

Neuro Health Equity Resource Guide

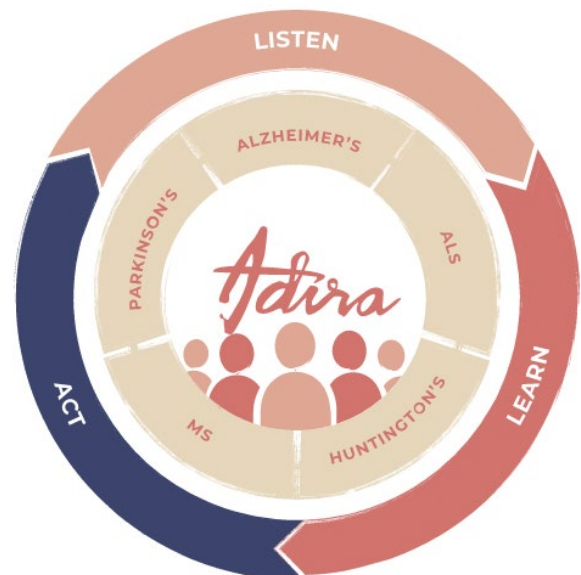
A curated guide to health equity resources including resources for:

- **Health Equity Education Resources (page 3)**
- **Programs for People of Color (page 6)**
Medical and support services created for people of color impacted by neurodegenerative diseases.
- **Stay Involved in Health Equity Efforts (page 10)**
Programs for people to engage in and influence health equity efforts.
- **Health Equity Solutions (page 11)**

Compiled by Adira Foundation from resources provided by “Neuro Health Equity: Let’s Talk” participants and partners.

About Adira Foundation

Adira’s mission is to invest in better lives for people with neurodegenerative diseases starting with Alzheimer’s disease and related dementias, ALS, Huntington’s disease, multiple sclerosis, and Parkinson’s disease. We bring these disease communities together to work on what they have in common. They name and set priorities for grants, then we co-finance and fund programs. We track and evaluate our progress to improve with each round.



Background

On April 15, 2021 as part of Minority Health Month, Adira Foundation convened people most impacted by neurodegenerative diseases (ND) and a diverse group of professionals who serve them to learn and talk about health equity in ND communities.

The event, *Neuro Health Equity: Let's Talk*, featured presentations from the two experts below on the “what, why, who, when, where and how” of health equity with a focus on the brain health of Black and Latino populations affected by Alzheimer’s and related dementias. As a group, we identified real examples of health inequities experienced by people most impacted by ND. In small groups we shared both successes and lessons learned from existing health equity solutions and brainstormed new ideas and approaches. Participants and partners offered the resources that follow.

SPEAKER BIOS



**Cynthia A. Gómez,
Ph.D.**

- **Professor Emerita, UCSF / SFSU**
- **Former Co-director, Center for AIDS Prevention Studies**
- **Founder, Health Equity Institute**

Cynthia has more than 30 years’ experience as a behavioral health scientist. She pioneered the integration of social determinants of health in research and community-based health interventions. She has over 100 scientific publications to her name (most recently: “[Addressing Health Equity and Social Determinants of Health Through Healthy People 2030](#)”) and served on the DHHS’ Secretary’s Advisory Committee for Healthy People 2030. She serves on the Board of Directors for ETR, Inc., San Francisco Community Health Center, the Guttmacher Institute, and Adira Foundation.



Jason Resendez

- **Executive Director, UsAgainstAlzheimer’s Center for Brain Health Equity**
- **Head, LatinosAgainstAlzheimer’s Coalition**

From clinical trial inclusion to paid family leave for dementia caregivers, Jason champions brain health at every level of the healthcare system. In 2020, he was recognized as one of America’s top 20 “Influencers in Aging” by PBS Next Avenue. He graduated from Georgetown University, is a Google Next Generation Policy Leader, and an Aspen Ideas Health Fellow.

Health Equity Education Resources

Allies for Reaching Community Health Equity (ARCHE)

healthequity.globalpolicysolutions.org

Led by the Center for Global Policy Solutions and supported by the Robert Wood Johnson Foundation, ARCHE promotes resources, learning, thought leadership, collaboration, and innovative solutions that advance health equity.

