

THE AGING & ALZHEIMER'S UPDATE

PUBLISHED BY THE LAYTON AGING & ALZHEIMER'S DISEASE CENTER
A NATIONAL INSTITUTE ON AGING ALZHEIMER'S DISEASE CENTER

FEBRUARY 2010

Patients with Early-onset Alzheimer's Disease Are Valuable Research Participants

While dementia most often affects older adults, people as young as 30 have been diagnosed with Alzheimer's disease or other dementias. Alois Alzheimer first described the disease named for him in 1906. His pioneering descriptions of symptoms (loss of cognitive function) and abnormal brain pathology (plaques and tangles in brain tissue) were based on observations and autopsy of a patient in her 50s. Today, life expectancy has increased, so more people are living to an age when the symptoms develop. Because we usually see older adults with memory loss and other cognitive problems, Alzheimer's disease and other dementias are popularly considered to only affect older adults. This is not always the case.

An estimated 5 to 10% of persons diagnosed with Alzheimer's develop the disease before age 65. The impact is significant for patients who are at the peak of active career and family life. The Alzheimer's Association estimates that 220,000 to 640,000 Americans have early-onset Alzheimer's disease or other dementias. Exact numbers are difficult to determine, because early-onset dementias are often misdiagnosed. Physicians may rule out dementia because the patient is younger than expected and appears healthy. Sometimes early-onset dementias are diagnosed as depression or as symptoms of stress.

Compared to later life dementia, early-onset dementia is more commonly an inherited disease. Up to half of the people with early-onset Alzheimer's disease have had another family member with the disease. Genetic testing can reveal the presence of three known gene mutations that are often associated with early-onset Alzheimer's disease.

As we use these terms in this newsletter, "young-onset," and "early-onset" refer to persons who show symptoms of dementia before the age of 65. These terms are in contrast to "early-stage" dementia that refers to those who are in early stages of the disease, no matter what their age.

Alzheimer's disease is the cause of about 30% of early-onset dementias. Other forms of dementia may also occur in younger adults. In frontotemporal dementia, or FTD, the damage to the brain is localized in the frontal and/or temporal lobes.

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Max and Emily Pedal 2K Miles; Collect Stories of Young-onset Dementia

In the spring of 2006, Max Larkin's 56 year old father, a physician whose character "has always been described as eccentric," started to behave oddly. Max and his family noticed things were a bit off, but they never expected the daunting diagnosis they received: young-onset dementia. The news was a shock to the whole family, as it meant a predictable end to their father's independence as well as his ability to support his family.

Max, his partner Emily Boardway, and the rest of the family, set out to learn about living with this progressive disease. They discovered that most available information and support services are designed to address the concerns of persons who are retirement age.

"We experienced firsthand the desperate need that exists for a network of support" for children of those with young-onset dementia, explains Max. It is common for patients and their families to experience isolation from friends and family who do not understand the disease. They may find themselves cut off from activities and associations that still give meaning to their lives. In response, Max and Emily became advocates and activists. They create connections between families living with this disease, specifically the children of those with young onset dementia, whom they call COYOD.

The pair formed a nonprofit organization, "Mindseries," to promote public health through the arts. Their first project, "Spoke Your Mind," took the couple on a 2,000 mile bicycle trip in search of other COYOD. During the trip from May to September, 2009, Max and Emily met with over 70 COYOD. They filmed interviews in Seattle, Portland, San Francisco, Boston, New York, and Washington DC. Now back at home in Seattle, they are working toward production of a documentary film based on their experience. The film will be the centerpiece of an online forum for people who are facing the social, mental, physical and financial challenges of young-onset dementia.

The first stop on Max and Emily's "Spoke Your Mind" tour was Portland. The enthusiastic reception they received from OHSU's Layton Center and from the Alzheimer's Association/Oregon was an encouraging beginning for their project. Emily recalls that, loaded with video and personal gear, they pedaled all the way up Marquam hill to meet with Linda Boise, education core director for the Layton Center. As they reached the OHSU, they were stopped by a young man who was curious about their bikes and gear. As it turned out, this young man's father suffers from young-onset dementia. This "COYOD Encounter" provided Max and Emily with an interview by chance. You can view the "COYOD Encounter" short, and a video overview of their Portland experience, at: www.spokeyourmind.org/spoketube.

