

Alzheimer's Disease and Related Disorders Commission
2nd Quarter Meeting
December 8, 2020

DRAFT MEETING MINUTES

*Due to the active state of emergency, this is an electronic meeting pursuant to
Item 4-0.01 of the 2020 Appropriation Act.*

Members Present

Laura Bowser, *Chair*
Travonia Brown Hughes
Karen Darner
Chris Desimone
Karen Garner
Rick Jackson
Khurrum Khan
Kim Kutner
Carol Manning
Lory Phillippo
Lana Sargent, *Vice-Chair*
Margie Shaver
Pam Teaster
Krystal Thompson
Ishan Williams

Guests

Carter Harrison, Alzheimer's
Association

Staff

Marcia DuBois, Deputy Commissioner,
Division for Community Living
Kathy Miller, Director of Aging
Programs
George Worthington, Dementia Services
Coordinator
Cecily Slasor, Administrative Support

Agenda Items	Speaker
Welcome and Introductions of Members and Guests George Worthington went over the requirements for electronic meetings and did a roll call for attendance. Chair Laura Bowser opened the meeting at 10:05, welcomed members and guests and asked them to introduce themselves. Ms. Bowser then read the purpose of the Commission as defined in the Code of Virginia.	Laura Bowser, Chair
Review and Adopt Meeting Agenda <i>Action Item:</i> Adopt Meeting Agenda Ms. Bowser asked if there were any changes to the draft agenda as presented. None were offered. Rick Jackson moved to approve the agenda and Pam Teaster seconded	Laura Bowser, Chair

<p>the motion. A roll call vote was taken to adopt the agenda.</p> <p><u>Roll Call Vote</u> Bowser – Yea Brown-Hughes – Yea Darner – Yea Desimone – Yea Garner – Yea Jackson – Yea Khan – Yea Kutner – Yea Manning – Yea Phillippo – Yea Sargent – Yea Shaver – Yea Teaster – Yea Thompson – Yea Williams – Yea The agenda was unanimously adopted.</p>	
<p>Review and Approval of Meeting Minutes Chair Bowser asked if members had reviewed the September 8, 2020 minutes and if any edits were needed. There were no corrections so Ms. Bowser declared the minutes adopted as presented.</p>	<p>Laura Bowser, Chair</p>
<p>Public Comment No public comments were received.</p>	<p>Laura Bowser</p>

<p>Division for Community Living Report</p> <p>Ms. DuBois welcomed Commission members and introduced a number of new staff (not in the meeting) within the Division for Community Living.</p> <ul style="list-style-type: none"> • Liza White will be the new Lifespan Respite Voucher program coordinator. Liza will be processing the respite vouchers sent in to DARS/DCL. • Ronisha Dennis is a Social Work Intern from VCU who is joining DARS to work on several projects. • A new Director of Administration position is currently being filled and will work on grant & contract administration, financial management and will oversee finance staff. • Catherine MacDonald joins DARS as the No Wrong Door Project Specialist working with grants and the new partnership with Virginia Assistive Technology Systems (VATS). Ms MacDonald, a Gerontologist, is the former director of the Longevity Project (formerly Greater Richmond Age Wave). <p>Virginia's No Wrong Door was one of two finalists in the Administration for Community Living's (ACL) Mental Health Innovation Challenge to Combat Social Isolation. As such, it received \$75,000. The winner will be chosen from the two finalists in January 2021.</p> <p>Our <i>Promising Practices</i> series showcases the work of the Area Agencies on Aging (AAAs) during the COVID-19 pandemic. They have done a remarkable job responding to the crisis. Particularly in the area of home delivered meals. AAAs have also come up with innovative ways to stay in touch with seniors to combat anxiety and isolation. Ms. DuBois and staff have compiled their stories and shared them with Virginia administration and federal officials.</p> <p>Where do we go from here? Technology and policies affected by COVID and how to rethink things for the future.</p> <p>Ms. DuBois will share the information with George Worthington so that he can share with commission members.</p>	<p>Marcia DuBois Deputy Commissioner</p>
<p>Dementia Services Coordinator Report (Handout)</p> <p>Mr. Worthington presented his report covering the period from September 9 through December 8, 2020.</p> <p>1. Outreach and Education</p>	<p>George Worthington</p>

