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Rare form of Alzheimer's marks Austin family

By Mary Ann Roser

Alzheimer's disease has stalked Paula Acosta Marks of Austin since birth, and now she knows: She will be the last member of her immediate family left to remember what it did to them.

Alzheimer's first attacked her mother, whose death in 1982 was attributed to a form of mad cow disease. Paula was just 5. Now, she is watching her two older sisters, ages 38 and 48, lose their memories to the same rare, inherited form of Alzheimer's disease.

Paula, 36, doesn't have the genetic mutation that is certain to cause Alzheimer's. She is the main caregiver to her unmarried 38-year-old sister, Lori Acosta, and copes with the sadness of losing her, bit by bit, by living in the moment and celebrating their time together. "Don't waste a day," she said. "Tell people you love them, every day."

At a time when Americans are living longer, Alzheimer's is considered an epidemic and one of medicine's most daunting puzzles. Experts predict a nearly threefold increase in diagnoses by 2050. Today, early-onset patients — those younger than 65 — represent 200,000 of the 5.2 million who have Alzheimer's disease.

The very early-onset Alzheimer's in Paula's family shows the disease at its cruelest. It steals the lives of adults in their prime — their 30s and 40s. It devastates caregivers.

But it is also a focus of researchers who hope to answer a burning question: If a person destined to get Alzheimer's receives a drug therapy before symptoms emerge, can the disease be prevented in all kinds of patients or, at least, forestalled?

“If one could intervene earlier, you would be able to exert a much stronger effect at delaying the disease,” said Dr. Clifford Jack Jr., a professor of radiology at the Mayo Clinic, in a written statement. He will lecture on Alzheimer’s prevention Sept. 16 at the University of Texas Southwestern Medical Center in Dallas.

Paula has enrolled in a study of early-onset Alzheimer’s being conducted by the Easton Center for Alzheimer’s Disease Research at the University of California, Los Angeles. Researchers want to learn how Alzheimer’s disease works, and families affected by one of three gene mutations, like Paula’s, can provide important clues.

“In most ways, it’s the same disease” regardless of onset, said Dr. John Ringman, a clinical professor of neurology involved in the study. That’s why the study, which continues to enroll patients, is so important, he said.

Previous trials that focused on people who already have symptoms failed because the intervention was too late. But with new tools, including brain scans, researchers are hoping to prevent the disease before symptoms appear.

Treatment isn’t part of the study Paula is involved in, Ringman said, but he and the other researchers in the Dominantly Inherited Alzheimer Network, or DIAN study, hope it will inform future therapies.

Paula, a newly graduated registered nurse, has the same hope. She also hopes her family’s story will raise awareness about the study and about early-onset Alzheimer’s.

“You can get real angry about this, but if you give back, you get a little control,” she said.

Dying young

Paula doesn’t question why her family has been so deeply affected by Alzheimer’s disease. “It’s the roll of the genetic dice,” she said, sitting on a couch in the small South Austin duplex she shares with husband, Barton Marks, 42, and their 2½-year-old daughter, Joslyn.

Children of a parent with early-onset Alzheimer’s have a 50-50 chance of inheriting the disease. Paula’s 20-year-old niece, Taylor Critendon, isn’t sure she wants to be tested. Her mother, Pam Critendon, can no longer talk and doesn’t always know who Taylor is. Getting tested “is something I think about every day,” Taylor said, “but I’m not ready right now.”

As Lori’s main caregiver, Paula never has enough time for her husband, daughter and sisters, not to mention herself. She makes countless calls seeking help for Lori; Medicare will pay for drugs and doctor visits starting next month. And she makes sure she visits Lori every day or has someone else lined up to come.

At times, she struggles with survivor's guilt. At other times, Paula feels blessed, she said, hugging Joslyn. The Alzheimer's trouble has slowed her down, shown her what's important in life and made her grateful for all she has, she said: "There's been a lot of tragedy in my life, but I'm so lucky to have a great husband, a great daughter and all of these wonderful things."

In the past four years, she has pieced together her family's unusual genetic destiny. Her mother's death is no longer mysterious. Barbara Acosta started showing signs of memory loss at age 38, before Paula was born, she said. Two or three years later, the mother of three girls and an adopted son was moved to a nursing home.

Paula has no memory of her mother's presence, only a gnawing sense of absence.

Her mother's death certificate says she died from a rare and fatal brain disorder, Creutzfeldt-Jakob encephalitis, Paula said.

Her father, Pete Acosta, coped with the loss by drinking, Paula said.

Two-and-a-half years after her mother died, Pete Acosta was dead from a heart attack at age 52. Pam, then 20, became the sole parent to Paula, then 8, Lori, 10, and David, 16.

With Social Security benefits and a trust their father had set up, they were able to stay in the family home. Pam married her high school sweetheart, Kevin Critendon, and he became a father to the three younger children.

At 17, Paula moved into an apartment with a friend. She attended the University of Texas, as well as Austin Community College, on and off for six years. When she was 19, her brother, who had been depressed, killed himself.

"Death is one thing, but it (kept) happening to these young people," she said. "I didn't know anyone who grew old and died." Not even her parents.

