

# ADRC Directors Meeting

Nina Silverberg, Ph.D.

Director, Alzheimer's Disease Research Centers Program

National Institute on Aging

May 1, 2020

# ADRC Administrative Supplement Calls

- Imaging:
  - Due Date: May 22, 2020
- Veteran Recruitment:
  - LOI with aims Due May 29, Application Due June 12
- Submit administrative supplements using PA-18-591  
<https://grants.nih.gov/grants/guide/pa-files/pa-18-591.html>

# Thank You

## Clinical Measures & Diagnosis Group

Greg Jicha (co-lead)  
Cindy Carlsson (co-lead)  
Jeff Burns  
Howie Rosen  
Brad Boeve  
Suzanne Schindler  
Teresa Gomez-Isla

Allan Levey, CTF Chair



**Remote  
Assessment**

Bud Kukull, NACC

## Cognitive Working Group

Andy Saykin (co-lead)  
Lisa Barnes (co-lead)  
Sandy Weintraub  
Rhoda Au  
Suzanne Craft  
Mary Sano

**SPECIAL THANKS!!:** Bonnie Sachs and Steve Rapp, Wake Forest

# ADRC Recent Accomplishments - Examples

**REC  
Trainees**

**Neuropath  
Trainees**

**Data Core  
Webinars**

**Latino ADC  
Special Interest  
Group**

**Remote  
Assessment**

**P20  
Exploratory  
Centers**

**NCRAD**

**NACC**

**SCAN/ Imaging  
Core Steering  
Committee**

# ADRC Recent Accomplishments - Examples

REC  
Trainees

Neuropath

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Latino ADC  
Special Interest  
Group

**BRAIN**  
A JOURNAL OF NEUROLOGY

**REVIEW**

**Limbic-predominant age-related TDP-43  
encephalopathy (LATE): consensus working  
group report**

P20  
Exploratory  
Centers

NCRAD

NACC

SCAN/ Imaging  
Core Steering  
Committee

# ADRC Steering Committees

**Directors  
Executive  
Committee**

**NACC Steering  
Committee**

**Clinical Task  
Force**

**Administrators  
Steering  
Committee**

**ORE Core  
Steering  
Committee**

**Neuropathology  
Core Steering  
Committee**

**Clinical Core  
Steering  
Committee**

**Imaging Core  
Steering  
Committee**

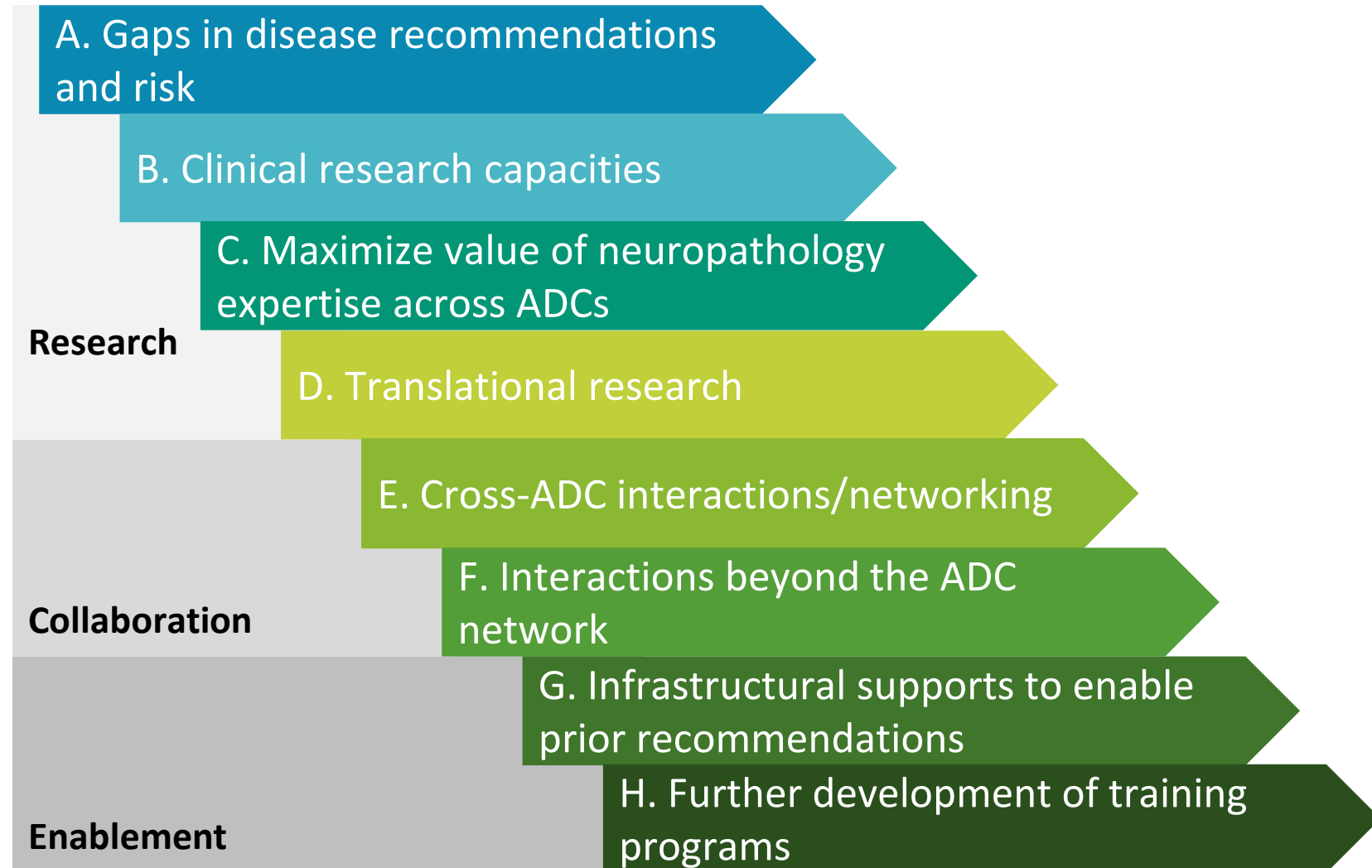
***Biomarker Core  
Steering  
Committee***