<p><i>Attended:</i> Numerous webinars including</p> <ul style="list-style-type: none"> • National Alzheimer's Disease Resource Center <ul style="list-style-type: none"> ○ Hospital2Home—Dementia Capable Care Transitions (September 15) ○ Providing In-Person Services and Supports to People Living With Dementia During Covid-19 (October 19) ○ Sustaining Dementia Programs (October 22) ○ Maintaining Services and Supports for People Living with Dementia and their Caregivers During Covid-19 (November 19) ○ Using Technology to Provide Services To People Living with Dementia and their Caregivers during Covid-19 (December 2) • Working with Clients with Diminished Capacity (September 15) • Four Pillars of the New Retirement: Dramatic Changes for Aging and Aging Services (September 16) • Covid Conversations: Until We Have a Vaccine (September 16) • AARP 8-80 for Age Friendly Communities in Virginia (September 21) • Virginia Governors Council on Aging: <ul style="list-style-type: none"> ○ Advance Care Planning (September 22) ○ Unique Challenges of Social Isolation During the Holidays (October 27) ○ Responding to the Pandemic (November 17) ○ Next Tuesday Dec 15 Well-Being at work: addressing stress as a caregiver or healthcare professional VGCOA.co • Social Isolation and Loneliness (Focus on Aging, September 28) • Advancing Racial Equity (American Public Health Association, September 29) • HCBS Innovation During COVID: Federal, State and DD Act Partners (October 1) • Visitation at Skilled Nursing Facilities Update (October 2) • Consumer Finance Protection Bureau Training for Caregivers (October 20) • Colliding Crises: Tackling Behavioral Health in a Pandemic (October 21) • Benjamin Rose Institute Katz Policy Lecture: Age Friendly Communities (October 29) • NCLER Representing a Person as Their Guardian (November 10) • Let's Talk About Dementia and Culture (November 10) • Transforming Dementia Care (November 18) • Person-Centered Dementia Care (November 30) 	
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<p>Virtual conferences:</p> <ul style="list-style-type: none"> • 2020 Annual Conference on Dementia (Alzheimer's Association Greater Richmond) (September 15/17) • Hampton University Alzheimer's Conference (October 16) • Public Health Law Summit (September 16/17) • Engaged Social Isolation Summit (September 24) • Northern Virginia Dementia Care Conference (November 9-13) <p><i>Presented:</i></p> <ul style="list-style-type: none"> • Alzheimer's Association Memory Care University Webinar: Faith, Family and Dementia (October 14) • Master of Social Work class, Christopher Newport University: Virginia's Dementia State Plan as an example of inter-agency collaboration (October 19) <p><i>Training</i></p> <ul style="list-style-type: none"> • Dementia Awareness for First Responders, Virginia State Police Academy, Richmond (September 10) *50 participants • Dementia Friends Champion training session (virtual) (September 25) *7 participants <p><i>Future</i></p> <ul style="list-style-type: none"> • Dementia Friends Champion training session (virtual) (January 20) • Partners in Prayer and Prevention (P3) webinar, <i>Brain Health and Dementia Programs</i> (TBD) • Virginia Governor's Conference on Aging, <i>Dementia State Plan/Dementia Friends joint session</i> (w/Laura Bowser, Lana Sargent, Karen Garner and Melissa Andrews—LeadingAge Virginia), Richmond, May 2021 (special pre-conference session)—tentative <p>2. Data</p> <ul style="list-style-type: none"> • CMS Medicare Beneficiary Chronic Conditions data—no updates (data available to 2017) • 2019 BRFSS Cognitive Decline and Caregiver modules—to update ADRDC on December 8, 2020 <p>3. Collaboration and Partnerships</p> <ul style="list-style-type: none"> • Virginia Caregiver Coalition (Secretary): <i>meeting on September 17, Executive Committee meeting on October 20</i> • Enhancing Family-Centered Approaches to Dementia Care Through Wellness and Training (Riverside ADPI grant) Advisory Council: <i>October 27</i> <ul style="list-style-type: none"> ◦ Medication Review Committee, <i>September 30</i> • Virginia Brain Injury Council: <i>October 23.</i> <ul style="list-style-type: none"> ◦ Brain Injury State Plan Committee: <i>October 9, November 10</i> • Geriatric Mental Health Partnership (Secretary): <i>Meetings cancelled during pandemic.</i> • RAISE Family Caregiver Council: <i>November 18.</i> 	
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- Advisory Council on Alzheimer's Research, Care and Services (National Plan) *November 9.*
- DARS No Wrong Door: *working on pilot project to enhance NWD dementia capability; pilot on hold.*
- Area Agencies on Aging/DSC workgroup on dementia protocols, *finalized protocol on November 16.*
- Virginia Department of Health: *included Dementia Friends notice in Partnership in Prayer and Prevention (P3) monthly newsletter. Will include messaging on brain health and offer brain health and Dementia Friends training/information sessions to congregations. This collaboration would be an integral part of the proposed BOLD Act Grant project.*
- Dementia Friendly Virginia:
 - *monthly phone call with DF Northern Virginia partnership.*
- Dementia Friendly Central Virginia (DFCV): *activities on hiatus*
 - Charlottesville Area Alliance (spearheading Age-Friendly/Livable Community initiative), elected Vice-Chair for 2021.
 - Charlottesville TRIAD, attended one monthly meeting
 - Continuing to explore including groups in Fluvanna, Culpeper and Farmville under DFCV umbrella while pursuing local initiatives

