



TEXAS BIRTH DEFECTS MONITOR

Volume 1, Number 1

April, 1995

Greetings from the Director

It has been a year since we opened the offices of the Texas Birth Defects Monitoring Division. Although our first appreciable data are several months away, much has been accomplished, and we felt it was time to provide an update. The enthusiasm shown by many of you for this new program has been appreciated. We are now fully staffed and collecting data in our two pilot regions. For a bit of recent history, here are the milestones of the Division:

April 1991	Anencephaly cluster identified in Brownsville
May 1993	Birth Defects Act passed by Legislature
June 1993	Birth Defects Act signed into law by Governor
September 1993	Birth Defects Act went into effect
March 1994	Division offices opened
October 1994	Board of Health rules adopted
December 1994	Data collection begun
January 1995	Scientific Advisory Committee convened
	Last of 22 staff hired

Mission and Objectives

The mission of the Texas Birth Defects Monitoring Division is as follows:

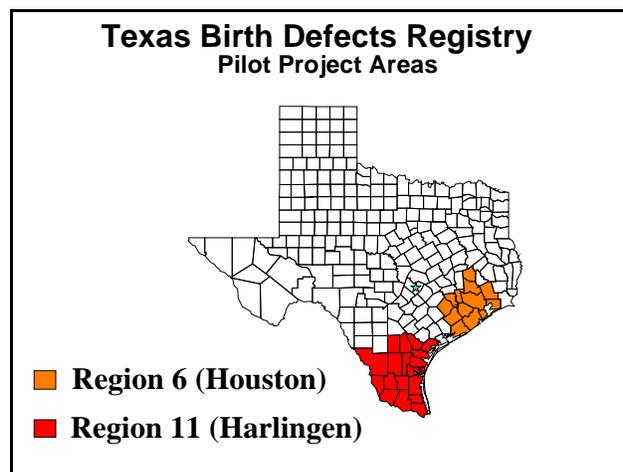
(1) to identify and describe the patterns of birth defects in Texas;

(2) to collaborate with others in finding causes of

birth defects, working towards prevention, and linking families with services.

The main objectives of our program are to set up a birth defects registry, monitor for changes in prevalence, conduct cluster investigations and research on birth defects, and refer affected children and their families into services. Confidentiality will be emphasized in all aspects of the program.

Where are We Operating?



The Texas Birth Defects Registry is being piloted in 2 of the 11 public health regions. In 1993, 76,980 live births were recorded in the 13-county Houston region, and 35,880 live births were registered in the 19-county Harlingen region. Together, these 32 counties record approximately one-third of all live births in the State.

In September, 1996, we plan to expand statewide with the Registry, depending on appropriations from the current legislative session. Background prevalence data are essential for conducting cluster investigations in an accurate and efficient manner.



Ongoing Birth Defect Cluster Investigations

What Are We Collecting?

We will be emphasizing structural malformations, based on the protocol from the Metropolitan Atlanta Congenital Defects Program. The Atlanta program is operated by the Centers for Disease Control and Prevention. We have also borrowed many ideas from the California Birth Defects Monitoring Program. For births in 1994, 23 major conditions are being piloted. Included in this list are neural tube defects (anencephaly and spina bifida), Down syndrome, fetal alcohol syndrome, limb reduction defects, and abdominal wall defects. For 1995, the above list of conditions will be expanded to include newborn screening disorders (e.g., sickle cell disease) and malformations caused by infections (e.g., congenital syphilis). In 1996, we plan to expand the list further to encompass all major structural defects.

The registry will include cases occurring among resident live births, fetal deaths, and prenatal diagnoses. Cases must be diagnosed, or signs and symptoms recognized, by the first birthday. The exception is fetal alcohol syndrome, for which the sixth birthday is the upper age limit.

How Are We Collecting Data?

The Texas Birth Defects Monitoring Division utilizes active surveillance techniques, whereby trained regional staff regularly search for cases in facilities where birth defects might be seen. A total of 10 field staff (7 in region 6 and 3 in region 11) will regularly visit hospitals, clinics and birthing centers. Once cases are identified, staff will abstract information from medical records onto a 10-page form. Eventually this will be accomplished using notebook computers.

Reporting Form Available

Providers or facilities who wish to report directly to the Division may do so on our short reporting form. From the information provided, regional staff will be sent to abstract records from one or more facilities identified by the reporting source. For reporting forms and return envelopes, please call our office.

The Division also responds to concerns raised by citizens or service providers about apparent clusters of birth defects. Four investigations are currently being conducted, all of them outside the pilot regions. A brief description is provided below:

Down Syndrome in Hood County: Five confirmed cases of Down syndrome were born to women residents in Hood County from 1992-1994. This was 10.2 times the number expected. More detailed information is being collected on risk factors and potential exposures of the affected families.

Down Syndrome in Ellis County: Eight cases of Down Syndrome were born from 1992-1994. If confirmed, this represents 4.9 times the expected number. Further case finding and case verification are underway.

