Alzheimer's Research: Get Involved!

By Craig Curtis, MD  
Medical Director, Compass Research

As an Alzheimer’s physician and researcher, I am often asked “Why should I participate in a clinical trial?” The answer to that question is simple - research provides hope. Hope that through research we can find a way to treat this devastating disease. Hope that through research we can lessen the burden on caregivers. Hope that through research we can lessen human suffering.

A clinical trial is a research study that involves people and the search for an answer to a particular medical condition. The goal of any clinical trial is to find a better way to prevent, diagnose or treat a disease. It is carefully thought out and planned prior to enrolling the first patient, with a specific goal for the study in mind.

At Compass Research, volunteer patients receive a study medication and are followed in our office for a specified length of time. Study participants are seen by our research coordinators and a physician specializing in clinical research. For example, a typical Alzheimer’s trial will run 18 months, involve a new medication and have memory testing performed at the start and at the end of the trial. There are many other data points that are collected during the trial that will be explained to a patient and their caregiver during their office visits.

Currently there are over 91,000 clinical trials for different diseases listed on the United States FDA website, www.clinical trials.gov. Of these, there are over 800 listed for Alzheimer’s. Stop and think about this for a few seconds - over 800!! These research studies vary from simple memory testing studies to studies involving new medications being designed to treat Alzheimer’s. All of these over 800 research studies require the same common denominator - a person to participate. Without research volunteers, no research would get done and no answers would be found.

Let me give you a little background on the disease, as this will help you understand how we are attacking Alzheimer’s disease through research.

Alzheimer’s disease is a progressive brain disorder that is probably caused by a buildup of protein plaques in the brain. Some of the ways researchers are attempting to treat the disease is by attempting to

Continued on Page 2
For hundreds if not thousands of years, art, music and poetry have made our world a more beautiful place. But did you know they can also enhance the world of a patient suffering from Alzheimer’s or other forms of dementia?

Those of you who attend our Caregiver Educational Conference each November may recall a 2008 session done on music therapy, which has been found to entertain and soothe patients in all stages of the disease. Similar programs exist involving art, such as the “Art’s the Spark” program offered at the Orlando Museum of Art.

Our agency is particularly interested in these types of alternative therapies because they are so effective at eliciting positive reactions from patients who may not be responsive in any other way.

Then we heard about the Alzheimer’s Poetry Project!

Central Florida was recently very fortunate to have two local foundations, the Edyth Bush Charitable Foundation and the Pabst Foundation for the Arts, provide funding to bring Gary Glazner, founder of the Alzheimer’s Poetry Project, to Orlando. ARC and three other agencies were trained to offer this unique program to local families and facilities.

Orlando Sentinel reporter Kate Santich interviewed those involved with the project and published an excellent article in the July 5th edition of the Sentinel. (See “ARC News” on our website for a copy). ARC staff provided a poetry session to Arden Courts Alzheimer’s Assisted Living residents a few weeks ago and we are looking for other facilities that may be interested in the program.

The Alzheimer’s Poetry Project, just like the art and music programs, are easily adaptable for use by caregivers who wish to provide them at home. If you’d like to know more, give us a call 407-843-1910!

For almost 27 years, the Alzheimer Resource Center has been “the source” for information on the finest programs available for the caregivers of those with Alzheimer’s and related dementias, and we’ll continue this important work until these illnesses are a part of history.

Warmest regards,

Nancy Squillacioti
Executive Director

Continued from Page 1

remove these “toxic” proteins through various methods. Some of these methods include trying to remove the protein plaque, trying to slow down the protein formation and trying to increase the destruction of the protein in the cell, before it has a chance to form plaque. There are many more theories and research options beyond the scope of this article which we can discuss in the office in person. One of the best sources for Alzheimer’s research content is www.alzforum.com.

Another very interesting area of research is in patients with pre-Alzheimer’s disease, otherwise known as Mild Cognitive Impairment (MCI). We are currently involved in a clinical trial trying to prevent the progression from MCI to Alzheimer’s disease using a study medication that slows down the production of the “toxic” proteins in the brain. For this study, we need patients with the earliest signs of memory loss.

