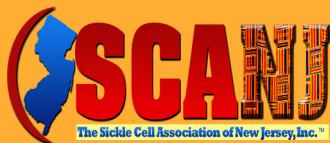


Sickle cell disease is an inherited blood disorder. People with sickle cell disease have red blood cells that become hard which can cause anemia, pain and many other serious health problems. Your involvement makes the difference in overcoming this disease.



Calendar Listings:

April

2nd-3rd SCDA Sickle Cell Advocacy Day on Capitol Hill. SCANJ Road Trip to Washington DC.

9th SCANJ Community Networking Lunch. 11:30am-1:00pm Van Vleck House and Gardens. 21 Van Vleck Street Montclair. Please RSVP for this free networking lunch.

SCANJ partners to offer FREE CDSMP Take Control of Your Health Six Week Community Workshops and Peer Leader Certification Course:

14-17th Peer Leader Certification 4 Day Course for Take Control of Your Health Chronic Disease Self Management Workshops. JFK Center Willingboro 9:30am-4:00pm each day. Call 973 482-9070 or register online. Enrollment is limited to the 20.

29th Mini Med-School Learn about Sickle Cell Disease Management Rutgers Cancer Institute of New Jersey Auditorium A First Floor. 195 Little Albany Street, New Brunswick. Buffet Dinner included. To RSVP call Priscilla Scheiner by April 22 at 732 235-6453. 5:00pm

Ongoing: Take Control of Your Health Chronic Disease Self Management Workshops hosted by SCANJ throughout the state.

For updates or to register for SCANJ programs, call 973 482-9070 or go to our event link via

www.sicklecellnewjersey.org

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association
of America



Volume 5
Issue 4

Say It Loud!

April 2014

Sickle Cell News You Can Use
Sickle Cell Association of New Jersey
PO Box 9501 Newark, NJ 07104

Greetings From Capitol Hill!



Mary Bentley LaMar
Founder
Executive Director

Our delegation of 14 from New Jersey has joined with hundreds from throughout the country for National Sickle Cell Disease Advocacy Day in Washington DC.

We just got energized from a training session on how to advocate for the reauthorization of the Sickle Cell Treatment Act (SCTA).

By the time you read this we will have converged on Capitol Hill. Most importantly, individuals with sickle cell disease are telling the senators and congressmen their story of what its like to live with this devastating

blood disorder. It is only through the story of those effected that our federal legislators will understand why it is so important that funding for the SCTA be reauthorized.

The following are the broad reauthorization priorities as identified by the SCDA:

- Swift reauthorization of the Sickle Cell Treatment Act (SCTA) prior to the conclusion of the 114th Congress
- Continuation of existing authorization with modifications intended to improve patient care and quality service
- Authorization of existing programs not already authorized (i.e.: the SCD Community Outreach Demonstration Project and Hemoglobinopathies Data System)

When we look at our mission it begins with the call to advocate..

We take that seriously.

~Mary

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."



Afterwords Part 4: Take Control of Your Health

Take Control of Your Health is a Chronic Disease Self Management Program developed by Stanford University School of Medicine. It's been proven to help individuals with chronic conditions learn how to better manage their health.

Thanks to a grant from the New Jersey Office of Minority and Multicultural Health and a grant and the Department of Human Services, SCANJ is glad to offer this evidence based program.

We love it because of its positive results. Studies have shown that workshop participants who complete the program report the following benefits:

~Improvements in physical activity, stamina and pain control

~Better communication with their health care providers

~Fewer doctor and emergency room visits.

Participants learn in small groups settings how to make better nutrition and exercise choices, relaxation techniques to help reduce stress, better ways to communicate with their doctor and loved ones about their health, and more.

The workshops are conducted by certified Peer leaders who lead the group with discussions and activities that are highly interactive, focusing on team building skills, sharing experiences and support. This is done once a week for 2.5 hours over a six week period. Our target population is participants with sickle cell disease and other chronic conditions such as diabetes, high blood pressure, asthma etc.

SCANJ conducts the 6 Week community workshops throughout the state. We also offer the Peer Leader Certification course for those interested in teaching the community workshops (calendar listings).

Now is the time to be pro-active and Take Control of Your Health. Register today for this empowering program.

Afterwords is a six part newsletter series to shed insight on the topics covered during the 2013 SCANJ Statewide Sickle Cell Symposium. This year's Statewide Sickle Cell Symposium will be November 22nd at the Liberty Science Center in Jersey City.

WWW.SICKLECELLNEWJERSEY.ORG



The Sickle Cell Association of New Jersey
Mailing Address

P.O. Box 9501 Newark NJ 07104
EIN# 80-0474935 SCANJ is a 501c 3 agency

Phone: 973 482-9070 Fax: 973 485-6591

NEW! email: info@sicklecellnewjersey.org

Let's Do Lunch!

SCANJ invites you to join us for a networking lunch
at the Van Vleck House and Gardens.

21 Van Vleck St. Montclair, NJ

Wednesday April 9th from 11:30am-1:00pm.

Enjoy delicious food and food for thought.

RSVP via [eventbrite.com](https://www.eventbrite.com) or call us.

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

Beverly Lucas-Editor

Tax deductible donations accepted by mail and via
www.sicklecellnewjersey.org



Where to Find Help Paying for Medication...

If you are having trouble paying for medication your doctor has prescribed, here are a few resources worth looking into. Keep in mind that eligibility requirements vary.

- NJ Family Care is a program run by the state of New Jersey. It provides healthcare insurance coverage, including prescription drug coverage, to qualified residents. Go to www.njfamilycare.org or call 800-701-0710.
- Pharmaceutical Assistance to the Aged and Disabled provides prescription payment assistance for low income New Jersey residents who are age 65 or older or who are at least 18 years of age and receiving Social Security Title II Disability benefits. (www.state.nj.us/human_services/doas/home/paaddetail.html)
- For a one-stop list of services offered by the state of New Jersey, go to www.NJHelps.org.

Many pharmaceutical companies offer assistance programs for some of the drugs they manufacture. One such program is the Johnson & Johnson Patient Assistance Foundation, Inc. (800-652-6227).

You can find additional information at no charge about other drug companies that offer similar programs through websites such as Rx4NJ (www.rx4nj.org; 888-793-6765), Partnership for Prescription Assistance (www.PPARX.org; 888-477-2669), and NeedyMeds (www.needymeds.org; 800-503-6897). These types of websites often provide free information about other assistance programs available to low-income uninsured patients, such as free or low-cost clinics and Federal and state government programs.

We suggest too that you check with your doctor often. They may become aware of a new program or clinical trial that could be of benefit to you. And if you find out about a prescription assistance program that will be of benefit to others, by all means, let us know and we will share the information.

Coming Soon:

Thursday's in May Breakfast Series Workshops

at the Van Vleck House and Gardens in Montclair. Bone Marrow Transplants is the topic during the Breakfast on May 8th at 9:00am. We're pleased to announce that Jennifer Krajewski M.D. of Hackensack Medical Center will be our presenter on May 8th at 9:00am.

June 14th. NFL McCourty Twins Tackle Sickle Cell Walk with SCANJ's "Walk the Talk" Team. 9:00am Liberty State Park in Jersey City.

June 21st SCANJ Commemorates World Sickle Cell Disease Day with the 5th Annual Sickle Cellabration

September TBD SCANJ's 24 Seven Line Dance Marathon.

October 1-4 SCANJ Road Trip to the SCDA National Convention Baltimore, MD