

Alzheimer's Prevention Registry

Jessica B. Langbaum, PhD

Principal Scientist, Banner Alzheimer's Institute
Associate Director, Alzheimer's Prevention Initiative



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

**Grand-children
of Alzheimer's
Sufferers
(n=252)**

**Adult Children
of Alzheimer's
Sufferers
(n=218)**

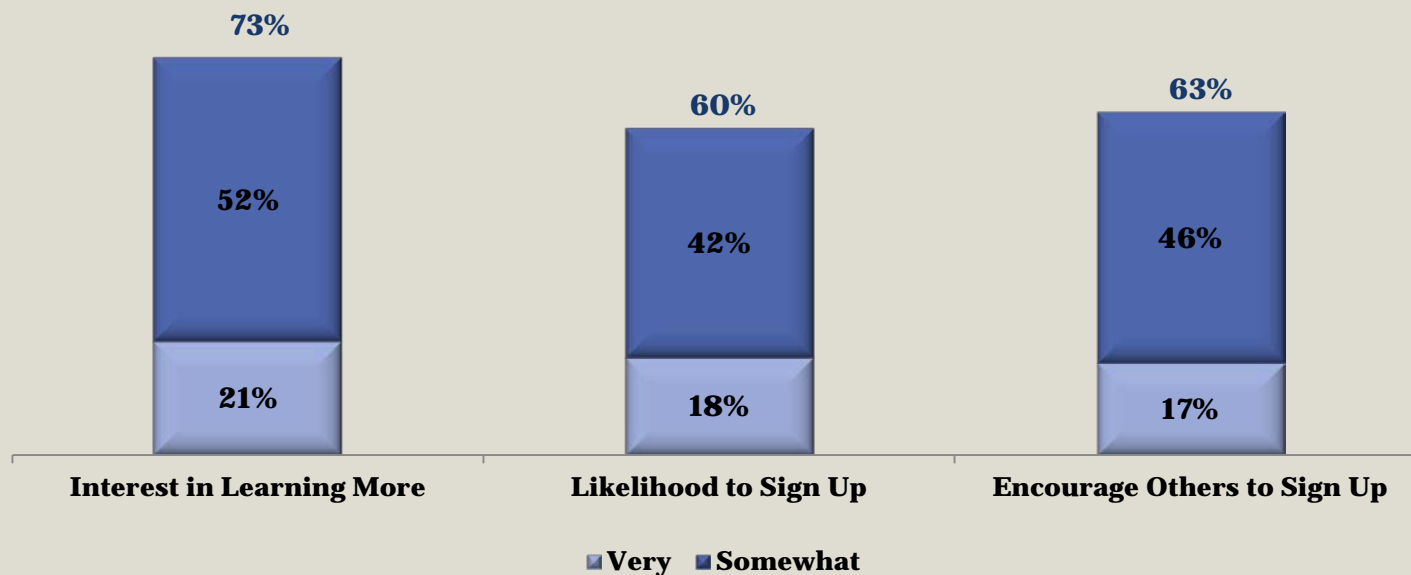
**1,024 US Adults, ages 18-75
Population Representative Distribution
Conducted June 29-July 11, 2012
Margin of error +/- 3.1 percentage points**

