

younger-onset connections

Oklahoma and Arkansas Chapter
Published quarterly for members of our Younger-onset
Connections program.

March 2010, Volume 6, Issue 4
www.alz.org/alzokar
1.800.272.3900

Living with Alzheimer's... And Advocating for Those with the Disease

by Ron Grant

It was while my daughter was talking with my wife and me about an event (that she claimed we all three were involved in) that I was first concerned something might be wrong with my memory. As she was describing what had happened I could not remember being there. When I told her she needed to give me the details, she insisted "Daddy you were there!" As I looked at her and my wife they had a puzzled look. After a moment, I did start to see what was like "broken pieces of glass" of the event, but never did recall the entire event.

The next time I went to my primary care physician I mentioned that I was having some minor memory issues so he sent me to a neurologist. The neurologist spent about forty-five minutes talking with me and then explained a plan of action he wanted to follow to try to eliminate what was not wrong while looking for the cause of my memory issues. From a MRI he found some areas of concern and ordered a PET scan. It was from the PET scan in October 2007 that the diagnosis of younger-onset Alzheimer's was given. I was fifty-five at the time of diagnosis.

My neurologist and Primary Care Physician worked together to come up with a medication plan that consists of Namenda, Lovaza, and supplements. I am now involved in a phase three research medication study.

I continued to work as Chaplain for the Oklahoma Department of Corrections through December 2008 (where I had worked for 13 years). While I was still working I had tremendous support from my administration.

It has taken a great amount of adjustment for my family. My wife Vicky (of 39 years) has been unbelievably strong and supportive. She takes care of and watches out for me with such love and compassion that it truly is God-given grace. My two daughters have each dealt with the diagnosis very differently, but both are extremely supportive, as are my sons-in-law.

I try to be involved in whatever the Alzheimer's Association asks me to do. Vicky and I have been involved with two Memory Walks, the 2009 Alzheimer's Symposium in Washington, DC, and I was appointed to the legislative Alzheimer's Task Force (for Oklahoma).

While it has caused us to make major changes in our life (now and in the future) we accept the fact that no matter what, God is aware of everything involved in our life past, present, and future and He loves us. With that in mind we try to make the best and most of each and every day. We try to make certain to enjoy our three grand children, daughters, and sons-in-law at every opportunity.



Vicky and Ron Grant

From Denyce's Desk:



The Alzheimer's Association is excited to share this news with you. The Social Security Administration (SSA) has added younger-onset Alzheimer's to the list of conditions under its Compassionate Allowance Initiative, giving those with the disease expedited access to Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). The Alzheimer's Association, a longtime advocate for those with younger-onset Alzheimer's, has played an integral role in this movement to reduce the length of disability decision process.

Under the Compassionate Allowance Initiative, the Social Security Administration (SSA) finds individuals with certain diseases/conditions eligible for Social Security disability (SSDI) and Supplemental Security Income (SSI) benefits by the nature of the disease. While applicants still have to meet other SSDI criteria and/or SSI criteria, when it comes to the disability criterion, they are considered eligible by virtue of the disease and fast-tracked for a favorable decision about their eligibility for SSDI and SSI benefits.

What is SSDI? Social Security disability benefits (SSDI) are paid to individuals who have worked for enough years and have a condition that is so severe that they are not able to work any longer. Administered by the SSA, SSDI makes monthly payments to eligible disabled individuals and is a significant benefit for individuals with early-onset (younger-onset) Alzheimer's disease. In addition to a monthly payment, it serves as entry to Medicare benefits for those under the age of 65. Family members (e.g., spouses and minor children) may also be eligible for benefits based on the applicant's work record.

Supplemental Security Income benefits (SSI) are paid each month to individuals who are aged, blind or disabled and have limited income and resources (assets). The "disability" criteria for SSI are the same as for SSDI benefits. Unlike SSDI, eligibility for SSI is not based on prior work experience. In addition, in most states, individuals who receive SSI are also automatically eligible for Medicaid (medical assistance) benefits.

Why is this important to individuals with Younger-onset Alzheimer's disease and related dementias? Because these individuals are often initially denied benefits – but usually win on appeal. Those affected by younger-onset Alzheimer's are often simultaneously faced with the enormous challenges that the disease presents, while also undergoing a long disability decision process that is financially and emotionally draining. By adding Alzheimer's disease to the list of "Compassionate Allowance" conditions, it will simplify and streamline the SSDI/SSI application process and should result in receiving SSDI/SSI benefits in an expedited manner.

