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# ROSTER

Program Title: ALZHEIMER'S DISEASE UPDATE (4 HR)

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## PEGCO, Inc. 532 N. Ridgewood Ave. Daytona Beach, Fl. 32114

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### ALZHEIMER'S DISEASE ANNUAL "2013" (4 Hour)

## AGENDA

I. The Year in Alzheimer Science

a. 100 years later

b. More Younger Individuals Than Expected Have Alzheimer's

c. Progress in Next-Generation Treatment

d. Caregiver Support Improves Life, Delays Nursing Home Care, Saves Money

e. Alzheimer's Association Awards Its Largest Grant Portfolio

f. Federal Funding Slips Drastically

g. Progress Report January-December 2006

**II.** New research sheds light on cause of Alzheimer's Disease

**III. Skin Patch Tested** 

V. "Biomarker" of Alzheimer's in Spinal fluid

IX. Building trust and using technology to reach out to American Indians

X. Promoting Successful Eating in Long Term Care: Relationships with Residents are Key

### New Research Sheds Light on Cause of Alzheimer's (From article in the Daytona Beach News-Journal)

Scientists injected a sticky goo from Alzheimer's victims into the brains of mice and watched it take over, provocative research that promises to help shed new light on the earliest stages of the memory-robbing disease.

No one knows if this sticky protein, called beta-amyloid, actually causes Alzheimer's, but it is the chief suspect, and the study reported Thursday adds to the evidence.

The German-led study found a tiny clump of bad betaamyloid triggers a buildup that results in Alzheimer's hallmark brain-crusting plaques-by physically pushing nearby healthy proteins into rotten shapes.

"It's a very exciting paper," said Dr. Sam Gandy, a neuroscientist and amyloid expert at Philadelphia's Thomas Jefferson University who assessed the study on behalf of the Alzheimer's Association.

"This may give us a novel way to try and understand the way amyloid changes its shape to become toxic, become poisonous," he explained.

Moreover, there appear to be different strains of abnormal amyloid, lead researcher Mathias Jucker, a neurology professor at Germany's University of Tublingen, reported in the journal Science. If scientists can determine which version drives plaque buildup, it may point to ways to attack Alzheimer's before it gains too big a hold on the brain, he said.

About a4.a5 million Americans have Alzheimer's, a toll expected to more than triple by 2050. The creeping brain disease gradually robs sufferers of their memories and ability to care for themselves, eventually killing them. There is no known cure; today's drugs only temporarily alleviate symptoms.

All brains contain beta-amyloid, although healthy cells somehow get rid of excess amounts. But in Alzheimer's patients' brains, abnormal beta-amyloid builds up into distinctive clumps, or plaques. What makes good beta-amyloid turn bad is a mystery.

But the new study suggests that once that first little clump forms, it acts as a seed that corrupts nearby healthy amyloid, said co-author Larry Walker of Emory University's Yerkes National Primate Research Center in Atlanta.

## SKIN PATCH TESTED

Alzheimer's patients may soon get the first skin patch to treat the creeping brain degeneration, a novel way to deliver an older drug so that it's easier to take and might even work a little better.

The patch, which infuses the drug Exelon through patients' skin, headlines a trio of innovative potential treatments unveiled Wednesday at an Alzheimer's meeting in Spain. Also under study are a prostate cancer drug that may help dementia, too, and an immune therapy to ward off the sticky gunk that is Alzheimer's brain-clogging hallmark.

Exelon's maker Novartis Pharmaceuticals Corp. is poised to seek U.S. sales.

'Biomarker' of Alzheimer's in Spinal Fluid (Article in Daytona Beach News-Journal)

Scientists appear to have found a fingerprint of Alzheimer's disease lurking in patient's spinal fluid, a step toward a long-awaited test for the memory-robbing disease that today can be diagnosed definitively only at autopsy.

Researchers at New York's Weill Cornell Medical College discovered a pattern of 23 proteins floating in spinal fluid that, in very preliminary testing, seems to identify Alzheimer's-not perfectly, but with pretty good accuracy.

