

The National Cell Repository for Alzheimer's Disease

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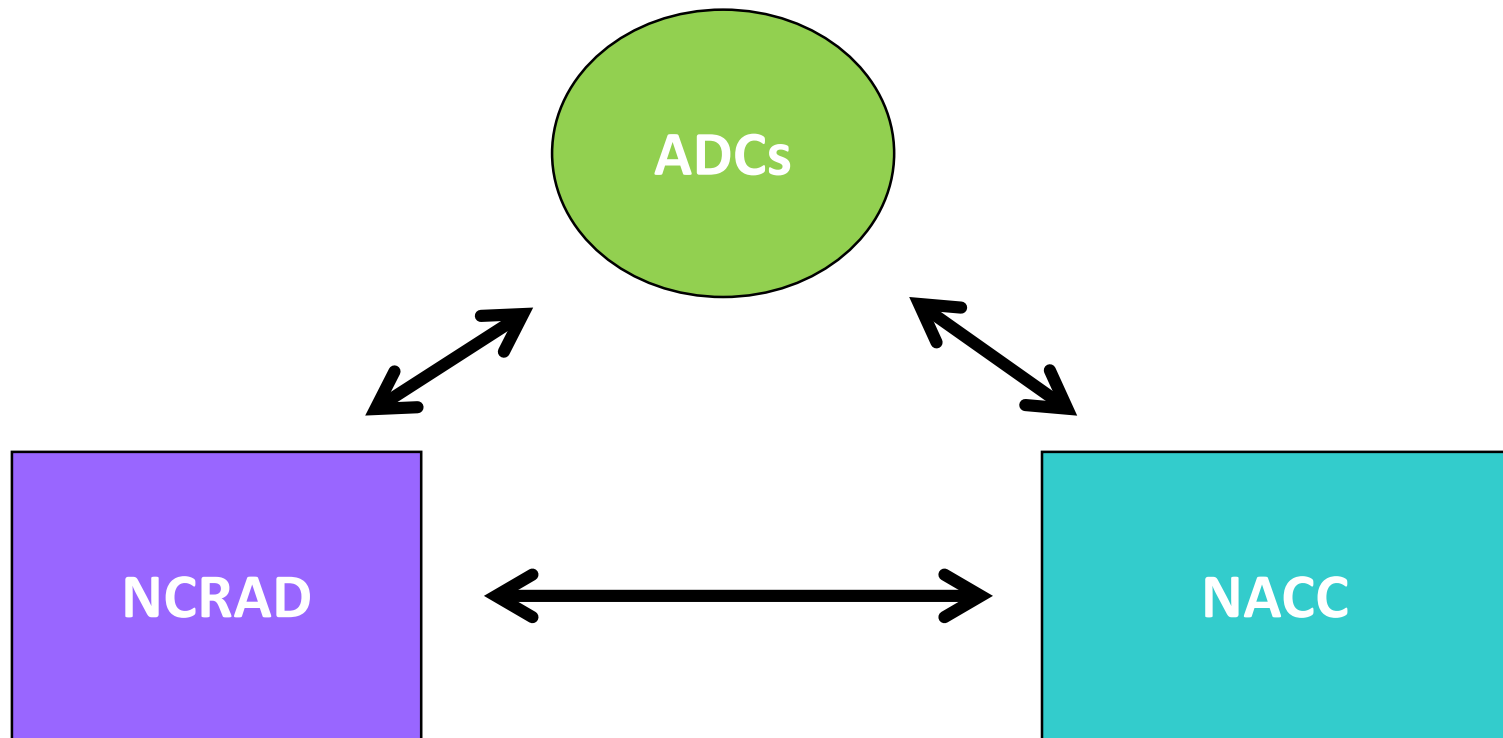
GDS needed for ADCs to contribute to Sequencing Initiatives

- For an ADC to contribute samples, they must have GDS approval
 - 29 sites with GDS approval
 - 6 sites without GDS approval (4 active ADC)


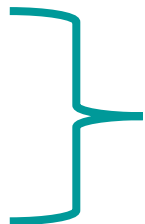
https://gds.nih.gov/Institutional_Certifications.html

