Birth defects and infant disorders, such as fetal alcohol spectrum disorders, are common, costly, and critical. Our unique state-based birth defects tracking, public health research, and world-renowned expertise provide a wealth of information used to

- Identify causes of birth defects and infant disorders;
- Find opportunities to prevent them; and
- Improve the health of babies born with these conditions.

Together with states, academic centers, healthcare providers, and other partners, we are working toward a day when all babies are born with the best health possible and every child thrives.

**Accomplishments**

- **Contributed to what is known about Zika virus infection during pregnancy.** Information collected from the U.S. Zika Pregnancy and Infant Registry was used to advance public health action to protect mothers and babies from Zika virus infection. In addition, data from this innovative monitoring system led to

  - Better understanding of the impact of Zika virus infection during pregnancy;
  - Updated clinical care recommendations;
  - Planning for medical and social services for families affected by Zika virus; and
  - Improved prevention of Zika virus infection during pregnancy.

- **Advanced the efforts examining the effectiveness of mandated screening for critical congenital heart defects (CCHDs) and the long-term outcomes and healthcare needs for children born with heart defects.** Mandated CCHD screening nationwide was estimated to potentially save the lives of 120 babies each year. NCBDDD estimated that 1 in 77 U.S. children were living with heart conditions in 2016 and that these children were more likely to have special healthcare needs, such as medication needs or physical or speech therapy. This research quantifies the impact of mandated CCHD screening, identifies the needs of those living with heart defects, and helps inform resource planning for this growing population.
• Expanded research and delivered reliable information about the use of certain medications, such as antibiotics and medications for attention-deficit/hyperactivity disorder, among pregnant women and women of reproductive age. These results from studies by NCBDDD researchers, using data from the National Birth Defects Prevention Study, provide a basis for further studies on medications identified as having a potential risk for birth defects. NCBDDD also provided new information on medication use during pregnancy through the Treating for Two website.

• Focused new fetal alcohol spectrum disorder (FASD) activities on
  - Implementing alcohol screening and brief intervention in health systems that provide women’s health services;
  - Expanding capacity of national professional organizations in the prevention, identification, and management of FASDs; and
  - Promoting resources for FASD awareness and prevention.

• Collaborated across CDC to evaluate a possible link between neural tube defects among infants born to women living with human immunodeficiency virus (HIV) and the use of the medication, dolutegravir, in early pregnancy. This comprehensive evaluation considered all risks and benefits to both mother and baby for the use of dolutegravir in early pregnancy.
NCBDDD will continue its work to protect women and babies through birth defects tracking and public health research. These activities provide knowledge about the factors that might increase or decrease the risk of having a baby with a birth defect or infant disorder. NCBDDD’s work on Zika virus is a reminder of the medical vulnerability of mothers and babies to emerging infections and other health threats, such as the opioid crisis and natural disasters. With new funding received for fiscal year 2019 for Surveillance of Emerging Threats to Mothers and Babies, NCBDDD will continue to leverage the innovative tracking and monitoring system developed to combat Zika virus, work to understand the full impact of Zika virus on infants and children, and pilot this system to capture data on other emerging threats that may affect mothers and babies. With new funding received for fiscal year 2019 for neonatal abstinence syndrome, NCBDDD will expand work with states and partners to build upon birth defects surveillance systems and explore more accurate ways of estimating the number of infants who have neonatal abstinence syndrome and the health needs for these children.

Notable Scientific Publications


American Academy of Pediatrics

Zika Response
Since 2016, the American Academy of Pediatrics (AAP) has worked hand-in-hand with the Centers for Disease Control and Prevention (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD) to ensure that infants impacted by Zika virus were identified, reported, and provided immediate and long-term treatment and care. This included input on updated clinical guidance, articles, and resources for clinicians, such as psychosocial support materials and an AAP Periodic Survey of Fellows to learn about pediatricians’ experiences with, and attitudes toward, infectious disease and disaster preparedness, with a focus on Zika virus. The AAP also partnered with the American College of Obstetricians and Gynecologists (ACOG) to conduct a national survey of its membership and focus groups, and evaluation of AAP/ACOG support to Zika contractual field assignees within local health departments. The AAP continues to express that

• Clinicians remain vigilant in preventing Zika during pregnancy;
• Healthcare providers provide consistent and clear presentation of information from provider-to-provider and from provider-to-patient; and
• Developing babies with suspected or possible congenital Zika virus infection need continued monitoring within a medical home.

The AAP believes this work and these collaborations are important to ensure the optimal health and development of infants with congenital Zika virus exposure.

Fetal Alcohol Spectrum Disorders
Prenatal exposure to alcohol is the leading preventable cause of birth defects, intellectual disabilities, and neurodevelopmental disorders. The non-diagnostic umbrella term fetal alcohol spectrum disorders (FASDs) is used to characterize the full range of diagnoses resulting from prenatal alcohol exposure. Research and other published data continue to document missed and underdiagnosed FASDs. Early identification of a child at risk for an FASD is facilitated by screening for prenatal alcohol exposure. Information to support pediatricians is available at www.aap.org/pae.

Through grant funding from NCBDDD, AAP has worked with the National Organization on Fetal Alcohol Syndrome and two university-based Practice and Implementation Centers at the University of California-San Diego and the University of Wisconsin-Madison. Through these partnerships, the centers developed multiple educational resources to ensure pediatric clinicians have the capacity to identify and manage the care for children with FASDs. These are available at www.aap.org/fasd.