UC San Diego Shiley-Marcos Alzheimer’s Disease Research Center

Brain Donation Program

Thank you for your participation in our program. Strides in research can only be made through the generosity of others. It is through these gifts that we can help promote research and fuel determination to find answers and a cure. We are grateful to you for your generous volunteerism; we cannot make progress without you! The following resource has been created as a guide for individuals participating in our brain donation program and includes:

1. Frequently asked questions
2. The specific steps involved in the brain autopsy process with our Shiley-Marcos ADRC
3. A copy of the “green card” that is provided to all participants who are consented to brain autopsy
4. A list of local post-autopsy resources for proactive planning
5. A post-autopsy planning and communication form

What is the purpose of the Brain Donation Program?

Although researchers have made significant progress in developing accurate tests to detect Alzheimer’s Disease and related dementias (ADRD) in living patients, the disease can still only be conclusively diagnosed by examining the brain after death in an autopsy to verify that the characteristic pathologies that define these diseases are present. Autopsy provides valuable information that can educate and enlighten families, physicians, and researchers, who are working to discover more reliable tests for AD. Information gained from autopsies is a vital part of the research conducted at the Alzheimer’s Disease Centers (ADCs) supported by the National Institute on Aging (NIA). The post-mortem data from the autopsy is corroborated with the clinical data collected from research participation during life to better understand the detection, diagnosis and treatment of neurodegenerative diseases.

Why is donating brain tissue important?

Brain donation offers benefits to families, researchers and the medical community, as well as society. Alzheimer’s disease progresses differently in each person, so it is important to receive brain tissue from diverse communities representing varied ethnicities. Participation for brain autopsy is lower among African Americans and Latinos, as they are still underrepresented in research. Receiving brain tissue from underserved populations will help researchers identify unique factors that are associated with Alzheimer’s and related dementias.

To Families: Because autopsy is still the gold standard for diagnosis, it can provide family members and loved ones with a sense of closure to facilitate the grieving process. Participation in brain autopsy can help family members attach meaning and purpose to their loved one’s experience by giving a gift of hope for future generations by helping to advance medical knowledge.

To Researchers and the Medical Community—Autopsy provides an important quality control tool by confirming the diagnosis. Autopsy results can help researchers develop and test better, more accurate diagnostic tools. Autopsies of non-demented persons and those in the early stages of AD can help scientists pinpoint the earliest signs of age-
related brain changes and how they differ from brain changes in early AD. This research will help inform new interventions and treatments and can give important information about where and how these diseases start and spread in the brain.

To Society—Autopsies provide more accurate disease rates of dementia, including vital statistics for state and national registries. Accurate diagnostic data from autopsy can provide information to those who advocate for laws and funding in support of AD patients and their families. As a result, society as a whole may benefit by additional services designed to ease the burden caused by AD and related dementias.

Who can participate in the program?

Our research center generally accepts brain donations only from individuals who are enrolled in our observational longitudinal research study. This is because the many years of clinical data gathered during those visits is corroborated with the pathology data to learn more about better detection, diagnosis, and treatment of neurodegenerative diseases. Our Shiley-Marcos ADRC is part of a large national study funded by the National Institute on Aging. In order for the brain donation to be most valuable to researchers, it is important that we have clinical data (ideally longitudinal in nature) on all individuals who make a brain donation. For certain diagnostic categories of patients, who may be of special interest to our scientists, we may be able to perform an autopsy to study the brain even if the individual was not enrolled in our observational longitudinal study. Less common neurodegenerative disorders, such as Multi-System Atrophy, young onset Alzheimer’s Disease and Fronto-Temporal Degeneration, and others are examples of this. This can only occur after the decision to do so is reviewed and pre-approved by our research leadership. In these instances, it is absolutely critical that we gather all the appropriate consents and documents to allow for access to clinical data and records that can be used in conjunction with the pathology data. We are unable to accept brain donations for persons that do not participate in our clinical research program or receive pre-approval and sign form that give us access to the relevant clinical information.

How can I become a participant in the program?

