Atypical Form of Alzheimer’s Disease May be Present in a More Widespread Number of Patients, Mayo Clinic Says

JACKSONVILLE, Fla. — Neuroscientists at Mayo Clinic in Florida have defined a subtype of Alzheimer’s disease (AD) that they say is neither well recognized nor treated appropriately.

The variant, called hippocampal sparing AD, made up 11 percent of the 1,821 AD-confirmed brains examined by Mayo Clinic researchers — suggesting this subtype is relatively widespread in the general population. The Alzheimer’s Association estimates that 5.2 million Americans are living with AD. And with nearly half of hippocampal sparing AD patients being misdiagnosed, this could mean that well over 600,000 Americans make up this AD variant, researchers say.

In an oral presentation at the annual meeting of the American Academy of Neurology in Philadelphia, scientists say hippocampal sparing AD often produces symptoms that are substantially different from the most commonly known form of AD, which affects the hippocampus, the center of memory.

The patients, mostly male, are afflicted at a much younger age, and their symptoms can be bizarre — behavioral problems such as frequent and sometimes profane angry outbursts, feelings that their limbs do not belong to them and are controlled by an “alien” unidentifiable force, or visual disturbances in the absence of eye problems, researchers say.

They also decline at a much faster rate than do patients with the most common form of AD.

“Many of these patients, however, have memories that are near normal, so clinicians often misdiagnose them with a variety of conditions that do not match the underlying neuropathology,” says the study’s lead author, Melissa Murray, Ph.D., an assistant professor of neuroscience at Mayo Clinic in Florida.

Continued on Page 3
A message from the EXECUTIVE DIRECTOR

If you’ve driven past our office on Lake Highland Drive recently, you will have seen a six-foot long banner hanging above our front porch proudly proclaiming “Celebrating our 30th Anniversary”. What a thrill it is to see that each day and be reminded of the thousands of families we have assisted over the years.

The Resource Center’s founder, Pat Jimison, shared her story about the origins of the Alzheimer Resource Center (now Alzheimer’s & Dementia Resource Center) in our Spring, 2014 Caring newsletter. Pat was very gracious to also provide me recently with a copy of a memoir she wrote for her family called “Do We Have a Destiny?” Pat’s memoir describes in detail so many of the accomplishments Pat spearheaded, along with lots of help from family members, friends and colleagues as she worked to provide comprehensive and effective programs to families seeking help from our agency.

And although little is accomplished without the special abilities of a leader like Mrs. Jimison, even she will undoubtedly agree that there were many in the community who contributed their time and talent to our agency and are also responsible for ADRC achieving 30 years of service to the community.

It would be almost impossible to thank all of those who supported the Resource Center, particularly in its early years, but we have spent much of our Anniversary so far recognizing those individuals and organizations as a way of thanking them for our longevity.

On Wednesday, October 22nd, ADRC is hosting a 30th Anniversary celebration at Dubsdread’s Historic Ballroom from 5:30 pm to 8:00 pm. (All are welcome to attend and tickets are just $75.00.) Special recognition will be made at that event of the long term support and funding our agency has received from the Edyth Bush Charitable Foundation, ADRC’s first funder.

The Resource Center has been fortunate to have a number of foundations and families who have made significant donations or bequests to our agency over the years. Special thanks go to the Joseph G. Markoly Foundation, the Tenzky family, Mt. Sinai Medical Center, Orlando Health, the Galloway Foundation, the Ryan Foundation, Central Florida Foundation, Publix Super Markets Charities, the VNA Foundation, Compass Research, Dr. and Mrs. Luis Allen (Dr. Allen is also on our board), the Percy family, the O’Donnell Foundation, the ChesleyMagruder Foundation, Fraternal Order of Eagles Aerie and Auxiliary #3496, Kathleen Flammia, P.A., the Jack and Annis Bowen Foundation, the Lee Foundation, the Chatlos Foundation and Florida Hospital.

ADRC has also been fortunate to have many community leaders on our board who have been passionate about our mission. The late Dr. Leslie Ellis, Retired UCF Dean of the College of Health, held our board chair position for many years and was directly responsible, along with Betsy McKeeby, R.N., for hiring me as Executive Director in 2004. Ms. McKeeby, a parish nurse as well as a Florida Hospital staff member, has also been a tremendous supporter of our agency and its staff for many years.

