2022 Report

The Iowa Registry for Congenital and Inherited Disorders (IRCID) continues to be a national leader in surveillance of congenital and inherited disorders and serves as a model program for other states. IRCID conducts active surveillance to identify information about congenital and inherited disorders that occur in Iowa and to Iowa residents.

Since 1983, IRCID has collected information for nearly 62,000 children with various birth defects. This information is used by health care providers and educators to provide treatment and support services, and by researchers to study risk factors for birth defects and evaluate treatments for birth defects.

IRCID also conducts surveillance for muscular dystrophies – Duchenne, Becker, congenital, distal, Emery-Dreifuss, facioscapulohumeral, limb-girdle, myotonic, and oculopharyngeal. In addition, IRCID has collaborated with the Centers for Disease Control and Prevention (CDC) to develop approaches for active surveillance for stillbirths, newborn screening disorders, birth defects that may be related to Zika virus infection, and delivery outcomes of pregnant people who tested positive for SARS-CoV-2. Most recently, IRCID collaborates with CDC to conduct surveillance for congenital cytomegalovirus infection.

The surveillance and research efforts of IRCID and its partners provide a valuable resource for the state of Iowa. While taking care to preserve the privacy of families affected by these disorders, IRCID provides important information to state policy makers and public health professionals. We are pleased to perform this important work on behalf of the citizens of Iowa.

Surveillance for Birth Defects

In the United States (US), CDC recognizes three surveillance approaches, each rated differently for completeness of ascertainment of pregnancies with a birth defect.

- Vital Record Reporting: Use of birth and fetal death certificates provided by the state's Department of Health (Rating: Poor)
- Passive Reporting: Use of medical reports submitted by staff from hospitals, clinics, or other facilities (Rating: Fair to Good)
- Active Reporting: Use of trained personnel who systematically review records in hospitals, clinics, or other facilities (Rating: Excellent)

The term "defect" refers to abnormal development related to body structure, body function, and metabolism, or an error in body chemistry. Typically, a defect is present at birth (congenital), but a recognizable defect may be diagnosed during pregnancy (prenatal) or following birth (postnatal).

Approximately 1 in 33 newborns is affected by a major birth defect in the US. Major defects come with personal and monetary costs for families of these children and for society. Nearly 20% of all infant deaths are caused by major defects. Hospitalizations associated with major defects are longer than those for other conditions and account for about $9 billion annually for infants.

IRCID has traditionally focused on structural birth defects, which involve a body part that is missing or malformed. Examples include heart defects, spina bifida, clubfoot, and cleft lip and palate. Since 2003, IRCID adopted the recommendations of the National Birth Defects Prevention Network (NBDPN) to focus largely on a core set of major birth defects (see Table 1). Prior to 2003, IRCID included many 'minor' defects, so this change represents a reduction in the number of defects that IRCID monitors.

Table 1. Prevalence (per 10,000 live births) for birth defects in Iowa, 2016-2020 deliveries

Birth Defect	Total	Prevalence
Brain/Spinal Cord		
Anencephalus	53	2.8
Encephalocele	22	1.2
Holoprosencephaly	45	2.4
Spina bifida without anencephalus	82	4.3
Eye		
Anophthalmia/microphthalmia	32	1.7
Congenital cataract	64	3.4
Ear		
Anotia/microtia	60	3.2
Heart		
Aortic valve stenosis	51	2.7
Atrial septal defect	444	23.5
Atrioventricular septal defect	94	5.0
Coarctation of aorta	135	7.1
Common truncus	11	0.6
Double outlet right ventricle	43	2.3
Ebstein anomaly	15	0.8
Hypoplastic left heart syndrome	56	3.0
Interrupted aortic arch	14	0.7
Pulmonary valve atresia and stenosis	176	9.3
Single ventricle	11	0.6
Tetralogy of Fallot	68	3.6
Total anomalous pulmonary venous return	24	1.3
Transposition of great arteries	54	2.9
Tricuspid valve atresia and stenosis	47	2.5
Ventricular septal defect	1000	52.9
Oral/Facial		
Choanal atresia	10	0.5
Cleft lip only	77	4.1
Cleft lip with cleft palate	150	7.9
Cleft palate without cleft lip	130	6.9
Gastrointestinal		
Biliary atresia	8	0.4
Esophageal atresia/tracheoesophageal fistula	47	2.5
Hirschsprung's disease (congenital megacolon)	31	1.6
Pyloric stenosis	314	16.6
Rectal and large intestinal atresia/stenosis	59	3.1
Small intestinal atresia and stenosis	61	3.2
Genital/Urinary		
Bladder exstrophy	5	0.3
Cloacal exstrophy	1	0.1
Congenital posterior urethral valves[†]	24	2.5
Hypospadias[*,†]	586	60.8
Renal agenesis/hypoplasia	134	7.1

