

What is necrotizing enterocolitis (NEC)?

NEC is an intestinal disease that can affect infants in their first weeks and months of life. "Necrotizing" means the process of tissue death, and "enterocolitis" means inflammation of the small intestine or colon. Babies who are born prematurely or with a medical condition, like a congenital heart defect, are most at risk of NEC, but sometimes full-term babies also develop NEC. Every year in the United States, NEC affects thousands of babies.

The NEC Society is a 501(c)(3) nonprofit organization led by patient-families, clinicians, and researchers who are working to build a world without NEC so babies and families never experience the devastation of this disease. The NEC Society is working tirelessly to advance NEC research, education, and advocacy for babies like yours.

More than **3500** babies are diagnosed annually in the US¹



About **1 in 10** very low birthweight babies develop NEC¹

What causes NEC?

NEC is a complex neonatal disease that causes severe inflammation of the intestinal tissue. Scientists are still working to discover why some babies develop NEC and how to prevent the disease. NEC does not have one single cause, and it is no one's fault if your baby develops NEC.

We need more science to build a world without NEC

RESEARCH: The NEC Biorepository collects tissue samples to help us understand the disease, so one day we can prevent NEC. The NEC Research Incubator advances science through knowledge sharing, collaboration, and research funding.

EDUCATION: The NEC Society organizes the NEC Symposium, the world's largest and most influential scientific conference on NEC. The NEC Society also creates resources and hosts webinars to share the latest in science and clinical practices.

RESOURCES FOR FAMILIES: The NEC Society has created a community for families to come together and honor their children in meaningful and impactful ways. The NEC Society's website provides evidence-based, compassionate information for families as well as informative resources for clinicians and scientists.

NEC Outcomes

Many babies recover fully from NEC, and many other babies recover but face lifelong neurological and nutritional complications. Some babies require surgery or many surgeries, and may have life-altering outcomes, such as short bowel syndrome, even after they are home. Tragically, some babies die from NEC. Your baby's care team will partner with you to help your baby thrive.



Learn more at
NECsociety.org

BUILDING A WORLD WITHOUT NEC

1. 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

10 Things to Know When Your Baby is Diagnosed with NEC

*Created by families affected by
NEC, for families affected by NEC*



1

This is not your fault. Babies develop NEC (necrotizing enterocolitis) for many reasons, even when they have the most dedicated parents and healthcare providers. Nothing you did caused your baby to develop NEC.

2

Learn and ask questions. NEC is a complicated disease. More research is needed to fully understand why and how NEC develops. You can learn more about the risk factors, protective factors, and potential outcomes by speaking with your baby's care team or visiting necsociety.org

3

You are the most important member of your baby's care team. When you can, participate in medical rounds, even remotely. Your questions, thoughts, and concerns are valid. Speak up. You are your baby's expert, and you know your baby best.

4

Ask for human milk. Human milk does not eliminate the risks of NEC, but it provides the most protection against NEC, helping your baby thrive. When mother's own milk is not available, pasteurized donor human milk offers the next best protection. Formula does not offer any protection against NEC.

5

NEC can be a life-altering disease. Many babies recover fully from NEC, and many other babies recover but face lifelong neurological and nutritional complications. Tragically, too many babies die from NEC. Your care team is working hard to help your baby thrive after NEC.

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

6

Build a team of nurses. Ask if the same group of nurses can care for your baby. This is called primary nursing. An established team helps provide more consistent care, fostering trust, rapport, and open communication. This continuity can also help your baby have better health outcomes.

7

Become an advocate. It can be hard to speak up and ask questions, especially when things feel overwhelming and scary. Sharing your thoughts and concerns can help you, your baby, and your family. Ask your baby's care team for more information so you can become more informed and empowered.

8

Prioritize yourself. Your baby needs you to be as well as possible. It helps to surround yourself with people who are uplifting and who can help to take care of you. By focusing on your needs, you'll feel more ready to participate as an active member of your baby's care team.

9

Connect with your baby. Even if your baby is unwell, you can bond and nurture your child by reading storybooks, singing lullabies, and resting your hands on their skin. Books, music, and touch can benefit both you and your baby.

10

Capture this moment. You'll never have this time back. Take photos and videos, even if your baby is critically ill. Use a stamp pad to capture your baby's handprints and footprints. Keep a journal to write down details about this experience, so you can reflect back on your family's journey together.



Building a world without NEC

NECsociety.org