4. Grant Writing and Administration

Virginia Center on Aging GTE Grant 2019: Awarded \$24,618 (project end date December 31, 2020)

- Received 6-month no-cost extension through December 31, 2020
- Some agencies proceeding with in-person workshops with appropriate precautions
- Rosalynn Carter Institute (RCI) released virtual DWD workshop in late August
- Training: Three virtual training sessions were offered (January 21/22, January 23/24, January 28/29). Twenty trainees participated (one additional trainee was unable to attend but will attend a virtual training in September) from 16 different agencies serving 54% of Virginia's population and 70 of Virginia's 133 local jurisdictions.
- Each trainer provided with 37-38 *Dealing with Dementia Guides for Caregivers* to allow up to a total of **783 caregivers** to attend the four-hour workshops at no cost. Goal is to deliver 20 workshops by end of December 2020 to 300 caregivers. *Guides* have been distributed to trainers.
- As of December 8, five workshops have been delivered virtually; most trainers are waiting to be able to deliver the workshops in person.

<ul style="list-style-type: none"> • RCI extended the registration for all trainers through September 2021. • Average cost per individual served would be \$31.45. <p><u>CDC BOLD Public Health Programs to Address Alzheimer's Disease and Related Dementias (ADRD)</u></p> <ul style="list-style-type: none"> • Grant awarded to VDH September 8, 2021. • Project period is September 1, 2020 through August 31, 2023. First partnership meetings held on October 27 and November 12 to discuss workplan modifications. • Enhanced grant required a published Dementia State Plan, Alzheimer's or dementia advisory committee active for at least two years, and a 30% match. • \$150,000-\$500,000 (total project \$195,000-\$650,000 including match) • VDH working with DARS, Alzheimer's Association, The Balm in Gilead, Hampton University and other partners • Goal is to develop a strong public health approach to ADRD <ul style="list-style-type: none"> ○ Risk reduction ○ Early diagnosis ○ Using data for priority setting and action ○ Support for caregiving for persons with dementia, including addressing social determinants of health <p>5. Tracking Policy</p> <p>Virginia General Assembly</p> <ul style="list-style-type: none"> • <u>HB310/SB256 Alzheimer's Disease and Related Disorders Commission; sunset.</u> Extend sunset to July 1, 2023. HB310 passed House, referred to Senate Rules Committee. SB256 passed both Senate/House • <u>SB572 BOLD implementation Act.</u> Passed both Senate and House. Tasks VDH in consultation with DARS, to address and reduce risks and impairments associated with ADRD. • <u>Budget Amendment Item 340#2s:</u> Provides \$300,000 per year from the general fund to support dementia care management for individuals and families with a dementia diagnosis at the UVA Memory and Aging Care Clinic. Approved \$150,000 in final budget, but eliminated (as new spending) as a result of Covid-19 response. <p>United States Congress (S=Senate, HR=House of Representatives)</p> <ul style="list-style-type: none"> • <u>Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act,</u> co-sponsored by Sen. Tim Kaine (D-VA), signed on December 31, 2018, directs CDC to: <ul style="list-style-type: none"> ○ Establish Alzheimer's Centers of Excellence ○ Award cooperative agreements to public health departments ○ Increase data collection, analysis and timely reporting • <u>S.3703/HR.6813 Promoting Alzheimer's Awareness to Prevent Elder Abuse Act.</u> Introduced May 12, 2020, S: Passed August 	
