

# Birth Defects Tracking: Ohio

## Ohio Connections for Children with Special Needs

The Ohio Connections for Children with Special Needs (OCCSN) is essential for understanding the impact of birth defects in the state. The program tracks babies and children with birth defects and connects their families with doctors and other services that will help these children thrive.



### About the Program

The OCCSN Program collects birth defects data from hospitals; facilitates referrals to services for children with birth defects and educates health professionals and the public about birth defects. OCCSN collects data on children from birth to five years of age. The first year of statewide data was collected in 2008. One of 14 birth defects tracking programs to receive a grant funded by CDC's National Center on Birth Defects and Developmental Disabilities, OCCSN receives data from approximately 160 hospitals across the state and uses the data to improve access to services and to target populations for education and intervention.

The OCCSN also partners with local and state programs on efforts to prevent birth defects. The OCCSN also shares its data with border states Kentucky and Michigan to improve their tracking efforts.

The OCCSN works to:

- Collect quality data on major birth defects, chromosome abnormalities (like Down syndrome), and developmentally disabling syndromes (like fetal alcohol syndrome) in children from birth to five years of age
- Help families of children with birth defects by connecting them with important health and support services
- Educate Ohio residents and health professionals about ways to prevent birth defects through online trainings and conference presentations
- Contribute to Ohio's infant mortality reduction efforts by collaborating on research projects and training health professionals

### Common. Costly. Critical.

- Of the 138,000 babies born in Ohio each year, **about 1 in every 33 is born with a birth defect.**
- Birth defects are costly – **hospital costs for the treatment of birth defects are more than \$2.5 billion each year in the United States.**
- **Babies born with a birth defect are more likely to die before their first birthday,** compared to babies born without a birth defect.

**1 in 33**  
babies born in Ohio has  
a major birth defect





## Making a Difference

### Impact on Families

*“It is wonderful that OCCSN can point parents to the resources that will bring their child the greatest benefits. A new parent of a special needs child is totally overwhelmed and any support that can be offered is so encouraging. The birth defects program is an amazing resource for us... [they are] always searching for ways that they can improve their response to the needs of the children in their program.”*

*-an Ohio parent*

### Impact on Partners

*“Ohio is playing a vital role in preventing birth defects by maintaining a birth defects monitoring program... This is an integral part of Ohio’s overall strategy to reduce infant mortality in our state.”*

*-Lisa Amlung Holloway, State Director of Program Services and Government Affairs, Services March of Dimes, Ohio Chapter*

*“The Reproductive Health and Wellness Program at the Ohio Department of Health feels that the collaboration with the OCCSN helps prevent birth defects in Ohio. We work together in providing folic acid to patients prior to pregnancy or very early in pregnancy and are also working together to assist patients in losing weight prior to pregnancy. Having these programs work together to improve the health of women and men is so important in having better birth outcomes”*

*-Lisa L. Wolfe, Reproductive Health and Wellness Program, Ohio Department of Health*

## Program in Action

- **Refers to services:** OCCSN refers families of children with birth defects to the Help Me Grow Part C early intervention program and collaborates with Ohio’s Title V Children with Special Health Care Needs Parent Advisor to obtain parent feedback with OCCSN activities.
- **Educates families and healthcare providers:** OCCSN’s prevention workgroup, Ohio Partners for Birth Defects Prevention, developed prevention activities including a Birth Defects: Causes and Prevention Strategies Handbook as a reference tool for health professionals; provided plenary presentations, breakout and roundtables at Ohio’s infant mortality summits each of the past 2 years; and developed 2 online trainings with continuing education for nurses.
- **Promotes preconception health:** OCCSN collaborated with Ohio’s Reproductive Health and Wellness Program to implement a brief intervention model to reduce obesity among women of childbearing age. Women who are obese when they get pregnant have a higher risk of having a baby with certain birth defects. This collaboration also is working to increase the use of folic acid before pregnancy. Folic acid is a B vitamin that can help prevent birth defects of a baby’s brain and spine.
- **Collaborates with regional partners:** OCCSN worked with the Michigan and Minnesota Birth Defects Prevention Program to update free self-study courses for healthcare providers to help women have healthy pregnancies.

### For more information, please contact:

Ohio Connections for Children with Special Needs (OCCSN)

(614) 752-9523 \* <http://www.odh.ohio.gov/odhprograms/cmh/bdefects/birthdefects1.aspx>