



# THE 2016 ALZHEIMER'S AND DEMENTIA DISPARITIES SUMMIT: DIVERSIFYING THE RACE FOR A CURE AND CARE

## Summit Recap Report



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## ***Diversifying the Race for a Cure & Care: The 2016 Alzheimer's and Dementia Disparities Summit Recap Report***

### **About Racial and Ethnic Disparities in Alzheimer's Disease and Other Dementias**

The Latino and African American 65 and older populations will grow 224 percent and 114 percent respectively by 2030, compared to a 65 percent growth for whites (Administration on Aging, 2005). This demographic trend foreshadows a tremendous growth of Alzheimer's and other dementias (AD) in communities of color. According to researchers, the number one risk factor for Alzheimer's is advanced age and the likelihood of developing the disease doubles about every five years after age 65; after age 85, the risk reaches nearly 50 percent (Gaskin et al. 2013; Chin et al., 2011; Alzheimer's Association 2015).

The nexus between race, cardiovascular diseases, and AD risk further underscores the need for action. Hypertension, diabetes, stroke, and coronary artery disease are all risk factors for AD (Chin et al., 2011). These chronic conditions are more prevalent in Latinos and African Americans compared to other Americans, resulting in African Americans being two times more likely and Latinos being one and a half times more likely to develop AD than the white community. Despite this higher prevalence, African Americans and Latinos with AD are, on average, less likely than non-Hispanic whites to have been diagnosed with the condition (Clark et al., 2005). In fact, according to CMS data, diagnosis awareness among persons with Alzheimer's disease and other dementias or their caregiver (65+ years) is 37 percent for African Americans and 37 percent for Latinos.

Stigma, misunderstanding, and weak linkages to our nation's healthcare system are leading to significant disparities in Alzheimer's and dementia diagnosis rates, access to treatment, quality care, and clinical research and trial participation rates among Latinos and African Americans (Medicare Current Beneficiary Survey, 2009).

### **Topline Recommendations**

UsAgainstAlzheimer's and the Leaders Engaged on Alzheimer's Disease (LEAD Coalition) convened over 60 leaders representing 40 national and state-based organizations and institutions on issues impacting aging, health disparities, government, and industry on September 27 in Washington, DC. This inaugural summit focused on identifying priorities and strategies for addressing disparities in Alzheimer's disease (AD) and related dementia diagnosis, care utilization, and research participation for Latinos and African Americans. Summit attendees urged for an increase in disease state education, intensified direct community engagement, and culturally targeted policy solutions to address the destabilizing effects of Alzheimer's and related dementias on communities of color. Through a series of workshops and working group sessions, summit attendees identified the below cross-cutting priorities that should be adopted by federal, private, and community-based stakeholders to address disparities in brain health affecting Latinos and African Americans.

Cross-Cutting Priorities identified by summit attendees included:

- Establishing national coordination and goal setting around AD and dementia disparities.

- Establishing a culturally tailored public awareness campaign at the national and state-based levels.
- Improving workforce diversity of researchers and community outreach staff.
- Engaging and educating minority serving physicians, specialists, and healthcare professionals (nurses, pharmacists, community health workers, etc.) to improve diagnosis and research referrals with a particular emphasis on specialty care practitioners that are likely to see AD patients for comorbid conditions such as heart disease and diabetes.
- Educating, training, and coordinating with emergency medical personnel as well as other public safety officers who are likely the first responders to dementia related incidents (e.g. wandering) and are in a position to identify current or potential AD patients in need of assistance.
- Encouraging transparency in the reporting of clinical trial enrollment numbers by subgroup and outreach methods utilized.
- Leveraging technology and big data to better understand disparities at the community-level and to engage underserved populations.
- Encouraging institution focused vs. person centric community engagement and outreach strategies.

## **About the Summit**

The summit was based on insights generated by the 2015 Minority Roundtable on Alzheimer's held at the 2015 UsAgainstAlzheimer's Summit. Attendees highlighted the need for a forum to build partnerships and strategies to increase awareness and understanding of the disease among communities of color. The 2016 Alzheimer's and Dementia Disparities Summit brought together a diverse range of stakeholders for expert panels, caregiver testimonials, and working group sessions where attendees identified recommendations and priorities for increasing public awareness of AD, improving diagnosis and detection of AD among Latinos and African Americans, and increasing the engagement of communities of color in clinical research and trials. The below sections highlight the priorities by working group session.

## **Priorities and Recommendations by Working Group Sessions**

**After hearing from morning presentations, participants were given an opportunity to self select into Working Groups to address key issues in a more focused manner. The following priorities and recommendations were identified by each of the groups.**

### **Working Group I: Increasing Public Awareness of AD Among Latinos & African Americans**

*Facilitators: Constantina Mizis, Latino Alzheimer's and Memory Disorders Alliance; Jason Resendez, LatinosAgainstAlzheimer's Network and Coalition*

This working group focused on methods, strategies, and policy changes necessary for increasing awareness of Alzheimer's and dementia in communities of color. Participant suggestions included addressing both structural issues such as stigma, ageism, language barriers, and cultural barriers, as well as institutional barriers such as providing better training for medical practitioners particularly on communication with patients around complicated health problems. The working group also focused on the need for national and state based coordination to adequately address dementia from a population health perspective.

