**SWHR Policy Agenda: Breaking Down the Burden of Alzheimer’s Disease for Women**

*Alzheimer’s disease is a progressive brain disorder that affects the parts of the brain that control thought, memory, and language—and it disproportionately affects women. The most common form of dementia, Alzheimer’s disease can result in loss of memory and the ability to carry on conversations and daily activities.*

The [Alzheimer’s Association](http://www.alz.org) estimates that there are 6.5 million adults age 65 and older who are living with Alzheimer’s disease in the United States—and this number is expected to rise. The same estimates project that the number of adults living with this disease could grow to 13.8 million by 2060.

Yet, the burden of Alzheimer’s disease—including its health, economic, and quality-of-life impacts—is not evenly distributed. Approximately [two-thirds of Americans](http://www.alz.org) living with the disease are women. After age 45, [1 in 5 women](http://www.alz.org) are expected to develop Alzheimer’s disease, compared to 1 in 10 men. Alzheimer’s disease is the [5th leading cause](http://www.alz.org) of death for women in the United States, compared to the [7th leading cause](http://www.alz.org) of death for men.

Non-Hispanic white women have the [highest mortality rate](http://www.alz.org) for Alzheimer’s disease (285.1 deaths per 100,000), compared to 234.7 for non-Hispanic Black women and 218.8 for Hispanic women. However, there are significant disparities in Alzheimer’s disease among communities of color. Black Americans are about twice as likely and Hispanic persons about 1.5 times as likely to [develop Alzheimer’s disease and related dementias](http://www.alz.org) than non-Hispanic white populations. Moreover, women of these racial groups are [less likely to be diagnosed](http://www.alz.org) than their white counterparts, and Black women report [higher rates of discrimination](http://www.alz.org) than non-Hispanic white Americans when seeking health care.

Beyond its direct implications on physical health, Alzheimer’s disease also threatens women’s well-being, including their mental health and their professional lives. More than [60% of Alzheimer’s disease caregivers](http://www.alz.org) are women—many of whom are uncompensated. Research has indicated that the cost of uncompensated (or informal) caregiving is the greatest economic challenge of Alzheimer’s disease that women face. According to a [2015 article in Women’s Health Issues](http://www.alz.org), “Throughout the lifetime, a female family member of a male Alzheimer’s disease patient will likely bear a burden of informal care six times greater than will a male family member of a female Alzheimer’s disease patient ($54,956 vs. $8,659).”

The Society for Women’s Health Research (SWHR) is committed to working with our partners in the Alzheimer’s disease space to raise awareness about Alzheimer’s disease’s disproportionate impact on women and communities of color and drive policy change to improve women’s health outcomes across the lifespan. Over the years, SWHR’s work in Alzheimer’s disease has sought to demonstrate the benefit of expanding research on sex and gender disparities in Alzheimer’s disease and related dementias and to identify research, clinical care, and policy gaps that could affect health care outcomes for women across the lifespan. These efforts have included bringing together interdisciplinary working groups to identify gaps and opportunities in Alzheimer’s disease across research, clinical care, education and awareness, and policy; publishing a [peer-reviewed commentary](http://www.alz.org) on the importance of better integration of sex as a biological variable in Alzheimer’s disease research; writing commentaries in outlets, including the [Scientific American](http://www.alz.org), on the significance of exploring the role of sex and gender in Alzheimer’s disease; and engaging with federal agencies, Congress, and independent organizations on policy measures that could improve women’s health and quality of life outcomes.

Building on SWHR’s past and current Alzheimer’s disease work, this policy agenda focuses on how the implementation of key policy measures spanning research, disease prevention and detection, and health care access and coverage, could yield tremendous benefits that lower health care costs, improve health care quality and access, support caregivers, advance health equity, and improve outcomes. SWHR’s [Policy Agenda: Breaking Down the Burden of Alzheimer’s Disease for Women](http://www.alz.org) is intended to serve as a roadmap outlining key areas of policy change to improve outcomes for women affected by Alzheimer’s disease—both as patients and caregivers.

