

CAREGIVER

Lifeline



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ALZHEIMER RESOURCE CENTER, INC

November is National Alzheimer's Awareness Month

As a fast-paced society it often takes a public figure to draw our attention to an issue. In November 1982, President Ronald Reagan signed a proclamation designating the first National Alzheimer's Awareness Week. That historic event marked the beginning of a greater awareness and understanding of Alzheimer's disease. Since that time, the Alzheimer's Resource Center has strived to use the month of November to further its mission of lightening the burden and improving the quality of life for families through education, counseling, support services, research, and hope.

As the population ages, this disease is fast becoming a major health threat. Worldwide it is estimated that about 16 million people currently have Alzheimer's disease, 4.5 million of them being American. For every person with Alzheimer's there is at least one other person who directly cares for them and a host of healthcare & social workers providing care in the background. With so many people directly or indirectly affected by this insidious disease it is essential that we set aside a time as a nation to promote awareness.

Alzheimer's disease is a progressive, degenerate disorder of the brain. Its cause is still unknown and presently there is no cure. But in the past twenty years we have progressed from helplessness to hope. We have made amazing progress in our fight against Alzheimer's and every year there is increased optimism as researchers continue to discover more about Alzheimer's disease, its causes, diagnosis,

prevention, medication, and ultimately, a cure.

Until that day, we must as a nation, pay tribute to all the people who have Alzheimer's disease and to all those who strive to make their lives better. But especially to all the caregivers who are the forgotten victims of this devastating disease, who love and care and who daily provide help to their loved ones, we say a special thank you in recognition of your dedication and devotion.

November is a month when Alzheimer's disease is fully in the spotlight, especially this year as we reach the one hundred year anniversary of the discovery of the disease. Take advantage of this opportunity to help raise awareness in your community. Your assistance is needed both through volunteerism and monetary gifts. Call (407) 843-1910 for more information on how you can help. Together we can make a difference!

How You Can Help Support the Alzheimer Resource Center



Volunteer

Join our giving society

Make a referral

*Make a donation in honor of a
loved one*

*Serve on our Board of
Directors*

Sponsor an event

*A message from the
Executive Director*

Welcome to the Fall, 2006 edition of the Alzheimer Resource Center's newsletter. I am pleased to share the exciting news that our agency will be moving to a new location as of the first week of November, 2006.

Our new home, located at 1506 Lake Highland Drive, Orlando, Florida, 32803, is the former parsonage for Reeves Memorial United Methodist Church and is adjacent to their facility at 1100 North Ferncreek Avenue. The staff and I are excited to be back in our "own" facility in the lovely Colonialtown neighborhood, and the property boasts plenty of parking for visitors.

This location provides us with some wonderful neighbors: Reeves United Methodist, of course, which hosts meetings by several other social service organizations such as RSVP, the Colonialtown Neighborhood Center, Marks Street Senior Center, Florida Hospital, Leu Gardens, and Ferncreek Elementary School.

Once we have settled in and the holidays are over (yes! They are just around the corner!) the board of directors, staff and I will be hosting an open house and hope you will join us for this occasion. Watch your mail for an invitation in early 2007!

The Alzheimer Resource Center has some special events planned between now and the end of the year, which are detailed elsewhere in our newsletter, but I would be remiss not to mention them here.

◆ Our Second Annual Breakfast of Champions is to be held at Leu Gardens on Wednesday, October 25th from 8:30 to 9:30 a.m., and will honor one of our special caregivers and volunteers - Gordon Peters. This is an important fund-raiser for us and is also meant to inform the community about the services our agency offers. If you'd like to attend, please call our office.

◆ ARC's 13th Annual Caregiver Educational Conference is planned for Saturday, November 11th and will take place at the Metro Life Church in Casselberry from 8:00 a.m. to 3:00 p.m. This year's theme is "A Century of Discovery", and all are welcome to attend. Call our office for more information or to sign up.

◆ We will welcome the holiday season with the 7th Annual Festival of Wreaths and Trees at Arden Courts on Thursday, December 7th from 5:00-7:00 p.m. This year's gathering promises to be the biggest and most beautiful holiday event to date, and I would like to thank the staff of Arden Courts and

Vitas Innovative Hospice Care for their dedication and hard work on our agency's behalf. If you've never attended this event before, be sure to come this year...and bring your friends! You will leave with a song in your heart, a bounce in your step and plenty of holiday spirit!

And speaking of the holidays, may yours be full of loving family, good friends and beautiful memories.

