Spring 2009

Texas Alzheimer's News

A publication of the
Texas Council on Alzheimer's Disease and Related Disorders

The Silver Alert Program: A Valuable Resource

If you know or care for a senior who is likely to wander, or perhaps become lost due to Alzheimer's disease or a related dementia, the Texas Silver Alert Program can serve as a valuable resource.

The Texas Department of Public Safety's (DPS) Missing Persons Clearinghouse and the Governor's Division of Emergency Management operate the Silver Alert Program. This program is similar to the Amber Alert Program by activating a public safety network that enlists law enforcement personnel around the state, the news media, and high-traffic billboards in the search and recovery of someone who has gone missing.

In order to issue a Silver Alert, the following six questions must be answered with a "yes":

1. Is the missing person 65 years of age or older?
2. Is the senior citizen's domicile in Texas?
3. Does the senior citizen have a diagnosed impaired mental condition, and does the senior citizen's disappearance pose a credible threat to the senior citizen's health and safety? Law enforcement requires the family or legal guardian of the missing senior citizen to provide documentation of the senior citizen's condition from a medical or mental health professional.
4. Is it confirmed that an investigation has taken place verifying that the senior citizen's disappearance is due to his/her impaired mental condition, and alternative reasons for the senior citizen's disappearance have been ruled out?
5. Is the Silver Alert request within 72 hours of the senior citizen's disappearance?
6. Is there sufficient information available to disseminate to the public that could assist in locating the senior citizen? (Highway signs will be activated only if accurate vehicle information is available and it is confirmed that the senior citizen was driving the vehicle at the time of the disappearance).

It is critical to note that in order to issue an alert the DPS requires written documentation of the person's diagnosed mental impairment. This documentation needs to be on a physician's letterhead, indicating the diagnosed mental impairment, and signed and dated by the physician.

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Thank you to Charlene Evans and Davie Lee Wright Johnson

The Texas Council on Alzheimer's Disease and Related Disorders (Council) expresses its deepest appreciation and sincere thanks to Ms. Charlene Evans of Harlingen and Ms. Davie Lee Wright Johnson of El Paso for their years of service to the citizens of the State of Texas, victims of Alzheimer's disease and related disorders, and their families and caregivers.

Ms. Evans was appointed to the Council in 2000 by Governor Rick Perry to complete the term of Margaret Sykes, and was reappointed in 2001 for a six-year term. Ms. Johnson was appointed to the Council by Governor Rick Perry in 2002 for a six-year term. We thank Ms. Evans and Ms. Johnson for the expertise they brought to the Council and for their long-term commitment over the years to Council membership.

How to Spice Up Foods for Patients With Alzheimer's Disease

Ronald Devere, M.D., FAAN, Director of the Alzheimer's Disease and Memory Disorder Center and Taste and Smell Disorders Clinic - Austin, Texas

It has been known for over twenty years that smell is impaired in Alzheimer's disease. This information has been shown by smell testing and by pathological observation that amyloid plaques and neurofibrillary tangles (the hallmark changes of Alzheimer's disease) are present in large quantities in the olfactory bulb, olfactory organ in the nose, and inside brain tissue that represents the smell portion of the brain (medial temporal lobe).

Over ninety percent of people with Alzheimer's disease do not complain of a change in smell or taste. Some will complain of altered taste especially if you ask the person or the caregivers directly. This impaired smell and secondary altered taste can often result in decreased appetite, weight loss, and depression. To understand how smell and taste disturbances can impair quality of life and how changes in food preparation can help, a few very basic points need to be discussed.

Our smell organ, which resides in the upper part of the nose is responsible for identifying odors. It is however, very important in recognizing flavors in our food (for example, chocolate or vanilla). If you put food in your mouth and hold your nose, you will still be able to identify flavors since the molecules of the food travel to the back of the throat and go up to the back nasal passages to reach the smell organ during the swallowing phase and exhaling phase. Humans are able to recognize five basic tastes because of many taste receptors located in the tongue, palate, and the back of the throat. These basic tastes are sweet, sour, bitter, salt, and umami. Umami is the Japanese word for a savory, broth-like taste that is best represented by monosodium glutamate (MSG). Umami has recently been added by scientists as a fifth basic taste.

