

Special 30th Anniversary Edition

Caring

Spring 2014



One Man Can Make A Difference

The words above were on a card attached to a large standing wreath of purple flowers with a white flower 'heart' in the center and sent to Cox-Parker Funeral Home for Jack's Memorial Service on June 23, 1998.

~~

30 years! Congratulations to the *Alzheimer's & Dementia Resource Center* for the work you do; for giving support to families who often question their ability to care for a loved one with dementia, often diagnosed as Alzheimer's. After Jack's diagnosis at age 54 in the early 1980's I had many questions. Shellie and I wondered if there were others like us living in Winter Park that we might get with to talk about our situations – help with an exchange of 'what works'. (We found there were!)

I made an appointment and met with David Roberts, Chairman, and Clifford Lee, attorney and Board Member at the Edyth Bush Charitable Foundation. I went to them with a dream and my story of a newly diagnosed husband with Alzheimer's disease. I had no experience with non-profit agencies. They were both immediately supportive and encouraging. We had coffee in a small board room and talked a long time with me outlining my 'dream'. Mr. Roberts said there was a need for such an agency in the area. Many meetings followed with both Mr. Roberts and Mr. Lee.

Mr. Lee said as a beginning I should do these things:

1. Incorporate. Get a Post Office Box number. Find an attorney who will work pro-bono and arrange for the necessary 501(c3) and non-profit status. Tom Kerney, young attorney with an Orlando law firm, accepted this position. (We quickly put together the minimum number of people together for a Board of Directors, needed on the application).
2. Find office space. It was suggested I meet with the President of Winter Park Hospital to see if they had vacant space among the property the hospital owned. When I met with him he was as helpful and encouraging as Mr. Roberts and Mr. Lee. We were offered space on one side of a duplex building across from the main entrance to Winter Park Hospital. An adult day care was in the other side. That was our first "real" office.

Continued on Page 3

WHAT'S HAPPENING

Alzheimer's & Dementia Resource Center celebrates its 30th Anniversary serving the community

2nd Annual Poker Run
Saturday, May 31st 2014
9:30 am – 3:30 pm

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

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A message from the EXECUTIVE DIRECTOR

This issue of our Caring newsletter is a very special one for you, our readers. As our 30th Anniversary celebration continues through 2014, we've asked Pat Jimison and Shellie Brassler, the family members who created the legacy that is ADRC, to share their reminiscences with us about the start of the agency.

Pat's husband, Jack, was diagnosed with Alzheimer's disease in 1984 at the age of 54. At the time, there was little to no information available in Central Florida about this "condition" so Pat and her family decided it was their destiny to help others in the same situation. The Alzheimer Resource Center was born and we are still the only agency in Central Florida providing a comprehensive array of programs and services for Alzheimer's caregivers and care recipients.

Thirty years later, we estimate that the agency has helped more than 100,000 caregivers, care recipients and their families tackle the challenges of Alzheimer's disease and related dementias. Our mission has always been to support caregivers in every way possible so that they and their loved ones can still enjoy life despite the diagnosis.

Over the past thirty years research has been ongoing about this group of diseases, although those of us working in the field, as well as many families dealing with dementia, would like to see a substantial increase in research dollars.

Previous estimates were that Alzheimer's disease was the 6th leading cause of death in the U.S. A recent study in the journal *Neurology* places the number of deaths attributable to Alzheimer's disease during 2010 at more than 500,000 people, rather than the 83,494 deaths the Centers for Disease Control counted.

If this study is confirmed by the government, it would make Alzheimer's disease the third...not the sixth...cause of death in the U.S. after heart disease and cancer. Interestingly, the amount of money spent on cancer research by the U.S. in 2014 is expected to be 5.4 billion and 1.2 billion is to be spent on heart disease. Compare those figures with the paltry funding for Alzheimer's disease at 666 million and you can see there's tremendous room for improvement.

The National Alzheimer's Project Act, which was signed into law in 2011, established a national plan intended to encourage the development of new treatments for these diseases, adding \$100 million more in federal funds to research and treatment. But more funding is still needed!

While our legislators wrestle with budgets and funding, ADRC continues to "Light a Candle of Hope" by providing families with staff members who understand the disease, helpful and effective programs and services that meet the needs of caregivers, the award-winning Brain Bank research program and the most up to date thinking about how to make a care recipient's life a full and happy one.

I would like to thank all of the wonderful ADRC staff members, both current employees and those from our past, who provided their expertise to so many families over the years.

A tremendous thank you to our supporters, as well, like those of you reading this newsletter. You have been instrumental in ADRC achieving 30 years of service to our community and for that we are so grateful.

