NBDPS News is distributed from the Centers for Disease Control and Prevention (CDC)-funded Centers for Birth Defects Research and Prevention.

The purpose of this newsletter is to inform study participants and the public of the Centers' activities and current news about birth defects.

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### **Recent Findings from the NBDPS**

The National Birth Defects Prevention (NBDPS) finished interviewing participants in March 2013, but its rich information will be analyzed for years to come. During the 14 years of interviews, 43,000 women from 10 states took part in the study. We also have cheek cell kits (genetic samples) from more than 23,500 families that will be used to understand how genes play a role in birth defects. More than 300 scientific and medical papers using NBDPS data have already been published. Here are some of the recent research findings:

#### Genetics and Congenital Heart Defects<sup>1</sup>

Congenital heart defects (CHDs) are the most common type of birth defects, affecting about one in every 100 babies born in the United States. Most CHDs are thought to be caused by a complex relationship between the mother's environment, her lifestyle, and genes.



Previous studies from the NBDPS found that a high body mass index (BMI) in mothers increases the risk for some birth defects. BMI is a measure based on body weight in relation to height. It reflects whether a person is normal weight, overweight, or obese. NBDPS studies have also shown that low diet quality before pregnancy is linked to an increased risk of certain birth defects. Diet quality is an overall measure of the



quality of a mother's diet, which reflects her intake of a variety of food groups (such as fruits and vegetables) and nutrients (such as folate and calcium) that are important during pregnancy.

Researchers from the California Center were interested in the combined effects of multiple factors that might modify the risk for a birth defect, rather than just looking at the effects of certain factors one at a time. The researchers studied 16 different birth defects among infants born to women who were overweight or obese who also had a low diet quality, compared to women who had normal BMI and a normal diet quality. Women with a high BMI (obese) who also had a low diet quality had an increased risk for the studied birth defects compared to women who had a lower BMI, had a better diet quality, or both. These types of studies, among women with multiple factors that might modify the risk for birth defects, can help us better understand what causes birth defects, who is at highest risk before pregnancy begins, and ultimately, how best to reduce some risks for birth defects.

Li M, Li J, Wei C, Tang X, Erickson SW, MacLeod SL, Hobbs CA. A three-way interaction among maternal and fetal variants contributing to congenital heart defects. *Ann Hum Genet*. 2016 Jan;80(1):20–31.

<sup>2</sup>Carmichael SL, Yang W, Gilboa S, Ailes E, Correa, A, Botto LD, Feldkamp ML, Shaw GM; National Birth Defects Prevention Study. Elevated body mass index and decreased diet quality among women and risk of birth defects in their offspring. *Birth Defects Res A Clin Mol Teratol*. 2016 Mar;106(3):164–71.



### A Closer Look at the Link Between Specific SSRIs and Birth Defects<sup>3</sup>

Selective serotonin reuptake inhibitors (SSRIs) are medicines used to treat depression and other mental health conditions.

Previous studies provide conflicting evidence about potential links between the use of SSRIs during pregnancy and certain birth defects. In a recent study, NBDPS researchers from the Georgia Center were able to refute some earlier reported links but



confirm other links observed between birth defects and some SSRIs.

Researchers found that some birth defects are two to three times more common among babies born to women who took certain SSRI medicines, such as fluoxetine (Prozac) and paroxetine (Paxil), early in pregnancy. However, links between birth defects and other SSRIs, like sertraline (Zoloft), were not observed in this Georgia/CDC Research Center study. This analysis can help guide healthcare providers and women to the safest options to appropriately treat depression or other mental health conditions during pregnancy while minimizing the risk of major birth defects in the developing baby.