Table 1. (continued from previous page)

Birth Defect	Total	Prevalence
Muscle/Skeletal		
Clubfoot	358	19.0
Craniosynostosis	104	5.5
Diaphragmatic hernia	57	3.0
Gastroschisis	53	2.8
Limb deficiencies (reduction defects)	104	5.5
Omphalocele	55	2.9
Syndromes/Chromosomes		
Deletion 22q11.2	28	1.5
Down syndrome (Trisomy 21)	290	15.4
Edwards syndrome (Trisomy 18)	71	3.8
Patau syndrome (Trisomy 13)	37	2.0
Turner syndrome‡	36	3.9

*Includes first-, second-, and third-degree hypospadias.
†Prevalence per 10,000 male live births.
‡Prevalence per 10,000 female live births.

Birth Defect Research

Because the causes of up to 70% of major defects that occur are unknown, research is a critical part of any strategy to prevent these defects. In 1996 the US Congress directed CDC to establish regional centers in birth defect research and prevention. The Iowa Center for Birth Defects Research and Prevention (CBDRP) is one of eight centers established by CDC to study risk factors for major defects. Interest in fostering collaboration among state birth defect programs also led to formation of NBDPN in 1998.

National Birth Defects Prevention Network (NBDPN)

IRCID is an active member of NBDPN, a nationwide association of birth defect programs. NBDPN provides guidelines to help programs organize their work in a consistent manner. NBDPN also provides educational materials to programs and informational resources to promote Birth Defects Prevention Month each January. Another goal of NBDPN is to encourage scientific collaboration among programs.

Iowa Center for Birth Defects Research and Prevention (CBDRP)

The Iowa CBDRP participated in the National Birth Defects Prevention Study (NBDPS) and currently participates in the Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS). NBDPS investigated risk factors for over 30 major defects. IRCID identified children with NBDPS-eligible defects and secured permission from mothers to share information with researchers. Mothers with a pregnancy affected by a major defect and those with an unaffected pregnancy were interviewed about their health, diet, and lifestyle during pregnancy. Biological specimens were requested from families to study genetic factors. Nationwide, over 43,000 interviews were completed, and over 25,000 families provided specimens.

NBDPS projects conducted by the Iowa CBDRP have the potential to positively impact the lives of Iowans. These projects examined agricultural chemicals, cigarette smoking, alcohol consumption, diet, medications, and compounds in drinking water, along with genetic factors. Projects published in 2022 that used IRCID data are listed below. Bolded names refer to Iowa investigators.

Iowa NBDPS Project Spotlight

Influenza (flu) vaccination during pregnancy is associated with fewer flu-related hospitalizations of pregnant people and infants less than six months of age. However, current information on flu vaccination during pregnancy and the risk of birth defects is limited. Using NBDPS data, researchers studied whether use of inactivated flu vaccine in early pregnancy was related to having a baby with one of 19 non-heart birth defects. Among the 5% of NBDPS participants who reported receiving the vaccine in early pregnancy, researchers did not find a relationship between vaccination and the birth defects, compared to women who did not receive the vaccine or received the vaccine later in pregnancy. This study supports use of inactivated flu vaccine during early pregnancy as recommended by the Advisory Committee on Immunization Practices and the American College of Obstetricians and Gynecologists.

Palmsten K, Suhl J, Conway KM, Kharbanda EO, Ailes EC, Cragan JD, Nestoridi E, Papadopoulos EA, Kerr SM, Young SG, DeStefano F, **Romitti PA** and the NBDPS. (2022) Influenza vaccination during pregnancy and risk of selected major structural non-cardiac birth defects, NBDPS 2006-2011. Pharmacoepidemiol Drug Saf 31:851-862.

Bolin EH, Gokun Y, **Romitti PA,** Tinker SC, Summers AD, Roberson PK, Hobbs CA, Malik S, Botto LD, Nembhard WN, and the NBDPS. (2022) Maternal smoking and congenital heart defects, NBDPS, 1997-2011. J Pediatr 240:79-86.e1.

