

Using Social Media for PR and Patient Recruitment

Presented by

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The Changing Face of Media

- The media world is changing constantly.
- Social media and the internet has changed how we communicate.
- Used to be people got their credible news from newspapers, TV news, radio news and magazines.
- All that has changed. Traditional media outlets closing down and reinventing.

What Exactly is Social Media?

- Social media are networking websites that allow people to interact with a website and its audience.
- Used to be people accessed these sites on their desktop computers. Now people are also accessing using mobile phone apps, tablets & laptops.

Examples of Social Media

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

Other Ways to Engage Online:

- <http://www.indiegogo.com> – a crowdfunding site that finds donations to support projects.
- <http://www.greedyorneedy.com> – fulfills everyday wishes. Formerly the Robin Hood Fund.
- <http://www.Inspire.com> – Online community where patients can learn/share info.
- <http://www.Clinicalresearch.com> – a study search engine & info resource (Quintiles)
- <http://www.PatientsLikeMe.com> – a study search engine & info source
- <http://centerwatch.com> – study search engine

The Stats

- Nielsen research: Americans spend 23% of their online time on social networks (SN) & blogs.
- Nielsen reports twice as many Americans 50+ visit social sites compared to the under 18 users.
- Pew Research Center: 66% of adults use SN, up from 29% in 2008. 57% of American adults web surf for health information.
- 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+.
- Adults 55+ are the fastest growing age segment of SN.

What's the Facebook Story?

- As of Feb 2012 Facebook (FB) had more than 845 million active users. It is the most popular SN in the world.
- Release of statistics by [DoubleClick](#) showed that FB reached one trillion page views in June 2011, making it the most visited website in the world.
- On average people spend eight hours a month on FB.



facebook

Search



Jeffree Itrich

Find Friends

Home



- Wall
- Info
- Photos
- Notes
- Friends
- Subscriptions

Find Friends

- Best Friends
- Coworkers
- Classmates

Add a Badge to Your Site

Jeffree Itrich

Lives in San Diego, California From San Diego, California Add where you work Add your school Edit Profile

Update Status Add Photo / Video

What's on your mind?



Jeffree Itrich

New blog post on Alzheimer's Insights, The Effect of Statin Drugs on Memory.
http://www.adcs.org/Blog/ADCSBlog.aspx

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 other clinical investigations aimed at furthering clinical knowledge of Alzheimer's Disease.

Like Comment Share 23 hours ago



Jeffree Itrich

March issue of ADIN research e-newsletter now online. http://adcs.org/Research/InformationNewsletters.aspx Not receiving it? Free subscription here: http://adcs.org/Research/registry.aspx

Alzheimer's Disease Cooperative Study
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 other clinical investigations aimed at furthering clinical knowledge of Alzheimer's Disease.

Like Comment Share March 7 at 2:18pm



Jeffree Itrich

The next meeting of the Advisory Council on AD Research, Care, Services is 3-14-12 1:00p - 5:00p EST. Meeting will be a teleconference. For call in info go to: http://aspe.hhs.gov/daltcp/napa/#Mar2012Mtg

March 14, 2012 Teleconference Advisory Council Meeting - National Alzheimer's Project Act: Main Pa
aspe.hhs.gov

The next meeting of the Advisory Council on Alzheimer's Research, Care, and Services will be held on Wednesday, March 14, 2012 from 1:00pm to 5:00pm EST. The meeting will be a teleconference.

Like Comment Share March 6 at 1:14pm



Jeffree Itrich

Prevalence and Impact of MCI in Latin America, China and India: Results from

Edit Profile

View As...

Sponsored

Create an Ad

Free-Motion Quilting

craftsy.com



Learn the secrets to machine quilting and begin finishing your own quilts today!

Cuidador de Alzheimer

brandinvitation.com



Novartis está buscando a personas que proveen cuidado a un miembro de su familia dispuestos a servir como asesores (inglés requerido).

Time for Tax Fairness

tammybaldwin.com



The "Buffett Rule" is gaining momentum. Sign Tammy Baldwin's petition and tell Congress it's time to pass tax reform.

The Fabric Block on Yardsellr



Fancy some new fabric? Click LIKE!

Like 16,230 people like this.

24 Blocks



Hit "like" if you love to quilt

Like 6,967 people like this.

USAgainstAlzheimer's



We are families. We are caregivers. We are researchers. We are enraged & engaged to stop Alzheimer's by 2020. Click "Like" to join us!

Like 24,076 people like this.

