



The Sickle Cell Foundation of Orange County **NEWSLETTER**

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**WHEN PASSION
MEET PURPOSE
BY BRETTE WOODS**



Have You Donated?

RuSH

CDC considers SCD a major public health concern and is working to learn more about it. In collaboration with the [National Heart, Lung, and Blood Institute](#), CDC is coordinating the Registry and Surveillance System for Hemoglobinopathies (**RuSH**).

RuSH is a program to collect surveillance health information on people with SCD and thalassemia, two common types of hemoglobinopathies (diseases affecting red blood cells).

The **RuSH** pilot program will occur over 4 years. The first 2 years will concentrate on creating a surveillance system, and the final 2 years will result in a system to collect clinical information from people with SCD or thalassemia. The information collected will help many people understand the disease better.

Determine How Many People Have SCD and Thalassemia

Data from the system will fill the need for statistically sound estimates of the prevalence of SCD and thalassemia. The pilot program will include people who have not been identified through newborn screening, such as immigrants and those born before newborn screening was implemented.

Create a Registry of Patients in Order to Conduct Research

Potential research topics might include:

Understanding how SCD affects a person's ability to have children.

Learning more about what happens to people with SCD as they age.

Understanding the impact of iron overload on people with thalassemia.

Develop Health Promotion and Education Materials

Emergency Department Visits of Sickle Cell Disease Patients by Age, 1999-2007

| | |
|-------------|-------|
| 0-9 years | 12.2% |
| 10-19 years | 15.0% |
| 20-29 years | 31.1% |
| 30-45 years | 34.6% |
| 45+ years | 7.0% |

General awareness of SCD is lacking in the public. CDC will partner with community-based organizations, academic institutions, and clinical care centers to develop education and training tools tailored for patients, families, and health care providers.

Have you been Tested for Sickle Cell Disease or Sickle Cell Trait?

Raising Money While Raising Awareness!



Unlike most youth her age playing throughout the summer and taking advantage of their Summer Vacation. Alyssa Simmons, decided to raise money while raising awareness for Sickle Cell Disease!

Alyssa know first hand the challenges that

come along with having the disease. Her brother (21 year old, Charon) and herself both live with the disease.

Alyssa, who is not only a patient of sickle cell disease but she is the Spokesperson for The All About Tots “ for The Sickle Cell Foundation of Orange County.

This summer, Alyssa asked her mom could she help raise funds on her own for sickle cell patients? So after getting permission from her mom and the support of her family, Alyssa decided to have a Lemonade Stand Sale! She raise \$89.50 in only four hours and since

then, Alyssa has decided to continue to raise money for the foundation and for “Operation Smile” which is a program through The Sickle Cell Foundation which provide smile packs for all toddlers, youth, and young adults through its program.

If you are interested in having your youth or yourself join Alyssa as an Ambassador for Sickle Cell, please contact us through our website: www.SCDFOC.org or call us at (949) 331.-8121.

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,

September Is: National Sickle Cell Month!

The Sickle Cell Foundation of Orange County (SCDFOC) has made significant progress in educating the community about sickle cell disease.

To keep this progress going, we need **your help!** It is our goal to continue educating the community and patients about sickle cell

disease, current research, clinical trials, and how to live a healthier lifestyle.

Please click the **donate button** and give generously this month is National Sickle Cell Month.



"Living by Design, Not by Diagnosis"

- ⇒ **September 17th,**
K.I.S. Celebrity
Bowling Tournament
PINZ Entertainment Center
12655 Ventura Blvd, Studio City, CA
www.kisfoundation.org
- ⇒ September 22, 2010
Annual Blood Drive
- ⇒ September 25th,
The "Picture Me
Project"

A Haunting Secret

Nakia Ransom, The fresh new face of Theater/Drama, is a brilliant writer, actor, director and producer. Born and raised in Jackson, MS but moved to Southern California to finish his education and pursue his dreams as a successful entrepreneur. The talent that is displayed in his writing and directing is one to be recognized. Nakia is the founder of JNJ Production an entertainment company which primarily focus is Performing Arts. Nakia has taken local actors and actresses from the Orange County and LA County areas and formed an outstanding diversified cast whom he has carefully shaped, groom and directed to tell his new compelling story the stage play "A Haunting Secret".

