TXD D1100.1 R299 1997
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EXECUTIVE COMMITTEE
TEXAS OFFICE
FOR PREVENTION
OF DEVELOPMENTAL DISABILITIES

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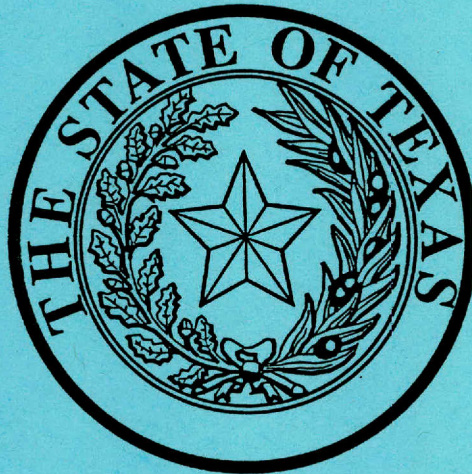

REPORT TO THE 75TH LEGISLATURE
JANUARY, 1997

The Texas Office for Prevention of Developmental DisabilitiesOffice of Disabilities Prevention

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November 1, 1996

The Honorable
George Bush
Governor of Texas

The Honorable
Bob Bullock
Lieutenant Governor of Texas

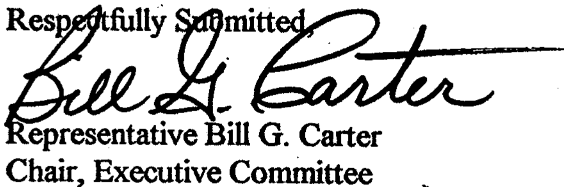
The Honorable
Pete Laney
Speaker of the Texas House of Representatives

The Honorable
Members, 75th Legislature

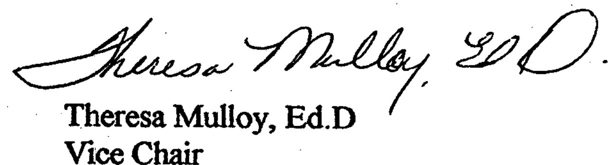
Dear Distinguished Colleagues:

It is our privilege to submit for your review this report to the 75th Legislature adopted unanimously by the Executive Committee of the Texas Office for Prevention of Developmental disabilities. Your continued support would be appreciated as we strive to develop this unique private-public initiative to prevent developmental disabilities in Texas. We are proud of our achievements thus far, and look forward to working with you for the prevention of developmental disabilities in Texas.

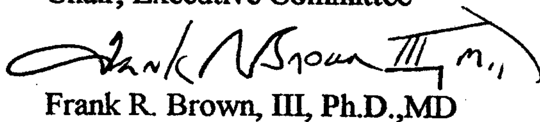
Respectfully Submitted,



Representative Bill G. Carter
Chair, Executive Committee



Theresa Mulloy, Ed.D
Vice Chair



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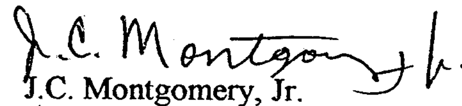

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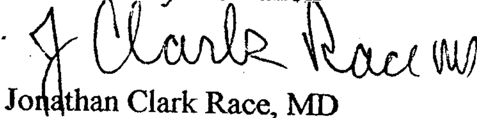
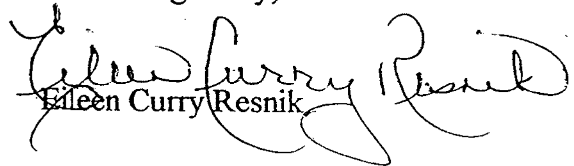
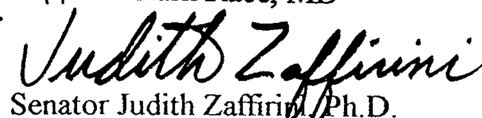


Jonathan Clark Race, MD



Eileen Curry Resnik



Senator Judith Zaffirini, Ph.D.

Introduction

An estimated 477,000 Texans are mentally retarded, or 2.9% of the population of Texas, according to figures released in the Texas Department of Mental Health and Mental Retardation's Strategic Plan FY 1992-1997. While these statistics are startling, they are even more dramatic in light of our belief that 50 percent of all mental retardation could be prevented, using present knowledge and techniques that are available and are utilized in other states. Applying findings of the President's Committee on Mental Retardation to Texas, there are more than 200,000 cases of mental retardation that, perhaps, could have been prevented.

Three factors which contribute clearly to the cause of mental retardation are teenage pregnancy, teenage substance abuse and teenage head injuries. Becoming pregnant during teen years, especially during the early teens, may mean a higher risk of having a baby with a lower-than-average birth weight, which may lead to mental retardation or brain damage. Recent studies show that Texas ranks highest in the nation in the number of teenage pregnancies among girls aged 17 and under. In 1995 there were 28,607 pregnancies reported to girls 13 to 17 in Texas.

A second factor concerns the abuse of substances among teenagers, especially if the substance abuse is by young teens during their pregnancies. Excessive alcohol in the blood, particularly during the first three months of pregnancy, may cause brain damage to a baby. Abuse of alcohol throughout pregnancy may cause a mother to have a baby with "fetal alcohol syndrome"--a baby that is malformed and mentally retarded in a certain way. The continued use of drugs by expectant mothers throughout pregnancy may also endanger the baby's development.

Substance abuse among teenagers also can result in severe developmental disabilities caused by injuries sustained as a result of driving while intoxicated or by prolonged use of hallucinogens, inhalants and other forms of recreational or prescription drugs. According to the Texas Department of Public Safety, in 1995, 1,138 people were killed and 31,720 injured by drunk drivers in the state. Of those fatalities, 122 were between the ages of 15 and 19. Of the injured 4,076 were between the ages of 15 and 19. In addition, there were 3,746 people between the ages of 15 and 19 arrested for drunk driving in 1995.

A 1994 survey on alcohol and drug abuse conducted by the Texas Commission on Alcohol and Drug Abuse (TCADA) indicates substance use trends for secondary students in Texas and nationwide show an increase in illicit drug use, especially marijuana, from 1992 to 1994. The 1994 Executive Summary of the Texas School Survey of Substance Use Among Students: Grades 7-12 shows Texas above the national figures for grades 8, 10, and 12 in 1994. The national figures for grades 8, 10, and 12 were 55.8%, 71.1% and 80.4% respectively, for Texas 59.3%, 81.1% and 85.5% for the same grades. It appears that alcohol remains the most widely used substance among Texas secondary students. According to the TCADA report, about 10% of all secondary students went to class while drunk during 1994. A majority of students reported that alcohol was very easy to obtain and that they did not consider alcohol dangerous.

Another leading cause of developmental disabilities is head injuries. According to the Texas Department of Health, approximately 19,000 Texans sustain head injuries annually at a cost for services estimated at $2.6 billion. Approximately 3,600 Texans die from head injuries each year or about 10 Texans a day. Texas must explore ways to reduce the number of head injury victims. The traditional focus of human services throughout the United States and Texas has been on long-term care and treatment. With passage of Senate Bill 1527 in 1989 sponsored by Senator Judith Zaffirini, D-Laredo, and Representative Bill Carter, R-Ft.Worth, Texas expressed a commitment to place a greater emphasis on prevention programs and activities. This legislation, signed into law by Governor William P. Clements on June 16, 1989, authorized the establishment of a Texas Office for Prevention of Developmental Disabilities (TOP).

