

# **Alzheimer's Disease and Related Dementias Research Update**

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## ***Advisory Council on Alzheimer's Research, Care, and Services Meeting***

**Richard Hodes, M.D.**

**Director, NIA**

**July 30, 2018**

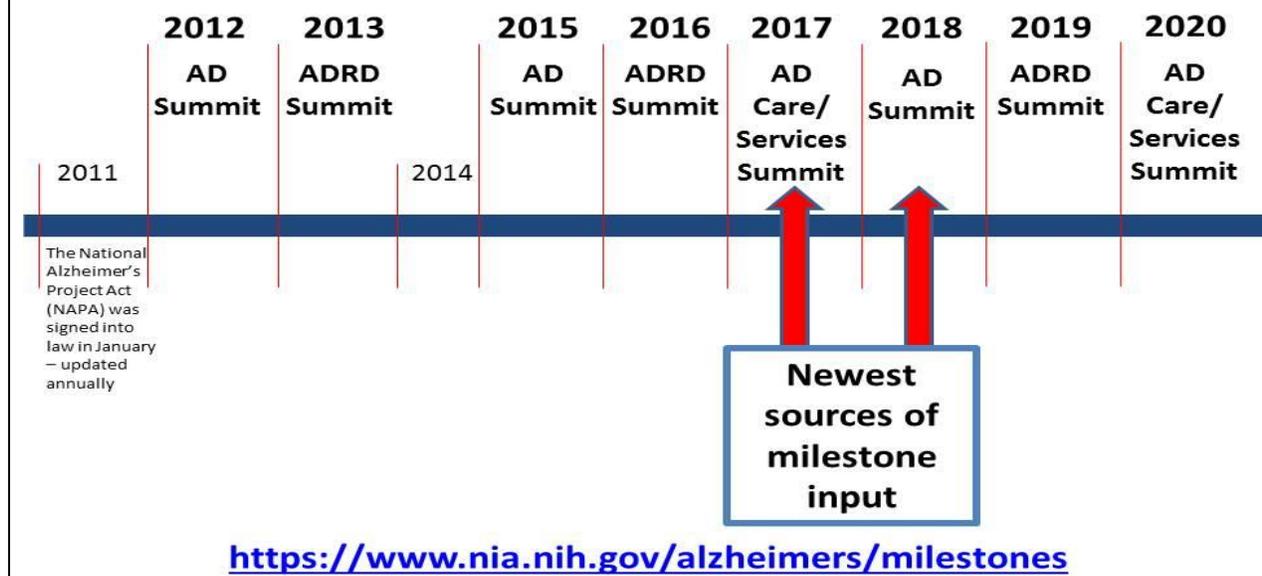


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## **AD/ADRD Research Implementation Milestones and Bypass Budget Process**

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## NIH Research Implementation Milestones are *Based on Broad Input*



## What Counts as AD/ADRD Research?

- The AD/ADRD pay line applies to applications/awards that are coded as AD or Alzheimer's disease- related dementias (ADRD)
- The ADRD RCDC categories that report related dementias specifically named in the National Plan to Address Alzheimer's Disease are:
  - Lewy Body dementia (LBD)
  - Frontotemporal dementia (FTD)
  - Vascular Cognitive Impairment/Dementia (VCI/D)

## Combined External and Internal Input – FY20 AD/ADRD Bypass Budget

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Input at 2012-2018 meetings:

- Academic research community
- Industry
- Non-governmental organizations

Other Input:

- 2017 Request for Information

Development of comprehensive milestones  
(NIH staff) – based on summit and  
other input

Trans-NIH (including NINDS) staff discussion;  
milestones edited to ensure comprehensive  
inclusion of priorities for FY20

NIH staff  
“price” the  
milestones

**Final budget  
estimate for  
FY20**

## Bypass Budget Language

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SEC. 230. Hereafter, for each fiscal year through fiscal year 2025, the Director of the National Institutes of Health shall **prepare and submit directly to the President for review and transmittal to Congress, after reasonable opportunity for comment, but without change, by the Secretary of Health and Human Services and the Advisory Council on Alzheimer’s Research, Care, and Services, an annual budget estimate (including an estimate of the number and type of personnel needs for the Institutes) for the initiatives of the National Institutes of Health pursuant to the National Alzheimer’s Plan**, as required under section 2(d)(2) of Public Law 111–375.

