



Fragile Infants: Evidence-Based Resources to Help Parents and Providers

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THE UNIVERSITY OF ARIZONA
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ACKNOWLEDGEMENTS AND DISCLOSURES

Resources reported in this webinar presentation were supported by the **Agency for Healthcare Research and Quality**, the **Robert Wood Johnson Foundation** and the **National Library of Medicine (NLM)**, **National Institutes of Health (NIH)** under **Cooperative Agreement number UG4LM012341**. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health, AHRQ or Robert Wood Johnson Foundation.

- Dr. Gephart created GutCheck^{NEC} and NEC-Zero. Both are open access and publically available.
- Dr. Gephart serves on the Scientific Advisory Council for the NEC Society and the Scientific Advisory Board of the Morgan Leary Vaughan Fund.

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The planners and presenters have no relevant financial relationships to disclose.

OUTCOMES

After viewing this webinar, participants will be able to:

- Recognize the conditions that put an infant at risk for necrotizing enterocolitis (NEC).
- Identify resources to promote health from National Library of Medicine (PubMed, LactMed & MedlinePlus).
- Locate and use trustworthy health information about NEC.
- Ask informed questions about NEC, NEC prevention and NEC resources.

WHAT IS NEC?



9000

3000

0%-6%-12%



Neonatal Intensive
Care Unit (NICU)
Practices

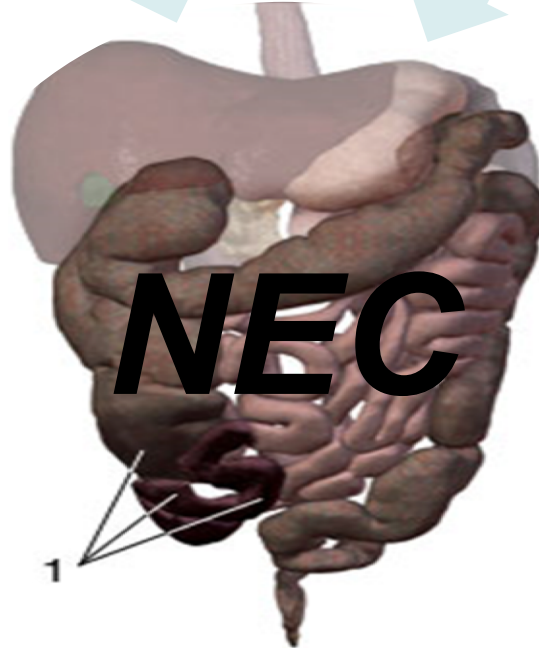
Too few helpful
bacteria and too
many harmful
bacteria in the
intestine

Conditions that
involve low oxygen
to the body that draw
oxygen away from
the intestine

Immature mucosa
(lining) of the
intestine

Effects of feeding-
especially products
that are not from
human milk or using
strategies that are
un-standardized

Exaggerated
and un-
regulated
inflammation



AMAZING FACTS ABOUT HUMAN MILK AND WHY IT IS SO IMPORTANT FOR PREMATURE BABIES



From Peekaboo ICU. Retrieved 03/26/2018 from <http://www.peekabooicu.com/developmental-care-in-the-nicu/nutrition-in-the-nicu/amazing-facts-about-human-milk-and-why-it-is-so-important-for-premature-babies/>

NEC Preventive Measures in NEC-Zero

Do...

- Stop antibiotics before 5 days if there is no infection
- Use a feeding protocol
- Give mother's milk and donor milk if don't have mother's milk
- Try to avoid anemia (e.g. with delayed umbilical cord clamping)
- Use a risk score for NEC

Don't...

- Use antacids
- Ignore early warning signs
- Ignore parents as partners
- Avoid talking about NEC as a potential complication because of being afraid to scare parents

10 THINGS ALL PARENTS OF PREEMIES NEED TO KNOW

1 You are an integral part of your preemie's care team. Your feelings and observations are critically important. Speak up, respectfully. Ask questions. Voice your concerns. Share what is important to you. If you feel strongly that something is in the best interest of your baby, insist on it being that way.



