## What is necrotizing enterocolitis (NEC)?

NEC 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.

The NEC Society is a 501(c)(3) nonprofit organization led by patient-families, clinicians, and researchers who are working to build a world without NEC so babies and families never experience the devastation of this disease. The NEC Society is working tirelessly to advance NEC research, education, and advocacy for babies like yours.



More than **3500** babies are diagnosed annually in the US<sup>1</sup>



About **1 in 10** very low birthweight babies develop NEC <sup>1</sup>

## What causes NEC?

NEC is a complex neonatal disease that causes severe inflammation of the intestinal tissue. Scientists are still working to discover why some babies develop NEC and how to prevent the disease. NEC does not have one single cause, and it is no one's fault if your baby develops NEC.

We need more science to build a world without NEC

**RESEARCH:** The NEC Biorepository collects tissue samples to help us understand the disease, so one day we can prevent NEC. The NEC Research Incubator advances science through knowledge sharing, collaboration, and research funding.

**EDUCATION:** The NEC Society organizes the NEC Symposium, the world's largest and most influential scientific conference on NEC. The NEC Society also creates resources and hosts webinars to share the latest in science and clinical practices.

**RESOURCES FOR FAMILIES:** The NEC Society has created a community for families to come together and honor their children in meaningful and impactful ways. The NEC Society's website provides evidence-based, compassionate information for families as well as informative resources for clinicians and scientists.

1. Han SM, Hong CR, Knell J, et al. Trends in incidence and outcomes of necrotizing enterocolitis over the last 12 years: A multicenter cohort analysis. J Pediatr Surg. 2020;55(6):998-1001. doi:10.1016/j.jpedsurg.2020.02.046

## **NEC Outcomes**

Many babies recover fully from NEC, and many other babies recover but face lifelong neurological and nutritional complications. Some babies require surgery or many surgeries, and may have life-altering outcomes, such as short bowel syndrome, even after they are home. Tragically, some babies die from NEC. Your baby's care team will partner with you to help your baby thrive.



**BUILDING A WORLD WITHOUT NEC** 

