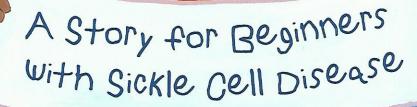
## Just Like Me!!!





1454.5 Story by
Tina Taylor, MSN, CNP

Pictures by Carla Golembe Property of: NH Family Voices 129 Pleasant St – Thayer Building Concord, NH 03301 (800) 852-3345 x 4525











# Just Like Me!!!





A Story for Beginners With Sickle Cell Disease







Many thanks to the wonderful sickle cell team at Children's Healthcare of Atlanta.

Our patients and families are truly special!

This book is dedicated to Mama (aka Lucy Armstrong), a true pioneer in pediatric nursing.

Tina A. Taylor, Author

For all medical practitioners who are also compassionate healers.

Carla Golembe, Illustrator

#### Introduction

Just Like Me!!! is a picture book designed for young children with sickle cell disease. Filled with colorful pictures and simple concepts, this resource is an easy reference for children to use when they have questions about their disease.

Parents, use this story to help your child understand the sickle cell disease process. This book can also be used by sickle cell providers and staff members as a resource for young sickle cell disease patients. Review the glossary of terms often used in the care of children with sickle cell disease.

This book does not replace the expertise of the healthcare providers who specialize in sickle cell disease. If you have specific questions, please consult your healthcare provider.

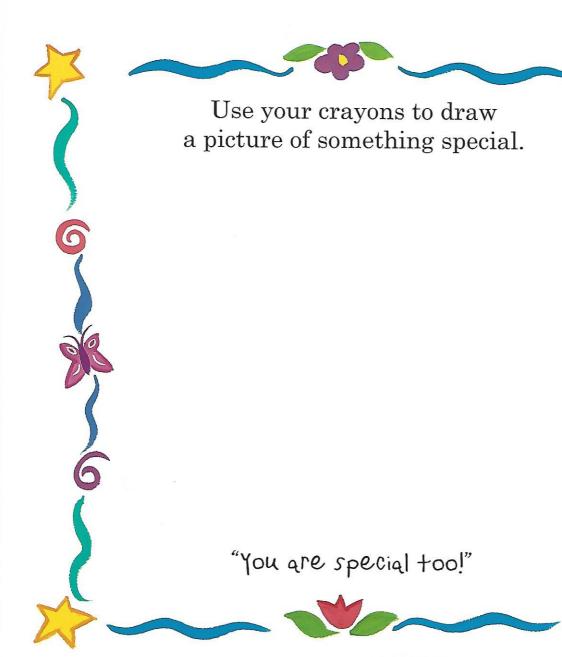
## This book belongs to:

Name:

Age: \_\_\_\_\_



"Hi!
My name is Buddy and I am special."







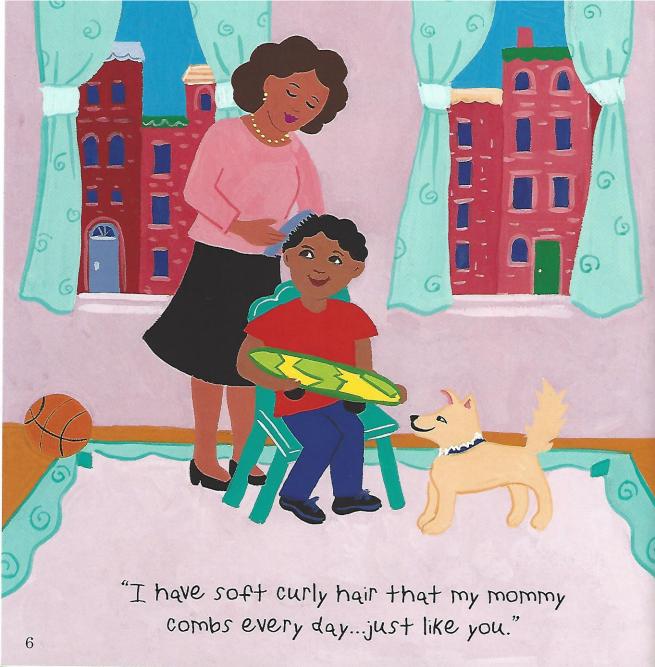








"I have big brown eyes to see butterflies and rainbows. Just like you."

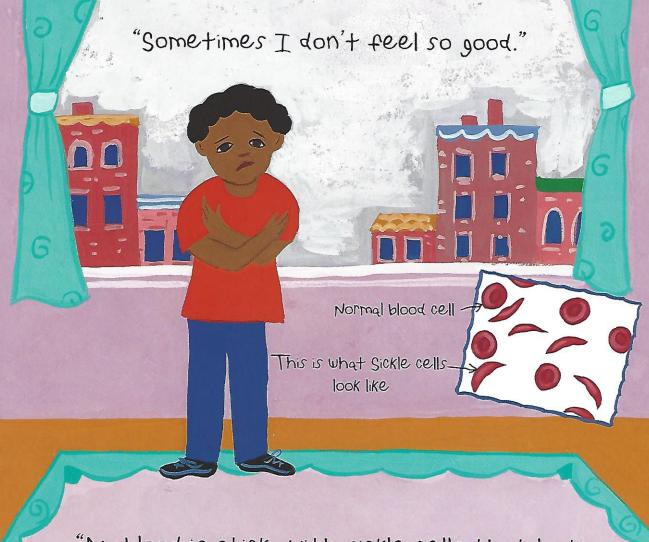




"I have a special family...just like you."