3 You know your preemie best. Learn your baby's cues. Premies can become critically ill fast. If you sense something isn't quite right, voice your concerns and make sure they are addressed. Watch for these subtle signs that something may be wrong:

- Abnormally distended belly
- Temperature instability
- Blood in stool
- Frequent dry diapers
- Frequent or large amounts of vomit
- Constipation
- Lethargic or not as responsive
- Difficulty or change in breathing

4 Insist on having primary caregivers. A primary team who knows your baby and family will help to ensure better communication and continuity of care, which increases patient safety. Take time to build a respectful, trusting relationship with your baby's primary caregivers.

Created by parents of NICU babies impacted by NEC: what we wish we had known from day one in the NICU

www.NECsociety.org

2 Premies need breast milk. Human milk can be life-saving for fragile infants. Mothers should begin pumping as soon as possible. When mothers' own milk is unavailable, pasteurized donor breast milk is the next best option. Formula increases a preemie's risk of developing NEC.

5 Learn how to care for your preemie. Ask your baby's nurse to teach you how to provide basic care for your preemie. Provide kangaroo care as often as you can. When you cannot kangaroo your baby, hold hands, sing and read to him/her.

6 Pay attention to details. Keep a journal documenting your baby's routines, behavior, as well as his/her setbacks and accomplishments. Take notes during rounds. You may notice details that no one else will.



Become your preemie's expert. Learn everything you can about your preemie's health or condition. If you're not sure where to find credible information, ask your baby's care team. Reach out to other NICU families. Reach out to other institutions, neonatologists or researchers if you have specific questions that your baby's care team cannot address.

8 You are your baby's voice. Attend rounds. Do not let anyone intimidate or shame you for being your baby's advocate. You are not annoying. You are not stupid. Your baby needs you to speak up for him/her, respectfully.



9 Create a haven of peace and healing. Leave behind your frustrations and fears so that you can be present and tune into your baby. Make your preemie's space your home away from home. Smile at your baby. Sing to your baby. Bring in special blankets. Hang up family photos. Play soothing music. Celebrate the smallest of milestones.

10 Live your life fully. Having a baby in the NICU is exhausting and overwhelming. The NICU journey may feel like it's never going to end, but it will be over soon. For better or worse, you'll never have this time back. Live it fully, without regrets. Make hand and footprints. Read special books to your baby. Take pictures and videos with your baby, even if s/he is critically ill. Savor this time with your baby.

NEC Warning Signs



- Lethargy or irritability
- Temperature unstable
- Decreasing oxygen levels, apnea or bradycardia
- “Not acting right”
- Not tolerating feeding (vomiting, milk not digesting in stomach from last feeding, increased abdominal girth)
- Bloody stool
- Vomiting
- Red or dusky abdomen
- Abdomen is taut, tender to touch

