

# Daily Pilot

THURSDAY, MAY 28, 2020 /// Now including Coastline Pilot and Huntington Beach Independent /// dailypilot.com

## Fight of his life

Costa Mesa resident Eric Stevens was relentless as a Cal football player. The 30-year-old battles ALS with the same approach.

BY NATHAN FENNO

The question returns to Eric Stevens each morning in the hazy seconds after waking up. “Is this really happening? Do I have ALS?”

The answer is always the same. Amyotrophic lateral sclerosis, also known as Lou Gehrig’s disease, hasn’t left. He hauls himself out of bed at his Costa Mesa apartment and takes the first halting steps of another day without a way to slow the disease that’s consuming his body.

Stevens used to make so many things look easy. He raced BMX bicycles and played hockey and wrestled at Palos Verdes Peninsula High. He surfed Haggerty’s break off Malaga Cove. He fly-fished. He captained the University of California-Berkeley football team, spent part of a season with the St. Louis Rams, joined the Los Angeles Fire Department as a firefighter and, last year before the diagnosis upended everything, married his college sweetheart.

See **Stevens**, page A3

**IT WASN’T LONG** after their marriage last year when Eric Stevens and Amanda learned that he had been diagnosed with ALS.

Robert Gauthier  
Los Angeles Times



## Newport clears path for outdoor dining

City approves a program to allow reconfiguration of parking areas for curbside pickup and expanded occupancy.

BY HILLARY DAVIS

Newport Beach has removed a regulatory hurdle for businesses — and churches — to spread out and regain their footing as the region reopens from two months of pandemic lockdown.

The City Council unanimously approved a permitting program Tuesday that allows businesses and religious institutions to temporarily expand into parking lots, sidewalks or other adjacent private or public property to maintain their usual occupancy — or at least get closer to it.

Mayor Will O’Neill said physical distancing mandates within businesses mean that shops and dining rooms aren’t at full capacity, so their parking won’t be filled, either, but the usual permitted path to utilizing lots as floor space would require a variance from the city Planning Commission, which can take some time.

The Fast Track Back to Business Initiative allows reconfiguration of parking and circulation areas to accommodate curbside pickup, takeout windows and expanded outdoor dining.

In addition to benefiting restaurants, the program can green-light boutiques to set up racks of merchandise in parking lots, or churches to give outdoor services or drive-through blessings. The program also allows for the extended duration of advertising banner permits.

“We’re trying to do everything

See **Outdoor**, page A2

## 5 new deaths reported in county due to COVID-19

BY MATT SZABO

Five new deaths due to COVID-19 were reported in Orange County on Wednesday, according to updated numbers from the Orange County Health Care Agency.

The deaths came after two straight days of no deaths from the respiratory disease. Currently, the county death toll due to COVID-19 sits at 136, including 54 skilled nursing facility residents.

There were 116 new cases reported Wednesday, bringing the total number of cases to 5,646. That figure includes 617 skilled nursing facility residents and 369 Orange County jail inmates.

The agency estimates that 2,090 people in the county have recovered from COVID-19.

Orange County Supervisors have agreed to pay \$75 million in federal funding to help cities, small businesses and nonprofit organizations with virus-related expenses.

The board also asked Orange County’s public health officer to modify a weekend order requiring face coverings in public.

A total of 274 people remain hospitalized, which is a single-day high for the county during the novel coronavirus pandemic. There are 101 cases in the intensive care unit, with 24 of 25 eligible hospitals reporting.

Only 1,088 COVID-19 tests were issued Tuesday, the lowest amount since May 17. Overall, 109,013 tests have been issued to date.

Of the total cases, 18% are people ages 25-34, and 18% more are in the 45-54 age range. There are 15% in the 35-44 age range, and 15% more are ages 55-64.

More than half of the deaths related to COVID-19 have been people age 75 or older. Those 75-84 account for 29%, and those 85 and older account for 28%.

