# RECRUITMENT FOR ADCS/ADNI TRIALS: LESSONS LEARNED

- Research sites should be selected to participate in clinical trials based on their ability to enroll subjects.
- Restrictive entry criteria negatively affects recruitment.
- Large scale trials require outside help (i.e., health communication/recruitment experts).
- Media outreach activities should be localized rather than nation-wide.
- A study should be branded with a name and/or logo so it's easily identifiable across the country.
- Use of focus group testing of the study name, logo, and key message points is beneficial to determine what resonates well with the target audience.
- Centrally prepared study flyers, brochures, bookmarks, speaker's kits and other related recruitment materials save busy study/recruitment coordinators time and provides a uniform look for study materials.
- Research sites that prefer to prepare their own recruitment materials should use the study name and logo adopted for national use.
- Recruitment metrics should be tracked and analyzed to determine effectiveness of recruitment materials and methods.
- Recruitment messages need to be seen or heard multiple times before your intended audience decides to make a call.
- Preparation of speaker's kits/slide presentations helps research sites with their community outreach.
- Become media savvy:
  - o Effectiveness of local media outreach efforts can be improved by establishing the PI at your site as the AD expert in your city.
  - Keep your media contacts informed about new developments/research at your site.
  - O Whenever your PI is going to be interviewed, provide lots of reminders to mention the name of the study you're promoting, name of your research site and your phone number. Mentioning this important information multiple times during the interview will increase the likelihood of it being included in the finished media piece.
  - See handout for additional resources and ideas
- Take advantage of available resources in order to maximize limited funds for recruitment related activities.
  - o Establish a working relationship with your institution's Public Information Office. Get them to assist with the dissemination of press releases, etc.
  - o See handout for additional resources and ideas

- Establish relationships with third party organizations that can help get the word out about your research.
  - o Women's organizations (often the caregivers of aging parents with memory concerns)
  - o Local retiree unions or organizations
- Expand your network of groups with whom you want to share your message
  - o Determine which groups best fit your issue
    - Medical/health professionals and specialties
    - Women/family/special populations
    - Aging/special populations
    - Faith-based communities
    - Service organizations
  - o Map out possible communications venues
  - o Inform the media of your scheduled presentations (see handouts).
- Share your success so others can learn from you. Likewise, when you're having trouble, ask for help or new ideas. The ADCS recruitment resource e-mail address is: brainlink@ucsd.edu

#### **BECOME MEDIA SAVVY**

Use the media to communicate key messages:

- Identify your targets
- Prepare your pitch

Use earned (free) media to get your message out:

- Send articles/stories to community newspapers, organization newsletters and bulletins, etc.
- List your community events/presentations on media calendars
- Facilitate interviews of your PI/local AD expert and the media
- Send PSAs (public service announcements/ads) to local media outlets (radio, newspapers).
- Identify the public service contact by calling the radio, TV, newspaper office and asking for the name of this individual. DO NOT ASK FOR THE ADVERTISING DEPARTMENT.
- Make a follow up call to the public service contact with your request that
  they run the PSA that has been sent to them for free. Let the media
  outlets know that there is a local site participating in the study that is being
  announced.

Media environment: Print/Internet

- Type:
  - Daily and weekly newspapers
  - o Monthly specialty papers (e.g., Senior News)
  - City and regional magazines
  - Online outlets
- Format:
  - Short deadlines (except magazines)
  - Single assignment
  - More knowledgeable reporter (knowledge depends on beat)
  - Longer stories/interviews
  - More detail

Media environment: Broadcast

- Type:
  - o Radio
  - Television
- Format:
  - Short deadlines
  - Tailored information by station demographics
  - Easy-to-understand generic stories
  - o Often live, but can be taped
  - Delivery/appearance is critical
  - Opportunity to control message

# Prepare your pitch:

- Research your target
  - o Know the reporter's name
  - Know when to call
  - o Tailor the pitch accordingly
  - Know what you want to say (Rehearse!)
- Review key message/talking points
- Think of what the story headline would be
- Prepare background materials
- Make the call
- Follow up

# Multiple story angles:

- Make it relevant
- Put a face on the issue
- Tie to national/local celebrities
- Focus on benefit to future generations
- Translate science/research into action
- Create a sense of urgency for finding a cure

#### What to communicate?

- Emotional appeal
- The facts
- Participant details about the clinical trial particularly where to obtain more information.

