



November 14, 2020

Dear Journey to Hope Participant:

Welcome to the 13th Annual Journey to Hope Conference on Memory Loss. This is our first experience presenting the conference virtually. We are excited to bring you a great line up of speakers and participants including Johns Hopkins University faculty members, memory care experts, and Memory Center families.

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

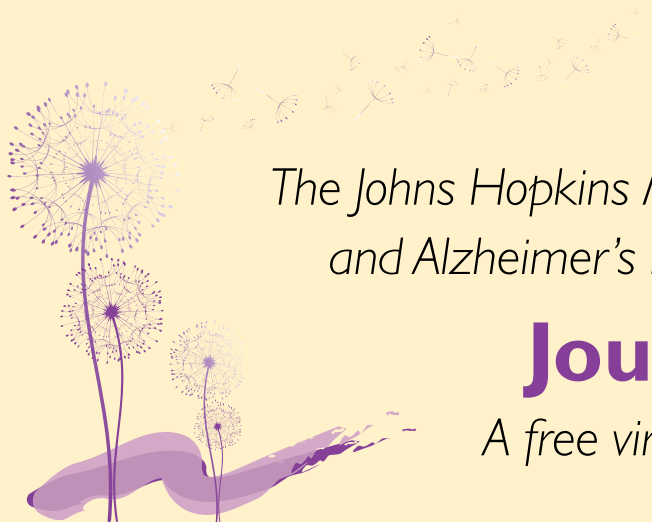
1. **Sit back and relax!**
2. **This event will be recorded and available soon afterwards on our website:**
https://www.hopkinsmedicine.org/psychiatry/specialty_areas/memory_center/events/journey_to_hope.html
3. **All attendees will be muted. If you have questions, please use the chat function, explained in the introduction.**
4. **Event packet includes:**
 - Event flyer/agenda
 - Dr. Yasar PowerPoint handout
 - Bios of speakers, panelists, awardees
 - List of Covid-19 Resources for Caregivers
 - Club Memory flyer
 - Information on memory loss research studies
 - Interested in Research form
 - Patient Family Advisory Council (PFAC) Membership Application
 - List of abbreviations
 - Pledge form

We hope you enjoy the conference!

Sincerely,

The Journey to Hope Planning Committee

5300 Alpha Commons Drive/ 4th Floor/ Baltimore, Maryland 21224



*The Johns Hopkins Memory & Alzheimer's Treatment Center
and Alzheimer's Disease Research Center invite you to*

Journey to Hope

A free virtual conference for caregivers

Join us to learn about the research and treatment of memory loss, and coping tips to manage during challenging times. You also will have an opportunity to "Ask the Expert" your questions about memory-related disorders.

Saturday, November 14, 2020

9 to 11:30 a.m.

Virtually, from the comfort of your home or office

Featuring:

Update on Alzheimer's Care and Research – *Sevil Yasar, M.D., Ph.D.*

Coping and Resilience in Isolation –

Panel Discussion Moderated by Andrea Nelson, MSN, RN

Ask the Expert – *Constantine Lyketsos, M.D., MHS*

**For more information or to register,
visit bit.ly/JourneytoHope2020.**



Agenda

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

Andrea Nelson, MSN, RN

Director, Memory Care Programs, Johns Hopkins Memory & Alzheimer's Treatment Center

Director, Patient-Family Advisory Council

9:10 - 9:30 a.m.

Update on Alzheimer's Care and Research

Sevil Yasar, M.D., Ph.D.

9:30 - 9:40 a.m.

Q&A with Dr. Yasar

Moderated by Andrea Nelson, MSN, RN, and Jennifer Mason, MSN, RN

9:40 - 9:45 a.m.

Break

9:45 - 10:30 a.m.

Panel Discussion: Coping and Resilience in Isolation

Moderated by Andrea Nelson, MSN, RN, and Jennifer Mason, MSN, RN

Janet Michel, *Caregiver and Patient-Family Advisory Council Member*

Pam South, *Caregiver and Patient-Family Advisory Council Member*

Yolanda Wright, MSW, *Alzheimer's Association*

Jessica Young, *Ferretto Eldercare Consulting, Inc.*

10:30 a.m.

Presentation of Awards (pre-recorded)

Caring Hands Award – Presented by Jane Marks, MS, RN, Johns Hopkins Geriatric Workforce Enhancement Program

Trailblazer Award – Kathy Rostkowski, Memory Center volunteer

Trailblazer Award – Tyrone Qualls, MACAB president

Pioneer Award – Reba Cornman, MSW

10:45 - 11:30 a.m.

Ask the Expert

Constantine Lyketsos, M.D., MHS

11:30 a.m.

Closing Remarks

Constantine Lyketsos, M.D., MHS

Call to Action

Mary Ann Esfandiari and Helen Hovdesven

Co-chairs, Memory Center Patient-Family Advisory Council



Journey to Hope

Update on Alzheimer's Care and Research

**"Lifetime Journey: Cognitive Aging and Dementia –
what we know and what we can do about it"**

Sevil Yasar, MD, PhD
Associate Professor
Division of Geriatric Medicine & Gerontology
11/14/2020

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Disclosure

- Nothing to disclose

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Objectives

- Epidemiology

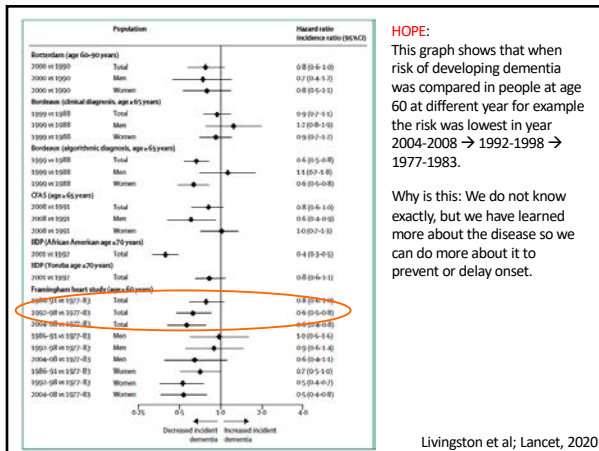
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Epidemiology: A little background

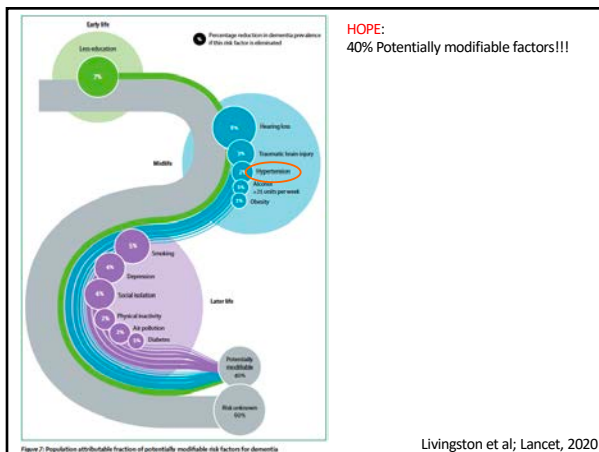
- The number of Americans ≥ 65 years is increasing from 40.2 million in 2010 \rightarrow to 88.5 million by 2050.
- 5.3 Million people have AD (2009) \rightarrow 14.3 million Americans will have the disease by 2050 (**350 % increase**).
- 85y and older ("oldest old") are the fastest-growing segment of the population.

