



**With Your Help,
We Can End
Alzheimer's.**

JOIN THE **50,000**
PEOPLE TAKING PART
IN ALZHEIMER'S
RESEARCH THROUGH THE
GENEMATCH PROGRAM.


Banner Health®

Learn more:
(602) 839-6500
www.endALZnow.org/GeneMatch

The Role of Genetics: Will I get Alzheimer's disease?

Scientists are still trying to determine the underlying causes of Alzheimer's disease. The hope is that one day we will be able to stop the disease from progressing or perhaps even prevent it altogether. To date, researchers have identified a few genes that play an important role in Alzheimer's. Some of these genes are simply risk factors for Alzheimer's disease. Other genes are hereditary and will cause (with nearly 100% certainty) Alzheimer's disease to develop.

There are two types of Alzheimer's disease: early-onset Alzheimer's disease and late-onset Alzheimer's disease. Early-onset Alzheimer's disease is rare, occurring in people age 60 and younger. This represents less than 5% of all people with Alzheimer's. One type of early-onset Alzheimer's disease is known as *autosomal dominant Alzheimer's disease (ADAD)* or *early-onset familial Alzheimer's disease (FAD)*. This is even more uncommon, affecting less than 1% of all people with Alzheimer's. What makes this type of early-onset Alzheimer's disease so unusual is that it is caused by a hereditary genetic mutation to one of three genes – PSEN1, PSEN2, or APP.

If a child whose birth mother or father carries a genetic mutation on one of these three genes, then the child has a 50% chance of inheriting that mutation from the affected parent. People who inherit one of these genetic mutations will (with nearly 100% certainty) develop Alzheimer's disease, usually before the age of 60. The genetic mutation is usually passed down from generation to generation. About 50% of the family members will develop the disease before the age of 60.

In contrast, late-onset Alzheimer's disease, which occurs in people over the age of 60, is much more common. Unlike with early-onset Alzheimer's disease, there is no known genetic mutation that causes someone with nearly 100% certainty to develop the disease. Instead, there are some genes that increase a person's risk of developing Alzheimer's disease. However, just because you carry that particular form of the gene does NOT mean you will develop the disease. APOE is the best known genetic risk factor (or susceptibility factor) for developing Alzheimer's in later life. APOE comes in 3 forms: e2, e3, e4. Each person inherits

one APOE gene from their birth mother, the other from their birth father. As a result, there are 6 possible APOE combinations: e2/e2, e2/e3, e3/e3, e3/e4, e4/e4. The e4 variant is associated with an increased risk of developing Alzheimer's in later-life. With each additional e4 type there is a higher risk of developing the disease at a younger age (but still after age 60). The e2 type is associated with a slightly reduced risk of developing the disease. Although other genes have been identified that are associated with an increased risk of developing Alzheimer's, APOE is the greatest risk. Efforts are underway to determine if there is one or more combination of genes that increases risk of the disease. This is particularly important in people without any copies of the e4 type of APOE. In addition, researchers are also busy looking for genes that may protect against Alzheimer's disease. For example, a very rare genetic mutation on the APP gene is associated with people living longer without Alzheimer's disease.

A recent study examined data from 4 large, observational studies of adults ages 60 and older. The study reported the association between various APOE genotypes and the risk of developing mild cognitive impairment (MCI) or dementia due to Alzheimer's by age 85 as follows:

- The e3/e3 APOE genotype is associated with a 10-15% risk of developing MCI dementia due to Alzheimer's disease by age 85.
- The e3/e4 APOE genotype is associated with a 20-25% risk of developing MCI or dementia due to Alzheimer's disease by age 85.
- The e4/e4 APOE genotype is associated with a 30-55% risk of developing MCI or dementia due to Alzheimer's disease by age 85.
- The e2 form of APOE is rare, so we have less information available about individuals with this form. As a result, we estimate it may be slightly lower or higher than the e3/e3 risk of 10-15% by age 85.

It is important to keep in mind that just because a person has 1 or 2 copies of the e4 type of APOE *does not* mean that you will develop dementia due to Alzheimer's disease. Likewise, just because a person has no copies of the e4 type of APOE does not mean they will not develop the disease.

