



United Way
of Greater St. Louis

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www.alzstl.org

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Cape Girardeau, MO 63701

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Dear supporter,

Thank you for your interest in joining the St. Louis Alzheimer's Association Research Registry.

This registry represents an important expansion of the St. Louis Chapter's commitment to research. Our mission is three-fold: to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

The goal of the registry is to link people interested in research to available studies and expedite the research process. Our goal is to include as many persons with a diagnosis of dementia or Alzheimer's as possible as well as their care partners and families.

The individuals in the registry have agreed to have their personal and basic health history shared with researchers conducting Alzheimer-related studies. The researchers have met strict guidelines for assuring confidentiality of this information and are conducting studies that have been independently approved by both their organization's institutional review board and the Alzheimer's Association quality assurance process.

We understand the enclosed application is lengthy and hope you will appreciate the safeguards that were intentionally implemented to assure the best support, protection and privacy for our loved ones with memory impairment and their families. Thank you for your investment of time to complete this application and to be a part of this movement to eliminate Alzheimer's disease.

What each of us does today to support research will make a difference to generations in the future.

My sincere thanks,

Joan D'Ambrose
President

the compassion to care, the leadership to conquer

St. Louis Alzheimer's Association Research Registry Application & consent form

Thank you for applying to join the St. Louis Alzheimer's Association Research Registry, sponsored by the Alzheimer's Association, St. Louis Chapter. Please take the time to review this application carefully. You may wish to talk to others, including the persons listed in this application, about your participation. If you have questions about the Registry, please contact the Alzheimer's Association, St. Louis Chapter at (314) 432-3422.

Information provided in this application will be used only for the purposes of Alzheimer research studies under the practices of the St. Louis Alzheimer's Association Research Registry. The information will be shared only with approved researchers, but not accessible to members of your family, yourself, your health care provider or representatives of the Alzheimer's Association.

The researchers and studies using the Registry have met strict guidelines for assuring confidentiality of registrants' information and are conducting studies that have been independently approved by both their institution's review board and the Alzheimer's Association quality assurance process.

Please sign and date that the Alzheimer's Association, St. Louis Chapter, has permission to collect, store and share the information provided in this application with Alzheimer researchers. A copy of this authorization (consent) form will be provided to you.

Person completing this form (Print)

Relationship to Research Registry applicant

Signature of person completing this form

Date

Research Registry Applicant (to be completed for the person who is applying to be in the registry; most often the person directly affected by Alzheimer's or dementia)

Last Name: _____ First Name: _____

Address: _____ City: _____ State: _____ Zip: _____

Home Phone: () _____ Other Phone: () _____

Email Address: _____

Study Partner (to be completed by the person who will accompany the applicant in research studies)

Last Name: _____ First Name: _____

Address: _____ City: _____ State: _____ Zip: _____

Home Phone: () _____ Other Phone: () _____

Email Address: _____

Relationship to Registry applicant: _____

Is study partner interested in additional caregiver research? Yes No *If yes, please complete another application*

Has study partner been granted legal authority to make decisions on behalf of the applicant? Yes No

If yes, please list how & skip to contact preferences _____

Legal representative (to be completed by a person holding legal power of attorney, the applicant's legal representative or surrogate. If authorized legal representative is the same as study partner, please note above & skip to contact preferences section.)

Last Name: _____ First Name: _____

Address: _____ City: _____ State: _____ Zip: _____

Home Phone: () _____ Other Phone: () _____

Email Address: _____

Relationship to Registry applicant: _____

Have you been granted legal authority to make decisions on behalf of the applicant? Yes No

If yes, please list how _____

Memory Evaluation History

Has the applicant ever been told he/she had dementia or Alzheimer's? Yes No

If yes, list the year of diagnosis: _ _ _ _

choose the diagnosis: Alzheimer's disease Parkinson's dementia
 Vascular dementia Dementia with Lewy Bodies
 Unknown Other dementia: _____

Is the applicant currently under a physician's care for dementia or Alzheimer's? Yes No

Does the applicant have immediate family (parent/sibling/child) with a diagnosis of Alzheimer's or dementia?

