

Advocating for Academic Success Among Children with Sickle Cell Disease

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Abstract

Sickle Cell Disease, one of the deadliest silent killers in the African-American community, does not get much media attention. This is a disease which impacts 1 out of every 500 children, mostly of African-American descent. Due to complications of the illness, school age children miss several days from school at a time. Not being able to attend school places the child at a higher risk for academic failure; therefore, academic performance can be significantly impaired for many children who suffer with Sickle Cell Disease. This paper will take a brief look at what Sickle Cell Disease is, the impact it has on school age children, some recommendations to assist and words of encouragement for the community of people who have to deal with this deadly disease on a daily basis.

Keywords: *Children; Sickle Cell Disease and education; Hemoglobin S*

Introduction

Sickle Cell Disease (SCD) is a disease that is most common among people who are of African-American heritage. Other racial ethnic groups can have this disease as well. SCD is an inherited blood disorder that is transmitted to children by their parents. People with SCD produce an abnormal type of hemoglobin, known as hemoglobin S (HbS) or sickle hemoglobin. Hemoglobin is the protein located in the blood cell which transports oxygen to the organs and other tissues throughout one's body. The abnormality of the red blood cell causes the red blood cell to be in the shape of a sickle or a banana. People with SCD have a decreased number of red blood cells, which causes them to be anemic. An anemic person suffers from decreased energy, breathlessness, and are likely to become pale in color.

There are different forms of SCD - Hemoglobin SS (Hb SS), Hemoglobin SC (Hb SC), Hemoglobin SB- thalassemia (Hb SB-t), Hemoglobin SB+ thalassemia (Hb SB+), Hemoglobin SD (Hb SD), and Hemoglobin SE (Hb SE). The most common form is the Hb SS which is when the child inherits an "S" gene from each of their parents. This is the most severe form of SCD. Hb SC is when the child inherits an "S" gene from one parent and "C" gene from the other parent. Another form of SCD is when a child inherits only one sickle cell gene and a gene for beta thalassemia.

People who suffer from SCD have red blood cells that are shaped like a donut compared to individuals who do not; their red blood cells are round shaped. The sickle shape cells are not able to freely pass through the blood vessel causing the blood to clog and break apart as they move through the blood vessels. Also, the sickle shape cells are not able to transport oxygen throughout the body causing the people with SCD severe pain, a reduced number of red blood cells (or anemia) and or stroke. People with SCD have no control of when the pain will strike them, as well as, the severity of health issues that come with the illness. However, there are people who have SCD who suffer from very little pain and they do not require constant hospitalization.

Some factors which can trigger a SCD crisis:

- Stress
- Dehydration
- Extreme physical activity
- Sudden change in temperature
- Cold and/or damp conditions
- Infections
- Use of alcohol or caffeine
- Smoking

It has been frequently quoted that our children are the future; however, for children who are faced with a life-threatening illness such as Sickle Cell Disease (SCD), chances are drastically reduced for them having a brighter future. SCD is an illness which is most prominent within the African American Community. This is coupled with the many other challenges African-American children encounter growing up in United States: i.e., poverty, drugs, gang violence, and lack of health care access. There has been research to suggest that children with SCD are more likely to suffer academically when compared to their counterparts.

You can tell a lot about a country when looking at how they treat their children. A country that is more sympathetic toward the children in the country is indeed a country that is invested in the future of that country. The ability to provide services to a group of children who have historically been overlooked is indeed a positive step in the right direction. Many children living with SCD are not given the opportunity to live a normal life and reap the benefits of obtaining a quality education.

