

The National Cell Repository for Alzheimer's Disease

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U24AG21886



NCRAD, NACC and the ADCs have a strong collaboration

- **Data for ADC Contributed Samples**

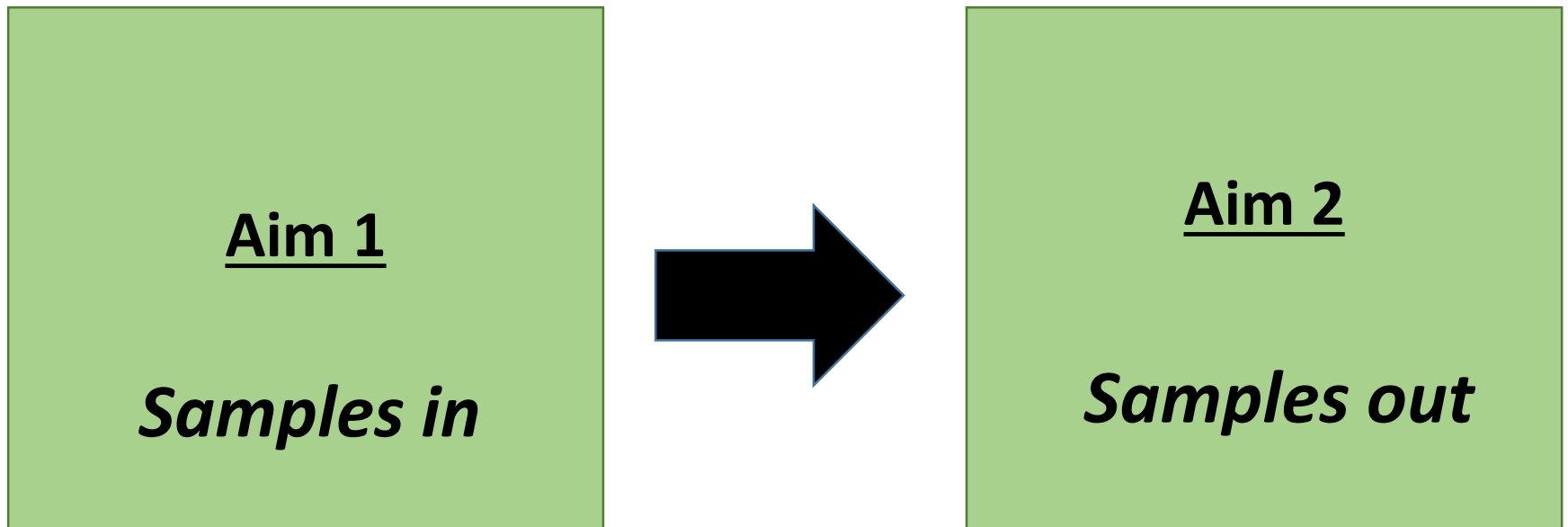
- **25,230** with APOE
 - **16,198** with GWAS ADC 1-9
 - **11,378** with exome chip
 - **3,261** with WES through the ADSP
 - **1,183** with WGS through the ADSP
 - ~3,000 more included in ADSP follow up studies
- } • ~9,000 individuals without GWAS
• Opportunity for new research efforts

*all totals above include Phase 1 and Phase 2 subjects

NCRAD banks samples for 28 studies

- One 'study' is the ADCs
- Bank samples from 27 other studies
 - Receive samples from ongoing studies as well as closed studies
- NCRAD has samples from > 63,000 subjects
 - ~500,000 sample aliquots received

NCRAD Specific Aims

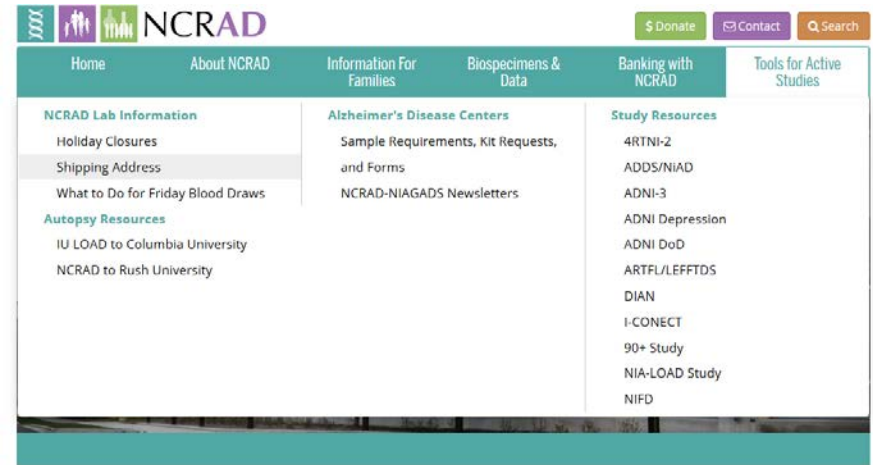


NCRAD Expansion

- **Goal: Meet the growing research needs due to increases in NIA funding**
- Meet needs of researchers requesting samples
 - Ensure that a broad range of biospecimens are available from a wide range of studies
- Offer central banking and biorepository management to more research studies
 - Prioritize studies with diverse cohorts, unique patient populations, extensive longitudinal data


NCRAD Study Support


<https://www.ncrad.org/>




 **144**
Researchers using
Samples from NCRAD

 **61K**
Subjects with
Samples at NCRAD


 **400**
Publications using
NCRAD Samples and
Data

 **27**
Studies with Samples
Banked at NCRAD


 **144**
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Tools for Active Studies




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ARTFL-LEFFTDS Active Study Page



Advancing Research & Treatment for Frontotemporal Lobar Degeneration



Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects
LEFFTDS

Welcome ARTFL-LEFFTDS Study staff, coordinators, and PI's. This section encompasses study specific tools and videos for your reference. If you have any questions, comments, or new ideas please contact Madeline Potter by email or phone (800)526-2839 or directly at (317)278-9546.

ARTFL-LEFFTDS Specimen Collection Overview

	ARTFL	LEFFTDS (Visit 1)	LEFFTDS (Visit 2)	LEFFTDS (Visit 3)
DNA (Buffy Coat)	✓	✓	✓	✓
Plasma	✓	✓	✓	✓
PBMC	✓	✓	✓	✓
Serum	✓	✓	✓	✓
RNA	✓	✓	✓	✓
CSF	✓*	✓	✓	✓

* Select patient populations to donate CSF

- ARTFL: 40-50 subjects
- LEFFTDS: 200-250 subjects

Study Resources

[Kit Request Module](#)

[Study Specific Sample Notification Forms](#)

[ARTFL-LEFFTDS Manual of Procedures](#)

[Study Related Video Tutorials](#)

[ARTFL-LEFFTDS Training Slides](#)

[ARTFL-LEFFTDS Study Common Questions and Answers](#)

[ARTFL-LEFFTDS Site Locations](#)

BANK SAMPLES with NCRAD

SAMPLETYPES we Bank

Download Documents

[Biological Sample and Shipment Notification Form](#)

[CSF Sample and Shipment Notification Form](#)

[Green Top-Sodium Heparin Redraw/Take Home Sample Form](#)

[Lavender Top-EDTA Redraw/Take Home Sample Form](#)

[ARTFL-LEFFTDS Manual of Procedures](#)

Additional Resources

[ARTFL LEFFTDS Kit Request System](#)

[Web-based Blood Sample Form](#)

[Web-based CSF Sample Form](#)

[ARTFL-LEFFTDS Videos](#)

[Friday Blood Draws](#)

[Shipping Address](#)

[Holiday Closures](#)

