

# Ohio Connections

for Children with Special Needs (OCCSN)



## Annual Report 2012

### Overview

Birth defects are a serious public health issue in Ohio and across the nation, affecting nearly three to four percent of all babies born in the United States. In Ohio, over 4,000 babies are born each year with birth defect. Birth defects are also one of the leading causes of infant mortality in Ohio and the nation. Ohio Connections for Children with Special Needs (OCCSN) is Ohio's birth defects information system. Ohio Revised Code (ORC) 3705.30 authorizes the Director of Health to require hospitals, physicians and freestanding birthing centers to report children from birth to five years of age with birth defects to the Ohio Department of Health (ODH). Surveillance of birth defects is an important public health function to quantify trends and determine prevention strategies.

The goals of OCCSN are to detect trends and epidemics; facilitate access to treatment and intervention services to improve children's health outcomes; and inform and educate health professionals and the public about birth defects and how they may be prevented. The OCCSN system is guided by an Advisory Council comprised of geneticists, genetic counselors, epidemiologists, academicians, parents, state and local public health staff. Through their expert guidance and the hard work of the ODH OCCSN staff, the system collected the first full year of data for the 2008 birth cohort. This report highlights activities and data for OCCSN in three key areas: surveillance, prevention and referrals.

### Surveillance: Reportable Conditions and Reporting Methods

All hospitals in Ohio that treat children are required to report cases of children from birth to 5 years of age with specific birth defects to the birth defects surveillance system through a secure web-based application. Reportable conditions include major congenital anomalies such as neural tube defects, oral facial clefts, cardiac disorders, chromosome abnormalities such as Trisomy 13, 18, and 21; as well as Fetal Alcohol Syndrome and certain genetic syndromes. Approximately 163 birthing, children's, and small hospitals across the state report cases to the ODH.

The OCCSN system relies on passive case ascertainment whereby hospitals report data to the system after a child is seen. Hospitals may either submit an electronic file of bulk data through a secure internet transmission, or may elect to manually key in the data through secure web-based data entry screens. The reports are merged with the child's birth certificate information which includes additional information. Collection of this data is crucial for identifying potential risk factors and targeting prevention strategies. This information will direct prevention efforts in the coming years.

To date, OCCSN staff have focused on confirming diagnoses from reported information for six reportable congenital anomalies as recommended by the Centers for Disease Control and Prevention (CDC), the National Birth Defects Prevention Network (NBDPN) and the OCCSN Advisory Council. Collection of surveillance information has a secondary function in facilitating referrals to services for children and families to local public health services.

### Ohio and National Passive Surveillance with Follow-Up Prevalence Rates.

Congenital Anomaly	Ohio's Cases, 2008	Ohio's Prevalence Rate (per 10,000 live births), 2008 <sup>1</sup>	National Passive Surveillance with Follow-Up Rate (per 10,000 live births), 2004-2006 <sup>2,3</sup>
Spina bifida without anencephalus	45	3.0	2.7
Cleft lip with or without cleft palate	141	9.5	8.7
Cleft palate without cleft lip	118	7.9	5.8
Trisomy 13 (Patau syndrome)	12	0.8*	1.1
Trisomy 18 (Edward syndrome)	23	1.5	1.8
Trisomy 21 (Down syndrome)	165	11.1	13.2

**Data sources:** OCCSN, Genetics, Vital Statistic live birth and death statistical files.

Data pulled July 2011 for spina bifida and orofacial clefts. Data pulled August 2011 for trisomy 12, 18 and 21.

<sup>1</sup> Ohio rate based on the 148,592 live births in the 2008 Ohio birth cohort.

<sup>2</sup> National and statewide comparisons may differ in case definitions, cover different time periods and may differ in data sources by state. Thus, caution should be exercised when making these comparisons.

<sup>3</sup> Colorado, Illinois, Kentucky, New Jersey, New Mexico, and New York. Cases might include live born infants, fetal deaths, and elective terminations. Birth Defects Research (Part A) 88:1008-1016 (2010)

\* Low numerator counts (<20) present issues of prevalence stability, thus a longer time period is suggested before comparisons are made.

Prepared on October 15, 2012 by Richard Thomas, MPH, Ohio Department of Health

Data from the 2008 birth cohort is the first year of data available for analysis and reporting. This table highlights prevalence rates for confirmed cases.



