

Equity and Engagement for Neurologic Research Participation at the Goizueta Alzheimer's Disease Research Center



EMORY
UNIVERSITY

**Goizueta Alzheimer's
Disease Research Center**

www.alzheimers.emory.edu

Trust Building

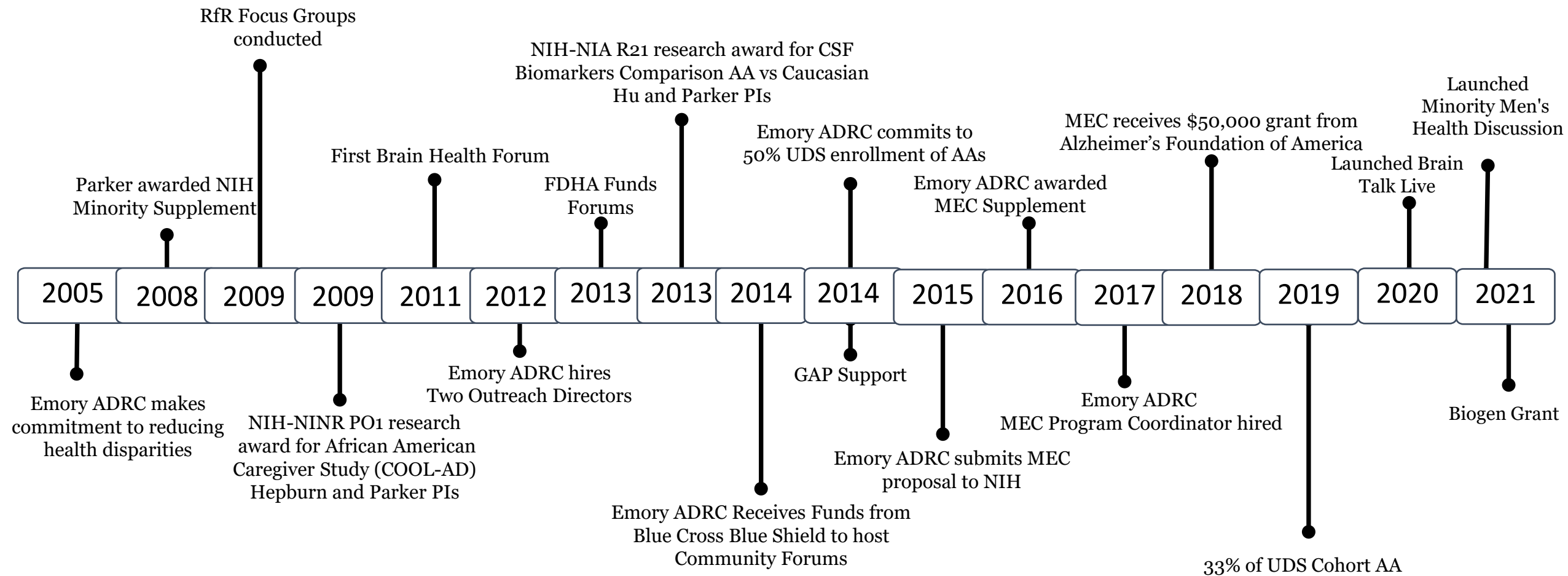
- Developed in 2008, with support from the **National Institutes of Health**, the **Registry for Remembrance Community Coalition** has been the cornerstone of the Emory Goizueta Alzheimer's Disease Research Center's effort to reduce the stigma and threat of clinical trial participation for women and minorities.
- Meaningful engagement to foster research participation was built on the combined strengths of a network of black churches, an African American **physician - Dr. Monica W. Parker**, and trust building activities.