## **Trans-NIH Input for FY20 ADBB**

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- Thirteen Institutes and Centers provided feedback that contributed to the development of this year's professional judgment budget:

- |         |         |
|---------|---------|
| ▪ NIA   | ▪ NIEHS |
| ▪ NINDS | ▪ NIGMS |
| ▪ NHLBI | ▪ NIMH  |
| ▪ NIAAA | ▪ NINR  |
| ▪ NICHD | ▪ NCATS |
| ▪ NIDCR | ▪ FIC   |
| ▪ NIDDK |         |

## **Using CADRO as a Framework**

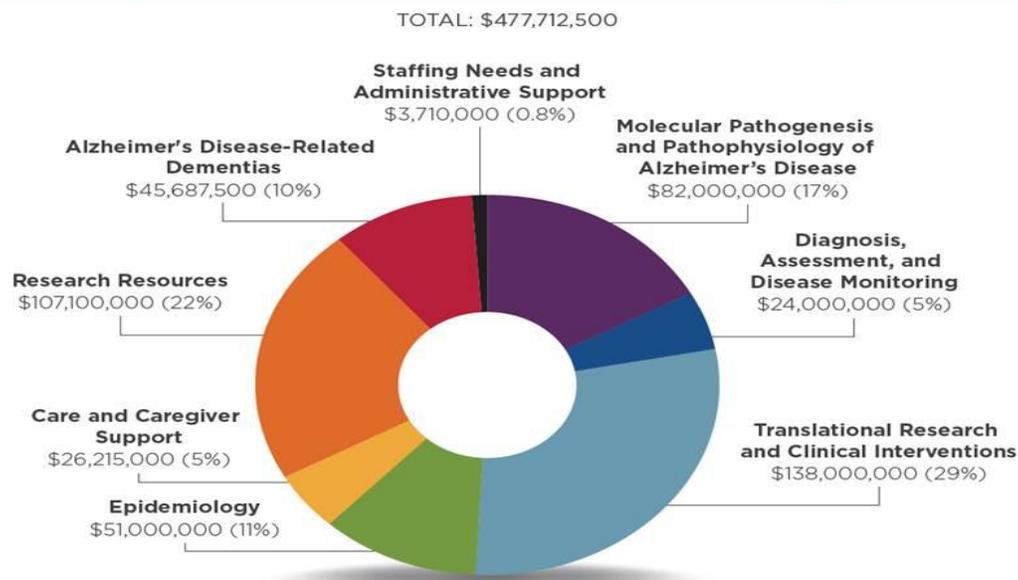
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- The eight CADRO (Common Alzheimer's Disease Research Ontology) categories provide the overarching framework for the FY20 AD Bypass Budget and narrative.
- CADRO provides the framework for IADRP (the International Alzheimer's Disease Research Portfolio) and will allow tracking of implementation in the budget areas in future years.

## FY20 Professional Judgment Budget – Additional Funding Needs

Molecular Pathogenesis and Pathophysiology of Alzheimer's Disease	\$82,000,000
Diagnosis, Assessment, and Disease Monitoring	\$24,000,000
Translational Research and Clinical Interventions	\$138,000,000
Epidemiology	\$51,000,000
Care and Caregiver Support	\$26,215,000
Research Resources	\$107,100,000
Alzheimer's Disease-Related Dementias	\$45,687,500
Staffing Needs and Administrative Support	\$3,710,000
<b>ADDITIONAL FY20 Resources Needed for New AD/ARD Research</b>	<b>\$477,712,500</b>

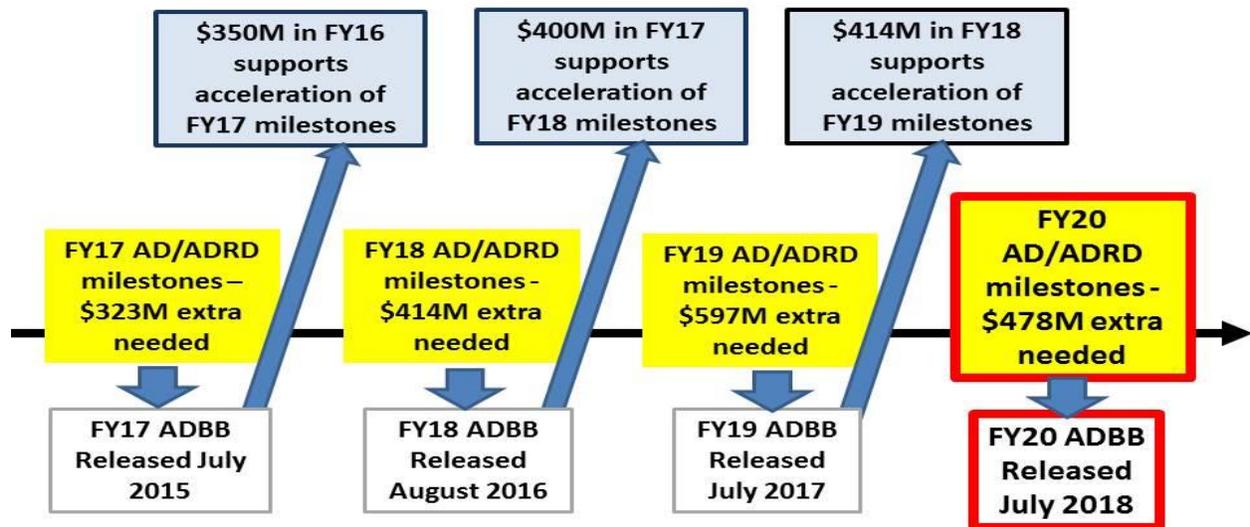
## Distribution of *Additional* Budget Funding Request Across Research Areas, FY20



