Alzheimer’s Prevention Registry

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Alzheimer’s Prevention Registry Overview

• Launched in May 2012 to accelerate enrollment into coming prevention studies and raise awareness about Alzheimer’s prevention research
• Intended to be a shared resource to the scientific community
• Enrollees provide minimal information at sign-up, receive eblasts with study opportunities within their communities
• Complements other national efforts (Alzheimer’s Association TrialMatch) and local registry efforts
• Numerous partnerships with academic, government, patient/family advocacy, and corporations
• Modeled after other disease research recruitment registries (Army of Women, Fox Trial Finder)
National Survey

1,024 US Adults, ages 18-75
Population Representative Distribution
Conducted June 29-July 11, 2012
Margin of error +/- 3.1 percentage points

- Grand-children of Alzheimer’s Sufferers (n=252)
- Adult Children of Alzheimer’s Sufferers (n=218)
- Donors to Disease-related causes (n=212)
- Ages 50+ with Family History of Alzheimer’s (n=274)
Perception of the Registry

Interest in Learning More and Likelihood to Sign Up
(Base: National Adults)

- **Interest in Learning More**: 73% (Very), 21% (Somewhat)
- **Likelihood to Sign Up**: 60% (Very), 18% (Somewhat)
- **Encourage Others to Sign Up**: 63% (Very), 17% (Somewhat)
As an American, it is my duty to help others who are or will be afflicted by Alzheimer’s and the Alzheimer’s Prevention Registry allows me to do this.

My family has a history of Alzheimer’s disease and participating in the Alzheimer’s Prevention Registry is my way to ensure that future generations do not have to deal with Alzheimer’s as I have.

Medical research on Alzheimer’s disease treatments is very costly, and my participation in clinical trials could help cut costs.

Care for people with Alzheimer’s disease is a costly burden on the national healthcare system, and my participation could help lessen the growing costs of Alzheimer’s care.

Alzheimer’s disease is a major public health crisis. By joining the Alzheimer’s Prevention Registry, I would be helping to protect others against Alzheimer’s.

Widespread participation in clinical trials is key to medical breakthroughs in Alzheimer’s disease.

My participation could help prevent me from developing Alzheimer’s disease.

Joining the Alzheimer’s Prevention Registry may benefit or prevent my family or loved ones from suffering from this terrible disease.

% Very/Somewhat Convincing Reason to Join Registry

- Prevent loved ones from suffering: 77%
- Prevent me from developing Alzheimer’s: 73%
- Clinical trials are key to medical breakthroughs: 72%
- Alzheimer’s is a major public health crisis: 71%
- Lessen the growing costs of Alzheimer’s care: 65%
- Could help cut medical research costs: 62%
- My family has a history of AD: 57%
- As an American, it is my duty to help others: 49%
Barriers To Joining the Registry (Top Tier)

% Statement Describes My Point of View About Registry

- Don’t know enough about who is running the registry/how my data would be used: 72%
- Don’t want to be part of a trial to test an unknown drug: 66%
- Concerned about confidentiality of my health data and how it could affect my insurance: 63%
- More concerned about other health issues: 52%

At this stage in my life, I am more concerned about other health issues, not Alzheimer’s disease.

I am concerned about the confidentiality of my personal health information if I participate in research and how it could affect my ability to be insured or the cost of my insurance.

I would not want to be part of a trial to test an unknown drug.

I don’t know enough about who is running the Alzheimer’s Prevention Registry and how my data would be used.

Don’t know enough about who is running the registry/how my data would be used

Concerned about confidentiality of my health data and how it could affect my insurance

More concerned about other health issues

Don’t want to be part of a trial to test an unknown drug

More concerned about other health issues

Concerned about confidentiality of my health data and how it could affect my insurance
Alzheimer’s Prevention Registry

www.endAlZnow.org

Executive Committee

Jessica Langbaum · Marilyn Albert · Kyle Brown · Meryl Comer · Jeff Cummings
Jennifer Manly · Ron Petersen · Reisa Sperling · Gabrielle Strobel · Michael Weiner
Pierre Tariot · Eric Reiman · Maria Carrillo (ex officio)
Registry Goals

1. Keep enrollees informed of latest news, advocacy to drive focus on Alzheimer’s prevention research

2. Provide an unprecedented resource of potential study participants for Alzheimer’s prevention studies

100,000 enrollees by end of 2013; 250,000 by 2015
We can end Alzheimer’s before we lose another generation. **Will you help?**

Yes! I will join the fight to end Alzheimer’s by signing up to join the Registry. [LEARN MORE >](#)

The Alzheimer’s Prevention Initiative is an international collaboration created to find effective ways to prevent Alzheimer’s disease as quickly as possible.
Together we can create a world without Alzheimer’s.

