

**Rush
Alzheimer's
Disease
Center**





Infrastructure

- Location of offices/clinic/lab
 - All one campus, different buildings
- Clinical core visits
 - All in the community
- Unique Core – Religious Orders Study Core



ROS Core

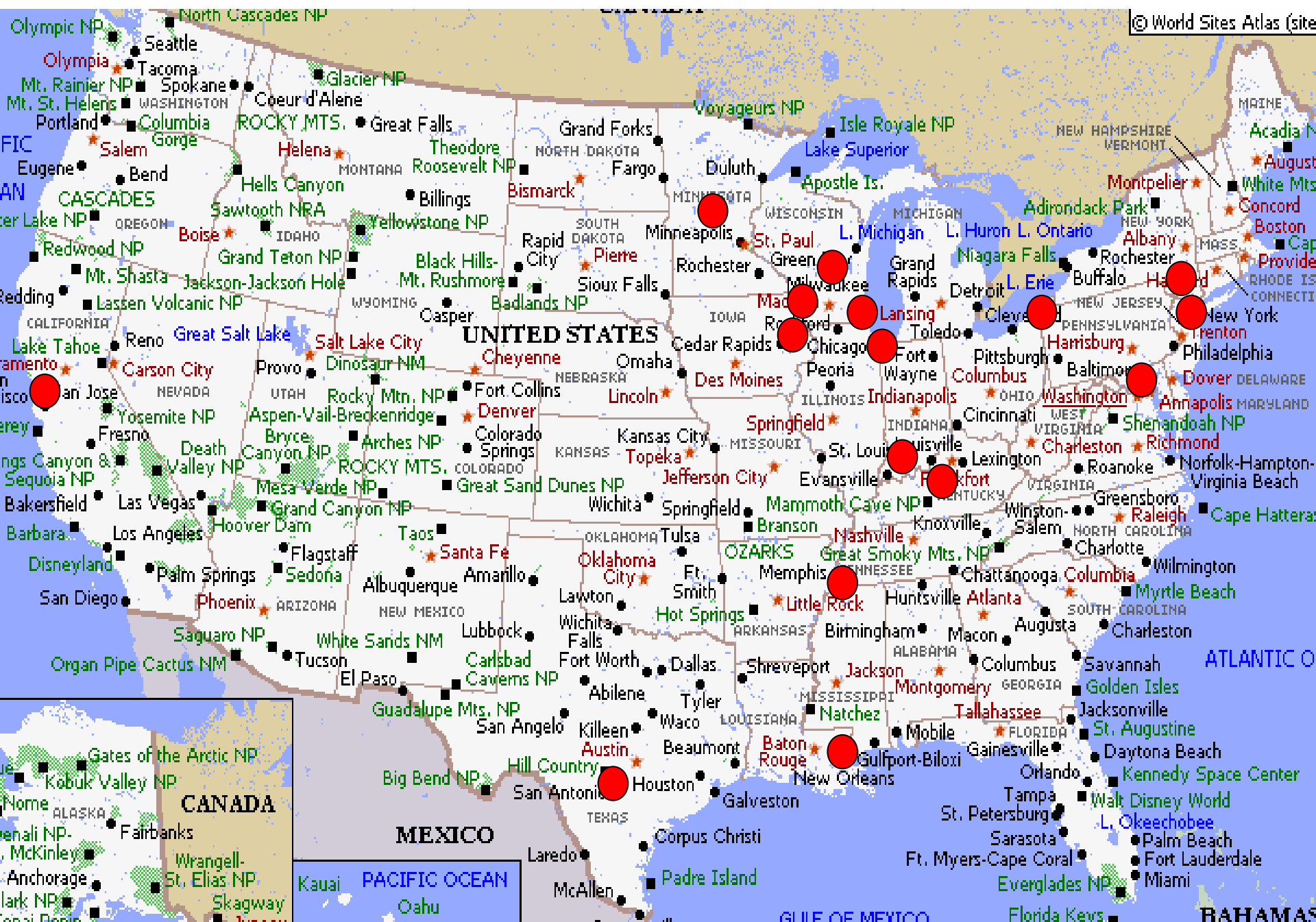
Religious Orders Study (ROS) Core

- One of only a few studies designed to study risk factors for incident AD that requires organ donation
- Focus on disease prevention and biologic pathways linking risk factors to clinical disease
- > 1,100 older nuns, priests, and brothers without known dementia from across the U.S.
- All agreed to annual cognitive and motor testing
- All agreed to brain donation at the time of death
- > 95% follow-up of survivors
- > 225 persons have developed incident AD
- > 90% autopsy rate with > 400 brain autopsies

