

Sickle Cell Disease

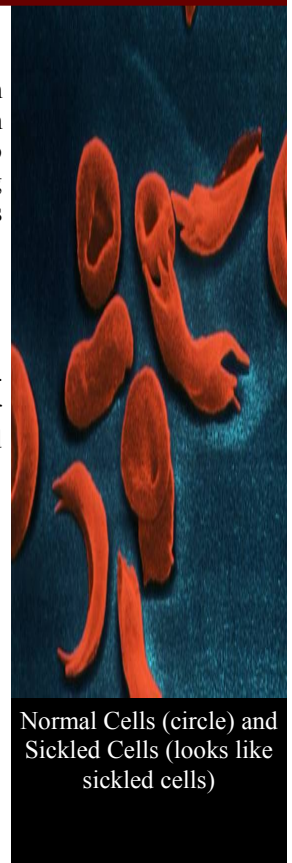
What is Sickle Cell Disease?

Sickle-cell anemia, also called sickle-cell disease, is a hereditary disorder in which abnormal hemoglobin* within the red blood cells (RBCs) causes the cells to take on abnormal sickle (crescent) shapes. This decreases the ability of the hemoglobin to transport oxygen throughout the body. The sickled cells tend to bunch up and clog the blood vessels, and they tend to break apart more easily than normal RBCs. This may cause inflammation, pain, tissue damage, and anemia.

What Causes Sickle Cell Disease?

The Sickle Cell gene is passed from generation to generation in a pattern of inheritance called autosomal recessive inheritance. This is where the father and mother have passed on the defective gene to the child. This disease is normally passed down by parents who have sickle cell trait

- **If an individual carries one gene**, they do not have disease and are called a "carrier" or said to have sickle trait.
- **When both parents have sickle trait**, there is a 25% chance of their children having sickle cell anemia, a 50% chance of their children having sickle trait, and a 25% chance of their children having no disease and no trait.
- **If only one parent carries the gene for sickle cell**, there is a 50% chance the child will have sickle trait and 50% chance the child will be normal and no chance that the child will have sickle cell anemia.



Normal Cells (circle) and Sickled Cells (looks like sickled cells)

Facts about Sickle Cell

Sickle Cell Anemia affects millions of people worldwide. It is particularly common among people whose ancestors come from Africa, Mediterranean countries (the Arabian Peninsula, India, and Spanish-speaking regions (So America, Central America, and parts of the Caribbean). Sickle Cell Anemia is the most common inherited blood disorder in the United States, affecting 70,000 to 80,000 Americans. The disease occurs in approximately 1 in 500 African American newborns and 1 in 1,000 to 1,400 Hispanic American births. About 2 million Americans, or 1 in 12 African Americans, carry the Sickle Cell Trait.

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- Educational Workshops
- SCDFOC 2nd Annual Inaugural Black Tie Event
- Sickle Cell Jog-A-Thon
- College Prep Workshop/Financial Aide Guide
- Parent Re-treat "R&R"

"All About Tots" Toddler Program



"All About Tots" is designed and catered to

our toddlers of ages (1) year to (6) year old. This program is designed to help parents understand their toddlers when they are having Sickle Cell Crisis. Our "All About Tots" program is design to: help toddlers cope with their pain, help parents identify when their child is going

through a crisis, how to care for your toddler when traveling, growth and development stages of toddlers with Sickle Cell Disease, and how to choose the right doctor for your toddler.

If you are interested in learning more about our "All About Tots" Program, please visit our website @ WWW.SCDFOC.ORG.

The Sickle Cell Foundation of Orange County, is dedicated to educating, empowering, and equipping youth and young adults with the authority and power to overcome the

challenges of sickle cell disease.

Give us a call and start your toddler today to **"Live by Design. Not by Diagnosis!"**

Vaccines

Vaccines are a way to help prevent serious infections.

- Flu vaccines every yr after 6 months of age.
- A pneumococcal vaccine at age 2 and 5 years of age
- Meningococcal vaccine (for some children)

Is there a cure for Sickle Cell? There is Hope!

In 1998, the FDA approved the drug Hydroxyurea responsible for reducing the number of painful sickle cell crisis in adults who suffers from severe sickle cell disease.

Hydroxyurea, destroys cells in the bone marrow, which results in an increase in special cells that can produce Hbf. Hbf, also known as fetal hemoglobin, which exists in the fetus and small infants. Most Hbf is later replaced by the hemoglobin that is present in the growing child and adult,

although some Hbf may persist. Fetal hemoglobin is able to block the sickling action of red blood cells so that infants with sickle cell disease do not develop symptoms of the illness while they still have hemoglobin F.

Adults who have sickle cell disease but still retain high levels of hemoglobin F generally have mild disease. While inheriting one copy of the mutation may cause mild symptoms, inheriting two copies of the mutation (one from the mother/one from the father) can cause major pain, hospitalizations, and could

even lead to a tragedy. Hydroxyurea is used to treat adults and adolescents with moderate to severe recurrent pain (pain in which usually occurs three, four or even more times in one year). The drug has proven to reduce sickle cell crisis, reduction in transfusions, and life threatening complications in this particular group. Although studies are still being done, their have been no protection from damage in the spleen or other bodily joints. Hydroxyurea is still being investigated in young people. To date, the response between children, teenagers,

Supporting Our Mission

There are two ways of spreading light: to be the candle or the mirror that reflects it.
Edith Wharton

The Sickle Cell Foundation of Orange County is seeking monetary contributions and in-kind services from businesses, corporations, foundations and organizations to support our mission. We know that corporate charitable giving, at its roots, helps to strengthen

the link between a company and its community. It's our corporate donors who provide our margin of excellence.