Questions/Comments

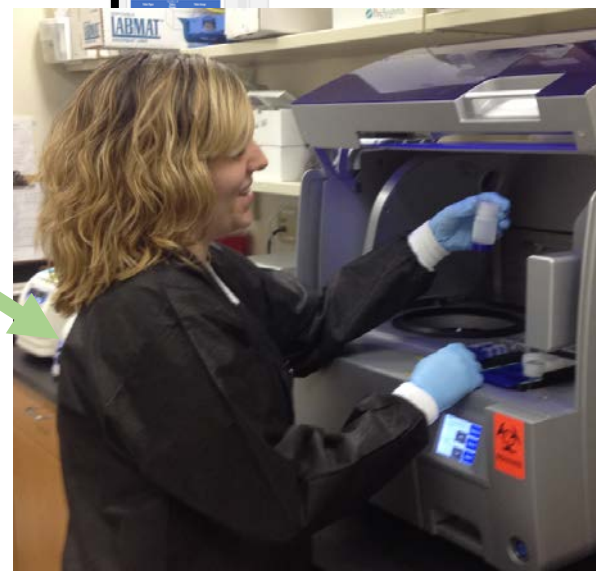
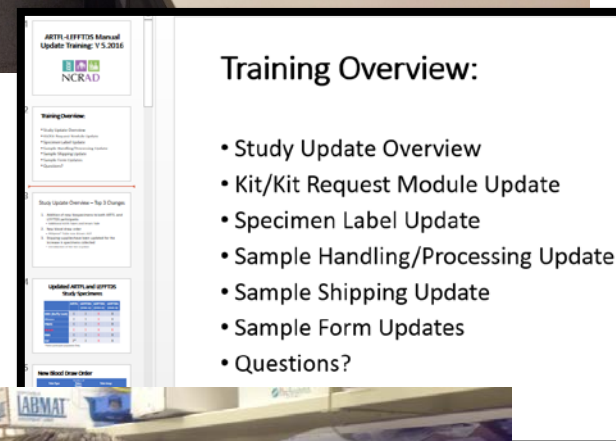
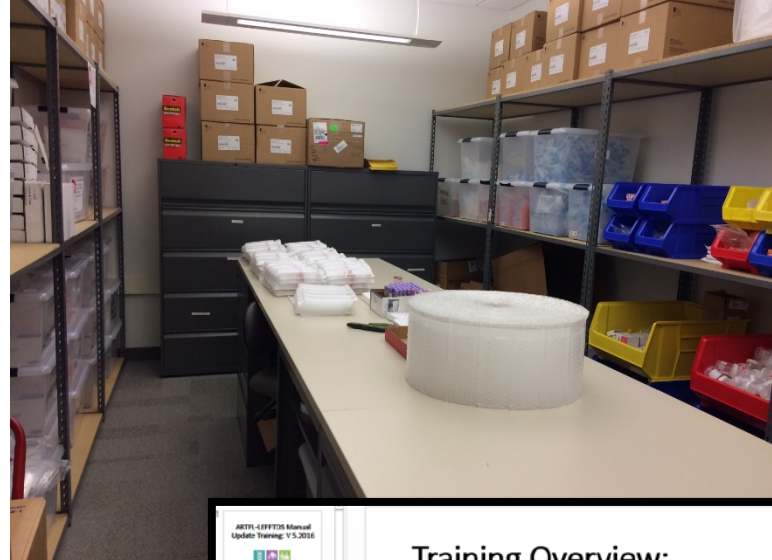
[Email: alzstudy@iu.edu](#)

[Phone: 800-526-2839](#)



NCRAD's Services:

- Create Manual of Procedures
- Supply Kits
 - Supplies to draw, process, and ship supplies back to NCRAD
- Provide Study Coordinator Training
- Array of Services Including Sample Receipt, Processing, and Storage
- Fulfill Sample Orders from Approved Investigators



To learn more....

- NIA encourages research studies to utilize NCRAD for biospecimen management
 - Contact NCRAD when preparing a grant application to obtain more information
 - Contact NCRAD if samples from a completed study could be shared with other researchers
- Is there a new specimen protocol you want to implement and need advice?.... Contact NCRAD
kelfaber@iu.edu or alzstudy@iu.edu

NCRAD Sample Distributions

	Since Inception (through 6/30/2017)
# researchers	145
# DNA	211,271
# blood	811
# cell lines	1,939
# plasma	6,418
# serum	115
# PBMC	12
# RNA	50

NCRAD Sample Distributions

- More requests for samples other than DNA
 - Plasma, serum, and CSF, increasing requested
- Investigators need to pair clinical data and genetic data to select samples for other studies
- NCRAD is developing approaches to make it easy to query this information and select samples

NCRAD Catalogs



144
Researchers using
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Navigating to the NCRAD Catalogs

Accessing Biospecimens and Data

In order to ensure that researchers have the most accurate information, the National Cell Repository for Alzheimer's Disease (NCRAD) is continually updated with new information. At the time data is requested, NCRAD will provide the researcher with the most current information. Therefore, NCRAD encourages all researchers to request an updated set of variables prior to publication and implementation of analyses involving samples acquired from the Repository. While every effort is made to verify all data and information, NCRAD cannot be responsible for any errors or omissions in the distributed data.

Cohort	Population	Genomic DNA	Cell Line DNA	RNA	Plasma	Serum	LCLs	PBMCs	CSF
ADNI	AD Cases, Controls, MCI	✓	✓	✓			✓		
AA Genetics	AD Cases, Controls		✓				✓		
ADCs	AD and other dementia cases, Controls, MCI	✓	✓					✓	
DIAN	Early Onset AD Families with known mutations		✓				✓		
GEMS	Dementia prevention	✓			✓	✓			
GIFT	AD, FTD, Controls	✓	✓				✓		
Indianapolis-Ibadan	Elderly African Americans from Indianapolis, Yoruba living in Ibadan	✓	✓				✓		
NCRAD Family	AD and other dementia families	✓	✓				✓	✓	
NIA-LOAD	Late Onset AD Families, Controls	✓	✓				✓		
ARTFL	FTLD syndrome cases and healthy family members	✓		✓	✓	✓		✓	✓
LEFFTDS	FTLD family study with known genetic mutations (symptomatic and asymptomatic family members)	✓		✓	✓	✓		✓	✓



Additional Resources

MTA for Receiving Samples
Publication Acknowledgement
Sample Types We Bank
NCRAD Executive Committee

Study Websites

ADNI
Alzheimer's Disease Neuroimaging Initiative

ADCs
Alzheimer's Disease Centers

DIAN
Dominantly Inherited Alzheimer's Network

Indianapolis-Ibadan
Indianapolis Ibadan Epidemiological Study of Dementia

Questions/Comments

Email: alzstudy@iu.edu
Phone: 800-526-2839

DIAN

GEMS

GIFT

Indianapolis-Ibadan

NCRAD Family

NIA-LOAD

The NIA Genetics Initiative/NIA-LOAD Study is a multi-site study initiated in 2002 with the purpose of identifying families with multiple members diagnosed with late-onset Alzheimer's Disease (LOAD). Autopsy is offered to all active study subjects.

Study Subjects

The study requires at least two full siblings with late onset Alzheimer's disease (symptoms developed after age 60) and a third family member who is either: 1) affected and over age 50; or 2) unaffected and over age 60. In addition, a control cohort was also enrolled. These subjects were enrolled over the age of 60 with no neurological problems such as Alzheimer's disease, Parkinson's disease or stroke and have no parents, children or siblings with Alzheimer's disease.

Available Data

Enrolled family members complete a study visit (in person or by telephone). Study subjects are followed longitudinally and complete a study visit approximately every 2 years.

The catalog for the NIA-LOAD Study consists of a subset of variables that can be used to better understand the dataset and perform initial feasibility studies. Sites submit study data quarterly to the study data coordinating center located at Columbia University. This catalog is then updated quarterly after data cleaning is complete. Additional data can be requested from Columbia University.