#### **Recommendations**

1. National coordination around public awareness efforts tailored to communities of color.
2. Focus on developing culturally sensitive and relevant messages and outreach tactics by community and subgroup (e.g. Mexican Americans, Puerto Ricans, etc.).
3. Leverage storytelling as a means of educating communities and engaging media on the importance of reducing stigma and to raise awareness of dementia among communities of color (e.g. Forget Me Not, telenovelas, etc.).

4. Development and deployment of user friendly technologies to provide educational content to communities of color.
5. Engaging minority serving physicians, specialists, and healthcare professionals (nurses, community health workers, etc.) to improve diagnosis and research referrals with a particular emphasis on specialty care practitioners that are likely to see AD patients for comorbid conditions such as heart disease and diabetes.

### **Working Group II: Prevention and Diagnosis**

*Facilitator: Dr. Glenda Wrenn, Morehouse School of Medicine*

The working group on prevention and diagnosis addressed the particular challenges that communities of color face when accessing preventative services, treatment, and care for Alzheimer's and related dementias. Barriers to seeking care included lack of awareness, stigma and fears surrounding the diagnosis. A need for a formalized referral system, training for clinicians, and improved transportation to improve access were also identified as hindering care. Solutions were presented to address these issues, including coordination across health systems and insurers, better training for medical practitioners for diagnostic interventions, as well as community-based services and educational outreach programs.

#### **Recommendations**

1. Given the disparity in diagnosis rates among Latinos, African Americans, and non-Hispanic whites, it is critical to set national goals to narrow these disparities by race and ethnicity.
2. Leverage mobile clinic and screening services to meet individuals in-community.
3. Improve provider education and awareness about what they must do to complete the cognitive screening requirement as part of the Medicare Annual Wellness Visit (AWV) and promote this benefit among diverse older adults and their families.
4. Identify or develop culturally competent care planning services and resource referrals for diverse patient populations.
5. Improve capabilities of minority serving physicians, nurses, social workers, and specialists to make an early and accurate diagnosis through professional training and brain health promotion.
6. Create a task force to review and evaluate diagnostic tools to eliminate potential biases based on race, cultural relevance, ethnicity and educational attainment).

### **Working Group III: Clinical Research and Trial Participation**

*Facilitator: Dr. Katya Rascovsky, University of Pennsylvania Perelman School of Medicine*

This working group addressed issues limiting minority participation in clinical trials and sought to develop suggestions for improving involvement through encouraging transparency, making public policy changes, and increasing community-based outreach. Many noted the challenges faced by communities of color in terms of lack of awareness and understanding of trials as well as the challenges faced by investigators under pressure to engage in high-performing research. Improving access along lines of culturally and linguistically appropriate engagement with the community emerged as a key theme in this working group.

#### **Recommendations**

1. Identify incentives such as a points reward system for federal grant scoring for Alzheimer's and dementia research to encourage the inclusion and recruitment of underrepresented populations.
2. Through incentives and accountability requirements, encourage transparency in the reporting and disaggregation of clinical trial enrollment data by community and subgroup.
3. Evaluate the reasonableness of strict inclusion and exclusion criteria for AD and related dementia studies that might impact the recruitment of underrepresented populations.
4. Develop a list or clearing house of AD and dementia trials that accept Spanish-speaking patients.
5. Ensure study sites are adequately resourced to engage diverse communities with culturally competent outreach staff.

6. Leverage diverse study participants and ongoing education and outreach efforts, e.g. community ambassadors.
7. Encourage institutional review boards to promote diversity and inclusion of underrepresented populations and ensure that IRB's are diverse bodies.
8. Evaluate the manner in which sponsors are paid (e.g. upfront payments).
9. Encourage the adoption of incentives and reimbursement practices related to clinical research and trial participation.
10. Establish Diversity awards and recognition opportunities for centers and sponsors that serve as centers of excellence in minority recruitment.
11. Evaluate structural bias in clinical assessment procedures at sponsor sites and research institutions.
12. Leverage the open enrollment phase of Medicare to educate public about clinical trials.
13. Prioritize the inclusion of diverse researchers and healthcare professionals on research teams, including the deployment of community health navigators to bridge the gap between communities and research institutions.

### **Case Study: Institution Focused Outreach and Recruitment**

In 2008, the Rush University Medical Center's Alzheimer's Disease Center (ADC) boldly changed their recruitment strategies. Previously, they had waited until someone was diagnosed with Alzheimer's before including him or her as a research participant. Today, their new approach includes following individuals over the course of their lives in order to learn more about the transition from normal aging into Alzheimer's. This change meant that recruiters went out into the community, working with community leaders to build trust and relationships, to engage individuals who might be interested in participating in research. As a result, their minority inclusion rates have significantly increased – almost 94% of individuals enrolled in their studies are African American.

Researchers credit their success in recruitment to giving back to the community and tailoring their approach to meet local needs, prioritizing the community. Many of the staff members are also community members, participating in local groups and churches. Rush ADC holds approximately 600 education events annually, provide exams in homes, give community lectures on the results of studies, and send regular newsletters and birthday cards to participants. These acts help to bridge the gap between the community and the researchers, minimize barriers to participation such as transportation, and keep up retention, as community members feel engaged, informed, and involved in the research process. The Rush ADC's motto in approaching the community, give before you get, has solidified strong relationships and made them a nationwide leader in minority recruitment.

## **Long-Term Vision For Continued Work Group Engagement**

Summit attendees established a framework for continued collaboration between grassroots, grass tops, private, and public stakeholders and will provide a platform for monitoring progress, sharing best practices, and adjusting course in the fight to address the growing impact of dementia and Alzheimer's on communities of color.