By joining the Alzheimer’s Prevention Registry, you are helping in the fight to end Alzheimer’s. The Registry is a community of people interested in the possibility of participating in Alzheimer’s prevention studies, now or in the future. Every person who joins will greatly accelerate our research and improve our chances of ending Alzheimer’s before we lose another generation.

Once you’ve completed your registration, we urge you to recruit your family and tell your friends. For more information about Registry, we encourage you to read the FAQs.

*Required Fields

First Name

Last Name

Date of Birth

Select options

Gender

Ethnicity

Primary Phone

United States

Country

Zip/Postal Code

Email Address

Verify Email Address

Username

Password

Re-enter Password

Have you been diagnosed with mild cognitive
Alzheimer’s Prevention Registry: ORIGINAL website

Primary Phone
Zip/Postal Code
Country
Email Address
Verify Email Address
Username
Password
Re-enter Password

Have you been diagnosed with mild cognitive impairment, Alzheimer’s disease or other dementia?

Do you have a family history of Alzheimer’s disease or other dementia?

Are you a member of a family that carries a specific Alzheimer’s disease genetic mutation? This inherited form of early-onset Alzheimer’s disease is rare, making up less than 1 percent of diagnoses worldwide.

Are you a caregiver for someone with mild cognitive impairment, Alzheimer’s disease or other dementia?

How did you learn about the registry?

I have read and accepted all terms and conditions of the user agreement.

Join the Registry
Barriers to Registry Enrollment: Original Website

- Call to action is unclear
- Sign up is not clearly visible from homepage
- Sign up page has too many fields, requires scrolling
- Sign up requires creating username and password
• Survey available for 1 week, 934 responded (9%)
• Top line results:
  – Registry members want frequent communication with the latest news, and email content focused on prevention, diagnosis and treatment
  – Current (non-redesigned) site requires too many clicks, must simplify
Alzheimer’s Prevention Registry:  NEW website

NOW IS THE TIME TO TAKE ACTION TO END ALZHEIMER’S
The memories you save could be your own...

JOIN US TODAY!

Why Now

If we do nothing, as many as 16 million people will be diagnosed with Alzheimer’s disease by 2050. You can help stop this disease by joining the Registry today.

The toll of Alzheimer’s disease is reaching epidemic proportions. One in nine Americans over age 65 is living with Alzheimer’s at a cost of $203 billion annually. Someone receives a devastating Alzheimer’s diagnosis every 68 seconds in the United States. The Alzheimer’s Association is leading the fight to free our communities of Alzheimer’s and all other dementia. With your help, we will make a difference. Can you make a commitment to support and care for those with Alzheimer’s and to work to end this disease for future generations? 

By joining you agree to the Terms and Conditions.

Enter your email to join the registry

Join us to receive email updates about Alzheimer’s prevention and research opportunities in your community.

JOIN US TODAY!
Media Coverage Increases Registry Enrollment

The New York Times

AARP Blog

The New Old Age

The Indianapolis Star

The Huffington Post

The Sacramento Bee

The Arizona Republic

Detroit Free Press

USA Today

Oprah.com

The Atlanta Journal Constitution

The Enquirer

Everyday Health.com

Because Hope Matters Radio

A Place for Mom

The Record
Alzheimer’s Prevention Registry: Enrollment*

As of October 3, 2013

Monthly Enrollment
Cumulative Enrollment

Media Coverage

20,169

As of October 3, 2013
Over 20,000 enrollees

Registry website redesign went live July 2013 → sign up is easier; mobile friendly version launched in September

- Age of Registrants (%)
  - 18-30: 13
  - 31-45: 25
  - 46-60: 30
  - 61-75: 20
  - 76+: 12

- Have You Been Diagnosed? (%)
  - No: 97
  - Yes: 3

- Gender of Registrants (%)
  - Male: 70
  - Female: 30

- Family History (%)
  - No: 67
  - Yes: 23
  - Not Sure: 10
As of October 3, 2013
HOME PAGE

User Experience Survey

THIS IMAGE WAS TESTED
Over time we will test for multiple page elements

BACKGROUND IMAGE
What is the best image to use for this background?

