

Using Social Media for PR and Patient Recruitment

Presented by

Jeffrey Itrich

Sr. Communications and Recruitment Specialist

ADCS, University of California San Diego

Electronic Media Evolves

- The media world is changing constantly.
- Social media and the internet changed how we communicate.
- Credible news comes from many electronic sources other than print, television and radio.
- To thrive, traditional media outlets must embrace electronic and social media.

What Exactly is Social Media?

- Social media are websites and applications used for social networking - allowing people to interact through website.
- Social networking is “the use of dedicated websites and applications to communicate with other users, or to find people with similar interests to one’s own”.*

* Oxford English Dictionary

Examples of Social Media

- Facebook, Twitter, LinkedIn, Tumblr (microblogging), YouTube, Google+, blogs, video/photo sharing, online encyclopedias (Wikipedia), Pinterest.
- Began as a way for people to connect and recommend others for linkage.
- Has grown to include business, academic and commercial communities.

More Ways to Engage Online:

- <http://www.indiegogo.com> – a crowdfunding site that finds donations to support projects.
- <http://www.kickstarter.com> – the world's largest funding program for creative projects.
- <http://crowdsourcing.org> – lists wide variety of crowd sourcing websites offering a wide variety of help.

Social Media Stats

- Nielsen research: Americans spend 23% of their online time on social networks (SN) & blogs.
- Average US internet user spends 32 hrs online each month = the equivalent to 4 million years online.
- Pew Research Center: 2/3 of adults using SN up 29% from 2008. 57% of American adults web surf for health information.
- Nielsen reports twice as many Americans 50+ visit social sites compared to the under 18 users.
- Dazeinfo reports that 1.43 billion internet users will log onto SN sites in 2012.

More Stats ...Think caregivers

- 57% of Facebook and 59% of Twitter users are women.
- 28% of Facebook users are 35 and older. 28 million are people 45+.
- 28% of Twitter's users are 30+.
- 25% of African Americans use Twitter compared to 9% of whites.
- Adults 55+ are the fastest growing age segment of SN.

What's the Facebook Story?

- As of April 2012 Facebook (FB) has 901 million active monthly users, 526 million are daily visitors.
- More than 13% of the world's population is now on FB = most popular SN in the world.
- DoubleClick statistics show: FB reached one trillion page views in 6/2011, making it the most visited website in the world.
- On average people spend eight hours a month on FB.

Tweet....Tweet....Tweet....

- Twitter is rapidly gaining in popularity.
- Generates over 1.6 billion search queries per day.
- Ranked as one of the 10 most-visited websites worldwide by Alexa's web traffic analysis.
- Twitter now has 140 million active users sending 340 million tweets per day.

Our Audience is Online

- It remains a common misconception that older people don't use social media.
- Social networking is growing among older users
 - Users 65+ grew 150% between 2009 and 2011 from 13% to 33%.
 - 47% of internet users ages 50-64 and 33% of internet users ages 65 and older are using social media*

*Madden, M. (2010). Older Adults and Social Media. *Pew Internet*, 1-13.

Beta Testing in the ADNI Trials

- The ADNI clinical trials have included funding for coordinating center recruitment activity – enabling us to beta test a number of social media tactics over the last two years.
- In ADNI, we have the full engagement of the PI - Mike Weiner, MD from UCSF - in our social and traditional media work.

The ADNI GO Trial

The Alzheimer's Disease Neuroimaging Initiative Grand Opportunity (ADNI GO) study was the first ADCS study to:

- Have a Facebook page
- Experiment in the social “mediasphere” to reach audiences.
- Use of website banner ads and electronic publication of blogs and articles.
- Since 2009, the ADNI GO FB page evolved into the ADCS FB page with both general AD news & news about all ADCS studies.

Sponsored

American Action Network



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Do-It-Yourself Marketing

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August

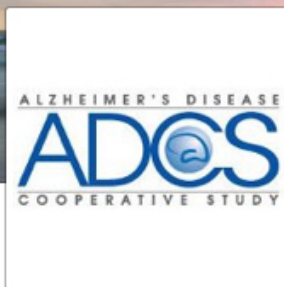
2012

2011

2010

Founded

Chat



Alzheimer's Disease Research

862 likes · 12 talking about this

Like

Message



Non-Profit Organization

Be a research participant today and make a difference for tomorrow!

About



Photos

862

Likes

Highlights



Alzheimer's Disease Research shared a link.

23 minutes ago

Dr. Mike Rafii writes on what AD research can learn from cancer research. Fascinating blog post.

