## **The Texas Birth Defects MONITOR**

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# Evaluating the Extent of Folic Acid Fortification of Corn Masa Products in Texas

Neural tube defects (NTDs) are serious birth defects of the brain and spine that occur early during a pregnancy.<sup>1</sup> The most common types of NTDs are spina bifida (a spine defect) and anencephaly (a brain defect).<sup>1</sup> Folic acid is a B vitamin that helps form the neural tube during pregnancy. If a woman consumes enough folic acid from foods and or vitamins before and during early pregnancy, it can help prevent most cases of spina bifida and anencephaly.<sup>1</sup> This is why the US Centers for Disease Control and Prevention (CDC) recommends that all women of reproductive age get 400 micrograms of folic acid every day.<sup>1</sup>

To ensure more women receive enough folic acid, in 1998 the U.S. Food and Drug Administration (FDA) required that manufacturers add folic acid to cereal grain products that are labeled "enriched".<sup>2</sup> This includes food items such as bread, pasta, rice, and cereal.<sup>2</sup> However, the 1998 mandate did not require fortification of corn masa flour. Corn masa flour is often used to make tortillas and other staple items in the diets of many Hispanic women. Hispanic women in the U.S. have a higher risk of having a neural tube defect-affected pregnancy than women of other races/ethnicities.<sup>3,4</sup> To address this disparity, in 2016 the FDA allowed voluntary fortification of corn masa flour.<sup>2</sup> In order to assess the extent to which the voluntary corn masa fortification is being implemented in Texas, the Birth Defects Epidemiology and Surveillance Branch (BDES) designed a 2-part project to survey establishments selling products made from corn masa flour in December 2019.

The first part of the project involved in-person visits to various grocery stores in El Paso and Brownsville, Texas. These two cities were selected because according to the U.S Census Bureau, over 80% of individuals residing there identify as Hispanic. A total of 33 establishments, which included grocery stores, factories, bakeries, and wholesalers were visited in El Paso and 4 grocery stores in Brownsville. Nutrition labels of a variety of tortilla and masa products at each store were examined. Inconsistencies were found in folic acid content between the same brands at the same stores, and at different stores. Very few products at the wholesale or retail level were fortified with folic acid and there were inconsistencies in labeling for products with similar packaging.

In the second part of the project, BDES conducted short phone interviews with employees from tortilla factories, restaurants, and stores selling tortillas in urban areas throughout Texas. BDES attempted to contact a total of 53 establishments that sold tortillas and interviewed employees from 15 locations. The locations reached were in Houston (11), San Antonio (2), and Austin (2). Among the 15 stores reached, 11 confirmed that they made their own corn tortillas in the store. We found that among the stores who ground their own corn to make tortillas, folic acid was not reported to have been added during the process. Among the five stores using pre-made masa, only two stores used pre-made corn masa containing folic acid. Of the 15 employees surveyed, 60% stated they were familiar with folic acid, and only 20% stated they were willing to add folic acid to their masa.

Method of Making Tortillas Among Stores Reached for Phone Interviews	Count	Percent
Grind corn	4	36%
Use pre-made masa	5	45%
Both grind corn and use pre-made masa	2	18%
Total	11	. 100%
Addition of Folic Acid to Ground Corn Used to Make Tortillas	Count	Percent
Add folic acid to ground corn	0	0%
Do NOT add folic acid to ground corn	6	100%
Total	6	100%
Folic Acid in Pre-Made Masa Used to Make Tortillas	Count	Percent
Pre-Made masa contains folic acid	2	29%
Pre-Made masa does NOT contain folic acid	3	43%
Unsure/no reponse	2	29%
Total	7	100%



Percentage of Employees Willing to Add Folic Acid to their Corn Masa



Consuming enough folic acid has been shown to decrease the likelihood of having an NTD-affected pregnancy<sup>1</sup>. The FDA does not currently mandate the fortification of corn masa – a staple in the diets of many Hispanic women. BDES reviewed corn masa products in person and conducted interviews with tortilla sellers to assess folic acid in corn masa products in large cities with a high population of Hispanics in Texas. Despite FDA's voluntary fortification policy, none of the tortilla sellers interviewed reported adding folic acid to their products but several employees previously heard about folic acid and were aware of some of its benefits. Among the stores visited in-person, fortification with folic acid was inconsistent and highly variable. Fortification of corn masa with folic acid to prevent NTDs in Hispanics living in Texas appears to be minimal.