Diagnosing and Treating NEC

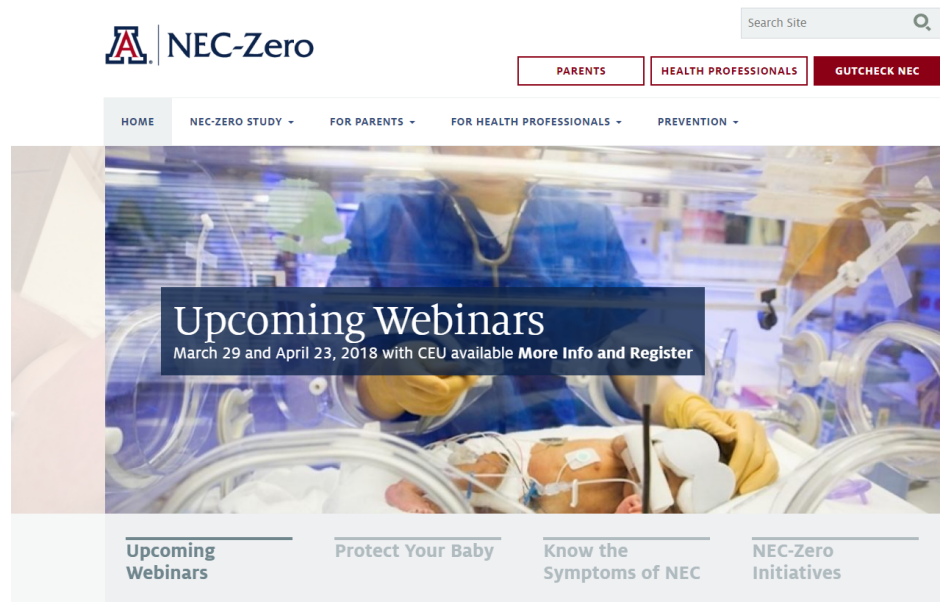



www.neczero.nursing.arizona.edu




NEC-Zero is a team delivered intervention with a goal to prevent and improve early diagnosis of NEC.

www.neczero.nursing.arizona.edu

A screenshot of the NEC-Zero website. The header includes the University of Arizona logo and "NEC-Zero" text, a search bar, and three red buttons: "PARENTS", "HEALTH PROFESSIONALS", and "GUTCHECK NEC". Below the header is a navigation bar with links: "HOME", "NEC-ZERO STUDY", "FOR PARENTS", "FOR HEALTH PROFESSIONALS", and "PREVENTION". The main content area features a large image of a newborn in a NICU with a text overlay: "Upcoming Webinars" and "March 29 and April 23, 2018 with CEU available More Info and Register". At the bottom, there are four columns with titles: "Upcoming Webinars", "Protect Your Baby", "Know the Symptoms of NEC", and "NEC-Zero Initiatives".

 **NEC-Zero**

Search Site 

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Upcoming Webinars
March 29 and April 23, 2018 with CEU available [More Info and Register](#)

Upcoming Webinars **Protect Your Baby** **Know the Symptoms of NEC** **NEC-Zero Initiatives**

For Parents

Questions to ask your healthcare provider

- When can my baby start getting my milk?
- What can I do if I'm having trouble with my milk supply?
- When can I start non-nutritive breastfeeding?
- Will my baby be able to breastfeed?

**Know the
Symptoms of NEC**

Protect Your Baby

www.neczero.nursing.arizona.edu/parents

Parent Education Materials



Expecting a Preemie?

How the gift of your
milk protects your new
baby.



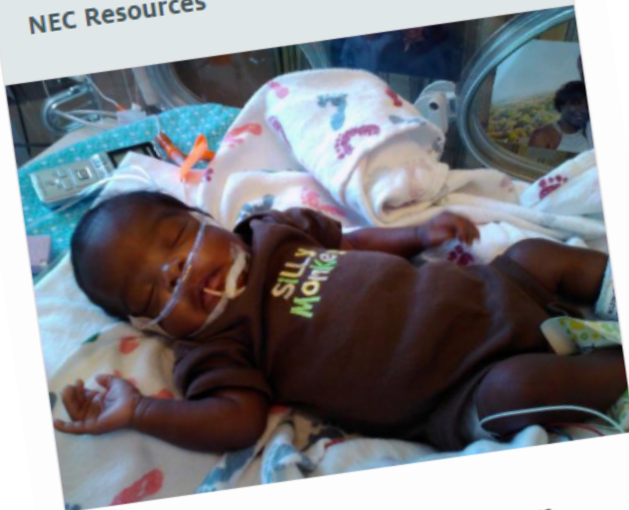
Prevent Complications!

It's a team effort!



What is Necrotizing Enterocolitis?

NEC Resources



It can be overwhelming caring for premature infant. There are resources available to support maternal needs and infant health.