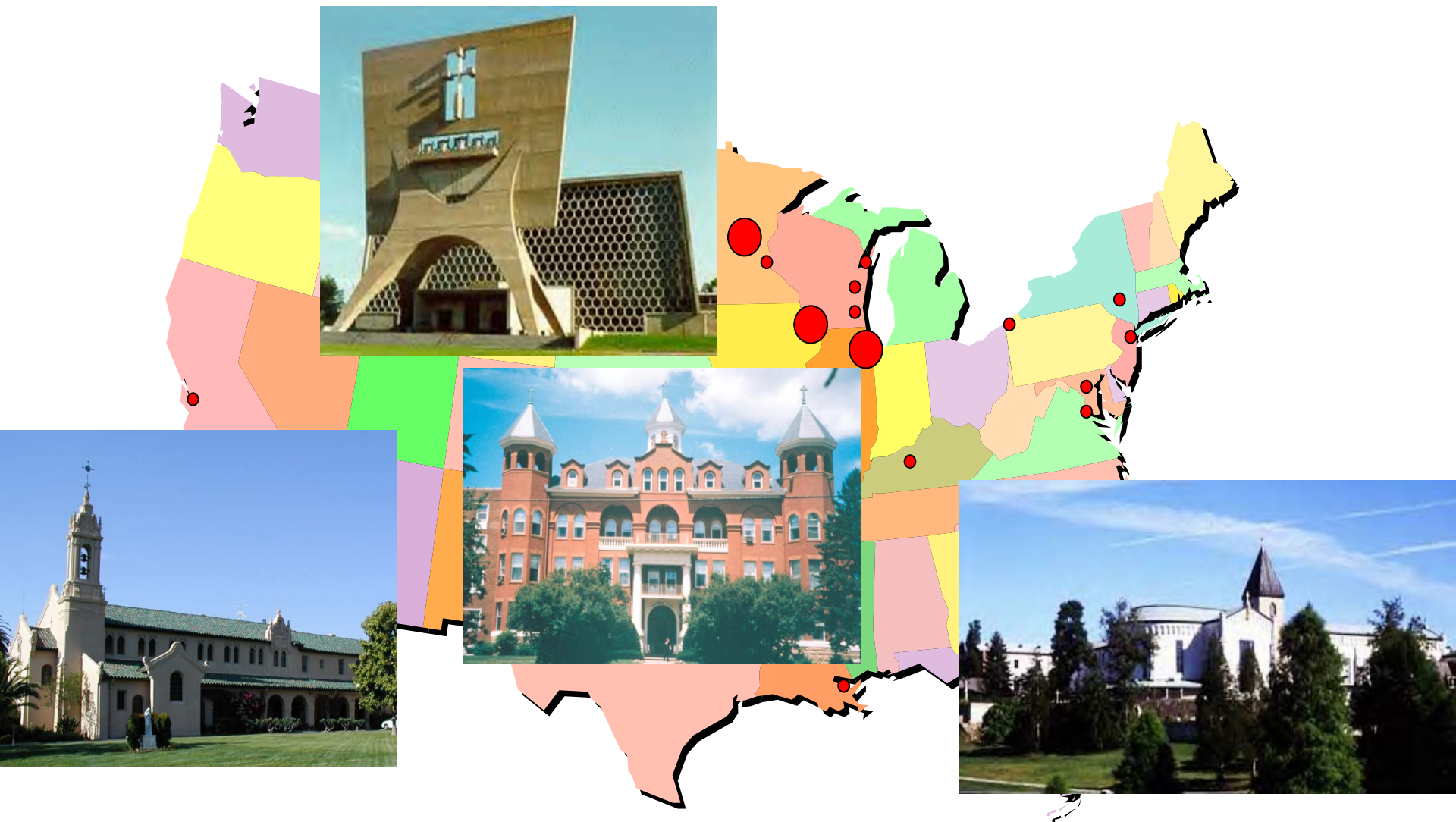
Local ROS Sites



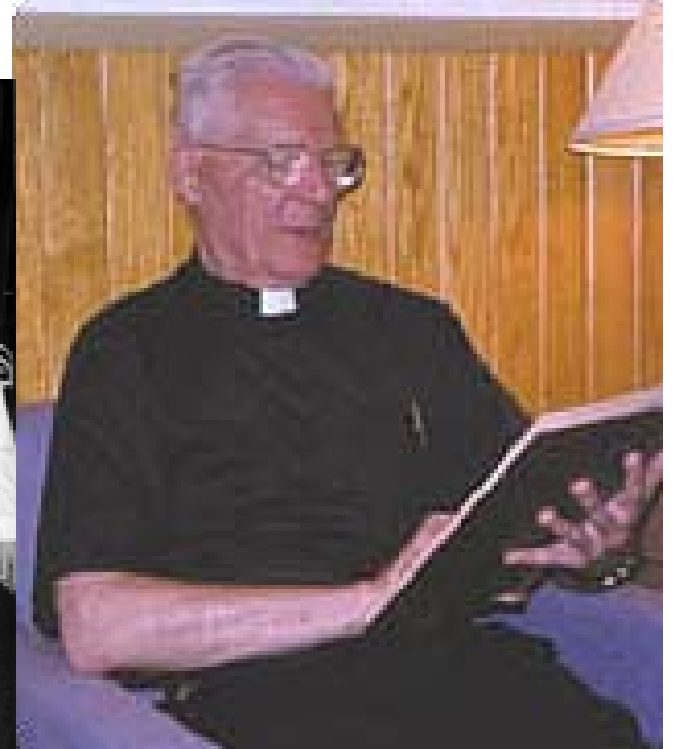
Religious Orders Study: Participating Sites



Religious Orders Study Sites







Specimen Distribution

- ROS is a longitudinal study of aging and AD with up to 15 waves of annual data
- ROS generates biospecimens from **comparable** persons with AD, MCI, and without cognitive impairment who underwent detailed evaluation
- The clinical data and specimens are in high demand
- Rush ADCC established an online request program
 - Used by internal and external requestors

Specimen Distribution

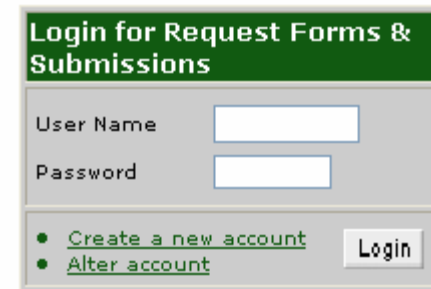
<http://www.crha.rush.edu/Tools/index.jsp>

Requests for Rush Alzheimer's Disease Center (RADC) Resources

The RADC has many resources available to investigators. These resources include 1) de-identified data, 2) personal identifiers for study recruitment, and 3) specimens. Please carefully review the Data and Resource Sharing Policy as well as the Data and Biologic Material Transfer Agreements.

You will need to create a User Name and Password to use the request system.