Participation in the Alzheimer’s Disease Center’s longitudinal research program entails an annual diagnostic evaluation, cognitive assessment, brain imaging, and other biomarker assessment during life. The collection of this data combined with the brain donation enables researchers to learn more about the progression of the disease and develop new prevention and treatment therapies. Participants with and without a diagnosis of dementia are eligible for participation in our program. We enroll seniors with normal cognition, individuals with a diagnosis of Mild Cognitive Impairment (MCI) and persons with dementia due to a wide array of neurodegenerative diseases, including Alzheimer’s Disease, Fronto-Temporal Dementia, Dementia with Lewy Bodies, Parkinson’s disease dementia, Multiple Systems Atrophy, Primary Progressive Aphasia, Progressive Supranuclear Palsy and Corticobasal Syndrome.

Please contact the Shiley-Marcos Alzheimer’s Disease Research Center at 858-822-4800 or email us at participate@ucsd.edu to determine your eligibility and learn more about participation.
Are there any costs associated with the program?

There is no cost to research participants in our program for the autopsy. Through research grants, the UC San Diego Shiley-Marcos Alzheimer’s Disease Research Center covers the expense of transportation to the autopsy facility and the cost of the tissue removal and analysis. The participant and their family is responsible for making their own post-mortem arrangements once the tissue removal is complete and will cover the costs associated with transportation and services from the autopsy facility forward.

Who can give consent for brain donation?

The participant can provide consent to donate their brain for research. If the participant is unable to do so themselves, consent can be given by the next of kin.

Will being registered as an organ donor affect brain donation arrangements?

The decision to be register as an organ donor is important to many people. Unfortunately, even though millions of people have registered to become organ donors, very few of us die in a way that lets us share the gift of life. The specific circumstances in which organ donation is viable, are somewhat nuanced and not regularly occurring. However, if the participant is a registered organ donor and they are in a hospital setting where organ donation is possible at time of death, the organ donation process will happen prior to the body being released to our contracted medical transport team for autopsy and brain donation. If you would like to learn more about how to become a registered organ donor and what that process looks like, please visit this website: https://www.organdonor.gov/about/process/deceased-donation.html

Will brain donation affect funeral arrangements?

The procedure does not cause a delay in funeral plans and it does not interfere with traditional or religious arrangements such as an open casket funeral. The brain autopsy is performed carefully through an incision in the back of the head and will not leave any visible, physical alterations on the face. The family is responsible for making all their own post-autopsy arrangements with the entity of their choosing. We do not endorse or recommend any specific service provider but have created a resource list of providers in San Diego (in alphabetical order) to help with the planning process.

Will brain donation affect body donation arrangements?

The decision to donate your brain for autopsy at the Shiley-Marcos ADRC does not impact your decision to donate your body to the UCSD body donation program. Many of our research participants have successfully donated their brain to the Shiley-Marcos ADRC and then the body is subsequently donated to the UCSD Body Donation Program instead of being taken to a funeral home or mortuary. Although we are both under the UCSD umbrella, we are distinctly separate entities, and each have our own unique policies and procedures. It is critical that as you are making post-autopsy arrangements, you plan ahead and reach out to the body donation program in advance. They require a registration process with the donor/designated individual before they will accept a body donation.
will need to provide you with instructions about their policies and procedures; they have their own driver who will pick up the body from the ADRC brain donation facility and take it to the body donation center. The number for UCSD Body donation is: 858-534-4536 (option 1 to report the death). 
https://medschool.ucsd.edu/education/body-donation/Pages/default.aspx

Will my decision to donate be compatible with my religion?

While many religious beliefs may influence attitudes toward brain donation, most religions allow and support brain tissue donation. It is also important to discuss the decision with your family. We encourage individuals to consult with their spiritual advisor if they need additional guidance in their decision to donate or have any questions.

Who should I inform about my decision to donate?

It is important to inform your family of your decision to participate in the brain donation program and plans for your end-of-life decision. Discussion with your loved ones about your decision is an important part of the process because it ensures that they can fulfill and honor your final wishes in a timely manner. In order to ensure the greatest research and diagnostic value for the brain tissue, it is essential that it is removed as quickly after death as possible. Therefore, we recommend that all persons involved with the care of the donor be made aware of the planned autopsy; these individuals need to know who to contact at the time of death to be sure the appropriate steps are taken in the critical timeframe. All research participants in our program must have a study partner and designated individual who will be involved in the end of life process.