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<p>6, 2020). HR: referred to House Committee on the Judiciary (Senate version held at desk August 14, 2020).</p> <ul style="list-style-type: none"> • <u>S.880/HR1873 Improving HOPE for Alzheimer's</u>. Introduced March 26, 2019. S: Read twice and referred to Senate Finance Committee. HR: Referred to Health Subcommittee. A bill to provide outreach and reporting on comprehensive Alzheimer's disease care planning services furnished under the Medicare program. • <u>S.740 Alzheimer's Caregiver Support Act</u>. Introduced March 12, 2019. Read twice and referred to Senate Health, Education, Labor and Pensions Committee. This bill authorizes the Department of Health and Human Services to award grants to public and nonprofit private health care providers to expand training and support services for families and caregivers of individuals living with Alzheimer's disease or a related dementia. • <u>HR.1903/S.901 Younger Onset Alzheimer's Disease Act</u>. Introduced March 27, 2019, referred to committee. A bill to support people under 60 diagnosed with Younger Onset Alzheimer's through Older Americans Act (OAA) programs (incorporated into the Supporting Older Americans Act 2020 and signed into law in March 2020). • <u>S.1126/HR.2283 Concentrating on High-value Alzheimer's Needs to Get an End (CHANGE) Act</u>. Introduced April 10, 2019. S: Read twice and referred to Finance Committee; H: Referred to Health Subcommittee. This bill would require referrals for positive cognitive screenings to appropriate diagnostic services, specialists or clinicians with diagnostic expertise, available community based services, and clinical trials. Effect changes to Medicare reflecting public health imperative of brain health, risk reduction of ADRD and incentivizing early detection and diagnosis and care planning services. 	
<p>Workgroup and Committee Reports</p>	
<p>Training Workgroup Rick Jackson, Chair <i>The Training workgroup met on November 18 to discuss the package of materials being prepared for the primary care workforce including screening tools, training materials and references.</i></p> <ul style="list-style-type: none"> • Members discussed the benefits of a unified brand for products supported by the Commission and agreed to bring the discussion to the full Commission. • Members reviewed several screening tools including the AD-8, MOCA, Mini-Cog, and SLUMS and discussed 	<p>Rick Jackson, Chair</p>

<p>their benefits and drawbacks including the availability of existing training materials.</p> <ul style="list-style-type: none"> • In the context of outreach, members discussed the early draft of a brochure advertising various training materials and resources around early detection and diagnosis and follow-up care. Such a brochure was felt to be useful to raise the profile of the Commission, DARS and the Dementia State Plan as well as to provide a quick guide to resources and trainings available. • Members discussed ways to encourage or improve workforce engagement with training including motivational interviewing. • Members supported the utilization and promotion of existing microlearning modules for training busy primary care workers. • Members discussed pilot sites for this project which will form one of the deliverables under the BOLD Act grant. <p>Following the branding discussion at today's Commission meeting, the DSC will update the attached brochure mock-up for further review at the next workgroup meeting in early 2021.</p> <p>Dr Brown-Hughes asked whether any of the validated screening tools could be administered online to aid her in screening research participants (members clarified the difference between screening tools that can be used virtually, while diagnostic assessments that should be done in person).</p> <p>Lana said one way to draw practitioners is to offer CMEs or CLEs to encourage primary care workers to take these trainings.</p>	
<p>Coordinated Care Workgroup <i>The Coordinated Care workgroup met on November 2, 2020 to continue working on the Dementia Road Map.</i></p> <ul style="list-style-type: none"> • The Coordinated Care Workgroup is focused on adapting the Washington State <i>Road Map for Dementia</i> for Virginia 	<p>Khurrum Khan, Chair</p>