### Alcohol Use during Pregnancy and Congenital Heart Defects<sup>4</sup>

Congenital heart defects (CHDs) are the leading cause of infant death from birth defects. Drinking alcohol during pregnancy is known to cause a group of conditions called Fetal Alcohol Spectrum Disorders. Animal studies also suggest a link



between exposure to alcohol during pregnancy and CHDs, but findings from human studies have been mixed. NBDPS researchers looked at eight types of CHDs (e.g., conotruncal, septal, left ventricular outflow tract obstructions, and right ventricular outflow tract obstructions) to see if there was a link between CHDs and mothers' reports of alcohol consumption early in pregnancy. Some pregnancies were affected by only one type of CHD, but others were affected by more than one type.

<sup>3</sup>Reefhuis J, Devine O, Friedman JM, Louik C, Honein MA; National Birth Defects Prevention Study. Specific SSRIs and birth defects: Bayesian analysis to interpret new data in the context of previous reports. *BMJ* 2015 Jul 8;351:h3190.

<sup>4</sup>Zhu Y, Romitti PA, Caspers Conway KM, Shen DH, Sun L, Browne ML, Botto LD, Lin AE, Druschel CM; National Birth Defects Prevention Study. Maternal periconceptional alcohol consumption and congenital heart defects. *Birth Defects Res A Clin Mol Teratol*. 2015 Jul;103(7):617–29.

Researchers did not find strong links between CHDs and mothers' reports of alcohol consumption. Some types of CHDs were more common if mothers reported drinking a higher number of alcoholic drinks in one sitting (four or more drinks at one time) or drinking stronger alcohol, such as distilled spirits. Additional studies are needed to better understand how the amount and type of alcohol women drink during early pregnancy may increase the risk for CHDs. Regardless, because of the known risk for Fetal Alcohol Spectrum Disorders, there is no known safe amount of alcohol use during pregnancy or when trying to get pregnant, and no safe time during pregnancy to drink.

## Gastroschisis and Mother's Residence in Early Pregnancy<sup>5</sup>

Gastroschisis is a birth defect of the abdominal (belly) wall. The baby's intestines lie outside of the baby's body, through a hole beside the belly button. The hole can be small or large and sometimes other organs, such as the stomach and



liver, can also lie outside of the baby's body. The causes of gastroschisis are not known, but there have been reports of clusters of babies born with gastroschisis in the same geographic area.

NBDPS researchers used information on where mothers lived in early pregnancy to investigate if there were any clusters within certain areas of Arkansas, California, and Utah. Studying patterns in birth defects can help determine if there are environmental factors that may increase the risk of birth defects. The researchers found patterns in specific locations where the moms lived, but could not rule out that these patterns were the result of random chance. More research is needed on whether or not gastroschisis occurs in geographic clusters.

#### Birth Defects among Males and Females<sup>6</sup>

NBDPS researchers compared how often specific birth defects occurred among male versus female infants. This comparison, known as the sex ratio, can help identify how birth defects develop. Researchers looked at the sex ratios for all babies in NBDPS with only one defect and babies with multiple defects, as well as the sex ratios among babies within each race/ethnicity.

<sup>5</sup>Yazdy MM, Werler MM, Feldkamp ML, Shaw GM, Mosley BS, Vieira VM; National Birth Defects Prevention Study. Spatial analysis of gastroschisis in the National Birth Defects Prevention Study. *Birth Defects Res A Clin Mol Teratol*. 2015 Jun;103(6):544–53.

<sup>6</sup>Michalski AM, Richardson SD, Browne ML, Carmichael SL, Canfield MA, VanZutphen AR, Anderka MT, Marshall EG, Druschel CM. Sex ratios among infants with birth defects, National Birth Defects Prevention Study, 1997–2009. *Am J Med Genet A*. 2015 May;167A(5):1071–81.



Several congenital heart defects (CHDs), such as aortic stenosis, coarctation of the aorta, and d-transposition of the great arteries, occurred more often in males compared to females. Cleft lip with cleft palate and craniosynostosis, a birth



defect of the skull, were also more common among males compared to females. Other CHDs, such as <u>pulmonary valve</u> <u>stenosis and atrial septal defect</u>, occurred more often in females compared to males. Choanal atresia, a birth defect of the nose, and cloacal exstrophy, a birth defect of the abdomen and genitals, were more common among females compared to males. Differences in the sex ratio by race/ethnicity were seen for some, but not all, birth defects. These results may inform future research that aims to understand how certain birth defects develop.

