



NEWSLETTER

www.SCDFOC.org

Story Highlights: O.C. businessman supports local charities and delivers Christmas wishes to children at Fountain Valley Hospital.

The Sickle Cell Foundation of Orange County

Some children don't get to go home for Christmas. "If we can help put a smile on their face – that's everything," So says local business owner, Mark Gombar. That enthusiasm is just what Star Simmons of the Sickle Cell Disease Foundation of Orange County was counting on when she asked Mark to sponsor a child's Christmas at Fountain Valley Hospital this year. "I asked the right person. Initially I thought I would have to contact a variety a businesses to raise funds to sponsor Christmas at the hospital this year. But Mark just told me to get whatever the kids needed," said Star.

Even though it is everyone's wish to be well enough to be able to spend the holidays at home, for some children, it just isn't possible. "For kids in the pediatric ICU and pediatric care wards, having to spend the holidays in the hospital is especially tough," Star explained. Every year Simmons finds a way to bring Christmas to them. "Mark and his company, In Every Way Gourmet, made this the best Christmas ever!"

Over the years the company has lent support to a variety of local charitable organizations including American Family Housing, The Western Eagle Foundation and Veterans First. According to Gombar the featured charity of choice in 2012 for In Every Way Gourmet will be Star's Foundation. This is a natural partnership as the company vice president, Dolumeter Wharton, is Star's sister and has been closely involved with the charity for many years. Wharton explained, "Both my niece and nephew are living with Sickle Cell

Disease and have spent so much time in and out of hospitals over the years. Bringing comfort to hospitalized children is really personal for me."

That is why Dolumeter joined Mark and Star to distribute gifts to the children in the pediatric ICU and pediatric care wards of Fountain Valley Hospital this past Friday before Christmas. Children had a wide variety of gifts from which to choose including everything from iPods and hand-held televisions to board games and dolls. "It was a lot of fun. The hospital staff was fantastic and I always enjoy working with Star's organization. There is nothing like a child's smile," said Mark.

The Sickle Cell Disease Foundation of Orange County is a 501(c)(3) organization founded in 2006 and dedicated to raising the awareness of Sickle Cell Disease. Services provided are listed on the organization's web-site (scdfoc.org) and include doctor referral programs, hospital care packages and school assistance programs among others.

In Every Way Gourmet's chef has developed recipes and meal plans tailored to the dietary needs of those living with sickle cell disease.



These recipes will be featured in The Sickle Cell Disease Foundation's quarterly newsletter throughout 2012.

In Every Way Gourmet is a boutique menu planning and food delivery service headquartered in Anaheim. The company helps consumers develop healthy eating plans supported by high quality meals and ingredients. Customers are assigned a personal shopper to tailor menus to a family's unique tastes, dietary goals and schedule. Chef and nutritionist services are

Battle of the Badges "Orange County Sheriff Dept Blood Drive

The Battle of the Badges Blood Drive will run for four weeks from Wednesday January 18th to Saturday, February 18TH 2012, as Badge Carrying Personnel, Family and Friends who can donate the most blood and ultimately save the most lives.

This year we will be teaming with "The Sickle Cell Foundation of Orange County" and "Be The Match"—Bone Marrow Registry. To learn more about

these organizations and what they do in the community please visit their web-sites. Sickle Cell Foundation of Orange County web site www.SCDFOC.org and Be The Match-Southwest District web site is www.BeTheMatch.org.

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Replenishment Blood Drive And Bone Marrow Screening

In Honor of Charon Simmons



Charon Simmons 22, was born with Sickle Cell Disease. He has lived in Orange County all his life and has served his community through several years with the Orange County Sheriffs Explorers and he is a graduated of Mater Dei High School. On September 1st, 2011, Charon went into cardiac arrest not once but twice and had multiple organs failure. Due to multiple organs failure, Charon needed over 75% of his blood replaced for a survival chance of living. He received multiple transfusions of red blood cells and platelets as a very important part of

his treatment. Charon is not only a Sickle Cell Disease Patient, Spokesperson, and he is also an Advocate for those living with the challenges of this disease.