S.B. 1527 was the culmination of a series of major efforts aimed at establishing a single entity in Texas to focus on prevention. As indications of support, a Texas Conference on Prevention of Mental Retardation and Related Developmental Disabilities was held in October, 1987, with the support of Lieutenant Governor William P. Hobby and House Speaker Gib Lewis and was attended by more than 150 persons from throughout Texas. Also in 1987, the Texas Legislature adopted Senate Concurrent Resolution 133 by Senator Zaffirini and Representative Charlie Evans, R-Ft. Worth. It called for establishing the Joint Committee on Prevention of Mental and Developmental Disabilities. According to the resolution, the committee's charge was to study the prevention of mental and developmental disabilities, to develop a comprehensive plan for prevention and to evaluate current offices of prevention in other states.

Lieutenant Governor Hobby and House Speaker Lewis continued to support these efforts. In January 1988, they appointed a 19-member steering committee charged with defining alternatives for developing a Texas Office for Prevention. The legislative leadership requested that the steering committee determine whether the Office should be established as a public or private entity, identify specific disabilities targeted for prevention during the first two years, identify ways for improving interagency cooperation and calculate the savings in dollars and human suffering as a result of the prevention measures taken the first two years.

Following months of intense discussion, members of the steering committee approved and submitted their report to the 71st Legislature in October, 1988.

S.B. 1527 was drafted using the steering committee's report and recommendations as a basic framework. As this legislation was debated during the regular session, it was supported and endorsed by 12 major statewide organizations including the Volunteer Services State Council, Mental Health Association in Texas, State Federation of Women's Clubs, State Mental Retardation Advisory Committee, Texas Board of Mental Health and Mental Retardation, Texas Department of Mental Health and Mental Retardation, Governor's Committee for Disabled Persons, Texas Women's Alliance, ARA Living Centers, Texas Medical Association, Parent Association for the Retarded of Texas and Association for Retarded Citizens of Texas.

Because it costs Texas citizens anywhere from $500,000 to $2 million to serve the needs of a

person with mental retardation over the course of his/her lifetime, an emphasis on prevention is critical. Although teenage pregnancy, substance abuse and head injuries can be viewed as separate and distinct issues, they share similarities and have equally devastating effects on many Texas citizens. State agencies and private organizations are developing programs aimed at reducing the incidence of these tragedies, and the Texas Office for Prevention of Developmental Disabilities has a key role to play in their activities.

TOP, with widespread cooperation and support from state agencies such as the Texas Department of Health, the Texas Youth Commission, the Texas Rehabilitation Commission and the Texas Department of Mental Health and Mental Retardation, works to coordinate and streamline the prevention activities (where they exist) of these groups. By researching existing programs and informing other groups as to the success of these programs, TOP hopes to increase the prevalence of statewide prevention activities.

OVERVIEW OF S.B. 1527

In authorizing the establishment of a Texas Office for Prevention of Developmental Disabilities, the purpose of this Act is to minimize the economic losses caused by preventable disabilities; to develop a unified, comprehensive prevention effort for Texas; and to establish a mechanism by which prevention activities can best be coordinated and needed prevention programs can be initiated and expanded.

A nine-member Executive Committee serves as the governing body for TOP. With three members appointed to staggered terms by the Governor, three by the Lieutenant Governor and three by the Speaker of the House of Representatives, this committee was directed to meet at least quarterly to adopt bylaws for the conduct of the meetings and to establish policies and procedures. S.B. 1527 also authorizes the Executive Committee to appoint a board of advisors and to create task forces to plan and implement prevention programs for specifically targeted disabilities, according to guidelines established by the committee.

Each task force is required to develop a plan and corresponding budget if necessary, designed to reduce the incidence of a specifically targeted disability. The plan, budget and evidence of funding commitments must be submitted to the Executive Committee for approval. S.B. 1527 specifically prohibits an appropriations request for general revenue funds from the legislature and authorizes the committee to apply for and distribute private, state and federal funds. This legislation requires that task forces be appointed initially in the areas of teenage substance abuse, teenage pregnancy and teenage head injuries to develop a prevention plan for developmental disabilities resulting from these problems.

EXECUTIVE COMMITTEE ACTIVITIES

As sponsors of the enabling legislation, Senator Zaffirini and Representative Carter scheduled the initial meeting of the Executive Committee on December 10, 1990. Members unanimously

elected Senator Zaffirini as Chair and Representative Carter as Vice-Chair. Senator Zaffirini served as chair until 1993 when Representative Carter was elected Chair and Dr. Theresa Mulloy elected Vice Chair. By laws outlining the purpose, duties, policies and procedures for TOP were adopted.

A priority for the committee was funding sources for the office. In 1991 the Texas Department of Health was awarded a grant from the U.S. Centers for Disease Control, CDC, for programs to prevent injury and disabilities in Texas. The Department of Health was awarded over $200,000 annually for five years. As an important part of that grant, TOP was funded approximately $100,000 each year for that five year period which ended September 30, 1996. However, CDC granted an extension of funds through June of 1997 to allow states participating in the disability prevention program to complete their projects and to allow CDC time to prepare a new request for proposal scheduled to be released in January 1997. The activities outlined in the CDC grant include plans to continue current activities and initiate new programs to reduce the incidence and impact of disabilities. The program is organized in Texas along the following lines:

1. Establish an Office for Disability Prevention within TOP to serve as an administrative program office and develop a five-year strategic plan.

   (Established August 1992 with the hiring of a program director. Planning for the development of a long range plan began almost immediately.)

2. Organize a statewide advisory committee to develop a long range state plan.

   (Organized in 1993. Convened quarterly in workshops throughout 1993 to work on elements of the long range state plan.)

3. Develop surveillance of spinal cord and traumatic brain injuries, as well as fetal alcohol syndrome.

   (An epidemiologist hired 1991 in the areas of spinal cord and brain injuries, also hired an epidemiologist for fetal alcohol syndrome surveillance both positions reside at the Texas Department of Health.)

4. Initiate community projects for prevention of secondary disabilities.

   (A specialist was hired 1991 at the Texas Rehabilitation Commission and through a contractual arrangement, directed to work on prevention of secondary disabilities.)

To administer the grant, the Executive Committee of TOP began a search for a project director. The position was posted, and a search committee chaired by Dr. Theresa Mulloy was appointed. The search committee interviewed potential candidates in July, 1992, and at the August 6, 1992, Executive Committee meeting, Jerry Ann Robinson was selected.

Simultaneous to the search for a project director, the committee turned its attention to locating suitable office space. The Texas Youth Commission offered TOP the use of two offices in its building in Austin. The Texas Medical Association agreed to allow TOP to use its facilities for Executive Committee meetings, task force meetings and other events.

In accordance with the requirements set forth in S.B. 1527, the Executive Committee established task forces to focus on preventing disabilities associated with teenage substance abuse, teenage pregnancy and teenage head injuries. Because of limited resources, the task forces' programs initially were developed on a regional basis in diverse geographic area. The intent was to expand those successful programs statewide as appropriate. Each task force was commissioned to develop a plan to reduce the incidence of a targeted disability, prepare a budget for implementing a plan, and seek funding. Each task force must submit plan, budget and evidence of funding commitments to the Executive Committee for approval.

Members of the task forces are interested public citizens and organizations which have been contributing their time and talents without the benefit of public funding. They were selected from nominations by interested agencies, organizations, and individuals, then appointed by the Executive Committee upon the recommendation of the respective task force.