If you are affected by younger-onset Alzheimer's, please use the Association's helpful checklist to make sure you have information and resources you need to apply for Social Security Disability and Supplemental Income benefits. The checklist can be found at: http://www.alz.org/alzokar/in_my_community_news.asp.

We are also asking for your help to get many students (age 13-17) to attend Austin's Camp Building Bridges. Please see page 3 for more information. Thank you for all you do to advocate for the Alzheimer's Association.

New Younger-onset Caregiver Counselor added to Tulsa Office

We are happy to announce Peggy Marsh as our new Younger-onset Counselor. She has a Master's in Marriage and Family Therapy. She also has a

private practice specializing in brain injury and brain disease. She also facilitates the Navigators Program (for those dealing with early stage dementia) at OASIS Adult Day Services in Tulsa, and also facilitates a Younger-onset support group in Tulsa.

Kids say: *Camp Building Bridges a Huge Success!*

Wonderful New Location for 2010 Austin's Camp Building Bridges July 18-24

This year's summer camp, Austin's Camp Building Bridges, will be held at New Life Ranch in Colcord, Oklahoma (10 miles west of Siloam Springs, Arkansas). Austin's Camp Building Bridges is a respite camp for teens entering grades 7-12, who are caring for a parent or grandparent with Alzheimer's or related dementia disease living in their home. The camp was founded by Tracy and Allen Mobley. They were inspired by their teenage son, Austin, who was only 7 when Tracy was diagnosed with younger-onset Alzheimer's disease and Frontal-temporal Lobe Dementia at age 38.

The purpose of the camp is to provide a setting where teenage caregivers can:

- Build healthy, supportive relationships with peers
- Learn information and coping skills to help navigate the journey of Alzheimer's
- Learn to become advocates and help others
- Get a break from caregiving
- Have a great time just being kids at camp

We are thrilled to announce that

this year's camp will be held at New Life Ranch, a non-denominational Christian camp that focuses on building friendship, character and teamwork. The week of camp will last from July 18 through July 24. Each day, campers will spend an hour or two in interactive learning activities with Alzheimer's Association staff. The rest of the time will be spent engaged in a wide variety of camp activities.

The camp offers quality lodging and meals as well as many activity options including: Archery, Drama, Mountain Men, Arts and Crafts, Canoeing, Swimming (either in the lake or pool), Gym and Field Sports, Discus Golf, Tennis, Weightlifting, Photography, Skeet Shooting, Hiking, Rock-wall climbing, rappelling, "The Slingshot," and much more.

There is a non-refundable registration fee of \$35.00 for each camper. Camp tuition is \$500.00, however the Alzheimer's Association, Oklahoma and Arkansas Chapter, is raising funding to ensure that scholarships are available for each camper who needs assistance. Campers who are not within driving



2009 Kids Camp attendees, counselors, and sponsors are pictured above.

distance, can fly into Tulsa International Airport. Campers will arrive at camp on Sunday in time for lunch followed by orientation from 1:00-3:00 pm. The camp's location is: New Life Ranch, 160 New Life Ranch Drive, Colcord, OK 74338. Be sure to check out the New Life website at www.newliferanch.com for more information, including packing list, etc. For more information about Austin's Camp Building Bridges and registration, please contact Denyce Willis at denyce.willis@alz.org or 918-494-5429.

Tulsa's Alzheimer's Association Education Conference Coming June 9

The Education Conference will be June 9, 2010. Join us to hear Gary Barg, author of "The Fearless Caregiver," as he discusses how to get the best care for your loved one and still have a life of your own. Our special Celebration of Excellence Award Luncheon will feature keynote speaker, actress Kate Mulgrew, who will discuss her personal journey with her mother who had Alzheimer's. Breakout sessions this year will include a younger-onset track. CEU's available include 3 hours of ethics. There will also be an Exhibitors Hall with information on all the services you need. For more information, or to register online, please visit us at: www.alz.org/alzokar/in_my_community_events.asp or call 800-272-3900. Register before May 7th and get our early bird discount. Prices include: Early Bird Special before May 7th: Professional: \$90, Caregiver: \$45, (Both the \$90 and \$45 include the luncheon), Luncheon only: \$50. After May 7th: Professional: \$125, Caregiver: \$60 (Both the \$125 and \$60 include the luncheon), and Luncheon only: \$60. Please contact Denyce Willis at Denyce.willis@alz.org for scholarship applications. LIFE Senior Services and OASIS will be providing off-site respite.

