

Testimony of Clay Jacobs
Alzheimer's: New Directions in Biomedical Research and Caregiving

Special Committee on Aging
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Chairman Collins, Ranking Member Casey, and members of the Committee, I am Clay Jacobs and I serve as the Executive Director of the Greater Pennsylvania Chapter of the Alzheimer's Association.

Thank you for the opportunity to testify before the Committee on how we are working to support persons living with Alzheimer's disease and related dementias, caregivers, and their providers.

Currently, 5.8 million Americans are living with Alzheimer's and, without significant action, nearly 14 million may have the disease by 2050. More than 16 million unpaid caregivers are supporting and caring for these individuals today at a cost of \$234 billion. In 2019, Alzheimer's and related dementias will cost the nation \$290 billion with Medicare and Medicaid bearing \$195 billion of that figure. In my home state of Pennsylvania, 280,000 older individuals have Alzheimer's today and in just a few years, 320,000 will likely be affected.

Among the millions of individuals living with Alzheimer's, we know that there are communities who are disproportionately affected but remain underserved. Older African Americans are approximately twice as likely to have Alzheimer's or other dementias as older whites, and older Hispanics are about one and one-half times as likely to be affected. Another population that is often under-recognized and underserved is the approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's disease. The need to reach everyone affected will grow significantly in the coming years and the Alzheimer's Association is working to reach as many of those people as possible. But Alzheimer's is also a local disease. Therefore, our nationwide network of chapters serve to respond to the specific needs in their communities.

We are doing just that in Pennsylvania. For example, we are aware of the unique challenges of younger Pennsylvanians with Alzheimer's and have developed and implemented a variety of programs in response. We offer early-stage education and support groups throughout the Commonwealth to promote social engagement in local communities by partnering with museums, local tourism boards, and libraries. We also work with the Pennsylvania Department of Aging to train facilitators for memory cafés.

In spite of these efforts to support this population, however, we know that they simply do not have access to many of the services they need. We believe that the Younger-Onset Alzheimer's Disease Act (S. 901/H.R. 1903) can change that. The legislation would allow individuals under the age of 60 living with Alzheimer's disease to access supports and services from programs under the Older Americans Act (OAA). Those programs include supportive services and respite care through the National Family Caregiver Support Program. The Alzheimer's Association is grateful to Senator Collins, Senator Casey, and Senator Jones on the Committee as well as Senator Capito, for introducing this important bill and we look forward to working with you to garner support for it.

As the leading voluntary health organization in Alzheimer's care, support, and research, we engage in a number of strategies and offer a wide variety of programs nationally. The Alzheimer's Association 24/7 Helpline (800.272.3900) is available around the clock, 365 days a year. Through this free service, specialists and master's-level clinicians offer confidential support and information to people living with the disease, caregivers, families, and the public. And while the Helpline serves individuals, the Association is also implementing a health systems strategy to address the crisis at a population level, influencing practice and care on a broad scale.

To reach members of under-represented and underserved communities, the Alzheimer's Association has undertaken several recent initiatives. We are recruiting volunteers to engage with faith and Spanish-speaking communities. The Association is partnering with the Mexican Consulate to engage the Hispanic and Latino communities with information on Alzheimer's detection and diagnosis, care, treatment, research, and access to culturally-appropriate resources. In collaboration with the National Hispanic Council on Aging, the Alzheimer's Association will also build a network of "promotores," or community health workers, who deliver Alzheimer's education in Latino communities and help connect people to resources and services in Spanish.

Recognizing the unique challenges younger individuals with Alzheimer's and related dementias face, the Alzheimer's Association convened its National Early-Stage Advisory Group in 2006. This cohort of individuals from across the United States are living in the early stage of dementia. They are leaders and spokespeople for the Association and provide guidance on appropriate programs for people living with early-stage Alzheimer's, raise awareness about early-stage issues, advocate to increase funding for research and support programs, and provide input to external groups regarding early-stage issues.

Our chapters in Pennsylvania are also working to support underserved individuals. In our Greater Pennsylvania Chapter, we conduct faith-based outreach and community education in partnership with the Alpha Kappa Alpha Mu Nu Omega Chapter and we have recruited and deployed Spanish-speaking volunteers for health fairs, education programs, and support groups. We have had the great pleasure of working with Senator Casey's staff on a number of these efforts. The Delaware Valley Chapter is a member of the University of Pennsylvania's African American Family Advisory Council to guide their efforts to increase diverse participation in clinical trial enrollment. With the local Area Agency on Aging, we work to reach Chinese, Korean, and Vietnamese organizations, attending their meetings and health fairs, working with interpreters when needed. As a member of the Department of Aging's Cultural Diversity Advisory Council, we advise the agency on services and trainings used throughout the Commonwealth's aging network, allowing us to have a statewide influence.

With 70 percent of Pennsylvania's counties considered rural, we have been deliberate in replicating our programming in rural communities with the help of already-embedded organizations to serve those individuals and families and to ensure that the providers caring for them have the tools to do so. We are also proud to work with Geisinger Health System as part of a trial focused on post-diagnostic support services in rural communities. The chapter has helped to convene stakeholders, contributed to the project design, provided materials to be shared after diagnosis, and many people are referred directly to us.