The United States has made great strides over the past 20 years concerning the plight of children with SCD. There have been some research studies carried out over the past 17 years to demonstrate the impact SCD has on school age children and their scholastic performance. Many of the studies have pointed out that SCD does indeed have an adverse impact on children's ability to learn, as compared to their counterparts who do not have SCD. A study conducted by Chu-Lim., *et al.* [1] showed that children with SCD had deficiencies in their school readiness skills. The children were evaluated with the Pediatric Examination of Education Readiness (PEER), an instrument designed to produce a set of observations of the child's strengths and weaknesses in playing and health education. The results suggested children with Hb SS (SCD) scored significantly lower than their normal counterparts in several domains, i.e., visual input, sequential input, short-term memory and fine motor output. The results of this study indicated children with SCD are more than likely to be impacted in ways that influence their learning experiences in the classrooms. In another study by Steen., *et al.* [2], they examined whether young children with SCD are at more risk for cognitive impairment. These children were assessed using the Developing Skill Check List, an instrument used to measure kindergarten skills of appropriateness. This instrument can be administered by classroom teachers; therefore, there was no need for a special examiner. The data was collected from 34 local school districts from children with SCD. These children were compared and matched with a control group of children who were also administered the Developing Skill Check list. The results revealed significantly lower scores in the children with SCD as compared to the control group specifically in auditory discrimination, a skill essential for phonics instruction and reading. Additionally, it was noted that the children with SCD had lower scores in language development.

Nettles [3] reported there was a direct correlation among children who suffer from SCD on their brain, the number of absentees from school due to sickle cell complications, and a child's poor school performance. It has also been reported that children with Hb SS and Hb SC disease score below the national norms in the areas of reading and mathematics when matched with comparison groups.

In conclusion, children suffering from SCD compared to their counterparts who do not have the illness, are more likely to have lower grades in reading, math, and are more likely to have low school attendance. They are at a greater educational risk than their healthy peers of school failures which cascade into other areas of their lives. Failure of any kind can be very detrimental to a child's self-esteem. Since these are children who have no control over their illness, this can be even more damaging, resulting in many children having no desire to return to school, feeling inadequate and simply feeling like they will never be able to keep up or catch up. These feelings lead to childhood depression, low self-esteem, and a sense of learned helplessness. There needs to be a continuous effort on the demand for research concerning children with SCD. This would allow for both the health care and educational institutions to be in a better position to improve the quality of life for children suffering with SCD.

Below is a list of educational guidelines developed by various organizations to assist teachers, school nurses, school administrators, parents and care givers in achieving academic success for children with SCD.

Classroom Guidelines

1. Disclosure of illness

Be respectful of whether or not the family wishes to share this information with the entire class.

Recommend: Speak with the parent, caregiver and the child regarding disclosing this information. There might be children who are okay with sharing they have SCD with their classmates and others who prefer to keep it confidential.

2. Academic Performance

Be aware that the academic performance of children with SCD may not be compatible with their actual abilities.

Recommend: Children with other impairments are given the opportunity to excel based on their abilities and not judged according to their disabilities. The same considerations need to be afforded to children with SCD.

3. Absenteeism

Complications as result of SCD may result in frequent absences. Most children with SCD can and will perform as well as their peers, so the expectations for students with SCD should be the same as all the other children.

Recommend: Be prepared to provide the parent/caregiver and or student with current work and makeup homework and, when necessary, suggest tutorial services. It has been proven that attendance is directly related to academic performance. Parents can also speak directly to the teacher(s) about establishing a homework buddy program for the entire class. Each student would be assigned a "buddy" who will collect the handouts and notify the absentee student of important future deadlines. Many teachers have websites where they post homework assignments and future dates for both parents and students.

4. Classroom Participation

Children with SCD have anemia so towards the end of a class day, they might experience some degree of fatigue.

Recommend: Excuse the child when possible from ongoing instructional activities so they can rest for short periods of time. Should the fatigue become chronic, do not hesitate to contact the parent and/or caregiver.

5. Pain Episodes

Pain episodes can occur during normal school hours.

