



September 2021

# Brain Health Buzz

*Brain health news for African Americans*



**Wisconsin Alzheimer's  
Disease Research Center**  
UNIVERSITY OF WISCONSIN  
SCHOOL OF MEDICINE AND PUBLIC HEALTH



**Wisconsin Registry  
for Alzheimer's Prevention**  
UNIVERSITY OF WISCONSIN  
SCHOOL OF MEDICINE AND PUBLIC HEALTH

## From My Heart to Yours

*By Dr. Fabu Phillis Carter, Senior Outreach Program Manager*

We are grateful for another great showing at our July 31 Resource Fair, with a record attendance of almost 250 people. So many attended that Chef Yusef Bin Rella had to put more hamburgers on the grill. We were also happy to support the August 21 Simpson Street Family Reunion, organized by Ms. Diane Small.



**Dr. Fabu Phillis Carter**

This month we welcome two new employees, Mrs. Lytonia Floyd and Mr. James Bester, to our recruitment and retention team. Mrs. Floyd has worked with the Get Movin' Exercise class as a nutritionist this year, and we are happy to have her join us as an employee. Mr. James Bester, a former Badger football player, has worked for years in our community

in a variety of roles. He is helping to organize an exercise class for men. With this increase in the size of our team, we expect to recruit even more African Americans. Both new team members will be delivering new iPads to participants. You can read more about them and see their photos in the side column.

Recently, experts at the Wisconsin ADRC held a Q&A panel on our Facebook page about the new drug, aducanumab. You can watch the recording at [www.fb.com/wisconsinadrc/videos](http://www.fb.com/wisconsinadrc/videos). Unfortunately, the research used very few people of color; only 7% of the research participants were African American, and it only included one Native American. This means we do not have enough data to know if it works for African Americans. Please contact me if you know people who would like to be in our study, and reach out to Lytonia Floyd at 608-265-4329 if you would like an iPad. As always, thank you very much for being a participant in our research. ♦

## Introducing our New Community Ambassadors

My name is James Bester, and I am a proud member of this Madison community with its unique blend of cultures. My spare time is filled with the emotions of poetry, sports, fishing and anything to do with cars, but the love of family has thrilled me the most.

This Wisconsin ADRC position gives me the

opportunity to continue helping my community.



**James Bester**

My name is Lytonia Floyd, I have many years of experience in healthcare and nutrition. I started as a little girl working in the garden with my parents — eating healthy was number one in our household. When any of my siblings would get sick, I would get the thermometer and the vapor rub and that was the cure. I went to Blackhawk Technical College and completed my certified nursing and registered medication program. I am excited to start at the ADRC!



**Lytonia Floyd**

## Get in Contact

**Dr. Fabu Phillis Carter:**

Monday – Friday, 8 a.m.–4:00 p.m.

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# Wisconsin ADRC Hosts Resource Fair and Vaccine Clinic

Almost 250 people attended the drive thru resource fair on July 31, which featured over 15 organizations with info on healthy aging, a free vaccination clinic partnership with Montee Ball, and free catered meals from Chef Yusuf Bin-Rella and TradeRoots Culinary Collective. The event was sponsored by UW Health with an aim to improve vaccination rates in Dane County for African Americans. Vaccines were made available for free and anyone 18 years old or older were offered a vaccine.

Attendees had the opportunity to meet Montee Ball, former Wisconsin Badger and NFL running back, and ask about his experience receiving the vaccine.

“I talk a lot about our Black and Brown communities, how we don’t really trust health care officials, physicians, providers, et cetera because of past experiments,” Ball said to NBC 15. “But I tell folks that this is not the one. This is not the one that they’re trying to fool us on. We need this.” ♦



**Chef Yusuf Bin-Rella provided meals for almost 250 attendees**

## Creating Health Studies That Fit the Needs of the Community

There are many reasons why some people live healthier lives than others. They may have access to better health care or live in healthier environments. Even drugs and medical treatments may be developed with some people more in mind than others. In fact, health studies tend to include limited types of people, mostly those White and middle class. This means that treatments and drugs are developed to suit only a portion of the people who actually get sick, even when scientists are studying diseases or conditions that affect other groups more, such as diabetes, heart disease, or Alzheimer’s disease.

Part of the reason people avoid health studies is because they don’t trust medical research. Throughout history, researchers have abused poor and vulnerable communities in the name of science as in the case of the Tuskegee Syphilis Study. People also have a hard time trusting doctors and others in healthcare professions due to continued experiences with discrimination. It is not reasonable to ask people to “get over” their fears and concerns about medical research. Researchers

must change to work with the community and earn trust.

Susan Passmore, PhD, created the Just Research project with this in mind. With help from her team in the UW School of Medicine and Public Health, which includes Dorothy Farrar Edwards, PhD, of the Wisconsin Alzheimer’s Disease Research Center and Gina Green Harris, MBA, with the Center for Community Engagement and Health Partnerships and the Wisconsin Alzheimer’s Institute, she designed the Just Research to learn from community members and help researchers build health studies that reflect their voices.

“The problem is not in the community. If people distrust us as researchers, it’s up to us to become more trustworthy.”

Dr. Passmore and her colleagues are working to ensure scientists and health researchers hear people’s voices. This is a multistep process that begins by collecting feedback about how research should be done from people in the community through interviews and surveys. The team then uses that information to guide young researchers and

developing scientists just beginning their careers in science through the Building Trust Program. This program, started in 2020, has already trained more than 50 researchers to conduct research that avoids biases and is tailored to the needs of research participants.

“Researchers need to understand that the only way to improve diversity in health studies is to work together with communities and to create programs that reflect what people want, need and value rather than what’s convenient for themselves.”

Just Research is looking for African American adults age 40 and older to participate in a 30- to 40-minute Zoom interview to provide their opinions about specific research studies. They hope to learn what factors help people feel most comfortable in joining studies that are key to the development of much needed treatments.

Those interested can reach out to the study team at 608-709-9010 or justresearch@ictr.wisc.edu, or visit the team website [ictr.wisc.edu/just-research](http://ictr.wisc.edu/just-research). ♦