

# What is necrotizing enterocolitis (NEC) and why does it matter?

## The cost of NEC:

500  
BABIES DIE ANNUALLY

20%  
OF NICU  
COSTS

\$5B  
ANNUAL  
COST

NEC is a devastating intestinal disease that affects infants in their first weeks and months of life. Babies who are born prematurely or with a medical condition, like a congenital heart defect, are most at risk of NEC. Every year in the United States, NEC affects thousands of babies and claims the lives of about 500 infants annually. The babies who do survive NEC often endure multiple surgeries, lengthy hospitalizations, and lifelong complications. NEC is also extremely costly, accounting for almost 20% of NICU costs annually -- more than \$5 billion annually just in the US. While NEC is not rare in the NICU, it is a rare disease because it affects fewer than 200,000 Americans.

The NEC Society is a 501(c)(3) charity organization led by families who have been personally impacted by necrotizing enterocolitis, known as NEC. The NEC Society brings together families, healthcare providers, and researchers who are committed to building a world without NEC.



Baby Leyden before NEC

### WHY ADVOCACY DAY?

NEC morbidity and mortality rates have not changed significantly in decades. The disease remains poorly understood, and prevention and intervention techniques are inadequate. Babies die from NEC every day in the US because we have not adequately prioritized the resources and funding necessary to better prevent and treat the disease. By reducing NEC rates, we can reduce healthcare costs and improve outcomes for thousands of infants.

### BENEFIT TO LAWMAKERS?

Building a world without necrotizing enterocolitis is an issue that brings everyone together. There is an urgent need to protect our most vulnerable babies from dying of this devastating neonatal disease. There is also an urgent need to assist survivors with complications. By reducing the number and severity of NEC cases, we will relieve the financial burden on our health care system. We are in need of champions who recognize the opportunity to prevent and eliminate a horrific disease that shatters young families every day in the US.

## WHAT DOES THE NEC SOCIETY WANT?

The NEC Society is asking Congress to increase funding for the National Institute of Child Health and Human Development to better fund urgent NEC research. Furthermore, the NEC Society is asking legislators to recognize World NEC Awareness Day and our commitment to understanding, preventing, and treating necrotizing enterocolitis in our most vulnerable babies.



Baby Leyden after NEC, just days before she passed away.

THIS IS NEC

 **NEC  
SOCIETY**  
Building a World Without NEC