Poster #37

The Tennessee Sickle Cell Disease Network

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Research Objective: Sickle cell disease is the most common inherited genetic disorder in the United States and affects 1 in every 500 African-American (AA) children born in the United States. In Tennessee (TN), according to the 2013 population estimates, there are approximately 1,104,316 AAs, of which an estimated 2,157 have SCD, of which 507 reside in rural parts of the state. Despite the high prevalence of individuals affected by SCD, comprehensive care, education, and training for people diagnosed with SCD is not as widely available as health care services for individuals managing other chronic illnesses. Our will engage the SCD community stakeholders in PCOR as an essential mechanism for advancing care and meaningful research for this rare disease population. A statewide SCD network will be developed to offer social support and increase access to education, medical care, engagement in research activities that affect the lives of SCD patients and their caregivers.

Study Design: Systematically identify patient partners with SCD in rural and urban communities in TN to establish a vibrant and sustainable infrastructure through a partnership with the Sickle Cell Foundation of Tennessee to engage urban and rural areas, with specific focus on connecting the SCD community through a potential service providing community based organization (CBO) to provide: 1) information on how to connect with other families; and be informed about SCD community activities, or educational offerings; 2) training in basic research principals and 3) opportunities to contribute to PCOR, including feedback on effective and practical ways for providing input on research efforts through patient centered input, comparing urban and rural area preferences

Population Studied: 400 SCD patient partners aged 18-50, of which 30% will come from rural areas throughout the state of Tennessee. Additionally, an executive committee, comprised of 87 stakeholders across the 3 regions of Tennessee will be recruited to assist in the development of the statewide network, and eventually serve as the governing body of the TN-SCD Network. These representatives include local physicians, community leaders, adults with SCD and parents of children with SCD.

Principal Findings: Findings to date include the recruitment of 54 patients across all three regions, and 35 executive committee members. Community ambassadors have

utilized health fairs, clinic days at various hospitals and community centers, and social media to spread awareness of the project, in addition to boosting the recruitment process.

Conclusion: Most rural and urban families affected SCD have no systematic way to engage in, or lend their expertise to, patient-centered outcomes research (PCOR). A statewide network of patient partners, community stakeholders, researchers, and medical professionals will ultimately increase the standard of care for patients, and provide valuable insight for sickle cell disease research.

Implications for Policy or Practice: The opportunity to create the underpinnings for coordinated patient-centered education and linking of individuals living with SCD and their caregivers, as well as SCD stakeholders throughout the state of TN holds promise for developing a scalable PCOR process model for replication and implementation in other states the success enabling other states with rare disease populations to emulate this model.