

The Texas Birth Defects Monitor



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June 1999

From the Director

Mark your calendars!

On January 21, 2000, professionals and concerned citizens from around the state will gather in Houston to share information about birth defects in Texas—the latest in research, prevention, identification, treatment, and advocacy. The Texas Birth Defects Conference 2000 is sponsored by the Texas Birth Defects Monitoring Division and is scheduled for January 21-22, 2000, in Houston at the Crowne Plaza Hotel. A Friday—Saturday agenda has been planned to enable family and other community members to attend sessions on Saturday.

Other sponsors include representatives from the Scientific Advisory Committee on Birth Defects in Texas, the Texas Birth Defects Research Center, Texas Department of Health Region 6/5 South, the Texas Neural Tube Defect Project, TEXTGENE, March of Dimes, Spina Bifida Association, Texas Association of Obstetrics and Gynecology, the University of Texas School of Public Health, Texas A & M School of Rural Public Health, the Texas Medical Association, Texas Association of Local Health Officers, City of Houston Health Department, and the Harris County Health Department (Houston area).

The purpose of this conference is to translate birth defects “science into action” by ensuring that Texas professionals of all disciplines who may be in contact with parents, women of childbearing age, or children and families affected by birth defects are aware of current research and clinical advances in the prevention and treatment of birth defects.

Conference offerings are being selected to meet

four broad objectives:

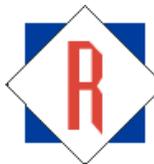
- Provide up-to-date information about the patterns and prevalence of birth defects in Texas.
- Present recent research results regarding the causes and prevention of birth defects and suggestions for incorporating this information into improvements in practice.
- Present an overview of specific programs, initiatives, and tools to enhance the care and treatment of children with birth defects and their families.
- Bring together and to foster networking among people who have a professional or personal interest in birth defects.

There are still one or two times open for additional topics! If you would like to propose a topic and/or speaker, please contact me as soon as possible at 512-458-7232, or E-mail mark.canfield@tdh.state.tx.us.

I would like to extend a personal invitation to this conference on behalf of the Texas Birth Defects Monitoring Division and the Conference Planning Committee. To receive more information, please contact Amy Case, Information Specialist, at 512-458-7232.

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Registry Update

1998 Cluster Investigations

In 1998, Texas Birth Defects Monitoring Division (TBDMD) epidemiologists conducted 16 investigations of birth defect clusters. Of nine investigations initiated in previous years, three were concluded in 1998. Six of the seven investigations begun in 1998 were still ongoing at the end of the year.

Nearly one-third of the reports investigated concerned neural tube defects (NTDs), and approximately 19% of all reports (three reports) investigated in 1998 concerned oral clefts.

Reports of clusters come from health care professionals, parents, and others in the community concerned about apparently unusual concentrations of birth defects. Birth defect investigations are then initiated to determine if these reported birth defects represent a rate that is higher than expected for a given area.

To obtain a copy of the 1998 Cluster Investigation Report, call Amy Case at 512-458-7232.



professionals throughout the state.

The following is a summary of studies coordinated by the Texas Birth Defects Research Center, listed with their respective partner agencies:

- The National Birth Defects Prevention Study—CDC, other state birth defects research centers
- Study of Hispanic Origin, Maternal Obesity, and Disorders of the Central Nervous System—University of Texas at Houston, School of Public Health (UTHSPH), University of Nebraska, Texas A&M University (TAMU)
- Drinking Water Disinfectant Byproducts Study—CDC, U.S. Environmental Protection Agency
- Supplemental funding of components of the Texas Neural Tube Defect Surveillance and Intervention Project, Texas Department of Health
- Extent and Impact of Prenatal Diagnosis in the Two Pilot Regions of the Texas Birth Defects Registry—UTHSPH
- Texas Women's Health Survey—(TAMU)
- Blood Folate Level Survey of Nonpregnant Texas Women—University Medical and Dental Schools of New Jersey
- Neural Tube Defect Recurrence Prevention Study—University of Texas Health Science Center of San Antonio
- Neural Tube Defect Occurrence Prevention Study (Provider Education)—UTHSPH
- Patterns of Infant Mortality Among Cases in the Texas Birth Defects Registry—UTHSPH



