



**GEOFFREY BEENE  
FOUNDATION  
ALZHEIMER'S  
INITIATIVE**

### Constant Contact Survey Results

**Survey Name:** Survey Questions for Researchers

**Response Status:** Completed

**Filter:** None

Dec 03, 2008 1:30:39 PM

#### What is your gender?

Answer	0%	100%	Number of Response(s)	Response Ratio
Female			87	35.3 %
Male			158	64.2 %
No Response(s)			1	<1 %
<b>Totals</b>			<b>246</b>	<b>100%</b>

#### What is your age?

Answer	0%	100%	Number of Response(s)	Response Ratio
20 or under			0	0.0 %
21-35			60	24.3 %
36-50			97	39.4 %
51-65			71	28.8 %
65-80			16	6.5 %
81 or over			2	<1 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>246</b>	<b>100%</b>

What is your direct experience with AD? (Select all that apply)

Answer	0%	100%	Number of Response(s)	Response Ratio
I am or have been a caregiver			25	6.9 %
I have a family history of AD			33	9.1 %
I have worked with people with AD professionally or as a volunteer			76	20.9 %
I am involved in research on AD			219	60.4 %
I have been diagnosed with AD			2	<1 %
I have little or no direct experience with AD			7	1.9 %
<b>Totals</b>			<b>362</b>	<b>100%</b>

If you have been a caregiver for someone with AD, please indicate the duration:

Answer	0%	100%	Number of Response(s)	Response Ratio
Less than one year			10	22.7 %
1-5 years			16	36.3 %
5-10 years			11	25.0 %
More than 10 years			7	15.9 %
<b>Totals</b>			<b>44</b>	<b>100%</b>

How concerned are you about your risk of developing AD?

Answer	0%	100%	Number of Response(s)	Response Ratio
Not very concerned			78	31.7 %
Somewhat concerned			132	53.6 %
Very concerned			29	11.7 %
No Response(s)			7	2.8 %
<b>Totals</b>			<b>246</b>	<b>100%</b>

Do you think there are adequate tools available to screen non-clinic-based populations for AD?

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			41	16.6 %
No			190	77.2 %
Don't know			13	5.2 %
No Response(s)			2	<1 %
<b>Totals</b>			<b>246</b>	<b>100%</b>

Do you think there are adequate tools available to screen clinic-based populations for AD?

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			123	50.0 %
No			110	44.7 %
Don't know			13	5.2 %
No Response(s)			0	0.0 %
<b>Totals</b>			<b>246</b>	<b>100%</b>

Of the currently available tests, rate the following for accuracy for detecting early-stage AD:

1 = 1-Most Accurate, 2 = 2, 3 = 3, 4 = 4, 5 = 5-Least Accurate


Answer	1	2	3	4	5	Number of Response(s)	Rating Score*
Mini Mental State Exam (MMSE)						234	3.1
Neuropsychological tests (memory and executive function)						235	2.2
Subject and informant interview (CDR)						236	2.7
A blood test for Abeta-42						223	3.5
A spinal fluid test for Abeta-42 and tau						228	2.7
Brain magnetic resonance imaging (MRI)						233	2.7
Brain glucose metabolism imaging (FDG-PET)						230	2.6
Brain amyloid imaging (PiB-PET)						233	2.3
Testing for the ApoE gene						235	3.2
Other						42	3.3

\*The Rating Score is the weighted average calculated by dividing the sum of all weighted ratings by the number of total responses.

Would you personally want to be screened for possible early signs of AD?

Answer	0%	100%	Number of Response(s)	Response Ratio
Yes			84	33.8 %
Maybe, but only if treatments were available to slow the progression of the disease			98	39.5 %
No, not with current tests			33	13.3 %
No, never			8	3.2 %
Unsure			21	8.4 %
Other			4	1.6 %
<b>Totals</b>			<b>248</b>	<b>100%</b>

Do you believe that some form of early screening for AD should be offered routinely? If so, beginning at what age?

Answer	0%	100%	Number of Response(s)	Response Ratio
40			56	22.7 %
50			68	27.6 %
60			51	20.7 %
70			22	8.9 %
Never			21	8.5 %
Other			21	8.5 %
No Response(s)			7	2.8 %
<b>Totals</b>			<b>246</b>	<b>100%</b>

Rate the importance of each of the following benefits of early screening of AD

1 = 1-Most Important, 2 = 2, 3 = 3, 4 = 4, 5 = 5-Least Important

Answer	1	2	3	4	5	Number of Response(s)	Rating Score*
May help patient access appropriate medical care earlier						241	1.7
May help patient better plan his or her future						242	1.8
May help patient deal with limitations at work or home						242	2.3
May help patient access appropriate disability benefits						240	2.4
May help patient access genetic counseling						241	3.1
Patient safety						240	2.5
Increases pool of volunteers for clinical trials						239	2.7

\*The Rating Score is the weighted average calculated by dividing the sum of all weighted ratings by the number of total responses.

## Rate the importance of each of the barriers to more widespread early screening for AD

1 = 1-Most Important, 2 = 2, 3 = 3, 4 = 4, 5 = 5-Least Important

Answer	1	2	3	4	5	Number of Response(s)	Rating Score*
Public unaware of screening options						237	2.3
Public is afraid to know their AD risk						239	2.3
Physicians don't see benefit of early AD screening to patient						233	2.0
Physicians think screening is harmful to patient						234	3.1
Lack of accurate screening tools						239	1.8
Lack of training to administer screening						235	2.5
Inadequate reimbursement for screening and follow-up diagnostic work						238	2.4
Risk of health insurance discrimination						237	2.0
Other						28	3.2

\*The Rating Score is the weighted average calculated by dividing the sum of all weighted ratings by the number of total responses.

## Given the current state of early detection and treatment of AD, what should a physician communicate to the patient/caregiver/family about early screening?

Answer	0%	100%	Number of Response(s)	Response Ratio
Nothing			2	<1 %
Nothing unless there is cause to worry, such as early symptoms or family history			81	28.2 %
When patients ask to be screened, advise against			2	<1 %
When patients ask to be screened, advise in favor			61	21.2 %
Proactively inform patients about the options and let them decide for themselves			141	49.1 %
Other			0	0.0 %
<b>Totals</b>			<b>287</b>	<b>100%</b>