



Say It Loud! Newsflash
July 16, 2020

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 and support your staying safely at home. That support takes many forms, such as online programs, gift cards for essentials, groceries, scholarships, online workshops and more.

As we work from home, we continue to be here for you, ready and willing to uplift and support. ~Mary Bentley LaMar, Executive Director



Mary Bentley LaMar, Executive Director & Founder

The SCDAAC Needs to Hear From YOU!

The SCDAAC Medical and Research Advisory Committee is seeking client and caregiver input to make specific recommendations to member organizations on a number of issues related to telemedicine and health and safety at school and in the workplace. This information is urgent and very time-sensitive, so please complete this immediately. All responses will be anonymous. The survey will be available until **July 28, 2020**, so please complete it as soon as possible so that your voices can be heard.

Survey link: <https://www.surveymonkey.com/r/CVPFJM7>

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



Register and 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! Visit www.WhenWeAllVote.org for more information.

Important Dates:

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

November 3, 2020 General Election Day



SCD Therapeutics Conference Registration Open

The Sickle Cell Disease Therapeutics Conference is September 15, 2020. Take this opportunity to hear and discuss the latest advancements and future trends for treating patients with sickle cell disease.

To register go to: <http://scdconference.com/> SCANJ's Executive Director, Mary Bentley LaMar is pleased to participate as a panel moderator.

Thanks to everyone who participated in the MaskUp4Sickle Cell Campaign on June 19th. We will continue the campaign in September as part of Sickle Cell Awareness Month.

SCANJ Operations during the COVID-19 Social Distance Restrictions:

Please note that the staff is working from home, however, we are still available by phone at 973 482-9070 and email at sicklecellanj@gmail.com.

Visit www.sicklecellnewjersey.org and click on events for current happenings.