Who should you contact at the time of death?

The family, hospice nurse, or care facility should be aware of the procedures outlined on the “green card” and know to contact the UC San Diego Shiley-Marcos ADRC at the time of death. Please contact the UCSD operator autopsy paging service at 619-543-6737*. Tell the operator that you are calling with the Shiley-Marcos ADRC Longitudinal Study and Dr. Rissman is the doctor on call. The family will be responsible for also contacting the post-autopsy service providers (mortuary, crematory, body donation, etc.). We highly recommend that all post-autopsy plans are made in advance and that these service providers are made aware of your brain donation plans prior to the time of death. This will minimize stress placed on your loved ones at the time of death. The family/donor’s designees are responsible for contacting all other post-autopsy providers.

*The Green Card indicates that you should call the ADRC main number during regular business hours and the autopsy paging service after hours. Due to COVID, this has changed and all calls should go to 619-543-6737 at all times to streamline the process.

What information will need to be provided at the time of death?

When our team receives a call regarding the death of a participant, we will need to gather some critical information to ensure that the process is efficiently conducted. Callers should be prepared to provide the donor’s first and last name, place and address of death for body pick up, as well as the time and cause of death. In addition, they will be asked to provide the caller’s name and relationship to the deceased, as well as the caller’s contact phone number.
and email address. Finally, it is critical that we also receive the following information in a timely manner: the name of the post-autopsy body recipient, their phone number, address, and email address.

**What happens to the brain once it has been donated?**

The brain is first extracted by a university contracted diener. At the time of removal, half the tissue is “frozen”, and the other half is “fixed” in formalin, which stiffens the tissue to make it possible to handle and analyze. The tissue is then transported to the Shiley-Marcos Alzheimer’s Disease Research Center Neuropathology Core on campus. At this point, the frozen tissue will be stored in our brain bank for future analysis and sharing. The fixed tissue will be examined by a neuropathologist to establish a definitive diagnosis and to make specific research analyses and counts that are recorded in our database. This process is quite complex and can take several months to complete. Once completed, a comprehensive report is sent to the participant’s family/designated next of kin. After the examination, portions of the brain will be stored for future investigations by researchers at the UC San Diego, Shiley-Marcos Alzheimer’s Disease Research Centers as well as researchers throughout the country. The identity of all brain donors remains strictly confidential.

**Who receives the autopsy results?**

At the time of autopsy consent, the participant will designate a next-of-kin or legal representative who will be responsible for helping with the arrangements for autopsy. That designated individual will be the one who will receive a written feedback letter with information regarding the autopsy-confirmed diagnosis. This typically takes approximately 6 months after the time of death.

**Why plan ahead?**

Planning for an autopsy should be done well ahead of time, because of the steps involved and the importance of informing all relevant individuals of the plans and process ahead of time. During the course of your participation in our study, we will check to be sure our records match your plans for post-autopsy arrangements, and we request that you keep us informed as you make decisions and alterations to your plans.

**Can the plans be cancelled?**

Plans to donate one’s brain for autopsy may be cancelled at any time by notifying the Shiley-Marcos Alzheimer’s Disease Research Center Autopsy Coordinator at 858-822-4800. Research participants always have the option of withdrawing their consent for any research related procedure or study participation.
How is the brain donation process performed?

- **Step 1:** Participants are enrolled in the longitudinal study and the brain donation program or are pre-approved by SMADRC leadership.

- **Step 2:** Participants and/or a family member will sign consent forms for participation in the study and the brain autopsy as well as HIPAA forms and Authorization Forms to Access Medical Records at the year 1 visit. At this time, participants will designate a “next of kin” who will be recorded as the individual responsible for carrying out the autopsy wishes and who will receive a copy of the pathology report. Participants and next of kin will also receive copies of the Shiley-Marcos ADRC “green card” that can be kept in an easy to access place and shared with families to ensure autopsy wishes are honored and carried out by appropriately.