Our ability to identify the texture, temperature, and spiciness of food depends on the sensory nerves that arise from the tongue, palate, teeth, and inside walls of the mouth that travel through the fifth cranial nerve called the trigeminal nerve. Your dentist will numb the branches of this nerve before you have any dental work done. The five basic tastes and the texture, temperature, and spiciness of food are usually normal in Alzheimer's disease. However, because of the smell impairment, flavor recognition is impaired and food doesn't always taste the same.

With this basic background information, you can appreciate that some changes in food preparation are often necessary to try to improve eating enjoyment, increase appetite, reduce weight loss, and help depression.

In our Taste and Smell Clinic, where many different causes of smell impairment are recognized, including Alzheimer's disease, we have studied many recipes. These recipes have been found helpful in improving eating enjoyment. Many of our patients have also discovered different recipes that are very helpful in improving their eating enjoyment. You will see that these recipes emphasize texture, spiciness, and basic taste (sour, sweet, umami). In addition there are also a number of basic tips about food preparation that have been successful in people with impaired smell and altered taste (flavors) including Alzheimer's patients.

- Foods that are creamy and thicker allow time to contact different parts of the mouth and tongue to stimulate more taste in the sensory receptor. Liquids in general like soups and beverages are usually quickly swallowed and spend less contact with the taste

receptors and are less likely to give enjoyment in eating.

- When making fish, chicken, or beef, try marinating them in fruit juices or sweet and sour sauce or Italian dressing. This emphasizes texture, temperature, spiciness, and basic tastants, which are normal in Alzheimer's disease and other disorders.
- Add a small amount of MSG (Accent ® has low sodium) to meat, fish, and chicken to give the savory taste sensation.
- Use salsa or other spice-like foods such as horseradish, mustard, etc., to baked potatoes, eggs, meat, and chicken.
- Trying adding flavor extracts in higher concentrations in some foods where flavors like vanilla, strawberry, chocolate, etc., are important, such as in desserts.

These recipes have been successful in trying to increase food enjoyment in patients who have taste and smell disorders, including those with Alzheimer's disease. These recipes emphasize temperature, texture, and spice along with basic tastants such as MSG, sweet, salt, and sour.

Lemon Pepper Grilled Chicken

¼ C lemon pepper
1 T dry mustard
1 T dried rosemary
5 skinless boneless chicken breast halves
4 cloves garlic, crushed
4 T fresh lemon juice
3 C dry white wine

Mix lemon pepper, dry mustard and dried rosemary in a small bowl. Place chicken breast halves in a medium bowl. Rub with garlic. Add the lemon pepper mixture and rub into chicken. Pour in lemon juice and dry white wine. Cover and refrigerate at least 3 hours before grilling.

Preheat outdoor grill for high heat and lightly oil the grates. Grill the marinated chicken breast until meat is no longer pink and juices run clear, or to desired doneness.

Barbequed Ground Beef

Recipe suggested by our taste and smell clinic patients

1 lb ground beef
2 T prepared mustard
1 C chopped green pepper
1 C diced onion
1 tsp salt
1 C ketchup
1 T vinegar
1 tsp cloves ground
2 T liquid smoke

Brown meat and mix in other ingredients. Simmer for 30 minutes. Serve on toasted hamburger buns.

Spicy Thai Beef Salad

7 T fresh lime juice
6 tsp Asian fish sauce
3 Thai chilies, minced
2 tsp sugar
½ pound rare beef, thinly sliced
5 small scallions cut into 1-inch lengths
3 med shallots, thinly sliced
1 C thinly sliced peeled cucumber
½ C chopped celery leaves

In a large bowl, mix lime juice, fish sauce, chilies and sugar; stir to dissolve sugar. Add beef, scallions, shallots, cucumber, and celery leaves, toss gently and serve.

