

Many of state's smallest babies not referred for follow-up care, study finds

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The tiniest babies need special follow-up care when they go home from the hospital after birth. But, of the thousands of very-low-birth-weight babies born in California during 2010 and 2011, 20 percent were not referred to the state's high-risk infant follow-up program, according to a new study by researchers at the Stanford University School of Medicine.

Babies who weigh less than 3.3 pounds at birth, nearly all of whom are born prematurely, are at risk for a variety of neurologic and developmental problems in childhood. In California, all babies with a very low birth weight who received care in a California Children's Services-approved neonatal [intensive care unit](#) qualify for a state-supported, follow-up program that provides diagnostic assessments and services until they turn 3.

"If we cannot succeed in that first step of getting these babies referred to follow-up, we're at a critical disconnect for what we can offer them as they grow and develop," said Susan Hintz, MD, professor of neonatal and developmental medicine and lead author of the study.

The study found that larger neonatal [intensive care](#) units were more likely to make referrals, whereas larger infants, as well as those of African-American or Hispanic descent, in the study were less likely to be referred.

Hintz collaborated on the study with other Stanford researchers, as well as with researchers at the California Perinatal Quality of Care

Collaborative, and at the California Department of Health Care Services. The study appears in the February issue of *The Journal of Pediatrics*, which was published online Jan. 22.

Tracking tiny infants

Hintz's team assessed data on 10,433 very-low-birth-weight babies born in California during 2010 and 2011, soon after the state's high-risk infant follow-up program was revamped. The researchers also analyzed clinical and demographic factors that they suspected might be linked to referral rates.

Of the infants in the study, 8,071 survived to hospital discharge, and 6,424 of these got referrals to high-risk infant follow-up care when they went home. Babies were more likely to be referred if they were born very prematurely, if they were quite small at birth, and if they had medical problems while in the hospital, such as needing a ventilator; had illnesses such as sepsis and meningitis; or underwent surgery for certain complications from prematurity. "Although it is a good thing that the very smallest and sickest babies are most likely to receive referrals, the American Academy of Pediatrics recommends multidisciplinary, neurodevelopmental follow-up for all of these tiny infants," Hintz noted.

"Referral for some babies may be falling through cracks because they're relatively bigger or more mature," she said.

The researchers ranked hospitals by their volume of very-low-birth-weight patients, finding that among the hospitals with the largest volume, an average of 85 percent of infants got referrals to follow-up care, while in the hospitals with the lowest volume, an average of 65 percent were referred. There was a wide range of referral rates for individual hospitals.

During the analysis process, California Children's Services was able to provide feedback to specific hospitals with low referral rates. Many have already taken steps to improve, Hintz said. It is also possible that some babies during the study period did receive high-risk, follow-up clinical care, but were never referred through the statewide system, she noted.

"The good news is that this data was collected relatively early in the state's revitalized program for high-risk infant follow-up," Hintz said. "We've already made substantial improvements in site-specific online tools and resources available to hospitals for nearly real-time feedback, and referral rates now appear to be higher than they were during 2010 and 2011."

California is ahead of other states in having a comprehensive, statewide program to help high-risk infants, Hintz added. "The expectation that all our high-risk infants will be referred is enormously innovative in this country," she said.

More work needed

However, the data indicates that there's still work to be done, she added. One-third of the state's largest CCS-approved neonatal intensive care units already have referral rates for very-low-birth-weight [babies](#) above 95 percent, Hintz noted. "We can look at those sites to try to understand what allows them to be so successful," she said. "This is an opportunity for us to learn where there may be disparities in resources among units across the state, launch quality-improvement initiatives, and look toward building more comprehensive, community-based early intervention programs to improve outcomes for children and families."

Provided by Stanford University Medical Center

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