

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.



# Say It Loud!

May 2017

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



Volume 7  
Issue 5

## Spring Into Action in This Merry Month of May

### Calendar Listings:

**MAY 2nd Connections Support Group** Tuesday 7:00pm –8:30pm  
Topic: Advocacy: A Call To Action  
JFK Center in Willingboro



**22nd SCD Awareness Program**  
Monday 6pm Overlook Medical Center Auditorium. 99 Beauvoir Ave. in Summit

**22, 23, 24 & 26 Stanford School of Medicine Diabetes Self Management 4-Day Peer Leader Certification Class.** 9:30am-4:30pm each day. 600 Parkview Dr. in Delanco

**31st Healthy Living Fair** in partnership with the Salem Health and Wellness Foundation. 12pm-4:00pm Union Presbyterian Church, 254 Shell Rd. Carney's Point.

### Coming in JUNE...

**17th Sickle Cellabration** Cherry Hill

**19-22nd Stanford School of Medicine's Diabetes Self Management 4 Day Peer Leader Certification Class.** Fords

**27,28, 29 & 30th Chronic Disease Self Management 4-Day Peer Leader Certification Class.** Newark

REGISTER via the events tab on [sicklecellnewjersey.org](http://sicklecellnewjersey.org) or call 973 482-9070

SCANJ is the New Jersey Chapter of the



Sickle Cell Disease Association of America



**Mary Bentley LaMar**  
Founder  
Executive Director

Thanks to everyone who participated in our Patient Centered Outcomes Research Institute (PCORI) Project "We'll Take The Village: Engaging The Community To Better Health." We have just completed Tier II of our Pipeline to Proposal Award and are preparing our proposal for Tier III.

Your input has led us to develop research ideas centered around addressing pain management. We look forward to your continued involvement as we shape our ideas into viable research questions that will make a real difference in the sickle cell community.

There is never a dull moment at the SCANJ. You can spring into action with any of the programs on the calendar. Take advantage

### SCANJ Mission Statement

*To advocate for and enhance our membership's ability to improve the quality of health, life and services for individuals, families and communities affected by sickle cell disease and related conditions, while promoting the search for a cure for all people in the world with sickle cell disease.*

of opportunities to connect with others with similar interests, have fun and learn new skills. For example, the UniverSoul Circus is FREE for our Get Connected families and transportation is provided from South Jersey (pg 2). And RSVP now for the SickleCellabration and for the Chronic Disease Self Management and Diabetes Self Management Peer Leader Trainings. You could get certified and learn a new skill.

**Carpe diem (Seize the day) ~Mary**

## Let's Talk Hydroxyurea: A Treatment Choice for Sickle Cell Disease

**Is hydroxyurea (HU) a cure?** While HU is not a cure, it is a medication that can decrease many of the complications of sickle cell disease (SCD). It is taken by mouth once a day and comes in liquid or capsule forms. It is also known by the brand names of Hydrea or Droxia.

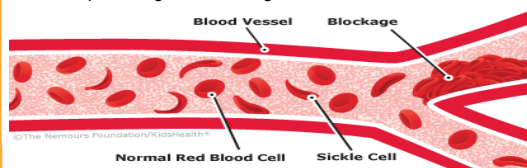
**Does it work?** Studies have shown that HU:

- Decreases the frequency of painful crises
- Decreases acute chest syndrome
- Decreases the need for blood transfusions
- Decreases hospitalizations

**How?** One of the ways that HU works is by increasing the amount of fetal hemoglobin and thereby decreasing the amount of sickle hemoglobin in the blood. Higher hemoglobin levels improve the shape and function of the red blood cells. Many of the complications in SCD are caused by blocked blood vessels. HU helps the red blood cells to travel more easily through your body.

**Other possible benefits of HU include:**

- Increased energy and quality of life
- Increased appetite and weight gain
- Decreased jaundice (yellow coloring of the eyes)
- Improved growth through childhood.



**Will taking HU work right away?** It usually takes several months to see the effects. The medication must be taken everyday for it to work well. If you have a pain crisis while taking HU, it does not mean that it is not working.

