

# **African Americans in Alzheimer's Research**

## **The Mollie and Ralph Richards Story**

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### **Toolkit Preface**

**By Dr. Robert Russell, MD**

As Alzheimer's research continues to advance, new therapeutics are being developed for the improvement of disease symptoms and to delay disease progression while future research efforts are working towards disease eradication. The following information and video are necessary tools in helping to educate African Americans, and those who provide them care, about why participation in Alzheimer's Disease research is so important. By acknowledging past misgivings in the history of research as it pertains to African Americans, this toolkit gives a strong overview of the challenges being addressed to ensure future generations will be equitably represented in research. The video is critical in helping ensure a world without Alzheimer's Disease includes everyone regardless of socioeconomic background, race, or ethnicity.

## 10 Steps for Increasing African American Participation in Clinical Studies and Trials for Alzheimer's Disease

**Statistics show that older African Americans are twice as likely to develop Alzheimer's Disease than older White Americans. Today, 21.3 percent of African Americans 70 or older live with Alzheimer's Disease.**

Doctors and scientists point to higher rates of diabetes and hypertension as possible drivers, but also note the effects of African American culture and lifestyle, access to quality health care, and delays in seeking treatment, due to a distrust of the medical community, as contributing factors. More than 80 percent of African Americans say they face barriers to accessing quality health care and support, and half say they have experienced discrimination while seeking care for a person living with Alzheimer's Disease.<sup>1</sup>

“By bringing in diversity, we're making sure that we design a drug that fits the way the United States looks.” - Dr. Jared Brosch, MD

Although older Black and Hispanic Americans are more likely to have Alzheimer's or other dementias than White Americans, fewer participate in research or clinical trials. Without participation by Black, Hispanic, Asian, Native Americans, and other people of color, a complete understanding of how racial and ethnic differences may impact potential new treatments is impossible.

“If we only have participation in clinical trials and observational research from people of usually European descent, then we are unlikely to develop a drug that is effective for everyone.” - Dr. Andrew Saykin, PsyD

Clinical trial providers and researchers **must do more** to gain the trust of communities of color. Social justice demands that new treatments are safe, available, and effective for *all people*.

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<sup>1</sup> Alzheimer's Association

“If you want to build trust, it's really about building a long-lasting relationship with that community that says you're not just here for the research. You're here for the betterment of the community.” – Dr. Robert Russell, MD

### **Meet Mollie and Ralph Richards**

Mollie and Ralph Richards have spent the past 25 years dedicated to educating members of the African American community about Alzheimer’s Disease through their unique community engagement model. This model includes one-to-one discussions, outreach to local faith-based community groups, participation in community symposiums, health fairs, and Town Hall meetings. This work is to further their aim of helping caregivers and those who may suspect that they have Mild Cognitive Impairment (MCI) to better understand the management of the disease. They also encourage participation in clinical trials and studies. Some of their success is owed to the importance of following up and suggesting continued conversations with patients and caregivers around Effective Communication Strategies, Behaviors and Dementia, and Healthy Living for the Brain and Body.

**Follow this QR code to view their story.**



## 10 Steps to Recruit African Americans into Clinical Trials and Studies

**1. Collaborate with local African American community organizations, churches, senior centers and Alzheimer's support groups to build trust** and establish relationships. Create your own passionate “why”. Share information about your trials and studies with existing groups that interact with the African American Community, such as the NAACP, the National Council of Negro Women, Greek organizations, Colleges, Universities, AARP, The Urban League, the Red Cross, the National Kidney Foundation, the American Heart Association and/or 100 Black Men Organization, etc.

**2. Engage with healthcare providers who serve African American communities**, including primary care physicians, neurologists, nurse practitioners, psychologist, psychiatrist, social workers, nurses, and geriatric specialists, to gain referrals and support. It is critically important that African Americans be represented on staff.

**3. Invite community members to participate on a local Community Advisory Board.**

**PURPOSE:** To reach the under-represented communities to share information about healthy aging and brain health.

**MISSION:** To increase people of color participating in screening and assessments through education and outreach and increase diversity in research study participation.

A Community Advisory Board will help clinicians and researchers understand the potential economic, cultural, or psychological barriers to participation from the African American and other communities and provide valuable connections through trusted organizations. The volunteer board could consist of local pastors and clergy, staff from the Department of Health, current and retired members of the medical community, attorneys, retirees, business owners, social workers, statisticians, recruiters, outreach coordinators, someone from the media and caregivers.

Those recruited to the Community Advisory Board should look like the people they will serve, have a personal history or testimony to share, have a passion for Alzheimer’s research, and be well connected within the community.

**4. Develop culturally appropriate recruitment materials**, including brochures, flyers, videos, and website content that resonate with the African American community. Highlight the importance of diversity in research and the potential benefits to the African American community. Be sure to include imagery and language that reflects diversity and encourages participation.

**5. Organize community outreach events** to raise awareness about Alzheimer's disease, clinical trials, and the importance of participation. These can include educational sessions on Alzheimer's disease that share facts about the clinical trial processes and the potential impact of research for African Americans. Provide information on available support services, caregiver resources, and community programs to address potential concerns and barriers.

6. **Offer incentives to participate in clinical trials that are meaningful** to the African American community, such as gift cards to local businesses or community events. Highlight the potential benefits of participation, including access to cutting-edge treatments, increased healthcare monitoring, and the opportunity to contribute to research that benefits their community.
7. **Ensure staff members are culturally aware, respectful, patient, and knowledgeable** about the unique experiences, beliefs, cultural holidays, and challenges faced by African American individuals and their care partners. Be sure to emphasize the importance of creating a welcoming and inclusive environment for participants. **Recommended resources include:**
  - “The Color of Care,” a documentary.
  - Videos and books by Dr. Joy De Gruy regarding “Post Traumatic Slave Syndrome” and its effects on African Americans’ research decisions.
8. **Offer caregiver support groups, respite care options, and educational workshops** specifically tailored to the African American community. Provide a person to help guide through this process and resources to alleviate caregiver burden, such as transportation assistance and flexible scheduling options for study visits.
9. **Collaborate with local newspapers, radio stations, and television networks** targeting African American audiences to share information about the research study. Use social media platforms popular among African Americans to disseminate study information and engage with potential participants.
10. **Foster ongoing relationships with participants and their care partners** beyond the study period. Provide regular updates on study progress, research findings, and community events related to Alzheimer's disease. Recognize and acknowledge birthdays and the contributions of participants and care partners through newsletters, acknowledgement letters, or recognition events.

**By implementing an appropriate 10-step recruitment plan, researchers can actively engage African Americans living with Alzheimer's disease and their care partners in clinical trials, ensuring diverse representation and enhancing the generalizability of research findings to this population.**