Working group participants include stakeholders from the Federal Drug Administration, Alzheimer's Mississippi, Faith United Against Alzheimer's Coalition of UsA2, Massachusetts General Hospital, the University of Pennsylvania School of Nursing, Alliance for Aging Research, and Caringkind.

### Working Group Framework

#### Information sharing

- Stay updated on important AD and dementia disparities research, policy proposals, news and related developments through working group email updates.

#### Partnership Building

- Be part of a listserve of likeminded organizations and stakeholders that you or your institution can reach out to for collaboration and coordination on research projects, advocacy efforts, and related projects.

#### Research & Policy Agenda Setting

- Collaborate with working group members to develop more fully key recommendations and priorities identified in this recap report, offering insights based on your area of expertise.
- Work with UsAgainstAlzheimer's and other working group members to translate recommendations into policy and practice through research collaboration and advocacy.

#### Time Commitment

- Quarterly one hour teleconference calls with the working group hosted by UsAgainstAlzheimer's with the possibility of other group calls based on working group committees (clinical research and trials, diagnosis and prevention, public awareness, caregiving).

### Next Steps

- The working group will hold its first call in mid-January to review the report recommendations and identify concrete projects for addressing the issues outlined by the report.

## About the Conveners

**UsAgainstAlzheimer's Network** is a disruptive, entrepreneurial organization advancing solutions to the Alzheimer's challenge by 2020. UsAgainstAlzheimer's speaks for persons with or at risk for Alzheimer's in pressing for greater urgency from government, industry and the scientific community – accomplishing this through relentless leadership, fierce advocacy, strategic investments and a focus on engaging women, African Americans and Latinos.

**AfricanAmericansAgainstAlzheimer's Network** engages individuals and organizations as the preeminent voice in and for the African-American community on Alzheimer's. Formed a little more than a year ago, the network has more than 2,400 members and has held successful awareness-raising events in multiple cities throughout the nation. It has innovatively used a play entitled *Forget Me Not* to increase general awareness as well as to help recruit African Americans to participate in clinical trials. This network, which participated in events that reached over 36,000 persons last year alone and had 1,500 persons attend six core events, would be one of two networks focused on outreach to patients and caregivers coming from diverse, minority populations. Stephanie Monroe leads the network.

**LatinosAgainstAlzheimer's Network and Coalition** represents the most rapidly aging segment of the American population, and one that is also disproportionately affected by Alzheimer's. The Latino Network raises awareness of Alzheimer's devastating impact on the Latino community by marshaling key health, community, and policy stakeholders in a coordinated effort to address Alzheimer's growing threat to the Latino community and the nation. The Latino Network launched the **LatinosAgainstAlzheimer's Coalition**, the nation's first-ever national coalition of Latino advocacy and health organizations dedicated to raising awareness of Alzheimer's impact on Latinos. Founding coalition members include the League of United Latin American Citizens (LULAC), Hispanic Federation, the Latino Alzheimer's & Memory Disorders Alliance, the National Hispanic Council on Aging, and the National Association of Hispanic Nurses and has grown to include other leading national and community-based organizations.

**Leaders Engaged on Alzheimer's Disease (LEAD)** is a diverse and growing national coalition of 87 member organizations including patient advocacy and voluntary health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, home and residential care providers, and biotechnology and pharmaceutical companies. LEAD is co-convened by UsAgainstAlzheimer's and Volunteers of America. The coalition works collaboratively to focus the nation's strategic attention on Alzheimer's disease and related dementias and to accelerate transformational progress in care and support to enrich quality of life, detection and diagnosis, and research leading to prevention, effective treatment and eventual cure.

## **APPENDIX**

### **Stakeholders in Attendance**

**Alliance for Aging Research  
Alzheimer's Greater Los Angeles  
Alzheimer's Mississippi  
Alzheimer's Orange County  
Biogen  
Caring Kind  
Columbia University  
Cure Alzheimer's Fund  
Eli Lilly  
Forget Me Not Project  
Fuerza Contra Alzheimer's  
Global Alzheimer's Platform Foundation  
Harvard Medical School, Massachusetts  
General Hospital  
Johns Hopkins University  
Latino Alzheimer's Alliance  
LatinosAgainstAlzheimer's Network  
Leaders Engaged on Alzheimer's Disease  
Lewy Body Dementia Association  
MaritaGolden.com  
Merck**

**Morehouse School of Medicine  
National Institute on Aging  
National Minority Quality Forum  
New York University School of Journalism  
NIH Information Center  
North Carolina A&T State University  
Rutgers University-Newark  
The Balm In Gilead, Inc  
The LatinosAgainstAlzheimer's Network &  
Coalition  
U.S. Food and Drug Administration (FDA)  
University of Pennsylvania  
University of Pennsylvania Perelman School  
of Medicine  
University of Texas Southwestern Medical  
Center Alzheimer's Disease Center  
UsAgainstAlzheimer's Network  
USC Edward R. Roybal Institute on Aging  
Volunteers of America  
WomenAgainstAlzheimer's Network**

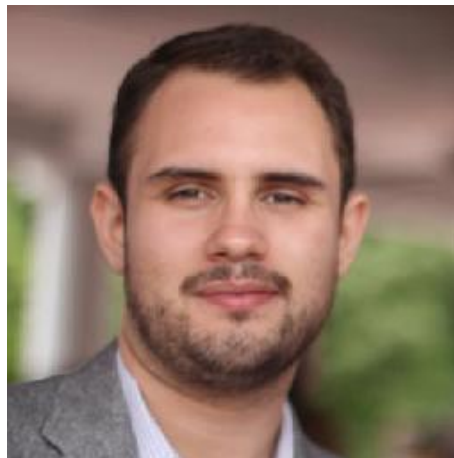
**PANELISTS AND BIOS (by order of appearance)**