5/9/2023

Confidential and Proprietary Information



Minority Engagement Milestones



Educational Programming

1. Designed to address the needs of targeted audience in accordance with their asks

Research processes; HIPAA; Investigator; topics

2. Global Messaging appropriate for any audience

Programs in the “community” contain specific resource identification

3. Programs are held early in the day before “rush hour” to enable safe travel for visual and traffic concerns



Educational Programming



4. Partnering organizations provide population access, advertisement, hosting and facility

5. ADRC programs have structured format that no longer than 2 hours

6. Pandemic limitations necessitated use of virtual program delivery which persists as we are able to reach more and “different audiences

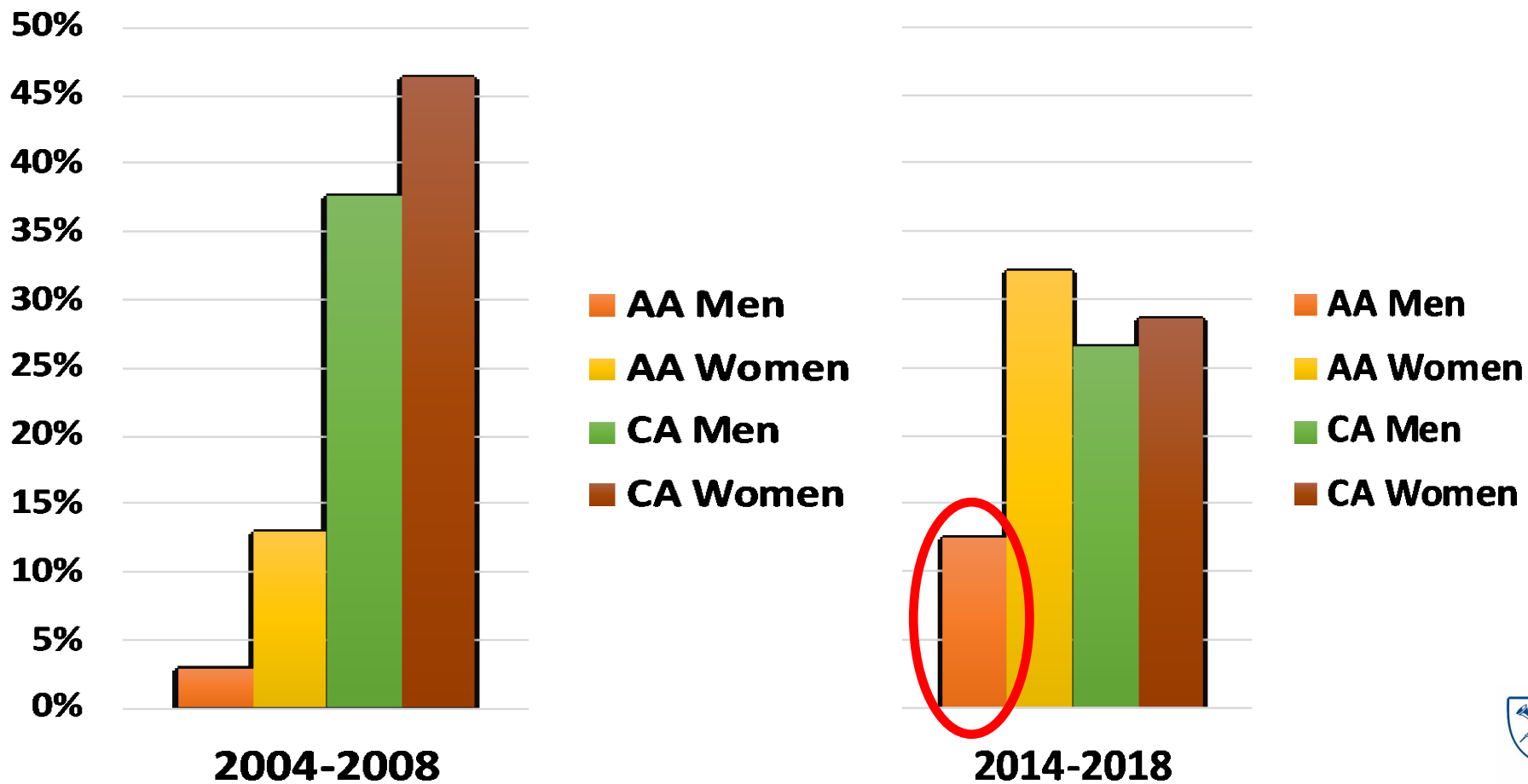
i.e., Vision Rehabilitation Services of Smyrna, GA