Thomas Kerney, Esquire, was the “young attorney” Pat Jimison wrote about in our Spring newsletter who handled all of the nonprofit incorporation documents pro bono when the Resource Center first started. Other champions include Dr. Richard Tucker, former board chair and agency friend, Mr. Frank Hubbard, Mr. Robert Klettner, Dr. Thomas Mendenhall, Dr. Richard Nelson, Dr. Levester Tubbs, Carole Arthurs, Fran Carlin-Rogers, Dr. Ignacio Hidalgo, Tanya Burns, Julie Fernandez, John VonLangen, Joy Block, Jim Salvage and Patricia Galloway.

I would also like to thank those champions who are currently on our board: Gail Baxter, board chair, Hank Charpentier, Bonnie Davis, Bob Hodges, Kim Hone, Margery Pabst Steinmetz and Richard Wenick. My deepest thanks to all of you for the time and talent you so readily provide to our agency.

My sincere apologies to all of those whose names I may have missed, along with my deepest thanks for the contributions you have made to ADRC and our community.

One of our caregivers, who became a volunteer with our agency after his wife passed away, used to explain the value of our help in this way: “I was a basket case for so long and then I found ADRC. You couldn’t “fix” my wife’s disease but you sure made a positive difference in my life!”

There’s no question that caring for a loved one with dementia can be a challenge, but the staff of the Alzheimer’s & Dementia Resource Center are committed to providing caregivers with all of the tools and support they will need as they take this journey with their loved one. After 30 years, making that “positive difference” in the lives of families continues to be our most important goal.

Warmest regards,

Nancy Squillacioti
Mary’s Garden

This year, ADRC lost one of its long-time volunteers, Mary Fleich. In celebration of her life and years of service to ADRC and to recognize the contributions of our volunteers, ADRC is putting in a garden in front of our building. Please join us for a memorial breakfast and planting party on Saturday, December 6th at 9:00 a.m. If you would like to help with planning the garden or to make a donation, please contact Cindi Spurgeon at 407-843-1910, ext. 301.

Continued from Page 1

Many of these patients are diagnosed with frontotemporal dementia, a disorder characterized by changes in personality and social behavior, or corticobasal syndrome, characterized by movement disorders and cognitive dysfunction. Language dysfunction is also more common in hippocampal sparing AD, although patients do not have vocal or hearing deficits.

“What is tragic is that these patients are commonly misdiagnosed and we have new evidence that suggests drugs now on the market for AD could work best in these hippocampal sparing patients — possibly better than they work in the common form of the disease,” Dr. Murray says.

The researchers benefit greatly from one of the largest brain banks in the country, the State of Florida’s Brain Bank Research Program. This program has contributed more than 6,500 brain donations and has created a collaborative environment between neuroscience research and neurology at Mayo Clinic, she says.

Both hallmark proteins of AD — amyloid beta (Aβ), which forms Aβ plaques, and tau, which produces tangles — are found across all subtypes of AD, including hippocampal sparing AD. The researchers developed a mathematical algorithm to classify AD subtypes using tangle counts. “What is fascinating is that all the AD patient subtypes had the same amount of amyloid, but for some reason tau tangles were found in strategic cortical regions disproportionate to the hippocampus.”

In these patients, tau preferentially damages and eventually destroys neurons in parts of the brain involved in behavior, motor awareness and recognition, as well as use of speech and vision, Dr. Murray says.

She says she hopes this research, the second high-profile Mayo study to highlight hippocampal sparing AD, will “open the minds” of clinicians who are trying to diagnose dementia, helping them understand that loss of memory is not present in every AD patient.

“Our studies support the notion that dementia related to AD does not necessarily equate to a loss of memory, and points to the need for more research in amyloid and tau imaging biomarkers to help clinicians accurately diagnose AD — regardless of subtype,” Dr. Murray says.
Caring for Caregivers at UCF

Daniel Paulson, PhD • University of Central Florida

Caregiving of older adults with life-limiting conditions is becoming increasingly common as the American population ages. Over 42 million Americans provide care to adults with limitations, and over 60 million provide functional support to another adult at some point each year. The economic value of informal caregiving is estimated at over $450 billion annually. Elder care in general is emerging as a critical public healthcare issue, with informal caregiving as one key aspect. As family members and friends of older adults, we can all work to preserve their wellbeing and ensure that basic needs are met. For those who provide the most direct support, caregiving for aging family members with degenerative disorders, such as Alzheimer's disease, can be both deeply rewarding and stressful.

