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Partners in adversity

A Centerport boy with a fatal disease teams up with his school and the star of a documentary to raise funds for a cure

BY MERLE ENGLISH

Special to Newsday

Dylan Thompson is 15 and wants to live to be 100, but he also fears getting older. Each birthday brings with it a scary possibility for the Centerport teenager: It could be his last.

On school days, the ninth- grader is up at 6 a.m. His mother lifts him out of bed and into a motorized wheelchair because he cannot walk. He cannot raise his arms, so she helps him get washed and dressed.

He steers his chair up a ramp in the living room to the dining table for breakfast, and later, still seated in his chair, he is hoisted aboard his specially equipped school bus. He will remain in his chair all day.

Thompson has Duchenne muscular dystrophy (DMD), the most severe form of the disease. "The cancer of all dystrophies," his mother, Gloria Thompson, remarked as she watched her son on a recent afternoon use his left arm to support his right hand to do his homework. The inherited illness affects only boys. It is characterized by rapid progression of muscle degeneration early in life, according to the National Institute of Neurological Disorders and Stroke. Death usually occurs by age 25 from respiratory or cardiac complications.

Dylan was 5 when an orthopedist diagnosed his condition. Unfamiliar symptoms had prompted his mother to get him medical attention. "He kept falling down. At night he would complain he had pains in his legs. He was tired a lot. He stopped walking when he was in the fifth grade," she said.

The diagnosis hit hard. "It was pretty devastating," Gloria Thompson said. "We were told a lot of kids pass on in their teens and early twenties."

Thompson's fervent wish is for a treatment or cure for her son's condition. Currently there is none. But a crusade sweeping the country sparked by a courageous teenage DMD patient has given her hope.

The logo for Mid-Island Y JCC Plainview is displayed on a light blue background with a subtle pattern of white clouds. The text "Mid-Island Y JCC" is in a large, bold, dark blue font, and "Plainview" is in a slightly smaller, bold, dark blue font below it.

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Darius Weems, 19, of Athens, Ga., is at the center of a nationwide, grassroots movement to spread awareness of DMD and sell in one year, ending in September, a million copies of a \$20 DVD: "Darius Goes West," which won 28 film festival awards, including the Audience Award for Best Documentary at the Palm Beach International Film Festival in 2007. Seventeen dollars from every DVD sold will be devoted to DMD research.

The push is to spur research that is said to be sparking optimism in medical circles that a treatment and a cure for Duchenne muscular dystrophy is in the foreseeable future.

Dylan's physician, Dr. Jennifer Semel, medical director of the Department of Physical Medicine and Rehabilitation at St. Charles Hospital in Port Jefferson, and co-director of the Pediatric MDA Clinic there, is among the hopeful.

"DMD is a devastating disease for both patients and families. The researchers have come a long way in identifying the genes associated with the disorder, and many of us are optimistic that we will find a cure for this debilitating disease," Semel said. "For now, oral steroids, physical and occupational therapy and close cardiac and pulmonary management are the mainstay of treatment."

Private money is needed to help fuel the studies, hence the fundraising "Darius Goes West" project. The DVD chronicles first-time experiences -- including white-water rafting in the Grand Canyon, spelunking in Carlsbad Caverns and riding in a hot-air balloon -- that were arranged for Weems when he was 15 and in a wheelchair.

A "crew" of about a dozen of his school mates from Clarke Central High School in Athens, Ga., and some college freshmen friends planned and filmed Weems' adventures during a 3 1/2-week, 7,000-mile, Georgia to California trip in an RV in the summer of 2005.

The crew was fulfilling a request by Weems' older brother, Mario, who asked a friend to look after his baby brother before Mario died at 19 from DMD complications. Crew members felt the DVD and the cross-country trip would be a "great way to teach a whole new generation about DMD."

Hundreds of excited, cheering students greeted Weems on March 18 when he wheeled into the auditorium at Harborfields High School in Greenlawn, one of about 100 schools the "Darius Goes West" team has visited since September, drumming up sales of the 90-minute DVD. "What's up y'all?" Weems said, acknowledging the school's welcome with a broad smile.

Administrators had previously screened the DVD for the entire school. The students raised more than \$5,000 so far with a variety of activities. A rock band competition and a dodgeball contest were held earlier this month, and later members of the boys and girls varsity basketball teams will play the faculty as a fundraiser.

Gloria Thompson is inspired.

"I'm so excited about this whole Darius thing," she said. She is selling the DVD and T-shirts in her neighborhood. "Watching the movie, I realized I have to start doing more to make people aware of this

disease that affects boys," she said. "Dylan is 15 and already lost the walking ability. There are some human trials starting now; I would like to see if Dylan can get into any of them. We want to make sure they find a cure that could save his life, and he could live for a long, long time."

A teenager's strength

The teenager takes strength from Weems' poise in the face of DMD's ticking time clock. He was in the Harborfields auditorium when the older teenager told the assembly that he plans a rap music career, although he is at the age when his older brother died.

"This is his brother's year of dying, but Darius sees it as his year of living," said Callie Oettinger, a spokeswoman for "Darius Goes West." "People often say to him, 'What's it like if you're dying?' and he'll say, 'We're all dying.' He lives like he's living and not like he's dying."