Max's dad now lives in a Seattle care facility. Max and Emily continue to work on the film, as they advocate for a widening community of families coping with this young-onset dementia. Their web site: www.spokeyourmind.org, is a valuable resource for information and support. ❄

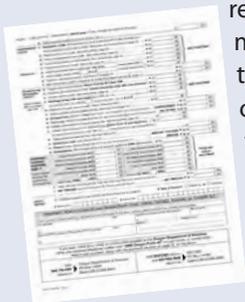


Max Larkin and Emily Boardway visit Washington DC during their bike tour to promote awareness of young-onset dementia.

Support Alzheimer's Disease Research on your Tax Return

To advance Alzheimer's research in our state, Oregon Health care professionals and researchers have established the Oregon Partnership for Alzheimer's Research (OPAR). OPAR administers the Oregon Alzheimer's Research Tax Check-Off Fund, which gives Oregonians the opportunity to donate a portion of their state income tax refund to Alzheimer's

research. The money collected in this way provides opportunities for Oregon researchers who want to conduct Alzheimer's research.



For the first time since this program began in 1989, this year's tax form will not include Alzheimer's disease research on the list. You can still donate to Alzheimer's research by designating a portion of your tax refund when you fill out your tax form.

Here's how:

Form 40: on line 68a or 69a, write "21." In box 68b or 69b write the amount you wish to donate.

Form 40S: on line 38a or 39a write "21." In box 38b or 39b write the amount you wish to donate.

Or ask your tax preparer to do so. ❄

Early onset dementia . . .

Continued from front page

FTD is most often marked by changes in personality or behavior, and/or the loss of language skills. In dementia with Lewy bodies, a build-up of protein called alpha-synuclein is distributed throughout the cerebral cortex. People with Lewy body dementia may exhibit movement disorders similar to those seen in Parkinson's disease. They may also have difficulty paying attention or understanding visual material. Vascular dementia, associated with problems of blood flow to the brain, can also occur in younger adults. Symptoms of vascular dementia are variable, and may include difficulty with organization, communication or motivation.

Early-onset dementia patients make an important contribution to research. They are often in good health otherwise, and so present fewer complicating factors as research subjects.

Clinical research requires large numbers of volunteers who will agree to help investigators collect information. Clinical trials test interventions that may help to diagnose, prevent, treat or cure the disease. OHSU's Layton Center is currently conducting trials to test the efficacy of the antibody bapineuzmab to affect buildup of amyloid in the brain. These trials so far show promising results. The antibody appears to diminish the accumulation of the harmful amyloid plaques that are a hallmark of Alzheimer's disease. According to The Layton Center's Dr. Joseph Quinn, once a clear relationship between the antibody and amyloid plaque accumulation is established, specific drugs may be developed to remove or prevent the toxic plaques that are associated with brain cell death. Among the several studies underway at The Layton Center, researchers detail the clinical history of patients to find out more about the progression of the disease. They may also use MRI (Magnetic Resonance Imaging) to study changes in the aging brain, and how such changes may affect

cognition. People who agree to participate in these trials and procedures as research subjects make an important contribution towards future treatment and prevention.

Chris Donham was 49 years old in 2005, when she first experienced difficulty finding her way to places she had been many times before. For Chris, this was the first sign that she may also be developing the Alzheimer's disease that had also afflicted many others in her family.



Mark and Chris Donham

Her husband Mark explains that Chris had always felt it was important to participate in research, to do what she could to help find a cure: "Chris' family has early onset Alzheimer's genetically, so we were always aware of the possibility.

Her mother passed away at the age of 53 and her only sister at the age of 49. She had been participating in research since early in the 1990's. She was never 'diagnosed' until [later, when] she had problems getting to her doctor appointments."

Though Chris began participation in research studies very early in her disease, she was not able to complete the most recent study. As Mark recalls, "for Chris, it was difficult as we neared the end of the clinical trial, because with the changes in [her] behavior doing the required MRI's was no longer possible. Dr. Quinn was great in helping us make the decision to end our participation just shy of the completion of the clinical trial."