"I have sickle cell disease...just like you."

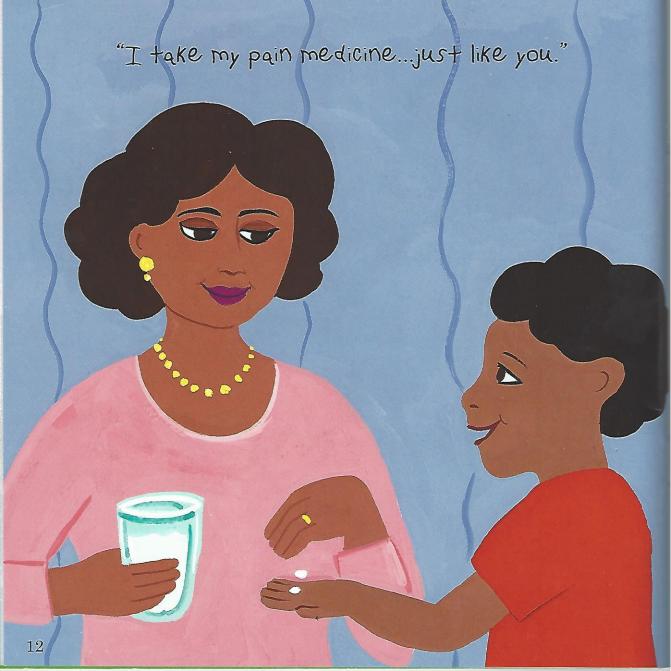


"My blood is sticky with sickle cells that look like raisins. They become sticky and clumpy in my blood vessels."

"Sometimes when this happens I become tired and have pain...just like you."

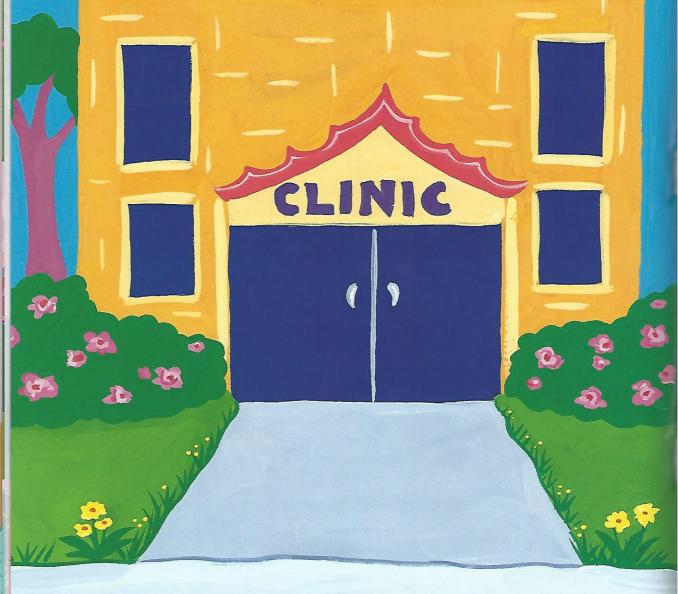








"I drink plenty of water...just like you."

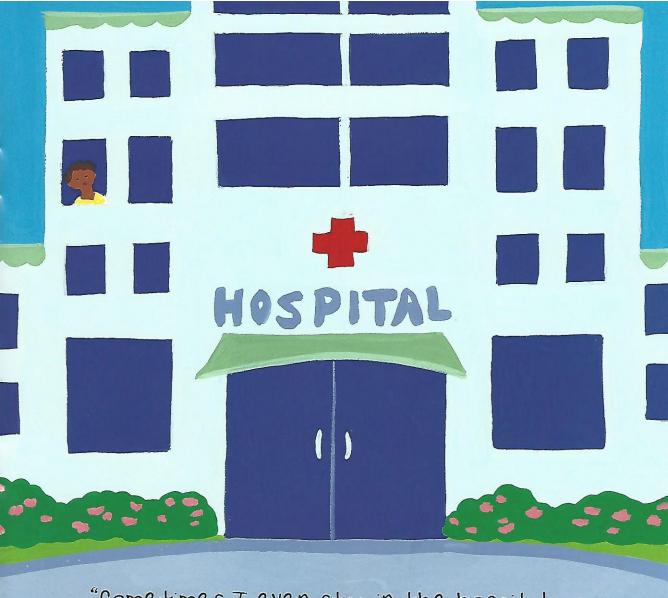


"I go to the sickle cell clinic...just like you."





"I have nice sickle cell providers and nurses who take care of me...just like you."



