



The Caregiver

Newsletter of the Duke Family Support Program

"We are a bridge to understanding your options"

Volume 28, Issue 2

Fall 2009

INSIDE THIS ISSUE:

Bryan ADRC Conference	5
Candlelight Reflections	6
A Man and His Art	7
Hospitalization Happens	8
Shooting Stars	11
From AA to AD	12
Have You Heard About?	14
New Online Help	16

Duke Family Support Program

Lisa Gwyther, MSW, LCSW
Edna Ballard, MSW, ACSW
Cheryl Copeland

The Caregiver is co-sponsored by the:

**Joseph and Kathleen Bryan
Alzheimer's Disease Research
Center**

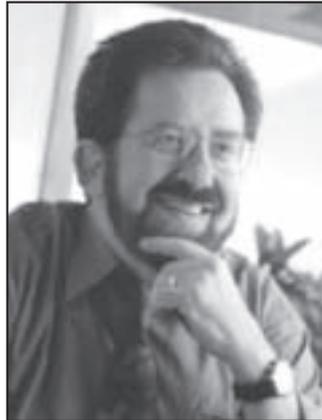
**Duke University Center for the
Study of Aging and Human
Development**

**Funding for this newsletter is
provided by the North Carolina
Division of Aging and Adult
Services.**

Subscriptions to *The Caregiver* are available free to North Carolina residents. Call 800-646-2028. View this newsletter online at www.dukefamilysupport.org.

A New Genetic Discovery May Offer Insights for Alzheimer's Disease Symptom Onset and Guide Future Treatments

Allen D. Roses, MD, Director, Duke Deane Drug Discovery Institute



It has been over 15 years (1993) since investigators at the Joseph and Kathleen Bryan Alzheimer's Disease Research Center (Bryan ADRC) at Duke first announced the important discovery that variations in the human gene, *apolipoprotein E* (*APOE*) were linked to the risk of developing Alzheimer's disease (AD). This early discovery from the Duke laboratories virtually changed the way the scientific community worldwide looked at the role of genetic factors in complex diseases. The finding that the *APOE4* form of the

gene is a risk factor for AD remains the most confirmed genetic finding in AD. Despite the importance of *APOE* in AD risk, inheritance of this gene cannot fully explain who will develop the disease and it offers no precision as to when AD symptoms are likely to express. Consequently, scientific laboratories across the globe have been actively searching to identify other genes as well as other non-genetic factors or exposures that may act to modify one's risk of developing AD.

Now Duke investigators, led by Allen Roses, MD of the Deane Drug Discovery Institute at Duke and the Bryan ADRC, announced at the July meeting of the International Conference on Alzheimer's Disease that they have identified a new gene for AD. When this new

gene is considered with *APOE*, scientists are able to better predict not only the risk of developing AD but the likely age of onset as well. It may be that this new gene is the long sought after genetic key to the illness. It may offer yet again a new perspective regarding the genetics of complex illnesses.

So what is this gene and what does it do? The new "TOMM40" gene is important in energy utilization by cells throughout the body. It is a gene that has been long known to be genetically associated with AD. However, the new findings from Roses' group indicate that specific forms of the TOMM40 gene linked to *APOE3* (a "good" form of the *APOE* gene) and *APOE4* (the "risky" form of the gene) are good predictors of whom over age 60 will

(continued on Page 3)

Duke Family Support Program
Box 3600 Duke University Medical Center
Durham, NC 27710
800.646.2028
919.660.7510
www.dukefamilysupport.org

National Alzheimer’s Association
225 North Michigan Avenue, Suite 1700
Chicago, IL 60601-7633
312.335.8700 800.272.3900
www.alz.org

Eastern North Carolina
400 Oberlin Road, Suite 220
Raleigh, NC 27605
919.832.3732
800.228.8738
awatkins@alznc.org
www.alznc.org

Western Carolina Chapter
Main Office, Piedmont Region
3800 Shamrock Drive
Charlotte, NC 28215-3220
704.532.7392
800.888.6671 (24-Hour Helpline)
www.alz-nc.org or email: info@alz-nc.org
www.alz.org/northcarolina

Caregiver Education Conferences
Lumberton – November 19
Southeastern Agricultural Center
Wilson – March 16, 2010
Barton College
Jacksonville – April 6, 2010
Onslow Multipurpose Complex
Sanford, May 11, 2010
St. Luke United Methodist Church

Mountain Regional Office
31 College Place, Suite D320
Asheville, NC 28801-2644
828.254.7363
800.522.2451

Fall Memory Walks
Wilmington – November 14

Foothills Area Office
260 1st Avenue NW, #218
Hickory, NC 28601-4757
828.267.7100

Triad Area Office in Winston-Salem
31 Melrose Street
Winston-Salem, NC 27103
336.721.3418

Triad Area Office in Greensboro
122 North Elm Street, Suite 800
Greensboro, NC 27401
Phone: 336.285.5920
Cell: 336.455.3499
Fax: 336.285.5922

Genetic Discovery

(continued from page 1)

develop AD within a five to seven year window of time.

This new information is particularly useful in explaining why some people with the good form of APOE3, get the disease. The two genes, APOE and TOMM40 are known to be inherited together in a block. If someone inherits APOE4 from their mother and APOE3 from their father, they will also inherit specific forms of TOMM40 linked to those APOE genes. Using a technology not widely employed in human genetics, Roses explains how the two genes act together to affect risk. As he explained in a DukeHealth.org article, his group looked at the differences in the block of DNA that contained the genes APOE and TOMM40. They found that in carriers of the APOE4 gene, the TOMM40 gene linked to it consisted of long repeats (perhaps 28-37 repeats of the sequences in the gene). In APOE3 carriers, the TOMM40 could be either short (12-16 repeats for example) or long (28-37 repeats). If the TOMM40 gene was a

short version attached to the APOE3 gene, then the person had a better chance of getting AD very late in life (after age 80). But if the TOMM40 was a long version with many repeated sequences attached to APOE3 gene, then chances of getting the illness early is higher before age 80 (as if they had the APOE4 genotype).