**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)



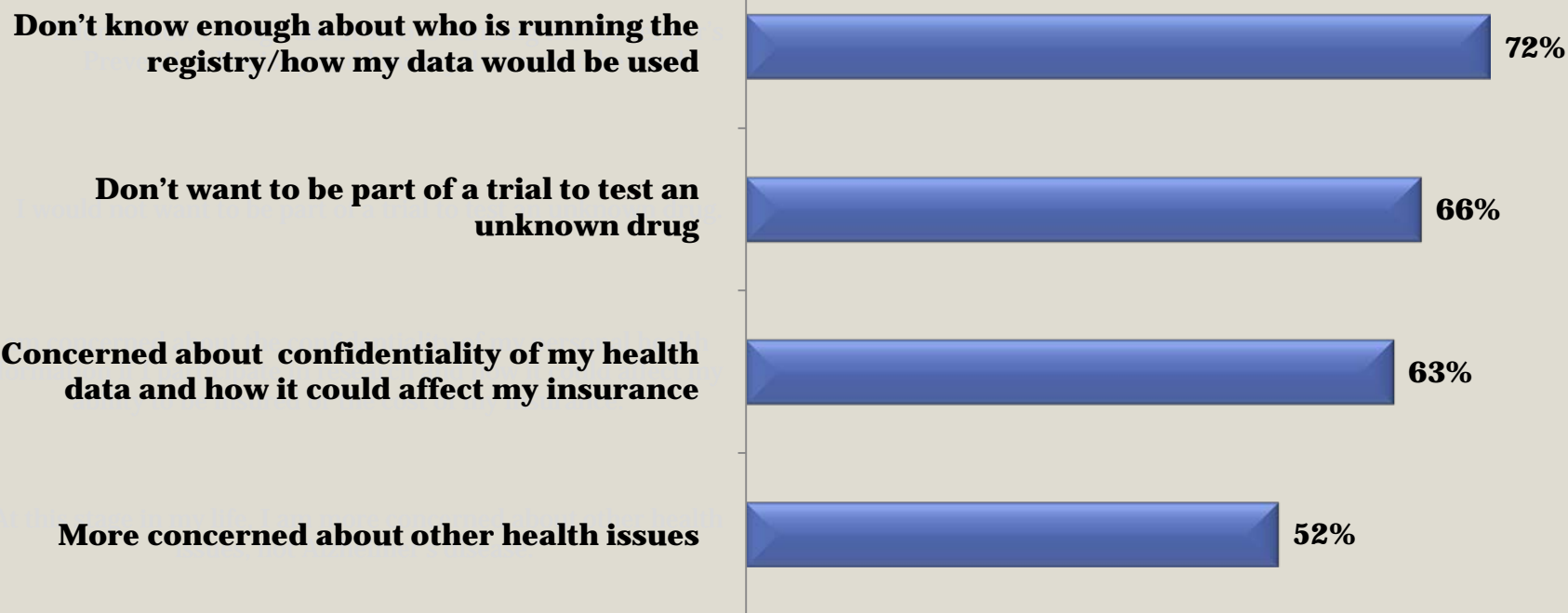
The Registry: Motivators for Joining

% Very/Somewhat Convincing Reason to Join Registry



Barriers To Joining the Registry (Top Tier)

**% Statement Describes My Point of View
About Registry**





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



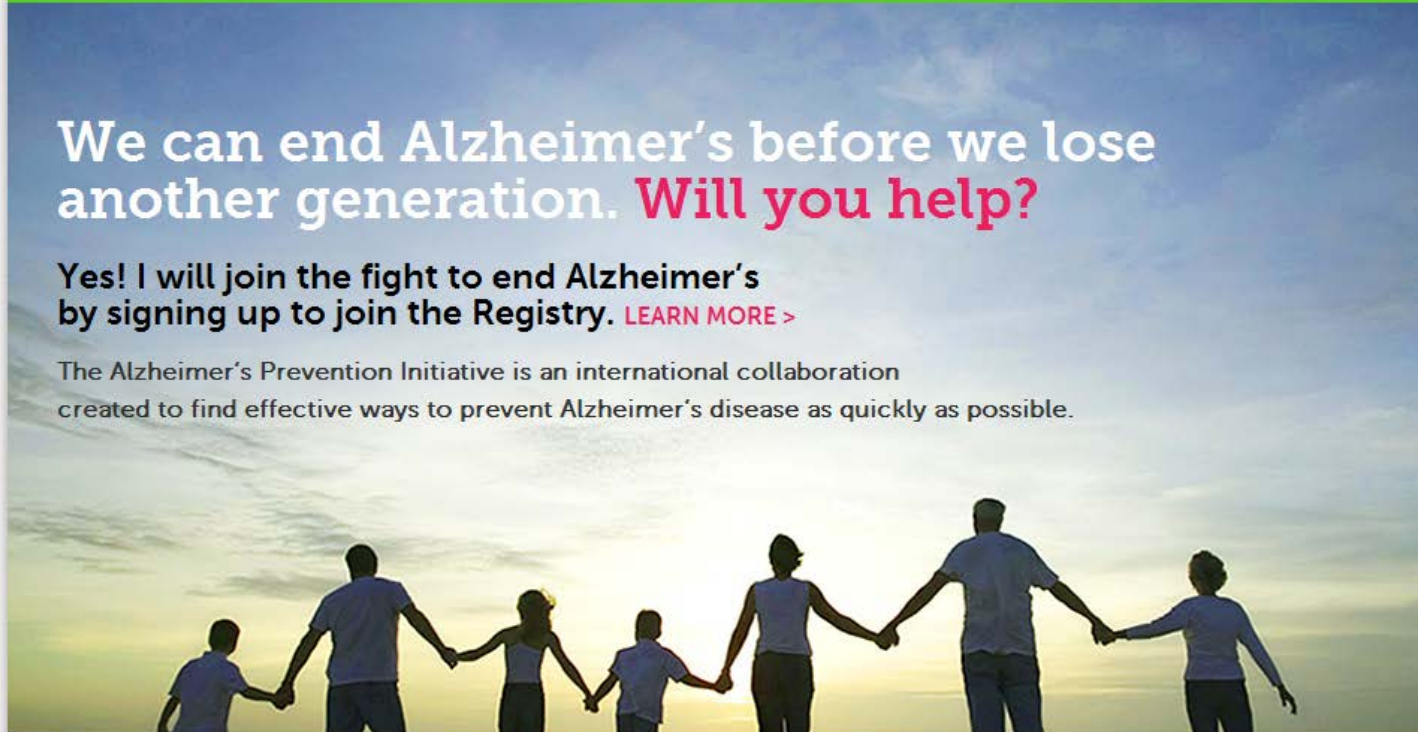
Alzheimer's Prevention Registry: ORIGINAL website