Tests, and dread

Five years ago, Paula and Barton were planning their wedding when Barton noticed something was wrong with Pam, then a schoolteacher. "She's telling a story and ... every sentence, there was a word she couldn't remember," he said.

Lori also noticed. "I'm worried about Pam," she told Paula.

Lori and Paula had been relieved after Pam turned 38, the age at which their mother began losing her memory. The two had long suspected something else — something genetic — had killed their mother. They hoped they were wrong.

“I thought she was having mini-strokes,” Barton said of Pam. “I was freaked out and said, ‘She has got to go to the doctor. Right now.’”

The tests confirmed Paula’s and Lori’s fears: Pam had Alzheimer’s. The diagnosis came in February 2009.

“I remember thinking, ‘That’s the worst thing that could happen,’” said Taylor Critendon, who was 16.

Paula figured out that her mother must have had Alzheimer’s and started to wonder: Did she have it, too?

“The anxiety of not knowing was causing me anxiety,” Paula said. “Every time I tripped on a word, I was worried.”

It didn’t matter to Barton.

“I was afraid she was going to get sick, but there never was a doubt I was going to marry her,” he said. “There was no way I was going to leave her.”

They married in May 2009.

Paula spent every Monday with Pam for four years. “We did all these bonding things. She helped me shop for my wedding dress. She helped me through the pregnancy, and we shopped for Joslyn’s first outfit,” Paula said.

In February 2011, Pam had a genetic test confirming that she had the rare, familial form of the disease. And then Paula noticed her other sister, Lori, was acting strangely.

Lori lost her job as a massage therapist in 2010 and was having a hard time finding work. Her personal life was a jumble of unpaid bills and unstable boyfriends. Lori had been savvy on Facebook, but now she couldn’t fill out an online job application. She didn’t have health insurance and couldn’t pay her rent. She resisted Paula’s insistence that she see a doctor.

“Nobody wanted to believe she was sick,” Paula said. “She was only 36.”

Lori made excuses for her problems but later confessed: She didn’t want to know. “She said, ‘If I know, I’m going to kill myself,’” Paula recalled.

Lori finally went to Dr. Ronald DeVere, an Austin neurologist, in June 2012. She was the youngest patient he had ever seen with Alzheimer’s, he said.

Paula also got tested in January 2012 as part of the DIAN study in which she is enrolled. She waited a long three weeks for the results. When she heard she didn't have the gene, "I immediately started crying," she said. "I jumped up and grabbed Barton and Joslyn."

The news also meant Joslyn wouldn't inherit the disease.

'No one else but me'

Lori is losing her abilities quickly, and psychiatric problems — which occur in some Alzheimer's patients — have emerged. Such an aggressive course is more common in early-onset disease and has been distressing to Paula. If Lori feels paranoid or anxious — which can happen in loud, crowded places — Paula will usher her out.

"You have to be extremely flexible and very patient," Paula said.

Lori lived with Paula and Barton in July, but she moved to an assisted living home early this month. It was too hard being around an energetic toddler.

Living with Paula's family "was really good," Lori said earlier this month, "but I hated it sometimes."

Paula lives modestly and pays for a second caregiver for Lori, who is unable to work or care for herself, in addition to paying for a chunk of Lori's living expenses.

When DeVere first saw Lori, he said, she scored an 11 out of 30 points on a cognitive test. Last month, she scored an 8. Barton said he sees declines from week to week.

Paula sees Lori almost every day and takes her swimming, out to eat and for walks. She's not sure how she will juggle that once she starts a new job next month as a full-time hospital nurse, but she is determined that Lori have the best quality of life possible.

As Paula has watched Pam decline, she cries when she thinks about Lori's future. Lori has struggled all of her life, but she still had big plans. "She wanted to find love. She wanted to get married again. She wanted to travel. She wanted to get a new career," Paula said. "Now she won't have any of that."

Instead, Lori will soon need a more restrictive environment. "When am I going to take everything away?" Paula asked. "I have guilt over taking all of her freedoms away while I get to have the love of my life and a beautiful daughter."

Paula knows she can't avoid it: "These is no else but me. I am IT for her."

She holds back tears and continues, “I have to talk about things. I have to see the positivity. She will leave this Earth, and I know we will have said all of these things that we needed to say to each other.”

That tightened bond with Lori and Pam are bright spots, Paula said. So is the DIAN study. All of the tragedies in her life have brought her to this moment. She knows and appreciates what is most important: life, love, family. She has learned to live in the moment, she said, and now, she can make peace with Alzheimer’s.

“All of this colored my life,” Paula said, “in a beautiful way.”

Living with Alzheimer’s

A series of free seminars, “Living with Alzheimer’s: For Caregivers,” starts Sept. 17 and continues from 3 to 4:30 p.m. every Tuesday through Nov. 26 in Austin.

Sponsored by the Alzheimer’s Association Capital of Texas Chapter, the classes give an overview of what to expect and how care for a loved one with dementia. Sessions will focus on legal and financial matters, safety, communication, treatment options, behavior management, caregiver well-being, local resources and more.

The classes will be at the chapter’s offices, 3520 Executive Center Drive, No. 140. Registration is required. Call 512-241-0420 or go to txprograms@txalz.org.