New York State Department of Health
Sickle Cell Disease Adolescent Transition Services Program

The New York State Department of Health seeks to improve health outcomes for adolescents and young adults ages 12-21 with sickle cell disease as they transition from pediatric to adult health care and strive to achieve self-care.

Why Focus on Health Care Transition?

- Adolescents and young adults with sickle cell disease are at high risk for morbidity and mortality at times of health care transition.
- Young adults with sickle cell disease experience significant health problems and high use of emergency and inpatient medical care.
- With early identification, entry into appropriate care, regular health evaluations and current treatments, most children with sickle cell disease survive, thrive, attend school, and participate with their peers who do not have sickle cell disease in all available activities.
- Navigating the health care system can be challenging for anyone with complex health conditions, but especially for individuals just learning to do so.

Program Administration

The New York State Department of Health's Bureau of Child Health administers the *Sickle Cell Disease Adolescent Transition Services Program* through five (5) Hemoglobinopathy Specialty Care Centers across New York State, including New York City. These partners work with local health department Children and Youth with Special Health Care Needs programs as well as Health Homes Serving Children to support ongoing engagement with the health care system. The program's goal is to enable a smooth transition for adolescents and young adults with sickle cell disease into the adult health care system through comprehensive care coordination and navigation services.

Program Activities

Activities include, but are not limited to:

- Develop and implement a transition and care management model using a health equity lens.
- Promote successful transition of adolescents and young adults with sickle cell disease to adult health care providers and self-care through consistent use of policies, protocols, practices, and tools, including Got Transition's® Six Core Elements of Health Care Transition™ and Health Care Transition Process Measurement Tool for Transitioning Youth to Adult Health Care Providers.
- Utilize Transition Navigators to assist adolescents and young adults in scheduling and keeping medical appointments using reminders, text messaging or home visits that best meet the needs of the population served.
- Provide support and linkages for the range of health and social supports and services needed by the adolescent or young adult with sickle cell disease and their families, including the Children and Youth with Special Health Care Needs Programs at local health departments.
- Provide and reinforce culturally competent educational messages to improve understanding of self-management and preventive health care including non-medical mechanisms for pain management.
- Promote engagement of Medicaid-eligible adolescents and young adults with sickle cell disease who need intensive care management with Health Homes Serving Children. Sickle cell disease is a single qualifying condition for Health Homes Serving Children and Health Homes Serving Adults.
- Involve families in the development of processes, policies and procedures as well

as providing ongoing input and involvement in quality improvement initiatives.

- Develop a system in which adolescents and young adults with sickle cell disease and their families provide peer information and support to other families experiencing sickle cell disease.

Contact Information:

For general information, please contact the New York State Department of Health Community-Based Health Unit at 518-474-1961 or CYSHCN@health.ny.gov.
For additional information, please see our website at https://health.ny.gov/CYSHCN