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.





Alzheimer's Prevention Registry: ORIGINAL website



ALZHEIMER'S
PREVENTION
INITIATIVE

Already registered? [Sign in](#)

A partnership to end Alzheimer's led by [Banner Alzheimer's Institute](#)

[About API](#) [About the Registry](#) [Our Partners](#) [FAQ](#) [News + Media](#) [Join the Registry](#)

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**

<input type="text"/>	<input type="text"/>
First Name *	Last Name *
<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
<input type="text"/> Date of Birth *	<input type="text"/> Select options
<input type="text"/> Gender *	<input type="text"/> Ethnicity
<input type="text"/> Primary Phone	<input type="text"/> Zip/Postal Code *
<input type="text"/> Country *	<input type="text"/>
<input type="text"/>	<input type="text"/>
Email Address *	Verify Email Address *
<input type="text"/>	<input type="text"/>
<input type="text"/> Username *	<input type="text"/> Password *
	<input type="text"/> Re-enter Password *


Have you been diagnosed with mild cognitive


WAYS TO GIVE

SHARE



Alzheimer's Prevention Registry: ORIGINAL website

UNITED STATES 


 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



Endalznow.org Website Re-imagination: Enrollee Survey

- 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



ALZHEIMER'S
PREVENTION
INITIATIVE

[Home](#) [About Us](#) [Press](#) [Contact Us](#)


[JOIN US TODAY!](#) [WHY NOW](#) [HOW IT WORKS](#) [NEWS](#) [RESOURCES](#)



NOW IS THE TIME TO TAKE ACTION TO END ALZHEIMER'S

The memories you save
could be your own...

JOIN **020169** OTHERS

 [Enter your email to join the registry](#)

By joining you agree to the
[Terms and Conditions](#)