**Data Core  
Steering  
Committee**

***REC Steering  
Committee***

# ADRC Steering Committees

- NACC and NIA put together for each committee a list of
  - Duties
    - Including Chair and member responsibilities
    - “The Chair should work with NIA, NACC and the Committee to set and achieve **1-3 major goals** during their term.”
  - Terms of Office
  - Election Process
- Future planning will support better transitions for new members



# Latino ADC – Special Interest Group

Co-Leads: Yakeel T. Quiroz and Katya Rascovsky

## Research Working Group:

- Accomplishments:
  - Website with information about ongoing research studies for Latinos
    - <http://mapp.mgh.harvard.edu/latino-adc/>
  - List of potential reviewers for papers/grants related to Latino issues
- Exploring opportunities for cross-Center research collaborations to improve the representation of diverse Latinos into our studies.
- Website will feature ongoing research with Latinos being conducted at the Centers, including our recent publications.

## Assessment Working Group:

Goals: Develop preliminary norms from the Spanish UDS3 and explore whether current norms apply to English-speaking Latino participants.

## Outreach, Caregiver and Central Repository Working Groups:

Working with NIA to:

- 1) Facilitate public dissemination of information for Latino participants and caregivers,
- 2) Develop culturally appropriate outreach and recruitment materials for Latino participants.

Welcome information about new studies and new potential reviewers. Please email [yquiroz@mgh.harvard.edu](mailto:yquiroz@mgh.harvard.edu) and [katyaras@penncmedicine.upenn.edu](mailto:katyaras@penncmedicine.upenn.edu)

