



TRIAL-READY COHORT FOR PRECLINICAL/PRODROMAL ALZHEIMER'S DISEASE WEBSITE PRIVACY POLICY

Last Revised [December 1, 2017](#) (“Effective Date”)

Thank you for your interest in the Keck School of Medicine of USC's Trial-Ready Cohort for Preclinical/Prodromal Alzheimer's Disease program (the “Program”). The Program is run or being developed by the Keck School of Medicine of USC's Alzheimer's Therapeutic Research Institute (“ATRI”), and the Program website and other websites, online locations and apps for the Program are used to provide information about the Program, provide information related to research and studies conducted through the Program, and to collect information from potential participants in the Program's early stage Alzheimer Disease studies and possible clinic trials.

The University of Southern California (“USC”), the Keck School of Medicine of USC, the Program, and ATRI, and their officers, agents, employees, and representatives (including the website provider identified below) are collectively referred to herein as “we”, “us”, or “our”.

This privacy policy (“Privacy Policy”) is a part of your Agreement that is described in the Terms of Use described and referenced below, and governs your use of the Program Sites (as defined in the Terms of Use Agreement). Any use of the Sites constitutes your agreement to this Privacy Policy, and all other terms and conditions that are part of your Agreement.

Contact Information

If you have any questions, requests, complaints, or comments about the Program website or other websites, online locations and apps for the Program, any protected health information that we might collect from you (described below under the “Collection of Your Personal Identifiable Information and Protected Health Information, Your Rights Regarding Such Information, and Our Responsibilities” heading), the separate, secure server and website used for you to submit or for us to collect any protected health information for the Program, or about the Program itself, you may contact us at:

USC Keck School of Medicine
Alzheimer's Therapeutic Research Institute
9860 Mesa Rim Road
San Diego, CA 92121
Phone: [858-877-3135](tel:858-877-3135)
Email: info@aptwebstudy.org

Keck School of Medicine of USC's Commitment to You

Protecting your privacy while visiting Program Sites is our top priority. We strive to use the highest privacy standards to allow our visitors to safely use our Sites to gain an overview and greater insight into the Program.

Disclaimer

All health and health-related information contained within the Sites is intended to be general in nature, do not contain medical advice, and should not be used as a substitute for medical consultation or treatment by a health care professional. Your health care provider should be consulted regarding matters concerning the medical condition, treatment and needs of you and your family. We do not monitor or communications from or provided through the Sites for medical diagnostic or emergency health care purposes.

Although we try to ensure that the material within the Sites is accurate and timely, it is provided for the convenience of the website user. You should not assume that information on any topic available on the Sites is accurate, complete, up-to-date, or applicable to any medical problem or condition you may have, and should not be considered official. Content, such as words, pictures, videos and other material found on the Sites, is for informational use only. Users of this website are advised to refer to and rely upon the official version of information when making significant decisions.

This information is provided without warranty for quality or accuracy. Neither we nor any other contributing author is responsible for any errors or omissions in any information provided on the Sites or the results obtained from the use of such information.

In the event of a medical emergency, call your doctor or dial 911 immediately. Do not disregard or delay seeking medical care or advice because of content you may have read on any Site.

Collection of Your Personal Identifiable Information and Protected Health Information, Your Rights Regarding Such Information, and Our Responsibilities

THIS SECTION PROVIDES A SUMMARY OF HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

FOR MORE INFORMATION REGARDING THE USE AND COLLECTION OF YOUR PROTECTED HEALTH INFORMATION, PLEASE VISIT THE OFFICE FOR THE PROTECTION OF RESEARCH SUBJECTS WEBSITE AT [HTTP://OPRS.USC.EDU](http://OPRS.USC.EDU).

Possible Collection of Electronic Submission of Personal Identifiable Information and Protected Health Information

Part of the purpose of the Program and the Sites is to collect information from potential participants in the Program's early stage Alzheimer Disease studies and possible clinic trials. You may be asked to electronically submit to ATRI through the Sites your personal identifiable information (such as name, address, email address, and telephone number) and your protected health information (defined below), which may fall under federal and state privacy laws or regulations, including the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"), Pub. L. No. 104-191, 110 Stat. 1936 (1996), codified at 29 U.S.C. § 1181 *et seq.*; 42 U.S.C. § 300gg; 42 USC 1320d *et seq.*

"Protected health information" means any information, whether orally or recorded in any form or medium, including demographic information, that (i) relates to the past, present, or future physical or mental health or condition of an individual, the provision of health care to an individual, or the past, present, or future payment for the provision of health care to an

individual, and (ii) either identifies the individual or there exists sufficient information to be able to identify the individual, which is transmitted by electronic media, maintained in electronic media, or transmitted or maintained in any other form or medium (“PHI”).