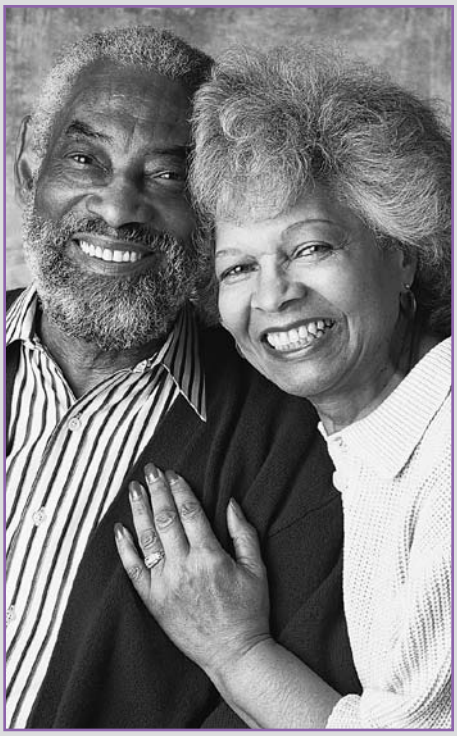
The Silver Alert Program: A Valuable Resource. . .continued from page 1

Anyone who cares for a person with a diagnosed mental impairment must plan ahead and have this documentation available at all times -- it may just save a life.

State officials also recommend providing the following information to assist local law enforcement in the recovery of a missing senior:

- A recent, close-up color photograph.
- The person's vehicle information, including make, model, year, color and license plate number.
- A list of places the person may go, such as former homes or places of employment.
- Physician phone numbers.
- List of current medications and dosages.

If you would like more information or training on the Silver Alert Program, please contact Sam Allen with the Governor's Division of Emergency Management, at 512-424-2208 or sam.allen@txdps.state.tx.us.



Governor Perry Appoints Ms. Frazier and Ms. Hortenstine

The Texas Council on Alzheimer's Disease and Related Disorders (Council) would like to recognize the following new appointments to the Council:

Rita Hortenstine of Dallas, Texas, was appointed by Governor Rick Perry on October 22, 2008. Ms. Hortenstine sits on the boards for both the Alzheimer's Association and the Alzheimer's Association-Greater Dallas Chapter. She was recognized for being one of three who worked with the state legislature to implement the Safe Return Alert Program. Ms. Hortenstine is managing partner of RRH Capital L.L.C. and since 1995 has dedicated her community service efforts to the prevention, cure, and care giving of persons living with Alzheimer's disease.

Carolyn Frazier, R.N., of Huffman, Texas, is the Risk Manager for St. James House in Baytown, Texas. She has significant healthcare professional experience in the areas of medical dispute resolution, coordination of clinical services, emergency care, and clinical risk. Ms. Frazier is a member of Phi Theta Kappa Honor Society, and authored and published The Guide to Compliance in Long Term Care: The Nuts and Bolts of Staying in Compliance. Ms. Frazier was appointed to the Council on October 22, 2008, by Governor Perry.

The Texas Alzheimer's Research Consortium Longitudinal Research Cohort: Study Design and Baseline Characteristics

Stephen C. Waring, Sid E. O'Bryant, Joan S. Reisch, Ramon Diaz-Arrastia, Janice Knebl, Rachelle Doody for the Texas Alzheimer's Research Consortium

Abstract

The Texas Alzheimer's Research Consortium (TARC) was established in 1999 by the 76th Texas Legislature representing a state mandated collaboration among Texas Tech University Health Sciences Center, University of North Texas Health Science Center, the University of Texas Southwestern Medical Center at Dallas, and Baylor College of Medicine in Houston. Funding began in 2005 with official start-up in June 2006 that continues with funding through the current biennium that ends August 2009. The primary goal of the Consortium was to develop a longitudinal multidisciplinary study of Alzheimer's disease (AD) that would generate a wealth of clinical, neuropsychological, lifestyle, genetic, and biomarker data following standardized research protocols and stored in a large, common, standardized, relational database to facilitate studies of AD in Texas. The availability of information from a well-characterized research cohort with ongoing recruitment and follow-up represents a unique resource for AD researchers in Texas that would not be available otherwise. TARC investigators are currently focusing on research questions that take advantage of the robust data on a large number of individuals to investigate the role of genetics and biomarkers in detection, prognosis, and prevention of AD. Indeed, this is a valuable resource for current and future research designed to further elucidate critical pathways associated with development and progression of AD that will help reduce the burden of this devastating disease on patients and families, public health, and health care systems throughout the state. This report is a description of the general research study design and baseline demographic and medical characteristics of the research cohort enrolled to date.