[“What is Health Equity?”](#)

[Health Equity Experts Network](#)

A braintrust of professionals with expertise on health equity topics.

Alzheimer’s Association

alz.org

The Alzheimer’s Association is a national organization supporting Alzheimer’s and other dementia by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.

[2021 Facts and Figures report](#)

The *2021 Facts and Figures* report provides an in-depth look at the latest national statistics on Alzheimer’s prevalence, incidence, mortality, costs of care and impact on caregivers.

- [Special Report: Race, Ethnicity and Alzheimer’s in America](#)

For the first time, the annual report is accompanied by a special report that examines the perspectives and experiences of Asian, Black, Hispanic, Native and White Americans in regard to Alzheimer’s and dementia care.

Diverse Elders Coalition (DEC)

diverseelders.org

DEC is made up of national organizations working to promote policy changes and programmatic solutions to support 5 groups of older people growing throughout the country, 1. American Indian and Alaska Native Elders, 2. Asian American, Pacific Islander, and Native Hawaiian older adults, 3. Black and African American older adults, 4. Hispanic and Latinx older adults, 5. Lesbian, gay, bisexual, and transgender (LGBT) older adults.



[Family Caregiving for Diverse Elders Resource Hub](#)

Find free online trainings, toolkits, and fact sheets created for healthcare and social services providers to better serve diverse family caregivers and older adults.

[Resource Library](#)

Access a large library of resources including original research and policy reports, fact sheets, webinars, and more. Browse by issue to focus on health equity topics most relevant to you. Some of the categories are [people of color](#), [caregiving](#), and [chronic illness](#).

Health Equity Institute at San Francisco State University

healthequity.sfsu.edu

The Health Equity Institute is a campus-wide interdisciplinary team at San Francisco State University advancing health equity through research, education, and community engagement.



[Health Equity Resources](#)

Learn about health equity here. Focus on the basics with “[Defining Health Equity](#)”, a [helpful video](#). Look deeper at the goals of health equity and what must happen to achieve it with [this series of infographics](#). Understand the impact of health inequities on the health outcomes of less privileged communities through a [motion graphic](#).

National Multiple Sclerosis Society

nationalmssociety.org

For 75 years National MS Society has led the charge to create a world free of MS. With more research it has become clear that a disease once thought to primarily affect Whites in fact has higher incidence (number of people newly diagnosed in a specific period of time) in Black communities and is impacting Latinos at increasing rates. The Society is dedicated to raising this awareness and working to ensure their programs and community truly reflect those they serve.



[The Black MS Experience Summit](#)

The summit is a three-day virtual event exploring the unique challenges and experiences of being Black and living with MS. Videos highlight the scientific and clinical differences in the disease, the inequities in the healthcare and other systems, and the powerful stories of real Black people living with MS.

[Momentum Magazine, special issue on MS and race](#)

This issue features articles on the gaps in MS research, diagnosis, and treatment. It also includes stories from people of color living with MS and care providers.

UsAgainstAlzheimer's

usagainstalzheimer.org

UsAgainstAlzheimer's was founded in 2010 to disrupt and diversify the movement to cure Alzheimer's. Through urgent and inclusive mobilization, they have worked to dramatically increase funding for Alzheimer's and dementia research and champion health equity and access for community of color and women disproportionately impacted by the disease.



Center for Brain Health Equity

- **Latinos and Alzheimer's: New Numbers Behind the Crisis**

A first-of-its kind report on the economic impact of Alzheimer's on Latino families and the American economy.

- **The Costs of Alzheimer's and Other Dementias for African Americans**

A report exploring the economic burden of Alzheimer's and other dementias for African Americans.

World Health Organization (WHO)

who.int

WHO is a specialized agency of the United Nations responsible for international public health. The WHO Constitution states its main objective as "the attainment by all peoples of the highest possible level of health."



"Health equity and its determinants"

World Health Day (April 7) 2021 marks the start of WHO's year-long campaign to place health equity center stage of world attention. This call to action explains what health equity is and why it is important. It also presents a framework of five actions to address the root causes of inequities and implement solutions within and beyond the health sector.

Programs for people of color

ALS Association

als.org

Since 1985, The ALS Association has led the way in research, care services, public education, and public policy for people affected by ALS. Through a national network of chapters they serve, advocate for, and empower people affected by ALS to live their lives to the fullest and work to discover treatments and a cure.