Chat

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.
- On September 7, 2011, Twitter announced that it has 100 million active users logging in at least once a month and 50 million active users every day.



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>

Edit your profile

402 TWEETS

881 FOLLOWING

469 FOLLOWERS

Tweets

[Following](#)

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Similar to you



Laurie Orlov @AgingTech
Following



Debra Sherman @DLSherman
Following



TENA Caregivers @CaregiversCafe
Following

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Tweets



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22h

New blog post on Alzheimer's Insights, The Effect of Statin Drugs on Memory. adcs.org/Blog/ADCSCBlog....



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7 Mar

March issue of ADIN research e-newsletter now online. adcs.org/Research/Infor... Not receiving it? Free subscription here: adcs.org/Research/regis...



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6 Mar

Advisory Council on AD Resrch, Care, Services is 3-14-12 1:00p - 5:00p EST. Meeting will be a teleconference. aspe.hhs.gov/daltcp/napa/#M...



Jeffree Itrich @ADCSComm

5 Mar

Prevalence and Impact of MCI in Latin America, China and India: Results from the 10/66 Study (in three parts). adcs.org/Blog/ADCSCBlog....



Dr. Rudy Tanzi @RudyTanzi

11 Feb

Alzheimer's caregivers are clamoring for bexarotene but so far it only worked in mice. Let's be patient and hope it works in humans first.

Retweeted by Jeffree Itrich



Michelle Herman @CureADGirl

4 Mar

"@AlzheimersVoice: Popular Doctors e-Bulletin Supports Study on Resveratrol's ... sns.mx/OPfey3" To start soon at UCSD! Tweet me!

Retweeted by Jeffree Itrich



Jeffree Itrich @ADCSComm

29 Feb

Insightful new post on Alzheimer's Insights: Omega-3 fatty acids and brain health. adcs.org/Blog/ADCSCBlog....

Jeffree Itrich @ADCSComm

22 Feb

Your Audience is Online

- Focusing on the elder population: common misconception that this specific population is not using social media.
- In fact, social networking is growing among older users:
 - Pew: The 74+ demo is fastest growing segment among SN users. Social network site usage for this oldest cohort has quadrupled since 2008, from 4% to 16%
 - Pew: Users 65+ grew 100% between April 2009 and May 2010, jumping from 13 percent to 26 percent.
 - Pew: 47% of internet users ages 50-64 and 26% of internet users ages 65 and older are using social media*

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

The ADNI GO Experiment

- The Alzheimer's Disease Neuroimaging Initiative Grand Opportunity (ADNI GO) study was the first ADCS study to have a Facebook page.
- Also the first to utilize the social mediasphere to reach various bloggers and their audiences, which generated website banner ads and blogs on ADNI GO.
- The FB page now features general AD news & news about all ADCS studies.

Example of ADNI GO Banner Ad

everydayHEALTH

TODAY'S THE DAY

Register | Sign In

Newsletters

Search

SEARCH

Home Health A-Z Drugs A-Z Symptom Checker Food and Fitness Community Health Tools My 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

Ask a Pharmacist

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

Ask your question now.

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



stopping the progression of Alzheimer's disease

Example of Blogger's Post



How Does the ADCS Use Social Media Today?

- The ADCS Blog on ADCS.org: *Alzheimer's Insights*. Dr. Mike Rafii of UCSD and Dr. Neelum Aggarwal of Rush University alternate weeks sending in posts. Since mid-2010 the blog has received 25k 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 with the URL <http://adcs.org/Blog/ADCSBlog.aspx>. The page features a header banner for the Alzheimer's Disease Cooperative Study (ADCS) with the tagline "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 displays a post titled "Alzheimer's Insights: an ADCS Blog" with a sub-header "Recent Post" and the date "Thursday, March 15, 2012". The post title is "The Effect of Statin Drugs on Memory". The text of the post discusses the FDA's review of adverse events related to statin therapy and its effect on cognition. A sidebar on the right contains an "Archive" section with links for 2010, 2011, and 2012, a "Helpful Sites" section with links to ADEAR, Alzheimer's Association, Alz Forum, Alzheimer's Foundation of America, Alzheimer's Poetry Project, and ClinicalTrials.gov, and an "About Us" section. The "About Us" section describes the ADCS as a major initiative for Alzheimer's disease (AD) clinical studies in the Federal government, addressing treatments for both cognitive and behavioral symptoms. The post text continues: "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

The ADCS & Social Media

Cont'd.....

