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Don't Underestimate Her: Desire to Excel Helps Kentucky Cadet Cope with Life-Threatening Genetic Disease



Cadet Col. Meagan Miller — like her fellow recipients of the Gen. Carl A. Spaatz Award, Civil Air Patrol's top cadet honor — knows about achievement. A sophomore in the Honors College at Northern Kentucky University in Highland Heights, Miller majors in cybersecurity and information technology with minors in computer science and music. She plays bass clarinet in her college band and church choir.

In high school, she competed on the archery team and was an award-winning musician in the band. She's a unified partner for the Special Olympics. And she knits. She's working on an online shop to sell the warm woolen goods she has made.

A member of the Kentucky Wing's Boone County Cadet Squadron, she crafts monthly online aerospace education quizzes to keep fellow cadets engaged.

There's another facet to Miller's story. She has accomplished all this and more while dealing with an ultrarare disease, Shwachman-Diamond Syndrome — a chronic, potentially life-threatening, genetic bone marrow failure syndrome with a predisposition to developing acute myeloid leukemia, a type of blood cancer.

Statistics show 30% of patients with SDS will develop AML by 30, with the percentages increasing with age. The average life expectancy of individuals with SDS is 37, though some die as toddlers while others live into their 60s.

To top it off, Miller experiences chronic leg pain and is slowly losing her ability to walk. She isn't sure what's causing that to happen, as mobility issues aren't usually a symptom of SDS.

"I use a cane to walk when it's a long distance or I'm having a bad day," she said.



But if you understand nothing else about Meagan Miller, know this: While her disability impacts her life, it doesn't define her.

There are no pity parties in the Miller household — just a relentless drive to achieve and help others to do the same.

Miller, now 20, launched her Civil Air Patrol journey at 12. Her mom — Capt. Pam Miller — pushed her to participate in an all-girls aerospace science club at Northern Kentucky Makerspace, a STEM-focused event celebrating innovation and technology.

"Our last meeting was flying drones at the local CAP squadron," she recalled. "I was the only one who showed up, and I just kind of stuck around after that." She signed up in July 2012.

As with many cadets, CAP brought the usually introverted Miller out of her shell, giving her a place to belong.

"Especially when I was younger, I struggled with the social aspect of trying to hang out with a group of people," she said. "That's something that CAP patched up for me.

"I figure that's probably something that kept me in, because I didn't feel like there was anywhere else that I actually belonged."

The higher she moved up the ranks, the more national opportunities she found for involvement, like seeking the Spaatz award and taking cyber security courses. She has served on staff for CAP's cyber-related National Cadet Special Activities.

Along with Miller's unquenchable thirst to excel, her story cannot be told without her parents. They refused to coddle or cloister their daughter and her brothers, two of whom also have SDS, even with the knowledge that their health could dangerously decline on a dime.

"We didn't want the marrow failure to define who they were," said Capt. Miller, who's the Kentucky Wing's director of administration as well as the Boone County squadron's deputy commander. "So we pushed Meagan and her brothers to do everything they could while they were able to do it, knowing that at some point, their health could take a turn that would make some of the stuff impossible anymore."

For Capt. Miller and her husband Randy, it was a case of playing the hand you're dealt.

"It's not what we wanted for our children. But it's what we were given with our children. So you've got to make the best of it," she said.

The Miller children have been able to chase their dreams — a chance many children with the disease don't get, Pam Miller said.

"We've been very lucky from that perspective," she said.

So her daughter continues to achieve, spitting in the face of SDS. But there's another hurdle to clear — a world that, acting on incorrect assumptions, closes doors to individuals with disabilities who want only acceptance and a fair shot to achieve, love, and live their best life.



And in Miller's case, she hasn't taken the easy path. When it came to the fitness portion of the Spaatz exam, she asked for only one break — a waiver of the 1-mile run. For Meagan, pursuing the top award seemed the natural thing to do.

It's important to note that she was training for the 1-mile run with her high school running club, unaware of the possibility of a waiver, until Col. Jaimie Henson, the Kentucky Wing commander, suggested it. Henson has known Miller since her first cadet meeting.

"She does not give up on herself," Henson said.