- Data and Resource Sharing Policy (READ THIS FIRST)
 - [Rush Alzheimer's Disease Core Center](#)
(Religious Orders Study and Clinical Core)
- [Data Transfer Agreement](#)
- Biologic Material Transfer Agreement
 - If your institution has entered into the Uniform Biologic Material Transfer Agreement (UBMTA) master agreement, please complete the following 2 forms:
 - [UBMTA Implementing Letter](#)
 - [Letter of Agreement](#)
 - If your institution has NOT entered into the UBMTA master agreement, please complete the following:
 - [Material Transfer Agreement](#)
- [Login](#)
- [Download SAS Statistical Macro Example \(requires login\)](#)



The screenshot shows a login interface with a green header titled "Login for Request Forms & Submissions". Below the header are two input fields: "User Name" and "Password". To the right of the "Password" field is a "Login" button. At the bottom left of the form, there are two links: "Create a new account" and "Alter account", each preceded by a green bullet point.

Main Menu

- [Submit a Request for De-identified Data](#)
- [Submit a Request for Personal Identifiers](#)
- [Submit a Specimen Request](#)
- Additional Documents
 - Data Dictionaries
- [Download SAS Statistical Macro Example](#)
- [Logout](#)

Specimen Distribution

[Main Requests Menu](#)

If you have any questions about any of the below items, please contact Annie Barz (anne_barz@rush.edu)

Submit a Request for Specimens

1. [Create a new request for biological specimen](#)

Submit an ongoing study or a grant proposal for consideration by the RADCC Tissue Committee

2. [View previously saved requests that have not been submitted](#) (0)

- [Modify requests](#)
- [Submit a saved request to RADCC Tissue Committee for review](#)

3. [View locked requests under review](#) (0)

- [Review submitted requests](#)

4. [Resubmit request after response from committee](#) (0)

5. [Submit an addendum to an approved request](#) (1)

- [Add an addendum to an approved request](#)
- [Use this form to request additions to your previously approved request](#)

6. Additional materials and documentation

- [Biologic Material Transfer Agreement](#)

Tissue will not be distributed without a signed Rush ADCC Biologic Material Transfer Agreement. The agreement was developed by the Rush ADCC in consultation with the External Advisory Committee, NIA staff, and the Rush Office of Legal Affairs. Some investigators have data collection in multiple laboratories for the same study; under these circumstances the BMTA must be signed by the co-investigator from each laboratory. **Tissue will be distributed from the RADCC only; tissue cannot be distributed to a third party.** Please indicate the additional investigator(s) who will need to sign the agreement by checking the "BMTA required?" box by each name in the request form.

7. [Logout](#)

Specimen Distribution

Step 1 - Principal Investigator or Project Leader:

Step 2 - Co-Investigators:

Step 3 - Study Information:

Step 4 - Requested Specimens:

Step 5 - Procedures - Experimental Plan:

Step 6 - Other Information:

Specimen Distribution

- Data and/or specimens have been distributed to numerous ADCs as well as other facilities in the US, Canada, and Europe including:
 - Arizona Alzheimer's Center
 - Boston University
 - Columbia University
 - Emory University
 - Florida Alzheimer's Center
 - Harvard University
 - Indiana University School of Medicine
 - Johns Hopkins University School of Medicine
 - Mayo Clinic
 - Northwestern University
 - Oregon Health Sciences University
 - University of California, Davis
 - University of California, Irvine
 - University of California, San Diego
 - University of Kentucky
 - University of Michigan
 - University of Pennsylvania
 - University of Pittsburgh
 - University of Washington

Collaboration

- Both Rush and Northwestern have ADCs located in the city of Chicago
 - About 15 minutes drive apart
- Collaboration
 - Path projects
 - NACC collaborative project
 - Collaborative P01s and R01s
 - Provide specimens
 - Education projects
 - Southside Dementia Consortium (SSDC)
 - Caregiver advisory Board (CAB)
 - The task force on AD for the city of Chicago (AD Task force)