Males account for 52% of the

See **Deaths**, page A2

### ALSO FROM THE DAILY PILOT:



Scott Smeltzer

**HUNTINGTON BEACH PIER, CLOSED SINCE MARCH, IS OPEN AGAIN**  
PAGE A2

**EMAIL** david.carrillo@latimes.com **TO SIGN UP FOR THE DAILY PILOT NEWSLETTER FEATURING THE LATEST NEWS INVOLVING NEWPORT BEACH, HUNTINGTON BEACH, COSTA MESA, LAGUNA BEACH, FOUNTAIN VALLEY AND OTHER PARTS OF ORANGE COUNTY.**

## Costa Mesa’s Measure Y won’t go before voters for changes

BY SARA CARDINE

The Costa Mesa City Council backed away Tuesday from a proposal that would have asked residents to decide in November on modifying Measure Y, a 2016 initiative requiring voter approval of development projects that pass certain zoning and impact thresholds.

Instead, the city will form a citizens advisory group tasked with creating a broader vision for encouraging economic development while still preserving Costa Mesa’s quality of life.

Council members discussed in a May 19 meeting the possibility of loosening Measure Y to exempt certain affordable housing projects, or create geographic areas of exemption, as the city anticipates receiving steep housing requirements from the state later this year.

But after hearing nearly two hours of public commentary in a meeting that lasted past 1 a.m., the panel decided to adjourn and

continue its discussion to a second meeting Tuesday.

Mayor Pro Tem John Stephens made a motion to receive and file the May 19 staff report, essentially scuttling the proposed new ballot initiative, claiming the city lacked clear direction on how to proceed.

“I just don’t think it’s appropriate to put this on the ballot,” Stephens said. “I don’t think we have consensus in our community about an amendment.”

Councilwoman Andrea Marr said during last week’s meeting the restrictions imposed by Measure Y have stood in the way of several projects that may have benefited the city, including two hotels and an art museum.

One current proposal, One Metro West — a mixed-use development that would add 1,057 residential units and thousands of square feet of office and retail space north of the 405 Freeway — is large enough to trigger Measure Y’s mandates and comes be-

See **Measure Y**, page A2

## Laguna Beach moves to implement economic recovery plan

BY LILLY NGUYEN

Lower Forest Avenue will be closing this summer after a unanimous vote to put into action a pilot program for a space where residents can eat and interact safely while allowing restaurants available space to operate at sustainable levels.

The Laguna Beach City Council voted to direct City Manager John Pietig to enter a contract with Coachella organizers Choura Events not exceeding \$145,703 to implement “Promenade on Forest,” an outdoor dining and entertainment program, by June 15. It also approved the temporary use permit and temporary coastal de-

velopment permit to do so.

Both permits are subject to conditions outlined in a resolution approved as a part of Tuesday’s motions. Other approvals include the waiving of temporary use permit fees and the delegation of authority to Community Development Director Marc Weiner to approve those permits for outdoor dining, displays and minor deviations on sign and banner standards through Sept. 7.

The conversion of Ocean Avenue to a one-way street will also be delayed until fall.

The presentation given by staff on Tuesday said the goal of Promenade on Forest was to create a safe environment for pedestrians

for the summer, with the intention of local businesses being able to expand their seating and merchandise displays into the street and to providing opportunities for artists. The project was included as part of an economic recovery and business development plan, approved by the City Council at its May 12 meeting.

The concept plan was designed by city staff, Choura Events and SWA Group, a local landscape architecture and urban design firm that designed the Downtown Action Plan.

Plans call for Promenade on Forest to be limited to the one-

See **Plan**, page A2



Don Leach | Staff Photographer

**SMALL GROUPS WAIT** on the sidewalk for phone-in, pickup orders at Active Culture in Laguna Beach on March 19.





## H.B Pier is open again

The city of Huntington Beach reopened the Huntington Beach Pier on Tuesday for the first time since late March.

Businesses along the pier have also opened, and fishing is being allowed, city spokesman Eric McCoy said.

“We’re asking people to keep moving and to be mindful of social distancing,” McCoy said.

Huntington Beach has

moved into full implementation of Phase 2 of reopening, which allows in-person dining and retail shopping with face masks and social distancing.

