Cystic Fibrosis Fund awards vests to siblings with the condition

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Monique Ortega, 24, and her brother Javien Ortega, 8, try on their donated AffloVests, which will help them battle cystic fibrosis, during Saturday night’s 19th annual Cystic Fibrosis Valentine’s Gala at the DoubleTree by Hilton hotel in Reading.

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There were many donors and important figures at the cystic fibrosis gala in Reading on Saturday but the real star was a 8-year-old boy with a huge heart.

The banquet room at DoubleTree by Hilton Reading filled with applause as hundreds of people cheered and stood for Javien Ortega after they heard his story of generosity in the face of his own pain and difficulty.
At Christmas, while Javien was being treated for cystic fibrosis at St. Christopher’s Hospital for Children in Philadelphia he wrote to Santa and asked for $1,000 for the homeless.

He ended up raising $2,500 for Opportunity House, emcee Brian Boland told the crowd at the 19th annual Valentine’s Gala to benefit the Cystic Fibrosis Fund of Berks County. The annual benefit is held by the Berks County Community Foundation.

But Javien didn't just receive accolades. He — and his 24-year-old sister Monique who also has CF and was in the hospital over Christmas — received a bit of freedom in the form of an AffloVest, which cost about $17,000 each.

AffloVest is a custom-fit portable device that shakes out the mucous that builds in the lungs of patients. The mobility means they aren't tied to tubes and compressors.

One of the vests was purchased by the Cystic Fibrosis Fund of Berks County. The other was donated by the vest’s manufacturer, Biophysics.

Sarah Ortega, Javien and Monique's mother, said her family felt grateful.

"It's all about courage and strength," she said, surrounded by her husband, Javier, and her children Javien, Monique, Melanie and Javier Jr. "We come together as a team. We do everything as a team."

She thanked everyone who has been with her family on their journey. For years, they have lived with cystic fibrosis without a lot of attention.

"Javien is amazing," she said. "He's a fighter. He's strong. He keeps us together."

Ryan Gombar, whose daughters received AffloVests last year, joined the Ortegas on stage.

"You don't realize it but it's freedom like you won't believe," he said. "My daughters have more freedom than I could ever imagine they would have."

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