[Learn More](#)

PARENTS

Want more information?

[LEARN MORE »](#)

Download Pamphlets

What is Necrotizing Enterocolitis (NEC)? / ¿Qué es la enterocolitis necrotizante (ENC)?

Prevent Complications! / ¡Prevenga complicaciones!

www.neczero.nursing.arizona.edu/parents/what-is-nec

For Health Professionals

Healthcare Professionals

Early Recognition

Caring for Babies with NEC in the Hospital

Breastfeeding

Breastfeeding and the Workplace

GutCheckNEC

Resources

Upcoming Webinars

HEALTH PROFESSIONALS

Be prepared for NEC

LEARN MORE »



www.neczero.nursing.arizona.edu/healthcare-professionals



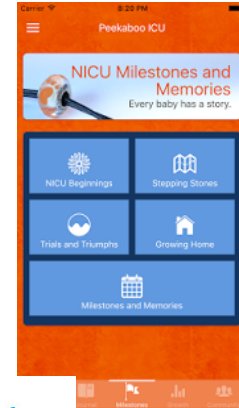
US Army 52599 Army Spouse Skates For Roller Derby Team

Video- novelas

Will soon be available

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Parent Support Communities



PREEMIES NEED HUMAN MILK!



**A HUMAN MILK DIET CAN
REDUCE NEC INCIDENCE
BY ALMOST 80%!**



**TALK TO YOUR BABY'S CARE
TEAM ABOUT THE BENEFITS
OF BREASTFEEDING,
PUMPING, & DONOR MILK**



**HUMAN MILK
SAVES LIVES!**

NEC SOCIETY
www.NECsociety.org

PARENTS ARE CARE PARTNERS

**YOU ARE AN
IMPORTANT PART
OF YOUR BABY'S
CARE TEAM**



Participate in care decisions
whenever possible

**SPEAK UP,
ASK QUESTIONS,
ATTEND ROUNDS**

You are
your
baby's
voice &
advocate



**PAY
ATTENTION
TO DETAILS**

You know your baby best & might
notice if something is not quite right



Skin to skin
contact has
health
benefits
for your
baby

**KANGAROO WITH
YOUR BABY,
IF POSSIBLE**

**PROVIDE
YOUR MILK,
IF YOU CAN**



If you can't, ask about donor milk.
Human milk is best for preemies.

NEC SOCIETY
www.NECsociety.org

<https://necsociety.org/2016/10/03/educational-resources/>

GutCheck ^{NEC} (< 1500 grams)				Points
Gestational age (weeks) (9 max.)		<28 9 points	28-31 6/7 8 points	≥ 32 0 points
Calculate GA in weeks at birth based preferably on due date determined by 1 st trimester ultrasound. If that is unavailable, use the gestational age assessment at delivery (Ballard or Dubowitz)		Black 2 points	Hispanic 2 points	Other races 0 points
Race (2 max) If the infant is either Black or Hispanic race assign 2 points. If both, assign only 2 points. If not Black or Hispanic, assign 0 points.		Yes 3 points	No 0 points	
Outborn (3 max) If the infant is transferred into this center from another hospital at any time after birth, assign 3 points.		Yes 3 points	No 0 points	
NICU NEC rate (23 max.) This is the annual calculated NEC rate for infants weighing less than 1500 grams at delivery. If < 2%, assign 0 points.		2- 4.99% 9 points	5- 7.99% 16 points	8-11.99% 19 points
Exclusive human milk feeding (0 max) Defined as human milk fed at both day 7 and day 14 of life. Volume of human milk fed is not defined. If any milk is fed at both day 7 and day 14, subtract 3 points from the total score. Points cannot be subtracted until day of life 14.		Yes -3 points	No 0 points	
Probiotics (0 max) If any probiotic preparation has been given at any dose or any volume, subtract 5 points from the total score.		Yes -5 points	No 0 points	
How many culture-proven infections has the infant had since day 3 of life? (6 points max)		One 4 points	Two 6 points	None 0 points
Packed Red Blood Cell transfusion history (8 max) If any PRBC transfusion has been given, regardless of feeding status or volume given. Once the infant receives a transfusion, from that time on it is scored "yes." Highest risk for NEC is associated within 48 hours of the transfusion.		Yes 8 points	No 0 points	
Hypotension treated with Inotropic Medication (4 max) If hypotension is severe and medications such as dopamine, dobutamine or milrinone are given to treat it, regardless of dose, frequency or duration of treatment. Once this is "yes" it stays "yes".		Yes 4 points	No 0 points	
Metabolic Acidosis (3 max) After the 1 st 12 hours of life, if the infant experiences metabolic acidosis, defined as low pH associated with low serum bicarbonate ($\text{HCO}_3^- < 17$) but normal or near normal pCO_2 ($\text{pH} < 7.30$) or lactate > 6.1 mmol/L. If ordering clinician (physician, NNP, PA-C) documents "metabolic acidosis" code as "yes"		Yes 3 points	No 0 points	
TOTAL: Score ≥ 32 At Risk; > 36 high risk (especially at 72 hours of age); 58 points maximum				
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Structured communication form for clinical concern when NEC is suspected