Research Recruitment “Fair”





Addressing Disparities in the Emory Goizueta ADRC



MEC Vital Outcomes and Implications

To ensure that the discovery and translation of new biomarkers, and pathogenic mechanisms to enable early identification, intervention and treatment of ADRD is applicable to all, African Americans, consistent with their percentage of the Atlanta metropolitan population must be represented in all clinical research investigation here.

- A) Center funding 2020-2025 was granted with AA recruitment emphasis as key role for MEC
- B) ADRC stated goal is for UDS Cohort 50% AA. We are currently at 33%
- C) African American Autopsy rates for UDS participants is 63%(vs. 67% all UDS) AA samples are in high demand
- D) AA UDS participants* are contributing CSF, MRI, saliva and other biospecimens supporting our proteomics and novel biomarker discoveries
- E) AA participation is required to support the multicenter trials focused on AA CSF- RO1 Washington University
- F) R01 - Emory Healthy Brain Study needs 3000 volunteers 33% of whom must be AA
- G) To maintain community trust, consistent and transparent relationships must be nurtured in AA and other URM communities to enable the successful recruitment of viable research volunteers.
- H) Effective recruitment of AA participants for ADNI and University of Pennsylvania; Geocoding- University of Wisconsin

Why AAs participate in research?

To advance
science

To learn how
to maintain
my brain's
health

So my
children/grandchildren
may benefit



Minority Engagement Core (MEC) 2016

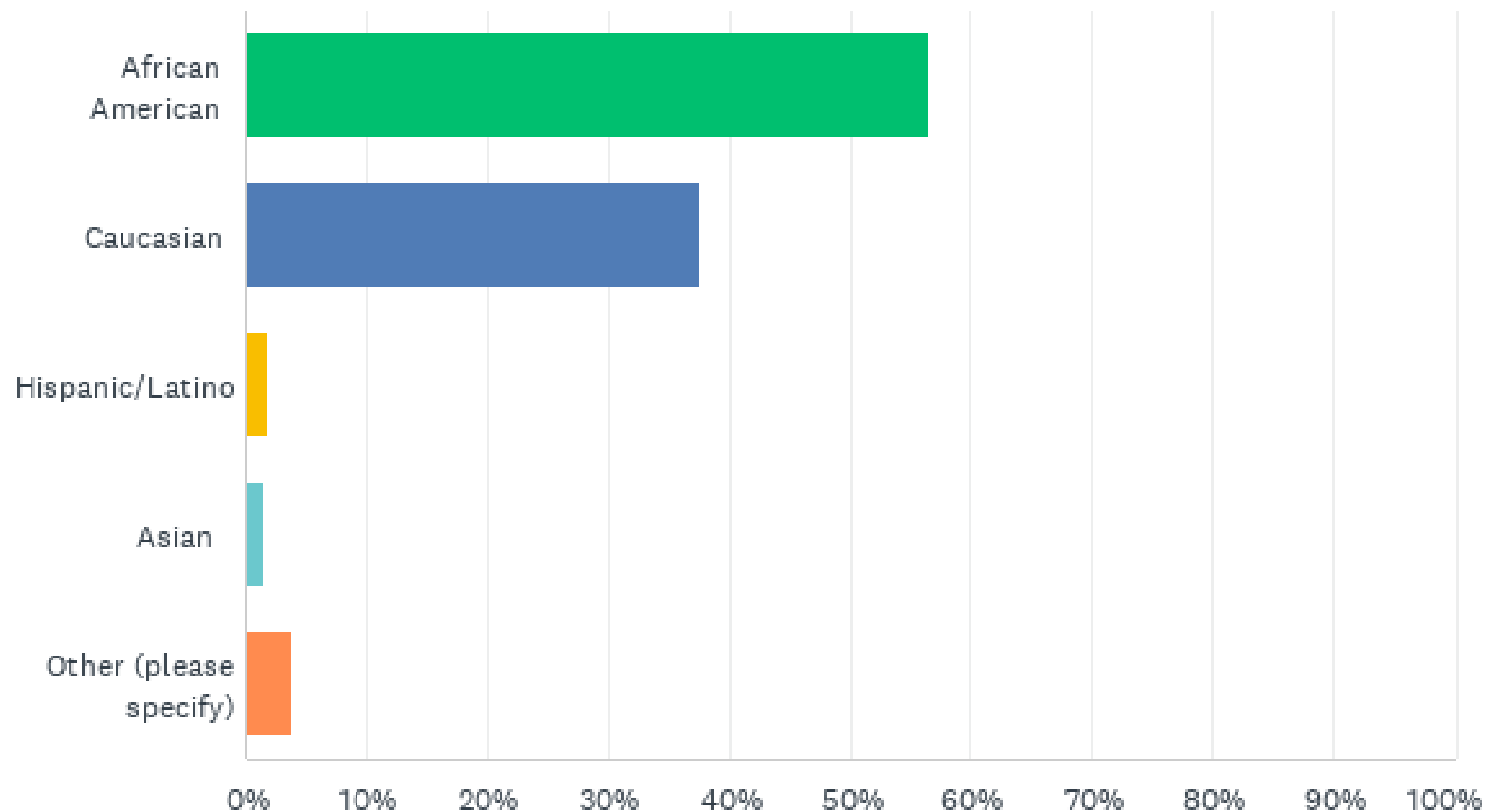
The **Minority Engagement Core (MEC)** focuses on the recruitment and retention of African Americans (AA) individuals into ADRC research, clinical trials and brain donation Disease (AD) among AA, while increasing participation in basic, clinical, and translational research that also acknowledges and explores racial differences.

