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### Seeing to the Continuity of Healthcare in the Era of COVID-19

**(Danbury, CT – October 8-9, 2020)** The Sickle Cell Thalassemia Patients Network (SCTPN) will participate in the Patient Community Building Poster Session during the NORD Rare Diseases and Orphan Products Breakthrough Summit.

The poster titled “*Seeing to the Continuity of Healthcare in an Era of Physical Distancing*” was co-authored by Teresa Ginger Davis, Candice Deler, MSW, Mark Goodwin, LCSW, Sabrina J. Lewis CHW, and Sarai Santiago, CHW, work with SCTPN, a community-based organization (CBO) located in the Crown Heights section of Brooklyn, NY. The 31-year old charity provides case management, referral to needed services, outreach and education about sickle cell disease and sickle trait.

Sickle Cell Disease (SCD), a rare disease, is the most common inherited disorder in the United States. Individuals and families living with SCD are a vulnerable population, lacking political and economic power, or access to equitable healthcare.

“In the face of SARS-CoV2 (COVID-19), the sickle cell community was hard hit. SCTPN turned its attention to ensuring continuity of its services, and advocacy for quality care, particularly for adults,” said Donnette Carroll, President. The increase mortality for emerging adults (age 20 to 30) living with sickle cell attests to the need for stronger community connections and delivery of information that will facilitate better access to quality care. Bridging the gap between young adults transitioning from pediatric to adult care, and assuring that adults receive comprehensive primary care from experienced sickle cell hematologists, ophthalmologist, orthopedics, respiratory specialists, dentists and all other subspecialties during mandated physical distancing, has become a priority.

“The CBO engages Community Health Workers to perform much of the legwork of its outreach. CHWs have been deployed as volunteers in hospital clinics and are partnered with a teaching hospital on a transition project,” said, Mark Goodwin, LCSW, project director and supervisor of the Community Health Workers. The advent of COVID-19 meant that the CHWs could no longer provide in-person engagement in clinics, or host support group meetings. Meetings for the community advisory board with a hospital partner in Bronx, NY were canceled.

Sickle cell disease advocate and media consultant Teresa Ginger Davis approached SCTPN with a proposal to convert all of its 2020 events to virtual offerings. By the first week of April, the CBO began delivering support interactions on Zoom and Facebook Live. Staff, board and

membership meetings all went virtual. The Community Connections Virtual Support Meeting is hosted monthly on Zoom and streamed to Facebook Live. LUNCH & LEARN connects pharmaceutical and medical device companies with healthcare professionals, other CBOs and rare disease advocates to exchange and disseminate information on current clinical trials, newly approved medicines and therapies.

“We are noticing an increase in participation at virtual programs over in-person events, said Candice Deler, MSW, founder and president of Candice’s Sickle Cell Fund, Inc., and Health Educator with SCTPN’s Care Coordination program. People are showing up consistently in large numbers for virtual monthly events.”

It was reported at the World Orphan Drug Congress last month, that patient attendance for telemed visits are better than in-person clinic visits. One of the advantage of telemedicine is it eliminates transportation issues, particularly when a person is not feeling well. Health care professionals can determine whether to guide at home treatment or have the patient transported to the hospital for further care.

The most surprising result of the virtual outreach and education implementation is the growing connection the Sickle Cell Thalassemia Patients Network is developing with the sickle cell disease community nationally and internationally. “Since World Sickle Cell Day, we are seeing our mission to reduce the negative impact of sickle cell disease on affected individuals and families take shape throughout New York State, in addition to seeing the positive effects of being connected with the global sickle cell community on Zoom and Facebook,” said Carroll.

Coronavirus has created a lot of uncertainty and fear about the future health for the rare disease community. The pandemic has been a strong catalyst for bringing a fragmented sickle community together. While observing physical distancing, the community is practicing social unity.

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