S	Situation: Purpose of call Hello, this is _____. I am calling about _____ in room _____ because I have some concerns about his/her assessment.
B	Background: All pertinent risk factors and recent history Gestational Age _____ Corrected GA _____ Day of Life _____ Risk Score (GutCheck ^{NEC}) _____ Feeding type (EBM, fortified?) and tolerance _____ Transfusion within the last 48 hours? _____ Relevant history _____
A	Assessment: Give your conclusion about the present situation based on assessment Is the parent concerned? Y N Tachycardia at rest? Y N Hypotension? Y/N Temp _{max} &/or Temp _{min} ≥ 24 hours outside normal limits? Y N Significant increase in rectal temperature? Y N Increased respiratory support or FiO ₂ ? Y N Increase in apnea/bradycardia spells? Y N Blood present in stool or emesis? Y N Change in color, fullness, or feel of abdomen? Y N Change in abdominal girth > 1cm? Y N Bowel sounds present? Y N Feeding tolerance: Residual color, amount, dark bilious? Y N Emesis in last 24 hours? Y N Stooling? Y N Change in general skin color or perfusion? Y N Behavior: Irritability (early) or lethargy (late)? Y N
R	Recommendation: Clarify expectations – may differ with severity of situation or institutional policy. ASK for something specific: <ul style="list-style-type: none"> Hold feeding? Abdominal x-ray? Come in to see baby? Order sepsis workup?
Content based on evidence about NEC risk and clinical presentation (Christensen et al., 2010; Gephart, Wetzel, & Krisman, 2014; Gregory, DeForge, Natale, Phillips, & Van Marter, 2011)	

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- Gephart, S. M., Wetzel, C., & Krisman, B. (2014). Prevention and early recognition of necrotizing enterocolitis: a tale of 2 tools—eNEC and GutCheckNEC. *Adv Neonatal Care*, 14(3), 201-210; quiz 211-202. doi:10.1097/anc.0000000000000063
- Gregory, K. E., DeForge, C. E., Natale, K. M., Phillips, M., & Van Marter, L. J. (2011). Necrotizing enterocolitis in the premature infant: neonatal nursing assessment, disease pathogenesis, and clinical presentation. *Adv Neonatal Care*, 11(3), 155-164; quiz 165-156. doi:10.1097/ANC.0b013e31821baaf4


