Research conducted and funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) has helped save lives, improve well-being, and reduce societal costs associated with illness and disability. The following sections provide examples of groundbreaking scientific findings made possible by NICHD.

Creating Vaccines for Infectious Childhood Diseases

A breakthrough by NICHD researchers led to the first vaccine against Haemophilus influenzae type b (Hib), a bacterium that was once the leading cause of meningitis (infection of the covering of the brain and spinal cord) and acquired intellectual disability in young children. Since Food and Drug Administration (FDA) approval during the 1980s, the vaccine has saved thousands of lives, spared many more children lifelong disability, and helped to avert billions in medical costs.¹

The NICHD-developed technology that made the Hib vaccine possible was also used to create FDA-approved vaccines against Streptococcus pneumoniae, which causes invasive pneumococcal disease (pneumonia, bacteremia [blood infection], or meningitis) in young children and the elderly. According to the Centers for Disease Control and Prevention, rates of invasive pneumococcal disease among children younger than 5 years old have dropped by nearly 90 percent since 2000, the year when the first conjugate pneumococcal vaccine was introduced.²
Developing and Expanding Newborn Screening

NICHD research confirmed the safety and effectiveness of a simple blood-spot test to screen for phenylketonuria (PKU), an inherited metabolic disorder that, when untreated, can damage the brain and cause severe intellectual disability. As a result of these findings, in 1965, New York became the first state to mandate screening of all newborns for PKU. Other states soon followed, allowing for early detection and immediate initiation of dietary therapy, which dramatically reduces the effects of the disorder.

Other efforts by NICHD-supported researchers produced the first blood-spot test to screen for congenital hypothyroidism, another treatable cause of intellectual disability. By 1983, most of the United States mandated screening all newborns for this disorder. Today, by using only a few drops of blood, newborn screening detects a treatable condition in about 1 in 300 babies born each year.

Pioneering the First Home Pregnancy Test

NICHD investigators identified the beta subunit of human chorionic gonadotropin (hCG) as the earliest marker of pregnancy, leading to the development and subsequent commercialization of the first home pregnancy test. The test detected the presence of hCG in urine even before the first missed period, enabling women to determine their pregnancy status in the privacy of their own homes. The $10 test hit the market in 1978 and quickly became one of most ubiquitous health care products in the world.

Improving Care and Survival of Premature Infants

NICHD-funded research on the care of preterm infants (those born before 37 weeks) has helped improve the standard of care for these tiny patients. In 1960, 26 of every 1,000 babies born in the United States died before their first birthday. By 2013, that rate had fallen to less than 6 per 1,000 babies. Some of the more significant findings include:

- Synthetic lung surfactant—developed and tested by NICHD—increased survival rates for respiratory distress syndrome in premature infants from about 5 percent in the 1960s to around 95 percent today.

- Progesterone, a naturally occurring hormone, reduced the rate of preterm birth. This finding led to FDA approval of a synthetic version of the hormone, called 17P, for preventing preterm birth among certain groups of high-risk women.

- Prenatal steroids—given to pregnant women at risk for preterm labor—improved survival and limited brain injury among infants born as early as the 23rd week of pregnancy.

- Early treatment to prevent severe jaundice in extremely preterm infants reduced the infants’ rate of brain injury.

- Giving magnesium sulfate to women at high risk for preterm birth prevented cerebral palsy and other neural injury in infants.
The mission of the NICHD is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from reproductive processes, and that all children have the chance to achieve their full potential for healthy and productive lives. NICHD also seeks to ensure the health, productivity, independence, and well-being of all people through optimal rehabilitation.

Identifying Fetal Alcohol Syndrome
NICHD-funded scientists were the first to diagnose abnormalities in children whose mothers drank alcohol during pregnancy. Research in the ensuing decades established the degree of risk posed by drinking alcohol during pregnancy and led to the Surgeon General’s warnings now seen on all alcoholic beverage containers.

Protecting Infants During Sleep
In 1994, NICHD and its collaborators launched the Back to Sleep campaign to educate parents and caregivers about reducing the risk of Sudden Infant Death Syndrome (SIDS) by placing infants on their backs to sleep during naptimes and at night. Since the start of the campaign, the SIDS rate in the United States has dropped by more than 60 percent. In 2012, NICHD and its collaborators expanded the campaign, now called Safe to Sleep®, to disseminate research-based recommendations aimed at lowering the risk of SIDS and other sleep-related causes of infant death, such as accidental suffocation.

Transforming the Study of Human Fertility
By identifying luteinizing hormone releasing factor (LHRF, now called gonadotropin-releasing hormone) and other releasing hormones produced by the hypothalamus, NICHD-funded scientists laid the foundation for groundbreaking studies of fertility, contraception, and assistive reproductive technologies, such as in vitro fertilization. In 1977, Roger Guillemin and Andrew Schally—leaders of two independent teams of researchers—won the Nobel Prize in Physiology or Medicine for their discoveries.

Preventing and Correcting Neural Tube Defects (NTDs)
NICHD research found that high numbers of women were genetically at risk for folate deficiency, predisposing them to have babies with NTDs, such as spina bifida. Additional NICHD-funded research showed that the right amount of folic acid, starting before conception and continuing throughout pregnancy, prevented most NTDs. These findings led to changes in recommended amounts and timing of folate intake for women.

In 2011, results from an NICHD-funded study showed the benefits and risks of prenatal surgery to repair myelomeningocele, the primary defect in the most severe form of spina bifida. The study showed that, despite a slight increase in risk for preterm delivery, women and their babies had better overall outcomes—including a greater likelihood of being able to walk independently—if the surgery was done before birth.
Nearly Eliminating Mother-to-Child Transmission of HIV

Since the mid-1990s, NIH research has informed the implementation of HIV testing and preventive measures that have led to a more than 90 percent decrease in the number of children perinatally infected with HIV in the United States. For example, research from NICHD and others showed that a three-drug regimen—called HAART, or highly active antiretroviral therapy—was better than the drug azidothymidine (AZT) at preventing mother-to-child transmission of HIV. A 2002 study funded by NICHD and others showed that HAART reduced the risk of perinatal HIV transmission to 1.2 percent.12,13

Isolating the Causes of Genetic Disorders

NICHD-supported researchers have discovered the causes of several genetic disorders, helping to expand treatment options for those affected. Examples of these discoveries include:

Identifying the genetic cause and mechanism of Fragile X syndrome, the leading cause of inherited intellectual disability.

Isolating the gene for Rett syndrome, a disorder in which seemingly healthy infant girls gradually lose their language capabilities, mental functioning, and ability to interact with others.

Discovering that non-classical congenital adrenal hyperplasia (CAH) is the most prevalent single-gene disorder in the general population. Later findings identified the broad spectrum of disorders caused by CAH and led to treatments for its variant forms, including the first prenatal treatment that prevents characteristic features of CAH, such as genital abnormalities.

To contact NICHD:

www.nichd.nih.gov
nichdpress@mail.nih.gov
301-496-5133

2 https://www.cdc.gov/pneumococcal/surveillance.html
6 https://www.nichd.nih.gov/cochrane_data/robertsd_01/robertsd_01.html