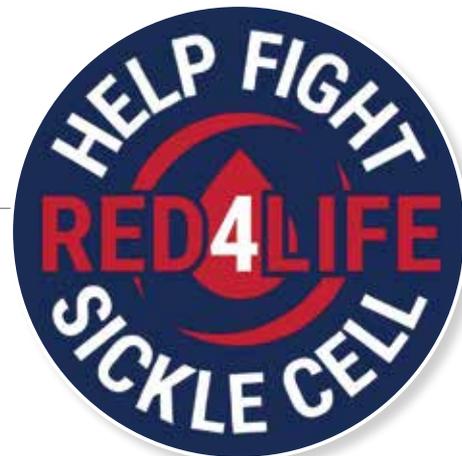


Stronger Together: Red4Life Program Advocates for Sickle Cell Warriors

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ImpactLife, an AABB institutional member, launched its “Red4Life: Sickle Cell Program” in 2021 to increase awareness, education and diversity among donors most likely to be an appropriate phenotype match for patients with sickle cell disease (SCD).

SCD affects approximately 100,000 Americans and millions of people worldwide. The inherited blood disorder occurs in 1 of every 365 Black births, impacting the African American community at a disproportionate rate. The ImpactLife Donor Relations team uses the Red4Life initiative to increase engagement with Black community organizations. Under the auspices of this program, ImpactLife has initiated support from and are doing blood drives with influential groups, such as 100 Black Men, the Urban League and Harris-Stowe State University, and has engaged in advertising campaigns with Black-owned media to help reach targeted communities and build credibility and awareness for the program.

In addition, the program uses a social media toolkit, presentations, educational material and sickle

cell warrior testimonials to expand its reach and increase the volume of blood components available for patients with sickle cell disease.

“The Red4Life program addresses one of our most important challenges, which is ensuring that the diversity of our donor base matches the diversity of the communities we serve,” stated Andrea Cole, manager, regional development at ImpactLife. “Volunteer donors give blood because they want to help save and improve lives in their community, and our Red4Life outreach helps us reach the right people with the right message, and this has helped us increase the number of donors who are an appropriate match for patients with sickle cell disease.”

AABB News spoke with sickle cell warriors Tiffani Jackson and Ashley Reed about their sickle cell journey and how the Red4Life program has impacted their lives. Learn more about their journeys below.



Tiffani Jackson – Beating the Odds

“I’m grateful for ImpactLife’s Red4Life Sickle Cell Program for raising awareness and providing relief for people with SCD.”

Because of SCD, Tiffani Jackson, 25, spent much of her childhood in hospitals, which resulted in homeschooling to monitor her health. Her hospitalizations increased while attending college due to her intense workload. However, Jackson refused to let the disease slow her down. She pursued a journalism degree, and in 2018, she founded Illinois State University’s first Black news team, training 20-30 new students in journalism skills each semester. Jackson said she hopes her story will inspire others.

“With sickle cell, you grow up hearing so much about life expectancy and limitations, which impacts your happiness. You have to decide if you’re going to beat the odds,” Jackson said. “I don’t want to just be remembered for having SCD. I want to be remembered for doing something that impacts others. I’d rather make the world a better place with my purpose than let a disease tie me down.”

Since starting her journalism career, Jackson noted she’s been able to encourage other sickle cell warriors with similar career aspirations. “They didn’t think it was possible to do this because of the challenges we face, but having a disease doesn’t mean you have to be restricted all your life. That’s why I go hard at everything I do,” Jackson told *AABB News*.

Battling Misconceptions

Jackson noted she frequently fell behind in college because of monthly hospitalizations. The misunderstanding with professors opened her eyes to the need for education about SCD on college campuses.

“It’s very hard to explain how serious SCD is and how you can have a crisis out of nowhere. Teachers don’t always understand, especially if it’s a White teacher or someone who doesn’t know about diseases that impact people of color,” Jackson said. “Most teachers think you automatically make a recovery, but it’s a process.”

Patients with SCD also face stigmas in health care settings due to implicit bias, she pointed out. “Not all health care providers understand SCD, or they have misconceptions about it, which is extremely difficult. They think you’re a drug addict because you constantly ask for medicine, though medication is an option for alleviating pain.”

Jackson encourages sickle cell warriors to advocate for themselves in every situation. “You have to be brave enough to deal with the hardships of being misunderstood and stand up for yourself, even in the hospital setting. Medical professionals are supposed to be the ones caring for you, but not everybody has taken away their bias, so sometimes you must be the one to educate them on how you should be cared for,” she said.



Jackson collaborates with ImpactLife to host blood drives and raise awareness in her community.



Jackson has received many blood transfusions throughout her journey as a course of treatment.



Power of Transfusions

Jackson, who describes a sickle cell crisis as the tip of broken glass stabbing her bones, said blood transfusions provide her with immediate and long-term relief and help to alleviate pain.