There are other factors that can increase or decrease a person's risk of developing Alzheimer's disease. This is also true for people with 2 copies of the e4 type of APOE. For example, age is the biggest non-genetic risk factor

for developing Alzheimer's disease. Therefore everyone is at risk for developing the disease as they age. Factors that may *decrease* a person's risk of developing dementia due to Alzheimer's include:

- no family history of dementia
- being male
- more years of education
- good cardiovascular health

Factors that may *increase* a person's risk of developing Alzheimer's include:

- having a family history of Alzheimer's
- older age
- being female
- fewer years of education
- cardiovascular disease and conditions such as diabetes and high blood pressure

In the past few years academic researchers, including those from Banner Alzheimer's Institute, have partnered with the National Institutes of Health (NIH) and pharmaceutical companies to launch several important Alzheimer's prevention trials. These trials are focused on healthy people with different genetic risk factors for Alzheimer's disease. The studies will determine if they can remove amyloid from the brain or stop its production, thereby slowing or stopping the disease. Hopefully this will prevent memory and thinking problems from occurring. If one of the treatments studied in any of these trials is found to delay the onset of cognitive decline associated with Alzheimer's or delay the onset of the disease itself, it opens the door to the possibility of testing the treatment's effectiveness in other at-risk groups. This also includes those without the genetic risk factors. Examples of these trials include:

- The Alzheimer's Prevention Initiative's Autosomal Dominant Alzheimer's Disease (ADAD) Trial is a study led by Banner Alzheimer's Institute and Genentech/Roche of approximately 300 members of the world's largest extended family of ADAD carriers is taking place in Colombia, South America.
- The Dominantly Inherited Alzheimer's Network (DIAN) Trial's Unit program is a study in people from families with a known ADAD mutation, taking place in the United States, Canada, Europe and Australia.
- The Alzheimer's Prevention Initiative's Generation Study 1 is a trial led by Banner Alzheimer's Institute, Novartis, and Amgen taking place the United States,

Looking for a way to make a gift to Banner Alzheimer's Foundation without spending your cash? A charitable bequest is a wonderful way for you to help further the work of Banner Alzheimer's Foundation and its mission of delivering care and hope to families while advancing research. For more information, please contact us at 602.747.GIVE (4483) or plannedgiving@bannerhealth.com.



Ask The Expert

Jessica Langbaum, PhD
Principal Scientist, Alzheimer's Prevention Initiative
Banner Alzheimer's Institute

Dear Dr. Langbaum,

My mother was recently diagnosed with dementia due to Alzheimer's disease, so I am interested in learning whether I am at increased genetic risk for developing the disease.

Sincerely,
Mark

Dear Mark,

I am often asked by people with a family history of Alzheimer's disease about their individual risk for also developing the disease. This is a natural question, and a highly personal one. It is important to remember that we are all at risk for developing Alzheimer's disease, even people without a family history of the disease. APOE is the best known genetic risk factor (or susceptibility factor) for developing dementia due to Alzheimer's disease in later life. The e4 form of APOE is associated with an increased risk of developing the disease. People with 2 copies of the e4 form of APOE are at higher risk than people with no copies of the e4 form.

If you are interested in learning whether you are at increased genetic risk, I encourage you to meet with a genetic counselor to discuss your personal questions and concerns. APOE testing is not part of routine medical care and it is important to speak with someone knowledgeable about the family, emotional, insurance and employment considerations before deciding whether to undergo genetic testing and counseling. Remember that APOE is not a definitive test. There is no genetic test that can predict with 100% certainty whether someone will develop Alzheimer's disease in later life. Although someone's APOE test result provides an estimated overall risk of developing the disease, it is not a definitive prediction. Even if someone does not have any copies of the e4 form of APOE, they could still develop dementia. As you can see, there are many factors involved in APOE genetic testing. This is one of the many reasons it is important to speak directly with an expert when learning this sensitive genetic information.

Studies have looked at the psychological impact of telling people with a family history of Alzheimer's disease their APOE test results. They found that with proper genetic counseling, overall people tolerated this information quite well. One limitation of these studies was that they required people to meet face-to-face with a genetic counselor over several sessions. We realize that in many areas of the country there are not enough genetic counselors available to provide this service to everyone who wants it. Studies such as the Generation Study 1 are helping researchers examine whether we can use telemedicine to tell people their APOE test result, either by speaking to a genetic counselor by telephone or video-conference. If you are interested in participating in the Generation Study 1 or another Alzheimer's prevention study, please consider joining the Alzheimer's Prevention Registry's GeneMatch program which helps match people to research studies based on their genetic background. GeneMatch is open to people ages 55-75 who live in the United States and who do not have a diagnosis of cognitive impairment, such as mild cognitive impairment or dementia, from a physician. Please visit www.endALZnow.org/genematch for more information.



www.banneralz.org
602.839.6900

Sentiments and Situations Group is a new support group to help caregivers to share and problem-solve difficult situations and feelings related to caregiving and dementia. In June we will discuss about concerns of getting Alzheimer's disease/related dementia or other identified topics. Please join us on Thursday, June 8, 2017 from 12:30 – 2:00pm at Banner Alzheimer's Institute, 901 E. Willetta Street, Phoenix, First Floor Education Center.