Finn J, Suhl J, Kancherla V, Conway KM, Oleson J, Sidhu A, Nestoridi E, Fisher SC, Rasmussen SA, Yang W, **Romitti PA** and the NBDPS. (2022) Maternal cigarette smoking and alcohol consumption and congenital diaphragmatic hernia. Birth Defects Res 114:746-758.

Fisher SC, Howley MM, **Romitti PA,** Desrosiers TA, Jabs EW, Browne ML, and the NBDPS. (2022) Maternal periconceptional alcohol consumption and gastroschisis in the NBDPS, 1997-2011. Paediatr Perinat Epidemiol 36:782-791.

Howley MM, Williford E, Agopian AJ, Lin AE, Botto LD, Cunniff CM, **Romitti PA,** Nestoridi E, Browne ML for the NBDPS. (2023) Patterns of multiple congenital anomalies in the NBDPS: Challenges and insights. Birth Defects Res 115:43-55.

Kerr S, Heinke D, Yazdy MM, Mitchell AA, Darling AM, Lin A, Nestoridi E, Werler MM; NBDPS. (2022) Use of vasoactive medications in pregnancy and the risk of stillbirth among birth defect cases. Birth Defects Res 114:277-294.

Li G, Yang W, Wang YJ, Ma C, Curry CJ, McGoldrick D, Nickerson DA, Chong JX, Blue EE, Mullikin JC, Reefhuis J, Nembhard WN, **Romitti PA,** Werler MM, Browne ML, Olshan AF, Finnell RH, Feldkamp ML, Pangilinan F, Almli LM, Bamshad MJ, Brody LC, Jenkins MM, Shaw GM, and NISC Comparative Sequencing Program, UW Center for Mendelian Genomics and NBDPS. (2022) Exome sequencing identifies a genetic basis in anophthalmia and microphthalmia. Am J Med Genet A 188:2376-2388.

Mohan Dass NL, Botto LD, Tinker SC, Canfield MA, Finnell RH, Gallaway MS, Hashmi SS, Hoyt AT, Nembhard WN, Waller DK; NBDPS. (2022) Associations between maternal reports of periconceptional fever from miscellaneous causes and structural birth defects. Birth Defects Res 114:885-894.

Nalbandyan M, Howley MM, Cunniff CM, Leckman-Westin E, Browne ML. (2022) Descriptive and risk factor analysis of infantile cataracts: NBDPS, 2000-2011. Am J Med Genet A 188:509-521.

Ou Y, Papadopoulos EA, Fisher SC, Browne ML, Lin Z, Soim A, Lu Y, Sheridan S, Reefhuis J, Langlois PH, **Romitti PA,** Bell EM, Feldkamp M, Malik S. (2022) Interaction of maternal medication use with ambient heat exposure on congenital heart defects in the NBDPS. Environ Res 215:114217.

Papadopoulos EA, Fisher SC, Howley MM, Browne ML; NBDPS. (2022) Maternal hereditary hemolytic anemia and birth defects in the NBDPS. Birth Defects Res 114:295-303.

Pitsava G, Feldkamp ML, Pankratz N, Lane J, Kay DM, **Conway KM,** Hobbs C, Shaw GM, Reefhuis J, Jenkins MM, Almli LM, Moore C, Werler M, Browne ML, Cunniff C, Olshan AF, Pangilinan F, **Brody LC,** Sicko RJ, Finnell RH, Bamshad MJ, McGoldrick D, Nickerson DA, Mullikin JC, **Romitti PA†, Mills JL†** UW Center for Mendelian Genomics, NISC Comparative Sequencing Program and the NBDPS. (2022) Exome sequencing identifies variants in infants with sacral agenesis. †co-senior authors Birth Defects Res 114:215-227.

Rashkin S, Cleves M, Shaw G, Nembhard W, Nestoridi E, Jenkins M, **Romitti P,** Lou X, Browne M, Mitchell L, Olshan A, Lomangino K, Bhattacharyya S, Witte J, Hobbs C. (2022) A genome-wide association study of obstructive heart defects among participants in the NBDPS. Am J Med Genet A 188:2303-2314.

Siegel MR, Rocheleau CM, Broadwater K, Santiago-Colón A, Johnson CY, Herdt ML, Chen IC, Lawson CC, NBDPS. (2022) Maternal occupation as a nail technician or hairdresser during pregnancy and birth defects, NBDPS, 1997-2011. Occup Environ Med 79:17-23.

Simeone RM, Reefhuis J, Jamieson DJ, Drews-Botsch CD, Lash TL, Fisher SC, Howley MM, Evans S, Howards PP, NBDPS. (2022) Delayed entry into prenatal care among women with pre-pregnancy health conditions, NBDPS, 1997-2011. Prev Med 164:107272.