<http://adcs.org/Blog/ADCSBlog.aspx>

FOLLOW US
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ADCS Blog
adcs.org

The Alzheimer's Disease Cooperative Study is a national research consortium funded by the National Institute on Aging which conducts multi-center clinical trials and

Likes

See All



eBags

Retail and Consumer Merchandise

Like



Northwestern University's Alzheimer's Disease Center (CNADC)

Product/Service

Like



National Institutes of Health (NIH)

Medical & Health · Government Agency

Like



Butler Hospital

Landmark

Like

Example of ADNI GO Banner Ad

everydayHEALTH

TODAY'S THE DAY

Register | Sign In


Newsletters

Search

SEARCH

HomeHealth A-ZDrugs A-ZSymptom CheckerFood and FitnessCommunityHealth ToolsMy Everyday Health

Every 70 seconds another person develops Alzheimer's, affecting 5.3 million Americans.



Happiness and Emotional Well-Being

A healthy diet and exercise are great for your body, but don't neglect your emotional health and well-being. Reducing stress, getting enough sleep, and having fun are all ways to find happiness.

By Diana Rodriguez
Medically reviewed by Pat F. Bass III, MD, MPH

When your mind is frazzled and stressed, and your emotions are taking over your thoughts and affecting your everyday activities, it's time to take a step back, take a deep breath, and relax. Of course focusing on your physical health is crucial, but so is treating your mind and spirit to the same attention. Your happiness goes a long way in protecting your overall well-being.

Happiness and Well-Being: Why It's Important

Emotions are one aspect of a person's health that often get neglected. But if your **emotional health** is suffering, your physical health will too.

Your emotional health is just a term for how you feel — your overall happiness and well-being. Are you stressed? Unhappy? Unsatisfied? Worried and anxious? Then your emotional health needs some serious attention, or your body will start paying the price.

Happiness and Well-Being: How It Feels


Being emotionally healthy is a huge plus. People with good emotional health:

- Believe that there is a good balance to their life between leisure time, activity, and work
- Feel good about themselves, and don't suffer from self-esteem issues
- Believe that there is a purpose to their lives
- Are able to accept changes better and just go with the flow
- Enjoy living, and know the value of fun and laughter
- Have less stress, and are better equipped to deal with **stress**

Related Topics

- ADD/ADHD
- Addiction
- Anxiety Disorders
- Bipolar Disorder
- Depression
- Schizophrenia
- Return to the Emotional Health Center

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No need to go to the drugstore. Send your questions to our pharmacists and you'll get an answer in your inbox — for free!

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Related Articles on Emotional Health


- **The Importance Of Friendships**
Being with friends is not only fun, it can be good for your health, too.
- **The Power Of Positive Psychology**
Positive psychology is a research field that looks at what makes people happy and suggests ways to increase an optimistic outlook...
- **Emotional Health Center - Everyday Health**
When emotional and mental well-being is compromised, other parts of our lives suffer as well...

Related Blogs on Emotional Health

- **A Tide Of Emotions**

EverydayHealth.com
Banner Placement

ALZHEIMER'S
DISEASE
NEUROIMAGING
INITIATIVE



Example of ADNI GO Blog

A screenshot of a Windows Internet Explorer browser window displaying a blog post titled "A Grand Opportunity for Alzheimer's Disease". The browser's address bar shows the URL: http://www.dailyspark.com/blog.asp?post=a_grand_opportunity_for_alzheimers_disease&utm_source=twitterfeed&utm_medium=twitter. The browser's menu bar includes File, Edit, View, Favorites, Tools, and Help. The toolbar shows various icons for navigation and search. The browser's status bar at the bottom indicates the page is from "Internet" and is 100% zoomed.

The blog post is titled "Your Healthy Lifestyle Blog" and "A Grand Opportunity for Alzheimer's Disease". It is written by Tanya Jolliffe on 6/14/2010 at 5:28:43 AM, with 84 comments and 8,926 views. The post features a photograph of an elderly man looking down at a newborn baby.

Ronald Reagan, Charlton Heston, Rita Hayworth, and Mary Ellen Westerman are all people that had one thing in common. The first three names are people that were important to the world in one way or another but the last was someone that was important to me. Mary Ellen Westerman was my grandmother and although she was physically healthy when she turned eighty, like millions of other people she battled a degenerative disease of the brain.

This degenerative brain disease is known as Alzheimer's and it causes a gradual loss of memory, judgment, and ultimately the total ability to function. As was the case with my grandmother, dementia typically appears in older people as subtle forgetfulness that worsens and limits their ability to function normally in many aspects of daily life. Familiar settings become confusing, memories focus on places and experiences from many years before, and routine tasks turn into a challenge. The decline of my grandmother stood in stark contrast to my then newborn son. As he was learning to walk, talk, and feed himself, she was losing her ability to do the same. Eventually like most others, she required total care during her advanced stages of the disease before losing the battle due to general body wasting. It is estimated that about 5.3 million people in the United States have Alzheimer's disease. Unfortunately for my family, not only does the risk of contracting the disease go up as we get older, it is also higher if a family member has had the disease. Since my husband also lost his grandmother to the same disease, I suppose the race is on to see which of us forgets the other first.