The city has established a website, HB Reopen, to aid local businesses with reopening.

The pier was originally closed March 24 to promote social distancing.

— Matt Szabo

## MEASURE Y

Continued from page A1

fore the City Council in June.

Many residents who have spoken against the project have drawn connections between the council’s consideration of One Metro West and talk of modifying Measure Y.

Backers of the development claim the project, brought by Beverly Hills developer Rose Equities, would help bring badly needed housing to Costa Mesa while bolstering the

local economy.

Marr said Tuesday she hoped the city could find some way to create a plan for fostering economic growth with input from residents and community stakeholders, particularly given the negative impact the coronavirus pandemic has had on local retailers.

“There’s got to be a way in which we can promote the vision of the city and slowly, methodically and thoughtfully provide an opportunity for improvements on some of our major thoroughfares,” she said.

Marr acknowledged dis-

cussing or possibly changing Measure Y could be undertaken by a citizens advisory group.

Councilwoman Sandy Genis said she came to Tuesday’s meeting prepared to defend Measure Y and was glad to see its potential modification would not be moving forward. Still, she said she was concerned about “false narratives” that implicated Measure Y as an impediment to growth.

“If the project is good enough, the residents will approve it. And if it’s not that good, you know what, a better project will come

along,” she said. “The voters’ vision should prevail.”

Passed in 2016, Measure Y stipulates developments that would both require changes to the city’s zoning code or general plan and meet at least one of a host of other requirements, including containing 40 or more residential units, adding 10,000 square feet or more of commercial space or generating more than 200 average daily vehicle trips, be put before voters in an upcoming election.

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## OUTDOOR

Continued from page A1

we can to ensure that all businesses are considered essential,” said Councilman Kevin Muldoon, who crafted the ordinance with O’Neill and Councilwoman Diane Dixon.

Certain businesses have been allowed to incrementally reopen, with restrictions, over the last three weeks.

Still, O’Neill said an “unfortunate number” of storefronts are shuttering around town as a result of stay-at-home orders that took effect in mid-March.

“When you have a business and you have overhead, every day that you are not open is a day that you are closer to that business



PATRONS LINE UP for food at Pipeline near the Newport Beach Pier on Wednesday.

Scott Smeltzer Staff Photographer

going out,” he said.

Community Development Director Seimone Jurjis said permit applications will receive expedited review from his office, the police and fire departments

and public works for safety and accessibility, with a response within 24 hours. The procedure will be done through email, and fees will be waived.

The permits will expire 14

days after the city’s pandemic-related emergency order is terminated or repealed.

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## PLAN

Continued from page A1

way section of Forest Avenue between Coast Highway and Glenneyre Street.

It will operate between 9 a.m. and 10 p.m. It also includes opportunities for dining decks, retail display decks and a performance art stage along with additional landscaping, temporary art installations.

Maintenance staff will also be on-site to disinfect the area.

Patrons will be able to purchase meals from any restaurant in the area to eat

at the Promenade. Outside alcohol will not be permitted but can be purchased on-site with meals at adjacent restaurants. City staff also received a parking study, which called for the postponement of Ocean Avenue’s conversion to a one-way street.

The conversion of Forest Avenue to Promenade on Forest will lead to the loss of 46 parking spaces, but city staff said that parking demand downtown will decrease this summer due to cancellation of the Festival of Arts and Pageant of the Masters and additional parking at the Village En-

trance and the bus depot on Ocean Avenue.

Assistant City Manager Shohreh Dupuis said that the city would also hire on-site, private security guards every day during operating hours to monitor physical distancing and report any noncompliance or crimes to the Laguna Beach Police Department. Officers will monitor the area periodically.

Promenade on Forest is estimated to cost \$248,703.

Dozens of people spoke to both sides of the argument during public comment. Many were in support of the plan to close

Forest Avenue, but others pointed to issues of parking, restrooms and city spending.

Councilwoman Toni Iseman said she was concerned about crowd capacities and physical distancing, adding that the tables and chairs were movable.