The many friends of Charon encourage community to donate blood at this special blood drive in support of his journey back to health and for many other area patients who receive their care in the community. Anyone donating blood at this drive may also elect to become a member of the BE THE MATCH REGISTRY free of charge by completing additional paperwork and submitting a sample mouth swab.

The Sickle Cell Foundation of Orange County a not-for-profit organization that educate and empower those living with sickle cell disease and the community!

If you are interested in being tested for Sickle Cell Disease, Please bring a doctors prescription to be tested, identification and insurance info and you will have the opportunity to be tested while you donate blood!

PLEASE DONATE in honor of Charon!

“Be the one who makes a difference and not sit and wait for something to happen”

Supporting Our Mission

The Sickle Cell Foundation of Orange County would like to give thanks to The Santa Ana Black Historical Society, The Omega PSI PHI, In Every Way Gourmet, and all others who donated clothing for our upcoming “Free Clothing Give-a-way!

Again, thank you all for your generous donations!



The SCDFOC has raised over 1,000 clothing articles to help those who are less fortunate. If you are interested in helping our continuous clothing drive, please reach out to out by calling us at 949-331-8121 or via email at Info@scdfoc.org.



New!

The Chefs Corner from In Every Way Gourmet



Patients with sickle cell anemia require high-calorie protein-rich meals and snacks to deal with excess fatigue caused by oxygen-starved cells, according to Nutrition. Ongoing fatigue should be closely monitored because it can trigger a sickle cell crisis --- a painful episode that occurs when sickle cells block normal blood flow in body organs.

SCDFOC has partnered with IEWG to bring healthy nutritional meals and recipes to those with SCD to live a healthier and more quality lifestyle. With the partnership with IEWG, the SCD-FOC has created "CHEFS CORNER". We will bring specialized healthy recipes for those with SCD. Patients with sickle cell anemia require high-calorie protein-rich meals and snacks to deal with excess fatigue caused by oxygen-starved cells, according to Nutrition. Ongoing fatigue should be closely monitored because it can trigger a sickle cell crisis --- a painful episode that occurs when sickle cells block normal blood flow in body organs.



The Sickle Cell Foundation of Orange County would like to welcome two of our newest Board Members to our team.

Mr. Monty Starks-Director of Programs, comes to us with a Bachelor of Arts Degree, a member of Omega Psi Phi Fraternity, Phi Alpha Theta History Honor's Society and African Culture Art Counsel with the Bowers Museum. Monty currently resides in Laguna Niguel, CA and he brings much to the foundation.

Ms. Terry Burden-Director of Marketing bring a joyful smile and enthusiastic feel to our foundation. Her compassion for those with sickle cell is deeply rooted from her compassion of giving to those less fortunate. Terry brings to the foundation a Bachelor Degree in Information Technology, over 25 years of telecommunications experience and smile that is bright as her spirit!

As President and Founder of the Sickle Cell Foundation, We welcome and appreciate you!

Sincerely,

Star Simmons/President

Sickle Cell Eye Disease



Sickle Cell vaso-occlusive events can affect every vascular bed in the eye, often with devastating visual consequences. Because early stages of sickle cell eye disease do not usually result in visual symptoms, the disease can go undetected unless a formal eye exam is performed by an ophthalmologist. The examination should include an accurate measurement of visual acuity, assessment of pupillary reactivity, careful evaluation of the anterior structures of the eye using a slit-lamp bio microscope, and a thorough examination of the posterior and peripheral retina through a dilated pupil. This last examination should include fluorescein angiography. Patients with sickle

hemoglobinopathies should have yearly eye examinations beginning in childhood and continuing through adulthood.

CLINICAL FINDINGS

The clinical manifestations of sickle hemoglobinopathies are grouped according to the presence or absence of revascularization in the eye. The distinction is clinically relevant because proliferation of new blood vessels on the retina is the key biological event that sets the stage for progression to vitreous hemorrhage and retinal detachment.

NONPROLIFERATIVE DISEASE

Non-neovascular ocular manifestations of sickle hemoglobinopathies include conjunctival vascular occlusions that transform smooth vessels into comma-shaped fragments, iris atrophy, retinal hemorrhages, retinal pigmentary changes, and other abnormalities of the retinal vasculature, macula, choroid, and optic disc. These clinical findings are readily apparent on dilated ophthalmoscopy, and all occur due to local vaso-occlusive events but rarely have visual consequences.

