

ASPIRE

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Giving Hope

“Who is this old man here with me?”

Those were the painful words Debbie Jones heard when her mother, Tish Smith, who was diagnosed with younger-onset Alzheimer’s disease at the age of 62, no longer recognized her own husband or the rest of her family.

“This disease threw us for a loop,” Debbie said. “The changes (in her) were difficult to watch. She stopped doing things she loved to do and would call us for help with recipes, even though she had always been a fabulous cook.”

Most troubling was when Tish, a charming Southern lady, went through an angry and aggressive stage and cursed for the first time in her life. “I didn’t know she even knew those words,” Debbie said.

As the disease progressed, Debbie’s father, Randolph, continued to act as Tish’s primary caregiver, and Debbie and her sisters took turns helping. Sadly, Randolph died before his beloved wife. “My father was a true story of a caregiver going first — he ignored his own cancer-related health problems,” Debbie said, “and it cost him his life.”

During her illness, Tish participated in a clinical trial by the National Institutes of Health (NIH) but had to drop out due to a reaction to the drug being tested. The experience introduced the family to Alzheimer’s research, inspiring their determination to help move knowledge forward.

“I promised my mom that I would never forget what this disease did to her and our family,” Debbie said. “I vowed to do everything I could to make a difference.”

Tish ultimately lost her battle with Alzheimer’s in 1999. Making good on the promise she made to her mother, Debbie and her husband Clay took action by getting involved with the Association. And after years of giving their time and resources to advance the cause, they wanted to do even more.

In 2014, Debbie and Clay pledged their support with a Zenith Society-level gift, directing a significant portion to the Association’s International Research Grant Program. They further leveraged their gift by participating in a national matching gift challenge. The 2014 Mother’s Day appeal featuring Debbie and Clay’s story raised nearly \$2.5 million for the care, support and research efforts of the Association.

“Clay and I give to the Alzheimer’s Association because we’re excited about the support we can help offer families facing the disease today, and provide hope for all of us in the future,” Debbie said. “We’ll never beat this disease without investing in the people who are leading this fight. That’s why we encourage others to join us in supporting the Association.”

The first portion of Debbie and Clay’s gift sponsors two New Investigator Research Grants, supporting investigations into drug efficacy and genome instability. The remainder of their donation will fund innovative projects recommended by the Association’s Medical and Scientific Advisory Council, providing flexibility to invest in high-impact research opportunities across the globe.



Debbie and Clay Jones

Debbie and Clay are passionate about doing their part to change the course of Alzheimer's. "Only by joining together can we work toward developing more effective treatments, preventing Alzheimer's and other dementias and, one day, finding a cure," Debbie said.

In addition to donating to the cause, Debbie is a member of the Association's national board and formerly served as director and chair of the East Central Iowa chapter. Heavily involved in public policy efforts, Debbie is also on the board of the Alzheimer's Impact Movement (AIM), the Association's sister organization that works in strategic partnership with the Association to make Alzheimer's a national priority. As part of their Zenith Society commitment, Debbie and Clay also financially support AIM at a leadership level.

"As long as I'm able, I'm going to fight this fight," Debbie said. "When you have an Alzheimer's diagnosis in your family, you become part of a club you didn't ask to join. Other people's stories are what keep me going, and I really want people to know that they are not alone. We're all in this together, and we can end this disease."

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-DEBBIE JONES

Building on a Foundation of Generosity

Stanley (Stan) Meisel was a decisive man who once had many business enterprises, a strong dedication to his family and a determination to help others. With his wife, Barbara, he raised four children — Michael, Kim, Peter and Robert — in an atmosphere of benevolence.

“I would help my dad deliver Christmas dinners to inner-city families,” recalled Kim Meisel Pesses. “One family that stood out was a single mom and her children who lived in a one-room apartment with a curtain dividing the ‘bedroom’ from the living space. It really opened my eyes to life situations unlike any I had been exposed to prior.”

Pesses’ experience that December day was one of many that helped instill a spirit of generosity in her and her siblings. “Growing up, it was never a question of whether we would give time and resources, but rather where and when,” she said. Little did they know that someday that trait would help them approach a challenge within their own family.

In 2009, Stan Meisel’s family, co-workers and friends began to notice changes in his behavior. The biggest tipoff, according to Pesses, was that her father was having a difficult time making decisions. They initially attributed his indecisiveness to normal aging, but the issue worsened. Meisel and his family sought a geriatric assessment, and the result was a diagnosis of Alzheimer’s.

Meisel’s life is now dramatically different from his days as a dynamic business executive, avid civic volunteer and world traveler. Pesses and her siblings found it difficult to watch their father, a man who was always in control, lose the ability to run his life and do the things he loved. Initially, despite advice from friends who have also been down this road, they thought they could face the disease on their own.