Available Biospecimens

Genomic DNA, Cell Line DNA, Lymphoblastoid Cell Lines (LCLs)

Price Structure

Catalog

Biospecimens

ARTFL-LEFFTDS

Within the NCRAD website, in the Accessing Biospecimens and Data section, catalogs can be accessed. https://www.ncrad.org/accessing_data.html

NCRAD Data Agreement



Data Agreement

I request access to data housed at the National Cell Repository for Alzheimer's Disease (NCRAD) for the purpose of scientific investigation, teaching, or the planning of clinical research studies and agree to the following terms:

Section I: Access, Use, and Safeguards

- A. I will receive de-identified data and will not attempt to establish the identity of, or attempt to contact any of the subjects with data in NCRAD.
- B. I will not attempt to identify any specific study sites, unless NCRAD has approved such identification as part of my project's protocol.
- C. I understand that distributing these data to a third party is prohibited, and therefore I will not distribute these data beyond the uses outlined in this agreement. A third party is defined as anyone who is not a collaborator or co-author on the analyses defined in my proposal.
- D. I will require anyone on my team who uses the data, or anyone with whom I share these data, to comply with this Data Agreement.
- E. I will accurately provide the requested information about persons who will use the data and analyses that are planned using these data.
- F. I will comply with any rules and regulations imposed by my institution and its Institutional review board in requesting and using these data.
- G. I understand that any data I download may change as new quality assurance measures are implemented and data records are updated.
- H. I will ensure that Investigators who utilize data obtained from NCRAD use appropriate administrative, physical, and technical safeguards to prevent use or disclosure of the data other than as provided for by this Agreement.
- I. I will report any use or disclosure of the data not provided for by this Agreement of which I become aware within 15 days of becoming aware of such use or disclosure.



Questions/Comments

Email: alzstudy@iu.edu

Phone: 800-526-2839

Section II: Data Analysis

- A. I will respond promptly and accurately to NCRAD's requests for updates on the status of my analyses.
- B. I will review the data documentation provided by NCRAD and consult with NCRAD research coordinators in order to ensure the accurate use and description of study data in my analysis and any ensuing presentations or publications, as well as to ensure the understanding of subtle data complexities.
- C. If more than 1 year passes before publication, I will download and update dataset to ensure the most accurate and up to date data is used.

Section III: Publication

- A. I will include the NCRAD acknowledgement for **all** samples and data obtained:
Samples and data from the National Cell Repository for Alzheimer's Disease (NCRAD), which receives government support under a cooperative agreement grant (U24 AG21886) awarded by the National Institute on Aging (NIA), were used in this study. We thank contributors who collected samples used in this study, as well as patients and their families, whose help and participation made this work possible.
- B. I will acknowledge the work by each specific study that went into accumulating the data and samples and its funding source(s), and will include language in the manuscripts associated with the correct collection. Every study has specific acknowledgement language. As new catalogs are added, additional language will continue to be listed.
 1. **NIA-LOAD:** The NIA-LOAD study supported the collection of samples used in this study through National Institute on Aging (NIA) grants U24AG026395 and R01AG041797. We thank contributors, including the Alzheimer's Disease Centers who collected samples used in this study, as well as patients and their families, whose help and participation made this work possible.
 2. **Indianapolis-Ibadan:** The Indianapolis-Ibadan dementia project is a 20 year comparative community based epidemiological study of the prevalence, incidence and risk factors for AD and dementia in populations of African origin, elderly African Americans in Indianapolis, Indiana and Yoruba in Ibadan, Nigeria. It was supported from 1991-2012 by NIH grants R01 AG09956 and P30 AG 10133. We would like to take this opportunity to thank the many faculty and staff of the University of Ibadan and Indiana University School of Medicine for their involvement as well as the 4000 plus elderly participants at each of the sites.
- C. I will notify NCRAD if my manuscript is accepted for publication and/or presentation.
- D. I will ensure the proper submission of all published work to PubMed Central (PMC) in order to comply with the NIH Public Access Policy.

I understand that failure to abide by these guidelines will result in termination of my privileges to access NCRAD data.

☐ I **AGREE** to the terms outlined above

You must click the "I AGREE" box above to proceed.

Researchers can complete a web-based Data Agreement to obtain a username and password to the restricted catalogs.

NCRAD Catalogs

After obtaining a username and password from the NCRAD staff, researchers will be able to log directly into the specimen catalog to review a subset of data.

Welcome to the IUGB Web Portal

Please Sign In

Username

mkpotter

Password

.....

Log in

Trouble signing in? [Click Here](#)

NINDS
BioSEND



NCRAD Catalogs

The catalog system is designed to allow researchers to determine which sample collections best fit their research needs and perform feasibility checks before applying for or requesting the samples. The researcher will have the option to download their selected sample set and include that with their application.

ARTFL_LEFFTDS Catalog		Dictionary Join Data Selection Download Help Tour							Signed in as mkpotter Logout	
Column Filter Search	GUID	ARTFL	LEFFTDS	Specimen Type	Visit	Specimen Quantity	Quantity UOM	Specimen Count		
<input checked="" type="checkbox"/> GUID	137140	PDRP439ND7	Yes	No	PLASMA	Cycle 1 - Blood	500 ul	10		
<input checked="" type="checkbox"/> ARTFL	137102	PDLH754MYK	Yes	No	PLASMA	Cycle 1 - Blood	500 ul	10		
<input checked="" type="checkbox"/> LEFFTDS	137136	PDCM442CZ2	Yes	Yes	PLASMA	Cycle 1 - Blood	500 ul	34		
<input type="checkbox"/> Sex	137169	PDTR790BWE	Yes	No	PLASMA	Cycle 1 - Blood	500 ul	9		
<input type="checkbox"/> Race	137580	PDMG002NNU	Yes	No	PLASMA	Cycle 1 - Blood	500 ul	9		
<input type="checkbox"/> Hispanic	137891	PDCY569XOC	Yes	No	CSF	Cycle 1 - CSF	500 ul	4		
<input type="checkbox"/> Deceased	137647	PCCC634EK2	Yes	Yes	CSF	Cycle 1 - CSF	500 ul	20		
<input type="checkbox"/> Age at Baseline Blood	137627	PDNN420JUH	Yes	Yes	CSF	Cycle 1 - CSF	500 ul	20		
<input type="checkbox"/> Age at Last Blood	137722	PDXZ993WHV	Yes	Yes	CSF	Cycle 1 - CSF	500 ul	20		
<input type="checkbox"/> Baseline Diagnosis	175685	PDUD490MM4	Yes	No	PLASMA	Cycle 1 - Blood	500 ul	9		
<input type="checkbox"/> Last Diagnosis	175746	PDBT334MKW	Yes	No	CSF	Cycle 1 - CSF	500 ul	25		
<input type="checkbox"/> Relevant Mutation	175780	PDGG098HHY	Yes	Yes	CSF	Cycle 1 - CSF	500 ul	21		
<input type="checkbox"/> Age at Onset	175906	PDBN316PWR	Yes	Yes	CSF	Cycle 1 - CSF	500 ul	26		
<input checked="" type="checkbox"/> Specimen Type	175969	PDNZ271VGZ	Yes	Yes	PLASMA	Cycle 1 - Blood	500 ul	10		
<input checked="" type="checkbox"/> Visit	175666	PDRN458WAK	Yes	No	PLASMA	Cycle 1 - Blood	500 ul	9		
<input checked="" type="checkbox"/> Specimen Quantity	175922	PDGG098HHY	Yes	Yes	PLASMA	Cycle 1 - Blood	500 ul	9		
<input checked="" type="checkbox"/> Quantity UOM	175980	PDBN316PWR	Yes	Yes	PLASMA	Cycle 1 - Blood	500 ul	9		
<input checked="" type="checkbox"/> Specimen Count	187010	PDVE306WBM	Yes	Yes	PLASMA	Cycle 1 - Blood	500 ul	6		
<input type="checkbox"/> Additional Stock	187036	PDFW368HKW	Yes	Yes	PLASMA	Cycle 1 - Blood	500 ul	6		
<input type="checkbox"/> Age at Baseline CSF	187074	PDNA720RL9	Yes	Yes	PLASMA	Cycle 1 - Blood	500 ul	6		
<input type="checkbox"/> Age at Last CSF	186809	PDHC477YNB	Yes	Yes	CSF	Cycle 1 - CSF	500 ul	24		
<input type="checkbox"/> Concentration	186866	PDFW368HKW	Yes	Yes	CSF	Cycle 1 - CSF	500 ul	32		
<input type="checkbox"/> Concentration UOM	186930	PDXW135MV3	Yes	Yes	CSF	Cycle 1 - CSF	500 ul	20		
<input type="checkbox"/> RIN Value	189403	PDFF049NGV	Yes	Yes	CSF	Cycle 1 - CSF	500 ul	33		
<input type="checkbox"/> 260/280 Ratio	189366	PDFP413JH5	Yes	Yes	CSF	Cycle 1 - CSF	1000 ul	0		
<input type="checkbox"/> 260/230 Ratio	189375	PDFP413JH5	Yes	Yes	CSF	Cycle 1 - CSF	500 ul	17		
<input type="checkbox"/> rRatio	189502	PDEM854TXH	Yes	Yes	PLASMA	Cycle 1 - Blood	500 ul	10		
	189598	PKB2302JK	Yes	Yes	PLASMA	Cycle 1 - Blood	500 ul	8		
	189287	PKB2302JK	Yes	Yes	CSF	Cycle 1 - CSF	500 ul	33		
	189345	PDHU712CEH	Yes	Yes	CSF	Cycle 1 - CSF	1000 ul	0		

