

## younger-onset connections

Oklahoma and Arkansas Chapter  
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### Living With Alzheimer's: *one family's journey*

STATEMENT OF JAY AND LAURA JONES  
LIGHTHOUSE POINT, FLORIDA for SOCIAL SECURITY  
ADMINISTRATION'S COMPASSIONATE ALLOWANCE  
INITIATIVE HEARING ON YOUNGER-ONSET ALZHEIMER'S  
DISEASE AND OTHER DEMENTIA. JULY 29, 2009

**Jay Jones:** Good afternoon, Commissioner Astrue, other social security officials and distinguished guests. I am Jay Jones and this is my wife, Laura. We are honored to be here today to share our story with you – a story that includes a 3-year search that ended with an Alzheimer's diagnosis – quite a shocking discovery for someone 49 years old. It meant the end of a successful professional career for me, visits to more than 20 different types of medical professionals and specialists – neurologists, psychologists, internists – you name it, more than \$30,000 of our own money spent trying to find answers, countless hours in doctor's offices, and quite a few hours spent



in our local Social Security office as well. This journey has taken a toll on our lives, marriage, family and both of our professional lives – but throughout it all, Laura has remained by my side.

**Laura Jones:** Yesterday we celebrated our 9th wedding anniversary and we have experienced the ups

and the downs. Four years ago, Jay was entering his 22nd year as President of a very successful yacht brokerage business. For 30 years, he helped to build and grow the 20-million dollar family business. A natural born salesman, Jay truly knew the ins and outs and every aspect of the business and it was a labor of love. I think it was actually me who first began to notice something wasn't quite right with Jay. I noticed he was a lot more forgetful, he would lose things constantly, and he just didn't seem like the person I married. He also began experiencing profound personality changes. When I brought these things to his attention, he just dismissed them or ignored them. When we would go to see his doctor, he dismissed it as well – our family

doctor said stress was to blame even after testing that showed poor results – still no one believed that there was anything wrong with Jay. I mean he looks incredible – he's physically fit, but I knew there was something more serious going on. I just felt it in my gut.

**Jay Jones:** I began to suspect there might be a problem when I kept losing things and forgetting how to get to places that I had been going to for years. I began to rely more heavily on taking notes while at work. I took copious notes to help me remember things. I know, too, that the people I worked with had to have noticed eventually I wasn't keeping up with things like I used to – but I was the President and I'm sure they didn't feel comfortable sharing whatever concerns they may have had with me.

**Laura Jones:** His math skills were some of the first skills to go for his job. As a salesman working with figures, percentages, and managing million dollar deals mathematical errors were very serious. I hired a math tutor to try to help him, but it didn't help. He tried to keep up in meetings, but had more and more difficulty keeping up with the others. From 2003 until about 2006, it was a very challenging time for us as we sought out a definitive diagnosis and tried to pinpoint what the exact problem was. There's no history of Alzheimer's disease in Jay's family, and especially in younger people, I guess doctors tend to want to rule everything else out, before they say Alzheimer's. One consideration was gastrointestinal cancer, which, we were told, sometimes causes cognitive impairment. Eventually we learned it was something that HAD NEVER OCCURRED TO EITHER OF US – Alzheimer's. A short time after we learned that Jay had younger-onset Alzheimer's disease, we told his business partners and they wanted him out immediately. It turned very ugly and eventually the company was dissolved then reorganized in order to remove Jay.

**Jay Jones:** That was a tremendous blow because I really did put my all – blood, sweat and tears into building the organization and this really took a toll on me and these long held relationships. It was especially hard as my former business partners proceeded to share my Alzheimer diagnosis with others in our business – really sabotaging any hope I had of getting work in the yacht sales business again.

