

**Decision-Making in Individuals At-Risk for Familial Alzheimer’s Disease When  
Considering Participation in Prevention Trials: A Questionnaire**

You are being asked to complete this survey because you are at-risk of inheriting a gene that causes familial Alzheimer's Disease (familial AD or FAD), you previously participated in Dr. John Ringman's study of FAD (UCLA IRB protocol # 03-11-067), and you indicated you were willing to be contacted about future research studies. If you are interested, please fill out the following questionnaire to the best of your abilities.

Though there are currently no interventions that have been proven to prevent or slow AD, there is great interest in developing such treatments. In order to study promising treatments in persons who will develop FAD in the future, it may be necessary to perform genetic testing on such persons to determine their eligibility. The purpose of this survey is to better understand how at-risk persons such as yourself would decide whether or not to undergo genetic testing and participate in such a study. After you have read each question, please circle the answer that best describes your opinion. You are under no obligation to complete this form and if you decide not to, it will not affect your relationship with Dr. Ringman, UCLA, The UCLA Department of Neurology, or the Mary S. Easton Center for Alzheimer's Disease Research. If the meaning of any of the questions is not clear to you, please call David Wharton at (310) 794-3055 (or by e-mail at DWharton@mednet.ucla.edu) for clarification. If the meaning of any question is still not clear to you, or you do not feel comfortable answering a given question, please do not answer it. You may consult with other family members as you complete this questionnaire. PLEASE CONSIDER EACH QUESTION VERY CAREFULLY BEFORE ANSWERING.

1. What is your age? \_\_\_\_\_
2. What is your gender? (circle one)                      MALE                      FEMALE
3. What country do you live in? \_\_\_\_\_
4. How many years of education have you completed? \_\_\_\_\_
5. Are you currently in school? (circle one)                      YES                      NO
  - 2a. If so, what are you studying? \_\_\_\_\_
  - 2.b. If not, do you have plans of undergoing more education? \_\_\_\_\_
6. Are you currently employed? (circle one)                      YES                      NO
  - 3a. If so, what do you do for a living? \_\_\_\_\_
7. Do you have children? (circle one)                      YES                      NO
  - 4a. How many children do you have and what are their ages? \_\_\_\_\_  
\_\_\_\_\_

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8. Are you currently planning on having any (more) children? (circle one)

YES NO

9. Do you currently want to know whether or not you have the gene for FAD? (circle one)

YES NO MAYBE

10. Would you consider genetic testing for FAD if your children asked you to do so for their own information? (circle one)

YES NO MAYBE NOT APPLICABLE

11. Would you, under any circumstances, ever consider participating in a clinical trial (research study) of an experimental medication to prevent the development of AD? (circle one)

YES NO MAYBE

Hypothetical Studies:

As indicated above, it might be necessary to perform genetic testing in persons such as yourself prior to enrollment in a study of a drug to prevent the development of FAD. In such studies, it may be necessary to assign some subjects to receive placebo (an inert, inactive intervention, or "sugar pill") in order to demonstrate that persons receiving the active drug develop AD at a lower rate. Below are some hypothetical research studies in which we want to know your thoughts as to whether or not you would be willing to undergo genetic testing and participate.

In ALL of the studies described below, the intervention being assessed shows substantial promise in the prevention of AD. All interventions have good scientific justification for being studied and all have been demonstrated to be effective in animal models of AD. In order to participate in any of these studies, you would first need to undergo genetic testing such that you found out whether or not you were going to develop FAD. If you were found to carry the gene, you would be eligible to participate. If you were not found to carry the gene, you could not participate.

Hypothetical Study #1:

An institution is looking for participants for a research study for a medication with substantial promise in preventing Alzheimer's disease (AD). The medication has been studied

extensively in animals and humans and **is felt to be very safe**. The treatment is a pill, taken twice a day, that would most likely be required for the rest of your life.

The study requires that you are tested prior to being accepted for the research study, which means you would have to be told whether or not you carry the gene and it is guaranteed that you receive active drug (no placebo). Knowing that there is a potential (but not a guarantee) to stop the development of AD, but that you would have to be told that you in fact are carrying the gene that causes FAD, would you participate in this study? Please circle your answer.

**YES**                      **NO**

If your answer is **YES**, please indicate why. You may choose more than one answer.

- a) \_\_\_\_\_ The possible benefits outweigh the risks of being made aware of genetic status
- b) \_\_\_\_\_ To help future generations
- c) \_\_\_\_\_ Other:

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If your answer is **NO**, please indicate why. You may choose more than one answer.

- d) \_\_\_\_\_ I do not wish to know my genetic status and the possible benefits aren't worth it
- e) \_\_\_\_\_ The risks and side effects are too high to justify possible benefits
- f) \_\_\_\_\_ Other:

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If there was, after testing, a 50% chance that you would receive placebo instead of the experimental drug, would you still want to be tested and enrolled? Please circle your answer.

**YES**                      **NO**

If yes, please indicate why. You may choose more than one answer.