The Bryan ADRC is working with Dr. Roses and the Deane Drug Discovery Group to validate the association of APOE and TOMM40 with age of disease onset in a larger more diverse population. This is a critical next step, as the risk relation of APOE and AD has been shown to be particularly complex within groups of African descent. Some laboratories have found the risk relationship between APOE and AD in African-Americans, while other studies have not seen the typical risk relationship. However, AD is very common in African-Americans, suggesting that there may be other genes operating to affect AD risk or that other health conditions (e.g., vascular disease) and environmental exposures (e.g., diet, stress) may be working with the genes to increase or decrease risk. Finding these factors is important for developing

treatments and prevention strategies for AD that are effective in all groups.

In this spirit, the team of investigators at the Deane Discovery laboratories and the Bryan ADRC are currently looking ahead to prospective studies aimed at preventing or delaying the onset of memory symptoms. Some of the future studies will examine drug trials to prevent the onset of symptoms of AD. Other investigations will use non-pharmacological approaches such as diet, exercise and cognitive-behavioral therapies to prevent progression in patients with mild memory symptoms. The Bryan ADRC is also in the process of developing a registry of individuals without memory disorders who would be interested in potentially participating in future studies. The *Alzheimer's Disease Prevention Registry* (ADPR) is a one of a kind registry, designed to get the word out quickly to normal individuals who might be interested in being in prevention studies when different opportunities become available fitting their expressed interests. By knowing the window of when symptoms are

more likely to develop, the investigators are hopeful that the new genetic findings may speed the development of treatments to prevent the occurrence of AD and might also lead to better diagnostic tests of AD, permitting very early treatment before the disease is fully expressed.

Co-authors for the genetic work include Michael W. Lutz, Matthew J.

Huentelman, Kathleen Welsh-Bohmer and Eric Reiman of the Bryan ADRC and Arizona ADC investigators. The study was funded by the Deane Family Trust and Zinfandel Pharmaceutical Inc.

*Wisdom consists
not so much in
knowing what to
do in the
ultimate as
knowing what to
do next.*

—Herbert Hoover

ADVANCING HEALTHY BRAIN AGING THROUGH DISCOVERY, PREVENTION, AND TREATMENT

Advancing Healthy Brain Aging Through



Discovery Prevention Treatment

Are you over age 55?
Are you interested in participating in future research opportunities?

Working together to realize healthy memory into old age and a life without Alzheimer's disease. Together we can make this dream a reality.

Please call the Joseph and Kathleen Bryan Alzheimer's Disease Research Center at Duke for more information and to join our **Alzheimer's Disease Prevention Registry.**

Contact Michelle McCart (Registry Coordinator)
Toll-free 1-866-444-2372 or 919-668-1605

alzheimer's association
Eastern North Carolina Chapter  #00012582

“Coming together is a beginning, staying together is progress, and working together is success.

—Henry Ford

“You’ve got to think about big things while you’re doing small things, so that all the small things go in the right direction.”

—Alvin Toffler

SAVE THE DATE!

24th Annual Joseph and Kathleen Bryan Alzheimer's Disease Research Center Conference

**“Alzheimer’s 2010: Pathways to
Discovery, Prevention, and Treatment”
February 11-12, 2010**



**Sheraton Imperial Hotel & Conference Center
4700 Emperor Boulevard
Research Triangle Park, NC**

This conference will emphasize new science and discoveries in Alzheimer's disease, their implications for current practice, and their translation into community approaches most likely to have an immediate, positive impact on public health. The focus is on research defining the earliest signs of AD and related conditions and the potential of these findings to inform future prevention strategies and drug discovery.

Kathleen A. Welsh-Bohmer, PhD

Kathleen A. Welsh-Bohmer, PhD, Bryan ADRC director, will set the stage for the two-day conference with a focus on Bryan ADRC research aimed at planned prevention studies.

James R. Burke, MD, PhD

Bryan ADRC associate director, Dr. James R. Burke, opens the second day with a focus on the current approaches to successful aging and dementia prevention and current models in the Bryan ADRC involving the community.

KEYNOTE SPEAKERS

Steven T. DeKosky, MD, FACP

Keynote speaker, Dr. Steven T. DeKosky will highlight recent advances in the development of disease biomarkers, highlighting the importance of this work for advancing treatment of Alzheimer's disease.



James E. Galvin, MD, MPH

The second keynote speaker, Dr. James E. Galvin, will describe differences in the course and biomarkers involved in Alzheimer's disease and the closely aligned condition of Lewy body dementia.



Rachelle Smith Doody, MD, PhD

Keynote speaker, Dr. Rachelle S. Doody, will move from the focus on prevention to current treatments and therapeutics for Alzheimer's disease.



Mary S. Mittelman, DrPH

The plenary program will conclude with a care-focused research presentation from Dr. Mary S. Mittelman on the powerful sustained effects of counseling and support on the physical and mental health of family caregivers.



For more information call Cheryl Copeland at 1-800-646-2028 or 919-660-7510, email cheryl.copeland@duke.edu or visit <http://adrc.mc.duke.edu>. To register for the conference: <http://events.duke.edu/alzhconf10>.

Candlelight Reflections

to honor, hope and remember...

Kirby Horton Hall, Doris Duke Center

Sarah P. Duke Gardens

November 5, 2009 6:00 PM—7:00 PM



**“We cannot hold a
torch to light
another’s path
without
brightening our
own.”**

—Ben Sweetland

The N.C. Alzheimer’s Associations, North Carolina Division of Aging and Adult Services (NC DAAS), the NC Family Caregiver Support Program, the NC Alzheimer’s Support Network and the Joseph and Kathleen Bryan Alzheimer’s Disease Research Center participate in a statewide initiative entitled **“Candlelight Reflections.”** *Candlelight Reflections* will take place at various locations across North Carolina on **Thursday, November 5, 2009** in honor of National Family Caregiver Month and National Alzheimer’s Disease Awareness Month.