**Laura Jones:** But the truth of the matter is, he couldn't work any longer. It was impossible to learn any new skills and he had a hard enough time remembering the things he once knew. He

see "Journey" pg. 3

## From JoAnn's Desk:

### *The Next Chapter in the Younger-Onset Program*



As we approach the seventh anniversary in November of my joining the Oklahoma and Arkansas Chapter of the association here in Tulsa as coordinator of the early-onset (now younger-onset) program, we have been reflecting on our past accomplishments.

Our database has grown to over 425 family units and 155 professionals from 38 states who have contacted us to receive our quarterly newsletter and many participate in “*email connections*”. This is the internet communications network where persons with dementia, spouses/partners, adult children, and children still in the home can communicate with their peers one on one. We have hosted six education conferences and one YO summit in 2005 where younger-onset and early stage issues have been discussed and awareness of these new young faces of Alzheimer's have been raised. These young clients and their families have told their stories eloquently in round table discussions and break out session groups, as well as in plenary sessions. This year we hosted our first ever post-conference event for younger-onset, “In Their Own Words” with 60 participants.

We have two support groups in the Tulsa area specifically for younger-onset families and two more groups formed in our regional offices. Numerous other groups for younger-onset are available through other chapters and online as a result of our encouragement and mentoring. Younger-onset clients have been frequent voices in public policy and advocacy events, both locally and on the national level. In partnership with Tracy Mobley we have held two summer camps for kids who have a parent or grandparent with dementia in their home. We have seen other chapters, research centers and groups reach out and start programs similar to ours for younger-onset clients. Younger-onset individuals have been very active as early stage advisors to the National Board of Directors the past 4 years.

Younger-onset folks are also making big

contributions to memory walks across the country.

As much as I would like to stay and finish the course, the time has come to pass the baton to another. So it is with mixed emotions that I write to you today. **There is still much to be accomplished.**

I am so pleased and happy to introduce to you Denyce Willis, one of my colleagues and dear friends here in the Tulsa office, as the new younger-onset coordinator. Denyce is currently the Helpline Specialist for our chapter in Tulsa. Her voice is the caring, compassionate voice you hear most often when you call our helpline. Prior to becoming the Helpline Specialist, she was Development Assistant; she has been a respite volunteer for younger-onset folks, substitute support facilitator, and most recently worked with our EASE and Caregiver Essential programs. Denyce has a heart for people and serves our clients in so many ways.



She also has so many of the technology skills that I have lacked. I know the program is in good hands with Denyce at the helm, and we have been working together for several weeks to make this a seamless transition.

You may reach Denyce by email at [denyce.willis@alz.org](mailto:denyce.willis@alz.org) or by phone at 918-494-5429.

While I am happy and confident in Denyce's abilities and her heart for younger-onset folks, I am sad to say farewell to all of you who have taught me so much, have been so encouraging and supportive in all the things we have tried to do, and given me ideas that have benefited so many. I appreciate all the times you said yes when I asked you to help in some way and the many times you told your story and reached out to another younger-onset family. Together we have made a difference. I ask you to continue to stand up, speak out and help Denyce as you have helped me.

**“Journey”**

tried working for a friend and business associate of 20 years. This man knew about Jay's Alzheimer's and was very compassionate, but there were so many nuances that Jay just couldn't get, so that job never even got off the ground. After that, we tried to think of other things Jay could do, but he couldn't learn any new skills, so it would have been impossible for him to function in a new job. After Jay was removed from his first job, in 2007, he had no benefits at all, and we filed for disability benefits. I filled out the paperwork for Jay and went to the Social Security office. I will say that this was one of the most challenging times for me. Our world had been turned upside down, I had to plan to return to work to support us, we had a four year- old daughter to raise and it was just so much. I went down to the Social Security office to file the paperwork; I had all of our documentation from the past several years – our paper trail of diagnosis. I admit it really was challenging because I was in such an emotional state. But I still felt like we presented a strong enough case. Even the person from Social Security who helped me with the paperwork thought we did it right. I can't even imagine how someone who is cognitively impaired is supposed to be able to fill out all of the paperwork, but again I thought, despite everything, we completed the paperwork successfully. Imagine our surprise, when 6 months later, we got Jay's denial letter.

