

Evening at  
the Ranch  
helps fami-  
lies in finan-  
cial need.



Page 13

## Morgan Hill couple is committed to making memories

Sue and Chuck Berghoff  
tackle Lewy Body  
Dementia condition  
with hope and courage

*By Donna Lane*

For Sue Berghoff, it started with words. Or, more accurately, the loss of them. A successful, well-educated business woman, the Morgan Hill resident was known for her skill in using not just the right word, but the precise word in conversations. Suddenly, she was struggling to access her impressive vocabulary. Her journey is chronicled in "Sue's Story," a short documentary detailing her battle with Lewy body dementia.

"I could see things happening in my ability to find the word I wanted to use," recalled Berghoff, 72, in the film's opening moments. "I had a 30-year career in senior management roles in the technology industry, and I spent eight years teaching business writing and English as a second language at San José State University."

Then a skill which had always been



*Photo by Marty Cheek*

Sue and Chuck Berghoff and their dog, Winston, in their Morgan Hill home. Sue was diagnosed with Lewy Body Dementia in 2017.

effortless was now challenging.

At age 68, Berghoff knew something was wrong. It was not only with her

words but also her equilibrium and her ability to do routine chores like balance a checkbook. In 2013, a checkup and

### Details

The Sue's Story Project is funded solely by donations and grants, including a \$10,000 grant from the Friends of the Morgan Hill Senior Center in 2017. Donations can be made online or by mail to the Lewy Body Dementia Awareness & Research Fund of the Morgan Hill Community Foundation. To learn more, visit [www.thesuesstoryproject.com](http://www.thesuesstoryproject.com)

some basic cognitive tests, mostly on paper, yielded a few concerns. But her doctor found her to be in good health. "See you in 10 years," was the message she received.

Then in 2017, a return visit to her doctor led to a referral to a neurologist in the Memory Care Unit at Kaiser Permanente. This time, exams and a PET

**See LEWY BODY, Page 11**

## Young people learn jobs skills at theme park

Gilroy Gardens  
employs about  
200 local teens

*By Donna Lane*

For many teens, summer means lazy days spent in the sand and surf. For some teens, summer also means responsibility and revenue. With more than 40 rides, gardens, exhibits, and water play areas, Gilroy Gardens Family Theme Park employs about 200 local teens between the ages of 15 and 17.

About half of them return from a previous season, giving them the opportunity to gain valuable



*Photo by Marty Cheek*

Cameron Childers, 18, poses with two Gilroy Garden Family Theme Park mascots.

job skills while earning a paycheck.

Barb Granter, the park's general manager, said,

"Gilroy Gardens is committed to providing the best first job experience for the youth of our com-

### Gilroy Gardens

**Where:** 3050 Hecker Pass Highway  
**Details:** Visit [www.gilroygardens.org](http://www.gilroygardens.org)

munity and their first opportunity to grow as supervisors and managers. Tourism is a dynamic industry, uniquely suited to this workforce."

Cameron Childers, 18, graduated from Christopher High School in 2017, and is now taking business classes at San Jose State University. The Gilroy resident started working at Gilroy

**See GARDENS, Page 12**

## MHUSD values reflected in opening of school year this week

The Morgan Hill Unified School District community is excited about opening the new 2018-'19 school year with the first day of classes Aug. 16. Earlier this month, we gathered our administrators together for a two-day "Leadership Charge" held at the Granada Theater.

The theme of this year's school year kick-off event was "all hands on deck." We encouraged all school principals, supervisors and directors to have fun together around the book "Lead Like a PIRATE: Make School Amazing for Your Students and Staff" by author Shelley Burgess. The word PIRATE serves as an acronym for Passion, Immerse, Rapport, Ask and Analyze, Transform-

**See BETANDO, Page 10**



Local Safeway produce guy picks music  
Page 5



Downtown plans are coming to fruition  
Page 6



Chef defends title at 40th annual Garlic Fest  
Page 8



MH gardeners can use succession planting  
Page 9

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## LEWY BODY - Morgan Hill woman determined to focus energies on educating others

Continued from front page

Scan revealed that LBD, a progressive brain disorder that damages areas of the brain that regulate language, movement, sleep, and other life functions. LBD is a dementia spectrum disorder, with some similarities to Alzheimer's and Parkinson's, making diagnosis difficult. There is no cure.