The Joseph and Kathleen Bryan Alzheimer’s Disease Research Center of Duke University Medical Center invites you to join us for a Durham community *Candlelight Reflections* on November 5, 2009 from 6:00 p.m. to 7:00 p.m. at the Kirby Horton Hall, in the Doris Duke Center at Sarah P. Duke Gardens in Durham.



This event is an opportunity to raise awareness of Alzheimer’s disease and related dementias, honor all caregivers who give unconditional support and celebrate the many lives of those affected by this condition across the U.S., but especially here in Durham, NC. *Candlelight Reflections* provides families an opportunity to share their loved one’s life with others through inspirational readings, poetry, songs or a favorite scripture reading, followed by the lighting of candles to honor and remember.

The ceremony will also include a musical tribute and a continuous slide presentation featuring Durham families affected by dementia. If you would like to submit a family photo for Candlelight Reflections, please request a photo release form giving permission to display the photo during the program. There will be no names shown on the photos. **All forms and photos will need to be submitted by Monday, November 2, 2009.**

To request a release form and submit a photo, please call Cheryl Copeland at 919-660-7510 or email cheryl.copeland@duke.edu.

Alzheimer's—A Man and His Art

Robin Winfree, Durham, NC



In the Summer 2009 issue of *The Caregiver*, I saw two very small pictures of “modern” artwork that looked so much like my husband’s paintings that I called Duke Family Support Program to see where they had found his artwork. It turns out it was just googled artwork, and it wasn’t Bob’s at all (Go to pages 8 and 12 of the summer *Caregiver* for reference). But it sure got my attention.

Let me start at the beginning of our odyssey into and our continuing journey through the Alzheimer’s maze. My husband, Bob, was an Associate Vice Chancellor at Duke Medical Center in 1997 when he was diagnosed with younger onset AD. He was not quite 54. As devastating as the news was, we decided to make the most of our time together. We took two European trips and went on a 1943 bi-wing plane tour around Durham. We welcomed our first and then our second grandchild.

Then I tried to think of what he could do as we spent more and more time at home. For some unexplainable reason, I chose to have Bob try his hand at painting pictures. He had never even been able to help me paint walls in his “before” life! But, with the help and guidance of a talented and flexible high school art teacher, Bob blossomed. From the early fall of 2002 until late summer 2003, Bob created some really remarkable paintings. Our local paper did an article on Bob. The article reported that I called his early artwork “wormy snakes.” The reporter then called his later work “slinkys on parade”, “smoosh and twirl.” It also mentioned that some people compared his art to Jackson Pollack.

We had an art show in the spring of 2003 at our church to give people who had known Bob an opportunity to see what he was doing. I wanted people to know that the diagnosis of Alzheimer’s wasn’t an immediate death knell. And then, a total surprise – folks started buying Bob’s artwork. It was the most amazing time of our



self – meeting and greeting. His smiles, eye contact and speech that day were a joy to witness.

Bob continued his art for several months and then in August ‘03, with an unexplained very high fever and a few weeks in the hospital, it all vanished. So did my Bob. From a functional Bob he became a man in need of total care. Our lives changed forever. He has resided in a memory care unit of a local facility since the fall of 2003.

I have had many opportunities to share his artwork. His art was chosen to be part of an exhibit at the college where we met and graduated. I have shared it with his caregivers and let them choose a piece they like to remember Bob and what he could do before his illness progressed.

Life is surely not what we envisioned at our age, but every time I share his artwork and our story of living life to the fullest as long as we can, I get a real sense of fulfillment. It helps to ease the daily pain of living without him by my side.

(continued on Page 8)

Alzheimer's—A Man and His Art

(continued from Page 7)

The reason for how our life has shifted direction is to let others know that the progress of Alzheimer's is different for everyone. I live each day as it comes. I go daily to feed Bob lunch and then to spend time cuddling in a two-person recliner and listening to music. I chat about long past memories and more often than not, he will laugh. Like his paintings, memories will always be there for me.

Hospitalization Happens: A Guide to Hospital Visits for Individuals with Memory Loss**

Hospital Emergencies: What You Can Do Now

Planning ahead is key to making an unexpected or planned trip to the hospital easier for you and your care partner. Here is what you should do now:

- **Think about and discuss hospitalization** before it happens and as the disease and associated memory loss progresses. Hospitalization is a choice.
- Talk about when Hospice may be a better and more appropriate alternative.
- **Register your relative for a MedicAlert® + Alzheimer's Association Safe Return® bracelet** through your local Alzheimer's Association Chapter. People who are lost may be taken to an emergency room. This bracelet will speed up the process of reconnecting you with your care partner. Learn more about safety-related programs such as Project Lifesaver International (www.projectlifesaverinternational.com).
- **Know who you can depend on.** You need a family member or trusted friend to stay with your care partner when he or she is admitted to the emergency room or hospital. Arrange to have at least two dependable family members, neighbors, or friends you can call on to go with you or meet you at the hospital at a moment's notice so that one person can take care of the paperwork and the other can stay with your care partner.