Guías de recursos vivir con ELA (Living with ALS guides)

Guías para personas que viven con ELA, sus familias, cuidadores, y personas interesadas en aprender más sobre ELA (guides for people living with ALS, family members, caregivers, and people interested in learning more about ALS).

Alzheimer's Association

alz.org

The Alzheimer's Association is a national organization supporting Alzheimer's and other dementia by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support.



Unidos Contra El Alzheimer: Alzheimer's Association Spanish group on Facebook:

un grupo de discusión privado para cuidadoras latinos de Alzheimer's (a private discussion group for Latinos caring for someone living with Alzheimer's)

Alzheimer's Los Angeles

alzheimersla.org

Alzheimer's Los Angeles is locally focused and nationally and internationally recognized for providing high-impact support, resources, and education to people and families facing the disease. They have made a commitment to the diverse families they serve to reflect their cultural and linguistic needs.

Support programs created specifically for people of color



Videos featuring families of color supporting someone with Alzheimer's or another dementia

"Recuerdos Perdidos", una telenovela Protagonizado por Elba Escobar ("Lost Memories", a telenovela starring Elba Escobar)

“Toma 5”, es importante que primero cuide de si mismo. Una serie de video y sugerencias (“Take 5”. It’s important to remember to take care of yourself first. A series of videos and suggestions)

Brigance Brigade Foundation

brigancebrigade.org

A Black-led organization, the Brigance Brigade Foundation is a nonprofit organization founded by O.J. Brigance and his wife, Chanda, with the mission to equip, encourage, and empower people living with ALS.

-  Chanda’s Caregiver Corner features the Caregiver Club and other ways to learn and connect

Dance for PD

danceforparkinsons.org


Founded in 2001, Dance for PD offers specialized dance classes to people with Parkinson’s, their families, friends and care partners. Classes offer people the chance to experience the benefits of creative dance while addressing symptoms such as balance, cognition, motor skills, depression, and physical confidence.

-  Dance for PD en Español
 - Un artículo reciente sobre Dance for PD en Español (a recent article about Dance for PD)

Family Caregiver Alliance (FCA)

caregiver.org

For more than 40 years, FCA has provided services to family caregivers of adults with physical and cognitive impairments, such as Parkinson’s, stroke, and Alzheimer’s.

-  Recursos para cuidadores en muchos idiomas (caregiving resources in many languages): English, Español, Korean, Tagalog, Tieng Viet, and Chinese (Traditional and Mandarin)

Latino Alzheimer's and Memory Disorders Alliance (LAMDA)

latinoalzheimersalliance.org

LAMDA educates and engages Latino caregivers and provides culturally sensitive training to healthcare providers. They have developed curriculum specifically for the Latino community and deliver caregiver workshops and other programs.

National Multiple Sclerosis Society

nationalmssociety.org

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[“Living Well with MS: A Guide for Black Americans”](#)

A 13-minute documentary about living with MS while Black. The documentary has [a companion guidebook with tips and information](#) to live well with MS.

[Esclerosis Multiple: información y programas en Español \(multiple sclerosis information and programs in Spanish\)](#)

Parkinson's Foundation

parkinson.org

The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything they do, they build on the energy, experience, and passion of the global Parkinson's community.

Fundación de Parkinson's alberga (Parkinson's Foundation hosts):

[Eventos en Español \(events in Spanish\)](#)

[Una biblioteca de recursos de Parkinson's en Español \(a library of Parkinson's resources in Spanish\)](#)

[Una conferencia anual en Español \(an annual Spanish-language conference\)](#)

[Un foro para gente de habla hispana y viven con la enfermedad de Parkinson's \(a forum for Spanish-speaking people living with Parkinson's\)](#)

Multiple Sclerosis Association of America (MSAA)

mymsaa.org

The MSAA is a nonprofit organization dedicated to enriching the quality of life for people affected by MS. They offer support and services to people with MS, their families, and their caregivers.