Acknowledgments: Vijaya Kancherla, PhD

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## **30-Year Milestone: Landmark Article on Folic Acid and the** Prevention of Recurrent Neural Tube Defects



In 2021, we observed an important 30-year anniversary of preventing serious birth defects of the spine and brain. In 1991, the Medical Research Council (MRC) Vitamin Study<sup>1</sup> showed that women who had a prior pregnancy diagnosed with a neural tube defect (NTD) could greatly reduce their risk in a future pregnancy by taking a daily dose of folic acid before becoming pregnant and during early pregnancy.

Folic acid is a B-vitamin that is necessary for proper cell growth. If taken before and during early pregnancy, folic acid can prevent up to 70% of these serious birth defects. All women who are of childbearing age should take 400 micrograms of folic acid daily to ensure they have enough in their system to reduce the risk of an NTD should they become pregnant. Women who have a prior pregnancy affected by an NTD should take ten times that amount (4.0 milligrams or 4,000 micrograms) of folic acid daily, starting at least one month before becoming pregnant.

1) Prevention of neural tube defects: results of the Medical Research Council Vitamin Study. MRC Vitamin Study Research Group. Lancet. 1991 Jul 20;338(8760):131-7. PMID: 1677062.

## **CDC-Supported Surveillance Activities**

In 2016, the Texas Birth Defects Epidemiology and Surveillance Branch (BDES) was awarded a four-year Centers for Disease Control and Prevention (CDC)-funded surveillance and data utilization cooperative agreement (i.e., "grant"). This grant focused on four general categories: evaluation of case ascertainment in the Texas Birth Defects Registry (TBDR); acquisition and evaluation of Texas Medicaid data to assess patterns of Medicaid enrollment and outcomes of children with birth defects; various outreach activities to affected families; and initiatives focused on improving program reach. Significant accomplishments resulted from the grant, and the collaboration between grant-supported and existing staff, agency partners, and grant-supported contracts with academic partners.

TBDR case ascertainment completeness was evaluated using databases for hospital inpatient discharges and outpatient visits. An award-winning poster on a "capture-recapture" topic was presented at the 2018 annual meeting of the National Birth Defects Prevention Network (NBDPN). By the second year of the grant, Medicaid data were acquired for the first time from another state agency, Health and Human Services. The purpose of this project was to better understand the extent, patterns, and predictors for Medicaid enrollment of children with birth defects who are linked to the Registry, and to explore co-morbidities and developmental outcomes identified within and outside inpatient hospitalizations for microcephaly and critical congenital heart defects.

In a third component of the CDC cooperative agreement, TBDR staff and colleagues carried out family outreach activities in which contact is made with families of children identified with specific birth defects in the TBDR. One activity is a prevention initiative targeted at preventing of neural tube defects, or NTDs. Mothers with recent deliveries affected by an NTD (anencephaly, spina bifida, or encephalocele) receive a packet (English and Spanish) that informs them of their increased risk in subsequent pregnancies and that folic acid can help prevent NTDs. Interviews later conducted with these mothers helped to evaluate this prevention effort, which has continued.

In another initiative that involved an important new partnership with the program, agency social workers contact mothers to identify needs and find services for families with young children living with spina bifida, encephalocele, orofacial clefts, Down syndrome, and critical congenital heart defects. TBDR used the data gathered by social workers to identify the utilization of and barriers to services. Since April 2019, social workers have reached 836 children with the selected birth defects and their families and made almost 3,000 referrals to programs for these families. The number of cases referred by defect, are shown in the figure on the next page. The programs with the most referrals made include Texas Parent to Parent (578 referrals), Medicaid Waiver Program (328 referrals), and Children with Special Healthcare Needs (CSHCN) (312 referrals).