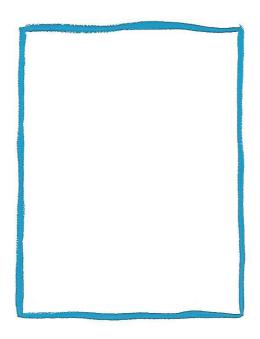
"Sometimes I even stay in the hospital...
just like you."





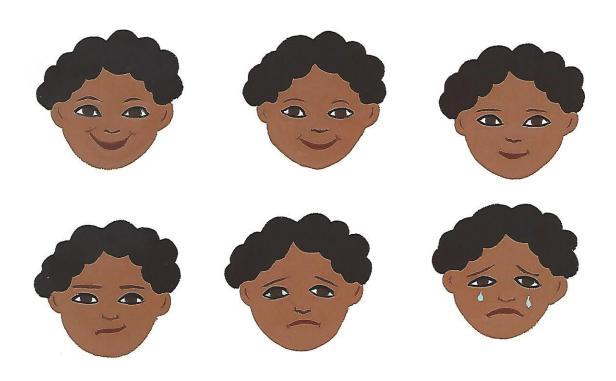
"Then I feel better. Just like you."

Attach a special picture of yourself.



"You are Special...Just Like Me!"

### HOW DO I Feel Today?



Use your crayons to circle the face that shows how you feel.





The End

#### Glossary

Acute Chest Syndrome The chest is congested due to pneumonia,

sickling, a fat embolism, or all of the above.

There may be coughing or even a fever. This

is diagnosed with a chest X-ray.

**Aplastic Crisis** A low hemoglobin (a substance found in the

blood that helps carry oxygen) and reticulocyte

(immature red blood cells) count because the

bone marrow is unable to produce red blood cells.

This can cause a child to look pale and feel weak.

**Dactylitis** 

The swelling of the hands and feet of infants (Dak-tie-lie-tis)

and toddlers. Often there is pain associated

with this condition

Electrophoresis

A way of separating closely related blood (E-lectro-for eesis) components on a laboratory slide. One

component is hemoglobin which helps carry

oxygen in the blood.

Fetal Hemoglobin The main type of hemoglobin (a substance in

the blood that helps carry oxygen) present at

birth. It is high for the infant's first 6 to 12

months of life and then begins to drop down.

Folic Acid A "B" vitamin that helps enhance more red

blood cell production.

Hemoglobin A substance that is found in red blood cells that carries oxygen to all parts of the body. The most common hemoglobin is adult hemoglobin or hemoglobin A. There are less common types of hemoglobin like hemoglobin S (sickle hemoglobin) and hemglobins C, Beta-Plus Thalassemia, Beta-Zero Thalassemia, and E. Hydroxyurea A drug therapy that stimulates the production of (Hi-drox-e-you rea) fetal hemoglobin (hemoglobin present at birth). Iron Overload An excess buildup of iron in the body often as a result of 10 or more blood transfusions. If left unmanaged, iron overload may lead to organ damage. **Jaundice** A condition where the skin and the eyes become (Jon-dis) yellowed due to bilirubin in the blood as a result of excessive red blood cell destruction. Painful Event A time when there is a great deal of pain. The pain is a result of sickling. The pain can be felt in the legs, arms, feet, hands, stomach or anywhere in the body. Penicillin An antibiotic used to prevent life-threatening bacterial infections in the first five years of life. Pneumovax An immunization given to children between the (New-mo-vax) ages of 2 to 5 who have sickle cell disease.

threatening bacterial infections.

Pneumovax helps prevent them from getting life-

Reticulocyte Count A blood test that measures how fast bone (Ree-tik you-lo-site) marrow makes new blood cells and releases them in the blood.

Sickle Cell Trait

It's when you have one normal gene and one sickle gene. A child with the trait does not have sickle cell disease and does not show any signs.

Spleen

An organ that acts like a filter for the blood stream. Sometimes sickle cells get trapped in the spleen. That makes the organ get bigger and cause extremely low blood counts.

Stroke

When sickle cells block the vessels that carry blood to the brain. This could lead to nerve and brain damage.

Transfusion

An IV infusion of normal red blood cells that replaces sickle red blood cells. Any person who has received 10 or more transfusions in his or her lifetime is at risk for iron overload. Make sure that your child's healthcare provider periodically tests your child for iron overload.

Vaso-Occlusive

(vaso-ok-KLOO-siv)

When round blood cells become "sickle" shaped due to a lack of oxygen. This makes it hard for the cells to flow freely through the bloodstream.



Tina A. Taylor, MSN, CPNP, is a pediatric nurse practitioner specializing in sickle cell disease in the Aflac Cancer Center and Blood Disorders Service at Children's Healthcare of Atlanta. She has been in pediatric nursing for over 25 years. Tina Lives in Johns Creek, Georgia with her husband Darcey, her two children, Imani and Khari, and her Lhasa Apso, Muffin.



Carla Golembe is a painter and illustrator. She has illustrated over 20 books for children. Carla teaches at the Art School of the Boca Raton Museum of Art. She lives with her husband, Joe Eudovich and their cats Zippy and Zoe, in Delray Beach, Florida



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