Simmons W, Stingone JA, Luben TJ, Sheridan SC, Langlois PH, Shaw GM, Reefhuis J, **Romitti PA,** Feldkamp ML, Nembhard WN, Desrosiers TA, Browne ML, Lin S, and the NBDPS. (2022) Modeling complex effects of exposure to particulate matter and extreme heat during pregnancy on congenital heart defects. Sci Total Environ 808:152150.

Suhl J, Conway KM, Rhoads A, Langlois PH, Feldkamp ML, Michalski AM, **Oleson J, Sidhu A, Kancherla V,** Obrycki J, Mazumdar M, **Romitti PA,** and the NBDPS. (2022) Pre-pregnancy exposure to arsenic in diet and non-cardiac birth defects. Public Health Nutr 27:1-13.

Wong EC, Fisher SC, Feldkamp ML, **Romitti PA**, Nestoridi E, Jenkins MM, Desrosiers TA. (2022) Factors associated with maternal consent for use of residual newborn bloodspots in the NBDPS. Birth Defects Res 114:238-248.

Zaganjor I, Keil AP, Luben TJ, Desrosiers TA, Engel LS, Reefhuis J, Michalski AM, Langlois PH, Olshan AF, NBDPS. (2022) Is maternal employment site a source of exposure misclassification in studies of environmental exposures and birth outcomes? A simulation-based bias analysis of haloacetic acids in tap water and hypospadias. Environ Epidemiol 6:e207.

Surveillance for Muscular Dystrophy

Muscular dystrophies (MDs) are a group of genetic progressive muscle diseases affecting an estimated 33 per 100,000 individuals and are characterized by worsening muscle weakness. Historically, types of MDs were diagnosed by known changes in muscle and clinical presentation; presently, diagnosis is determined largely by genetic analysis. Ages at symptom onset of MDs can range from birth through late adulthood. In children, Duchenne is the most common childhood MD, followed by congenital MDs. In adults, myotonic dystrophy is the most common MD, followed by facioscapulohumeral MD.

Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet)

MD STAR*net* is a surveillance program currently active in seven states (Florida, Iowa, New York, North Carolina, South Carolina, Utah, Virginia) and funded by CDC. The goals of MD STAR*net* are to define and describe the MD population in the US, define and describe healthcare needs and outcomes for

individuals living with MD, and collect information to guide MD care, treatment, and policy. On behalf of MD STAR*net*, IRCID conducts surveillance of Iowans who have been diagnosed with one of eight MDs and meet residence, diagnostic, and treatment period criteria (Table 2). Our surveillance consists of identification and ongoing medical chart review to identify individuals with at least one eligible MD diagnostic code (International Classification of Disease [ICD], ICD-9, ICD-10). The table below summarizes the number of Iowa individuals identified for MD STAR*net,* followed by MD STARnet projects published in 2022. Bolded names refer to Iowa investigators.

Table 2. Number of individuals identified with a muscular dystrophy among Iowa residents

Phase of Surveillance/Muscular Dystrophy	Total
Phase I*	
Duchenne or Becker	140
Phase II†	
Becker	52
Congenital	24
Distal	5
Duchenne	105
Emery-Dreifuss	12
Facioscapulohumeral	81
Limb-Girdle	66
Myotonic	253
Oculopharyngeal	17
Phases III and IV	
Becker‡	30
Congenital^	35
Distal^	8
Duchenne‡	79
Emery-Dreifuss^	20
Facioscapulohumeral^	131
Limb-Girdle^	142
Myotonic^	419
Oculopharyngeal§	37

*Resident individual with MD diagnosis born on or after January 1, 1982 through December 31, 2011 who lived in Arizona, Colorado, Georgia, Hawaii, Iowa, or western New York.

†Resident individual with MD diagnosis and health encounter from January 1, 2007 through December 31, 2011 who lived in Arizona, Colorado, Iowa, or western New York.

‡Phase III: Resident individual with MD diagnosis born on or after January 1, 2000 and health encounter from January 1, 2000 through December 31, 2015 who lived in Colorado, Iowa, western New York, North Carolina, South Carolina, or Utah.
Phase IV: Resident individual with MD diagnosis born on or after January 1, 2000 and health encounter from January 1, 2000 through December 31, 2020 who lived in Florida, Iowa, western New York, North Carolina, South Carolina, Utah, or Virginia.