“This would not be considered a success unless the number of people on Forest Avenue today were not multiplied by a factor of 10. That’s how many it would take to get that sense of vitality that we’re looking for,” Iseman said. “I think it’s a toughie. I don’t know how we’re going to do it, but I think we have to address that if this weren’t the season of the virus, this is a great thing.”

“But, we keep talking about the virus and yet we’re doing something that’s a little risky,” Iseman said.

Councilman Peter Blake protested the inclusion of public comment on whether to go ahead with the program, arguing that public comment had already been received at the May 12 meeting and that the plan had already been approved.

Blake said Tuesday’s discussion should focus on the permits and resolution allowing for Promenade on Forest to occur.

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## DEATHS

Continued from page A1

cumulative cases in the county and 57% of the cumulative deaths.

Among local cities, Santa Ana has the most cases with 1,063, which is 19% of the county’s total number of cases. Santa Ana also has the most cases, 31.5, per 10,000 residents.

Here are the latest case counts for select cities, with their numbers per 10,000 residents:

- Santa Ana: 1,063 (31.5 cases per 10,000 residents)
- Anaheim: 944 (26.3 cases per 10,000 residents)
- Huntington Beach: 329 (16.1 cases per 10,000 residents)
- Irvine: 183 (6.5 cases per 10,000 residents)
- Newport Beach: 140 (16.1 cases per 10,000 residents)
- Costa Mesa: 107 (9.2 cases per 10,000 residents)
- Fountain Valley: 55 (9.7 cases per 10,000 residents)
- Laguna Beach: 45 (19.3 cases per 10,000 residents)

Updated figures are posted daily at [ochealthinfo.com/coronavirus-in-oc](https://ochealthinfo.com/coronavirus-in-oc).

For information on getting tested, visit [ochealthinfo.com/covid-19-testing-and-screening](https://ochealthinfo.com/covid-19-testing-and-screening).

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10x15	Dale Pearlman
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10x20	Kevin Wear

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NOTICE OF AMENDED PETITION TO ADMINISTER ESTATE OF:  
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30-2019-01091478-PR-LA-CJC

To all heirs, beneficiaries, creditors, contingent creditors, and persons who may otherwise be interested in the will or estate, or both, of: **TIMOTHY EDWARD ROETTELE**

**A PETITION FOR PROBATE** has been filed by **BARBARA ANN ROETTELE** in the Superior Court of California, County of ORANGE.

**THE PETITION FOR PROBATE** requests that **MARY MAKLER** be appointed as personal representative to administer the estate of the decedent.

**THE PETITION** requests authority to administer the estate under the Independent Administration of Estates Act. (This authority will allow the personal representative to take many actions without obtaining court approval. Before taking certain very important actions, however, the personal representative will be required to give notice to interested persons unless they have waived notice or consented to the proposed action.) The independent administration authority will be granted unless an interested person files an objection to the petition and shows good cause why the court should not grant the authority.

**A HEARING** on the petition will be held on **June 18, 2020 at 2:00 P.M. in Dept. C6** located at  
700 CIVIC CENTER DRIVE WEST,  
SANTA ANA, CA 92701

**IF YOU OBJECT** to the granting of the petition, you should appear at the hearing and state your objections or file written objections with the court before the hearing. Your appearance may be in person or by your attorney.

**IF YOU ARE A CREDITOR** or contingent creditor of the decedent, you must file your claim with the court and mail a copy to the personal representative appointed by the court within the later of either (1) four months from the date of first issuance of letters to a general personal representative, as defined in section 58(b) of the California Probate Code, or (2) 60 days from the date of mailing or personal delivery to you of a notice under section 9052 of the California Probate Code. Other California statutes and legal authority may affect your rights as a creditor. You may want to consult with an attorney knowledgeable in California law.

