

MACHE U19 Press Release Language

Dr. Goldie Byrd, the Director of the Maya Angelou Center for Health Equity (MACHE) at the Wake Forest University School of Medicine will lead community-engaged research, outreach, recruitment, and retention efforts of a \$46 million grant awarded to the John P. Hussman Institute for Human Genomics (HIHG) at the University of Miami Miller School of Medicine (UMMSM) by the National Institute on Aging (NIA), and in part by the National Institutes of Health (NIH). This new initiative is designed to build a resource that greatly expands the representation of currently underrepresented African ancestry and Hispanic/Latinx individuals in Alzheimer's disease (AD) genetic studies.

HIHG will lead this major five-year, international multi-site initiative with Case Western Reserve University (CWRU), Columbia University (CU), Wake Forest University (WFU), the University of Pennsylvania (UPenn) and the University of Ibadan (UI) - lead institution for the African Dementia Consortium (AfDC).

"Increasing diversity in Alzheimer's Disease research and clinical trials closes the disparity gap and in turn helps to close gaps in health disparities," said Dr. Goldie Byrd. Alzheimer's is a complex disease with a pronounced genetic component, where its estimated heritability is 60% to 80%. Though the disease can be found in individuals across a diverse group of populations, affecting almost all ethnic and ancestral groups, efforts for genetic studies historically have not been so well diversified. In fact, most genetic-based studies in AD have been performed on non-Hispanic Whites (NHW) of European ancestry, with communities of Hispanic and African ancestries largely ignored. Dr. Goldie Byrd also stated that "A large portion of our community suffers from poorer health outcomes and shorter lifespans because of social drivers, such as where they live and sleep, what they eat and do, and everyday discrimination and stress."

Margaret A. Pericak-Vance, Ph.D., director of the HIHG and Dr. John T. Macdonald Foundation Professor of Human Genetics, will oversee the overall efforts of the principal investigators across several domestic and international sites. She is joined by her co-PIs Drs. Brian Kunkle and Jeffery Vance (HIHG, UMMSM); Drs. Jonathan Haines and William Bush (CWRU); Dr. Goldie Byrd (WFU School of Medicine); and Drs. Christiane Reitz and Giuseppe Tosto (CU).

This new multi-site enterprise will help to bridge the research disparities that have historically existed in diverse communities. Through the recruitment, assessment, and genetic analysis of a significantly large cohort of participants of Hispanic/Latinx (HL) and African (AF) ancestries clinical, phenotypic, and genetic data along with social determinants of health (SDOH) factors will be collected to create a large genomic study resource. This cohort will include 5000 individuals from various African Countries, 4000 African Americans (AA), and 4000 HL. The data collected from participants will be added to existing databases of harmonized data from other ongoing studies as part of the Alzheimer's Disease Sequencing Project (ADSP).

The recruitment in Africa will be done under the umbrella of the African Dementia Consortium (AfDC). The AfDC, led by Rufus Akinyemi, M.B.,B.S., Ph.D., F.M.C.P., and Adesola Ogunniyi, M.B.,Ch.B.,

F.M.C.P., is a coalition of African dementia researchers in a multidisciplinary framework working together with the aim of generating clinical, cognitive, socioeconomic, neuroimaging, genomic and biomarker data to improve the phenotypic characterization of dementia, particularly AD, in Africa. The AfDC further fosters the translation of evidence to policy and practice and reduction of the future burden of dementia among Africans, diaspora African ancestry populations and ultimately contribute to the reduction of the global burden of dementia. Currently the AfDC includes researchers from ten African countries including Nigeria, Ghana, Uganda, Benin, Cameroon, Kenya, Mozambique, Tanzania, and Ethiopia.

This new initiative is particularly significant because despite the lack of diversity within AD genetic research studies, AA and HL communities are at increased risk of developing AD within their lifetime. Past studies in NHW and limited AA and HL populations have shown that both risk effect size (the level of risk of a specific gene's presence and risk loci (specific location of risk effect on chromosome)) differ vastly among differing ancestries. The lack of homogeneity in these causal factors indicates the importance of the need for a much more diverse data pool, as research based on data from largely NHW populations may not hold any therapeutic relevance in individuals of differing ancestries.

In addition to Dr Goldie. Byrd, the Wake Forest University School of Medicine team includes Dr. Allison Caban-Holt, Dr. Shawnta Lloyd, Ms. Takiyah Starks and Ms. Tayla Ford and Mr. Dustin Sellers. "Embracing this unique opportunity to view our surroundings, engage our neighbors, and our past with clarity with the goal of equity can help us make a significant investment in our community and our society," said Dr. Byrd.

For more information, or to participate in our study, please contact our study coordinators at 833.491.2817 or visit www.READD-ADSP.org. To learn more about

About The Maya Angelou Center for Health Equity (MACHE)

MACHE is located at the Wake Forest University School of Medicine in Winston Salem North Carolina. The Center focuses on community engagement with specific populations that have historically experienced health disparities. Our research associates and staff conduct independent research and collaborate with faculty across the Wake Forest Baptist Medical Center and beyond.

Vision

The center's vision is to be nationally known as a preeminent health equity center that reduces health disparities in the most underserved populations.

Mission

Its mission is to dismantle systemic inequity and support the health of communities through:

- Building and nurturing mutually beneficial and reciprocal relationships
- Respecting and honoring community as experts and equal partners
- Engaging, educating, and empowering communities
- Cultivating formal and informal leadership

- Creating a culture of transparency and fairness in research
- Promoting advocacy and policy change

To learn more about MACHE please visit our website:

<https://school.wakehealth.edu/research/institutes-and-centers/clinical-and-translational-science-institute/maya-angelou-center-for-health-equity>