- Alzheimer's Disease Information Newsletter (ADIN). This e-newsletter goes out to over 3,000 subscribers the beginning of each month.
- When it is emailed we simultaneously post the link on adcs.org and onto FB & Twitter.
- Each week as we find AD articles of interest we post to both.

Example of ADIN

http://adcs.org/research/eNewsletter/ADIN_E-Newsletter_March_2012.pdf - Windows Internet Explorer

Convert Select

ALZHEIMER'S DISEASE
ADCS
COOPERATIVE STUDY

Alzheimer's Disease
Information Network
ADIN Monthly E-News



Alzheimer's Disease Cooperative Study • March 2012 • No. 40

Bexarotene in Context: A Look at the Exciting Results

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

In February 2012, the journal *Science* published findings of a research team, led by Gary Landreth out of Case Western Reserve University, regarding the FDA approved cancer drug bexarotene and its ability to rapidly remove beta-amyloid from the brains of animal models of Alzheimer's Disease (AD), and even reverses some symptoms of dementia. The results were heralded throughout the mainstream and web-based media.



The researchers looked at the drug Bexarotene (Targretin), approved in 1999 for cutaneous T cell lymphomas. Landreth and colleagues fed bexarotene to demented mice, and with just a single dose it lowered the most toxic form of beta-amyloid in the brain by 25 percent within six hours, an effect that lasted for up to three days; after two weeks, there was a 75 percent decline in the amount of amyloid plaques. The drug did its job with unprecedented speed. Mice that were cognitively impaired resumed normal behaviors after 72 hours of treatment: They began to crinkle toilet paper placed nearby to make nests, a skill lost as amyloid increased in their brains.

The drug also restored some of the animals' other normal behaviors. After treatment, the mice could identify a smell and perform better on water maze tests requiring them to remember how to find a submerged platform. They were also better able to remember a cage in which they had been shocked, all behaviors that are lost with the progression of the illness.

Bexarotene activates retinoid receptors on brain cells that increases the production of apolipoprotein E, which readers of this blog will recall, is known to remove excess beta-amyloid from the brain. It also appears to enhance another cleanup process, called phagocytosis. Bexarotene functions differently than the amyloid-clearance approach using monoclonal antibodies, which are further down the drug development pipeline. Those antibodies bind directly to amyloid and then remove it. Bexarotene activates the ApoE clearance mechanism of beta-amyloid.

Recent Posts from the ADCS blog...

- Omega-3 Fatty Acids and Brain Health
- Electrical Brain Stimulation and Memory Enhancement
- Impact of the New Criteria on MCI Diagnoses

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

CTAD 2012 in Monte Carlo

October 29 - 31, 2012
5th Conference
Clinical Trials in Alzheimer's Disease (CTAD)

Call for Abstracts is Open!
<http://www.ctad.fr/03-abstract/abstract.asp>

Again this year you can submit online your abstract for symposia, oral communication or poster session.

CTAD Important Deadlines:

- May 15, 2012: Deadline for submitting a symposium
- June 15, 2012: Deadline for submitting an oral communication or poster presentation

Registration and Program Information:

<http://www.ctad.fr/>

More Ways to Social Network.....

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](#)