^Phase III: Resident individual with MD diagnosis since January 1, 2008 and health encounter from January 1, 2008 through December 31, 2016 who lived in Colorado, Iowa, western New York, North Carolina, South Carolina, or Utah.
Phase IV: Resident individual with MD diagnosis and health encounter from January 1, 2008 through December 31, 2020 who lived in Florida, Iowa, western New York, North Carolina, South Carolina, Utah, or Virginia.

§Phase III: Resident individual with MD diagnosis and health encounter from January 1, 2006 through December 31, 2016 who lived in Colorado, Iowa, western New York, North Carolina, South Carolina, or Utah.

Iowa MD STAR*net* Project Spotlight

Scoliosis is a common comorbidity among individuals diagnosed with a dystrophinopathy. We examined relationships between scoliosis and clinical predictors and treatment. Approximately 25% of individuals had a curvature of at least 20°, the clinical definition of scoliosis. Maintenance of independent ambulation and corticosteroids was associated with lower risk of scoliosis. Additionally, scoliosis was less frequent among individuals who continued corticosteroids after loss of independent ambulation compared to those who stopped treatment. The frequency of scoliosis surgery among individuals who lost independent ambulation and who did not use corticosteroids was more than double compared to those who used corticosteroids. Our study showed that corticosteroids may delay spinal curvature progression and need for scoliosis surgery. Continuing corticosteroids after loss of ambulation also showed potential benefits of delaying curvature progression.

Conway KM, Gedlinske A, Mathews KD, Perlman S, Johnson N, Butterfield R, Hungg M, Bounsangah J, Matthews D, Oleszeki J, **Romitti PA**. (2022) A population-based study of scoliosis among males diagnosed with a dystrophinopathy identified by the Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet). Muscle Nerve 65:193-202.

Andrews JG, Lamb MM, **Conway KM,** Street N, Westfield C, Ciafaloni E, Matthews D, Pandya S; MD STARnet. (2022) Differentiation of pediatric-onset Duchenne and Becker muscular dystrophy subphenotypes using data from the Muscular Dystrophy Surveillance Tracking and Research Network (MD STAR*net*). J Neuromuscul Dis 9:171-178.

Butterfield RJ, Krikov S, **Conway KM,** Johnson N, Matthews D, Phan H, Cai B, Paramsothy P, Thomas S, Feldkamp ML. (2022) Evaluation of effects of continued corticosteroid treatment on cardiac and pulmonary function in non-ambulatory males with Duchenne Muscular Dystrophy from MD STAR*net*. Muscle Nerve 66:15-23.

Conway K, Grosse S, Ouyang, L, Street N, **Romitti PA**. (2022) Direct costs of adhering to selected Duchenne muscular dystrophy Care Considerations: Estimates from a midwestern state. Muscle Nerve 65:574-580.

Paramsothy P, Wang Y, Cai, B, Conway KM, Johnson NE, Pandya S, Ciafaloni E, Mathews KD, **Romitti PA**, Howard JF Jr, Riley C. (2022) Selected clinical and demographic factors and all-cause mortality among individuals with Duchenne muscular dystrophy in the MD STAR*net*. Neuromuscul Disord 32:468-476.

Peay HL, Do BT, Khosla N, Paramsothy P, Erickson SW, Lamb MM, Whitehead N, Fox DJ, Pandya S, Kinnett K, Wolff J, Howard JF. (2022) Role attainment in emerging adulthood: subjective evaluation by male adolescents and adults with Duchenne and Becker muscular dystrophy. J Neuromuscul Dis 9:447-456.

Thomas S, **Conway K,** Fapo O, Street N, **Mathews KD,** Mann JR, **Romitti PA,** Soim A, Westfield C, Fox DJ, Ciafaloni E, and the Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STAR*net*). (2022) Diagnosis of Duchenne muscular dystrophy continues to be delayed: Findings from the Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STAR*net*), 2000-2015. Muscle Nerve 66:193-197.

Surveillance for Emerging Threats to Mothers and Babies Network (SET-NET)

SET-NET aims to understand effects of emerging and reemerging threats on pregnant people and their infants. To accomplish this, surveillance programs participating in SET-NET work to detect the effects of these threats by collecting data from pregnancy through childhood and use these data to inform clinical decision-making and public health action. IRCID participated in national projects led by CDC.