To increase the understanding of Alzheimer's disease and related disorders, Our goal of increased URG research participation will be accomplished through the following aims:

- **Aim 1.** Increase the participation of persons from the African-American community in clinical trials and other research at the ADRC.
- **Aim 2.** Continue outreach, recruitment, and engagement activities centered on capacity-building strategies.
- **Aim 3.** Develop and evaluate innovative research, recruitment, and engagement activities aimed at enhancing the relevance of ADRC research for other ethnic minority and underrepresented groups.

Brain Talk LIVE - breakdown by race

- Answered: ~3,000



Geographic Distribution of BTL Attendees

Top 10 Zip Codes	County	# of Participants
30331	Fulton	84
30032	Dekalb	50
30083	Dekalb	34
30038	Dekalb	32
30349	Fulton	31
30030	Dekalb	28
30345	Dekalb	27
30087	Dekalb	25
30034	Dekalb	23
30281	Henry	22

NOTE:

There are 355 additional zip codes **(both national and international)** represented on BTL reaching 1120 individuals.

Goizueta ADRC Outreach Summary

- 1) Recruitment and retention of URM requires an intentional , consistent and demonstrable effort.
 - a) Dedicated personnel must be assigned and focused on this task.
- 2) Establishing collaborative relationships with organized community groups, serving targeted community with similar health interests, will amplify efforts, foster trust and project success.
 - a) Non- Profits, Faith organizations, Advocacy groups, Fraternities, Sororities-
- 3) Community Outreach must address the health interests, needs and resources of the targeted population.
 - a) Health preservation and healthy aging
 - b) Patient navigation
 - c) Healthcare access and resources
 - d) Explaining and clarifying the research “process” and accountability for research activities
- 4) Educational outreach approaches must be specifically tailored for engaging older adults, of different cultures, in ongoing health and neurologic research.