Recommend: Consult with parents regarding who should be notified. All pain episodes are not emergencies but don't take any chances. The school nurse should be notified as soon as possible. A fever should always warrant immediate medical attention. Students can be an excellent resource as to whether their pain is mild or moderate and if it will pass. Under no circumstances should you encourage the child to suffer through it. Often, in clinics or hospitals, doctors use a scale of 1 - 10 to rate their pain. You may want to use the same sort of measurement to check in periodically with the student to assess their level of pain so you will know when emergency contact is warranted (1 being least severe and 10 being the most severe).

Create an individualized care plan for each student with SCD. The plan should have input from the following personnel to maximize the plan effectiveness - the teachers, school nurse, the student(s) and his or her family. The plans may include instruction on how to administer pain medicine to include who is responsible for administering the medicine and deciding what medicine should be given to the student. Check your local school policies on procedures for administering medicine to students. Students with SCD can be prescribed some extremely strong medications, such as: narcotics (e.g., Tylenol with codeine, Darvocet), anti-inflammatory medications (e.g. Toradol, Advil) or steroids (e.g. Prednisone) to relieve pain.

6. Take special care of injuries

Never apply a cold pack on an injury for pain.

Recommend: Other first aid measures can be utilized to keep children with SCD safe when they are injured, which include: applying direct pressure for bleeding, wrapping with an ace bandage, or simply elevating the limb. Be sure to contact the school nurse and or parents when necessary.

7. Watch for signs of stroke

Many children with SCD may experience difficulties due to health problems associated with stroke (blockage of blood vessels in the brain which can cause brain damage).

Recommend: Strokes can often be very difficult to detect when they affect a very small portion of the brain, but it is important to watch for them with SCD children because they are common. Teachers are in a unique position because they are one of the first to take note of changes within a child with SCD in their school performance indicating a stroke. Do not brush it off as poor attention in class due to the child's lack of motivation or desire to do well in school. Teachers should notify the parent(s) who can contact the child's doctor immediately or if necessary contact emergency personnel should the situation warrant. Formal neurocognitive and educational testing are required to determine if there are any learning difficulties caused by the stroke. These kinds of testing are beneficial to the teacher because this would allow the school personnel to develop the best teaching strategies for the students. Many students with SCD may qualify for a 504 plan or an individualized education plan (IEP).

8. Water Fountain Privileges

Children with SCD are required to drink large amounts of water to prevent dehydration.

Recommend: Unlimited access to water throughout the school day. Frequent amounts of water are better than attempting to consume a large quantity at one time. Allow the students to have a water bottle at their desk.

9. Bathroom Privileges

SCD can result in frequent urination due to kidney's inability to concentrate urine and the amount of fluid intake consumed by the child.

Recommend: Allow the children with sickle cell unlimited bathroom access. Even if this mean they need to sit by the door so they do not feel like they are disrupting the classroom.

10. Gym Participation

Children with sickle cell disease can experience shortness of breath or other symptoms due to strenuous physical activity.

Recommend: Gym participation should be encouraged but the students may have to take frequent rest stops. Should the student's physician excuse them, then an appropriate alternative can be put in place. Teachers may modify the curriculum for less strenuous roles, such as being the physical education teacher's assistant, scorekeeper, or umpire.

11. Outside Recess

Children with SCD are extremely sensitive to hot or cold weather. Make every effort to avoid cold or hot weather which can trigger a pain crisis.

Recommend: Ensure the child dresses appropriately for the weather. Avoid over exposure to extreme hot or cold weather. Teachers should not assign a student with SCD a seat in a drafty location i.e. in front of a fan or directly under the air condition vents. Permit students to wear extra layers of clothing if they need too. Remind students with SCD to wear a jacket outside during the cold or rainy weather or to take off a layer of clothing when it is too hot. Children with SCD should never exercise in any extreme conditions.

12. Self-Esteem

Children with SCD are very prone to low self-esteem and poor self-image.

Recommend: Create a classroom with opportunities for all children to feel good about who they are regardless of what is going on in their lives. This is especially important for children with a chronic illness.

