



# Say It Loud!

## NEWSLETTER

September 14th, 2020

### The Sickle Cell Association of New Jersey

---

#### SEPTEMBER IS SICKLE CELL AWARENESS MONTH!

Pump up the volume by sharing this newsletter with someone else! Doing so will help us to amplify the voices of individuals living with sickle cell disease. We thank you in advance for

helping us raise awareness not only this month but throughout the year. Sickle Cell Awareness Month began in 1975 with awareness campaigns initiated by the late Dr. Charles F. Whitten through the National Association for SCD (now the SCDA). In 1983, then President Reagan signed it into law recognizing it nationally as SCD Awareness Month.



Close to home, we can thank New Jersey State Senator Shirley L. Turner, and

Senator Nettie Pou, for making the month of September poised to officially become recognized as Sickle Cell Awareness Month in the state of New Jersey. Senators Turner and Pou sponsored the SJR38 Resolution designating September as Sickle Cell Awareness Month in New Jersey. Co-sponsors were Assemblymen; Annette Quijano, Britnee Timberlake, Ralph Caputo, Gordon Johnson, Shanique Speight and Nicholas Chiaravolloti. We appreciate the support of Senate President Stephen M. Sweeney and Speaker Craig Coughlin. The resolution passed unanimously. We anticipate that Governor Chris Murphy will sign it into law soon.

We are thrilled that this designation will help us to make a bigger impact in the lives of individuals living with sickle cell disease. I'm proud that the SCANJ added a footnote to the state's history by providing some content for the resolution and being cited in the bill as a community-based resource for the sickle cell community. Please read the entire newsletter and give us a call. We are here for you! All the best!

~Mary Bentley LaMar, Founder & Executive Director

## SCANJ's SCD AWARENESS VIRTUAL WALK

### Addressing Health Disparities In The Sickle Cell Community One Step At A Time

Join our Virtual SCD Awareness Month Walk by walking in the location of your choice any day this month. You will be raising awareness and support for individuals living with sickle cell disease. And please allow us to suggest walking on Saturday September 26<sup>th</sup> at the Van Vleck House and Gardens, 21 Van Vleck Street in Montclair. We will have SCD facts throughout the grounds as you enjoy your socially distanced walk during the open hours of the gardens. Remember to #MaskUp4 Sickle Cell and donate to our cause:

<https://charity.gofundme.com/o/en/campaign/scanj-walk-the-talk>

The advent of COVID-19 has intensified the health disparities already prevalent in the sickle cell community. Sickle cell disease is a life threatening, painful blood disorder. Individuals with sickle cell disease often have co-morbidities including, cardiovascular disease, diabetes and asthma. It primarily affects people of African descent but it is also common in other racial/ethnic groups. According to the Centers for Disease Control and

Prevention (CDC), in the United States, sickle cell disease affects 90,000 to 100,000 Americans. Approximately 6000 are affected with sickle cell disease in New Jersey.

---

### Patients Needed for Clinical Trial Evaluating a One-Time Only Gene Therapy For Sickle Cell Disease

The MOMENTUM study is evaluating a one-time only gene therapy for patients with Sickle Cell Disease. Spots in MOMENTUM are currently available!

Current treatment options for sickle cell disease have limitations: they may not work for everyone and need to be taken forever to maintain benefits. The MOMENTUM study is evaluating an investigational gene therapy, ARU-1801, given only one time that allows the body to produce fetal hemoglobin. Higher levels of fetal hemoglobin are known to reduce vaso-occlusive crises that can cause acute pain episodes in people with sickle cell disease.

The purpose of MOMENTUM is to see if ARU-1801 is a safe and effective way to make the body produce fetal hemoglobin again as adults. Study participants must be ages 18 to 45 with severe sickle cell disease.

If you are interested in joining the clinical trial or learning more about it, please contact [clinicaltrials@aruvant.com](mailto:clinicaltrials@aruvant.com)



**Thanks to everyone who participated in the #MaskUp4 Sickle Cell Campaign. We are continuing the campaign in September as part of Sickle Cell Awareness Month.**

---

**There's Still Time to view the 9<sup>th</sup> Annual SCD Therapeutics Conference**

You can take this opportunity to hear and discuss the latest advancements and future trends for treating patients with sickle cell disease.

