



# Building a world without necrotizing enterocolitis



[NECsociety.org](https://necsociety.org)

The NEC Society is the world's leading nonprofit organization dedicated to understanding and preventing necrotizing enterocolitis (NEC). We're led by a global community of patient-families, clinicians, and scientists.

Together, we are building a world without NEC by advancing research, education, and advocacy.



# Turning Pain into Power

Necrotizing enterocolitis (NEC) is a devastating intestinal disease that can affect vulnerable infants during their first weeks and months of life. NEC moves aggressively and leads to severe inflammation. Upon diagnosis, many babies have only hours or days before their intestines become necrotic, progressing to sepsis, multisystem organ failure, and death.

**In the US, one baby dies from NEC every day.**

Each year, more than 3,500 infants in the US develop NEC. Right now, there is no cure for this disease. In the most severe cases, the mortality rate can reach 50-100%. Infants who survive NEC often struggle with lifelong digestive, nutritional, motor, and cognitive complications.



**"Losing Micah to NEC has compelled our family to give and do all we can to prevent this devastating disease. Together, with your support, we can move mountains."**

*-Jennifer Canvasser, Founder & Executive Director*

**1 out of 10**  
**very low**  
**birthweight babies**  
**develop NEC**

The NEC Society's mission is to build a world without NEC by advancing research, education, and advocacy to overcome the inadequate treatment and prevention options that have devastated our community for decades.

**"We've created a framework for collaborative teams to work together in the fight against NEC so that babies, families, and clinicians never have to face this disease in the intensive care unit."**

*-Misty Good, MD, MS, Division Chief, Neonatal-Perinatal Medicine  
UNC Health Children's Hospital, Director of NEC Biorepository*



# Turning Pain into Progress

## NEC causes at least 1 in 10 infant deaths in NICUs across the US.

To prevent and treat NEC, we need more research to better understand how and why the disease occurs, and more engagement to implement the most protective care practices.

The NEC Society gives our community the information and resources necessary to better prevent, diagnose, and treat NEC.



*Rex, who tragically passed away from NEC*

# Turning Pain into Hope

The NEC Society's work is driven by our intimate understanding of the devastation of NEC. Patient-families and clinician-scientists join our community because they are compelled to advance our mission. The NEC Society gives hope amid feelings of helplessness, and connection amid feelings of isolation.



## We center babies and families in everything we do.

Our work focuses on the urgent need to prevent this disease. Every day, more infants are diagnosed with NEC, and too many do not make it home to their families.

*Brooks, who tragically passed away from NEC*

The NEC Society is a 501(c)(3) nonprofit organization that relies on donations from individuals and foundations. **We have come so far. Yet, there is so much more that needs to be done. You can help protect infants from this devastating disease.** Please join us by making a donation. Every dollar donated to the NEC Society is transformed into impactful work.

**"Without my son, Cash Owen, physically in my arms, I parent him from afar by fundraising for the NEC Society, saying his name, and raising awareness about NEC."**

*-Shannan Finnegan, mother to Cash, who tragically passed away from NEC.*



## Will you join us in building a world without NEC?



# How we are building a world without NEC

## Advancing Research

**NEC Biorepository:** Includes 8 research centers across the United States that collect NEC-related human tissue samples. In this groundbreaking collaboration, centers are sharing these hard-to-acquire samples, accelerating the pace of NEC research.

**NEC Research Incubator:** Advances science through knowledge sharing, collaboration, and research funding.

**NEC Research Awards:** Cultivates the next generation of scientists and clinicians focused on NEC.



## Improving Education

**NEC Symposium:** The world's largest conference dedicated to NEC. The NEC Society has organized the NEC Symposium biennially since 2017. By uniting hundreds of clinicians, scientists, patient-family leaders, and others, the NEC Symposium advances innovative strategies to better understand, prevent, diagnose, and treat NEC.

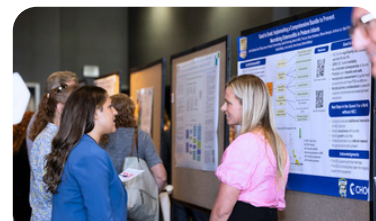
At the NEC Symposium, attendees are inspired to integrate and implement new practices and research projects because of their participation and the connections they gained.

## Increasing Advocacy

**NEC Awareness Month:** May is NEC Awareness Month, and May 17 is NEC Awareness Day – an essential time to unite the global community to advance research, education, and advocacy.

**Family Resources:** The NEC Society provides free resources to families diagnosed with NEC, or who have tragically lost their child to this disease.

**Community:** The NEC Society brings together patient-families, clinician-scientists, advocates, and stakeholders through groups like our Industry and Nonprofit Champions, Nurse Ambassadors, and Advisory Councils.



# The NEC Registry

## A Natural History Study of Necrotizing Enterocolitis (NEC)

The NEC Registry is a platform for patient-families around the world to elevate their voices and share information about necrotizing enterocolitis. This global resource will help researchers find better ways to understand and care for families affected by NEC.

*The NEC Registry is more than just a data collection system. It's an interactive, participant-driven resource that empowers the NEC community.*



Understand the long-term effects of NEC



Develop recommendations and standards of care



Advance research and support the design of clinical trials

**"This disease is devastating for families and clinicians. We urgently need better strategies to prevent and treat NEC. At the NEC Society, patient-families work alongside researchers and clinicians, which inspires our broader community to collaborate. The NEC Society is pivotal to progress."**

*-Ravi Mangal Patel, MD, MSc, Professor of Pediatrics Emory University School of Medicine Children's Healthcare of Atlanta*



**Donate  
Here**



Checks can be mailed to:  
NEC Society  
140 B Street, Suite 5, #128  
Davis, CA 95616

EIN# 46-4426455



# BUILDING A WORLD WITHOUT ONEC