Microcephaly and Other Birth Defects Related to Zika Virus Exposure

Congenital microcephaly (MC) is a serious birth defect characterized by an abnormally small head size in affected infants compared to infants of the same sex and gestational age. A dramatic increase in MC in infants in Brazil was linked to pregnant people infected with Zika virus. Zika virus exposure poses a serious risk to an unborn fetus; thus, more timely surveillance is needed for monitoring MC and other birth defects that may be related to Zika virus exposure among pregnant people. To conduct this surveillance, IRCID created a rapid response team comprised of experienced surveillance professionals.

Outcomes Related to SARS-CoV-2 infection among Pregnant People

In 2021, IRCID joined the CDC SET-NET to study outcomes for pregnant people infected by the SARS-CoV-2 virus and their offspring. The initial focus of this work is to conduct statewide surveillance of birth outcomes among pregnant people with a laboratory-confirmed SARS-CoV-2 infection in 2020. To date, IRCID has identified more than 3,000 deliveries among pregnant people in Iowa with SARS-CoV-2 infection during pregnancy.

2022 SET-NET Publications Using IRCID Data (Bolded names refer to Iowa investigators)

Delaney A, Olson SM, Roth N, Cragan JD, Godfred-Cato S, Smoots AN, Fornoff J, Nestoridi E, Eckert V, Forkner A, Stolz A, Crawford K, Cho SJ, Elmore A, Langlois P, Nance A, Denson L, Forestieri N, Leedom VO, Tran T, Valencia-Prado M, **Romitti P**, Barton JE, St. John K, Mann S, Orantes L, DeWilde L, Tong VT, Gilboa SM, Moore CA, Honein MA. (2022) Prevalence of individual brain and eye defects potentially related to Zika virus in pregnancy in 22 U.S. states and territories, January 2016 - June 2017. Birth Defects Res 114:805-811.

Neelam V, Reeves E, Woodworth K, O'Malley Olsen E, Reynolds M, Rende J, Wingate H, Manning S, **Romitti P,** Ojo K, Silcox K, Barton J, Mobley E, Longcore N, Sokale A, Lush M, Delgado-Lopez C, Diedhiou A, Mbotha D, Simon W, Reynolds B, Hamdan TS, Beauregard S, Ellis E, Seo J, Bennett A, Ellington S, Hall AJ, Azziz-Baumgartner E, Tong V, Gilboa S. (2022) Pregnancy and infant outcomes by trimester of SARS-CoV-2 infection in pregnancy – SET-NET, 22 jurisdictions, 12/25/2020-12/31/2020. Birth Defects Res 115:145-159.

Newton SM, Reeves EL, O'Malley Olsen E, Woodworth KR, Farr SL, Galang RR, Reynolds MR, Harvey E, Shi J, Nestoridi E, Barton J, Ngo VP, Lush M, Longcore ND, Dzimira P, Im LK, Sokale A, Siebman S, Delgado López C, Chen T, Mobley EL, Khuwaja S, **Romitti PA,** Fredette C, Ellis EM, Silcox K, Hall AJ, Azziz-Baumgartner E, Gilboa SM, Shapiro-Mendoza CK, Tong VT. (2022) Preterm birth among pregnant persons with severe acute respiratory syndrome Coronavirus 2 infection. J Perinatol. 42:1328-1337.

Roth NM, Reynolds MR, Lewis EL, Woodworth KR, Godfred-Cato A, Delaney A, Akosa A, Valencia-Prado M, Lash M, Elmore A, Langlois P, Khuwaja S, Tufa A, Ellis EM, Nestoridi E, Lyu C, Longcore ND, Piccardi M, Lind L, Starr S, Johnson L, Browne SE, Gosciminski M, Velasco PE, Johnson-Clarke F, Locklear A, Chan M, Fornoff J, Toews KAE, Tonzel J, Marzec NS, Hale S, Nance AE, Willabus T, Contreras D, Adibhatla SN, Iguchi L, Potts E, Schiffman E, Lolley K, Stricklin B, Ludwig E, Garstang H, Marx M, Ferrell E, Moreno-Gorrin C, Signs K, **Romitti P**, Leedom V, Martin B, Castrodale L, Cook A, Fredette C, Denson L, Conquist L, Nahabedian JF III, Shinde N, Polen K, Gilboa SM, Martin SW, Cragan JD, Meaney-Delman D, Honein MA, Tong VT, Moore CA. (2022) Zika-associated birth defects reported in pregnancies with laboratory evidence of confirmed or possible Zika virus infection — U.S. Zika Pregnancy and Infant Registry, December 1, 2015–March 31, 2018. MMWR Morb Mortal Wkly Rep 71:73-79.

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