



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 brings together families, healthcare providers, researchers, and other diverse stakeholders who are committed to building a world without NEC.



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 (not formula) and probiotics can reduce, but not eliminate, the risk of NEC. Researchers are working to find new ways to prevent NEC, as the current therapies are inadequate.

WHAT DOES THE NEC SOCIETY DO?

The NEC Society advances NEC research, education, and advocacy. We help to empower parents with information so they can participate as informed members of their child’s care team. Along with our nonprofit partners around the world, we established NEC Awareness Day (May 17). We provide education, like our webinar series, which shares the latest science and practice advances.

The NEC Society conducts and supports research about NEC. Our Research Collaborative brings together families and multidisciplinary scientists to conduct research as a team. The NEC Society is proud to support the world’s first multi-center NEC Biorepository, where scientists collect and share tissue samples to learn how to eliminate NEC.

Learn more at www.NECsociety.org

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 survival 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.