For more information about what information constitutes PHI under HIPAA, you may visit the U.S. Department of Health & Human Services’ website at www.hhs.gov, or contact them at 200 Independence Avenue, S.W., Washington, D.C. 20201, Toll Free Call Center: (877) 696-6775.

Transmission of PHI

You should never transmit PHI by email. We have contracted with a HIPAA complaint hosting provider with [Amazon Web Services](#) to receive and store any PHI you electronically transmit.

Our Uses and Disclosures

We may use and share your personal identifiable information and your PHI with researchers, physicians, nurses, scientists, other health care providers or professionals, volunteers, administrators, medical and office assistants, and staff members (including University students who are students, volunteers or staff members in the Program, and other universities and organizations that may be collaborating with us in or assisting us with the Program) as we:

- Evaluate your candidacy to participate in the Program’s early stage Alzheimer Disease studies
- Evaluate your candidacy to participate in the Program’s early stage Alzheimer Disease clinic trials
- Treat you
 - We can use your health information and share it with other professionals who are treating you (for example: a doctor treating you for an injury might ask another doctor about your overall health condition).
- Run our organization
 - We can use and share your health information to run our practice, improve your care, and contact you when necessary (for example: we might use health information about you to manage your treatment and services).
- Bill for your services
 - If applicable, we can use and share your health information to bill and get payment from health plans or other entities (for example: we might give information about you to your health insurance plan so it will pay for your services).

We are allowed or required to share your information in other ways—usually in ways that contribute to the public good, such as public health and research. We have to meet many conditions in the law before we can share your information for these purposes. The following is a summary of some of the circumstances in which we may be allowed or required to share your information.

- To help with public health and safety issues, we can share health information about you for certain situations such as:

- Preventing disease
- Helping with product recalls
- Reporting adverse reactions to medications
- Reporting suspected abuse, neglect, or domestic violence
- Preventing or reducing a serious threat to anyone's health or safety
- We can use or share your information for health research
- To comply with the law, we will share information about you if state or federal laws require it, including with the Department of Health and Human Services if it wants to see that we're complying with federal privacy law
- To respond to organ and tissue donation requests, we can share health information about you with organ procurement organizations
- To work with a medical examiner or funeral director, we can share health information with a coroner, medical examiner, or funeral director when an individual dies
- To address workers' compensation, law enforcement, and other government requests, we can use or share health information about you:
 - For workers' compensation claims
 - For law enforcement purposes or with a law enforcement official
 - With health oversight agencies for activities authorized by law
 - For special government functions such as military, national security, and presidential protective services
- To respond to lawsuits and legal actions, we can share health information about you in response to a court or administrative order, or in response to a subpoena

For more information about HIPAA, please visit:
www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/index.html.

For more information about our policies and procedures regarding the collection, use, and sharing of PHI, please visit the HSIRB website at: <http://oprs.usc.edu>.

Our Responsibilities

- We are required by law to maintain the privacy and security of your protected health information.
- We will let you know promptly if a breach occurs that may have compromised the privacy or security of your information.
- We must follow the duties and privacy practices described in this notice and give you a copy of it.
- We will not use or share your information other than as described here unless you tell us we can in writing. If you tell us we can, you may change your mind at any time. Let us know in writing if you change your mind.

For more information about HIPAA, please visit:
www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/noticepp.html.

For more information about our policies and procedures regarding the collection, use, and sharing of PHI, please visit the HSIRB website at: <http://oprs.usc.edu>.

Your Rights

When it comes to your PHI, you have certain rights. This section explains your rights and some of our responsibilities to help you. You may:

