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Original Communications

Effort Required to Contact Primary Care Providers After Newborn Screening Identifies Sick Cell Trait

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People with heterozygous status for sickle cell disease (also called sickle cell trait) are essentially healthy, but evidence of rare health problems has increased interest in screening adolescents and young adults prior to enlisting in athletics or military service. Ironically, almost everyone with sickle cell trait is already identified during routine newborn screening for sickle cell disease, but this identification may never reach the parents. As part of a larger statewide study of communication after newborn screening, we decided to document the amount of labor required to connect sickle cell trait screening results with primary care providers (PCPs). Case review methods examined records and call logs from the first 150 cases in a 42-month project. Our study procedures identified PCPs for 136 of 150 infants (90.6%); a total of 266 phone calls were needed. We identified 9 categories of experiences, ranging from incorrect baby names to restrictions on accepting Medicaid patients. Cases demonstrate that it is possible to connect with most PCPs after newborn screening despite warnings about difficulties with this population. Success was due to persistence, relationships with clinics and hospitals, and Internet search capabilities. If sickle cell trait identification is necessary to protect health, then only modest increases in effort will be needed to reduce disparities in service.

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Keywords

sickle cell disease; newborn screening; genetics; patient-provider communication

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