## FY20 Professional Judgment Budget – Total Funding Needs

FY19 President’s Budget Request for AD/ADRD Research (Baseline estimate)	\$1,516,000,000
Difference between the FY19 President’s Budget Request and FY18 Omnibus Appropriation for AD/ADRD Research	\$399,000,000
ADDITIONAL FY20 Resources Needed for New AD/ADRD Research	\$477,712,500
<b>TOTAL FY20 Resources Needed for AD/ADRD Research</b>	<b>\$2,392,712,500</b>

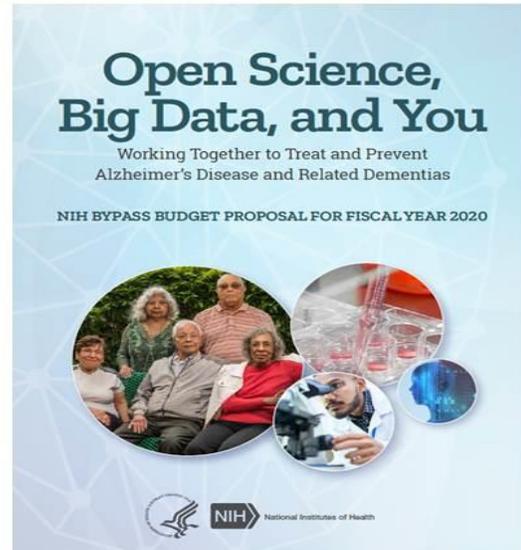
## Timing of ADBB Releases and AD/ADRD Appropriations



## AD/ADRD Progress Report – An important part of the ADBB

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The AD/ADRD Bypass Budget *narrative* includes many examples of recent **science advances across multiple research topics** – basic to clinical, care/caregiving, etc.



## Implementation Tracking

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- **IADRP: <http://iadrp.nia.nih.gov/>**
  - *Will continue to offer detailed tracking of initiatives and awards with respect to our research milestones, under the CADRO categories*
- **Web-based tool for tracking funding initiatives and activities:**  
**<https://www.nia.nih.gov/alzheimers/milestones>**
  - *Developed by the NIH and other AD funding organizations*
  - *Aimed at addressing the research milestones associated with NAPA*

## **Complex Considerations for this and Future Bypass Budgets**

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- Past/current appropriations, including funds that have allowed us to address milestones “in advance”
- Progress on milestones – what have we accomplished? what new milestones are emerging?
- Incorporating new milestones, including focus on care/services, target identification and drug development
- Emerging investments by other groups – what gaps are best filled by the NIA/NIH?
- Successes in recruiting new and established researchers to AD/ADRD research and capacity of the field

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## **Other Updates**

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## FY19 Budget Status

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- FY19 Appropriations bills include additional NIH/NIA funds above FY18 levels
  - **Senate**
    - ❑ \$3.08 Billion total for NIA (\$2.34 Billion total for AD/ADRD)
  - **House**
    - ❑ \$3.01 Billion total for NIA (\$2.25 Billion total for AD/ADRD)

## **NEW** Planned Evidence Review: *Care Interventions for Individuals with Dementia and Their Caregivers*

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- **Two parts:**
  - ❑ **National Academies of Sciences, Engineering, and Medicine:** *Expert panel input on questions and study design*  
[www.nationalacademies.org/dementiacare](http://www.nationalacademies.org/dementiacare)
  - ❑ **Agency for Healthcare Research & Quality:** *Evidence review*
- **Status:**
  - ❑ **AHRQ Evidence-Based Practice Center award in process**
  - ❑ **NASEM Committee in final stages of vetting – will be posted to the URL above when available**

## Eureka Prize Planning

- The 21<sup>st</sup> Century Cures Act directed the NIH to use its authority to establish Eureka prize competitions in the areas of biomedical science that could improve health outcomes in conditions that represent a serious and significant disease burden
- NIA is in the process of planning an **AD/ADRD focused prize competition targeted towards *technological innovations in care coordination and navigation***
- We have solicited public input at various stages of the planning process and anticipate announcing the competition later this fiscal year



## ADRD NGO Roundtable at NIH

### Alzheimer's Disease-Related Dementias (ADRD) NGO Roundtable

- **June 22, 2018** on the NIH Campus in Rockville, MD
- **Participants:** NINDS and NIA leadership, program staff, and 7 ADRD-related NGOs
- Provided updates on ADRD research activities and discussed opportunities for potential collaboration, including planning for next ADRD Summit in 2019



***Save the date!* ADRD Summit (III)**  
**March 14-15, 2019**

**Location: Natcher on the NIH Main Campus, Bethesda MD**

## Save the Date

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**ADRD Summit I**  
**May 2013**



**ADRD Summit II**  
**March 2016**



**Alzheimer's Disease-Related Dementias  
(ADRD) Summit III**  
**March 14-15, 2019**  
**Bethesda, MD**

## Additional Save the Date

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**AD/ADRD Care/Services Summit (II)**  
**March 24-25, 2020**  
**Natcher Conference Center**  
**Bethesda, MD**