- **Step 3:** At the time of the donor’s death (within 8 hours of death), a family member, hospice provider or long term care representative should call 619-543-6737 (after hours, weekends, holidays) to report the death. Tell the operator you are calling from the SMADRC Longitudinal Study and Dr. Rissman is the doctor on call. The number is staffed seven days a week, 24 hours a day.

- **Step 4:** The caller should be prepared to provide important information, including:
  - Deceased individual’s full name
  - Time and cause of death
  - Place and address where body should be picked up
  - Full name of caller and relationship to deceased
  - Phone number and email address of caller for additional contact
  - Name of facility, phone number, and address where body should be taken after the autopsy is complete

*At this time, the participant’s representative should also call the post-autopsy entity (where the body will be taken once the autopsy is complete) to give them notice of the person’s passing, remind them about the brain autopsy interim step, and notify them that the diener will contact them as soon as the body is ready for pick up (same day).*

- **Step 5:** An ADRC contracted driver (Mike Looney at 92MIKE) will be dispatched to pick up the body and transport it to the university-contracted facility, called Autopsy Pathology Services at 1591 N. Cuyamaca Street, El Cajon, CA 92020, where the brain will be removed and processed. The Shiley-Marcos ADRC will cover the cost of this transport and the cost of the tissue removal.

- **Step 6:** After the tissue collection has taken place, the ADRC diener will contact the pre-specified post-autopsy entity directly to notify them that the body is ready for pick up by their transportation service.

- **Step 7:** The body is picked up by the post-autopsy entity selected by the family responsible for handling post-mortem arrangements. The cost of that transport will be covered by the family, as it would have been, had the body not been taken to the brain autopsy facility first.

- **Step 8:** The brain tissue will be transported to UCSD Neuropathology Core Facility.

- **Step 9:** The brain tissue along with other medical data and measurements will be used in determining the final diagnosis.
• **Step 10:** The donor’s designated next of kin will receive a pathology report and letter from the Neuropathologist explaining the diagnosis. *This may take up to 6 months from the time of death.* The SMADRC will need to verify that the name and address of the recipient has been specified.

This is a copy of the SMADRC issued “Green Card” given to family and next of kin at time of autopsy consent.

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**What if I move out of the area?**

Participants that move out of the area will need to make individual arrangements with qualified professionals. The participant is responsible for finding a facility in their new area of residence that can remove the brain tissue and ship it to the UC San Diego Shiley-Marcos Alzheimer’s Disease Research Center. The Shiley-Marcos ADRC will cover the cost of the autopsy and provide feedback to the participant but will not be able to cover the cost of tissue removal or shipping. Participants interested in working through the steps to make these arrangements will need to be able to supply the facility that will remove the tissue with the following information (we will supply at the time the facility is identified and the arrangements are communicated to our team):

   a) A copy of the consent
   b) The tissue donation protocol.
   c) The fixation and storage protocol.
   d) Shipment instructions/shipping safety instructions.
San Diego County Post-Mortem Planning

Reduce anxiety about post-mortem arrangements, including cremation, funeral, and burial services. Advanced planning for the funeral and burial can provide a sense of peace and reduce anxiety for both the person with Alzheimer's and the family. Making these arrangements and communicating them to our center, prior to the time of death, will facilitate a much more efficient process and minimize stress and burden to grieving family members at the time of death.

Research participants at the Shiley-Marcos Alzheimer’s Disease Research Center that agree to brain autopsy are asked to make their own preferred post-mortem arrangements. The following list has been compiled from the internet to serve as a resource to families. The UC San Diego Shiley-Marcos Alzheimer’s Disease Research Center DOES NOT have any official partnership or formal relationship with any of the local organizations listed below, nor do we specifically recommend any of these organizations. They have been organized in alphabetical order. We hope this list may be helpful during the planning process. If you have questions or need assistance, you can contact our social worker, Tracey Truscott, LCSW ttruscott@ucsd.edu or 858-822-4800.