#### Workplace Solvent Exposure and Low Birth Weight<sup>7</sup>

Organic solvents are chemicals found in many workplace and household products like paint, fuel, glue, cleaning solutions, and pesticides. Previous NBDPS research suggested a link between coming into contact with solvents at work



(workplace exposure) and having a baby with a birth defect. In this study, researchers examined the potential effect of workplace solvent exposure during pregnancy and lower birth weight among babies without a birth defect. Babies that are born smaller than expected may face higher rates of illness (morbidity) and death (mortality) in infancy as well as later in life.

Researchers found that about 10% of women who participated in the NBDPS worked in jobs with solvent exposure. The most common jobs with solvent exposure were housekeepers/janitors and pest control workers; textile, apparel and furnishing workers; and health technicians. In this study, the researchers did not find a link between solvent exposure and birth weight. The growth of babies during pregnancy did not appear to be affected by solvent exposure at work. Other studies have found different results, and more research is needed to better understand the effect of solvents on a developing baby.

<sup>7</sup>Desrosiers TA, Lawson CC, Meyer RE, Stewart PA, Waters MA, Correa A, Olshan AF; National Birth Defects Prevention Study. Assessed occupational exposure to chlorinated, aromatic and Stoddard solvents during pregnancy and risk of fetal growth restriction. *Occup Environ Med*. 2015 Aug;72(8):587–93.

## Maternal Workplace Exposure to Ionizing Radiation and Birth Defects<sup>8</sup>

Ionizing radiation (IR) is known to cause cancer and changes (mutations) in genes, but relatively little is known about its potential relationship to birth defects. NBDPS researchers at the Texas Center examined whether working in occupations with potential exposure to



IR was linked to certain birth defects. Some people can be exposed to IR at work, such as those who work with x-ray equipment, in nuclear power plants, or in certain research laboratories. Mothers exposed to IR in their workplace had a small increased risk of having a baby affected by several different types of birth defects compared to all other working mothers in the study. However, these mothers had a reduced risk for one type of birth defect of the brain. The results should be interpreted cautiously, but may be helpful for future studies.

### Factors Linked to Dandy-Walker Malformation, a Rare Birth Defect of the Brain<sup>9</sup>

NBDPS Researchers from the Utah Center looked at specific factors that might increase the risk of having a

baby with Dandy-Walker malformation (DWM), a rare birth defect that affects the back part of the brain. Researchers looked at many different factors, such as the race of the mother and father, mother's education and age, and certain



exposures before and during pregnancy, such as smoking, alcohol use, and infections. They found that most of these factors were not related to having a baby with DWM. The researchers did identify a few factors that were more common among babies with DWM compared to babies without DWM, including mothers who were non-Hispanic black, twinning, and mothers who had infertility treatment. Future studies are needed to further examine the roles of race, twinning, infertility, infertility treatment, and genes in the development of DWM.

<sup>8</sup>Lim H, Agopian AJ, Whitehead LW, Beasley CW, Langlois PH, Emery RJ, Waller DK, and the National Birth Defects Prevention Study. Maternal occupational exposure to ionizing radiation and major structural birth defects. *Birth Defects Res A Clin Mol Teratol*. 2015 Apr;103(4): 243–54.

<sup>9</sup>Reeder MR, Botto LD, Keppler-Noreuil KM, Carey JC, Byrne JL, Feldkamp ML; National Birth Defects Prevention Study. Risk factors for Dandy-Walker malformation: A population-based assessment. *Am J Med Genet A*. 2015 Sep;167(9):2009–16.