**STEPHANIE J. MONROE** is Executive Director of UsAgainstAlzheimer's African American Network, which is the first national network created specifically to respond to Alzheimer's disease and its disparate impact on African Americans. By working nationally, locally, and through strategic partnerships, African Americans Against Alzheimer's is raising awareness of the critical need for additional research investments and arming African Americans and others with the information needed to engage, connect, and mobilize individuals, businesses, and community and faith-based organizations in efforts that advance our national commitment to ending Alzheimer's by 2025. One of the primary focuses is a multi-tiered effort to inform and encourage more African Americans to participate in clinical trials. An attorney with three decades of federal public policy experience. Stephanie served as the Assistant Secretary of Education for Civil Rights from 2005-2009. In that position, she was the Secretary of Education's primary adviser on civil rights issues. Prior to serving in the Executive Branch, Stephanie ended her 25 years on Capitol Hill after holding a number of key senior staff positions in the United States Congress.



**JASON RESENDEZ** is Executive Director, the LatinosAgainstAlzheimer's Network & Coalition. In this capacity he spearheads UsAgainstAlzheimer's efforts to drive awareness and action on Alzheimer's and dementia's disproportionate impact on the Latino community through strategic convening, policy analysis, and advocacy. LatinosAgainstAlzheimer's is a network of UsAgainstAlzheimer's, a disruptive and inclusive advocacy organization focused on stopping Alzheimer's by 2025. Jason serves as the co-chair of the diversity advisory committee of the National Alzheimer's & Dementia Patient & Caregiver-Powered Research Network, funded by the Patient Centered Outcomes Research Institute (PCORI).

Jason currently serves as an external advisor to several key initiatives in the technology and aging space, including AT&T's Advisory Panel on Access and Aging,



the Center for Aging in Diverse Communities at the University of California San Francisco (UCSF), and the Administration for Community Living's Hispanic Technical Expert Board.

**IAN KREMER** is Executive Director, Leaders Engaged on Alzheimer's Disease (LEAD Coalition). Ian became the LEAD Coalition's executive director in 2012, and has worked on dementia policy for nearly two decades. Throughout his career, Kremer has served as a board or advisory committee member for a variety of public service organizations, non-profits and government appointed panels in the fields of aging, technology and health. Kremer holds degrees from Washington University and the University of Michigan School of Law. He is a member of the Virginia State Bar and the American Bar Association. With Kremer at the helm, the LEAD Coalition has more than doubled in size while contributing to development of the National Plan to Address Alzheimer's Disease, securing historic increases in funding for dementia research at the National Institutes of Health, and working with the Centers for Medicare and Medicaid Services, the Food & Drug Administration and the Centers for Disease Control & Prevention to implement bold new programs to improve detection and diagnosis of cognitive impairment. Currently, Kremer is working with national and international organizations designing the future of dementia care practice, a blueprint for dementia care policy, protocols for early detection and diagnosis of cognitive impairment, and strategic initiatives to accelerate the global research enterprise.



**GEORGE VRADENBURG** is Chairman of UsAgainstAlzheimer's, which he co-founded in October 2010. George was named by U.S. Health and Human Services Secretary Kathleen Sebelius to serve on the Advisory Council on Research, Care, and Services established by the National Alzheimer's Project Act and has testified before Congress about the global Alzheimer's pandemic. He is a member of the World Dementia Council. George and USAgainstAlzheimer's co-convene both the Leaders Engaged on Alzheimer's Disease (LEAD) Coalition and the Global CEO Initiative on Alzheimer's Disease. He and his wife, Trish, have long been dedicated members of Washington's civic and philanthropic community. George served as Chairman of the Phillips Collection for 13 years, and is a member of the Council on Foreign Relations and The Economic Club of Washington. He has served in senior executive and legal positions at CBS, FOX and AOL/Time Warner. George and Trish published Tikkun Magazine for 10 years (Editor-in-Chief Rabbi Michael Lerner is Trish's brother).



**DR. GLENDA WRENN, M.D.** Dr. Wrenn is a psychiatrist and health policy/mental health services researcher at Morehouse School of Medicine where she directs the Division of Behavioral Health in the Satcher Health Leadership Institute (SHLI) and serves as Interim Co-Director of the Kennedy Center for Mental Health Policy and Research. Although much of her research focuses on systems of care improvements related to the culturally-centered integration of behavioral health and primary care, Dr. Wrenn's passion and overall research aim is to help create environments where individuals adversely impacted by trauma will face a path forward that makes it easier for them to recover and build a good life. As there are many paths to the trans-theoretical construct of resilience, Dr. Wrenn's work has examined diverse health conditions and approaches to fostering individual and community resource development and recovery.