The Executive Committee also held a meeting of the commissioners and executive directors of the state agencies representing health and human services to orient them to TOP and to seek their endorsement and support. TOP has received extraordinary support and encouragement from these state agencies. The Texas Youth Commission provided office space and utilities for almost four years, the Texas Department of Health continues to work with members in support of funding and administration of the CDC grant and the Texas Department of Mental Health and Mental Retardation provided the initial staff support and printing for the first TOP Report to the 72nd Legislature. The Texas Medical Association has provided printing services for the Head and Spinal Cord Injury Prevention Task Force. The Texas Employment Commission provided postage for the first distribution of the completed Long Range State Plan for Disability Prevention.

The Executive Committee has supported legislative initiatives such as the statewide birth defects registry, the Injury Prevention and Control Act and a bill for bicycle helmet requirements.

TASK FORCE ACTIVITIES

Preventing Disabilities Associated with Head and Spinal Cord Injuries

The task force on head and spinal cord injuries initially was based in the Houston and Beaumont areas and chaired by Jonathan Clark Race, M.D. Participants were interested in researching programs designed to increase public awareness about the seriousness and long-term effects of head injuries. One program "Think First", aimed at ninth graders was suggested as a possibility for funding to increase the scope of the program and take it statewide. However, it was

determined by the Executive Committee that in order to recommend the program statewide there should be a scientific evaluation of the program in order to determine its effectiveness. A one-year evaluation by the Southwest Regional Brain Injury Rehabilitation and Prevention Center, a department of The Institute for Rehabilitation and Research, in Houston, was approved by the Executive Committee and funded through the CDC Grant. That report is on file in the TOP Administrative Office and available upon request.

The evaluation of Think First was not as statistically significant as was hoped. However, there is enough indication that the program is effective to some degree to support its use. TOP made two recommendations to National Think First as a result of the evaluation: (1) that the National THINK FIRST organization redesign the program for younger children. It is believed that attitudes and behaviors are so integrated by the time a child is in high school that it may be too late for major changes. By exposing younger children to the learning available in THINK FIRST, there might be noticeable attitudinal and behavioral changes. (2) That a post-test be designed and administered six months to one year after the intervention to aid in determining efficacy of the THINK FIRST program; i.e., do attitudes and behaviors change and stay changed toward certain risk behavior. There is still a deep belief that the THINK FIRST program does save lives and TOP supports the program.

Texans for Bicycle Helmets

As a result of the review of head and spinal cord injuries in Texas, TOP asked Dr. Race to look into head/brain injuries resulting from bicycle crashes, especially among children. A review of hospital data and the Texas Department of Public Safety Accident Reports, as well as available literature on the subject, resulted in a recommendation to increase bicycle helmet usage. Bicycle helmets are shown to be from 85% to 90% effective in reducing the risk of serious head/brain injury. To this end, a coalition of interested individuals, safety experts, bicyclists, childhood injury specialists were convened and developed a plan of action. This coalition developed into the Texans for Bicycle Helmets group chaired by Dr. Clift Price, Legislative Affairs, Texas Pediatric Society. The Texans for Bicycle Helmets group reports to Dr. Race of the Head and Spinal Cord Prevention Task Force which reports or make recommendations to TOP at TOP Quarterly Meetings.

Texans for Bicycle Helmets has a focus in four areas regarding bicycle helmets: data, distribution, education, and legislation. The data issue is addressed through the Texas Department of Health, Hospital Associations, and the Department of Public Safety. Also, Safe Kids Coalitions contribute to several task force areas. Distribution has been addressed by the Texas Medical Association with their campaign for each physician to contribute one helmet a year for a needy youth rider (this program has been taken to the American Medical Association and is expected to be adopted this year). Distribution is also being done by Safe Kids Coalitions, Hospital Associations, Law Enforcement Offices, the Texas Department of Health, and local health departments. To date over 35,000 bicycle helmets have been distributed to needy Texas children. There is funding and plans in place to distribute over 16,000 more during the first six months of

1997. It was quickly discovered that funding for bicycle helmets for needy bicyclists is readily available. Texas Department of Health has taken the lead in coordinating the various resources for bicycle helmet funding. A fund was established through the Public Health Foundation to purchase bicycle helmets in bulk at greatly reduced rates, sometimes as small as $7 a helmet.

Education in bicycling in general and in correct use of bicycle helmets is addressed by a multitude of organizations. Leading the effort are local law enforcement groups who periodically conduct Bicycle Rodeo's at which trained law enforcement officers teach children rules of the road, bicycle maintenance, and correct usage of bicycle helmets. Safe Kids Coalitions often assist local law enforcement offices, or conduct their own educational programs in schools. The Texas Department of Health, Pedestrian/Bicycle Safety Program, conducts in school programs as well as community based programs. Some parent/teacher associations conduct bicycle safety programs.

The Texas Department of Health received a Centers for Disease Control Three Year Grant in 1993 to do bicycle helmet education. The grant included funds for distribution of helmets as well as provisions for a position devoted to bicycle helmet efforts. In collaboration with TOP, the TDH bicycle helmet person participated in the Texans for Bicycle Helmets coalition and provided information in the efforts to determine effectiveness of legislation for bicycle helmets.

Legislative efforts for bicycle helmets grew out of the research and review of other states efforts for increasing bicycle helmet usage and the rising death and injury rates in Texas due to bicycle crashes (deaths - 1995 = 69, 1994 = 57, 1993 = 52, 1992 = 50, 1991 = 54 and injuries - 1995 = 2933, 1994 = 2986, 1993 = 2848, 1992 = 3014, 1991 = 2775).

A simple bicycle helmet bill with no penalty was filed late in the session in 1993 by Representative Bill Carter and Senator Judith Zaffirini. The bill did not make it out of committee. However an independent bill requiring the development of a bicycle education curriculum was passed though unfunded. The Department of Public Safety with financial assistance from the Texas department of Transportation and others developed and piloted an award winning curriculum which was available for release in 1996. Representatives from the Department of Public Safety, particularly, Ms. Theresa Gross, Motorcycle, ATV and Bicycle Safety Division, is an active member of Texans for Bicycle Helmets. A public demonstration and media event celebrating the completion of the curriculum was conducted in October 1995 in the Thompson Auditorium of the Texas Medical Association with Representative Carter presiding.

Two bicycle helmet bills were introduced in the 74th Legislative Session. One by Senator Zaffirini, S.B. 332 which required use of a bicycle helmet by people under age 18. H.B. 619 was filed by Representative Carter that required all ages to wear a bicycle helmet when riding a bicycle on public right of way. Senator Zaffirini passed the senate version through the senate with a narrow margin and Representative Carter accepted that version in the House. It failed to pass by 5 votes.

Texans for Bicycle Helmets continued to meet on a regular basis throughout 1996. Through its

efforts combined with city bicycle helmet coalitions, the head and brain injury associations, trauma associations and local health departments several city ordinance were passed during 1996. Houston, Austin, Dallas, Bedford, and Benbrook. Austin and Dallas have the only all age ordinances in the United States and are considered landmark municiple ordinances by the medical and injury prevention professions. Several other states are now looking to change their child-only laws to all age laws.

Both Senator Zaffirini (D) and Representative Carter (R) have stated that they will file bicycle helmet bills in the 75th Legislative Session. These two legislators, founders and participants in TOP, have proven their dedication to the safety of Texas children by their unyielding efforts to bring effective and efficient injury prevention legislation to the Texas Legislature.

Preventing Disabilities Associated with Teenage Pregnancy and Teenage Substance Abuse

The early task forces on the issue of teenage pregnancy and teenage substance abuse prepared TOP for its present focus on Fetal Alcohol Syndrome by their diligent review and analysis of information on pre and post natal care, lack of parenting skills in young mothers, and the rising use of alcohol by people 17 and under. The original plan called for a task force to work with the Governor's Adolescent Pregnancy and Prevention Council in 1993. The Council did conduct focus groups throughout the state and prepared an extensive report for the 73rd Legislature. However, because of lack of understanding of some of the goals and activities, the report was virtually tabled.

