

Caregivers—heroes among us



Jim Williams

Every day we live and work with people who are true heroes in our world. No, I'm not talking about the firefighter who sacrifices his or her life so that another can live. Nor am I thinking about the police officer who protects those who cannot protect themselves. I'm not even referring to those carriers we read about in *The Postal Record* who perform feats of bravery. All of the folks described above are recognized as heroes by our society and we do not take them for granted. Their efforts are appreciated by us all.

But there are people who toil in silence to help those who cannot help themselves in even the most basic ways. They put their lives on hold to give care to those who many times cannot walk, brush their teeth or use the toilet.

The plans for the future they once had are irretrievably altered when their loved one is diagnosed with muscular dystrophy.

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...rifice, will never be honored by a parade, and will not be remembered by the public.

Yet they are heroes in the true sense of the word. The dictionary definition is revealing. A hero is “somebody who commits an act of remarkable bravery or who has shown an admirable quality such as great courage or strength of character.”

Here is a story of one such hero.

When Vance Taylor was a boy, he didn't know any adult he could look to and say, “There's somebody like me.”

His mother, Morena Noyes, recalls the first time she took Vance and his sister Kathy—both of whom have limb-girdle muscular dystrophy—to MDA summer camp.

“We were still in the parking lot, in our Astro van,” Noyes says. “Vance looked, and then he turned to his sister and said, ‘Kathy, there are people like you and me here!’ He was just beaming.”

Today, Taylor, 33, is married and has two young daughters. A graduate of Brigham Young University, he holds a master's degree in homeland security and is a partner at a top consulting firm in Washington, DC. A full-time power chair user,

he lives in the Virginia suburbs and commutes to work using public transportation for people with disabilities.

Taylor has grown up to be the role model he never had. But as he makes clear, he didn't get that way on his own.

He credits his mother with instilling in him the values and determination he needed to become an independent adult despite his disability.

“She's a rock,” he says simply of Noyes, a Salvadoran immigrant and single parent whose husband abandoned her after learning that two of their three children had muscular dystrophy.

Although it wasn't easy, Noyes—just like many other parents of independent adults with neuromuscular diseases—did what she had to do to prepare her children to make it on their own. Taylor recalls that in his darkest moments, when he was off at school by himself and feeling discouraged about his future, he would telephone his mother.

“Don't worry, it will all work out,” Morena Noyes would say, after listening to Vance's troubles.

“How do you know that?” Vance would ask. “Because it has to,” she'd say. And it has.

When Vance and his sister were first diagnosed, Noyes says, the doctor told her they may not live long. He advised her to not worry about getting them through high school, let alone college.

“I thought, only God knows when and how,” Noyes says. “In the meantime, I'm going to do my part.”

Because she valued education, Noyes taught her children to be bilingual in Spanish and English, to work hard and do their best in school, and to understand from an early age that they were expected to go to college.

“I always asked them, ‘Which college do you want to attend? What do you want to study? You will not have your physical strength, so it's extremely important to have mental strength.’”

“I told their teachers, ‘Don't go easy on them. What I want you to do, if you're giving 50 problems a month for homework, maybe give them 30. Because it's difficult for them because of the writing. But other than that, they need to have a solid education.’”

Morena Noyes is just one example of the many parents of a child with MD. Heroes come in all shapes and sizes, ethnic groups and situations. All I know is, every child who benefits from their courage and commitment will never be the same, and that is the mark of a true hero.

An update to MDA Honor Roll

As usual, some of the numbers were reported in error even though we asked our NBAs to check. Please be advised that Boston Branch 34 should have had \$22,000 listed, Louisville, KY Branch 14 should have had \$12,311 credited to it, and Freehold, NJ Branch 924 garnered \$2,002. Thanks to all those who worked to raise funds.