I previously told you about a participation opportunity for the [VITAL study](#), a research study designed to see if taking omega 3 fatty acids or vitamin D supplements could reduce the development of cancer, heart disease and strokes in healthy people. Now there is another opportunity I wanted to bring to your attention.

In October of 2004, the Alzheimer's Disease Neuroimaging Initiative (ADNI) started as a public-private partnership study to collect and evaluate specific disease indicators like genetic profiles and blood biomarkers. As the collection got underway, the original goal quickly shifted to using biomarkers for

Affordable Alzheimer's Care
Get Free Information on Affordable Alzheimer's Care Across the U.S.
SeniorLivingSource.org/Alzheimers

San Diego Coupons
1 ridiculously huge coupon a day. Like doing San Diego at 90% off!
www.Groupon.com/San-Diego

Alzheimer's Foundation
Help Those Who Help Your Loved One. Donate to Caregivers Today!
alzfdn.org


Alzheimer's Research
Investigational Drug Treatment - Phase 3 Trial Seeking Patients Now
www.CancerStudy.com

Ads by Google

Related Entries

- [Do Vacations Really Make You Happier?](#)
194 Comments
- [Senior Playgrounds Offer New Exercise Options](#)
110 Comments
- [A Younger Look May Mean Living Longer](#)
104 Comments
- [The Secret to Staying Sharp as We Age](#)
94 Comments
- [New Study Uncovers a Surprising Health Risk for Pear-Shaped Women](#)
84 Comments

Example of ADNI 2 Landing Page for Geotargeted Ad Campaign



How will you change the face of Alzheimer's disease?

Alzheimer's Disease Neuroimaging Initiative

ADNI is a landmark study to find more sensitive and accurate methods to detect Alzheimer's Disease (AD) at earlier stages and mark its progression through biomarkers. This research could speed the search for new treatments. Scientists are looking for new ways to measure changes in the brain that occur with normal aging and with the progression of mild cognitive impairment, often a precursor to AD.

Seeking people who:

- Are between 55 and 90 years of age
- Have mild cognitive impairment (MCI) or mild to moderate AD
- Willing and able to undergo test procedures

Help make a difference!

Be a part of the historic ADNI study

Name *

Email *

Zip Code *

[Learn More](#)

We will never send you spam. Promise.

ADNI Beta Testing Continued

ADNI “earned” media is the focus of ADNI 2 and enjoys a significant blog and news



The New York Times Magazine

How Does the ADCS Use Social Media Today?

- The ADCS Blog *Alzheimer's Insights*.
- Mike Rafii, MD (UCSD) and Neelum Aggarwal, MD (Rush) alternate weeks sending in posts. Since mid-2010 the blog has received nearly 38k views.
- When we post their articles we link the page to our FB & Twitter pages.

Example of ADCS Blog Page



The screenshot shows a web browser window displaying the ADCS Blog page. The browser's address bar shows the URL <http://adcs.org/Blog/ADCSBlog.aspx>. The page features a header banner with the text "ALZHEIMER'S DISEASE COOPERATIVE STUDY" and "Advancing Alzheimer's Disease Therapeutic Research". Below the banner is a navigation menu with links: Home, Alzheimer's Disease, ADCS, Public & Participants, ADCS Investigators, Academic & Industry, and Donors. The main content area is titled "Alzheimer's Insights: an ADCS Blog" and includes a "Recent Post" section. The recent post is dated Thursday, March 15, 2012, and is titled "The Effect of Statin Drugs on Memory". The post text discusses the FDA's review of adverse events related to statin therapy and its effect on cognition. To the right of the main content, there is a sidebar with sections: "Archive" (listing years 2010, 2011, and 2012), "Helpful Sites" (listing ADEAR, Alzheimer's Association, Alz Forum, Alzheimer's Foundation of America, Alzheimer's Poetry Project, and ClinicalTrials.gov), and "About Us" (providing background on the Alzheimer's Disease Cooperative Study (ADCS)).

ALZHEIMER'S DISEASE COOPERATIVE STUDY

Advancing Alzheimer's Disease Therapeutic Research

Home Alzheimer's Disease ADCS Public & Participants ADCS Investigators Academic & Industry Donors

Home > ADCS > Alzheimer's Insights: an ADCS Blog

 Alzheimer's Insights:
an ADCS Blog

[Recent Post](#)

Thursday, March 15, 2012

The Effect of Statin Drugs on Memory

The FDA recently reviewed their national database of reported adverse events, published medical literature, and randomized clinical trials to evaluate the effect of statins on cognition. Based on their review, they have decided to add memory-problems to the list of potential side-effects of this class of medications.

