

APOE Gene Test Results & Risk Information

This sheet summarizes the APOE Gene Test information provided to you as part of screening for Generation Study 1.

It should be attached to the Standardized APOE Risk Information handout used during your visit.

Genetic Testing Result: Your *APOE* gene test result is: **e3r (rare e3) / e3r (rare e3)**

Risk Information for Mild Cognitive Impairment or Dementia due to Alzheimer's Disease:

- The e3 form is the most common form of the APOE gene, however, the e3r (rare e3) variant form is very rare. We have no data available on individuals with the e3r (rare e3) type and their risk of developing mild cognitive impairment (MCI) or dementia due to Alzheimer's disease.
- For this reason, we do not have specific risk estimates for e3r (rare e3) results. However, there is no evidence to suggest that the e3r (rare e3) variant would impact risk any differently than the common e3 type.
- Because the e3r (rare e3) result is so rare we are not able to provide a specific estimate of risk through age 85 of developing MCI or dementia due to Alzheimer's disease for someone with the e3r (rare e3)/e3r (rare e3) result.
- However, given the lack of evidence to suggest that the e3r (rare e3) variant would impact risk any differently than the common e3 type, an individual with an e3r (rare e3) / e3r (rare e3) result likely has a similar estimated risk as an individual with an e3/e3 result. The risk of developing dementia due to Alzheimer's disease for someone with the e3/e3 result is 10-15%.

It is important to remember that there are other factors, besides APOE, that could increase or decrease risk when estimating an individual's risk for MCI or dementia due to Alzheimer's disease.

Limitations of the risk estimates:

- There is a wide range of information regarding the APOE gene's impact on the risk of Alzheimer's disease; other studies may have reported higher or lower risks related to the APOE gene. The risk information that we provided you is our best estimate at this time and is based on one large study.
- The risk information we are sharing with you is drawn from studies in which the majority of participants were White. We do not know if the risks are similar for all racial and ethnic groups.

Resources:

Please refer to the slide titled "For More Information" in your packet for a list of resources that may provide you with additional information and support.

Questions:

If you have any questions about any of the information presented in this document, please contact:

Langlois CM, Bradbury A, Wood EM, Roberts JS, Kim SYH, Riviere ME, Liu F, Reiman EM, Tariot PN, Karlawish J, Langbaum JB. Alzheimer's Prevention Initiative Generation Program: Development of an *APOE* genetic counseling and disclosure process in the context of clinical trials. *Alzheimer's Dement* (N Y). 2019 Nov 6;5:705-716. doi: 10.1016/j.trci.2019.09.013.

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