# Spotlight on NBDPS Research Centers and the Principal Investigators

NBDPS finished its last interview in 2013, but all of the NBDPS Research Centers work together to continue analyzing the information collected. Many of these Centers also continue the work in researching birth defects in the <u>Birth Defects Study To Evaluate Pregnancy exposureS</u>, or <u>BD-STEPS</u>, which started interviews in 2014. Read below for more information about the NBDPS Centers and the Principal Investigators at these Centers.

#### **ARKANSAS**

About 1,300 babies are born with a birth defect and more than 100 babies will die because of them each year in Arkansas. The Arkansas Center for Birth Defects Research and Prevention collects data from the <u>Arkansas Reproductive Health Monitoring System</u>, one of the oldest active birth defects monitoring systems.

Research at the Arkansas Center focuses on genetic (inherited) factors that might increase the risk for birth defects, specifically <u>congenital heart defects</u> and <u>hypospadias</u>. The Arkansas Center also looks at genes\* and how they might be influenced by a woman's lifestyle habits and exposures such as tobacco smoke.

Charlotte Hobbs, MD, PhD has been the Arkansas Center's Principal Investigator and the Medical Director of Arkansas Reproductive Health Monitoring System since 1997. Dr. Hobbs has devoted her career to the study and prevention of birth defects.



#### **CALIFORNIA**

About 17,000 babies are born with birth defects in California each year and almost 2,000 of these babies will die in their first year. The California Center of Excellence is a partnership between Stanford University School of Medicine and the

California Birth Defects Monitoring
Program in the Department of Public
Health. The Center collects data from
women who live in eight counties in
the Central Valley. The Center has been
part of the CDC-funded Centers for
Birth Defects Research and Prevention
since 1997. The California Center I
ooks at how nutrition, environmental
exposures, and genes impact the risk
of birth defects.

**Gary Shaw, DrPH**, and **Suzan Carmichael, PhD**, are the Co-Principal Investigators for the California
Center. Dr. Shaw has conducted birth defects research for over 25 years.
Dr. Carmichael has focused on birth



defects research for the past 15 years. They look at how diet, obesity, drugs, alcohol, stress, pollution, jobs, and genes affect birth defect risk.

#### **GEORGIA (CDC)**

An estimated 4,000 births are affected by birth defects in Georgia annually. CDC coordinates BD-STEPS study activities and serves as the Georgia study site. CDC studies medicine use among pregnant women and how certain medicines might affect birth defect risk. The Georgia Center also tracks the number of birth defects in Atlanta through the Metropolitan Atlanta Congenital Defects Program, which has collected data in Atlanta since 1968 and serves as a model for other state birth defects tracking systems.

More than 3,000 women in Georgia helped CDC understand the causes of birth defects by taking part in the NBDPS. The Georgia Center is eager to follow up on NBDPS research findings with BD-STEPS.

The Principal Investigator for the Georgia Center is **Sarah Tinker, PhD**. She oversees data collection and evaluates data from local study subjects and ensures that the study at the Georgia site runs smoothly.

Jennita Reefhuis, PhD is the lead investigator for the BD-STEPS and NBDPS Centers at CDC. Dr. Reefhuis works with a team of computer programmers, communication specialists, and scientists to coordinate the study logistics. Dr. Reefhuis' research focuses on how fertility treatments and other medicines affect a woman's risk of having a baby born with a birth defect.





#### **IOWA**

Over 1,500 pregnancies are affected by birth defects in lowa each year. The BD-STEPS study area includes more than 3 million people comprised of urban and rural residents who have differences in personal behaviors, such as smoking, alcohol use, and exposure to farming chemicals and other toxins. The <a href="Lowa Registry for Congenital and Inherited Disorders">Lowa Registry for Congenital and Inherited Disorders</a> was established partly to study how a person's genes and their behaviors might affect birth defect risk.



**Paul Romitti, PhD** is the Principal Investigator for the Iowa Center, and he leads the Iowa Registry for Congenital and Inherited Disorders. Dr. Romitti has worked with the registry since 1989. His research focuses on environmental exposures and the role of genes in birth defects.