The adverse event reports generally described individuals over the age of 50 years who experienced notable, but poorly-defined memory loss that was reversible upon discontinuation of statin therapy. Time to onset of the event was highly variable, ranging from one day to years after taking the statin medication. None of the cases reported were associated with Alzheimer's disease. The review also did not reveal an association between the adverse event and a specific statin, the statin dose, or any interaction between statins and other medications. Finally, the data did not suggest that statin use leads to clinically significant cognitive decline.

In this blog, I would like to review some data from the scientific literature on the effect of statins on cognition. One of the larger clinical trials to include the effect of statins on memory is the 17,802-patient study of Crestor called JUPITER. This study showed that Crestor reduced the risk of a major cardiovascular or cerebrovascular event by 44%. In these people, the risk of a heart problem during the course of the study was low: 142 of

Archive

Expand All Collapse All

- + 2010
- + 2011
- + 2012

Helpful Sites

-  ADEAR
-  Alzheimer's Association
-  Alz Forum
-  Alzheimer's Foundation of America
-  Alzheimer's Poetry Project
-  ClinicalTrials.gov

About Us

The Alzheimer's Disease Cooperative Study (ADCS) was formed in 1991 as a cooperative agreement between the National Institute on Aging (NIA) and the University of California, San Diego. The ADCS is a major initiative for Alzheimer's disease (AD) clinical studies in the Federal government, addressing treatments for both cognitive and behavioral symptoms. This is part of the NIA Division of Neuroscience's effort to

The ADCS & Social Media


Cont'd.....

- Alzheimer's Disease Information Newsletter (ADIN). This e-newsletter goes out to over 3,100 subscribers worldwide the beginning of each month.
- When it goes out we post it on adcs.org and link on FB & Twitter.
- Each week as we find AD articles of interest we post to both and to the adcs.org research news page.

Example of ADIN

Alzheimer's Disease Information Network
ADIN Monthly E-News

Alzheimer's Disease
Cooperative Study
September 2012
No. 46



**Timing is Everything:
Immunotherapy Results Illustrate Need for
Earlier Intervention**

By Michael Rafii, MD, PhD
Director, Memory Disorders Clinic
Associate Medical Core Director
Alzheimer's Disease Cooperative Study
University of California, San Diego

As many of you have undoubtedly read or heard, results from multiple clinical trials were reported this past summer involving both Bapineuzumab and Solanezumab, two of the leading drug candidates under development for slowing down the progression of AD. Solanezumab and Bapineuzumab are both classified as immunotherapies. These drugs are monoclonal antibodies against beta amyloid, the protein that accumulates in the brain of patients with AD and is thought to be causative of the disease. The studies were all large, Phase 3, double-blind, placebo-controlled trials in patients with mild-to-moderate AD.

Although the trials were negative, a possible efficacy signal was discovered in prespecified secondary analyses of Solanezumab trials, offering a glimmer of hope. When data from the two Solanezumab trials were combined, the results suggested a significant slowing of cognitive decline in the overall study population. Furthermore, a statistically significant effect on cognition was noted in the mild AD patient subgroup, but not moderate AD subgroup, as compared to placebo. In its release of the trial results, Lilly emphasized that these are the first Phase III data with an anti-beta amyloid agent that appear to show a slowing of cognitive decline, and that the pooled data support the amyloid hypothesis.

The results indicate that drugs against beta-amyloid will need to be tested even earlier in the course of the disease, perhaps in the prodromal stage where symptoms are even milder. This concept of earlier treatment is akin to the need to start cholesterol medication years before a heart attack occurs in order to derive benefit from its use.

Despite the negative results for Bapineuzumab, Pfizer and Johnson & Johnson remain committed to its development as a potential therapy, and in fact, will continue with another trial of bapineuzumab that is being delivered as a subcutaneous injection, rather than intravenous treatment. This method of drug delivery may actually overcome some of the barriers faced by intravenous Bapineuzumab, in that the drug may linger in the system for longer by virtue of the subcutaneous route, and have longer access times to beta-amyloid in the brain.

The Alzheimer's disease community now awaits the upcoming American Neurological Association (ANA) annual meeting and the Clinical Trials in Alzheimer's disease (CTAD) conference in October, as the full analysis on the pooled and subgroup data are released.

CTAD 2012
5th Conference

Clinical Trials in
Alzheimer's Disease
October 29-31
Monte Carlo
Grimaldi Forum

CTAD is accepting late
breaking abstracts
beginning
September 1, 2012

CTAD 2012
<http://ctad.fr/>

Recent posts in the
ADCS Blog...

Dementia Incidence,
Cognitive Reserve and
Mortality...

