

MEETING SUMMARY
ILLINOIS DEPARTMENT OF PUBLIC HEALTH
ALZHEIMER'S DISEASE ADVISORY COMMITTEE (ADAC) MEETING
October 5, 2020 1:00 p.m. to 4:00 p.m.
WebEx
Approved April 29, 2021

Welcome

- Jennifer welcomed members and stakeholders to the first meeting under the new membership structure.

Introductions *(Listed in the order outlined in the legislation)*

Voting Member	Position	Agency
Jen Belkov	A statewide association dedicated to Alzheimer's care, support, and research	Alzheimer's Association, Illinois Chapter
Jennifer Martin	The Dementia Coordinator of the Illinois Department of Public Health, or the Dementia Coordinator's designee	Illinois Department of Public Health
Phyllis Roate	Representing the Community Care Program's Home and Community Services Division	Illinois Department on Aging
Dana Wilkerson	Representing the Adult Protective Services Unit	Illinois Department on Aging
Dr. Erin Hascup	1 of 3 individuals from Alzheimer's Disease Assistance Centers	Center for Alzheimer's Disease and Related Disorders (SIU-SOM)
Dr. Darby Morhardt	2 of 3 individuals from Alzheimer's Disease Assistance Centers	The Mesulam Center for Cognitive Neurology and Alzheimer's Disease, (Northwestern)
Dr. Raj Shah	A statewide trade organization representing the interests of physicians licensed to practice medicine in all of its branches in Illinois - the Illinois Academy of Family Physicians	Rush University Medical Center
Shana Lister	representing long-term care facilities licensed under the Nursing Home Care Act, an assisted living establishment licensed under the Assisted Living and Shared Housing Act, or supportive living facilities	Regency Nursing Care
Carol Mauck	A statewide association representing the interests of social workers – the National Association of Social Work, Illinois Chapter	University of Illinois at Urbana-Champaign, School of Social Work
Dr. Marsel Mesulam	Individual with medical or academic experience with early onset Alzheimer's disease or related disorders	The Mesulam Center for Cognitive Neurology and Alzheimer's Disease

Absent Voting Member(s): Colette Jordan (Representing Area Agencies on Aging)

Non-Voting Member Agency

Becky Dragoo	State Dept. of Designee/Illinois Department on Aging
Sarah Smith	State Dept. of Designee/Guardianship and Advocacy Commission

Absent Non-Voting Member(s): Geunyeong Pyo (Illinois Department of Human Services)

Stakeholders Agency

- Lt. Governor Juliana Stratton
- Cheryl Adam Illinois HomeCare & Hospice Council
- Dr. David Bennett Rush University Medical Center
- Janene Brickey Illinois Department of Healthcare and Family Services, Bureau of Long-Term Care
- Samantha Brill Illinois Department on Aging
- Patricia Boyle Rush Alzheimer's Disease Center

- Ebone Lott Illinois Department of Human Services
- Dr. Karen Mancera-Cuevas Illinois Department of Public Health, Office of Health Promotion
- Robert Mannis Office of Illinois Lt. Governor Juliana Stratton
- David Olsen Alzheimer's Association, Illinois Chapter
- Laura Vaught Illinois Department of Public Health, Governmental Affairs

