

Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



Calendar Listings:

March 4th SCANJ Presentation at Ramapo College. 1:00pm

March Breakfast Series Mini Workshops 9:00am-10:30am Thursday's at the Van Vleck House, 21 Van Vleck Street in Montclair.

- **14th Introduction to Chronic Disease Self Management Program and Volunteerism**
- **21st Community Based Programs for Sickle Cell Disease.**
- **28th Treatment Updates; What You Need to Know About Hydroxyurea.** Guest Presenter- Jill Menell, MD, Chief of Hematology/Oncology at St. Joseph's Hospital in Paterson.

What You Need to Know About Hydroxyurea. Guest Presenter- Jill Menell, MD, Chief of Hematology/Oncology at St. Joseph's Hospital in Paterson.

SCANJ partners to offer FREE CDSMP **Take Control of Your Health Six Week Community Workshops:**

- **Feb.21st begins** Community Partner- NAACP. Thursdays at the Van Vleck House in Montclair. Enrollment now closed.

- **Mar.2 begins** Community Partner -Independent Club of Colonia. Saturdays at 10 am in Colonia

- **March 6 begins** Community Partners- Family Success Center of Rio Grande partnering with The Concerned Citizens of Whitesboro. (Cape May County) Wednesdays at 6:30pm. In Rio Grande

You can register for programs listed by phone 973 482-9070. Online via sicklecellnewjersey.org calendar or scanj.eventbrite.com

SCANJ is the New Jersey Chapter of the



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Issue 3

Say It Loud!

March 2013

Sickle Cell News You Can Use

The Sickle Cell Association of New Jersey

A Note From The Executive Director: Beyond The Game...



Mary Bentley LaMar, Founder & Executive Director, gets the rules of the game from Rich Petriccione, SVP, Philanthropy & Community Relations, Super Bowl 2014

I hope this note is finding you in good health and just as importantly, in good spirits.

I am in good spirits, thanks in part to the inspiration I get every day as a result of working with, and assisting, courageous, individuals and families dealing with sickle cell disease.

When you read the monthly issue of *Say It Loud*, you catch only a small glimpse of what is currently in play.

Each time I finish an issue and send it out, without fail, I receive more information that I wish I could have included. Somebody calls me, I read something, or I attend a meeting that opens up a whole new idea, program or service that the sickle cell community could benefit from. This has encouraged me just knowing that there is a whole team out there fighting.

Santonio Holmes of the NY Jets with his *Third and Long Foundation* is on that team. Twins, Jason McCorty of the Tennessee Titans and Devin McCorty of the New England Patriots with *Tackle Sickle Cell* are on that team. You, in your own way, are on that team.

So I ask you to look beyond your current circumstances.

Know that there is a team with you constantly creating opportunities to improve the quality of life for individuals living with sickle cell disease.

~Mary

"The success of the group as a whole is the basis for any tradition which we may create. In such traditions lies the sense of discipline and the inspiration which serves as a guide for those who come after, so that each man's job is not just his job alone but a part of a greater job whose horizons we at present can only dimly imagine for they are beyond our view."

Excerpt of letter from Dr. Charles R. Drew to his resident, Jack White in 1946.

Senator Lautenberg, to issue a proclamation acknowledging the late Frances Thompson-Walton's role in New Jersey's sickle cell history and the scholarship established by SCANJ in her honor.

You're Invited To Breakfast Every Thursday This Month

The Sickle Cell Association of New Jersey (SCANJ) invites you to join us for a free breakfast series of mini-workshops related to sickle cell disease Thursday's this month from 9:00am to 10:30 AM at the Van Vleck House, 21 Van Vleck Street, Montclair, NJ (see calendar listings).

The series will conclude on Thursday March 28th with "Treatment Updates: What You Should Know About Hydroxyurea." featuring guest presenter, Dr. Jill Menell, Chief of Pediatric Hematology/Oncology at St. Joseph's Children's Hospital in Paterson, NJ.

Hydroxyurea is a major advance in the treatment of sickle cell disease that has been shown to help reduce the frequency of pain and acute chest syndrome episodes. Yet, only a fraction of people who might benefit from it have received treatment, according to the National Institutes of Health.