No one knows which method, if any, will work best and they all require a large number of people to take the medication to see if it works. If you or a loved one has Alzheimer’s disease please, consider joining a clinical trial. It will take one person at a time to overcome this disease and make a difference.

These research studies involve no financial cost to you and we never contact your health insurance. For a free consultation or memory evaluation, please feel free to call me at my office in Orlando at 407-426-9299 or through our website: www.CompassResearch.org.
The Alzheimer Resource Center, Inc. is celebrating our 27th year of service dedicated to providing education and support services for those families who care for loved ones suffering from Alzheimer’s disease and related dementias. Our focus is on the “forgotten victim,” the caregiver, coping with unending responsibilities as well as isolation, depression and stress.

This annual fund-raising event is crucial to the agency and its ability to continue assisting caregivers in the community. Come bid on sky box tickets for Magic game donated by Mayor Buddy Dyer or “a massage a month for a year.” How about dinner and a limo ride for eight? This year’s auction will be hosted again by Jenelle Taylor from Gala Gals and includes music, gourmet sit-down dinner, appetizers, beverages and a cash bar as well as amazing auction items focusing on “Opportunities and Experiences.” We anticipate 150 attendees - tickets are on sale now - so don’t wait!

Corporate tables start at $500 and individual tickets are $75. Unusual silent and live auction items may still be donated. For more information contact Lorraine Gismondi, Development Manager, at 407-843-1910, ext. 303.

Want to help the Alzheimer Resource Center without spending an additional dime out of your own pocket? Then make sure to dine at the Columbia Restaurant located in Celebration, Florida during the month of September.

During the month of September, Columbia Restaurant will donate 5% of all guests’ lunch and dinner checks to local charitable organizations CHOSEN by their customers. All you have to do is enjoy an amazing meal at the Columbia Restaurant located in Celebration, Florida and select The Alzheimer Resource Center on the ballot provided by your server. That’s it! Then 5 percent of your bill will be donated to our organization! If you have any questions, please call 407-843-1910.
What is the Brain Bank? How do I get my loved one enrolled into the Brain Bank? How does the Brain Bank program work?

The Brain Bank was established with the following goals in mind:

- provide brain tissue of the many different types of dementias for researchers to study
- provide a definitive diagnosis to the family, which can only be determined through autopsy
- provide a pathologic diagnoses to the physician who provided care to the patient.

Countless research articles, abstracts, and symposium presentations have resulted from the State of Florida’s Brain Bank program as well as tissue shared worldwide for international research.

The process of enrollment involves:

- Caregivers call our office for information about the program, at which time an application packet is mailed to them.
- The application is completed by the spouse or person with the Durable Power of Attorney for Healthcare and/or guardianship. One of the most important pieces of information required is identifying the doctor who originally diagnosed their loved one and all other doctors whose focus has been on the care and treatment of the neurological illness, such as neurologists, neuropsychologists, psychiatrists, or geriatricians, etc.
- These medical records will be retrieved by our agency’s staff before the application is reviewed for completeness and forwarded to the pathologist in charge of this program for final acceptance.

What happens once accepted?

- The caregiver is called and later receives a formal letter of acceptance. If the patient is at home, a home protocol is also sent.
- If the patient is in a facility, the facility will receive a letter including the Brain Bank protocol and a chart label as an alert to staff that this resident is a Brain Bank Donor.
- The funeral home is also sent a protocol letter for the family’s file.

The process of retrieval involves:

- The location of the patient may change over time which is no problem as long as the coordinator at the Alzheimer Resource Center is kept informed of the patient’s whereabouts.

The decision to have an autopsy will not interfere with any funeral or cremation arrangements you have planned. You can even have a viewing, if you wish.

THE ENROLLMENT PROCESS CAN TAKE SEVERAL MONTHS. WHY?

It can take several months to retrieve required medical records. If this is a program you want to become involved in, please don’t put it off!

It breaks my heart to tell a caregiver at the time of their loved one’s death that the patient has not been accepted into the program because we lack medical records, and I’ve had to do this twice in the last few weeks. I’ve also had to tell families, funeral directors, and professional caregivers (hospice and facility staff) that enrollment CANNOT be achieved as the patient is actively dying.

