Memory Matters



A publication of the Johns Hopkins Memory & Alzheimer's Treatment Center and Alzheimer's Disease Research Center

Fall/Winter 2017

Staff Spotlight:

Chloe Jackson Johns Hopkins ADRC Community Relations Coordinator



Chloe Jackson joined the Johns Hopkins Alzheimer's Disease Research Center as Community Relations Coordinator in April of 2017. She has extensive experience in outreach and educa-

tion through both her professional work and volunteer efforts.

What do you look forward to most about working in your position?

I am most looking forward to speaking to people and hearing their stories. I am also looking forward to playing a part in linking people to resources through my outreach and study recruitment efforts.

Do you have any specific initiatives that you would like to pursue in order to help increase dementia awareness, education, and/or research participation?

I would love to pursue making a series of educational public service announcements to increase awareness about dementia, and educate the public on the resources available to those whose lives are touched by Alzheimer's disease.

We encourage you to share this with your family and friends. If you would like extra copies, please call **Emily Braverman** at **410-550-9021** or **ebraver2@jhmi.edu**.

National Efforts to Increase Volunteers for Research

Clinical research and clinical trials are necessary for discovering new methods to detect, treat, delay or prevent disease. Recent Congressional budget increases for Alzheimer's disease research are facilitating the fight against Alzheimer's. This means researchers are now-more than ever-accelerating efforts to learn more about the disease and search for treatments. However, the success of this research critically depends on study participants, including individuals with mild memory problems,

those diagnosed with dementia and their caregivers, as well as healthy volunteers.

Although essential to progress, research studies often have difficulty enrolling the numbers of subjects needed. Nearly



80% of studies in Alzheimer's disease and healthy aging, for example, are delayed for

this reason. To help overcome enrollment issues, several national registries have been developed for matching volunteers to available studies.

Most of the registries function in a similar way. Interested volunteers complete an online profile and answer questions about themselves. The registries then compare this profile to the studies that are actively seeking volunteers. Some registries notify the individual about potential studies that fit with their characteristics, whereas others notify the study to let them know a volunteer may meet their entry criteria, so they can contact them. The next step is a more detailed screening. At every step along the way, the volunteer can decide whether or not they would like to participate in any particular study.

Calendar of Events

Oct. 28, 2017: Walk to End Alzheimer's Registration: 9 a.m. Canton Waterfront Park 3001 Boston St., Baltimore, MD 21224 Info: 410-561-9099, ext. 205 or kjames@alz.org

Nov. 4, 2017: Pythias A. and Virginia I. Jones African American Community Forum on Memory Loss

8 a.m. to 3 p.m. Coppin State University, Talon Center 2500 W. North Ave., Baltimore, MD 21216 Registration/Info: 1-800-272-3900 or jdaniels@alz.org

Nov. 11, 2017: Journey to Hope Conference on Memory Loss

8:30 a.m. to 2 p.m. Johns Hopkins Bayview Campus Asthma & Allergy Center Auditorium 5501 Hopkins Bayview Cir., Baltimore, MD 21224 Registration/Info: 1-800-769-1707

Apr. 13, 2018: Alzheimer's Association Annual Dementia Conference

8 a.m. to 4 p.m. Sheraton Baltimore North Hotel 903 Dulaney Valley Rd., Towson, MD 21204 Info: 1-800-272-3900 or jdaniels@alz.org

June 2018: Holistic Health Seminar on Memory Loss

8:30 a.m. to 12:30 p.m. Randallstown Community Center 3505 Resource Dr., Randallstown, MD 21133 Info: 410-550-2281

June 2018: Annual Alzheimer's Awareness Purple Weekend

Inform your congregation about resources and information on Alzheimer's disease by going purple during the month of June! Registration/Info: 1-800-272-3900 or jdaniels@alz.org

June 12, 2018: ADRC Annual Conference on Aging and Dementia

9:30 a.m. to 2:30 p.m. Owen Auditorium (CRB) 1550 Orleans St., Baltimore MD 21287 Info: 410-614-0363

Club Memory attendees play a game of balloon toss!

Educational and Support Resources Available Through the Memory Center

In addition to delivering expert patient care, the Johns Hopkins Memory and Alzheimer's Treatment Center (MATC) is dedicated to providing educational and support resources for individuals with cognitive impairment, as well as their families and caregivers.

One such program is Club Memory, which is celebrating its second year. Club Memory is a social club for individuals with earlystage dementia and their spouses, partners, and caregivers. The goal of Club Memory is to provide a supportive social community and stigma-free environment for gathering, socializing, and engaging in individual and group activities (including field trips, crafts, puzzles, and games). Club meetings also allow attendees to build social networks within the dementia community. Club Memory meets on the **first Tuesday of every month from 2-4 p.m. in the Medicine Education Conference Room of the Harrison Library in the Francis Scott Key Pavilion on the Johns Hopkins Bayview Campus** (4940 Eastern Avenue). There is no charge to attend Club Memory, though attendees will have to pay for parking (attendees should park in the East Parking Garage and enter at the blue awning).

Another resource available through the MATC is the recently opened Family Resource Center (FRC). The FRC houses print and online educational materials about brain diseases, ongoing research studies, and local resources for families. It is also home to the Caregiver's Library, with information for caregivers and examples of activities that caregivers and individuals with cognitive impairment can do at home–puzzles, crafts, games, and more. **The Family Resource Center is located within the MATC on the Johns Hopkins Bayview campus** (5300 Alpha Commons Drive).