But most of all, my hopes and wishes are for the families and their loved ones who deal with these diseases day after day. It is for them that we do what we do and we'll continue to provide quality programs until these diseases are a thing of the past. That's my Anniversary wish!

Warmest regards,



Nancy Squillaciotti

P.S. I would also like to remind you that ADRC is in the midst of an exciting opportunity wherein the Edyth Bush Charitable Foundation will match dollar for dollar any new donation we receive between now and May 31st. If you haven't thought about donating to ADRC, now is the perfect time to double your support! Don't let this opportunity pass you by!

Continued from Page 1

Meantime Mr. Roberts asked that I submit a grant to the Bush foundation for them to consider at the Fall Board Meeting. I had never seen a written grant, much less write one. I said I would have one there by September 1. I had three months to learn to write a grant. (Mr. Roberts stopped me as I left his office and said “put a salary for yourself in it”)

The grant request was awarded in the amount of \$65,000. We received our non-profit status within a few months and the Alzheimer Resource Center (ARC) began to develop programs for caregivers. The first support group began to branch out to many locations.

An artist with Walt Disney World visited the ARC soon after we moved to our new space and offered to design a logo for our new agency. It was beautiful...and he called it “Candle of Hope”.

As the agency grew we became involved with other related services including the Florida Brain Bank. Before affiliating with the State of Florida’s Brain Bank research program, I decided to explore another idea or dream. I started working in this area when Alzheimer’s was first beginning to be diagnosed. It had been called Hardening of the Arteries or Organic Brain Syndrome. The MRI became available and a better diagnosis could be made. We were out beating the drum trying to get the medical community to diagnose better - so tired of hearing “Senility” and “Hardening of the Arteries”. Then, suddenly everybody was diagnosed with “Alzheimer’s”. I wanted to have a program for brain autopsy to get us a definite diagnosis without so much guess work. I had no thought of “research”.

I asked a friend if he knew of a pathologist who would work with us to get autopsies to confirm a clinical diagnosis and Dr. Gary Pearl, a neuropathologist with Orlando Health agreed to do each one for an incredibly reasonable fee. We started that program for diagnosis purposes only.

Then Dr. Ranjan Duara with the Mt. Sinai Medical Center in Miami heard about the autopsies Dr. Pearl was performing for us. Dr. Duara was (and still is) director of the State of Florida Brain Bank research program and he asked our agency to begin the Central Florida Brain Bank program, but for research not only diagnosis.

On the Science & Medicine page of the Orlando Sentinel on February 14, 1988, a story appeared with the heading “First Brain In The Bank”. The story read *“The Central Florida branch of Florida’s Brain Bank has acquired its first brain tissue donation, said Pat Jimison, coordinator of the program and executive director of the Alzheimer Resource Center in Winter Park. In addition, Jimison said, as many as half a dozen people are registering for the program that began this month”.*

There were many people who helped with time, money, and encouraging words. I have met some outstanding people of strength and character who met the challenge as a caregiver with grace and dignity for their loved one and themselves. It was quite a journey. I often told Jack when I had to leave him with a sitter as I went off to facilitate one support group meeting after another “your illness has served a purpose” and he liked knowing that.

Thank you for allowing me to walk down Memory Lane. Many, many people helped along the way...like Frank Hubbard and A Friends Foundation; and volunteers Peggy Haldeen and her husband Roy, who died last July. Barbara Tindall became a support group leader in Sanford who was loved by many and Esther Gay who put her weekly bridge winnings in our donation box!

I have no doubt the Alzheimer’s & Dementia Resource Center will be helping caregivers another 30 years....thank you Nancy and all the Staff for keeping my ‘dream’ alive.

Pat Jimison



Ken Smiley one of our most loyal early caregivers lights the “Candle of Hope”

Memories from Shellie Brassler

In April 1982, my husband and I received a call from my mother, Pat Jimison, telling us that dad had been diagnosed with Alzheimer's disease. I remember mother saying, Alzheimer's disease is a neurological condition. What does that mean? We had no idea what was going on.

After the call, I looked up Alzheimer's disease in a medical book I had. There was one paragraph describing the possible anomalies that could occur during the course of the disease. I had never heard of such a thing. I was numb struck.

And that was how it all started. Pat and I felt that we could not possibly be the only people in the Orlando area living with someone who looked so 'normal' yet acted in ways we couldn't understand – all due to the disease that was so new to us. In an effort to get together with others to share concerns and coping strategies, we decided to have a meeting, wondering if anyone would come. Dad, still highly functioning, rode around in the car with me with posters we had made telling of a support group for people caring for someone with Alzheimer's disease. As we found a business that would allow us to post our sign, dad would write down the name of the business on a yellow legal pad. Before long we had a rather lengthy list.