Yes No

In order for an applicant to participate in the registry, researchers need to have information about the applicant's basic health history. Please initial that the Alzheimer's Association, St. Louis Chapter, has permission to ask questions about the applicant's current state of health.

initial

State of Health (Please check all conditions that applicant has experienced within the last 5 years)

- | | |
|--|---|
| <input type="checkbox"/> Heart Attack | <input type="checkbox"/> Anemia |
| <input type="checkbox"/> Angioplasty/stent | <input type="checkbox"/> Other blood illnesses: specify _____ |
| <input type="checkbox"/> Cardiac Bypass procedure | |
| <input type="checkbox"/> Pacemaker | <input type="checkbox"/> Vision problem |
| <input type="checkbox"/> Other heart conditions: specify _____ | <input type="checkbox"/> Hearing problem |
| | <input type="checkbox"/> Speech problem |
| <input type="checkbox"/> High Blood Pressure | <input type="checkbox"/> Swallowing problem |
| <input type="checkbox"/> High Cholesterol | <input type="checkbox"/> Stroke |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Parkinson's disease |
| <input type="checkbox"/> Liver Disease | <input type="checkbox"/> Seizures/epilepsy |
| <input type="checkbox"/> Kidney Disease | <input type="checkbox"/> Cancer |
| <input type="checkbox"/> Significant gastrointestinal disease | <input type="checkbox"/> Depression |
| <input type="checkbox"/> Thyroid Condition | <input type="checkbox"/> Other psychiatric diagnosis: specify |

Does applicant have any allergies to medications? Yes No If so, list: _____

Is applicant taking prescription medications? Yes No

If applicant taking any over-the-counter medications or nutritional supplements? Yes No

Is the applicant currently enrolled in a medication study? Yes No

If so, when is it scheduled to end? _____

Research Interests

How often is the applicant able/willing to come in to a research setting for study visits? (check all that apply)

1 time only Weekly Monthly Every 6 months Annually Every 2 years

How often is the applicant able/willing to participate in a phone study or home visit study?

1 time only Weekly Monthly Every 6 months Annually Every 2 years

Is the study partner available to accompany applicant to all study visits? Yes / No

Check the types of studies the applicant is interested in: (check all that apply)

- Treatment studies (clinical trials of possible treatments for AD)
- Prevention studies of promising investigational medications or other
- Other interventions (e.g. dietary changes or supplements, or stress management, or peer support, or an exercise routine)
- Biomarker studies (studies that include taking blood or cerebral spinal fluid for diagnosis of Alzheimer's)
- Brain imaging research (studies that include MRI or brain scans)
- Caregiver studies

Referral Source

How did you hear about the St. Louis Alzheimer's Association Research Registry? (Check all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Alzheimer's Association staff / volunteer | <input type="checkbox"/> Mailed invitation |
| <input type="checkbox"/> Seminar / lecture | <input type="checkbox"/> Health professional |
| <input type="checkbox"/> News story | <input type="checkbox"/> Brochure |
| <input type="checkbox"/> Advertisement | <input type="checkbox"/> Other: _____ |

I have thoroughly completed the attached St. Louis Alzheimer's Association Research Registry application to the best of my knowledge. I authorize the Alzheimer's Association, St. Louis Chapter to store the attached information in a secured, confidential database to be viewed only by approved researchers conducting qualified studies.

I have discussed the application with the persons listed as contacts.

I understand that I will be contacted periodically by the Alzheimer's Association, St. Louis Chapter, about the Research Registry. I also understand that my participation in the St. Louis Alzheimer's Association Research Registry is 100% voluntary and that I can withdraw my application at any time with no concern about future service from the Alzheimer's Association. There is no fee to participate in the Registry.

I understand that this consent does not take the place of any consent that needs to be given to participate in actual research studies. I understand that it is possible to be contacted by more than one Alzheimer study or not contacted at all.

Applicant's name (Print)

Date

Signature of applicant

The above-named individual may be unable to provide direct authorization for the use and disclosure of information provided for this Registry because _____. Therefore, by signing this form, I give permission for the use and disclosure of his/her medical record information for the purpose of this research study.

Representative's name (Print)

Representative's relationship to applicant

Signature of representative

Date