A constant theme of all of our outreach is the importance of care planning after diagnosis. We often hear directly from constituents who are trying to live well with Alzheimer's, and while we are able to provide pieces, there are still gaps in the support they need. Care planning is essential to learning about medical and non-medical treatments, clinical trials, and support services. These services result in fewer hospitalizations and emergency room visits, and a higher quality of life. This is also true for caregivers, who too often find themselves serving as "the plan" with little support after a diagnosis. The Association was grateful for the support of the members of the Committee who sponsored or cosponsored the HOPE for Alzheimer's Act in the 114th Congress and to the Centers for Medicare & Medicaid Services for now covering care planning services. We are concerned, however, that access remains an issue. That is why the Association supports the Improving HOPE for Alzheimer's Act (S. 880/H.R. 1873), which would help educate clinicians on Alzheimer's and dementia care planning services through Medicare. With that knowledge, clinicians will be better equipped to support patients and caregivers. We are grateful to Senator Collins for her leadership on the legislation and we look forward to advocating for better access to care planning services for persons living with dementia and caregivers.

To illustrate how elusive care planning has been for many people, I'd like to tell you about Michele Castro, one of our Early-Stage Ambassadors. Her mother, a manager for Section 8 housing in New York City, started exhibiting signs before their family even knew what early- or younger-onset Alzheimer's was. As her mother's caregiver, Michele watched her mother move in and out of psychiatric hospitals to try to address the behaviors that we now know to be part of the disease but that were a mystery to the family because her mother wasn't diagnosed until later. She passed away at age 59. Not long after, Michele's brother Joe, a New York City firefighter and first responder on 9/11, started to exhibit heartbreakingly similar signs at age 43. He tested positive for the PS1 genetic mutation for early-onset Alzheimer's. His wife and two young children cared for Joe before he passed away at age 58. With her family history, Michele chose to be tested as well--for planning purposes. When she tested positive for the gene, she knew she needed a plan in order to cope. While she is living well now and is grateful for every day, the only reason she knew to pursue diagnosis and care planning was through her family's devastating experiences. The Improving HOPE for Alzheimer's Act could prevent others with no or little knowledge of the disease from having to stagger through it.

Another invaluable collaboration in Pennsylvania has been with the Alzheimer's Disease Research Center (ADRC) in Pittsburgh. With the ADRC, we offer support groups, community education events, clinical trial recruitment, and overall engagement with the community. Partnering with the Pittsburgh ADRC allows us to reach a much broader audience than we could on our own as well as target efforts in the local African American community. As millions more Americans develop Alzheimer's, a broader, population-level approach is critical, so the Alzheimer's Association is grateful to both chambers of Congress for passing the bipartisan Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406), and particularly to the bill's champions on this Committee. The BOLD Infrastructure for Alzheimer's Act, now law, will create a public health infrastructure across the country to tackle Alzheimer's as the urgent and growing public health crisis it is. This infrastructure, through the establishment of Alzheimer's Disease and Related Dementias Public Health Centers of Excellence and funding to public health departments at the state, local, and tribal levels, will implement public health interventions focused on increasing early detection and diagnosis, reducing risk of the disease, and preventing avoidable hospitalizations, among other important priorities. The Centers of Excellence will

also take the great research findings from the ADRCs and help translate the evidence into public health interventions in communities across the country. Finally, the law also increases the data analysis and timely reporting that is critical to identifying opportunities, helping stakeholders track progress in the public health response, and enabling state and federal policymakers to make informed decisions when developing plans and policies. The overwhelming bipartisan support for the bill underscores the need for such an infrastructure and that is why the Alzheimer's Association supports an appropriation of \$20 million in Fiscal Year 2020 for BOLD's implementation.

I would like to conclude with an example of how important it is to reach a variety of communities affected by Alzheimer's and why outreach matters.

Ruben Deoleo, an evacuee from Puerto Rico, was born in the Dominican Republic. He moved to Pennsylvania in his 20s to serve as a minister, a drug and alcohol counselor, and a motivational speaker for the Dauphin County Prison. He continued his life of service by helping youth, being a hospital interpreter, and serving a local church's Spanish ministry. Memory problems, however, began to affect his life's calling. After losing several jobs, his wife Rosayna asked Ruben to see a doctor. For two years they grappled with what was happening and, just four months ago, he was diagnosed with Alzheimer's at the age of 58. They struggled with the diagnosis and, in particular, the fact that it is an untreatable illness. However, when Ruben learned about an Early-Stage Engagement group at Lancaster General-Penn Medicine and that other individuals living with the disease cope and can live well, he decided to fight back. Ruben has a sense of purpose as a member of the group, he is energized, and he wants to create the same opportunities for others. He is now a volunteer for the Alzheimer's Association, helping the Spanish-speaking community to understand Alzheimer's and the resources that are available. Ruben is getting valuable support while reaching more people in need.

Thank you for your time and the invitation to be here with you today. I am happy to answer any questions.