NEC (pronounced “neck”) is an intestinal disease that can affect infants in their first weeks and months of life. “Necrotizing” means the process of tissue death and “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.

**What is necrotizing enterocolitis (NEC)?**

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

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. The NEC Society also hosts educational webinars, 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 as well as informative, current information for clinicians and scientists.

Learn more at [NECsociety.org](https://NECsociety.org)


**WHAT CAUSES NEC?**

NEC is a complex disease and is not well understood. When NEC occurs, inflammation leads to tissue injury in the intestine. NEC does not have one single cause, 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. Researchers are working to find new ways to prevent and treat NEC, as the current therapies are inadequate.

**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.”

Some babies recover fully from NEC with no complications. Many 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. Your baby’s care team can provide you with guidance and more information.