“We thought we could handle it,” said Pesses. “But we quickly learned we couldn’t, and it was OK to seek help.”

The family turned to the Alzheimer’s Association Cleveland Area Chapter. “Our initial meeting with a care consultant was eye-opening,” Pesses said. “I was amazed at the level of services the Association offered.” The online resources and one-on-one support from staff and volunteers were just what Pesses and her siblings needed as they learned how to deal with their father’s diagnosis.

After the meeting, the family knew they wanted to get involved with the Association on a higher level. Pesses volunteered to co-chair the chapter’s annual fundraising dinner; soon after, she joined the chapter’s board of directors and then became the chair of its fund development committee.

The family’s commitment grew to include monetary contributions. Via the Meisel Family Foundation, a supporting organization of the Jewish Community Federation of Cleveland, the family made a donation to the Association to help fund the resources they had found so helpful themselves. Their generous \$25,000 gift was used to hire a full-time support group coordinator at the Cleveland Area chapter.



Barbara and Stanley Meisel (center) surrounded by family at their 60th wedding anniversary celebration in 2012.

In 2014, the foundation donated \$50,000 — an amount matched by an additional \$50,000 through an Association matching challenge — to support Alzheimer’s research. The family worked with the Association’s International Research Grant Program to identify a peer-reviewed research opportunity in their own backyard at the Cleveland Clinic with Jagan A. Pillai, Ph.D., an Alzheimer’s Association New Investigator Research Grant program recipient. Dr. Jagan’s study, “Inflammatory Biomarkers in Rapidly Progressive Alzheimer’s Disease,” looks at the role of inflammation in the progression of Alzheimer’s disease and examines different treatments that combat inflammation.

The Meisel family works hard to be a strong example of volunteerism and philanthropy, just as their parents before them. Through their generosity, they’re helping to ensure that people facing Alzheimer’s disease will continue to receive support while paving the way so future generations may never need it.

“Growing up, it was never a question of whether we would give time and resources, but rather where and when.”

-KIM MEISEL PESSES

To learn more about sponsoring research programs and initiatives or issuing a challenge grant, please email leadershipgiving@alz.org or call 800.272.3900.

A Reason to Fight, a Reason to Hope

In 2001, while volunteering for a fair in their community, Mark Levy of Dayton, Ohio, began noticing changes in his wife Janet's behavior. As team captains, they were tasked with preparing post-event reports. "Janet just couldn't do it," Mark said. "She couldn't organize the facts and put them on paper."

Janet also began having difficulty with driving. She didn't know what to do with the lines on the road; she couldn't comprehend why they were there. Despite knowing that something wasn't right, Janet didn't want to discuss the symptoms with her doctor. But the symptoms couldn't go unaddressed forever.

In 2005, a neurologist diagnosed Janet, age 54, with younger-onset Alzheimer's disease. Receiving the diagnosis turned out to be a blessing, as it allowed Mark and Janet to prepare to face what was ahead, and that included building a network of support.

As the disease progressed, Janet remained calm. "She rarely showed aggression or anger, which is one of the main reasons we were able to manage her care for so many years at home," Mark said. "The other factor was that we had a large care team.

"Our friends, neighbors, our youngest son, Jim, and oldest son, Andrew, who lived out of town but checked in frequently, all contributed to Janet's care," Mark continued. "It truly was a community of support, and I was grateful."