The Response to AD...
www.adcs.org

The new HHS website
designed for AD
caregivers
www.alzheimers.gov

This newsletter is
prepared monthly by
the Alzheimer's Dis-
ease Cooperative
Study at the University
of California, San
Diego. Content is
intended to educate
the public about AD
research endeavors
and other AD issues.

Questions or com-
ments?
Please email:
brainlink@ucsd.edu

Tweet, tweet, tweet.....



Twitter

Search

Have an account? [Sign in](#)

 **Jeffree Itrich**
@ADCSComm

The ADCS is an NIH-funded national consortium of Alzheimer's disease researchers conducting AD clinical trials throughout the U.S. and Canada.
San Diego, CA · <http://www.adcs.org>

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468 TWEETS

860 FOLLOWING

524 FOLLOWERS

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Tweets

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Tweets

 **Jeffree Itrich** @ADCSComm 18 Sep
If you or a loved one have [#AD](#), please volunteer for the ADNI study. We need participants with [#Alzheimer's](#). adcs.org/Studies/Imagin...
[Expand](#)

 **Jeffree Itrich** @ADCSComm 12 Sep
NFL players in at least 5 seasons are 3 times more likely to die of a neurodegen disease than the gen'l population.
adcs.org/Alzheimers/New...
[Expand](#)

 **Jeffree Itrich** @ADCSComm 12 Sep
Dr. Mike Rafii writes on what [#Alzheimer's](#) research can learn from [#Cancer](#) research. Fascinating blog post.
adcs.org/Blog/ADCSCBlog...
[Expand](#)

 **Jeffree Itrich** @ADCSComm 6 Sep
Dr. Mike Rafii writes about the FDA's approval of the higher dose [#Exelon](#) Patch & JNK3 elimination in [#AD](#) mice.

Using Visuals to Harness SM.....

Videos:

- [NGF study video](#) on adcs.org and YouTube
- [ADNI2 video](#) on ADCS.org

YouTube

Edit info

Edit video

[Edit annotations](#)

[Edit captions/subtitles](#)

[AudioSwap](#)

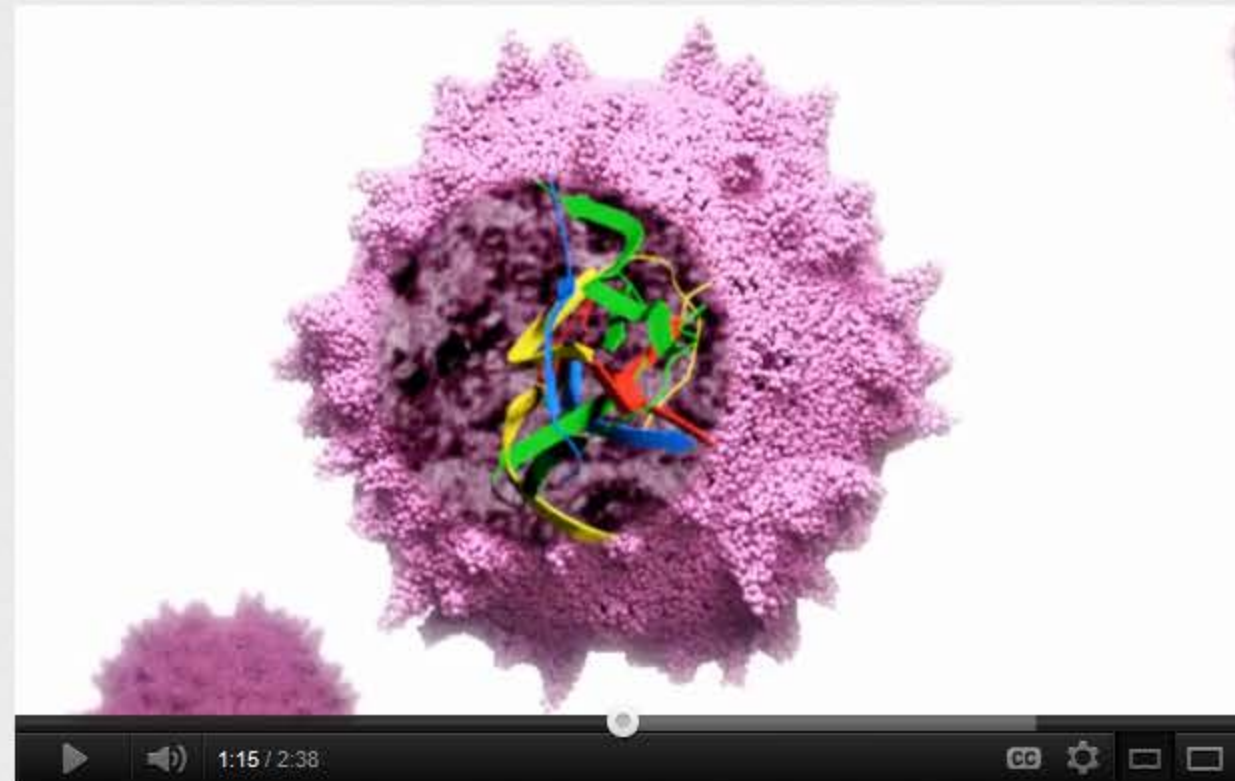
[Analytics](#)