Pack an "Emergency Bag" containing the following:

- **Personal Information Sheet** -- Create a document that includes the following information on your care partner:
- Preferred name and language (some people may revert to native languages in late stage Alzheimer's disease)
- Contact information for doctors, key family members, minister and helpful friends (also program into cell phone, if applicable)
- Illness or medical conditions

(continued on Page 9)

Hospitalization Happens

(continued from Page 8)

- All current medicines and dosage instructions; update whenever there is a change
- Any medicines that have ever caused a bad reaction
- Any allergies to medicines or foods; special diets
- Need for glasses, dentures or hearing aid
- Degree of impairment and amount of assistance needed for activities
- Family information, living situation, major life events
- Work, leisure and spiritual history
- Daily schedule and patterns, self-care preferences
- Favorite foods and music; touch and visual resources
- Highlight behaviors of concern; how your relative communicates needs and expresses emotions

Paperwork: Include copies of important documents such as:

- Insurance cards (include policy numbers and pre-authorization phone numbers)
- Medicaid and/or Medicare cards, Durable Power of Attorney, Health Care Power of Attorney, Living Will and/or an original DNR (do not resuscitate) order

Supplies for the Care Partner:

- A change of clothing, toiletries and personal medications
- Extra adult briefs (e.g., Depends), if usually worn. These may not be available in the emergency room if needed
- Moist hand wipes such as Wet Ones. Plastic bags for soiled clothing and/or adult briefs, reassuring or comforting objects
- An iPod, MP3 or CD player; earphones or speakers

Supplies for the Caregiver:

- A change of clothing, toiletries and personal medications.
- Pain medicine such as Advil, Tylenol or aspirin. A trip to the emergency room may take longer than you think. Stress can lead to a headache or other symptoms.
- A pad of paper and pen to write down information and directions given to you by hospital staff. Keep a log on your care partner's symptoms and problems. You may be asked the same questions by many people. Show them what you have written instead of repeating your answers.
- A sealed snack such as a pack of crackers and a bottle of water or juice for you and your care partner. You may have to wait for quite awhile.
- A small amount of cash.
- Put a note on the outside of the "Emergency Bag" to take a cell phone with you.

By taking these steps in advance, you can reduce the stress and confusion that often accompanies a hospital visit, particularly if the visit is an unplanned trip to the emergency room.

(continued on Page 10)

Hospitalization Happens

(continued from Page 9)

At the Emergency Room

A trip to the emergency room may fatigue or even frighten your care partner. There are some important things to remember:

- **Be patient.** It could be a long wait if the reason for your visit is not life threatening.
- Recognize that results from lab tests take time.
- Offer physical and emotional comfort and verbal reassurance to your relative. Stay calm and positive. How you are feeling will get absorbed by others.
- Realize that just because you do not see staff at work, does not mean they are not working.
- Be aware that emergency room staff often have limited training in Alzheimer's disease and related dementias so try to help them better understand your care partner.
- Encourage hospital staff to see your relative as an individual and not just another patient with dementia who is confused and disoriented from the disease.
- Do not assume your care partner will be admitted to the hospital.
- Do not leave the emergency room to go home without a follow-up plan. If you are sent home, make sure you have all instructions for follow-up care.
- Have an emergency bag prepared for your trip to the hospital that includes items like over-the-counter pain medication, sealed snacks and bottled water.

** The above is directly taken from two sections of a longer pamphlet originally designed and produced by the North Carolina Division of Aging and Adult Services (NC/DAAS) in conjunction with the Joseph and Kathleen Bryan Alzheimer's Disease Research Center through the U.S. Administration on Aging grant #90AZ2246. It was revised in August 2008 by NC/DAAS through grant #90AZ2782 in conjunction with the Joseph and Kathleen Bryan Alzheimer's Disease Research Center, Alzheimer's Association – Eastern NC Chapter, Duke Aging Center Family Support Program and Positive Approach, LLC.

Distributed by and single copies available free from: Alzheimer's Disease Education and Referral Center, www.nia.nih.gov/Alzheimers, P.O. Box 8250, Silver Spring, MD 20907-8250, 800-438-4380, adear@nia.nih.gov, A Service of: *National Institute on Aging, National Institutes of Health, U.S. Department of Health and Human Services, December 2008.*

“Life is about knowing, having to change, taking the moment and making the best of it without knowing what’s going to happen next.”

—Gilda Radner (1946-1989)

SHOOTING STARS

KATHE HARRIS
BREVARD, NC

Alzheimer's disease has colored the last ten years of our lives. My husband has been on a dementia unit for three years. But we have enjoyed many magic moments in our life together and those moments continue.

We were blessed to be able to travel a great deal before the disease progressed. One of the most memorable moments occurred on a cruise ship deep in the Caribbean sea. The night was black with no ambient light and the stars blanketed the sky as we stood on the uppermost deck. Suddenly, we began to see shooting stars streaming overhead. They were glorious and time seemed suspended for us as we watched nature's light show. Just then a meteor screamed just off the side of the ship – so close we could hear the sizzling sound as it sped by. We were mesmerized and knew we had shared a truly magic moment.



A few years later we retired to our mountainside in western North Carolina. One August we woke in the wee hours and lay on our deck to watch the Perseid meteor shower. In three hours we saw hundreds of shooting stars. It was another night of nature's magic! From out of a blackened sky came amazing displays of awesome light.

Alzheimer's has stopped the traveling and my husband no longer communicates well verbally. But there are still the "magic moments", the "shooting stars" in our lives.

From out of the Alzheimer's word jungle will sometimes come a complete, cogent sentence. He may suddenly read a sign or a headline. Occasionally he will remember and call my name from across the room – magic!

I spend several hours a day with him and always tell him that I love him. Typically there is no response. Once in awhile he will try to feebly and robotically repeat the words. Last week, hugging him gently I whispered "I love you." He looked at me for a moment, said "I love you", then stopped abruptly, as though suddenly awake, and said "**I love you, I really love you!**" That was one of our magic moments. He is my shooting star. Alzheimer's is difficult at best but in its midst there is love and closeness and yes, magic.

"The greatest happiness is to transform one's feelings into action."

—Germaine de Stael

FROM AA TO AD, A Wistful Travelogue

Mike Donohue
Minneapolis, MN

Editor's Note: Mike Donohue is a successful retired trial attorney and an early stage advisor to and speaker (with his wife, Diane) for the national Alzheimer's Association. He was diagnosed with early stage Alzheimer's disease at age 69.

