2018 - Year in Review
by Donnette Carroll

SCTPN on the Move – HRSA Project

SCTPN was a recipient of a HRSA newborn screening grant. The staff attended a grant kickoff meeting in Atlanta in February 2018. Sixteen sites in fifteen States are collaborating with the Sickle Cell Disease Association of America (SCDAA) on this project.

The goal is to partner with hospitals to develop a community-based care coordination and finding individuals living with sickle cell who are lost to care. We are building health homes of coordinated care, including primary, hematology, dentistry and ophthalmology. Project Director Mark Goodwin will supervise the Community Health Workers. SCTPN also contracted with Candice Deler of Candice Sickle Cell Fund to provide education on hydroxyurea and other treatments.

PCORI Project

SCTPN is engaged on a PCORI project with Montefiore Medical Center to improve the transition program. The project involves working with teens and young adults and develop a patient advisory group.

This project runs from 2018 – 2023. Key personnel are Mark Goodwin and Candice Deler. The Primary Investigator on the project is Atrium Health in Charlotte, North Carolina. This is a quality improvement project based on the curriculum at gottransition.org.

Meet the HRSA Project Staff

- Mark Goodwin MSW/LCSW, Project Director is working on several initiatives, including a Community Health Worker program and educational outreach. He is also a Spanish interpreter.
- Candice Deler MSW, will provide education on Hydroxyurea and other treatments.
- Unis Phillips, Social Work intern, will participate in field work with SCTPN 2018 – 2019. She is a BSW candidate at Medgar Evers College, a CUNY division in Brooklyn.
- Esme Hilman CHW, is also HIPPA certified and continuing her training at SCTPN.
- Sarai Santiago, Community Outreach Worker, is HIPPA certified and studying towards Community Health Worker certification.
- Sabrina Lewis CHW, supporting Brooklyn community at Kings County, Downstate and Interfaith Hospitals.

Sickle Cell Disease Act of 2018

The U.S. Senate 115th Congress unanimously passed the Sickle Cell Disease Research, Surveillance, Prevention and Treatment Act of 2018 (S. 2465) to improve understanding of the healthcare system and establish cost-effective practices for disease treatment and improvement of patient survival. In 2017, NY State allocated $250,000 to sickle cell in its annual budget. Legislation to boost that funding has been introduced in both the Assembly and Senate, asking for a budget of $3 million.

Funding would establish eight demonstration programs and one coordinating center for education and treatment in NY State. This new infrastructure would encourage patients to get preventative care, as well as improve treatment received in emergency rooms and hospitals. Legislation has yet to pass, and was not reflected in Governor Cuomo’s 2019 Executive Budget announced on Jan. 15. The bill was reintroduced for the 2019 to 2020 legislative session.
Annual Gala

On Saturday April 21st, 2018 we hosted our 25th Annual Silver Anniversary and Lifetime Achievement Gala at The Grand Prospect Hall, Brooklyn NY.

Distinguished Service Awards were presented to:

- Caterina P. Minniti, MD
  Director, Sickle Cell Center
  Division of Hematology, Department of Oncology
  Montefiore Medical Center
- Banu Aygun, MD
  Section Head, Sickle Cell Disease
  Pediatric Hematology/Oncology & Stem Cell Transplantation
  Cohen's Children Medical Center
- Howard Grodman, MD
  Pediatric Hematology/Oncology, Bronx Lebanon Medical Center

Outstanding Service Award was presented to:

- Ms. Amy Waldman, News Director New York – PIX11

Lifetime Achievement Awards were presented to:

- Harvey Dosik, New York Presbyterian Brooklyn Methodist
- Rita Bellevue, New York Presbyterian Brooklyn Methodist
- Maud Bertoni, Wyckoff Medical Center

Scholastic Achievement Award:

- Najah Bilal, graduate of Medgar Evers College

Advocacy

On June 6, 2018, SCTPN and other SC community leaders travelled to Albany for Advocacy Day. Presentations were made by SCDAAP president Beverly Francis-Gibson, M.A; Lori Luck, MD, Medical Director, Global Medical Affairs, Sickle Cell Disease, Pfizer; Dr. Cassandra Dobson representing Queens Sickle Cell Advocacy Network; William Mollette, MA representing Sickles Cell Awareness Foundation International.

A panel of individuals affected by sickle cell shared their personal experiences.

Assemblywoman Alicia Hyndman invited Advocates to the Assembly Chambers. The goal of Advocacy Day is to focus community needs in the consciousness of the legislative body.

Too many legislators are unaware of the impact SCD has on their constituents; we are committed to educating and reminding them.

Educational Forums

In July we hosted the first sickle cell bilingual (English-Spanish) forum in Washington Heights. Another is planned for 2019.

On October 27, in collaboration with Medgar Evers College, we hosted a Community Forum. Many nursing and social work students benefited from the program. Additional colleges will be added for 2019.

2018 Walk for Sickle Cell, Central Park NY

The annual event held on September 15, a fun day that brings the community together in solidarity. The many faces of sickle cell were reflected in hundreds who came to celebrate and Walk with us.
2018-2019 Scholarship Awards

Three $1,000 scholarships were awarded to students.

Bronx Community - Family Fun Day, Crotona Park

August 26, 2018 saw many from the Bronx community attend the family fun day. There were dancers, food, games, face painting, arts and crafts for all the young ones. School supplies were also distributed.

Stay Tuned for 2019 Events:

February 2 – SCTPN Volunteers Appreciation Dinner

February 19 – SC Community Education - New York City Technical College

February 24-28 – Rare Disease Week and Day 2019

April 6 – Annual Gala honoring doctors, nurses, social workers, community leaders and others working on behalf of the New York SC community

June 22 – World Sickle Cell Day & Dance for SC, Rochester NY

July 13 – SC Community Forum (Spanish/English) - Washington Heights, Manhattan

August 24 – Dance for SC, Manhattan

August 25 – Community/Family Sickle Cell Fun Day - Crotona Park - Bronx

September 14 – Annual Walk for Sickle Cell, NY Central Park

September 19 – SC Community Education - Medgar Evers College

October 26 – SC Community Education Forum

Thanks to all our sponsors, partners and supporters – with you on our side we are stronger!