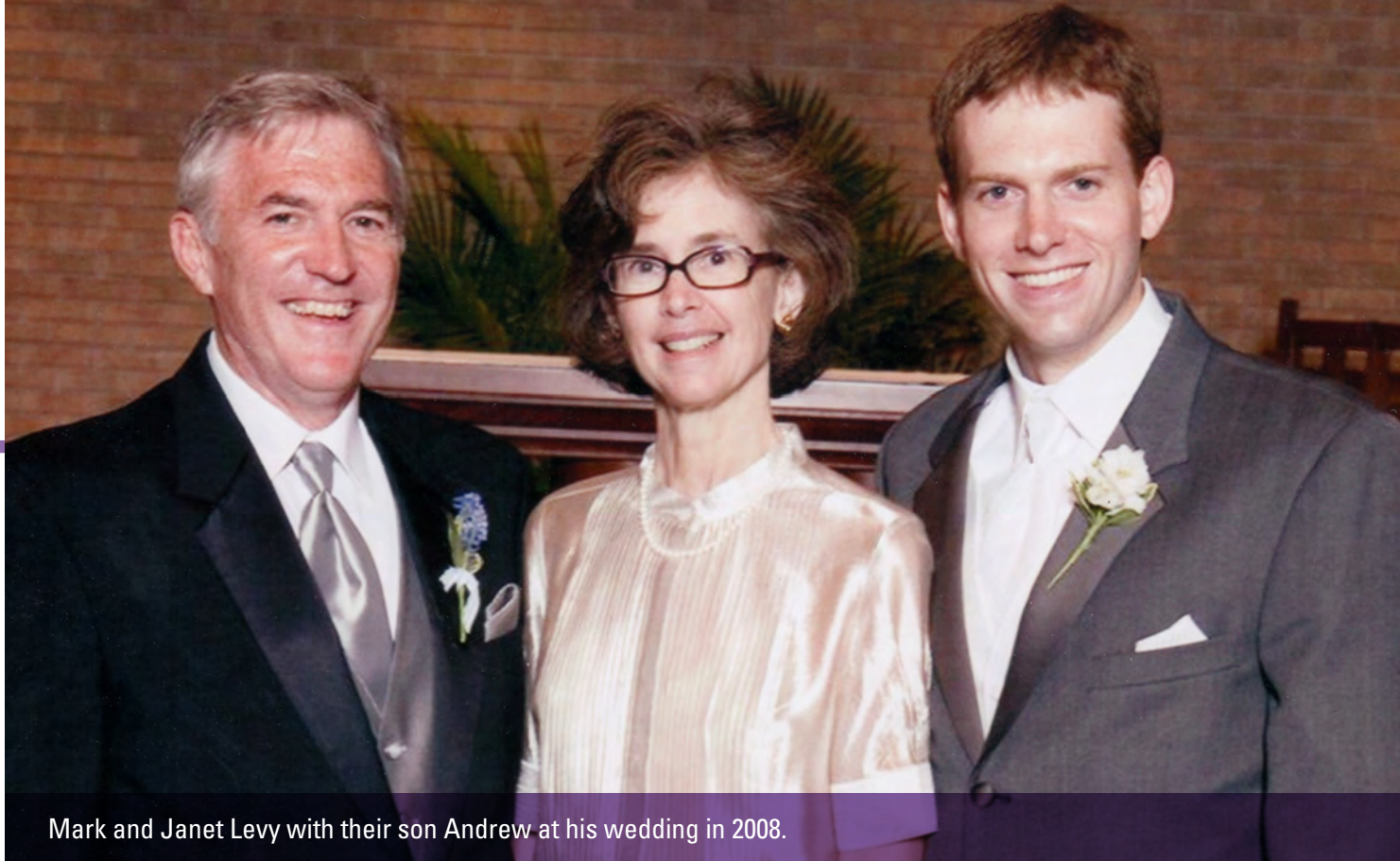
Engaging in the arts also played an important role in Janet's care, providing an outlet for self-expression. Mark arranged for an art teacher to visit half a day each week to lead Janet, an art history enthusiast, in projects like drawing and making clay pots. In addition, a friend visited with Janet once a week to listen to show tunes and sing.

Mark later hired 24/7 in-home care to manage Janet's increased needs. It was around this time that he was invited by a friend to attend an Alzheimer's Association support group. "The group was a tremendous help," he said. "As we shared experiences, I realized I was not alone." Mark also contacted the Association numerous times for advice on handling certain situations.

In late 2010, as Janet began to require more intensive, around-the-clock care, Mark made the decision to move her to an assisted-living facility, where she stayed until she died in March 2012 at the age of 61.

Shortly after Janet's death, Mark's sister, Patty King, attended an Alzheimer's Association Reason to Hope event in Columbus, Ohio. At the event, attendees were asked to stand as the host asked who they knew with the disease — grandparents, parents, spouses, brothers, sisters, friends and co-workers. The list went on; eventually, everyone in the room was standing.

"Patty was overwhelmed by the visual display of those affected by the disease and insisted I approach the Miami Valley chapter to host a Reason to Hope event," Mark said. "I didn't hesitate."



Mark and Janet Levy with their son Andrew at his wedding in 2008.

In 2013, Mark served on the planning committee and made a generous donation to fully fund the event, which drew 400 attendees and raised \$80,000 for the Association. Mark funded the event again in 2014, drawing 500 attendees and raising \$120,000. He has plans to keep the momentum going in 2015.

Grateful for all the Association has done for them, Mark and his family are dedicated and varied in their support of the Association. He volunteers with the Association's 24/7 Helpline one day per week and serves on the Miami Valley chapter's board of directors. His son, Jim, is on the Miami Valley chapter junior committee. And each year, Mark and many of his family and friends participate in Walk to End Alzheimer's.

"My heart goes out to caregivers who think they have no one to lean on," Mark said. "We need to make sure those living with Alzheimer's and their caregivers know what resources the Association offers so they can get the help they need. I'll continue to do all I can to ensure people are not alone in facing the disease."

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-MARK LEVY

To find a support group near you, visit alz.org/findus. For information on Reason to Hope events, email leadershipgiving@alz.org or call 800.272.3900.