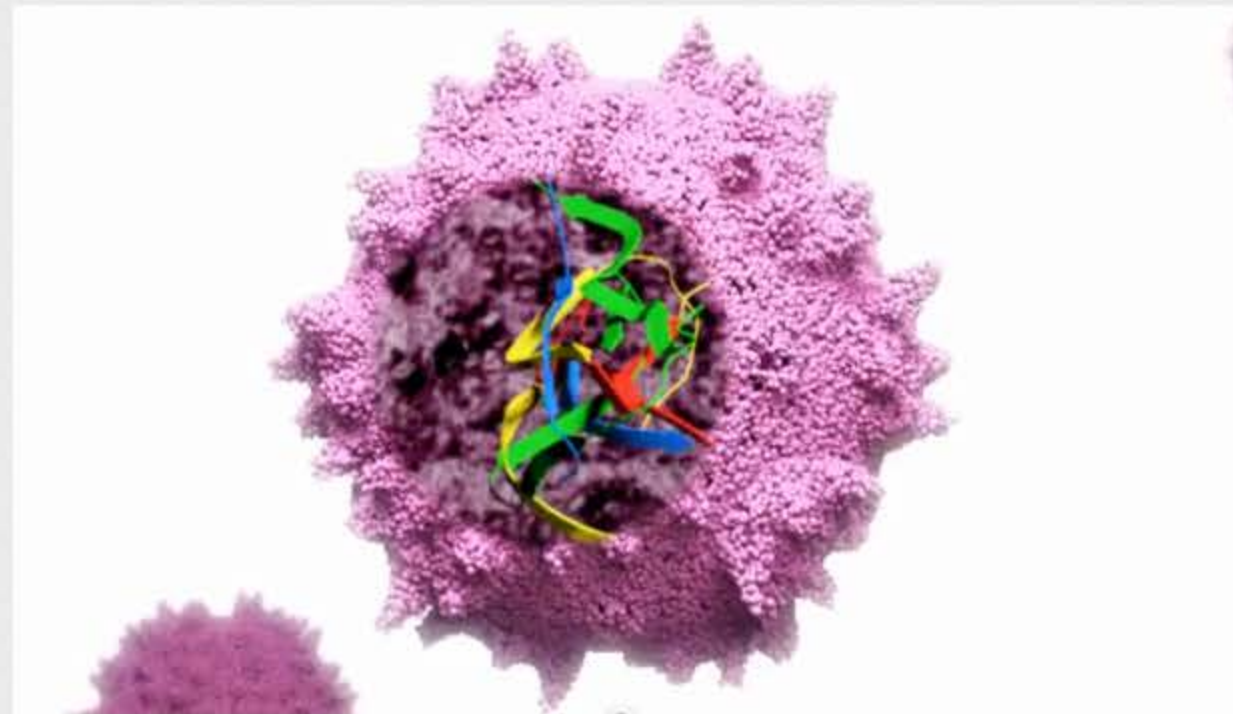
[Analytics](#)

Nerve Growth Factor Study for Alzheimer's Disease

Jitrich1

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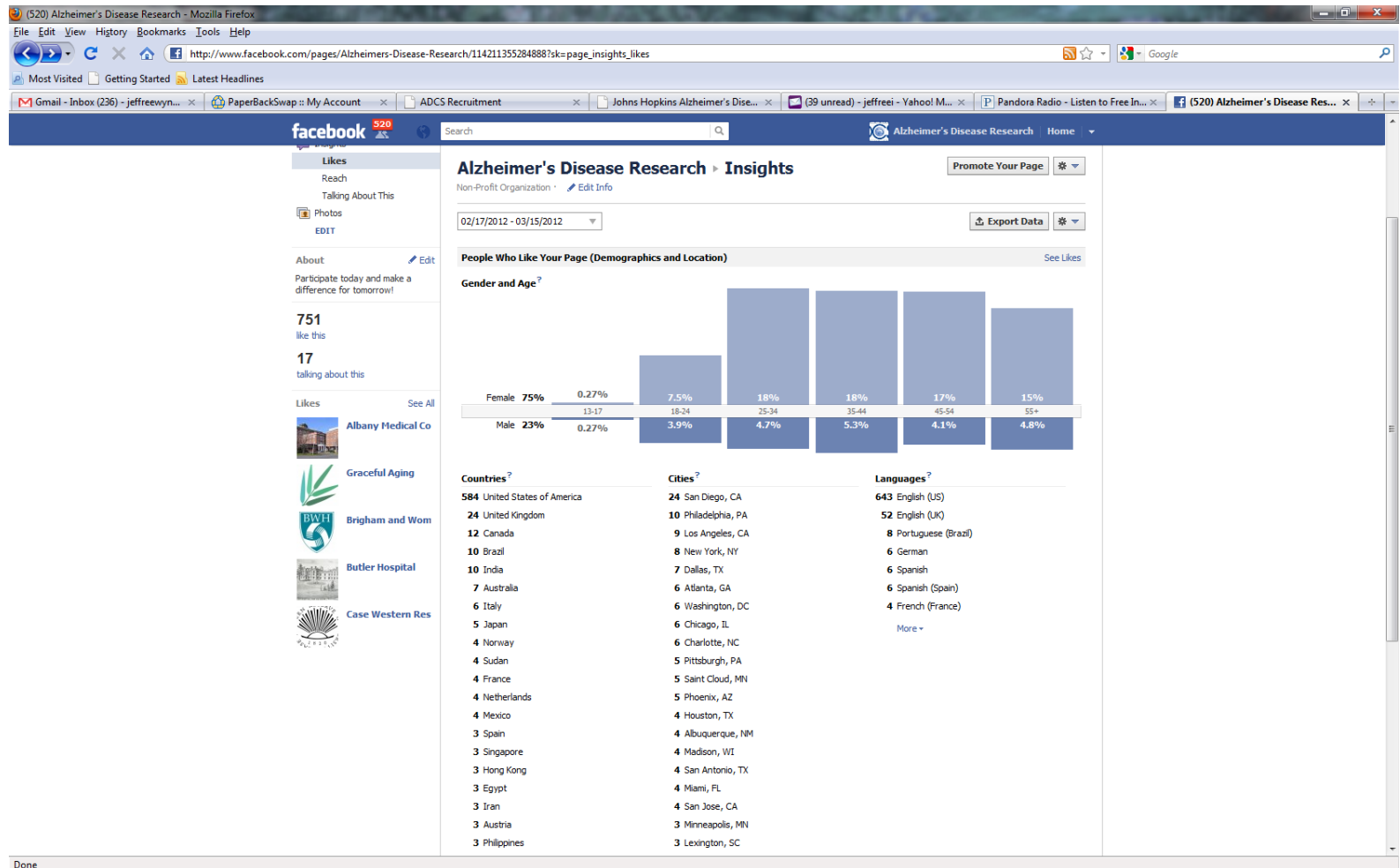
1 video ▾



