About NEC & the NEC Society

for bereaved families

We are so sorry for the devastating loss of your precious child. We also lost our child to this cruel disease, and this is the information we wish someone had given to us.

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, thousands of babies are diagnosed with NEC, and tragically, hundreds pass away from the disease.

More than **3500** babies are diagnosed annually in the US[1]

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About **1 in 10** very low birthweight babies develop NEC [1]

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.

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.

What is 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 when a baby develops NEC.

Child Loss

Our hearts are shattered with yours. You will always carry your boundless love for your child, along with your grief. You are always your child’s parent. You are never alone. Within the NEC Society is a community of families who have also tragically lost their children to NEC. You may find comfort in the NEC Society’s community. We hope you can find ways to honor your child and carry their light in a way that feels right to you. The passage of time will never change the bond between you and your baby. We wish you peace.

NECsociety.org
BUILDING A WORLD
WITHOUT NEC

NEC SOCIETY

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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 for Bereaved Parents to Know

Created by bereaved parents, for bereaved parents

NECSOCIETY
Building a world without NEC

1

You are always your child's parent. Your child is forever a part of your life. Nothing can ever change that.

2

You are not alone. No one wants to be part of this tragic community, and still, it is comforting to know the NEC Society understands your grief because we have also lost our children to NEC. Being part of this community can help you navigate the unfathomable days, months, and years ahead.

3

Do what feels right to you. There is no "right way" to grieve. We all grieve in different ways. Give yourself permission to follow your own lead on this lifelong journey. Your loved ones may grieve in a way that is different from you. That is okay. The key is common grace and empathy.

4

Nature can be soothing. A walk in nature or time in the garden can have a calming effect. Spending time outside can help you process the trauma of child loss and clarify what you need to carry your child in your heart.

5

There is no "moving on" from child loss. The loss of your child is unfair and devastating. Time does not heal all wounds. This is not a loss to "get over." A parent's love for their child is eternal, even when they are not physically with us.

6

Grief, joy, and gratitude coexist. Give yourself permission to experience and feel the full range of your emotions. If you have questions about what happened to your child, it can be helpful to share these questions with your child's doctors, even months or more after your child's passing. There will likely be some questions that no one can answer.

7

It is helpful to find ways to honor your child. It can be small or elaborate, quiet or public, just as long as it feels right to you. Creating art or keeping a journal can be meaningful ways to honor your child. Honoring your child can help you find a sense of peace and meaning.

8

Some experiences will trigger strong emotions. In the coming weeks, months, and years, you will have certain experiences that remind you of your child. You will learn to anticipate some triggers, but others will be sudden and unexpected. While these triggers may be painful and distressing, it is helpful to remember that they stem from the deep, everlasting love between you and your child.

9

Tell your loved ones how you want to be supported. You can help them understand that nothing and no one can ever replace your child. You can let them know what is helpful and what is hurtful. Loved ones mean well, but they often need guidance on how to provide their comfort and support.

10

You will learn how to carry the crushing weight of your devastating loss. You will learn how to carry your child in your heart, instead of your arms. It will never be easy. Every day, you will become stronger. You can lean into the community of families who have also lost their children to NEC.

NECsociety.org

We share your overwhelming heartache as you grieve the devastating loss of your precious child. As you make it through the initial hours, days, and weeks as a bereaved parent, you may have questions about your breastmilk. We are here to offer a possible pathway toward a sense of peace and community.

What if I am still making breastmilk?

Our bodies start to make milk early in pregnancy. Our bodies do not know when our babies pass away. Even without your baby in your arms, your breasts may leak milk and become full.

What should I do if I still have or produce breastmilk?

There are different options, and there is no right or wrong decision. You should do what feels right to you. There are ways to donate your breastmilk or to stop your milk production. You can even learn how to do both. To stop your breastmilk production, please connect with your healthcare team.

I have breastmilk. How can I donate my milk in honor of my child?

Donating breastmilk in honor of your child can be a meaningful way to build community and connection. Nonprofit milk banks pasteurize milk for infants in the intensive care unit. Any amount of breastmilk you donate will help save another infant's life. Many nonprofit milk banks offer beautiful ways to carry and share the memory of babies like yours.

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If you have breastmilk that you'd prefer to donate, you can reach out to your nearest nonprofit milk bank at HMBANA.org/find-a-milk-bank/

HUMAN MILK BANKING
ASSOCIATION OF NORTH AMERICA