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Gotham Center 42-09 28th Street Long Island City, NY 11101 Dear Colleague,

In honor of National Sickle Cell Anemia Awareness Month, the New York City Department of Health and Mental Hygiene (NYC Health Department) wants to spotlight sickle cell trait (SCT), a common genetic condition with significant reproductive and health implications. More than 3 million Americans carry SCT, yet many are unaware of their status, which leads to uninformed reproductive decisions and missed opportunities for preventive health measures. Although SCT is identified through newborn screening, there is currently no standardized follow up system for documenting and counseling families. In 2023, of the more than 91,000 newborns screened in NYC, more than 2600 were identified with SCT (**Table 1**).

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Primary care providers play a vital role in counseling individuals with SCT, as well as the parents of children with SCT so they can make informed decisions about their health and future. The NYC Health Department encourages clinicians to:

- **1.** Educate families on the difference between SCT and sickle cell disease (SCD).
 - Reassure families that SCT carriers generally lead normal lives but inform them about the genetic implications.
- **2.** Discuss the genetic risks of having a child with SCD.
 - Risk depends on whether the partner carries a trait such as beta thalassemia or other beta chain mutation such as hemoglobin S or hemoglobin C.
 - Referral to genetic counseling is standard of care; provide information about genetic testing of partners.
- **3.** Discuss <u>family planning options</u> for partners at risk for having a child with SCD.

- 4. Inform carriers and their families about potential health issues related to SCT.
 - SCT is one of many genetic predispositions, which we all have, that puts us at risk for rare complications.
 - This knowledge allows families to manage potential risks and live healthy, normal lives.
- **5.** Encourage open communication among family members (ie, parents, children, and other extended family members) about SCT status and how it may affect them.
- **6.** Connect carriers and their families with genetic counselors, support groups, and <u>resources</u> for further information and support.
 - NYC-based organizations
 - o Candice's Sickle Cell Fund, Inc (CSCF)
 - o Falling Angels (Rockland County)
 - o Medicaid Health Homes Comprehensive Care Management
 - New York State Sickle Cell Advocacy Network, Inc (NYSSCAN)
 - Sickle Cell Awareness Foundation Corp International (SCAFCORPINT)
 - Sickle Cell Thalassemia Patient Network (SCTPN)
 - Westchester Sickle Cell Outreach (WSCO)
 - National Organizations
 - Sickle Cell Adult Provider Network (SCAPN)
 - American Society of Hematology (ASH)
 - o Sickle Cell Disease Association of America (SCDAA)
 - o National Alliance of Sickle Cell Centers (NASCC)
- **7.** Maintain confidentiality and respect the individual's privacy and decisions throughout the counseling process.

Data on SCT in New York City

Newborn screening is conducted routinely on all babies born in the state as part of New York State's comprehensive newborn screening program after the child is born. In 2023, 91,188 babies were screened in the five boroughs, and 2602 were born with SCT.

Table 1. New York State Sickle Cell Trait Newborn Screening by Borough, 2023

	Manhattan	Bronx	Brooklyn	Queens	Staten Island	Total
Sickle Cell Trait	317	960	764	481	80	2,602
Infants Screened	13,666	16,076	33,042	23,666	4,738	91,188
Data source: New York State Department of Health						

For more information on SCD and resources, refer to the <u>Health Advisory: NYC Health Department Recommendations on Destignatizing and Improving Provider Attitudes Towards Pain in Sickle Cell Disease.</u>

Thank you for protecting and promoting the health of all New Yorkers.

Sincerely,

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