The following edited excerpts are taken from his blog, <http://ic-mike.blogspot.com/>, with his permission, following his presentation with Lisa Gwyther and two other early stage advisors and their families at the Administration on Aging Alzheimer's Disease Supportive Services Program Annual Meeting in Arlington, VA in June, 2009. Mike was pleased to have a recent opinion page letter published on July 10, 2009 in the *New York Times* in response to a feature story titled "Living in the Moment."

This Blog is about becoming an Alcoholic. It is about Recovery from Alcoholism. It is also about getting Alzheimer's Disease (AD). It is about the tools of Alcoholics Anonymous (AA), how I used them to recover from alcoholism and then to face (AD). It is about how the tools of AA secure peace and serenity in the face of both. It is about the spiritual reasons this is so.

From my personal view having this disease causes only the anguish of asking why me? Haven't I suffered enough? My answer is found in my acceptance of the inevitability of its progression. It is found upon accepting it the desire to make having it worth it. I can share my experience with others to help them understand how to cope. I can also speak and write to advocate on issues regarding Alzheimer's Disease with the hope of bettering the lot of all of us suffering from it.

What I hope will be my final adventure is a life full of love and compassion. My AD is the vehicle given me with which to do that. Although I could get along quite nicely without this awful disease, I welcome the irrevocable opportunity of having it for the ultimate good I can do with it.

My AD diagnosis in June, 2006, staggered me. I had survived so much loss in my life, I had strived so hard to overcome each event, haven't I had enough? Surprisingly I took it with far more equanimity than I thought I was capable of. I wasn't expecting it. I was at the point in life however that nothing was about to surprise me any longer. The worst was not what was to happen to me, but it was what was in store for my wife Diane. This part broke my heart.

(continued on Page 13)

“The self is not something ready-made, but something in continuous formation through choice of action.”

—John Dewey

FROM AA TO AD

(continued from Page 11)

She had married this successful lawyer, a guy who was alive, totally with it, ready to embrace life and all the fun to be had in it. What did she get? I was not caring for her as much as she was caring for me.

We worked through the loss of my firm and the start of the new practice. We built a cabin in the North Woods of Minnesota's North Shore that was paradise in the escape it offered us. We went on, but "I was not the same person" she said. I lost my spark. I marked time as I went along rather than once again embracing life.

For ten years this cloud shadowed me and I lost my acuity along with my spark. I missed things, I got things balled up and tasks that had been simple became hard. So much of my work took longer to do and seemed confused in its final product. The stress of trial work became overwhelming. I got into fights with judges and other lawyers. I missed appointments, needed to get away from work, but could not stay away from work. My work production fell through the floor then through the cellar floor.

I was little better at home. I had little initiative. I became pliant and passive. It seemed part of me was gone.

My diagnosis happened this way: I felt my wife was nagging me about my driving; there was nothing wrong with it. I agreed to a meeting with my doctor to discuss her complaints. He told me not to drive. To foil the view of my wife and doctor and show them how wrong they were, I took a simulated driving test in Minneapolis. I failed it miserably. It was all downhill after that.

After many examinations ending in a Neuro Psychometric test of some four hours, I was diagnosed as having an atypical Alzheimer's. They explained it was atypical in that my memory was pretty good. But there were other faults. These deficiencies suggested damage in the front and right side of the brain. This affected my ability to multi-task, difficulty in what they called executive functioning and in my peripheral visual perceptible ability.

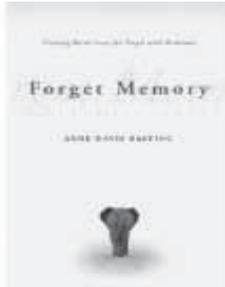
The perception deficiency explained why I was screwing up driving, why I was falling after tripping over things in plain view. The rest explained why I couldn't handle money or bank accounts, couldn't keep up in work and in social settings. It explained why I could no longer handle stress.

For 43 years I was a successful trial attorney, ran a decent sized law office and was skilled in the trial of cases. A lawsuit calls on a great deal of skill in multi tasking. I could keep countless balls in the air, try a complicated case, manage my office, supervise the sixteen lawyers working for me and be the primary rainmaker for a firm handling cases nationally.

I had a sense of relief when I got the diagnosis. This explained why I was falling behind, why I was in such stress in a social setting, why every thing became so hard. I was relieved, it was something I could do nothing about and it made no sense to keep trying. I was amazed because things started to get easier.

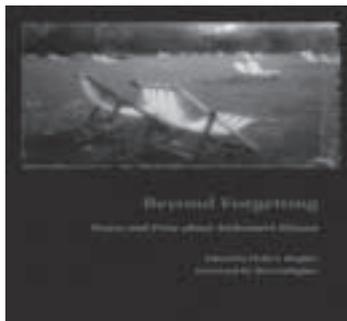
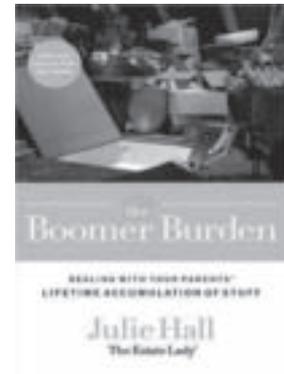
(continued on Page 17)

Have You Heard About?



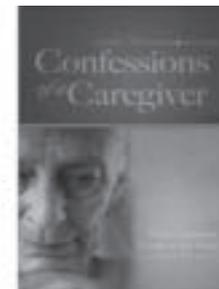
Basting, Anne Davis (2009). Based on ten years of practice and research in the field, her bold, optimistic, and innovative approach emphasizes the importance of activities that focus on the present to improve the lives of persons with Alzheimer's disease and other dementias.