- Get a copy of your paper or electronic medical record
 - You can ask to see or get an electronic or paper copy of your medical record and other health information we have about you. Ask us how to do this.
 - We will provide a copy or a summary of your health information, usually within 30 days of your request. We may charge a reasonable, cost-based fee.
- Ask us to correct your paper or electronic medical record
 - You can ask us to correct health information about you that you think is incorrect or incomplete. Ask us how to do this.
 - We may say “no” to your request, but we’ll tell you why in writing within 60 days,
- Request confidential communication
 - You can ask us to contact you in a specific way (for example, home or office phone) or to send mail to a different address.
 - We will say “yes” to all reasonable requests.
- Ask us to limit the PHI we share
 - You can ask us not to use or share certain health information for treatment, payment, or our operations. We are not required to agree to your request, and we may say “no” if it would affect your care.
 - If you pay for a service or health care item out-of-pocket in full, you can ask us not to share that information for the purpose of payment or our operations with your health insurer. We will say “yes” unless a law requires us to share that information.
- Request a list of those with whom we’ve shared your PHI
 - You can ask for a list (accounting) of the times we’ve shared your health information for six years prior to the date you ask, who we shared it with, and why.
 - We will include all the disclosures except for those about treatment, payment, and health care operations, and certain other disclosures (such as any you asked us to make). We’ll provide one accounting a year for free but will charge a reasonable, cost-based fee if you ask for another one within 12 months.
- Request a copy of this privacy notice
 - You can ask for a paper copy of this notice at any time, even if you have agreed to receive the notice electronically. We will provide you with a paper copy promptly.

- Choose someone to act for you
 - If you have given someone medical power of attorney or if someone is your legal guardian, that person can exercise your rights and make choices about your health information.
 - We will make sure the person has this authority and can act for you before we take any action.
- File a complaint if you believe your privacy rights have been violated
 - You can complain if you feel we have violated your rights by contacting ATRI (see the “Contact Information” section and heading above).
 - You can file a complaint with the U.S. Department of Health and Human Services Office for Civil Rights by sending a letter to 200 Independence Avenue, S.W., Washington, D.C. 20201, calling 1-877-696-6775, or visiting www.hhs.gov/ocr/privacy/hipaa/complaints.
 - We will not retaliate against you for filing a complaint.

Your Choices

For certain health information, you can tell us your choices about what we share. If you have a clear preference for how we share your information in the situations described below, tell us what you want us to do, and we will follow your instructions.

In these cases, you have both the right and choice to tell us to:

- Share information with your family, close friends, or others involved in your care
- Share information in a disaster relief situation
- Include your information in a hospital directory

If you are not able to tell us your preference, for example if you are unconscious, we may go ahead and share your information if we believe it is in your best interest. We may also share your information when needed to lessen a serious and imminent threat to health or safety.

We never market or sell personal information, and, in these cases, we never share your information unless you give us written permission:

- Marketing purposes
- Sale of your information
- Most sharing of psychotherapy notes

In the case of fundraising:

- We may contact you for fundraising efforts, but you can tell us not to contact you again.

However, you are under **no obligation** to provide personal information through our Sites. You can contact ATRI for alternative methods of submission (see the “Contact Information” section and heading above).

If you do submit personal information, you have the option of asking that such information be removed from our site once the service has been completed and may end any subscription or

request for information by submitting a cancellation request to the Website administrator (see the “Contact Information” section and heading above).

What Information is Automatically Collected Through the Sites?

We may use cookies or other technologies to collect certain information when you visit the Sites or interact with emails. For example, we may automatically collect certain non-personal information from you, such as your internet protocol (“IP”) address, browser type, operating system, device identifier, device model, software version, mobile or ISP carrier information, and origin and site navigation of website visitors, the domain name from which you accessed the Sites, times and dates you access the Sites, the areas or pages of the Sites that you visit, the amount of time you spend using the Sites, the number of times you return to the Sites, and whether you open, forward, or click-through emails.

Tracking Options and California Do Not Track Disclosures. You may adjust your browser or operating system settings to limit this tracking or to decline cookies; however, if you do so, you may be unable to access certain areas of the Sites. Check the “help” menu of your browser or operating system to learn how to change your tracking settings or cookie preferences. On your mobile device, you may be able to adjust your privacy and advertising settings to limit your tracking for advertising or control whether you receive more relevant advertising. Note that our systems may not recognize Do Not Track headers or requests from some or all browsers.

We do not collect any identifying or personal data, such as name, email or address, on site users unless that information is submitted as part of a request for service or information, such as requesting an appointment.

If a visitor submits identifying information, only authorized USC staff will view the information and provide the appropriate response. We do not give, share, or sell any personal information to a third party unless required by law.

Cookie Policy

By using or accessing our Sites, you are consenting to our using and sending one or more “cookies” to your computer or other device. “Cookies” are text-only pieces of information that a website transfers to an individual’s hard drive or other website-browsing equipment for record-keeping purposes. Session cookies are temporary cookies that remain in the cookie file of your browser until you leave the Sites. Persistent cookies remain in the cookie file of your browser for a longer period that depends on the “lifetime” of the cookie.

