

**District of Columbia Commission on Aging  
Draft Meeting Minutes<sup>1</sup> for  
Wednesday, April 19, 2017**

**Commissioners Present**

Romaine Thomas; Ron Swanda; Barbara S. Hair; Grace Lewis; Clarence “Buddy” Moore; George Arnstein; Guleford Bobo; Carolyn Nicholas; Guleford Bobo; Marguerite Pridgen; and Brenda Atkinson-Willoughby.

**Ex-Officio Members**

Raka Choudhury, DDOT; Mary Terrell, DOES; and Veronica Longstreth, DOH.

**D.C. Office on Aging (DCOA) Staff Present**

Laura Newland, Executive Director; Tanya Reid, Executive Assistant; Michael Kirkwood, General Counsel; Alice Thompson, External Affairs and Communication; and Garret King, Chief of Staff.

**Guests Present:**

Heather Foote, Senior Advisory Commission; Karen Rarog, ALS Association; Judy Taylor, ALS Association; and Sadaf Ahmad, Alzheimer’s Association.

**Call to Order**

Chairwoman R. Thomas (Chairwoman) called the meeting to order at 10:09 a.m.

**Inspiration**

Chairwoman shared a positive message from an Easter card. And she shared a message given to her from Commissioner Moore: “Reach for the stars. It is good to let a little sunshine out as well as in.”

**Review and Approval of Minutes**

The meeting minutes from the Commission’s March 29, 2017 meeting were reviewed; hearing no corrections the minutes were approved as read. Commissioner Moore moved the minutes be approved as read; his motion was seconded; and they were approved by voice vote.

Vice-Chair Swanda abstained from the vote because he was not present for the meeting.

**Presentations**

**A. ALS Association, Judy Taylor, Executive Director, DC/MD/VA Chapter and Karen Rarog, Executive Assistant**

**Background**

ALS (amyotrophic laterals sclerosis), commonly known as Lou Gehrig’s disease, is a neurodegenerative disease. There is no cure at this time. It may strike any person, at any time, regardless of age, race, etc. The average age (of someone with ALS) is 55 years of age. 75% of

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<sup>1</sup> The final (approved) meeting minutes will be posted on Wednesday, May 31, 2017, the Commission’s next meeting date.

people with ALS lose their ability to speak at all. It costs a family about \$250,000 a year in medical expenses. Most ALS patients stay in their home and are cared for by family members. Currently, life expectancy (of someone with ALS) is two to five years.

ALS Association's Board of Directors and many of its corporate partnerships are located in Washington, DC. They host many events during the year to raise funds for the organization; its two main events include the: 1) DC Walk to Defeat ALS, which is held on the national mall and most recently raised \$1.3 million; and 2) DC Dine to Defeat ALS, which will be held at the Mayflower Hotel this year.

### **DC/MD/VA Chapter's Work in DC**

The DMV chapter strives to be a resource to the patient and their family. Its services are free. The chapter provides home visits. For instance, a coordinator will go into a home to provide resources and support while the patient is on his/her ALS journey. The chapter also provides assistive technology. Communication devices are crucial because so many patients lose their ability to speak.

ALS has multi-disciplinary clinics in this area. At the clinics patients meet with a neurologist, nutritionist, occupational therapists, etc. The clinics provide durable medical equipment: walkers, power chairs, canes, etc. The equipment is loaned to patients at no cost.

The clinics offer monthly support groups. The groups allow patients to learn from others that are dealing with the disease. They also offer transportation grants to assist people with getting to medical appointments.

The DC area has the only certified medical disciplinary clinic. (Another one will be opening soon at Georgetown University Hospital.) The clinic has all of the latest communication devices. Patients can visit the clinic and try out devices to help determine if they'll be able to use it for two years, which is a requirement of the clinical program.

### **Commission's Support**

ALS Association requests that the Commission spreads the word about ALS. ALS is a small organization and needs help getting the word out about its services.

In 2015, Commissioner "Buddy" Moore received a national award from the foundation recognizing his contributions to the fight. Buddy's wife was diagnosed with ALS in 2009. She passed away approximately one year later. His family thought she had roughly two years to live. They knew nothing about the disease when she was diagnosed. Luckily, they were advised to visit the GWU Hospital clinic for information and services. ALS loaned Buddy's wife a manual wheelchair, hospital bed, and a power chair. She was also given technology that connected to her eyeglasses; the device permitted her to spell things out to her family for communication.

### **Questions/Concerns:**

Comm. Hair: Has there been any breakthroughs? A drug coming out soon that may slow the progression of the disease down; it is an infusion. There is currently a drug out that will slow the progression of the disease down for three months.

