementia Friendly Massachusetts and a consultant with the Massachusetts Lifespan Respite Coalition, evaluating innovative respite programs and hosting a TV show called, Caring for Others, Caring for Ourselves. Emily has facilitated memory cafés, dementia-supportive fitness programs at the Y, Dementia Dialogues at the public library, and retreats. She has also created a multimedia art installation called Dementia's Way. Emily earned a doctorate in sociology from Boston College and an Executive MBA from Northeastern University. She is also a Certified Dementia Practitioner, End of Life Doula, Somatic Care Consultant, Installation Artist and Reiki Master. Emily's personal experience care partnering with her parents, who both lived with dementia, was life-changing, catapulting her into what is now her first love—reframing dementia and supporting those who live with it. Emily is committed to change-making, including innovative programming and community education, so that individuals living with dementia may continue to live well, experiencing joy and meaningful engagement in communities that support and celebrate them and the life they choose.

Russell Kempner
Member, Memory Center Patient Family Advisory Council (PFAC)

(MPA, U. of Texas at Austin, MAS Johns Hopkins University) has been a member of the Memory Center PFAC for several years. His wife Janet was diagnosed at Johns Hopkins with a defect In the C90RF72 gene and probable Alzheimer's disease in 2013. They had made arrangements prior to the diagnosis to retire In Panama, where they had obtained residency. Those plans were discarded as Janet's disease progressed. Janet has been a full-time resident in a memory facility in Columbia, MD since 2017. Russell continues to work full-time in a family business and is able to visit Janet every day. He is accompanied in these visits by his friend Debra, who sings to Janet and is amazingly gifted at interacting with Janet and the other residents. Janet continues to defy the odds and charms the staff, residents, visitors and, especially Russell, with her adorable smile and expressions.

Karen Paide
Member, Memory Center Patient Family Advisory Council

Kay's husband, Tony, was diagnosed with dementia prior to his diagnosis of atypical Parkinson's. She was his soul caregiver from 2011 until he entered an assisted living facility (thankfully, close to their home) in late 2017, where he passed away on October 1, 2019. Tony and Kay both joined the Memory Center Patient Family Advisory Council (PFAC) in 2015. Together they attended the annual Journey To Hope conference for several years. Kay continues to support JTH as a planner, participant and supporter as she believes the outreach is so import to families on their unknown journey.

MODERATOR

Andrea Nelson RN, MSN

Andrea Nelson is a geriatric and psychiatric nurse with over 30 years' experience working in psychiatry, long-term care and dementia care. Before joining the Hopkins team in 2004 as a senior research nurse for the Alzheimer's Disease Research Center, she worked in numerous settings including hospitals, nursing homes, assisted living facilities, adult day centers, continuing care retirement communities, and for two chapters of the Alzheimer's Association. She is currently the Director of Memory Care Programs with the Memory and Alzheimer's Treatment Center at Johns Hopkins Bayview. In this role, she works closely with patients and families in the Memory Center, develops programs for patients at Johns Hopkins Bayview, designs and presents dementia care training and curriculum, and is actively engaged in outreach on the local, national, and international scale. Andrea received her Bachelor of Science degree in Nursing and her Master of Science degree in Health Systems Management from the Johns Hopkins University School of Nursing.

Patient & Family Advisory Council Membership Application

Thank you for your interest in the Patient & Family Advisory Council (PFAC). Membership on PFAC requires your successful completion of a formal interview with a PFAC member and the completion of the registration process with the Johns Hopkins Bayview Medical Center's Volunteer Services Department, including TB testing, a criminal background check, a formal interview process, as well as a mandatory volunteer orientation.

All of your information will be treated as confidential. Membership on the Council requires attendance at quarterly meetings.

Please* PRINT *all information clearly:

Name:
_____
_

Address:
_____

City/State/Zip
Code:_____

Telephone number(s): Please indicate preferred phone number and best time to reach you:
_____

Work: _____-_____-_____ Home: _____-_____-_____

Cell: _____-_____-_____ Fax: _____-_____-_____

Being environmentally conscience, the majority of the Council's correspondence is via email. If you do not have email, please do not worry and write ***I do not have email****. The Council will use postal mail or telephone contact as forms of communication with you.*

Email Address:_____

Please indicate if you are:

Person with dementia
Family member of person with dementia
Bereaved family member

If family member, what is relationship to patient?
_____

Diagnosis (cause of
dementia)_____

Year of original diagnosis_____

How long have been receiving care for the dementia diagnosis at Johns Hopkins?
_____ *Please indicate estimated months/years*

Why would you like to become a member of the Council?

_____

_____

Comments related to treatment experience(s):

_____

_____

_____

_____

Please read before signing

I certify that the statements made in this application are true and correct and have been given voluntarily. I understand that I will not be paid for my services as a volunteer member of the Patient and Family Council. I agree to respect patient confidentiality and to uphold the traditions and standards of the Johns Hopkins Medical Institution. I understand that membership on the Patient & Family Council is based on approval from the Council Co-Chairpersons and Staff Liaison. Volunteers will demonstrate a readiness to help others, maintain respect for collaboration and assist the Memory Center in delivering quality patient dementia care.

Applicant's
Signature_____Date_____

Please return completed application via mail, email or fax to:

Andrea Nelson, RN, MSN – Director of Memory Care Programs
Staff Liaison - Patient & Family Advisory Council
The Johns Hopkins Memory and Alzheimer's Treatment Center
5300 Alpha Commons Dr. 4th Floor
Baltimore, MD 21224
410-550-7211
Fax: 410-550-1407
anelso18@jhmi.edu

THE JOHNS HOPKINS
Memory & Alzheimer's
TREATMENT
CENTER

JOHNS HOPKINS
MEDICINE
JOHNS HOPKINS
BAYVIEW MEDICAL CENTER

Memory Research at Johns Hopkins

- Are you interested in memory research at Johns Hopkins?
- Are you familiar with the different types of research opportunities available?
- The research team at the Johns Hopkins Memory Center offers numerous opportunities for those interested in participating in a study. There are different types of research going on at any given time.

Observational studies – also referred to as paper/pencil studies, observational studies involve a researcher observing and asking questions of a participant and their study partner (close friend or family member). An example of this is our study of Memory and Aging through the Alzheimer's Disease Research Center. Participants visit once a year for 2-3 hours, undergo an hour of memory testing and are given the results of the testing. They also receive a small financial honorarium.

Clinical drug trials – these are studies that evaluate the effectiveness and safety of medications or medical devices by monitoring their effects on study participants. Participants are generally divided into two groups, including a control group that does not receive the experimental treatment, and receives a placebo instead. In most cases, research subjects are paid for their participation.

Imaging studies – studies in which pictures are taken of the brain via CAT scan, PET scan, MRI, or SPECT scans to determine normal and abnormal brain function. The imaging techniques may shed new light on the way a disorder affects the brain, so that new treatment methods can be discovered. In some cases, study participants can receive the results of their scans. In most cases, research subjects are paid for their participation.

If you are interested in learning more, please provide us with your contact information and we will be happy to answer any of your questions.

Submitting this form DOES NOT commit you to participating in a study!

Name_____

Email address_____

Phone_____