



**GEOFFREY BEENE  
FOUNDATION  
ALZHEIMER'S  
INITIATIVE**

### Constant Contact Survey Results

**Survey Name:** Survey Questions for the Public

**Response Status:** Completed

**Filter:** None

Dec 03, 2008 1:32:06 PM

What is your gender?

| Answer         | 0% | 100% | Number of Response(s) | Response Ratio |
|----------------|----|------|-----------------------|----------------|
| Female         |    |      | 101                   | 63.1 %         |
| Male           |    |      | 57                    | 35.6 %         |
| No Response(s) |    |      | 2                     | 1.2 %          |
| <b>Totals</b>  |    |      | <b>160</b>            | <b>100%</b>    |

What is your age?

| Answer         | 0% | 100% | Number of Response(s) | Response Ratio |
|----------------|----|------|-----------------------|----------------|
| 20 or under    |    |      | 2                     | 1.2 %          |
| 21-35          |    |      | 9                     | 5.6 %          |
| 36-50          |    |      | 35                    | 21.8 %         |
| 51-65          |    |      | 79                    | 49.3 %         |
| 65-80          |    |      | 28                    | 17.5 %         |
| 81 or over     |    |      | 6                     | 3.7 %          |
| No Response(s) |    |      | 1                     | <1 %           |
| <b>Totals</b>  |    |      | <b>160</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                                      |    |      | 89                    | 37.5 %         |
| I have a family history of AD                                      |    |      | 79                    | 33.3 %         |
| I have worked with people with AD professionally or as a volunteer |    |      | 41                    | 17.2 %         |
| I am involved in research on AD                                    |    |      | 13                    | 5.4 %          |
| I have been diagnosed with AD                                      |    |      | 4                     | 1.6 %          |
| I have little or no direct experience with AD                      |    |      | 11                    | 4.6 %          |
| <b>Totals</b>  |    |      | <b>237</b>            | <b>100%</b>    |

If you have you 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                    | 10.1 %         |
| 1-5 years          |    |      | 39                    | 39.3 %         |
| 5-10 years         |    |      | 32                    | 32.3 %         |
| More than 10 years |    |      | 18                    | 18.1 %         |
| <b>Totals</b>      |    |      | <b>99</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 |    |      | 30                    | 18.7 %         |
| Somewhat concerned |    |      | 80                    | 50.0 %         |
| Very concerned     |    |      | 46                    | 28.7 %         |
| No Response(s)     |    |      | 4                     | 2.5 %          |
| <b>Totals</b>      |    |      | <b>160</b>            | <b>100%</b>    |






Rate your level of knowledge about AD:

1 = Uninformed, 2 = I know the basics, 3 = Well informed, 4 = Not sure

|  | 1 | 2 | 3 | 4 | Number of Response(s) | Rating Score* |
|--|---|---|---|---|-----------------------|---------------|
|  |   |   |   |   | 159                   | 2.7           |





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

Which of these statements about AD is true?

| Answer  | 0%  | 100% | Number of Response(s) | Response Ratio |
|---|---|------|-----------------------|----------------|
| Primary care physicians routinely screen for it in older people             |  |      | 8                     | 4.3 %          |
| Primary care physicians routinely diagnose it with better than 70% accuracy |  |      | 11                    | 6.0 %          |
| A highly trained expert can diagnose it with better than 90% accuracy       |  |      | 64                    | 34.9 %         |
| It cannot be diagnosed except by a brain autopsy                            |  |      | 93                    | 50.8 %         |
| Don't know  |  |      | 7                     | 3.8 %          |
| <b>Totals</b>   |   |      | <b>183</b>            | <b>100%</b>    |

















































Complete the following statement: "Current treatments for Alzheimer disease are most effective at..."