Dementia Dialogue Webinar: The Role of Genetics: Will I get Alzheimer's disease?

Dr. Jessica Langbaum will lead the discussion on Wednesday, June 21, 2017, 12N – 1pm (AZ time). Registration required: www.banneralz.org/dementiadialogues or call 623-832-3248.

A tree provides enough oxygen for three people to breathe. Please assist us in our Go Green campaign and consider receiving our new and improved online BAI Beacon Newsletter version. Please email us at bannerresearch@bannerhealth.com with feedback or to refer others who wish to receive this web version

Have a Question?

To submit your question for future consideration email us at: baiinfo@bannerhealth.com





Banner Health®

Banner Alzheimer's Institute
Banner Sun Health Research Institute

Banner Health
901 East Willetta Street
Phoenix, AZ 85006

The Role of Genetics: Will I get Alzheimer's disease? (con't)

Canada, Europe and Australia in approximately 1300 people with 2 copies of the e4 type of APOE.

Other trials are in various stages of planning to launch later in 2017, 2018 and beyond.

To help with the recruitment for these and other prevention trials, Banner Alzheimer's Institute created two online registries to help connect researchers with adults interested in potentially participating in the studies. The **Alzheimer's Prevention Registry** (www.endALZnow.org) is open to anyone age 18 and older, with and without memory and thinking problems, who live anywhere in the world. To date, over 265,000 people have joined this program which provides monthly newsletters to members and sends email notifications when study opportunities are available at a nearby location. Members are under no obligation to participate in any of the studies and their information is kept safe and secure and never shared without the person's permission.

GeneMatch is another registry that is a program of the Alzheimer's Prevention Registry. It is open to people ages 55-75 who live in the United States and

who do not have a diagnosis from a physician of cognitive impairment, like mild cognitive impairment or dementia, (www.endALZnow.org/genematch). After joining GeneMatch, enrollees are sent a cheek swab kit to their home which they complete and return to the lab for APOE genotyping. The participant simply swabs the sides of the cheeks in the mouth and places the specimen into the container to be mailed and processed. GeneMatch *does not* tell enrollees' their APOE results, but uses the results in part to help match people to studies taking place in their communities. As with the Registry, GeneMatch enrollees are under no obligation to participate in any of these studies and their information is kept safe and secure and never shared without their permission. GeneMatch is currently helping with recruitment for the Alzheimer's Prevention Initiative Generation Study. More studies will begin recruiting from GeneMatch later in 2017 and beyond.

In summary, the role of genetics is playing an important role in not only understanding Alzheimer's disease but testing new therapies that may one day lead to a world without Alzheimer's.



CAREGIVER EDUCATION PROGRAM SCHEDULE

June/July 2017

June

Date	Time	Name of Class	Location	To Register
June 7, Wed.	10:00 – 11:30 a.m.	Residential Care: When moving becomes the best option	BSHRI	623.832.3248
June 8, Thurs.	10:00 – 11:30 a.m.	Communication: Avoiding Arguments	BAI	602.839.6850
June 13, Tues.	10:00 – Noon	Planning Ahead Class for Caregivers	BAI	602.839.6850
June 14, Wed.	1:00 – 2:30 p.m.	As Dementia Progresses: Next Steps for Caregivers	BSHRI	623.832.3248
June 14, Wed.	1:00 – 2:30 p.m.	Dementia Friendly Tempe Presents: Family Conflicts on the Dementia Journey	Tempe Public Library	602.839.6850
June 15, Thurs.	1:00 – 2:30 p.m.	Help at Home: Support for the Person Living at Home	Banner Gateway Medical Center	602.839.6850
June 16, Fri.	1:00 – 3:30 p.m.	Banner Brain Health Program	BAI	602.230.CARE (2273)
June 20, Tues.	10:00 – 11:30 a.m.	Medications for Dementia: What are they & what can I expect?	Mesa Red Mountain Library	602.839.6850
June 21, Wed.	9:30 – 11:00 a.m.	Behaviors: Expressing What Words Cannot	BSHRI	623.832.3248
June 21, Wed.	Noon – 1:00 p.m. (AZ Time)	Dementia Dialogues Webinar Series: The Role of Genetics: Will I get Alzheimer's disease?	Online	www.banneralz.org under events/education
June 22, Thurs.	4:00 – 5:30 p.m.	After the Dementia Diagnosis (formerly COMPASS)	BAI	602.839.6850
June 26, Mon.	1:00 – 2:30 p.m.	Activities: Filling the Day with Meaning and Purpose	BAI	602.839.6850
June 27, Tues.	1:00 – 2:30 p.m.	Medications for Dementia: What are they & what can I expect?	BSHRI	623.832.3248