Hall, Julie (2009). *The Boomer Burden: Dealing with Your Parents' Lifetime Accumulation of Stuff*. The Boomer Burden addresses how to deal with "lots of stuff" — how to clear out an estate and avoid family squabbles over heirlooms. Hall also provides advice on how to take care of yourself and on how to keep memories of parents alive. This is a very readable book with lots of practical information to help families deal with a difficult situation.



Hughes, Holly J (2009). *Beyond Forgetting: Poetry and Prose about Alzheimer's Disease*. For the many people now trying to cope with this disease, this collection will provide solace and valuable insight for family members as well as for those in the medical community who work with anyone with Alzheimer's disease.

Skillin, Joe (2009). *Confessions of a Caregiver: When Alzheimer's Comes to Your Home*. Joe bares his anger, resentment, frustrations, and eventually his love and hope as he and his wife live the caregiver's life. While reading of his trials and triumphs, you will understand the tools he uses to cope with the daily frustrations and difficulties.



Snyder, Lisa (2009). *Speaking Our Minds: Revised and Updated 2009*. This book is ideal for people with early-stage Alzheimer's and related dementias as well as for anyone who interacts with that person, including professional or family caregivers, friends, and relatives.

Phipps, Ellen and Braddock, Barbara A. (In Press—will be available at Bryan ADRC 2010 Conference). *Connections: Engagement in Life for Persons Diagnosed with Dementia—A Complete Activities Guide*. Connections has been designed to help caregivers structure the day and modify the environment in order to provide an
(continued on Page 15)

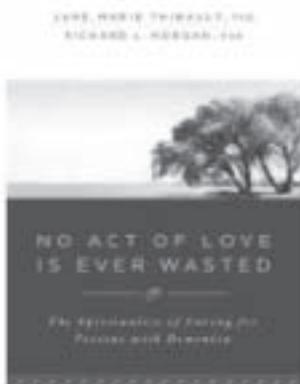
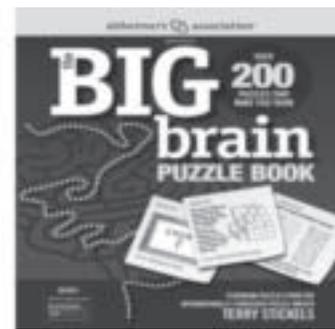
(Continued from Page 14)

opportunity for engagement in life of their family member. Connections provides the necessary tools and strategies for enhanced Caregiver/Care-receiver relationships. The Connections helps caregivers to set up Activities Stations at home, wherever home may be. For more information: www.alz.org/cwva.



Span, Paula (2009). *When the Time Comes: Families with Aging Parents Share Their Struggles and Solutions*. This book offers a realistic look at the challenges of caring for an aging parent that is both hopeful and practical.

Stickels, Terry (2009). *The Big Brain Puzzle Book* (paperbook). The Alzheimer's Association is proud to share The Big Brain Puzzle Book with fans of games, trivia and teasers across America. It's a fun and easy way to activate the brain, and it may inspire you to learn more about Alzheimer's.



Thibault, Jane Marie and Morgan, Richard L. (2009). *No Act of Love is Ever Wasted: The Spirituality of Caring for Persons with Dementia* (Upper Room Books). This little book puts a new, restorative option into the caring of, and love for, those with or affected by dementia.

Travland, David A. and Rhonda (2009). *The Tough and Tender Caregiver: A Handbook for the Well Spouse*. This book gives caregivers of chronically ill/disabled partners the knowledge to take better care of themselves, and thereby take better care of their ill spouses.



Ziegler, Rae-Lynn (2009). *Let's Look Together: An Interactive Picture Book for People with Alzheimer's and Other Forms of Memory Loss*. Occupational therapist Rae-Lynn Ziegler of North Carolina presents photographs that trigger multiple and varied sensory reactions. Tested with people with middle to late Alzheimer's disease, Ziegler's work demonstrates that spending time with an interactive picture book can help people with memory loss stay connected and engaged.

New Online Help



www.strengthforcaring.com. Johnson and Johnson consumer products free download for their Caregiver initiative. Includes new free iPhone application for family caregivers about health insurance, prescription drugs, treatment information, physician and emergency contact information. Families may also use this application to take notes during healthcare appointments and access videos and message boards about caregiving.

www.parentgiving.com. Elder care news, senior care parent and caregiver services, resources and products.

www.genworth.com. Roll over the Genworth Financial interactive map to compare your state or region's median cost of care to other areas in the country. Click a state or region to view and calculate current and projected long term care costs. Scroll down the page to learn more about long term care, long term care options, and the methodology used for the Genworth 2009 Cost of Care survey.

www.medicare.gov/NHcompare. Ratings for nursing homes throughout the U.S.

www.dhhs.state.nc.us/dhsr/acls/star/search.asp. Use the new N.C. Star rating system to review all adult care homes and assisted living.

www.dhhs.state.nc.us.dhs/acls/adultcarehomefines.html. Check on fines for recent deficiencies in N.C. adult care homes.

www.heinzfamily.org/tenquestions. Heinz Family Philanthropies—Foundation for the Future of Aging—10 questions to answer on long-term care, especially geared toward older women.

www.disabilityinfo.gov. Medicare Basics: A guide for families and friends of people with Medicare, is a useful tool for persons and families with Medicare on the other resources that are available for the person in need of care. It can also be helpful to those who want to brush up on what they already know. To access the entire book, go to http://www.disability.gov/health_insurance/medicare.

npr.org/templates/transcript/transcript.php?storyID=111623212. Treating Delirium: An Often Missed Diagnosis—read or listen to one family story.

www.thealzheimerspouse.com. This is a resource on younger onset dementias such as LBD, Vascular, FTD, and Huntington's.

<http://henryalzheimersbook.com>. This site was built to share *The Maze and Her Path*—the story of Henry Walker's mother within the story Alzheimer's tells.

(Continued on page 17)

New Online Help

(continued from Page 16)

<http://mysafehome.net>. Home Safety Council checklists by room to make homes safer and easier for persons with disabilities.