Nerve Growth Factor Study for Alzheimer's Disease

Jitrich1

Subscribe

1 video ▾



The Scope of ADCS Social Media Outreach to Date

- 862 Facebook likes (9-19-12)
- 468 Tweets to 524 followers (9-19-12)
- What does this mean?
 - The social media conundrum:
Lots of followers (quantity) just for the sake of high numbers vs fewer (quality) who have an interest in AD

Facebook Stats Sept 2012

Total Likes?

862 ↑0.58%

Friends of Fans?

350,004 ↑1.98%

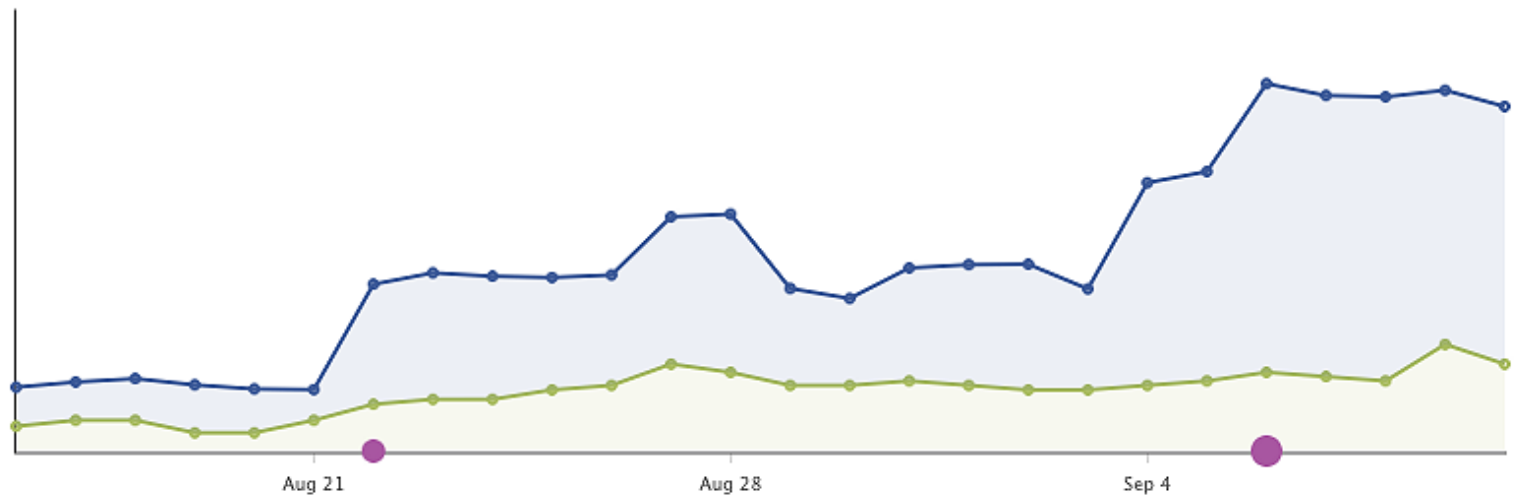
Weekly Total Reach?

776 ↑173.24%

Total Subscribes

--

Posts? People Talking About This? Weekly Total Reach?

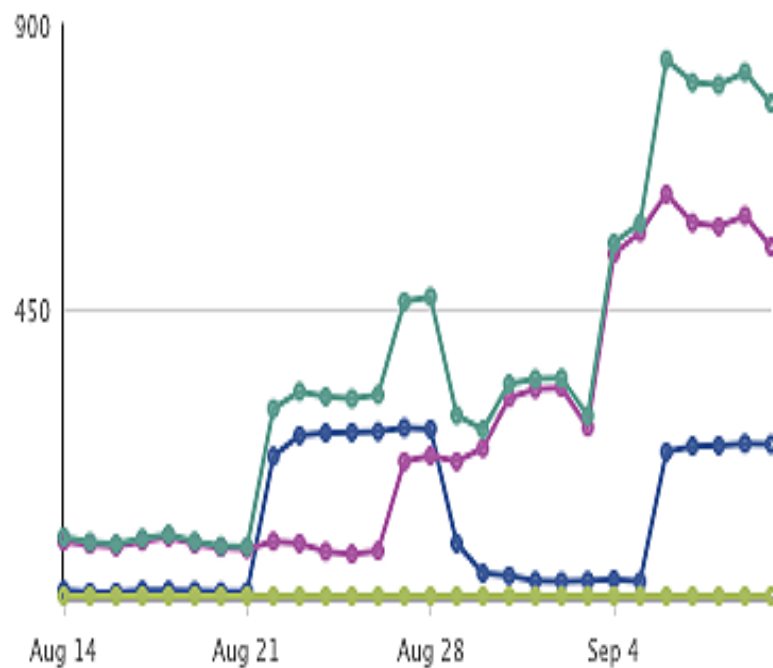


How You Reached People (Reach and Frequency)

