



Calendar Listings:

April

5th. Liberty Science Center Community Evening. 6-9pm. Visit SCANJ's booth. Free admission. Jersey City.

10-11 Sick Cell Learning Collaborative. Bethesda MD. SCANJ participates with Newark Beth Israel Hospital's SCD Team.

25 Planning Committee Meeting for Sick Cellabration 6:30pm. Place TBA. Call 973 482-9070 to volunteer for this committee.

26 Say It Loud! Webinars; Building an Accurate Family History, Constructing a Pedigree-An Overview for Primary Care. Sponsored by the Genetics In Primary Care Institute 1-1:30pm EST. Visit this link to register: <https://www2.gotomeeting.com/register/486497370>.

Hemoglobinopathies Webinars Sponsored by the Center for Disease Control This month's topic is on the Adult Provider's Network. Every 4th Thursday of the Month from 2-3pm EST. Dial in information is on our website events page.

May

5th Asbury Park Health Fair and Bone Marrow Drive. Boardwalk. More details TBA.

7 & 8th, NJ Governors Conference For Women. Atlantic City Convention Center. Visit the SCANJ booth in the Health Fair. Registration is \$125.00 in advance and \$150.00 on site (pg 2). You can apply for a partial scholarship offered through SCANJ Advocates Program.

Date TBA SCANJ Meet and Greet Cape May County. Check our website or call for more information on this empowering program.

June

9th SCANJ's Sick Cellabration. Jersey Explorer Children's Museum. 192 Dodd Street in East Orange. 10am-3pm. **This event is FREE. however you must RSVP via sicklecellnewjersey.org, phone or email.**



Volume 3
Issue 4

Say It Loud!

April 2012

Sickle Cell News You Can Use

The Sick Cell Association of New Jersey

A Note From the Executive Director...



Mary
Bentley LaMar

It was Tuesday March 27th. I had flown in that afternoon to Charlotte NC.

I made my way to the American College of Medical Genetics and Genomics Annual Clinical Meeting. I was in the midst of physicians, geneticists, researchers, educators and others interested in how one's heredity affects the body (genetics).

I was selected to attend as an Advocate Leader, by the New York Mid Atlantic Consortium For Genetic Disorders (NYMAC).

Being that sickle cell disease is the number one genetic blood disorder in the United States, I was anxious to learn more about genetics.

The first session I attended was on Telegenetics. Doctors would be able to connect to patients and providers

in medically underserved locations through technologies such as video conferencing, interactive imaging and remote diagnosis.

I thought that if this is an indication of the rest of the conference, I am in for new and exciting information that can benefit the families we serve. I was right about that, however, the sessions were presented in scientific jargon that was at times difficult to understand for a lay professional like me.

NYMAC, in their wisdom, assigned wonderful genetics students from the University of Arkansas, to help the Advocates understand much of the scientific information presented. We also had "Faculty" briefings from well respected geneticists at breakfast and lunch to help us process the information. With graduate student, Katy Williams assisting me, I was able to navigate the conference successfully.

I met other patient advocates for many diseases I had never even heard of.

We helped each other to have a better understanding and to share best practices in meeting challenges. It was encouraging to hear presentations on genetic diseases and research findings that have led to better treatments.

Fast forward to today (April 13) I just returned the other night from a 2 day Learning Collaborative in Bethesda MD on Sickle Cell Disease as part of Newark Beth Israel Hospital's Sickle Cell Network Team.

Reflecting on these recent gatherings, I keep thinking that "connections" are the key here. Connections to our past (genetics) inform our present... connections to our present (collaborate) brighten our future... and connections to our future (your actions) are a bridge to the cure.

You may notice that I said "our." I believe we're all in this together...

~Mary

Connections...



Plans are coming together for the 3rd Annual Sick Cellabration; a world festival of fun and learning in commemoration of World Sickle Cell Disease Day (calendar listings). If you've attended before, you know you will enjoy a great day, filled with informative workshops, the Teen Summit, a Red Cross Sickle Cell Blood Drive, the Poster Child Luncheon and great Jersey Explorer Museum activities for the whole family. And everything is FREE!

We're thrilled that Dr. Wanda Whitten-Shurney has accepted our invitation to present on the latest developments in sickle cell disease. She serves on the Medical and Research Advisory Committee for the National Sickle Cell Disease Association of America (SCDAA).

It's In The Genes...

A highlight of her career was presenting the Charles F. Whitten Lecture at the 2007 National SCDAA Convention with her father, Dr. Charles F. Whitten, co-founder of the SCDAA, in the audience. Dr. Whitten died in 2008.

Dr. Shurney honored his legacy as the featured lecturer when her father's papers were transferred to the National Library of Medicine at the National Institutes of Health in Bethesda, MD.

Dr. Shurney makes a difference in the community she serves, and by connecting to the world community affected by sickle cell disease.