JOIN US TODAY ▶

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

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



Media Coverage Increases Registry Enrollment

The New York Times

AARP BLOG

THE INDIANAPOLIS STAR

THE ARIZONA
REPUBLIC



THE
HUFFINGTON
POST

Detroit Free Press



The Sacramento Bee

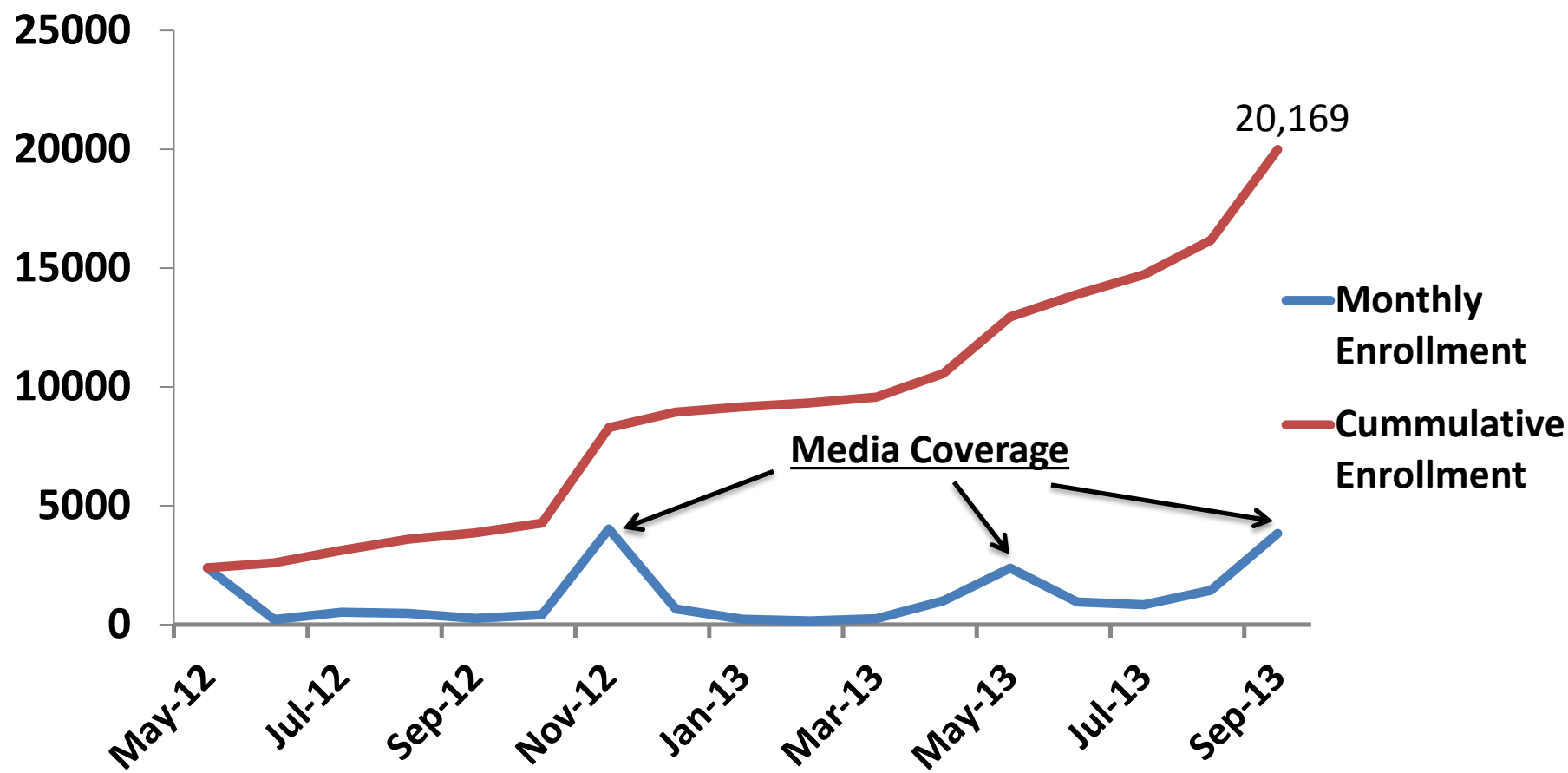
The Atlanta
Journal-
Constitution

THE