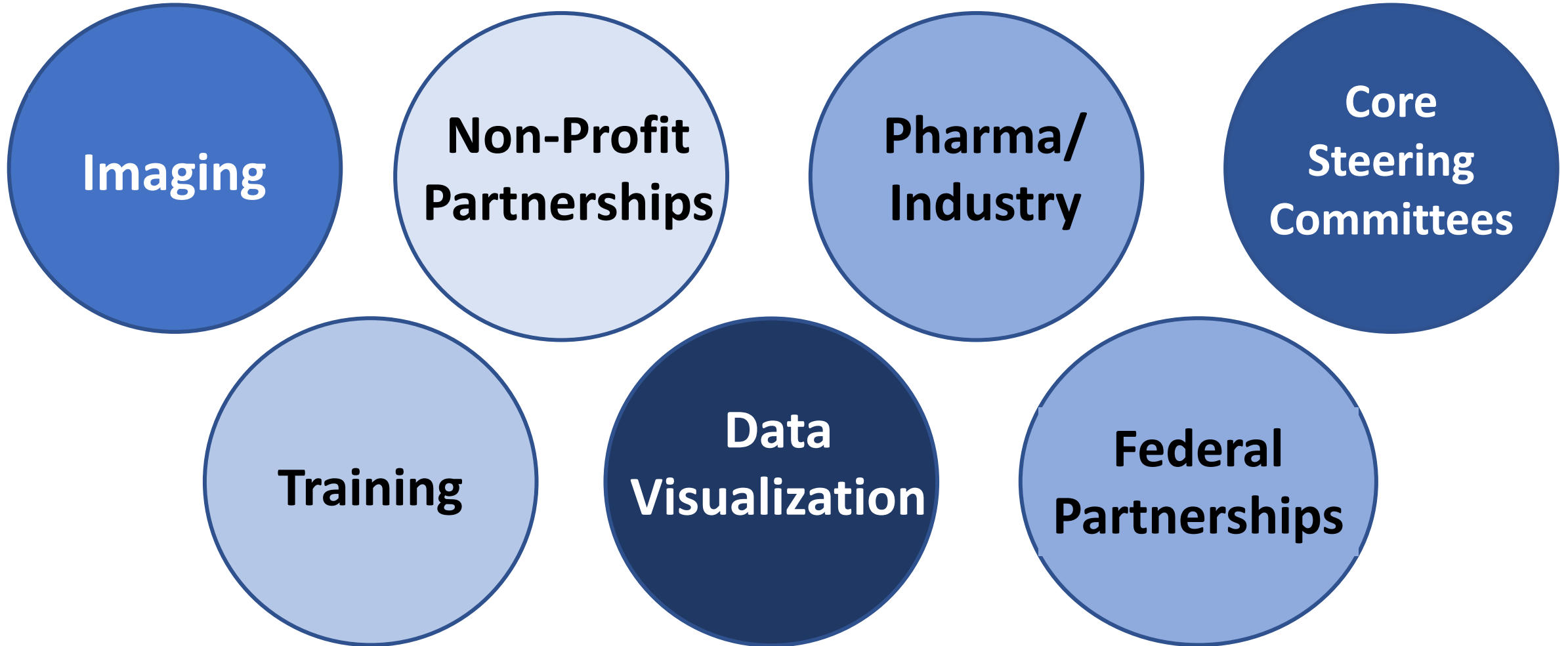


Follow us  
on Twitter  
[@Latino\\_ADC](https://twitter.com/Latino_ADC)



# ADRC Plans: 2020

*Based on Panel Recommendations*



# Focus on Aging: Federal Partners' Webinar Series

## Upcoming Webinars

### May 2020: Supporting Older Adults in Emergencies: Preparedness, Response, and Recovery

*Wednesday, May 13, 2020, 1:30-3:00 p.m. ET*

#### Speakers:

1. Samir Sinha, MD, DPhil, FRCPC, Sinai Health
2. Margaret Sanders, MA, LSW, Northeast Ohio Medical University
3. Jeffrey Klein, FACHE, Nevada Senior Services
4. Kathryn Hyer, PhD, MPP, University of South Florida
5. Nia Reed, PhD, Centers for Disease Control and Prevention



**NinaB** @Nina\_BSil · 6h 

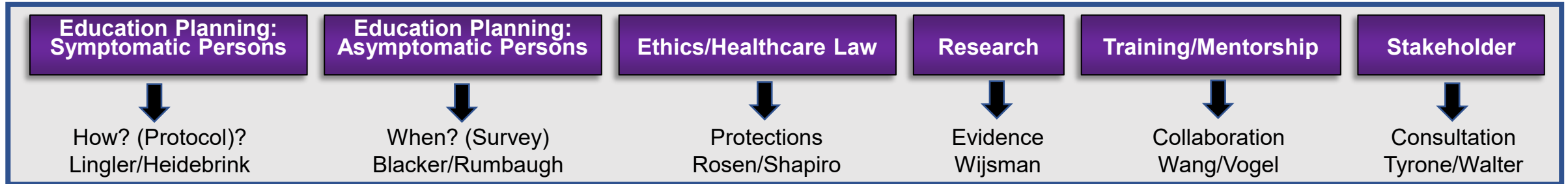
We're pleased to announce the "Focus on Aging" webinar series with @ACLGov @CDC @HRSAgov and NIA. The first webinar, "Supporting Older Adults in Emergencies: Preparedness, Response, and Recovery" will be held May 13 at 1:30 ET. Register today!