Body Donation

The UC San Diego Body Donation Program:
https://medschool.ucsd.edu/education/body-donation/Pages/default.aspx
858-534-4536 option 1 to report the death

The UCSD Body Donation Program is separate from the UCSD Shiley-Marcos Alzheimer’s Disease Research Center. Individuals interested in body donation in lieu of other post-autopsy arrangements should contact the Body Donation Program directly in advance and “register” in order to have the body donation accepted. All arrangements with the Body Donation Program are managed with the Body Donation Program staff directly, just as they would with other service providers. They have their own body transport arrangements and will pick the body up from the brain donation center and deliver it to the body donation center.
Mortuary Options

Am Israel Mortuary
6316 El Cajon Blvd, San Diego, CA 92115
(619) 583-8850
https://www.amisraelmortuary.com/

Anderson-Ragsdale Mortuary
5050 Federal Blvd, San Diego, CA 92102
(619) 263-3141
https://www.andersonragsdalemortuary.com/listings

Aztlan Mortuary
7865 La Mesa Blvd, La Mesa, CA 91942
(619) 337-8100
http://aztlanmortuary.com/

Beardsley-Mitchell Funeral Home
1818 Sunset Cliffs Blvd, San Diego, CA 92107
(619) 223-100

Bishop Mortuary
3444 Citrus St, Lemon Grove, CA 91945
(619) 466-4462
https://www.bishopmortuaryinc.com/

Clairemont Mortuary
4266 Mt Abernathy Ave San Diego, CA 92117
(858) 609-8713
https://www.clairemontmortuary.com/
Mortuary Options Continued

Cypress View Mausoleum, Mortuary, and Crematory
3953 Imperial Ave San Diego, CA 92113
(619) 264-3168
https://www.dignymemorial.com

East County Mortuary & Cremation
372 N Magnolia Ave, El Cajon, CA 92020
(619) 440-9900
https://www.eastcountymortuary.com/

El Camino Memorial – Sorrento Valley
5600 Carroll Canyon Rd, San Diego, CA 92121
(858) 453-2121

 Feathering Mortuary
6322 El Cajon Blvd, San Diego, CA 92115
(619) 583-9511
http://www.featheringillmortuary.com/

Funerals Your Way
4858 Mercury St #102, San Diego, CA 92111
(619) 550-7807
https://funeralsyourway.com/

Goodbody Mortuary
5027 El Cajon Blvd, San Diego, CA 92115
(619) 582-1700
Mortuary Options Continued

Greenwood Memorial Park and Mortuary
4300 Imperial Ave, San Diego, CA 92113
(619) 450-1479
https://www.greenwoodmemorial.com/

Merkley-Mitchell Mortuary
3655 Fifth Ave, San Diego, CA 92103
(619) 295-2177

San Diego Funeral Service
6334 University Ave, San Diego, CA 92115
(619) 786-6715
http://sandiegoaffordablefunerals.com/

Trinity Funeral Services
333 H St #5000, Chula Vista, CA 91910
(619) 308-6571
3914 Murphy Canyon Rd #A238, San Diego, CA 92123
(619) 344-0875
http://trinityfuneralservices.com/

Cremation Options

Accu-care Cremation & Funerals
7709 Convoy Ct Unit E
San Diego, CA 92111
(844) 550-7897
https://www.accucarecremation.com/san-diego/
Cremation Options Continued

Alhiser-Comer Mortuary
225 South Broadway Escondido, CA 92025
(760) 745-2162
https://www.alhiser-comer.com/

American Cremation Services
6136 Mission Gorge Rd, San Diego, CA 92120
(619) 283-5842
http://amcremation.com/

Balboa Cremation Services
4658 30th St, San Diego, CA 92116
(619) 563-8810
https://www.cremationservicessandiegoca.com/

Bayview Crematory & Burial Services
7510 Clairemont Mesa Blvd Ste 109, San Diego, CA 92111
(800) 516-4404
http://www.bvcrematory.com/

Best Cremation Care
3525 del Mar Heights Rd Unit 1011 San Diego, CA 92130
(619) 365-9343
https://www.bestcremation.com/san-diego-cremation/

California Cremation & Burial
5880 El Cajon Blvd, San Diego, CA 92115
(619) 234-3272
http://www.californiacremation.com/

Care center Cremation & Burial Services
7403 Princess View Dr E, San Diego, CA 92120
(619) 677-2599
https://www.carefuneralhomesandiego.com/
Cremation Options Continued