Dr. Menell will focus on what you should know about hydroxyurea as a treatment for sickle cell disease and will answer audience questions.

The workshops are an opportunity to learn about the latest treatments and programs for sickle cell disease offered throughout the state of New Jersey.

The March 28 workshop will include a proclamation issued from US Senator Lautenberg, acknowledging the late Frances Thompson-Walton's role in New Jersey's sickle cell history as part of Women's History Month. Mrs. Walton founded Action for Sickle Cell Anemia, Inc., of Hudson County in 1971 and served as its president until 1994. A scholarship has been established in her honor by the SCANJ.

People with sickle cell disease, family members, caregivers, healthcare professionals and others interested in learning more about sickle cell disease should attend. To register or for more information on SCANJ's Mini-Workshops visit www.scanj.eventbrite.com or call our office at 973 482-9070.

The Treatment Updates: Hydroxyurea Mini-Workshop is funded thanks to a grant from the SCDAA.

If you like our work...

Donate to support it! Just saying...

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Spotlight on Artist, Hertz Nazaire His life has been a struggle with the reality of sickle cell disease and his art beautifully educates through that journey. To support the work of this great artist, SCANJ is pleased to post Hertz's online store <http://www.zazzle.com/nazaire> where you can purchase his inspiring art. New this month are postage stamps and a canvas just created.

"My pain is still very annoying, but I keep on moving through my art". ~ Nazaire



The Say It Loud Newsletter is published monthly. Archived copies are available for download from our website.

Beverly Lucas-Editor

Thanks to everyone who made our Sickle Cell Awareness Blood Drive on February 16, 2013 a success! Especially WBLs Radio, the Men of Omega Psi Phi Fraternity, 2nd District and New Jersey City University.



1 blood donation saves 3 lives.



Like us on Facebook

Tax deductible donations accepted online and by mail

www.sicklecellnewjersey.org



American Red Cross



Part 2. Dr. Charles R. Drew...Connections



Dr. Charles R. Drew completed his dissertation in 1940 on "Banked Blood: A Study of Blood Preservation." He designed experiments that had direct implications for the transport and storage of blood during World War II. He meticulously described the processes for blood typing donors and drawing

blood. Overall Dr. Drew concluded that blood could be stored for a week under certain conditions.

During a time of rampant racial discrimination in America, Dr. Drew, an African American, took a leave of absence from teaching at Howard University to serve as Medical Director of the Blood for Britain project. In 1941 he became the first Medical Director for the American Red Cross where he proposed a pilot program that led to mobile units being used for the first time to collect blood. This pilot program served as a model for the organization and operation of the American Red Cross national blood plasma program.

Dr. Drew returned to teaching at Howard University in April of 1941. He was named Chair of the Department of Surgery and Chief Surgeon at Howard's Freedmen's Hospital, a position he held until his death.

Dr. Drew was dedicated to every aspect of his students well being. He was a member of Omega Psi Phi Fraternity and to this day his fraternity brothers honor him by supporting blood drives all around the country. Dr. Drew received many honors and awards. Tragically Dr. Drew died while driving with colleagues to an annual medical conference in Tuskegee Alabama. Around 7:30 am on April 1, 1950 in Alamance County, North Carolina. He apparently fell asleep at the wheel which resulted in a crash.

Many lives have been saved as a result of Dr. Drew's work. He spoke out against discrimination at a time when it was dangerous to do so. Although he died tragically, he left a legacy of life to many who live as a result of his pioneering efforts in blood storage.

Part 1. is in the February 2013 issue of *Say It Loud*.

Both Parts 1 & 2 are adapted from an excerpt from *The Legacy of Charles R. Drew, MD, CM, MDSc*, written by B.A.Wilson, W.G. O'Connor, and M.S. Willis

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Coming Soon:

April 11th SCDA
Advocacy Day
Washington DC.

15th SCANJ on
Panel for Minority
Health Month
Celebration
Conference.
Rutgers-New
Brunswick

20th Community
Resources
Networking Brunch