Office of the Lt. Governor's Update

- Lt. Governor Juliana Stratton joined the ADAC meeting to share an overview of efforts to address Alzheimer's disease. She has made Alzheimer's disease and all dementia a priority issue. The #ThroughOurEyes campaign, which kicked off in June 2019 with a 6-month listening tour. They heard about the challenges facing families and healthcare professionals in diverse communities across the state. The tour included 11 small-group listening sessions, 2 Alzheimer's Walks, numerous social media videos, and culminated in a large event with Governor Pritzker to share learnings from the tour in December 2019.
- She shared it was important the listening tour resulted in change. Their first policy initiative was introducing legislation, in spring 2020, to require dementia training for physicians. This would address diagnosis of Alzheimer's disease and other dementias, including recognizing the signs and symptoms of dementia; person-centered care; assessment and care planning; and culturally competent health care. The suspension of the spring legislative session due to COVID-19 temporarily halted progress, which will continue in upcoming sessions.
 - David recommended gaining CME credits through a professional association. Physicians are required to receive a certain number of certifications.
- The second policy initiative was to explore the creation of a taskforce focusing on access to services for people living with a dementia. Robert will table asking for a task force until the next ADAC meeting, to allow more time to talk with stakeholders.
- A memo outlining the proposed efforts was shared with ADAC prior to the meeting.
- Lt. Governor Stratton concluded she is a champion and is excited to uplift ADAC efforts.
- Marsel appreciated early onset of dementia was included in the efforts. These families have different needs and challenges. He also looks forward to seeing services harmonized.

Review & approval of October 28, 2019 meeting minutes *

- Copies of the minutes were distributed prior to the meeting and available at the meeting. Raj motioned for the approval of the minutes, with a second from David. Motion carried.

Illinois Department of Public Health Updates (Reporting: Karen)

- Dementia Coordinator position –the Department is continuing to work with CMS on hiring the Dementia Coordinator. An interview panel is being formed.
- Behavioral Risk Factors Surveillance Survey – the Department is moving forward with the BRFSS Caregiver Module.
- The annual updates from the Regional Alzheimer's Disease Assistance Centers and State Agencies Serving Persons with Dementia (FY2020) were distributed prior to the meeting.

Alzheimer Disease Research Funds Update (Reporting: Karen)

- Given the limitations on the use of the Alzheimer's Research Fund (currently specific to Grants only), the Department has submitted a supplemental appropriation bill in order to allow more spending flexibility. The Department is also seeking for FY22, The \$1M in GRF appropriations for Alzheimer's and an increase in spending authority from the Alzheimer's Disease Research Fund.

Bylaw Revisions * (Reporting: Jennifer)

- Draft bylaws were created to reflect the new membership structure. The format was based on a template provided by the Department; however, the content mirrors the previous bylaws.
- Discussion:
 - Is there a limit to the number of terms? No

- Is it ADAC's responsibility to review administrative rules? The bylaw template includes a section to address administrative rules review. Members took it under consideration. Laura explained the rules would not go to ADAC unless they were statutorily updated, then goes to the board of health (meets 4 times a year). Members decided to remove this section from the bylaws based on the following factors – 1) ADAC has not served that role before. 2) Unsure how many ADAC members have expertise in rules. The question arose about if this section is removed, does that take ADAC out of the discussion. The responses were 1) Any member of ADAC can provide recommendations through their own agencies. 2) All meetings of the board of health are open to the public and ADAC can provide comments as a group during the comment period.
- Raj motioned for the approval of the draft bylaws, with the removal of the section pertaining to administrative rules review, with a second from David. Motion carried.

Regional Alzheimer Disease Research Centers Annual Update

Each center shared their appreciation to ADAC, state association, and the families for the support over the years.