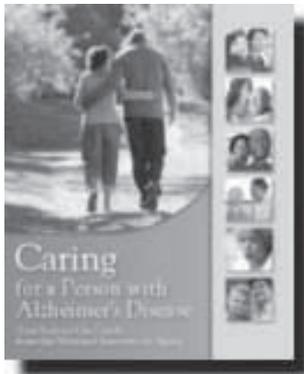
www.alzquilts.org/afpbp.html. Quilter Helen Marshall's "Once a Shining Star" is traveling through the United States as one of 52 quilts in the "Alzheimer's: Forgetting Piece by Piece" exhibition. Helen is the only New Zealander involved in the Alzheimer's Art Quilt Initiative, a non-profit volunteer organization.

www.getinvolved.gov. Seniors who want to remain active and engaged often turn to volunteering. A new government website sponsored by the Corporation for National and Community Service is promoting volunteerism for seniors.

<http://painanddementia.ualberta.ca/>. Observing and talking about pain behaviors—an online workshop for family members of persons with Alzheimer's disease and other dementias.

www.healthywomen.org. The Aging and Memory Center offers tips on keeping your memory sharp and your body strong as you enjoy later years.

NEWS FLASH



Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide from the National Institute on Aging

This latest guidebook is designed for caregivers of people with Alzheimer's disease (AD). It will help you understand and cope with the many challenges of caring for someone with AD. This free guide is available through the National Institute on Aging by calling 800-438-4380 or visit: [http://www.nia.nih.gov/Alzheimers/publications/Caring AD](http://www.nia.nih.gov/Alzheimers/publications/Caring%20AD).

FROM AA TO AD

(continued from Page 13)

As an example: I always found public speaking easy and enjoyable. In the years leading to diagnosis I found I no longer cared to speak publicly. It was painfully stressful. I first told the folks at the Alzheimer's Assn. in Minneapolis when I volunteered that I could not do any speaking. After that I did have occasion to speak about my Alzheimer's to a group and was pleasantly surprised how well it went and how enjoyable it was. After my diagnosis and the relaxation I experienced knowing why I found things difficult, my impediment over speaking passed away.

(To be continued: *The Caregiver*, Spring 2010).

Joseph & Kathleen Bryan Alzheimer's Disease Research Center Donors

5/31/2009 - 9/30/2009

General Research Donations

Grand Chapter Order of the Eastern Star
IBM Corporation Employee Services Center
Ms. Carol Hood
Ms. Jocelyn Broadwater
Ms. Margaret Dendy

In Honor of Betty Pace

Ms. Totsie Farr

In Honor of Ruth H. Updegraff

George and Marsha Alala

In Memory of Bernice Willis Adams

RSM McGladrey, Inc.

In Memory of James David Adams

RSM McGladrey, Inc.

In Memory of Elwynne Atnip

Ms. Leoda Atnip

In Memory of Thomas J. Atnip

Ms. Leoda Atnip

In Memory of Wanda Dixon Banther

Mr. and Mrs. Cladora Fogleman

In Memory of Edward E. Buffington

Ms. Eloise J. Bryan

In Memory of J. Norton Dendy

Mrs. Margaret L. Dendy

In Memory of Simon Forsythe

Dr. Sylvia Smith

In Memory of Joseph Garcia

Mr. and Mrs. Anthony Schettler

Mr. and Mrs. Harold Dauber

Mr. and Mrs. James Gentles

Mr. and Mrs. James Spotts

Mr. and Mrs. Jim Wise

Mrs. Carol Southon

Mrs. Jean Brown

Mrs. Juania Adams

Ms. Marcia Stromberg

In Memory of Henry Boone Grant

Dr. H. Stan & Linda Ford

Linus and Sara Jauniskis

Milton and Lea Fields

Mr. and Mrs. A. Stencil Barnes

Mr. and Mrs. Daniel O'Leary

Mr. and Mrs. George & Margaret Burton

Mr. and Mrs. John & Mary Tanis

Ms. Alice K. Kunka

Ms. Barbara L. Willis

Ms. Beverly Fellows

Ms. Churchill B. Young

Ms. Elizabeth Amend

Ms. Rebecca Gupton

Ms. Sharon Pindell

Nick and Betsy Boddie

Ray and Mary Ellen Jackson

Sterling Retirement Resources, Inc.

Tarboro Savings Bank, SSB

In Memory of Cora Lee Stone Harrelson

Donald and Demetris "Dee" Cumbo

George and Marsha Alala

Mr. and Mrs. Ty & Cynthia Hart

Ms. J. Catherine Ward

In Memory of Naomi Johnson

Ms. Judith Voynow

In Memory of Lanier Earl Matthews

Mrs. Ella L. Matthews

In Memory of Martin Herbert Maynor

Huda and Susan Martin

Ms. Rosa Absalom and Worthy Absalom

Surgical Oncology Clinic 1-A

In Memory of Helen Cline Measamer

Dr. & Mrs. J.R. Darwin

Dr. & Mrs. Malkiat Dhatt

John & Gail Atwater, Jr. D.D.S.

Mr. & Mrs. Donnie & Cerelda Hammer

Mr. & Mrs. J.B. Davis

Mr. & Mrs. James & Elaine Moose

Mr. & Mrs. Wayne & Brenda Thomas

Mr. & Mrs. William & Camille Redding

Mr. and Mrs. Bill & Dorothy Key

Mr. and Mrs. Carey & Billie Durham

Mr. and Mrs. Danny & Vivian Owens

Mr. and Mrs. David & Janet Jones

Mr. and Mrs. Eugene & Phyllis Andrews

Mr. and Mrs. James & Joan Culberson

Mr. and Mrs. Robert Shaffner

Mr. Andrew Huffine

Ridge Funeral Home

Mr. Donald McCrann

Ms. Luann InMan

Ms. Robin Liles & Family

Ms. Susan Soule

In Memory of Joseph Moore

Mr. and Mrs. Charles Thomasson

Ms. Margaret Thomasson

In Memory of Emily Fisher Nuckols

Mr. Kenneth M. Fulcher, II

Ms. Anne W. Hales

Ms. Louise A. Fulcher

(continued on Page 19)

Bryan ADRC Donors

In Memory of John William Pace, III

Chris and Lyn Fogarty
Dr. and Mrs. Todd Engerson
Mr. and Mrs. Bobby & Caroleen Ferrell

In Memory of Daniel Lee Willis, Sr.