“A lot of people with SCD would be suffering constantly without transfusions, but now we have a treatment to look forward to,” she said. “A sickle cell crisis can be life-or-death. Being able to get a blood transfusion can help prolong your life after having a crisis. The moment you get a match and a donor with

your blood type, you think, ‘Wow, I could live a little longer and I don’t have to keep suffering through this pain, because somebody else thought enough about me to want to donate.’”

Research shows the best match for a blood transfusion is from a Black donor. However, the number of patients with SCD needing blood transfusions exceeds the number of Black blood donors. Increasing blood donations in the Black community begins with education to eradicate legitimate fears, Jackson said.

“The fears within the Black community regarding medical settings are not unwarranted because of the history of medical racism in this country, such as the Tuskegee Syphilis experiment. It can make it hard to think beyond self and help others,” Jackson stated. “Education is the first step. The knowledge gained after hearing other people’s stories can also motivate people to get involved and make a difference.”

Making an Impact

As a Red4Life advocate, Jackson collaborates with ImpactLife to host community blood drives and share

her sickle cell journey to raise awareness. She said volunteering with ImpactLife reminds her that she’s not alone.

“I didn’t know there was a specific program dedicated to helping people who have debilitating diseases like me,” Jackson said. “A lot of times I feel like I’m the only one, but I discovered I don’t have to do this by myself. ImpactLife is dedicated to the cause and plays a huge role in providing relief to people with SCD in Central Illinois through blood transfusions.”

She added her involvement also educated her on the overall importance of blood and blood donations. To that end, she started advocating for more blood donations from people of color on her college campus and educating her peers on donating blood. People have come out to blood drives and donated because they knew about her journey, she pointed out.

“The Red4Life Program specifically helps people with SCD. I truly appreciate ImpactLife and how it advocates in the community by hosting blood drives and providing resources to break the stigmas surrounding SCD from miseducation,” Jackson said.



Ashley Reed – Gratitude and New Beginnings

“Donors truly save/give life with their donations.”

Ashley Reed, 32, was diagnosed with SCD at birth. The SCD crises she experienced throughout childhood often left her bedbound, impacting her social life and physical health. Although her genotype of sickle cell does not experience as many pain crises as other genotypes, Reed noted she still suffered with symptoms and complications from the disease.

“I was often not able to participate in sports activities because it would cause too much physical exertion that could result in a pain crisis. I also missed out on a lot of social activities at the beginning of the school year as a child,” she said. “As an adult, I have a better understanding of my body and my sickle cell. I am aware of what triggers my crisis – including dehydration and stress – and I am better able to prevent crises from happening by taking my medications and daily vitamins, staying active through daily exercise and making sure I eat food that is going to make me feel well physically and mentally.”

Reed experienced her most serious complication of SCD when she went into premature labor with her son in 2017 and underwent an emergency cesarean section after being in active labor for 36 hours. The physical stress of delivery, she noted, triggered a sickle cell crisis. Reed recalled feeling excruciating pain throughout her limbs in the recovery room. Then, her breathing changed.

“It felt like an elephant was sitting on my chest, and my body began to swell with fluid,” she recalled. “This was not pain from giving childbirth, but a pain I was very familiar with.”

Reed was transferred to the University hospital and diagnosed with acute chest syndrome and a deep vein thrombosis blood clot. She was placed in a medically induced coma and underwent a blood exchange transfusion. The procedure saved her life.

“More than 70% of the blood in my body had sickled and had to be exchanged out with 70% donor blood using an apheresis machine,” Reed explained. “I awoke from the medically induced coma nine days later and was finally able to go home with my son. I would continue to recover over the next three months, as I needed physical therapy, occupational therapy and some speech therapy to relearn how to be independent.”

Since having her son, Reed has undergone blood transfusions as a preventative measure before major surgery to prevent pain crisis and/or acute chest syndrome.

“My hematologist has determined that my body cannot handle the stress and exertion that comes with having surgery,” Reed said. “Before the preventative transfusions, I would be hospitalized for weeks from a surgery that should’ve only taken two to three days to recover from. Now that we do the preventative transfusions, I no longer have the crisis, and I can get home to my family and back to daily life sooner.”

Saving Lives

As an elementary teacher and educator, Reed understands the importance of equipping people with knowledge. She recommends raising awareness of SCD in the Black community as a first step in increasing donors.



Reed nearly lost her life in 2017 after giving birth to her son. A blood exchange transfusion saved her life.



“Black people need Black blood; more of us need to contribute to help us,” Reed noted. “I recommend making others in the Black community knowledgeable of the problem. I would also point out the different ways blood donations are used to save lives—sickle cell transfusions, gun violence, trauma victims, etc.”

Reed expressed her gratitude to ImpactLife and its Red4Life program for providing her with a platform to share a piece of her sickle cell journey. The initiative helps her advocate for other sickle cell warriors and bring awareness to the program, she added.

“Donors equal gratitude and new beginnings,” Reed told *AABB News*. “Without donors, I wouldn’t be alive today to watch my son grow. Donors truly save and give life with their donations.” ■



September is National Sickle Cell Awareness Month. Check out AABB’s social media pages throughout the month for more sickle cell warriors’ stories and to learn about AABB institutional members supporting patients with SCD.