Research Center

Birth Defects Research—A Collaborative Effort

Since October 1996, the Centers for Disease Control and Prevention (CDC) has maintained a cooperative agreement with the Texas Department of Health to enhance population-based research and evaluation of birth defects in Texas. This agreement created the Texas Birth Defects Research Center (TBDRC), one of eight such Centers of Birth Defects Research and Prevention in the nation. An essential component of studies sponsored through the TBDRC is collaboration with academic and medical research



FAS Corner

Screening for Alcohol Use during Pregnancy

Alcohol consumption during pregnancy can cause fetal alcohol syndrome (FAS) and other alcohol related birth defects. An important step in preventing FAS is identifying women at risk for alcohol abuse. Tests for alcohol in blood, urine or on the breath only detect very recent consumption. The most reliable method to evaluate alcohol consumption is by using an alcohol screening tool. Screening tools are short questionnaires, usually four or five questions long, designed to identify women who are at risk of alcohol

or other substance abuse.

An excellent report by Barbara Morse, Shelly Gehshan and Ellen Hutchins entitled "Screening for Substance Abuse during Pregnancy: Improving Care, Improving Health," was produced by the National Center for Education in Maternal and Child Health, in cooperation with the Maternal and Child Health Bureau of the U.S. Public Health Service. The report includes five alcohol screening tools and discusses the benefits of screening; the role of health care providers in detecting and reducing substance abuse during pregnancy; how to ask screening questions and how to respond; and referral sources for further assessment or substance abuse treatment.

Morse and colleagues recommend that health care providers incorporate alcohol screening questions into routine prenatal care, just as screening for diabetes has become a routine part of prenatal care. Because screening for alcohol use takes only a few minutes and because half of all pregnancies in this country are unplanned, we encourage health care providers to consider screening all female patients capable of becoming pregnant. Asking even non-pregnant patients about alcohol use provides an opportunity to educate women on the risks of alcohol use during pregnancy and the benefits of stopping before they become pregnant or as soon as they suspect they may be pregnant.

"Screening for Substance Abuse during Pregnancy: Improving Care, Improving Health" is available on the Internet at <http://www.nmchc.org/html/fulltext.htm>. If you are not able to access this document on the web or would prefer to receive a paper copy, contact Mary Ethen, Texas Birth Defects Monitoring Division, at (512) 458-7232 or by email at mary.ethen@tdh.state.tx.us.

Citation: Morse B, Gehshan S, Hutchins E.

1997. Screening for Substance Abuse During Pregnancy: Improving Care, Improving Health. Arlington, VA: National Center for Education in Maternal and Child Health.



iving with Birth Defects

CHIPS Update

On May 28, 1999, Governor Bush signed into law Senate Bill 445, the Children's Health Insurance Program (CHIP). This bill authorizes state agencies to develop a program to provide comprehensive health insurance to children from low-income families. The program will have the following features:

- Ö If the family of a child aged birth to 18 has an income less than 200% of the federal poverty level (\$33,400 for a family of four), he or she could be eligible for CHIP.
- Ö Parents will pay some of the costs of enrollment, office visits, and prescriptions.
- Ö Children of legal immigrants are covered.
- Ö There will be a waiting period for children previously covered under a private plan.
- Ö Children who can qualify for Medicaid will not be eligible for CHIP.
- Ö CHIP coverage will be available by mid-2000.

Families who need coverage for their children before CHIP becomes available can contact the Texas Health Kids Corporation at 1-800-943-5437 or the Medicaid Hotline at 1-800-252-8263.

We're On-Line!

Be sure to visit our home page at <http://www.tdh.texas.gov/tbdmd/index.htm>. Current and past TBDMD publications, slide shows, related links and more!





Prevention Notes

Texas Folic Acid Council

The Texas Folic Acid Council (TFAC), a collaboration between several TDH programs, professional groups, and nonprofit health agencies concerned with the prevention of birth defects through the use of folic acid, was established in February 1999 in response to a charge from the National Office of the March of Dimes.

The TFAC immediately leapt into action, planning several events for May 1999 with Laura Bush, First Lady of Texas, serving as honorary spokesperson for the Texas Folic Acid Campaign. In this role, she appeared at the following events: a May 3 kick-off breakfast on the Capitol grounds; a May 13 Laredo Community Forum focusing on current projects in the Lower Grande Valley to prevent neural tube defects through the use of folic acid; and a May 18 tour of the Texas Birth Defects Research Lab at Texas A & M University.