Health Information Designs, Inc.
Mr. and Mrs. John & Sherry Stuart
Mr. and Mrs. L.H. Stuart, Jr.
Ms. Bobbie F. Pace
Ms. Gaylyn M. Miller
Ms. Marguerite G. Miller
Ms. Mary Anne Moore
Ms. Totsie Farr
The Clearwater Office Staff
The SSI Group, Inc.
Wade and Susie Pace Kennedy
Wilkins Miller, P.C.

In Memory of Viva Davis Piner

Allen and Kandice Davis

In Memory of Kenneth F. Ragan

Ms. Meredith Parnell

In Memory of Bernadine Rains

Ms. Leoda Atnip

In Memory of Roberts Rees

Ms. Sally Earnest

In Memory of Edward Z. Rutkowski

Mr. and Mrs. John Reese

In Memory of Helen Sable

Measured Progress, Inc
Mr. and Mrs. Lloyd Sanborn
Ms. Janet Katien

In Memory of Ray Ellison Smith

Dr. Sylvia Smith
Ms. Lynne Smith Forrest

In Memory of Robert Stanford

Mr. and Mrs. Bruce & Iretta Hanna

In Memory of Milred Williams

Liberty Elementary School

In Memory of Oliver "Huck" Williams

Bill & Ruth and Billy & Charley
Danny and Hilda Wilson
Mr. and Mrs. Charles & Wanza Broome
Mr. and Mrs. E. Rettammel
Mr. and Mrs. Gary Gammill
Mr. and Mrs. Kenneth Galloway
Mr. and Mrs. Rao Bhandaru
Mr. and Mrs. Stuart & Joanne Randolph
Mr. and Mrs. W.R. & Brenda Whitehurst
Mr. Jason Renzaglia
Mr. Keith Lunday
Terry and Mildred Scharton

In Memory of Ada Currie Willis

Mr. and Mrs. Bobby & Caroleen Ferrell
Mitchell, McLeod, Pugh, & Williams, Inc.
Mrs. Patricia Ziegelhofer

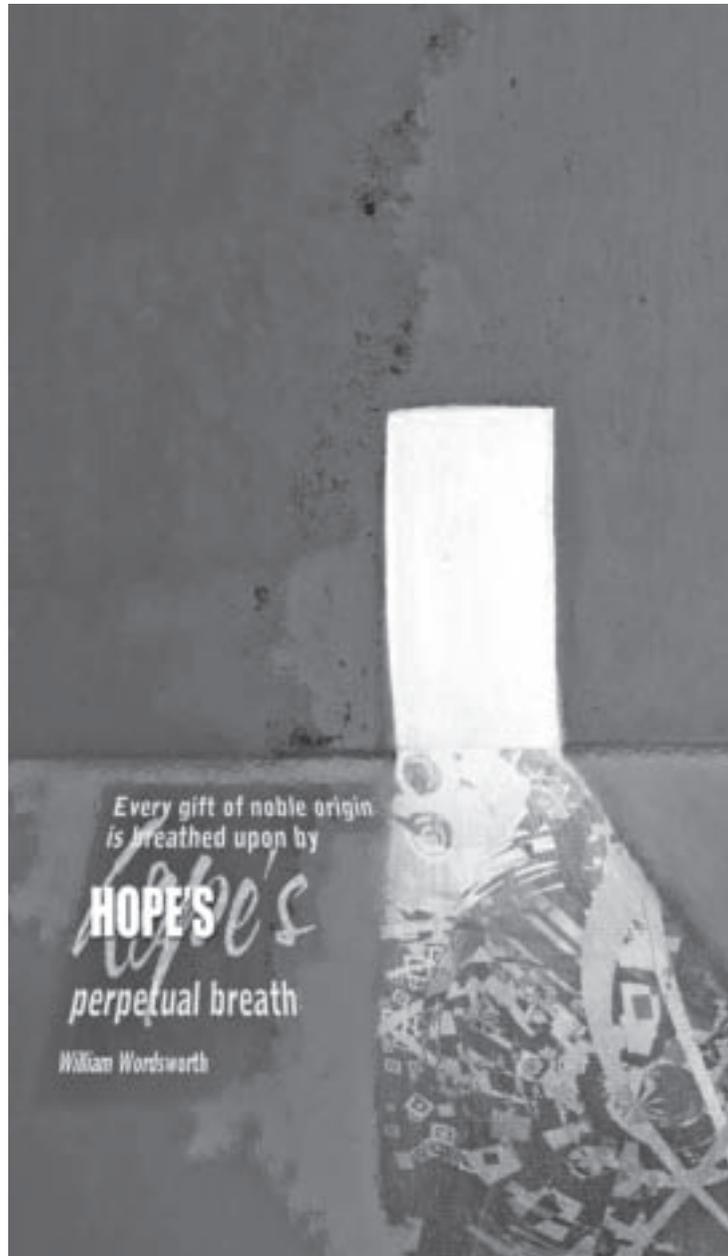


Image: Original color version: Undy | Dreamstime. Photoshop effects: Carol Edwards

Duke Family Support Program

Duke University Medical Center
Box 3600

Durham, North Carolina 27710

Phone: 919-660-7510

800-646-2028

www.dukefamilysupport.org

NON-PROFIT ORG

US POSTAGE

PAID

DURHAM, NC

PERMIT NO 60.