Fondly,



Nancy Squillaciotti
Executive Director





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13th Annual Caregiver Educational Conference

Saturday, November 11, 2006
8:00 a.m. - 3:00 p.m.

Metro Life Church
910 S. Winter Park Drive - Casselberry

“A Century of Discovery”

This year's conference will take a look back over the advances of the past one hundred years since the landmark discovery of the disease. Keynote Speaker, Dr. Ira Goodman of Orlando Regional Healthcare's Memory Disorder Clinic, will expand your knowledge and understanding of the disease itself, while various breakout sessions will concentrate on the practical issues faced by every Caregiver.



Breakout Sessions will include two choices of the following:

- ◆ **Stem Cell Research in Alzheimer's Therapies** - Kiminobu Sugaya, Ph.D. - Professor of Molecular Biology, Director of Stem Cell Laboratory, University of Central Florida
- ◆ **The Importance of a Neuropsychological Evaluation in Assessment** - Dr. Robert Cohen, Psy.D. - Orlando Regional Healthcare, Memory Disorder Clinic
- ◆ **Treating Caregivers: Best Practice for Hope and Healing** - Dr. Christine Cauffield - Aspire Behavioral Health
- ◆ **Legal Issues for Caregivers** - Kathleen Flammia, Counselor and Attorney at Law
- ◆ **The Importance of Advanced Directives** - Rosalind Smith-McCarthy, VITAS

For the convenience of our family caregivers, respite will be provided on-site by Senior Partner Care Services. If you need day care for your loved one, please call by November 3rd in order to secure your respite place as space is limited.

The cost of this event is \$30.00 for early registration or \$35.00 at the door. Conference Fees includes Registration, Continental Breakfast, and Lunch. Some scholarships may be available. **Please call the office at 407-843-1910 for more information!** We hope to see you there!

Upcoming Events



Candle Lighting Orlando

Saturday, November 11, 2006

6:00 p.m.

Lake Eola Amphitheater
Downtown Orlando, Rosalind at Washington

VITAS Innovative Hospice Care of Central Florida and New Hope for Kids invite you to attend a special holiday preparation event for those coping with the death of a loved one, divorce, or other major loss. Candle Lighting Orlando will feature professional speakers and volunteer voices who will share concerns about the holidays and offer practical suggestions for coping. The program will offer time for personal reflection, sharing, music, and a candle lighting ceremony designed to inspire and bring peace to those who attend. This event is free and open to the public. For more information call Elizabeth Knowlton at 407-691-4579.



7th Annual Festival of Wreaths

Thursday, December 7, 2006

5:00 p.m. - 7:00 p.m.

Arden Courts Alzheimer's Assisted Living
1057 Willa Springs Drive, Winter Springs, FL 32708

You are cordially invited to the seventh annual Festival of Wreaths presented by Arden Courts and VITAS Innovative Hospice Care. A silent auction full of beautifully decorated wreaths, full size holiday trees, and more will be on display throughout the facility for your viewing and bidding pleasure. All proceeds from the silent auction will benefit the Alzheimer Resource Center. The celebration is free and open to the public; holiday refreshments and hors d'oeuvres will be provided. Call 407-696-8400 by November 30th to RSVP!

Withdrawals from the Bank

*Contributed by: Martha Purdy, LCSW, ACSW
Brain Bank Program Specialist*

THE STATE OF FLORIDA ALZHEIMER DISEASE INITIATIVE BRAIN BANK PROGRAM

It has been a long time since this program has been discussed in our newsletter and we have many new readers; therefore those of you who are quit familiar with it can save time and just skip over this article! But for those of you who have no clue what the Brain Bank is all about please tune in, as I hate seeing tears and hearing "Why didn't I know about this program before my mother died? My children want to know specifically what Grandma's diagnosis was?" Some say what does it matter? The reason it matters is that some of the 200 different dementias have no genetic link, therefore the adult children and grandchildren don't need to worry about inheriting Grandma's disease. On the other hand, others dementias definitely do!

There are only two requirements for being accepted into the Brain Bank program which are: 1.) the patient has had a complete diagnostic work-up (neurological evaluation, special blood work, and brain imaging) 2.) the patient has a pre-need arrangement with a local funeral home.

The decision to obtain a brain autopsy must be done by family members in advance. It can take up to 6 weeks to get the original diagnostic work up and all the medical records required for acceptance into this program. Also pre-planning minimizes additional upset at the time of death. These medical records are studied as the brain tissue is being studied.