**Does HU work for everyone?** Not all people experience all of the benefits and some, although, rare, experience no benefits. Doctors feel that at least some of these treatment failures occur because the medication is not taken as directed. HU must be taken everyday at the right dose in order to work well.

**Is HU safe?** HU has been used for over 30 years to treat sickle cell disease and even longer for other conditions. Many clinical trials have proven that it is safe and effective. Most patients experience very few or no complications. Possible side effects are a decreased white blood cell count (WBC). WBCs are important for fighting infections. Your doctor will need to test and monitor your WBC periodically to adjust your dosage if necessary. Please talk with your doctor to learn if hydroxyurea (HU) would be of benefit to you. You can also find out more about HU at some of the community programs on our calendar.

*The information provided in this article is courtesy of the SCDA Michigan Chapter. It is not a substitution for medical advice.*

[WWW.SICKLECELLNEWJERSEY.ORG](http://WWW.SICKLECELLNEWJERSEY.ORG)



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**Connections  
 Support Group**



**Meetings on the first  
 Tuesday of each month**

**at 7:00PM. South Jersey** location in the odd numbered months i.e., January, March, May, September and November. **North Jersey** location in the even numbered months i.e., February, April, June, October and December. **May Topic: Advocacy: A Call to Action.**

**June Topic: Paint Chat and Chew**

**This month's meeting is Tuesday May 2nd at the JFK Center 429 Kennedy Pkwy in Willingboro.** Next month's meeting is June 6th. Location: 1016 Broad St. Newark. For more information and to RSVP you may register online via our events tab, call our office at 973 482-9070, or call our Community Outreach Coordinator, Darlene Young at 862 371-7138.

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

Beverly Lucas-Editor

[www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org)



SCANJ Invites You To Get Connected. . .

**SICKLE CELL AWARENESS DAY  
 MAY 10, 2017 / 7PM**

**UNIVERSOUL CIRCUS**

**SICKLE CELL AWARENESS  
 & VOTER REGISTRATION DRIVES  
 AT THE CIRCUS MAY 9<sup>TH</sup> - 14<sup>TH</sup>**

GET TICKETS: [WWW.UNIVERSOULCIRCUS.COM](http://WWW.UNIVERSOULCIRCUS.COM)  
**USE DISCOUNT CODE: SCANJP**  
 WHERE: 430 BROAD ST NEWARK, NJ

Guest Ringmasters on May 10th

SCANJ's Teen Spokesperson,  
 Georgios Kalogeropoulos  
 and Child Ambassador

Konstantinos Kalogeropoulos

We invite you to enjoy the *UniverSoul Circus*; a highly interactive combination of circus arts, theater, and music that spans genres including Pop, Classic R&B, Latin, Hip Hop, Jazz and Gospel. It embraces and celebrates the unique and familiar aspects of pop culture globally by bringing them center stage with a cast of international performers.

SCANJ is sponsoring a limited number of FREE tickets to the UniverSoul Circus via our eventbrite page for the SCD Friends & Family Day 7pm Show on May 10th. These FREE tickets are for individuals who have sickle cell disease **AND** who have completed profiles in the Get Connected Registry. All others can buy tickets through [www.universoulcircus.com](http://www.universoulcircus.com) using the "SCANJP" discount code or buy tickets via our eventbrite page if you wish to sit with the SCANJ block.

Contact Darlene Young, Community Outreach Coordinator for more information at 862 371-7138.

**WORLD SICKLE CELL DISEASE DAY**

**SICKLE CELL ABRAZATION**

**SATURDAY, JUNE 17, 2017**  
**9:30 AM TO 2:00 PM**  
 Garden State Discovery Museum 2040 Springdale Ave. Cherry Hill

A WORLD FESTIVAL OF FUN & LEARNING,  
 INTERNATIONAL CUISINE, AWARDING OF  
 THE FRANCES THOMPSON WALTON SCHOLARSHIPS

**SPECIAL GUEST  
 STORYTELLER  
 QUEEN NUR**

SELECTION OF THE 2017-2018 NEW JERSEY SICKLE CELL CHILD AMBASSADOR AND TEEN SPOKESPERSON



Register Now

[www.getconnectedscd.org](http://www.getconnectedscd.org)