

The 2019 CHANGE Act (H.R. 2283 / S. 1126)

UsAgainstAlzheimer's Action urges Congress to pass as soon as possible the **2019 Concentrating on High-value Alzheimer's Needs to Get to an End (CHANGE) Act (H.R. 2283 / S. 1126)**. The CHANGE Act is a bipartisan piece of legislation that encourages early detection, diagnosis, and access to needed interventions.

Alzheimer's is currently America's biggest healthcare crisis – economically, socially, and medically. While the latest emerging science – much of which is NIH-supported – indicates that proactive, risk-modifying measures exist that can strengthen brain health and increase resiliency against cognitive decline, Alzheimer's remains the sixth-leading cause of death in the United States and the only top-ten cause of death without an effective treatment or cure.

While the Centers for Medicare and Medicaid Services (CMS) has recognized the importance of dementia detection, unfortunately, the policies in place do not properly get those services to those with Alzheimer's. There are existing, evidence-based, reliable, and NIH-identified cognitive impairment detection tools that must replace detection by direct observation in the Medicare Annual and Welcome to Medicare visits. The NIH-identified tools will allow for appropriate follow-up instead of delaying diagnosis or clinical trial participation, and the passage of the CHANGE Act will help make this transition possible.

- **Urge your congressional representatives in both the House and Senate to cosponsor¹ and support the 2019 CHANGE Act (H.R. 2283/ S. 1126).** The bill will incentivize and equip providers with the tools they need to accurately detect and diagnose Alzheimer's at its earliest stages by directing CMS to require the use of cognitive impairment detection tools by the NIH. Use of these tools will incentivize clinicians to detect and diagnose Alzheimer's and related dementias in their earliest stages. If cognitive impairment is detected, patients are to be referred for additional testing, to community-based support services, and to appropriate clinical trials. Further, the act requires CMS to lead, create, adopt, and recognize quality measures and incentives to promote the detection and diagnosis of Alzheimer's disease and related dementias and appropriate care-planning services, including potential for clinical trial participation.
- **Remind your representatives that this bill will improve quality of life for Medicare beneficiaries living with Alzheimer's disease.** Studies consistently show that proper detection and diagnosis and active management of Alzheimer's can delay the onset of symptoms and improve quality of life through all stages of the disease for patients and their caregivers.
- **Call on congressional leaders to work to reduce the impact of one of America's costliest diseases.** At an annual cost of \$290 billion – including \$195 billion in Medicare and Medicaid payments – the economic impact of Alzheimer's disease on our country is equivalent to that of smoking, according to the CDC. The CHANGE Act works to reduce the total economic burden on our healthcare system.

¹ **Current House cosponsors:** Reps. DeFazio, DelBene, Fitzpatrick, Higgins, Kuster, Lahood, Lieu, Lowenthal, Mast, Matsui, McMorris Rodgers, Napolitano, Pocan, Scott, C. Smith, Stevens, and Waters. **Current Senate cosponsors:** Sens. Blumenthal, Blunt, Casey, Collins, Cornyn, Hoeven, Hyde-Smith, Klobuchar, Menendez, Shaheen, Stabenow, Tillis, Van Hollen, and Wicker.

2019 Congressional Appropriations for the NIH

Since the new Congress has been in session, UsAgainstAlzheimer's Action and its advocates have been rallying around a call for a \$350 million increase in FY 2020 funding for Alzheimer's research at the National Institutes of Health (NIH). Despite aggressive efforts, the House of Representatives still passed an appropriations bill that underfunds Alzheimer's research by \$290 million. Now, with the appropriations bill in the Senate, UsAgainstAlzheimer's Action and its allies have a new opportunity to mobilize and ensure that members of the Senate understand that people in the Alzheimer's community are paying attention to their votes.

Our nation has set a goal of finding an effective means of treatment or prevention, and ultimately a cure, for Alzheimer's by 2025. After a decade of increasing funding every year for Alzheimer's research, we cannot afford to halt that trend now. There are currently 5.8 million Americans living with Alzheimer's at an annual cost of \$290 billion. By 2050, if no breakthrough treatment or cure is developed, these numbers will balloon to nearly 14 million at an annual cost of more than \$1 trillion.

Tell Congress that we need to fully fund Alzheimer's research.

- **We can't afford to halt the year-over-year increase that Alzheimer's funding has experienced over the past decade.** In the years since UsAgainstAlzheimer's Action was founded, our advocates have pushed Congress to dramatically increase funding for Alzheimer's research from a total of \$450 million in 2010 to \$2.3 billion in 2019 – a 400% increase. With our 2025 national goal quickly closing in, now is not the time to take our foot off the gas.
- **The proposed House funding number underfunds Alzheimer's research by \$290 million.** UsAgainstAlzheimer's Action and our network of advocates appreciates the current \$60 million increase in funding approved by the House Labor, Health and Human Services, Education, and Related Agencies Subcommittee. But, with that number now before the Senate, they must hear from constituents this is far short of the \$350 million increase we need, and isn't commensurate with the magnitude of the crisis we face.
- **If Alzheimer's funding at the NIH remains at current proposed levels, critical new research will be dramatically underfunded.** Currently, there are 140 research studies on Alzheimer's currently underway at the NIH. More than 60 of them are focused on non-pharmacological interventions that could lead us to an effective means of treatment or prevention. The emerging findings from these studies are sparking ideas about new ways to treat Alzheimer's through risk reduction, early detection, and possibly prevention.
- **Alzheimer's is the greatest public health crisis facing our nation today.** With Alzheimer's deaths increasing 147% since 2000, we must urge Congress to continue efforts to increase federal funding for Alzheimer's research and bring it in line with other critical diseases of our time, like cancer and HIV/AIDS. At current funding levels, the NIH does not have enough resources to fund all the studies necessary to properly examine Alzheimer's. In light of the rising costs and impact of this disease, we simply cannot afford to leave scientific opportunity on the table by underfunding the NIH by \$290 million.