

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



Volume 8
Issue 1

Say It Loud!

January 2018

Sickle Cell News You Can Use

Sickle Cell Association of New Jersey

P.O. Box 9501 Newark, NJ 07104



Calendar Listings

JANUARY

1st Frances Thompson Walton Scholarship Applications now being accepted. Visit our website and click on the events tab to apply online. Deadline May 1st, 2018

2nd Connections Support Group
7:00pm –8:30pm AMC Movie Theatre Cherry Hill

7th Mission Sunday. SCANJ presented with the Helping Hands Award. 9:30am Service. St. Luke's Baptist Church 139 Tyler Place in Paterson, NJ

13th SCANJ honored by Grand Temple Daughters of the Elks of the Improved Benevolent Protective Order of Elks of The World. 10:30am Radisson in Freehold NJ

22nd-25th Chronic Disease Self Management 4 Day Peer Leader Certification Class. 9:30AM-4PM. Living Springs Residential Center. 600 Pariview Rd. Delanco. Enrollment is limited.

SCANJ EVENTS ARE FREE UNLESS OTHERWISE NOTED

REGISTER via the events tab on sicklecellnewjersey.org or call 973 482-9070

SCANJ is the
New Jersey Chapter of the



Sickle Cell Disease Association
of America

A New Year's Message From the Executive Director. . .



Mary Bentley LaMar
Founder
Executive Director

I was sitting in my office working on routine matters when a phone call came in from a mom who had just relocated to New Jersey. She remembered that our agency was able to assist her several years ago and reached out to us to help her navigate her new town.

Of course, we jumped right in to welcome her and provide whatever guidance we could to get her family settled in the area. I was humbled by her sincere appreciation of what we had done in the past and were able to do now.

It is because of families like this mom's, that we are inspired to keep working on our mission. It is yet further confirmation that we are on the right path as we begin our 9th year of operation. I'm encouraged. I hope you are encouraged too.

When you review the calendar listings each month, please know that it is there to help you to get involved.

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.

Most of our trainings and programs are free to families directly effected by sickle cell disease. And, if you have attended our programs in the past, you know that we try our best to make them engaging, helpful and informative.

At the SCANJ we serve the 6,000 individuals living with sickle cell disease in the state of New Jersey with a relatively small staff of 3, several community partners and hundreds of volunteers.

As we begin this new year, please be assured that there is a small group of people determined to make a difference for a large group of people and in doing so, we can change the world.

Stay on the Mission! ~Mary

The 411 On The New FDA Approved Drug for SCD

The U.S. Food and Drug Administration recently approved Endari (L-glutamine oral powder) for patients age five years and older with sickle cell disease to reduce severe complications associated with the blood disorder.

"Endari is the first treatment approved for patients with sickle cell disease in almost 20 years," said Richard Pazdur, M.D., acting director of the Office of Hematology and Oncology Products in the FDA's Center for Drug Evaluation and Research and director of the FDA's Oncology Center of Excellence. "Until now, only one other drug was approved for patients living with this serious, debilitating condition."

The safety and efficacy of Endari were studied in a randomized trial of patients ages five to 58 years old with sickle cell disease who had two or more painful crises within the 12 months prior to enrollment in the trial. Patients were assigned to treatment with Endari or placebo, and then evaluated over 48 weeks. Patients who were treated with Endari experienced fewer hospital visits for pain treated with a parenterally administered narcotic or ketorolac (sickle cell crises), on average, compared to patients who received a placebo (median 3 vs. median 4), fewer hospitalizations for sickle cell pain (median 2 vs. median 3), and fewer days in the hospital (median 6.5 days vs. median 11 days).

Patients who received Endari also had fewer occurrences of acute chest syndrome (a life-threatening complication of sickle cell disease) compared with patients who received a placebo (8.6 percent vs. 23.1 percent).

Common side effects of Endari include constipation, nausea, headache, abdominal pain, cough, pain in the extremities, back pain and chest pain.

Endari received Orphan Drug designation for this use, which provides incentives to assist and encourage the development of drugs for rare diseases. In addition, development of this drug was in part supported by the FDA Orphan Products Grants Program, which provides grants for clinical studies on safety and/or effectiveness of products for use in rare diseases or conditions.

The FDA, an agency within the U.S. Department of Health and Human Services, protects the public health by assuring the safety, effectiveness, and security of human and veterinary drugs, vaccines and other biological products for human use, and medical devices.

This article is based on a press release from the FDA. SCANJ plans to host an information forum this spring on Endari and other drug developments in SCD.

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Connections Support Group Meets
 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

January and February Activity: Movie Outings

January 2nd at the AMC Movie Theatre in Cherry Hill. February 6th at the AMC Movie Theatre in West Orange (Essex Green) For more information and to RSVP you may register online via our events tab 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



THANK YOU RESEARCH COMMUNITY! Your work brings hope. Periodically we post opportunities to participate in research studies for sickle cell disease (see below). We are happy to support The Caring For Caregivers Project. Please contact Ms. Nwanonyiri for more information.



Caring for Caregivers



CONTACT INFORMATION

To find out more about this study, please contact:

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 or

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**SICKLE CELL DISEASE IN CHILDREN:
 AN EXPLORATION OF FAMILY RESILIENCE
 THROUGH THE EXPERIENCES OF FAMILY CAREGIVERS.**

Principal Investigator: Dorothy Nwanonyiri, MSN, RN-BC

Purpose of this Study:
 (a) To further explore the phenomenon of family resilience through the lived experiences of family caregivers of children with sickle cell disease
 (b) To examine the family resilience processes that may be considered important to fostering family adaptation.

- To participate in this research you must:**
- Be between 18 and 55 years old
 - Live in the same household as your child with sickle cell disease.
 - Be the primary caregiver of your child with sickle cell disease.
 - Communicate in English

- Participation in this study requires:**
- A time commitment of 45 – 60 mins
 - Participation is strictly voluntary
 - Participants are free to withdraw at any time.
 - No monetary benefit.
 - No financial obligation to you.
 - Participation is confidential



Get Connected to SCANJ to take advantage of...

- Get Connected Pop Up Events
- CDSMP and DSMP Peer Leader Certification
- Support Groups
- The Village; Patient Centered Research Group
- Scholarships



Register Now

www.getconnectedscd.org