**Jay Jones:** It really was a shock. We had visited a number of doctors over two years – including the head of neurology at the Mayo Clinic – and had numerous medical reports that documented my condition. But because the reports were older than 6 months, they were not accepted. In fact, all the documentation we had from the past four years which showed the progression of the disease was not considered because it had not been conducted in the past 6 months. Instead, we were referred to yet another physician by Social Security. In the final report, this physician wrote little about my dementia, and instead wrote that I was “eccentric” and “effeminate”. I felt that our proof was overwhelming, but yet again, we were denied. Laura immediately went out and got an attorney and we filed for reconsideration.

**Laura Jones:** The process of trying to get a diagnosis coupled with trying to secure disability benefits was exhausting and overwhelming – an unimaginable ordeal. We were living off of our savings, I had returned to work – pretty much just to get the health insurance. With all of the challenges we had to endure to get a diagnosis, then to try to get disability benefits – it was quite a difficult time. Eventually it took more than 12 months to get approved and then only after we had hired an attorney to help us, who as per social security rules is awarded 25% of the past benefit, in our case was more than \$5000. I can't imagine what it's like for those who don't have the financial means to survive the wait. As part of the reconsideration process, Jay was told to go to the same doctor who had originally said he was eccentric. I called the attorney who was furious and requested a different doctor which we were granted. The new doctor paid very close attention and listened to everything we had to say; she requested additional records and this time, we were approved. And here I was trying to manage and handle the new responsibilities I was facing and not knowing what to ask or who to ask --- that's the situation that I'm afraid too many caregivers may find themselves in.

**Jay Jones:** To get this terrible disease and have to explain to so many people that you simply can't do what you've always been able to. Believe me; I would like nothing better than to be able to work and to continue doing what I love to do. With Alzheimer's you just can't. You can't do what you used to do – can't remember old things, can't learn new things and suddenly all things you know become unfamiliar. It was hard for me because people look at me and see a healthy young 52 year-old man who is physically fit, and yet this disease invades your mind – it truly robs you of your livelihood.

**Laura Jones:** If I had to give any advice to someone who was going to apply for Social Security disability, I would tell them to get \$300 or \$400 and hire an attorney to guide them through the initial paperwork process because it's too overwhelming and complicated to do on one's own. We would like to thank all of you for listening to us and certainly for considering this disease under the Compassionate Allowance initiative. We hope that by sharing with you our story and the ordeal that we faced – you will do what you can to ensure it's not the experience that others have. We also would like to thank the Alzheimer's Association for giving us the opportunity to speak with you today and specifically the Early Stage Advisory Group for embracing us and letting us know we aren't alone.

**Jay Jones:** Thank you all very much.

## Social Security Administration Hosts hearing on Younger-onset

On Wednesday, July 29, the Social Security Administration (SSA) held a hearing examining whether people with younger-onset Alzheimer's disease and related dementias (under age 65) should be included in SSA's Compassionate Allowances Initiative for Social Security benefits.

The Compassionate Allowances Initiative is an effort to improve and expedite the Social Security disability (SSDI) determination process for a recognized class of medical conditions and diseases that are severely debilitating and/or life threatening that prevent individuals from being able to work for at least 12 months.

The hearing featured testimony from five panels, including experts in the field as well as those directly affected by Alzheimer's and related dementias. Association panelists include Harry Johns, president and CEO; Jay Jones, early-stage advisor, Southeast Florida Chapter; Laura Jones, Southeast Florida Chapter; and Joyce Simons, early-stage advisor, New York City Chapter.

For people under age 65 with Alzheimer's disease and related dementias, their diminished cognitive impairment can quickly reach a point where they can no longer maintain gainful employment. Currently, many people with younger-onset Alzheimer's disease and related dementias face multiple challenges when applying for SSDI, including a lengthy decision process and multiple appeals.