Dr. Wrenn has helped to advance integration in several large health systems and individual practices of all sizes. She is a community engaged researcher, with frequent knowledge exchanges in the community through speaking and events; and also serves as an advisor for several local, regional, and national health-related organizations

**WILLIAM VEGA, Ph.D.,** is a Provost Professor at USC with appointments in social work, preventive medicine, psychiatry, family medicine, psychology and gerontology. He is the Cleofas and Victor Ramirez Professor of Practice, Policy, Research and Advocacy for the Latino Population at the USC School of Social Work. William is also the executive director of the USC Edward R. Roybal Institute on Aging and an emeritus professor at the University of California, Berkeley, School of Public Health. Prior to joining the USC Roybal Institute, he was director of the Luskin Center on Innovation and an Associate Provost at UCLA. An elected member of the National Academy of Medicine, William has conducted community and clinical research projects on health, mental health and substance abuse throughout the United States and in Latin America. He has published more than 200 articles and chapters, in addition to several books.



**GARY PUCKREIN, Ph.D.** Dr. Gary A. Puckrein is President and Chief Executive Officer of the National Minority Quality Forum. The Forum is dedicated to improving the quality of health care through the use of evidence-based, data driven initiatives. The Forum maintains a centralized data warehouse of vital statistics, demographics, environmental information, provider claims, prescription drug use, clinical laboratory values, health-care access points, and other data. The Forum employs these data resources to build web-based indexes and atlases that enable users to measure and forecast health status and disease prevalence in small geographic areas, evaluate the impact of specific interventions, and monitor changes in health outcomes. The Forum has also recently launched the Clinical Trial Engagement Network, the health-care industry resource addressing a critical need in drug research: improving the representation of diverse populations, including African Americans, Asian Americans and Hispanics, in clinical trials.



Dr. Puckrein is considered a preeminent authority on health information products and was the publisher of *American Visions* and *Minority Health Today*. Dr. Puckrein has served on numerous health-care advisory boards, including the National Advisory Board on Health Disparities for the Health Research and Educational Trust (American Hospital Association), the CLAS/Health Disparities Expert Panel (National Committee for Quality Assurance), and the Pharmacy Education Advisory Council (American Association of Colleges of Pharmacy). Between 1974 and 1992, Dr. Puckrein taught and lectured at Brown University, Rutgers University, Connecticut College, and Roger Williams College. Dr. Puckrein has received many awards and honors, including being named a visiting scholar and fellow at the Smithsonian's National Museum of American History and a visiting fellow at Princeton University. He was awarded doctoral and master's degrees in history from Brown University, and a bachelor's degree from California State University at Los Angeles

**DARRELL GASKIN, Ph.D.** is the William C. and Nancy F. Richardson Professor of Health Policy and Director of the Hopkins Center for Health Disparities Solutions at the Johns Hopkins Bloomberg School of Public Health in the Department of Health Policy and Management. Dr. Gaskin is a health services researcher and an internationally known expert in health and healthcare disparities, access to care for vulnerable populations, and safety net hospitals. He seeks to identify and understand barriers to care for vulnerable populations; to develop and promote policies and practices that improve access to care for the poor, minorities and other vulnerable populations; and to reduce and eliminate disparities in health and healthcare by race, ethnicity, socioeconomic status and geography. The NIMHD, AHRQ, NICHD, NIA, NHLBI, HRSA-MCHB, The Commonwealth Fund, the Kaiser Family Foundation, Giovannis Foundation, Aetna Foundation and the Robert Wood Johnson Foundation have supported his research. Dr. Gaskin's has published in the leading health services research and public health journals, including *American Journal of Public Health*, *Health Affairs*, *HSR*, *Medical Care*, *Medical Care Research and Review*, and *Social Science and Medicine*. He serves on the Editorial Boards of *HSR*, *Medical Care* and *Medical Care Research and Review*. He is the Chairman of the Board of Directors of AcademyHealth. He is a member of Board of Directors of Center for Health Policy Development, the governing body of the National Academy of State Health Policy. His Ph.D. is in public health economics from the Johns Hopkins University. He holds a MS degree in economics from the Massachusetts Institute of Technology, and a BA degree in economics from Brandeis University.



**JENNIFER J. MANLY, Ph.D.** is Associate Professor, Neuropsychology in Neurology, G.H. Sergievsky Center & Taub Institute for Research in Aging & Alzheimer's Disease, Columbia University where she works to improve the diagnostic accuracy of neuropsychological tests when used to detect cognitive impairment and Alzheimer's disease among African American and Hispanic elders. This work clarifies the independent influences of language, acculturation, educational experiences, racial socialization, and socioeconomic status on cognitive test performance, with the ultimate goal of understanding more about the relationship between culture and cognition. Recent work focuses on the specificity of cognitive tasks in detecting subtle cognitive decline among illiterate and low-literacy elders. This work has important implications for determining the complex influence of reading and writing skills on brain function.



**KATYA RASCOVSKY, Ph.D.** is a Research Assistant Professor in the Department of Neurology, University of Pennsylvania Perelman School of Medicine. She received her BA in Biological Basis of Behavior and Psychology from the University of Pennsylvania and a MA in Psychology from New York University. From 1995-1999 she worked in a memory disorder's clinic and taught neuropsychology in her native country of Colombia. In 2005, she was awarded her PhD in Clinical Psychology from the University of California, San Diego and completed a two-year postdoctoral fellowship in Neuropsychology at the Memory and Aging Center, University of California San Francisco, where she also worked as an Instructor and Assistant Professor. Rascovsky's research has focused on identifying the cognitive and behavioral markers of behavioral variant frontotemporal dementia (bvFTD). Her research also includes studies of survival and clinical progression of patients with frontotemporal degeneration. Current research interests include social norm violation, politeness and compulsivity in bvFTD, as well as studies of impulsivity using neuroeconomic methods. She also conducts cross-cultural studies of young-onset dementia in Latin America.



