



NECSOCIETY®

PRESS KIT 2026

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.

NECsociety.org

Updated Aug 2026

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ABOUT THE NEC SOCIETY

The NEC Society is the world's leading nonprofit organization dedicated to necrotizing enterocolitis (NEC).

NEC is the most common and deadly gastrointestinal disease affecting premature and medically fragile infants and is a leading cause of death in neonatal intensive care units (NICUs).

The NEC Society was launched in January of 2014 by Jennifer Canvasser after her son, Micah, died from complications of NEC just before his first birthday. Today, patient-families and experts from around the world work together to improve outcomes for the most vulnerable infants at risk of NEC.



Mission Statement

The NEC Society's mission is to bring together patient-families, clinicians, and scientists to advance NEC **research, education, and advocacy**. Together, we will build a world without NEC so no baby or family has to endure the devastation of this cruel disease.

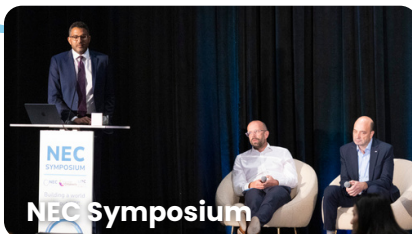
Research

- 1,193 babies enrolled in the **NEC Biorepository**
- 120+ global institutions represented in the **Research Incubator**
- **Research awards** supporting early-career clinician-scientists
- Collaborative **NEC Registry**
- Scientific Council of **world-leading neonatologists**



Education

- **Resources** for diagnosed and bereaved families
- **NEC Symposium**, the world's largest NEC-focused scientific conference
- The world's first in-person **NEC Family Summit**
- Expert presentations at **scientific and educational meetings**



Advocacy

- NEC Awareness Resolutions in **15 states & US Congress**
- **NEC Awareness Month** recognized globally
- Collaboration between **clinicians, scientists, and patient-families**
- **Community events** across the globe
- Engagement with the FDA to advocate for



Learn more about the NEC Society

ABOUT NECROTIZING ENTEROCOLITIS (NEC)

Necrotizing enterocolitis (NEC) is a devastating intestinal disease that primarily affects premature infants. NEC can also affect term babies, especially infants with a medical condition, like a congenital heart defect. NEC causes severe inflammation of the intestine, leading to a bacterial infection causing necrosis (tissue death).

NEC is a leading cause of death in neonatal intensive care units (NICUs) and is the **most common cause of death for extremely preterm infants between 2 weeks and 2 months of age**. Many babies recover fully from NEC. Some babies recover but face lifelong neurological and nutritional complications. Tragically, some babies die from NEC.



1 out of **10**

very low birthweight babies develop NEC



More than

3500

babies are diagnosed annually in the US

More research is urgently needed to fully understand why NEC occurs, when NEC occurs, how NEC occurs, and which neonates will develop the disease.

What Causes NEC?

NEC is multifactorial and there is no single cause. Factors that increase the risk for NEC include premature birth, low birth weight, absence of mother's (or donor) milk, and severe anemia.

Researchers are working to find new ways to prevent and treat NEC, as the current therapies are inadequate.

Mother's own milk provides the most protection against NEC. When mother's own milk is not available, pasteurized donor milk offers the next best protection.

NEC Outcomes

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

Some babies with NEC can be treated with medication alone, this is called "medical NEC." Some babies will require surgery, which might include placing a drain in their abdomen or surgically removing portions of the intestine. This is called "surgical NEC." Some babies recover fully from NEC with no complications. Many babies recover but may experience long-term problems with cognition, muscle function, and poor intestinal function. Tragically, about a third of babies who require surgery die from NEC.

Learn more about NEC

LEADERS FOR A WORLD WITHOUT NEC

The NEC Society is guided by a dedicated community of leaders, experts, and advocates who help ensure our work is both scientifically rigorous and grounded in lived experience. Our **Board of Directors** provides governance and strategic direction, our **Scientific Advisory Council** brings internationally recognized expertise to guide our programs and materials, and our **Patient-Family Advisory Council** ensures that patient-family voices are integrated into all our work. Together, this team is advancing our shared vision of a world without NEC.