\*The branch began referring children with CCHDs to social work more recently (May 2021) than other birth defects shown. Note: The birth defect diagnosis of a child may have changed since being referred to social work because the registry is continuously updated.

In 2021, as the grant was ending, the Birth Defects and Epidemiology Surveillance Branch was awarded a new 5-year cooperative agreement from CDC for enhanced surveillance. The goals of the new grant are to strengthen surveillance of birth defects, improve the quality of birth defects surveillance data, increase contribution of multi-state data in scientific understanding of birth defects epidemiology, increase knowledge of the prevention of birth defects, and increase the ability to rapidly respond to emerging threats to mothers and babies, and increase the ability to support the primary and secondary prevention of birth defects.

## **Birth Defect Investigations in Texas: The First 25 Years**

From 1994 to 2020, program staff conducted and completed 127 birth defect investigations in Texas. Most requests to conduct investigations came from health care providers (36%) or public health staff (33%), followed by requests from families (16%), residents (13%), and the media (2%). The figure below shows the types of birth defects investigated by the Registry during this time.



These types of investigations provide an important tool for identifying if possible increases in birth defects in an area have occurred and, if so, if there is a possible exposure that can be linked. This provides many benefits, such as potentially identifying exposures that can affect pregnancy, providing a public health service by investigating public concerns, alleviating potential concerns if found to have occurred by chance, and other benefits.

## **Connecting Children with Spina Bifida and Encephalocele to** Health and Social Services

Spina Bifida and encephalocele are severe birth defects of the brain and spine known as neural tube defects (NTDs). NTDs occur when the neural tube, which forms the brain and spine, does not close properly during early pregnancy. The Birth Defects Epidemiology and Surveillance Branch

(BDES) refers 9- to 18-month old children with selected birth defects, including spina bifida and encephalocele, to regional social workers from Specialized Health and Social Services (SHSS). SHSS social workers assist families in accessing health and social service programs. In addition to connecting children and their families to valuable programs, social workers also assess the healthcare needs and challenges these families face.



Since April 2019, social workers reported reaching 67% (92/138) of the children with spina bifida or encephalocele referred by BDES. An additional 7% (9/138) of families were also reached but declined services or a data collection form was not fully completed.

Among the 92 children reached, 81 had spina bifida and 11 had encephalocele.



When asked when their child was diagnosed with spina bifida or encephalocele, 62% (57/92) of families indicated their child was diagnosed during the mother's pregnancy, followed by 27% (25/92) at birth or delivery, and 9% (8/92) after delivery/discharge from the delivery facility. One family indicated they did not know or remember when their child was diagnosed, and another family indicated their child was misdiagnosed or did not have a birth defect.

Social workers referred families to various types of health and social service programs including medical, financial, developmental, educational and family support programs. A total of 334 referrals were made among the 92 families. The individual programs to which the greatest number of referrals made were made included: Texas Parent to Parent (64 referrals), Medicaid Waiver Program (35 referrals), and Children with Special Healthcare Needs (CSHCN) (33 referrals). When asked about the services they were already accessing, the most accessed programs included: a pediatrician (97%), specialty care (85%) and a physical, speech, and/or occupational therapist (66%). For the Early Childhood Intervention Program (ECI), 49% of families reported already accessing ECI, 22% (20/92) of families were referred to ECI, and 28% (26/92) indicated ECI was not applicable to their child.

SHSS social workers also assessed whether the child was meeting the CDC developmental milestones (i.e. keeping up physically or with their learning) for their age group. Among the 92

families reached, 59% reported that their child was not meeting CDC milestones for their age group. Recently, social workers began assessing if the family has been informed by a healthcare provider that their child is not meeting CDC milestones. Among the 23 families that have responded to this new question so far, 70% indicated they were informed by a healthcare provider that their child is not meeting CDC developmental milestones.

When families were asked about the barriers they face, 61% of the 92 families reported they were not experiencing any barriers at this time. Among the 36 families who reported one or more barriers, the most common barriers were: finances (44% - 16/36), issues navigating services (22% - 8/36) and other/free response answers (22% - 7/32). Some of the free response answers cited by families included restrictions due to Covid-19, lack of social support, and limited resources.