Ferri et al, Lancet, 2005
Prince et al, Alzheimers demet, 2013

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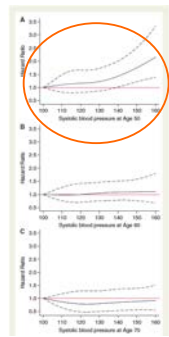


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Blood Pressure

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Midlife Blood Pressure and Dementia Risk



- Study in England (Whitehall II) of 8,639 participants who were followed for ~ 25 years.
- Participants were followed from age 50 through age 60, 70
- What they found that at age when systolic blood pressure (the upper number of your blood pressure) was > 130 at Age 50, but not age 60 or 70, the risk for developing dementia was 40% higher.

Abell et al, Eur Heart J, 2018

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What about Late Life Hypertension and Dementia Risk ?

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SPRINT and SPRINT-MIND study

- The Systolic Blood Pressure Intervention Trial (SPRINT)
 - To test hypothesis whether intensive blood pressure control such as keeping the upper blood pressure number < 120 mm Hg would reduce new heart attacks or strokes or deaths when compared to standard goal of keeping blood pressure number < 140 mmHg.
 - There were 9361 people enrolled and they were followed for ~3.26 years.
 - Study was stopped earlier due to significantly lower number of deaths by ~ 30% in the group which achieved lower blood pressure cause, cardiovascular mortality (~30%), even in older people (>75 y).

The SPRINT research Group, NEJM, 2015

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Cont'd

- SPRINT Memory and Cognition IN Decreased Hypertension (MIND)
 - To test hypothesis whether intensive blood pressure control such as keeping the upper blood pressure number < 120 mm Hg would reduce would reduce new diagnosis of dementia or mild cognitive impairment (MCI) when compared to standard goal of keeping blood pressure number < 140 mmHg.
 - There were 2800 people enrolled in this study and they were followed for ~3.2 years.
 - Results showed significantly reduced risk of 19% for developing 19% (while there was non-significant 17% decrease in dementia risk).

Williamson et al, JAMA, 2019.

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Cont'd

Table 2. Incidence of Probable Dementia and Mild Cognitive Impairment by Treatment Group

Outcomes	Intensive		Standard		Hazard Ratio (95% CI)*	P Value
	No. With Outcome/Person-Years	Cases per 1000 Person-Years	No. With Outcome/Person-Years	Cases per 1000 Person-Years		
Probable dementia	149/20 569	7.2	176/20 378	8.6	0.83 (0.67-1.04)	.10
Mild cognitive impairment ^b	287/19 690	14.6	353/19 781	18.3	0.81 (0.69-0.95)	.007
Composite of mild cognitive impairment or probable dementia	402/19 873	20.2	469/19 408	24.1	0.85 (0.74-0.97)	.01

*Intensive treatment group vs standard treatment group based on Cox proportional hazards regression.

^bParticipants adjudicated as having probable dementia at the first follow-up visit (year 2) do not contribute to the analyses of mild cognitive impairment.

SBP < 120 mmHg over 3-year period, even in older adults, reduced risk by ~ 19% of developing mild cognitive impairment.

Williamson et al, JAMA, 2019

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Blood Pressure Medications (BPM)

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BPM

- Blood Pressure Medication groups:
 - Calcium channel blockers = **CCB** (for example: amlodipine, nifedipine).
 - Beta blockers = **BB** (for example: metoprolol, atenolol)
 - Angiotensin converting enzyme inhibitors = **ACE-I** (for example: lisinopril, enalapril)
 - Angiotensin receptor blocker = **ARB** (for example: losartan, candesartan, telmisartan)
 - **Diuretic** (for example: hydrochlorothiazide, furosemide)

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BPM and Dementia Risk

- We collected information on 56,866 participants from 27 studies where we had information on BPM and dementia diagnosis.
- We wanted to see whether any of these BPM group (ACE-I, ARB, BB, CCB, diuretic) was protective and reducing the risk of:
 - Cognitive function measured by simple test calle MMSE.
 - Dementia.

Peters R, Yasar S et al, Neurology, 2020

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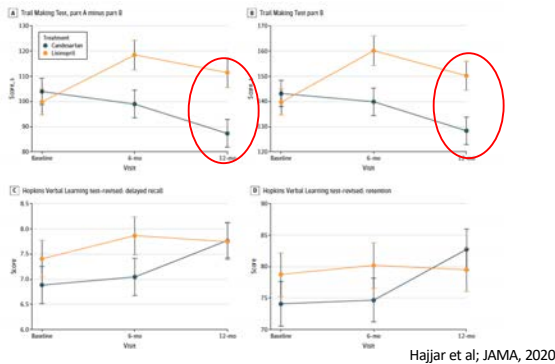
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- This study included 176 participants with MCI and hypertension:
 - To test hypothesis whether treatment of hypertension with lisinopril (ACE-I) or candesartan (ARB) for 1 year is better for cognition (specifically executive function measured by Trail Making Test, B).
 - Cognitive test were done at baseline, 6 and 12 months.
 - Blood pressure control was similar between two types of medications (systolic blood pressure 130 vs 134 mmHg).