**YOU MAY EXAMINE** the file kept by the court. If you are a person interested in the estate, you may file with the court a Request for Special Notice (form DE-154) of the filing of an inventory and appraisal of estate assets or of any petition or account as provided in Probate Code section 1250. A Request for Special Notice form is available from the court clerk. Attorney for the Petitioner:  
MONICA GOEL, ESQ  
TREDWAY, LUMSDAINE & DOYLE, LLP  
3900 KILROY AIRPORT WAY, STE 240  
LONG BEACH, CA 90806  
(562) 923-0971  
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BSC 218251

Think inside the boxes.

		h
a	p	p
	y	

a		
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t		

5	3				8
		8			4
				6	7
	6				
8		3	4	1	9
	2				

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LA Times





Robert Gauthier | Los Angeles Times

**DURING THE COVID-19** pandemic, Eric Stevens and his wife rarely go out in public.

## STEVENS

Continued from page A1

He is 30, and his time is running out. His balance is failing. Breathing is more difficult. His words are thick and labored. Muscles spasm nonstop. His hands cramp when he grabs an object. Simple tasks like closing the tailgate of his pickup truck or doing pushups challenge him.

"Every little thing you do is hard," Stevens said. "I feel like there's a 30-pound trenchcoat of water on me. Just heavy. It's like I'm walking in quicksand."

He downs more than 20 vitamins and supplements each morning. He drinks celery juice. He relaxes in a donated sauna. He tries to swim laps and walks the neighborhood and does Pilates three times each week. He lifts light weights and exercises with resistance bands. He pushes to raise awareness of ALS and fast-track experimental treatments. He fights to stay positive but can't escape what his body says. The disease steals a little more each day.

Playing fullback for Cal almost a decade ago, Stevens took a handoff early in a game against UCLA. He bounced off one defender, then another

**"It's such a horrific disease because they tend to be mentally clear until they're very, very deep into it because they have this progressive inability to move which makes it very tough to watch and take care of."**

— Dr. Ann McKee

Chief of neuropathology for the VA Boston Healthcare System and director of the Boston University CTE Center, whose research includes ALS.

and another. The situation looked impossible, but he wouldn't stop fighting to move forward. He bowled ahead, a 240-pound battering ram breaking five tackles to gain a handful of yards. This was the relentless approach — hurdling opponents or delivering big hits on special teams — that made him a favorite among coaches and teammates.

"Off the field, he's mild-mannered, extremely bright," said Ron Gould, who coached running backs at Cal. "On the field, he'll eat your heart out. He's a Tasmanian devil. He didn't back down from anybody."

Stevens is the youngest of four brothers. The middle two became firefighters. The oldest, Craig,

spent eight seasons in the NFL with the Tennessee Titans. Jeff Fisher, who coached the team, remembered Craig as a "muscle-up badass, freakin' hard-working, smart tight end."

Fisher, who moved on to join the Rams as coach, didn't hesitate to sign Eric Stevens as an undrafted free agent in 2013. "That was a no-brainer," Fisher said. "If this is a Stevens, I'm going to bring this kid to camp."

The toll of years of football-related injuries, including several concussions, ended his career before he appeared in a regular-season game. Besides, he wanted to help people. The next step was obvious. He followed the