13. Teasing

SCD children can be teased because:

Yellow discoloration of the white part of their eyes- (jaundice).

Small stature- Experience a delay in developmental growth.

Recommend: Zero tolerance for teasing and or bullying. Have classroom conversations about the need to be accepting of other's differences. Help students gain understanding of individual differences and that people do not have any control over their physical condition and that teasing and bullying can greatly damage one's self-esteem.

14. Career Goals

Be prepared to discuss career opportunity limitations due to SCD.

Recommend: This is something to take under consideration with all children but more specifically with children with a chronic illness. Students should be challenged to set realistic and obtainable career goals. Occupations that require physical labor should not be advised.

15. Maintain open communication with parents

Teachers are in an excellent situation to create a positive relationship between home and school.

Recommend: Teachers should maintain an open line of communication with parents who have a child with SCD. It can be strengthened by using notes, e-mails, phone calls, or conferences to discuss the student's performance and well-being in the classroom and at home.

Special Situation Where Teachers Should Call 911

When the child experiences:

- Difficulty Breathing
- Loss of Consciousness
- Severe Headache
- Difficulty Speaking or Slurring of Speech
- Weakness of Limbs
- Seizure Activity
- Fever greater than 39°F
- Unexplained Lethargy/Sleepiness/Persistent Vomiting

What Parents and other Caregivers can do to support children with Sickle Cell Disease

1. Set up a meeting to discuss SCD with the teacher

This is an opportunity for the parent(s) to explain to the school what sickle cell disease is and how the child copes. Additionally, the meeting should discuss who should be contacted in the case of emergency. Parents can also check in with the teacher periodically throughout the school year by simply calling, sending e-mail, texting, or dropping by when needed.

2. Talk with the teachers about a 504 plan or Individualized Education Plan (IEP)

A 504 plan is designed to assist a child with special healthcare needs which can limit one or more major life functions. 504 plans provide an opportunity for the child to participate in general education programs. For example, the 504 plan is where the students and families may make a written request for access to an extra set of books for home, more frequent bathroom breaks, access to water throughout the day or the need for an extra layer of clothing. A 504 plan is administered in schools that obtain federal funds (i.e. public schools). It is a written document which outlines reasonable accommodations for students with disabilities. The 504 plan ensures students with SCD have equal access and will be fully able to participate in all activities without any discrimination. The 504 plan does not address issues of remedial instructions. An IEP is designed to address issues concerning remedial instructions. When health problems with SCD have a negative impact on the lives of student's academic performance, special education services are highly recommended. An IEP is a written document developed between school administrators along with families to assure specialized or remedial instructions. Also, federal funding is given to the school to provide a broad range of services depending on the needs of the students. Both a 504 and IEP plan should be updated annually to meet the needs of the student.

3. Develop an Individualized Care Plan

An individualized care plan is a written document that is specifically tailored to the healthcare of the student with SCD. An individualized care plan requires input from the teacher, the school nurse, the child and the family. The plan should include emergency contact information and any special needs the student might have along with medication guidance, i.e., who should give or administer the medicine and when will it be needed. It is extremely important that the school policy on administering medicine be in compliance. Individualized care plans should be updated on an annual basis.

4. Tell the teachers about changes in your child's health

The parents should play an active role in their child's school performance by letting the teacher know when their child is sick, has been hospitalized and as result will not be able to attend classes. This kind of open dialogue allows for both the teachers and parents to work collectively to ensure students obtain the highest quality of education. Many things can be specifically annotated in the 504 plan as to how parents can obtain lesson plans, homework or ask for homebound teachers to prevent the student from falling behind in their academic course work. Homebound instructors can assist students with making up missed school work due to occasional and extended absences because of hospitalizations or other ill health. Speak with the teacher about tutoring, assignment plans, a second set of books to have at home or online resources for class work to ensure the student has a successful school year.

Five (5) of the most frequently asked questions to parents or caregivers by the school staff

Question: Is sickle cell disease contagious?