Annual gifts of \$1,000 or more and planned gifts are recognized in the Contributing Partner Program, and include complimentary tickets to our annual VIP Dinner and ongoing events. Other benefits also include quarterly newsletters, name recognition on all

printed, radio, and TV advertisements and so much more.

For more details, visit WWW.SCDFOC.ORG.

It is through your generous gifts that we are able to continue our mission, helping those with sickle cell to **"Live by Design, Not by Diagnosis"**.

What is the SCDFOC doing to support families with Sickle Cell Disease?

SCDFOC was founded in response to the ever-increasing disparities among Orange County youth with the disease of Sickle Cell and the support services available to them in Orange County. SCDFOC specifically targets children and youth who live and go to school in Orange County communities as well as the Riverside, Oceanside, and San Bernardino Counties.

Our mission and goal is simple; we will educate, empower, and equip youth and young adults with the authority and power to overcome the challenges of Sickle Cell Disease and is dedicated to educating, parents, teachers, and family members to help raise awareness to this disease and how it is important to take control of the challenges that come with having sickle cell or knowing someone that is affected by the disease.

The SCDFOC has a variety of support

programs that are extended to those with sickle cell disease, family members, caregivers, and educators affected by the disease. "We are here to help those who can't help themselves" said Teen Spokesperson, Charon Simmons. "I have been challenged by sickle cell for the past fifteen years of my life and I refuse to, " let this obstacle control my life, I choose to **"Live by Design, not by Diagnosis"**.

The Sickle Cell Foundation of Orange County is here to give support to those who are fighting this challenge. The SCDFOC offers family support, doctor referral programs, financial assistance, tutoring programs, transportation assistance, and educational programs. The SCDFOC hope to bring awareness to the forefront in the public and private school system as well. "There was never anyone in the school system to assist me and my family when my

son was in school and I had to educate the teachers and caregivers about SCD, said Star Simmons (parent of sickle cell patient).

The Sickle Cell Foundation of Orange County, has established an environment in which members are at liberty to express their feelings and personal challenges related to SCD with others, who have a unique understanding of their issues. To provide a forum in which members can give and receive from their peers.

The Sickle Cell Foundation of Orange County is committed to sowing our time, compassion and understanding to each participant. This support group was designed to be a vessel in which members can share and give back to those with SCD. The scope of the discussion is determined by the group members.



A Day in My Walk

It is important that individuals dealing with the challenges of Sickle Cell Disease know that there is hope. Although, there is currently no cure for the disease, some people can still live somewhat of a lengthy life. With the right medical attention, proper health care and a healthy mindset, there is still hope. **The Sickle Cell Foundation of Orange County** has provided a way for those coping with the disease, to give others hope. The daily walk in a person's life dealing with sickle cell dis-

ease, can sometimes be very lonely. The complication from SCD can cause some to be hospitalized for long periods of time, which will cause them to sometimes be separated from their normal day to day activities. **"A Day in My Walk"** was created for those dealing with SCD, to log their social, physical, emotional, and spiritual feelings down. This journal was created to not only track one's challenges, but ones accomplishments. This Daily Journal was designed to give others

"Hope". By allowing others who are experiencing the same physical challenges you are feeling with this disease, but also allowing one to see how you have not allowed this challenge to control your life, one has given another the will to **"Live by Design, not by Diagnosis"**. If you would like to share your testimony of **"A Day in My Walk"**, please send your Journal Form to: Info@scdfoc.org, and we will post your story, to give others encouragement and hope.

The Word by Pastor Ronald Ozase-Griffin

Living by Design. Not by Diagnosis

Life and Death are in the Power of Our Tongue. The famous quote from Thumper in Bambi is, "If you don't have nothing nice to say don't say nothing at all." If I say that I am "Living by Design and not by

Diagnosis," it is more than a witty phrase or a positive affirmation. It is a Life Style grounded in Gods way of thinking. Gods Word says, "If we ask according to His Will, it will be Given to Us." Gods Will has always been for us to have Life and Good Health. The Power of Gods Spoken Word gave Life. Gods

design was to create us in His Image and Likeness. His Image Exudes Life, His Likeness Always Speaks Life.

Therefore, with the Power of our Tongue let us commit to Live and Say, **We Live Life by Design. Not Diagnosis.** "

Live by Design...
not by diagnosis

Our Vision

*A Message
from the Founder*



As a parent of two, both diagnosed with Sickle Cell Disease, I understand the challenges of dealing with this disease first hand. My family and I have agreed on one accord to give our life experiences, challenges, obstacles, education, and support to those dealing with the disease. We hope that you know and understand that the Sickle Cell Foundation of Orange County is committed to helping you overcome your challenges of Sickle Cell Disease. Please know that life a gift. We must always "Live by Design, not by Diagnosis", we determine the outcome. We will never know our limits, until we test how far we can go. Start today! Live life to the fullest! Never give up and always know "Without hope, there is nothing to look forward to". When you dream, that is hope. Start living today.

To educate, empower and equip children, young adults and adults with the authority and power to overcome the challenges of Sickle Cell Disease. To educate youth and young adults who are dealing with the physical and psychological complications of Sickle Cell Disease. To provide self-assurance, disease management and the ability to overcome obstacles and to boldly walk towards their purpose and destiny.

We would love to hear from you. If you would like to share your story on how you are "Living by Design, not by Diagnosis", please submit it today and maybe your story will be printed in the next newsletter. Submit your story via email: supportservices@scdfoc.org

Please visit our website @ www.scdfoc.org and post your comments at the Sickle Cell Forum Board @ www.scdfoc.org/forum/

Remember you, have a choice "Live by Design. not by Diagnosis".



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