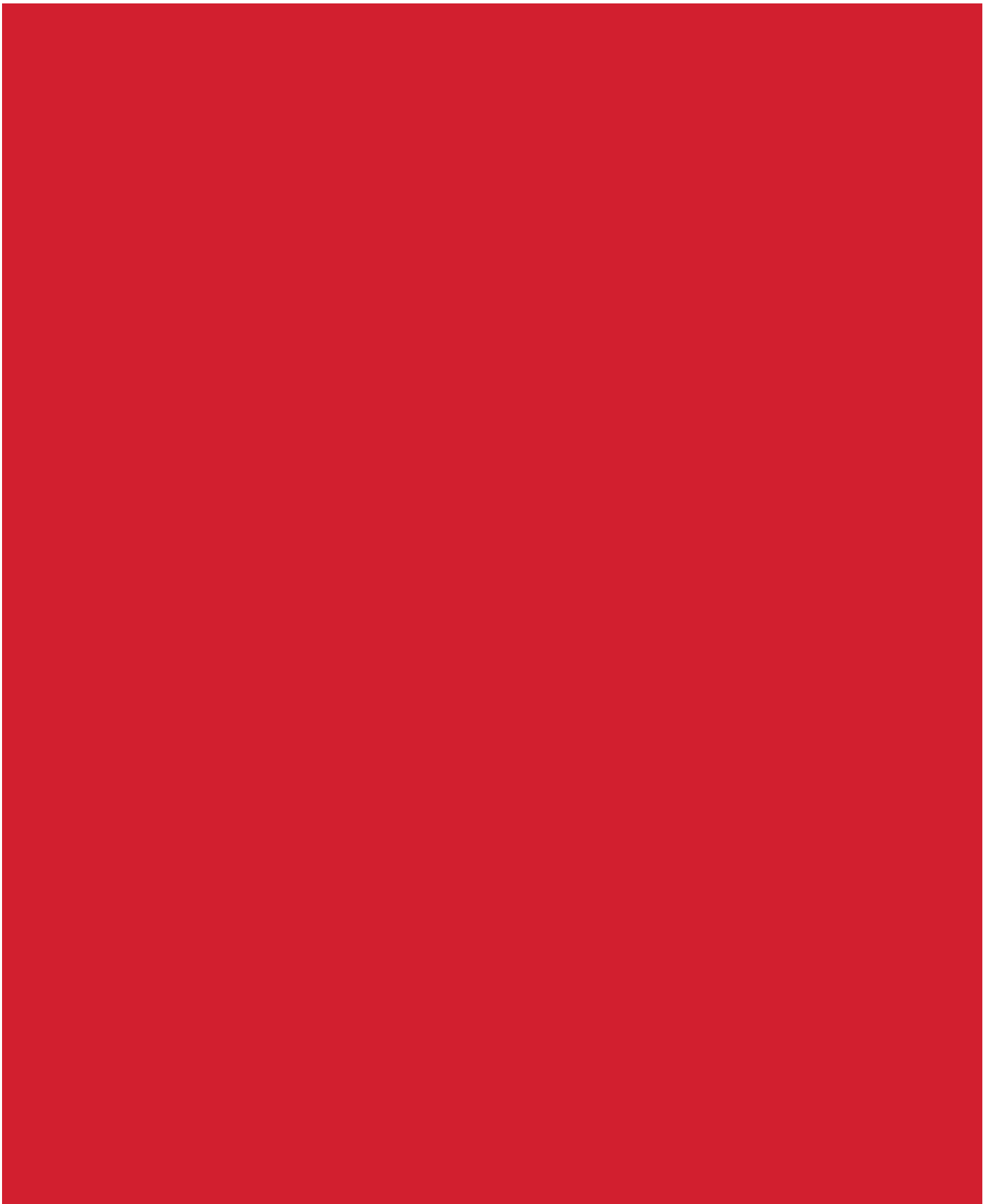


AfricanAmerican Network**4**gainst Alzheimer's

KEY FINDINGS AND POLICY RECOMMENDATIONS:
The Costs of Alzheimer's and Other Dementia
for African Americans

Stand up. Speak out. Overcome.



