

## **MEETING SUMMARY**

### **ILLINOIS DEPARTMENT OF PUBLIC HEALTH ALZHEIMER'S DISEASE ADVISORY COMMITTEE (ADAC) MEETING October 22, 2018, 12:00 noon to 3:00 p.m.**

*Approved April 15, 2019*

Rush University Medical Center  
Searle Conference Center - 5th Floor – Room 507/Sippy  
Professional Building - 1725 W. Harrison  
Chicago  
*(Zoom was available to those unable to join in-person)*

#### **Welcome and Introductions**

- *Appointed/Pending Members Present:* Dr. Tom Ala, Jen Belkov, Evan Davis, Cindy DeGroot, Nancy Flowers, Dr. Jeannine Forrest, Colette Jordan, Shana Lister, Jennifer Martin, Dr. M. Marsel Mesulam, Dr. Darby Morhardt, Phyllis Roate, Dr. Raj Shah, and Orlinda Speckhart.
- *Guests Present:* Dr. David Bennett, Dr. Beth Phelps, and Dr. Robert Struble.
- *Appointed/Pending Members Absent:* Jeff Christiansen, Dr. Mary Milano, Conny Moody, Robert Thieman, Susan Helm, Sam Hill, and Lori Kerns.

#### **Review and Approval of April 19, 2018 Meeting Minutes**

- Copies of the minutes were distributed prior to the meeting and available at the meeting. Ms. Flowers motioned for the approval of the minutes, with a second from Dr. Ala, motion carried.

#### **Illinois Department of Public Health Update**

- Ms. Martin reminded members of the training requirements – ethics training, sexual harassment prevention training, and Open Meetings Act Annual Training.
- The core competencies and updated ADAC member list was added to the IDPH Alzheimer's Disease webpage.
- The annual documentation of the service network and designation of regional centers and primary providers was distributed last week.
- New appointed members introduced themselves.
- Update on nominee/vacancies –
  - Nominee – Colette Jordan, representative for Illinois Association of Area Agencies on Aging.
  - Vacancies – nominations due October 26th – 1) Representative of SLF Serving Persons with Dementia, 2) Person with early stage AD (2 positions), 3) Family Member/representative (2 positions), and 4) General Public (over age 65).

#### **Alzheimer Disease Research Fund Update**

- A summary of the FY18 grantee reports were sent to members last week.
- A reminder of the current FY19 grantee was provided.
- Ms. Martin reported the Notice of Funding Opportunity will be posted online and be live until the end of January. Members are asked to help distribute the information widely. In December, she will be seeking peer reviewers.
- Review of survey results - During the April 2018 Alzheimer's Disease Advisory Committee (ADAC) meeting, there were several recommendations for changes to the Alzheimer's Disease Research Fund (ADRF)

monetary award and review process. The survey outlines the five recommendations and includes a summary of the discussion. Members were asked to share their vote on the recommendations by voting through Survey Monkey. If adopted, these changes will require changes to the current administrative rules, a process which takes an estimated 7 to 9 months to complete.

1. Recommendations with regards to MONETARY AWARD.
  - a. Increase the ADRF award to \$50,000. (9=yes; 0=No)
  - b. Cap indirect cost at 10%. (9=yes; 0=No)
  - c. Allow indirect costs to be in addition to direct costs. (7=yes; 2=No)
  - d. Limit grantees to one award. (7=yes; 2=No)
2. Recommendation with regards to ADRF REVIEW PROCESS.
  - a. Change the Tier 3 to focus on impact review. (7=yes; 2=No)

Ms. Belkov stated the Alzheimer's Association is proposing a different approach to revising the ADRF monetary award and review process. She and Dr. Shah, in his role with the Illinois Cognitive Resource Center, proposed changing the ADRF legislation to refocus funds to support a coordinator and Behavioral Risk Factor Surveillance System (BRFSS) modules – any funds that remain would support research. They recognize they need support from IDPH and ADAC, which led to today's discussion.

- Rationale
  - The association looked at the amount of ADRF funds each year and noticed the funds increased each year. They believe donations are up but the interest by researchers to apply is down.
  - In general, there are many funds for research but not much for the public health arena.
  - Political environment is changing – a large amount of additional federal funding is anticipated to pass for Alzheimer's research, in addition to the anticipated passage of the "Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act" which creates public health infrastructure at the state and local level. It looks good to pass. The act would direct the Centers for Disease Control and Prevention (CDC) to 1) establish Alzheimer's Centers of Excellence, 2) award cooperative agreements to public health departments, and 3) increase data collection, analysis and timely reporting. Other states have coordinators to implement Alzheimer's interventions and strategic actions. With additional support federally, Illinois will need the infrastructure at the state level.
- Proposal
  - Revise the tax check off to Alzheimer's Research and Education Tax Check Off to allow funding for BRFSS (which the association believes data are research) and support a coordinator. Dr. Shah explained it this way- ADRF would fund the coordinator position. Whatever funds were left over would support BRFSS modules when needed. If there were funds remaining, then those would be utilized for research grants. They believe, one of the coordinator's role would be to increase awareness of the tax check off; therefore, leading to more donations and more funds to support these efforts, including grants to researchers. There is an early draft of a coordinator's job description. They would allow IDPH to see the draft first.
  - Session starts in January. The association would like to change the ADRF language and divert funds to include the coordinator and BRFSS. Ms. Belkov shared the only reason they were proposing this approach was because it appeared there isn't interest in the ADRF funds by researcher as there was before; otherwise, they wouldn't have looked at this option.
- ADAC comments
  - ADAC members shared they just changed the ADRF monetary award to attract more researchers. Some felt we should see how that goes first before trying a different approach.
  - Some members mentioned it is a research fund, so funds need to be spent the way the taxpayer intended - research. (Ms. Belkov shared that is why the tax check off would be renamed to add "education" to title.) Taxpayers need to know what they are donating to.