NCRAD and NACC goal

Samples from 21,904 ADC subjects at NCRAD

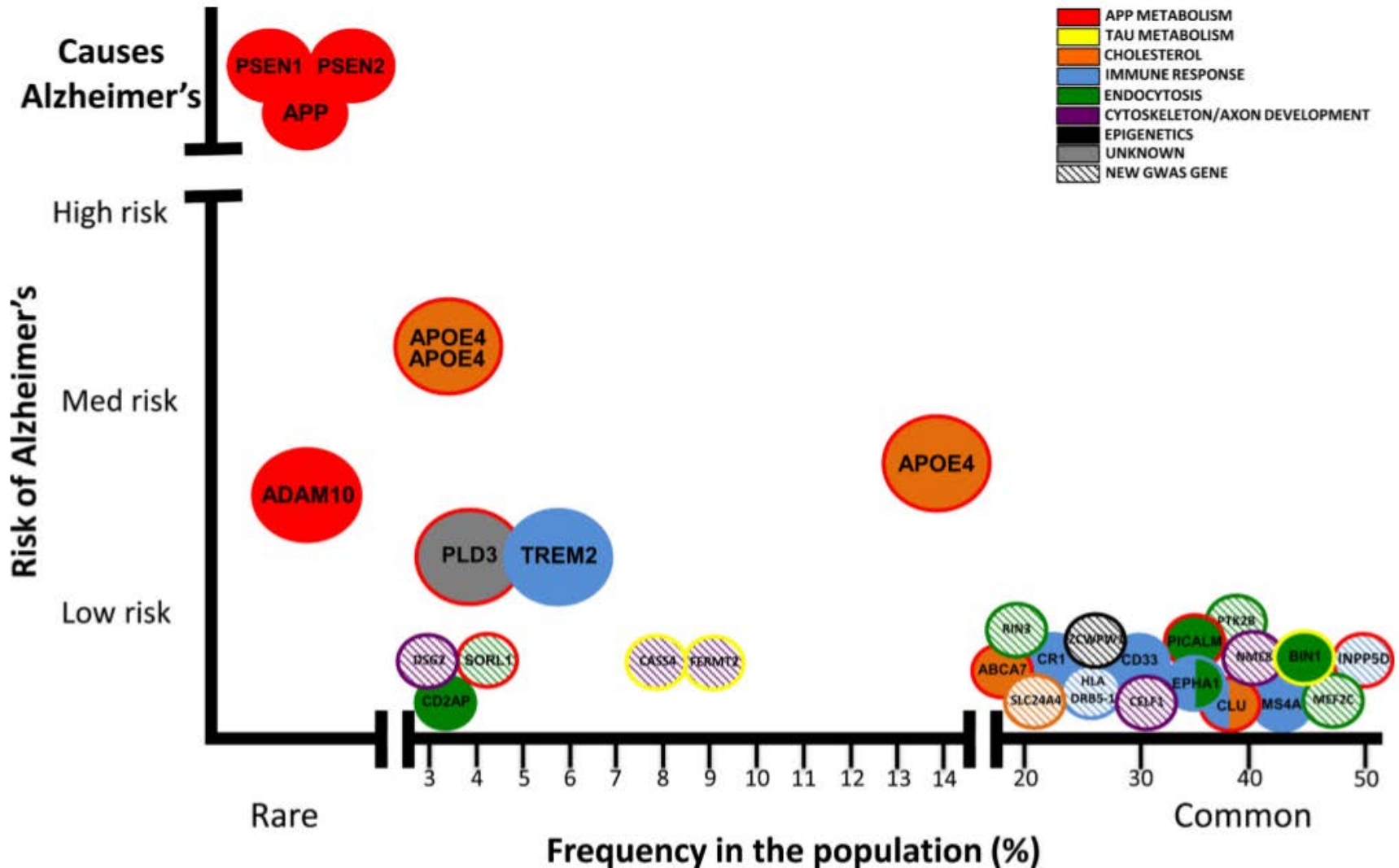


Data for ADC Contributed Samples

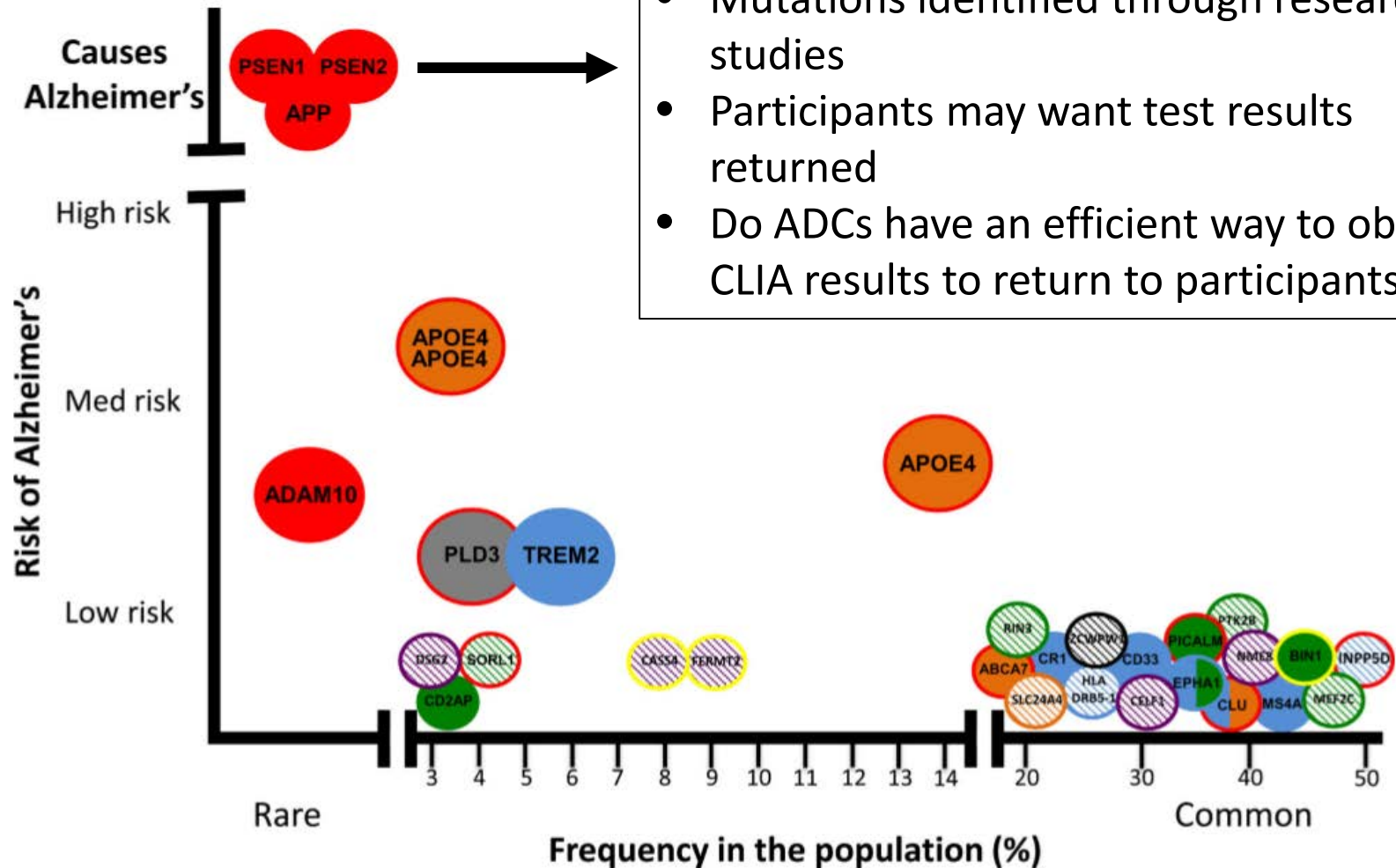
- **25,172** with APOE 
 - **13,824** with GWAS ADC 1-8
 - ~2,000 more in ADC 9
 - **11,378** with exome chip
 - **3,261** with WES through the ADSP
 - **1,183** with WGS through the ADSP
- Latest round of APOE just posted to NACC**
- ~9,000 individuals without GWAS
 - Opportunity for new research efforts

