



## Yesterday

- When President John F. Kennedy and his wife Jacqueline lost their newborn son, Patrick Bouvier Kennedy, to respiratory distress syndrome in 1963, the nation watched helplessly. As with many preterm infants, Patrick's lungs were not sufficiently developed to take in the oxygen he needed.
- At the time, such infants rarely survived. In fact, whether for respiratory causes or other reasons, more than 25 of every 1,000 babies born in the United States died before their first birthday.

## Today

- By 2006, the infant mortality rate was 6.7 per 1,000 births, half that of a generation before. A sustained, long-term effort informed in large part by NIH research has led to substantial improvements in the survival rates of infants born preterm and to advances in care for all newborns. Because of this research, doctors now have specialized equipment and effective new treatment techniques at their disposal.
- In addition to increasing infant survival, advances from research supported by the NIH have helped reduce the risk of preterm births and improved the health of infants born full term, or whose mothers carry the human immunodeficiency virus (HIV), the virus that causes AIDS. Women can transmit the virus to their infants during pregnancy, labor, delivery, or breast feeding. In the United States, the yearly total of **children infected with HIV** before or during birth peaked in 1992, at an estimated total of 1,760. By 2005, this number had fallen to an estimated 142. These advances came largely from a major investment by the NIH. Rapid, accurate, and inexpensive *HIV testing* made it possible to screen large numbers of at-risk pregnant women. New *anti-HIV drug combinations* reduced the risk of infection before or during birth and the discovery that *HIV could be transmitted through breast milk* made it more likely that U.S. women would feed their infants formula, eliminating another means of infection.
- In developing countries, clean water for formula may not be available. NIH supported studies found that giving the anti HIV drugs to mothers who were breast feeding their infants reduced the rate of mother-to-child HIV transmission by 50 percent. A related study found that giving an anti HIV drug to breast feeding infants substantially reduced their rate of HIV infection.
- Many **preterm infants**—those born before the 37<sup>th</sup> week of pregnancy—have difficulty breathing because their immature lungs do not produce *surfactant*, a substance that keeps breathing pathways open. NIH-supported research in the 1980s and 1990s showed that treating infants' lungs with an artificial form of surfactant keeps the air sacs open and makes breathing possible. Now, this treatment is used widely in hospitals across the country.
- In 2010, investigators verified that an *alternative therapy* whose use has grown in recent years is as effective at helping preterm babies survive without complications as the standard therapy. Traditionally, a ventilator tube is placed in the infant's windpipe to deliver oxygen and surfactant. The alternative involves continuous positive airway pressure (CPAP), which involves passing air through an infant's nose via prongs that rest in the nostrils. The study found that CPAP had added benefits, such as being non-invasive and reducing the need for additional treatments to help the baby's lungs develop.
- Preterm birth is associated with an increased risk for **cerebral palsy**, a group of neurological disorders affecting movement and posture. A third of all cerebral palsy cases are associated with preterm birth. An NIH supported study found magnesium sulphate (Epsom salt), which is commonly used to delay labor, reduced preterm infants' risk for the condition.
- An NIH study also found that one common treatment for preterm infants was, in fact, harmful. Preterm infants who received a common acid reflux medication were slightly more likely to develop a potentially fatal bowel disorder than infants who were not given the therapy.

- **Hypoxic ischemic encephalopathy (HIE)** occurs when an infant's brain fails to receive sufficient oxygen or sufficient blood before birth. Researchers supported by the NIH were able to reduce the rate of death and disability associated with HIE by lowering a newborn's temperature to 92 degrees Fahrenheit within the first six hours of life.
- **Sudden Infant Death Syndrome, or SIDS**, the unexplained death of an otherwise healthy infant during the first year of life, claims the lives of roughly 2,500 U.S. infants each year. Although the cause of SIDS is unknown, decades of painstaking research supported by the NIH identified the major risk factors for SIDS, as well as the means to reduce the risk for SIDS.
- Since *The Back to Sleep* campaign (<https://www.nichd.nih.gov/research/supported/eksiddrc.cfm>) began in 1994, the SIDS rate has declined by more than 50 percent. The campaign resulted from a body of research that showed infants who sleep on their backs are less likely to die of SIDS than are infants who sleep on their stomachs. Led by NIH, the campaign is a public-private partnership between federal agencies and various private organizations.
- **Nearly 3 million stillbirths occur worldwide each year.** An NIH funded study found that the rate of stillbirths in rural areas of six developing countries fell more than 30 percent after a training program in newborn care for birth attendants. Research staff taught local health care workers how to assess infant health and provided them with hand-held pumps and masks to fill babies' lungs with air. The researchers believe the improvements were seen in infants who had not drawn a breath on their own and would have been considered to have been born dead by birth attendants who had not received the early newborn care training.

## Tomorrow

- More than 26,000 American women experience a stillbirth each year. The NIH also supports a network of researchers working with local hospitals to learn more about the causes of stillbirth, the death of a fetus after the midpoint of a pregnancy.
- NIH aims to ensure all children are born healthy and have the chance to achieve their full potential for healthy, productive lives. Because preterm birth plays such a large role in infant death and disability, NIH research places a priority on identifying risk factors for preterm birth as well

as the means to prevent it. Ongoing research also seeks to understand and prevent other causes of infant mortality and illness.

- In particular, it is difficult to predict the risk for **first-time mothers** of a preterm delivery or other outcomes of concern. The NIH is supporting a large research study examining both genetic and environmental factors that could help identify which expectant mothers are at the highest risk for birth complications such as preeclampsia, delayed growth in the womb or stillbirth.
- Research has shown **progesterone therapy** is effective for reducing the chance of preterm delivery in one category of women. However, it is not effective for women carrying twins or triplets and its effectiveness for other groups is not known. Some evidence suggests the babies of first-time mothers with a short cervix might benefit from this treatment, and research to confirm this possibility is ongoing.
- Drugs known as corticosteroids, when given to expectant mothers at high risk of delivering before the 33<sup>rd</sup> week of pregnancy, help infants' lungs to mature, reducing the chances for respiratory problems. An NIH funded study is evaluating whether corticosteroids can prevent breathing difficulties and improve outcome in pregnancies at risk of delivery in the late preterm period (between 34 and 37 weeks' gestation).
- Because the risk of poor health outcomes is not the same for all racial and ethnic groups, eliminating health disparities is another priority of NIH research. The five centers making up the Community Child Health Research Network (<http://www.nichd.nih.gov/research/supported/cchn.cfm>)—the only community-based, participatory research effort in the field—aim to work with more than 5,000 parents to evaluate the ways stress affects a mother's health and that of her baby.

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