Answer: No, sickle cell disease is not something you can catch like a cold or flu. Sickle cell disease is a genetically inherited disorder that is transmitted by one's parents.

Question: Why does your child miss a lot of school days?

Answer: Sickle Cell Disease often requires a person to be seen by a doctor more frequently than other patients. Also, Sickle Cell Disease causes people to be in a severe amount of pain which may cause them not to be able to attend school.

Question: Why do people with sickle cell disease have yellow eyes?

Answer: Sickle cell causes a person's red blood cells to die more quickly, thus resulting in their eyes becoming yellow due to a substance that is released when the red blood cells break down.

Question: Why do students with sickle cell disease need to have a water bottle at their desk or need more water fountain and restroom breaks?

Answer: Students with sickle cell disease need to have access to water since it helps reduce the pain that can occur as result of their disease. The water access will increase the size of the person's veins and allow the sickle-shaped cells to flow through the blood vessel more easily. So, children with SCD must drink more water because sickle cell disease can affect the kidneys, which in turn requires the students to have more frequent bathroom usage.

Question: Why are children with sickle cell disease smaller or less physically developed than other children?

Answer: Red blood cells are needed to carry oxygen throughout the body, which in turn helps with a child's body growth. Children with sickle cell disease do not have the red blood cells to assist them with their growth, which in turn stunts their growth. Also, with the red blood cells not being able to carry oxygen throughout the body for energy, it results in the person with Sickle Cell Disease having a lot less energy than someone with normal red blood cells.

Adopted: National Center on Birth Defects and Developmental Disabilities-Centers for Disease Control and Prevention [4]

Who Will Speak for Me

Who will speak for me, a child who feels abandoned and alone? A child who has a pain that I refuse to call my own.

Who will speak for me, when the medical society seems to think that pain is what my life is limited to, or they simply do not know what to do.

They really can't explain what is happening to me, and often times chose not to give me anything for this horrible pain; that they just send me home just the same. They look at me and tell me to endure, because you will be back because medical science has no cure.

Who will speak for me when I can barely read or write? I am told by research, I can have a silent stroke which can impact my brain, walk and my talk.

Can you imagine how frightening this is for me? I really wish you could only see what an agony, SCD has been for me.

Who will speak for me, because I do not have the strength to fight on my own? As a child, I am doing all I can just to stay alive. I try to hold my head high and walk with some degree of dignity and pride.

Who will speak for me, because in this ole world I feel so all alone? I am simply a child, pleading how I wish SCD would leave my body alone.

Who will speak for me, when I often hear my mother crying late in the midnight hour, when she thinks I am fast asleep "Lord please help my child. Do not take my child away. Do provide more time on this earth for him to stay. Can you please do something, to take his pain away." Who will speak for me, just so I can get a good night's sleep?

Who will speak for me, when my classmates often taunt and tease me? Why are you so short and your eyes so yellow? I know that they simply do not understand. But for me, it makes me truly sad when they are always picking on me. I know you heard the saying sticks and stones will break your bones but words will never hurt. Well I am a living witness that words do hurt. They make you feel like dirt.

I often have to miss a lot of days from school due to the complications of my illness. Yes, this sickness put me in a lot of misery. I would love to be at school with the rest of my friends obtaining an education so that I can have a better quality of life and one day grow up to reach my God ordained destiny. Who will speak for me?

My teachers, they try really hard to understand but the school board puts them under so many strict demands. But, I am so grateful for the many wonderful teachers I have had thus far. Because they do look me in my eyes, to let me know, I am not alone, and with you I will stand. I pray often for all the teachers who refuse to give up on me. I want you to know, you have truly encouraged me to keep picking myself up and to never stay on the floor.

Who will speak for me, because I have cried all the tears I know to cry. I often feel like giving up or simply just die. Who will speak for me, the pain goes on and on. I try to stop it, but yet instead, it stops me!