**JOSEFINA MELENDEZ-CABRERO, Ph.D.** is the clinical director of the Alzheimer's Prevention Clinic & Research Center in Puerto Rico. She is currently part-time faculty at Weill Cornell Medicine, serving as Clinical Assistant Professor of Neuropsychology in the Neurology department, and also an adjunct professor at the Carlos Albizu University in San Juan. She specializes in adult and geriatric neuropsychology focused on the early detection of neurocognitive disorders related to Alzheimer's Disease. She obtained her doctoral degree in Clinical Psychology at the Carlos Albizu University in San Juan, and received her specialty in Neuropsychology and Dementias through the Miguel de Cervantes University in Valladolid, Spain.



Dr. Meléndez-Cabrero has been co-investigator of NIH funded studies on Alzheimer's in collaboration with the San Juan's

Veteran's Hospital, University of Puerto Rico Medical Science, and Mount Sinai School of Medicine in New York. She has also co-authored several scientific journal articles and posters associated with Alzheimer's genetics, neuropsychological profiles and prevention. She is also leading a research collaboration with Dr. Richard Isaacson, focusing on the online educational tool and app, Alzheimer's Universe ([AlzU.org](http://AlzU.org)), leading its translation to Spanish.

**MALCOLM IAN CROSS AND GURTEEN**

**SCHIAVO**, *In lieu of a bio, please see this statement from Malcolm Ian Cross, about the Alzheimer's diagnosis of his mother, Gurteen Schiavo and their subsequent journey together:*

My mother, Gurteen Schiavo was diagnosed with Alzheimer's four years ago. But I had noticed signs of the disease many years prior to the official diagnosis and just thought it was stress or naturally old age. As this horrific disease progressed, I realized she needed to be here, with me in California full time. I have an older brother and older sister, but I was the one to step up and take my mom in and this disease on. I am her primary caretaker. It's been both a blessing and very challenging. Besides my mother slowly losing herself, there have been many sacrifices for us both. This disease has cost us numerous relationships. Including a marriage. There has been much financial strain and burden. And time. Oh my, the time invested into this disease. And at the end of the day, I wouldn't exchange it at all because the greatest blessing is the time with this amazing woman and providing her with some happiness ease, grace and tons of love, making this part of her life as awesome as possible.



**MIKE SIMMONS** is Director of Global Advocacy and Professional Relations at Eli Lilly and Company. His current role allows him to draw on both his professional experience at Lilly as well as his advocacy experience with various local and national mental health groups, particularly Mental Health America. Mike has also held leadership roles with the Marion County Commission on Youth, the United Way of Central Indiana and volunteers his time as part of Butler University's Emerging Leaders Program and the College of Business's Strategic Marketing Board.



**NINA SILVERBERG, Ph.D.** serves as the National Institute on Aging's Director of the Alzheimer's Disease Core Centers Program. She helps manage and support the efforts of 29 NIA-funded Centers at major medical institutions across the country; the Centers translate research advances into improved diagnosis, care and treatments for people with Alzheimer's, as well as enhanced support for their caregivers. I

n addition, Nina is a program officer overseeing dementia research portfolios covering: research ethics; cognitive, functional and behavioral assessment; clinical care; and technology. She supports efforts to reduce health disparities, with the goal of ensuring that underrepresented populations receive access to research opportunities as well as research training.

She is also a leader in NIA's efforts to educate the public and health care providers about the importance of research participation. Dr. Silverberg received her Ph.D. in cognitive psychology from the University of Arizona, Tucson. Before joining NIA in 2005, she was a clinical research scientist at the NIA-funded Alzheimer's Disease Center at Banner Sun Health Research Institute in Sun City, Az. There, she coordinated the American Indian outreach program and was the principal investigator on a study assessing the usefulness of various neuropsychological assessment tools in an American Indian population.



**DR JONCA BULL, M.D.** is Assistant Commissioner for Minority Health, U.S. Food and Drug Administration (FDA) a position she has held since 2012. In this capacity, Dr. Bull provides strategic leadership, coordination, and oversight for FDA's initiatives in addressing the reduction of racial and ethnic health disparities, working across FDA product centers, HHS, and with external stakeholders. These efforts include FDA policy, research programs, clinical trial participation and outreach efforts to protect and advance the health of diverse populations.

Dr. Bull has also been instrumental in coordinating FDA's response to the FDA Safety and Innovation Act of 2012 addressing demographic inclusion in clinical trials and outreach to underserved communities. Dr. Bull received her medical degree from Duke University and postgraduate training at George Washington University. She continues to serve as an assistant professor at George Washington University Medical Center.



**JOHN R. DWYER, JR.** is a Founding Board Member of UsAgainstAlzheimer's and President, the Global Alzheimer's Platform Foundation. John also serves as a Special Advisor to one of the largest Washington law firms, Arent, Fox LLP. John first became a CEO at the age of 30. In the following twenty-five years, he has held "C" level positions in six emerging growth companies in the healthcare or financial services industries. John is a frequent speaker on financing and regulatory issues of critical importance to emerging health technology companies. He regularly speaks on health information issues, business risks associated with the FDA approval process and patent insurance. John co-founded the first political action committee focused on a specific disease, the Alzheimer's Action PAC. Mr. Dwyer is also on the Executive Council of Leaders Engaged on Alzheimer's Disease (LEAD), which brings together key stakeholders from the government, business and civic sectors to increase attention to and awareness of Alzheimer's disease, its care, treatment, prevention and eventual cure.