*all totals above include Phase 1 and Phase 2 subjects

Genetics and the ADCs

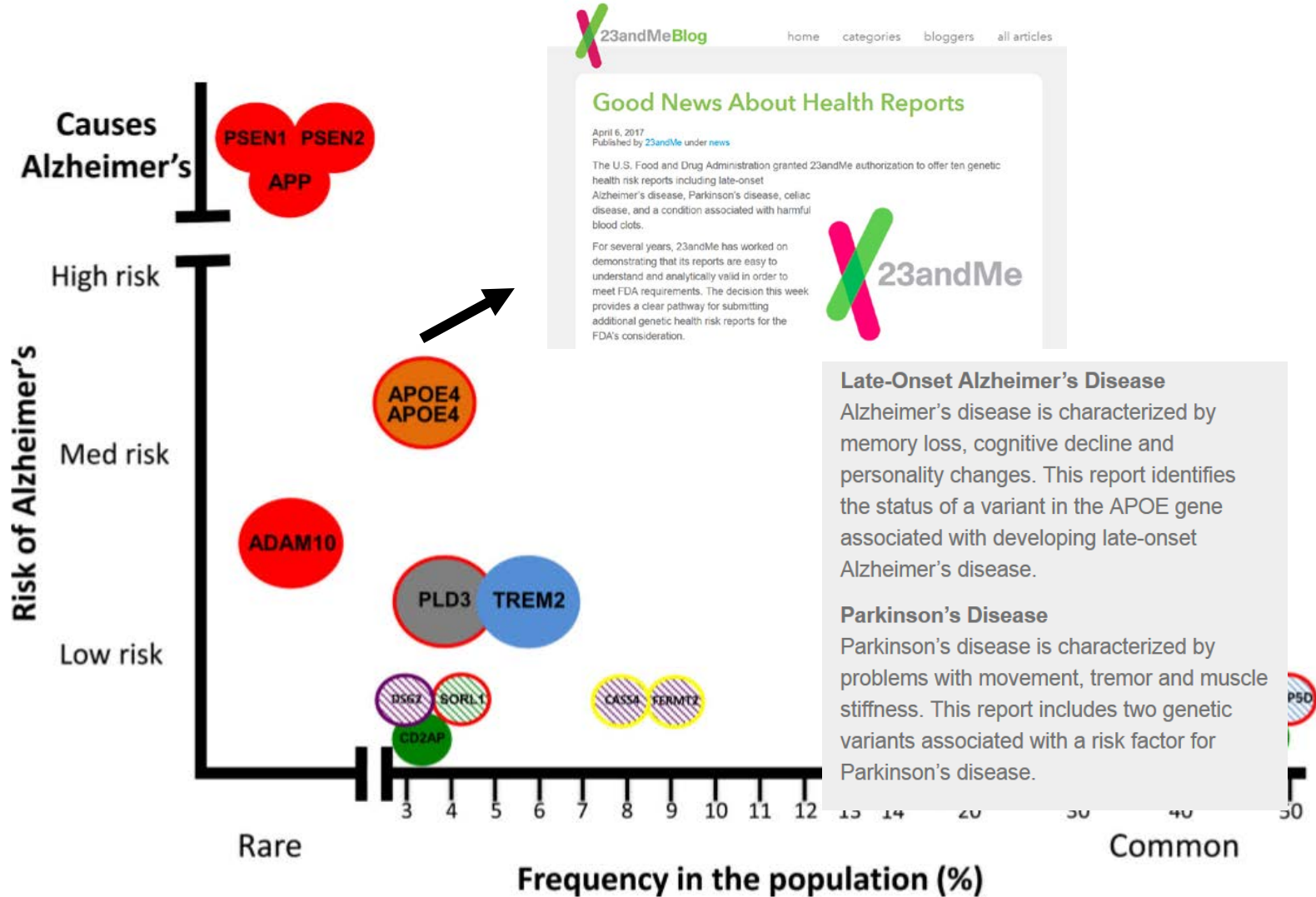


Genetics and the ADCs



- Mutations identified through research studies
- Participants may want test results returned
- Do ADCs have an efficient way to obtain CLIA results to return to participants