To view go to: [https://www.youtube.com/c/GBTnews\\_Biotech/featured](https://www.youtube.com/c/GBTnews_Biotech/featured). SCANJ's Executive Director, Mary Bentley LaMar is pleased to participate as the panel moderator for Session 2

---

The 9th Annual  
**Sickle Cell Disease Therapeutics  
Conference Virtual**

Hosted by Beverley Francis-Gibson  
President and CEO of SCDAA

**NEXT TUES** Sept. 15 | 9:00 a.m. - 3:45 p.m. ET

To learn more and register visit [SCDconference.com](http://SCDconference.com)  
#SCDTC

Presented by **GBT**

Partnering with

**Connections: More Than A Support Group**

**The first Tuesday of each month we meet to uplift and empower each other.**

**The October 6<sup>th</sup> Topic is Advocacy and the Power of the Vote**

Elected leaders know that an involved voting citizen is one to listen to. You can raise the volume from the sickle cell community in addressing health disparities by demanding better health care. But first, you must register and then you must VOTE! We will explore this topic and take training on how to Plan Your Vote.

Register for Connections Support Group via [www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org) and click on the events tab.

Visit [www.WhenWeAllVote.org](http://www.WhenWeAllVote.org) for more information on voting.

WHEN WE ALL  
**VOTE**

**Important Dates:**

October 13, 2020 last day to register to vote in New Jersey for the General (including Presidential) Election.

Plan Your Vote

November 3, 2020 General Election Day

---

**SAVE THE DATE: October 14, 21 & 28. National Maternal Health PCOR Network Symposium**

## Symposium

This October join the National Maternal Health PCOR Network (NMHPN) for a Virtual Symposium - Moving Towards Justice in Maternal Health: A Roadmap for Action. Be there as we discuss maternal justice and the key systems that impact maternal health.

NMHPN is also seeking abstracts for poster presentations, panel/roundtable discussions, and oral presentations for its 2020 Symposium at the symposium. To learn more, go to <https://bit.ly/2FIECnn> #NMHPN #MaternalJustice.

SCANJ plans to submit an abstract highlighting how health disparities affect the maternal health of women with sickle cell disease. Please contact our office at 973 482-9070 or email us at [sicklecellanj@gmail.com](mailto:sicklecellanj@gmail.com) if you are willing to let us to use your story to raise awareness.



A graphic for a virtual symposium. The background shows a woman in a pink shirt sitting on a bed, and another woman in a white shirt sitting on the floor next to her, using a stethoscope. The text is overlaid on this image. At the top, it says 'SAVE THE DATE' in large pink letters. Below that is the NMHPN logo, which consists of two hands holding a heart, followed by the text 'nmHPN National Maternal Health PCOR Network'. The main title is 'Virtual Symposium' in large white letters, followed by 'Moving Towards Justice In Maternal Health: A Roadmap For Action' in smaller white letters. At the bottom, there is a dark red bar with three white boxes containing dates and times: '14 OCTOBER 2020 5:00-7:00 PM EST', '21 OCTOBER 2020 5:00-7:00 PM EST', and '28 OCTOBER 2020 5:00-7:00 PM EST'.

## Registration is Now Open for the Annual SCDA National Convention October 14-17, 2020

The SCDA is pleased to offer scholarships for patients to attend SCDA's National Convention next month. The SCDA will accept applications on a **first come first serve basis** (and only from a member organization i.e., SCANJ). Please complete the survey link below at your earliest convenience. The SCDA has reduced the cost to attend the Convention per scholarship to \$25.00 for this virtual convention. Once approved you will receive a discount code to register. Contact SCANJ should you have any questions.

Survey Link: <https://www.surveymonkey.com/r/RNWM9KK>





---

The Sickle Cell Association of New Jersey (SCANJ) encourages you to participate in #SCANJSafeAtHome. Businesses may be “opening” up, but remember that COVID-19 has not closed shop. Please continue to stay at home as much as possible and refrain from going out unless absolutely necessary. We have a COVID-19 Relief Program to support your staying safely at home. That support takes many forms, such as online programs, gift cards and more. Call us at 973 492-9070 or email info @[sicklecellnewjersey.org](mailto:info@sicklecellnewjersey.org). You can also register for through our events tab on [www.sicklecellnewjersey.org](http://www.sicklecellnewjersey.org).

Follow us on Facebook, Twitter, and Instagram or visit [SickleCellNewJersey.org](http://SickleCellNewJersey.org).



[view this email in your browser](#)