# Potential Communications Resources for ADNI Sites Pattie Yu, GYMR

A number of organizations, typically nonprofit groups, are known to seek extra "arms and legs" requiring public relations/marketing/advertising outreach.

Throughout the years in this business, I have seen time and again organizations, large and small, tap the local or national chapters of communications related professional societies for support. These sources might be the national or local chapters of Public Relations Society of America (e.g., tobacco cessation) or PRSSA (student chapter) or the American Association of Advertising Agencies; journalism, public relations, communications departments at various university campuses; postings on the career center bulletin boards etc.

Students tracking in the communications arena often are hungry to build their portfolios and sometimes through the encouragement of their professors, sign up to take on a pro bono community project or secure credits in exchange for their on-site support.

While every chapter/national group/campus varies in their policies and protocol, it never hurts to ask. I have seen local universities support the American Cancer Society and American Heart Association as well as national tobacco cessation efforts. Sometimes the issues are homeless and domestic violent; other times it is taking on a public health crisis. Sometimes the professional societies issue a challenge and then hold a competition for the most creative, strategic plan, execution and recognize the student winners publicly.

Below, thanks to Ashleah, are a few links to kick start the possible linkages local study sites could forge with their local communities.

# **Public Relations Student Society of America (PRSSA)**

http://www.prssa.org

To cultivate a favorable and mutually advantageous relationship between students and professional public relations practitioners

The Public Relations Student Society of America has more than 8,500 members in 270 chapters on college campuses across the country.

#### **American Marketing Association (AMA)**

Has over 250 student chapters in the States and specifically highlights volunteer opportunities on their Web site, http://www.marketingpower.com.

#### **The Association for Women in Communications**

http://www.womcom.org

Champions the advancement of women across all communications disciplines by recognizing excellence, promoting leadership and positioning its members at the forefront of the evolving communications era

Some of the student chapter Web sites indicate that they do pro-bono work.

# In addition, they might want to:

- post on Craig's List, a nationwide bulletin board, organized by city. It features a variety of subjects from internships to housing needs.
- tap Career Centers at universities
- run ads in the student daily newspapers and radio bulletin boards
- seek out communications and marketing departments at local colleges and universities
- tap the departments that train the web/interactive media students, if different from communications departments
- Ad Clubs affiliated with AAAA
- local chapters of Society of Public Health Education (SOPHE)
- local chapters of American Public Health Association
- In D.C., we have Washington Independent Writers; there are probably comparable groups of freelance communications people in other cities.



# **Suggested Venues for Potential Speaking Opportunities**

- Local senior centers
- Retirement communities (e.g., Marriott, Hyatt hotels)
- · Nursing homes (especially dementia or Alzheimer's care units) for caregiver families
- Assisted living communities
- Area hospitals
- AARP local chapters
- YMCAs/YWCAs
- · Park and Recreation departments
- Local Senior Corps chapters
- Veteran associations
- Senior Olympics
- Local AD support groups/Caregiver organizations
- Local faith based organizations and prayer groups
- Local volunteer groups (e.g., Meals on Wheels, Ronald McDonald House, Volunteers of America, AARP's Community Service Program)
- Local libraries
- · Senior chat forums online
- Retired union employees (e.g., AFL-CIO, SEIU, AFSCME, UAW, American Federation of Teachers).
- Retiree groups (e.g., Alliance for Retired American, National Association of Retired Federal Employees)
- Women's groups (e.g., Garden Club, Older Women's League)
- State and local aging organizations (visit <u>www.aoa.gov/eldfam/How To Find/Agencies/Agencies.asp)</u>



#### FOR IMMEDIATE RELEASE

**CONTACT:** [study coordinator]

XXX-XXX-XXXX

### Media Alert

Largest Alzheimer's Study of Its Kind Underway in [name of city here]—
Local Expert Speaks to Community [Date] at [Location]

What:

Alzheimer's disease affects one in 10 Americans over the age of 65. By the year 2050, 13 million Americans may suffer from the disease. Without research or a known solution in sight, the disease will continue to devastate our communities.