# Advisory Group on Risk Evidence Education for Dementia (AGREED)

Aggarwal, Gleason, Rosen

## Aims:

- 1) Risk Evidence Evaluation of Science
- 2) Guide When and How to Provide Effective Risk Evidence Education
- 3) Consultation to support ethical and legal risk mitigation



## Progress:

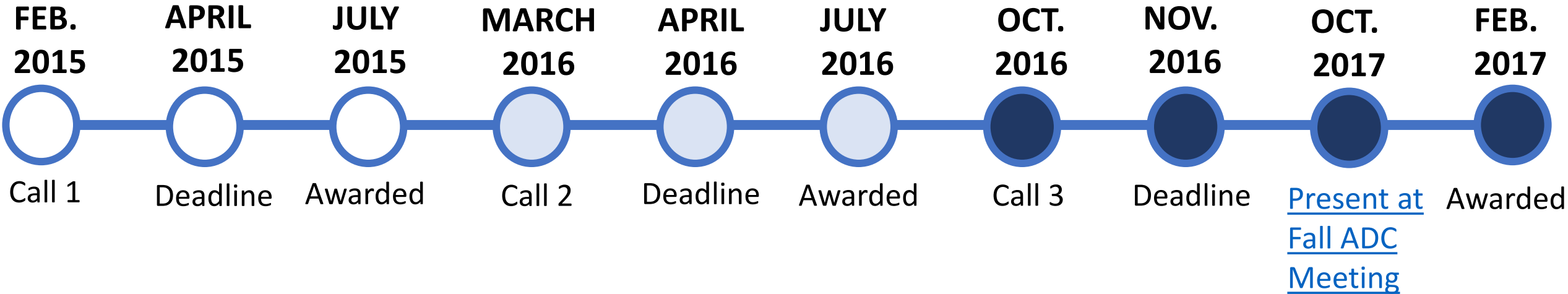
- **Forthcoming Abstracts/Papers/Products**
  - AGREED Formation –Paper and AAIC abstract (Allyson Rosen, Carey Gleason, Neelum Aggarwal and All Members)
  - Survey of ADC’s Regarding APOE Communication Practices (Scott Roberts and Education-Asymptomatic Persons)
  - Decision Aid for MCI patients for PET amyloid disclosure (Jennifer Lingler, Judy Heidebrink and Education-Symptomatic Persons)
- **Consultation/Liaisons to Other Groups**
  - ACTC-Stakeholder Engagement Group (Sarah Walter)
  - ADNI-Consent regarding MRI defacing (Elizabeth Schaffer, Chris Schwarz)
- **Educational Seminars**
  - Direct to Consumer Genetics, Decision Aids for APOE, Pharmacogenetics applications, COVID issues
  - Sharing papers published from group members (e.g. Ecological Momentary Assessment, Engaging Stakeholders, Disclosure Risks)
- **Grants**
  - Returning Research Results that Indicate Risk of Alzheimer Disease to Healthy Participants in Longitudinal Studies: R01AG065234 (Sarah Hartz & Jessica Mozersky) 2/1/2020-1/31/2025

# ADRC Biospecimen Best Practices Guidelines

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**Microbiome Guideline**

# Neuropathology Trainee Administrative Supplements



Awarded supplements for **15 trainees**

8 trainees  
**Senior NP Core Personnel**

Awards during/after training:  
**4 K awards**  
**4 R01s**  
**1 RF1**



# Brain Donation

## Collaboration, culture, coordination: Keys to supporting brain donation

March 04, 2020



Nina SILVERBERG,  
*Director, Alzheimer's Disease Centers Program,  
Division of Neuroscience (DN).*

Since Dr. Alois Alzheimer first studied the brain of Auguste D., research on brain tissue has been crucial to advancing understanding of Alzheimer's disease and related dementias (AD/ADRD). Many Americans are aware of the life-saving impact of organ donation, but Alzheimer's and dementia's emotional toll on families, combined with cultural and religious values, can make conversations about the research value of brain donation difficult.