If SSA decides to include younger-onset Alzheimer's disease and related dementias on the list of Compassionate Allowances, it would simplify and streamline the SSDI application process, decrease the wait time for benefits and help people access the assistance they need. The hearing provided SSA with an opportunity to be briefed and introduced to the broad range of issues concerning those with younger-onset Alzheimer's and other dementias.

## Austin's Camp Building Bridges 2009

*YMCA Camp Takatoka, Chouteau, Okla.*

Extensive marketing of the 2009 Austin's Camp Building Bridges yielded registration of nine teens ages 12-17 for this year's camp. Seven kids from five states attended, including new children as well as those returning from last year. Sessions went very well. Emily Balfour, a twenty year old from Georgia, spoke candidly and passionately about her life since her father's diagnosis and the impact it has had on her and her family. Each presenter endeavored to share content while fostering interaction between the campers.

The children were very open to information and ideas. Most of them seemed to be very willing to participate in activities and discussions, particularly the second day. Some of their questions indicated that there is much they do not know and it is important to have experts available to answer questions about the disease. Feedback from the kids indicated that there was much good that occurred

in the camp, but that there is also room for growth. Some of their feedback included the following:

- They preferred the interactive exercises and discussions to the didactic presentations.
- They would like more comfortable accommodations and more access to junk food.

The camp met our main objectives: to assist the Mobley's in carrying out their vision of a respite camp for teenagers who are caring for a loved one with dementia at home, a chance to "just be kids." It is our hope that future camps will reach even more caregiving kids and provide increasingly effective programs.

Visit Austin's Camp Building Bridges on Facebook

**NOVEMBER**

**NATIONAL ALZHEIMER'S  
DISEASE AWARENESS MONTH**

CHECK OUR WEBSITE FOR EVENT  
UPDATES

[www.alz.org/alzokar](http://www.alz.org/alzokar)

## *A Mother's Birthday Wish*

Today is a birthday prayer, one that is a little unusual. You see my son just turned 15 today and even though he had his own wishes before blowing out the candles on his cake, I had mine, too. I am ever so grateful that I have been blessed and been able to be here for him this long. For those of you that don't know me, my story started in

2000, though I was actually diagnosed in 2002. I have frontal temporal lobe dementia. Dementia is a very ugly disease and I think that FTD is the ugliest of all due to the verbal and physical aggression that is involved with the disease process. Well, my wish is to be able to see him and be cognitively aware of my surroundings, see him turn 16 and get his first car. Being able to see him turn 17 would be even better, seeing him in his handsome tux as he takes his date to prom night. But, 18 would be the greatest, as that is when he will graduate from high school. I know we are supposed to keep our wish a secret but I thought that maybe if I verbalize it, just maybe God will have a little mercy on me. This is a Mother's birthday wish for her and her son.



Tracy Mobley, Shay Nation, and Austin Mobley.

*Tracy Mobley*

## We're on the MOVE to End Alzheimer's

We are fast approaching Memory walk season across the chapter and country. The Tulsa Memory Walk is less than one month away; Saturday, October 3, 2009 on the ORU campus, Tulsa. Visit

[www.tulsamemorywalk.com](http://www.tulsamemorywalk.com) for details. If you have younger-onset Alzheimer's or other dementia and would like to join the younger-onset

group of teams please do so. Currently we have 5 younger onset teams registered here in the Tulsa area. You may join with your family as a family team, join with the Tulsa support groups' team, Forget Us NOT or form a team of your family and friends under this team group.

The OKC walk is October 24 in OKC.

If you live outside Oklahoma and Arkansas, contact your local chapter and join a team there in your area.