Filter by Specimen Criteria

Researchers can use the sidebar to filter for the specific samples that meet their request criteria. When the categories on the left are selected, they will appear in the dataset to the right. Variables can be chosen by range of numbers, such as age, or text options, such as baseline diagnosis.

ARTFL_LEFFTDS Catalog

Column Filter Search

☒ GUID

☒ ARTFL

☒ LEFFTDS

☐ Sex

☐ Race

☐ Hispanic

☐ Deceased

☐ Age at Baseline Blood

☐ Age at Last Blood

☒ Baseline Diagnosis

☒ Quantity UOM

☒ Specimen Count

☐ Additional Stock

☐ Age at Baseline CSF

☐ Age at Last CSF

☐ Concentration

☐ Concentration UOM

☐ RIN Value

☐ 260/280 Ratio

☐ 260/230 Ratio

Dictionary

Join Data

Selection

Download

Help

Tour

Signed in as mkpotter Logout

GUID	ARTFL	LEFFTDS	Baseline Diagnosis	Specimen Type	Visit	Specimen Quantity	Quantity UOM	Specimen Count
220981	PDHK258TNG	Yes	Yes	Alzheimers disease dementia	PLASMA	Cycle 1 - Blood	500 ul	8
220987.2	PDHK258TNG	Yes	Yes	Alzheimers disease dementia	PBMC	Cycle 1 - Blood	2.3 x10^6 cells/1ml	5
259149	PDNF087ZAW	No	Yes	Alzheimers disease dementia	CSF	Cycle 1 - CSF	500 ul	20
399107	PDWR937LJ2	Yes	No	Alzheimers disease dementia	RNA	Cycle 1 - Blood	10000 ul	0
399112	PDWR937LJ2	Yes	No	Alzheimers disease dementia	PLASMA	Cycle 1 - Blood	500 ul	8
404380	PDFH409TGY	Yes	No	Alzheimers disease dementia	RNA	Cycle 1 - Blood	10000 ul	0
259136	PDNF087ZAW	No	Yes	Alzheimers disease dementia	CSF	Cycle 1 - CSF	1000 ul	0
399106.2	PDWR937LJ2	Yes	No	Alzheimers disease dementia	RNA	Cycle 1 - Blood	2 ug	8
648848	PDBG783XGC	Yes	No	Alzheimers disease dementia	PLASMA	Cycle 1 - Blood	500 ul	23
648886	PDBG783XGC	Yes	No	Alzheimers disease dementia	SERUM	Cycle 1 - Blood	500 ul	6
429155.2	PDNF087ZAW	No	Yes	Alzheimers disease dementia	RNA	Cycle 1 - Blood	2 ug	4
834970.2	PDPW717KAQ						2.08 x10^6 cells/1ml	9
811808	PDNF087ZAW						500 ul	21
811823	PDNF087ZAW						1000 ul	0
811555	PDNF087ZAW						500 ul	29
							500 ul	9
							1000 ul	0
834957	PDPW717KAQ						500 ul	30
834984	PDPW717KAQ						10000 ul	0
288943.4	PDPW717KAQ						200 ul	7
288933.5	PDPW717KAQ	Yes	Yes	Alzheimers disease dementia	CSF	Cycle 1 - CSF	170 ul	0
259131.4	PDNF087ZAW	No	Yes	Alzheimers disease dementia	CSF	Cycle 1 - CSF	200 ul	8
259131.6	PDNF087ZAW	No	Yes	Alzheimers disease dementia	CSF	Cycle 1 - CSF	54.8 ul	0
429156	PDNF087ZAW	No	Yes	Alzheimers disease dementia	PLASMA	Cycle 1 - Blood	500 ul	8
811584.1	PDNF087ZAW	No	Yes	Alzheimers disease dementia	PBMC	Cycle 2 - Blood	1 each	0
429162.1	PDNF087ZAW	No	Yes	Alzheimers disease dementia	PLASMA	Cycle 1 - Blood	200 ul	3
288937	PDPW717KAQ	Yes	Yes	Alzheimers disease dementia	CSF	Cycle 1 - CSF	500 ul	19
400295	PDPW717KAQ	Yes	Yes	Alzheimers disease dementia	PLASMA	Cycle 1 - Blood	500 ul	7
400306.2	PDPW717KAQ	Yes	Yes	Alzheimers disease dementia	PBMC	Cycle 1 - Blood	2.27 x10^6 cells/1ml	3
404393.1	PDFH409TGY	Yes	No	Alzheimers disease dementia	PBMC	Cycle 1 - Blood	2.081 x10^6 cells/1ml	4
429168.1	PDNF087ZAW	No	Yes	Alzheimers disease dementia	PBMC	Cycle 1 - Blood	2.79 x10^6 cells/1ml	2
400293.1	PDPW717KAQ	Yes	Yes	Alzheimers disease dementia	RNA	Cycle 1 - Blood	2 ug	6

