

\$20,000 donation a run-up to Avery's Roar to the Shore

Not a mere drop in the bucket to help defeat unnamed disease

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WESTBROOK » It all began with a \$5 check on a dreary early-April Monday morning at Bill's Seafood at the Singing Bridge.

That was well before Avery's Roar to the Shore, the annual all-day event on Sunday, June 5 at Westbrook Elks Lodge that includes a scenic coastal motorcycle ride, a Classic Car Show, balloon rides,

and a special appearance by Dallas Cowboys Hall of Fame running back Tony Dorsett.

The event is named for Old Saybrook's Avery Rose Leopoldino, 8, who suffers from CDKL5, a rare genetic mutation that has stolen her ability to walk, talk, and use her hands, and subjects her to daily and nightly seizures.

While all proceeds on Sunday will benefit the International Foundation for CDKL5 Research, Bill's Seafood also keeps a bright yellow bucket hanging in its bar for patrons wishing to donate their pocket change to Team Avery, a charity established by the Community Foundation of Middlesex County to raise awareness and afford research funds for the disease.

That was how Avery's father Mark Leopoldino, Bill's longtime manager, came upon the \$5 contribution.

"I don't know why I decided to empty the bucket that morning, but I remember saying to the bookkeeper how nice it was, that someone would take the time to write out a check," he recalled earlier this week while seated at a picnic table on the restaurant's outdoor deck.

Little did he know what would come next.

Around lunchtime, there was a knock on his office door. Bartender Paul "Barney" McMahon told Leopoldino a couple had just put a \$100 bill into the Team Avery bucket. Would he like to thank them personally?



Avery Leopoldino at last year's Roar to the Shore.

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Leopoldino crossed the rain-soaked parking lot and met the two at their hightop table by the bar. He fielded a few questions from them about Avery, about her condition, about the continuing efforts of his family, the restaurant, and the larger community to support research to find a cure for CDKL5.

But only a few questions. Because, as Leopoldino recalled, all at once, "the man turned to the woman and said 'write the check.'" The woman reached into her purse and took out her checkbook. She asked Leopoldino the date, then made out the check and pushed it across the table.

Leopoldino looked at the check. He felt his knees buckle. Tears formed in

his eyes. "I was speechless," he said. "Shocked."

It was for \$20,000. Once he had collected himself and thanked the couple again, he ran to his office.

He called his father. He called the Community Foundation of Middlesex which has raised upwards of \$310,000 since Avery was diagnosed at 2 years old.

Then he rejoined the staff, many of whom have been working with Leopoldino at Bill's for years. "They were so excited," he said. "So emotional. The whole place was buzzing."

All of them recognized that a rare disease like CDKL5 — so rare that it has yet to be commonly identified by a proper name — has little chance of getting research funding, shifting the burden to families already overwhelmed with the 24-hour care it requires.

By then, the couple had finished their lunch and were gone.

"Here were people, perfect strangers, who could do something and did," said Leopoldino. "Just a random act of kindness. And a quiet one."

With that, he looked out toward the Singing Bridge and grinned.

"Every little bit helps," he said. "But to think I was so excited about \$5 just that morning."

Avery's Roar to the Shore will take place at Westbrook Elks Lodge, 142 Seaside Avenue, Westbrook on Sunday, June 5. Rain or shine. Avery at last year's event.

Ride registration takes



Mark Leopoldino and Paul "Barney" McMahon under the Team Avery bucket.

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place from 9:30-11 a.m. Scenic ride from 11 a.m.-noon. Riders \$25, passengers \$10. ReMax balloon rides take place 9-11 a.m.

Open to the public for an admission fee of \$15. Kids \$10. 7 and under free. For more info, visit teamaverycdkl5.com.



Dallas Cowboys Hall of Fame running back Tony Dorsett at last year's Avery Roar to the Shore as official starter.

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