#### **MASSACHUSETTS**

About 1,700 pregnancies are affected by birth defects in Massachusetts each year. The Massachusetts Center for Birth Defects Research and Prevention started in 1997 and is a partnership between the Massachusetts Department of Public Health, Boston University's Slone Epidemiology Center, and the Genetics Unit at Massachusetts General Hospital for Children. The Massachusetts Center has experts in many research areas including congenital heart defects and other birth defects.

The Massachusetts Center is a leader in research on the safety and risks of medicine use during pregnancy, including a study showing that medicine use during pregnancy has increased dramatically over the past 30 years.

Mahsa Yazdy, PhD (pictured on top) is the Principal Investigator and the Director of the Massachusetts Center at the Massachusetts Department of Public Health. Dr. Yazdy has over 10 years of experience in birth defects research. She replaces Marlene Anderka, ScD, who retired after 37 years working in maternal and child health. Dr. Anderka played a key role in expanding the Massachusetts Center and served as the Principal Investigator and the Director for 15 years. She continues to work with the Massachusetts team on BD-STEPS and NBDPS projects. Dr. Yazdy works closely with two co-investigators: Allen Mitchell, MD, Director Emeritus of the





Slone Epidemiology Center at Boston University, and Lewis Holmes, MD, Director Emeritus of the Genetics Unit at Massachusetts General Hospital for Children.

#### **NEW JERSEY**

The New Jersey Department of Health and Senior Services was part of the NBDPS from 1998 through 2003. Pregnancies affected by birth defects were identified through the <u>Special Child Health Services Registry</u>. Data and specimens collected from more than 2,200 families in New Jersey have been included in many studies, and continue to help identify causes of birth defects. If you are from New Jersey and would like to reach a study coordinator, please contact the Georgia/CDC Research Center.

#### **NEW YORK**

Over 12,000 babies are born with a major birth defect every year in New York State. Experts at the New York Center study medicine use during pregnancy, as well as environmental exposures at work and other places that might lead to birth defects. The Center often collaborates with the Wadsworth Center, the research-focused public health laboratory at the New York State Department of Health. Their colleagues at Wadsworth have developed ways to do genetic and environmental analyses of newborn screening blood spots for birth defects research.

Marilyn Browne, PhD (pictured on top) and Charlotte Druschel, MD, PhD, served as the Principal Investigators for the New York Center for NBDPS. Dr. Druschel was an integral part of the New York Center for 17 years and retired in 2014. Dr. Druschel has more than 25 years of experience in birth defects research. Her most recent publications focused on illnesses that mothers had or medicines taken during pregnancy and the risks for birth defects, as well as environmental exposures and the role of genes in specific birth defects. Dr. Browne has worked in birth defects





research for more than 15 years. Her work focuses on gaps in knowledge about the risks and benefits of different ways to treat a woman's longstanding medical conditions.

Dr. Browne has published studies on thyroid medicine, migraine medicine, butalbital, and caffeine use during pregnancy. She and her team track adolescents and adults with congenital heart defects to learn about their healthcare needs and study how genes affect birth defect risk.

#### **NORTH CAROLINA**

More than 3,500 babies are born with major birth defects in North Carolina each year. The North Carolina Center carries out birth defects research in 33 counties in central North Carolina. Children with birth defects are identified through the North Carolina Birth Defects Monitoring Program, which has been run by the state since 1995. The North Carolina Center has two partners: the Department of Epidemiology at the University of North Carolina (UNC) Gillings School of Global Public Health in Chapel Hill and the North Carolina Birth Defects Monitoring Program at the State Center for Health Statistics, Division of Public Health, in Raleigh.

The North Carolina Center works to find exposures during early pregnancy that put women at higher risk of having a baby with a birth defect. Researchers focus on factors that increase the risk for birth defects that might be modified, including diet, obesity, exercise, and work exposures; the role of genes and how genes interact with environmental exposures; and new methods of studying birth defects.