Henson has worked with youth for decades, in capacities ranging from a Girl Scout leader to soccer referee to choir director. Miller's story illustrates that the organization meets every kid where they are, from the jock to the clarinetist in the band to the computer wizard.

"It goes to the absolute core of what the human experience should be," Henson said. "That is, taking people where they are and getting them to a better place, but still in their world. They don't have to be part of my world to be successful.

"That to me is the absolute illustration of what Meagan has done. She succeeded in her world on her terms."

"She just seems to take everything that was thrown at her. I found her selflessness and her resilience absolutely inspiring."

Maj. Gen. Edward D. Phelka

Henson added, "She didn't give an inch. She didn't cut corners. It was 100%, all the time."

And even if Miller wasn't coping with the challenge of SDS, the wing commander said, she would still be an outstanding cadet.

The naysayers provided an unexpected spark along the road to a cadet's highest honor. The critics in their ignorance decided what her abilities were.

"I faced a lot of people thinking I was not good enough, or I was not worthy because I'm not a particularly outgoing person," Meagan said. "People underestimate my abilities. Part of what kept me going was the desire to prove them wrong."

She added, "I was tired of all the years of people telling me I wasn't good enough. I wanted to prove to them that I was."



Her story caught the attention of Maj. Gen. Edward D. Phelka, CAP national commander/CEO, himself a Spaatz recipient. He traveled to Kentucky to personally present Miller's Spaatz award.

He calls her "inspirational."

"She just seems to take everything that was thrown at her," Phelka said. "I found her selflessness and her resilience absolutely inspiring."

He added, "She clearly demonstrates that volunteer service on a regular basis. Where she could be focused on her own achievement, she takes what she's learned, and she makes it available throughout the country through aerospace quizzes. ... She's embracing the Cadet Oath and being of service to others."

Cadet Oath

"I pledge to serve faithfully in the Civil Air Patrol cadet program and that I will attend meetings regularly, participate actively in unit activities, obey my officers, wear my uniform properly, and advance my education and training rapidly to prepare myself to be of service to my community, state, and nation."

Meagan acknowledges that her mobility issues mean there are some things she cannot do, and she sometimes struggles with the notion of inspiring others.

"I'm not doing things to be an inspiration and all cool. I'm not doing things to be all cool and 'Hey look at me, I can do this.' I'm just trying to live and do my own thing," she said.

"If people want to take that as inspiration, I guess, sure. But if there's anyone I want to take what I've done as an inspiration, it's people who have struggles too."

Asked if she felt she had been handed a bad break, Miller, who was diagnosed with SDS at 10, was matter of fact.

"I guess some people could view it that way. But honestly, it's all I know," she said.

So even with her chronic pain and mobility issues, Meagan Miller pushes on, often beyond the limit, doing her own thing, knitting together a good life.

"She just wants to keep overachieving," Pam Miller said.

Miller, who serves as administrative officer for the Kentucky Wing, tells a story about her daughter's visit with Phelka the day before the Spaatz presentation. The commander asked the cadet what she wanted to do next.

"Nothing is too big. Keep going. Keep trying and you will achieve your dreams."

Cadet Col. Meagan Miller

"She said, 'I just want to help other cadets do this.' Pam Miller recalled. "For her, it's about paying it forward and helping the next batch of cadets.

"It's like with SDS, we participate in every study she can be in. It may not help her, but it may help other people in the future."

Her daughter's credo is simple:

"Nothing is too big. Keep going. Keep trying, and you will achieve your dreams," she said.

She added, "Don't underestimate people who aren't necessarily the same because we're able to do things. It's just a matter of 'Will you let us?'"

The essence of Miller's story?

"The only limitations a person has are those they place on themselves. It didn't matter what was thrown at her, she overcame it."

Paul South

Contributing Writer

For more information on Shwachman-Diamond Syndrome, or to contribute to research, visit shwachman-diamond.org. Capt. Pam Miller is the executive director of the Shwachman-Diamond Foundation.

Here is [an eServices link](#) to Miller's Monthly AE Quizzes.

This profile of Cadet Col. Meagan Miller of the Kentucky Wing's Boone County Composite Squadron is 22nd in [a regular series of articles](#) showcasing how CAP and its members make an impact in their communities and throughout the nation.

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