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

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

Cognitive Working Group

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

Allan Levey, CTF Chair

Remote Assessment

Bud Kukull, NACC

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

REVIEW
Limbic-predominant age-related TDP-43 encephalopathy (LATE): consensus working group report
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/](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@pennmedicine.upenn.edu](mailto:katyaras@pennmedicine.upenn.edu)
ADRC Plans: 2020
Based on Panel Recommendations

- Imaging
- Non-Profit Partnerships
- Pharma/Industry
- Core Steering Committees
- Training
- Data Visualization
- Federal Partnerships
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, FRCP, 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

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

Table of Contents

Blood and Urine Guideline .................................................................................................................. 2
Cerebrospinal Fluid Guideline ............................................................................................................ 6
Brain Guideline .................................................................................................................................. 9
DNA / RNA / Protein Guideline ......................................................................................................... 12
Induced Pluripotent Stem Cells Guideline ......................................................................................... 15
Metabolomics and Proteomics Guidelines ......................................................................................... 16
Informatics Guideline ........................................................................................................................ 22
Informed Consent, Confidentiality and Privacy Guideline ................................................................. 24
Disseminating and Discarding Guideline .......................................................................................... 27
Cost Recovery Guideline ................................................................................................................... 31
Intellectual Property Guideline .......................................................................................................... 33
Material Transfer Guideline ............................................................................................................. 34

Microbiome Guideline

https://www.alz.washington.edu/BiospecimenTaskForce.html
Neuropathology Trainee Administrative Supplements

Call 1  Deadline  Awarded  Call 2  Deadline  Awarded  Call 3  Deadline  Awarded

Awarded supplements for 15 trainees
8 trainees Senior NP Core Personnel

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

Present at Fall ADC Meeting
Collaboration, culture, coordination: Keys to supporting brain donation

March 04, 2020

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

<table>
<thead>
<tr>
<th>Pilot Project</th>
<th>Goals:</th>
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</thead>
<tbody>
<tr>
<td>• Led by Dirk Keene, UW</td>
<td>• Identify/develop ways to advance brain donation and utilization for ADRD research</td>
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<tr>
<td>• Monthly calls since July 2018</td>
<td>• Demonstrate feasibility</td>
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<tr>
<td>• <a href="#">The Brain Donor Project</a></td>
<td>• Determine if donor coordination can improve frequency and utility of brain donation</td>
</tr>
<tr>
<td>• ADRC NP Cores (UW, Yale, Pitt, Wake Forest)</td>
<td>• Identify areas for improvement</td>
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<tr>
<td>• Neurobiobank</td>
<td>• Extend to the broader research community</td>
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<td>• NIA/NINDS</td>
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### 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**
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
EMAIL: “Spring 2020 ADRC webinar -- Final instructions”
sent by naccmail@uw.edu Thursday afternoon

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