

Texas Birth Defects Monitor

Texas Birth Defects Monitoring Division

Texas Department of Health

Vol. 3, No. 1, August 1997

From the Director



Registry Goes Statewide: The final expansion phase of the Texas Birth Defects Registry is underway. Beginning with 1998 deliveries, the Registry will be a statewide program, as originally planned. The remaining areas to be added are the Texas Panhandle (Lubbock/Amarillo), Central Texas (Temple/Austin/Waco), and East Texas (Tyler/Sulphur Springs/Nacogdoches). This final expansion, comprising roughly 20% of all live births in Texas, was mandated by the State Legislature and will be funded by the Department with existing funds. Accordingly, we have looked at creative ways to accomplish this expansion at a lower cost. We plan to open only a sixth regional program office in Temple (Region 7). Region 4 will be covered by one new staff member, housed in Tyler and supervised by the new Region 7 office. Region 5 North will be covered by an

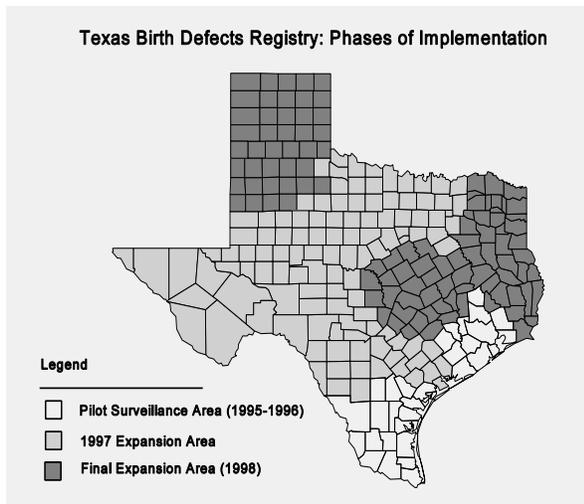
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additional staff member in the Houston office. The existing program office in El Paso will receive two additional field staff, one of whom will be housed in Lubbock. This will result in a large combined West Texas/Panhandle region (1/9/10), all of which will be managed from El Paso.

Research Center: The Texas Birth Defects Research Center is progressing nicely. We have worked diligently with our collaborators in other states to implement the National Birth Defects Prevention Study. This program, coordinated by the Centers for Disease Control and Prevention, utilizes case-control studies on selected conditions ascertained through existing surveillance systems (registries). Local studies pertaining to Hispanic origin, obesity, glycemic control, and birth defects will be undertaken as well. Interviews with parents of cases and controls in Texas will be initiated in Fall 1997. Several other Texas studies were funded as well. We have been able to support a research initiative of the Texas Neural Tube Defect (NTD) Project, which uses sophisticated computerized mapping

Texas Birth Defects Registry: Phases of Implementation



to look for environmental causes of NTDs along the border. Also funded was a study in the Houston area which examines the extent of prenatal diagnosis, as well as its impact on the prevalence of birth defects. The final project is the Texas Women's Health Survey, a cross-sectional statewide telephone survey consisting of 1200 completed interviews with females of childbearing age (15-44). The questionnaire has been completed and will be administered in September 1997. Topics to be covered

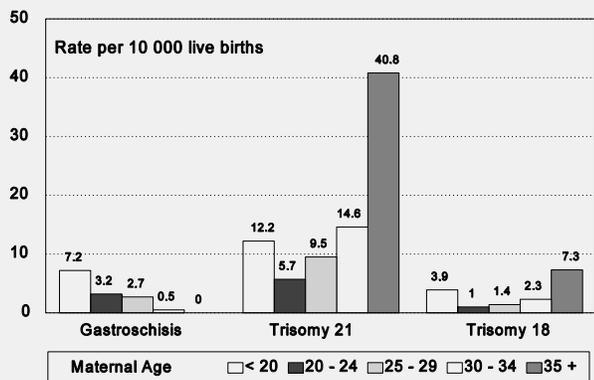
include the daily use of multivitamins, awareness about folic acid consumption and the prevention of certain birth defects, and knowledge about drinking alcohol during pregnancy and birth defects. Estimated percentages for these and other responses will be provided by ethnic group and area of residence. This should allow us to target prevention efforts more efficiently. For more information, please contact Donna Wright, M.P.H., Research Grant Coordinator at (512) 458-7232 or dwright@epi.tdh.state.tx.us.