- Northwestern University Feinberg School of Medicine (Reporting: Darby) – Power point presentation provided.
 - Working with many populations. Saw over 2300 patient visits in FY20. They continued to see patients and families via telehealth and now in person in a restricted capacity.
 - Quality of Life Engagement
 - Buddy program ended the year 2020 remotely. A directory of online sources was created.
 - Support groups have moved to an online format.
 - SEED (Support and Education for Early Dementia) program - getting ready for Fall SEED.
 - New York University is looking to replicate the prog into a research project.
 - Arts for Brain Health Coalition continues to meet and developed a package of activities postal mailed to those unable to connect to online arts programming. Members include Art Institute Chicago, La Brocha, Lookingglass Theatre Company, NorthShore Dance Company, Northwestern University, and Rush University.
 - Northwestern Civitas Music Café – provided a pilot online music café.
 - Education
 - Alzheimer's Day in May was postponed and offered online in September - 350 people attended.
 - PPA Conference 2020 had to be canceled. This would have been the first ever PPA conference. It included a professional track. In process to move the conference to next year.
 - Seminar series is offered as an online bimonthly platform.
 - Community engagement – partner with community partners to raise dementia awareness.
 - Training program includes aging and dementia training, in addition to fellowships in behavioral neurology and in neurocognitive disorders.
 - Research
 - Use AOSLO (Adaptive Optics Scanning Laser Ophthalmology) as a potential early biomarker of AD.
 - Attitudes about Brain Donation among African American Research Participants – a project to see why there was less participation among AA research participants. Focus groups were conducted.
 - PPA Tele-Savvy - Pilot grant to adapt the Tele-Savvy to PPA Caregivers.
 - Super Aging – the research continues.
 - Microglia in Human Aging is a continuation of a project funded by the ADRF. Shows the difference between super agers, young, and normal old brains (super ager, and young are similar).
 - A coordination coordinator was hired. They started a monthly email. Sign up at the link or email to Darby.
- Southern Illinois University School of Medicine (Reporting: Erin) – Power point presentation provided.
 - A photo of the center's faculty and staff was shared. There are 11 Faculty, 22 Staff across 6 departments/centers.
 - Changes in FY20

- Erin was appointed as the Director in January 2020. Dr. Tom Ala was instated as the Medical Director. Greg Kyrouac, Director of Education and Outreach, retired. A research scientist was added to the staff.
 - Diagnose and Treat - 276 individuals for initial clinical assessment. 2,595 follow-up visits. Individual and family consultations. Collaborations with the NSI and Departments of Neurology, Psychiatry, Internal Medicine, and Family & Community Medicine on joint and individual cases.
 - Primary Provider Program – continue to support the Memory and Aging Networks (MAN). There are 32 sites - representing hospitals, clinics, health departments, mental health and counseling centers – allowing them to serve a large area.
 - Research slide
 - Clinical - 14 Investigator Initiated Research Studies, 10 Industry Sponsored Clinical Trials, 139 Patients Enrolled in Clinical Trials, and 8 Publications.
 - Bench/Translational - 9 Investigator Initiated Research Studies and 13 Publications.
 - Training education and comm
 - Effected by COVID-19. Was able to host the Fall conference on Memory Loss; however, the Spring Risk and Prevention Conference was cancelled.
 - The Extension for Community Healthcare Outcomes had monthly mtgs to address aspects of Alzheimer’s disease and related disorders. It is virtual. It started this year and there has been much participation.
 - More than 220 educational programs in FY20
 - More than 5,530 attendees for healthcare providers and community members.
 - Beyond the Medical Center Program – have had some difficulty transfer to virtual platform but making progress.
 - Central data collection – 3 different forms: CADRD and MAN clinical information, CADRD Brain Bank, and Longitudinal Neurocognitive database.
 - Federal Financial Participation
 - Current (bench/translational research) and potential research (Clinical, Translational, Epidemiological, and Beyond the Medical Center Programs.)
 - FY21 and Beyond – want to foster collaboration with RADAC, Research/evidence approach to all aspects of CADRD, Virtual BTMC programs to expand to reach MAN and other communities, Longitudinal Biospecimen Bank, Rural/urban disparities, Racial disparities, Mobile/tele health, Recruit a Director of Community Engagement, and Recruit 1-2 additional clinical faculty.
- Rush University Medical Center (Reporting: David)
 - Overview of the center – conduct clinical trials; prevention of cognitive and motor function, gait disorders and disability; common neurodegenerative disease and stroke; resilience; metabolic disease; HIV and aging; health equity; sleep and circadian rhythms; immune function; diet, nutrition, and metals; traumatic brain injury; intracerebral hemorrhage; ICU-dementia’ behavioral- and neuro-economics; well-being; decision science; neuroimaging; biomedical devices; pathologic anatomy; genetics; molecular genomics; computational biology; novel biomarkers; novel therapeutic targets, and human cell modeling.
 - RADAC timeline. Started with funding from IDPH and NIH. Expanded to many studies. Currently have 33 faculty, 2 visiting professors, many strategic partners plus 150+ staff.
 - Decision science – healthcare decision making and literacy study.
 - Seeing a change in the labor force. The Labor Force is Aging. The trend is increasing, combined with the fact there is a shift in retirement plans. The way people get their retirement benefits has changed. Before, many had any defined benefit, now it is a defined contribution only plan.)
 - Now they get a lump sum, and people have to manage their own money. Also. people are targeting older people.
 - Many years ago, they created a “Healthcare Decision Making” and “Financial Decision Making” to assist in deciding a health plan.
 - Literacy – asks about domain-specific knowledge, including questions about healthcare knowledge, financial knowledge, and intuitional knowledge. Literacy impacts financial and healthcare decisions