The decision to provide in-home care for loved ones is a very personal one. Even the most committed caregivers often struggle to balance demands of caregiving with careersand managing their own needs. In addition to these challenges, research has identified psychiatric symptoms common among older adults with dementia – uncharacteristic angry outbursts, depression, and argumentativeness to name a few – as the primary reasons caregivers consider residential long-term care options such as nursing homes. Most older adults prefer to age in place, and despite the escalating challenges associated with aging and dementia care, many family members wish to provide in-home support for as long as possible. Though compassionate care sometimes requires professional nursing facilities, we are constantly researching and developing new strategies to help caregivers extend in-home care.

As a new Assistant Professor in the Department of Psychology at the University of Central Florida, my foremost goal is to work with caregivers to improve the quality of informal care and reduce caregiver burden. Our ultimate objective is to help others work toward their own goals of caring for older adults with life-limiting conditions such as dementia. To this end, much of my research and clinical work focuses on caregiver support groups. This past summer, I lead the first caregiver support group at Pegasus Health on University Blvd. This brief, weekly support group was developed to help caregivers identify problem behaviors – including some of those mentioned above – and to develop constructive ways of working with older adults. In response to feedback from past group members, I have reached out to the ADRC for greater collaboration around identifying critical professional and social services. The ADRC has generously offered their time and support, and I look forward to our work together with future groups.

We look forward to starting our next series of support groups this September at Pegasus Health. If you or someone you know may benefit from participation in a caregiver support group, please contact me anytime.

Daniel Paulson, PhD
Phone: 407-823-3578
Email: Daniel.Paulson2@ucf.edu
Upcoming Events

30th Anniversary Celebration
Join us to honor Edyth Bush Charitable Foundation and support our cause
Wednesday, October 22nd, 2014
5:30 pm – 8:00 pm
Tickets $75 per person
To purchase tickets on-line go to www.adrccares.org/news-and-events
Enjoy Cocktails, Hors d’oeuvres and Music
Historic Dubsdread Ballroom
549 West Par Street
Orlando, FL 32804
For more information contact the Alzheimer’s & Dementia Resource Center at 407-843-1910

21st Annual Caregiver Educational Conference
“Your Caregiving Journey”
Helping You Navigate the Continuum of Care
Saturday, November 1st, 2014
8:00 am – 1:30 pm
Calvary Assembly Church
1199 Clay Street
Winter Park, FL 32789
Registration fee $25 per person (Limited scholarships available for family caregivers)
Breakout sessions will include: Brain Health, How to Survive Caregiving, Legal Considerations for Caregivers and the Brain Bank Research Program.
Visit with vendors, enjoy a light breakfast and boxed lunch. For more information and to register contact Cindi Spurgeon: 407-843-1910, ext. 301. Registration fees are due by October 24, 2014. Corporate sponsorships are available.

15th Annual Festival of Wreaths
Thursday, December 4th, 2014
5:00 pm – 7:00 pm
Sponsored by:
Arden Courts
Innovative Hospice Care
Please join us at Arden Courts, 1057 Willa Springs Drive, Winter Springs to celebrate the Festival of Wreaths, a silent auction fundraiser. All proceeds benefit the Alzheimer’s & Dementia Resource Center. If you would like to attend and/or create a wreath, please contact Susan Tibbals at 407-696-8400. All wreaths need to be dropped off by December 1st.

Free Community Workshop
Caregiving Matters
Friday: December 5, 2014
“How to Survive Your Role as Caregiver”
Jerry Hamilton MSEd
Registration: 9:15 am
Workshop begins: 9:30 am – 11:30 am
Please RSVP or for more information call ADRC at 407-843-1910.

Location:
Reeves United Methodist Church
1100 N. Ferncreek Ave.
Orlando, FL 32803

www.ADRCcares.org
IN HONOR / MEMORY OF:

In Honor Of:
Robert Backas
Delores Carter
Kathy Hailpin
Rhonda Keating
Melissa Mault
Ernest Parker
Mary Scott
Chuck and Margery Steinmetz
Nancy Squillacioti
Robert Warshel
Martin Wenick
Richard Wenick

In Memory Of:
Jean Boardman
Lillian Bremer
Jewell Bryant
Russell Burns

WITH GRATITUDE:

Special thanks go to the following foundations, corporations and individuals who have donated to ADRC since our last newsletter:

Dr. and Mrs. Luis Allen
Mr. Peter Barr
Mr. Kevin Beyreuther
Mr. Russell Blackwell
Ms. Tanya Burns
Ms. Beverly Coll
Mr. and Mrs. Bob Davis
Mr. Ramon Garriga
Ms. Norma Keating
Mr. Bruce Morse
Ms. Katie Ozdemir
Mrs. Dorothy Robinson
Mr. Joseph Rogers
Mr. Jerry Vaughn
Ms. Tanya Williams
ABC Companies
Atria at Lake Forest
Black Hammock Adventures
Columbia Restaurants
Comfort Keepers
Compass Research
Edyth Bush Charitable Foundation
Fox Head Lounge
Kathleen Flammia
Fraternal Order of Eagles
Aerie and Auxiliary #3496
The Lee Foundation
Longwood Health Care Center
Maitland Rotary Club
Joseph G. Markoly Foundation
O’Donnell Family Foundation
Orlando Health
Partners in Healthcare
Patio Grill Restaurant and Lounge
PhRMA Medicare Rx Access
Network of Florida
Post Time Lounge
Publix Super Market Charities
Senior Helpers
Serenades by Sonata Winter Garden and Longwood
Sutton Homes
TenderCare Home Health
Universal Orlando Foundation
Visiting Angels
Vitas Innovative Hospice
Winter Park Towers

We know how physically and emotionally exhausting it is to care for the person who used to care for you. When our interdisciplinary team comes to the home or nursing home, everyone feels better. The VITAS team brings the same compassion to the bedside that you would bring—on your best days. We address psychological and emotional pain as well as physical pain and symptoms.

With VITAS there to share the burden, you can be there to share a memory.

Find strength in our care.

VITAS
Innovative Hospice Care®

Information: 1.800.723.3233 • Referrals: 1.800.93.VITAS
VITAS.com • twitter.com/VITASHospice

AFFORDABLE Peace of Mind

All Caregivers are:
• Certified • Verified • Screened • Insured

For a Free In-Home consultation Call (407) 273-1010 or Visit www.americaninhomecare.com

American In-Home Care
The Columbia Restaurant was founded in 1905 and is the oldest restaurant in Florida. Locations include the flagship restaurant in Tampa’s Historic Ybor City, St. Armands Circle in Sarasota, the Historic District in St. Augustine, The Pier in St. Petersburg, Sand Key on Clearwater Beach, Central Florida’s town of Celebration, and the Columbia Café on the Riverwalk in Tampa. All Columbia locations are owned and operated by 4th and 5th generation members of the founding family, Casimiro Hernandez Sr.

During the month of September, Columbia Restaurant hosts the Community Harvest Fundraiser. The restaurant donates 5% of all guests’ lunch and dinner checks to local charitable organizations in the form of gift certificates. For the seventh year in a row, the Alzheimer’s & Dementia Resource Center has been selected to participate. Our agency has received over $6,300 in gift certificates which are used as gifts of appreciation for our volunteers, caregivers and as auction items for our fundraisers. All you have to do is enjoy an amazing meal at the **Columbia Restaurant in Celebration** and select **The Alzheimer’s & Dementia Resource Center** on the ballot provided by your server. If you have any questions call 407-843-1910.
Support Groups

The Alzheimer’s & Dementia Resource Center provides support groups for caregivers and family members as noted below.

Every Monday @ 9:30 A.M.
Arbor Village
490 S. Old Wire Road
Wildwood, FL 34785
(respite care available during the meeting, call for more information at 352-748-3322)

3rd Monday @ 10:00 A.M.
Reeves United Methodist Church
1100 N. Ferncreek Avenue
Orlando, FL 32803
(Use the Fellowship Hall entrance in the back of the church)

1st Tuesday @ 6:30 P.M.
Atria at Lake Forest
5433 West State Road 46
Sanford, FL 32771

2nd Tuesday @ 10:00 A.M.
Reeves United Methodist Church
1100 N. Ferncreek Avenue
Orlando, FL 32803
(Use the Fellowship Hall entrance in the back of the church)

3rd Tuesday @ 6:30 P.M.
Oakmonte Village at Lake Mary
1001 Royal Gardens Circle
Lake Mary, FL 32746
(New assisted living and memory care building - 1st building when you arrive)

2nd Wednesday @ 9:00 A.M.
Eastbrooke Gardens
201 North Sunset Drive
Casselberry, FL 32707
(respite care available during the meeting, call ahead at 407-699-9002)

1st Thursday @ 10:00 A.M. and
3rd Thursday @ 10:00 A.M.
Men’s Breakfast Club
Mt. Vernon Inn
110 S. Orlando Avenue
Winter Park, FL 32789
(An informal and unstructured gathering of male caregivers)

Sponsored by ADRC, the State of Florida Department of Elder Affairs, the Senior Resource Alliance and the Orlando Health Memory Disorder Clinic