Hajjar et al; JAMA, 2020

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Participants taking candesartan (ARB) did better at 6 and 12-months on processing speed and executive function



Hajjar et al; JAMA, 2020

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Dementia Risk: BPM compared to people on no-BPM

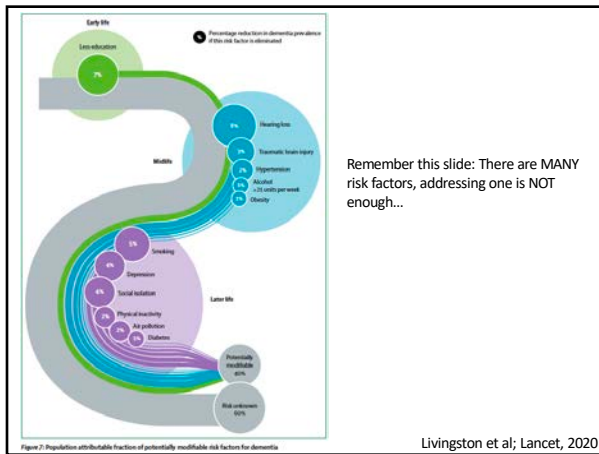
Supplementary table 3: Pooled odds ratios and associated 95% confidence intervals for APOE εε compared to no treatment or to placebo, in those aged <65

		Risk of developing dementia (Pooled OR, 95% CI)	Risk of developing dementia (Pooled OR, 95% CI)	Risk of developing cognitive decline as measured using the Mini-Mental State Exam (MMSE) (Pooled OR, 95% CI)	Risk of developing cognitive decline as measured using the Mini-Mental State Exam (MMSE) (Pooled OR, 95% CI)
		For those with <1 year follow-up	For those with ≥1 year follow-up	For those with <1 year follow-up	For those with ≥1 year follow-up
RCT	Unadjusted	0.88 (0.74-1.04)	0.67 (0.52-0.85)	0.97 (0.74-1.26)	0.39 (0.10-0.79)
	Adjusted**	0.86 (0.72-1.02)	0.65 (0.51-0.82)	0.95 (0.66-1.37)	0.44 (0.13-1.23)
		4 trials	3 trials	3 trials	3 trials
Cohort studies	Unadjusted	1.116 (0.932-1.307)	1.18 (0.78-1.78)	0.98 (0.82-1.11)	1.04 (0.84-1.29)
	Adjusted**	1.12 (0.98-1.28)	1.12 (0.74-1.70)	0.87 (0.75-1.01)	1.01 (0.78-1.31)
		7 cohorts	9 cohorts	15 cohorts	14 cohorts

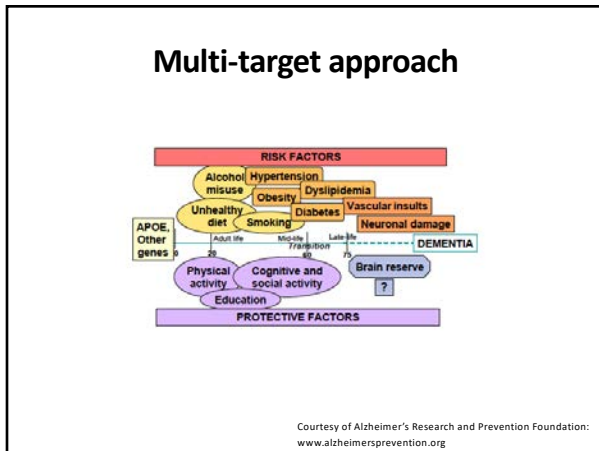
Although in our big analysis of observational studies we did not found an effect, but when we did look combination of 3 clinical trials that BPM reduced risk of dementia by 45%.

Peters, Yasar et al, Neurology, 2020

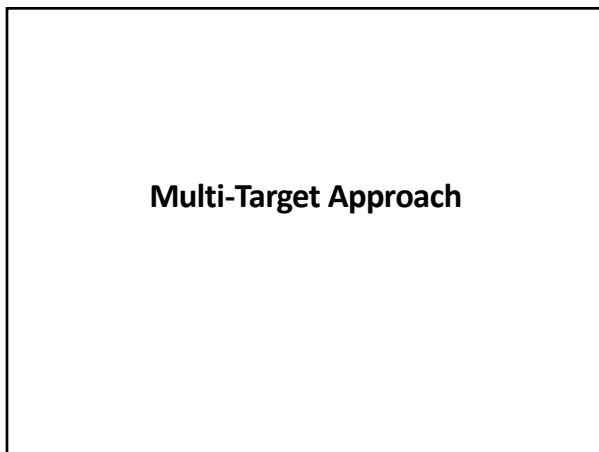
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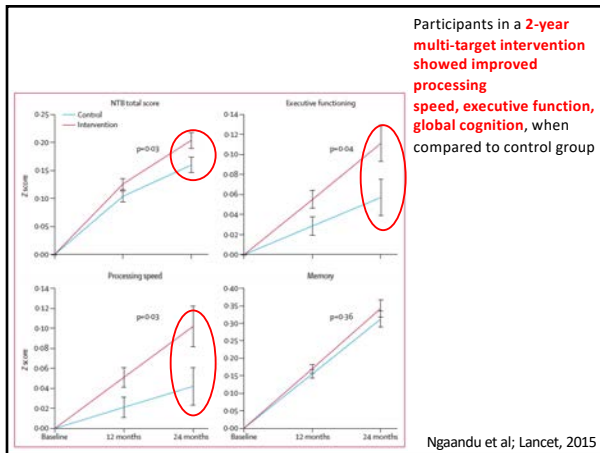
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Multi-target approach

- **FINGER trial**
 - Double-blind RCT of people with **high vascular risk factor** (such as history of high blood pressure, high cholesterol etc) burden undergoing general health education (N=591) or multimodal intervention (N=631) over 2-year period.
 - Multimodal intervention:
 - diet 3 individual and 9 group session.
 - exercise (1-3 per week muscle strength and 2-5 aerobic exercise).
 - cognitive training (10 group session, individual home online sessions).
 - vascular risk factor monitoring (by nurse or MD, BP, weight - no medications prescribed).
 - Outcome – change in cognition over 2 years.

Ngaandu et al; Lancet, 2015

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- **Pointer - US**
- **World Wide FINGERS**

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Summary

- **HOPE**
- Risks factors and protective factors should be addressed at midlife, but it is never late to address those in late life to reduce risk for dementia.
- The approach has to be multi-target approach → additionally it will have to be personalized approach.
- Recognizing the importance of personalized medicine the **“The Richman Family Precision Medicine Center of Excellence in Alzheimer Disease”** was founded under the leadership of Dr. Kostas Lyketsos.
- (BP management is important and the jury is still out on BP medications).

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Thank you!

- Questions?