It's about "A young single mother whose teenage son have been diagnose with Leukemia. As she desperately races against time to save her son's life. She receives shocking revelation that forces her to revisit her past even if it threatens to destroy her family relationship.

He has been performing this stage play through out Southern California since February 2009. The story line, breathtaking content and powerful message that Nakia tells in this stage play has gotten the attention of such prominent non-profit organization like Be The Match (National Marrow Donor Program), YWCA (Empowering young women and adult women to Live, Learn and Grow), H.A.L.O (Focuses on the Family), and since then he have partnered and rewrote parts his script to incorporate the supporting organization. He was able to take what they advocate to communities and make it apart of his story, amazing.

This adjustment took "A Haunting Secret" to another level. What are they saying? Aundrae Russell-Radio Free 102.3 KJLA said "Riveting, Best Acting I've Seen On Stage", Bill Sutherland-City Councilman of Torrance, CA said "Enlightening, Relevant and A Must See Play", Rodman-Comedian said "Very Tense", Donna Collins-Be The Match said "Totally Suspenseful and I Couldn't Stop Crying", Nita Thompson- AA4SCDAwareness said "So Impressive and The Performance was Outstanding" to name a few. This is what makes him a Prolific Thinker/American Play write. His God given talent continues to expose him to prominent and respected people throughout southern California.

Once again Nakia is so honored to have his stage play "A Haunting Secret" recognized by the well respected and honored Star Simmons, the founder of The Sickle Cell Foundation of Orange County. He is so excited to work with Mrs. Star Simmons in bringing awareness to sickle cell disease in every community. So get ready Orange County, Star Simmons is bringing Nakia Ransom stage play "A Haunting Secret" to the OC. A story so "Griping" it will leave you speechless. So remember come out to meet the Host Star Simmons and Writer/Director/Producer Nakia Ransom. Support the cause.

"Real Life + Real Stories = Reality Drama"
-Nakia Ransom-



UPCOMING EVENTS

- ⇒ **October**
Annual Blood Drive with The Orange County Register
- ⇒ **October 23rd,**
Annual Black Tie Event at The Parrot in Orange County
- ⇒ **October 30th,**
Annual "All About Tots" Harvest Event
- ⇒ **October 30th,**
Operation Smile FVRH
- ⇒ **November**
Annual Thanksgiving Food Giveaway
- ⇒ **November**
JNJ Productions Presents "A Haunting Secret" Dates: Show times may vary

As those familiar with Sickle cell disease (SCD) know, it is a terribly debilitating genetic disease. It results in episodes of great pain ("sickle cell crisis"), long term organ damage, exercise intolerance, increased stroke and infection rates, and decreased lifespan for approximately 70,000 to 100,000 SCD sufferers in the U.S. and more than 4 million people worldwide.



Emmaus Medical, Inc., a private pharmaceutical company in Torrance, California, was founded with a primary goal of finding an effective therapy for SCD.

A novel therapy for SCD using L-glutamine is now in the Phase III clinical trial. In 2009, the FDA authorized Emmaus to begin the Phase III clinical trial directed to study L-glutamine as an experimental agent to reduce sickle cell crisis. Patient enrollment for the Phase III clinical trial began in mid-2010.

“As a physician I have seen firsthand the severe pain in patients with sickle cell disease, so

I am very pleased we have reached this stage in our development of this potential treatment,” said Dr. Niihara.

In the Phase II clinical trial, we observed an excellent safety profile and positive trends in decreasing the number of crises as well as reducing the frequency of hospitalizations in sickle cell disease patients. We look forward to the findings from the much larger group of research volunteers in the Phase III clinical trial.”

In the Phase III clinical trial, researchers at 20 to 25 sites around the country will be enrolling up to 225 homozygous sickle cell anemia or sickle β^0 -thalassemia patients as research volunteers, age 5 years and older, with a history of at least two episodes of painful crisis during the past 12 months. This 57-week study will require a monthly clinical visit. Eighteen sites are already in various stages of negotiations to participate in this multi-center research trial and additional sites are expected to sign up soon.

For information on participation and participating sites, please call Emmaus toll-free at 1-877-420-6493 and ask for Henry Macan, M.D. or Rafael Razon, M.D.