Introduction

The role of genetics and biomarkers in AD is under intense investigation with the expectation that these studies will elucidate important biological pathways that could lead to development of better diagnostic tests and better therapeutic agents that would benefit those already diagnosed with AD, delay onset for individuals at risk for developing AD, and ultimately prevent AD. The availability of large well-characterized representative groups of individuals followed longitudinally to monitor development of disease or differences among individuals with disease in a broad range of characteristics is critical to understanding the underlying biological mechanisms that lead to development of AD. This requires a commitment of time, money, and resources in order to accurately transform knowledge gained from clinical studies into earlier detection, improved treatment options, and ultimate prevention. Long-term follow-up of individuals with disease and individuals without disease allows researchers to detect changes that can provide important clues about risk for developing AD, factors that influence treatment and progression of disease, and quality of life among individuals with AD.

The primary goal of the Consortium was to develop a longitudinal multidisciplinary study of AD that would generate a wealth of clinical, neuropsychological, lifestyle, genetic, and biomarker data following standardized research protocols and stored in a large, common, standardized, relational database to facilitate studies of AD in Texas. This comprehensive database and bio-banking system is aided by the collective research expertise at each of the member sites along with state-of-the-art bioinformatics and high-density high throughput

genotyping and biomarker discovery. The availability of information from a well-characterized research cohort with ongoing recruitment and follow-up represents a valuable and unique resource for AD researchers, in Texas and beyond, that would not be possible otherwise. Indeed, this has allowed TARC investigators to focus research questions requiring detailed information on a large number of individuals to investigate the role of genetics and biomarkers in detection, prognosis, and prevention of AD.

Methods

Subjects are recruited from the four TARC member institutions. The purpose of the study is explained to individuals meeting eligibility requirements. They also are advised of what is expected from them and asked to sign IRB-approved informed consent (with appropriate legal representation for cognitively impaired individuals) to participate in the study.

Clinical and neuropsychological evaluation

Once the informed consent form has been obtained, the subject's history is collected and all inclusion/exclusion criteria verified. Individuals must be at least 55 years of age with a diagnosis of Probable AD or normal cognition based on a Clinical Dementia Rating Global Score of 0.

Clinical, neurological, and neuropsychological examinations performed at each site follow the TARC research protocol that has been adopted from the standard clinical work-up for dementia. All subjects are examined at baseline and at each annual follow-up visit.

Information is obtained from the clinical and neurological examination on age at onset of symptoms (if AD patient), family history of dementia in first degree relatives, cardiovascular disease and cardiovascular disease risk factors. Subjects also undergo a battery of neuropsychological tests as part of the TARC research protocol to include measures of global cognitive functioning/status.

Additional clinical information obtained from each visit includes self-report or direct assessment of hyperlipidemia, diabetes mellitus, hypertension, body mass index (BMI), smoking and alcohol exposure, and use of non-steroidal anti-inflammatory agents. Dose and duration of anti-dementia medications and vitamin E therapy is also recorded at each clinical visit.

Biological Specimens

Participants are asked but not required to provide blood samples (serum, plasma, DNA) at each visit for the planned genotyping and biomarker assays and for bio-banking. At the time of the blood draw, a research coordinator records time of draw and time elapsed since the most recent meal or snack. DNA is extracted and stored as well. Samples are batch shipped to the facilities performing the various genetic and biomarker analyses required for the current research protocols.

Laboratory Analysis

Biomarker analysis is performed on all samples by Rules Based Medicine (RBM) in Austin. This procedure yields a large panel of precise measurements of over 200 biological markers of cancer, infectious disease, autoimmunity, cardiovascular risk, as well as hormones, growth factors, and numerous other proteins measured simultaneously. The current research questions investigate a specific set of markers of cardiovascular disease, inflammation, and metabolism. However, all of the markers included in the panels are available to address additional research questions in the future.The role of these markers in understanding cardiovascular disease risk factors in AD are the subject of current investigation.