Far more research is needed before doctors could try spinaltap tests in people worried they have Alzheimer's, specialists' caution.

But the scientists already are preparing for larger studies to see if this potential "biomarker" of Alzheimer's, reported today in the journal Annals of Neurology, holds up. "We're looking to an era in which the kinds of uncertainties that many patients and their families face about the diagnosis of Alzheimer's disease will no longer be a problem," predicts Dr. Norman Relkin, a neurologist and the study's senior researcher.

About 4.5 million Americans have Alzheimer's, a toll expected to more than triple by 2050 as the population grays. The creeping brain disease gradually robs sufferers of their memories and ability to care for themselves, eventually resulting in death. There is no known cure; today's drugs only temporarily alleviate symptoms.

Currently, doctors diagnose Alzheimer's mainly by symptoms. That makes early diagnosis particularly difficult, and even more advanced disease can be confused with other forms of dementia. Nor is there a good way to track the disease's progression, important for decisions about patient care and in testing the effectiveness of new drugs.

Major research is under way to try to change that, including a \$60 million study to give brain scans to 800 older Americans to try to pin down the earliest brain changes associated with Alzheimer's.

## Building Trust and Using Technology to Reach Out to American Indians (From Alzheimer's Connections, Vol. 13, #3-4)

Alzheimer's Disease Centers (ADCs) work hard to bring diagnosis, treatment, and education services to the diverse populations they serve, including rural and urban groups, the poor, Hispanics, African-Americans, Asian Americans, American Indians, and people with low health literacy. Providing the full range of services to American Indians is particularly challenging. Significant barriers include language, cultural differences, distrust, location and geography, access to technology, and funding and allocation of resources. As difficult as these obstacles are, three ADCs in areas with large American Indian populations—in Oregon, Texas, and Arizona—are using a combination of technology and good old fashioned relationshipbuilding to serve local American Indian communities.

# Population and health status of American Indians

Today there are an estimated 4.4 million American Indians according to the U.S. Census Bureau, with about 550,000 living on reservations or other trust ands. The largest tribes are the Cherokee (234,000 and Navajo (204,000). Other tribes with more than 50,000 include Apache, Chippewa, Choctaw, Lumbee, Pueblo, and Sioux.

According to the Census Bureau, 7 percent of American Indians and Alaska Natives are over age 65, while 12.5 % of the population at large is over age 65. Thus, the proportion of American Indians who are older is considerably lower than the national average, American Indians have high rates of certain chronic and debilitating diseases or conditions, including diabetes, cardiovascular disease, alcoholism, and obesity, according to data from the National Center for Health Statistics. The interrelated conditions of diabetes and obesity are two of the most serious health challenges facing the American population overall, and American Indians especially.

Data from the Center for Health Statistics indicate that AD mortality rate is 8.9 per 100,000 in American Indians and is 19.0 per 100,000 for the population overall. In Caucasians, studies have shown that health problems like obesity, cardiovascular disease, and diabetes, when combined with poor access to health care, typically are associated with higher rates of dementia. Incidence and prevalence of dementia in the American Indian population, however, may b inadequately documented.

According to the Gerontological Society of America, "little is currently known about the prevalence of dementia among older American Indians despite anecdotal accounts by clinicians that it is rarely encountered." Genetics may play a role. One small 1996 study indicates that the Cherokee Indians may have a lower incidence of ApoE4. Roger Rosenberg, M.D., Director of the UT Southwestern ADC, studied the relationship of genetic factors in Cherokee Indians with the development of AD and ApoE4 allele type. He concluded that a greater genetic degree of Cherokee ancestry reduces the risk of developing AD; therefore, the Cherokee genetic background appears to have protective characteristics. The relationship between Cherokee background and the incidence of AD is independent of ApoE allele type, according to the study. Incidence of AD continues to increase with age, however, but to a lesser extent in Cherokees. Most experts agree that while all tribes are different, most American Indians share certain cultural similarities, such as a strong spirituality and attachment to the land-believing in a balance between the body, mind, and spirit. Many American Indians feel strongly about retaining their culture and identity, including language. Researchers have learned that equivalent medical words or concepts may not exist in some native languages. For example, the concept of dementia can be different within American Indian cultures relative to the majority population. The ability to describe the concept of progressive memory loss varies from tribe to tribe and is an uncertain term at best (evening the English language). Researchers also say that spiritual and traditional forms of medicine practiced by many American Indians can influence acceptance of health care and research conducted by outsiders, in addition, American Indians may have a different understanding of some of the symptoms of AD.