<ul style="list-style-type: none"> • Virginia's BOLD Act Public Health Programs grant submission included funding to print 5,000 copies of the finished product and a 12-month workplan • Members discussed sections of the Road Map not covered in June, including a new section with specific information for caregivers themselves such as the importance of self-care. • Members discussed branding, marketing and training around the <i>Road Map</i> and other initiatives supported by the Commission and agreed to bring the discussion to the full Commission • The DSC suggested using artwork or photographs created by people living with dementia rather than photos of Virginia landmarks or nature. Members approved this suggestion and noted that it supports the message that one can have a good quality of life with dementia. • Members suggested ensuring the title includes people living with dementia in some way. The original publication is <i>Dementia Road Map: A Guide for Family and Care Partners</i>; this will be amended to <i>Dementia Road Map: A Guide for Virginians Impacted by Dementia</i> • A draft will be ready ahead of the next workgroup meeting in early 2021, which will then be made available to stakeholders for comment and feedback. • The final product is expected to be ready for approval by the Commission in June 2021 	
<p>Data and Research Workgroup <i>The Data and Research workgroup met on October 22 to further develop the concept of a Dementia Research Forum that would provide opportunities for researchers, consumers and potentially providers to network and market research opportunities and results.</i> Members discussed the proposed Dementia Research Forum and related topics:</p> <ul style="list-style-type: none"> • Members were provided with a link to the Us Against Alzheimer's conference session on engaging underserved populations with research. 	<p>Lana Sargent, Chair</p>

<ul style="list-style-type: none"> • Members discussed the benefits of picking up from the work done by the moribund Virginia Neuroscience Initiative and its Alzheimer's interest group in the proposed Dementia Research Forum • Members also discussed the benefits of asynchronous (non real-time) vs synchronous (real-time) offerings and agreed that a hybrid model would be best, beginning with asynchronous offerings and moving toward holding a mix of live and recorded sessions/presentations • Flash presentations: five-minute pre-recorded segments available delivered by researchers, individuals impacted by dementia (including from individuals talking about their experience of participating in research projects) and service providers • Forum-related metrics and data collections such as the number of people connecting with research • Developing a community-informed approach to research in Virginia • Creating a space for research to report to community and vice versa to generate potential research topics. • Members also discussed the logistics around the brief flash presentations including production and warehousing of videos • Ms Sargent and Ms Teaster volunteered to do mock-up flash presentations ahead of the next meeting in early 2021 	
<p>Branding of Commission-supported Initiatives Since the publication of the Dementia State Plan 202-2024, the Alzheimer's Disease & Related Disorders Commission has been working on specific projects aimed at achieving or partially realizing Plan recommendations. These include projects aimed at 3 different but related audiences: Consumers/individuals, providers, and researchers. The Dementia Services Coordinator is suggesting that these projects be brought under a unified branding to promote awareness and visibility of these initiatives and to raise the profile of the Dementia State Plan. The DSC has been using</p>	<p>Laura Bowser, All</p>