The TOP Teenage Substance Abuse Task Force was chaired by Ms. Eva Salinas in El Paso. Their goal was to reduce the incidence of substance abuse by Texas children and adolescents, with a focus on the metroplexes along the Texas border. To achieve that goal the task force applied for a grant from the City of El Paso to educate communities about the dangers of inhalant abuse. The task force also planned to develop a matrix of agencies and their services that address substance abuse which would be available to children, adolescents and their families. Ms. Salinas had to resign her TOP position due to personal reasons. The grant application was denied and efforts to reduce substance abuse by teens along the border were tabled by TOP due to lack of guidance and funding.

The efforts of TOP members in the area of teenage pregnancy and substance abuse have been combined in a concerted effort to reduce alcohol related birth defects. Particularly have Ann Clements and Lila Thompson (Ms. Thompson is no longer on the TOP Executive Committee but still active as co chair of the Fetal Alcohol Syndrome, FAS, Prevention Task Force) been active in efforts to develop a plan to reduce FAS. TOP sponsored, through the FAS Task Force the formation of an FAS Prevention Consortium. This dedicated group of experts and parents has been innovative in their approach to public awareness and education of health care professionals. The Consortium is also looking into the possibility of legislation requiring warning signs where alcoholic beverages are sold or consumed. Warning signs would state simply that drinking alcohol during pregnancy may cause irreversible birth defects.

There are approximately 600 babies born with Fetal Alcohol Syndrome in Texas each year. Experts in the field estimate that probably five times that many or 3,000 are born with alcohol related birth defects or alcohol related neurodevelopmental defects. The diagnostic criteria for FAS is low or below normal birth weight and height, central nervous system involvement, and a distinctive cluster of facial anomalies, with mental retardation being the most devastating effect of alcohol consumption in utero. It is estimated that $2 million is spent on the treatment and care of a person with mental retardation over a life time. More for more severe retardation. This number is staggering in the light of the knowledge that if a woman doesn't drink alcohol when she is pregnant a child cannot have alcohol related birth defects. This is a disabling condition that is 100% preventable. The TOP sponsored Consortium for FAS Prevention endeavors to bring this little known syndrome into public and private consciousness.

FUTURE ACTIVITIES AND GOALS

TOP has focused its energy on identifying prevention programs which are achievable and address the problem areas outlined in the enabling legislation while meeting the requirements of the CDC grant. In 1993, TOP pledged to work closely with the then newly created Health and Human Services Commission as it reviewed structure and functions of agencies involved in health and human services. The TOP administrative office, The Office of Disabilities Prevention, (ODP) is presently located in space provided by the Health and Human Services Commission in the Brown-Heatly Building, 4900 N. Lamar, Austin. With a project director and project secretary as its only staff, the TOP Executive Committee decided to focus its efforts for the completion of the present funding; i.e., June 30, 1997; on the efforts of the Texans for Bicycle Helmets Coalition and the FAS Prevention Consortium. Both, considerable projects.

Texans for Bicycle Helmets meets monthly to review data sources, report on educational activities and distribution efforts and to discuss the effectiveness of city ordinances and look at benefits of a statewide law requiring bicycle helmets be worn when riding a bicycle on public right of way. TOP's administrative office provides limited staff services for this group in the form of meeting announcements and Texas Register Open Meeting Announcements. Texas Medical Association provides meeting space, printing and distribution services. Members of the coalition attend at their own expense. See participants list attached.

The FAS Prevention Consortium was formed by invitations to key persons in the medical and academic communities who could best provide information regarding alcohol related birth defects and who might have policy or decision positions in agencies that deal with alcohol related birth defects. Parents of children with FAS are encouraged to participate. Presently there is only one adoptive mother of a child with FAS in attendance. Other parents are being sought, especially the birth mother of a child with FAS. Some members of the FAS Consortium are reimbursed for direct travel expenses from assigned CDC funds.. Approximately $1,500 has been expended to reimburse travel expenses to members of the Consortium in 1996. (The first meeting of the Consortium was November 1995.) A list of FAS Prevention Consortium members is included as Attachment 3.

The Consortium is committed enthusiastically to the prevention of FAS and secondary disabilities resulting from FAS; i.e., failure to learn to read. Members of the Consortium are considering a strategy by which they may apply for additional funds from the CDC to continue in FAS prevention activities such as raising public awareness, training of health care professionals, training of teachers and students, and working with the public sector to reduce alcohol consumption by women who are pregnant (insuring treatment services are available).

During the initial work in FAS the administrative staff became painfully aware that not only are men and women unaware of the risks involved with drinking alcohol while pregnant, few people realize that a beer, a glass of wine, or a mixed drink all contain the same amount of alcohol. In other words, there is no safe alcoholic drink for a pregnant woman. In addition, during training sessions with nurses, it was revealed that most doctors and nurses do not discuss the risks associated with drinking alcohol while pregnant with their patients, in fact, several women have reported that their physician recommended, when they were pregnant, they drink a glass of wine or a beer in the evening to help them relax and rest.

The original Long Range State Plan for Disabilitiles Prevention developed in 1994 is under revision and the revised plan will be published and distributed in 1997.

Great strides have been made since our original report to the 72nd Legislature. The establishment of an office with appropriate staffing, the receipt of the Centers for Disease Control grant and the formalization task force structures have enabled us to move forward to fulfill our mission of preventing the occurrence of certain disabling conditions and to promote the health and well-being of disabled citizens of Texas. Through collaborative efforts with many organizations, state agencies, and private entities, TOP will continue to develop and promote prevention strategies which will improve the quality of life for many Texans.

The TOP Executive Committee gratefully acknowledges the cooperation and support of many legislators, professionals, volunteers and organizations, especially Dennis Perrotta, Ph.D., Chief, Bureau of Epidemiology, Texas Department of Health and Michael McKinny, Commissioner, Health and Human Services Commission. Also to be acknowledged are: Steve Robinson, Executive Director, Texas Youth Commission; Dr. Clift Price, Texas Pediatric Society, Harold Freeman, Texas Medical Association, and Mary Cerverha, Texas Board of Health for their untiring efforts in the support of the Texas Office for Prevention of Developmental Disabilities.

Attachments:

S.B. 1527
TOP Member list
By Laws
Fetal Alcohol Syndrome in Texas (fact sheet)
Texans for Bicycle Helmets Supporters
FAS consortium Members

Executive Committee

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TOP BYLAWS
November 17, 1992

TEXAS OFFICE FOR THE PREVENTION OF DEVELOPMENTAL DISABILITIES

I. NAME

The name of this organization shall be the Texas Office for the Prevention of Developmental Disabilities, to be referred to in brief as TOP.

II. PURPOSE

A. To minimize the economic and human losses in Texas caused by preventable disabilities through the establishment of a joint private-public initiative;

B. To develop a unified, comprehensive prevention effort in Texas, while recognizing that many state agencies, as well as private organizations and local public agencies, are involved in prevention activities that can reduce the incidence and severity of developmental disabilities, and

C. To establish a mechanism by which prevention activities can better be coordinated and needed prevention activities can be initiated.

