ADRC Directors Meeting

Nina Silverberg, Ph.D.
Director, Alzheimer’s Disease Research Centers Program
National Institute on Aging
October 2, 2020
Announcing P20 Exploratory Alzheimer’s Disease Research Centers

- P20 Exploratory ADRCs
  - Cleveland Clinic Lou Ruvo Center for Brain Health (NV) (PI: Sabbagh)
  - University of Alabama at Birmingham (AL) (PI: Roberson)
  - University of New Mexico (NM) (PI: Rosenberg)
  - Vanderbilt University (TN) (PI: Jefferson)

- **Award date:** August 2020
- **Project period:** August 2020 – July 2023
### Thank You: ADRC Clinical Task Force

<table>
<thead>
<tr>
<th>Clinical Measures &amp; Diagnosis Group</th>
<th>Cognitive Working Group</th>
<th>Technology Group</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Allan Levey, CTF Chair</strong></td>
<td>Andy Saykin (co-lead)</td>
<td>Rhoda Au (lead)</td>
</tr>
<tr>
<td><strong>Bud Kukull, NACC</strong></td>
<td>Lisa Barnes (co-lead)</td>
<td>Jeffrey Kaye</td>
</tr>
<tr>
<td><strong>Suzanne Schindler</strong></td>
<td>Sandy Weintraub</td>
<td>Zachary Beattie</td>
</tr>
<tr>
<td><strong>Jeff Burns</strong></td>
<td>Rhoda Au</td>
<td>Felicia Goldstein</td>
</tr>
<tr>
<td><strong>Howie Rosen</strong></td>
<td>Suzanne Craft</td>
<td>Gregory Jicha</td>
</tr>
<tr>
<td><strong>Brad Boeve</strong></td>
<td>Mary Sano</td>
<td>Jason Hassenstab</td>
</tr>
<tr>
<td><strong>Suzanne Craft</strong></td>
<td></td>
<td>Howie Rosen</td>
</tr>
<tr>
<td><strong>Teresa Gomez-Isla</strong></td>
<td></td>
<td>Ihab Hajjar</td>
</tr>
<tr>
<td><strong>Liana Apostolova</strong></td>
<td></td>
<td>Theresa Gomez-Isla</td>
</tr>
</tbody>
</table>

NIA staff
Remote Assessment Adoption Survey Results

• 31 Centers responded to the survey
• 12 Centers have already adopted the **Telephone Initial Visit Packet (TIP) v3.0** and 12 Centers are planning to
• 23 Centers have adopted the **Telephone Follow-up Packet (TFP) v3.2** and 5 Centers are planning to
• 23 Centers have already adopted the **C2T (T-Cog) test battery** and 6 Centers are planning to
• 23 Centers have adopted the **COVID Impact Survey**
• 20 Centers have adopted the **COVID Technology Survey**, 8 are using a local form to capture similar information
COVID-19: Developed and disseminated a survey for participants and caregivers to all centers; analysis pending
Aiming to better capture features relevant to the broader spectrum of AD and ADRD
Exploring a hybrid model for UDS 4 (in-person, phone/video, web-based modules) with recommended/optional items

Clinical Measures Working Group:
- Aiming to better integrate social determinants of health
- Considering adequacy of standardized assessment of medical conditions, labs, and medications that may impact dementia course
- Planning to develop standardized guidelines for consensus diagnostic conferences

Neuropsychology workgroup:
- Evaluating initial results using UDS 3 T-Cog/V-Cog
- Initial design concept is to pair a conventional validated clinical test and a next generation technology-based assessment for each key domain
- Planning for psychometrics (reliability, validity) and cross-walk studies
- MoCA

Technology workgroup:
- Optimizing digital phenotyping within the UDS protocol that is consistent across ADCs
- Enabling a customized digital strategy that is ADC site specific
- Developing aggregated data resource needed for discovery and validation of digital biomarkers