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Karen Boone

FutureCAre Canton Harbor

Caring Hands Award Winner

Karen has worked at FutureCare Canton Harbor for 20 years, helping short-term and long-term residents with all activities of daily living. Karen is also a preceptor for new staff to the building.



Reba Cornman, MSW

Co-Chair of the Baltimore City Commission on Aging

Pioneer Award Winner

Barbara (Reba) Cornman, MSW is the Acting Chair of the Baltimore City Commission on Aging. Prior to her retirement in January, 2019, Ms. Cornman was the Director of the Geriatrics and Gerontology Education and Research (GGEAR) Program at the University of Maryland Baltimore for 28 years. As Director of the Program, Ms. Cornman planned and implemented interprofessional programs for professionals in the field of aging, matriculating students at the University of Maryland System campuses and family caregivers throughout the State of Maryland. Ms. Cornman worked with the staff of Area Agencies on Aging, The Eastern Shore Area Health Education Center, AHEC West, local Departments of Social Services, The Johns Hopkins Geriatric Workforce Enhancement Program (GWEP, formerly the Hopkins Geriatric Education Center), hospital health professionals, the Alzheimer Association of Central Maryland Chapters, faculty of University of Maryland System campuses and students in planning programs which enhanced information about older adults health and service needs. She also facilitated numerous interprofessional educational and research activities at the University of Maryland, Baltimore. Prior to the GGEAR Program, Ms. Cornman was the Executive Director of the Maryland Gerontological Association and helped start the state's first dementia care conferences with the Central Maryland Chapter of the Alzheimer's Association.

Since her retirement, she became acting co-Chair of the Baltimore City Commission on Aging Ms. Cornman is also the Chair of St. Mary's Outreach Center located in Hampden (serving community dwelling older adults) and is also on the boards of Action in Maturity (AIM) and Govans Ecumenical Development Corporation (GEDCO); and serves on the advisory boards of Housing Upgrades to Benefit Seniors (HUBS) and Comprehensive Housing Assistance, Inc. (CHAI). Reba Cornman received her MSW degree from the Boston University School of Social Work, Gerontology Concentration.



Mary Ann Esfandiari

Co-chair, Patient Family Advisory Council of the Memory and Alzheimer's Treatment Center

Call to Action

Mary Ann retired from federal service in 2014 after 39 years with NASA / Goddard Space Flight Center. She also served as a member of the Navy Reserve for 27 years including deployments to Afghanistan and Guantanamo Bay, Cuba, retiring with the rank of Commander in 2016. Her experience with dementia and memory loss comes from her mother and more recently her husband. Her mother was diagnosed with Alzheimer's disease in the 90s in her mid-seventies. Over a ten-year period, her mother's memory and cognitive abilities eroded slowly until her death. She lived with Mary Ann and her sister for several years until she required full care in a facility. Mary Ann's husband was diagnosed with Mild Cognitive Impairment in 2016. He held a PhD in Physics, had no major health issues and participated in sports, social activities as well as learning French in his retirement. He was being treated at the Johns Hopkins Memory and Alzheimer's Clinic and was a participant in one of studies. A PET scan was done as part of the study and showed clear Alzheimer's indications. In 2017, he suffered two hemorrhagic strokes several months apart and died in May 2017.

**Helen Hovdesven**

Co-chair, Patient Family Advisory Council of the Memory and Alzheimer's Treatment Center

Call To Action

Helen joined the Hopkins Advisory Board of the Department of Psychiatry in 2003. When the Memory Center was being developed, Helen agreed to be Co-chair of the initial PFAC, later becoming the Chair when it opened in 2008. She has been Chair until 2020 and is presently Co-chair. Helen walked the path with her husband, Arne, and after his death, completed a series of podcasts in 2010, "Alzheimer's from Diagnosis to Death" and "Brain Autopsy." These are available on the Memory Center's website. Helen was awarded the Trailblazer Award at the 8th Annual Journey To Hope conference in 2015 for her "Dedicated Advocacy and Support of Alzheimer's Patients and their Caregivers." She was appointed to the Committee on Care Interventions for Individuals with Dementia and their Caregivers - Phase II of the National Academies of Sciences, Engineering and Medicine in Washington, DC. This is Helen's 13th Journey to Hope.



Constantine G. Lyketsos, MD, MHS, FACP, FACPsych, FACNP

Elizabeth Plank Althouse Professor, School of Medicine, Johns Hopkins University

Chair, Department of Psychiatry and Behavioral Sciences, Johns Hopkins Bayview

Speaker: Ask the Expert

A native of Athens, Greece, Dr. Lyketsos graduated from Athens College, Northwestern University and Washington University Medical School in St. Louis. He completed residency and Chief Residency in psychiatry at Johns Hopkins, as well as a fellowship in clinical epidemiology. An active clinician, teacher, and researcher he founded the Johns Hopkins Memory and Alzheimer's Center which he directs. Dr. Lyketsos leads the Johns Hopkins Precision Medicine Center of Excellence on Alzheimer's Disease, and is Associate Director of NIH-funded Alzheimer's Disease Research Center. A world authority in treatment development for Alzheimer's, he has received multiple major awards, and authored over 400 peer-reviewed articles, chapters, commentaries, as well as five books. His work has been cited over 52,000 times with an h-index of 123 (Google Scholar). Castle-Connolly has named him as one of *America's Top Doctors* every year since 2001.



Jane Marks, RN, MS

Associate Director, Geriatric Workforce Enhancement Program

Presenter: Caring Hands Award

Jane Marks RN, MS is the Associate Director of the Johns Hopkins Geriatric Workforce Enhancement Program (GWEP) in the Division of Geriatric Medicine and Gerontology. She works with primary care practices to integrate geriatric concepts and reaches out to communities with community partners to educate patients, families and caregivers.



Jennifer Mason MSN, RN

Senior Nurse – Johns Hopkins Memory and Alzheimer’s Treatment Center

Conference Moderator

Jennifer Mason received her Bachelor of Science degree from Johns Hopkins University School of Nursing in 1988. She then served in various roles through the years as a medical and psychiatric nurse at Hopkins , a program coordinator at Union Memorial Hospital’s Counseling Center, as well as a school and community health nurse while her children were school age. Jen became part of the original team who opened the memory clinic doors in 2008 and began seeing patients in the summer of that year. From that point on, Jen was instrumental in developing nurse lead education visits as well as developing and running the community based educational seminars for caregivers in the memory center for the next 7 years. Jen then went on to become the interim and clinic manager of the memory clinic until she returned to school for her MSN in 2016 attending Stevenson University for a Master’s degree in Nursing Education. Jen has volunteered as a memory café facilitator for the Alzheimer’s association for the past 4 years and has served as a community liaison for caregivers from the café in her community. She is a member of the Alzheimer’s Impact movement (AIM) who serve to support efforts to change policy on Capitol Hill, and is a member of the American Nurses Association. Jen hopes to continue her passion for educating caregivers and patients with Alzheimer’s disease in the community and is looking forward to many more years supporting this amazing group of people.