See **Stevens**, page A4

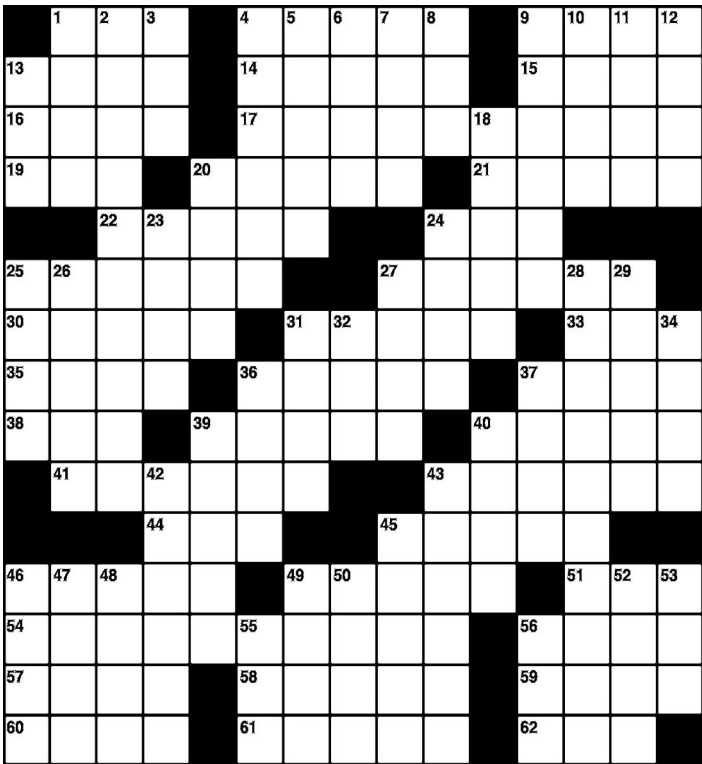
## THE DAILY COMMUTER PUZZLE

By Jacqueline E. Mathews

### ACROSS

1 \_-fetched;  
preposterous  
4 Shot carefully  
9 Lasting mark  
13 Star's car  
14 \_ ear and out the other  
15 \_ shirt; golf attire  
16 Catch sight of  
17 Rockets  
19 Request for silence  
20 Woodwind instrument  
21 Uptight  
22 Narrow waterway  
24 On a \_ with; equal to  
25 Newborns  
27 Profession  
30 "\_ Blue Gown"  
31 Mustang & Taurus  
33 Brewer's barrel  
35 Breakfast \_; kitchen alcove  
36 Actress Claire  
37 Behrs of TV's "2 Broke Girls"  
38 Horned animal  
39 Large parrot  
40 Shriver or Bello  
41 Accompany to a party  
43 Deep narrow valley  
44 Polished off  
45 Give fresh life to  
46 Supermarket  
49 Speak one's mind  
51 "\_ Just Not That Into You"; 2009 film  
54 Beside the point  
56 Healthy  
57 Reclines  
58 In a \_; sort of  
59 Military force  
60 British restrooms  
61 Scornful look  
62 TV's "Say \_ to the Dress"

### DOWN



## SUDOKU

By The Mephram Group

Complete the grid so each row, column and 3-by-3 box (in bold borders) contains every digit, 1 to 9. For strategies on how to solve Sudoku, visit [sudoku.org.uk](http://sudoku.org.uk).

3	1		5	7				9
			4			2	7	
		3		4		7		
	4		6		7		8	
		8		1		5		
		1				8		
9				6	4		1	

**For answers to the crossword and Sudoku puzzles, see page A4.**

1 Carp or flounder  
2 Able to live on land or water  
3 Singer Orbison  
4 Theater walkways  
5 Two cents' worth offered  
6 Castle

surrounding  
7 Suffix for confer or refer  
8 Billy \_ Williams  
9 Globe  
10 Nickel or dime  
11 "Heidi" setting  
12 "A \_ by any other name"

13 " \_ Miserables"  
18 Marquee names  
20 Get away  
23 Furniture ding  
24 Hippie homes  
25 Gunshot sound  
26 By yourself  
27 Rowing team  
28 In all places  
29 Numerical comparison  
31 In \_; actually  
32 \_ pedestal; lovingly honored  
34 Other \_; besides  
36 Show boldness  
37 Source of misery  
39 Traveler's stop  
40 Horse hair  
42 Hug  
43 Middle  
45 Dishwasher cycle  
46 Window ledge  
47 Singing group, perhaps  
48 Nabisco snack  
49 GE appliance  
50 Rectangular piece of glass  
52 Fast-growing trees  
53 \_ as a fox  
55 Suffix for giant or govern  
56 All the \_; fully

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“Eric is extremely tired and progressing at what we think is a faster rate. He should be home resting right now, but we all know Eric is a fighter, and that is why he is working so hard to make a change.”

— Craig Stevens

Eric’s brother, after a trip to lobby members of Congress to aid in fighting ALS

STEVENS

Continued from page A3

path of his brothers Brett and Jeff and became a firefighter.

In March 2019, Eric Stevens noticed he was tiring easily. His left hand felt weak. The fingers didn’t seem to work the way they should. He dropped tools. His left hand slipped off the bar when doing pull-ups. The routine task of deploying ladders with the Los Angeles Fire Department was no longer routine.