Over the last five years, Mark Donham has supported Chris in every way possible as they coped together with her decline. Throughout this time, he has felt that their involvement with the Layton Aging and Alzheimer's Disease Center provided an important way for their painful journey to hold meaning and hope for the future. As Mark says, "It was good to feel like she was helping to find treatments, and hopefully a cure, for this terrible disease." ❁

Helpful resources

www.mayoclinic.com/health/alzheimers/AZ00009/NSECTIONGROUP=2

Alzheimer's Association. Early Onset Dementia: A National Challenge, A Future Crisis. 2006.

http://www.alz.org/professionals_and_researchers_early_onset.aspx

Hodges, John R, Carol Gregory, Colleen McKinnon, Wendy Kelso, Eneida Mioshi, Olivier Piguet. Younger Onset Dementia: A Practical Guide. Alzheimer's Australia. 2009. <http://www.alzheimers.org.au/content.cfm?topicid=55> ❁

Coming Together for Hope

A courageous family gathers to celebrate lives touched by early-onset Alzheimer's Disease.

By Bob Read

On August 22nd, 2009, the family of Margo Read threw a party called *Celebrate With Margo!* Margo was diagnosed with early-onset Alzheimer's disease in the fall of 2005 at the age of 51. Since her condition had progressed from mild to moderate impairment, gathering together the people of her life while she is still strong seemed like a smashing idea.

Friends and relatives came from near and far and included twelve members of her husband Bob's family from Canada. In total, 120 people graced the dance floor of the Majestic in Dallas, Oregon.

Organic pinot noir wine and pale ale were served along with potluck edibles. Introduced for the very first time ever was the virgin, delicious, "*Margo-read-ta*," a concoction of tropical juices. A chocolate cake, in the form of an amazing representation of Stonehenge, was the delectable dessert.



Bob and Margo Read with friend Christopher Dobson

A video of Margo's life was shown, followed by a ring renewal ceremony. Margo and Bob have been married for 33 years. They lived all their lives together in the forested hills west of Dallas, Oregon where they raised their two children, Ian and Kelly. Dancing and merriment included a challenging and entertaining limbo contest. "How low can you go?"

The event doubled as a fundraiser for OHSU's Layton Aging and Alzheimer's

Disease Center. For every drink consumed a dollar was donated by Bob's brothers. Other donations were collected and have continued to be sent to OHSU in honor of Margo Read. In all, over \$1,400 was raised to support Alzheimer's research studies.

Presentations and speeches included a *Book of Memories*, presented on behalf of Margo's countless friends at West Valley Hospital where she worked for 22 years. Margo's brother Shawn gave an impassioned speech, sharing all the doors Margo had opened and continued to open for him, the newest one being grief. Ian and Kelly, in their opening thoughts had this to say:

"Please know that our family recognizes that grief and loss are part of the human journey. Though this event may not be the easiest to attend, or plan, or speak in, we feel the benefits of gathering in community outweigh avoidance of things that are emotional or difficult. Perhaps in celebrating with our family tonight we are celebrating us all, coming together for hope."

Margo, who carried the evening with her trademark grace and dignity, thanked everyone for coming.

In a post-celebration comment Bob expressed, "I don't know if I feel any less afraid of the future now, but I feel less alone." ❀

UPCOMING EVENTS

OHSU Brain Institute Brain Awareness Season Lectures

02/15/2010

Battling Brain Disorders: The Critical Importance of Mental Health Advocacy —For the Individual and For Society
Congressman Patrick Kennedy,
Rhode Island

02/22/2010

The Mercurial Mind:
Bipolar Disorder and Creativity
Kay Redfield Jamison

03/01/2010

The Emotional Brain: The Mysterious Underpinnings of Emotional Life
Joseph LeDoux

03/08/2010

The Executive Brain: The Frontal Lobes and the Civilized Mind
Jordan Grafman

03/15/2010

Free Marquam Hill Lecture ADHD: What Goes Wrong, And Why? The Latest Thinking on the Intersection of Brain and Development in ADHD
Joel Nigg