<p>“Dementia Capable Virginia” as a working brand while realizing the specific projects the Commission workgroups are developing.</p> <p>Commission projects that are currently underway are largely due to be completed by the end of June 2021.</p> <p>The <i>Dementia Road Map: A Guide for People Impacted by Dementia</i>, is a deliverable under the BOLD Act for Public Health Programs grant. The brand thus needs to be finalized and ready for launch by mid-2021.</p> <p>For Consumers:</p> <ul style="list-style-type: none"> • Dementia Road Map (ADRDC) • Tipsheets (DSC) • Webinars (AlzPossible) • Dealing with Dementia Workshops for Caregivers (DSC) • FAMILIES (DSC) <p>For Providers</p> <ul style="list-style-type: none"> • Dementia Capability Training (DSC) • Dementia Capability for DD Support Workers (DSC) • Tools for Primary Care Providers (ADRDC) <ul style="list-style-type: none"> ○ Screening tools ○ Clinical practice guides ○ Microlearning episodes <p>For Researchers</p> <ul style="list-style-type: none"> • Dementia Research Forum (ADRDC) • Data (Can we brand it? AlzPossible) <p>Mr. Worthington explained the concept of branding and shared branding examples from other states (Dementia-Capable Wisconsin, Dementia Capable Tennessee, Dementia-Capable Napa County). He discussed the working title “Dementia-Capable Virginia” analogous to the Virginia Department of Health’s “Live Well Virginia” brand. Several logo concepts were shared with members including an ‘exploded Virginia’ suggesting lobes of the brain. Mr. Worthington also shared a mock-up of a brochure for the Primary Care workforce offerings that</p>	
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<p>highlighted three buckets “training”, “resources” and “referrals.”</p> <p>Members felt that anything including the shape of Virginia should be a unified whole to represent inclusivity. Members liked the name Dementia-Capable Virginia; Mr. Harrison noted that Virginia was an early adopter of this concept of dementia capable and could leverage that by using Dementia-Capable Virginia. This also ties into the name of the “Dementia State Plan 2020-2024: Building a Dementia-Capable Virginia”. Ms. Phillippo said that the ‘human aspect’ of one of the logos really appealed to her, rather than just a shape or a brain. Ms. Garner suggested perhaps some element of the “Virginia is for Lovers” including some sense of empathy.</p> <p>Members discussed the brochure including the need to have an electronic offering, and whether this would be physical as well. It would be important to have some way of receiving feedback from the target audiences.</p> <p>Lana Sargent noted that she had worked with a biomedical engineer to create a mobile caregiver platform app, and it remains available on iOS and Android, and offered this to the Commission to potentially use. Mr. Worthington will explore this further with Ms Sargent and her colleague.</p> <p>Laura Bowser highlighted the use of QR codes to connect people with information and suggested these be incorporated.</p>	
<p>Data Collection and 2019 BRFSS (Behavioral Risk Factor Surveillance System) Data</p> <p>Mr. Worthington guided members through the results of the 2019 Behavioral Risk Factor Surveillance System) Cognitive Decline and the Caregiver module</p> <p>Cognitive decline module asks five questions 8.9% in 2015 to 9.5% in 2019 of respondents over 45 reported memory concerns that were getting worse over time. Around a third of respondents noted they needed help, and only just over half had spoken about their</p>	<p>Laura Browser Lana Sargent</p>

<p>concerns with their doctor, little changed from 2015. When the module is next asked, in 2023 or so, Mr. Worthington hopes to see an increase as the current projects of the Commission are rolled out.</p> <p>The Caregiver module asks nine questions. The main take away points were:</p> <ul style="list-style-type: none"> • 1 in 5 Virginians providing care • Primary needs: dementia & heard disease • Over half have been providing care for more than two years. Many for five years • Expectation of providing care w/in two years high <p>Dr. Manning suggested it would be interesting to write up and publish a report on this data, and asked whether other members would be interested in working on this. Mr. Harrison would like to be involved, and several other members felt this would be an important project.</p> <p>Mr. Worthington has been developing a protocol for better identifying persons with cognitive impairment in No Wrong Door, for the AAAs. He shared a flowchart of this that he developed with a group of frontline staff from several AAAs. The pilot project for this will move forward later in 2021 once the focus on the pandemic is reduced.</p>	
<p>New ADRD Treatments on the Horizon Virtual conference in October – VCU Dr. Brown-Hughes shared a video of Dr. Hamid Okhravi speaking at Hampton University's third annual Alzheimer's Conference in October talking about clinical trials for drugs for Alzheimer's patients. One promising treatment was noted in particular, although it ultimately did not receive FDA approval in November. Dr. Manning commented that maybe the drug will ultimately get FDA approval, but the more trials, the better. Members discussed the need for the Commission to remain independent, particularly when it comes to private sector entities that have vested financial interests in their products.</p>	<p>Travonia Brown-Hughes</p>

<p>Future Meeting Dates and 2021 Calendar December 8, 2020 2021 Dates are:</p> <p style="padding-left: 40px;"> March 9, 2021 June 8, 2021 September 14, 2021 December 14, 2021 </p>	<p>Laura Bowser</p>
<p>New Business Karen Garner shared that she hoped everyone would participate January 21, 2021 in Alzheimer's Association's virtual Day on the Hill in Richmond. The more voices that are there, the better. Ms. Garner asked members to please <i>text "AIM" to 52886</i> to support Alzheimer's advocacy, and the registration materials will be sent out after the meeting. Ms. Garner noted that it is important for members of the General Assembly (GA) to hear from members of the Commission during the shortened GA session.</p> <p>Chris DeSimone suggested having photos of members for new members.</p>	<p>Laura Bowser</p>
<p>Adjournment Laura Bowser adjourned the meeting at 12:18 p.m.</p>	<p>Laura Bowser</p>