Weems, who won several awards for courage and maintaining a positive outlook, told the Harborfields students, "You don't have to be down because of your condition. You can get up and do something about it."

Duchenne muscular dystrophy is the most common fatal genetic disorder diagnosed in childhood, according to Parent Project Muscular Dystrophy (PPMD), the largest nonprofit organization in the United States leading the fight to end the disease. DMD affects about one in every 3,500 live male births, and there are about 18,000 to 20,000 young men with the illness in the United States.

"Approximately 35 percent of cases occur because of a random, spontaneous mutation, so it can affect anyone," said Pat Furlong, founder of PPMD. Furlong lost two sons, ages 15 and 17, to the disease. She spoke confidently of a promising outlook. "Within three to five years we'll be treating this disease," she said.

Dylan is about 4 feet tall and weighs 90 pounds. "He needs help every day with things like going to the bathroom, using the shower, getting dressed and going to bed," his mother said. An ache in her back from lifting him "is starting to affect me," she said.

A mechanical lift would ease the strain, but Thompson cannot afford one. She left her job as an interior decorator at Saks Fifth Avenue to take care of her son when he got sick at age 5. A divorcee, she lives on child support and her earnings from babysitting. Several aides Suffolk County provided quit one after the other. "We went through like five aides," Dylan Thompson said.

His social life is limited because Gloria Thompson cannot buy a \$30,000 to \$50,000 customized van to transport him. He comes home from school, has a snack, does his homework, eats dinner, then sits before the television or listens to music, interacts with his Facebook pals, or plays video sports games. He cannot visit a friend with DMD who lives nearby, but he has many friends at school where his sister, Deanna, 17, is a senior.

There, Dylan thrives in a supportive atmosphere fostered by the principal, Dave Bennardo, school psychologist Anita Quiett and the rest of the staff and students.

The school district provides an aide to hang up his coat, get him to classes and take out books from his book

bag. Another aide accompanies him on the school bus, and he gets his physical and occupational therapy at the school.

Managing sports teams

A sports enthusiast, Dylan Thompson requested and was given the responsibility of managing the boys varsity basketball and girls varsity softball teams. Sports is his passion. "Before I was 5, I played soccer," he said.

As the girls varsity softball manager, "I go and watch and am in charge of the clock," he said. "I sit with the team and the coaches. I feel like a teammate." Sports would be his choice for a career. "I might have liked to play professional basketball or football . . . anything in sports," he said.

His affirming life to the extent that he can is heartening for his school community.

"Dylan has been able to have us find inner strength we never knew we had," Bennardo said. "He helped teach us what's important. The kids love him. All 1,100 students saw the movie and decided they wanted to raise money."

Quiett said, "The students knew what Dylan has, so they were really enthused about raising the money. My role has mainly been to support him in being able to do the things that he wants to do. He's a kindhearted person whose smile is endearing."

His friends are pulling for him. His ninth-grade classmate and neighbor, Danielle Roche, said, "He's one of the nicest boys I've ever met. Everyone loves him. I hope that through the money they're raising . . . that he'll be able to walk again and live longer."

All of this is comforting for the boy's mother. "I'm so happy that I'm in that district," Gloria Thompson said. "Everybody is so supportive of Dylan's needs and my needs for him," she said. "I've had a difficult time after the divorce and everything. He's a shy kid. He feels like people are always staring at him. He comes out of his shell at the high school."

Despite his physical challenges, Dylan doesn't complain. He wears glasses, because the disease affects his eye muscles. He could develop cataracts. "That's something we have to look for," his mother said. His legs are permanently bent from sitting, but he is happy to have his "power" chair.

"I want to feel independent," Dylan Thompson said. "I didn't want someone to push me around. I want to go where I want to go. I can stand in it, I can lay down, tilt the back. It can also lift me up, like to reach stuff."

He lost his ability to lift things, but Mallie, his blonde, golden retriever provided by Canine Companions, is trained to pick up things off the floor with her mouth. "She understands 40 commands," Dylan Thompson said proudly.

Dylan has had one dream come true. On Oct. 16, 2007, his birthday, the Make-A-Wish Foundation made it possible for him to watch filming of an episode of the television series "Smallville" in Vancouver, British Columbia.

His mother has a wish of her own: the customized van. "It would mean I could do after-school stuff without having to worry about a bus." (Gloria Thompson said Dylan's dad, Paul, who has an accessible van, spends time with Dylan every other weekend and takes him shopping or to sports events.)

She would also like to have her two-bedroom house made accessible for her son. Mark Gunthner, owner of a Hauppauge restoration company, is seeking contributions and will donate services to build handrails and ramps, widen doors, and add another bedroom.

Mother and son are bearing up under their hardships, buoyed by the "Darius Goes West" movement. Dylan wants to emulate the celebrated teen.

"With my friends, we're trying to plan an adventure across the country, like Darius," he said.

"Where are you going?" asked his mother.

"I don't know mom," Dylan said. "I have to figure this out. I just want to end on that note."

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