As was mentioned, this is a state program and there is a network of researchers in Florida who share the information gleaned from each brain donation. These donations have become a part of a lot of important research and advances that are happening daily.

The primary goal of this program is to find a cure. Secondary goals are to find more effective treatment modalities, and diagnostic tools as well to provide the families with a definitive diagnosis. The neuropathology report is also given, with the blessings of the family, to the doctors providing the required medical records for them to compare their pre-morbid diagnosis with the actual diagnoses. (Usually there is more than one diagnosis)

This program is also actively seeking folks willing to donate their healthy brain as there is the need to compare the healthy brains with the diseased brains to find out what went wrong and why?

There are other special studies being done within our state and at Indiana University's Alzheimer Disease Center National Cell Repository. There are those looking at why one blood sibling



Call for Brains

There are many of you who have expressed an interest in donating your brain as a "Control" for researchers who are desperately in need of normal brains to study along side of diseased brains.

Well, finally after several years of struggling with this, we have made progress.

Please call me to confirm that you continue to have interest in this invaluable contribution to the research at 407-843-1910 or 1-800-330-1910 Ext. 19

gets dementia and others don't why does one Identical Twin have dementia and the other doesn't, why do spouses both get dementia (is it environmental)? Indiana is looking at two or more living blood relatives with dementia. We have been able to provide them with at least 10 families that comply with their criteria. What are the genetic components going on in these families? Your grandchildren will benefit from the knowledge that is gleaned from these studies.

To sum up the importance of this program, a quote from the daughter/caregiver of a brain donor, "Thank you...for giving my mother her last hurrah, a gift to science and a gift to the future!"

Questions and Answers about Brain Bank and the Autopsy

Who may request and autopsy? Legally if the spouse is deceased, the Durable Power of Attorney for medical decisions or a guardian is the person to make the decision and sign all the forms.

Is a complete body autopsy performed? No.

Can a donor's organs be donated at the same time as the autopsy of the brain? Since we are not sure how one gets dementia or how it's transmitted, the only organ that has no blood passing through it is the cornea and therefore is the only possible organ donation other than the brain. An organ donation of the brain is the most important donation to bring an end to this insidious disease.

Can I have an open casket? Yes. Harvesting the brain for diagnosis and research leaves no disfigurement. Only on very

close inspection would anyone know that an autopsy had been performed.

Is it important for children of dementia parents to have a confirmed diagnosis through autopsy? Yes. As our knowledge increases, it is clear that some cases of AD and other dementias run in families. Other disorders are also occasionally mistaken for AD and an AD like illness can sometimes be due to other diseases. When genetic test or other tests become available, it is important to know that AD is the actual diagnosis. If other family members might be prone to develop AD, this information will be important for early diagnosis and treatment. Doctors treating off-spring of dementia parents want a definite diagnosis particularly if the off-spring are showing early signs of dementia.

Are there other ways to definitely establish an accurate diagnosis? Currently there are no ways to diagnose AD or other dementias other than by examining brain tissue; however, autopsy tissue and fluids provide invaluable material for developing less invasive diagnostic tests in the future.

Six Reasons for Getting an Early Diagnosis

1. Determine if it's a reversible dementia and treat it.
2. Determine as closely as possible what type of dementia it is as treatments vary and the wrong treatment can cause catastrophic results.
3. If diagnosed early the patient can participate in a support group with others and get a great deal of emotional benefit from the group as well as learn about the disease and make important decisions about the future with their family.
4. The patient will also be able to be involved in making legal, financial, and end of life decisions for himself and his family.
5. The medications work better early-on in the disease to slow down the progression of the disease and many new drugs in trials now are aimed at stopping the progression of the disease.
6. Clinical trials for new medications are usually looking for patients early in the disease and newly diagnosed. These are also the patients who benefit the most from the new drug that is being tested.

These are only a few reasons that an early diagnosis is extremely important.

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CAREtenders
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Professional Caregiver Training offered by ARC

The Florida Department of Elder Affairs requires that all staff in agencies and facilities that provide direct services to individuals with Alzheimer's Disease and Related Disorders meet specific training requirements. These agencies and facilities include: Adult Day Care Centers, Home Health Care Agencies, Hospice Agencies, Assisted Living Facilities and Nursing Homes.

Staff must attend training that has providers and curriculums approved by the Florida Department of Elder Affairs.