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## Book Review of Still Alice, by Lisa Genova

Review by Wendy Smith, January 2009

Lisa Genova's debut novel about a 50-year-old woman diagnosed with early-onset Alzheimer's disease follows Alice Howland over the course of two years, from disquieting episodes of forgetfulness to the sad final scene in which she sits, holding her first grandchild without knowing who the baby is.

Genova, who holds a Ph.D. in neuroscience and is an online columnist for the Alzheimer's Association, skillfully explains the difference between ordinary forgetfulness caused by age, stress, menopause, or lack of sleep and the accumulating cognitive failures that signal Alzheimer's.

This is a question (and her answer) posed to Dr. Genova: In choosing to tell a story about a woman with Alzheimer's disease, why did you make Alice a fifty-year-old Harvard professor rather than an eighty-year-old retired grandmother? Well, one is that the fifty-year-old will notice and be alarmed by this disease in its earliest moments. Because we as a culture expect eighty-five-year-olds to be forgetful, because retired grandparents are no longer accountable to corporate bosses, because they don't have to produce a certain number and quality of widgets each day, because they might be widowed and living alone with no one to regularly witness the full extent of what is happening, because it is far easier to deny what is happening well after we suspect it or even trip over it, we don't usually see Alzheimer's in its beginning. In someone who is fifty, who is at the peak of her career, whose status in life and identity depends on a highly functioning brain, you'll see the beginning. And when the rug is pulled out, it's a long and terrifying fall.

Near the end of the book, Genova writes about Alice's thoughts and what she would like to say to her husband John: "I used to know how the mind handled language, and I could communicate what I knew. I used to be someone who knew a lot. No one asks for my opinion or advice anymore. I miss that. I used to be curious and independent and confident. I miss being sure of things. There's no peace in being unsure of everything all the time. I miss doing everything easily. I miss being a part of what's happening. I miss feeling wanted. I miss my life and my family. I loved my life and my family." She wanted to tell him everything she remembered and thought, but she couldn't send all those memories and thoughts, composed of so many words, phrases and sentences, past the choking weeds and sludge into audible sound. She boiled it down and put all her effort into what was most essential. The rest would have to remain in the pristine place, hanging on.

*Alice said: "I miss myself." John replied: "I miss you, too, Ali, so much." Alice said: "I never planned to get like this." John said: "I know."*

***Saint Louis conference on the Dominantly Inherited Alzheimer's Network study***

The 7th Leonard Berg Symposium will take place on October 1-2, 2009, at the Eric P. Newman Education Center on the campus of Washington University School of Medicine, and sponsored in part by the Alzheimer's Disease Education and Research Center at Washington University.

This 2-day conference will provide a comprehensive review of the presymptomatic detection of dominantly inherited Alzheimer's disease and its challenges and opportunities. Some of the most active and distinguished researchers in this exciting area will be speaking.

Physicians, dementia specialists, neuroscientists, university medical/science faculty, graduate students, scientists and professionals from industry, and other professional or lay individuals with interests in the detection of dominantly inherited Alzheimer's disease (etad) or early/younger familial Alzheimer's are welcome. Thanks to one of my clients, who will be attending, for alerting us. The link below has more detailed information.

<http://alzheimervustl.edu/education/berg/berg2009/>

**Useful Resources**

**National Alzheimer's Association: [www.alz.org](http://www.alz.org)**  
 Find your local chapter, the younger-onset Message Board and Clinical Trials.

If you have moved and have a new mailing address, phone number and/or email address, please let Denyce Willis, younger-onset coordinator, know of this change. We want to stay connected with you and by providing us up-to-date information we can ensure you have the information you need. [denyce.willis@alz.org](mailto:denyce.willis@alz.org), 918-494-5429.

**CareFinder: [www.alz.org/carefinder/index.asp](http://www.alz.org/carefinder/index.asp)**  
 A website to assist in finding good care, coordinating care, planning and resources in your community.

**Neddy Meds: [www.neddymeds.com](http://www.neddymeds.com)**  
 A useful website for finding financial assistance for getting prescription medications.

