

## BUILDING A WORLD WITHOUT NEC

NECsociety.org

The NEC Society is the world's leading charity focused on necrotizing enterocolitis (NEC). We are a patient-led organization working in partnership with renowned clinicians, researchers, and other diverse stakeholders toward a world where babies never experience the devastation of NEC.





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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

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## 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. "Necrotizing" means the process of tissue death and "enterocolitis" means inflammation of the small intestine or colon.

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

Each year, more than 3,500 infants in the US develop NEC. Tragically, up to 30% of the babies diagnosed with NEC will die from the disease, with the most severe cases approaching 100%. Infants who survive NEC often struggle with lifelong digestive, nutritional, motor, and cognitive complications.

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 thwarted progress for decades.

Founded by a bereaved mother, the NEC Society brings together patient-families and experts from around the world to improve outcomes for the most vulnerable infants at risk of NEC.

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It is about creating a framework for collaborative teams to work together in the fight against NEC so that babies, families, and health care providers never have to deal with this disease in the intensive care unit again.

- Misty Good, MD, MS



## **Turning Pain into Progress**

Despite NEC **causing 1 in 10 deaths** in NICUs across the country, relatively little progress has been made in understanding, preventing, and treating the disease. The NEC Society is equipping medical professionals with the information and resources they need to identify, prevent, and treat NEC.



## Turning Pain into Hope

Our work is deeply personal; we often meet patient-families in moments of raw crisis. For families who experience the devastation of NEC, our organization represents hope amid feelings of helplessness and a sense of community amid feelings of isolation.

**These families are our "why."** They drive and compel our work. Every day, more infants are diagnosed with NEC and too many do not make it home to their families.

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. No gift is too small, and every contribution makes a difference.

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

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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 Finegan, bereaved mother



## 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 Registry:** Collects data from patient-families affected by NEC. This information will help researchers better understand NEC and its long-term effects.



### Education

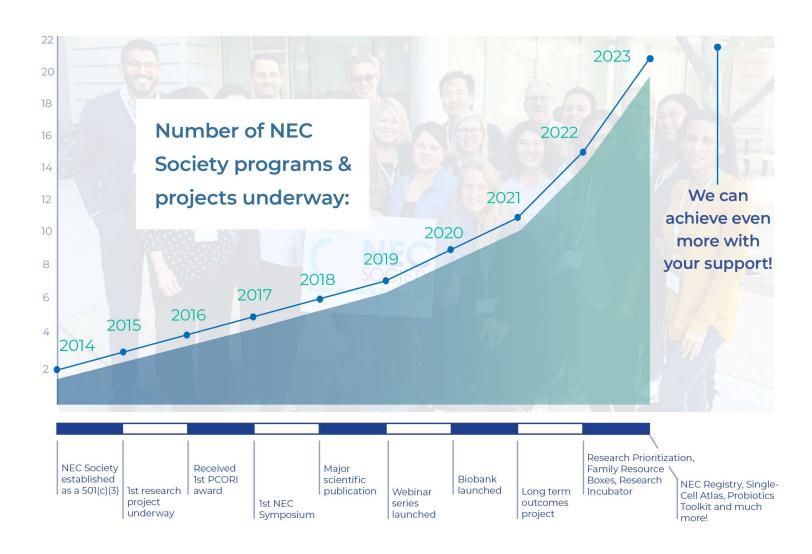
**NEC Symposium**: North America's only international scientific conference on NEC. The NEC Society's 2023 Symposium convened 200 diverse participants from 9 countries and 35 states, with 20 educational sessions presented by 60 renowned faculty members. The collaborations, research, and advocacy stemming from the 2023 NEC Symposium will reverberate in the NICU community for years.



## Resources for Families

The NEC Society provides **free resource boxes** to families newly diagnosed with NEC or who have tragically lost their child to this disease. Our resources empower families with information and comfort when they need it most.

The NEC Society's **website** provides evidence-based, compassionate information about the disease for families. The website is a vital resource for families searching for information and community. NECsociety.org features families who share their stories in hopes of conveying lessons so others can learn from their experience and find comfort in knowing they're not alone.







## TO DONATE: NECsociety.org/Donate

Checks can be mailed to:

NEC Society 140 B Street, Suite 5, #128 Davis, CA 95616



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