III. DUTIES OF TOP

The office shall:

A. Educate the public and attempt to promote sound public policy regarding the prevention of developmental disabilities;

B. Identify, collect, and disseminate information and data concerning the causes, frequency of occurrence, and preventability of developmental disabilities;

C. Work with state agencies and other entities to develop a coordinated long range plan to effectively monitor and reduce the incidence or severity of developmental disabilities;

D. Promote and facilitate the identification, development, coordination, and delivery of needed prevention services;

E. Solicit, receive, and spend grants and donations from public, private, state, and federal sources;

F. Identify and encourage establishment of needed reporting systems to tract the causes and frequencies of occurrence of developmental disabilities;

G. Monitor and assess the effectiveness of state agencies to prevent developmental disabilities;

H. Facilitate coordination of state agency prevention services and activities; and

I. Encourage cooperative, comprehensive, and complementary planning among public, private, and volunteer individuals and organizations engaged in prevention activities, providing prevention services, or conducting related research.

IV. EXECUTIVE COMMITTEE

The Executive Committee is the governing body of TOP.

A. This Committee is composed of 9 members who have expertise in the field of developmental disabilities of which 3 are appointed by the Governor, 3 by the Lieutenant Governor and 3 by the Speaker of the House of Representatives.

B. Members serve 2 year terms that expire on February 1, Executive Committee members receive no compensation but are entitled to reimbursement for actual and necessary expenses incurred in the performance of their duties.

C. The Executive Committee shall establish policies and procedures to establish TOP

V. OFFICERS

Members of the Executive Committee annually shall elect one member to serve as Chair and one to serve as Vice Chair.

VI. CHANGES IN POLICIES AND PROCEDURES

These policies and procedures may be amended at any regular meeting of the Executive Committee provided that a copy of the proposed changes is sent to each Executive Committee member at least 30 days prior to the meeting date.

VII. MEETINGS

A. The Executive Committee shall meet at least quarterly and shall adopt bylaws for the conduct of the meetings.

B. Five members of the Executive Committee constitute a quorum for the transaction of business.

C. In its deliberations, the Executive Committee shall be governed by Roberts' Rules of Order, Revised.

BYLAWS approved by majority vote of the Executive Committee, November 17, 1992.

Approved

Judith Zaffirini 9/28/93

Judith Zaffirini, Ph.D. Date
Chair

Approved

Bill G. Carter

Bill G. Carter Date
Vice Chair

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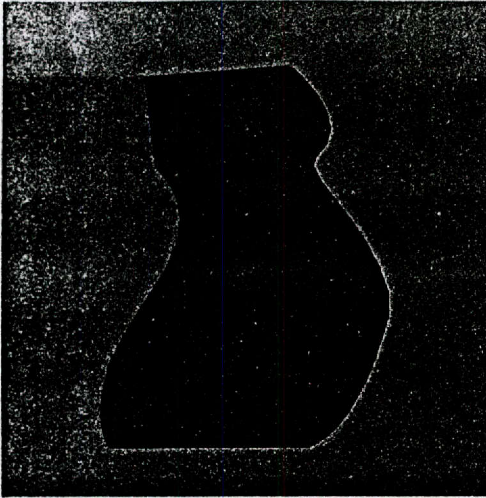


Fetal Alcohol Syndrome in Texas

The FAS (Fetal Alcohol Syndrome) Consortium is sponsored by the Texas Office for the Prevention of Developmental Disabilities (TOPDD) in collaboration with the Association of Retarded Citizens (ARC) of Texas, and the Texas Department of Health (TDH).

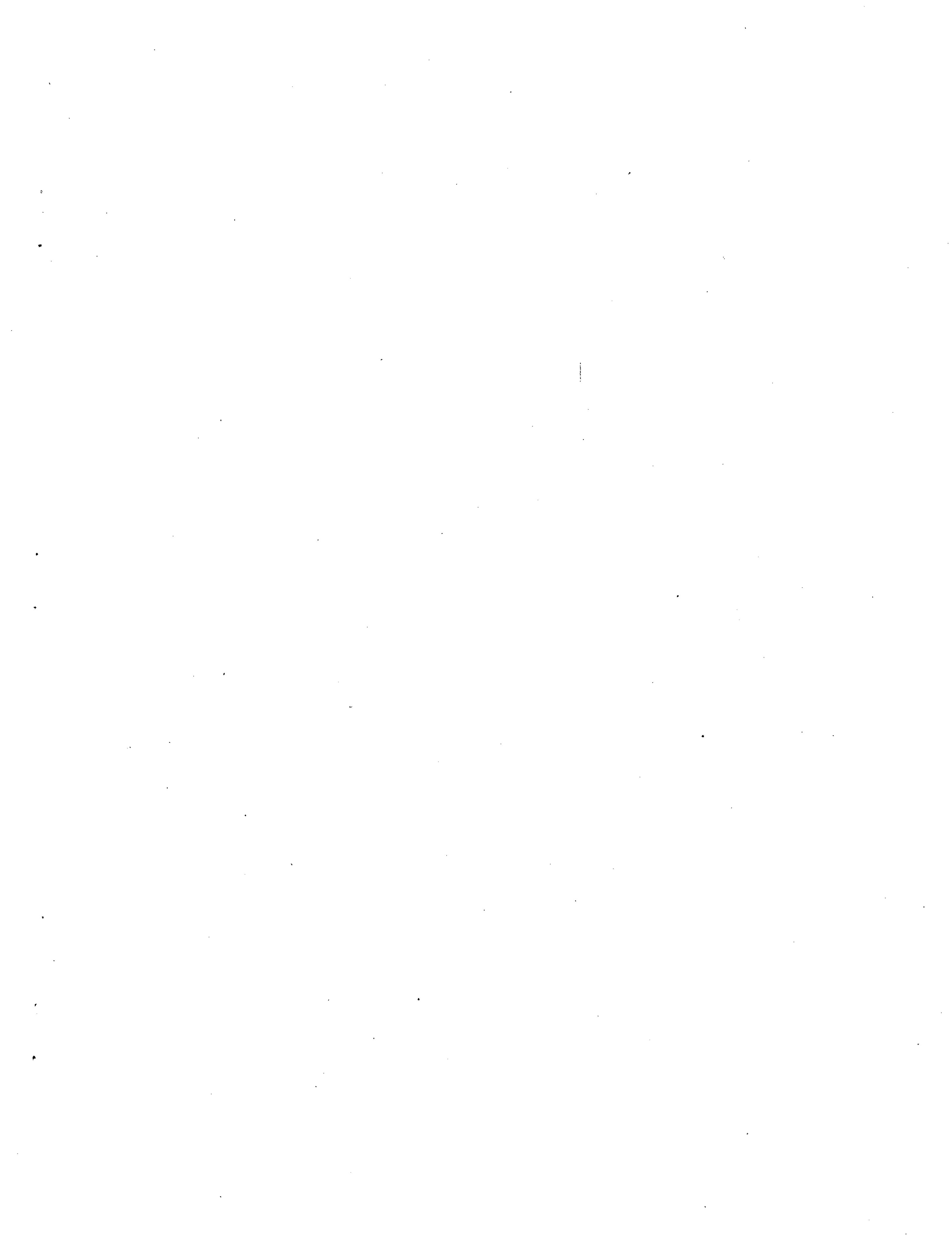
The Consortium was assembled by TOPDD in response to recent research and review that indicate increasing numbers of women drinking alcohol. (Texas Commission on Alcohol and Drug Abuse, 1991) Many women who are addicted to alcohol continue to drink even though pregnant. Pilot surveys and discussions with health care providers during FAS Training reveal that **most doctors and nurses do not discuss the risks associated with drinking alcohol while pregnant with their patients.** Apparently alcohol is so pervasive within our society that even health care professionals are unwilling or untrained to discuss the effects of alcohol on a fetus with their clients or patients.