Janet Michel

Family Caregiver

Founding member, Patient Family Advisory Council of the
Memory and Alzheimer's Treatment Center

Panelist

Janet and her husband Kevin live in Havre de Grace, MD. She lovingly takes care of Kevin who is diagnosed with Alzheimer's disease. She advocates for learning about this disease , coping with the challenges, and utilizing the community resources available to all families. Janet is an active, founding member of the Johns Hopkins Memory Center Patient Family Advisory Council, volunteers in the Family Resource Center, and enjoys the monthly Club Memory at Hopkins. In addition, Janet and Kevin participate in many programs offered by the Alzheimer's Association including support group meetings, Memory Cafe , and the annual Walk to End Alzheimer's in Harford County.



Andrea Nelson, MSN, RN

Director, Memory Care Programs

Johns Hopkins Memory and Alzheimer's Treatment Center

**Director, Journey To Hope Conference
Conference Moderator**

Andrea Nelson is the Director of Memory Care Programs at the Memory and Alzheimer's Treatment Center at Johns Hopkins Bayview Medical Center. In this role, she designs and implements a multitude of services and programs for patients, families, and caregivers. She has extensive background in both geriatric and psychiatric nursing, having worked in acute inpatient psychiatry, and in numerous long-term care settings including assisted living facilities, skilled nursing facilities and adult day centers. She has done consulting work for several chapters of the Alzheimer's Association and numerous assisted living communities in Maryland, Virginia, Washington D.C., and Florida. She works with dementia patients and their families as they navigate the steps of their journey, including managing daily care, considering research opportunities and discussing future planning. Andrea received her Bachelor of Science in Nursing and her Masters degree in Health Systems Management from the Johns Hopkins University School of Nursing.



Tyrone Qualls Bio

Tyrone Qualls, a Certified Health Coach and a Certified Lifestyle Coach, is committed to working with individuals and organizations to teach them how to obtain a healthy lifestyle through weight loss management, healthy eating and regular exercise.

A retired Telecommunication Executive, Business Owner, and a two time stroke survivor, Mr. Qualls has made it his passion to help get people healthy.

Mr. Qualls was also a Health Ambassador for the American Diabetes Association. As an Ambassador, he conducted workshops on prevention and management of diabetes and its complications, on nutrition, and physical activity. All workshops are informative, interactive and engaging. The workshops are appropriate for Hospitals, churches, social

organizations, community organizations, libraries, senior centers and apartment complexes.

Mr. Qualls is also certified to teach the CDC (Center for Disease Control and Prevention) Course, **National Diabetes Prevention Program** and the Stanford University's Courses, **The Living Well Program**, which includes, **CDSMP** (Chronic Disease Self-Management Program) and **DSMP** (Diabetes Self-Management Program). He is also certified to teach **Cardiovascular Disease Prevention Program** , **The Stepping On** program and the **Walk with Ease** program for the Arthritis Foundation.

Mr. Qualls is the Chairperson of the **MACAB (Memory and Aging Community Advisory Board)**, the Committee outreach board for Johns Hopkins Alzheimer Association.



Kathy Rostkowski

Family Resource Center Volunteer

Trailblazer Award Winner

Kathy is a retired Radiologic Technologist with the Johns Hopkins Bayview Medical Center (JHBMC) Imaging Department. She first started her career at Baltimore City Hospital (BCH) in 1975, after graduating from a 2-year accredited Radiology program from BCH (now JHBMC). She came back in 1988 to Francis Scott Key Medical Center / Johns Hopkins Bayview Medical Center Radiology Department until 1997, where she worked as a Clinical Imaging Supervisor until her retirement in 2015. In 2016, Kathy began volunteering at the Family Resource Center in the Memory and Alzheimer's Treatment Center at JHBMC and continues to assist with Club Memory. Her hobbies include spending time with her three grandchildren, grand-dogs, reading books and chalk painting.

**Pam South**

Family Caregiver

Member, Patient Family Advisory Council of the Memory and Alzheimer's Treatment Center

Panelist

Pam serves as a Care Partner and advocate for her husband Nathan, who for the last 12 years has lived with dementia, and balance and gait issues resulting from a very rare degenerative condition called Spinal Cerebellar Ataxia (SCA17). Pam is a recently retired Marketing professional and business owner who is now blessed to be able to focus her time and attention on the challenges of this journey with Nathan. She leans heavily on her faith and the encouragement, educational and social benefits of the Alzheimer's Support group, Hopkins Club Memory and the Hopkins Ataxia Support group for Care Providers.

Pam is also privileged to serve on the Johns Hopkins Memory Center Patient Family Advisory Council and at her local church.

Pam and Nathan live in Bel Air, Maryland with their son and his family, which allows her the ultimate joy of spoiling her 7 year old granddaughter.

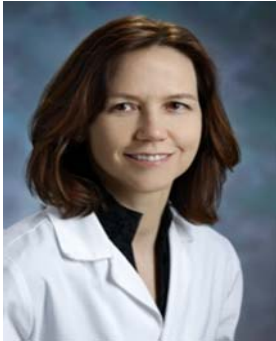


Yolanda Wright, MSW, LMSW

Early Stage and Support Group Coordinator
Alzheimer's Association, Greater Maryland Chapter

Panelist

Yolanda Wright, a native of North Carolina, comes to us with a background of social work. Upon receiving her Bachelor in Social Work from UNC-Greensboro, she began her early career journey working with special needs children and their families in the Rowan County Public School System; later on moving into the job training and placement field. Ms. Wright then discovered her real passion of helping people in the medical field. She worked with the Rowan County Home Health and Hospice as social worker and later as Supportive Services Coordinator. Ms. Wright moved to Maryland in 1989, which took her to Church Home and Hospital's Home Health and Hospice; eventually becoming MedStar Home Health and Hospice. For 19 years, within the MedStar Health System, she held numerous positions, including social worker, bereavement coordinator, volunteer coordinator, and program coordinator. Additionally, Ms. Wright furthered her education at the University of Maryland- Baltimore and received her Master's in Social Work with a specialization in Health and a concentration in Clinical & Human Services Management. The year 2000 brought on a new adventure as she moved into the medical adult day care arena at Church/Harbor Hospital. The hospital brought opportunities within the in-patient setting and also ER crisis intervention. In 2008, she accepted Center Director position with Active Day-Parkville. She also worked as a Memory Care Director at a Senior Living Community. Yolanda joined the Alzheimer's Association- Greater Maryland Chapter in October 2012 as the Early Stage and Support Group Coordinator. Ms. Wright brings 41 years of experience with dementia, grief and loss on both a professional and personal level.



