Connecting Newborns to Case Management Services throughout North Carolina

"As a Sickle Cell Disease Case Manager, the patient education materials assist me in engagement and education. I utilize the sheets with clients, in medical centers and at community events."

Lateasha Grant-Lennon, MSW, LCSW
Case Manager & Transition Coordinator , PHSSCA, NC

At a Glance

Understanding where newborns with SCD are located and connecting them to local resources are essential to improve the wellbeing of all people living with SCD.

Collaborating with local partners to link newborns and their families with needed resources is critical to facilitating access to quality comprehensive sickle cell care.

Challenge

A new report from the Sickle Cell Data Collection program estimates that one in every 350 non-Hispanic African American newborns have sickle cell disease (SCD) and two out of three newborns with SCD live in disadvantaged areas in the United States[1]. Understanding where newborns with SCD live in North Carolina is the first step to connect them to local resources to overcome these disadvantages and improve their health outcomes. Developing and disseminating tailored public education materials can facilitate connecting newborns and their families to resources in their communities.

Approach

To raise community awareness of the occurrence of SCD in NC and connect those affected by SCD with resources in their area, NC SCDC developed 12 region-specific infographics detailing the number of SCD births in NC between 2016-2020 and the contact details for sickle cell educator counselors and case managers. The project originated from a collaboration between Piedmont Health Services and Sickle Cell Agency, NC Division of Public Health and individuals living with SCD.

This project began by incorporating the perspectives of those living with SCD, ensuring their voices were heard from the start. We developed both English and Spanish infographics to reach a wider audience and featured images representing the diversity of the sickle cell population. This approach ensured our materials were relevant and useful.

Teresa Balazsi and Justina Williams disseminating public education materials at a health fair

Impact

We surveyed sickle cell educator counselors and case managers to assess the impact of the infographics, and 53% completed the survey. All respondents found the infographics useful in disseminating information to their community. They reported distributing the infographics at more than 50 health fairs, community events, and client interactions and sharing with medical centers and local health departments in their region. They recommended to add links to the infographics, translate them into other languages (e.g., French), include contact information for the nearest comprehensive sickle cell medical centers, and add a statewide map with specified regions and the approximate number of people living with SCD in each region. An important lesson learned was the importance of the voice of people living with sickle cell throughout the infographic development process.

The findings and conclusions in this success story are those of the authors and do not necessarily represent the official position of the North Carolina Department of Health and Human Services or the Centers for Disease Control and Prevention (CDC).

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Email:
nc_sickledata@duke.edu

Website
sites.duke.edu/ncscdc/

[1]Kayle M, Blewer AL, Pan W, et al. Birth Prevalence of Sickle Cell Disease and County-Level Social Vulnerability — Sickle Cell Data Collection Program, 11 States, 2016–2020. MMWR Morb Mortal Wkly Rep 2024;73:248–254. DOI: http://dx.doi.org/10.15585/mmwr.mm7312a1