bd steps NEWS 2016

BD-STEPS News is a periodic newsletter of 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.

In this issue

About BD-STEPS

The Birth Defects Study To Evaluate Pregnancy exposureS, or BD-STEPS continues to build on the promising findings of other studies, such as the National Birth Defects Prevention Study (NBDPS), which have been active for over 25 years.

BD–STEPS studies factors that might put a woman at risk to have a baby with a birth defect. The study focus primarily on factors that a woman might be able to change to reduce the chance of her baby being born with a birth defect. Factors that can affect the risk of birth defects include

- Diabetes, obesity and lack of physical activity;
- Treatments for long term chronic health conditions such as asthma and high blood pressure;
- Infertility treatments; and
- Other medicines.

In July 2014, BD-STEPS began interviews by phone with mothers of children affected by birth defects and mothers of children not affected by birth defects. Mothers who participate in BD-STEPS live in the following states: Arkansas, California, Georgia, Iowa, Massachusetts, New York, and North Carolina.

BD-STEPS researchers are developing online tools that will make it easier for women to participate in the study. Researchers anticipate these tools will be available sometime in 2017.

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National Center on Birth Defects and Developmental Disabilities

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Spotlight on BD-STEPS Research Centers and the Principal Investigators

Seven Centers across the United States work together as part of BD-STEPS. Each site brings unique experience and expertise to the research efforts. Read below for more information about the seven BD-STEPS 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 Arkansas Reproductive Health Monitoring System, 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 congenital heart defects and hypospadias. 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 looks 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.

*"Gene—a part of DNA (the genetic instructions in all living things). People inherit one copy of each gene from their mother and one copy from their father. The genes that a person inherits from his or her parents can determine many things, like what a person will look like and whether the person might have certain diseases."

IOWA

Over 1,500 pregnancies are affected by birth defects in Iowa 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 Iowa Registry for Congenital and Inherited Disorders was established partly to study how a person's genes and their behaviors might affect birth defect risk.

For BD-STEPS, the Iowa Center will look at the impact of personal behaviors and environmental exposures, along with genes, on birth defects. **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.

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 (*pictured below Dr. Yazdy*) 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 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 serves as the Principal Investigator for the New York Center. She has worked in birth defects research for more than 15 years, and her work focuses on gaps in knowledge about the risks and benefits of different treatments for a variety of medical conditions.

Dr. Browne and her team hope their research will provide information about which medicines are safer for pregnant women to treat long-standing health problems, like diabetes and asthma. She 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 health care 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** (*pictured at the bottom*) 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 study-related 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.

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.

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. http://acaai.org/resources/connect/letters-editor/letters-to-web-editor-5

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. http://mothertobaby.org/fact-sheets-parent/

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. https://www.cdc.gov/pregnancy/meds/treatingfortwo/index.html

STRESS AND PREGNANCY

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

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. http://www.mothertobaby.org/files/stress.pdf

CONGENITAL HEART DEFECTS

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

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

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. http://www.cdc.gov/ncbddd/birthdefects/cleftlip.html

The Cleft Palate Foundation has information for parents of children with cleft lip with or without cleft palate. http://www.cleftline.org/parents-individuals/

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. http://www.ccakids.com

CHOANAL ATRESIA

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

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 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. http://www.averysangels.org/

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. http://www.cdc.gov/ncbddd/genetics/

Directory of the Research Centers

To reach a NBDPS or BD-STEPS study coordinator by phone, please call (404) 498-4315. Please see below for specific contact information to each BD-STEPS Center.

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CALIFORNIA
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http://www.cdph.ca.gov/programs/cbdmp/Pages/default.aspx

GEORGIA/CDC
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http://www.cdc.gov/ncbddd

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

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

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

share your stories

Newsletter Ideas and Mailing:

Please contact your Center listed in the directory if you:

- Want to share your experience about the NBDPS,
- No longer wish to receive this newsletter,
- Need to update your mailing address, or
- Would like to receive the newsletter via e-mail.

Also, please let us know if you have topic ideas for future issues.