Sevil Yasar MD, PhD

Associate Professor of Medicine and Neurology
Department of Medicine
Division of Geriatric Medicine & Gerontology
Johns Hopkins University

Speaker: Update on Alzheimer's Care and Research

Dr. Yasar received her medical degree from the Semmelweis Medical University, School of Medical Sciences, (Budapest, Hungary) and later her Ph.D. in pharmacology at the the Semmelweis Medical University, School of Pharmacological Sciences. She received her geriatric medicine fellowship training at Johns Hopkins University (JHU) and joined the Division of Geriatric Medicine and Gerontology at Johns Hopkins University in 2001.

Dr. Yasar is a practicing physician at the Johns Hopkins Memory and Alzheimer's Disease Treatment Center (MATC) and also at the Johns Hopkins Cerebrospinal Fluid Disorder Center.

Dr. Yasar's research is closely related to her clinical work with focus on dementia and cognitive ageing. Her research interest is in evaluating effects of cardiovascular risk factors, such as hypertension and hyperlipidemia, and associated medication use on cognitive ageing and dementia risk. She is core faculty of the Johns Hopkins Center of Aging at Health and a member of the Richman Family Precision Medicine Center of Excellence in Alzheimer's Disease.



Jessica Young

Care Manager, Ferretto Eldercare

Panelist

Jessica has been in healthcare administration for over 15 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 has taken this experience and is now a Care Manager with Ferretto Eldercare Consulting 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.

Covid-19 Resources for Dementia Caregivers

Andrea Nelson, MSN, RN

Paul Rosenberg, MD

Valerie Cotter, DrNP

Updated November 10, 2020

CHALLENGES	SOLUTIONS/RESOURCES
<p>1. Social distancing and resultant changes in social networks.</p> <p>Isolation and loneliness – people who live alone or with their caregiver, are suddenly cut off from social networks; strain from spending too much time together.</p> <p>AARP –Coronavirus Updates for Caregivers https://www.aarp.org/health/conditions-treatments/info-2020/coronavirus-facts.html?intcmp=AE-CAR-HEA-R1-C1-CORONA</p> <p>Alzheimer’s Disease International: ADI Offers Support and Advice During Covid-19 https://www.alz.co.uk/news/adi-offers-advice-and-support-during-covid-19</p> <p>CDC - Guidance for Administrators and Leaders of Community- and Faith-Based Organizations to Plan, Prepare, and Respond to Covid19 https://www.cdc.gov/coronavirus/2019-ncov/community/organizations/guidance-community-faith-organizations.html</p> <p>Department of Health and Human Services - Recommended Preventative Practices and FAQs for Faith-based and Community Leaders during Covid-19 https://www.hhs.gov/sites/default/files/3-17-20-faith-and-community-based-covid-19-faq.pdf</p>	<ul style="list-style-type: none">• Gain understanding that the challenges they are experiencing are to be expected and there are resources and support systems available• Utilize social media (Facetime, Zoom, Skype, etc.) to stay in touch with friends, family, social contacts and improve the quality of support and interactions• Seek out education, support and resources specific to caring for a loved one with dementia• Distance caregivers can enroll community support networks (neighbor calls and checks, local community centers) to check on family members/ neighbors with dementia who live alone• Utilize faith-based communities in providing services for PWD and their caregivers (emotional and spiritual support, virtual religious services, meal delivery, education regarding virus prevention and safety)

<p>2. Worry and anxiety</p> <p>Anxiety, stress, worry related to the pandemic; concern about contagion for person with dementia or caregiver contracting the virus; concerns about shopping for necessities, groceries, medication</p> <p>AARP – Apps for Caregivers https://www.aarp.org/home-family/personal-technology/info-2019/top-caregiving-apps.html</p> <p>CDC - Running Essential Errands: Grocery Shopping, Take-Out, Banking, and Getting Gas https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/essential-goods-services.html</p> <p>Alzheimer’s Foundation of America: Coronavirus Information for Caregivers https://alzfdn.org/coronavirus/</p> <p>Daily Caring – Website for Dementia Caregivers https://dailycaring.com/?s=covid+19</p> <p>Family Caregiver Alliance – Resources for Family Caregivers https://www.caregiver.org/coronavirus-covid-19-resources-and-articles-family-caregivers</p> <p>National Council on Aging: Ensuring Access to Needed Medications During Covid19 https://www.ncoa.org/blog/ensuring-access-to-needed-medications-during-the-covid-19-pandemic/</p>	<ul style="list-style-type: none"> • Provide basic reminders about how to stay safe and avoid exposure to the virus • Utilize online shopping with delivery service, or take advantage of special shopping hours for seniors • Pharmaceutical delivery – bubble packs for daily med dosing • Avoid TV/ news or only watch once daily • Utilize resources to take one's mind off of crisis (see activities below) • Suggest caregiver-assisted apps or apps specifically designed for dementia caregivers
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<p>3. Concerns about financial stability</p> <p>Consumer Financial Protection Bureau: Tips for financial caregivers during the coronavirus pandemic</p> <p>https://www.consumerfinance.gov/coronavirus/older-adults/</p>	<ul style="list-style-type: none"> • Address concerns about elder financial exploitation, scammers or financial abuse • Allow trusted family and/or friends access to monitor financial activity through access to online banking and credit card statements
<p>4. Changes to daily routine and loss of caregiver respite resources</p> <p>Disruption of daily schedule – no longer attending adult day center, seeing friends/family on a regular basis</p> <p>Alzheimer’s Society – UK</p> <p>Exercise in Early To Middle Stages of Dementia</p> <p>https://www.alzheimers.org.uk/get-support/daily-living/exercise/early-middle-dementia</p> <p>Better Health Channel – Department HHS Victoria Australia</p> <p>https://www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/dementia-activities-and-exercise</p> <p>Gentle Chair Yoga for Dementia</p> <p>https://www.youtube.com/watch?v=uEihWUbnqdk</p> <p>National Institute on Aging - Staying Physically Active with Alzheimer’s</p> <p>https://www.nia.nih.gov/health/staying-physically-active-alzheimers</p> <p>Seated Tai Chi for Seniors</p> <p>https://www.youtube.com/watch?v=_V29hE0_oBE</p> <p><u>Vive Health</u>: 18 Chair Exercises for Seniors & How to Get Started</p> <p>https://www.vivehealth.com/blogs/resources/chair-exercises-for-seniors</p>	<ul style="list-style-type: none"> • Create a new schedule to include social media gatherings with friends and family via Zoom, Facetime, Skype, etc. • Establish a new daily schedule to include simple activities in the home such as gardening, household chores (folding laundry, dusting, sweeping, etc.) • Maintain healthy habits: <ul style="list-style-type: none"> ○ Regular exercise (short walks outside, seated exercise, gentle stretching) ○ Health diet – healthy food prep or delivery • Sleep hygiene – maintain consistent sleep schedule