Comm. Lewis: What are the symptoms before onset? Some examples of pre-onset symptoms are slurred speech or a leg that sort of drags behind them. Unfortunately, it takes a long time to be diagnosed with ALS.

Comm. Atkinson-Willoughby: Is there a specific test for ALS? No.

Comm. Pridgen: How many people in DC suffer from ALS? They may not know the number of people who are diagnosed; but the DMV chapter serves 20 to 50 people per year. Most people find the chapter online. The chapter will be implementing outreach to all the neurologists in the DC/MD/VA area soon.

Comm. Arnstein: Where does the other half of your budget come from? The chapter receives individual donations, the dinner program, and it receives grant funding. Where do your public funds come from? ALS does not receive government funding.

Comm. Atkinson-Willoughby: What is the DC Dine to Defeat ALS? ALS started this program because four to five years ago it did not have any corporate connections and wanted to diversify how funds were coming in. The organization honors community leaders whom helps it fundraise; it helps ALS grow its base of supporters. Is there any other demographic information about who suffers? Athletes; a lot of its patients are marathon runners. ALS serves a lot of veterans. For instance, Lou Gehrig played football before he played baseball. The DMV chapter currently serves an active marine who is 35 years old that was diagnosed with ALS.

Vice-Chair Swanda: How do you provide transportation? ALS contracts with a company to provide the service.

Comm. Pridgen: Are you supported by a main organization? The chapter works in partnership with the main association.

Comm. Bobo (question directed to Buddy Moore): How active was your wife? She was not active at all.

Vice-Chair Swanda: Is there any legislation or backing here in DC for you? ALS is looking at legislation on the federal level that will: 1) Waive the 5 months waiting period for federal social security; 2) Allow patients to have access to complex rehabilitative technology; 3) allow sign up for the ALS registry; and 4) give patients access to home health care and home health aides.

Chairwoman Thomas: In terms of the senior population, do you have a significant number of seniors that you serve? Over half of the people ALS provides services for are over the age of 60 years old. It's approximately 68% here DC/MD/VA.

## **B. Office on Aging Update from Laura Newland, Executive Director**

Director Newland (Director) reminded the commissioners that all upcoming events are listed on a handout in their folders. She encouraged the Commissioners to attend the upcoming Centenarian luncheon. And she informed them that the Sr. Symposium will held at Ballou High School on June 20, 2017; it is the first time the event will be held east of the river.

## **2018 Budget**

Director thanked those Commissioners who attended some of the town halls she recently held around the city. Director's council hearing to testify about the agency's budget will be conducted on April 25, 2017.

Director also referenced the budget presentation handout located in the Commissioners' folders. Her budget discussions with the community implored citizens to consider whether DCOA's programs are doing what seniors need them to do and are the programs what the community wants and needs at this point in their lives.

Budget engagement forums: There were three of them conducted at various locations around the city. Each table of citizens in attendance were asked how they would allocate \$100 of a fictitious budget. With regard to the budget sources, Director stressed to seniors that what happens at the federal level impacts the local because of the amount of money allocated to certain programs.

DC Values (as evidenced by the budget): Combat Isolation, Promote Wellness, Support Aging in Place, Invest Wisely, and Listen. Director asked the group, "Is wellness accessible to you?" DCOA must coordinate and communicate the wellness activities that occur in the two wards that do not have a brick and mortar wellness center.

Safe at Home is a great example of a creative solution. And it's an example of when we get it right in government. It was the result of another program that was slow and people did not understand it. The success of Safe at Home is that it's easily understood and easily accessible.

The Mayor allocated \$330,000 for senior villages in FY218. The villages are grass roots organizations. Although grateful and appreciative of the funding, Director would like to avoid the creation another non-profit that relies on the government to exist. Therefore, she wants to use the funding in a smart way.

DCOA is eliminating part of the grant because it funds the same service in different ways. One of DCOA's grantees provides a duplicative service with DCOA funds. DCOA operates a call center within its headquarters and receives a federal dollar match for the service. A similar service was also being funded by DCOA at IONA; it was the only lead agency with a call center. In FY18, DCOA will no longer fund the \$105K for information and referral at IONA because DCOA headquarters provides the same service.

Listening: 1) PACE<sup>2</sup> is the program of all-inclusive care. DC is one of few jurisdictions that does not have a PACE program. It's a fairly cost effective model for keeping people out of nursing homes. FY18 will be a planning year for a PACE program here and FY19 will be an implementation year for it. DHCF will be in charge of it.