[Insert name], MD, study investigator at [insert site name] will be speaking to your community about this major public health problem and what you can do to help scientists learn how to possibly prevent the disease in future generations.

[Insert name] will also be discussing the latest Alzheimer's disease research including a landmark research study, sponsored by the National Institutes of Health, being conducted in (name of city). Called the Alzheimer's Disease Neuroimaging Initiative, it is the largest and most comprehensive study of its kind, involving 58 clinical sites across the United States and Canada.

The goal of the initiative is to speed up the search for treatments and cures for Alzheimer's disease by seeing whether imaging of the brain, through magnetic resonance imaging (MRI) or positron emission tomography (PET) scans, every 6 months can help predict and monitor the onset and progression of Alzheimer's.

When:

Date

Location City, State

Contact:

[Insert name]

XXX-XXX-XXXX; [Insert email]

###



# **Media Outreach Tips**

Consider the following tactics to publicize your presentation before it happens.

#### 1. Tailor and distribute the media alert

- Drop speaker, location, date and contact information into the media alert included in your speaker's kit.
- Compile a list of reporters at the daily and weekly newspapers, radio and television stations in your area. Contact information can be found in the phone book. Look for the news desk or news assignment editor fax number or email. Feel free to call the media outlets if you are unsure of where to send the alert — they can provide the appropriate contact.
- Consider contacting senior publications or newsletters in your area as well.
- □ Look for opportunities to publicize your presentation on local calendar of events in publications, on Web sites or even a bulletin board at your library.

#### 2. Reach out to your community

- □ Post flyers at your church, fitness club, YMCA/YWCA, library and grocery store.
- □ Encourage local organizations (e.g., volunteer programs like Meals on Wheels, women's groups like Junior League, AARP, etc.) to post information on their Web sites.
- □ Engage local chapters of Older American organizations (e.g., AARP chapters) to announce the presentation at a meeting.
- Visit a local health fair and/or mall walking group/club to hand out information about the study.
- □ Ask about announcing the study in homilies or sermons given at your church.



#### [ADNI STUDY SITE VERSION]

# NATIONAL BRAIN IMAGING STUDY ON ALZHEIMER'S UNDERWAY AT [INSERT NAME OF STUDY SITE]

Largest, Most Comprehensive Study of Its Kind

XXX, XX 2006 — [Insert name of study site] is participating in a landmark research study called the Alzheimer's Disease Neuroimaging Initiative (ADNI). Sponsored by the National Institutes of Health, it is the largest and most comprehensive study of its kind, involving 58 clinical sites across the country.

The goal of the initiative is to speed up the search for treatments and cures for Alzheimer's disease by seeing whether imaging of the brain, through magnetic resonance imaging (MRI) or positron emission tomography (PET) scans, every 6 months can help predict and monitor the onset and progression of Alzheimer's. In addition, samples of blood and, for some participants, cerebral spinal fluid will be collected and tested to determine if these biomarkers can predict and monitor the disease. It is hoped that imaging techniques and biomarkers will prove useful in testing the effectiveness of new therapies in slowing the progression of Alzheimer's or preventing the disease altogether.

Alzheimer's disease affects one in 10 Americans over the age of 65. By the year 2050, 13 million Americans may suffer from the disease.

Researchers are looking for people who are in good general health with no memory problems, or are in good general health but have memory problems or concerns, or have a diagnosis of mild cognitive impairment or early Alzheimer's disease.

For more information about the study, please contact the NIA's Alzheimer's Disease Education & Referral (ADEAR) Center at 800-438-4380 or visit <a href="https://www.alzheimers.org/imagine">www.alzheimers.org/imagine</a>.

###