Get connected. Commemorate World Sickle Cell Day with us at the Sick Cellabration. As Gandhi so wisely said... "be the change you want to see in the world."

Dr. Wanda Whitten-Shurney



CEO and Medical Director for the SCDAA Michigan Chapter and pediatrician at the Comprehensive Sickle Cell Clinic at Children's Hospital in Detroit, MI.

Featured Workshop Presenter for the Sick Cellabration on June 9th.

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SCANJ is a 501c 3 agency

Donations are tax deductible.

Please make a contribution today.

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Attention; SCANJ Advocate Awards Available!!

Do you like learning and being around dynamic people?

Are you on available on May 8th and willing to share information with others about the Sickel Cell Association of New Jersey?

Help us spread the word about services for people living with sickle cell disease.

SCANJ is offering partial scholarships to attend the *NJ Governor's Conference For Women* in Atlantic City (see below) as a "SCANJ Advocate." You can apply online via www.sicklecellnewjersey.org, via www.scanjadvocate.eventbrite.com, or call our office. Priority is given to SCANJ volunteers and individuals with SCD.

Advocates will be notified by May 3rd.

SCANJ's Executive Director, Mary Bentley LaMar, serves on the Steering Committee for the NJ Conference for Women, and chairs the Welcome Reception.

*To register for the conference on your own (see below), go to www.njwomensconference.com
Registration is \$99-125.00 in advance and \$150.00 on site. It's well worth it!*

May 7th & 8th, 2012 * Atlantic City Convention Center

The NJ Governor's Conference for Women

2012

IT'S ALL ABOUT YOU!

Conference Highlights Include:

- Special guests and nationally recognized speakers
- Golf outing and clinic (new this year) on May 7th at the A.C. Country Club
- Welcome Reception on May 7th from 5:30p.m. - 7:30p.m. and Dessert Reception featuring Dr. Ian Smith from TV's *Celebrity Fit Club* from 9:00 p.m. - 11:00 p.m. at the Sheraton Atlantic City Convention Center Hotel
- The "Passport To A Healthy Lifestyle" Health Fair: Back by popular demand for a fifth straight year, visit our enhanced Health Fair for FREE health screenings & giveaways
- NEW JERSEY WORKS: An ongoing, all-day workshop providing women with "one stop" counsel on career building, resume review and employment opportunities. Resources provided by the NJ Departments of Labor, Economic Development Authority and others

Now in its 19th year, the Governor's Conference for Women is a one-of-a-kind event just for women! This year's theme, **IT'S ALL ABOUT YOU!** reflects the Conference's goals of providing women with comprehensive, practical information on: Career, Health, Starting or Growing a Business, Politics, and Finance.

The Conference features a variety of dynamic speakers and expert panelists that you won't want to miss! Participants may choose from five subject tracks which include:

Health | Personal Development
Politics | Women in Business
Women, Power & Money

Set aside time to visit the "one-stop" counseling center, which will provide feedback on career building, resumes and employment opportunities with staff and resources provided by the NJ Departments of Labor, Economic Development Authority and others.

Each year the New Jersey Governor's Conference for Women draws over a thousand women from around the state... join them this year for a conference filled with opportunities to learn, grow and network!

Coming Soon...

Say It Loud! PSA Video Contest winners announced in the May issue of Say It Loud!

Summer Camps: Visit our website resource page for links to summer camps for children with sickle cell disease.

Scholarships & Awards:

April 30th deadline for Donna T. Darrien Memorial Foundation for Sickle Cell Scholarship. Visit dtdsicklecell.org for details.

June 9th. SCANJ Poster Child Program Applications due at or before the **Sickle Cellabration**. Poster Child and Teen Spokesperson selected receive \$500.00 education stipend and all expenses paid (including chaperone's expenses) to the national Sickle Cell Disease Association of America Convention. **Sickle Cellabration is SCANJ's commemoration of World Sickle Cell Disease Day (June 19)**

"Say It Loud"

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Beverly Lucas-Editor



Featured Speaker
DONNA BRAZILE
Professor, Author, Syndicated Columnist & TV Political Commentator



Featured Speaker
CARLA HARRIS
Best Selling Author & Managing Director, Morgan Stanley



Keynote Speaker
DR. LOIS FRANKEL
President, Corporate Coaching Consulting Firm & Author of *Nice Girls Don't Get the Corner Office*



Featured Speaker
DR. IAN SMITH
Medical/Diet Expert, *Celebrity Fit Club*



Featured Speaker
PEGGY NOONAN
Columnist, *The Wall Street Journal* & Best Selling Author



Featured Speaker
BONNIE ST. JOHN
Author, Inspirational Speaker, Executive Coach, TV Personality & Former Olympic Skier

For sponsorship information or to register online please visit www.njwomensconference.com