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The Costs of Alzheimer's and Other Dementia for African Americans

EXECUTIVE SUMMARY

While African Americans make up only 13.6% of the U.S. population, they bear a third of the costs of Alzheimer's disease and other dementias (AD). This is due to substantial, but under appreciated, racial disparities in the prevalence of AD. Older African Americans are two to three times more likely to have AD compared to non-Hispanic whites. More than 20% of Americans with AD are African Americans.

The economic burden of Alzheimer's and other dementias for African Americans was \$71.6 billion in 2012. Caregiving for African Americans with AD represents the bulk of these costs—more than 60%. More than 60% of the costs are borne by the families of African American women with AD, and close to half of the costs are concentrated in the southern states.

The estimated direct medical and long-term care costs of AD for African Americans were \$21.4 billion dollars. This includes \$5.5 billion in direct medical costs, \$1.3 billion in costs of adult day care in non-institutional settings, and \$14.6 billion in nursing home costs. Taxpayers pay for the majority of these health care-related costs through Medicare and Medicaid.

While the economic burden of AD is quite high, the full impact of AD cannot be expressed in dollars. The toll on patients with Alzheimer's disease and their loved ones is difficult to quantify. AD exacts an emotional burden on families and a physical and psychological burden on caregivers and

removes from society the memories, experiences and wisdom that its victims can no longer share. We have not quantified the loss of quality of life of victims and their families. If we were able to compute these costs of AD, our estimates would be exceedingly higher.

Nationally, estimates show that the economic burden of AD is comparable to those of heart disease, cancer and diabetes. Yet, society does not devote proportionate resources to research, education, prevention, treatment and policy to address this leading cause of death. The prevention and treatment of AD are especially important to African Americans. We expect African Americans to bear an increasing share of the economic costs of AD. Based on the prevalence rate, the distribution of health care costs, and the growth and aging of the African American population, we expect the costs of AD for African Americans to more than double by 2050. Hence, society needs to develop prevention strategies and treatments that restore functional status to patients with this disease. There is also a great need for policies, programs and interventions that assist caregivers and reduce the impact of AD on caregivers' earnings, savings, health and overall quality of life.

KEY FINDINGS

While African Americans make up 13.6% of the U.S. population, they bear one-third (33%) of the nation's total costs of Alzheimer's and other dementia.

The estimated annual cost to African Americans for Alzheimer's and other dementia in 2012 was \$71.6 billion. More than 60% of these costs are borne by the families of African American women with Alzheimer's and other dementia, and close to half of the costs are concentrated in the South.

African Americans provide \$43.6 billion annually — more than 17.4 billion hours — in unpaid caregiving for their loved ones with Alzheimer's.

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care in non-institutional settings, and \$14.6 billion in nursing home costs.

While Medicare is the primary payer for the medical care costs, paying 59%, African Americans pay \$554 million out-of-pocket.

African Americans between the ages of 40 and 64 lost \$6.1 billion in labor market productivity due to Alzheimer's — mostly from lost wages.

The prevalence of cognitive impairment is two to three times higher for African Americans. Based on the prevalence rate and the distribution of health care costs, we expect that the costs of Alzheimer's care for African Americans will rise substantially in the future as the African American population ages. The prospects of 1 in 3 and then 1 in 2 older African Americans with cognitive impairment presents a significant challenge to African American families and society at large.

CONCLUSION: PUBLIC POLICY RECOMMENDATIONS

Despite the challenges reflected in this report, there are reasons for optimism about achieving the national goal of preventing and effectively treating Alzheimer's disease by 2025, if not sooner. In setting a bold and time-based goal for this pursuit, our nation has elevated Alzheimer's disease to a level of prioritization not previously seen. Now, the task before the entire nation—including both the public and private sectors—is to deliver meaningful actions and commit the resources necessary to achieve

this and other goals of the plan. Just as the national plan focuses on research, patient care and caregiver supports, so, too, do the following policy recommendations put forward by the AfricanAmericanNetworkAgainstAlzheimer's.