For example, hallucinations may be seen as "communication from the other side" and therefore may be viewed in a positive light.

Although incidence and prevalence of dementia may not be well documented, mild cognitive impairment, Alzheimer's disease, and related dementias are considered by health care professionals to be serious medical problems facing American Indians. Three ADCs—in Arizona, Texas, and Oregon—are harnessing technology and a variety of other methods to overcome some of the barriers between American Indians and health care providers.

## **Telemedicine serves Oklahoma Choctaws**

One approach at the University of Texas Southwestern ADC includes new uses for an older technology. Myron Weiner, M.D., and his colleagues are working on a telemedicine program with the Choctaw Nation in Southeastern Oklahoma. Telemedicine is not new, particularly as it has been used to provide health services to rural communities, but Dr. Weiner's team has found a novel application for it in follow-up dementia care in American Indian patients. According to Dr. Weiner, members of the Choctaw tribe, which was displaced from the Carolinas in 1830, may be more comfortable than other, more remote tribes in using contemporary technology.

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Since 1991, the UT Southwestern ADC has screened and interviewed 212 American Indians for dementia. Dr. Rosenberg and ADC physician Kyle Womack, M.D., travel to Talihina, Oklahoma about five times a year to conduct initial patient examinations and diagnostic testing. The telemedicine program provides a live video feed, connecting Dr. Weiner and his colleagues in Texas to Oklahoma, where patients diagnosed with dementia are followed in a monthly video clinic conducted via satellite.

Connected to the Choctaw Nation Health Care Center in Talihina, the telemedicine program serves as a checkup on the patients and their respective caregivers as well.

"Our program allows us to stretch limited resources and provide comprehensive follow-ups. It's very difficult for Choctaws to arrange to come to our ADC Center. But it's much easier on them and their caregivers to come to the Talihina Center, where we can conduct follow up visits," says Dr. Weiner.

Depending on the length of time since their initial assessment, patients may be given a battery of psychological tests to assess cognitive abilities shortly before the "telemeeting." The caregiver is also interviewed before the patient (and not in the presence of the patient) over the live video feed. Using this information and scores from several rating scales (two full-time people in Oklahoma rate the patients); Dr. Weiner discusses with staff the possible need for clinical intervention. In most cases (60%), patients will need intervention. According to Dr. Rosenberg, "We are very pleased with the telemedicine program, it allows us to focus collective clinical dementia expertise on a population that otherwise might not have access to these services. Members of the Choctaw Nation are pleased with this service, are responding well, and are spreading the word throughout their community." The UT Southwestern group plans soon to undertake an experiment in administering neuropsychological tests by live video.

Drs. Weiner and Rosenberg are also studying the relationship between cardiovascular risk factors in American Indians and whether they correlate with the risk of developing AD. The most recent research indicates that certain cardiovascular factors may increase the risk of AD, including high cholesterol and high blood pressure.

# **Circuit Rider Program also Successful**

Telemedicine is not the only outreach program at UT Southwestern. The Education Core also employs a "circuit rider," who visits the 10 counties of the Choctaw Nation throughout the year, traveling to senior centers and medical clinics to build relationships with the tribe. During short, informal presentations, Carey Fuller, the circuit rider," be comes better acquainted with tribal Elders and talks about memory loss and offers "memory checkups." According to Margaret Higgins, M.S., Education Core Director, the word "Alzheimer's" is never used in publications or on signs, "Memory loss" is more culturally and linguistically acceptable to the tribes. Those patients who have memory problems are asked to return to have a private exam at their respective senior center.