Monthly Updates in NACC report and newsletter
Will be seeking input from all Centers – watch for surveys and other opportunities to provide input!
ADRC Recent Accomplishments - Examples

- COVID Survey
- COVID Adjustments Paper
- Steering Committee Led Webinars
- Brief Data Set
- Study Cessation Group
- Imaging Administrative Supplements
- Veterans Administrative Supplements
- Joint ADRC/IDDRC Meeting
- Remote Assessment
• 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

A. Gaps in disease recommendations and risk
B. Clinical research capacities
C. Maximize value of neuropathology expertise across ADCs
D. Translational research
E. Cross-ADC interactions/networking
F. Interactions beyond the ADC network
G. Infrastructural supports to enable prior recommendations
H. Further development of training programs

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

https://www.alz.washington.edu/NONMEMBER/adc_comm.html
# ADRC Listservs

---

## ADC Interest groups

<table>
<thead>
<tr>
<th>ADC Interest groups</th>
<th>Email Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADC African American Interest Group</td>
<td><a href="mailto:ADC_AfrAm@uw.edu">ADC_AfrAm@uw.edu</a></td>
</tr>
<tr>
<td>ADC Latinx Interest Group</td>
<td><a href="mailto:ADC_Latino@uw.edu">ADC_Latino@uw.edu</a></td>
</tr>
<tr>
<td>ADC Vascular Interest Group</td>
<td><a href="mailto:ADC_Vascular@uw.edu">ADC_Vascular@uw.edu</a></td>
</tr>
<tr>
<td>ADC Native American Interest Group</td>
<td><a href="mailto:ADC_NatAm@uw.edu">ADC_NatAm@uw.edu</a></td>
</tr>
<tr>
<td>ADC Down Syndrome Interest Group</td>
<td><a href="mailto:ADC_DownSyn@uw.edu">ADC_DownSyn@uw.edu</a></td>
</tr>
<tr>
<td>ADGC and NCRAD Interest Group</td>
<td><a href="mailto:ADC_Genetics@uw.edu">ADC_Genetics@uw.edu</a></td>
</tr>
<tr>
<td>ADC Lewy Body Dementia Interest Group</td>
<td><a href="mailto:ADC_LBD@uw.edu">ADC_LBD@uw.edu</a></td>
</tr>
</tbody>
</table>

## ADC core-focused listservs

<table>
<thead>
<tr>
<th>CORE</th>
<th>FOR USE OF CORE LEADERS ONLY</th>
<th>UMBRELLA LISTSERV (Includes core leaders, others)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Directors</td>
<td><a href="mailto:ADC_Director@uw.edu">ADC_Director@uw.edu</a></td>
<td><a href="mailto:ADC_Dir@uw.edu">ADC_Dir@uw.edu</a></td>
</tr>
<tr>
<td>Administrators</td>
<td><a href="mailto:ADC_Administrator@uw.edu">ADC_Administrator@uw.edu</a></td>
<td><a href="mailto:ADC_Admin@uw.edu">ADC_Admin@uw.edu</a></td>
</tr>
<tr>
<td>Clinical Core</td>
<td><a href="mailto:ADC_Clin_Leader@uw.edu">ADC_Clin_Leader@uw.edu</a></td>
<td><a href="mailto:ADC_Clin@uw.edu">ADC_Clin@uw.edu</a></td>
</tr>
<tr>
<td>Neuropathology Core</td>
<td><a href="mailto:ADC_NP_Leader@uw.edu">ADC_NP_Leader@uw.edu</a></td>
<td><a href="mailto:ADC_NP@uw.edu">ADC_NP@uw.edu</a></td>
</tr>
<tr>
<td>ORE Core</td>
<td><a href="mailto:ADC_ORE_Leader@uw.edu">ADC_ORE_Leader@uw.edu</a></td>
<td><a href="mailto:ADC_ORE@uw.edu">ADC_ORE@uw.edu</a></td>
</tr>
<tr>
<td>Data Core</td>
<td><a href="mailto:ADC_Data_Leader@uw.edu">ADC_Data_Leader@uw.edu</a></td>
<td><a href="mailto:datamngrs@uw.edu">datamngrs@uw.edu</a></td>
</tr>
<tr>
<td>REC</td>
<td><a href="mailto:ADC_REC_Leader@uw.edu">ADC_REC_Leader@uw.edu</a></td>
<td><a href="mailto:ADC_REC@uw.edu">ADC_REC@uw.edu</a></td>
</tr>
<tr>
<td>Biomarkers Core</td>
<td>N/A at this time</td>
<td><a href="mailto:ADC_Biom@uw.edu">ADC_Biom@uw.edu</a></td>
</tr>
<tr>
<td>Imaging Core</td>
<td><a href="mailto:ADC_Image_Leader@uw.edu">ADC_Image_Leader@uw.edu</a></td>
<td><a href="mailto:ADC_Image@uw.edu">ADC_Image@uw.edu</a></td>
</tr>
</tbody>
</table>