ENQUIRER
Cincinnati.com





Alzheimer's Prevention Registry: Enrollment*

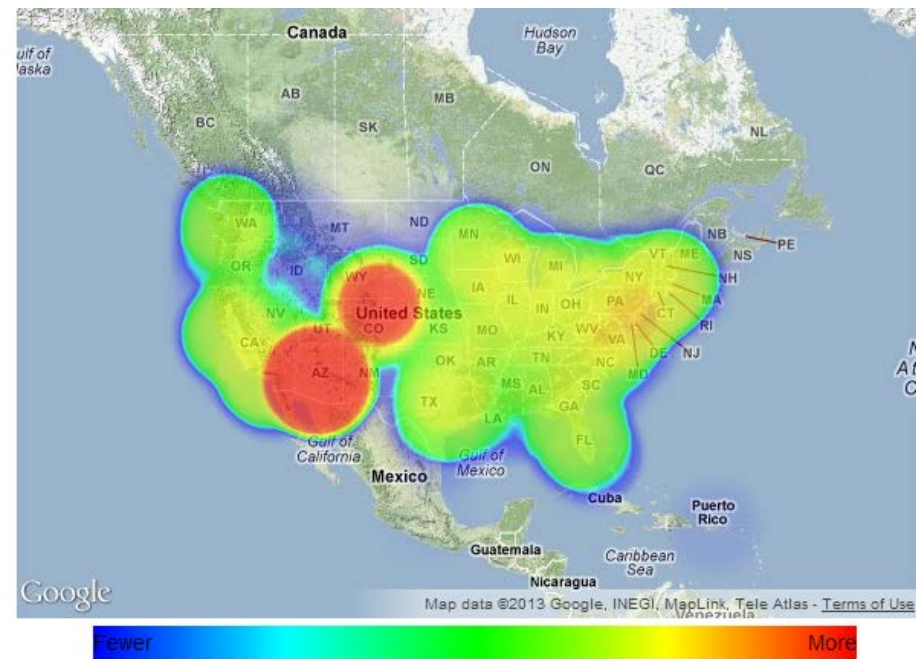
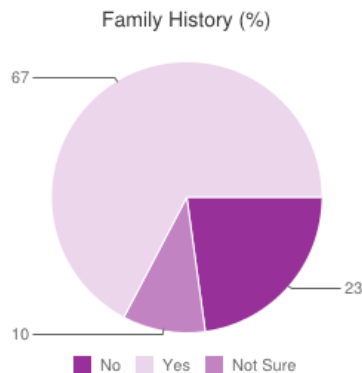
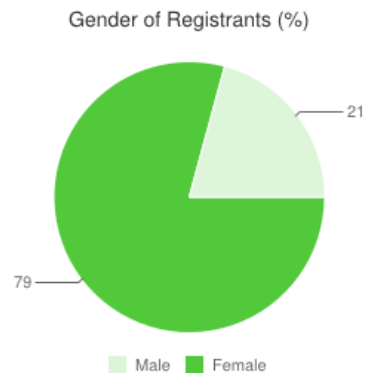
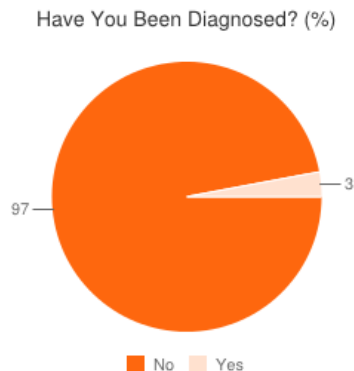
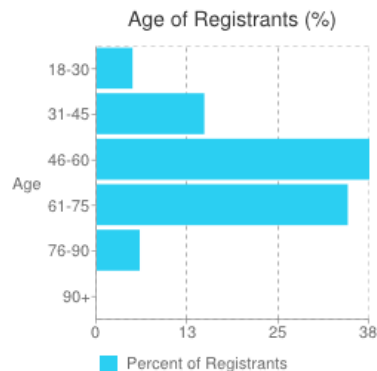


As of October 3, 2013



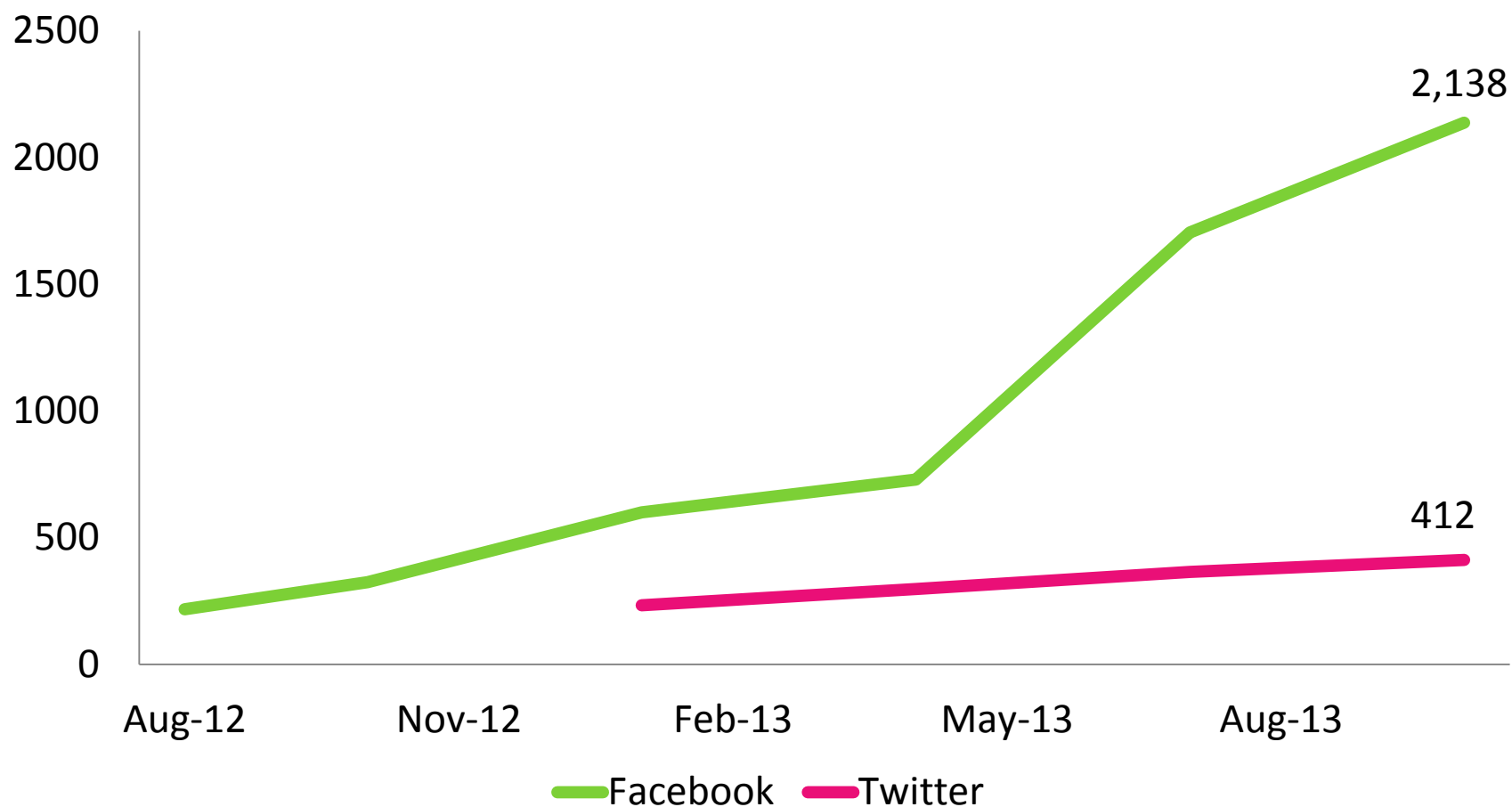
Alzheimer's Prevention Registry: Current Status

