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Protocol # 161491

## University of California, San Diego Consent to Act as a Research Subject

Alzheimer's Disease Research Center (ADRC)
Registry
TELEPHONE SCREENING
GENERAL CONSENT

We are talking today because you are interested in receiving information on studies conducted here at UCSD. Dr. Galasko and colleagues and associates from the University of California San Diego (UCSD) Department of Neuroscience are conducting initial evaluations to enroll subjects in a database (call back list) in order to assess subjects for their eligibility to participate in current, ongoing and future research studies. Participants in this registry will be both males and females and primarily over the age of 65. Approximately 1,000 subjects per year will be entered into the database. Participation in this registry is not limited to residents of San Diego; it is open to people from all over the country.

I am going to provide you with some information about this database study, if you are still interested, I would like to ask you a few questions. Completion of this phone screen should take approximately 15 minutes. Your participation in this phone screen is entirely voluntary and you can discontinue at any time. The data that was collected up to that point will be destroyed and no data will be entered into the database. There are no costs to participants and there is no financial compensation for your participation in this phone screen. However, the information that you provide will assist in the proper selection of participants for studies and for your inclusion in the database. Would you like to continue?

(if informant wants to discontinue phone screen AT ANY TIME or at the END of the phone screen: cease phone screen, thank caller for his/her time and read the following: If you would like to discuss this research study in more detail or have any other questions or research related problems, you may contact the principal investigator, (858) 822-4800. You may also call the UCSD Human Research Protection Program at (858)246-4777 to inquire about your rights as a research subject or to report research-related problems.)

Participating in this phone screen may involve some mild risks or discomfort. These include fatigue, boredom, or irritation during the phone screen. You will be asked to answer a series of questions regarding your medical, psychological, and substance use history during this phone screen. Some of them are rather personal. If, however, there are any questions that you do not feel comfortable answering, you may refuse to do so.

If you are injured as a result of participation in this study, the University of California will provide any medical care you need to treat those injuries. The University will not provide any other form of compensation to you if you are injured. You may call the Human Research Protections Program at (858) 246-4777 for more information about this, to inquire about your rights as a research subject or to report research-related problems.

Results of this phone screen will be used for research purposes. As such, results will not be made available to participants, their family members or their physicians. In the case that you express intent to hurt yourself, or present a danger to others, we are required by law to conduct further assessment and possibly share this information with a trained clinician on our study staff or the appropriate authorities.

There is a risk that information obtained in this prescreen may become available outside of the research setting. However, we will attempt to limit this risk by keeping it in a secure electronic database that has been approved by the Human Research Protection Program. The UCSD Human Research protections Program will have access to review records. The hard copy of this material will be kept in a secure location accessible only to the research staff associated with this database study. If you agree to participate, your information will be necessary for long-term research and will be stored indefinitely. You may request at any time that your information be destroyed by calling Dr. Galasko at the following phone number: (858) 822-4800. Should you decline or withdraw from this prescreening tool, there will be no jeopardy to the care that you will receive at this institution or loss of benefits to which you are entitled. Nor will any of your information be stored in our registry and previously stored information will be deleted.

There is no direct benefit to you for participating in this study. The researchers, however, may be able to contact you regarding studies for which you may qualify. There is no cost or compensation for participation in this study.

Because this is a research study, there may be some unknown risks that are currently unforeseeable. You will be informed of any significant new findings that may affect your willingness to continue. The alternative to participation in this study is not to participate.

Once this prescreening tool is complete, you may be contacted within the next two years by the associated study doctors or study staff when a study becomes available that you may interest you.

Do you agree to be contacted? Yes or No

## Would you like to continue with the phone screen?

Yes No

## **General Consent Screening Form**

At this time I will be asking you some general and detailed questions in order to determine if you are an appropriate candidate for the types of studies that we are conducting. For your own safety, it is important to disclose all of your past and present diseases, allergies and medical conditions that you are aware of and all medications and drugs you are taking.

Does this sound like something you would be interested in?	<u></u> Yes	∐No
Do you give your consent to answer some questions regarding your appropriateness	ess for our studies?	
	<u></u> Yes	□No
(If informant agrees to continue - questions from the IRB approved regis	try will be filled out o	ver the phone
directly in the registry)	, ,	1