He first mentioned the odd problems to Brett while they surfed in Orange County. They joked about not being as limber as their younger days. But the hand didn’t improve. Eric brought it up whenever they saw each other.

One day while working out before Eric’s wedding in July, the man who once was Cal football’s senior lifter of the year and bench pressed 225 pounds 25 times while auditioning for NFL teams could barely raise a dumbbell over his head. The brothers were always competitive. Brett thought he was finally gaining an edge.

Eric’s speech slowed, he struggled to pronounce words and sometimes slurred them. His muscles twitched. The movement continued day or night, waking or sleeping.

“He didn’t want to go see a doctor about it in fear of what the reality actually was,” Brett Stevens said. “He wasn’t ready to face that. He didn’t want people to worry about him before the wedding.”

Eric scoured the internet for answers. Each symptom matched ALS. The motor neuron disease affects an estimated two out of every 100,000 people, typically striking between ages 40 and 70. The average age of onset is 55.

Eric told himself he was in great shape. He ate right. He was helping people

while working at LAFD’s Station 21 in South L.A. He was about to marry former Cal soccer player Amanda Glass. He was just 29. The internet self-diagnosis couldn’t be real.

Brett cautioned against jumping to the worst-case scenario. Maybe an old football injury or pinched nerve lurked behind the symptoms.

Nothing seemed wrong when Eric and Amanda married on a cloudless day in San Luis Obispo on July 27. Former Cal quarterback Beau Sweeney performed the ceremony.

“She is so excited,” Sweeney told the family and friends assembled in front of a white barn, “to start a family one day and can’t wait to watch Eric become an amazing father.”

Three words on the candle label next to the cake summed up the speeches and toasts and smiles: “Happily ever after.”

The couple waited in a neurologist’s office after Eric underwent a battery of tests one month after their wedding. They had honeymooned in Montana, watching bison, fly-fishing the Blackfoot River, riding horses and discussing saving for a house. But they couldn’t ignore the symptoms any longer.

The doctor pecked at his computer without speaking for what felt like a half-hour, then finally turned to them and said he believed Eric had ALS. There wasn’t any treatment. The average life expectancy was two to five years. Paralysis usually came sooner. The color drained from Eric’s face. He almost passed out. Amanda caught him.

“These past few weeks have been absolutely devastating for our family, but we have chosen to FIGHT and if you know Eric you know he will fight HARD,” Amanda later wrote on Facebook. “He is the strongest man I know and if anyone can get through this, it’s him. I know that he will never give up, but I also know that we will need help.”



Robert Gauthier | Los Angeles Times

**ERIC AND** Amanda Stevens started the #AxeALS hashtag and have raised more than \$900,000 on a GoFundMe. “We’re not just fighting for him, we’re fighting for this whole community that’s become our new family,” Amanda said.

They sought a second opinion in L.A., then a third in Boston. Both reached the same conclusion.

“You’re just searching for a different answer, a plan or a protocol to slow it down and there’s nothing,” Eric said. “Everything in my life has been so regimented. Here’s the game plan. This is how we’re going to fix it or how we’re going to approach it. Here are the steps to do it. With this, there’s nothing. You’re on your own.”

At least nine other former NFL players are currently living with ALS. They range in age from 36 to 70, though most are in their mid-50s. Among them is Steve Gleason, the former New Orleans Saints standout whose fight against the disease was chronicled in the 2016 documentary “Gleason” and who earned a Congressional Gold Medal. He uses a feeding tube and breathes with the aid of a ventilator, living in the “glass coffin” that some patients call the disease that slowly robs their ability to walk, speak, swallow and move.

“It’s absolutely illogical,” Gleason tweeted earlier this month. “My physical body is totally useless, yet in this moment I’m completely free. Senseless liberation.”

The total number of NFL players, living or dead, with ALS isn’t known. But the settlement to concussion litigation between more than 20,000 former players and the league provides a hint. The most recent data from the agreement shows

56 players or their estates applied for compensation for ALS — 39 have been approved, 14 are being reviewed for compliance with the agreement’s statute of limitations and three have been denied. The demographics of those claims, including how many of them are living, aren’t public.