Future events promoting the use of folic acid by Texas women of childbearing potential are now in the planning phase. For more information about TFAC, contact Jennifer Lee at 512-477-3221.

Folic Acid Fortification Studies Inconclusive

A study published in the May 13 issue of The New England Journal of Medicine and subsequently reported by the Associated Press (AP) indicated that folic acid fortification of grain products had virtually eliminated folic acid deficiency in the U.S.

Disputing the AP report, the March of Dimes

Birth Defects Foundation issued a news release stating that there is not sufficient evidence for a claim that deficiency of the B vitamin folic acid "has all but vanished in the United States" as a result of food fortification.

"The FDA set standards for fortification of various grain products with folic acid in order to prevent certain severe birth defects of the brain and spinal cord," said March of Dimes medical director Donald Mattison, MD. "To succeed, this strategy must raise blood levels of the vitamin among women of childbearing age — and raise them enough to have a strong preventive effect against birth defects. As yet, there is no direct evidence that women in the 15 to 40 year age range have generally attained protective blood levels of folic acid."

The AP report was based on a study of 350 middle aged and older men and women showed that since folic acid fortification began in 1997, blood levels of the vitamin had doubled, and very few individuals had levels below the cutoff point commonly used to define deficiency.

"These findings are very encouraging," Dr. Mattison said. "But because the study focused on people whose average age was well above the usual childbearing years, it falls short of the kind of study that's now urgently needed to show how much fortification will have optimal effect in preventing birth defects."

"What we need next," he said, "is a similar study to learn whether food fortification is having the same measurable effect among younger women of childbearing age. They're the ones for whom this public health policy, for prevention of birth defects, is intended."

"We also need to know whether preventing these birth defects takes more than the 3 nanograms per milliliter blood level of folic acid that is commonly considered adequate for other health purposes."

The March of Dimes and other health agencies have long urged raising the standard level of folic acid fortification of certain grain products from the present 140 micrograms per 100 grams of product to 350 micrograms, because of evidence that the higher level could prevent many more birth defects of the brain and spinal cord.



Mark Canfield, Ph.D. and Texas First Lady Laura Bush discuss the potential for preventing neural tube defects at the Texas Folic Acid Campaign kick-off breakfast.



Reading List

Prenatal Diagnosis and Down Syndrome: An investigation by researchers in Boston found that the prenatal diagnosis and subsequent elective termination of fetuses affected by Down syndrome resulted in a steep decline in the number of live births with the birth defect born at a Boston hospital between 1972 and 1994. [Genetics in Medicine 1998;1:22-28]

Nuchal Translucency and Heart Defects: Researchers in London have reported that fetal nuchal translucency (fluid collecting in the back of the neck) measurements can be used to screen for major defects of the heart and great arteries in the first trimester. [BMJ 1999;318:81-85]

Spina Bifida and Fetal Surgery: Researchers in Tennessee describe the use of maternal skin graft to cover exposed spina bifida in their fetuses in utero and the outcome of such fetal surgery. [Am J Obstet Gynecol 1999;180:153-158]

Down Syndrome and Prenatal Screening: A study in Connecticut reports that combining urinary hCG beta-core fragment analyte, nuchal thickness, and maternal age, a high proportion of fetal Down syndrome cases can be identified with a low false-positive rate. [Am J Obstet Gynecol 1999;180:169-173]

Binge Drinking and Pregnancy: Analysis of Behavioral Risk Factor Surveillance System data from 46 states indicates that between 1991 and 1995, the prevalence of binge drinking among pregnant women increased significantly from 0.7% to 2.9% while the prevalence among nonpregnant women changed little (11.3% vs. 11.2%). Overall, pregnant women were one-fifth as likely to binge drink as nonpregnant women. Pregnancy-related reduction in binge drinking was greatest among women 30 years or younger and women who had quit smoking. Among pregnant women, subgroups at highest risk for binge drinking were unmarried women, employed women and current smokers. [Am J Obstet Gynecol 1999;180:1-7]

