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Necrotizing Enterocolitis: Information for Parents

*Necrotizing enterocolitis* (NEC) is a disease that affects the intestines of sick babies. NEC occurs more often in premature babies—the earlier the baby is born, the greater the risk of NEC. Up to 10% of all babies admitted to the neonatal intensive care unit (NICU) can have NEC.

NEC is an inflammatory disease of the intestine (also known as the bowel). First, the intestinal wall lining becomes damaged. Then, bacteria attack the intestine to cause swelling and infection. This can lead to a rupture, or perforation, of the intestine. If the intestine ruptures, bacteria can get into the abdomen, which can be life threatening. The exact cause of NEC is unknown, but the most consistent risk factor is related to feeding. Babies who are fed formula are more likely to have NEC than those who are fed breast milk (human breast milk has a protective effect against NEC).

It can be difficult to identify NEC because the premature infant may have other issues that appear similar to NEC. Symptoms of NEC may include feeding intolerance, a round stomach or belly with “loops of bowel” notice- able, vomiting, bloody stools, not being active (lethargy), and times of not breathing and slowing of the heartbeat (apnea and bradycardia). Your baby may need assistance with breathing, such as the use of a ventilator. The best way to diagnose NEC is with an X ray of the stomach.

NEC treatment includes allowing the bowel to rest, so feedings will be stopped. This may be for as little as 3 days but may last for several days or weeks. A tube

from your baby’s mouth to the stomach will be placed to remove fluid and air from the stomach. Blood sampling will be done and intravenous fluids will be started for nutrition as well as antibiotics. Abdominal X rays will be frequent.

Many infants who have NEC do not need surgery, but there are some infants who will—if surgery is needed, a pediatric surgeon will be involved. During surgery, the sick part of the intestine will be removed, but sometimes, the healthy ends of the intestine can be sewn back together. Other times, the two ends of the intestine are brought to an opening in the skin called an ostomy. Your baby will stool through the ostomy into a bag. The ostomy may last a few weeks to months before the ends of the intestines are healed enough to be reconnected. After your baby has recovered from surgery and the anti- biotics are done, he or she will be able to start feedings again.

Some babies experience narrowing of the intestines and poor digestion of feedings after having had NEC. When narrowing (also called *strictures*) happens, it can cause a blockage in the intestine. Poor digestion of feedings (called *malabsorption*) also may occur. If this happens, the use of human milk or another easy-to-digest formula may help.

During the initial diagnosis of NEC, you may not be able to hold your baby because he or she is so sick. Please ask questions of the NICU staff. The staff is here to support you together as a family.