

Too many babies are still dying from serious intestinal disease, as improvements slow and disparities persist

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Micah, before he developed necrotizing enterocolitis. Credit: Jennifer Canvasser, NEC Society

A study published in *JAMA Network Open* has found that in the U.S.

between 1999 and 2020, Black infants disproportionately died from necrotizing enterocolitis compared to White infants, despite overall improvements in the rates of death from the disease.

Necrotizing enterocolitis (NEC) is one of the most common causes of [death](#) in [preterm infants](#). Medically fragile term infants, such as neonates born with a [congenital heart defect](#), are also at an elevated risk of NEC. Two prior studies reported conflicting trends in NEC rates. One study from 2000–2011 showed increasing rates of death from the condition over time. Another study reported declining rates of NEC from 2006–2017.

Researchers in the current study wanted to determine the trends in NEC-related deaths in the US spanning both of these periods. They also examined racial disparities and geographic differences.

The study used data on U.S. infant deaths from 1999 through 2020 from the Centers for Disease Control and Prevention and the National Center for Health Statistics. The researchers analyzed all infant deaths up to one year of age, with the underlying cause being NEC.

Of 88,125,233 live births, 8,951 infants died of NEC. Rates of NEC-related deaths per 100,000 [live births](#) were higher among Black infants (16.1) compared to White infants (6.4). The study found that in 2007, there was an inflection with a change in U.S. trends in NEC-related deaths; NEC-related deaths decreased by 7.7% per year from 2007 through 2012. However, there were no additional declines after 2012. Racial differences in NEC-related deaths decreased over time, although in 2020, Black infants were still 2.5 times more likely to die from NEC than White infants.

Dr. Mattie Wolf, first-author of this study and a post-doctoral fellow at Emory University and Children's Healthcare of Atlanta, notes, "These

data clearly show improvements in NEC-related death in the U.S., although we do not know exactly what factors are driving these improvements."

"Our results show we have made progress in reducing deaths related to NEC, but given the lack of improvements since 2012, we still have continued work to do to reduce the burden of this disease," says Ravi Patel, MD, MSc, Associate Professor of Pediatrics at Emory University School of Medicine and Children's Healthcare of Atlanta and senior author of this article.

Jennifer Canvasser, MSW, Founder and Executive Director of the NEC Society and co-author of the study, shares, "These data reveal that someone's child died from NEC each day, on average, over this period. My son Micah is one of the 8,951 babies. Clinicians, scientists, and patient-families intimately understand the devastation of NEC. Together, with [policy-makers](#) and stakeholders who care, we are working tirelessly to improve outcomes and provide equitable care so that all babies can thrive and avoid the devastation of this disease."

More information: Trends and Racial and Geographic Differences in Infant Mortality in the United States Due to Necrotizing Enterocolitis, 1999 to 2020, *JAMA Network Open* (2023). [DOI: 10.1001/jamanetworkopen.2023.1511](#)

Provided by Necrotizing Enterocolitis (NEC) Society

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