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**Society for Women’s Health Research**

**November 2022**
Despite the growing prevalence of Alzheimer’s disease in the United States, there is still a stigma attached to Alzheimer’s disease. According to research released by AARP in June 2021, “Misperceptions and stigma about dementia are hindering efforts to appropriately address brain-healthy behaviors among adults 40 and older.” The survey found that 1 in 5 adults said they would feel ashamed or embarrassed if they had dementia, and 48% of adults believe they will have dementia (less than 11% of adults over the age of 65 have Alzheimer’s disease). As stated by AARP, these results make clear the “opportunity to inform providers and the public about the real concerns surrounding dementia and the known lifestyle habits that can help maintain brain function as people age.”

While there is currently no cure for Alzheimer’s disease, there are promising interventions on the horizon, and research indicates there may be a window of opportunity to prevent or delay dementia symptoms. A 2017 consensus study report from the National Academies of Sciences, Engineering, and Medicine (NASEM) found “encouraging but inconclusive evidence” for preventing or delaying Alzheimer’s disease or age-related cognitive decline through increased physical activity, blood pressure control for those with hypertension, and cognitive training. Moreover, a 2020 report of the Lancet Commission found that modifying 12 risk factors—which include hypertension, physical health, alcohol use, and smoking—might “prevent or delay up to 40% of dementias.”

As the U.S. Centers for Disease Control and Prevention (CDC) describes, “[F]ear and stigma associated with Alzheimer’s disease may cause individuals to delay seeking a diagnosis and care.” However, there are many benefits to the early detection and diagnosis of Alzheimer’s disease for individuals and their families. They include offering an explanation for the symptoms the individual is experiencing, determining whether the individual qualifies for a clinical trial, providing additional time to put together a financial and care plan, determining which treatments and interventions may be appropriate, and identifying resources that can support individuals and their families throughout their journey.

There are steps policymakers can take to support and promote early detection and diagnosis.

I. Execute a Multi-Faceted Public Health Awareness Campaign about Alzheimer’s Disease and Related Dementias, the Importance of Early Detection, and How People Can Access Relevant Resources

Alzheimer’s disease is a growing public health crisis. While there is tremendous promise in research and innovation, tackling the Alzheimer’s disease crisis at a societal level involves ensuring that the public is familiar with the disease—including what it is, the signs and symptoms to look for, what the risk factors are, and how adhering to a “brain healthy lifestyle” may affect outcomes.

SWHR encourages carrying out far-reaching and multi-faceted public awareness campaigns that tackle knowledge gaps and misperceptions surrounding Alzheimer’s disease, review the signs and symptoms of Alzheimer’s disease, and discuss the value of early detection and diagnosis. Importantly, campaigns and stakeholders should also share resources that highlight where people can go to access support for Alzheimer’s disease as well as where they can access prevention-focused tools and services.

II. Promote and Ensure Utilization of Cognition Assessments in Medicare Annual Wellness Visit

Assessing cognitive impairment is one of the required components of the Medicare Annual Wellness Visit (AWV), a preventive care-focused visit with a primary care provider to create or update a Personalized Prevention Plan and perform a Health Risk Assessment. A 2021 study in Health Services Research revealed that “dementia diagnosis rates increased with AWV implementation with heterogeneous effects by race and ethnicity.”

SWHR encourages the U.S. Preventive Services Task Force to reassess its recommendations on dementia screening for older adults and supports the expanded utilization of the Medicare AWV for providers to discuss cognitive health with their patients, including the risk factors of cognitive decline and guidance on how to promote brain health as they age through physical, behavioral, and lifestyle changes.
Engage Stakeholders to Review Existing Alzheimer's Disease Resources and Recommend Gaps and Opportunities for Creating Culturally- and Linguistically- Tailored Federal Tools and Resources

In order to take an active role in decision-making about their health care, people need access to quality, evidence-based information and resources. These resources should be culturally and linguistically appropriate and mindful of different circumstances and life stages so that they are responsive to the diverse patients for whom they are intended to serve.