Results

To date, 559 persons have completed the baseline clinical evaluation: 439 with a diagnosis of probable AD and 120 with normal cognition. Both groups are predominantly Caucasian (> 90%) and less likely to be living alone. Individuals with AD are significantly older, less likely to have completed a high school education, less likely to be currently married, and less likely to be living in a single family dwelling compared to cognitively normal individuals. Among individuals with AD the

estimated age at symptom onset was 71 years, ranging from 19% with onset prior to 65 years of age, 43% with onset between 65 and 74 years of age, and 38% with onset at 75 years of age or older. Score on the Mini-Mental State Examination was significantly lower for individuals with AD compared to cognitively normal individuals (19.9 vs 29.2). The majority of individuals with AD (68%) were experiencing symptoms of mild dementia at baseline examination based on the Clinical Dementia Rating Global Score of 0.5 (questionable dementia) to 1 (mild dementia). Results of all baseline neuropsychological tests are the subject of a separate manuscript and are not presented here.

Prevalence of medical conditions is based on self-report of medical conditions or examination procedures. Cardiovascular disease (33% vs 23%), cerebrovascular disease (8% vs 2%), and urinary or bowel incontinence (20% vs 10%) are more frequent in individuals with AD compared to cognitively normal individuals. Obesity, as defined by BMI greater than or equal to 30 based on height and weight measurements at baseline examination, is significantly less prevalent among individuals with AD compared to normal controls (14% vs 22%, respectively). Prevalence of diabetes mellitus, hypertension, hypercholesterolemia, and neurological conditions such as head trauma, parkinsonism, and seizures are similar between the two groups.

Discussion

The Texas Alzheimer's Research Consortium has enrolled over 500 individuals from 4 geographically distinct metropolitan areas in Texas. Although there are several ongoing laboratory and clinical studies of AD at institutions in Texas, this is the first large-scale multicenter study of AD among academic research institutions in Texas that enrolls only residents of the state. The TARC cohort primarily reflects the demographic make-up of the patient populations of these four specialty centers, with participants being predominantly Caucasian with more years of education compared to the general population of the state, similar to AD studies at other academic referral centers throughout the US. The prevalence of clinical or medical history characteristics among individuals with AD compared to normal controls has been reported by others. The extent to which these differences reflect changes associated with disease development or progression as opposed to aging in general is currently under investigation.

In addition to assembling a large representative cohort to begin cross-sectional analyses of genetics and biomarkers associated with age at onset, eventual long-term follow-up of this cohort will provide a wealth of information to further refine questions regarding the genetics and biomarkers associated with onset and progression of AD. It is the expectation of all TARC investigators that this will lead to a number of significant findings that will further our understanding of underlying mechanisms that can be transformed into better diagnostics and earlier detection, better treatments and improved treatment outcomes, reduction of risk, delaying onset and ultimately preventing AD in Texas and beyond. Without the commitment of the state legislature to fund this endeavor, this unique resource would not be available. Indeed, the TARC research cohort is a valuable asset for addressing critical research questions in AD and "normal" aging that will make valuable contributions now and well into the future to help reduce the burden of this devastating disease on patients and families, public health, and health care systems throughout the state.

Excerpted from:
Stephen C. Waring, Sid E. O'Bryant, Joan S. Reisch, Ramon Diaz-Arrastia, Janice Knebl, Rachelle Doody for the Texas Alzheimer's Research Consortium. TARC Longitudinal Research Cohort Study Design and Baseline Characteristics, Texas Public Health Journal, Volume 60, Issue 3, Summer 2008, pp. 10-13.

Permission to reprint/edit obtained from Steve Waring, DVM, PhD.

New Publication From the National Institute on Aging:

