# SERIOUS HEALTH CONDITIONS—FROM A LOVING PARENT OF A SICKLE CELL ANEMIA SURVIVOR

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A few months ago, my daughter suffered a major sickle cell pain crisis which led to other serious complications. She was hospitalized for more than two months and continues to receive professional therapy. Through the prayers of many, a great team of physicians, nurses, technicians and most importantly through the grace of God, she is a survivor!

Through this crisis and her recovery, she has been cared for by family, friends and an outside team of quality physicians and dedicated professional therapists. It takes a loving and caring village.

Research has determined that the disease of Sickle Cell is not by happenstance. It does not suddenly appear, and it does not occur by living an unhealthy lifestyle. Sickle cell disease is one of a group of inherited disorders.

Her mother and I both have the trait but never had symptoms. It was a shock to be called into the doctor's office to be informed that your beautiful baby has an incurable disease, not through her own making.

Through this crisis, we have become aware that sickle cell disease affects millions of people worldwide. It is particularly common among those whose ancestors came from parts of the world where malaria is or was common: Sub-Saharan Africa; Spanish speaking regions of {South America, the Caribbean and Central America); Saudi Arabia, India and the Mediterranean countries of Turkey, Greece, and Italy.

Sickle cell disease in the United States affects approximately 100,000 people. More than 90% of people with Sickle Cell Disease are non-Hispanic Black or African American {Black), and an estimated 3% - 9% are Hispanic or Latino. With about 1 in 13 Black or African American babies is born with sickle cell trait (inherited from a single cell gene from only one parent).

## DO YOU KNOW OR WORK WITH SOMEONE THAT HAS ONE OF THESE MEDICAL CONDITIONS?

Sickle cell anemia is a genetic disorder. An inherited medical condition caused by a DNA abnormality. Other common types are: Down syndrome, Cystic fibrosis, Huntington's disease, Duchenne muscular dystrophy, Hemophilia, Thalassemia and Fragile X syndrome. Genetics also play a significant role in the development of Type 1 Diabetes with a higher risk based on family history. Type 2 diabetes is the most common, accounting for approximately 90% of the cases caused by a combination of genetic and lifestyle factors, such as diet and exercise, which are controllable.

The need for leave due to Sickle Cell and other diseases that may be chronic or long term is protected under the Family Medical Leave Act (FMLA). This Act entitles eligible employees to be absent for up to 12 work weeks per year when they are unable to work or to care for a spouse, son, daughter, or parent with a serious health condition. An employee's rights and entitlements under the FMLA and to utilize paid sick leave are listed in USPS ELM Chapter 5, and Article 10.6 of NPMHU's (CIM) Contract Interpretation Manual's (Version 6) which includes Q & A.

## CAUSES OF SICKLE CELL ANEMIA:

Sickle cell anemia is caused by a change in the gene that tells the body to make hemoglobin. For a child to unfortunately have sickle cell amenia both parents must each carry one copy of the sickle cell gene (sickle cell trait or SCT) and pass both copies to the child.

If both parents have SCT, there is a 50% chance that any child of theirs will have SCT and a 25% chance (or 1 in 4) chance that any child of theirs will have Sickle Cell Disease. There is also a 25% chance that the child will not have either SCT or the disease.

Sickle cell anemia affects the shape of red blood cells, which are normally round and flexible and carry oxygen to all parts of the body. In sickle cell anemia, the red blood cells resemble a sickle, a farm tool used to cut wheat or a quarter moon for us 'star gazers.' These cells become rigid and sticky, which can slow or block blood flow. Normal red blood cells live up to 120 days, but sickle cells usually die in 10 to 20 days, leaving a shortage of red blood cells known as anemia. This shortage of red blood cells does not allow the body to get enough oxygen which causes fatigue.

## SYMPTOMS

Symptoms of sickle cell anemia usually appear around 6 months of age and they may include:

- **ANEMIA.** Sickle cells break apart and die.
- **EPISODES OF PAIN.** Episodes of extreme pain, called pain crisis which affected my daughter.
- **SWELLING OF HANDS AND FEET.** Sickled cells block blood circulation in the hands and feet.
- **FREQUENT INFECTIONS.** Sickle cells can damage the spleen, raising the risk of developing infections such as flu, meningitis, and pneumonia.
- **DELAYED GROWTH OR PUBERTY.** Shortage of red blood cells can slow growth and delay puberty in teens.
- **VISION PROBLEMS.** Tiny blood vessels that supply blood to the eyes can be plugged with sickle cells.

**Life expectancy for individuals with Sickle Cell has increased by more than 68% since 2016.**

There are simple steps that can help prevent and reduce the occurrences of pain crisis from sickle cell, including the following: managing stress; getting enough good quality sleep; drinking plenty of water; trying not to get too hot or cold; trying to avoid places or situations that cause exposure to high altitudes (such as flying, mountain climbing, or visiting cities with a high elevation). They should also try to avoid places or situations with exposure to low oxygen levels or extreme exercising and training.

Preventing pain caused by the sickling of blood cells includes taking the prescribed medicines of hydroxyurea, Endari, voxelotor (Oxybryta), or crizanlizumab (Adakveo). **Some patients such as my daughter benefited from the treatment of a blood transfusion which saved her life.**

People with sickle cell disease are also at high risk for complications including stroke and kidney disease which can be worsened by high blood pressure (hypertension). Maintaining a healthy blood pressure level must be done in consultation with your health care provider and can include such steps as, being physically active for at least 30 minutes, 5 days a week, eating heart healthy foods such as foods rich in potassium, fiber, and protein, and low in salt (sodium) and saturated fat, reducing/quitting smoking, and limiting the intake of alcoholic beverages.

## COMPLICATIONS OF SICKLE CELL DISEASE AFFECTING DAILY WORKING LIFE INCLUDE:

Stroke; Acute chest syndrome; Avascular necrosis; Pulmonary hypertension; Organ damage; Splenic sequestration; Blindness; Leg Ulcers; Gallstones; Priapism; Deep vein thrombosis and Pregnancy implications.

As we see, sickle cell disease is a serious health condition with no known cure but educating the public and with increased medical attention and testing, will hopefully develop cures for these other debilitating illnesses.

## SOURCES:


- (CDC) Centers for Disease Control & The (NIH) National Heart, Lung, Blood Institute