NEC Society Staff



Jennifer Canvasser, MSW
Executive Director and Founder



Erin Pryor, MPH, RDN, LD
Research Director



Sarah Piephoff
Communications Director

TESTIMONIALS



"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."

Ravi Patel, MD, MSc, NEC Society Scientific Advisor and neonatologist at Emory University and Children's Hospital of Atlanta

"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, NEC Society Scientific Advisor



"It's so great to have a stage to tell my son's story, and incredible to be around parents who have gone through what I went through—who understand that pain in a totally different way. And to meet parents who have been able to take their children home and watch them grow, to hear about the challenges and the successes of that. To have different perspectives together has been extremely inspiring."

Nicola Juri, Mom of Ronan, who tragically passed away from NEC, speaking about meeting families through the NEC Society; NEC Society Board Member

Explore the Scientific Advisory Council

NEC SOCIETY IN THE NEWS

The NEC Society is recognized as a trusted voice in the field of necrotizing enterocolitis (NEC), bringing together the perspectives of families, clinicians, and researchers to advance meaningful change. The NEC Society is frequently featured in media conversations about the latest developments in NEC prevention, treatment, innovation, and public policy.

Study Reassures on Probiotic Sepsis Risk in Very Preterm Infants

MedPage Today August 2026

Probiotic-associated invasive infections were rare in very preterm infants, according to a large retrospective cohort study.

[Read More](#)

Thompson, Kiley, Miller Introduce Tripartisan Resolution Designating May 17 as Necrotizing Enterocolitis Awareness Day

Representative Mike Thompson, May 2026

Today, Reps. Mike Thompson (D-CA-04), Kevin Kiley (I-CA-03), and Carol Miller (R-WV-01) introduced a tripartisan resolution to designate May 17th as Necrotizing Enterocolitis Awareness Day.

[Read More](#)

She's running Boston in memory of her son, and for necrotizing enterocolitis

Boston.com, April 2026

"I have learned to carry the unfathomable loss of Micah and channel all that love and energy into fueling the NEC Society's work."

[Read More](#)

Explore the NEC Society's blog

Explore the NEC Society Leadership's Research Publications



NEC SOCIETY IN THE NEWS

Hundreds of lawsuits allege Abbott Laboratories' formula for premature infants made babies sick. But is the formula to blame?

Chicago Tribune, November 2024

Jennifer Canvasser, of California, started the NEC Society to help advance research and raise awareness of the disease after her son Micah...

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Doctors, FDA Fight Over Giving Probiotics to Premature Babies

Wall Street Journal, November 2023

Doctors say FDA crackdown on products for premature babies has left them without a key tool for preventing a deadly gut disease.

[Read More](#)

NEC Symposium Wrap Up with Jennifer Canvasser and Jae Kim

The Incubator Podcast, August 2023

"I have learned to carry the unfathomable loss of Micah and channel all that love and energy into fueling the NEC Society's work."

[Read More](#)

Carolina Researchers Awarded \$1 Million by CZI to Combat Necrotizing Enterocolitis

UNC Health, December 2022

Principal investigators Misty Good, MD, MS, and Scott Magness, PhD, at the UNC School of Medicine, and Jennifer Canvasser, MSW, NEC Society, will lead a \$1-million project funded through the Chan Zuckerberg Initiative to map cellular roles in necrotizing enterocolitis (NEC).

[Read More](#)

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Explore the NEC Society Leadership's Research Publications



BOILERPLATE AND MEDIA CONTACT

Boiletplate

The NEC Society is the world's leading nonprofit dedicated to necrotizing enterocolitis (NEC), a devastating neonatal intestinal disease that is a leading cause of death for premature infants. Since 2014, the NEC Society has brought together patient families, clinicians, and scientists to advance NEC research, education, and advocacy for a world without NEC.

Learn about the NEC Society's initiatives at NECsociety.org

Visual Assets

To access approved photos, video, and brand assets, please reach out to the NEC Society's Media Contact.

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BUILDING A WORLD WITHOUT ONEC