Inaugural Data from the Texas Birth Defects Registry

The Division is finalizing its compilation of data for births from the first full pilot year (1995) of the Texas Birth Defects Registry. The pilot area consisted of the Houston/Galveston Region and the Lower Rio Grande Valley (see map on p. 1). Some of these data were presented formally at the

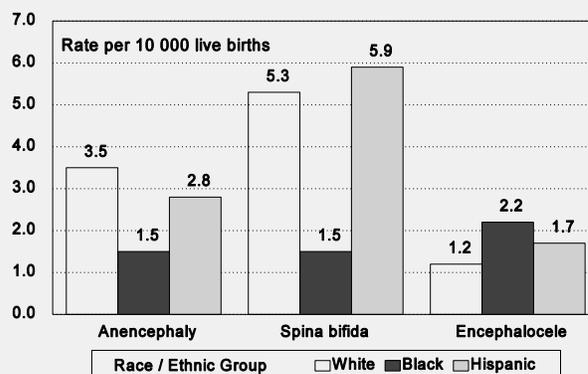
Scientific and Community Forum on Neural Tube Defects in South Texas during April 1997. The first official report will be issued within the next two months. Below we have selected some graphic data to share with readers while the report is being prepared. **If you would like to receive a copy of the report when it becomes available, please contact Sandy Wicker at (512) 458-7232 or swicker@epi.tdh.state.tx.us.**

Prevalence of selected birth defects by mother's age among 1995 deliveries to residents of pilot surveillance area



Texas Birth Defects Monitoring Division, Texas Department of Health

Prevalence of neural tube defects by mother's race / ethnic group among 1995 deliveries to residents of pilot surveillance area



Texas Birth Defects Monitoring Division, Texas Department of Health

Fetal Alcohol Syndrome and Alcohol Consumption Patterns during Pregnancy

Fetal Alcohol Syndrome (FAS) is a permanent, incurable, but preventable birth defect caused by consuming alcohol during pregnancy. When a pregnant woman drinks, alcohol crosses the placenta and can affect the unborn fetus both physically and mentally. People with FAS have abnormal facial features, mental impairments, and growth retardation. Babies with FAS are small at birth, in terms of weight, length and head size. They don't catch up during childhood and remain small even as adults.

Most people with FAS have below average intelligence. In fact, FAS is the leading known cause of mental retardation in the United States. People with FAS experience many learning and behavioral problems. They have difficulty reading faces and understanding non-verbal social cues. They have trouble dealing with math, money, time, and other abstract concepts. They have memory problems, difficulty generalizing information from one situation to another (for example, applying rules), difficulty predicting outcomes, and are easily frustrated.

As a result of these impairments, people with FAS suffer lifelong disabilities. A study released in August 1996 by Dr. Ann Streissguth and colleagues at the University of Washington School of Medicine in Seattle found that over 90 percent of people with FAS experienced mental health problems. Eighty percent were unable to live independently, and 80 percent had problems with employment. Sixty percent had been in trouble with the law, and 60 percent had

been suspended or expelled from school or had dropped out of school. The research did turn up some good news: people with FAS who had been diagnosed by age six and who had lived in a stable and nurturant home were much less likely to experience these social problems.

Fetal Alcohol Syndrome can be prevented in two ways: by helping women who drink alcohol to avoid becoming pregnant, or by helping pregnant women to avoid drinking alcohol. Unfortunately, a study in the April 25, 1997 issue of the CDC publication *Morbidity and Mortality Weekly Report* indicates that although frequent drinking has remained stable among all women of childbearing ages in the United States, frequent drinking among pregnant women is on the rise. Frequent drinking means having five or more alcoholic beverages on at least one occasion or having an average of seven or more drinks per week in the month prior to the survey. In 1991, less than one percent (0.8 percent) of pregnant women surveyed reported frequent drinking, but by 1995 this figure had risen to 3.5 percent. While this report does not show the percentage of pregnant women in Texas who drink frequently, it does show that the rate of frequent drinking among all women ages 18-44 is higher in Texas than in 39 other states and the United States as a whole. In Texas, 15.8 percent of women surveyed in 1995 drank frequently, compared to 12.6 percent for the entire United States.