<https://www.nia.nih.gov/research/blog/2020/03/collaboration-culture-coordination-keys-supporting-brain-donation>

# Working Group of ADRC NP Cores and Neurobiobank

## Pilot Project

- Led by Dirk Keene, UW
- Monthly calls since July 2018
- [The Brain Donor Project](#)
- ADRC NP Cores (UW, Yale, Pitt, Wake Forest)
- Neurobiobank
- NIA/NINDS

## Goals:

- Identify/develop ways to advance brain donation and utilization for ADRD research
- Demonstrate feasibility
- Determine if donor coordination can improve frequency and utility of brain donation
- Identify areas for improvement
- Extend to the broader research community

## Results of Pilot so far:

- Criteria for inclusion/exclusion into the pilot have been established (e.g. Controls, Diverse populations, AD families, Clinical trial participants)
- Communication protocols/pipeline set up between The Brain Donor Project and NP Cores to refer donors
- At least 8 donors referred and consented
- At least 4 successful donations (3 UW, 1 Pitt)
- NP Cores upload NP data to NBB
- NP Cores will honor tissue requests through NBB catalog

## Benefits of ADRC NP Cores and NBB Collaboration:

- **Promotes collaboration** across NBB, ADCs, BDP to enhance national access for brain donation and brain research in AD, ADRD
- Allows both NBB and ADCs ability to accept **greater number and greater diversity of community-based AD**, related dementia and control donations
- Shared approaches/protocols can help **cross-pollinate best practices** across programs
- **Improved and harmonized methods** to provide access to brain donors and scientists and for stakeholders to communicate with each other and donors/scientists.
- Small catchment area and specific expertise of ADCs **allows for rapid autopsy and tissue processing for next generation research approaches**



# Future ADRC Directors' Meetings

## October 2020, Los Angeles

- Keep NACC updated on your institution travel restrictions
- Steering Committees participating
  - ORE Core
  - Neuropath Core
  - Data Core
  - NACC/Data Methods
  - Directors
  - <https://www.alz.washington.edu/WEB/futureADCmeetings.html>

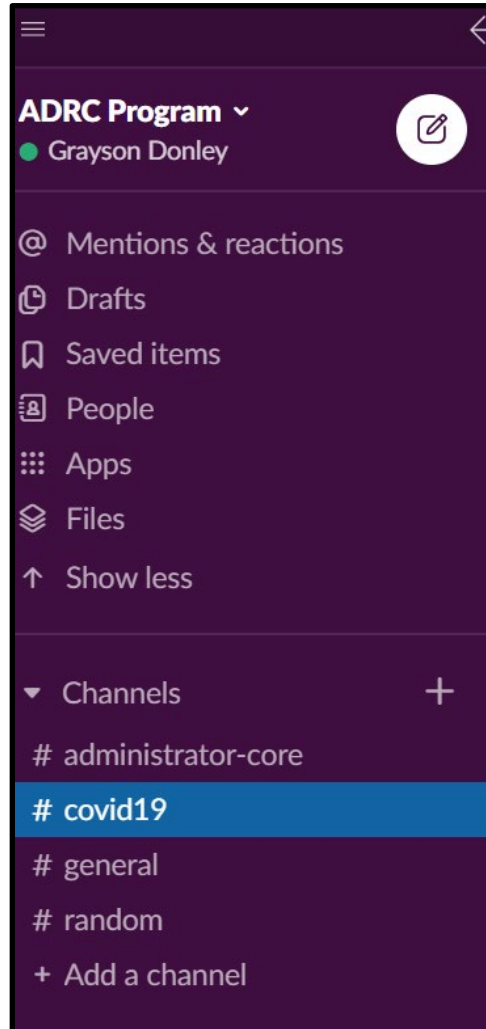
# Final Instructions

EMAIL: “**Spring 2020 ADRC webinar -- Final instructions**”  
sent by [naccmail@uw.edu](mailto:naccmail@uw.edu) Thursday afternoon

- Final Agenda
- ADSP data harmonization initiative
- Spring Webinar Evaluation
- Recording reminder, this meeting will be archived
- Slack



# Slack



- **Brian Stahly sent out an email 04/03/20**
- ADRC program Slack workspace
- Slack is a free chat program that allows quick conversation with individuals or groups
- For anyone that hasn't been invited, you can use [this invitation](#) to join the workspace.
- Brian created a channel called [#covid19](#) that everyone is welcome to join.