Once someone has been accepted into the program, they will remain enrolled as long as the state continues to fund the program. Someone recently passed away who had been in the program since 1998!

PLAN AHEAD!

Involve the patient in the application process, if appropriate. Many patients will tell me that I can’t have their brain yet because they are still using it, but they are very proud that they’ll be helping advance future research efforts.

So why should you get involved?

- You and your loved one will be making an invaluable donation to research, a very positive act in an illness where there are few positive things that you can do.
- The patient’s family will get a definitive diagnosis, which usually includes several different disease processes.
- You’ll also be doing something positive for your children and grandchildren by providing them with information about their family medical history. That knowledge is power.

Earlier in this article I stated that the Brain Bank program will be around as long as the state continues to fund it.

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Up until the last few hours of this year’s legislative session, our representatives had decided not to fund the Brain Bank or any of the other programs which comprise Florida’s Alzheimer’s Disease Initiative for the coming year!

That decision was ultimately reversed with a great deal of advocacy on the part of our wonderful caregivers, but the funding is non recurring funding through 2011.

That means that next year we will again be in a position of fighting for continued funding of these programs, so if any of you are so inclined, please consider contacting your representatives. Educate them on the importance of these invaluable programs to you and your loved ones, and the need to continue to support them.

Ongoing research is a critical component in finding a cure for Alzheimer’s and related dementias, which can be evidenced by the large amount of funding that has been earmarked over the years for cancer and cardiac research, resulting in a decrease in the number of deaths caused by these diseases. If you wish to contact your legislators, call me at 407-843-1910 Ext. 308 and I’ll help you with this.

I often ask families to write and tell me how their involvement in Brain Bank impacted their lives, and I want to leave you with one of my favorite comments from a caregiver: "Thank you for giving my mother her last hoorah, a gift to science and a gift to our future."

So, if you think you may want your loved one enrolled in this invaluable research, START TODAY by calling me at 407-843-1910 Ext. 308 to get the application process underway. It is the perfect way for your loved one to leave behind an important legacy.
Gene-test kits that promise to tell consumers their risk of Alzheimer’s disease, breast cancer and numerous illnesses must be approved by regulators whether the tests are sold online or in stores, a U.S. official said.

The Food and Drug Administration has grappled with how to regulate a growing number of gene-testing companies in recent years, said Alberto Gutierrez, director of the FDA office that regulates diagnostic tests. The agency now believes developers of the tests are making health claims that must be cleared by the government if their products are to be sold directly to consumers, he said in an interview yesterday. To date, no such test has been approved or rejected by the FDA, he said.

The FDA wants “to make sure the public is protected from tests that aren’t accurate or a lack of counseling,” Loss said in a telephone interview.

“You don’t have to think very long to see how people could possibly make poor decisions concerning their future because of a test that doesn’t properly explain things to them."

Pathway had been marketing consumer gene-tests online before agreeing to sell the product at Deerfield, Illinois-based Walgreens, the largest U.S. drugstore chain. The retailer halted plans to start selling the home-use saliva collection kit after the FDA released a letter May 12 telling Pathway the product appears to be a medical device subject to agency review.

PATHWAY COMMENT
A spokesman for Pathway declined to comment after sending a statement that said the company respects Walgreens decision and is communicating with the FDA. “Pathway works very diligently to ensure that our business is compliant with all applicable regulations and guidelines,” the statement said.

Some gene tests offer guidance on the probability that would-be parents will pass certain genes linked to diseases on to their offspring. The American Society of Human Genetics said such tests may affect the choice of whether or whom a person marries, the decision to have children and whether to have an abortion.

Navigenics of Foster City, California, 23andMe of Mountain View, California, and DeCode Genetics Inc. of Reykjavik, Iceland, are among the companies that market genetic tests online. Navigenics was invited by the FDA to provide information about its service in May 2009, and believes it complies with all state and federal regulations, the company said in a statement.