- Over 20,000 enrollees
- Registry website redesign went live July 2013 → sign up is easier; mobile friendly version launched in September





Social Media Summary*



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



What do you think you are signing up for?

fundraising

to fight alzheimers? a newsletter maybe?

Sponsered charity events

a petition

an organization that helps fight alzheimers

Not sure, didn't get that far. Read the copy on the left first, which made me think its a fundraiser

alzheimer's

Some kind of action group regarding Alzheimer's

Information about Alzheimer

an event/cause to prevent Alzheimer's

What do you think this page was about?

Fundraising - against Alzheimer's

organization against alzheimers

Charity

supporting alzheimers sufferers

showing support for alzheimer's/possibly donating

ending alzheimers

alzheimer's

Alzheimer's action group

[no response]

Alzheimer's

Which element on the page did you focus on the most?

The text

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.

Huge title

the number

the form

left copy

right bottom button

The large graphical tagline

the number on the right side "20021"

pledge count

What do you think you would join by signing up?

[no response]

a newsletter or maybe a donation subscription?

[no response]

petition

a newsletter

really not sure

an organisation beating alzheimer's

Not sure. Probably a support organization

[no response]

Alzheimer's cause



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
INITIATIVE

Alzheimer's Prevention Registry Executive Committee and Partners

alzheimer's association®
trialmatch®



US Against Alzheimer's
we can stop it by 2020.

**GEOFFREY BEENE
FOUNDATION**
ALZHEIMER'S INITIATIVE

 **The Brain Initiative**

**GLOBAL
CEO INITIATIVE**
— ON ALZHEIMER'S DISEASE —

 **Banner Alzheimer's
Institute**

 **ADNI**

 **JOHNS HOPKINS
SCHOOL of MEDICINE**
ALZHEIMER'S DISEASE RESEARCH CENTER



 **COLUMBIA UNIVERSITY
MEDICAL CENTER**

mindcrowd
A research project by TGen



**MASSACHUSETTS
alzheimer's disease
research center**

**MAYO
CLINIC**




B.A.B.E.S.
BEATING ALZHEIMER'S BY EMBRACING SCIENCE

ROPER  **ST. FRANCIS**
CLINICAL BIOTECHNOLOGY RESEARCH INSTITUTE - CBRI

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

**JOIN THE
FIGHT
TO END
ALZHEIMER'S**

*the memories you
save may be your
own...*

visit:

endALZnow.org

SIGN UP TODAY:

endALZnow.org

visit:

endALZnow.org