SWHR encourages agencies within the U.S. Department of Health and Human Services to engage a broad group of stakeholders to review existing educational materials, tools, and resources on Alzheimer’s disease and related dementias and identify where there are opportunities to revise existing resources or create new resources to improve their public reach and effectiveness.
Alzheimer’s disease is costly—to both individuals and to society. According to Genworth’s Cost of Care Survey, long-term care services can range from median monthly costs of $1,690 for adult day health care to $9,034 for a private room in a nursing home. The total payments for individuals with Alzheimer’s disease or other dementias in 2022 are estimated at $321 billion, with Medicare and Medicaid expected to cover $206 billion (64%) of total health care and long-term care payments.

Given the rising prevalence of Alzheimer’s disease, equipping health care systems to serve those with Alzheimer’s disease and related dementias will be increasingly important. Yet, fewer than 1% of physicians in the United States are specialized in geriatrics, the field for medical doctors who specialize in care and treatment for individuals aged 65 and older. Further, the National Center for Health Workforce Analysis projects that by 2025, the demand for geriatricians is expected to exceed supply and will result in a national shortage of nearly 27,000 full-time equivalents. Beyond specialists, primary care providers should be trained to serve those with Alzheimer’s disease and related dementias.

Building a dementia-capable system that accommodates the needs of those with Alzheimer’s disease and supports both patients and caregivers will require ensuring the necessary training and resources are in place for health care providers; improving paths for detection and diagnosis; and utilizing data collection and monitoring tools to track changes, identify best practices, and improve care coordination.

1. **Incentivize Physicians from Diverse and Underrepresented Groups to Practice Geriatric Medicine**

Building a strong geriatric workforce is dependent upon bringing more practitioners into geriatric medicine. While increasing the number of practicing geriatricians will require dedicated changes across the health care system—including increasing the geriatric content taught within medical programs—the federal government should explore additional incentives—similar to the Health Resources and Services Administration’s Health Professional Shortage Area Physician Bonus Program—to bring people, including women and individuals unrepresented in the field, into geriatric medicine.

Increasing the diversity of the physician workforce can help improve health care delivery; evidence has shown that when physicians and patients share the same race or ethnicity, patients find visits more satisfactory, more participatory, and can better perceive factors, such as cancer risk and recommended treatment—to name a few.

SWHR encourages identifying additional incentives to bring more physicians into the field of geriatric medicine.

2. **Require Certain Number of Hours for Geriatric Medicine Training for Medicare-Certified Health Providers**

The geriatrician shortage in the United States will pose a challenge given the growing aging population in the United States. Therefore, it will be increasingly important for health care providers to be well-versed in the health care needs of older adults.

SWHR supports requiring Medicare-certified health care providers to receive a certain number of hours of training in geriatric medicine in order to meet their certification requirements, creating an incentive program for geriatric training, and increasing the resource clearinghouse of information and training to support health care providers in geriatric medicine.

3. **Expand Access to Telehealth Services**

During the COVID-19 pandemic, telehealth service utilization increased significantly among both privately-insured patients and Medicare beneficiaries, demonstrating the role this service could play in improving access to care. Applied to Alzheimer’s disease and dementia care, telehealth has the potential to improve access and improve outcomes. Not only could telehealth reduce some of the burdens associated with accessing care (e.g., living in a rural area, having limited mobility, lacking the transportation or support needed to see a provider, or serving as an informal
caregiver for an Alzheimer’s disease patient), but research has also indicated that telehealth dementia services may reduce emergency department visits.

SWHR supports policies that make providing and receiving telehealth services easier. This includes, but is not limited to, policies that were implemented during the COVID-19 pandemic, such as allowing telehealth services to be delivered across state lines and providing greater flexibility under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) for providers to use everyday technology for virtual health care visits.

**IV. Require CMS to Use Evidence-Based Screening Tools as Opposed to Direct Observation in AWV**
Assessing cognitive impairment is a required component of the Medicare AWV. Currently, the Centers for Medicare & Medicaid Services (CMS) calls for providers to assess an individual’s cognitive function by direct observation or by considering information from the patient, family, friends, caregivers, and others. However, these measures are subjective. Evidence-based screening tools and tests designed to detect cognitive impairment and signs of dementia at early stages, including some listed on the National Institute on Aging’s (NIA) website, could better serve older adults in receiving accurate diagnoses.