Genetics and the ADCs



Important Topics for Consideration

- Growing number of opportunities for individuals to obtain genetic results
- Genetic results are increasingly being used in trial inclusion criteria
- ADCs have growing amount of 'research' genetic results but limited amounts of 'CLIA' genetic results

Considerations for Return of Genetic Results

- CLIA Laboratory
 - Scope of testing
 - Genotype, targeted sequencing, exome, genome
 - Incidental findings
- Genetic counseling
 - In person
 - Telephone
 - Video conferencing

Initiatives ongoing that are returning results to participants
(REVEAL, A4, PPMI)

Genetics Working Group

- Important to bring together groups to consider how ADCs can share the increasing amount of genetic information being generated from research studies.....
 - What to share?
 - How to share?
 - Resources needed to share?

NCRAD Overview

- Bank samples from 27 different studies with more starting soon
 - Over 61,000 sampled subjects
- Broad focus on dementia-related studies
 - Store and distribute samples from currently funded studies
 - Receive and distribute samples from closed studies
- Contact NCRAD as designing study to discuss sample banking

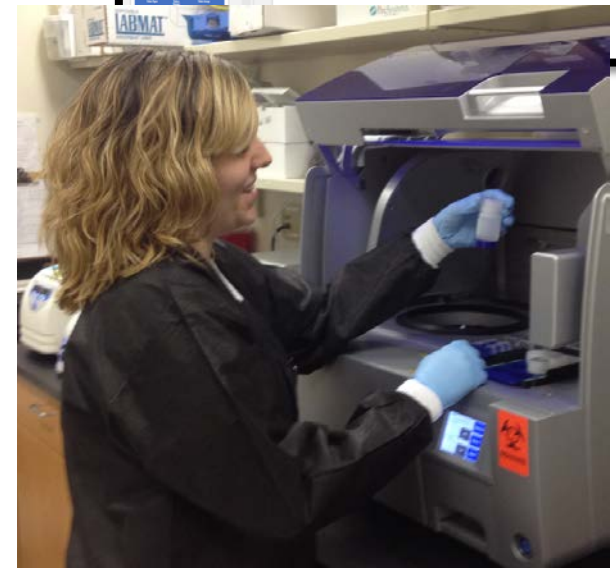
NCRAD's Services:

- Create Manual of Procedures
- Supplying Kits
 - Supplies to draw, process, and ship supplies back to NCRAD
- Study Coordinator Training
- Sample Receipt, Processing, and Storage
- Fulfilling Sample Orders from Approved Investigators



Training Overview:

- Study Update Overview
- Kit/Kit Request Module Update
- Specimen Label Update
- Sample Handling/Processing Update
- Sample Shipping Update
- Sample Form Updates
- Questions?



NCRAD Website



About NCRAD

 **125**
Researchers using
Samples from NCRAD

 **50K**
Subjects with
samples at NCRAD

 **400**
Publications using
NCRAD Samples and
Data

 **22**
Studies with samples
banked at NCRAD

Additional Resources



ClinicalTrials.gov

10 Signs of Alzheimer's Disease

- | | |
|---|------------------------------------|
| 1. Memory Loss | 6. Problems with Abstract Thinking |
| 2. Difficulty Performing Familiar Tasks | 7. Misplacing Things |
| 3. Problems with Language | 8. Changes in Personality |
| 4. Disorientation to Time and Place | 9. Changes in Mood or Behavior |
| 5. Poor or Decreased Judgement | 10. Loss of Initiative |

For more information, call the Alzheimer's Association at (800) 272-3901

Information about:

- Collecting samples
- Sending specimens
- Forms
- Requesting samples
- Consent language
- Newsletters

- Much more....

www.NCRAD.org

Acknowledgements

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- Alzheimer's Disease Centers
- Studies contributing samples to NCRAD
- NACC
- NIAGADS
- ADGC
- NIA
- NCRAD Executive Committee
 - Deborah Blacker (Chair)
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