Andrew F. Olshan, PhD (pictured on top) and Robert Meyer,

PhD lead the North Carolina Center as Co-Principal Investigators. Dr. Olshan researches how genes and the environment affect reproduction, birth defects, and cancer. He was among the first researchers to explore how a father's occupation (work environment) might increase the risk for birth defects in his offspring. Dr. Olshan directs the North Carolina Center's research, staff, and studyrelated activities. Dr. Meyer directs the North Carolina Birth Defects Monitoring Program and oversees the clinical data collection activities of the Center. His research focuses on potential environmental causes of





birth defects, and long-term outcomes among children affected by birth defects and their families, including survival, educational achievement, and quality of life.

#### **TEXAS**

In Texas, over 20,000 births each year will have a major birth defect recorded in the <u>Texas Birth Defects Registry (TBDR)</u>. The Texas Birth Defects Registry has been operating since 1994 and is housed in the Texas Department of State Health Services. The Texas Center for Birth Defects Research and Prevention is composed of staff at the TBDR and partners across the state, including the Schools of Public Health and Medicine at the University of Texas (multiple locations), University of Texas (Austin), University of Texas Southwestern (Dallas), Texas State University (San Marcos), Texas A&M Public Policy Research Institute and School of Public Health (College Station), and Baylor College of Medicine (Houston).

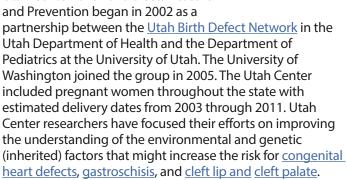
Researchers at the Texas Center investigate

- Why certain racial/ethnic groups have higher risk of birth defects;
- What causes birth defects, like <u>anencephaly</u> and <u>spina</u> <u>bifida</u> (severe birth defects of the brain and spine);
- The combined effect of genes and diet or environmental factors on birth defects;
- What happens to children with birth defects–what is their quality of life and how long do they live;
- Occupational and environmental factors that might increase the risk for birth defects, such as chemicals hat occur in the workplace or result from water disinfection; and
- Exposures to other chemicals that might increase the risk for birth defects, such as nitrates or similar substances found in food, water, and certain medicines.

Peter Langlois, PhD (pictured on top), and Mark A. Canfield, PhD have been with the TBDR since its first year and they are Co-Principal Investigators for the Texas Center for Birth Defects Research and Prevention. In 2016, the Texas Center received the State Leadership Award from the National Birth Defects Prevention Network.



Each year in Utah, around 1,200 babies are born with a birth defect and nearly 75 babies will die in their first year of life because of them. The Utah Center for Birth Defects Research and Prevention began in 2002 as a



for about 1 in 4 birth defects in Utah. Gastroschisis, although not as common, has increased among all babies born over time for reasons that are still unclear. Cleft lip and cleft palate rates in Utah are among the highest in the nation and the world. Finding the causes of these birth defects will help researchers understand ways to lower the risk of birth defects and help families have healthy babies.

Congenital heart defects are common and are responsible

Marcia Feldkamp, PhD, PA, MSPH and Lorenzo Botto, MD are Co-Principal Investigators for the Utah Center. Dr. Feldkamp is interested in the contribution of genes, infections in the mother and inflammation as factors that might increase the risk for birth defects. Dr. Botto's research looks at genes and environmental factors that increase the risk for congenital heart defects.







### **Parent's Viewpoint**

In 2012, I was asked if I would participate in the National Birth Defects Prevention Study (NBDPS). Maternal and child health issues are close to my heart. I gladly participated in the phone interview and later even provided [cheek cell] swabs from our whole family. It was just one small way I could help a cause I feel deeply about.