(Select all that apply)

| Answer  | 0%   | 100% | Number of Response(s) | Response Ratio |
|---|--|------|-----------------------|----------------|
| Stopping the progression of the disease                           |   |      | 4                     | 2.5 %          |
| Reversing damage already done by the disease                      |   |      | 0                     | 0.0 %          |
| Temporarily relieving some of the symptoms or slowing the decline |  |      | 154                   | 96.2 %         |
| Don't know  |   |      | 2                     | 1.2 %          |
| <b>Totals</b>   |  |      | <b>160</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, 6 = Don't Know

| Answer  | 1   | 2   | 3   | 4   | 5   | 6   | Number of Response(s) | Rating Score* |
|---|---|---|---|---|---|---|-----------------------|---------------|
| Memory test                                   |  |  |  |  |  |  | 158                   | 2.9           |
| Patient and caregiver interview               |  |  |  |  |  |  | 153                   | 2.7           |
| Blood test                                    |  |  |  |  |  |  | 151                   | 4.9           |
| Spinal fluid test                             |  |  |  |  |  |  | 149                   | 4.6           |
| Magnetic resonance imaging (MRI) of the brain |  |  |  |  |  |  | 153                   | 3.1           |
| PET scan of brain activity                    |  |  |  |  |  |  | 153                   | 2.9           |
| Brain amyloid imaging                         |  |  |  |  |  |  | 152                   | 3.3           |
| Testing for the ApoE gene                     |  |  |  |  |  |  | 153                   | 3.7           |

\*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   |    |      | 68                    | 42.5 %         |
| Maybe, but only if treatments were available to slow the progression of the disease |    |      | 43                    | 26.8 %         |
| No, not with current tests  |    |      | 24                    | 15.0 %         |
| No, never   |    |      | 3                     | 1.8 %          |
| Unsure  |    |      | 21                    | 13.1 %         |
| Other   |    |      | 1                     | <1 %           |
| <b>Totals</b>   |    |      | <b>160</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             |    |      | 43                    | 26.8 %         |
| 50             |    |      | 56                    | 35.0 %         |
| 60             |    |      | 26                    | 16.2 %         |
| 70             |    |      | 11                    | 6.8 %          |
| Never          |    |      | 3                     | 1.8 %          |
| Don't know     |    |      | 15                    | 9.3 %          |
| Other          |    |      | 4                     | 2.5 %          |
| No Response(s) |    |      | 2                     | 1.2 %          |
| <b>Totals</b>  |    |      | <b>160</b>            | <b>100%</b>    |

How would you rate the potential benefits of early screening of AD using today's techniques?

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 |   |   |   |   |   | 149                   | 1.5           |
| May help patient better plan his or her future           |   |   |   |   |   | 153                   | 1.4           |
| May help patient deal with limitations at work or home   |   |   |   |   |   | 152                   | 1.9           |
| May help patient access appropriate disability benefits  |   |   |   |   |   | 150                   | 2.2           |
| May help patient access genetic counseling               |   |   |   |   |   | 146                   | 3.1           |
| Patient safety   |   |   |   |   |   | 149                   | 2.3           |
| Increases pool of volunteers for clinical trials         |   |   |   |   |   | 149                   | 2.5           |
| Other  |   |   |   |   |   | 22                    | 3.5           |

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




How would you rate the importance of the following factors in discouraging you from being screened for cognitive impairment?

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* |
|---|---|---|---|---|---|-----------------------|---------------|
| Lack of information about it            |   |   |   |   |   | 143                   | 3.0           |
| Fear of learning my risk of AD          |   |   |   |   |   | 143                   | 3.2           |
| Being counseled not to by my physician  |   |   |   |   |   | 137                   | 3.8           |
| Doubts about the accuracy of the tests  |   |   |   |   |   | 144                   | 2.6           |
| Lack of effective treatment             |   |   |   |   |   | 148                   | 2.3           |
| Fear of losing health insurance         |   |   |   |   |   | 144                   | 2.3           |
| Fear of discrimination at work          |   |   |   |   |   | 141                   | 2.7           |
| Fear of losing long-term care insurance |   |   |   |   |   | 142                   | 2.3           |

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

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

| Answer   | 0%  | 100% | Number of Response(s) | Response Ratio |
|--|---|------|-----------------------|----------------|
| Nothing  |   |      | 1                     | <1 %           |
| Nothing unless there is cause to worry, such as early symptoms or family history |  |      | 29                    | 14.6 %         |
| When patients ask to be screened, advise against                                 |   |      | 0                     | 0.0 %          |
| When patients ask to be screened, advise in favor                                |  |      | 49                    | 24.7 %         |
| Proactively inform patients about the options and let them decide for themselves |  |      | 119                   | 60.1 %         |
| <b>Totals</b>  |   |      | <b>198</b>            | <b>100%</b>    |