National figures state that approximately 2 births in 1,000 result in an alcohol related birth defect (ARBD) known as Fetal Alcohol Syndrome. Preliminary new studies indicate the figure is probably 3 to 5. Also, Fetal Alcohol Effect, a less known Alcohol Related Birth Defect, and much harder to diagnose is probably closer to 300 in every 1,000. Based upon the national rate, it is estimated that 600 children with FAS are born each year in Texas. These figures are shocking when one realizes that FAS or FAE are 100% preventable. If a women does not drink alcohol while pregnant, she cannot have a child with FAS/E.

Not only are men and women unaware of the risks involved with drinking alcohol while pregnant, few people realize that a beer, a glass of wine, or a mixed drink all contain the same amount of alcohol. There is NO SAFE LEVEL of alcohol that can be consumed without risk to the fetus.

The FAS Consortium is attempting to prevent FAS and FAE by raising public awareness, by training of health care professionals, teachers and students, and working with the public sector to reduce alcohol consumption by women who are pregnant.

The FAS Consortium, TOPDD, The Restaurant Association, the ARC of Texas, the Department of Health, and Texas Alcohol Beverage Control are collaborating on a voluntary sign project which will encourage pregnant women to select non-alcoholic drinks when dinning out. These collaborative efforts will help to keep all new-born Texans healthy and alcohol free.



The Texas Birth Defects

MONITOR

TEXAS
Department of State Health Services
Birth Defects Epidemiology and Surveillance

A Semi-Annual Data and Research Update

Volume 18, Issue 1 July 2012

INDICATORS OF HEALTH AMONG WOMEN BEFORE PREGNANCY—TEXAS, 2002-2010

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Promoting preconception health is an essential component of any broad strategy to prevent adverse pregnancy outcomes, including both birth defects and preterm delivery. Women who are planning pregnancy or may become pregnant, should have a preconception health evaluation and adopt appropriate health behaviors. The Texas Department of State Health Services (DSHS) analyzed Pregnancy Risk Assessment Monitoring System (PRAMS) responses regarding preconception health of Texas.

Data from 15,386 respondents aged 13–47 years who delivered a live-born infant during 2002–2010 in Texas were analyzed. Prevalence estimates and crude prevalence ratios of preconception health indicators were calculated by race/ethnicity, education, age, health care coverage before pregnancy, whether delivery was paid for by Medicaid, and whether the pregnancy was intended.

Main findings from this research:

- Women in Texas reported unfavorable levels of preconception health indicators that are traditionally associated with adverse birth outcomes. Forty eight percent of women had no health care coverage before pregnancy and 46% reported an unplanned pregnancy. Forty-five percent of women reported consuming alcohol during the 3 months before pregnancy, of which 18% reported binge drinking.
- Women without health care coverage before pregnancy were generally more likely to report unfavorable behavioral characteristics and health conditions compared with women with health care coverage, even if the pregnancy was planned.

(Continued on page 4)

www.dshs.state.tx.us/birthdefects

From the Registry

Birth Defects and Time Trends

Staff at the Texas Birth Defects Registry (TBDR) observed a 29% increase in total birth defects from 1999 through 2007. This analysis explored that more fully to see if we could find potential explanations.

We used a statistical technique called Poisson regression to fit trend lines to the data over time for total birth defects, and for every birth defect collected by the TBDR. We also grouped data on birth defects and on affected children various ways.

Main findings from this research:

From 1999 through 2007, the occurrence (birth prevalence) of total birth defects in Texas increased 3.6% per year on average. Increases were seen for:

- All age groups except mothers over 40
- All racial/ethnic groups
- All education levels
- A wide variety of birth defects

There were no obvious changes over time in the demographic makeup of the population that would explain this increase. Increases were greatest in:

- Urban areas of Texas
- Children with less severe birth defects
- Defects that are more susceptible to diagnostic variation (for example, some birth defects are picked up more if doctors start routinely using different screening technology) (see figure 1). One exception was gastroschisis, which is not very susceptible to diagnostic variation but showed an average increase of over 5% per year. Increases in this defect have been observed in other parts of the country and overseas.

Conclusions and Discussion:

This research suggests that the observed increase in total birth defects and in many specific birth defects may be due to increased awareness, detection, or other changes in health care delivery practices, resulting in the TBDR picking up cases of birth defects more completely over time.

Translating research to practice and policy:

A statewide, active program for birth defects surveillance is an important tool for detecting whether or not there have been changes in rates. However, it is important to understand the many factors can influence time trends. These factors include changes in screening, diagnosis, and medical record documentation.

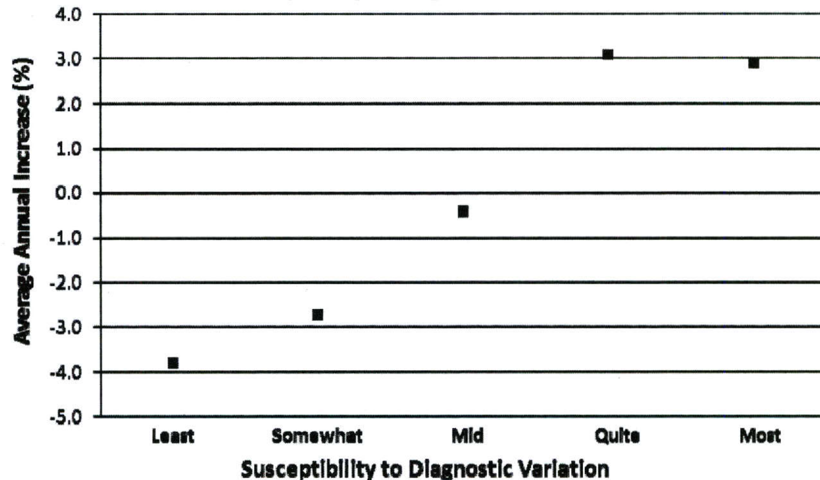
Citation:

Langlois PH, Marengo LK, Canfield MA. Time trends in the prevalence of birth defects in Texas: Real or artifactual? Birth Defects Research (Part A) Clinical and Molecular Teratology 2011: In press.

For more information:

Please contact Dr. Peter Langlois at peter.langlois@dshs.state.tx.us or (512) 776-7232.

Figure 1. Time Trend in Birth Defects Ranked into Quintiles of Susceptibility to Diagnostic Variation



BIRTH DEFECTS AND CHILDHOOD CANCERS

Studies have consistently shown that infants born with certain types of birth defects are at increased risk of developing cancer during their childhood. Staff at the Texas Birth Defects Registry (TBDR) and the Texas Cancer Registry, in collaboration with Dr. Sue Carozza, previously of the Texas A&M University School of Rural Public Health, looked at infants born in Texas between 1996 and 2005 to evaluate whether children with birth defects were more likely to develop cancers than children without birth defects.

A cohort study design was used for this epidemiologic study and relative occurrence was calculated to compare cancer prevalence among children with vs. without birth defects diagnosed during infancy. Over three million birth records were included in the study. Of these, 115,686 subjects had birth defects and among infants with birth defects, 2,351 had cancer during childhood.

Main findings from this research:

Overall, children with a birth defect had three times the risk of developing cancer when compared to children without birth defects.

All major birth defect groups, except for musculoskeletal, had increased cancer incidence.