SOCIAL PROOF
What is the impact of showing this number?

CALL TO ACTION
What is the best text for this headline?

ANXIETY
What is the best wording and position for terms & conditions?

USER EXPERIENCE SURVEY RESULTS
The following results are just the beginning. The results are not statistically significant because of the limited sample size, however, these results are helpful in exploring a variety of scenarios quickly, gaining immediate interactive feedback, and developing hypotheses that can be tested.

THE QUESTIONS

1. WHAT DO YOU THINK YOU ARE SIGNING UP FOR?
2. WHICH ELEMENT ON THE PAGE DID YOU FOCUS ON THE MOST?
3. WHAT DO YOU THINK THIS PAGE WAS ABOUT?
4. WHAT DO YOU THINK YOU WOULD JOIN BY SIGNING UP?
<table>
<thead>
<tr>
<th>What do you think you are signing up for?</th>
<th>Which element on the page did you focus on the most?</th>
</tr>
</thead>
<tbody>
<tr>
<td>fundraising</td>
<td>The text</td>
</tr>
<tr>
<td>to fight alzheimers? a newsletter maybe?</td>
<td>the large text on the left side. it was hard to read the whole sentence since it was so large. had to re-read it several times.</td>
</tr>
<tr>
<td>Sponsored charity events</td>
<td>Huge title</td>
</tr>
<tr>
<td>a petition</td>
<td>the number</td>
</tr>
<tr>
<td>an organization that helps fight alzheimers</td>
<td>the form</td>
</tr>
<tr>
<td>Not sure, didn't get that far. Read the copy on the left first, which made me think its a fundraiser</td>
<td>left copy</td>
</tr>
<tr>
<td>alzheimer's</td>
<td>right bottom button</td>
</tr>
<tr>
<td>Some kind of action group regarding Alzheimer's</td>
<td>The large graphical tagline</td>
</tr>
<tr>
<td>Information about Alzheimer</td>
<td>the number on the right side &quot;20021&quot;</td>
</tr>
<tr>
<td>an event/cause to prevent Alzheimer's</td>
<td>pledge count</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What do you think this page was about?</th>
<th>What do you think you would join by signing up?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fundraising - against Alzheimer's</td>
<td>[no response]</td>
</tr>
<tr>
<td>organization against alzheimers</td>
<td>a newsletter or maybe a donation subscription?</td>
</tr>
<tr>
<td>Charity</td>
<td>[no response]</td>
</tr>
<tr>
<td>supporting alzheimers sufferers</td>
<td>petition</td>
</tr>
<tr>
<td>showing support for alzheimer's/possibly donating</td>
<td>a newsletter</td>
</tr>
<tr>
<td>ending alzheimers</td>
<td>really not sure</td>
</tr>
<tr>
<td>alzheimer's</td>
<td>an organisation beating alzheimer's</td>
</tr>
<tr>
<td>Alzheimer's action group</td>
<td>Not sure. Probably a support organization</td>
</tr>
<tr>
<td>[no response]</td>
<td>[no response]</td>
</tr>
<tr>
<td>Alzheimer's</td>
<td>Alzheimer's cause</td>
</tr>
</tbody>
</table>
Challenges to Increasing Enrollment Numbers

• Low awareness about Alzheimer’s prevention research
• Uncertainty about participating in research, what it entails
• No reason to join if not able to join a trial TODAY
• Internet access
• Talks, community events have not resulted in signups
• No survivors to tell their story, motivate others (opposite of breast cancer)
Next Steps

• Website A/B testing
• Expand engagement tactics (drip emails, newsletters, toolkits)
• Test various outreach methods (list building, online advertising, PSAs, etc)
• Continue to engage with potential partners
Alzheimer's Prevention Registry Executive Committee and Partners

The Brain Initiative

Columbia University Medical Center

Massachusetts Alzheimer's Disease Research Center

Mayo Clinic

Roper St. Francis

Anti-Amyloid Treatment in Asymptomatic AD – The A4 Trial
The Alzheimer’s Prevention Registry is open to ANYONE age 18+, regardless of family history of Alzheimer’s

JOIN THE FIGHT TO END ALZHEIMER’S

Sign Up Today: endALZnow.org

the memories you save may be your own...
Questions?

I remember...
...the smell of grandma's kitchen

visit: endALZnow.org

Yours Is A Life Worth Remembering.

visit: endALZnow.org

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the memories you save may be your own...

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