“It’s such a horrific disease because they tend to be mentally clear until they’re very, very deep into it because they have this progressive inability to move which makes it very tough to watch and take care of,” said Dr. Ann McKee, chief of neuropathology for the VA Boston Healthcare System and director of the Boston University CTE Center, whose research includes ALS.

Some researchers have suggested that repeated brain trauma like the kind experienced by NFL players increases the risk of ALS.

“At first you’re like, ‘What the heck? Was it football that did this?’ ” Eric said. “No one really has a solid idea. You can’t blame football. Could it have maybe increased my chances of getting it? Maybe. But was it the sole factor? If I didn’t play football would I not have this? I don’t think so.”

The couple searched for a treatment, a solution, a prayer.

Just four drugs have been approved by the Food and Drug Administration to treat ALS symptoms, according to the nonprofit

ALS Association. Two of the drugs might slow the disease’s progression. There is nothing to stop it, nothing to reverse it, nothing to cure it.

When one of their doctors mentioned ongoing clinical trials for ALS treatments last year, the couple’s excitement vanished when they learned about the byzantine process that governs study and approval of such medications. The disease doesn’t work on the same timeline.

Along with friends and family, they poured their energy into raising awareness about ALS and lobbying to remove bureaucratic obstacles to terminally ill patients trying experimental therapies.

“We’re not just fighting for him, we’re fighting for this whole community that’s become our new family,” said Amanda, who quit her job as a second-grade teacher to care for Eric. “No one really understands the feeling of your body failing on you and shutting down and not being able to do anything about it. I’m seeing it happen to him. ... We have an opportunity here to really make noise and hopefully create some change.”

They started the #AxeALS hashtag. Scores of fire departments around the world posted pictures on social media of them posing with the words. They’ve raised more than \$900,000 on a GoFundMe. They made videos. They attended fundraisers. They visited a dozen members of Congress in November to share their story and plead for help to fight the disease.

“Eric is extremely tired and progressing at what we think is a faster rate,” Craig Stevens wrote after the trip. “He should be home resting right now, but we all know Eric is a fighter, and that is why he is working so hard to make a change.”

The novel coronavirus redoubled their efforts. Eric and Amanda rarely venture out in public to reduce the chance of Eric contracting the illness. Friends and family members drop groceries on their porch. The couple watches regulations

be waived or streamlined to address the pandemic and wonder why a similar approach isn’t taken to help the estimated 16,000 people suffering from ALS in the U.S.

“People have told us over and over again that it’s not possible, we can’t do that, it’s out of our hands, and with COVID-19 we see that anything’s possible,” Eric said. “They’ve moved mountains. I mean, as bad as COVID-19 is, the death rate is less than 10%. With ALS, it’s 100%. ... When you’re diagnosed with ALS today, they kind of write you off as a loss because these trial processes take so long. Why not let these people try, right? We know what’s going to happen if we don’t try it, and that’s death.”

There is an urgency to the words and, really, everything the couple does these days. He dropped from 225 pounds to 190 pounds in the last six months as muscles slowly atrophy.

He tries not to think about the disease’s cruel progression, about what he’s lost, about no longer being able to perform basic tasks like tying flies to fish, about the glass coffin. Each morning, after getting out of bed and taking two steps, Eric pauses and says thank you. “I’m grateful I’m still alive,” Eric said. “It’s hard to walk. But I still can walk. So, I’m thankful for that. It’s harder to breathe. But I can still breathe. So I’m grateful.”

In April, Eric and Amanda filmed another video raising awareness about ALS. As part of the effort, they did five pushups in honor of National Pushup Day. Amanda remembered how Eric used to seem like he could do them all day without much effort. These were slow and methodical. He favored his right side each time he heaved upward. His arms quivered on the last one. He didn’t quit.

*Los Angeles Times staff writer Gary Klein contributed to this story.*

**NATHAN FENNO** is a staff writer with the Los Angeles Times.

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