Sue and her husband, Chuck Berghoff, were devastated. She had enjoyed an active lifestyle, a loving family, and varied interests. Now she was wondering how to battle a disease she'd never heard of, facing an uncertain future. And with it, an underlying social stigma that has made dementia challenging to discuss.

"I spent six weeks feeling sorry for myself," she recalled in the documentary. "Then I said to myself, 'Alright, Sue. That's enough.' I got my feisty side back ... I thought, 'I have choices. I want to help others.'"

Sue decided to focus her energies on educating others about LBD, and Chuck supported her idea.

While LBD is the second most prevalent form of dementia next to Alzheimer's, affecting roughly 1.5 million Americans, few had heard of it before the deaths of Robin Williams and Casey Kasem drew attention to the disease.

The risk of dementia nearly doubles every decade after the age of 65. With about 10,000 to 15,000 Americans turning 65 each day, a doctor diagnoses someone with dementia about every 66 seconds. The prognosis for LBD can vary greatly depending on the patient but is six to nine years from the date of diagnosis, on average.

In September of 2017 the Berghoffs hosted a backyard fundraiser that raised \$43,000 for two nonprofits dedicated to LBD awareness and caregiver support. Chuck asked how many of the guests knew someone with dementia and was stunned when everyone raised their hands.

Inspired by Sue's mission, a team of local filmmakers including Robin Shepherd, Mattie Scariot, and Nils Myers began working on a documentary they called "Sue's Story." For seven months they carved out time for scripting, filming, and editing sessions,



*Photo by Marty Cheek*

Sue and Chuck Berghoff in the backyard of their Morgan Hill home.

at the Berghoffs' home and at Stanford University.

"Sue's Story" debuted at the 2018 Poppy Jasper International Film Festival and won Audience Choice for Best Documentary. After the screening, Sue and Chuck were joined onstage for a Q&A with experts from Stanford, Genentech, the Brain Support Network, and Kaiser Permanente who appeared in the film. From that moment, a discussion about dementia, previously left unspoken, began to ripple through the community.

The Berghoffs worked with Robin Shepherd to create The Sue's Story Project, a model for social impact and engagement. Its goal is to advance Sue's mission through partnerships to host community awareness-building events, increase funding for research, and advocate for support services for families living with LBD.

In the film, Sue said, "Doing positive things for others is better than worrying about yourself." Her soft blue eyes welled up, but she continued with a determined tone, "This is the most important thing I feel I've ever done in my life."

Currently, the only way to confirm an LBD diagnosis is postmortem, through a brain autopsy. That makes it diffi-

cult to attract funding for research or to conduct clinical trials, which could lead to therapies and a cure for LBD. Sue has already decided that after she passes, her brain will be donated for dementia research.

After the diagnosis, the Berghoffs began searching for helpful resources. That led them to find Robin Riddle of the Brain Support Network in San Mateo. She invited Chuck into her LBD caregiver support group and connected the Berghoffs with Dr. Kathleen Poston who spearheads LBD research at Stanford. They continue to stay in touch with Riddle and Poston, exploring new ways to raise awareness for LBD.

The Berghoffs are advocates for an LBD caregiver support network here in the South Valley. Morgan Hill and Gilroy are officially recognized by the World Health Organization as Aging-Friendly Cities and working creatively to fulfill this designation.

Day by day, the Berghoffs are adjusting to the quality of life changes that LBD brings. They spend their time with family and families and keep attending community events. It's often a challenge for Sue to struggle to keep up with people's conversations.