Email Connections: *an easy way to stay connected*

Email Connections is a national data base for Younger-onset families and for professionals who would like to share ideas, connect with each other and have a listening ear. “Email Connections” is specifically for families, and the data base is divided into several peer groups: those who have a spouse, parent, child or themselves with the disease or have children still at home and want to chat via email with others in a similar situation.

If you would like to join “Email Connections”, please go to our website and fill out the referral sheet at the Oklahoma and Arkansas Chapter website at www.alz.org/alzokar, then click on programs and services.

To be added to the data base, it is only necessary to send a request to (Denyce Willis, Younger-onset Coordinator, Denyce.willis@alz.org) with some additional information about yourself or the person about whom you are concerned if you are a family member, or the client population with whom you work (if you are a professional). If you have questions or concerns, please email Denyce or call her at 918-494-5429.

Association applauds Social Security Administration for adding Early-onset Alzheimer’s to its Compassionate Allowances Initiative

Washington, DC February 11, 2010 – In its effort to improve and expedite the disability determination process, the Social Security Administration (SSA) has announced that it will add early-onset Alzheimer’s disease to its Compassionate Allowances Initiative. The initiative identifies debilitating diseases and medical conditions that meet the SSA’s disability standards for Social Security Disability Income (SSDI) or Supplemental Security Income (SSI). Inclusion in the initiative allows for faster payment of Social Security benefits to individuals with Alzheimer’s disease. The Alzheimer’s Association applauds Social Security Commissioner Michael Astrue and the SSA for understanding that the cognitive impairment caused by Alzheimer’s disease leaves individuals unable to maintain gainful

employment and deserving of an expedited disability determination.

“As the leading research, advocacy, and support organization for Alzheimer’s disease, the Alzheimer’s Association has actively sought the inclusion of early-onset Alzheimer’s in the Social Security Administration’s Compassionate Allowances Initiative,” says Harry Johns, President and CEO of the Alzheimer’s Association. “Now, individuals who are dealing with the enormous challenges of Alzheimer’s won’t also have to endure the financial and emotional toll of a long disability decision process.”

Since 2003, the Alzheimer’s Association has been advocating on behalf of individuals with early-onset Alzheimer’s as they navigate the Social Security disability determinations process and welcomes the SSA’s decision. Until now, individuals with early-onset Alzheimer’s disease have faced a myriad of challenges when applying for SSDI or SSI, including a long decision process, initial denials, and multiple appeals. Today’s decision will simplify and streamline the SSDI/SSI application process and decrease the wait time for benefits, which for some has lasted as long as three years.

There are currently an estimated 5.3 million Americans with Alzheimer’s disease. Although the majority of Alzheimer cases are individuals age 65 and older, a significant number of people under age 65 are also affected by this fatal disease and have few financial options other than the Social Security disability program.

In addition to Alzheimer’s disease, mixed-dementia and Primary Progressive Aphasia were also added to the Compassionate Allowances Initiative under the SSA’s recent decision. To determine which diseases and conditions to include, SSA has held several public outreach hearings throughout the country that have included testimony from medical and scientific experts, as well as those directly affected by these diseases and conditions. The July 2009 Compassionate Allowance Hearing on Early-Onset Alzheimer’s Disease and Related Dementias, held in Chicago, included testimony from Johns, several of the nation’s top Alzheimer researchers, and caregivers and individuals with early-onset Alzheimer’s who discussed the challenges they faced during the disability application process. During

see “SSA” pg. 5

“SSA” cont.

the day-long hearing, SSA officials heard about the terminal nature of Alzheimer's, the disabilities that often prohibit work in even the earliest stages of the disease, and the lack of effective treatments to modify or halt the progression of Alzheimer's.

