



Calendar Listings:

October 6th WWOR
TV Channel 9 NEWS at
10pm airs story on
Sickle Cell Disease.

SCANJ's Teen Spokesperson,
Amanda will share her journey
to being cured.

October 7-8 SCANJ
24Seven Line Dance
Marathon

New Jersey City University
2039 Kennedy Blvd. Jersey
City Friday 1pm – Saturday
1pm

October 14 Minority Association
of Pre Health Students at
Princeton University "Dance Vs.
Disease" to Benefit the Sick
Cell Association of New Jersey.
6:30pm Princeton

October 29th and 30th
Cabaret For Life and the Mon-
mouth Civic Chorus
Present Titanic The Musical
Axlerod Performing Arts Center
100 Grant Ave. Deal
For tickets call 732 531-9100
Thank you Cabaret For Life for
supporting SCANJ.

November 19 SCANJ Thanks
for Giving Concert. Sick Cell
Sabbath 3:00pm Location
TBA. All are invited. Freewill
offering and toy donations for
the holiday party are appreciated.
Reception will follow.

December 10, SCANJ Holiday
Open House-Van Vleck Mansion
in Montclair. RSVP only. Free
for families affected by sickle
cell disease. Special appearance
by Kenta Klaus.



Volume 2
Issue 10

Say It Loud!

October 2011

Sickle Cell News You Can Use
The Sick Cell Association of New
Jersey

A Note From the Executive Director...



Mary Bentley LaMar

We're coming off
of a whirlwind
September Sick
Cell Awareness
Month. ...so many
opportunities to get
connected with
others who are
making a real differ-
ence in improving

the quality of life for individuals living with
this terrible life threatening inherited blood
disorder. I hope you were able to take
advantage of some of the many offerings.

Last week the 39th Annual Convention of
the Sick Cell Disease Association of
America (SCDAA) convened in Memphis
Tennessee and it was awesome!

Our SCANJ attendees included our
Teen Spokesperson, Amanda and her
Mom, Lizette Salazar, Poster Child,
Sanaa and her Mom, Kisha Terrell and
yours truly. Exciting news from the
convention is the SCDAA research
foundation that is being formed. Hear
more about the SCDAA convention
during the Live and Learn Health Fair
this Friday at the 24 Seven.

On the home front, we're excited that
WWOR Channel 9 News at 10pm will
air a story on sickle cell disease that
includes SCANJ. **Please spread the
word to watch Channel 9 News at
10pm this Thursday October 6th.**

After viewing, go to their website,
www.MY9TV.COM, click on "fyi" and
then do your social media thing...make
Comments, email the link, upload to

your websites, whatever you can do
to give the story wings will help raise
awareness.

SCANJ uses drumming to begin
many of our programs. Well, I'm beat-
ing the drum now asking you to sup-
port our first fundraiser; the 24 Seven
Line Dance Marathon (pg 2).

A special shout out to the Student
Government Organizations from New
Jersey City University and all teams
who are leading the charge with com-
munity service for the 24 Seven.
Thank you New Jersey City University
for serving as our host sponsor for
this first ever 24 Seven Line Dance
Marathon.

YOU CAN BRING IT!
~Mary

SCDAA Convention Musings from the SCANJ Attendees:



Kisha: "I didn't know so
many people were so pas-
sionate about sickle cell
disease and the work they
do with sickle cell patients,
infants teenagers and
adults."

Lizette: "I want them to
know that knowledge is power.

Seeing the new clinical trials and
what they're working on was em-
powering. It's good to know
they're working on other things
like pain management, prevention
of crisis and working more toward
the goal, which is the cure for
sickle cell. I see how other chap-
ters are so involved in fundraising
and developing their organizations.
Creating different ideas in learning
and supporting each other."

Amanda: "Many people were
concerned with the transition
from teenagers to adults. There
was a lot of focus on that.
I learned about different organi-
zations that also work on sickle
cell. There's a common bond
that people fight for. We're all
fighting for the same thing.

I joined the International Asso-
ciation of Sick Cell Nurses and
Physician's Assistants. They put
me on the technology commit-
tee. We're working to spread
awareness, but we need every-
one's help in this. If you want to
see something do something."

More about the convention
will be shared at the

24 Seven!

Based on your experience at
the SCDAA national con-
vention, what do you want
others to know?

Sanaa "It was fun. I got lots of
knowledge about sickle cell
cell...learned lot's of new stuff that
I didn't know. Lots of people
don't know about sickle cell and
could learn about it. Memphis
was really beautiful. I'm glad I
came."

Mailing Address for SCANJ

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EIN# 80-0474935 SCANJ is a 501c 3 agency

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

email: sicklecellanj@gmail.com

**The 24 Seven begins Friday October 7 at
1:00pm and won't stop until**

Saturday 1:00pm October 8th!

New Jersey City University Student Union Bldg. 2nd floor

Register at the event or online at

www.sicklecellnewjersey.org

To raise funds and awareness for sickle cell disease.

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

Beverly Lucas-Editor



Why Support the 24 Seven? Because...

the individuals and families who suffer from this life threatening inherited blood disorder don't have enough support for their needs and not enough people know how sickle cell disease is passed on. **You can help**

SCANJ make a difference in the fight against sickle cell disease.

Look at our record...SCANJ initiated the New Jersey Sickle Cell Poster Child/Teen Spokesperson Program. We assist families affected by sickle cell disease with emergency social services. We educate and raise awareness through our website, www.sicklecellnewjersey.org, newsletters, brochures, media appearances, road trips for families, workshops, seminars and special events.

We bring families affected by sickle cell disease together for mutual support. We have been recognized by the State of New Jersey Health and Senior Services for best practices for our Chronic Disease Self Management Workshops. We support efforts of other organizations in the fight against sickle cell disease.

We present on sickle cell disease at national conferences. And just this past week in Memphis Tennessee, we presented at the national convention of the Sickle Cell Disease Association of America.

Please contribute towards our work. With enough donations we can increase our existing services and establish a permanent office for SCANJ with a social worker, genetic counseling and access to research and resource materials. No matter how small, every contribution will help us break the cycle of sickle cell disease.

I hope you will agree that we are worthy of your financial support. Contributions can be made online, by mail payable to: SCANJ P.O. Box 9501, Newark, NJ 07104 or you can also bring your donation to the 24 Seven at New Jersey City University.

Feel free to call us at 973 482-9070 or visit our website for more information.

Thank you.

24 Seven Event Day Schedule

Friday October 7th

12 noon Check In/Registration

1pm Line Dancing

(24 Hrs)

Donations Collected

Community Service Fair

Live & Learn Health Fair

Phone A Thon

3pm-5pm SCD Workshops

6 pm Dinner Par-tay

7pm Movies

10 pm Laugh A Thon

Midnight Band Jam

Saturday October 8

Cards, Wii, Dominoes, Games

1 am Pizza and Wings Fling

6am Stretch and Exercise

7 am Breakfast

**11am Awards Recognition
and Acknowledgements**

1pm Celebration Closing

Dress comfortably

Parking available in the

Culver Street Garage

Schedule is subject to change.