Although the plan is only in its second year, it is bring welcomed by increasing numbers of tribal Elders, says Higgins.

# In Arizona, Building Relationships

Eric Reiman, M.D., Director of the Arizona ADC and his colleagues have been meeting regularly with representatives from several regional tribes. "We have been working closely with our American Indian partners to explore how we could address some of their needs in the most culturally sensitive and effective way. We have begun to provide some of these services, promoting further communication through a series of conferences, and only then to consider the studies that will best serve their needs. Our outreach efforts are based on common goals, shared commitments, close communication, and the patience, persistence, and small steps needed to make a real difference," says Dr. Reiman.

Alfred Kaszniak, Ph.D., directs the Arizona ADC Education Core. He promotes awareness of AD in Latino and American Indian groups through a Diversity Committee. In educational pamphlets and booklets on Ad., the Core carefully evaluates the material to identify possible cultural sensitivities. The materials encourage Latinos and American Indians to learn about memory impairment and how they can get help. "In addition to providing educational seminars and brochures to the local tribes about memory loss, we're also stepping up our efforts to increase participation of American Indian Elders in AD research and developing assessment tools that are culturally relevant and sensitive to the Elders we evaluate," says Dr. Kaszniak. A partnership with the Desert Southwest Chapter of the Alzheimer's Association helps develop outreach programs to minority health care professionals as well. The Chapter maintains an active Medical and Scientific Advisory Committee which coordinates the publication of a newsletter. Although aimed at a general audience, the newsletter includes information on recent AD research on American Indians and research participation opportunist.

Joint education and outreach projects target Latinos and American Indians provide speakers and information for caregiver conferences and public television spots, and offer opportunities for ADC staff to "shadow" a family are consultant at the chapter's offices in Sun City.

Minnie Jim, an American Indian and the program assistant and Outreach Coordinator, helped initiate a support group in the Navajo Nation to build relationships and provide useful caregiver support. Brochures and videos on memory loss produced for American Indians are distributed as well. Efforts to use an internet-based education program with Navajos at a local community center did not fare well because residents did not utilize this resource. Staff concluded that more direct contact was necessary, so presentations to Elders and health care professionals in tribal communities are under way throughout Arizona.

A Native American Memory Disorders Clinic near Phoenix began 2 years ago under the guidance of Marwan Sabbagh, M.D. He is planning more presentations to Elders and health care professionals in tribal communities and at health conferences and fairs. Dr. Sabbagh and Ms. Jim collaborate with Association Chapter staff to help Elders recognize the early signs of AD and how to access appropriate health care. According to Dr. Kasznick, "Overall, our American Indian outreach program goal is to increase awareness of AD and other age-related illnesses. As we get to know the tribes and they get to know us, and as awareness of the symptoms of AD increases, we hope interest and participation in our research will gradually increase as well."

# Oregon ADC Reaching American Indians Through Face-To-Face Contact

Oregon ADC Director Jeffrey Kaye, M.D., and his staff have been working closely with the Confederated Tribes of the Warm Springs Reservation for the past 10 years. The project, funded by the ADC Satellite program, focused on geriatric assessment in this remote community. ADC staff worked hard to earn trust and carefully build relationships Setbacks were encountered when Elders who are community leaders become ill or died. Other challenges included using assessment instruments that were not designed to be used in the rural American Indian setting. Dr. Kaye says that being on site as much as possible is key because travel to distant parts of Oregon is especially daunting during winter months or in the summer during wild fire season.

In fact, Dr. Kaye reports now that the ADC may have to close the Warm Springs program because of a number of constraints, including loss of the Elder leading the project on site, certain issues with data collection standards and requirements, and the cost of supporting on-site staff.