Alzheimers disease dementia

Behavioral variant frontotemporal dementia

Clinically normal

Corticobasal syndrome typical or variant

Dementia with Lewy bodies

FTD/ALS

MCI behavior

MCI cognitive variants aMCIsd aMCIcmd

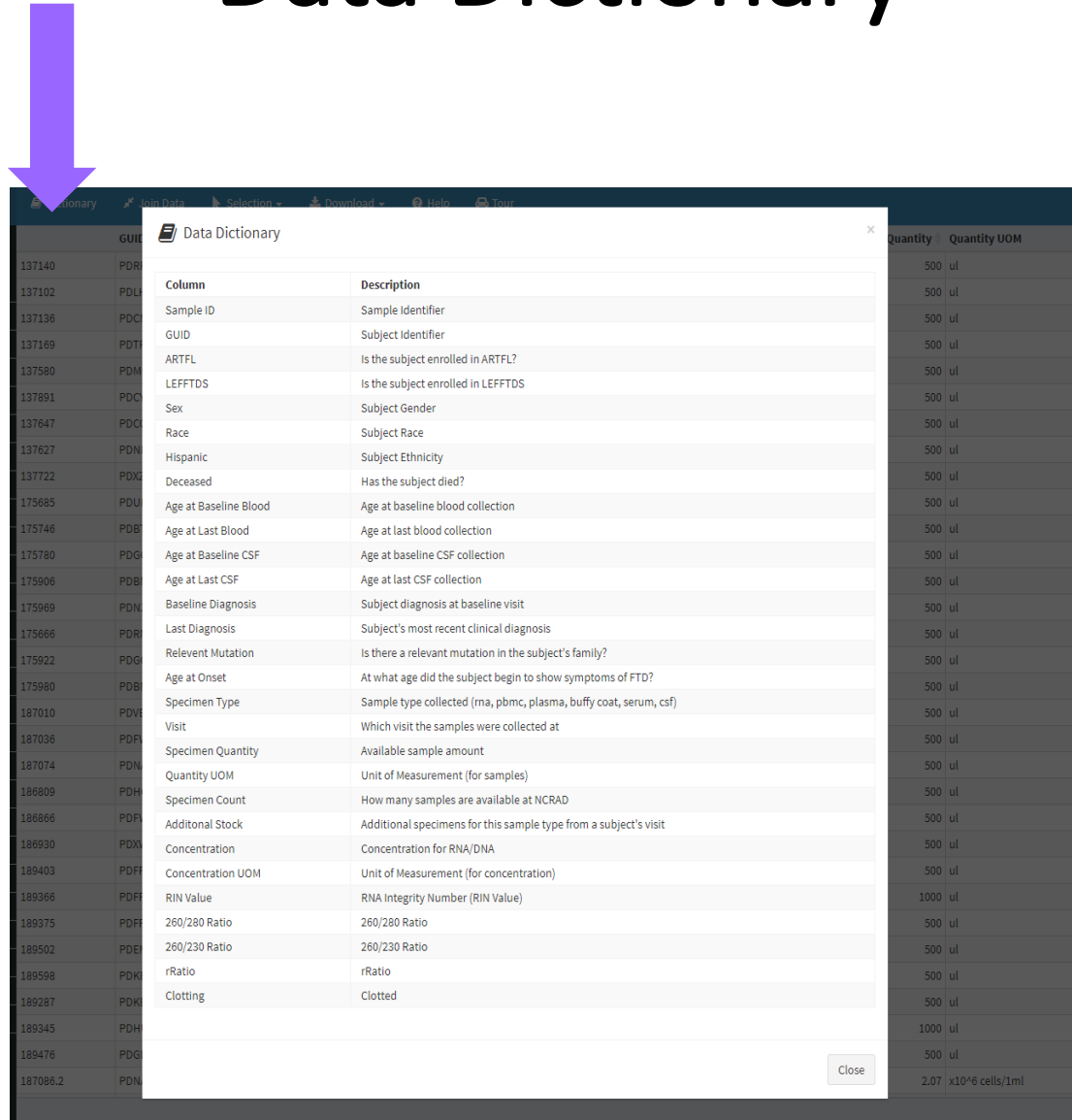
naMCIsd naMCIcmd

For variable "Baseline diagnosis"- Alzheimer's disease dementia was chosen as a variable and therefore shows up in the dataset.

Displaying 62 records filtered from 4,184 total (12 Selected)

Data Dictionary

By clicking here,
the data
dictionary box
appears.



The screenshot shows a software interface with a top navigation bar containing buttons for 'Data Dictionary', 'Edit Data', 'Selection', 'Download', 'Help', and 'Tour'. A purple arrow points from the text 'By clicking here, the data dictionary box appears.' to the 'Data Dictionary' button. The 'Data Dictionary' modal box is open, displaying a table with the following columns and descriptions:

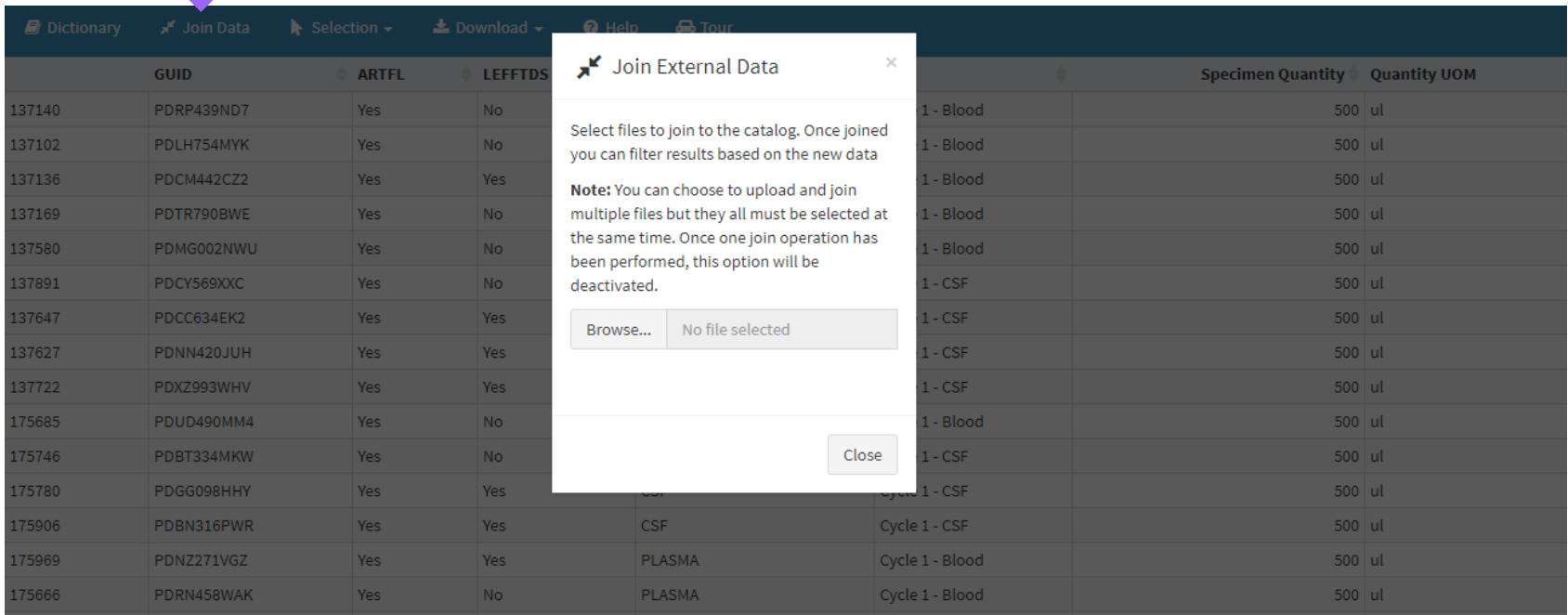
Column	Description
Sample ID	Sample Identifier
GUID	Subject Identifier
ARTFL	Is the subject enrolled in ARTFL?
LEFFTDS	Is the subject enrolled in LEFFTDS
Sex	Subject Gender
Race	Subject Race
Hispanic	Subject Ethnicity
Deceased	Has the subject died?
Age at Baseline Blood	Age at baseline blood collection
Age at Last Blood	Age at last blood collection
Age at Baseline CSF	Age at baseline CSF collection
Age at Last CSF	Age at last CSF collection
Baseline Diagnosis	Subject diagnosis at baseline visit
Last Diagnosis	Subject's most recent clinical diagnosis
Relevant Mutation	Is there a relevant mutation in the subject's family?
Age at Onset	At what age did the subject begin to show symptoms of FTD?
Specimen Type	Sample type collected (rna, pbmc, plasma, buffy coat, serum, csf)
Visit	Which visit the samples were collected at
Specimen Quantity	Available sample amount
Quantity UOM	Unit of Measurement (for samples)
Specimen Count	How many samples are available at NCRAD
Additional Stock	Additional specimens for this sample type from a subject's visit
Concentration	Concentration for RNA/DNA
Concentration UOM	Unit of Measurement (for concentration)
RIN Value	RNA Integrity Number (RIN Value)
260/280 Ratio	260/280 Ratio
260/230 Ratio	260/230 Ratio
rRatio	rRatio
Clotting	Clotted

The background shows a table with columns 'Quantity' and 'Quantity UOM'. The 'Data Dictionary' modal box has a 'Close' button in the bottom right corner.

Join Data

For many studies, more extensive data can be obtained from the study's data coordinating center. The catalog system supports joining this external data with the NCRAD biospecimen catalog data. This allows researchers to easily filter and select specimens based on criteria outside of those available in the catalog.

By clicking here, the join external data box appears.



The screenshot displays the NCRAD biospecimen catalog interface. A purple arrow points to the 'Join Data' button in the top navigation bar. A modal dialog box titled 'Join External Data' is open in the center, providing instructions on how to join external data files. The background shows a table of specimen data with columns for GUID, ARTFL, LEFFTDS, Specimen Quantity, and Quantity UOM.

Join External Data

Select files to join to the catalog. Once joined you can filter results based on the new data

Note: You can choose to upload and join multiple files but they all must be selected at the same time. Once one join operation has been performed, this option will be deactivated.