---

[https://www.alz.washington.edu/WEB/listservs.html](https://www.alz.washington.edu/WEB/listservs.html)
Latino ADC – Special Interest Group

Co-Leads: Yakeel T. Quiroz and Katya Rascovsky

<table>
<thead>
<tr>
<th>Research Working Group:</th>
<th>Assessment Working Group:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Accomplishments:</td>
<td>• Spanish translation and adaptation of UDS T-Cog, COVID and technology surveys. (formatted drafts in 1-2 weeks).</td>
</tr>
<tr>
<td>• Website with information about ongoing research studies for Latinos</td>
<td>• Preliminary norms for Spanish UDS3 neuropsychological battery (ongoing)</td>
</tr>
<tr>
<td>• <a href="http://mapp.mgh.harvard.edu/latino-adc/">http://mapp.mgh.harvard.edu/latino-adc/</a></td>
<td></td>
</tr>
<tr>
<td>• List of potential reviewers for papers/grants related to Latino issues</td>
<td></td>
</tr>
<tr>
<td>• Exploring opportunities for cross-Center research collaborations to improve the representation of diverse Latinos into our studies.</td>
<td></td>
</tr>
<tr>
<td>• Website will feature ongoing research with Latinos being conducted at the Centers, including our recent publications.</td>
<td></td>
</tr>
</tbody>
</table>

Welcome information about new studies and new potential reviewers. Please email yquiroz@mgh.harvard.edu and katyaras@pennmedicine.upenn.edu
## ADRC Webinars

### Previous webinars:

- **Data Core: Implementing Electronic Data Capture for a Decentralized Visit Model**
  - June 4, 2020

- **Clinical Core: Social Determinants of Health**
  - June 26, 2020

- **ORE Core: COVID Response**
  - September 3, 2020

- **Clinical Core: Researching New Models of Dementia Care**
  - September 25, 2020

### Upcoming webinars:

- **ORE Core**
  - October 23, 2020

- **Imaging Core**
  - November 6, 2020

Translational Webinars Series

- **Aim:** Enhance bidirectional knowledge and resource sharing between NIA’s Alzheimer’s Translational Research Program and the ADRCs

- **First webinar:** October 26, 3:00 PM – 5:00 PM EDT

- **Topic: Increasing Research Rigor, Reproducibility and Translatability**
  - Improving the Rigor, Reproducibility and Predictive Validity of Preclinical Research for Alzheimer’s Disease: Alzheimer's Disease Preclinical Efficacy Database (AlzPED) Lorenzo Refolo, NIA
  - Bridging the Preclinical to Clinical Translation Gap in Alzheimer’s Disease: MODEL-AD Preclinical Testing Pipeline Stacey Rizzo, University of Pittsburgh and Paul Territo, Indiana University
  - Rigor in Validation of Commercial Antibodies for Neurodegeneration Research Carl LaFlamme and Peter McPherson, McGill University
## SCAN Update:
*(Standardized Centralized Alzheimer’s & Related Dementias Neuroimaging)*