DiGeorge Syndrome and Ufd1 Gene: Researchers in Texas and Tokyo have found the deletion of a gene (Ufd1) on chromosome 22 in all patients with DiGeorge syndrome they studied. This gene appears to act in the degradation of certain proteins during

the formation of portions of the heart from neural crest cells. [Science 1999;283:1091-1093 and 1158-1161]

Oral Clefts and Alcohol: A recent study from California reported no increased risk for oral clefts with periconceptional maternal consumption of low quantities of alcohol. However, there was an increased risk with higher levels of alcohol consumption. [J Pediatr 1999;134:298-303]

Birth Defects and Organic Solvents: A prospective study in Toronto found that women who reported exposure to organic solvents and symptoms from this exposure were more likely to have a fetus with a major birth defect than women who did not report exposure. Moreover, women who were exposed to organic solvents also reported more previous miscarriages. [JAMA 1999;281:1106-1109]



Regional Bulletins

Region 2/3

Region 2/3 has completed 1997 surveillance activities. Staff has approached 1998 surveillance in a new and more efficient way. Hospital personnel will find teams of two or more collecting data in their facilities, and staying for shorter periods. This approach was begun in January 1999 and already the regional program has seen efficiency increase by as much as 40%.

The region is conducting active surveillance with certified nurse midwives and have identified cases that would not otherwise be found.

Region 6

Surveillance of 1998 births is expected to be completed in the Houston/Gulf Coast area by December of 1999. Two surveillance specialist positions are available in the Houston area—interested parties should contact Trilyon Taylor at 713-767-3310.

The position of Program Manager is also open, due to the relocation of Ann Phelps (See Region 8).

Region 7

January is national "Birth Defects Prevention" month and Region 7 began this year with a regional kick-off by inviting March of Dimes representatives and local board members, regional staff, and local news media. Information was provided about the

Continued on page 6

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Texas Birth Defects Monitoring Division (TBDMD) and the need to take folic acid. More recently, staff presented information to the Waco Mayor's Committee for People with Disabilities, and The Travis County Perinatal Coalition Committee. Staff members were also disseminated information at conferences for Children with Special Health Care Needs.

Region 7 expects to complete 1998 surveillance activities by August 1999. 1999 surveillance has already begun at some hospitals.

Region 8

On June 11, the Texas Birth Defects Monitoring Division said good-bye to Bill Moore, MHA, Regional Program Manager in Region 8, the San Antonio and South Texas area. Mr. Moore served in this position since TBDMD was expanded to the Region 8 area in 1995. Prior to his service at TBDMD, he held several positions in public health for the State of Texas (including TEXTGENE coordinator), the U.S. military, and private foundations.

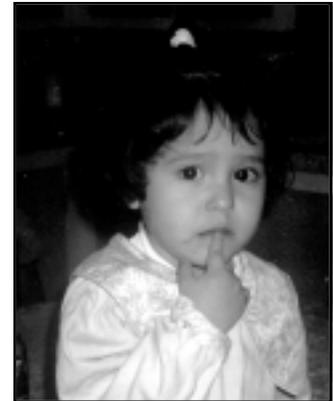
Mr. Moore has made a lasting contribution to public health, and his presence will be missed as he retires, or in his words, "goes to chase rainbows."

Ann F. Phelps, MPH will become Program Manager for Region 8 beginning August 1, 1999. Ms. Phelps has been Program Manager in the Houston/Gulf Coast area (Region 6) since the program's inception in 1994.



- New Publications from the TBDMD: To request any of the following materials, please contact Amy Case, 512-458-7232, E-mail: amy.case@tdh.state.tx.us.
 - Ö An updated brochure about the Texas Birth Defects Monitoring Division
 - Ö A fact sheet about the Texas Birth Defects Research Center and current studies
 - Ö Report of 1998 Cluster Investigations
 - Ö Glossary of Birth Defect Terms
 - A Houston area folic acid council has been formed, with Lowell Sever, Ph.D. of the U.T. Houston School of Public Health as Chairperson. For information about Houston activities, please call Janet Shephard, March of Dimes at (713)623-2020 x120
 - The March of Dimes North Texas Chapter has

launched a campaign to establish an endowed birth defects research center at the University of Texas Southwestern Medical Center at Dallas. The North Texas March of Dimes will raise \$1 million, which will be matched by an anonymous donor to create a \$2 million restricted endowment for medical equipment and research supplies.