Who will speak for me, the pain is often so strong to bear. It feels like a sledge hammer hitting me straight to my bones over and over again. It's truly my worst nightmare.

I beg it, please let go, but it simply says NO! When it gets into my blood running all through my tiny little veins, it feels like broken glass cutting me into a million pieces. Yes, it drives me completely insane.

Who will speak for me, when SCD has squeezed all the life out of me?

Who will speak for me when I am lying in the hospital trying so hard to be strong? And I am simply just trying to do is hang on. In all honestly, it seems like all my hope is gone.

Who will speak for me, when I am screaming to the top of my lungs because the pain seems to have gotten the best of me?

Who will speak for me, when I have needles covering my entire body, and I am simply saying in my mind, I wish, I can just be normal like my friends. But then, I hear this strong voice out of nowhere boldly confessing this is your normal. All I can say, it takes my breath away.

Who will speak for me, I am just a child simply wanting to smile. I am like any other child who wants to partake in childlike activities, eat ice cream, run, jump, skip, and hop, spend a day in the park, catch a movie or two, or simply play with my siblings and my friends too. But most of the time, SCD has me bedridden; it continues, simply to give me the blues. Please tell me what must I do?

Yes, I will always do my best to speak for me, as long as I can, and as loudly as I can, until someone takes notice of me.

Thank you for taking the time to listen and read what I have to say. But before I go, I have one more thing I would like to say. Would you be so kind to join my hand so that we both can speak so loudly that the whole world will understand?

This is not simply a little request, to put you through a test. This is a demand, I seek from you and all the rest, who would be willing to take the challenge test.

Yes, I will always do my best to speak for me, as long as I can, and as loudly as I can, until someone takes notice of me.

I hope you will answer the call to not only speak for me, but for all GOD's children who suffer with this dreaded illness. It is a disease that causes our lives to be of much pain and misery.

Who will speak for me? I hope you will join hands with mine, and together we can speak for me.

A Letter to a Sickle Cell Disease Friend

Dear Friend,

I hope this letter finds you doing well today. I called you but you don't answer. I reached for you, but you are not there. You tell me that you had another bad crisis - it was so hard it knocked you to your knees, flat on your back - you did not even know where you were. I know you spend a great deal of time in the most unimaginable accentuating pain. I wish you would allow me in your world so I can be by your side. I know that I will never really understand what you go through. Please know that there are many of us who really truly care. You have repeatedly attempted to share with me what a crisis feels like but I simply do not know what to do.

Please forgive me for my lack of understanding. For many of us a crisis is (1) when we get a stain on our clothes, (2) when we go to start our vehicle and it won't crank, (3) when we miss a deadline at work or are scorned by our supervisor, (4) we don't obtain the promotion we had been praying for the last 36 months, or (5) we simply do not get things our way.

I know, I tend to major in the minor, but you my dear friend, you have to deal with the most unspeakable pain of living life with an illness many know nothing about or care to know. I am reminded of the most profound words which you echo that are in the book by Ms. Harper Lee in her award winning Pulitzer prize book *To Kill a Mocking Bird*, "You never really understand a person until you consider things from his point of view... and you climb inside of his skin and walk around in it." Well, I want to do just that if you will simply let me in and allow me to be your friend. Yes, life is full of pain and tragedy but it so much better when you allow others who care to be there with you.

I know you have told me not to weep for you. But, I often hear you in the late midnight hour crying yourself to sleep or simply murmuring during daylight, "Why me?" So, stretch out your hands, allow others to enter your heart. Because yes, we do want to understand.

To my wonderful dearest friend please know, I plan to be with you until the very end!