Clairemont Mortuary
4266 Mt Abernathy Ave San Diego, CA 92117
(858) 609-8713
https://www.clairemontmortuary.com/

Cypress View Mausoleum, Mortuary, and Crematory
3953 Imperial Ave San Diego, CA 92113
(619) 264-3168
https://www.dignymemorial.com

Legacy Funeral & Cremation Care
7043 University Ave, La Mesa, CA 91942
(619) 202-2099
https://www.legacyfuneralcare.com/

National Cremation Services
4300 Imperial Ave, San Diego, CA 92113
(858) 573-6806
https://www.nationalcremation.com/

Preferred Cremation & Burial
6406 University Ave, San Diego, CA 92115
(619) 584-7000
http://www.preferredcremation.org/

San Diego Cremation Service
3318, 1761 Hotel Cir S #122, San Diego, CA 92108
(619) 299-8839
https://www.sandiegocremationservice.com/
Cremation Options Continued

Telophase Cremation Society
7851 Mission Center Ct #104, San Diego, CA 92108
(619) 299-0805
http://telophasesociety.com/

Trident Society Cremation Services – San Diego
9242 Miramar Rd #37, San Diego, CA 92126
(858) 527-1585
https://www.tridentsociety.com/location/san-diego-ca/

Trinity Funeral Services
333 H St #5000, Chula Vista, CA 91910
(619) 308-6571
3914 Murphy Canyon Rd #A238, San Diego, CA 92123
(619) 344-0875
http://trinityfuneralservices.com/

Village Cremation Services
303 F St, Chula Vista, CA 91910
(619) 422-7900
http://www.villagecremations.com/
Additional Funeral Options

California Funeral Alternatives
14168 Poway Rd #106, Poway, CA 92064
(858) 842-3000
https://www.cafuneralt.com/

Funeraria del Angel Chula Vista
753 Broadway, Chula Vista, CA 91910
(619) 425-9111

Funeraria del Angel National City
607 National City Blvd, National City, CA 91950
(619) 474-6565

Funeraria del Angel San Diego
3960 Imperial Ave, San Diego, CA 92113
(619) 241-4704

Funeraria La Paz
2601 Imperial Ave, San Diego, CA 92102
(619) 531-8800
http://www.funeralialapaz.net/
Additional Funeral Options Continued

Pacific Beach – La Jolla Chapel
4710 Cass St, San Diego, CA 92109
(858) 488-5553

Prima Cemetery Services
2341 Judson St, San Diego, CA 92111
(619) 785-3930
http://primacemeteryservices.com/

San Diego Burial at Sea
2240 Shelter Island Dr, San Diego, CA 92106
(619) 987-0663
https://sandiegoburialatsea.com/

Simple Tribute Funeral
7851 Mission center Ct #104, San Diego, CA 92108
(619) 401-8560
(619) 299-0805

Thresholds Home and Family-Directed Funerals
2560 B St, San Diego, CA 92102
(619) 414-2651
Planned Post-Mortem Communication Form

This form is to be completed only by active research participants/study partners in the UCSD/ADRC Longitudinal Study.

Once you have had the opportunity to review this packet and finalize your post-mortem plans, please submit this form so that it can be stored with your consent to autopsy forms. This information will best ensure that your wishes are followed, and that unnecessary hardship does not fall to loved ones. Thank you for agreeing to brain autopsy and supporting this critical component of Alzheimer’s disease and related dementias research.

You may submit this form by email to adrc@ucsd.edu with the subject line “Autopsy Form Submission” or by mail to 9444 Medical Center Drive Ste. 1-100 La Jolla, CA 92037.

I, ________________________________, have made arrangements:

☐ to donate my body to UCSD Body Donation Program and have received verification of enrollment. (Please attach copy of UCSD Body Donation enrollment verification to this form)

-OR-

☐ with a post-mortem facility and wish for my remains to be transported there after autopsy is complete.

Post-Mortem Facility Name: ___________________________________________________________
Post-Mortem Facility Phone Number: ___________________________________________________
Post-Mortem Facility Address (where body should be delivered following autopsy completion):

_________________________________________________________________________________