**GOLDIE BYRD, Ph.D.** is Professor of Biology and Interim Director for the Center for Outreach in Alzheimer's, Aging and Community Health at North Carolina A&T State University. She is the former Dean for the College of Arts and Sciences, Chair of Biology and the Nathan F. Simms Endowed Distinguished Professor of Biology at A&T. Goldie received her PhD in Microbial Genetics from Meharry Medical College, and two undergraduate degrees in biology and in education at North Carolina A&T. She received post-doctoral training and sabbatical training at the University of North Carolina at Chapel Hill and at Duke University, where she remains adjunct professor of genetics.



As dean, she founded the Center for Outreach in Alzheimer's Aging and Community Health, a cross disciplinary center made possible by a major gift from the Merck Foundation. Along with five of her chairs, she also co-founded the STEM Center of Excellence for Active Learning, funded by the NC GlaxoSmithKline Foundation. Dr. Byrd conducts research in the Genetics of Alzheimer's disease in African Americans. Her work has been presented more than 200 times, including in 8 different countries, and has been published in over 50 journals and books articles and chapters.

Goldie has received numerous awards for her leadership, teaching, research, student mentoring and service, including the UNC Board of Governors Award for Teaching Excellence, the Leadership North Carolina Stanley Frank Leadership Award, the National Black College Hall of Fame Award for Science, and the Presidential Award for Excellence in Science Mathematics and Engineering Mentoring (PAESMEM). This award was received from President Barak Obama, at a White House ceremony. She

has raised more than \$60 million dollars in her career for student research training, student scholarships, community engagement, faculty mentoring and research.

She serves on panels, ad hoc groups and advisory boards for the Council of Colleges of Arts and Sciences, the National Science Foundation, the National Institutes of Health, the Alzheimer's Association, the North Carolina Biotechnology Center, the North Carolina Institute of Medicine and the National Academy of Science.

**ERIN MAHONEY** is an Associate Principal Clinical Scientist at Merck where she is currently the Program Clinical Scientist in Global Clinical Trial Operations at Merck for verubecestat, which is a BACE Inhibitor that is in late-stage development for the treatment of Alzheimer's disease, with two ongoing global Phase 3 clinical trials. Prior to rejoining Merck in 2016, Erin was the Phase 3 Program Lead for aducanumab, which is a monoclonal antibody that is being developed by Biogen, where she was responsible for the start-up and execution of this global Phase 3 program which is under investigation for the treatment of early Alzheimer's disease. Erin's earlier tenure at Merck began in 2004, where she held various roles of increasing responsibility which included Protocol Lead Clinical Research Specialist and Program Lead Clinical Scientist across several disease areas including diabetes, migraine, insomnia, depression and neuropathic pain. Erin was a significant contributor to the clinical development of the Januvia™ and Janumet™ programs for Type 2 Diabetes as well as a primary author on several regulatory submission documents for Maxalt™ for pediatric migraine.



Prior to joining Merck, Erin was a Study Coordinator for the Chairman of Psychiatry at Boston University School of Medicine where she focused on addiction research. Erin has a BA in Psychology from Eckerd College and has completed several courses towards a graduate degree in Public Health at Boston University and the University of Pennsylvania. She is a member of Drug Information Association and the Alzheimer's Association.

**CONSTANTINA MIZIS** is the founding Executive Director of the Latino Alzheimer's and Memory Disorders Alliance (LAMDA) based in Chicago, IL. LAMDA is on the frontline of addressing Alzheimer's growing impact on the Latino community and provides direct services to thousands of Latinos struggling with Alzheimer's annually.

Constantina has dedicated over 25 years of service to Latino older adults and their family caregivers, consulted and trained extensively throughout the United States, and has worked with National organizations on the development of programs for the Latino elderly.

Mrs. Mizis' work and commitment to excellence have earned recognition, including the Illinois Office of Governor, and Illinois Department on Aging. NPR, Chicago Tribune, LA Times, Univision, NBC, La Opinion, and Seattle

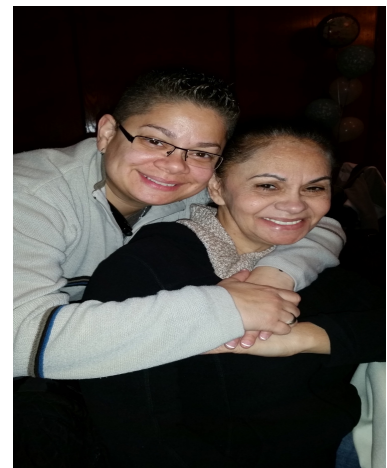


Times, are some of the Media that highlight the efforts of Constantina Mizis on the Latino community who are suffering from Alzheimer's disease. Prior to founding LAMDA, Mizis served as a multicultural outreach manager for the Alzheimer's Association Illinois Chapter and as a multicultural outreach and community affairs manager at the Sinai Community Institute (SCI). She is an active board member and consultant of Nation's top health committees, such as, the National Alzheimer's & Dementia Patient & Caregiver-Powered Research Network (AD-PCPRN) Governance Board.