RESEARCH

The costs of Alzheimer's to the African American community are substantial and disparate, making the imperative for a means of prevention and treatment even more crucial to this community. Stopping Alzheimer's by 2020, 2025—or any other point in time—requires scientific and

medical breakthroughs and discoveries that can be developed into safe and effective therapies, treatments and means of prevention. Such goals are impossible absent appropriate resources.

The AfricanAmericanNetworkAgainstAlzheimer's recognizes the challenging fiscal pressures the Administration and Congress are facing and applauds the Administration in particular for reallocating funding in recent fiscal years to further support research into Alzheimer's disease and dementia by the National Institutes of Health (NIH). While helpful, even these additional allocations are but a drop in the bucket of the \$2 billion of annual NIH funding for Alzheimer's research that leading researchers think is necessary to achieve the 2025 goal. As such, the Network strongly supports efforts to ramp up NIH funding for Alzheimer's research, to meet or exceed \$2 billion annually within five years. In addition, the Network supports investment in AD prevention research, such as examining the role of environmental and lifestyle risk factors.

CLINICAL TRIALS: MINORITY PARTICIPATION

In addition to funding, the Network is encouraged to see our national plan recognize the underrepresentation of minority populations in Alzheimer's disease research trials and to set an objective of increased participation by these populations in research. Lives are saved every day due to discoveries made in clinical trials. Yet African Americans, who stand to benefit significantly from medical research, are often reluctant to participate and often underrepresented in important medical research

to find treatments for the very diseases that most impact them. This low participation makes it difficult to assess how new drugs will affect African American patients, which in turn makes it harder to resolve disparities in health.

The Network recognizes that achieving the goal of increased minority participation in research will require the engagement of government, industry, patients, physicians, community and faith-based organizations, and other stakeholders. This is a major priority for the Network, which urges all parties to come together to develop clear, coordinated, community-based strategies to ensure robust minority population participation in forthcoming clinical trials.

PATIENT CARE

The lack of a timely and accurate Alzheimer's diagnosis is a major impediment to patients today. Current estimates indicate that only about half of all patients with Alzheimer's ever receive such a diagnosis, and the picture is even worse for African Americans, who tend to be diagnosed later if at all. The absence or significant delay of a diagnosis forces patients to travel a tortuous, expensive and emotionally draining journey as they seek to understand their condition and treatment options.

To rectify this situation, the Network strongly supports and urges Congress to enact the Health Outcomes Planning and Education (HOPE) for Alzheimer's Act. This bipartisan and bicameral legislation will amend Medicare to establish a comprehensive Alzheimer's diagnosis and services benefit for Medicare beneficiaries whose physicians think an evaluation of Alzheimer's