The center is expected to serve as a catalyst in bringing researchers and medical specialists together in a multi-disciplinary, collaborative and interactive approach to improved childhood medical research.

- National Women's Health Center Web Site and Hotline launched by the U.S. Public Health Service—People interested in topics pertaining to women's health can obtain publications and links to all federal agencies by contacting 1-800-994-WOMAN or www.4woman.gov.

- The March of Dimes Prize in Developmental Biology is awarded to an investigator who has made a seminal discovery in biology: one that has revealed a new principle of relevance to birth defects, and who has not previously received a major prize for this work. A medal and \$100,000 are included with the award. Nominations of candidates are being sought for the 1999 award on or before September 15, 1999.

Nomination forms are available Michael Katz, M.D., Vice President for Research, March of Dimes Birth Defects Foundation, 1275 Mamaroneck Ave., White Plains, NY 10605. (914) 997-4555 FAX: (914) 997-4560 E-mail: mkatz@modimes.org.

- The March of Dimes also invites all qualified scientists with faculty appointments or the equivalent, at universities, hospitals and research institutions, to submit applications for research grants directed at the prevention of birth defects. Research subjects include basic biological processes governing development, genetics, clinical studies, studies of reproductive health, environmental toxicology, and social and behavioral studies relevant to the MOD mission.

Contact March of Dimes Birth Defects Foundation, 1275 Mamaroneck Ave., White Plains, NY 10605, E-mail: Research_Grants@modimes.org.

- The Infant Mortality Update, a quarterly publication, is available from the Texas Gulf Coast Chapter of the March of Dimes. Contact Christina Valentine at 713-623-2020.



September 10, 1999 Perspectives in Public Health: TDH Quarterly CME Conference, North Austin Medical Center, 12221 N. MoPac Blvd., Austin. Information: 800-252-8239, press 4, or 512-458-7677. Sponsored by TDH.

September 25-26, 1999 HealthFind 1999, State Office of Rural Health, the Center for Rural Health Initiatives, 211 East 7th Street, Suite 915, Austin. Contact Bob Moore at 512-479-8891, toll free at 877-839-2744, or by e-mail at bobmore@crhi.state.tx.us.

October 19 -23, 1999 49th Annual Meeting of the American Society of Human Genetics, Moscone Center in San Francisco, California. Contact the ASHG Administrative Office at 301-571-1825.

November 12-15, 1999 Alliance of Genetic Support Groups, Genetics in the New Millennium: Meeting the Challenge, Key Bridge Marriott, Arlington, VA. Contact Darlene Allison at 202-966-5557 (x201).

December 10, 1999 Perspectives in Public Health: TDH Quarterly CME Conference, North Austin Medical Center, 12221 N. MoPac Blvd., Austin. Information: 800-252-8239, press 4, or 512-458-7677. Sponsored by TDH.

January 6-8, 2000 Sixth Biennial Infant Mental Health Advocacy Conference 2000, Dallas. Sponsored by the Texas Association for Infant Mental Health. Contact Gail Surles, TAIMH, 660 Preston Forest Ctr., Box 212, Dallas, 75230

January 21-22, 2000 Texas Birth Defects Conference 2000, Crowne Plaza Galleria, Houston Texas. Contact Amy Case at 512-458-7232, E-mail: amy.case@tdh.state.tx.us. See article on page one.

January 31 - February 2, 2000 National Birth Defects Prevention Network, Crowne Plaza Hotel, New Orleans, Louisiana. Contact Kerda DeHann at 502-564-2154, Ext. 32.

September 14 - 16, 2000 1st International Symposium on Prevention and Epidemiology of Congenital Malformations, Cardiff, UK. Sponsored by the International Clearinghouse for Birth Defects Monitoring Systems (ICBDMS), E-mail: mc2459@mclink.it.



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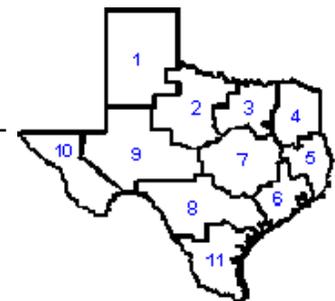
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