<p>5. Caregivers' increased need for emotional help and practical problem-solving Caregivers feeling overwhelmed, refusing to ask for help, not recognizing their need for help, dealing with challenging behaviors - potential for abuse/neglect</p> <p>Alzheimer's Association - Online Support Groups https://www.alz.org/help-support/community/support-groups</p> <p>Alzheimer's Association – HelpLine 24 hours/day https://www.alz.org/help-support/resources/helpline</p> <p>Alzheimer's Foundation – HelpLine 7 days/week https://alzfdn.org/afahelpline/</p> <p>National Caregiving Foundation – Free Caregiver's Support Kit https://caregivingfoundation.org</p> <p>HHS.gov: How do I report elder abuse or abuse of an older person or senior? https://www.hhs.gov/answers/programs-for-families-and-children/how-do-i-report-elder-abuse/index.html</p> <p>National Center on Elder Abuse: Covid-19 and Elder Abuse https://ncea.acl.gov/Resources/COVID-19.aspx</p> <p>The Conversation: Reaching Out To Isolated Older Adults During Covid-19 https://theconversation.com/reaching-out-to-isolated-older-adults-is-essential-during-coronavirus-here-are-7-specific-things-you-can-do-just-for-starters-134221</p> <p>Daughterhood – Support site for daughters of aging parents https://www.daughterhood.org/</p>	<ul style="list-style-type: none"> • Provide outside support for caregiver (offer to do errands or arrange grocery/medication delivery, connect seniors with community organizations,) • Provide phone based HelpLine support services for caregivers, 365 days per year • Maintain contact, devise daily check-in systems via community groups/friend/family to determine potential for elder abuse
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6. Lack of fulfilling activities for both caregivers and persons with dementia

12 World-Class Museum online tours

<https://www.mentalfloss.com/article/75809/12-world-class-museums-you-can-visit-online>

28 Free Virtual Field Trips and Activities for Families in Quarantine

<https://www.wearethemighty.com/MIGHTY-SURVIVAL/free-virtual-field-trips-quarantine?rebellitem=1#rebellitem1>

Aging Care – Lockdown Activities for an Aging Loved One

<https://www.agingcare.com/articles/lockdown-activities-for-an-elderly-loved-one-457557.htm>

Birdwatching – online live cams for many different types of birds

<https://birdwatchinghq.com/>

Classical Music – Free online classical music

<https://www accuradio.com/classical/>

ElderSong - Quarantine Activity Guide

<https://blog.eldersong.com/2020/03/quarantine-activity-guide/>

Fact Slides – Online trivia site with tons of interesting information

<https://www.factslices.com/>

Frank Lloyd Wright Virtual Visits

<https://savewright.org/news/public-wright-sites-swap-virtual-visits/>

Google Arts and Culture – Visit museums, art galleries and famous places online

<https://artsandculture.google.com/story/xwWh9Tju8Vkerw>

- Engage in activities to stimulate conversation and interest, deter boredom
- Incorporate creative interventions into daily schedule: games storytelling, crafts, virtual concerts, zoo tours, nature tours, museum tours, travel, trivia, science facts
- Reminiscence by looking at photo albums, listening to favorite music, watching classic movies/TV shows, listening to audiobooks

Jazzblog - Coronavirus Livestreams from Lincoln Center

https://www.jazz.org/blog/coronavirus-jazz-livestreams/?_ga=2.66791406.1903630973.1586222244-261175935.1586222244

Metropolitan Opera – Free Live Streams during Coronavirus

<https://www.metopera.org/>

Mindstart – Activities for Dementia

<https://www.mind-start.com/>

NASA Live – Official NASA Live Stream of things happening in space

<https://www.nasa.gov/nasalive>

Nature Cams – access to live nature and animal cams

<https://www.youtube.com/channel/UC-2KSeUU5SMCX6XLRD-AEvw>

Pier 39 Sea Lion webcam – Watch sea lions interact and play

<https://www.pier39.com/sealions/>

ReRun Century – Free Online Classic TV Shows

<https://www.reruncentury.com/ia/>

Timeslips Creativity website – engagement in the home setting

<https://timeslips.org/services/family-friend>

Tubi TV – Free Online Classic Movies

<https://tubitv.com/category/classics>

Violin Channel – Living Room Livestream Concerts from Around the World

<https://theviolinchannel.com/vc-live-violin-channel-living-room-livestream-concerts-coronavirus-covid19/>

7. General resources

Alzheimer's Association: Tips for Caregivers

[https://www.alz.org/help-support/caregiving/coronavirus-\(covid-19\)-tips-for-dementia-care](https://www.alz.org/help-support/caregiving/coronavirus-(covid-19)-tips-for-dementia-care)

Alzheimer's Association: Tips for Caregiver Professionals

<https://www.alz.org/professionals/professional-providers/coronavirus-covid-19-tips-for-dementia-caregivers>



VIRTUAL CLUB MEMORY

A stigma-free social group for people with early-stage Alzheimer's disease, mild cognitive impairment or other forms of dementia, and their caregivers.

1st and 3rd Wednesday of every month

2 to 3 p.m.

<https://jhjhm.zoom.us/j/91677376798>

Upcoming Sessions

October 21

November 4

December 2

November 18

December 16

For more information, email anelso18@jhmi.edu.