The Alzheimer Resource Center offers Alzheimer's and Related Dementia Training (ADRD) to Professional Caregivers that meets the standards established by the Florida Department of Elder Affairs.



The Alzheimer Resource Center has the following approved curriculums:

- ◆ Adult Day Care, Hospice and Nursing Home ADRD - One Hour Training
- ◆ Adult Day Care, Hospice and Nursing Home ADRD - Three Hour Training
- ◆ Home Health Care ADRD - Two Hour Training
- ◆ Assisted Living Facility ADRD Level I - Four Hour Training
- ◆ Assisted Living Facility ADRD Level II - Four Hour Training

For more information contact Jerry Hamilton 847-843-1910, Ext. 21.

Our New Address

**Alzheimer Resource Center
1506 Lake Highland Drive
Orlando, FL 32803**

Thanks to all of the amazing community support, the Alzheimer Resource Center has found a new home. We will be relocating as of November 1st to a small house owned by Reeves United Methodist Church. Please stop by and visit us at our new home and look for an announcement to come for our Open House.

Staff News

Martha Purdy, Brain Bank Program Specialist has been appointed by Governor Jeb Bush to the Alzheimer Disease Initiative Committee for the next four years. The ADI Committee studies issues impacting the dementia patient and their caregivers, monitors for best practices, etc. and makes recommendations to the Department of Elder Affairs who in turn passes these recommendations on to the legislature and the Governor.

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Orlando is host site for 1st International Conference on Brain Aging

Nationally, we're just a few years away from a dramatic demographic shift. The baby boom generation is getting older. We're going to go from about 40 million people over 65 to upwards of 75 million over the next several years. The latest predictions say that by the year 2030, one in five Americans will be 65 or older.

Although everybody wants to be healthy active adults, unfortunately, aging causes deterioration of various aspects of performance in normal adults. Memory loss extends along a spectrum from "benign senescent forgetfulness" to dementia including neurodegenerative diseases. We in the Orlando area: The University of Central Florida, Orlando Regional Health Center, Alzheimer's Association, Florida Hospital, and Alzheimer Resource Center are teaming up in the fight against this issue.



Rosen Hospitality Center

We are delighted to invite you to attend the **1st Orlando International Aging Brain Conference**. The Conference will take place in the state of the art Rosen Hospitality Center, the University of Central Florida (a new off campus extension) located near by Universal Studio from **January 19 to 21, 2007**.

In this conference we will have lectures on the most up-to-date techniques and research findings in neurological related research by renowned professionals, including subject matter that is unique in that it deals with issues related to the age associated neurological disorders, as well as the expected problems that occur with the normal "Aging Brain".

For more details, please contact us at OIABC@sugaya.ucf.edu or visit our web site <http://www.brainconference.org>.

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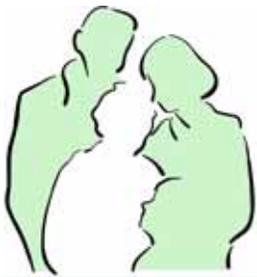
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CAREGIVER FALL 2006

Meet Other Caregivers

The Center has several support group meetings available throughout the Central Florida Community. If one of these does not fit your schedule, please give us a call so that we can put you in touch with other support groups that can assist you.

Caregiver Support Groups

1st Tuesday, 10:00 a.m. *
Easter Seals Daybreak
Winter Park

1st Tuesday, 6:00 p.m.
The Gables of Lake Mary
Lake Mary

1st Friday, 12:00 noon
Osceola Council on Aging at the
Senior Center
Kissimmee

2nd Thursday, 6:00 p.m.
Arden Courts
Winter Springs

3rd Tuesday, 10:00 a.m.
St. Richard's Episcopal Church
Winter Park

4th Mondays, 6:30 p.m.
Merrill Gardens at Lake Orienta
Altamonte Springs

4th Tuesday, 6:00 p.m.
Golden Pond Communities
Ocoee

Last Thursday, 6:30 p.m.
Summerville Assisted Living
Ocoee

* Respite Care Provided Upon Request.



Home Caregiver Support Group

(For caregivers and families caring for their loved one in the home.)

2nd Tuesday, 10:00 a.m.
Alzheimer Resource Center

New Beginnings Support Group

(For those who have lost a loved one to Alzheimer's disease.)

4th Thursday, 10:30 a.m.
Alzheimer Resource Center

Orlando Men's Breakfast Club

1st and 3rd Thursday, 10:00 a.m.
Bakely's Restaurant Winter Park

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