For more information, please contact Mary Ethen, M.P.H., Epidemiologist and Fetal Alcohol Syndrome Specialist at (512) 458-7232 or methen@epi.tdh.state.tx.us.

***“Sounds of Texas” Project:
Searching for All Babies with
Hearing Loss***

During the past decade there has been an increased awareness of the importance of the early identification of hearing loss in infants and the necessity for immediate intervention. One of the early intervention leaders in the nation, Dr. Christine Yoshinaga-Itano, was awarded a grant in 1996 to look at the issue of screening all babies for hearing loss and giving them access to intervention programs. Texas is one of 17 states working with this project. ***Dr. Yoshinaga-Itano’s research in early intervention shows that the window of maximum opportunity for the development of the auditory pathways in the brain is prior to six months of age.*** This information is a timely addition to the growing body of information on brain development. Since 1993, the U.S. has had national standards for the universal detection of hearing loss in newborns, and technology and software are available that make it possible to do the testing in a cost-effective manner.

The Audiology Services section in the Bureau of Children’s Health at TDH has recently formed a public-private partnership with others to facilitate implementation of a pilot project to screen the hearing of some of the approximately 323 000 babies born annually in Texas. Of the 261 birthing hospitals, only 15 currently screen the hearing of all babies born at their facilities. This Project will facilitate the implementation of twelve more programs in the next year. This cooperative effort is unique in the United States, and includes state agencies, private non-profit

organizations, a university, and a for-profit corporation. The partners include the following:

- **The Meadows Foundation**, a private non-profit organization, provided a one-time grant of \$397 200 to purchase infant hearing screening systems to be loaned to participating hospitals.
- **Hearing Health Institute (HHI)**, a private non-profit organization dedicated to identifying hearing loss in neonates, provides a variety of services that relate to identification of hearing loss in infants, including staff training, environmental assessments of hospitals, information packets, presentations to professionals, parents, other staff, technical support for test equipment, and software and audiology consultation. The Executive Director of HHI is the Director of the Sounds of Texas Project.
- **OZ Corporation**, a private for-profit corporation, is donating staff time and technical support to the Project, and is building the infant screening systems with their SIMS software as the core. The cost-effectiveness and quality assurance for our effort have their base in the software. We anticipate having the results from 50 000 newborn hearing screens by June 1998.
- **The University of Texas at Dallas/Callier Center for Communication Disorders** is providing salaries for some members of the training team. The Center is also offering a referral component which will link

babies to appropriate services for evaluation and intervention.

- **The Commission for Deaf and Hard of Hearing**, the point of contact for information and referral services for hard of hearing and deaf consumers in Texas, is sending officials to make appearances at media events at hospital sites to encourage the early identification of hearing loss.
- The project team is working closely with **Early Childhood Intervention (ECI)** to develop a good referral system that will assure immediate intervention. We believe that a strong connection to services for intervention is a major part of an effective statewide program. ECI has a memorandum of agreement with Texas Education Agency (TEA) to provide parent advisors to work with families who have children with hearing loss.
- **The Texas Department of Health** is providing Maternal and Child Health Title V Block Grant funding to support some of the efforts by HHI and the Callier Center. The TDH Program for Amplification for Children of Texas (PACT) provides services and hearing aids to children who have permanent hearing loss and live at or below 150% of the federal poverty level.

The Audiology Services section is enthusiastic about this project and hopes that it will begin the process of finding all babies with hearing loss at birth so that they can maximize their auditory potential. For further information on this project contact Joy O'Neal at (512) 458-7726. Information regarding this grant can be found at <http://www.tdh.state.tx.us/child/meadows.htm>.

Preventing Birth Defects Due to Thalidomide

Representatives from federal agencies, pharmaceutical companies, health care provider organizations, health educators, and patient advocacy groups gathered in Atlanta recently to discuss the expected approval of thalidomide for use in the U.S.