PROLIFERATIVE DISEASE

Progression to neovascularization or to the proliferative stage involves the growth of abnormal vascular fronds that place patients at risk of vitreous hemorrhage and retinal detachment. The initiating event in the pathogenesis of proliferative disease is thought to be peripheral retinal arteriolar occlusions. Local ischemia from repeated episodes of arteriolar closure is presumed to trigger angiogenesis through the production of endogenous vascular growth factors, such as vascular endothelial growth factor and basic fibroblast growth factor (1,2). Goldberg has defined five stages of proliferative retinopathy (3). In stage I, peripheral arteriolar occlusion is present. In stage II, vascular remodeling occurs at the boundary between perfused and nonperfused peripheral retina with the formation of arteriovenous anastomoses. In stage III, actual pre-retinal neovascularization occurs. The neovascular fronds typically assume a shape that resembles the marine invertebrate *Gorgonia flabellum*, known commonly as the "sea fan." Stage IV is defined by the presence of vitreous hemorrhage, and stage V is defined by the presence of retinal detachment. This last complication results from mechanical traction created by chronic, enlarging fibrovascular retinal membranes, with or without hole formation in the retina.

Although peripheral vaso-occlusion may be observed as early as 20 months of age (4), clinically detectable retinal disease is found most commonly between 15 and 30 years of age (5). Sickle retinopathy is found more often and earlier in SCD-SC, but is also common in SCD-SS and sickle thalassemia. Observational cohort studies have also shown that stages IV and V retinopathy occur more often in SCDSC subjects than in those with SCD-SS (6). It is a paradox that despite the less dramatic systemic consequences of their disease, subjects with SCD-SC and sickle thalassemia are more likely than SCD-SS patients to have serious ocular manifestations. Research has not been able to explain the reason for this profound discrepancy in the severity of the retinal and systemic manifestations among the various sickle hemoglobinopathies (see the introductory material and chapter 2, Neonatal Screening, for an overview of disease subtypes).

Santa Ana Black Historical Society



The Santa Ana Black Historical Society (SABHS) extends our appreciation to each and every one for a year of outstanding collaborative effort in the African American community.

We are fortunate and blessed here in Orange County, California to be among the ranks of many organizations who strive to further our collective, collaborative and individual goals. SABHS applauds the accomplishments of our

colleagues throughout the community and across cultural disciplines. We welcome 2010 in anticipation of a year of hope, promise and realization for all.

SABHS was founded in 2004 by two dynamic women – Mrs. Barbara Lawrence-Hill and Mrs. Harriet Wooderts-Tyler. They envisioned establishing a repository to record the substantial history of African Americans in Santa Ana and Orange County

Under the leadership of T. Leon Berry, SABHS continues to grow and develop in its scope and realm. We are committed to archiving and promoting the unique and varied legacy of local African Americans and their myriad contributions to our region's benefit, as well as the achievements and endeavors of the people of the African Diaspora.

Towards these objectives, SABHS sponsored several events that celebrated African American life in our county:

The Santa Ana Black Historical Society hopes that as we embrace the spirit of UMOJA (unity), we may count on your participation and support. To this end, we are requesting you, your company and your organization to include SABHS in your budgetary plans each year.

We are seeking donations of \$5000; for our building fund however; all contributions will be appreciated and responsibly applied to SABHS endeavors for fiscal year 2010- 2011. SABHS is a non-profit, 501 (c) (3) foundation, such that your contributions are tax-deductible.

We thank you for your continued interest in the Santa Ana Black Historical Society. Here's to– another year of tremendous achievement!

T. Leon Berry

Healthy Diets for Sickle Cell Disease Patients

Sickle cell anemia is a genetic condition in which the body produces red blood cells shaped like sickles instead of the normal round shape, according to Medline Plus. Sickled red blood cells cannot transport enough oxygenated blood to body tissues, which leads to anemia. The sickled red blood cells also get stuck in blood vessels, which can cause pain and organ damage. Patients with sickle cell should eat foods high in calories, proteins and folic acid.