SWHR supports the passage of the Concentrating on High-Value Alzheimer’s Needs to Get to an End (CHANGE) Act, which would modify the requirements under Medicare for diagnosing and treating Alzheimer’s disease and cognitive impairment by expanding the cognitive impairment detection visit during AWVs to require the use of identified detection tools and documentation of results in the patient’s medical records.

**V. Revise CMS Policy on Beta Amyloid Positron Emission Tomography (PET) in Dementia and Neurodegenerative Disease**
Currently, CMS has a policy that provides each patient coverage for one beta-amyloid PET scan per lifetime and that patients access the amyloid PET scan through a clinical study via coverage with evidence development (CED). As the only U.S. Food and Drug Administration (FDA) approved diagnostic tool that allows health care providers to visualize when a patient experiencing a mild cognitive impairment has beta-amyloid neurotic plaques, a hallmark pathology of Alzheimer’s disease, PET scans serve an important diagnostic role. Enhancing access to these scans could help clinicians have greater assurance of a patient’s diagnosis and their treatment recommendations.

SWHR supports removing the once per lifetime per patient limit on beta-amyloid PET scans for those with cognitive impairments, which can change and develop over time, in order to place greater decision-making authority in the hands of clinicians and could yield positive results for patients and their families. SWHR also supports reviewing the current CED policy in place for beta-amyloid PET scans to determine its potential impact on patient access.

**VI. Modify CMS Coverage Policy for Monoclonal Antibodies Targeting Amyloid for the Treatment of Alzheimer’s Disease**
The 2022 CMS decision not to cover FDA-approved monoclonal antibodies that target amyloid (plaque) for the treatment of Alzheimer’s disease, except in limited circumstances, could not only present challenges to patient access and outcomes, but also exacerbate inequities in care. Among the concerning factors of this policy are how the decision applies to the entire class of anti-amyloid monoclonal antibodies, including those in development and those not yet invented; how it could prematurely deter future, potentially groundbreaking research into this class of drugs, which could have different target populations and efficacy profiles; and how it makes a distinction between drugs approved under the accelerated approval pathway and drugs that have received traditional approval.

SWHR urges CMS to provide coverage to label for all FDA-approved treatments, which would help ensure that the agency does not unnecessarily restrict, patients’ access to effective and potential quality-of-life-improving treatments for Alzheimer’s disease.
There are significant sex differences in the brain. As summarized in a 2022 article in *Alzheimer’s Research & Therapy*, “Well-known sex differences in Alzheimer’s disease dementia include the disproportionate higher prevalence and lifetime risk for developing Alzheimer’s disease dementia in females compared to males, with previous studies showing that females are shown to be more vulnerable to Alzheimer’s disease pathology and Alzheimer’s disease risk factors compared to males. Furthermore, prior research has suggested more severe cognitive deficits and faster cognitive decline among females with Alzheimer’s disease dementia.”

Yet, despite the significant progress that has been made in Alzheimer’s disease research and the more than seven-fold increase in federal Alzheimer’s disease and dementia research funding since 2011, Alzheimer’s is severely underfunded when considering the societal cost of Alzheimer’s disease, and it is underfunded compared to other conditions, such as cancer. In 2019, more than 1.75 million people were diagnosed with cancer, and almost 600,000 people died of cancer, compared to the more than 6 million Americans living with Alzheimer’s disease and approximately 122,000 deaths. Yet, the National Cancer Institute received $6.9 billion in fiscal year 2022, whereas Alzheimer’s disease funding for 2022 is estimated at $3.5 billion. There remain myriad opportunities in Alzheimer’s disease research, including on sex differences in Alzheimer’s disease and racial and ethnic differences in Alzheimer’s disease and related dementias.