There were 13 people in attendance at the first support group meeting. Thirteen people! We were thrilled with our 'success'. These people had not had previous opportunities to talk about what they were going through until now. They needed help. And now they had a resource! We had our work cut out for us without question.

It seemed that with each meeting the attendance grew by leaps and bounds. The meetings were moved from a private residence to a clubhouse at a condominium complex. Pat was studying like crazy and attending seminars where ever she heard one was going on! We were researching everything we could to help the folks who called or attended our meetings. Actually, sitting around her dining room table is where the first Alzheimer Resource guide was put together!

Somewhere along the line the media became interested which brought even more attention to the group. That exposure put everything on the fast track. After a period of time (and hard work for Pat) we were blessed with funding from the Edyth Bush Charitable Foundation that allowed the Center to move forward providing good, caring people with information about the disease, a place for them to receive loving support and most importantly HOPE!

Our family was fortunate to have been able to turn our personal situation into such a positive platform that allowed others in our community an outlet and resource for coping and education. We were blessed every day by those who walked through our doors for help. They didn't realize how much we were being helped too.

Congratulations on your 30th Anniversary and thank you Nancy and the staff of the Alzheimer's & Dementia Resource Center for continuing to provide families with loving care and support as they travel a most difficult journey with their loved one.

Shellie Brassler



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Upcoming Events



Free Community Workshops

Please RSVP or call ADRC
for more information call
407-843-1910

Registration: 9:15 am

Workshop begins: 9:30 am – 11:30 am

Friday: June 6, 2014

“How to Communicate When Logic Doesn’t Work”

Jerry Hamilton MSED

Alzheimer’s & Dementia Resource Center

Friday: September 5, 2014

“Alzheimer’s Disease and Brain Health –Basics”

Nancy Squillaciotti, Executive Director

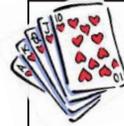
Alzheimer’s & Dementia Resource Center

Friday: December 5, 2014

“How to Survive Your Role as Caregiver”

Jerry Hamilton MSED

Alzheimer’s & Dementia Resource Center



2nd Annual Poker Run

Saturday, May 31, 2014

9:30 am – 3:00 pm

Proceeds to benefit the Alzheimer’s &
Dementia Resource Center and Longwood
Health Care Center

The event begins at Longwood Health Care

Center where each car or motorcycle
participant registers for \$20. The route
includes five locations where riders pick up
a poker card. Best hand wins. Raffle prizes,
50/50 and more.

Sponsorships are available. Donations of gift
cards and prizes are greatly appreciated.

For more information call Emma Scott,
Activity Director 407-339-9200 or email at

vs cott@gchc.com

MARY FRANCES FLEICH

1940-2014



Mary was the second child born to Earl and Frances Thoma. She was born December 9, 1940 in Mineola, Long Island, NY. She had two brothers and three sisters. She grew up in Roosevelt, NY.

Mary graduated from Hempstead High School and later from Grace Institute. Upon graduating from Grace Institute she went to work for what is now Bank of America.

Mary met her future husband, Adam Fleich, and they married on July 5, 1959. They had two children, Thomas and Kathleen. In time, they were blessed with a granddaughter, Kristina, and two great grandchildren, Laila and Harry.

After the children were in school, Mary returned to work. She went to work for Slomin’s Oil Company and soon became their Customer Service Manager. Mary gave 100% to customers and employees alike.

Mary also did a great deal of volunteer work for her church and many other organizations. ADRC was blessed to have Mary as a volunteer and friend to all of us. She was all about giving of her time, her talent and her finances.

After many dedicated years at Slomin’s, she retired and she and Adam relocated to Florida. For several years they enjoyed their leisure. However, she never stopped volunteering. Adam’s Alzheimer’s disease was progressing, so she started volunteering with the ADRC. It helped her to learn about this disease and it also helped her to help others. She was so grateful for both opportunities. Eventually, Mary became a caregiver 24-7. Her whole life revolved around Adam and she gave him all the love and care one could possibly give.

After Adam passed, she continued to care for her entire family (she was the matriarch of the family). She also continued with the ADRC. Mary leaves a great void for all who knew and loved her.