GUID	ARTFL	LEFFTDS	Specimen Quantity	Quantity UOM
137140	PDRP439ND7	Yes	No	1 - Blood
137102	PDLH754MYK	Yes	No	1 - Blood
137136	PDCM442CZ2	Yes	Yes	1 - Blood
137169	PDTR790BWE	Yes	No	1 - Blood
137580	PDMG002NWU	Yes	No	1 - Blood
137891	PDCY569XXC	Yes	No	1 - CSF
137647	PDCC634EK2	Yes	Yes	1 - CSF
137627	PDNN420JUH	Yes	Yes	1 - CSF
137722	PDXZ993WHV	Yes	Yes	1 - CSF
175685	PDUD490MM4	Yes	No	1 - Blood
175746	PDBT334MKW	Yes	No	1 - CSF
175780	PDGG098HHY	Yes	Yes	1 - CSF
175906	PDBN316PWR	Yes	Yes	CSF
175969	PDNZ271VGZ	Yes	Yes	PLASMA
175666	PDRN458WAK	Yes	No	PLASMA

Sample Selection

Researchers can individually select the samples they want, which highlights the selection in blue. They can also use the selection tool at the top to select all, none, or invert their selection.

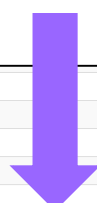


By clicking here, selection options appear.

ARTFL_LEFFTDS Catalog				Dictionary	Join Data	Selection	Download	Help	Tour	Signed in as mkpottter Logout		
Column Filter Search		GUID	Select All	LEFFTDS	Specimen Type	Visit	Specimen Quantity	Quantity UOM	Specimen Count			
		137140	PDRP435 Select None	No	PLASMA	Cycle 1 - Blood	500	ul	10			
		137102	PDLH754 Invert Selection	No	PLASMA	Cycle 1 - Blood	500	ul	10			
<input checked="" type="checkbox"/> GUID		137136	PDCM442CZ2	Yes	PLASMA	Cycle 1 - Blood	500	ul	34			
<input checked="" type="checkbox"/> ARTFL		137169	PDTR790BWE	Yes	PLASMA	Cycle 1 - Blood	500	ul	9			
<input checked="" type="checkbox"/> LEFFTDS		137580	PDMG002NWU	Yes	PLASMA	Cycle 1 - Blood	500	ul	9			
<input type="checkbox"/> Sex		137891	PDCY569XXC	Yes	CSF	Cycle 1 - CSF	500	ul	4			
<input type="checkbox"/> Race		137647	PDC634EK2	Yes	CSF	Cycle 1 - CSF	500	ul	20			
<input type="checkbox"/> Hispanic		137627	PDNN420JUH	Yes	CSF	Cycle 1 - CSF	500	ul	20			
<input type="checkbox"/> Deceased		137722	PDXZ993WHV	Yes	CSF	Cycle 1 - CSF	500	ul	20			
<input type="checkbox"/> Age at Baseline Blood		175685	PDUD490MM4	Yes	PLASMA	Cycle 1 - Blood	500	ul	9			
<input type="checkbox"/> Age at Last Blood		175746	PDBT334MKW	Yes	CSF	Cycle 1 - CSF	500	ul	25			
<input type="checkbox"/> Baseline Diagnosis		175780	PDGG098HHY	Yes	CSF	Cycle 1 - CSF	500	ul	21			
<input type="checkbox"/> Last Diagnosis		175906	PDBN316PWR	Yes	CSF	Cycle 1 - CSF	500	ul	26			
<input type="checkbox"/> Relevant Mutation		175969	PDNZ271VGZ	Yes	PLASMA	Cycle 1 - Blood	500	ul	10			
<input type="checkbox"/> Age at Onset		175666	PDRN458WAK	No	PLASMA	Cycle 1 - Blood						
<input checked="" type="checkbox"/> Specimen Type		175922	PDGG098HHY	Yes	PLASMA	Cycle 1 - Blood						
<input checked="" type="checkbox"/> Visit		175980	PDBN316PWR	Yes	PLASMA	Cycle 1 - Blood						
<input checked="" type="checkbox"/> Specimen Quantity		187010	PDVE306WBM	Yes	PLASMA	Cycle 1 - Blood						
<input checked="" type="checkbox"/> Quantity UOM		187036	PDFW368HKW	Yes	PLASMA	Cycle 1 - Blood						
<input checked="" type="checkbox"/> Specimen Count		187074	PDNA720RL9	Yes	PLASMA	Cycle 1 - Blood						
<input type="checkbox"/> Additional Stock		186809	PDHC477YNB	Yes	CSF	Cycle 1 - CSF						
<input type="checkbox"/> Age at Baseline CSF		186866	PDFW368HKW	Yes	CSF	Cycle 1 - CSF						
<input type="checkbox"/> Age at Last CSF		186930	PDXW135MV3	Yes	CSF	Cycle 1 - CSF						
<input type="checkbox"/> Concentration		189403	PDFF049NGV	Yes	CSF	Cycle 1 - CSF						
<input type="checkbox"/> Concentration UOM		189366	PDFP413JH5	Yes	CSF	Cycle 1 - CSF						
<input type="checkbox"/> RIN Value		189375	PDFP413JH5	Yes	CSF	Cycle 1 - CSF						
<input type="checkbox"/> 260/280 Ratio		189502	PDEM854TXH	Yes	PLASMA	Cycle 1 - Blood						
<input type="checkbox"/> 260/230 Ratio		189598	PDKB230ZJK	Yes	PLASMA	Cycle 1 - Blood	500	ul			8	
<input type="checkbox"/> rRatio		189287	PDKB230ZJK	Yes	CSF	Cycle 1 - CSF	500	ul			33	
		189345	PDHU712CEH	Yes	CSF	Cycle 1 - CSF	1000	ul			0	
		189476	PDGD954WZF	Yes	PLASMA	Cycle 1 - Blood	500	ul			11	
		187086.2	PDNA720RL9	Yes	PBMC	Cycle 1 - Blood	2.07	x10 ⁶ cells/1ml			6	
Displaying 4,184 records (12 Selected)												

In the bottom right corner, the catalog will show how many samples are selected and how many samples are displayed.

In the bottom right corner, the catalog will show how many samples are selected and how many samples are displayed.



Download Selection

Researchers will have the option to download the entire dataset, just the filtered specimens, or their selected specimens. An excel file will download to the desktop.



By clicking here, download options appear.