Recipe for Living Well with Sickle Cell Disease

Ingredients:

1 Cup of Kindness
3 Cups of Laughter
3 Tablespoon of Humor
1 Ounce of Pure Joy
A pint of Self Care
A Dash of Love and Respect
2 Cups of Understanding
3/4 Cup of pure excitement
A handful of generosity and Trust
A Full Bag of Fun
1 lbs. of Tenderness

Directions: Take all the above ingredients and mix well in a big bowl of patience, stir with determination and integrity, until all the lumps are out and then blend with sensitivity. Drain out all the fears and doubts. Compassionately let it sit for the next couple of hours. Set the oven to bake at 350 Degrees. Lightly grease your favorite pan with large smiles and a dose of self-esteem. Place in the oven for approximately 30 minutes and gently serve to all your friends, family, acquaintances, and the world for a life time.

Sickle Cell Warrior

Be strong, hold your head up and never give up!

Be confident and courageous because the battle is not given to the swift but the one who endures until the end. Endurance is indeed your first, middle and last name.

Be happy and humble because God almighty has created you to be bold, beautiful, and without any blunders.

Be an overcomer against prejudice, stereotypes, and discrimination against who you are because you are the brightest star.

Be the person who never lets your disease define who you are. Hold your head high and walk with a great deal of dignity and pride. You are the best of queens and kings because God is always on your side.

Be watchful of what you put in your body because it is delicate and needs lots of nurturing and nourishment to “keep on keeping on!” Drink plenty of water, and eat lots of vegetables and fruits. Yes, you can do this!

Be the person you want to be, and not the one the world has described you to be. Be a warrior and fighter until the end, then the world would have to say here lies the greatest woman or man.

Be not afraid of the pain when it seems to get you down and snatches away your laughter and joy. Pain so strong that words cannot describe. It knocks you to your knees, crying hopelessly and it seems like no one actually cares. Hold on Sickle Cell Warrior, you’re built to take a licking and keep on ticking. Yes, Yes, and Yes, you were built to last. This too shall pass.

Be a Sickle Cell Warrior, mighty and strong because you are the most awesome person who can live on and on.

Be a light in the darkest of times because you are built with greatness in spite of what you have on your mind!

Be the Sickle Cell Warrior who will continue to fight and fight even thou it takes all your might.

Be the Sickle Cell Warrior that others look up to because you are mighty and strong. Yes, your story will live on.

Stop, take a deep breath, hold on because you are all that you have, and know God almighty will never leave or forsake you. Yes, Sickle Cell Warrior “keep on keeping on”.

Commandments of Sickle Cell Person

- Thy shall drink plenty of water.
- Thy shall eat plenty of vegetables and fruits.
- Thy shall get plenty of sleep.
- Thy shall take all medication as prescribed by your primary doctor.
- Thy shall get to know your own body and acknowledge when it is cry-ing out for help!
- Thy shall always be kind and gentle to yourself.
- Thy shall not be afraid to inform family, friends, and personal acquaintances when you are not feeling up to par.
- Thy shall never feel ashamed, embarrassed, or humiliated by your illness.
- Thy shall always educate yourself concerning your illness.
- Thy shall never define oneself according to their illness.
- Thy shall set small obtainable and reachable goals.
- Thy shall avoid all toxic relationships, as much as possible.
- Thy shall live life on purpose!

Bill of Rights of Sickle Cell Person

As a person with SCD you have the right to the following:

1. Be treated with the utmost respect and dignity at all times.
2. Ask questions and get the appropriate answers about treatment and services.
3. Have 100 % participation in any decisions about your treatment and services.
4. Know the names of all the medications you are taking, why you are prescribed the medications and what are the side effects of the medications?
5. Not to be subject to any form of verbal, physical, sexual, emotional, financial abuse or harsh treatment.
6. Make a complaint, have it heard, and receive a prompt response, and to receive any maltreatment compensation as a result.
7. File a grievance if you are not satisfied with the outcome of your complaint.
8. Your own privacy.
9. Access to your medical records and to decide who else can see your records.
10. Education.
11. Employment.

12. An adequate standard of living.
13. Not to be discriminated against on the basis of race, age, sex, religion, national
14. Origin, sexual orientation, disability or marital status.

