

GeneMatch FAQs

1. What is the GeneMatch Program?
 - a. **GeneMatch is a program of the Alzheimer's Prevention Registry and led by Banner Alzheimer's Institute to identify a large group of people interested in participating in Alzheimer's studies based in part on their genetic information.**
2. What genetic information is GeneMatch collecting?
 - a. **GeneMatch only collects information about which copies of a gene, known as the APOE gene, you have. We do not store your DNA for future testing.**
3. Who is eligible to join?
 - a. **To participate in GeneMatch, you must be between 55 and 75 years old, live in the United States, and not have a diagnosis of cognitive impairment, such as mild cognitive impairment (MCI), Alzheimer's disease, or dementia**
4. Are there any costs associated with participating in GeneMatch?
 - a. **No, there is no cost associated with participation in GeneMatch**
5. Will I be able to learn my genetic results through GeneMatch?
 - a. **No, GeneMatch does not disclose genetic information to participants. GeneMatch may, however, refer you to research studies that may ask you to learn your results. You are under no obligation to participate in any study to which you are referred.**
6. Why does GeneMatch not disclose genetic information? How can I learn my APOE genotype outside of GeneMatch?
 - a. **At this time, it is not recommended to learn your APOE genetic test results as part of your routine medical care. For more information on this recommendation from the American College of Medical Genetics and Genomics click [here](#)*. If you are still considering to pursue APOE genetic testing we encourage you to speak with a genetic counselor, based on the [recommendations](#)** from the American College of Medical Genetics and the National Society of Genetic Counselors.**
7. Can my participation in GeneMatch affect my long-term care insurance?
 - a. **Participation in GeneMatch does not impact your insurance since GeneMatch does not disclosure your test results. In addition, the study staff has obtained a Certificate of Confidentiality from the National Institutes of Health. The researchers can use this Certificate to legally refuse to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings, for example, if there is a court subpoena. Please see the informed consent document for more information. GeneMatch may refer you to studies which ask you to learn your APOE test results. The choice is always yours whether to pursue these opportunities. Before you decide to learn your results you should know that there is a federal law in the United States, called the Genetic**

Information Nondiscrimination Act (GINA, for short) that protects individuals in most employment and health insurance settings. This law does not cover other types of insurance, such as life or long-term care, or small workplaces. If you are considering making any changes to these types of policies, it might be advisable to take action prior to learning your APOE gene result.

8. If I learn my results, do I need to report that information to my insurance company?
 - a. **If you enroll in a study which requires you to learn your APOE results and ultimately do learn the results, then yes, if an insurance company asks whether you know your results you are required to respond truthfully. Many such studies have additional protections in place for individuals who learn their test results. Examples of protections include Certificates of Confidentiality, which prohibit information from being shared due to a subpoena. If you do decide to enroll in a study which asks you to learn your APOE results it will be important you discuss the pros/cons with the enrolling study.**
9. Do I have to participate in the studies I am referred to?
 - a. **The choice to participate in any research study that you are referred to is always yours. GeneMatch will not share any information with the study until you have agreed to participate.**
10. If I am referred to a study, does it mean I have a higher risk of developing Alzheimer's disease?
 - a. **No. Each study has its own recruitment criteria which will be clearly explained to you when you receive a study invitation.**
11. How long will GeneMatch be recruiting participants?
 - a. **We anticipate that this program will be enrolling participants over the next several years, so please do not worry if you are not eligible to join right away.**
12. I already know my APOE4 genetic results. Can I still participate in GeneMatch?
 - a. **Yes, you can still participate in GeneMatch.**
13. How long will I be in the GeneMatch database?
 - a. **Your genetic information will be stored in the GeneMatch database for as long as the program is active. If you wish to remove your information from our database, please contact us at GeneMatch@endalznw.org**
14. Who can I contact if I have questions about GeneMatch?
 - a. **Please email GeneMatch@endalznw.org with any questions you may have about the program.**
15. What types of medical conditions would disqualify me from participating in GeneMatch?
 - a. **The only excluded medical condition is a diagnosis of a cognitive impairment, such as mild cognitive impairment (MCI), Alzheimer's disease, or dementia**
16. How is my confidentiality maintained?

- a. DNA samples will be destroyed by the lab following *APOE* genotyping and entry of the genotype into the secure, HIPAA compliant database. Genotype information will be kept in a database that is separate from your other information (e.g., demographic and contact information).
- b. In addition, the study staff has obtained a Certificate of Confidentiality from the National Institutes of Health. The researchers can use this Certificate to legally refuse to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings, for example, if there is a court subpoena.

<http://www.choosingwisely.org/clinician-lists/american-college-medical-genetics-genomics-apoe-genetic-testing-to-predict-alzheimer-disease/>

https://www.acmg.net/staticcontent/ppg/genetic_counseling_and_testing_for_alzheimer.16.pdf