Social workers offered families ongoing case management. Of the 92 families, 26% requested ongoing case management. BDES plans to continue referring children from the birth defects registry to SHSS social workers to ensure these children have access to the programs and services they need.

For more information on this family outreach initiative, visit <u>dshs.texas.gov/birthdefects/Spina-Bifida-and-Encephalocele.pdf</u>.

### January is National Birth Defects Awareness Month

This January, National Birth Defects Awareness Month focuses on 'Awareness of Birth Defects Across the Lifespan'. Birth defects affect people in each phase of life: before and during pregnancy, during infancy, childhood, adolescence, and adulthood.

- There are steps women can take to reduce the risk of birth defects before and during pregnancy. Taking at least 400 micrograms of folic acid every day, preventing infections, visiting the doctor regularly, avoiding harmful substances such as alcohol and tobacco, and managing conditions such as obesity and diabetes, are all some ways that help reduce birth defect risk.
- Birth defects are leading cause of death among infants in the United States. Improvements in care and screening are important during infancy. Newborn screening for congenital heart defects, for example, is an important tool to identify and provide treatment quickly.
- Some research shows that children born with certain birth defects have difficulty with learning or keeping up with developmental milestones. Access to resources such as Early Childhood Intervention and services such as physical therapy and special education can positively impact the development of a child born with birth defects.
- In adolescence, individuals with certain conditions face new challenges while transitioning from childhood to adulthood, such as changes in insurance and doctors. Some may begin making their own healthcare decisions. Recognizing and planning for these changes can improve the transition to adult health care.
- Birth defects affect individuals in adulthood in many ways. People living with birth defects should talk with their doctor about how pregnancy may affect them and their baby. Women who have had a previous pregnancy affected by a neural tube defect are increased risk for a subsequent NTD-affected pregnancy. To learn about genetic risks of having a baby with a birth defect, individuals can talk with a genetic counselor or clinical geneticist.

Visit <u>cdc.gov/ncbddd/birthdefects/awareness-month/index.html</u> to learn more about National Birth Defects Awareness month.

Content source: National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention



March 3 is World Birth Defects Day. Join us in our effort to raise awareness of birth defects, their causes, and their impact around the world!

#### **Recent Publications from BDES Staff and Collaborators**

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### Calendar 2022

#### January:

National Birth Defects **Prevention Month** February: American Heart Month **February:** International Prenatal Infection Prevention Month February 14: **Congenital Heart Defect** Awareness Day Spring 2021: March of Dimes March for Babies (check with MOD for specific dates and locations) March: National Nutrition Month March: National Developmental **Disabilities Awareness** Month March 3: World Birth Defects Day April: Alcohol Awareness Month April: National Autism Awareness Month April: National Minority Health Month April: STD Awareness Month

#### **April 4-10:**

National Public Health Week June: National Congenital Cytomegalovirus Awareness Month June 13-14: 35nd Annual Meeting of the Society for Pediatric and Perinatal Epidemiologic Research, Chicago, IL June 25-29: 62st Annual Meeting for the Society for Birth Defects Research and Prevention, Vancouver, BC July: National Cleft and Craniofacial Awareness & **Prevention Month** July 30: Gastroschisis Awareness Day September: **Newborn Screening** Awareness Month September: National Infant Mortality Awareness Month September 11-17: Folic Acid Awareness Week **October:** National Spina Bifida Awareness Month

#### **October:**

National Down Syndrome Awareness Month October: 48<sup>th</sup> Annual Meeting of the

International

Clearinghouse for Birth Defects Surveillance and **Research** (meeting dates pending)

#### November:

Prematurity Awareness Month (March of Dimes) November:

Prematurity Awareness Month (March of Dimes)

## **About the Monitor**

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Please visit the BDES website for updated information and to sign up for Branch updates: <u>dshs.texas.gov/birthdefects/</u>.

Requests for copies or back issues may be made to: **birthdefects@dshs.texas.gov**.

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