

Illness Spurs Life of Achieving

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Eighteen-year-old Amanda Bory steers her wheelchair through the halls of Perry Hall High School before graduation with the precision of a race car driver. She does it effortlessly. She never asks for help, and a wide smile seems to indicate it's all under control.

When she tells her story, she paints a panorama of illness, surgeries, pain and optimism. Despite suffering from a debilitating disease, Amanda created a program to benefit sick children, earned straight A's in school, and adopted an orphanage in South Africa.

Amanda's story begins with a childhood incident that changed her life forever.

"When she was about 18 months old, Amanda was playing in the back yard with a little neighbor boy," said her mother, Mary Jayne Bory. "He pushed her as kids do, and she fell down. He didn't push her hard, just playfully. She just lay on the ground and screamed. We couldn't figure out why she seemed to be in so much pain."

Mary Jayne Bory and her husband, Bill, took Amanda to the hospital. The diagnosis was a spiral fracture to the femur (the bone that runs from the hip to the knee). Even more shocking was the cause - McCune Albright Syndrome.

The high school senior suffers from the rare disease, which, according to Amanda, has only about 50 diagnosed cases in the United States.

Amanda, who's well-versed in her disease, said it weakens her bones. She said that small holes form in the bones, which fill with a jelly-like substance, a condition known as fibrous dysplasia. Other symptoms include early puberty and a rapid rate of growth at an early age that abruptly stops.

"No one is sure of the cause," Amanda said. "It's a mutation of a gene. Something just goes wrong. There's very little precedent for the disease. The one thing we know for sure is that it's incurable."

"My illness has helped me turn obstacles into opportunities. It makes me run 100 miles an hour because I don't know when things will stop for me."

Some days she feels like things will stop sooner than others. Every day Amanda faces excruciating pain. She has to be careful wherever she goes. A slight bump or hit can break a bone; she has found that out the hard way. When she makes plans to go with friends to a movie or other activity, she has to plan ahead.

"I have to think about the doors, elevators and wheelchair accessibility," Amanda said. "If there aren't elevators, I have to come up with alternatives. I can't stand for a long time. I have to walk with a cane or use my wheelchair."

A full schedule

Amanda does the things that matter most to her. At school, she's on the student council; is editor in chief of *The Vignette*; and a member of the class senate, the National Honor Society, the Music Honor Society and Quill & Scroll.

In her spare time, she does what she can to help others - especially sick and needy children.

"I feel like through all my experiences I have a responsibility to give back to my community," Amanda said. "When I feel most empty, I give and that fills me up again."

Her life experiences have sparked ideas for ways she can give.

Amanda has had seven surgeries, five of which required a full body cast. Her parents bought a hospital bed to use downstairs in their home. These aren't the things Amanda remembers most. What she recalls most vividly is how scared she was when they took her to the cold, dark, surgical rooms - alone.

"I remember being scared and wanting my parents," Amanda said. "So my Mom and Dad would sleep with my blanket before a surgery and give it to me to take with me when they took me back. I could smell their perfume and cologne, and it made me feel better. It was like a fuzzy hug from my parents."

Amanda used her experience to make life easier for other kids with illnesses with a program she affectionately dubbed "Fuzzy Hugs."

"I called Oak Crest Village [retirement community] and asked if they would like to knit or crochet some blankets for my program," Amanda said. "They generously offered to help out. When I went to pick them up, they had made like a hundred blankets. There were all sorts of them."

Amanda took the blankets to the Kennedy Krieger Institute's PACT day care program for sick children and Harford County Social Services.

Audrey Leviton, executive director of PACT, said the blankets were a hit.

"We talked to the parents before Amanda came to the center," Leviton said. "We wanted everyone to know what we were doing. But everyone loved the idea, and the kids love their blankets. I have moms telling me their kids won't let anyone take their blankets. And I think it's inspirational to the parents of the kids because they worry about their sick children, and when they see what Amanda's doing ... it gives them hope."

'Just wonderful'

Amanda recalled one child who felt right at home with the situation.

"I went into the center in my wheelchair and we brought the blankets in for the kids and let them pick one out," she said. "Their little faces were priceless. One little girl came up and picked out her blanket, climbed into my lap and fell asleep. It was just wonderful!"

Amanda has more blankets to donate and deliver to other places through the program. She hopes to continue to make other kids feel better for as long as she can get blankets.

Another activity she calls "Cocoa Grams" benefited local cold weather shelters. She filled insulated cups with cocoa, put notes on them and gave them to the shelters. She also helps prepare meals for families using the Ronald McDonald House at the local hospital.

In addition to her volunteer efforts, Amanda was able to maintain her grades.

"Amanda would come home in a full body cast," said her mother. "She would have to keep it on for about three months. When she finished she had to go through rehab and then learn to walk again. As I watched her deal with her pain, I saw a different side of life. She never gave up. She was so brave. She would do her homework upside down. She couldn't turn so she had it on a tray above her face instead of beneath it on a table."

Amanda's hard work resulted in her graduating fourth in her class of more than 550 students. She earned straight A's.

During her hard work and on top of her volunteering, Amanda came up with yet another idea about a year and a half ago while watching The Oprah Winfrey Show.

"Oprah was airing her Christmas Kindness shows in December," Amanda said. "Oprah had gone to South Africa and visited an orphanage called God's Golden Acre. I watched the show and cried. I decided I wanted to try to do something to help those kids. I contacted someone at the orphanage and asked what they needed."

Amanda learned that 70 children lived at the orphanage, but that it helps more than 4,000 kids in the area. They sent her a long list of items needed.

"I wanted to continue what Oprah started," Amanda said. "I thought I would give other kids a chance to help, too."

Amanda contacted the five schools in her area and asked whether they wanted to help gather donations for the orphanage. All five schools agreed.

"We received 26 boxes of books," Amanda said. "A local shipping company paid to ship them. We also received baby items, toys, stuffed animals and toiletries. Perry Hall Middle School is doing a school supplies drive. Perry Hall Elementary School donated 40 lap chalkboards, and we bought 210 pairs of flip-flops."

To raise money for shipping the items, Amanda organized fund-raisers.

"We did basket bingo and raised about \$3,000," Amanda said. "We also made crystal angels at Christmas and raised more. We have about 90 boxes to ship and are still getting stuff. We are trying to figure out how to get the rest shipped."

As Amanda sits back, her mom pitches in her side of the story.

"Amanda is so active and so giving that people sometimes forget that she doesn't know what it feels like to be a normal, healthy kid," Mary Jayne Bory said. "She doesn't know what it feels like to run or go to dances. She doesn't know what it feels like to not be in a wheelchair."

"Amanda knows she doesn't have control over God's plan for her, but she also knows she does have control over her reaction to it."