Nina Simone White
Fort Worth, Texas

Nina's mom and dad did not know they both carried the sickle cell trait until Nicole was pregnant with Eriyan, their now 11 year old daughter. They were told at that time that there was a 50% chance of their child inheriting the trait, 25% chance that the trait would not be present at all and a 25% chance that their child would have sickle cell anemia. Their oldest daughter was born without the trait.

When Nicole became pregnant with Nina, they did not think about the blood disorder since it had not been part of their lives. That was until Nina was born and her blood work was completed. As a newborn, Nina was diagnosed with sickle cell anemia. When her parents took her home from the hospital six years ago, they knew what to look for. The symptoms included swelling in her hands and feet because blood did not circulate well, pain, complications with her spleen and infections that caused a fever of over 101.5. If her temperature was higher than that, Nicole was to be taken to the hospital.

Nicole commented that "kids get sick"… and they made many a trip to the Emergency Room to check on a fever. Four out of 10 times, Nina had to be hospitalized. Before she was a year old, Nina had two blood transfusions. She took penicillin twice a day for five years in an effort to forestall infection. Additionally Nina could not go to regular day care or school for fear of being exposed to infections. She would need in-home care. They were fortunate to find a lady who only cared for two children and could take care of Nina. Still they worried that if Nina got sick they would have to get to her quickly. Because of the disease, Nina is at high risk for strokes and other complications. Both parents worked at IBM. In 2005 IBM arranged for them to work from from home so they could be near Nina.

When Nina was 5 years old, their hospital received a new transcranial Doppler that could test the blood flow to the brain. Only 5% of those infected with sickle cell have strokes but it was determined that Nina was at high risk. In fact, it was discovered that she had already had some small strokes. There were two possible courses of action, chronic blood transfusions once a month or a bone marrow transplant, which can some times be a cure.

The bone marrow transplant requires a prefect match and none of family members was that match. Without that, the risks of the procedure are extremely great so a transplant was not an option. Chronic blood transfusions seemed to be the available method to help Nina begin to live

a healthier life and allow her family to begin to have a more normal routine. At first Nina had a transfusion every 2 weeks and then she began to receive them at three week intervals. For the last year, Nina has received transfusions once a month and, according to Nicole, it has changed their lives. She said that

> "*without them this last winter would have been horrible. But Nina had only one little cold all season*."

The transfusions help keep a delicate balance in her body.

She is now in first grade at regular school. A happy, prissy child, Nina loves to sing, dance and perform.

According to her dad, when Nina gets her transfusions she has said

> "*I hate getting my IV but I love the way I feel after I get the blood*"

Sickle cell anemia: A genetic blood disease a blood disease which shortens life expectancy due to the presence of an abnormal form of hemoglobin, namely hemoglobin S. Hemoglobin is the molecule in red blood cells that transports oxygen from the lungs to the farthest areas of the body. It is caused by inherited abnormal hemoglobin

Sickle cell anemia affects millions of people throughout the world. It is particularly common among people whose ancestors came from sub-Saharan Africa; Spanish-speaking regions (South America, Cuba, Central America); Saudi Arabia; India; and Mediterranean countries, such as Turkey, Greece, and Italy. In the USA, sickle cell disease occurs in about 1 in every 500 African-American births and 1 in every 1,000-1,400 Hispanic-American births.

Symptoms may include bacterial infections, painful swelling of the hands and feet, fever, arthritis, leg ulcers, fatigue, anemia, eye damage, and lung and heart injury. Treatment for sickle cell anemia aims to manage and prevent the worst manifestations of the disease and focuses on therapies that block red blood cells from stacking together, which can lead to tissue and organ damage and pain.