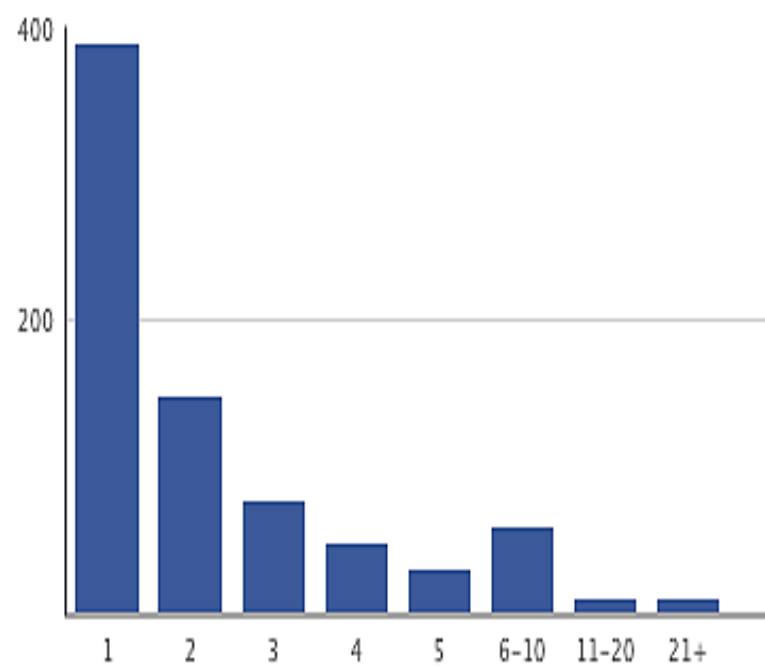
All Page Content ▾

Reach?

☒ Organic? ☒ Paid? ☒ Viral? ☒ Total?



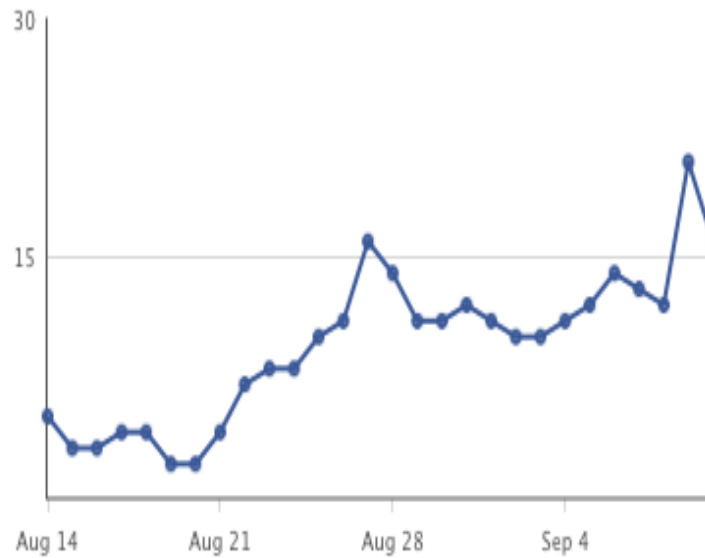
Unique Users by Frequency?



How People Are Talking About Your Page

All Stories ▾

Talking About This?