**Investing in Women’s Alzheimer’s Disease and Related Dementias Research Could Yield Tremendous Returns**

According to a 2021 research report from the RAND Corporation, “Assuming 0.01% improvement in health from small reductions in age incidence and Alzheimer’s disease and related dementias disease severity, more than 6,000 years with Alzheimer’s disease and related dementias can be saved across 30 years, with substantial gains in health-related quality of life; nursing home costs could drop by more than $360 million; and the return on investment is 224 percent for doubling investment in women’s health research.”

**Prioritize Investments in Federal Research Related to Cognitive Health**

While investments in Alzheimer’s disease research have increased substantially in the past decade, as a rapidly growing public health epidemic, Alzheimer’s disease must remain a focus of federal research investments. Although there is ample opportunity to build upon the existing evidence base in Alzheimer’s disease, some research areas that could elucidate risk and improve Alzheimer’s disease outcomes include the following:

a. The potential mechanisms underlying the etiology and pathogenesis of Alzheimer’s disease that may help explain why more women are impacted

b. Contributions of biological factors to one’s risk of developing Alzheimer’s disease (e.g., how pregnancy may affect a woman’s Alzheimer’s disease risk)

c. Genetic risk profiles of Alzheimer’s disease

d. Structural contributors to underlying biology (e.g., biological impacts of racism and trauma on cognitive function)

e. Validation in larger and more diverse populations to better understand how biological sex and gender considerations may contribute to disease-related brain changes

f. Mechanisms driving differences in Alzheimer’s disease across different races and ethnicities, including biological and social factors

g. Potential biological and social influences that impact Alzheimer’s disease outcomes in the LGBTQ+ community

h. Advancement of blood diagnostics efforts to help make an Alzheimer’s disease diagnosis more easily accessible to all populations
Implement Policies to Meaningfully Increase Diversity in Clinical Trials

It is well-documented that certain populations—including people who identify as a racial or ethnic minority, those with low socioeconomic status, or who live in rural areas—have been historically underrepresented in Alzheimer’s disease clinical trials despite being at increased risk for developing it.

Tackling Alzheimer’s disease at a societal level hinges on identifying treatments and interventions that work for everyone, regardless of sex, gender, race, or ethnicity. Therefore, recruiting and retaining a diversity of patient populations within clinical trials is essential.

SWHR supports the implementation of policies that ensure that the trial population reflects the treatment population. This includes policies that:

a. Seek to improve the recruitment and retention of underrepresented and marginalized populations in clinical trials

b. Critically assess clinical trial exclusion criteria to ensure that it will not inadvertently omit members of the treatment population for whom the intervention is intended to serve

c. Create mechanisms—with input from key stakeholders—for internal and external accountability, including monitoring efforts to engage communities in clinical trials
Caregivers—both formal and informal—play an instrumental role in the lives of those living with Alzheimer’s disease and in society. In 2021, more than 11 million informal caregivers provided an estimated 16 billion hours of unpaid care to people with Alzheimer’s disease and other dementias, amounting to an economic value of $271.6 billion. While caregiving can be a rewarding and fulfilling experience, the responsibilities can also take a toll on caregivers’ physical, emotional, and mental health as well as on their financial security.

According to a 2020 fact sheet from the Alzheimer’s Association:

- Nearly 75% of Alzheimer’s disease and dementia caregivers are somewhat or very concerned about maintaining their own health since becoming a caregiver.
- Over 1 in 3 dementia caregivers say their health has gotten worse due to their care responsibilities, and more than a quarter of dementia caregivers delay or don’t pursue things they should to maintain their own health.
- Nearly 60% of Alzheimer’s disease and dementia caregivers rate the emotional stress of caregiving as “high” or “very high.”

Women, in particular, are impacted by caregiving responsibilities. More than 60% of Alzheimer’s disease and related dementias caregivers are women.

Research has indicated that the cost of uncompensated informal caregiving is the greatest economic challenge of Alzheimer’s disease that women face. According to a 2015 article in Women’s Health Issues, “Throughout the lifetime, a female family member of a male Alzheimer’s disease patient will likely bear a burden of informal care six times greater than will a male family member of a female Alzheimer’s disease patient ($54,956 vs. $8,659).”