When Passion meets Purpose by Brette Woods of Anaheim Team

I had the pleasure of meeting Star Simmons at a Community Outreach Event. As I listened to her tell me the story behind her foundation I was struck by how uninformed I was on Sickle Cell even though I'd lost a family member to the disease. I immediately knew that Star Simmons was a woman with a passion for helping others.

I on the other hand have found a purpose for my life recently after becoming involved in voter registration over the summer. What I learned changed my life for ever and brought into focus for me why some communities suffer while others prosper. It's because those of us in who live the best lives VOTE! The answer I thought was just lack of information and to test my theory my husband and I formed an outreach team. Our singular purpose is to get as much information as we can to the general public on issues that affect the quality of their lives.



Armed with a purpose I set out to prove my theory I attended an event in an underserved community. My husband and I met a community of amazing people who found themselves at the bottom of society. Some were there due to bad decision making, but the majority was there because of the current economic situation. The people we met were Democrats, Independents, Republicans, Educated, Uneducated, different races & different faces with one thing in common, they had nothing!

The information I provided them was intended to let them know how to use the political system to change their lives. My intention was to leave them armed with the tools they would need to accomplish their goals so they would be empowered from that day forward.

We gave them this simple plan:

Always remember to vote because if you don't vote you don't exist!

If you don't like your schools... VOTE for the guy who cares about schools funding

If you want job training... VOTE for the person who supports job programs

If you want safer neighborhoods... VOTE for the guy who wants to put more officers on the street.

If you want job opportunities... VOTE for the guy who's against our sourcing jobs

Organize and volunteer to help your community and its causes.

Write letters to your local, state or federal governments.

Put together petitions and collect signatures to put things on the ballot so they can be voted on.

When I was done with my presentation my husband and I went around and asked each individual to commit to vote on November 4, 2010. One older gentleman grabbed my husband by the hand and said, "Thank you so much for talking to us. The LORD must have sent you guys because no one ever comes here and tries to help us!

When Star and I spoke it became clear to us that some of the people I'd encountered may have had Sickle Cell Anemia and not have known it. It also became clear that the information she provides needs to reach as many people as possible. From that moment on we realized we had similar goals in mind and decided to work together. Star's passion and my purpose meet at a political time in our country. I ask that all who read this article consider the least of us when casting your votes this November. Need is a universal concept that crosses party lines and ideologies. I ask that everyone vote this November 4, 2010. I also ask that you fact check everything you hear and read so that you don't inadvertently vote for something or someone who stands against the things you stand for. I'd suggest websites like FAC-TCHECK.ORG which is non-partisan.

Please keep in mind that some of the Sickle Cell patients Star's foundation helps are dependent on social programs to stay healthy. So I humbly ask that you consider their needs when casting your vote this November 4, 2010. Let's stand together and support the least of us!

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Blood Supply

Blood Transfusions are vitally important in the treatment of those living with Sickle Cell Disease.



Yearly Checklist

To ensure that there is no lack, let us continue to give. Get involved today!

You can help ensure that when you or your family member need blood, by doing your part today! To get started, contact Star Simmons (949) 331-8121 and invite your friends, co-workers, church members, and everyone you know. Do your part today!

Remember: Children ages 3 and under with Sickle Cell Disease must have the following tests performed each year:

- Dental Exam
- Full Eye Exam
- TCD (to measure the speed of blood flow to the brain, to identify patients at great risk for having a stroke)
- MRI/MRA
- Blood Test for liver and kidney functions
- Blood count, reticulocyte count and oxygen saturation measurement

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.



Founder/Star Simmons

Sickle Cell Foundation of Orange
County
P.O. Box 3780



Once again, The Sickle Cell
Foundation of Orange County
would like to give a “Special
Thanks” to Trinity Broad-
cast
Network” TBN.

TBN has been very generous
to our foundation in helping
us spread the word and bring
awareness about Sickle Cell
Disease.

It is through Paul and Jan
Crouch unselfishness to oth-
ers, that they have help us by
being the conduit of spread-
ing the word to the commu-
nity about Sickle Cell Disease.

**Airs on KTBN on 09/17@
10 am, 09/20 @ 8:30 am**