03/17/2010

Wisdom:
From Philosophy to Neuroscience
Stephen Hall

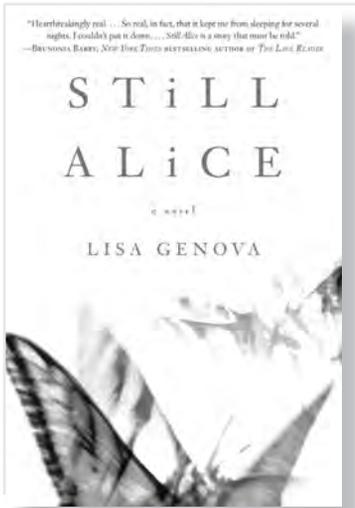
For more information visit

www.oregonbrains.org

Brain Fair at OMSI

3/14/10

Learn about the amazing adaptive power of the brain. The largest Brain Fair in the country returns to OMSI March 14. The free fair is the grand finale of Oregon Health & Science University's (OHSU) Brain Awareness Season 2010. This year's cerebral celebration will include interactive exhibits, real human brains, crafts, demonstrations, prizes, and OHSU neuroscientists explaining their groundbreaking research.



Author Lisa Genova holds a Ph.D. in neuroscience from Harvard University. She has conducted research on the molecular etiology of depression, Parkinson's disease and memory loss following stroke. Her book, in part, portrays the value of organizations such as the Dementia Advocacy & Support Network International (DASNI) for whole family support of those living with early-onset dementia.

Still Alice Imagines the Early-onset Alzheimer's Disease Experience

Harvard professor Alice Howland, age 50, becomes lost while jogging in her neighborhood. A few weeks later, she forgets the subject of a lecture she has delivered scores of times. At a party, she does not recall having met a guest just a few minutes earlier. For a while, Alice, a fictional character portrayed in the novel *Still Alice*, brushes these incidents aside. She feels they must result from her busy and stressful professional life. Eventually, she can no longer ignore her worsening symptoms; she seeks help from her physician. Thorough examination and testing result in Alice's diagnosis: early-onset Alzheimer's disease.

The novel, written by neuroscientist Lisa Genova, presents a compelling story from the viewpoint of the person suffering from the disease. The reader shares in Alice's difficult journey, as she changes from a highly regarded academic professional to a woman who requires help with every aspect of her daily life. The book offers imaginative insight into the broad impact of early-onset Alzheimer's disease on both the patient and her family. ❀

If you are interested in inquiring about clinical studies, please contact Joyce Lear at the Layton Center: 503-494-7615

Thanks to a Team Effort, Layton Center Web Site Easier to Use

Mary Zenorini, LAADC research assistant, along with Chris Baunach, Neurology web specialist, devoted many hours last year to improving the Layton Center Web Site. Their first goal was to make the structure and appearance consistent with the overall OHSU format. Next, they improved the links between topics for easier, more logical navigation. New additions include a redesign of the research participation form, expanded biographical profiles of Layton Center staff and more information about Layton research projects. Adjustments continue as we discover more ways to improve access and to keep the information current. Our goal is to provide useful information about Alzheimer's disease, dementia and aging research and resources. Visit our improved web site at www.ohsu.edu/xd/research/centers-institutes/neurology/alzheimers/. We welcome your suggestions and feedback.

Mary Zenorini pursues career in end of life care

Mary Zenorini is now pursuing a master's in social work degree from Portland State University. Before starting the PSU program in September 2009 she found a home at the Layton Aging and Alzheimer's Center, working in the

education core for Linda Boise. Mary said, "A big gap in my gerontology knowledge was in dementia, and the Layton Center took care of that!" During her employment at the Layton Center she made many valuable contributions. In addition to web site restructuring, she organized the clinic resource area, reviewed OPAR grant applications and created the last issue of this *Update*.

Of her current goals, Mary says, "Once I complete my MSW, I hope to work in my home community, Hood River, addressing the needs of the elderly, the medically frail and terminally ill of any age.

Mary has received the 2009 United Way- Hood River County Volunteer of the Year award for her work with Hospice of the Gorge. She is also a volunteer for Compassion and Choices of Oregon. ❀



Mary Zenorini, former Layton Center research assistant, is currently a Masters in Social Work degree candidate at Portland State University.

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