The National Cell Repository for Alzheimer’s Disease

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The National Cell Repository for Alzheimer’s Disease

• Significant expansion in the past 5 years
  • Number of samples being banked
    • Particularly from the ADCs
  • Number of studies banking samples
    • 22 studies
• Types of samples banked
  • DNA, RNA, plasma, serum, CSF, LCL, PBMC
• Collaboration with large-scale studies
  • ADGC, ADSP, ADNI

www.NCRAD.org
The **National Cell Repository for Alzheimer’s Disease**

- Facilitate the receipt of samples from approved studies
  - Develop training materials for sites
  - Receive a variety of biospecimens
  - Generate regular reports for sites, study PIs and NIA summarizing sample collections
- Distribute samples to approved studies
  - Coordinate the request for samples
  - Assist researchers in the selection of samples for research studies
  - Distribute samples (and in some cases data) to approved researchers
New NCRAD Web-site

www.NCRAD.org
New NCRAD Web-site

- How to Request Samples
- How to Bank Samples/Sample Types Currently Banked
- Tools for Active Studies
- Helpful Resources for Families Participating in Research

www.NCRAD.org
ADC Web-based Tools

www.NCRAD.org
ADC Web-based Tools

ADGC Study Blood Sample Form

Please complete this form when sending blood to NCRAD. The form can be submitted electronically or it may be printed and faxed. If faxing the form, please do so as soon as possible after the blood is drawn. NCRAD would like to receive this form before the blood arrives.

**Instructions for Electronic Submittal**

1. Fill out the form completely.
2. Click the ‘Submit Form’ button at the bottom of the page
3. Print a paper copy of the form to include with the physical sample when shipped

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<table>
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<th>Subject Information</th>
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<table>
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<th>Sample Information</th>
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<td>Date Blood Drawn:</td>
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ADC Web-based Tools

Web-based kit request module for blood kits, DNA tubes, brain tissue tubes and buffy coat tubes. This can be found through the ADC section of the NCRAD web-site under each sample type or can be reached directly at kits.iu.edu/adc.
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.

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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

www.NCRAD.org
Accessing Catalogs

- DIAN
- GEMS
- GIFT

**Indianapolis-Ibadan**

Established in 1991 as a longitudinal, prospective, population-based, comparative epidemiological study of the prevalence, incidence rates, and risk factors for Alzheimer’s disease and other age-associated dementias.

**Study Subjects**

The project enrolled community-dwelling, elderly (age >65 years) African Americans living in Indianapolis and Yoruba living in Ibadan, Nigeria, employing the same research design, methods, and investigators.

**Available Data**

The funding for this study ended in 2012. During the course of the study, over 8000 (n=8528) elderly African American and Yoruba participants were evaluated over a 20 year period. A fixed minimal dataset is available through the NCRAD catalog. An additional dataset can be requested through the Indianapolis Ibadan Executive Committee.

**Available Biospecimens**

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

Price Structure  |  Catalog  |  Request Access to Biospecimens

- NCRAD Family
- NIA-LOAD

More detailed information can be found for each cohort listed in the table by clicking on the name in these boxes. More than one box can be opened at a time to allow comparison across studies.

Study specific price structures, catalogs and request forms are found in the detailed boxes.

www.NCRAD.org
Step-by-step instructions walk researchers through each feature.

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.

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

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

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.

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@iupui.edu or 800-526-2839.

Indianapolis Ibadan Epidemiological Study Catalog

Welcome and thank you for visiting the NCRAD catalog for the Indy-Ibadan 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 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@iupui.edu or 800-526-2839.

Showing 1 to 25 of 2,914 entries

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Show 25 entries
Services Offered for New Studies

- Kit Request Modules
- Sample Forms
- Manual of Procedures
- Video Tutorials
- Web-based Training Sessions
- FAQs

www.NCRAD.org
ADCs Role in Genetic Research

• NCRAD receives samples
• NACC maintains clinical data
• NIAGADS manages genetic data obtained from samples

• Together, these 3 groups support ongoing research studies
ADC Samples Received
> 27,000 samples received

This is total number of samples, not unique subjects
Acknowledgements

- NCRAD Staff
  - Kelley Faber
  - Ashley Vetor
  - Kelly Horner
  - Jan Hamer
  - Colleen Mitchell
  - Chris Hobbick

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

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

- ADSP Replication Working Group
  - Richard Mayeux
  - Sudha Seshadri