To learn more about Club Memory or the Family Resource Center, contact Andrea Nelson, RN, Director of Memory Programs, at anelso18@jhmi.edu.



Hopkins Researchers Assess Community-Based Dementia Care Coordination Model

One of the largest challenges in caring for individuals with dementia is organizing care, resources, and services that allow them to remain comfortably at home for as long as possible. To address this challenge, a group of Johns Hopkins researchers, led by Dr. Quincy Samus, is exploring the impact of a program called Maximizing Independence at Home–or MIND at Home–to determine if care coordination maximizes quality of life and reduces health care costs.

In this community-based program, individuals with dementia and their caregivers work with Memory Care Coordinators to identify unmet, dementia-related needs. Needs are assessed in a variety of medical and nonmedical domains, including medication and symptom management, home safety, assistance with daily and meaningful activities, dementia education, service referrals, and more. Care Coordinators then collaborate with a team of healthcare providers (sometimes using remote video communication) to create in-



Dr. Deirdre Johnston and Memory Care Coordinator Lynn Huntley discuss care strategies with a family member using telecommunication. (Photo credit: Donna DeLeno Neuworth)

dividualized plans that systematically address unmet needs by providing connections with resources, skill building, and education; in addition, needs are monitored over time and care plans are updated as needed. This model of care is compared with a group who also receives a comprehensive assessment of needs and information about addressing these needs, but individualized care plans and coordination of services are not provided.

A previous pilot study showed that after 18 months, the group that received care coordination services lived at home for a longer period of time, reported a higher quality of life, and had a larger reduction in unmet dementiarelated needs relative to a group that received usual care. The current MIND at Home project is further testing the effectiveness of this model and determining whether it is cost effective. For more information about MIND at Home, visit the study website: **mindathome.org**

Save the Date!

Walk to End Alzheimer's Saturday, October 28, 2017 Canton Waterfront Park sponsored by the Alzheimer's Association

Help raise awareness and funds for Alzheimer's disease research, care, and support. There is no fee to register, but fundraising is encouraged.

For more information about the walk and a list of other locations in the greater Baltimore area where the walk will be taking place, visit **alz.org**. National Efforts (continued from page 1)

To learn more about some of the current national registries seeking volunteers, see the sites listed below:

- (1) Alzheimer's Association Trial Match (trialmatch.alz.org)
- (2) Alzheimer's Prevention Registry (endalznow.org)
- (3) Brain Health Registry (brainhealthregistry.org)



Research Studies at Johns Hopkins Seeking Participants

You can help us learn more about the diagnosis and treatment of individuals with memory problems by volunteering for a research study. Each study has different eligibility requirements for participants. Procedures, length of study and compensation vary.

Memory and Aging Study of the ADRC: 410-550-9021

Medication Trials in Individuals with Dementia: 410-550-9022

Dietary Study in Patients with Memory Problems: 410-955-1647

Magnetic Resonance Imaging (MRI) Studies in Cognitively Normal Individuals or Individuals with Mild Memory Problems: 410-955-5057

Positron Emission Tomography (PET) Studies in Individuals with Mild Memory Problems: gsmith95@jhmi.edu

For more information about research studies conducted by the Johns Hopkins Alzheimer's Disease Research Center, visit alzresearch.org.



The Johns Hopkins Alzheimer's Disease Research Center

Director Marilyn Albert, Ph.D.

Associate Directors

Constantine Lyketsos, M.D., MHS Philip Wong, Ph.D.

Community Outreach: 410-550-2281

Education Resources: 410-614-0463

Research Opportunities: 410-550-9054

Web: alzresearch.org

The Johns Hopkins Memory & Alzheimer's Treatment Center

Director

Constantine Lyketsos, M.D., MHS

Associate Directors Samuel Durso, M.D.

Marilyn Albert, Ph.D.

Clinical Associate Directors Paul Rosenberg, M.D. Esther Oh, M.D., Ph.D. Clinic Info: 410-550-6337 Web: hopkinsmedicine.org/psychiatry/specialty_areas/memory_center/

Patient and Family Support Services

A variety of support services are available that offer patients and caregivers opportunities to speak with others who have similar concerns and questions about coping with Alzheimer's disease or related disorders. These services also provide practical information and help members learn more about living with memory loss. The programs below are free and open to the public.

Hopkins ElderPlus Caregivers Support Group

Second Thursday of every month, 12:30-1:30 p.m. Johns Hopkins Bayview, 4940 Eastern Ave., Baltimore, MD Mason F. Lord Building, East Tower, Room E106 Info: 410-550-7044

Frontotemporal Dementia Group

Second Wednesday of every month, 10:30 a.m-12:30 p.m. Alzheimer's Association, 1850 York Rd., Suite D, Timonium, MD Info: 1-800-272-3900

Club Memory - social club for individuals with dementia and their caregivers First Tuesday of every month, 2-4 p.m. Johns Hopkins Bayview, 4940 Eastern Ave., Baltimore, MD Harrison Library and Education Center Info: 410-550-7211 or anelso18@jhmi.edu

Web-based Family Support Group

Supported by the Jane K. Shapiro Dementia Care Program Info: hopkinsmedicine.org/psychiatry/specialty_areas/memory_center/rabins_alzheimers/index.html

For more information about support groups in your area, visit alz.org/Maryland and click on "Support Groups".