One reason I feel so deeply about participating is that a girl I went to church with had a son with a heart defect. He ended up passing away and that made it very real to me. I saw how hard it was for her and her husband. If anything positive can come from such pain, it was the motivation for me to participate in the NBDPS. My own son was just a baby at the time and it made me realize what a precious gift he and all children are.

My mama heart goes out to all parents of children with birth defects. It is my prayer that one day no parent will have to go through that pain. This is why I would encourage other mothers to participate in the study.

Life moves at such a quick pace. I am now a mom to two little boys. As mothers (and fathers) we all belong to the same tribe, and we are strong when we stick together.

Much love, Elly York



**Editor's Note:** This family has allowed to us to share their story. The privacy of study participants is important to us. We will not name anyone in the study in any report or publication unless we have been given permission to do so. Family stories are an important part of our newsletters and websites. We hope other families will share their stories with us.

# **Babies to Adults: Special Note to Study Participants**

NBDPS has interviewed mothers for more than 16 years! Some babies of the earliest participants have now reached 18 years of age. Participants can withdraw themselves, their child, or both from the study at any time. In addition, when a child reaches 18 years of age, he or she can also decide to withdraw from the study at any time. For a child, withdrawing means we will destroy the cheek cell sample and the data from the sample that we received when he or she was a baby. That means that the sample will no longer be used. To withdraw from the study, call 404-498-4315 or e-mail NBDPS2@cdc.gov. For any person who withdraws from the study, we will not use his or her information in the future. Information from findings or articles that have already been published cannot be removed; however, no publications provide specific identifying information that can be linked to a particular person.





### **Resource Corner**

Listed below are several resources that might be of interest. The Centers are not responsible for the content found on these websites.

#### **Medication and Pregnancy**

The American College of Allergy, Asthma, and Immunology has information on asthma and allergies during pregnancy. <a href="http://acaai.org/resources/connect/letters-editor/letters-to-web-editor-5">http://acaai.org/resources/connect/letters-editor/letters-to-web-editor-5</a>

The **Mother to Baby** website contains a library of fact sheets in English and Spanish about different medicines and whether they are safe to use during pregnancy and breastfeeding. <a href="http://mothertobaby.org/fact-sheets-parent/">http://mothertobaby.org/fact-sheets-parent/</a>

**Treating for Two: Safer Medication Use in Pregnancy** is a CDC initiative that works to provide better information to women and healthcare providers about medicine use during pregnancy, an index site of CDC.gov, provides this information and other resources. <a href="https://www.cdc.gov/pregnancy/meds/treatingfortwo/index.html">https://www.cdc.gov/pregnancy/meds/treatingfortwo/index.html</a>

#### **Stress and Pregnancy**

The **March of Dimes** website covers life changes during pregnancy, causes of stress, and ways to reduce stress during pregnancy. <a href="http://www.marchofdimes.org/pregnancy/stress-and-pregnancy.aspx">http://www.marchofdimes.org/pregnancy/stress-and-pregnancy.aspx</a>

The **Mother to Baby** website has a fact sheet on stress during pregnancy. It covers what stress is, if moms-to-be should be concerned, ways to reduce stress, and where to go for help. <a href="http://www.mothertobaby.org/files/stress.pdf">http://www.mothertobaby.org/files/stress.pdf</a>

#### **Congenital Heart Defects**

CDC's website has information on **congenital heart defects**, including specific heart defects, research, and statistics, among other useful resources. <a href="https://www.cdc.gov/ncbddd/heartdefects/">https://www.cdc.gov/ncbddd/heartdefects/</a>

CDC's website has information on **critical congenital heart** defects. The webpage has information on screening, current research activities, and information for healthcare providers. <a href="https://www.cdc.gov/ncbddd/heartdefects/cchd-facts.html">https://www.cdc.gov/ncbddd/heartdefects/cchd-facts.html</a>

