







Building a world without necrotizing enterocolitis





NEC SOCIETY

NECsociety.org

The NEC Society is the world's leading nonprofit organization dedicated to 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, NEC Society Founder & Executive Director

1 out of 10

very low birthweight babies develop NEC

The NEC Society's mission is to advance research, education, and advocacy so every baby is protected from the devastation of NEC.

"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



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Building a world without NEC

Get involved at NECsociety.org

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 it occurs, and stronger strategies to implement the most protective care practices equitably.

Our community depends on the NEC Society for the latest information and resources to better prevent, diagnose, and treat NEC.



Ronan, 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 offers hope amid helplessness and connection amid 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.

Babies who survive NEC often experience life-altering digestive and neurological complications.

Freddie survived NEC in the NICU and now lives with the long-term complications of this disease.

The NEC Society is a 501(c)(3) nonprofit organization that relies on donations from people who care about babies and families. **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.


NEC Biorepository



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.

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

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.

The world's only NEC Family Summit: Families impacted by NEC unite with clinicians and industry partners to transform the pain and trauma of NEC into power and actionable strategies to fuel our shared vision of a world without NEC.

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


NEC Family Summit

Program Highlights

NEC Registry: A Natural History Study of 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.**

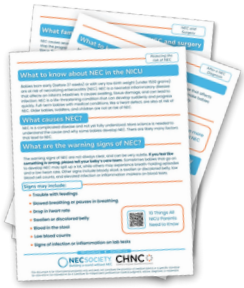


Educational Resources for NICUs

Resource boxes are available for families diagnosed with NEC or who have tragically lost their child to the disease.



Fact Sheets on the risk of NEC, NEC and surgery, feeding, and more, guide clinicians and families alike.



NEC Awareness State and Congressional Resolutions

15 states formally recognize May 17th as NEC Awareness Day or May as NEC Awareness Month. Additionally, the NEC Awareness Resolution has been **introduced to Congress annually** since 2024.

Taylor and Dustin led the introduction of the Illinois NEC Awareness Resolution in memory of their son, Walter





"This disease is devastating for families *and* clinicians. 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

Gifts can be mailed to:
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