Recognizing the pivotal role of caregivers in long-term care in the United States, the U.S. Department of Health and Human Services (HHS), through its Administration for Community Living, released the 2022 National Strategy to Support Family Caregivers, highlighting “nearly 350 actions the federal government will take to support family caregivers and more than 150 actions that can be adopted at other levels of government and across the private sector to build a system to support family caregivers.” SWHR applauds the administration for recognizing the role of caregivers in this country and for prioritizing their livelihoods and well-being through this plan and suggests the following additional steps to incorporate caregiver perspectives and improve both patient and caregiver wellness.

I. Include Caregivers in Health Care and Research Teams

Caregivers serve a critical role in the U.S. health care and long-term care ecosystem by helping adults carry out everyday tasks and in supporting their care (e.g., driving adults to their doctor’s appointments). Given their close relationship to the individual for whom they are caring, caregivers have an important vantage point for monitoring changes in that individual’s health and in their needs. However, despite the role they play, caregivers can be overlooked as key participants in an individual’s health care journey.

SWHR supports policies that include caregivers in both health care and research teams from the outset through the individual’s care journey and that will improve the inclusion of caregivers in care to promote better care coordination.

II. Include Caregivers in Paid Family and Medical Leave Legislation

In March 2021, 23% of civilian workers had access to paid family leave; 89% had access to unpaid family leave. While the Family and Medical Leave Act (FMLA) entitles eligible employees of covered employers up to 12 weeks of job-protected unpaid leave each year to recover from their own serious health conditions or to care for a newborn, newly adopted or foster child, or a seriously ill family member, many cannot afford to take unpaid leave, and only 56% of U.S. employees are eligible for FMLA. Passing paid family and medical leave legislation would support family
caregivers, “who for too long have struggled to balance care for a family member living with dementia and their job,” as emphasized by UsAgainstAlzheimer’s chair and co-founder George Vradenburg.

SWHR supports legislation that provides paid family and medical leave for people living with Alzheimer’s disease and other serious medical conditions and their caregivers as well as policies that incentivize family caregiver-friendly initiatives in the workplace.

III. Create Tools, Resources, and Information to Support Caregivers

Given their role in and contributions to society, caregivers should have easy access to the tools, resources, and information that they need not only to support those for whom they are caring, but also to the information that will allow them to better support their own health and well-being.

SWHR supports the federal government’s efforts to create and maintain national educational resources and efforts that:

a. Educate caregivers about their employment rights, how to access any caregiving benefits, which resources are available, and connect them with support services

b. Provide information about caregiving benefits in federal insurance programs

c. Relay information aimed at supporting caregiver health and well-being

d. Serve a diversity of audiences by being culturally and language appropriate

IV. Ensure Caregivers and the Caregiver Burden is Represented in Health Care Value Assessment Frameworks

As the U.S. health care system moves from a model based on volume to one based on value, it will be vital for value to be defined based on what matters most to patients, caregivers, and society in order to ensure that the frameworks are serving diverse populations. Notably, these value frameworks should incorporate caregiver outcomes, caregiver perspectives, and the costs of informal caregiving.

SWHR supports incorporating the perspectives of caregivers and caregiver-related factors, such as caregiver availability, into health care value assessment work to best serve all patients.
Alzheimer’s disease does not affect all populations equally. Alzheimer’s disease disproportionately affects women, Black people (twice as likely to have Alzheimer’s disease and related dementias compared to White people), and Hispanic people (1.5 times as likely to develop dementia). While non-Hispanic white women have the highest mortality rate (285.1 deaths per 100,000) for Alzheimer’s disease (compared to 234.7 for non-Hispanic Black women and 218.8 for Hispanic women), Black Americans are about twice as likely and Hispanic persons about 1.5 times as likely to develop Alzheimer’s disease and related dementias than non-Hispanic white populations. When stratified by sex, women of these racial groups are at even higher risk of being diagnosed.