Thalidomide's history has been well documented in Europe and South America in the 1950-60's, where it was prescribed to pregnant women to relieve sleeplessness or nausea during pregnancy and resulted in serious limb birth defects. Current demand for Thalidomide has arisen for treating specific debilitating diseases when no other treatment is available (e.g., for leprosy, AIDS-wasting, severe oral ulcers, and others) and it may soon be approved for use by the FDA. **The Birth Defects & Genetics Diseases branch of the CDC is concerned with ensuring that Thalidomide is not taken by pregnant women, or by women who may become pregnant during the course of treatment.** This meeting was designed to bring together groups and individuals who share this prevention goal. Presentations covered the following topics: contraception effectiveness, other teratogen-prevention programs (such as Accutane), drug registries, measures to ensure appropriate use, and ethical issues. Attendees then discussed guidelines and limitations for use, patient education, and health care provider education.

Contributed by the Birth Defects and Genetic Diseases Branch, Centers for Disease Control and Prevention

***Disability Grant Awarded
to Texas:
“On the Right Track”***

Effective July 1, 1997, the Texas Department of Health was awarded a four-year State Capacity Project for assessing and preventing secondary conditions associated with disabilities, as well as promoting the health of persons with disabilities. This “On the Right Track” grant was funded by the Centers for Disease Control and Prevention. The co-Principal Investigators are Lesa Walker, M.D., M.P.H., Director, Systems Development Unit, Children with Special Health Care Needs Planning and Policy Division, Bureau of Children’s Health and Dennis Perrotta, Ph.D., Chief, Bureau of Epidemiology. The project will focus specifically on secondary conditions in the “learning domain” (for example, poor academic experience) that relate to fetal alcohol syndrome, spina bifida, Down syndrome, cerebral palsy, autistic spectrum disorders, very low birth weight, spinal cord injuries, traumatic brain injuries, and submersions. Through this grant, a behavioral risk factor survey will be conducted, and pilot studies will be initiated in Harris County to document secondary conditions associated with learning. Another important aim of this project is to strengthen the leadership of the Texas Department of Health in the prevention of secondary conditions associated with disability.

For more information, please contact Dr. Walker at (512) 458-7111, ext. 3019.

Announcements

- The “Report of Birth Defects among 1995 Deliveries in Texas” is nearing completion. To order a copy, please contact Sandy Wicker at (512) 458-7232 or swicker@epi.tdh.state.tx.us.
- “Proceedings of the Scientific and Community Forum on Neural Tube Defects in South Texas” are now available. If you would like a copy and have not already received one, please contact Sandy Wicker at (512) 458-7232 or swicker@epi.tdh.state.tx.us.
- Two recent documents relating to birth defect clusters are now available from the Texas Birth Defects Monitoring Division. To receive a copy of either the “Birth Defect Cluster Investigation Protocol” or the “Summary Report of Birth Defect Investigations for 1996,” please contact Sandy Wicker at (512) 458-7232 or swicker@epi.tdh.state.tx.us.
- The first newsletter for the Texas NTD Project is available, as is the most recent semiannual report (dated 10/1/96 - 3/31/97). For more information, please call (512) 458-7328.
- The TEXGENE Annual Meetings and Conference will be held in Galveston on September 17-19, 1997, at the Tremont House. The conference on September 19 is entitled, “Genetics in Texas: New Frontiers.” Among other topics, Dr. Mark Canfield from TDH will present “Birth Defects in Texas” and Dr. Joe Mulinare from CDC will provide a “National Birth Defects Update.” For more information, please contact Judith Livingston at (512) 458-7111, ext. 2129.

Announcements, continued

- The first newsletter of the National Birth Defects Prevention Network is now available. This Network is comprised of individuals from various state programs devoted to the surveillance, prevention, and research of birth defects. To receive a copy of this newsletter, please contact the editor at robert_meyer@mail.ehnr.state.nc.us.
- The CDC-sponsored 1997 Maternal, Infant, and Child Health Epidemiology Program (MICHEP) Workshop will be

held on December 9 and 10, 1997 in Atlanta. Preceding and held in conjunction with the MICHEP Workshop, there will be a one-day workshop of the National Birth Defects Prevention Network on December 8. The Network workshop is targeted to personnel in State surveillance and prevention programs. There will be no registration fee for either workshop. For more information, please contact Ms. Linda Mitchell at CDC at (770) 488-5187 or lom0@cdc.gov.

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