Infants born with chromosomal disorders were over fifteen times more likely to develop cancer in childhood. The types of cancers that showed the strongest statistical associations with birth defects included the following:

- germ cell tumors (cancer usually found in the gonads)
- retinoblastomas (cancer of the retina)
- soft-tissue sarcomas (cancer of the tissues that protect, support, or surround organs)
- leukemia (cancer of the blood or bone marrow)

Conclusions and Discussion:

This research confirms that infants with birth defects are at higher risk of developing cancer during their childhood than infants without birth defects. In addition, some specific types of cancer appear to be more common among children with birth defects. Untangling the strong relationship between birth defects and childhood cancers could lead to a better understanding of the genetic and environmental factors which affect both conditions.

Translating research to practice and policy:

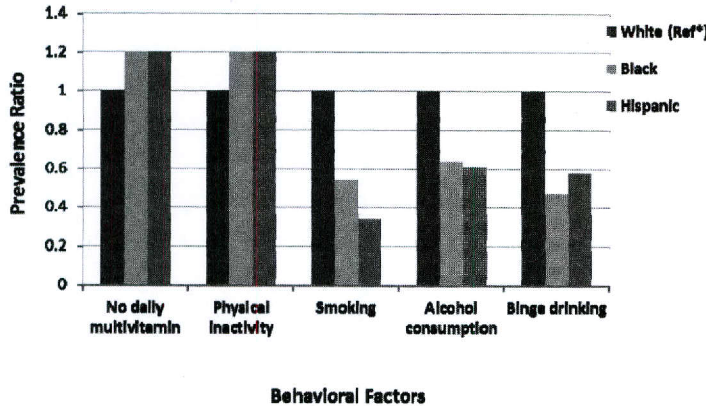
A statewide, active program for birth defects surveillance is an important tool for detecting trends in birth defects. Understanding the relationship between cancer and birth defects is one example. It is important to note that there are a variety of ways the presence of birth defects may influence risk of childhood cancer development. These ways include shared genetic and/or environmental factors, changes in organ structure or function, and lifestyle adaptations related to the birth defect.

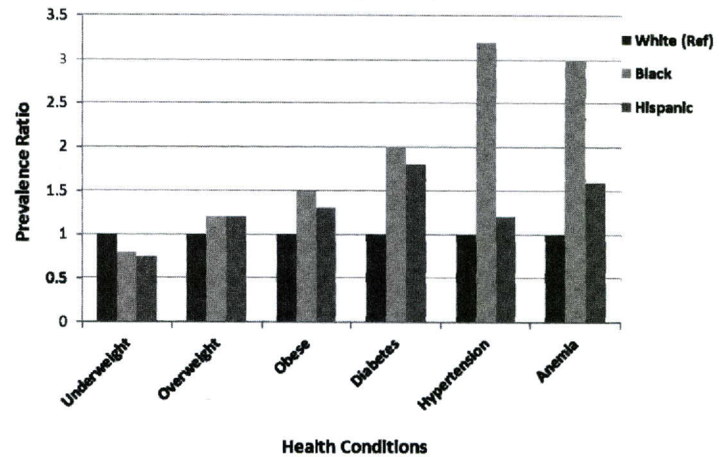
Citation:

Carozza SE, Langlois PH, Miller EA, Canfield M. Are children with birth defects at higher risk of childhood cancers? Am J Epidemiol. 2012 Apr 24: In press.

For more information:

Please contact Dr. Susan Carozza at susan.carozza@oregonstate.edu or (541) 737-5949





*Prevalence ratio is a measure of the relative risk compared to the referent group which in this case is Whites (ref, with ratio = 1). For example, in figure 1 above, compared to Whites, Blacks and Hispanics have a 20% higher prevalence of not consuming a multivitamin (PR=1.2).

(Continued from page 1)

- o Among women with a planned pregnancy, lack of health care coverage before pregnancy was associated with a 70% higher prevalence of anemia, 50% higher prevalence of underweight, 30% higher prevalence of obesity and not consuming daily multivitamins, and a 20% higher prevalence of physical inactivity.

- Compared with non-Hispanic white women, non-Hispanic black and Hispanic women reported:
  - o A 20% higher prevalence of not consuming a daily multivitamin, physical inactivity, and being overweight (figure 1 and 2).
  - o Nearly twice the prevalence of prepregnancy diabetes (figure 2).
  - o A 50% and 30% higher prevalence respectively, of obesity (figure 2).

- Compared with non-Hispanic whites, non-Hispanic black women had three times the prevalence of hypertension and anemia and among Hispanic women, the prevalence of anemia was 60% higher than among non-Hispanic whites (figure 2).

- Women for whom Medicaid paid for delivery (59%) and those who did not have health care coverage before pregnancy (48%) had a higher prevalence of smoking, physical inactivity, not consuming daily multivitamins, and adverse health conditions.

Conclusions and Discussion:

Access to health care is crucial for improving women's pregnancy outcomes. Preconception health care visits provide an opportunity to assess and address unhealthy behaviors and health conditions known to adversely affect pregnancy outcomes including birth defects and preterm delivery. Nearly half of Texas women (48%) did not have any health care coverage before pregnancy. Among Hispanic women, only 37% had health care coverage before pregnancy and Hispanic women accounted for 50% of live-births in Texas in 2009. Given the rapidly growing Hispanic population in Texas more efforts and outreach are needed to en-

(Continued on page 5)

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Texas more efforts and outreach are needed to enroll poor women, especially Hispanics, in Medicaid coverage before they become pregnant.

Additionally, since almost half of pregnancies in Texas were unintended, it is imperative that women receive preconception care during any encounter with the health care system. Education messages targeting both the health care providers and women in the reproductive years are needed to close the gap.

Citation

CDC. Preconception health indicators among women – Texas, 2002-2010. Morbidity and Mortality Weekly 2012; 61:550-555. [July 27]

(Reported by Rochelle Kingsley, Rebecca Martin, Mark Canfield, Amy Case, Diana Bensyl, Noha Farag)

Link to article:

http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6129a3.htm?s_cid=mm6129a3_w

For more information

Please contact Dr. Noha Farag at iym0@cdc.gov or (512) 776-6197.

ANNOUNCEMENTS

8TH BIENNIAL BIRTH DEFECTS RESEARCH SYMPOSIUM TO BE HELD

The 2012 Biennial Birth Defects Research Symposium will be held on November 15th in Dallas, TX. Registration is free. Contact Katie Tengelsen (katie.tengelsen@dshs.state.tx.us) with questions. We hope to see you there!

BIRTH DEFECTS ANNUAL REPORT RELEASED

The new Birth Defects Annual Report for 2000-2009 can be found on the birth defects website at http://www.dshs.state.tx.us/birthdefects/data/BD_Data_00-09/Report-of-Birth-Defects-Among-2000---2009-Deliveries/.

DATA COMPLETION TIMELINESS STANDARD MET!

The timeliness of the Registry's data completion is evaluated against the timeliness standard set by the National Birth Defects Prevention Network (NBDPN). The standard states that the data for a given delivery year should be at least 95% complete within 24 months following the end of that delivery year. For delivery year 2008, the Texas Birth Defects Registry met this national standard for the first time! From delivery year (DY) 2003 to DY 2008, the number of months from the end of the delivery year to 95% completeness of the data for that delivery year decreased from 28.6 for DY 2003 to 23.2 for DY 2008 (the most recently completed delivery year). We congratulate our regional staff for their timely work and contribution to the citizens of Texas.

CHANGING THE TEXAS BIRTH DEFECTS REGISTRY DATABASE

The Texas Birth Defects Registry is in the final stages of developing a new data collection system. The new system is part of the Health Registries Improvement Project at the Texas Department

of State Health Services. In addition to replacing the functionality of the old system, the new system will incorporate several major business process improvements and several other data sets that were previously maintained separately (e.g., all of our quality assurance data). The result should lead to more efficient data collection and processing, higher data quality, and timelier data. Piloting of the new system is currently underway. The new system is scheduled to go live in August.