By participating in this session, you acknowledge that those other participants in the session will be able to see and hear information about you. To ensure maximum confidentiality of all participants, please ensure you are connecting from a quiet and private space with no interruptions or distractions from people or other devices. No one else, other than yourself, should be able to hear the content of the session or see anyone on the screen. As a reminder, everything that is discussed or shared during this session including names or contact information, should be kept confidential. While we have taken steps to ensure the platform we are using meets all the requirements of HIPAA, we cannot guarantee absolute privacy, so we are asking all participants to do their part. Finally, recording or photographing the group session or any other group member is strictly prohibited.



PARTICIPANTS NEEDED

FOR A RESEACH STUDY EXAMINING THE USE OF SMART HOME DEVICES IN INDIVIDUALS WITH COGNITIVE IMPAIRMENT AND THEIR CAREGIVERS

We are looking for interested patients and caregivers to participate in a research study exploring the use of smart home devices (e.g., Amazon Alexa, Google Home) in those with cognitive impairment. Participation will include a one-time 90-minute focus group through a videoconferencing platform, so you can participate from home!



Who do we need?

- Patients diagnosed with mild-to-moderate dementia.
- Have relevant lived experiences of communication changes related to dementia.
- Each patient must identify one caregiver as a study partner (\geq 18 years old).
- Ability to complete one 90-minute focus group through videoconferencing platform.

Please ask your provider about the study today! Participation will involve research consent, the 90-minute focus group, and the opportunity to review the summary findings from the focus group and make suggestions.

Dr. Allison Bailey
Email: Bailey@jhmi.edu
Cell: 443-478-3569

The Johns Hopkins Memory Center is Recruiting for Research Studies on Healthy Aging & Memory Loss

- ✓ **Observational studies that include memory testing**
- ✓ **Imaging studies that provide information about brain changes with aging or memory loss**
- ✓ **Studies to test interventions, such as lifestyle changes or drugs, to see if they delay the progression of memory disorders**
- ✓ **Studies to reduce behavioral problems in patients with memory disorders**



- 55-85 years old?
- Have no memory problems but are interested in research studies?
- Experiencing mild memory problems?
- Affected by Alzheimer's disease?
- Willing to travel to Johns Hopkins at Bayview or Downtown?

For more information, call (410) 550-9021



Help provide new insights into the earliest phases of Alzheimer's disease!

Participate in the BIOCARD Study

This research study focuses on individuals who have no problems with their memory. The goal is to learn more about the earliest phase of Alzheimer's disease, and to better understand health and lifestyle factors that might protect your brain from developing cognitive impairment and dementia.

You may be eligible if you:

- Are 50-70 years old
- Have no memory problems
- Are willing to come in for yearly visits and complete the study procedures



What's involved?

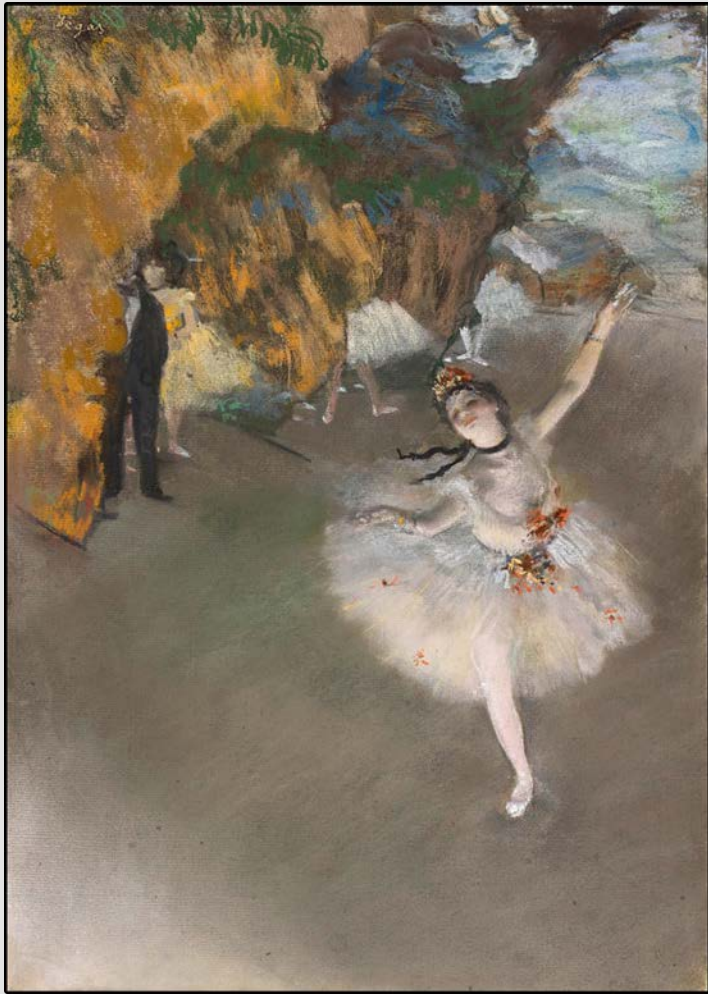
- Annual clinical and cognitive assessments, and blood draws
- Approximately every other year, procedures that allow us to track changes in the brain over time (including MRI and PET scans)

Participation includes:

- Coverage of travel expenses related to the study (e.g., transportation; hotel if needed)
- Honorarium for completing the research procedures (up to \$500)
- Annual memory testing and physical exam
- Annual meeting for participants with updates on study findings

For more information:

Call 410-446-6161 or Email mgrega@jhmi.edu
Visit the BIOCARD website at <https://biocard-se.org/>



Does your loved one with memory problems enjoy looking at art?

Would you both be interested in talking about art with others?



Please email anelso18@jhmi.edu



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_____

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 13th Annual Journey To Hope Conference
November 14, 2020

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

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

VA – Department of Veterans Affairs

VD – Vascular dementia

LINK TO JOHNS HOPKINS MEMORY CENTER WEBSITE

https://www.hopkinsmedicine.org/psychiatry/specialty_areas/memory_center/





We are grateful for your participation in Journey to Hope. This program is offered yearly, free of charge to all participants. We welcome your donations to defray the costs of the conference in the future.

- ❖ To make an online gift, click <https://secure.jhu.edu/form/psych>
In the designation box, choose “Other” and enter Journey to Hope

- ❖ If you wish to send a check, please make it payable to:

Johns Hopkins University
Memo Area: Journey to Hope

Mail to:
550 N Broadway
Suite 916
Baltimore MD 21205
Attention: Betsy Rutherford

- ❖ If you would like to make a gift of appreciated securities or have other questions, please contact Betsy Rutherford, Sr. Associate Director of Development
betsy@jhmi.edu or (443) 743-0758

THANK YOU!