Cookies are used to notify the Site when you return, what site referred the visitor to our Sites, and to allow our Sites to remember important information that will make your use of the site more convenient. We use cookies to continuously improve our site. By knowing how often you visit our site and what information is most interesting to you, we are able to create content that better serves our visitor’s needs. You can reset your browser to refuse all cookies or to indicate when a cookie is being sent. However, some website features or services may not function properly without cookies.

We use session cookies to track the total number of visitors to our Sites on an anonymous aggregate basis, without any personal data. When we use cookies to remember your computer when it is used to return to the Sites, to help customize your use of our Sites or to make your use

of our Sites more convenient, we may associate personal information with a cookie file. You may use the options in your web browser if you do not wish to receive a cookie or if you wish to set your browser to notify you when you receive a cookie. You can delete any cookies that have been installed in the cookie folder of your browser. The help menu on your browser may provide information on how to change cookie settings on the browser.

Cookies typically contain the name of the domain from which the cookie has come, the “lifetime” of the cookie, and randomly generated unique number or other value used for tracking purposes. Certain cookies will be used on the Site regardless of whether you are logged in to your account or not. Like many websites, we use cookies to:

- Analyze user activity to improve our Sites, such as looking at the quantities and types of searches that users perform on our Sites, which allows us to gain insights about how to improve the functionality and user experience of the Sites
- Store user preferences on our Sites, including the quantities and types of searches that users perform on our Sites, and storing recent searches users have performed, which allow users to repeat those searches when returning to our Sites

Our Use of Google Analytics

We use Google Analytics to help us better examine ways improve the functionality and user experience of our Sites. Google Analytics is a web analytics tool that helps website owners understand how visitors engage with their website. Google Analytics customers can view a variety of reports about how visitors interact with their website so that they can improve it.

Like many services, Google Analytics uses first-party cookies to track visitor interactions as in our case, where they are used to collect information about how visitors use our site. We then use the information to compile reports and to help us improve our site.

Google Analytics collects information anonymously. It reports website trends without identifying individual visitors. **You can opt out of Google Analytics without affecting how you visit our site.** For more information on opting out of being tracked by Google Analytics across all websites you use, visit the Google Analytics Opt-out Browser Add-on page at <https://tools.google.com/dlpage/gaoptout>.

To learn more about how Google uses data when websites use its Google Analytics tool, visit the “How Google uses data when you use our partners' sites or apps” page at <https://www.google.com/policies/privacy/partners/>.

Information Security

To ensure the highest level of security, access to your data on our site is password-protected, and sensitive data is protected by encryption when it is exchanged between your web browser and our Site. We regularly monitor our system for possible vulnerabilities and attacks, and have security measures in place to help prevent unauthorized access to and misuse of personal information. We have contracted with a HIPAA complaint hosting provider with [Amazon Web Services](#) to receive and store any PHI you electronically transmit.

Email Security

You should never transmit PHI by email. The Sites offer opportunities to communicate with some staff members by email. Because normal email is not encrypted, the possibility exists that unauthorized individuals may intercept email messages with us. We are not responsible for privacy of email messages except those stored in our system. Please note that we would never ask for personal information such as bank account information through email. Should you ever receive such a request, contact the Internet Crime Complaint Center, which is a partnership between the FBI and the National White Collar Crime Center.

Links to Other Sites

To provide other sources of information for our visitors, some pages within our Sites may be linked to third-party websites that we do not manage or control. Please note that we do not review, control or take responsibility for the content of those sites. In addition, these links do not imply endorsement or credibility of service, information or products.

Terms of Use

You must agree to the Terms of Use, which is available at <http://aptwebstudy.org/webstudy/terms-of-use> together with this Privacy Policy and any other policy or guidelines incorporated into your Agreement for your access to and use of the Sites, before you access, browse or use the Sites. If you do not agree to the terms set forth in the Agreement, you may not use or access the Sites or any content. By using or accessing the Sites, registering to create an online account on a Site, or clicking that you accept or agree to these terms if presented with the option to do so, you acknowledge that you have read, understand, and agree to be bound by this Privacy Policy, the Terms of Use, and any other policy or guidelines incorporated into the Agreement by reference.

Modifications or Changes to This Privacy Policy

We reserve the right to modify or change the terms of this Privacy Policy notice, and the changes will apply to all information we have about you. The new notice will be available upon request, in our office, and on our web site. Any such modifications are effective immediately when posted. Each use of the Sites by you constitutes your unconditional acceptance of the then-current versions of the Privacy Policy at the time of your use. You are encouraged to periodically review this Privacy Policy, to stay informed of any updates or changes.