Very Rare Birth Defects (VRD) Study Publication

The VRD project has produced eight papers plus one introductory paper, which made up the entire last 2011 issue (November 15) of the American Journal Medical Genetics, part C (Seminars). This series of papers, as other past initiatives, constitute an excellent example of what International Clearinghouse for Birth Defects Surveillance and Research members can do together, and demonstrate the value that our organization can add to the work of individual programs. The only way to calculate relevant prevalence estimates for the eight very rare birth defects was by pooling data. Included in the studies were 25 million pregnancy outcomes that were provided by 22 Clearinghouse-member programs. Texas is one of only three U.S. programs currently in the Clearinghouse and is well represented, being one of the largest submitters of data overall. The birth defects studied and number of cases included in the papers are as follows:

1. ***Amelia***: lacking one or more limbs. (319 cases included).
2. ***Phocomelia***: congenital disorder involving the limbs. (127 cases included).
3. ***Acardia***: complex malformation of monozygotic twinning. (164 cases included).
4. ***Cloacal exstrophy***: many of the abdominal organs are exposed. (186 cases included).
5. ***Conjoined twins***: identical twins whose bodies are joined in utero. (383 cases included).
6. ***Cyclopia***: characterized by the presence of a single eye, with varying degrees of doubling of the intrinsic ocular structures, located in the middle of the face. (178 cases included).
7. ***Sirenomelia***: limb anomaly in which the normally paired lower limbs are replaced by a single midline limb. (249 cases included).
8. ***Bladder exstrophy***: characterized by a defect in the closure of the lower abdominal wall and bladder. (537 cases included).

Pulse Oximetry Screening for Critical Congenital Heart Defects

In the United States, about 4,800 babies born each year have one of seven critical congenital heart defects (CCHDs). These seven defects include hypoplastic left heart syndrome, pulmonary atresia (with intact septum), tetralogy of Fallot, total anomalous pulmonary venous return, transposition of the great arteries, tricuspid atresia, and truncus arteriosus. In September 2011, HHS Secretary Sebelius approved adding CCHD to the Recommended Uniform Screening Panel.

Babies with these heart defects might appear to be healthy at first and are sent home to their families. These babies are at risk for having serious problems within the first few days or weeks of their lives. The pulse oximetry screening within 24 hours of birth can identify some babies with a CCHD before they show signs. These infants can then be seen by specialist and receive medical care that could prevent death or disability early on.

The screening is completed using a machine called a pulse oximetery, which measures the oxygen levels in the blood. The test is painless and takes only a few minutes. The estimated cost for each test is between $5-$10.

If the pulse oximetry results are negative with in-range results, it means that the baby's test results

Research Center News

Recent Publications from Texas Collaborators

- Agopian AJ, Canfield MA, Olney RS, Lupo PJ, Ramadhani T, Mitchell LE, Shaw GM, Moore CA; the National Birth Defects Prevention Study. Spina bifida subtypes and subphenotypes by maternal race/ethnicity in the National Birth Defects Prevention Study. *Am J Med Genet A*, 2011. [In Press]
- Agopian AJ, Lupo PJ, Tinker SC, Canfield MA, Mitchell LE, and the National Birth Defects Prevention Study. Working Towards a Risk Prediction Model for Neural Tube Defects. *Birth Defects Res A Clin Mol Teratol*, 2012. [In Press]
- Agopian AJ, Marengo LK, Mitchell LE. Predictors of trisomy 21 in the offspring of older and younger women. *Birth Defects Res A Clin Mol Teratol*. 2012 Jan;94(1):31-5.
- Brender JD, Werler MM, Kelley KE, Vuong AM, Shinde MU, Shinde QZ, Huber JC, Sharkey JR, Griesenbeck JS, Romitti PA, Langlois PH, Suarez L, Canfield MA, and the National Birth Defects Prevention Study. Nitrosatable drug exposure during early pregnancy and neural tube defects in offspring. *Am J Epidemiology*, 2011; 174(11): 1286-1295.
- Carozza S, Langlois P, Miller EA, Canfield MA. Are children with birth defects at higher risk of childhood cancers? *Am J Epidemiology*, 2011. [In Press]
- Duong HT, Hoyt AT, Carmichael SL, Gilboa SM, Canfield MA, Case AP, McNeese ML, Waller DK and the National Birth Defects Prevention Study. Is maternal parity an independent risk factor for birth defects? *Birth Defects Res A Clin Mol Teratol*, 2012. [In Press]
- Lupo PJ, Canfield MA, Chapa C, Lu W, Agopian AJ, Mitchell LE, Shaw GM, Waller DK, Olshan AF, Finnell RH, Zhu H. Diabetes and Obesity-Related Genes and the Risk of Neural Tube Defects in the National Birth Defects Prevention Study. American Journal of Epidemiology, 2012. [In Press]
- Langlois P, Marengo L, Canfield MA. Time trends in the prevalence of birth defects in Texas 1999-2007: Real or artifactual? *Birth Defects Res A Clin Mol Teratol*, 2011; 91(10): 902-917.
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- Lupo PJ, Lee LJ, Okcu MF, Bondy ML, Scheurer ME. An exploratory case-only analysis of gene-hazardous air pollutant interactions and the risk of childhood medulloblastoma. *Pediatr Blood Cancer*. 2012 Mar 2. doi: 10.1002/pbc.24105. [Epub ahead of print]
- Marengo L, Ramadhani T, Farag NH, Canfield MA. Should Aggregate U.S. Census Data Be Used as a Proxy for Individual Household Income in a Birth Defects Registry? *Journal of Registry Management*, 2011 Spring: 38(1): 9-14.
- Moffitt KB, Abiri OO, Scheuerle AE, Langlois PH. Descriptive epidemiology of selected heritable birth defects in Texas. *Birth Defects Res A Clin Mol Teratol*, 2011; 91(12): 990 – 994.
- Scheuerle A. Clinical differentiation of patent foramen ovale and secundum atrial septal defect: a survey of pediatric cardiologists in Dallas, Texas, USA. *J Registry Manag*. 2011 Spring;38(1):4-8.
- Suarez L, Felkner M, Brender JD, Canfield MA. Dieting to lose weight and occurrence of neural tube defects in offspring of mexican-american women. *Matern Child Health J*. 2012 May;16 (4):844-9.

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The Monitor is published twice a year by the Birth Defects Epidemiology and Surveillance Branch, Texas Department of State Health Services:

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Please visit the BDES website for updated information: www.dshs.state.tx.us/birthdefects.

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CALENDAR

DSHS Pub. No. 58-10955

2012

- September: Infant Mortality Awareness Month
- September 26, 2012: Grand Rounds-Integration of Public Health Research and Congenital Heart Disease, 11:00am-12:30pm DSHS K-100 Auditorium
- October 1-3: 84th American Health Information Management Annual Meeting; Chicago, IL.
- October 17-20, 2012: 28th National Association of Neonatal Nurses Educational Conference; Palm Springs, CA.
- October 31–November 2: 39th Annual International Clearinghouse for Birth Defects Surveillance and Research; Ottawa, Canada.
- November 15: 8th Biennial Texas Birth Defects Research Symposium; Dallas, TX. Contact: Katie Tengelsen, 512-776-2814, katie.tengelsen@dshs.state.tx.us.

This publication was funded in part by the Office of Title V & Family Health, Texas Department of State Health Services, using Title V Maternal and Child Health Block Grant Funds.