ARTFL_LEFFTDS Catalog		Dictionary		Join Data		Selection		Download		Help		Tour		Signed in as mkipotter Logout			
Column Filter Search		GUID		A		Download All		Specimen Type		Visit		Specimen Quantity		Quantity UOM		Specimen Count	
		137140	PDRP439ND7	Yi	Download Filtered			PLASMA	Cycle 1 - Blood	500	ul					10	
<input checked="" type="checkbox"/> GUID		137102	PDLH754MYK	Yi	Download Selected			PLASMA	Cycle 1 - Blood	500	ul					10	
<input checked="" type="checkbox"/> ARTFL		137136	PDCM442CZ2	Yes	Yes			PLASMA	Cycle 1 - Blood	500	ul					34	
<input checked="" type="checkbox"/> LEFFTDS		137169	PDTR790BWE	Yes	No			PLASMA	Cycle 1 - Blood	500	ul					9	
<input checked="" type="checkbox"/> Sex		137580	PDMG002NWU	Yes	No			PLASMA	Cycle 1 - Blood	500	ul					9	
<input checked="" type="checkbox"/> Race		137891	PDCY569XXC	Yes	No			CSF	Cycle 1 - CSF	500	ul					4	
<input checked="" type="checkbox"/> Hispanic		137647	PDCC634EK2	Yes	Yes			CSF	Cycle 1 - CSF	500	ul					20	
<input checked="" type="checkbox"/> Deceased		137627	PDNN420JUH	Yes	Yes			CSF	Cycle 1 - CSF	500	ul					20	
<input checked="" type="checkbox"/> Age at Baseline Blood		137722	PDXZ993WHV	Yes	Yes			CSF	Cycle 1 - CSF	500	ul					20	
<input checked="" type="checkbox"/> Age at Last Blood		175685	PDUD490MM4	Yes	No			PLASMA	Cycle 1 - Blood	500	ul					9	
<input checked="" type="checkbox"/> Baseline Diagnosis		175746	PDBT334MKW	Yes	No			CSF	Cycle 1 - CSF	500	ul					25	
<input checked="" type="checkbox"/> Last Diagnosis		175780	PDGG098HHY	Yes	Yes			CSF	Cycle 1 - CSF	500	ul					21	
<input checked="" type="checkbox"/> Relevant Mutation		175906	PDBN316PWR	Yes	Yes			CSF	Cycle 1 - CSF	500	ul					26	
<input checked="" type="checkbox"/> Age at Onset		175969	PDNZ271VGZ	Yes	Yes			PLASMA	Cycle 1 - Blood	500	ul					10	
<input checked="" type="checkbox"/> Specimen Type		175666	PDRN458WAK	Yes	No			PLASMA	Cycle 1 - Blood	500	ul					9	
<input checked="" type="checkbox"/> Visit		175922	PDGG098HHY	Yes	Yes			PLASMA	Cycle 1 - Blood	500	ul					9	
<input checked="" type="checkbox"/> Specimen Quantity		175980	PDBN316PWR	Yes	Yes			PLASMA	Cycle 1 - Blood	500	ul					9	
<input checked="" type="checkbox"/> Quantity UOM		187010	PDVE306WBM	Yes	Yes			PLASMA	Cycle 1 - Blood	500	ul					6	
<input checked="" type="checkbox"/> Specimen Count		187036	PDFW368HKW	Yes	Yes			PLASMA	Cycle 1 - Blood	500	ul					6	
<input checked="" type="checkbox"/> Additional Stock		187074	PDNA720RL9	Yes	Yes			PLASMA	Cycle 1 - Blood	500	ul					6	
<input checked="" type="checkbox"/> Age at Baseline CSF		186809	PDHC477YNB	Yes	Yes			CSF	Cycle 1 - CSF	500	ul					24	
<input checked="" type="checkbox"/> Age at Last CSF		186866	PDFW368HKW	Yes	Yes			CSF	Cycle 1 - CSF	500	ul					32	
<input checked="" type="checkbox"/> Concentration		186930	PDXW135MV3	Yes	Yes			CSF	Cycle 1 - CSF	500	ul					20	
<input checked="" type="checkbox"/> Concentration UOM		189403	PDFF049NGV	Yes	Yes			CSF	Cycle 1 - CSF	500	ul					33	
<input checked="" type="checkbox"/> RIN Value		189366	PDFP413JH5	Yes	Yes			CSF	Cycle 1 - CSF	1000	ul					0	
<input checked="" type="checkbox"/> 260/280 Ratio		189375	PDFP413JH5	Yes	Yes			CSF	Cycle 1 - CSF	500	ul					17	
<input checked="" type="checkbox"/> 260/230 Ratio		189502	PDEM854TXH	Yes	Yes			PLASMA	Cycle 1 - Blood	500	ul					10	
<input checked="" type="checkbox"/> rRatio		189598	PDKB230ZJK	Yes	Yes			PLASMA	Cycle 1 - Blood	500	ul					8	
		189287	PDKB230ZJK	Yes	Yes			CSF	Cycle 1 - CSF	500	ul					33	
		189345	PDHU712CEH	Yes	Yes			CSF	Cycle 1 - CSF	1000	ul					0	
		189476	PDGD954WZF	Yes	No			PLASMA	Cycle 1 - Blood	500	ul					11	
		187086.2	PDNA720RL9	Yes	Yes			PBMC	Cycle 1 - Blood	2.07	x10^6 cells/1ml					6	
Displaying 4,184 records (12 Selected)																	

Help

The “Help” tab walks researchers through the catalog sections such as the toolbar and sidebar. It explains in detail how to filter, join data, and download files.

By clicking here, the help section will appear and can be explored with its different tabs.

Tour

This portion of the catalog walks researchers through the dataset step by step, such as explaining how to filter for specimen criteria or how to join data.

By clicking here, the tour will begin to walk through the catalog functions one by one.



ARTFL_LEFFTDS Catalog

☒ LEFFTDS
 ☐ Sex
 ☐ Hispanic
 ☐ Deceased
 ☐ Age at Baseline Blood
 ☐ Age at Last Blood
 ☐ Baseline Diagnosis
 ☐ Last Diagnosis
 ☐ Age at Onset
 ☒ Specimen Type
 ☒ Visit
 ☒ Specimen Quantity
 ☒ Specimen Count
 ☐ Additional Stock
 ☐ Age at Baseline CSF
 ☐ Age at Last CSF

Filter Sidebar

The sidebar has been filtered down to just those columns with an 's' in the column name.

« Prev

Next »

End tour

Section ▾

Download ▾

Help ?

Tour

ARTFL	LEFFTDS	Specimen Type	Visit
Yes	No	PLASMA	Cycle 1 - Blood
Yes	No	PLASMA	Cycle 1 - Blood
Yes	Yes	PLASMA	Cycle 1 - Blood
Yes	No	PLASMA	Cycle 1 - Blood
Yes	No	PLASMA	Cycle 1 - Blood
Yes	No	CSF	Cycle 1 - CSF
Yes	Yes	CSF	Cycle 1 - CSF
Yes	Yes	CSF	Cycle 1 - CSF
Yes	Yes	CSF	Cycle 1 - CSF
Yes	No	PLASMA	Cycle 1 - Blood
Yes	No	CSF	Cycle 1 - CSF
Yes	Yes	CSF	Cycle 1 - CSF
Yes	Yes	CSF	Cycle 1 - CSF
Yes	No	PLASMA	Cycle 1 - Blood
Yes	Yes	PLASMA	Cycle 1 - Blood
Yes	Yes	PLASMA	Cycle 1 - Blood
Yes	Yes	PLASMA	Cycle 1 - Blood
Yes	Yes	PLASMA	Cycle 1 - Blood
Yes	Yes	CSF	Cycle 1 - CSF
Yes	Yes	CSF	Cycle 1 - CSF

Link to NIAGADS

Catalog Selections

Please follow the steps below to select the criteria necessary for your research.

1. View the study **Data Dictionary** to see all available catalog fields* and their descriptions.

[Dictionary](#)

*Additional data were collected for this study. To download a list of additional variables [click here](#). Contact us to request more information about data that are not available in this catalog: alzstudy@iu.edu or 800-526-2839.

2. Click on **Select Columns** below to choose the fields you would like to display in the catalog.

[Select Columns](#)

3. Click on **Filter Columns** below to filter the catalog by applying criteria to individual fields.

[Filter Columns](#)

4. Please **Download** the records you have selected from the catalog. The downloaded CSV file will include all of the columns you have selected and the subjects that met your filtering criteria. Please use this list to work with your statistician to determine feasibility for your research project.

[Download](#)

5. **Contact us!** Please use your downloaded file to work with your statistician to determine feasibility for your research project. When you feel comfortable with the list of samples you have selected, please contact NCRAD to work through the request process. You can reach us at: alzstudy@iu.edu or 800-526-2839.

Late-Onset Alzheimer's Disease Family Study

Welcome and thank you for visiting the NCRAD catalog for the NIA-LOAD study! Please use this tool to help you determine feasibility of this collection for your request. Located on the left hand side of the screen, you will find expandable data mining tools for personalized sample selection. Use these tools to narrow our catalog to only those samples applicable for your research. This application is designed to help you find a list of subjects that can meet your research needs. Please do not hesitate to contact us at any point in the process to ask any questions, provide comments, or talk through your sample needs. You can reach us at: alzstudy@iu.edu or 800-526-2839.

