

### Annual Sample Distribution Reports

It is time again for NCRAD's annual Sample Distribution Reports. This is sent out every January to the Center Director. Please contact Kelley Faber ([kelfaber@iu.edu](mailto:kelfaber@iu.edu)) if you would like a copy sent to you directly as well. As a reminder, this report is intended to assist your Center in demonstrating your contribution to sample banking efforts encouraged by NIA.

The report summarizes the number of samples provided by your site as part of initiatives banking samples at NCRAD. For example, a Center could be sending samples as part of the ADGC, ADNI, and LOAD initiatives. Please note that the number of samples provided on the report is a count of unique individuals within a study. Some studies are collecting longitudinal samples or multiple types of samples and these are not distinguished.

The annual report also summarizes how frequently samples contributed by your site are requested by researchers. The report shows the total number of samples contributed by your site that were ever distributed to researchers as well as the number that were distributed in the past year. This is a total count and is not restricted to unique subjects. Samples from the same subject may be requested by more than one investigator. This count does not reflect the samples that were returned to the contributing site as their one free aliquot.

Our summary report also provides the number of unique investigators that have requested samples contributed by your Center. We provide this information for the past year and also in a cumulative form across all years. Finally, all NIH grants that were supported by the samples contributed by your site are listed.

We always welcome suggestions for how to improve our report. We are also glad to answer any questions you have after you review the report.

Please contact us with any questions or concerns about NCRAD at 800-526-2839/317-274-7360, by email at [kelfaber@iu.edu](mailto:kelfaber@iu.edu) or visit our web-site: [www.ncrad.org](http://www.ncrad.org) Thanks!!

### ADSP-Alzheimer's Disease Sequencing Project

The ADSP Replication/Follow-up project planning is moving forward rapidly. This follow-up study will be used to validate the initial results from the whole exome and whole genome sequencing performed in the Discovery samples. NIH has recently issued the Genomic Data Sharing Policy (<http://gds.nih.gov/>) which is designed to ensure the broad and responsible sharing of genomic research data. Investigators providing samples that will be used in the ADSP Follow-Up Study (all of the ADCs) will need to abide by the policy statement to ensure that their samples can be used in the study.

There are several steps that must be completed in order to allow samples to be used:

1. **IRB approval:** This approval must ensure that samples provided were appropriately consented for sharing genomic data that will be made available on an NIH supported database.
  - a. **IRB consent category designation:** The IRB must also define the level of consent for which the study can be included. Please see the chart on the following page.
2. **Institutional Certification:** A signing official from the investigator's institution providing certification that the samples meet the Policy requirements.
3. **Informed Consent Form:** If a copy of the consent document(s) have not already been sent, please send a copy to Kelley.

We ask investigators to begin the steps listed above since we realize that this may be a lengthy process at some sites. Should you have any questions, please contact Kelley Faber.

## IRB consent category designation

	Category Code	Category Description
1	Health/Medical/Biomedical (IRB) (HMB-IRB)	Subject consented to genetic research of any human disease conducted by non-profit and for profit (pharmaceutical and biotechnology companies)
2	Health/Medical/Biomedical (IRB, NPU) (HMB-IRB-NPU)	Subject consented to genetic research of any human disease conducted by non-profit
3	Disease-Specific (Alzheimer Disease, IRB) (DS-ALZ-IRB)	Subject consented to Alzheimer disease research conducted by non-profit and for profit (pharmaceutical and biotechnology companies)
4	Disease-Specific (Alzheimer Disease, IRB, NPU) (DS-ALZ-IRB-NPU)	Subject consented to Alzheimer disease research conducted by non-profit organizations
5	Disease-Specific (Neurodegenerative Disease, IRB) (DS-ND-IRB)	Subject consented to neurodegenerative disease research conducted by non-profit and for profit (pharmaceutical and biotechnology companies) organizations
6	Disease-Specific (Neurodegenerative Disease, IRB, NPU - DS-ND-IRB-NPU)	Subject consented to neurodegenerative disease research conducted by non-profit organizations

## ADC samples to NCRAD

NCRAD continues to accept samples from all subjects on the NACC Phase 1 and 2 lists. There is limited funding to reimburse for transferred samples. Once the funding is depleted, there will not be further monetary compensation at this time. However, when sending blood, NCRAD will continue to cover the cost of shipping, provide a blood kit and return 25ug of DNA for free. In addition, APOE genotyping will be done on all samples submitted. Please continue to send samples for this very valuable project.

## Annual Calls

Every year we hold a call with each ADC to discuss current and upcoming initiatives. In the coming weeks, please look for an email from Kelley to schedule this. We would like to speak with the Center Director and/or Clinical Core Director at each ADC. This year we plan to discuss the ADSP Replication project in a bit more detail and review the IRB approval and Institutional Certification request discussed above. We hope you find the calls informative and please don't hesitate to contact us if you have further questions!

A Central Repository with DNA available to match the rich dataset collected for all subjects seen in the ADCs is a very valuable resource for the field of AD research. We hope you will continue to support this effort!

Please contact us with any questions or concerns about NCRAD at 800-526-2839/317-274-7360, by email at [kelfaber@iu.edu](mailto:kelfaber@iu.edu) or visit our web-site: [www.ncrad.org](http://www.ncrad.org) Thanks!!

## ADGC Collection Available

NIAGADS is in the process of finishing depositing published ADGC data into NIAGADS. 12 out of 15 datasets deposited with 2 in progress. Added imputation data for HapMap2 and 1000 Genomed. Received first CSF dataset.

<https://www.niagads.org>

## ADSP Data Available

ADSP has completed generation of 578 whole genomes and 10,939 whole exomes. NIAGADS is the data coordinating center for ADSP. Approved investigators can browse and download available data through the [ADSP Data Portal](#) or through the [dbGaP Study page](#).

<https://www.niagads.org/adsp>

## NIAGADS Featured on NIA Blog

NIAGADS was featured in the NIA blog post written by Dr. Marilyn Miller.

[Check out the article!](#)

## Recent Datasets Added to NIAGADS

NG00039

- [Summary Statistics for the ADGC African-American GWAS Collection](#)
- GWAS data coming soon!

NG00038

- [RNA Expression Levels from Brain in AD Case-Control Study](#)
- Cases/Controls: 180/312
- Markers: 48,803

NG00037

- [Progressive Supranuclear Palsy \(PSP\) GWAS](#)
- Autopsied Cases: 1,112
- Diagnosed PSP Cases: 1,051
- Total Markers: 561,882

30 datasets | 45,000 subjects | 24 billion genotypes

### Request Access to NIAGADS Data

Data request application instructions can be found at [www.niagads.org/data-request](http://www.niagads.org/data-request)

Send questions and suggestions about NIAGADS to [support@niagads.org](mailto:support@niagads.org).

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WELCOME TO NIAGADS!  
THE NATIONAL INSTITUTE ON AGING GENETICS OF ALZHEIMER'S DISEASE DATA STORAGE SITE

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REQUEST DATA  
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**PROJECTS**  
ADSP  
ADGC

**RESOURCES**  
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