High Calorie Foods

Patients with sickle cell anemia need more calories in order to fuel the production of red blood cells to replace damaged sickled red blood cells, according to Nutrition. These patients can become easily fatigued due to the lack of oxygen transported to body tissues. High calorie foods provide extra energy. Example of high calorie foods include cereals with added milk and sugar, pasta, whole grain breads, croissants, muffins, starchy vegetables such as potatoes, bananas, avocado, milk shakes, yogurt, fried meats, cream-based soups, whole milk and whole milk products.

High Protein Foods

Patients with sickle cell anemia should eat a high protein diet, according to Medline Plus. Protein helps the body make new red blood cells. Protein also enables the body to maintain lean body mass. Sources of proteins include lean meat, poultry, fish, beans and dairy products.

Folic Acid

Patients with sickle cell anemia need extra folic acid in their diet, according to MayoClinic.com. Folic acid is important in the formation of new red blood cells. Folic acid is found in foods such as green leafy vegetables such as spinach, kale and broccoli, fruits and grains. The doctor may also prescribe a folic acid supplement.

Fluids

Patients with sickle cell anemia should drink at least eight glasses of water everyday, according to MayoClinic.com. Staying hydrated helps dilute the blood, reducing the chances that sickle red blood cells will form.

References

Medline Plus: Sickle Cell Anemia

MayoClinic.com: Sickle Cell Anemia

Nutrition: Sickle Cell Anemia Diet

The President's Corner



“The passion that I have for service comes from a deep sense of respect for the individuals, parents and families who face the daily struggle of how to cope with the many issues caused by this devastating disease. I have personally suffered from these same struggles. I am a parent of two children both with sickle cell disease and I have supported several families or individuals who lost love ones to underlying causes associated with sickle cell disease. As a parent of sickle cell patients and advocate for sickle cell disease, I have seen the lack of coordinated medical and psychosocial services available for these individuals. I have seen the disproportion of research dollars for sickle cell disease in contrast to other less prevalent diseases. Because of these issues, I would like to use my experience and passion for Sickle Cell Disease to become the voice that commands the respect it deserves to support services and inspire the research to find a cure for this disease.”

The Sickle Cell Foundation of Orange County was founded in 2006, as a 501(c)(3) organization of the Internal Revenue Service. Starlerra knows first hand the complications and challenges that come with Sickle Cell Disease. Founded in response to the ever-increasing disparities among Orange County youth and adults living with SCD.

The Sickle Cell Foundation of Orange County is committed to increasing the public's awareness of sickle cell disease; through educational seminars, community based workshops, educational activities, and other support programs. Our goal is to provide continuous education about the disease, its management, and its myriad of issues. Our strategy is to educate youth, young adults, parents, caregivers, family member, teachers, and the community; by helping raise awareness about Sickle Cell Disease.

The need of Public Awareness for Sickle Cell Disease is so urgently clear: without the serious jointed effort of education and support for those affected with SCD, those affected have no real chance of living a long and healthy life. The impact will mitigate the challenges to truly **“Live by Design, and not by Diagnosis”**. By educating, empowering, and equipping those individuals with Sickle Cell Disease to take charge of the disease. The program also provide education on dealing with the physical, psychological, mental, social, economical, health care, and pain management .

SCDFOC, specifically targets those with Sickle Cell Disease and their families. Secondary, will be the educational awareness to caregivers, educators, and the community. Because each of our lives are closely knit to one another, by significantly impacting one; you will have a positively outcome of touching them all. We are focus on bringing aware throughout the entire Orange County surrounding areas.

Sincerely,

Star Simmons

President & Founder

The Sickle Cell Foundation of Orange County



The SCDFOC is committed to increasing the public's awareness about sickle cell disease; through educational seminars, workshops, community-based activities, and other support programs.

It is because of your generous donations and unselfishness to give, that has allowed us to be the pillar for those suffering by the complications of sickle cell disease. My family and I, truly appreciate and are humble for your loving response and immediate desire to give to those who are affected by the disease.

We pray and believe with your continuous support, that 2012 will be a year of explosive giving and prosperous returns!

President & Founder
The Sickle Cell Foundation of Orange County



The Sickle Cell Foundation of Orange County

Post Office Box 3780