The Scope of ADCS Social Media Outreach to Date

- Over 750 Facebook likes
 - 402 Tweets to 470+ followers
 - What does this mean?
- The social media conundrum:
Lots of followers (quantity – i.e. Justin Bieber) just for the sake of high numbers vs fewer (quality) who have an interest in AD.

Facebook Stats for 751 Likes



Why Should a Research Organization Use Social Media?

The Good News:

- Huge free media exposure opportunity for studies. Small time investment can result in a large return.
- Can “geotarget” online ads to reach specific populations in specific geographic areas.


The Bad News:

- “Going Viral” -- every social media professional’s dream -- can be a huge boost but can turn into a nightmare if the information is wrong.
- No way to stop “the message”. Stays on the Net until the end of time.

Example of a Geotargeted Ad

ALZHEIMER'S DISEASE
ADCS
COOPERATIVE STUDY

The **Next Generation** In Alzheimer's
Therapeutic Research



Help us advance Alzheimer's research!

- ▶ Experts are conducting an innovative clinical study evaluating the potential benefits and safety of CERE-110
- ▶ The gene in CERE-110 is responsible for producing nerve growth factor (NGF)
- ▶ Delivery of NGF to the cells affected by Alzheimer's may restore damaged cholinergic neurons and protect them from further degeneration

Start Here

See if you are eligible
(For a clinical trial of CERE-110)

Name *

Email *

Phone *

☐ By checking this box I am authorizing you to contact me regarding the NGF trial

Submit

Who Can Enroll in the Study?

- Age 50 to 80 years
- Are on standard stable AD treatments for three months prior to screening
- Have a study partner who has contact with you an average of 10 hours/week or more
- Must be in good general health

Are there any costs to participate?

There are no costs to participate in this study. All study-related expenses will be provided at no cost.

What is the goal of the study?

The purpose of this phase 2 clinical trial is to find out if a new type of gene therapy treatment, CERE-110, is safe, well-tolerated and of benefit when administered to people with Alzheimer's disease.

What We Know So Far ...ADNI2

How Are We Finding New Subjects?

- Internal db & physician referrals : 56%

However, we also know:

- 13% Word of Mouth
- 10% Advertisements
- 10% Media (news reports/stories)
- 11% Internet

Caveat: This is a special population of participants; determining source of clinical trial info due to cognitive issues is an ongoing challenge.

Increase in Web Activity on ADCS.org

- Visits to ADCS.org website as of 2/2012:
 - Homepage : 219,860
 - IgIV Study: 13,500
 - ADNI GO & ADNI 2 combined: 23,948
 - NGF Study: 14,465
 - Alzheimer's Insights (ADCS) blog: 24,482

Vehicles that drove the public to these pages:

ADEAR, clinicaltrials.gov, ADCS website, ADIN e-newsletter, FB & Twitter, ads in LHJ, Newsweek.

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. Start following others with an AD interest; they in turn will follow you back.
- Converse with blogosphere to answer AD & study questions. If you don't already have one, set up a blog for your site.
- Update your pages once or more per week. As you build your following if you don't keep up the conversations people will leave and not come back.

Final Thoughts

- Clearly your audience is online, are you?
- The media landscape is ever changing – use it to benefit the public, your organization and studies.
- 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.

Questions?

Feel free to contact me
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Or the ADCS Communications Team
brainlink@ucsd.edu