Banner Alzheimer's Institute (BAI Downtown Phoenix)
901 E. Willetta Street, Phoenix
Register at: 602.839.6850

Banner Sun Health Research Institute (BSHRI Sun City)
10515 W. Santa Fe, Sun City
Register at: 623.832.3248

Tempe Public Library
3500 S. Rural Road, Tempe
Register at: 602.839.6850

Mesa Red Mountain Library
635 N. Power Road, Mesa
Register at: 602.839.6850

Banner Gateway Medical Center
1900 N. Higley Road, Gilbert
Register at: 602.839.6850

Dementia Dialogues Webinar Series
Register at: www.banneralz.org/dementialogues. Please note that all webinars are recorded and archived on website 24-28 hours after live session or call 623.832.3248



July

Date	Time	Name of Class	Location	To Register
July 11, Tues.	2:00 – 3:30 p.m.	After the Dementia Diagnosis (formerly COMPASS)	BSHRI	623.832.3248
July 11, Tues.	4:00 – 6:00 p.m.	Planning Ahead Class for Caregivers	BAI	602.839.6850
July 12, Wed.	1:00 – 2:30 p.m.	Dementia Friendly Tempe Presents: Become a Dementia Friend!	Tempe Public Library	602.839.6850
July 17, Mon.	10:00 – 11:30 a.m.	After the Dementia Diagnosis (formerly COMPASS)	BAI	602.839.6850
July 18, Tues.	10:00 – Noon	As Dementia Progresses: Next Steps for Caregivers	Mesa Red Mountain Library	602.839.6850
July 19, Wed.	Noon – 1:00 p.m. (AZ Time)	Dementia Dialogues Webinar Series: How Can I Advocate for my Person's Needs when He no Longer Lives at Home?	Online	www.banneralz.org under events/education
July 19, Wed.	1:30 – 2:30 p.m.	Understanding ALTCS – Session 1	BSHRI	623.832.3248
July 19, Wed.	3:00 – 4:00 p.m.	VA Benefits – Session 2	BSHRI	623.832.3248
July 20, Thurs.	10:00 – 11:30 a.m.	Behaviors: Expressing What Words Cannot	BAI	602.839.6850
July 21, Fri.	9:00 – Noon	Free Memory Screening	BAI	602.839.6850
July 24, Mon.	9:30 – Noon	Banner Brain Health Program	BAI	602.230.CARE (2273)
July 26, Wed.	9:30 – Noon	Banner Brain Health Program	BSHRI	602.230.CARE (2273)
July 27, Thurs.	10:00 – Noon	As Dementia Progresses: Next Steps for Caregivers	BAI	602.839.6850

Banner Alzheimer's Institute (BAI Downtown Phoenix)
901 E. Willetta Street, Phoenix
Register at: 602.839.6850

Banner Sun Health Research Institute (BSHRI Sun City)
10515 W. Santa Fe, Sun City
Register at: 623.832.3248

Tempe Public Library
3500 S. Rural Road, Tempe
Register at: 602.839.6850

Mesa Red Mountain Library
635 N. Power Road, Mesa
Register at: 602.839.6850

Dementia Dialogues Webinar Series
Register at: www.banneralz.org/dementialogues
Please note that all webinars are recorded and archived on website 24-28 hours after live session or call 623.832.3248



To learn about upcoming education and support programs dates at:

- Banner Alzheimer's Institute, visit www.banneralz.org and click on "Events Calendar" icon or call Deidra Colvin, Events Coordinator at 602.839.6850
- Banner Sun Health Research Institute, visit www.bannershri.org and click on calendar or call Veronica Flores, Events Coordinator at 623.832.3248

These programs are made possible by the generous support of the Banner Alzheimer's Foundation.



Banner Alzheimer's Institute
Banner Sun Health Research Institute