



LIFELINES

The Newsletter of Blood Centers of the Pacific · Fall 2013



How My Daughter is a Survivor of Sickle Cell Disease



Adrienne Easter with her daughter Avonna

No mother wants to see her child experience pain. But unfortunately, it is something Adrienne Easter has seen her daughter Avonna go through everyday for the past 27 years. And sadly, will see her experience for the rest of her life. Avonna has sickle cell disease.

"I never knew anything about sickle cell disease, and I didn't even know I had the trait until I was six months pregnant," said Adrienne. "My husband had the trait as well. And when Avonna was born, she was diagnosed with sickle cell anemia and I remember screaming, 'Why me?'"

About 100,000 people in the United States suffer from sickle cell disease, mostly African-Americans. These patients - most of whom are children - need to undergo regular blood transfusions. Often, they develop antibodies to the blood they receive, leading to potentially life-threatening transfusion reactions. But if they can receive blood that's more closely matched to their own, that risk is minimized. And the best matches are found among other African-Americans.

Avonna received her first blood transfusion at just 9-months-old, and will most likely need them for the rest of her life. She currently receives a pint of blood every three weeks, and when she travels out of town, she receives two.

There are many different types of sickle cell disease. The three primary types of the disease are: Hemoglobin SS, Hemoglobin SC and Sickle Beta Thalassemia. Some people with sickle cell disease have complications than others. Typically, Hemoglobin SS referred to as sickle cell anemia, is the most aggressive and problematic form of the disease. And sadly, Avonna has that type.

"It's hard for me to see my daughter suffer,"

said Adrienne, a pre-school teacher. "I wish it was me instead of her. I love her so much. And it hurts me to see her have to go through all this pain."

To help others understand the disease better and to provide support for survivors of the disease, Adrienne decided to write a book aptly titled, "How My Daughter is a Survivor of Sickle Cell Disease." In it she describes her struggles as her role as a parent with a child with sickle cell disease. Adrienne also talks about her daughter's strength and how she coped with her disease growing up. "If I can just touch one person's life, so they don't have to go through what I did, I'd feel that I have helped someone," said Adrienne.

Avonna is now 27-years-old but still faces challenges with SS. According to her mother, some days are better than others. However, Avonna is quite the fighter! As she says, "In spite of all I have been through, I can say 'You can be a survivor of sickle cell anemia!'"

Adrienne and her daughter are available to speak at engagements to educate others about sickle cell disease. Adrienne loves to hear from her readers, please email her at adrienneeaster@comcast.com to say hi!



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The Newsletter of Blood Centers of the Pacific · Spring 2013



A Fighter: Like Mother, Like Daughter

Meghan Masterson is no stranger to hospital visits. In the fall of 2001 at age 19, Meghan was diagnosed with Thrombotic Thrombocytopenic Purpura or Hemolytic Uremic Syndrome and needed 987 pints of blood to save her life.

The rare disease meant that Meghan's red blood cells were being destroyed, consequently clogging her kidneys and entering her plasma. Plasma filled with shards of red blood cells isn't functional, so it needed to be removed daily. Meghan was hospitalized for three months and received daily plasma exchanges, an estimated 17 bags a day, in addition to weekly blood transfusions, chemotherapy and multiple medications. As if that weren't enough, she also endured eight months of dialysis for kidney failure.

Despite the setbacks, Meghan was able to graduate with her college class in May 2004. In the years after, Meghan resumed her active lifestyle, met and married the love of her life, Ray, and moved from California to Arizona. Life was good. Until last June.

Twenty-five weeks into her first pregnancy, Meghan's blood pressure started climbing. "My perinatologist had always told us that my blood pressure may go up as the pregnancy continues due to my pre-existing hypertension, so we were not worked up about it and figured they would probably need to adjust my medications," said Meghan. However, things took a turn for the unexpected and she remained hospitalized for the next three weeks under close medical supervision. Meghan had superimposed preeclampsia and

while she would not be reaching full term, the delivery date was delayed so long as mother and baby were doing well.

On July 6th, doctors finally determined that it was time for delivery and baby Farrah was born prematurely weighing 1 pound 12 ounces.

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Meghan Masterson with her husband, Ray, and baby Farrah

Donate Blood from Home!

Don't forget you can now complete an electronic donor history questionnaire (eDHQ) from the comfort of your home and save time at your next center donation (not yet available for blood drives).

Simply visit <https://edhq.bloodcenters.org> and follow the instructions!



Continued from cover page.

Farrah was closely monitored for the next 85 days in the neonatal intensive care unit until she was able to breathe on her own. And while Meghan didn't need any blood this time, Farrah did. "Due to issues around her prematurity, Farrah received four units of blood," said Meghan. "The transfusions were not emergent, but she had anemia of prematurity and did not create enough red blood cells fast enough to replenish the supply that was depleted for numerous blood tests done daily."

On September 28th, on what was supposed to be her due date, Farrah was finally able to go home.

Today, Farrah continues to do well and now weighs more than 12 pounds! "Looking at Farrah today, no one would be able to guess that she was born so early. She is a happy, healthy baby," said Meghan. "The pulmonologist who has been overseeing her care is very pleased with her progress. She is on track developmentally and adds so much joy to our lives. She smiles, laughs, and just rolled over for the first time. Lots of regular baby stuff, which is wonderful."

BCP thanks Meghan for sharing her story with us, and is proud to once again sponsor the Bay Area Promise Walk for Preeclampsia.



Farrah Masterson at 7-months-old

BCP Gives Back!

AIDS Walk - 6.2 miles

This past July, our BCP/BSRI AIDS Walk team walked 6.2 miles through San Francisco's Golden Gate Park to fundraise and help a great cause. We successfully reached our fundraising goal of \$2,040, which will help support the services provided by San Francisco AIDS Foundation and dozens of other Bay Area service organizations. Great job team!



The BCP AIDS Walk Team

MedShare

Also in July, BCP/BSRI staff volunteered on a Saturday to help sort medical supplies at MedShare, a nonprofit organization dedicated to helping improve healthcare and the environment through the efficient recovery and redistribution of the surplus medical supplies and equipment to those most in need. We sorted and boxed breathing supplies, and had a great time helping the community. Being first-time volunteers, we were also given a tour of the vast facility and learned that U.S. hospitals generate more than two million tons of medical



Debbie Spencer, BCP's Customer Account Manager helping to sort out medical supplies at MedShare

waste each year, much of which are unused medical supplies and equipment. Meanwhile, the World Health Organization estimates that more than 10 million children under the age of five die in the developing world due to inadequate medical care.

While it was our first time volunteering at MedShare, it won't be our last!

Curry Senior Center

Several BCP and BSRI staff volunteered their time on Saturday, September 14th, at the Curry Senior Center, San Francisco. The Curry Senior Center has been a leader and a lifeline to seniors in San Francisco for more than 40 years, a place where they easily access a wide range of essential services from healthcare to housing and everything in between. BCP and BSRI staff served meals to more than 180 seniors that day as well as played bingo with them, and stayed to help clean-up after. Prizes were generously donated by BCP and BSRI. Everyone had fun that day and are looking forward to the next volunteer event!



Top picture: Group photo with the seniors

Bottom picture: Curry Senior Center, Yen-Michael Hsu, UCSF/BCP Transfusion Medicine Fellow, handing out a bingo prize to a senior