Some days she delights in working in

### Upcoming events

**What:** Music as Language Benefit Concert for the "Sue's Story" Project

**When:** 6 p.m., Aug. 18

**Where:** Miramar Vineyards, 12255 New Ave., San Martin

**Details:** (408) 782-4793 or visit [www.musicaslanguagelanguage.com](http://www.musicaslanguagelanguage.com)

**What:** City of Morgan Hill Senior Resource Fair: Screening of "Sue's Story" followed by Q & A

**When:** 10:30 a.m. to noon, Oct. 12

**Where:** Morgan Hill Community & Cultural Center, 17000 Monterey Road

**Details:** (408) 782-0008 or visit [www.morganhill.ca.gov](http://www.morganhill.ca.gov)

### Resources

Sue's Story website: [www.thesuesstoryproject.com](http://www.thesuesstoryproject.com)

Lewy Body Dementia Association website: [www.lbda.org](http://www.lbda.org)

Bay Area — Lewy Body Dementia Caregiver Support Network: Meets about every six weeks from 5 to 7 p.m., Sundays. Call for dates and location. This group is for caregivers of LBD patients. Contact Robin Riddle at (650) 814-0848, or [robin.riddle@brainsupportnetwork.org](mailto:robin.riddle@brainsupportnetwork.org).

her garden. Other days, she's frustrated at not being able to follow her favorite recipe. Chuck is learning to live in Sue's reality, striving to keep her days simple, organized, with as much activity as his wife can manage.

Once again showing her feisty side, Sue said, "We're not doing enough. And we've got to do something quickly, because there is no cure. I don't know what comes next for me. But hopefully I can contribute and help make things better."

Her words, so heartfelt, couldn't be more precise.

## Symptoms can be frustrating, leading to aggression and paranoia

LBD is a complex disease that is progressively debilitating

By Donna Lane

Unlike Alzheimer's, in which patients gradually forget memories, names, and events, Lewy body dementia (LBD) can be cruel. While Alzheimer's patients forget something and never remember it again, LBD patients are aware that they're forgetting things, and sometimes recall them later. This leads to frustration, which can manifest as aggression, paranoia, and other unusual behaviors that can be startlingly different from the patient's inherent personality.

An especially troublesome aspect of LBD is Sun-downer's Syndrome, which can be prevalent in Alzheimer's patients as well.

It commonly occurs in the evening, hence the name. During this time, an LBD patient can become highly agitated, fearful, paranoid, delusional, and aggressive. Behavior can change in an instant, causing high distress for the patient as well as family mem-

### Symptoms

According to the Lewy Body Dementia Association, the central feature is progressive dementia, meaning patients experience deficits in attention and executive function. In the early stages, prominent memory failure may be noticeable. Other symptoms include fluctuating cognition with pronounced variations in alertness and attention. Complex visual hallucinations can occur, as well as spontaneous Parkinsonism (tremors, change in gait, body stiffness, and frequent falls).

bers and caregivers.

No one knows what causes LBD. Research on the condition is ongoing. It's likely that there are multiple factors, including genetics, environmental risks, and the natural aging process.

According to the Lewy Body Dementia Association, "Dementia is a process whereby the person becomes progressively confused. The earliest signs are usually memory problems, changes in their way of speaking, such as forgetting words, and personality problems. Cognitive symptoms of dementia include poor problem solving, difficulty with learning new skills, and impaired decision making."

Furthermore, LBD is a complex disease that can affect alertness, cause problems with movement including tremors, stiffness, slowness and difficulty walking, bring on hallucinations, and alter sleep and behavior.

Progressively debilitating, it can present with issues affecting blood pressure control, temperature regulation, and bladder and bowel function. LBD can also cause people to experience visual hallucinations or act out their dreams.

With such a wide range of symptoms and behaviors, LBD can be overwhelming to treat. A solid, unified team of caregivers is a necessity.