<http://neczero.nursing.arizona.edu/gutchecknec>




<https://pixabay.com/en/baby-learn-laptop-question-2709666/>




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[Maternal, fetal and perinatal factors associated with necrotizing enterocolitis in Sweden. A national case-control study.](#)
 Ahle M, Drott P, Elfvin A, Andersson RE.
 PLoS One. 2018 Mar 23;13(3):e0194352. doi: 10.1371/journal.pone.0194352. eCollection 2018.
 PMID: 29570713
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 Silano M, Milani GP, Fattore G, Agostoni C.
 Clin Nutr. 2018 Mar 10. pii: S0261-5614(18)30115-8. doi: 10.1016/j.clnu.2018.03.004. [Epub ahead of print]
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LactMed
A TOXNET DATABASE

Drugs and Lactation Database (LactMed)

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About LactMed

What is LactMed?
The LactMed® database contains information on drugs and other chemicals to which breastfeeding mothers may be exposed. It includes information on the levels of such substances in breast milk and infant blood, and the possible adverse effects in the nursing infant. Suggested therapeutic alternatives to those drugs are provided, where appropriate. All data are derived from the scientific literature and fully referenced. A peer review panel reviews the data to assure scientific validity and currency.

Did you know

 **How do I obtain the full TOXNET dataset?**


The following TOXNET datasets are available: ChemIDplus, CCRIS, GENE-TOX, HSDB, LactMed, and TOXLINE.

For further information visit the [NLM Data Distribution Program](#) from the National Library of Medicine.

[More FAQs](#)

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LACTMED: GARLIC CASRN: 8008-99-9 This record appears in multiple databases.

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Garlic

CASRN: 8008-99-9

FULL RECORD DISPLAY

Displays all fields in the record.

For other data, click on the Table of Contents

Drug Levels and Effects:

Summary of Use during Lactation:

Garlic (*Allium sativum*) contains alliin, which is metabolized by the enzyme alliinase to allicin, thought to be responsible for most of **garlic**'s medicinal properties and odor. **Garlic** has been used to lower cholesterol and blood pressure. It has no specific indications for use during lactation in western countries. **Garlic** has been used as a galactagogue in India,[1][2] although no scientific data could be located on its use alone as a galactagogue. **Garlic**'s odor is transmitted to breastmilk, which may increase infant sucking time acutely and might enhance the breastfed infant's food choices in the long term. **Garlic** has a long history of use as a food and medicine and is "generally recognized as safe" (GRAS) as a food flavoring by the U.S. Food and Drug Administration, including during lactation. [3] Limited scientific data found that a few days of oral **garlic** supplementation caused no adverse effects in nursing mothers or infants. When used as a medicinal, **garlic** is generally well tolerated in adults, but gastrointestinal side

https://medlineplus.gov





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Short bowel syndrome



Short bowel syndrome is a problem that occurs when part of the small intestine is missing or has been removed during surgery. Nutrients are not properly absorbed into the body as a result.

Causes

The small intestine absorbs much of the nutrients found in foods we eat. When one half or more of our small intestine is missing, the body may not absorb enough food to stay healthy and maintain your weight.

Some infants are born missing part or much of their small intestine.

More often, short bowel syndrome occurs because much of the small intestine is removed during surgery. This type of surgery may be needed:

- After gunshots or other trauma damaged the intestines
- For someone with severe [Crohn disease](#)
- For infants, often born too early, when [part of their intestines dies](#)



THANK YOU!

- Alan Carr, Associate Director of the NNLM Pacific Southwest Region, The UCLA Library and the staff at the Darling Biomedical Library who are assisting us in this project
- The University of Arizona, CON, Office of Learning and Healthcare Technology Innovations Staff – Peg, David, Stephan, and Princess – Thank you so much!
- The University of Arizona, CON, Continuing Professional Education Staff – Janelle, Paula and Dr. Koithan
- Parent advocates who graciously shared their adorable baby pictures with us.



Evaluation: Let us know what you think and get Continuing Nursing Education hours

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<https://tinyurl.com/ycszlo2e>

Sheila Gephart, PhD, RN
gepharts@email.arizona.edu

[illegible]

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