**Questions?**  
Please contact the  
Ohio Department of Health  
OCCSN at (614) 752-9523



<http://www.odh.ohio.gov/odhprograms/cmh/bdefects/birthdefects1.aspx>

## Prevention Activities

The Ohio Partners for Birth Defects Prevention (OPBDP) was established as the prevention arm for birth defects education in 2005 through a partnership agreement between ODH and the March of Dimes, Ohio Chapter. The multi-discipline group, representing public and private agencies and consumers, is a subcommittee of the OCCSN Advisory Council. The purpose of OPBDP is to increase the knowledge of health professionals and the awareness of the public about prevention strategies. The OPBDP identifies gaps, develops unique products, supports evidence based interventions and measures outcomes. OPBDP Accomplishments include:

- Developed a handbook for health professionals on Birth Defects Causes and Prevention Strategies
- Implemented regional trainings throughout the state highlighting the handbook's content
- Developed a Healthy Steps bookmark for women about preconception health and tips
- Published Birth Defects Fact Sheets
- Conducted a survey in Ohio Myelomeningocele clinics to assess mothers' knowledge about folic acid
- Promote Folic Acid Week and National Birth Defects Prevention Month in January every year
- Broadcast social media messages about birth defects prevention strategies
- Participate on the Ohio Collaborative to Prevent Infant Mortality

The OCCSN program collaborated with the Michigan Department of Community Health to offer two free educational self-study trainings for nursing and other health care providers interested in improving the preconception (before pregnancy) and interconception (in between pregnancies) health of women of childbearing age (18-44 years). These self-studies provide information and resources addressing some common risk factors for poor reproductive outcomes, with a particular emphasis on recognizing and decreasing the risk for birth defects. (See <https://oh.train.org/DesktopShell.aspx> for "Folic Acid in the Prevention of NTDs" (CN#1028507) and "Having a Healthy Baby—Focus on Five" (CN#1028474).

## Referrals to Services

OCCSN facilitates referrals to services to assist parents and families through early and important referrals to specialized services. The OCCSN system makes referrals to programs such as the Bureau for Children with Medical Handicaps (BCMh) and Help Me Grow. OCCSN staff makes referrals to local agencies for follow-up to assure that families and children are informed of medical and support services available. Children are referred to programs in the county where they reside. Parents are then contacted by local providers with information about programs and services. Parents may decide if they wish to receive services. The OCCSN program collaborates closely with the BCMh Parent Consultant regarding the parents' perspective of these referrals. Additionally, parents serve on the OCCSN Advisory Council to provide input on administrative and program activities as they relate to parents of children with a birth defect.

## Parent's Perspective — Maryanne Ferrell, Parent

### • Why is a birth defects information system in Ohio important?

A birth defects information system is extremely important for any parent who has, or may be facing the birth of, a child with a birth defect or special need. With today's advancements in radiology, parents can find out about the concerns that may be present with their unborn child via ultrasound. That was the case for my husband and I a little over 10 years ago when we found out I was carrying a child who had a birth defect. I was at approximately 26 weeks when my O.B. ordered a Level II US and it was discovered that our daughter, Elley, had spina bifida (a neural tube birth defect) and also hydrocephalus, along with several other related diagnoses. On that Valentine's Day, Feb. 14th, 2002, my husband and I were given some tough news, but we knew that God had fearfully and wonderfully created Elley just as she was and by His strength and grace, we would do everything we could to give her quality of life.

### • How has your child with a birth defect impacted your family?

Elley has taught us the importance of counting every victory and being thankful for every day that we are given. As a result of having a special needs child, we want to reach out to other parents who also have children with special needs and try to impact their lives in a positive way as Elley has impacted us.

### • What value does the birth defects program bring to you as a parent?

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. Ohio's Help Me Grow and the BCMh have both been a "godsend" in our lives! I honestly don't know what we would have done financially without BCMh as a resource for deductibles and co-pays for Elley. It is wonderful that OCCSN can point parents to the resources that will bring their child the greatest benefits.

I am privileged to currently serve on the Parent Advisory Council for BCMh and offer comments and suggestions from a parent's perspective. BCMh is always searching for ways that they can improve their response to the needs of the children through their program. Having a PAC in place makes the BCMh program more valuable to parents because they are taking a proactive approach to discovering first-hand the challenges parents of special needs children are facing today.

For additional information about the OCCSN program, please contact the Bureau for Children with Developmental and Special Health Needs at the Ohio Department of Health at 614-752-9523 or see <http://www.odh.ohio.gov/odhPrograms/cmh/bdefects/birthdefects1.aspx>