

18-Year-Old EGPA/Churg-Strauss Patient Avery Becker: Helping Others From His Hospital Room

By John Fries for the Vasculitis Foundation

Like other 18-year-olds across the country, Avery Becker of Aurora, Colorado was really looking forward to his senior prom on May 27. He'd made all the arrangements--tuxedo, corsage, car, restaurant. Most importantly, he'd secured a "yes" from a pretty classmate when he asked her if she would be his date. Everything was in place, and Avery was eagerly anticipating the special night.

Unfortunately, as the song says, life is what happens when you're busy making other plans. On Saturday night, instead of dancing with his date under a mirror ball and lots of colorful streamers, Avery found himself in the intensive care unit at Children's Hospital Colorado, his mother, Pamela, at his side.

For virtually all of his young life, Avery has been fighting, managing and coping with eosinophilic granulomatosis with polyangiitis, also known as EGPA/Churg-Strauss Syndrome (CSS), one of the rarest forms of vasculitis. CSS mainly affects the smaller blood vessels and can be accompanied by one or more of a variety of serious side effects. Two days before the prom, Avery suffered a severe medical episode and had to be taken to the hospital immediately for treatment.

"It was really scary," said Pamela. "He was admitted right away. At first, he was on the regular floor due to sepsis; his meds cause him to become immuno-suppressed. Two weeks later, he again became septic, went into septic shock and almost died. At that point, he was transferred to the ICU."

During his 18 years, Avery has become accustomed to lengthy hospital stays, spending more time there than at home due to a disease that seldom afflicts people in his age range. For most patients, CSS doesn't show up until around age 50. According to his mother, since last October, Avery has been confined to a room at the hospital for all but four days.

"Because of his illness," she said, "he was unable to attend his sister's wedding in January--the only one of my five children not at the church or reception. And the opportunity to go to the prom meant so much to him. In fact, as a gesture of support, the doctors and nurses who take care of him even signed the tie he was going to wear that night."

In Avery's case, being confined to his hospital room means confinement. "Because of the fragility of his condition," said Pam, "he can't leave his room. He's not allowed to walk the halls, visit the gift shop or even stop by the nurses' station." It's a lonely existence for such a friendly, outgoing young man who connects easily with people and has developed friendships with many of the hospital's doctors and nurses," Pam said that Avery's ingenuity has provided him with a way to meet and bond with hospital staff.

"He likes to sing," she says, "so he began singing loudly as a way of attracting visitors to his room. They hear him, stop in and often sing along with him. Before you know it he's made another new friend. His father and I encourage him to make his life as good as it can be, and to make a difference."

Such an existence would frustrate anyone at any age, but Avery, whose Christian faith and optimistic attitude are strong forces in his life, keeps a smile on his face. And, following his mother's encouragement, he finds ways to make a difference in others' lives. Earlier this year he established a Walkathon to raise funds for CSS research.

"He asked one of his doctors how much money would typically be needed to fund a medical research project," said Pam. "The doctor estimated that the cost would probably be between \$10,000 and 50,000. So Avery developed a plan to raise funds for CSS research and set a \$10,000 goal."

Avery also decided early on that the Vasculitis Foundation should receive the raised funds, due to its long history of raising funds to support medical research related to vasculitis. We greatly appreciate his consideration of our efforts, especially in light of the current and recent projects. In 2015, through the generosity of Ben and Kathy Johnson, we were able to provide \$98,000 in funding for two major research projects focused on EGPA/Churg-Strauss Syndrome. One is a two-year study, now underway, led by Davide Martorana, PhD, at the University Hospital of Parma in Italy. The other, a one-year project, is being conducted at McMaster University in Toronto, Canada under the joint leadership of Manali Mukherjee, MD, and Nader Khaladi, MD.

Early this year, Avery began planning the CSS awareness and support campaign from his hospital room. The idea was to encourage people to walk for their own health while raising funds for CSS research. Avery committed to leading the campaign by example by walking himself. To do this, he would need a treadmill in his room, and it wasn't long before one was donated. The campaign also needed a name, and one of Avery's physicians suggested calling the event "Walk With BRAVERY," noting that Avery's name is synonymous with, and part of the word, "bravery." Facebook and Go Fund Me pages were set up to create awareness, provide Avery and his family with platforms for interacting with participants and collect donations. Participants were asked to walk, cultivate per-mile sponsors and donate their funds and miles, or simply make donations.

"Walk With BRAVERY" was launched online in early March 2016 to an enthusiastic response. Since then, more than 800 people all over the world have walked for CSS, many wearing "Walk With BRAVERY" t-shirts. Although the campaign hasn't yet reached its financial goal, Pam says that she and Avery are extremely grateful for the outpouring of support they've received so far.

Although Avery, not wanting to be the center of attention, tends to deflect a lot of the praise he receives for his efforts, his mother is glad that he's able to be so sunny and positive in the face of what's been lifelong adversity. "He never complains and never feels sorry for himself," she says. "He just finds ways to turn bad things into good things."

She's especially proud that her son--whose disease has, sadly, caused him to miss out on so many of the fun childhood and teenage experiences most young people enjoy--is directing his energy into trying to help others who suffer from CSS.

"A lot of people have been posting messages online about this 18-year-old who's bringing the Churg-Strauss community together," she says.