**Mission:** Standardize MR/PET image acquisition, provide QC, harmonization, data analysis, curation

---

### Timetable

<table>
<thead>
<tr>
<th>Period</th>
<th>Task Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Q4 2020:</strong></td>
<td>Survey sites for image equipment, publish website</td>
</tr>
<tr>
<td></td>
<td>Produce tech manuals, data upload procedures</td>
</tr>
<tr>
<td><strong>Q1/2 2021:</strong></td>
<td>Image uploads (via LONI)/QC/analysis begin</td>
</tr>
<tr>
<td><strong>Q3/4 2021:</strong></td>
<td>Expand website with documentation, upload links, FAQs/help</td>
</tr>
</tbody>
</table>
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

Collecting Communication Protocols: Please Contribute! (Jen Lingler, Judy Heidebrink)

- Other Modalities (e.g. Blood-based Biomarkers, Digital),
- Other Information (e.g. Tau, High Penetrance Mutations)
- Populations: Diverse Cohorts
- Settings: Research, Clinical
- Phase: Before Disclosure (decision), After Disclosure (education)
- Outcome Measures: Emotional Distress, Trust in Clinician, Feeling of Empowerment, Healthy Behaviors

Other Activities
- Planning for Spring Webinar: Disclosure of Research and Clinical Findings Related to Cognition
- Educational Library: Stigma (Stites), Perspectives of Person with Dementia (Huling-Hummel), Participant Scientist (Walter/Aggarwal)
<table>
<thead>
<tr>
<th>Blood/Urine/Saliva</th>
<th>DNA/RNA/Protein</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain</td>
<td>Informatics</td>
</tr>
<tr>
<td>CSF</td>
<td>Intellectual Property</td>
</tr>
<tr>
<td>Consent/Confidentiality</td>
<td>iPSCs</td>
</tr>
<tr>
<td>COVID Concerns?</td>
<td>Material Transfer</td>
</tr>
<tr>
<td>CSF</td>
<td>Metabolomics/Proteomics</td>
</tr>
<tr>
<td>Digital Neuropathology <strong>(NEW!)</strong></td>
<td>Microbiome <strong>(NEW!)</strong></td>
</tr>
<tr>
<td>Disseminating/Discarding</td>
<td>Technology <strong>(NEW!)</strong></td>
</tr>
</tbody>
</table>

- Release of ~1/2 of the new modules by mid-October 2020 with more to follow
- Planning for a more “living” document than previous
- Thank you to everyone who has contributed! And to Krista Moulder for overseeing!

Table A7 – Biospecimens available

<table>
<thead>
<tr>
<th></th>
<th>Plasma</th>
<th>Serum</th>
<th>Buffy Coat</th>
<th>CSF</th>
<th>DNA</th>
<th>DNA at NCRAD</th>
<th>Frozen Tissue</th>
<th>Fixed Tissue</th>
<th>Dermal Fibroblast</th>
<th>IPSCs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quantity</td>
<td>25,567</td>
<td>17,449</td>
<td>8,980</td>
<td>6,963</td>
<td>2,4050</td>
<td>17,560</td>
<td>11,284</td>
<td>14,014</td>
<td>885</td>
<td>146</td>
</tr>
</tbody>
</table>

[https://www.alz.washington.edu/NONMEMBER/progrep.html](https://www.alz.washington.edu/NONMEMBER/progrep.html)
Brain Donation Resources

Brain Donation: A Gift for Future Generations

Brain donation helps researchers study brain disorders, such as Alzheimer’s disease and related dementias, that affect millions of people. Learn about why people donate their brains, the process of brain donation, and how you can enroll to make this generous gift.