However, despite these populations being at increased risk of developing dementias, a recent analysis from the National Institute on Aging reveals that Black participants in Alzheimer’s disease research studies were 35% less likely to be diagnosed with Alzheimer’s disease and related dementias than white participants. Further, they report higher rates of discrimination when seeking health care than non-Hispanic white Americans.

In August 2022, SWHR hosted an interdisciplinary roundtable of clinicians, researchers, policy experts, and patients and patient advocates on where there are policy needs and opportunities in the Alzheimer’s disease space to improve outcomes for women. During the roundtable, working group members discussed the need to fundamentally shift our nation’s approach to Alzheimer’s disease in order to address and advance health equity.

This shift requires a change in approach not only from the research and clinical care perspective, but also from an awareness and education perspective.

Implementing meaningful change with respect to the nation’s brain health and addressing the disparities that underserved populations and communities of color face in brain health will require, but is not limited to, the following:

- Cognitive health campaigns, in addition to focusing on general messages about sustaining a brain healthy lifestyle and reaching the communities in greatest need, should also focus on how and where people can access the resources they need. These campaigns, resources, and programs—as recommended by UsAgainstAlzheimer’s—should be culturally tailored to serve a diversity of populations and should be linked to social services in order to address social determinants of health factors that impact brain health. Each of these steps will be essential for creating capacity in communities to address Alzheimer’s disease.

- There is a critical need to improve recruitment and retention of diverse populations in Alzheimer’s disease and related dementia research and clinical trials. This will involve reaching certain populations where there are, rather than placing the burden on those populations to reach the research; incentivizing clinical trial participation and providing relief for ancillary costs, such as transportation costs and time off work; increasing diversity within the research workforce; and building relationships in communities over time. Strategies may involve working with local, cultural, and faith-based organizations and bringing in researchers and volunteers who speak a certain language to reach those communities. Research efforts should also create a role for both internal and external monitoring and accountability to guarantee that the steps being taken appropriately involve these communities throughout the research process.

- In addition to insights gleaned from research and clinical trials, a concerted effort should also be made to improve data collection efforts across subpopulations, and namely among women of color. Having access to this data is necessary for understanding the prevalence of Alzheimer’s disease across communities and the potential role of social determinants of health in communities’ risk for developing Alzheimer’s disease as well as for using that data to implement meaningful policy changes.

- Another important aspect of care is serving vulnerable rural, and low-income communities, who may experience greater challenges accessing health care. These challenges were exacerbated by the COVID-19 pandemic. According to data from the Urban Institute, during the pandemic, Black and Latino adults reported higher rates of family financial insecurity and hardship, resulting in difficulties buying food or using savings or increased credit card debt. Low-income and Hispanic adults experienced the greatest job income and losses. Beyond access to
care implications, minority populations also disproportionately serve as family caregivers, which can have physical, mental, and economic effects. Supporting these communities will involve ensuring that Medicaid and home services consider these communities and that policies are in place to support family caregivers.

- To support informal caregivers playing a critical role in society, we must officially recognize the role of caregivers by considering the inclusion of caregivers in paid family and medical leave legislation and incentivizing family caregiver-friendly policies in the workplace.
- Finally, policies must be implemented to address the systemic barriers that impact the ability of populations to access health care with the ultimate goal of achieving equity. These policies should address areas including, but not limited to, discrimination, diversity in the medical workforce, socioeconomic disparities, and clinical trial accessibility.

This policy agenda, Breaking Down the Burden of Alzheimer’s Disease for Women, was informed by an Alzheimer’s Disease Policy Roundtable convened by SWHR in August 2022. The Roundtable brought together an interdisciplinary group of experts working throughout research, policy, clinical care, and patient advocacy.

ABOUT SWHR

The Society for Women’s Health Research (SWHR) is a national nonprofit and thought leader dedicated to promoting research on biological sex differences in disease and improving women’s health through science, policy, and education. Founded in 1990 by a group of physicians, medical researchers, and health advocates, SWHR is making women’s health mainstream by addressing unmet needs and research gaps in women’s health. Thanks to SWHR’s efforts, women are now routinely included in most major medical research studies and more scientists are considering sex as a biological variable in their research. Visit www.swhr.org for more information.