**JONATHAN JACKSON, Ph.D.** is a cognitive neuroscientist on faculty at Harvard Medical School, investigating the early detection of Alzheimer's disease, particularly in the absence of overt memory problems. He also serves on Massachusetts General Hospital's Alzheimer's Disease Research Center (ADRC) and MGH's Cancer Center Equity Program, specializing in identifying and overcoming barriers to clinical research for people and communities of color. His research focuses on midlife and late-life health disparities in clinical settings that affect Black populations, relevant to both dementia and oncology research. He has also served on the ADRC's Outreach Recruitment and Education (ORE) Core since 2014 and has become a well-known MGH representative to communities of color and dozens of affiliated organizations, particularly regarding clinical research.



**DAISY DUARTE** is a caregiver advocate for the LatinosAgainstAlzheimer's Network, bringing a critical voice to UsAgainstAlzheimer's advocacy, policy, and research discussions about the growing impact of Alzheimer's on the Latino community. Daisy is a caregiver for her mother Sonia who was diagnosed with early onset Alzheimer's at age 55. Daisy tested positive for the gene linked to early onset Alzheimer's Disease in 2014 and is currently enrolled in the Dominantly Inherited Alzheimer's Network (DIAN) clinical trial at the Washington University School of Medicine in St. Louis. As one of the few Latinos enrolled in Alzheimer's clinical trial research, Daisy is committed to raising awareness of the importance of Alzheimer's research and funding. According to Daisy, "It's so important for Latinos and other minorities to engage in clinical trial research, we need to make sure that our communities have a voice in the research process. We have to take responsibility for our families and for ourselves."



**PAMELA PRICE** is the Deputy Director for The Balm In Gilead where she manages and oversees the multi-faceted health initiatives of the organization, whose mission is to prevent diseases and to improve the health status of African-Americans. Under her leadership the organization provides support to faith institutions nationally in areas of program design, implementation and evaluation of programs and services that contribute to the elimination of health disparities.



Mrs. Price has over 15 years of experience in public health, epidemiology, and healthcare. She was a member of the US Army Nurse Corp and has served in both government and non-government agencies providing leadership and guidance in program management, quality improvement, and staff development. She also serves as the Director for The National Brain Health Center for African-Americans, an initiative of The Balm in Gilead to address cognitive health issues within African-American families and communities.

**GLORIA ADRIANA PEREZ, Ph.D., ANP**, is an Assistant Professor of Nursing and Senior Fellow, at the Leonard Davis Institute of Health Economics at the University of Pennsylvania, School of Nursing. Her research promoting healthy aging in older Latinas has been funded by the National Hartford Centers of Gerontological Nursing Excellence, NIH/NINR individual NRSA, Sigma Theta Tau International, National Coalition of Ethnic Minority Nurses, and St. Luke's Health Initiative. As a result of her work and because of the high relevance to environmental health policy, she was selected as a Congressional Fellow supported by the Atlantic Philanthropies and Centers for Disease Control & Prevention, Healthy Aging Program.



Currently, Dr. Perez serves as PI for two grants, including: the “Hispanic Nurses Educating Multicultural Communities on the Affordable Care Act,” funded by the U.S. Department of Health & Human Services through the “Partnerships to Increase Coverage in Communities,” initiative; and “Physical Activity to Promote Cognitive Health Among Older Latinas,” funded by the NIA/NIH under Award Number P30AG043097. Dr. Perez’s commitment to addressing health disparities is evident in her work with the Future of Nursing: Campaign for Action. She consults with state action coalitions in developing sustainable diversity action plans. She is a Fellow of the American Academy of Nursing and was awarded the 2014 Dr. Janie Menchaca Wilson Award for Outstanding Leadership from NAHN, the 2014 Phoenix Business Journal Health Care Hero Award, and Arizona first’s cohort of Leadership in Action Award by the Arizona Action Coalition. She is a member of the UnitedHealth Group External Nursing Advisory Board and co-chair of the American Academy’s Expert Panel on Aging.

**GARRETT DAVIS** is CEO and Founder of the Forget Me Not Project. Davis has been labeled as one of the most prolific, anointed talents in urban theater and named by NAACP as the “Funniest Playwright.” Davis’ plays entertain but also have a purpose, bringing real-life situations to the stage and combining faith-inspired messages with entertainment, education and awareness.

In 2010 he began developing an idea to allow one of his most poignant works to become a means for communicating to diverse audiences about Alzheimer’s disease, with his production of *Forget Me Not*. Davis realizes the power of the arts to reach out to audiences with understanding about complicated issues such as Alzheimer’s and the value of grassroots community involvement.



As a result, he has developed the Forget Me Not Project whose mission is to raise the awareness of Alzheimer’s disease in all communities and to enhance the capacity of and support for caregivers, while educating the general public—with special emphasis on underserved communities where health disparities exist. The Forget Me Not Project has partnered with UsAgainstAlzheimer’s African American Network to take this play and message across the United States to raise community awareness about Alzheimer’s disease and its impact, encourage communities to do their part by participating in clinical trials, and to promote public policy aimed at learning more about the disease’s disparate impact on minorities as well as research aimed at finding more effective treatments or a cure.

**ASHLEE SHAW**, Ph.D. is Co-Director of the African American Brain Health Initiative at Rutgers University-Newark and Professor of Neuroscience and a postdoctoral researcher in the Gluck lab at Rutgers University-Newark. She completed her Ph.D. in psychology at the University of Connecticut, and received her B.S. in psychology at Vanderbilt University. Ashlee has also been a dance and fitness instructor for the past nine years. As a part of the African American Brain Health Initiative, she combines her passion for psychology research with her passion for health and fitness, and does so in a way that is directly beneficial to the local community.