- a) \_\_\_\_\_ The possible benefits outweigh the risks of being made aware of genetic status
- b) \_\_\_\_\_ To help future generations
- c) \_\_\_\_\_ Other:

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- e) \_\_\_\_\_ The risks and side effects are too high to justify possible benefits
- f) \_\_\_\_\_ I do not want to risk being told I am a carrier and then be placed in the placebo group
- g) \_\_\_\_\_ Other:

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If your answer was "NO" because you do not want a 50% chance of receiving placebo (response "F"), what degree of chance that you would receive placebo would you be willing to accept in order to participate? (For example, answering "20%" means you would be willing to participate if the chance that you received placebo would only be 1 in 5). Please answer in a percent between 0 and 50%.

\_\_\_\_\_ %

Hypothetical Study #2:

A research study is looking at the effects of a vaccination that is given once per year for the rest of your life and hopefully will provide protection from the development of AD. Earlier studies of this vaccination in people have shown a 5% risk of brain inflammation that leads to permanent neurological disability (like a stroke) in 1% of subjects.

The study also requires that you are tested prior to being accepted for the research study, which means you **would have to be told** whether or not you carry the gene and it is guaranteed that you receive active vaccination (no placebo). Knowing that there is a potential (but not a guarantee) to stop the development of AD, but that you would have to be told that you in fact are carrying the gene that causes FAD, would you participate in this study?

**YES**                      **NO**

If your answer is **YES**, please indicate why. You may choose more than one answer.

- a) \_\_\_\_\_ The possible benefits outweigh the risks of being made aware of genetic status
- b) \_\_\_\_\_ To help future generations
- c) \_\_\_\_\_ Other:

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- f) \_\_\_\_\_ Other:

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If there was, after testing, a 50% chance that you would receive placebo instead of the experimental drug, would you still want to be tested and enrolled? Please circle your answer.

**YES**                      **NO**

If yes, please indicate why. You may choose more than one answer.

- a) \_\_\_\_\_ The possible benefits outweigh the risks of being made aware of genetic status
- b) \_\_\_\_\_ To help future generations
- c) \_\_\_\_\_ Other:

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\_\_\_\_\_ %

### Hypothetical Study #3:

A drug company wants to test a medication that would be administered intravenously every three months for the rest of persons' lives. Similar to the vaccination study, prior research in people has shown a 5% risk of brain inflammation that leads to permanent neurological disability (like a stroke) in 1% of subjects.

The study also requires that you are tested prior to being accepted for the research study, which means you **would have to be told** whether or not you carry the gene and it is guaranteed that you receive the active infusion (no placebo). Knowing that there is a potential (but not a guarantee) to stop the development of AD, but that you would have to be told that you in fact are carrying the gene that causes FAD, would you participate in this study?

**YES**                      **NO**

If your answer is **YES**, please indicate why. You may choose more than one answer.

- a) \_\_\_\_\_ The possible benefits outweigh the risks of being made aware of genetic status
- b) \_\_\_\_\_ To help future generations
- c) \_\_\_\_\_ Other:

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If your answer is **NO**, please indicate why. You may choose more than one answer.

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If there was, after testing, a 50% chance that you would receive placebo instead of the experimental drug, would you still want to be tested and enrolled? Please circle your answer.

**YES                      NO**

If yes, please indicate why. You may choose more than one answer.

- a) \_\_\_\_\_ The possible benefits outweigh the risks of being made aware of genetic status
- b) \_\_\_\_\_ To help future generations
- c) \_\_\_\_\_ Other:

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\_\_\_\_\_ %

Hypothetical Study #4:

A research study is looking for participants for a high-risk clinical trial involving brain surgery. In this study, a neurosurgeon would drill small holes, one on each side of your skull while you are asleep under anesthesia. They would then implant a substance directly into your brain. You would only have to undergo this procedure once in your lifetime. The risks of the surgery and anesthesia can be high, and may include death. Results cannot be guaranteed. However, if the treatment worked, you would not develop AD or it would develop later in life than you would have otherwise.

The study also requires that you are tested prior to being accepted for the research study, which means you **would have to be told** whether or not you carry the gene and it is guaranteed that you receive the active surgery (no placebo). Knowing that there is a potential (but not a guarantee) to stop the development of AD, but that you would have to be told that you in fact are carrying the gene that causes FAD, would you participate in this study?

**YES**            **NO**

If your answer is **YES**, please indicate why. You may choose more than one answer.

- a) \_\_\_\_\_ The possible benefits outweigh the risks of being made aware of genetic status
- b) \_\_\_\_\_ To help future generations
- c) \_\_\_\_\_ Other:

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If your answer is **NO**, please indicate why. You may choose more than one answer.

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- e) \_\_\_\_\_ The risks and side effects are too high to justify possible benefits
- f) \_\_\_\_\_ Other:

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If there was, after testing, a 50% chance that you would receive placebo instead of the experimental drug, would you still want to be tested and enrolled? Please circle your answer.

**YES**            **NO**

If yes, please indicate why. You may choose more than one answer.

- a) \_\_\_\_\_ The possible benefits outweigh the risks of being made aware of genetic status
- b) \_\_\_\_\_ To help future generations
- c) \_\_\_\_\_ Other:

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If your answer is **NO**, please indicate why. You may choose more than one answer.

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  - e) \_\_\_\_\_ The risks and side effects are too high to justify possible benefits
  - f) \_\_\_\_\_ I do not want to risk being told I am a carrier and then be placed in the placebo group
  - g) \_\_\_\_\_ Other:
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\_\_\_\_\_ %

THANK YOU FOR PARTICIPATING!