In addition to participation in the hearing, as many as 600 people with Alzheimer's and other dementias and their caregivers responded to the Association's request to submit written comments to SSA about their experiences applying for disability benefits. A sample of these comments are posted on SSA's Compassionate Allowances website: <http://www.socialsecurity.gov/compassionateallowances/statements.htm>

The Social Security Administration's proactive efforts to “fast track” certain conditions will help

to reduce the backlog of disability claims and, more importantly, ensure those claims that fall under this initiative will be decided within days instead of months or years.

“The diagnosis of Alzheimer's indicates significant enough cognitive impairment to interfere with daily living activities, including the ability to work. This decision will help a significant number of Alzheimer families. It will also help the Social Security Administration, since long delays and appeals in the disability determination process are costly for the agency,” says Johns. “The Alzheimer's Association praises SSA for this decision and remains committed to continue to work with Commissioner Astrue and his colleagues at the Social Security Administration in support of its implementation nationwide.”

New Report reveals Impact of Alzheimer's Disease

According to the Alzheimer's Association's 2010 Alzheimer's Disease Facts and Figures, which was just released today, there are 5.3 million Americans living with Alzheimer's disease. The growing prevalence and escalating impact of this disease should not be underestimated. As the first wave of baby boomers begins turning 65 next year — now is the time to address the ways to tame the threat of one of the most significant public health crises facing the nation.

Rising Prevalence

- There are 5.3 million Americans living with the disease.
- There are 74,000 people living with Alzheimer's disease in Oklahoma alone and that number is expected to rise to 96,000 by 2025.

“Alzheimer's is a significant threat not only for the nation – but also for the people of Oklahoma,” said Tonda Ames, VP of Marketing for the Alzheimer's Association Oklahoma and Arkansas Chapter.

Special Report on Race, Ethnicity and Alzheimer's Disease

- Although whites makes up the great majority of the more than five million people with Alzheimer's disease and other dementias, African-Americans are about two times more likely than whites to have Alzheimer's and other dementias, and Hispanics are about one and one-half times more likely than whites to have Alzheimer's and other dementias.
- There are no known genetic factors that can explain the greater prevalence of Alzheimer's and other dementias in African-Americans and Hispanics than in whites.
- Conditions such as high blood pressure and diabetes, which are known risk factors for Alzheimer's and other dementias in all groups, are more common in African-Americans and Hispanics than in whites. High blood pressure and diabetes are potentially modifiable conditions and better management of these conditions could help to reduce the prevalence of Alzheimer's and other dementias.
- Although African-Americans and/or Hispanics are more likely than whites to have Alzheimer's and dementia, they are less likely than whites to have a diagnosis of the condition.
- Delays in diagnosis means that African-Americans and/or Hispanics are not getting treatment in the earlier stages of the disease when treatments are most effective and they also miss the opportunity to make legal, financial and care plans.

The full text of the Alzheimer's Association's 2010 Alzheimer's Disease Facts and Figures can be viewed at www.alz.org/alzokar.

Useful Resources
National Alzheimer's Association: www.alz.org.
Find your local chapter, the younger-onset Message Board and Clinical Trials. Go to: alz.org and proceed to the message boards. The Alzheimer's Association message boards and chat rooms are your online communication forum. Share your thoughts and experiences, query your colleagues and make new friends. Also, read and comment on postings by our blogger Lisa Genova, author of "Still Alice".

Please Be Patient Cards

Did you know that the Alzheimer's Association (Tulsa office) offers "Please Be Patient" cards that read: (on one side) "The person with me has Alzheimer's disease and may require a few extra moments. Thank you for understanding". (on the other side) A few words about Alzheimer's and our contact information. You can also order similar cards from the Alzheimer's Store, www.alzstore.com, 1-800-752-3238. Use either set of cards to discreetly let someone know that your loved one has Alzheimer's and that it may take them a little longer to make a decision. Carry these cards with you when you take your loved one to a restaurant, shopping, and/or traveling. The cards are free from our office, but have a cost from the Alzheimer's store: 20 cards (business card size) for \$5.00.

Some of the affordable products that the Alzheimer's Store carries items under the headings listed here:
Forgetfulness, Activities of Daily Living, Safety, Wandering, Brain Health Exercises, Videos & Books, Physical Exercise, and Spirituality & Inspiration.

alzheimer's association

Oklahoma and Arkansas Chapter
6465 South Yale, Suite 312
Tulsa, OK 74136
www.alz.org/alzokar

younger-onset connections available
online at www.alz.org/alzokar