Neural Tube Defects (NTDs) in Maverick County: Two cases of anencephaly and one of spina bifida were born to Eagle Pass residents between December 1994 and February 1995. If confirmed, this is 7.3 times the expected number. More detailed information is being collected by Neural Tube Defects Project personnel on risk factors and potential exposures of affected families. The Texas Department of Health (TDH) is also working with Mexican authorities in Piedras Negras on a cluster of five NTD cases occurring during the same time period..

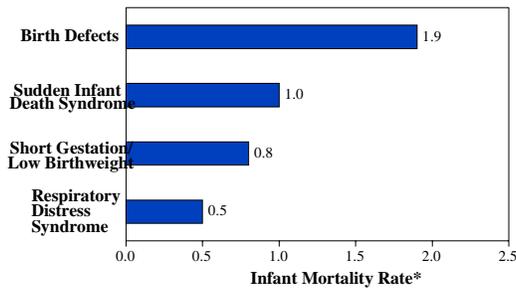
Cleft Lip and Palate in Gaines County: Three cases were born from July 1994 to February 1995. If confirmed, this would be 16.1 times the expected number. Further case finding and case verification are underway.

For more information on these investigations, or to receive a copy of a summary of birth defect investigations conducted in 1994, contact Peter Langlois, Ph.D., Senior Epidemiologist for the Division.

Birth Defects Continue as

Leading Cause of Infant Death

Leading Causes of Infant Mortality Texas, 1993



* Infant deaths per 1,000 live births

Scientific Advisory Committee Meets

The first meeting of the Scientific Advisory Committee on Birth Defects in Texas was held in Austin, TX on January 30, 1995. The purpose of the committee is to advise the Division and the Department on issues relating to birth defects in the State. The 11-member committee and its chair, Dr. Celia Kaye, were appointed by Dr. David Smith, Commissioner of Health. Members bring expertise in birth defects, genetics, medicine, and epidemiology. Joining the committee are three representatives from environmental agencies (EPA, Texas Natural Resource and Conservation Commission, Texas Department of Agriculture). Much of the meeting was spent bringing members up-to-date on birth defect activities at the Texas Department of Health. Minutes from this first meeting are available upon request.

Available from the Texas Birth Defects Monitoring Division

- Brochure on the Texas Birth Defects Monitoring Division (English, Spanish)
- Brochure on Fetal Alcohol Syndrome (English, Spanish)
- Recent Trends in Neural Tube Defects in Texas
- Leading Causes of Infant Mortality in Texas, 1993
- Summary Report on Birth Defect Cluster Investigations Conducted in 1994
- List of Conditions Included in the Birth Defects Registry
- Texas Birth Defects Law and Board of Health Rules

Supporters of Birth Defects Registry Honored

At a "Motherhood and Apple Pie" ceremony held at the Capitol on February 28, 1995, Ann and David Andis of the Woodlands (in Montgomery County, north of Houston) were honored by the March of Dimes for the legislative work they did in 1993 in helping to establish a birth defects registry for the State of Texas. We congratulate the Andis family for this recognition of their efforts.

Resources

Baby Love Hotline (1-800-4-BABY-LOVE)

A toll-free information and referral service for women and children in Texas (e.g., services for pregnant women, special programs for medically fragile children). Operated by the Bureau of Women and Children, Texas Department of Health.

Teratogen Hotline (1-800-733-4727)

A toll-free information line for pregnant women concerned about exposures (e.g., to drugs, alcohol, poisons). Operated by Genetic Screening and Counseling Services, Texas Department of Health.

March of Dimes Birth Defects Foundation

Advocacy organization with the mission of preventing birth defects and infant mortality. Information on birth defects and services. Call your nearest office.

Association of Retarded Citizens, Texas (ARC) (1-512-454-6694)

Nationwide advocacy organization promoting the needs and rights of people with disabilities.

Early Childhood Intervention (ECI) (1-512-502-4920)

Services for infants and toddlers with developmental delays and their families.

Texas Genetics Network (TEXGENE) (1-512-458-7700)

Newsletter and information on support groups for birth defects.

How You Can Reach Us

Austin: (512) 458-7232
Houston: (713) 414-6238
Harlingen: (210) 423-0130

The Texas Birth Defects Monitor is a free publication of the Texas Department of Health, Bureau of Epidemiology. If you would like to be added to our mailing list, please contact us by phone, fax, or mail:

Editor, Texas Birth Defects Monitor
Texas Birth Defects Monitoring Division
Texas Department of Health
1100 W. 49th Street
Austin, TX 78756-3180
phone: (512) 458-7232
fax: (512) 458-7689

Editor: Mark A. Canfield, Ph.D., Director,
Texas Birth Defects Monitoring Division
Associate Editor : Gladys V. Sánchez, M.S.,
Epidemiologist, Texas Birth Defects Monitoring
Division.

Plans for the Monitor

If there are topics you would like to have covered in subsequent issues of the Texas Birth Defects Monitor, please let us know.

Texas Birth Defects Monitoring Division
Bureau of Epidemiology
Texas Department of Health
1100 West 49th Street
Austin, Texas 78756-3180

Address Correction Requested