Overview

Management of children with sickle cell disease in the emergency department benefits from a strong model of care and multi-disciplinary approach including nurses, physicians, social workers, and child life specialists. At the center of this approach is the important role of the child, parent and family. Patient and family centered care can guide important aspects of management of children with sickle cell disease in the emergency department. *The Family Centered Pediatric Emergency Department Sickle Cell Assessment of Needs and Strengths* (FC-Peds-ED-SCANS) is a quality improvement framework and includes a set of five algorithms that can guide emergency departments in important principles of care of the child with Sickle Cell Disease. Important aspects of care identified through the development of the FC-Peds-ED-SCANS include:

- Role of parent
- Triage
- Analgesic management
- Diagnostic evaluation
- Disposition
- High risk evaluation
- Referrals for unmet psychosocial needs at discharge

Background

Children with sickle cell disease (SCD) present to the emergency department (ED) with complex medical and psychosocial needs. Little research has been conducted to understand elements necessary to provide a comprehensive approach. Dr. Paula Tanabe, in partnership with the Region 4 Midwest Genetics Collaborative, conducted nine focus groups and two individual interviews with ED nurses, ED physicians, parents, one SCD nurse practitioner and one SCD hematologist in six states. The primary aim of the study was to assess the appropriateness of the ED-SCANS for pediatric patients. Participants were asked to discuss important aspects of ED management. Transcripts were analyzed according to five key decision points and common themes were identified for each decision. Participants identified critical areas that can be used to organize and improve the assessment, management, and disposition/referral decisions to improve care provided to children with SCD in the ED. Parent input was critical for each decision.
**Region 4 Genetics Collaborative- Hemoglobinopathies Workgroup**

The Region 4 Midwest Genetics Collaborative is one of seven regional collaborative groups and is made up of seven states: Illinois, Indiana, Kentucky, Michigan, Minnesota, Ohio and Wisconsin. The project is administered by Michigan Public Health Institute in Okemos, Michigan and funded by the Health Resources and Services Administration (HRSA). Since the initiation of Region 4 in 2004, a great deal of progress has been made to promote sharing among states and the maximization of available newborn screening and genetic resources.

Region 4 uses a regional approach to improve access to services, quality care, and genetics expertise in a medical home environment that is culturally sensitive. There are over 120 members from the seven states representing state public health agencies, geneticists and other sub-specialists, primary care providers, newborn screening and genetic testing laboratories and families of children with genetic conditions. The Hemoglobinopathies Workgroup provides a space for stakeholders within the region to share best practices and models for improving newborn screening, follow-up and genetic care coordination for children with hemoglobinopathies and their families.

**Paula Tanabe, PhD**

*The Family Centered Pediatric Emergency Department Sickle Cell Assessment of Needs and Strengths* (FC-Peds-ED-SCANS) was developed through a partnership with Dr. Paula Tanabe, Associate Professor in the School of Nursing with secondary appointments in the Divisions of Hematology and Emergency Medicine at Duke University. Dr. Tanabe is a national expert in the area of the emergency management of adults with sickle cell disease. She has conducted several research projects aimed at improving the analgesic management of adults with SCD in the ED. She has also conducted prospective cohort studies, structured medical record reviews, and several qualitative projects using focus groups. Funded by the National Institutes of Health, Dr. Tanabe developed the *Emergency Department Sickle Cell Assessment of Needs and Strengths* (ED-SCANS) for adults. Dr. Tanabe worked with Region 4 and the Hemoglobinopathies workgroup to modify the adult ED-SCANS for use in pediatric patients with sickle cell disease seen in the emergency department.