#### **Cleft Lip and Palate**

CDC's information on **cleft lip and cleft palate** provides information on what these conditions are, some of the known causes of cleft lip and palate, and diagnosis and treatment options. <a href="http://www.cdc.gov/ncbddd/birthdefects/cleftlip.html">http://www.cdc.gov/ncbddd/birthdefects/cleftlip.html</a>

**The Cleft Palate Foundation** has information for parents of children with cleft lip with or without cleft palate. <a href="http://www.cleftline.org/parents-individuals/">http://www.cleftline.org/parents-individuals/</a>

**Children's Craniofacial Association** has information about birth defects of the head and face. They have resources on connecting with other parents and families as well as information on each condition. <a href="http://www.ccakids.com">http://www.ccakids.com</a>

#### **Choanal Atresia**

The **Children's Choanal Atresia Foundation** provides information, research, and support about choanal atresia, a birth defect of the nasal passage. <a href="http://choanalatresia.org/index.html">http://choanalatresia.org/index.html</a>

#### **Gastroschisis**

CDC'sinformation on **gastroschisis** explains what gastroschisis is and how it is diagnosed and treated. http://www.cdc.gov/ncbddd/birthdefects/gastroschisis.html

Avery's Angels Gastroschisis Foundation helps children and families affected by gastroschisis. The website has resources for connecting with other families and ways to raise awareness about gastroschisis. <a href="http://www.averysangels.org/">http://www.averysangels.org/</a>

#### Genetics

CDC's website on **Family Health History and Genetics** has information on how genes impact family health history. It also has information about newborn screening. <a href="http://www.cdc.gov/ncbddd/genetics/">http://www.cdc.gov/ncbddd/genetics/</a>





### **Directory of the Research Centers**

To reach a NBDPS study coordinator by phone, please call (404) 498-4315. Below is the contact information for each NBDPS Center.

#### **ARKANSAS**

#### Charlotte Hobbs, MD, PhD

University of Arkansas for Medical Sciences

Arkansas Children's Hospital E-mail: <a href="mailto:ar@bdsteps.org">ar@bdsteps.org</a>

http://arbirthdefectsresearch.uams.edu

#### **CALIFORNIA**

#### Suzan Carmichael, PhD Gary Shaw, DrPH

Stanford University E-mail: <a href="mailto:ca@bdsteps.org">ca@bdsteps.org</a>

http://www.cdph.ca.gov/programs/cbdmp/Pages/

<u>default.aspx</u>

#### **GEORGIA/CDC**

#### Jennita Reefhuis, PhD Sarah Tinker, PhD

Centers for Disease Control and Prevention

E-mail: ga@bdsteps.org http://www.cdc.gov/ncbddd

#### **IOWA**

#### Paul Romitti, PhD

University of Iowa

E-mail: ia@bdsteps.org

http://www.public-health.uiowa.edu/ircid

#### **MASSACHUSETTS**

#### Marlene Anderka, ScD, MPH

Massachusetts Department of Public Health

E-mail: ma@bdsteps.org

http://www.mass.gov/dph/birthdefects

#### **NEW JERSEY**

To reach a study coordinator, please contact the Georgia/CDC Center.

#### **NEW YORK**

#### Marilyn Browne, PhD

New York State Department of Health

E-mail: ny@bdsteps.org

http://www.health.ny.gov/diseases/congenital

malformations/

#### **NORTH CAROLINA**

#### **Andrew Olshan, PhD**

University of North Carolina, Chapel Hill

#### Robert Meyer, PhD

North Carolina Department of Health & Human Services

E-mail: nc@bdsteps.org

http://www.schs.state.nc.us/units/bdmp/

#### **TEXAS**

### Mark Canfield, PhD

Peter Langlois, PhD

Texas Department of State Health Services

E-mail: tx@nbdps.org

http://www.dshs.state.tx.us/birthdefects/

#### **UTAH**

Lorenzo Botto, MD

Marcia Feldkamp, PhD, PA, MSPH

University of Utah

E-mail: ut@nbdps.org

http://health.utah.gov/ubdn/

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