## Fueling hope one gallon at a time for Team Avery



Wilcox Energy rallies for local girl with rare disease

By Lisa Reisman lisareisman27@gmail.com 5 / 3 / 13 WESTBROOK - Last Wednesday was Secretaries Day and like any boss who appreciates his employees, David Foster, president of Westbrook's Wilcox Energy, treated his staff to lunch on the deck of Bill's Seafood just up the road.

But something else happened after their plates had been cleared under the bright, sunny

Wilcox Energy is donating a penny for every gallon sold to Team Avery. Chirstine Hussey photo.

skies, something that began with an idea a year before. Julie Valvo, market-

Julie Valvo, marketing director at Wilcox, had seen propane trucks of other fuel companies painted bright pink to promote breast-cancer awareness.

Wilcox Energy, though, is a decidedly local company, staffed by local

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## **Team Avery:** Wilcox Energy rallies for local girl with rare disease

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employees, and serving a radius of 20 miles from its Westbrook headquarters. Foster had mentioned he wanted to do something to give back to the community.

So, as any astute marketing director of a local company would do, Valvo narrowed her lens.

She knew Mark Leopoldino, the manager of Bill's, the iconic seafood restaurant, where she and her co-workers would be lunching a year later. She knew his young daughter Avery suffered from CDKL5, a rare and devastating genetic disorder that has stolen her ability to walk, talk, and use her hands; that subjects her to seizures that daily and nightly tear through her brain; and requires her parents to sleep four feet from her bed.

She also knew about Team Avery, a group

whose embrace, ever since Avery's diagnosis, has grown to comprise the surrounding communities of Old Saybrook, Westbrook, Haddam, Killingworth and Clinton, and together has rallied to raise both awareness and funding for CDKL5.

The members of Team Avery knew, as did Valvo, that a disease so rare that it afflicts only 400 girls worldwide — so rare that it has yet to be commonly identified by a proper name — has little chance of getting research that someone in our comfunding, shifting the burden to families already overwhelmed with the 24hour care it requires.

Thus sprung the idea that led to Wilcox **Energy's Propane** Division's pledge beginning last spring to donate, finished their clam strips for each gallon of propane they sold, a penny to Team Avery "a penny of hope in every gallon," as Valvo put it. So far

they've raised \$1,452.24. It also offered something more, emblazoning a picture of 5-year-old Avery Leopoldino on each side of its propane trucks that daily motor through the streets of Westbrook. Guilford, Chester, East Lyme, and Deep River, among other towns.

"Every time anyone sees Avery's picture on one of our trucks, every time they see the name of her disease, that's one more person who's aware not just that it exists, but munity, a little girl, is fighting it," said Foster.

"Whether you use propane or not, we hope that makes a difference."

So it was that Foster. along with Valvo and the rest of his staff, having and lobster roll, presented a check to Leopoldino to benefit Team Avery, together with a promise to extend its campaign



Wilcox Energy presents a check for \$1,452.24 from Penny of Hope in Every Gallon Campaign to Team Avery at Bill's Seafood in Westbrook. From left are: Linda Scully, Mary Ellen Damrau, Autumn Bonati, Kathye Bichir, Ruth Ragner, Danielle Doyle, David Foster, Julie Valvo and Avery's dad, Mark Leopoldino. Photo by Christine Hussey.

through 2014. Giving back on Secretaries Day, in more

ways than one. Visit www.CDKL5. com for more information about the disease

and wilcox-energy. com/team-avery for infor- Avery's Fund and mailed mation about Wilcox Propane's Team Avery Campaign. Donations for the awareness and research of CDKL5 should

be made payable to MCCF to Middlesex County **Community Foundation**, 211 South Main St., Middletown, CT 06457.