Caregiving: There needs to be places where caregivers can drop-off their loved ones and get respite. It is expensive to provide individual caregiver support but it's not as expensive if there is

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<sup>2</sup> PACE stands for Programs of All-Inclusive Care for the Elderly (PACE); it provides comprehensive medical and social services to certain frail, community-dwelling elderly individuals, most of whom are dually eligible for Medicare and Medicaid benefits.

a center for multiple caregivers because it's much more cost effective. There is a gap with caregiving and adult day health centers.

**Questions/Concerns:**

Comm. Atkinson-Willoughby: "Would it be appropriate to support these things listed or to say, "Aging"? We're funded under the Health and Human Services cluster which is listed on the handout.

Comm. Nicholas: What is the budget breakdown for Human Services? The vast majority of the \$4.7 billion is for Medicaid. What are the implications of a lower budget growth than in the past? You can expect to see an increase in agency budgets. In 2017, the approved DCOA budget was \$40 million. For FY18 it's \$45 million, roughly an 11% increase from FY17.

Vice-Chair Swanda: How will you expand transportation? We plan to fund transportation to all of our sites. Each wellness center will have at least one bus and a driver they'll be able to have access to.

Comm. Bobo: A recreation center will be built in Ward 8 and will be an intergenerational center; will DCOA be involved in this? This is the first I've heard of it but we welcome the chance to be a part of it.

Comm. Moore: The wellness centers are beginning to need additional space. What about using the recreation centers that are not being used during the school year? We have \$350,000 to develop wellness programs with DPR; the money will be in DCOA's budget but will require DCOA to develop a formal relationship with DPR.

Comm. Hair: Can we put a daycare in Ward 8? Adult day health is not just for people with ALS or dementia.

Comm. Atkinson-Willoughby: Will there be information on who received the villages grants? Are there examples of what a really good grants looks like? Yes. And the OPGS<sup>3</sup> offers training for groups. We funded the creation of a village in Ward 8, via a church, and to support one on Capitol Hill in Ward 6.

Comm. Bobo: The \$300,000 is that for the establishment and to support villages? It's to "support" villages; and I find there's a lot of flexibility in that language.

Comm. Pridgen: Is the input we're providing and community engagement impacting your decision on the budget allocation or are you just reporting to us how the money will be spent? You should express your thoughts regardless of what we intend to do. This is the budget that I will defend.

Vice-Chair Swanda: Was the Alzheimer's program a federal grant? It was a three year grant and this is the final year. We'll be applying for another grant this summer. The original grant was for \$700,000 for three years. There are ways the program can be run differently.

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<sup>3</sup> Office of Partnerships and Grants Services.

Comm. Bobo: What is the scope of Safe at Home; would someone in a condo qualify for the program? Yes. The program will accommodate condos.

Comm. Nicholas: Are we making strides to providing more caregivers or home health aides? I haven't heard there's been a shortage. I've heard of staffing problems in the past but not recently. Do we have data beyond the Needs Assessment as to who actually needs those services? No. Data has been a tough nut for us to crack.

Comm. Pridgen: Do you have a sense of how many people need the service? I think we need to define what "service" means?

Comm. Moore: Seabury Connector Card, how is the program going? It's partly funded through a separate grant. It is at capacity now; we don't anticipate additional changes to the program.

### **Committee Reports**

Chairwoman Thomas: Rather than call them committee "chairs," she suggested committee heads be referred to as lead commissioners. She also indicated it would be good to have mini-commissioners serve on commission committees. She asked if there were objections to her suggestions; there were none.

Vice-Chair Swanda: Mentioned the big study done to help the Commission communicate better to the community. He distributed a handout and asked if Commissioners had ideas on what the Chairwoman should say to the council at the upcoming budget hearing please forward them to either he or the Chairwoman as soon as possible.

Chairwoman Thomas: Asked for the reports from the lead commissioners.

Elder Abuse and Financial Exploitation: Comm. Nicholas shared that the subcommittee with the Elder Abuse Prevention Committee recently had a productive meeting with the OAG. The group hopes to move forward with a strategy to get the new financial exploitation law enforced and not just sitting there on the books.

No other committee reports were provided.

### **Ward Reports**

There were no Ward reports.

Comm. Pridgen: She inquired if it would be of value to have commission's committees similar to or identical to the Age-Friendly domains. It would be something we should consider down the road.

Comm. Bobo: Shared that there is an issue of bed bugs at a senior facility at Ward 8. We're trying to address the issue.

### **Public Comment**

There was no public comment.

**Announcements**

There were no announcements.

**Adjournment**

The meeting was adjourned at 12:37 p.m.

These minutes were recorded by Michael Kirkwood, General Counsel, D.C. Office on Aging, and were formally approved by the Commission on Aging on [date].

Respectfully Submitted,

Michael Kirkwood  
General Counsel  
District of Columbia Office on Aging

DRAFT