made by older adults. Lower total literacy was associated with higher burden of global AD pathology.

- When you put this together, someone with Mild Cognitive Impairment is susceptible to scams. Higher scam awareness was associated with higher burden of AD pathology.
- Summary – RADC provides clinical services and engages in a broad range of aging and AD research. Health and financial decision making associated with mortality, incident AD and MCI, and AD pathology. Health and financial literacy associated with mortality, incident AD and MCI and, AD pathology. Older persons retiring with more wealth are susceptible to scam which is associated with cognitive decline and AD pathology.

State Agency Updates

- Illinois Department on Aging (Reporting: Phyllis)
 - Funding from the Older Americans Act
 - DHS and IDoA to work together.
 - PPC and Opening Minds through Art (Older American Services funded)
 - CARESACT and other federal funding - \$38 millions – majority went to home meals (a service for those with dementia under 60). Delivery method changed due to COVID.
 - April – Sept 30 – home delivers of over 5 million meals. Signed up many new participants. Also, delivered toilet paper and information packets with meals.
 - Legal services – wills, power of attorney, and other services offered through drive up.
 - Face to face services – offered protective and safety equipment.
 - Additional funding for caregiver support.
 - State funding – at last ADAC meeting, shared information about two funded projects. Since that meeting, they were impacted by COVID. The projects were adapted.
 - Social isolation – those with dementia and caregivers are audiences with most at risk of isolation.
 - Adapted equipment program
 - Some AAA put together packages to send along with meal and home checks.
 - AD
 - Savvy caregiver - continue to offer because the authors of the program created tips and guidelines for trainers on how to conduct the program online.
 - Funding Stress Busters for Caregivers – entire program is focused on caregiver self-care.
 - IDoA was going to bring trainers to IL to train the AAA, then they were impacted by COVID. Currently not available online so this program is on hold since it is face to face is the only option.
 - \$1 million to do Savvy or Stress Busters for Caregivers – AAA could chose to do one or both. Since they couldn't do Stress Busters for Caregivers, now the funds can be used for a third project (Gap Filling).
 - Committed to training providers. They asked for more information about how to work with those with dementia so they developed the Dementia Care Specialist Course, based on competencies created by ADAC. The course is for non-clinical professionals. They completed two sessions, then suspended the next session due to COVID. They are in the process of adapting the course.
- Illinois Department of Healthcare and Family Services – no update
- Illinois Department of Human Services – no update
- Illinois Guardianship & Advocacy Commission
 - Sarah - discussed their program. They are available to those who need help with health and/or financial issues; AD is a large portion. COVID – comorbidity has made it challenging for those they serve. Some facilities are high risk, so they are not able to open.

Illinois Cognitive Resource Network Update

- Materials will be shared with members after the meeting.

Identify Potential Meeting Dates for 2021

- IDPH will wait until the dementia coordinator is hired before setting the 2021 meeting dates.
- Members were asked if there were dates, they'd have conflicts to meet in 2021. For the April meeting, ADAC should meet on day the legislature is not in session.
- Tentatively, 2021 meetings will be held in WebEx.

Other ADAC Discussion

- None

Agency Announcements

- None