

# About NEC & the NEC Society

## for bereaved families

We are so sorry for the devastating loss of your precious child. We also lost our child to this cruel disease, and this is the information we wish someone had given to us.

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, thousands of babies are diagnosed with NEC, and tragically, hundreds pass away from the disease.

*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.*

### 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.



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 is 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 when a baby develops NEC.

## Child Loss

Our hearts are shattered with yours. You will always carry your boundless love for your child, along with your grief. You are always your child's parent. You are never alone. Within the NEC Society is a community of families who have also tragically lost their children to NEC. You may find comfort in the NEC Society's community. We hope you can find ways to honor your child and carry their light in a way that feels right to you. The passage of time will never change the bond between you and your baby. We wish you peace.



**NECsociety.org**  
BUILDING A WORLD  
WITHOUT NEC



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