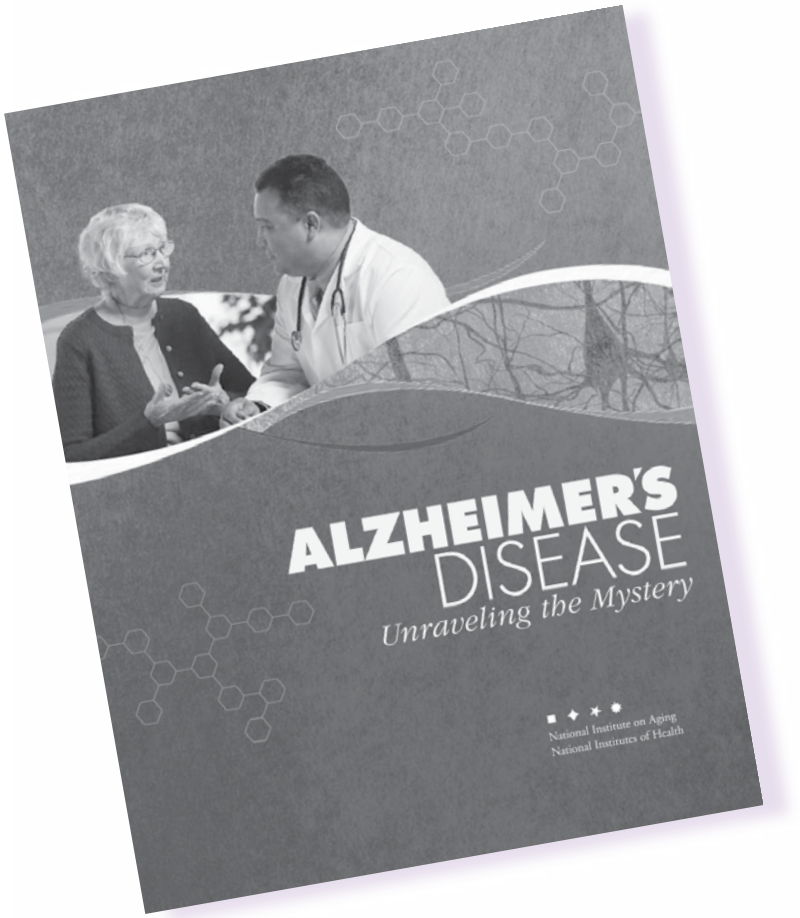
Alzheimer's Disease: Unraveling the Mystery

Alzheimer's disease (AD) is a major public health problem that has a severe impact on millions of older Americans and their families. The National Institute on Aging (NIA) began its AD program in 1978, and since then, the study of AD has become one of NIA's top priorities.

Due to the work of NIH institutes, other research organizations around the world, and many private-sector research, education, and advocacy groups, the study of AD is moving ahead rapidly.

Alzheimer's Disease: Unraveling the Mystery, is a colorful, 80-page book that looks at the basics of the healthy brain, describes what happens when someone has AD, highlights recent AD research, and lists resources for caregivers and others.

To order your free copy or download this publication, go to: http://www.nia.nih.gov/Alzheimers/Publications/Unraveling



NIA Offers Helpful Website

Accurate, up-to-date information on health issues for seniors is available online from the National Institute on Aging (NIA), part of the National Institutes of Health. This user-friendly website has free printed and downloadable information in English and Spanish on a wide range of health topics, including diseases such as Alzheimer's, cancer and diabetes. Helpful tips on caregiving, choosing a doctor, and maintaining a healthy lifestyle are all available at: http://www.nia.nih.gov/HealthInformation/Publications/

Making health information available to elders is a vital part of NIA's outreach. The NIA leads the federal government's efforts in conducting and supporting research on the biomedical, social, and behavioral aspects of aging. For comprehensive information on aging research, clinical trials, and the Spotlight on Aging Research Newsletter, please visit the website at: http://www.nia.nih.gov

Attention Readers!

To continue receiving this newsletter, please email **Mary Somerville** at Mary.Somerville@dshs.state.tx.us or call 800.242.3399.

There is no cost to receive Texas Alzheimer's News. Newsletters are posted and available for downloading at www.dshs.state.tx.us/alzheimers/

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The 70th Legislature passed HB 1066 creating the Texas Council on Alzheimer's Disease and Related Disorders

The Council was established to serve as the state's advocate for persons with Alzheimer's disease and those who care for them. The Governor, Lieutenant Governor, and Speaker of the House appoint members.

The Council is composed of seventeen members. There are five public members, seven professional members, and five members representing the Health and Human Services Commission, Department of State Health Services, and Department of Aging and Disability Services. *(See page 3 for more information)*

The Council has adopted as its mission to:

- Disseminate information on services and related activities to the medical and academic communities, caregivers, advocacy associations, and the general public to heighten awareness and education of Alzheimer's disease and related disorders.
- Coordinate, collaborate, and support services and activities of state agencies, associations, and other service providers.
- Encourage statewide coordinated research.