IN HONOR / MEMORY OF:

In Honor Of:

David Cathers
Anne DiStefano
Schima
Rhonda Keating
Annelle McIntyre
Clara Nissan
Christopher Rangel
Nancy Squillacioti

Janet Dilts
William Duby
Elaine Dudley
Dr. E. Duane Elbert
Grace Evans
Harold and Marilyn
Gerry
Ralph Griffith
Gordon Grimm
David Halpin

Fred Odena
Carole and Frank Oles
Mary Owens
Anderson Clarke
Frances Ybarra
Rangel
Jane Ranger
Carol Rauch
Elizabeth Rife
Jacquine Sanchez
Eugenia Shaw
Anne Skambis
Domenick Squillacioti
Opha Stephens
Mary Stout Hundley
James Stueve
Dorothy Thornton
Charles Trainer
Elizabeth Vandergriff
Richard Van Frank
W. Leo Waldon
Doris Wilcosz
Miguel Yanez

In Memory Of:

Dorothy Armbruster
John Barry
Jean Boardman
Stella Maria Boffi
Mary Brumbaugh
James Carroll
Dr. Sidney and
Barbara Cassin
Mary Cline
Garnet Davis
Roger Emerson
Decker

Betty Joan Henry
Glen Hermening
Patricia Holdcraft
George Jacobs
Louise Kinnie
Carolyn Knowles
Candace Kovey
Paula Rosa Lopez
Opal Maratus
Ramona McKinnon
Henry Meyer
Max Millitzer
Alan Mooty

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
Dr. and Mrs. Thomas Thames
Mr. and Mrs. Dean Anderson
Mr. and Mrs. Lewis Percy
Mr. and Mrs. Ron Twyford
Mr. Peter Barr
Mr. Ramon Garriga
Mrs. Harriett Lake
Mrs. Margery Pabst
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Sagora Senior Living
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A special message for caregivers,

As we grow older, we would all like to maintain our cognitive abilities at the highest possible level. With this in mind, I am writing to let you know about a clinical research study that I think might be of interest to you. The TOMM-ORROW study seeks to learn more about the genetic risk for developing Alzheimer's disease, and whether a medication might prove effective in delaying or preventing memory loss.

In recent years, the focus of clinical research in Alzheimer's disease has begun to shift toward prevention. It may be that early intervention is a more effective approach than attempting to modify the disease once the brain changes characteristic of Alzheimer's disease have occurred. The TOMM-ORROW study has two main goals. First, it will evaluate whether a new test looking at two specific genes can predict a person's risk for developing memory loss in the next 5 years. The second goal is to explore whether a medication will delay the first symptoms of Alzheimer's disease in people who currently do not have memory loss.

We are inviting individuals between age 65 and 83 years of age, with no current diagnosis of Alzheimer's disease to consider participating. If you are eligible to participate, you will be able to proactively measure your cognitive health and contribute to the understanding of how age and how genetic factors affect the health of our minds. Over 5,000 adults will take part in this study at approximately 50 study centers in North America, Europe, and Australia.

If you are interested in participating and qualify for the study, you and your project partner (a friend or family member who knows you well) will attend office visits every 6 months. At these visits, you will receive memory testing and check-ups (blood work, EKG, physical exam, etc.) You may also choose to participate in an optional sub-study to receive MRI scans of the brain at no cost. Participation in the study does not require any payment at any time, and both you and your study partner are compensated \$50 for each visit to cover travel expenses. We may also offer transportation at no cost for individuals who need assistance.

Participating in this study presents a unique opportunity to explore your cognitive health while making a contribution to scientific discovery, and I hope that you will consider the potential impact of this research while you are making your decision. The TOMM-ORROW study is taking place at Compass Research in Orlando, Florida. Compass Research is located in the Lucerne Medical Plaza at 100 West Gore Street, Suite 202, Orlando, FL 32806. Please feel free to contact me at the number below if you have any questions or would like more information on how to participate.

Dr. Chelsea Mabry
 Medical Science Liaison for Compass Research, LLC
 Phone: 407-404-7997
 Email: DrMabry@CompassResearch.com



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Support Groups

The Alzheimer's & Dementia Resource Center provides monthly professionally facilitated support groups for caregivers and family members as noted below.

3rd Monday @ 10:00 A.M.
 NEW SUPPORT GROUP
ADRC Family Support Group:
For caregivers and their loved ones
(Use the Fellowship Hall entrance in the back of the church)
 1100 N. Ferncreek Avenue
 Orlando, FL 32803

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

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

1st Tuesday @ 10:00 A.M.
Easter Seals Daybreak at the
Miller Center Support Group
 2010 Mizell Avenue
 Winter Park, FL 32792
(respite care available during the meeting, call ahead at 407-629-4565)

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

In partnership with the State of
Florida Department of Elder Affairs
and the Orlando Health Memory
Disorder Clinic

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



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