- A member stated though there are increase in federal funds, there are some interventions that don't have an AD focus, so those researchers would still need access to research funds.
- Overall there were questions about this approach. Members were willing to hear more about it but requested information be shared in writing.

### **Regional Alzheimer Disease Research Centers Update**

*Members were encouraged to refer to the center summaries within the Regional Alzheimer's Disease Assistance Center FY2018 report.*

- Northwestern (Dr. Morhardt) –Their center will have a new name and new space in the next month. They will have a revised mission and new staff structure. They will continue many of the same observation studies but also begin new studies. Dr. Morhardt showed a video from the Today Show highlighting Northwestern's study on "Super Agers". She also shared an overview of various programs and initiatives.
- Rush (Dr. Bennett) – most of their research is focused on prevention of dementia. Their Dementia Care Clinic is a referral clinic and works closely with providers to increase services. They provide educational outreach to health care staff such as the annual certified nursing assistants conference. They conduct many clinical trials and outreach efforts to communities. They are part of five research trials – one national trial, one trial in Cook County, and three trials in Chicago.
- Southern Illinois University (Dr. Ala) – the center began receiving state funding. They lost several staff positions and now will rebuild. Dr. Ala shared the number of initial visits and follow-up visits from SIU and their 32 provider sites over the fiscal years. He shared information about their clinical trials, research, training and education initiatives. Dr. Erin Hascup received two National Institutes of Health grants and will hire more researchers. Dr. Ala shared their plans for FY19.

### **State Agency Updates**

- *Illinois Department on Aging (IDoA)*– Ms. Roate reported they had three Alzheimer's Disease related grants over time, their current grant is an expansion grant. They partnered with Southern Illinois University School of Medicine (e.g., programs and webinars), Alzheimer's Association (e.g., Savvy Caregiver and Care Navigation) and Coalition of Limited English Speaking (e.g., Savvy Caregiver in other locations). She explained their dementia capable series was based on ADAC core competencies. The training will be provided on the IDoA website and in-person. Several area agencies on aging have chosen the Dementia Friendly America program as a priority in their three-year plans.
- *Illinois Department of Healthcare and Family Services (HFS)* – Ms. Martin spoke to staff at HFS and gained the following update. As Susan Fonfa reported in the past, HFS had a pilot program for Supportive Living Program Dementia Care Settings. HFS's SLP program has three settings 1) conventional setting for older adults 65+ 2) settings for persons with physical disabilities (ages 22-64), and 3) Dementia care setting. The pilot included 5 settings and they are expanding the number of settings. They are unsure how many will be added but will keep us updated.

### **Illinois Cognitive Resource Network (ICRN) Update**

- Dr. Shah displayed the ICRN website - <https://ilbrainhealth.org/>. Everyone involved are volunteers. ICRN is the official representative for technical support for Dementia Friendly America (DFA) in Illinois. They collaborate with IDoA and follow IDPH's efforts. Their goal is to have a DFA presence in each region and each Chicago neighborhood. ICRN brought Dementia Friends, a DFA initiative, to Illinois, which encourages individuals to consider how they can support people in their communities. They are training Dementia Friends Illinois champions.

### FY19 meeting dates

- Members agree to maintain bi-yearly meetings in April (Springfield) and October (Chicago). Members provided guidance on days to avoid. Members also agreed to extend the meetings to four-hours in 2019 to accommodate the additional discussion related to the strategic plan revision.

### Other ADAC Discussion

- **State plan revision** – Ms. Martin reported the Alzheimer’s Disease state plan is updated every three years. The last plan was released in December 2016, so the next plan will be due December 2019. The following timeline was shared with ADAC:
  - **Oct 2018** - Form ad hoc committee at ADAC meeting.
  - **Nov 2018 to Oct 2019** - Ad hoc committee meet regularly from to draft
    - **Nov to Dec 2018** – Ad hoc committee finalize timeline revising the plan
    - **Jan to October 2019** – develop the plan
      - **April 2019** – Ad hoc committee provide update on the plan revision to ADAC
    - **Oct 2019** - Draft plan presented to ADAC for review
  - **Nov to Dec 2019** – IDPH internal review
  - **December 31, 2019** – plan is released
- The following people volunteered to serve on the ad hoc committee: Ms. Belkov, Dr. Forrest, Ms. Flowers, Dr. Morhardt, Dr. Raj Shah, and Ms. Speckhart. One of their tasks will be to determine what short-term recommendations have been met and which long-term recommendations needs to be moved to short-term. Ms. Martin will send an invitation to the ADAC members and stakeholder to encourage others to join the ad hoc committee.

### Agency Announcements

- Dr. Morhardt shared copies of their center’s newsletter.