[información y programas en Español \(information and programs in Spanish\)](#)

[Experiencia Hispanoamericana sobre Esclerosis Múltiple \(Hispanic American experience on MS\)](#)

National Brain Health Center for African Americans (NBHCAA)

brainhealthcenterforafricanamericans.org

The mission of NBHCAA is to raise awareness of the issues of cognitive health among African Americans. The Brain Health Center serves as an information hub on the human brain that must be shared throughout all networks that reach and touch approximately 40 million African Americans living in the United States.

We Are Ill

weareillmatic.com

We Are ILL is a nonprofit patient advocacy organization redefining what sick looks for Black women living with multiple sclerosis (MS). They increase Black women's visibility in and access to patient care, research, education, and the MS community as a whole.



[Programs focus on four initiatives](#), 1. MRI education and funding for Black MS patients, 2. Increasing Black diversity in clinical trials, 3. Patient advocacy and wellness education that is culturally conscious, 4. Community building among Black women with MS.

Stay Involved in Health Equity Efforts

Accelerated Cure Project

acceleratedcure.org

Accelerated Cure Project is a patient-founded, nonprofit organization that focuses on meeting the research needs and interests of people with multiple sclerosis and research communities.

MS Minority Research Network

The Network welcomes new members who share the mission and goal to address gaps in minority engagement in MS clinical research and health disparities. Individuals and organizations are invited to identify and understand barriers to taking part in research and develop strategies to address those barriers.

Adira Foundation

adirafoundation.org

Adira Foundation's mission is to invest in better lives for people with neurodegenerative diseases.

Sounding Board

Directly inform the priorities of Adira by weighing in on what matters most to people impacted by ND. Choose the topics you are interested in, including health equity.

[Share your story](#)

Share a lived equity experience in just a few minutes with our story capturing tool.

I AM ALS

iamals.org

I AM ALS is a patient-led community that provides critical support and resources to patients, caregivers, and loved ones.

I AM ALS' Racial Equity Group

A weekly listening session for people who are Black and impacted by ALS

UsAgainstAlzheimer's

[usagainstalzheimers.org](https://www.usagainstalzheimers.org)

UsAgainstAlzheimer's was founded in 2010 to disrupt and diversify the movement to cure Alzheimer's. Through urgent and inclusive mobilization, they have worked to dramatically increase funding for Alzheimer's and dementia research and champion health equity and access for community of color and women disproportionately impacted by the disease.



The A-List

Connect to share insights with doctors, researchers, and regulators on what matters most to you (people living with Alzheimer's or other dementias, are at risk for Alzheimer's or other dementias, or are a caregiver)

AfricanAmericansAgainstAlzheimer's

AfricanAmericansAgainstAlzheimer's is the nation's first organization dedicated to building a coordinated national response to eliminate and address Alzheimer's disease among African Americans.

LatinosAgainstAlzheimer's

LatinosAgainstAlzheimer's marshalls resources and action to address the growing impact of Alzheimer's and dementia on our nation's 55 million Latino families.

Health Equity Solutions – Examples

Participants shared these specific examples of health equity interventions during the event discussion:

Community Health Workers: A Resource for Healthy Aging and Addressing Dementia

<https://www.alz.org/media/Documents/community-health-workers-a-resource-for-healthy-aging-and-addressing-dementia.pdf>

Created by the Alzheimer's Association and Association of State and Territorial Health Officials, this resource guide provides an easy way for health departments to learn about available training, education, frameworks, and tools to build partnerships with CHWs. Users will also find examples of state health department initiatives to train and support CHWs as they educate their communities about healthy aging and cognitive health.

Project ECHO (Extension for Community Healthcare Outcomes)

hsc.unm.edu/echo/

Project ECHO is a revolutionary guided-practice model that reduces health disparities in under-served and remote areas of the state, nation, and world. Through innovative telementoring, the ECHO model uses a hub-and-spoke knowledge-sharing approach where expert teams lead virtual clinics, amplifying the capacity for providers to deliver best-in-practice care to the underserved in their own communities.

The Nasiona Podcast

thenasiona.com

The Nasiona is a volunteer-led nonfiction storytelling organization that humanizes the Other by amplifying the voices and experiences of the systemically marginalized, undervalued, overlooked, silenced, and forgotten.

**A big thank you to all who contributed.
Especially to our sponsor:**

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We hope you'll [stay in touch!](#)



Thank you