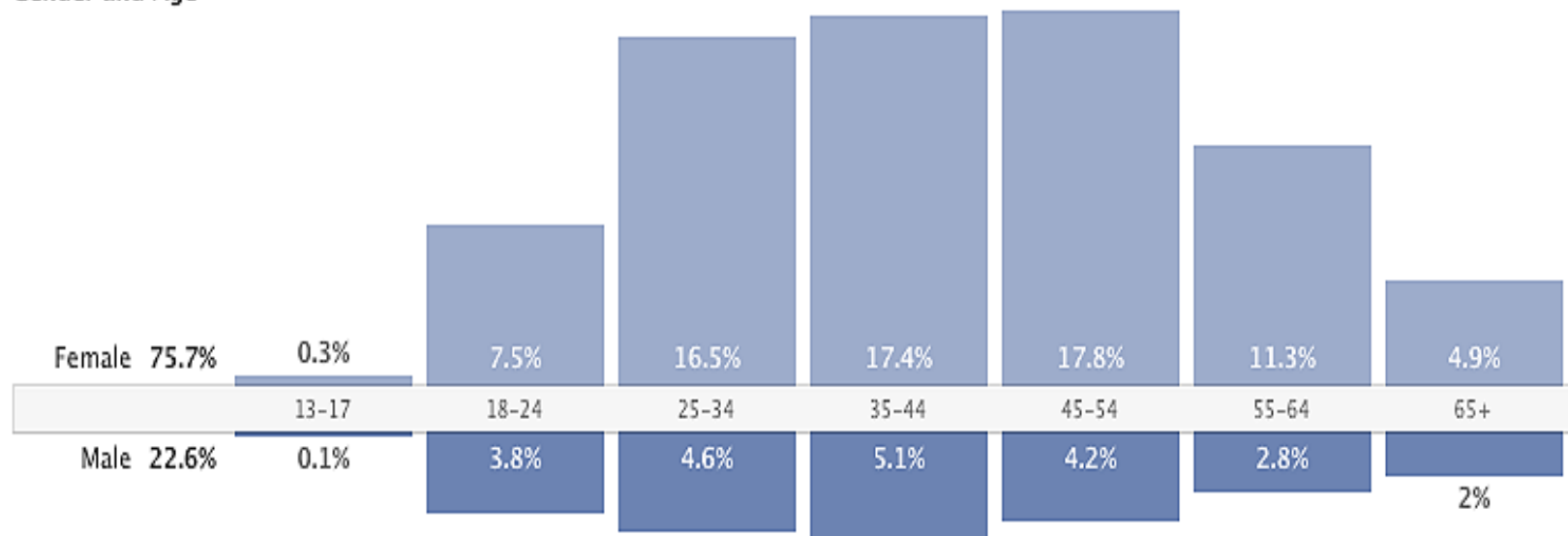
Viral Reach?



People Who Like Your Page (Demographics and Location)

[See Likes](#)

Gender and Age?



Countries?

673 United States of America
 24 United Kingdom
 17 Brazil
 13 India
 11 Canada
 7 Australia
 7 Norway

[More ▼](#)

Cities?

30 San Diego, CA
 11 Los Angeles, CA
 10 New York, NY
 9 Philadelphia, PA
 8 Dallas, TX
 6 Washington, DC
 6 Atlanta, GA

[More ▼](#)

Languages?

733 English (US)
 59 English (UK)
 15 Portuguese (Brazil)
 8 Spanish
 6 Norwegian (Bokmal)
 6 Spanish (Spain)
 5 German

[More ▼](#)

Why Should a Research Organization Use Social Media?

The Good News:

- Huge free media exposure opportunity for studies.
- Can “geotarget” online ads to reach specific populations in specific geographic areas.

The Bad News:

- “Going Viral – can’t be planned but can be planned for. It can be a huge boost but can turn into a nightmare if the information is wrong.
- No way to stop “the message”.

Increase in Web Activity on ADCS.org

Visits to the ADCS.org website as of
Sept 21, 2012:

- Homepage : 276,029 (up 56,169 since 3/2012)
- Blog: 37,986 (up 5,506 since 3/2012)
- ADNI GO/ADNI 2 combo: 23,948 (up 9,975 since 3/2012)
- NGF Study: 17,593 (up 3,128 since 3/2012)
- Total website visitors: 529,792 (up 155,303 since 3/2012)

How to Create Conversations with the Public Using Social Media

- Visit various social networks, find one or more that fits your organization.
- Connect with followers to provide info on current AD research.
- Converse with blogosphere to answer AD & study questions.
- Follow the 4 C rule: **Consistently Create Compelling Content**. If it's not interesting or you don't "show up" your followers will desert you and not come back.

An Example of Tracking SM Use

A Weekly Summary of UCSD Health Sciences in the Media

- **Week of September 10**

Facebook: likes 4,853 (+83) Google+: followers 643 (+7)
Tumblr: followers 19,508 (+570) Twitter: followers 3,801 (+10)
YouTube: views 9,040

- **NATIONAL & INTERNATIONAL MEDIA**

- “Amino-acid deficiency underlies rare form of autism,” **Nature**, features **Joseph Gleeson, MD**
- “Gene therapy restores sense of smell to mice,” **Nature**, features **Joseph Gleeson, MD**
- “*Alzheimer’s drugs take a new tack*,” **Nature**, features *Paul Aisen, MD*

Final Thoughts

- Clearly your audience is online, are you?
- The media landscape is ever changing – use it to benefit the public and your org.
- Utilize the opportunity for free media.
- Reach and create conversations with your audience to provide awareness and more knowledge of the cause.
- The simultaneous use of old and new media saturates the public domain and creates more exposure.
- Need help? Hire a student!

Questions

Feel free to contact the me
jitrich@ucsd.edu

Or the ADCS Communications Team
brainlink@ucsd.edu