Brain Donation Resources for ADRCs

- Brain Donation FAQs
- Tips on Communicating About Brain Donation

BRAIN DONATION FAQs

We have created this list of FAQs to help support your ADRC’s communication efforts about brain donation. This is a template—you can pick and choose which questions you want to use, based on your Center’s policies and participant demographics. Please note that the answers to some questions are customizable based on your Center.

https://www.nia.nih.gov/health/brain-donation-resources-adrcs
https://www.nia.nih.gov/braindonationtoolkit

Collaboration, culture, coordination: Keys to supporting brain donation

March 04, 2020

https://www.nia.nih.gov/research/blog/2020/03/collaboration-culture-coordination-keys-supporting-brain-donation
## 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)
- 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
- 9 controls; 23 future donors w/reported AD, dementia, vascular dementia, generalized dementia or MCI have been referred to ADRCs
- 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
The group, led by Brittany Dugger and Melissa Murray, includes people from many ADRCs, additional subject matter experts, as well as NACC.

- Produced FAQ Sheet on Digital slide scanners and associated infrastructure
- ADRC-wide survey results on digital pathology
- Beta test of workflow process to de-identify the slide labels kindly shared by Dr. Thomas Pearce (Pitt)
- Also working to harmonize with NINDS U54s on TBI
Future Planning
PAR 20-099: Harmonization of ADRD Genetic, Epidemiologic, and Clinical Data for the ADSP (U24)

A component of the Alzheimer’s Disease Sequencing Project (ADSP)

Harmonize phenotypic data using established best practices

Targeting all cohorts within ADSP (~60 cohort studies, many with longitudinal biomarkers)

Establish harmonized data sets as a “legacy” data set that will be perpetually curated and shared

By 2023 at least 50,000 whole genomes, multi-ethnic

Transparent, scalable data harmonization with wide data sharing through a central data repository (www.niagads.org)

ADCs have ~ 20,000 subjects with sequencing, clinical / phenotypic data

Comprehensive catalogue of metadata including data dictionaries and availability tables to be made freely available to the research community

Informal work group of domain experts formed in 2018

Contact: timothy.j.hohman@vumc.org

Background

Purpose

Available Data

- Longitudinal Clinical and Cognitive Data
- Imaging: Structural MRI, PET Amyloid/Tau
- Neuropathology Data
- Cardiovascular Risk Factor Data
- Fluid Biomarker Data
The N3C is a partnership among the NCATS-supported Clinical and Translational Science Awards (CTSA) Program hubs and the National Center for Data to Health (CD2H), with overall stewardship by NCATS. Collaborators will contribute and use COVID-19 clinical data to answer critical research questions to address the pandemic.

https://ncats.nih.gov/n3c
Potential of EHR and Other Data Linkages to Propel AD/ADRD Research

NACC’s goal is to support ADRCs to leverage existing local institutional infrastructure to collect and harmonize electronic health record data to enhance other existing data offerings within the consortium.

*EHR and Claims data can augment existing and planned clinical research datasets*

*Standardize consent for linkages*

Next steps: If your ADRC is interested in EHR linkages, please reach out to nacchelp@uw.edu
May 2021, Los Angeles

– Keep NACC updated on your institutional travel restrictions
– Steering Committees participating
  • Imaging Core
  • Biomarker Core
  • Administrators
  • Clinical Core
  • Directors
  • REC
  • https://www.alz.washington.edu/WEB/futureADCmeetings.html
Concluding comments

• Virtual Format Benefits – Inclusive, available later, live demos, cross core interactions!
• Thank You! Cerise and Grayson
  – NACC (esp Elizabeth) - Welcome to Kari Stephens and Sean Mooney!
  – CTF
• Numerous accomplishments, even with COVID
• Steering Committees – essential roles in future planning
• Our work is benefitting the larger community
• Dementia is still such a common condition, even with COVID we still need to continue our dementia research
• We look forward to planning for the spring meeting
• Next Steps
  – Launch all Steering Committees
  – Maximize biomarker analysis (Biomarker Steering Committee)
  – Centralized, standardized imaging data to research community
  – Getting participant level data connected to biospecimens