According to Linda Boise, Ph.D., Educational Core Director, the Oregon ADC is encouraging relationships between Ed Core leaders and local native Elders by increasing participation at regional events geared to American Indian audiences. For example, the local Aging Services Office held a Native American Caregiver Conference attended by ADC staff, and another conference in southern Oregon is planned so that American Indians can learn more about health issues.

One way Dr. Boise plans to expand the ADC's outreach is to involve a younger audience. At Portland State University, an American Indian Community Center offers a facility where students and local American Indians can gather. "The younger generation of American Indians is an effective outreach medium to the Elders, as they are more socially acclimated to varied cultures and less inhibited with modern communication techniques such as email and the internet," commented Dr. Boise. The younger generation of American Indians in Portland is comfortable using more modern communication technologies, but Dr. Boise also relies on the occasional spontaneous visit and one-on-one personal discussions to build trust and meaningful relationships.

# **A Slow but Rewarding Process**

Successful outreach to American Indians involves both innovative uses of proven technology and had-won-respect and trust through face-to-face contact, meetings, conferences, and careful preparation of educational materials. Raising awareness, providing diagnoses, and offering treatment evolve slowly as ADC staff work to build interpersonal relationships. Staff finds that sometimes it can be a painstakingly slow process (particularly as measured by today's performance standards). Even though progress is sometimes measured in very small steps, staff is striving to foster partnerships with American Indians in their local communities. As these partnerships grow stronger, researchers, clinicians, and educators are overcoming significant barriers in order to both learn from and provide information and state-ofthe-art health care to American Indians.

# ALZHEIMER'S DISEASE ANNUAL "2013" QUIZ (4 Hour)

1. The Alzheimer's Association estimates there are how many Americans age 55 to 64 with early onset Alzheimer's and other dementias?

2. Dementia-related hospitalizations of a husband or wife raises the non-hospitalized spouse's risk of dying by what percentage?\_\_\_\_\_

3. Alzheimer's disease is ranked in\_\_\_\_\_place among leading killers of Americans.

4. A German led study, injected a sticky protein into the brains of mice. What was this substance name?\_\_\_\_\_

5. What drug is used on the skin patch for treating Alzheimer's Disease?\_\_\_\_\_

6. Researchers at New York's Weill Cornell Medical College discovered what floating in spinal fluid?\_\_\_\_\_

7. Dr. Rosenberg concluded that if Cherokee Indians had what, reduces the risk of developing Alzheimer's Disease?\_\_\_\_\_

8. What program are Dr. Weiner and his colleagues in Texas using on a monthly basis to follow patients diagnosed with dementia?

9. What did Dr. Marwan Sabbagh start 2 years ago near Phoenix that helps Elders recognize the early signs of AD and how to access appropriate health care?\_\_\_\_\_

10. Oregon Alzheimer's Disease Center director, Dr. Jeffery Kaye and his staff work with what group and what reservation?

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### PROGRAM EVALUATION

#### COURSE TITLE: <u>ALZHEIMER'S DISEASE ANNUAL UPDATE (4 HR)</u>

DATE:\_\_\_\_LOCATION: \_\_\_\_\_

#### Please evaluate by circling the appropriate rating: 5-Excellent 4-Above average 3-Average 2-Fair 1-Poor

1. Overall quality of the program	54321
<ol> <li>Overall content of the program</li> <li>a. content can improve my ability to perform my job</li> <li>b. content reflected knowledge level and needs of learner</li> <li>c. the material was current</li> </ol>	5 4 3 2 1 5 4 3 2 1 5 4 3 2 1
<ul> <li>3. Achieved stated objectives</li> <li>a. total number of objectives in program</li> <li>b. circle the number of met objectives</li> <li>c. the test material reflected the objectives listed</li> </ul>	1 2 3 4 5 6 7 8 9 10 5 4 3 2 1
<ul><li>4. Overall organization of the program</li><li>a. material was organized to facilitate learning</li><li>b. material covered was adequate and accurate</li></ul>	5 4 3 2 1 5 4 3 2 1
What did you like best about the program?	

Your suggestions for improving this program.

Any topic ideas for future in-service programs

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