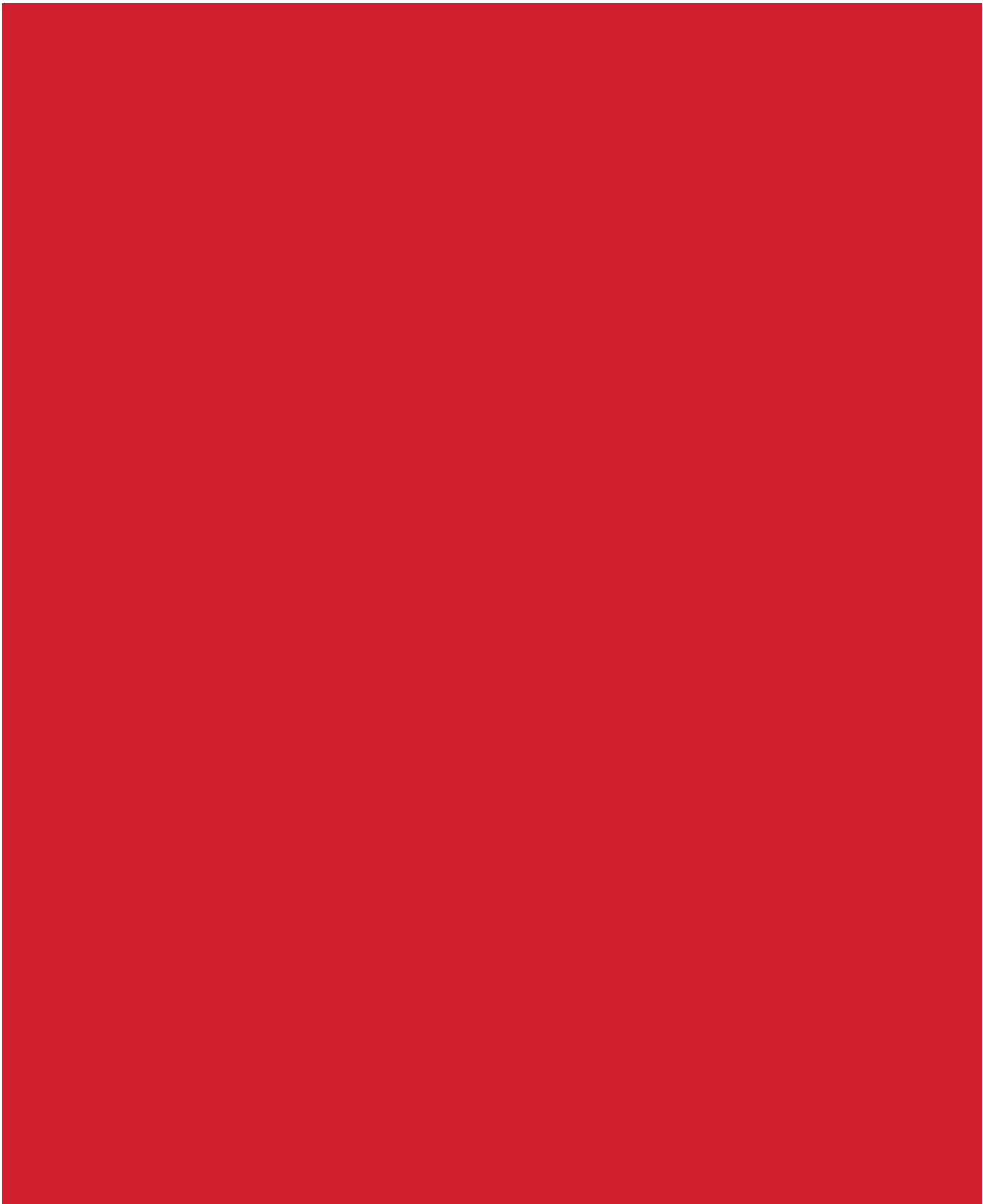
is warranted. If such a diagnosis is made, the beneficiary along with his/her personal representative or family caregivers would be eligible to receive valuable care planning and related guidance. This will help give the beneficiary access to the full array of appropriate medical and non-medical treatment options and will support families in caring for such patients.

CAREGIVER SUPPORTS

As noted above, the HOPE Act will benefit both patients and caregivers. While the patient would receive an accurate diagnosis and access to all necessary care and services, the caregiver would benefit from the enhanced care planning, which would include information on access to caregiver supports. Such planning and supports have been

shown to help alleviate the immense stress that Alzheimer's places on family caregivers and to help caregivers to care for their loved ones in the home for a longer period of time.

In addition to governmental efforts to support family caregivers in navigating a diagnosis of Alzheimer's disease, the AfricanAmericanNetworkAgainstAlzheimer's calls upon employers, particularly those in the private sector, to recognize the enormous impact such a diagnosis has on caregivers and to enact family-friendly workplace policies that can provide a high degree of support. Such policies will allow employees serving as Alzheimer's family caregivers to take care of their loved one without fearing loss of a job, reduced hours or other harmful economic ramifications that such changes often bring.



African Americans are at least twice as likely to develop Alzheimer's as non-Hispanic White Americans. While Alzheimer's is the 6th leading cause of death for all Americans, it is the 4th leading cause of death for older African Americans. The African American Network Against Alzheimer's unites and mobilizes the powerful voice of the African American community to speed the pace of research and build real momentum to end Alzheimer's disease. The African American Network Against Alzheimer's is an initiative of USAgainstAlzheimer's.

To join or learn more, please visit: www.AfricanAmericansAgainstAlzheimers.org
