



What is necrotizing enterocolitis (NEC)?



THOUSANDS OF BABIES DIAGNOSED ANNUALLY IN THE US¹



1 IN 10 VERY LOW BIRTHWEIGHT BABIES ARE EXPECTED TO DEVELOP NEC²

NEC (pronounced “neck”) is an intestinal disease that affects infants in their first weeks and months of life. The word “necrotizing” means the process of tissue death and the word “enterocolitis” means inflammation of the small intestine or colon. Babies who are born prematurely or with a medical condition, like a congenital heart defect, are most at risk of NEC, but sometimes full term babies also develop NEC. Every year in the United States, NEC affects thousands of babies.

The NEC Society is a 501(c)(3) charity organization led by families who have been personally affected by the disease. The NEC Society’s mission is to **build a world without NEC** by advancing research, education, and advocacy.



SCAN TO DONATE

WHAT CAUSES NEC?

NEC is a complex disease and is still not well understood. The best explanation is an injury to the lining of the intestine allows bacteria to travel from inside the intestine into the bloodstream. There is no one cause of NEC, and it is no one’s fault if your baby gets NEC.

We do know that the use of human milk can reduce, but not eliminate, the risk of NEC. Probiotics may also reduce the risk. Researchers are working to find new ways to prevent NEC, as the current therapies are inadequate.

HOW WE ARE BUILDING A WORLD WITHOUT NEC

ADVANCING RESEARCH: The NEC Biorepository includes 8 research centers across the United States that collect and share NEC-related human tissue samples to accelerate research. The NEC Society’s Research Incubator advances science through knowledge sharing, collaboration, and research funding.

EDUCATION: The NEC Society organizes the NEC Symposium, North America’s only international scientific conference on NEC. Also, since 2019, the NEC Society has hosted over 20 educational webinars for researchers, clinicians, and families, sharing the latest in science and clinical practices.

RESOURCES FOR FAMILIES: The NEC Society provides resource boxes to families newly diagnosed with NEC or who have tragically lost their child to this disease. The NEC Society’s website provides evidence-based, compassionate information for families about the disease.

NEC OUTCOMES

Some babies with NEC can be treated with medication alone, this is called “medical NEC.” Some babies will require surgery, which might include placing a drain in their abdomen or surgically removing portions of the intestine. This is called “surgical NEC.”

Many babies recover fully from NEC with no complications. Some babies recover but may experience long-term problems with cognition, muscle function, and poor intestinal function. Sadly, about a third of babies who require surgery die from NEC, although surgical NEC rates are improving³. Your baby’s care team can provide you with guidance and more information.

1. Bhoomika K. Patel, Jigna S. Shah (2012). Necrotizing Enterocolitis in Very Low Birth Weight Infants: A Systemic Review, ISRN Gastroenterol. 2012: 562594. doi: 10.5402/2012/562594 2. Hamilton, B. E., Martin, J. A., & Ventura, S. J. (2011). Births: Preliminary data for 2010. National Vital Statistics Reports, 60(2), 1–25. Retrieved August 1, 2012 3. F Fredriksson and H Engstrand Lilja (2019), Survival rates for surgically treated necrotising enterocolitis have improved over the last four decades, Acta Paediatr. 2019 Sep; 108(9): 1603–1608.



BUILDING A WORLD WITHOUT NEC