OTHER MAKERS
23andMe, started in 2006 by Linda Avey and Anne Wojcicki, wife of Sergey Brin, co-founder of Google Inc., declined to comment. Google, the operator of the most popular Internet search engine, has invested at least $6.5 million since 2007 in the company, according to regulatory filings.

Pathway’s test kits offer to analyze customers’ genes for three purposes: to predict what each individual’s risk is for diseases ranging from Alzheimer’s to prostate cancer, to assess would-be parents’ probability of passing on health problems to offspring and to evaluate how the test-taker will respond to certain drugs.

Pathway’s test kit aim to provide information about how customers’ genes affect their risk for developing 26 health conditions and the likelihood of passing any of 37 inherited conditions to unborn children. It also describes how customer’s genes affect their propensity to respond to such drugs as Bristol-Myers Squibb Co.’s blood-thinner Plavix as well as cholesterol-lowering statins such as Pfizer Inc.’s Lipitor.

FICTITIOUS PATIENT
A 95-page sample report contains some information about a fictitious patient’s risk of Alzheimer’s disease.

“There is no singular test that can definitively diagnose Alzheimer’s disease, but your genetics suggest that you may be vulnerable to having this disease at some point in your life."

That kind of information won’t help people, said Joanne Boughman, executive vice president of the American Society of Human Genetics in Bethesda, Maryland.

“For a disease like AD, for which there is no intervention or treatment, that isn’t useful information,” Boughman said. “In fact I would consider it info that could be disturbing or distressing and therefore harmful.

“The genetics community has been seeking oversight for more than a decade,” Boughman said in a telephone interview yesterday.

Editors: Donna Alvarado, Andrew Pollac. To contact the reporter on this story: Rob Waters in San Francisco at rwaters5@bloomberg.net.
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Jim Stueve
Mary Middleton

In Memory Of:
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Mary Asenjo
James Basham
Robert Carmichael
Aleyne Childred
Sue Conaway
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Westminster Communities of Florida
Winter Park Health Foundation

Focus on Customer Satisfaction
With over 15 years experience, Arden Courts has established itself as a proven leader in providing quality Alzheimer’s and dementia care.

As part of our continual efforts to meet your standards, Arden Courts uses an outside resource, MyInnerView, Inc., to survey our family members on a regular basis. MyInnerView specializes in the collection of satisfaction information for health care organizations. The survey measures satisfaction with many important areas related to the experience customers have at the facility. MyInnerView satisfaction survey results for Arden Courts of Winter Springs have been among the best in the assisted living industry in several important areas.

For more information about our customer service results or to schedule a tour, please contact:

1057 Willa Springs Drive
Winter Springs, FL 32708
407-696-8400

IN HONOR/MEMORY OF:
WITH GRATITUDE:

Special thanks go to the following foundations, corporations and individuals for their major contributions:
A lifeline for the family today. Hope for the family of tomorrow.

Alzheimer Resource Center
1506 Lake Highland Drive
Orlando FL 32803
(407) 843-1910

www.AlzheimerResourceCenter.org

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.

1st Tuesday @ 10:00 A.M.
Easter Seals Daybreak at the Miller Center
2100 Mizell Avenue
Winter Park, FL 32792
(Respite Care Available 407-629-4565)

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

1st Thursday @ 10:00 A.M. & 3rd Thursday @ 10:00 A.M.
“Men’s Breakfast Club”
(Mt. Vernon Inn
110 S. Orlando Ave
Winter Park, FL 32789

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

2nd Thursday @ 6:00 P.M.
Arden Courts
1057 Willa Springs Drive
Winter Springs, FL 32708

2nd Friday @ 12:00 Noon
Osceola Council on Aging
at the Senior Center
(Bring your own brown bag lunch)
700 Generation Pointe
Kissimmee, FL 34744

3rd Thursday @ 6:30 P.M.
Emeritus at Ocoee
80 N. Clarke Road
Ocoee, FL 34761

NEW BEREAVEMENT SUPPORT GROUP
Anyone interested in attending a bereavement support group should call the office at 407 - 843-1910. No commitment is required at the time of the call, but we are trying to gauge the level of interest in such a group from our caregivers and readers.