Showing 1 to 25 of 7,126 entries

Subject ID	Family ID	Sex	Autopsy	Dementia Status	Age at Onset	NIAGADS Data
100001	1000	Female	Missing/Unknown	Probable AD	72	NG000020, NG000032
100101	1001	Female	Missing/Unknown	Probable AD	78	NG000020, NG000032
100102	1001	Male	Missing/Unknown	Probable AD	65	NG000020, NG000032
100103	1001	Female	Missing/Unknown	Not demented, no neurological disorder		NG000020, NG000032
100104	1001	Female	Missing/Unknown	Not demented, no neurological disorder		NG000020, NG000032
100201	1002	Female	Missing/Unknown	Probable AD	73	NG000020, NG000032
100301	1003	Male	Missing/Unknown	Probable AD	69	NG000020, NG000032
521641	1003	Female	Missing/Unknown	Probable AD	71	
100401	1004	Female	Missing/Unknown	Probable AD	63	NG000020, NG000032
521642	1004	Male	Missing/Unknown	Questionable dementia or cognitive impairment		
521643	1004	Female	Missing/Unknown	Dementia by family report	70	
521644	1004	Male	Missing/Unknown	Not demented, no neurological disorder		
100501	1005	Female	Missing/Unknown	Probable AD	76	NG000020, NG000032
521645	1005	Male	Missing/Unknown	Other		
100601	1006	Female	Missing/Unknown	Probable AD	81	NG000020, NG000032
100604	1006	Male	Missing/Unknown	Not demented, no neurological disorder		NG000020, NG000032
100605	1006	Female	Missing/Unknown	Possible AD	65	NG000020, NG000032

Samples with genetic data at NIAGADS are hyperlinked directly to the information page for the dataset.

Link at NACC to NCRAD

FTLD type, most recent FTLD module visit	<input type="radio"/>	<input type="radio"/>	
+ Genetics			
Available as:	ROW	COLUMN	PAGE
APOE genotype available at NACC	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
APOE genotype	<input type="radio"/>	<input type="radio"/>	
Number of APOE e4 alleles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Subject/family has known AD Mutation (APP, PS1, PS2)	<input type="radio"/>	<input type="radio"/>	
Subject/family has known FTLD mutation (MAPT, PGRN, C9ORF72, FUS)	<input type="radio"/>	<input type="radio"/>	
Genomic data/DNA samples available outside of NACC (ADGC, NIAGADS, NCRAD)	<input checked="" type="radio"/>	<input type="radio"/>	

NACC Query System: UDS Subjects

NOTE: This query used versions 1-3 of UDS data

**These data should be used only as rough, preliminary numbers.
For publication purposes, please submit a custom data request**

Genomic data/DNA samples available outside of NACC (ADGC, NIAGADS, NCRAD)

Genomic data/DNA samples available outside of NACC (ADGC, NIAGADS, NCRAD)	Frequency (n)
Genotype data available at ADGC	11057
Genotype data available at NIAGADS	3285
Exome sequencing data available from dbGaP / ADSP	1867
DNA sample available at NCRAD	22683
Total UDS subjects	35768

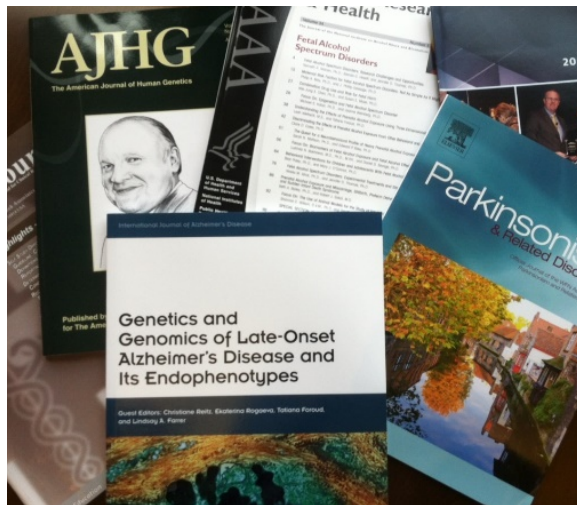
Data from [Additional genetic data](#)
Created on September 1, 2017
Data as of June 1, 2017
www.alz.washington.edu

Link at NIAGADS to NCRAD

[illegible]

Publications using NCRAD Samples

- 500 publications to date using NCRAD samples
- <https://ncrad.org/publications.html>



Publications

Samples and/or data from the National Cell Repository for Alzheimer's Disease (NCRAD), which receives government support under a cooperative agreement grant (U24 AG21886) awarded by the National Institute on Aging (NIA), were utilized by the following publications. We thank contributors who collected samples and data used in these studies, as well as patients and their families, whose help and participation made this work possible.

Please feel free to click through the publications below. We have made available all publications which have been released publicly. Those which are not downloadable will be made available as soon as possible.

Filter Publications

Sort Publications

Vardarajan, B. and K. Faber, Age-specific incidence rate for dementia and Alzheimer's disease in NIA-LOAD/NCRAD and EFGA families. 2014.

[Details](#) [Download](#)

Wang, L., et al., Rarity of the alzheimer disease-protective app a673t variant in the united states. JAMA Neurology, 2015. 72(2): p. 209-216.

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Wang, H.F., et al., Effect of EPHA1 genetic variation on cerebrospinal fluid and neuroimaging biomarkers in healthy, mild cognitive impairment and Alzheimer's disease cohorts. J Alzheimers Dis, 2015. 44(1): p. 115-23.

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Vardarajan, B.N., et al., Coding mutations in SORL1 and Alzheimer disease. Annals of Neurology, 2015. 77(2): p. 215-227.

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Sun, Y., et al., An Integrated Bioinformatics Approach for Identifying Genetic Markers that Predict Cerebrospinal Fluid Biomarker p-tau181/Abeta1-42 Ratio in APOE4-Negative Mild Cognitive Impairment Patients. J Alzheimers Dis, 2015. 26: p. 26.

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Shi, J., et al., Studying ventricular abnormalities in mild cognitive impairment with hyperbolic Ricci flow and tensor-based morphometry. Neuroimage, 2015. 104: p. 1-20.

[Details](#) [Download](#)

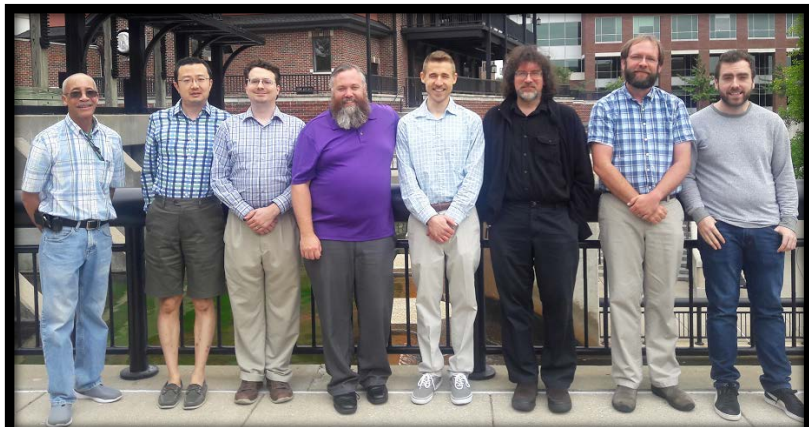
Nho, K., et al., Comprehensive Gene- and Pathway-Based Analysis of Depressive Symptoms in Older Adults. Journal of Alzheimer's Disease, 2015.

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Nho, K., et al., Protective variant for hippocampal atrophy identified by whole exome sequencing. Annals of Neurology, 2015. 77(3): p. 547-552.

[Details](#) [Download](#)

Our Team



Acknowledgement

- NIA
- Alzheimer Disease Centers
- NACC
- NIAGADS
- ADGC
- Studies contributing samples to NCRAD

Questions/Contact:
kelfaber@iu.edu or
alzstudy@iu.edu

- NCRAD Executive Committee
 - Deborah Blacker (Chair)
 - Steve DeKosky
 - Bernie Devlin
 - Alison Goate
 - David Holtzman
 - Bud Kukull
 - Richard Mayeux
 - Rosa Rademakers
 - Gerard Schellenberg
 - Julie Schneider

Funding: U24AG21886