Campaign Pledge to Fight Sickle Cell Disease

I pledge on this day and forward, that I will take a stand, to stand up, stand out, and speak up on behalf of the SCD community. A community of people who have historically grossly suffered, been ostracized, set aside, marginalized, stereotyped and discriminated against simply because they have a life threatening, debilitating, deteriorating illness which overwhelmingly impacts their overall quality of life. The SCD community has experienced first-hand, more than any other group, excessive prejudice in the areas of education, employment, housing, and health care. Therefore, I plan to use my time, talent, and treasure to fight the good fight to ensure the SCD community’s voice is silent no more. Their voices are heard at the local, state, national, and global level to improve their quality of lives and respect that is long overdue. I will make it my business daily to educate, empower, motivate, and stimulate others to stand in the gap with me to ensure the SCD community is given the maximum quality of care, for every child, woman, and man regardless of their station in life! I make this pledge with a sound body and mind.

Name

Date

Recommended Books

- A Time of Sickle Cell Crisis by Angel Woods, Laurie Denktash, and Caleb Woods
- Back to Our Roots: Cooking for the Control of Sickle Cell Anemia and Disease Prevention by Ujamaa
- Breaking Silence: Living with Sickle Cell Anemia: Paperback by James Griffin (III).
- Cruising with Tahira by Samir K. Ballas, Lippincott Williams and Wilkins.
- Dying in the City of the Blue: Gettreys Story: A Time of Sickle Cell Crisis by Angel Woods, Laurie Dekatch & Caleb Woods.
- Evidence-Based Management of Sickle Cell Disease by M. D. M. Sc Yawn, M.S. P. H. Barbara M. D., George R. Buchanan, M. D. M. P. H. Afrenyi-Annan, Araba.
- Genetic Nemesis HBss Sickle Cell Anemia by Tosin Coker
- I Only Cry at Night: Living with Sickle Cell Disease by P. Allen Jones

- Let's Talk About Sickle Cell Anemia by Melanie Apel Gordon
- Living with Sickle Cell by Tahira Yvonne-Givhan
- Living with Sickle Cell: The Inside Story by Judy Gray Johnson
- My Health And Wellness Journal: Keeping Track of My Sickle Cell Medical History
- Now You See Me Now You Don't by Jan Reed Givhan
- Official Patient's Source Book on Sickle Cell Anemia by Jerry Story "A Time of Sickle Cell Crisis"
- Politics of Sickle Cell and Thalassemia by Elizabeth N. Anionwu
- "Sickle" A Personal Story of Pain, Purpose, and Perseverance by Dominique Friend
- Sickle Cell Anemia: Hardcover; by Judy Monroe Peterson
- Sickle Cell Disease: Psychological and Psychosocial Issues Publication by Anita Hurtig
- Sickle Cell Disease, 100 Years Later by Dan Moore, Sr. Phyllis Zachery- Thomas
- Sickle Cell Nature Healing: A Mother's Journey (Book) Paperback by Tamika Moseley
- Sickle Cell Pain by Samir K. Ballas Lippincott Williams & Wilkins
- The Enemy Within by Judith McBride
- The Pathophysiology of Sickle Cell Disease by Katherine Wood
- Understanding Sickle Cell Disease (Understanding Health and Sickness Series) by Miriam Bloom

Suggested Resources

- Link to Centers for Disease Control and Prevention (CDC) information on Sickle Cell Disease <http://www.cdc.gov/ncbddd/sickle-cell/facts.html>.
- Link to the U.S. Department of Education (DOE) information on IEP <http://ed.gov/parents/needs/spaced/iepguide/index.html>.
- Link to the U. S. Department of Education (DOE) information on 504 Plans <http://www2.ed.gov/about/offices/list/ocr/504faq.html>

Dedication

All the people who are currently suffering with Sickle Cell Disease and in memory of those who have died from Sickle Disease.

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